Applied Nursing Research 46 (2019) 24–27

Contents lists available at ScienceDirect

Applied Nursing Research

journal homepage: www.elsevier.com/locate/apnr

Mothers caring for technology-dependent children at home: What is most helpful and least helpful?

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1. Introduction

Advances in healthcare have contributed to the growing population of children with complex, chronic conditions who require daily use of life-sustaining technological equipment such as mechanical ventilators or feeding tubes for continued survival (Office of Technology Assessment [OTA], 1987; Spratling, 2015). Often their mothers are the primary caregivers for these technology-dependent (TD) children at home (Chung et al., 2013; National Alliance for Caregiving, 2009). Providing daily care and treatments for a TD child at home is especially demanding while balancing family life and the needs of their well siblings, if present (Brenner et al., 2015; Toly, Blanchette, Sikorski, Musil, & Al Hamed,). Although past research indicates that caring for a TD child at home is a daunting task, mothers' perceptions of what is most helpful and least helpful to them remains unexplored.

1.1. *Study purpose*

The purpose of this study was to explore what is most helpful and least helpful for mothers who care for their technology-dependent children at home.

2. Methods

2.1. *Design*

A qualitative, descriptive design was employed. This secondary analysis was part of a larger institutional review board approved descriptive, correlational, cross-sectional study examining relationships among the TD children's severity of illness, the mothers' depressive symptoms and normalization efforts with family functioning in mothers caring for TD children at home (Toly, Musil, & Carl, 2012).

2.2. *Sample*

A convenience sample of mothers (primary female caregivers [$N = 103$]) caring for TD children ≤16 years old were enrolled in the larger study (Toly et al., 2012). Participants were ≥ 18 years of age and cared for a TD child at home. Children were classified based on OTA (1987) criteria: Group 1 - mechanical ventilation; Group 2 - intravenous nutrition/medication; Group 3 - respiratory or nutritional support. Exclusion criteria were mothers of children with cancer or in the terminal stages of illness.

2.3. *Measures*

The Feetham Family Functioning Survey (FFFS) (Roberts & Feetham, 1982) was administered which includes 25, 7-point Likert scale questions ($\alpha = 0.87$ this study) followed by two open-ended questions. Concurrent validity is supported by the Family Functioning Index (Roberts & Feetham, 1982). This secondary analysis examined solely maternal responses to question #26, “What is most helpful to you now?” and question #27, “What is least helpful to you now?” in regard to caring for the TD child at home.

2.4. *Procedures*

2.4.1. *Subject screening and recruitment*

The mothers were identified by staff from several pediatric specialty clinics (e. g., Pulmonology, Gastroenterology, Trach/Vent, Preterm Infant Follow-Up) at a large, Midwestern children's hospital. Introductory letters were mailed to potential participants describing the study and requesting that the mother contact the researcher. Those who did not contact the study office within 2 weeks were called by a research team member. Data collection appointments were scheduled for interested mothers in a private place of their choosing such as their home, public library or the clinical research unit.

2.5. *Data collection*

In the larger study, all data were collected during face-to-face interviews (Toly et al., 2012). Informed consent was obtained and code numbers were used to maintain confidentiality. A $15 gift card was given to participants following interview completion. This study

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https://doi.org/10.1016/j.apnr.2019.02.001
Received 7 November 2018; Received in revised form 5 February 2019; Accepted 7 February 2019

includes only the responses to open-ended questions 26–27 from the FFFS and an investigator-developed demographic survey to describe maternal and TD child characteristics.

2.6. Data analysis

A qualitative, descriptive design was employed that included both qualitative and quantitative components (Neuendorf, 2002; Sandelowski, 2000). The first two authors independently read participants' responses to both FFFS open-ended questions several times, marking key words and phrases, developing a list of codes within each case as well as across cases that were then collapsed into categories followed by identification of themes. Themes and subthemes were further refined following a group cross check and discussion until a consensus was reached. The first author then selected illustrative quotes. Quantitative content analysis included tallying the frequencies for participant verbalization of each theme/subtheme to describe data patterns. Qualitative rigor was maintained by meeting steps of trustworthiness: credibility, transferability, and confirmability (Elo et al., 2014). Descriptive analyses of demographic data included frequencies and examination of central tendency and dispersion of scores.

3. Results

3.1. Sample characteristics

The mothers ($n = 93$) responded to at least one of the open-ended questions; 92 responded to FFFS #26 (most helpful) and 74 responded to FFFS #27 (least helpful). The majority of responses were single words or short phrases. The mothers ranged from 21 to 66 years of age ($M = 37.9$, $SD = 9.4$), were predominately Caucasian Non-Hispanic ($n = 67$, 72%), married or partnered ($n = 68$, 73%) with an annual family income of $60,000 or less ($n = 47$, 50.5%).

The TD children ranged in age from 7 months to 16.8 years ($M = 6.5$). A majority of children were primarily diagnosed with a neuromuscular ($n = 40$, 43%) or respiratory dysfunction ($n = 20$, 21.5%) and dependent on a respiratory or nutritional support technology (OTA, 1987; Group 3; $n = 71$, 73.8%). The most frequent technology used was a feeding tube ($n = 79$, 85%), followed by supplemental oxygen ($n = 38$, 40.9%) and tracheostomy tubes ($n = 27$, 29%). Approximately half of the children ($n = 46$, 49.5%) required between two and four types of technology.

3.2. Qualitative analysis results: most helpful

An overwhelming majority of mothers identified the presence of support as most helpful (Table 1). In particular, emotional support from family such as parents, in-laws, siblings, cousins or well-siblings of the TD child, support from nurses and emotional support from their partner were subthemes most often reported. Other major themes included daily life habits such as positivity, self-care and presence of resources e.g., respite and flexible schedule.

3.3. Qualitative analysis results: least helpful

Mothers' responses to what was least helpful were primarily associated with two major themes (Table 2): absence of support (e.g., family, health care providers, social network) and disruption to daily life (scheduling conflicts, lack of normalcy, self-care deficit, negativity, mental health). Subthemes mentioned most often were the absence of support from family members other than their partner (parents, in-laws, siblings) and last minute cancellations of private duty shifts by home care nurses.

4. Discussion

The mothers, paradoxically, perceived family support as both most helpful and least helpful. By far, mothers indicated the emotional support from family members (partner, parents, in-laws, siblings, well-children) was most helpful. One mother responded that her parents were the most helpful, “My parents input with my children. It allows me to have time for myself”. Another stated her spouse was the most helpful, “Knowing that through it all, my husband not only loves me and understands me but chooses to stay and gives as much as he can”. Another mother said, “My spouse…we have remained happy and encouraging to one another through these difficulties”. On the contrary, lack of a physical presence, assistance with caregiving or emotional support from these same family members was viewed as least helpful. Some described it as a lack of understanding by family members, a reluctance to render help due to fear of the technological equipment or fear of rendering the wrong type of help. One mother said, “My extended family is still very nervous around our child and does not know how to care for him”. In prior studies, parents found other family members helpful only after they received home medical care education (Desai, Durkin, Jacob-Files, & Mangione-Smith, 2016). Including other family members in discharge education can help demystify the technological equipment and associated procedures and potentially ameliorate many of these fears. Furthermore, reducing such fear may address the tendency of family members to withdraw, further compounding the mother's sense of isolation and perceived lack of understanding and support. Contrary to prior research, mothers in this study did not report caregiver support groups as among the helpful

Table 1
Theme frequencies and examples: what is most helpful ($N = 92$).

Theme	Examples	n (%)
Presence of support		79 (85.9)
Family		
Partner	Emotional support from partner, father of TD child	22 (23.9)
Other family	Emotional support from parents, in-laws, sibling, cousin or well-sibling of TD child	35 (38)
Health care provider		
Nursing	Support from home health nurses, clinic nurses	25 (27.2)
Other HCP	Support from physician, occupational therapist, social worker	5 (5.4)
Social	Emotional support from friends, going out with friends	11 (12)
Faith-based	Support from religious community, church friends, prayer	11 (12)
Daily life habits		14 (15.2)
Positivity	Positive thoughts, hope	11 (12)
Self-care	Taking time for oneself, sleeping, exercise	3 (3.3)
Presence of resources		12 (13)
Respite care	Respite care for TD child by family, friends, unspecified others	7 (7.6)
Flexible schedule	Work flexibility	5 (5.4)

Note: Some participants included more than one response item.

Table 2
Theme frequencies and examples: what is least helpful ($N = 74$).

Theme	Examples	n (%)
Absence of support		30 (40.5)
Family		
Partner	Lack of emotional support, disagreements, divorce	7 (9.5)
Other family	Parents, in-laws, siblings and cousins unable to understand situation or provide help, fear of technological equipment or providing wrong type of help	13 (17.6)
Health care provider	Unable to provide health information	7 (9.5)
Social	Lack of social life, loneliness, friends unable to understand	6 (8.1)
Disruption to daily life		27 (36.5)
Scheduling conflicts	Issues coordinating TD child's therapies and appointments	8 (10.8)
Lack of normalcy	Difficulty going out in public with family, living a life that is “different than expected”	5 (6.8)
Self-care deficit	Lack of sleep, inability to address personal care needs	5 (6.8)
Negativity	Negative societal attitudes toward disabled child	5 (6.8)
Mental Health	Depression, stress, pressure to balance life	5 (6.8)
Absence of resources		21 (28.4)
Care coverage	Home care nurses cancel at last minute; no back-up coverage	9 (12.2)
Supplies/Equipment	Issues ordering medical equipment or supplies, disagreement with supply company, receive wrong supplies	7 (9.5)
Financial	Lack of financial coverage for equipment/supplies, cost of transportation to TD child's appointments, financial stress	7 (9.5)
Nothing	Nothing is least helpful	3 (4.1)

Note: Some participants included more than one response item.

strategies (Desai et al., 2016; Edelstein, Schippke, Sheffe, & Kingsnorth, 2016).

Similar to Suzuki, Sato, Emoto, & Kamibeppu (2017) support from home health nurses was reported as one of the top most helpful subthemes. However, consistent with prior research, home health nurses were also identified as least helpful due to last minute cancellations of their shift and other staffing issues (Weaver et al., 2018). One mother reported, “The nursing agency is not able to cover scheduled shifts of care for my child”. This often left the TD child without nursing coverage which was particularly problematic during night shift for the already sleep deprived mothers. Therefore, having backup nursing coverage is essential.

Finally, mothers reported that disruption to daily life such as scheduling conflicts with therapy/physician appointments and absence of resources such as issues with medical equipment or supplies and financial coverage were least helpful. Interdisciplinary assessment and planning by nursing, medicine, social work, occupational/physical therapy prior to discharge and care coordination thereafter is essential for optimal care of the TD child and their parent caregivers (Suzuki et al., 2017).

4.1. Limitations

The limitations that impact generalizability are that the sample included only female caregivers and it was drawn from one geographic region. In addition, the FFFS questions provided limited space for their response thus a fully expounded response was not possible. Future research should include interviews of parent caregivers (male, female) to allow for full elaboration of what they perceive as most and least helpful. Additionally, future research should explore educational interventions for other family members (parents, in-laws, etc.) to demystify technological equipment and provide education regarding support and respite care. Finally, based on principles of family nursing (Bell, 2013), future research should explore interventions focused on collaborative relationships with other key support family members using therapeutic conversations (Bell, 2016; International Family Nursing Association, 2015) between the nurse and the family member.

5. Conclusion

Mothers of TD children overwhelming reported that the presence of support was most helpful to them. Family members were perceived as both most helpful and least helpful. In particular, mothers voiced family members' fear of the technological equipment as a factor in their withdrawal and lack of crucial emotional support, understanding and respite necessary as they cared for their TD child. Discharge education related to TD child's technological equipment should be offered to other family members deemed to be key support persons by the parents. Additionally, ongoing care coordination is essential to support this vulnerable population of children and their parent caregivers. Nurses are well suited to lead this future intervention work.

Declaration of interest

None.

Funding

This work was supported by the Alpha Mu Chapter of Sigma Theta Tau International, Frances Payne Bolton School of Nursing Alumni Association, Case Western Reserve University Research ShowCASE, and the Society of Pediatric Nurses. This study was supported by grant UL 1RR024989, the Clinical and Translational Collaborative at Case Western Reserve University, Dahms Clinical Research Unit. The funding sponsors had no role in study design; in collection, analysis and interpretation of data, in writing the report, and in the decision to submit the article for publication.

Acknowledgements

The authors acknowledge the contributions of Maureen Caro and Wananani Tshiamo on review of earlier drafts of this manuscript.

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