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Physio-psychological Burdens and Social Restrictions on Parents of Children With Technology Dependency are Associated With Care Coordination by Nurses

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ABSTRACT

Purpose: To determine the association between parental care burdens and care coordination provided by nurses for children with technology dependency, specifically regarding physio-psychological burdens and social restrictions.

Design and Methods: A cross-sectional study was conducted between October and November 2015. Participants were recruited via home-visit nursing stations, social worker offices, and special-needs schools. A total of 246 parents of children with technology dependency completed anonymous self-report questionnaires. Parental burden was measured using the Zarit Burden Interview. Care coordination for children with technology dependency was examined using items extracted from focus group interviews involving three nursing administrators at home-visit nursing stations, two social workers, and a coordinator of school education for children with special health care needs. Multiple regression analysis was performed to examine the relationship between parental burden and care coordination among 172 parents who contracted with visiting nurses.

Results: Parents and children with nursing support were significantly younger and had higher medical care needs and higher parental role strain than those without nursing support. Care coordination from nurses predicted reduced parental burden, role strain, and personal strain ($\beta = -0.247$, $p = 0.002$; $\beta = -0.272$, $p = 0.001$; $\beta = -0.221$, $p = 0.009$, respectively).

Conclusion: Nurses' care coordination appears to be associated with a reduction in parents' care burden resulting from home medical care of children with technology dependency, especially the social restrictions and physio-psychological burdens.

Practice Implications: Strengthening nursing functioning as care coordinators may contribute to reducing care burdens for parents of children with technology dependency.

Advances in pediatric health care and medical equipment have sparked an interest in the care modalities of children with various medical complexities and who have the most intensive health care needs (Cohen et al., 2011). Presently, an increasing number of children with technology dependency (CTD) characterized by medical fragility and dependence on technology, are discharged from the hospital and receive continuous medical care in home settings (Berry et al., 2016). CTD need daily care involving medical devices (e.g., suction, airway management by mechanical ventilator, and parenteral nutrition). Japanese medical standards of pediatric care are among the highest in developed countries, that is, the neonatal mortality rate is lower in Japan (1.0 per 1000 live births) than in the European Region (6.1 per 1000 live births). In addition, the infant mortality rate and the under-five mortality rate have decreased by half in the last two decades in Japan (World Health Statistics, 2015). In Japan, at least 17,000 children need medical device in their homes, and the number of children aged <19 years who need home ventilators increased more than tenfold over the last decade (Ministry of Health, Labour and Welfare, 2015). We, therefore, focused on children with medical complexities who had a continuous dependence on medical technology. The purpose of this study was to consider nursing roles for CTD and their parents in a home care setting.

Parents of CTD face various types of strains and have unmet needs about care coordination. Parents (particularly mothers) are typically primary caregivers for CTD at home (Kirk, Glendinning, & Callery, 2005). Additionally, parents caring for CTD assume a variety of roles (e.g., guardian, care provider, advocate, case manager), and they often experience physical burdens (e.g., lower back pain and sleep deprivation; Crowe, VanLeit, & Berghmans, 2000; Heaton, Noyes, Sloper, & Shah, 2005), severe

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psychological burdens (e.g., anxiety and depression; Kuster & Badr, 2006; Raina et al., 2005; Rehm, 2013), and social restrictions (e.g., loss of job opportunities and respite care; Heaton et al., 2005; Thyen, Kuhlthau, & Perrin, 1999). Although parents of CTD need numerous community health care services, available welfare services are limited for CTD and their parents. Parents of CTD often lack information concerning regional welfare services (Woodgate, Edwards, Ripat, Borton, & Rempel, 2015) and spend considerable time organizing and coordinating services for their child (Kirk & Glendinning, 2004). Parents of CTD have a great need for professional care coordination (Jachimiec, Obrecht, & Kavanaugh, 2015; Ray, 2002; Toomey, Chien, Elliott, Ratner, & Schuster, 2013).

The American Academy of Pediatrics Council on Children with Disabilities (2005) defines care coordination as “a process that facilitates the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health.” Adequate care coordination by health care providers can improve service satisfaction and fulfill care needs of parents of CTD (Boudreau et al., 2014; Turchi et al., 2009). Home visiting nurses may coordinate care with parents of CTD through the assessment of family functioning and potential needs (Kanaizumi, 2013). They administer part of the children's required daily care and reduce parental anxiety and financial burdens (Parab, Cooper, Woolfenden, & Piper, 2013). Additionally, collaborative care coordinated between parents and nurses has been shown to improve parental satisfaction with services, and it meets the family's informational needs (Farmer, Clark, Drewel, Swenson, & Ge, 2011; Palfrey et al., 2004).

In this context, care coordination by nurses has become an important resource of support for CTD and their parents; however, it is unclear how care coordination affects parents' burdens. This study aimed to identify the aspects of care coordination by visiting nurses that affect care burden among parents of CTD. This study's findings could provide recommendations regarding the role of nurses for CTD and their parents.

Methods

Study Design and Participants

A cross-sectional survey involving an anonymous self-report questionnaire was completed by the parents of CTD enrolled in the study. Eligible participants included parents living with children aged <18 years who needed medical care involving the use of a medical device (i.e., tracheostomy, home oxygen therapy, home ventilator, nasal airway, suction, nebulizer, total parenteral nutrition, nasogastric tube, gastrostomy, nasojejunal tube, jejunostomy, enteral infusion pump, peritoneal dialysis, ureterostomy, urethral catheterization, or colostomy).

Procedure

To reduce the possibility of selection bias due to age and residential area of CTD, recruitment was done through three facility types. First, all social work offices for children with special health care needs in Tokyo were approached via telephone and were asked to identify eligible participants (308 offices). Next, the social work offices that identified the eligible participants (124 offices), all special-needs schools for children with mobility and intellectual disability in Tokyo (18 schools), and four home-visit nursing stations for CTD were asked to participate in this research. Finally, eligible parents received letters requesting their participation via 47 social work offices, 11 special-needs schools, and 2 home-visit nursing stations for CTD (Fig. 1). Questionnaires were distributed to participants via staff members from each affiliated institution between October and November 2015. Participants returned their completed questionnaires directly to the researchers by mail using an anonymous envelope.

Measures

This study used a conceptual framework adapted from the structural models regarding caregiver burden among families of children with developmental disabilities by McManus et al. (2011). We included parental care burden as the dependent variable and perceived nursing care coordination as the main independent variable. For the analysis, we controlled for family support and demographic variables.

Parental Care Burden

The Japanese version of the Zarit Burden Interview (ZBI; Arai et al., 1997; Zarit, Reever, & Bach-Peterson, 1980) was used to measure caregiver burden in parents. The ZBI generalizes the physio-psychological

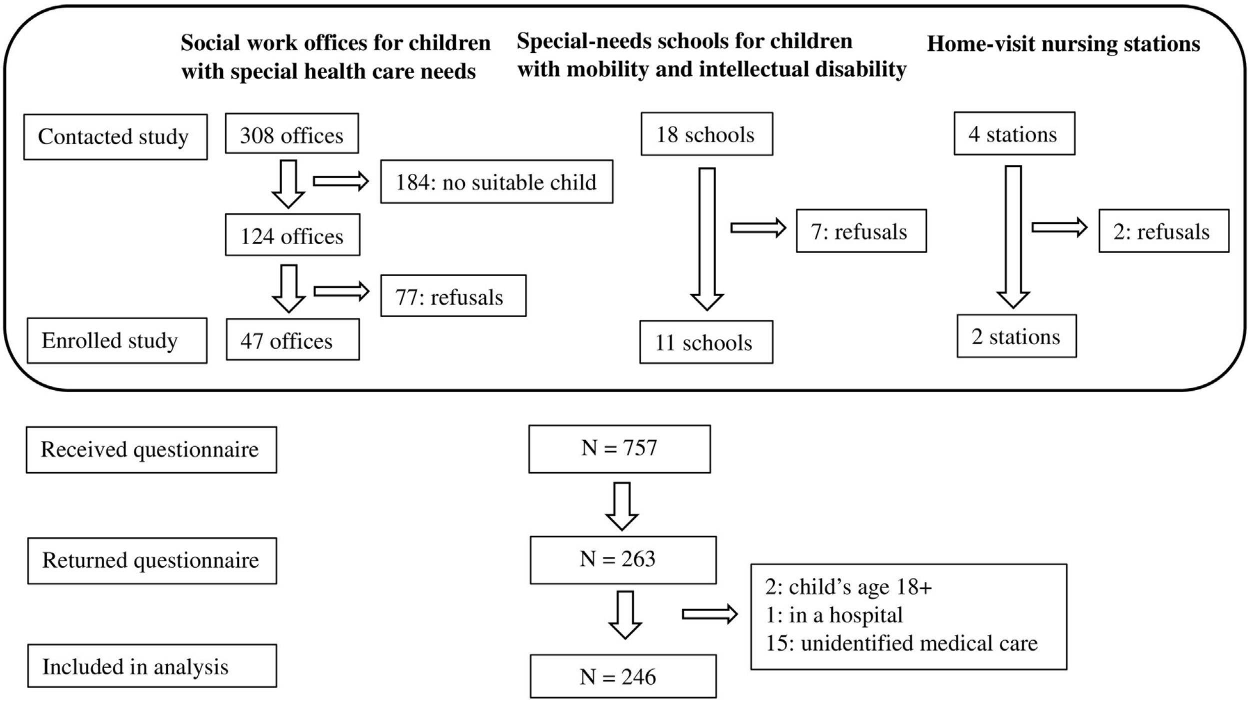

Fig. 1. Flow diagram of survey participants' progress.