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**TOWARDS IMPROVED CARE AND LONG-TERM
WELL-BEING OF MEN WHO LOSE A WIFE TO
CANCER – A POPULATION BASED STUDY**

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“The Herringmanway” – a hiking route between Hvalfjörður and Skorradalur on Iceland’s west coast.

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To widowers – those who participated and all others

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LIST OF PAPERS

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

- I. **Hauksdóttir A**, Steineck G, Fürst CJ, Valdimarsdóttir U. Long-term Mental Health of Widowers with and without a new Relationship – a Population based Follow-up. Submitted.
- II. Dahlstrand H, **Hauksdóttir A**, Valdimarsdóttir U, Fürst CJ, Bergmark K, Steineck G. Disclosure of Incurable Illness to Spouses: Do They Want to Know? A Swedish Population-Based Follow-up Study. *J Clin Oncol* 2008;26:3372-9.
- III. **Hauksdóttir A**, Steineck G, Fürst CJ, Valdimarsdóttir U. Long-term harm of Low Preparedness for a Wife's Death to Cancer – a Population-Based Follow-up of Widowers 4-5 Years after the Loss. Submitted.
- IV. **Hauksdóttir A**, Valdimarsdóttir U, Fürst CJ, Onelöv E, Steineck G. Health Care Related Predictors of Husbands' Preparedness for a Wife's death to Cancer – A Population-Based Follow-up. *Ann Onc* 2009 (Epub ahead of print, July 24, 2009).
- V. **Hauksdóttir A**, Steineck G, Fürst CJ, Valdimarsdóttir U. Towards Better Measurements in Bereavement Research: Order of Questions and Assessed Psychological Morbidity. *Palliat Med* 2006;20:11-6.

ABSTRACT

Background: Grief can be seen as the mirror of love. However, some persons suffer beyond what can be viewed as normal grief, experiencing long-lasting decline of both mental and physical health - and even death. Investigating additional and avoidable risk factors connected to the loss may therefore be of vital importance for the development of preventive interventions.

Aims: To identify avoidable risk factors for the long-term psychological morbidity of widowers. We hypothesized that widowers, compared to married men, have a higher risk for psychological morbidity 4-5 years after their loss. We also postulated that this excess morbidity is determined by the degree of preparedness for the wife's death at the time of death. Moreover, we suggest that such preparedness can be facilitated by providing several kinds of health-care interventions.

Methods: Following a qualitative phase for study preparation, a study specific questionnaire (including questions on psychological morbidity and questions about the wife's disease period) was constructed and tested for face validity and for response rate and logistics in a pilot study on 76 widowers. The study base in the main study consisted of 907 men in Sweden who had lost a wife to cancer in the breast, ovary or colon in 2000 and 2001. Furthermore, we collected data from a control group of 330 married men who were frequency matched for age and residence. The questionnaires were sent out from November 2004 to November 2005.

Results: Participation rate was 76 percent for the widowers and 79 percent for the married men. Single widowers reported more psychological morbidity 4-5 years after the loss of a wife than widowers who were in a new romantic relationship at the time of follow-up. Highest relative risks obtained were for depression (RR 2.3), emotional numbness (RR 2.2) and waking up at night with anxiety (RR 2.3). Widowers in a new romantic relationship did not report more morbidity compared to married men.

Eighty-six percent of the widowers reported that the next-of-kin should be told immediately when the patient's cancer cannot be cured. Eighty percent of the widowers reported that they were told that the wife's cancer was incurable and a quarter of them were informed within one week before the patient's death.

Our data indicated that a low degree of preparedness at the time of wife's death increases a younger widower's (38 to 61 years old) risk for (among other symptoms): anxiety (RR 2.3), emotional numbness (RR 2.2) and having difficulty falling asleep (RR 2.2) 4-5 years after loss. For older widowers (62 to 80 years old), this pattern was not as evident. Several possible avoidable predictors for preparedness were identified: longer duration of the widower's intellectual awareness time before his wife's death (RR 4.1), if the widower could take in the information that his wife's disease could not be cured (RR 3.5), the couple had arranged their economic affairs (RR 1.5) and if the wife had stayed at a palliative care unit during the last months of her life (RR 1.2).

Findings: Widowers who remain single 4-5 years after their loss are at increased risk of psychological morbidity. Furthermore, the degree of preparedness before the wife's death may affect the long-term psychological well-being for widowers. Several care-related facilitators of preparedness were identified.

Implication: Improved care of men whose wives are dying of cancer may diminish the widowers' risk of long-term morbidity. An intervention study, aiming at influencing preparedness before the death of a loved one, can be designed based on our findings. Such an intervention may entail significant public health effects by decreasing psychological and even physical morbidity of widowers.

BACKGROUND

More than 22,000 (22,440 in 2007¹) people die annually in Sweden due to cancer, leaving behind wives or husbands, children, parents, siblings, other relatives or friends. Due to the surviving next-of-kin's excess risk of long-term somatic and psychological morbidity, and even mortality, the stress of losing a loved one to cancer constitutes a major public health concern.

The focus of this thesis is on the long-term mental health of men who lose a wife to cancer. The aim was to identify if and how health care can intervene during the disease period or around the moment of death to decrease the widowers' long-term psychological morbidity, thereby increasing their quality of life.

Being a spouse of a cancer patient

A diagnosis of cancer causes a great trauma for the patients and their families. After the diagnosis and during the disease period that follows, spouses and other family members are sources of support for the patient, and even participate in the care of the patient. This can be of great positive value for both the patient and the spouse, but it is also an enormous source of stress and worrying for the couple. Most spouses adjust to new challenges and cope well with the care-giving role, and many couples even experience positive life changes as a result of facing the trauma together.² However, for some the stress leads to marital problems³ and psychological morbidity both for the patient and spouse,⁴⁻⁶ especially if the cancer is advanced.⁷

Some data indicate that female spouses of cancer patients are more affected by their spouse's disease than male spouses and experience more emotional distress during the disease period.^{3,6} In contrast to these studies, Baider and co-workers found that husbands experience more distress during their sick spouse's disease period than wives to sick husbands do, and their distress was as high as that of patients of both genders.⁸ In a longitudinal study following 56 colon cancer patients and their spouses up to one year after surgery, the investigators found that female spouses reported more problems in the beginning, followed by a gradual decrease over time, but for male spouses, the problems increased over time.³ Giving careful attention to the time point for identifying psychological problems for spouses of cancer patients may therefore be of the essence, since the problems may peak at different time points for men and women. In addition, for both patients and spouses, low levels of perceived social support have been found to be associated with high psychological distress.⁸

However, male spouses seem to have fewer sources of social support and to receive less support than women during the patient's disease period⁸⁻¹⁰ which might explain their increased stress levels during the disease period, compared to female partners.

While a husband is an important source of support for his wife with cancer,¹¹ women may also have other sources of support through extended social networks. In contrast, for a husband, his wife may be his primary source of support. In a study of 431 prostate cancer patients and 435 randomly selected men (a control group), Helgason and co-workers found that among those men living with a partner, the spouse was identified as the ground resource of support, 71 percent of the cancer patients said that they could share all or most concerns with their wife but 82 percent shared few or no concern with someone else than their wife.¹² Similar numbers were obtained for the group of men not having been diagnosed with prostate cancer. The question arises: When the man is in the role of a spouse of a cancer patient – to whom should he then turn in seeking support?

Through the years, providing care has been considered more an automatic part of the female role, but may be more unfamiliar for a man, both for him personally and within the health-care setting. The participation of a man in his wife's care may not be as welcomed by health-care providers as is the participation of the female spouse, which may make the man uncomfortable and push him away. However, activating the spouse in caring for the patient, may benefit all parties and can even decrease the risk of psychological morbidity for the surviving spouse.¹³

Becoming widowed

The loss of a loved one is a great trauma and results in grief, a normal and inevitable process. For most widowed people levels of psychological morbidity are higher during the first year after loss, but decline thereafter. In a longitudinal study, Mendes de Leon and co-workers did a follow-up on 1046 married persons (65 years and older), 139 of which became widowed during the three-year follow-up period. They found that depression scores (measured by CES-D) increased during the first year of bereavement, but returned to pre-widowhood levels after that.¹⁴ Furthermore, Onrust and Cuijpers conducted a systematic literature review focusing on mood and anxiety disorders in widowhood, including only studies diagnosing disorders in a structure diagnostic interview.¹⁵ They found that prevalence of depression and anxiety disorders were significantly elevated in widowed individuals, especially during the

first year of bereavement. The relative risks of disorders ranged from 3.5-9.8 compared to control subjects.

Increased risks of psychological morbidity following a loss of a spouse are evident up to two years post loss.¹⁶ Less is known about the duration of symptoms, that is, if the widowed have higher risks for anxiety and depression still several years after their loss. Turvey and co-workers found that rates of depression are still high two years after the loss of a spouse.¹⁷ In addition, Bennett found that experiencing loss of a spouse has a negative impact on widows' well-being up to four years after loss.¹⁸

Results from studies concentrating on mortality rates of the widowed illustrate that for some of the widowed population, life does not get "back to normal" after two years of grieving. It is well demonstrated within the literature that the widowed have increased mortality rates, especially after short rather than long duration of bereavement.¹⁹⁻²¹ Effects on spousal loss on mortality rates have also been found during later years of widowhood.^{22 23} In a cohort study of 373,189 elderly married couples who were followed up from 1993 and 2002, the authors found that death of a spouse increased risk of mortality of the bereaved partner (18 percent increase in all-cause mortality for men and 16 percent for women).¹⁹ Taken together, these results suggest in a convincing way that the effects of a spousal loss may be fatal for a subgroup of the widowed population – often called "the widowhood effect" in the literature. Whatever the mechanism behind this effect may be, further investigation is needed before conclusions can be made.

Widowers and married men

In the initial phase of this study, in March 2004, a review of the literature on loss and relatives indicated that widowers have been neglected within bereavement research. A search in Medline at that time revealed that 144 studies had the word "widows" in the title, but the corresponding number of studies with the word "widowers" in the title was 37. This is not a definite or precise measurement, but may give an indication of the relative emphasis in bereavement research through the years. A recent review on the bereavement literature did not change our understanding in that regard.

Results from the few studies retrieved that concentrate on men only, suggest that widowers have increased risk of morbidity compared to married men. A study by Byrne and Raphael, including widowers and married men (N=57 in each group), found that widowers report more anxiety, psychological distress, sleep disturbances and

thoughts of death and suicide than married men.^{24 25} The authors did not find differences for reported depression or loneliness. Results from the same data set also revealed that a higher proportion of widowers reported hazardous drinking (drinking five or more standard drinks per drinking day) (19 percent) than for married men (8 percent).²⁶ On the other hand, alcohol consumption was not correlated with the widowers' levels of grief or anxiety. Another study, including 113 widowers that had been widowed up to 12 months and a control group consisting of 111 married men, found that the widowers experienced more distress than the married men, and that highly distressed widowers had more problems with working outside the home or doing housework, and they were less satisfied with their social network than less distressed widowers.²⁷

Comparing widowers and widows

As mentioned above, most bereavement studies have focused on women or groups of both genders where men have been in minority. Relatively few studies have focused on men as a specific group. It is therefore necessary and useful to review that part of the bereavement literature comparing the impact of loss on widows and widowers.

Women have higher levels of anxiety and depression in general and bereaved women are more likely to express their needs and seek professional help than bereaved men, as indicated in two literature review articles.^{28 29} In addition, because of higher survival rates of women, the percentage of widows in the general population is greater than widowers²⁹ and they may therefore be more apparent within bereavement research and counseling and support groups after loss. These facts have led researchers through the years to believe that women are more affected by losing a spouse than men are. For example, a study by Lund and co-workers (including 192 bereaved persons and no control groups) did not find differences between males and females on bereavement outcomes.³⁰

Although women often show more distress-related symptoms during the first year after the loss, and are more likely to seek professional help, men take longer time to adjust to the loss and a new life.³¹ When comparing health of widowers and widows, the use of control groups, including individuals that have not lost a spouse, is of importance. Only then is it possible to identify the impact of loss on general well-being for men and women separately. Gender differences have been found in most bereavement studies utilizing control groups, indicating that widowers have a higher

risk than widows for psychological dysfunction^{32 33 34 35} and mortality.³⁶ In a national survey (N=3614), Umberson and co-workers found that having lost a spouse is associated with depression and this association is stronger in men than in women.³⁷ The authors suggested that the difference found can be explained by the fact that widowhood does not affect men and women in the same way: men seem to experience widowhood as a more distressing period than women do.

When looking at mortality rates, similar patterns are noted. A large Finnish cohort study found that excess mortality in widowhood is greater among men than women³⁸ with the highest excess risk of death early on in bereavement.^{38 39} While gradually decreasing for both genders, the effect is more consistent in later times during the bereavement period for widowers.^{36 38} In one study the risk of mortality increased for widowers under the age of 65.²³ Suicide has been found to be 3.3 times more common among widowers than for married men and this difference in risks for suicide was not observed among widows compared with married women.⁴⁰ Elevated risks of suicide have been found for both genders, although significantly higher for men, especially under the age of 50.⁴¹ Results from yet another study indicate that the relative risk for suicide may be even more profound for the oldest of older widowers (80 years +), or 10.0 compared to 2.1 for widows in same age group; a difference less evident for younger age groups.⁴²

Explaining the widowhood effect

It is therefore well documented that losing a spouse increases morbidity and mortality in men, but exactly how and what can be done to eliminate the widower's additional suffering, remains unclear. When considering the fact that widowhood seems to have a more detrimental effect on men than women, few factors reveal themselves as being especially important. Being married involves social support from a spouse, which may in turn lead to health advantages. By giving emotional and social support, spouses may discourage risky behavioral patterns and encourage health promoting behavior such as positive eating habits and visits to a physician. This spousal support may be of greater importance for men than for women, and, in fact, men seem to benefit more from marriage than women in terms of better self-reported health.⁴³ Gaining a spouse increases men's life satisfaction while this association was not found for women.⁴⁴ This applies also for social support in general; social network size (number of people the respondent had as informal social contact) affects mortality risk for men indirectly through their health status, but this effect was not found for

women.⁴⁵ A direct effect was found for both genders; however, men gained protection at a lower level than women.

Avoidable risk factors

From a public health perspective, the concept of avoidable risk factors becomes important when the goal is to study how health care might be modified for the benefit of both patients and relatives. Our research group (Clinical Cancer epidemiology at Karolinska Institutet in Stockholm and Sahlgrenska Hospital in Gothenburg) has focused on studies, all based on epidemiological methods, that might improve quality of life of cancer patients⁴⁶⁻⁵² and, importantly for our current study, of those who lose a next-of-kin to cancer.⁵³⁻⁶²

Additional risk factors of morbidity after the loss of a loved one

Being aware that an impending death is to be caused by cancer provides not only an opportunity for the surviving next-of-kin to prepare for the loss, but also to experience additional stressors, like the prolonged suffering of the patient. The focus of studies within our research group on persons who have lost a loved one to cancer (until now, studies of widows, parents and widowers) is placed on avoidable psychological traumata that perhaps are unnecessarily induced by health-care professionals during a cancer patient's incurable illness, traumata that can cause long-term psychological morbidity in the surviving relative. In our previous studies, we have found that next-of-kin are subjected to a number of unnecessary stressors resulting in psychological traumata, above and beyond the loss itself, when they have a relative dying of cancer. These psychological traumata may result in an excess risk of long-term psychological morbidity (e.g. anxiety).

The first study from our research group, indicating that it is possible to identify stressors that lead to psychological complications following the loss of a loved one, was a study by Ingela Rådestad and co-workers on 380 women who delivered a stillborn child and 379 women who experienced a live birth.⁵⁷ The results from this study revealed that delay of delivery of 25 hours or more after diagnosis of death in the uterus has a strong association with anxiety that is present for as long as three years after the delivery. In addition, women who reported that they wished to see the stillborn child but did not, also had an increased risk of developing anxiety three years later. These results indicate that it may be possible to decrease the distress of labor and delivery during stillbirth and the long-term psychological morbidity following the loss.

The second study within the next-of-kin tradition in our group was conducted by Unnur Valdimarsdóttir and co-workers who investigated 506 widows who had lost their husbands due to prostate or urinary bladder cancer and a control group including 287 female population controls. Their study showed that widows with an awareness time (the duration of the time a widow understands intellectually that her husband will die of his disease) of 24 hours or shorter or widows whose husband's psychological health status had been poor during his last three months of life were at increased risk of long-term psychological morbidity (anxiety and depression) two to four years later.⁶⁰ These results indicate that it may be possible to decrease the risk of long-term psychological morbidity of widows by providing more accurate information about their husbands' prognoses and treating the husband's psychological problems more efficiently.

Ulrika Kreicbergs and co-workers investigated 561 parents who had lost a child to cancer four to nine years earlier and a control group of 659 non-bereaved parents. Their results indicated that parents who hesitate to talk with their dying child about death might be encouraged to do so by the health care system: 27 percent of those parents who had not talked to their child regretted this.⁵⁵ Parents who regretted not having talked with the child had an increased risk of anxiety and depression four to nine years after their loss, something not seen in non-regretting parents. Furthermore, for fathers, having had short emotional awareness time (less than 24 hours) increased the risk of depression and being absent from employment due to taking sick leave or early retirement at the time of follow-up.⁶²

The results from these three research projects stress the importance of identifying risk factors for psychological morbidity following a loss. Several avoidable key stressors that have been discovered to date are: the mother's lack of exposure to a stillborn child, the widow's lack of awareness of or preparation for her husband's impending death as well as poor psychological well-being of the dying patient and finally, parents' lack of communication with a dying child. The identification of avoidable stressors might give health-care professionals opportunities to eliminate harmful routines or introduce fruitful interventions. Such alterations may decrease the risk of long-term psychological morbidity of those who face a loss of a loved one.

In addition to the fourth research project (on widowers, described in this thesis), four other research projects on the impact of loss on next-of-kin and additional risk factors now being prepared or conducted within our research group are studies of: young adults having lost a parent to cancer, young adults having lost a sibling to

cancer, parents having lost a child to suicide and young adults having lost a sibling to suicide.

The focus of our current study on widowers is based on previous findings and focuses on the possible effects of a man's preparedness before a wife's death to cancer on his long-term psychological health and if and how health-care interventions can influence his preparedness before his wife's death.

Being forewarned

The concept of preparedness

In the literature, the concept of forewarning has been measured by different means, including duration of illness,⁶³ how far in advance the relative was aware of the approaching death,^{60 62 64} or as we have done in our current study, by asking the relative to evaluate his or her degree of preparedness at the time of death (see also Barry and co-workers⁶⁵). As pointed out in a study by Steinhäuser and co-workers, preparedness or expectedness of the death of a loved one can be described as multi-dimensional, with medical, psychosocial, spiritual and practical dimensions.⁶⁶ "Preparedness" for a husband of a dying wife can therefore be regarded differently for different persons, and may include any or all of the following: having received information, having communicated about the forthcoming death, having made practical arrangements, and praying. This was also evident from the deep-interviews which were conducted with widowers when preparing the study, where we learned that it was hard to reach a consensus on what "preparedness" was for different persons (emotional, practical, cognitive). Thus, after careful consideration, results from the current literature and the deep-interviews we decided to aim at measuring the concept of preparedness in a general way, simply by asking: "How prepared were you before your wife's death?"

Impact of being prepared for a loved one's death

Results from previous studies on the value of being forewarned, using different measurements (time of illness, length of awareness time, preparedness), have differed. Some results indicate that forewarning is of limited value for the relative's later psychological well-being; for example, Breckenridge studied 196 widows and widowers and found no relationship between expectedness of death and the widow(er)'s depression two months after death.⁶⁷ In a study of 112 widows and widowers, Houts and co-workers found that the length of time during which they had

with awareness before death was not related to the extent of depression after loss.⁶⁸ In another study focusing on warning time and psychological morbidity six and 18 months after loss, no association was observed with the exception that sudden death increased the risk of intrusive thoughts six months after loss.⁶⁹ Other studies have not found any relationship – or an inconclusive one – between forewarning and psychological morbidity.^{70 71}

On the other hand, results from other studies have demonstrated that having some kind of forewarning may be of importance for later psychological well-being. Studies that have focused especially on widows have found that forewarning (expected death or awareness time) is associated with more intense grief reactions (especially young widows⁷²) and worse psychological health.⁷³ In an additional study of widows (N=506) with longer follow-up time, short awareness time for the widow was associated with anxiety and intake of tranquillizing drugs two to four years after loss.⁶⁰ Short awareness time has also been found of importance for fathers four to nine years after a loss of a child to cancer.⁶² Other studies including more diverse group of participants (spouses, parents) have come to a similar conclusion, for example that unexpected death predicts more intense grief eight years after loss,⁶³ more depression six months after loss⁷⁴ or anxiety seven months after loss.⁷⁵ Finally, little preparedness at the time of spouse's death has been associated with complicated grief four and nine months following loss and even depression at nine months after loss.⁶⁵

Diverse groups of participants (gender, cause of death, age) may partly explain these contradictory results. Age of the widowed person may be of significance, older people may be more prepared for a death of a loved one “in general” while for younger persons it may be more important to prepare specifically for the loss of the spouse. For example, the study by Carr and co-workers in which no relationship was observed,⁶⁹ focused on widow(er)s 65 years and older. In another study of younger widows (18-62 years old), less forewarning was associated with increased risk of psychological morbidity after loss.⁷³ In addition, spousal caregivers of patients with advanced cancer who have dependent children (mean age of caregivers 46 years) have a higher risk of depression and anxiety than do caregivers without dependent children (mean age 62 years).⁷⁶ Younger persons might therefore be more vulnerable to the exposure of not being prepared because of lack of time (being occupationally active and perhaps having young children living at home) and more psychological morbidity during the disease period.

Despite contradictory results from the current literature, it is reasonable to assume that preparedness (or another indicator of forewarning) may be of importance for the loved one's psychological well-being after loss. However, interpretation of some of the earlier studies (or making conclusions thereof) may be compromised due to large variation in causes of death, low participation rate, short follow-up time or variation in kinship and age of the participants. In addition, no study known to us has focused specifically on a man's preparedness for a wife's death and his long-term psychological well-being.

Predictors of preparedness

If the degree of a man's preparedness at the time of his wife's death predicts his long-term psychological well-being after loss, possible predictors of preparedness become important, especially factors that health care might influence. Is it possible for the health care system in some way to enhance a man's preparedness before his wife death?

Information

To be able to prepare before the impending death of a loved one, one must receive clear information: "Your loved one is going to die". A systematic review revealed that patients and caregivers have a clear information need at all stages of the disease,⁷⁷ where, for example, one of the studies found that 87 percent of cancer patients want all information, good or bad.⁷⁸ In spite of these findings, the caregiver's need for information is often not met. In a study of 206 family caregivers of patients with incurable cancer, 20 percent reported that they never received the information that the patient's illness could not be cured.⁷⁹ Of those receiving the information on the incurable stage of the illness, 67 percent said that they only understood that the patient's illness was incurable when they received this information from the physician, which demonstrates the importance of the physician's role. There may be several reasons why the caregiver does not receive this information from the physician, and it is also possible that the patient himself or herself may receive the information but hides the truth from the spouse because of protective reasons. In addition, the physician may be unsure of survival estimates or be reluctant for some reason to share the information with the patient or the caregiver. In contrast with studies based on results from patients and caregivers as described above, many physicians believe that the truth is unwanted; only 26 percent of the studied European palliative care specialists stated that the

majority of their patients wanted to know about the terminal stage of their illness (compared to 93 percent of their Canadian colleagues).⁸⁰ On the other hand, almost all of them stated that if they had terminal cancers, they would like to know. Physicians may find this communication difficult to deal with and not have the appropriate training or support to convey such a difficult message, and if it is delivered, they may be left with difficult emotions. A study of 1133 consultants (gastroenterologists, surgeons, radiologists and oncologists) demonstrated that 45 percent of them judged that they had received adequate training in communication skills and those who did not report such training had an increased risk of burnout in their work.⁸¹ There may therefore be room for improvement in the field of communicating bad news, not only for the benefit of the patients and their relatives, but also for the physicians.

Disclosure of information on the incurable state of the illness marks the first step in becoming aware; results from studies of women who have lost a husband to cancer and parents having lost a child to cancer reveal that receiving such information is a protective factor for having had short awareness time before the loved one's death.^{60 62} In addition, in a study of 122 recently bereaved persons, 25 percent reported that doctors or health professionals could have done something more to help make them feel better prepared for the death of their loved one. The participants mentioned the physician's lack of communication concerning the prognosis, which in turn may have limited the opportunities for making closure with respect to family matters.⁸²

Support from health-care professionals

To be able to prepare in the best way, psychological support or counseling from health-care professionals can be of importance. During the terminal stage of a disease period, health-care professionals may find opportunities to offer psychological support, to encourage communication within the family, to facilitate participation in the patient's care, encourage necessary practical arrangements or thoughts about the future – in other words: encourage preparedness. Encouraging this kind of communication or behavior is often a systematic part of terminal care, especially within the palliative setting, perhaps benefitting the patient and his or her family. Results from one study revealed that caregivers and spouses of patients who had enrolled in a hospice three days or shorter before the death of the patient had higher risk of depression after their loss than caregivers of those who were given longer-term hospice care.⁸³ These authors interpreted their results as indicating that earlier enrolment in a palliative care setting offers opportunities for more counselling and

psychological support, which can help the family to prepare for the loved one's death. Increased support from health-care providers may therefore be essential, as has also been shown by results from a randomized controlled trial by Lautrette and co-workers. Their results showed that including more information and more time to talk and express emotions (which could be predictors of preparedness) decreased the risk of psychological morbidity three months after loss.⁸⁴

To be able to prepare is regarded by dying patients as very important; in one study (N=340), 86 percent felt it was important to resolve unfinished business with family or friends, 90 percent rated saying goodbye to nearest and dearest as important and 94 percent said that it was important to have financial affairs in order.⁸⁵ When their relatives were contacted six months to one year after loss (N=332) they expressed similar attitudes about these factors that might be regarded as components of preparing.

Facilitating preparedness within the health care setting may therefore be of great importance for the long-term psychological health of the surviving relative. However, it is not entirely clear if and how such health-care related factors facilitate/enhance preparedness for a loved one's death.

RESEARCH APPROACH

Preparation – qualitative phase

In the initial phase of the study in-depth interviews were conducted in Iceland to aid in constructing a research model for the study and in preparing a questionnaire. An introductory letter was sent to eligible participants (men who had lost their wives to cancer one to five years earlier) and a few days later they were contacted by telephone and asked if they would be willing to participate. This part of the study was approved by the National Bioethics Committee in Iceland; The Icelandic Data Protection Committee was also informed. The study as a whole (interviews, pilot study and main study) was approved by the Regional Ethics Committee of Karolinska Institutet in Stockholm.

Ten individuals were interviewed: eight men who had lost their wives to cancer and two health care professionals; a nurse working in palliative home care and a priest working in a palliative care unit. The widowers were 45 to 70 years old; two were retired but the others were still working in various occupations. All of them had children. Most of the children had moved away from home, but two of the widowers still had children living at home. The amount of time that had passed since the loss of the wife ranged from 18 months to five years, most commonly two to three years. Five widowers (of eight interviewed) were involved in a new romantic relationship at the time of the interview.

The interviews were semi-structured. Each interview began in an open manner, but was then successively narrowed down. Several topics were raised, but the emphasis was on gathering information on what happened during the terminal disease period, the couple's communication with health-care professionals (both negative and positive aspects) and communication with each other. We also focused on identifying factors and situations within the health care system that might either inhibit or encourage the man in preparing for his wife's death (see Figure 1). Early in the interview process certain ideas were extracted (themes) and then pursued in later interviews. A simple content analysis was used in the interviews to investigate the widower's experience to ground our theory and the research model.

All interviews were audio taped and transcribed for data analysis. Some of the transcribed interviews also contained field notes, description of surroundings, ideas and reflections about the interview. Three main themes were extracted; 1) time

(awareness time before death, precious time with wife); 2) support (from health-care professionals, family and friends); and 3) communication (with health-care professionals and with wife). These themes were all utilized when constructing the questionnaire, they are therefore described briefly.

Awareness time

During the last months before his wife's death, the man has to face the inevitability of her death. A precondition for being able to prepare before a wife's death is an intellectual acknowledgement of the fact that the patient is dying. The point at which the man is able to acknowledge this defines the onset of awareness time, the time that passes from the intellectual understanding of the fact that the patient will die until he or she dies.⁶⁰

But how does one come to this point? According to the widowers interviewed, receiving information from health-care professionals was the most important factor for the husband to be able to acknowledge the fact that his wife was dying. However, the patients and their husbands frequently had to speculate about the prognosis because of shortage of information and rely on their own evaluation of the patient's condition or comparison to other patients.

Support

The widowers stated in the interviews that both emotional and practical support was extremely important for them. However, some of them said that too much emotional support made them uncomfortable and they expressed their need for a different kind of support. "Lack of time" during the terminal period, either because of the progression of the disease or because the men did not get sufficient support to spend time with their wife, was an important theme. Practical support could be especially important for the widowers, both during the illness period and after the wife's death. This applies to housework, care of the children and providing support for the future life as a widower.

Communication

None of the widowers interviewed stated that they discussed emotional issues with their wife before her death. This fact could be explained in two ways. One is that it was not important for them or their preparedness; their closure was reached by other means, for example by talking about more practical issues, through intimacy or caring gestures without words. The other explanation is that it would have been important for

them to engage in such a discussion with their wife, but they did not recognize this importance; which might possibly have hindered them in preparing for the wife's death. One widower in our interviews recognized the need for closure before his wife's death, but was unable to go through with it because he felt that his wife's severe symptoms prevented difficult emotional confrontation.

Many factors, like access to the patient and privacy of patient and spouse and encouraging their communication, can be controlled within the health care system. The comments of the widowers in our interview study showed that increased access can enhance the couple's probability of a meaningful and precious time together during the terminal period.

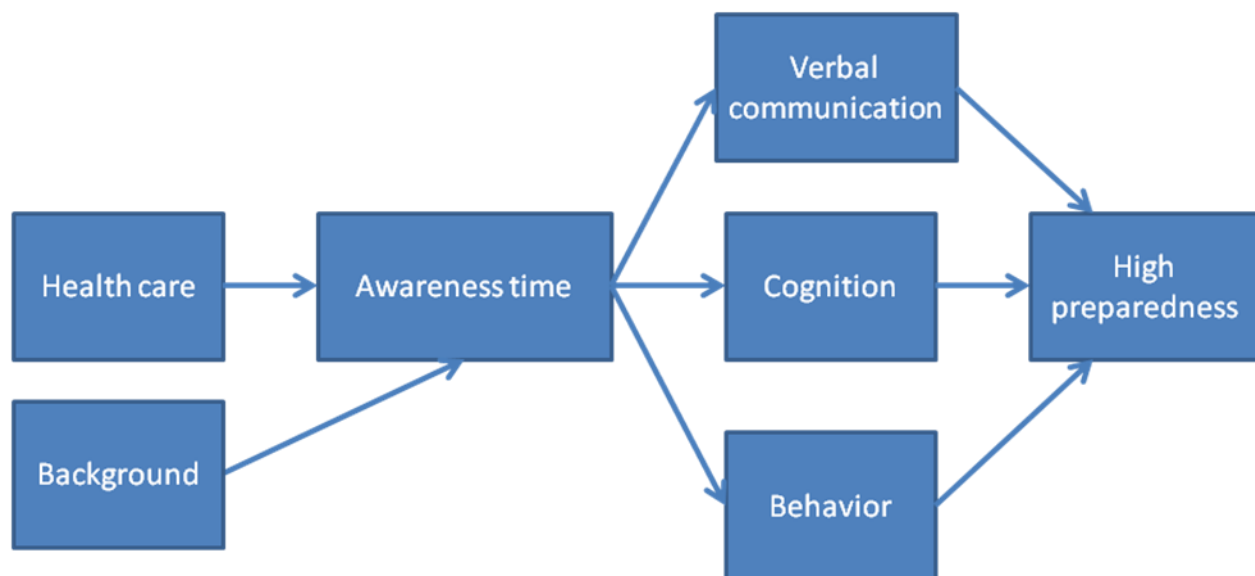
Cognition – mental rehearsal

An important aspect of preparedness for the wife's death may be the widower's pre-death engagement in thoughts and imageries about what is ahead, e.g. moment of death, funeral, and being alone. This mental imagery of what is coming may increase the man's degree of preparedness and might even be encouraged by health-care professionals.

The proposed research model

Based on the interviews and previous research, both from our research group and other scientific literature, we proposed a research model. The model suggests that a man whose wife's is dying of cancer needs some degree of *preparedness* before his wife's death in order to reduce the probability that the moment of death entails an additional psychological trauma which may increase the risk of long-term psychological morbidity. Factors within the health care system (information, support) may either inhibit or facilitate the process of becoming prepared (see figure 1).

Figure 1: Predictors for a man's high preparedness at the time of wife's death:
Proposed causal pathways



Aim

The aim of the study was to identify avoidable risk factors for the long-term physical and psychological morbidity of widowers. In the beginning of the research project, it was hypothesized that:

- 1) Widowers, compared to married men, have a higher risk for psychological morbidity (e.g. anxiety and depression) four to five years after their loss.
- 2) This excess morbidity is determined by the man's degree of preparedness for the wife's death at the time of death.
- 3) A man's preparedness before his wife's death to cancer can be enhanced by the health care system in several ways, for example, by giving more clear-cut information from the physician that the disease is fatal, by encouraging communication between the couple about the future death during the palliative period and by supporting the man in thinking and planning for the future in living without his wife.

Questionnaire – content

Based on our qualitative study, the research model and the literature, a study-specific questionnaire was constructed. The questionnaire was prepared and tested for face-validity on 10 widowers until no changes were suggested by the participants.

Psychological morbidity and well-being

For measuring the men's psychological morbidity at the time of follow-up, the questionnaire included a well-established psychometric scale, Hospital Anxiety Depression Scale (HADS).⁸⁶ Moreover, we included questions on other manifestations of psychological morbidity, for example, emotional numbness, general psychological well-being, if the man felt his life was meaningful or not, quality of life, sleep disturbances and intake of medication (anti-depressants, tranquilizers and sleep medications). We asked, for example, "Have you felt emotionally numb during the last month?" with a scale ranging from 1 (labeled "My life was completely meaningless") to 7 (labeled "My life was completely meaningful"). Questions on intake of medication were for example: "Have you taken sleep medications during the last month" with response categories "No, never", "Yes, 1-3 times per month", "Yes, 1-2 times per week", "Yes, 3-4 times per week", "Yes, 5-6 times per week" and "Yes, every day". Quality of life was measured with a single-item question: "How would you rate your quality of life during the last month?" with a scale from 1 ("No quality of life") to 7 ("Best possible quality of life"). Questions about certain aspects of quality of life were: "How satisfied are you with your appetite?" and "How satisfied are you with your economy?" with scales going from 1 (labeled "Not at all satisfied") to 7 (labeled "Completely satisfied"). Previous psychological morbidity was measured with three questions: "Did you experience anxiety during the year prior to your wife's diagnosis?" and "Did you experience depression during the year prior to your wife's diagnosis?" both answered on a visual-digital scale ranging from 1-7. The following question "Did you receive treatment (medical or psychological) for anxiety, depression or other psychological problems before your wife's diagnosis?" was also included in the questionnaire, with response alternatives being "yes" or "no".

Preparedness

The husband's preparedness was measured with a direct question, referring to the moment of death: "How prepared were you before your wife's death?" The answer was given on a seven-point digital visual scale anchored by "Not at all prepared" and "Very much prepared". Concerning possible predictors for preparedness, the questionnaire included for example questions about the information and the support received during the disease period, about the communication between the man and his wife before death and about the man's thoughts of the future. We asked, "During the last two weeks of your wife's life, did any of the health-care professionals tell you that your wife did not have a long time left to live?" (response categories "yes" or "no")

and “Did you and your wife talk about your wife’s impending death?” and asked if the man (during his wife’s illness) had thought about how he would manage as a widower in the future (response categories for both questions “No, never”, “Yes, once”, “Yes, a few times” and “Yes, several times”).

Receiving information

We assessed whether the widower had been informed that the wife’s cancer was incurable by asking the question, “When did you receive the information that your wife’s illness was incurable?” Responses included “Not relevant, I was never informed” and nine other time point alternatives ranging from “The same day she died” to “More than two years before she died.” The questions asking the widowers if they thought that the next-of-kin and the patient should be informed about the incurability of the illness were phrased: “Do you think the physician should immediately inform the next-of-kin when there is no hope left of cure?” and “Do you think the physician should immediately inform the patient when there is no hope left of cure?”; both of the questions had response categories of “Yes” and “No.” Information on who told the widowers about the incurability of their wife’s cancer was obtained by asking, “Who told you that your wife’s cancer could not be cured?”; the response alternatives were “Not relevant, I was never informed,” “My wife,” “The physician,” “The health-care professionals,” “A family member,” “A friend,” and “Other person.”

Pilot study

The questionnaire was tested in a pilot study for response rate and logistics. The pilot study included 76 men in Stockholm who had lost a wife to cancer (breast, ovarian or colon) in 1999 (see Paper V for details of population). The response rate was 80 percent, which was regarded as sufficient to move on to the main data collection. Due to the scarce literature on the issue, we decided to use the pilot study to investigate if the structure of the questionnaire (sequence of questions) might affect how participants evaluate their current psychological health. We therefore investigated if the participants were more likely to report depression and anxiety after they had answered questions about their wife’s disease period and loss, as compared to before. The men were randomly allocated to one of two questionnaires with identical content but varying design. One version began with questions about the wife’s disease and ended with the respondent’s current well-being (morbidity-last group) and the other version had a reversed order (morbidity-first group) (see Table 1 for illustration).

Table 1 Different design of the questionnaire in the pilot study.

	Morbidity-last group Chronological design	Morbidity-first group Reversed design
Part I	The wife's disease period Awareness of impending death, the couple's communication during the final illness, access to and support from the health care system during the final illness.	Current situation Demographics, well-being and health (psychological and physical): Depression, anxiety and physical symptoms.
Part II	First six months after wife's death Access to and support from the health care system during this period.	The wife's disease period Awareness of impending death, the couple's communication during the final illness, access to and support from the health care system during the final illness.
Part III	Current situation Demographics, well-being and health (psychological and physical): Depression, anxiety and physical symptoms.	First six months after wife's death Access to and support from the health care system during this period.

Results from this methodological investigation nested within the pilot study suggested that the design of the questionnaire might affect reports of psychological morbidity; having gone through questions on a wife's disease period increased the likelihood that participants reported psychological morbidity (Paper V). To avoid the possibility of detrimental bias, we therefore decided to use the "morbidity-first" design in the main study, that is, asking first about the widower's current situation, including questions on psychological well-being, and finally about the wife's disease period and first six months after wife's death.

Main study

Population

For the main study, we identified all women in Sweden who died of cancer in the breast, ovary or colon in 2000 or 2001 and lived in Northern Sweden, Gothenburg, Stockholm or Uppsala health regions at time of death. A diagnosis of cancer 14 days or earlier before death was required. The names and identification numbers of 2473 women were obtained from the Swedish Cause of Death Registry and by record-linkage connected to information in the Swedish Cancer Registry. From the Swedish Population registry we identified whether the women were married at time of death and if their husbands were alive at the time of study. A husband was identified as

eligible for the study if he was 80 years or younger at the time of the study, was born in one of the Nordic countries, had a registered telephone number, understood Swedish and had been living with his wife at the time of her disease and death. Nine hundred and seven men met the criteria and were included in the study (see Table 2). Furthermore, we collected data from a control group of 330 married men who were frequency-matched for age and residence.

Data collection

In the initial phase of the data collection, an introductory letter was sent to all the widowers, with an explanation about the study and an invitation to participate. A week later, we telephoned the widowers and asked them about their willingness to participate; 795 said yes and received a postal questionnaire. The questionnaires were returned by post, and a signed reply card was returned in a separate envelope. Ten days after mailing the questionnaire, all participating widowers received a thank-you-card, also serving as a reminder for those who had not returned a reply card. This reminder was followed up by a telephone call a week later, if necessary. As for the controls, a similar method was used, with the exception that the introductory letter said that a questionnaire would be sent to them a few days later, unless they contacted us and declined participation. This method for data collection has been used in a number of previous data collections within our research group.^{48 49 52 54 59} The questionnaires were sent out from November 2004 to November 2005.

The questionnaires received were entered in the EpiData software program, which was pre-programmed to identify possible false entries (inappropriate values) in an effort to minimize bias. Furthermore, twenty randomly chosen questionnaires were re-entered to test the reliability of data-entering.

All statistical analyses were done by using the statistical programs SPSS and SAS (see manuscripts I-V for details of statistical analyses of each study).

Table 2 Widowers and married men – the study population

	<i>Widowers¹</i>	<i>Married men²</i>
Number of identified deceased women	3473	-
Women who were not married at the time of death	1954	-
Number of identified men	1519	350
Deceased widowers	233	-
Widowers 80 yrs or older	298	0
Not found in the Swedish population register	3	-
No registered telephone number	16	4
Not born in the Nordic countries	62	15
From the Nordic countries, but did not understand Swedish		1
Number of men included	907	330
Deceased after start of data collection	2 (0)	0 (0)
No telephone contact	12 (1)	0 (0)
Refused participation due to:		
- Physical sickness	2 (0)	8 (2)
- Mental sickness	5 (1)	1 (0)
- Psychological burden	26 (3)	1 (0)
- No reason given/other reasons	52 (6)	58 (18)
- Someone else refused (daughter, son, new wife)	10 (1)	0 (0)
- Couple was divorced several years before the wife's death	2 (0)	-
- Husband claimed wife was still alive	1 (0)	-
Agreed to participate but did not return questionnaire	104 (11)	(0)
Number of returned questionnaires (%)	691 (76)	262 (79)

¹ *Widowers: Men in Sweden who lost a wife to cancer in breast, ovary or colon in 2000 or 2001 (Norrland, Göteborg area, Stockholm area, Gotland, Uppsala area included. Malmö and Linköping area excluded.)*

² *Married men: A sample from the general population of 350 married men, 80 years and younger, matched on a group level with widowers for age and residence area.*

RESULTS

Main study

Participation rate and characteristics of the population

The participation rate was 76 percent (691 of 907) for the widowers-group and 79 percent (262 of 330) for the married men (see table 2 for details). Since the two groups were frequency matched for age and residence, these background factors had similar distribution (mean age of widowers was 65.5 and 66.2 for married men). Widowers and married men also had similar levels of education and religiousness and similar employment status (see Paper II, table 2 for further details of the population's characteristics).

Paper I – Well-being of widowers and married men

In this study, the group of widowers was split up by relationship status at the time of follow-up. Widowers in a new relationship were younger, more likely to have finished higher levels of education and more likely to be employed, compared to single widowers. Widowers in a new relationship had a similar risk of psychological morbidity compared to married men. However, compared with widowers in a new relationship, single widowers reported increased risks of (among other symptoms): depression (RR 2.3, CI 1.6-3.3), anxiety (RR 1.7, CI 1.1-2.5) emotional numbness (RR 2.2, CI 1.7-2.8), low or moderate sense of psychological well-being (RR 1.7, CI 1.4-2.1), low or moderate sense of having a meaningful live (RR 2.3, CI 1.8-2.8), waking up at night with anxiety (RR 2.3, CI 1.4-3.7) and having difficulty falling asleep (RR 1.8, CI 1.3-2.4) during the last month before follow-up (RR adjusted for age).

Paper II – Disclosure of incurable illness

Eighty percent of the widowers reported that they were told that the wife's cancer was incurable and a quarter of them were informed within 1 week before the patient's death. 14 percent of the widowers did not think the next-of-kin should be told immediately when the patient's cancer is beyond cure and 39 percent did not want the same information being disclosed to the patient. Seventy one percent of the men who were never informed answered that the next-of-kin should receive that information.

Paper III – Preparedness and long-term psychological health

The purpose of this study was to investigate the impact of a man's degree of preparedness before his wife's death to cancer on his risk of long-term morbidity. Results indicated that men (38 to 61 years old) with low degree of preparedness at time of spouse's death had an increased risk of: anxiety (RR 2.3, CI 1.2-4.3), worrying (RR 1.9, CI 1.3-3.0), emotional numbness (RR 2.2, CI 1.4-3.4), no or little grief resolution (RR 2.5, CI 1.4-4.5), sleep disorders (RR 2.0, CI 1.6-3.4), difficulty falling asleep (RR 2.2, CI 1.3-3.7) and low/moderate quality of life (RR 1.7, CI 1.3-2.2) four to five years after the loss. For older widowers (62 to 80 years old), low degree of preparedness increased the risk of having repeated painful memories (RR 1.9, CI 1.1-3.2), heightened startle response (RR 3.6, CI 1.1-12.0) and no or little grief resolution (RR 1.7, CI 1.1-2.7) at the time of follow-up.

Paper IV – Predictors for preparedness

The purpose of this study was to identify possible predictors for a man's preparedness before his wife's death. Results indicated the following possible predictors, among others: the length of the widower's intellectual awareness time before his wife's death (RR 4.1, CI 2.7-6.1), the widower could take in the information that his wife's disease could not be cured (RR 3.5, CI 2.3-5.2), the couple had arranged their economic affairs (RR 1.5, CI 1.3-1.7), the wife had stayed at a palliative care unit during her last months of life (RR 1.2, CI 1.1-1.4) and health-care professionals supported the husband in participating in his wife's care (RR 1.6, CI 1.3-2.1).

Pilot study

Paper V - Studying optimal design of the questionnaire

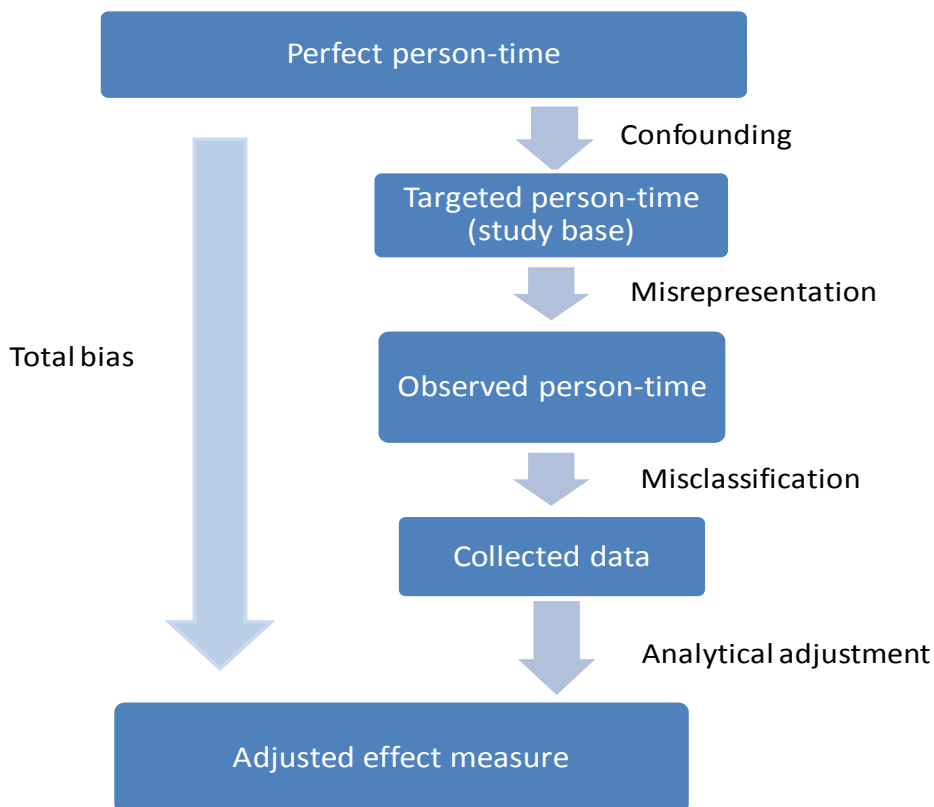
The aim of this study was to determine if the order of questions in a study of men who have lost a wife to cancer affects self-assessed measures of psychological morbidity. Results showed that the design of a questionnaire affected self-assessed psychological morbidity; all relative risks for these measures were above 1.0 in the morbidity-last group, both for anxiety (measured by visual-analogue-scale and HADS) RR 2.6 (CI 0.8-8.8) and RR 3.4 (CI 0.8-15.0) respectively and for depression; RR 3.0 (CI 1.1-8.3) and RR 2.4 (0.5-11.5) respectively for measurement by visual-analogue-scale and HADS.

DISCUSSION

Validity

“The perfect study” is not attainable in real life. In all studies, errors are regarded as systematic or random; while the former may introduce bias to a study, the latter deals mainly with the precision of a study and statistical issues. Within our research group, we have utilized epidemiological methods as applied by the hierarchical step-model for causation of bias⁸⁷ with the aim of minimizing systematic errors (see figure 2). According to the model, each new phase of a study introduces a novel and special source of error. Figure 2 describes how a real life study (for example like ours) departs from the perfect trial and step by step moves toward the calculated adjusted affect measure. In this chapter, these steps are described according to the model and the main sources of systematic errors that may threaten the validity of our study are discussed; confounding, misclassification and misrepresentation.

Figure 2. Different stages in a clinical study with corresponding biasing factors – A hierarchical step-model for causation of bias.



Confounding

Errors introduced during the first step may often be foreseen – having the means to control confounding is central for an epidemiological study like ours.^{88 89} When designing the study, we used restriction to diminish the risk of confounding; we only study men and only widowers who lost a wife from one cause of death, cancer (although including deaths from cancer at three sites may introduce some confounding). We furthermore aimed at including questions on many of possible confounders, like, age, education, number of children, religiousness and previous psychological morbidity to be able to control for these potential sources of confounding if necessary in the analysis part of the study. In Paper I on widowers and married men, confounding may be an issue when comparing single widowers to widowers who are in new relationship at the time of follow-up. Since the latter group is younger, the possibility arises that “age” is the causal factor on psychological well-being after loss, not their relationship status. However, controlling for age in these analyses did not change the relationship between the widowers’ marital status at time of follow-up and their psychological well-being. Another risk for confounding or reverse causation in this study concerns the possibility that healthier widowers became engaged in a new relationship and are consequently also healthier at follow-up - without the new relationship having an effect on health per se. We have no data on the men’s psychological well-being during the whole period elapsed since loss, we cannot therefore exclude the possibility of confounding because of some unmeasured resiliency factor (see Paper I for further discussion).

In paper III, on the man’s preparedness (exposure) and his long-term psychological well-being (the outcome), the man’s previous psychological morbidity (before wife’s diagnosis) may be regarded as a potential confounder, i.e. that the men who were more anxious or depressed in the beginning (before wife’s disease) and were less prepared before their wife’s death are still depressed four to five years after their wife’s loss. However, we did not find any strong association between previous psychological morbidity and preparedness; controlling for previous psychological morbidity did therefore not alter our interpretation that low preparedness is associated with higher risk of long-term psychological morbidity for younger men.

Misrepresentation

According to the hierarchical step-model for causation of bias, the second step of a study may introduce bias due to non-participation and selection-induced problems may therefore occur (difference between targeted person-time and observed person-time). In our study, we used a large population-based cohort of widowers and had a relatively high participation rate (76 percent for the widowers and 79 percent for the married men) which might minimize potential problems of selection. However, we cannot exclude the possibility that those who did not participate were somehow different than the participants (more depressed, lower well-being), which might in turn affect the validity of our results. In Paper I for example, if both widowers and married men are equally likely to dismiss participation due to an underlying depression this would not significantly affect the outcome – on the other hand, if this non-participation is selectively chosen by depressed married men then it would tend to exaggerate the relative risks of a true positive association. Misrepresentation would also occur if men with low degree of preparedness and high levels of morbidity are selectively present among the attrition group – this would bias the outcome estimate towards 1.0. This is of course highly unlikely, but we have no evidence to draw a conclusion on this matter.

Misclassification

Another type of systematic error in a study may originate when the information collected is incorrect for some reason (due to measuring errors).⁸⁹ In the third step of the model, such errors may be introduced, resulting in difference between the calculated effect-measure in the observed person-time and the crude effect measure in the data.⁸⁷ On the whole, we strive to diminish the risk of measuring errors by extensively preparing our measurements in the initial phase of the study. Interviews with men who have the same experiences as the source population, taking into account their perspective when constructing the questionnaire and then testing the questionnaire are two ways towards this mean.

For papers I and V, the main outcome measurements are based on current psychological well-being, as measured by the Hospital and Anxiety scale,⁸⁶ which has been shown to perform well in estimating symptom severity and caseness of anxiety disorders and depression in various populations.⁹⁰ In addition, we used single-item questions that have been tested and used within our research tradition in earlier data collections and/or in our qualitative process. Predictor measurements in studies I and V

are clear-cut, i.e. if the men are involved in a new relationship or not (Paper I) and receiving a certain version of a questionnaire which the researchers had total control over (Paper V).

For papers II-IV it is important to emphasize that we were interested in the long-term situation of widowers, choosing to follow them up four to five years after their wife's death. Part of our study is therefore retrospective concerning the assessment of certain possible causal factors, collecting information on the widower's experiences on events that took place four to five years before follow-up. This may introduce recall-induced problems. As a result, it may therefore be possible that such problems may affect results of studies presented in papers II-IV.

For paper II, in which we asked the widowers if they received the information of the fatal diagnosis of their wife, it is quite possible that some of them, who said that they never received the information, actually received it without acknowledging it. However, this would not have any detrimental effect on the results, since the aim of this particular study was not to make an association with current well-being or to try to explore causal relations of any sort, but rather to describe the widowers' experiences and opinions regarding information from health-care professionals. Here it is the experience of the participants that may be of the essence.

Recall-induced problems might however be important for papers III and IV, if for example, those widowers who are more depressed remember things differently than others, estimating themselves as having been less prepared before their wife's death than they actually were. Memory of the widowers may be affected by their current situation so that the sensitivity and specificity of the measurement of preparedness may vary with the outcome (psychological morbidity), resulting in an unpredictable influence on the effect-measure. This would exaggerate the observed relative risk. Or, as in paper IV, having been less prepared makes the participant remember health-care related factors in a different way producing a false association between a potential predictor of preparedness and degree of preparedness. However, we have no data indicating that recall-induced problems vary between preparedness categories. In a previous study of bereaved parents and the length of their awareness time before their child's death to cancer, the authors did not observe any clear relationship between ratings of short awareness time and time from bereavement (that ranged from 4-9 years) - implying that potential recall-induced problems do not change with time of follow-up after loss.⁶² Still, we cannot exclude the possibility that false recall may differ between categories of dependent variables (e.g. depression at follow-up) and

thus affect the relationship between degree of preparedness and psychological well-being at follow-up.

Random error

Errors regarded as random, are those who remain after systematic error is eliminated. Statistics are used to estimate effects after correcting for biases such as confounding.⁸⁹ In all of our papers, we present our results as relative risks with the use of 95 percent confidence intervals as measurements of precision in the point estimate of the effect measure. In paper IV we also performed a statistical test, obtaining a p-value, to investigate whether or not noise explains the deviation from unity for the effect measure.

Findings

Psychological health of widowers and married men

When comparing the long-term well-being of widowers and men not having lost their wife, our findings emphasize the importance of taking the widowers' current marriage status into account. Four to five years after the loss, widowers who have remained single have an increased risk of psychological morbidity, while widowers who are involved in a new romantic relationship at the time of follow-up have a risk of psychological morbidity equal to that of men who have not lost their wives. The question arises - does new love heal?

In general do widowers show more interest in dating and forming new romantic relationship than widows; this has been shown to be true both six months (17 percent of widowers and 6 percent of widows interested in dating) and 18 months post loss (37 percent of widowers and 15 percent of widows).⁹¹ Another study found that by 25 months after a spouse's death, 61 percent of widowers are remarried or involved in a new romantic relationship, and 19 percent of widows.⁹² Interestingly, this association was not modified by gendered patterns in the marriage with the deceased spouse, for example, if one had to rely on the spouse for home maintenance or homemaking. The authors of this study point out that interest in dating and remarrying might reflect the desire for emotional support and companionship, rather than wish for instrumental support or economic stability. Being remarried has been associated with better psychological well-being;⁹² however, another study did not find any relationship between romantic involvement and depressive symptoms after having controlled for

socioeconomic status.⁹¹ This relationship may also be gender-specific, as noted by Chipperfield and Havens; gaining a new spouse may bring more benefits for a widower than for a widow.⁴⁴ In addition, remarriage after a loss of a spouse has been found to decrease mortality rates for widowers, but not so for widows.²²

When comparing long-term psychological well-being of widowers and married men, current marital status of the widowers may therefore be of importance. The mechanism behind this effect remains unclear. The possibility of a) a selection of more healthy widowers into a new relationship and b) the beneficial nature of social support of a new relationship are two proposed explanations for the results (see Paper I for detailed discussion).

Preparedness before the death of a wife

In papers IV and V, we focused on the man's degree of preparedness before his wife's death due to cancer and on determining if such preparedness could possibly be affected by the health care system in some way. We found that a man's low degree of preparedness at the time of his wife's death due to cancer is associated with his increased risk of anxiety and anxiety-related symptoms four to five years after the loss for younger men (age 38 to 61 at the time of follow-up). Furthermore, for this age group, we found that a low degree of preparedness is associated with increased risk of sleep disorders, experiencing emotional numbness, low or moderate quality of life and having had no or little work through grief at the time of follow-up. The pattern was not as evident for men in the older group (62 to 80 years old). In addition, we identified several factors that predicted for a man's high preparedness at the time of his wife's death such as: how long the husband had known that his wife would die from her disease (awareness time), if he could take in the information that his wife's disease could not be cured, if health-care professionals made it easier for him to participate in his wife's care, if the wife had stayed at a palliative care unit during her disease period, if the couple had arranged their economical affairs before the wife's death and if the widower could spend as much time as he wanted with his wife during her last three months. It may be assumed that some of these factors, such as clarity of information and support from health-care professionals, might be modifiable within the health care system to the benefit of long-term health of the widowers.

Previous studies on forewarning (measured by various means) have either indicated that preparedness before a death of a loved one is of benefit for the surviving relative,^{60 62-65 72-75} or that it is not.^{67-71 93} However, interpretation of results of some of those studies may be hampered due to the small number of participants, low

participation rate, short follow-up time or confounding. Of the seven studies retrieved that had reasonable participant numbers (100 or more) and a stated participation rate over 50 percent, results from five of them indicated that not being prepared (or forewarned) before the death of a loved one increases the risk of psychological problems for the relative after loss.^{60 62 65 73 74} For example, Barry and co-workers investigated 122 bereaved persons and found that perception of lack of preparedness at time of death was associated with complicated grief four months and nine months post loss as well as major depressive disorder nine months after loss.⁶⁵ Furthermore, they found that depressive symptoms increased in the unprepared group between four and nine months after loss, indicating the possibility that as time passes after the loss, the risk of morbidity due to low preparedness increases. The time point of follow-up may therefore be of vital importance when investigating the effect of preparedness on long-term morbidity. Our findings imply that the effects can be more prolonged than have been assumed until now (up to four to five years after death) and include more diverse symptoms of morbidity than previously reported, including anxiety, low or moderate quality of life and sleep disorders. Our population-based study, including 907 widowers, high participation rate, one cause of death (cancer) and follow-up time of four to five years may therefore hopefully extend the existing knowledge base on this issue.

Regarding predictors for preparedness – how to make the next-of-kin more prepared for the death of a loved one – the literature is very limited. Results from our study on widowers indicate that receiving information on the fatal prognosis is a prerequisite for being able to prepare (Paper IV), results also founded in previous studies within our research group on factors that affect the length of awareness time.⁶⁰ ⁶² Receiving information is indeed wanted by the next-of-kin; 86 percent of the widowers in our study reported that the next-of-kin should be given immediate information if the disease could not be cured (see Paper II), which is similar to percentages found in other studies.⁹⁴ Results from another study showed that if patients and caregivers had engaged in end-of-life discussions with a doctor, the patient received less aggressive medical care at the end of life and was more likely to receive hospice services for more than a week.⁹⁵ This in turn led to better quality of life and mental health for the surviving caregiver after loss (a median follow-up time of 6.5 months post loss). These data indicate that not only is such communication wanted by the relatives, it is also of benefit for their long-term mental health. However, many of the widowers in our data reported lack of information, 41 percent of the husbands

reported that they received information on the fatal prognosis during the last week of the patient's life or not at all (Paper II). In yet another study including 122 bereaved persons, the authors found that 20 percent reported that health-care professionals could have done something more in preparing them for the death of their loved one, including providing better information from the physician concerning prognosis and if and when death might be expected.⁸² The above results indicate that there is probably room for improvement in the level of communication between health-care professionals and husbands of women with incurable cancer.

Not surprisingly, husbands of patients that had stayed at a palliative care unit at any time point during disease period were better prepared for the death of the wife than others (Paper IV). Palliative care often involves a family-focused approach or provision of enhanced psychological support, including end-of-life discussions, which may help the patient and the family members to be better prepared for the coming death. Still, the difference in preparedness for "palliative" husbands and others was not as high as might have been expected; 64 percent of those whose wife had stayed at a palliative care unit reported high preparedness, compared to 52 percent of other widowers (RR 1.2, CI 1.1-1.4).

Our experience from the qualitative study (conducted in the beginning of the project) stressed the importance of activating husbands in their wife's care and providing them with support, on their own terms, which might mean a different kind of support than for female spouses. While some men may benefit from "support meetings" others may benefit more – and be more likely to attend – an "information meeting". Some men benefit from deep emotional discussions with their wife's palliative nurse – while other men have a desperate need to talk about the weather or about the truck in their garage. In conclusion, men need and benefit from support. Whatever the support may be, it results in providing them with a more valuable time with their wife during the disease period and if worse comes to worst – provide the widower with precious memories, which may strengthen him for the difficult consequences of loss.

In conclusion, our results indicated that to improve the long-term situation for widowers after a wife's death it may be fruitful to test care-related facilitators of preparedness in intervention studies aiming at influencing preparedness before the death of a loved one.

Structuring a valid questionnaire

In our preparation phase, we worked thoroughly with identifying the right questions to ask and how to construct them to build a questionnaire that would help us in confirming or rejecting our hypotheses. The structure of the questionnaire was a special concern, since results from some studies have suggested that thinking about positive and negative experiences from the past might affect the participants' current stage of emotions.^{96 97} We did not find any methodological study specifically aimed at investigating the structure of a bereavement related questionnaire and therefore utilized our pilot study to identify the optimal design. We found that the order of questions in our study specific questionnaire affected the widowers' ratings of self-assessed psychological morbidity: we obtained higher relative risks when questions of current levels of depression were last in the questionnaire as compared to when they were first. We therefore concluded that when studying traumatic events such as bereavement and the intention is to compare to a group not having experienced such trauma, it is probably best to begin a questionnaire asking questions on current well-being, to avoid a systematic error which might threaten the validity of the study. This conclusion led us to change the structure of the questionnaire for the main study, from asking chronologically (questions on disease period first, then questions on psychological morbidity) to reversed-design, that is, asking first about psychological health, then about wife's disease period.

Ethical issues

For our research projects, the ethics are of special concern – we ask our participants to go through an extremely difficult period in their life and ask them questions that may be sensitive. In each step of our data collection process, initially developed for women having experienced stillbirth,⁵⁷ we therefore strive to minimize potential harm that might be inflicted by being contacted and going through difficult memories. Our experience from collecting data from close to 10,000 subjects in several data collections tells us that the first introductory letter, as formulated by us, and the first telephone call do not cause harm. The introductory letter clearly states why the subject has been selected (in this case because he is a widower) and that it is easy to interrupt participation at any point without any pressure from us. Thorough work with the questionnaire to insure that the participants realize it is tailored for them increases the motivation to take part, and then to anonymously (also for us) return the questionnaire. Since many of the widowers are still suffering after their loss, we

invited everyone to break the anonymity and contact us to talk or to get contact information for additional support. At the end of the questionnaire we asked the participants three questions on how they experienced completing the questionnaire. Results from these data point out that almost all the participants (99 percent) found the study valuable (Hauksdóttir and co-workers, unpublished data). In addition, 73 percent were moderately or much positively affected by their participation and 25 percent were negatively affected (and some of them were also positively affected). Similar results were found in the study of Kreicbergs and co-workers on parents having lost a child to cancer.⁹⁸

The results from the surveys, the content of the large amount of text written in the open-ended questions in the questionnaires, as well as our personal experience from earlier projects tell us that the psychological suffering the questionnaire induces is limited. In fact, the telephone contact with the widowers and their answers to the open-ended questions gave us the impression that even though the subject was difficult, the widowers were grateful for being contacted, grateful for being able to share their experiences and grateful for possibly having helped others in the same situation. However, we have no data to be able to draw conclusions on the potential long-term effects of completing the questionnaire.

THE FUTURE

As pointed out before, there is a great imbalance in the number of studies that have been done on widows and widowers, with the greater number being research on widows. Still, the literature points to the fact that widowers suffer after the loss of a wife even more than widows do after the loss of their spouse. This indicates that there indeed is room for improvement in helping widowers and by so doing decreasing their mortality and psychological and physical morbidity.

Of course, our findings raise further research questions, for example:

- Based on our results on predictors for preparedness, the next step is to conduct a prospective intervention study. Important research questions are: which factors have the greatest effects on preparedness and which are most easily modifiable by health-care providers? Such an intervention study might include the factors identified and reported in Paper IV, along with others, with the aim of sorting out factors with the strongest joint effect on preparedness after intervention-induced changes.
- Widowers who are still single four to five years after their loss have an increased risk of psychological morbidity compared to widowers who have entered a new romantic relationship. This fact raises interest in two potential research questions: a) Identifying predictors for entering a new relationship which appear to be an important factor for the men's well-being, and b) Modifying a simple intervention program for widowers who remain single, possibly by providing social support and promoting positive health related behavior (alcohol intake, nutrition habits, physical activity).
- From a qualitative perspective, the questionnaires contain massive amount of qualitative data from the open-ended questions asked at numerous places in the questionnaire. Analysis of these would contribute to and deepen our knowledge of various aspects of the wife's disease period, like, who wants information and who does not, preparedness, life afterwards and what constitutes quality of life for those men who lose a wife to cancer.
- 86 percent of the widowers stated that a relative should be immediately informed about a fatal prognosis of the patient, 14 percent stated the opposite. For health-care professionals it becomes of interest to identify the willingness of the relative to receive such information. For example, for those 14 percent

who do not want immediate information, do they want information later, or not at all?

CONCLUSIONS

Our research method places special importance on identifying additional and avoidable risk factors for long-term psychological morbidity for those who lose a loved one. The knowledge from this study can hopefully contribute to the scientific literature, with the aim of implementation within health care to eliminate the risk factors and thereby increase the well-being and quality of life for men who lose a wife in cancer.

In conclusion, we found that:

- Four to five years after the loss, widowers who have remained single have an increased risk of psychological morbidity, while widowers who are involved in a new romantic relationship at the time of follow-up have a risk of psychological morbidity equal to that of men who have not lost their wives.
- 86 percent of the widowers believed that the relative should be informed immediately about the incurable nature of the disease. More than 40 percent of the men were either never told that their wife's condition was incurable or were informed at a late stage (during the last week of her life).
- For younger men (age 38 to 61 at the time of follow-up), we found that a man's low degree of preparedness at the time of wife's death due to cancer is associated with increased risk of anxiety and anxiety-related symptoms, sleep disorders, experiencing emotional numbness, low or moderate quality of life and having had no or little work through grief four to five years after the loss. The pattern was not as evident for men in the older group (62 to 80 years old).
- Several factors that predicted for a man's high preparedness at the time of his wife's death were identified, such as: how long the husband had known that his wife would die from her disease (awareness time), if he could take in the information that his wife's disease could not be cured, if health-care professionals made it easier for him to participate in his wife's care, if the wife had stayed at a palliative care unit during her disease period, if the couple had arranged their economical affairs before the wife's death and if the widower could spend as much time as he wanted with his wife during her last three months.
- Lastly, we found that the order of questions in our study specific questionnaire affected the widowers' ratings of self-assessed psychological morbidity:

higher relative risks were obtained when questions of current levels of depression were last in the questionnaire as compared to when they were first.

SUMMARY IN ICELANDIC

Bakgrunnur: Oft er sagt að sorgin sé spegilmynd ástarinnar. Fyrir utan þá sorg sem fylgir ástvinamissi, eru þeir sem eftir standa í aukinni áhættu á langvinnnum sálrænum og líkamlegum heilsubresti, jafnvel dauða. Því er mikilvægt að rannsaka áhættuþætti heilsubrests í þessum hópi, með áherslu á þætti sem má breyta með inngrípum.

Markmið rannsókna: Að greina breytanlega áhættuþætti fyrir langvinnan sálrænan heilsubrest ekkla. Þær tilgátur voru settar fram að: a) Samanborið við gifta menn hafi ekkjar meiri áhættu á sálrænum heilsubresti 4-5 árum eftir missi eiginkonu úr krabbameini, b) að lítil undirbúningur fyrir lát eiginkonu auki líkur á sálrænum heilsubresti ekkilsins 4-5 árum eftir missinn og c) að þættir í heilbrigðisþjónustunni geti haft áhrif á hversu undirbúinn maðurinn er fyrir lát eiginkonu sinnar.

Aðferð: Í kjölfar djúpvíðtala við ekkla var saminn sérstakur spurningalisti sem innihélt m.a. spurningar um sjúkdómstíma konunnar og núverandi líðan mannsins. Spurningalistinn var forprófaður í viðtölum og í forrannsókn á ekkjum (N=76) til þess að athuga virkni spurninga og svarshlutfall. Aðalhluti rannsóknarinnar, sem byggðist á faraldsfræðilegum aðferðum, tók til 907 manna í Svíþjóð sem misst höfðu eiginkonu úr brjóst-, eggjastokka- eða ristilkrabbameini árið 2000 eða 2001. Að auki var gögnum safnað frá 330 giftum mönnum til samanburðar sem paraðir voru við ekkjana með tillit til aldurs og búsetu. Gagnasöfnun fór fram frá nóvember 2004 til nóvember 2005.

Niðurstöður: Svarshlutfall var 76% (ekklar) og 79% (giftir menn). Í ljós kom að þeir ekkjar sem enn voru einhleypir 4-5 árum eftir lát eiginkonu sinnar voru í aukinni áhættu á sálrænum heilsubresti samanborið við ekkla sem voru komnir í nýtt ástarsamband á sama tíma. Mesta áhættan mældist fyrir þunglyndi (RR 2.3), tilfinningadoða (RR 2.2) og að vakna upp á næturnar með kvíða (RR 2.3). Sálrænt heilsufar ekkla sem komnir voru í nýtt ástarsamband var sambærilegt við samanburðarhóp giftra manna sem ekki höfðu misst eiginkonu.

Ekkjarnir voru spurðir sérstaklega um viðhorf sitt til þess hvort upplýsa eigi um að sjúkdómurinn sé ólæknandi. 86% ekkjana töldu að upplýsa ætti nánasta ættingja strax og ljóst er orðið að krabbameinið verður ekki læknað. 80% ekkjana var sagt að krabbamein eiginkonu þeirra væri ólæknandi, þar af fjórðungi í vikunni fyrir lát hennar.

Ennfremur kom fram að lítil undirbúningur mannsins fyrir lát eiginkonu eykur hættu hans á m.a. kvíða (RR 2.3), tilfinningadoða (RR2.2) og svefnörðugleikum (RR 2.2) 4-5 árum eftir lát eiginkonunnar. Þetta gildi frekar fyrir yngri ekkla (38 til 61 árs) en eldri ekkla (62-80 ára). Forspárþættir fyrir undirbúning voru t.d. hversu lengi ekkillinn hafði vitað fyrirfram að eiginkona hans myndi deyja (RR 4.1), ef hann gat meðtekið þær upplýsingar að sjúkdómur eiginkonu hans væri ólæknandi (RR 3.5), ef parið hafði komið fjármálum sínum í horf fyrir lát konunnar (RR 1.5) og ef konan hafði dvalist á líknardeild um tíma síðustu mánuði ævi sinnar (RR 1.2).

Lærdómur: Ekkjar sem eru einhleypir 4-5 árum eftir missi konu sinnar eru í aukinni áhættu fyrir sálræna erfiðleika. Að auki virðist magn undirbúnings fyrir lát eiginkonunnar skipta miklu máli fyrir langtíma sálræna og líkamlega heilsu yngri ekkla. Rannsóknin gefur vísbendingar um forspárþætti fyrir undirbúning, sem mögulega má hafa áhrif á innan heilbrigðisþjónustunnar.

Hagnýting: Bætt umönnun í aðdraganda andláts eiginkonu úr krabbameini getur minnkað áhættu ekkla á langvinnnum heilsubresti. Nota mætti niðurstöður þessarar rannsóknar í íhlutandi rannsókn með það að markmiði að hafa áhrif á undirbúning fyrir ástvinamissi. Slík íhlutun gæti haft lýðheilsuleg áhrif með því að minnka sálræn og jafnvel líkamleg heilsufarsvandamál ekkla.

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*Hey Jude, don't make it bad.
Take a sad song and make it better.
Remember to let her into your heart,
Then you can start to make it better.*

(John Lennon/Paul McCartney, 1968)