Walking a mile in their shoes: anxiety and depression among partners and caregivers of cancer survivors at six and 12 months post-diagnosis

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Abstract

Purpose: To examine the prevalence of and psychosocial variables associated with anxiety and depression among partners and caregivers of cancer survivors, compare prevalence with community norms, and report differences across cancer diagnosis.

Methods: A prospective survey of partners and caregivers was undertaken to assess anxiety and depression and potential psychosocial variables associated with these outcomes at six and 12 months post-survivor diagnosis (n=436).

Results: Although the proportion of anxious participants decreased over time (p=0.01), the percentage of those depressed remained stable (p=0.68). Most participants who were depressed were also anxious. To a certain extent, prevalence of anxiety and depression exceeded community norms and varied across cancer type. Partners and caregivers particularly vulnerable included those of lung, haematological or head and neck survivors. High use of avoidant coping and interference in regular activities were associated with *both* anxiety and depression *across time points*. Of the different types of support measured, only lower emotional/informational support was associated with anxiety and depression at 6 months, whereas lower positive social interaction was associated with depression at 12 months. Additional variables associated with anxiety and depression at 12 months included higher unmet needs and involvement in personal and medical tasks, respectively.

Conclusions: Even at 12 months post-survivor diagnosis, almost a third of participants reported anxiety, a result partially predicted by high use of avoidant coping and interference in regular activities. Understanding variables associated with partners' and caregivers' anxiety and depression can lead to optimal referral to supportive care services and inform the tailoring of interventions.

Keywords: anxiety, depression, caregivers, coping, social support, caregiving burden

Introduction

Since the early 1990s, research on the psychosocial impact of a cancer diagnosis on partners and caregivers has increased exponentially, now constituting a research priority area in psycho-oncology [1]. This interest has not only been stimulated by studies showing that partners and caregivers are intimately affected by the cancer diagnosis, but also that their reactions and illness adjustment impact on patients’ adjustment [2,3]. Furthermore, an increase in the proportion of patients treated as outpatients and reduced hospitalization also mean partners and caregivers are becoming increasingly responsible for patients’ physical and emotional care. A better understanding of partners’ and caregivers’ cancer experiences is thus a critical first step towards designing effective health care services to optimise partners’ and caregivers’ and, indirectly, patients’ illness adjustment.

Despite advances in treatment, a cancer diagnosis remains a major life stressor and presents patients and partners and caregivers with numerous questions to be answered and issues and emotions to be faced [2,4-10]. However, partners and caregiver often put their concerns aside and neglect their own health and needs to focus on supporting patients [8], which often includes assisting with daily activities, taking on additional family responsibilities and, depending on patient’s diagnosis, engaging in illness management tasks [2]. Kim & Schulz [11] have found that cancer and dementia caregivers provided more hours of care per week, assisted with a greater number of daily activities, and reported greater levels of physical burden and psychological distress than caregivers of individuals with diabetes or frail elderly. Cancer caregivers have also been found to experience levels of burden equivalent to those caring for individuals with AIDS [12].

Cancer caregiving responsibilities can be stressful and may affect partners’ and caregivers’ physical, social, and emotional health [5,8]. A recent review has identified more than 200 problems and burdens related to cancer caregiving responsibilities, including pain, fatigue, financial difficulties, social isolation, anxiety, and depression [5]. Anxiety and depression among partners and caregivers ranges from 16% to 56% and 10% to 52%, respectively [6,7]. In some studies, partners' and caregivers' rates of anxiety and depression exceed those of patients [7,13,14]. Variables associated with partners' and caregivers' anxiety or depression, include demographics (e.g., young age, female gender); patients' illness characteristics (e.g., later disease stage and higher symptom burden); and characteristics of the care situation (e.g., poor patient-caregiver relationship quality and high burden) [4].

Although partners' and caregivers' anxiety and depression have received considerable attention in the literature [4], several gaps remain and warrant additional studies. Most studies focus on partners of men with prostate cancer or women with breast cancer [2], are cross-sectional [2,4,5], and utilise small study samples [2,15]. Many studies include a mix of partners and caregivers from the acute diagnosis to survivorship phases, making it difficult to differentiate distress levels as partners and caregivers confront distinct stages or milestones [5]. Only two studies have identified predictors of partners' and caregivers' *clinical* levels of depression [16,17] and none were found to explore predictors of *clinical* levels of anxiety. This study addresses these gaps and:

1) Describes the prevalence of anxiety and depression among a large sample of partners and caregivers of cancer survivors at six to eight and 12 months post-survivor diagnosis.
2) Compares partners' and caregivers' anxiety and depression with community norms [18].
3) Reports prevalence of anxiety and depression across cancer diagnoses.
4) Identifies the psychosocial variables associated with *borderline/clinical* levels of anxiety or depression. Selection of variables was guided by the theoretical work of Lazarus & Folkman [19] and empirical evidence [4,7] and included antecedent variables (current burdens and unmet needs), coping strategies (avoidant and active), and personal resources such as social support and physical well-being. The focus of this analysis was to identify psychosocial variables associated with distress that are amenable to an intervention; hence demographics and illness variables were controlled for, but not considered as separate correlates. It was hypothesised that borderline/clinical anxiety or depression would be associated with: a) higher caregiving burden, including reporting higher levels of involvement in caregiving tasks,

interference in daily activities due to caregiving role, and financial burden; b) higher level of unmet supportive care needs; c) higher use of avoidant coping, d) poorer physical well-being; and e) lower social support.

Materials and Methods

Participants

Partners or caregivers were referred to the *Partners and Caregivers Study* (P&CS), a five-year longitudinal study of the impact of caring for, or living with, a cancer survivor, between October 2005 and November 2007 by eligible cancer survivors participating in the *Cancer Survival Study* (CSS), also conducted by the research team [20]. Survivors were recruited from the two largest state-based cancer registries in Australia, and eligible for the CSS if they were English-speaking; aged 18 to 80 years; resident of Victoria or New South Wales at diagnosis; diagnosed with their first histologically confirmed prostate, bowel, female breast, head and neck, or lung cancer, or melanoma, Non-Hodgkin's lymphoma, or leukaemia in the past six months; aware of their cancer diagnosis according to their treating physician; and capable of completing a survey. An additional P&CS inclusion criterion was caring for or living with the cancer survivor. A 'caregiver' was defined as a person nominated by the patient as most involved in supporting them through the illness, regardless of family ties, as long as they were not remunerated [21]. The study also included partners who might provide emotional support, but might not identify themselves as a 'caregiver'. For the sake of brevity, 'partners and caregivers' are hereafter referred to collectively as 'caregivers'. If the patient died during the course of the CSS, the caregiver was invited to participate in the bereavement sub-study.

Procedure

At six to eight months post-diagnosis, in addition to their own survey, CSS participants were sent a separate, sealed study pack to pass on to their caregiver, inviting participation in the P&CS. Each survivor could only nominate one caregiver. Interested caregivers returned a consent form directly to the P&CS research team and the P&CS team then followed-up directly with the same caregiver throughout the duration of their participation in the study. The Human Research Ethics Committees of the University of Newcastle and Cancer Councils New South Wales and Victoria approved the study. No financial incentive was provided to CSS or P&CS participants; however, they were sent promotional material produced by the state Cancer Council (e.g., fridge magnet, pen) as a token of appreciation for their time.

Data collection

At each data collection time points (six to eight, 12, and 24 months, 3.5 and five years post-survivor diagnosis), consenting caregivers were mailed the P&CS self-administered survey and a reply-paid envelope. This paper focuses on caregivers' anxiety and depression in the acute survivorship phase (i.e., six to eight and 12 months).

Dependent variables

Anxiety and depression were measured using the 14-item Hospital Anxiety and Depression Scale (HADS) [22]. Items were rated from 0 to 3 (variable response scale) and subscale scores (ranging from 0 to 21) were then categorised as normal (<8), borderline (8-10), or clinical (11-21) anxiety or depression [22]. Although there is debate about the optimal cut-point to use [23], a review of the validity of the individual HADS subscales found that the best trade-off between sensitivity and specificity was achieved using a subscale cut-off point of 8 or above for identifying 'cases' [24]. Reliability across the subscales have been found to range from alpha = 0.67 to 0.93

[24] and the scale had acceptable psychometric properties in the present sample (alpha= 0.86 to 0.89) [25].

Independent variables

The following variables were considered for their association with anxiety and depression:

Physical well-being was captured by the Physical Component Score (PCS) of the Medical Outcome Survey Short Form-12 (SF-12) [26]. The PCS score was calculated using weighted scoring and standardised from 0–100 (US norm mean = 50, SD= 10) [26]. PCS scores were then categorised in percentiles according to the US population norms [26]. Sanderson & Andrews [27] found the US-derived summary scores acceptable among Australians and recommended the US SF-12 to allow for comparison across studies. Reliabilities in the current study (alpha = .89 - .90) are comparable to those reported by others (alpha =0.73-.89) [26]. The Mental Component Score was not used, as moderate correlations with HADS-A (r = - 0.74) and HADS-D (r= -0.75) were found, indicative of conceptual overlap.

C*aregiving burden* was captured through three independent questions. First, caregivers were asked to indicate for 13 tasks from 1 '*daily*' to 4 '*not at all*'- '*How often do you perform the following tasks in your role as a partner/caregiver?*' (items adapted from South Australia Health Omnibus Survey [28]). Exploratory factor analysis with oblique rotation revealed two task clusters across the time points: 1) Personal and medical tasks (alpha = 0.87) and 2) Emotional support, household, and practical tasks (alpha =0.73-0.79). Within each task cluster, item's raw scores were summed and standardised (0 to 10; higher score = lower involvement). Second, caregivers rated, using a 10-point visual analogue scale, adapted from the Work Productivity and Activity Impairment instrument [29], '*How much did your role as a partner or caregiver affects your ability* *to do your regular activities*?' Last, participants were asked how they met out-of-pocket expenses and this was then categorised as out-of-pocket expenses yes/no.

Preferences for 14 *coping strategies* were assessed using the 28-item Brief COPE [30]. Each item is rated on a 4-point response scale: 1 '*I haven't been doing this at all'* to 4 '*I've been doing this a lot'*. According to other studies with caregivers [31] and informed by exploratory factor analysis with oblique rotation performed on the 14 subscales, a two-factor structure was used: 1) Active coping (12 items) (active, emotional and instrumental support, positive reframing, planning and acceptance – alpha =0.88 -0.89) and 2) Avoidant coping (10 items) (behavioural disengagement, self-distraction, denial, venting and self-blame – alpha =0.76 - 0 .78). Similar to other studies [31] and to have a consistent measure of coping across all time points, the humour, religion, and substance abuse subscales were not included, as they did not load on either factor at one or all time points. Participants' active and avoidant coping scores were standardised from 0 to 10.

Social support was measured using 19 items of the MOS-Social Support Scale, [32] which captures four types of support: 1) emotional/informational support, 2) tangible support, 3) affectionate support, and 4) positive social interaction. Each item was rated from 1 'n*one of the time*' to 5 'a*ll of the time*', with raw scores standardised from 0 to 100. Original report of internal consistency [32] was similar to those found in the present study (alpha= 0.96-0.98).

Number of *unmet supportive care needs* experienced was captured by the Supportive Care Needs Survey – Partners and Caregivers (SCNS−P&C) (maximum = 44 needs) [33]. Each item is rated on a 5-point response scale: 1 '*no need-not applicable*' to 5 '*some need-high'*. Moderate/high unmet need count (i.e., response of 4 or 5) was used in this analysis to remain consistent with the caregiver literature [7].

Demographic and illness variables

Nine items assessed caregivers' *demographic* characteristics: age, sex, country of birth, marital status, education, employment, current household income, relationship to the person they are caring for, and caregiver-patient living arrangements. Patients' age and cancer type were obtained directly from the CSS (n_{age}= 236; n_{cancer} = 252) for patient-caregiver pairs who agreed to data linking or by caregiver self-report.

Data analysis

Analysis was generated using SAS software, Version 9.2. Descriptive statistics were initially performed to describe the sample. McNemar test was performed to examine change over time in anxiety and depression. Chi-square tests were used to compare caregivers' prevalence of anxiety and depression with community norms. As no Australian normative HADS data were available at the time of this analysis, the British population norms published by Crawford, Henri & Cormbi were used [18]. This was appropriate given the comparable prevalence of mental disorders in the British and Australian populations (British 17% [34] versus Australian 20% [35], $p = .72$). The British norms have also been recently used in another Australian study [36]. Initial associations between anxiety and depression and psychosocial variables were examined using t-tests for continuous data and chi-square for categorical data. Variables with an association of $p \leq 0.2$ are generally considered for inclusion in a logistic regression [37]; however, owing to the large number of analyses, a $p < .05$ was applied to these analyses. To examine the association between psychosocial variables and anxiety and depression, data were recoded as either normal or borderline/clinical, and analysed using backward stepwise logistic regression, controlling for caregiver sex, caregiver and patient age, household income, education and cancer type. Logistic regression is a widely used and accepted method to assess the effects of multiple explanatory variables, which can be numeric and/or categorical, on a dichotomous outcome variable and obtain a parsimonious model [38].Variables with the highest p-value were deleted in turn from the model, until remaining variables had a $p < .05$ on the Wald chi-square test. The final models were reviewed for interpretability and tested for possible interactions (none significant). Beta weights, standard error, Wald chi-square test and p-value, odds ratio and 95% confidence intervals are reported for variables included in the final model. Missing values for psychosocial variables and outcomes of interest did not follow a particular pattern and were less than 5%. For HADS, a single missing item from a subscale was inferred by using the mean of the remaining six items. Subscales missing more than one item were not used. For missing SF-12 data, the on-line scoring software available through the QualityMetric Incorporated website was used. For the purpose of this analysis, only participants who had a completed HADS survey at both data collection time points were included in the analysis (N=436).

Results

Participants

A P&Cs pack was sent to 1698 CSS participants to be passed onto their caregiver. A total of 747 caregivers consented to study participation (consent rate = 44%), of which six were ineligible, as the patients was diagnosed with a cancer other than those considered for this study and two returned their consent too late to be included in the first two data collection time points for this study. Thirty nine and 58 participants withdrew at six months and 12 months, respectively. Reasons provided included (n=97) survey not relevant (23.7%), survey too personal/invasive (5.2%) or distressing (4.1%), caregiver too ill (4.1%) or too busy (4.1%), no longer interested (5.2%), patient deceased (18.6%), ineligible (7.2%), deceased (1.0%), or no reason provided (26.8%). A total of 444 caregivers completed a baseline, 6-month survey and a 12-months survey and 436 caregivers had completed the HADS at both time points and were considered for this analysis. Participants' characteristics are shown in Table 1. The majority were female (70.2%) and were married to and living with the survivor. Almost half of the caregivers were currently employed. Mean age of caregivers and survivors was 60.8 years (SD=10.5, range 21-85 years) and 60.8 years (SD=10.4; range=27-79), respectively. A third of survivors were diagnosed with prostate cancer.

Prevalence of anxiety and depression

The proportion of anxious caregivers decreased over time (p =0.01, N=436), with 35.8% caregivers reporting borderline/clinical anxiety at 6 months, down to 30.5% at 12 months. Conversely, the proportion of depressed caregivers was comparable across time (p=0.68, N=436), with 15.1% and 15.9% of caregivers reporting borderline/clinical depression at six and 12 months, respectively. At six and 12 months, 13.3% and 13.5% of participants reported both borderline/clinical anxiety and depression, respectively

As indicated in Table 2, at six months, compared to community norms, a greater proportion of caregivers reported clinical anxiety (p=0.01). For depression, findings suggest a more notable elevation in borderline rather than clinical depression (p=0.04 and 0.01 at 6 and 12 months, respectively).

Prevalence of anxiety and depression by cancer types

At 6 months, only anxiety varied across cancer type only, whereas both anxiety and depression were found to vary across cancer types at 12 months (see Table 3). A greater proportion of lung cancer caregivers reported anxiety (57.7%) at 6 months and to a certain extent at 12 months (42.3%) compared to some of the other caregivers. Rates of depression were also notable among lung cancer survivors at 12 months (26.9%). Rates of anxiety and/or depression were also elevated for caregivers of haematological (6 months anxiety = 46.8%; 12 months anxiety = 43.6%; 12 months depression = 27.4%) or head and neck (12 months anxiety = 40.0%) survivors.

Variables associated with anxiety and depression

Preliminary analyses revealed that the majority of hypothesised variables were significantly associated with anxiety and depression and were therefore considered for regression analyses (Table 4). The only exception was that physical well-being was not significantly associated with anxiety at

12 months. Logistic regression analyses are shown in Tables 5 and 6. At six months, predictors of anxiety and depression were similar and included higher use of avoidant coping, higher interference in regular activities due to caregiving role, and lower emotional/informational support.

Higher use of avoidant coping and higher interference in regular activities were also related to both anxiety and depression at 12 months. Higher unmet needs were only associated with anxiety, whereas reporting more involvement in personal and medical tasks and lower positive social interactions were related to depression only.

Discussion

To our knowledge, this is the first Australian study to document the prevalence of anxiety and depression among a large, heterogeneous sample of partners and caregivers of cancer survivors. Of note, at 6 months, although the CSS participants reported comparable rates of depression (14%), they reported less anxiety (24%) [20] than the caregivers. To a certain extent our findings corroborated those of Price et al. [36], who found that caregiver anxiety and depression rates exceeded community norms. Couper et al. [13] also found that, at diagnosis, wives of men with prostate cancer had rates of major depression and generalised anxiety disorder twice those of patients and of other women in the community. This is of concern as a recent meta-analysis by Hagedoorn et al.[39] found a moderate, positive association between patients' and partners' levels of distress ($r=.29$, $p < .001$), which implies mutuality in response (i.e., a partner's high distress is not only detrimental for their own illness adjustment, but also for their partner's adjustment). Although anxiety findings corroborated those of other longitudinal studies with decreasing prevalence with time [13,40], in the present study, rates of depression were sustained across the two time points. Psychological difficulties might be prolonged for caregivers, as they often do not seek additional support [41], prioritise patient's welfare over their own [42], and try to shelter patients from cancer challenges and further distress [4].

To our knowledge, this study is the first to report on anxiety and depression across a range of cancer caregiver groups, revealing the particular vulnerability of caregivers of lung, head and neck, or haematological cancer survivors. Blaming the patient for the cancer [43] and/or the poor prognosis often associated with lung cancer might in part explain these findings [44]. Blaming the patient for the cancer might also explain high distress among caregivers of head and neck survivors [43,45], in addition to lingering symptoms [45], physical and functional impairments [45], and body images concerns, which in turn can lead to social isolation [46]. Comparable to our findings, Shelby et al. [47] found that caregivers of individuals with haematological malignancies reported higher levels of depression and anxiety than patients and a non-medical (healthy) comparison group within the first year post-stem cell transplant, which was attributed to the uncertainty of the situation, unmet expectations about recovery, isolation, and lack of support.

Overall, regression analyses partially supported hypotheses and three findings are notable. First, higher use of avoidant coping and higher level of interference in regular activities were associated with *both* anxiety *and* depression *across time points*. Our findings on avoidant coping corroborated those of others [48,49]. For instance, in their study of husband's adjustment to breast cancer, Dalton et al. [48] found that husbands' avoidant coping had the greatest influence on their illness adjustment. Interestingly, Ko et al. [49] found that dysfunctional problem-solving among wives of men with prostate cancer not only predicted the wives' distress, it also predicted men's distress, a relationship mediated by wives' distress. This is concerning as a study by Papastravrou et al. [50] suggested that caregivers seemed to prefer avoidant coping over problem-focused coping as burden increased.

The relationship between caregiver burden, including interference in regular activities, and distress has also been documented by others [4,16]. For instance, Rhee et al. [16] found that caregivers' inability to function normally and feeling of mental or emotional burden were significant predictors of depression. A study by Kurtz, Kurtz, Given & Given [40] found that impact on schedule was the most prominent caregiver experience, and caregivers of patients who recently had surgery, had more severe symptoms and worse physical functioning and depression, and diagnosed with colon or lung cancer experienced more impact on their schedule, which in turn was associated with caregiver depression.

A second notable finding from our regression analyses was that only particular types of social support were associated with anxiety and/or depression, with differences across time. At six months, of the different types of support considered, only lower emotional/informational support was associated with both outcomes, whereas at 12 months, only lower positive social interaction was related to depression. Nijboer et al. [51] partially corroborated our results and found that of the different types of support measured only daily emotional support (e.g., people that “cuddle / hug you”) was associated with less depression; whereas negative interactions or support (e.g., “people blame you for things”) was associated with more depression.

Last, our regression findings are first to document the varied impact of caregiver unmet needs and involvement in personal and medical tasks on anxiety or depression across time and address several gaps in the literature. Our findings add to the literature on the impact of caregiving tasks on psychological adjustment by documenting that it is higher involvement in personal and medical tasks at 12 months - rather than emotional support, household and practical tasks - that impacted on depression. Partners and caregivers might have expected initial involvement in tasks, but as time passes, they might not have thought that these would be sustained and it might be more trying for them to carry on. Managing patient medication might also be an indirect indicator of the patients’ illness severity, which in turn might be related to caregivers’ depression [4].

Implications and Recommendations

Interest in the role of psychosocial variables in caregivers’ illness adjustment continues to grow, in part because it is assumed that interventions can modulate their experience and optimise not only caregivers’, but indirectly patients’ adjustment [51,3]. Our results suggest that interventions may have the greatest impact if implemented early in the survivorship phase and sustained at least a year post-diagnosis. Although our findings further confirmed the need for coping skills interventions, they also suggest the content of interventions need to be tailored to address those variables contributing to anxiety and depression at a particular point in time. In a recent meta-analysis by Northouse et al. [52], many of the variables identified in the regression analyses responded favourably to interventions, including coping and burden.

Strengths and Limitations

The strengths of this study are its relatively large sample size, the heterogeneous sample of caregivers, the population-based sample of cancer survivors, and the inclusion of modifiable risk factors. One limitation is the less than optimal consent rate, which cannot be precisely calculated, as the number of caregivers invited by survivors and the number of survivors who had a caregiver are both unknown, and follow-up with non-respondents was not ethically allowed. Ethical procedures also precluded linking data from the *CSS* and *P&CS* without the explicit approval of both the survivor and their partner/caregiver. As only a small sub-group provided consent to ‘data linking’ (n < 300), we could not include many of the survivor variables in the analyses (e.g., cancer stage) that was not self-reported by the caregivers. Although cancer registry recruitment provided a population-based sample, it missed caregivers in the early diagnosis phase, a time when distress might be more prevalent. Also, this study was conducted in the two states of Australia and findings might not be generalizable to other countries and health care settings. Although the HADS is a reliable and valid measure of anxiety and depression, it is acknowledged that some debates surround its use and scoring [23], which in turn might have influenced findings.

Table 1. Caregivers' characteristics (N=436, unless specified otherwise)

Demographics	**N (%) All**
Sex	
Male	130 (29.8)
Female	306 (70.2)
Age (N=435)	
Less than 60 years	188 (43.2)
60 or more years	247 (56.8)
Marital status	
With partner	423 (97.0)
Without partner	13 (3.0)
Country of origin (N=435)	
Australia	356 (81.8)
Other	79 (18.2)
Education (N=430)	
Primary school	84 (19.6)
Secondary school	106 (24.6)
Trade or TAFE	90 (20.9)
University	150 (34.9)
Employment (N=434)	
Employed	201 (45.3)
Student	3 (0.7)
Unemployed/retired	179 (41.3)
Household duties	43 (9.9)
Other	8 (1.8)
Current household income (N=427)	
<$500 per week	131 (30.7)
$500-$799 per week	98 (23.0)
$800-$1000 per week	59 (13.8)
>$1000 per week	86 (20.1)
Prefer not to say	53 (12.4)
Out-of-pocket expenses (N= 428)	
Yes	321 (75.0)
No	107 (25.0)
Relationship with patient	
Partner	399 (91.5)
Family	30 (6.9)
Non-family	7 (1.6)
Patient-caregiver living arrangement (N=435)	
Together	404 (92.9)
Not together	31 (7.1)
Patient age (N=388)	
Less than 60 years	168 (43.3)
61 or more years	220 (56.7)
Cancer type (N=389)	
Prostate	127 (32.7)
Haematological*	62 (15.9)
Breast	52 (13.4)
Melanoma	46 (11.8)
Colorectal	46 (11.8)
Head and neck	30 (7.7)
Lung	26 (6.7)

***** Haematological = Non-Hodgkin Lymphoma and leukemia

Table 2. Comparison of caregiver anxiety and depression with community norms at six (time 1) and 12 (time 2) months

HADS category	**Community norms***	**Participants**		**χ2 for participants versus norms**	
		Time 1	**Time 2**	**Time 1**	**Time 2**
			Anxiety		
Normal	66.8%	64.2.%	69.5%	χ2 (2) = 8.63 p =0.01	χ2 (2) = 2.32p=0.31
Borderline	20.6%	18.6%	17.7%		
Clinical	12.6%	17.2%	12.8%		
			Depression		
Normal	88.6%	84.9%	84.2%	χ2 (2) = 6.46 p = 0.04	χ2 (2) = 9.18 p=0.01
Borderline	7.8%	9.9%	11.5%		
Clinical	3.6%	5.2%	4.4%		

*From Crawford et al.[18].

Table 3. Caregiver anxiety and depression by cancer type at six (time 1) and 12 (time 2) months

	Cancer Type **% of sample (95% CI)**														χ2	
	Time 1							**Time 2**								
	Colorectal	**Breast**	**Prostate**	**Melanoma**	**Lung**	**Haematological***	**Head and Neck**	**Colorectal**	**Breast**	**Prostate**	**Melanoma**	**Lung**	**Haematological***	**Head and Neck**	**Time 1**	**Time 2**
Anxiety	28.3 (15.2-41.3)	26.9 (14.8-39.0)	28.4 (20.5-36.2)	23.9 (11.5-36.3)	57.7 (38.6-76.8)	46.8 (34.3-59.3)	43.3 (25.5-61.1)	30.4 (17.1-43.8)	17.3 (7.0-27.6)	22.1 (14.8-29.3)	30.4 (17.1-43.8)	42.3 (23.2-61.4)	43.6 (31.2-55.9)	40.0 (22.4-57.6)	χ2 (6) = 18.0 **p= .006**	χ2 (6) = 16.7 **p = .01**
Depression	10.9 (1.8-19.9)	17.3 (7.0-27.6)	9.5 (4.3-14.6)	8.7 (0.5-16.9)	23.1 (6.8-39.3)	17.7 (8.2-27.3)	23.3 (8.1-38.5)	15.22 (4.8-25.6)	13.5 (4.1-22.8)	8.7 (3.8-13.6)	13.0 (3.3-22.8)	26.9 (9.8-44.1)	27.4 (16.3 – 38.6)	13.3 (1.1-25.6)	χ2 (6) = 8.8 **p=.18**	χ2 (6) = 14.6 **p = .02**

CI = confidence interval; ± Borderline/clinical anxiety or depression (score 8 or more on the respective subscale); *Haematological = Non-Hodgkin Lymphoma and leukemia

Table 4. Preliminary analyses to identify psychosocial variables associated with anxiety or depression at six (time 1) and 12 (time 2) months

Variables	Time 1				Time 2			
	Anxiety		Depression		Anxiety		Depression	
	Anxiety < 8	Anxiety ≥ 8	Depression <8	Depression ≥ 8	Anxiety < 8	Anxiety ≥ 8	Depression <8	Depression ≥ 8
Personal and medical tasks* (mean SD, range = 0-10)	9.2 (1.4)	8.3 (2.3)***	9.1 (1.5)	7.6 (2.8)***	9.5 (1.3)	8.4 (2.3)***	9.4 (1.4)	7.7 (2.7)***
Emotional support, household and practical tasks* (mean SD, range = 0-10)	5.7 (2.4)	4.4 (2.4)***	5.5 (2.4)	3.5 (2.3)***	6.4 (2.5)	4.7 (2.5)***	6.3 (2.5)	3.9 (2.6)***
Interference in daily activities due to caregiving role (mean SD, range = 0-10)	1.9 (1.8)	3.8 (2.9)***	2.2 (2.0)	5.1 (3.0)***	1.4 (1.1)	3.2 (2.7)***	1.5 (1.3)	4.2 (2.9)***
Out-of-pocket expenses (%)								
Yes	68.2	87.0***	71.5	93.9***	59.4	75.4**	61.7	77.9**
No	31.8	13.0	28.5	6.1	40.6	24.6	38.3	22.1
Physical well-being (%)								
0-25th percentile (0 – 46.5)	26.5	38.5**	27.4	49.2**	30.5	41.2	30.6	50.8**
25th -50th percentile (46.5– 53.6)	23.5	23.0	23.3	23.8	22.7	21.3	23.4	16.4
50th-75th percentile (53.6-56.5)	22.8	8.8	19.9	6.4	20.7	16.0	20.9	10.4
75th-100th percentile (56.5 - 100)	27.2	29.7	29.4	20.6	26.1	21.4	25.1	22.4
Unmet supportive care needs (mean SD, range = 0-44)	2.5 (5.8)	8.4 (10.0)***	3.5 (6.8)	11.0 (11.3)***	1.0 (3.1)	6.9 (9.2)***	1.7 (4.6)	8.6 (9.8)***
Emotional/Informational support (mean SD, range = 0-100)	67.1 (29.2)	50.7 (29.1)***	64.1 (29.5)	45.0 (28.9)***	64.7 (32.2)	52.6 (29.6)**	63.3 (32.1)	48.7 (27.7)**
Tangible support (mean SD, range = 0-100)	65.0 (33.4)	49.0 (34.6)***	61.6 (34.5)	46.1 (32.5)**	64.2 (34.0)	51.2 (34.0)**	63.2 (34.2)	43.8 (31.4)***
Affectionate support (mean SD, range = 0-100)	79.8 (28.4)	68.4 (31.2)**	78.3 (28.9)	61.0 (31.7)***	78.2 (31.9)	67.9 (31.0)**	77.9 (30.8)	59.1 (34.3)***
Positive interaction (mean SD, range = 0-100)	75.7 (28.1)	60.6 (30.8)***	73.3 (29.1)	52.9 (29.0)***	76.4 (30.0)	60.4 (31.3)***	75.6 (29.3)	48.4 (32.4)***
Avoidant coping (mean SD, range = 0-10)	.9 (1.0)	2.6 (1.8)***	1.3 (1.4)	2.9 (1.8)***	0.7 (1.1)	2.4 (1.6)***	1.0 (1.2)	2.9 (1.8)***
Active coping (mean SD, range = 0-10)	3.2 (2.1)	4.4 (2.0)***	3.5 (2.2)	4.5 (1.8)**	2.5 (2.1)	4.2 (1.9)***	2.8 (2.1)	4.3 (2.0)***

* higher score = lower involvement ** $p < 0.05$, *** $p < 0.0001$ N 6 months = 420-435; N 12 months = 417-432

Table 5. *Final logistic regression models* for borderline or clinical anxiety in caregivers at six (time 1) and 12 (time 2) months*

Variables	**Time 1** (N=409)						**Time 2** (N=409)					
	β	**SE β**	**Wald chi-square test**	**df**	**p**	**Odds ratio** (95% CI)	**β**	**SE β**	**Wald chi-square test**	**df**	**p**	**Odds ratio** (95% CI)
Interference in regular activities due to caregiving role	0.24	0.06	16.62	1	< 0.0001	1.28 (1.14 – 1.44)	0.27	0.09	9.11	1	0.003	1.31 (1.10-1.57)
Avoidant coping	0.86	0.12	51.97	1	< 0.0001	2.37 (1.87 – 2.99)	0.78	0.13	38.8	1	< 0.0001	2.18 (1.71 – 2.79)
Emotional/Informational support	-0.15	0.05	9.89	1	0.002	.86 (0.78 - 0.95)	-	-	-	-	-	-
Unmet supportive care needs[a]	-		-	-	-	-	0.09	0.03	8.12	1	0.004	1.10 (1.03 – 1.17)

SE = standard error; CI = Confidence interval; p-value on the Wald chi-square analysis of effects test; [a] = Moderate or high unmet supportive care needs count - Response of 4 or 5 on the Supportive Care Needs Survey- Partners and Caregivers [33]. *Model results of backward stepwise regression controlling for caregiver sex, caregiver and patient age, household income, education, and cancer type. At 6 months, variables removed from the anxiety model, in order, were emotional support, household and practical tasks; active coping; personal and medical tasks; positive social interaction; tangible support; out-of-pocket expenses; moderate/high unmet needs; affectionate support; and physical well-being. At 12 months, initial variables removed from anxiety model, in order, were emotional support; household and practical tasks; personal and medical tasks; emotional/informational support; affectionate support; tangible support; out-of-pocket expenses; positive social interaction; and active coping. Hosmer and Lemeshow goodness-of-fit tests $p_{anxiety}$=0.28 - 0.47.

Table 6. *Final logistic regression models* for borderline or clinical depression in caregivers at six (time 1) and 12 (time 2) months*

Variables	**Time 1** (N=413)						**Time 2** (N=395)					
	β	**SE β**	**Wald chi-square test**	**df**	**p**	**Odds ratio** (95% CI)	**β**	**SE β**	**Wald chi-square test**	**df**	**p**	**Odds ratio** (95% CI)
Personal and medical tasks	-	-	-	-	-	-	-0.29	0.13	4.88	1	0.03	0.75 (0.58 – 0.97)
Interference in regular activities due to caregiving role	0.30	0.06	22.50	1	<0.001	1.35 (1.20-1.54)	0.31	0.11	7.83	1	0.005	1.37 (1.10 – 1.70)
Avoidant coping	0.51	0.12	18.93	1	<0.001	1.67 (1.32 – 2.10)	0.78	0.15	27.19	1	< 0.001	2.18 (1.63-2.92)
Emotional/Informational support	-0.20	0.06	10.34	1	0.001	0.82 (0.73-0.93)	-	-	-	-	-	-
Positive social interaction	-	-	-	-	-	-	-0.23	0.07	11.50	1	0.0007	0.79 (0.69-0.91)

SE = standard error; CI = Confidence interval; p-value on the Wald chi-square analysis of effects test. *Model results of backward stepwise regression controlling for caregiver sex, caregiver and patient age, household income, education, and cancer type. At 6 months, variables removed from the depression model, in order, were emotional support, household and practical tasks; personal and medical tasks; affectionate support; positive social interaction; out-of-pocket expenses; physical well-being; active coping; unmet supportive care needs; and tangible support. At 12 months, initial variables removed from depression model, in order, were moderate/high unmet needs, affectionate support; active coping; out-of-pocket expenses; emotional support; household and practical tasks; tangible support; physical well-being; and emotional/informational support. Hosmer and Lemeshow goodness-of-fit tests p=0.80- 0.87.

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