**Psychological Aspects of Chronic and Terminal illness**

**Uncertainty: A Key Characteristic of Chronic Illness (non-curable long-term illnesses)**

**The course of events is unpredictable in chronic illness, in which
remissions and exacerbations occur. In fact, chronic illness has been described by Wiener (1975) as an experience of living with chronic uncertainty. Uncertainty does not represent the total experience of chronic illness, yet it is a constant and most problematic part of it. Thus, the concept of uncertainty must be addressed in order to understand the problematic nature of chronic illnesses. Uncertainty is defined as the inability to determine the meaning of events occurs in a situation where the decision-maker is unable to assign definite values to objects and events and/or is unable to predict outcomes accurately.**

**In the illness experience, uncertainty arises when (1) people lack
information about the diagnosis and seriousness of their illness (2) they cannot make predictions as to the course of the illness and its prognosis (3) they have ambiguity concerning the stage of their illness (e.g., how advanced it is), and (4) they lack information regarding the best and/or alternate treatments and systems of care.**

**The Stigma of Chronic Illness**

**According to Jennings, Callahan, and Caplan ( 1988, p. 6), "Chronic illness and disability are often stigmatizing; intolerance, fear, and misunderstanding, at one extreme, and well meaning but humiliating and patronizing sympathy at the other often greet the chronically ill in their everyday social lives."**

**In our society, as in most, any illness is negatively valued, and
non-curable long-term illnesses are particularly problematic. The expectation regarding health is the desirability of mastery of the problems of health. the concept of health is tied to the society's value system, which emphasizes independence and individual achievement, and the high level of differentiation in its social structure. Illness is regarded as dysfunctional to the social system because it hinders individuals and weakens their effective performance of social roles. Society views illness as a form of deviance that needs to be controlled because it poses problems both for the individual and society.
Persons who are ill are allowed certain exemptions and privileges denied to healthy individuals. i.e the sick role.**

**Social Isolation: A Major Consequence**

**Lessened and impaired social contact and a sense of social isolation are among the more detrimental consequences of chronic illness.
Social isolation refers to a negative state of aloneness or diminished participation in social relationships. Impaired social interaction relates to the state in which participation in social exchanges occurs but is dysfunctional or ineffective because of discomfort in social situations, unsuccessful social behaviors, or dysfunctional communication patterns. Of course, the worse the illness (and/or its phases), then the more the probability exists that the ill persons will feel or become isolated. This isolation can happen in two ways: either the ill person, because of the symptoms, unexpected crises, difficult regimens, and loss of energy, withdraws from most social contact, or the ill person is avoided or even abandoned by friends and relatives. In either ease, social relationships are disrupted or falter and break down. All persons with long-term health problems are at high risk for social isolation. Social relationships are frequently disrupted and usually disintegrate under the stress of chronic illness and its management because chronic illnesses often involve disfigurement etc**

**Managing Chronic Illness: Adaptation**

**If you haven't the strength to impose your own terms upon life, you must accept the terms it offers you.**

**-- T. S. Eliot**

**The act of living itself is an adaptive process. By adulthood, everyone achieves a certain level of life adaptation, but chronic illness disrupts this achievement, because the additional burdens in dealing with the many problems of chronic illness diminish the capacity of individuals to respond in satisfactory ways. Adaptation implies a balance between demands and expectations of a given situation and the capacities of an individual to respond to those
demands. Failure to adapt, then, means that there is a discrepancy between demands and capabilities. it is difficult to define and operationalize the concept of adaptation for several reasons. First of all, adaptation is dynamic; it changes as the environment changes. With respect to chronic illness, there are periods of progress and regress, depending on changes in the illness conditions, and chronically ill individuals must respond to those changes.**

 **Adaptation as Distinguished from Coping**

**Adaptation and coping are often treated as synonymous terms, but they are distinct from each other. Coping "is the special mobilization of effort and the drawing upon unused resources or potentials, [and] always involves some type of stress," whereas "adaptation is a broader concept that includes routine or automatized actions."
Adaptation, in a psychological sense, "refers to *individual* survival, as well as to the capacity to sustain a high quality of life and to function effectively on a social level. In this use of the word, the focus is on outcome from an evaluative perspective -- adaptive or maladaptive"
Initially, I also thought that "coping" and "adaptation" were synonymous concepts, that is, day-to-day symptom management strategies people employ to adjust to illness demands. It soon became obvious that they were indeed distinct from each other, although in many cases it is virtually impossible to make a distinction between these concepts because they are so interrelated. Indeed, while chronically ill individuals routinely deal with the daily demands of their illness, they are also trying to cope with sudden and/or unpredictable changes. As one of my respondents stated, "I can adjust to it [the illness], live with it on a day-to-day basis . . . but these damn changes, I can't cope**

**Factors Influencing Adaptation**

**Some adaptation strategies are mainly illness related and involve
dealing with the incapacitation, discomfort, and symptoms of the
illness itself. Depending on the specific illness, these strategies can involve controlling pain, dizziness, incontinence, extreme weakness, paralysis, the feeling of suffocation in respiratory ailments, and loss of control in convulsive disorders. Particularly, the course of illness, type of onset, kinds of limitations, and changes in physical appearance and functions interacting with situational variables affect the adaptive responses of individuals with chronic illness. These factors also influence the way people define the illness and attach meaning to it.**

**In other words, there are the challenges of the specific illness in
question. It has been pointed out that there are at least three major characteristics of illness that are critical to the long-term adaptive responses of the chronically ill person. These characteristics are: the type of onset and expected course of the illness, the nature and extent of limitation, and the type and extent of changes in physical appearance and bodily functions.**

**Living with Chronic Illness: Normalization**

**When life's terms offer you a lemon, make lemonade!**

**-- Popular Folk Saying**

**Normalization refers to processes a chronically ill person uses to
continue what that person perceives to be a normal life. There is a general presumption that people who work and participate in social activities lead normal lives; that is, they have the capacity to perform a variety of physical tasks, including self-care activities. Self-care is defined as the process by which persons deliberately act on their own behalf for the prevention of illness, health promotion, and the detection and treatment of health deviations. But with chronic illness, a person's capacity to perform these tasks becomes limited or activities become restricted as consequence of the illness. Patient compliance, a concept related to self-care, is defined as the
extent to which a patient's behavior coincides with the prescribed
treatment recommendations (Sackett & Snow 1979).**

**Factors Affecting Normalization**

**A primary set of normalization tasks involves preserving a reasonable emotional balance by controlling upsetting and negative feelings aroused by the illness. Anxiety and apprehension caused by not knowing what will happen next, feelings of inadequacy, and resentments in the face of difficult demands are understandable and inevitable, yet these feelings must be managed so that the more mundane tasks of learning to deal with these demands can be undertaken. Many respondents talked about having to control negative emotions such as a sense of failure or inferiority, and two people in particular talked about feelings of self-blame, possibly for past wrongdoings.
Two other persons mentioned being extremely depressed, even suicidal, particularly at the onset of their illness:**

**Behavioral Strategies of Normalization**

**Chronically ill persons develop a repertoire of behavioral strategies to assist in normalizing their lives, that is, to continue to live, as much as possible, the way they were living before they became ill, and to proceed with activities and goals as if the illness did not exist or was not an important part of their lives. One way they try to accomplish this is by carrying on as usual.**

**ENGAGING IN USUAL ACTIVITIES DESPITE SEVERE LIMITATIONS**

**Many chronically ill people keep the same schedule they met before the diagnosis of their illness, despite exhaustion, the need for extra time for rest to restore energy, and, in many cases, exacerbation of their symptoms. They try very hard to keep up with what they consider normal activities, such as maintaining a job, taking care of household chores, cooking meals, and participating in their usual social events**

**Cognitive Strategies of Normalization**

**When behavioral strategies fail to accomplish the desired results,
chronically ill people also resort to cognitive strategies to normalize their lives. In fact, most of these people use several behavioral and cognitive strategies simultaneously. One of their favorite strategies seems to be to minimize their struggles.**

**MINIMIZING STRUGGLES AND ADJUSTMENTS**

**Chronically ill individuals try to avoid acknowledging and dealing
with the serious nature of their illness by minimizing symptoms and hardships created by therapy and particularly by playing down consequences of their illness. For instance, throughout one interview, the respondent described his symptoms and the limitations imposed by these symptoms on his activities. He then ended the interview by saying, "I have no real physical problem! . . . My sister has the same problem and the doctors told her not to drive, and she does. So, I still play ball!" A young woman who can no longer function independently because she is almost totally blind said, "I just have a disease, that's all. But it's just, OK, it's a malfunction. That's all it is**

**Crucial Dilemma for Chronically Ill Persons**

**I believe you have to look reality in the eye . . . and deny it.**

**-- Garrison Keillor**

**The basic difference between chronic sufferers and relatively healthy people is merely that the former have additional burdens; they must learn to live with their incurable illness, their ever-present and sometimes unpredictable symptoms, and often with their special, costly, and difficult treatment regimens. As a result, the illness becomes the central focus of chronically ill persons' lives. By necessity, everything else becomes of secondary importance, at least initially, in the business of trying to normalize life, to continue to live, to carry on; as much as possible, the way the chronically ill were living before they became ill. In fact, it appears that some chronically ill individuals try even harder to carry on than most so-called healthy people, both because of the threat the illness poses to their self-identity and because of their sense of impending mortality.**

**The Struggle for Identity:
Lessons from the Chronically III**

**People experience life through a self-centered filter.**

**-- Anthony Greenwald**

**Over the years I have known more than a few people who were devastated by the experience of discovering that they had a serious chronic illness. They were not easily able to accept and learn to live with the limitations imposed by the illness and go on with their lives, not so much because of the medical aspects of the illness, but because of all the social and psychological problems created by the ongoing illness experience. Some of these people became withdrawn and bitter about life in general, giving up on cherished activities and goals and consequently letting the chronic illness control their existence. Yet others were able to survive the initial shock of finding out that they had to learn to live with an incurable, severe, and ongoing illness.
These people seemed to be able to "shift gears," readapt to less than perfect conditions, renegotiate their roles, and get on with their lives.**

**Needed Changes for Health Care**

**Suffering of some is simply and literally unknown to many in society. This is a special part of reality which, I think is one of our
important responsibilities to understand and communicate.**

**-- Alvin Gouldner**

**In the continuing debate among health care providers, policy makers, medical sociologists, and health psychologists on reforming the delivery of health care, it is necessary to address the social as well as the medical issues relevant to those whose special health care needs have thus far been inadequately met: chronically ill persons. Traditionally, problems of health and illness were the province of medical personnel, of the doctors and nurses whose training is geared specifically toward curing specific diseases. Indeed, our health care system has been so oriented toward acute conditions and so successful in its efforts both to eliminate diseases (e.g., polio, smallpox, diphtheria) and to provide intensive care in medical emergencies (e.g., trauma, myocardial infarction) that chronic illness has historically not received the same attention.**

**LOSS THERAPY**

**Denial, Anger, Bargaining, Depression and Acceptance**

**The stages have evolved since their introduction and they have been very misunderstood over the past three decades. They were never meant to help tuck messy emotions into neat packages. They are responses to loss that many people have, but there is not a typical response to loss as there is no typical loss. Our grief is as individual as our lives.**

**The five stages, denial, anger, bargaining, depression and acceptance are a part of the framework that makes up our learning to live with the one we lost. They are tools to help us frame and identify what we may be feeling. But they are not stops on some linear timeline in grief. Not everyone goes through all of them or in a prescribed order. Our hope is that with these stages comes the knowledge of grief’s terrain, making us better equipped to cope with life and loss.**

**Denial**

**This first stage of grieving helps us to survive the loss. In this stage, the world becomes meaningless and overwhelming. Life makes no sense. We are in a state of shock and denial. We go numb. We wonder how we can go on, if we can go on, why we should go on. We try to find a way to simply get through each day. Denial and shock help us to cope and make survival possible. Denial helps us to pace our feelings of grief. There is a grace in denial. It is nature’s way of letting in only as much as we can handle.**

**As you accept the reality of the loss and start to ask yourself questions, you are unknowingly beginning the healing process. You are becoming stronger, and the denial is beginning to fade. But as you proceed, all the feelings you were denying begin to surface.**

**Anger**

**Anger is a necessary stage of the healing process. Be willing to feel your anger, even though it may seem endless. The more you truly feel it, the more it will begin to dissipate and the more you will heal. There are many other emotions under the anger and you will get to them in time, but anger is the emotion we are most used to managing. The truth is that anger has no limits. It can extend not only to your friends, the doctors, your family, yourself and your loved one who died, but also to God. You may ask, "Where is God in this?**

**Underneath anger is pain, your pain. It is natural to feel deserted and abandoned, but we live in a society that fears anger. Anger is strength and it can be an anchor, giving temporary structure to the nothingness of loss. At first grief feels like being lost at sea: no connection to anything. Then you get angry at someone, maybe a person who didn’t attend the funeral, maybe a person who isn’t around, maybe a person who is different now that your loved one has died. Suddenly you have a structure – - your anger toward them. The anger becomes a bridge over the open sea, a connection from you to them. It is something to hold onto; and a connection made from the strength of anger feels better than nothing. We usually know more about suppressing anger than feeling it. The anger is just another indication of the intensity of your love.**

**Bargaining**

**Before a loss, it seems like you will do anything if only your loved one would be spared. “Please God,” you bargain, “I will never be angry at my wife again if you’ll just let her live.” After a loss, bargaining may take the form of a temporary truce. “What if I devote the rest of my life to helping others? Then can I wake up and realize this has all been a bad dream?”We become lost in a maze of “If only…” or “What if…” statements. We want life returned to what is was; we want our loved one restored. We want to go back in time: find the tumor sooner, recognize the illness more quickly, stop the accident from happening…if only, if only, if only. Guilt is often bargaining’s companion. The “if onlys” cause us to find fault in ourselves and what we “think” we could have done differently. We may even bargain with the pain. We will do anything not to feel the pain of this loss. We remain in the past, trying to negotiate our way out of the hurt. People often think of the stages as lasting weeks or months. They forget that the stages are responses to feelings that can last for minutes or hours as we flip in and out of one and then another. We do not enter and leave each individual stage in a linear fashion. We may feel one, then another and back again to the first one.**

**Depression**

**After bargaining, our attention moves squarely into the present. Empty feelings present themselves, and grief enters our lives on a deeper level, deeper than we ever imagined. This depressive stage feels as though it will last forever. It’s important to understand that this depression is not a sign of mental illness. It is the appropriate response to a great loss. We withdraw from life, left in a fog of intense sadness, wondering, perhaps, if there is any point in going on alone? Why go on at all? Depression after a loss is too often seen as unnatural: a state to be fixed, something to snap out of. The first question to ask yourself is whether or not the situation you’re in is actually depressing. The loss of a loved one is a very depressing situation, and depression is a normal and appropriate response. To not experience depression after a loved one dies would be unusual. When a loss fully settles in your soul, the realization that your loved one didn’t get better this time and is not coming back is understandably depressing. If grief is a process of healing, then depression is one of the many necessary steps along the way.**

**Acceptance**

**Acceptance is often confused with the notion of being “all right” or “OK” with what has happened. This is not the case. Most people don’t ever feel OK or all right about the loss of a loved one. This stage is about accepting the reality that our loved one is physically gone and recognizing that this new reality is the permanent reality. We will never like this reality or make it OK, but eventually we accept it. We learn to live with it. It is the new norm with which we must learn to live. We must try to live now in a world where our loved one is missing. In resisting this new norm, at first many people want to maintain life as it was before a loved one died. In time, through bits and pieces of acceptance, however, we see that we cannot maintain the past intact. It has been forever changed and we must readjust. We must learn to reorganize roles, re-assign them to others or take them on ourselves. Finding acceptance may be just having more good days than bad ones. As we begin to live again and enjoy our life, we often feel that in doing so, we are betraying our loved one. We can never replace what has been lost, but we can make new connections, new meaningful relationships, new inter-dependencies. Instead of denying our feelings, we listen to our needs; we move, we change, we grow, we evolve. We may start to reach out to others and become involved in their lives. We invest in our friendships and in our relationship with ourselves. We begin to live again, but we cannot do so until we have given grief its time.**