



ORIGINAL ARTICLE

Supporting the Supporters: What are the Unmet Needs and Quality of Life of Caregivers of Cancer Patients in Singapore?

Gek Phin Chua^{1*}, Quan Sing Ng², Hiang Khoon Tan³ and Whee Sze Ong⁴

¹CEIS (Research & Data), National Cancer Centre Singapore, Singapore

²Division of Medical Oncology, National Cancer Centre Singapore, Singapore

³Division of Surgery and Surgical Oncology, National Cancer Centre Singapore, Singapore

⁴Division of Clinical Trials and Epidemiological Sciences, National Cancer Centre Singapore, Singapore

*Corresponding author: Gek Phin Chua, CEIS (Research & Data), National Cancer Centre Singapore, 11 Hospital Crescent, Singapore 169610, Singapore, Tel: +65-6236-9448, Fax: +65-6536-5503



Abstract

Background: Caregivers of cancer patients may assume diverse responsibilities during the patient's cancer trajectory, providing physical assistance, emotional and financial support. These responsibilities can be highly demanding, emotionally stressful and financially draining and can impact on the caregivers' quality of life (QOL).

This study aims to determine the unmet needs of caregivers of cancer patients in Singapore and establish if the unmet needs are associated with their QOL in order to guide practice.

Methods: A cross-sectional survey was conducted with 986 caregivers of cancer patients. Determinants of caregivers' unmet needs and QOL were assessed by the Support Person Unmet Needs Survey (SPUNS-SF) and the Singapore version of the Caregiver Quality of Life Index-Cancer (CQOLC-S25).

Results: The mean overall score of unmet needs was 20.98 ± 20.1 . The top 3 items with the highest mean score of unmet needs were all from the "Future" domain viz. "dealing with worry about cancer getting worse" (1.50 ± 1.4), "dealing with not knowing what lies in the future" (1.43 ± 1.3) and "dealing with worry about cancer coming back" (1.20 ± 1.3). Caregivers who were younger, the primary caregivers, caregivers who provided financial assistance to the patients they cared for, caregivers whose health status were made worse by caregiving activities, caregivers who were taking care of female patients, lung cancer patients and patients on palliative care had significantly higher mean overall score of unmet needs. The mean overall QOL score was 71.34 ± 17.5 . The overall QOL scores were negatively correlated with

the overall scores of unmet needs. There were significant negative correlation between QOL and all domains of unmet needs.

Conclusion: Our results demonstrate that caregivers of cancer have many unmet needs and these unmet needs have a significant negative effect on their QOL. Thus, addressing their unmet needs is critical to enhance their coping skills and ultimately their QOL.

Keywords

Caregivers, Cancer, Oncology, Quality of life, Unmet needs

Abbreviations

QOL: Quality of Life; NCCS: National Cancer Centre Singapore; CIRB: Centralised Institutional Review Board; SPUNS-SF: Support Person's Unmet Needs Survey - Short Form; CQOLC-S25: Caregiver Quality of Life Index - Cancer - Singapore version; ANOVA: Analysis of Variance; FOR: Fear of Recurrence

Introduction

Cancer is a major cause of morbidity and mortality worldwide and in the year 2018, cancer claimed 9.6 million lives worldwide, accounting for 1 in 6 deaths globally [1]. Similarly, in Singapore, an young island nation situated at the southern tip of the Malayan Peninsula, cancer is the leading cause of death accounting for 29.7% of deaths in 2015 [2]. The three most common types of cancers in men are colorectal, lung and prostate cancers, while the three most common types of cancers

in women are breast, colorectal and lung cancers [2]. Singapore is a multi-racial and multi-cultural country, consisting of Chinese (76.2%), Malays (15%) and Indians (7.4%) [3].

Unlike many other diseases, cancer is a complex disease and demands intense treatment and its resultant side-effects can be life-long. Cancer not only represents a crisis for the patient but also affects those close to them, encompassing partners, family members and close friends [4,5]. They may assume diverse responsibilities throughout the cancer patient's trajectory and are thus, an invaluable source of support to individual with cancer in their adaptation and coping process [6,7]. Caregiving for cancer patients constitutes both tangible assistance such as personal care activities, changing dressings, medication administration and monitoring side effects, symptom management, feeding, meal preparation; and intangible assistance, such as providing emotional, social, financial and spiritual support, decision making and communication with healthcare professionals and family members [7-9]. These responsibilities which can be highly demanding, physically and emotionally stressful and financially draining can impact the caregivers' quality of life (QOL). Studies have shown that family caregivers actually experience as much distress as the patients, if not more [9-11]. Evidence in literature also attests to the heightened burden placed not only on primary caregivers but also on informal caregivers and its impact on both mental and physical health outcomes [9,11-13].

The distress and burden for caring for a person with cancer may be higher in the Asian society than the Western society. Asian society has expectations that differ from Western society. Whereas, Western society emphasizes independence as a means of maintaining self-esteem, in the Asian context, families are more involved in caring for one another. Asian society promotes filial piety, social cohesion, family harmony and interdependence where the family members assume a greater role in caring for its members, especially the elderly, sick or disabled. Hence, the family is expected to take on the role of informal caregiving including but not limited to providing physical care, emotional, social and financial support and decision making.

The four general categories of caregiver needs identified are: 1) Information; 2) Personal and emotional; 3) Work and finance; and 4) Healthcare access and continuity [7,13-18] and studies revealed that a substantial percentage of caregivers have unmet needs while providing their complex roles of caregiving [4,9,15,19-26]. A study in Germany by Sklenarova, et al. [4] on 188 primary caregivers of lung, urological and gastrointestinal cancers found only 24.4% had no unmet needs while 43.6% reported having > 10 unmet needs. Items of unmet needs identified were the need for support in: 1) Addressing fears about the patient's physical or mental

deterioration (52.7%); 2) Managing concerns about cancer coming back (44.6%); and 3) Working through your feelings about death and dying (40.8%). In Korea, Kim & Yi [21] reported the prevalence of unmet needs was high and ranged from 57% to 88.9%, depending on the domain. The highest rates of unmet needs were in domains of: 1) Healthcare staff (88.9%) e.g. seeing a doctor quickly and easily when in need; 2) Information (84%) e.g. information about the current status of patient's illness and its future course (84%); and 3) Hospital facilities/services (78.8%). Heckel, et al. [23] study in 4 Australian Hospitals established that caregivers experienced significant levels of moderate/ high unmet needs with more than half of caregivers (57%) reporting at least one unmet need and with 15% having at least 10 unmet needs. The majority of unmet needs were in the domains of information and health care service needs. In a recent study in Iran on 200 family caregivers, Ashrafi, et al. [15] found that the 3 most important needs of the family caregivers were in the domain of: 1) Information, 2) Healthcare staff (physicians and nurses), and 3) Health and psychological problems. Although studies have established the unmet needs of caregivers of cancer patients; however, there were conflicting findings [15,20,21,27] which may be due to the setting, the sample, sampling method and sample size. Besides, family caregiving in Singapore may differ from other countries because of the different attitudes, norms, practices and expectations including the healthcare financing system. There is also no reported study on the unmet needs and QOL of caregivers of cancer patients in the local setting. Besides, without assessing caregivers' unmet needs, their personal well-being and own health may be at risk, which may, in turn, jeopardize their ability to continue providing care and support for the cancer patient. In view of the unique role they play in supporting the cancer patients and the adverse consequences to their personal health due to their unmet needs, the identification of caregivers' unmet needs and QOL would be helpful in directing and developing strategies and programmes to help and support caregivers in carrying out their important and often vital role.

The purpose of the current study was to determine the unmet needs and QOL of caregivers of cancer patients in Singapore. The specific aims were:

- To determine the unmet needs and QOL of caregivers of cancer patients.
- To assess if the unmet needs of caregivers were associated with their QOL.
- To identify those caregivers whose needs were less likely to be met based on demographic characteristics.

Methods

Design, Sample and Setting

This was a cross-sectional survey study conducted at the National Cancer Centre Singapore (NCCS) between 10 September and 7 December 2018. The targeted sample size of the survey was 400 respondents, and this was determined such that the margin of errors of a 95% confidence interval for a population proportion would be kept at a maximum of 5%.

Eligible caregivers to participate in this survey were identified based on the National Cancer Institute's definition of "family caregiver" [28]. These were unpaid individuals who might be the parents, children, spouses, relatives, or friends who were helping cancer patients with their activities of daily living and healthcare needs (including coping with the disease process at home). Caregivers must be able to read and/or write English or Mandarin, and the cancer patients they were providing care to have attended the National Cancer Centre Singapore (NCCS) for at least one month. Domestic maids or helpers who were paid to take care of the patients and caregivers of walk-in patients were excluded from the study.

The research assistants confirmed the eligibility criteria of each potential eligible caregiver with the patients during their clinic visit. Eligible caregivers who accompanied the patients during their clinic visit were invited to participate in the survey and given the questionnaire to complete. Explanation was given about the purpose of the study, the voluntary nature and procedures including how to fill up the questionnaire. For those patients whose caregivers met the eligibility criteria but did not accompany the patients during their clinic visit, the questionnaire with its explanatory note was given to the patients in a pre-paid envelope to bring home for the caregivers to complete.

Ethics and consent to participate: Ethical consent was obtained from the SingHealth Centralised Institutional Review Board (CIRB) prior to the study. Waiver of written informed consent was obtained as no personal identifiers of respondents were obtained.

Instruments

Demographic and patient-related characteristics: These caregiver-related characteristics were collected: Age, sex, race, marital status, highest education level attained, economic status, monthly household income, housing type, relationship to cancer patient, whether living with cancer patient, type of caregiver, duration of care provision, type of care provided, time spent per week providing care, health status and impact of care provision on health status of caregiver.

These patient-related characteristics were collected: Age, sex, marital status, type of cancer, time since cancer diagnosis, disease stage, current cancer trajectory stage and treatment received in the last month prior to survey.

Unmet needs: The SPUNS-SF developed and validated by Campbell and colleagues [29] contained 26 items which assessed a caregiver's unmet needs in 6 domains viz. (i) Information (6 items); (ii) Personal (4 items); (iii) Emotional (3 items); (iv) Work and finance (5 items); (v) Healthcare access and continuity (5 items); and (vi) Concerns about the future (3 items). An unmet need was a need that the caregiver has not been able to satisfy on his or her own, and required professional support. A 5-point Likert response scale was used to measure the extent of unmet needs (0 = no unmet needs, 1 = low unmet needs, 2 = moderate unmet needs, 3 = high unmet needs, and 4 = very high unmet needs) of a caregiver on each item in the past month prior to the survey. Cronbach's alphas co-efficient for all subscales were ≥ 0.87 [29].

Quality of life: The CQOLC-S25 is developed and validated by Mahendran and colleagues [30] contained 25 items which assessed a caregiver's QOL in 5 domains: (i) Burden (8 items); (ii) Physical and practical concerns (5 items); (iii) Emotional reactivity (4 items); (iv) Self-needs (4 items); and (v) Social support (4 items). A 5-point Likert response scale was used to measure how true was each item (0 = not at all, 1 = somewhat, 2 = a little bit, 3 = quite a bit, and 4 = very much) to a caregiver in the past week prior to the survey. The Cronbach alpha coefficient has been found to be 0.89 [30].

Statistical analysis

Scoring of SPUNS-SF and CQOLC-S25 were performed according to the guidelines of each survey instrument. The overall score of unmet needs was the sum of all the responses to the 26 SPUNS-SF items, and ranged from 0 to 104. The higher the overall score of unmet needs, the higher the level of unmet needs. The overall QOL score was the sum of all the responses to the 25 CQOLC-S25 items, and ranged from 0 to 100. The items in the burden, physical and practical concerns, emotional reactivity and self-needs domain were reverse-coded and scored accordingly (i.e. a "0 = not at all" response was allocated 4 points, "1 = somewhat" response was allocated 3 points, "2 = a little bit" response was allocated 2 points, "3 = quite a bit" response was allocated 1 point, and "4 = very much" response was allocated 0 point) so that a higher overall QOL score would reflect a better QOL. Descriptive statistics were used to summarise the data. Differences in mean overall score of unmet needs by caregiver and patient characteristics were assessed based on one-way Analysis of Variance (ANOVA), and independent predictors of overall score of unmet needs were identified based on multiple linear regression analyses. Corresponding analyses were performed for overall QOL score. Pearson's correlation coefficient (r) was used to assess the extent of linear correlation between the overall score of unmet needs and the overall QOL score. All analyses were performed using SAS version 9.4 [31].

Results

Response rate and caregiver and patient characteristics

A total of 2498 caregivers were eligible to participate in the survey, of which 1250 (50%) filled up and returned their survey forms to the study team. Only 986 responded caregivers completed all the questions in the 2 sections and were included in the analysis population.

Of the 986 analysed caregivers, median age was 41 years (range, 14-84 years) and 55% were female (Table 1). Majority of the caregivers had at least a post-sec-

Table 1: Characteristics of caregivers.

Variable	Category	(N = 986)	
		No.	%
Age, years	≤ 30	216	21.9
	> 30 - ≤ 40	223	22.6
	> 40 - ≤ 50	224	22.7
	> 50 - ≤ 60	146	14.8
	> 60	98	9.9
	Missing	79	8.0
	Median (range) ¹	41 (14-84)	
Sex	Male	441	44.7
	Female	538	54.6
	Missing	7	0.7
Race	Chinese	720	73.0
	Malays	145	14.7
	Indians	59	6.0
	Others	42	4.3
	Missing	20	2.0
		Missing	20
Marital status	Single	363	36.8
	Married	575	58.3
	Widowed	9	0.9
	Divorced/separated	22	2.2
	Missing	17	1.7
Highest education Attained	No formal education	13	1.3
	Primary	35	3.5
	Secondary	130	13.2
	Post-secondary	301	30.5
	Tertiary	482	48.9
	Missing	25	2.5
Economic status	Full time	607	61.6
	Part time	52	5.3
	Schooling	63	6.4
	Unemployed	48	4.9
	Retired	78	7.9
	Homemaker	74	7.5
	Others	32	3.2
	Missing	32	3.2

Gross monthly household income, \$	Not applicable	253	25.7
	≤ 1000	23	2.3
	> 1000 - ≤ 2000	37	3.8
	> 2000 - ≤ 3000	73	7.4
	> 3000 - ≤ 4000	103	10.4
	> 4000 - ≤ 6000	171	17.3
	> 6000 - ≤ 8000	102	10.3
	> 8000 - ≤ 10000	44	4.5
	> 10000	72	7.3
	Missing	108	11.0
Housing type	HDB 1- & 2-room flats	18	1.8
	HDB 3-room flats	137	13.9
	HDB 4-room flats	326	33.1
	HDB 5-room flats	259	26.3
	Private housing	201	20.4
	Missing	45	4.6
Relationship to cancer patient	Parent	60	6.1
	Child	500	50.7
	Sibling	71	7.2
	Spouse/partner	218	22.1
	Friend	24	2.4
	Others	94	9.5
	Missing	19	1.9
Living with cancer patient	Yes	609	61.8
	No	357	36.2
	Missing	20	2.0
No. of household members (among caregivers who lived with their patients)	Median (range) ¹	4 (1-10)	
Type of caregiver	Primary	275	27.9
	Non-primary	673	68.3
	Missing	38	3.9
Duration of care, years	≤ 0.5	227	23.0
	> 0.5 - ≤ 1	148	15.0
	> 1 - ≤ 3	209	21.2
	> 3 - ≤ 5	140	14.2
	> 5	234	23.7
	Missing	28	2.8
Type of care			
Companionship	Yes	901	91.4
	No	61	6.2
	Missing	24	2.4
Transportation	Yes	760	77.1
	No	202	20.5
	Missing	24	2.4
Homemaking	Yes	431	43.7
	No	531	53.9
	Missing	24	2.4

Personal care Assistance	Yes	125	12.7
	No	837	84.9
	Missing	24	2.4
Healthcare assistance	Yes	255	25.9
	No	707	71.7
	Missing	24	2.4
Financial assistance	Yes	470	47.7
	No	492	49.9
	Missing	24	2.4
Others	Yes	8	0.8
	No	954	96.8
	Missing	24	2.4
Time spent on caregiving per week, hours	≤ 5	184	18.7
	> 5 - ≤ 20	358	36.3
	> 20 - ≤ 40	162	16.4
	> 40	249	25.3
	Missing	33	3.3
Health status	Excellent	242	24.5
	Good	405	41.1
	Satisfactory	285	28.9
	Poor	23	2.3
	Missing	31	3.1
Impact of caregiving on health status	Made it better	51	5.2
	Did not affect it	814	82.6
	Made it worse	87	8.8
	Missing	34	3.4

¹Among patients with non-missing data.

Table 2: Characteristics of cancer patients.

Variable	Category	Analysed (N = 986)	
		No.	%
Age, years	≤ 40	85	8.6
	> 40 - ≤ 50	109	11.1
	> 50 - ≤ 60	193	19.6
	> 60 - ≤ 70	237	24.0
	> 70 - ≤ 80	200	20.3
	> 80	64	6.5
	Missing	98	9.9
	Median (range) ¹	63 (13-95)	
Sex	Male	327	33.2
	Female	645	65.4
	Missing	14	1.4
Marital status	Single	108	11.0
	Married	657	66.6
	Widowed	156	15.8
	Divorced/separated	39	4.0
	Missing	26	2.6
Type of cancer			
	Breast		
	Yes	265	26.9
	No	694	70.4

	Missing	27	2.7
Lung	Yes	120	12.2
	No	839	85.1
	Missing	27	2.7
Prostate	Yes	58	5.9
	No	901	91.4
	Missing	27	2.7
Colon & rectum	Yes	112	11.4
	No	847	85.9
	Missing	27	2.7
Liver	Yes	62	6.3
	No	897	91.0
	Missing	27	2.7
Brain	Yes	26	2.6
	No	933	94.6
	Missing	27	2.7
Cervix	Yes	61	6.2
	No	898	91.1
	Missing	27	2.7
Uterus	Yes	58	5.9
	No	901	91.4
	Missing	27	2.7
asopharyngeal	Yes	33	3.3
	No	926	93.9
	Missing	27	2.7
Stomach	Yes	50	5.1
	No	909	92.2
	Missing	27	2.7
Kidney	Yes	13	1.3
	No	946	95.9
	Missing	27	2.7
Lymphoma	Yes	54	5.5
	No	905	91.8
	Missing	27	2.7
Pancreas	Yes	22	2.2
	No	937	95.0
	Missing	27	2.7
Others	Yes	122	12.4
	No	837	84.9
	Missing	27	2.7
Cancer stage	Stage 0	43	4.4
	Stage I	77	7.8
	Stage II	215	21.8
	Stage III	214	21.7
	Stage IV	293	29.7
	Missing	144	14.6
Time since diagnosis, years	< 5	738	74.8
	≥ 5 - < 10	142	14.4
	≥ 10	74	7.5
	Missing	32	3.2

Cancer trajectory	Active treatment	523	53.0
	Completed treatment	209	21.2
	Cancer-free status	103	10.4
	Dealing with relapse	80	8.1
	Palliative care	13	1.3
	Others	22	2.2
	Missing	36	3.7
Had treatment in last month	Yes	800	81.1
	No	159	16.1
	Missing	27	2.7
Had FU visit to cancer clinic	Yes	393	39.9
	No	566	57.4
	Missing	27	2.7
Treatment received			
Surgery	Yes	91	9.2
	No	868	88.0
	Missing	27	2.7
Chemotherapy	Yes	448	45.4
	No	511	51.8
	Missing	27	2.7
Radiation therapy	Yes	112	11.4
	No	847	85.9
	Missing	27	2.7
Hormonal Therapy	Yes	49	5.0
	No	910	92.3
	Missing	27	2.7
Antibody Treatment	Yes	33	3.3
	No	926	93.9
	Missing	27	2.7
Others	Yes	28	2.8
	No	931	94.4
	Missing	27	2.7

¹Among patients with non-missing data.

ondary education (79%) and were working (70%). Half of the caregivers were providing care to their parents, and another 22% were taking care of their spouses or partners. Most of the caregivers were the non-primary caregiver of the patients they cared for (68%), and had been taking care of their patients for > 1 year (59%). The most common type of care provided was companionship (91%), followed by transportation (77%) and financial assistance (48%). The health status of majority of the caregivers (83%) was not affected by their caregiving activities.

The median age of patients was 63 years (range, 13-95 years) and 65% were female (Table 2). Slightly more than a quarter (27%) of the patients was diagnosed with breast cancer, 12% with lung cancer and 11% with col-

orectal cancer. About half of the patients' disease were in advanced stage - 22% were in stage 3 and 30% were in stage 4. In terms of cancer trajectory, 53% were on active treatment, 31% had completed treatment and were cancer-free, and 8% were dealing with recurrence or second cancers.

Unmet needs of caregivers

The mean overall score of unmet needs was 20.98 ± 20.1 (Table 3). The top 3 items with the highest mean score of unmet needs were all from the "Future" domain. The top item was "dealing with worry about cancer getting worse" (1.50 ± 1.4), followed by "dealing with not knowing what lies in the future" (1.43 ± 1.3) and "dealing with worry about cancer coming back" (1.20 ± 1.3). On the other hand, the 3 items with the lowest mean score of unmet needs were mostly from the "Information" domain: "finding information about cancer and its impact on sexual relationship" (0.44 ± 0.8), "dealing with the way co-workers feel about my situation" (0.50 ± 0.9) and "being about to talk openly on feelings/worries with healthcare professional" (0.65 ± 0.9).

One-way ANOVA revealed that there were significant differences in the mean overall score of unmet needs by several characteristics of caregivers and patients (Table 4). On multiple linear regression analysis, caregivers who were younger ($P = 0.001$), the primary caregivers ($P < 0.001$), caregivers who provided financial assistance to the patients they cared for ($P = 0.007$), caregivers whose health status were made worse by caregiving activities ($P < 0.001$), caregivers who were taking care of female patients ($P = 0.004$), lung cancer patients ($P = 0.013$) and patients on palliative care ($P < 0.001$) had significantly higher mean overall score of unmet needs. This multivariable model, though statistically significant ($P < 0.001$), was only able to explain 22.6% of the variance in the overall scores of unmet needs.

Quality of life of caregivers

The mean overall QOL score was 71.34 ± 17.5 (Table 5). The 3 items with the lowest mean QOL score were mostly from the "Social support" domain: "family communication has increased" (1.68 ± 1.4), "I have developed a closer relationship with my loved one" (1.86 ± 1.5), and "I fear my loved one will die" (2.07 ± 1.6). The 3 items with the highest mean QOL score was "I feel guilty" (3.40 ± 1.1), "the need to protect my loved one bothers me" (3.35 ± 1.1) and "it bothers me that I need to be available to chauffeur my loved one to appointments" (3.33 ± 1.1).

The overall QOL scores were negatively correlated with the overall scores of unmet needs ($r = -0.76$; $P < 0.001$) (Figure 1). There were significant negative correlation between QOL and all the domains of unmet needs. The unmet needs domain with the highest cor-

Table 3: Unmet needs of caregivers.

Domain	Item	Total		No		Low		Moderate		High		Very high		Score		Rank ¹
		No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	Mean	SD			
Information	Finding info about how to manage illness at home	986 (100)	539 (54.7)	194 (19.7)	187 (19.0)	57 (5.8)	9 (0.9)	0.79 (1.0)	16 ²							
	Finding info about cancer and its impact on sexual relationships	986 (100)	713 (72.3)	137 (13.9)	110 (11.2)	24 (2.4)	2 (0.2)	0.44 (0.8)	26							
	Being able to talk openly on feelings/worries with healthcare professional	986 (100)	594 (60.2)	191 (19.4)	158 (16.0)	39 (4.0)	4 (0.4)	0.65 (0.9)	24							
Personal	Finding info about complementary/alternative therapies	986 (100)	490 (49.7)	197 (20.0)	195 (19.8)	85 (8.6)	19 (1.9)	0.93 (1.1)	8							
	Finding info about long-term effects of treatment & medications	986 (100)	477 (48.4)	202 (20.5)	202 (20.5)	90 (9.1)	15 (1.5)	0.95 (1.1)	6 ²							
	Knowing how to speak openly about cancer with the person I support	986 (100)	520 (52.7)	211 (21.4)	172 (17.4)	62 (6.3)	21 (2.1)	0.84 (1.1)	11							
Emotional	Not sleeping well	986 (100)	510 (51.7)	213 (21.6)	178 (18.1)	65 (6.6)	20 (2.0)	0.86 (1.1)	10							
	Dealing with feeling stressed	986 (100)	467 (47.4)	219 (22.2)	195 (19.8)	80 (8.1)	25 (2.5)	0.96 (1.1)	6 ²							
	Dealing with worries about emotional well-being of your family	986 (100)	449 (45.5)	215 (21.8)	198 (20.1)	98 (9.9)	26 (2.6)	1.02 (1.1)	4							
Work & Finance	Working around the house (cooking, cleaning, home repairs)	986 (100)	630 (63.9)	191 (19.4)	111 (11.3)	44 (4.5)	10 (1.0)	0.59 (0.9)	22							
	Knowing that I am doing the best I can	986 (100)	580 (58.8)	204 (20.7)	138 (14.0)	52 (5.3)	12 (1.2)	0.69 (1.0)	18							
	Dealing with feeling like I'm letting the person I support down	986 (100)	577 (58.5)	219 (22.2)	128 (13.0)	50 (5.1)	12 (1.2)	0.68 (1.0)	19 ²							
Access & continuity of healthcare	Finding meaning in this experience	986 (100)	565 (57.3)	213 (21.6)	142 (14.4)	46 (4.7)	20 (2.0)	0.73 (1.0)	16 ²							
	Getting my boss to be more supportive & understanding	986 (100)	635 (64.4)	150 (15.2)	134 (13.6)	47 (4.8)	20 (2.0)	0.65 (1.0)	15							
	Being able to keep on working	986 (100)	656 (66.5)	146 (14.8)	110 (11.2)	53 (5.4)	21 (2.1)	0.62 (1.0)	14							
Future	Paying non-medical costs (e.g. travel, special food)	986 (100)	606 (61.5)	146 (14.8)	136 (13.8)	68 (6.9)	30 (3.0)	0.75 (1.1)	9							
	Dealing with the way co-workers feel about my situation	986 (100)	698 (70.8)	135 (13.7)	111 (11.3)	29 (2.9)	13 (1.3)	0.50 (0.9)	25							
	Finding and getting financial help	986 (100)	552 (56.0)	171 (17.3)	153 (15.5)	67 (6.8)	43 (4.4)	0.86 (1.2)	5							
Overall	Having access to a variety of healthcare services and providers	986 (100)	610 (61.9)	178 (18.1)	145 (14.7)	43 (4.4)	10 (1.0)	0.65 (1.0)	23							
	Getting appointments with healthcare providers quickly enough	986 (100)	600 (60.9)	178 (18.1)	130 (13.2)	63 (6.4)	15 (1.5)	0.70 (1.0)	13							
	Making sure the person I support could see the same healthcare professional at each follow-up visit	986 (100)	623 (63.2)	187 (19.0)	114 (11.6)	45 (4.6)	17 (1.7)	0.63 (1.0)	19 ²							
Overall	Having enough time with the doctor	986 (100)	618 (62.7)	188 (19.1)	119 (12.1)	50 (5.1)	11 (1.1)	0.63 (1.0)	21							
	Getting test results for the person I support quickly enough	986 (100)	578 (58.6)	183 (18.6)	145 (14.7)	60 (6.1)	20 (2.0)	0.74 (1.1)	12							
	Dealing with worry about cancer coming back	986 (100)	428 (43.4)	180 (18.3)	206 (20.9)	101 (10.2)	71 (7.2)	1.20 (1.3)	3							
Overall	Dealing with worry about the cancer getting worse	986 (100)	343 (34.8)	169 (17.1)	216 (21.9)	155 (15.7)	103 (10.4)	1.50 (1.4)	1							
	Dealing with not knowing what lies in the future	986 (100)	348 (35.3)	184 (18.7)	231 (23.4)	131 (13.3)	92 (9.3)	1.43 (1.3)	2							
								20.98 (20.1)								

¹ Based on the percentage of caregivers who reported "high or very high" unmet needs; ² Tie

Table 4: Mean overall score of unmet needs of caregivers.

Variable	Category	Univariate analysis				Multiple analysis		
		No.	Mean score (SD)	Difference (95% CI)	p-value	Adj. mean score	Difference (95% CI)	p-value
Age, years	≤ 30	216	22.2 (21.1)	7.4 (2.7, 12.1)	0.003	35.4	9.4 (3.8, 15.0)	0.001
	> 30 - ≤ 40	223	23.0 (19.2)	8.2 (3.5, 12.9)		31.2	5.2 (-0.4, 10.7)	
	> 40 - ≤ 50	224	20.0 (19.8)	5.2 (0.5, 9.8)		29.5	3.5 (-2.2, 9.2)	
	> 50 - ≤ 60	146	18.0 (18.7)	3.2 (-1.8, 8.3)		26.0	0.0 (-6.1, 6.2)	
	> 60	98	14.8 (18.3)	reference		26.0	Reference	
Sex	Male	441	21.6 (21.2)	1.1 (-1.4, 3.7)	0.375			
	Female	538	20.5 (19.1)	reference				
Race	Chinese	720	21.5 (20.4)	-6.4 (-12.7, -0.2)	0.027			
	Malays	145	18.5 (17.7)	-9.5 (-16.4, -2.6)				
	Indians	59	17.8 (18.9)	-10.1(-18.1, -2.2)				
	Others	42	27.9 (23.2)	reference				
Marital status	Single	363	20.3 (19.3)	1.7 (-5.7, 9.1)	0.464			
	Married	575	21.7 (20.7)	3.1 (-4.2, 10.4)				
	Widowed/divorced/separated	31	18.5 (18.0)	reference				
Highest education attained	No formal education/Primary	48	26.2 (25.5)	3.1 (-2.8, 9.0)	< 0.001			
	Secondary	130	18.2 (19.2)	-4.9 (-8.7, -1.0)				
	Post-secondary	301	17.8 (18.6)	-5.3 (-8.2, -2.4)				
	Tertiary	482	23.1 (20.1)	reference				
Economic status	Full time	607	22.2 (19.8)	-3.3 (-10.5, 3.8)	0.018			
	Part time	52	20.4 (19.0)	-5.2 (-14.0, 3.7)				
	Schooling	63	15.0 (17.8)	-10.5 (-19.1, -2.0)				
	Unemployed	48	24.2 (22.4)	-1.3 (-10.3, 7.6)				
	Retired	78	16.3 (20.6)	-9.3 (-17.5, -1.0)				
	Homemaker	74	19.5 (20.5)	-6.1 (-14.4, 2.3)				
	Others	32	25.6 (23.7)	reference				
Gross monthly household income, \$	Not applicable	253	16.4 (18.9)	-4.9 (-10.0, 0.2)	< 0.001			
	≤ 2000	60	28.5 (20.5)	7.2 (0.5, 13.9)				
	> 2000 - ≤ 3000	73	24.8 (23.6)	3.6 (-2.8, 9.9)				
	> 3000 - ≤ 4000	103	18.6 (17.7)	-2.7 (-8.6, 3.1)				
	> 4000 - ≤ 6000	171	21.5 (20.2)	0.2 (-5.2, 5.6)				
	> 6000 - ≤ 8000	102	18.9 (16.3)	-2.4 (-8.3, 3.5)				
	> 8000 - ≤ 10000	44	27.0 (22.2)	5.7 (-1.6, 13.0)				
	> 10000	72	21.3 (18.9)	reference				
Housing type	HDB 1- to 3-room	155	21.9 (20.9)	0.9 (-3.4, 5.1)	0.927			
	HDB 4-rooms	326	20.6 (20.1)	-0.5 (-4.0, 3.1)				
	HDB 5-rooms	259	21.1 (19.9)	0 (-3.7, 3.7)				
	Private housing	201	21.1 (19.6)	reference				
Relationship to cancer patient	Parent	60	25.8 (21.7)	9.7 (3.5, 15.9)	< 0.001			
	Child	500	23.2 (19.9)	7.1 (3.1, 11.1)				
	Sibling	71	17.4 (18.6)	1.3 (-4.6, 7.1)				
	Spouse/partner	218	18.6 (20.4)	2.5 (-2.0, 6.9)				
	Friend/others	118	16.1 (18.5)	reference				
Living with cancer patient	Yes	609	21.1 (20.3)	0.1 (-2.5, 2.7)	0.953			
	No	357	21.0 (19.8)	reference				
Type of Caregiver	Primary	275	29.1 (22.3)	11.6 (8.9, 14.3)	< 0.001	32.8	6.4 (3.1, 9.8)	< 0.001
	Non-primary	673	17.5 (18.0)	reference		26.4	Reference	

Duration of care, years	≤ 0.5	227	24.9 (21.8)	10.3 (6.7, 13.9)	< 0.001			
	> 0.5 - ≤ 1	148	24.2 (19.7)	9.6 (5.5, 13.6)				
	> 1 - ≤ 3	209	24.6 (20.7)	10.1 (6.4, 13.7)				
	> 3 - ≤ 5	140	17.4 (18.2)	2.8 (-1.3, 6.9)				
	> 5	234	14.6 (17.3)	reference				
Type of care								
Companionship	Yes	901	20.4 (19.6)	-10.5 (-15.7, -5.3)	< 0.001			
	No	61	31.0 (23.9)	reference				
Transportation	Yes	760	20.7 (19.9)	-1.8 (-4.9, 1.3)	0.254			
	No	202	22.5 (20.8)	reference				
Homemaking	Yes	431	22.6 (20.7)	2.7 (0.1, 5.2)	0.041			
	No	531	19.9 (19.5)	reference				
Personal care Assistance	Yes	125	30.0 (22.7)	10.3 (6.5, 14.0)	< 0.001			
	No	837	19.8 (19.3)	reference				
Healthcare Assistance	Yes	255	26.5 (21.3)	7.4 (4.5, 10.2)	< 0.001			
	No	707	19.2 (19.3)	reference				
Financial Assistance	Yes	470	24.5 (21.2)	6.6 (4.1, 9.1)	< 0.001	31.7	4.2 (1.2, 7.2)	0.007
	No	492	17.9 (18.5)	reference		27.5	Reference	
Others	Yes	8	38.3 (24.1)	17.3 (3.3, 31.3)	0.015			
	No	954	21.0 (20.0)	reference				
Time spent on caregiving per week, hours	≤ 5	184	19.0 (17.8)	-0.5 (-4.3, 3.4)	0.033			
	> 5 - ≤ 20	358	23.5 (21.0)	4.0 (0.8, 7.3)				
	> 20 - ≤ 40	162	21.2 (20.5)	1.8 (-2.2, 5.7)				
	> 40	249	19.5 (19.7)	reference				
Health status	Excellent	242	18.8 (19.1)	-11.5 (-20.0, -2.9)	0.037		^	
	Good	405	21.4 (19.5)	-8.9 (-17.3, -0.4)				
	Satisfactory	285	21.9 (20.9)	-8.4 (-16.9, 0.1)				
	Poor	23	30.3 (27.1)	reference				
Impact of caregiving on health status	Made it better	51	31.8 (22.7)	-5.9 (-12.5, 0.8)	< 0.001	31.4	-4.2 (-11.9, 3.4)	< 0.001
	Did not affect it	814	18.7 (18.4)	-19.0 (-23.3, -14.8)		21.7	-13.9 (-18.9, -9.0)	
	Made it worse	87	37.7 (23.0)	reference		35.7	Reference	
Patient's age, years	≤ 40	85	19.3 (19.1)	5.8 (-0.6, 12.1)	< 0.001			
	> 40 - ≤ 50	109	18.6 (18.3)	5.0 (-1.0, 11.0)				
	> 50 - ≤ 60	193	23.5 (21.6)	9.9 (4.4, 15.4)				
	> 60 - ≤ 70	237	23.1 (20.0)	9.5 (4.2, 14.9)				
	> 70 - ≤ 80	200	17.5 (18.1)	3.9 (-1.6, 9.4)				
	> 80	64	13.6 (16.2)	reference				
Patient's sex	Male	327	18.9 (18.6)	-3.3 (-5.9, -0.6)	0.017	27.4	-4.4 (-7.5, -1.4)	0.004
	Female	645	22.1 (20.7)	reference		31.8	Reference	
Patient's marital status	Single	108	19.3 (19.9)	-8.4 (-15.7, -1.0)	0.115			
	Married	657	21.4 (20.3)	-6.3 (-12.8, 0.2)				
	Widowed	156	19.7 (18.3)	-8.0 (-15.0, -0.9)				
	Divorced/ Separated	39	27.6 (23.1)	reference				
Type of cancer								
Breast	Yes	265	21.8 (21.2)	1.0 (-1.9, 3.8)	0.499			
	No	694	20.9 (19.6)	reference				
Lung	Yes	120	28.0 (21.1)	7.8 (4.0, 11.6)	< 0.001	32.5	5.8 (1.2, 10.4)	0.013
	No	839	20.1 (19.7)	reference		26.7	Reference	
Prostate	Yes	58	14.9 (16.1)	-6.6 (-11.9, -1.3)	0.015			
	No	901	21.5 (20.2)	reference				
Colon & Rectum	Yes	112	20.6 (18.7)	-0.6 (-4.6, 3.3)	0.751			
	No	847	21.2 (20.2)	reference				
Liver	Yes	62	20.0 (19.8)	-1.2 (-6.4, 3.9)	0.636			

	No	897	21.2 (20.1)	reference				
Brain	Yes	26	25.4 (25.5)	4.3 (-3.5, 12.2)	0.276			
	No	933	21.0 (19.9)	reference				
Cervix	Yes	61	27.6 (21.4)	6.9 (1.7, 12.1)	0.009			
	No	898	20.7 (19.9)	reference				
Uterus	Yes	58	11.9 (14.0)	-9.9 (-15.1, -4.6)	< 0.001			
	No	901	21.7 (20.2)	reference				
NPC	Yes	33	13.9 (11.6)	-7.5 (-14.4, -0.5)	0.035			
	No	926	21.4 (20.2)	reference				
Stomach	Yes	50	18.6 (16.1)	-2.7 (-8.4, 3.0)	0.358			
	No	909	21.3 (20.2)	reference				
Kidney	Yes	13	29.8 (22.4)	8.8 (-2.2, 19.7)	0.117			
	No	946	21.0 (20.0)	reference				
Lymphoma	Yes	54	9.5 (10.6)	-12.3 (-17.7, -6.8)	< 0.001			
	No	905	21.8 (20.3)	reference				
Pancreas	Yes	22	26.0 (23.4)	5.0 (-3.5, 13.4)	0.252			
	No	937	21.0 (20.0)	reference				
Others	Yes	122	23.2 (20.8)	2.4 (-1.4, 6.2)	0.213			
	No	837	20.8 (19.9)	reference				
Cancer stage	Stage 0	43	16.5 (21.6)	-10.0 (-16.5, -3.6)	< 0.001			
	Stage I	77	13.4 (14.5)	-13.2 (-18.2, -8.1)				
	Stage II	215	20.7 (19.6)	-5.9 (-9.4, -2.4)				
	Stage III	214	23.3 (20.4)	-3.3 (-6.8, 0.3)				
	Stage IV	293	26.6 (21.0)	reference				
Time since diagnosis, Years	< 5	738	22.9 (20.4)	8.7 (4.0, 13.4)	< 0.001			
	≥ 5 - < 10	142	13.9 (16.7)	-0.3 (-5.9, 5.2)				
	≥ 10	74	14.2 (17.7)	reference				
Cancer Trajectory	Active treatment	523	24.5 (20.9)	-0.8 (-7.4, 5.8)	< 0.001	31.9	-4.8 (-12.3, 2.7)	< 0.001
	Completed treatment	209	15.8 (17.2)	-9.5 (-16.4, -2.6)		25.4	-11.3 (-19.1, -3.4)	
	Cancer-free Status	103	8.0 (11.9)	-17.3 (-24.7, -9.9)		18.2	-18.5 (-27.1, -9.8)	
	Dealing with relapse	80	28.4 (20.6)	3.1 (-4.6, 10.7)		35.9	-0.8 (-9.5, 7.9)	
	Palliative care/ others	35	25.3 (18.2)	reference		36.7	Reference	
Had treatment in last 1 month	Yes	800	23.0 (20.3)	10.6 (7.2, 13.9)	< 0.001			
	No	159	12.4 (16.3)	reference				
Treatment type								
Surgery	Yes	91	28.0 (21.4)	7.5 (3.2, 11.8)	0.001			
	No	868	20.5 (19.8)	reference				
Chemotherapy	Yes	448	24.5 (20.7)	6.1 (3.6, 8.6)	< 0.001			
	No	511	18.4 (19.1)	reference				
Radiation Therapy	Yes	112	23.8 (18.8)	2.9 (-1.1, 6.8)	0.154			
	No	847	20.9 (20.3)	reference				
Hormonal Therapy	Yes	49	26.8 (24.9)	5.9 (0.1, 11.6)	0.047			
	No	910	21.0 (19.8)	reference				
Antibody Treatment	Yes	33	32.7 (19.2)	11.8 (4.9, 18.8)	0.001			
	No	926	20.8 (20.0)	reference				
Others	Yes	28	24.6 (23.0)	3.5 (-4.1, 11.1)	0.365			
	No	931	21.2 (20.0)	reference				

Note: A low R2 for the model suggested that there were variables that have not been collected to explain the overall score of unmet needs.

Table 5: Quality of life of caregivers.

Domain	Item	Total		Not at all		Somewhat		A little bit		Quite a bit		Very much		Score	
		No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	Mean	SD
Burden	I feel nervous	986 (100)	557 (56.5)	163 (16.5)	142 (14.4)	77 (7.8)	47 (4.8)	3.12	(1.2)						
	I feel frustrated	986 (100)	582 (59.0)	157 (15.9)	123 (12.5)	75 (7.6)	49 (5.0)	3.16	(1.2)						
	I feel guilty	986 (100)	675 (68.5)	136 (13.8)	96 (9.7)	48 (4.9)	31 (3.1)	3.40	(1.1)						
	I worry about the impact my loved one's illness has had on my children or other family members	986 (100)	449 (45.5)	203 (20.6)	155 (15.7)	100 (10.1)	79 (8.0)	2.85	(1.3)						
Physical/ Practical Concerns	I feel under increased mental strain.	986 (100)	487 (49.4)	205 (20.8)	137 (13.9)	108 (11.0)	49 (5.0)	2.99	(1.2)						
	I am discouraged about the future.	986 (100)	593 (60.1)	167 (16.9)	132 (13.4)	59 (6.0)	35 (3.6)	3.24	(1.1)						
	I have difficulty dealing with my loved one's changing eating habits	986 (100)	560 (56.8)	173 (17.5)	133 (13.5)	81 (8.2)	39 (4.0)	3.15	(1.2)						
	It bothers me, limiting my focus to day-to-day	986 (100)	498 (50.5)	193 (19.6)	150 (15.2)	91 (9.2)	54 (5.5)	3.00	(1.2)						
	My daily life is imposed upon.	986 (100)	579 (58.7)	193 (19.6)	128 (13.0)	69 (7.0)	17 (1.7)	3.27	(1.0)						
	My sleep is less restful.	986 (100)	515 (52.2)	196 (19.9)	154 (15.6)	96 (9.7)	25 (2.5)	3.10	(1.1)						
	It bothers me that my daily routine is altered.	986 (100)	558 (56.6)	196 (19.9)	136 (13.8)	79 (8.0)	17 (1.7)	3.22	(1.1)						
	It is a challenge to maintain my outside interests	986 (100)	539 (54.7)	188 (19.1)	132 (13.4)	89 (9.0)	38 (3.9)	3.12	(1.2)						
	I am under a financial strain	986 (100)	539 (54.7)	199 (20.2)	127 (12.9)	76 (7.7)	45 (4.6)	3.13	(1.2)						
	It upsets me to see my loved one deteriorate	986 (100)	314 (31.8)	140 (14.2)	165 (16.7)	187 (19.0)	180 (18.3)	2.22	(1.5)						
Emotional Reactivity	I fear my loved one will die.	986 (100)	272 (27.6)	166 (16.8)	154 (15.6)	146 (14.8)	248 (25.2)	2.07	(1.6)						
	The need to manage my loved one's pain is overwhelming	986 (100)	474 (48.1)	156 (15.8)	145 (14.7)	126 (12.8)	85 (8.6)	2.82	(1.4)						
	I fear the adverse effects of treatment on my loved one	986 (100)	349 (35.4)	184 (18.7)	187 (19.0)	164 (16.6)	102 (10.3)	2.52	(1.4)						
	It bothers me that my priorities have changed	986 (100)	607 (61.6)	156 (15.8)	134 (13.6)	62 (6.3)	27 (2.7)	3.27	(1.1)						
	The need to protect my loved one bothers me	986 (100)	662 (67.1)	126 (12.8)	114 (11.6)	51 (5.2)	33 (3.3)	3.35	(1.1)						
	It bothers me that I need to be available to chauffeur my loved one to appointments	986 (100)	639 (64.8)	153 (15.5)	103 (10.4)	66 (6.7)	25 (2.5)	3.33	(1.1)						
	The responsibility I have for my loved one's care at home is overwhelming	986 (100)	550 (55.8)	178 (18.1)	140 (14.2)	79 (8.0)	39 (4.0)	3.14	(1.2)						
	I have developed a closer relationship with my loved one	986 (100)	271 (27.5)	167 (16.9)	162 (16.4)	199 (20.2)	187 (19.0)	1.86	(1.5)						
	I feel adequately informed about my loved one's illness	986 (100)	157 (15.9)	182 (18.5)	192 (19.5)	309 (31.3)	146 (14.8)	2.11	(1.3)						
	Family communication has increased	986 (100)	289 (29.3)	188 (19.1)	185 (18.8)	193 (19.6)	131 (13.3)	1.68	(1.4)						
Social Support	I am satisfied with the support I get from my family	986 (100)	188 (19.1)	142 (14.4)	172 (17.4)	237 (24.0)	247 (25.1)	2.22	(1.5)						
	Overall							71.34	(17.5)						

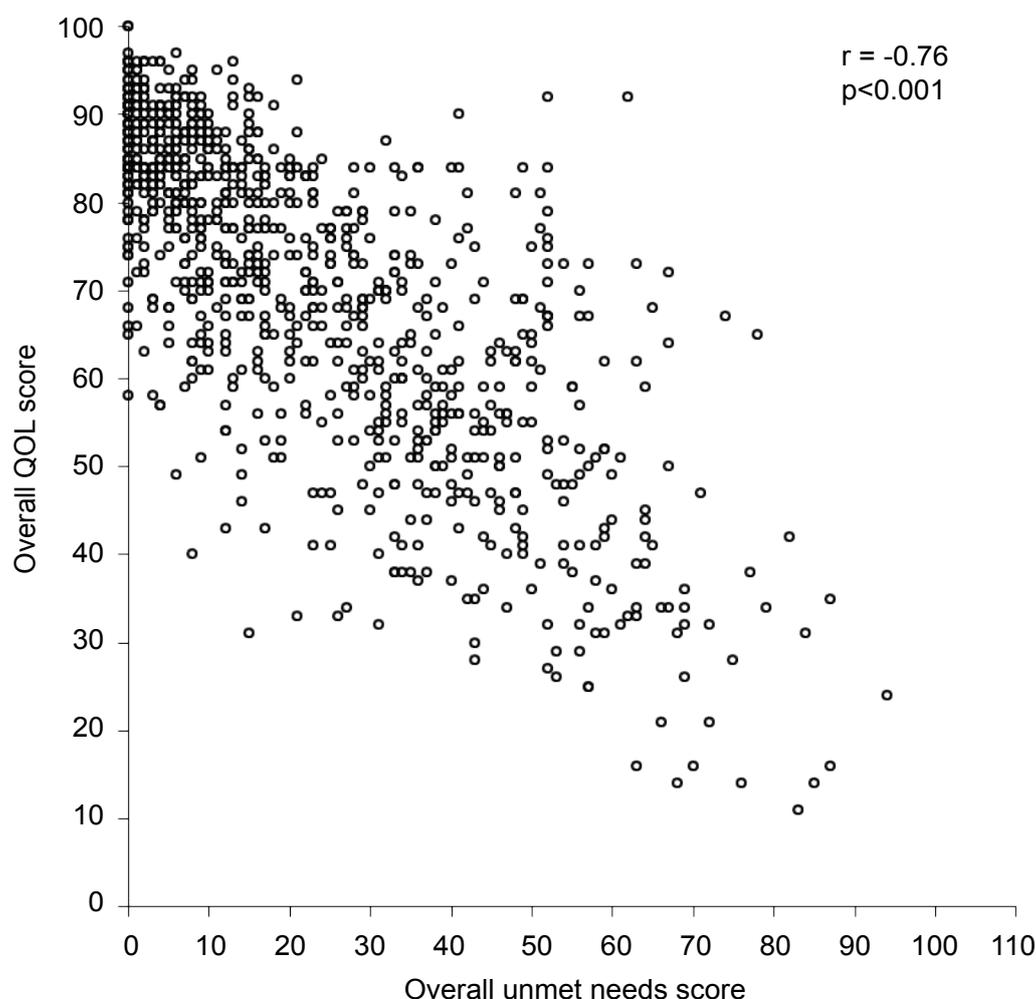


Figure 1: Scatterplot of overall scores of quality of life and unmet needs.

relation with QOL was “Personal” ($r = -0.71$; $P < 0.001$), followed by “Future” and “Emotional” (both domain’s $r = -0.66$; $P < 0.001$), “Information” ($r = -0.63$; $P < 0.001$), “Work and finance” ($r = -0.61$; $P < 0.001$) and “Access and continuity of healthcare” ($r = -0.60$; $P < 0.001$).

The mean overall QOL score was reduced by 0.7 points (95% CI, -0.7, -0.6) for every additional point increase in the overall score of unmet needs (Table 6). Overall score of unmet needs remained significantly associated with the mean overall QOL score on multiple linear regression analysis. The other independent variables associated with the mean overall QOL scores were the impact of caregiving on health status of caregivers and whether caregivers were taking care of breast cancer patients. The multivariable model explained 59% of the variability in the overall QOL scores.

Discussion

This is the first study to assess the unmet needs and QOL of caregivers of cancer patients in Singapore and findings from this survey contribute to the body of knowledge that is currently lacking in this field. These findings also provide an evidence-based approach in developing a comprehensive support system for caregivers of cancer patients in Singapore.

Prevalence of caregivers’ unmet needs

Our findings indicate that caregivers of cancer patients have many unmet needs as suggested by previous studies [19-21,23-26] and that these unmet needs have a negative impact on their QOL. The highest scores of unmet needs were all found in the domain of “future” which contrasts with existing literature [15,21,23] but corresponds with the results by Han, et al. [32] and Doubova, et al. [20]. In a large study in Mexico of 826 primary caregivers of cancer patients, Doubova, et al. [20] found that the most frequent unmet needs were related to uncertainty about the future: dealing with worry about cancer coming back (42.9%), dealing with future uncertainty (39.7%), and “dealing with worry about cancer getting worse” (38.7%). Our findings strongly indicate the psychological impact experienced by these caregivers. The fear of recurrence (FOR) is defined as the worry or fear that the cancer will return, progress or spread [33] has well been reported in the studies [34-39]. Evidence in literature reveals the negative impacts associated with FOR, including emotional distress [40]; functional status [41]; and QOL [41-44]. This may imply the fear and possible threat of losing a loved one which is confirmed by the lower score on QOL

Table 6: Mean overall quality of life scores of caregivers.

Variable	Category	Univariate analysis				Multiple analysis		
		No.	Mean score (SD)	Difference (95% CI)	p-value	Adj. mean score	Difference (95% CI)	p-value
Age, years	≤ 30	216	70.8 (18.1)	-5.6 (-9.7, -1.5)	0.002			
	> 30 - ≤ 40	223	69.1 (16.8)	-7.3 (-11.5, -3.2)				
	> 40 - ≤ 50	224	71.6 (17.1)	-4.8 (-8.9, -0.7)				
	> 50 - ≤ 60	146	74.5 (16.5)	-1.9 (-6.3, 2.5)				
	> 60	98	76.4 (18.2)	reference				
Sex	Male	441	71.5 (17.9)	0.3 (-1.9, 2.5)	0.793			
	Female	538	71.2 (17.2)	reference				
Race	Chinese	720	70.6 (18.0)	-1.2 (-6.7, 4.3)	0.262			
	Malays	145	73.5 (15.1)	1.6 (-4.4, 7.7)				
	Indians	59	73.3 (19.0)	1.4 (-5.5, 8.4)				
	Others	42	71.8 (15.9)	reference				
Marital status	Single	363	71.7 (17.8)	-2.1 (-8.5, 4.4)	0.546			
	Married	575	70.8 (17.5)	-2.9 (-9.3, 3.4)				
	Widowed/ divorced/ separated	31	73.8 (15.6)	reference				
Highest education attained	No formal education/ Primary	48	71.5 (19.7)	1.7 (-3.5, 6.8)	0.021			
	Secondary	130	74.1 (17.2)	4.4 (1.0, 7.7)				
	Post-secondary	301	72.9 (16.8)	3.1 (0.6, 5.7)				
	Tertiary	482	69.8 (17.6)	reference				
Economic Status	Full time	607	70.0 (17.6)	-1.1 (-7.3, 5.1)	0.001			
	Part time	52	71.5 (16.7)	0.4 (-7.2, 8.1)				
	Schooling	63	76.6 (16.2)	5.4 (-2.0, 12.8)				
	Unemployed	48	68.5 (18.5)	-2.6 (-10.4, 5.2)				
	Retired	78	78.0 (16.8)	6.9 (-0.3, 14.0)				
	Homemaker	74	72.0 (16.7)	0.9 (-6.3, 8.1)				
	Others	32	71.1 (17.8)	reference				
Gross monthly household income, \$	Not applicable	253	75.1 (16.5)	3.7 (-0.8, 8.2)	0.003			
	≤ 2000	60	66.6 (18.5)	-4.9 (-10.7, 1.0)				
	> 2000 - ≤ 3000	73	68.5 (19.6)	-3.0 (-8.5, 2.6)				
	> 3000 - ≤ 4000	103	72.4 (15.3)	0.9 (-4.3, 6.1)				
	> 4000 - ≤ 6000	171	70.5 (18.6)	-0.9 (-5.7, 3.8)				
	> 6000 - ≤ 8000	102	72.0 (15.9)	0.5 (-4.7, 5.7)				
	> 8000 - ≤ 10000	44	67.4 (17.9)	-4.0 (-10.5, 2.4)				
	> 10000	72	71.5 (15.4)	reference				
Housing type	HDB 1- to 3-room	155	70.0 (17.2)	-1.5 (-5.1, 2.2)	0.774			
	HDB 4-rooms	326	71.3 (18.1)	-0.1 (-3.2, 3.0)				
	HDB 5-rooms	259	71.8 (18.0)	0.4 (-2.9, 3.6)				
	Private housing	201	71.4 (16.0)	reference				

Relationship to cancer patient	Parent	60	68.1 (18.6)	-9.1 (-14.5, -3.7)	< 0.001			
	Child	500	69.0 (17.5)	-8.2 (-11.7, -4.7)				
	Sibling	71	77.2 (15.7)	-0.0 (-5.1, 5.1)				
	Spouse/partner	218	72.4 (18.9)	-4.8 (-8.7, -0.9)				
	Friend/others	118	77.2 (13.6)	reference				
Living with cancer patient	Yes	609	71.1 (18.1)	-0.8 (-3.1, 1.5)	0.489			
	No	357	71.9 (16.6)	reference				
Type of Caregiver	Primary	275	64.5 (18.4)	-9.6 (-12.0, -7.3)	< 0.001			
	Non-primary	673	74.2 (16.3)	reference				
Duration of care, years	≤ 0.5	227	68.1 (19.0)	-7.5 (-10.6, -4.3)	< 0.001			
	> 0.5 - ≤ 1	148	69.5 (17.7)	-6.1 (-9.6, -2.5)				
	> 1 - ≤ 3	209	69.2 (18.8)	-6.4 (-9.7, -3.2)				
	> 3 - ≤ 5	140	74.2 (14.9)	-1.4 (-5.1, 2.2)				
	> 5	234	75.6 (15.5)	reference				
Type of care								
Companionship	Yes	901	71.5 (17.5)	4.1 (-0.4, 8.7)	0.075			
	No	61	67.4 (18.1)	reference				
Transportation	Yes	760	71.7 (16.9)	2.3 (-0.4, 5.0)	0.097			
	No	202	69.4 (20.0)	reference				
Homemaking	Yes	431	69.8 (18.4)	-2.7 (-4.9, -0.5)	0.018			
	No	531	72.5 (16.8)	reference				
Personal care Assistance	Yes	125	63.1 (20.0)	-9.4 (-12.7, -6.1)	< 0.001			
	No	837	72.5 (16.9)	reference				
Healthcare Assistance	Yes	255	65.5 (19.3)	-7.8 (-10.3, -5.3)	< 0.001			
	No	707	73.3 (16.5)	reference				
Financial Assistance	Yes	470	67.6 (18.4)	-7.2 (-9.4, -5.1)	< 0.001			
	No	492	74.8 (16.0)	reference				
Others	Yes	8	65.5 (16.1)	-5.8 (-18.1, 6.4)	0.353			
	No	954	71.3 (17.6)	reference				
Time spent on caregiving per week, hours	≤ 5	184	74.8 (15.2)	5.0 (1.7, 8.4)	0.015			
	> 5 - ≤ 20	358	70.2 (17.7)	0.4 (-2.4, 3.3)				
	> 20 - ≤ 40	162	71.3 (18.7)	1.5 (-2.0, 5.0)				
	> 40	249	69.8 (18.1)	reference				
Health status	Excellent	242	74.5 (15.2)	13.3 (5.8, 20.7)	0.001		^	
	Good	405	71.0 (17.0)	9.8 (2.4, 17.1)				
	Satisfactory	285	69.9 (18.9)	8.7 (1.2, 16.1)				
	Poor	23	61.2 (26.4)	reference				
Impact of caregiving on health status	Made it better	51	70.0 (16.1)	16.3 (10.5, 22.1)	< 0.001	78.2	13.0 (8.3, 17.7)	< 0.001
	Did not affect it	814	73.2 (16.3)	19.4 (15.7, 23.1)		71.8	6.6 (3.5, 9.7)	
	Made it worse	87	53.7 (20.4)	reference		65.2	Reference	
Patient's age, Years	≤ 40	85	73.8 (17.9)	-2.5 (-8.1, 3.2)	0.019			
	> 40 - ≤ 50	109	72.3 (18.4)	-4.0 (-9.4, 1.3)				
	> 50 - ≤ 60	193	69.5 (19.1)	-6.8 (-11.7, -1.9)				
	> 60 - ≤ 70	237	70.2 (16.8)	-6.1 (-10.8, -1.3)				
	> 70 - ≤ 80	200	73.8 (16.0)	-2.5 (-7.4, 2.4)				
	> 80	64	76.3 (14.3)	reference				
Patient's sex	Male	327	71.1 (16.6)	-0.3 (-2.6, 2.1)	0.829			
	Female	645	71.3 (18.1)	reference				

Patient's marital status	Single	108	73.9 (18.6)	8.6 (2.1, 15.0)	0.049			
	Married	657	70.8 (17.8)	5.5 (-0.2, 11.2)				
	Widowed	156	72.3 (15.1)	7.0 (0.9, 13.2)				
	Divorced/ Separated	39	65.3 (18.5)	reference				
Type of cancer								
Breast	Yes	265	73.1 (18.6)	2.6 (0.1, 5.1)	0.042	73.8	4.1 (2.2, 6.1)	< 0.001
	No	694	70.5 (17.2)	reference		69.7	Reference	
Lung	Yes	120	66.7 (17.8)	-5.2 (-8.6, -1.8)	0.003			
	No	839	71.9 (17.6)	reference				
Prostate	Yes	58	74.4 (15.4)	3.4 (-1.3, 8.1)	0.160			
	No	901	71.0 (17.8)	reference				
Colon & Rectum	Yes	112	71.3 (16.3)	0 (-3.4, 3.5)	0.979			
	No	847	71.2 (17.8)	reference				
Liver	Yes	62	71.1 (17.6)	-0.1 (-4.7, 4.4)	0.949			
	No	897	71.2 (17.7)	reference				
Brain	Yes	26	63.5 (24.8)	-8.0 (-14.8, -1.1)	0.024			
	No	933	71.5 (17.4)	reference				
Cervix	Yes	61	67.3 (18.3)	-4.2 (-8.8, 0.4)	0.072			
	No	898	71.5 (17.6)	reference				
Uterus	Yes	58	78.4 (13.8)	7.6 (3.0, 12.3)	0.001			
	No	901	70.8 (17.8)	reference				
NPC	Yes	33	69.2 (13.0)	-2.1 (-8.3, 4.0)	0.497			
	No	926	71.3 (17.8)	reference				
Stomach	Yes	50	67.1 (16.8)	-4.3 (-9.4, 0.7)	0.091			
	No	909	71.5 (17.7)	reference				
Kidney	Yes	13	61.6 (17.1)	-9.8 (-19.4, -0.1)	0.048			
	No	946	71.4 (17.6)	reference				
Lymphoma	Yes	54	79.9 (14.9)	9.1 (4.3, 14.0)	< 0.001			
	No	905	70.7 (17.7)	reference				
Pancreas	Yes	22	67.1 (20.0)	-4.2 (-11.7, 3.3)	0.271			
	No	937	71.3 (17.6)	reference				
Others	Yes	122	68.5 (18.1)	-3.2 (-6.5, 0.2)	0.062			
	No	837	71.6 (17.6)	reference				
Cancer stage	Stage 0	43	73.5 (19.1)	7.8 (2.2, 13.4)	< 0.001			
	Stage I	77	77.0 (15.8)	11.3 (7.0, 15.7)				
	Stage II	215	73.2 (16.9)	7.5 (4.5, 10.6)				
	Stage III	214	69.3 (17.4)	3.6 (0.6, 6.7)				
	Stage IV	293	65.7 (18.0)	reference				
Time since diagnosis, Years	< 5	738	69.9 (17.9)	-5.0 (-9.1, -0.9)	< 0.001			
	≥ 5 - < 10	142	76.6 (14.2)	1.7 (-3.2, 6.5)				
	≥ 10	74	74.9 (16.7)	reference				
Cancer Trajectory	Active treatment	523	69.0 (18.0)	0.9 (-4.8, 6.7)	< 0.001			
	Completed treatment	209	75.5 (14.7)	7.3 (1.3, 13.4)				
	Cancer-free status	103	81.9 (12.5)	13.8 (7.3, 20.2)				
	Dealing with relapse	80	62.5 (18.2)	-5.6 (-12.3, 1.1)				
	Palliative care/ Others	35	68.1 (18.0)	reference				

Had treatment in last 1 month	Yes	800	69.8 (17.8)	-7.9 (-10.9, -5.0)	< 0.001			
	No	159	77.8 (14.9)	reference				
Treatment type								
Surgery	Yes	91	65.4 (21.1)	-6.3 (-10.1, -2.6)	0.001			
	No	868	71.8 (17.1)	reference				
Chemotherapy	Yes	448	68.3 (18.3)	-5.4 (-7.6, -3.2)	< 0.001			
	No	511	73.7 (16.6)	reference				
Radiation Therapy	Yes	112	67.6 (17.8)	-4.1 (-7.5, -0.6)	0.022			
	No	847	71.6 (17.6)	reference				
Hormonal Therapy	Yes	49	68.8 (20.6)	-2.5 (-7.6, 2.6)	0.331			
	No	910	71.3 (17.5)	reference				
Antibody Treatment	Yes	33	64.2 (18.4)	-7.2 (-13.3, -1.1)	0.022			
	No	926	71.4 (17.6)	reference				
Others	Yes	28	70.4 (18.7)	-0.8 (-7.4, 5.9)	0.824			
	No	931	71.2 (17.6)	reference				
Overall unmet needs score	Per unit increase	986	71.3 (17.5)	-0.7 (-0.7, -0.6)	< 0.001	70.6	-0.65 (-0.7, -0.6)	< 0.001

under the “Emotional” domain: “I fear my loved one will die”. Based on current evidence, the FOR is the top unmet needs in caregivers of cancer patients and the fear and possible threat of losing a loved one has a negative effect on their QOL, may indicate a need for psychological screening and the importance of enhancing the information delivery and supportive care services to meet the emotional and psychological needs of caregivers.

Findings also revealed that the lowest scores rate of unmet needs were mostly from the “Information” domain and “finding information about cancer and its impact on sexual relationship” obtained the lowest score 0. This finding is similar to another study [45] where the researchers found that patients receiving active cancer treatment rated information on sexuality as the least important. Although cultural values and beliefs may have influenced the caregivers’ behaviours, another possible explanation is that only 22% of caregivers were spouses and the majority (51%) of caregivers was children caring for their parents with cancer. In addition, half of the patients were in advanced stage and concerns relating to patients’ life expectancy may be of more immediate concern.

Can we predict whose needs are less likely to be met based on demographic characteristics?: Several caregivers’ and patients’ characteristics were independently associated with cancer caregivers’ unmet needs. Firstly, a primary caregiver had higher mean score of unmet needs than a non-primary caregiver (difference = 6.4, 95% CI, 3.1-9.8). As primary caregiver by definition is the caregiver most involved with the provision of care to the patient, the finding that primary caregivers had higher score of unmet needs may be attributable to the higher burden of caregiving. A study by Lund and colleagues [46] established that primary caregivers experienced the highest caregiving workload. Secondly, younger

caregivers had higher mean scores of unmet needs than older caregivers aged > 60 years. This was not unexpected considering that younger caregivers may have competing demands from their careers and young families while taking care of the cancer patients [7,26,47]. Thirdly, caregivers who provided financial assistance to the patients they cared for also have significantly higher unmet needs than those who did not. Healthcare in Singapore is financed by a combination of employee medical benefits, insurance, compulsory savings in the form of Medisave and out-of-pocket payment (families polling resources for medical expenses) and government subsidies in the public healthcare systems [48]. The financial concerns caused by cancer are well reported in the literature [14,16,19,27,38-40,47]. In a study in Korea, it was found that 61.9% of families used up their family savings, 17.1% had to move to a less expensive home, 13.2% had to delay care for another family member and 26.5% had to change educational plans for another family member [13]. A recent study in India on the impact of breast cancer on the patient and the family found that 43% (144) had financial difficulty with cost of treatment and had to resort to desperate measures such as selling their property or taking on high-interest personal loans [49]. As 48% of caregivers are providing financial assistance to the cancer patients, and although 70% of the caregivers in this study are working, the finding may indicate that caregivers may have financial concerns in spite of the Government’s implementation of MediShield Life and MediFund schemes which are designed to address catastrophic medical conditions including cancer. Based on the finding, more financial support for cancer patients through government subsidies and other supporting mechanisms may significantly lighten the financial burden imposed on their caregivers. In addition, further studies are needed to assess cancer caregivers’ unmet financial needs/burden are warranted.

Our findings also established that caregivers of patients on palliative care, lung cancer patients, and caregivers whose health were made worse by caregiving activities, were the predictors of unmet needs. These findings are in concordance with previous studies [22,50,51]. Although our finding also revealed a significant association of caregiver unmet needs with caring for female patients, however, this finding contradicted the finding by Heckel, et al. [23]. In view of the contradictions and that to date, few studies have investigated such a relationship; therefore, more research is needed to draw a reliable conclusion.

Our findings underscore the importance of understanding socio-demographic characteristics of caregivers who are more vulnerable so that efforts could be channeled to those caregivers whose needs are less likely to be met.

Caregivers' quality of life

In our study, the mean overall QOL score was 71.34 ± 17.5 . This is a relative low score as compared with the 74.62 ± 20.54 obtained in a Korean study [21]. The items that received relatively low QOL scores were under the "Emotional" domain: "I fear my loved one will die", "It upsets me to see my loved one deteriorate" and "I fear the adverse effects of treatment on my loved ones" however were similar to Kim and Yee's study. This may suggest the psychological pressure exerted on the caregivers in relation to the deterioration of patient's functional status.

The study also established that the impact of caregiving on the health status of caregivers is associated with the mean overall QOL scores. This may suggest the burden of caregiving in relation to caregivers' health status. The burden of caregiving is well reported in the literature. In a large study involving 590 cancer caregivers, Lund, et al. [46] established that cancer caregiving is burdensome and demanding and it may jeopardize the caregivers' own well-being. A large proportion of caregivers experienced substantial caregiving workload related to practical help, provision of psychological support, and transport. Caregivers reported a range of negative consequences, most commonly stress (59%) and 16% reported some or a lot of negative effect on their own physical health. Burdened caregivers are 6 times more at risk of depression [13]. The impact on health was found to have a negative influence on the health-related QOL and mental health [52]. As supporting their loved ones to the best of their ability without complaint is expected in the Asian society, this finding indicates the need for caregivers assessment to identify those at risk of negative outcomes. In addition, resources to assist caregivers to provide needed care and early identification and referral to respite care or support services, including the promotion of active coping are also needed [7,53].

Additionally, the mean overall QOL scores were as-

sociated with caregivers who were taking care of breast cancer patients. The challenges confronting breast cancer patients are well reported in the literature [44,54,55]. Even 2 to 10 years post cancer treatment; high rates of anxiety are reported by disease-free breast cancer survivors [56]. We postulate that the challenges confronting the breast cancer patients may have posed a burden on their caregiver and warrants further investigation.

Literature indicates the positive benefits that can be derived from caring for a loved one. These include personal satisfaction [7], closer relationship [7,53,57] and fulfillment from helping to relieve another's suffering [57]. Our findings that "family communication has increased" and "I have developed a closer relationship with my loved one" lowest mean scores may suggest that these are not an issue with regard to affecting their QOL but in contrast may imply that caregivers view the cancer experience has improved the communication and relationship with their loved ones.

Caregivers' unmet needs relate to QOL

Our findings indicated that that every domain of unmet needs of the cancer caregiver affects their QOL negatively. With the top three scores of unmet needs that relate most with their QOL fall in the domains of "Personal", "Future" and "Emotional", and the most commonly reported psychological effects which affect the caregivers QOL are sleep problems, stress and worries, it further confirms the psychological challenges confronting them and warrant attention. The impact on psychological health in the form of insomnia [7], distress [13], anxiety [4,58,59], worry [7], depression [13,23,58] on caregivers has been frequently identified as negative consequence of caregiving. This significant negative association between QOL and psychological and emotional unmet needs highlights the importance of addressing and helping caregivers with coping skills and emotional support as part of patient care.

The mean overall QOL score was reduced by 0.7 points for every additional point increase in the overall score of unmet needs and the overall score of unmet needs remained significantly associated with the mean overall QOL score. This further indicates that caregivers QOL would be enhanced when the caregiver's unmet needs in the context of cancer care are met. This suggests that it is critical to consider developing information and supportive care interventions to help the caregivers. Particular importance must also be paid to the support relating to their fear of recurrence and disease progression; the fear of losing their loved ones and the more vulnerable group of caregivers in order for them to support and maximize the well-being of the individual coping with cancer.

Limitations

There were several limitations in this study. The

main limitation of this study is the study was performed only in a group of cancer caregivers who attended an ambulatory centre in Singapore; this may limit generalizability of the results. Another limitation is the high rejection rate; therefore, there could be a nonresponse bias and thus the results must be interpreted with caution. However, the Centre we conducted the study is the largest ambulatory cancer centre in the country where the vast majority of cancer patients receive care and the large sample size may help to mitigate these limitations. Moreover, measurement of unmet needs and QOL were via standardized, validated tools that addressed unmet needs across six domains and QOL across five domains.

Conclusion

This study contributes to the cancer caregivers' literature especially in the context in Singapore as there is no reported study to date. Based on our findings, we demonstrated that caregivers of cancer patients have many unmet needs and these unmet needs have a significant negative impact on their QOL. Cancer caregiving is demanding, burdensome and stressful and may jeopardize the well-being of the caregivers and affect their ability to render care and support to the cancer patients. Given the important role caregivers play in supporting the cancer patients, addressing their unmet needs will help enhance their coping skills and ultimately improve their QOL.

Our findings provide an evidence-based guide for the design and implementation of comprehensive supportive care services that address the diverse needs of caregivers of cancer patients. Of particular importance that warrants attention are the non-physical aspects of caregiving such as the psychological and emotional dimensions as these are the most distinctive findings of this study. The findings also highlight the importance of encouraging caregivers to voice their needs early and assessing the needs of caregivers of cancer patients paying particular attention to the more vulnerable groups as revealed in this study.

Acknowledgements

We express appreciation to participants in this study and the patients they care for.

Ethics Approval and Consent to Participate

Ethical consent was obtained from SingHealth Centralised Institutional Review Board (CIRB) prior to the study. Waiver of documentation of informed consent was approved based on ethical consideration as no personal identifiers of respondents were obtained.

Competing Interest

The authors have no conflict of interest to declare.

Source of Support

This study was supported by a grant from the Na-

tional Cancer Centre Research Fund (NCCRF-YR2018-JAN-PG6).

Statement of Equal Authors' Contribution

CGP conceptualised and designed the study. Data collection was managed by CGP. OWS performed data cleaning and statistical analysis. NQS and THK supervised and provided guidance and expertise. All authors read and approved the final manuscript.

References

1. World Health Organization (2018) Latest global cancer data: Cancer burden rises to 18.1 million new cases and 9.6 million cancer deaths in 2018.
2. (2017) National Registry of Diseases Office. Singapore cancer registry annual registry report 2015.
3. Department of Statistics Singapore (2018) Death and life expectancy.
4. Sklenarova H, Krumpelmann A, Haun MW, Friederich HC, Huber J, et al. (2015) When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer* 121: 1513-1519.
5. Shin DW, Park JH, Shim EJ, Park JH, Choi JY, et al. (2011) The development of a comprehensive needs assessment tool for cancer-caregivers in patient-caregiver dyads. *Psychooncology* 20: 1342-1352.
6. Loke AY, Liu CF, Szeto Y (2003) The difficulties faced by informal caregivers of patients with terminal cancer in Hong Kong and the available social support. *Cancer Nurs* 26: 276-283.
7. Given BA, Given CW, Sherwood P (2012) The challenge of quality cancer care for family caregivers. *Semin Oncol Nurs* 28: 205-212.
8. Berry LL, Dalwadi SM, Jacobson JO (2017) Supporting the supporters: What family caregivers need to care for a loved one with cancer. *J Oncol Pract* 13: 35-41.
9. van Ryn M, Sanders S, Kahn K, van Houtven C, Griffin JM, et al. (2011) Objective burden, resources, and other stressors among informal cancer caregivers: A hidden quality issue? *Psychooncology* 20: 44-52.
10. Lopez V, Copp G, Molassiotis A (2012) Male caregivers of patients with breast and gynecologic cancer: Experiences from caring from their spouses and partners. *Cancer Nurs* 35: 402-410.
11. Cassidy T, McLaughlin M (2015) Psychological distress of female caregivers of significant others with cancer. *Cogent Psychology* 2: 999405.
12. Kaltenbaugh DJ, Klem ML, Hu L, Turi E, Haines AJ, et al. (2015) Using web-based interventions to support caregivers of patients with cancer: A systematic review. *Oncol Nurs Forum* 42: 156-164.
13. Rhee YS, Yun YH, Park S, Shin DO, Lee KM, et al. (2008) Depression in family caregivers of cancer patients: The feeling of burden as a predictor of depression. *J Clin Oncol* 26: 5890-5895.
14. Al-Jauissy MS (2010) Health care needs of Jordanian caregivers of patients with cancer receiving chemotherapy on an outpatient basis. *East Mediterr Health J* 16: 1091-1097.
15. Ashrafian S, Feizollahzadeh H, Rahmani A, Davoodi A

- (2018) The unmet needs of the family caregivers of patients with cancer visiting a referral hospital in Iran. *Asia Pac J Oncol Nurs* 5: 342-352.
16. Honea NJ (2012) Influences of self-care in the context of caregiving for a spouse with a brain tumor: A theoretical model. University of Utah, Utah.
17. Longacre M (2013) Cancer caregivers information needs and resource preferences. *J Cancer Educ* 28: 297-305.
18. Chen SC (2014) Information needs and information sources of family caregivers of cancer patients. *Aslib Journal of Information Management* 66: 623-639.
19. Campbell HS, Sanson-Fisher R, Taylor-Brown J, Hayward L, Wang XS, et al. (2009) The cancer support person's unmet needs survey: Psychometric properties. *Cancer* 115: 3351-3359.
20. Doubova SV, Aguirre-Hernandez R, Infante-Castaneda C, Martinez-Vega I, Perez-Cuevas R (2015) Needs of caregivers of cancer patients: Validation of the Mexican version of the Support Person Unmet Needs Survey (SPUNS-SFM). *Support Care Cancer* 23: 2925-2935.
21. Kim H, Yi M (2015) Unmet needs and quality of life of family caregivers of cancer patients in South Korea. *Asia Pac J Oncol Nurs* 2: 152-159.
22. Lambert SD, Harrison JD, Smith E, Bonevski B, Carey M, et al. (2012) The unmet needs of partners and caregivers of adults diagnosed with cancer: A systematic review. *BMJ Support Palliat Care* 2: 224-230.
23. Heckel L, Fennell KM, Reynolds J, Osborne RH, Chirgwin J, et al. (2015) Unmet needs and depression among carers of people newly diagnosed with cancer. *Eur J Cancer* 51: 2049-2057.
24. Frioriksdottir N, Saevarsdottir P, Halfdanardottir SI, Jonsdottir A, Magnusdottir H, et al. (2011) Family members of cancer patients: Needs, quality of life and symptoms of anxiety and depression. *Acta Oncol* 50: 252-258.
25. Regan T, Levesque JV, Lambert SD, Kelly B (2015) A qualitative investigation of health care professionals', patients' and partners' views on psychosocial issues and related interventions for couples coping with cancer. *PLoS One* 10: e0133837.
26. Kim Y, Kashy DA, Spillers RL, Evans TV (2010) Needs assessment of family caregivers of cancer survivors: Three cohorts comparison. *Psychooncology* 19: 573-582.
27. Wang T, Molassiotis A, Chung BPM, Tan JY (2018) Unmet care needs of advanced cancer patients and their informal caregivers: A systematic review. *BMC Palliat Care* 17: 96.
28. National Cancer Institute (2015) Family caregivers in cancer (PDQ®) - patient version.
29. Campbell SH, Carey M, Sanson-Fisher R, Barker D, Turner D, et al. (2014) Measuring the unmet supportive care needs of cancer support persons: The development of the support person's unmet needs survey-short form. *Eur J Cancer Care* 23: 255-262.
30. Mahendran R, Lim HA, Chua J, Peh CX, Lim SE, et al. (2015) The caregiver quality of life index-cancer (CQOLC) in Singapore: A new preliminary factor structure for caregivers of ambulatory patients with cancer. *Qual Life Res* 24: 399-404.
31. (2019) SAS Institute Inc. SAS version 9.4.
32. Han Y, Zhou Y, Wang J, Hall A, Zhao Q, et al. (2019) Chinese version of the cancer support person's unmet needs survey-sort form: A psychometric study. *Eur J Cancer Care* 28: e12963.
33. Lebel S, Ozakinci G, Humphris G, Mutsaers B, Thewes B, et al. (2016) From normal response to clinical problem: Definition and clinical features of fear of cancer recurrence. *Support Care Cancer* 24: 3265-3268.
34. Tan AS, Nagler RH, Hornik RC, DeMichele A (2015) Evolving information needs among colon, breast, and prostate cancer survivors: Results from a longitudinal mixed-effects analysis. *Cancer Epidemiol Biomarkers Prev* 24: 1071-1078.
35. Ness S, Kokal J, Fee-Schroeder K, Novotny P, Satele D, et al. (2013) Concerns across the survivorship trajectory: Results from a survey of cancer survivors. *Oncol Nurs Forum* 40: 35-42.
36. Birken SA, Mayer DK, Weiner BJ (2013) Survivorship care plans: Prevalence and barriers to use. *J Cancer Educ* 28: 290-296.
37. Mazanec SR, Gallagher P, Miano WR, Sattar A, Daly BJ (2017) Comprehensive assessment of cancer survivors' concerns to inform program development. *JCSO* 15: e155-e162.
38. Koch L, Jansen L, Brenner H, Arndt V (2013) Fear of recurrence and disease progression in long-term (≥ 5 years) cancer survivors - a systematic review of quantitative studies. *Psychooncology* 22: 1-11.
39. Cupit-Link M, Syrjala KL, Hashmi SK (2018) Damocles' syndrome revisited: Updates on the fear of cancer recurrence in the complex world of today's treatments and survivorship. *Hematol Oncol Stem Cell Ther* 11: 129-134.
40. Jimenez RB, Perez GK, Rabin J, Hall D, Quain K, et al. (2017) Fear of recurrence among cancer survivors. *Journal of Clinical Oncology* 35: 10053.
41. Sarkar S, Scherwath A, Schirmer L, Schulz-Kindermann F, Neumann K, et al. (2014) Fear of recurrence and its impact on quality of life in patients with hematological cancers in the course of allogeneic hematopoietic SCT. *Bone Marrow Transplant* 49: 1217-1222.
42. Kim Y, Carver CS, Spillers RL, Love-Ghaffari M, Kaw CK (2012) Dyadic effects of fear of recurrence on the quality of life of cancer survivors and their caregivers. *Qual Life Res* 21: 517-525.
43. Petzel MQB, Parker NH, Valentine AD, Simard S, Gonzalez GMN, et al. (2012) Fear of cancer recurrence and quality of life among survivors of pancreatic and periampullary neoplasms. *Journal of Clinical Oncology* 30: 289.
44. van den Beuken-van Everdingen MHJ, Peters ML, de Rijke JM, Schouten HC, van Kleef M, et al. (2008) Concerns of former breast cancer patients about disease recurrence: A validation and prevalence study. *Psychooncology* 17: 1137-1145.
45. Chua GP, Tan HK, Gandhi M (2018) What information do cancer patients want and how well are their needs being met? *Ecancermedicallscience* 12: 873.
46. Lund L, Ross L, Peterson MA, Groenvold M (2014) Cancer caregiving tasks and consequences and their associations with caregiver status and the caregiver's relationship to the patient: A survey. *BMC Cancer* 14: 541.
47. Girgis A, Lambert S, Lecathelinais C (2011) The supportive care needs survey for partners and caregivers of cancer survivors: Development and psychometric evaluation. *Psychooncology* 20: 387-393.

48. Lim J (2017) Sustainable health care financing: The Singapore experience. *Global Policy* 8: 103-109.
49. Alexander A, Kaluve R, Prabhu JS, Korlimarla A, Srinath BS, et al. (2019) The impact of breast cancer on the patient and the family in Indian perspective. *Indian J Palliat Care* 25: 66-72.
50. Nasrullah G (2017) Caregivers' experiences of unmet needs during palliative care. Jonkoping University, Smaland.
51. Malik FA, Gysels M, Higginson IJ (2013) Living with breathlessness: A survey of caregivers of breathless patients with lung cancer or heart failure. *Palliat Med* 27: 647-656.
52. Song JI, Shin DW, Choi JY, Kang J, Baik YJ, et al. (2011) Quality of life and mental health in family caregivers of patients with terminal cancer. *Support Care Cancer* 19: 1519-1526.
53. Northouse LL (2012) Helping patients and their family caregivers cope with cancer. *Oncol Nurs Forum* 39: 500-506.
54. Mollica M, Nemeth L (2015) Transition from patient to survivor in African American breast cancer survivors. *Cancer Nurs* 38: 16-22.
55. Ochayon L, Zelker R, Kaduri L, Kadmon I (2010) Relationship between severity of symptoms and quality of life in patients with breast cancer receiving adjuvant hormonal therapy. *Oncol Nurs Forum* 37: E349-E358.
56. Hodgkinson K, Butow P, Hunt GE, Pendlebury S, Hobbs KM, et al. (2007) Breast cancer survivors' supportive care needs 2-10 years after diagnosis. *Support Care Cancer* 15: 515-523.
57. Park CH, Shin DW, Choi JY, Kang J, Baik YJ, et al. (2012) Determinants of the burden and positivity of family caregivers of terminally ill cancer patients in Korea. *Psychooncology* 21: 282-290.
58. Ullrich A, Ascherfeld L, Marx G, Bokemeyer C, Bergelt C, et al. (2017). Quality of life, psychological burden, needs, and satisfaction during specialized inpatient palliative care in family caregivers of advanced cancer patients. *BMC Palliative Care* 16: 31.
59. Soylu C, Ozaslan E, Karaca H, Ozkan M (2016) Psychological distress and loneliness in caregiver of advanced oncological inpatients. *J Health Psychol* 21: 1896-1906.