

The Psychology of Chronic Illness

By Nancy Drummond

Objectives:

At the conclusion of this course, the learner will be able to . . .

1. Define chronic illness and explain how chronic illness differs from acute illness
2. List at least three common challenges associated with chronic illness
3. List at least five common emotions associated with chronic illness
4. List and explain the steps of the grieving process
5. Identify at least three tools to ease the challenges of chronic illness
6. Discuss the statistical relationship between chronic illness and depression

Imagine waking up every morning – for the rest of your life – knowing that you are sick. Imagine knowing that the good days will become fewer and further between, and the bad days will become more frequent. Imagine the fear, frustration and hopelessness you would face. Imagine the impact on your family, your friendships, your finances and your future. Welcome to the world of chronic illness.

Chronic illness is defined as an illness that lasts a long time and usually cannot be cured completely, but can often be managed through diet, exercise, lifestyle and medical care. Some chronic illnesses are a death sentence, terminal in nature; more often, however, chronic illness is a life sentence, something that impacts and forever changes the life of a person who is diagnosed. Many of us are more accustomed to more common acute illnesses – a very different phenomenon from chronic illness.

Acute illnesses – the common cold, stomach viruses, most headaches and many other “everyday” ailments – have a finite term, meaning they only last for a set period of time. When an acute illness is over, the sufferer recovers and moves on with life. Chronic illness, on the other hand, can last for a lifetime; there may be periods of recovery or

remission, but a relapse at some point is fairly certain. Acute illnesses also have a minimal or temporary life impact, as life returns to normal when the illness is over. Chronic illnesses generally require major life adaptations, as permanent changes to lifestyle must be made.

People also often find it harder to relate to those with chronic illness. We can all relate to acute conditions by experience, but it can be difficult to comprehend the life-changing effects of a chronic condition. As a result, people often resort to pity and over-protection, smothering the patient with chronic illness. On the other end of the spectrum, some people express a sense of intolerance, impatience and frustration with the chronically ill. The inability to effectively understand and relate to those with chronic illness often leads to both relationship and communication challenges.

The most significant challenges associated with chronic illness, however, are the challenges faced by the person who has been diagnosed with the illness or condition. Adaptation to necessary changes is possible, and a full and happy life can be achieved, but there are certainly challenges to be surmounted. In many cases, overcoming these challenges requires cooperation between the patient, family and friends, caregivers and other medical professionals.

Often the first challenges faced in chronic illness are the physical challenges associated with symptoms of the illness or condition. Visible, external symptoms can be easier to cope with, as they are more obvious and often more “treatable.” It can be easier to deal with symptoms that can be seen by and explained to everyone; invisible, internal symptoms are often more difficult to describe, prove and cope with. The invisible symptoms of chronic illness can be constant and are often more severe than the visible symptoms, but because they are unseen and generally not measurable, they are easier for both medical professionals and friends and family to discount. A person with chronic invisible symptoms may suffer in silence to avoid appearing “whiny.”

Another challenge faced by those suffering from chronic illness is reduced ability. Even chronic illnesses that have few limiting physical effects have been shown to increase fatigue levels and decrease strength and stamina. The frustration experienced as a result of reduced physical or mental abilities can be as debilitating as the illness or condition itself. Finding things that a person with chronic illness can do often helps alleviate the sense of loss experienced when abilities are limited.

Financial challenges are also faced by those with chronic illness. Even with adequate insurance coverage, medical bills and co-pays can easily add up and place a significant financial burden on an individual or family. Additional financial challenges arise when a chronically ill person is no longer able to work or produce a previously-earned income. This factor, combined with medical bills, can induce massive stress due to financial woes.

All of these factors unite to produce potential relationship challenges for both the chronically ill individual and his or her family. As you treat your chronically ill patients, it is important to remember that their families are also dramatically impacted by diagnosis of and living with chronic illness. Illness can create a dependence on others that may not be welcomed by the patient or by his or her family members. It can also breed a negative attitude or sense of self-deprecation that can be discouraging to family members who are trying to be helpful and understanding.

Finally, chronic illness presents immense challenges to a person's sense of self-image and self-worth. The physical symptoms, reduced abilities, financial woes and relationship challenges of chronic illness can breed strong feelings of self-doubt and worthlessness. The resulting decreased self-esteem leads to feelings of guilt and a tendency toward social isolation. Isolation and guilt, however, further damage a person's self-image, creating a vicious cycle of negativity that can be difficult to break.

Negative emotions and feelings are very common in chronic illness. In fact, studies have identified ten basic emotions experienced frequently by patients with chronic illness:

- **Helplessness** – Helplessness is often the result of necessary reliance on others and a loss of independence due to reduced abilities.
- **Frustration** – Reduced abilities, persistent physical or mental symptoms and a general loss of control over life can all lead to extreme frustration.
- **Hopelessness** – Chronic illness breeds hopelessness for the present due to symptoms and lost abilities, and hopelessness for the future due to uncertainty.
- **Sadness** – People with chronic illness often experience both a sadness for what they are facing and a sadness for what they have lost.
- **Resentment** – Resentment in chronic illness can be aimed at oneself due to inabilities, at others due to abundance of abilities, or both simultaneously.
- **Anxiety** – A sense of fear and anxiety are common in chronic illness, both in terms of the present and in terms of the future.
- **Irritability** – The frustration, resentment, anxiety and hopelessness of chronic illness can cause a person to be irritable with him or herself and with others.
- **Tension** – Physical, financial, relationship and other challenges can cause physical and emotional tension that often further aggravates chronic illness.
- **Stress** – External factors (physical symptoms, financial troubles, etc.) combine with internal factors (relationship and self-image challenges, etc.) to cause stress.
- **Anger** – Those with chronic illness may feel angry at themselves for being ill, at others for not “fixing” things, or at a “higher power” for punishing them.

These negative feelings and emotions are all a natural part of the grieving process experienced by many – if not all – individuals diagnosed with chronic illness. A diagnosis of chronic illness usually means a loss of some type for both the individual and his or her family. The normal human response to loss is to follow a grieving process that ends in an acceptance of the diagnosis and a willingness to make the most of life in spite of the illness or condition. Most people’s grief follows a progression that can be outlined in five basic steps:

Step 1:

At this stage, a person is unwilling to accept the diagnosis. He or she will often deny that the diagnosis is correct and may discount symptoms and even medical tests. He or she may refuse medication or treatment and try to maintain a previous standard of life or activity.

Step 2:

At this stage, a person has accepted the diagnosis as real and experiences a strong sense of the unfairness of the situation. He or she may be angry, irritable, frustrated or bitter and may display some degree of hostility, especially toward medical personnel and caregivers.

Step 3:

At this stage, a person has moved past his or her sense of unfairness or injustice and has a temporarily renewed sense of hope. He or she may try to reason with doctors and other medical professionals about a cure, may throw him or herself into research of the illness or condition, or may try to make deals with God or another “higher power.”

Step 4:

At this stage, a person’s bargaining, reasoning and dealing have all come to a screeching halt and the revived hope is completely deflated. He or she enters a period of extreme sadness and depression, often exhibiting hopelessness and a desire for isolation. Suicidal thoughts may also become evident at this stage.

Stage 5:

At this stage, a person finally comes to a sense of true acceptance of his or her diagnosis. He or she develops coping strategies and learns to live with and adapt to the specifics of his or her illness or condition. He or she may also be willing to offer support and encouragement to others at this stage.

This grief process can be especially challenging for children and teens diagnosed with a chronic illness. While admittedly devastating to an adult, diagnosis of a chronic illness or condition can be earth-shattering and seemingly life-ending for a young person. Children and young adults often feel a higher level of shock, hopelessness, denial, anger and guilt when diagnosed. They are also at a dramatically increased risk for depression and other emotional challenges.

Age-appropriate education can help alleviate some of the emotional response typical in children and young adults who have been diagnosed with chronic illness. Education can also help with anxiety and fear for the future, allowing young adults, in particular, to realistically plan for the next phase of their lives. Energy directed at self-education or developing new hobbies and interests is very positive and should be strongly encouraged.

There are a number of tools available to help patients deal with chronic illness. Support groups are one of the best avenues for help. They provide current, accurate information and patient education, helping alleviate the uncertainty associated with chronic illness. Support groups are also useful for getting patients to share their experiences, helping them understand that they are not alone in their journey. This revelation helps reduce the common sense of isolation and helps build a sense of community.

Individual counseling is another tool that can help chronically ill patients cope with challenges. While support groups are best at building community, they do not allow for the privacy necessary in dealing with sensitive issues. Individual counseling and family counseling can help expose sensitive emotions and relationship issues, and can help a

person or family group move toward resolution of these challenges. It is important that both the patient and the family receive the individualized help they need.

Another tool that can ease the challenges of chronic illness is a set of adaptive strategies designed specifically for a patient and his or her situation. These strategies can often be best designed in conjunction with a physical and/or occupational therapist that has information about both the patient's condition and lifestyle. Adaptive strategies should be positive and upbeat, infused with a sense of hope, but they also need to be realistic and applicable to a patient's personal situation. These strategies can help a person cope effectively with the necessary lifestyle changes that often accompany a diagnosis of chronic illness.

Caregivers and medical professionals can also use a pre-defined set of coping strategies as a tool to help patients deal with chronic illness. There are five basic steps that can help nearly any patient better cope with his or her challenges:

1. Establish a support network of family and friends who want to help.
2. Surround yourself with things that inspire joy, happiness and encouragement (favorite books, inspirational sayings, family photos, etc.).
3. Educate yourself about your disease or condition using credible, current sources; knowledge helps dispel fear and anxiety.
4. Take care of yourself by eating right, maintaining your appearance, getting plenty of sleep, exercising and having fun.
5. Have a routine and do something – accomplish a task, however small – every day to lend stability and consistency to your life.

These five simple coping strategies can help patients learn to live a full life in spite of chronic illness. Positive thoughts and acceptance of a diagnosis can help ward off depression and other potential emotional and physical complications that are common in chronically ill patients.

Chronic illnesses – regardless of the severity of their symptoms – make a patient more susceptible to a number of psychological conditions and disorders. In 2004, the American Psychological Association found that even something as simple as chronic tension headaches decreased work and social function in a majority of individuals and made a person three to 15 times more likely to be diagnosed with a mood or anxiety disorder (APA, 2004). This propensity to psychological complications is most evident in the incidence of depression among those with chronic illness.

The incidence of depression in the general population is approximately 10-25% for females and 5-12% for males. In those with chronic illness, however, the incidence of depression jumps to 25-33% across the population (Fram, 2006). Exacerbation of a chronic illness and physical symptoms or limitations can easily lead to feelings of depression. The symptoms of depression – including poor eating habits, lack of exercise, poor hygiene and social and/or physical isolation – can, in turn, further exacerbate many chronic illnesses, creating a cyclic downward spiral.

To prevent this downward spiral, it is important that depression be diagnosed as early as possible. This can prove challenging, as a certain amount of despair and sadness is a normal symptom of the grieving process associated with chronic illness. Additionally, many families and even medical professionals dismiss symptoms of depression as a normal feature of chronic illness. This is a dangerous attitude, as depression can aggravate many chronic conditions, intensifying pain, causing fatigue, and triggering or worsening a sense of isolation. In worst case scenarios, depression associated with chronic illness can even result in suicide.

Depression is one of the most common complications of chronic illness. In fact, up to one-third of those with serious chronic conditions experience clinical symptoms of depression (Fram, 2006). Studies have shown that these symptoms generally emerge within the first two years after diagnosis with a chronic illness (APA, 2004). And while depression and chronic illness often co-exist, they are separate conditions and require separate care and treatment.

Early treatment of depression associated with chronic illness has been shown to improve symptoms and dramatically reduce the chances of serious complications such as suicide. This early treatment is especially critical for chronically ill children and teens who are experiencing symptoms of depression. Clinical treatment of depression in patients with chronic illness has been shown to improve both psychological and physical conditions, enhancing quality of life.

As caregivers and medical professionals, it is important to understand the undeniable psychological component of chronic illness. When you understand the grieving process and the emotions and challenges associated with chronic illness, you are better equipped to help your patients learn to cope with their new situation.

Some tips to help patients with chronic illness include:

- Teach them to live effectively with their physical symptoms
- Teach them to live effectively with necessary treatments
- Remind them to communicate clearly and honestly with medical professionals
- Teach them to maintain emotional balance
- Encourage them and help them maintain a positive attitude
- Do things to help them feel good about themselves and improve their self-image
- Give them information and expose them to things that will help build hope
- Encourage them to get help when it is medically or psychologically indicated

Use the tools available to you to help prevent depression and to assist those in your care as they learn to adapt to the specific needs of their illness or condition. Through

understanding, education, encouragement and support, you have the power to change the outlook of a patient with chronic illness. Be positive, upbeat and realistic, and you will help your chronically ill patients find the hope they need for the future.

References:

“Alzheimer’s Disease: Coping with Chronic Illness.” (2005) *ClevelandClinic.org*.
Accessed on 10/24/2007.

American Academy of Child and Adolescent Psychiatry. (2002) “Facts for Families, No. 19: The Child with a Long-Term Illness.” *AACAP.org*.
Posted on 11/01/2002. Accessed on 10/24/2007.

American Psychological Association. (2004) “Chronic Illness.”
APAHelpCenter.org. Accessed on 10/24/2007.

Fram, David H., Ed. (2006) “Depression Caused by Chronic Illness.”
WebMD.com. Posted on 12/01/2006. Accessed on 10/24/2007.