

Hospital-To-Home Transition: Experiences of Children and Youth with Chronic Disease and Their Caregivers

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Abstract

Children and adolescents/young adults (AYAs) with chronic diseases frequently experience hospitalization [1]. The transition to home is challenging for patients' families [2, 3]. This qualitative study explored the experiences and perspectives of hospital-to-home transition from children and AYA patients with chronic disease and their family caregivers in Hong Kong. We conducted four focus group interviews with 29 participants (13 patients aged 24 or below and 16 family caregivers). This study was guided by the Innovative Care for Chronic Conditions (ICCC) framework [4] which included components at the patient and family; healthcare organization and community, and policy levels for the prevention and management of chronic health conditions in health transition. Data was analysed using framework analysis [5].

We identified nine themes in the three levels, aligning with the three levels of the ICCC framework. For the patient and family level, themes included difficulties adapting to the new environment, family conflicts on care plan and time management, feelings of social isolation, and unmet information and psychological support needs. For the healthcare facility level, family caregivers reported needs for continuity and high-quality healthcare and for increasing healthcare services in the community. For the policy level, insufficient human resources in the healthcare system and needs for financial assistance were reported.

This study demonstrated the challenging experience for the hospital-to-home transition of children and AYA patients and their families. A comprehensive strategy covering the three levels of the ICCC is needed. Nurses should provide sufficient health education on care skills to the patients and caregivers before discharge. The patients and their families need continuous psychological support and a means of communication with healthcare professionals at home. For policy, the study findings suggested the need to increase healthcare resources in communities and financial support to improve transition care quality.