Unmet needs and depression among carers of people newly diagnosed with cancer

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Abstract *Aims:* The aims of this analysis were to examine levels of unmet needs and depression among carers of people newly diagnosed with cancer and to identify groups who may be at higher risk, by examining relationships with demographic characteristics.

Methods: One hundred and fifty dyads of people newly diagnosed with cancer and their carers, aged 18 years and older, were recruited from four Australian hospitals. People with cancer receiving adjuvant cancer treatment with curative intent, were eligible to participate. Carers completed the Supportive Care Needs Survey-Partners & Caregivers (SCNS-P&C45), and both carers and patients completed the Centre of Epidemiologic-Depression Scale (CES-D).

Results: Overall, 57% of carers reported at least one, 37% at least three, 31% at least five, and 15% at least 10 unmet needs; the most commonly endorsed unmet needs were in the domains of information and health care service needs. Thirty percent of carers and 36% of patients were at risk of clinical depression. A weak to moderate positive relationship was observed between unmet needs and carer depression ($r = 0.30$, $p < 0.001$). Carer levels of unmet needs were significantly associated with carer age, hospital type, treatment type, cancer type, living situation, relationship status (in both uni- and multi-factor analysis); person with cancer age and carer level of education (in unifactor analysis only); but not with carer gender or patient gender (in both uni- and multi-factor analyses).

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Conclusion: Findings highlight the importance of developing tailored programmes to systematically assist carers who are supporting patients through the early stages of cancer treatment.

1. Introduction

With an increasing incidence of cancer in western society, family members and friends have assumed responsibility for the role of informal carers providing practical and emotional support to the person with cancer [1]. Prevalence of depression among carers is significant with up to 70% experiencing depressed mood [2,3]. Previous research has focused on the assessment of unmet needs experienced by carers during the cancer survivorship phase [4–9] and at end-of-life stage [10–14]. Findings suggest higher prevalence of unmet needs in carers of palliative care patients than among those caring for patients who are in the survivorship phase [15] and a decrease in carer unmet needs throughout the survivorship phase [16].

Limited information is available on the prevalence of unmet needs in carers of persons newly diagnosed with cancer receiving treatment with curative intent. Soothill et al. [17] assessed the universal, situational, and personal needs of persons diagnosed with one of four tumour types and their carers at four different time points: early post-diagnosis, early survivorship phase, first recurrence, and at early palliative care stage. While the authors identified carer and patient specific support needs, no analysis was undertaken as to the time point during the cancer trajectory these needs occurred. Ream et al. [18] examined unmet needs in carers of persons newly diagnosed with colorectal cancer and lymphoma receiving chemotherapy. Overall, nearly 70% of carers reported one or no unmet needs and nearly one-quarter reported 5–10 unmet needs, most commonly in the information domain. This study included carers of palliative care as well as curative patients, thus it is unclear whether differences in unmet needs existed between these two carer groups. Kim et al. [19] conducted a cross-sectional study assessing unmet needs in carers of colorectal cancer patients at two months and at two and five years post-diagnosis. Results indicated that 68% of carers experienced at least one unmet need two months post-diagnosis and a decrease in unmet needs over time was observed. Finally, Nikoletti et al. [20] assessed unmet needs in carers of newly diagnosed early stage breast cancer patients receiving adjuvant chemo- or radiotherapy at two different time points post-surgery (one week, two to three weeks later). The highest ranked needs reported were health care service and communication needs and again, a decrease in unmet needs between the two assessment points was observed. Since this study focused solely on breast cancer patients and the majority of carers were male (70%), generalisation of findings to other carer groups is compromised. Similar results were found by Kilpatrick et al. [21] who examined unmet needs in 84 male carers of newly diagnosed breast cancer patients.

The literature highlights the existence of unmet needs in carers throughout the cancer trajectory, with a particular focus on end-of-life stage, survivorship phase, specific tumour sites and carer groups. Limited research has been carried out to assess unmet needs in carers of newly diagnosed persons with cancer of various types, receiving treatment with curative intent. Therefore, this study aimed to examine levels and types of unmet needs in this less well-understood group of carers and the relationship between unmet needs and depression.

2. Methods

2.1. Design

This analysis forms part of a multi-centre, randomised, controlled trial to test the efficacy and cost-effectiveness of a telephone intervention to reduce carer burden and depression in carers of persons with cancer [PROTECT study]. The PROTECT study design is described in detail elsewhere [22]. Briefly, patients and their caregivers were recruited at three Victorian health services and one South Australian health service. These hospitals are public or private with a socially diverse patient population. The sites are metropolitan and regional with large catchment areas stretching as far as the border of New South Wales and the Northern Territory. Persons with cancer attending cycles' 2–5 of adjuvant chemotherapy or fraction 2–10 for radiotherapy [approx. 2-months post-diagnosis, determined in pilot work to be the optimal time to approach prospective participants] and receiving treatment with curative intent, together with their carers, were recruited into the study. Each dyad was given a brief introduction to the study and initial consent was sought from both individuals for a researcher to contact them. Consenting dyads were asked to complete the consent form and baseline questionnaires and post them back to the researchers. Ethics approval was obtained from Deakin University Human Research Ethics Committee: 2012-083. The PROTECT study is registered with the Australian New Zealand Clinical Trial Registry: ACTRN12613000731796.

2.2. Measures

Demographic characteristics A demographic questionnaire was used to gather carer information on age, gender, type of relationship to the person with cancer, living situation, household size, and level of education. Information gathered on the person with cancer included age, gender, postcode, treatment type, and cancer diagnosis.

Carer unmet needs were measured using the Supportive Care Needs Survey for Partners & Caregivers (SCNS-P&C). This 44-item instrument comprises four domains (Health Care Service Needs, Psychological and Emotional Needs, Work and Social Needs, and Information Needs) and assesses the need for help for partners/carers of persons with cancer across the illness trajectory. This scale has demonstrated good validity and reliability in cancer research [23].

Depression in carers and in persons with cancer, experienced in the past week, was assessed using the Centre for Epidemiological Studies-Depression Scale (CES-D). This tool consists of 20 items, measured on a 4-point Likert scale ranging from 'Rarely or None of the time' (0) to 'Most or All the time' (3). A total score is calculated by summing individual items (range from zero to 60) with higher scores indicating more symptom severity. The CES-D has demonstrated strong concurrent and construct validity and has well-established internal consistency [24].

2.3. Data analysis

Depression in carers and people with cancer was assessed by summing scores on each item of the CES-D with higher scores indicating more symptoms. The usual cut-off point of 16 was applied to identify those at risk for depression [2,25]. Description of carer unmet needs was performed in accordance with the literature [16,26] and included only moderate/high unmet needs experienced by carers (scores 4 and 5 on the SCNS-P&C). In addition, the percentage of carers reporting at least one, three, five, or 10 unmet needs, and the top ten endorsed unmet needs were examined. Missing values for unmet needs and depression were very low (0.8%, 1.8%; respectively), thus unlikely to have biased the results of this analysis.

The data comprised baseline measures from a larger randomised controlled trial which included carer unmet needs and depression. The PROTECT study was designed to have at least 90% power for two-sided *t*-tests at the 5% significance level to detect effect sizes of 0.5 in both the primary end-point (carer burden as measured by the Zarit Burden Interview) and the key secondary end-point (CES-D). As a consequence, in the current analysis, baseline comparisons of two sub-groups of size 75, 50 or 25 had 80% power to detect effect sizes of 0.46,

0.57 and 0.81 respectively. Descriptive statistics were used to describe sample characteristics, frequency of unmet needs and level of depression. The Pearson correlation coefficient was used to examine the relationship between carers' unmet needs (moderate/high) and depression. The association of categorical factors (e.g. living arrangements) with scores (e.g. CES-D) were investigated with *t*-tests and one-way anovas. Poisson log-linear regression was used to investigate associations between the discrete counts of unmet needs and other baseline factors. Wald Tests were used to ascertain the significance of these factors and for pairwise comparisons between the levels of each factor. The Akiake Information Criterion (AIC) was used to select models according to established conventions [27].

3. Results

3.1. Sample characteristics

A total of 504 patients were screened, of those 57 were excluded as either the person with cancer or the caregiver did not meet eligibility criteria ($n = 11$) or the person with cancer did not have a caregiver ($n = 46$). From a total of 447 eligible patient/caregiver dyads, 297 refused to participate (Fig. 1), resulting in a participation rate of 34% ($n = 150$). Of those 150 carer/person with cancer dyads, 70 carers were male (47%) and mean age of carers was 56.4 years (SD 12.6) ranging from 21 to 84 years. The majority of carers were spouses/partners (83%), of which 88% lived with the person who was receiving treatment for cancer; the median household size was 2.0 persons [range: 7] and 39% of carers reported that secondary school was their highest level of education, while 36% had a university degree. There was a significant association between the gender of carers and the gender of patients, characterised by fewer males caring for a male person with cancer than expected under the hypothesis of no association ($\chi^2 = 71.99$, $p < 0.001$). Mean age of persons diagnosed with cancer was 58.9 years (SD 12.7) ranging from 23 to 82 years, 61 were male (41%). Forty-five percent were receiving chemotherapy only and 85% were diagnosed with a solid tumour. Sample characteristics are presented in Table 1.

3.2. Prevalence of carer unmet needs and depression

Carer unmet needs are presented in Table 2 and includes the percentage of carers experiencing at least one, three, five, or ten unmet needs, and the ten most frequently reported unmet needs. The mean number of moderate/high unmet needs measured was 3.9 (SD 6.3). Overall, 57% reported at least one unmet need, 37% at least three, 31% at least five, and 15% at least ten unmet needs. The majority of the unmet needs
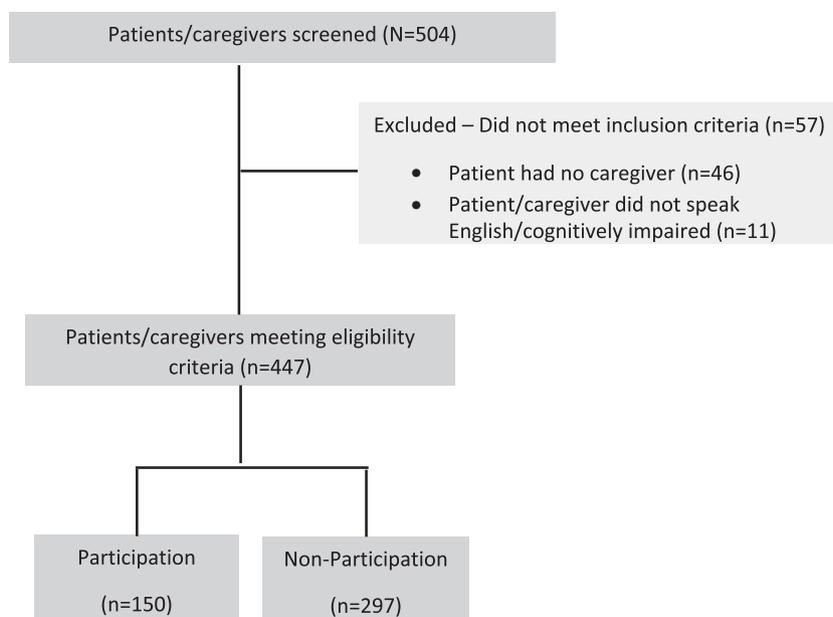
Fig. 1. Flow of participation.

experienced by carers were in the domains of information and health care service needs.

In terms of depression, for carers, the mean score on the CES-D scale was 11.9 (SD = 9.4) with a minimum score of 0 and a maximum score of 43. Overall, 30% of carers had a depression score of ⩾16 and were at risk for clinical depression. For persons with cancer, the mean score on the CES-D scale was 14.5 (SD = 9.9) with a minimum score of 0 and a maximum score of 44. Overall, 36% scored above the cut-off score of ⩾16 for depression.

3.3. Relationship between carer unmet needs and depression

Correlations between carer unmet needs and depression are presented in Table 3. Pearson correlation coefficients showed a weak to moderate positive relationship between carer unmet needs and carer depression ($r = 0.30$, $p < 0.001$). No significant relationships were found between carer unmet needs and persons with cancer depression scores or between carer level of depression and persons with cancer depression scores. No significant relationships were found between carer depression and sample characteristics.

3.4. Relationship between carer unmet needs and sample characteristics

Pearson's correlation coefficients showed a weak negative relationship between carer unmet needs and carer age ($r = -0.201$, $p = 0.014$) and also with person with cancer age ($r = -0.201$, $p = 0.014$).

In unifactor analyses of the ten dyad characteristics selected for investigation, all but gender of carer and gender of person with cancer had significant associations with carer unmet needs ($p < 0.001$). There were statistically significant reductions in carer unmet needs associated with public hospitals in comparison to private hospitals, radiotherapy in comparison to chemotherapy, and increased ages of carers and persons with cancer (Table 4). There were statistically significant elevations in carer unmet needs associated with living apart in comparison to living together, haematological cancers as opposed to solid tumours, post-secondary levels of education in comparison to secondary level of education and parents caring for children in comparison to spouses caring for spouses.

Multifactor analyses further indicated no statistically significant associations of carer unmet needs with gender of either the carer or the person with cancer. Moreover, in models that included the ages of carers and persons with cancer, as well as the relationship factor, the age of the person with cancer was not statistically significant. Consequently, a 7-factor model was fitted with the gender factors and the age of persons with cancer excluded (Table 4) and while the associations with carer age, hospital type, living situation and cancer type that were noted in unifactor analyses, did not change appreciably in terms of Wald Test results and directionality, there were changes in the pairwise comparisons of levels within the remaining three factors – treatment, education and relationship of patient to carer. When each factor was dropped one at a time from the 7-factor model, the AIC increased by more than 10 units indicating an appreciable increase in lack of fit, apart from the education factor, for which an increase of <1 unit was observed and this was consistent with Wald Test results ($p < 0.001$ for all factors except education for which $p = 0.108$).

Table 1
Sample characteristics (*n* = 150, unless otherwise specified) of carer/person with cancer dyads.

	Carer characteristics *n* (%)	Person with cancer characteristics *n* (%)
Gender		
Male	70 (47)	61 (41)
Female	80 (53)	89 (59)
Age		
Mean (SD)	56.4 (12.6)	58.9 (12.7)
Range	21–84 years	23–82 years
Education	*n* = 149	
Primary school	1 (1)	
Secondary school	58 (39)	
Certificate or diploma	36 (24)	
University degree	54 (36)	
Relationship to person with cancer		
Spouse/partner	124 (83)	
Parent	15 (10)	
Child	5 (3)	
Other	6 (4)	
Living arrangements		
Together	132 (88)	
Not together	18 (12)	
Household size	*n* = 148	
Median (range)	2.0 (7)	
Cancer type		
Solid tumour total		128 (85)
Breast		65 (43)
Prostate/testicular		22 (15)
Bowel		11 (7)
Lung		9 (6)
Head & Neck		7 (5)
Other (e.g. ovarian, stomach)		14 (24)
Haematological tumour		22 (15)
Treatment type		
Chemotherapy		67 (45)
Radiotherapy		47 (31)
Combined		36 (24)
Hospital type		
Public		79 (53)
Private		71 (47)

4. Discussion

This analysis revealed new insights into the prevalence of carer unmet needs and psychological morbidity during adjuvant cancer treatment by examining the levels of unmet needs among carers of persons newly diagnosed with cancer who were receiving treatment with curative intent. This study further established the prevalence of depression in this population and investigated the relationship between depression and carer unmet needs.

Carers experienced significant levels of moderate/high unmet needs with more than half of carers (57%) reporting at least one unmet need and with 15% having at least ten unmet needs. The percentage of carers experiencing at least one unmet need in our study was higher compared to carers of cancer survivors and even palliative care patients, which ranged from one-third to almost half [6,8,11,16,28,29], but lower when compared to Kim et al. [19] who reported 68% prevalence of unmet needs in carers of persons diagnosed with colorectal cancer two months post-diagnosis. However, given the two months post-diagnosis assessment point only included colorectal cancer patients and their carers were primarily female (79%), generalisation of Kim et al.'s [19] findings to other cancer and carer groups is limited.

The most frequently reported unmet needs identified in our study were in the domains of information and health care service needs. Emotional and psychological needs were not dominant which was in contrast to the survivorship and palliative care literature where high unmet needs in this area were reported [4,6,12]. It is possible that during the treatment phase, carers' main focus

Table 2
Frequency and types of Carers' moderate/high unmet needs (n = 150).

Carer moderate or high unmet needs (% of carers answering 4 or 5 on each item)	(n) %
Mean 3.94 (SD 6.31)	
At least one unmet need	(86) 57
At least three unmet needs	(55) 37
At least five unmet needs	(46) 31
At least 10 unmet needs	(22) 15
Ten most frequently reported unmet needs	

Rank	Domain	Need item	(n) %
1	IN	Accessing information about the benefits and side-effects of treatments	(29) 19
2	IN	Accessing information on what the person with cancer's physical needs are likely to be	(28) 19
3	IN	Accessing information about the person with cancer's prognosis, or likely outcome	(27) 18
4	IN	Accessing information relevant to your needs as a carers/partners	(25) 17
5	IN	Finding out about financial support and government benefits	(22) 15
6	WSN	The impact that caring has had on your working life or usual activities	(21) 14
=6	HCSN	Obtaining the best medical care for the person with cancer	(21) 14
7	HCSN	Having opportunities to discuss your concerns with the doctors	(20) 13
8	HCSN	Reducing stress in the person with cancer's life	(19) 13
9	IN	Accessing information about alternative therapies	(18) 12
10	IN	Accessing information about support services for carers/partners of people with cancer	(17) 11

Note: IN = Information Needs, HCSN = Health Care Service Needs, WSN = Work and Social Needs.

Table 3
Relationship between carer unmet needs and depression (n = 149).

	SCNS-45 P&C	CES-D carer	CES-D person with cancer
Mean (SD)	3.9 (6.3)	11.9 (9.4)	14.5 (9.9)
SCNS-45 P&C		r = 0.30[**]	r = 0.12
CES-D Carer			r = 0.16

Note: SCNS-45 P&C = Supportive Care Needs Survey-45 Partners & Caregivers; CES-D = Centre for Epidemiologic Studies-Depression Scale.
  [**] Correlation is significant at the 0.001 level.

is on the well-being of the person with cancer whereas during the later phases of the cancer trajectory, carers' focus may shift to concerns regarding the patient's life expectancy as well as their own health with carers becoming more aware of the impact the cancer has had on themselves.

Nearly one third of carers in this study had a depression score of 16 or above (usual cut-off point) and were found at risk of clinical depression. The occurrence of depressive symptoms in our caregivers is higher compared to those found in community based samples where only 20% had a score of 16 or above on the CES-D [25]. Further, we found that the prevalence of moderate/high unmet needs was clearly related to carers' psychological morbidity which is consistent with the survivorship and palliative care literature [7,12,15,19,28]. Compared to unmet needs, caregivers' level of depressive symptoms was not associated with any demographic variable or person with cancers' depression scores. This is in line with Stafford et al. [28] who did not find a relationship between caregivers'

depression and patient depression or between any sample characteristics including patients' clinical features. In our study, only high/moderate unmet needs seemed to play a role in the existence of depressive symptoms in caregivers. Due to the cross-sectional nature of our analysis, it is unclear whether psychological distress preceded or followed unmet needs. Providing psychological support for carers during the early stages of treatment may be beneficial in reducing distress and subsequently alleviating unmet needs over time. On the other hand, making sure that caregivers' information and health service needs are being met may help to reduce the risk of depression in this group.

Moderate/high level of unmet needs were particularly common in carers of younger age and this corresponds with the existing survivorship and palliative care literature [19,30]. Our findings are also consistent with Mason [31] who studied unmet needs in female carers of patients with stage II prostate cancer shortly after surgery and found that carer age was negatively associated with levels of unmet needs. However, it is difficult

Table 4
Summary of poisson log-linear regression models for factors potentially associated with carer unmet needs.

Carer unmet needs	Factor level or units	Unifactor analyses					Multifactor analyses[1]				
		B estimate standard error (SE)	95% confidence interval (CI) lower, upper	Wald χ^2	p	Akaike Information Criterion (AIC)	B estimate SE	95% CI Lower, Upper	Wald χ^2	p	AIC[2]
Carer age	Years	−0.024 (0.003)	−0.030, −0.018	60.59	<0.001	1384.806	−0.039 (0.005)	−0.048, −0.030	74.09	<0.001	1199.071[3] (1274.547)
Hospital type (Reference level = Private)	Public	−0.608 (0.085)	−0.774, −0.441	51.28	<0.001	1390.705	−0.665 (0.104)	−0.869, −0.461	40.73	<0.001	(1238.331)
Living situation (Reference level = Together)	Not together	0.717 (0.100)	0.522, 0.912	51.80	<0.001	1398.878	1.087 (0.186)	0.722, 1.452	34.03	<0.001	(1231.450)
Cancer type (Reference level = Solid tumour)	Haematological	0.383 (0.103)	0.182, 0.584	13.95	<0.001	1430.911	0.635 (0.143)	0.356, 0.915	19.84	<0.001	(1216.213)
Treatment (Reference level = Chemotherapy)	Combined	−0.113 (0.097)	−0.304, 0.078	1.34	0.247	1395.540	0.589 (0.125)	0.344, 0.835	22.14	<0.001	(1218.831)
	Radiotherapy	−0.729 (0.110)	−0.945, −0.513	43.65	<0.001		0.153 (0.142)	−0.126, 0.432	1.16	0.282	
Education (Reference level = Secondary)	Certificate or diploma	0.507 (0.115)	0.282, 0.733	19.43	<0.001	1360.194	0.239 (0.122)	0.001, 0.478	3.87	0.049	(1199.433)
	University degree	0.673 (0.102)	0.473, 0.872	43.57	<0.001		0.067 (0.123)	−0.175, 0.308	0.29	0.590	
Relationship of patient to carer (Reference level = Spouse)	Child	0.750 (0.167)	0.423, 1.077	20.20	<0.001	1429.286	0.523 (0.220)	0.092, 0.955	5.64	0.018	(1250.581)
	Other	0.236 (0.195)	−0.146, 0.618	1.47	0.225		−1.153 (0.266)	−1.674, −0.632	18.82	<0.001	
	Parent	0.192 (0.131)	−0.064, 0.449	2.16	0.142		−1.079 (0.204)	−1.479, −0.680	28.04	<0.001	
Person-with-cancer age	Years	−0.024 (0.003)	−0.030, −0.018	60.59	<0.001	1384.852	0.012 (0.009)	−0.005, 0.030	1.90	0.168	[1199.177]
Gender of carer (Reference level = Male)	Female	0.087 (0.083)	−0.075, 0.250	1.11	0.291	1442.694	0.174 (0.104)	−0.031, 0.378	2.78	0.095	[1198.300]
Gender of person-with-cancer (Reference level = Male)	Female	0.102 (0.085)	−0.064, 0.268	1.44	0.230	1442.359	−0.174 (0.108)	−0.385, 0.037	2.61	0.106	[1198.475]

[1] The selected multifactor model included 7 factors (carer age, hospital type, living situation, cancer type, treatment, education and relationship of patient to carer).
[2] AIC values in parentheses () refer to the 6-factor models obtained by deleting the corresponding factor. AIC values in square brackets [ ] refer to the 8-factor models obtained by incorporating the corresponding factor into the final model – estimates and Wald Test results are also presented for these three additional factors.
[3] AIC for the 7-factor model.

to compare their results with ours as their study focused on female carers aged 40+ years and did not include carers of younger age. We also found that parents who were looking after their adult child with a diagnosis of cancer experienced greater amounts of moderate/high unmet needs compared to spouses caring for their spouses. In addition, carers who did not live in the same residence as the person with cancer experienced higher unmet needs than those who lived in the same household. Therefore, tailored interventions are needed to address carer needs that are specific to their relationship with the person they are caring for.

We also found that the level of moderate/high unmet needs experienced by carers correlated significantly with specific variables related to the person with cancer. Those carers who were looking after a person diagnosed with a solid cancer versus a haematological cancer, reported significantly fewer unmet needs. This is in contrast to previous studies investigating this relationship in carers of cancer survivors where no significant associations were found [5,28]. However, to date only few studies have investigated such a relationship and more research is needed to draw reliable conclusions. Further, carers of persons receiving radiotherapy compared to those receiving chemotherapy reported significantly fewer unmet needs. This suggests that the severity of toxicity in chemotherapy correlates with the level of unmet needs experienced by carers. Further research is needed to also explore the relationship between carer unmet needs and the chance of cure.

In addition, carers looking after a person admitted to a public hospital for cancer treatment experienced fewer unmet needs compared to those where the person was admitted to a private health service. Interestingly, Nikoletti at al. [20] also reported increased numbers of unmet needs in carers of newly diagnosed stage I–III breast cancer patients admitted to a private hospital in Western Australia compared to carers of patients admitted to a public health service. More research is needed to further explore the specific aspects of the model of care delivery in the private health sector that may be associated with higher levels of unmet needs in carers.

Findings of the present analysis should be interpreted in light of limitations. The relatively low participation rate of 34% as well as the distribution of certain cancer types may limit the generalisability of our findings. For example, compared to the incidences of common cancers in the Australian population [32] (breast: 28%, prostate: 30%, bowel: 13%, lung: 9%), in our sample breast cancer (43%) was over-represented, while prostate (15%) and bowel (7%) cancer were under-represented and the incidence of lung cancer (6%) was slightly lower to that of the Australian population [32]. In addition, the cross-sectional design precluded causal interpretations of results. However, the aim of this analysis was to undertake a snapshot of unmet needs during the early treatment phase when carers assume their carer responsibilities. Through extensive consultations with oncologists and clinical staff, it was decided not to approach dyads during their first treatment session as it was considered an overwhelming experience for the dyad. Thus, dyads were approached during treatment cycle 2–5 (chemotherapy) or fraction 2–10 (radiotherapy). It could be possible that levels of unmet needs or depression may have been higher if dyads were recruited into the study earlier.

Findings highlight the importance of providing adequate support to address the diversity of carers' needs and to reduce the level of depressive symptoms at the early stages of treatment, thereby ensuring sustainable provision of care and support to the patient. In addition, more research to investigate the specific aspects of the model of care delivery in the Australian private health sector that may be associated with higher levels of unmet needs in carers would be beneficial.

Role of the funding source

Conflict of interest statement

None declared.

Acknowledgements

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