

# Factors Contributing to the Unmet Needs of Primary Caregivers of Omani Children Diagnosed with Leukemia

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## ABSTRACT

**Objectives:** Childhood cancers affect 6.7% of those under 14 in Oman, with leukemia being the most common. The psychological distress of having a child with leukemia is often compounded by perceived unmet needs by the child's primary caregiver. We aimed to identify factors contributing to perceived unmet needs among primary caregivers of Omani children with leukemia. **Methods:** We conducted a cross-sectional study among 119 Omani caregivers accompanying their children to the National Oncology Center, Muscat, Oman. We used an Arabic version of the Needs Assessment of Family Caregivers-Cancer (NAFC-C) questionnaire to assess perceived unmet needs in seven domains. **Results:** A total of 119 Omani primary caregivers were contacted; 101 agreed to participate in the study (response rate: 84.9%). Linear regression analysis showed significant correlations between total NAFC-C scores and the child's ( $p = 0.014$ ) and caregiver's age ( $p < 0.001$ ), and employment status ( $p = 0.024$ ) and income ( $p = 0.028$ ). Unmet needs in the obtaining information domain correlated with caregiver's age ( $p < 0.001$ ), caring time ( $p = 0.018$ ), and number of family members ( $p < 0.001$ ), whereas needs in the maintaining own strength domain correlated with the child's gender ( $p = 0.028$ ), time since diagnosis ( $p = 0.004$ ), caregiver's age ( $p < 0.001$ ), and education level ( $p = 0.019$ ). Unmet needs in the accompanying the sick child domain were correlated with the child's gender ( $p = 0.049$ ), caregiver's gender ( $p < 0.001$ ), and income ( $p < 0.001$ ). **Conclusions:** Various sociodemographic variables affected the unmet needs of primary caregivers of children with leukemias in Oman. Healthcare professionals in Oman should be aware of such factors to reduce caregiver distress.

Childhood cancers account for 2%–3% of all cancers, affecting more than 300 000 children worldwide annually, with the incidence of such cancers expected to increase in the future.<sup>1</sup> Globally, leukemia is the most common type of childhood cancer (34%), followed by brain tumors (23%) and lymphoma (12%).<sup>2</sup>

In the Gulf Cooperation Council region, cancers in children under the age of 15 years accounted for 4.0%–9.5% of all registered cancer cases between 1998–2001.<sup>3</sup> In low- and middle-income countries, the burden of childhood cancers is greater than in high-income countries, with the likelihood of death being four times higher.<sup>4</sup> In general, most childhood cancer-related causes of death in low- and middle-income countries can be attributed to a lack of access to care, limited

treatment resources and specialized training, and delays in diagnosis.<sup>1,4</sup>

A diagnosis of childhood cancer can have a profound social, emotional, financial, and psychological impacts on the affected child and their primary caregivers.<sup>5</sup> In this context, a primary caregiver is defined as the individual who provides the greatest amount of care to and accepts responsibility for the sick child during the illness, treatment, and rehabilitation process.<sup>6,7</sup> These individuals may experience a great deal of fear and anxiety stemming from various factors, such as concern over the child's wellbeing, difficulties associated with living with and caring for a sick child, and the possibility of treatment-related side-effects or death.<sup>8</sup>

Primary caregivers are often required to juggle their normal daily responsibilities and the additional

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tasks associated with caring for a sick child, such as symptom and pain management, disease monitoring, and the administration of medications.<sup>9</sup> When such responsibilities exceed available resources or their ability to cope, primary caregivers may develop adverse psychological symptoms.<sup>10</sup> Compared to caregivers of other types of patients or parents with healthy children, prevalence rates of mental health conditions such as anxiety, depression, and post-traumatic stress disorder are considerably higher among primary caregivers of children with cancer.<sup>11</sup>

In particular, perceptions of unmet needs among caregivers have been found to act as a strong predictor of their psychological and mental health.<sup>12</sup> Empirical evidence has shown that failing to address the unmet needs of patients or their primary caregivers can result in harmful consequences.<sup>13</sup> Thus, the assessment of unmet needs on the part of primary caregivers of children with cancer is essential to ensure satisfaction, the integrity of the healing process, and minimize psychological distress.<sup>14</sup> Furthermore, specific inquiries into the perceived unmet needs of cancer patients' primary caregivers should be incorporated into routine cancer care to ensure that such needs are met.<sup>15</sup> In particular, addressing unmet needs is essential to help increase the quality of life of caregivers, as such individuals play a vital role in the context of cancer care.<sup>16</sup>

Oman is a developing country located on the South-Eastern coast of the Arabian Peninsula. Approximately half of the local Omani population is under 15 years of age.<sup>17</sup> In 2017, there were 2101 cancer cases registered in Oman, of which 1892 (90.0%) constituted Omani citizens, 188 (8.9%) expatriates, and 21 (1.0%) were of unknown nationality due to missing data.<sup>18</sup> Of the 1892 cancer cases reported among Omanis, 127 (6.7%) were children aged 14 years and under.<sup>19</sup> The most common types of cancers in this group were lymphoid leukemia (26.0%), followed by neuroblastoma/ganglioneuroblastoma (11.0%), Hodgkin's lymphoma (8.7%), non-Hodgkin's lymphoma (11.0%), nephroblastoma/other nonepithelial renal tumors (8.0%), and intracranial and intraspinal embryonal tumors (8.0%).<sup>18</sup>

As in other Arab cultures, the needs of the family in Oman are often prioritized over the needs of the individual; as such, treatment decision-making in cancer patients is generally based on a strong sense of moral responsibility to other family

members.<sup>20</sup> Furthermore, although most children diagnosed with cancer adjust during their first year of treatment, many caregivers experience various psychological symptoms and distress, including symptoms of depression, anxiety, and post-traumatic stress; thus, researchers have suggested the development of psychopathological interventions targeting caregivers.<sup>21</sup> However, the perspectives of Omani primary caregivers to children with cancer have received little attention in the literature. This study was conducted to identify factors contributing to perceived unmet needs among the primary caregivers of Omani children with leukemia. We focused primarily on leukemia, the most frequently diagnosed type of childhood cancer in Oman.<sup>18</sup> No previous study has yet attempted to gather data on this topic to the best of our knowledge.

## METHODS

We conducted a cross-sectional study among adult Omani primary caregivers accompanying children diagnosed with leukemia to the National Oncology Center (NOC) of the Royal Hospital. In general, the vast majority of cancer patients (both adult and pediatric) in Oman are referred for treatment to either the NOC at Royal Hospital or the Oncology Unit of the Sultan Qaboos University Hospital (SQUH), both located in Muscat, the capital city of Oman.<sup>22</sup> The pediatric oncology section at NOC is larger than SQUH and contains a 30-bed oncology ward for children diagnosed with all types of cancers.

The incidence of leukemia among children in Oman is estimated to be 38 cases per year, with an approximate prevalence of 152 cases over the last three years (2017–2020).<sup>17</sup> Based on these estimations, the necessary sample size for the study was calculated to be 100 caregivers using an online sample size calculator (Raosoft Inc., Seattle, Washington, USA), at a 95% confidence level ( $\alpha = 0.05$ ) and 5% margin of error. However, 119 caregivers were recruited to account for attrition and missing data.

An electronic medical record review was conducted by the first author to identify all Omani children aged 14 years or younger diagnosed with any type of leukemia and admitted to NOC wards or attending the day care unit for chemotherapy treatment during the study period (19 May 2020–12 November 2020). Subsequently, any Omani adults accompanying the child were approached by

one of the researchers to determine whether they were the primary caregiver and, if so, to invite them to participate in the study. The purpose of the study was explained to all potential respondents and written consent was obtained before their participation.

A questionnaire was created in two parts. The first section was designed to collect sociodemographic information about the family caregivers and those they cared for (i.e., the children with leukemia). In addition, two additional questions were included related to the beliefs of the caregiver regarding whether they were able to obtain all the answers/information they needed about their child's condition and whether they felt a need for professional support and counseling from a psychologist. The questionnaire was self-administered by each of the participants; however, for those who were illiterate, questionnaires were completed by a researcher as a result of data collected during face-to-face interviews.

The second part of the questionnaire consisted of an Arabic version of the Needs Assessment of Family Caregivers-Cancer (NAFC-C) tool. The original NAFC-C questionnaire is designed to measure the perceived degree of unmet need for 60 items among caregivers caring for a family member diagnosed with cancer.<sup>23</sup> Participants were asked to estimate both the perceived degree of importance and the level of satisfaction separately for each of the 60 items of the questionnaire. In terms of the degree of perceived importance, the participant was requested to answer the question: "How important is this need to you?" Each item was then scored on a 5-point Likert scale ranging from 0 (not at all/not applicable) to 4 (very important).

Regarding the level of perceived satisfaction, the caregiver was requested to answer the question: "How satisfied are you with meeting this need now?" Each item was scored on a 5-point Likert scale ranging from 0 (not at all/not available) to 4 (very satisfied). Subsequently, scores for importance and satisfaction for each item were combined to determine the level of perceived unmet need. Next, scores for satisfaction were reversed and multiplied with scores for the importance of each item. This resulted in a possible total score of 0 to 16, with higher scores indicating a higher level of unmet or fulfilled need.<sup>16,23</sup> For total needs and sub-domains scores, the average total (ranging from 0 to 16) was used for further analysis.

The questionnaire covers seven distinct domains of caregiving needs across different survivorship phases, including: (1) obtaining information (10 items); (2) mobilizing community resources (12 items); (3) confronting family issues (11 items); (4) maintaining the caregiver's strength (7 items); (5) facilitating the continuous growth and development of the child (8 items); (6) negotiating with healthcare professionals (5 items); and (7) accompanying the sick child (7 items).<sup>23</sup> Total scores in each domain range from 0 to 16, with higher scores indicating a greater perceived degree of non-fulfillment of the need in question. According to previous research, the original NAFC-C has shown good internal consistency ( $\alpha = 0.90$ ), excellent test-retest reliability ( $r = 0.80$ ), and concurrent validity ( $r = 0.27, p < 0.001$ ).<sup>24</sup>

For the current study, the NAFC-C questionnaire was translated into Arabic using forward-backward translation methods by two certified translators. The translated version was reviewed alongside the original copy to verify the accuracy of the translation and the integrity of the language; thereafter, a list of procedural definitions was created by a panel of five specialized arbitrators, consisting of three specialists from the Department of Oncology at the NOC and two nurses from the Department of Behavioral Psychology at Al Massarah Hospital, a psychiatry hospital in Oman. These experts were requested to assess the clarity of the terminology used in the translated questionnaire and its relevance to the local cultural environment. The frequency of agreement between the five arbitrators was 81% per item, which was considered acceptable.<sup>25</sup> In addition, the Arabic version of the NAFC-C was found to have acceptable reliability, both overall (Cronbach's alpha coefficient: 0.805) and for each of the seven domains of caregiving needs (Cronbach's alpha coefficient range: 0.602–0.847).

We used IBM SPSS Statistics for Windows, version 27 (IBM Corp., Armonk, N.Y., USA) for data analysis. Descriptive statistics (e.g., percentages, frequencies, means, and standard deviations) were used to describe the basic demographic characteristics of the children and their caregivers and the caregivers' NAFC-C scores. Subsequently, a stepwise linear regression analysis was conducted to determine which demographic factors contributed to the caregivers' total and subdomain unmet need scores. All tests were two-

**Table 1:** Demographic characteristics of Omani children with leukemia (N = 101).

Characteristic	n (%)
<b>Gender</b>	
Male	56 (55.4)
Female	45 (44.6)
<b>Age, years</b>	
Mean ± SD	6.8 ± 3.2
Median (range)	7.0 (1.0–13.0)
<b>Diagnosis</b>	
ALL	77 (76.2)
AML	20 (19.8)
Mixed	2 (2.0)
Other	2 (2.0)
<b>Time since diagnosis, months</b>	
< 3	4 (4.0)
3–11	56 (55.4)
12–48	41 (40.6)
<b>Currently undergoing treatment</b>	
Yes	96 (95.0)
No	5 (5.0)
<b>Treatment type</b>	
Chemotherapy	89 (88.1)
Radiotherapy	5 (5.0)
Transplant	4 (4.0)
Other	3 (3.0)
<b>Number of family members</b>	
< 4	3 (3.0)
4–6	62 (61.4)
7–9	32 (31.7)
≥ 10	4 (4.0)

SD: standard deviation; ALL: acute lymphatic leukemia; AML: acute myelogenous leukemia.

tailed, with a *p*-value of < 0.050 being considered statistically significant.

This research was approved by the Research and Ethical Review and Approval Committee of the Ministry of Health in Oman (#MOH/DGPS/PROPOSAL\_APPROVED/24/2020).

## RESULTS

Of the 119 primary caregivers contacted, 101 agreed to participate in the study (response rate: 84.9%). Of these, the majority (n = 76; 75.2%) were recruited while accompanying children admitted to the NOC inpatient pediatric oncology ward, while the others (n = 25; 24.8%) were recruited from the day care unit. The mean age of the children was 6.8±3.2

**Table 2:** Demographic characteristics of primary caregivers of Omani children with leukemia (N = 101).

Characteristic	n (%)
<b>Relationship with child</b>	
Father	12 (11.9)
Mother	89 (88.1)
<b>Age, years</b>	
Mean ± SD	36.1 ± 6.0
Median (range)	33.0 (24.0–50.0)
<b>Employment status</b>	
Employed full-time	39 (38.6)
Employed part-time	4 (4.0)
Unemployed	58 (57.4)
<b>Marital status</b>	
Married	99 (98.0)
Divorced	2 (2.0)
<b>Education level</b>	
Primary	6 (5.9)
Secondary	11 (10.9)
High school	49 (48.5)
Diploma/bachelor's degree	33 (32.7)
Postgraduate degree	2 (2.0)
<b>Time spent caring for child, hours/day</b>	
< 4	1 (1.0)
4–6	23 (22.8)
7–12	18 (17.8)
13–18	14 (13.9)
19–24	45 (44.6)
<b>Monthly income, OMR</b>	
< 500	37 (36.6)
500–1000	39 (38.6)
1001–1500	12 (11.9)
≥ 1501	13 (12.9)
<b>Need for psychotherapy/counseling</b>	
Yes	69 (68.3)
No	32 (31.7)
<b>Has all information needed about the child's condition</b>	
Yes	63 (62.4)
No	38 (37.6)

SD: standard deviation; OMR: Omani Riyals.

years (median: 7.0 years, range: 1.0–13.0 years) and most were male (n = 56; 55.4%). The majority had acute lymphatic leukemia (n = 77; 76.2%) and were currently undergoing treatment (n = 96; 95.0%), with the most common form of treatment being chemotherapy (n = 89; 88.1%). Most children had been diagnosed > 11 months prior (n = 60; 59.4%) and had a family size of 4–6 members (n = 62; 61.4%) [Table 1].

**Table 3:** Unmet need scores\* among primary caregivers of Omani children with leukemia (N = 101).

Domain of questionnaire	Mean $\pm$ SD**	Median (Range)
Obtaining information (10 items)	4.2 $\pm$ 1.2	4.0 (0.8–8.0)
Mobilizing community resources (12 items)	3.6 $\pm$ 2.0	3.5 (0.3–9.3)
Confronting family issues (11 items)	4.5 $\pm$ 1.2	4.3 (2.2–7.4)
Maintaining caregiver own strength (7 items)	5.2 $\pm$ 1.7	5.0 (2.4–8.6)
Facilitating the growth and development of the child (8 items)	3.9 $\pm$ 1.3	3.8 (1.1–8.6)
Negotiating with healthcare professionals (5 items)	4.3 $\pm$ 1.5	4.2 (0.6–9.6)
Accompanying the sick child (7 items)	2.6 $\pm$ 1.5	2.9 (0.0–7.6)
Total need (60 items)	4.0 $\pm$ 0.8	3.9 (2.5–6.7)

SD: standard deviation.

\*Using an Arabic version of the Needs Assessment of Family Caregivers-Cancer tool.<sup>23</sup> \*\*Total scores in each domain range from 0–16, with higher scores indicating a greater perceived degree of non-fulfillment of the need in question.

The caregivers' mean age was 36.1 $\pm$ 6.0 years (median: 33.0 years, range: 24.0–50.0 years). The majority were mothers (n = 89; 88.1%). Most caregivers were married (n = 99; 98.0%), unemployed (n = 58; 57.4%), and educated to the high school level or above (n = 84, 83.2%). All of the caregivers lived with the child. Just under half (n = 45; 44.6%) spent > 19 hours caring for the child daily. The majority reported a monthly income of < 1000 OMR per month (n = 76; 75.2%). Most caregivers stated that they needed counseling (n = 69; 68.3%) and had all the answers they needed about their child's condition (n = 63; 62.4%) [Table 2]. The caregivers' mean scores in each of the seven domains of unmet needs are shown in Table 3.

A linear regression stepwise analysis was conducted to determine which demographic factors contributed to the caregivers' total and subdomain unmet needs scores. Statistically significant correlations were observed between total scores and the age of both the child ( $\beta = 0.068$ ;  $p = 0.014$ ) and caregiver ( $\beta = 0.084$ ;  $p < 0.001$ ), as well as the employment status ( $\beta = 0.516$ ;  $p = 0.024$ ) and income ( $\beta = 0.195$ ;  $p = 0.028$ ) of the caregiver. With regards to scores in the domain of obtaining information, significant correlations were observed with caregiver's age ( $\beta = 0.118$ ;  $p < 0.001$ ), amount of time spent caring ( $\beta = 0.615$ ;  $p = 0.018$ ), and number of family members ( $\beta = -1.056$ ;  $p < 0.001$ ). Caregiver's age ( $\beta = 0.075$ ;  $p < 0.001$ ) and employment status ( $\beta = 1.423$ ;  $p < 0.001$ ) contributed significantly to unmet need scores in the mobilizing community resources domain. Similarly, correlations were found between the caregiver's age ( $\beta = 0.097$ ;  $p < 0.001$ ), education level ( $\beta = 0.500$ ;  $p = 0.018$ ), and income ( $\beta = 0.351$ ;  $p = 0.019$ ), and scores in the confronting family issues

domain. Adjusted R<sup>2</sup> values were 0.635 for overall need and 0.525, 0.665, and 0.537 for the domains of obtaining information, mobilizing community resources, and confronting family issues, respectively.

With regards to scores in the domain of maintaining the caregiver's own strength, significant correlations were found for child's gender ( $\beta = -0.808$ ;  $p = 0.028$ ), time since diagnosis ( $\beta = 1.024$ ;  $p = 0.004$ ), caregiver's age ( $\beta = 0.123$ ;  $p < 0.001$ ), and education level ( $\beta = 0.562$ ;  $p = 0.019$ ). Scores in the facilitating the growth and development of the child domain correlated with the child's age ( $\beta = 0.138$ ;  $p < 0.001$ ), caregiver's age ( $\beta = 0.068$ ;  $p < 0.001$ ), and income ( $\beta = 0.490$ ;  $p < 0.001$ ). The caregiver's gender ( $\beta = 1.396$ ;  $p = 0.001$ ), age ( $\beta = 0.092$ ;  $p < 0.001$ ), and having all information needed about their child's condition ( $\beta = -0.788$ ;  $p = 0.014$ ) correlated with scores in the negotiating with healthcare professional's domain. Finally, scores in the accompanying the sick child domain were significantly correlated with the child's gender ( $\beta = 0.553$ ;  $p = 0.049$ ) as well as the gender ( $\beta = 0.046$ ;  $p < 0.001$ ) and income ( $\beta = 0.709$ ;  $p < 0.001$ ) of the caregiver. Adjusted R<sup>2</sup> values were 0.572, 0.542, 0.672, and 0.631 for the domains of maintaining the caregiver's own strength, facilitating the continuous growth and development of the child, negotiating with healthcare professionals, and accompanying the sick child, respectively [Table 4].

## DISCUSSION

The setting of cancer care has moved from primarily hospital-based to home-based, in part due to increased survival rates and greater utilization of outpatient services.<sup>26</sup> Moreover, caregivers are

**Table 4:** Linear (stepwise) regression models for associations between unmet needs scores\* and demographic characteristics.

Variables	Total need		Obtaining information		Mobilizing community resources		Confronting family issues	
	$\beta$	p-value	$\beta$	p-value	$\beta$	p-value	$\beta$	p-value
<b>Children with leukemia</b>								
Gender (0 = boy, 1 = girl)								
Age, (years)	0.068	0.014						
Diagnosis (0 = not ALL, 1 = ALL)								
Diagnosis (0 = not AML, 1 = AML)								
Type of treatment received (0 = CTX, 1 = other therapy)								
Time since diagnosis (0 = < 11 months, 1 = 1–4 years)								
Currently undergoing treatment (0 = yes, 1 = no)								
Number of family members (0 = ≤ 6, 1 = ≥ 7)			-1.056	< 0.001				
<b>Caregivers</b>								
Gender (0 = male, 1 = female)								
Age	0.084	< 0.001	0.118	< 0.001	0.075	< 0.001	0.097	< 0.001
Employment status (0 = employed, 1 = unemployed)	0.516	0.024			1.423	< 0.001	0.500	0.018
Education level (0 = secondary or below, 1 = high school, 2 = diploma or above)								
Time spent caring for child (hours/day) (0 = ≤ 6, 1 = 7–12, 2 = 13–18, 3 = 19–24)			0.615	0.018				
Family members (0 ≤ 6, 1 ≥ 7)			-1.056	< 0.001				
Monthly income (OMR) (0 = < 500, 1 = 500–1000, 2 = 1001–1500, 3 = ≥ 1501)	0.195	0.028					0.351	0.019
Has all information needed about the child's condition (0 = Yes, 1 = No)								
Need for psychological therapy/ counseling (0 = yes, 1 = no)								
<b>Adjusted R<sup>2</sup></b>	<b>0.635</b>		<b>0.525</b>		<b>0.665</b>		<b>0.537</b>	

**Table 4:** Linear (stepwise) regression models for associations between unmet needs scores\* and demographic characteristics.

-continued

Variables	Total need		Obtaining information		Mobilizing community resources		Confronting family issues	
	$\beta$	p-value	$\beta$	p-value	$\beta$	p-value	$\beta$	p-value
<b>Children with leukemia</b>								
Gender (0 = boy, 1 = girl)	-0.808	0.028	0.138	< 0.001			0.553	0.049
Age								
Diagnosis (0 = not ALL, 1 = ALL)								
Diagnosis (0 = not AML, 1 = AML)								
Type of treatment received (0 = CTX, 1 = other therapy)								
Time since diagnosis (0 = < 11 months, 1 = 1-4 years)								
Currently undergoing treatment (0 = yes, 1 = no)	1.024	0.004						
Number of family members (0 = ≤ 6, 1 = ≥ 7)					1.396	0.001	0.046	< 0.001
<b>Caregivers</b>								
Gender (0 = male, 1 = female)	0.123	< 0.001	0.068	< 0.001	0.092	< 0.001		
Age								
Employment status (0 = employed, 1 = unemployed)								
Education level (0 = secondary or below, 1 = high school, 2 = diploma or above)	0.562	0.019						
Time spent caring for child (hours/day) (0 = ≤ 6, 1 = 7-12, 2 = 13-18, 3 = 19-24)								
Monthly income (OMR) (0 = < 500, 1 = 500-1000, 2 = 1001-1500, 3 = ≥ 1501)			0.490	< 0.001			0.709	< 0.001
Has all information needed about the child's condition (0 = yes, 1 = no)					-0.788	0.014		
Need for psychological therapy/ counseling (0 = yes, 1 = no)								
<b>Adjusted R<sup>2</sup></b>	<b>0.572</b>		<b>0.542</b>		<b>0.672</b>		<b>0.631</b>	

ALL: acute lymphatic leukemia; AML: acute myelogenous leukemia; CTX: chemotherapy; OMR: Omani riyads.

\*Using an Arabic version of the Needs Assessment of Family Caregivers-Cancer tool.<sup>23</sup>

involved not only in the diagnostic and treatment phases of cancer care but across the entire care trajectory, including survivorship. As such, they play a crucial role in providing pediatric cancer care. This is the first study conducted in Oman to explore factors contributing to the unmet needs of primary caregivers of Omani children diagnosed with leukemia.

In the current study, perceived unmet needs in the obtaining information domain increased with the caregiver's age, time spent caring, and the number of family members. The longer a primary caregiver cares for their sick child, the more likely they are to require additional information and other supportive care services to successfully carry out caregiving tasks, including coordination, communication, and interactions with healthcare providers.<sup>27</sup> Moreover, with increasing age, primary caregivers are more likely to have other responsibilities besides caring for their sick child; similarly, caring for a chronically sick child while also providing emotional and financial support for other children living in the household can cause additional psychosocial distress.<sup>8</sup> Therefore, such individuals will require more information and support than those with fewer responsibilities.<sup>16</sup>

A primary caregiver's ability to cope with their sick child's physical, mental, and emotional needs is important to maintain family function and stability. However, the burden of taking care of a child with leukemia is likely to increase over time, as treatment may span several years. Therefore, primary caregivers in such situations are more prone to develop negative psychosocial outcomes, such as depression, anxiety, and social isolation, thus necessitating psychological support.<sup>28</sup> Furthermore, perception of caregiving burden is influenced by several factors, such as lack of confidence and inadequate preparation to perform expected caregiving tasks.<sup>21</sup> Thus, it is understandable that older primary caregivers in our study were more likely to report unmet needs in the confronting family issues domain as they might not be able to cope with the emotional and psychological fallout of caring for a sick child over a prolonged period, especially as many are also required to continue providing emotional and financial support to other household members.<sup>8</sup> Indeed, caregivers have shown an increased risk of developing depression, anxiety, and post-traumatic stress symptoms during the first year of treatment, with a lack of improvement of such symptoms over time.<sup>21</sup> Thus, it is important that interventions be

provided to minimize these distressing symptoms, such as the provision of psychosocial services for caregivers via home visits or electronically using telehealth or e-health modalities.<sup>21</sup>

The child's age was also associated with perceived unmet needs across all domains, particularly in the domain of facilitating the growth and development of the child. Children with leukemia are frequently hospitalized, undergo invasive surgery, and treated with chemotherapy or radiotherapy; such experiences have short- and long-term effects on growth and development.<sup>29</sup> As the child grows, primary caregivers face increasing pressure to provide social, emotional, financial, educational, and psychological care.<sup>15</sup>

In the study, most primary caregivers were female. In addition, female gender was significantly correlated with unmet needs in the domains of negotiating with healthcare professionals and accompanying the sick child to the hospital. As in other countries, mothers of sick children in Oman are more likely to take on the primary caregiver role than fathers or other family members.<sup>29</sup> Although research shows that the mothers of children with cancer demonstrate impressive levels of resilience and ability to cope with their child's disease, many develop high levels of stress and feelings of shock, confusion, and grief that escalate or persist over time.<sup>30</sup> Previous research has identified various coping mechanisms to reduce psychological symptoms among Omani women with breast cancer, including acceptance of the diagnosis, reliance on support from family members, and Islamic beliefs and practices. Such strategies may be equally helpful to Omani mothers caring for children with leukemia.<sup>31</sup>

Another study showed that a decline in caregiving-related stress reduced depression and anxiety among the mothers of newly diagnosed pediatric cancer patients, with self-efficacy in their ability to perform caregiving tasks and effective communication with healthcare professionals found to increase over time.<sup>32</sup> Similarly, positive socialization between mother caregivers and their children has been found to benefit the child's development and wellbeing, particularly when communication with childcare providers also improves.<sup>33</sup> On the other hand, another study demonstrated that the caregiving mothers of children undergoing active cancer treatment often resorted to the Internet when receiving contrary advice from healthcare professionals as a coping

strategy to build their self-efficacy and enhance their ability to manage the crisis.<sup>30</sup>

Another important finding of the study was that highly educated primary caregivers were more likely to have fewer unmet needs in the domains of maintaining their own strength and confronting family issues than those who were less educated. Primary caregivers are often forced to assume a caregiving role very suddenly without adequate preparation, support, or guidance from the healthcare system.<sup>34</sup> Thus, well-educated caregivers might have fewer unmet needs in the aforementioned domains as they are more likely to seek additional information from the Internet or establish a social support network to maintain their strength.<sup>30</sup> Furthermore, educated family caregivers in Oman have been found to maintain good levels of communication with oncologists and play a key role in cancer treatment decision-making.<sup>35</sup>

Although cancer treatment is provided free-of-charge to the local Omani population, income was a significant predictor of unmet needs in facilitating the child's growth and development domain and accompanying the child to the hospital. In general, caregivers of children with cancer tend to suffer greater financial hardship than caregivers of children with other serious illnesses, such as diabetes.<sup>36</sup> Awareness of financial assistance programs and resources can mitigate the psychosocial burden of cancer caregiving on both the patient and caregiver.<sup>37</sup> In countries where cancer treatment is not free, the time and finances needed to care for a sick child have been identified as considerable stressors for primary caregivers, with some seeking financial support from other family members.<sup>38</sup>

Our data showed that unemployed caregivers had greater unmet needs across all domains of caregiving, particularly for mobilizing community resources. Despite the availability of free cancer treatment, caregivers in Oman likely would also have to meet several expenses associated with traveling to and from the hospital, particularly if they reside outside of Muscat. Moreover, previous research shows that frequent trips to the hospital and time spent away from home to care for a sick child can adversely affect the quality of caregivers' relationships with other family members.<sup>34</sup> Thus, as cancer survivorship for children increases in conjunction with advances in medical technology and treatment, there is a need for additional financial and logistical assistance to

help the families of children diagnosed with cancer to accompany the sick child to the hospital.<sup>36</sup>

Our study has certain limitations. First, this was a cross-sectional study based on a sample of participants with specific characteristics and in which the majority of collected data relied on self-reported measures. These methodological limitations may have exposed the results to recall, response, and/or personal bias errors. Moreover, although we translated the NAFC-C questionnaire using forward-backward translation methods, with the translated tool subsequently found to have high reliability (total Cronbach's alpha: 0.80), we did not test the tool for validity as this was beyond the scope of this study.

## CONCLUSION

Several sociodemographic factors were found to influence unmet needs among the primary caregivers of Omani children diagnosed with leukemia. In particular, as time progressed, caregivers more frequently experienced unmet needs in the domains of negotiating with healthcare professionals and obtaining information. Healthcare professionals should provide comprehensive information to caregivers as the disease progresses, including expected symptoms, long- and short-term effects of cancer treatment, and the child's medical condition. Moreover, as the child got older, primary caregivers reported greater unmet needs in the domain of maintaining their own strength. Incorporating additional support services for primary caregivers in routine oncology care, such as psychological counseling and peer support groups, is recommended to enhance coping strategies and reduce distress. Finally, female caregivers had significantly greater unmet needs in the domains of negotiating with healthcare professionals and accompanying the sick child. Healthcare professionals should consider allocating more time during consultations with these caregivers to answer questions and address concerns. In addition, financial assistance programs and transportation services to and from the hospital could reduce economic and logistical stressors associated with caring for a child with cancer.

### Disclosure

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