Making a difference: More than just respiratory care

Alisha Nelson RRT

Our practice as registered respiratory therapists is heavily guided by evidence-based medicine, scientific studies and professional practice standards. However, our practice can also be shaped by inspiring stories. Dr Remen writes in her book, *Kitchen Table Wisdom*, "Life is the ultimate teacher, but it is usually through experience and not scientific research that we discover its deepest lessons" (1).

Brianna was a 17-year-old girl facing the end of her life – misdiagnosed, and then re-diagnosed with a fatal spinal cord tumour – within a six-month timeframe. Her biggest wishes after dealing with all of her medical issues, which left her paralyzed and attached to a ventilator 24 h per day, were simple: to go home and to graduate from high school. Unfortunately, this was not possible, but it inspired one of our pediatricians to facilitate a meeting among health care providers to brainstorm ideas to optimize Brianna's stay in hospital.

After this meeting, the BC Children's Hospital pediatric intensive care unit worked together to help Brianna and her family create memories outside of the hospital environment. To do this, Brianna and her family required resources: namely, a nurse and respiratory therapist at all times, which led to our increased involvement outside of regular working hours, including outings to concerts, botanical gardens and local amusement fairs. Our team also supplied health care providers in her home on a few occasions, which enabled her to be a part of family celebrations, anniversary parties and birthdays.

One of Brianna's major accomplishments was finishing high school. Through determination, she did this by using sip and puff technology and an iPad from her hospital bed. We had decided to celebrate her graduation ceremony at the hospital because we were not sure she would make it to her own ceremony in a month's time. In the matter of a couple of weeks we had different speakers, graduation programs, her high school diploma released from the province, a flash mob routine, a food committee, a decoration committee and, to top it off, a red carpet for Brianna to wheel across as she received her diploma. In the end, Brianna did make it to her high school graduation ceremony, where she received a standing ovation from a full theatre as she was wheeled across the stage by her father. She passed away shortly after this graduation ceremony, in the comfort of her own home.

Respiratory therapists see many traumatizing events, including deaths and devastated family members. To say that we are never affected by any of this is to say that we are not human. This separation of emotion can lead to a career of dissatisfaction, feeling undervalued, unmotivated and numb. According to the *Cancer Nursing Journal (2)*:

> Compassion fatigue leaves a heavy toll on nurses as they experience continued loss of patients. Many nurses go about their days experiencing increased stress with little understanding as to what is happening to them until they become ill, numb, or despondent"… some nurses make the ultimate sacrifice of leaving the profession when they no longer feel they are making a difference.

This statement could be applied to any health care provider, including respiratory therapists.

Although therapists can practice self-care, including yoga, leading an active lifestyle, and debriefing after a tragic event, it is important to grieve the loss of life. Dr Remen writes:

> In my experience, burnout only really begins to heal when people learn how to grieve… Grieving is not meant to be of help to any particular patient. You grieve because it's of help to you. "On to the next" is a denial of common humanity… it is a rejection of wholeness, of human connection that is fundamental (1).

Dehumanizing patients can hurt not only the patients and families we care for, but also ourselves.

It is important to consider our role as respiratory therapists, including being part of an end-of-life situation. In some cases, not only do we have to tend to our patient's medical needs, but also their emotional, social and spiritual needs, and the needs of a family facing the end of someone's life. We have to be very flexible and open minded, and sometimes do things outside of our general role as respiratory therapists, including stepping outside of our comfort zone to comfort a family member.

The experience of working with Brianna made it clear that excellent patient care cannot be given alone. The World Health Organization definition of pediatric palliative care states:

> Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited (3).

Indeed, "it takes a village" (4) that understands and respects each other's roles, that has leadership and that allows individuals on the team to speak up when something needs to be said.

In a recent editorial published in the *Journal* (5), "Patient and family centered care in respiratory therapy: A fundamental right?," Buell and Menard argue that:

> For RRTs to effectively implement the patient and family centred approach, there must be a shift in practice from the traditional hierarchical relationship toward a focus on creating an equal partnership among all health care providers involved with the patient and family.

Throughout Brianna's journey, our little 'village' at BC Children's Hospital consisted of many individuals. Many disciplines worked together to achieve excellent family centred care.

Respiratory therapists, as well as the rest of the health care team, need to work together to leave positive, lasting impressions on the patients and family members. We need to understand that compassion and empathy are equally as important as academic scores and clinical competence. When speaking with Brianna's family, it was evident that

BC Children's Hospital, Vancouver, British Columbia
Correspondence: Ms Alisha Nelson, BC Children's Hospital, 4480 Oak Street, Vancouver, British Columbia V6H 3V4.
Telephone 604-875-3955, e-mail alisha.nelson@cw.bc.ca

they had been emotionally affected by negative comments health care providers had made. Although we reminisced about all the amazing things we did with Brianna at the end of her life, we also spoke about specific examples of negative health care provider and family interactions. Brianna's mother described an example of a nurse in the late afternoon complaining to Brianna that she hadn't gone for her break yet after Brianna had asked to be changed. This left Brianna apologizing to the nurse, and Brianna's mother very upset (4). This was followed by many more examples of negative interactions. It should be remembered that what we say and do in front of patients and their family members can affect them long after the episode of care. Dr Remen states that:

> Health care professionals are taught that competence and expertise are the two most important and respected qualities in the medical subculture, as well as in our society, but as important as they are, they do not fully sustain us (1).

This illustrates how important compassion and empathy are in health care. They sustain us in this business – these emotions help us understand that caring is not just an emotion, it is a conscious act (6).

Going forward in this profession, we all need to be positive role models for the next generation of respiratory therapists. We need to teach and lead our peers by example that the patient and family come first, and the task comes second. The role of respiratory therapists is ever evolving. We are spending more time at our patient's bedsides and we are depended on for patient management. If we allow for time in our career to listen, reflect and change, we can come to understand that our patients and their families can be our greatest teachers. While we go about our daily work, it is important to remember the true meaning of why we do what we do, and that what we do can make a difference.

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