

Focusing on family helps mothers of technology-dependent children function

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Normal everyday life for parents requires organization. Parents of children who require ventilators, oxygen, IVs and other tools to live, those day-to-day tasks can be time-consuming, difficult and stressful on the family. But researchers from Case Western Reserve University found that mothers who successfully integrate the care of the technology-dependent child into family life have families that function better.

"It's about the [perception](#) of the child's illness," said Valerie Toly from the Frances Payne Bolton School of Nursing at Case Western Reserve University. She is the lead researcher on the study, "A [Longitudinal Study](#) of Families with Technology-Dependent Children," in the journal of *Research in Nursing & Health*.

Toly's research is one of the first longitudinal studies to see how families function and reach normalcy once children leave the hospital equipped with technology to keep them alive. She studied 82 [mothers](#), recruited during visits to a hospital's specialty clinic.

The mothers were interviewed and given six surveys after leaving the hospital, and then again 12 months later to track changes in the mother's psychological wellbeing, [family](#) functioning and normalcy.

The mothers—primarily Caucasian (79 percent), African-American (17 percent), Hispanic (6 percent) and Asian (2 percent)—ranged in age from 22 to 66. About 75 percent had some college education, a third worked full time and 75 percent had other children, some of whom also

are technology dependent.

About a third of the mothers tested for clinical depression, and that percentage increased by 7 percent at the second visit. (Mothers with high levels of depression were provided mental health resource information.)

At the beginning of the study, children ranged in age from 6.75 months to 16.83 years, with an average age of 6.41 years. Nearly half of the children had medical issues related to neuromuscular diagnoses like cerebral palsy, and half of the children needed more than one technology. Overall, an average of 45 hours of home care help was needed at the first interview, and that need grew by the second interview.

The researcher found mothers whose children no longer used technologies had the greatest improvement in [family functioning](#) and normalcy.

Toly said children in the study "are in a high risk, vulnerable group...3 children died in the one year span of time between interviews and one mother died. This is much higher than the general population."

But for those who continue to require technology, integrating the child into family events is critical. Toly has seen mothers pack up the technology and take the child along with other siblings to soccer practice and other family events. In another instance, one mother missed an annual family camping trip because of the extra work required to include the technology-dependent child in the trip; the following year, the extended family pitched in and built ramps, making it possible for the mother and child to join in the camping fun.

Examples like these keep families on the normal track. "Mothers integrate technology-dependent child into the family by being flexible about when to give medications or food," Toly said.

But, adhering to rigid schedules can interfere with what others in the family need to do, and it can create problems, Toly added.

"A mother's depression plays a greater role in family functioning than the child's severity of illness," Toly reported.

As early as the 1980s, Toly saw technological advances were keeping preemies alive, but "we didn't know what the long-term impact that technology would have on the families and the [children](#)."

She said that even 30 years later, the effect is unknown. She has set out to understand what families encounter and help the families have a normal life even among the tubes, monitors and medications.

More information: View the article at: onlinelibrary.wiley.com/doi/10.1111/nur.21454/abstract

Provided by Case Western Reserve University

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