Kodama et al., Int J Nurs Clin Pract 2025, 12: 406
https://doi.org/10.15344/2394-4978/2025/406

International Journal of
Nursing & Clinical Practices

Original Article
Open Access
Special Issue: Case Studies of Family Nursing Practice

Psychosocial Support for Families of Children with Medical Complexity Transitioning from Hospital to Home Care

Kuniko Kodama[1*], **Atsuo Nonoyama**[2] **and Aya Yamauchi**[3]

[1]*Department of Nursing, School of Medicine, Tokai University, 143 Shimo-kasuya, Isehara City, Kanagawa 259-1193, Japan*
[2]*Aichi Developmental Disability Center, Aichi, Japan*
[3]*Osaka Prefectural Hospital Organization, Osaka Women's and Children Hospital, Osaka, Japan*

Abstract

Background: In recent years, the number of children living at home with medical complexity has been increasing; however, psychosocial support for these children and their families remains inadequate. This study aimed to clarify psychosocial support for families of children with medical complexity (CMC) in the process of transitioning from hospital to home care.

Methods: Our study employed a case study approach. Data were collected by reviewing the records and experiences of the specialized nurses responsible for CMC, then extracting and summarizing the content of nursing practice from the start of consultation through the transition from hospital to home (H2H) in chronological order. Data analysis was conducted with ten experts focusing on psychosocial support, and the main themes of support were extracted. We obtained approval from the Ethical Review Committee and consent from the target participants.

Results: Four stages of psychosocial support were identified for the H2H transition.

(1) Build a supportive relationship with the family by establishing a trust-based relationship between the family and medical professionals as the foundation for the H2H transition. (2) Support the family's sense of loss to help them acknowledge their sense of loss in relation to their child's disability. (3) Assist the family to reshape their future, where professionals help the family develop a new vision for their family life with and for their child with a disability. (4) Promote internal family coordination for the transition to home care, encourage dialogue among family members, and improve adaptability to prepare for living with the child at home.

Conclusion: Given the complex psychosocial circumstances the CMCs and their families undergo, it is suggested that H2H transition care should be implemented from an early stage and over the long term.

Publication History:

Received: January 23, 2025
Accepted: February 05, 2025
Published: February 07, 2025

Keywords:

Child, Children with medical complexity, Hospital-to-home transition, Family care, Psychosocial

Abbreviations:

CMC: Children with medical complexity
CNSF: Certified Nurse Specialist in family health nursing
H2H: hospital to home
PICU: Pediatric intensive care unit

Introduction

In Japan, the survival rate of children with disabilities has improved with the development of medical systems and advances in medical technologies. Furthermore, the number of children living at home receiving complex medical care (hereafter referred to as "children with medical complexity" or "CMC") is increasing. In 2021, the number of children requiring daily medical care, such as artificial respiration and sputum suction, has risen to around 20,000, doubling in the last 15 years. In response, a legal framework was established to support these children and their families [1]. To support CMCs as they transition out of the hospital, the entire process must be coordinated through close collaboration between the child, family, and medical team, and support should be provided to the family from the earliest stages [2]. Families of CMCs face gaps in service coordination and communication during the children's transition from hospital to home, often resulting in unsuccessful medical care transitions and deterioration of the children's condition. This suggests that these families require continuous support, while helpers need to understand their vulnerabilities in order to provide appropriate support [3,4].

Furthermore, in response to the growing number of CMCs being transferred from hospital to home care, part of the Japanese Child Welfare Law was revised in 2016 to improve support systems for CMCs in local communities. As CMC support requires not only dealing with complex medical needs, but also childcare and education, the law made it mandatory for all relevant organizations to work together to create a collaborative support system. Approximately 65% of CMCs in home medical care were bedridden and received tube feeding and sputum suctioning, while one-fifth required the use of artificial respirators. Moreover, some CMCs in home medical care receive education and public welfare support by commuting to specialized outpatient hospitals as well as by using home visits from doctors, nurses, and rehabilitation services [5]. As a result, numerous social programs have been implemented to ensure smooth transition from hospital to home care for CMCs and their families. These included the development of home medical care systems, home and residential care services, childcare and special needs education projects, medical system projects in schools and educational sites, and financial support, such as medical fee subsidies and the issue of disability certificates. After CMCs and their families have been transferred from high-care units, such as the intensive care unit, to general hospital wards and have acquired the necessary medical care

---

[*]**Corresponding Author:** Dr. Kuniko Kodama, Department of Nursing, School of Medicine, Tokai University, 143 Shimo-kasuya, Isehara City, Kanagawa 259-1193, Japan; Tel/Fax: +81-463-90-2067.

Citation: Kodama K, Nonoyama A, Yamauchi A (2025) Psychosocial Support for Families of Children with Medical Complexity Transitioning from Hospital to Home Care. Int J Nurs Clin Pract 12: 406. doi: https://doi.org/10.15344/2394-4978/2025/406

Citation: Kodama K, Nonoyama A, Yamauchi A (2025) Psychosocial Support for Families of Children with Medical Complexity Transitioning from Hospital to Home Care. Int J Nurs Clin Pract 12: 406. doi: https://doi.org/10.15344/2394-4978/2025/406

skills, they need to continue receiving medical care in a variety of settings, including at home and in facilities. Therefore, the support systems for these children and their families involve a very complex set of arrangements, which is why the law stipulates the development of consultation systems with highly specialized knowledge and comprehensive perspectives to provide appropriate support to them. Efforts are currently being made to train and develop CMC-specific consultants [6,7]. Going forward, psychosocial support for CMCs and their families is likely to become more essential.

In the case of CMCs' hospital-to-home (H2H) transition, families are expected to face not only the challenge of mastering skills for providing medical care, but also psychosocial struggles, while specific details of the care required for families remain unidentified.

Research Objective

To explore the psychosocial support provided to families of CMCs involved in the transition from hospital to home care.

Research Methods

Research design

This research is based on a case study describing the nursing practices of psychosocial support provided to a child with medical complexity and their family members during the transition from hospital to home care.

Data collection method

We explored the experience of a Certified Nurse Specialist in Family Health (CNSF) with specialized consultation skills in children with complex medical care needs and their families at a specialist hospital. The CNSF reflected a case that made a particularly strong impression on it during the CMC's transition from hospital to home care. The medical and consultation records of the child were used to elucidate the support provided from the start of consultation to the completion of the transition to home care. The course of nursing practice was then summarized in chronological order. We particularly focused on psychosocial support and described the child and family situation, as well as the contents of the assessment and nursing practices.

Analysis method

Using the case history records, ten CNSFs analyzed the case and reviewed the content of the practices. They organized the content of the practices in chronological order, summarized them, classified them into periods, and named the characteristics of the practices. Simultaneously, they created genograms (diagrams of the family's internal and external relational structures) and structural diagrams showing the family's interactions, identifying themes related to psychosocial support through a series of discussions. We strived to improve the reliability of the results through discussions with two CNSF members (collaborators) with extensive experience in supporting CMCs and their families.

Ethical consideration

This study was conducted after receiving ethical review from a representative institution and obtaining written and verbal consent from the participants.

Results

Facility outline

The target facility is a designated hospital with a mother-child health center that serves many children with complex medical complexity.

Case overview

Family Structure (Figure 1)

A child with medical complexity, age 9, had encephalitis. He had been healthy before the onset of the illness. A three-person household with a father (in his 40s, busy with work) and mother (in her 40s, deeply interested in her child's education). The grandparents of the child on the mother's side were close, but those on the father's side were distant. The child's grandfather on the mother's side passed away, and the second child (sister) was born during hospitalization.

The child's medical history

X years to X+1 years: The child developed a serious form of encephalitis of unknown cause, leading to a life-threatening condition.

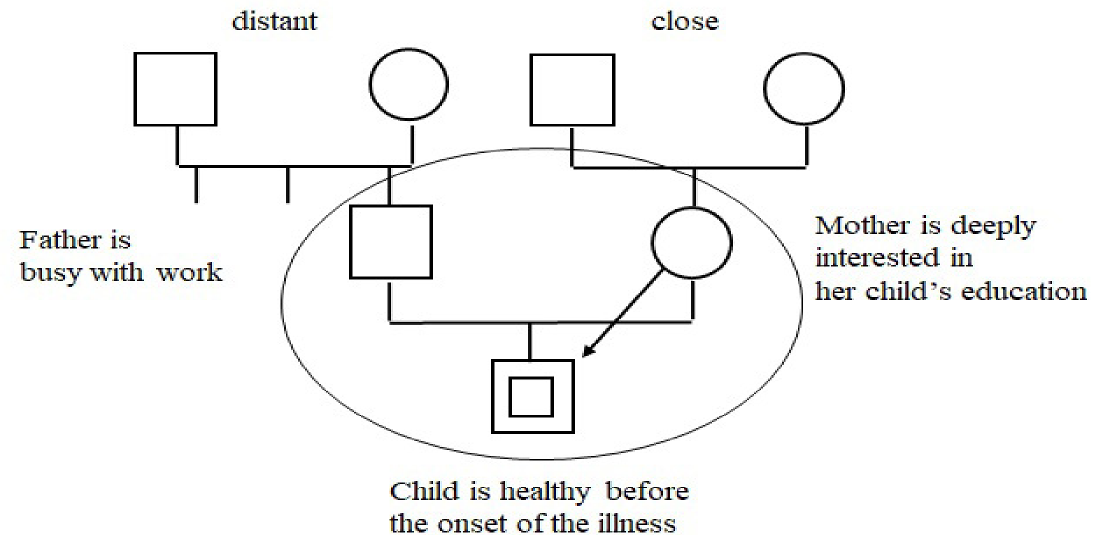


Figure 1: Genogram.

However, because of the intensive treatments provided in the pediatric intensive care unit (PICU), the child began to recover and was transferred to a general ward approximately six months later. As the child was suffering from severe brain dysfunction, with repeated episodes of convulsions and aspiration pneumonia, a serious disability was foreseen. The patient's motor function declined to a bedridden state, and intellectual function deteriorated to the level of a three-year-old child. Activities of daily living required full assistance, including sputum suctioning and tube feeding, every few hours as medical care.

Circumstances requiring support for the family

Medical professionals began to explain to the child's parents about the possibility of their child having a disability. The parents were often unable to accept the medical professionals' assessments and expressed their distrust in them, which led to the need for enhanced psychosocial support.

The Actual Practice of Nursing

Due to the child's unstable condition, it took about four years to complete the course of nursing practice. In addition to the child with medical complexity and his family, many medical and welfare professionals (medical doctors, nurses, social workers, specialists in pediatric and family care, rehabilitation staff, visiting nurses, visiting doctors, city hall staff, special needs teachers, etc.) were involved.

The case analysis identified the four stages of psychosocial support for the family of the child with medical complexity transitioning from hospital to home care, and the core themes of the support were also suggested.

The nursing practices are indicated in line with Table 1. The core themes of support for each stage are indicated, the characteristics of nursing practice are indicated in brackets '', and the details of nursing practices is indicated in brackets []. The challenges and changes in the family are indicated in Table 1 in a genogram to illustrate the family structure.

Stage 1: Build a supportive relationship between family and medical professionals

This stage focused on building a relationship of trust between family and medical staff that would form the basis of the process of transitioning to home care. In year X, following a complaint from the family about a lack of trust in the medical staff, psychosocial support was strengthened in the PICU. [Assessing the vicious circle pattern between family and medical professionals] found dissonance between the family and medical professionals. On the one hand, the parents complained that "there is no treatment that can reverse the situation, and the delay in treatment is causing a problem." On the other hand, the doctors and nurses saw the parents' statements and behaviors as a problem, responding, "The family doesn't understand."

In response, the CNSF tried to 'ease the vicious cycle between family and medical professionals' by [encouraging the medical professionals to understand how the family is experiencing the child's illness] while also [acknowledging the complex emotions of both the family and medical professionals]. After the intervention, medical professionals began to show a greater understanding of the family, and parents mentioned that it became easier to consult with medical professionals. In addition to doctors and nurses, interventions by rehabilitation staff, pediatric nursing specialists, medical social worker medical social worker, and nurses specialized in supporting patients returning home made it possible to implement initiatives to [share the goals of family care among those involved] at conferences and to 'maintain an effective support system'. Thanks to the partnership formed with the family, the child smiled more.

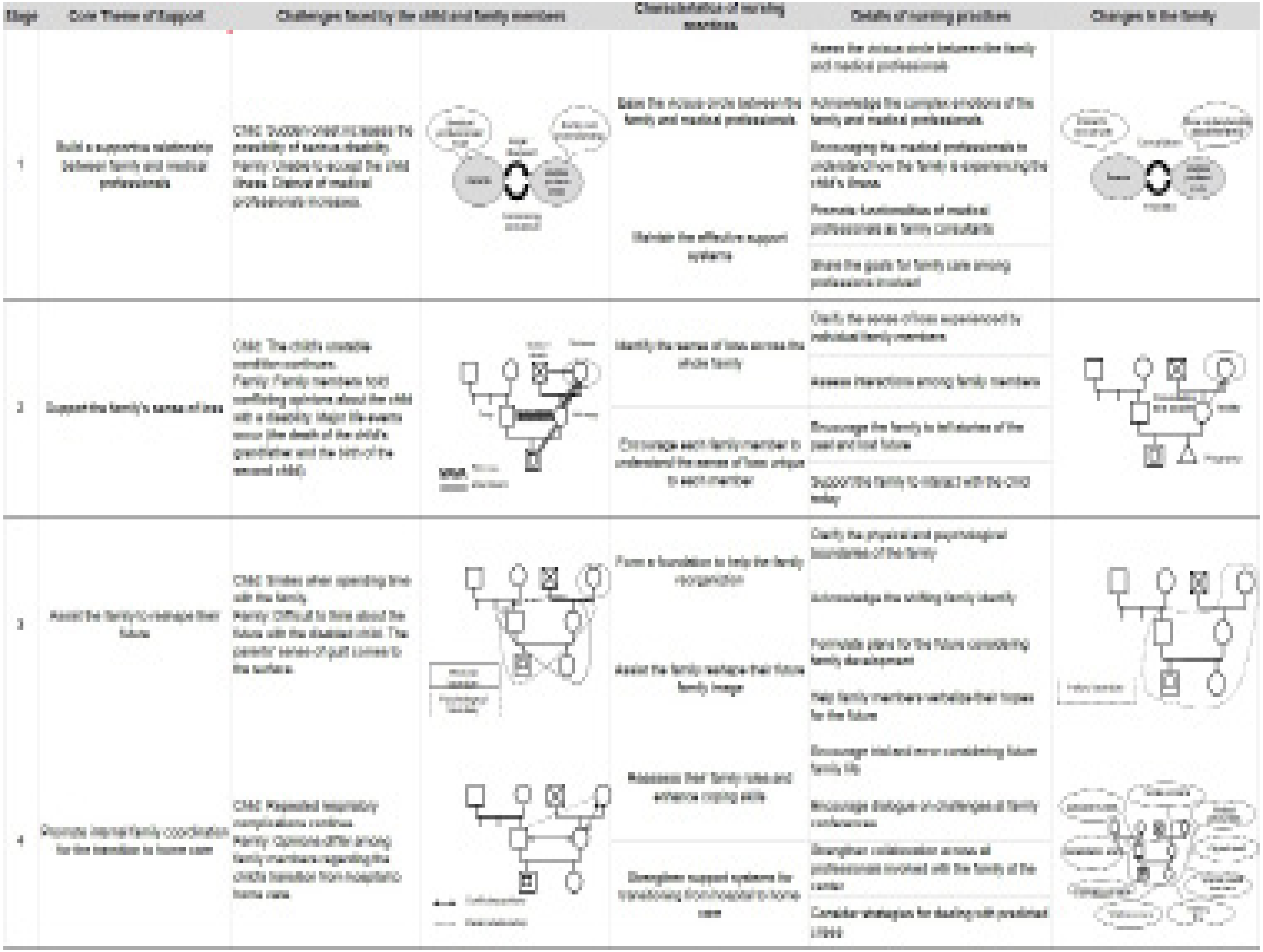
Stage 2: Support the family's sense of loss

At this stage, the family needed help to acknowledge their sense of loss regarding their child's disability. X+2 years: The family faced a turning point with the sudden death of the child's grandfather and the mother's pregnancy with their second child, which brought family tensions to the surface because of conflicting opinions within the family regarding the child with a disability. As the child's unstable condition continued, the medical team began to give up on the idea that the child could transition from hospital to home. The CNSF team deepened their understanding of the family by [assessing interactions among family members] the father became absorbed in his work and hobbies, and his visits with the child grew less frequently. The grandmother said, "It would have been better if the child had not survived," which led to the mother expressing her resentment toward other family members, saying, "I feel sorry for the child." As these were perceived as reactions to loss, each family member was encouraged to express their emotions individually to [clarify the sense of loss experienced by individual family members].

By helping the family to 'identify the sense of loss across the whole family', the medical team became aware that the conflict within the family manifested the sense of loss experienced by the family, so they explored approaches to supporting the family's sense of loss. First, the support team encouraged the family to [encourage the family to tell stories of the past and lost future] and helped the family to [support the family to interact with the child today]. The father talked about the memories of the annual family trips while looking at old photos, and then said, "We can't travel together anymore, can we?" In response, we incorporated the family trip experience into activities when the father was interacting with the child. When the child showed a happy face, the father started talking to him, saying, "I feel like my child understands. Let's travel together again." The mother talked about how her child had been bright with dreams of advancing to higher education and starting a career. In response, the mother was invited to attend the classes taught by the special needs teacher. The mother became aware that her child was responding well in certain areas and said, "My child may not be able to fully recover, but I would like to help develop his abilities as much as possible." The grandmother also talked about how the child loved his grandfather so much and said that it was very impressive to see the child carefree and happy. To help the grandmother work through her grief, she was encouraged to tell stories about his grandfather and the child. Gradually, she began to express her feelings about the death of the child's grandfather, saying, "He passed away as if he had carried the child's illness away with him." She expressed a wish to survive. Through the process of 'encourage each family member to understand the sense of loss unique to each member,' they began to look more relaxed. In response to the changes in the family, the medical team resumed discussions about the child's transition from hospital to home.

Stage 3: Assist the family to reshape their future

This stage is to help the family envision a new family image with the child having a disability. X+3 years: The family spent more time with



Stage	Core Theme of Support	Challenges faced by the child and family members	Characteristics of nursing practices	Details of nursing practices	Changes in the family
1	Build a supportive relationship between family and medical professionals	CMC: [illegible] possibility of serious disability. Family: Unable to accept the child illness. Distrust of medical professionals increases.	Ease the vicious circle between the family and medical professionals	Assess the vicious circle between the family and medical professionals Acknowledge the complex emotions of the family and medical professionals Encouraging the medical professionals to understand how the family is experiencing the child's illness Promote functionalities of medical professionals as family consultants	
			Maintain the effective support systems	Share the goals for family care among professionals involved	
2	Support the family's sense of loss	CMC: The child's unstable condition continues. Family: Family members hold conflicting opinions about the child with a disability. Major life events occur (the death of the child's grandfather and the birth of the second child).	Identify the sense of loss across the whole family	Clarify the sense of loss experienced by individual family members Assess interactions among family members	
			Encourage each family member to understand the sense of loss unique to each member	Encourage the family to tell stories of the past and lost future Support the family to interact with the child today	
3	Assist the family to reshape their future	CMC: Smiles when spending time with the family. Family: Difficult to think about the future with the disabled child. The parents' sense of guilt comes to the surface.	Form a foundation to help the family reorganization	Clarify the physical and psychological boundaries of the family Acknowledge the shifting family identity	
			Assist the family reshape their future family image	Formulate plans for the future considering family development Help family members verbalize their hopes for the future	
4	Promote internal family coordination for the transition to home care	CMC: Repeated respiratory complications continue. Family: Opinions differ among family members regarding the child's transition from hospital to home care.	Reassess their family roles and enhance coping skills	Encourage trial and error considering future family life Encourage dialogue on challenges at family conferences	
			Strengthen support systems for transitioning from hospital to home care	Strengthen collaboration across all professionals involved with the family of the center Consider strategies for dealing with predicted crises	

Table 1: Aspects of psychosocial support for families of CMC transitioning from hospital to home care.

the child, and the child began to smile. The family's resistance to thinking about the future with the disabled child eased, so we held a specific conversation about transitioning to home care. The mother responded, "It's impossible to think about the future now." The child with the disability needs to stay in the hospital until his younger sister starts elementary school." To help the family [clarify their physical and psychological boundaries], they were encouraged to become aware of the changes in their family structure that involved the child's illness. The mother said, "The child stays in the hospital, and the younger sister stays at home. It's just like having two separate families." In response to a question about what would happen if the child were to come home, the mother replied, "The child's room remains as it was before his illness, making it impossible for us to move forward." The mother struggled with the idea that the sick child did not exist in their family life at home. By [acknowledging the shifting family identity], the team aimed to help the family 'form a foundation to be capable of responding to changes in the family structure.'

CNSF questioned the mother about what she would like to cherish in terms of [formulating plans for the future, considering family development]. As the mother wished for the healthy growth of the child's younger sister, she was encouraged to talk about concrete plans for the family. Because it is difficult to envision the future of the family while caring for the sick child, the mother was encouraged to think about what the birth of a younger sister would mean for the family to [help the family verbalize their hopes for the future]. The mother realized that she had hoped for the birth of his younger sister to take care of her disabled sibling. She also mentioned that she had experienced distress after the birth of his younger sister, realizing that the younger sister would have her own life. She was also encouraged to think about her wishes for how these siblings would live together in the family and with whom she would like them to be surrounded, to ' assist the family reshape their future family image.' The mother was able to verbalize her wishes, saying that she hoped that the whole family would spend time together, and that she wanted the younger sister to know that her older brother was living with a disability and the older brother to know that he had a younger sister. The whole family began to spend more time together during their hospital visits.

Stage 4: Promote internal family coordination for the transition to home

This stage focused on improving coping skills by promoting dialogue between family members in preparation for life at home with a child. X+4 years: As the child repeatedly suffered from respiratory complications, ensuring his safety at home remains a challenge. Medical care coordination began looking ahead to the child's life at home. [Encouage dialogue on issues at family conferences] made it clear that all family members needed to change their lifestyle and that differences of opinion existed within the family about their goals for family life. Therefore, the team tried to 'reassess their family roles and enhance coping skills' through practicing overnight stays at the hospital [to encourage trial and error while considering future family life]. The family commented, "We realized that we had to consider our roles from more angles than expected" and came to understand the various roles and functions involved in caring for the child. To [strengthen collaboration across all professionals involved with the family at the center], a series of family conferences were held with the staff involved in home-based medical care. During this period, all medical professionals, with the family at the center, communicated in person and by other means such as the telephone, which helped to identify the challenges involved in living at home. To ensure the child's stable breathing and to secure sleep time for the family, a night-time home artificial respirator was introduced. In addition, a care plan was created in line with the weekly and daily schedules for the child and family, and medical and welfare services were coordinated. To [consider strategies for dealing with potential crises], trial overnight stays at home were arranged, and measures were examined to deal with any possible problems. The family expressed positive comments such as, "It feels like everyone in the family has changed. We might be able to manage on our own after the child returns home. We feel more secure now that the medical staff are coming to our home," which led to the transition from hospital to home care. After the child was transferred out of the hospital, care coordination and consultation support were provided for the family through the homecare team, and the family reported being able to live autonomously.

Discussion

Here we describe the characteristics of psychosocial support for families of CMCs transitioning from hospital to home care. In this case, intensive psychosocial support for the family began in the early stages of the child's treatment in the PICU. In the early stages, the family's distrust of the medical profession came to the surface, creating a dissonance between the medical professionals and the family, which led to serious communication issues. The strengthening of psychosocial support can improve communication between the family and medical professionals, preventing problems related to the transition of medical care, as well as helping to form a partnership with the family. For CMC to transition from hospital to home, intervention is recommended as early as possible, even before the child becomes medically stable [2]. Intervention with families at an early stage and partnership building, considering the psychosocial situation, was always necessary in the second stage and beyond, serving as the foundation for transition support to home care.

The second characteristic is that appropriate support was provided for the family's sense of loss and the conflicts within the family regarding the child's disability. The impact of feeling lost on the family life cycle is severe, suggesting that the family feels like their future with the child has been stolen [8]. Awareness of their loss experience led them to transformative change: the father, through the memories of trips and activities with the child; the mother, through educational interaction with the child; and the grandmother, through recounting memories with the child's grandfather. The family's loss experience was a dynamic journey connecting memories of the past with the child to a narrative of the unrealized future that could have been. Moreover, the reactions of family members to the loss were unique and complex: for example, the father escaped into work; the mother became angry with other family members and obsessively attached to the child; and the grandmother grieved and wished for the child to be dead. It is known that parents of CMCs suffer a variety of emotions, including feelings of helplessness, guilt, resentment, and grief; therefore, they need to receive emotional support and empowerment [9]. Intervention by specialists was useful not only for properly assessing those affected and providing appropriate psychological care for each family member but also for helping medical professionals to understand the family's needs.

The third characteristic is the need for long-term care management, taking family reorganization into account. The CMC with unstable medical conditions requires high-level nursing care daily at home. For this reason, providing safe medical care at home is extremely complex, requiring considerable coordination to bridge the communication gap. Under such circumstances, the parents struggled with guilt about not being able to envision family life with their child, even after the child's disability was confirmed. The emotional pains caused by the long-term family divide between the sick child and the second child, the younger sister, were difficult for the family to recognize. Parents of children with severe rare diseases face overwhelming psychosocial challenges and go through a long process of gaining experience [10]. On the other hand, long-term hospitalization of CMCs can lead to social isolation of the family [9]. When supporting the families of CMCs, it is important to consider this contradiction and provide support that allows the family to go through the process of reorganization while gaining their own experiences.

Conclusion

We identified the following as psychosocial support for CMCs transitioning from hospital to home care: building a supportive relationship with the family, supporting the family's sense of loss, assisting the family to reshape their future, and promoting internal family coordination for the transition to home care. The results suggest the importance of providing these types of care from an early stage and over the long term.

Competing Interests

The author and all co-authors have no conflicts of interest with any companies related to medical research that should be disclosed.

Acknowledgment

We would like to express our gratitude to the participating family members and CNSFs for their cooperation in this study.

References

1. Ministry of Health, Labour and Welfare (2021) Children with medical complexity.
2. Complex Care at home for Children (CMC) in Canada, Hospital discharge of the child with medical complexity.
3. McIntosh J, Runciman P (2008) Exploring the role of partnership in the home care of children with special health needs: qualitative findings from two service evaluations. Int J Nurs Stud 45: 714-26.
4. McIntosh J, Runciman P (2008) Exploring the role of partnership in the home care of children with special health needs: qualitative findings from two service evaluations. Int J Nurs Stud 45: 714-26.
5. Mizuho Information & Research Institute, Inc. (2016) Research on childeren requiring home medical care.
6. Ministry of Health, Labour and Welfare (2021) Laws Concerning Support for Children with Medical Complexity and Their Families.
7. Ministry of Health, Labour and Welfare (2020) Policy trends related to support for children with medical complexity, and other Needs.
8. Rolland JS (1990) Anticipatory loss: a family systems developmental framework. Fam Process 29: 229-44.
9. Van de Riet L, Alsem MW, Beijneveld RSI, van Woensel JBM, van Karnebeek CD (2023) Delineating family needs in the transition from hospital to home for children with medical complexity: part 2, a phenomenological study. Orphanet J Rare Dis 18: 387.
10. Tumiene B (2022) Unmet psychosocial needs of parents of children with rare, complex, and severe genetic diseases. Dev Med Child Neurol 64: 13.

This article was originally published in a special issue:

Case Studies of Family Nursing Practice

Handled by Editor(s):

Prof. Reiko Inoue
Department of Nursing
Tokai University
Japan