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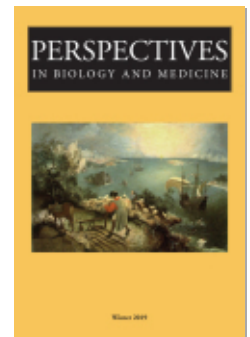
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Cassell Should Not Have the Last Word

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# WHAT WE MEAN WHEN WE TALK ABOUT SUFFERING—AND WHY ERIC CASSELL SHOULD NOT HAVE THE LAST WORD

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TYLER TATE\* AND ROBERT PEARLMAN†

**ABSTRACT** This paper analyzes the phenomenon of suffering and its relationship to medical practice by focusing on the paradigmatic work of Eric Cassell. First, it explains Cassell’s influential model of suffering. Second, it surveys various critiques of Cassell. Next it outlines the authors’ concerns with Cassell’s model: it is aggressive, obscure, and fails to capture important features of the suffering experience. Finally, the authors propose a conceptual framework to help clarify the distinctive nature of subjective patient suffering. This framework contains two necessary conditions: (1) a loss of a person’s sense of self, and (2) a negative affective experience. The authors suggest how this framework can be used in the medical encounter to promote clinician-patient communication and the relief of suffering.

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MARIE WAS 15 WHEN HER ABDOMINAL PAIN BEGAN. After two years of negative work-ups, countless visits to gastroenterologists, and over 70 days of high school missed, she found herself readmitted to the hospital. “Refractory abdominal pain” was her ostensible diagnosis; “troubled teen” who was “going to be difficult” was embedded in the emergency department’s (ED) sign-out. When the medical team arrived to meet Marie, she was huddled in the corner of her hospital bed, silent and withdrawn. Her intern noted the numerous scars cutting across her forearms as she felt for her radial pulses. Marie squirmed in pain when the intern palpated her abdomen.

The ED’s work-up had been negative for abdominal pathology. When the attending physician sat down beside Marie to recapitulate the negative work-up, Marie cut him off and snapped, “I get it. I GET it. There’s nothing wrong with me. And you’re just another doctor who’s going to remind me of that. Gabapentin doesn’t work. Nothing works. No one understands what this is like. I don’t even care about the pain! Can someone just give me my life back?”

The attending tried to respond—but Marie knew he didn’t understand. So she rolled over in her bed, pushed in her iPhone earbuds, and retreated from the world.

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What is suffering? What is its relationship to medicine? These are not easy questions. It is uncontroversial to claim that the alleviation of suffering is central to the goals of medicine. Yet while many of medicine’s actions are grounded in a desire to decrease suffering, the nature of suffering remains vague and difficult to articulate. This difficulty is exposed in Marie’s case. Although the physicians are moved by compassion and a desire to help Marie, they are separated from her suffering. Suffering is an intimate experience, and the sufferer is often isolated from her surroundings and peers. This separation can make caring for suffering patients extremely challenging. It can also lead to frustration and withdrawal, an experience described by Anthony Back and colleagues (2015) as “hypo-engagement,” which is associated with clinician apathy and feelings of helplessness. However, the challenge of suffering should not prevent clinicians or caretakers from attempting to bridge this gulf.

The purpose of this paper is to analyze the phenomenon of suffering and its relationship to medical practice. To do so, we will focus on the paradigmatic work of Eric Cassell. First, we will explain Cassell’s influential model of suffering. Second, in order for the reader to locate themselves within the current dialectic, we will survey various critiques of Cassell. Then we will describe our own concerns with Cassell’s model: it is aggressive, obscure, and fails to capture important features of the suffering experience. Next, we will propose a conceptual framework to help clarify the distinctive nature of subjective patient suffering.

This framework contains two necessary conditions: (1) a loss of a person's sense of self, and (2) a negative affective experience. Finally, we will suggest how this framework can be used in the medical encounter to promote clinician-patient communication and the relief suffering.

### **ERIC CASSELL AND THE EXPERIENCE OF SUFFERING**

The medical scholarship on suffering is deeply influenced by the work of physician Eric Cassell. Cassell (2004) defines suffering as “the state of severe distress associated with events that threaten the intactness of the person” (32). For Cassell, a *person* is an intricate composite of past experiences, future hopes, roles, duties, relationships, and sociocultural and political norms, and only *persons* can suffer. Cassell's suffering can have a variety of causes, such as pain, humiliation, diagnostic uncertainty, constrained perceptions of the future, or the actions of the physician, and it can occur with either the threat of injury or the actual injury of a person's intactness or integrity (Cassell 1991).

Regardless of its source, Cassell views suffering as an essentially subjective experience. In *The Nature of Suffering and the Goals of Medicine* (2004), Cassell argues that suffering is subjective because its presence, absence, or magnitude are contingent upon meaning—namely, what a thing (such as chest pain) signifies for the subject, and its degree of personal importance. For Cassell, the content and emotional valence of all first-person experience is determined by the way a person interprets and labels an event or phenomena, or assigns it a meaning. Meaning is generated through a personalized lens—a lens crafted over time from specific physical, genetic, cultural, religious, and relational experiences. Hence, two people with the same symptoms can experience illness and suffering in remarkably different ways.

As a symptom continues or worsens and the illness experience broadens to affect more and more aspects of the person, an injury develops and subsequently deepens. The global state of distress associated with this injury constitutes a person's suffering. Cassell argues that suffering can grow until it becomes primary and “looms larger than the actual physical symptom, disease, or life situation that produced the suffering” (274). An individual's suffering can corrode all parts of their person by damaging friendships, frustrating desires, or stealing their sense of purpose. Because all subjectively significant parts of human life are enmeshed with meaning, and suffering damages the meaning-generating lens of the individual (in other words, all the things that make them a *person*), suffering can paradoxically render a person incapable of being the very person that they are.

### **SURVEYING CRITIQUES OF ERIC CASSELL**

Over the last few decades, Cassell's model has become close to canonical and has been an important resource for clinicians trying to resist the depersonalizing

and reductionist “Baconian” project of medicine (McKenny 1997). It is clearly powerful and erudite. Yet, Cassell’s model has several problems. These problems fall generally into one of two categories: (1) problems internal to his subjectivist account, and (2) problems with his dismissal of objective suffering. We offer a few salient examples.

Within the first category, Cassell’s model is seen as being overly stringent. This concern is voiced by Stephen Edwards (2003). Edwards accurately takes Cassell’s position to include a necessary condition that the intactness of a person must actually be threatened or injured (neither Cassell nor Edwards seem to distinguish between the two) if an experience is to count as suffering. However, Edwards is convinced that a person need not lose their intactness to be suffering and pleads his case by rhetorically asking the reader why a person home with the flu, who knows they will recover, cannot be suffering. For Edwards then, Cassell’s bar is simply too high, and his argument hangs on the reader’s intuition that he is correct—an intuition we do not share. Another worry with Cassell’s notion of intactness comes from Noelia Bueno-Gómez (2017), who argues convincingly that Cassell’s model is unduly “essentialist” in that it presupposes a “normative definition” of the self that has been disproven by Freudian psychoanalysis and post-structuralist thought (5–6).

Lastly, Jeffrey Bishop (2011) demonstrates how Cassell’s model inadvertently smuggles in and underwrites a mind-body dualism. For Bishop, this dualism originates when Cassell severs the person from their body by claiming that “bodies do not suffer, persons suffer,” and “[e]very person *has* a body” (295). Then, by fixing the capacity for meaning-making to the “person,” and disease to the biological body, Cassell ironically dissolves the holism he is so intent on maintaining. Bishop uses a phenomenological approach to show that human suffering is inseparable from human embodiment and the embodied projects that constitute a meaningful life. Bishop ultimately calls for “listening” and for allowing oneself to be “moved by the suffering of the other” (304). This he distinguishes from Cassell’s antidote for suffering, namely, the re-narration of the patient’s experience which can transform “suffering into meaning” (297). For Bishop however, Cassell’s “transformation” represents a form of biological reductionism and biopolitical control and invites powerful clinicians and policymakers to manipulate patient’s stories for their own ends.

Category two problems are of a different nature. Here, because Cassell denies any objective dimensions to suffering, he is susceptible to the important critique of Stan van Hooft (1998), who argues that suffering simply *is* the objective frustration of human flourishing. Van Hooft claims that Cassell cannot account for the suffering of someone lacking insight into their own experience (for example, a child in an exploitive sexual relationship whose trauma is normalized by the perpetrator). This claim also overlaps with a religious perspective of human life, which, as a crucial point, is the perspective of many patients in the United States

and worldwide. For at least the three major monotheistic religions, Islam, Judaism, and Christianity, all of which have been influenced by Aristotle's teleology, you cannot give a full account of human suffering without an objective teleology—in other words, the idea that human life is best understood in reference to a species-specific end, goal, or purpose, and therefore has standards of flourishing that are independent of the individual's subjective determination.

A rich description of this view is outlined by Eleonore Stump (2010), who understands suffering as that which either undermines flourishing or deprives a person of the desires of her heart (or both). Stump begins the work of separating suffering into subjective and objective domains, a distinction we favor for several reasons. For one, it is more consistent with ordinary language use. In addition, it supports the intuition that individuals are not always the best judges of the degree to which they are suffering. Following this intuition, we do not think that a “happy” child in a sexually abusive relationship, a “happy” drug addict affording heroin through prostitution, or a “happy” billionaire driven on by greed and recognition yet seldom seeing his family are not suffering in important ways, even if they deny it.

Because of his resistance to any objective view, Cassell is forced to make other bold claims. For instance, in *The Nature of Healing* (2013), he argues that infants and people with severe dementia or brain injury cannot suffer because they do not have a sense of the future and cannot attach meaning to their experiences. It follows then that Cassell's definition of suffering is quite narrow, contradictory to much of normal language use and intuition, and exclusive to linguistically competent beings with high degrees of agency—those patients who can articulate and actualize their emotional, intellectual, and physical intentions—which, incidentally, reflects the population of patients that Cassell treated as an internist in New York City. (For example, see his four paradigm cases of human suffering [Cassell 2013, 223].)

In reality, we see much of the confusion and disagreement in both categories resolving naturally once suffering is understood as having both subjective and objective dimensions, dimensions which may or may not be able to be folded into one overarching theory. However, for the remainder of this article we will actually ignore the possibility of “objective” suffering. Rather, we will turn to interact with Cassell on his own subjectivist terms and show why his model, even for linguistically competent adults with agency, is flawed.

### **SUFFERING: ATTACK OR LOSS? A FEW LESSONS FROM LITERATURE**

According to Cassell's (2013) subjectivist account, although suffering can involve a “disintegration” of the person, it is best conceptualized through the bellicose metaphors of attack, threat, or injury. Our concern is that although these hostile

metaphors certainly identify some experiences of suffering, they do not capture its range or essential properties, and in fact distort the reality of suffering in several important ways. For one, attack metaphors are needlessly aggressive and suggest that suffering is an inherently violent experience. In addition, attack metaphors imply that the source of suffering is identifiable and external to the psychological “self” of the sufferer. This forces an a priori structure of violence, source agency, and outward to inward directionality on the experience of suffering. Yet, this is not the universal experience of the sufferer.

It is not the universal experience of the sufferer because it is not the universal story of suffering patients, whether in a physical hospital, or those found within the pages of literature. A brief analysis of five literary cases of suffering will help to illustrate this idea.

When the French novelist Alphonse Daudet (2002) was dying from the complications of syphilis, which included fiery nerve pain, weakness, and cognitive slowing, he detailed his suffering as a “sterility” (45) and an “extraordinary moral blindness” (43). In order to help the reader visualize what his suffering is like, Daudet points to a variety of everyday events in which he can now no longer participate, such as giving alms to the poor, avoiding traffic on a busy road, or crossing a waxed floor without falling. In doing so, he paints a picture of absence and loss (often complaining of *being lost*). In *sterility*, Daudet experiences the loss of virility; in moral *blindness*, morphine use and pain has led to a loss of moral clarity. For Daudet, suffering simply *is* the experience of his existence fading away, of “any personal sense of self” being “completely lost” (43). Despite his near-constant pain, Daudet rarely describes his suffering as an injury, attack or threat.

Georges Bernanos’s priest in his 1937 novel *Journal d’un curé de campagne* (*The Diary of a Country Priest*) employs similar language as he chronicles his mysterious stomach pains, suffering, and eventual death from gastric cancer, all while trying to sustain tireless service to his parish. Bernanos’s young cleric is desperate to remain strong and spiritually faithful for his parishioners, even while enduring nausea, agonizing pain, and a dramatic and unsightly weight loss; yet, in the confidence of his own journal, he writes that he is “flowing to waste” (30), living in “complete and hateful solitude” (105), and “stretched at the edge of a gulf, a void . . . a corpse” that “waited to be picked up” (106). This is the cry of spiritual distress; it is the suffering of a man trying to remain theologically intelligible to himself and to his parish, but seeing that intelligibility slowly slip away. Importantly, the structure of the priest’s suffering parallels Daudet’s: it is the experience of diminishment, futility, and the gradual loss of self-understanding and self-acknowledgment.

Along similar lines, physician-writer Paul Kalanithi speaks poignantly about his own experience dying from cancer in *When Breath Becomes Air* (2016). Kalanithi is a husband, soon-to-be father, and neurosurgery resident with a promising academic career ahead of him when his life is cut short by a rare lung cancer. For

Kalanithi, suffering is like being “lost in a featureless wasteland” (149); his suffering is related both to personal diminishment, and to how he perceives his own loss of identity and approaching death as intertwined with the loss he knows his family is simultaneously experiencing. This is portrayed by Kalanithi imagining his loved ones moving along a “trajectory that was no longer mine” (147) and grieving that his own life had become “a fading page” (139).

In her memoir *An Unquiet Mind* (1995), Kay Redfield Jamison describes the dark and isolating experience of having bipolar affective disorder. Throughout the memoir, Jamison’s suffering is inseparable from her psychiatric symptoms. She is plagued by fluctuating episodes of depression and mania, which cause her to feel “flat,” “unresponsive,” and “bloodless” (110), as if a “blackness” or creeping “darkness” is encroaching upon her life (44, 79). Jamison’s important account demonstrates why mental illness and suffering so frequently go hand in hand—with suffering, there is nearly always a loss or distortion of identity, and the effects of mental illness on identity are particular, and profound.

Finally, there is the Hebrew Bible’s story of Job, a man who loses all of his family and possessions to the destructive power of Satan, after God removes His protection over Job’s life. Job describes his misery as “heavier than the sand of the sea” (Job 6:3). He feels alienated from God and scorned by his community. The anatomy of his faith, the very fabric of Job’s reality, is turned upside down, when suddenly God appears to be rewarding righteousness with punishment (which is not unlike the experience of many patients we meet during palliative care consultations). This plunges Job into existential suffering, or “deep darkness” (Job 16:16), as if his “days are passed” (Job 17:11). Like in these other stories, Job’s suffering is experienced as a kind of absence, detachment, and loss. A common theme in all of these accounts is identified by Virginia Woolf (1930) when she notices that in illness we can lose self-recognition—that often in illness “We do not know our own souls” (11).

These passages suggest that while suffering can surely take the form of a threat or an injury, it is often conceived of more simply as a loss. As practicing hospice and palliative care physicians, we also find that the metaphor of suffering as loss has greater fidelity to the experiences of our patients. However, a metaphor of loss raises a central question: a loss of what? For Cassell, the answer would likely be a loss of the person. As discussed, Cassell’s “person” is complex, and we think it paints a reasonably accurate picture of the social, emotional, and story-centric human life. Even so, we worry that Cassell’s person presents a more serious pragmatic problem.

The whole point, we would argue, of writing about suffering in medicine is to help the suffering patient, and we fear that the often abstruse complexity of Cassell’s person makes it a difficult concept for practicing clinicians to use when caring for patients. In fact, Cassell’s person seems to just barely track with the language and self-descriptions of most patients, and his explanations often read



more like an abstract defense of personhood. Rather than conceptualizing their suffering as a “threat to the person,” most English-speaking patients report a loss of identity, a loss of selfhood. They say things like, “Doc, I just don’t feel like myself anymore.” In what appears to be sensible and authentic speech, people say that they have “lost their sense of self.” This idea is confirmed in the examined narratives above and also has empirical support (Charmaz 1983). Therefore, to honor this common language of the hospital and clinic, we will sketch that very sense of self which is lost in suffering. In doing so, we maintain Cassell’s basic conceptual structure, namely that subjective suffering involves some kind of change in life or identity with an associated negative feeling. However, we differ in content, and do so in ways that help to circumvent many of the highlighted critiques of Cassell’s work.

### WHAT IS THIS SELF THAT IT CAN BE LOST?

Most human beings conceive of themselves as having a self. This means that humans can be the object of their own actions—they can talk about loving or hating themselves, or look in the mirror and say “OK, *you can do this*” before a race or job interview. A person’s sense of self is also important. It is what people talk about when claiming attributes such as “I’m a good friend,” or “No, I am *not* superficial!”

A person’s sense of self is constituted in at least three different domains: their relationships, their roles, and their self-narrative. A sense of self—the “I” for which a person must give an account anytime they are asked “Who are you?” or “Tell me about yourself”—is built out of the relationships a person has, the roles they have assumed, and the narrative that renders their life intelligible. When one of these domains fade, a person opens herself up to suffering. We will briefly elaborate and clarify.

#### *Relationships*

A person’s sense of self is relational, and to a significant degree is given to them by others. Indeed, for post-structuralists like Judith Butler (2005), the idea of a self-determining “self” is incoherent, because selves are formed and sustained through discourse and the interrogation that discourse provides (an understanding which we feel resolves the conflict between Cassell and Bueno-Gómez’s conceptions of the self). Butler’s sense of self is relational, and it can become partly irrecoverable to us as our relationships wax and then inevitably wane at different points throughout our lives. It follows that there is an opacity to the self that seems built into its very formation, and that this opacity has profound implications for a person’s ability to claim self-knowledge. Charles Taylor (1989) reflects on this view, noting that,

even as the most independent adult, there are moments when I cannot clarify what I feel until I talk about it with certain special partners, who know me, or have wisdom, or with whom I have an affinity. . . . This is the sense in which one cannot be a self on one's own. I am a self only in relation to certain interlocutors. (36)

If one part of a person's sense of self is their specific relationships with others, it follows that when a relationship is lost part of the self is lost along with it. This is what people often experience when a childhood friend dies. Along with their physical death comes the death of their memories, many of which will never be accessible again. "Kate, what color was that crazy hat mom used to wear? I can't remember for the life of me!" Memories are the threads that form the tapestry that is the story of a human life. But it is not just memories that vanish with the loss of a friend. One can no longer *reminisce* over old shared adventures, *laugh* about silly childhood crushes, or *reflect* on how much they have changed over the years. Entire ways of being vanish. It is because human beings exhibit this fundamental dependency on others for their sense of self that the destruction of relationships is a component of their suffering.

#### *Roles*

A sense of self is constituted in the roles that people inhabit (Turner 1978). With roles come specific responsibilities. A mother may nurse her infant, yet her movements are not merely the delivery of nutrition, for her acts are saturated with meanings. She may believe that to be a good mother she must feed her child, and a failure to do so is a failure of *her*, since she has come to define herself *as* a mother. Roles, shaped by our culture and community, confer meaning on what we do and help to form our sense of self. And, like with relationships, when a person is deprived of a role that is constitutive of their sense of self, they lose something vital and are made vulnerable to suffering.

#### *Narrative*

A person's sense of self is also narrative. This is an empirical claim: most adult humans conceive of themselves as having a past, a present, and a future, and it is only as narrative creatures that human acts and agency can even be understood. This is the view that Marya Schechtman (2011) calls a "hermeneutical narrative" (395).<sup>1</sup>

As Alasdair MacIntyre (2007) argues, it is only through a narrative understanding of a human life that such a life is rendered intelligible. The actions of people are intelligible just when their intentions and priorities are understood to be im-

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<sup>1</sup>For reference and perspective, the notion of a hermeneutical narrative has its recent detractors (see Behrendt 2017; Bueno-Gómez 2017; Strawson 2004) and responders (MacIntyre 2016; Taylor 2016).

bedded within, and originating out of, a story. This story exists as a dynamic narrative matrix of relationships, roles, duties, histories, and important life-projects, and understanding this matrix is crucial to a person's ability to identify occurrences in the world as actions. And as MacIntyre notices, when an agent's actions become unintelligible to their own self in addition to everyone else, the agent is rightly understood to be suffering in some significant way.

How this relates to illness and medical care is evident. A person's narrative forms a tight skein with the welfare and general state of their body, as people's stories rise and fall with the vicissitudes of their health. This is why, as frequently noted by Cassell, both the pain and the stress associated with diagnostic uncertainty can be enormous sources of suffering, since both can precipitate a loss of one's narrative sense of self.

### **TWO CONDITIONS OF SUFFERING AND THE SUFFERING PATIENT**

Up to this point our discussion has remained theoretical and grounded in third-person descriptions. However, subjective suffering must be *experienced*, and accordingly any rational framework must fold into a first-person perspective. Hence, there must be two conditions that comprise subjective patient suffering.

#### *Loss of Sense of Self*

To recapitulate, one condition of suffering is the loss of a sense of self. This loss normally has a precipitating event, something that takes place in the body or in the outside world. Something tragic, like the death of a child—a precipitating event—can destroy a special relationship, deny someone of their identity-defining role as a parent, or deprive them of the narrative through which they have constructed and anticipated their future. In medicine the precipitating event is often illness. Illness comes with functional impairment and a variety of symptoms, such as pain, nausea, blindness, anxiety, or fatigue. However, neither impairment nor symptoms necessitate suffering, since someone can have these but not suffer. In addition, merely losing your sense of self is not sufficient for suffering, since people frequently lose a self-defining role or relationship but do not suffer. The distinction here is that with suffering one also experiences the world in a particularly negative way.

#### *The Suffering Affect*

Therefore, there must also be an affective condition to suffering that can be caused by or associated with the loss of a person's sense of self. This is the feeling that a person experiences—the *feeling* of suffering. But what is this feeling like? The work of Fredrik Svenaeus (2014) is helpful here. Svenaeus describes the feeling of suffering as negative, intense, prolonged, and life-altering. According

to Svenaeus, suffering is a mood—a phenomenological state that determines “the way the whole world appears to us, opening up the world to the person in a certain tone or colour” (409). It is through a mood that events and actions are woven into one intelligible and cohesive story. A mood is not an emotion, which is a feeling about a specific thing at a specific time. Rather, a mood is the window through which a person interprets any thought, object, or decision presented to them by the world. A mood is a way of interpreting all internal (hunger pains) or external (a misty morning sunrise) events and creating an integrated pattern that makes subjective sense of the phenomenal world.

This affective part of suffering can shape the sufferer’s world and render the psychological life of the sufferer dark and hopeless. This affect is described throughout many works of literature as a mode of being in the world; for example, C. S. Lewis (1961) referred to life after the death of his wife as if there were “a sort of invisible blanket between the world and me” (3). In poignant prose Lewis goes on to lament that: “I see the rowan berries reddening and I don’t know for a moment why they, of all things, should be depressing. I hear a clock strike and some quality it always had before has gone out of the sound. What’s wrong with the world to make it so flat, shabby, and worn out looking” (35). Suffering had become the affective frame through which Lewis’s narrative is being constructed.

### *The Suffering Patient*

In summary, the two conditions for subjective suffering are: (1) a loss of a sense of self, and (2) a negative affective experience. This kind of suffering can be labeled *subjective patient suffering*, or SPS, and it is the necessity of condition (1) that helps to distinguish SPS from more superficial and transient emotional states, such as ennui, brief anxiety, or fear. These two conditions of SPS can reinforce and be the cause of each other. For instance, when a precipitating event such as a patient’s dyspnea has gotten so severe that she can no longer go on walks with her husband, she may experience a breakdown in her relationship, her roles, and her vision of a future of graceful aging. This is a loss of her sense of self. As her disease progresses, she cannot even finish a meal without gasping for air; she begins living with the constant sense of doom described by dyspneic patients. She may then experience a negative affect—a negative feeling that colors the rest of her life. This negative affect may cause her to further neglect her husband or friends, plunging her into isolation, and leading to a further loss of her relationships, roles, and narrative. Suffering can become a vicious cycle.

Importantly, this biconditional framework is confirmed by the lives and stories of many patients that we treat. The stories revealed in the hospital and clinic are often desperate accounts of loss, and many patients seem to have sorrow etched down into their bones. We care for many patients whose narratives seem to have ruptured—who suffer so deeply that they can hardly recognize their own story in the face of despair. And most of the suffering patients we care for demonstrate

these two conditions: they seem to have lost some crucial part of their sense of self, and they report a sustained negative feeling.

### CONNECTIONS AND IMPLICATIONS

As Eric Cassell noted nearly 40 years ago in a 1982 article for the *New England Journal of Medicine*, the relief of suffering is one of the pillars of the medical profession. Although this is not an uncontroversial claim, on some basic level it is certainly true. Yet the nature of suffering remains difficult to capture in any finite set of descriptions. It is our hope that this framework will give clinicians a starting point from which they can begin an inquiry into the origins of their patients' suffering, an inroad into the mist. But what does this framework enjoin? At a minimum, attention to suffering should be aimed at recognizing its presence, characterizing its quality and form of expression, and identifying avenues of conversation so the patient and others can achieve a shared understanding and thereby try to jointly ameliorate the distress. To accomplish this, we believe clinicians can start by (1) *seeking* to understand their patients' lived experience; (2) *inquiring* into their patients' experiences by paying particular attention to their loss of relationships, roles, and narrative; and (3) *actively listening and exploring* the words and stories that their patients share. Although these three pathways may seem simple, in practice they are frequently forgotten, despite the fact they can measurably improve patient health and well-being.

A patient's suffering is often connected directly to their experience of illness (Kleinman 1988; Kleinman, Eisenberg, and Good 1978). Further, we know that the words and actions of clinicians have a distinct power to assuage this illness experience, and thereby assuage patients' suffering. For example, as has been recognized in psychotherapy for decades (Rogers 1942), words can be therapeutic, in that a clinician who validates a patient's perspective or expresses empathy may improve the patient's psychological well-being, leading to fewer negative emotions (such as anxiety and fear) and more positive ones (such as hope, optimism, and self-worth) (see Fogarty et al. 1999; Ong et al. 2000; Schofield et al. 2003). In addition, words can affect more "physical" symptoms, as exemplified by one study that demonstrated a link between empathetic communication and decreased pain in patients with irritable bowel syndrome (Kwekkeboom 1997). By generating trusting relationships with their patients and proving that they will not be abandoned and are being heard and understood, clinicians can promote well-being, reduce isolation, and improve overall patient satisfaction (Henman et al. 2002; Kim, Kim, and Boren 2008; Salkeld et al. 2004). Furthermore, the thoughtful words and actions of the clinician can create genuine camaraderie for the patient and effectuate a narrative that includes the clinician as a significant relationship (Egnew 2005, 259).

In short, the language and embodied acts of the clinician, as situated within the patient–clinician relationship, are not benign. Rather, they can alter the course of a patient’s illness and alleviate the patient’s suffering, just like a prescribed drug or therapy. This can be put into practice through the clinical activities of seeking to understand, inquiring into the patient’s experiences, and actively listening to and exploring the patient’s words and stories.

We can now return to Marie, our introductory case. Will this discussion and analysis help her? There is clearly more to her story than can be explained by lab tests or CT scans. Using our framework, her clinicians may have a starting point from which they can begin seeking to understand, inquiring, and actively listening to and exploring Marie’s words and stories. In practice, the clinician could ask about what important relationships her pain has affected, what functional roles she has lost, and how the structure of her hopes and goals has had to change. This process may reveal important psychosocial or historical information that will modify her treatment plan—for example, by giving her the space to talk about a history of trauma (an often-missed association with chronic abdominal pain), or by helping her brainstorm new roles that could refortify her sense of self—and increase Marie’s satisfaction with and openness to care.

However, this process will likely not be enough, for responding to suffering takes more than an algorithm or set of prescriptions. Here we differ again from Cassell (both in target and mood of response). Cassell (2013) seems to believe that suffering will be alleviated if physicians just ask questions about patient “goals and purposes” (246), understand (or master, as Bishop would see it) the whole of the patient (245), effectively re–describe the meaninglessness of patient illness, and return agency and control to patients (253)—all the while remaining “in control of the conversation” (246). Oddly enough, Cassell even claims that this clinical process is not done out of kindness, but in order to be “*maximally* [sic] effective” (254), which reminds us of Bishop’s concern vis-à-vis suffering and biopolitical control. In any case, this is not how we see it. In many situations subjective suffering will not be relieved and control will never be reclaimed, since suffering and loss are inevitable parts of human life.

By our account, intention, sustained presence, and the act of recognizing and acknowledging the patient’s suffering are the ends to be achieved, even if the relief of suffering is not attained. Nevertheless, at the same time it is important to admit that sitting with the silence of suffering is hard and may not always be emotionally sustainable or logistically feasible. Returning to a suffering patient’s room day after day often feels supererogatory, or above the call of duty. And yet paradoxically, in our experience, this is the heart of medicine. As Cassell would likely affirm, the best medicine requires more than clinical expertise. The best medicine also requires, wisdom, empathy, compassion, courage, and humility. Indeed, the calling of the clinician is to return, to sit, to stay, and ultimately, one can hope, to heal. Medicine is a moral art.

Still, there is much work to be done. From a theoretical standpoint, there is a need for further conceptual clarification and the development of a robust “typology of suffering”—a rethinking of what Eric Cassell (2013) has dismissed as “invalid distinctions” (219). For example, what is the relationship between “objective” and “subjective” suffering? What are the distinctions among different types of suffering, such as overwhelming pain, nonverbal suffering of infants and animals, chronic vs. acute suffering, or psychological, existential, spiritual, and social suffering? In addition, what are the political implications of these clarifications, such as in the debates surrounding suffering being used as a justification for euthanasia or medical aid in dying? And finally, importantly, what is the connection between suffering and resilience? It is clear that some people respond to the loss of relationships, roles, or narrative with immense suffering, while others seem to adapt to these losses in stride. Why are some patients more immune to suffering, and how can resilience be cultivated among patients experiencing great loss? These are just a few areas ripe for scholarly exploration.

### RECONCEPTUALIZING SUFFERING

When illness enters someone’s life, the effects can be devastating—and it is often in these dire moments that the sufferer meets the clinician. Eric Cassell laid a groundwork that has enabled Western medicine to begin reimagining the suffering patient. Nevertheless, even Cassell realized that his project was not a success, that in health care the person continues to be marginalized by the disease. Unfortunately, clinicians—albeit often inadvertently and with good intentions—reduce suffering patients to their laboratory abnormalities, x-ray findings, or diagnostic labels. There are many reasons for this, but one may be, as we have illustrated, Cassell’s own conceptualization. By focusing on only one aspect of the suffering experience—suffering as threat or injury—and abstracting personhood from the ordinary language and lives of patients, Cassell’s understanding fails to gain a footing in everyday medical practice. Therefore, we have proposed a more grounded conceptualization of subjective patient suffering (SPS) as a loss of sense of self with an associated negative affect.

With this framework in mind, clinicians will be better equipped to recognize and address their patients’ suffering by seeking to understand, inquiring into the patient’s experiences, and actively listening to and exploring their words and stories. It is our hope that this reconceptualization of patient suffering will lead to more thoughtful and compassionate care of suffering patients and establish a foundation for further scholarship and research.

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