

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

Amal Al-Dhawani,¹ Karima Al-Hinai,² Moon Fai Chan³, Mohammed Al-Azri^{3*}

¹Directorate General of Specialized Medical Care, Ministry of Health, PO Box 393, Postal Code 100, Muscat, Oman

²National Oncology Center, Royal Hospital, Ministry of Health, PO Box 1331, Postal Code 111, Muscat, Oman

³Department of Family Medicine and Public Health, College of Medicine and Health Sciences, Sultan Qaboos University, PO Box 38, Postal Code 123, Muscat, Oman

Received: 30 May 2021

Accepted: 01 August 2021

*Corresponding author: mhalazri@squ.edu.om

DOI 10.5001/omj.2022.40

ABSTRACT

Objectives: Childhood cancers affect 6.7% of those under 14 years of age in Oman, with leukemia being most common. The psychological distress of having a child with leukemia is often compounded by perceived unmet needs on the part of the child's primary caregiver. This study aimed to identify factors contributing to perceived unmet needs among primary caregivers of Omani children with leukemia. **Methods:** A cross-sectional study was conducted among 119 Omani caregivers accompanying their children to the National Oncology Center, Muscat, Oman. An Arabic version of the Needs Assessment of Family Caregivers-Cancer (NAFC-C) questionnaire was utilized to assess perceived unmet needs in seven domains. Ethical approval for the study was obtained from the Ministry of Health in Oman. **Results:** A total of 119 of Omani primary caregivers were contacted; of these, 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 age ($p = 0.014$) and caregiver's age ($p < 0.001$), 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 were found to affect the unmet needs of primary caregivers of children with leukemias in Oman. Healthcare professionals in Oman should be aware of such factors in order to reduce caregiver distress.

Keywords: Caregivers; Children; Leukemia; Health Services Needs and Demand; Needs Assessment; Oman.

Introduction

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 future.¹ Globally, leukemia is the most common type of childhood cancer (34%), followed by brain tumors (23%) and lymphoma (12%).² 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 1998–2001.³ 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.⁴ 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.^{1,4}

A diagnosis of childhood cancer can have a profound social, emotional, financial, and psychological impact on the affected child, as well as on their primary caregivers.⁵ 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.^{6,7} These individuals may experience a great deal of fear and anxiety stemming from a variety of 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.⁸

Primary caregivers are often required to juggle both their normal daily responsibilities as well as the additional tasks associated with caring for a sick child, such as symptom and pain management, disease monitoring, and the administration of medications.⁹ When such responsibilities exceed available resources or their ability to cope, primary caregivers may develop adverse psychological symptoms.¹⁰ 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.¹¹

In particular, perceptions of unmet needs among caregivers have been found to act as a strong predictor of their psychological and mental health.¹² Empirical evidence has shown that failing to address the unmet needs of patients or their primary caregivers can result in harmful consequences.¹³ 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.¹⁴ Furthermore, specific inquiries into the perceived unmet needs of cancer patients' primary caregivers should be incorporated into routine cancer care in order to ensure that such needs are being met.¹⁵ 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.¹⁶

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.¹⁷ In 2017, there were a total of 2,101 cancer cases registered in Oman, of which 1,892 (90.05%) constituted Omani citizens, 188 (8.95%) expatriates, and 21 (1%) were of unknown nationality due to missing data.¹⁸ Of the 1,892 cancer cases reported among Omanis, a total of 127 (6.7%) were children aged 14 years and under.¹⁹ 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%).¹⁸

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.²⁰ Furthermore, although most

children diagnosed with cancer adjust during their first year of cancer 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.²¹ However, the perspectives of Omani primary caregivers to children with cancer have so far received little attention in the literature. As such, this study was conducted in order to identify factors contributing to perceived unmet needs among the primary caregivers of Omani children with leukemia. We focused primarily on leukemia as this is the most frequently diagnosed type of childhood cancer in Oman.¹⁸ To our knowledge, no previous study has yet attempted to gather data on this topic.

Methods

A cross-sectional study was conducted 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 of which are located in Muscat, the capital city of Oman.²² 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, for an approximate prevalence of 152 cases over the last three years (2017–2020).¹⁷ 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, a total of 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 to 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 obtained prior to 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.²³ 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 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).

With regards to 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 combined to determine the level of perceived unmet need. 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.^{16,23} 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 own 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).²³ 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. 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 ($r = 0.27, p < 0.001$).²⁴

For the purposes of the current study, the NAFC-C questionnaire was translated into Arabic using forward-backwards 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.²⁵ 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)

The Statistical Package for the Social Sciences (SPSS), Version 27 (IBM Corp., Armonk, New York, USA), was used 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 as well as 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-tailed with a p value of <0.05 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 of Omani children with leukemia who were contacted, a total of 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.

Among the children with leukemia, the mean age was 6.8 ± 3.2 years (median: 7.0 years, range: 1–13 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 previously ($n = 60$; 59.4%) and had a family size of between 4–6 members ($n = 62$; 61.3%) [Table 1].

Among the caregivers, the mean age was 36.1 ± 6.0 years (median: 33.0 years, range: 24–50 years). In terms of their relationship with the child, the majority were mothers ($n = 89$; 88.1%). Most 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 more than 19 hours caring for the child on a daily basis. The majority reported a monthly income of <1,000 Omani riyals 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^2 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; $p = 0.004$) and 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 professionals 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^2 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, due to in part to increased survival rates as well as greater utilization of outpatient services.²⁶ Moreover, caregivers are 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 the provision of pediatric cancer care. To our knowledge, 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 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 in order to successfully carry out caregiving tasks, including coordination, communication, and interactions with healthcare providers.²⁷ Moreover, with increasing age, primary caregivers are more likely to have other responsibilities in addition to 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.⁸ Therefore, such individuals will require more information and support compared to those with fewer responsibilities.¹⁶

A primary caregiver's ability to cope with the physical, mental, and emotional needs of their sick child is important in order 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. Primary caregivers in such situations are therefore more prone to develop negative psychosocial outcomes, such as depression, anxiety, and social isolation, thus necessitating psychological support.²⁸ Furthermore, perception of caregiving burden is influenced by several factors, such as lack of confidence and inadequate preparation to perform expected caregiving tasks.²⁹ 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 of time, especially as many are also required to continue providing emotional and financial support to other household members.⁸ 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.²¹ 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.²¹

The age of the child 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 both short- and long-term effects on growth and development.³⁰ As the child grows, primary caregivers face increasing pressure to provide social, emotional, financial, educational, and psychological care.¹⁵

In the study, the majority of 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 role of primary caregiver compared to fathers or other family members.³⁰ 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 as well as feelings of shock, confusion, and grief which escalate or persist over time.³¹ 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.³²

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 ability to perform caregiving tasks and effective communication with healthcare professionals found to increase over time.³³ 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.³⁴ 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.³¹

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 as well as confronting family issues compared to those who were less educated. Primary caregivers are often forced to assume a caregiving role very suddenly and without adequate preparation, support, or guidance from the healthcare system.³⁵ 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.³¹ 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.³⁶

Although cancer treatment is provided free of the charge to the local Omani population, income was found to be a significant predictor of unmet needs in the domains of facilitating the growth and development of the child and accompanying the child to the hospital. In general, caregivers of children with cancer tend to suffer greater financial hardship compared to caregivers of children with other serious illnesses, such as diabetes.³⁷ Awareness of financial assistance programs and resources can mitigate the psychosocial burden of cancer caregiving on both the part of the patient and caregiver.³⁸ 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.³⁹

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 a number of expenses associated with travelling to and from the hospital, particularly if they were residents of areas outside of Muscat, the capital city. 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' family relationships with other family members.³⁵ 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 accompany the sick child to hospital.³⁷

The study has certain limitations. 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 errors related to recall, response, and/or personal bias. Moreover, although we translated the NAFC-C questionnaire using forwards-backwards 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.

Conclusions

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 information regarding 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. Incorporation of 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

The authors declared no conflicts of interest. No funding was received for this study.

References

1. World Health Organization. WHO report on cancer: setting priorities, investing wisely and providing care for all. Available at: <https://apps.who.int/iris/handle/10665/330745>. Accessed March 2, 2021.
2. Steliarova-Foucher E, Colombet M, Ries LAG, Moreno F, Dolya A, Bray F, et al. International incidence of childhood cancer, 2001-10: a population-based registry study. *Lancet Oncol* 2017 Jun;18(6):719-731.
3. Al-Hamdan N, Ravichandran K, Al-Sayyad J, Al-Lawati J, Khazal Z, Al-Khateeb F, et al. Incidence of cancer in Gulf Cooperation Council countries, 1998-2001. *East Mediterr Health J* May-Jun 2009;15(3):600-611.
4. World Health Organization. Global initiative for childhood cancer. Available at: <https://www.who.int/cancer/childhood-cancer/en/>. Accessed March 2, 2021.
5. Lang D, Lim LC. Effects of art therapy for family caregivers of cancer patients: a systematic review protocol. *JBIC Database System Rev Implement Rep* 2014 Apr;12(3):374-394.
6. Amador DD, Gomes IP, da Silva Reichert AP, Collet N. [Impact of childhood cancer for family caregivers: integrative review]. *Rev Bras Enferm* 2013 Mar-Apr;66(2):264-270.
7. Cox T. Caregivers reflecting on the early days of childhood cancer. *Eur J Cancer Care (Engl)* 2018 Jan;27(1):e12499.
8. Given BA, Given CW, Kozachik S. Family support in advanced cancer. *CA Cancer J Clin* 2001 Jul-Aug;51(4):213-231.
9. Shin DW, Cho J, Roter DL, Kim SY, Sohn SK, Yoon MS, et al. Preferences for and experiences of family involvement in cancer treatment decision-making: patient-caregiver dyads study. *Psychooncology* 2013 Nov;22(11):2624-2631.
10. Northouse LL, Katapodi MC, Schafenacker AM, Weiss D. The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Semin Oncol Nurs* 2012 Nov;28(4):236-245.
11. Kristjanson LJ, Atwood J, Degner LF. Validity and reliability of the family inventory of

- needs (FIN): measuring the care needs of families of advanced cancer patients. *J Nurs Meas* 1995 Winter;3(2):109-126.
12. Hwang SS, Chang VT, Alejandro Y, Osenenko P, Davis C, Cogswell J, et al. Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs (VA) medical center. *Palliat Support Care* 2003 Dec;1(4):319-329.
 13. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 1999 Dec;282(23):2215-9.
 14. Given CW. Family caregiving for cancer patients: the state of the literature and a direction for research to link the informal and formal care systems to improve quality and outcomes. *Semin Oncol Nurs* 2019 Aug;35(4):389-394.
 15. Battles H, Bedoya SZ, Pao M, Mullins LL, Wiener L. Caring for a child with cancer: the experience of the “lone” parent, and why it matters. *Psychooncology* 2018 Dec;27(12):2869-2872.
 16. Kim Y, Kashy DA, Spillers RL, Evans TV. Needs assessment of family caregivers of cancer survivors: three cohorts comparison. *Psychooncology* 2010 Jun;19(6):573-582.
 17. National Center for Statistics and Information, Oman. Information portal. Available at: <https://www.ncsi.gov.om/Pages/NCSI.aspx>. Accessed March 4, 2021.
 18. Ministry of Health, Oman. Cancer incidence in Oman 2017. National Cancer Registry, 2007.
 19. Al-Lawati JA, Al-Zakwani I, Fadhil I, Al-Bahrani BJ. Cancer incidence in Oman (1996-2015). *Oman Med J* 2019 Jul;34(4):271-273.
 20. Al-Bahri A, Al-Moundhri M, Al-Mandhari Z, Al-Azri M. The role of patients’ families in treatment decision-making among adult cancer patients in the Sultanate of Oman. *Eur J Cancer Care (Engl)* 2018 May;27(3):e12845.
 21. Katz LF, Fladeboe K, King K, Gurtovenko K, Kawamura J, Friedman D, et al. Trajectories of child and caregiver psychological adjustment in families of children with cancer. *Health Psychol* 2018 Aug;37(8):725-735.
 22. Ministry of Health, Oman. Annual health report 2019. Available at: <https://www.moh.gov.om/en/web/statistics/-/-2019>. Accessed March 4, 2021.
 23. Kuan HY. Identifying the needs of Chinese family caregivers of children with cancer in Hong Kong. PhD dissertation, Hong Kong Polytechnic University, 2000. Available at: <https://theses.lib.polyu.edu.hk/handle/200/5579>. Accessed March 4, 2021.

24. Yang WFZ, Liu J, Chan YH, Griva K, Kuparasundram S, Mahendran R. Validation of the needs assessment of Family Caregivers-Cancer scale in an Asian population. *BMC Psychol* 2020 Aug 12;8(1):84.
25. Fleiss JL, Levin B, Paik MC. The measurement of interrater agreement. In: *Statistical Methods for Rates and Proportions*, 3rd ed. Wiley Series in Probability and Statistics. John Wiley & Sons: Hoboken, 2003. Chapter 3.
26. Glajchen M. The emerging role and needs of family caregivers in cancer care. *J Support Oncol* 2004 Mar-Apr;2(2):145-155.
27. Bužgová R, Hajnová E, Sikorová L, Jarošová D. Association between unmet needs and quality of life in hospitalised cancer patients no longer receiving anti-cancer treatment. *Eur J Cancer Care (Engl)* 2014 Sep;23(5):685-694.
28. Northouse L, Williams AL, Given B, McCorkle R. Psychosocial care for family caregivers of patients with cancer. *J Clin Oncol* 2012 Apr;30(11):1227-1234.
29. Katz LF, Fladeboe K, King K, Gurtovenko K, Kawamura J, Friedman D, et al. Trajectories of child and caregiver psychological adjustment in families of children with cancer. *Health Psychol* 2018 Aug;37(8):725-735.
30. Young B, Dixon-Woods M, Findlay M, Heney D. Parenting in a crisis: conceptualising mothers of children with cancer. *Soc Sci Med* 2002 Nov;55(10):1835-1847.
31. Tan R, Koh S, Wong ME, Rui M, Shorey S. Caregiver stress, coping strategies, and support needs of mothers caring for their children who are undergoing active cancer treatments. *Clin Nurs Res* 2020 Sep;29(7):460-468.
32. Al-Azri MH, Al-Awisi H, Al-Rasbi S, Al-Moundhri M. Coping with a diagnosis of breast cancer among Omani women. *J Health Psychol* 2014 Jul;19(7):836-846.
33. Sulkers E, Tissing WJE, Brinksma A, Roodbol PF, Kamps WA, Stewart RA, et al. Providing care to a child with cancer: a longitudinal study on the course, predictors, and impact of caregiving stress during the first year after diagnosis. *Psychooncology* 2015 Mar;24(3):318-324.
34. Owen MT, Ware AM, Barfoot B. Caregiver-mother partnership behavior and the quality of caregiver-child and mother-child interactions. *Early Child Res Q* 2000 Autumn;15(3):413-428.
35. Yantzi N, Rosenberg MW, Burke SO, Harrison MB. The impacts of distance to hospital on families with a child with a chronic condition. *Soc Sci Med* 2001 Jun;52(12):1777-1791.
36. Al-Bahri A, Al-Moundhri M, Al-Mandhari Z, Al-Azri M. Role of the family in treatment

decision-making process for Omani women diagnosed with breast cancer. *Patient Education and Counseling* 2019 Feb;102(2):352-359.

37. Miedema B, Easley J, Fortin P, Hamilton R, Mathews M. The economic impact on families when a child is diagnosed with cancer. *Curr Oncol* 2008 Aug;15(4):173-178.
38. Balfe M, Butow P, O'Sullivan E, Gooberman-Hill R, Timmons A, Sharp L. The financial impact of head and neck cancer caregiving: a qualitative study. *Psychooncology* 2016 Dec;25(12):1441-1447.
39. dos Santos Alves DF, de Brito Guirardello E, Kurashima AY. Stress related to care: the impact of childhood cancer on the lives of parents. *Rev Lat Am Enfermagem* 2013 Feb;21(1):356-362.

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

Characteristic	n (%)
Gender	
Male	56 (55.4)
Female	45 (44.6)
Age (years)	
Mean ± SD	6.8 ± 3.2
Median [range]	7.0 [1.0–13.0]
Diagnosis	
ALL	77 (76.2)
AML	20 (19.8)
Mixed	2 (2.0)
Other	2 (2.0)
Time since diagnosis (months)	
<3	4 (4.0)
3–11	56 (55.4)
12–48	41 (40.6)
Currently undergoing treatment	
Yes	96 (95.0)
No	5 (5.0)
Type of treatment received	
Chemotherapy	89 (88.1)
Radiotherapy	5 (4.9)
Transplant	4 (4.0)
Other	3 (3.0)
Number of family members	
<4	3 (3.0)
4–6	62 (61.3)
7–9	32 (31.7)
≥10	4 (4.0)

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

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

Characteristic	n (%)
Relationship with child	
Father	12 (11.9)
Mother	89 (88.1)
Age (years)	
Mean ± SD	36.1 ± 6.0
Median [range]	33.0 [24.0–50.0]
Employment status	
Employed full-time	39 (38.6)
Employed part-time	4 (4.0)
Unemployed	58 (57.4)
Marital status	
Married	99 (98.0)
Divorced	2 (2.0)
Education level	
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)
Time spent caring for child (hours/day)	
<4	1 (1.0)
4–6	23 (22.8)
7–12	18 (17.8)
13–18	14 (13.9)
19–24	45 (44.6)
Monthly income (OMR)	
<500	37 (36.6)
500–1,000	39 (38.6)
1,001–1,500	12 (11.9)
≥1,501	13 (12.9)
Need for psychotherapy/ counseling	
Yes	69 (68.3)
No	32 (31.7)
Has all information needed about the child's condition	
Yes	63 (62.4)
No	38 (37.6)

SD: standard deviation; OMR: Omani riyals.

Factors Contributing to Unmet Needs of Omani Caregivers

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

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

SD: standard deviation.

*Using an Arabic version of the Needs Assessment of Family Caregivers-Cancer tool.²³

**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.

Factors Contributing to Unmet Needs of Omani Caregivers

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

	Total need		Obtaining information		Mobilizing community resources		Confronting family issues	
	Beta	p value	Beta	p value	Beta	p value	Beta	p value
Children with leukemia								
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				
Caregivers								
Gender (0 = Male, 1 = Female)								
Age (years)	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		
Education level (0 = Secondary or below, 1 = High school, 2 = Diploma or above)							0.500	0.018
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	<.001				
Monthly income (OMR) (0 = <500, 1 = 500–1,000, 2 = 1,001–1,500, 3 = ≥1,501+)	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)								
Adjusted R²	0.635		0.525		0.665		0.537	

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

*Using an Arabic version of the Needs Assessment of Family Caregivers-Cancer tool.²³

Factors Contributing to Unmet Needs of Omani Caregivers

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

	Maintaining caregiver own strength		Facilitating the growth and development of the child		Negotiating with healthcare professionals		Accompanying the sick child	
	Beta	p value	Beta	p value	Beta	p value	Beta	p value
Children with leukemia								
Gender (0 = boy, 1 = girl)	-0.808	0.028					0.553	0.049
Age (years)			0.138	<0.001				
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)	1.024	0.004						
Currently undergoing treatment (0 = Yes, 1 = No)								
Number of family members (0 = ≤6, 1 = ≥7)								
Caregivers								
Gender (0 = Male, 1 = Female)					1.396	0.001	0.046	<.001
Age (years)	0.123	<0.001	0.068	<0.001	0.092	<0.001		
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 = 500–1,000, 2 = 1,001–1,500, 3 = ≥1,501)			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)								
Adjusted R²	0.572		0.542		0.672		0.631	

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

*Using an Arabic version of the Needs Assessment of Family Caregivers-Cancer tool.^{2,3}