Identifying the Unmet Supportive Care Needs, with Concomitant Influencing Factors, in Family Caregivers of Cancer Patients in China

Aifang Niu[1], Chunyong Guo[1], Daozhu Zhong[1], Guirong He[1], Wenbo Zhong[2], Lanmei Wang[1], Yu Chen[1], Lei Shang[3], Jufang Fu[4]

[1]Department of Internal Medicine, 947th Army Hospital, Kashgar, [2]Department of Internal Medicine, Xinjiang Military District General Hospital, Urumqi, Xinjiang, [3]Department of Preventive Medicine, Air Force Medical University, Xi'an, Shaanxi, [4]Nursing Department, Shenzhen University General Hospital, Shenzhen, Guangdong, China.

Corresponding author: Jufang Fu, MD. Nursing Department, Shenzhen University General Hospital, Shenzhen, Guangdong, China. E-mail: fjf688@126.com

ABSTRACT

Objective: The objective of the study is to assess the unmet needs of cancer caregivers and to identify the possible predictors of their supportive care needs in China. **Methods:** This multicenter, cross-sectional study enrolled 449 cancer patients' family caregivers' dyads. Patients provided general information and Karnofsky performance status (KPS); caregivers provided general information and completed a survey of Chinese version of the Supportive Care Needs Survey-Partners and Caregivers Scale. The independent samples *t*-test, one-way analysis of variance, and multiple stepwise regression were used to analyze the factors that influence the needs of caregivers. **Results:** A proportion of caregivers who had no needs were 5.6%. A proportion of caregivers with ≥ 5 moderate or high unmet needs and with ≥ 10 moderate or high unmet needs were 77.7% and 63.2%, respectively. Healthcare services and information needs and communication and relationship needs were the most prominent areas of caregivers' unmet needs. The item

"Finding out about financial support and government benefits for you and/or the person with cancer" was the highest level of unmet needs at 78.6%. The level of unmet needs was related to the patient's physical function (KPS score), caregiver's educational levels, financial burden of healthcare, as well as the level of burden related to caregiving (working status, caring for others, caregiving experience, and total caregiving time). **Conclusions:** The level of unmet needs of family caregivers of cancer patients in China was higher. In clinical practice, more attention should be paid to family caregivers who take care of the patient with poor physical function, those who are highly educated, faced with higher financial burden of healthcare, and are currently working, as well as those who need to take care of others, spend more time caregiving, and have no caregiving experience.

Key words: Cancer, family caregiver, needs

Introduction

At present, the incidence of cancer is increasing year by year. It was estimated that there would be 18.1 million

new cases and 9.6 million cancer deaths worldwide in 2018, of which nearly 24% of these cancer cases and 30% of deaths have occurred in China. The age-standardized cancer incidence in China is comparable to that of the overall worldwide incidence. However, China had a much higher cancer mortality than the UK and the USA.[1] With the continuous implementation of new clinical treatment modalities, the 5-year survival rate of cancer patients worldwide has reached as high as 68%,[2] and malignant tumors have now become a chronic, exhausting condition that threatens the well-being of families.

Given the effect of the disease itself as well as the impact of surgery, radiotherapy, and chemotherapy, cancer patients require ongoing attention and care from their caregivers for years or even decades. In China, the caregivers of cancer patients are often members of the family, with family carers undertaking 70%–80% of the care.[3] Traditional Chinese values such as Confucianism placed a heavy emphasis on filial piety and mutual support among kinship groups. It is an obligation for families to take care of sick parents, children, spouses, and other relatives.[4] The focus of the whole family was the cancer patients. Moreover, family caregivers' health was somewhat neglected.

Studies have shown that caregivers encounter various problems when providing care, particularly physical, psychosocial, and mental health effects, as well as economic stress.[5,6] Every day, caregivers need to deal with many problems from family, work, hospital, and society. They are too busy to aware of their own unmet needs and also unsure how to address them.[7,8] As a result, many needs are being overlooked and not met.[9] It has been shown that when caregivers' need for support and help in caring for cancer patients is not met, the caregiver's quality of life and their physical and psychological well-being suffer.[10] Their long-term quality of life,[11] their ability to care, and the quality and standard of care they provide will all experience a negative impact.[12,13] Ultimately, the patient's treatment, recovery, and subsequent quality of life with illness will be affected, which increases the suffering of the patient.[14]

China's existing healthcare system mainly focuses on cancer patients and does not view family caregivers as service receivers. Family caregivers, as a special group, have been given only negligible attention and have not received sufficient professional assistance to meet the challenges of caregiving.[15] At present, there are very few reports on the supportive care needs of cancer patient caregivers in China. Therefore, this study explored the current state of unmet needs of caregivers in China, as well as the factors that contribute to unmet needs, to provide a theoretical basis for targeted interventions that can be clinically implemented.

The purpose of this study was to examine the unmet needs of family caregivers of cancer patients in China. The specific aims were as follows:
1. To examine the prevalence of unmet needs
2. To identify factors that influence unmet needs.

Methods

Design and sample

In this study, a convenience sampling method was used to recruit participants from 15 departments treating cancer patients in five tertiary hospitals in Xi'an. The study was approved by the institutional review board. Informed written consent was obtained from all participants before their enrollments in this study.

Inclusion criteria

Patients

1. Inpatients with a pathologically confirmed diagnosis of cancer
2. The patient had no history of psychiatric disorders and had the capacity to communicate normally
3. Voluntary participation in the study.

Family caregiver

1. The caregiver was over the age of 18 years
2. The caregiver had been identified as such by the main caregiver himself/herself or by the patient, and the cumulative care time in the hospital was >72 h
3. The caregiver had no history of mental illness or psychiatric disorder and can complete the questionnaire by themselves or with the help of the investigator
4. The caregiver had knowledge of the patient's condition, agreed to participate in the research, and signed a consent form.

Exclusion criteria

Caregivers who withdrew mid-way through the study or those who refused to participate in the study were excluded.

Instruments

General situation questionnaire

Patients' and caregivers' demographic data were collected by self-report, and medical factors were collected from the medical record review with their consent. Information gathered on the patient included demographic characteristics (e.g., gender, age, religious, education level, marital status, and occupation) and their clinical situation (e.g., type of cancer, medical treatment, number of treatments). The information of caregiver included demographic date (e.g., living arrangement, relationship to patient, working status, chronic health condition, self-appraised health status, and

financial burden), and caregiving situation (e.g., daily time spent caregiving, type of care, hours of sleep per day, weekly respite, previous caregiving experience, caring for others, and total time spent caregiving).

Karnofsky performance status

The Karnofsky performance status (KPS) was defined by Dr. Joseph H. Bruchenal and Dr. David A. Karnofsky in 1949. The KPS has been widely used throughout the world for performance assessment of cancer patients for many years.[16] The functional status of a patient is assessed on an 11-point scale ranging from full well-being (100) to death (0), decreasing ten points at each level. According to the assessment results, the patients are divided into three groups; Group 1 (100–80, independent) can independently perform daily activities, Group 2 (70–50, semi-independent) can perform daily activities with help, and Group 3 (≤40, dependent) requires continuous assistance and approaches death progressively.[17]

Supportive Care Needs Scale for Caregivers of Cancer Patients

In 2011, Girgis *et al*.[18] carried out SCNS-P and C reliability, validity, and psychometric testing, which demonstrated that this tool had good reliability, validity, and internal consistency and was suitable for evaluating caregivers of cancer patients throughout a disease. Furthermore, the tool was not only capable of distinguishing between the multifaceted supportive care needs of caregivers at different stages of the disease but could also identify their unmet needs. In 2016, Chinese researchers conducted psychometric tests on SCNS-P and C, and it was found that the tool had good internal consistency. The Cronbach's alpha coefficient was between 0.79 and 0.89, and the total of the four subscales was 0.94, indicating that the tool could be used effectively to evaluate the supportive care needs of the partners and caregivers of Chinese cancer patients. The SCNS-P and C-C is comprised of a total of 45 items and four domains, including healthcare service and information needs, social and work needs, communication and relationship needs, as well as psychological and emotional needs, and mainly measures the caregiver's needs in the past month. The level of need is calculated on a 5-point scale. 1 point represents "no need," 2 points represents satisfied need, and 3 points represents a low level of unmet needs, which means the caregiver's needs have not yet been met and a little additional help is required. The higher the score, the more help is required, and the higher the level of unmet needs.[19] According to each response, we calculated the percentage of the five levels of help needed. Across four dimensions, the level of need in every entry, rank of each entry, and percentage of unmet needs were evaluated. We summed the scores overall and for each domain that

generated descriptive statistics for all variables. Cronbach's alpha for the SCNS-P and C-C in this study was 0.92.

Data collection

The data were collected by two study assistants who were trained in data collection for 1 day. From 2015 to 2016, the study participants were informed about the purpose of the study, selection criteria, and procedures, including how to fill the questionnaires. The investigator conducted the survey after obtaining consent from the relevant departments of the hospital. After the patient and caregiver signed the informed consent form, the investigator issued the questionnaire. If the caregiver or patient was unable to independently complete the questionnaire due to problems with vision, education levels, or other reasons, the investigator read the questionnaires to them and filled in their responses to each question. After the survey, responses were reviewed on the spot, and if certain parts of the questionnaire were left out or completed incorrectly, the investigator, with the caregiver's agreement, would ask for the relevant sections to be completed or amended, to ensure survey quality. The total time for data collection took approximately 30 min.

Statistical analysis

SPSS statistical software (version 21.0, IBM Corp., Armonk, NY, USA) was used to analyze the data. Frequency, percentage, mean, and standard deviation were used to describe the general information of the caregivers and patients, as well as the needs of caregivers. The independent samples *t*-test, one-way variance analysis, and multiple stepwise regression were used to analyze the factors that influence the needs of caregivers.

Results

General information

A total of 480 questionnaires were sent out to 15 departments that treat cancer patients in five tertiary hospitals in Xi'an, and 463 questionnaires were returned. 449 questionnaires were valid, giving a questionnaire efficiency of 96.9%.

The demographical and clinical characteristics data of the considered study subjects are detailed in Table 1 and Table 2. The mean age of the patients was 54.29 ± 13.18 years, the most common cancer was gastrointestinal malignancy (40.8%), diagnosed between 1 and 6 months ago (42.5%), and chemotherapy/radiotherapy was the most common treatment (67.0%). The mean age of the caregivers was 40.75 ± 12.91 years. Most caregivers were married (85.7%), currently not working (76.4%), and living with family (94.7%). Most caregivers were the son or daughter of the patients (47.2%), with family monthly

Table 1: Sample characteristics of patients (*n*=449)	
Variable	*n* (%)
Gender	
Male	226 (50.3)
Female	223 (49.7)
Age (years)	
18-40	59 (13.1)
40-50	72 (16.0)
50-60	157 (35.0)
≥60	161 (35.9)
Religious (*n*=363)	
No	339 (93.4)
Yes	24 (6.6)
Education	
Primary or below	110 (24.5)
Secondary	246 (54.8)
College or above	93 (20.7)
Marital status	
Single	15 (3.3)
Married	418 (93.1)
Other	16 (3.6)
Occupation	
Builder	71 (15.8)
Farmer	161 (35.9)
Executive	62 (13.8)
Science and technology	66 (14.7)
Business	58 (12.9)
Other	31 (6.9)
Cancer type	
Lung cancer	74 (16.5)
Gastrointestinal malignancy	183 (40.8)
Breast cancer	61 (13.6)
Hematological malignancies	69 (15.4)
Gynecological malignancies	36 (8.0)
Other	26 (5.7)
Time since diagnosis (months)	
<1	115 (25.6)
1-6	191 (42.5)
6-12	52 (11.6)
≥12	91 (20.3)
Medical treatment	
Surgery	51 (11.4)
Chemo/radiotherapy	301 (67.0)
Symptomatic treatment	21 (4.7)
Supportive treatment	73 (16.3)
Other	3 (0.7)
Number of treatments	
First treatment	104 (23.2)
Multiple treatment	345 (76.8)
KPS	
≤40	57 (12.7)
50-70	88 (19.6)
≥80	304 (67.7)
KPS: Karnofsky performance status	

income per capita lower than expenditure (55.0%). Most had to deal with medical expenses (86.7%) and the time spent per day providing care was >12 h (74.2%), with no respite throughout the week (45.9%). Most caregivers had to provide care for the patients by themselves (61.7%) and had no previous experience of providing care (57.7%).

The status of needs

In terms of domains, healthcare service and information needs ranked highest for unmet needs (60.9%), while psychological and emotional needs ranked least for unmet needs (38.4%). 61.6% of the caregivers indicated "no need or satisfied" to psychological and emotional needs. The results of this study showed that 5.6% of caregivers had no needs and a proportion of caregivers with ≥5 moderate or high unmet needs and with ≥10 moderate or high unmet needs were 77.7% and 63.2%, respectively. Table 3 lists top 10 entries for the percentage of unmet needs. Among the top 10 entries, eight entries belong to the healthcare service and information dimension. The need items corresponding to the top three highest level of unmet needs were "Finding out about financial support and government benefits for you and/or the person with cancer," "Managing concerns about the cancer coming back," and "Accessing information about the benefits and side-effects of treatments." Other results are summarized in Tables 3 and 4.

Factors influencing of unmet needs

After testing the data for normality and homogeneity of variance, we screened for single factors (*t*-test and one-way analysis of variance) that independently influenced each dimension of SCNS-P and C [Table 5]. The results reveal that one or more single factor/s were associated with and significantly influenced each dimension of SCNS-P and C. Further these factors were subjected to multiple linear stepwise regression analysis, the results of which are listed in Table 6.

Discussion

The level of unmet supportive care needs of the caregivers was relatively high. The level of needs that have been unmet in caregivers was higher than that in cancer patients in China and higher than the level in caregivers in Taiwan and abroad (American, Australia, and Germany). The results of this study showed that the proportion of caregivers who had no needs and those whose needs had been met (5.6%) were less than that reported in Sklenarova *et al.*'s survey of supportive needs of caregivers of cancer patients (14.4%). A proportion of caregivers with ≥5 moderate or high unmet needs and with ≥10 moderate or high needs were 77.7% and 63.2%, respectively, which were higher than the levels reported by Sklenarova *et al.* (56.4% vs. 43.6%).[20] These findings indicate that the survey respondents had an overall high degree of unmet needs. The rate of unmet needs for caregivers in all domains was 38.4%–60.9%, which was

Table 2: Sample characteristics of caregivers (*n*=449)	
Variable	*n* (%)
Gender	
Male	239 (53.2)
Female	210 (46.8)
Age (years)	
18-40	222 (49.4)
40-50	98 (21.8)
50-60	84 (18.7)
≥60	45 (10.0)
Religious (*n*=363)	
No	331 (91.2)
Yes	32 (8.8)
Residence	
City	287 (63.9)
Rural	162 (36.1)
Education	
Primary or below	25 (5.6)
Secondary	239 (53.2)
College and above	185 (41.2)
Marital status	
Single	59 (13.1)
Married	385 (85.7)
Other	5 (1.1)
Relationship to patient	
Spouse	190 (42.3)
Children	212 (47.2)
Parent	19 (4.2)
Other	28 (6.2)
Occupation	
Builder	96 (21.4)
Farmer	110 (24.5)
Executive	51 (11.4)
Science and technology	65 (14.5)
Business	89 (19.8)
Other	38 (8.5)
Working status	
Currently working	106 (23.6)
Currently not working	343 (76.4)
Living arrangement	
Living alone	24 (5.3)
Living with family	425 (94.7)
Self-appraised health status	
Good	243 (54.1)
Fair	135 (30.1)
Poor	62 (13.8)
Very poor	9 (2.0)
Chronic health condition (yes/no)	
No	360 (80.2)
Yes	89 (19.8)
Family monthly income per person	
Lower than expenditure	247 (55.0)
The same as expenditure	128 (28.5)
Higher than expenditure	74 (16.5)
Financial burden of healthcare	
No significant burden	60 (13.4)
Some burden	210 (46.8)
	Contd...

Table 2: Contd...	
Variable	*n* (%)
Significant burden	179 (39.9)
Daily time spent caregiving (h)	
<6	38 (8.5)
6-12	78 (17.4)
≥12	333 (74.2)
Type of care	
Caregiving with assistance	172 (38.3)
Caregiving alone	277 (61.7)
Hours of sleep per day (h)	
<6	79 (17.6)
6-8	200 (44.5)
≥8	170 (37.9)
Weekly respite	
No weekly respite	206 (45.9)
Scheduled weekly respite	103 (22.9)
Unscheduled weekly respite	140 (31.2)
Previous caregiving experience (yes/no)	
No	259 (57.7)
Yes	190 (42.3)
Caring for others (yes/no)	
No	224 (49.9)
Yes	225 (50.1)
Total time spent caregiving (months)	
<1	99 (22.0)
1-6	216 (48.1)
6-12	66 (14.7)
≥12	68 (15.1)

slightly higher than that reported in lung cancer patients by Giuliani *et al*. (22.0%–66.0%).[21] The rate of top ten unmet needs was 66.4%–78.6%, which was higher than the level of unmet needs for supportive caregivers of lung cancer patients reported by Chen *et al*. (56.1%–78.3%).[22] Since China has an economy that is still in the development phase, and the country has a relatively large population and insufficient number of medical and nursing staffs, we, as a country, have not been giving enough attention to caregivers. Indeed, as a group, family caregivers have been overlooked by public health and community services, as well as hospitals. As a result of cultural influences, caregivers view caring for patients as their own duty and responsibility. They are too busy to aware of their own unmet needs and also unsure how to address them.[7,8] As a result, many needs are being overlooked and not met. Most do not actively seek professional support. As such, as medical professionals, we should take the initiative to understand the needs of caregivers.

The results of this study showed that healthcare service and information needs and communication and relationship needs are the most prominent areas of caregivers' unmet needs. Psychological and emotional dimension was the last in the list of SCNS-P and C; within this dimension, we found

Table 3: Top 10 entries for the percentage of unmet needs (*n*=449, %)

Rank	Need item	Domain	No need or satisfied (%)	Low need (%)	Moderate need (%)	High need (%)	Total (%)
					Unmet needs		
1	Finding out information about financial support and government benefits for you and/or the person with cancer	SWN	21.3	7.8	16.9	53.9	78.6
2	Managing concerns about the cancer coming back	CRN	22.5	11.4	20.0	46.1	77.5
3	Accessing information about the benefits and side effects of treatments	HCIN	25.6	11.6	19.4	43.4	74.4
4	Reducing stress in the person with cancer's life	HCIN	26.1	9.4	15.4	49.2	73.9
5	Accessing information on what the cancer person's physical needs are likely to be	HCIN	26.5	11.8	24.3	37.4	73.5
6	Having opportunities to discuss your concerns with the doctors	HCIN	28.5	12.5	21.8	37.2	71.5
7	Accessing information about alternative therapies	HCIN	29.6	13.1	20.9	36.3	70.4
8	Accessing information about the person with cancer's prognosis or likely outcomes	HCIN	30.1	10.9	18.3	40.8	69.9
9	Obtaining the best medical care for the person with cancer	HCIN	33.6	4.5	18.9	43.0	66.4
10	Accessing local healthcare services when needed	HCIN	33.6	10.5	19.6	36.3	66.4

HCIN: Healthcare service and information needs; SWN: Social and work needs; CRN: Communication and relationship needs; PEN: Psychological and emotional needs

Table 4: Percentage for unmet needs in each dimension and range (*n*=449, %)

Domain	No need or satisfied (%)	Low need (%)	Moderate need (%)	High need (%)	Total scores
		Unmet needs			
Healthcare service and information needs	39.1	11.5	18.5	30.9	60.9
Social and work needs	53.1	13.2	13.7	20.0	46.9
Communication and relationship needs	48.4	14.0	17.2	20.4	51.6
Psychological and emotional needs	61.6	12.5	13.2	12.7	38.4
Percentage for no need or moderate/high unmet needs (percentage of carers answering 1/2 or 4/5 on each item)					Percentage
Caregivers with no need					5.6
Caregivers with at least 5 moderate or high needs					77.7
Caregivers with at least 10 moderate or high needs					63.2

that 61.6% of caregivers expressed no need and satisfied for help and 38.4% of caregivers had need for help. This result is inconsistent with the findings of other countries, such as Germany, Korea, and Iran.[20,23,24] The highest level of unmet need in this study was the domain of healthcare service and information needs, which is consistent with the results of many previous studies.[23,25-27] It can be attributed to the differences in research setting and context, as well as methodology. People from different countries may have different needs. At present, the distribution of medical resources in China is uneven. Patients are concentrated in tertiary hospitals, and there is a serious shortage of medical staffs, with a relatively large workload and a lack of communication between medical staffs and patients.[28] Little attention is paid to caregivers. Although clinical departments have adopted methods to provide care-related information to caregivers, due to traditional and cultural factors in China, family members prefer patients to have no idea about their condition, which has a limiting effect on the information medical professionals provide. However, since caregivers still have a strong need for oncology professionals to provide relevant information and educational support, it is necessary for oncology professionals to communicate effectively with caregivers and provide disease-related

services and information through appropriate health education methods.

The results of this study showed that the need item "Finding out about financial support and government benefits for you and/or the person with cancer" was the highest rate unmet needs, which is different from the results of many other countries (American, Australia, Germany, England, and Thai).[10,20,29-31] The families of cancer patients often confront payment burden at the current medical system in China. The relationship between economic burden and needs may not so significant in other countries, such as American, Australia, Germany, and England. These countries have implemented free medical treatment for citizens, which has greatly reduced the financial burden on caregivers. At the same time, a series of policies and regulations have been introduced to address the problems faced by caregivers, offering much needed policy support and legal protection for caregivers, such as statutory sickness pay, incapacity benefits, nursing allowances, carer allowances, and grants for carers,[32] all of which greatly reduce the financial burden on caregivers and at the same time provide a strong assurance for caregivers to focus on looking after patients. China is a developing country, where government investment in public hospitals is insufficient,

Table 5: Univariate analysis of supportive care needs (independent samples *t*-test or one-way analysis of variance, $\bar{x}\pm s$)				
Variable	**HCIN**	**SWN**	**CRN**	**PEN**
Carers' gender				
Male	50.37±14.35	30.77±10.16	29.85±10.18	19.76±7.95
Female	47.66±14.21	28.97±9.47	29.00±10.04	19.14±6.96
t/F	2.009	1.932	0.893	0.872
P	0.045	0.054	0.372	0.383
Carers' age (years)				
18-40	49.13±14.53	30.09±10.08	29.05±10.10	19.46±7.77
40-50	49.01±15.43	30.09±10.67	29.86±10.25	19.18±7.69
50-60	51.92±12.13	30.94±8.77	31.13±10.09	20.57±6.70
≥60	43.91±13.66	26.87±8.65	27.40±9.73	18.07±7.09
t/F	3.091	1.776	1.565	1.177
P	0.027	0.151	0.197	0.318
Carers' education				
Primary or below	40.16±14.87	28.08±9.74	27.68±8.82	18.64±6.32
Secondary	47.87±14.17	29.09±9.70	28.99±10.05	19.01±7.53
College and above	51.90±13.82	31.26±10.01	30.28±10.33	20.17±7.60
t/F	9.635	3.003	1.255	1.399
P	0.000	0.051	0.286	0.248
Self-appraised health status				
Good	49.57±14.26	29.95±10.19	29.17±10.21	19.26±7.50
Fair	49.73±14.15	30.31±9.22	29.87±9.42	20.13±7.44
Poor	45.42±13.64	27.98±8.83	28.69±10.83	17.95±6.80
Very poor	52.44±21.20	37.11±14.53	35.89±11.62	25.44±10.21
t/F	1.708	2.481	1.474	3.209
P	0.165	0.060	0.221	0.023
Working status				
Currently working	52.30±14.45	32.51±10.38	30.13±10.03	20.54±7.87
Currently not working	48.11±14.18	29.13±9.59	29.24±10.14	19.14±7.37
t/F	2.647	3.108	0.794	1.683
P	0.008	0.002	0.407	0.093
Family monthly income per person				
Lower than expenditure	50.31±13.73	31.06±9.71	30.59±9.93	20.38±7.39
The same as expenditure	47.78±14.21	28.30±9.56	27.72±9.88	18.07±7.03
Higher than expenditure	47.36±16.23	28.99±10.57	28.65±10.72	18.82±8.28
t/F	1.969	3.742	3.715	4.403
P	0.141	0.024	0.025	0.013
Financial burden of healthcare				
No significant burden	45.47±15.53	26.28±9.54	26.55±10.60	16.77±7.01
Some burden	48.93±14.16	29.54±9.95	28.92±9.89	19.12±7.33
Significant burden	50.53±13.97	31.61±9.56	31.04±9.98	20.78±7.61
t/F	2.850	7.030	5.074	7.047
P	0.059	0.001	0.007	0.001
Daily time spent caregiving (h)				
<6	50.45±15.33	31.82±10.98	29.08±11.37	20.29±8.98
6-12	47.69±13.12	27.46±8.71	27.17±9.65	18.03±6.81
≥12	49.28±14.51	30.29±9.93	30.03±10.02	19.71±7.46
t/F	0.569	3.389	2.574	1.852
P	0.567	0.035	0.077	0.158
Total time spent caregiving (months)				
<1	47.36±13.66	27.75±8.99	28.18±9.87	17.68±7.19
1-6	50.25±14.08	30.50±10.00	29.99±10.03	20.01±7.55
6-12	48.62±14.80	29.06±10.27	27.68±10.59	18.45±7.92
≥12	48.44±15.58	32.12±9.85	31.29±9.98	21.34±6.83
t/F	1.024	3.185	2.168	4.151
P	0.382	0.024	0.091	0.006

Contd...

Table 5: Contd...

Variable	HCIN	SWN	CRN	PEN
Type of care				
Caregiving with assistance	51.01±13.55	30.83±9.77	29.95±9.99	20.02±7.84
Caregiving alone	47.92±14.70	29.37±9.91	29.14±10.19	19.12±7.28
t/F	2.277	1.529	0.822	1.237
P	0.023	0.127	0.412	0.217
Previous caregiving experience (yes/no)				
No	50.66±13.26	30.58±9.63	29.86±9.87	19.69±7.30
Yes	46.98±15.47	29.05±10.15	28.89±10.43	19.17±7.78
t/F	2.708	1.623	0.996	0.724
P	0.007	0.105	0.320	0.470
Caring for others (yes/no)				
No	46.01±14.20	27.61±9.24	27.42±9.61	17.73±6.86
Yes	52.18±13.82	32.24±9.96	31.48±10.21	21.20±7.73
t/F	−4.667	−5.098	−4.338	−5.021
P	0.000	0.000	0.000	0.000
Patient' KPS score				
≤40	54.86±12.22	31.41±9.66	32.16±10.43	21.78±8.07
50-70	50.82±15.69	31.30±10.71	30.79±9.90	20.85±7.99
≥80	47.43±13.95	29.21±9.59	28.50±10.01	18.58±7.08
t/F	7.584	2.371	4.275	6.586
P	0.001	0.095	0.014	0.002

HCIN: Healthcare service and information needs; SWN: Social and work needs; CRN: Communication and relationship needs; PEN: Psychological and emotional needs; KPS: Karnofsky performance status

Table 6: Factors influencing of unmet needs (multiple linear regression analysis)

Dimension	Variable	Unstandardized coefficients		Standardized coefficients	R^2	Cumulative R^2	*t*	*P*
		B	SE	β				
Healthcare service and information needs	Constant	41.848	4.353		0.128	0.120	9.613	0.000
	Caring for others	5.915	1.276	0.207			4.636	0.000
	Carers' education	4.894	1.087	0.200			4.502	0.000
	Patient' KPS score	−3.186	0.897	−0.158			−3.552	0.000
	Caregiving experience	−3.577	1.288	−0.123			−2.776	0.006
Social and work needs	Constant	22.912	2.665		0.116	0.109	8.599	0.000
	Caring for others	4.335	0.884	0.220			4.904	0.000
	Financial burden of healthcare	2.404	0.662	0.166			3.633	0.000
	Carers' working status	−4.095	1.049	−0.176			−3.905	0.000
	Total caregiving time	1.025	0.463	0.100			2.217	0.027
Communication and relationship needs	Constant	23.870	2.719		0.071	0.065	8.778	0.000
	Caring for others	3.599	0.931	0.178			3.866	0.000
	Financial burden of healthcare	1.915	0.682	0.129			2.808	0.005
	Patient' KPS score	−1.643	0.651	−0.116			−2.524	0.012
Psychological and emotional needs	Constant	17.040	2.391		0.125	0.115	7.127	0.000
	Caring for others	3.034	0.672	0.202			4.515	0.000
	Financial burden of healthcare	1.670	0.501	0.151			3.331	0.001
	Patient' KPS score	−1.767	0.476	−0.168			−3.711	0.000
	Total caregiving time	1.005	0.355	0.129			2.833	0.005
	Carers' working status	−2.083	0.795	−0.118			−2.620	0.009

SE: Standard errors; KPS: Karnofsky performance status

the financial guarantee of the medical insurance system is weak, and individual out-of-pocket healthcare expenses are excessively high.[28] Cancer not only increases the direct financial expenditure of families but also affects the ability of caregivers to continue working as before. Caregivers have to opt for unpaid leave, reduced working hours, lower pay jobs, or working from home to meet caregiving requirements.[33] Caregiving commitment also reduces one's opportunities for employment, further causing loss of income and benefits to family members and aggravating

financial burden.[34] Hayman *et al.*[30] found that an increase of 3.1 h per week in informal care due to an increase in the level of treatment of cancer patients is equivalent to an average additional cost of $1200 (USD) per patient per year and an additional cost of more than $1 billion (USD) nationwide. Yabroff and Kim[35] found that within 2 years of diagnosis in cancer patients, the financial loss arising from informal carers' opportunity cost of time ranged from $ 38,334 to 72,702 (USD).

We found that the worse the patient's physical function, the worse the unmet needs of the caregiver, especially healthcare service and information needs, communication and relationship needs, and psychological and emotional needs. This is consistent with the results of the study by Chen *et al.* and Cui *et al.*[26,36] When patients have poor physical activity and serious illness, caregivers need to spend more time and energy taking care of them, which not only reduces the caregiver's connections to society but also adversely affect their physical and mental health.[37] Oechsle *et al.* reported that the psychological state of the main caregiver of cancer patients became worse as the patient's condition deteriorated and functional status declined.[38] This means that a series of symptoms of cancer patients were the stronger stimulus to family caregivers. Caregivers have to worry about the patient's prognosis and experience helplessness, despair, and hopelessness from fear of losing a loved one, which also affects the physical and mental health of the caregiver.

This study found that highly educated caregivers had a higher level of unmet needs, especially healthcare service and information needs, which is consistent with previous research results.[30,39] The higher the education level of caregivers, the more they want to use various resources to obtain healthcare service and information, and the higher their demand for them.[40] The reason may be that caregivers with a high level of education have higher requirements for work and life and require themselves to provide patients with higher quality of care. They need to understand or learn more information and knowledge, so they need more information and healthcare. It was also found that the heavier the burden of medical costs, the greater the level of unmet need, especially social and work needs and communication and relationship needs, which is consistent with the results of Balfe *et al.* and Cui *et al.*[31,36] A study by Girgis *et al.* found that as the treatment period lengthened, family carers' expenditure on medical fees gradually increased, and due to the increase in waiting time for diagnosis, their level of unmet financial needs also gradually increased.[41] Therefore, medical staffs should tailor interventions to address the unmet needs of caregivers based on the assessment of their needs.

The study also found that caregivers with a high burden of care experienced had a high rate of unmet needs in all dimensions. This included working caregivers, or who need to care for other family members, or who have to provide care for long periods, or who have no previous experience of providing care. In addition to their usual work commitment, caregivers who are still working must also manage the patient's treatment and life in the hospital. They often have to travel between units and have a heavy burden of care, within both the hospital and family. Therefore, clinical medical staffs should give more attention and support to caregivers who are still working, to help them complete the transition of the role smoothly and thus improve the life quality of both the patient and family. Girgis *et al.* conducted a follow-up survey of caregivers of cancer patients. As the treatment period lengthened, caregiving commitment interfered with the daily activities of caregivers and their unmet needs increased over time.[41] If the caregiver is responsible for many people, not only will this consume a lot of energy and time but extended periods of relatively heavy caregiving commitment will also affect the caregiver's physical and mental health. Experienced caregivers have caregiving knowledge and skills, as well as the ability to deal with unexpected events that occur in relation to the patient. Caregivers without prior experience, on the other hand, feel that they are not prepared for caregiving[42] or have no confidence in their caregiving ability.[43] Therefore, healthcare workers should pay more attention to caregivers who have no experience in caregiving and help them to actively cope with various difficulties.

Limitations

There are many limitations to our research. First, the convenience sampling method which we used may be a source of sampling bias. Second, this study is a cross-sectional study that is specific to a point in time and with no analysis to track the changes in supportive care needs over time. Moreover, the study does not account for any preexisting need that the caregiver had that is totally not dependent on caregiving. Third, although the response rate of the questionnaire survey was high, we cannot rule out potential nonresponse bias. Compared with the patients and caregivers who were surveyed, the supportive care needs of nonresponders may be different. Fourth, the study does not address the relationship between the individual unmet needs and the desired outcomes. This is the problem that our research team needs to solve and the focus of our future research. The study should be replicated to verify whether the results are transferable to other settings.

Conclusions

This study found that the level of unmet needs of caregivers in China is higher, while healthcare service and

information needs and communication and relationship needs are the most prominent areas of caregivers' unmet needs. Cancer not only has physical and psychosocial effects on patients but also negatively affects caregivers and even the entire family. The caregivers of cancer patients should receive more attention from medical staffs and indeed from other sections of society. We must focus on the physical and mental state, as well as the supportive care needs of caregivers, especially those looking after patients with poor physical function, as well as those caregivers who are highly educated and burdened with medical costs and heavy care commitment. Although our results are derived from data from Xi'an, we hope that the results can be generalized to the other parts of the country. When formulating and implementing interventions for caregivers, full consideration should be given to the unmet needs of caregivers to improve their life quality and thus improve the quality of their caregiving and the life quality of patients.

Financial support and sponsorship

Conflicts of interest

There are no conflicts of interest.

References

1. Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin 2018;68:394-424.

2. Jemal A, Bray F, Center MM, Ferlay J, Ward E, Forman D. Global cancer statistics. CA Cancer J Clin 2011;61:69-90.

3. Given BA, Given CW, Sherwood P. The challenge of quality cancer care for family caregivers. Semin Oncol Nurs 2012;28:205-12.

4. Neufeldt V, Guralnik DB. Webster's New World Dictionary. 3rd ed. New York, NY, USA: Webster's New World; 1988.

5. Given BA, Given CW, Sherwood PR. Family and caregiver needs over the course of the cancer trajectory. J Support Oncol 2012;10:57-64.

6. Carney S, Koetters T, Cho M, West C, Paul SM, Dunn L, *et al.* Differences in sleep disturbance parameters between oncology outpatients and their family caregivers. J Clin Oncol 2011;29:1001-6.

7. Shaw J, Harrison J, Young J, Butow P, Sandroussi C, Martin D, *et al.* Coping with newly diagnosed upper gastrointestinal cancer: A longitudinal qualitative study of family caregivers' role perception and supportive care needs. Support Care Cancer 2013;21:749-56.

8. Sherman DW, McGuire DB, Free D, Cheon JY. A pilot study of the experience of family caregivers of patients with advanced pancreatic cancer using a mixed methods approach. J Pain Symptom Manage 2014;48:385-990.

9. Richardson A, Plant H, Moore S, Medina J, Cornwall A, Ream E. Developing supportive care for family members of people with lung cancer: A feasibility study. Support Care Cancer 2007;15:1259-69.

10. Molassiotis A, Wilson B, Blair S, Howe T, Cavet J. Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners. Psychooncology 2011;20:88-97.

11. Swash B, Hulbert-Williams N, Bramwell R. Unmet psychosocial needs in haematological cancer: A systematic review. Support Care Cancer 2014;22:1131-41.

12. Pawl JD, Lee SY, Clark PC, Sherwood PR. Sleep characteristics of family caregivers of individuals with a primary malignant brain tumor. Oncol Nurs Forum 2013;40:171-9.

13. Park SM, Kim YJ, Kim S, Choi JS, Lim HY, Choi YS, *et al.* Impact of caregivers' unmet needs for supportive care on quality of terminal cancer care delivered and caregiver's workforce performance. Supportive Care Cancer 2010;18:699-706.

14. Milbury K, Badr H, Fossella F, Pisters KM, Carmack CL. Longitudinal associations between caregiver burden and patient and spouse distress in couples coping with lung cancer. Support Care Cancer 2013;21:2371-9.

15. Kim Y, Kashy DA, Spillers RL, Evans TV. Needs assessment of family caregivers of cancer survivors: Three cohorts comparison. Psychooncology 2010;19:573-82.

16. Yıldız CN, Suren M, Demir O, Okan I. Karnofsky performance scale validity and reliability of Turkish palliative cancer patients. Turk J Med Sci 2019;49:894-8.

17. Yıldız CN, Okan I. Patient approach and evaluation scales in palliative care. Turkey Klinikleri Family Med Spec Topics 2017;8:241.

18. Girgis A, Lambert S, Lecathelinais C. The supportive care needs survey for partners and caregivers of cancer survivors: Development and psychometric evaluation. Psychooncology 2011;20:387-93.

19. Liu JJ, Liu QH, He HY, Zhang T, Song YX, Wang W, *et al.* Psychometric testing of the Chinese version of supportive care needs survey for partners and caregivers of cancer patients. J Cancer Educ 2020;35:76-85.

20. Sklenarova H, Krümpelmann A, Haun MW, Friederich HC, Huber J, Thomas M, *et al.* 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 2015;121:1513-9.

21. Giuliani ME, Milne RA, Puts M, Sampson LR, Kwan JY, Le LW, *et al.* The prevalence and nature of supportive care needs in lung cancer patients. Curr Oncol 2016;23:258-65.

22. Chen SC, Chiou SC, Yu CJ, Lee YH, Liao WY, Hsieh PY, *et al.* The unmet supportive care needs-what advanced lung cancer patients' caregivers need and related factors. Support Care Cancer 2016;24:2999-3009.

23. Kim H, Yi M. Unmet needs and quality of life of family caregivers of cancer patients in South Korea. Asia Pac J Oncol Nurs 2015;2:152-9.

24. Ashrafian S, Feizollahzadeh H, Rahmani A, Davoodi A. The unmet needs of the family caregivers of patients with cancer visiting a referral hospital in Iran. Asia Pac J Oncol Nurs 2018;5:342-52.

25. Aziza YD, Wang ST, Huang MC. Unmet supportive care needs and psychological distress among parents of children with cancer in Indonesia. Psychooncology 2019;28:92-8.

26. Chen SC, Lai YH, Liao CT, Huang BS, Lin CY, Fan KH, *et al.* Unmet supportive care needs and characteristics of family caregivers of patients with oral cancer after surgery. Psychooncology 2014;23:569-77.

27. Heckel L, Fennell KM, Reynolds J, Osborne RH, Chirgwin J,

Botti M, *et al.* Unmet needs and depression among carers of people newly diagnosed with cancer. Eur J Cancer 2015;51:2049-57.

28. Pan QX, Liang LB, Wu QH. Analysis of factors influencing the doctor-patient relationship: A perspective based on the doctors and patients in public hospitals. Chin Hosp Manag 2016;36:68-70.

29. Pongthavornkamol K, Lekdamrongkul P, Pinsuntorn P, Molassiotis A. Physical symptoms, unmet needs, and quality of life in thai cancer survivors after the completion of primary treatment. Asia Pac J Oncol Nurs 2019;6:363-71.

30. Hayman JA, Langa KM, Kabeto MU, Katz SJ, DeMonner SM, Chernew ME, *et al.* Estimating the cost of informal caregiving for elderly patients with cancer. J Clin Oncol 2001;19:3219-25.

31. Balfe M, O'Brien K, Timmons A, Butow P, O' Sullivan E, Gooberman-Hill R, *et al.* The unmet supportive care needs of long-term head and neck cancer caregivers in the extended survivorship period. J Clin Nurs 2016;25:1576-86.

32. Niu AF, Fu JF, Tu WP. Yang YB, Zhang HH, He GR, Ding L. Advances in research on supportive services for primary caregivers of patients with chronic diseases. J Nurs Manag 2019;19:594-8.

33. Grunfeld E, Coyle D, Whelan T, Clinch J, Reyno L, Earle CC, *et al.* Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. CMAJ 2004;170:1795-801.

34. Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. Ann Intern Med 2000;132:451-9.

35. Yabroff KR, Kim Y. Time costs associated with informal caregiving for cancer survivors. Cancer 2009;115:4362-73.

36. Cui J, Song LJ, Zhou LJ, Meng H, Zhao JJ. Needs of family caregivers of advanced cancer patients: A survey in Shanghai of China. Eur J Cancer Care (Engl) 2014;23:562-9.

37. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. Psychooncology 2010;19:1013-25.

38. Oechsle K, Goerth K, Bokemeyer C, Mehnert A. Anxiety and depression in caregivers of terminally ill cancer patients: Impact on their perspective of the patients' symptom burden. J Palliat Med 2013;16:1095-101.

39. Longacre ML. Cancer caregivers information needs and resource preferences. J Cancer Educ 2013;28:297-305.

40. Matteo B, Pierluigi B. Descriptive survey about causes of illness given by the parents of children with cancer. Eur J Oncol Nurs 2008;12:134-41.

41. Girgis A, Lambert SD, McElduff P, Bonevski B, Lecathelinais C, Boyes A, *et al.* Some things change, some things stay the same: A longitudinal analysis of cancer caregivers' unmet supportive care needs. Psychooncology 2013;22:1557-64.

42. Schumacher KL, Stewart BJ, Archbold PG, Caparro M, Mutale F, Agrawal S. Effects of caregiving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment. Oncol Nurs Forum 2008;35:49-56.

43. Kurtz ME, Kurtz JC, Given CW, Given B. A randomized, controlled trial of a patient/caregiver symptom control intervention: Effects on depressive symptomatology of caregivers of cancer patients. J Pain Symptom Manage 2005;30:112-22.