



## Original Article

## Unmet needs, anxiety, depression, and quality of life among caregivers of adolescents and young adults with cancer: A cross-sectional study

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## ABSTRACT

**Objective:** To assess unmet needs, anxiety, depression, and quality of life of caregivers of adolescents and young adults with cancer and examine their associations.

**Methods:** A total of 282 caregivers of adolescents and young adults with cancer were recruited by convenience sampling at a tertiary cancer hospital in Chinese Mainland. The participants' unmet needs, anxiety, depression, and quality of life were assessed using self-reported questionnaires. Hierarchical regression analyses were conducted to examine associations between unmet needs and health outcomes.

**Results:** The five most prevalent high unmet needs were related to 'worries about future' and 'information', including dealing with not knowing what lies in the future ( $n = 161, 57.1\%$ ), dealing with worry about the cancer getting worse ( $n = 151, 53.5\%$ ), dealing with worry about the cancer coming back ( $n = 147, 52.1\%$ ), finding information about complementary or alternative therapies ( $n = 137, 48.6\%$ ), and finding information about the long-term side effects of treatments and medicines ( $n = 126, 44.7\%$ ). Around 40% of the caregivers reported moderate to severe anxiety and depression. After adjusting for sociodemographic and clinical characteristics, personal and emotional needs, healthcare access and continuity, and financial needs remained significantly associated with anxiety, depression, or quality of life.

**Conclusions:** Nurses need to be aware of the unmet needs of caregivers of adolescents and young adults with cancer. More effort is needed to identify services and interventions that address the unmet needs, particularly personal and emotional, healthcare access and continuity, and financial needs, to improve the caregivers' health outcomes.

## Introduction

Adolescents and young adults (AYAs) with cancer are patients who are diagnosed with cancer between 15 to 39 years old.<sup>1</sup> Since the developmental stage of AYAs with cancer involves active engagement in education, employment, fertility, and developing or sustaining a family, their psychosocial and supportive care needs have been increasingly recognized.<sup>2–4</sup> Moreover, AYAs with cancer need to be supported by their informal caregivers to face these unique challenges. Informal caregivers are people who are the primary source of help and support for patients. They may be patients' family members, partners, or close friends.<sup>5</sup> Some of these caregivers may view providing informal care for a patient with cancer as a physical, emotional, and financial burden.<sup>6</sup> This process is also a challenge for caregivers because they do not receive any professional training or structured instruction in supporting and caring for patients with cancer.<sup>5</sup> In this process, the caregivers would have

supportive care needs in various dimensions, including information, physical, psychological, financial, cancer care service, and so on.<sup>7</sup> It is important to obtain an overview of the caregivers' needs and identify which needs remain unmet. This information can provide clues about appropriate interventions for caregivers.<sup>8</sup>

Many studies have explored the needs of caregivers of adults with cancer, but only a few have specifically targeted caregivers of AYAs with cancer. One study found that 28%–36% of the parents and other caregivers of AYAs with cancer had a high or very high level of unmet needs, particularly related to information about the long-term effects of treatment and the young person's fertility.<sup>9</sup> In another study, similar findings were found.<sup>10</sup> The parents of AYAs with cancer had a high level of unmet need for information. In particular, they needed information about adolescents' and young adults' cancers and fertility issues, such as long-term treatment effects, patients' problems with having their own children, monitoring and management of cancer recurrence, and the possibility of

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getting another type of cancer. In another study,<sup>11</sup> the parents of AYAs with cancer reported a high level of need for information on pain management, diets, and emotional support, which partly remained unmet.

Being a caregiver would affect the caregivers' own health.<sup>12</sup> Previous studies have found that almost one-third of the parents of AYAs with cancer reported moderate to severe elevated anxiety and depressive symptoms.<sup>13,14</sup> Another study found that a high proportion of parents of AYAs with cancer had insomnia and a lower quality of life after transitioning to the caregiver's role.<sup>15</sup> However, this study only evaluated caregivers' overall quality of life in the past week using a single question. Such findings might fail to reflect the multidimensional quality of life of these caregivers.

Although previous studies have examined the relationship between unmet needs and health outcomes among caregivers, the majority focused on those of adults with cancer. Most studies found significant associations between unmet needs, anxiety, depression, and quality of life.<sup>16-18</sup> A few studies have focused on caregivers of AYAs with cancer.<sup>10,11</sup> A few studies have found significant negative associations between unmet needs and psychological distress among the parents of AYAs with cancer.<sup>10,11</sup> However, the kind of unmet needs that has the most significant association with these health-related variables remains unknown.

To conclude, existing knowledge of unmet needs and health outcomes among caregivers of AYAs with cancer is very limited and mostly in the Western context. While cultural differences may impact caregivers' experience,<sup>19,20</sup> additional research is needed to produce applicable evidence relevant to Chinese caregivers. To address this research gap, this study aimed to investigate the unmet needs and health outcomes (anxiety, depression, and quality of life) among caregivers of AYAs with cancer in China. The primary objective of this study was to examine and rank the unmet needs of caregivers of AYAs with cancer. We also assessed three health-related outcomes in caregivers—namely, anxiety, depression, and quality of life—and examined the associations between caregivers' unmet needs and these outcomes.

## Methods

### Design

This study was a cross-sectional descriptive, correlational study. Ethical approval was obtained from Survey and Behavioral Research Ethics Committee of the Chinese University of Hong Kong (Ref. No.: SBRE-20-792) and the study hospital (Ref. No.: 2021-33).

### Setting and subjects

This study was conducted in the inpatient wards of a tertiary cancer hospital in Changsha, Hunan Province, China. With more than 1000 beds, this provincial hospital serves patients with cancer and with various diagnoses from both rural and urban areas. Participants were recruited by a convenience sampling method from the caregivers of AYAs with cancer who were hospitalized between July and September 2021. The inclusion criteria were (1) caregivers who were caring for AYAs with cancer, who are diagnosed with any type of cancer between 15 and 39 years of age (if there were two or more caregivers, the one undertaking the main caregiving responsibility was included); (2) aged above 18 years; (3) able to communicate in Chinese; (4) able to provide informed consent to participate in this study. The exclusion criteria were (1) caregivers who were being paid; (2) caregivers of AYAs with cancer who were receiving hospice care; (3) caregivers who were mentally unstable and had cognitive impairments that resulted in the inability to participate in the investigation.

### Sample size planning

The sample size of this cross-sectional study was determined based on the precision for estimating the levels of unmet needs of caregivers of

AYAs with cancer. By using the sample size formula for estimating the mean of a continuous variable with the width of 95% confidence interval confined to  $d [n = 4SD^2(1.96)^2/d^2]$ ,<sup>21</sup> a sample size of 246 participants is required to estimate the mean levels of unmet needs with a precision of  $\pm 1/8$  SD, which is generally considered to be precise enough.<sup>22</sup> Allowing for up to 10% incompleteness or invalid responses in questionnaires, the target sample size for this stage is 274.

### Outcome measures

#### Sociodemographic and clinical characteristics

Caregivers' sociodemographic characteristics (ie. gender, age, education level, marital status, place of residence, employment, family income, and relationship with the patients) and patients' sociodemographic characteristics (ie. gender, age, and medical insurance) as well as clinical characteristics (ie. type of cancer, age when diagnosed, stage of cancer, and current treatment) were collected using a structured data collection form.

#### Unmet needs

Unmet needs were assessed using the Chinese version of the Support Person's Unmet Needs Survey-Short Form (SPUNS-SF). The SPUNS-SF is a short version of Support Person's Unmet Needs Survey that is used to comprehensively evaluate the caregivers' unmet needs.<sup>23</sup> The Chinese version of SPUNS-SF (SPUNS-SFC) has 21 items in total and four subscales: information needs, worries about future, financial needs, healthcare access and continuity, and personal and emotional needs<sup>24</sup>; all items are rated on a 5-point Likert scale ranging from 'no unmet need (0)' to 'very high unmet need (4)'. Responses with a score of 0 were identified as 'None'; responses scored 1 or 2 were combined into 'Low to Moderate level' unmet needs, and those scored 3 or 4 were combined and classified as 'High level' unmet needs. Scores of each subscale and the total score are summed up to indicate the unmet needs of each dimension and the total unmet needs, respectively. A mean score ranging from 0 to 4 can be calculated for each dimension, with a higher score representing a higher level of unmet need. The SPUNS-SFC was validated in 1026 Chinese caregivers of patients with cancer and showed good internal consistency (Cronbach's alpha = 0.94) and construct validity.<sup>24</sup>

#### Anxiety

Anxiety was assessed using the generalized anxiety disorder scale (GAD-7). The GAD-7 is a seven-item self-reported scale used to evaluate the respondents' experience of anxiety. The respondents are asked how often they have been bothered by the listed seven core symptoms of GAD in the past two weeks. Response options are 'not at all (0)', 'several days (1)', 'more than half of the days (2)', and 'nearly every day (3)'. Therefore, the total score ranges from 0 to 21. The thresholds of  $\geq 5$ ,  $\geq 10$ , and  $\geq 15$  represent mild, moderate, and severe anxiety levels, respectively.<sup>25,26</sup> A threshold of  $\geq 10$  was used as the cut-off score for clinically significant anxiety.<sup>27</sup> The Chinese version of GAD-7 has good internal consistency (Cronbach's alpha = 0.898).<sup>27</sup>

#### Depression

Depression was assessed using the patient health questionnaire-9 (PHQ-9). The PHQ-9 is an instrument used to evaluate the severity of depression in the general population during the past two weeks. A 4-point Likert scale was used to rate the degree of severity from 'not at all (0)' to 'nearly every day (3)'. The total score of PHQ-9 ranges from 0 to 27, with the thresholds of  $\geq 5$ ,  $\geq 10$ ,  $\geq 15$ , and  $\geq 20$  representing mild, moderate, moderately severe, and severe depression.<sup>28,29</sup> A threshold of  $\geq 10$  was used as the cut-off score for clinically significant depression.<sup>30</sup> The simplified Chinese version of PHQ-9 has shown good internal consistency (Cronbach's alpha = 0.857).<sup>31</sup>

#### Quality of life

Quality of life was assessed using the Quality of Life Scale-Family Version. This tool is a self-reported questionnaire developed by the

National Medical Centre and Institute to evaluate the quality of life of caregivers of patients with cancer.<sup>32</sup> The Chinese version of the Quality of Life Scale-Family Version was validated by Liu et al.<sup>33</sup> It has 35 items in total and four dimensions: physical well-being (7 items), psychological well-being (10 items), social concerns (9 items), and spiritual well-being (9 items). The items 1–4, 6, 8, 12–19, 21, 23–28, and 32 need to be scored in reverse order. The total score ranges from 0 to 350. The Chinese version of the QOL scale demonstrates good internal consistency (Cronbach's alpha = 0.794) and construct validity and has been used widely among caregivers of patients with cancer.

#### Data collection procedures

Five postgraduate nursing students with previous data collection experience in nursing research were recruited as research assistants. After being trained by the principal investigator, they collected data in the inpatient ward of the study site. The research assistants recruited the caregivers by identifying AYAs with cancer, assessing the eligibility of their caregivers, and explaining study procedures. After providing informed consent, the participants completed the questionnaires. Any questions about the items in the survey were answered by the research assistants. If the participants had difficulty in reading the written questions, the research assistants read the questions and options to the patients without inducement. After they completed the questionnaire, the research assistants checked the questionnaires and reminded the participants to complete unanswered questions on a voluntary basis.

#### Data analysis

IBM SPSS 26.0 (IBM Corp., Armonk, NY) was used for data analysis. The sociodemographic and clinical characteristics, as well as the caregivers' unmet needs, anxiety, depression, and quality of life were summarized using appropriate descriptive statistics. All continuous data were checked for normality by their skewness and kurtosis statistics. Normality is determined if both skewness and kurtosis of the data are between  $-2$  and  $+2$ .<sup>34</sup> Continuous variables are presented as means (standard deviations) if they were normally distributed and as medians (inter-quartile ranges) if they were non-normally distributed, while categorical variables were expressed as numbers ( $n$ ) and percentages (%).

Associations of unmet needs with anxiety, depression, and quality of life were examined using hierarchical regression analysis with the three health outcome variables set as dependent variables separately. First, all sociodemographic and clinical characteristics were entered into the model. Second, scores of each of the five dimensions of unmet needs were entered into the second block of the model separately, to assess their increments in  $R^2$  (proportion of variance explained in the dependent variable). The unmet dimension score which had the greatest significant increment in  $R^2$  was retained in the second block. Third, the remaining unmet needs dimensions were input into the third block of the model and the procedures in step 2 were repeated until no more dimension score had a significant increment in  $R^2$ . The values for the unstandardized regression coefficient ( $B$ ), 95% confidence intervals,  $R^2$ , the change in  $R^2$ , and the change in  $F$  are presented for each step, together with the  $p$ -values of the  $F$ -test for the change in  $R^2$ . Dummy codings were applied for categorical variables with the first category as the reference category.<sup>35</sup> All statistical tests were two-tailed; a  $P$ -value below 0.05 was considered statistically significant.

## Results

#### Sociodemographic and clinical characteristics

We approached 587 caregivers of AYAs with cancer, among whom 293 caregivers agreed to participate in this study. Eleven participants

refused to complete the questionnaires. Finally, a total of 282 valid questionnaires were obtained. The results of the normality test show that all of the continuous variables were normally distributed.

Among the 282 caregivers of AYAs with cancer, half were female (50.4%); their mean age was 40.9 (SD = 10.08), ranging from 19 to 70 years. Most of the caregivers had a junior high-school level of education (35.8%), were married (94.0%), lived in rural areas (64.9%), and were unemployed (55.3%). The per capita monthly family income of most of the caregivers was 3001–5000 Chinese Yuan. More than half of the caregivers (53.2%) were the spouses or partners of the AYAs. The majority of the AYAs with cancer being cared for were female (70.6%). The average age of the patients was 31.61 (SD = 6.72, range = 15–43). The majority of the patients (92.6%) had medical insurance. Regarding the clinical characteristics of the AYAs, all had been diagnosed with cancer when they were aged 15–39 (mean age at diagnosis = 31.29, SD = 6.73). More than one-third had been diagnosed with head and neck cancer (35.1%) and approximately one-third were diagnosed at stage 2 (31.6%) and most (50.7%) were receiving chemotherapy. Other information about the caregivers and patients is presented in Table 1.

#### Unmet needs

The mean scores of each unmet need dimensions and the responses to the individual unmet need items are listed in Table 2. Among the caregivers, 98.9% had at least one unmet need. The five most prevalent unmet needs rated as 'high level' were dealing with not knowing what lies in the future ( $n = 161$ , 57.1%), dealing with worry about the cancer getting worse ( $n = 151$ , 53.5%), dealing with worry about the cancer coming back ( $n = 147$ , 52.1%), finding information about complementary or alternative therapies ( $n = 137$ , 48.6%), and finding information about the long-term side effects of treatments and medicines ( $n = 126$ , 44.7%). The top three items were in the 'worries about future' dimension and the other two were in the 'information needs' dimension.

#### Anxiety, depression, and quality of life

The mean score of anxiety among caregivers of AYAs with cancer was 9.37 (SD = 5.69), ranging from 0 to 21. Among 282 caregivers, 79.4% had at least mild anxiety, with 39.4% reporting moderate to severe levels of anxiety. The mean score of depression among caregivers of AYAs with cancer was 8.71 (SD = 6.43), ranging from 0 to 27. Among 282 caregivers, 67.4% had at least mild depression symptoms, with 40.4% reporting moderate to severe depression symptoms (Table 3).

The mean score of overall quality of life was 165.91 (of a possible 350), showing impairment in perceived overall quality of life. The scores of different dimensions of their quality of life are presented in Table 4. Out of the four dimensions of quality of life, the caregivers' psychological well-being was the lowest, followed by social, spiritual, and physical well-being.

#### Associations between unmet needs, anxiety, depression, and quality of life

##### Unmet needs and anxiety

After adjusting for the sociodemographic and clinical characteristics, the five dimensions of unmet needs were input into the model.  $R^2$  changes were 0.081, 0.139, 0.096, 0.136, and 0.240 for information needs, worries about future, financial needs, healthcare access and continuity, and personal and emotional needs, respectively. The final model (Table 5) showed that, after adjusting for sociodemographic and clinical characteristics, personal and emotional needs ( $B = 0.524$ , 95% CI: 0.383, 0.665,  $P < 0.001$ ), and healthcare access and continuity ( $B = 0.187$ , 95% CI: 0.069, 0.305,  $P = 0.002$ ) were both significantly associated with increased caregivers' anxiety level.

##### Unmet needs and depression

After adjusting for all the sociodemographic and clinical characteristics, the five dimensions of unmet needs were input into the model.  $R^2$

**Table 1**

The sociodemographic characteristics and clinical characteristics of caregivers and AYAs with cancer (N = 282).

Variable	n	%	Variable	n	%
<b>Caregivers</b>					
Age (years)	Mean ± SD: 40.9±10.08 (range: 19–70)				
<b>Gender</b>					
Male	140	49.6	<b>Employment</b>		
Female	142	50.4	Employed	126	44.7
<b>Education level</b>					
Primary school or below	35	12.4	Not being employed	156	55.3
Junior high-school	101	35.8	<b>Family income (Per capita monthly)</b>		
Senior high-school	68	24.1	1000 CNY <sup>a</sup> /month or below	46	16.3
College or above	78	27.7	1001-3000 CNY/month	83	29.4
<b>Marital status</b>					
Married	265	94.0	3001-5000 CNY/month	92	32.6
Unmarried/Widowed/divorced	17	6.0	5001-8000 CNY/month	39	13.8
<b>Place of residence</b>					
Urban	99	35.1	8001 CNY/month or above	22	7.8
Rural	183	64.9	<b>Relationship with the patients</b>		
<b>AYAs with cancer</b>					
Age (years)	Mean ± SD: 31.61 ± 6.72 (range: 15–43)				
<b>Gender</b>					
Male	83	29.4	Spouses/partners	150	53.2
Female	199	70.6	Parents	91	32.3
<b>Whether having medical insurance</b>					
No	21	7.4	Others <sup>b</sup>	41	14.5
Yes	261	92.6	<b>Stage of cancer</b>		
<b>Type of cancer</b>					
Head and neck	99	35.1	Stage 1	42	14.9
Gynecological	35	12.4	Stage 2	89	31.6
Lymphoma	22	7.8	Stage 3	40	14.2
Breast	72	25.5	Stage 4	40	14.2
Sarcoma	23	8.2	Unclear	71	25.2
Other <sup>c</sup>	31	11.0	<b>Current treatment</b>		
<b>Age when diagnosed (years)</b>					
Mean ± SD: 31.29 ± 6.73 (range: 15–39)					
			Surgery	130	46.1
			Chemotherapy	143	50.7
			Others <sup>d</sup>	9	3.2

<sup>a</sup> 1 CNY = 0.16 USD (March 25, 2022; Source: <https://www.xe.com/>).

<sup>b</sup> Siblings, sons, daughters, and other relative relationships.

<sup>c</sup> Gastrointestinal and liver cancer, brain cancer, lung cancer, melanoma, pancreatic cancer, esophagus cancer, germinoma.

<sup>d</sup> Radiotherapy and Traditional Chinese Medicine therapy.

changes were 0.082, 0.087, 0.068, 0.144, and 0.203 for information needs, worries about future, financial needs, healthcare access and continuity, and personal and emotional needs, respectively. The final model (Table 5) showed that, after adjusting for sociodemographic and clinical characteristics, personal and emotional needs (B = 0.508, 95% CI: 0.347, 0.669,  $P < 0.001$ ), and healthcare access and continuity (B = 0.258, 95% CI: 0.124, 0.393,  $P < 0.001$ ) were both significantly associated with increased caregivers' depression level.

#### Unmet needs and quality of life

After adjusting for all the sociodemographic and clinical characteristics, the different five dimensions of unmet needs were input into the model.  $R^2$  changes were 0.043, 0.089, 0.108, 0.039, and 0.216 for information needs, worries about future, financial needs, healthcare access and continuity, and personal and emotional needs, respectively. The final model (Table 5) showed that personal and emotional needs (B = -3.864, 95% CI: -4.828, -2.899,  $P < 0.001$ ) and financial needs (B = -2.800, 95% CI: -4.737, -0.864,  $P = 0.005$ ) were both significantly associated with the decreased level of caregivers' quality of life after adjusting for sociodemographic and clinical characteristics.

#### Discussion

To the best of our knowledge, this cross-sectional study is the first to assess unmet needs, anxiety, depression, and quality of life among caregivers of AYAs with cancer and examine the associations of the unmet needs with these health outcomes. The results contribute to a better understanding of the unmet needs and health-related outcomes of caregivers of AYAs with cancer and serve as a basis to inform the development of appropriate interventions.

In this study, 98.9% of the caregivers had at least one unmet need, suggesting that unmet needs were common among caregivers of AYAs with cancer. Among all unmet needs, the three most prevalent high unmet needs were related to the 'worries about future' dimension; this was similar to findings of previous studies that used the same needs assessment instrument among caregivers of adult patients with cancer.<sup>24,36</sup> The high unmet needs on the three items in worries about future can be explained by the long-term effects and uncertainty associated with cancer treatment. Given the advancement of cancer treatment, the five-year survival of adolescent and young adult patients is currently higher than 80%.<sup>37</sup> However, great uncertainty about cancer progression and recurrence still exists. Meanwhile, the AYAs with cancer were at a relatively young age (ie. 15-43 years old) in this study; cancer and its treatments may have long-term impacts on their lives, including effects on physical health, mental health, education, work, and family planning.<sup>38</sup> Therefore, their caregivers expressed high levels of worries about future. This finding indicated that these unmet needs should be prioritized and worries about future need to be addressed proactively in clinical practice. In the SPUNS-SFC, items regarding caregivers' worries about future were related to the uncertainties of disease progression. While this uncertainty may not be easily manageable for health care providers, it is very critical to support the caregivers emotionally and foster their positive thinking to relieve their worries.<sup>39</sup>

The other two items in the five most prevalent high unmet needs belonged to the information needs. This finding differed from a previous study in Australia,<sup>40</sup> which found that personal needs were reported most frequently in the high unmet needs apart from 'worries about future'. This difference may be caused by the different cultural contexts. In traditional Chinese cultures, it is believed that individuals have a responsibility to care for ill family members.<sup>41</sup> Consequently, they may

**Table 2**  
Distribution of responses obtained for each unmet need (N = 282).

Unmet needs	No unmet needs, n (%)	Low to moderate level unmet needs, n (%)	High level unmet needs, n (%)	Rank <sup>a</sup>
<b>Information (Mean ± SD: 1.93 ± 1.07)</b>				
1. Finding information about how to manage the illness at home	52 (18.4)	125 (44.3)	105 (37.2)	9
2. Finding information about cancer and its impact on sexual relationships	69 (24.5)	117 (41.5)	96 (34.1)	11
3. Being able to talk openly about my feelings or worries with healthcare professionals	87 (30.9)	117 (41.5)	78 (27.7)	15
4. Finding information about complementary or alternative therapies	52 (18.4)	93 (33.0)	137 (48.6)	4
5. Finding information about the long-term side effects of treatments and medicines	55 (19.5)	101 (35.8)	126 (44.7)	5
6. Knowing how to speak openly about cancer with the person I support	83 (29.4)	111 (39.4)	88 (31.2)	12
<b>Worries about future (Mean ± SD: 2.48 ± 1.34)</b>				
7. Dealing with worry about the cancer coming back	32 (11.3)	103 (36.5)	147 (52.1)	3
8. Dealing with worry about the cancer getting worse	35 (12.4)	96 (34.0)	151 (53.5)	2
9. Dealing with not knowing what lies in the future	33 (11.7)	88 (31.2)	161 (57.1)	1
<b>Financial (Mean ± SD: 1.85 ± 1.25)</b>				
10. Paying non-medical costs (such as travel, special foods)	60 (21.3)	139 (49.3)	83 (29.4)	14
11. Finding and getting financial help	67 (23.8)	104 (36.9)	111 (39.4)	7
<b>Healthcare access and continuity (Mean ± SD: 1.78 ± 1.14)</b>				
12. Having access to a variety of healthcare services and providers (dietitians, physiotherapists, occupational therapists)	43 (15.2)	116 (41.1)	123 (43.6)	6
13. Getting appointments with healthcare providers quickly enough	81 (28.7)	127 (45.0)	74 (26.2)	16
14. Making sure the person I support could see the same healthcare professional at each follow-up visit	82 (29.1)	115 (40.8)	85 (30.1)	13
15. Having enough time with the doctor	59 (20.9)	113 (40.1)	110 (39.0)	8
16. Getting test results for the person I support quickly enough	83 (29.4)	130 (46.1)	69 (24.5)	17
<b>Personal and Emotional Needs (Mean ± SD: 1.75 ± 0.95)</b>				
17. Not sleeping well	50 (17.7)	154 (54.6)	78 (27.7)	15
18. Dealing with feeling stressed	31 (11.0)	141 (50.0)	110 (39.0)	8
19. Dealing with worries about the emotional well-being of your family	34 (12.1)	150 (53.2)	98 (34.8)	10
20. Working around the house (cooking, cleaning, home repairs, etc.)	94 (33.3)	146 (51.8)	42 (14.9)	19
21. Dealing with feeling like I'm letting the person I support down	71 (25.2)	153 (54.3)	58 (20.6)	18
<b>Total unmet needs (Mean ± SD: 1.92 ± 0.89)</b>				

<sup>a</sup> Ranked by the proportion of participants rating the unmet needs as high unmet.

often neglect their own health/personal needs and place additional emphasis on their family members' health. This could explain the relatively low levels of personal and emotional needs in this study. In addition, we recognized the high unmet needs on the two items in

**Table 3**  
Anxiety and depression among caregivers of AYAs with cancer (N = 282).

Variable	n	%
<b>Anxiety</b>		
No	58	20.6
Mild	113	40.1
Moderately	53	18.8
Severe	58	20.6
<b>Depression</b>		
No	92	32.6
Mild	76	27.0
Moderate	63	22.3
Moderately severe	29	10.3
Severe	22	7.8

‘information needs’; accordingly, healthcare professionals could provide caregivers with relevant information via verbal education, written material, and social media.

Another important finding was that caregivers' psychological health warrants our attention. In this study, we found that 39.4% and 40.4% of caregivers reported moderate to severe levels of anxiety and depression, respectively. The prevalence of clinically significant anxiety and depression among caregivers of AYAs with cancer in our study was higher than that in previous studies conducted in other countries.<sup>13,14</sup> The relatively high proportion of anxiety and depression can be explained by the following reasons. First, the illness of family members and caring-related issues were major stressors creating a psychological burden for caregivers.<sup>42,43</sup> Further, the patients being cared for in this study were mainly young adult patients with cancer. In Chinese Mainland, the most common family structures are nuclear families (parents living with their unmarried children or single parents living with their unmarried children, regardless of the age of the unmarried children) or extended families (older parents living with their married children and



**Table 4**  
Quality of life among caregivers of AYAs with cancer (N = 282).

Variable	Mean score (Mean ± SD)	Actual range of score	Item-average score (Mean ± SD)
Physical well-being	43.47 ± 12.06	11–70	6.21 ± 1.72
Psychological well-being	25.88 ± 15.21	0–83	2.59 ± 1.52
Social concerns	43.72 ± 15.08	10–82	4.86 ± 1.68
Spiritual well-being	52.84 ± 14.27	5–88	5.87 ± 1.59
Overall	165.91 ± 42.84	41–305	4.74 ± 1.22

their spouses, and possibly also living with other relatives [ie. three or four generations living under the same roof]).<sup>44</sup> In these family structures, married children and their spouses (both of whom are young adults) are usually the core supporting members. Therefore, the illness of young adults caused great stress for the family. The patients' spouses may need to undertake more responsibilities and burdens, facing more practical issues, such as parenting young children, supporting elder parents, and sustaining a marriage. These issues, apart from the care tasks, would further increase the psychological burden of caregivers. In addition, because of the one-child policy from 1979 to 2015 in the Chinese Mainland,<sup>45</sup> patients' parents may need to cope with the risk of losing their only child. This risk would pose a great psychological burden for parents.<sup>46</sup>

In this study, the overall quality of life of caregivers of AYAs was much lower than that reported in other studies conducted on caregivers of adults with cancer in Western countries with the same assessment instrument.<sup>47,48</sup> This finding revealed that the quality of life of the caregivers in this study was impaired, which may be related to the patients' illnesses and the care tasks.<sup>15,43,49</sup> Among all dimensions of quality of life, the caregivers' psychological well-being was the lowest, which was consistent with previous studies.<sup>47,50,51</sup> The lowest score of psychological well-being was consistent with the relatively high level of anxiety and depression in this study. This finding emphasized the significance of focusing on caregivers' psychological health.

In terms of the association between the unmet needs and health outcomes, we found that personal and emotional needs, and healthcare access and continuity were significantly associated with caregivers' anxiety and depression, while personal and emotional needs and financial needs were significantly associated with lower quality of life among caregivers. The results were similar to those of a previous study,<sup>17</sup> which found that unmet needs related to psychological problems were the most

**Table 5**  
Hierarchical regression analyses of anxiety, depression and quality of life among caregivers of AYAs with cancer (N = 282).

	B	95% CI	R <sup>2</sup>	R <sup>2</sup> change	F Change	P-value
Anxiety as the dependent variable						
Model 0			0.144			
Model 1			0.384	0.240	97.563	< 0.001
Personal and emotional needs	0.631	0.505, 0.757				
Model 2			0.407	0.023	9.739	0.002
Personal and emotional needs	0.524	0.383, 0.665				
Healthcare access and continuity	0.187	0.069, 0.305				
Depression as the dependent variable						
Model 0			0.156			
Model 1			0.359	0.203	79.293	< 0.001
Personal and emotional needs	0.657	0.511, 0.802				
Model 2			0.393	0.035	14.252	< 0.001
Personal and emotional needs	0.508	0.347, 0.669				
Healthcare access and continuity	0.258	0.124, 0.393				
Quality of life as the dependent variable						
Model 0			0.270			
Model 1			0.486	0.216	105.459	< 0.001
Personal and emotional needs	-4.514	-5.379, -3.648				
Model 2			0.502	0.016	8.115	0.005
Personal and emotional needs	-3.864	-4.828, -2.899				
Financial needs	-2.800	-4.737, -0.864				

Model 0 include all sociodemographic and clinical characteristics listed in Table 1; Model 1 and Model 2 include sociodemographic and clinical characteristics and the ent.

influential unmet needs on caregivers' quality of life. These results indicate that healthcare services addressing the personal and emotional needs, healthcare access and continuity, and financial needs need to be strengthened, so as to improve caregivers' health.

Through the above-mentioned results, we interestingly found that the most prevalent high unmet needs were not associated with health outcomes but other less prevalent high unmet needs were associated with severe anxiety and depression and poor quality of life. In this study, the top five high unmet needs were related to 'worries about future' and 'information', which were not associated with health outcomes significantly. These results revealed that the most prevalent high unmet needs are not necessarily the most distressing ones. Therefore, prevalence is not the only indicator when selecting which needs to address. We need to pay additional attention to the unmet needs associated with the caregivers' health outcomes.

*Implications*

This study has important implications for nursing practice and research. In clinical practice, caregivers are always neglected despite being termed 'invisible patients'.<sup>52</sup> The association of unmet needs with the caregivers' health indicated the imperative for nurses, who have the closest contact with these caregivers, to fulfill their unmet needs in clinical practice. Apart from implications in nursing clinical practice, this study also demonstrates the need for nurse researchers to develop interventions, which address caregivers' unmet needs and improve their health. Nurse researchers could draw upon interventions developed for the caregivers of adult patients with cancer to develop and apply interventions to support caregivers of AYAs with cancer. Some interventions for caregivers of adult patients with cancer have recently been developed and their possible mechanisms elucidated with reference to theoretical frameworks such as stress and coping theory frameworks.<sup>53</sup> However, these frameworks lack perspectives on the actual needs of caregivers and failure to meet these needs may compromise the effectiveness of interventions and lead to participant dropout.<sup>53</sup> Therefore, interventions based on caregivers' unmet needs are required to improve outcomes.<sup>8</sup> In order to design effective interventions for caregivers, the most prominent and distressing unmet needs must be targeted.<sup>53</sup> In this study, we found that needs relevant to worries about future and information were the two highest unmet needs among the caregivers. Personal and emotional needs, health care and continuity, and financial needs were the most distressing ones associated with their anxiety, depression,

or quality of life. Therefore, the interventions for caregivers need address all these unmet needs.

### Strengths and limitations

This study had several strengths. First, to the best of our knowledge, this is the first study to assess the unmet needs, anxiety, depression, and quality of life among caregivers of AYAs with cancer in China. Considering the special psychosocial needs of AYAs with cancer, this research is of great importance to know more about their caregivers and draw attention to this under-recognized population. Second, we also further explored the associations of different unmet needs with anxiety, depression, and quality of life, to examine which kinds of unmet needs had significant associations with the caregivers' health. Research in this area remains limited.

The limitations of this study also need to be acknowledged. The participants were recruited from only one hospital. Although they came from different areas of the province, the results may be limited in generalizability to populations in other regions. We assessed the unmet needs of caregivers of AYAs with cancer using a questionnaire suitable for caregivers of adult patients with cancer. Needs that are specific to these caregivers might have been ignored. Specific needs assessment instrument targeting caregivers of AYAs with cancer warrants further research.

### Conclusions

The results of this study showed that almost all of the caregivers (98.9%) of AYAs with cancer had at least one unmet need. Around 40% of the caregivers reported moderate to severe levels of anxiety and depression. The caregivers' personal and emotional needs, healthcare access and continuity, and financial needs were associated with their anxiety, depression, or quality of life, respectively. Nurses need to be aware of the unmet needs of caregivers of AYAs with cancer. The findings indicate that unmet needs, particularly personal and emotional, healthcare access and continuity, and financial needs, can have adverse impacts on psychological well-being and quality of life in caregivers of AYAs with cancer. More effort is needed to identify services and interventions that address the unmet needs throughout the cancer care continuum in order to improve the caregivers' health-related outcomes.

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### Author contributions

Qinqin Cheng: Conceptualization, Methodology, Resources, Data curation, Formal analysis, Writing-original draft. Marques S. N. Ng: Supervision, Writing-review & editing. Kai Chow Choi: Formal analysis, Writing-review & editing. Winnie K.W. So: Supervision, Methodology, Writing-review & editing. All authors have read and approved the final version of the article.

### Declaration of competing interest

The corresponding author, Prof. Winnie, K. W. So, is the Editor-in-Chief of the journal. The article was subject to the journal's standard procedures, with peer review handled independently of Prof. So and their research groups.

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