

Gender differences in caregiver burden and its determinants in family members of terminally ill cancer patients

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Abstract

Objective: Female family caregivers consistently report higher levels of stress and burden compared to male caregivers. Explanations for the apparently higher psychological vulnerability of female caregivers are largely missing to date. This study assesses the correlates and determinants of caregiver burden in family caregivers of advanced cancer patients with a specific focus on gender differences.

Methods: Three hundred and eight self-identified main informal caregivers of advanced cancer patients were cross-sectionally assessed using structured questionnaires for caregiver burden and hypothesised determinants of burden, including sociodemographic characteristics, caring arrangements, support needs, hope and coping style. Gender differences and predictors of burden were assessed using *t*-tests, chi-squared tests and univariate linear regression. Significant univariate predictors were entered in an analysis of covariance separately for men and women.

Results: Burden was significantly higher in women. Hope was the most significant protective factor against burden in both genders, together with perceived fulfilment of support needs. Only in women emotion-oriented coping and being in employment while caring were significantly predictive of higher burden in the multivariate analysis. The model explained 36% of the variance in burden in men and 29% in women.

Conclusion: Psychological support interventions for family caregivers should take gender-specific risk factors into account. Interventions focusing on keeping up hope while caring for a terminally ill family member may be a valuable addition to palliative services to improve support for family carers. Women may benefit from interventions that address adaptive coping and strategies to deal with the dual demands of employment and caring.

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Background

It is well known that family caregivers of patients with advanced cancer suffer from high levels of psychological distress often surpassing that of the dying individual [1–4]. By providing physical care as well as emotional, social and financial support, they have to fulfil a demanding and challenging role that puts them at increased risk of developing mental health problems (e.g. anxiety and depression) as well as psychological repercussions (e.g. lower well-being and quality of life) [3–6]. Consequently, access to services and support for family caregivers have been proposed as a quality indicator for palliative care [5,7], and increased emphasis on identifying and supporting burdened caregivers has been highlighted as a priority [4,5,8–10].

Caregivers' gender has been suggested to be a major determinant of the caregiving experience [4,11–13], and gender differences are believed to influence type and amount of care provided, different coping styles as well as access to formal and informal resources that may

alleviate caregiver strain [4,11]. Recent data confirm that female caregivers report higher levels of burden, stress, anxiety and fatigue as well as lower self-esteem and optimism compared with male caregivers [4,14,15]. They are reported to spend more hours caring, perform more intimate care duties such as toilet tasks, more often change their employment status because of caregiving responsibilities and less often draw on support by other family members or professional services [15,16].

Research on family carers typically is methodologically complex and challenging [5,8,10]. However, one of the most consistent findings is that the vast majority of informal caregivers are women. Family caregiving has long been viewed as a 'female' issue and an expansion of the traditional responsibilities of a wife or a daughter [14,17]. Paying respect to the change in traditional gender roles, the growing number of cancer patients as well as the worldwide rising trend of home-based palliative care, the distinct facets of caregiving need to be understood to strengthen informal caregivers, in their role as an ongoing support system for terminally ill family members [4,10,17,18].

Importantly, explanations for the apparently higher psychosocial vulnerability of female caregivers in palliative care are largely missing to date [6].

The aim of this study was to examine the influences on psychosocial burden in caregivers of terminally ill cancer patients with a specific focus on gender differences. First, in line with the existing literature, we hypothesised that a female caregiver experiences higher burden than male caregivers. Second, we sought to determine how psychological and caring factors differ in their effect on burden depending on caregiver gender.

Methods

Setting and participants

This study uses data from an ongoing prospective research programme, screening family caregivers of terminally ill cancer patients for a range of psychiatric diagnoses and their predictors before and after the death of the patient. The ongoing (hitherto unpublished) research programme is a naturalistic follow-up study conducted at three hospitals in Vienna. It started in March 2011 and assesses caregivers in 9-month intervals including once after the patient has died. The main outcome for the present study was the difference in burden between men and women. The sample size was chosen to detect a small effect size at alpha 0.05 with a power of 0.90, meaning that all baseline assessments up until March 2014 were included. All participants were presently self-identified primary caregivers of terminally ill cancer patients. Inclusion criteria for participants were as follows: age at least 18 years, fluent in German and capable to give written-informed consent. Research staff screened patient records at the participating wards on a biweekly basis. Patient inclusion criteria (i.e. terminal illness) were confirmed by a member of the responsible clinical team. Individuals listed as primary caregivers in routine documentation were approached. After sending an initial information letter, the eligible family members were contacted via telephone and informed about the study. If willing to participate, participants received the questionnaires, information sheets and consent form, together with a prepaid return envelope. The study protocol was approved by the Ethics Committee of the Medical University of Vienna (1003/2010).

Measurement tools

All scales were chosen because of their established psychometric properties and proven feasibility in the given population. On all scales, higher scores represent higher presence of the respective construct.

Burden

The Zarit Caregiver Burden Interview (ZBI) has been successfully used with family carers in oncology, with the 12-

item short version (i.e. ZBI-12) shown to be best suited for the palliative care setting [19,20]. Items are rated on a 5-point Likert scale resulting in mean scores between 0 and 4. The scale also allows calculation of two domains of burden, that is, personal and role strain. Cronbach's alpha lies between 0.85 and 0.89 [19,20].

Caregiving support needs

The Family Inventory of Needs (FIN) measures the support needs of family caregivers of advanced cancer patients and the extent to which these are met [21]. Its 20 items are rated on two subscales: FIN-importance (rating the importance of each care need on Likert scale between 1 and 5) and FIN-fulfilment (rating whether each need was met as fully met, i.e. 1, partly met, i.e. 0.5, or not met, i.e. 0). Means are calculated for both subscales [21]. The German version of the scale shows an internal consistency of $\alpha=0.94$ for FIN-importance and $\alpha=0.96$ for FIN-fulfilment, and a retest reliability of $r=0.97$ [22].

Coping style

The Coping Inventory for Stressful Situations contains 24 items asking respondents to indicate how much they engage in various coping activities during a stressful situation on a Likert scale between 1 and 5, resulting in a separate mean score for three main coping styles, that is, task-oriented coping, emotion-oriented coping and avoidance coping [23]. Cronbach's alpha for the three subscales ranges between 0.61 and 0.88 [23].

Hope

The Integrative Hope Scale (IHS) comprehensively covers the complex concept of hope. It contains 23 items rated on a Likert scale between 1 and 6 resulting in overall values (i.e. sum scores) of between 23 and 138 [24]. Cronbach's alpha lies at 0.92, its test-retest reliability at 0.85 [24]. The IHS allows calculation of four subdomains, which, however, are not well evaluated. Hence, this study used the well-evaluated overall hope score only.

Sociodemographic variables and caring information

Background variables hypothesised to impact on individual burden included age, partnership status, sustenance, sharing the household with the terminally ill person, weekly time spent with caring tasks, length of overall caring period, household income and private expenses for caring. In addition, we asked participants whether they felt they had a moral obligation to care for a terminally ill family member, following the hypothesis that those who feel obliged may perceive pressure differently to those who do not feel morally obliged.

Data analysis

Gender differences in burden, sociodemographic and caregiving variables were assessed using *t*-tests and chi-squared tests. To analyse the influence of possible determining factors on caregiver burden, first, univariate linear regression analyses were computed for all continuous variables using ZBI-12 mean scores as the dependent variable. Ordinal and nominal variables were dichotomised, in order to increase the statistical power of the analyses, either according to the median (e.g. weekly caring time) or according to rational considerations (such as partnership). For income, previous research in the same population (unpublished manuscript) showed that differences in psychopathology were most pronounced between those earning below and above €2000 per month. Hence, we used this threshold for dichotomisation. The resulting dichotomised variables were as follows: (i) partnership (alone/partnered), (ii) sustenance (working/not working), (iii) caregiver shares household with patient (yes/no), (iv) weekly time spent with caring tasks (below/above 20 h), (v) overall caring period (below/above 12 months), (vi) monthly household income (below/above €2000), (vii) monthly private expenses for caring (below/above €100) and (viii) moral obligation to care for a terminally ill family member (yes/no). Given the distribution of the data and the large sample size, the use of parametric statistical methods was deemed appropriate (central limit theorem). *t*-tests were calculated to compare the means of caregiver burden for all dichotomised variables. The analyses were performed separately for men and women. All variables with a *p*-value < 0.05 were further considered in an analysis of covariance (separate models for men and women) simultaneously entering all predictors and using ZBI-12 mean scores as the dependent variable. To assess the robustness of the results, we determined potential multicollinearity using the variance inflation factor and tested for significant correlations between the variables included in the analysis of covariance. Those variables with at least moderate correlations were additionally entered with interaction terms in order to assess whether they may have a differential effect on outcome depending on each other. All analyses were performed using SPSS 21 and the software package R 2.15.2 (SPSS Inc., Chicago, IL, USA).

Results

Initial telephone contact was established with 810 caregivers. One hundred and nine (13.5%) reported that the patient had died in the meanwhile, 73 (9%) did not want to participate for different reasons and 17 (2.1%) were not sufficiently fluent in German. Study materials were sent to 612 assenting caregivers and returned by 308 (50.3%). Their sociodemographic characteristics and caring arrangements are displayed in Table 1.

Burden in male and female carers

There was a significant difference in mean burden between men ($M=1.01$ and $SD=0.63$) and women ($M=1.38$, $SD=0.72$ and $p=0.029$). The difference in burden appeared to be mainly due to differential personal strain ($M=0.92$, $SD=0.70$ vs $M=1.37$, $SD=0.81$ and $p<0.001$). In the domain role strain, men reached lower mean scores than women, but the difference was not significant. Univariate regression showed gender to be a highly significant predictor of overall burden ($\beta=0.26$ and $p<0.001$).

Determinants of burden in male and female carers

The mean scores of the hypothesised psychological determinants of burden are displayed in Table 2.

Univariate regression analyses for women showed that age ($\beta=-0.17$ and $p=0.021$), hope ($\beta=-0.40$ and $p<0.001$), emotion-oriented coping ($\beta=0.33$ and $p<0.001$) and need fulfilment ($\beta=-0.41$ and $p<0.001$) had a significant influence on burden. Older age, more hope and more perceived fulfilment of support needs were protective against burden, while more emotion-oriented coping constituted a risk factor for higher burden. Task-oriented coping, avoidance-oriented coping and the perceived importance of support needs had no effect on mean burden. Results were the same for men, with age ($\beta=-0.24$) significant at $p=0.009$, and hope ($\beta=-0.51$), emotion-oriented coping ($\beta=0.46$) and perceived fulfilment of support needs ($\beta=-0.33$) at $p<0.001$, respectively.

Results for *t*-tests on the dichotomised sociodemographic characteristics and caring arrangements showed that none of the indicators was significantly associated with different burden in women, except for sustenance ($p=0.005$), with those in work being more burdened than those not working ($M=1.51$, $SD=0.74$ vs $M=1.15$ and $SD=0.61$). For men, sustenance was of borderline significant at $p=0.068$ ($M=1.14$, $SD=0.63$ for those in work vs $M=0.87$ and $SD=0.61$ for those not in work). Results of the multivariate analysis are shown in Table 3, separately for men and women.

Hope was the most important protective factor for both genders, while emotion-oriented coping and being in work significantly predicted higher burden in women only. The model explained 29% of the variance in burden in women ($F(5,156)=14.15$) and 36% of the variance in burden in men ($F(4,101)=1568$).

While the low variance inflation factor suggests that multicollinearity did not inflate the regression results, the correlation matrix revealed some significant correlations. In men, hope was moderately negatively correlated with emotion-oriented coping ($r=-0.6$) and weakly positively correlated with perceived need fulfilment ($r=0.3$). In women, weak to moderate positive

Table 1. Characteristics of the study sample (N = 308)

Variable		Men Mean (s.d.) 57 (14.0) N (%)	Women Mean (s.d.) 51 (14.7) N (%)	Sig.
Age (years)				0.001
Partnership	In partnership	102 (85.7)	141 (78.8)	n.s.
	Single	16 (13.4)	37 (20.7)	
Education	Primary education	5 (4.2)	17 (9.5)	0.017
	Vocational training	47 (39.5)	43 (24.0)	
	Secondary education	43 (36.1)	83 (46.4)	
	Higher education	24 (20.2)	35 (19.6)	
Sustenance	Working (employment, including sick leave)	60 (50.4)	107 (59.8)	n.s.
	Not working (including retired, unemployed, student and housewife)	61 (51.2)	74 (42.0)	
Relationship with patient	Partner	76 (63.9)	78 (43.6)	0.002
	Child	25 (21.0)	68 (38.0)	
	Parent	6 (5.0)	9 (5.0)	
	Sibling	4 (3.4)	1 (0.5)	
	Other close relationship	8 (6.8)	23 (12.9)	
Shares household with patient		79 (66.4)	93 (52.0)	0.016
Monthly household income	<€1,000	8 (6.7)	15 (9.1)	n.s.
	<€2,000	39 (32.7)	67 (40.6)	
	<€3,000	36 (30.3)	46 (27.9)	
	<€5,000	32 (26.9)	31 (18.8)	
	>€5,000	4 (3.4)	6 (3.6)	
Monthly private expenses for caring	<€100	43 (36.7)	67 (44.4)	n.s.
	<€500	57 (48.7)	70 (46.4)	
	<€1,000	11 (9.4)	6 (4.0)	
	>€1,000	6 (5.1)	8 (5.3)	
Weekly time spent with caring tasks	<10	29 (23.5)	32 (18.6)	n.s.
	10–20	29 (24.4)	46 (26.7)	
	20–30	15 (12.6)	27 (15.7)	
	30–40	14 (11.8)	21 (12.2)	
	>40	33 (27.7)	46 (26.7)	
Overall caring period	<12 months	60 (50.4)	89 (49.7)	n.s.
	>12 months	59 (49.6)	90 (50.3)	
	Yes	109 (91.6)	164 (91.6)	n.s.

s.d., standard deviation; sig., significance level; n.s., not significant; €, Euro; N, number of participants.

Table 2. Mean scores of hypothesised determinants of burden in men and women

Variable	Men Mean (s.d.)	Women Mean (s.d.)	Sig.
Perceived support need importance	4.16 (0.76)	4.26 (0.73)	n.s.
Perceived support need fulfilment	0.70 (0.22)	0.66 (0.23)	n.s.
Hope	106.47 (14.82)	105.16 (14.84)	n.s.
Task-oriented coping	3.62 (0.74)	3.48 (0.65)	n.s.
Avoidance coping	2.78 (0.80)	2.89 (0.81)	n.s.
Emotion-oriented coping	2.44 (0.79)	2.64 (0.70)	0.020

s.d., standard deviation; sig., significance level; n.s., not significant.

correlation was found between perceived need fulfilment and age ($r=0.2$) as well as hope ($r=0.4$), and negative correlations between emotion-oriented coping and hope as well as perceived need fulfilment (both at $r=-0.4$). While not reported in the published literature, it is conceivable that those variables interact with each other in their effect on burden. However, entering interaction terms for the moderately correlated variables into the multiple linear regression showed no significant effect.

Table 3. Analysis of covariance simultaneously entering all significant ($p < 0.05$) univariate predictors

Variable	Women (N = 162)			Men (N = 110)		
	B	s.e.	p	B	s.e.	p
Age	-0.0014	0.004	n.s.	-0.0091	0.004	0.05
Hope	-0.3160	0.090	0.001	-0.3603	0.102	0.001
Emotion-oriented coping	0.1643	0.078	0.05	0.1511	0.085	n.s.
Support need fulfilment	-0.6516	0.237	0.01	-0.5044	0.246	0.05
Sustenance	-0.3333	0.110	0.01	n.a.	n.a.	n.a.

N, number of participants; s.e., standard error; n.s., not significant; n.a., not applicable.

Age was the only predictor variable that differed significantly between men and women in our sample. Hence, one possible explanation for the apparently higher burden of women may be the relatively young age of our female carer population. However, age was not significantly correlated with any of the other predictor variables. An additional analysis of covariance for the entire sample with gender as a predictor variable left all variables highly significantly predictive of burden with the effect of the risk factor gender clearly surpassing that of the slightly

protective factor age. We also explored the potential impact of caregiver relationship on burden. Comparing spousal caregivers with all others resulted in no significant differences in mean burden. However, when comparing three groups in different generations, that is, children, partners and siblings, and parents, we found significant differences in mean burden between children ($M=1.38$ and $SD=0.72$) and parents ($M=0.84$ and $SD=0.57$) at $p=0.007$, and between partners and siblings ($M=1.22$ and $SD=0.71$) and parents at $p=0.05$.

Discussion

This study aimed to determine influences on psychosocial burden in caregivers of terminally ill cancer patients with a specific focus on gender. Our results show that women felt significantly more burdened than men did. This is in line with previous findings for caregivers of outpatients with advanced cancer [4] impaired elders [14] and dementia patients [25,26].

To our knowledge, this is the first study to show a difference in the determinants of burden between women and men for carers of terminally ill cancer patients. We tested for a range of possible determinants; only five of which showed a significant statistical influence on burden in the univariate analysis. Higher age, level of hope and of fulfilled support needs were significantly related to decreased burden, while higher level of emotion-oriented coping and being a working woman were significantly related to higher levels of burden. In the multivariate analysis, hope remained the most powerful predictor of lower burden in both genders. Two variables remained gender-specific significant predictors of burden, that is, age in men and emotion-oriented coping in women. The overall model explained 29% of the variance in burden in women and 36% in men. These results indicate that the determinants of burden differ between men and women, as does the degree to which they determine burden.

While age had a small effect on burden only, causal relationships for its impact may be complex. Overall, our sample was relatively young, with female caregivers being significantly younger than their male counterparts. Consistent with the findings of previous studies, younger caregivers experience worse psychosocial outcomes than older caregivers [6]. Proposed gender-related explanations for this phenomenon include the suggestion that women, especially of older generations, were socialised to be nurturant and family orientated [17]. Higher age was protective of burden in our sample but remained significant in the multivariate analysis only for men. This may in part reflect the contemporary situation of an overall younger female caregiver population experiencing double burden due to employment in addition to caregiving responsibilities. Qualitative research also suggests that younger adult caregivers who have a family of their own find it

particularly difficult to deal with competing demands, which may evoke feelings of guilt and further add to the caregiving burden [16]. Literature suggests that educating caregivers how to best utilize additional resources for personal emotional support may be beneficial for their individual quality of life especially in women [3]. However, future research will need to explore the impact and implications of double burden in younger female caregivers in more detail.

This study did not assess patient age. However, on average male caregivers were older than female caregivers, and they were more often patients' partners (i.e. presumably of similar age), while female caregivers were more frequently parents to the patients. Both may further help to explain the higher burden in females. Higher sample sizes in the individual groups of caregivers are needed to meaningfully include categorical variables like relationship with the patient into multivariate regression analyses. However, we explored the difference in mean burden in three generations of caregivers, that is, children, spouses and siblings, and parents of patients. Results showed that children were most highly burdened and significant differences emerged between children and parents, and spouses/siblings and parents. With respect to emotion-oriented coping, different directions of associations are conceivable. Emotion-oriented coping may lead to a perception of higher burden. However, the reverse may also be true. Persons in a situation they cannot change or control may be more prone to using emotion-oriented coping, but caregivers who are in a situation where they feel they can perform 'tasks' may be less likely to use such coping styles. The exact mechanisms and directions of associations between caregiver variables, emotion-oriented coping and burden will have to be explored in future research. The same is true for hope. While hope has been shown in the literature to be a protective factor [27,28], it is not possible to rule out that caregivers who perceive only limited burden feel more hope than caregivers who are overwhelmed by their caring tasks.

Possible explanations for higher burden of female caregivers include that women are more likely to carry out personal care and household tasks that require more constant, time-consuming and burdensome commitment [29,30]. By contrast, male caregivers have been found to provide more informational support and to be more likely to use community services and home health care to support them with their caring responsibilities [30,31]. However, in the present study, neither the weekly time spent with caring tasks nor the monthly expenses for caring were significantly different between men and women.

While the impact of the investigated determinants differed in the multivariate analysis, univariate results were very similar for men and women. Gender-specifically different intercorrelations between the individual variables cannot explain this result. It appears that gender is a distinct factor determining a person's reaction to the challenges of caring for a terminally ill family member.

Limitations

An important limitation of this study may be the low response rate (50%) that may limit the generalisability of study findings and lead to bias. Especially those not participating because the patient had died may have experienced particularly high burden. Higher response rates by those less troubled, with better self-reflection, or higher sociodemographic status has been described in the literature before. Generalisability of the current findings is further limited to Caucasian caregivers who are relatively young and well educated. The young age of participants may be explained by recruitment mainly from a tertiary oncological centre with a potentially younger cohort of cancer patients. Potential barriers for accessing community care services [4,8] were not assessed nor were additional burden of performing household and toilet tasks [3,30]. The impact of caregivers' gender and relationship to the care recipient might also vary depending on cancer type and associated symptoms. The assessment of cancer type could have added more precise information about burden and specific challenges caregivers might perceive [3,32].

Conclusions and clinical implications

The results of this study have implications for research and practice in palliative and supportive care. Providing support to a critically ill person is a demanding task potentially causing high burden for family caregivers and putting them at risk for the development of impaired health. With cancer and other life-limiting diseases on the rise, family caregivers are the backbone of the social care delivery system, and healthcare professionals need to be sensitive to caregivers' needs. This study shows that psychological variables, in addition to practical support needs, may play an important role in explaining the extent of burden in family caregivers in palliative cancer care. Importantly, these variables seem to be partly gender specific. This knowledge provides a basis for the development of psychological interventions

to reduce and prevent high burden in family caregivers. Such intervention should be gender sensitive, with more emphasis placed on the dual burden of employment and caregiving and the detrimental effects of relying on emotion-oriented coping strategies in women [29]. Because women are more likely than men to be sensitive to interpersonal issues, they may tend to perceive a lack of emotional mutuality or reciprocity as an indicator of their deficiencies [3]. As a consequence, this could lead to increase feelings of isolation as well as social inadequacy contributing to the poorer quality of life in a caring situation [3]. Fulfilment of support needs and hope is important determinants of burden in both genders [27,33]. While support needs may already be commonly addressed in palliative care settings, fostering hope may not yet be a widely acknowledged goal of interventions [27,34]. Interventions addressing hope are established for cancer patients [35]. However to date, there are hardly any psychological interventions to address hope in their caregivers [27,36,37]. Interventions to foster hope and resilience may be valuable to attenuate burden in caregivers and protect them from developing secondary psychiatric problems such as depression, anxiety, prolonged grief or alcohol abuse [27,29,38–40]. However, the studied variables only account for about one third of the variance in caregiver burden, which implies that there are important factors beyond those investigated in the present study. The identification of these variables should be a priority in future research and specifically investigate the implications of female double burden of work and caring.

Conflict of interest

The authors declare no conflict of interest. All data obtained within the study and related to this paper can be found at the Medical University of Vienna, Clinical Division of Palliative Care and are accessible with the first author Beate Schrank and the corresponding author Sophie Schur.

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