



The Case for Investing in Psychosocial Care and Rights of Children with Chronic Medical Conditions in India

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Received: 4 September 2020 / Accepted: 8 September 2022 / Published online: 18 January 2023
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Abstract This narrative review paper aims to build a common understanding of the vulnerabilities of children with chronic medical conditions who face exceptional challenges due to nature of the illness, deformity, injury, and traumatic healthcare encounters which could potentially lead to long-term psychological effects. The presence of chronic medical diagnoses in children and the subsequent impacts including social stigma, as well as their age and developmental level, may amplify adjustment challenges in parenting considerations, school, peer relations, career, and future relationships. Children may be traumatized by unfamiliar and painful healthcare experiences. Hospitalization can lead to increased feelings of isolation, fear, and self-doubt when children do not receive emotionally safe psychological support necessary to minimize the accompanying stress and anxiety. School experiences and parenting children with chronic illnesses have additional intersecting socialization characteristics. This paper highlights a vision for furthering the groundwork within Indian pediatric settings to promote emotional safety and psychosocial care. Principles from the United Nations Convention on the Rights of the Child and the World Health Organization's definition of health create

an impetus for giving a voice to children with chronic medical conditions. While there are sporadic psychosocial services for children with chronic needs, they lack consistency, and this indicates a need and an opportunity for developing a unique career for human development and psychology professionals to address these concerns. As exemplars, two psychosocial care programs in India that help foster resilience in these children are highlighted. Although limited, extant research regarding the experiences of children with chronic medical conditions in India is discussed, and implications for future research and academic initiatives are interwoven within this paper.

Keywords Children's rights · Childhood illnesses · Psychosocial care · Resilience

Abbreviations

CL/CP	Cleft lip or cleft palate or both.....
7, 8, 9
HDFS	Human Development and Family Studies.....
21, 22
KGPOCH	Kashiben Gordhandas Patel Children Hospital.....
20, 21, 22
UNCRC	United Nations Convention on the Rights of Children.....
3, 23

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Introduction

The Trauma of Living with a Chronic Illness in Childhood

Due to advances in medical treatment, more children are living with chronic medical conditions. Children's hospitalization and other healthcare encounters such as pediatric clinic

visits, ambulatory care, outpatient surgery, or emergency services can be traumatic when they receive treatment that is unsympathetic toward their developmental, emotional, and family support needs (Rollins et al., 2018). Despite efforts to make improvements in the quality and access to healthcare for children, especially in disadvantaged countries, children are still dying or becoming disabled from preventable or treatable illnesses, deformities, and injuries. The degree of disruption and debilitation due to the illness, injury, or congenital deformity ranges from mild to severe. Secondary conditions such as malnutrition, anemia, disabilities, and lack of self-efficacy will impact both the child and family and will make their daily routines more challenging. Children suffer unnecessary pain, fear, and anxiety, both when receiving medical treatment and after treatment if their emotional and psychosocial health needs are disregarded (Thompson et al., 2018). While not all healthcare experiences are negative, often the situational difficulties arising for children can trigger feelings such as fear of failure, self-doubt, reduced efficacy, or loss of friendships. These children are at risk for being shunned or bullied by peers and individuals in the community. The intent of this narrative review is to analyze and summarize the relevant literature regarding children's experiences within healthcare settings, living with chronic medical conditions, how these could influence their socialization experiences, and make a case for investing in much needed pediatric psychosocial services in India.

Children's Rights and Need to Promote Emotional Safety in Healthcare Settings

The United Nations Convention on the Rights of Children (UNCRC), with its 54 articles, covers comprehensive protections for children and outlines civil, political, economic, social, and cultural rights of children everywhere (United Nations Children's Fund, 1989). Being a signatory to the UNCRC obligates the Indian government agencies, non-government organizations, and individuals to uphold the articles for the best interest of all children. These rights provide a structure for the integration of the principles of children's rights into healthcare environments. Child participation means enabling children to express their views and creating a healthcare environment where their voices are heard. The right-based advocacy provides the impetus to approach the government or healthcare policy makers in India to create the necessary changes to promote child and family-centered care services in hospitals. Another advocacy instrument is the World Health Organization's definition of health (1948): "Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity." This definition is holistic and pays attention to both the biological and psychosocial factors in their contribution

to health and illness. Attaining such a state of physical and emotional health will require collaborative efforts of medical providers and human ecology professionals in the fields of human development and family studies, psychology, and social work (Desai, 2009).

Defining Chronic Medical Conditions

There is a considerable degree of variation in the use of the term chronic disease within professional groups (Bernell & Howard, 2016). For this paper, the term chronic medical conditions refers to any illnesses or conditions in children characterized by continuing for a minimum duration of three months that could necessitate frequent medical/surgical interventions, long-term or repeated hospitalizations over a period of a month, including the potential for premature death (Hicks & Davitt, 2018). Frequently, these conditions are present for the child's entire life in cases such as diabetes or thalassemia and may require extended treatments, lead to altered daily life and family routines, and could have an uncertain outcome. Some conditions involve degenerative processes such as in diagnoses like cancer, kidney, ophthalmic, or heart disease. Living with congenital birth defects such as facial cleft conditions and congenital or acquired ophthalmic conditions are included in this paper, as these could result in long-lasting functional disability for children. This paper highlights how individuals with child/human development and psychology training can promote evidence-based psychosocial interventions which mitigate these stressors and promote resiliency for children and their families. Implications for future research and academic initiatives are provided.

An Overview with Some Statistics of Child Health in India

Children represent about 39%, i.e., 472 million of the total 1.21 billion population of India. According to United Nations Children's Fund's (2017) basic health indicator data for 2016, India's Under-5 mortality rate is 43 per 1000 live births and the infant mortality rate is 35 per thousand live births. The most common causes of death for children under five years include infections (pneumonia and sepsis), diarrheal diseases, measles, malaria, and acquired immunodeficiency syndrome. Malnutrition is a major leading risk factor for disease burden and was the predominant risk factor for death in children younger than 5 years of age in every state of India in 2017, accounting for 68.2% (95% UI 65.8–70.7) of the total under-5 deaths (India State-Level Disease Burden Initiative Malnutrition Collaborators, 2019). In the absence of national survey data on chronic childhood illnesses, it is not possible to accurately estimate how many children with complex medical needs are living in India. However,

hospital-based admission records and statistics would be available from various private, trust run or government clinics and hospitals. Living with childhood cancer, ophthalmic diseases, and facial cleft conditions are just three examples included in this paper of the numerous chronic medical conditions prevalent in India's children. Piecemeal prevalence data available about these conditions are provided.

Understanding Perspectives of Children with Chronic Conditions and their Families

Childhood Cancer

It is estimated that annually, nearly, 40–50,000 children are diagnosed with cancer in India. CanKids, a leading childhood cancer support organization, estimates that roughly only half of new cases are diagnosed (CanKids, 2020a). Of those children that are diagnosed, a large percentage are brought to receive treatment in advanced stages of cancer. Despite the high cure rates in developed countries, it is estimated that in India, 70% children die from cancer due to lack of awareness, late detection, delayed diagnosis, inadequate facilities, the high cost of treatment, and the absence of supportive care. These children's voices are prematurely silenced. Various types of cancers experienced in childhood include leukemias, solid tumors, and other cancers such as Wilms' Tumor. Childhood cancer treatment includes chemotherapy, radiation, and/or surgery. The nature and duration of treatments range from a few months to several years and depend on various factors including the type and severity of cancer and the child's age. If the cancer relapses, the treatment cycles may be repeated. Children undergo various painful medical procedures in clinics or hospitals, suffer many side effects, and endure restrictions which can be psychologically traumatic. During and after treatment children miss out on typical childhood experiences for play, peer interactions, or attending school, and often suffer ongoing stigma and rejection as young adults in different aspects of their lives. The following personal testimony of a childhood cancer survivor sheds light on her lived experience of social stigma whereby she is negatively discriminated due to getting labeled as being different from the "normal."

At age 12 years, while living in Nairobi, Kenya, I was diagnosed with Ewing's Sarcoma, a rare type of bone or soft tissue cancer. My specific diagnosis was bone cancer with the tumor attached on the skull bone on the right side of my head. My family relocated to Mumbai for a yearlong intensive specialized treatment involving surgery, chemotherapy, and radiation therapy, and we continued living there for my sister and my school education. The scars of that year of excruciating treatments were not as painful as facing subsequent hurdles of judgements and biases. My four years of schooling in Mumbai were most traumatic from the initial

and vehement reluctance of the principal to give me admission due to being perceived as having a disability, to being judged by teachers as being an incompetent and an unworthy student since I had to repeat a school year, mind-well necessitated due to medical treatment. Thankfully, I found one supportive teacher and other encouraging teachers later in junior college. With their and family support, I slogged on my self-confidence, and I have achieved master's and post-graduate diploma level education. The next hurdle awaited when I sought to get married. I was honest to potential life partners about defeating cancer, but my honesty backfired. I would be rejected time and again with a straight NO without any explanation. Now at age 31 years I am still a single woman and continue being rejected for marriage. I am shifting focus toward building my career... (K. Mistry, Personal Communication, 2021).

Pediatric Ophthalmic Diseases

Ailments afflicting the eyes are another common chronic condition for India's children and with many consequences. While there is a paucity of national data regarding eye diseases among children, in a regional study of ocular morbidity among 16,168 school aged children 6–14 years old in Rajasthan, the prevalence was 31.6% or 5,104 cases. These ophthalmic conditions included refractive errors, congenital disorders, Vitamin A deficiency, cataracts, squint, retinopathy of prematurity, retinoblastoma, strabismus, eye injuries and more (Mohan et al., 2017). In a study of 122 survivors of retinoblastoma (cancer of the retina in the eye), children voiced concerns that they felt unable to compete with peer groups and experienced teasing by other students in school (Batra et al., 2016). While they did not report difficulties in maintaining existing friendships, they perceived a sense of unwillingness by new children to befriend them. They reported higher school absences due to hospital visits, had difficulties in engaging in school activities and worried about their overall future. In another study of 93 patients aged 4–16 years with strabismus, 70% were distressed due to having the squint, 65% experienced ongoing worry, 57% felt severely ostracized, 55% experienced extreme stress due to people's remarks, 50% struggled to cope with the impact of their eye condition, and 38% had difficulty in communication (Kothari et al., 2009). Children and youth with strabismus have poor self-image, have difficulties with interpersonal relationships, face ridicule at school and work, have increased social anxiety, and poor job opportunities as adults (Kothari et al., 2009; Menon et al., 2002). In a case study of a six-year-old child with retinoblastoma, who had to receive enucleation (removal of the eye with cancer), Shah and colleagues (2015) reported the child was timid and apprehensive because of the psychological effects of surgery. Parents also reported peer rejection, and child's refusal to go

to school or play with other children. An ocular prosthesis was fitted to restore the patient's self-confidence. Authors recognized the value of interdisciplinary collaboration for the management of children with retinoblastoma, since the entire experience of being diagnosed with cancer in the eye, subsequent surgery, fitting a prosthetic eye, and body image issues is challenging and raises several psychosocial concerns.

Facial Cleft Conditions

Children born with congenital defects such as cleft lip or cleft palate or both (CL/CP) experience potential lifelong repercussions. Cleft lip and cleft palate are openings or splits in the upper lip, the roof of the mouth (palate) or both. The term CL/CP does not adequately describe the potential complexities of the craniofacial deformity which may involve nose, lips, alveolus, or palate. Consequently, breathing, appearance, dentition, dental occlusion, facial growth, speech, and hearing can all be affected leading to several health and psychosocial implications (Dvivedi & Dvivedi, 2012). Depending on the region of the world, one out of 700 children is born with craniofacial abnormality such as cleft lip, cleft palate, or both (Dvivedi & Dvivedi, 2012). In high-income countries, these children have access to corrective surgeries and undergo reparative surgery during the first few months after birth with follow-up surgeries in later years. However, in India, there is a backlog estimated to be as high as one million for children with CL/CP to receive corrective surgeries, particularly among families from lower socio-economic strata (Poenaru, 2012). If not treated in infancy, CL/CP can result in significant disadvantages in later life due to poor nutritional intake during infancy (Burca et al., 2016), and social exclusion by peers thought to originate from unclear speech as well as difference in facial appearance (Zajac & Vallino, 2017).

In a study of 4,657 patients with cleft lip or palate seen in a tertiary care hospital in Dehradun, over a period of 5 years, Dvivedi, and Dvivedi (2012), noted that 93.6% were children and youth (between birth-20 years). Nearly, 52% of the parents of these children were not literate, and majority came from low-income strata. The CL/CP diagnosis was believed to be a curse of God by most families from this Garhwal region and the children born with these deformities were called “*Khandu*” (incomplete). Often these children with extreme facial deformities were not enrolled in schools because of concerns that they would experience social stigma, bullying, and social exclusion. These parents would benefit from parenting education, resources, and support, especially given their access to care and affordability challenges.

Wydict and colleagues (2020) completed a study with adolescents with CL/CP in India to examine the two

components of social integration: social inclusion (the degree to which a person can form relationships with community) and social behavior (the degree to which one's behavior adheres to appropriate social norms). They found significant negative effects from CL/CP status on the index of social integration. This effect was likely derived from a lower level of social inclusion, which was a result of the adolescents' experiences of bullying and teasing. Their study measured the causal effects and adverse impacts of living with CL/CP on life outcomes to be wide-ranging and statistically significant. These included poorer speech, social exclusion, higher levels of depression, and lower cognitive ability. CL/CP surgery can at least partially restore some of these outcomes, especially speech, when surgery is performed before five years of age and can help to improve social inclusion. Their results on social integration and inclusion are important because of the potential long-standing effect in later life. For youth, adverse impacts could create barriers to entering the labor market, establishing healthy relationships, and in marriage and family formation (Wolke & Lereya, 2015). Social inclusion was not impacted just by improvements in the adolescents' appearance, but remarkably, the speech quality mediated social exclusion more than visual appearance. This suggests not only early age surgery, but the importance of follow-up speech therapy after surgery as an important step to fostering social inclusion (Wydict et al., 2020). As noted by the example of adolescents with CL/CP in India, this chronic medical condition requires several adjustments for the child and family beyond having a surgical repair and may be difficult to manage when there is a lack of awareness, affordability, and access to all necessary services including speech therapy.

Next, to provide the context for the rationale for this paper, healthcare settings such as hospitals-where children with chronic conditions receive frequent medical treatments and could become an institutional setting with socialization influences are described.

Continuum of Care Across Pediatric Healthcare Settings

Childhood illnesses vary from acute to chronic and require different levels of healthcare services, including primary, secondary, or tertiary care. Primary care includes routine healthcare checkups and treatments for minor ailments. Secondary care is more specialized for chronic and long-term treatment. Tertiary care is highly specialized and comprises of intensive care for unique and complex health problems, including conditions without absolute cures, such as cancer (Rollins et al., 2018). Many children with chronic illnesses require secondary and tertiary level care, which could mean they may have more frequent and longer stays in the hospital, as well as increased exposure to the negative effects

of hospitalization. Children receive healthcare in various types of healthcare settings and institutions with multiple transitions across the continuum of care. The treatment continuum consists of several phases, depending on the child's diagnosis and healthcare needs. Children experience different phases of care, such as emergency treatment, surgery, intensive care, inpatient hospitalization, rehabilitation, ongoing outpatient care, or home-based care. In India, pediatric healthcare services are provided in a variety of setups depending on where children live and where their families' can afford treatment. These setups include primary health centers, government health facilities, private pediatricians' offices, and private, charitable, or corporate run full-service hospitals.

Across the continuum of healthcare, professionals in developed countries tend to advocate for children to receive developmentally appropriate explanation about their diagnoses, have a greater voice regarding their healthcare experience, and make choices when given the opportunity (Rollins et al., 2018). In idealistic scenarios children should be encouraged to make their views known in routines that affect them, such as changes in diet, exercise, or ability to participate in school activities. Giving children a voice and advocating for their role in their own care improves the healthcare experience for children, thus acting as a buffer for negative experiences (Rollins et al., 2018). But this does not routinely happen in Indian pediatric hospitals, privacy can be denied, and often children suffer psychological trauma due to their illness and traumatic healthcare experiences.

Stress in Children with Chronic Medical Conditions

Children with chronic medical conditions and their families face ongoing medical appointments, treatments, and procedures, as well as changes in daily life. Children who are traumatized by their healthcare experiences may suffer both immediate and/or long-term psychological consequences. Hospitalization produces stress which is an appraisal of threat for situations in which children have little control. Stress appraisal is subjective, reflects social and cultural values, as well as individual differences in developmental level, temperament, and prior experiences (Hollon et al., 2018). Stressors which threaten a child's physical and psychological wellbeing in the hospital include fear of separation from parents, unfamiliar and unpleasant sensory stimulation, fear of unknown, pain from procedure/illness, losing control, loss of autonomy due to restriction of movement during medical procedures, invasion of privacy, fear of bodily mutilation, lack of play and lack of other developmentally supportive opportunities (Hollon et al., 2018). Psychological problems are often prevalent in children following discharge from the hospital. These manifest as behavioral changes, increased separation anxiety, regression, increased sleep anxiety,

increased aggression toward authority, negative body image, and impaired basic trust (Rollins et al., 2018). According to Hicks and Davitt (2018), beyond hospitalization, living with a chronic illness poses considerations for children regarding socialization constructs related to *mastery* (gaining sense of accomplishment through academic, creative, or other means); *competency* (having internal resources to perceiving success); *autonomy/independence* (having privacy, inclusion in decision-making, and self-care responsibility); *identity* (necessity to form a new reality due to chronic condition); *peer relationships* (less contact, misconceptions of peers); *body image* (adapting to physical changes due to condition, and related self-esteem issues); and *having hope* (developing hope-inspiring strategies).

Developmental Perspective for Understanding Children's Hospitalization

Illness, injury, and hospitalization can directly affect a child in all domains of development. Depending on the type of illness or injury, the cognitive, physical, perceptual, emotional, and social development could be affected. Conversely, the child's age, level of development and temperament can affect the way the child responds to hospitalization (Thompson et al., 2018). Children's reactions and hospitalization issues will differ for infants, toddlers, preschoolers, school age children, and adolescents. Erikson's theory of personality development and Piaget's cognitive development theories are used most widely in pediatrics (Turner, 2018). The psychosocial conflict and type of thinking present for each developmental stage influences children's perceptions of healthcare encounters, which consequently lead to age specific fears, misconceptions, and other psychosocial issues. To be effective, supportive psychosocial interventions must be provided to meet the needs of children according to their developmental stage.

For example, the psychosocial conflict for infants, birth-1 year, is "trust vs. mistrust," and they are in the Piagetian stage of sensorimotor thinking. Their principal hospitalization issues are related to separation from caregivers, lack of stimulation, and pain. These may result in attachment issues, failure to bond, distrust, anxiety, and delays in skill development. Supportive child development interventions for this stage would be to empower parents with information and encourage their active participation in the child's care as well as provide developmental stimulation as tolerated for the infant (Rollins et al., 2018). Whereas the psychosocial conflict for school age children is "industry vs. inferiority," and their main hospitalization-related stressors are related to separation from normal activities associated with home, school, and peers. They have concrete literal thoughts about their chronic condition, possibly resulting in misunderstanding and reduced self-esteem. Supportive psychosocial interventions for children in this age group would be to promote

opportunities for peer interaction, parental support, provide activities that allow for success, and supporting connections between child's home and school (Turner, 2018). Next, we briefly examine school as an institution impacting the socialization experiences of children with chronic medical conditions.

Socialization Influences in School Settings for Children with Chronic Medical Conditions

Living with a chronic medical condition often complicates the school experience of these children, and they often fail to achieve their full potential. From a psychological standpoint, attending school implies normalcy and familiarity. From the developmental standpoint, school offers children the opportunity to be industrious and develop a strong sense of self while academic skills are being mastered, and social interaction skills with peers are being established (Weiner et al., 2018). Children with chronic medical conditions often miss school due to exacerbation of their illness and/or hospitalization. In many countries, there are national, state, and local laws which recommend that sick children receive hospital-based and home instruction with appropriate medical documentation, and that there is a smooth transition from home to school after these children recuperate. Often when children with medical conditions return to school, they experience isolation, or even bullying, and will need more support to maximize social and academic success in the classroom. School re-entry anxiety is a concern for children who had extended absences due to their illnesses. The student with the medical condition, the family, teachers, and classmates should all be prepared to integrate the child returning to school. Teachers and peers must be educated regarding the impact of illness and healthcare experiences such as painful procedures, medications, possible limb amputations, and side effects such as nausea, hair loss, or weight gain/loss, and lack of energy to participate in school sports. Bridging the gap from the hospital to home to school is considered an integral part of not only education planning, but also life planning for pediatric patients to ensure continuity for these children's instruction (Weiner et al., 2018). Based on anecdotal experiences of the first two authors, often, in India, children with cancer or other serious illnesses and serious injuries are kept out of school for extended periods or even drop out without opportunities for remedial education. Thus, these children face dual loss of normalcy and the opportunity for optimal development from lack of support from the educational infrastructure.

Need for Education Sector Policies and Resources

Through initiatives such as the *Sarva Shiksha Abhiyan/Samagra Shiksha* and the Right to Education Act,

India has made remarkable strides in recent years in attaining near universal enrollment in elementary education, yet retention of children in schools continues to remain problematic in some sectors. While examining India's National Education Policy (2020, p. 9) which proposes new curricular and pedagogical guidelines covering children from 3 to 18 years, it is recognized that "children are unable to learn optimally when they are undernourished or unwell" (Sect. 2.9). However, then, the focus of the policy is on provision of nutritious school meals, health checkups, and immunization. While there is some reference to inclusion of children with special needs/disabilities or *Divyangs*, there is no specific reference for ongoing educational provisions for children with chronic illnesses or serious injuries who drop out from school or might be frequently absent from school due to their medical condition. There are no guidelines for schools to offer support to children and their families during this crucial time. There is an opportunity in India for human development professionals or counselors to work in the school system to liaise with healthcare professionals to create a school re-entry transition plan to help children living with chronic conditions become successful in their academic schoolwork and have a satisfying social life. Next, we briefly examine how families must adjust when a child in the home has chronic medical needs, and how it impacts the children's socialization experiences.

Socialization Influences: Parenting a Child with Chronic Illness

Hospitalization and Family-Centered Care

Parental anxiety is strongly correlated with children's unfavorable responses during hospitalization. Children feel higher emotional distress during invasive medical procedures when their mothers are more anxious (Rennick et al., 2014). For example, caregivers of children operated for congenital glaucoma at an eye institute in Hyderabad, expressed feeling depressed, anxious, having decreased self-confidence, lack of appetite, sleepless nights, anger, irritability, and feeling powerless in facing the disease and a lack of interest to pursue leisure activities (Gothwal et al., 2016). Research suggests that supporting highly anxious mothers by providing them with information, preparation, and tools for the children to understand their diagnosis, manage their disease, its treatment, pain, and adjustments to daily routines will enhance the psychosocial outcomes of hospitalized children (Rollins et al., 2018). Therefore, parental empowerment and participation in their child's care in a family friendly healthcare atmosphere is important. Family-centered care is based on the recognition that the family is the constant in the child's life with significant influence over the child's health

and wellbeing. All families must be treated with respect and dignity, educated regarding their child's diagnosis and treatment plan, as well as supported and encouraged in their caregiving and decision-making during hospitalization and other healthcare experiences (Cross et al., 2018). Provision of such family-centered services requires interdisciplinary collaboration.

Parenting a Child with a Chronic Medical Condition

Parenting a child with a chronic medical condition provides a unique set of challenges for parents and even siblings throughout the child's lifespan and has socialization implications (Hicks & Davitt, 2018). Before the child is discharged from the hospital, the family's priorities and resources must be considered as they will be forced to restructure home routines to care for their child with the chronic health condition. These families face unique circumstances depending on the type of onset of the child's illness, deformity, or injury, and experience ongoing social, psychological, and financial stressors (Khanna et al., 2015). Family functioning is a powerful determinant of overall quality of life and wellbeing in children with chronic medical conditions and may be impacted differently based on specific characteristics of a child's chronic medical condition (Herzer et al., 2010; Kesarwani et al., 2019). Also, westernized healthcare and conventional indigenous health practices merge, and this poses another challenge for families of sick children in India. It is important to ensure that the family's health culture is respected throughout the care their child receives (Cligrow, 2010). For example, Verloo et al. (2016) noted that children with type 1 diabetes reported the importance of maintaining their diet within their family context. One child mentioned keeping a wheat and *ragi*-based diet that the child's grandmother with diabetes followed. Another youth mentioned that neither the parents nor the youth were aware of the need to be treated by a diabetologist. Children reported wanting information about their diagnoses, treatment, medical specialists, and their prognosis (Cligrow, 2010; Verloo et al., 2016). In a study completed in Bengaluru, parents who could not read acknowledged that their child "wants to know everything" about his cancer even if the parents do not want him to learn about it. They were resigned to the idea that they could not do anything because their child could read and would learn about his diagnosis. More indigenous research regarding disclosure of medical diagnosis from children's and parental perspectives is needed.

The family must acknowledge the child's illness, define a new normal in family life, minimize social consequences of the disease, engage in behaviors consistent with the view of family life as normal, allow the child to continue their original role in the family, and take an active role in understanding the diagnosis and managing his or her treatment

(Rollins et al., 2018). On the contrary, when parents treat the child with a chronic illness without honestly communicating about the medical condition, and as if they are in a weak and dependent situation, the child could be socialized toward a sense of learned helplessness. This perception of helplessness because of the illness could influence the patient's emotional or physical state and treatment adherence (Nowicka-Sauer et al., 2017). Learned helplessness is defined, as the feeling that there is little control over their illness and subsequent experience, sensing no hope in fighting the symptoms of the illness, and resulting in a passive coping style. Psychosocial intervention such as patient empowerment and modification of negative perception of self is essential to reduce maladaptive psychological functioning (Nowicka-Sauer et al., 2017).

Colletti et al. (2008) examined the relationship of three parenting capacity variables: parental overprotection, perceived child vulnerability, and parental distress to parent-reported adjustment outcomes in children with cancer. Higher level of parental distress was more associated with poorer behavioral and social adjustment in children with cancer, compared with parental overprotection or perceived child vulnerability. While overprotectiveness may serve as a positive function during the active medical treatment phase, but if overprotective behaviors continue long-term and post-treatment, it may prevent children from achieving increased levels of independence (Colletti et al., 2008). This suggests that parents must be supported, provided with resources to reduce their personal distress, educated, and empowered to provide informed care to their child with chronic health needs.

Thus far, the review suggests that children with chronic illnesses and their parents would benefit from psychosocial care to reduce the challenges they face. The remaining sections of the paper will highlight strategies to promote their wellbeing and showcase two programs in India which are currently addressing these needs.

Envisioning a New Workforce in India

Children process information from the world around them much differently than adults and have distinct needs for managing the effects of stress and trauma. Without the assistance of a professional who understands their unique perspectives, children living with chronic health conditions and hospitalized children of all ages may experience emotions such as fear, shame, confusion, and loneliness which can inhibit their natural development and have lasting negative effects on their wellbeing. Parents and children are introduced to medical language, treatment protocols, and care in the context of hospital rules and medical staff preferences. Key to connecting with children and families is respectful listening and communication, by recognizing that children

and families make their own appraisals of stress (Desai & Pandya, 2013). Educating parents regarding the need to be honest with children about healthcare encounters and their medical condition are important. While emotional safety of children is everyone's responsibility, given the busy patient volume for doctors and other healthcare providers, they should collaborate with specially trained human development or psychology professionals to enhance children's coping with stressful healthcare encounters and build their resiliency. In USA, United Kingdom, and other countries, professionals called child life specialists or health play specialists work in children's hospitals as integral members of the pediatric team to help elevate children's viewpoints and rights in the healthcare setting. Their primary role is to promote effective coping and reduce the stress of hospitalized children and their families by focusing on the emotional, social, and developmental wellbeing of children (Association of Child Life Professionals, 2020; National Association of Health Play Specialists, 2020). Child life specialists help children process healthcare information more effectively by using consistent supportive interactions to provide age-appropriate diagnosis education, psychological preparation and procedural support for healthcare experiences, non-pharmacological pain management, play, normalizing the environment, and creating opportunities to voice their concerns and feelings. These professionals also support parents to provide honest and age-appropriate information for their children.

Care must be taken in creating psychosocial services which are relevant and feasible within India's sociocultural, healthcare, and economic context. Desai (2009) provides an aspirational blueprint including developing a curriculum to train a pediatric psychosocial care workforce to offer holistic care for children with healthcare needs. Getting approval from visionary higher education policy makers, implementing the academic and clinical training, and creating these jobs in collaboration with pediatric leaders, hospital administrators, and the Ministry of Health would be a momentous leap toward humanizing healthcare for India's children and their families.

Core Interventions to Promote Coping and Resiliency for Children in Hospitals

There are evidence-based interventions, the "4 Ps," that promote a child and family's coping and psychological wellbeing in hospitals and minimize long-term trauma. Play, Psychological preparation for hospital experiences, Parent and Family Empowerment, and Pain management are essential for a child's coping. Research suggests that these interventions contribute toward children's successful adaptation to the hospital environment (Thompson et al., 2018). Empirical evidence in Indian context has shown that effective

therapeutic play experiences reduce psychological stress in hospitalized children (Anandhukrishnan et al., 2018; Chari et al., 2013). Provision for continuity of schoolwork especially for children who face repeated hospitalizations is important for their education and development (Weiner et al., 2018). Psychological preparation for medical procedures is the evidence-based process of communicating accurate and developmentally appropriate information prior to the procedure, building trust, identifying stressors, providing clarification, and rehearsing coping strategies. This intervention has empirically shown to reduce both short-term emotional disturbances in hospitalized children and promote long-term coping and adjustment for future medical challenges (Goldberger et al., 2018). Another major concern for children facing hospitalization is experiencing painful procedures. Advocacy and preparation for pain management as well as rehearsing non-pharmacological pain management techniques is vital. Resiliency is defined as the ability to return rapidly to a previous psychologic or physiologic state (Rutter, 1987). It is important to note that children with chronic medical conditions can successfully integrate living with their chronic diagnosis and develop resiliency if given the right tools and support by trained professionals to do so (Rollins et al., 2018).

Examples of Two Indian Programs Providing Psychological Care to Children with Illnesses

While sparse, there are a few existing programs within India which provide psychological care to children with chronic conditions. Here we highlight just two different models of psychosocial care programming for children receiving care in pediatric settings.

Play program at Kashiben Gordhandas Patel Children Hospital (KGPCH), Vadodara

KGPCH is a public charitable trust run teaching hospital, with inpatient pediatric beds, neonatal and pediatric intensive care units, and outpatient specialty clinics, including 24/7 emergency care. The hospital admitted 8,680 children in 2019 for various medical and surgical treatments, including children with cancer, ophthalmic, and cleft conditions (KGPCH Annual Report, 2019). In 2011, in collaboration with the first author, the hospital formally initiated a Child Life and Child Development program with seed money from donor funding. Currently, the program is included within the hospital's budget. KGPCH administration welcomes psychosocial services and has hired a human development professional to provide play, leisure/normalization activities, preparation for procedures, and family support services. Due to the COVID-19 pandemic, the inpatient playroom was repurposed, and play is being provided for children at their

bedside until a new playroom space is designated. An outpatient area playroom has been designated.

The hospital management also encourages the development of a pediatric psychosocial workforce through field-work student placements. The first author supervised a child life internship student at this site to provide the “4Ps” of psychosocial care. Also, while the affiliation predates 2011, more consistently since 2013, the Maharaja Sayajirao University of Baroda’s Human Development and Family Studies (HDFS) program places approximately six undergraduate students each semester with KGPCCH’s Child Life and Child Development program as part of a university community collaboration. Temporarily paused during COVID-19 pandemic, this placement will resume once restrictions are lifted. Under their field work supervisor’s guidance, the students plan and implement play and learning activities for children in the hospital and provide parent support. This extends about 400–600 hours of supervised play for the hospitalized children per each academic semester. They also plan and host in-services for nurses, residents, and parents regarding creating child friendly healthcare environment, and celebrate holidays such as Diwali and Christmas. This collaboration creates an exemplary amalgamation of student service learning, community participation, and promoting psychosocial wellbeing of hospitalized children. This partnership enhances education, training, research opportunities, and exploration for HDFS students for a potential career development opportunity (Desai & Wadhvani, 2019). In a study by Mishra (2017), nurses at KGPCCH were asked to report their observations of the benefits of play for hospitalized children. Participants noted that play opportunities led to reduction in stress and anxiety for children and distraction from pain. Play also provided a medium for nurses to interact with children to develop a rapport and more positive child-nurse relationships. Nurses also reported that when parents saw their hospitalized child playing, it made them more relaxed and hopeful for their child’s recovery due to seeing their child engaged in the normal childhood behavior of play. By creating awareness among medical staff regarding hospitalized children’s psychological needs and capacity building for psychosocial care professionals, this program could serve as a role model for other children’s hospitals and academic institutions in India. The following feedback by a resident doctor in their oncology ward highlights the value of promoting psychosocial care:

I have been working for a month with a 10-year-old child hospitalized with spinal primitive neuroectodermal tumor, who had developed problems with mobility as well as bladder and bowel control due to his diagnosis. During my interactions, he was always sad and impassive. But, after receiving child life interventions such as getting emotional support, art activities, and education about his diagnosis, I saw drastic changes in his behavior from sadness to feeling

some normalcy, even some happiness, and from impassivity to alert engagement. Such interventions are very important for our patients’ emotional wellbeing and must be continued. (Personal Communication, Dr. M. Moradiya, 2021).

CanKids...KidsCan (CanKids), New Delhi

CanKids...KidsCan—The National Society for Change for Childhood Cancer in India is a national non-governmental organization working across the entire spectrum of childhood cancer care and is providing exemplary psychosocial services. Through their signature program “You are not alone,” they provide holistic support to children with cancer and their families, from detection of symptoms, through diagnosis, treatment and after. They serve children through outreach and networking with Cankids hospitals support units in 121 hospitals in 22 states and 47 cities, 13 Cankids care centers, 10 regional care coordinating centers and other statewide advocacy projects throughout India (CanKids, 2020b). Cankids’ Pediatric Psycho-oncology Program leaders recognize that in India, the focus of care is medical treatment centric and not holistic. They recognize that financial support needs override all other needs, and often families do not focus on their emotions. They acknowledge that often medical professionals are not sensitized to children’s rights during their treatment and have poor communication skills for sharing difficult diagnosis or prognosis related news, and children are often talked “over.” This team recognizes that according to the UNCRC, children with cancer have the right for a full and decent life including access to equal opportunities for educational, cultural, artistic, recreational, play, and leisure activities. (CanKids, 2020c). To fulfill this need for the critical component of the holistic care and support, the team of dedicated psychologists focuses beyond medical treatment to provide individualized attention to each child and their family throughout all stages of the cancer treatment, including during remission, palliative care, and for survivors. This program outlines a set protocol for patient support interventions such as promoting child friendly wards, explanation and clarification of diagnosis, disease-oriented counseling for parents and the child, expressive and group therapies, non-pharmacological interventions for procedural pain, as well as bereavement support for children in terminal stages. They also offer capacity and skill building for the social support team and sensitization workshops for healthcare providers, research and tool development and an internship in pediatric psycho-oncology (CanKids, 2020c). CanKids’ *Chattai* therapy and CanShala programs focus on education and school reintegration needs of children with cancer. CanKids’ KidsCan Konnect program successfully offers peer support childhood cancer survivors to learn to look after their health and cope with late side effects of their cancer treatment.

Conclusion

As highlighted, throughout the paper existing research indicates long-term benefits of investing in psychosocial services for children with chronic conditions in ensuring their education, development, and wellbeing. The commitment to addressing the inequities facing children with chronic medical conditions and envisioning their resiliency is an urgent collective responsibility of all the relevant stakeholders in India. Advocating for all children and families to be seen and heard in their healthcare journey, reducing their fears, and promoting their coping and resilience is a natural role for human development professionals. Desai (2009) provides a detailed framework for developing this workforce in India and suggests opportunities for indigenous research, teaching, and service. Making this vision a reality means asking pediatric and human development professionals to question their own beliefs about what is possible and reimagine how they can work with children with chronic illnesses. It means asking hospital administrators to prioritize policies to also include focus on a broader set of psychosocial outcomes. It means asking the government and other agencies to allocate funds and resources for promoting pediatric psychosocial care. It means asking researchers to delve more into indigenous research regarding psychological needs of children with chronic illnesses and their families. It means asking families to understand the needs of their children and work with pediatric providers and institutions to advocate for their children's psychosocial needs. It means implementing a pediatric psychosocial curriculum and standardized training toward developing a new skilled and credentialed workforce within India, fueled with a vision for fostering resilience in all children with chronic medical conditions and their families through providing evidence-based interventions. It means taking action for creating this urgent change for children's wellbeing.

Author Contributions The article's idea was of PPD. She worked with Perminder Wadhvani to develop the idea for the Indian context. PPD developed the manuscript, and writing support was provided by Lisa Staniec. All authors read and approved the final manuscript. PPD is the corresponding author for this manuscript.

Funding No funds, grants, or other support were received for this work.

Declarations

Conflict of interest The authors have no conflicts of interest to declare that are relevant to the content of this article.

Consent for Publication Will be provided if article is accepted; and per Springer's requirement.

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