

Some things change, some things stay the same:

A longitudinal analysis of cancer caregivers' unmet supportive care needs

Afaf Girgis, PhD*

Sylvie D Lambert, PhD*

Patrick McElduff, PhD**

Billie Bonevski, PhD**

Christophe Lecathelinais, DESS de Mathématiques Appliquées***

Allison Boyes, MPH**

Fiona Stacey, BAppSc (ConSc) (Hons)**

* Translational Cancer Research Unit, Ingham Institute for Applied Medical Research, South Western Sydney Clinical School, Faculty of Medicine, The University of New South Wales, Liverpool, Australia

** School of Medicine and Public Health, The University of Newcastle, Newcastle, Australia

*** Hunter New England Population Health, Hunter New England Area Health Service, Wallsend, Australia

Corresponding author:

Dr Sylvie Lambert

Ingham Institute for Applied Medical Research, South Western Sydney Clinical School

Faculty of Medicine, The University of New South Wales

Locked Bag 7103

LIVERPOOL BC Australia NSW 1871

Tel: +61 0407713024

E-mail 1: sylvie.d.lambert@gmail.com

E-mail 2: s.lambert@unsw.edu.au

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Keywords: needs, cancer, oncology, longitudinal study, cancer survivors, partners

Abstract

Objective: Identify caregivers' unmet needs and the psychosocial variables associated with unmet need count within the first 24 months post-survivor diagnosis.

Methods: Caregivers completed a comprehensive survey measuring the primary outcome, psychosocial variables, and demographics of interest at six (n=547), 12 (n=519), and 24 (n=443) months post-survivor diagnosis.

Results: Although prevalence of unmet needs significantly decreased over time, almost a third of caregivers still reported unmet needs at 24 months. Unmet needs were more prevalent among caregivers of lung cancer survivors, at 6 and 24 months. Top ranking unmet needs across time included '*managing concerns about cancer coming back*', '*reducing stress in the person with cancer's life*', '*understanding the experience of the person with cancer*', and '*accessible hospital parking*'. At 24 months, some of the top ranking unmet needs were related to caregivers' well-being and relationships. Increased interference in activities due to caregiving, anxiety, depression, avoidant and active coping, and out-of-pocket expenses were associated with reporting more unmet needs. Less involvement in caregiving roles and increased physical well-being and social support were associated with reporting less unmet needs. For some variables (e.g., anxiety and depression), association with unmet needs strengthened over time.

Conclusions: This is the first longitudinal analysis of caregivers' unmet needs as they enter early and extended survivorship. Findings provide valuable insights into caregiver's unmet needs over time and identified a sub-group of caregivers at risk of experiencing unmet needs, extending previous research and informing timing and content of psychosocial services.

Introduction

Although advances in detection and treatment of cancer have resulted in improved survival, a cancer diagnosis remains a major life event, and impacts not only on the quality of life of those diagnosed, but also greatly affects their partner and caregiver (1-6). Partners and caregivers are typically the patient's primary support person and, throughout the illness experience, often provide assistance with activities of daily living, take on additional family responsibilities, help the patient cope with the stress of the illness and treatment, and engage in illness management tasks (4). Partners and caregivers are typically facing these caring responsibilities with little to no formal training and additional support (2, 5, 7) and caregiving has been associated with increased physical health issues (e.g., pain, poor sleep quality), social and financial problems (e.g., isolation, reducing work hours) and decreased emotional well-being (e.g., anxiety, depression) (2, 7). Partners and caregivers are particularly vulnerable to distress, with studies reporting distress rates exceeding patients' distress (1, 8-13).

Recognition of the impact of cancer on partners and caregivers has prompted in-depth documentation of their unmet supportive care needs (unmet needs) to inform the implementation of effective cancer care services (6, 14-18). 'Unmet needs' is typically defined as the difference between the services or support required to deal with a particular challenge and the actual services or support received (19). From a health care delivery perspective, the dichotomy of 'needs' versus 'unmet needs' is an important one, as although a 'need' identifies a 'problem', an 'unmet need' provides additional information as to where support is lacking. This in turn can be used for service planning and delivery. (19, 20). Partners and caregivers have been found to report more unmet needs than patients, potentially reflecting their comparative neglect (14, 21). The concern is that unmet needs not only compromise partners' and caregivers' quality of life (22) and contribute to their distress and burden (1, 6, 23), but also might adversely impact on patients' distress (23). Hence,

determining what needs remain unmet for partners and caregivers is the first step in the development of programs and services to enhance caregivers' and, indirectly, patients' illness adjustment (6).

A recent systematic review by Lambert et al. (24) found caregivers' unmet needs clustered in the domains of comprehensive cancer care (e.g., access to services, relationship with health care professionals), emotional and psychological (e.g. dealing with own emotional distress), partner or caregiver impact and daily activities (e.g. finances, maintaining a sense of control), relationship (e.g. communicating with patient or others), information (e.g. knowing what to expect), and spirituality (e.g. hope for the future). In particular, caregivers who were female, were not the spouse or living with the patient, had lower social support, and/or reported distress were found to be more at risk of experiencing unmet needs (24). Although existing partner or caregiver unmet needs studies point to some areas of care needing more attention (e.g., helping caregiver manage patient stress, more accessible hospital parking), the majority of caregiver unmet needs studies are cross-sectional (24), providing little indication as to how these might change over time. Kim et al. (6) recently examined caregivers' unmet needs across three cross-sectional cohorts (2 months, 2 and 5 years post-diagnosis) and found that although prevalence of unmet needs decreased as time from diagnosis increased, the prevalence of psychosocial unmet needs was noticeable across all three cohorts. However, the cross-sectional nature of the data limits interpretations. Moreover, with the exception of demographics and distress, few studies have explored the association between psychosocial variables, or characteristics of the caregiving environment, that are amenable to intervention to reduce unmet needs (24).

Thus, the aims of this study were to:

- 1) Identify the type and prevalence of unmet needs among partners and caregivers at six, 12 and 24 months post-survivor diagnosis.
- 2) Examine the prevalence of unmet needs by cancer type across these time points.

3) Examine the association between psychosocial variables and unmet need count at six, 12 and 24 months post-diagnosis. Based on available empirical evidence (24) and guided by the theoretical work of Lazarus & Folkman (25), it was hypothesised that an increase in unmet needs would be related to: 1) higher caregiving burden (14); 2) lower physical well-being (14, 21, 26, 27); 3) higher anxiety and depression (1, 26-30); 4) lower social support (14, 27); and 5) higher use of avoidant coping. To our knowledge, this is the first study to examine how these variables are associated with caregivers' unmet needs in the acute to extended survivorship phases.

Methods

Participants

Between October 2005 and November 2007, partners and caregivers were referred to the *Partners and Caregivers Study (P&CS)* (31) by eligible cancer survivors participating in the *Cancer Survival Study (CSS)*. The *CSS* is a population-based, longitudinal study tracking the psychosocial well-being and lifestyle behaviours of cancer survivors in Australia over the first five years post-diagnosis (32). The *P&CS* was conducted in parallel to document the psychosocial, occupational, and financial impacts of the diagnosis on the cancer survivor's partner or main caregiver (not necessarily the spouse). Cancer survivors were recruited from the two largest state-based cancer registries in Australia. Eligible survivors were: English-speaking; aged 18 to 80 years; resident of Victoria or New South Wales (NSW) at diagnosis; diagnosed within the previous four months with a primary prostate, bowel, female breast, head and neck, or lung cancer, melanoma, Non-Hodgkin's lymphoma, or leukaemia; considered by their treating physician to be aware of their cancer diagnosis; and capable of completing a survey.

Procedure

At six to eight months post-diagnosis, along with their own survey, CSS participants received a sealed *P&CS* pack to pass on '*to the person who is most likely to be affected by your cancer diagnosis*'. Each survivor could nominate only one partner or caregiver for the *P&CS*. Definitions of 'partner' and 'caregiver' were provided to help survivors determine who they should pass on the *P&CS* study pack to. The following definition of 'caregiver' was provided: "*a main caregiver is the person who springs to mind as most involved in supporting you through your illness, often your partner, but sometimes a sister, child, other relative, or a friend[...]*." [definition based on Thomas et al.(15)]. Partners or caregivers who returned a signed consent form to the *P&CS* team were sent their first survey. The *P&CS* team followed-up directly with the same partner or caregiver throughout the duration of their participation in the study. Caregivers who did not respond to the initial mail out were re-invited close to the CSS 12-month data collection time point. For the sake of brevity, 'partners and caregivers' are hereafter referred to collectively as 'caregivers'. The Human Research Ethics Committees of the University of Newcastle and Cancer Councils NSW and Victoria approved the study.

Data collection

Participants were surveyed at six to eight months, 12 months, 24 months, 3.5 years, and five years post-survivor diagnosis. This paper examines unmet needs as caregivers transition from acute to extended survival (i.e., first three data collection time points) (33).

Outcome (dependent) variable

Unmet needs were captured by the Supportive Care Needs Survey – Partners and Caregivers (SCNS–P&C) - a self-administered questionnaire based on the SCNS (20) and designed to assess 44 needs across the information, health care service, psychological and

emotional, and work and social needs domains (34). Participants were asked to indicate the extent to which they needed help with each item, as a result of caring for or living with a cancer survivor, on a 5-point response scale. A response of 1 or 2 was indicative of a need that was either '*not applicable*' or '*satisfied*', respectively. Responses 3 to 5 characterised the extent to which a need remained unsatisfied or unmet (low, moderate, or high). The SCNS-P&C has been used in several studies to assess caregivers' unmet needs (1, 35, 36) and has adequate internal consistency ($\alpha = 0.88-0.94$) (34, 35). In this analysis we focused on moderate/high unmet needs to remain consistent with the patient (18, 19, 37) and caregiver (1, 19, 21, 22, 27, 37) literature and to maximise clinical utility in a resource-stretched health care environment.

Independent variables

Physical well-being, anxiety, depression, caregiving burden, coping, and social support were examined for their association with number of unmet needs. Questionnaires used to capture each variable are described in turn.

Physical well-being was assessed by the Physical Component Score (PCS) of the Medical Outcome Survey Short Form-12 (SF-12) (38). The SF-12 has been used with a variety of populations, including caregivers (39). The PCS score was calculated using weighted scoring and standardised from 0–100 (US norm mean = 50, SD= 10) (38).

Anxiety and depression were measured by the Hospital Anxiety and Depression Scale (HADS) (40), a 14-item, self-administered questionnaire with seven items assigned to each the HADS-Anxiety and HADS-Depression subscales. Each item was rated on a four-point response scale (0 to 3 – variable response scale).

Three independent questions were used to ascertain caregiving burden. First, caregivers were asked to indicate, on a 4-point response scale (1 '*Daily*' to 4 '*Not at all*'), how often they performed 13 caregiving tasks (items adapted from South Australia Health Omnibus Survey (41)). Exploratory factor analysis, with oblique rotation, revealed the 13 tasks clustered into: 1) Personal and medical tasks (e.g., 'organise appointments') and 2) Emotional support, household and practical tasks (e.g., 'provide financial assistance'). Within each role grouping, items' raw scores were summed and the total was standardised from 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 (42), '*During the past seven days, how much did your role as a partner or caregiver affect your ability to do your regular activities, other than work at a job or attend classes?*' Last, financial burden was ascertained by asking participants whether they incurred any out-of-pocket expenses, as a result of caring for a cancer survivor (yes/no).

Coping strategies were assessed by the 28-item Brief COPE, which asked participants to rate from 1 '*I haven't been doing this at all*' to 4 '*I've been doing this a lot*' their use of 14 different coping strategies (43). With reference to other caregiver research (44) and an exploratory factor analysis with oblique rotation performed on the 14 subscales, a two-factor structure was used: 1) Active coping (12 items - active, emotional/instrumental support, positive reframing, planning, and acceptance) and 2) Avoidant coping (10 items -behavioural disengagement, self-distraction, denial, venting, and self-blame). The humour, religion, and substance abuse subscales were excluded, as the subscales did not load on either factor at one, or all, time points. Participants' active and avoidant coping scores were standardised from 0 to 10 to allow for comparison between subscales.

Perceived social support was measured by 19 items of Sherbourne & Stewart's (45) Medical Outcome Survey – Social Support Survey (MOS-SSS) (45). The MOS-SSS assessed 'How often is each of the following kinds of support available to you if you need it?' Items were rated from 1 'none of the time' to 5 'all of the time' across four domains of support: 1) Emotional/informational, 2) Tangible, 3) Affectionate, and 4) Positive social interaction. Raw domain scores were standardised from 0 to 100.

Demographic characteristics and illness variables

Caregiver *demographics* assessed were 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 CSS ($n_{\text{age}} = 236$; $n_{\text{cancer}} = 252$) for patient-caregiver pairs who agreed to data linking, or by caregiver self-report.

Data Analysis

Data analysis was conducted using SAS software, Version 9.2. Descriptive statistics were used to describe the sample and the unmet needs experienced. Description of unmet needs is in accordance with the published literature and includes mean number of unmet needs experienced (1, 29, 46) and percentage of caregivers reporting at least one (6, 21, 27, 29, 47, 48), three (21), or 10 (47) unmet needs. A longitudinal logistic regression model was used to examine difference in prevalence across time. The difference in the mean number of reported unmet needs by cancer type was examined with Wilcoxon's signed rank test. Post-hoc analyses with bonferroni adjustment ($p = .05/21 = .002$) were carried out to identify which combinations of cancer type were different from each other.

Analysis of association between psychosocial variables and level of moderate/high unmet need was undertaken in two steps. First, for each psychosocial variable of interest, at

each time point, a negative binomial model (49) was undertaken to derive an incident rate ratio (IRR), adjusting for demographic characteristics (caregiver sex, age, household income, education, along with patient age and cancer type). An IRR indicates whether there is a significant increase or decrease in the number of moderate/high unmet needs attributable to the variable of interest (e.g., an IRR=1.15 means that a 1 unit increase in the variable of interest is associated with a 15% increase in unmet needs). Second, a longitudinal negative binomial model was used to assess whether the impact of the variable on unmet needs changed over time by examining the statistical significance of their interaction with time, still adjusting for the same demographics ($p < 0.05$ significant).

Chi-square analyses tested differences between study participants and those who withdrew, on key demographics and illness variables. Missing values for unmet needs and psychosocial variables included in this analysis did not follow a particular pattern and were less than 5%, thus it is unlikely they would impact on results. Missing HADS and SF-12 data were dealt with in accordance with the scales' manuals.

Results

Sample

At six months, 673 caregivers consented to study participation with an additional 78 caregivers consenting at 12 months (overall consent rate 44.2%). Figure 1 details participant recruitment and retention. The mean age of participants at six months was 60.6 years ($SD=11$; range 16-85) and more than two-thirds were women. The average age of the cancer survivors at diagnosis was 60.5 years ($SD=10.6$; range=24-80). Additional sample characteristics are listed in Table 1. Comparison of baseline demographics between those who withdrew (data available for 88 caregivers) with those that remained in the study revealed that caregivers who withdrew reported lower income ($p = .02$) and were older ($p = .02$).

Aim 1 – Prevalence and type of unmet needs

The proportion of caregivers reporting unmet needs decreased significantly with time ($p < .01$) with 30.7% of caregivers reporting unmet needs at 24 months (Table 2). On average, caregivers reported 4.6 (SD= 8.0), 2.9 (SD = 6.4), and 2.1 (SD = 5.4) unmet needs across time points. Table 2 also reports the percentage of participants reporting at least three, five, or 10 unmet needs.

The top 10 unmet needs across time points are reported in Table 3. At six months, the most prevalent unmet needs included '*managing concerns about cancer coming back*', '*reducing stress in the person with cancer's life*', '*understanding the experiences of the person with cancer*', '*more accessible hospital parking*', and '*information about benefits and side effects of treatment*'. Seven of the top 10 unmet needs overlapped between six and 12 months (Table 3). Although caregivers seemed to require less help with '*information about benefits and side effects of treatment*', '*obtaining the best medical care*', and '*adjusting to changes in the person with cancer's body*', they still identified needing assistance with '*looking after own health*', '*impact cancer has had on your relationship with the person with cancer*', and '*dealing with others not acknowledging impact of caring on your life*'. The prevalent unmet needs at 24 months further emphasised that caregivers needed assistance with taking care of oneself, including '*looking after your own health*', '*impact cancer has had on relationship*', '*working through feelings about death/dying*', and '*getting emotional support for self*'.

Aim 2- Prevalence of unmet needs by cancer type

Table 4 details the mean number of unmet needs reported by caregivers across cancer types. At six and 24 months, caregivers' mean number of unmet needs varied by cancer type ($p_{6 \text{ months}} = .003$, $p_{24 \text{ months}} = .01$). Post-hoc analyses revealed that caregivers of lung cancer survivors experienced significantly more unmet needs than those of individuals with prostate

($p_{6 \text{ months}}$ and $p_{24 \text{ months}} < .001$) or breast cancer ($p_{24 \text{ months}} < .001$) or melanoma ($p_{6 \text{ months}}$ and $p_{24 \text{ months}} < .001$).

Aim 3- Variables associated with unmet needs

As shown in Table 5, increased interference in activities due to caregiving, anxiety, depression, avoidant and active coping, and incurring out-of-pocket expenses had a stronger impact on level of unmet needs as time progressed. Increased interference in activities due to caregiving was associated with a significant 29% increase in reported unmet needs at six months, and to a 51% and 59% increase in reported unmet needs at 12 and 24 months. At six months, increased anxiety was associated with a 21% increase in reported unmet needs and to a 34% and 42% increase at 12 and 24 months, respectively. A comparable relationship between depression and unmet needs was found. At 12 and 24 months, caregivers reporting more avoidant coping experienced 2.1 and 3.5 times more unmet needs, respectively, than those reporting less avoidant coping. Active coping was also associated with reporting more unmet needs. Caregivers that incurred out-of-pocket expenses reported 2 to 5 times more unmet needs than those reporting no out of pocket expenses.

Less involvement in caregiving roles and increased physical well-being and social support were associated with a decrease in unmet needs. At six months, less involvement in personal and medical roles were associated with a 21% decrease in reported unmet needs and to an even greater decrease at 12 months (31%) and 24 months post-diagnosis (44%). A similar relationship was identified between providing emotional support, involvement in household and practical roles and unmet needs. Although emotional/informational and affectionate support and positive social interaction had a similar relationship with unmet needs across time, tangible support had a stronger impact on level of unmet needs as time

progressed. Physical well-being was associated with a marginal 3%-4% decrease in unmet needs across time.

Discussion

The present study is the first to document the prevalence of caregivers' unmet needs as they transition from acute to extended survivorship, compare level of unmet needs across cancer types, and examine psychosocial variables associated with unmet needs over time. Half of the cancer caregivers experienced at least one unmet need at six months post-diagnosis, with almost one-third still experiencing unmet needs at 24 months. Overall, these rates are comparable to previous caregiver (14, 33) and patient (18) studies. Kim et al. (6) also found that as time from diagnosis increased, prevalence of unmet needs decreased, with 38%-68% of caregivers reporting unmet needs at 2 months; 49% -60% at 2 years; and 19%-36% at 5 years, across the psychosocial, medical, financial, and daily activities domains.

The rank ordering of the SCNS-P&C items in this study revealed some consistent or core unmet needs across time, including *'managing concerns about cancer coming back'*, *'reducing stress in the person with cancer's life'*, *'understanding the experience of the person with cancer'*, and *'more accessible hospital parking'*. Few other studies have corroborated the significance of these unmet needs across other caregiving contexts (1, 26, 33). However, with time, a shift was apparent with almost half of the top ranking unmet needs at 12 and 24 months relating to caregivers' well-being and relationships. This might reflect the shift in caregivers' focus from the patient's recovery in the first year post-diagnosis to processing and managing the impact cancer has had on themselves in the medium and extended survivorship phases. Although *'Working through feelings about death and dying'* was not highly ranked at six and 12 months, it was 9th at 24 months. This shift might coincide with some survivors being diagnosed with a recurrence or deteriorating health (20% of survivors were diagnosed with late or more progressed cancer) (32).

At six and 24 months post-diagnosis, caregivers of lung cancer survivors were particularly vulnerable to unmet needs. The higher level of unmet needs at six months might be in part due to the distress associated with the poor prognosis of lung cancer relative to other cancer types (50). Although caregivers experienced a decrease in unmet needs at 12 months, the increase at 24 months might have coincided with challenges associated with patients' deteriorating health, possible entry into palliation care, and impending death. Soothill et al. (14) also found that a greater proportion of partners of individuals experiencing a recurrence (48%) or in palliation (60%) reported unmet needs, compared to those at diagnosis (39%) or end of treatment (29%).

Most hypotheses about the association between psychosocial variables and unmet needs were supported. Although others have linked some of the aforementioned psychosocial variables to caregivers' unmet needs (1, 26), our analysis extends these by reporting on their increased effect over time. It was not expected that higher active coping would be associated with higher unmet need count across time. This might indicate that although caregivers tried to actively address their unmet needs, these efforts were unsuccessful and guidance from health care professionals might be needed to mobilise the resources required.

The strengths of this study lie in its relatively large sample size, the heterogeneous sample of caregivers, and the inclusion of modifiable risk factors. One limitation of the study is the less than ideal consent rate. Regrettably, an accurate response rate cannot be determined, as the number of caregivers actually invited by survivors, or the number of survivors with a caregiver, is unknown. Furthermore, reliance on survivors to sample caregivers might have influenced who was invited to participate in the study, potentially towards those with less burden. Although retention across data collection time points remained above 70%, those that withdrew differed on household income and caregiver age, which in turn might compromise the representativeness of the sample. Caregivers who did not respond to the initial mail out were re-invited at 12 months; however, these additional

consenters were more likely than initial ones to be without a partner ($p = .001$), not the survivor's partner ($p = .002$), or not living with the survivor ($p = 0.004$). Finally, findings might not be generalizable to other countries and health care contexts.

Conclusions

Despite these limitations, our findings have several useful research and clinical implications. First, a set of core unmet needs were identified, which in turn provides an evidence base to guide the design and implementation of interventions. In particular, interventions focusing on stress management and coping skills training seem promising. Second, the change in top ranking needs over time emphasises that caregiver interventions in survivorship need to include content focusing on taking care of oneself and obtaining emotional support. Third, regression findings identified a group of caregivers at risk of experiencing more unmet needs, further supporting the need for interventions aimed at helping caregivers manage burden, get the support required, and stress management skills. Finally, that some variables had a stronger impact on level of unmet needs as time progressed, suggests that interventions are needed in the early survivorship phase to prevent unmet needs from escalating.

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Table 1. Caregivers' characteristics at six months post-survivor diagnosis (n=547, unless specified otherwise)

Demographics	%
Sex	
Male	30.2
Female	69.8
Age (n=546)	
Less than 60 years	43.6
60 or more years	56.4
Marital status	
With partner	95.8
Without partner	4.2
Country of origin	
Australia	81.0
Other	19.0
Education (n=544)	
Primary school	20.2
Secondary school	23.9
Trade or TAFE	21.5
University	33.6
Other	0.8
Employment (n=542)	
Employed	47.4
Student	0.9
Unemployed/retired	39.3
Household duties	10.0
Other	2.4
Current household income (n=532)	
<\$500 per week	31.8
\$500-\$799 per week	21.4
\$800-\$1000 per week	13.9
>\$1000 per week	19.4
Prefer not to say	13.5
Relationship with patient	
Partner	90.3
Family	7.5
Non-family	2.2
Patient-caregiver living arrangement (n=539)	
Together	92.4
Not together	7.6
Patient age (n=428)	
Less than 60 years	45.3
60 or more years	54.7
Cancer type (n=431)	
Prostate	31.6
Haematological	16.0
Breast	13.3
Melanoma	12.3
Colorectal	11.6
Head and neck	7.9
Lung	7.3

* Haematological = Non-Hodgkin Lymphoma and leukaemia

Table 2. Percentage of participants reporting moderate or high unmet needs across time

	% of total Sample			P
	6 months 95%CI (n=544)	12 months 95%CI (n=515)	24 months 95%CI (n=440)	
At least one unmet need	50.2 (46.0 – 54.4)	35.9 (31.8 – 40.1)	30.7 (26.4 – 35.0)	<.01
At least three unmet needs	36.0 (32.0 – 40.1)	23.5 (19.8 – 27.2)	17.5 (13.9 – 21.1)	<.01
At least five unmet needs	28.9 (25.0 – 32.7)	18.5 (15.1 – 21.8)	12.7 (9.6 – 15.9)	<.01
At least 10 unmet needs	17.8 (14.6 – 21.1)	11.5 (8.7 – 14.2)	6.8 (4.5 – 9.2)	<.01

CI = confidence interval, p value from longitudinal regression model.

Table 3. Ten highest unmet needs across time

	6 months Rank (percentage of participants answered 4 or 5; 95%CI) n=536-543	12 months Rank (percentage of participants answered 4 or 5; 95%CI) n=506-512	24 months Rank (percentage of participants answered 4 or 5; 95%CI) n=427-437
Managing concerns about cancer coming back	1 (18.7; 15.4-22.0)	2 (13.2; 10.3 – 16.2)	2 (10.0; 7.1 – 12.8)
Reducing stress in the person with cancer's life	2 (18.2; 15-21.5)	1 (12.4; 10.5 – 16.4)	3 (9.4; 6.7 – 12.2)
Understanding the experience of the person with cancer	3 (16.1; 13.0-19.2)	5 (10.6; 7.9 – 13.3)	6 (7.7; 5.1 – 10.2)
More accessible hospital parking	4 (16.0; 12.9 – 19.1)	6 (10.4; 7.7 – 13.0)	1 (10.1; 7.3 – 12.9)
Information about benefits and side effects of treatments	5 (15.0; 12.0 – 18.0)	13 (7.3; 5.0 – 9.5)	26 (3.5; 1.7 – 5.2)
Balancing needs of the person with cancer and yours	5 (15.0; 12.0 – 18.0)	3 (11.3; 8.5 – 14.0)	7 (7.6; 5.1 – 10.2)
Obtaining best medical care	6 (14.9; 11.9 – 17.9)	13 (7.3; 5.0 – 9.5)	21 (4.6; 2.6 – 6.6)
Addressing fears about person with cancer's deterioration	7 (14.4; 11.5 – 17.4)	8 (9.4; 6.9 – 12.0)	14 (5.5; 3.4 – 7.7)
Adjusting to changes in the person with cancer's body	8 (13.7; 10.8 – 16.6)	14 (7.1; 4.9 – 9.4)	18 (5.1; 3.0 – 7.2)
Addressing problems with sex life	9 (13.6; 10.7 – 16.5)	8 (9.4; 6.9 – 12.0)	8 (7.2; 4.7 – 9.6)
Accessing information – prognosis	10 (13.5; 10.6-16.4)	11 (8.2; 5.8 – 10.6)	24 (4.6; 2.6 – 6.5)
Having opportunities to discuss concern with doctor	12 (13.3; 10.4 – 16.2)	10 (8.8; 6.4 – 11.3)	17 (5.3; 3.2 – 7.4)
Looking after own health	15 (12.7; 9.9 – 15.5)	4 (11.0; 8.3 – 13.7)	5 (7.8; 5.3 – 10.3)
Impact that cancer has had on your relationship with the person with cancer	16 (12.6; 9.8 – 15.4)	7 (9.8; 7.2 – 12.4)	4 (8.4; 5.7 – 11.0)
Getting emotional support for self	17 (12.4; 9.6 – 15.2)	10 (8.8; 6.4 – 11.3)	10 (6.7; 4.4 – 9.1)
Working through feelings about death and dying	18 (12.2; 9.5 – 15.0)	22 (6.1; 4.0 – 8.2)	9 (6.8; 4.4 – 9.2)
Finding about financial or government support	19 (12.0; 9.3 – 14.5)	15 (7.1; 4.8 – 9.3)	11 (6.6; 4.2 – 8.9)
Dealing with others not acknowledging impact of caring on your life	20 (11.9; 9.1 – 14.6)	9 (9.1; 6.6 – 11.6)	16 (5.4; 3.2 – 7.5)

Note. Rank ordering based on proportion of caregivers answering 4 or 5 on that item. CI = confidence interval. Items rank in the top 10 unmet needs at six, 12, or 24 months listed. Items bolded to indicate shift in or out of the top 10.

Table 4. Mean number of moderate or high unmet needs reported by caregivers by cancer type

Time points	Cancer Type Mean (SD)							p*
	Colorectal	Breast	Prostate	Melanoma	Lung	Haematological	Head and Neck	
6 months (n= 419)	4.2 (7.8)	3.7 (6.6)	3.6 (7.3)	2.5 (4.4)	7.7 (10.1)	6.0 (9.0)	6.7 (10.7)	.003
12 months (n= 381)	1.8 (4.5)	2.2 (4.9)	2.4 (5.6)	1.9 (5.5)	4.8 (7.7)	4.0 (7.8)	3.6 (8.0)	.08
24 months (n=355)	1.4 (3.4)	1.2 (3.2)	1.8 (4.8)	0.9 (2.8)	7.0 (9.9)	2.9 (7.4)	2.1 (4.5)	.01

Note. SD = standard deviation, Haematological = Non-Hodgkin Lymphoma and Leukemia. *Wilcoxon signed rank sum test

Table 5. Relative prevalence of unmet needs for each variable potentially associated with unmet needs

Variables	6 months (n=506-521)	12 months (n=358-371)		24 months (n=326-337)	
	IRR (95% CI) [‡]	IRR (95% CI)	p (vs 6 months)	IRR (95% CI)	p (vs 6 months)
Personal and medical roles (range = 0-10)	0.79 (0.70 - 0.88)	0.69 (0.55 - 0.87)	0.002	0.56 (0.43 - 0.74)	<0.001
Emotional support, household and practical roles (range = 0-10)	0.82 (0.76 - 0.89)	0.78 (0.69 - 0.87)	0.02	0.70 (0.62 - 0.80)	0.001
Interference in daily activities due to caregiving role (range = 0-10)	1.29 (1.19 - 1.40)	1.51 (1.27 - 1.79)	<0.001	1.59 (1.32 - 1.91)	<0.001
Out-of-pocket expenses (% yes/no)	1.94 (1.23 - 3.05)	2.86 (1.42 - 5.75)	0.16	5.08 (2.55 - 10.12)	0.02
Physical <i>well-being</i> (range = 0-100)	0.97 (0.95 - 0.99)	0.97 (0.94 - 1.00)	0.73	0.96 (0.92 - 0.99)	0.07
Anxiety (range = 0-21)	1.21 (1.16 - 1.27)	1.34 (1.24 - 1.43)	<0.001	1.42 (1.31 - 1.54)	<0.001
Depression (range = 0-21)	1.29 (1.22 - 1.37)	1.37 (1.26 - 1.49)	0.11	1.47 (1.33 - 1.63)	<0.001
Emotional/informational support (range = 0-100)	0.83 (0.78 - 0.89)	0.82 (0.73 - 0.92)	0.1	0.88 (0.78 - 1.01)	0.75
Tangible support (range = 0-100)±	0.87 (0.83 - 0.92)	0.79 (0.72 - 0.87)	<0.001	0.79 (0.71 - 0.88)	0.04
Affectionate support (range = 0-100)±	0.86 (0.81 - 0.92)	0.81 (0.73 - 0.91)	0.56	0.87 (0.77 - 0.98)	0.96
Positive interaction (range = 0-100)±	0.85 (0.79 - 0.90)	0.79 (0.71 - 0.88)	0.15	0.84 (0.75 - 0.95)	0.88
Avoidant Coping (range = 0-100)	1.55 (1.36 - 1.78)	2.10 (1.70 - 2.59)	<0.001	3.54 (2.52 - 4.96)	<0.001
Active Coping (mean SD, range = 0-100)	1.36 (1.23 - 1.51)	1.68 (1.43 - 1.97)	<0.001	1.81 (1.54 - 2.13)	<0.001

Note. [‡]IRR = incident rate ratio adjusted for key demographics; CI = confidence interval. ± IRR corresponds to a 10 point increase in social support

