

FEEDING THE GHOSTS: EXISTENTIAL CONCERNS OF CLIENTS WITH CHRONIC DISEASE

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Abstract

This paper explores existential and spiritual concerns related to living with chronic disease, such as type 1 diabetes; its purpose is to support clinical social work practitioners serving clients who face these concerns. The paper cites the work of existential philosophers and therapists, contemporary Buddhist thinkers, and psychodynamic psychotherapists, tracing ways that existential dilemmas can manifest in the lives of people with chronic conditions. The view taken is that these dilemmas are universal, and that exploring them is an inherently therapeutic act. The paper concludes by discussing ways to support clients who might benefit from such an exploration of existential concerns.

Social work practitioners often assist people facing difficulties profoundly different from their own. At times, such problems can seem foreign and intimidating. This paper aims to support practitioners who help people with chronic disease. It seeks to reveal the connections between these clients' dilemmas and fundamental aspects of the human condition. The paper uses the example of type 1 diabetes because diabetes treatment presents a clear view of these concerns; its focus on controlling bodily processes that are essentially uncontrollable pushes sufferers of the disease to confront particular spiritual and existential concerns. This paper will argue that "facing into" such concerns can be enormously useful for both clients and practitioners. Following the convention of many who write about spiritual and existential issues, the first person plural is used.

CHALLENGES OF THE DISEASE

According to the American Diabetes Association, approximately 0.2% of children in the United States will develop type 1 diabetes before they reach adulthood; onset rarely occurs after age 35 (Hanas 2005, 15). Unlike type 2 diabetes, which is far more common, type 1 diabetes is currently neither preventable nor reversible, and appears triggered by complex environmental factors in people genetically susceptible (Eckman 2010). In people who have type 1 diabetes (referred to hereafter as “diabetes”), the pancreas ceases to produce insulin, which means that the body cannot process glucose—“blood sugar”—from food. Therefore, people with diabetes must inject insulin into their bodies daily. However, it is nearly impossible to calculate the precise amount that the body needs at any given time; even with careful treatment, blood-sugar levels can fluctuate widely during the course of a day, with a variety of deleterious effects on the body. Diabetes is life threatening. In the long term, complications can affect major organs. In the short term, the body will enter a coma if blood-sugar levels become too high or too low (Eckman 2010).

For people with diabetes, the crucial health goal is to maintain blood glucose levels that are within a relatively healthy range. This is referred to as being in good “control” (Hanas 2005). However, since glucose levels are affected by a variety of factors, including emotional stress level, physical activity, and innumerable variations within the body, even diligent monitoring and adjustment can fail to produce desired levels. Thus, while the goal of “control” is a difficult one even for those highly motivated, living with diabetes creates physical, psychological, and spiritual complications that can erode motivation itself.

The physical effects of blood sugar variation can include physical weakness, sweating, vomiting, confusion, and loss of consciousness. For people with diabetes, the frequent, sometimes daily, experience of being pulled into debilitating physical states can create a disturbing sense of dissonance: “I am supposed to be in control, and I am trying so hard, but I am still out of control.” This dissonance can result in a “weariness of the spirit” (Williamson 1997, 244).

This dissonance may also lead the sufferer to confront concerns that reach beyond the experience of diabetes. The human impulse to seek control and certainty inspires suffering, since life is continually turning up the unexpected and unwanted and, to a great extent, unrelated to will or action, forcefully exposes the reality of our vulnerability (Berger 2006). Since the disease may have its way, patients can suffer from feelings of impotence, “powerlessness and futility and a sense that nothing [can] change” (Berger 2006, 44). If “control” has to do with an individual’s ability to shape fate through action, certainty relates to an individual’s ability

to predict that fate. Chronic disease also foils this universal desire for a predictable future—initially because its diagnosis is often unanticipated, and later because its ongoing effects, large and small, may occur without warning (Hatfield 2006).

Of the many possible outcomes of diabetes, the most dramatic is death. Many Buddhist and existential thinkers assert that the fear of one's own death is a source of profound anxiety for all people, until it is faced squarely (Breitbart, Gibson, Poppito and Berg 2004; Beck 1993; Diggory 1967). While a *terminal* illness can push a person toward the difficult work of coming to terms with death, a chronic disease, like diabetes, creates, in some ways, a more complicated struggle (Berger 2006). On one hand, people with diabetes are told that they can live lives of “normal” length (Hanas 2005), and they are encouraged to work diligently to care for themselves in order to “live well with diabetes” (Syrkiewicz 2008). And yet, as one physician and spiritual thinker writes, “all acts of health carry [a] grayish, dark side to them, because they remind us what we most wish to avoid: illness and death are inevitable, and try as we might, we can never separate health from illness, nor death from birth” (Dossey 1991, 92). This statement speaks to a tension inherent in life with diabetes. Those with this disease live with the reality that without a regular administration of insulin they would die within days. They also know that the toll of diabetes upon the body can lead to death in a variety of ways. They must live with these profoundly anxiety-provoking realities, while nonetheless performing the implicitly hopeful “acts of health” that keep them alive.

Sigmund Freud (1922) famously described a universal “death instinct” that works in conflict with a “life instinct.” This is one way of describing what some psychodynamic thinkers have seen as a struggle that occurs within each person; one side pulls toward life, toward “goodness,” wholeness and unity, while another side pulls toward destructive forces like “ambivalence, aggression, sadism, and masochism” (Hatfield 2006, 87). Those engaged in performing routine “self-care” related to diabetes might experience an inner struggle between the pull of living and the pull of despair, destruction, and death.

RESPONSES TO EXISTENTIAL CHALLENGES

In considering the painful tensions described above, thinkers from across many psychological and spiritual traditions make one essential recommendation: face squarely the existential challenges of chronic disease. These thinkers assert that our avoidance of darker, threatening realities only perpetuates our fear and suffering. They say, move toward the realities of our non-control, the uncertainty of our fate, our self-destructive tendencies,

our intimate, inevitable relationship with death and even the most difficult aspects of existence can be experienced directly and accepted. As we become less involved in fearful avoidance, we discover a greater sense of freedom and more capacity to connect with others (Bennett-Goleman 2001).

For practitioners looking to incorporate such a perspective into their practice, it is interesting to note that thinkers from different traditions articulate these notions in distinct idioms. Pema Chodron, a prominent teacher within an American strain of Tibetan Buddhism, says that a certain “unreasonableness” can crop up unexpectedly in us, and might feel like fear, or sadness, or fury (1994). In response, she applies a principle she translates as “feeding the ghosts.” The practice is to find a way to welcome the ghost—the unreasonableness—by saying, for example: “Not only do I not want you to go away, you can come back any time you like” (Chodron 1994, 76). Chodron’s point is that even painful feelings are natural, and that we are best off facing and accepting what seems to be unreasonable.

The psychodynamic psychotherapists at WPF Counseling and Psychotherapy, an agency in Great Britain, seem to bring a similar attitude to their work with clients living with life-threatening illnesses. In weekly psychotherapy sessions, clients at WPF explore their experiences living with illness, including the feelings of shame, anger, and fear that may not have found expression elsewhere (Archer 2006). All clients have their own stories to tell about what it was like to be diagnosed, how those around them responded, and how they have found themselves feeling, thinking, and acting, over the years, as the experience of illness intersects with other experiences of their lives. As they explore these stories, clients commune with “ghosts”—the frustration and depression that gathers around their daily experience of disease. For clients, this work loosens some of the tensions trapped inside them and allows new, more satisfying meanings and experiences to emerge (Archer 2006).

Merle Mishel (1999), a social psychologist and psychiatric nurse, also approaches the issue of uncertainty and chronic illness as a process of orienting oneself anew. In the Mishel model, gradually embracing the experience of uncertainty initially leads to a period of “disorganization” in which basic understandings of self and of living are dismantled. Over time, for those whose context supports a process of “reorganization,” new understandings can emerge, understandings in which views of living are more complex, and are experienced as more meaningful and more satisfying (Mishel 1999). Mishel’s concept of “disorganization,” and its ultimate usefulness, is also echoed by Zen teacher Charlotte Joko Beck (2008), who discusses the importance of moments when life brings us what we least want—whether it is a diagnosis of diabetes or a particular instance of dangerously low blood sugar. She says that spiritual practice is not about

“succeeding,” but about “failure, illness, disappointment, and even agony, sometimes” (Beck 2008). In moving through such “failures,” and steadily attending to our inner experience of them, we can discover “the ability, instead of running, avoiding, covering, emoting, dramatizing, to just head right into that place of disappointment or whatever it is” (Beck 2008). Beck describes a kind of “courage” that develops through this turning toward difficult experiences (Beck 2008).

Similarly, Emmy van Deurzen (2002), an existential psychotherapist, asserts the potential benefits of turning specifically toward “existential anxiety,” which she describes as “that basic unease which we experience as soon as we become self-conscious and aware of our vulnerability and possible death” (61). If Beck speaks of courage, van Duerzen describes a “sense of being in charge of your own life” that can emerge only through facing directly into our feelings about death (184). Again, the idea is that our avoidance perpetuates a sense of helplessness, and that accepting and exploring our responses allows them to evolve.

IMPLICATIONS FOR SOCIAL WORK PRACTICE

For practitioners looking to apply these ideas to people with chronic diseases like diabetes, it is important to begin by appreciating the potential dangers. Armed with “spiritual truths” and assumptions about the ideal way for people to approach their experience of chronic illness, a practitioner might overlook the crucial particulars of the person before them—the client’s strengths, limitations, beliefs, desires, etc. As many practitioners agree, the client’s own internal process provides crucial guidance for therapeutic work (Casement 1991). In this understanding, the practitioner’s primary role is to create space for clients to think and feel their own way through their difficulties.

Many of the thinkers discussed above recognize that all people have the opportunity to work through existential crises, opening up the potential for personal transformation. Those with a serious illness, however, did not choose this “opportunity,” this “shape” for their personal journey. The pace is rushed, forced by the powerful reality of the illness. There is an opportunity to make space for the difficulties, to “feed the ghosts,” but this is delicate work. Spiritual practices and psychotherapeutic techniques offer tools for helping clients reckon with their inner experiences, but there is no real guidebook. Each person is unique. Times of despair are always possible.

Those with diabetes, for instance, are forced, by the nature of the disease, to balance these realities with particular caution. The daily requirements of self-monitoring and insulin injection mean that, though it

may be possible to allow oneself to “feel the feelings” that arise in the course of a day, there is little room for these feelings to influence behavior. People without serious illness can allow themselves, at times, to be overtaken by emotions that lead to unhealthy behavior choices. But for those with diabetes, every decision can have severe consequences, and these decisions must be made continually throughout the day. They may find themselves trapped between the desire to despair and the pressure to keep going, and painful feelings like resistance, rage, and despair can feel “caught,” because there is no real room to experience them fully.

The psychotherapists at WPF Counseling and Psychotherapy might frame this dilemma in terms of a “dual reality” that is ever-present for people with serious illness (Hatfield 2006). There is the ephemeral experience of thoughts and feelings *and* the reality of the body’s demands and effects. For practitioners who support clients struggling with this dual reality, WPF psychotherapists make particular recommendations. They suggest learning about the physical realities of the disease, in part from listening directly to those who live with that disease (Hatfield 2006). They also emphasize the importance of respecting the individuality of each client—never presuming to understand a client’s experience based on prior knowledge about what others have experienced in similar circumstances (Hatfield 2006).

These recommendations require practitioners to adopt a kind of humility in their way of relating to clients. Living with serious illness carries many experiences of relative vulnerability. Patients navigate power struggles within their relationships with doctors and other “support people,” including loved ones (Heschel 1964). Therefore, the social worker’s goal is not to push for a particular outcome, but to create a space in which clients can experience and create what feels right to them, what is most needed in their own process.

A practitioner’s humility should not be mistaken for passivity. Maroda (1998) argues that empathy and understanding are not sufficient when helping clients face, and alter, self-destructive behavioral patterns. Casement (1991) likewise describes the therapeutic process as a constant, often unstated exchange between client and therapist, in which the therapist must work diligently to remain receptive to the client’s reality. If willing to experience difficult emotions that clients may harbor but may not be ready to experience for themselves, the therapist may thus be an active holder of the “light,” of hope when clients are immersed in the “shadow” of the illness experience (Snowdon 2006). This need for “light” in the healing experience is echoed by Jon Kabat-Zinn (1994). A physician who brings Buddhist mindfulness principles into his work with people living with chronic pain, Kabat-Zinn writes, “The wounds are important, but so are our inner goodness, our caring, our kindness toward others, the wisdom of the body, our capacity to think, to know what’s what” (193).

This work requires practitioners to engage in diligent self-examination. They must be cautious that their unquestioned assumptions—about illness, about the goals of client work, about their own role—do not unnecessarily hinder the therapeutic process. Perhaps more importantly, practitioners must also be willing to explore their own responses to the dilemmas faced by clients, and their own feelings about these existential realities (Hatfield 2006). What is the practitioner’s relationship to uncertainty, self-destructiveness, illness and death? Clients are acutely attuned to that against which practitioners defend themselves (Foster 1998). The act of creating space for the exploration of “shadow” is, fundamentally, a shared one.

CONCLUSION

By recognizing the existential concerns that may be operating for clients with chronic disease, social work practitioners have an opportunity to work alongside clients in a powerful and moving process. At the same time, practitioners must recognize that the process belongs to the client. Clients face a range of interwoven concerns—physical, psychological, social, as well as spiritual. Some are related to the illness and some are not. Ultimately, the client alone steers her own process of experiencing, exploring, and meaning-making (Casement 1991). Practitioners can offer observations, queries, perspectives, but clients will choose what is best for them as they engage in an ongoing negotiation of their relationship to their own experience. When existential concerns arise, however, the social work practitioner has an opportunity to make space for these in the therapeutic process. Even if the practitioner has visited these concerns before, they appear in unique ways with each client and in each practitioner-client relationship. The appropriate stance can be an openness to what might emerge, even a kind of awe in the face of the client’s own mysterious process, and an ability to “attend . . . with an empty mind” (Coltart 1992, 10).

In some ways, existential concerns are never exhausted, never entirely “worked through.” As Paul Tillich (1952), the Christian theologian and existentialist philosopher, writes, “The basic anxiety, the anxiety of a finite being about the threat of non-being, cannot be eliminated. It belongs to existence itself” (39). For clients who have diabetes, as well as for practitioners, these questions are with us throughout our lives, troubling us, pushing us beyond our boundaries. They are concerns for a lifetime.

REFERENCES

- Archer, Ruth. 2006. "Introduction." In *Dual Realities: The Search for Meaning—Psychodynamic Therapy with Physically Ill People*, edited by Ruth Archer, 1-6. London: Karnac Books.
- Beck, Charlotte Joko. 1993. *Nothing Special: Living Zen*. New York: Harper Collins.
- . 2008. *Living Everyday Zen*. Audio recording, Sounds True, W1233D.
- Bennett-Goleman, Tara. 2001. *Emotional Alchemy: How the Mind Can Heal the Heart*. New York: Three Rivers Press.
- Berger, Susan. 2006. "Avoiding the Issues: The Consequences of Poorly Managed Diabetes." In *Dual Realities: The Search for Meaning—Psychodynamic Therapy with Physically Ill People*, edited by Ruth Archer, 40-50. London: Karnac Books.
- Breitbart, William, Christopher Gibson, Shannon R. Poppito, and Amy Berg. 2004. "Psychotherapeutic Interventions at the End of Life: A Focus on Meaning and Spirituality." *Canadian Journal of Psychiatry* 49 (6): 366-372.
- Casement, Patrick. 1991. *Learning from the Patient*. New York: Guilford Press.
- Chodron, Pema. 1994. *Start Where You Are: A Guide to Compassionate Living*. Boston: Shambhala.
- Coltart, Nina. 1992. *Slouching towards Bethlehem*. New York: Guilford Press.
- Diggory, James C. 1967. "The Components of Personal Despair." In *Essays in Self Destruction*, edited by Edwin S. Shneidman, 300-323. New York: Science House.
- Dossey, Larry. 1991. "The Light of Health, the Shadow of Illness." In *Meeting the Shadow: The Hidden Power of the Dark Side of Human Nature*, edited by Connie Zweig and Jeremiah Adams, 91-92. Los Angeles: Jeremy P. Tarcher, Inc.
- Eckman, Ari S. 2010. "Type 1 Diabetes." *Medline Plus*. Last updated on May 10, 2010. <http://www.nlm.nih.gov/medlineplus/ency/article/000305.htm>.
- Foster, Rosemarie Perez. 1998. "The Clinician's Cultural Countertransference: The Psychodynamics of Culturally Competent Practice." *Clinical Social Work Journal* 26 (3): 253-270.
- Freud, Sigmund. 1922. *Beyond the Pleasure Principle*. London: The International Psychoanalytical Press.
- Hanas, Ragnar. 2005. *Type 1 Diabetes: A Guide for Children, Adolescents, Young Adults—and Their Caregivers*. New York: Marlowe and Company.
- Hatfield, Linette. 2006. "Working with Dual Realities: Psychological and Physical." In *Dual Realities: The Search for Meaning—Psychodynamic Therapy with Physically Ill People*, edited by Ruth Archer, 79-91. London: Karnac Books.

- Heschel, Abraham Joshua. 1972. "The Patient as Person." In *The Insecurity of Freedom: Essays on Human Existence*, edited by Abraham J. Heschel, 24-38. New York: Schocken Books.
- Kabat-Zinn, Jon. 1994. *Wherever You Go There You Are*. New York: Hyperion.
- Maroda, Karen J. 1998. *Seduction, Surrender, and Transformation*. Hillsdale, NJ: Analytic Press.
- Mishel, Merle H. 1999. "Uncertainty in Chronic Illness." *Annual Review of Nursing Research* (17): 269-294.
- Snowdon, Lynda. 2006. "Living in the Shadow of Death." In *Dual Realities: The Search for Meaning—Psychodynamic Therapy with Physically Ill People*, edited by Ruth Archer, 51-62. London: Karnac Books.
- Syrkiewicz, Jen. 2008. "How to Live Well With Diabetes." *Suite101*. Last updated on November 6, 2008. http://diabetes-treatment.suite101.com/article.cfm/how_to_live_well_with_diabetes.
- Tillich, Paul. 1952. *The Courage to Be*. New Haven: Yale University Press.
- Van Deurzen, Emmy. 2002. *Existential Counseling and Psychotherapy in Practice*. London: Sage.
- Williamson, Donald S. 1997. "On Not Taking Illness Too Seriously: Aging with Diabetes." In *The Shared Experience of Illness: Stories of Patients, Families and Their Therapists*, edited by Susan McDaniel, Jeri Hepworth, and William J. Doherty, 242-250. New York: Basic Books.

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