

Mothers have key role in family life for children with technology dependencies

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Creating a family life incorporating the care needs of a child dependent on technology is a daunting task. Much of this task seems to fall upon mothers to help everyone in the family adjust. However, mothers often need help of their own to cope with the challenges of raising these children, a research study from Case Western Reserve University has found.

"The family takes its cues from me," one mother told Valerie Toly, PhD, R.N., C.P.N.P., an Instructor of Nursing at the Frances Payne Bolton School of Nursing at Case Western Reserve University.

Toly's research with 103 mothers of children dependent upon technology, such as mechanical ventilators and feeding tubes, examines family functioning in the lives of children with medical challenges. She was interested in finding out why some families seem resilient in the face of technology dependence while others struggle. Little quantitative research has been done on this topic.

The researcher reports that the key defining factor in creating as normal of a <u>family life</u> as possible while still meeting a child's care needs, as well as family functioning, was the level of the mothers' depression. The more symptoms of depression a mother had, the poorer the family functioning and the less able she was to problem solve and make a normal life for her family, says Toly.

Toly conducted face-to-face interviews with mothers in their homes or



during clinic visits. She found nearly 40 percent of the mothers studied had a level of <u>depressive symptoms</u> indicating a high risk for clinical depression, and 25 percent of those depressed mothers had a level of symptoms so severe that they required some resource support at the time of the interview.

The mothers were raising children who were between the ages of seven months and 16 years of age and who used from one to four technologies to survive. The majority of the children's medical needs originated from neuromuscular and respiratory dysfunctions that required special technology, such as mechanical ventilation, intravenous medications/nutrition, oxygen, tracheostomies or feeding tubes.

About a third of the children were former preemies who were able to go home but needed the additional medical support to survive.

About 75 percent of the mothers also had other children at home who required attention. "Some mothers said they never left home," says Toly.

While some struggled, Toly found others were able to make a normal family life by thinking of ways to pack up ventilation and other medical equipment and take their children to doctor appointments or on family vacations. Some mothers kept elaborate notebooks or computer spreadsheets to document medications, surgeries and doctor appointments.

Those mothers have more normal lives than mothers who were unable to figure out solutions to overcoming some of the challenges in everyday life, says Toly. Mothers with greater problem-solving skills also showed fewer symptoms of depression.

As much as the children need medical help, moms need some support from the heath care system, too, says Toly. "The health care community



needs to think of the whole family as the unit of care. Health care professionals need to ask mothers how they are managing at home and be alert to depressive symptoms." The high level of depressive symptoms was often not apparent during the interview and was only revealed using the questionnaire.

Toly had the opportunity to present her findings during the annual meeting of the National Association of Pediatric Nurse Practitioners in San Diego, March 18-22.

Source: Case Western Reserve University (<u>news</u>: <u>web</u>)

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