

available at [www.sciencedirect.com](http://www.sciencedirect.com)journal homepage: [www.ejconline.com](http://www.ejconline.com)

## Couples' communication before the wife's death to cancer and the widower's feelings of guilt or regret after the loss – A population-based investigation

Junmei Miao Jonasson <sup>a,b,c,\*</sup>, Arna Hauksdóttir <sup>a,d</sup>, Szilard Nemes <sup>c</sup>, Pamela J. Surkan <sup>e</sup>,  
Unnur Valdimarsdóttir <sup>b,d,f</sup>, Erik Onelöv <sup>b</sup>, Gunnar Steineck <sup>b,c</sup>

<sup>a</sup> National Diabetes Register, Registercentrum i Västra Götaland, NHV, Box 12133, SE-402 42 Göteborg, Sweden

<sup>b</sup> Division of Clinical Cancer Epidemiology, Department of Oncology–Pathology, KarolinskaInstitutet, Z5:U1, Karolinska Hospital, SE-17176 Stockholm, Sweden

<sup>c</sup> Division of Clinical Cancer Epidemiology, Department of Oncology, Sahlgrenska Academy, Göteborg's University, Kapellgängen 9, Landala, 41345 Göteborg, Sweden

<sup>d</sup> Center of Public Health Sciences, University of Iceland, Stapi. Hringbraut, 101 Reykjavík, Iceland

<sup>e</sup> Department of International Health, Johns Hopkins Bloomberg School of Public Health, 615 North Wolfe St., Baltimore, MD 21205-2179, USA

<sup>f</sup> Department of Medical Epidemiology and Biostatistics, KarolinskaInstitutet, Nobel väg 12a, Box 281, 17177 Stockholm, Sweden

### ARTICLE INFO

#### Article history:

Received 25 October 2010

Received in revised form 10 January 2011

Accepted 20 January 2011

Available online 18 February 2011

#### Keywords:

Cancer

Guilt feelings

Regret

End-of-life communication

Bereavement

### ABSTRACT

**Aim:** To investigate the association between couples' communication before the wife's death to cancer and the widower's feelings of guilt and regret after the loss, in a population-based data.

**Methods:** Men ( $n = 907$ ) younger than 80 years and living in Sweden, who had lost their wives due to cancer, were asked 4–5 years after their loss to answer an anonymous postal questionnaire it included questions about the couple's end-of-life communication during the last 3 months of life and the widower's feelings of guilt or regret during the first 6 months after the wife's death.

**Results:** During the last 3 months of their wives' lives, men who had not talked about the impending death with their wives had a higher risk of experiencing feelings of guilt than men who did talk (relative risk (RR) 2.0, 95% confidence interval [CI] 1.2–3.4). Men who were not able to spend as much time as they wished with their wives had an increase in the risk of having feelings of guilt twice that of men who spent time (RR 2.0 95% CI 1.5–2.7). Men who did not talk with their wives about how they could cope practically or emotionally after the death had elevated risks of guilt feelings compared with men who talked (RR 1.8, 95% CI 1.0–3.0; RR 1.7, 95% CI 1.0–2.9, respectively). Men who realised it was too late to discuss the impending death had an increased risk of guilt feelings (RR 4.3, 95% CI 2.9–6.6). Men who thought that not everything had been brought to closure before their wives' deaths had 3.3 times increased risk of guilt feeling (RR 3.3, 95% CI 1.7–6.4).

**Conclusions:** A man who does not have end-of-life discussions with his wife during the last 3 months before her death from cancer may be subject to a significantly greater risk of experiencing feelings of guilt or regret in widowhood than men who did engage in such discussions.

© 2011 Elsevier Ltd. All rights reserved.

\* Corresponding author: Address: National Diabetes Register, Registercentrum i Västra Götaland, NHV, Box 12133, SE-402 42 Göteborg, Sweden. Tel.: +46 739053278; fax: +46 31 209250.

E-mail addresses: [junmei.jonasson@oc.gu.se](mailto:junmei.jonasson@oc.gu.se), [junmei.miao.jonasson@gmail.com](mailto:junmei.miao.jonasson@gmail.com) (J.M. Jonasson).

0959-8049/\$ - see front matter © 2011 Elsevier Ltd. All rights reserved.

doi:10.1016/j.ejca.2011.01.010

## 1. Introduction

Guilt or regret may be experienced as an unpleasant feeling of self-blame resulting from the perception of having done something wrong or of not having done something you should have done. This self-criticism may be associated with remorse and may be related to acts, impulses or thoughts contrary to one's conscience for which one feels personal responsibility. Bereaved persons, like parents who have lost children or women who have lost husbands, often experience feelings of guilt.<sup>1–6</sup> In these contexts, feelings of guilt or regret often include self-reproach for having done something that might have contributed to the death of a loved one or for having failed to help prevent the death.<sup>7</sup> Feelings of guilt related to bereavement may lead to difficulties in long-term adjustment, and they may, for example, manifest themselves as symptoms of psychological morbidity in surviving family members.<sup>8</sup>

Open communication is a very important part of end-of-life care of many terminal cancer patients.<sup>9</sup> Having talked about death at the end of life has been found to be related to better quality of life for the patient and to the ability of the relative to start the adjustment process during bereavement.<sup>10</sup> Husbands who talked about death with their dying wives were often better prepared for the moment of death than husbands who did not talk.<sup>11</sup> We also found that low preparedness at the time of wife's death increases the widower's risk of psychological morbidity 4–5 years after the loss.<sup>12</sup> Even if this is true, we know that it can be difficult for both physicians and family members to talk openly about death with the patients.<sup>10,13</sup> Therefore it would seem that researchers and caretakers would want to know more about the possible benefits to be obtained from such communication. Yet, to our knowledge, there are no previous published reports about a husband's discussion about death with his dying wife and his subsequent feelings of guilt or regret. In this population-based survey, we investigated the association between a couple's communication about the wife's impending death and the husband's feelings of guilt or regret during the first 6 months after the death.

## 2. Materials and methods

### 2.1. Study design

This is a population-based investigation of men 4–5 years after they lost their wives to cancer. The questionnaire is divided into three sections: questions of the men's current life and health condition, questions with regard to women's disease period and the moment of death, and the 6-months period following the wife's death. The latter two sections were retrospective since they happened 4–5 years ago when their wives were living with end-stage of cancer and half years after they lost their wives due to cancer. There were 69 questions concerning the men's current life and health condition, 52 questions about the women's disease period and the moment of death, and 30 questions regarding to the 6-months period after the wife's death. The outcome in this study: guilt

feelings or regret in the first 6 months after the wife's happened 4–5 years ago. The exposure variables: the discussion about death related issues happened before the wife's death.

### 2.2. Study population

The study population included all men in three major metropolitan areas of Sweden and also a broader area of northern Sweden who lost their wives to one of three types of cancer in 2000 and 2001. First, we identified 3473 women from the Swedish Cancer Register who died from breast, ovary or colon cancer in 2000 or 2001 and who lived in, metropolitan Gothenburg, Stockholm, and Uppsala and in Northern Sweden at the time of death. Through linkage to the Swedish Total Population Register, information on the husbands of these women was obtained. To be eligible, the husband had to be younger than 80 years at the time of the study, be born in a Nordic country, have a registered phone number, understand Swedish, and must have been living with his wife at the time of her disease and death. A total of 907 men met these eligibility criteria. The study population has been described in detail elsewhere.<sup>14–18</sup>

### 2.3. Questionnaire

During a preparatory phase, we developed a study-specific questionnaire on the basis of previous survivorship projects at the Division of Clinical Cancer (described in previous publications<sup>15,19–22</sup>). First, we conducted ten in-depth interviews to collect data to aid in the development of a questionnaire. Then, we tested the validity of the questionnaire in an additional ten face-to-face interviews. After a pilot study including 76 men, we used the anonymous questionnaire to collect data between November 2004 and November 2005. The questionnaire included 153 questions divided into three sections: (1) the men's current life and health condition, (2) the moment of death and the period during which the women was ill, and (3) the 6 month period following the wife's death.

The study's outcome variable, experiencing feelings of guilt or regret in the first 6 months after the wife's death was assessed using the binary answers "Yes" and "No" to the question "Did you have any guilt feelings or regret after your wife's death?" The exposure variables consisted of the questions about communication between husband and wife during the last 3 months of her life: "Did you and your wife talk about death during her last 3 months of life?" (response categories were 'No, never', 'Yes, once', 'Yes, a few times', and 'Yes, many times'), "During your wife's last 3 months, were you able to spend as much time as you wished with your wife?" (response categories were 'Yes' and 'No'). "During your wife's last 3 months, did you and your wife talk about emotional problems?", "During your wife's last 3 months, did you and your wife talk about issues from the past?", "During your wife's last 3 months, did you and your wife talk about how you would cope practically after her death?" and "During your wife's last 3 months, did you and your wife talk about how you would cope emotionally after her death?" The response categories for these questions were 'No', 'Never', 'Yes, once',

'Yes, a few times', and 'Yes, many times'. In addition, the following statements were included: 'I realised too late that there were things my wife and I should have discussed', 'My wife did not want to discuss things I considered important before her death', 'I did not want to discuss things my wife considered important before her death' and lastly 'Everything was brought to closure before my wife's death'. The response categories for these statements were 'No, does not apply', 'Yes, applies somewhat', 'Yes, applies to large extent' and 'Yes, applies completely'.

#### 2.4. Statistical analysis

We calculated the percentage of subjects in each category of the independent variables with outcome and formed ratio of these percentages ("relative risks", RRs) as a measure of the strength of the association between the independent variable and the outcome. Stepwise model selection procedure showed the need for adjustment for age and education. All statistical analyses were performed by using SAS statistical software version 9.2 (SAS Institute, Cary, NC, USA).

### 3. Results

Of the 907 men who were eligible for the study, 691 (76%) completed the questionnaire. Ninety-five (10%) men declined participation when first contacted, 104 (11%) men agreed to consider participation but did not return the questionnaire, 12 (1%) men were not reachable, two men (0.2%) died after the start of the data collection and three men (0.3%) did not participate for other reasons. The mean age of study participants was 66 years and the mean age of non-participants was 71 years. The characteristics of the participating widowers are listed in Table 1.

Compared to men who talked about death several times with their wives in the 3 months before the death of the wives, men who never talked about death, or who had talked about death only once or few times, had approximately between a two- and three-fold greater risk of experiencing feelings of guilt or regret after their wife's death. Men who could not spend as much time as they wished with their wives during her last 3 months had a two-fold higher risk of guilt feelings, compared to those who got to spend time. During the wives' last 3 months, men who did not talk or who only talked once about how they would cope practically with their wives after death had a 1.8 times higher risk of guilt feelings or regret than did those men who talked many times. Similarly, during the wives' last 3 months, men who never talked about how they would cope emotionally without their wives after death had a 1.7 higher risk of guilt feeling than those who talked many times. Compared to men who stated that everything was brought to closure before their wives died, those who did not had a relative risk 3.3 times greater risk of guilt feelings. Compared to men who answered 'No' to the statement 'I realised too late that there were things my wife and I should have discussed' those who answered 'Yes, applies completely', 'Yes, applies to large extent' or 'Yes, applies somewhat', had in the same order a 2.6, 3.4, and 4.3 relative risk of experiencing guilt feelings (Table 2).

**Table 1 – Characteristics of participating widowers.**

Characteristics <sup>a</sup>	No. of men	%
<i>Age at the study (years)</i>		
30–50	43	6
51–60	154	22
61–70	283	41
71–80	207	30
Not indicated	4	1
<i>Wife's primary cancer<sup>b</sup></i>		
Breast	398	58
Ovarian	140	20
Colon	107	15
Other <sup>c</sup>	29	4
Not indicated	17	2
<i>Employment status</i>		
Employed	270	39
Retired	382	55
On sick leave	26	4
Unemployed	7	1
Home supported by wife	3	0
Not indicated	3	0
<i>Level of education</i>		
Primary school	264	38
Secondary school, 2 years	117	17
Secondary school, 3 years	126	18
University	180	26
Not indicated	4	1
<i>Place of residence</i>		
Rural	132	19
Small town	167	24
Medium-sized town	232	34
City > 500,000 inhabitants	157	23
Not indicated	3	0
<i>Current marital status</i>		
Married/cohabiting	123	18
Single	338	49
Has a partner but lives alone	210	30
Not indicated	20	3
<i>Religiosity</i>		
Very religious	45	7
Quite religious	197	29
Somewhat religious	268	39
Not religious at all (atheist)	166	24
Not indicated	15	2

<sup>a</sup> At time of response to the questionnaire.

<sup>b</sup> The primary cancer location according to the husband.

<sup>c</sup> Other primary cancers reported were liver and gastrointestinal cancer. The diagnoses drawn from the Swedish Cancer Registry included only breast, colon, and ovarian cancer.

Fig. 1 shows the percentage of men who had feelings of guilt feelings or regret during the first 6 months after their wives death due to cancer in relation the men's answer to the question 'Did you and your wife talk about death during her last 3 months of life' (in blue colour) and the statement 'I realised too late that there were things my wife and I should have discussed' (in red). For the question 'Did you and your wife talk about death during her last 3 months of life', 22% of the men who never talked about death with the wife had guilt feelings, 34% of the men who talked only once had guilt feelings, 24% of the men who talked a few times and 14% of

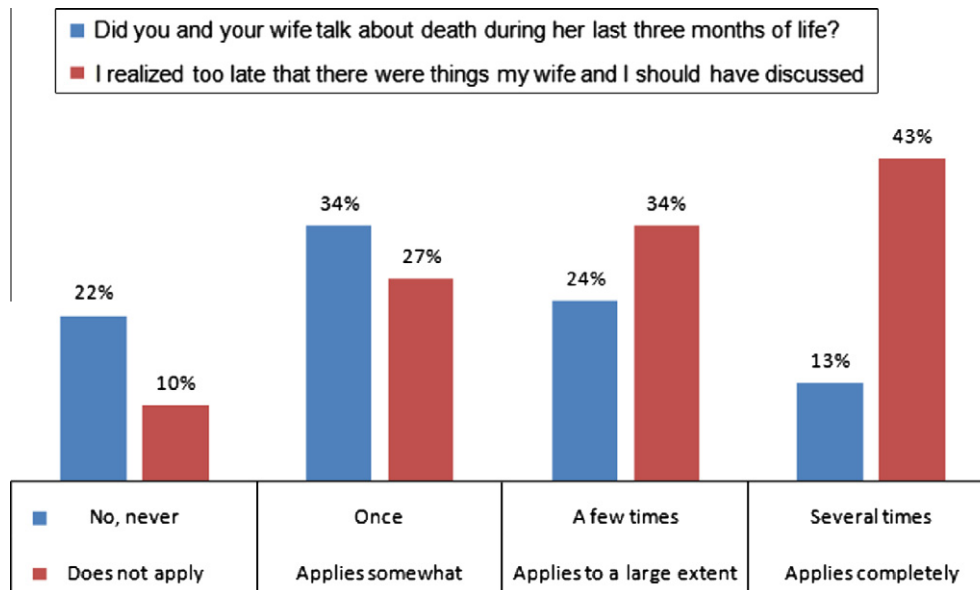
**Table 2 – The relative risks for guilt feelings or regret among widowers in relation to having talked about death with their wives during their last 3 months of life.**

	No./total no. (%)	Relative risk (95% confidence interval [CI])	
		Crude	Multivariate model <sup>a</sup>
<i>Did you and your wife talk about death during her last 3 months of life?</i>			
No, never	66/294 (22)	1.7 (1.0–2.9)	2.0 (1.2–3.4)
Yes, once	15/44 (34)	2.6 (1.4–4.9)	2.7 (1.5–5.0)
Yes, a few times	42/176 (24)	1.8 (1.0–3.1)	1.9 (1.1–3.3)
Yes, many times	14/106 (13)	Reference	Reference
<i>During your wife's last 3 months, were you able to spend as much time as you wished with your wife?</i>			
No	49/124 (40)	2.2 (1.7–3.0)	2.0 (1.5–2.7)
Yes	93/529 (18)	Reference	Reference
<i>During your wife's last 3 months, did you and your wife talk about emotional problems?</i>			
No, never	56/245 (23)	1.2 (0.8–2.0)	1.5 (0.9–2.3)
Yes, once	7/37 (19)	1.0 (0.5–2.2)	1.2 (0.6–2.6)
Yes, a few times	61/257 (24)	1.3 (0.8–2.0)	1.5 (0.9–2.4)
Yes, many times	18/96 (19)	Reference	Reference
<i>During your wife's last 3 months, did you and your wife talk about issues from the past?</i>			
No, never	59/265 (22)	1.0 (0.7–1.4)	1.2 (0.8–1.7)
Yes, once	5/23 (22)	0.9 (0.4–2.2)	1.2 (0.5–2.8)
Yes, a few times	47/219 (21)	0.9 (0.6–1.4)	1.0 (0.6–1.4)
Yes, many times	29/126 (23)	Reference	Reference
<i>During your wife's last 3 months, did you and your wife talk about how you would cope practically after her death?</i>			
No, never	83/341 (24)	1.7 (1.0–2.9)	1.8 (1.0–3.0)
Yes, once	14/46 (30)	2.2 (1.1–4.2)	1.9 (1.0–3.6)
Yes, a few times	32/167 (19)	1.4 (0.8–2.5)	1.2 (0.7–2.2)
Yes, many times	13/92 (14)	Reference	Reference
<i>During your wife's last 3 months, did you and your wife talk about how you would cope emotionally after her death?</i>			
No, never	86/378 (23)	1.5 (0.9–2.7)	1.7 (1.0–2.9)
Yes, once	11/42 (26)	1.8 (0.9–3.7)	1.9 (0.9–3.9)
Yes, a few times	33/144 (23)	1.5 (0.8–2.8)	1.5 (0.8–2.8)
Yes, many times	12/81 (15)	Reference	Reference
<i>How much do you agree with the following that regarding to you and your wife's discussion before your wife died?</i>			
<i>A. I realised to late that there were things my wife and I should have discussed</i>			
No, does not apply	30/294 (10)	Reference	Reference
Yes, applies somewhat	46/169 (27)	2.7 (1.8–4.1)	2.6 (1.7–3.9)
Yes, applies to large extent	32/94 (34)	3.3 (2.1–5.2)	3.4 (2.2–5.2)
Yes, applies completely	34/79 (43)	4.2 (2.8–6.4)	4.3 (2.9–6.6)
<i>B. 'My wife did not want to discuss things I considered important before her death</i>			
No, does not apply	84/418 (20)	Reference	Reference
Yes, applies somewhat	33/118 (28)	1.2 (0.9–1.4)	1.2 (1.0–1.4)
Yes, applies to large extent	10/51 (20)	1.0 (0.8–1.3)	1.0 (0.8–1.3)
Yes, applies completely	14/45 (31)	1.2 (0.9–1.5)	1.1 (0.9–1.4)
<i>C. I did not want to discuss things my wife considered important before her death</i>			
No, does not apply	98/467 (21)	Reference	Reference
Yes, applies somewhat	32/112 (29)	1.4 (1.0–1.9)	1.5 (1.1–2.1)
Yes, applies to large extent	5/31 (16)	0.8 (0.3–1.7)	0.9 (0.4–2.1)
Yes, applies completely	5/20 (25)	1.2(0.5–2.6)	1.6 (0.7–3.4)
<i>D. Everything was brought to closure before my wife's death'</i>			
No, does not apply	82/259 (32)	3.6 (1.9–6.9)	3.3 (1.7–6.4)
Yes, applies somewhat	25/110 (23)	2.6 (1.3–5.3)	2.2 (1.1–4.6)
Yes, applies to large extent	22/158 (14)	1.6 (0.8–3.3)	1.4 (0.7–2.9)
Yes, applies completely	9/103 (9)	Reference	Reference

<sup>a</sup> Adjusted for age, education.

the men who talked several times had guilt feelings. For the statement 'I realised too late that there were things my wife and I should have discussed'. Among men who answered this question with 'Does not apply', 10% had guilt feelings. Among

men who answered with 'Applies somewhat', 27% had guilt feelings. Among men who answered 'applies to large extent', 34% had guilt feelings. Of men who answered 'Applies completely', 43% had guilt feelings.



**Fig. 1 – The percentage of men who experienced feelings of guilt feelings or regret during the first 6 months after his wife died from cancer in relation to the men’s answer to the question ‘Did you and your wife talk about death during her last 3 months of life’ (in blue colour) and the statement ‘I realised too late that there were things my wife and I should have discussed’ (in red). (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)**

#### 4. Discussion

Our results suggest that feelings of guilt in widowers during the first 6 months after a wife’s death to cancer are clearly associated with not having talked about death with the wife before she died, of not having been able to spend as much time with her as was desired, of not having talked about how to cope practically or emotionally after the loss, and of not having finalised everything before her death.

Available data support the belief that there is a beneficial long-term effect for the next of kin when the next of kin discusses death with a family member suffering from cancer during a several month period immediately preceding death. Parents who lost a child due to cancer did not regret talking about death with the child before his/her death.<sup>19</sup> Furthermore, poor communication between terminally ill patients and their family members appears to increase the risk of psychological morbidity of surviving family members.<sup>23</sup> Open communication about concerns related to death and illness, emotional support, and facilitating systems seem therefore to be of great importance, both to the patients and family members.<sup>24</sup> The perception of not being able to prevent the death of the loved one may be related to feelings of guilt during bereavement.<sup>4</sup> Our results also indicate that frequency of communication may be important, men who talked once with their wives during the last 3 months of their lives had a higher relative risk of experiencing guilt or regret, compared to men who talked several times. We are not aware of any other data suggesting that touching on sensitive issues without fully working through them is worse than not talking at all.

Regarding whether the husbands felt it was too late when they realised that they should have discussed some issues with their wives, there is a clear dose–response relationship between the extent of the agreement with this question and

the risk of experiencing guilt feelings. One reason that the men realised too late that there were issues to be discussed with their wives might be due the fact that the men themselves received information about the wives’ medical situation too late or not at all. In a previous publication based on the same cohort, 41% of the men reported that they either never received the information that the patient’s cancer was beyond curing or received this information during the last week of the patient’s life.<sup>16</sup> Another reason might be that if they received the information, they were not able to accept it because of personal attitudes. Previous results from this study showed that 14% of the widowers did not think that next of kin should be informed immediately when the patient’s cancer is found to be not curable and 39% of the men did not want the patient to be immediately informed.<sup>16</sup>

The relationship of feelings of guilt or regret to the nature of the health care received close to the time of death and at the moment of death has been examined in two previous studies conducted by our group. In a study of 449 parents who lost their children due to cancer, the bereaved parents’ perceptions of inadequate health care were associated with later guilt feelings.<sup>3</sup> This study also showed that compared to parents who shared at least half of their emotional problems with someone else, those that shared none or less than half of their emotional problems had a 2.7 times increased risk of guilt feelings. Likewise, in a study of 379 women who had lost a husband to cancer, a relationship between feelings of guilt and the perception of experiencing inadequate health care during the last months and at the actual moment of death was also reported.<sup>4</sup> The widows had a 1.7 greater relative risk of guilt feelings or regret if they perceived that their husbands did not get enough pain relief during his disease period compared to widows who felt that their husbands had adequate pain relief. Widows had around a two times



higher increased risk of guilt feelings or regret if they believed their husbands received less satisfactory care or treatment.<sup>4</sup>

A strength of our study is the population-based design. With use of the Swedish National Cancer and Population Registries, we approached all men who lost their wives to these three types of cancer between 2000 and 2001 in a large part of Sweden, enabling us to enroll a non-selected cohort. To our knowledge, this is one of the largest sets of data collected from a cohort of widowers. Moreover, our questionnaire was finalised after extensive preparation and validation, which minimises potential measurement error. The questionnaire included 153 questions containing possible confounding factors. There is not interviewer-related bias since we used anonymous self-administered questionnaires.

Our study has some limitations. First, if the recall in used problems differs between the categories of guilt, a bias that could increase the relative risk could happen. However, the essential question is to what extent this source of bias is differential with respect to the widowers' outcome status, e.g. the experience of guilt. A previous study on widows did not find that depressive status of the widow led to an over reporting of the husband's unrelieved pain during the last 3 months of life.<sup>25</sup> These findings lend support to the notion that the widowers' guilt may not affect their retrospective assessments of their communication with their wives. Nevertheless, we cannot entirely rule out this source of bias and further studies with prospective assessment of exposure are needed. Second, the association between the couple's communication and presence of guilt could be different among those not participating. However, the high participating rate of the investigation might minimise these problems. Because people from diverse cultures experience feelings of guilt or regret different ways, this investigation's results may not be generalizable to other cultures.<sup>26</sup> In addition, multiple comparisons might be a concern since we conducted statistical tests regarding 10 different questions on the end life communications. However, adjustment for multiple comparisons would not change the interpretation of results.

Our results suggest that a man who does not have end-of-life discussions with his wife during her last 3 months before death from cancer may be at increased of experiencing subsequent guilt feelings. Our study adds to the existing literature, suggesting that active communication between the next of kin and terminally ill cancer patients and may benefit the next of kin's psychological health after the loss. Future studies may elucidate which aspects of care facilitate discussions about death between the next-of-kin and the cancer patient.

### Conflict of interest statement

None declared.

### REFERENCES

- Rando TA. Bereaved parents: particular difficulties, unique factors, and treatment issues. *Soc Work* 1985;**30**(1):19–23.
- Steele LL. The death surround: factors influencing the grief experience of survivors. *Oncol Nurs Forum* 1990;**17**(2):235–41.
- Surkan PJ, Kreicbergs U, Valdimarsdottir U, et al. Perceptions of inadequate health care and feelings of guilt in parents after the death of a child to a malignancy: a population-based long-term follow-up. *J Palliat Med* 2006;**9**(2):317–31.
- Ylitalo N, Valdimarsdottir U, Onelov E, Dickman PW, Steineck G. Guilt after the loss of a husband to cancer: is there a relation with the health care provided? *Acta Oncol* 2008;**47**(5):870–8.
- Rubin SS, Malkinson R, Witztum E. Trauma and bereavement: conceptual and clinical issues revolving around relationships. *Death Stud* 2003;**27**(8):667–90.
- Zisook S, Shuchter SR. Time course of spousal bereavement. *Gen Hosp Psychiatry* 1985;**7**(2):95–100.
- Stroebe M, van Son M, Stroebe W, et al. On the classification and diagnosis of pathological grief. *Clin Psychol Rev* 2000;**20**(1):57–75.
- Weinberg N. Does apologizing help? The role of self-blame and making amends in recovery from bereavement. *Health Soc Work* 1995;**20**(4):294–9.
- Andershed B. Relatives in end-of-life care—part 1: a systematic review of the literature the five last years, January 1999–February 2004. *J Clin Nurs* 2006;**15**(9):1158–69.
- Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;**300**(14):1665–73.
- Hauksdottir A, Valdimarsdottir U, Furst CJ, Onelov E, Steineck G. Health care-related predictors of husbands' preparedness for the death of a wife to cancer – a population-based follow-up. *Ann Oncol* 2010;**21**(2):354–61.
- Hauksdottir A, Steineck G, Furst CJ, Valdimarsdottir U. Long-term harm of low preparedness for a wife's death from cancer – a population-based study of widowers 4–5 years after the loss. *Am J Epidemiol* 2010;**172**(4):389–96.
- Dunne K, Sullivan K. Family experiences of palliative care in the acute hospital setting. *Int J Palliat Nurs* 2000;**6**(4):170–8.
- Hauksdottir A, Valdimarsdottir U, Furst CJ, Onelov E, Steineck G. Health care-related predictors of husbands' preparedness for the death of a wife to cancer – a population-based follow-up. *Ann Oncol* 2009.
- Jonasson JM, Hauksdottir A, Valdimarsdottir U, et al. Unrelieved symptoms of female cancer patients during their last months of life and long-term psychological morbidity in their widowers: a nationwide population-based study. *Eur J Cancer* 2009;**45**(10):1839–45.
- Dahlstrand H, Hauksdottir A, Valdimarsdottir U, et al. Disclosure of incurable illness to spouses: do they want to know? A Swedish population-based follow-up study. *J Clin Oncol* 2008;**26**(20):3372–9.
- Onelov E, Steineck G, Nyberg U, et al. Measuring anxiety and depression in the oncology setting using visual-analogue scales. *Acta Oncol* 2007;**46**(6):810–6.
- Hauksdottir A, Steineck G, Furst CJ, Valdimarsdottir U. Towards better measurements in bereavement research: order of questions and assessed psychological morbidity. *Palliat Med* 2006;**20**(1):11–6.
- Kreicbergs U, Valdimarsdottir U, Onelov E, Henter JI, Steineck G. Talking about death with children who have severe malignant disease. *N Engl J Med* 2004;**351**(12):1175–86.
- Valdimarsdottir U, Helgason AR, Furst CJ, Adolfsson J, Steineck G. Need for and access to bereavement support after loss of a husband to urologic cancers: a nationwide follow-up of Swedish widows. *Scand J Urol Nephrol* 2005;**39**(4):271–6.
- Bergmark K, Avall-Lundqvist E, Dickman PW, Henningsohn L, Steineck G. Vaginal changes and sexuality in women with a history of cervical cancer. *N Engl J Med* 1999;**340**(18):1383–9.

- 
22. Valdimarsdottir U, Helgason AR, Furst CJ, Adolfsson J, Steineck G. The unrecognised cost of cancer patients' unrelieved symptoms: a nationwide follow-up of their surviving partners. *Br J Cancer* 2002;**86**(10):1540–5.
  23. Valdimarsdottir U, Kreicbergs U, Hauksdottir A, et al. Parents' intellectual and emotional awareness of their child's impending death to cancer: a population-based long-term follow-up study. *Lancet Oncol* 2007;**8**(8):706–14.
  24. Higginson IJ, Costantini M. Dying with cancer, living well with advanced cancer. *Eur J Cancer* 2008;**44**(10):1414–24.
  25. Valdimarsdóttir U, Helgason AR, Fürst CJ, Adolfsson J, Steineck G. The unrecognised cost of cancer patients' unrelieved symptoms: a nationwide follow-up of their surviving partners. *Br J Cancer* 2002;**86**(10):1540–5.
  26. Draguns JG, Tanaka-Matsumi J. Assessment of psychopathology across and within cultures: issues and findings. *Behav Res Ther* 2003;**41**(7):755–76.