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Empathic sight

Sophia N. Zupanc, в.а. 🔟

Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, MA

Essay/Personal Reflection

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Author for correspondence:

Sophia N. Zupanc, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, 375 Longwood Avenue, Boston, MA 02215, USA. E-mail: sophian_zupanc@dfci.harvard.edu "Is there anything else you'd like me to know about you or your project?"

I was interviewing for the Watson Fellowship, a 1-year grant that funds purposeful, independent exploration outside of the USA. I had just spent the prior hour trying to convince my interviewer to send me, a college senior graduating with a degree in economics, around the world to study palliative and end-of-life care.

By the time that I interviewed for the fellowship, I had experience from a few years of palliative care research and volunteering at a local hospice to draw examples from; yet, what came to mind was a moment during my sophomore year of college when I found myself braced against a bathroom doorway.

I was 19 and in love with someone who had been diagnosed with leukemia. Rather than return home and pause her college education to pursue full-time treatment, she opted to continue carrying a full academic load. She often insisted that she only had cancer on Tuesdays and Thursdays and, crucially, that a cancer day could be canceled if it might cause conflict with the university's college football schedule.

Naively, I never expected that serious illness would touch my life so early.

After a particularly difficult round of chemotherapy, I stood, bracing myself against the bathroom doorway, looking on as she vomited uncontrollably. I was overtaken — uniquely aware of gravity pushing against every inch of my body.

For the first time, I had felt the full weight of my humanity.

When we later spoke of her wishes for care, I wondered if they would be honored. Beyond the personal, existential questions I began to ask, the conversations that she and I had about her illness stuck with me. I worried: Would her clinical team see "only having cancer on Tuesdays and Thursdays" as denial? Could they understand the importance of tailgating that week's football game?

My voice broke as I responded to my interviewer:

"This really matters."

The Watson Foundation believed me. I spent the next year living in Greece, the UK, India, New Zealand, and Colombia investigating the shape and form palliative care took in each place. As a Watson Fellow, I was expressly discouraged from conducting any formal research or affiliating myself too closely to any one organization. In other words, I was to rid my universe of its ordinary ordering forces: grades, due dates, and expectations.

I wasn't always sure what I was looking for, but, halfway through my fellowship, I was frustrated because I felt like I kept seeing the same thing. Certainly, the expectations that guided the experience of and care for serious illness at a refugee camp in Lesvos, during a home visit in the outskirts of New Delhi, or within the walls of the UK's oldest hospice differed, the sum of those differences did not equate to disparate emotions or desires. Rather, their sum was something obvious, that we all generally want the same things: to love, to be loved, to feel valued, and to be free of pain. Our needs and desires are more a function of our humanity than our homeland.

When frustrated, I'd ask myself, "Did it really take a trip around the world for me to realize that we all just want to be loved and valued?" But, upon reflection, I realized that there was an even more interesting question nested within that seemingly obvious realization: What about this trip had changed my gaze?

I often feared that my project was voyeuristic. If illness reveals our vulnerability and frailty, then the clinical encounter with a seriously ill individual puts them center stage. If I had no role to play — was not a clinician, researcher, or even somebody that understood the language being spoken around me — how was I to be a just member of the audience?

I decided that I would do the only thing that I could do: be present.

Unbeknownst to me, my lack of a role, what had permeated my fear of being voyeuristic, is what allowed for the shift in my view. Rather than witnessing clinical encounters as an aspiring physician or member of a research team, I was viewing them only from the seat of my humanity.

Without an agenda, my sight could be wholly and simply empathic.

And still, I struggled: As a physician, won't I always be entering into clinical situations with the goal of using my role to provide care for the other?

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As I begin the long process of applying to medical school, I worry that the price I will pay for the privilege of a white coat and a stethoscope is a clouding of the empathic sight I experienced during my Watson year. The medical gaze — the ability to recognize signs and symptoms of disease upon inspection — is instrumental to the practice of doctoring but often translates patient narratives directly into biomedical knowledge. In other words, it allows one to be the other's physician but does not guarantee that they are present for the other.

At its best, clinical communication makes deliberate efforts to educate and involve the patient in their care, fostering empathic sight within the context of the medical gaze. However, what is truly shared during a medical encounter is disproportionally a function of the clinician's capacity to value a patient's narrative than the patient's ability to articulate or express it.

And yet, what is always shared during a clinical encounter is the space that exists between two individuals — a space in which one, the patient, puts themself on display to seek understanding and interpretation by the other, the clinician.

Moments in which I was present during my Watson year made me keenly aware of the power of this shared space. For instance, while I was shadowing a home-based palliative care team in Kerala, one of India's southernmost states, we entered the home of a woman with a stomach tumor so large that my untrained eye initially mistook her as pregnant. I couldn't understand any of what was being said as the doctors and nurses rushed around me speaking rapid Malayalam, but I didn't need to in order to sense the woman's distress. All I could do was think "I am here with you," then do my best to allow every part of myself to be in those moments with her.

I felt tears welling.

I didn't allow myself to cry, only to meet her eyes as we left while offering a soft smile and a small nod, both of which she graciously returned.

Like the moment braced against the bathroom doorway, the moment that the woman and I shared is one I often revisit. Though my role in those two situations was entirely different — in the former I was a partner and caregiver; in the latter, I was an observer — there was a quality that was similar.

What mattered most in both moments was not making any sort of tangible difference, but rather bringing the qualities afforded by empathic sight into them — embracing the pain, tragedy, and joy that comes with our shared human condition; being unafraid to touch another with my humanity and to allow myself to be touched by theirs.

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