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EDUCATION

2019	**Doctor of Philosophy in Nursing** University of Maryland School of Nursing, Baltimore, MD, USA
2011	**Master of Science in Health Care Education** Glasgow Caledonian University, Glasgow, UK
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2000	**Diploma in Nursing** Muscat Nursing Institute, Muscat, Sultanate of Oman

RESEARCH ROTATIONS AND CONTRIBUTIONS

2017	University of Maryland, Baltimore, MD, USA Research rotation with Dr. Jennifer Schneider Main question explored: Is volunteering associated with preventable health behavior among older adults in a continuum-care retirement community? Developed synthesis table on volunteering and preventable health behavior Performed basic statistical analysis, demographic characteristics, cross tabulation, and logistic regression
2016	Johns Hopkins Hospital, USA Research rotation with Dr. Kathy Ruble Transcribed audio-recorded face-to-face and focus-group interviews verbatim, exploring the experience of a mother with a child on the autism spectrum Developed a synthesis table on reimmunizing children with cancer after chemotherapy completion Evaluated assistance animal therapy (AAT) survey

TEACHING EXPERIENCE

2008–present	***Assistant Tutor*, Oman Nursing Institute, Muscat, Oman** Teaches Child Health Nursing to undergraduate nursing students (theory, lab, and clinical supervision) *Other subjects taught*

Fundamentals of Nursing, Psychosocial Science, Communication Skills, Adult Health Nursing, Introduction to Nursing Research, Community Health Nursing, and First Aid

Other responsibilities held

Served as cochair of Child Health Nursing Department (2014–2015)

Serves as students' advisor for academic support

Prepares and participates in students' midterm and final exams

Evaluates students' performance (clinical, lab, and theory)

WORK EXPERIENCE

2002–2005 Senior staff nurse, Ibra Hospital, North Sharqia, Oman

Provided care for children with various medical illnesses

Served as preceptor for novice staff nurses (interns) and nursing students

2007 (April 7–July 7) Chair of Staff Development Department, Ibra Hospital, Oman

Provided and led continuing education program for staff

2006 (Feb 6–July 28) Senior staff nurse

Provided medical and surgical care for adult patients

2000 Internship program, Sinaw Hospital, Oman

Participated in six-month internship program in various units: medical, surgical, pediatric nursing, and obstetrics and gynecology

PUBLICATIONS

2014 Ranganathan, L., Al-Touby, S., **Al-Balushi, A.**, Shamnad, M., I., Malathy, Muniswamy, S., Sanjayan, D. (2014). A study to compare the teacher's perception on faculty allocation approach: Bridge the gap between theory and practice at Oman Nursing Institute, *Galaxy Journal*, *an International Multidisciplinary Research Journal.* vol. III (iv), ISSN 2278-9529

2014 Ranganathan, L., Ramasubramaniam, S., Al-Toubia, S., Sishen, V., **Al-Balushi, A.**, Al-Amri, W., Al-Nasseri, Y., Al-Rawahi, Y. (2014). What do Omani women know about breast cancer symptoms? *Oman Medical Journal*. vol. 29 (6): 408–413. doi:10.5001

PROFESSIONAL ACTIVITIES

2012–2013 Member. Research committee at Oman Nursing Institute, Oman

2012 Member. Directorate of Nursing and Midwifery Affairs, professional committee research group, Oman

2014 Presenter. Critical Day Care Day, second symposium, Oman

2013	Reviewer**.** Integrated Management of Childhood Nursing (IMCI) Preservice Education, reviewed IMCI manual, Oman
2012	Presenter. Innovative Use of Evidence Based in Nursing Practice, Sur Nursing Institute, Oman
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PROFESSIONAL ORGANIZATIONS

International Family Association
Oman Cancer Association (OAC)
Sigma Theta Tatu

Abstract

Title of Dissertation: Psychosocial Care Needs of Children with Cancer and Their Families: Perceptions and Experiences of Omani Oncologists and Nurses

Amal Al Balushi, Doctor of Philosophy, 2019

Dissertation directed by: Dr. Mary Johantgen, Associate Professor, Organizational Systems and Adult Health, and Dr. Kim Mooney-Doyle, Assistant Professor, Family and Community Health

Background: Much evidence demonstrates the psychosocial impact of childhood cancer on children and their families. While many health care systems are evolving to integrate psychosocial services into clinical care, barriers exist that must be understood before changes can be implemented in systems new to this care. Oncologists and nurses are on the front lines of care and have unique perspectives about the needs of their patients and families.

Objectives: The purposes of this study were: 1) describe the experiences and perceptions of pediatric oncology physicians and nurses in Oman regarding the psychosocial care needs of children with cancer and their families; and 2) describe the barriers and facilitators to providing psychosocial care.

Methods: A qualitative, phenomenological study was conducted. Purposive sampling strategy was used to recruit 26 oncologists and nurses with experience caring for children with cancer and their families. Individual, semi-structured interviews were conducted and recorded. Coliazzi's method of data analysis was utilized to inductively determine themes, clusters, and categories. Data saturation was achieved, and methodical rigor was established.

Result: Four themes emerged from the data. The first was “perceived need for care beyond medicine.” The oncologists and nurses recognized that more psychosocial assessment, care and services were needed. The second theme was “recognition of pediatric oncology as a challenging clinical practice area,” which had two subthemes: emotional burden and challenging situations. Participants described the challenges they faced trying to meet needs of children and extended families. The third theme was “barriers to providing effective psychosocial care,” which had three subthemes: barriers related to the health care system, barriers related to health care providers, and barriers related to infrastructure and environment. The fourth theme was “providing optimal supportive care within the available facilities,” which had two subthemes: supportive care and facilitating factors. Cultural and community factors were highlighted.

Conclusion: As the pediatric oncology services in Oman mature, clinicians are eager to develop the psychosocial assessments and needed services. Future research is needed to elicit the perspectives of Omani children with cancer and their families. Resources will be needed from higher authorities to design, implement, and evaluate the recommended changes.

Psychosocial Care Needs of Children with Cancer and Their Families: Perceptions and Experiences of Omani Oncologists and Nurses

by

Amal Al Balushi

Dissertation submitted to the Faculty of Graduate School of the
University of Maryland, Baltimore in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
2019

DEDICATION

I dedicate this doctoral dissertation to my parents; they raised me to be a devoted and sincere person who utilizes all opportunities to learn. This work is also dedicated to my beloved sisters and brothers, for their continuous support, love, and encouragement.

Additionally, I dedicate this work to my daughter, Shahla, and my son, Firas, who have continuously inspired me to complete the PhD program

To my Almightily God, thank you for being around me and for offering me such strength, patience, and wisdom.

ACKNOWLEGEMENT

The successful completion of this thesis would not have been possible without the support of many people. First and foremost, I would like to thank my dissertation committee: Dr. Johantgen, Dr. Mooney-Doyle, Dr. DeForge, Dr. Rogers, and Dr. Ibrahim Al-Ghaithi. Special thanks are extended to the co-chairs: Dr. Johantgen and Dr. Mooney-Doyle. Thank you very much for your time and patience; for believing in me; and for providing me with priceless guidance, encouragement, and motivation. Thank you for valuing the need to bring change to my country, the Sultanate of Oman, and for preparing me to assume such a great role. I would also like to thank Dr. Ghada, the external qualitative expert, for her help and guidance throughout the analysis.

A big thank-you goes to my family, who supported me and believed in me when I sometimes doubted myself. To my sisters, Houda, Nuha, and Shamsa who lovingly care for my children and help put my mind at ease, thank you. To my brothers (Isa and Jamal) their wives (Hanan and Mulhat), who were there for me when no one else was, thank you. To my amazing daughter, Shahla, who stood by me and supported me with love and the wisdom of someone beyond her age, thank you. Shahla, your love and support strengthened me and gave me the power to move forward. Thank you so much for holding our family together while I studied. Thank you to Firas, my sweet baby boy, who smiled at me and said, "Mom, study! You will do it!"

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I would also like to acknowledge how grateful I am to my country, the Sultanate of Oman, and His Majesty Sultan Qaboos for empowering Omani women; encouraging me; and giving me the chance to pursue my PhD at the University of Maryland, one of the world's leading universities in nursing studies. Finally, I would like to thank Almighty Allah for sustaining and watching over me and my family and for granting me the courage to pursue this PhD. *Alhamdulillah*.

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Chapter 1: Introduction

1.1 Introduction

This study sought to describe healthcare providers' experiences with and perceptions of the psychosocial care needs of families who have a child being treated for cancer. It was anticipated that knowledge generated from this inquiry would offer new insights and thus inform clinical practice, research, and education. This research employed a qualitative phenomenological study to illustrate the phenomenon under investigation. Participants in this study were purposefully selected because of their experiences in caring for children with cancer and their families. Semi-structured interview was conducted yielded in 26 participants. This chapter begins with an overview of the context and background that frame the study. Following this are the problems statement, the purpose of the study, and accompanying research questions. The chapter concludes with the significance of this research study and definitions of some of the key terminology used.

1.2 Background and Context

Every year, more than 200,000 children are diagnosed with cancer worldwide (World Health Orgnization, 2017). In the Sultanate of Oman, a country located in the Middle East, there are few childhood cancer cases diagnosed annually (60–80 cases) (Bhattacharjee, 2016). However, nearly 2,000 children with cancer are being admitted or readmitted to pediatric oncology departments for treatment of cancer and cancer-associated problems every year (Bhattacharjee, 2016). A diagnosis of cancer is a particularly severe threat and a potentially traumatic event for the children's families (Gibbins, Steinhardt, & Beinart, 2012). Based on the socioecological model, childhood cancer affects every member of the family (Kazak, 2006). Children with cancer and their families may

experience numerous stress reactions, ranging from normal adaptive responses to symptoms of anxiety and depression and, occasionally reaching the level of psychopathology(Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005). Evidence has shown that the majority of families are able to cope with and adjust to new circumstances; however, a small but substantial number of families display problems in adapting or present risk factors for developing psychological difficulties. There is strong evidence about the psychosocial impact of cancer in different cultures (Gibbins et al., 2012; Kohlsdorf & Costa, 2012; Kiernan, Meyler, & Guerin, 2010). Evidence from the Middle Eastern culture has shown that families' experience psychosocial influences because of caring for a child with cancer. This has ranged from uncertainty related to outcome and fear of recurrence, to impaired quality of life, to added burden and responsibilities, and disruption of family functioning and dynamic (Khoury, Huijer, & Doumit, 2013). Parents, in another study, also experienced distress associated with considerable family, social, and employment disruption (Lakkis, Khoury, Mahmassani, Ramia, & Hamadeh, 2016), and adolescents experienced adverse biopsychosocial effects as a result of their chemotherapy treatment (Al Omari & Wynaden, 2014). In Oman, the impact of childhood cancer on Omani families remains unclear, and the state of standards for psychosocial services offered in the healthcare system is also not known.

The Omani healthcare system is a universal system providing free primary, secondary, and tertiary care to Omani citizens. Under the leadership of Oman's Ministry of Health (MOH), access to quality healthcare has expanded and been recognized internationally. In 2000, the World Health Organization (WHO) ranked Oman first among 191 WHO member states in its overall performance in the level of health (World Health

Report, 2000), and more recently, Oman has been recognized as being at the top of the world's ten leading countries that made greatest progress in the recent decade in public health. Pediatric oncology care has been centralized in two hospitals in Muscat, the Capital of Oman. All patients are transferred to Muscat to receive their therapy. Efforts directed by the MOH have promoted the professional education and advancement of Omani healthcare providers. However, much of this care is still provided by expatriates from India, the Philippines, Indonesia, Egypt, Pakistan, Jordan, and Iraq. This circumstance may also influence the assessment and care provided to meet the psychosocial healthcare needs of children with cancer and their families. The availability of psychosocial services and the healthcare providers at pediatric oncology departments play an important role in fulfilling such families' psychosocial needs. Whilst Western standards screening for psychological distress and comprehensive psychosocial support services are endorsed (Wiener et al., 2015), little is known about the psychosocial services that have been offered to the children and their families and Omani families' psychosocial experiences.

1.3 Problem Statement

Every year, more than 200,000 children are diagnosed with cancer worldwide (World Health Orgnization, 2017). In the Sultanate of Oman, a country located in the Middle East, few childhood cancer cases are diagnosed annually (60–80 cases) (Bhattacharjee, 2016). However, nearly 2,000 of the children in Oman with cancer (both old and new cases) are admitted to pediatric oncology departments every year (Bhattacharjee, 2016). Pediatric oncology departments lack a standardized and structured approach to the psychosocial screening of families as well as dedicated psychosocial resources to address those needs. In Omani culture, extended families and friends often

fulfill these needs instead. The psychosocial support provided to parents and children is attributed to the cultural and religious beliefs that call for support and social cohesion among the people, especially in the case of illness. In contrast, the unmet needs of children and families and the influence this may have on health outcomes have been underexplored. More fundamentally, it remains unclear whether or not nurses and oncologists perceive providing psychosocial care as part of their role as healthcare providers. It is also unclear whether healthcare providers perceive a need for extended psychosocial care resources to help these children and their families.

1.4 Statement of Purpose and Research Questions

The overall aim of this study is to describe healthcare providers' experiences with and perceptions of the psychosocial care needs of families who have a child being treated for cancer. Their experiences and perceptions form the broad area of focus. More specific areas of exploration include the psychosocial needs of families from a healthcare provider's perspective, the current psychosocial care provided, challenges encountered when providing such support, and potential solutions for overcoming these challenges. To understand healthcare providers' experiences and perceptions and families' psychosocial care needs, and to lay the foundation for psychosocial support services for families who have had a child being treated for cancer, three research questions are addressed. A qualitative study is needed to address the gap in knowledge about healthcare providers' experiences and perceptions and families' psychosocial care needs and lay the foundation for psychosocial support services for families who have had a child admitted to a pediatric oncology department with cancer. To gain this knowledge, a descriptive phenomenological

approach was employed in this study. Accordingly, the questions of the proposed study are as follows:

1. What are providers' perceptions of the psychosocial care needs of children with cancer and their families?
2. What are the experiences of providers in caring for children with cancer and their families?
3. What are providers' perceptions of the barriers to and facilitators of psychosocial care?

1.5 Significance of Study

There is a dearth of evidence that addresses the perceptions of healthcare providers concerning the psychosocial care needs in a pediatric oncology context globally and specifically in Middle Eastern or Arabic countries. Thus, this qualitative study adds to the body of knowledge a deep insight regarding healthcare providers' perceptions and experiences regarding the following: (1) psychosocial care needs of children with cancer and their families in Oman, (2) caring for children with cancer and their families, (3) and barriers to and facilitators of providing psychosocial support.

1.6 Theoretical Framework

The Socioecological Model (SEM) provide the foundation for this study (Kazak, 2006). The SEM was adopted to conceptualize the psychosocial impact of childhood cancer on families in a comprehensive, systematic way and identify their potential psychosocial needs. The SEM has been widely used in studies of families dealing with pediatric chronic illness (Michael & Copeland, 1987). The SEM stems from the work of developmental

psychologist Bronfenbrenner (Bronfenbrenner, 1979), which conceptualizes the child as positioned at a center nested within an expanding set of systems: the microsystem, mesosystem, exosystem, and macrosystem. These systems, or layers, are interrelated and have reciprocal relationships with each other and the child. The *microsystem* is the innermost layer surrounding the child, which has a direct and immediate influence on the child. This layer consists of contexts such as the family (parents, siblings) and healthcare providers (nurses, doctors, social workers, psychologists, and others). According to Bronfenbrenner, the relationships at this level are bidirectional. The second layer is the *mesosystem*, which comprises the interrelations between two or more systems within the microsystem, such as family and healthcare team interaction. The *exosystem* is the third layer, which contains both the microsystem and mesosystem and has indirect contact with the child. For example, a parent's workplace, community health and welfare services, the mass media, and extended family may have indirect contact with the child. Finally, the outermost layer, which represents the larger social and cultural elements, is called the *macrosystem.* It can be seen, for example, in laws, policies, general beliefs, culture, and subculture. The *chronosystem* relates to the dimension of changes pertaining to the child and environment (Kazak, 2006) (Figure 1).

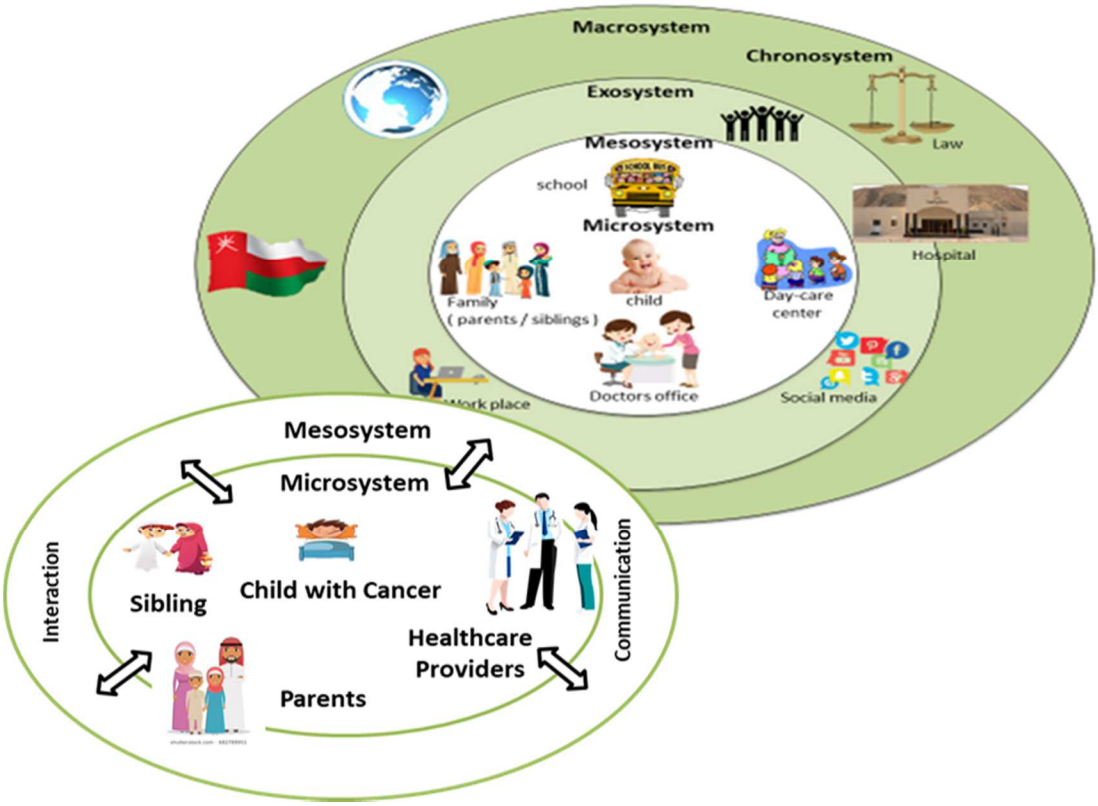


Figure 1. Socioecological Model.

Adopted from Kazak, A. E. (2006). Pediatric Psychosocial Preventative Health Model (PPPHM): Research, practice, and collaboration in pediatric family systems medicine. *Am Psychol Association*, *24*(4), 381-395. doi:10.1037/1091-7527.24.4.381.

The child grows and develops within a number of microsystems, one of which is the family. If the child becomes sick with cancer, the potentially deleterious impact of cancer and its treatment extends beyond the child's own development to involve the entire family. Therefore, marital, parenting, and sibling relationships are all affected (Kazak, Rourke, & Navsaria, 2003) This study focuses on the microsystem, which consists of the child with cancer, the family (parents and siblings), and the healthcare system (nurses and doctors). In addition to the microsystem, the study examines the mesosystem because of its focus on exploring the full range of supports that may be provided to families and

children. The interplay of the levels provides justification for exploring the perceptions of healthcare providers.

Next section describes the evidence found in the literature about the psychosocial care in relation to the services available and standards of psychosocial care. It also discussed the psychosocial needs of children with cancer and their families from healthcare providers as well as families' perspectives. Moreover, the following section highlights the healthcare system in Oman and the psychosocial services.

Chapter 2: Literature Review

2.1 Overview

This chapter addresses an overview about Oman's characteristics, family, culture and religious, and health care delivery system. In addition, this chapter presents an overview of psychosocial care (standards of psychosocial care, assessment and screening, family risk classification and psychosocial services, psychosocial interventions), healthcare providers' perceptions of psychosocial care needs and families' perceptions and expectations of care. Of particular interest is the communication between healthcare providers and families and the common need for emotional support and information as described in the literature. Finally, barriers and enablers to psychosocial care for families and children with cancer are also explored.

2.2 Literature Search Strategy

The scientific literature covered in this review was identified using the search engines of the University of Maryland, Baltimore; the Health Science and Human Services Library; and Google Scholar. The following databases were selected: Medline, PubMed, ScienceDirect, CINAHL, and Psych INFO. Further references were identified using reference lists of selected articles and committee recommendations. To allow for historical perspectives and references, no time limit was applied. The search terms used were "patient[s]," "family," "families," "child[ren]," "psychosocial care," "healthcare providers," "nurse[s]," "oncologist[s]," "perception," "experience," "psychosocial care need," "psychosocial issues," "pediatric oncology," and "cancer." Combinations of terms were used to locate qualitative and quantitative studies. Although a few studies on the perceptions and experiences of healthcare providers in pediatric oncology were found,

other relevant studies were in pediatric chronic illnesses provided additional relevant studies.

2.3 Characteristics of Oman

Oman (officially The Sultanate of Oman) is an Arab country located in the southeastern corner of the Arabian Peninsula. It is administratively divided into 11 governorates: Muscat, Dhofar, Musandam, Burraimi, Ad Dahiliyah, Al Dhahirah, Al Batinah North, Al Batinah South, Al Wusta, Ash Sharqiyah North, and Ash Sharqiyah South. These are further divided into 61 Wilayat's (districts) (Ministry of Health, Sultanate of Oman, 2016). The population in 2016 was 4,414, 051, of which 1,986,226 were non-Omani who came to Oman to seek employment. Oman is a young country. In 2016, about 14.9% of population was under the age of 5 and 36.1% was under the age of 15. However, only about 5.9% of the total population were 60 years and above (Ministry of Health, Sultanate of Oman, 2016). Oman has a traditional Arab tribal organization which is considered as the basis of society. The population is divided into hundreds of tribes of various sizes and cohesiveness that regulate their different relationship such as social, territorial, economic and political (Al-Barwani & Alberry, 2007).

Although the official language is Arabic, English is spoken widely. The country's main religion is Islam, but others are represented among the immigrant workers and foreign settlers, including Hinduism and Christianity (Ministry of Information, 2014; Ministry of Health, Sultanate of Oman, 2016).

2.3.1 The Omani Family

Traditionally, the family has been viewed as a social unit whose function is to

replicate and ensure the health and survival of its members(Al-Barwani & Alberry, 2007). Like other Middle Eastern cultures, Omani culture involves extended families with close relationships; as a result, one person's sickness affects the whole family unit. Family relationships in Oman are also guided by Islamic principles: the husband and father is viewed as the guardian of his wife, his children, and other family members under his care. Parents are obligated to nurture their children and promote their physical, emotional, social, and spiritual development from infancy to adulthood. Children usually live with their parents until they marry and remain connected with them afterward (Lipson & Meleis, 1983).

Families play an important role in healthcare and may even themselves act as care providers for admitted patients. This type of family support is a part of the healing process, according to Silbermann and Hassan, (2011) The emotional support provided by families plays a significant role in patients' feelings of not being left alone. This support has been manifested in the form of continuous encouragement and the provision of hope at different stages of disease (Al-Azri, Al-Awisi, Al-Rasbi, & Al-Moundhri, 2014). In a collective society like Oman, family love is a strong coping strategy for difficult times. According to Mahoney, Pargament, Murray-swank, and Murry-Swank, (2019) "Family relationships involve more than biological, psychological, and social processes; people often believe these bonds tap directly into the spiritual realm. . . . [I]n short, people often view family relationships as sacred." The sanctification of the family can aid recovery in two ways: on the family's part, giving hope and strength to the sick so that they are not alone; on the sick person's part, trying to recover so that the problems of the sickness do not disturb the family or make its members unhappy(Ahmadi, Mohamed, Hussin, & Mohammad, 2018).

2.3.2 Religion and Culture

The Quran, the holy book of Islam, described children as the "joy of our eyes" (25:74). The prophet Mohammed emphasized the importance of the proper upbringing of children. Parents are not merely legal guardians and caretakers; they are expected to treat their children respectfully as individual (Hedayat, 2006). In general, death is an accepted fact in Islam, something willed by God, on the basis of the verse "Wherever you are, death will find you out, even if you are in towers built up strong and high" (4:78).

As in other religions, a high degree of religiosity can reduce the anxiety of grief among Muslim (Suhail & Akram, 2002). In Islam, the death of an infant or a child is responded to with three consolations: patience, intercession, and substitution (Hedayat.,2006). Patience is considered a great quality in a Muslim. Muslims believe that God's grace comes most to those who worship in both goodness and hardship, including when a child dies (Gil'adi, 1992). On intercession, the prophet Mohammed taught that a child who dies will intercede on their parents' behalf and will grant them automatic entrance to heaven along with the child, without judgment. Conveying this sentiment to grieving parents can ease their pain. With substitution, as the word indicates, it is believed that God's wisdom leads him to take this child away so that another, more virtuous child may be given to the parents (Hedayat K., 2006). The Quran says, "So their Lord desired to give them in place [of the son who died] one better than him in purity and nearer to having compassion" (18:18).

The use of religion as a coping mechanism has been thoroughly discussed in the Islamic literature. The work of Ahmad, Muhammad, and Abdullah, (2011) on Malaysian

Muslim women diagnosed with breast cancer showed that some patients with life-threatening illnesses accepted their disease as a gift from God to wipe out their sins and hence grant them a place in heaven. They valued the disease as an awakening sign telling them to perceive life differently and enjoy it as never before. They also regained the strength to face life's difficulties more openly and optimistically.

The acceptance of life-threating diseases, in oneself or loved ones, as a gift from God has been also highlighted by Ahmadi, Ahmadi, Erbil, & Cetrez, (2019).They studied cancer patients in Turkey and found that people's religious beliefs directly determined the coping methods they used—for instance, thinking about the meaning of life or the purpose of existence from a religious perspective, or finding new meaning in life by changing one's priorities.

The notion of being rewarded for tolerance (Sabr) and acceptance of the destiny written by God was also reviewed by (Ahmadi et al., 2019).They studied Muslim Turkish patients and found that religious coping was strongly embraced as a coping method. A similar study conducted in Oman (Al-Azri et al., 2014) identified six coping strategies, including denial, optimism, withdrawal, Islamic beliefs and practices, and the support of family members and healthcare providers with more reliance on Islamic beliefs and practices (Al-Azri et al., 2014). The last refers to the patient's strong belief in God, and their belief that the illness is a test from God that they gracefully accept. The patients reported that their religious practices, such as reciting the Quran and praying, gave them a sense of peace, helped them through difficult times, and alleviated their worries about death and departure from this world and their loved ones.

Omanis tend to be very devout, with religious beliefs playing a significant role in

all aspects of their lives. In addition, religious and social structures are interconnected and difficult to separate. Culture can dictate some healthcare practices, such as health decisions, disclosure of bad news, end-of-life care, spiritual care, and related care issues.

Overall, spirituality and religion play prominent roles in patients' and families' emotional and psychological well-being, so healthcare providers should take those into consideration when planning care, establishing standards, and building and training specialized psychosocial or multidisciplinary teams.

2.4 Oman's Healthcare System

Omani has a universal healthcare system that provides free access to citizens and subsidized care to the foreign population. In 2000, the World Health Organization (WHO) ranked it first among 191 member states in overall performance in level of health (World Health Report, 2000), and in 2010 United Nations listed it first among countries that had made the greatest progress in public health in the previous decade (United Nations Develompent Programme, 2010).

Oman's healthcare system is divided into three levels of care: primary, secondary, and tertiary. Primary healthcare is provided mainly through healthcare centers, extended health centers, and local hospitals. Regional referral hospitals mainly provide secondary medical care, and national hospitals such as the Royal Hospital (RH) and the Sultan Qaboos University Hospital (SQUH), both located in the capital, Muscat, provide tertiary medical care. Figure 2. shows the pyramid structure of the referral system linking these levels.

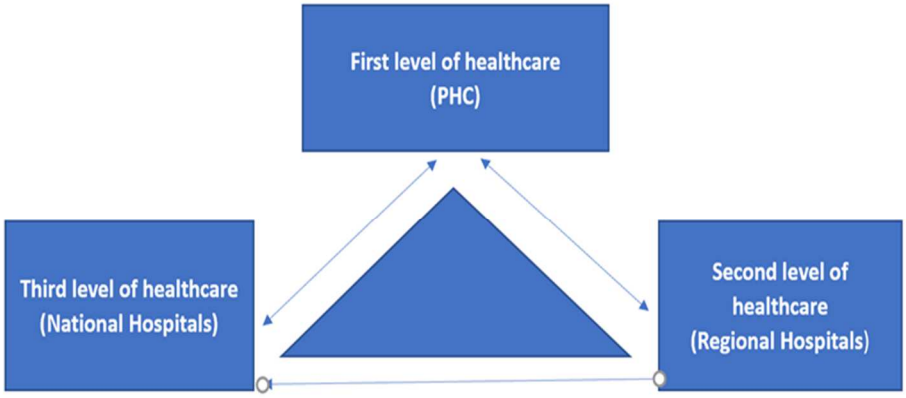


Figure 2. Illustration of Omani Health Care Levels.

Children diagnosed with cancer are transferred to national hospitals for treatment, management, and follow-up care. The pediatric oncology and hematology department (POHD) at the SQUH provides care only for blood cancer, whereas the RH deals with the full spectrum of childhood cancers, including leukemia, the most common, along with cancer of the lymphatic system, brain tumors, neuroblastoma, Wilms's tumor (cancer of the kidney), and bone tumors (Bhattacharjee, 2016). In addition, Oman has a registry of all cancer patients. These departments also serve children with hematological disorders such as thalassemia, hemophilia, and sickle cell anemia. The healthcare providers for children with cancer and their families are diverse in both hospitals. Alongside Omani nurses and physicians, there are many healthcare providers from other countries such as India, the Philippines, Indonesia, Egypt, Iraq, and Malaysia.

A recent report highlighted the lack of children's and adolescent's mental health services in Oman due to staff shortage and misdistribution of facilities, even though the number of young people with mental illness is increasing. Mental health services are

centered in Muscat, at the SQUH and Al-Massarah hospitals, both of which offer in-patient and out-patient services for children and adolescents (Mirza, 2018). The report also addressed the consequences of children making long commutes to receive mental health care, including missed school and missed workdays by their caregivers. Suggestions offered included training more interested providers in child and adolescent psychiatry, and decentralizing the mental care services at all three levels of healthcare in Oman (Mirza, 2018).

2.5 Psychosocial Care for Children with Cancer in Oman

In Oman, psychosocial services in the POHDs of both the RH and the SQUH are underdeveloped. Pediatric oncology at both hospitals lacks psychosocial resources, including assessment tools and personnel such as psychologists, social workers, child life specialists, and spiritual leaders. Despite these limited resources, healthcare providers have introduced some diversional activities that can lessen the psychological impact of cancer on children, including painting, building with blocks, and singing. These activities are provided by volunteers offering their time to ease families' suffering. The Oman Cancer Association (OCA) has sponsored some volunteer activities for children with cancer and their families. In addition, Dar Al-Hanan, a temporary home for children with cancer from outside Muscat, is available to up to 16 families at a time and is supported by non-governmental sponsorship.

2.6 Overview of Psychosocial Care in Western Countries

2.6.1 Psychosocial Care Standards

The need to develop a universal pediatric blood and cancer standard to meet the

psychosocial needs of children with acute illnesses and their families has been recognized globally. Several international organizations, including the Institute of Medicine, the American Society of Pediatric Hematology, the Canadian Association of Psychosocial Oncology, and the European Society of Pediatric Oncology, have published standards for the psychosocial care of patients with cancer and their families (Wiener, Viola, Koretski, Perper, & Patenaude, 2016). However, there remains a lack of evidence-based, up-to-date, specific, comprehensive, and universal standards of care to guide the provision of essential psychosocial care to pediatric cancer patients and their families (Wiener et al., 2015). For this reason, the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) published a set of 15 standards (Wiener et al., 2015) developed by a group of interdisciplinary experts and other stakeholders, funded by the Mattie Miracle Cancer Foundation. Standards of the psychosocial care of families who have a child with cancer are recommended (Wiener et al., 2015). However, these standards were developed and implemented in Western countries, such as the U.S., Canada, and European countries. It is not known to what extent they can be operationalized and implemented in Middle Eastern cultures, so these standards still need to be explored and examined in other settings.

2.6.2 Assessment and Screening

Parents of children with cancer experience post-traumatic stress more frequently than their ill children (Kohlsdorf & Costa, 2012). Ongoing assessment of both children and their parents and caregivers is this highly recommended to identify their mental health needs (Kearney, Salley, & Muriel, 2015). Indeed, as recommended by the PSCPCC, "Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial health care needs" (Kearney et al., 2015, p. 429). These

standards facilitate the early identification of psychosocial risks and resiliencies.

The Pediatric Psychosocial Preventative Health Model (PPPHM) was developed to identify families psychosocial risk levels and the services they need. As part of the model, it is essential to screen families for psychosocial risk levels. The Psychosocial Assessment Tool (PAT) and Distress Thermometer (DT) are evidence-based approaches to psychosocial screening (Kazak et al., 2015). The PAT is used to assess psychosocial needs and is linked to the classifications of this model (Kazak et al., 2015).

2.6.3 Family Risk Classification and Psychosocial Services

The PPPHM pairs families with interventions that match their psychosocial risk levels (Kazak, 2006). The model is illustrated in a pyramid with three tiers: "universal" at the base, "targeted" at the middle, and "clinical" at the top (Figure 3). According to the PPPHM, most families of children with cancer are at the universal tier because they are resilient and able to cope with the illness and its treatment. In this tier, the families are provided with services such as social workers, child life specialists, chaplains, creative arts programs, family-centered care programs, and financial counselors (Schepers, 2017). At the targeted tier, psychosocial distress is higher; families in this tier may have other already-existing sources of distress. Additional psychosocial services offered at this level include cognitive behavioral therapy for pain, and multicomponent, intensive, and targeted interventions, such as ensuring adherence to medication. At the clinical tier, families have severe distress due to chronic problems and need comprehensive, intensive, and targeted interventions (Kazak, Schneider, Didonato, & Pai, 2015).

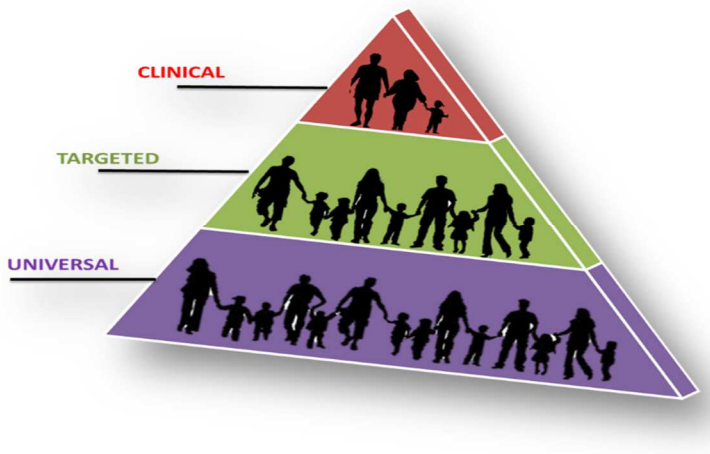


Figure 3. The Pediatric Psychosocial Preventative Health Model (PPPHM; adopted from Kazak et al., 2015).

2.6.4 Psychosocial Interventions

In the past few decades, researchers have examined several types of interventions used to give psychosocial support to the families of children with cancer. According to Kazak (2006), studies of psychosocial care needs have focused on four main areas: (1) understanding procedural pain; (2) realizing long-term consequences; (3) appreciating distress, both at diagnosis and over time; and (4) knowing the importance of social relationships. A meta-analysis of 29 randomized controlled trials from 1983 to 2009 revealed that the families of children with cancer had received psycho-educational skills training and therapeutic counseling (Northouse, Katapodi, Song, Zhang, & Mood, 2010). More importantly these interventions were shown to increase the families' quality of life and coping self-efficacy and to reduce their burdens. Other studies have used a range of formal and structured psychosocial interventions, such as "RRIGHT IDEA," "Celie Cancer Coping Kit," and "Shoptalk." These interventions have shown their efficacy for alleviating anxiety and depression, improving coping and adjustment, providing information about

treatments and procedures, and building rapport with healthcare providers (Sahler et al., 2005). Access to such psychosocial supports and interventions throughout the cancer trajectory is highly recommended according to the standards of psychosocial care.

2.7 Psychosocial Care Needs

2.7.1 Healthcare Providers' Perceptions of Psychosocial Care Needs

Healthcare providers' perceptions of families' psychosocial issues and care needs have been examined in several pediatric oncology contexts. Kiernan, Meyler, and Guerin (2010) investigated physicians' and nurses' perceptions and awareness of the psychosocial care needs of children with cancer and their families in Ireland. They found that the providers knew about the impact of childhood cancer on children, siblings, and their extended families despite a lack of training in psychosocial care. Moreover, although members of both professions acknowledged that they played a pivotal role in providing psychosocial care, they viewed formal psychosocial interventions as being provided by other disciplines (e.g., psychologists, social workers, and other counselors). Physicians' and nurses' roles in providing psychosocial care were described as handling families' concerns, questions, and emotions, with nurses playing a greater role in this than physicians; physicians' perceived responsibilities to be centered on breaking bad news and making referral decisions. These psychosocial care practices are congruent with a review by Hickes and Lavender (2004) in which they explored current trends and common psychosocial practices in the last twenty-five years of working with children with cancer and their families.

A study conducted in Sweden to assess the most important aspects of cancer care

for children and their families as perceived by nurses (Von Essen, Enskär, & Skolin, 2001). The authors found that most nurses recognized the importance of information, emotional support, wellness care for the child, social competence, and participation in decision making. Interestingly, the most important perceived aspect of psychosocial care was providing families with information and emotional support; providing honest information to parents throughout the child's disease trajectory helps them gain knowledge and feel in control and reduces their uncertainty about the illness. Uncertainty and worry about the child's future were the most common problems for parents, so providing such information is warranted.

The provision of emotional care was viewed differently by nurses and doctors in a study conducted in the United Kingdom by Forsey, Salmon, Eden, and Young, (2013). Although the nurses focused on assuaging parents' emotions and concerns to provide emotional care, doctors viewed reassuring parents about clinical care and the curative nature of treatment as more important than emotional interaction, providing a theoretical grounding for role-based differences in the care perceived to be needed and provided.

However, little is known about these perceptions in the Arabic context. In the one study from a Middle Eastern country. Borhani, Abbaszadeh, Mohsenpour, Asadi (2013) conducted a qualitative study to understand the experiences of Iranian nurses of caring for children with cancer. Five major themes emerged from the study: (1) attachment (mutual attachment between nurses and patients), (2) supportive care, (3) trying to repress feelings, (4) feeling of helplessness, and (5) need for emotional support. The findings of the study revealed that working in pediatric oncology departments have had a significant impact on nurses' professional, individual, and family lives. Emotional relationship between nurses,

children and their families was developed overtime. Nurses perceived that children need physical as well as emotional support. Feelings of helplessness, weakness and purposelessness regarding the disease and its progress were common among nurses. However, nurses tried to repress their feelings and control their emotions in order to support the families (Borhani et al., 2013).

2.7.2 Families' Expectations of Psychosocial Care Needs

When planning or organizing psychosocial care, attention must be given to the elements preferred by families at each stage of cancer care. For example, in a study in Canada, information, self-management therapy, and social support were all perceived as highly important to families during the treatment phase (Fagerlind, Kettis, Glimelius, & Ring, 2013). However, these needs were not met to the families' expectations. In the same study, parents and adolescents ranked written information, face-to-face peer social support, and preparation by a therapist for self-management therapy as the highest and most preferred forms of support (Fagerlind et al., 2013). Similarly, a study in the United Kingdom evaluated families' unmet needs for psychosocial care and found that age-appropriate facilities, emotional support, and access to information were the most lacking (Ljungman et al., 2003). Therefore, parents' expectations and perceptions of psychosocial needs must be better understood and acknowledged by healthcare providers they can assess and plan for psychosocial care more appropriately.

In the cases of other pediatric chronic illnesses, parents preferred psychosocial care centered on physicians and nurses meeting illness-related demands and instrumental needs and providing information and emotional and social support. The demands that arise from hospitalization and decompensation can be frustrating, as revealed in the work of Mooney-

Doyle, Rodrigues, Szylit, and Deatrick (2017). Providing material support and fulfilling the specific needs of each family was found to help settle the chaos and bring back control over their lives to those affected by illness. Instrumental needs include concerns about day-to-day costs, home maintenance, job security, and flexible work arrangements (Mooney-Doyle et al., 2017).

Şener and Karaca (2017) assessed the mutual expectations of mothers and nurses in a pediatric department in Turkey. Many mothers' expectations of nurses were beyond the physical care of the child. Some said they would like nurses to be friendly, emotionally caring, approachable, and receptive to the mothers' questions and expressions of anxiety. However, these needs were not always met as expected (Şener & Karaca, 2017). The nurses in this study were acquainted with these expectations, but because of their challenging working environment, exemplified by a lack of staff and a heavy workload, they could not meet them (Şener & Karaca, 2017). This is in line with the findings of Mooney-Doyle (2017) on parents' expectations of mutuality of care; such care goes beyond completing the task to providing care with love. Parents also emphasized their deep desire for healthcare providers to offer support that built on their parenting abilities, that truly acknowledged children and families, and that helped them to stay strong to provide the emotional and cognitive support that are intrinsic to parenting. The need for such support was illuminated in some themes generated in the same study: "Help us survive this," "Let's fight together: please fight with me, not against me, to care for my family," and "Guide me through the darkness: I am suffering" (Mooney-Doyle et al., 2017).

The work environment and other factors influenced the actual provision of the expected optimal care. Parents' perception of the quality of pediatric oncology inpatient

care and their satisfaction with it were assessed by Keiza, Chege, and Omuga (2017), who found that the care provided did not meet parents' optimal expectations; their dissatisfaction was related to the required resources and to the educational and psychosocial needs of the parents.

Overall, the evidence suggests a pivotal role for healthcare providers in fulfilling the psychosocial needs of the families, but limited literature was found on the experiences and perceptions of healthcare providers regarding families' psychosocial care needs. It is also worth noting that most of these studies were conducted in Western countries, and little is known about the needs specific to pediatric oncology in Middle Eastern countries such as Oman. Given that healthcare systems, social structures, and cultural practices vary between countries, the need for a qualitative study of Omani healthcare providers' experiences with and perceptions of the psychosocial care needs of families with children in pediatric oncology care is apparent.

2.7.3 Information and Emotional Support

Evidence has shown that information and emotional support were mentioned the most by parents of children with cancer when asked what supportive care they required (Kerr, Harrison, Medves, & Tranmer, 2004). A systemic review of the psychosocial needs of such parents supported this finding that information was their primary need (Ilyas, Iram, & Jafri, 2016). Healthcare providers' perceptions about providing information to these parents were also evaluated. Twenty providers on a Swedish pediatric oncology ward, including nurses and physicians, participated in four focus group interviews (Ringnér, Jansson, & Graneheim, 2011). The study identified the most important activities, which included: (1) balancing the amount of information; (2) providing correct, consistent, and

understandable information; and (3) delivering information at the right time. Because the use of the Internet to gather information was difficult for some parents, due to misleading and overloaded information, the authors recommended that families be provided with quality-assured web-based information that is accessible at their convenience (Ringnér et al., 2011).

Although emotional support is viewed as an important aspect of psychosocial care, it is managed and delivered differently by different healthcare providers. Thirty doctors and nurses working in six United Kingdom pediatric oncology and hematology treatment centers participated in a qualitative study which found that healthcare providers relied on each other to ensure their parents' emotional needs were met by the multidisciplinary team. Nurses tended to have open conversations with parents to assess their emotional needs and provide further reassurance, whereas physicians focused more on reassuring parents about the nature of the treatment (Forsey et al., 2013).

2.8 Communication Between Healthcare Providers and Families

Effective communication characterized by openness, honesty, and collaboration between healthcare providers and children and their families is a cornerstone of patient- and family-centered care (Aldefer & Kazak, 2006). In addition, families' values, beliefs, cultures, perspectives, and choices must be taken into consideration for effective communication and family-centered care (Canadian Association of Psychosocial Oncology, 2010). Communication is a crucial skill with which healthcare providers across the continuum of cancer care must be equipped. Thus, recommendations for communication and collaboration in pediatric psycho-oncology are strongly supported by IOM and PSCPCC. Evidence has suggested that effective communication—including

active listening, expressions of empathy, and responsiveness to patients' emotional cues —can improve psychological adjustment, adherence to treatment, and satisfaction with care (Epstein & Street, 2007; IOM, 2008). A study of the interpersonal, informational, and decision preferences of families with childhood cancer found that young children and parents strongly favored honesty, support, and open communication about care with healthcare providers (Zwaanswijk et al., 2007). These family preferences are also in line with the cultural preference of Oman, so families' decision preferences need to be assessed and taken into consideration. With regard to decision making, most participants agreed on the importance of collaboration between healthcare providers, parents, and children. The differences in their views involved what should be discussed in front of the child. However, these findings cannot be generalized because of the qualitative nature of the study and the small sample size (Zwaanswijk et al., 2007).

Similar views were reported in a study of parents' and healthcare providers' perspectives on children's participation in information-sharing and communicative interaction. This study found that healthcare providers supported an open and honest approach to information sharing but parents did not. Parents felt that they needed to maintain hope, spirit, and optimism by not sharing all information with their children (Coyne, Amory, Gibson, & Kiernan, 2016). Both studies did support the idea of considering patients' and families' preferences for sharing information with sick children (Coyne et al., 2016; Zwaanswijk, et al., 2007;). Thus, the extent to which information is to be shared with sick children depends largely on families' preferences.

2.9 Perceived Barriers and Enablers when Providing Psychosocial Care

Evidence has shown that providers in various healthcare contexts recognized the psychosocial impact of cancer on children and their families. However, there are still many challenges and barriers to providing the best psychosocial care. In the U.S., a cross-sectional, web-based survey completed by 400 Oncology Nurses Society members with diverse backgrounds, perspectives, ages, education levels, primary work settings, and professional responsibilities found that lack of time and resources were identified as barriers to assessing psychosocial problems and providing psychosocial care in at an oncology context (Gosselin, Crane-Okada, Irwin, & Wenzel, 2011). The most remarkable finding was that most nurses perceived that patients held psychosocial issues to be less important than medical care, and that patients experienced stigmas about disclosing their psychosocial problems to healthcare providers. In the same study, the assessment tool either was not used or was used infrequently; this might have influenced the in-depth identification of psychosocial issues (Gosselin et al., 2011).

The enabling factors suggested in Gosselin et al.'s study included: nurses being prepared to take an active role in learning about the assessment tool and adopting it in their daily practices; collaboration between oncology nurses and the multidisciplinary team, given the limits to healthcare providers' time; and community resources. Therefore, a broader net of support can be created to provide such care. The use of "patient navigators" or "patients' advocates" might also be helpful for meeting patients and their families' instrumental, financial, and medical needs (Gosselin et al., 2011).

Similarly, a recent integrated review was conducted to explore the barriers to providing psychosocial care to children with chronic illnesses as reported by healthcare

providers and families (Tallon, Kendall, Priddis, Newall, & Young, 2017). The review revealed that healthcare providers recognized the emotional distress experienced by patients but felt constrained by a healthcare system that focused on the "medical model" of care. Other experienced barriers were lack of time, lack of confidence in communication skills, and the perception that patients and their families prioritized physical care over psychosocial care. Patients and their families reported that the healthcare system focused on medical care more than on supportive care.

Fagerlind, Kettis, Glimelius, and Ring (2013) explored oncologists' psychosocial attitudes and beliefs and their perceptions of barriers to psychosocial communication during out-patient consultations. The most commonly identified barriers were insufficient time, a lack of resources for handling potential problems, and a lack of appropriate tools for evaluating patients' health. In addition, the older and more trained oncologists and those who worked at palliative homes or hospices were more oriented toward psychosocial care than younger and untrained participants and those who worked at the university hospital (Fagerlind et al., 2013). There was also a positive correlation between the Physician Psychosocial Beliefs Scale and the number of perceived barriers; less psychosocially oriented oncologists perceived more barriers (Fagerlind et al., 2013).

Nurses perceived the same barriers in their clinical practices, according to a review by Dilworth, Higgins, Parker, Kelly, and Turner (2014). In the same review, a complex interplay of perceived barriers was found at multiple levels, organizational, cultural, and individual. To overcome such barriers and sustain a good practice, the study recommended interventions that are aligned with care pathways, communication skills training, and clinical supervision. It could be argued that communication skills training would be helpful

because communication skills reduce the time needed to assess the psychosocial care needs of parents and their families. Razavi et al., (2003) reported that communication training improves clinicians' attitudes toward psychosocial care and their skills and confidence in recognizing psychological problems.

Given the importance of the professional training, Leaf et al. (2004) investigated the association of pediatrician training on the identification and management of emotional or behavioral problems among children 4–8 years in 19 practices in south-central Connecticut. Their study revealed that pediatricians who received advanced and moderate training were more likely to identify and manage psychosocial difficulties than others. Moreover, training and education of healthcare providers is a part of the set of psychosocial care standards (Patenaude, Pelletier, & Bingen, 2015). Recommendations for training domains and topics related to pediatric psychology have been well-described by Palermo et al. (2014).

2.10 Summary of Literature

Childhood cancer is a disease associated with many destructive effects that shake both the physical and psychosocial lives of children and their families. Studies have shown that healthcare providers were aware of these harmful effects on the child and the entire family and therefore, they believed in the importance of providing holistic care rather than and not only treating the disease itself. Worldwide, there is universality in care providers desire to provide better care but the emphasis, training, and support systems vary considerably. Previous studies have also revealed that care providers considered that the most important perceived aspects of psychosocial care were; providing families with information, emotional support, and utilizing age-appropriate facilities. Effective

communication was viewed as the cornerstone and one of the most important skills that healthcare providers must master in order to assess the needs and concerns of patients and their families and hence meet those needs accordingly. Several challenges and barriers to providing effective psychosocial care were discussed in literature. However, it could be argued that most of these challenges can be addressed through the coordination of services, training, and research. In Oman, there are no studies that explored the psychosocial care needs of parents and children with childhood cancer from the perspectives of healthcare providers. A study is therefore required to investigate this issue, considering that providers have different cultural backgrounds that the Omani families that they serve. This study employed a phenomenological approach to identify the essence of human experiences in that phenomenon as it was embarked from the participants' perspectives. Building on the previous studies conducted worldwide, this study will gain insight into understanding about healthcare providers' perceptions of psychosocial care needs and therefore, it may reveal new perspectives associated with the uniqueness of Oman culture.

Chapter 3. Research Design and Methods

3.1 Introduction

The purpose of this qualitative study was to explore health-care providers' experiences with and perceptions of the psychosocial care needs of families of children with cancer who have been admitted to a pediatric oncology department. This chapter describes the study's research methodology and includes discussion of the following topics: overview of research design, description of research sample, method of data collection, analysis of the study, ethical considerations, issues of trustworthiness, and limitations of the study. The chapter culminates with a brief concluding summary.

3.2 Overview of Research Design

This qualitative study was guided by a descriptive-phenomenological methodology. A phenomenological study describes the common meaning of a group of individuals' lived experiences of a phenomenon (Creswell, 2013; Lopez & Willis, 2004a) Phenomenology, a means of qualitative inductive research, is rooted in the 20th-century philosophical traditions of Edmund Husserl (descriptive) and Martin Heidegger (interpretive). For this study, descriptive phenomenology was employed to facilitate exploration of hidden meanings that may help to understand phenomena. Husserlian descriptive phenomenology privileges the experience of the phenomena, which could be an object of scientific study(Lopez & Willis, 2004b). Therefore, this methodology could help in understanding the phenomenon of the psychosocial care needs of children with cancer, as experienced and perceived by health-care providers. Descriptive phenomenology was selected over hermeneutics because little is known about health-care providers' experiences and perceptions of the psychosocial care needs of families in Oman

and because the researcher does not have direct engagement with this phenomenon. A similar approach was used by Kieran and colleagues but in different cultural context (Kiernan, Meyler, & Guerin, 2010).

One of the most important components of Husserlian phenomenology is the achievement of transcendental subjectivity (Lopez & Willis, 2004a). Transcendental means "in which everything is perceived freshly, as if for the first time," (Moustakas, 1994 p. 34). Therefore, in order to understand the essence of the lived experiences of the phenomenon under exploration, the researcher must minimize potential influences on data collection and data analysis. For this study, maintaining transcendental subjectivity was achieved through bracketing. Bracketing, or *epoché*, is "a scientific process in which a researcher suspends or holds in abeyance his or her presuppositions, biases, assumptions, theories, or previous experiences to see and describe the phenomenon"(Gearing, 2004, p130). In this case, the researcher suspended any prior knowledge, experiences, and perceptions throughout the study. The researcher gained knowledge of and experience with the phenomenon of psychosocial care needs of children and families by reviewing the literature prior to data collection and working as a pediatric nurse in a general pediatrics ward. The researcher was fully aware that such knowledge and experience could impose bias on data collection and analysis. Therefore, the researcher reflected throughout the study process. For example, before data collection, the researcher reflected on the experience of providing nursing care to children and mothers, and what finding might be expected. In addition, before and during commencing of the analysis, the researcher and a member of the dissertation committee reflected on their experience as nurses, mothers, in

addition to their understanding of concept of psychosocial care. The researcher maintained a reflective journal of decisions made, themes that emerged, and personal responses.

3.3 Research Sample

The purposive sampling that was employed in this study allowed the investigator to learn from a variety of voices in order to generate a deeper understanding of the psychosocial care needs of children and their families. The intent of the sampling strategy was to recruit a sample that included a wide spectrum of participant ages, genders, nationalities, credentials, educational levels, and durations of clinical experiences. The criteria for selection of participants included (1) a minimum of 2 years' experience working in pediatric oncology departments, and (2) the ability to speak English fluently. Former students of the researcher were excluded. A total of 26 providers participated in this study. The sample consisted of Omanis and non-Omanis. The non-Omani providers were from various countries, including the Middle Eastern and Southern Asia. Nurses and doctors who participated in this study were diverse in relation to their years of experience, levels of education, ages, genders, and nationalities.

3.4 Recruitment Procedures

Approval from the Institutional Review Board (IRB) was obtained from the University of Maryland, Baltimore (Appendix A); Ministry of Health, Sultanate of Oman (Appendix B); and Sultan Qaboos University Hospital, Oman (Appendix C). The researcher personally met with executive directors and nursing affairs directors of both hospitals in order to gain formal access to the potential participants. After securing IRB approval, the researcher recruited participants by using multiple techniques, including presentations, emails, and recruitment flyers. Doctors and nurses who were caring for pediatric cancer

patients in the hematology and oncology departments at the two hospitals were invited to attend a presentation that described the study. On the day of the presentation, the recruitment flyers (Appendix D) and detailed study information were distributed. Recruitment flyers were also placed on bulletin boards in pediatric oncology departments at both hospitals. The flyers provided detailed information about the study and also included the researcher's contact information. After obtaining department heads' permission to access providers' emails, the researcher sent emails to all providers (Appendix E). Providers who were interested in participating in the study contacted the researcher directly or by phone. During the recruitment period, which lasted 6 weeks, the researcher engaged with providers from both hospitals in order to bridge the gap between the researcher and the health-care providers and to establish connections with them.

3.5 Pilot Testing

Prior to starting interview, a pilot test was conducted to refine the interview guide and adapt the research procedures. Initially, the interview guide was reviewed by the dissertation committee, and feedback was obtained regarding the wording, language, and relevance. A nurse and a doctor participated in a pilot test of the interview guide and demographic data questionnaire. Written informed consent was obtained and a semi-structured, face-to-face interview was conducted in a seminar room. The interviews were digitally recorded. Participants conveyed satisfaction with the clarity, wording, and relevance of the guide; they did so immediately after the interview and via email. Therefore, no further modifications were made, and the data were included in the study sample.

3.6 Data Collection

Initial recruiting contact with study participants took place within the pediatric oncology departments of the two tertiary-care-referral hospitals. Upon agreeing to study participation, the participants provided written informed consent. The process of consent was conducted in a private room. In an effort to obtain rich information about providers' experiences and perceptions, face-to-face semi-structured interviews were conducted, guided by an interview guide (see Appendix F). The interviews' venues and times were scheduled based on the participants' convenience. Most interviews were conducted in a private seminar room; two were in a private exam room. The duration of the interviews varied, ranging from 25 to 60 minutes, and all interviews were conducted by the principle investigator. Each participant was asked to respond to a brief demographic questionnaire, which is included in Appendix G.

Participants were asked open-ended questions about their experiences regarding the psychosocial care needs of families of children with childhood cancer. Each interview started with a broad question to capture the wide array of experiences: "Tell me about your experience regarding care for children with cancer and their families." Then, specific questions were asked. For example, "How did you assess/screen for the psychosocial needs of children with cancer and their families?" and "From your experience, tell me about the psychosocial needs of children with cancer and their families?". The guide consisted of 13 main open-ended questions and some additional follow-up or probing questions. Each interview was transcribed by a professional transcriptionist. The issues of privacy and nondisclosure of information were assured.

All interviews were recorded using two digital recorders and then transcribed verbatim following data collection. Each participant was interviewed once. Each interview was transcribed by a professional transcriptionist. The issue of privacy and nondisclosure of information were assured. Follow-up emails with the transcripts attached were sent to all participants for verification of their experiences and as an opportunity for participants to add further experiences, if needed. One-third of the health-care providers verified their experiences via email. The feedback conveyed their satisfaction with what was documented in the transcripts, which represented the providers' experiences of the psychosocial care needs of children and their families.

3.7 Data Analysis

Demographic data were summarized with frequencies and percentages. Colaizzi,'s (1978) methods of data analysis were utilized to inductively determine themes, clusters, and categories. MAXQDA computer software was used to organize and manage data. Colaizzi, (1978) seven-step strategy for data analysis, rooted in Husserl's descriptive phenomenology, was used for analysis The steps included extracting significant statements, formulating meanings, organizing formulated meanings into clusters of themes, exhaustively describing the investigated phenomenon, describing the fundamental structure of the phenomenon, and returning to participants to validate the findings. The following steps were employed and confirmed by another qualitative researcher.

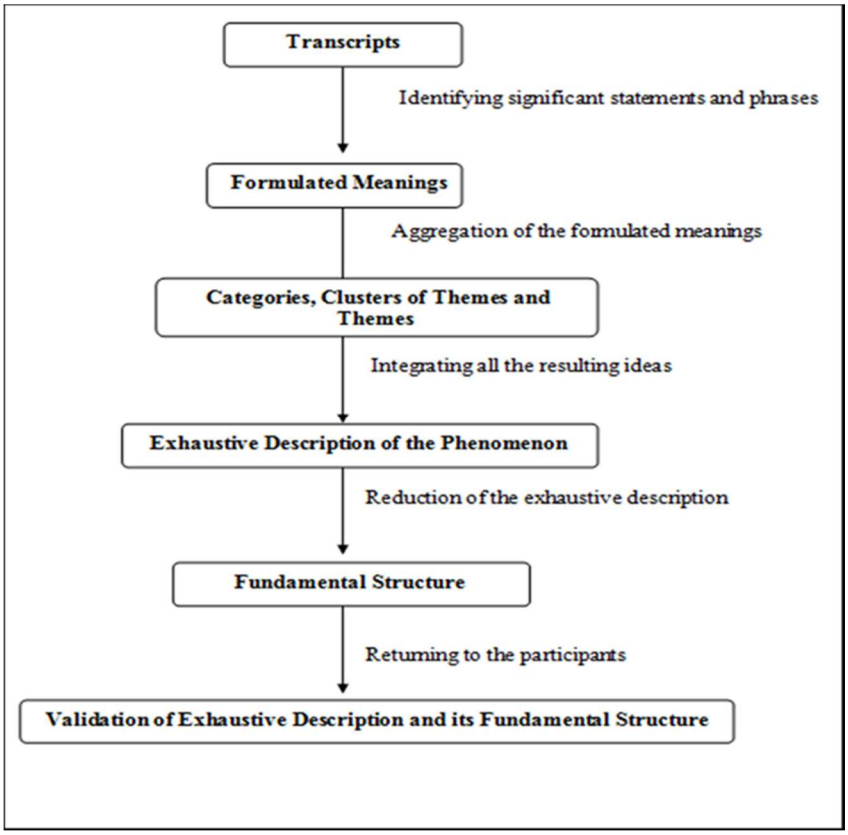


Figure 4. Colaizzi's strategy for phenomenological data analysis. Adopted from "Employment of Colaizzi's strategy in descriptive phenomenology: a reflection of a researcher," by G. Abu Shosha, 2006, European Scientific Journal, vol. 8, p. 34. Copyright 2019(Abu Shosha, 2006).

Step 1: Acquiring a sense of each transcript (see Appendix H). The researcher read and reread the transcript of each interview several times to gain a sense of the content. During this stage, thoughts, ideas, and feelings that arose from the researcher were added to the bracketing diary. Colaizzi,'s (1978), suggested reading participant narratives to gain a sense of what was said. In this study, the researcher also listened to the audiotapes several times. Listening to the audio-several times was adopted from previous study by Sanders, (2003).

Step 2: Extracting significant statements. For each transcript, the significant statements that pertained to perceptions and experiences regarding the psychosocial care

needs of children with cancer and their families were extracted. A new document was created to display and collect the significant statements, including 1690 significant statements from 26 participants (see Appendix I).

Step 3: Formulating meanings. Meanings were formulated from these significant statements, and each of the underlying meanings were coded in one category. The meanings reflected the exhaustive descriptions. All formulated meanings were verified by another qualitative researcher (Appendix J).

Step 4: Organizing formulated meanings into clusters of themes. Next, the formulated meanings were grouped into categories that reflected a unique structure or cluster of themes. For description of psychosocial care, 1,690 formulated meanings were arranged into 45 theme clusters, which were then collapsed into seven themes, which were common among all participants' descriptions of experiences with psychosocial care. All themes were internally convergent and externally divergent. In other words, each formulated meaning fell into one theme cluster that had a description of meaning that was unique from other structures (Mason, 2002)(Appendix K).

Step 5: Exhaustively describing the investigated phenomenon. In this fifth stage of analysis, the findings of all emergent themes were given exhaustive descriptions. The entire structure of the providers' experiences and perceptions was achieved by incorporating the emergent themes, theme clusters, and formulated meanings to create the overall structure that captured all elements of the experiences.

Step 6: Describing the fundamental structure of the phenomenon. In this stage, the exhaustive descriptions were reduced to an essential structure of the phenomenon. Any

redundant information was eradicated from the overall structure to create the fundamental structure.

Step 7: Returning to participants to validate the findings. The goal of this stage was to validate findings by using the member-checking technique. The researcher accomplished this by discussing the main findings with a provider from each profession, via telephone. Participants' feedback corroborated their experiences.

3.8 Trustworthiness of the Findings

According to Lincoln and Guba (Lincolon & Guba, 1985), techniques such as credibility, transferability, dependability, and confirmability can be used to ensure the trustworthiness of a study's findings. Ensuring credibility involves confirming the truth of findings and interpretations. To ensure the credibility of this study, the *member-checking* approach was applied, as described above. Furthermore, the researcher met every 2 weeks with members of the dissertation committee to discuss and reflect on analytical decisions. This was done throughout the stages of analysis. Additionally, the researcher debriefed and discussed with external qualitative experts about all analytical decisions, the development of all clusters of codes, and emergent themes. A member of the committee was also extracted the significant statements for four transcripts and added meaning to them.

Transferability, the applicability of a study's findings to other populations or contexts, was maintained through the adoption of a maximum-variation sampling. This approach allowed for diversity of participants. The findings yielded a diverse sampling in terms of nationalities, years of experience, genders, ages, and education levels. Furthermore, transferability was achieved through *thick description*, which involved detailed descriptions of health-care providers' experiences and allowed for contextual

comparison. *Dependability*, referring to the consistency of findings that would occur if the study were replicated with a similar population, was maintained through documentation of the audit trail and all decision-making that occurred throughout the study. *Confirmability*, or neutrality, was maintained by verifying participants' experiences via phone after the researcher reviewed and coded the data as well as through an audit trail. In the latter case, all decisions made pertaining to data collection and analysis were recorded, and field notes were maintained. *Reflexivity* was also maintained throughout the study process; the researcher's own presuppositions about the perceptions of health-care providers were bracketed and documented.

3.9 Human Subjects Risk

The major risks to the participants were related to coercion and confidentiality. As noted above, some of the participants may feel that they were expected to participate as part of their position, professional obligation, or expertise. That this was not the case was reinforced throughout the information and consent procedure, and during data collection proceedings, reminding them they could skip questions or decline answering any they chose.

Efforts were made to minimize the risk of breaching the participants' confidential data. To protect confidentiality, a unique code number was assigned to each participant in all documentation; the numbers were used instead of the participants' names. Therefore, the findings of this study were presented anonymously, and data were used solely for research purposes. Short quotes utilized to demonstrate the validity of the findings were assigned unique codes. Care was taken to ensure that the quotes did not contain information that would enable others to identify the participants. All data were retained in a locked cabinet and password protected computer. The participants' names and code numbers were

kept on a separate sheet and not stored with the data. The interviews were digitally recorded by the researcher and immediately transferred to a secure university-based research drive as well as an encrypted file on the investigator's personal computer.

It should be noted that some nurses were emotionally disturbed by recalling uncomfortable experiences during the delivery of care to the children and families. The researcher told each nurse that they could stop the interview at any time if needed. Tissues and water were offered. None of the participants asked to stop the interview. The study may not have any direct benefit to the participants. However, the information obtained will add to the body of knowledge about the psychosocial care needs of families that have children with cancer. This would also establish the foundation for the development of psychosocial support services.

Chapter 4. Findings of the Study

4.1 Introduction

This chapter presents the demographic characteristics of the participants and the thematic findings regarding healthcare providers' perceptions of the psychosocial care needs of parents and children with childhood cancer in Oman. Four themes emerged from the analysis that captured the perceptions and experiences of health care providers and answer the study questions. At the end of the section, the overall findings are summarized.

4.2 Participant Characteristics

Twenty-six healthcare providers from pediatric hematology and oncology departments at two tertiary teaching hospitals in the Sultanate of Oman participated in the study (see Table 1). The sample consisted of nurses (n = 12, 46.2%), doctors (n = 12, 46.2%), and nurses administrators (n = 2, 7.7 %), with a mean age of 40 years (SD=8.68, range 30–60). Most participants were female (n = 17, 65.4%) and non-Omani (n = 17, 65.4%), who came from Middle Eastern countries and South East Asia. The nurse participants had a spectrum of educational backgrounds with 15.4% having a diploma in nursing, 3.8 % with a post-basic diploma in oncology nursing, 30.8% with a Bachelor of Science in nursing, and 3.8, prepared for a master's degree in advanced practice cancer care. All physicians were oncologists; among them, many were fellowship trained (34.6%), or had a master's degree (7.7%) or pediatrician oncologists (3.8%). Healthcare providers with more than twenty years' experience in clinical practice made up 30.8% of the sample, while 30.5% had 6–10 years' experience in oncology and hematology. Most of the healthcare providers were Muslim (61.5%); other religious affiliations included

Christianity (15.4%) and Hinduism (7.7%). Most of them also had religious views and cultural beliefs about psychosocial care (76.9%).

Characteristics	Category	N (%)	Mean (SD)	Range
Age			40.4 (8.68)	30–60
Gender	Male	9 (34.6)		
	Female	17 (65.4)		
Nationality	Omani	9 (34.6)		
	Non-Omani	17 (65.4)		
Specialty	Nurse	12 (46.2)		
	Doctor	12 (46.2)		
	Nurses-Admn	2.0 (7.7)		
Highest level of education	Fellowship, doctor	9 (34.6)		
	Pediatrician Oncologists	1 (3.8)		
	Master's degree, doctor	2 (7.7)		
	Master's degree, nurse	1 (3.8)		
	Diploma in general nursing	4 (15.4)		
	Bachelor of science in nursing	8 (30.8)		
	Post-basic diploma in oncology nursing	1 (3.8)		
Religion	Muslim	16 (61.5)		
	Non-Muslim	10 (38.5)		
Religious affiliation of non-Muslims	Catholic	4 (15.4)		
	Christian	4 (15.4)		
	Hindu	2 (7.7)		
Years in clinical practice	2–5	1.0 (3.8)		
	6–10	7.0(26.9)		
	11–15	3.0(11.5)		
	16–20	7.0(26.9)		
	More than 20	8.0(30.8)		
Years in pediatric oncology practice	2–5	5.0(19.2)		
	6–10	10 (38.5)		
	11–15	5.0(19.2)		
	16–20	—		
	More than 20	6 (23.1)		
Has religious beliefs	Yes	20 (76.9)		
	No	6.0(23.1)		

Table 1. Participant demographics.

4.3 Emergent Themes

As mentioned in the previous chapter, 1,690 formulated meanings were arranged into (45) theme clusters, which were then organized into four common emergent themes. Table 2. illustrates the themes and subthemes.

Theme	Subthemes
Perceived need for care beyond medicine	
Recognition of pediatric oncology as a challenging clinical practice area	Emotional burden Challenging situations
Barriers to providing effective psychosocial care	Barriers related to healthcare providers Barriers related to healthcare system Barriers related to infrastructure and environment
Providing optimal supportive care within the available facilities	Supportive care Facilitating factors

Table 2. Summary of the emergent themes and subthemes.

4.3.1 Theme 1: Perceived need for care beyond medicine

This theme included healthcare providers' perceptions of the psychosocial care needs of children with cancer and their families that go beyond disease treatment and medication administration. Healthcare providers believed that children and their families need comprehensive care that includes psychological, social, spiritual, and instrumental support in addition to health education and counseling.

Psychological support. Children with cancer face multiple challenges due to prolonged hospitalization, recurrent admission, absence from school, "being in a strange environment with strangers," "restraint from their usual activities, siblings, and home," and "fear of death." These challenges can have many consequences in their lives. Healthcare

providers noticed that the psychosocial impact of cancer on children and adolescents often manifested as depression and anxiety. One oncologist, for example, described how lengthy hospital stays affected the psychological well-being of children and adolescents:

> We face children with depression very frequently. It's not only teenagers, but also small kids, like five years or six years. After prolonged stays, they really become depressed. You will see them not interested even in their surroundings, not interested in playing.

Providers explained that the children might lose a whole year not attending the school. Providers also commented on the lack of policies related to providing children with opportunities to continue their education in the hospital:

> We are as a Ministry of Health; it seems like we are dissociated from the Ministry of Education and other ministries. So we have to all be in one boundary: that if you have a kid who is admitted to . . . any hospital, you have to get an excuse for that. Not that when we give them a certificate that their kid is admitted, they say that in [the parents'] work, it is not accepted. This is really—I don't know how to say it, but it's really something we . . . it keeps our hands tied, so we cannot help even if we want to. So I think these are the main things.

In addition, the providers found that preventing children from going outside or having visitors could add to their stressors and anxiety. They noted that the children came from a culture in which they spent most of their time with siblings and friends, but when they were admitted, they are isolated with their mothers in the same room, mainly due to neutropenia. Consequently, the providers sometimes had difficulty dealing with depressed children because they were not cooperative during any interventions. They also noted that when a child became depressed, the entire family became depressed as well. The providers believed that it was not only the children who needed psychological support, but their whole families. One oncologist said, "When cancer comes, not only the child is affected, but the whole family."

It was also common for providers to see mothers worried, stressed, fatigued, or

shocked. They believed that psychological support should be started when the bad news is broken. They described parents' emotions toward childhood cancer diagnoses as "a big shock," "trauma," "very stressful," and a "painful situation" for the entire family. The initial days were generally the most difficult for families, and they needed the most in emotional and psychological support. One nurse said,

> It's quite a difficult situation, especially when they break the bad news. Soon after that, we see families crying.

Another nurse described a father's emotional reaction to his child's diagnosis:

> I saw a man crying because he couldn't tolerate [it] . . . so at that time, they need support from us.

Another situation in which families need more psychological support, according to one participant, is at the end-of-life stage:

> They need somebody to talk to them. . . . They need somebody to be with them. [The patient is] palliative; that means they are waiting for him to die.

The majority of nurses and oncologists explained that mothers were the primary caregivers to sick children, so they are worried and stressed most of time. The inability to live their usual lives, the disruption of family dynamics, prolonged hospitalization, and the nature of the treatment were identified as influences on the psychological well-being of families. One participant reported,

> The family is fatigued. They said "No, we don't want further treatment." The child is an infant. The mother is here [in the hospital], and the other kids at home. Who looks after them? So that's also a need! Even as we're treating the child, the mother is becoming a psychiatric patient.

Similarly, the medical conditions themselves and poor prognoses for children had psychological impacts on parents. One oncologist expressed it this way:

> Another problem is that there are many children who have a disease and get no treatment for long time. So the parents become themselves depressed, and they also

> need to be referred to psychologists. Their problems need to be solved . . . whenever we go to speak to the mother, we feel that she is on fire [very worried]. She is depressed, she is tired and exhausted.

Participants also observed that the physical separation of parents during long hospital stays could add to their psychosocial burdens. Most of the time, participants felt that parents' marriages were on hold because they were devoting their time to helping the sick child. The participants reported that mothers stayed with children in the hospital, but fathers had to meet their obligations to address financial needs. Most of the time, the fathers were supporting the mothers at hospital at the same time as they were juggling other tasks of daily life. Thus, all family dynamics were affected, adding psychosocial burdens and stressors to both parents. Providers observed that keeping their marriage on hold added extra stressors and anxiety to both parents. A nurse shared the story of a mother who was sad because her husband felt lonely and was calling her to express that emotion. On the other hand, physical separation can lead to gaps in marital relationships and psychological distress, and some of couples got divorced. One oncologist reported,

> Sometimes, in some families, both parents don't come to the hospital, so maybe that psychosocial stress creates gaps between the husband and wife.

Notably, psychological well-being was linked to families' and patient's health outcomes and quality of life. The majority of the participants believed that both parents need psychological support, so that if families are coping well with an illness, the children can do so too. Moreover, the providers perceived a positive connection between the psychological well-being of children and their health outcomes:

> My perception is, if the child is not very happy, their progress is not very fast, you know? They will feel depressed and they will have all these infections. Their condition will deteriorate like that. But for happy children, I think they improve faster and, really, better than those depressed children.

The participants perceived that family-centered psychosocial care provided by specialists could improve families' experiences by encouraging positive, adoptive, and coping behaviors rather than hopelessness. An oncologist explained,

> The psychologist would help raise the morale of the family and [their acceptance of] the treatment. I believe that if the patient and the family are encouraged and optimistic about treatment, they do better than those who are pessimistic about it.

Social support. Another important psychosocial need described by participants was social support or extended family support. The providers reported that most of the families they cared for were large, with five or six children, and that the extended family played a significant role in providing social support. Participants believed that the families experienced a lot of "social cost," and "social burden" that required "a lot of social support." One oncologist, for example, explained the impact of illness on family dynamics and day-to-day routines:

> We need a lot of support from the family because "it's a rollercoaster ride," plus it takes a lot of time. They need to be admitted. So unlike an adult, when a child is admitted, the family is more affected because when the child comes, Mom has to come and stay with the child, and Mom doesn't come alone; she comes with the father. Then, when Mom is here, the other kids are affected. So it's a lot of social cost.

Participants reported that some families received support from relatives but others did not. The participants also believed that "social support is not enough." One Omani nurse, for example, believed that there had been a cultural shift in the social and extended-family support systems:

> In our society, previously, mothers could find someone to sit with the child, but nowadays everybody is working. Some mothers don't have such support. They are forced to stay even though they are in their eighth or ninth month of pregnancy.

The same nurse added,

> Previously, in our culture, we used to be more together. Now everybody has his or

> her own children. So the mother, if she is also sick, doesn't have somebody to stay and come to her. So even with her sickness, she will stay. . . . Support is less now than previously.

Moreover, most of the families lived far from the hospital, and it was difficult for them to manage both patients' care and other responsibilities; they needed social support. Providers also noted that extended family support could help meet the needs of healthy siblings left at home. An oncologist explained,

> I think [people] with frequent visits also need social support because most of the families are probably not from Muscat, not from the capital. . . . It is a hassle for them, especially if they have other children, to leave these children at home or at school. They don't know how to manage this and then to bring this child for treatment once or twice a week or to be admitted for a few days for chemotherapy.

Providers also noted the lack of respite care in the hospital, particularly needed when there is limited extended family support. Respite care mean, somebody come to look after child for a period of time. Thus, the couple could have a time to spend together or parents could carry-out with other responsibilities. It could also play a significant role in sustaining marital relationships and reducing the psychosocial burden and stressors on couples. Participants identified the importance of giving couples the opportunity to spend time together. They believed that this could promote the psychological well-being of parents. One participant said,

> Parents separated for a long time . . . need to have some time together . . . because it takes months before they can be discharged.

Social support or extended family support was also viewed as important part of emotional support. With it, families could feel that they were not struggling alone: "Parents need social support from their extended-families so they will not feel lonely." In addition, to ensure that the parents' need had been met during hospitalization, providers allowed for two members of the family to stay with them, if needed. All in all, extended family support

could help in meeting the needs of parents, such as instrumental and emotional needs.

Spiritual support. Spiritual support was also identified as a psychosocial need of children with cancer and their families. Participants believed that religion and spirituality played an important role in Omani society generally and in the health of patients and families specifically. Thus, providers identified a need for spiritual support because families were suffering and facing a lot of stressors. Although the participants made efforts to provide spiritual support by reminding parents of the meaning of illness and of the idea of God's rewards for their tolerance, spiritual support from religious leaders was lacking:

> Families need religious support because [spiritual leaders] are not coming [to the pediatric ward]. I wish there were more support, like once a week, or a religious support group who would come to see these children and their parents

Participants believed that spiritual support can be critical when bad news is being broken and in end-of-life situations. They believed it could contribute to families' acceptance of illness at the time of diagnosis, or when child is labeled as Do Not Resuscitate (DNR), or even at the loss of the child. As one oncologist described it,

> Here people are deeply religious . . . and religion plays an important role . . . especially if it's an end-of-life situation, and especially when breaking bad news.

Providers believed that spiritual supports could have many other advantages for Muslims believers. For instance, it could empower them with patience and tolerance by reminding them of the meaning of illness, and of God's rewards:

> They also need religious support and reminders that the disease is from [God's will]. We say in Arabic *Ibtilaa* [test from God]. You will be *Insha'Allah*, paid back for your patience.

More importantly, spiritual support was believed by participants to be a source of comfort and hope:

> People know that we are Muslims . . . but sometimes still . . . some people lose

> faith, and they lose trust, and they think that nothing is going to work or nothing will help them. So we need, from time to time, to bring them back, to say, "Hold on, you are not alone. There is support, and God is there to help you and hear your prayers."

One participant described the power of spiritual beliefs and their positive impact on families' coping and acceptance by relating a mother's experience:

> I know that she is dying and that she is going to a better place because I know that *Allah* [God] is really more merciful than all of us. But I don't want to show anyone that I lost faith in God. I lost the faith that she might get better, but I know she is dying.

Overall, providers believed that patients and their families needed spiritual support because it could help the parents through all cancer trajectories and promote coping and acceptance. They believed in the role of spiritual leaders—dedicated specialists who could provide spiritual support and ensure patients' and families' spiritual needs were met. The following statements illustrated this point:

> They need to hear [Muslims spiritual beliefs about illness and death] . . . not from a medical person, but from somebody else whom families can really feel comfortable talking to.
>
> When I was in . . . we always had someone, not only at the time of diagnosis but all along . . . including a *Shaikh* [religious leader] . . . so everyone available was on board.

Instrumental support. Instrumental supports help families manage day-to-day living with cancer by supporting them in finances, accommodation, transportation, and other matters. Providers said that families had free access to medical treatment, and the government supported them with some money as compensation for the cost of their transportation to appointments. However, some families were poor and needed financial support. Providers believed that the largest psychosocial impact of cancer on children and families was not financial but social: "It's not an economic burden, because [at the hospital] they provide the therapy for free. It's sort of a social burden." However, providers believed

that some families were not financially capable, either because they had no jobs or had lost them [especially those who work in the private sector] and didn't have income. One oncologist said,

> There was a family who lost their work. Some of them were working in the private sector, and they ended up losing their wages. Some of them also lost their jobs.

A similar situation involved parents who needed financial support because they had consumed their leave time and were taking days off without pay to care for the child and support the mothers:

> I faced four fathers; they lost their jobs because of this. They would have . . . annual leave, and after that the company would not pay them. So they were fired.

Therefore, providers believed that demands of cancer care forced some parents to quit their jobs, be fired, or take leave without pay, indicating a need for financial support.

Participants believed that some families also needed accommodation and transportation because they were not from the capital. Some lived far from the hospital where their child received care. Participants reported that the Oman Cancer Association provided temporary accommodation to families who come from great distances, and four studio apartments were also offered to some families. However, the providers believed that these accommodations were inadequate. One oncologist commented,

> The family support is not enough. We have some places for them to stay if they are coming far, but still that is not enough for them. We need more places for parents to stay and for long chemotherapy, and we need psychosocial support for them.

To solve this problem, providers suggested expanding accommodation for families, especially families who lived far from medical centers.

Providers also believed that some families needed support for transportation. They were poor and couldn't afford travel costs, so they were not attending therapy on schedule:

> Most people come from far areas, far villages. They don't have their own transportation. . . . Most of the time, when they are due for chemo, they do not come. They call here [and say], "Doctor, change the date, we can't come on this day."

Although the families identified as having transportation difficulties were less than 10%, providers believed that addressing this need was necessary. They thought that families needed to have attention paid to such everyday needs to maintain sound psychosocial functioning.

Information and counseling. Health education and counseling were also identified as psychosocial needs. Participants believed that both could promote patients' and families' understanding of disease. Interestingly, providers believed that the priority was to provide families with the information about the nature of the illness. They also believed that families' current understanding must be assessed before they are provided with more information. Education on nutrition, diet, hygiene, and treatments was also identified as important. Along with this, providers believed that families need continuous counseling. They saw families' acceptance of illness as difficult at the beginning, and found that gaining their trust in the care provided was also challenging. They therefore believed that counseling and health education were what the families needed. The following statements described that:

> On day one, when they are diagnosed, it is very difficult for them to accept, and they need counseling even before the treatment is started for their child.

Providing families with information by addressing their concerns was believed to promote their emotional well-being and reassurance:

> Providing mothers with information promotes their assurance. Providing answers to the families' questions, such as "Is my child going to be okay?" . . . "What is the condition of my child?" You're going to like to present the reality. They will not be hurt. They will be prepared, but at least you are not going to tell them

brutally that this will happen to their child.

Accordingly, healthcare providers identified health information about cancer and its treatment and continuous counseling as a need for children and their families.

Given all the above points, the psychological, social, spiritual, and instrumental impact of cancer on children and their families is huge, as are the psychosocial distress and burden. Therefore, providers insisted that more resources are needed to meet families' and children's psychosocial needs. They made suggestions to help in the early identification and management of psychosocial difficulties. For example, they suggested having a structured screening tool that could help them identify families at risk for psychosocial distress or difficulties:

> So I think more that if we can have some assessment in the beginning, and frequent assessment throughout, we can pick this early and deal with it.

Providers also believed that the psychosocial needs of families had to be met by specialists. A multidisciplinary team could play an important role in providing effective psychosocial care and meeting the perceived psychosocial needs of families. Fulfilling a family's needs could increase their satisfaction and improve their health outcomes. An oncologist explained,

> Developing multidisciplinary teams is a good investment, as it would improve treatment outcomes and family satisfaction.

Providers noted that absence from school could lead to depression, and children might miss school for a whole year. Thus, they suggested supporting children in their schooling formally. They said that school-age children should be followed up with on their schooling even during the period of treatment as in-patients:

> We [providers] also need to support them in school. . . . These patients might lose a year of study, so we also need this support, like school days or teachers in the

hospital, like the way other countries have teachers to help children in hospitals.

Providers also suggested collaboration between the Ministry of Health and the Ministry of Education to establish a formal educational plan for these children:

> But regular teaching, we are not able to run. They themselves are reading, but we are not sure how far they can do that, so that school support, if you are giving it, must be especially for smaller classes. We will be able to save them one year—many of the children lose one year. But that needs a lot of discussions with the government and the school's support. That is not happening very well.

Moreover, because of a lack of social support, the impact of physical separation on couples, and the ongoing disruption of family functioning and day-to-day routines, providers suggested respite care. They believed that this could help couples sustain marital relationships and maintain family functioning. A nurse explained,

> Most of the time they are here. So I think it's important to look into respite care too. For example, when families go to see their other children at home or to see to other needs, somebody will be with their children in the hospital for maybe a few hours.

Providers also suggested increasing psychosocial support through collaboration between the hospital and other community institutions like schools, mosques, and libraries. They suggested improving the community's understanding of cancer and support for patients' and family's psychosocial needs. The providers believed that this support must go beyond providing them with toys, and the community must be directed and oriented on the need of families. They suggested involving religious leaders in this orientation, and this could be done during the "Al Jema'ah speech" or the Friday prayer sermon. One participant added:

> We need to bridge the patient's daily life and medical life. The patient's medical life is our responsibility, but their daily life or their practical life relates to many different aspects of life, like school. I've mentioned *Al Masjid* [prayer place or mosque] and the mosques' role. Sometimes I do not know whether the library, the general library, that kind of education center, can play that kind of role.

In summary, this section discussed the psychological, spiritual, social, and instrumental needs of children and their families as they were described by participants. Providers believed that meeting the psychosocial needs of families could help them accept their diagnoses and overcome the related challenges. In particular, multidisciplinary teams, psychosocial assessment tools, and respite care were suggested as ways to maximize family support.

4.3.2 Theme 2: Pediatric oncology as a challenging area of clinical practice

This theme involved oncologists' and oncology nurses' experiences of working in pediatric oncology departments and the challenges they face dealing with children who have cancer and their families. It has two subthemes: (1) emotional burden and (2) challenging tasks.

Subtheme 1: Emotional burden. Being an oncology nurse or an oncologist is emotionally painful. Healthcare providers described their experiences using phrases such as "very hard," "heartwarming," "distressing," "needs a big heart," "sad," "extremely emotional," "heartbroken," and "emotionally attached." Most of the providers, both Omanis and expatriates, described the emotional difficulties they had supporting children and their families through the most stressful conditions.

Participants reported that due to long journeys for treatment and frequent engagement and communication with families, they often became emotionally attached to the children and their families. They believed that such close attachment without boundaries affected them negatively:

> Sometimes when the patient is very sick, it touches you. The patient stays with us for a long time. You get connected with the family. . . . It's a long journey. It's not like one visit, two visits, and the patient will go.

A nurse described similar experiences:

> You will feel something. . . . These patients will be going to this end stage. It is hard for me . . . having these emotions with their parents also. Like, you cannot look at their eyes, especially at that point of a child's life. They are gasping for air or fighting for their life.

Most nurse participants reported becoming emotionally affected by and empathetic to families' experiences. As such, they reported that when they started working in the pediatric oncology department, they were emotionally overwhelmed: "When I started . . . I was really extremely emotional. . . . I was crying in front of patients or their families." Similarly, another nurse said: "I remember the first days when I started here. I was not controlling myself. So I would go somewhere to cry. . . . It's very difficult." However, with more experience, they were able to handle their emotions. One nurse explained, "Year after year, I started controlling my emotions—at least not crying in front of patients." Nurses felt that caring for oncology patients was emotionally stressful but at the same time fulfilling, "especially if the child will be discharged. He will say 'Thank you. . . . Goodbye, sister".

On the other hand, some providers described the need for keeping boundaries and not having too-close relationships with families, to better support them. An oncologist said,

> I am emotionally attached to them. I should separate myself as a doctor . . . maybe because I have kids and I am a female. Still, I have such emotions.

Providers expressed their need for psychological supports to help them overcome their stressors and reduce burnout. A nurse said,

> The grieving that we [nurses] are getting after the death or whatever . . . sometimes we do not know how to deal with that. I mean, even for us, the staff, we do not have support for, like, post-events, or whatever we are having in the unit.

Overall, the participants believed that working in a pediatric oncology department

was distressing and emotionally burdensome. Close attachments could aggravate the difficult emotions. The participants believed that providers who had to work in pediatric oncology departments should be "strong enough to handle such responsibility," and had to have a "big heart," otherwise they wouldn't able to "survive" in the unit.

Subtheme 2: Challenging task. This subtheme involved the challenges that healthcare providers encountered while caring for children with cancer and their families. Breaking bad news, seeking a second opinion, encountering interference from extended family members, and disclosing information were the most challenging problems they described.

Giving bad news was reported to be one of most difficult roles of oncologists, and one that needs "special skills." Providers viewed the day on which bad news was given as difficult not only for families but for the providers themselves. Although the oncologists were responsible for disclosing diagnoses to parents, nurses dealt more with the families' emotions. Several factors identified by the healthcare providers added further burdens to this, including preconceived thoughts about cancer as death, and families' reactions and emotions. One oncologist said,

> So we really face a difficult time when breaking news and giving treatment. You are telling someone, "Your child has cancer," and the idea we have in our culture is that cancer is a disease that is not treatable, and only a few cases survive.

Another provider said that parents' unexpected reactions and feelings were a matter of concern:

> The main problem is that at the time of diagnosis, when you are facing the family and telling them the bad news about the child's malignancy . . . and that he will need chemotherapy. . . . This is the most difficult day, or one of the most difficult days, in providing care for pediatric oncology patients, when you are breaking the bad news and facing many mixed reactions from the family and the children.

Providers explained that dealing with families on the first days of admission was difficult. They reported that families were generally in a "denial stage," and still doubted the diagnosis and did not accept medical or nursing interventions. One nurse said,

> We have to care for the patients (e.g., taking vitals and doing blood work), [but] these things, when we go and do them, they will not accept. The parents will be in a denial stage and angry. They will show anger to us.

As a result of doubting the diagnosis, families were also not receptive to health education:

> Some of the families are very difficult to deal with. They do not give you a chance even to explain, especially in the first weeks. They are in a denial phase, so they thinks "Does my child really have this disease? Maybe something is still wrong with the result." . . . So you will feel like you are talking, but they are actually not with you. They are not listening. . . . Whatever health education you give them . . . they are in denial phase, so their thinking is about something else. They are not thinking about what you are telling them.

Second, going abroad for a second opinion was also perceived as a challenge. Some of the providers thought that it had a negative impact on the outcome because of the delay to the initiation of treatment. Providers believed that the practice of going abroad was a part of their "culture" or habit. When bad news was broken, the first response of many families was to go abroad. An oncologist said,

> When we are diagnosing leukemia, one-third of the cases go abroad. Then they come again for further treatment. So it makes for delay and waste. This injures the life of the child, as well as prolonging the duration of treatment.

Providers believed that even with state-of-the-art medicine, families were going abroad for second opinions to ensure the best quality of care their beloved could get. An oncologist said,

> Oman has developed very rapidly in the last two or three decades, so people in some of areas have seen the advancement, but in other areas they still feel, you know, that we are not there yet. So they [parents] still feel it would be better if they went abroad.

Likewise, another oncologist said,

> We are explaining that the quality of services provided here is not different from any other place. And we have state-of-the-art personnel, state-of-the-art medications and chemotherapy, and all the services required for blood transfusion.

Providers believed that when families sought second opinions, it was a sign of lack of trust, which had the potential to hurt their relationship. One oncologist commented,

> Many people feel that they have to get a second opinion before treating any cancer . . . so that was a very big obstacle to having this bond at the beginning.

Third, providers believed that extended family support generally came with good intentions, but this was not true in all cases, as some extended families interfered with treatment-related decisions by parents, with negative consequences. The following statements illustrate that:

> In this country and many developing countries, the concept of the large and extended families is there. So we get many influences from uncles, from aunts, from grandparents, and it is very difficult. The influence of the other family member is huge and challenging.

> They [the extended family] feel that they are doing good things for the family, but it distracts the family, it shakes them up. It gives them doubts about treatments . . . and results in interruption of the therapy and complications or even relapses. This even happens sometimes because of unplanned or uninformed advice from people in the community. They are trying to offer support, but in the wrong way.

Providers suggested having a formal support group to let newly diagnosed families share their experiences and increase confidence in Omani Health Care Providers and System and reduce their belief and desire to get a second opinion abroad.

limit questions about going abroad:

> What happens is that most of the time when we tell them the diagnosis, the parents say, "We will go abroad for a second opinion." If there were a group of families with similar experiences who are doing well now, this would curtail the desire for a second opinion.

In addition, information sharing and telling the truth were also viewed as difficult. Most of the time, children were not involved in receiving the bad news, making a treatment plan, or other cancer-related information and expectations. Most of the providers, however,

recognized the importance of disclosing the information to the children. However, some mothers preferred not to tell the truth to their children, while others were willing to disclose the medical information. One nurse shared a story about a mother who struggled over how disclose the bad news to the child:

> A child asked a mother: "Why have I been admitted here?" The mother was not sure how to disclose such information because she didn't want to give "those guns" [information about her illness] to the child at once, and she was in doubt: "I couldn't explain in the way that I wanted her to understand it [illness]." In addition, she expressed a need for help in disclosing this information. She said, "I don't know if anyone could help."

The same nurse felt the need to support these children to "break the gap" and advocate for their needs:

> After that, I really made up my mind that I have to be around. Those kids really need someone to sit with them, to explain to them about everything they are going through. They really have the right to know. So that's why I'm here, and I feel if I am here [the oncology department], I will help with that. . . . The main element is the communication between the doctors, children, and families. Doctor will only [disclose information] to the caregivers, not to the children.

Another provider supported disclosing information and telling the truth:

> When [children] are labeled as DNR . . . when the child is three years or about ten years old, even some children are mature enough at eight years or older. So just explain to them the truth, because they don't know. I feel we are not meeting that point! We are not telling the truth! Even at fourteen years old, we are not telling the truth.

By contrast, providers found that some mothers did not support disclosing the information or telling the truth:

> The reasons that we [providers] are not including the kids is because some of the parents they don't like their kids to know about their disease—that they have cancer.

Participants reported that children were using social media and the internet to look for information, yet some noted that information from untrustworthy sources on the internet

was “half info and half fact.” They believed that if children had preconceived views about their illnesses based on such sources, disclosing information to them would be an obstacle. Withholding information from children, especially death-related information, and not involving them in treatment plans and expectations, could have negative consequences. One nurse said,

> Whenever we are doing something for her, she will go immediately to the internet. Sometimes her mom was coming to us [nurses]. She was telling us, “Tell her the truth!” We were telling her the truth, because we know she is big enough to understand everything. You cannot lie to her because she knows. Anyway, she will go to the internet and [search for information], so we really were telling her the truth, but we didn’t tell her that she had reached this or that stage, or that she would die.

Providers felt that they were not prepared to disclose bad news to children. A nurse described that:

> So, that also is maybe something we are lacking. We do not really . . . know how to tell them! Maybe showing them a movie. But it will feel . . . you will feel depressed too, but at least maybe they will understand.

Despite the challenges and emotional burdens providers faced, some of them expressed job satisfaction. One oncologist said,

> The leukemia survivor thanks God they are doing very well. So that also gives [providers] a lot of encouragement. It is a tough job, but at the end of the day you see somebody who was struggling to survive it and is now a doctor, a nurse, or a business professional. There is a lot of job satisfaction.

4.3.3 Theme 3: Barriers to effective psychosocial care

This section describes barriers to psychosocial care. It covers three subthemes, barriers related to: (1) healthcare providers, (2) the healthcare system, and (3) infrastructure and environment.

Subtheme 1. Barriers related to healthcare providers. Barriers related to providers themselves can be categorized into language barriers and lack of formal training.

Language barriers. This was one of most common provider-related barriers, especially for expatriates and non-Arabic speakers. They believed that differences in language between providers and families could hinder the provision of psychosocial support. The providers also noted that assessing families' psychosocial difficulties required deep and one-to-one talks with children and families, so effective communication was crucial to providing psychosocial support. One oncologist described how his unfamiliarity with families' languages and terminologies hindered his providing psychosocial support:

> There is a significant language barrier. What I know is only a few terms in Arabic that I can speak, only related to the treatment. For social units, there is a big vocabulary, but I do not have it. So this is the main barrier, the language barrier. That is why it is difficult for me to provide psychosocial support.

Another oncologist had difficulty providing emotional support and being sensitive to families' concerns because of not being versed in the local accent. He said,

> My difficulty is not a difference of language; I don't what it's called. Sometimes I don't understand . . . Arabic people's accent. . . . I do not understand at all. So to these people, I cannot explain anything. I cannot be emotional. I cannot give them emotional support.

A similar experience was brought up by nurses. One said,

> Here I find difficulty because of the language barrier. Because at this level, I think [nurses] need a very good mastery of language to really help people, for them also to really understand what you're saying or what you're trying . . . to convey to them.

Thus, psychosocial support requires effective communication and understanding of the language and culture.

Lack of formal training in providing comprehensive psychosocial care was another provider-related barrier. Most of the healthcare providers believed that they had some theoretical background on psychosocial care but were not equipped with the special skill required to provide psychosocial support at an expert level. The majority of the oncologists

were mainly prepared to provide medical care, though they were involved to some extent in psychosocial care—they described it as a part of their roles but said they couldn't provide such care completely. The following statements illustrate that:

> We can do it daily, but not to the expert level. It comes by experience. It's part of the package. It is never done perfectly unless you have somebody dedicated to do it.

> It is part of our job. It is part of our responsibilities. But we cannot indulge in the details, partly also not to affect the treatment of the child. I would not say I could provide it fully, but partly we are doing it.

A similar experience with formal training was described by nurses, for example:

> We [nurses] are not. I mean, it is just, like, hints that we get in our schools and colleges. . . . It is only in our readings, but we do not have a lot of proper training in [psychosocial care].

Across developing countries, providers were not prepared to provide psychosocial care, and it was not given much priority, an oncologist said:

> We did not get any [training] in . . . didactic lectures or special training or education for [psychosocial care] from the system. We were brought up in the developing world.

Notably, despite a lack of training and preparation for psychosocial care, providers' experiences in oncological care helped them provide psychosocial care to children and their families. The following statement illustrates that:

> It [psychosocial care training] was not a part of our medical training . . . especially when we did general pediatrics before specializing in [pediatric oncology]. But it is not provided as spoon-feeding. It comes with practice; it comes with experience.

Similarly,

> With years of experience, we developed, I think, a good way of communicating and providing psychosocial support.

In conclusion, most participants saw their training in psychosocial care as limited and needing to be improved so they could provide such care effectively. One oncologist

said,

> What we need is to sharpen [our psychosocial care skills] and have [specialists] to guide us to the point where we can focus on helping these patients and their families.

For this, providers suggested continuous workshops and training courses. The suggested focuses included counseling, communication, and mental health. They also recommended training on how to support families during death, grieving, and depression, and they suggested having guidance and orientation on how to screen families for psychosocial distress and provide for their basic psychosocial needs. The following statements illustrated that:

> We should orient our doctors or our nurses, the medical providers, whatever their grade, to close up this gap—to know how to deal with patients who would be predicted to have this mental illness or mental problem; how to measure the severity of psychosocial needs; and how to provide at least the beginning levels of support.

> We need sessions for the staff to teach them how to deal with the cases and, mainly, the situations. The cases are manageable, but the situations we have . . . like the deaths, the depression, the grieving . . . we need training on that. We need someone to come and teach us how to do that.

Subtheme 2. Barriers related to the healthcare system. Barriers related to the healthcare system can be categorized as (1) lack of time, excessive workload, and shortage of staff (mainly Omanis); and (2) under-structured psychosocial services and support groups.

Lack of time. Lack of time was a commonly reported barrier by both professions. Providers believed that giving their full attention to psychosocial care was impossible because of a lack of time. Their priority was providing medical care and fulfilling family's psychosocial needs. In addition to a lack of preparation and resources for psychosocial care, the providers believed that a lack of time was another hindrance. A doctor said,

> One problem actually is the resources, because whatever we try, the psychosocial care that has been given by doctors is limited because we are not trained for that, and we have lots of other things to do: the main thing, the treatment part, and other things. So we don't have the time, and we don't any real resources. So that is the main problem.

Similar beliefs were raised by nurses; general patient care was their main priority. Most often, providers had to weigh the urgent needs of the patients against the prospect of psychosocial support. One nurse shared her opinion on this:

> Our limitation is also the timing, lack of time. I am a bedside nurse, for example. I have four patients or six patients when I come in for duty. I feel that families need psychosocial support. But on the other hand, I have a very sick child who needs observation. I will give only five minutes or less to support them because I have to go and take care of that child. Even if the child is not severely sick, I have to administer blood transfusions or chemotherapy. We have limited time to do all of these.

Notably, providers voiced a willingness to support families to the optimal level, but because of time constraints, psychosocial support was not the main focus of their care. One oncologist noted:

> First of all . . . our time is usually limited. We are doing rounds or in the clinic, so the time is really limited. You would love to give psychosocial care, but you are bound with the time because you have so many patients and you need to finish the round. I might come back at the end of the round if I have time and sit with this mother or that. That's just to give them some brief information or words to help them, but they need more than that.

Workload. Because the center of oncology care was in these hospitals, the providers assumed a lot of responsibilities, ranging from being responsible for in-patient care to being responsible for out-patient care, and most often they were also regulating all referrals across governorates. When oncologists assumed these roles, they had to attend to calls for the referral regions or provide consultations if required. Both hospitals are also teaching institutions. Some of the senior consultants were involved in teaching and supervising undergraduates and postgraduates during their clinical practice or were teaching at the

university. One oncologist said,

> We have a reference service available 24/7. So any doctor in the regional hospital can call . . . the oncologist who is taking this role [attending to referral needs] . . . during the daytime and during the off hours. They have devoted pagers, so they can call at any time and be referred to us, and based on how urgent it is, we accept the patients for admission or advice.

As they had multiple roles and responsibilities, the providers commented on the contribution of the number of patients to the quality of medical and psychosocial care they provided. One oncologist said,

> The number of patients plays a role [in providing such care], because sometimes we might admit 10 or 12 patients.

Another said,

> The problem is we [are] always busy. We need time. . . . We already have 25 patients. If you counsel everyone or you want to give support, it will take at least 30 minutes, 45 minutes, and you cannot do something like this.

Similarly, assessing the psychosocial difficulties of patients and their mothers was difficult because of the workload. One nurse commented,

> We are taking care of four or five patients. So time to sit and counsel sometimes, or to sit and socialize with the patients and their families . . . will not be there for us [nurses].

Shortage of staff. A shortage of care providers in general and of Omani providers in particular was also acknowledged. Providers explained that the main source of psychosocial support was Omanis because of commonalities in culture, background, and language with patients. According to a nurse,

> This situation was the most challenging. We have a lack of staff. . . . Many experienced Omanis who can talk the same language as the patients are leaving the hospital. We are left with expatriates who have a hard time communicating with patients. Every time, they call us to translate whatever they want to say.

Due to the staff shortage—described by some as a "severe shortage"— psychosocial

support was delayed for a lack of providers. For example, a nurse explained,

> We are not always available, Omani staff, in each shift. We have more expatriates. In the duty roster, there should be one Omani at least on each shift. But you cannot guarantee that they will be there all the time. It is difficult sometimes, but no one is available.

Taken together, providers face multiple constraints on their time to meet competing obligations.

Lack of screening tools and specialists. Psychosocial services in Oman were described as "under-structured," or "under-developed," because of a lack of specialists, psychosocial assessment tools, and resources. The main providers of such support were nurses, doctors, and social workers, despite their lack of training and specialization. According to the participants, there were no multidisciplinary teams, palliative care teams, or dedicated personnel to provide psychosocial care. The providers said that specialists in psychosocial care were not there; there were few psychologists, psychotherapists, trained social workers, play therapists, nutritionists, chaplains or religious leaders, pharma-oncologists, or translators. As a result, the providers reported that psychosocial care was put on their own shoulders: "We don't have psychosocial [specialists]. We have only ourselves, staff nurses." Another provider said, "We do not have psychologists. I did not see any psychologists here. I think there is a department of psychology, but I have not seen anyone, and they are not involved in the care."

Screening assessment tools were also lacking. Despite participants' belief in the importance of standardized assessment tools, neither hospital had any such tool to screen for psychosocial problems. Attempts were made to adopt screening tool for both hospitals, but it did not work well:

> We had one, provided to us sometime back by the adolescent-medicine doctor, but that was very general, where we had . . . the doctors and nurses give their . . . input.

> It was an initial-under at the time of diagnosis screening tool, and accordingly they would follow it up, but it wasn't really tailored to our patients. So it fell through. For a few weeks it worked.
>
> I do not think we have this [screening tool]. They provided one checklist last year for those who are diagnosed with relapse. A checklist of changes in children's behavior, such as sleeping patterns, relationships with friends and family. . . . It was like a trial.

Because of the lack of a structured psychosocial screening tool, providers' day-to-day functioning in their roles was affected. They were not capturing psychosocial distress immediately, and they were only triggered by children's problems. Children with depression, for example, were also handled only minimally. The providers explained that they were relying on their experience, daily physical examinations, nurses' and parents' feedback, and changes in children's behavior to identify families' psychosocial difficulties. One oncologist said,

> We don't have a checklist, but definitely, when we are visiting them on a daily basis, we ask the parents, "How is the kid? Is there any difference in his or her behavior?" Routine behavior, all we see ourselves or the staff tells us. We don't have a checklist, but just daily examinations. When we see a difference, that alerts us.

Some of the long-term impacts or psychosocial sequelae of cancer were not identified or managed because of a lack of specialists in this area: "We don't have somebody to look after [neuropsychological evaluation]." Being restricted by an inability to screen for or identify psychosocial difficulties, providers attempted to find immediate practical solutions when families were psychologically disturbed, such as sending them home or discharging them as early as possible. The following statement described that:

> Most of the time, when we think that the child or the family . . . has become psychosocially disturbed . . . we try to discharge them as soon as possible to change the environment. This makes a lot of difference.

Similarly, the support provided by social workers and play therapists was not

adequate in the participants' view. Although, both social workers and play therapists played a crucial role in providing psychosocial support to patients and children, they were not trained or specialized in this area. Social workers most often focus on social and financial support:

> We do have some support, but they [social workers] are not trained. They will come . . . because we also tried to arrange some social and financial help for some of the needy families.

Similar, play therapists may be involved children in fun activities, but their role was not sufficient to meet the children' psychological needs because they were not trained to assume their role as play therapists.

> Even though [the play therapist] is trying her best to do her job, we still don't have professional play therapists who can look at the patients from different angles.

Also, play therapists' contribution to supporting children was restricted to the morning shift:

> Play therapists will only come in the morning. They will just take part in some paintings. They will go, and after four o'clock, nobody is here. Even in the evening, the children will be alone. They are always seeing the nurses' faces or the doctors'. They do not have any encouragement or entertainment other than in the morning.

Overall, providers believed that the resources in the pediatric oncology departments were not adequate to meet the need of the families. They believed that their units were not giving adequate attention to psychosocial care, unlike adult oncology departments. The following statement illustrates that:

> The system still, I'm sorry to say . . . does not give much importance to pediatric cancers. This is my personal feeling. Thank God all areas are well respected, but compared to adult oncology. . . . They are already adults, they are big people. . . . They get more opportunities for resources than pediatric oncology.

As the healthcare providers saw it, the first step to improvement could be enhancing administrators' and providers' awareness of the importance of psychosocial care for

pediatric oncology. The following statement described that:

> First of all, healthcare professionals should understand the importance of psychosocial management. . . . Everybody in the hospital, doctors, nurses, paramedical staff, and the administrators. So everyone across the board in a health care setting should be sensitive to this need for psychosocial management and how much it can benefit the patients. It is not just a luxury; it has a direct effect on your outcome.

After that, providing more material and human resources to meet the psychosocial need of families was important. Along with an emphasis on structured screening tools, the participants described a need for more providers, including nurses, oncologists, dieticians, onco-pharmacists, clinical psychologists, psychiatrists, religious leaders, social workers, play therapists, and translators. The recommended personnel should be trained, well-versed in Omani or Arabic culture, and dedicated to the pediatric oncology department. The following statements convey these suggestions:

> So that is one thing. We need more resources, personnel, and other things. . . . And then more beds too, we always have a problem with this. So we know we need more workers, we need more doctors, we need more nurses, and we need support services like an in-house dietician and a full psychosocial team.

Another participant said,

> Psychologists are needed badly for both parents and children, actually, and the role of the psychologist does not start only when we need them. It starts on day one of the diagnosis. He or she should be with the child from diagnosis through monitoring.

To reduce the workload, decentralization of cancer care was also recommended. Palliative care, for example, could be provided at local or regional hospitals. One participant said:

> Children in palliative care are terminally ill. . . . The aim of their therapy is not to cure them but to provide comfort and support. So those kinds of patients . . . need to be seen in local health care facilities, in regional facilities, because it is better for the family to be close by.

Subtheme 3. Barriers related to environment and infrastructure. Participants commented that the pediatric oncology department was not well-designed to accommodate children with chronic illness, who would stay for long periods of time. Patients' rooms were small and had no bathrooms and no private counseling rooms for families. The following statement described that:

> One challenge was the space—there is no space. No space, but many are coming: I want a room—big room. No room, no big room. Many [families] complain about rooms. There is no bathroom in the room. I believe that there should be a bathroom in every room, especially for children with cancer and their mothers. It is difficult to go outside the rooms.

In addition, facilities for entertainment devices were also lacking:

> These rooms weren't equipped with entertainment devices, such as PlayStations, and there was no Wi-Fi.

There was no prayer or meditation room families could use for prayer and relief.

> They want to just go to a quiet place to pray, meditate, or to read the Holy Quran. But there's no place, there's only the room of the child. I mean, the mothers will be praying, putting their prayer mats on the floor beside the child. . . . They would like to read the Holy Quran, and they would like to pray to Allah to heal the child. They would like to cry, but they will hold it in because they don't want their child to see them crying or expressing those feelings.

Overall, the pediatric oncology environment and infrastructure were not well designed to meet the psychosocial needs of children and their families. They lacked a lot of resources, such as spacious rooms, entertainment services, innovative playrooms, places for prayer or meditation, and playgrounds. Providers, therefore, suggested having a more spacious rooms with bathroom inside them, a prayer room, and entertainment facilities in each room that could be provided with Wi-Fi and PlayStations. Providers also recommend more spacious and innovative playrooms with full entertainment facilities and extended working hours. A nurse said,

> If you have seen our playroom . . . it is not really for patients who are staying here for months. It is not; it needs more innovations and more services as well.

Providers shed light on the need for more innovative environments for cancer care, which could be situated on the ground floor with an outdoor playground:

> I would like to suggest that the hematology and oncology center, especially for children, should be on the ground floor and not on the second floor, third floor, or fourth floor, and that there should be a place outside to play, or at least to see flowers, to see something outside. Because they are children, they like to play. . . . There should be a safe place to go outside.

4.3.4 Theme 4. Providing optimal supportive care within the available facilities

This theme describes the actual supportive care given by healthcare providers and the factors that helped them do so. It is divided into two subthemes: (1) supportive care, and (2) facilitating factors.

Subtheme 1. Supportive care. Some participants reported that family support follows a "holistic approach." It starts the day the child and family come through "the door of the pediatric oncology ward" and lasts until the end of the treatment, or even after the child's death. Most participants said that their love of supporting families makes them more sensitive to the families' needs. Given the number of challenges they faced in their pediatric oncology departments, the participants "tried their best to support the family" by providing holistic care. This is evident in the following statement: "In general, we care for them not only physically but mentally, spiritually, and socially."

Participants recognized families' need for the utmost in support because they were highly stressed, for instance during the breaking of bad news and at the end of life. Although talking with families, listening to them, being around for them, and counseling them was something that participants did on a daily basis, they tried their best to meet families' specific needs. Nurses, especially the Omanis, were the main providers of

psychosocial support, and they were advocates for families' needs. The following statement shows appreciation for this support:

> We are blessed. We have good nursing support. Our nurses are good because, you know, most of the nurses are Omani, and we developed a good rapport with the families.

Spiritual support. Most of the healthcare providers (Muslim and non-Muslim) had a religious belief that tend to relate to the meaning of health and illness. Those beliefs were found to be beneficial to families' acceptance and coping abilities. For example, the belief that God's grace caused a child to die early so he could go to heaven and intercede for his parents was one way to provide spiritual support:

> For younger children, it's okay. I can deal with the family. I try to make them accept whatever Allah gives them, and I always tell them this is a gift and . . . if something bad happens [the child] will go to heaven and will [intercede for his parents there], and *alhamdulillah* [thank God] most of them are accepting.

Another example was the belief that God is a source of health; building trust and faith in God made families more comfortable:

> As I am a non-Muslim, I cannot give spiritual [support], but I can say one or two words, like "God is there! He will help you . . . emotionally." . . . It is a difficult situation. I include spiritual support like "God is there! He will give a good, speedy recovery. We can take care [of you], and the medicine will work slowly. Your child will be okay.

Most participants valued such spiritual beliefs and religious practices and tried their best to provide spiritual support. For instance, a non-Muslim nurse provided end-of-life spiritual support using her own prayers:

> For spiritual support, I am not a Muslim, but I pray for the children. For example, if they are sick and dying, I pray and hold them. I pray our prayers.

In another situation, mothers and patients were respected while practicing their religious rituals. A nurse described it this way:

> If they are praying at the bedside, we will not disturb them. We will let them finish their prayers. If they are reading the Holy Quran, at least, we will not disturb them, especially the mothers. Sometimes we have these children who are reading the Holy Quran or praying, and we will not disturb them either. At least, [we give] them time to pray. . . . We keep quiet and give them an environment to pray.

Such support can build trusting relationships between healthcare providers and families and make children happier. One non-Muslim nurse described using the words of Muslim blessings:

> I learned before cannulation, for example, [to say] "*bismillah*" [the name of God]. The children will be happier; not only will they be happier, but they will trust us.

The overall impact of spiritual support was also evident in the following statement:

> *Alhamdulillah* [thank God] at least that they are comfortable here, because our religion or our nationality already makes them more accepting of their disease and their suffering

Thus, they described how a dedicated specialist in this area, such as a chaplain or religious leader, should be available to support families.

Emotional support. Emotional support was also provided, such as listening to families, letting them express their feelings and grief, and providing them with loving care. Participants described their major role in providing emotional support as "being there for them" or "being around." The following phrases illustrated this: "staying at their bedside just for them to be happy," and "staying [with them] to have a chat, and let them forget they are in the hospital" and "to create a less stressful environment, you can at least alleviate their feelings of emotional stress." Moreover, participants believed that emotional support showed care and compassion for families. One Omani nurse said,

> When I followed her [a mother], I went inside the room, and she was still really strong. She didn't show anything. Then I just looked at her and told her "You've had enough. You can cry now." You cannot imagine . . . she started hugging me, screaming and crying . . . I stayed with her until maybe 4 p.m., then she was begging me to go home: "Your kids are waiting, you go home, I will be fine." I went home

> for not even an hour. Around five-something, they called me. I had told them in the unit to call me. They called me saying that the child was very sick, so I came back to the hospital, but she had already died.

Allowing healthy siblings to visit was also valuable for helping the children express their feelings and for providing them with emotional support:

> We are also allowing the siblings to sometimes come and visit them, so they will divert themselves from thinking about only the disease. They will be playing and expressing their feelings to others, especially those younger than nine.

In addition, emotional support was extended to grieving families beyond hospital care. The following quotations illustrates providers' support for grieving families:

> In some cases of people who had died or passed away, we were arranging for some members of the team or nursing staff, or even our social worker, three or four days later, to go and visit the family. It happened five or six times that we would visit the family, tackle their needs, and ask about them.

> We have experience in this. We have had so many children pass away and we stayed in contact with their families, helping them a lot to feel relaxed, to get relief from the stress of losing their children. So really, our part is very important for them.

Overall, participants reported that the foremost type of support they provided was spiritual and emotional: "We are just working [in providing support] on areas related to emotional and spiritual support, no more than that." Spiritual and emotional support were described through the participants' experiences:

> She was continuously crying. I don't think she even listened to anything of the plan. I just took her out of the counseling room and stayed with her. . . . I gave her spiritual support and emotional support. This is what you can do. It's already happened, and you have to cope with it. Your kid is like five years old and she sees you crying. She'll start to cry too, so you have to be strong to cope with this thing and let it go.

Psychological support. Psychological support was also described by healthcare providers, though it was not structured, and they were not trained to provide it. One oncologist said,

> It is not a usual time for the child or the parents. It is difficult. But we try our best medically and psychologically.

Providing health information to the children and their families, or "helping them to understand" was one way to prepare them psychologically. For example, informing families of the side effects of cancer treatment and how they can cope was described:

> Regarding side effects of medication, we explain to them what is expected, and then we can offer them suggestions for how to cope with this. . . . like children having their hair fall out. At least they won't see that much hair on their pillows when they get up in the morning. We will suggest that they shave their hair, at least for this stage of treatment, because we expect hair loss. We are going to what's perceptible to them in the future, the reality of this treatment, so that at least they will be ready and will accept it emotionally, and then they will cope better with this.

Instrumental support. Instrumental support was evidenced in allowing healthy siblings visit; arranging families' transportation or providing them with money to return home, if needed; arranging for temporary accommodations (Dar Al-Hanan); allowing for more than one attendant, if needed; allowing for male attendants; assisting mothers with patients' usual care; letting kids under two years old stay with their mothers in the hospital; arranging for families' financial support; and coordinating with school administrators or parents' workplaces. The following statement describes such supports:

> For healthy sibling visits, we have a policy saying from age 12 upwards, we have to allow them to come to the hospital and enter during visiting hours. So we call security and tell them to allow the children in.

Thus, to provide maximum support to patients, nurses suggested adapting the rules to suit the visitation and food needs of the children and their families:

> For oncology patients, I mean especially in the oncology center, there should be different rules from other wards, different policies! Regarding visiting times, food, coming and going from the hospital, and so on.

The following statements illustrates financial support as a way of providing instrumental support.

> For example, if we know that patients or their parents are financially [not well off] . . . we refer them to social workers, and they refer them to the Ministry of Social Development, and they get some help. Sometimes we give it to them, sometimes they get help from the unit itself.

Furthermore, doctors made extra efforts to support families beyond the hospital boundaries (e.g., with house assessment and toilet buildings):

> Another patient with leukemia used to get a lot of worm infections every time he came, sometimes even from tapeworms that aren't around here. We sent a social worker to their house . . . and they found that they didn't have a proper toilet. So we also built a toilet for them.

Information and counseling. Families were provided with information and counseling on a daily basis. Providers described how counseling began when they were breaking bad news, and notably they viewed counseling as an essential component of care. They explained that counseling had helped them overcome challenges and build trusting relationships with families:

> With counseling, we can overcome most things because most of the patients are very simple and nice. That makes a lot of difference, and once they develop confidence in us, things go easier.

Providers reported that families were provided with information and given time to ask questions:

> That is, in-patients, and out-patients also, they have enough time. We have given them up to thirty minutes, so you can see the patient and then they can ask whatever questions they have about the disease. We also have to explain them the therapy and the side effects.

Overall, healthcare providers invested in all the available facilities to provide psychosocial support for children and their families.

Subtheme 2. Facilitating factors. Providers described several factors that they believed could facilitate the provision of psychosocial care, including (1) being Omani, (2) peer support and collaborative work, (3) providers' experiences, (4) sharing families'

experiences and stories, (5) building a family-friendly environment, and (6) motivation.

Being Omani. Being an Omani national was viewed as one of the most significant enabling factors for providing psychosocial support to children and their families. Omani providers shared similar languages, cultures, and religions with the families: "Maybe being Omani, we know our culture, and we know our religion." Because the majority of the providers were non-Omanis, language was one of the commonly perceived barriers.

In addition, conversation and therapeutic communication were used to identify families' needs and to meet them. Omanis who spoke Arabic were viewed as a critical element in this. This was evident in cases where non-Omanis providers had difficulty supporting families beyond medical care because they spoke different languages. The providers explained that eliciting and assessing for social, spiritual, and psychological difficulties required "a big vocabulary." The following statement described that:

> I feel also because we are the Omani staff, just a minimum of us. So sometimes the mothers need support and ask only us to go and talk to them, because there are no language barriers. We can understand each other. So our in-charges are helpful in that, and our doctors too.

Shared cultural and religious beliefs were also believed to be enabling factors. It was not only nurses' and oncologists' responsibilities to their professions that drove them to support families; their eagerness was also rooted in Omani culture and religious beliefs. Omani providers shed light on their belief in "supporting each other" as a core principles of Islam and their worship of God. The Muslim nurses and oncologists were raised in families that did this, so supporting others became a part of their culture and practices:

> How we should deal with others is there in our religions, not just in us, because we have been practicing this since we were young and saw it in our own families . . . like helping each other, supporting each other, if something is wrong.

Sharing similar cultures and religious beliefs with patients also facilitated communication

and understanding, allowing for more effective psychosocial support. An oncologist said,

> Fortunately, I come from the same culture as my patient, which makes communication easier. . . . We are from the same religion, we are from the same culture, so I know how we can speak about fairness—how can we think about everything as a problem, how we will get our reward from our God! So that is a strength of our practice as Arabic doctors here.

Thus, the Omani providers and families bonded through shared culture, religion, and language, as they understood each other better. Not surprisingly, all participants reported similar experiences of relying on Omani nurses for help in supporting families:

> We will ask our nurses to help as well, but it is mainly the Omani nurses who can help because of their culture and language. The other nurses cannot help.

Similarly, families' views of being supported by Omani providers with whom they shared languages, cultures, and beliefs, or being "the same," were highlighted by one oncologist:

> People mentioned to me, "We came to you because we are the same. We are 'cousins and brothers.'" We are all Omanis; that's the idea, that we care about each other. So a lot of patients, even if I wasn't directly involved with them, ended up coming to me for support or questions, even though my colleagues are also very good and very supportive.

All in all, being Omani and sharing the culture, beliefs, and languages of patients was viewed as a facilitating factor to psychosocial care.

Peer support and collaborative work. Healthcare providers worked together to support families. They tended to discuss the families' needs and concerns in order to find the best way to help them. One nurse explained,

> We [nurses and doctors] support each other. So if we feel a need for further support, we [nurses] will talk to the doctors, and they can do the same, and sometimes we can discuss the best things we can do to help the patients and their families.

Providers valued their oncology teams. Non-Omani providers sought help from Omanis or from other specialists for interpretation, assessment for psychosocial difficulties, or meeting families' psychosocial needs. This is illustrated in the following statement:

> In cases like this, especially for expatriate nurses, it's a very difficult situation to deal with. Usually we refer to Omani nurses. We see the problem, we ask them to talk to the patient, or we refer them. We have a play therapist. She is also good, so if we see something that concerns us, we talk to her and say, "Can you please ask this mother what she thinks about this, what is the issue?" And she will convey the problem to us, and we will see what needs to be done.

Moreover, other providers such as play therapists, social workers, and volunteers were involved in psychosocial care, even though they were not specialized in the roles they assumed. Social workers met the instrumental needs of families (e.g., financial and social needs). The following statements describing social workers' role as it was described by participants:

> Usually, there are zones that I can't touch and some areas I do not intervene in, especially sensitive ones. For example, if there is a divorce . . . I usually go to the social worker. . . . I ask her, please kindly get involved in this matter and try to solve their problem.

> That is what we do. If we identify difficult circumstances, we refer them to our social worker. He writes a letter to the Ministry of Social Affairs, and they give [the family] some allowance monthly, or sometimes per appointment, whenever they need it. Depending on their appointments, each visit they get some.

One nurse described the role of play therapists was to involve children in diversional activities such as drawing and painting and to provide them with presents:

> We have somebody who always comes and talks to them and makes them play when they're okay—makes them draw things. And there are a lot of presents for them, especially on special occasions.

Providers' experience. The providers' experience was one factor they identified as helping them support families. Most believed that the ability to provide psychosocial care "comes with practice" and "with experience." For example, participants' experience sharpened their therapeutic communication and counseling skills, and it helped them control their emotions or "hide their feeling" and "be strong" to support families. Experience also helps providers identify families' needs and support them in difficult

situations. Moreover, expatriate nurses learned about Omani families' cultures and religious beliefs over time. Years of experiences equipped the participants with the skills to provide psychosocial support. One nurse described it this way:

> . . . 21 years of practice in pediatric hematology oncology. I can tell you that without anything else, I can provide all the care they need. I can play with them, joke with them, provide them with psychological support, and change their mood. If they have any difficulties, [like if] patients refuse care, they come and say to me, "Sister, please talk to [the child]. Then I will go and explain to him. . . . They depend on us, the seniors [most experience providers] because we are very attached to our patients.

Moreover, with experience, participants became more sensitive to families' needs. One said, "I'm putting myself in their situation so I can understand them well." They also reported several factors that helped them assess psychosocial difficulties. These included changes in children's and parents' behavior (not talking, avoiding them), non-verbal behavior (e.g., becoming sad), the participants' own mutual feelings and discussions with families, and taking the history of the child's behavior (e.g., eating, sleeping, and playing). One nurse described how she became connected with families to extent the she "knew them" and noticed when their moods changed:

> Because of prolonged hospitalization, you see them every day. You know them, you know when they are breaking down, and you know when they are in a good mood.

Sharing family experiences and stories. Participants revealed that sharing experiences and stories of families was an effective mode of support. They also sought help from more experienced mothers whose children were doing well to support newly diagnosed mothers. Sharing family stories could prepare newly diagnosed families psychologically. One participant said,

> We [providers] get the most experienced mother, the one who has stayed in the hospital the longest, and we ask her to [go to] the newcomer to interact with her and

talk to her, and to [provide support] so they can share [experiences].

Another participant stated,

> There was a person I called on the phone. . . . He [the experienced father who already had a child diagnosed with cancer] gave them [newly diagnosed] counseling over the phone. This helped a lot to settle them psychologically.

Building a family-friendly environment. Providers built a family-friendly environment by maintaining good relationships with children. These relationships were regarded as "tender loving care." They described their approach to dealing with children as full of affection. For example, they said they would smile when they saw the children, hug them, run toward them, play with them, talk and interacting with them, share stories, and provide them with gifts if possible. One oncologist described it this way:

> We give tender love and care. When we go to the children, we meet them in a very positive way so that they will trust us. We give them gifts sometimes, especially during evening rounds. We bring them gifts and provide them with support. We take them out with us. That way, when they see a doctor, they don't think of him as a doctor but as a friend.

Over years of work, providers were able to build a good connection with patients and their families. They viewed those attachments as key elements of trust—trusting in the care provided and caregivers in Oman. The providers explained that they were dealing with families and patients as members of their own families. One nurse said, "We are like one family here in our department." The bonding and love they built were bidirectional; parents and children felt the same about the provider as the provider felt about them. This is evident in the following statement, which shows how parents considered the oncology department as a "second home":

> Sometimes I hear mothers say, "This is like is a second home for us. We have one home there, and this is like a home house for us. So we feel like we are family. If we have any problems, we will come to you."

Many providers even took their white coats off to build good relationships with children. Other elements they believed were keys to a good relationship included approachability and accessibility to families, honesty, patience, and showing kindness and love. They also created a positive atmosphere by celebrating the children's birthdays, the New Year, and the World Cancer Day. Volunteers sometimes accompanied children on trips or other fun activities, or distributed gifts to them. One participant explained:

> There are volunteers from the community who come and do storytelling, and they even do traditional day. They will do some activities, and sometimes school children will come. We believe in that, so we have a good atmosphere here.

Motivation. Healthcare providers' support for families in a challenging department was evidenced in their motivations as health care professionals. The providers' inner drive to support families was evidenced by several statements: they described a "passion to help people" and said "We are just doing it out of our interest, our humanity," and "I really made up my mind that I had to sit with them and explain to them about everything." They also referred to patients "needing your commitment and your work," and the importance of "being sensitive to what they feel and what they need," "We go an extra mile to try to help" and "I love this branch."

While the majority of the nurses' were driven by inner motivations to support families, others also described some external motivations. One nurses discussed her satisfaction about children's feedback on Facebook:

> We got a lot of appreciation from the administration. . . . Yesterday, I got nice messages on Twitter and Facebook. . . . One patient thanked pediatric oncology and hematology and the Royal Hospital for their care. They are really like angels. . . . The words he said made us proud. This motivates us to work, to give more and more, and to support children more.

Similarly, a doctor said,

> It's a tough job, but at the end of the day you see that somebody who was struggling to survive is now a doctor, a nurse, or a business professional, so you get a lot of job satisfaction.

Summary of Findings

This chapter elucidated four themes that emerged from the data. Admittedly, there is overlap in the themes and the words of the doctors and nurses. Yet, there were many profound revelations that are relevant for the maturing pediatric oncology care in Oman. The results of this study have important implications for administration, clinical practice, education, and research, which are elucidated in the next chapter.

Chapter 5. Discussion

5.1 Introduction

This chapter begins with an overview of the study, highlighting its purpose, research questions, and methodology. Then, it summarizes and discusses the following: (1) brief summary of findings, (2) providers' perceptions of the need for psychosocial care, (3) their experiences in caring and challenges in pediatric oncology, and (4) barriers and facilitators to providing psychosocial care. Then, this section concludes with a summary of limitations and implications for practice, policy, and research.

5.2 Overview of the Study

The major purpose of this study was to describe healthcare providers' experiences with and perceptions of the psychosocial care needs of the families of children with cancer admitted to pediatric oncology departments in Oman. More specific areas of exploration included providers' understanding of the families' psychosocial needs, the psychosocial care currently practiced, the challenges and barriers to such support, and potential ways of overcoming these. To gain this knowledge, a descriptive phenomenological approach was employed, informed by a socioecological model. The following research questions were investigated:

What are providers' perceptions of the psychosocial care needs of children with cancer and their families?

What are providers' experiences in caring for children with cancer and their families?

What are providers' perceptions of the barriers to and facilitators of psychosocial care?

5.3 Brief Summary of Findings

One of the memorable events in this study was the eagerness of healthcare providers to participate. Providers' exhaustive descriptions of their experiences, perceptions, opinions, thoughts, and feelings evidenced their eagerness to engage in this study. Additionally, providers recognized and praised the researcher's work and effort in conducting this study and prompting for improvement. The most remarkable finding was the uniqueness of the care provided to children and families, which was described as a tender, loving, and family-friendly care. Patients and their families were regarded as family members, not as patients or strangers. This attachment was an important facilitator in care provision, and it contributed to the families' satisfaction.

Providers' inner drive to support the families was rooted not only in their obligation to their work, but also in their culture and religious beliefs. Supporting each other is one of the core principles of Islam, and many providers were raised in families who believed in those principles; thus, it has become part of their culture and practices. Not surprisingly, providers tried to provide the optimal supportive care with the available resources. Psychosocial care was underdeveloped because of limited human and material resources, as well as a lack of training for providers in providing psychosocial care. On the other hand, some of the shared characteristics that formed a supportive environment were found to contribute to supporting the families, such as being from a similar nationality with a shared culture, religious beliefs, and language, the collaborative work among the team, families sharing their experiences and stories with newly diagnosed families with childhood cancer, and building family-friendly environment.

5.4 Providers' Perception of the Need for Psychosocial Care

The providers described the "need for care beyond the medicine." They believed that families who have a child being treated for cancer need comprehensive support, which includes psychological, social, spiritual, and instrumental support, as well as information and counseling. Providers explained that providing psychosocial support should be initiated at an early stage of the cancer trajectory, such as once the diagnosis is disclosed. At the time of diagnosis and in the following days, parents experience severe psychological distress. Participants described families as "shocked," "traumatized," and "guilt-ridden" about their children's sickness. At diagnosis and throughout the cancer trajectory, providers believed that families needed spiritual support, psychological support, and counseling.

As noted above, the participants believed that spiritual beliefs and culture play significant roles in all aspects of Omani families' lives. Therefore, they believed that the family's spirituality is a good source of support during cancer diagnosis and treatment in the context of a Muslim society. The providers described that families sought meaning for their experiences and possible explanations for their child's disease from their religious beliefs and practices. Participants reported that finding meaning for the child's illness and the family's suffering enabled them to cope. This is consistent with other studies where spirituality was considered a source of comfort and hope, contributing to a better acceptance of the children's chronic condition by both the children themselves and their families (Lima et al., 2013; Marzband, Hosseini, & Hamzehgardeshi, 2016).

Along with spiritual support, providers felt that families needed psychological support. They believed that parents needed more psychological support than their children. Providers perceived a relationship between the patient's and family's psychological well-

being, health outcomes, and quality of life. Providers perceived that parents had an easier time coping when they could be optimistic and the child's health status was stable. Alternatively, providers perceived that parents had a harder time coping and experienced more stress when the child's prognosis was poor. This is consistent with the findings of previous literature, in which parents' attributes such as optimism and the use of problem-solving coping strategies decreased parental distress (Grootenhuis & Last, 1997). Moreover, the need for continuous counseling was also valued as an early intervention to help families address psychosocial stressors in general and, importantly, to accept the diagnosis at an early stage of the cancer trajectory. Yet, as discussed below under barriers, the participants also identified that other professionals, such as psychologists and social workers, are needed to meet these needs.

Many participants also described that families were often confronted with multiple additional challenges when the child was diagnosed with cancer. Families must attempt to meet the child's physical and psychosocial needs while simultaneously maintaining normal family functioning. Providers also described the demanding medical regimens in which children with cancer and their families are subjected to, with multiple and pervasive stressors, including significant medical side effects, considerable changes in day-to-day activities, disruption of family roles, and disruption of marital relationship. The psychosocial impact of cancer on children and their families from a healthcare provider's perspective has been noted in other research (G. Kiernan et al., 2010). Therefore, to maintain the functioning of the family and meet the needs of the sick child, providers saw that families also need social and instrumental support. Participants also perceived that families need more extended family support. They conveyed that extended family support

can help the immediate family by helping with food and housing, as well as care of the sick child's siblings. However, in some cases, the geographical distance from the cancer center (hospital) is a barrier to extended family instrumental support. The providers explained that the families who lived far from the hospital tended to be isolated and had less social support than the ones who lived in greater proximity. Notably, providers also described that there was a culture shift in regarding to the extended family support. As such, they illustrated that this cultural shift happen due to an increase in both parents working, made extended family less likely to be able to provide support, and was an issue in contributing to lack of extended family support for these families.

In Oman, the extended family support was remarkable, to the extent that family stay on the hospital grounds to provide food, support, and relief for parents who stay with their children. Extended family support has been found to be a major factor in nuclear family resilience (McCubbin, Balling, Possin, Frierdrich, & Bryne, 2002), as well as an important source of instrumental, emotional, and financial support after a child is diagnosed (Kelada et al., 2019; McCubbin et al., 2002).

As perceived by healthcare providers, families also need instrumental support in managing the day-to-day living with cancer, including financial, transportation, and accommodation arrangements. The demanding medical regimen of cancer treatment-imposed disruptions on parents' work schedules. Not surprisingly, providers in this study described that some caregivers quit their jobs, changed jobs, were fired, or took leave without payment. However, some other families had financial hardships even before the cancer diagnosis and treatment, as reported by healthcare providers. Supporting this view, another study also found that one-third of caregivers reported that they quit or changed jobs

due to a child's cancer diagnosis (Fluchel et al., 2014).

All families experiencing childhood cancer in Oman receive monthly financial support from the government. However, this financial support, as perceived by healthcare providers, was inadequate for some families because of the pre-existing financial hardship or employment disruption. Participants believed that such needs should be met to prevent additional psychosocial burden. Given that access to the healthcare system in Oman is free, there was no significant financial burden related to medical cost. However, it could be argued that frequent travel over long distances to medical centers could be a problematic out-of-pocket expense for some families in financial hardship. Other problematic out-of-pocket expenses could include food, accommodations, family care, and other miscellaneous spending. Given that the access to cancer care is located in the capital, some families faced difficulty in finding places to stay. Providers viewed the difficulty in transportation as a significant problem because families were not appearing for scheduled chemotherapy treatments and often requested to change treatment dates. Oncologists in this study underscored the need to deliver chemotherapy on time. In relation to accommodation, despite the temporary housing afforded by the non-governmental, non-profit organization the Oman Cancer Association (OCA), families still needed greater support.

Many others have noted that part of the supportive care for children with cancer and their families is the need to provide detailed information (Ilyas, Iram, & Jafri, 2016; Kerr, Harrison, Medves, & Tranmer, 2004). Many participants described that families' need reliable information related to cancer and its treatment, side-effects of chemotherapy (e.g., hair loss), diet, nutrition and hygiene. It should also be noted that there are limited teaching guides or written materials for families the study hospitals.

5.5 Experiences in Caring and Challenges in Pediatric Oncology

5.5.1 Emotional Burden

Participants described their work in pediatric oncology as an "emotional burden" because of the cumulative exposure to highly stressful traumatic events. Along with providing medical care, oncologists and nurses also handle the psychosocial issues of children and their families. The long journey of cancer treatment and frequent engagement and communication with families is stressful. Participants spoke of becoming emotionally attached to the children and their families. Notably, a reciprocal bonding developed between providers and the patients and their families. Providers regarded children and their families as one of the family members while simultaneously some noted that families considered the pediatric oncology department as a "second home."

It could be argued that this attachment can be positive when it facilitates providing holistic care to patients and their families and build trust relationship or negative due to the emotional impact on healthcare providers. With such a close relationship, the sense of painful experiences for children and families is intensified. A study found that loss and grief experienced by nurses were intensified when patients were lost either through end of treatment or death (Conte, 2014). This was also found in the present study. The death of patients was reported to be the most stressful and emotionally burdensome experience encountered by many healthcare providers. Nurses, during the interview, nurses cried and expressed emotions when they recalled a child or adolescents' death. Most of the care providers, including both Omanis and expatriates explicitly conveyed the emotional burden they experienced. Being frontline providers in cancer care, nurses were continuously exposed to the psychosocial ramifications of providing intimate care to children and their

families. However, both doctors and nurses expressed their need for psychological support. Similarly, in an Iranian study of pediatric oncology department, the nurses revealed the need for emotional or psychological support for themselves because of the negative consequences of the deep mutual attachment that was developed between the nurses and the patients and their families (Borhani, Abbaszadeh, Mohsenpour, & Asadi, 2013).

5.5.2 Challenging Situations

Participants described other challenging situations they faced when working with families, including breaking bad news, working with families who inquire about and seek second opinions, handling interference from other extended family members, and disclosing information related to diagnosis or prognosis to the child. The task of breaking bad news was not only difficult for families, but also for healthcare providers. In this study, breaking bad news was seen as a challenging situation. The role of breaking bad news or "being a messenger of life-threatening conditions" has been viewed as the main concern of oncologists (Stenmarker, Hallberg, Palm, Marky, 2010).

Seeking second opinions outside of Oman was another challenge identified by participants. Families' going abroad for second opinions was viewed as a habit in their culture. It likely reflects the history where expert specialized medical care was not available, yet the Omanis' motivations for seeking second opinions remain speculation (Burney, 2009). However, providers in this study postulated that seeking a second opinion was a sign of lack of trust in the care provided, and these had the potential to negatively affect it. While others said that seeking another opinion delaying in the initiation of treatment. Majority of families, however, after seeking second opinion abroad tend to have their treatment in Oman. This is especially true because of the increasing number of

patients being admitted for treatment and providers experiences of the workload. Another point also raised by the health care providers is that they believe that Oman is on par with the other countries in term of the quality of care provided. Therefore, they were uncertain why families were wasting their time, effort and money going abroad for second opinions.

Extended family support generally came with good intentions, but this was not true in all cases according to the providers. Some extended family members, although well intentioned, interfered with cancer management plans or treatments. Providers reported that this resulted in families questioning the treatment provided, interrupting to the therapy, and sometimes complications or even relapse. Most importantly, it disrupted the families' trust in the services they received. Like other Middle Eastern cultures, Oman is well known for extended family support and tight relationships, and Omani families are usually involved in decisions together. Family decision-making is thus a particular challenge in the Middle East. With adult patients, for example, the role of extended family is a major component of the socio-cultural attitude toward patients' autonomy; all decisions are family-centered decisions. Family members and even friends feel obligated by genuine cultural and religious values to extend their help and support (Silbermann & Hassan, 2011). It could be argued that to minimize the negative aspects of this influence, healthcare providers must assess the roles and engagement of extended family members in the patients' care and decisions. Furthermore, if parents prefer to involve a member of the extended family, this member must be involved in all discussions and receive all the necessary information. Maintaining open lines of communication in this way between parents, extended family members, and providers can build trust in the services provided and prevent further negative interference.

Disclosing stressful information to children, such as a cancer diagnosis or prognosis or having reached limits of curative therapy and being labeled as DNR was a matter of concern for both parents and healthcare providers. The participants said that parents appeared to hold different opinions on telling the truth to children. Some preferred not to disclose bad news, while others were willing to have open communication with them.

In Omani culture, parents are the legal guardians and caretakers of children and adolescents until they get married. In cases of chronic illness like this, Omani families usually prefer to maintain hope and good spirits to protect the child. They therefore restrict information on things like cancer diagnoses or poor prognosis. It could be argued that providers must assess families' readiness to disclose such information to their children, in additions to the extent to what information should be shared at all and the appropriate time for doing so. Earlier studies have supported the idea of considering patients' and families' preferences for sharing such information (Coyne, Amory, Gibson, & Kiernan, 2016; Zwaanswijk et al., 2007).

5.6 Barriers and Facilitators to Providing Psychosocial Care

Providers perceived that psychosocial care was as important as medical care; however, several barriers hindered the provision of optimal psychosocial care. The barriers experienced during the provision of psychosocial support can be attributed to health-care providers (e.g., language and culture barriers, and lack of formal training), the health-care system (e.g., heavy workloads, time shortages, staff shortages, and under-structured psychosocial services), and infrastructure and environment.

5.6.1 Language and Cultural Barriers

Language and lack of formal training were the barriers most often encountered by both nurses and oncologists. Because the majority of the participants were non-Omanis (expatriates and non-Arabic speakers) language was most common hindrance to psychosocial support. The participants had difficulty engaging in deeper conversations with families to assess their psychosocial needs and provide appropriate support. There were more non-Omanis than Omanis in both pediatric oncology departments, and they came from several countries with different languages and cultural backgrounds.

Evidence has shown that effective communication—which takes into account language, cultural differences, and health literacy—is a key process in safe, high-quality health care (Schyve, 2007). Anthropologists have reported several possible relationships between language and culture, and language is the most important part of a culture (Crystal & Henery Robins, 2019). According to Fuller and Wardhaugh (2014), (1) social structure may influence or determine linguistic structures and behaviors, (2) linguistic structures and behaviors may influence or determine social structures, (3) there could be a bidirectional relationship between language and society, or (4) there could be no relationship between linguistic and social structures.

Linguistic differences are not just differences in spoken words, but in the meanings and beliefs behind them (Gregg & Saha, 2007). The experience of the providers in this study was similar to that of the nurses in a study by Alosaimi and Ahmed, (2016), which was conducted in a similar cultural and hospital context in Oman. That study found that language and culture barriers hindered nurses from providing proper care to patients. The authors concluded that nurses should be trained and educated in culturally competent care.

5.6.2 Lack of Formal Training

Participants tried their best to provide psychosocial support to the families, but they believed that due to lack of formal education and psychosocial care training, the care they provided might still be inefficient and underdeveloped. Although they were well trained to assume their medical and nursing roles, the providers also lacked training in psychosocial support and counseling. Similarly, the providers reported that the social workers and play therapists were also not formally trained in their roles, though the help they gave to families was noticeable.

In Middle Eastern countries, lack of education, training, resources, and funding have been identified as barriers to palliative care services (Bingley & Clark, 2009). Training is an essential component of the psychosocial standards of cancer care, which require that all pediatric psychosocial providers have "specialized training and education, and be credentialed in their discipline to provide developmentally appropriate assessment for children with cancer and their families" (Patenaude, Pelletier, & Bingen, 2015, p. 871). Therefore, providers' preparedness to give psychosocial care is an area for future investigation and intervention.

Participants reported that the current psychosocial care training programs were inadequate and suggested topics on which personnel needed training: how to support families through death and grieving, how to deal with depressed children, and how to improve communication and counseling. They also recommended more on-the-job training and supervision during psychosocial screening.

5.6.3 Under-Structured Psychosocial Services

Participants described psychosocial services as "under-developed" or "under-structured" because of a lack of specialists, psychosocial assessment tools, and resources. They reported having no multidisciplinary team, palliative care team, or dedicated personnel to provide psychosocial care. Specialists—such as psychologists, psychiatrists, trained social workers and play therapists, nutritionists, chaplains or religious leaders, and pharma-oncologists—were generally not available. In addition, despite the providers' attempts to adopt a structured psychosocial assessment tool to screen for psychosocial difficulties or distress, no such tool had been fully implemented. The participants instead relied on behavior changes in children and on parental reports to gauge the need for psychosocial interventions.

Although Omani nurses were at the front line in proving psychosocial care, other providers such as doctors, social workers, and play therapists also contributed to the delivery of such treatment. However, due to time constrains and increased workloads, providers were unable to give their complete attention to psychosocial care. Most often, participants had to weigh the urgent needs of the patients against the possible psychosocial needs of their families. Similarly, a cross-sectional U.S. study involving a web-based survey completed by 400 diverse members of the Oncology Nurses Society identified lack of time and lack of resources as barriers to assessing psychosocial problems and providing psychosocial care in the oncology context (Gosselin et al., 2011). These participants worked in tertiary, referral, and teaching hospitals. They cared for inpatients and outpatients and also had teaching loads in clinical practice or academic settings.

The providers said that health-care system workers and administrators should be oriented toward establishing effective psychosocial services, and that the government should provide secure funding, specialists, materials, and other human resources. The providers described these services as "not just luxury," but as having "a direct effect on the patients' outcomes." Improving these services was thus perceived to be a good investment. In addition, most of the healthcare providers emphasized the need for a structured psychosocial assessment tool that could capture psychosocial difficulties at early stages.

These findings indicated that nurses and oncologists recognized the basic components of psychosocial care services, as illustrated by the psychosocial preventive health model (PPHM). According to the PPHM, the families of children being treated for cancer must have access to basic psychosocial care at the universal level (the lowest level of the pyramid that represents the basic need of families). This level includes social workers, child-life specialists, chaplains, creative arts programs, family-centered programs, financial coaching, and counselors (Kazak, Schneider, Didonato, & Pai, 2015). The literature has suggested that most families are initially screened as at the universal level, where their basic needs are addressed. However some families require additional, higher-tier services such as those at the target or clinical level (see Chapter 2). Therefore, when the PPHM is applied to pediatric oncology services, one area that needs further investigation is the extent to which Oman's current psychosocial services are aligned with the universal level that represents the basic psychosocial care needs of families.

5.6.4 Lack of Support Groups

Participants reported that no support group was available to families. They suggested that a support group could offer families the opportunity to share their illness-related experiences and learn from others with similar experiences. This mutual support could strengthen their coping skills and increase their knowledge (Hicks & Lavender, 2004). The participants valued the work of such support groups and looked forward to having a formal group to help families in pediatric oncology. They suggested that the Ministry of Health of Oman could establish a 24-hour hotline for assessing the psychosocial needs of children and families.

5.6.5 Infrastructure and Environment

Other reported barriers were related to environment and infrastructure. Some providers remarked that the pediatric oncology department was not designed to effectively accommodate children with chronic illnesses for long periods of time. The department lacked many resources, such as spacious rooms, entertainment services, innovative playrooms, places for prayer or meditation, and playgrounds. Therefore, the providers suggested installing more spacious rooms, en-suite bathrooms, a prayer room, and entertainment facilities, including Wi-Fi and PlayStations in each room. They also recommended a more spacious and innovative playroom with full entertainment facilities and extended working hours for play therapists.

A study was conducted in Saudi Arabia to explore the impact of child-friendly hospital environments on pediatric cancer patients and their families. Several interventions were applied, including wall posters designed to mimic a zoo, playrooms designated for certain age groups, quiet patient rooms for families to rest, an attractive waiting room, and

plasma televisions with kids' channels. After these interventions were applied, the patients' and providers' satisfaction were found to have increased (Hamdan et al., 2016).

5.7 Facilitating Factors

Several factors contributed to providers' ability to offer psychosocial support to families and to promote a supportive environment: being Omani or of a similar nationality and culture; sharing religious beliefs and languages; having peer support and collaborative work; allowing the families of children with cancer to share their experiences with families of children with newly diagnosed cancer; and promoting a friendly environment.

5.7.1 Being Omani

Most providers, both Omani and non-Omani, described the significant role Omani providers played in supporting children and their families. Omani providers shared languages, cultures, and religions with the families. Societies such as Oman's tend to ascribe multiple meanings to diseases that are often separate from the diseases' scientific explanations. These meanings are rooted in Omani cultural and spiritual beliefs. Some might argue that the mutual connections and understandings of Omani providers and families were due to their shared languages and cultural and religious beliefs. The families were more likely to seek more support from the Omani providers. Conversely, religious, cultural, and language barriers rendered the expatriate nurses in the Saudi Arabia study unable to carry out their nursing duties and provide proper support to families (Alosaimi & Ahmed, 2016).

5.7.2 Peer Support and Collaboration

Relevant supervision and peer support are crucial for working with children who have serious chronic illnesses and are promoted in professional standards for psychosocial

care (Patenaude et al., 2015). In this study, participants claimed that their experiences working in oncology departments and dealing with families made them more confident in providing psychosocial support to families. The participants also noticed that junior providers sought senior providers' support for conducting consultations and meeting families' needs. Participants perceived that they were more sensitive to families' needs and better able to rely on common sense to assess psychosocial difficulties. They were thus able to identify and react to psychosocial distress because of their extensive experience. For example, they found that their experiences helped them pick up on children's and parents' distress, ask mothers directly about their troubles, and share the experiences of other families whose children had gone through cancer treatment.

5.7.3 Family-Friendly Environment

Building a friendly environment involved maintaining good relationships with the children. These relationships were regarded as "tender loving care." Participants' described their approach to dealing with children as full of affection. Other elements they believed were key to good relationships included approachability, accessibility, honesty, and patience. The providers reported using diversional activities to improve the psychological well-being of children and creating a positive atmosphere by celebrating important events, including children's birthdays, the new year, and the oncology celebration day. The work of volunteers was also noticeable at both hospitals; volunteers sometimes accompanied children on trips or other fun activities, or distributed gifts.

5.8 Supportive Care Provided

Family support followed a holistic approach. It started the day the child and the family came through the door of the pediatric oncology ward and lasted until the end of the

treatment, or even through the bereavement period. The providers' inner desires motivated them to do their best to support families. Their support included spiritual, emotional, instrumental, and psychological care, and provision of information. Although oncologists played a large role in counseling families and meeting their specific needs, nurses focused more on emotional support; this took the form of talking to families, listening to them, and being around them, especially during the most stressful events. Although participants attempted to support families psychologically, for example by helping them understand and providing them with information, the psychological support they gave was not structured or evidence-based. Other researchers have highlighted the effectiveness of psychosocial interventions such as "RRIGHT IDEA," "Celie Cancer Coping Kit," and "Shoptalk" (Sahler et al., 2005) for alleviating anxiety and depression, improving coping and adjustment, providing information on treatments and procedures, and building rapport with healthcare providers (Sahler et al., 2005). Access to such supports and interventions throughout cancer trajectory is strongly recommended in the standards of psychosocial care.

Interestingly, most of the participants had religious perspectives or philosophical views. As such, they used families' spiritual beliefs and words of blessing to provide hope and comfort. For example, non-Muslims used the word *bismillah* ("in the name of God") before starting an intervention (e.g., cannulation), and reminded patients about God and that he was always there for them. Nurses also prayed their own prayers for families, and Muslims providers added to families' hope and comfort by reminding them of the rewards they would get from God for being patient, of God's grace for the death of the child, and of the meaning of the child's illness and suffering.

Instrumental support was also apparent in this study. This included allowing healthy siblings to visit, arranging families' transportation or providing them with money to return home if needed, arranging for temporary accommodations (Dar Al-Hanan), allowing for more than one attendant, allowing for male attendants, helping mothers with patients' usual care, letting kids under two years old stay with their mothers in the hospital, arranging financial support, and coordinating with school administrators or parents' workplaces. The visitation policy says that children under twelve are not allowed to visit in-patients and that home food is not allowed for in-patients. However, the providers were aware of how much emotional support sick children can get from their siblings' visits, so they allowed these. The nurses also talked about food and how children might develop a poor appetite, or nausea and vomiting as a side effect of medication, so they sometimes asked to have their favorite foods from home. The participants also suggested modifying food and visitation policies for children with cancer.

5.9 Limitations

To my knowledge, this study is the first to explore nurses' and oncologists' experiences and perceptions regarding the psychosocial care needs of children with cancer and their families and to investigate the barriers and facilitators to the provision of psychosocial care in Oman and possibly other Arabic countries. No concrete limitations can be inferred about the study's method and data analysis techniques, as the sample was sufficiently large and diverse, with a wide range of years of experience and clinical backgrounds. The technique of phenomenological data analysis was also robust enough to generate trustworthy findings.

The only reservation is that the generalizability of the findings cannot be predicted,

due to the restrictions on generalizing qualitative studies. However, the findings can be transferred and applied to similar settings, such as Arabic and Gulf countries with similar healthcare systems and diversities in healthcare providers. The transferability of qualitative research does not mean generalization of findings across individuals or settings. Rather, it relies on the rich description of the themes developed from a specific site in a contextual form but suited to inform the work of other qualitative researchers in other settings (Creswell, 2013). Therefore, as mentioned in Chapter 3, some strategies were used to enhance the transferability of the findings.

Another limitation could be that the interviews were conducted in English language despite the fact that both the Omanis and the non-Omanis did not speak English as a primary language. English was chosen nonetheless because it is the main language of communication between these providers, and to unify the interview guide. This also eased the process of analysis and theme generation. But using a language other than the participants' native language for qualitative interviews could have imposed bias on the study. The quality of the data might have been reduced by the use of a corporate language rather than the interviewees' native languages (Welch & Piekkari, 2006). This is because people tend to express themselves better in their native languages than in others, which leads to more authentic answers (Welch & Piekkari, 2006). However, these problems were overcome through member checking (returning transcripts to participants for verification) and discussion of the findings with the providers.

5.10 Implications for Practice

5.10.1 Healthcare System

According to the healthcare providers' experiences and perceptions, children with cancer and their families have extensive psychosocial needs that require urgent interventions and access to family-centered psychosocial care services. Therefore, multidisciplinary family-centered psychosocial care should be provided in pediatric oncology departments. The purpose of these services is to enhance a holistic care approach for the patients and their families and to strengthen their resilience and coping by building on family strengths. To achieve that goal, a team must be formed that includes advanced-practice nurses or nurse specialists, clinical psychologists, trained social workers and child-life specialists, psychiatrists, specialized neuropsychologists, and chaplains (imams or shaikhs). Healthcare providers must ensure that all families with childhood cancer have access to the basic psychosocial services indicated in the PPPHM, and further support should be provided as needed.

Because Omani nurses provide psychosocial care most directly in these departments, clinical nurse specialists are needed who are specifically trained and dedicated to caring for these children and their families and who can organize structural psychosocial screenings to identify their problems quickly. These specialized nurses should be well-versed in Omani culture, language, and religion to ensure effective care.

Psychosocial support should be provided to children and their families throughout the cancer trajectory, as early identification of psychosocial distress is an important step toward the provision of appropriate and timely care. Thus, the adaptation of a culturally accepted screening tool is warranted. More importantly, because most of the providers

were expatriates and had difficulty communicating with families, professional translators must be hired to ensure that families' needs are met. Resources for providing families with health information are essential. The families can be directed to secure, trusted websites or provided with educational materials in Arabic. A trusted Ministry of Health website for cancer patients and their families should be created to give them access to appropriate resources and information.

Other suggestions were made for improving the psychosocial services among the available of resources. Psychologists or psychiatrists could visit from other hospitals, such Al Mussarh Hospital or Sultan Qaboos Hospitals (both of which have psychologist specialties). They can do rounds or visit twice a week or as needed to assess for psychosocial difficulties and provide support. The hospital could also adopt the pediatric distress thermometer (DT). This tool has three faces that illustrate different feelings (not sad or worried, sometime sad or worried, always sad or worried). This tool is simple and easy to use.

Another possibility would be a hotline: a community-based helpline for children with cancer and their families. This could be run by a social worker and a nurse from the pediatric oncology department, who could use the distress thermometer–parents (DT–P). This tool can guide providers in screening for psychosocial difficulties via hotline. It is categorized into sections for emotional, social, practical, spiritual, and physical problems, and lets the workers provide the support that is needed. Families across Oman with childhood cancer could call the helpline at any time if they have difficulties and need support (see Appendix).

5.10.2 Healthcare Providers

Because of their lack of formal education in psychosocial care, nurses and oncologists need additional specialized training and an on-the-job training program to ensure that they can provide effective psychosocial care. The following topics were suggested: therapeutic counseling, effective communication, supporting families during death and grieving, and supporting children with depression and anxiety. Programs should also include the use of psychosocial assessment tools. Providers should be trained to give therapeutic counseling and psychoeducation. Because of the emotional burden and challenging situations oncology providers encounter, they need psychological support to sustain their work with cancer patients and their families.

5.10.3 Patients and Families

According to the providers, the benefits of sharing experiences and stories between newly diagnosed families and more experienced ones indicates a need for a more formal support group. This could be led by the specialized nurses in the unit. Because of how demanding cancer treatments are and their psychosocial impact on the entire family, the need for respite care is high. This could help sustain family functioning and marital relationships by allowing parents to spend time together and handle other responsibilities.

5.10.4 Community

There should be a community awareness program directed toward improving people's knowledge of childhood cancer, its therapeutic management, and the resources available for it in Oman, as well as to orient people on the psychosocial needs of families who have a child with cancer. This program could help community members learn more about cancer and overcome any misconceptions they have. In addition, it could bridge the

gap between community members and service providers and build trust in the healthcare system in Oman. Because schooling and learning are crucial to adolescents and school-age children, a way for them to resume their education in the hospital setting must be established and maintained.

5.11 Implications for Research

This study has focused on healthcare providers' experiences with and perceptions of the psychosocial care needs of children and their families. Further studies are required to explore the children's and parents' experiences.

In this study, I described the lived experiences of both nurses and oncologists; future studies will be required to examine the differences in the experiences and perceptions of different professionals (e.g., oncologists vs. oncology nurses) and different nationalities (Omanis vs. non-Omanis). It will also be necessary to translate and test the applicability of the Psychosocial Assessment Tool (PAT) in the Omani context. And further study is needed to explore social workers' experiences and perceptions using a similar guide once this one has been translated into Arabic.

Figure 5 illustrates some suggestions for enhancing the psychosocial services in Oman.

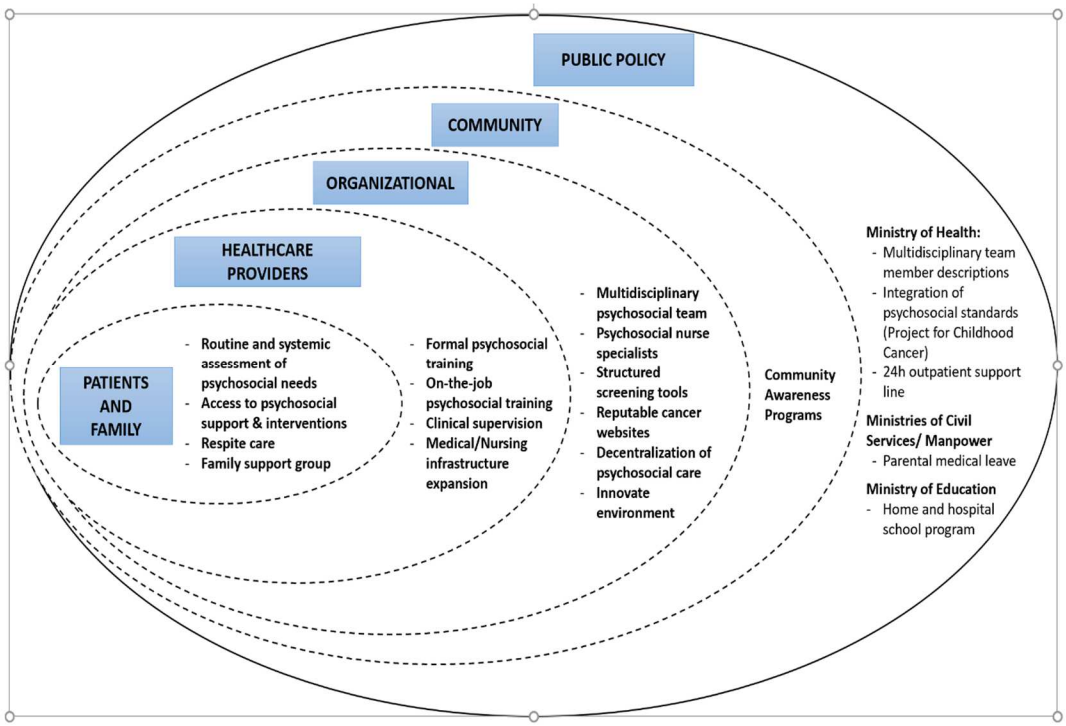


Figure 5. Model- Suggestions for Introducing Psychosocial Services

5.12 Implications for Policy

The Ministry of Health should implement policies to support the integration of psychosocial services into the healthcare system; to incorporate psychosocial care; to improve or establish adequate funding; to ensure that all healthcare providers have access to postgraduate training in psychosocial care; and to support infrastructure expansion for medical and nursing training in Oman. In addition, the project for childhood cancer (PSCPCC) will be introduced to the Ministry of Health to support the integration of psychosocial care.

There should be collaboration between the Ministry of Health, the Ministry of Civil Services (governmental), and the Ministry of Manpower (non-governmental) to establish policies regulating and supporting parents and employers who have children with chronic illnesses and who need frequent admissions and follow-up appointments. In addition, the Ministry of Health and the Ministry of Education should collaborate to establish policy for

a hospital school program through which they can provide certified teachers to help children keep up with their classwork and remain engaged in school. This could inject some normalcy into their lives and help them maintain social connections.

Appendix A

Ethical Approval Letter -University of Maryland, Baltimore

University of Maryland, Baltimore
Institutional Review Board (IRB)
Phone: (410) 706-5037
Fax: (410) 706-4189
Email: hrpo@umaryland.edu

APPROVAL OF RESEARCH NOTIFICATION

Date: December 20, 2018

To: Mary Johantgen
RE: HP-00083486
Type of Submission: Initial Review
Type of IRB Review: Expedited

Approval for this project is valid from 12/20/2018 to 12/19/2019

This is to certify that the University of Maryland, Baltimore (UMB) Institutional Review Board (IRB) approved the above referenced protocol entitled, "*Psychosocial care needs of parents and children with childhood cancer in Oman: Perspectives of providers*".

The IRB has determined that this protocol qualifies for expedited review pursuant to Federal regulations 45 CFR 46.110, 21 CFR 56.110, & 38 CRF 16.110 category(ies):
(6) - Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) - Research on individual or group characteristics or behavior or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

The IRB made the following determinations regarding this submission:
- Written informed consent is required. Only the valid IRB-approved informed consent form(s) in CICERO can be used.

This study is approved to enroll 30 local participants.

This study is approved to enroll 30 worldwide participants.

Below is a list of the documents attached to your application that have been approved:
Consent form_18Dec18.docx
Eligibility Checklist for HP-00083486 v11-30-2018-1543588761665
supporting litreture summary.docx
Recruitment_presentation_final.pptx
Recruitment email_rev.docx
Demographic Questionnaire
recruitment_flyer_final_18Dec19.jpg
Interview_Guide_18Dec04.docx
Demographic survey_placeholder.docx
CITItraining_Amal Al Balushi.pdf

HIPAA_201_AlBalushi.pdf
Data analysis-training certificate.pdf
Data colleciton method training certificate.pdf

In conducting this research you are required to follow the requirements listed in the INVESTIGATOR MANUAL. Investigators are reminded that the IRB must be notified of any changes in the study. In addition, the PI is responsible for ensuring prompt reporting to the IRB of proposed changes in a research activity, and for ensuring that such changes in approved research, during the period for which IRB approval has already been given, may not be initiated without IRB review and approval except when necessary to eliminate apparent immediate hazards to the subject (45 CFR 46.103(4)(iii)). The PI must also inform the IRB of any new and significant information that may impact a research participants' safety or willingness to continue in the study and any unanticipated problems involving risks to participants or others.

DHHS regulations at 45 CFR 46.109 (e) require that **continuing review** of research be conducted by the IRB at intervals appropriate to the degree of risk and **not less than once per year.** The regulations make **no provision for any grace period extending the conduct of the research beyond 12/19/2019.** You will receive continuing review email reminder notices prior to this date; however, it is your responsibility to submit your continuing review report in a timely manner to allow adequate time for substantive and meaningful IRB review and assure that this study is not conducted beyond **12/19/2019**. Investigators should submit continuing review reports in the electronic system at least six weeks prior to this date.

Research activity in which the VA Maryland Healthcare System (VAMHCS) is a recruitment site or in which VA resources (i.e., space, equipment, personnel, funding, data) are otherwise involved, must also be approved by the VAMHCS Research and Development Committee prior to initiation at the VAMHCS. Contact the VA Research Office at 410-605-7000 ext. 6568 for assistance.

The UMB IRB is organized and operated according to guidelines of the International Council on Harmonization, the United States Office for Human Research Protections and the United States Code of Federal Regulations and operates under Federal Wide Assurance No. FWA00007145.

If you have any questions about this review or questions, concerns, and/or suggestions regarding the Human Research Protection Program (HRPP), please do not hesitate to contact the Human Research Protections Office (HRPO) at (410) 706-5037 or HRPO@umaryland.edu.

Appendix B

Ethical Approval Letter - Ministry of Health

Sultanate of Oman
Ministry of Health
Directorate General of Planning and Studies

سلطنة عمان
وزارة الصحة
المديرية العامة للتخطيط والدراسات

Ref. MoH/DGPS/CSR/PROPOSAL_ APPROVED/1/2019

Date 3.1.2019

الرقم:

التاريخ:

الموافق:

Amal Al Balushi
Principal Investigator

Study Title Psychosocial Care Needs of Parents and Children with Childhood Cancer in Oman: Perspectives of Healthcare Providers

Proposal IDMoH/CSR/18/9643

After compliments,

We are pleased to inform you that your research proposal **Psychosocial Care Needs of Parents and Children with Childhood Cancer in Oman: Perspectives of Healthcare Providers** has been approved by the Research and Ethical Review & Approval Committee, Ministry of Health.

On completion of the study, you are required to provide a copy of the final report within 2 months to the Centre of Studies and Research.

Regards,

DIRECTORATE GENERAL OF PLANNING AND STUDIES
SULTANATE OF OMAN MINISTRY OF HEALTH

Dr. Ahmed Mohamed Al-Qasmi
Director General of Planning and Studies
Chairman, Research and Ethical Review & Approval Committee
Ministry of Health, Sultanate of Oman.

Cc
Day file

P.O. Box : 393, Postal Code: 100, Muscat
Tel.: 22357254, Fax : 22357260
E-mail: dg.plan@moh.gov.om
ص.ب : ٣٩٣، الرمز البريدي : ١٠٠
مسقط ، هاتف: ٢٢٣٥٧٢٥٤، فاكس : ٢٢٣٥٧٢٦٠

Appendix C

Ethical Approval Letter – Sultan Qaboos University Hospital

Sultan Qaboos University
COLLEGE OF MEDICINE & HEALTH SCIENCES

جامعة السلطان قابوس
كلية الطب والعلوم الصحية

REF. NO. SQU-EC/001/19
MREC Approval #1837

TO: Dr. Huda Al Awaisi
Principal Investigator, Nursing Directorate
Sultan Qaboos University Hospital

SUBJECT: ***Approval of the Research Project "Psychosocial Care Needs of Parents and Children with Childhood Cancer in Oman: Perspectives of Providers"***

DATE: 20th January 2019

I am pleased to inform you that the abovementioned research project submitted to the Medical Research Ethics Committee (MREC), College of Medicine & Health Sciences, Sultan Qaboos University for review and approval was discussed during its meeting of 10th January 2019.

The Committee has considered your research project acceptable and therefore **approval is granted.**

I wish you a productive study with your research work.

With kind regards,

Murtadha Al Khabori
BSc, MD, FRCPC, ABIM, M.Sc, CIP
Deputy Chairman, Medical Research Ethics Committee
College of Medicine & Health Sciences
Sultan Qaboos University

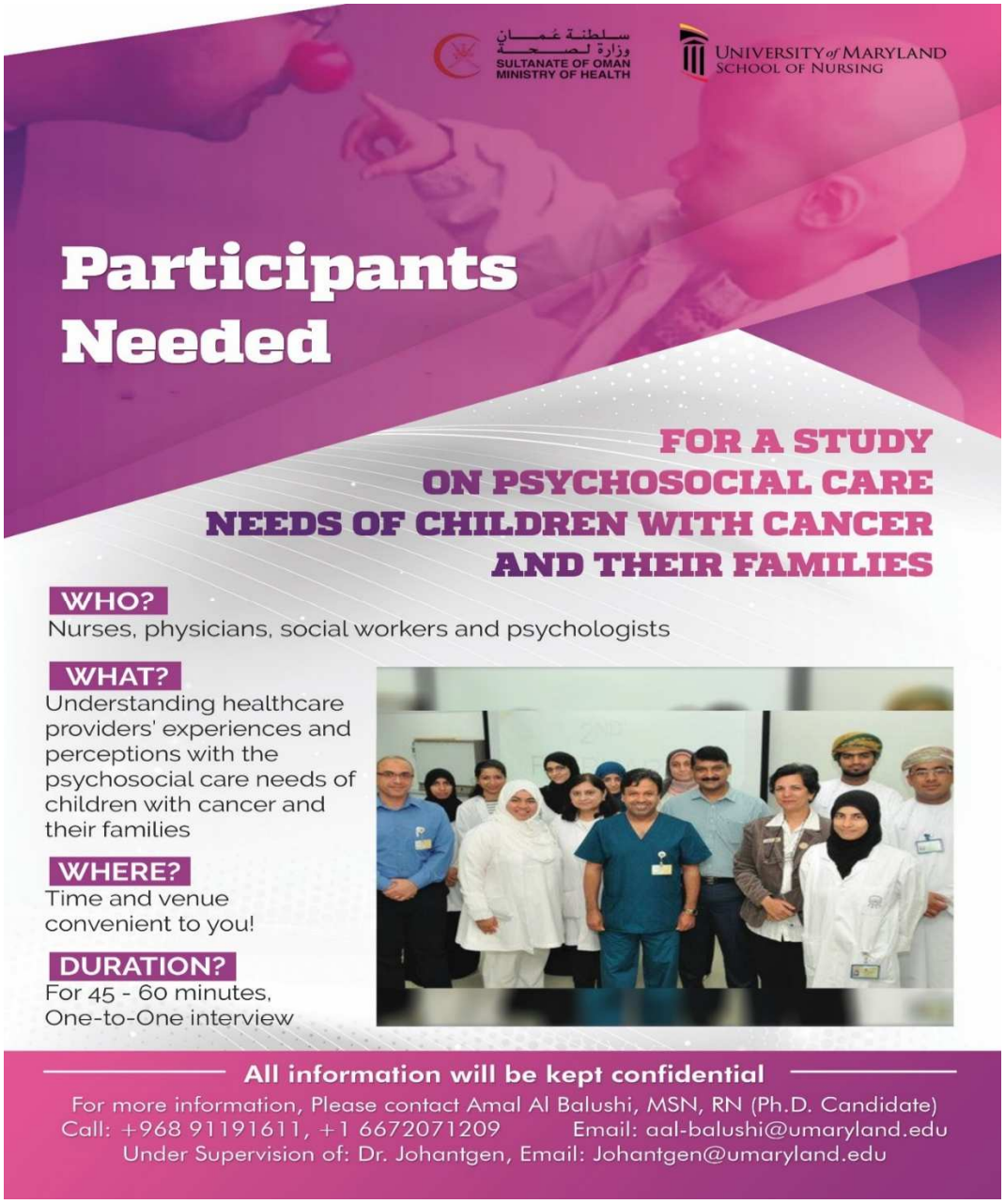
:lrc
cc: Dr. Mohammed Al Zaabi, Asst. Dean, Postgraduate and Research Studies, COM&HS, SQU

P.O. Box: 35
Al-Khodh - Sultanate of Oman
Postal Code 123
Telephone: (+968) 24141103 Telefax: (+968) 24413419

صندوق البريد: ٣٥
الخوض - سلطنة عُمان
الرمز البريدي: ١٢٣
هاتف: ٢٤١٤١١٠٣ (٩٦٨+) فاكس: ٢٤٤١٣٤١٩ (٩٦٨+)

Appendix D

Recuritment- Flyer



Appendix E

Recuritment- Email

Date:
Title: Participation in a research study

Dear Healthcare Providers,

Hello, my name is Amal Al Balushi and I am a PhD nursing student at the University of Maryland, School of Nursing, in the U.S. As part of my doctoral dissertation, I am conducting a research study to understand healthcare providers' experiences with and perceptions of the psychosocial care needs of families who have had a child admitted to pediatric oncology department with cancer at two hospitals in Oman. I am recruiting nurses, physicians, social workers and psychologists who have had at least two years of experience in providing oncological care in pediatric departments as well as who speak English fluently, since the interview will be conducted in English.

If you are interested to take part in this study, you will be asked to do the followings:

1. Complete demographic questionnaires
2. Be interviewed for 45-60 minutes in a convenient place/time to you, the interview will be recorded using a digital recorder.
3. Verify the interview transcript which will be returned to you. You can add further information, if desired.

Your participation is completely voluntary and there are no consequences for choosing not to participate or withdrawing from the study. Confidentiality of all participants will be maintained. The data will be kept secure and, on a password,protected computer.

Any additional questions regarding the project can be directed to me, [Amal Al Balushi] at [+968 91191611] or [aal-balushi@umaryland.edu]. I look forward to hearing your experiences, perceptions, views and opinion.

Respectfully,

Amal Al Balushi
PhD Candidate, MSN, RN
University of Maryland, Baltimore

Appendix F

Interview Guide

Psychosocial Care Needs of Parents and Children with Childhood Cancer in Oman: Perspectives of Healthcare Providers

Date:
Place of interview:
Interviewee codes:
Time of the interview:

Introduction:
Thank you for agreeing to participate in the study. My name is Amal Al Balushi and I am a PhD nursing student at the University of Maryland, School of Nursing. I am conducting a research to understand healthcare providers' experiences with and perceptions of psychosocial care needs of families who have had a child admitted to a pediatric oncology department with cancer. I am interested to hear about your own personal experiences, opinions, and views as a healthcare provider caring for these children and their families. So, please don't feel shy. Your perceptions and experiences are really valuable, and I am here to learn from you. I want you to know that your participation in this interview is completely voluntary, and if you want to stop at any time please don't hesitate to let me know. Also, all the interview will be completely confidential and anything you say will not be shared with any providers. I want you to know that all research documents relating to our conversation will not include your name or any personal information.

Please don't mentioned any names for your patients or colleagues because our aim is to understand your perceptions and experiences. If you don't mind, I would like to record our interview using a digital recorder so that I don't miss or forget anything that we talk about. **Do you feel comfortable with recording this discussion?** I will ask some questions but there are no right or wrong answers, so, fell free to share your experiences**. Do you have any questions before we start?** At any point during the interview, feel free to ask any questions or clarifications with as we go along**.**

Research Question

What is the lived experience of providers caring for children with cancer and their families?

Major Statement

"Tell me about your experience regarding care for children with cancer and their families."

<u>Additional Questions/Prompts</u>

1. Please tell me about your job at [Royal Hospital or the Sultan Qaboos University Hospital]?

2. Tell me about your responsibilities as a [nurse, physician, social worker, or psychologist] in pediatric oncology?

3. From your experience, tell me about the needs of children with cancer and their families?

4. What about the psychosocial needs of children with cancer and their families? Have you identified any? Tell me about that.

5. How did you assess/screen for the psychosocial needs of families and children with cancer?
   Probe:
   Have you used any tool/checklist to assess for psychosocial needs?
   If the answer is yes, tell me about the tool/checklist.
   If the answer is no, what helped you in identifying the psychosocial needs of families and their children with childhood cancer?

6. How did you address those psychosocial needs for the children and their families?

7. Describe the psychosocial care you have provided to the families?

   Probe: To whom have you provided the care? (e.g., Patient, Parent, Sibling)

   What type of psychosocial care have you provided to the families? (e.g., emotional, spiritual, counseling)

8. Did you feel prepared to provide psychosocial care? If no, explain.

9. What helped you with providing psychosocial care?

10. What were the challenges or barriers, if any, that you encountered when providing psychosocial care to families who have a child admitted with cancer?
    If you did face difficulty in providing such care:

    What made it difficult?

    How did you overcome the barriers or challenges?

    Did you ask for help? Did you know what to do and who to go for help?

11. Is there additional support that would have been helpful?

12. What do you believe would improve the psychosocial services of pediatric oncology in the Sultanate of Oman? Give me examples.

13. Is there anything else you would like to share that we did not discuss?

I appreciate you taking the time to provide me with insights about the psychosocial healthcare needs of children with cancer and their families.

Thank you,

Amal

Appendix G

Demographic Questionnaire

Principal investigator Amal Al Balushi, PhD Candidate, aal-balushi@umaryland.edu
Tel no +968 91191611, +1 6672071209, Supervised by Dr. Johantgen,
johantgen@umaryland.edu

Participant number: _____

Date: _____

Thank you for agreeing to be part of this study.

General Questions

1. What is your age? _____

2. What is your gender?

Male
Female

3. What is your nationality?

Omani
Non-Omani

If non-Omani, state your nationality and your country of origin. _____

4. What are your religious affiliations?

Muslim
Non-Muslim

If non-Muslim, please state your religious affiliations. _____

5. What is your specialty?

Nurse
Doctor
Social worker
Psychologist
Administrator
Other _____

7. State your highest level of education. _____

8. How long have you been **in clinical practice**?

2–5 years
6–10 years
11–15 years
16–20 years
More than 20 years

9. How long have you been in **pediatric oncology practice**?

2–5 years
6–10 years
11–15 years
16–20 years
More than 20 years

10. Do you have any religious or philosophical views that guide, affect, or shape your psychosocial care of children and their families?

Yes
No

11. Does your culture have any beliefs about psychosocial care?

Yes
No

Appendix I

Step 1 – Extract Significant Statement

Stage Three: "Extract Significant Statement"

Significant Statement	Trans No.	Line No.	Page No.
"I take care of children with chronic hematological disorders, like Sickle Cell and Thalassemia, and in addition to oncology, mostly in our hospitals we deal with Leukemia other malignancies. In addition to that, I do a bone marrow transplant for both malignancies and for benign diseases. So, inpatient, outpatients and calls"	25	4-8	1
"it can be tough a little bit dealing with the patients, and their families, especially when there is influence from others into the family, that interferes with their plans and managements"	25	11-13	1
"Sometimes when the patient is very sick, it touches you."	25	13	1
"The patient stays with us for a long time; you got connected with the family. It is a long journey. It is not like a one visit two visits and the patient will go. "	25	13-15	1
"So you need to build up that relationship with the family and for the best interest of the child and involve this child when possible, even at the slightest, to get them on board with you to complete the journey to the cure."	25	16-18	1
"This is our culture has a lot of beliefs that actually is supportive, but this support in ,my opinion, can lead to two things; positive support that helps the patient and the family to go through the process of treatment and the complications and reach to the cure; and negative supports with a good intention. So people who do this, they do not feel that they are actually impacting negatively."	25	20-24	1
"They feel that they are doing good things for the family, but it distracts the family, it shakes them. It gives them doubts about treatments, about things may actually lead to interruption of therapy, my lead to any results in complication or even relapses sometimes because of unplanned or uninformed advises from people in the community. And who are trying to support, but in the wrong way."	25	24-29	1
"So, in addition to good medical team, you would need them to be exposed to psychologists, social workers, educators because these children are growing, and nutritionist. So it is a multidisciplinary team, you cannot really do the proper comprehensive care unless you have all these domains"	25	32-35	1-2
"The psychologist would help raising the morale of the family, and accepting the treatment. I believe that if the patient and the	25	35-36	2

Appendix J

Step 2 – Formulation of Meaning

Significant Statement	Formulation of Meaning
"I take care of children with chronic hematological disorders, like Sickle Cell and Thalassemia, and in addition to oncology, mostly in our hospitals we deal with Leukemia other malignancies. In addition to that, I do a bone marrow transplant for both malignancies and for benign diseases. So, inpatient, outpatients and calls"	The doctor is responsible for the inpatients and outpatients care, as well as performing bone marrow transplantation.
"it can be tough a little bit dealing with the patients, and their families, especially when there is influence from others into the family, that interferes with their plans and managements"	Healthcare providers experience difficulty dealing with patients and families when there are interferences from others that impact the management plan.
"Sometimes when the patient is very sick, it touches you."	Dealing with very sick patients is emotionally painful for the doctor.
The patient stays with us for a long time; you got connected with the family. It is a long journey. It is not like a one visit two visits and the patient will go.	Doctors get connected with the families and their children because of long journey of treatment.
"So you need to build up that relationship with the family and for the best interest of the child and involve this child when possible, even at the slightest, to get them on board with you to complete the journey to the cure."	Build-up the relationship with families is required for the best interest of the child.
"This is our culture has a lot of beliefs that actually is supportive, but this support in my opinion, can lead to two things; positive support that helps the patient and the family to go through the process of treatment and the complications and reach to the cure; and negative supports with a good intention. So people who do this, they do not feel that they are actually impacting negatively"	Support resulting from cultural beliefs could be either "positive support" that moves patient and family toward the cure, or "negative support" that adversely impacts patient's health.
"They feel that they are doing good things for the family, but it distracts the family, it shakes them. It gives them doubts about treatments, about things may actually lead	Interferences from other people in the community lead to a lack of conviction in the therapeutic plan and thus delayed treatment.

Appendix H

Step 3 – Creating of Categories/Clustering of themes/Emerging Themes

Significant Statements	Cluster of themes	Emerging Themes
Theme 1. Perceived need for care beyond medicine • Psychological support • Spiritual support • Instrumental support • Health information and counseling		
1. Teenagers are sometime depressed because of recurrent admission 2. Children get into depression because of the long stay at hospital and absence from school 3. Children develop depression because of being in an unfamiliar environment with a strange people 4. Doctors might face children who are depressed because of prolonged hospitalization period 5. Prolonged hospitalization has an impact on the children negatively (e.g. become depressed) and there is no routine psychosocial support 6. Children at the end of their lives need a consistent psychosocial support not only from families but also from specialized healthcare providers	**Recurrent admission, being in unfamiliar strange environment and prolonged hospitalization results in change in psychological status such as depression and stress.	**Theme 1. Perceived need for care beyond medicine** **Categories** A). The need for psychological support

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