Focusing on the Mental and Physical Health Needs of Caregivers of Children with Medical Complexity and Life Limiting Conditions

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Improving the health of children with medical complexity (CMC) is a top priority for our journal. Yet what about the family members who work to take care of children with medical complexity? Are there consequences to the mental and physical wellbeing of caregivers of children with medical complexity including those with life-limiting conditions?

To answer this question, we offer three articles this month-a study of the mental health of parents of children with medical complexity by Bayer et al (10.1542/peds.2020-023358), a systematic review of the physical health of caregivers of children experiencing life-limiting conditions by Hartley et al (10.1542/peds.2020-014423); and an accompanying commentary by theologian and ethicist Jessica Shriver (10.1542/peds.2021-050222), that is a gut-wrenching call to action.

The Bayer et al study analyzed data from the 2016/17 National Survey of Children's Health and compared families of CMC with those children who had special health care needs but were non-complex and a third group of children and parents who had children without special health care needs. The authors found that parents with CMC had the highest risk of self-reported mental health problems. These parents also reported that they did not know where to find the community help they needed.

The Hartley et al systematic review of 81 studies evaluated the impact of caring for a child with a life-limiting illness on caregiver physical. Nearly all of the included studies found that the health of caregivers was negatively impacted, with pain and sleep problems leading the list.

It is one thing to be made aware of issues regarding the mental and physical wellbeing of caregivers of CMC through the data compiled in these two studies. It is another thing to read the narrative contained in the commentary by Ms. Shriver, who shares her own story of carrying a child of medical complexity while dealing with her own diagnosis of breast cancer. Her words are a call to action for more assistance, including mental health services, home nursing, and better access to coverage for home care. These three studies should make us all better advocates to help these families navigate the health system not just for their children but for themselves. Link to all three and then consider what you can to do to make things less complicated for the health and wellbeing of both children and their caregivers who have round-the-clock challenges for the children they love.
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