

Parents of children with complex medical conditions more likely to struggle with mental health

June 22 2021



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Parents of children with the most complex medical conditions are more likely to report poor or fair mental health and struggle to find

community help, according to a study completed by researchers at University of Rochester Medical Center (URMC) and Golisano Children's Hospital. The study was published in *Pediatrics*, the journal of the American Academy of Pediatrics (AAP).

The study, "A National Mental Health Profile of Parents of Children with Medical Complexity," examined parent-reported data from the National Survey of Children's Health, and compared three groups: households of [children](#) with medical complexity (CMC), households of noncomplex children with special health care needs, and households of children without special health care needs.

CMC are defined as the 1 percent of children with the most complex medical conditions. They tend to have multiple chronic health conditions and disabilities, and frequently utilize [health care services](#). Examples of CMC include those with cerebral palsy, serious congenital heart defects, or genetic disorders. Given these children's significant needs, their caregivers are challenged to balance treating their child with completing other [family responsibilities](#).

The study found the following:

- About 20 percent of [parents](#) of CMC reported poor or fair mental health, more than five times the proportion of parents of children who did not have medical problems.
- In addition, 36 percent of parents of CMC reported not knowing where to go for help in their community when they encounter difficulties, which was more than two times the proportion of parents of children who did not have medical problems.

These findings indicate that health care systems should be proactive in trying to serve parents of CMC and provide support resources, and that mental health should be prioritized, according to Nathaniel Bayer, M.D.,

assistant professor and pediatric hospitalist at Golisano Children's Hospital in the UPMC Department of Pediatrics and lead author of the study.

"As we partner with these families, we need to make sure we're taking care of the parents as well as the children," said Bayer, "It is our job as pediatricians and health care teams to recognize the parents' needs and connect them to services."

Only 15 percent of parents of CMC reported access to peer support groups, which are critical for families to be able to exchange ideas and support each other, according to Bayer. To help address these gaps, hospitals should offer peer-to-peer [support groups](#) and grow [family advisory councils](#) to support the health and emotional wellness of caregivers of CMC.

"Having a child with this level of needs affects families in so many different ways. With the right support, these families thrive and fulfill their goals," said Bayer. "Without enough support, these families often struggle with the emotional and physical demands of constant caregiving, financial stressors, and employment issues. They may also be unable to find assistance from community services and home nurses, which are under-funded and under-reimbursed."

Research on families and parents of CMC is an emerging field, because kids with complex conditions are living longer as healthcare interventions have improved in the 21st century. "In the last decade, there's a heightened interest in discussing and focusing on these children and their families because we are increasingly recognizing that they need more support to successfully navigate the complicated health, education, and community systems."

The study also found that families of lower socio-economic status (SES)

reported feeling significantly more isolated and unaware of how to seek support. "Families of lower SES often do not have the resources to easily access services. They may lack the transportation to travel to the clinic or struggle to find community resources in their area. If your family is also struggling to put food on the table or keep the lights on, it's harder to manage your child's medical needs and take care of yourself," said Bayer.

In addition to health care systems providing more peer-to-peer services, more federal and state support of CMC parents—including greater reimbursement for home-health services and caregivers, expanded services and access for kids with disabilities, and improved early intervention support—can all help parents of CMC, according to Bayer. Behavioral health and wellness services—both for children and parents—should also be expanded.

"Mental health is a part of health," said Bayer, "Parent and caregiver mental health is a major issue that has a significant impact on children's health. We need to talk more about parent mental health, screen for it more, and proactively support it."

Bayer and his research team plans to continue studying the [mental health](#) of CMC parents, the resilience of their families, and their abilities to adapt to challenges. The team is currently surveying and interviewing local families of CMC in the Rochester region to examine these topics. After studying how resilience and emotional wellness develop in families of children with complex medical conditions, he is planning to build family support programs and study their impact on child and caregiver [health](#).

More information: Nathaniel D. Bayer et al, A National Mental Health Profile of Parents of Children With Medical Complexity, *Pediatrics* (2021). [DOI: 10.1542/peds.2020-023358](https://doi.org/10.1542/peds.2020-023358)

Provided by University of Rochester Medical Center

Citation: Parents of children with complex medical conditions more likely to struggle with mental health (2021, June 22) retrieved 7 May 2024 from <https://medicalxpress.com/news/2021-06-parents-children-complex-medical-conditions.html>

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