

## How a Child With Cancer Moved From Vulnerability to Resilience

Tracey S. Danaher, Sarah R. Brand, Lucy S.S. Pickard, Jennifer W. Mack, and Leonard L. Berry

Author affiliations and support information (if applicable) appear at the end of this article.

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Corresponding author: Tracey S. Danaher, PhD, Monash Business School, Monash University, PO Box 197, Caulfield East, Victoria 3145, Australia; e-mail: Tracey.Danaher@monash.edu.

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This is the story of a real 4-year-old boy we will call Ben, as told by his mother.

“It is our first round of chemotherapy. We have been in the hospital for 14 days. Anxious and stressed, we are struggling to rearrange our lives. Ben is febrile and neutropenic, his body covered with an angry rash, and he has severe mucositis. The oncology team make their daily rounds. I now see they do not have all the answers. Specialist teams come and go— infectious diseases, dermatology, and surgery. Our oncologist modifies the narcotics and antibiotics, adds an antifungal. No improvement.

Amid all of this, Ben fights and screams for nearly every procedure and intervention (it takes three of us to hold him still). Play, music, art therapy—nothing calms him. He knows what to expect when—the anticipation itself is toxic. Even hourly observations heighten his anxiety; Ben fears every passing doctor and nurse. My heart is breaking into a million pieces. I feel I have failed as a mother and am an accomplice to his trauma. He is difficult and demanding, desperately trying to regain some degree of control. He is profoundly vulnerable, coping the only way he knows.

Computed tomography scans, x-rays, blood tests, and the doctors still cannot isolate the infection. They have no words of reassurance because they, too, are not in control. I no longer fear the cancer; the treatment is now the enemy. The intensive care unit has been notified of Ben’s deteriorating condition. The consultants talk about modifying the antibiotics and antifungals again, but each

change yields increasingly bad side effects. I cannot remember the last time I slept, ate, or took a deep breath. I control nothing, dependent on a system and people I have lost faith in. My son and I are vulnerable beyond words.”

### VULNERABILITY IN BEN’S CANCER JOURNEY

A cancer diagnosis is devastating to children like Ben and their families. It launches a long, emotional journey involving traumatic medical procedures, cycles of hospitalization and recovery, and possible relapse and end-of-life care. Not surprisingly, cancer can trigger vulnerability—a state of powerlessness and dependence that may hinder shared decision making between clinicians and patients, reduce adherence to medical advice, and erode resilience and confidence.<sup>1</sup>

We focus in this article on how a child with cancer and his family evolved from vulnerability to resilience. Although this is the story of 4-year-old Ben, we believe that his and his family’s experiences are relevant to patients of any age who have cancer. (We preserve his anonymity to empower him to decide whether and how to tell his story of vulnerability as an adult.)

When Ben was diagnosed with cancer, his orderly and benevolent world of school, family, artwork, and bicycles was suddenly upended. For Ben to receive proper medical care, his mother had to expose him to the suffering of necessary procedures and treatment. Feeling like an accomplice to the trauma, his mother became less sure of her identity as a protective parent: She told us, “I had the choice to remain with Ben during a procedure or to be his ‘safe place’ after it was over, but I did not want to abandon my child when he needed me most. So during procedures, I would restrain him while trying to soothe him—but it was almost unbearable to endure. I did not feel like a good mother anymore.”

Ben’s cancer was a family experience, but it was Ben’s body and mind that directly bore the

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burdens of cancer and its intermittently painful, traumatic treatment. A young child, like Ben, who undergoes intensive chemotherapy is hospitalized multiple times. Ben knew that hospital admission meant he would face the trauma of access to his central line. Given that Ben could not understand the importance of the procedure, the mere mention of it spiked his vulnerability. “When Ben developed a neutropenic fever, he knew what that meant,” his mother told us. “His face would fall, and he would cry silently.”

## THE CONSEQUENCES OF VULNERABILITY

Whenever Ben’s condition deteriorated, his mother felt physical anxiety in the form of nausea and exhaustion, making it tougher to address Ben’s everyday needs. Ben’s own physical stress as he resisted each medical procedure amplified his mother’s vulnerability, which worsened his, in a vicious cycle. Ben’s mother says he had a hierarchy of what he called hurt things. At the top of the list was central line access, then finger-prick blood tests, and finally granulocyte colony-stimulating factor injections. These procedures caused anticipatory anxiety for Ben and, by extension, his mother, especially when he would ask, “Mommy, why do you let them do this to me?”

Vulnerability can likewise lead the patient and family to isolate themselves from others, including other patients with cancer and their families, as well as their own extended families and friends. Trying to maintain a brave face for the oncology team on daily rounds was difficult for Ben’s mother. Her inability to regulate her emotions made her hesitate to speak openly about her concerns, fearing she might cry and then feel embarrassed. She remembers standing in her pajamas in Ben’s hospital room in front of the medical team after a painful night for Ben. His mother recalls, “I had hoped that his blood counts would show signs of recovery. When they did not, my anxiety and exhaustion overwhelmed me. I could not stop the tears from welling up.” Although she had a list of questions about Ben’s latest prognosis, Ben’s mother felt so embarrassed under the gaze of the clinicians that she let them leave without asking them anything.

As Ben’s adverse effects worsened, his mother felt increasingly removed from decisions about his care, particularly given her lack of experience with the health system and the complexity of Ben’s medical needs. Family members and patients themselves may hesitate to assert their views because they worry that taking a critical stance may affect the quality of care they receive.<sup>2</sup> Vulnerability can also lead to passivity, neglect of health-maintenance activities, resistance to or refusal of treatment and advice, impaired immune response, loneliness, and depression.<sup>3</sup> As the medical interventions Ben needed increased in frequency, he began to resist even basic activities such as oral and skin care. His mother writes, “I would try to put cream on his rash, but he would push me away and beg for me to not touch him.” As a result, his mother would sometimes forgo these activities just to alleviate Ben’s disempowerment.

## MOVING FROM VULNERABILITY TO RESILIENCE

During a cancer journey, patients and their families can transition from vulnerability to resilience, or the ability to bounce back from hardship and then cope, move forward, and adapt.<sup>4</sup> To reduce Ben’s vulnerability in the early stages of treatment, his parents and care

team worked closely to draft a list of his likes and dislikes that they called Ben’s treatment rules. Placed on the door to his hospital room, the list mentioned, for instance, that Ben preferred not having lots of people in his room at once and that he valued silence during procedures. In fact, when clinicians, nurses, or child life therapists tried to engage him in conversation or otherwise distract him during a procedure, his anxiety and fear seemed to increase. The list of rules honored that preference and codified it.

Resilience depends on continuously open, respectful communication among the care team, patients, and families. Clinicians must offer information and anticipatory guidance about disease trajectory, treatment, adverse effects, hospitalizations, and procedures and in a sensitive, individually tailored manner.<sup>5,6</sup> For example, Ben’s oncologist mapped out on paper what a typical cycle of chemotherapy would look like, which was helpful to the family as they rearranged their lives to accommodate hospital stays and medication adverse effects.

The care team may also need to help parents understand that they are still the same good people they were before the child’s diagnosis. This effort might include acknowledging that feelings of distress and failure are normal while celebrating moments of magnificent parenting. Ben and his mother formed close bonds with the nurses on the oncology ward, who hugged them and told them they were doing a great job after difficult procedures. With this encouragement, Ben’s mother grew confident enough to begin administering some of his medications and managing his nasogastric feeds. This active work on Ben’s behalf reduced her feelings of inadequacy.

Ben and his family found comfort in the predictability of treatment cycles, in the care and expertise of their team, and in the relationships they built with this team. As they came to trust the nurses, physicians, psychologists, counselors, and other staff during Ben’s many lengthy hospitalizations, day visits, and appointments, their shared decision making in Ben’s care naturally increased. “We never assumed that the care team would work miracles,” Ben’s mother says, “just that they would listen to reasonable requests, do what they could when it was feasible, and tell us why they could not when our requests were unrealistic.”

As Ben’s family became more resilient, they began to build relationships with other families on the oncology ward by sharing their experiences, advice, and mutual support.

“I remember the late-night cups of tea with other parents, shared cheese and crackers, and a smuggled bottle of wine at Christmas, Easter, and the many holidays and birthdays when we were in the hospital. At other times we watched Ben and his hospital friends run around the ward pushing their intravenous poles—their bald heads rushing by as they dashed past us. Ben would be keen to see who else was on the ward when we arrived for chemotherapy. Knowing other children who were going through treatment just like him seemed to help him deal with his own anxiety.”

Ben and his family also drew on their individual strengths for mutual support, and Ben’s mother worked with the medical team to increase her son’s sense of empowerment. For instance, Ben was allowed to self-administer oral medication through his nasogastric

tube and to control the rate of his own granulocyte colony-stimulating factor injections by telling the nurse when to stop and go. His growing sense of control shored up his resilience, and he put up less resistance to procedures. Care became easier to administer, thereby reducing his mother's vulnerability and bolstering her resilience. In effect, the vicious cycle became a more virtuous one. This positive pattern now persists as they navigate the post-treatment phase of Ben's journey.

Ben's mother believes that the care team's efforts to minimize Ben's trauma helped him build resilience so that he would not forever carry the burden of cancer treatment in his everyday life. "That is why psychologists and child-life (play, art, and music) therapists are on care teams," she observes. "Trauma must be recognized and addressed directly if patients are to achieve anything like normalcy again."

As Ben's treatment finished and he entered school, his care team (social worker, clinical psychologist, audiologist) and the school staff worked together closely to ensure that his return was supportive and positive. School professionals received information and recommendations about Ben's diagnosis and treatment—and their implications for the learning environment. Ben's mother believes that the resilience he built during his cancer journey is evident in the ease with which he returned to school. Ben is now confident asking questions, is a leader in his peer group, and excels academically despite the health-related trauma and vulnerability he faced.

Instead of moving helplessly from one difficult event to the next, Ben, his family, and his clinicians had to empower themselves—and one another—to understand what was happening at each stage of the diagnosis, treatment, and long-term care process. It was only through such self-awareness and mutual support that resilience emerged from vulnerability, allowing Ben and his family to persevere with dignity and purpose as they continue to face and overcome their challenges.

"Those very first weeks of chemotherapy, when everything seemed to be going wrong and we were so anxious and afraid of what was to come, seem so long ago now. Now, when Ben has a medical appointment this is how it tends to go: Ben has magnetic resonance imaging (MRI) and lumbar puncture scheduled. He bounces through the doors to greet his care team, excited to see his favorite nurses and play a special game that he and one of his clinicians invented together during those first weeks of diagnosis and treatment. Ben rushes to the playroom to see if any of his friends might be there and then sets about playing.

Later, at MRI, he tells his anesthetist, 'I have done this a 1,000 times, so I am very experienced. I will send myself off for a magic sleep. I will blow the balloon up so big this time that it will burst.' I hug Ben to me as he places the mask over his own nose and inhales deeply. I look around at the MRI equipment, the team standing close by. This place would be so unfamiliar to most mothers but not to those of us who have a child with cancer. I kiss his cheek and tell him a story as the anesthetic takes effect.

The MRI clinicians know us well and have been a part of our journey on many occasions. The anesthetist looks to me and says, 'I know only part of what Ben has been through, but I want to say to you that you have a very special, resilient, and brave little boy there. You should be so proud of him.' And I am.

We have found our place within this community of caring professionals and fellow patients. It is not a place anyone chooses to be, but the support of our team has made us resilient to face whatever the future may hold for Ben. We are enormously grateful for the dedication of our care team, for the friends we have made on this journey, and for every moment of every day we have with Ben."

#### AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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#### Affiliations

Tracey S. Danaher, Monash University, Melbourne, Australia; Sarah R. Brand and Jennifer W. Mack, Dana-Farber Cancer Institute; Jennifer W. Mack, Boston Children's Hospital, Boston; Sarah R. Brand, Lucy S.S. Pickard, and Leonard L. Berry, Institute for Healthcare Improvement, Cambridge, MA; Lucy S.S. Pickard, Imperial College Healthcare NHS Trust, London, United Kingdom; and Leonard L. Berry, Texas A&M University, College Station, TX.

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**Tracey S. Danaher**

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**Sarah R. Brand**

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**Lucy S.S. Pickard**

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