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Satoe Iki
Department of Nursing Sciences, Graduate School
of Comprehensive Human Sciences,
University of Tsukuba

Experiences of primary caregivers who rear children with SMID (severe motor and intellectual disabilities) and of siblings during the transition from hospital care to home care

Recently, advancements in medical care have made it possible to save the lives of SMID children; therefore, support is required during these children's transition to home care. It is important to support not only parents, but also siblings during the transition, however studies that focus on siblings are rare

Therefore, this study aims to clarify the experience of primary caregivers of SMID children with siblings during the handicapped children's transition to home care. We conducted an online semi-structured interviews with 19 primary caregivers as subjects, and performed a Krippendorff (2012) content analysis.

As the result, 95 codes, 25 subcategories, and five categories were extracted as the experiences of the primary caregivers during the transition of SMID children with siblings to home care. The five categories were: "Discharge from the hospital while maintaining a balance with childcare for siblings"; "Struggling to balance caring for the SMID child and siblings"; "Observing the relationship between the SMID children and their siblings"; "Concern about the impact of a sibling on the relationship and the burden of caring"; and "Establishing new relationships between a sibling child and oneself".

"Discharge from the hospital while maintaining a balance with childcare for siblings" refers to the experience of the primary caregiver. The primary caregiver had to secure human resources and make adjustments for life at home, while struggling to balance visits to the SMID child and caring for the siblings.

"Struggling to balance caring for the SMID child and siblings" is also the experience of the primary caregiver. After discharge, the primary caregiver was busy providing care for the SMID child. As a result, they may have been unable to care for siblings and to live a life without the help of others.

"Observing the relationship between the SMID children and their siblings" as well as encouraging their interaction is the experience of the caregivers even in situations where it is difficult to establish the sibling relationship.

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"Concern about the impact of a sibling on the relationship and the burden of caring" refers to the primary caregiver's concern about the impact of the SMID child on their relationships and the burden of caring imposed by the SMID child.

"Establishing new relationships between a sibling child and oneself" refers to the experience of the primary caregiver who also feels supported by the presence of a sibling child, while trying to build a relationship with both the SMID child and the sibling child.

During the transition to home care, the primary caregiver finds it difficult to balance caring for the SMID child and the siblings but they support that the siblings can adapt to the new environment, and so they rebuild the relationship between themselves and the siblings.

Nurses should support primary caregivers when they are adapting to the transition to home care. Furthermore, they should encourage the development of relationships between the SMID child and their siblings and rebuilding of the relationships between the primary caregiver and the siblings.

Biography

Satoe Iki received her master's degree from the University of Tsukuba at the age of 26.

Currently, she is a PhD student at the University of Tsukuba.

From 2017 to 2019, she worked as a pediatric nurse at the University of Tsukuba Hospital. She is also currently working as a part-time nurse at a rehabilitation facility for children with disabilities.

She has given several presentations at international and Japanese conferences, and is currently preparing to submit her master's thesis.

s2130421@s.tsukuba.ac.ip