
Living with Dying: Chronic Illness through an Existential Lens
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I am in limbo, my life a compromise between side effects and an HIV regimen that seems to be keeping me alive; a process of sustaining a body that will never be well, but may very well be.

Richard Goldman (2001, p. 5)

Chronic Illness

Chronic illness and disease (CID) is an umbrella term that encompasses illnesses which do not go away easily, may go on indefinitely, and usually will not be successfully cured (Catlan, & Green, 2001). The medical world views such illnesses as diabetes, cancer, depression, lupus, Human Immunodeficiency Virus (HIV) as diagnoses that fall under the definition of CID.

Although most of these diseases may eventually lead to death, the road there can sometimes take

a lifetime. That same road can be fraught with psychological and emotional distress if the chronic illness is not emotionally processed. Bishop (2005) stated that for most the onset of CID begins, “lifelong process of adapting to significant physical, psychological, social, and environmental changes” (p. 219).

Livneh and Antonak (2005) related that 54 million Americans are living with an illness that impedes physical, sensory, psychiatric and cognitive functioning. Further, they go on to state that 80% of the deaths in America are the end result of a chronic illness. These numbers are evidence that CID will most likely affect everyone in their lifetime, directly or indirectly.

Social work has always been invested in working with the disenfranchised and underrepresented. Essentially, social workers attempt to give a voice to those who have been silenced or who have lost their own. This is best exemplified in the work we do with the chronically ill. Not only does CID affect someone on a personal level, but it also extends to the family and eventually permeates the community. The micro, macro, and mezzo systems are all impacted by this beast we call chronic illness. For example, it is not just one person who will be diagnosed with pancreatic cancer, it is also someone’s father, brother, husband, and friend.

If social workers were trained to look at CID from a theoretical perspective, which theory would best describe all of the parts that make up chronic illness and disease? One post-modern theory that may be useful is existential theory. This patchwork of philosophy, psychology, and spirituality makes up a lens which perhaps best captures all the dynamics of CID.

Existential Theory

Existentialism first came to be noticed as a cultural movement in the mid 20th century. Although the roots of this philosophical phenomenon began with the nineteenth century philosophers Kierkegaard and Nietzsche, the word existentialism began to take on a life of its own post World War II. Essentially existentialism views human behavior as far outside the realm of natural science. Victor Frankl, who many would consider the father of existential theory within the psychotherapeutic realm, addressed existentialism as a general way of finding meaning in life. At its core, existentialism is anti-establishment in that it does not seek to find reason in everything, but is content with the fact that the search for reason is never ending (Cromwell, 2004).

Existentialism describes a *meaning vacuum* that is present in all of us. The power in this vacuum is increased whenever we are confronted with trauma, such as CID. The object of therapy from an existential point of view is to find meaning within this vacuum. Instead of viewing life as empty, existentialism views it as fraught with meaning for those who investigate such angst.

Existential psychology is the psychology of human existence, including all of its complexities and paradoxes (Wong, 2004). How then do we incorporate this non-way of knowing into the concrete practice of social work? How do social workers assisting families dealing with death in the journey to find meaning?

Review of Literature

Multiple studies have been conducted in the realm of existentialism and chronic illness. First, Laubmeier, Zkowski, and Bair (2004) investigated the role of spirituality in psychological adjustment to cancer. By basing their study on two different theoretical models, Frankl’s existential and Paloutzian and Ellison’s conceptualization of spirituality, they examined whether

or not spirituality and emotional well-being are moderated by degree of perceived life threat (PLT). This study attempted to explore spirituality, PLT, and psychological adjustment in patients diagnosed with cancer.

The authors stated that cancer is the second leading cause of death in the United States (Laubmeier et al, 2004). They cited treatments as well as the illness itself provide patients with high levels of stress and anxiety. These researchers felt as though few studies have examined the relationship between spirituality and stress and coping. In fact, their study was relevant in that few, “have examined both existential and religious components of spirituality by using standardized measures within a theoretical framework” (p. 54).

One interesting facet of this study was that based on existential theory, “cancer may be viewed as a temporal constraint and a catalyst for finding meaning” (Laubmeier et al., 2004, p. 49). The authors continue to state that although this view can be rewarding, it can also be challenging and can result in a state of *noogenic neurosis*. This *noogenic neurosis* is described as, “a state of distress that arises from existential or spiritual problems such as a lack of meaning and purpose in life” (p. 49).

Secondly, Lantz and Gregoire (2000) also utilized existential theory in their dealings with couples coping with breast cancer. This qualitative research followed 27 couples for 20 years to explore the dynamics that breast cancer played in the couples’ relationships. Recognizing that existential theory lends itself well to those facing CID, the authors believed that meaning could be found in something as devastating as breast cancer.

Lantz and Gregoire recognized that a diagnosis of breast cancer could easily throw a couple’s search for meaning in life into a tailspin. They believed that once this search for meaning was disrupted, symptoms such as anxiety and depression could materialize. In order to prepare a couple for such a challenge, the authors attempted to help the couples recognize and honor the meanings and meaning potentials of everyday family life, in spite of and in accordance with the diagnosis of breast cancer. Throughout this process, the authors stressed that the therapist, “empathetic availability allows the therapist to be ‘touched’ by the couple’s difficulties and pain” (p. 320). This highlighted the ongoing theme within existential theory of the joining that happens between therapist and client. When dealing with a difficult issue such as life-threatening cancer, this joining would seem instrumental in finding meaning.

Treatment themes found while treating the 27 couples included the couples finding more appreciation of marital life. The compromise to this new-found meaning was a loss of control. Many couples exerted endless amounts of energy into the area of controlling the situation while others were able to use such exercises as guided imagery and meditation to come to the conclusion that cancer was the responsible party for the loss of control and not themselves. Everyone involved in the study reported some disruption in communication. At the same time all 27 couples relayed that couples’ counseling had helped them sort out such communication problems (Lantz & Gregoire, 2000).

Thirdly, existential theory also played a role in Furman and Bender’s (2003) work in the area of depression. These authors used four theoretical frameworks for exploring depression, a condition so prevalent it was referred to as the *common cold* (Turnbull, 1991). The authors identified the epidemic nature of depression in the sheer volume of self-help books that have been recently published to help those cope with depression. Further, they reported that approximately 10% of men and 22% of women would be affected by depression at some point in their lives.

Currently, the medical model is the model being used most often to treat and understand depression (Furman & Bender, 2003). This model combines medication with scant psychotherapy to help those who are dealing with depression. Although this model is somewhat useful, especially where costs are concerned, the authors questioned what it would be like to treat depression primarily with psychotherapy from four psychodynamic therapies, including existential theory. Furman and Bender investigated about the core roots of existentialism, including the search for meaning that is born out of a state of nothingness. They related that depression has many parallels to this search for meaning in that from depression, which can seem like a state of nothingness, can arise a search for meaning to alleviate the feelings that come along with this state of nothingness.

Furman and Bender (2003) also explored the same loss of control that those with breast cancer felt. This loss of control seemed to be an underlying theme in those who were dealing with depression. Wondering if those who were experiencing this external loss of control were less likely to take responsibility for their behavior, they explored the correlation between depression and loss of control. Further they emphasized that if this loss of control could be explored, perhaps it could be reined in, thereby relieving the symptoms of depression.

Lastly, Havens and Ghaemi (2005) studied the importance of the therapeutic alliance in working with patients with bipolar disorder. They stressed that work could be done very effectively if the alliance was developed through existential and interpersonal methods. Further this alliance could even be mood stabilizing, enhancing the effects of psychotropics. This attitude displays the strong influence that the existential lens can have while working with patients who are experiencing a bipolar mood shift. The authors stressed that, “in this work, the therapist must struggle to avoid theorizing or judging, but rather should seek simply to think, feel, and experience what is happening as the patient is thinking, feeling, and experiencing it” (Havens & Ghaemi, p. 138).

The above research displays an ongoing theme that threads its way through CID, that thread being most people seek to make meaning out of situations that on the surface appear meaningless. Something as horrific as a diagnosis of cancer can in fact have a positive impact on one’s life. Cancer can strengthen relationships with significant others as well as family members. It can also facilitate inner growth in the area of spirituality. CID can be a catalyst for finding inner strength and resolve if viewed in a certain manner.

Existentialism attempts to make sense of the mundane as well as the magnificent, and everything in between. While using glasses coated with an existential tint, one has the power to turn tragedy into opportunities for growth. This growth can lead to an enhanced life experience that would have been hindered if not for the existential theory.

The above research exemplifies the fact that those in the helping profession, including social work, see a positive link between existentialism and CID. Through the review of relevant research one can see that existentialism did in fact alleviate negative symptoms of CID. Not only did it relieve negative symptoms, but it also brought about the opportunity to replace those negative symptoms with positive ones.

Existential theory provides an interesting framework for helping those dealing with issues around CID. In fact, the very gray nature of existential theory bodes well with the uncertainty that most face with CID. It would seem this broad and ambiguous theory mirrors the broad and ambiguous nature of CID. This mirroring seems to be an effective way to explore issues around chronic illness and disease. If effectively utilized this mirroring can produce positive meanings in life.

Although other theories may provide more concrete ways to deal with CID, what they do not provide for is the experiences of growth that existentialism does. Existentialism is unique in that it comes from a place of not being afraid of everything that this society is afraid of, namely death. Instead of fearing this inevitable part of life, existentialism teaches us that we can come away from illness with many gifts, both for ourselves and for those around us. These gifts are not without their price. But for those willing to take the chance, these gifts can be priceless.

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