Review of Contemporary Philosophy
ISSN: 1841-5261, e-ISSN: 2471-089X
Vol 22 (1), 2023
Pp 6421 - 6432

Parent-Nurse Communication in Pediatric Wards: A Comprehensive Review of the Inpatient Care Experience for Children with Medical Complexities and their Families

[1]- Amnah Nasser Suliman,[2]-Amani Mohsen Sufyani,[3]-Aishah Shoei Mohammed Maghfoori,[4]-Naif Mohamad Almutairi,[5]-Naifeh Jabr Ajaj Aljemeeli,[6]-Mohammed Fathudeen Zakri,[7]- Hassan Darwish Hassan Faqih,[8]- Salah Hussain Shammakhi,[9]- Maged Yahya Sabei,[10]- Jaber Ali Nami,[11]- Mohammed Abdurahman Alsaidmohammed Zorbotan,[12]- Sharifah Fathudeen Zakri,[13]- Alyah Ismail Shamakhi,[14]-Zohour Essa Mousa ,[15]- Rafaa Mohammed Jaber

[1] Ksa, Ministry Of Health, King Fahd Hospital
[2] Ksa, Ministry Of Health, King Salman Hospital
[3] Ksa, Ministry Of Health, Eradah Hospital And Mental Health
[4] Ksa, Ministry Of Health, Wathilan General Hospital
[5] Ksa, Ministry Of Health, Hospital Children's And Maternity
[6] Ksa, Ministry Of Health, S.G.H
[7] Ksa, Ministry Of Health, Sabya .G.H
[8] Ksa, Ministry Of Health, Sabya .G.H
[9] Ksa, Ministry Of Health, Sabya .G.H
[10] Ksa, Ministry Of Health, King. S. H
[11] Ksa, Ministry Of Health, Sabya .G.H
[12] Ksa, Ministry Of Health, Sabya .G.H
[13] Ksa, Ministry Of Health, King Fahd Hospital
[14] Ksa, Ministry Of Health, King Fahd Hospital
[15] Ksa, Ministry Of Health, Jazan General Hospital

Abstract

Background: Children with medical complexities (CMC) represent a significant and growing demographic within pediatric healthcare, characterized by high hospitalization rates and complex care needs. This population often experiences lower satisfaction with inpatient care due to challenges in communication and collaboration between healthcare professionals and families.

Methods: This scoping review aimed to consolidate existing literature on the inpatient care experiences of CMC and their families. A comprehensive search of databases including EMBASE, CINAHL, MEDLINE, and others was conducted. The review focused on identifying key themes related to parent-nurse communication, shared decision-making, and the integration of parental expertise into care.

Results: The findings revealed that effective communication and collaborative decision-making are crucial for enhancing the care experience of CMC. Parents expressed a desire for active participation in care decisions, emphasizing the importance of establishing mutual goals with healthcare professionals. Additionally, the study highlighted the need for improved continuity of care and the integration of parental knowledge into treatment plans. Barriers to effective communication, such as inconsistent messaging and lack of empathy from healthcare providers, were identified as significant challenges.

Conclusion: Enhancing parent-nurse communication and fostering collaborative relationships are essential for improving the inpatient care experience of CMC and their families. Future research should focus on developing and evaluating interventions that promote shared decision-making and effective communication strategies. Addressing these areas will not only improve patient satisfaction but also contribute to better health outcomes for children with medical complexities.

Keywords: Children with medical complexities, parent-nurse communication, shared decision-making, inpatient care, healthcare collaboration.

Received: 10 october 2023 **Revised**: 24 November 2023 **Accepted:** 08 December 2023

1. Introduction

Child with medical complexities (CMC) have the highest inpatient use rates in pediatrics, representing up to fifty percent of admissions to tertiary care pediatric hospitals [1, 2]. Chronic illnesses exhibit features such as elevated healthcare utilization, significant care requirements in home and community settings, and functional impairments [3]. They represent one of the most rapidly expanding demographics in pediatrics, together constituting one-third of expenditures on child health [4, 5]. Significant efforts have been directed towards identifying optimal care strategies for these kids [6, 7]. A significant portion of this effort has concentrated on outpatient care coordinating programs. Nonetheless, as a significant consumer of inpatient resources, assessing and developing hospitalization models is a critical concern.

Patients with chronic medical conditions are at heightened risk of negative occurrences and incidents throughout hospital stays. Various variables impede the management of CMC in hospitals, including polypharmacy, uncommon disorders, the requirement for multispecialty and interdisciplinary treatment, sophisticated technology, and intrinsic fragility [8, 9]. Their hospitalizations tend to be extended, and they have elevated readmission rates compared to comparable pediatric cohorts [10, 11]. They are more prone to need acute care and have elevated mortality rates [12-14]. Side effects and medication mistakes are more prevalent amongst CMC [11, 15, 16]. Children with medical complexity (CMC) and their families exhibit lower satisfaction with inpatient treatment compared to kids who have acute illnesses or those with uncomplicated chronic disorders [17, 18].

The Academy for Healthcare Improvement paradigm for value-based care prioritizes patient experience as a fundamental objective [19]. The experience of care encompasses all interactions, influenced by an organization's society, that affect an individual's perspective of the care received [20, 21]. This includes functional components like wait times and relational aspects such as interactions with healthcare professionals (HCPs) [22]. This result demonstrates continuous favorable correlations with patient safety, compliance with treatment protocols, and objectively assessed health outcomes [22]. The patients and their family's perception of care include their views and evaluations of the provided care, which may be affected by individual circumstances and prior experiences [23, 24].

It is thus unsurprising that CMC and their relatives frequently evaluate their treatment experience less favorably than other patient demographics [24]. This may be associated with their increased incidence of negative consequences. Nevertheless, qualitative research indicates other possible factors. Parents providing extensive professional care at home may have difficulties with a lack of authority in the hospital environment [25]. Healthcare professionals lack a framework for incorporating parental knowledge into hospital treatment [26]. The necessity to negotiate positions between knowledgeable parents and healthcare professionals might create supplementary stress and anxiety [27]. The vulnerability of young children and the regularity of their hospitalizations must not be overlooked as significant stressors for families [28, 29].

Enhancing the management of children with medical complexity in the hospital environment is a growing emphasis in pediatric hospital medicine. In 2020, a Canadian national James Lind Alliance (JLA) prioritized collaboration highlighted the need of identifying optimal methods and models of inpatient treatment for CMC [30]. Creating these models requires meticulous focus on all aspects of care—patient security, clinical efficacy, and care experience—to have maximum impact. Scientific data about the process of treatment for CMC may elucidate critical pressure points, although it is now dispersed across several fields. Moreover, existing research are constrained by small sample numbers from particular groups in isolated clinical environments, which probably do not represent the whole experience of CMC. If consolidated, this information might serve as a crucial basis for the development of new care models.

This scoping review aimed to consolidate research about the inpatient care experience of CMC and their relatives in order to inform the future growth and evaluation of hospitalized medical care for this demographic.

2. Search Methodology

A scoping evaluation was selected as the most suitable approach to delineate the available literature about a subject.The search was created under the direction of an academic health sciences librarian. The databases examined were CINAHL, EMBASE, MEDLINE, Web of Science Core Collection, as well as APA PsycInfo.

3. Agreement of Healthcare Responsibilities

Treatment duties must be discussed and defined at various points during inpatient treatment, fostering a feeling of collaboration and cooperation [25, 31, 32]. A transparent dialogue on the duties and responsibilities of both nurses and families fostered trust and mutual comprehension [33]. The discussion of care limits required considerable time and effort to create, sometimes resulting in friction stemming from ambiguous job definitions. Certain parents discovered that they had to contend with healthcare professionals to fulfill their obligations and provide the necessary parental care for their kid, but this was not a common observation. Occasionally, bargaining over a parent's preparedness to understand care interventions and technology was necessary [31, 34]. Authors of a review study proposed that modifications in parental responsibilities inside hospitals are crucial for guaranteeing safe and high-quality treatment, especially for kids with intellectual impairments [35].

4. Collaborative Decision-Making

Numerous research has elucidated parents' desire to collaborate in decision-making for care of their kids [27, 35-40]. Parents valued participation in decision-making or exerting control over decision-making [35, 36]. Many anticipated becoming equal members of the team and sought involvement in decisions about their child's therapy. Parents prioritized that selections were tailored to their own kid rather than just based on the diagnosis [38]. Children articulated their want to participate in decision-making. Shared Decision-Making (SDM) was facilitated by effective communication skills and attentive listening, especially on family values and concerns, together with parental expertise and information sources. Obstacles to shared decision-making included inadequate healthcare provider communication skills, an extensive medical team that may be frightening, inadequate time for families to prepare, and health system issues such as the availability of certain healthcare providers. The temporal urgency of the issue impacted parental involvement in shared decision-making [58, 41]. Despite their desire for significant engagement, parents often conveyed uncertainty over decision-making, which was inadequately addressed [41]. Quantitative research indicated that a considerable number of parents (40%) prefer shared decision-making (SDM), although a notable percentage (41%) want to retain the authority to make the ultimate choice alone. In singular research done in the Middle East, participants (mothers) expressed that decision-making ought to be the physician's duty [42].

5. Universal Objective Establishment

Directly associated with particular, contextual shared decision-making was the establishment of agreed objectives for hospitalization. Physicians often failed to inquire about parents' objectives for their child at the onset of hospitalization; yet several parents want to communicate their objectives to physicians. Parents articulated that establishing broader objectives for their kid or the hospital stay was a significant aspect of their responsibility [43]. Generally, clinicians and parents united in the primary objective of facilitating the child's recovery for discharge. Discrepancies in objectives between parents and doctors were also seen [35, 44-48]. Parents identified several unaddressed goals, including the limitation of unnecessary testing, the establishment of follow-up plans, comprehension of their child's healthcare prognosis and diagnosis, the development of strategies to avert future hospitalizations, enhancement of their child's daily life, the creation of palliative care plans, and the empowerment of parents. In a study, researchers discovered that parents tended to prioritize goals associated with their child's life skills, such as fostering independence and enhancing communication, while physicians were more inclined to concentrate on reducing parental burden, preventing hospitalizations, avoiding complications, and managing care [42].

6. Interrelationships Among CMC, Families, and Healthcare Professionals

Relationships with healthcare professionals, as articulated by children with medical complexities and their relatives, were founded on rapport, continuity of treatment, and trust [49]. A recent study by English et al. provided an additional definition of rapport in healthcare interactions: 'a sense of connection with another human characterized by acceptance, respect, empathy, and a reciprocal commitment to the relationship' [49]. Parents participating in this research identified healthcare provider elements that fostered rapport, including trustworthiness, honesty, respect, and helpful knowledge and behaviors [31, 36, 50]. The healthcare professional's capacity to understand the problem from the parent's viewpoint and consider the broader context fostered rapport, as did an absence of prejudice about the kid [45]. Rapport was sustained throughout challenging circumstances when healthcare professionals exhibited flexibility, open-mindedness, compassion, and humility [45]. Rapport was hindered when healthcare professionals misinterpreted a child's baseline in connection to their present condition or neglected to recognize parental intuition. Unempathetic personnel and the medical culture, characterized by the anxiety of being categorized as a 'difficult' parent, were obstacles to establishing rapport. Quantitative studies demonstrate that parents of children with complicated medical conditions (CMC) express diminished perceptions of staff understanding of their child's requirements in comparison to families of non-complex children; yet they frequently cite 'respectful and supportive care' as one of their most favorable experiences.

The literature defines continuity of care as including two primary elements: an ongoing caring connection and seamless collaboration across providers and systems [51]. Parents in this study underscored the significance of these elements in their medical encounters [27, 43-45, 52, 53] and the adverse effects resulting from a lack of continuity [54-56]. Continuity positively influenced the quality of service and promoted tailored care. CMC supported ongoing interactions and explicitly indicated that this would provide support and comfort [25]. A deficiency in continuity adversely affected care experiences related to integrated treatment strategies, patient administration, and readmissions [43, 48, 51, 56, 56, 57]. Parents were apprehensive that a lack of consistency might result in healthcare professionals lacking sufficient understanding of the kid to provide appropriate treatment [43]. Parents recognized disruptions in continuity of treatment and the consequent negative experiences that shaped their expectations for future hospitalizations [56]. Continuity was seen as the cornerstone for rapport, trust, and a feeling of security with healthcare professionals, as well as fostering stable bonds among patients and nurses or families.

Trust was fundamental to the link among CMC/family as well as HCP [45, 46]. Trust was established via collaborative experiences with healthcare professionals throughout the child's sickness, effective communication, continuity of care, cooperation, and the observation of cohesive healthcare teams. Giambra et al. discovered that trust was the paramount demand recognized by parents [37]. Certain parents expressed a deficiency of faith in healthcare professionals. In the absence of established confidence, parents may hesitate to depart from their kid's bedside [58]. Adverse prior experiences with hospitalizations may negatively affect the establishment of confidence in future connections and interactions [59].

The many types of competence were emphasized in several research. Alongside the professional and technical proficiency of healthcare professionals, there existed parental competence derived from information accumulation, familiarity with the kid, and intuition.Parental competence was attained via the caregiving of their difficult kid at home, skill enhancement, independent investigation, and networking with other families [43, 60]. Collaboration was enabled when parents' unique knowledge and skills about their child were acknowledged and integrated into decision-making and care provision [60-62]. Parents said that healthcare professionals must see families as authorities in their child's treatment [60, 62, 63], and they conveyed discontent when nurses attempted to dictate the provision of care [62]. Certain parents believed that their interaction with the medical staff should vary from that of parents of non-complex medical children (CMC) because to their specialized knowledge of their intricate kid.

Parents often felt that their knowledge was unappreciated, resulting in suboptimal hospital experiences [64]. Certain parents experienced exclusion from caregiving, hindering their ability to perform parental tasks and feeling unacknowledged for the care they rendered to their kid. Parents saw their role as knowledgeable caregivers as a safeguard for guaranteeing high-quality care and mitigating mistakes [55]. In a study, researchers discovered that the advanced understanding of some families might substantially modify the care flow [65].

Parents emphasized the significance of healthcare professional skills in fostering healthy connections. They need healthcare professionals to exhibit specialized training and expertise in their child's situation [25, 60], capabilities in specialized care, management of intricate medical scenarios, understanding of diverse intellectual disability classifications, and advocacy skills [27, 55, 66]. Healthcare professionals and parents successfully established collaborations when the competence of healthcare professionals was evident and boldly used. Parents indicated that insufficient understanding among healthcare professionals, resulting in erroneous assumptions about complex medical conditions, might lead to substandard treatment [55]. In research including interviews with children, participants indicated a desire for their physicians and nurses to exhibit competence, knowledge, and order [25].

Another emphasis in current research is to the pragmatic dimensions of communication, irrespective of the kind of healthcare professional connection and the presence or lack of continuity.The capacity to convey information clearly and precisely was a significant factor in the relationship [45, 48, 57, 63, 67, 68]. Parents want to be informed about the treatment plan, daily objectives, and test outcomes. In several instances, parents sought more information and dialogue to elucidate the risks and advantages of treatment alternatives [57]. Communication problems were apparent in the insufficient incorporation of home care schedules and habits within inpatient care, leading to mistakes and issues upon discharge [67, 68]. Parents believed that enhanced information exchange might facilitate the transfer of school services after hospitalization [45]. In quantitative research, parents of CMC report 'sharing general knowledge' as one of the lowest satisfaction levels, much lower than those of families of non-CMC [27, 65, 69].

Multiple tactics were outlined that improved the level of interaction [70]. Parents appreciated having healthcare professionals who were available, dependable in addressing inquiries, participated in regular in-person conversations [80], and had strong listening abilities [46, 48, 60, 71]. Expressions of compassion and generosity enhanced communication between parents and nurses [71]. Children appreciated nurses who explained uncomfortable procedures and used humor to alleviate tension [25]. Giambra et al. delineated the Theory of Shared Collaboration (TSC) [70], emphasizing the necessity of honoring both personal and collective expertise, as well as essential communication behaviors such as behaves (questioning and listening), acts (describing and promoting), and results (establishing comprehending and establishing responsibilities) [46, 47].

Various detrimental communication methods were delineated, including 'rude' or brusque behaviors [60]. Inconsistent information from various healthcare professionals was seen as ineffective communication, as was the revelation of a diagnosis devoid of sufficient empathy or support. Assumptions, preconceptions, and judgmental language toward the kid frequently resulted in ineffective communication [55].

7. Hospital Context and Surroundings

Parents elaborated on how disruptions to routine affected their caregiving experience [65]. Standard hospital protocols, including regular monitoring of vital signs, interrupted the child's habit and adversely affected the quality of care received [51, 57, 71]. Baird et al. delineated implicit and explicit regulations inside the Pediatric Intensive Care Unit (PICU) [33]. Families were inherently expected to be aware of the nursing staff's working hours, the educational requirements of the resident doctors, and the scheduled delivery periods for materials and prescriptions [42]. Requests from parents to modify or disrupt this timetable were unwelcome [42]. Regulations may be modified to provide individualized care; nevertheless, this led to confusion when adjustments were made for certain families but not for others [42]. Modifying hospital protocols to accommodate the requirements of each CMC was seen as enhancing the treatment experience [60].

The hospital's social and physical setting influenced the experiences of children and their families. The environment may jeopardize connections among parents and their kids owing to insufficient confidentiality, a shortage of autonomy, and a diminished sense of individuality [25, 59, 62]. Hospitals disrupted sleep, generated noise, and exposed children to the danger of nosocomial infections [24, 25, 59, 60, 62, 66, 72]. The use of medical technology in pediatric care induced concern [73]. Parents recognized difficulties related to 'hospital life,' including the availability of suitable lodgings for themselves [48]. The need for sufficient sleep clashed with the parent's obligation to remain at their kid's bedtime to provide optimal care [73].

8. Discussion

This scoping review aimed to delineate the current literature about the outcomes of inpatient treatment for children with medical complexities (CMC) and their families, elucidate the many elements and techniques, and identify knowledge deficiencies. This evaluation explicitly addresses the process of care from the perspective of a 'user' of medical care [20, 37]. CMC and family members who took part in this research had diverse experiences of care compared to their 'ideal' condition. Participants articulated the significance of elements including interactions, relationships, and the integration of knowledge from CMC, their families, and healthcare professionals, as well as the considerable effects of the hospital environment, using both qualitative and quantitative methodologies.

These findings validate and emphasize the importance that CMC and family members attribute to essential factors during hospitalizations, including role negotiation, shared decision-making, and goal alignment. The relational components of treatment are essential, aligning with findings from various hospital environments and demographics [28, 36]. This study emphasized the importance of connections with healthcare professionals (HCPs), the development and integration of knowledge from both patients/parents and HCPs, and effective communication as crucial for facilitating pleasant experiences for children with medical complexities (CMC) and their families. Healthcare system considerations not only affect these relationship components but also foster an atmosphere that may be limiting, generic, and unsupportive.

Numerous themes outlined in this comprehensive overview are fundamental principles of patient- and family-centered care (PFCC). PFCC represents the benchmark in pediatric care delivery and aims to foster collaborations with patients and their families [73]. PFCC underscores the significance of integrating patient and family insights, effective communication strategies, collaborative decision-making, and maintaining a supportive physical environment [23]. PFCC correlates with enhanced quality of care by elevating contentment, diminishing stress, augmenting patient comprehension and self-management abilities, and perhaps decreasing hospital period of stay [55, 59]. Concerningly, the patterns recognized in this analysis that closely aligned with PFCC were frequently the approaches deemed most inadequate by CMC and their relatives. This indicates a disparity between knowledge and practice in the application of PFCC, particularly with this group of CMC and their relatives. The provision of patient- and Family-Centered Care (PFCC) to Clinical Management Committees (CMC) in hospitals is further hampered by a deficiency of evidence-based care models, as seen by our research, which identified just four interventional studies. These were also constrained by restricted sample numbers, a single-institution design, and the absence of a control group. Subsequent research should concentrate on the development and assessment of inpatient therapies for CMC that aim to address the care experience defined in this study, in conjunction with clinical, economic, and patient-centered outcomes.

This review aimed to uncover deficiencies in the literature. Despite the availability of approved tools to assess experience of care concepts, there is a notable lack of quantitative investigations. Most studies that gathered quantitative data used non-validated survey tools, which limit their rigor and hinder replication and comparability with other research [89]. There is a general deficiency of interventional studies, particularly those that use substantial patient and family interaction (such as co-design) and include patient- and family-centered outcomes into their evaluative framework. Such research may possess the most potential to impact care experiences for children with medical complexities and their families.

Another possible limitation is if this research encompasses all the critical dimensions of the care experience for CMC and their parents. Certain writers focused their study on certain features, including SDM, while others aimed to depict the experience of care in a broader context [41, 54, 56, 59, 61, 69, 72]. The current study has certainly addressed several significant difficulties with CMC and their families; nevertheless, it is still conceivable that some vital components were overlooked. Another factor is the representativeness of the individuals in this research of the broader community of CMC and their families. The demographic data of research participants were given, although often omitted elements that might identify racial minorities or gender-diverse persons. Individuals with restricted English language competence were almost always excluded. Likewise, dads were inadequately represented in these investigations. Consequently, this account of care experiences may not accurately represent the viewpoints of a heterogeneous CMC community.

9. Conclusion

This comprehensive review underscores the critical importance of effective communication and collaboration between parents and healthcare professionals in pediatric wards, particularly for children with medical complexities (CMC). The unique challenges faced by CMC and their families necessitate a tailored approach to care that recognizes the value of parental expertise and active participation in decision-making processes. Parents often feel overwhelmed by the complexities of their child's medical condition, and their desire to engage meaningfully in their child's healthcare should be met with supportive structures within the hospital environment. The findings indicate that fostering a culture of shared decision-making not only enhances parents' experiences but also contributes to improved clinical outcomes for CMC.

Healthcare professionals must be trained to communicate effectively, demonstrating empathy and understanding towards the concerns of families. This includes establishing clear, consistent messaging about treatment plans and care objectives, which can alleviate anxiety and foster trust. The integration of parental knowledge into care strategies is essential; when parents feel recognized as knowledgeable partners, they are more likely to engage positively in the treatment process. Given the growing prevalence of CMC in pediatric healthcare, it is imperative that future research continues to explore effective communication strategies and collaborative care models. This should include the development of evidence-based interventions aimed at bridging the gap between parental expectations and healthcare delivery. By prioritizing the experiences and insights of families, healthcare systems can transform the inpatient care landscape, ensuring that CMC receive the high-quality, family-centered care they deserve. Ultimately, enhancing parent-nurse communication is a vital step toward building a more responsive and effective pediatric healthcare system.

References

1. L. Rogozinski, A. Young, C. Grybauskas, P. Donohue, R. Boss, and E. Biondi, “Point Prevalence of Children Hospitalized With Chronic Critical Illness in the General Inpatient Units,” Hospital Pediatrics 9, no. 7 (2019): 545–549.
2. A. Peltz, M. Hall, D. M. Rubin, et al., “Hospital Utilization Among Children With the Highest Annual Inpatient Cost,” Pediatrics 137, no. 2 (2016): e20151829.
3. E. Cohen, D. Z. Kuo, R. Agrawal, et al., “Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives,” Pediatrics 127, no. 3 (2011): 529–538.

4. E. Cohen, J. G. Berry, X. Camacho, G. Anderson, W. Wodchis, and A. Guttmann, "Patterns and Costs of Health Care Use of Children With Medical Complexity," Pediatrics 130, no. 6 (2012): e1463–e1470.
5. J. G. Berry, M. Hall, D. E. Hall, et al., "Inpatient Growth and Resource Use in 28 Children's Hospitals: A Longitudinal, Multi-Institutional Study," JAMA Pediatrics 167, no. 2 (2013): 170.
6. C. Krantz, M. Hynes, A. DesLauriers, et al., "Helping Families Thrive: Co-Designing a Program to Support Parents of Children With Medical Complexity," Healthcare Quarterly 24, no. 2 (2021): 40–46.
7. C. M. White, J. E. Thomson, A. M. Statile, et al., "Development of a New Care Model for Hospitalized Children With Medical Complexity," Hospital Pediatrics 7, no. 7 (2017): 410–414.
8. C. J. Russell and T. D. Simon, "Care of Children With Medical Complexity in the Hospital Setting," Pediatric Annals 43, no. 7 (2014): e157–e162.
9. R. Srivastava, B. L. Stone, and N. A. Murphy, "Hospitalist Care of the Medically Complex Child," Pediatric Clinics of North America 52, no. 4 (2005): 1165–1187.
10. J. G. Berry, "Hospital Utilization and Characteristics of Patients Experiencing Recurrent Readmissions Within Children's Hospitals," JAMA 305, no. 7 (2011): 682–690.
11. J. C. Winer, E. Aragona, A. I. Fields, and D. C. Stockwell, "Comparison of Clinical Risk Factors Among Pediatric Patients With Single Admission, Multiple Admissions (Without Any 7-Day Readmissions), and 7-Day Readmission," Hospital Pediatrics 6, no. 3 (2016): 119–125.
12. J. D. Edwards, A. J. Houtrow, E. E. Vasilevskis, et al., "Chronic Conditions Among Children Admitted to U.S. Pediatric Intensive Care Units: Their Prevalence and Impact on Risk for Mortality and Prolonged Length of Stay," Critical Care Medicine 40, no. 7 (2012): 2196–2203.
13. L. O'Mahony, D. S. O'Mahony, T. D. Simon, J. Neff, E. J. Klein, and L. Quan, "Medical Complexity and Pediatric Emergency Department and Inpatient Utilization," Pediatrics 131, no. 2 (2013): e559–e565.
14. T. Chan, J. Rodean, T. Richardson, et al., "Pediatric Critical Care Resource Use by Children With Medical Complexity," Journal of Pediatrics 177 (2016): 197–203.
15. K. Blaine, J. Wright, A. Pinkham, et al., "Medication Order Errors at Hospital Admission Among Children With Medical Complexity," Journal of Patient Safety 18, no. 1 (2022): e156–e162.
16. A. G. Matlow, G. R. Baker, V. Flintoft, et al., "Adverse Events Among Children in Canadian Hospitals: The Canadian Paediatric Adverse Events Study," Canadian Medical Association Journal 184, no. 13 (2012): E709–E718.
17. D. Z. Kuo, A. Goudie, E. Cohen, et al., "Inequities in Health Care Needs for Children With Medical Complexity," Health Affairs 33, no. 12 (2014): 2190–2198.
18. M. Iannelli, A. Harvey, J. O'Neill, and D. Reddihough, "Parental Satisfaction With Inpatient Care of Children With Cerebral Palsy," Journal of Paediatrics and Child Health 51, no. 11 (2015): 1089–1096.
19. D. M. Berwick, T. W. Nolan, and J. Whittington, "The Triple Aim: Care, Health, and Cost," Health Affairs 27, no. 3 (2008): 759–769.
20. P. Oben, "Understanding the Patient Experience: A Conceptual Framework," Journal of Patient Experience 7, no. 6 (2020): 906–910.
21. Institute of Medicine (US) Committee on Quality of Health Care in America, Crossing the Quality Chasm: A New Health System for the 21st Century (Washington, DC: National Academies Press US, 2001).
22. C. Doyle, L. Lennox, and D. Bell, "A Systematic Review of Evidence on the Links Between Patient Experience and Clinical Safety and Effectiveness," BMJ Open 3, no. 1 (2013): e001570.
23. F. Ahmed, J. Burt, and M. Roland, "Measuring Patient Experience: Concepts and Methods," Patient—Patient-Centered Outcomes Research 7, no. 3 (2014): 235–241.
24. K. A. Kemp, P. Fairie, B. Steele, et al., "The Experience of Parents of Hospitalized Children Living With Medical Complexity," Hospital Pediatrics 11, no. 10 (2021): 1065–1072.
25. V. Shilling, V. Edwards, M. Rogers, and C. Morris, "The Experience of Disabled Children as Inpatients: A Structured Review and Synthesis of Qualitative Studies Reporting the Views of Children, Parents and Professionals," Child: Care, Health and Development 38, no. 6 (2012): 778–788.
26. K. Balling and M. McCubbin, "Hospitalized Children With Chronic Illness: Parental Caregiving Needs and Valuing Parental Expertise," Journal of Pediatric Nursing 16, no. 2 (2001): 110–119.

27. B. Seliner, B. Latal, and R. Spirig, “When Children With Profound Multiple Disabilities Are Hospitalized: A Cross-Sectional Survey of Parental Burden of Care, Quality of Life of Parents and Their Hospitalized Children, and Satisfaction With Family-Centered Care,” Journal for Specialists in Pediatric Nursing 21, no. 3 (2016): 147–157.
28. L. MacKay, K. Benzies, C. Barnard, and S. Raffin Bouchal, “Parental Experiences Caring for Their Hospitalized Medically Fragile Infants: A Description of Grief, Stress, and Coping,” Canadian Journal of Nursing Research 53, no. 3 (2021): 191–201.
29. V. Phua, S. M. Reid, J. E. Walstab, and D. S. Reddihough, “Inpatient Care of Children With Cerebral Palsy as Perceived by Their Parents,” Journal of Paediatrics and Child Health 41, no. 8 (2005): 432–436.
30. P. Gill, K. Cowan, D. Arafeh, et al., “James Lind Alliance Priority Setting Partnerships, Pediatric Hospital Care Published,” (2021).
31. J. M. N. O. Alves, J. J. P. Amendoeira, and Z. B. Charepe, “A parceria de cuidados pelo olhar dos pais de crianças com necessidades especiais de saúde,” Revista Gaúcha de Enfermagem 38, no. 4 (2017): e2016–e2070.
32. M. Atout, P. Hemingway, and J. Seymour, “The Experience of Decision Making in the Care of Children With Palliative Care Needs: The Experiences of Jordanian Mothers,” Comprehensive Child and Adolescent Nursing 40, no. 4 (2017): 240–256.
33. J. Baird, B. Davies, P. S. Hinds, C. Baggott, and R. S. Rehm, “What Impact Do Hospital and Unit-Based Rules Have Upon Patient and Family-Centered Care in the Pediatric Intensive Care Unit?,” Journal of Pediatric Nursing 30, no. 1 (2015): 133–142.
34. J. Baird, R. S. Rehm, P. S. Hinds, C. Baggott, and B. Davies, “Do You Know My Child? Continuity of Nursing Care in the Pediatric Intensive Care Unit,” Nursing Research 65, no. 2 (2016): 142–150.
35. J. F. Bogetz, A. Trowbridge, H. Lewis, D. Jonas, J. Hauer, and A. R. Rosenberg, “Forming Clinician-Parent Therapeutic Alliance for Children With Severe Neurologic Impairment,” Hospital Pediatrics 12, no. 3 (2022): 282–292.
36. J. A. Borgioli and C. H. Kennedy, “Transitions Between School and Hospital for Students With Multiple Disabilities: A Survey of Causes, Educational Continuity, and Parental Perceptions,” Research and Practice for Persons With Severe Disabilities 28, no. 1 (2003): 1–6.
37. B. K. Giambra, M. E. Broome, T. Sabourin, J. Buelow, and D. Stiffler, “Integration of Parent and Nurse Perspectives of Communication to Plan Care for Technology Dependent Children: The Theory of Shared Communication,” Journal of Pediatric Nursing 34 (2017): 29–35.
38. B. K. Giambra, T. Sabourin, M. E. Broome, and J. Buelow, “The Theory of Shared Communication: How Parents of Technology-Dependent Children Communicate With Nurses on the Inpatient Unit,” Journal of Pediatric Nursing 29, no. 1 (2014): 14–22.
39. C. Grandjean, P. Ullmann, M. Marston, M. C. Maitre, M. H. Perez, and A. S. Ramelet, “Sources of Stress, Family Functioning, and Needs of Families With a Chronic Critically Ill Child: A Qualitative Study,” Frontiers in Pediatrics 9, no. 101615492 (2021): 740598.
40. K. Hoang, B. Halpern-Felsher, M. Brooks, and R. Blankenburg, “Addressing Goals of Parents of Hospitalized Children: A Qualitative Analysis of Parents' and Physicians' Perspectives,” Academic Pediatrics 21, no. 2 (2021): 244–251.
41. K. Hoang, B. Halpern-Felsher, M. Brooks, and R. Blankenburg, “Shared Decision-Making With Parents of Hospitalized Children: A Qualitative Analysis of Parents' and Providers' Perspectives,” Hospital Pediatrics 10, no. 11 (2020): 977–985.
42. J. C. Leary, R. Krcmar, G. H. Yoon, K. M. Freund, and A. M. LeClair, “Parent Perspectives During Hospital Readmissions for Children With Medical Complexity: A Qualitative Study,” Hospital Pediatrics 10, no. 3 (2020): 222–229.
43. K. LeGrow, E. Hodnett, R. Stremler, and E. Cohen, “Evaluating the Feasibility of a Parent-Briefing Intervention in a Pediatric Acute Care Setting,” Journal for Specialists in Pediatric Nursing 19, no. 3 (2014): 219–228.

44. V. N. Madrigal, K. W. Carroll, J. A. Faerber, J. K. Walter, W. E. Morrison, and C. Feudtner, “Parental Sources of Support and Guidance When Making Difficult Decisions in the Pediatric Intensive Care Unit,” Journal of Pediatrics 169 (2016): 221–226.
45. V. N. Madrigal, K. W. Carroll, K. R. Hexem, J. A. Faerber, W. E. Morrison, and C. Feudtner, “Parental Decision-Making Preferences in the Pediatric Intensive Care Unit,” Critical Care Medicine 40, no. 10 (2012): 2876–2882.
46. L. Mimmo, R. Harrison, and R. Hinchcliff, “Patient Safety Vulnerabilities for Children With Intellectual Disability in Hospital: A Systematic Review and Narrative Synthesis,” BMJ Paediatrics Open 2, no. 1 (2018): e000201.
47. L. Mimmo, S. Woolfenden, J. Travaglia, and R. Harrison, “Partnerships for Safe Care: A Meta-Narrative of the Experience for the Parent of a Child With Intellectual Disability in Hospital,” Health Expectations 22, no. 6 (2019): 1199–1212.
48. D. V. Murrell, T. E. Lotze, H. J. Farber, C. A. Crawford, and C. M. Wiemann, “The Experience of Families With Children With Spinal Muscular Atrophy Type I Across Health Care Systems,” Journal of Child Neurology 32, no. 11 (2017): 917–923.
49. R. Nolan, B. Luther, P. Young, and N. A. Murphy, “Differing Perceptions Regarding Quality of Life and Inpatient Treatment Goals for Children With Severe Disabilities,” Academic Pediatrics 14, no. 6 (2014): 574–580.
50. J. Noyes, “Ventilator-Dependent” Children Who Spend Prolonged Periods of Time in Intensive Care Units When They No Longer Have a Medical Need or Want to Be There,” Journal of Clinical Nursing 9, no. 5 (2000): 774–783.
51. K. Oulton, D. Sell, and F. Gibson, “Hospitalized Children With Intellectual Disability: Parents as Partners in Their Care,” Journal of Applied Research in Intellectual Disabilities 33, no. 5 (2020): 917–926.
52. K. Oulton, D. Sell, and F. Gibson, “‘Learn'ing What Is Important to Children and Young People With Intellectual Disabilities When They Are in Hospital,” Journal of Applied Research in Intellectual Disabilities 31, no. 5 (2018): 792–803.
53. E. Reeves, S. Timmons, and S. Dampier, “Parents' Experiences of Negotiating Care for Their Technology-Dependent Child,” Journal of Child Health Care 10, no. 3 (2006): 228–239.
54. B. Seliner, B. Latal, and R. Spirig, “Effectiveness of a Nurse-Led Preadmission Intervention for Parents of Children With Profound Multiple Disabilities Undergoing Hip-Joint Surgery: A Quasi-Experimental Pilot Study,” Journal for Specialists in Pediatric Nursing 22, no. 3 (2017): e12184.
55. K. T. Sobush, “Principles of Managing Children With Medical Complexity and a New Delivery Model,” Missouri Medicine 116, no. 2 (2019): 134–139.
56. B. L. Stone, N. A. Murphy, M. B. Mundorff, H. B. Parker, P. R. Peterson, and R. Srivastava, “Children With Chronic Complex Medical Illnesses: Is Inpatient Care Family-Centered?,” Journal of Pediatric Rehabilitation Medicine 1, no. 3 (2008): 237–243.
57. F. Taib, K. T. Beng, and L. C. Chan, “The Challenges, Coping Mechanisms, and the Needs of the Inhospital Parents Caring for Children With Life-Limiting Neurological Disorders: A Qualitative Study,” Indian Journal of Palliative Care 27, no. 4 (2021): 483–489.
58. K. D. Woodson, S. Thakkar, M. Burbage, J. Kichler, and L. Nabors, “Children With Chronic Illnesses: Factors Influencing Family Hardiness,” Issues in Comprehensive Pediatric Nursing 38, no. 1 (2015): 57–69.
59. L. A. Wright-Sexton, C. E. Compretta, C. Blackshear, and C. M. Henderson, “Isolation in Parents and Providers of Children With Chronic Critical Illness,” Pediatric Critical Care Medicine 21, no. 8 (2020): e530–e537.
60. J. L. Lin, C. L. Clark, B. Halpern-Felsher, et al., “Parent Perspectives in Shared Decision-Making for Children With Medical Complexity,” Academic Pediatrics 20, no. 8 (2020): 1101–1108.
61. W. English, M. Gott, and J. Robinson, “The Meaning of Rapport for Patients, Families, and Healthcare Professionals: A Scoping Review,” Patient Education and Counseling 105, no. 1 (2022): 2–14.

62. M. Gulliford, S. Naithani, and M. Morgan, “What Is ‘Continuity of Care’?,” Journal of Health Services Research & Policy 11, no. 4 (2006): 248–250.
63. I. C. Guerini, P. K. Santana Cordeiro, S. Zirke Osta, and E. M. Ribeiro, “ Relatives' Perception Regarding the Stressors Resulting From the Care Demands of Technology-Dependent Children and Adolescents,” Texto & Contexto: Enfermagem 21, no. 2 (2012): 348–355.
64. Google Scholar
65. 73A. Bull and M. Gillies, “Spiritual Needs of Children With Complex Healthcare Needs in Hospital,” Paediatric Nursing 19, no. 9 (2007): 34–38.
66. A. P. Borschuk, S. E. Williams, J. M. McClure, et al., “A Novel Behavioral Health Program for Family Caregivers of Children Admitted to a Transitional Chronic Ventilator Unit,” Pediatric Pulmonology 56, no. 6 (2021): 1635–1643.
67. L. J. Williams, K. Waller, R. P. Chenoweth, and A. L. Ersig, “Stakeholder Perspectives: Communication, Care Coordination, and Transitions in Care for Children With Medical Complexity,” Journal for Specialists in Pediatric Nursing 26, no. 1 (2021): e12314.
68. C. M. Henderson, E. P. Williams, M. C. Shapiro, et al., “‘Stuck in the ICU’: Caring for Children With Chronic Critical Illness,” Pediatric Critical Care Medicine 18, no. 11 (2017): e561–e568.
69. G. Colditz and K. Emmons, “ The Promise and Challenges of Dissemination and Implementation Research,” in Dissemination and Implementation Research in Health, eds. R. C. Brownson, G. A. Colditz, and E. K. Proctor (New York, NY, USA: Oxford Academic, 2018), 1–18.
70. B. K. Giambra, D. Stiffler, and M. E. Broome, “An Integrative Review of Communication Between Parents and Nurses of Hospitalized Technology-Dependent Children,” Worldviews on Evidence-Based Nursing 11, no. 6 (2014): 369–375.
71. J. E. Rennick, I. St-Sauveur, A. M. Knox, and M. Ruddy, “Exploring the Experiences of Parent Caregivers of Children With Chronic Medical Complexity During Pediatric Intensive Care Unit Hospitalization: An Interpretive Descriptive Study,” BMC Pediatrics 19, no. 1 (2019): 272.
72. P. W. Brady, B. K. Giambra, S. N. Sherman, et al., “The Parent Role in Advocating for a Deteriorating Child: A Qualitative Study,” Hospital Pediatrics 10, no. 9 (2020): 728–742.
73. J. Engler, D. Gruber, F. Engler, et al., “Parents' Perspectives on Hospital Care for Children and Adolescents With Life-Limiting Conditions: A Grounded Theory Analysis of Narrative Interviews,” Journal of Palliative Medicine 23, no. 4 (2020): 466–474.

التواصل بين أولياء الأمور والممرضات في أقسام الأطفال: مراجعة شاملة لتجربة الرعاية داخل المستشفى للأطفال ذوي الحالات الطبية المعقدة وأسرهم

الملخص

الخلفية:يمثل الأطفال ذوو الحالات الطبية المعقدة (CMC) شريحة هامة ومتزايدة في مجال الرعاية الصحية للأطفال، حيث يتميزون بمعدلات عالية من الاستشفاء واحتياجات رعاية معقدة. غالبًا ما يعاني هؤلاء الأطفال وأسرهم من انخفاض مستوى الرضا عن الرعاية داخل المستشفى بسبب التحديات في التواصل والتعاون بين المهنيين الصحيين والأسر.

الطرق: هدفت هذه المراجعة إلى تجميع الأدبيات الموجودة حول تجارب الرعاية داخل المستشفى للأطفال ذوي الحالات الطبية المعقدة وأسرهم. تم إجراء بحث شامل في قواعد بيانات متعددة مثل EMBASE و CINAHL وMEDLINEوغيرها. ركزت المراجعة على تحديد الموضوعات الرئيسية المتعلقة بتواصل أولياء الأمور مع الممرضات، اتخاذ القرارات المشتركة، ودمج خبرات أولياء الأمور في الرعاية.

النتائج:كشفت النتائج أن التواصل الفعّال واتخاذ القرارات المشتركة يلعبان دورًا حاسمًا في تحسين تجربة الرعاية للأطفال ذوي الحالات الطبية المعقدة. أعرب أولياء الأمور عن رغبتهم في المشاركة النشطة في اتخاذ القرارات المتعلقة بالرعاية، مؤكدين أهمية تحديد أهداف مشتركة مع المهنيين الصحيين. كما سلطت الدراسة الضوء على الحاجة إلى تحسين استمرارية الرعاية ودمج معرفة أولياء الأمور في خطط العلاج. وتم تحديد حواجز أمام التواصل الفعّال، مثل الرسائل غير المتسقة وغياب التعاطف من قبل مقدمي الرعاية الصحية، كعوامل تحدٍ رئيسية.

الاستنتاج:يعد تعزيز التواصل بين أولياء الأمور والممرضات وتعزيز العلاقات التعاونية أمرًا ضروريًا لتحسين تجربة الرعاية داخل المستشفى للأطفال ذوي الحالات الطبية المعقدة وأسرهم. ينبغي أن تركز الأبحاث المستقبلية على تطوير وتقييم تدخلات تعزز اتخاذ القرارات المشتركة واستراتيجيات التواصل الفعّال. معالجة هذه الجوانب لن تؤدي فقط إلى تحسين رضا المرضى بل ستساهم أيضًا في تحقيق نتائج صحية أفضل للأطفال ذوي الحالات الطبية المعقدة.

الكلمات المفتاحية:الأطفال ذوو الحالات الطبية المعقدة، التواصل بين أولياء الأمور والممرضات، اتخاذ القرارات المشتركة، الرعاية داخل المستشفى، التعاون في الرعاية الصحية.