

Stories from Kids: The Unheard Voices of Pediatric Patients

By Kelley Yuan

Narrative medicine is filled with rich stories from physicians, medical students, and adult patients who can eloquently express their thoughts about illness and treatment. They use descriptive imagery, metaphors, and transcripts of their internal dialogue to convey their experiences and thoughts. We can understand the way they write, and their words fit neatly among the pages of an academic journal and other publications.

But what about the children? The grade school and adolescent patients who represent an equally important segment of the treated? Patient stories of younger children are often told through the accounts of parents, and rarely do we get to understand what recovery felt like through the eyes of the child.

Granted, younger patients are limited by their command of words, but that doesn't detract from the words they *can* say. The Alphabet Wall at one pediatric hospital features the words and artwork of patients, capturing a swath of emotions and experiences they face (Figure 1).¹ From the flood of question marks to the bright doodles of stars and flowers, we catch a glimpse of how kids make sense of their illness. Kids are not the only ones to benefit either. Healthcare providers have used feedback from children to identify their needs and find ways to improve care.^{2,3}

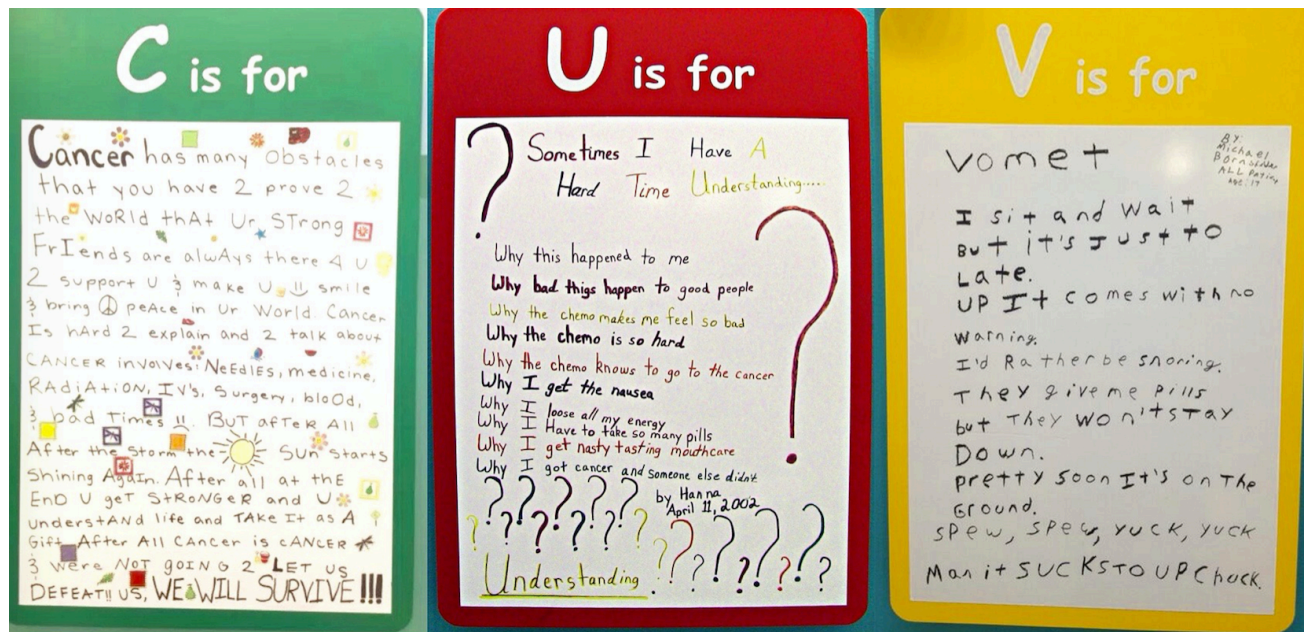


Figure 1. Alphabet Wall, St. Jude Children’s Research Hospital (Memphis, TN).

Other hospitals feature patient videos describing their diagnosis and recovery. One patient describes her reaction to the diagnosis of leukemia at ten years old and the nausea and needles accompanying chemotherapy.⁴ Patient self-narration has been shown to help other physicians and themselves reach a clearer perception of their illness, and it strengthens them to face future treatment.⁵

Yet these stories rarely get documented in journals of narrative medicine, and few works seek to examine the experience of the child himself. In the middle of ongoing treatment, encouraging a child to share his emotions and thoughts plays a vital role in helping him find meaning in the illness he is fighting. To ensure that children are acknowledged and receive empathy, it is important to document what they experience as thoroughly as we do for adults.

Similarly, the stories of teenage patients are underrepresented in the literature. However, we can try to see their thoughts by piecing together what they have written to each other.

At Daily Strength, an online support group forum, teen cancer patients can reach out to survivors for advice and friendship.⁶ Among the threads filled with questions and concerns are fears and dreams laid raw. Teens worry about finishing their studies, taking care of their younger siblings, losing their positions on sports teams, and adding extra stress on their families (Figure 2). The conversations there pull back the curtain to a world of support, coping strategies, and emotional tumult characteristically different from the usual stories of older cancer patients.

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Hi I am 14 years old and just about to start highschool I am getting very anxious. This is my first time on a support group so bear with me. I have a spinal cord tumor that was deemed inoperable by all of the neurosurgeons where I lived so my mom took me out of state to see a doctor. We held off on surgery until my hands started going numb. They took out about 30% of the tumor. So far I have been stable it is too risky to do radiation and chemo may do more harm than good so I frequently I get an MRI and talk to my doctor. So I have to go out of state to hear that I am fine and I hate leaving my home and everything I know, my mom refuses to let me see the doctor here even though the doctor said I could. There is also this problem I have with swimming I used to be on a club team I was really good winning events and when I came back I was in last place for every event. Know I am struggling with if I should do the highschool team. It feels like torture and is a lot. Everyone is pressuring me and I'm stuck. Any advice anyone has would help. Thank you.



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Leave A Reply

Figure 2. DailyStrength.org, post from Teens With Cancer Support Group.

The Scoliosis Research Society features Patient Stories written by patients themselves. Paige, a professional dancer who overcame scoliosis, describes the confusion and fear of hearing her diagnosis and recounts the difficulties of coping with scoliosis in high school.⁷ Her narrative serves as a beacon of hope and sympathy for other teenage patients, and it represents the best of what narrative medicine can do.

Teenage voices also take root in blogs, some of which collect accounts of cancer patients. *Stupid Cancer Blog* hosts a variety of open letters from cancer patients written to caregivers, family members, and fellow cancer fighters.⁸ Pieces capture the changes in self that patients have noticed since diagnosis, as well as the frustration and the strain of living with the disease.

“Yes, you. I see you there. The ‘cancer just chewed you up, spit you out and now, afraid of your own shadow’ you. Before the big C, you were that social butterfly, new friend maker and now you’re that shy wallflower no one approaches. You lost your hair, some of your dignity when you puked at your friend’s party from being sick and now, what feels like part of you. I remember that.”

They offer an unprecedented candidness and clarity of how teen patients feel enduring therapy, finding support groups, and spending time with loved ones. Against the backdrop of a diagnosis, teens are also using their writing to establish an identity and navigate the features that truly define who they are.^{9,10} Yet so few of these accounts join the narrative medicine discussions of today. Sift through the accounts of family members, training residents, and patients themselves, and the average reader will be hard-pressed to find an account of a teenager battling lymphoma, or a view of surgery through the eyes of an eight-year-old.

Telling personal stories is essential to interpreting illness and finding hope in the future.¹¹ For pediatric patients with limited narrative experience, understanding how they interpret their illness is vital. Their voices are missing in today’s narrative medicine. Their artwork needs to reach a larger audience, and their words need to be recorded, even if they cannot write yet. The writings of adolescent patients, struggling to grasp both a diagnosis and a sense of identity, grappling with both treatment plans and their outlook on life, deserve a space in the public discourse.

Narrative medicine doesn't just take the form of polished prose. It also takes shape amidst crayon sketches in the pediatric ward, song lyrics penned from a hospital bed, and online forum threads posted after the latest lab results came back. These narratives embody the unique *youth* perspective of disease and recovery, and we need them now more than ever before.

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