To Joan Wyatt, Emmanuel College,
in honor of her professional career
as a nurse, minister, professor,
and supporter of the arts

and to my sisters
My friend Jane was admitted to the emergency room of a busy urban hospital after having a seizure at home. While talking to her on the phone, I heard the phone fall from her hand while she had what was later determined to be a grand mal seizure. Another friend had been having tea with her, so she had called the ambulance that took Jane to the university hospital. I raced downtown to the urban hospital when I got her message. I was not allowed immediate access to Jane because tests were being done. Locating a hard plastic chair in the waiting room, I tried to tune out the relentless noise of the TV and the ugliness of the fluorescent-lit waiting room. I wished I had brought something to read.

Two young children slept in one corner, leaning against each other, with no parent in sight. Another woman moaned in pain as her granddaughter tried to comfort her. The security guard blocked the door to the patient care area and ignored those in the waiting area while a triage nurse interviewed the next patient in line. The entire setting created an inhospitable space.

When I was finally allowed to enter the curtained cubicle where Jane was trying to deal with a severe headache, the nurse placed EKG chest leads on her while ignoring both of us. She pulled the patient gown up to Jane's neck without a warning and exposed her breasts with no concern for her modesty. Jane was clearly embarrassed by the lack of privacy. Only an hour before, she had been an independent person—a professional, with a career and friends. Within moments of arriving at the hospital, Jane was given a new identity based on illness. Her choices were either to resist or submit.

Through the curtain, the nurse carried on a conversation with a coworker about how inebriated she had been at a party the previous night. I realized that the nurse was functioning in an automatic way that
Empathic Communities

was technically correct, but she missed an opportunity to connect with
the patient. I was tempted to point out this behavior to the nurse, but
kept silent because I knew that my friend would pay in numerous ways if
we irritated her nurse. Being labeled a problem or difficult patient would
not be helpful for my friend.

Practitioners who receive clients into the care of an organization
or clinic provide the first point of contact for the patient. Consider the
following questions:

1. What might the nurse have done differently in this situation?
2. What messages was the nurse giving the patient about her
body and about her illness?
3. If you were the patient, how would you feel in this situation?
4. What kinds of suffering were happening here? As a helping
professional, what would be your role in this situation?
5. Write your own definition of suffering.
6. What are the policy implications of the use of urgent care in
your location?

Defining the Person

The notion of suffering is sometimes lost in the focus on specific aspects
of treatment regimens, outcomes, learning goals, quality improvement,
and sheer overwork. In health care, the suffering of the patient and fam-
ily are traditionally the responsibility of the nurses and pastoral staff
who have more intimate and daily knowledge of the patient’s situation.
In some settings such as palliative and hospice care, interdisciplinary
conferences bring staff together to talk about the overall situation of the
patient and to compare perspectives. The notion of entering imaginatio-
vely into each other’s practices counters decades of specialization and
parallel practice, as well as the professionalizing strategy that seeks to
contain expertise and protect boundaries.

Professional training often has little room for suffering as a guiding
concept for care. The notion of suffering disrupts Western beliefs
in progress and technological advances that promise to cure or at least
extend life. Suffering also carries connotations of religious and philo-
sophical inquiries that seem more suited to the humanities than to the
work of science.

Regarding Suffering

Advances in medicine have indeed brought cures and extended
life expectancy, but survivors of cancer and other diseases or those with
chronic illnesses experience altered lives under conditions that may in-
clude suffering. For those in the helping professions, suffering in all its
forms will be their daily focus. As medicine has increasingly specialized,
the body has been divided up according to professional expertise. In a
postmodern culture, what does it mean to suffer? And who is there to
witness that suffering? How can students be prepared to recognize the
many forms that suffering can take? And can they be taught to reflect
on their own suffering as they encounter the myriad ways that children,
young adults, and adults suffer?

Even though the obligation for physicians to relieve human suf-
fering goes back to antiquity, Eric Cassell observes that little attention
is given to the subject in medical education, research, or practice. In or-
der for medicine to understand what suffering is and how physicians
might be devoted to its relief, medicine must overcome “its traditional
dichotomy between mind and body, subjective and objective, and per-
son and object.”1 When personhood is restricted to mind, spirit, and the
subject, the notion of suffering becomes a private matter of that domain.
Suffering, he argues, occurs when “an impending destruction of the
person is perceived; it continues until the threat of disintegration has
passed or until the integrity of the person can be restored in some other
manner.”2 Under the rubric of personhood, Cassell includes all the com-
ponents of an individual’s complexity, such as family, life experiences,
cultural background, roles, and relationships, as well as a transcendent
dimension. Such multifaceted creatures cannot be reduced to mecha-
nical injury but have a potential for injury and suffering that is complex.

The Biomedical System and (Dis)Regard
of Suffering

Recent scholarship recognizes that biomedicine has supported crucial
innovations in medicine but also shapes the culture in which practitio-
ners deal with patients. Medical anthropologist Arthur Kleinman ob-
erves that biomedicine reduces life to nature as a physical and knowable

1. Cassell, Nature of Suffering, 32.
2. Ibid.
object. Biomedicine, according to anthropologist Margaret Lock, is a product of the nineteenth-century emergence of biology, where nature is understood as comprised of laws independent of both society and culture. The shift meant that disease and health could be "assessed and controlled independent of the circumstances in which individuals are situated."

For practitioners of biomedicine, the focus is on constructing disease using objective data while disregarding the patient's subjective experience of suffering. Although not opposed to progress in biomedicine, Kleinman laments the loss of "a humanly significant relationship of witnessing, affirming, and engaging the patient and family's existential experience." By denying the patient and family experience, and possibly pastoral care givers as well, doctors in effect deny patients and their families and other helping professions an opportunity to pass through suffering and to make sense of the ultimate meaning of life. Biomedicine decontextualizes diagnostics and therapeutics to the interior of the body or to individual behavior, and ultimately it is removed from the moral realm. The notion that biomedicine is free of "cultural and moral evaluation is itself a moral position."

As biomedicine grew into an increasingly bureaucratized and rationalized system, the health care division of labor became divided into systems: diagnosis and prescription to doctors; care of the body to nurses; and spirituality increasingly to professionalized clergy. One disadvantage of this rationalized system was that each of these care groups was shaped by the culture of their professional education (whether based primarily in the humanities or in science), and there were few opportunities to share observations or to gain insight from shared knowledge. The fracture of science from humanities has been further consolidated by the postmodern insistence on the relative and private nature of each individual's beliefs. Some communities see their own strengths in contrast to biomedicine and refuse to submit to the reductionism involved in modern medicine. In a study of African-American healing, Stephanie Mitchem notes that concepts of the body and healing in black culture contrast sharply with those of institutional medicine. Relationships are central to healing processes and acts in which the body has meaning because of connections with "the past, the future, the family, and the divine."

INDIVIDUAL SUFFERING

Suffering is a universal human experience located in the body, mind, spirit, or in a combination of those aspects. Rather than isolating suffering in one aspect, one can regard the person as a whole; thus, when health is diminished in one aspect of human life, other areas are also affected. Although some individuals do not encounter suffering until they are mature adults, others experience it already from birth or at a very young age. Halpern notes that in suffering, "expectations about the reliability of the world and of one's capacity to achieve any of one's goals can be destroyed." Thus, suffering has the potential to provoke a crisis of faith, not necessarily in the sense of religion, but in one's view of the world and one's place in it. Suffering also has the capacity to build new capacities for care, gratitude, and appreciation for life.

Suffering is an interruption to one's sense of the world that challenges presuppositions about one's identity, purpose, and expectations of how the future would unfold. Suffering can provoke a transformative experience similar to the process that Jack Mezirow describes for adult learning, wherein education causes a shift in frames of reference and a restructuring of frames to incorporate new knowledge. Suffering can provide a disorienting dilemma that results in a rethinking of previously held assumptions. Suffering individuals sometimes describe their experience as transformative—a language that is shared by adult educators. That is not to suggest that individuals should seek out suffering in order to be transformed. The health care practitioner can, however, be influential in helping an individual seek wholeness in the face of changes that are potentially transformative, even when the individual can never return to the state of being experienced prior to illness. The new frame of reference may include a new way of inhabiting the body or of experiencing the world.

8. Doornbos et al., Transforming Care, 78.
9. Halpern, From Detached Concern, 112.
An important part of this re-sorting of values and meaning is the opportunity to lament what has been lost. Nursing professor Mary Doornbos distinguishes lament from despair and argues that nurses work with the double vision of shalom that "allows us to see what is not yet, while at the same time we see what we are called to at this time."

Lament is an essential part of both individual and communal experience of suffering as well as the movement towards healing. Although suffering is often described for the individual, it is important that helping professionals recognize how suffering is shared and experienced communally through such practices as lament and ritual. Lament as such enables the expression and sharing of suffering and the questioning of larger issues of justice.

For helping professionals, a willingness to face the suffering other and to transcend a particular belief system in order to understand each patient is a challenge that properly begins in professional school and continues throughout one's career. An appreciation of the intercultural and interreligious ways that communities and individuals experience and express suffering is an essential skill that can allow the professional to engage with the client and family in meaningful ways. In addition, such an ability to engage with the suffering other demands an awareness of the suffering self.

**SOURCES OF SUFFERING & THE SUFFERER EXPERIENCE**

The source of suffering may be a physical condition present at birth, such as a congenital anomaly; a physical condition acquired through illness or injury; an emotional state or mental illness; or a combination of these. Some children grow up in conditions that do not allow them to thrive because they lack physical or emotional basics or because they have been subjected to emotional or physical abuse. Essential for all helping professions is a critical awareness of the systemic causes of suffering.

When suffering is a result of illness or disease, theories of natural causation (infection, stress, organic deterioration, accident, or overt human aggression) may be used as an explanation. Many cultures rely on theories of supernatural causation to explain disease and illness, including mystical causation, animistic causation, and magical causation. The experience of suffering is expressed through metaphors and culturally constructed narratives that help the individual and the family or community deal with feelings and anxiety about the experience.

**PAIN**

Pain can accompany suffering, but pain is not essential to defining what constitutes a suffering experience. Because pain tolerance differs greatly between individuals, an injury that might be experienced as a mere nuisance to one person might be devastating to another. Some individuals might faint at the sight of an injury, whereas others would not require anesthetic for some procedures. Each individual situation alters the experience of suffering; for example, a foot injury would be experienced differently by someone whose mobility was essential to his or her job, compared to someone who could work at a computer. Some individuals withdraw when faced with suffering; others seek community to survive the experience. Each person thus experiences suffering differently, and no system can predict the individual response to suffering.

The professional who regards and evaluates suffering will be influenced by his or her own notion of suffering. How we answer the why of suffering can affect how we experience or endure it, and how we regard the suffering of another. Diana Cates distinguishes emotional pain from physical pain. Physical pain takes as its object a particular bodily sensation, and emotional pain takes as its object some occurrence or circumstance in the larger world of personal experience. Part of suffering is related to our intactness as persons and the sense of loss "in relation to the world of objects, events and relationships," sustaining a sense of loss that comes not just from the body, but from the web of relationships that surrounds a person. Supporting the loss, grief, altered identity, changed relations, and uncertainty that illness brings is a challenge for all levels of helping professions. It also offers the potential for deep engagement in the suffering of another.

**ISOLATION**

Suffering can either isolate the individual from normal life or can ultimately bind that person into communion with others. The experience

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of suffering may ultimately increase the individual's ability to identify with others who suffer. The exact mechanics of this increased sensitivity to suffering is unclear; perhaps as the more social and inauthentic self is dismantled by suffering, the senses are more open to hearing the pain of others. While sharing the pain of another, we generally do not experience the exact same sensation; however, Cates argues it is possible to share a similar set of experiences. Those who have a very high capacity for empathy might in fact be quite vulnerable to developing similar symptoms as the client with whom they are identifying—and for those students, training is necessary to manage this wealth of empathic feeling that might threaten their own health.

**TIME**

Time is a factor in suffering, because suffering depends on whether the condition causing it is acute and treatable or chronic and ongoing. To the person who is suffering, the perception of time can be distorted as suffering takes them into a realm of experience disconnected from daily routines. Cassell notes that suffering will influence people's perception of the future; if pain is perceived as taking over the future, people fear they will be overwhelmed. David Kahn and Richard Steeves note that suffering disrupts not only the sense of time, but also people's sense of embodiment and the social world, in the form of human relationships. Certain forms of suffering distort time to such an extent that the future can no longer be visualized, as in the case of trauma.

**CUMULATIVE SUFFERING**

Suffering can be cumulative. For example, Diane spent two hours at the dentist undergoing a root canal procedure. Then, because her appointment had already been set, she also underwent a routine cleaning. During the second procedure, she was so uncomfortable that she burst into tears and asked the hygienist to stop. The cumulative effect of the discomfort reached a point where she could no longer bear it. As a practitioner, it is difficult to see the cumulative suffering that a client has endured over time because the practitioner is often focusing on a discrete presenting event. The history is an important part of the client narrative, not only for diagnostic information, but also for a more complete understanding of the experience of illness over time.

Suffering can be so intense that the individual person feels obliterated. French philosopher Simone Weil (1909–1943) describes this immense suffering as affliction. Weil notes that there are three types of affliction: physical pain, social exclusion, and spiritual distress. Weil believed that in the deepest affliction one could be attuned to the truth of God. Theologian Dorothee Soelle affirms the view that some suffering goes beyond pain and affects every dimension of life, to the point that “no discourse is possible any longer, in which a person ceases reacting as a human agent.” The dehumanizing effects of affliction or intense suffering impede human action and leave clients unable to act or speak.

**THE BODY**

Suffering may begin in one domain, such as the body, and may precipitate or be joined by suffering in another. For example, one student finishing a residency in dental surgery developed a condition where she could not use her arm. When the condition appeared to be permanent, the student grieved the loss of her chosen profession and became depressed. Bodily suffering resulted in a suffering spirit. The doctor who treated her was primarily concerned with healing her arm, a healing that did not seem to be forthcoming. After several months of depression, the woman consulted a counselor who facilitated the verbalization of fears related to the loss of her chosen profession and the change in her identity. Prior to this physical setback, she had never questioned her own success or experienced any obstacles to obtaining her goals. She confessed that she had felt immune to such suffering, protected by her professional qualifications and her success. Her experience of suffering contained an intrapersonal element, wherein she worked to integrate new information about herself, and an interpersonal aspect, wherein professionals worked with her physical symptoms and her emotional experience of suffering.

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It is important to note that such processes occur simultaneously while the patient is coping with the experience of suffering.

Suffering is experienced in and through the body, but that suffering is also interpreted through the lenses of gender, race, class, age, ethnicity, religious or spiritual perspectives, personal history, and context. Suffering interrupts the "normal" routines of daily life and exposes core beliefs for critical examination. That reassessment of the taken-for-granted nature of one's daily life (work, relationships) may also involve a deeper confrontation with values, such as the meaning of life and the transience of one's experience. Although such an encounter with either unexamined or deeply-held values through suffering may seem unavoidable, Western culture provides endless distractions from the task. Suffering might offer transformation; however, such an outcome is not inevitable since some may resist changes imposed by illness to previously held beliefs.

A practitioner will encounter a wide variety of beliefs related to suffering and disease causation that may differ tremendously from his or her own beliefs. The role of empathy in encountering suffering is to stand with the individual or community in the face of suffering, with willingness to imagine how things might feel for the other. Such "standing with" requires suspension of the tendency to judge or to criticize the other for beliefs that contradict one's own. A professional will allow clients to express their sadness through lament, to experience weakness, and to search for new perspectives through this experience.

HEALING PLACE

When hospice care was first established at St. Christopher's Hospice in England (1967) and at the Connecticut Hospice in the United States (1980), architecture was considered an essential part of the mission to provide end-of-life care. Unfortunately, the same priority for the environment of care is generally ignored in most hospitals and clinics.

After accompanying his young daughter through a medical crisis, designer John Thackara observed that because medical knowledge is embodied, the design of work environments needs to enhance tacit and embodied knowledge. He observed that ultimately the best exchange of information occurs in a collaborative situation, with face-to-face exchange. Some organizations have attempted to design space with natural light, a small garden, or a labyrinth to counter the often impersonal and desolate spaces where care is given.

SOCIAL SUFFERING

Although many studies focus on the individual, suffering is also a social experience. The voicelessness of suffering creates further isolation and marginalization—loss of voice may ultimately result in a total shattering of self. Suffering is "a social status that we extend or withhold ... depending largely on whether the sufferer falls within our moral community." 22

In the case of trauma, survivors and communities are not faced with a life/death opposition, but experience a living death in the midst of their survival.

When communities experience harsh physical conditions, natural disasters, or forms of oppression such as institutional racism, economic inequity, genocide, or poverty, the resulting communal suffering denies them the opportunity to be fully human. Social suffering is a term used to link the individual experience of suffering to wider social events and structural conditions.

The intergenerational and enduring aspects of this suffering have not been sufficiently documented. In displacements, individuals and communities in transition through immigration or forced relocation suffer a variety of physical and emotional disorders. Recent research demonstrates that trauma can be inherited by subsequent generations. Cross-generational passage of trauma is a subject of growing scholarly interest to neurobiologists and psychologists. Donna Nagata examines the cross-generational impact of the Japanese American internment;

22. Thackara, In the Bubble, 110–11. See also Wright and Adams, Sacred Space.
23. Kleinman et al., Social Suffering, 58.
the Sansei Research project uses a cross-generational framework to examine the transmission of trauma and injustice from the Nisei to the Sansei generation. Among the many findings, Nagata observes that severe injustices produce effects that extend far beyond the individuals who experienced the unjust event. The internment reminds many Sansei that Japanese Americans suffered a grave wrong, and thus many feel responsible for preventing injustices in their own world. Research continues to examine the resilience as well as the suffering of generations affected by trauma or violence; for example, the neurobiology of trauma and the use of pharmacological interventions is the focus of ongoing research.

Communal suffering is complex and overwhelming to the individual. When the complexity of the suffering has been misread and the cure addresses only one aspect but ignores another, such as providing education with no opportunities for jobs, the proposed solution may not take root or may be met with resistance. Communities that have lost their connection to their historic identity or their spiritual roots cannot be cured by mere physical interventions. Affliction can require a spiritual cure, as well as physical and practical interventions. A variety of aboriginal programs for youth and adults refer to the return to the sacred as an adoption of native practices that bring healing to individuals and to the earth.

What does a broken or suffering spirit look like in communities of oppression and suffering, and how is it expressed in health and illness? Suffering is evident in increased rates of mortality, traumatic injury or death, hospitalization for pneumonia, and adolescent suicide. Suffering is also expressed in the increased incidence of Type II diabetes, asthma, and heart disease in both aboriginal communities and African-American communities. How can a helping professional respond to the suffering of communities and the individuals within them whose suffering is shaped by structural inequalities? The first step is learning to regard the suffering without judgment and with close awareness of and reflection on any personal discomfort.

As an outsider to the suffering of a particular community, how can one ever understand the complexity of suffering in addition to the resistance that accompanies it? Medical anthropologist Nancy Schep-Hughes returned to a field site in Brazil where she had worked years before. During her early fieldwork in Brazil in the 1960s, Schep-Hughes sought to keep a positive view of the shantytown by attributing the misery she witnessed to external causes such as poverty, racism, class exploitation, and imperialism. Her research was guided by an assumption that was common to Western scholars; she observed the people and projected her own assumptions of sameness onto them. She assumed that underneath cultural difference, human beings were essentially alike. These assumptions did not help her explain why women seemed to be indifferent to the deaths of their small children. She found that she and the people did not understand each other, and she was faced with the opacity of culture. Seeming maternal indifference in Brazil was matched by bureaucratic and church indifference, leaving the social determinants of child death hidden from view. What seemed like indifference on the part of the women was actually a deeper response to structural poverty and hopelessness.

Schep-Hughes attempted to articulate the suffering of both the women and children while being aware of the impossibility of finding speech for those too young to speak. Concerning this challenge, she realized that her options were limited to one stance, namely, that of "being there" and "bearing witness" to the suffering of the silent or silenced others—in this instance, mothers and babies. She begins with an assumption of difference and avoids 'all 'essentializing' and 'universalizing' discourses, whether they originate in the biomedical and psychological sciences or in philosophical or cultural feminism.'

Regarding suffering can mean encountering an unexplored landscape of incomprehensible difference that challenges one's most basic and unexamined assumptions. For many professional students, the confrontation with otherness can generate deep discomfort, anxiety, anger, and a desire to turn away. Despite the recognition of deep difference, one must sometimes struggle to find that which binds people in common human relation, even when no connection can be imagined. A clinician interprets the behavior of another, but such judgment is always mediated by the practitioner's own cultural presuppositions.

Medical anthropologist and physician Paul Farmer documents suffering in a number of locations, including Haiti. Farmer notes that the suffering associated with structural violence can seem almost invisible.

26. Ibid., 355.
One of the reasons for this invisibility is the exoticization of suffering, which allows us to distance ourselves from suffering that is more remote from our own lives. He writes that the sheer weight of suffering makes it difficult to describe, since facts and numbers objectify the victims. The dynamics and distribution of suffering are poorly understood. Individual case studies of people give us insight into suffering, but they must be read against the backdrop of culture, history, and political economy. Farmer believes that liberation theology does a better job of attempting to understand the suffering along with social analysis than many theologies or philosophies. He warns against the tendency to confuse structural violence with cultural difference, which is one form of essentialism used to explain away suffering by suggesting that certain practices are just “part of the culture.” Suffering, he argues, is universal, but not all suffering is equal. Uncovering the hidden suffering and attending to it and to the context that surrounds it is a task that he feels should be given priority.27

RESPONDING TO SUFFERING AS A PROFESSIONAL

A variety of skills are necessary for the professional regard of suffering. Professionals are expected to regard suffering in the context of an individual’s life and with an appreciation for the intercultural differences that might shape that suffering. Professionals also need to maintain a balance between imagining the suffering as if it were their own and regarding it without being destroyed by empathic overload.

Each profession has a history of regarding suffering and expected responses to that suffering. Helga Kuhse describes the history of nineteenth-century nursing as subservience based on two metaphors, namely, nurse as helpmate and nurse as dutiful soldier.28 The gender division in regarding suffering and finding its cause meant that professions valued different aspects of this professional regard. Doctors focused on the symptom and remained emotionally detached while diagnosing the problem and deciding on the treatment.

William Hurt, in his role as a highly skilled surgeon in the film The Doctor (1991), exemplifies technically proficient but joking detachment as he makes fun of colleagues, patients, and medical students in the course of his workday. His manner changes radically when he finds himself a patient. He chastises medical students for referring to patients by their diagnoses rather than by their names.

When regarding suffering, how can one manage the emotional challenge while simultaneously offering competent care? Halpern argues that by learning how to empathize, “physicians gain access to a source of understanding illness and suffering that can make them more effective healers.”29 In order to empathize accurately, physicians need to be self-aware and avoid projection of their own unacknowledged emotions onto patients. Nursing literature describes ways of knowing for nurses that include “personal knowing.” This type of knowledge depends on reflection and perspective-taking that acknowledges the other as subject rather than object.30

WESTERN MEDICINE

Technical superiority and caring can sometimes be interpreted as being in opposition to each other. Western medicine is often presented as more detached, objective, and rational than other forms of medicine. High degrees of specialization allow Western medicine to offer specialized expertise on, for example, the bones of the hand. Such specialized knowledge privileges knowledge over empathy and may or may not be accompanied by caring on the part of the professional.

Alternative forms of care, such as shiatsu, osteopathy, and Reiki place empathy at the forefront of the diagnostic process through a highly skilled form of listening. Although the presenting symptom or source of suffering may be located in the hand, the practitioner considers all the meanings of that source and its interconnection to other parts of the body that may be triggering that suffering or participating in that pain.

The professional culture and context of society affects how one regards suffering; judgments can be so much a part of the professional culture that the individual practitioner may not even be aware of them. Kleinman observes that “the Western tradition's emphasis on the subjective feelings of the afflicted individual, often viewed as isolated and forlorn, is the dominant analytic paradigm for understanding the suffering that results from chronic illness and disability.”31 The range of

27. Farmer, Pathologies of Power, 40.
29. Halpern, From Detached Concern, xi.
31. Kleinman, Writing at the Margin, 163.
socially acceptable suffering from certain conditions and diseases excludes others, resulting in individuals suffering alone. Those contemplating or undergoing sexual reassignment or transgender surgery, for example, often find themselves extremely isolated, lonely, and lacking social support. Conditions with social stigma lack the resources that are accorded other diseases; when a disease becomes a cause, however, the situation can change.

Suffering challenges our perception and expectation of the good life. We do not care to be reminded that life can change in an instant. Death and all the stages of suffering that might precede it are too difficult to imagine. Even health care professionals who daily confront various manifestations of illness and suffering find it easier to keep that suffering at a distance than to imagine being in the client’s place. Imagine that place is, however, a key step in engaging empathy, as we will see further on.

Regarding suffering is not limited to health care professions; it is a challenge for many helping professions. Teachers, for example, are faced daily with the suffering of children and adults whose context has shaped their ability to learn. Young children of immigrant parents arrive at their neighborhood schools, and teachers are expected to deal with their varying levels of readiness for school. As a child, I was brought to the local kindergarten with few English language skills. The teacher, nearing the end of her career, had no patience for the extra work involved in making me “school-ready.” I remember spending many hours consigned to a corner where I wept quietly in utter misery. For that teacher, an immigrant child was an exception; in many schools today, particularly in the cities, a diverse classroom has become the norm. However, the needs of some displaced and refugee people are enormous, and those who seek to help them will likely confront overwhelming suffering.

CHANGES IN DISEASE, DETECTION, AND DECISIONS
New diseases and new cures punctuate the history of medicine, and social stigma attached to new or old forms of disease and suffering are socially constructed. William McNeill’s study of the history of plagues provides a historical overview of society’s reception of different diseases and the suffering they engender. Historians of health or medicine have studied one specific disease, such as the history of cholera or tuberculosis, or broader concepts, such as disease prevention, sanitation, or public health. The outbreak of a new disease or the sudden occurrence of a natural disaster exposes conflicts in social values and priorities. Maureen O’Connell examines the aftermath of Hurricane Katrina and the conflicting values towards the poor that hindered an effective response. New technologies and innovative treatments simultaneously offer hope for the eradication of suffering and create new complexities and ethical dilemmas. Screening increases early detection, but in the case of prenatal care, it forces individuals and society to confront their notions of the kinds of lives they feel are worth preserving.

Disability advocates argue for a more inclusive definition of normal. Thomas Reynolds expands the notion of hospitality to include those most vulnerable. Advances in medical care have increased the life expectancy of those with certain diseases but created new suffering related to their unexpected survivorship. Suffering is thus continually being redefined, with newly framed cultural expectations. Mel Haberman observes that cancer is being redefined as a chronic, life-threatening disease rather than a terminal disease. Although patients are considered cancer-free, a normal response to survivorship is called chronic sorrow. Sheila Santacroce and Ya-Ling Lee have examined post-traumatic stress symptoms (PTSS) in young adult survivors of childhood cancer. Adaptation requires careful communication between survivor and practitioner to address the complex issues that surround survivorship.

LEARNING TO REGARD SUFFERING
The professional regard of suffering is filtered through the practitioner’s personal experiences of suffering. Although many students feel the need to disconnect their personal histories from their clinical experiences, such detachment does not result in a completely objective stance towards patients. Some personal experiences may increase a practitioner’s ability to understand a client, whereas others might make a client’s scenario too close for comfort.

33. O’Connell, Compassion.
34. Reynolds, Vulnerable Communion.
A practitioner who is a breast cancer survivor may have a great deal of empathy for someone who has had the same experiences. If, however, the patient has been diagnosed with further metastases, the encounter may bring many fears to the surface for the practitioner and cause a great deal of discomfort. Practitioners who are themselves parents of young children may find certain clinical situations almost unbearable.

A practitioner may have little patience or empathy for a patient who has contributed to ill health through self-destructive practices. In fact, such discriminatory practices on the part of practitioners can contribute to stigmatization and moral blaming. This is particularly true when a patient is seen as suffering from chronic lifestyle diseases, such as lung cancer resulting from smoking. Professionals may hold judgmental attitudes towards specific populations, such as the homeless, or towards specific illnesses, such as diabetes or hepatitis B, or to patients who are obese, addicted, or labeled noncompliant. Transforming deeply held prejudices and judgments requires educational interventions through transformative learning, which allows the practitioner to see clients in all the complexities of their circumstances and the suffering that encompasses them (see chapter 5). Empathy is a key element in observing the other and in recognizing the experience and suffering of the other without judgment.

ACKNOWLEDGING SUFFERING AND ANSWERING WHY

According to theologian Douglas John Hall, acknowledging the reality of suffering is the first step in being able to enter into the suffering of others. By extension, ignoring individual suffering will close the door on developing a patient-practitioner relationship or constrain it to such an extent that patients cannot authentically share their situation with the observer. Regarding suffering also challenges us to examine how we have responded to our own suffering in personal and professional contexts and how to reconstruct the way our experiences and beliefs have shaped that response. Without this personal work of reviewing one's beliefs, the practitioner may be unaware of the blocks that inhibit full understanding of the other.

Several years ago, I worked as a research nurse on an epidemiological study of congenital defects in infants. The target population of the study was children aged six months or less who had been born with a birth defect. My initial contact with the parents explained the study and asked for their participation in an interview. To do the interview, I traveled to their homes, within a geographic range of no more than four hours from the city in which I lived. I visited women in urban high rises and housing projects, suburban homes, farms, and cottages. In most cases, their lives were changed from the moment they gave birth. When I arrived at each home, I was never sure if the child was still alive or if the defect had been so severe that the infant might have died shortly after birth. In the first few moments in each home, I knew that I had to quickly establish trust. Uniformly, the parents were desperate for answers to the questions "Why me?" and "Why this child?" Those were, of course, the questions that I was unable to answer and had been trained to deflect. As a blind interviewer, I had no inside information to the study, so I could not even express an opinion as to why the defect had happened. Some women were concerned about health issues in their community, particularly when they believed there was an environmental cause. Others felt isolated in their experience of having a child with a defect.

I often wished I could give mothers an answer that would allow them to settle the why questions—that would persist for many of them for years as they struggled to balance this inexplicable reality with their own sense of responsibility.

Illness or suffering disrupts ordinary life and focuses the attention of clients and families on questions such as, "Why me?", "Why now?", or "What for?" When asked these questions by patients, many health care professionals view them as unanswerable and outside of their expertise. Part of being able to hear and respond to such questions requires helping professionals to deal with their own spiritual questions, and also to be comfortable with the diverse range of questions and answers that are held by an increasingly pluralistic world. If professional students have not done such personal work prior to their professional education, it is important that such reflection be encouraged by the curriculum. Such reflection must be unfolded in an atmosphere of trust and acceptance, providing students with safety and confidentiality. This encounter with deep differences is a transformative learning task that requires mentoring and support as new understandings become integrated into one's habit of mind.

37. Hall, God and Human Suffering, 140–41.

PARKER PALMER AND REGARDING SUFFERING

Educator Parker Palmer described his experience with depression and the various types of assistance he received from his well-intentioned friends. When one group of friends attempted to commiserate by saying, “I know exactly how you feel,” Palmer tuned out the rest of their conversation. He could no longer hear their words because they were false and made him feel even more isolated. By contrast, one friend provided exactly what he needed when he arrived almost daily to sit in silence with him and to massage his feet.

The challenge in being present a suffering person is to “simply stand respectfully at the edge of that person’s mystery and misery. Standing there, we feel useless and powerless, which is exactly how a depressed person feels—and our unconscious need as Job’s comforters is to reassure ourselves that we are not like the sad soul before us.” The posture of silent attention and waiting is a necessary moment in the extension of empathic regard.

NARRATIVE

In The Diving Bell and the Butterfly, successful magazine editor Jean-Dominique Bauby describes locked-in syndrome, which he experienced after a stroke left his body paralyzed but his mind completely aware. His memoir was dictated to an assistant using an abbreviated code based on the blink of his eyelid, the only body part over which he had any control. Such a memoir disrupts our sense of how life should go. Bauby had enjoyed a privileged and comfortable life; with little warning, his life was turned upside down. All his relationships were affected—relationships with his body, his family, and his future. Illness narratives such as these can help to engage practitioners and students with suffering in ways that facilitate reflection and empathy.

Listening to such a story in person can establish the beginning of an empathic professional relationship. Rita Charon notes that when patients tell stories of their illnesses, they are “revealing aspects of self closest to the skin thus obliging practitioners morally to listen to the lives of others.” Memoir can provide one way to open the discussion of illness experience to practitioners and to engage their imagination with questions like, “What would someone like Bauby experience?” or “How would I cope with such a loss of independence?” By reading a patient narrative using the imagination, one “relinquishes one’s own coherent experience of the world for another’s unexpected, unexplored, unplumbed, potentially volatile viewpoint.”

Fiction can also provide insight into human responses to suffering. In recent years, popular fiction books such as The Shack have struck a chord with readers who struggle to find meaning in suffering. In The Shack, a father attempts to come to terms with the kidnapping and death of his child by engaging in conversation with a God who challenges his preconceived notions of both God and the nature of forgiveness.

Elie Wiesel’s exploration of evil in his book Night continues to challenge readers to understand how such things could happen and to ensure that they are not forgotten. Fiction does not require that the reader has had the same experience of losing a child or experiencing genocide to be able to imagine the nature of the suffering described. Reading or listening allows one to experience alternate visions of reality and trains the imagination to expand from what it knows concretely to what it can imagine. This ability is essential to empathy, since empathy relies on the imagination to provide insight into the other.

Reluctance to regard the suffering of individuals or communities creates an inauthentic situation for professionals. This is because ignoring the suffering in favor of treatment leads to disconnection in the aims of treatment and in the potential relationality of the situation. As Charon observes, the ability to hear the suffering of another means that one has confronted and found at least provisional answers to life’s big questions. Some students might have addressed such questions before entering professional school as a result of personal illness or family circumstance. Others discover, during their education, the prevalence of suffering and the limits of available treatments to relieve that suffering. Education should offer the opportunity for students to be mentored and accompanied through their experiences of witnessing suffering regardless of their previous personal experience with suffering.

40. Bauby, Diving Bell and the Butterfly.
41. Charon, Narrative Medicine, 78.
42. Ibid., 112.
43. Young, The Shack.
44. Wiesel, Night.
Can the conversation about suffering at any level explore both what unites human experience and what is experienced differently? How have various cultural, religious and spiritual traditions attempted to respond to the issue of suffering, and how has art, ritual, and liturgy embodied a response to that suffering? How can professionals learn to respond to the big questions of suffering, while dealing with individual and family instances of that suffering? Meaningful engagement with practices of different traditions related to care of the sick person, care of the body, and care of the dying person allows the helping professional to encounter the diversity of beliefs in a pluralistic world. In addition to cultural differences, students in helping professions will also meet those for whom their traditions no longer speak meaningfully and who are essentially homeless in a spiritual sense. As part of the professional training, one must engage with the spiritual questions personally in order to be able to hear and meet the needs of suffering clients. Meaningful questions that will challenge the helping professional might include the following:

1. Why me?
2. Why now?
3. What can be done?
4. Will things ever be the same?
5. Will others still care about me if I am changed in various ways?
6. What hope can I have in this situation?
7. Where will I find the courage or resources to deal with this?
8. What will the rest of my life be like?
9. What will happen to me if this treatment or intervention does not work?
10. What happens to me when I die?
11. Who will care?

Perhaps one way to sort out the why questions is into two categories: (1) questions about the human condition and (2) questions related to where to find hope in the face of that knowledge. The first category of why questions can be answered from a variety of philosophical, theological, comparative religious, or psychological perspectives. The notion of hope, however, is complex, since most helping professionals are care-ful to balance presenting false hope with clinical realities. In the past, professionals believed it was acceptable to lie to the patient in order to preserve hope. Hope for clients with chronic conditions requires a re-framing of one's expectations and requires transformation at the deepest levels. Hope and trust are spiritual concepts that can affect health promotion and health-affirming choices in clients. Sally Thorne has studied the role of communication between patients and health-care providers and has argued that communication can facilitate "coping, self-care management, and an optimal quality of life for those with chronic illness."  

The stress on positive thinking in combating certain illnesses shifts blame to patients who do not show the heroic courage that many survivors exhibit. A practitioner may personally believe that a patient's prognosis is grave or hopeless, but may later be surprised by an unexpected remission or healing.

The professional regard towards suffering may include an admission that mystery and uncertainty can allow for unexplained interruptions of the course of illness. That uncertainty may be ascribed to the randomness of the universe or to the intervention of divine forces of healing, but openness to different perspectives that allows for empathic regard. For some, these interventions can be encouraged by the use of prayer, laying on of hands, meditation, complementary or alternative medicine, massage, music, art therapy, or therapeutic touch.  A practitioner's ability to be open to a patient's choice of these types of alternatives may affect how much the patient is willing to share about his or her beliefs and experiences.

REFLECTING ON POSSIBLE ANSWERS

Suffering triggers questions that draw us into the diversity of other beliefs and answers. Most world religions address the notion of suffering and the meaning of life. Individual responses to such answers vary widely. Philosophers, novelists, artists, and musicians respond to suffering in ways that speak the unspeakable and can provide solace to those who feel alone in their experience. For practitioners who will regard suffering throughout their careers, a broad exposure to both explanations of suffering and creative responses to it through the arts will be essential parts.

46. See Sperry, Spirituality in Clinical Practice, chapter 7.
of their professional training. Some faculties have created space in the formal curriculum for social, cultural, and religious aspects of suffering and encourage exposing students to the arts as a way to generate reflection and perspective on their experiences.

Robert Smith describes three aspects of the religious response to suffering (of either individuals or communities) that exist across cultures. These include the intellectual dimension, ethical dimension, and experiential dimension. The intellectual dimension includes a search for meaning. The ethical dimension "often occurs as a set of questions about how to respond to the threat of personal disintegration." Helping people sort through their own understanding of the moral understanding of suffering requires great respect for both diversity of belief and flexibility for change in a person's understanding over time. The experiential aspect of suffering is the experience that the person must pass through, which will lead to a different understanding of self and of life. Although suffering in this dimension can be ultimately transformative, everyone does not necessarily experience it in that way.

WORLD RELIGIONS

Most of the major world religions address the nature and purpose of suffering. John Bowker analyzes how suffering is explained in Judaism, Christianity, Islam, Marxism, Hinduism, and Buddhism. However, understanding a belief system does not illuminate how individuals live out those beliefs in their daily experience, particularly when disrupted by the experience of suffering. Sacred texts or scriptures can provide the basis for ongoing interpretation. Authorities who are acquainted with the history of the texts and their reading provide learned commentary on the texts. Suffering sometimes brings a closer encounter with those texts, with enhanced understanding of the meaning of suffering.

Each religion recommends practices for the faithful, which may include showing compassion or care for the neighbor or stranger, practicing forgiveness, or working for justice. A moral stance can be deduced from different religions that inform how one is to live life while on earth. Most religions are further distinguished by different schools of thought or denominations that have specific histories, traditions, and interpretations of beliefs. In full acknowledgment of the complexity of those belief systems, it is beyond the scope of this book to do more than introduce the student to the notion of religions and spirituality in order to better understand some of the answers to the question, "What is suffering, and where does it originate?"

The question of suffering was placed at the heart of Buddhism when its founder Gautama (c.566–c.480 BC) asked, "Why do pain and suffering exist?" The Buddha teaches that suffering in its "universal and existential state can be fought, first and foremost, by recognizing it." Suffering has been translated as dukkha, meaning intolerable or unsustainable. The nature of suffering in Buddhism has two principle aspects. The first is the practical side, namely, the inevitable experience of every man, woman, and child; the second aspect of suffering is philosophical—why does one suffer? There is no permanent self in Buddhism, since the individual is composed of changing physical or mental forces that can be divided into five aggregates. The five aggregates include the four great elements (our five senses), sensations derived from contact with the world, perceptions, mental formations, and consciousness. These five groups constitute the "I" and are constantly changing.

The Four Noble Truths are central to Buddhism and include the following: all is suffering, suffering is caused by desire or attachment, eliminating desire/attachment will eliminate suffering, and the Noble Eight-fold path can eliminate desire/attachment. The Eight-fold path includes holding to right views, right intent, right speech, right conduct, right livelihood, right effort, right mindfulness, and right concentration.

The Theravada tradition of Buddhism teaches that everyone must individually seek salvation through his or her own efforts. To attain nirvana, one must relinquish earthly desires and live a monastic life. The Mahayana tradition teaches that salvation comes through the grace of bodhisattvas. Bodhisattvas defer their own enlightenment to help others, thus enabling many more living beings to attain salvation. The seeker hopes to reach nirvana, which is a state in which there are no desires and no individual consciousness, but one in which suffering ends. The end of suffering or dukkha is also then the end of craving. Suffering is not to be avoided but is part of the path to nirvana. Realizing the truths of death and chance allows the individual to attain enlightenment.

47. Smith, "Theological Perspectives," 159–72.
49. Lampert, Traditions of Compassion, xviii.
50. Selles, "Concept of Dukkha."
According to Islamic belief, suffering can be attributed to the power of sin or the testing by God of an individual. Sin can be forgiven, and reconciliation is possible. Islam teaches one to endure suffering with hope and faith. We are not counseled to resist it, or to ask why. Instead, we accept it as God’s will and live through it with faith that God never asks more of us than we can endure. However, Islam also teaches us to work actively to alleviate the suffering of others. Recognizing that we are the cause of our own suffering, we work to bring suffering to an end. In the Islamic view, righteous individuals are revealed through patient acceptance of their own suffering and through their good works for others. And if we are suffering as a consequence of our own unbelief, then good works will relieve our pain.  

Suffering is an essential component of life in the Hindu belief system, wherein each person is accountable for his or her actions. That is the basis of Karma. Our lives at any given point are a net result of our past actions, both good and evil. We are capable of good as well as evil, since God gave us intelligence and independence. Therefore, we are responsible for the consequences of our actions. The Hindu belief system also includes the belief that our soul, which is immortal, goes through endless life cycles and somehow carries with it an imprint of our past actions. Therefore, the suffering of a good person can be the result of actions in past lives. When a person suffers in this life, they are paying their debt back to the universe to bring balance back to the circle of life. One can experience less suffering in the next life by doing acts of good in the present. Hindus believe their position in life is based on their actions in a previous life, or lives; This is the Law of Karma, which states that from good must come good, and from evil must come evil. Hinduism embraces the existence of suffering in the world and in doing so teaches the paths for one to be free of suffering and obtain moksha, which means freedom or liberation, which is the ultimate human goal.

In one of the schools of Hindu thought, the Samkhya system, pain can be described as threefold: originating from the sufferer, from created beings, and from the gods. Pain is located within the very nature of things. The potential pain or pain yet to come is called the purpose of life. Suffering in the form of pain, decay, and death are common to human experience but do not form the sum total of reality.

The permanent cessation of pain cannot be brought about by thought, but rather by moksha. The individual experiences three kinds of suffering: from internal causes, from physical or material causes, and from circumstances. The way out of suffering is through right knowledge that destroys ignorance and replaces it with understanding. Through the process of liberation, the false self is shed and the true self comes into being. Suffering is not then part of the soul but part of the false self or ego. First, dukkha is revealed to have a redemptive quality; it functions as a guide to knowledge that will end suffering. Second, dukkha is connected to a state of ignorance that leads one to place ultimate importance in the physical body or the immediate. Third, one can eventually escape suffering. Unlike the explanation of a “fall” into sin, Sankhya argues that all is as it always was. Suffering is part of the objective reality of the world and has always been so (prakriti). The universe also contains purusa that is unchanging and neutral, both free from pain and pleasure. Discrimination allows one to distinguish prakriti from purusa. The path to knowledge is attained through detachment and meditation.

Although specific doctrines might change, several themes are common to many world religions. Religion describes the role of the self and the other and how they are related to each other. Such religious beliefs can also teach one how to live in the present reality with compassion for the self and the other. Lessons are provided in how to regard human failure and willingness to change. The role of illusion in Buddhism is important, warning the individual to regard present reality as passing. Finally, the centrality of compassion underscores the importance of kindness to the stranger.

Many patients carry unexamined or inherited beliefs about suffering that are attributed to Christian beliefs but that represent misunderstandings of the nature of suffering and the hope of the gospel. Patients may believe that God is punishing them through the illness experience or that they should somehow choose suffering as part of their education. Choosing suffering or inflicting suffering as some pedagogical exercise is not an acceptable interpretation of Christian doctrine. Religion does not exempt us from the realities of human life—suffering and death are parts of that life. Belief in a future where suffering and death will no longer dominate our lives is part of the promises of Christian faith. The literature on the meaning of suffering is vast and well-covered elsewhere.

51. For discussions of suffering in Islam, see Koslowski, Origins and Overcoming of Evil. See also Heemskerk, Suffering in Mutezilite Theology.

52. Selles, “Concept of Dukkha.”
Professional students need to be introduced to the literature on suffering from both a religious studies and a social scientific perspective. Such reading will enable them to put into perspective their own experiences of suffering, but also to develop empathic regard for others who suffer or who understand their suffering differently. An understanding of pastoral practices in relation to care of the body in illness, health, and death, as well as ritual and liturgical practice, can only improve professional practice and the ability to empathize.

In addition to the answers given by theologians, philosophers, and other thinkers, the patient perspective allows us to see how some of these ideas are lived out in the lives of patients and clients. In a study of the responses of children and their families to children's cancer symptoms, R. L. Woodgate and L. F. Degner examine how patients regard suffering when it is seen as part of the necessary regimen towards finding a cure.53

Patients and clients with established belief systems and those who have never closely examined their beliefs find ways to deal with their hopes and fears in practical ways that may include contradictions between belief and practice, faith and confidence in an unseen future, or denial of previously held beliefs. Such transitions and adaptations to the power of suffering in individuals and communities are important to the course of their illness and to their participation in activities that support or detract from wholeness.

SUFFERING AS COMMUNAL CHALLENGE

Suffering has been the target of many platitudes that are largely unhelpful to those experiencing suffering. Yet suffering presents the greatest challenge to human individuals and communities, namely the challenge to be present to those suffering. As part of the human reality on earth, we have an active role to play in regarding suffering. Douglas John Hall notes, "In whatever ways God continues to suffer with those who suffer—and they are numberless—we for our part know that this is our vocation. We are part of the response of God to the massive suffering of God's world."54 Such an active role requires a willingness to experience pain and to stand with those who are alone in challenging situations.

For those who share diverse religious beliefs, that challenge means forming not communities of comfort and like-mindedness, but communities of suffering. Hall notes that gathering as a suffering community and sharing burdens is the beginning of the healing process. He contrasts this active participation in suffering to a passive "spectator spirituality" that exists in a suffering world "without passion or compassion." Although the concept of rejoicing in suffering has often been both unattainable and misrepresented, Hall says that the source of rejoicing in suffering is not due to evidence of personal redemption but because it points "towards a hope for our world."55

Liberation theologian Jon Sobrino defines mercy as the basic attitude toward the suffering of another whereby one reacts to eradicate that suffering for the sole reason that it exists. We do not have the option to turn away in the face of suffering because the suffering of another challenges our being. Action responds to the belief that the suffering of another ought not to be. Mercy, in Sobrino's definition, is not just the work of the individual, but also of the church, whose job it is to be with the suffering other. He describes the recognition of suffering and the response of compassion as something pre-theological and even pre-religious. The elimination of suffering from the world is the priority.56

On the subject of suffering, Dorothee Soelle notes that suffering people must find a way to express their experiences rather than having someone speak on their behalf. She challenges us to work to abolish the circumstances that lead to suffering, including poverty and political tyranny. Suffering, she notes, affects every dimension of life. Her critique of traditional Christian views of suffering targets the notion that, on the one hand, they emphasize divine power, and on the other hand, they highlight the Christian willingness to suffer. The ultimate result of such an understanding merely contributes to Christian masochism, since "suffering is there to break our pride, demonstrate our powerlessness, exploit our dependency. Affliction has the intention of bringing us back to

53. Woodgate and Degner, "Expectations and Beliefs about Children's Cancer," 479-91.
54. Hall, God and Human Suffering, 141.
55. Ibid., 142.
56. Sobrino, Principle of Mercy.
a God who only becomes great when he makes us small.” 57 She critiques the notion that all suffering is punishment for sin.

Applied to modern faith communities, Soelle’s ideas would suggest that the health of a faith community might be measured, not by the budget or the luxury cars in the parking lot, but by its ability to create honest space for members to share their suffering and to stand with the suffering of those outside the walls of the faith community. Rather than hide the pain of brokenness behind smiling faces, members could weep together at the evidence of broken relations around them. Pain therefore leads a person to look outward in order to achieve solidarity. Soelle writes, “The sufferer himself must find a way to express and identify his suffering; it is not sufficient to have someone speak on his behalf. If people cannot speak about affliction they will be destroyed by it, or swallowed up by apathy.”

These approaches to suffering challenge us find connections between sufferers and observers and to enter willingly into a place of deep attentiveness and listening. Choosing to enter into suffering is a far more challenging task than blaming the victims or isolating them from the others. This task of mit-leiden, or suffering with, is not restricted to professionals, or to faith communities, but is part of our human responsibility to recognize the interconnectedness of our life on earth. If professional students do not encounter what Giroux has called a “pedagogy of responsibility,” how can they be expected to work out of a politics of commitment? 58

SUFFERING IN ACUTE OR CHRONIC SITUATIONS

Cassell distinguishes disease from illness, with diseases being specific entities characterized by disturbances in the structure or function of any part, organ, or system of the body. By contrast, illnesses affect the whole person and are the set of “disordered functions, body sensations, and feelings by which persons know themselves to be unwell.” 60 Although a chronic disease may be present, one cannot assume that the person is suffering from chronic illness. In some cases, disease may be absent but

57. Soelle, Suffering, 19.
58. Ibid., 76.
60. Cassell, Nature of Suffering, 49.

the pain may still be disabling, as in chronic pain syndrome, for example. In a sense, his work highlights the individual nature of suffering. It is an important reminder for professionals that despite our knowledge about the expected course of illness or the normal and abnormal limits that are expected, we must leave room for individual variations and experiences. Professionals who lack the necessary humility forget that patients’ experiences are their own, and expertise in a professional field does not automatically provide one with precise insight into patients’ experiences. For this, one must practice empathic regard, attempting to view the patient’s experience from within, rather than impose generalized understandings on that experience.

ANTHROPOLOGY OF SUFFERING

Global suffering has many names, including torture and genocide as intentional forms of harm. In addition, “untended” harm is done by globalization, unequal distribution of resources, exploitation, and disregard for ecological questions. Only by understanding local suffering and its relation to global inequities can one accurately confront the suffering of the world’s poor or marginalized.

Although it is a challenge for an outsider to describe the experience of suffering in other cultures, there are common elements that transcend culture. Professionals who work with suffering populations or individuals could benefit from anthropological understandings of how people suffer and the diverse cultural meanings of that suffering. To respond effectively to the diverse populations who seek help, such intercultural understanding will be an essential skill. The ability to contextualize suffering is an essential prerequisite to effective and empathic response.

CONCLUSION: REGARDING SUFFERING

Witnessing suffering is a difficult task for many. Observers report being exhausted, drained, or emotionally challenged when placed face-to-face with a suffering person. The desire to fix the situation, alleviate the pain, or change the conditions that led to the pain can overwhelm the observer. Identification with the sufferer can lead the observer to experience similar pain. For some observers, awkwardness and the inability to find an appropriate response can trigger emotional or physical withdrawal. In addition, practitioners are simultaneously learning to complete a
procedure, deal with technology, reassure family, appear more skilled than they are, and deal with their own anxieties in these situations.

For beginning practitioners, it may be easier to focus on the technology, or on the specific injury, wound, or procedure, than it is to relate to the patient's suffering in the situation. Although the student may be learning to start an IV, the patient has not only that moment to deal with, but also the cumulated effects of all the previous procedures, pain, and uncertainty that accompany that experience. Because the suffering is subjective and individual, a professional might choose to focus on the technique or procedure rather than the suffering. The patient's side of this encounter likely includes the memory of past suffering, whereas time for the clinician is often experienced as discrete events that need to be done under intense pressure. Notions of time and suffering are shaped by the professional culture and the client experience of suffering, and they may be marked in very different ways.

Student practitioners in health settings may panic when they witness for the first time a post-surgical complication, an acute myocardial infarction, a woman in childbirth, or a patient in deep depression. A profound sense of inadequacy and incompetence can accompany such experiences. Often the student attempts to compensate for such identification by assuming a detached professional role. Mentors can either provide space and time for the examination of these complex emotions or choose to shut down discussion completely. Such a choice will have important consequences for the professional student in the future.

Regarding suffering is not enough. Margaret Farley notes that compassion is a powerful response to human need and suffering. Sometimes, however, an appeal to compassion can remain an empty appeal—not because the experience of compassion is empty but because the recognition of what compassion requires is missing. Further, Farley reminds us that compassion needs to be normatively shaped. Farley calls for an attitude of compassionate respect that recognizes that care has normative requirements. Care has several meanings, including a disposition to affective response, affective response itself, and actions that express affective response. The determinants of right caring, she notes, depend on the reality of the cared for as well as the carer, and the nature of the relationship governs what kind of caring happens.

62. Farley, Compassionate Respect, 64.
63. Kleinman, Illness Narrative, 251.
QUESTIONS FOR FURTHER DISCUSSION

1. Describe an experience where you witnessed suffering. Describe the feelings you had at the time. Recall what you said or did at the time.

2. Describe an experience of your own suffering. What were the things that made the experience better or worse for you? Do you prefer isolation, or do you seek out others?

3. The media is filled with stories of social suffering. Research one such location of suffering. What factors contribute to this suffering? What sources of assistance have been provided? When you read the media coverage, do you feel empathy for these people, or do you feel detached? Describe your feelings.

4. When you have experienced suffering in your family or among friends, what was their response to you? Describe an experience of suffering from your childhood.

5. As a child, what explanations were you given for suffering? What explanations do you currently give to explain suffering?

6. Do you belong to any organizations or faith communities that respond to the suffering in the world? What types of response do they provide?

7. Have you ever experienced healing space? What, for you, are the characteristics of healing space? Can you draw or describe it?

8. Have you participated in rituals or liturgies that respond to suffering? Describe the ritual and how it made you feel.

9. Choose one art form (film, novel, poetry, music) that deals with suffering. Write a short reflection on how the piece engaged with suffering and how it affected you.

10. Visit a faith community and observe how its practices engage with suffering. Journal or blog a short reflection on your observations as an outsider or guest in this community.

INTRODUCTION

I worked as a per-diem nurse in a suburban group home for adults with physical and intellectual disabilities. One of my regular clients was Marie. Her few possessions included some street clothes and institutional pajamas. She was autistic and had spent decades in an institution. She did not communicate in any discernible way and preferred to stay in her room. I tried to connect with her through singing, speaking, and talking in her native language, but I never observed a response.

My other client was Stan, a man in his sixties who was surprisingly robust considering that he had been bedridden for years. Caring for him included placing him on a lift and taking him to the whirlpool bath. He also received feeding by stomach tube, medications, and passive exercises to his limbs. Stan would make some sounds, perhaps in protest, in response to treatment, but he did not communicate in a way that might be called interactive or intentional.

The care of Stan, Marie, and others in a state-funded group home was compassionate and followed state regulations. Staff continued to communicate with the clients even if the communication appeared to be one-sided. These clients had spent a large proportion of their lives in state institutions and had been moved out to smaller, homelike settings.

1. Charon, Narrative Medicine, 180–81.
2. Client names have been changed.