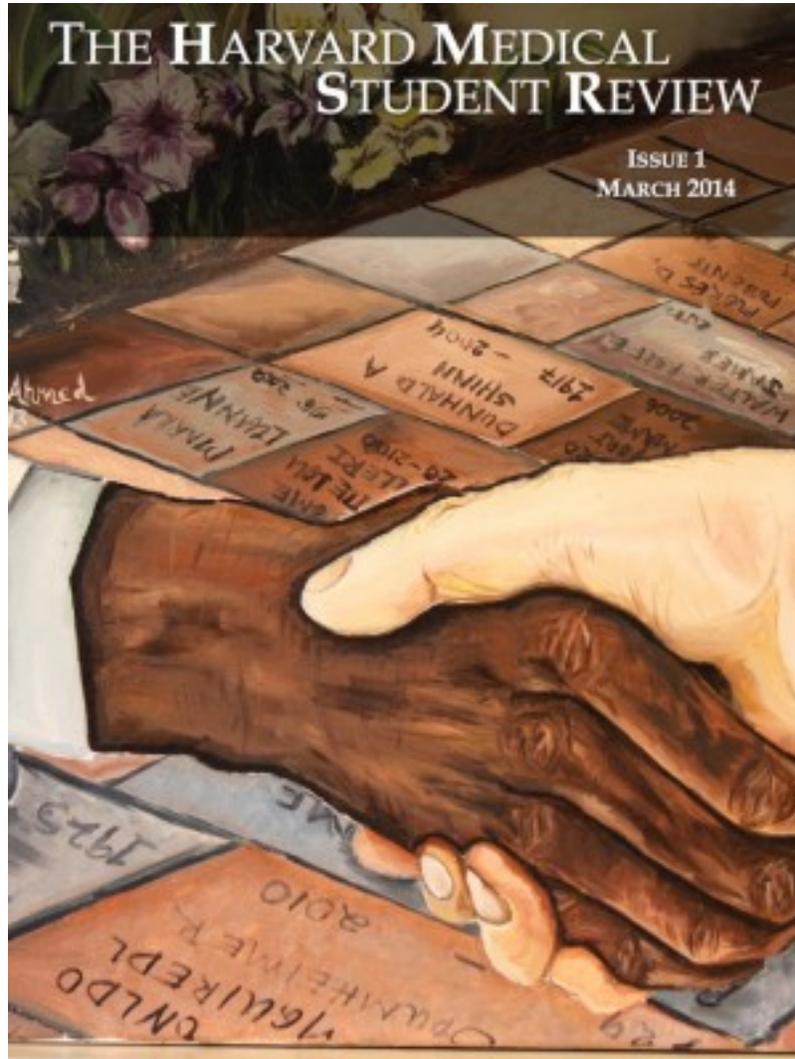


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Redefining Suffering and Illness

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Introduction

In order to nuance and reframe dialogues around healthcare, I introduce and define fundamental terms and

concepts with the aid of anthropological and sociological literature, modifying and updating them as reason, need, and humanity require. I establish *suffering* as the experience of threat or damage to *personhood*, with *illness* as its manifestation. I then describe and distinguish two ways of attempting to manage *health*: *caregiving*, a moral exchange that sustains personhood for both provider and receiver; and *biomedicine*, an interpretive system that seeks mainly to govern pathophysiological *disease*. I briefly apply these concepts to highlight shortcomings within the current focus of the medical profession, and I invite continued engagement with these terms in order to bring closer to lived-experience our conceptualization of what is at stake.

Suffering and Personhood

The condition of suffering is universally familiar as something experienced both directly and empathically. Nonetheless, it can be a difficult concept to circumscribe; for example, it certainly applies to experiences beyond pain, and not all pain is suffering. We have long sought to concretize our intuition and management of suffering through systems as seemingly disparate as Buddhism and anesthesiology, and it occupies a fundamental role in our senses of living, purpose, and morality. Eric Cassell thoughtfully provides a definition of *suffering* that I find rigorous and robust, and I will adopt it in my discussion.

Most generally, suffering can be defined as the state of severe distress associated with events that threaten the intactness of person. [1]

Some might accuse this definition of circularity if they equate the concepts of distress and suffering, but *distress* is a set of bodily events that we observe and can attempt to measure (e.g. tachycardia, tachypnea, endocrine and neurocrine shifts, electroencephalic re-patterning) while *suffering* relies upon subjectivity. “Suffering is an affliction of the *person*, not the body.” [1]

To strengthen this distinction and provide the definition with utility, we require an elaboration of *personhood*. Cassell anticipates this requirement with the provision of a “simplified description of the person” that enumerates and explains what he argues to be requisite components.

A person has a past...

A person has a family...

A person has a cultural background...

A person has roles...

A person has a relationship with himself or herself...

A person is a political being...

Persons do things...

Persons are often, to one degree or another, unaware of much that happens to them and why...

Persons have regular behaviors...

Every person has a body...

Everyone has a secret life...

Every person has a perceived future...

Everyone has a transcendent dimension—a life of the spirit, however expressed or known. [1]

This operational definition is useful and largely correct. For example, pain (which we intuit must at least sometimes be a type of suffering) can be understood as suffering inasmuch as it responds to threats against the individual body and against the potential for agency in the future; grieving the loss of a loved one can be understood as suffering inasmuch as it represents response to fractures of family, network, and social role.

However, as Cassell himself notes, this definition only as a simplifying, general model. It has likely exceptions, and I do not argue that every criterion above need be satisfied in every case for personhood to be understood. For example, consider how this definition would apply to mentally- and physically-disabled individuals, who may experience severe lifelong limitations in agency, political activity, cultural engagement, expression of subjectivity, and so on, but who still occupy important positions in families and communities. For many, if not all, the prevailing intuition is that these individuals are still persons, and so an even more comprehensive crystallization of personhood remains to be crafted.

Health, Illness, and Disease

Next, I define the concepts of *health*, *illness*, and *disease*. The World Health Organization stands by a rather grandiose definition of health that it drafted in 1946:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. [2]

I have heard it said in jest that this state is only achieved during orgasm; in all seriousness, it is difficult to imagine that very many people ever achieve it for very long. Indeed, this definition is operationally inaccessible. Health can be better understood as a state in which personhood is relatively stable, a state in which illness is minimized. Arthur Kleinman, Leon Eisenberg, and Byron Good defined the concept of illness that I borrow from and expand, and they contrasted it with the concept of disease:

...disease in the Western medical paradigm is malfunctioning or maladaptation of biologic and psychophysiologic processes in the individual; whereas illness represents personal, interpersonal, and cultural reactions to disease or discomfort. [3]

This distinction has held sway in recent discourse around health and suffering, for it does formalize a dichotomy that is intuitively accessible within American culture. Disease is a biomedical, pathophysiologic concept dressed with jargon and redressed institutionally, while illness, like suffering, is concerned with subjectivity, intersubjectivity, and personhood. This definition, however, is problematic because it suggests that disease is ontologically prior to illness; that is, it implies that biomedical diseases are objective and factual, rather than the fluctuating cultural models and in-group interpretations that they are. Thus, while these two terms can be very useful within their cultures of origin, I propose that *illness* be redefined in the following way for greater robustness and broader utility:

Illness represents the personal and interpersonal manifestations of and responses to *suffering*.

This modification allows for applicability outside of the cultures that spawned the original illness/disease distinction (if personhood can still be agreed upon), and it is consistent with the first definition of health I proposed.

This conceptualization is validated by my own experiences with patients, whose experiences with suffering ought to be trusted as a primary source in such a discussion as this. I have sometimes heard those with chronic or congenital diseases describe themselves as healthy – not ill, diseased, or sick – because they had come to reconcile their identities with their disease states, thus refortifying their personhoods. They may live with chronic aches or functional deficits, or they may know that their lifespans will be cut short, but it is possible for their senses of self and integration to remain or re-emerge intact and healthy.

Conversely, this conceptualization would label those in mourning, for example, as “ill” or “unhealthy.” This may seem inappropriate or even offensive, but only inasmuch as illness and health are held categorically to be medical concepts. I suggest that it is culture-bound and myopic to believe that experiences and states of suffering must be wed to the biomedical model; even the WHO definition of *health* explicitly requires social well-being, though unfortunately this often falls outside the realm of medicine as typically practiced. It is both rigorous and practical to recognize the epistemological priority of *suffering* and, concordantly, to grant it more linguistic referentiality than *disease*. This can be achieved by redefining our normative terminology with respect to it, as I have done here.

Caregiving

There are two dominant approaches for managing *suffering*, *personhood*, *health*, *illness*, and *disease*; they are *caregiving* and *biomedicine*. Caregiving is an intersubjective, reciprocal exchange between a caregiver and a sufferer that maintains personhood for both. It is one of Kleinman’s primary concerns, and he has explicated it in several ways in some of his Perspectives in *The Lancet*. In one, he offers a slightly culture-bound, operational definition:

Caregivers protect the vulnerable and dependent. To use the experience-distorting technical language: they offer cognitive, behavioural, and emotional support [4].

While he bemoans the distortions in this terminology, the definition is familiar, for it recalls the functions we as Americans might perform or be told to perform when friends or family are suffering. With this familiarity invoked, Kleinman abstracts and generalizes the concept of caregiving, emphasizing its phenomenological foundation:

But, to use the close experiential language of actually doing it, caregiving is also a defining moral practice. It is a practice of empathic imagination, responsibility, witnessing, and solidarity with those in great need. It is a moral practice that makes caregivers, and at times even the care-receivers, more present and thereby fully human [4].

He also describes the intersubjective activities of caregiving more explicitly:

The person receiving care shares her experience and story as a gift with the caregiver, in reciprocation for the practical things that need doing along with a sensibility akin to love. What is exchanged is the moral responsibility, emotional sensibility, and social capital of the relationship. The exchange changes the subjectivity of both the caregiver and the person receiving care [5].

These definitions recall Cassell's personhood, and we can see in them how caregiving attends to many of its elements to allay threats thereto. The caregiver provides a physically and figuratively safe space through "empathic imagination", "witnessing", and "solidarity." This allows the sufferer to share and to come to terms with changing understandings of body, spirit, past, present, and future. Interpersonal roles and identities for both the caregiver and sufferer evolve, and agency is redefined and reestablished in the sufferer. "Responsibility" in this endeavor lies in the management of interpersonal politics and "social capital", which are disequilibrated when the suffering are distinguished from the well. These are only some of the ways in which caregiving can be understood as therapy and management of personhood, and so it is easy to see why Kleinman argues that the practice can make both parties more "fully human."

Drawing in part from Kleinman's discussions, it is possible to distill several features that further characterize caregiving; as a practice, it is idiosyncratic, dynamic, uncertain, committed, and reciprocal. By idiosyncratic, I mean that caregiving is entirely dependent on the relationship between the provider and sufferer; it is necessarily contingent upon culture, relationship, and personal history, and so in some respects it is fundamentally individualized and unsystematizable. By dynamic, I mean that caregiving must be responsive to the evolutions of both the sufferer and the provider through the course of illness. Thus, prognoses will necessarily be uncertain, and many questions may remain unanswered; ideal caregiving can only ever assure the outcome that the sufferer's personhood will not have been neglected. Given this uncertainty, caregivers must remain committed to their healing endeavors because failures of caregiving result in insult to the personhoods of both parties and, thus, increase suffering. This emphasizes the reciprocal nature of caregiving, as the provider is fulfilling a critical and fundamental human role for herself/himself at the same time that she/he is accompanying the suffering. Idiosyncratic, dynamic, uncertain, committed, and reciprocal: caregiving is the quintessence of our partaking in and of our service to humanity in a world of suffering.

Biomedicine

Biomedicine does not operate solely at the level of interpersonal practice like caregiving, but, as Good describes, it is a "culture" and a system of "symbolic formation" with "organizing activities." That is to say, it "formulates the human body and disease in a culturally distinctive fashion" whereby participants "construct sick persons as patients, perceived, analyzed, and presented as appropriate for medical treatment." While biomedicine is often touted as an endeavor to relieve suffering, it specifically holds diagnosis and treatment of pathophysiological disease as paramount, and it is founded upon a "devotion to maintaining *biological* life." The theoretical underpinning of this focus is the belief that "ultimacy resides in depth, downward to the levels that generate surface phenomena"; "experiential or behavioral matters ... are matters separate from the real object of medicine. The fundamental reality is human biology." [6]

As Good describes biomedicine, he states that "this means of interpreting reality is both powerful, illuminating

many disease phenomena and providing the basis for therapeutics, and at the same time profoundly ideological and often misleading.” [6] That biomedicine sometimes has incredible healing utility is undeniable inasmuch as diagnostic and therapeutic technologies can at times alleviate both disease and suffering. The ways in which biomedicine can be misleading are several, and they stem from its epistemological architecture – that is, its reliance upon science as the method of discerning fundamental, truthful knowledge of reality. For example, it is a common belief that *“the promise of scientific medicine is that the knowledge does the work.”* [1] Cassell elaborates that this implicit belief underlies the movement towards patient empowerment and also the willingness to allow interns to treat patients as frequently as (if not more often than) attending physicians do. While these two consequences are not manifestly problematic, discontinuity of care and devaluation of the therapeutic alliance are. Exalting science without valuing the power of intersubjective care in the relief of suffering is hypocritical, and I believe it to be a failure of humanity.

Another epistemic error underlies the increasing fetishization of technology. I have already argued that uncertainty is a necessity in caregiving, yet it has long been considered one of the thorns in the side of biomedicine. As early as the 1950s, ethnography of medical students cheerily dubbed it “idealism” that “many students... hoped never to treat a patient without first establishing a diagnosis” since “any clunk can carry out the treatment once you know what the trouble is.” [7] And as recently as July 2013, physician-author Chris Adrian explained his failure to become a hospital chaplain in this way: “As a physician I don’t believe that what we do as technicians of illness and health ultimately means anything unless it succeeds.” [8] As Cassell simply states, “uncertainty is intolerable” [1] to many physicians, so their historical pattern has been the zealous adoption of novel technologies – “machines, instruments, drug treatments” – that have accompanied continuing scientific discovery. They use them to “oversimplify the inherently complex and produce certainty where doubt is necessarily present.” [1] This pattern has progressed into a dependency that has reshaped our pathways of care, resulting in profound but unspoken institutional fetishization. Concomitantly, the norm in episodes of suffering is over-treatment of users, rather than individualized, dynamic, and uncertain care of persons.

Applying the Terms in a Discussion of Medical Education

There should be no wonder that dissatisfaction and calls for reform abound when the hegemonic hermeneutic of suffering systematically fails its proclaimed mission, as it minimizes subjectivity and humanity. The inculcation of this hermeneutic is one of the functions of graduate medical education. Byron Good provides an ethnographic analysis of Harvard Medical School students [6] that rigorously details the reconstruction of medical student lifeworlds.^a The humanistic inclinations of medical students, the desires to engage in the moral experience of caregiving, are indefinitely suppressed as they are forced to handle patients uniformly, rigidly, definitively, transiently, and unidirectionally. The impetus to return caregiving to medicine on individual or institutional scales is denied a safe space for expression and it is all but extinguished as the framework of biomedicine perpetuates itself. Kleinman describes this phenomenon as well.

Absent a moral sensibility of what clinical work should be in a world of divided and hidden values, idealistic students are remade as cynics, much like the residents and attendings they emulate. And I also

think this is why there is increasing suspicion and distrust among the public of what physicians and policy experts really value in health system reform. That is, self-interest in career advancement, efficiency, cost control, and profits are suspected to lie behind words about quality of care as the not so disguised, hypocritical primary values of health-care professionals. [9]

However, he holds out hope for biomedicine as he describes a way that physicians could better resolve this inner conflict.

The pedagogy for engaging hidden values and divided selves is the moral building of the clinician as a fully developed human being. Such pedagogy uses the humanities not to educate students to be social scientists, humanists, or ethicists, but instead to cultivate and develop a deeper, richer, and more receptive sensibility: critical, aesthetically alert, and morally responsive. It is this sensibility that animates and is animated by the everyday practice of caregiving... [9]

There are glimmers of hope that Kleinman's wishes may come to fruition. The Medical College Admissions Test in 2015 will include a section called "Psychological, Social, and Biological Foundations of Behavior" that will require all American pre-medical students to prepare for their medical careers in new ways. Graduate medical courses in social medicine are becoming more common and better liked, as are courses concerned with meditation, therapeutic touch, and longitudinal care. At the same time, Dr. Hunter "Patch" Adams (famous for the eponymous 1998 Hollywood film starring Robin Williams) and his Gesundheit! Institute have been advocating fiercely but unsuccessfully for more than 40 years that our nation redesign its structures in a more person-centered manner. As a second-year medical student myself, with only a few weeks separating me from the wards, I am grateful and impressed that I have been taught to have as much awareness as I have of the issues I address here. At the same time, I am curious to see how and why I will succeed and fail to give meaningful care as my training continues.

Conclusion

I have attempted to clarify central elements relating to healthcare, not as a political problem but as a philosophical entity. I presented health and illness as conditions related first and foremost to personhood, elevating them beyond the purviews of biomedicine and disease alone. Concordantly, I introduced caregiving as the maintenance activity of personhood, which functions to alleviate suffering. With these terms in place, I applied them briefly in a discussion of medical education to give new critical language to the uneasiness and dissatisfaction a number of individuals in training and in the field bear.

I understand the ambition of my definitions and welcome critical discourse as much as further application of these terms. My greatest concern is that, as political discussions and fiscal debates revolve in their perpetual ebb and flow, the humanity that we ought to aspire to is forgotten. It is of the utmost importance, then, that we approach purpose and action – within healthcare and beyond it in our lives – without forgetting the ideal breadth of our concerns or the ideal humanity of our activities.

Endnote

^a 'Lifeworlds' are the specific sets of epistemological referents, values, and practices implicitly accepted and shared amongst groups of individuals (ie. Heideggerian referential totalities). One could less precisely explain that one's lifeworld consists of all the things one takes for granted as normal.

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