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My patients prepared me well

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My patients prepared me well

Why do so many doctors seemingly have to experience a life-threatening illness before they truly develop empathy? Despite years spent caring for patients, why is it that it takes their own illness to realise that being unwell can be frightening and demoralising for the soul as well as wreaking havoc on the body?

Stories of doctors experiencing illness are common. Major illness is life-changing for most people, and the impact on doctors can be particularly profound.(1-5) The unifying theme in articles written by doctors finding themselves in the patient role is that being a patient can be frightening, undignified and disempowering.

“I will never forget how illness attacks one’s sense of self, and I will be tireless in reminding patients they are whole human beings despite their illness.”(1)

“Now I understand the feelings and fears that my patients go through every day, because I was ‘them.’”(2)

Of particular interest are the reflections of medical practitioners about how differently they relate to their patients.

“From now on, I will be more thoughtful about the effect so many tests and therapies may have on the lives of patients. I will also offer patients the utmost respect, especially when I place them in humiliating situations.” (1)

Doctors may also offer advice they give to other doctors about to treat patients with serious illness.

“Believe your patients. Really listen to your patients. What they are saying is of concern and of importance.”(2)

As I read these commentaries, I wonder why my own cancer experience didn't hold surprises for me. Why has it not resulted in a dramatic change in my perspective or a change in my clinical practice? Why has there been no enlightened transformation? The answer is the simple realisation that my patients had prepared me well for the journey. In 19 years of specialty practice, I had seen breast cancer affect women from all walks of life. I didn't feel immune and I had no faith that being one of 'us' would protect me. Rather, I had a feeling of inevitability that it would eventually get me too. So, when it did, I didn't feel shock, anger or disbelief; I thought "this is ok, it could have been so much worse."

I had had the privilege of listening to so many stories of patient experiences, and there was much comfort in this for me. I knew what was ahead and I knew how to prepare. I knew I was not the first one to struggle with loss of control, to face each investigation with dread and to wonder if the bad news would ever stop. It was not a shock to find that depending on others during recovery was a frustrating experience for an independent woman, that the combination of surgical menopause and aromatase inhibitors was downright miserable, that my doctor wasn't hearing me, that many friends just didn't understand, and that returning to work was like climbing a mountain every single day. I wasn't the first to wonder if this disease was going to define me forever, to wonder how long 'forever' might actually be for me, to just want my

old life and the old 'me' back. It was tough, and it continues to be, but I also know that it feels like this for most.

With this experience, I wonder how it is that some experienced physicians, highly regarded by their peers, can get many years into a medical career (even an oncology career), yet only realise that 'what patients say is important,' that they are 'human beings despite their illness' and that we should 'believe' and 'respect' our patients after going through a cancer ordeal themselves.

If we, as doctors, are truly patient-focused and we are tuned in to our patients' narratives, then none of our own illnesses should surprise or profoundly change us. The fact that they so often do is a poor reflection on us as medical practitioners and as medical educators. We can't possibly experience every illness ourselves, and if it were essential to experience all (or even just one) serious illnesses in order to be compassionate doctors who listen to our patients, then we would all be extremely poorly equipped for clinical practice. We need to focus on training our students in patient-centred care, which starts with actively listening to the patient's story, considering the context of the illness and refraining from imposing our own judgment and agenda on the consultation. We need to approach a consultation with the assumption that the patient is 'right.' Above all, we need to realise that while a patient may have a 'common' illness that we, as specialists, see day after day, their experience of that illness is unique and individual. This is the art of

medicine and the fascination of medicine— that patients with the same diagnosis can be affected in such vastly different ways.

Illness narratives written by doctors can and should be used in medical education as powerful case studies. However, their importance must not be over-emphasised or placed above the 'normal' patient perspective. Physician narratives can help medical students realise that we are not immune to illness; on the contrary, some conditions such as mental illness and addiction are more common among physicians. Narratives can demonstrate to students the importance of looking after their own health, having their own doctor and being able to discuss symptoms that arise.

As physicians, we must listen to and better connect with our patients.

The metaphoric wall between doctors and their patients is not helpful as it stops doctors from listening and understanding and it may foster an unconscious expectation that physicians have immunity from illness. It is inevitable that we will all have experiences 'on the other side,' and a career in medicine should leave us well prepared. Yes, we should listen to our patients. The privilege of joining them on their extraordinary and personal journey may just help us in ways we never expect.

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