

## Subjective Experience and Medical Practice

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Careful attention to patient experience is often neglected in contemporary medicine. For the doctors who care for patients, the patient's experience is often understood as, at best, a story that points them to the truth of an illness or as, at worst, a set of propositions about a state of affairs experienced by one person and potentially false. Of course, the best physicians will take the description of that state of affairs as a true account. Yet even for the best among us, that account is quickly subsumed under the heading "HPI" in the admission History and Physical or under the heading of "subjective" in the daily SOAP note. And as any physician knows, "subjective" is a term of equivocation: what falls under the "subjective" account may or may not be true.

Still, any good clinician knows that the vast majority of diagnoses are made in the story told by the patient or rather in the history taken by the physician; for surely, the history is already a translation or interpretation of sorts, and like all histories, the medical history is told with a purpose that I, as the physician, have in making a diagnosis.

In the story that has been reconstituted as a history, I, as a physician, understand that the patient's story is filtered through a set of cultural meanings. Or perhaps better, I understand that the patient experience, say of pain, is always already experienced in a cultural idiom. Hopefully, it is a cultural idiom of which I am aware; for only then can a proper translation and interpretation occur. Still, it is almost as if the cultural significance is lost in translation. Moreover, since all experience is always already in a cultural idiom, to some extent, the experience itself drops out and is distilled into a supposedly acultural anatomic or physiological "truth" by the interpretive activity of the physician. The medical belief structure is that this new reconstituted "truth" is not just subjective, but something that can be triangulated through the physical exam and other forms of testing, something that is real in the world, something that I can get my head around, or my hands on; something that is the source of the patient's distress that I can manipulate for the good of the patient.

Yet, something is always lost in each act of translation from patient experience in a cultural idiom to the supposedly acultural “truth” about a set of affairs in the mind-independent world. This issue of the *Journal of Medicine and Philosophy* is devoted to those aspects of patient experience that are lost in the act of interpretation that is medical practice. Much is lost, as the essays in this issue show us. From experiences of dying in different cultures to experiences of pain and the need for compassion, to experiences of time in depression, to experiences of identity after transplantation, to experiences of wholeness when illness makes itself known, these essays ask those of us who practice to pause and to carefully attune to what is lost in patient experience.

In her essay, “Bioethics, Cultural Differences and the Problem of Moral Disagreements in End of Life Care,” Megan-Jane Johnstone analyzes what has become a problem in recent years (Johnstone, 2012). Doctors and nurses, like patients, are culture-bound creatures. Given the cultural plurality that presently exists, it is not uncommon to see differences appear, especially as patients are dying. Surely dying is an intensely personal and culturally bound experience. Johnstone notes that, even with a strong emphasis placed both on policy resources and on patient-centered care, there are still many harmful moral outcomes in end-of-life care. Drawing on the work of Ernest Becker, as well as work by Greenberg, Pyszcznski, and Solomon, Johnstone suggests that, in part, culture arises out of the fear and anxiety that humans face in death. And when faced with death, people tend to turn to their culturally bound practices. Thus, in a morally pluralistic society, it is not uncommon for people to find themselves facing a culture of medicine that is not aware of the significance of culture in their experience of dying. Johnstone concludes that, with more careful attunement to the experiences of the dying, which are necessarily experienced through cultural symbols and meanings, practitioners might be able to avoid harms and be able to support patients through this final experience.

Like one’s dying, pain is also an entirely personal and subjective experience. Laura W. Ekstrom’s essay, “Liars, Medicine, and Compassion,” explores the problem of pain and how compassion, rightly understood, might help to bridge the gap between patient experience and the medical model of pain (Ekstrom, 2012). Traditionally, we doctors are taught to search for a cause of pain. When a cause is found, then the inciting cause is to be removed. However, for many people in pain, no easily identified cause emerges. There is no “thing,” no clear cause that is triangulated through examination or through further testing. There is “nothing” there to treat, except the subjective experience of pain. Now, every doctor has a story of being burned by a patient, who was caught selling their prescription pain killers on the street or taking too much of their medication. These experiences of having been “burned” by a patient, combined with the fact that “nothing” is found on “objective” examination, can result in an insidious mistrust of people in pain. Of course,

the experience of being called a liar by one's doctor likely only heightens one's experience of pain. There is then a gulf, perhaps no more clearly perceived than when one is in pain, between the one who experiences pain and the person judging whether the experience warrants treatment.

Ekstrom understands compassion to be a means by which that gap can be negotiated between the person in pain and the practitioner. She argues for what she calls the Rousseauian Account of Compassion; it states: "Compassion is a painful feeling occasioned at the awareness or recognition of someone else's suffering or misfortune that triggers action aimed at alleviating the suffering" (Ekstrom, 2012). In other words, one might feel the pain of another, only differently so, and this negative experience calls one to act on behalf of the other.<sup>1</sup> Put differently, yet again, compassion is to feel the pain of another and to work diligently to alleviate it as best as one can. Ekstrom concludes: "One cannot be conscious of another's distress and moved to help alleviate it—the hallmarks of compassion—without first believing in the distress, taking the patient at her word in her description of her problem, and without having the humility that prevents one from assuming that one can discern the answers to unasked relevant questions by a glance" (Ekstrom, 2012). In addition to a few structural recommendations, Ekstrom notes that a tincture of humility and trust and a goal-directed compassion would go a long way to bridging the gap between subjective experience of the patient and the call to respond to that experience by the practitioner.

In a fascinating essay on the experience of time in depression, Matthew Ratcliffe turns our attention to a different dimension of patient experience. Ratcliffe calls his essay "Varieties of Temporal Experience in Depression" because there are a variety of experiences of time in depression (Ratcliffe, 2012). Ratcliffe offers us a careful and engaging description of how time has been differently experienced by those who have suffered depression. Some describe time as standing still or as moving slowly. Others describe it as speeding toward catastrophe. In addition, Ratcliffe unpacks the way that the past, the present, and the future are experienced in depression. Yet most fascinating are his conclusions. Although there have been an explosion of different drugs used to treat depression, we really know next to nothing about depression. For instance, one could imagine that today's treatments focused on Selective Serotonin Reuptake Inhibitors may only be directed at the final common pathway of a myriad of different mechanisms for depression. Ratcliffe, pointing to the different experiences of patients, suggests that perhaps the term "major depression" is really just a general category for what may turn out to be different conditions with one condition resulting in a patient experiencing time as standing still and another condition resulting in another patient experiencing time as rushing toward the abyss. In other words, might a more careful phenomenological exploration of temporal experiences in depression uncover something new about the physiology of depression?

Fredrik Svenaeus explores a different avenue of human experience, namely personal identity after transplantation. Unpacking the way that kidney, heart, hand, and face transplants differently reconstitute identity, Svenaeus carefully describes three layers of selfhood affected by transplantation: embodied selfhood, self-reflection, and social narrative identity. Organ transplantation presents a rather stark process of alienation, for something foreign is introduced to the body. That foreign introduction is experienced differently. A kidney is hidden away and might only affect notions of embodied selfhood, whereas a heart, which is also a hidden organ affects different dimensions because it is also felt beating in one's chest and also because the heart carries a cultural significance that kidneys do not. A hand, although not absolutely necessarily integral to living, is in a way more integral to self-identity than a heart or kidney. The hand is at the surface and represents the self to the world and the world to the self, especially through its instrumental interacting with the world.

Yet, a face transplant represents a more robust challenge to self-identity. The face is that by which we are most identified. How does one's self-image change after facial transplant? How does one's experience of oneself change in face transplant? Even while face transplants do not result in taking on the identity of the face donor, as technological and immunological modulation improve, one could come to look very much like the donor. With face transplants, one's interpersonal identity is reconstituted. Svenaeus notes: "Facial identity does not depend mainly on how my face feels 'from the inside', so to speak; it is expressed by our outer appearance in the relationships we form with others" (Svenaeus, 2012). In this sense, Svenaeus can claim, we are our faces more than we are our brains when it comes to social interactive and narrative construal of identity and self-experience.

Finally, Havi Carel, speaking from her own experience as a patient, reminds us of the importance of the first person experience of illness.<sup>2</sup> In modern medicine that experience is often rapidly transformed and reconstituted medically, marginalizing the patient from him- or herself. Carel proposes a toolkit to help remedy this problem. In her essay "Philosophy as a Resource for Patients: A Phenomenological Proposal" (Carel, 2012), Carel proposes a new form of therapy for patients. Where there is social psychology and social work, as well as psychotherapy, Carel holds that there is something to be said for a phenomenological tool kit for patients. She argues, after giving a philosophical argument for a phenomenological tool kit, that a workshop and tool kit that trains people to engage in phenomenological reflection might allow patients to reflect on and expand their understanding of their illnesses, offering existential help. Carel, drawing from Merleau-Ponty's seminal work, describes a workshop that she and other colleagues are planning to offer to patients. Carel's hope is that by presenting illness as a limit case of embodied existence, patients will not only gain deeper insights into their illnesses but also into embodiment and into the experience of illness as part of being human.

Each of the essays in this issue of *Journal of Medicine and Philosophy* brings into relief the centrality of subjective, first-person experience. Not only does it give insight into living and dying well but also into the way in which pain is experienced and understood differently if pain is to be treated. Subjective experience of self might bring insight into personal identity in the experience of those who have undergone transplantation, which presents an extreme case of self-alienation. Subjective experience of time might even be able to bring into relief different understandings about the mechanisms operative in depression. Subjective experience is also essential to all experience of illness and might even be essential to living well in the face of disease. On the one hand, my subjective experience is mine alone. It is essential to my existence, to my self-knowledge. On the other hand, my subjective experience is a point of entry into conversation and dialogue with others in the intersubjective dialogue that is constitutive of self-identity. Subjective experience is essential to the human condition, not only because it will allow doctors to gain insight into diagnosis and treatment but also because we are the kind of animals that both construct and are constructed by those experiences. We are the animals that both produce and are produced by human experience.

#### NOTES

1. Ekstrom's characterization seems similar to what I have argued elsewhere. See chapter 10 of *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying* (Notre Dame, IN: University of Notre Dame Press, 2011).
2. For an account of Carel's experience of illness, see her book, *Illness: The Cry of the Flesh* (Durham, UK: Acumen, 2008).

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