How caring for my child with cancer changed my approach to clinical care and research

Sarah McCarthy

I am a clinical psychologist who specialises in helping children with medical illnesses and their families. I am also a mother of twin girls. And in April 2020 my 3-year-old daughter was diagnosed with two different types of cancer. In less than 24 hours I went from being Dr McCarthy, providing psychological services to children in our paediatric hospital, to the mom of a patient with very complex cancer. If you had asked me 3 years ago and if I had a good understanding of what paediatric oncology families go through during treatment, I probably would have answered yes. After living through cancer with my daughter, I now know that I was wrong. There were huge gaps in my knowledge about what it is like to be a parent caregiver and to navigate our healthcare system. What I have learnt about the unseen work of caregivers has changed my work as a clinician and researcher.

As a parent caregiver, I quickly learnt how overwhelming around-the-clock care can be. After my daughter’s bone marrow transplant, I was running 4–6 hours of intravenous medications a day. When I discussed this plan with the medical team before discharge, it seemed difficult but manageable. But I failed to consider so many things. Like the anxiety accompanying constant fever monitoring, which could be a sign of a serious problem. Or the sleep deprivation that comes with waking up to do diaper changes every 2 hours due to all the fluids. And on top of this, I had oral medications to administer, 3–8 appointments per week to attend and plus blood and platelet transfusion. In all the chaos, I often forgot things: doses of medication; appointments. Despite taking copious notes at appointments, setting alarms for medications and making lists of all the tasks that needed to be done, I missed a lot. I tried so incredibly hard, but was still ‘non-adherent’. The exhaustion took a toll. I did not have the energy to maintain my own physical and mental health while also taking care of everyone else. And yet, despite being a healthcare provider, I never mentioned any of this to my daughter’s medical team.

As clinicians, we often focus on what we see in front of us. When we work with patients and parent caregivers to devise treatment plans, we rarely ask about how this will fit into life outside the hospital. We do not ask how the medication schedule we devise will impact a caregiver’s sleep or ability to work. I wonder if a clinician had asked me after my daughter moved home what a ‘typical’ day looked like for our family, if this invitation would have begged a response as to how exhausting each day was for me, and how this affected my daughter’s care. As clinicians, when we only focus on the medical aspects and forget about our patients’ lives outside the hospital, we miss the opportunity to consider our caregivers’ mental and physical burdens when designing a plan of care.

As a paediatric oncology patient, my daughter was invited to participate in many different types of research studies. As I read through one of the consent forms, I was struck as a mother by how inconsequential the outcomes of the study seemed. How important was a change in my child’s Diet Quality Index Score a year after treatment? As I began to view study protocols and published research as a clinician, I realised that most of the research published in my field (including my own research), failed to answer questions such as how the study could impact the daily life of a child like mine. There was often no indication as to how the research questions addressed by the protocols would provide meaningful change to our family.

I have since returned to my clinical work as a paediatric psychologist. My experience opened my eyes to the depth of the physical, emotional and mental burden that parents of a child with a serious medical illness silently carry. And while I do not routinely discuss my own experience with the families that I work with, it is with me in my clinical encounters. My experience reminds me of the importance of approaching every single interaction with compassion and empathy. It pushes me to be flexible with appointment times and modalities and to advocate for more flexibility within our care systems. When families are approaching discharge, I encourage the medical teams to start thinking with the family about how to make the hospital medication plan work in this particular family’s home. I am in the process of redesigning my current research projects to actively include the voice of patients and caregivers and am committed to submitting new projects that are codesigned with families living with serious medical illnesses. And I share my story, highlighting what I did not know as a healthcare provider. Because knowing where the gaps are is the first step in addressing them.

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