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# Illness and Meaning: A Review of Select Writings

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## Abstract

This article explores select writings of seven authors who have examined the experience of serious illness, the meaning of it, and how individuals create or discover that meaning. These authors have been seminal thinkers in the field, and their works have influenced current thinking about illness and meaning. This article explores six major themes from select works of these authors: (a) postmodernism, culture, and illness; (b) embodied knowledge and the sick person; (c) illness narratives and their moral function; (d) key relationships for the sick person; (e) illness and death; and (f) the meaning of being ill. Apart from these, areas for future exploration are included.

## Keywords

illness, meaning, death, postmodernism

Nietzsche (1887/1967) proclaimed an uncomfortable truth: “Man is more sick, uncertain, changeable, indeterminate than any other animal, there is no doubt of that—he is *the* sick animal” (p. 121). Being sick or ill is not something we like to contemplate. At best, illness interrupts briefly the normal flow of our lives, and we go on without much pause or consideration; at worst, we shudder with the realization that an illness may precede our death.

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Like Tolstoy's (1886/1960) Ivan Ilych, we deny and think, "It cannot be that I ought to die. That would be too terrible" (p. 131). Those who die of a final illness travel back and forth between the land of the well and the land of the sick (Sontag, 1977), usually happy to relinquish their passport to the land of the sick on leaving, hoping never to return, or at least not for a long time.

This article explores select writings of seven influential authors who have examined the experience of critical illness. Their works probe several key questions: (a) What is it like to be seriously ill? (b) What does it mean to be sick? (c) How do individuals make or discover meaning in their illness? If Nietzsche is correct, these are not academic questions; rather, they explore the essence of what it means to be human. I have purposely limited my selection of writers to review to several who have been seminal thinkers in the field and whose works have influenced our notions about illness and meaning over the past three decades. Their works include personal narratives of illness, essays, scholarly research, and philosophical exposition. In this article, I examine the major ideas from their writings and explore the implications for additional study.

In 1977, Susan Sontag published *Illness as Metaphor*; this groundbreaking book initiated much of the discussion about sickness over the past 30 years. A cancer survivor, she challenged current thinking about illness because she highlighted the negative cultural meanings that society attaches to illnesses, and the risk that these meanings pose for patients. Sontag (1990) extended her ideas in a later work about acquired immune deficiency syndrome (AIDS), *AIDS and Its Metaphors*. Arthur Kleinman's (1988) *The Illness Narratives* demonstrated that patients could use narrative to order and create meaning from their painful experiences; in addition, he proposed a model for analyzing illness narratives at several levels and, being a medical doctor and a psychiatrist, he suggested an ethnographic praxis for health professionals to use to understand the world of the sick person. The writings of both Arthur W. Frank and Anatole Broyard are excellent examples of personal narratives about the lived experience of serious illness. A university professor, Frank (1991) described his experiences with a viral heart infection and testicular cancer in *At the Will of the Body*; Broyard (1992), who was a book critic and editor for *The New York Times*, wrote *Intoxicated by My Illness*, one of several essays in a book of the same title, where he explored his relationship with prostate cancer while he was dying from it. Both books exemplify the emotional power of illness narratives. Exploring the importance of narrative from a more scholarly view, Frank (1995) also wrote *The Wounded Storyteller*, an analysis of narrative types and their functions.

Gay Becker's (1997) ethnographic study *Disrupted Lives* examined in detail the cultural implications of illness stories of individuals who participated in studies about infertility, life transitions, and the impacts of strokes. As researcher, she presented a cogent argument for the pervasive influence of culture on the experience of illness and the meanings associated with it. Similarly, *Illness and Culture in the Postmodern Age* by the essayist David B. Morris (1998) assessed the impact of the postmodern culture on the experience and meaning of illness. Morris challenged our single-minded focus on the biomedical model and suggested that illness is a biocultural phenomenon. Finally, in *Conversations on the Edge*, Richard M. Zaner (2004), a medical ethicist, employed a phenomenological orientation in listening to the lived experiences of individuals undergoing illness crises; using the patients' stories as a starting point, he explored the philosophical implications of their struggles.

This article examines important ideas about illness and meaning from the nine books of these seven authors. The six major themes from these works that I examine are (a) postmodernism, culture, and illness; (b) embodied knowledge and the sick person; (c) illness narratives and their moral function; (d) key relationships for the sick person; (e) illness and death; and (f) the meaning of illness. Based on these themes, the article suggests areas for further consideration and study.

It is important to note certain terms used in this article. To discuss the meaning of illness begs the question about the definition of the word *meaning*. By meaning, I refer to first, what the illness signifies to the person who experienced it, in other words, the importance of it to the individual; and second, to the outcome from different levels of analysis that may be employed to understand illness (Kleinman, 1988). Also, I use the terms *illness* and *sickness* interchangeably in spite of the fact that several authors make a distinction. Kleinman distinguishes between the lived experience of the patient (illness), the objective classification of a medical disorder (disease), and the manifestations of a disorder across populations (sickness). Frank (1991) discriminates similarly between illness and *disease* but remains silent on any specific use of the term *sickness*; and Morris (1998), while recognizing the difference between illness and disease, believes that both terms are arbitrary conventions, remnants of Cartesian dualism that separates the mind and the body into subjective (illness) and objective (disease) realities. As noted, I use illness and sickness interchangeably, usually referring to the lived experience of the patient; when referring to the formal medical disorder, I typically use the term *disease*. This approach reflects common usage of these words and acknowledges that the medical term *myocardial infarction* says little about the lived experience of the person who has had a heart attack.

## Postmodernism, Culture, and Illness

According to Morris (1998), *postmodernism* refers to the culture of the Western world since the end of the Second World War. Postmodernism is not a well-defined or systematic worldview but a collection of perspectives that are “pluralistic and multicultural, a freewheeling consortium of heterogeneous parts” (p. 24). Those parts include ideas that our world is constructed of images and representations, reflecting assumptions of the social, political, and cultural environment; that those representations are media generated and often *hyperreal*, creating a world where images count as more real than reality; and that our world consists of fragmented images and voices, consumerism, and global marketing. Morris claims that postmodernism has transformed the experience and meaning of illness. He cites AIDS as an example: AIDS is not just a biological disorder but a condition existing against the cultural backdrop of homophobia, gay rights, the geopolitics of distributing life-extending drugs to Third World countries and the political agendas of advocacy groups. The biomedical model—which has dominated thinking for over a century—views AIDS only as a disease within a particular taxonomy, and the model no longer fits; in the postmodern world, disease is *biocultural*, a construction of biology and culture that affects the experience and meaning of illness for the person and family.

Frank (1995) also agrees that postmodernism has affected the patient’s experience of illness. He sees a clear cultural divide between modern and postmodern notions of illness and treatment: In the modern view of illness, technology dominates as the answer to disease and dying; medical experts colonize the body, viewing it as a territory to be conquered or cured; individuals are either well or sick, and each of these states carries certain responsibilities; and individual suffering becomes lost in disease nosology as defined by medicine. In the postmodern world, however, patients give voice to their illness experience, rejecting the official medical story of their condition as incomplete; they realize that they are neither sick nor well, but members of the “remission society” (p. 9) who appreciate that health and sickness form a unified whole rather than mutually exclusive parts; and their illness stories express their unique suffering, often untold by the medical establishment.

### *The Patient and the Physician*

The relationship between the patient and the physician represents a clear flash point indicating the cultural divide between the modern and postmodern experience of illness. Physicians are trained in the biomedical model—the

essence of the modernist approach to illness and the sick person—and as Frank (1991) has noted, one of the implications of this worldview is the colonization of the body. Based on his experiences with testicular cancer, he believes that patients often assume a passive role, surrendering their bodies to medical professionals who try to restore these out-of-control bodies; the relationship is asymmetrical because patients share intimate details about their lives and bodies, whereas physicians can choose what they will share, if anything. Physicians often remind patients in subtle ways of their lack of knowledge, and medical professionals have little time, other than a perfunctory acknowledgment, to understand the suffering of the sick person.

Broyard (1992) also wrote a personal account of his struggles with a serious disease. Ironically, Broyard titles one of his essays “The Patient Examines the Doctor,” and he turns the biomedical model on its head by reversing roles and examining his physicians’ suitability to care for him. He finds them wanting and proceeds to describe the kind of doctor required in a postmodern world. Broyard wants a doctor who values relationships with others; who understands the loneliness and panic of the patient; who is metaphysical, a doctor of the soul; who figures out what it is like to be a patient; who acts as an empathic witness for the patient’s suffering; and who is able to talk at length with the patient. Ultimately, the physician functions as a kind of Virgil, guiding the patient through the mental and physical purgatory of serious illness.

Similarly, Morris (1998) confirms the need for physicians to listen in a postmodern world where some patients seek a voice in their diagnosis and treatment. Kleinman (1988) provides such a methodology with his ethnographic approach to the chronically ill. The physician completes several steps through a series of in-depth interviews: (a) reconstruct the illness narrative of the patient; (b) analyze it for meanings associated with symptoms, culture, personal, and interpersonal relationships; (c) record the psychosocial problems associated with the disease and the steps the patient has taken to resolve them; (d) capture a brief life history of the patient; (e) discover the patient and family’s explanatory models about the disease; (f) negotiate treatment with the patient and family based on a discussion of all the explanatory models, including the physician’s; and (g) reassess the physician’s model for bias based on previous negotiation with the patient and family. Kleinman proposes a level of engagement and understanding between patient and physician that is atypical in the modernist biomedical model.

Zaner (2004) powerfully demonstrates the critical nature of the patient–doctor relationship in his third narrative “Hope Against Hope.” It is the story of Mrs. Oland, a 72-year-old woman dying from multiple illnesses: hypotension, pneumothorax (air in the pleural cavity), respiratory problems, and end-stage kidney failure. Mrs. Oland was not expected to recover and was connected to a

ventilator for life support. Her husband refused to allow the doctors to remove his wife from the ventilator and feeding tube and insisted on similar support for her at home. The medical staff assumed that he was in denial about her impending death, although he believed that they were insensitive to his wife's wishes to be at home and only wanted to force a decision from him about life support. Zaner, a medical ethicist, came in to break the impasse.

Zaner (2004) discovered a significant insight about the patient–doctor relationship as he entered Mrs. Oland's hospital room one day. He noticed that she had a compelling effect on him because of her vulnerability. The medical staff and technology overwhelmed the diminutive patient, yet in spite of this asymmetry, Mrs. Oland drew others to her. She was the center of attention. Zaner reflects on the power of the medical establishment over the patient, the “existential reality” (p. 58) of that situation. The asymmetry of power inheres in the patient–doctor relationship, particularly in the biomedical model that has dominated Western culture. Zaner then asks, given such imbalance, why does the healer not take advantage of the patient? What prevents this from happening? He proposes that for doctors true to the Hippocratic tradition, the compelling vulnerability of the patient paradoxically prevents this from occurring: “Precisely because the physician can take advantage, therefore this ought never be done” (p. 65). The patient's sick body awakens a moral cognizance and a sense of responsibility on the part of the healer. There are subtle and not so subtle ways in which physicians hold power over their patients and, given the tendency of the modernist biomedical model to reinforce this imbalance, physicians must consciously cultivate a relationship that respects the inherent dangers in that asymmetry. That requires a post-modern sensibility.

Zaner's (2004) narrative also points to the kind of patient–doctor relationship characterized by honest talk and empathic listening. When this occurs, the patient exudes vulnerability, and the appeal for help compels engagement from the physician. In such an encounter, Zaner discovered the real reason for Mr. Oland's resistance: not denial, but guilt that he never allowed his wife to talk about her death because he could not face the discussion. The prospect of that was simply too much for him.

### *Cultural Meanings and Illness*

Societies attach cultural meanings to a disease, and this affects the experiences of individuals who are sick. Sontag (1977) presents cogent examples of the cultural meanings attached to diseases throughout history. Two examples are tuberculosis (TB) and cancer. She highlights differences in the way Western

society has viewed these two diseases: TB as a spiritual disease, cancer as a bodily disease; the TB death as refined and beautiful, the cancer death, fearful and agonizing; TB as an aphrodisiac, cancer as desexualizing; and TB as a disease of passion involving excess or sublimated desire, cancer as a disease of passion involving insufficient or repressed desire. Not surprisingly, 19th-century society romanticized TB, while 20th-century society has demonized cancer. In effect, illness becomes a metaphor, a container of meaning.

For Sontag (1977), both characterizations are false: TB is not a spiritual disease that refines the intellect and soul nor is cancer a “demonic pregnancy” (p. 14) that overtakes the body. These perspectives reflect cultural attitudes of the time and often change, according to Sontag, when the cause for the illness no longer remains mysterious. For example, the myths associated with TB disappeared after the discovery of the tubercle bacillus, the discovery of streptomycin, and the introduction of isoniazid in the mid-20th century. In the case of cancer, medicine has not identified a single cause so the associated metaphors continue to hold power over individuals with disastrous effects. Sontag (1990) states that the negative associations surrounding cancer—bolstered by the use of military metaphors—demonize the disease and indirectly stigmatize the cancer patient; on this slippery slope, many cancer patients feel at fault for having the disease, and then some fail to seek the appropriate treatment. She cites as an example AIDS patients who, under the burden of shame and guilt, seek out unproven, questionable therapies rather than use scientifically proven, illness-specific treatments.

Sontag (1977) offers an insightful and convincing discussion of illness as metaphor. Her solution, however is radical and flawed: “My point is that illness is *not* a metaphor, and that the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking” (p. 3). She abandons interpretation or metaphorical thinking about illness because it is moralistic, and she calls for the elimination of metaphors associated with illness, especially military ones.

What Sontag (1977) does not address is the possibility that individuals derive significance from their illness experiences and that those meanings are not necessarily moralistic or negative. The literature abounds with quest narratives (Frank, 1995) describing the odysseys of those who have come out on the other side of serious illness. Since the publication of *Illness as Metaphor*, some writers have acknowledged Sontag’s groundbreaking ideas but at the same time have criticized her wholesale abandonment of metaphor and meaning.

Broyard (1992) argues that Sontag condemns the use of metaphor too harshly and that her discussion conceptualizes illness, rather than deals with

it at the level of those who are sick every day. For him, metaphor affords a way of learning about one's illness or even identifying with it; he suggests that patients use metaphors to reframe their illnesses as uniquely theirs, something they have earned. Sontag would bristle at the notion of patients taking responsibility for their illnesses; however, Broyard playfully searches for new ways to understand and relate to illness. Through metaphor, he assesses his sickness with humor and insight about what it is like to feel that death has bypassed him, at least temporarily: "In my own case, after a brush with death, I feel that just to be alive is a permanent orgasm" (p. 28).

Morris (1998) also takes issue with Sontag (1977) and claims that cleansing illness of all meaning diminishes the positive value of cultural traditions associated with illness that serve a function of safety or protection. He cites as examples the traditional Apache ailments of bear-sickness and snake-sickness, which comprise different syndromes afflicting those who encountered bears or snakes; Morris theorizes that these illnesses grew out of a cultural tradition that recognized the possibility of a fatal encounter with a Southwestern prairie rattler or a bear. The illnesses serve to remind individuals of this reality. Morris insists that all illnesses are biocultural, and if so, then Sontag's wish to eliminate meaning from illness is futile because the cultural context always combines with biology to produce an illness experience. In fact, metaphor may be necessary to explain illness: Metaphoric language contains emotional power and the sick person often uses metaphors to share emotions, express bodily distress, help understand loss and disorder, or create continuity between the life before illness and the life after (Becker, 1997).

Beyond the specific meanings that a culture attaches to a disease, cultural ideologies pervade society and affect the experiences of the chronically ill. Becker's (1997) ethnographic study of disruption highlights underlying ideologies in the United States about life, health, and productivity that shape individual responses to disease. One such ideology is the notion that life is predictable, that there is a linear continuity extending throughout one's life. Life is supposed to be orderly; when this does not happen people experience disorder and chaos. Becker notes that illness narratives often reflect this cultural ideology because they demonstrate a search for coherence and integration after disruption. They show a desire on the part of the sick person to conform to how life should be lived—according to the culture. The stories are "moral discourses" (p. 16) because of the innate tension between the normalcy of the cultural ideology and the actual, disrupted life of the sick person; the illness narrative will reflect the ideology and show how the person tried to live up to it or was unable to. One such ideology is the culturally inbred desire to persevere, be determined, and be self-reliant. Other notions also influence people's

experiences and responses to illness, such as “individuals can control their environment,” and “people should take responsibility for their own health.”

## Embodied Knowledge and the Sick Person

Several writers refer to the body as the vehicle for self-knowledge and experience. We live our lives in our bodies and when the body breaks down—as it does in serious illness—so do we; disease denotes a body out of control, and when disease disrupts the body, our lives become chaotic as well (Frank, 1991). Frank discards Cartesian dualism in claiming that he was not a separate self observing his body fight cancer tumors; his self, body, and tumors were all one. Becker (1997) also espouses the dominance of the body regarding knowledge and experience: A person is an embodied self, and illness changes the knowledge of one's body; the individual experiences illness from the perspective of the historical body. In fact, the first task of recovery following illness is to confront the body because that is where the restoration of order begins. That is where the person strives for normalcy and seeks to regain continuity with the historical body that was once healthy. It is through the body that the recovering person begins to create the meaning of the illness experience (Becker, 1997).

Both Morris (1998) and Kleinman (1988) propose that the historical body reflects cultural influences as well as biological processes, hence making bodily disease biocultural. For example, arteriosclerosis is the biological symptom of coronary heart disease; however, cultural factors—alcohol and cigarette consumption, obesity, lack of exercise, diet, and stress associated with lifestyle—all contribute to the embodied experience of people with this disease. As Kleinman (1988) notes, somatic symptoms include knowledge about the self, the body, and their relationship to each other and other aspects of the person's world. For him, the illness experience comes out of the dialectic of personal and cultural meanings on the one side and the inexorable biological processes on the other.

The concept of illness as a biocultural phenomenon originated largely in the pioneering studies of Selye (1976), who began his career as an endocrinology researcher at McGill University in Canada. During his early attempts to discover a new sex hormone, Selye noticed a set of common physiological symptoms in sick people that were independent of any specific disease. From these findings, he developed a theory of stress response, which he called the *general adaptation syndrome* (GAS). According to Selye, the stress syndrome is the body's response to perceived emotional or psychological duress. The syndrome consists of three stages: (a) an alarm stage, where the individual's autonomic nervous system reacts to the stressors with hormonal

changes that produce a flight-or-flight response; (b) a resistance or adaptation stage, where the body adjusts to sustained stress, often to the detriment of the person; and (c) an exhaustion stage, where the individual's finite supply of adaptation runs out, and death eventually ensues.

The impact of Selye's (1976) work has been far-reaching. The links between psychological duress and illness have altered the way lay people and health professionals interpret illness. New terms have emerged such as *psychobiology*, *mind/body healing*, and *psychoneuroimmunology*; also, new industries have arisen in response to the demand for more holistic perspectives toward health and illness. Ongoing research since Selye supports the notion that sustained duress—without some kind of compensation—puts individuals at increased risk for many health problems because of the effects of stress on the immune system (Suter, 1986).

There is, of course, a dark side to the concepts of illness as a biocultural phenomenon, and illness as stress induced—that being the inordinate accountability that some patients assume for their illnesses. Describing the new paradigm of health, Capra (1982) states that “mental attitudes and processes not only play a significant part in getting sick; they can also play a significant part in getting well” (p. 328). As true as we now believe this to be, if taken to the extreme, it burdens the sick person unjustifiably. The tendency to judge or blame the patient angers Sontag (1977), who notes the characterization of cancer patients as unemotional, inhibited, and sexually repressed. As stated earlier, she believes that such meanings harm patients.

### *A Typology of Embodiment and Illness*

Frank (1995) presents the most in-depth discussion about embodiment and illness. According to him, the key problems of embodiment are (a) control of bodily functions, (b) body-relatedness, (c) relationship to other bodies, and (d) expression of desire through the body. A person or body-self responds to each of these issues through actions covering a spectrum of possibilities. For example, the sick person dealing with control of bodily processes lives along a continuum of choices from predictable to contingent, one end representing control and the other end representing chaos, where the body cannot be controlled. Frank proposes that where the sick person lives on this continuum—which involves choice—becomes critical as society stigmatizes those without mastery over bodily functions. Regarding the problem of body-relatedness or the relationship of the self to the body, the continuum of action goes from dissociated to associated; regarding the relationship to others, the spectrum goes from monadic (the body-self as existentially alone) to dyadic

(the connection to other body-selves who suffer); and regarding the expression of desire, the range of behavior goes from lacking (the cessation of desire) to productive (the initiation of meaningful action).

According to Frank (1995), the choices that body-selves make in the face of illness result in the four ideal typical bodies: (a) the disciplined body, (b) the mirroring body, (c) the dominating body, and (d) the communicative body. The disciplined body strives for predictability, practices self-regimentation; it is dissociated as the body becomes an “it” to be managed, and it rarely seeks association with others, making it monadic. In its ideal form—when regimentation and compliance become ends in themselves—the disciplined body lacks desire. The mirroring body also seeks predictability in its goal of being like other bodies that represent the culturally sanctioned view of health; it does this through endless consumption of goods and services. The mirroring body is monadic in its self-absorption and concern about others as either friends or enemies, and it exhibits desire, but that desire is monadic in its single-minded focus on the body-self. The dominating body acknowledges the contingency in disease, but refuses to accept it, and displaces the resulting rage and disappointment onto others. It is dissociated from itself because the body is out of control and unacceptable; however, unlike the disciplined body, the dominating body is dyadic as it turns against others in its disgust of itself.

The most idealized type for Frank (1995) is the communicative body. It accepts contingency as an inevitable part of life and is fully associated with itself, recognizing the complete interdependence and unity of the body-self. The communicative body is dyadic because it recognizes its own suffering in the pain of others; it desires because it wants to relieve the discomfort of others. The communicative body represents for Frank the most ethical choice for the sick person. The individual choosing this option communes with others through the body; “the body itself is the message” (Frank, 1995, p. 50). The problems of embodiment, the choices of action, the four ideal body types—all these form an integrated typology about the body-self and the experience of illness. The typology provides the sick person and health professional with a way of understanding the problems associated with serious illness and the responses available.

### *Other Views Regarding Embodiment and Illness*

Morris (1998) points to some of the same problems of embodiment with the perspective of postmodernism. He suggests that many in the postmodern world follow a utopian vision of health: the solitary, private body that is sculpted to perfection, valued only as an object of vision. This body is much

like the mirroring body noted above where the self—rather than existing as an embodied being, an interdependent unity of body and self—simply equals the body. For Morris, this perspective results in confusion about health and illness. Health of the private body becomes the highest good, including the appearance of health; health also equates with beauty and eroticism. Ironically, illness—which is often concealed or denied—comes from the pursuit of perfect health through diet pills, anabolic steroids, silicon injections, or plastic surgery. This distorted view of health and illness diverges considerably from the notion that illness is not an accident but a part of life and a vulnerability to be accepted, not denied (Frank, 1991).

Becker (1997) emphasizes the chaos that occurs when disorder pervades the body: Illness threatens the embodied self with disruption and possibly death. Prior to being sick, the person pays little attention to the body, but the disruption interferes with bodily routines, forcing the individual to fill the void by redrawing the relationship between the self, the body, and the environment. The sick person, according to Becker, contends with ideal representations of the body in culture; if the individual cannot exemplify those ideal images, then bodily stress may be great. In response, the individual may fight the prevailing cultural norms, redefine normalcy, or follow other ideologies more consistent with actual bodily experience.

## **Illness Narratives and Their Moral Function**

If illness obscures the individual's destination in life and disrupts a worldview, then narratives attempt to repair the damage by redrawing the map and highlighting new destinations (Frank, 1995). At the personal level, according to Frank, narratives restore memory or the sense of coherence and sequencing that illness has thrown into disarray. A new self—the one required after illness—comes into being in the creation of a narrative. Broyard (1992) sees narrative as a way to control or detoxify illness; if written with style, the narrative serves as a creative counter to the disease. It becomes the vehicle through which others can understand the dying person. Similarly, Kleinman (1988) states that illness narratives help the sick person to order and give coherence to events. He cites an example when he was working on a rehabilitation unit as a medical resident and had to find a way of comforting a 7-year-old, female burn victim. Only by telling her story and, thus, ordering her experience was the young patient able to calm down and endure her treatment without screaming.

Becker (1997) also believes that narratives organize the disruption often initiated by illness. Illness stories express bodily distress and despair; they present the embodied knowledge of the body-self to the body-self and to

others. In doing so, the narratives reflect experience as the person sees it and as that person wants others to see it. According to Becker, narratives contain several key elements: (a) a common plot, which is disruption followed by efforts to restore continuity and normalcy; (b) emplotment, the process that individuals use to configure a sequence of events; and (c) a beginning, a middle, and an end. Becker views the act of creating a narrative as a cultural process because the final story shows how individuals experience disruption, how they attempt to restore continuity, and how they struggle with the disparity between their lives and the pervasive cultural ideologies. Individuals may respond—as reflected in their narratives—to the dominant ideologies by attempting to conform to them, resisting them, and adhering to others that allow more continuity with the past, or by creating new standards of normalcy.

Through the lens of postmodernism, Morris (1998) extends the function of narratives even further. Narratives bring suffering out of the silence and into awareness; the suffering of others reaffirms the many voices, often unheard in narratives, for example, the black and feminist voices. These voices spur dialogue, dissent, and the potential for social change; the possibility for change arises because suffering is not a static state of being, but it is intimately tied to a sequence of related actions, namely, the plot as told through the narrative (Morris, 1998). The action inherent in the narrative prompts insights on the part of the storyteller or the listener that may lead to personal or social change. Cultures write the plots of illness narratives, and Morris highlights the plots underlying the AIDS narrative that relay information about the origin of the disease, the type of victims, and the resistance to the disease. These plots cause harm because society stigmatizes specific groups and individuals based on them; Morris believes that plots can be rewritten with a different sequence of actions and, therefore, with less suffering as the outcome.

Of the seven authors, Frank (1995) is the only one who proposes a typology of narratives: the restitution narrative, the chaos narrative, and the quest narrative. Each type reflects strong cultural and personal preferences. The plot of the restitution narrative is about being healthy, getting sick, and then recovering again; it is a story about health. Frank maintains that it is the culturally preferred story because it reinforces what medicine expects of the sick person and what society expects from medicine. The narrator of the restitution story wants control and predictability restored. The plot of the chaos narrative is that things will never get better; disruption has destroyed continuity with no end in sight. Accordingly, the sick person only lives the chaos story because it cannot be told (Frank, 1995). Chaos experiences remove all semblance of control, sweeping the sick person along.

The quest story stands in stark contrast to both the restitution and chaos narratives. The narrator confronts illness and embarks on a journey of discovery. The plot typically follows the pattern of departure, initiation, and return (Campbell, 1949/1972). The body-self of the quest narrative accepts contingency, demonstrates productive desire, and seeks to share its story with others (Frank, 1995). Quest narrators write about their bodies in great detail and honesty; they want others to understand their embodied condition. The quest narrative is the vehicle through which the body-self offers itself to listeners and tells them what it has become as a result of the illness journey. Frank's typology of narratives acts as a companion piece to his typology of embodiment and illness; together they provide an integrated view of the illness experience and the role of narratives in helping individuals redraw their worldview.

All the writers affirm the benefit that accrues to individuals in sharing their stories. Zaner (2004) relates the story of Jim and Sue whose newborn, premature twins were undergoing serious difficulties during the first few hours of life. The parents faced moral dilemmas in deciding what treatment to provide or stop, given the likelihood of severe neurological damage; the medical staff were puzzled that while Sue was devastated by the events, her husband, Jim, said nothing. He did not respond to the information about his babies' condition or to questions from the doctors and nurses about how they should treat his children. Zaner met privately with Jim and Sue, and heard their story. Jim was troubled by a story he had watched previously on television where a couple decided not to treat their baby who was seriously ill; the couple was subjected to endless scrutiny by the public, which was something Jim did not want for him and his spouse. He also did not want either of his children to be condemned to a life of impairment. Both sides benefited from the telling of this father's narrative: Zaner offered the gift of listening to the distressed father, and the father the gift of his story to the medical ethicist. The couple also gained in the sharing of their story because it "took care of them when they desperately needed to be cared for" (p. 9). The gift that Zaner received in listening to Jim and Sue's story was a realization of the connection with others, a link forged by the narrative between the sufferer and the listener. In the process, the listener feels increased compassion for the sufferer and takes on the moral responsibility to share the story with others.

Frank (1995) proposes a similar argument for the moral function of narrative, but he extends the idea further. In the postmodern world of illness, both the storyteller and the listener assume moral obligations: On one hand, the sick person bears responsibility to live for the other, to witness his or her illness experience for the benefit of the listener; on the other hand, the listener

also becomes a witness by assuming the burden of telling the sufferer's story. The common link between the narrator and the listener is the suffering body. The communicative body of the sick person awakens compassion in the other because the listener realizes personal, bodily vulnerability; that body connection must exist in order for deep communion to occur. Frank espouses the value of "narrative ethics" (p. 155), a process whereby the listener becomes someone different in the hearing of the illness narrative and, as a result, takes moral action.

As noted previously, Morris (1998) suggests that the plot of the illness narrative can lead to clarifications and insights that precipitate personal and social change. His term for the moral function of narrative is *narrative bioethics* (p. 264). Illness narratives function ethically in three ways: (a) the promotion of listening as a moral act between individuals, (b) the development of listening skills in health professionals who interact with the sick, and (c) a focus on ethical understanding of the everyday world that affects the sick person. Narrative bioethics helps us live with illness and its losses as they reconfigure our lives. As Morris states,

Inseparable from its trials and its sometimes permanent losses, illness fills our lives with everyday routines and experiences—a kind of altered but inescapable dailiness—that narrative bioethics invites us to rethink. In threatening to undo or unfix the self, in showing us a picture of ourselves that we desperately do not wish to see, illness also holds the potential to reveal the everyday world in a new light, to show us beauty or truth or mystery inscribed in ordinary events whose everydayness we dismiss in the quest for something better. (p. 272)

## Key Relationships for the Sick Person

In experiencing a severe or chronic illness, the sick person manages at least two critical relationships, one to a partner or spouse, and the other to the illness itself. The marital relationship for many patients remains a central aspect of the illness experience. This section explores the key ideas from the various authors about these critical relationships.

### *The Relationship of the Sick Person to the Spouse*

Referring to his struggle with a viral heart infection and with testicular cancer, Frank (1991) comments that his illnesses did not just happen to him but to him and his spouse as a couple. His statement recognizes that the impact of

a serious illness extends beyond the patient; often, the sick person does not realize the fear and uncertainty that ripples throughout the family, but most keenly in the spouse. Frank also notes that the medical community ignores or discounts the changes occurring in the patient's spouse; hospitals rarely, if ever, offer support to the spouse who shifts roles from partner to caregiver. It is sobering for the sick person to realize that survival has come at a cost to one's partner, no matter how valued that survival is. Small gestures may provide the only way to show gratitude to the suffering spouse. Franks shares a poignant story from his illness experience. Awakened by pain one night, he had the choice to either arouse his wife and be comforted, or allow her to rest. His reasoning reflects the subtle, give-and-take relationship of a couple who are ill: "If I could not sleep, I could still love her sleep. Disturbing it would have been the most painful thing I could do" (Frank, 1991, p. 33).

In Broyard's (1992) account of his illness, he says nothing about his spouse, yet in the "Epilogue" to his book, Alexandra Broyard indicates that she was an intimate part of his illness experience and his exploration of death. When she met her husband, they "had both been in the land of the dying" (p. 133) because their parents had died several years earlier; 29 years later they journeyed to that foreign land again when Anatole was diagnosed with prostate cancer. She helped him respond to his illness with style and, most important, to be alive when he died.

Zaner's (2004) narrative about Mr. Oland who wanted his spouse kept on life support provides insights into the relationship between patients and doctors, but it also highlights the complexities of the marital relationship in the midst of illness. While his spouse was sick at home, Mr. Oland would not allow her to talk about her impending death, or what was to be done if she required life support; the irony of this close relationship is that Mr. Oland could not face his spouse's death and could not endure the pain of even talking about the possibility of her dying. However, when Mrs. Oland came out of her coma briefly, she announced that she did not want any extraordinary efforts made to keep her alive.

### *The Relationship of the Sick Person to the Illness*

Several authors explored the relationship between the sick person and the disease ravaging the body-self; the nature of this relationship varies depending on the background and disposition of the individual. Some authors examined the issue from a personal perspective as they told their own illness stories; others shared illness narratives and gleaned from them the nature of the alliance between patient and disease. During his struggle with cancer, Frank

(1991)—perhaps counterintuitively—begins to wonder at his body, realizing that neither he nor the physicians can control it. He does not discount the need or value of treatment but recognizes that the body will do what it does regardless of treatment and that is reason enough to marvel. Even living in a diseased body, the sick person can experience joy in that body. Frank discovered this one morning while walking to the hospital in a September rain when, for that brief time, he reveled in the sensuous downpour.

To find wonder in a diseased body suggests a gentler approach to one's illness than the typical stance. Frank (1991) notes that people, or the obituaries written about them, often speak of a "long battle" with some illness or the "valiant fight" waged against the ravaging disease. Military metaphors portray a person at war with the body, as if the body is divided into two camps each waging a campaign against the other. Frank suggests that this is not the case; the disease is not separate from the body but one with it, and once he was able to wonder at his body, he was able to let go of the fight, allowing his body to take its course aided by medical treatment. Adopting a gentler attitude toward his illness made Frank realize that the cancer just happened: He could not take responsibility for its cause any more than he could for the cure; what he could take responsibility for was his response to the experience of illness.

Broyard (1992) speaks of developing a style toward one's illness, a stance that keeps the sick person loving the self rather than dismissing it because of bodily weakness or disfigurement. Having style also means having voice, being more oneself, and meeting the disease on one's own terms and making it part of one's illness narrative. He describes a writer friend, Paul Breslow, who while dying of cancer spent his last few months under painstaking conditions writing the *Great American Novel*. Breslow was unable to finish the book, but for Broyard it did not matter because Paul exemplified that "style is the man and literature isn't everything" (p. 88). Broyard sees no value in being angry at one's illness; although illness causes frustrations, people can do much to distract and defend themselves and perhaps even transcend their illness.

From her ethnographic studies, Becker (1997) concludes that illness does not define a person; neither is the person wholly the illness. People exist outside their disease, but they may have to struggle to avoid being engulfed by it. It is possible to understand individuals' illnesses only from the context of their whole lives and their interpretations of their life events; they experience illnesses as part of their personal histories and the meanings they have constructed from those histories (Becker, 1997). Because of the Western emphasis on will, on controlling the outcome of illness through hope and

determination, Becker claims that her participants sought active roles in their healing; they sought normalcy and continuity in their lives, to make sense of the disruption caused by illness. They attempted to transcend their illnesses through narratives that displayed themes of death and rebirth (cf. Frank's quest stories).

Morris (1998) does not define the relationship of individuals to their illness, but he suggests that cultural forces always mediate that relationship; he claims "selfhood, like illness, is a biocultural construction" (p. 75). Culture influences one's experience of illness and the relationship one has with it. Even admitting this, he does not accept that the sick person has no choice outside culturally sculpted roles; he references Broyard's (1992) essay "The Patient Examines the Doctor" as an example of someone who rebels against the prevailing cultural ideology with the weapons of biting wit and irony.

## Illness and Death

Death lurks in the shadows behind all our illness stories, ready to disrupt our lives and routines permanently. Ultimately, the sentiments expressed by Emily Dickinson (1863/1973) speak for all of us: "Because I could not stop for Death—/He kindly stopped for me" (p. 1250). Other than Sontag (1977) who views death as just an "obscene mystery" (p. 55), most of the authors make important connections between the illness experience and death. Death's arrival following illness is not a failure or the loss of a heroic battle; rather, it is the result of the body's natural processes (Frank, 1991). The sick person prevails regardless of the outcome—life or death—and can only demonstrate faith in the completeness of either outcome. Faith in the body's wisdom replaces willful fighting with the disease.

Broyard (1992) discovers in his father's illness and death two elemental human needs: one, to be comforted by others in our fears at the moment of death, and second, to be recognized in our leaving. The second need presents a much higher hurdle to meet than the first. As Broyard comments about his father's dying moments: "You want everybody on earth to stop what they're doing and come to say good-bye *personally* to you. You want *humanity* to see you off, the way close friends see you off on a boat" (p. 122). Broyard provided the personal contact his father wanted and attempted to recognize him for all he had done. In the end, Broyard's father prevailed in death, and Broyard concludes by stating that he will sift through his father's ashes until his father rises from them like a phoenix.

Kleinman (1988) also affirms that a fatal illness in others teaches us something valuable, namely, how to confront and respond to the reality that we

will all die. He tells the story of Gordon Stuart, a 38-year-old writer dying of cancer whose family doctor spent hours preparing him for his death. Gordon met his death head on, still somewhat angry, but resigned nevertheless; he talked about his feelings openly and was fully prepared when his end came. His physician, Dr. Hadley, believed that Gordon's death "confirmed his life" (p. 149). For Kleinman, illness and death provide insights into the fundamentals of the human condition.

Many in our postmodern world do not want to confront death. In fact, Morris (1998) suggests that it is not so much death that people ignore or deny, as it is the extended process of dying. He notes the lack of images in our society of the dying or the chronically ill, in comparison to the many images of death in the news media and horror films. The modernist perspective is that illness can be cured and death staved off, maybe even cheated through technology. The result is a world that uses technology to keep people alive beyond their time, and a society that seeks physician-assisted suicide rather than suffer such a fate (Morris, 1998). He suggests a new approach where growth and development are the end-of-life goals, not immortality; from this perspective, illness and dying offer positive cultural value and meaning.

If a sick person has religious or spiritual beliefs, then illness and the threat of death may be linked to transcendent forces. Becker (1997) notes that the threat of death destroys a person's sense of order; illness and death implicate the destruction of the embodied self and raise questions as to whether someone has time to fashion a new embodied self. Biography may help the sick person deal with death by linking existence to the transcendent. Becker relates the story of Mr. Post, a 62-year-old African American, who survived a sudden heart attack. His daughter proposed that it was because God did not want him dead; it was not his time to go. Their religious background made the explanation plausible, and it became part of the illness narrative that Mr. Post shared with Becker.

## **The Meaning of Illness**

What then is the significance or meaning of illness, particularly to the sick person? All seven authors wrestled with this question. Sontag (1977) provides the starkest answer of the group: nothing. There is no meaning behind illness, it just is; it is a biological process, nothing more or less. She argues against the current predilection to find psychogenic causes for illness, to psychologize it; such meaning makes it easy for others to blame the sick and make them feel they have deserved their illness. Frank's (1991) views place him at the other end of the spectrum from Sontag. He sees illness as an interruption, but an

opportunity to examine one's life, to slow down the daily routines that keep us occupied but unaware of what is happening. Illness allows us to choose something different from the status quo in our lives, to "organize its [illness] experience to make our lives meaningful" (p. 90). For Frank, part of making life meaningful is to see what things were previously taken for granted, such as the beauty of the natural world and the joy of human relationships. The meaning or significance of illness becomes an individual preference, and each person must identify what that is.

Broyard (1992) also claims that to be ill is to be disrupted, to live through a series of disconnected shocks; illness and the threat of death makes one realize that immortality is a fiction, and this reduces life to its essence. Illness means that people can be more free to own their prejudices and opinions; it gives life a sense of concentration and focus, as well as a sense of drama where there is capacity for joy and suffering. According to Broyard, to be dying means to realize with poignancy that beauty and wisdom come too late; he concludes from personal experience and his readings that death is easier to accept if a person has lived ardently. In the face of a life-threatening illness, completeness in one's life becomes more important than longevity.

Morris (1998) remarks that illness undoes our sense of who we are; when our organs act up, we experience our bodies and the world differently because we live our lives through them. To be ill also means that we suffer from diseases constructed or reconstructed by the external environment. Sickle-cell anemia is one example. The disease developed in Africa and India thousands of years ago through a mutation of the hemoglobin molecule, resulting in a recessive sickle-cell gene. Oddly enough, the gene protects against malaria. Because the African environment included the malaria spore, children who had the sickle-cell gene were protected against malaria, but the sickle-cell gene thrived; as a result, 25% of all black newborns in the United States have sickle-cell anemia or an associated disease (Morris, 1998).

Becker's (1997) ethnographic studies indicate that illness threatens the perceived order of things and throws the individual into chaos. Medical treatment contributes to the disruption by wreaking havoc with people's schedules and sense of order and by wresting control away from them. Because serious illness precipitates disruption, the individual continually reassesses the disease and its meaning; the stroke victims whom Becker studied tried to restore normalcy in their lives through their daily activities. These patients infused their lives with meaning through their daily regimens, thereby reflecting the ideology that sick people should persevere in the midst of adversity.

Kleinman (1988) asserts, "Illness always has meaning" (p. 144), and a person accesses that meaning through multiple levels of analysis that include

the illness symptoms, the cultural significance of illness, the personal and social significance of illness, and the explanatory models developed by the patients and family members to understand the cause, duration, and impact of the illness. Kleinman does not use the term *biocultural*, but he nevertheless describes the illness experience as a dialectic between the personal and cultural forces on one side and the inexorable biological processes on the other. Kleinman's method of analysis enables the health professional to uncover multiple meanings present in the person's unique situation; regarding the patient, he believes that the individual creates meaning about illness, rather than discovers it, through the struggles with limited resources and the unpredictability of life.

## **Possible Future Directions**

### *The Practice of Medicine*

Several writers underscore that the relationship between the patient and the physician needs repair. The biomedical model of modernism leads to a hierarchical and asymmetrical relationship where the patient lacks voice; postmodern sensibilities are changing this, but slowly. However, medical technology is becoming increasingly more sophisticated and with it our faith in science to save us from all ills, including death (Morris, 1998). In this highly technical world, what is being done to promote patient–doctor relationships like the one Broyard (1992) wanted but never found? Do medical school curriculums reflect the need to train metaphysicists as much as body technicians? Studies are needed on successful patient–doctor relationships in the context of serious illness. What are their characteristics? The results could form the training to help the next generation of physicians become better listeners. Matsuyama's (2004) study has begun the exploration of these questions and points to the need for additional research. Her work identifies important attributes, attitudes, and behaviors of physicians who establish deep meaning and connect with their dying patients.

### *The Importance of the Marital Relationship*

Illness does not just happen to a patient but to the spouse as well (Frank, 1991). Spouses provide necessary emotional support to their partners, which in turn creates stress for the spouses. As Frank (1991) noted, when he was sick, there was little consideration for his spouse who had become a full-time caregiver in addition to a marital partner. Patients receive all the attention,

and the spouse is expected to do whatever is necessary to support the partner's recovery. One possible solution is that spouses of former patients who had the same illness provide support to spouses whose partners are currently sick. In addition, more support could be offered to couples undergoing serious illness. Group workshops or therapy sessions that involve couples would be useful in preparing them for the strains of living with illness. Professionals conducting these sessions could assess a couple's functioning early in the process, and interventions could be designed around the evolving needs of the couple.

### *The Use of Illness Narratives*

For many doctors, hearing the patient's story comprises a few minutes of a short period where they have to listen, diagnose, and provide treatment. Few physicians take the time to follow the method outlined by Kleinman (1988) to explore the intricacies of the patient and family's stories. Yet some reaching of the doctor into the soul of the patient is exactly what these writers claim is necessary. Broyard (1992) wanted a physician who would spend the time to find out what it is like to be dying from a terminal disease; he wanted a doctor who thought about suffering. What if patients were encouraged to write about their illness, either in the hospital or at home? Could these stories become a catalyst for discussions between doctors and patients? What if hospitals sponsored support groups where patients shared their stories and physicians were part of these groups? Much more needs to be done to explore how narratives can be used to help patients redraw their world maps and to help doctors understand the lived experience of illness.

### *Cultural Meanings and Metaphors About Illness*

Sontag (1977) undisputedly points out the dangers of cultural meanings that societies attach to illness, often through metaphorical language. Nevertheless, her argument goes too far in deconstructing any meaning behind illness because of the ability of language to harm. It can also help. Questions worth exploring in the future are "What metaphors or ways of speaking about illness help us understand it and help those who suffer?" "Can we speak about the meaning of illness without moralizing about the causes or denigrating those who are sick?" If there is no strong demarcation between the land of the sick and the land of the well as Frank (1995) claims, then being sick is part of the human condition, not an aberration that occurs

occasionally; as such, illness deserves a place in our language that is not denuded of metaphor, which is an essential meaning-making aspect of language.

## Conclusion

The seven authors reviewed in this essay explore the world of illness from personal and societal perspectives. Some of the writers challenge outdated modes of medical care, and others ask why society condemns the cancer victim, but not the cardiac patient (unless, of course, the cardiac patient does nothing to alter the course of the disease); some explore the problems of the sick body, and others examine the function of illness narratives in telling the patient's story; some look at the relationship between illness and death, and others ask what it means to be ill. In all cases, these authors prompt us to consider what it means to hold a dual passport, one that accesses the land of the healthy and the land of the sick. More important, they make us think about the experience of being sick—something we all know and fear.

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## Bio



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