

My weekends with B: Grieving the loss of an admired patient

A reflection from a family medicine clinic

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It is not often that family physicians, or physicians in general for that matter, are afforded an opportunity to grieve openly about a patient they know well and have cared for when they pass away.

This story is not simply an expression of my grief, but one of advocacy to encourage some reflection. Professionals do that: we experience, we reflect, and hopefully, we become better at what we do.

B was my patient for 4 years and I saw her regularly. It was easy to see she was a special person - a genuine character. She was special for her ability to laugh and to make me laugh along with our clinic staff. She filled a room with her presence, and she had a warm personality. B was a mother and a grandmother, and it was obvious she cared immensely for family. She would often share little moments of their worlds with me as update on life, like friends might do over coffee.

B was also special because she was one of only very few patients, ever, who would ask me at each clinic appointment or virtual phone call, "How are you doing?" She would ask this meaningfully and respectfully. Like any family physician in practice long enough, you develop a relationship with your patients. It's one of the best parts of being a family physician - relational continuity - and involves building trust to the point where patients feel safe to share and not feel judged.

B knew a little about my family and always asked about my son and spouse. She would thank me for my time when I called her, especially on weekends, as she knew my family time mattered too. We would typically share a good laugh at the end of each call, no matter the circumstance.

B had diabetes and was on insulin; she was meticulous about managing it. She listened when we spoke by phone or met in clinic, asked good questions, and challenged me often. B was also diagnosed with obesity. Having delivered each of three daughters vaginally, she suffered in her later life with urinary issues, including incontinence. Her condition led to chronic skin irritation and eventually genital dermatitis. B was plagued by recurrent urinary infections with multiple bacterial species (she and I would call them 'unwelcomed inhabitants') resistant to standard antimicrobials. She experienced countless days with symptoms, investigations, treatments, and strangers in her house applying creams and caring for her, somehow tolerating it all.

For years, I would need to call B on the weekend to review a urine culture report or follow-up on a treatment plan, or at times to discuss the need for higher levels of care when she was unwell. B was honest in her communication and posed valid questions about my medical reasoning and advice. We had good discussions and we listened to each other.

As I came to know and understand B's full medical story, it was more than just her physical symptom(s) that were abnormal. B was nervous, even frightened about going to the hospital.

I knew that hospitals were unpleasant environments for her, as she shared this with me. Her feelings were well-placed. Notwithstanding COVID-19, B attended hospital and outpatient clinics for a variety of urogynecological procedures and consultations. I worried a little each time she went, and how she would manage and be treated, as I knew she often needed a higher level of care than I could provide.

On one occasion, when she had respiratory symptoms difficult to control at home due to a viral illness, I directed her to return to urgent care, in fear that her symptoms might worsen. It was more than I could assess over the phone. She later shared the delight of being cared for by a physician who she had seen before and remembered

her and treated her well; her relief was obvious.

Other encounters she shared were not as nice. When being assessed for dermatitis from regular exposure to urine-soaked pads, a consultant remarked upon entering the exam room, "What's all this?" (referring to B's body habitus while she was sitting quietly in a wheelchair). B was not examined and was instructed to take pictures of her genital area to assist with the consultation. On another occasion at the ED, a nurse commented: "If only you tried harder..." (you could lose that weight) - this made her cry. And when she told me, she cried again. Sadly, these are only a few experiences B shared. I suspect there were others, but she likely didn't wish to bother sharing or impose on anyone to draw further attention. B knew discrimination and faced it often. She once tried to explain her obesity history with me. "After, my girls were born," she once told me, "I just couldn't lose the weight." I listened quietly.

In the last year of caring for B, things became medically complicated for her, like many others her age. Each new consultant report either opened with, or emphasized **in bold**, the fact that her BMI was elevated. Sometimes it was headlined prior to the patient identifiers. The message seemed clear: B was identified as "Obese, Class III (WHO classification)" to be exact. Along with this, as we know, came an inherent increased risk for complications with many common procedures and tests. My own medical interpretation was, yes, this is correct and important to identify, but I was always left feeling that although many medical and surgical practitioners were working hard for B, doing their best, there was also another message being conveyed highlighting the fact that if complications did occur, or treatment failed, it was to be expected. This was her reality.

It was eventually determined that B had recalcitrant renal stones, a possible source for many of her recurrent urinary issue and a common reason for our weekend chats by phone. This diagnosis took almost 2 years to fully sort out.

Having survived more than her share of urinary procedures, and multiple falls, B was eventually transferred to a long-term care facility. After a brief placement in her new home and a new physician, she developed a cough and was not herself. It was attributed to being "inactive, obese, morbidly obese." She was encouraged to 'move more' and 'do better.' In the end, B died of complications from pneumonia. She was 78 years old.

As her family physician, I am sad for B and her family, and sad for some in our health care system who did not get to know her like I did. Sometimes I think to myself, if only I had tried harder to advocate for her, to call out those who were unprofessional and unkind to her, perhaps her experiences would have been different. As health care providers, we (and the system) can do a better job of recognizing B and patients like her for more than their body types. We can communicate in person-first language, in our notes and our conversations stating: 'patient with obesity' rather than 'obese patient.' We can also use evidence-based staging systems (like the Edmonton Obesity Staging System or EOSS) to describe the severity of the patient's obesity rather than using terms such as 'morbidly obese.'

As family physicians, patient advocacy is our daily business, no matter the patient's body size, age, gender, race or medical condition(s). With this in mind, here is some sage advice I took note of on behalf of B from our weekend chats.

"If you don't have an established and trusting relationship with a patient, like many family physicians do, then please consider not making a comment about their body shape and size - the patient already knows about it and is very likely doing their best."

My weekends won't ever be the same. B and I talked on many occasions about her experiences with the health care system and we had planned to write this together. I wrote this for her on a weekend.

B. & T.M.

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