

**THE LOSS OF A HUSBAND TO CANCER:  
ADDITIONAL AND AVOIDABLE PSYCHOLOGICAL TRAUMATA**



**Unnur Anna Valdimarsdóttir**



**Stockholm 2003**

*Til mömmu og þabba*



*Takk fyrir ykkur, takk fyrir mig.*

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## LIST OF PAPERS

This thesis is based on the following papers, referenced to by their Roman numerals:

- I. Valdimarsdóttir, U., Helgason, Á., Fürst, C-J., Adolfsson, J. & Steineck, G. (2003). Long-term effects of widowhood after terminal cancer: a Swedish nationwide follow-up. *Scandinavian Journal of Public Health*, 31, 31-36.
- II. Valdimarsdóttir, U., Helgason, Á., Fürst, C-J., Adolfsson, J. & Steineck, G. The wife's awareness time when a husband dies of cancer: A nationwide follow-up of Swedish widows. *Submitted*.
- III. Valdimarsdóttir, U., Helgason, Á., Fürst, C-J., Adolfsson, J. & Steineck, G. (2002). The unrecognised cost of cancer patient's unrelieved symptoms: a nationwide follow-up of their surviving partners. *British Journal of Cancer*, 86, 1540-1545.
- IV. Valdimarsdóttir, U., Helgason, Á., Fürst, C-J., Adolfsson, J. & Steineck, G. Needs for and access to bereavement support: a nationwide follow-up of women who lost their partner from cancer. *Submitted*.

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## ABSTRACT

**Background:** The loss of a loved partner is a stressful event and the long-term outcome of such a trauma may partly be determined by characteristics of the death. When death is the result of a chronic illness such as cancer, the future widow may have an opportunity to prepare for the forthcoming death but may also be exposed to the additional burden of her husband's suffering. We investigated long-term physical and psychological morbidity of widows who had lost their husband to cancer and risk factors for such morbidity; risk factors being the length of time the widow was aware of the impending death (awareness time) and exposure to unrelieved suffering.

**Methods:** We identified all men in Sweden 74 years or younger who had died owing to cancer of the prostate 1996 or of the urinary bladder 1995 or 1996, after a minimum disease duration of 3 months. All their surviving widows or partners (n=506) who were alive on the 1<sup>st</sup> of April 1999 and were 79 years or younger were contacted and compared to an age-matched control group of women married to or living with a man (n=287). The widows anonymously answered a questionnaire concerning their husband's disease and death, and both groups answered questions regarding their current health and functioning.

**Results:** We received 379 (75 percent) questionnaires from the widows and 220 (77 percent) from the controls. The groups (mean age 67 years) were similar on all background characteristics and by an average of three years had elapsed from the time of death. Compared with controls, the widows had increased risk of anxiety (relative risk (RR) 1.9), depression (RR 2.2), sleep disturbance (RR 2.0), diabetes (RR 3.5) and economic dissatisfaction (RR 1.6). The widows' duration of time with awareness of the impending death varied greatly, with 48 percent having 3 months or shorter and 15 percent 24 hours or shorter. Awareness time predicted the widows' risk of psychological morbidity, with short awareness time carrying the highest risk, awareness time of three to six months typically carrying the lowest risk and awareness time of one year or longer having a tendency to give an increased risk. Compared with awareness time of three to six months, time of 24 hours or less gave a relative risk for anxiety of 1.9 and for depression 1.6. Information and psychological support from health care givers were the greatest predictors of awareness time; the absence of such predicted short awareness time. The patient's unrelieved psychological symptoms (but not physical) predicted the widows' psychological morbidity. If the patient was reported anxious during the last three months of life the relative risks for the widows' depression was 2.5, the corresponding figure for patient's unrelieved pain was 0.8. Thirty-three percent of the widows reported moderate or much access to psychological support for the patient but 93 percent reported access to physical pain relief. Approximately two-thirds of the widows indicated a need for contact with health care (information, psychological support or economic advice) during the first six months following their husband's death, but only about 20 percent of these reported access to such.

**Conclusion:** A widow's long-term risk of psychological morbidity following the death of her husband from cancer is determined by her awareness time and exposure to the patient's unrelieved psychological symptoms. These risk factors are in turn closely related to the quality of health care; working for an optimal awareness time and relieving the patient's anxiety and depression may benefit the long-term situation of the surviving spouse.

**Key words:** widowhood; neoplasms; risk factors; communication; prognosis; adaptation, psychological; anxiety; depression; epidemiology.

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## I. INTRODUCTION

Although marriage or partnership affords some protection against mortality (Lund, Due, Modvig, Hostein, Damsgaard & Andersen, 2002), every continuing relationship will ultimately end with one of the partners dying. While relatively peaceful times and economic and technological prosperity have diminished the risk of premature deaths owing to life struggles and war, deaths owing to chronic diseases are now the leading causes of death in the western world. In Sweden alone, approximately 22,000 people die each year owing to cancer (23% of all deaths) and almost 50 percent of the dying patients leave behind a living partner or spouse (Causes of death, 2002). Improved diagnostic and life-prolonging means have increased the duration of time cancer patients live with their disease (Sato, Arimoto, Ishikawa, Yoshimura, Kaneko, Koshiji, Talada & Yamaguchi, 2002; Paquette, Sun, Paquette, Conelly, Mcleod & Moul, 2002); this may add to the impact of the terminal illness on the surviving spouse.

Irrespective of the cause of death, the loss of a loved partner or a life-long spouse is inevitably a stressful event exposing the widow(er) to enormous challenges. The notion of a terminal illness preceding the loss implies both the threat of being exposed to additional suffering (e.g. the patient's) but also the opportunity of preparing for the loss. Professional health caregivers are usually present during the process of terminal illness and their work and interventions affect the patient's and the surviving partner's life and well-being. The prospect of health care interventions influencing the long-term outcome of widowhood motivated this research project.

### *1.1. The experience of widowhood – grief*

Grief has been defined as the emotional reaction to the loss of a loved one through death (Stroebe, Hansson, Stroebe & Schut, 2001). In addition to the psychological pain, grief incorporates cognitive and behavioural mechanisms as well as a physiological strain. Widowhood implies not only the loss of an affectionate bond to another person per se, but also secondary losses of physical, emotional, sexual, social, practical and financial support. The importance of these secondary losses will vary from one widow to another.

The widow has to revise her “assumptive world” (Parkes, 1975) - her assumptions about herself, her husband and her life, and establish a new identity in a changed world.

### *The emotional reaction*

It is reasonable to believe that there is a fixed, evolution-based, emotional component in human grief. When social animals are separated from their social group they show a fixed behaviour pattern of separation distress - intense vocalisations followed by a behaviourally inhibited despair phase (Panksepp, 1998). These responses can be induced artificially by electrical stimulation of sub-cortical structures of the animal brain, or the so-called “panic circuit,” proximate to areas mediating physical pain (Panksepp, 1998). Humans show similar responses of separation distress or grief when faced with the loss of a significant other.

From studies of children separated from their mothers and of adult widows and widowers reactions to their loss, Bowlby and Parkes (1970) described human stages of grief to be: 1) shock or emotional numbness, 2) yearning and searching (or pangs of grief/separation anxiety), 3) disorganisation and despair (depression), and 4) reorganisation and adjustment (in Parkes, 2001). These stages do not pass in an orderly fashion or in a given time range - the stage model describes roughly how human grief passes through the emotional sequelae of anxiety responses resulting in depression-like state before the individual adapts to the new reality. Interestingly, childhood separation distress has been associated with risk of both panic disorder (Manicavasagar, Silove & Hadzi-Pavlovic, 1998) and depression (Kendler, Sheth, Gardner & Prescott, 2002) in adult non-bereaved populations. Thus, although grief may involve many different emotions (e.g. anger, craving search, relief, guilt and loneliness), there is reason to believe that anxiety and depression may be the core of the emotional response to loss of a partner.

The emotional reactions that characterise the different grief stages have been documented among the widowed. Half of the widows in Parkes’ London study reported to have experienced a period of emotional numbness starting within a few minutes following their loss and lasting from hours to a few days (Parkes, 1972). In a study of 350 widows and widowers, Zisook and Shucter (1993) reported that at two months post loss,



12 percent suffered from emotional numbness, 70 percent found the death hard to believe and 21 percent could not accept the death. At 13 months, numbness had dropped to 4 percent, not accepting to 12 percent, but disbelief was still reported by 49 percent of the sample.

Symptoms of anxiety are well documented during the first year of bereavement (Parkes, 1972; Jacobs, Hansen, Kasl, Ostfeld, Berkman & Kim, 1990; Zisook & Shuchter, 1991; Surtees, 1995). Jacobs and co-workers found that 25 percent of widows and widowers met criteria for at least one type of anxiety disorder during the first six months of bereavement and 44 percent during the second part of the first year. Generalised anxiety disorder (GAD) and panic disorder were most prevalent: the bereaved had 10-20-fold increase in risk of panic and 2-5-fold increase in GAD compared with community rates (Jacobs *et al.*, 1990). Moreover, two months post loss owing to chronic illness, 10 percent of the widowed have been reported to suffer from post-traumatic stress disorder (Zisook, Chentsova-Dutton & Shuchter, 1998). Little is known about the duration of time anxiety symptoms are overrepresented in the widowed population or indeed if they ever return to normal levels. The studies of Prigerson and co-workers indicate that the rates of high anxiety do not decline during the first year of bereavement like rates of depression, but continue to be stable during the second year of bereavement (Prigerson, Bierhals, Kasl, Reynolds, Shear, Day, Beery, Newsom & Jacobs, 1997).

Elevated depression levels among the widowed have been well documented during the first (Jacobs, Hansen, Berkman, Kasl & Ostfeld, 1989; Zisook & Shuchter, 1991; Harlow, Goldberg & Comstock, 1991) and second year of widowhood (Parkes & Brown, 1972; Zisook, Paulus, Shuchter & Judd, 1997; Turvey, Carney, Arndt, Wallace & Herzog, 1999; Carnelley, Wortman & Kessler, 1999). In the study of Zisook and co-workers (1997), the rates of minor and major depression among the widowed were: 40 percent at 2 months, 38 percent at 7 months, 29 percent at 13 months, 20 percent at 19 months and 19 percent at 25 months, compared to 3 percent in a married comparison group. As with anxiety, it is not clear for how long depression is overrepresented in the bereaved population; Turvey *et al.* (1999) and Carnelley *et al.* (1999) found no difference for those widowed for more than two years whereas Parkes and Brown (1972) found elevated levels for widowers and Bennet (1997) for widows up to 4 years post loss.

### *The stress reaction – effect on health and functioning*

The presence of threat (stressor) causes an adaptive physiological reactivity – arousal - that empowers us to “fight or flee”. This involves activation of the sympathetic nervous system and a neuroendocrine system known as the hypothalamic-pituitary-adrenal (HPA)-axis (Sternberg & Gold, 1997). Prolonged or inescapable (chronic) stress, as in the case of bereavement, may impair the negative feedback function of the HPA-axis resulting in high levels of cortisol and suppressed immune function (Sternberg & Gold, 1997; Sarafino, 2002). Bereavement has been associated with inability to suppress cortisol (Shuchter, Zisook, Kirkorowicz & Risch, 1986; Jacobs, Mason, Kosten, Kasl, Ostfeld & Wahby, 1987; Weller, Weller, Fristad & Bowes, 1990) and impaired immune response (Irwin, Daniels, Risch, Bloom & Weiner, 1988) especially if the bereavement reaction is marked by high psychological distress.

Widowhood has also been related to worsened health related behaviours such as poor dietary habits and less physical activity (Rosenbloom CA & Whittington FJ, 1993). Whether caused by chronic stress or altered behaviour, or both, widowhood has been associated with worsened physical health (Thompson, Breckenridge, Gallagher & Peterson, 1984; Prigerson, Maciejewski & Rosenheck, 1999) and increased mortality (Mellström, Nilsson, Oden, Rundgren & Svanborg, 1982; Lichtenstein, Gatz & Berg, 1998). Thomson and co-workers found 40 percent increase in risk of new or worsened physical illness and 70 percent increased risk of new or increased medication use among the widowed two months post loss (Thompson *et al.*, 1984).

### *Coping*

What complicates the description of human grief is our unique neocortex and the diversity of social environments and modes in which human loss experiences occur. We can exaggerate or extend our emotional reaction through appraisal of the loss and our situation, and by memories of and ongoing interaction with the diseased. But we also possess cognitive and behavioural strategies to cope with our emotional reactions, adapt

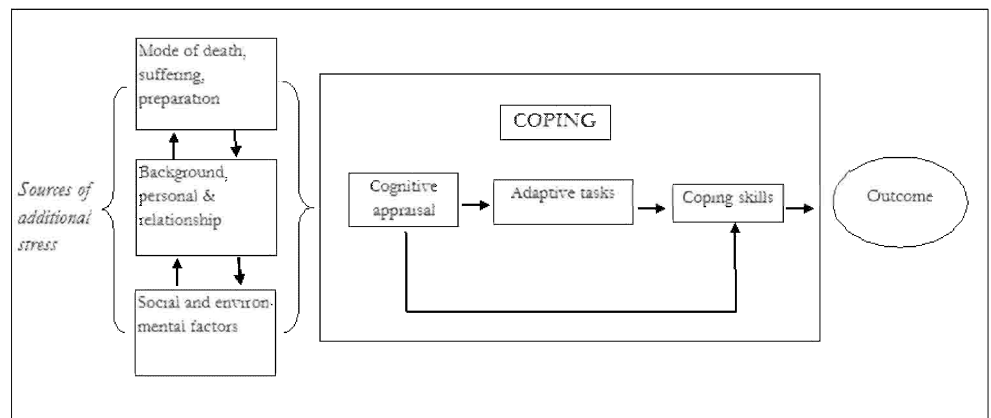
to the new reality and establish a new identity. Some of these coping strategies have been documented by Zisook and Shucter (1993). Of 250 widows and 100 widowers interviewed at 13 months post loss, 49 percent still found the death hard to believe (disbelief), 47 percent pushed their feelings away, 34 percent found the spouse's death for the best (rationalisation), 70 percent found comfort in faith, 16 percent avoided items associated with or memories of the deceased, 38 percent talked to others and 60 percent thought and expressed feelings about the deceased, 59 percent had become involved in helping others, 30 percent had increased their alcohol intake and 40 percent increased their smoking.

Confrontation with or avoidance of the reality of loss is a central issue in studies of adaptive coping in bereavement. Although research indicates that traumatised individuals benefit in terms of psychological and physical health by confronting the traumatic experience in writing assignments (Smyth, 1998), the evidence that this also works for the bereaved is not as convincing. In a recent study, no differences were found in psychological health or frequency of physician visits of widows and widowers with respect to self-assessed emotional disclosure or experimental writing tasks (Stroebe, Stroebe, Schut, Zech & van der Bout, 2002). On the other hand, some studies have found that consequences of confrontation or disclosure vary depending on whether it is characterised by negative or positive appraisal of the bereavement experience, negative appraisal being detrimental (Nolen-Hoeksema, Parker & Larson, 1994) while positive appraisal may enhance adjustment (Bonanno & Keltner, 1997). Stroebe and Schut have summarised existing evidence and theoretical perspectives into the Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999). The model considers adaptive coping as being an oscillation between two kinds of stressors, "loss oriented" (lost relationship) and "restoration oriented" (secondary losses), and then avoidance of stressors of any kind. It also incorporates the idea that appraisal and meaning construction when confronted with these two kinds of stressors may be positive or negative.

How a widow copes with her loss and widowhood, in terms of appraisal of the event and coping style, will not only depend on her predispositions (e.g. proneness to psychological distress and general coping capacity), but also on the nature of the stressor. Adapting Moos' crisis model (1982) (in Sarafino, 2002) to bereavement provides a useful summary of stressors and coping processes leading to a bereavement outcome.

Bereavement incorporates one constant stressor; loss of a loved one. Appraisal, coping and the outcome are likely to be affected by the additional stressors of the loss experience owing to differences in: 1) mode of death, 2) the widow's background, predisposition and relationship with her husband, and 3) the level of social resources.

Some aspects related to the mode of death have received little attention in the literature; other aspects have received considerable attention, but definite conclusions have been hampered by methodological difficulties. Mode of death as a risk factor for bereavement outcome is the main theme in the studies included in this thesis.



**Figure 1:** *The crisis of bereavement – Adaptation from Moos' (1982) crisis model.*

## ***1.2. Beyond normality***

In a scientific context, one must use different measures in an attempt to operationalise a valid concept of grief. The task's complexity stems from the dilemma of disentangling normal from abnormal grief, and as with all human conditions, the reference point of normality is distorted by differences in culture, conditions, relationships and individuals. Several specific grief syndromes have been suggested, such as the syndromes of unexpected grief (Parkes, 1985) and traumatic grief (Jacobs, Mazure & Prigerson, 2000), but none of these have yet been incorporated into official diagnostic

systems (DSM or ICD). As opposed to these *qualitatively* unique syndromes, some authors emphasise the fact that loss of a loved one is a stressful event giving rise to varying *quantity* of already defined mental and physical syndromes. Middleton and co-workers have proposed the following:

Where grief for a particular individual, in a particular culture, appears to deviate from the expected course in such a way that it is associated with excessive or prolonged psychological or physical morbidity, it may be labelled as pathological (Middleton, Raphael, Martinek & Misso, 1993).

If abnormalities may be viewed in terms of duration of symptoms, how long is a “normal” period of grief expected to be? Few authors give definite answers; Parkes (1998) states that: “Most people will recognise that they are recovering at some time in the course of the second year.” Similarly, Stroebe and Stroebe’s data indicate that: “...the majority of the bereaved recover over a 2 year period” (in Stroebe, Stroebe & Hansson, 1993). However, many people may experience emotions of grief for longer periods of time, especially around anniversaries and other significant dates.

Going beyond grief as a special syndrome, the studies in the thesis focus on the widows’ risk of long-term psychological morbidity.

### ***1.3. Mode of death as risk factor of bereavement morbidity***

In their review of risk factors of bereavement outcome, Stroebe and Schut (2001) divide the risk factors into: personal risk factors, interpersonal risk factors and mode of death (or situational risk factors). From the evidence they conclude that younger age, male gender, lack of social support and loss of an adult child (compared to loss of a spouse, parents or siblings) have consistently been associated with additional morbidity while the evidence for mode of death are inconsistent.

As previously stated, I concentrate the discussion on mode of death as a risk factor for widowhood morbidity.

### *Sudden or unexpected deaths*

For decades, suddenness or unexpectedness of death has been assumed to be a major risk factor for adjustment to bereavement. Animal models show that predictable aversive stimuli assert less strain than unpredictable ones (Weiss, 1972), thus, it seems logical that forewarning of death would “soften” the transition of becoming widowed by providing opportunity for finishing unfinished business and saying farewell, as well as rehearsal and enhancement of available coping strategies. Lindemann (1944) was first to describe the concept of anticipatory grief during the World War II after having studied the emotional consequences of people facing the prospects of loss. The grief-like response – characterised by depression, preoccupation with thoughts of person to be lost, the death and adjustment to it - could be so effective that a woman was found to be emotionally detached from her soldier-husband when he returned. Based on his observations, Lindemann proposed that anticipatory grief was adaptive for bereavement adjustment. Later, Parkes described an unexpected grief syndrome following unexpected and untimely losses:

...they give rise to a defensive reaction of shock or disbelief, which delays the full emotional reaction but does not prevent moderate to high levels of anxiety from being experienced. Typically, the grieving process is complicated by a persisting sense of the presence of the dead person, feelings of self-reproach, and feelings of continued obligation to the dead which make it hard for the bereaved to make a fresh start (Parkes, 1985).

In spite of a thorough theoretical background and the clear logic of the assumption that forewarning might be of benefit to the bereaved and that lack of forewarning would hinder adjustment, the empirical evidence for this is not conclusive (Appendix 1). Forewarning has been operationalised in terms of experienced symptoms of anticipatory grief (Clayton, Halikas, Maurice & Robins, 1973; Levy, Martinowski & Derby, 1994), duration of terminal illness exceeding some reference point (Clayton *et al.*, 1973; Gerber, Rusalem, Hannon, Battin & Arkin, 1975; Ball, 1977; Sanders, 1982; Lundin, 1984), subjectively rated duration of time with awareness of the impending death (Cameron & Parkes, 1983; Kitson & Zyzanski, 1987; Houts, Lipton, Harvey, Simmons & Bartholomew, 1989; Carr, House, Worthman, Nesse & Kessler, 2001) and subjectively

rated degree of preparation for the death (Breckenridge, Gallagher, Thompson & Peterson, 1986; Schut, de Keijser, Van den Bout & Dijkhuis, 1991; Barry, Kasl & Prigerson, 2001). Studies have also varied with respect to methodological qualities, population studied, cause of death included and controlled for, follow-up time in bereavement (from one months up to eight years), and use of outcome measures. Probably, owing to these differences, some studies have found beneficial effects for the survivors (Ball, 1977; Richards & McCallum, 1979; Cameron & Parkes, 1983; Lundin, 1984; Kitson & Zyzanski, 1987; Schut *et al.*, 1991; Zisook & Shuchter, 1991; Barry *et al.*, 2001), others have not found any difference (Breckenridge *et al.*, 1986; Hill, Thompson & Gallagher, 1988) or have obtained mixed results (Carey, 1977; Sanders, 1982; Houts *et al.*, 1989; Carr *et al.*, 2001) or even the reverse: that forewarning may actually be worse for subsequent adjustment (Clayton *et al.*, 1973; Gerber *et al.*, 1975; Levy *et al.*, 1994). Studies that conclude that forewarning leads to a negative bereavement outcome have typically had a relatively early follow-up, used depression as an outcome measure, used retrospectively assessed symptoms of anticipatory grief or duration of chronic illness leading up to the death as proxy for the amount of forewarning. Although there is somewhat more evidence for the notion that forewarning is beneficial for adjustment to bereavement, these studies suffer frequently from low response rates and little control for potential confounding factors such as varying causes of death or burden of illness, and with the exception of the studies of Lundin and Schut, duration of follow-up in bereavement is relatively short.

#### *Exposure to suffering of the dying*

How suffering or unrelieved symptoms of the dying affect the surviving spouse, especially with regard to bereavement outcome, has received little attention by the scientific community. Yet, in the palliative setting, the spouse's psychological morbidity has been reported to be affected by the patient's physical (Hodgson, Higginson, McDonnell & Butters, 1997) and psychological condition (Cassileth, Lusk, Strouse, Miller, Brown & Cross, 1985; Kurz, Kurz, Given & Given, 1995; Hodgson *et al.*, 1997). The question is how persistent is that effect? Does it die with the patient or does it continue to burden the spouse in bereavement? Notably, 10 percent of those losing a spouse

from chronic illness suffer during the first year of a post-traumatic stress disorder (Zisook *et al.*, 1998). Why would a person who loses a spouse due to natural causes suffer from a condition, which is normally associated with traumata out of the ordinary? The condition is characterised by high levels of anxiety and flashbacks from the traumatic event and the probability of developing it depends to some extent on the traumatic or violent nature of the event (Kaltman & Bonanno, 2003) and sense of helplessness associated with the event (Joseph, Yule, Williams & Hodgkinson, 1994).

There are many things that can be labelled as traumatic or that may cause a sense of helplessness during a patient's progressing terminal illness and death, but what comes first to mind is the patient's suffering. Cameron and Parkes (1983) reported favourable bereavement outcome for survivors whose significant other died in a palliative care unit where symptom control was optimal. On the other hand, Barry and co-workers (2001) found no effect of degree of suffering at the time of death on complicated grief scores, major depression or post-traumatic stress disorder among the bereaved. The study had an early follow-up, did not discriminate between emotional and physical suffering. It is unclear how a prolonged period of exposure affects long-term bereavement outcome.

#### ***1.4. Health care and risk factors of widowhood morbidity***

Terminal illness such as cancer affects not only the patient but also all his/her significant others – studies indicate that compared to the patients' psychological well-being, that of spouses' is as much affected, if not more (Baider & Kaplan De-Nour, 1988). Some cancer patients are cured from their disease; others die as a result of their illness after a variable length of time. For the surviving spouse this may imply two things: 1) the possibility of forewarning for the impending death, 2) the likelihood of being exposed to prolonged physical and emotional suffering of the dying spouse. As will be argued below, health-care-givers are in control of medical information and the patients' symptom relief, and therefore it is reasonable to assume that their work may be an important predictor of the mode of death owing to cancer.



### *Forewarning of death from cancer*

Throughout history, cancer has been considered “the killer” and being diagnosed with cancer is still a great shock for most people. Yet, in the first stages of the disease, symptoms may not be all that severe and when the patient is introduced to continuously improved treatment options, the possibility of the illness being fatal may seem unreal. After the first treatment, symptoms may disappear and the patient may live for some time without any major concerns. The cancer may relapse and the cycle of “tumour relapse – treatment – remission” may occur a few times with increasing physical and psychological burden on the patient. But still, the hope of cure may remain – “why should I not beat it this time like before?” As illustrated in increased survival rates (Sato *et al.*, 2002; Paquette *et al.*, 2002), treatments for cancer have advanced and the general public is given these tidings through the media. As a result, the perception of the illness or the belief system people hold about cancer may be changing towards increased hope for cure. This applies both to those patients who will be cured and those who will not. Moreover, improved means for symptom relief (Portenoy & Lesage, 1999) may hide the seriousness of the patient’s medical condition. In sum, it may be reasonable to assume that patients and their spouses are increasingly dependent on verbal communication from treating physicians regarding the actual condition, and in the absence of such they may be unaware of the fact that the patient’s disease is incurable.

Physicians may refrain from breaking bad news about a patient’s poor prognosis. One reason is the common belief among physicians that the patients don’t want to know the truth (Curtis, Patrick, Caldwell & Collier, 2000), they may also worry about the patients’ emotional and intellectual capacity to benefit from the bad news (Rodrigues-Marín, Lopez-Roig & Pastor, 1996). It has been reported that while all palliative care specialists would like to be told the truth about their terminal illness, only 26 percent of European palliative care specialists thought that the majority of patients would want this disclosed (Bruera, Neumann, Mazzacato, Stiefel & Sala, 2000). Moreover, physicians have been reported to lack confidence and to experience much distress when breaking bad news to patients (Fallowfield, Lipkin & Hall, 1998; Ptacek, Fies, Eberhardt & Ptacek, 1999). “Taking away the patient’s hope”, “dealing with the patient’s emotions” and “lack of time” were identified by oncologists as important sources of stress when giving bad

news (Baile, Buckman, Lenzi, Glober, Beale & Kudelka, 2000). Ambiguous language or use of medical jargon may also produce unsuccessful attempts to inform patients and their relatives. Oncologists have been reported to focus their discussion on treatment, and by doing so may provide patients with false optimism (The, Hak, Koëter & van der Wal, 2000). The expression: “the treatment was successful” may have a very different meaning for the patient (cure) than intended by the physician (e.g. reduce tumour burden).

In actual fact, the large majority of cancer patients - 87 percent as reported in a British study by Jenkins, Fallowfield & Saul (2001) – want all possible information, whether good or bad, and 91 percent want to know the chance of cure (Meredith, Symonds, Webster, Lamont, Pyper, Gillis & Fallowfield, 1996). Cancer patients frequently report low satisfaction with communication with health care providers (Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birkenbaum, Heggan & Martin, 1993), and their psychological morbidity is associated with communication problems or patients not being informed about their illness and prognosis (Lerman *et al.*, 1993). So, there clearly is some discrepancy between the physicians’ beliefs and what the patients actually want and need.

The discrepancy between patients’ and doctors’ knowledge of the disease, treatment and prognosis is illustrated in the study by Quirt, Mackillop & Ginsburg (1997). They found that while almost all patients knew they had cancer, the concordance or agreement percentage between patients and doctors was low: 36 percent about the probability of cure and 14 percent about the probability that the treatment would prolong life. Most of the patients who disagreed with their doctor overestimated the probabilities.

The patient may choose to withhold facts and fears about his illness from his spouse, and studies have reported large communication barriers between patient and family during the course of terminal illness (Boehmer & Clark, 2001; Higginson & Constantini, 2002). In in-depth interviews with incurably ill patients and widows, we came across this fact several times: that communication from both sides was withheld in order to “protect” the other party from worries (unpublished data). Possibly, the lack of communication was causing an anxiety spiral where both patient and spouse sensed each other’s worries but could not share them or comfort each other. The physicians may not recognise the importance of informing the spouse - they may assume that the patient does so himself or that they would have had their spouses with them if it would be necessary.

On the other hand, relatives seem to rely on communication from doctors regarding the patient's condition (Krant & Johnston, 1978) and in a recent report 25% of bereaved relatives indicated that physicians could have prepared them better for the imminent death (Barry & Prigerson, 2002). Moreover, in spite of having been informed of their husband's fatal prognosis, 12 of 19 widows reported not to have believed what they were told (Parkes, 1972). Thus, there are several barriers that keep cancer patients' spouses unaware of the inevitability of the patient's death, and the length of time when they have this awareness has been shown to vary and sometimes be very short (Houts *et al.*, 1989). It stands to reason that time with awareness of the impending death is a necessary condition for a preparatory process or anticipatory grief. Too late recognition of the impending death robs the patient and the spouse of the opportunity of doing things that would have been done if they had had some time with this awareness. This may include: finishing unfinished business or discussions, plan the rest of life together and do meaningful things, make plans for death and funeral and so on. Specifically for the well spouse, it may take away the opportunity of engaging in care and prepare psychologically and cognitively for the impending loss. As previously mentioned, although some studies have found the reverse, more evidence seem to indicate that unexpected losses may be harmful for bereavement outcome.

#### *Unrelieved suffering*

It has been estimated that 90 percent of cancer patients' pain could be relieved (Portenoy & Lesage, 1999), thus it may be possible to largely diminish the traumatic experience for patients and their well spouses related to unrelieved pain. But in actual fact, the quality of pain relief varies considerably (Addington-Hall & McCarthy, 1995): relatives assessed that 88 percent of cancer patients had been in pain at some stage during the last year of life and that attempts to relieve it were successful ("at least completely some of the time") in 53-65 percent of cases. Reasons for inadequate symptom relief may be: poor access to health care (e.g. owing to large distances), health care professionals not updated on new and improved methods, or the emphasis on controlling the disease rather than symptoms.

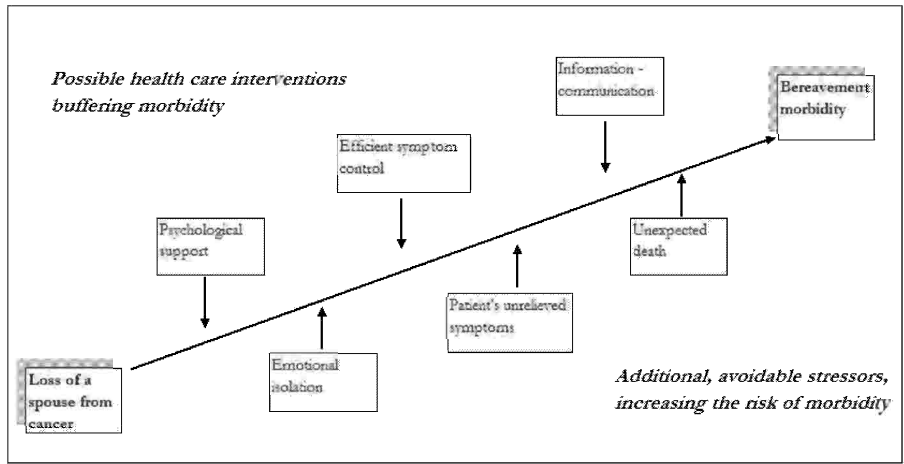
Cancer patients frequently suffer from psychological disorders: Derogatis and co-workers found that 47% of cancer patients of varying stages met criteria for DSM-III diagnosis with 85% of these having anxiety or depression as a central symptom (Derogatis, Marrow, Fetting, Penman, Piasetsky, Schmale, Henrichs & Carnicke, 1983). Rates of anxiety and depression have been reported to be 50-66 percent respectively in cancer patients the last two months of life (Fulton, 1997). A recent meta-analysis of psychological interventions for cancer patients indicates that interventions may be effective for anxiety but not for depression and that interventions should preferably be aimed at those most at risk (Sheard & Maguire, 1999). Oncologists have been reported to have inadequate skills in assessing patients' psychological symptoms - to underestimate the magnitude of the problem and the patients' need for psychological interventions (Fallowfield, Ratcliffe, Jenkins & Saul, 2001; Sollner, DeVries, Steixner, Lukas, Sprinzl, Rumpold & Maislinger, 2001). Moreover, medical establishments differ in how well the psychological needs of cancer patients are addressed and hospice care is reported to be superior in this respect (Seale & Kelly, 1997).

Even if unrelieved physical and psychological symptoms affect the spouse's well-being while the patient lives, it is not known if exposure to these constitutes a source of painful memories, long-term anxiety and depression during bereavement.

### ***1.5. Aims – Are health care deficits causing unnecessary psychological traumata?***

Above, I have described factors that may affect bereavement outcome and pointed out how health care interventions during a cancer patient's fatal illness and death may modify the mode of death and buffer possible serious consequences on the health of the surviving spouse. Of particular interest, as a function of health care practice, is if the duration of time the spouse is aware of the patient's impending death and the patient's level of physical and emotional suffering are related to long-term morbidity of the surviving partner. Furthermore, since lack of social support is a well established risk factor of bereavement morbidity (Stroebe & Schut, 2001) it is of interest to investigate needs for and access to psychological support from health care personnel following the loss. The separation from spouse by death is an unavoidable psychological trauma, but

the aim of this investigation is to study additional traumata that may accompany this life event and put the surviving spouse at additional risk of long-term morbidity (Figure 2).



**Figure 2:** *Additional stressors and health care interventions when a spouse dies of cancer.*

## II. SUBJECTS AND METHODS

Before we started our inquiries into the long-term outcome of widowhood, we interviewed men with hormone-resistant prostate cancer (incurably ill) at Huddinge University Hospital in the southern part of Stockholm. When we asked them what factors determined their quality of life, the general theme that seemed to emerge from their worried tales was: their wives. Problems in communication, worries about her worrying, and most importantly: “What will happen to her when I’m gone?” As a result, we made their wives the subjects of our scientific inquiry.

### *II.1. Preparation of the study*

Seventeen widows who had lost a husband to cancer at Huddinge University Hospital or Stockholms Sjukhem were identified in local registries and contacted via a letter of introduction and then a telephone call and asked to participate in an in-depth interview. The widows were paid a home visit lasting between two to four hours. The interviews were semi-structured; first, the widow was allowed to express herself freely about her experience of her husband’s illness and of widowhood, and later, we made successively more specific enquiries into the experience. The themes emerging from these interviews, along with literature screening and interviews with health care professionals who work with the terminally ill, confirmed the themes that had emerged in previous interviews with the patients and strengthened our belief that aspects of the terminal illness, e.g. patient’s unrelieved symptoms and awareness of impending death, might affect long-term morbidity in widowhood.

These themes were operationalised into questions, which were modified successively in face-validity trials. In the face-validity sessions, we checked that the population of widows could answer the questions appropriately and that there was a consensus of understanding and subjective interpretation of the questions among the widows. For example, we constructed a question regarding when, before the actual death, the wife had known that the patient would die. If not properly constructed, this question could have been open to various interpretations, such as: 1) the time they were aware of the fact that

cancer can be a fatal disease, 2) the time they were aware that their husband was mortal, 3) the time they were aware that their husband was about to die, or, as intended, 4) the time they were aware that their husband's condition was incurable and that he would die from it. With the widows' help, we modified wording and structure of the question and response categories until face validity indicated that the question was understood correctly and could be answered appropriately.

After ethical approval, two pilot studies were conducted in Stockholm county to test the logistics of the study procedure. The former comprised 15 widows whose husbands had died of prostate or urinary bladder cancer in 1996; these widows were contacted first by letter and then through a telephone call. Two of the widows refused to participate when called on the telephone, 13 were thus sent the questionnaire and 10 questionnaires were returned. The resulting response rate of 67 percent was too low. Consequently, we called the widows and inquired about their experiences of participation. We found that two widows out of the three that did not return the questionnaire had been overwhelmed by the length of the questionnaire and had not tried to answer it. One widow tried to answer but found certain elements of the questionnaire too psychologically burdening. Hence, we made the following alterations before going on to the second pilot study: The questionnaire was printed on both sides of the pages and 25 percent of the questions removed – those not directly associated with the main scientific questions or reported to imply a psychological burden. The widows had indicated the importance of anonymity, being afraid that the information they gave would go back to the health care facility that had cared for their husband and would probably later care for them. Consequently, the anonymity of the participation of the study was emphasised both in the introduction letter, telephone call and in the questionnaire. The second pilot study comprised 19 widows in Stockholm county who had lost a husband to prostate or urinary bladder cancer in 1996, of which 18 had non-confidential telephone numbers. One refused through the telephone contact but the 17 others consented to fill in the questionnaire and 15 returned them. We considered a response rate of 83 percent to be acceptable and proceeded to the national study.

## ***II.2. The study base – National study***

The study population comprised 506 wives or female partners of men who died of prostate cancer in 1996 or of urinary bladder cancer in 1995 and 1996, at 45-74 years of age. At the time of the follow-up (spring and summer 1999), the women were to be 79 years old or younger, live in Sweden, understand Swedish, and have a listed, non-confidential telephone number.

The men were identified in the Swedish Registry of the Causes of Death and their diagnoses were double-checked in the Swedish Cancer Registry. As the majority of questions concerned the three month period leading to the death, the minimum duration of diagnosed illness of three months was necessary (see Table 1, paper II).

For ethical concerns, and to ensure the validity of our study, we decided to exclude women of 80 years or older. Past studies in our research group (unpublished data) have resulted in a low response rate in this age group. We also excluded women with confidential telephone numbers as the ethics and methodology of our study procedure relies on a telephone contact. We are not aware of any evidence indicating that this group of women differs psychologically from those with non-confidential telephone numbers.

From the Swedish National Registry we also collected data on 287 married women or women living with a man, matched with the widows' age and residence region.

## ***II.3. Questionnaire***

The questionnaire comprised 275 questions and was divided into three sections: 1) Questions referring to the period preceding and during the husband's death (independent variables and predictors of these); 2) A short section referring to the first six months after the husband's death (independent and dependent variables); 3) Questions regarding the widow's current situation and health (dependent variables, potential confounding factors).

The most important questions concerning independent variables measured the widow's awareness time (i.e. the duration of time she was aware of the patient's impending death), the patient's level of suffering, and the widow's need for and access to psychological support following the husband's death (Appendix 2).



Outcome measures comprised questions of psychological symptoms, sleep-related symptoms, intake of drugs, self-assessed quality of life and physical health. After reviewing the literature, we judged symptoms of anxiety and depression as being the most relevant variables for widowhood morbidity and used two types of measures for these purposes. First, we used two psychometric scales: Centre for Epidemiological Studies Depression Scale (CES-D) for depression-related symptoms (Radloff, 1994) and the STAI-T measure of Spielberger's State-Trait Anxiety Inventory for anxiety-related symptoms (Spielberger, Gorsuch, Lunshene, Vagg & Jacobs, 1983). In addition, we included two single-item, seven-point visual digital scales measuring the subjective evaluation of anxiety and depression (Appendix 2). The visual digital scales have been thoroughly tested for face validity and used before in several research projects within the research group of Clinical Cancer Epidemiology (Radestad, Steineck, Nordin & Sjogren, 1996; Helgason, Adolfsson, Steineck, 1997; Bergmark, Avall-Lundqvist, Dickman, Henningsohn & Steineck, 1999; Henningsohn, Wijkström, Dickman, Bergmark & Steineck, 2001). Both visual digital scales correlate well to scores of CES-D (Spearman's rho 0.628,  $p < 0.01$ ) and STAI-T (Spearman's rho 0.530,  $p < 0.01$ ). Internal consistency was high for the psychometric scales – Cronbach's alpha was 0.87 for CES-D and 0.89 for STAI-T.

Visual digital scales were also used for measuring self-assessed quality of life and sense of well-being. Sleep-related symptoms (latency of sleep and disrupted sleep) and intake of medicines (tranquillisers and sleeping pills) were measured using a five-point verbal estimate. We included items from Tibblin's quality of life scale (Tibblin, Tibblin, Peciva, Kullman & Svardsudd, 1990) to document relevant aspects of quality of life and social situation. A checklist of diseases and medical conditions (including high blood pressure, weak heart, vascular spasm, lung disease, stomach or intestine problems, epilepsy, kidney disease, long-term pain, diabetes, tumour/cancer, chronic tiredness, sleep difficulties) was answered in a "yes-no" manner. Relevant factors for widowhood morbidity (other than those under study) were included for study of confounding, for example: the widow's age, duration of the patient's illness, the widow's social background and level of religious belief, prior treatment for psychiatric problems, level of emotional relations (social support) and participation in caregiving.

#### ***II.4. Data collection – procedure***

The data collection from both widows and control women (who only answered questions regarding their current situation and health) took place during the spring and summer (April-August) of 1999. The widows received an introductory letter explaining the objectives of the study and were then telephoned and asked if they would participate. Those who authorised participation were sent a questionnaire, which they returned separately from a reply card in order to safeguard their anonymity. The widows were given contact information for queries or if they needed any help or support.

#### ***II.5. Statistical analysis***

The raw data from the questionnaires were manually coded with help of the program STAN55. The reliability of the coding was tested by re-coding (“double checking”) of ten randomly chosen questionnaires.

Analyses were conducted using the statistical program SPSS 10.0.

### III. RESULTS

#### *III.1. Response rates and general characteristics*

Three hundred seventy-nine of 506 widows (75 percent) returned their questionnaire and 220 of 287 controls (77 percent). The women were on average 67 years of age and all background factors, with the exception of marital status, were evenly distributed between the groups. An average of three years had elapsed from the death of the patient to the point of follow-up (see table 1, paper I).

#### *III.2. Paper 1. Widowhood morbidity*

Two to four years after their husband's death from cancer, widows had increased risk of psychological and physical morbidity as well as dissatisfaction with financial situation and appetite. Compared to non-widowed population controls, the widows had approximately doubled relative risk of psychological symptoms such as anxiety and depression (visual digital scales), latency and disruption of sleep and intake of sleeping pills. When we used a cut-off score of >16 on the CES-D, the relative risk for widows compared to controls was 1.7, confidence interval 1.2 to 2.4. With a cut-off score >39 on the STAI-T, the relative risk for the widows' anxiety was 1.4, CI 1.1-1.7. Moreover, they were 40 percent more likely to report low or moderate self-assessed quality of life and 80 percent more likely to report low or moderate sense of well-being. No significant differences on psychological variables were found between widows bereaved for two to three years compared to those bereaved for three to four years. The widows had more than tripled risk of having diabetes mellitus and a 50 percent increased risk of reporting dissatisfaction with their appetite. Dissatisfaction with economy was 60 percent more common among the widows and they were also more likely to report low self-esteem and lack of meaningfulness outside the home.

### ***III.3. Paper 2. Awareness time and widowhood morbidity***

While the mean duration of illness was 3.6 years, the length of time the women were aware of their husband's impending death from cancer varied greatly, with 48 percent of the cases knowing for three months or less and for 15 percent the awareness time was as short as 24 hours or less. An inverted J-shaped relationship was obtained between awareness time and risk of psychological morbidity, with awareness time of three to six months typically carrying the lowest prevalence of symptoms and 24 hours or less carrying the highest. Having an awareness time of 24 hours or shorter increased greatly the risk of experiencing the death as shocking, the risk of psychological morbidity at follow-up (especially anxiety and sleep disturbances) and not having come to terms with the loss. Health care factors were the main predictors of awareness time: having had poor access to psychological support from health caregivers and lacking information on the "incurable nature" of the husband's condition doubled to tripled the risk of having an awareness time of 24 hours or less.

### ***III.4. Paper 3. The patient's unrelieved symptoms and widowhood morbidity***

The patient's unrelieved psychological symptoms, but not physical pain or symptoms from the urinary tract, oedema, constipation and vomiting, increased the widow's risk of psychological morbidity. If the patient was reported to have been moderately or very anxious or depressed during his last three months of life, the widow's risk of psychological symptoms and sleep disturbances was typically two to three times higher. The patients were reported to have good access to physical pain relief (93 percent of the men having moderate or much access) but little access to psychological support (33 percent with moderate or much access).

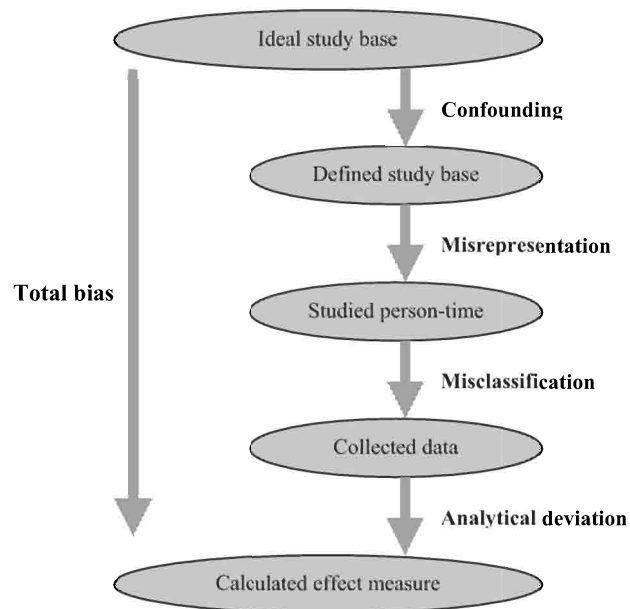
### ***III.5. Paper 4. Need for and access to bereavement interventions from health care***

During the first six months following their husband's death, only about one-third of the widows reported not having had any need for psychological support. The remaining two-thirds reported poor access to psychological support: 67 percent reported no access, 10 percent little access, 11 percent moderate access and 12 percent much access. Similar figures could be seen for access to information about the patient's illness or death, information on probable grief reactions, group therapy and economic advice. Predictors of having moderate or much access to psychological support from health care were: emotional relations with someone other than spouse during terminal phase, intensity of faith, higher education, prior mental health problems and a husband with a diagnosis of prostate cancer.

## IV. DISCUSSION

### *IV.1. Validity*

The perfect study exists only in theory. Perfectly valid data may be gained from a large, randomised and triple-blind study with perfect measurements and no dropouts. What inevitably affects all studies to varying degrees is systematic errors that make the measured estimate deviate from the true value in a systematic way, i.e. the errors are unequally distributed between the conditions of the independent variable or between different groups being studied (Steineck, Kass & Ahlbom, 1998). These systematic errors can be grouped under confounding, misrepresentation, misclassification and analytical deviation (Figure 3).



**Figure 3:** *Different stages in a clinical study with corresponding biasing factors.*

Our study is no exception from the rule and we run the risk of making false inferences owing to systematic errors, but efforts have been made to diminish this risk with the help of the methodology developed within the research group of Clinical Cancer Epidemiology.

### *Confounding*

A studied independent variable may be erroneously inferred as a causal factor, if the real causal factor is associated with both the independent and the dependent variable. To avoid this problem, one needs to identify possible causal factors and take into account their impact on the relationship under study. Hence, in our study, we tried to accumulate as much information as possible on potential confounding factors (factors previously associated with bereavement morbidity), such as the widow's age, current marital status, treatment for psychiatric problems before the husband's illness, access to psychological support six months after the loss, emotional relations, intensity of religious faith, participation in care during patient's illness, education, diagnosis and duration of illness. Furthermore, given that we had a homogeneous sample - women who had lost their husbands owing to cancer of only two sites – we had control for the influence of gender and causes of death.

Our main validity concern owing to confounding is in article II, where we have inferred a relationship between a short awareness time and anxiety. It is possible that a woman who is prone to anxiety or neurotism (confounder) defends herself against information regarding the fact of her husband's impending death: hence the short awareness time and the high levels of anxiety at follow-up. Although not a perfect proxy for proneness to anxiety or neurotism, controlling for treatment for mental problems (anxiety and depression) prior to the patient's illness did not change the obtained relationship between awareness time and anxiety. Moreover, we observed a tendency that long awareness time (one year or more) was associated with higher levels of anxiety than an awareness time of three to six months. Thus the relationship between anxiety proneness and awareness time must be complex if it is to explain the associations we interpret as real. Also, anxiety has been reported to enhance attention to threatening

stimuli (Ohman, Flykt & Esteves, 2001; Derryberry & Reed, 2002). Still, we cannot rule out the possibility of confounding due to an anxiety-prone personality and this will have to be studied further.

### *Misrepresentation*

Misrepresentation of a studied sample refers to the extent to which it deviates from the defined study base. With the excellent national population registers in Sweden as well as the national cancer register and of causes of death, we have 100 percent coverage over the defined study base. Through our research tradition at the Department of Clinical Cancer Epidemiology, we have also developed routines to diminish risk of non-participation. First, we carefully evaluate through in-depth interviews, face validity trials and pilot studies that the items in our questionnaire do not overwhelm the participant's cognitive and emotional capacity. Second, the personal contact that we establish (through introduction letter and telephone call) and the offers of help and support during the participation as well as a routine for reminders (in the form of a thank you note after two weeks, then a telephone call after another two weeks) are all important elements of maintaining the response rate. The response rates of 75 percent and 77 percent are high, especially when compared to other bereavement follow-ups.

When comparing reasons for non-participation in the widowed population with those of the non-widowed population we found that the widows were more likely to refuse/drop out because of (or for fear of) psychological burden and physical illness. This means that the relationship between widowhood and physical and psychological morbidity may in fact be stronger and that we may have missed some true relationships (false negatives). However, this does not undermine the associations we interpreted as real; if anything, this indicates that they might be stronger.

### *Misclassification*

Errors in the measurement of the independent variable are a threat to validity when they are unequally distributed between categories of the dependent variable (or vice versa). As previously mentioned, we went to great lengths to improve the validity of the



measures in our questionnaire. The questions about the independent variables were formulated in close co-operation with widows and through face validity trials we made certain that other widows understood the questions correctly and could answer them appropriately. For the dependent variables we have created simple subjective measures of psychological symptoms (e.g. anxiety and depression) that have been used in several research projects and that correlate nicely with the psychometric scales we have included to increase the validity of our inferences (i.e. we are more careful in interpretation if a factor is only related to one measure but not the other). Also, by using self-administered, anonymous questionnaires we diminished the risk of the answers being affected by an interviewer or the women feeling pressure to report only good things (previously noted as important, see method section).

There are concerns of misclassification, especially in paper III where we infer a relationship between the patient's unrelieved psychological symptoms and the widow's long-term morbidity. As the accounts of the patient's unrelieved symptoms are evaluated retrospectively by the widow, an obvious suspicion is that a depressed widow may view the past in a negative manner and thus report her husband as suffering more than he actually did. However, only the patient's psychological symptoms were related to the widow's psychological symptoms, but not physical pain, oedema, vomiting and symptoms from the urinary tract, which indicates that a depressed widow was as able as a non-depressed widow to report low level of suffering of the late husband. Still, the suggested association has to be studied prospectively before definite conclusions can be drawn.

Another source of misclassification may be in paper II where we have reported lack of information about the patient's prognosis as being the most important predictor of short awareness time. It is possible that the chronic stress resulting from the lack of forewarning has affected the memory of those women in such a way that they are less likely to remember having received this information. Thus, although there is reason for caution and further study, previous studies support the notion that forewarning can be effected by informative interventions (Cameron & Parkes, 1983; Häggmark, 1989).

### *Analysis*

In our analysis we dichotomised all variables and present the data as relative risks, calculated as the proportion of widows with symptoms (e.g. anxiety) that have a particular problem (e.g. short awareness time) divided by the proportion of widows with symptoms but without that particular problem. We consider this way of presenting data to be more pedagogical than correlation or regression coefficients, as well as being stringent (as it decreases statistical power) and it can therefore not be a source of error for those associations we interpreted as real.

### *On random error*

If our study bases had been larger and the studied person-times in our studies been larger, obviously we would have been more certain that deviations from unity were not due to unaccounted or random errors. To understand the precision of the calculated effect measures, we calculated 95 percent confidence intervals.

## ***IV.2. Findings***

### *Widowhood morbidity*

Two to four years following a husband's death of cancer, the widow has increased risk of anxiety, depression, disrupted sleep and intake of sleeping pills, diabetes, dissatisfaction with appetite, economic situation and self-esteem.

Previous research on depression beyond the second year of bereavement has been inconsistent. Carnelley *et al.* (1999) and Turvey *et al.* (1999) found no differences, whereas Parkes and Brown (1972) found significant differences in depression among widowers (but not among widows) two to four years post loss and Bennet (1997) found widows to differ from married and never married up to 4 years post loss. Small sample size (Carnelley), older population and possibly long duration of bereavement (Turvey), low follow-up rate (Parkes and Brown) and differences in measurement (anxiety and depression were not reported separately in Bennet's study) may account for some of the

differences. Our findings indicate that depression may still be a problem two to four years following a loss of a husband from cancer.

As previously stated, anxiety symptoms during the first year of bereavement are well documented - Jacobs and co-workers (1990) reported for example that 44 percent of their bereaved sample had at least one type of anxiety disorder. To our knowledge, few studies have investigated anxiety rates among the widowed (as compared to married controls) beyond the first year of bereavement. Prigerson and co-workers' study (1997) illustrates that contrary to depression and symptoms of traumatic grief, high anxiety (PERI) remains stable (20 percent) in a widowed population during the first 25 months of bereavement. Our results indicate that anxiety continues to be above normal (or married) levels up to 4 years into bereavement.

Sleep disturbances among the widowed have been reported before. In a Japanese national cohort study (Doi, Minowa, Okawa & Uchiyama, 2000) the prevalence of difficulty initiating and maintaining sleep and use of hypnotic medication use among women was strongly associated with being widowed. The sleep disturbances of the widows may be symptoms of other psychological complications, e.g. depression and anxiety. Haunting memories from the partner's illness and death as well as practical or social concerns may be one cause: it has been reported that intrusive thoughts and avoidance behaviours were associated with longer sleep latency and lower delta sleep ratio among 40 bereaved men and women with major depression (Hall, Buysse, Drew, Prigerson, Kupfer & Reynolds, 1997).

Diabetes has previously been reported as one cause of increased mortality in widowhood (Mergenhagen, Lee & Grove, 1985). It remains unclear whether diabetes is caused by common life style before the husband's illness (leading both to the man's cancer and the woman's diabetes), changed life style following bereavement or the stress associated with the terminal illness and the death. People have been reported to change their lifestyle in widowhood, e.g. eat less nutritious food (Rosenbloom & Whittington, 1993; Quandt, McDonald, Arcury, Bell & Vitolins, 2000) and exercise less (Rosenbloom & Whittington, 1993). Stressful life-events have been associated with the onset of diabetes (Mooy, de Vries, Grootenhuis, Bouter & Heine, 2000). Further analysis of our material shows substantially increased relative risks of diabetes (though not statistically significant) when associated with previously identified risk factors, such as short

awareness time (RR=4.0, 0.5-34.6) and patients' unrelieved psychological symptoms (RR=1.6, 0.7-3.7).

Poor economic situation of the widowed has been reported before (Avis, Brambilla, Vass & McKinlay, 1991; Byles, Feldman & Mishra, 1999) and may affect the widow's quality of life and health related behavior. The decreased self-esteem may stem from loss of the caregiver role and the loss of identity (as "the wife"). Interestingly, relationship with family and social activities are rated about the same as in the non-widowed population.

The findings of following papers indicate that some of the long-term psychological morbidity may be prevented with appropriate interventions and support by health care.

#### *Awareness time – forewarning*

Irrespective of the duration of the terminal illness, the amount of time during which the women are aware of their husbands' impending death varies and can be as short as zero. An awareness time of 24 hours or less increases the risk of long-term psychological morbidity (especially anxiety). The risk posed by a short awareness time increases if the woman was not informed of her husband's incurable prognosis or if she did not have access to psychological support from health care personnel during her husband's last months of life. At the other extreme, very long awareness time tends to carry an increased risk of morbidity, so there may be an optimal duration of awareness time; our data indicate that it may be in the vicinity of three to six months.

Our findings on the impact of awareness time on subsequent widowhood morbidity may be mediated by two possible mechanisms: either by prohibiting shock at the time of death or by giving rise to a preparatory process, or both. It is reasonable to believe that time with intellectual understanding of the prognosis is a necessary condition for a preparatory process or anticipatory grief. A moderate duration (not too long or short) of time with awareness of impending death may give an optimal amount of confrontation with the harsh reality. Awareness time of three to six months gave the women opportunity to spend time alone with the patient, finalise unfinished business and be there at the time of death. Still, among those with awareness time of three to six months, 64 percent reported not to have finalised unfinished business with the dying

patient, indicating that an awareness time is not a sufficient condition for a preparation to take place. Further investigation is needed to understand what means people use to prepare and achieve emotional acceptance as well as what contributes to or hinders such a process when people already have an intellectual understanding of the impending death.

The buffering effects of awareness time are reasonably mediated by the protection from experiencing shock; ninety-one percent of the widows with short awareness time (24 hours or less) reported being in a state of shock at the time of death and it is possible that the overwhelming situation may have hindered adaptive coping in bereavement. Stroebe and Stroebe (1993) have reported that self-esteem and internal locus of control may explain why some cope better than others in the long run when faced with an unexpected death. Further research is needed to explain why an awareness time of one year or more gives tendencies for increased morbidity. Our data suggest possible explanations such as increased caregiving burden or the effect of having become accustomed to the patient's fluctuating health in such a way that awareness faded and the death came as a shock.

Our findings are supported by previous investigations that have found similar pattern in outcome related to preparation. Compared to sudden accidental death and long-term terminal illness, Sanders (1982) found an illness of six months or shorter to have a tendency for more favourable outcome, in terms of symptoms of grief 18 months after a loss. Carr *et al.* (2001) found prolonged forewarning of longer than 6 months to be related to anxiety 18 months after a loss, but obtained no relationship between "no forewarning" and anxiety at the 18 month follow-up. It is possible that the complex inverted J-shaped relationship obtained in our study between awareness time and outcome may have contributed to some of the negative findings on the effect of forewarning (Clayton *et al.*, 1973; Gerber *et al.*, 1975; Houts *et al.*, 1989). The majority of previous studies have though found adaptive effects of forewarning as opposed to unexpected death. In their intervention study, Cameron and Parkes (1983) compared bereaved survivors whose loved ones had died one year before in an experimental palliative care unit or standard care unit at the same hospital. Although definite conclusions were hampered by small number of participants, they found the palliative care unit survivors to fare better in terms of psychological morbidity, which they explained among other things with the emphasis on preparation for the impending death in the experimental group. Subsequently, Lundin (1984) reported that bereaved people as

a result of accident or illness of shorter duration than two hours to score higher on Texas inventory of grief eight years later, compared to those losing a relative owing to illness of a longer duration. Here, cancer is considered as an expected death, however, our results illustrate that awareness time may be as short as zero. Accordingly, Schut *et al.* (1991) found self-reported forewarning and “having said farewell”, but not duration of illness, to be related to post-traumatic stress symptoms at 18 months in bereavement. A recent report by Barry and co-workers (2001), found insufficient subjective rated preparedness to predict complicated grief, major depression and PTSD in a bereaved population 4 and 9 months in bereavement.

In addition to the inconsistencies of the findings of previous research, conclusions from individual studies have often been hampered owing to methodological shortcoming, most related to recruitment of participants, attrition and lack of control of potential confounding factors. Attrition may be related to outcome (physical and psychological morbidity) as well as forewarning, and the burden or level of exposure to traumatic circumstances may be differentially associated with different causes of death and awareness time. Furthermore, the effect of additional psychological traumata associated with the loss (such as short awareness time) may be difficult to identify in an early follow-up of the bereaved when psychological morbidity may be high irrespective of exposure.

We found that the physicians had only informed half of the women about their husband’s fatal prognosis - not being informed increased the risk of having a short awareness time. Access to psychological support during the patient’s last months of life protected the widow from having a very short awareness time but less than one-third of the widows had moderate or much access to support. Friedrichsen, Strang & Carlsson, (2000) found that patients are better able to cope with bad news if they have a personal and trusting relationship with the physician, and this probably holds true also for the healthy partners. Previously conducted intervention studies by Cameron and Parkes (1983) and Häggmark (1989) support the notion that relatives’ forewarning of patients’ death may indeed be affected with information and psychological support.

Thus, the results emphasise the importance of the communication between physician and patient’s family – there is reasonably an optimal time for this message of incurable prognosis to be delivered and it is not clear if current techniques of prognostication can provide such precision. Studies indicate that physicians generally

overestimate survival time of their patients and that they should preferably rely on senior colleagues' opinions from objective data (Christakis & Lamont, 2000). Also, it remains to be determined to what extent sudden imminent causes of death, such as pulmonary embolus, or a wife's blunting personality, compromised the physician's opportunity to inform.

### *Cancer patients' psychological health*

In my astonishment I showed a colleague of mine the high rates (66 percent) of anxiety and depression among the patients, as reported by their wives or female partners. Her reaction was not of astonishment but rather of indifference – she responded: “These men were dying Unnur, no wonder they were depressed!” I realised that while my astonishment may have been a bit naïve, my colleague's reaction is the very reason why incurably ill cancer patients are “allowed” to be depressed – it is considered as inevitable or normal. However, physical pain is also normal when the body is about to give up, but we do not settle for that – we relieve the pain.

Group interventions for female patients with advanced cancer have been reported to improve the patients' mood, anxiety and coping, to alleviate their pain and even improve their survival (Spiegel, Bloom & Yalom, 1981; Spiegel, Bloom, Kraemer & Gottheil, 1989) but little is known about the efficiency of these techniques in male populations. Our in-depth interviews with patients indicate that efforts to improve the communication between patient and spouse may be efficient in improving psychological well-being of both parties. Pharmacological alternatives are frequently used for depression in the general population, but a recent report indicates that research on the efficiency of such medications in the palliative care setting are lacking (Ly, Chidgey, Addington-Hall & Hotopf, 2002). Only a third of the patients with psychological symptoms were reported to have taken psychotropic medication during their last months of life, and access to psychological support was poor compared with access to physical pain relief. In sum, our findings indicate that the psychological health of patients with advanced cancer should be given more attention and more studies are needed for investigating the efficiency of potential interventions. The effort may not only benefit the patients but also their surviving spouses.

We found that the patient's unrelieved psychological symptoms (but not pain and other physical symptoms) increased the widow's risk of long-term psychological morbidity. The association between patient's psychological health and survivor's psychological morbidity in bereavement has to our knowledge not been reported before. But in contrast to our findings, Barry and co-workers (2001) did not find any association between physical suffering at time of death and the survivors' risk of complicated grief, major depression or PTSD four and nine months after bereavement. However, as previously stated, the study had an early follow-up and did not discriminate between emotional and physical suffering.

Why do the patient's psychological but not physical symptoms have a lasting effect on surviving partners? A probable explanation may be feelings of helplessness when exposed to the patient's suffering. In the case of physical pain, health care personnel made efforts to relieve it, and the wife is more likely to have been informed in how to help the patient with these problems. As the psychological symptoms were to a large extent unaddressed by health care givers, the wife is likely to have been poorly equipped to respond to these. And as a life partner, the wife may have felt more responsibility for "lifting the mood" as compared to the "doctor's job" of relieving the pain.

Prospective trials are needed to rule out systematic error of reverse causation and to definitely settle whether the observed relationship is real.

#### *Bereavement support*

Lack of social support has consistently been associated with worse bereavement outcome (Stroebe & Schut, 2001). So, the third way in which health care may help people who are in the process of losing a partner to terminal illness is to provide them with psychological support. Many would assert that systematically offering people bereavement counselling following their loss would be to "abnormalise" the natural process. However, just as women are offered guidance and medical help during their "natural" pregnancies, guidance for the bereaved may prevent excess morbidity and identify and treat abnormalities when they occur. Simple advice concerning economy and nutritional vulnerability of widows may diminish the risk of additional stress and worsened physical health (e.g. diabetes).



We found that two-thirds of the widows would have preferred some formal contact for advice or psychological support from health care givers but as few as one of every five had moderate or much access to it. Systematic bereavement follow-up is an infrequent practice in Sweden and it is probable that most of the women who received support sought the services themselves on tips from friends, relatives or health care workers. We found that those widows who reported good emotional relations with others than their husband during their husband's last months of life were more likely to have had access to bereavement support. This may be an indication of already established supportive contact with health care.

Bereavement counselling has been reported to help in terms of diminished morbidity, especially when given to groups who are at excess risk (Raphael, 1977). Additional analysis revealed that having had moderate or much access to psychological support and economic advice (but not access to support groups and information interventions) diminished the risk of long-term morbidity. However, methodological difficulties, including the confounding effects of adaptive coping and risk of misclassification (negative recall of support owing to depressed mood), hamper firm conclusions. There is, however, reason to believe that a systematic bereavement support would be well received by widows – simple advice might benefit those who are not so troubled, and screening for and helping those who are troubled might be life-saving.

### ***IV.3. Ethical considerations***

The notion of making enquiries about such a traumatic event as the loss of a husband from cancer evokes concerns, not only among clinicians and ethical committees but also among the researchers themselves. While we were convinced that we possessed methodology to answer important scientific questions in this research group, we were well aware of the risk of causing distress to our participants and made every effort to diminish the risk. In a series of preparatory studies, the emotional burden of items in the questionnaire was weighed against their scientific utility. Furthermore, we implemented an established routine for approaching individuals for studies on sensitive issues such as stillbirth and cancer in genito-urinary sites. The information about the study and enquiries of potential participation were presented gently, first in an introductory letter

and then in a telephone call (hence the exclusion of widows with unlisted numbers from the study base) and the widow did not receive the questionnaire without a clear and explicit informed consent. The widows received a contact number if they had queries or needed support and they were also told that they could terminate their participation whenever they wished during the study. Moreover, the participation was anonymous which, as previously mentioned, proved to be important for some widows. With these strict ethical-guidelines incorporated into the study design and implementation, the study was approved by the Local and Regional Ethics Committees of the Karolinska Institute.

Overall, as revealed in in-depth interviews, pilot-studies, during telephone contact and in open-ended questions in the questionnaire, the widows were positive towards the study: they found some questions emotionally difficult but they still found it important to participate. Some even expressed that they found a therapeutic value in their participation. This satisfaction is also illustrated in the high response rate (75 percent) which is unique when compared with other studies of bereavement.

However, we cannot exclude the possibility that someone may have been harmed by our contact or during participation. This harm may have been inflicted by the introductory letter, during the telephone call or when answering the questions – when participation was denied or terminated, we found it unethical to ask these women for information about harm caused by our contact. Systematic documentation of inflicted harm and benefit should have been a part of our research - this routine has now been established in a subsequent study of parents who lost a child to malignancy.

## V. CONCLUSIONS

The loss of a husband from cancer causes long-term psychological and physical morbidity in the widow, which to some extent may be avoided with appropriate action from health care personnel. These actions include:

- **Promoting an optimal awareness time** by informing the wife when the evidence indicates that the patient's condition will prove fatal within a year. An established relationship of trust and support between physician and the future widow is more likely to succeed in providing the spouse with an awareness time and thus diminish the risk of additional psychological trauma at the time of death.

- **Emphasis on the patient's psychological symptoms.** Improved conventions in monitoring and treating a terminally ill patient's psychological problems may benefit not only the patient, but also the surviving widow by diminishing her exposure to traumatic experiences related to the patient's emotional suffering.

- **Bereavement support.** Two of every three widows indicate a wish for contact with health care following the loss of their husband from cancer. While the process of loss and grief is normal, abnormalities may occur and thus may be detected and possibly prevented by routine bereavement support.

## VI. FUTURE STUDIES

The findings of these studies raise new questions for future research. Some may be answered with a similar research design as used in this study but others may be more appropriately addressed in clinical intervention design.

### *Awareness time*

- How do people benefit from the awareness time, i.e., what strategies (emotional, cognitive) do people use to prepare for the impending loss and achieve emotional acceptance? Why do some get blocked in this process?

- Why does an awareness time of more than one year increase the risk of long-term morbidity in bereavement?

- Is there a gender or kinship difference in the effect of the awareness time?

- Do deaths from immediate causes (as opposed to underlying causes) or unreceptive personalities of the wives compromise the physician's opportunity to inform?

- Can an optimal awareness time be promoted with systematic use of prognostication as well as information and support?

### *Symptom relief in the palliative setting*

- Can interest in and the capacity to diagnose and treat psychological symptoms in advanced cancer patients be increased among oncology staff?

- Are current interventions effective in relieving psychological distress in the palliative oncology setting?

- Can an intervention for a cancer patient's psychological symptoms also decrease the surviving partner's risk of long-term psychological morbidity?

*Other questions*

- What are the determinants of having diabetes two to four years after a husband's death of cancer? Previous lifestyle, stresses of illness and loss, or changed lifestyle following the husband's death?

- How effective are systematic and short interventions (e.g., concerning economic matters and nutritional vulnerability) in buffering long-term economic stress and risk of diabetes in widowhood?

## VII. SUMMARY IN ICELANDIC

### AÐ MISSA EIGINMANN ÚR KRABBAMEINI: ÁHRIFAÞÆTTIR LANGVARANDI KVÍÐA OG ÞUNGLYNDIS

**Bakgrunnur:** Sorgin er óhjákvæmilegur fylgifiskur ástvinamissis. Þó er mögulegt að koma megi í veg fyrir langvarandi kvíða- og þunglyndiseinkenni sem orsakast af aðstæðum við andlát. Þegar krónískur sjúkdómur á borð við krabbamein leiðir til dauða, er mögulegt að sjá fyrir að sjúklingurinn sé deyandi og getur sá tími fyrir andlátið (vitundartími) fært tækifæri til undirbúnings. Hins vegar fylgir slíku tímabili einnig aukið álag, m.a. vegna þjáninga sjúklingsins. Rannsakað var hvort þjáningar krabbameinssjúklinga og vitundartími maka þeirra hefðu langtímaáhrif á kvíða- og þunglyndiseinkenni ekknanna.

**Aðferð:** Allir karlmenn í Svíþjóð, 74 ára eða yngri sem látist höfðu úr krabbameini í blöðruhálskirtli árið 1996 eða krabbameini í þvagblöðru 1995 eða 1996 og höfðu að minnsta kosti þriggja mánaða sjúkdómslengd, voru fundnir í gagnagrunni yfir dánarorsakir. Vorið 1999 var leitað til allra eftirlifandi ekkna/sambýliskvenna þeirra (n=506), sem voru þá 79 ára og yngri, og þær beðnar að taka þátt í rannsókn um reynslu sína. Ekkjurnar voru bornar saman við hóp kvenna á sambærilegum aldri sem voru giftar eða í sambúð (n=287). Ekkjurnar svöruðu nafnlausum spurningalista um sjúkdóm og lát mannsins síns og báðir hópar (rannsóknarhópur og samanburðarhópur) svöruðu spurningum um núverandi heilsu og virkni.

**Niðurstöður:** Svarhlutfall var 75% hjá ekkjunum og 77% hjá samanburðarhópnum. Meðalaldur hópanna var sá sami (67,5 ár) og hóparnir voru svipaðir hvað annan bakgrunn varðaði. Að meðaltali höfðu liðið þrjú ár frá láti mannsins. Í ljós kom að borið saman við samanburðarhópinn áttu ekkjurnar aukna hættu á kvíða (relative risk (RR) 1,9), þunglyndi (RR 2,2), svefntruflunum (RR 2,0), sykursýki (RR 3,5) og óánægju með fjárhagsstöðu (RR 1,6). Lengd vitundartíma fyrir yfirvofandi andlát var mjög mismunandi meðal ekknanna, 48% höfðu þrjú mánuði eða minna og 15% höfðu 24 klst. eða minna. Vitundartími spáði fyrir um hættu á andlegri vanlíðan, þar sem stuttur vitundartími fól í sér mesta áhættu, þriggja til sex mánaða vitundartími fól í sér minnsta áhættu og lengri vitundartími en eitt ár sýndi tilhneigingu í átt að aukinni áhættu. Í samanburði við þriggja til sex mánaða vitundartíma, jók mjög stuttur vitundartími (styttri en sólarhringur) áhættu á kvíða um (RR 1,9) og áhættu á þunglyndi um (RR 1,6). Upplýsingar og stuðningur frá læknum og öðru heilbrigðisstarfsfólki gáfu besta forspá um lengd vitundartímans. Andleg (en ekki líkamleg) þjáning sjúklingsins á síðustu mánuðum lífsins spáðu fyrir um kvíða- og depurðareinkenni ekknanna. Ef sjúklingur hafði verið kvíðinn síðustu þrjú mánuðina fyrir lát sitt, jók það hættu á þunglyndi ekkjunnar (RR 2,5). 33% ekknanna sögðu að sjúklingurinn hefði haft nokkuð greiðan aðgang að sálfræðilegum stuðningi en 93% sögðu að hann hefði haft slíkan aðgang að verkjastillandi meðferð. U.þ.b. 2/3 ekknanna sögðust hafa haft þörf fyrir samskipti við heilbrigðisstarfsfólk eða faglega ráðgjöf (upplýsingar, sálfræðilegan stuðning, fjárhagslega ráðgjöf) fyrstu sex mánuðina eftir lát manns þeirra, en einungis 20% höfðu haft slíkan aðgang.

**Umræða/ályktun:** Vitundartími ekkju og andlegar þjáningar sjúklings fyrir andlát hans eru áhrifaþættir langvarandi kvíða og þunglyndis ekkjunnar. Þessir áhættuþættir eru nátengdir gæðum heilbrigðisþjónustu.

**Lykilorð:** krabbamein; ekkjur/ekklar; áhættuþættir; upplýsingar; stjórnun sjúkdómseinkenna; sálfræðilegur stuðningur; aðlögun, sálfræðileg; kvíði; þunglyndi; faraldsfræði.

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## X. APPENDIX 1

**Table 1:** Studies on the effect of forewarning of death and psychological morbidity in bereavement.

Reference	Design	Population N Response rate%	Follow-up time	Independent variable	Outcome measures	Main findings	Comments
Ball (1977)	Cross sectional	81 widows (18-73 years) 42% of those identified in registers.	6-9 months	1) Sudden death (<5 days from illness onset) vs. expected death 2) Widows' age	Grief symptoms measured on five scales from one to five.	Young age (18-46) and sudden death caused more intense grief reactions. Forewarning especially important for young widows.	- Low response rate - Early follow-up
Barry, Kasl & Prigerson (2002)	Longitudinal design with retrospective ratings of independent variables.	122 bereaved adults (mean age 64 years, 71% women). 46% of 265 on 4-month interview 84% of 145 on both interviews	4 months and 9 months	Subjective evaluation of: 1) Preparedness for the death. 2) Deceased degree of suffering before death.	Inventory of Complicated Grief (ICG-R) Current Major Depressive Disorder & Post Traumatic Stress Disorder (SCID)	Little preparedness was associated with complicated grief 4 and 9 months and major depression at 9 months following loss. Suffering not related to psychiatric disorders.	- Short follow-up time - Response rate? - Stringent measures of dependent variables - Controlled for previous psychiatric history.
Breckenridge (1986)	Cross sectional	196 widows and widowers, mean age 68 yr. Response rate not indicated	2 months	Self rated expectation (yes/no)	Beck's Depression Inventory – BDI	No difference between those who stated that they had expected the loss to those who did not.	- Early follow-up - Response rate and causes of death not given.
Cameron & Parkes (1983)	Experimental design	40 bereaved individuals (28 women, 12 men) whose loved ones had died in palliative care unit (PCU, n=20) or in standard hospital care (n=20) 59%.	12 months	1) PCU vs. standard care. 2) Amount of warning +/- 4 days. 3) Patients' degree of suffering.	Health adjustment inventory (32 items).	PCU survivors were better adjusted than standard care survivors. More forewarning associated with better outcome – (not significant, small sample).	- Experimental design. - Small sample size.

Carey (1977)	Cross sectional	119 widows(ers) (28-70 years) 54% of 221 in study base 75% of contactable	13-16 months	1) Gender 2) Forewarning (+/- 2 weeks)	Validated adjustment scale (8 items with 3 response categories)	Forewarning was associated with better adjustment among widows but not for widowers who were better adjusted.	- Important gender difference regarding forewarning. - 20% of widowers had remarried.
Carr, House, Worthman, Nesse & Kessler (2001)	Longitudinal design with retrospective ratings of some indep. variables.	210 widows(ers) (65 years and older) 66% of 316 in study base	6 months and 18 months	Warning time: 1) no warning 2) 0-6 months 3) 6 months or more	Anxiety (Symptom Checklist 90 Revised) Depression (CES-D) Items of grief. Shock, anger, yearning, intrusive thoughts.	Warning time unrelated to depression and grief symptoms. Sudden death increased risk of intrusive thoughts at 6 months after loss. Prolonged forewarning associated with elevated anxiety at 6 and 18 months.	- Not controlled for different causes of deaths or the impact of gender. - Controlled for age of the deceased, prior mental health, the survivor's participation in care and communication with the dying partner.
Clayton, Halikas, Maurice & Robbins (1973)	Cross sectional	92 widows(ers) (mean age 61) whose spouses had died of illness duration 5 days or more. 84% of 109 in study base.	1 month and 13 months.	1) Long vs. short term illness (cut-off 6 months). 2) Anticipatory grief = depression the month before death.	Depression operationalised as the occurrence of cluster of depressive symptoms.	Duration of illness was unrelated to risk of depression. Those experiencing anticipatory grief were more likely to be depressed 1 month but not 13 months after loss.	- Short follow-up time - Operationalisation of anticipatory grief? - Not controlled for different causes of deaths or the survivors caregiving burden.
Gerber, Rusalem, Hannon, Battin & Arkin (1975)	Cross sectional	81 widows(ers) (mean 67 years) Response rate not reported or detectable.	6 months.	1) Anticipatory grief (defined as illness longer than 2 months) 2) +/- 6 months duration of illness 3) Survivor's sex	1) Number of physician office visits 2) Number of times ill without physician contact 3) Psychotropic drug use	No benefit of anticipatory grief. Longer chronic illness associated with poorer adjustment.	- Response rate? - Operationalisation of anticipatory grief? - Early follow-up.

Hill, Thomson & Gallagher (1988)	Longitudinal design with some retrospective ratings.	95 widows (mean: 67 years) 30%	2 months, 6 months and 12 months.	Expected vs subjectively stated unexpectedness death and illness shorter than 1 month. Rehearsal (or not) of death thoughts/actions	Beck's depression inventory (BDI) Brief symptom inventory (BSI) Physical health items. Intensity of grief (TRIG).	No effect of expectancy or rehearsal. Significant reduction of symptoms over time.	- Low response rate - Short follow-up time
Houts (1989)	Cross sectional	112 widows and widowers, mean age 60 yr. Response rate 85%	11 months (1-29 mo.)	Spouses time with awareness Patient & spouse discussion of impending death	Centre for Epidemiological studies CES-D. Six items from Grief experience inventory GEL.	Time with awareness was not related to outcome. Avoidance to think about the patient's death and spouse's level of upset during last month predicted outcome.	- Early follow-up - All cancers - Effect measure depression.
Kitson & Zysanski (1987)	Cross sectional	201 widows and divorcees (age 18-62 years) 57% of 353 in study base 70% of 288 contactable	3 months	Widows vs. divorcees. Vulnerabilities, e.g. amount of forewarning (self-reports).	BSI, Zung self rating depression scale, grief symptoms, physical health.	Widows fared worse than divorcees and expectedness was protective for widows but not for divorcees.	- Well defined and reported study base - Valid measurements - Theoretically important finding that expectedness protects widows but not divorcees.
Levy, Martinkovsky & Derby (1994)	Longitudinal design with retrospective ratings.	131 widows(ers) of deceased cancer patients (mean age 61 yr) 47% of all 82% of willing	3, 6, 13 & 18 months.	Anticipatory grief inventory	Depression (CES-D) Subjective stress – Impact of Event Scale (IES)	AG associated with more depression and subjective stress. Conjugal coping had some protective effects.	- Retrospective ratings - Low response rate
Lundin (1984)	Longitudinal	78 bereaved parents and spouses (40-50 years old at time of death) 60% of 130	8 years	Expected vs. unexpected – deceased under the age of 65, less than 2 hours from illness onset or accident	Texas Inventory of Grief (TIG).	Unexpected death and parenthood predicted poor outcome.	- Many causes of death (controlled for disease/accidents). - Suicides excluded. - Longitudinal design. - Expectedness determined by records/objective data.

Richards & McCallum (1979)	Cross sectional	100 widows (ers) 65 years + Spouses died of different causes 75% of 133	6 months	- Age - Gender - Expectedness	Depression 24 questions (yes/no)	At least one week of terminal illness, expecting the death & talking with spouse about the impending death predicted less depression.	- Short follow-up time - Measure of depression?
Sanders (1982-83)	Longitudinal	86 bereaved who lost a parent, child or a spouse. Response rate not stated	18 months	Mode of death - Sudden death - Short-term illness (<6 mo.) - Long-term illness (>6 mo.)	Grief Experience Inventory GEL MMPI	Best adjustment for short-term illness survivors. Sudden death group had more somatic symptoms, anger and guilt. Long-term group was more isolated and alienated.	Short-term group had large proportion of parental death while sudden group had large proportion child death. - Response rate? Effect of different causes of death?
Schut (1991)	Longitudinal	128 widows and widowers <66 yr Response rate 25-30%	4 months 11 months 18 months 25 months	Self-rated anticipation Duration of illness Cause of death	PTSD Adopted from DSM-III-R	Little anticipation and not having said goodbye predicted higher PTSD score only at 25 months. Duration and cause of illness had no/ little impact.	- Low response rate
Zisook (1991)	Longitudinal	350 widows and widowers, mean age 61 years. Response rate less than 20%	2 months 7 months	Anticipation -nature of death; prolonged illness (>3 months); sudden illness or accident/suicide	Hopkins Symp. Checklist HSCL Zung Depression Scale	Lack of anticipation predicted anxiety scores at 7 months.	- Low response rate

## XI. APPENDIX 2

### EXAMPLES OF INDEPENDENT VARIABLES

- When did you realise that your husband would die from the disease?

*- Please check the alternative which best describes your experience -*

- I realised it when it happened
- Few hours before he died
- The day before he died
- Few days before he died
- A week before he died
- 2-4 weeks before he died
- 1-3 months before he died
- 3-6 months before he died
- 6-12 months before he died
- More than one year before he died

- Here below are examples of problems which can be distressful for a man with cancer. **Did you notice** that any of these influenced your husband's well-being the last three months of his life? [*Here are only given few examples of items*]

*- Please check the alternative which best describes your experience -*

	No, not at all	Yes, a little	Yes, moderately	Yes, much
Pain				
Constipation				
Poor appetite				
Depression				
Anxiety				

- *Following question relates to health care resources for the first six months following your husband's death.*  
Please indicate to what extent you had access to psychological support the first six months following your husband's death:

- Not relevant, I had no need
- No access
- Little access
- Moderate
- Much access



## EXAMPLES OF DEPENDENT VARIABLES

- Please try to estimate how you have felt in general. Put a circle around the number which best describes your feelings.

- Have you experienced anxiety for the last week?

1-----2-----3-----4-----5-----6-----7  
Never Always

- Have you felt depressed or sad for the last week?

1-----2-----3-----4-----5-----6-----7  
Never Always

- Have you ever woken up at night with anxiety or an unpleasant feeling the last month?

- *Please check the alternative which best describes your experience -*

- No, never
- Yes, once or twice
- Yes, a few times (approximately once or twice a week)
- Yes, several times (approximately 3-4 times a week)
- Yes, almost always/every night

- Have you taken tranquilizers the last month?

- *Please check the alternative which best describes your experience -*

- No, never
- Yes, once or twice
- Yes, a few times (approximately once or twice a week)
- Yes, several times (approximately 3-4 times a week)
- Yes, almost always/every day