

Challenges of Home Care Support Systems for Pediatric Patients with Cancer and Their Families in Japan

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1. Abstract

This study reviewed the existing research on home care support systems for pediatric patients with cancer and their families to identify the challenges in sustaining effective home care. Papers published between 2000 and 2022 were searched using keywords such as “pediatric cancer” and “home care” on Ichushi-Web, and 13 studies that met the selection criteria were analyzed and evaluated. These papers focused on end-of-life and terminal care at home, support during the transition from hospitalization to home care, and care for families and mothers. Studies on end-of-life and terminal care highlight the need to establish medical collaboration systems, particularly noting insufficient collaboration among specialized hospitals, home care physicians, tertiary care hospitals, and home health care facilities. For support during the transition from hospitalization to home care, determining the appropriate transition timing and its impact on the quality of life was emphasized, underscoring the importance of supporting the entire family.

2. Introduction

Owing to the rarity of pediatric cancer cases, data on the current situation are limited, and support systems addressing the medical, psychological, and social needs of affected children and their families are not yet fully developed. However, the perception of “pediatric cancer as a curable disease” is becoming more established in society (Children’s Cancer Association of Japan, 2016). In recent years, the number of children receiving disability-related medical care, including for pediatric cancer, while living at home has

increased (Ministry of Internal Affairs and Administrative Evaluation Bureau, 2024). According to the Central Social Insurance Medical Council, the number of home healthcare users under 15 years of age was 18,774 in 2019, which is approximately three times that in 2011. The proportion of those requiring care for cancer (malignant tumors), intractable diseases, or medical concerns increased 2.7 times compared with 2011 (Central Social Insurance Medical Council, 2019). In this context, these patients face various challenges in home care and find it difficult to obtain appropriate medical care. Although research on supporting children and families undergoing pediatric cancer treatment in medical institutions is progressing, research on establishing support systems for home care and its associated challenges remains insufficient. This indicates that support systems for the home care of pediatric patients with cancer and their families have not yet been fully established. Given the current emphasis on community-based integrated care, developing and enhancing regional home care systems for children in Japan is imperative.

This study aimed to review prior research on home care support for pediatric patients with cancer and their families and identify the challenges necessary for maintaining high-quality home care. The findings of this study are expected to serve as a foundational resource for promoting regional collaboration in home care for pediatric patients with cancer.

3. Objective

This study aimed to review existing research on home care support systems for pediatric patients with cancer and their families to identify the challenges that need to be addressed to sustain effective home care.

4. Methods

This study involved a comprehensive literature review. The literature was searched for papers published between 2000 and 2022 using the keywords “pediatric cancer” and “home care” in Ichushi-Web, Japan’s largest medical literature repository. The analysis involved classifying, organizing, and evaluating the research objectives, findings, and discussions of studies that examined home care support for pediatric patients with cancer and their families.

5. Results

5.1. Publication Years and Research Methods of Target Papers

A total of 13 studies met our inclusion criteria. Two papers were published from 2000 to 2009, nine from 2010 to 2019, and two from 2020 to 2022, with eleven papers published since 2010. The research methods included eight case studies, two surveys, one survey combined with interviews and case studies, and one study combined with other methods. The authors’ professions included ten doctors, one home health nurse, and two nursing faculty members. Of these doctors, nine were affiliated with public or university hospitals, and one was affiliated with a home-visiting clinic.

5.2. Main Content of the Papers

Nine papers (Ohsugi et al., 2009; Park et al., 2014; Sugishita et al., 2016; Ohashi et al., 2015; Yanagisawa et al., 2018; Jitsukawa et al., 2019; Ueda et al., 2019; Morita et al., 2020; Takenouchi et al., 2022) focused on end-of-life and terminal care at home. Two studies (Mogami et al., 2017; Kawada et al., 2019) addressed support during the transition from hospitalization to home care. Two studies (Onda et al., 2006; Takenouchi, 2018) discussed care for families and mothers.

All papers on end-of-life and terminal care at home emphasized the need to establish medical collaboration systems. Specifically, issues such as insufficient collaboration among specialize hospitals, home care physicians, tertiary care hospitals, and home healthcare facilities were highlighted. Given the characteristics of home care, which aim to ensure the quality of life (QOL) and a secure care environment, discussions focused on building collaboration systems among relevant professions and institutions and the importance of continuous collaboration and information sharing before the transition to home care. Morita et al. (2020) and Jitsukawa et al. (2019) proposed the establishment of educational training sessions and case discussions for the professionals involved in providing high-quality care (Morita et al., 2020; Jitsukawa et al., 2019). In particular, research by Morita et al. (2020) on eight years of home-based end-of-life care for pediatric patients with

cancer suggested that interventions by home health care and home care physicians are crucial for promoting home-based end-of-life care, and the implementation of home medical procedures might contribute to extending the duration of home care.

Studies on support during the transition from hospitalization to home care have stressed the importance of determining the appropriate timing for the transition, which significantly impacts the quality of subsequent care. Specifically, adaptation to physical conditions, the care environment, and school life at home were emphasized. Kawada et al. (2019) introduced a case where a physician with no pediatric experience acted as a palliative care specialist, playing a significant role through collaboration with specialized hospital physicians despite the shortage of pediatric medical facilities and home care physicians.

Research on care for families and mothers has highlighted the experiences of mothers who received home care during their child’s terminal phase, emphasizing the need for support for the entire family, including mothers. Care providers must respect the family’s experiences and emotions and support their unique lifestyle. Onda et al. (2006) suggested that although mothers receive support from fathers, grandparents, and siblings, they still experience new stress in caring for their children, making continuous care important. Thus, the studies focused on improving end-of-life and terminal care at home, support during the transition, and care for families, with each study emphasizing the importance of medical collaboration and the provision of high-quality care.

6. Discussion

6.1. Background of Paper Publications

The number of research papers on home care support systems for pediatric patients with cancer has increased since 2010, indicating a rising awareness of the patients’ home care needs during this period and underscoring the need to develop home care systems. Additionally, the shortage of medical institutions, pediatric specialists, home health nursing stations, and home health nurses in supporting pediatric patients with cancer and their families has been a significant challenge. Although there have been changes in legislation and regional enthusiasm for promoting pediatric home healthcare in recent years, securing medical institutions and various professionals for home care support systems remain substantial challenges that need to be addressed. Furthermore, as most authors of these papers are physicians affiliated with public or university hospitals, it can be inferred that physicians from these institutions have primarily spearheaded research on developing home-care support systems for pediatric patients with cancer.

6.2. Strengthening Regional and Home Care Collaboration for Pediatric Patients With Cancer

In the modern era of integrated community care, ensuring that all individuals receiving home care, including pediatric patients with

cancer, have access to high-quality care to maintain and enhance their QOL is essential. Regional collaboration is indispensable to achieve this goal. However, the development of regional integrated care systems is ongoing, and delays in establishing foundational systems for continuing home care, especially for pediatric patients, remain problematic. Efforts are being made to create opportunities for system development through educational training sessions and case discussions, as demonstrated in the studies by Jitsukawa et al. (2019) and Morita et al. (2020). Addressing common issues across related institutions is crucial to strengthening collaboration.

In supporting pediatric patients with cancer, it is crucial to maintain and continue home care by considering the characteristics of their illnesses and collaborating with medical institutions and professionals and educational, childcare, and psychological support organizations and specialists. Previous studies have highlighted concerns among mothers of pediatric patients with cancer regarding the lack of appropriate counseling for their children's academic delays, social relationships, and development (Shoji, 2014; Kudo et al., 2022). These concerns suggest anxiety regarding disease progression, the continuation of home care, and the child's future during home care. Additionally, in end-of-life and terminal care, it is important to establish support systems that provide the necessary educational and developmental support and facilitate social interactions among children to help them fully live their lives. Such support is essential to fulfill children's rights and ensure their overall well-being.

Therefore, supporters and organizations involved in home care for pediatric patients with cancer must transcend their individual specialties and play a role in supporting the growth and development of the children as individuals.

6.3. Support for Transition to Home Care

To implement home healthcare for pediatric patients with cancer, it is essential to have medical content that can be provided in home care settings. According to a survey by Yokosuka et al. (2022) of 1,075 home-visit clinics, general clinics, and 24-hour home health nursing stations in Kanagawa Prefecture, many facilities reported that medical content suitable for adults did not apply to children. This indicates the difficulty in realizing home care for pediatric patients. The selection and judgment of the transition to home care by families is significantly influenced by the child's condition and changes in their health. The timing of this transition can affect the prognosis of subsequent home care (Mogami et al., 2017). Therefore, meticulous collaboration among family members, hospital physicians, nurses, medical social workers, psychologists, and relevant organizations ensures a smooth home-care transition. As pointed out by Kawada et al. (2019), communication with specialists at inpatient medical institutions is necessary for an effective transition and continued home care.

Additionally, discussing the timing of collaboration with educational, childcare, and psychological experts is necessary during the transition phase. Furthermore, to enable families to support their children's home care with peace of mind, stakeholders must share specific needs, concerns, and uncertainties and develop a care plan with clear expectations. It is essential to consider comprehensive care content that addresses both short- and long-term home care needs during the transition phase.

7. Conclusion

Existing research on home healthcare for pediatric patients with cancer has mainly focused on end-of-life and terminal care, highlighting the need for medical collaboration in these settings. To improve the QOL of patients and their families, it is essential to establish a system for information-sharing and collaboration among specialized hospitals, regional medical institutions, home visit clinics, and home health nursing stations. During the transition from hospitalization to home care, timely and tailored support is crucial as its success significantly affects the quality of ongoing care. This phase requires family involvement and close coordination with hospital staff and home care stakeholders, including medical social workers and psychologists. Additionally, creating an environment that supports children's medical needs, development, education, and social skills through collaboration with relevant institutions is vital. Strengthening home health nursing and the network of medical and related institutions is key to advancing home healthcare for pediatric patients with cancer. Future efforts should focus on building a comprehensive and continuous support system to ensure the efficient use of resources and prompt and appropriate care.

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9. Conflict of Interest Disclosure

The authors declare no conflict of interest related to this study. Measures were taken to ensure that the objectivity of this study was not compromised by the receipt of grants.

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