

Psychosocial Needs of Families with Children with Medical Complexity

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ABSTRACT

Approximately 3 million U.S. children are considered to have medical complexity, a subset of children that are the most medically fragile, have highest healthcare utilization, special education accommodations, unmet mental health needs but who are living longer lives with improved medical advancements. Families with children with medical complexity often experience a myriad of physical, mental, and financial stressors impacting their well-being, family functioning, and mental health. Pediatric providers can prepare themselves to better understanding the unique factors of families with children with medical complexity and inform their clinical approaches with trauma-informed and health equity lenses. As children with medical complexity and their siblings are often seen in general pediatric environments, the unique psychosocial needs of families will be discussed to benefit pediatric providers.

Keywords: Medical trauma; Health equity; Pediatrician; Medical complexity

INTRODUCTION

Psychosocial needs of families with children with medical complexity

Children with special health care needs are at increased risk for chronic physical, developmental, behavioral or emotional conditions and require health and related services of a type or amount beyond that required by children generally [1]. Children and Youth with Special Health Care Needs (CYSHCN), defined by the Maternal and Child Health Bureau (MCHB) as having or being at increased risk for a chronic physical, developmental, behavioral or emotional condition and requiring health and related services beyond that required by children generally (HRSA, 2021)[1].

Within the group of children with special health care needs exists a smaller subgroup of children with medical complexity. These children and their siblings are often seen in general pediatric environments, particularly in geographical locations with limited access to patient centered health homes or hospital-based complex care clinics. This article will outline the unique factors impacting families with children with medical complexity and discuss psychosocial implications for pediatric providers.

Approximately 3 million US children are considered to have medical complexity. These Medically Complex Children (CMC) are the most medically fragile and have the most intensive health care needs of all children with special health care needs [1]. Medical complexity suggests a combination of multi organ system involvement from chronic health conditions, functional limitations, ongoing use of medical technology and high resource need [1]. Children with medical complexity share similar healthcare needs including intensive utilization of medical providers (either hospital or outpatient), reliance on assistive technology, polypharmacy and ongoing home care to maintain an essential quality of life [2]. They also have an increased risk of hospitalizations and need for care coordination [2]. Example conditions are heterogeneous and have diagnoses including extreme prematurity, severe cerebral palsy, rare genetic syndromes, chromosomal abnormalities, brain anomalies and congenital heart disease. Children with medical complexity comprise 6% of the total number of children on medicaid while accounting for approximately 40% of total medicaid spending [3].

Pediatricians report numerous barriers to providing adequate care to children with medical complexity, including polypharmacy, patient interactions are time-intensive,

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inadequate time to spend with the patient, multi organ system disease, rare or unfamiliar diagnosis and number of specialists involved in care, frequent care transitions, technology dependence, inadequate ancillary support and unclear care goals. Current insurance and reimbursement models impede the provision of high-quality care for these children. For example, payers, including state medicaid programs, may limit the amount, scope and duration of covered health services for children with medical complexity [3]. Services needed by families with children with complex medical needs are often not covered by insurers, thus enhancing family burden [3].

LITERATURE REVIEW

Frameworks for clinical practice

Families with children with complex medical conditions are a unique group with myriad stressors related to their family context. Without adequate knowledge and understanding of the intricate and complicated stressors facing these families, pediatric providers run the risk of not providing an informed and safe place for clients to fully engage in healthcare. The frameworks of health equity and trauma informed care and may be well-suited to prepare pediatric providers to effectively serve this population.

Health equity lens

A health equity lens can assist pediatric providers to adequately understand the unique barriers facing each family based on their cultural, community and other systemic influences. Systemic health barriers for people of color, immigrants, people who experience poverty and other marginalized groups are pervasive. Providers can better assist clients in the medical space through addressing systemic and historical inequities impacting the family as well as support the family through advocacy, appropriate referral and other resources to overcome health barriers inhibiting their access to equitable healthcare. Equitable healthcare requires removing obstacles to health such as “poverty, discrimination and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments and health care” [4]. For children and youth with special health care needs, social determinants of health are associated with the presence and severity of health conditions and this population can be more severely impacted as the number and severity of physical and mental health conditions increase [5]. Furthermore, the Coronavirus Disease-19 (COVID-19) pandemic disproportionately impacted communities of color, thus negatively impacting mental health, physical health and socioeconomic outcomes [6].

Access to financial resources is a prominent social determinant of health, one that impacts various health indicators over time and research has linked poverty to lower ratings on measures of well-being across the life span. Financial hardship, including food insecurity and housing instability are common experiences for this population due to extensive medical costs and the necessity for caregivers to often exit the workforce to keep up with the home care for their child [7]. One study showed that of

their sample of 167 families with children with medical complexity experienced financial hardship, including food insecurity and housing instability. In many cases, parents are unable to work full-time because of the demands of their caregiving responsibilities. During the pandemic, parents of lower income were more susceptible to declines in wellness than parents with higher household incomes [8]. Families with children with complex health needs often face critical financial stressors, increasing the systemic barriers faced within the healthcare system. Financial stress intersects with families who also have marginalized identities and research shows that minority families with children with special health care needs face high levels of income inequality and other systemic barriers impacting their overall financial stability (CDC, 2022). There is currently a paucity of available pediatric home nursing and licensed childcare centers nationally that can provide needed medical care for CMC, often forcing families to choose between employment and providing daily care for their child, which furthers income gaps with increased out of pocket costs for medical and therapeutic care, increasing the financial stress to families.

Trauma informed care

Medical trauma may include parents’ perceptions of their child experiencing significant pain, the perceived threat to their child’s life and degree of concern that they might die related to an ongoing medical condition or medical diagnosis [9]. Parents of children with complex medical conditions are highly likely to have experienced some form of medical trauma over the lifetime of their children and are at significant risk of developing Post-Traumatic Stress Disorder (PTSD), depression, anxiety and complicated grief [10]. Traumatic experiences are linked to maladaptive coping techniques and myriad negative health outcomes such as increased symptoms of anxiety and depression, increased substance use, cardiac issues, chronic pain and other physical illnesses [11]. A trauma-informed approach when working with families with children with medical complexity is necessary for effective pediatric care in order to create a safe space for families to discuss their experiences without being retraumatized by the clinician or health system.

Psychosocial family needs

Parent caregivers of children with medical complexity report many unmet care needs, including difficulty accessing specialized equipment, communication and mobility aids; inadequate dental care, respite care, family support, care coordination, financial burdens and unmet mental health care for not only the patient but the family at large [12]. Many children with complex health needs have developmental and intellectual delays and/or functional limitations that require long-term assistance. Children may also receive multiple diagnoses for mental health challenges, including autism spectrum disorder.

The cumulative impact can be overwhelming for families as parents often take on significant healthcare roles within their family including administering medication, case management, using assistive technology and cleaning/providing ongoing

maintenance of health equipment [13]. Parents typically become involved in every aspect of their child's care and come to possess a significant amount of knowledge of their child, their treatment and their health [13,14]. Caregiving for children with complex health needs is time-consuming, physically arduous and highly stressful [13].

Parent caregivers with children with medical complexity face untenable levels of stress with substantial unmet mental and behavioral healthcare needs and consistently report elevated levels of depression, anxiety, fatigue, distress, poor physical health, isolation, cardiovascular issues and other mental health complaints [12]. Parents endorse myriad physical and mental health problems such as fatigue, headaches, decreased cognitive function, social isolation, emotional distress [13]. Over 80% of families in one sample reported challenges with family daily activities including problems with family relationships, lack of communication and increased stress and conflict [13]. Psychological impacts include grief around the loss of a dream for their child, watching their child in pain, tensions with their spouse and the family system, chronic fatigue, social isolation and lack of support from family and friends [7,13]. Mothers of children with disabilities or chronic illness have higher rates of mental illness (e.g. depression, anxiety and suicidality), role strain and decreased marital satisfaction when compared to mothers of healthy children [14].

Social isolation is another major health problem for families with children with complex health needs [13]. Parent caregivers often have no time to leave the home as they have difficulty securing substitute childcare that can safely manage their child's health needs. Further, the social networks of these parents typically cannot relate to their life experiences, which increases isolation. Taking children out of the home is time-consuming and cumbersome, as equipment and adaptive technology is often necessary. Managing complex healthcare in the home can become a burden and an ongoing stressor for parent caregivers and can significantly affect family functioning and daily life activities. Parent caregivers often must maintain a complex schedule of treatments, therapies and health appointments, which also prevents socialization.

Data suggest that families with Medically Complex Children (CMC) are at increased likelihood to have contact and involvement with child welfare services; with some samples showing a quarter of families having documented contact. The extensive individual and family challenges coupled with systemic issues such as poverty have negative cumulative consequences on child safety and adverse childhood events are prevalent including neglect, parent caregiver mental illness, and family violence.

DISCUSSION

Child mental health and well-being

Parent caregiver's mental health and overall family health is intricately related to children's well-being. Despite evidence that parental emotional support plays a protective role for siblings, studies have shown parents often lack in their capacity to

provide such support due to their own trauma and burnout related to the demands of caring for a child with complex health needs [15]. It is estimated that 75% of families who are caring for a child with complex needs are also caring for a well-child [16].

Children with disabilities have poorer health-related quality of life, emotional and social functioning than their counterparts without disabilities. Children may experience long-term impacts including parent-child relationship disruptions and traumatic reactions from stays in hospital intensive care units and other outpatient medical procedures. Repeated exposure to severely stressful medical procedures can activate an infant or child's stress response, thus increasing the potential for experiencing long term trauma as a result of ongoing and sustained medical treatments. Second, siblings of children with medical complexity have been shown to have increased risk of negative emotional, social and academic outcomes [17-19]. The psychological and social well-being of siblings of Medically Complex Children (CMC) is threatened by ongoing stress, lack of support by parents and intrusive lack of family stability [15]. Prevalent feelings expressed by siblings may include helplessness and hopelessness, both psychological indicators of depression and mood symptoms [15].

Resilience

Areas of resilience are important to acknowledge and foster in this population. Resilience is well known as an important trait related to wellbeing, mental wellness and our ability to heal, recover and make meaning from challenging or traumatic experiences. Families with children with medical complexity are incredibly resilient, particularly when it comes to relationships, altruistic and positive behaviors among children [16]. Discussing family perspectives of their strengths and resilience into medical treatment can be an important component of their care.

Medical provider support for parents who have and continue to endure trauma as a result of ongoing medical interventions for their children has direct mental and emotional health benefits for the parent, child and entire family system. The health and functioning of parent caregivers and family functioning are clinically important to ensure optimal health and functioning of children with complex health conditions [12,13].

CONCLUSION

Approximately 3 million U.S. children are considered to have medical complexity, a subset of children that are the most medically fragile and have the most intensive health care needs of all children with special health care needs. Families with children with medical complexity often experience myriad physical, mental and financial stressors impacting their well-being, family functioning and mental health. Accessible, effective and trauma-informed healthcare services are necessary to support parents, caregivers and family members through past and ongoing medical and other challenges. Pediatric providers can prepare themselves to better understanding the unique factors of families with children with medical complexity and inform their clinical approaches with trauma-informed and

health equity lenses. Overall, families with children with complex medical needs have significant stressors and deserve effective and accessible health care to support the overall wellbeing of the family system.

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