

Poor access to in-home nursing for medically complex children quantified

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Medically complex children and their families face barriers to in-home nursing care. Credit: ATS

For American families with medically complex children, access to home health nursing is often inadequate and the families face major financial burdens, according to research published at the [ATS 2024](#) International Conference held May 17–22 in San Diego.

This study defines medically complex children as those who are supported by tracheostomy and mechanical ventilation, required full-time skilled nursing care.

"This study is the first to focus on the in-home nursing and caregiving environment," said lead author Brian Jordan, MD, MCR, Ph.D., director of advanced [mechanical ventilation](#) and associate professor of pediatrics, Division of Neonatology, Oregon Health & Science University.

"While prior studies have evaluated the home health nursing shortage from the point of view of the medical community, this study quantifies its impact as experienced and reported by medically complex families themselves."

Between May and July 2023, Dr. Jordan and colleagues conducted a survey of American families with medically complex children. Survey questions were designed to explore barriers to accessing in-home nursing and included branching logic, which controls respondents' individual paths to point them to appropriate follow-up questions.

The survey was done in collaboration with Hello Nurze, a 501(c)3 [nonprofit organization](#) that provides a free platform that empowers families with medically complex children to connect with home health nurses in their area.

The researchers received 242 responses from families in 34 states and

the District of Columbia. Although 86.8% of families desired home health nursing and had home health nursing hours approved by their insurers, 47.5% reported fewer than half of approved hours were covered and 28.3% reported no in-home nursing at the time their child was discharged from the hospital. A total of 37.9% reported that their child's hospital stay was extended due solely to lack of access to available in-home nursing.

Financially, 87.8% of families reported having to make significant employment changes due to lack of in-home nursing, including 31.8% of families reporting a yearly reduction in household income of \$50,000–\$100,000. Families reported that these employment changes were not shared equally between parents, affecting 78.4% of mothers surveyed.

"Establishing a quantitative view of job and income impacts, access to non-parent caregiving support, and the percentage of approved nursing hours that are actually filled all combine to form a clearer view of the medically complex family life in the home and the trade-offs families face," said Dr. Jordan.

"We hope that bringing visibility to the reality of in-home caretaking and the hardships families endure will motivate [policy makers](#) and regional organizations to enact more supportive legislation and services to better support families with disabilities."

To help ensure that they were reaching the right families, Hello Nurze shared the survey on Instagram and Facebook, focusing on Facebook groups used by families that have a special needs or medically complex child requiring home health nursing, such as those with a g-tube (a gastronomy tube that brings nutrients directly to the stomach) or tracheostomy, or have a reliance on medical equipment to stay alive. These families were among the most likely to qualify for private duty

nursing. Survey posts received 40,000 impressions on Instagram alone.

Hello Nurze launched a free web platform at hellonurze.com to help connect medically-complex families with nurses in their community—serving as a brand new way to extend nursing searches for families and a tool to encourage more nurses to consider joining the home health industry.

Hellonurze.com introduces family and nurse profiles, something not previously available within the [home health](#) sector. Families and nurses can share as much or as little as they want about themselves via the profiles, allowing nurses to highlight their skills and certifications and allowing families to showcase their child's personality, tell their story, and emphasize that they are so much more than just a diagnosis or case number.

When site users find a potential match, they can communicate directly on the site to ask additional questions and determine if they are a good fit. If both parties feel it's a good match, they work with a third-party nursing agency of their choice to formalize the nurse/patient relationship and onboard the case.

More information: Session: Session A96 – Improving the Care of Patients with Diverse Pulmonary Conditions and Sleep Disordered Breathing, The State of Home Health Nursing for Medically Complex Children in the United States

Provided by American Thoracic Society

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