

Cost of Caregiving on Parents of Children With Medical Complexity and Life-Limiting Conditions

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In this issue of *Pediatrics*, two studies are presented in which researchers explore challenges faced by parent caregivers. Hartley et al¹ draw attention to reduced physical health among parents caring for children with life-limiting conditions (LLCs), whereas Bayer et al² highlight decreased mental and emotional health in parents of children with medical complexity (CMC). For >10 years, I have worked in biomedical ethics and patient advocacy with families of CMC, many of whom also have LLCs. Sadly, I find it unsurprising that Hartley et al¹ found 84% of studies in which researchers look at the physical health of caregivers for children with LLCs showed “parent health was directly and negatively impacted by the nature of the care they provided to their child,” whereas Bayer et al² found “almost one-fifth of parents of CMC self-report poor or fair mental health.” I can speak to these truths both professionally and personally. Among caregivers with whom I have worked (most of whom are mothers), the inability to achieve time for self-care (whether emotional, mental, or physical) is a common topic. This ranges from one mother unable to leave her child with complex medical problems long enough to get a haircut for over 2 years, to multiple mothers repeatedly missing physical or mental health appointments for themselves. Inability to address these needs presents further in our

conversations as reports of long-standing sleep deprivation, frequent health problems like colds and tooth abscesses, increased irritability, and anxiety over their ability to fulfill caregiving and family obligations.

My professional insight is built on my own caregiving experiences because both of my children were born with a complex rare disease that can shorten life expectancy. My daughter, the more affected child, died shortly before age five. My son is stable at the age of 12 years, albeit with a high level of care. A total of 15 years of parenting medically complex children with LLCs has been the most intense and exhausting experience of my life. At the time my daughter died, my husband and I had provided >800 days of round-the-clock home care and endured >1000 days living with her in a hospital. I first realized the effect caregiving had on my own health when she was about 3. We had recently finished a long hospital stay, and during the first week at home, I had handled both overnight and daytime care. That night, her medications sat in sterile syringes, ready to be given through her central line at 12 AM, 2 AM, 4 AM, and 8 AM. Between doses, I planned to lie down on her carpet for a few minutes of sleep. Instead, I fell fully asleep until 5 AM; the 2 AM medication in one hand and 4 AM medication in the other. My daughter’s health was fragile, and the

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consequences of making mistakes were potentially serious. Anxiety surged through me, as tears of exhaustion and frustration spilled down my face.

Hartley et al¹ report that “informal care undertaken by parents entails a tremendous amount of time-consuming, complex, physical and mental work.” Sitting in the dark that night, I realized for the first time the magnitude of the mental, emotional, and physical burden of this work, and feared I could not handle it. Caregiving was both the most important and hardest work I had ever been given. Neither my undergraduate or graduate studies, nor outside jobs I had held, could compare with the unrelenting responsibility of maintaining my child’s physical health. Like 75% of the parents of CMC that Bayer et al² surveyed, I was struggling to meet the demands of parenting a child with such complex needs. Yet, as a parent, what were my choices that night? I did not have the luxury to consider my own physical or mental health; my daughter was relying on me. The only path forward was to wipe away the tears, suppress the ache of sleep deprivation, and get off the floor and back to caregiving.

Parenting my son has been less intense but offers its own challenges. Experience has enabled my family to meet most of his needs at home, with few hospital stays. Although home care is ultimately best for both my son and the health care system, it is possible only if we maintain an intricate 24-hour routine involving 2 parents and multiple nurses. Most of this commentary has been written during my 11 PM to 8 AM care shifts, backed by the yellow glow of monitor screens and the sigh-and-whirr of medical pumps. I have been covering overnights since we unexpectedly lost our night nurse to coronavirus disease 2019

shutdowns in March 2020. We tried finding a replacement, but because of the emerging pandemic, reluctantly decided against weeks to months of interviewing candidates. Bringing people into our home posed a threat not only to our medically complex child, but also to my own chemotherapy-riddled immune system.

Yes, chemotherapy. In the summer of 2019, I was diagnosed with stage II breast cancer. The diagnosis followed a year of severe medical problems for our son, causing intense mental, emotional, and physical stress for my husband and me. I woke one morning to find a lump in my right breast; a biopsy confirmed cancer, and suddenly a new world of medical challenges lay at our feet. In my late thirties, I am one of the younger patients in my breast cancer program. No one can prove correlation between my cancer and years of stressful caregiving and child loss, but on hearing my story most physicians comment to the effect of the following: “Wow. I think we know why you have cancer; there has been an unbelievable amount of stress in your life!” Balancing cancer treatments with caring for my son has been, unsurprisingly, quite challenging. Despite this, our family has done what we do best: redistribute tasks and get on with it. What else can we do?

In their review, Hartley et al¹ noted many parent caregivers assume work that includes “operating supportive and life-saving technologies, administering medications, monitoring and recording symptoms” and “delivering care at night as well as coordinating care given to their child by professionals.” Parents are told that sacrifices like these make us “superheroes”: above and beyond other parents. Although such sentiments seem complimentary,

experience leads me to believe they may be harmful. In my own life and work, I have learned there are no “super parents.” Parent caregivers are normal parents living through abnormal circumstances. Like most parents, we are trying to promote our child’s best interests. We learn new skills, including complex medical care, when doing so enables our children to live longer and better lives. Seeing our children happy and as healthy as possible is the reward for our efforts. Conversely, failing our children (or fearing we may fail them) is highly stressful. My work with parent caregivers supports Bayer et al,² who report that “as the health care system works to avoid hospitalizations and decrease lengths of stay, parents of CMC may feel increasingly stressed as they bear more responsibility for home care.” Parents I encounter admit feeling they must not take time from their child’s care, even when it means sacrificing jobs, hobbies, other important relationships, and their own mental and physical health. Unfortunately, because these parents do not have the superpowers attributed to them, the ultimate outcome of this extreme caregiving is negative for all involved. Both Hartley et al¹ and Bayer et al² found children with LLCs or medical complexity and their families all fared worse when caregiver health was compromised.

Finally, although parent caregivers frequently become experts at managing their children’s health care, concurrently managing their own health needs may be much harder. Hartley et al¹ showed parents “were aware that they should attend regular health checks,” but, as with many self-care tasks for parents of CMC or children with LLCs, “caregiving was a barrier to attendance at these appointments.” Many caregivers I

encounter spend their days and nights performing specialized care for their medically affected child, plus normal care for other children in the home. Tasks like bills, food shopping, and laundry require time as well. Furthermore, if primary caregivers want to hold a job outside of caregiving, or are compelled by financial circumstances to do so, time to spend on their own mental and physical health may be functionally nonexistent. Overburdened schedules may partly explain why parents of CMC and children with LLCs have “higher levels of stress, marriage tensions, [and] financial difficulties.”² They also highlight why helping caregivers understand the need for self-care and helping them find time for self-care must be approached as distinct problems.

The work by Hartley et al¹ and Bayer et al² advances our understanding of how families of children with complex and life-limiting medical conditions can best be helped. Moving forward,

clarifying questions we should ask include: Do providers accustomed to hospital-based systems truly understand what home care for CMC or children with LLCs requires from parent caregivers? Are providers remembering the needs of family members other than the medically affected child in care plans? Do state or national services and support programs provide enough assistance to give parents a genuine break from caregiving? These and similar questions further explore the strengths and limitations of family-based care and the toll such care takes on parent caregivers. We all know the rule of flying: first apply your own oxygen mask before attempting to help others. As in aviation, the merits of parents maintaining stable health to help their children seems straightforward. Nevertheless, incorporating self-care into the lives of caregivers remains a complex problem. Fortunately, solutions to these issues are likely to benefit more families than just those of children with LLCs or CMC.

Care practices able to sustain families of medically complex and fragile patients should effectively decrease caregiver burdens across other areas of pediatric medicine as well. Our success in caring for our most vulnerable patients and families is a measure of our overall success as a health care system; thus, we should take seriously the opportunity to improve support for families of CMC and children with LLCs.

ABBREVIATIONS

CMC: children with medical complexity
LLC: life-limiting condition

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