

Moms of children on life-sustaining devices embrace tips for managing over-stressed lives

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Many mothers with children on life-sustaining medical devices, such as ventilators and breathing or feeding tubes, suffer physical and psychological distress from the stress of juggling treatments, appointments, therapies and daily family pressures.

But researchers from the Case Western Reserve University nursing school found that an <u>intervention</u>, called "Resourcefulness," which teaches moms how to better cope, bolsters the mother's wellbeing and, in turn, benefits the whole family.

Findings from a small pilot study of 22 mothers, "Resourcefulness training intervention: A promising approach to improve mental health of mothers with technology-dependent children," were published this month in the journal of Applied Nursing Research. A National Institute of Health's Clinical and Translational Collaborative at Case Western Reserve supported the study.

Valerie Boebel Toly, of Case Western Reserve's Frances Payne Bolton School of Nursing, directed the study with nursing school professors Carol Musil and Jaclene Zauszniewski, who had previously used the intervention to help grandmothers who are primary caregivers for their grandchildren.

Among the short eight Resourcefulness tips were organize your day to provide a family routine that works for everyone and rely on family and friends, who may want to help but are waiting to be asked.



"We wanted to see if the Resourcefulness Training intervention also worked for these mothers," Toly said.

The researchers found that it did. The intervention had a positive effect on the mothers' mental health. In particular, mothers experienced a decrease in negative emotions and depressive cognitions.

Toly recalled one mother commented that, for the first time, she felt she had someone coming alongside her during her day—even though most of the interactions with researchers were weekly phone calls to discuss the mother's needs.

Mothers care for about 20 percent of pediatric patients who are discharged from hospitals but remain dependent on some form of life-sustaining medical devices at home.

Because of the physical and emotional demands of caring for their child, many mothers struggle with poor physical health and depression, she said.

The researchers hoped to reduce their distress by focusing intervention training on two areas: social (help-seeking) and personal (self-help) skills.

Researchers recruited mothers with children on life-sustaining devices from the pulmonary and gastroenterology clinics at a Midwestern children's hospital. The mothers were primarily Caucasian, had an average age of 41, and an annual family income of \$41,000 to \$80,000.

The women were divided into two groups: A test group received the special Resourcefulness intervention through in-person training and reminder cards about how to be resourceful. They also kept a journal about coping tips they learned and used with their families. For some,



the journal also became a place to vent emotions.

The control group also kept journals, but did not receive the intervention training.

All participants received weekly phone calls from researchers to discuss their experiences. Participants also were given pre-study and post-study tests to measure and track physical and emotional changes during the four-week study.

The researchers were surprised and pleased to learn that 95 percent of the participants wrote in their journals 23 of the 28 days, and 91 percent completed all the testing.

The study is important, Toly said, because the children's medical conditions vary, as do a mother's needs. So no one-size-fits-all approach works. Mothers need a flexible program that matches their individual situations, she said.

For example, children on ventilators need 24-hour care to keep breathing tubes open. That can require a night nurse on watch or, if unavailable, a mother sleeping near her child throughout the night to listen for any changes in breathing.

Toly plans to expand the study to gauge the effectiveness of the Resourcefulness Training intervention with a much larger group of mothers facing similar challenges.

More information: "Resourcefulness training intervention: A promising approach to improve mental health of mothers with technology-dependent children." Toly VB, Musil CM, Zauszniewski JA. *Appl Nurs Res.* 2014 Feb;27(1):87-90. <u>DOI: 10.1016/j.apnr.2013.11.003</u>. Epub 2013 Nov 11.



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