

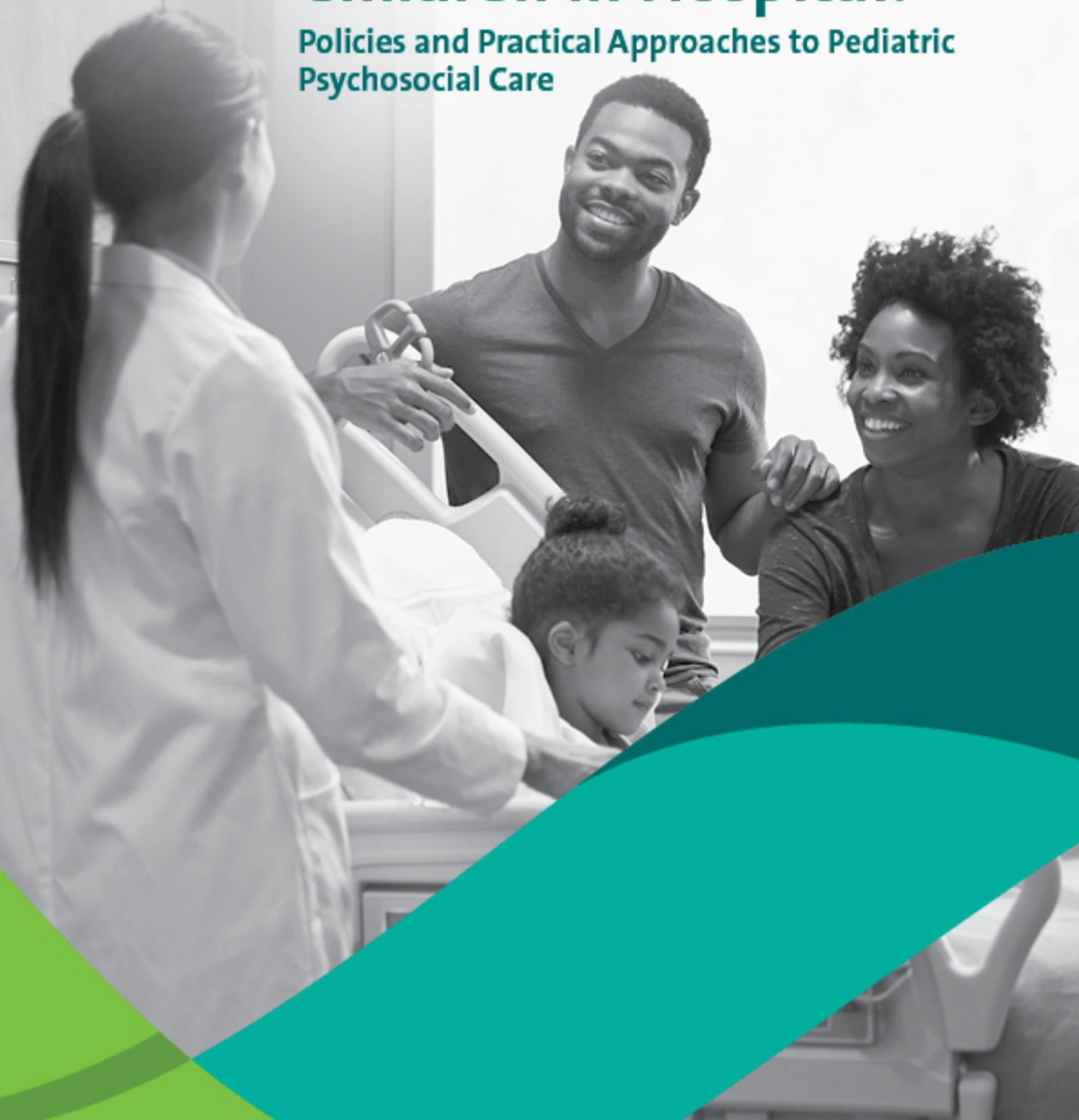


**DIFI**

معهد الدوحة الدولي للأسرة  
Doha International Family Institute  
البحوث لدعم الممارسات الأسرية  
Research to advance family policies

# Supporting Families & Children in Hospital:

## Policies and Practical Approaches to Pediatric Psychosocial Care



# SUPPORTING FAMILIES AND CHILDREN IN HOSPITAL: POLICIES AND PRACTICAL APPROACHES TO PEDIATRIC PSYCHOSOCIAL CARE



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## CONTRIBUTORS

This report was prepared by: Natalie A. Williams, PhD, Assistant Professor, Department of Child, Youth, and Family Studies, University of Nebraska-Lincoln, USA; Justin M. Petkus, MS, CFLE, CCLS, Child Life Specialist, Hamad Medical Corporation, Qatar and Doctoral Student, Department of Child, Youth, and Family Studies, University of Nebraska-Lincoln, USA; Holly Clark, MS, CTRS, CCLS, Head of Child Life Services, Hamad Medical Corporation, Qatar; and Rachel Kazemi, BA, Department of Child, Youth, and Family Studies, University of Nebraska-Lincoln, USA.

Staff from DIFI, namely, Heba Al Fara, Family Policy Officer, and Anis Ben Brik, PhD, Director of the Family Policy Department, also contributed to this publication.

# CONTENTS

<b>DOHA INTERNATIONAL FAMILY INSTITUTE</b>	<b>7</b>
<b>ACKNOWLEDGMENT</b>	<b>7</b>
<b>FOREWORD</b>	<b>9</b>
<b>EXECUTIVE SUMMARY</b>	<b>11</b>
<b>INTRODUCTION</b>	<b>13</b>
<b>CHAPTER ONE: PEDIATRIC PSYCHOSOCIAL CARE</b>	<b>13</b>
1.1. Rationale	13
1.2. Historical Foundations	14
1.3. Theoretical Foundations	16
<b>CHAPTER TWO: CHILD- AND FAMILY-FRIENDLY SUPPORTIVE PSYCHOSOCIAL SERVICES</b>	<b>21</b>
2.1. Therapeutic Play	21
2.2. Psychological Preparation and Coping	24
2.3. Family Support/Family-Centered Care	28
2.4. Psychosocial Support in Critical and End-of-Life Care	33
<b>CHAPTER THREE: CASE STUDY ILLUSTRATIONS OF BEST PRACTICES</b>	<b>39</b>
3.1. Case Study 1 – Qatar	39
3.2. Case Study 2 – Qatar	43
3.3. Case Study 3 – United States	45
3.4. Case Study 4 – India	48

<b>CHAPTER FOUR: PEDIATRIC PSYCHOSOCIAL CARE AND QUALITY OF LIFE IN QATAR</b>	<b>52</b>
4. 1. History and Challenges	52
4. 2. Policy Implications	53
<b>CHAPTER FIVE: RECOMMENDATIONS FOR IMPLEMENTING PEDIATRIC PSYCHOSOCIAL CARE</b>	<b>55</b>
5. 1. Education and Training	55
5. 2. Healthcare Environment	56
5. 3. Financial Support and Advocacy	57
5. 4. Research and Audits	57
<b>CONCLUSIONS</b>	<b>59</b>
<b>REFERENCES</b>	<b>60</b>



## **DOHA INTERNATIONAL FAMILY INSTITUTE**

Doha International Family Institute (DIFI), a member of Qatar Foundation for Education, Science and Community Development (QF), was established in 2006. The Institute works to strengthen the family through the development and dissemination of high-quality research on Arab families, encouraging knowledge exchange on issues relevant to the family and making the family a priority for policymakers through advocacy and outreach at the national, regional and international levels. Among the Institute's most important initiatives are the Annual Conference on the Family and, in collaboration with the Qatar National Research Fund, the OSRA Research Grant, an annual grant that encourages research related to the Arab family and family policy. The Institute has special consultative status with the United Nations Economic and Social Council (ECOSOC).

For more information about Doha International Family Institute, please visit [www.difi.org.qa](http://www.difi.org.qa).

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## FOREWORD

The illness of a child can have a traumatic effect on the child and their family members. Research has shown that separation from family members, changes in familiar routines and environments, exposure to medical procedures, and fears about how the illness will affect the child's future are significant sources of stress that affect the entire family. Family-centered care in pediatrics is based on the understanding that the family is the child's primary source of strength and support, and that the perspectives of the child and their family are important in clinical decision-making. Research shows that family-centered care can improve patient and family outcomes, increase patient and family satisfaction, build on child and family strengths, increase professional satisfaction, decrease health care costs, and lead to a more effective use of healthcare resources.

The provision of psychosocial support for child patients and their families is often undermined by treatment plans that focus solely on the patient's physical symptoms. Psychosocial support mechanisms aim to enhance the overall well-being of the patient and their family and to strengthen their skills and abilities in dealing with their healthcare needs. Psychosocial support involves attending to the emotional, psychological, social, spiritual, and practical needs and wishes of the patient, using the support of their community of family, friends, and neighbors. It is important to create a supportive environment in healthcare facilities for children and their families in order to facilitate their participation in their own healthcare. Overall, the primary goal of pediatric psychosocial care is to promote both child and family resilience and adaptive responses within the challenging medical context.

By conducting this study, Doha International Family Institute (DIFI) is contributing to efforts to highlight the presence and participation of family members as a fundamental component of patient- and family-centered care that has a significant positive effect on a child's adjustment to the health care experience. The report presents concepts, approaches, and challenges in pediatric psychosocial care as well as case studies that illustrate the application of child- and family- friendly pediatric psychosocial care in pediatric healthcare settings in Qatar and elsewhere in the world.

Finally, I would like to thank the project team from DIFI, Dr. Anis Ben Brik, Director of Family Policy, and Ms. Heba Al Fara, Family Policy Officer, for their valuable insights and comments that informed this important report.



**Noor Al Malki Al Jehani**  
**Executive Director**  
**Doha International Family Institute**



## EXECUTIVE SUMMARY

Serious child illness and hospitalization is a major family crisis that can have a lasting negative impact on children and their families. Family separations, changes in familiar routines and environments, exposure to medically necessary but painful and frightening procedures, and fears about how the child's health will affect his or her future are serious and common challenges to family well-being. Around the world, pediatric psychosocial care approaches are increasingly being implemented to promote child and family resilience within medical settings and to optimize quality of life for children affected by chronic health conditions.

This report situates contemporary approaches to pediatric psychosocial care within their historical context, from their beginnings in the early 20th century in response to changes in public and professional perspectives on the effects of hospitalization on child development and emotional well-being. Prominent theories that guide pediatric psychosocial care professionals' work with hospitalized children and their families are reviewed, including those based in cognitive, social learning, attachment, stress and coping, temperament, and family systems traditions. The practical implications of theories are highlighted throughout the discussion.

Concepts and practices central to the work of pediatric psychosocial care professionals are then presented. The nature, value, and use of therapeutic play for hospitalized children are first described, followed by a review of the rationale for psychological preparation and coping interventions and specific strategies for implementation. Consideration of child and family factors in implementing these approaches is emphasized to underscore the importance of viewing the strengths and vulnerabilities of the child within the context of his or her family. Opportunities for family involvement in pediatric psychosocial care are further elaborated in a review of the guiding principles of family-centered care and their application to the provision of psychosocial services for hospitalized children. Common barriers to the implementation of family-centered care in pediatric health care settings are described, to facilitate problem identification and resolution. Finally, we address the unique psychosocial needs of children in critical/end-of-life care together with their families, who face numerous novel and potentially overwhelming experiences. This section highlights sources of stress and appropriate psychosocial care approaches within this context for parents and siblings as well as the ill child.

Next, four case studies illustrating best practices in pediatric psychosocial care are presented and discussed, to provide a bridge between theory/research and practice. The first two case studies are based in Qatar, the third in the United States, and the fourth in India. Each case study begins with a description of a hypothetical patient and his or her presenting concerns, followed by a discussion of the key issues relating to assessment and case conceptualization. Considerations in planning psychosocial care approaches and implementing interventions are then described. Treatment outcomes and discussion of lessons learned conclude each case presentation.

The remainder of this report addresses pediatric psychosocial care and quality of life in Qatar, including the recent recognition of “Child Life Specialist” as a profession and definition of professional standards for practice. The rapidly expanding medical infrastructure in Qatar presents numerous opportunities to adopt best practices and transform into a state-of-the-art healthcare system responsive to the needs of pediatric patients and their families. Recommendations are therefore made for implementing pediatric psychosocial care. To maximize effectiveness, it is recommended that pediatric psychosocial care programs be implemented through a multipronged approach that systematically integrates evidence-based child- and family-friendly practices into multiple pediatric service areas within a particular healthcare organization. Comprehensive education and training programs, changes to the healthcare environment to support psychosocial care practices, financial support for program sustainability, community outreach and involvement, and support for audits and cutting-edge culturally informed research are highlighted as strategies for advancing pediatric psychosocial care in Qatar.

# INTRODUCTION

The World Health Organization (WHO) defines health not merely as the absence of disease or infirmity, but as a state of complete physical, mental and social well-being. Sufficient and nutritious food, clean water, good sanitization, immunizations, and shelter are necessary but not sufficient to sustain health. Four other determinants are also essential to ensure optimal health and development in children:

- protection from harm and neglect
- relationships that nurture healthy social and biological growth
- experiences that foster opportunity and hope
- socially responsive policies that promote community caring and responsiveness to child and family needs.

These universal social determinants contribute to human resilience and positive developmental outcomes throughout the lifespan. This comprehensive conceptualization of health has clear implications for pediatric healthcare professionals, whose work centers on optimizing health and well-being in children.

## CHAPTER ONE: PEDIATRIC PSYCHOSOCIAL CARE

### 1.1. Rationale

Illness and hospitalization constitute a major crisis for children and their families that can have a lasting adverse effect on physical and mental health (Aspesberro, Mangione-Smith, & Zimmerman, 2015; Board & Ryan-Wenger, 2002; Humphreys & LeBlanc, 2016; Manning, Hemingway, & Redsell, 2014; Muranjan, Birajdar, Shah, Sundaraman, & Tullu, 2008; Rennick & Rashotte, 2009; Vessey, 2003). Treatment of childhood illness profoundly alters children's lifestyle. Separation from family members, changes in familiar routines and environments, exposure to medically necessary but painful and frightening procedures, and fears about how the illness will affect the child's future are significant sources of stress that impact the entire family (Coyne, 2006; Oxley, 2015). The primary goal of pediatric psychosocial care is to promote child and family resilience and adaptive responses within the challenging medical context, and optimize quality of life (QoL) as the indicator of resilience in the context of chronic health conditions (Humphreys & LeBlanc, 2016; American Academy of Pediatrics Child Life Council and Committee on Hospital Care & Wilson, 2006; Beickert & Mora, 2017). As such, the work of pediatric psychosocial care professionals addresses a range of issues related to physical and psychological development, health, and illness among children of all ages and their families. Individuals involved in pediatric psychosocial care come from a range of training specialties and backgrounds (e.g., psychology, child life, QoL, social work, and nursing). Regardless of the professional identity of the provider, the work of pediatric psychosocial care should be undertaken with an understanding of the importance of the relationships

among psychological and physical health, and with the goal of protecting the welfare of the developmentally vulnerable child. Consideration of the many contexts within which children are embedded – including their families, hospitals and healthcare systems, schools, peers, community, and culture – is a hallmark of best practice in pediatric psychosocial care.

## 1.2. Historical Foundations

Contemporary approaches to pediatric psychosocial care emerged during the first decades of the 20th century and grew in response to recognition of the damaging effects of hospitalization on children’s development and emotional well-being. At that time it was common practice for hospitalized children to be separated from their families and allowed only limited contact with their parents (e.g., a few hours per week) (Connell & Bradley, 2000; Davies, 2010). Children were typically not given information regarding their illness or medical treatment, the intention being to prevent unnecessary anxiety or distress. Healthcare providers intentionally maintained strict professional boundaries, and their relationships with children were psychologically distant and emotionally disengaged (Davies, 2010; Hunt, 1974). In this environment, infants and young children experienced developmental regressions, excessive fears, and altered behaviors during hospitalization (Jolley, 2007), behaviors that often persisted following their discharge from the hospital. Increased awareness of these negative responses to hospitalization gradually led to changes in the physical environment of the hospital as well as the basic psychological approach to caring for children during their inpatient stays (van der Horst & van der Veer, 2009).

During the 1920s and ’30s, pediatric psychosocial care was delivered through a few hospital play programs located at children’s hospitals within the United States and Canada. These early programs utilized volunteers and hospital staff known as “play ladies” or “play teachers” (Rubin, 1992). At the time, critics viewed play for hospitalized children as unnecessary or even detrimental, based on the belief that if a child must be hospitalized, he or she is too sick to play. Pioneering advocates of hospital play programs, led by Emma Plank, countered that play is an essential activity of childhood and that incorporating play into hospital settings is vital to address the psychological and developmental needs of children during hospitalization (Plank, 1962). As these early play programs grew in number, they slowly transformed the pediatric healthcare experience and drew international attention to the unique needs of hospitalized children. Research published in the 1950s further documented how the care children received in hospital was detrimental to their emotional and psychological well-being (Children in Hospital, 1955; Illingworth & Holt, 1955; Knudson & Natterson, 1960). In 1959, the Platt Report, “**The welfare of children in hospital,**” published by the United Kingdom’s Ministry of Health, concluded that conditions for children in hospitals were in need of significant reform.

The 1960s and ’70s were pivotal decades for the progression and formalization of pediatric psychosocial care. In the United States, the American Academy of Pediatrics (AAP), a widely known and highly regarded pediatric medical professional organization, published a report outlining practices for the care of children in hospitals (American

Academy of Pediatrics Committee on Hospital Care, 1960). This report offered specific recommendations that remain relevant today, such as that all pediatric units should have a playroom supplied with developmentally appropriate games, toys, and books. In the United Kingdom, an organization now known as Action for Sick Children (formerly the National Association for the Welfare of Children in Hospital) was formed with the central mission of advocating for improvement in the psychosocial care of children receiving healthcare. Momentum in the field continued to build throughout the mid-1960s, with conferences organized and attended by pediatric healthcare professionals dedicated to improving psychosocial services for children and families in healthcare settings. In the United States, these professional meetings resulted in the establishment of a multidisciplinary organization nowadays known as the Association for the Care of Children's Health (ACCH, formerly the Association for the Care of Children in Hospitals). The ACCH grew rapidly over the next ten years, and in 1979 produced and ratified a key document, The Child Life Position Statement. This detailed the rationale and core components of child life programs and the professional competencies expected of individuals identifying as child life specialists – providing a much-needed role definition for key players in pediatric psychosocial care.

Attention to providing healthcare that is “in the best interests of the child” was elevated on the global stage in the late 1980s with the adoption of the United Nations Convention on the Rights of the Child (UNCRC) (UN General Assembly, 1989). This comprehensive international human rights document addresses critical issues affecting children's well-being, including education, healthcare, play, family life, communication, and decision-making, with the overarching goal of protecting children and adolescents from stressful life situations, diminishing their suffering, and promoting their full development. The UNCRC has informed the development of several international initiatives aimed at enhancing supportive care for children facing medical stressors together with their families. For example, based upon articles of the UNCRC, the Canadian Institute of Child Health produced a document titled “The Rights of the Child in the Healthcare System” (Canadian Institute of Child Health, 2002). Child Advocacy International's Child-Friendly Healthcare Initiative (CFHI), based in the United Kingdom, is another model project based on the principles of the UNCRC. The objective of the CFHI is to support healthcare professionals to improve pediatric healthcare standards in state hospitals located in poorly resourced countries. Also noteworthy is the Kuwait Association for the Care of Children in Hospital, founded in 1989 to help children and families cope with the stressors of hospitalization.

Today, numerous organizations around the world advocate on behalf of children in healthcare settings, with the goal of building the capacity of individuals and institutions to promote resilience and positive adaptation for families facing child illness and hospitalization, and optimizing quality of life for chronic patients. In North America alone, there are over 400 child life programs in operation. These programs typically provide services to children and youths aged 0-21 years. Similar programs are found in many other countries, including but not limited to the United Kingdom, Australia, New Zealand, South Africa, Japan, Thailand, Mexico, the Philippines, Qatar, Kuwait, Laos, India, and Serbia. In Europe, the European Association for Children in

Hospital (EACH) is the umbrella organization for member associations involved in the welfare of children before, during or after hospitalization. The EACH Charter recognizes and promotes the rights of the child as stipulated in the UNCRC, and in particular the key principle that in all situations the best interests of the child should prevail (art. 3). In addition, the EACH Charter relates to the UNCRC General Comment No. 15 (2013) on the child's right to the enjoyment of the highest attainable standard of health (art. 24), and to the UNCRC General Comment No. 4 (2003) on adolescent health and development. EACH works to enhance the implementation of the EACH Charter in all of Europe.

These programs have had documented positive impacts, including outcomes such as reduced emotional distress in pediatric patients and their families, improved understanding of medical procedures and better coping during procedures, reduced length of hospital stays, less time spent on narcotic medications, and better post-discharge adjustment (American Academy of Pediatrics, 2014). Despite these benefits, significant challenges persist in providing optimal psychosocial care for hospitalized children. Barriers that impact these programs' effectiveness and reach include lack of sustainable program funding, inadequate staff-patient ratios, lack of recognition of the impact of hospitalization on children and families, insufficient staff training and education, and beliefs regarding the care of sick children (e.g., children should not play when ill; children should not be given information about their illness).

### 1.3. Theoretical Foundations

**Overview.** Theory plays a central role in guiding the provision of pediatric psychosocial care services. Professionals draw on theories to guide their interactions with hospitalized children and their families and make sense of their observations and experiences with pediatric patients, and to guide their determination of the appropriate intervention (Turner, 2009). In practice, pediatric psychosocial care is often theoretically eclectic. Case conceptualizations and intervention approaches typically reflect an integration of specific theories, including those from cognitive, social learning, attachment, and family systems traditions. The principal theories guiding contemporary approaches to pediatric psychosocial care are described below.

**Cognitive theories.** Three widely known cognitive theories – Piagetian, information processing, and Vygotskian – guide pediatric psychosocial care practice by helping professionals to understand children's thinking in general, and more specifically to understand how changes in children's thinking can occur. Piagetian theory posits a maturational process of cognitive development in which children develop cognitive skills in a predictable sequence of stages as a result of increasing maturity and exposure to novel experiences (Piaget & Cook, 1952; Piaget, 1936). The child is conceptualized as an active participant in learning, which occurs through his encounters with novel experiences. Information gained from these experiences that fits into the child's existing ways of thinking, or schemas, is assimilated into their knowledge base, whereas information that challenges their existing ways of thinking leads to accommodation and revision of their current ways of thinking (Ginsburg & Opper, 1979). Through these processes, the child's understanding of the world is advanced.

In contrast to Piagetian theory, classic information processing theory emphasizes an ongoing process of learning that focuses on steps involved in solving problems (e.g., encoding, making generalizations, organizing information, constructing strategies) (Atkinson & Shiffrin, 1968; Bransford, 1979; Craik & Lockhart, 1972). As their brains mature children become more efficient at processing information and utilizing goal-directed strategies. However, it is well documented that stress and emotional responses can interfere with effective information processing and memory formation (Yaribeygi, Panahi, Sahraei, Johnston, & Sahebkar, 2017; Schwabe, Joëls, Roozendaal, Wolf, & Oitzl, 2012). This highlights the importance of helping children to process cognitive and sensory information effectively in potentially stressful situations during hospitalization, such as during medical procedures or separations from their caregivers.

Finally, Vygotskian theory highlights the influence of social and cultural context on children's developing knowledge about the world: the cultural context influences what children learn and also how they learn it (Vygotsky, 1978). From this perspective, children's cognitive abilities reflect the integration of where they are in terms of their cognitive development with the demands imposed on them by the social or cultural context in which they are embedded. A concept central to Vygotskian theory with relevance for professionals involved in pediatric psychosocial care is the "zone of proximal development," or ZPD. This refers to the difference between a child's actual developmental capabilities when working alone and their potential capabilities when guided by a supportive partner. "Scaffolding" refers to the use of guidance strategies that provide children with sufficient challenge to advance their capabilities while adapting the environment in ways that promote their learning. Assessing a pediatric patient's ZPD, and then using scaffolding techniques to help the child master coping skills, is a useful application of Vygotskian theory to the practice of pediatric psychosocial care.

**Social learning theory.** In social learning theory, the child is viewed as an active learner whose knowledge about the world is influenced primarily by watching others in his or her immediate environment and the larger context (Bandura, 1977). A key concept in this theory that explains how information is transmitted to affect the child's behavior is observational learning. In pediatric psychosocial care, the process of observational learning is enacted when competent adults model behaviors for children and provide them with information in engaging ways that facilitate their retention of the information. Children are then given opportunities to imitate and practice the targeted behaviors, with the adult model providing positive reinforcement when the child demonstrates the desired behaviors. Effective use of modeling and observational learning with hospitalized children helps them to master coping skills and gain confidence in their coping abilities.

**Attachment theory.** Attachment theory is relevant to pediatric psychosocial care because it addresses the key role of the parent-child relationship relative to the emotional well-being of the hospitalized child (van der Horst & van der Veer, 2009). Formation of a secure attachment pattern is a critical milestone of early development that provides the foundation for positive psychological and health-related outcomes throughout the lifespan (Sroufe, 2005; Puig, Englund, Simpson, & Collins, 2013).

Attachment patterns develop within the context of young children's interactions with their primary caregivers (Ainsworth, Blehar, Waters, & Wall, 1978). Caregivers who are available to their children and provide consistent, appropriate, and sensitive responses to children's emotions and behaviors facilitate the development of a secure attachment relationship. In contrast, an insecure attachment relationship is likely to develop when there is a disruption in the communication between infants and their caregivers, characterized by inconsistent or nonresponsive interactions and caregiver unavailability. Consistency, comfort, and predictability are desirable features in pediatric healthcare settings. They are also essential to sustain a secure attachment relationship between the parent and the child during hospitalization. Attachment theory provides a useful framework for understanding both family and child responses to stressful healthcare experiences and for guiding care practices. Regarding the latter, supportive interventions for hospitalized children should strive to facilitate children's sense of protection and safety, while maintaining proximity between the child and their primary attachment figure.

**Temperament theory.** Temperament theory also provides a useful lens through which to understand individual differences in children's reactions to healthcare stressors and experiences (McLeod & McGlowry, 1990). Temperament traits, defined as constitutionally based individual differences in reactivity and self-regulation, influence how children respond to their environments (Goldsmith, Buss, Plomin, et al., 1987; Rothbart, Ahadi, & Evans, 2000; Derryberry & Rothbart, 1997; Chess & Thomas, 1984). Temperament has been found to be a consistent predictor of children's responses during and after hospitalization. In general, children who score higher on the temperamental traits of positive emotionality, predictability, and approachability/adaptability, and lower on reactivity, tend to respond better to healthcare experiences than those of their peers who are rated by their parents as more passive, emotionally reactive, and temperamentally difficult. One goal for professionals involved in pediatric psychosocial care is to provide a supportive environment that best matches the child's needs with the requirements of the healthcare setting (i.e., maximizes "goodness of fit") (McClowry, Rodriguez, & Koslowitz, 2008). Some children are temperamentally "easy", meaning that they are adaptable and generally have a positive mood. Anxiety in these children may best be dealt with by providing advance planning and preparation. In contrast, the temperamentally "difficult" child, who is characterized as demanding, highly active, and expressing more negative emotions in response to the environment, may benefit from interventions aimed at enhancing the child's sense of having choices and control over his circumstances. Finally, for "slow to warm" children, being allowed extra time to adjust to novel situations is often effective in preventing them from becoming overwhelmed and withdrawn.

**Stress and coping.** Stress and coping theories focus on the individual viewpoint or appraisal of a stressful situation, with the presumption that a child's coping responses may look different depending on the situation at hand. A classic definition of coping describes it as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984). Stress and coping theory is commonly utilized in the practice of pediatric psychosocial and quality of life care to

assess children's coping styles and implement interventions that are tailored to the child's preferred ways of coping. Coping style is determined by the child's cognitive, affective, and behavioral responses to stress, and indicates their general approach to dealing with stressors. One consideration in identifying children's coping styles is their use of emotion-focused coping versus problem-focused coping. Emotion-based coping strategies aim to modify the emotional response to a stressor, and include techniques such as reappraisal or tension release. In contrast, problem-based strategies are enacted to change the situation or solve the presenting problem. Another consideration is children's preferred approach to novel stressors. When confronted with a stressor, children tend to be either information-avoidant ("blunters") or information-seeking ("monitors"). Those who are information-avoidant tend to deny their worries and fears, avoid thinking or learning about an upcoming stressful event, and detach from stressful stimuli. In contrast, information seekers are most comfortable when they actively seek out information related to the stressor and are highly focused on the stressor. Pediatric psychosocial care professionals should help the child to have an accurate understanding of a presenting stressor and how to evaluate it. They should then support the child's use of coping strategies that fit the situation and his or her preferred coping style.

**Systems theories.** It is critically important to recognize the complex interactions among the child, the family, and the environment in order to develop effective interventions in pediatric medical settings. Systems theories offer a framework for understanding how a child's response to hospitalization may be impacted by family factors as well as more distal influences, such as schools, neighborhoods, and culture. Two systems theories in particular have been applied to guide practice with children and families in the context of hospitalization. First, family systems theory considers the child's behavior and development to be highly dependent upon the functioning of the family as a whole (Bowen, 1966). In the complex family system, change in the behavior of one family member is theorized to lead to change in all other members of the family. Families are believed to have great capacity for change, although changes in individual family members' behaviors or attitudes often occur for the purpose of sustaining balance, or homeostasis, in the family system (Tharp & Otis, 1966). Thus, change may not always be associated with positive outcomes.

The family is also viewed as a key influence on the child in Bronfenbrenner's ecological theory (Bronfenbrenner, 1979, 1977). Here the child is conceptualized as existing at the center of a series of overlapping circles that represent various domains of influence ranging from immediate or proximal influences (e.g., family, school, hospital) to more distal influences (e.g., community, culture/society). Interactions within and across various contexts over time jointly impact children's development and well-being.

Systems theories have clear implications for pediatric psychosocial care. The child's medical condition can be a major source of stress for the entire family, and often results in adjustments to the usual parenting role. A common initial family response to child illness is disbelief (especially when the onset is sudden and serious in nature), followed by feelings of anger and guilt. The family's response is an important consideration because it affects their ability to provide physical and emotional support to their hospitalized child. Assessment of parental well-being and family

functioning can help to inform treatment planning. For example, although parental stress and anxiety are normal reactions to a child's illness and hospitalization, high levels of parental anxiety can have an adverse effect on the child's coping (Brown, De Young, Kimble, & Kenardy, 2018). Studies have shown that children of highly anxious mothers demonstrate more emotional distress during invasive procedures, as well as more negative behaviors such as aggression and hyperactivity. In contrast, parents who display low anxiety are better able to serve as a calming presence for their child during stressful procedures. These findings underscore the importance of providing adequate family support and family-centered care (discussed later in this publication) in pediatric psychosocial care.

# CHAPTER TWO: CHILD- AND FAMILY-FRIENDLY SUPPORTIVE PSYCHOSOCIAL SERVICES

## 2.1. Therapeutic Play

**Overview.** Play serves an important function in child development and is recognized in Article 31 of the UNCRC as a universal right for every child, regardless of gender, culture, or circumstance. Play has been described as “the work of children” (Montessori, 1973). Play is an essential activity for children that underlies good health and adaptation to changing environments, provides a mechanism for psychological coping with stress, and promotes the development of social skills that facilitate success later in life (Ginsburg, 2007; Pellegrini, 2010). Professionals who routinely work with children appreciate the power of children’s play for their development as human beings; nonetheless, play is often viewed as inappropriate or unnecessary in traumatic or stressful circumstances. This viewpoint is contrary to the vast literature highlighting the benefits of play for children, particularly in times of stress and trauma. Indeed, appreciating the purpose and benefits of children’s play especially in times of challenge is essential. Leveraging children’s play to help them successfully manage stress is the foundation of pediatric psychosocial care and is an essential tool to promote flourishing in the face of adversity (Koukourikos, Tzaha, Pantelidou, & Tsaloglidou, 2015).

**Purpose of play.** Play can serve several different functions for children. One basic function is that of recreation and enjoyment. Children are intrinsically motivated to play because it is a pleasurable activity for them. Play for enjoyment is a child-directed activity that involves attention to the means (i.e., process) rather than as a means to an end (i.e., goal-directed) (Hughes, 2010). Children’s play activities are self-imposed, flexible (e.g., rules are created and changed at the child’s whim), and self-satisfying. Recreational play is often symbolic, allowing children to transform their present realities into make-believe situations and interactions that reflect their unconscious desires and feelings. Children engaged in play typically appear focused, enthusiastic, and joyful. This type of play “belongs” to the child. As such, adults should not interfere with or attempt to manipulate the child’s play activities.

A second purpose of children’s play is learning and development. Play looks somewhat different at each stage of development due to the child’s developmental competencies and their goals. For example, during the first two years of life the central goal of play is exploration (Tait, 2017). Infants’ and toddlers’ play activities help to expand their knowledge of the world through seeing, touching, and physically manipulating objects. As children develop their play becomes more complex, goal-directed, and socially interactive (Hughes, 2010). Pretend play (i.e., dramatic play) emerges in preschool years. With advances in language development and cognitive abilities, preschoolers begin to incorporate more complex symbolic themes into their play. As symbolic play become more sophisticated, enacted themes begin to represent the child’s inner fantasy world. Consequently, play becomes a powerful tool to help them recreate and control real-life experiences, allowing them to effectively process

overwhelming past events in ways that are more manageable (Gleason, 2017). For school-aged children, play activities provide a mechanism for developing their unique talents, skills, and abilities, and demonstrating to themselves and others that they are competent. Children have a natural tendency to play with materials in ways that have meaning in their lives. Thus, through play children can learn and hone their problem-solving skills, building a sense of control over challenges they encounter. During adolescence, play serves as a mechanism for developing more sophisticated skills in preparation for adulthood. Adolescents in particular also value the social and peer relational aspects of play. It is in these interactions that they gain self-awareness and practice interpersonal skills that prepare them for adulthood.

A third purpose of play with particular relevance for pediatric psychosocial care is play as therapy. When used as a therapeutic tool, play allows children to express unwelcome and scary feelings, or thoughts that may be socially unacceptable, without negative consequences (e.g., parental disapproval) (Lin & Bratton, 2015). As such, observing children's play can yield insight into their unexpressed worries, desires, and psychological conflicts. In turn, this knowledge can be utilized to develop interventions that address specific identified needs (Kool & Lawver, 2017). For therapeutic play to be effective, the professional must establish an environment in which the child feels accepted unconditionally. Such an environment is fostered when the professional conveys feelings of warmth towards the child and acknowledges the child's feelings, both positive and negative. Further, the child must be allowed control and decision-making authority over the play that is enacted. Generally, using play as a therapeutic tool is guided by three main goals:

- To establish contact with the child
- To observe and collect data about the child
- To interpret behaviors and inform future interventions (Jessee & Gaynard, 2008)

In addition to the purposes of play described above, play serves another critical function for hospitalized children – as a “place” of comfort and normalization in times of distress. It is human nature to seek comfort and safety, and this instinct is greatest when we experience distress. The places and activities that comfort individuals are diverse, and reflect personal preferences built on prior experiences. For children, play represents a place that is easily accessible, familiar, and associated with positive feelings. As such, play is an ideal context for psychological healing and activity to promote children's well-being and improved quality of life in healthcare contexts (Koukourikos, Tzaha, Pantelidou, & Tsaloglidou, 2015). Play has both intrapersonal and interpersonal functions for children. During play, children reconnect with themselves in a familiar and pleasurable activity. Through play activities, they explore their emotions, resolve inner conflicts, and build their understanding of themselves and their environments without adult interference. Play is also action-oriented. Children actively engaged in play are occupied both physically and mentally, which prevents intrusive thoughts from entering their consciousness and causing distress. Play gives children control. Heightened perceptions of control can reduce the child's feelings of being overwhelmed by frightening events.

Comfort play also has interpersonal aspects. Engaged in social play, children connect emotionally with others and establish relationships as places of comfort. Establishing a play-based relationship with a child can be an effective means of helping the child to identify individuals who are available to serve as “places” of comfort in times of stress. The child-professional play relationship is so important that it has been identified as a critical component of intervention in pediatric psychosocial care (American Academy of Pediatrics, 2014; Koller, 2008). A positive relationship often allows children to generalize the safety of the play relationship to other relationships, expanding the availability of safe “places” in their environment and adding the play subjects (e.g., peers, facilitators) to their catalogue of normal life.

A final purpose of play is that of promoting hope and resilience. The importance of promoting hope and resilience is embedded in the field of positive psychology, where the ability of some individuals who have experienced traumatic and dangerous life circumstances to continue to thrive and achieve positive outcomes is well documented (Folkman, 1997; Folkman & Moskowitz, 2000). Among the internal and external characteristics found to promote flourishing in the face of adversity is hope (i.e., a positive outlook on the future or a belief that things will work out in the end despite unfavorable odds). Intervention research in positive psychology demonstrates that resilience-promoting individual characteristics and attitudes can be learned and impact individuals’ well-being (Bolier, Haverman, Westerhof, Riper, Smit, & Bohlmeijer, 2013). In working with children, play provides a useful context for helping children to maintain hope and resilience (Humphreys & LeBlanc, 2016). Just as adults often fantasize about hopeful and positive events, children’s fantasy play can also be leveraged to sustain children’s hope and effort in the face of medical stressors and illness. Facilitating children’s engagement in socio-dramatic play reflecting positive future-oriented themes can enhance their quality of life, promote the use of creative problem-solving skills, foster adaptability, and reduce negative emotions and fatigue.

**Play in healthcare settings.** Opportunities to engage children in play for all of the purposes described above abound within the hospital. Frightening and painful experiences are commonplace when children are ill and hospitalized; play can therefore be a useful tool for helping children to release tension and manage their emotional reactions to stressful medical experiences. Play can also be used effectively to promote children’s understanding of what is happening to them and to help them master coping skills. With learning as the goal, the pediatric psychosocial care professional assumes the role of teacher, exposing children to new information in developmentally appropriate and non-threatening ways, and then providing guided play opportunities to facilitate internalization of the novel information. Finally, engaging children in play during their hospitalization is beneficial for the entire family. Watching their child immersed in play, and playing with the child, brings comfort and a sense of normality to parents (Hagstrom, 2017). As such, allowing children to play

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in the hospital can benefit the well-being of the parents, who bear a tremendous emotional burden in the context of serious child illness. Unaddressed, this stress can exacerbate existing marital problems, or contribute to the development of marital problems, as couples strive to manage their own strong emotions while meeting the emotional and support needs of their family members.

Play in the hospital should be adapted to address the unique needs of each patient based on his or her developmental level, interests, illness and treatment considerations, and psychosocial vulnerabilities (American Academy of Pediatrics, 2014). Play can occur in various settings within the hospital, including at the bedside and in clinics, waiting rooms, and dedicated playrooms. Although there is a paucity of methodologically rigorous published empirical studies examining the effectiveness of play with hospitalized children, the available evidence indicates that play has beneficial effects for children and their families in pediatric healthcare contexts (Moore & Russ, 2006). The most common outcome assessed in these studies is children's emotional responses. Overall, findings indicate that offering children therapeutic play with a medical theme reduces anxiety (Brewer, Gleditsch, Syblik, Tietjens, & Vacik, 2006; Li & Lopez, 2008; Bloch & Toker, 2008; Tsai, Tsai, Yen, et al., 2013). and negative emotions (Li, Chung, Ho, & Kwok, 2016). Studies examining the effects of play-based procedural preparation have found that children who receive a play intervention are calmer and demonstrate fewer negative responses during actual medical procedures (Zahr, 1998; Hatava, Olsson, & Lagerkranser, 2000). Evidence suggests that the beneficial effects of play interventions extend to the parents. For example, in one study parents of children who received a play intervention reported decreased anxiety and increased satisfaction with care (Li & Lopez, 2008). Finally, play appears to offer additional benefits relevant to patient care and institutional considerations. Specifically, play-based procedural preparation has been shown to decrease the use of daily sedation during radiation therapy in children with central nervous system tumors, leading to significantly reduced healthcare costs (Grissom, Boles, Bailey, et al., 2016).

## 2.2. Psychological Preparation and Coping

**Overview.** Although the hospital may be a familiar context for the professionals who have dedicated their careers to caring for sick children, from the child's perspective a hospital is generally experienced as a new and scary place. In this environment, children are exposed almost daily to stressors that pose a risk to their emotional well-being. The importance of preparing children to deal with hospitalization-related stressors, such as medical procedures, has long been recognized in the fields of child life and pediatric psychology. Psychological preparation involves informing the child and family about what they can expect during the procedure, and teaching coping strategies that can be used to reduce the child's distress.

**Consideration of child and family variables in designing and implementing psychological preparation and coping interventions.** Each child and family brings a unique set of strengths and potential vulnerabilities to the hospital. Assessing these individual strengths and vulnerabilities can help professionals involved in pediatric

psychosocial care to pinpoint specific “stress points” for each patient, develop appropriate interventions, and prioritize care. Children’s responses to stressors present in the healthcare setting may be influenced by a variety of factors discussed previously, including developmental stage and needs, cognitive abilities, temperament/personality, and coping style and strategies (see preceding discussion of Theoretical Foundations). Another important factor to consider with relevance to the planning of preparation and coping interventions is children’s prior experiences with hospitalization. Although previous medical experiences may decrease children’s anxiety surrounding hospitalization, what seems to

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be most important in this regard is whether children experienced their previous hospitalizations as positive or negative. Compared with children who have had prior negative experiences with hospitalization, children with positive prior experiences tend to report less anxiety in response to hospitalization. Illness variables (e.g., diagnosis, treatment type and length) are also important to consider because they impact the length of hospitalization, frequency of repeat admissions, exposure to invasive procedures, experience of physical side effects, and functional limitations (e.g., mobility). It is equally important to consider adjustments to family dynamics, which are often disrupted by the process of the child’s hospitalization. It is vital to take account of this variable in preparing the child’s family unit to cope, readjust and recover the normal quality of their family life as far as possible in the circumstances.

**Preparation and coping approaches.** Psychological preparation interventions can occur at different times and in various contexts during the child’s hospitalization experience. These interventions can also involve parents if they are present. For children of single parents who are not able to maintain a consistent presence with the child, other adults with whom the child has established a trusting relationship can be involved in preparation activities. (Note: consideration of single parenthood in relation to pediatric psychosocial care for hospitalized children is further discussed in Case Study 3). Interventions that are initiated at first knowledge of an impending event constitute advance preparation. Advance preparation is undertaken with three objectives:

- To familiarize the child with the impending event
- To provide a forum for the active rehearsal of coping strategies
- To help the child appraise the situation as manageable (American Academy of Pediatrics, 2014; Sale, Burgmeier, & Schmidt, 1988; Dalley & McMurtry, 2016; Boles, 2016).

Research suggests that advance preparation is most effective when it provides both procedural and sensory information and implements cognitive-behavioral approaches to influence children’s coping skills and appraisals (Tak & van Bon, 2006; Alcock, Feldman, Goodman, McGrath, & Park, 1985). Thus, advance preparation

activities should familiarize the child with the expected sights, sounds, smells, tastes, and/or sensations that he or she will experience. The real-life procedure should be approximated as accurately as possible because this will help the child to cope more effectively later during the actual procedure. During advance preparation, children are coached in the use of coping skills (e.g., breathing, relaxation, reframing, distraction) and given the opportunity to practice these skills. For highly anxious children, advance preparation activities may also include systematic desensitization. Using this approach, the child is encouraged to maintain adaptive coping behaviors as he or she is exposed to stimuli that progressively approximate the actual procedure (e.g., equipment or locations such as the MRI or surgical unit).

Preparation and coping approaches can also occur during the child's medical procedure. Here, the focus for pediatric psychosocial care professionals is on providing the child with emotional support and assisting them with the use of coping strategies. A wide range of techniques can be used to lower pain and distress in children during medical procedures, including distraction, relaxation, guided imagery (i.e., helping the child to envision in detail an image or place that is comforting), sensory focusing, deep or patterned breathing, positive reinforcement of desirable behaviors, thought stopping (i.e., encouraging positive self-talk to limit negative thoughts and promote self-control), modeling, and coaching to promote the use of coping strategies (especially helpful for younger children) (Cohen, 2008; Kuppenheimer & Brown, 2002). Among these techniques, the strongest research support is for the use of distraction (i.e., conscious choice of an alternative focus) (Chambers, Taddio, Uman, McMurtry, & HELPinKIDS Team, 2009; Birnie, Noel, Parker, et al., 2014; Flowers & Birnie, 2015). Selection of a specific distraction technique should be guided by the child, based on what they believe will be most effective in shifting their focus away from the stressors. For example, younger children may prefer being read a favorite picture book by their parent, whereas older children may prefer to watch a favorite television show on a handheld electronic device. Having a child perform a cognitive task, such as reciting the alphabet, counting backwards, or spelling words from a vocabulary list, can also be effective distraction activities.

In addition to these cognitive-behavioral approaches, sensory interventions may also facilitate children's coping during medical procedures. One easily implemented and effective sensory technique is comfort positioning, a research-based approach to reduce stress and anxiety and manage pain for children during medical procedures (Krauss, Calligaris, Green, & Barbi, 2016). Comfort positioning is implemented during procedures by having the child held by the parent, ideally in the parent's lap and facing her or him (Cohen, 2008; Cavender, Goff, Hollon, & Guzzetta, 2004). For young infants, swaddling in a blanket may enhance the feeling of physical security. Other sensory approaches that may be useful during procedures include soothing touch massage, movement (e.g., rocking or patting the child), thermal regulation (e.g., using hot packs, heating pads, cold packs, ice, or cool cloths), and playing music the child finds soothing.

Preparation and coping interventions should also take place after the medical event. Post-procedural work with the child and family is based on the premise that past experiences serve as psychological preparation for the present and future. Helping the child and family to process what happened is important to "prepare a memory" that

will facilitate the child's adaptive coping when similar situations are encountered in the future. Thus, it is useful to learn from the child and family their perceptions of what helped the child cope, what made it hard for the child, and what they believe might make this procedure or similar ones go more easily in the future. In this discussion, engaging the family in reframing (i.e., rethinking past experiences in a new light to highlight actions the child took that may have been helpful) is one strategy to position the child and family for success in coping with future medical events. Post-procedural evaluation is recommended regardless of whether the medical procedure has been conducted following careful advance preparation or occurred without advance notice in response to a sudden crisis.

**Tools that facilitate preparation and coping.** A variety of props and other materials can assist the pediatric psychosocial care professional in their psychological preparation and coping work with children (Jaaniste, Hayes, & Von Baeyer, 2007). Dolls and puppets are commonly used in these activities. Plastic dolls with anatomically accurate features are useful for many preparation activities, especially with toddlers and preschoolers. For older children, cloth dolls are helpful in preparing children for medical procedures because they can be placed in the positions that the child may need to assume for the procedure. In addition, cloth dolls allow for the use of real needles. Allowing children to keep and personalize their own cloth dolls has important benefits. One is that having individual dolls that are not shared between patients reduces the spread of infectious diseases. Another benefit is that the child will have more opportunities to engage in continued practice of medical procedures, which facilitates their sense of mastery over the procedure, decreases their stress, and increases their self-confidence in their ability to cope with the practiced procedure. Dolls can also be used as puppets to help guide children to use new coping strategies. Verbalizing their thoughts and fears through puppets is emotionally safer for some children than expressing them directly. Thus, observing children in puppet play can provide useful information to guide future interventions.

In addition to dolls, real or toy medical equipment is a useful tool for facilitating procedural preparation and coping. The use of real medical supplies and equipment is recommended because it is the most effective way for children to become familiar with an upcoming procedure. Equipment chosen should be in proportion to the child's medical doll, if one is being used, as this empowers the child and raises her self-efficacy. For children who are frightened of real equipment, commercial toy equipment can be used to help them prepare for the impending procedure. The overarching goals remain the same, regardless of whether real or facsimile equipment is used – to transform an unfamiliar medical event into a predictable one, and to plan and allow children to practice their coping strategies.

Finally, visual materials can be helpful tools for psychological preparation and coping activities with families. Carefully selected photographs and videos give children and their families insight into unfamiliar medical experiences. Goldberger and colleagues (Goldberger, Mohl, & Thompson, 2009) highlight the following important considerations for pediatric psychosocial care professionals in using photographs and videos as training tools: 1) the amount of detail that is appropriate to show, so as to not overwhelm the child; 2) the privacy of the child in the photo/video and similarity

to the patient; 3) that the emotional responses of patients and staff depicted in the visual material are appropriate; 4) how closely the details in the photo or video mirror what the child will experience; and 5) how to present the visual material and use it to achieve the goals of psychological preparation and coping (i.e., familiarization, active rehearsal, facilitating positive appraisals).

### 2.3. Family Support/Family-Centered Care

**Background.** The concept of family-centered care was developed in Britain following publication of the Platt Report, which drew on seminal attachment research to create awareness that separation of the family from the hospitalized child was detrimental to the well-being of both child and family (Davies, 2010; van der Horst & van der Veer, 2009). As the family was increasingly acknowledged as being critically important in the emotional, developmental, and medical care of the hospitalized child, family-centered care emerged as way of including parents during pediatric hospitalization and medical encounters (Jolley & Shields, 2009). Family-centered care in the pediatric setting is intended to address the needs of the whole family, not just the identified patient, to improve patient outcomes. Since its inception, family-centered care has been formalized into many international, national and local government policies and is embraced by professional organizations that provide healthcare for children and families (American Academy of Pediatrics, 2003).

**Family-centered care in the pediatric setting is intended to address the needs of the whole family, not just the identified patient, to improve patient outcomes**

**Guiding principles.** Family-centered care (FCC) is an approach to healthcare that seeks to establish and maintain mutually beneficial partnerships among patients, families, and healthcare professionals (Pettoello-Mantovani, Campanozzi, Maiuri, & Giardino, 2009; Richards, Starks, O'Connor, & Doorenbos, 2017). These partnerships are viewed as integral to the care and support of individual children and their families. Although a consensus definition of FCC practices is lacking, there is agreement on the core principles of family-centered care (Kuo, Houtrow, Arango, Kuhlthau, Simmons, & Neff, 2012):

- **Information-sharing.** The exchange of information is open, objective, and unbiased.
- **Respect and honoring differences.** The working relationship is marked by respect for diversity, cultural and linguistic traditions, and care preferences.
- **Partnership and collaboration.** Medically appropriate decisions that best fit the needs, strengths, values, and abilities of all involved are made together by the involved parties, including families at the level they choose.
- **Negotiation.** The desired outcomes of medical care plans are flexible and not absolute.
- **Care in the context of family and community.** Direct medical care and decision-making reflect the child within the context of his/her family, home, school, daily activities, and quality of life within the community.

**Applications.** The guiding principles of family-centered care have informed four main areas of contemporary pediatric hospital practice (Meert, Clark, & Eggly, 2013; American Academy of Pediatrics, 2012). Unrestricted family visitation policies, exemplified by 24-hour open visitation access, are consistent with family-centered care. Studies indicate that parents typically want to be close to their hospitalized child, want to be kept informed regarding their child’s health and plan of care, and want to participate in caregiving tasks for their hospitalized child (Corlett & Twycross, 2006). Thus, even in circumstances where the child has complex health needs that must be attended to by healthcare professionals, allowing parents to be present and involved serves important caregiving needs for both the parent and the child. Family-centered rounding occurs when attending physician rounds, case presentations, and discussions occur at the bedside of the hospitalized child and in the presence of his or her parents (Mittal, 2014; Subramony, Hametz, & Balmer, 2014). During rounds, parents are given opportunities to ask and answer questions, and to clarify information and misunderstandings related to the child’s condition or care plan. Parents are also encouraged to participate in medical decision-making for their child. Another illustration of family-centered care relating to parental presence is the practice of allowing parents to be present during child cardiopulmonary resuscitation and invasive procedures, including those occurring in emergency departments and critical care units. It is generally recommended that hospital policies relating to parental presence in these circumstances should:

- Define “family member” (i.e., who can and who cannot be present)
- Specify the procedures for which family member presence is allowable, and those from which parents are to be excluded
- Identify the individuals who will facilitate the family’s presence before, during, and after the procedure(s)
- Determine how any disagreements will be resolved
- Specify how the healthcare team will be supported and safety maintained (Henderson & Knapp, 2006; Oczkowski, Mazzetti, Cupido, Fox-Robichaud, & Canadian Critical Care Society, 2015).

Family conferences, or planned meetings between family members and members of the child’s healthcare team, are used to share information and engage the family in the process of shared decision-making and treatment planning. During family conferences, information regarding diagnosis/prognosis and available treatment options is exchanged among all individuals present, with the goal of developing a care plan that reflects the preferences of the patient and family. Family conferences play a critically important role in every phase of end-of-life decision making (Suttle, Jenkins, & Tamburro, 2017).

**Benefits.** The study of family-centered care outcomes has explored diverse perspectives, ranging from the individual patient to the broader healthcare system. A caveat to this research is that most studies have been conducted in countries with well-established healthcare systems; consequently, the extent to which these benefits apply more generally is unclear (Foster, Whitehead, & Maybee, 2010).

Research investigating patient and parent perspectives generally supports the benefits of family-centered care practices in pediatric healthcare settings, including critical care environments (Hill, Knafl, & Santacroce, 2017; Kuo, Bird, & Tilford, 2011). The preponderance of evidence indicates that parental presence and involvement in children's care is associated with positive outcomes for both child and family. For example, parental involvement in children's specific healthcare experiences, such as being present with the child during medical procedures, is associated with reduced child anxiety and better coping, and is viewed favorably by parents. This is true even in emergency care settings and during child resuscitation, where parents report finding comfort in being with their child and appreciating the opportunity to understand what is happening and to advocate for their child (O'Connell, Fritzeen, Guzzetta, et al., 2017; McAlvin & Carew-Lyons, 2014). Other studies, focused more broadly on parental presence, have shown that when there is accommodation for parents to stay with their child during hospitalization (e.g., in the child's room or in a nearby housing facility) parents report reduced distress and greater satisfaction with the healthcare experience (Franck, Gay, & Rubin, 2013). Positive impacts have also been reported with respect to shared medical decision-making and family-centered pediatric rounds. Research on these family-centered care practices finds that parents appreciate the opportunity to express their preferences regarding their child's care and that patients may experience medical benefits, such as improved medical and neurobehavioral outcomes, and requiring fewer and/or less intensive tests or treatments (Aronson, Shapiro, Niccolai, & Fraenkel, 2018; Yu, Hsieh, Hsu, et al., 2017; Rea, Rao, Hill, Saylor, & Cousino, 2018).

Although scant, there is evidence to suggest that a family-centered care approach has a positive impact for healthcare providers too, despite the challenges of implementing family-centered care practices in some hospital settings (Coats, Bourget, Starks, et al., 2018; Gupta, Perkins, Hascall, Shelak, Demirel, & Buchholz, 2017). Physicians who implement family-centered care in their practice report stronger and more positive relationships with their patients' families (Holm, Patterson, & Gurney, 2003). Family-centered care practices have also been found to enhance the learning environment and serve an educational function for health professionals in training (Hanson & Randall, 2007). For example, in one recent study medical residents reported that family-centered rounds enhanced their education by increasing patient encounters and improving their physical exam skills, allowing for direct observation and real-time feedback, and for better communication with families (Mittal, Krieger, Lee, et al., 2013). Family-centered care also fosters staff satisfaction. Nurses endorse positive perceptions of family-centered care, especially higher satisfaction with rounds when families are present (Rosen, Stenger, Bochkoris, Hannon, & Kwoh, 2009; Rappaport, Ketterer, Nilforoshan, & Sharif, 2012). In another study, spanning many years, parent participation in children's post-anesthesia care was consistently rated as rewarding for nurses (Fina, Lopas, Stagnone, & Santucci, 1997). Other studies have found that family-centered care is associated with more positive attitudes regarding the work environment and higher job satisfaction (Hemmelgarn, Glisson, & Dukes, 2001). Long-term positive consequences of staff satisfaction may be reduced job turnover and better job performance, which lower overall costs for the healthcare system.

Emerging evidence suggests that implementing family-centered care can indeed help to reduce healthcare costs – a central concern for hospitals and other healthcare institutions, as well as the broader healthcare system. Cost reductions are realized through decreased resource utilization, including fewer patient visits to clinics and emergency departments, shorter hospital stays, and less frequent readmissions for inpatient hospital care. Much of the research evidence for these cost savings comes from evaluations of the effects of family-centered care programs implemented in neonatal intensive care units, where reductions in the length of inpatient stays and number of hospitalizations contribute to significantly reduced expenditure (Forsythe, 1998). Improved patient and family satisfaction as a result of family-centered care is an important outcome from an institutional perspective too; it is especially critical for private hospitals, which may be publicly ranked on this outcome and experience decreased revenue if families opt to seek care for the child elsewhere. Moreover, from a risk management perspective, families who are satisfied with their care are less likely to initiate malpractice claims against physicians and hospitals where care was received (Beckman, Markakis, Suchman, & Frankel, 1994). Other benefits of family-centered care practices, such as decreased communication problems and misunderstandings, may also reduce the risk of lawsuits (Johnson, Ford, & Abraham, 2010; Levinson, (1997).

**Performance standards.** In 1992, the Institute for Patient- and Family-Centered Care (IPFCC) was established in the United States to advance both the understanding and the practice of patient- and family-centered care. In partnership with the Association for the Care of Children’s Health, the IPFCC proposed nine elements that characterize family-centered healthcare services. From these nine elements, Trivette and colleagues (Trivette, Dunst, Allen, & Wall, 1993) elaborated a set of performance standards that specify concrete strategies to assist pediatric psychosocial care professionals in translating family-centered care principles into practice. These elements and associated performance standards have been described in detail elsewhere (Foster, Whitehead, & Maybee, 2015) and are summarized in Table 1, along with examples of potential challenges to implementation.

Table 1. Summary of family-centered care elements and performance standards

Family-Centered Care Element	Performance Standard/Translation to Practice	Challenges to Implementation
Recognize that the family is the constant in the child's life, while healthcare professionals and service systems often change.	Pediatric psychosocial care professionals should ask the child and family on a daily basis to identify their concerns, questions, and priorities for psychosocial support. Conversations should seek information regarding the child/family's assessment of their current care plan and support needs. Families should be asked how they would like to be included in their child's care, with the goal of meeting their wishes.	Parental absence or limited presence; parent and provider role expectations regarding family input into clinical decision-making
Facilitate collaboration between family members and healthcare providers at all levels of healthcare.	Nurture mutual respect for skills, knowledge, and care of the pediatric patient between the family and treatment team. Support partnerships that include families in defining daily care plans, service delivery, and evaluation of interventions. Be proactive in seeking opportunities to engage pediatric patients and their family members in planning and evaluating programs, services, and the general environment to help meet their needs.	Providers are hesitant to involve parents; providers lack training in effective healthcare communication with families; applications of FCC, such as family-centered rounds and family conferences, do not occur.
Honor the racial, ethnic, cultural, and socioeconomic diversity of families.	Maintain self-awareness of personal values, biases, and beliefs that may influence interactions with patients and their families and adversely affect patient care. To the extent possible, acknowledge and honor diverse family values, customs, and experiences. Discuss with the family their preferred systems and spiritual resources very early in the hospitalization, and include language interpreters or cultural consultants if deemed useful.	Cultural values and beliefs regarding identity; racial/ethnic differences and language discordance
Share complete and unbiased information with the child's family on a continuing basis and in a supportive manner.	On a recurring basis, ask the patient and family to share their understanding of the patient's condition and treatment plan, remembering that patients and families wish to receive information in different ways (e.g., verbally or in writing, privately and individually or as a group). Provide information using language that conveys respect for the patient and all family members and empowers them to seek additional information.	Parental absence; hospital policies that do not support providers' efforts to establish partnerships; beliefs that families should not know everything about the child's condition
Implement comprehensive policies and programs that provide emotional and financial support to meet family needs.	Collaborate with the family and maintain communication to encourage the family to express their emotional, educational, spiritual, and financial needs. Help them to know what resources are available to them in the hospital. Solicit family requests and recommendations for improvements and follow these up with the family (even when they cannot be addressed to the family's satisfaction) to ensure the family feels heard. Value, respect, and facilitate private time for families.	Parental absence; lack of staff resources to support programs; hospital infrastructure not designed to provide family support; families not viewed as central to the child's health outcomes or treatment
Recognize individual family strengths and respect various methods of coping.	Avoid making assumptions regarding what would be most useful for the family. Respect the family's coping style and encourage use of the usual forms of coping as well as new strategies. In conducting assessments, practice a strengths-based approach that seeks to identify positive characteristics that can be leveraged to help the family, rather than deficits.	Parental absence; healthcare providers' lack of experience with emotional and behavioral aspects of treatment or hospitalization
Understand and incorporate the developmental needs of infants, children, adolescents, and their families into the healthcare system.	Have a strong foundation in human development to help recognize children's developmental risks and needs for support, and provide interventions that foster optimal development. Incorporate families' perceptions regarding their children's developmental needs and strengths, and address their priorities and ideas on how interventions to foster developmental outcomes should be included in treatment plans. When the child's medical circumstances result in altered developmental status, parents should be helped to anticipate new educational needs and access available opportunities to support their child. Work with families to identify and address sibling needs, with the goal of minimizing any negative effects of the hospitalization on their adjustment.	Parents and siblings not present or considered central to the pediatric patient's health and well-being; lack of appropriate developmental support in hospitals, schools, or communities; insufficient communication between families and providers due to lack of opportunity or desire

Encourage and facilitate family-to-family support and networking.	A significant source of support for children and families during inpatient child hospitalizations is the relationships they establish with other families of hospitalized children. While some families develop these “peer” support networks naturally, others may need assistance to do so. Pediatric psychosocial care professionals should be proactive in regularly soliciting information from children and their families regarding their interest in making such connections, remembering that their desire to connect with others can change over time. Families who express an interest should be given opportunities to meet other families. This may include direct introductions, or helping them to become aware of and explore hospital, community, national, and internet resources, groups, and organizations.	Parental absence; multiple cultures and languages represented; families may not easily connect with others or desire connections with other families.
Design accessible healthcare delivery systems that are flexible, culturally competent, and responsive to the needs that families identify.	Include families at the broader systems level of care in the hospital, and make them feel respected. In every family interaction, pediatric psychosocial care professionals should seek to be responsive to cues from the family and priorities related to their hospital experience. The child’s and family’s input regarding program development and improvement of facilities should be valued. One strategy for achieving this is to create ways for families to actively participate in planning, implementing, and evaluating systems of care (e.g., family advisory boards). To achieve culturally competent care, healthcare professionals should be sensitive to individual family values and traditions. Listen to children and families, as they are often the best source of information regarding their cultures, values, and beliefs, and how these aspects of their identity can be respected and accommodated in the context of hospitalization. Learning from families, rather than making assumptions based on stereotypes, is critical. Efforts to make families from diverse cultural backgrounds feel welcome, and advocating for their preferences, are central to providing family-centered, culturally competent care.	Parental absence; pathways to facilitate communication have not been established within the hospital structure and programs; language discordance between families and providers; insufficient opportunities for providers to receive training in cultural competence and effective healthcare communication

## 2.4. Psychosocial Support in Critical and End-of-Life Care

**Overview.** The critical/intensive care environment presents many novel and potentially overwhelming experiences for children and their families (Stremler, Haddad, Pullenayegum, & Parshuram, 2017). Admission to a critical care unit may be an anticipated event (e.g., following a scheduled surgery) or occur in response to an unexpected worsening of an illness or sudden onset of a serious illness or injury. While many children recover and eventually transfer off the critical care unit, others do not. No matter what the presenting circumstances and expected outcomes, it is clear that children and their families, including parents, siblings, and extended family members who may be present, need support to cope effectively with the numerous stressors that characterize this intense and potentially overwhelming experience. Understanding sources of stress for all members of the family is important to ensure that appropriate psychosocial care services are provided.

**Parental stressors and interventions.** The stressors parents experience in the pediatric critical care setting generally fall into four domains (Pearson, 2009). Environmental stressors are physical aspects of the critical care unit that may not be directly associated with their own child’s care but influence the general atmosphere of the unit and consequently the parents’ emotional experience. Examples include the sights and sounds of patient monitoring equipment, viewing medical procedures, and observing

other patients and their families on the unit. Communication stressors, another common concern for parents (Merk & Merk, 2013), include receiving too little (or too much) information from the medical team in charge of the child's care, and having inadequate opportunities to ask questions. Family stressors include worries about the well-being of the patient's siblings as well as the pediatric patient (Hagstrom, 2017; Shudy, de Almeida, Ly, et al., 2006). Parents often report feeling stressed by and unsure how to manage the emotional and behavioral responses of their children in the stressful critical care context. Finally, role stressors relate to alterations in the parenting role. For example, visiting policies and rules regarding the child's physical condition can deprive parents of opportunities to care for their child as they would like, such as holding a young child in their arms, leaving them feeling ineffective as parents (Corlett & Twycross, 2006; Foster, Whitehead, & Maybee, 2015; October, Fisher, Feudtner, & Hinds, 2014).

Pediatric psychosocial care professionals are uniquely positioned to identify and advocate for policies and practices that support the family's ability to cope with the stressors inherent in the highly technological medical environment (Aldridge, 2005; Miles & Mathes, 1991). Efforts should be made to provide parents in advance, or as early possible in their child's critical care experience, with opportunities to learn what to expect and identify potential stressors (Purcell, 1996). Parents can be given a tour of the critical care unit to familiarize them with the physical setting, including the sights and sounds they will encounter. Parents can also be prepared by letting them know what to expect in terms of their child's emotional and behavioral responses to the critical care hospitalization and how the experience may change their parenting role. Once parents have identified likely "stress points," professionals can then work with them to develop effective coping strategies to facilitate empowerment and positive adaptation (Melnyk, Alpert-Gillis, Feinstein, et al., 2004). Even when advance preparation is not possible, there is evidence that coping support interventions delivered during hospitalization are effective in alleviating parents' psychological distress (Doupnik, Hill, Palakshappa, et al., 2017). Pediatric psychosocial care professionals should also be alert to communication stressors and check in regularly with parents to determine if their needs for information are being adequately met. If not, the professional can provide information and clarify points of confusion to the best of his/her ability and knowledge, serving as a "communication bridge" between the parents and members of the medical team. In this way, the psychosocial support professional can address gaps in family-provider communication and alert medical staff to the parents' specific unmet communication needs.

**Pediatric patient stressors and interventions.** Perhaps the most common stressor for the child is sensory overload, which contributes to increased child distress during their critical care hospitalization and after discharge (Manning, Hemingway, & Redsell, 2014; Foster, Whitehead, & Maybee, 2015; Rattray & Hull, 2008; Rennick, Dougherty, Chambers, et al., 2014). Critical care units often have a purposefully open floor plan to allow the healthcare team to monitor all patients from a central location; however, a consequence is that these units tend to be loud, busy, and brightly lit. These environmental factors have been shown to affect children negatively both physically (e.g., disrupted sleep patterns, higher blood pressure, and breathing issues) and emotionally (e.g., heightened distress due to observing other patients' distress

and, sometimes, end of life). Tactile sensations, such as painful touch during medical procedures or routine care, add to the overwhelming sensory experience for the child. In addition to sensory overload, another common stressor for children is limitations on their ability to communicate. Children may be alert but unable to talk due to dependence on a ventilator or a tracheostomy, or may have difficulty expressing themselves effectively due to the side effects of medication or as a consequence of their illness or injury (e.g., brain injury). Other patients, especially young children, may not communicate due to being frightened or overwhelmed. Finally, for older children and adolescents, the lack of privacy created by the open physical layout of the critical care unit can be a significant source of stress.

Although some aspects of the critical care unit cannot be modified, steps can be taken to reduce children's experience of the stressors inherent in this environment. For infants and young children, for example, playing soothing music or recordings of a parent's voice singing or reading can bring comfort while also blocking out the sounds of monitoring equipment. For very young children, a blanket can be carefully placed over the crib or Isolette to help block out extraneous noise, light, and the sight of other patients. For older children and adolescents who are awake and alert, providing them with headphones and videos of favorite movies or television shows can bring comfort while distracting them from sights and sounds related to other patients' treatments or discomfort (Pearson, 2009; Dolidze, Smith, & Tchanturia, 2013).

Although the physical limitations of patients on the critical care unit can make it difficult for children to actively engage in play activities, play is still recommended to address children's developmental needs, and may help to diminish any long-term negative effects stemming from the child's critical care hospitalization. Play does not have to be active to be effective – even passive play yields benefits. For very ill or physically limited children, the psychosocial care professional can play “for” the child while the child watches. This type of play can be used to entertain, or to help the child express his or her feelings of frustration, sadness, or loss of control. Giving children on the critical care unit access to books, games, toys, and movies can help to engage them in play. Art and craft activities may also be effective, and have the additional benefit of producing something with which to personalize the child's space and increase his or her comfort in the space.

To address stressors related to the child's ability to communicate effectively, it is often useful to consult with allied health professionals, including speech, physical, and occupational therapists. These professionals can provide mechanical speaking aids, communication boards, or training in the use of hand and eye signals to help children communicate their needs. For children whose lack of communication is a result of feeling frightened or overwhelmed by the critical care environment, it is useful for the professional to work with the child to help them gain more comfort and reduce their fears by building supportive and responsive relationships with the medical staff (Foster, Whitehead, & Maybee, 2015; Purcell, 1996). It is also important to remember that children vary in their temperaments, and some may need more time than others to engage in communication in a stressful environment. Giving children different options for communication and allowing them to proceed at their own pace is critical, and can increase their sense of control in an otherwise uncontrollable situation.

Finally, issues of privacy can be addressed by being conscious of the child's location on the unit. A good option is to place patients who express privacy concerns in low traffic areas. When this is not possible, patient privacy can be improved by using movable screens to create the illusion of separation in an otherwise open space (Pearson, 2009). Attention to privacy needs is especially important when medical procedures are conducted. Pediatric psychosocial care professionals may need to heighten awareness of a patient's privacy concerns for medical staff, whose attention may be more focused on providing treatments.

**Sibling stressors and interventions.** The illness and hospitalization of a sibling is a significant event in the life of a child (O'Brien, Duffy, & Nicholl, 2009; Gerhardt, Lehmann, Long, & Alderfer, 2015). Siblings often share a deep emotional bond, and the illness of a brother or sister represents a major life stressor. When a child is ill and hospitalized, siblings experience separation not only from the ill brother or sister but also from their parents, who may maintain a constant presence at the bedside of their ill child. Studies indicate that the primary sources of stress for siblings include family separations and fears about the illness/injury and potential adverse outcomes (e.g., death) (Shudy, de Almeida, Ly, et al., 2006; Craft, 1993). Feelings of anger and guilt are common, and are exacerbated when siblings are denied information about their hospitalized brother or sister. Particularly for younger children, the stress experienced by the sibling may be expressed behaviorally (e.g., acting out, increased or new onset of symptoms of anxiety or depression), resulting in additional stress for the entire family.

Although hospitals have increasingly relaxed their policies regarding sibling visitation on critical care units, it is not a widespread practice. However, sibling presence on the critical care unit is consistent with the principles of family-centered care and can yield benefits for the entire family, including the hospitalized child (Richards, Starks, O'Connor, & Doorenbos, 2017; Rozdilsky, 2005). Nonetheless, for many families their strong desire to involve siblings is overshadowed by fears of how siblings will cope with exposure to their critically ill and perhaps unresponsive brother or sister and, simultaneously, how they will manage the difficult emotions that may arise from having their family together in such difficult circumstances. As such, appropriate psychosocial care resources must be provided to the family to ensure that sibling visitation and involvement is beneficial for all (Humphreys & LeBlanc, 2016; American Academy of Pediatrics Child Life Council and Committee on Hospital Care & Wilson, 2006; Koller, 2008). Psychological preparation activities can be an effective tool for facilitating a positive experience for the family. For example, photographs, videos and exposure to medical equipment can help siblings to become familiar with features of the critical care unit prior to their visit. Providing opportunities for siblings to engage in play activities to learn and practice coping skills is also an important component of sibling preparation. This can be done on an individual basis or through group programming on the unit that is specifically developed for siblings. Professionals can work with parents to help them model language and behaviors that help siblings to understand appropriate responses to the critical care environment. Additionally, they are well positioned to facilitate discussions between parents and siblings about their feelings regarding the hospitalized child.

Support for siblings can, and ideally should, extend beyond the boundaries of the hospital. Sometimes, due to the distance between the family home and the hospital, it is not possible for siblings to be physically present at their brother or sister's bedside. However, this should not prevent all sibling involvement. Phone calls, letters, and video-conferencing can serve as effective tools to bridge the gap between the siblings at home and their family members at the hospital. Professionals can also increase support for distant siblings by working with parents at the hospital to help them understand and meet the needs of their well children. Whenever possible, school personnel and child care providers should also be kept abreast of the situation, so that they can understand the challenges siblings are facing and provide effective support.

**End-of-life needs and psychosocial care.** Although the hope is that each child who is admitted to hospital will recover and return home, the unfortunate reality is that some children do not survive. A child with a life-limiting medical condition, and the members of his or her family, may respond emotionally in various ways and demonstrate a range of different behaviors in the face of this tragic circumstance. Pediatric psychosocial care is appropriate and beneficial for families to help address the emotional and coping needs of the dying child, as well as his or her parents and siblings.

The value of communication between the child and family at the end of life is well established. Although parents may wish to protect the child by keeping information about their health from them, this can have unintended negative impacts on the child. Specifically, it can prevent the dying child from seeking support, create additional anxiety, break trust in the parent-child relationship, and complicate the child's response to the crisis. In general, children nearing the end of life benefit from expressing their concerns and getting answers to their many questions. Several intervention guidelines are recommended in pediatric palliative care (Richards, Starks, O'Connor, & Doorenbos, 2017; Gilmer, 2002; Himmelstein, Hilden, Boldt, & Weissman, 2004). First, families and healthcare providers should not underestimate the child's ability to understand what is happening to them. Following the child's lead, and providing honest information at a developmentally appropriate level that addresses what the patient wants to know, is critical. Second, the child should be provided with opportunities to express strong feelings about what is happening and maintain any control that they can have over the situation. Feelings of anger, guilt, and deep sadness are normal and should not be discouraged. Allowing the child to decide when and with whom to share these feelings will help to promote a sense of control. Third, efforts should be made to create a comfortable environment for the child that promotes quality of life and family interaction. Ensuring that pain is adequately controlled and only necessary medical equipment is present will help to make the child comfortable and engaged in living rather than dying. Retain child-focused routines as much as possible, and create a space for the child in the family living area. Support the family to engage in enjoyable family activities that create special memories and positive feelings following the child's death. Fourth, to the extent possible and consistent with the patient's developmental level, involve the dying child or adolescent in end-of-life decision-making. This includes allowing the patient input on procedures, choice of pain medication, and coping approaches.

The death of a child is widely regarded as one of the most devastating experiences a parent can suffer in their lifetime. Parental distress around the time of a child's death relates to fears of abandonment or isolation, feelings of failure in their role as parent and protector, and having to cope with the child's pain and death (Mooney-Doyle, Deatrick, Ulrich, Meghani, & Feudtner, 2018). Parents recall in vivid detail the event and experiences surrounding their loss of their child, even years after the child's death. Parent-directed interventions that may be facilitated by pediatric psychosocial care professionals include the following:

- Helping the family stay connected with the child until death
- Enabling effective communication
- Helping the family make memories that they can cherish when their child is gone
- Helping parents navigate the complexities of the medical system
- Helping parents allow the child a death that is consistent with the goals, values, and lifestyle of the dying child and family
- Helping parents talk about death and funeral plans, being sensitive to the family's personal belief systems and cultural norms (Suttle, Jenkins, & Tamburro, 2017; Pearson, 2009; Rozdilsky, 2005).

Interventions with siblings should become a priority for those involved in the provision of pediatric psychosocial care when it becomes clear that a pediatric patient will not survive. Studies show that the long-term adjustment of siblings is associated with the extent to which they have been included in the illness and death experience (Fullerton, Totsika, Hain, & Hastings, 2017; Wallin, Steineck, Nyberg, & Kreicbergs, 2016; Lövgren, Jalmsell, Eilegård Wallin, Steineck, & Kreicbergs, 2016). Sibling involvement can include allowing their presence in the hospital, as well as encouraging them to participate in activities with the dying child at his or her bedside (Rozdilsky, 2005). If possible, siblings should be involved throughout the diagnosis or initial treatment phases, as well as subsequent medical care. These involvements help them to understand the inevitability of their sibling's death and foster a sense of predictability – a critical component of positive coping outcomes. Sibling involvement in family activities that promote feelings of connectedness and affiliation with their dying brother or sister are particularly beneficial. Siblings may need to be psychologically prepared to participate in these activities and feel at ease in the hospital setting (Gursky, 2007). It is important to assess and identify siblings' understanding of death in order to design useful preparation activities. As is the case with the dying child, explanations for siblings should be truthful, clear, concise, and developmentally appropriate, as well as sensitive to the wishes of the parents. Having comfort objects (these may be objects or people) available to the siblings may help them feel safe and manage the strong emotions that may arise during preparation and family activities.

## CHAPTER THREE: CASE STUDY ILLUSTRATIONS OF BEST PRACTICES

Four composite case studies are presented and discussed below to illustrate best practices in pediatric psychosocial care. The first two are based on cases in Qatar, the third on cases in the United States, and the fourth on cases in India. They were all developed for this report purely for educational purposes, as illustrations of best practices, and are not intended to represent actual persons, living or deceased. Each case study reflects aspects of multiple individuals and their experiences, and no case study is based on a single patient, family, or healthcare provider. In addition, details regarding any actual children and their care providers have been significantly altered, to protect patient confidentiality and prevent identification of individual patients and families.

### 3.1. Case Study 1 – Qatar

**Description of patient and presenting concerns.** A Certified Child Life Specialist (CCLS) was consulted at the request of nursing and social work staff for a psychosocial assessment of a 7-year-old Qatari female patient in the children’s acute rehabilitation unit of the public hospital system in Doha, Qatar. The nursing staff’s rationale for the referral was that the patient had lived at the hospital since birth and her family did not visit her or employ a nanny to stay at the hospital with the patient (as is commonly done in Qatar). According to the social worker, the child’s family did not respond to requests from the medical team to visit the patient. Additionally, the social worker had requested the family to come to the hospital to sign documentation that would permit the patient to leave the hospital on a “day pass” to attend school, but the family refused. The social worker attempted to report the family to the Protection and Social Rehabilitation Centre (AMAN), but no action was taken. The nursing staff said there was no need for the patient to live at the hospital. The patient was diagnosed with spina bifida and used a wheelchair, but could walk with assistance such as holding the hand of a medical provider or holding the rail to walk down the hallway of the unit. The patient had no additional medical concerns and was a typically developing child. In the respective experiences of the nurses and social workers involved, there is sometimes a social stigma surrounding people with disabilities in Qatar. As such, it is not uncommon to find Qatari children with disabilities remaining in hospitals and being cared for by hospital staff, or a nanny, rather than at home. This is evidenced by the lived reality of the Qatari child depicted here.

**Key issues related to assessment and case conceptualization.** Prior to conducting an initial psychosocial assessment, the CCLS asked the nursing and social work staff about the patient’s interests. They reported that the patient had an interest in art. In an effort to build a non-threatening rapport with the patient, the CCLS introduced herself and provided a range of art activities for the patient, with stickers (various options) or coloring (crayons or markers). According to the CCLS, the patient engaged in developmentally appropriate art activity, and demonstrated the ability to make choices verbally. The CCLS noted the patient’s ability to speak multiple languages.

The patient is cared for by medical staff from many countries, including nationals of India, the Philippines, Jordan, Egypt, Ireland, Iraq, and the United States. Thus, the patient developed her multilingual speech through seven years of encountering many languages in the healthcare environment in which she has lived her whole life.

Over time, the CCLS continued art interventions with the patient as a child-centered approach to engage with her interests and encourage self-expression, and as a tool to assess the child's coping with psychosocial factors. In one example, the CCLS asked the child to draw a picture of her family. The patient did not draw the picture, but instead informed the CCLS that she was "angry at family." The CCLS noted the lack of a secure attachment figure in the child's life, as evidenced by her comment and the lack of family involvement noted by the medical team.

The CCLS observed that the patient was one of the most typically developing children, with the least complex medical issues, on the unit. This was a meaningful observation, as it implied that it was an unusual occurrence for the patient to have social interaction with other children on the unit. The patient therefore lacked social-emotional support from peers, as she was not attending school and did not have children on the unit who were medically able and at an appropriate developmental level for her to play with. The CCLS also took note that the patient remained inside the hospital every day. The unit had an outside terrace where, according to nurses, the patient could safely go – with supervision. However, the nurses cited time restraints as limiting their ability to take this, or any, patient outside for very long. The CCLS determined that it was a rare exception for patients to be brought outside to the terrace. Inside the unit, the CCLS also noted that there was no designated play space for children. Nurses informed the CCLS that the patient often refused to eat, as well as to take her medication. The CCLS observed meal times and medication times with the patient and nurses. She had noticed that the patient always had a doll with her; however, at meal times the doll would be removed. Nurses would tell the patient that she could not have her doll unless she ate. The CCLS observed the patient protesting by crying and refusing to eat when her doll was taken away. She would then also refuse to take her medication.

**Considerations in planning psychosocial care approach and implementing selected intervention(s).** In working with this patient, the psychosocial care team considered many factors, including culturally specific considerations. Although this child was Qatari, her experiences and cultural identity had been shaped primarily by her attachment figures, who were the multinational hospital employees. The child did not have any Qatari medical staff caring for her, and had almost no contact with her family of origin. To facilitate a connection with her culture, a female Qatari unit secretary was utilized as a resource. Specifically, on several occasions the CCLS facilitated non-directive medical play sessions between the Qatari unit secretary and the patient.

Given her identity as a cultural outsider, the CCLS addressed the psychosocial concerns through a variety of interventions to improve the patient's coping and support her normalized development within the scope of her ability and cultural appropriateness. Given that the patient was not attending school, the CCLS would read books with the

patient to improve her reading skills. The patient actively engaged in reading activities. The reading would occur outside of the patient's room, as a way to discourage room isolation. At the same time, the CCLS wanted to indicate to the medical team that the patient's room was her "safe place," and that interventions (medical or psychosocial) should occur outside the patient's room whenever possible.

The CCLS began taking the patient outside, as a way to increase her familiarity with the world beyond the walls of the hospital. On the first attempt, the CCLS noted that the patient easily became overstimulated by the environment. This was evidenced by the patient clenching her body and saying, "water. I don't want. I want to go inside," when she saw the water sprinklers turn on, felt the wind on her face, and saw a bug. After that, the patient consistently expressed verbal refusal of attempts to take her outside. By way of intervention, the CCLS would enact outside environmental conditions with the patient while inside the hospital, with the aim of transitioning her to experiencing the situation outside with increased coping ability. For example, the CCLS and the patient would practice "flying like birds" by waving their arms in the air and making the noise "tweet-tweet." The CCLS would enact the bird's behavior through play to increase patient familiarity with birds, and to normalize the experience in a developmentally appropriate way.

Indoors, the CCLS created a play space with developmentally appropriate toys for all the patients. The space had previously been used as a storage area. The CCLS encouraged social interaction between the patient and other patients in this area when possible. The CCLS created a monthly schedule that was placed in each patient's room, outlining the specific activities that would be happening in the play space throughout the month.

During mealtimes, the CCLS attended multidisciplinary medical rounds and encouraged the team to allow the patient to keep her doll with her while she was eating. The CCLS explained that the doll was a safe item for the patient, to which she had developed an attachment. The CCLS also developed a plan of care to utilize the doll with the patient to encourage medication-taking. That is, the patient could "play nurse" with her doll by giving the doll pretend medication. The nurses, in turn, would not only give medication to the patient, but also engage the doll in the process by pretending to administer medication to it too.

**Outcomes.** The CCLS noted the patient's improvement in both speaking and reading English after continued reading interventions. The patient would also excitedly ask other staff to read with her. After practicing the outside conditions scenarios over a period of time, the patient agreed to go outside again. The CCLS engaged the patient in pretending to be birds when they saw birds outside. The CCLS would say to the patient, "what does the bird say?" and she would say, "tweet-tweet" and flap her arms to imitate a bird flying. The CCLS would also play the "what do you see/what does it do?" game with the patient. For example, in one intervention the CCLS asked, "what do you see?" The patient responded, "water" and the CCLS responded, "water makes the grass grow." The patient then responded, "water makes the grass grow." In this way, the intervention was not only successful in improving the patient's comfort with the unfamiliar outside environment, but also served as a teaching experience to help

her understand the purpose and function of what she was seeing. The CCLS reported that the patient increased cooperation with mealtimes and medication-taking following the staff's medical play interventions with her doll. Ultimately, the CCLS was transferred from the unit because of two administrators' cultural beliefs about who should provide psychosocial care interventions to inpatient children. When the CCLS left the Pediatric Rehabilitation Unit, the medical team was still attempting to contact the parents and obtain permission for the patient to attend school.

**Lessons learned.** The child portrayed faced multiple psychosocial issues putting her at risk of continued delayed development. This was largely the consequence of a lack of protection of the child's rights in this situation. While the medical team indeed advocated for the patient as best they could, the lack of infrastructure and laws in place outside the hospital severely restrained its ability to take legal action to protect her rights. The family had apparently not broken any laws; hence there was no legal basis to withdraw their parental rights on grounds of child neglect. Furthermore, the medical team faced with this situation discovered there were no clear reporting mechanisms, avenues, policies/guidelines, or resources in the country to successfully resolve the lack of parental involvement. The same was true internally at the hospital, and so the team simply attempted to problem-solve their way through. In general, there is limited state involvement in parenting practices in Qatar. As a traditionally private society, it is not common practice for the government, or anyone else, to direct parents' decision-making concerning their children. Parenting is believed to be the role and responsibility of parents, without interference. However, despite these external obstacles, medical teams can develop internal systems of care and supportive interventions that foster psychosocial protection for the children in their care, as was done in this case example.

In addition, concern for patients' cultural identity development suggests that some changes to the healthcare system might be beneficial. For Qatari children at the stage of development in which identity formation takes place, practitioners are advised to be aware of the potential implications of having limited contact with Qatari nationals for patients' psychosocial well-being and developing cultural identity. Patients who are not given opportunities to develop their Qatari identity may be at elevated risk when discharged from the hospital at a later stage without an understanding of the need to adhere to Qatari cultural norms and expectations of males and females. This underlines the importance of Qataris increasing their presence in the healthcare industry in order to help maintain important cultural influences for future generations when children with medical conditions are separated from their families of origin and primarily cared for by non-Qataris within the hospital setting.

A final lesson from this case is the importance of prioritizing cultural humility and responsiveness. Psychosocial care practitioners who provide services to pediatric patients and families outside the cultural context of their home countries are in danger of delivering culturally insensitive care. Cultural outsiders' frames of reference and assumptions about best practices for psychosocial care are influenced by their own experiences, perspectives, and deeply held beliefs that are difficult to change. It is therefore essential to reflect on the cultural appropriateness of potential treatment approaches prior to instituting interventions. What is appropriate and beneficial for

one patient/family or institution may be at odds with the values or expectations of care for another patient/family or institution. When the practice of psychosocial care is informed by continuous critical reflective learning and elicits personal and social transformation in the practitioner, culturally responsive care for patients and their families is fostered.

### 3.2. Case Study 2 – Qatar

**Description of patient and presenting concerns.** The CCLS was asked by the nursing staff to conduct a psychosocial assessment of a 3-year-old female Arab patient with traumatic brain injury arising from a car accident. The patient was on the acute pediatric rehabilitation unit of a public hospital in Doha, Qatar. The reason given by the nursing staff for consulting the CCLS was that the patient demonstrated uncooperative behavior regarding medical treatments and fear of staff entering her room, as evidenced by her immediately screaming and physically clinging to her parents whenever staff came in.

**Key issues related to assessment and case conceptualization.** Given the patient's elevated level of fear and anxiety with unfamiliar people, the CCLS first asked to speak with the patient's mother and father without the patient present. The CCLS provided an introduction to psychosocial support services by explaining his role as being to promote normalized development, facilitate coping, and reduce overall stress and anxiety for both the patient and the family. The parents expressed gratitude, confirmed the elevated fears of their daughter, and asked what the CCLS could do to help her. In an effort to understand the patient's development through a strengths-based approach, the CCLS asked the parents about her interests. The parents shared with the CCLS that their daughter loved to play and was typically "not shy." They said her behavior since being hospitalized "was not her." The CCLS explained to the patient's parents that their description of their daughter's change in behavior since hospitalization was a developmentally appropriate response to an unfamiliar environment. The CCLS explained that he would meet with the medical team and develop a multidisciplinary plan of care individualized to their daughter's needs, given the identified concerns.

**Considerations in planning psychosocial care approach and implementing selected intervention(s).** One of the CCLS's aims was to reestablish the patient's normal socialization and increase her familiarity with the medical environment, thereby minimizing her fear. Given the information shared by the patient's parents that she enjoyed play, the CCLS decided to utilize medical play as both a family-centered and a developmentally appropriate intervention to accomplish this multifaceted goal.

A team approach to understanding the patient's needs, with all members following the same psychosocial care plan, was essential to success. Therefore, the CCLS attended a multidisciplinary team meeting to share the results of his assessment and to help develop a team plan of care. Knowing that the patient was fearful of clinicians, the CCLS suggested reducing the number of staff entering the patient's room, and ensuring that only a consistent few staff who were critical to her care would go in.

Additionally, to make the physicians appear more normal, the CCLS suggested that they remove their white lab coats before entering her room. The team also agreed that at times when no medical intervention was needed but a message had to be communicated to the patient's parents, the staff would not enter her room to speak to them but rather request to meet with the parents privately.

The CCLS also created a play space on the unit where the parents could go with their child. The team agreed that unless medically necessary, they would not approach the child and family while they were in the play space. The aim was to encourage a normalized routine of parent-child interaction following the interest of the patient, and communicate to the family that this time was an important part of their daughter's psychosocial healing that the team valued and respected.

**Outcomes.** The CCLS introduced medical play to the patient and her mother by preparing a play space with pretend medical equipment and an Elmo doll. For the first several medical play sessions, the CCLS remained at a safe distance in the room, while the patient and her mother played with the pretend medical tools. The CCLS intentionally remained at a distance with the aim of gradually improving the patient's comfort level enough for him to join the play sessions. The CCLS would gradually bring new play materials to the patient and her mother and provide words of encouragement, while assessing the patient's behavioral response to his presence. Initially the patient verbally protested the CCLS's presence. However, over time the CCLS began not only to provide new play materials to the patient and her mother, but also to place a heart sticker on his hand, followed by the mother's hand, then invite the patient to select a sticker of whatever color she would like, and attempt to apply it to her hand. This was successful in building the patient's trust, as evidenced by her acceptance. Eventually the CCLS joined the medical play sessions with the patient and her mother. The patient also kept the Elmo doll in her hospital room, and the medical team was encouraged to prepare her for medical interventions by first showing her what they were planning to do by doing it on Elmo. This was particularly helpful in improving the patient's cooperation with vital checks. Having found success in building trust by giving the patient stickers, the CCLS communicated this to the medical team and encouraged them to give her stickers too when interacting with her. This was successful in building a rapport with the staff who were consistently providing her care. On the final day of the patient's stay in hospital, she willingly engaged in a medical play session with the CCLS and another patient. This was the first time in her nearly month-long stay that she participated in peer socialization. When the patient departed from the unit for the final time, the CCLS gave her a packet of heart stickers, and she waved goodbye to the medical team on the unit while walking out the door.

**Lessons learned.** Recognizing the family as a key part of the team in addressing the psychosocial needs of the patient was critical to the successful result of her improved coping. Giving the mother and father roles as active participants in the interventions also decreased their stress and anxiety, as evidenced by their verbal feedback (e.g., "having the play time makes this experience better").

Another key factor for success was the multidisciplinary planning and approach to the patient's psychosocial health needs. Communicating on multidisciplinary team rounds by sharing individual experiences with the patient and family, and agreeing on specific approaches and modifications to be incorporated into the team care, made a difference in ensuring consistency, from which both patient and family benefited.

Lastly, for the CCLS practitioner, it was important to recognize and reflect on his own role and the potential consequences of his involvement with the patient. The CCLS strove to maintain the family's normal routine while in the hospital, because many of the psychosocial issues the child was facing were due to a disruption in routine, and he was not part of the patient and family's routine outside the hospital. Therefore, to suddenly be present while trying to help the patient could actually have had the unintended consequence of further disrupting what was normal for her. Thus, it was important to be present behind the scenes to help ensure the conditions for the patient's psychosocial health to thrive, yet remain physically absent until she demonstrated comfort in allowing the CCLS into her routine.

### 3.3. Case Study 3 – United States

**Description of patient and presenting concerns.** The CCLS was consulted by nursing staff regarding a 13-year-old African-American male patient with sickle cell disease and autism spectrum disorder. The patient was experiencing a pain crisis and had been admitted onto the general medical unit of a children's hospital in Chicago, Illinois, USA. Nursing staff said the reason for consulting the CCLS was recent changes in the patient's ability to cope with and withstand procedures, specifically IV starts. During previous hospitalizations for this patient, IV starts were successful at the first attempt. During this admission, however, multiple attempts had been made to start an IV, all of which were unsuccessful. The evening duty CCLS was called in for assistance with another attempt, but it was still unsuccessful as the patient screamed, hugged his arms to his body, and would not allow any staff member to touch him.

**Key issues related to assessment and case conceptualization.** After discussion with nursing staff and the evening psychosocial support team, the CCLS was able to identify several factors that could have contributed to these recent changes in the patient's coping behaviors. Nursing staff informed the CCLS of changes in family support. In all previous hospitalizations, the patient's mother was present and able to provide support to her son. During this admission, the patient's mother was unable to be present due to a new baby at home, which was distressing to both the mother and the patient. According to nursing staff, the patient seemed distraught in the absence of his mother and repeatedly cried, "I want my mama!" throughout the night. The patient's mother was a single parent; his biological father was not involved in his life, and no other family members were available to be present with the patient.

By talking with the evening duty team, the CCLS learned that there had also been a lack of choices offered to the patient, and that his access to the hospital's playroom had been restricted by nursing staff. According to the evening psychosocial support staff, after the first couple of unsuccessful attempts at an IV start, a nurse had told

the patient that he was no longer allowed to go to the playroom since he “can’t hold still”. Based on previous hospitalizations, it was known to most staff members that the patient enjoyed going to the playroom, as it provided him with an opportunity to express himself, engage in social interaction, and gain a sense of normalcy. The evening psychosocial support team said the patient appeared to be angered by what the nurse had said, and his challenging behaviors (i.e., screaming, tensing up his body) intensified.

**Considerations in planning psychosocial care approach and implementing selected intervention(s).** One goal of the CCLS was to facilitate interaction and collaboration with the patient’s mother. In order to compensate for the mother’s absence, the CCLS encouraged family interaction through scheduled FaceTime calls. The patient used his cell phone to FaceTime his mother once in the morning and once in the afternoon. In addition, the patient and his mother decided to FaceTime prior to any procedures, including an IV start.

Another goal for the CCLS was to assist the patient in identifying both previously used and new coping techniques that could help to reduce his anxiety. To do this, the CCLS and the patient worked together to create a “coping toolbox” unique to the patient and his needs. The CCLS offered a wide range of items for the patient to put in his toolbox, thus providing an opportunity for appropriate decision-making and autonomy. Once the toolbox was complete, the CCLS encouraged the patient to choose specific items or strategies from it to utilize during the next attempt at an IV start. The patient chose two specific coping techniques and the CCLS and patient practiced using them together.

Additionally, the CCLS collaborated with nursing staff and playroom staff to establish a “first, then” rule for the patient’s access to the playroom. Restricting the patient’s use of the playroom was being seen as a punishment, and eliminated the opportunity for play, socialization, and development. By implementing the “first, then” rule, the patient had access to the playroom after he had completed certain tasks. For example, “First, I will get my IV. Then, I will go to the playroom” or “First, I will finish eating my breakfast. Then, I will go to the playroom.”

**Outcomes.** When the time came for the next attempt at an IV start, the CCLS and the patient prepared beforehand by calling the patient’s mother on FaceTime and practicing the patient’s selected coping strategies one more time. The two coping supports he chose were a deep breathing exercise and a compact disc with his favorite song. The CCLS put the compact disc in a player, turned on the music, and guided the patient through the deep breathing exercise. Nursing staff then entered the room and began to prepare for the IV start. The patient requested that the CCLS restart the compact disc from the beginning and sit by the bed during the IV insertion. The CCLS continued to guide the patient through the deep breathing exercise as the nursing staff successfully placed his IV. The CCLS did note facial expressions of discomfort from the patient, but he was able to sit still for the entirety of the IV insertion and keep calm so that the nurses could easily access his veins. Having fostered family interaction and support via FaceTime, the CCLS noted positive changes in the patient’s coping skills. After the patient and his mother spoke on FaceTime, the patient appeared more

calm and compliant with all medical procedures. Eliminating the restriction on his playroom use enabled the patient to engage in developmentally appropriate play and social interaction with other patients. The CCLS believes that this also helped the patient to have lower levels of anxiety during this hospitalization. Throughout the remainder of his stay, the patient was able to utilize the coping techniques and tools from the toolbox he had created. He frequented the playroom and was able to cope more effectively with procedures and treatments. On the day he was discharged the patient decided to take his toolbox with him, stating that he would “use it at home” to help manage his chronic pain.

**Lessons learned.** Promoting the patient’s autonomy and providing him with opportunities to make decisions about his coping strategies was key. Giving the patient some control over how to manage his anxiety surrounding the IV start enabled him to identify supports and use them properly to cope better with this hospitalization. The patient seemed to thoroughly enjoy his coping toolbox, as shown by his frequent use of the items and strategies contained in it, as well as his decision to take the toolbox home and continue to use it there.

An additional aspect of care that was critical to success in this case was recognizing the importance of family support and encouraging family interaction despite physical distance. Working with children of single parents (whether due to divorce, being widowed, or other circumstances resulting in parental absence) presents unique challenges for the pediatric psychosocial care professional. Often, single parents are less able to be present with their hospitalized child because they have obligations to care for healthy children who remain at home, and/or have to keep working to maintain employment and income to support the family. Single parents have also been shown to exhibit diminished parenting capacity and report lower quality of life compared with partnered parents (Mullins, Wolfe-Christensen, Chaney, et al., 2011; Wallenwein, Schwarz, & Goldbeck, 2017). As such, efforts must be made to ensure that the needs of the child and family are being addressed in a way that overcomes the challenges imposed by single parenthood. For the patient and family described in this case study, scheduling FaceTime calls with the patient’s mother allowed the CCLS to foster family connectedness and a feeling of support for both the patient and his family. The patient was able to receive support from his mother, interact with his new sibling, and feel a sense of normalcy, all of which made him better equipped to cope with this hospitalization experience.

Lastly, a multidisciplinary approach to addressing the patient’s psychosocial needs was necessary to help restore the patient’s positive coping behaviors. By collaborating with the nursing staff, playroom staff, and fellow child life specialists, the CCLS ensured agreement and understanding across all disciplines as to what the patient’s coping plan entailed, his access to the playroom, and more. This multidisciplinary approach allowed for more consistent patient-centered care during this hospitalization, as well as for future admissions.

### 3.4. Case Study 4 – India

**Description of patient and presenting concerns.** This patient was initially referred for Child Life consultation during Child Life team rounds, and later through his primary attending physician, with specific notation regarding developmental regression. The patient was a 4-year-old boy from a small village in the north of Karnataka, India, recently diagnosed with acute myeloid leukemia (AML). He was an only child who normally resided with both parents and attended preschool with his peers. He initially traveled with his family two hours by train to come to a private hospital in Bangalore for needed medical intervention and treatment, estimated to last six to eight months. At initial presentation he was withdrawn, as evidenced by his unwillingness to communicate or maintain eye contact with hospital team members or to engage cooperatively with medical care. Prior to meeting with the Child Life team, which included both local and international members, the patient had had a port inserted in preparation for upcoming chemotherapy treatment. During his first meeting with Child Life, he expressed difficulty in coping with the port and its accompanying bandages, and often asked for it to be removed or attempted to remove it himself. He also expressed his desire to leave the hospital and return home, and cried often.

During initial treatment, the patient quickly regressed and CCLS team members assessed his developmental age to be two years. Although he originally presented as being cooperative with his family, he later became increasingly irritable with staff, rejecting his mother's offers of food and her encouragement to engage with Child Life team members. At this stage his previously established independent self-care routines were reduced to a minimum and he became increasingly dependent on his parents for feeding, dressing and general maintenance of hygiene. He developed a consistent fear towards medical procedures coupled with high levels of stranger anxiety, and he would not allow his nurse or other team members to touch or talk to him for the purpose of medical examination. This often resulted in the escalation of minor situations and dependence on one of his parents to soothe his worries. Additionally, a lack of control over his surrounding environment resulted in his rejecting previously preferred play activities and spending the most of his time in bed, lying prone all day for much of his inpatient stay.

The patient's family expressed concern that the initial medical interventions were negatively affecting their child's behavior and physical appearance. They expressed the view that the sole reason for their child's aggression towards them and others was the steroids he was taking. Additionally, they noted that his food intake had decreased because his taste buds had changed due to the chemotherapy and the dietary options on offer were different from those at home. In addition, because the family's permanent residence was over two hours away by train from the medical facility, only one parent was consistently available to be present at the hospital – typically the mother, because of the father's work duties and other responsibilities. This arrangement presented some challenges for the family. In addition to economic challenges, the patient's mother experienced separation from the rest of the extended family. She became isolated, and had insufficient emotional support from family members to help her cope during this stressful time.

Psychosocial risk factors for this young patient were his limited baseline coping skills to manage medical stressors, due to his age and development, and his inability to understand his diagnosis and treatment plan. In addition, his medical treatments and the prolonged separation from his family and home environment because of his long-term hospitalization posed risks to his normal growth and development.

**Key issues related to assessment and case conceptualization:** Several issues were considered in developing an understanding of the patient and his family and their support needs during his hospitalization. They included:

- Culturally specific parenting styles
- Impact of nutrition/malnutrition on physical development
- Cultural norms regarding educating patients about a cancer diagnosis
- Language discordance (i.e., native language of family different from languages of healthcare team and international team members, as well as language differences within the team)
- Patient's medical status and prognosis
- Healthcare practices and approaches of the medical team/system

**Considerations in planning psychosocial care approach and implementing selected intervention(s).** In view of the above, it was seen as important to adopt a patient- and family-centered approach, which encourages the patient and family to participate in needed medical intervention whenever possible. Normalization, education and emotional support were also prioritized in hopes of assisting the patient and his family to cope better with the hospital environment. Considerations directing this approach included the following:

- The length of the patient's stay in the hospital
- Recognition that he and his family were in a new geographic location for needed healthcare intervention and separated from their normal routines, support system and home community
- The need for collaboration with the healthcare team to build consistent caregiving routines for the patient and family
- The need to partner with the parents to address the patient's need for developmentally appropriate education
- The need to partner with the patient to provide support during medical procedures
- The need to partner with the patient to provide developmentally appropriate education regarding diagnosis and medical procedures.

During initial medical play sessions, the patient was hesitant to engage and tried to avoid using the tools, believing the play medical tools were going to be used for a real medical intervention and cause pain. However, he eventually began to participate in non-directive play with the Child Life team and to communicate his emotions and thoughts through play. After that, directive play sessions were introduced in

which the Child Life team provided guidance and more structure. His mother was encouraged to participate in medical play sessions, as she was available, but respite for her was prioritized. Meanwhile, Child Life made a referral to the social work team to better address the family's basic needs during long stays at the hospital, such as phone cards to facilitate communication and economic support for transportation to and from their permanent residence.

**Outcomes.** The patient responded well to the introduction of medical play. He eventually was able to play through stressful dressing change procedures and build skill in “helping” the nurse with the process. His mother became visibly more relaxed and engaged in comfort measures with him during his healthcare experiences. He was able to improve his physical and social development through introductions to other patients and through participation in social play activities. As he began using the play medical kit on a regular basis and on his own terms, he started feeling more comfortable holding the syringe and placed it into the provided medical doll. This in turn helped him to overcome his generalized fears towards medical procedures and cope better in the clinical environment. The child was open to procedural support and adjusted well to the hospital set-up as he began sharing his thoughts regarding various medical procedures and also his concerns. Later he would often demonstrate on the doll procedures that had been carried out on him, and when needed ask medical team members for clarification of the way a procedure was done. This sense of autonomy brought about a great change in the way he perceived information and coped with the environment around him.

At the end of his hospital stay, he appeared to be both comfortable and well adjusted during required medical procedures, and he thrived during group play. Providing normalcy, by bringing out toys similar to those he had at home and trying to follow his timetable as much as possible, made him feel at home even while he was in hospital. To further decrease the isolation of the patient and family from their permanent residence, home care was prioritized whenever possible, and especially towards the end of his treatment. In hopes of helping the family feel more confident about caring for their child at home, Child Life provided additional education and demonstrations of non-pharmacological interventions used for this patient by the multidisciplinary team at the hospital. These techniques included deep breathing, distraction and comfort positioning during procedures.

**Lessons learned.** Assessing the relevant cultural norms regarding children in healthcare was vital to help establish trust with the child's parents, which in turn allowed needed medical intervention to be provided. Examples particular to this case that do not apply generally to the overall culture were:

- Not being truthful with the patient, in order to avoid upsetting him, and the belief that sharing information might reduce his ability to recover
- Not engaging with social support for fear of their child being stigmatized by other family members and/or the larger community
- Ayurveda practices regarding appropriate and sufficient nutrition for a pediatric patient facing long-term treatment for a significant medical condition.

This case study also illustrates the importance of play, which has a multitude of benefits for children in hospital. In this case, play helped to overcome language barriers; reduce the child's stress and anxiety regarding needed medical intervention, resulting in a more cooperative patient; and provide opportunities for normalized activity to support the child's development and self-efficacy in an unfamiliar environment.

Communication is much more than words, and numerous subtleties may be lost when a healthcare professional is facilitating care in a culture that is not their own. It is important to acknowledge that psychosocial intervention may not be as accurately targeted as the professional intends, that provided supports may be ill-timed, and that attempts to make systematic change may be perceived as excessive or culturally insensitive. Providing step-by-step education for staff regarding Child Life interventions for this patient was essential to build trust and encourage a better understanding of psychosocial care practices for the whole treatment team. Engaging scaffolding skill-building techniques allowed both foreign educators and Indian patients, families and staff to gain insight into each other's goals and visions.

# CHAPTER FOUR: PEDIATRIC PSYCHOSOCIAL CARE AND QUALITY OF LIFE IN QATAR

## 4.1. History and Challenges

The practice of pediatric psychosocial care and quality of life (QoL) assessment and intervention is in its infancy in Qatar. In 2011, psychosocial gaps were identified by SickKids International subject matter experts (SMEs) who provided a professional consultation to Hamad Medical Corporation (HMC), the principal public healthcare provider in Qatar. HMC manages 10 hospitals – seven specialist hospitals and three community hospitals – as well as the National Ambulance Service and home and residential care services. The SMEs recommended the development of a Child Life Services Department and the hiring of professional overseas staff. In 2014, HMC hired Certified Child Life Specialists as psychosocial care experts to implement a sustainable service for its pediatric patients aged 0-13 years. At the time of this publication, patients aged 14 years and older receive healthcare through adult services. This was the first Child Life Services Department to be established in Qatar, followed by another Child Life Services Department at Sidra Medicine, a newly constructed private hospital.

In 2014, HMC's Child Life Services Department, in collaboration with the Oncology Department's QoL unit, carried out a study to identify gaps in services for children (0-13) at Hamad General Hospital (HGH) and adolescents and young adults (14-25) at the National Center for Cancer Care and Research (NCCCR). The study identified significant compromises in psychosocial domains in more than 30% of the oncology patient population of HGH and NCCCR (both part of HMC). In 2016 a pilot intervention was launched to address these gaps. This developed into a clinical QoL service at both hospitals that is also planned to cover oncology patients at Sidra Medicine as it starts operating. The service includes a weekly clinic, QoL rounding, and a monthly psychosocial and QoL multidisciplinary team round at both hospitals.

Healthcare continues to evolve in Qatar, with the adoption of more comprehensive integrative multidisciplinary care models and a preventive approach to disease and patient management (Chouchane, Mamtani, Al-Thani, Al-Thani, Ameduri, & Sheikh, 2011). However, one challenge to the provision of pediatric psychosocial care as discussed in this report is the existence of certain beliefs regarding the roles of nurses and other staff who are ideally positioned to support the implementation of best practices in pediatric psychosocial care and QoL. In the latter half of the 20th century, Western models of healthcare began giving more autonomy to nurses, who now play a central role in providing patient care, with increased authority in shared decision-making and interprofessional teamwork and collaboration (Brown, Wickline, Ecoff, & Glaser, 2009). This shift has had a positive impact on patient outcomes in not only clinical and medical but also psychosocial terms (Penz & Bassendowski, 2006). However, the entrenched model of healthcare in Qatar generally remains one in which nurses serve largely as administrators of care defined by physicians. Nurses are not yet fully trusted to engage in holistic or interdisciplinary health service provisions because they are often viewed as subservient to physicians (Carlone & Igbirieh, 2014).

Recent strides to empower nurses in Qatar, with the development of more advanced training, educational standards and opportunities by the University of Calgary in Qatar, HMC and Sidra Medicine, are beginning to positively impact the image of the profession and enhance the quality and safety of patient outcomes.

## 4. 2. Policy Implications

Tribal and family connections represent an important feature of Qatari culture (Al Dulaimi & Bin Sailan, 2011). This presents some challenges for Qatar in the integration of foreign healthcare concepts and practices into the unique indigenous culture, together with the influx of new residents who have come to Qatar from over 80 other countries (Goodman, 2015). For psychosocial practices to be implemented in the Qatari health system effectively, local staff must be trained to provide pediatric psychosocial intervention, as they are typically the people best placed and most trusted to provide and facilitate mutual support. In addition, to achieve improvements in culturally competent care, all healthcare providers, regardless of nationality, should have opportunities to undertake communication skills training to help them develop effective relationships with patients and their families. The Quality of Life service has in this way succeeded in providing a culturally tailored model for cancer care in the country that can be expanded and implemented across all medical disciplines in conjunction with Child Life Services.

As of May 2018, the Ministry of Public Health (MoPH) in Qatar officially recognizes “Child Life Specialist” as a profession and has defined professional standards for Child Life practice. This new policy provision is a result of joint advocacy by the Child Life Service leads at HMC and Sidra Medicine to secure the adoption of appropriate professional guidelines and standards for overseas candidates as well as Qatari nationals and residents, in order to enhance professional psychosocial care in Qatar.

The Scope of Practice for the Child Life Specialist is defined as follows:

- A Child Life Specialist is a trained, qualified healthcare professional who helps children and families cope with the stress and uncertainty of illness, injury, disability, and hospitalization. To do this, the Child Life Specialist undertakes assessments, interventions, program planning and implementation, regular reviews, and related documentation, using systematic clinical reasoning and decision-making.
- Child Life Specialists are child development experts who work to ensure that life remains as normal as possible for children in healthcare settings and other challenging environments. They promote effective coping through play, age-appropriate medical preparation and education, and self-expression activities.
- As advocates of family-centered care, Child Life Specialists work in partnership with doctors, nurses, social workers and others to meet the unique emotional, developmental and cultural needs of each child and family.
- The Child Life Specialist assumes responsibility for the delivery, safety and effectiveness of child life services provided. Child Life Specialists may practice at different levels based on their competencies and job profiles.

The Registration & Licensing Department of Qatar Council for Healthcare Practitioners (QCHP) regulates healthcare practitioners who wish to work in the State of Qatar, with the objective of upgrading levels of targeted healthcare services in order to maintain the health quality of residents in the State of Qatar. It applies unified policies approved by QCHP to all applicants regardless of their country of origin or the source of their certification. The department comprises teams for each of the following professions: physicians, dentists, nurses, pharmacists, allied healthcare practitioners, and complementary medicine practitioners. In order to practice as a Child Life Specialist, which is considered an allied healthcare practitioner in Qatar, candidates must meet minimum standards of education and experience. These standards are summarized in Table 2.

Table 2. Standards of education and experience required to practice as a Child Life Specialist in Qatar

<b>Education</b>	A bachelor's degree or higher in Child Life, Child Development, Education (early childhood-secondary), Expressive Therapies (art, music, play), Social Work/Care, Recreational Therapy, or related area
<b>Certification</b>	Successful completion of the Child Life Professional Certification Examination (available worldwide) resulting in a current Certified Child Life Specialist (CCLS) credential OR
	Current registration as a Hospital/Healthcare Play Specialist (UK, NZ)
<b>Experience</b>	Overseas candidates: Two (2) years' experience as a Certified Child Life Specialist or registered Hospital/Healthcare Play Specialist
	Qatari nationals and permanent residents: Evidence of clinical practice or equivalent internship program in the field of Child Life

Educational resources available in Qatar should also seek to integrate education and training related to MoPH policy provision and licensure regarding the child life specialist profession, in addition to best practices in pediatric psychosocial care, for other healthcare professionals. Education City, a part of Qatar Foundation, was developed to provide world-class education and to support the development of research infrastructure and innovations in healthcare in Qatar (Chouchane, Mamtani, Al-Thani, Al-Thani, Ameduri, & Sheikh, 2011). At present, Education City is comprised of branch campuses of six American universities, one British university, and one French university. Despite this impressive access to high-quality education, currently there are no degree programs in the field of Child Life, requiring local students to travel abroad for training. A Child Life course of study needs to be established at the university level to promote the infusion of well-trained Qatari child life specialists into Qatar's healthcare workforce.

## CHAPTER FIVE: RECOMMENDATIONS FOR IMPLEMENTING PEDIATRIC PSYCHOSOCIAL CARE

In general, it is recommended that pediatric psychosocial care be implemented through a multipronged approach aimed at systematically integrating evidence-based child- and family-friendly practices into multiple pediatric service areas within healthcare organizations. Specific recommendations to facilitate pediatric psychosocial care in hospitals are described below, organized by suggestions for education and training; the healthcare environment; financial support and advocacy; and research and audits. Note that the examples described below of how psychosocial care initiatives consistent with the recommendations have been successfully integrated into various pediatric service areas at HMC, such as the collaborative work with QoL in the area of oncology, are currently limited to these specific areas and are not yet corporation-wide.

### 5. 1. Education and Training

Provision of a well-defined and comprehensive training curriculum for healthcare providers can help to address gaps in understanding regarding the benefits of pediatric psychosocial care and strategies for implementation. An exemplar is provided by HMC's Child Life Services Department, which has prioritized the development of training curricula, and provides regular education sessions for the Nursing and Midwifery Education Research (NMER) service across the corporation. These trainings are developed to address critical topics in pediatric psychosocial care, and typically include the following:

- Impact of hospitalization on child growth and development
- Age-appropriate care and communication
- Importance of play in clinical settings/normalization
- Optimizing quality of life
- Psychological preparation/coping
- Non-pharmacological pain management
- Family-centered care
- End-of-life care

In addition to these trainings, education has been provided to other multidisciplinary staff (allied health professionals, physicians, dentists) in the form of departmental/grand rounds and tailored training regarding specific medical procedures and care for specialized clinical populations, such as burns, dental, and critical care patients, and children with special needs. The effectiveness of formal training sessions can be enhanced by providing supplementary materials to guide psychosocial practice and support practitioner-patient-family relationships. At HMC, for example, a lumbar puncture teaching brochure has been developed for use as a communication tool pre-operatively, allowing families and staff to partner in developing an advance plan to improve children's comfort during medical procedures. The brochure also serves as a guide for staff to encourage parental presence during the procedure, and describes specific ways in which the parent or caregiver can contribute to its success through active participation.

Another approach to encouraging a consistent team commitment to comforting children and families is to make guidelines for pediatric psychosocial care visible. For example, in HMC's outpatient Pediatric Emergency Centers staff are reminded to use best practices in pediatric psychosocial care by guidelines posted throughout the hospital. Specifically, the guidelines in these settings state that staff should

- Greet children at eye level
- Examine young children on a caregiver's lap or in their arms
- Allow children to sit up whenever possible
- Distract children with play and words
- Minimize unnecessary pain, stress, and fear
- Answer caregivers' and children's questions
- Allow families to be present to comfort their children whenever possible.

These guidelines are relevant to numerous settings within the hospital and associated clinics, but could also be adapted or expanded for specialized settings. An added benefit of posted guidelines is that it conveys to patients and their families the commitment of the medical team and hospital to providing child- and family-friendly care.

## 5. 2. Healthcare Environment

The importance of creating child-friendly environments within hospital pediatric units cannot be overstated with regard to its importance for child adaptation. Environmental considerations include the appearance of the public and private physical spaces in which healthcare is provided, as well as the availability of equipment that enables implementation of supportive psychosocial care practices. For example, a new child- and family-friendly phlebotomy chair in an HMC Pediatric Emergency Center allows children to sit up with a family member while the phlebotomist takes a blood sample. As a result of no longer requiring children to lie flat, staff have witnessed an increase in patient and parent cooperativeness, reduced wait times for other patients, and improved family satisfaction with children's blood draw experiences.

Pediatric hospital spaces are recommended to be colorful and engaging for children of all ages and abilities to help promote feelings of comfort and normalcy within the stressful medical setting. This includes creating playroom spaces equipped with developmentally appropriate toys and games that can be taken to the bedside of children whose physical condition may limit access to the playroom. Playroom spaces can be used for play-based procedural preparation and coping skills training; however, no actual procedures should occur in this space, in order to preserve it as a place of comfort and safety for the child.

## 5. 3. Financial Support and Advocacy

Pediatric psychosocial services and the cost of staff to provide these services (e.g., child life specialists) should be included within the hospital operating budget as an essential component of pediatric care. Funding should be sufficient to support staff-patient ratios that allow for the needs of all children to be met. Settings in which medically or psychosocially complex patients are served will require greater staff support and consequently a higher staff-patient ratio. In addition, hospital financial support is needed to provide families and physicians with access to interpreting services, given the high rate of language discordance in this multicultural country (Abdelrahim, Elnashar, Khidir, et al., 2017).

Advocacy and support for hospital-based pediatric psychosocial care programs is critical, and can occur not only within but also outside the hospital in community and government settings. Community engagement will help awareness of the importance of pediatric psychosocial care to grow so that it becomes a valued and expected aspect of the pediatric hospital experience. An exemplar of sustained community engagement is provided by the Pediatric Volunteer Mentorship Program at HMC. This program was initiated at Hamad General Hospital in 2013, at the request of its Chief Executive Officer, by Child Life experts from SickKids International; then in 2014 HMC's Child Life Services Department assumed responsibility for the program, redesigned it, and integrated it into the existing infrastructure of pediatric care.

Currently, each week 30 community volunteers provide developmentally appropriate bedside support to the inpatient pediatric population and respite to their parents/caregivers. Support includes play, art, and social engagement. Volunteers are recruited from the local community and trained in child-friendly practice, infection control, fire safety and environmental safety policies. Once training is complete, new volunteers are mentored by existing volunteers before volunteering independently and being asked to commit to a minimum of 100 hours of service. In addition to this unique hospital-based program, community collaborations have been formed with established businesses and educational institutions in Qatar to promote culturally appropriate, child-friendly art installations in various pediatric service areas across HMC. Community donors' contributions also provide needed developmentally appropriate resources for pediatric hospital populations, to ensure access for children during their hospitalization.

## 5. 4. Research and Audits

In general, there is a need for additional high-quality research and audits to be conducted on the impact of pediatric psychosocial care services in hospital settings. In particular, there is a need for studies to document the effects of these services on both patient and family outcomes, including children's and parents' psychosocial outcomes and experiences, children's physical health and treatment outcomes, and the child's and family's experiences and satisfaction with the healthcare they receive during hospitalization. In addition, research is needed to determine ideal staff-patient ratios and establish the cost-effectiveness of pediatric psychosocial care

for the hospital organization (e.g., does providing pediatric psychosocial care reduce length of stays or other healthcare expenditures?).

Research on child life and the impact of implementing psychosocial care principles in Qatar is critically needed to provide evidence and justification for changes in healthcare policies and practices in the country. The extent to which existing research on pediatric psychosocial care applies to Qatar's unique cultural context is surmised but largely unproven in the research literature. As such, conducting research to establish the benefits of pediatric psychosocial care in Qatar is strongly recommended. One example of the type of research needed is an ongoing study led by the Child Life Services Department at HMC aiming to understand the preferences of children, their caregivers, and nurses regarding the position used for blood draws and intravenous line insertions in the Pediatric Emergency Center. Specifically, children's behavioral responses to being restrained in a supine position (current practice) versus being held sitting up in a comfort position on the lap of a parent during the procedure are compared. Parent and nurse satisfaction scores are also obtained. Studies such as this are essential to provide a solid evidence base upon which to implement psychosocial care practices in Qatar.

Research related to pediatric psychosocial care and quality of life should be supported financially and instrumentally by healthcare organizations, medical training programs and academic institutions, private foundations, and government agencies. Researchers should carefully consider and address potential barriers to conducting rigorous studies, such as challenges to participant recruitment or retention and selection biases that may affect the generalizability of findings (Khidir, Asad, Abdelrahim, et al., 2016; Killawi, Khidir, Elnashar, et al., 2014). Research results should be disseminated through peer-reviewed scientific publications as well as policy briefs targeting appropriate audiences in order to translate research into practice and positively impact patient care

## CONCLUSIONS

Serious child illness and hospitalization is a major family crisis that can have a lasting negative impact on children's physical and mental health and quality of life in general. Around the world, pediatric psychosocial care approaches are increasingly being implemented to promote child and family resilience within medical contexts. Although pediatric psychosocial care is in its infancy in Qatar, the rapidly expanding medical infrastructure presents numerous opportunities to adopt best practices and transform into a state-of-the-art healthcare system that is responsive to the needs of pediatric patients and their families. To be most effective, pediatric psychosocial care programs should be implemented through a multipronged approach that systematically integrates evidence-based child- and family-friendly practices into multiple pediatric service areas within a particular healthcare organization. Comprehensive education and training programs, changes to the healthcare environment to support psychosocial care practices, commitment of financial resources for program sustainability, community outreach and involvement, and support for audits and cutting-edge culturally informed research are recommended to advance supportive pediatric psychosocial care in Qatar.

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