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Changing Roles, Changing Perspectives—Vulnerability as a Patient

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Abstract

As an assistant professor of nursing and nurse in an emergency department, I offer my perspective on being a patient with cancer and the element of feeling vulnerable associated with an "insiders" viewpoint of the health-care system.

Keywords

cancer, caregiving, clinician–patient relationship, patient/relationship centered skills, patent perspectives/narratives

For some years I've seen the call for papers in the *Journal of Patient Experiences* and as many tenure line professors think, I thought I could write something about the patient care I give and the patient care I teach about. It wasn't until my experiences since June 2017 that I realized I might be the topic of a article. As of today, it's been 205 days since the words breast cancer and my name were uttered in the same sentence. Over 200 days of this being at the forefront of my being . . . in the midst of my being a mom, wife, emergency department nurse, and assistant professor in a college of nursing and over 200 days since I went from the role of caregiver to care receiver. In this time, I experienced a feeling of vulnerably related to my "insider's knowledge" and one that subsequently changed how I teach and provide patient care.

I'm not the first nurse who has experienced breast cancer and gained some insight from the perspective of caregiver turned patient. I'm not the first professor either. In the days since my diagnosis, I've felt many things including fear and anger, hope, and even the love and support of friends, family, and colleagues. These feelings were somewhat expected and even welcomed as a way to cope with my diagnosis. What I didn't expect was feeling a feeling of vulnerability that seemed to permeate everything since that day in June. This sense of vulnerability was not so much related to me but rather as it related to my reliance on the other humans in the health-care system. In my own work in health care both as an educator and as a per diem nurse in an emergency department I thought I had first-hand knowledge and experience in patient care and in addressing patient needs. What I didn't know was that these experiences in health care would contribute significantly to my feeling vulnerable.

I initially became aware of my vulnerability when I went for the first of many laboratory draws. Some of the nurses and laboratory technicians knew I was a nurse and went so far as to comment that they felt nervous sticking "another nurse, especially a professor." I did my best to smile and reassure them that I was just like any other patient. I feared coming across like that patient who has spent way too much time on Google or WebMD looking up their symptoms and telling the health-care providers how they should be cared for. I became what I hoped would be a model patient; I didn't say a word when laboratory test results or IVs were attempted in a bad spot and then missed, I gritted my teeth when someone forgot to flush a line or even wash their hands. I feared not being seen as a human being with breast cancer but as that patient with cancer who thinks she knows everything. I also wanted to be liked by my caregivers knowing that "difficult" patients are sometimes treated differently in some subtle ways whether it's a delay in responding to a call light or in the way one is described by the physicians in their notes. I wanted to be described as "a pleasant 51 yo female with invasive ductal carcinoma . . . " rather than "the noncompliant" or "difficult."

The height of this feeling occurred after an early chemotherapy session that culminated in a seizure and subsequent (or simultaneous—we still don't know) onset of atrial fibrillation. I was now an inpatient, dependent and feeling as if I had neither control of, nor an understanding of my

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environment. I remember at one point a nurse coming in at about 10 PM to take my blood pressure and despite an unusually low reading of 83/54, she said goodnight and walked out. I laid in bed thinking that something was wrong but she didn't notice. I waited a moment before pressing the call light and when no one came I started peeling off the leads to my cardiac monitor. Still no one came for 27-long minutes. During these 1620 seconds, I lay there wondering what was happening, then got worried, then angry, then scared, and then . . . then I simply started crying. I cried because I was afraid I was suddenly going to die, I cried because I was bald, I cried because I was in the hospital instead of at home working on a syllabus, I cried because even if I got through this night, I would still have more of this "crap" in this system to go through. I cried because I wasn't in control and even my experience in nursing or my hard earned PhD wasn't going to get me through this. I cried because I felt vulnerable and was seemingly at the mercy of this health-care system comprised of human beings who sometimes make mistakes.

In health care, we linearly move patients from a state of illness to one of optimum health. We collaborate with one another as part of an interprofessional team toward this common purpose. In my role as a nurse and nurse educator, I was aware of how dependent health-care professionals are on one another and how tenuous these interactions can sometimes be. There are breakdowns in communications, misinterpretations of results, and even lapses in care. We are reliant on everyone doing their job and doing it well. But much like a cog in a machine if one part is broken or perhaps managed incorrectly—the other pieces may not work as well and a breakdown will result. Furthermore, sometimes we make mistakes . . . a lot of them actually. We interpret a laboratory value wrong, we miss a vital sign, and we even make medication errors. In 1999, the Institute of Medicine1 published their landmark report *To Err Is Human: Building a Safer System* that stated as many as 98 000 people die in hospitals every year as a result of preventable medical errors. Although significant efforts have been made in the health-care industry since that report to improve patient safety I still felt afraid and vulnerable not because I was weak or ill-informed but because I had an insider's knowledge of how we can and do make mistakes. I was receiving care in a variety of settings (clinic, laboratory test results, hospital, and outpatient) by a variety of providers over an extended period of time. To me it seemed inevitable that somewhere along the line there would be a breakdown; a mistake, and I feared I would be helpless to prevent it.

Since then, what has somewhat helped mitigate this feeling of vulnerability is a sense of having a larger role in my own care and not worrying as much about what my care providers think of me. Since my hospitalization, I've signed up for a patient portal that allows me to view test results, ask questions of my health-care team, and even request follow-up appointments. No longer are my laboratory results sequestered in some hidden chart viewable only to physicians and nurses, now I know what they are and can anticipate to some extent what I need to worry about next. I've also taken a stronger role in advocating for my care and speaking out when something doesn't make sense or seems to be done incorrectly. I question everything. I'm no longer trying to be a model patient so that the nurses, physicians, and techs will like me—I'm trying to kindly share my perspective, my fears, my knowledge, and my strengths, and weaknesses. I'm also allowing my health-care providers to see me not as a patient with cancer but as a human being with cancer. One that is afraid and one that feels vulnerable. And I've found that since I've shared this side of myself I feel more confident and less vulnerable.

I've also noticed a change in my perspectives on and in patient care and in my teaching. I encourage every patient to ask questions, I explain procedures like I've never done before, and I have more patience when someone comes in believing they have something they've just read about on the Internet. I've seen first-hand that patient care is about more than the tests, procedures, following orders, or protocols. It's about a team of professionals working together to address needs that goes beyond the science of the human body but also pays attention to the human inside the body. The human that feels, thinks, emotes, cries, laughs, and feels vulnerable at times.

Although I'm not confident we will eliminate all preventable medical errors, I am teaching my nursing students about the role they have in mitigating them. Just as I had to find my voice, I'm teaching my students to use theirs. I'm teaching them to be conscientious of what they know, how they communicate, to listen to their patients, and how important each of their roles are in patient care. I also teach them not to be afraid to ask questions of each other and of other members of the health-care team. Finally, I teach them to look at the patient as more than a patient with cancer but as a patient first who happens to have cancer.

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1. Institute of Medicine (IOM). To err is human: Building a safer health system. Washington, DC: National Academy Press; 2000.

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