Thrown Into a New World

I used to live, what many would call, a normal life with 2 healthy sons and working full time as an information technology consultant. Six years ago, that life changed dramatically from 1 day to the next, when my youngest son, then aged 7 years, went from being an active boy to becoming totally paralyzed from his chest down. One Saturday evening, he started complaining of back pain. His right leg became numb and did not “wake-up” when my husband and I asked him to walk around the room. We went to the hospital and after a couple of hours in the emergency room, the staff told us to stay the night. The next morning, my son could no longer move his leg or empty his bladder. We panicked. Then everything happened very fast. After a magnetic resonance imaging examination, a neurologist told us our son had a cavernoma, a vascular malformation, in his spinal cord at the C4-6 level. He was moved to the intensive care unit and was surrounded by staff putting needles in him and connecting devices to him.

My son was now completely paralyzed from his chest down and he could not feel or move anything below that level. He could not move his hands and had a hard time breathing. My husband and I struggled to figure out how to relieve his pain and fear. When the doctors told us that our son had a cavernoma, we thought he could be treated and cured. Three days later, we were taken to a room full of doctors and told our son had a permanent spinal cord injury (SCI) and that his legs would never support him again. I asked about his hands but got no reply. I remember how my legs started to shake uncontrollably trying to understand what all the people in the room were saying and what that meant for my son’s life. I left that meeting feeling as if I was falling into a big black hole. I remember repeating a mantra in my head. “I must eat so I can be there for my son.” “I must sleep/get dressed so I can be there for my son.” “To be there for my son”—was the only thing that mattered.

Failed by the System

My son had surgery after 3 weeks, and my husband and I believed he received good care in the acute phase up to the surgery. But after that, we felt utterly lost. We were a family in crisis trying to grasp what had happened to our son, to us, and at the same time we were trying to be parents to our older son. We met new doctors every week, but no one had the time to sit down with us and talk about our son’s injury or his future. I felt like I was perceived as an annoying parent. We had a long list of questions and things we needed help with, but when we asked staff for help, we were often told to ask someone else. We believed that our son needed intensive rehabilitation to regain as much function as possible, but he had less than 2 hours of physiotherapy per week. I was terrified and desperate, feeling that my son was failed by the system and that important recovery time was slipping away.

The devastation this injury meant for my son was almost incomprehensible and he needed me as a mother more than ever. However, the design of the system resulted in a lot of my time being occupied battling the system instead of focusing on just being there for my son.

Safe in a System

I spent every evening searching for information about SCI and found a hospital in another country and continent, specializing in children with SCI. We contacted them, desperate for support. They replied right away that they could admit us. To our extreme relief, we learned that we need not pay for our son’s care since the hospital’s mission is to provide the highest quality of care without regard to national origin or ability to pay. After a 24-hour trip with a delayed flight, we arrived at the hospital on a cold and snowy morning, less
than 3 months after my son’s initial injury. Though I was tired and worried, knew nothing about being at a hospital in another country, I felt safe for the first time since my son was injured. Right away, I noticed that the staff took time to talk to me, to listen to all my fears, anxiety, and questions. I felt I was treated like a parent in a crisis, like a person, a worried mother for whose son they needed to create the best care and rehabilitation. On the very first day, we met my son’s doctor and his four therapists who gave him his 4 hours/day training schedule. In the first session of physiotherapy, my son took his first steps since the injury. I could trust that professionals were taking care of my son and if I asked someone for help, I was never handed off to someone else. The person I asked would take responsibility to answer my questions or fix the thing my son needed. I could focus on being a mother for my son, supporting him, playing games, reading books, and planning fun activities. We ended up staying for 3 months and I felt totally confident that my son got the care and rehabilitation he needed. My son came to the hospital in a wheelchair and left 3 months later walking with crutches. He had received training in using his hands and upper body and we had everyday routines that worked. I had gained much-needed knowledge about my son’s health and injury, confidence about how to take care of my son and hope for my son’s future.

Lost in the Wider System

Back home, the services my son had received from a coordinated team at the specialized hospital were spread over more than 15 different locations and more than 30 people. The result of the design of the services meant that people rarely communicated, coordinated, or planned activities together. Each clinic had its own communication channel and schedule. It was our responsibility as parents to coordinate all the activities, book appointments, and create a schedule that worked for our son. As well as the differences in the healthcare system, being back home meant additional contacts with the school, administrators for our municipality, the social insurance office, and our insurance company. I feared that important information was getting lost in this complex system. I felt that my husband and I were the only ones taking responsibility for our son’s care and rehabilitation and that we did not have the right knowledge, information, or mandate. I did not understand my role and often felt like I was in a fight with the system instead of the system supporting us and similar experiences are described in the literature regarding other parents of children with SCI (1).

Using Experiences and Research to Improve the Care

Cancer patient and researcher Musa Mayer (2) describes a path of healthcare advocacy that often begins with a devastating illness or condition, of our own, or that of someone we love. As we become “experienced,” moving past our initial coping, many are motivated to reach out to others affected. What begins as a difficult personal experience is eventually transformed into an avocation and a mission to be of help to others (2). I wanted to use our experiences to do something to help other families in a similar situation as ours and I found a master’s program in healthcare improvement that allowed me to use my professional and personal experience for the greater good. Enrolling in this program proved to be my first step from feeling failed by and lost in the system to becoming an empowered parent-researcher. Before starting the program, I often felt like I was a patient, just like my son in relation to the healthcare system. The master’s program was continuously challenging for me, as for example when we learned about clinical microsystem theory (3) we were asked to describe the microsystem of our work. All my classmates were in the program because of their professional role and so their microsystems were easy to define. But what microsystem should I as a parent describe—the habilitation unit, the local hospital or perhaps the specialized hospital? Eventually, I decided to describe the microsystem of parents in relation to children with SCI and discuss the importance of parents using system thinking for the work we are performing every day. The learning journey during the master’s program encouraged me to continue researching the systems surrounding children with SCI and their families, and I became a PhD student in November 2019.

Combining roles and being both a parent and a researcher provides both challenges and possibilities. Karen E. Norum (4) problematizes how a researcher’s own personal experience biases research by asking: What happens when the distance between the “researched” and “researcher” is minimized because of a shared, similar experience and how much of our own experience influences what we “hear” and do not hear when we are interviewing others? (4) I will be biased with my experiences—but my experiential bias is also a strength and enables me to be an embedded researcher, as a part of the system which is being researched. The strengths and bias risks are taken in consideration when designing and performing research, a similar challenge that all researchers face. As a researcher, you are engaged in ethical decisions about how to work with the people you are researching, how to represent their stories, and how to work with your own biases (4).

Learnings from my experiences have informed my research focus. I have experienced feeling failed by the system at the local hospital, feeling safe in the system at the specialized hospital, and lost in the system in my everyday life trying to coordinate support, care, and rehabilitation for my son (Figure 1). Based on my experiences, these are some of the questions that I am carrying with me into my research to further explore:

- What is the role of parents of children with SCI, both in relation to the child and everyday life and in
relation to other systems, for example healthcare and school?

- What are the reasons behind my very different experiences in a different hospital system, and what is the effect of compassion and communication?
- How can we as parents use our experiences to bring change and improve the care for our children and for others?

My experiences are from different countries on different continents, where I was feeling safe in the system at a specialized hospital in another country with a different healthcare system. I have met native families who had traveled domestically to the specialized hospital with very similar experiences as mine from their hometowns. I believe the difference is something else, including but not limited to the specific organizational culture at the specialized hospital with a clear vision to do everything to help the child. From this experience, I have gleaned that it is possible to create high-quality care and support both for children in the acute phase and in the ongoing aftercare, regardless of the healthcare system.

Current research shows that caregivers of children with SCI describe stressful interactions with systems of care and the data suggest the need for ongoing caregiver interventions and strengthened family-centered care, including professional assistance navigating healthcare systems and peer support (1). Using quality improvement and coproduction methods in which users and professionals work together to improve healthcare and social services (5), my research will aim to explore and improve the care in the everyday life of children with SCI by involving parents together with health and school professionals, among others. With my research, I hope to find answers to my above questions and clarify: The role of the parent, care and treatments that children with SCI and their parents need, and how we parents can use our experiences to improve the care for our children and others.

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