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Psychological Distress in Mothers of Technology-Dependent Children: An Expert Interview With Valerie Boebel-Toly, MSN, PhD, CPNP, RN

Laurie Barclay, MD

April 6, 2009 — *Editor's note: Mothers of children who are technology-dependent are at high risk for psychological distress that can affect overall family functioning, according to a presentation at the National Association of Pediatric Nurse Practitioners (NAPNP) 30th Annual Conference on Pediatric Health Care, held from March 19 to 22, in San Diego, California.*

To learn more about how pediatric nurse practitioners can help identify and manage psychological distress in these families, Medscape Nursing interviewed presenter Valerie Boebel-Toly, MSN, PhD(c), CPNP, PhD, RN, CPNP, instructor of nursing and director of the Pediatric Nurse Practitioner Program at Frances Payne Bolton School of Nursing, Case Western Reserve University, in Cleveland, Ohio.

Medscape: What was the impetus behind your study of the effects that children who are technology-dependent and living at home have on their family's functioning?

Dr. Boebel-Toly: As a pediatric home healthcare nurse, I was interested in why some families are resilient and others flounder when faced with the circumstances of caring for a child who is technology-dependent. Also, as I reviewed the literature, I found that few quantitative research studies have been conducted with this population of children and their families; despite the fact that they are small in number, they account for a large percentage of the healthcare expenditures for children.

Medscape: What were the main findings of this study?

Dr. Boebel-Toly: A surprising finding from this study is that a mother's depressive symptoms was the only significant predictor of family functioning, after controlling for covariates (caregiving duration, amount of home healthcare nursing, race, family income, child's age). The child's severity of illness and normalization efforts the family used were not significant predictors of family functioning.

Approximately 40% of mothers had scores on the Center for Epidemiological Studies-Depression Scale (CES-D) of 16 or higher, indicating high risk for clinical depression, and 25% had scores of 21 or above, indicating very high risk. Therefore, mothers of children who are technology-dependent are at high risk for psychological distress that can affect overall family functioning. A total of 35% of the variance in family functioning was explained by the mother's depressive symptoms. Additionally, there were no statistical differences in family functioning, mother's depressive symptoms, or normalization efforts based on the type of technology the child used (mechanical ventilation, intravenous medication/nutrition, respiratory/nutrition support).

Medscape: What are the clinical implications of these findings?

Dr. Boebel-Toly: Based on interviews with 103 mothers who participated in this study and subsequent analysis of the data, I formulated an acronym that summarizes important points that healthcare professionals need to keep in mind when working with these children and their families — EASE:

Educate about the practical application of care and treatments in the home, management techniques (such as organizational strategies), flexibility, and how to transport the child for outings. Many mothers indicated that during discharge teaching they were shown how to perform a treatment a few times, but how to carry it out in the midst of juggling the myriad other family responsibilities in the home setting was not addressed. Furthermore, parents need to be given tips, such as organizational strategies (charts, notebooks, spreadsheets), to keep track of appointments, medications, treatments, etc. They also need to be educated about flexibility and the leeway time that they have for performing treatments and administering feedings and

medications.

Assess objectively a caregiver's level of depressive symptoms using a questionnaire such as the CES-D and ask how things are going at home. It is imperative for clinicians to objectively assess parents, particularly mothers, in a systematic manner during the routine follow-up of these children, not only to detect risk for clinical depression but also to address the potential for difficulty with overall family functioning. Often, even as an experienced clinician, it was difficult for me to detect the high level of depressive symptoms during an interview, and it was only discovered when the CES-D questionnaire was scored. Parents will often want to appear upbeat during clinic visits so that there is no question of their competence to continue caring for their child. Expressing a genuine interest in how things are going at home goes a long way to support these mothers and will give healthcare providers a window into their world.

Support caregivers by providing a referral for mental healthcare as needed. However, simply referring families to mental healthcare professionals may prove to be inadequate. It is essential to identify mental healthcare professionals in your community who are familiar with the complex medical and psychosocial issues these families face and who have adequate training with this population to provide the necessary help.

Encourage caregivers by saying things such as: "You are doing an awesome job!" Mothers are most often the primary caregiver and pour themselves out caring for the child and attending to other responsibilities, so they greatly appreciate positive encouragement! Incorporating these strategies in the context of interdisciplinary, family-centered, holistic care would be beneficial to parents, children, and society in general. Identifying high levels of depressive symptoms in mothers that could chronicle problems with poorer family functioning is a wise investment. Difficulties with family functioning can lead to difficulties managing the child's care and translates into high cost for the system resulting from hospital readmission, frequently in the intensive care unit, for prolonged periods of time.

Medscape: What are the strengths and limitations of this study?

Dr. Boebel-Toly: The strengths of this study include the size and the diversity of the sample of mothers and children who are technology-dependent. There was diversity as far as the age of the child, type of technology used, primary diagnosis, duration of caregiving, amount of home healthcare nursing hours per week, family income, and mother's age and education.

A limitation of the study was that the sample did not include a large number of African American, Hispanic, or Asian mothers, although it did model the race/ethnicity makeup of northeast Ohio. Study findings should therefore be interpreted with caution for those populations. Additionally, although this was a convenience sample, every attempt was made to include all potential participants.

Medscape: What can be done to prevent and reduce psychological distress and to optimize family function in children who are technology-dependent?

Dr. Boebel-Toly: Great strides can be made in the reduction of mental distress in families of children who are technology-dependent by implementing the clinical suggestions in EASE. Also, it is particularly important to establish a comprehensive, interdisciplinary, family-centered program and care coordination for these children, who often require a multitude of specialists and therapies. A plan for the prevention and reduction of mental distress for these families should include preventive mental-health support from professionals who are familiar with the issues these families face; this should be in place prior to hospital discharge.

Caring for these children after discharge from the hospital is a daunting task for any parent, no matter the educational background, financial resources, or discharge preparation, as can be attested to in this study. Preventive mental-health support that is flexible and can be provided in the home would be an essential support for families. Finally, the establishment of a qualified system of respite healthcare providers who have the knowledge and skills to care for these children would give parents a well-deserved break.

Medscape: What additional research needs to be done?

Dr. Boebel-Toly: Longitudinal research needs to be conducted to examine these families and children over time. A 12-month follow-up study of these families is currently underway that is looking at the effects of living in a family with a technology-

dependent child on healthy siblings and the impact on family finances. The goal of this study is to provide a foundation to design and implement interventions to address mothers' high levels of psychological distress.

Medscape: From the other material presented at the NAPNAP meeting, what most caught your attention, and why?

Dr. Boebel-Toly: The presentation entitled Redefining Beauty really resonated with me, and I can see the application to children who are technology-dependent and their families. The outside observer of these children may see only the tubes, equipment, and possibly physical differences between them and other typically developing children.

Rick Guidotti, director and founder of Positive Exposures, illustrated the beauty that can be seen in every child in his magnificent photographic collage presentation. Each picture had a story and each child was portrayed beautifully despite their differences, which helped the room full of pediatric nurse practitioners to remember that children with special healthcare needs are children first. Our job as healthcare providers is to make sure to provide them with as full and happy a childhood as possible and to help them to grow and develop to reach their full potential.

Medscape: What do you regard as the greatest challenges facing pediatric nurse practitioners today?

Dr. Boebel-Toly: I believe the greatest challenge is to deliver comprehensive holistic care to children within the time and fiscal constraints of the clinical arena. Another challenge is to keep on top of the explosion of information today and to be savvy consumers of evidenced-based practice. It is important to stay current! Although pediatric nurse practitioners are often asked to do more with less time and fewer resources, it is important to conduct research so that we can work smarter, not harder.

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Authors and Disclosures

Journalist

Laurie Barclay, MD

Laurie Barclay, MD, is a freelance writer and reviewer for Medscape.

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