

When roles are reversed: Perspectives from the physician as patient

I believe we can enhance patient care through empathy and compassion, and that we must remember that our profession does not make us immune to the human experience that comes with being sick. I hope my experience can help us in our quest for optimal patient care and that by sharing my experience I can help us become more conscientious and holistic physicians.

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From the time we start our medical training to the moment we embark on our careers as physicians, we are taught about the importance of empathy in patient care. In my experience, this teaching often comes with the assumption that all medical trainees are healthy and without chronic disease. The teaching of empathy is often under the pretense that no medical student, resident, or physician could possibly know what it is like to be a patient. We are taught how to apply population statistics when assessing risk for disease, but rarely is it acknowledged that we could be part of that population. The message seems to be that, as physicians, we are a separate entity, immune from illness and chronic disease.

Living with type 1 diabetes for 29 years, as well as a metabolic bone disorder, I've been on both sides of the health care system for most of my life. However, it was my recent experience as a transplant patient that made me truly

aware of the distress, anxiety, and hardship a patient can experience. I have learned that there are certain aspects about being a patient that we, as physicians, cannot fully appreciate until we are on the other side, and that a significant impasse to optimal patient care is the discrepancy between what is important to the patient and what is important to the physician. These can be two very separate matters and can lead to frustration in both the patient and the physician. I have also learned that sometimes, even despite a wonderful and capable care team, a patient can feel unprepared for what is to come.

Another challenge I have experienced is that of being a physician-patient. On one hand, as a physician, I am very much aware of the challenges that we face, how amid our busy schedules we must triage cases based on urgency, despite having hundreds of patients whose concerns are all important and valid. On the other hand, being a physician does not make me immune to the emotions that can result from being a patient with a serious medical condition. I have experienced the anxiety of having to wait several weeks to discuss results, knowing that they are already available. I have felt the frustration of being consistently reassured

about my symptoms while they greatly affected my quality of life and precluded me from doing the things that I love. I have felt the nervousness that comes with being told that the next available appointment is several weeks away when the thought of waiting that long to hear my physician's opinion seemed impossible. And then there is the interesting dichotomy of how physician-patients are treated—at times as a

colleague (asked to look up our results once they are available), and at times as a patient (told not to contact our doctors via email, when we would be able to as a colleague). It can all be very unclear

and, at times, frustrating.

After much introspection, I have realized the experiences I have had as a patient are important and have taught me things I would not have learned had I not been “sick” for the better part of a year. I have become aware of details that are essential to patient care but that are not necessarily taught in medical school. Although my journey over this past year has been tremendously difficult, it has provided me with tools to become an even better physician. I believe we can enhance patient care through empathy and compassion, and that we must remember that our profession does not make us immune

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The physician-patient

In my experiences as a patient, I often heard the phrase “We don’t need to tell you about this; of course you already know!” In fact, many years ago, I even had a specialist say to me, “You don’t need me; you know how to manage diabetes!” Comments like these are problematic. First, they can make a patient hesitant to come forward and admit that they do not know this information and want to be informed and educated. Second, when you’re a patient, most of your objective medical knowledge goes out the window. There is a reason it is prohibited to be your own physician: it is exceedingly difficult to be objective when it comes to your own medical challenges. There seems to be a false assumption that physicians are immune to the fear, anxiety, and vulnerability a patient can experience. We also want, and have a right to, the same level of care as any other patient, and that includes thorough explanations of diagnosis,

prognosis, and management, without the assumption that we already know everything that is going to happen. It can be disconcerting to find out about a procedure (in my case a PICC line) or an investigation without being told in advance, because the assumption was that you must have known because you’re a doctor. To put it simply, physicians want to be treated like any other patient. The need to feel safe and cared for is a need common to all humanity, regardless of profession.

A note on informed consent

We are all familiar with the notion of informed consent—that is, a patient’s right to know a reasonable amount of information so they can make an informed decision on how to proceed. The question is what is reasonable. What may be reasonable to one patient may be irrelevant to another. We cannot accurately determine what information is reasonable for a particular patient without knowing about their lifestyle, values, and goals. True informed consent is predicated on taking the time to get to know your patient. For example, a concert pianist may

be very concerned about a medication’s small risk of neuropathy, which could end their music career, but may not be as bothered about the associated risk of nausea. Conversely, a patient that does not have an occupation dependent on dexterity may be worried more about other side effects.

This concept of true informed consent came from my experience as a patient. Prior to my transplant, I was a competitive runner who also had a rheumatological disorder that predisposed me to fracture. I did not become aware of the risk of bone loss associated with my immunosuppressant medications until after I had been taking them for several months, and after being diagnosed with new fractures. Given my lifestyle, this risk of bone loss is very relevant to my informed consent, but as it was a rare side effect, it was not something that was highlighted to me. The high risk of diarrhea associated with these medications was not a side effect particularly concerning to me, although I was counseled on it several times. The same applies to the rare side effect of dyspnea, which I had. It was distressing to have severe difficulty

breathing without knowing why, until I learned that this can also be a rare side effect of my medications. Because my transplant was part of a clinical trial with voluntary participation, I questioned whether I would have consented had I known these risks beforehand. As a physician, I appreciate that it is virtually impossible to inform our patients of every potential risk of treatment. Nevertheless, it was these experiences, and the resulting effect on my quality of life, that led to my realization that informed consent requires us to do a thorough social history on our patients and take the time to get to know our patients—their hobbies, interests, careers, and values. Having a frank discussion with our patients about what is important to them can avoid future distress on the patient's part and can also inform us on the impact of our treatment plan on their lives. For example, how frequent are their appointments? How often will they have to go to a lab to get bloodwork? How far do they have to travel? Will they need to take time off work? Do they need to find child care or a pet sitter to accommodate appointments? All these factors can have an impact on a patient's life, and to be able to answer these questions, we need to know much more about our patient than their medical diagnosis. I understand that, as physicians, we are often challenged for time, and it can be difficult to take a detailed social history, but it is one of the most essential parts of the patient's medical history if we aspire toward optimal patient care and patient satisfaction. Furthermore, this notion needs to be instilled at the medical student level. We need to teach our students the importance of a social history and to lead by example. True informed consent is predicated on taking the time to get to know your patient.

Our words make a difference

Without question, communicating effectively and compassionately with our patients is integral to optimal patient care, and we carry a significant responsibility in what we communicate to patients. If not well thought out, our words can lead to false hope, misunderstandings, and misguided expectations.

Human nature makes us want to convey hope and positivity to patients, but rarely should we state facts with absolute certainty.

Statements such as “I know you will be just fine” or “You will feel better in no time” appear benign, even kind, but they can provide dangerously false hope and the misleading assurance that nothing will go wrong. We may sometimes be hesitant to convey uncertainty or to share difficult information with our patients; however, I don't think we give our patients enough credit in terms of what they can handle emotionally and how much worse things can be if patients feel misled. It is vital that patients are also prepared for rare adverse outcomes; they have a

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right to know what serious adverse effects are possible, not only those that are likely to occur. As a patient who experienced rare side effects and toxicities from my medications, and whose postoperative course had unexpected complications, I felt unprepared for my experience having been given assurances prior to my procedure that things would go well. I can't emphasize enough that we can never know how a patient's course is going to play out, and vocabulary that communicates certainty can be problematic.

The significance of mental health in chronic disease

The link between having a chronic disease and suffering from mental illness such as depression, anxiety, and other psychiatric conditions has been well described in the literature; however, it has been my experience that it is a concept rarely addressed in clinical practice. Throughout my years as a patient, I have often felt that my mental health wasn't given the same level of attention as my physical health. Only a select few of my health care providers asked me the simple question “How are you doing?” unless it related to my physical well-being. It seems that unless I initiate the conversation, or until it becomes obvious that I am struggling emotionally from my chronic health issues, my mental health is overlooked.

I'll be frank: my entire life was turned upside down this year. Things that provide me with a sense of identity, self-worth, purpose, and joy were taken away unexpectedly. For several months, I was unable to practise medicine, teach my medical students, or run competitively. Although my journey has been incredibly challenging from a physical perspective, the impact on my mental health has been equally difficult. Sometimes a patient may be less interested in their latest test results than in regaining their happiness and sense of purpose. We can help by simply asking questions and showing interest in our patients' mental welfare.

I believe all patients being treated for chronic disease should be asked about their mental health and screened for mental health disorders. We should not rely solely on a referral to a psychiatrist or counselor, which can take several months, when as physicians, we have all been trained on how to take a psychiatric history. I found it very impactful when a physician asked me “How are you doing? How is your mental state? How are you coping emotionally?” Upon my gradual return to practising medicine after my illness, there have been several occasions when, upon asking my patients these same questions, they have been overcome with emotion, and it has led to a long discussion about their difficulties in coping with their illness. Clearly, these are questions we need to be asking our patients.

Closing thoughts

We can be better physicians if we truly get to know our patients and what is important in their lives. Our agenda should be aligned with our patients'. The physician-patient alliance can be strengthened through this shared vision, and the patient experience can be enhanced. Furthermore, we must remember that we, as physicians, are not immune to illness, and we should be mindful of how we care for our physician-patients. Although I would not want anyone to experience illness in order to gain these insights, I hope that by sharing my experiences I can help us become more conscientious and holistic physicians. ■

Competing interests

None declared.