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Review Article

Challenges and Support Needs of Caregivers of Children with Medically Complex Conditions and Disabilities: A Mini Review

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Abstract

The enhanced survival rates of children with life-threatening conditions have led to an increased demand for caregiving support among this population. Children with medical complexity represent a small proportion of the pediatric population but account for disproportionately high healthcare use, costs, and family burden due to their extensive medical and psychosocial needs. Their care requires multidisciplinary teams and is increasingly supported by pediatric palliative care to optimize quality of life through symptom management and family support. General principles for models of care for CMC include medical comanagement, care coordination and family or caregiver support. Patient-Centered Care (PCC), Complex Care (CC), and Episode-Based (EB) models provide structured approaches for children with medical complexity. Each model offers benefits in continuity and specialized management but faces challenges such as high costs, limited resources, poor communication, and increased risks from fragmented care. The concept of caregiving in children with medical complexity is characterized by tasks including daily and instrumental activities, transitions such as delegation and shifts toward institutional care, roles beyond family duties with reciprocal nurturing and the overall caregiving process. We found that the affected domains of parental caregiver experience can be divided into four domains. Firstly, personal domain includes identity, physical and mental health. Second, family domain that is characterized by marriage, sibling and their quality of life. Third, social domain includes time limitations and isolating lived experience. Finally, financial domain include employment, medical and accessibility costs. Supporting caregivers of children with medical complexity requires accessible, comprehensive services that extend beyond the child's medical needs to address family well-being and caregiver mental health. So, the caring for the caregiver (C4C) model is a phased, integrated approach that partners pediatric complex care programs with psychiatry. It provides tailored mental health support for caregivers, addressing the unique demands of caring for children with medical complexity. This model focuses on depression, trauma, anxiety, and related illnesses that may face caregivers.

Keywords: caregivers; children; disabilities; medically complex conditions; palliative care; primary care

Key Message

- Given the challenges associated with caring for children with complex medical conditions, it is essential to implement early detection and effective proactive intervention systems to assist these caregivers.
- Psychological or pharmacological interventions can improve the caregiver's mental health.
- An enhanced psychological comprehension of caregiver experiences can guide the development of more effective interventions and improve mental health outcomes for families dealing with complex pediatric conditions.

Introduction

Children with medical complexity (CMC) represent a specific group within the population of patients with special healthcare needs. They are characterized by the presence of multiple chronic health conditions that impact various organ systems, leading to significantly elevated healthcare utilization and dependence on medical technology. [1].

Patients with CMC frequently necessitate emergency care, endure prolonged inpatient stays, and encounter recurrent hospital readmissions.[2] Children with medical complexity requires a coordinated transition from the hospital to home to achieve positive outcomes for patients and families, as well as to ensure the continued efficient utilization of the healthcare system. [3]. Caregivers of children with complex medical conditions experience distinct needs and stressors in contrast to those caring for children without such complexities. A caregiver is defined as an individual who coordinates and engages in unpaid care, excluding nurses and professional paid caregivers.[4] The financial burden associated with caring for CMC is extensively documented. Research indicates that more than half of families with CMC experience considerable financial stress and elevated rates of workforce attrition due to their child's health, which further intensifies the financial strain on these families.[5,6] The prevalence of unmet needs related to income level and insurance status for CMC has prompted some researchers to propose that medical complexity may serve as an independent risk factor for health inequity.[7]. Higher levels of family functioning in children with chronic conditions correlate with enhanced quality of life (QoL), treatment adherence, and physical health. [8]. The emotional well-being of parents, along with community and emotional support, significantly influences family functioning. [9]. National organizations, CMC clinician experts, and family stakeholders have identified family health, well-being, and community integration as priority targets for the national research agenda.[10,11]. Pediatricians are uniquely equipped to recognize emotional distress and provide support to caregivers of children with significant needs. Pediatricians can offer interventions for mild cases, whereas more severe cases may necessitate a referral to a mental health provider. This role is challenging yet has the potential to enhance outcomes for parents, children, and overall family well-being. [12]. In order to capture all facets of the topic, this research examined several key themes, such as definition of children with medical complexity, their burden and their models of care delivery. In addition, our work described definition of concept of caregiving, the role of the caregivers, affected domains of parental caregiver experience and caregiver coping in pediatric complex hospitalization. We also focused on how to support caregivers of children with medical complexity to overcome challenges through discussing a program called "caring for the caregiver model" while also considering the development of this model to provide a comprehensive perspective on supporting caregivers of children with medical complexity.

Children With Medical Complexity

Children with medical complexity are characterized by the presence or risk of pathologies that may impact neurological development and lead to chronic behavioral or emotional issues. They require a broader and more intensive level of healthcare than what is typically necessary for the general pediatric population. [13,14] Children with medical complexity has been a specific focus for health system enhancement in individuals with chronic diseases due to their significant health care utilization, functional limitations, and family needs. [15] Care for CMC generally necessitates the involvement of multidisciplinary teams comprising pediatricians, pulmonologists, neurologists, gastroenterologists, nutritionists, respiratory physiotherapists, and specialized nurses who manage devices like tracheostomies and gastrostomies.[16] Population prevalence estimates for children vary significantly, ranging from 0.20% to 11.4%, largely due to inconsistent identification methods. [17,18] This group's significance stems from their distinct and profound needs, which health systems and caregivers frequently struggle to address. Population-level analyses indicate that while their prevalence is low, their impact is significant. [19,20] Despite comprising less than 1% of the pediatric population, children with CMC represent 33% of total pediatric health care expenditures, 37% of hospitalizations, 54% of inpatient days, and 57% of hospital costs.21-24 Their prevalence is expected to increase due to higher survival rates among premature infants, children with congenital anomalies, and oncology survivors. [16] All CMC classes shared common diseases specifically gastrointestinal disorders, respiratory diseases, and trauma.[25] These diseases account for the major causes of hospitalization rates together with congenital anomalies, and cardiovascular and oncological diseases. The oncology class contained 36.0% of all CMC and was predominated by individuals aged up to 5 years. In accordance with the natural development of most respiratory diseases, its prevalence was highest in the mid-age range, and it accounted for 30% of all the CMC. [26]. In the last 10 years the percentage of prematurity has remained virtually unchanged (1 out of 10 new births), while the percentage of very preterm newborns that are part of CMC, has increased.[27]. Pediatric Palliative Care (PPC) is increasingly responsible for managing CMC. Palliative care focuses on providing comprehensive support for patients with life-limiting or life-threatening conditions and their families.[28]. The objectives PPC include ensuring symptom management, preventing suffering, and supporting families, with the aim of optimizing QoL. To achieve adequate symptom management, CMC frequently undergo treatment with complex medication regimens (CMRs) and polypharmacy. [29]

Models of Care Delivery for Children with Medical Complexity

General principles for models of care for CMC

Most current models of care for CMC incorporate enhanced care coordination services alongside additional supports.[30]Care coordination in this context comprises a collection of services delivered by a designated team, focusing on patient and family-centered approaches, driven by assessments, and aimed at fulfilling the goals and needs of both the patient and family.[31] Enhanced care coordination emphasizes continuity, familiarity, accessibility, partnership, and early recognition of crises. The ideal care delivery model for CMC emphasizes the development of proactive plans aligned with family and children's goals, ensures timely treatment of urgent acute health issues, facilitates multidisciplinary shared decision-making, and involves a provider who is familiar with the child and/or family in addressing comprehensive needs.

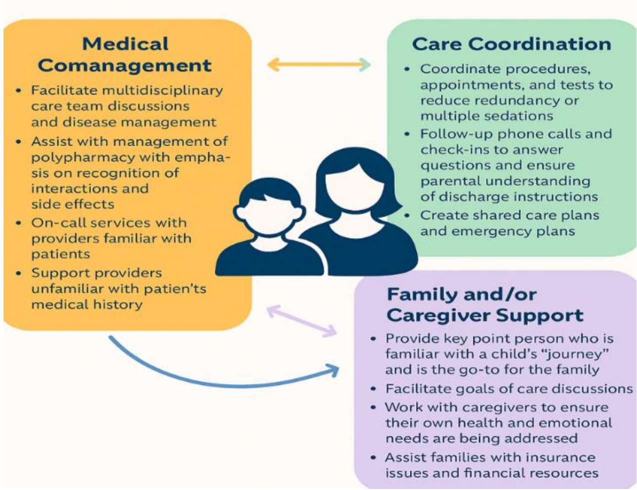


Figure 1: Examples of Services Provided by Models of Care for CMC.[32]

Models of Care Delivery for Children with Medical Complexity are categorized into three main types: primary care–centered (PCC) models, consultative- or ecomanagement-centered (CC) models, and episode-based (EB) models.[32]

Primary care–centered models of care

The PCC models for care delivery in children with medical complexity incorporate the principles of the medical home as defined by the American Academy of Pediatrics.[33]The models can be categorized as community or tertiary care-based, focusing on the provision of services that are continuous, coordinated, compassionate, and culturally appropriate within a primary care center. [34]Various health, policy, and nonprofit organizations advocate for care coordination via patient-centered care models. Also, PCC models leverage established relationships among primary care practices, families, and local communities. [35]Relationships between primary care teams and families may commence prior to the onset of a child's illness, positioning providers within PCC models to deliver diverse services as the needs of children with medical complexities and their families develop.[32]While frequently endorsed as the optimal model, meeting the needs of this varied and intricate population poses challenges for primary care physicians (PCPs).[36]Primary care providers identify several barriers to delivering care, including elevated costs, insufficient reimbursement, and the time required for service provision, inadequate communication and coordination tools, limited knowledge for managing complex acute illnesses, and a scarcity of personnel and community resources.[37]

Consultative-centered models of care

Regarding CC models refer to frameworks where providers in subspecialty or complex care programs at tertiary care centers offer care coordination services, frequently collaborating with primary care physicians.[38]. Unlike PCC models, CC models typically do not serve as the initial access point for patients seeking health care and frequently exclude routine childcare services. The efforts of CC models, like those of numerous palliative care programs, primarily emphasize care coordination services, goal-directed co-management of medical issues, and serving as a link between the tertiary care center and the community.[31]

Episode-based models of care

Episode-based models typically involve time- or location-restricted interventions aimed at delivering medical management and care coordination for a particular illness episode or transitional phase.[39]Examples of EB models encompass an inpatient service where a specialized care team experienced in managing complex conditions attends a specific group of CMC, transitional care homes that provide a living arrangement for children between hos[40]. Pitalization and home while their parents receive training on new medical equipment, and inpatient rehabilitation facilities. The benefits arise from the capacity of trained personnel to provide continuous care during periods of heightened vulnerability for children and families. Parents of children with medical complexities report feelings of isolation during hospitalizations, express concerns for their children's well-being, experience anxiety regarding their other children and missed workdays, and confront difficult decisions related to end-of-life care. The disadvantages are associated with the location and episodic characteristics of EB models. The increase in hand-offs necessary for 24/7 care, coupled with insufficient communication with ambulatory care teams (such as home nurses, schools, primary care providers, and outpatient subspecialists), significantly elevates the risk of medical errors and care gaps for children with medical complexity.[32] Features of each model are described below and summarized in Table 1

Model	PCC	CC	EB
Advantages	Ease of travel for families	Connection to tertiary-based services	Ability to assess and impact treatment and/or clinical status at sickest time
	Awareness of local culture, values, and resources	Cohorting of patients allows for streamlining processes and development of trained workforce	Burden of care provision not on family

	Covisits with siblings	Provider familiarity and comfort with complex diseases and/or creation of specialized “complex-ology” workforce	Focus on transitions: for example, the creation of discharge standardization to limit gaps in care and aim to reduce readmissions
Disadvantages	Insufficient infrastructure and personnel for care coordination	Enrollment criteria may result in missing children with unmet needs	Services often provided at a distance from family
	Time constraint	Finite tertiary center financial, structural, and staff resources	Risk of poor continuity of care between care locations
	Obstacles to sharing medical records across different systems	Service delivery may be more expensive	Inconsistent care teams
	Lack of skill set	Risk of diffusion of responsibility, given unclear patient ownership	----
	CMC may receive majority of care elsewhere	Lack of integration with community-based services	----

Table 1: Features of the three categories of care for CMC.

Caregiver and concept of caregiving

A caregiver is defined as an individual who offers support and assistance, whether formal or informal, to people with disabilities, long-term conditions, or elderly individuals. This individual may offer emotional or financial assistance, in addition to practical support with various tasks. A significant number of caregivers are young individuals, including children. [42]Caregiving can adversely impact the mental and physical health, along with the economic and financial stability, of caregivers. [42]Research indicates that caregiving correlates with heightened psychological stress, anxiety, depression, physical health issues, and diminished social and family interactions.[43] The provision of long-term cares for chronically ill family members or significant others at home elevate the risk of financial difficulties for caregivers. [44,45]Employed caregivers have reported absenteeism; personal days taken, early retirement, and reduced paid working hours to fulfill caregiving responsibilities. [46]Caregiving may enhance positive self-identity and self-worth while fostering a sense of belonging among young caregivers. [47]A conceptual analysis identified four characteristics of family caregiving: tasks, transition, roles, and process [48]The identified tasks encompass activities of daily living, instrumental activities of daily living, the extent of care provided, and both direct and indirect care.[49] Transitions emphasize care management, delegation, and the shift from family to institutional care. Caregiving roles extend beyond typical family care and encompass reciprocal nurturing behaviors.[50]The concept of caregiving has been examined and applied in various disciplines beyond nursing. In sociology, caregiving is defined as the care provided by unpaid workers, including family members, friends, neighbors, and individuals associated with religious institutions.[51]Psychology is a discipline that examines caregiving, focusing on the psychological ramifications associated with the act. [50]We found that the affected domains of parental caregiver experience can be divided into four domains. Firstly, personal domain includes identity, physical and mental health. Second, family domain that is characterized by marriage, sibling and their quality of life. Third, social domain includes time limitations and isolating lived experience. Finally, financial domain include employment, medical and accessibility costs.

Affected Domains of Parental Caregiver Experience

Four major categories were identified to describe affected domains of parental caregiver experience: personal, family, social, and financial (Figure 2).

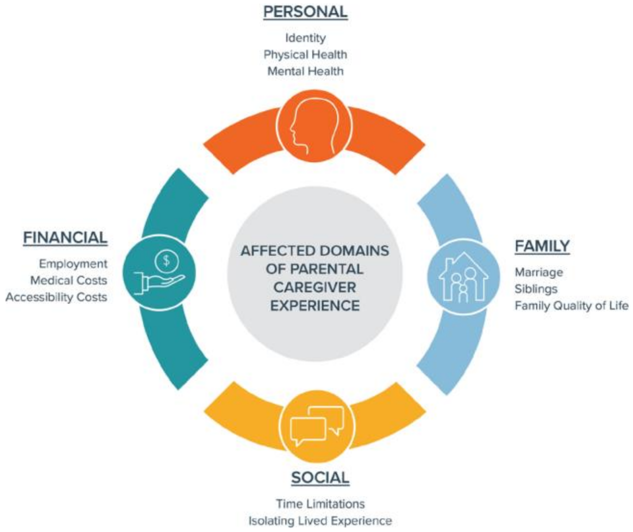


Figure 2: Affected domains of parental caregiver experience[53].

Personal

- **Identity:** According to several participants, taking on the role of caretaker radically altered every element of their lives.[52].Caregivers stated that their jobs as advocates, medical educators**,** and health care providers had supplanted their identification as "parents." According to **Teicher et al.** [53]some caregivers felt that their newfound social and financial reliance on others was inconsistent with their self-sufficiency identity.
- **Physical Health:** A lot of caregivers mentioned that they were unable to take care of their own physical health because of the work involved in providing care. Examples were inadequate primary care access, musculoskeletal problems from lifting duties associated with caring, decreased exercise, sleep loss, poor nutrition, and weight increase[53]
- **Mental Health:** In reaction to their child's diagnosis, prognosis, or perceived limits, some caregivers experienced clinical depression or symptoms of intense sadness; others expressed feelings of worry or rage**.[53,54]**Accessibility issues at the individual and systemic levels were identified as obstacles to receiving mental health care. Numerous caregivers brought out how burnout negatively impacts coping.[53]

Family

- ***Marriage***: According to **Aksin et al.[56]** some caregivers mentioned their marriage as a vital source of cooperation and support when providing care. Limited time spent together, or unequal caring obligations caused stress in other relationships. Talking about their CMC's needs with their spouse was restricted by health and financial concerns, according to several interviewees. Through shared custody, one participant separated from their spouse in part to provide respite for caring.[53]
- ***Siblings***: Concerns were voiced by caregivers who had more than one child over the restricted amount of time they could spend with the CMC's siblings.[57,58] The majority said that the CMC's apparent prioritizing disrupted the bond between parents and siblings, negatively impacted behavior and emotional control, or fueled siblings jealously. Some caregivers emphasized how having a CMC as a sibling helped their other kids grow up.[59]
- ***Family Quality of Life***: A few caregivers talked about how the CMC's bad health has a detrimental effect on their family's ability to cope.[60]Many participants prioritized family quality of life over other considerations when choosing a place to live, such as living close to green areas or medical facilities.[61,62]

Social

- ***Time Limitations***: According to **Teicher et al.[62]**, providing care takes up most of their time, which restricts or eliminates social interaction with friends, family, and their religious community. It was highlighted that caregivers of children with CMC had a particular social constraint due to the child's rigorous medication and dietary regimen.[63]
- ***Isolating Lived Experience***: Several caregivers talked about how their lived experience made it hard to relate to those who weren't also CMC caregivers because they didn't comprehend the intricacy or scope of the caring responsibilities of a CMC. [64]

Financial

- ***Employment***: Because of the child's requirements or the effects of caregiving on mental health, participants' employment was restricted. Only a small percentage of employers offered remote work opportunities and other relevant accommodation. Participants who worked for themselves reported more flexibility at the price of steady income.[53]
- ***Medical Costs***: Hospital expenses, private childcare, prescription drugs, and rehabilitation programs were among the high medical costs of caregiving that caregivers reported were not adequately covered by social assistance; even some "covered" costs were said to require a sizable upfront payment followed by reimbursement.[53]
- ***Accessibility Costs***: According to a few caregivers, their CMC's accessibility requirements required more costly houses or larger cars.[65]Others described the high cost of car adaptations or housing modifications linked to accessibility, as well as the challenges in obtaining financial subsidies for these costs.[66]

Caregiver Coping in Pediatric Complex Hospitalization

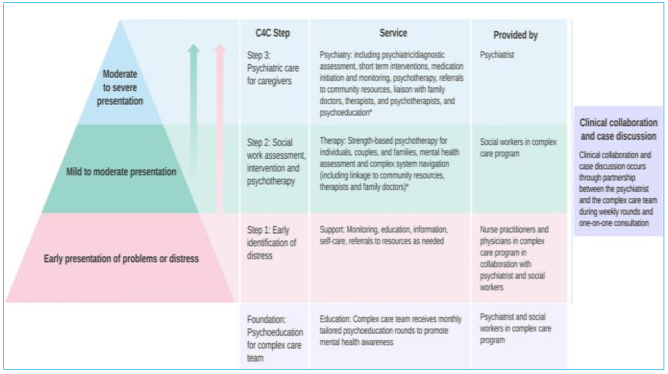
When a kid is admitted to the hospital, their caretakers may experience communication, psychological, and physical difficulties.[67]A viable intervention target to enhance the health and welfare of CMC caregivers may be caregiver coping, which is described as the behavioral or cognitive strategies an individual uses to reduce their discomfort.[68,69] Little is known about how to support caregiver coping during hospitalizations for the CMC population, even though interventions aimed at improving caregiver coping of hospitalized children have the potential to affect caregiver anxiety, stress, and quality of life. [70,71] Three factors, according to a recent study, influence how CMC caregivers cope when their children are in the hospital: they believe their child's interdisciplinary team is trustworthy, they feel their self-care routines are seamlessly integrated into the hospital's routine and flow, and they feel they are putting their child's needs ahead of their own. When developing future interventions, these CMC-specific variables should be considered as a chance to improve caregiver support. [72]Additionally, CMC caregivers discussed how crucial it is to concentrate on their child's needs when they are in the hospital. In addition to being in line with patient and family-centered care guidelines, this affirmation of the caregiver role may make caregivers feel more supported while they are in the hospital.**53)** One element that helped caregivers cope was their confidence in the interdisciplinary team member's expertise and regular communication. Even though the benefits of open communication and continuity of care with CMC caregivers have been extensively discussed, trust is a complicated concept, and further study is required to fully comprehend the subtleties of how trust improves caregivers coping with CMC hospitalizations.[73,74]Caregivers' coping skills are enhanced when they perceive that their self-care routines are regularly included into the hospital flow. [75]Numerous facets of the caregiver's life are disturbed when a kid is admitted to the hospital, such as their capacity to manage work, sleep, family responsibilities, and their practice of self-care routines. [76]Potential benefits of interventions that assist caregivers in modifying their current self-care routines for the hospital environment were proposed.[72]

Supporting caregivers of children with medical complexity

In order to support caregivers of CMC, families and healthcare professionals have realized the need for more thorough and easily accessible care.[72,12] While most pediatric complex care programs concentrate on the child's medical need, some have created more allencompassing family support models. [79]Psychiatric treatment is necessary for evaluating and diagnosing caregiver psychiatric disorders, starting medication, and suggesting suitable management interventions, even though pediatric teams offer a variety of caregiver support services.[78] The incapacity of pediatric complex care programs to diagnose and treat adult patients in a pediatric setting is currently a limitation.[80].Geographical barriers, finding a provider who understands the unique dynamics of caring for CMC, limited access to psychiatric care, insurance barriers, and timely access given high caregiving demands and prolonged hospital admissions are some of the obstacles that caregivers of CMC face when trying to access appropriate mental health services.[12,82] Parents may be able to meet their caregiving responsibilities and enhance the health of both themselves and their children by having access to psychiatric treatment and other psychosocial supports.[82] Additionally, positive child psychosocial and functional outcomes are linked to psychosocial therapies for parents of preterm infants.[83] Supporting the caregiver in addition to the child may result in better health results for both parties through a two-generation approach to care.[84]

Caring for the caregiver model

An innovative partnership between a pediatric complicated care program and a psychiatrist is the Caring for the Caregiver (C4C) integrated, phased care model. Through this collaboration, a pediatric hospital's complicated care program integrates an outside psychiatrist to offer mental care that is tailored to the circumstances of caring for CMC patients.[85] By offering psychiatric therapies, the pediatric complex care program bridges a knowledge gap. Caregivers of CMC with suspected depression, trauma, anxiety, and related illnesses are the focus of the C4C model.[86,87]According to **Cardenas et al.[88]** in 2023, the paradigm comprises three steps: 1) early distress identification; 2) social work assessment, intervention, and psychotherapy; and 3) psychiatric care, including diagnosis or medication introduction, through visits with the integrated psychiatrist. The C4C approach seeks to enhance outcomes including stress, anxiety, and depression while also making it easier for caregivers to get mental health care.[89]



C4C Step	Service	Provided by
Step 3: Psychiatric care for caregivers	Psychiatry: including psychiatric/diagnostic assessment, short term interventions, medication initiation and monitoring, psychotherapy, referrals to community resources, liaison with family doctors, therapists, and psychotherapists, and psychoeducation*	Psychiatrist
Step 2: Social work assessment, intervention and psychotherapy	Therapy: Strength-based psychotherapy for individuals, couples, and families, mental health assessment and complex system navigation (including linkage to community resources, therapists and family doctors)*	Social workers in complex care program
Step 1: Early identification of distress	Support: Monitoring, education, information, self-care, referrals to resources as needed	Nurse practitioners and physicians in complex care program in collaboration with psychiatrist and social workers
Foundation: Psychoeducation for complex care team	Education: Complex care team receives monthly tailored psychoeducation rounds to promote mental health awareness	Psychiatrist and social workers in complex care program

Clinical collaboration and case discussion

Clinical collaboration and case discussion occurs through partnership between the psychiatrist and the complex care team during weekly rounds and one-on-one consultation

Figure 3: The three steps of caring for the caregiver integrated stepped care model.[88]

This is the first model to use an integrated stepped care model embedded in a pediatric complex care program to address the mental health needs of caregivers of CMC by integrating adult and pediatric health care delivery. This model creates a framework for subsequent research to explore integrated stepped care models of mental health support for caregivers, where the needs of both the child and family are addressed.

Step 1: Early identification of distress

For patients and families, nurse practitioners (NP) in the complicated care program are essential staff members who collaborate with doctors.[90,91] According to **Alshaharni et al.[92]** , NPs assist families with all facets of their clinical care requirements and collaborate with community providers to guarantee that the patient and family have the right kind of assistance in place. Adapting this paradigm to other clinical settings could allow equally qualified advanced practice nurses to undertake this position. Through routine visits to the complicated care clinic and more frequent check-ins depending on need, NPs maintain communication with families. During regular business hours, NPs are also available to talk to parents.[93]. Given their knowledge of continuing stressors and caregiver burden, NPs may recognize caregivers who require mental health help and recommend them to complex care social workers for evaluation. In addition to addressing parents' immediate worries and pressures, NPs offer parents comprehensive psychosocial assistance by referring them to local services and providers when necessary.[88] According to **Foster et al.** [80]and **Nonoyama et al.[84]**, community support can include financial and housing support programs, respite care, childcare, early intervention services, school and educational resources, support groups, psychosocial support, home or community care nursing, rehabilitation, pediatricians, and more. Additionally, by recommending respite care or altering medication and feeding regimens, NPs can lessen the strain caregivers place on families. The innovative partnership with an integrated psychiatrist is one of the resources for CMC families that are highlighted in Figure 2. The complicated care program's participants collaborate to guarantee that caregivers receive adequate, comprehensive care. Many caregivers may find that these resources meet most of their needs.[88]

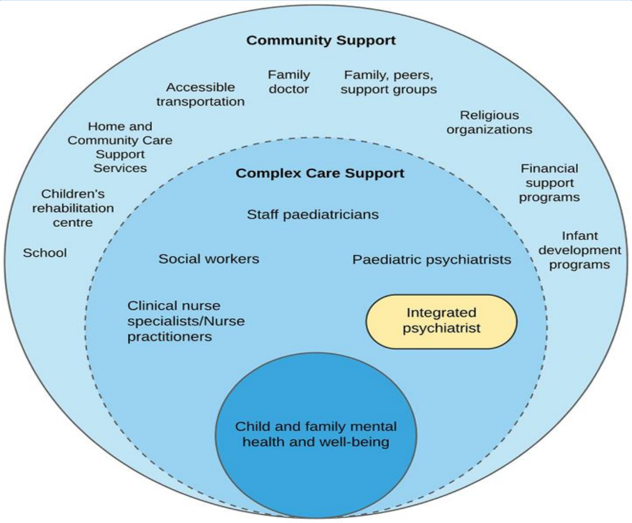


Figure 4: Sources of support for the mental health and well-being of families of children with medical complexity.[88]

Step 2: Social work assessment, intervention and psychotherapy

Members of the complex care team interview carers about their mental health and possible stressors as part of a complicated routine care unit. In the event that concerns are raised, Step 2 is started and caregivers are sent to the pediatric social workers employed by the complicated care program. [95].Social workers provide psychotherapy and support to caregivers who are exhibiting signs of depression, anxiety, trauma, and related disorders, such as stress and adjustment disorders.[96,97]. Doctors and NPs also provide continuing assistance. People, couples, and families (including siblings) can get continuous strength-based psychotherapy, safety planning, and mental health evaluation from complex care social workers who have received training in grieving and trauma treatment.[88]

Dialectical behavior therapy, internal family systems therapy, narrative therapy, narrative exposure therapy, emotion-focused therapy, and cognitive behavioral therapy are examples of psychotherapies.[98] If a caregiver gives their agreement, social workers can coordinate treatment plans with their primary care physician, home care coordinator, or community social worker.[99,100]According to **Hudson et al,[101]** social workers can mediate a crisis by recommending referrals for respite, connecting families with more community resources and support, or sending caregivers for immediate assessment or admission. To guarantee proper medical and/or mental health evaluation, members of the complex care team may consult with the caregiver's primary care physician.[102] According to the care required, social workers will keep evaluating and modifying the psychotherapeutic treatment plan until a case is settled or a caregiver is referred for further assistance. Visits for social work and complicated clinical care take place independently. These visits may be made by caregivers alone or in collaboration with their partners.[103]

Step 3: Psychiatric care for caregivers

Referrals can be made to the integrated psychiatrist when caregivers have a known or suspected mental health diagnosis that is significantly impairing function or causing distress and requires management beyond the psychotherapeutic interventions provided by the complex care program.[104,105].A member of the complicated care team or the caregiver's primary care physician may make the recommendation after obtaining the caregiver's consent. Following a referral, preexisting support from community services and the complex care program continues.[106] Through psychotherapy, medication initiation and monitoring, short-term therapies, and psychiatric/diagnostic evaluation, the psychiatrist offers non-emergent care. [88]In addition to communicating with the caregiver's primary care physician and offering psychoeducation on issues including trauma, mental health, and the transition to parenting, the psychiatrist may refer the caregiver to therapists, psychotherapists, and community resources.[107] The caregiver's primary care physician may give the psychiatrist a medical history, suggest additional resources for the caregiver, or follow up on medical concerns/investigations and medication management/initiation.[108] The psychiatrist may be accessible for up to six appointments, contingent on the diagnosis, treatment plan, and available supports. Appointments for psychiatry can be made in person or online, and they are scheduled separately from appointments for complex care. [88]For caregiver appointments, the psychiatrist has set aside one day each week. [109]In order to offer the caregiver and child with educated care that considers their mental health concerns, the psychiatrist will speak with the complex care social workers if the caregiver gives permission for information to be shared with the complicated care program. A strong treatment plan and sufficient follow-up are ensured by the psychiatrist's active involvement through interaction with members of the complex care team.[88]

Development of the Caregiver Care Model

To provide ongoing treatment, general practice plays a crucial role.[110] Primary care teams play a crucial role in starting and supporting patients and their family caregivers in primary palliative care.[111] Furthermore, according to **Nielsen et al.** [112]caregivers who experience the most grieving symptoms also typically interact with general practitioners more frequently. However, there is a knowledge gap in clinical assessment and caregiver support pathways, and caregiver support is not provided in an organized manner, even though general practitioners (GPs) view supporting family caregivers as a fundamental role.[113]To improve usability and facilitate adoption, a systematic approach to offering caregiver interventions in general practice must be established in a clinical setting with caregivers and medical professionals involved **114,115)**. Involving caregivers and medical professionals in the development process helped to guarantee that the intervention would work in a clinical setting. To promote sustainable acceptance and implementation in a "real-world" context, an implementation-based approach to intervention development was used. [116]. Three steps were taken to establish the Caregiver Care Model: **Mygind et al.** [117]. Conducted a workshop with medical professionals, pilot testing in general practice clinics, and a workshop with general practitioners from the pilot clinics (Figure 5).

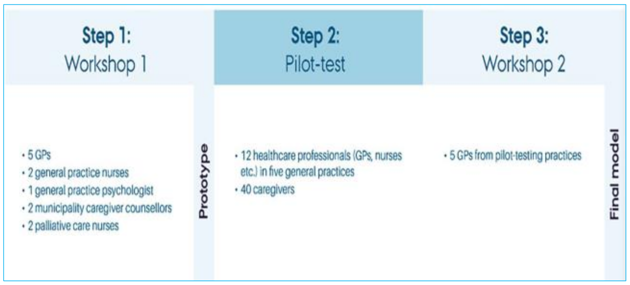


Figure 5: Development steps of the Caregiver Care Model.[117)]

Conclusion

Proactive planning, pediatric palliative care, and family-centered coordination are all essential components of effective care models. Additionally, providing care, particularly for parents, entails hazards of stress, declining health, and financial difficulties. As demonstrated by the C4C approach, incorporating caregiver-focused mental health support and early stress screening offers promising ways to boost the wellbeing of caregivers. The necessity of systemic, multidisciplinary solutions is highlighted by the recognition of caregiving as a structured process with psychological components. The need to integrate caregiver interventions to transform mental health service delivery for children and their families has been identified in the literature and in clinical practice.

Declaration

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