

# The intensity of caregiving is a more important predictor of adverse bereavement outcomes for adult–child than spousal caregivers of patients who die of cancer

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## Abstract

Increasing attention is being paid to specific difficulties experienced by bereaved family caregivers (FCs). Limited capacity within health and social care structures results in high intensity of informal caregiving. The focus of recent research is the identification of specific predictors of adverse FC outcomes, in order to identify those FCs who will benefit most from intervention and support. Research is challenged by multiple influencing and confounding variables. This study aimed to evaluate factors of care associated with higher grief intensity in bereaved adult–child (AC-FCs) and spousal FCs (S-FCs). Data from the Qualycare study, a mortality follow-back study of bereaved FCs of patients who died of cancer, was analyzed. Four hundred eighty-four patient–FC dyads were included: 246 AC-FCs and 238 S-FCs. S-FCs received more formal (SPC) ( $p=0.026$ ), and AC-FCs more informal ( $p < 0.001$ ), support. AC-FCs were more likely to continue to work while caregiving ( $p < 0.001$ ). Patients with AC-FCs were more likely to spend time in and die in a nursing home ( $p < 0.001$ ). Higher grief intensity was associated with higher caregiving intensity ( $p < 0.001$ ), as well as other factors. AC-FCs whose relative died in NH experienced significantly lower grief intensity ( $p < 0.001$ ). Intensity of caregiving predicted 11.6% of variance in grief intensity for AC-FCs compared to 0.5% for S-FCs. The ‘relief model’ of bereavement is relevant for AC-FCs. The support needs of AC-FCs and S-FCs differ. AC-FCs should be targeted for practical supports and interventions, in order to support home-death, if desired by patient and FC, and optimize bereavement outcomes.

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## Introduction

Increasing attention is being paid to the specific difficulties experienced by family caregivers in bereavement [1]. Family caregiving describes the informal, unpaid care provided by family members that goes beyond normative social support. The role of family caregivers includes providing support in the home, assisting in personal care and symptom management, and acting as a proxy for patients. Between 31 and 94.9% [2] of primary caregivers are spouses or partners of the patient, and other caregivers are adult–children, other relatives, friends, and neighbors [3]. Family caregivers occupy a unique position as both providers and recipients of support. It has been proposed that the needs of the caregiver can exceed those of the patient [4].

Caregiving may represent a rewarding experience, and families may experience increased cohesiveness [5], and a sense of meaningfulness [6]. However, caregiving is more commonly associated with negative consequences, including depression, anxiety, and higher grief intensity in bereavement [7,8]. Complicated grief (CG) describes a pathological outcome involving psychological, social, or physical morbidity following a bereavement [9]. CG,

worsens physical and mental health, and is associated with increased mortality [7]. The incidence of CG in bereaved caregivers is higher than population norms, ranging from 13 to 40% depending on the population studied and tools used [10].

Theoretical models describing the bereavement experiences of family caregivers include the ‘depletion model,’ proposing that caregiver stress accumulates over time and diminishes coping resources for bereavement [11–13], thus increasing vulnerability to CG. In contrast, the ‘relief model’ proposes that, following the patient’s death, the vanished demands of caregiving provide a sense of relief and decreased overload that eases the bereavement process [14].

Risk factors (RFs) for CG are situational and intra- and inter-personal characteristics associated with increased vulnerability to adverse bereavement outcomes [15]. Difficulties involved in identifying the RFs of caregivers for CG include the multiple potentially influencing and confounding variables involved. The focus for much research on caregivers to date has been the individual, and the caregiver–patient dyad; examining variables such as the influence of caregiver age and gender on their outcomes in bereavement. However, the broader context of

caregiving, including factors such as the intensity of care provided; informal or formal supports available; and the organizational features of health and social care services utilized, on caregiver bereavement outcomes have been examined to a lesser extent [5,16].

Psychosocial interventions which reduce the burden of caregiving can modify caregivers' risk of CG [17]. Appropriate risk assessment to identify those at risk of CG early, allows services and effective interventions to be targeted appropriately [9]. When preventative interventions are targeted to those at risk, benefits ensue, but intervention targeted at those not at risk may be harmful [7].

However, there remains a paucity of data regarding reliable methods of screening for and identifying caregivers at risk of CG [1,10]. The focus of research is shifting towards identifying specific predictors of caregiver outcomes, thus aiming to identify caregivers with higher need for intervention [16]. An integrative approach to risk assessment is required, which takes into account both specific risk factors, and the characteristics of individuals [15]. The pre-bereavement period represents a 'window of opportunity' for risk assessment and intervention which is often missed [15,18]. Palliative care practitioners are ideally placed to identify those at risk of adverse bereavement outcomes [7].

Research involving bereaved caregivers is complicated by factors including conflicting models of grief in this group; and multiple influencing and confounding variables [19]. Furthermore, a lack of specificity in key definitions makes it difficult to compare studies, and contributes to contradictory findings between studies [16]. For example, many studies do not or only minimally define terms such as 'caregiver,' 'care'; durations, and extents, e.g. 'majority of care' [16]. Where there is a network of carers, it may be difficult to identify a primary caregiver, and people labeled as 'carers' may not identify themselves as such [20]. Other factors, which challenge comparisons between studies, include varying methodology, designs, and instruments used [13].

Research to date is predominantly qualitative, retrospective, or cross-sectional [13], using small, non-random convenience samples [16]. There is a paucity of longitudinal data, few interventional studies, and a lack of adequate comparison groups [21]. In cross-sectional studies, causal direction is very difficult to interpret and establish, with possible reciprocal causal pathways existing between dependent and independent variables.

The current study uses data from the Qalycare study, a mortality follow-back study, which examined variation in the quality of care and costs of care provided, patient and caregiver preferences, and palliative outcomes, associated with home versus institutional death in cancer [22,23]. The objectives of the current study were to evaluate the factors of care associated with adverse bereavement outcomes in spousal and adult-child caregivers of patients

who have died of advanced cancer; and to determine whether the identified factors influenced the outcomes of adult-child or spousal caregivers differently. Particular attention was paid to the identification of risk factors which may be modified following risk-assessment and intervention prior to bereavement, including the burden associated with caregiving and role strain which is experienced by adult-child caregivers in particular.

## Methods

### Study sample

The QUALYCARE study (UKCRN7041) is a case-control study that used a mortality-follow back postal survey methodology of bereaved relatives [23]. The study took place in four health districts in London comprising 1.3 million residents. Participants were identified from death registrations and approached by the Office for National Statistics. Potential participants were persons that registered the death of an adult who had died from cancer between March 2009 and March 2010. Of a sample of 1516, 596 relatives of cancer patients completed the questionnaire, between four and ten months post-bereavement. Data was collected at one point in time, and a follow-up telephone interview occurred to clarify information if required [22]. Data from 484 respondents, representing 484 caregiver-patient dyads, were included in the current study: 246 sons and daughters of patients (adult-child caregivers), and 238 spouses or partners of the patient (spousal caregivers).

Secondary data analysis involves the use of an existing dataset to answer a new research question, or an innovative perspective on a research question [24]. Large sample sizes allow precision in analyzing subgroups [24].

### Measures

Four validated outcome measures were included in the questionnaire. The Client Service Receipt Inventory (CSRI) [22] measures health and social care service use. The Palliative Outcome Scale (POS) [25] is a self-report tool which evaluates patient palliative outcomes, including physical symptoms, emotional, spiritual, and information and support needs, during the week prior to death. The EQ-5D [26] is a health-related quality of life measure which measures problems in five areas (mobility, self-care, usual activities, pain, and anxiety) and generates a single index value for health status.

The Texas Revised Inventory of Grief (TRIG) was developed in order to identify deviant grief reactions and to measure changes in grief intensity over time [27]. The grief intensity of spousal and adult-child caregivers, as measured by TRIG scores, was measured and compared [22]. The TRIG questionnaire is a 21-item scale composed of two Likert-like sub-scales: the first eight-item subscale

measures feelings and actions at the time the patient's death (TRIG I—past feelings); and the second 13-item subscale measures feelings at the time of questionnaire completion (TRIG II—present feelings). The tool therefore measures changes in grief over time [15,27]. The TRIG tool has been shown to demonstrate good internal consistency for comparing groups, with a Cronbach's alpha estimate of 0.86 (TRIG I) and 0.93 (TRIG II) [28]. TRIG scores were recorded for analysis, so that higher scores were indicative of higher grief intensity.

In addition, whether the bereaved relative sought formal support in bereavement was used as an independent outcome measure indicating higher grief intensity. Information on eight individual physical symptoms experienced by the patient during the last week of life was also collected, and rated in terms of severity by the bereaved relative.

### Ethics

The QUALYCARE study was approved by the King's College London Research Ethics Committee (ref: 09/H0909/85). No further new data was gathered from participants for the purposes of the current study. The storage, handling, and supervised secondary analysis of QUALYCARE data complied with the Data Protection Act and the King's College guidelines, and the ethical approval of the original study.

### Specific limitations

There is evidence for higher attrition rates for male than for female respondents in similar studies, which may lead to the impact of bereavement being underestimated for widowers, and overestimated for widows [8]. The range of duration following bereavement at which the bereaved caregiver completed the survey was four to ten months, however the analysis demonstrated no association between duration following bereavement and grief intensity ( $p=0.821$ ). The TRIG scores in this sample were overall higher than population norms reported by Faschingbauer in the original TRIG manual, probably relating to the order of questions in the questionnaire [29]; however, this does not impact on the within-group analysis.

### Statistical analysis

Data was checked and cleaned prior to secondary analysis. Independent variables were: patient and caregiver circumstances; characteristics of care which the patient received during the last three months of life; and characteristics of the patient experience during the last week of life, e.g. physical symptoms. Dependent variables were the bereavement outcomes of the bereaved caregiver. Data was analyzed using IBM SPSS Version 22 for Windows. All tests were conducted at a 5% significance level. Missing data was dealt with using listwise deletion.

$P$ -values and 95% confidence intervals were calculated for each analysis. Independent samples  $t$ -tests were used to compare groups, and  $\chi^2$ -tests were used to compare proportions. Pearson and Spearman correlation were used to examine the strength of association between variables.

Multiple regression analysis was used in order to determine which variables could explain variations in bereavement outcomes within the group of caregivers as a whole; and in order to determine which variables, or confounding factors, could explain the differences in bereavement outcomes between the two groups of caregivers.

## Results

### Sample characteristics

Data from 484 respondents, representing 484 caregiver–patient dyads, were included in the analysis: 246 sons and daughters of patients (adult–child caregivers), and 238 spouses or partners of the patient (spousal caregivers).

Both adult–child and spousal caregivers were more likely to be female than male. Spousal caregivers were significantly older than adult–child caregivers (mean 68.4 vs. 50.7 years;  $t(474)=18.885$ ,  $p < 0.001$ ) (Table 1).

### Characteristics of care

The nature of care provided by spousal and adult–child caregivers was similar, although spousal caregivers spent significantly more time providing personal care; assistance with medical procedures; and assisting around the home. However, spousal caregivers also spent significantly more time with their relative in a non-caring capacity than adult–child caregivers ( $p < 0.001$ ). Three hundred thirty-five patients (69.2%) received specialist palliative care (SPC) input (hospice, palliative care, Marie Curie, or Macmillan nursing) at home. Patients with spousal caregivers were more likely to receive SPC input at home than patients with adult–child caregivers ( $\chi^2=4.926$ ,  $p=0.026$ ).

Two-thirds of respondents received additional informal help from family members or friends. If this was the case, a mean of 2.56 other people, excluding the respondent ( $n=304$ ; 95% CI 2.41 – 2.71) helped them. Adult–child caregivers were more likely to have additional informal support than spousal caregivers ( $p < 0.001$ ). However, adult–child caregivers were significantly more likely to continue working unchanged hours outside the home, in addition to caregiving, than spousal caregivers, who were more likely to reduce their working hours or to give up work while caregiving ( $\chi^2=23.28$ ,  $p < 0.001$ ).

Approximately one-third of patients died at home (their own home or that of a relative or friend); one-third died in a hospice; and one-third died in either a hospital or a nursing or residential setting. Patients with adult–child caregivers were significantly more likely to spend time in a nursing

**Table 1.** Patient characteristics

Characteristic	Patients with adult-child caregivers (n = 246)	Patients with spousal caregivers (n = 238)	
Gender			
Male (%)	94 (38%)	162 (68%)	$\chi^2 (1, 254) = 43.27 p < 0.001$
Female (%)	152 (62%)	76 (32%)	
Age years (SD)	79.6 (9.7)	70.6 (11.5)	$t(482) = 8.82 p < 0.001$
Marital status			
Married/partner	65 (26%)	238 (100%)	
Widowed	140 (57%)		
Divorced	24 (9%)		
Never married	3 (1%)		
Days spent at home * (SD)	63.6 (26)	68.3 (24)	$t(431) = 1.946 p = 0.052$
Place of death			
Home (own or family/friend)	74 (15%)	84 (18%)	$t(431) = 1.946 p = 0.052$
Hospital	67 (14%)	63 (13%)	
Hospice	73 (15%)	85 (18%)	
Residential setting/nursing home	31 (6%)	4 (0.8%)	

\*During the last three months of life.

or residential home in the last three months of life, than patients with a spousal caregiver ( $\chi^2 = 17.940, p < 0.001$ ). Patients with adult-child caregivers were significantly more likely than patients with a spousal caregiver to die in a nursing residential home ( $t = 38.75, p < 0.001$ ).

### Characteristics of care associated with higher grief intensity

Independent samples *t*-tests demonstrated that spousal caregivers experienced significantly higher intensity of grief than adult-child caregivers, in terms of both their past and present grief intensity: TRIG I score 21.53 vs. 19.92 ( $p = 0.032$ ); TRIG II score 49.00 vs. 41.44 ( $p < 0.001$ ). One-third of spousal caregivers experienced prolonged grief (TRIG I and II scores both above the 50<sup>th</sup> centile), compared to one-quarter of adult-child caregivers. Spousal caregivers also sought formal bereavement supports more frequently than adult-child caregivers ( $\chi^2 = 13.007, p < 0.001$ ).

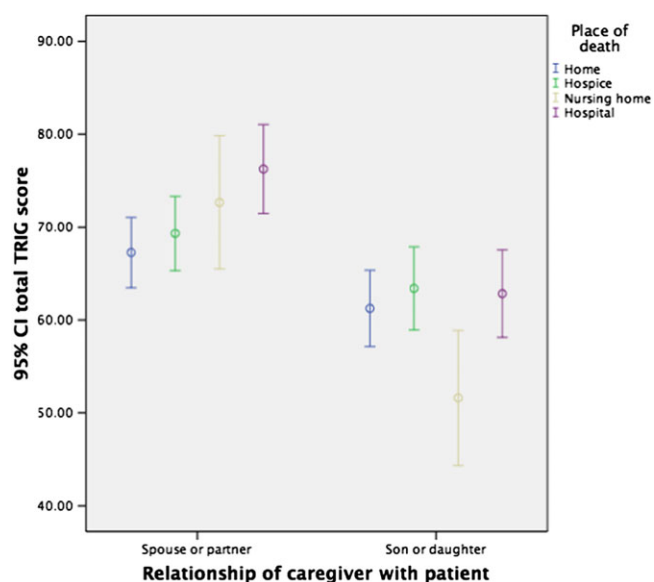
Female caregivers experienced significantly higher intensity of both past and present grief than male caregivers ( $p < 0.001$ ), and sought formal bereavement help more often than male caregivers ( $p = 0.048$ ). An inverse correlation was demonstrated between grief intensity and the age of the deceased patient ( $p < 0.001$ ). A shorter duration of illness experienced by the patient was associated with higher grief intensity for adult-child caregivers (Spearman's  $r = 0.141, p = 0.038$ ); but not spousal caregivers ( $r = 0.003, p = 0.973$ ).

Higher caregiving intensity (measured by hours/week spent caregiving) was associated with higher grief intensity (Spearman  $r = 0.244, p < 0.001$ ). One-way ANOVA demonstrated that the highest grief intensity was seen in those caregivers whose relative died in hospital, compared to home or hospice. The lowest grief intensity was seen in those respondents whose relatives died in a nursing home or residential center. Post hoc tests (Tukey HSD)

conducted in order to control for alpha-inflation indicated that the greatest difference in total TRIG scores were between death in hospital and death in a nursing or residential home ( $p < 0.001$ ). When the place of death was a nursing or residential home, adult-child caregivers experienced significantly lower grief intensity than spousal caregivers, although this represented a small subset of the total sample ( $n = 31, p < 0.001$ ) (Figure 1).

### Greater symptom burden associated with higher grief intensity

Higher total POS scores, reflecting higher patient physical and psychological distress, during the last week of life,



**Figure 1.** Total TRIG scores and place of death: spousal and adult-child caregivers

were significantly associated with higher grief intensity in the bereaved relative (*Pearson*  $r=0.199$ ,  $p<0.001$ ). The domains of the POS especially associated with higher grief intensity were: whether the patient felt depressed; whether the patient was anxious or worried about their illness or treatment; and whether family or friends were anxious or worried about the patient.

Physical symptom burden, in particular drowsiness and weakness, during the last week of life, was significantly associated with higher TRIG I and total TRIG scores ( $r=0.215$ ,  $p<0.001$ ;  $r=0.171$ ,  $p=0.002$ ); and to a lesser extent, with TRIG II scores ( $r=0.106$ ,  $p=0.049$ ). A cumulative score for total symptom burden in the last week of life (sum of physical symptom intensity and total POS scores) was also significantly associated with higher grief intensity ( $r=0.245$ ,  $p<0.001$ ).

### Regression analysis

Based on the findings of the bivariate analysis, variables were grouped into three models, of which model 1, demographic characteristics (lower age of deceased and female gender of caregiver), explained the greatest proportion of variance in total TRIG scores (20.6%). Of modifiable variables, symptom burden, as measured by POS scores and total physical symptom intensity (total symptom burden), explained 6.1% of the total TRIG score. When POS and the physical symptom intensity were combined into a single variable (total symptom burden), linear regression analysis demonstrated that the total TRIG score could be predicted by this measure of total symptom burden in the last week of life ( $\beta=0.260$ ,  $p<0.001$ ).

In order to determine whether these models applied differently to spousal and adult-child caregivers, multiple regression analysis was performed on each group of caregivers separately using the same models. Total symptom burden remained a significant predictor of grief intensity for both groups of caregivers. Demographic characteristics (age of deceased patient and gender of caregiver) again explained the greatest proportion of variance in total TRIG scores (24.2% for adult-child caregivers and 8.3% for spousal caregivers).

Significantly, the intensity of caregiving provided, as measured by the number of hours of care provided per week, was a more significant predictor of higher grief intensity for adult-child caregivers than for spousal caregivers, with the burden of care predicting 11.6% of variance in total TRIG scores in adult-child caregivers compared to 0.5% in spousal caregivers.

### Discussion

It is difficult to define a 'good outcome' in bereavement, but the concept has several aspects which are often related to one another: a return to feelings of well-being; a

regained capacity to cope with problems of everyday life; and a decline in preoccupation with grief [7]. Informal family caregivers are becoming an increasingly integral part of the system of caring for patients with life-limiting conditions, and service providers are mandated to ensure that caregivers receive appropriate interventions both during caregiving and in bereavement to maximize the possibility of a 'good outcome' [16].

Several findings of the current study are in concordance with previous research. Spousal caregivers have been shown to experience more intense and prolonged grief than adult-child caregivers [30]. This pattern of prolonged grief is in contrast to the evidence that, in general, grief intensity lessens with time. However, further investigation is required to disentangle the effects of relationship effects versus age or generational effects [16,20].

The death of younger patients has been shown to be associated with higher grief intensity, possibly relating to a relative expectation of, and the ability to find meaning in, the death of older people [31]. There remain unanswered questions regarding the effect of caregiver gender. Female spouses are more likely to be the sole caregiver for husbands, while male spouses are shown to receive more assistance from adult children in caregiving [32]. However, female caregivers have been shown to self-select into research studies, potentially introducing bias [8].

Higher physical symptom burden has been shown to be significantly associated with higher grief intensity, corresponding with evidence that witnessing distressing death events predicts future use of bereavement services [33], and that physical symptoms are used by caregivers as a barometer to indicate impending death, representing a source of distress [5].

An understanding of non-modifiable risk factors should enable effective risk assessment and intervention; and identification of modifiable risk factors enables appropriate interventions to be put in place, with the potential to not only improve caregivers' outcomes in bereavement, but in addition to improve patient outcomes and experiences.

Previous research has demonstrated that greater intensity of care provided by family caregivers in general is associated with adverse bereavement outcomes [16]. In the current study, adult-child caregivers were significantly more likely to continue working outside the home while caregiving. Although adult-child caregivers received more informal help at home, spousal caregivers were more likely to be supported by SPC services at home. Adult-child caregivers were younger than spousal caregivers, and it has been shown that younger caregivers exhibit more caregiver strain [34]. The concept of role strain describes the overlapping responsibilities that accompany simultaneous family roles [12]. It can be hypothesized that, in addition to the difficulties associated with caregiving experienced by all family caregivers, an additional element of caregiver strain is imposed upon adult-child caregivers arising from

the competing demands of caregiving, and work outside the home. Multiple regression analysis demonstrated that, for adult-child caregivers, intensity of caregiving predicted 11.6% of variance in total TRIG scores, compared to 0.5% of variance amongst spousal caregivers.

In this study, a shorter duration of illness of the deceased relative was associated with higher grief intensity for adult-child, but not spousal, caregivers. Younger caregivers who provide care for less than 12 months are more likely to describe the experience as negative than those who undertake longer-term care [35]. When the duration of caregiving is short, support networks for caregivers have little time to form [36]. This may result in higher caregiver burden for younger, adult-child caregivers as compared to older, spousal caregivers.

It has been shown that most people with advanced cancer would prefer to die at home [22]. Having a caregiver is the single most important predictor of home death, where this is the wish of both the patient and the caregiver [2,37]; however, a principal cause of unplanned patient admissions is caregiver strain [38]. In the current study, patients with an adult-child caregiver were more likely to spend time in a nursing or residential home during the last three months of life, and more likely to die in a nursing or residential home. Adult-child caregivers whose relative died in a nursing or residential home experienced lower grief intensity than spousal caregivers whose relatives died in the same setting. The 'relief' model of bereavement is likely to be particularly relevant to the experience of adult-child caregivers.

Therefore, it appears that, for adult-child caregivers, a shorter, more intense and burdensome period of caregiving, is associated with higher grief intensity and a higher likelihood of adverse outcomes in bereavement, than is a longer, less intense duration of caregiving, supported by SPC services, for spousal caregivers. These results should be taken into account when planning care for patients and their adult-child caregivers.

Limited capacity within formal health and social care structures can result in high intensity of informal caregiving

[1]. Pre-bereavement interventions designed to support and to enhance outcomes for family caregivers include: services focused on the coping, knowledge, and skills of the caregiver; spiritual support; respite; financial support; and practical help, for example with transportation or bathing [16]. Adult-child caregivers may particularly benefit from practical supports such as respite care, or support with practical tasks such as patient transportation, and should be targeted for such interventions, as well as SPC input at home.

Studies, which evaluate caregiver satisfaction with formal supports, do not always differentiate between the caregiver's satisfaction with care provided to the patient, and care provided in order to support them as caregiver [16]. The needs of caregivers may be different to the patients' needs. Caregivers already experiencing role strain have limited personal resources to engage in support activities such as support groups and psychotherapy, and may perceive such activities as an additional burden. The model of community SPC provision for adult-child caregivers may need to be different to that provided to spousal caregivers, for example, more flexible. Valuable resources should be targeted thoughtfully. Empirical evaluation of the effectiveness of such targeted interventions, using validated bereavement outcome measures, is required.

As research into this topic evolves, and research into caregiving and bereavement become increasingly integrated, clinical practice should improve, with parallel improvements in outcomes for this group of important and, often unacknowledged, individuals.

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## References

1. Stroebe M, Boerner K. Caregiving and bereavement research: bridges over the gap. *Palliat Med* 2015;**29**(7):574–576.
2. Currow DC, Burns C, Agar M, Phillips J, McCaffrey N, Abernethy AP. Palliative caregivers who would not take on the caring role again. *J Pain Symptom Manage* 2011; **41**(4):661–672.
3. Fakhoury WK, McCarthy M, Addington-Hall J. The effects of the clinical characteristics of dying cancer patients on informal caregivers' satisfaction with palliative care. *Palliat Med* 1997;**11**(2):107–115.
4. Higginson I, Wade A, McCarthy M. Palliative care: views of patients and their families. *BMJ* 1990;**301**(6746):277–281.
5. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology* 2010;**19**(10):1013–1025.
6. Milberg A, Strang P, Jakobsson M. Next of kin's experience of powerlessness and helplessness in palliative home care. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*. 2004;**12**(2):120–128.
7. Parkes C. *Bereavement: Studies of Grief in Adult Life*. Madison, editor: International Universities Press; 1998.
8. M Stroebe WS, R Hannsson. *Handbook of Bereavement*. Cambridge: Cambridge University Press; 1993.
9. Doyle D. *Oxford Textbook of Palliative Medicine*. 3rd ed. Oxford, New York: Oxford University Press; 2004. xxv, 1244p. p.
10. Wiese CH, Morgenthal HC, Bartels UE, Vossen-Wellmann A, Graf BM, Hanekop GG. Post-mortal bereavement of family caregivers in Germany: a prospective interview-based investigation. *Wien Klin Wochenschr* 2010;**122**(13–14):384–389.
11. Burton AM, Haley WE, Small BJ, Finley MR, Dillinger-Vasille M, Schonwetter R. Predictors of well-being in bereaved former hospice caregivers: the role of caregiving stressors, appraisals, and social resources. *Palliat Support Care* 2008;**6**(2):149–158.
12. Waldrop DP. Caregiver grief in terminal illness and bereavement: a mixed-methods study. *Health Soc Work* 2007;**32**(3):197–206.
13. Grov EK, Dahl AA, Moum T, Fossa SD. Anxiety, depression, and quality of life in caregivers of patients with cancer in late

- palliative phase. *Annals of Oncology: Official Journal of the European Society for Medical Oncology/ESMO*. 2005;**16**(7):1185-1191.
14. Bass DM, Bowman K. The transition from caregiving to bereavement: the relationship of care-related strain and adjustment to death. *Gerontologist* 1990;**30**(1):35-42.
  15. Agnew A, Manktelow R, Taylor B, Jones L. Bereavement needs assessment in specialist palliative care: a review of the literature. *Palliat Med* 2010;**24**(1):46-59.
  16. Stajduhar K, Funk L, Toye C, Grande G, Aoun S, Todd C. Part 1: Home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998-2008). *Palliat Med* 2010;**24**(6):573-593.
  17. Schulz R, Mendelsohn AB, Haley WE, et al. End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *N Engl J Med* 2003;**349**(20):1936-1942.
  18. Sealey M, Breen LJ, O'Connor M, Aoun SM. A scoping review of bereavement risk assessment measures: implications for palliative care. *Palliat Med* 2015;**29**(7):577-589.
  19. Koffman JS, Higginson IJ. Fit to care? A comparison of informal caregivers of first-generation Black Caribbeans and White dependants with advanced progressive disease in the UK. *Health Soc Care Community* 2003;**11**(6):528-536.
  20. Grande G, Stajduhar K, Aoun S, et al. Supporting lay carers in end of life care: current gaps and future priorities. *Palliat Med* 2009;**23**(4):339-344.
  21. Breen LJ. The effect of caring on post-bereavement outcome: research gaps and practice priorities. *Progress in Palliative Care*. 2012;**20**(1):27.
  22. Gomes B, McCrone P, Hall S, Koffman J, Higginson IJ. Variations in the quality and costs of end-of-life care, preferences and palliative outcomes for cancer patients by place of death: the QUALYCARE study. *BMC Cancer* 2010;**10**:400.
  23. Gomes B, Calanzani N, Koffman J, Higginson IJ. Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study. *BMC Med* 2015;**13**:235.
  24. Doolan DM, Froelicher ES. Using an existing data set to answer new research questions: a methodological review. *Res Theory Nurs Pract* 2009;**23**(3):203-215.
  25. Siegert RJ, Gao W, Walkey FH, Higginson IJ. Psychological well-being and quality of care: a factor-analytic examination of the palliative care outcome scale. *J Pain Symptom Manage* 2010;**40**(1):67-74.
  26. EuroQol—a new facility for the measurement of health-related quality of life. *Health Policy* 1990;**16**(3):199-208.
  27. Faschingbauer TR. *Texas Revised Inventory of Grief—A Manual*. Honeycomb Publishing Company, Honeycomb Publishing Company: Houston, Texas, 1981.
  28. Bland JM, Altman DG. Cronbach's alpha. *BMJ* 1997;**314**(7080):572.
  29. 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):11-16.
  30. Kersting A, Braehler E, Glaesmer H, Wagner B. Prevalence of complicated grief in a representative population-based sample. *J Affect Disord* 2011;**131**(1-3):339-343.
  31. Ringdal GI, Jordhoy MS, Ringdal K, Kaasa S. Factors affecting grief reactions in close family members to individuals who have died of cancer. *J Pain Symptom Manage* 2001;**22**(6):1016-1026.
  32. Katz S, Kravetz S, Grynbaum F. Wives' coping flexibility, time since husbands' injury and the perceived burden of wives of men with traumatic brain injury. *Brain Injury: [BI]*. 2005;**19**(1):59-66.
  33. Cherlin EJ, Barry CL, Prigerson HG, et al. Bereavement services for family caregivers: how often used, why, and why not. *J Palliat Med* 2007;**10**(1):148-158.
  34. Payne S, Smith P, Dean S. Identifying the concerns of informal carers in palliative care. *Palliat Med* 1999;**13**(1):37-44.
  35. Burns CM, LeBlanc TW, Abernethy A, Currow D. Young caregivers in the end-of-life setting: a population-based profile of an emerging group. *J Palliat Med* 2010;**13**(10):1225-1235.
  36. Zapart S, Kenny P, Hall J, Servis B, Wiley S. Home-based palliative care in Sydney, Australia: the carer's perspective on the provision of informal care. *Health Soc Care Community* 2007;**15**(2):97-107.
  37. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006;**332**(7540):515-521.
  38. Harding R, Higginson IJ, Donaldson N. The relationship between patient characteristics and carer psychological status in home palliative cancer care. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*. 2003;**11**(10):638-643.