The Emotional Life of Patients with Chronic Diseases: A Framework for Health Promotion Strategies

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Abstract—Being a patient with a chronic disease is both a physical and emotional experience. The ability to recognize a patient's emotional health is an important part of a health care provider's skills. For the purposes of this paper, emotional health is viewed as the way that we feel, and the way that our feelings affect us. Understanding the patient's emotional health leads to improved provider-patient relationships and health outcomes. For example, when a patient first hears his or her diagnosis from a provider, they might find it difficult to cope with their emotions. Struggling to cope with emotions interferes with the patient's ability to read, understand, and act on health information and services. As a result, the patient becomes more frustrated and confused, creating barriers to accessing healthcare services. These barriers are challenging for both the patient and their healthcare providers. There are five basic emotions that are part of who we are and are always with us: fear, anger, sadness, joy, and compassion. Living with a chronic disease however can cause a patient to experience and express these emotions in new and unique ways. Within the provider-patient relationship, there needs to be an understanding that each patient experiences these five emotions and, experiences them at different times. In response to this need, the paper highlights a health promotion framework for patients with chronic disease. This framework emphasizes the emotional health of patients.

Keywords—Health promotion, emotional health, patients with chronic disease, patient-centered care

I. INTRODUCTION

BEING a patient is both a physical and emotional experience, one that continually demands adjustments to cope with the inherent stress of being a patient [1]-[4]. The ability to recognize a patient's emotions and emotional health is an important part of a healthcare provider's communication skills.

There are many different definitions of emotional health. For purposes of this paper, emotional health is defined as the way that we feel, and the way that our feelings affect us [4]. Recognizing and understanding a patient's emotional health can lead to improved provider-patient relationships as well as health outcomes [5]. For example, when patients first hear their chronic disease diagnosis, they often find it difficult to cope with the range of emotional stress. Struggling to cope with different emotions can interfere with the patient's ability to hear, to understand or to act on information related to

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treatment options [5]. As a result, the patient often becomes more confused, fearful and anxious. The patient may behave or interact in ways that are not in their best interest such as being non-compliant with their treatment plan. This type behavior or interaction is frustrating for the patient and the provider because it creates stumbling blocks in communications. It also contributes to rising costs in the patient's healthcare services [2], [5], [6].

II. EMOTIONAL HEALTH

Living with a chronic disease causes a patient to experience and express emotions in new ways [3], [7]. As part of the provider-patient relationship, there needs to be the understanding that each patient with a chronic disease has a unique way of expressing emotions. As part of this understanding, there is recognition by the provider that the patient's emotional health plays a pivotal role in the delivery of healthcare services. This recognition leads the provider to view the patient as a human being—not just as a product of his or her disease [7], [8].

One way to view an emotion is to see it as a flow of energy that changes a person's relationships with self and others [9]. With this view in mind, an emotion is seen as an energy field [9]. For example, it is not unusual to "feel" someone else's anger or sadness. How we chose to release that emotional energy determines how we are in the world—that is, how we are seen and how we interact with others [9].

There are five basic emotions that are part of who we are and are always with us: fear, anger, sadness or sorrow, joy, and compassion [9]. Emotional health is not a matter of learning to overcome and deny emotions but rather to live with them in a way that expresses their power in healthy ways-When we are a patient, we experience these five emotions differently and, we spend a lot of time expressing them. Sometimes a patient can express just one emotion such as sadness for a long period of time. A patient can also express more than one emotion or a range of emotions in short periods of time. There is no one acceptable way for a patient to express these five emotions.

When a patient does express one or more emotions it is not the responsibility of the provider to be judgemental because there is no right or wrong way to express emotions. Emotions come and go like clouds in the sky, and just as the sky cannot control clouds, we cannot control emotions [9]. However, providers can guide patients to express emotions directly and effectively which can lead to better health outcomes.

World Academy of Science, Engineering and Technology
International Journal of Medical and Health Sciences
Vol:11, No:11, 2017

Fear is a primal response and it helps us survive. How a patient chooses to respond to a diagnosis is often based on a sense of survival – that is, can I survive this disease? [9]. Fear is a protective mechanism. It is a healthy response to a frightful situation such as being diagnosed with a life-threatening chronic disease. The flight-or-fight response is rooted in fear and we chose to flight or fight based on perceived benefits [9]. Feeling afraid leads to a defensive behavior or flight from that which is feared. For example, a patient may not be compliant with a treatment plan because she sees no perceived benefit for compliance. If the patient does decide to fight and thus to follow their treatment plan, that decision is usually based on the expectation of a positive outcome. Patients are more likely to follow their treatment plan as long as they believe that there is a chance of a positive benefit or outcome—no matter how small. In other words, patients will fight back against their disease if there is a benefit to fighting [9]. It is interesting to note the importance of the flight or fight response in relation to certain chronic diseases such as cancer. It is not uncommon for a patient with cancer to view their treatment as a 'battle" and whether they "won" or "lost" the battle.

Fear is a healthy response to a chronic disease diagnosis. However, because fear is such a strong emotion it can become the dominant or overriding emotion; when this happens, it is known as *maladaptive fear* and it can turn into *paranoia,* which is excessive suspicion of others or excessive fear of events such as a disability or death [9]. Sometimes a patient can experience an intense fear of being disabled or of death. This maladaptive fear can be so strong that it can cause a patient to have physiological complications. In other words, a patient can literally worry herself into a disability or even death [9].

Anger is related to fear. It helps a patient move from self-blame to placing responsibility on the external causes of the disease [9]. It can mobilize a patient to action and to change [9]. When the cause is revealed and anger is expressed in healthy ways, then the patient is less likely to feel hopeless and helpless.

When anger is expressed in negative ways, it is *destructive anger* and can spiral out of control [9]. For example, a patient might be so angry that they act hostile towards their providers. This type of anger can interfere with the patient's treatment plan and ultimately, their health outcomes. A patient can instead have *constructive anger*, behaving in ways that lead to positive action and change [9]. For example, a patient can use anger to their advantage and motivate himself to be their own health advocate.

Sadness or *sorrow* is the third emotion that patients commonly experience. Embracing sadness is accepting one's vulnerability [9]. Sadness means opening up to loss. Once a patient opens up to their loss of health, then there is the possibility for more openness to and acceptance of self and others [9].

Embracing sadness depends on support from others. A function of sadness is to be open to support and to offer support to others [9]. When a patient actively seek support from others, then she can support others in similar situations [9]. For example, attending support groups for patients with chronic diseases is often an essential part of treatment plans. Support groups help patients cope with the physical and emotional burdens of their chronic disease and to share these burdens with others.

A patient also experiences *joy.* Joy enables a patient to see with new eyes after being released from fear, anger, or sadness [9]. When a person sees himself with new eyes, he can listen in new ways. He can listen to new possibilities rather than limit himself to the role of a patient [9]. For example, it is not unusual for a patient who recovers from a life-threatening disease to make major changes in their life. He can experience new possibilities rather than experience the limiting role of being a "patient" with its endless routine and often, lack of progress. With feelings of joy, the possibilities can be endless. Having joy does not mean that fear, anger, or sadness go away; instead, joy allows these emotions to exist in relation to each other [9]. Each emotion has its own time for expression but there is always the potential for new possibilities.

Compassion is the strongest emotion and is considered one that is healing [9]. Feeling compassion for others and oneself can help in the healing process [9]. However, to feel compassion, a person has to love and forgive all their strengths and weaknesses. It requires a celebration of your talents and yet forgiveness of yourself when experiencing challenges and defeats [9]. In other words, compassion is an acceptance of self.

Compassion depends on our ability to be, love, to know, and to see in ways that are empty of judgment [9]. It means being open to ourselves and the world around us. The calmness that comes from compassion is constructive because it allows not only for a stillness of being but also encourages social engagement [9]. For example, at an Alcoholics Anonymous (AA) meeting, those in recovery can often experience the compassion of others who are open, supportive, nonjudgmental, and accepting. When struggling with addiction, to receive kindness and support from others allows a person to feel less alone and isolated.

Trust is not one of the five emotions but it is a feeling integral to these emotions [9]. Trusting is an attitude that reflects positive beliefs, feelings and emotions towards others while *distrust* is the opposite. We learn to trust or distrust others according to our experiences with them. For patients with a chronic disease, trust is fundamental to the provider-patient relationship. That is, the patient needs to trust their provider to provide quality healthcare services and the provider needs to trust the patient to be active and compliant in their treatment plan. Trust in the-provider-patient relationship is based on positive feelings toward another. Those positive feelings towards another are part of the belief that the other person has a good will towards you. Trust relies on mutual caring about the interest of the other(s). The provider's interest is delivering quality healthcare services that allow patients to live healthy and productive lives. The patient's interest is receiving quality healthcare services that allow for a healthy and productive life.

World Academy of Science, Engineering and Technology
International Journal of Medical and Health Sciences
Vol:11, No:11, 2017

III. HEALTH PROMOTION STRATEGIES

The 20th and 21st centuries have seen improvements in disease prevention. The world is now a place where many people live longer and often have healthier lives or better quality of life than they did in earlier periods [10]. Reference [11] reported that this increase in life expectancy and quality of life is due not to medical technology but to disease prevention. Health promotion is the major strategy of disease prevention [10]. The 1998 WHO definition of *health promotion* is "the process of enabling people to increase control over their health and its determinants, and thereby improve their health." By this definition, health promotion does not focus only on the individual but also on the influences or determinants that affect a person's health such as emotional health [10].

Health promotion strategies are put to use at three levels: primary, secondary, and tertiary [11]. *Primary prevention strategies* prevent or stop a person from getting a specific disease or engaging in health-compromising behaviors. These strategies target healthy people. Primary prevention strategies include efforts to reduce causes or risk factors associated with a disease. Examples include vaccinations, restricted sales of tobacco products, and prenatal care.

Although primary prevention strategies have significance for members of the general population who are healthy, the next two levels of prevention, secondary and tertiary, are the focus of this paper's proposed health promotion framework. *Secondary prevention strategies* try to prevent a disease from getting worse. These strategies try to stop a disease from progressing once a person is exposed to it or at risk of becoming exposed. Examples include screenings that detect disease at an early stage such as breast mammograms or colonoscopies. Screenings find people who are likely to have a disease, or they look for factors that put a person at risk for disease [12].

Tertiary prevention strategies soften the negative effects of having a disease. These strategies include services that minimize illness and improve outcomes once someone has a disease. Examples include rehabilitation services like physical therapy or occupational therapy. Other examples are Alcoholics Anonymous (AA), Narcotics Anonymous or Overeaters Anonymous (OA) which are support groups for those with alcohol, drugs or food addictions [12].

The proposed health promotion framework for health promotion applies the five basic emotions along with trust as the basis for secondary and tertiary prevention levels. This framework targets patients with chronic diseases. The framework is designed to help patients in two ways. First, it helps patients to learn ways of emotional expression that improve provider-patient relationships, enhances patient self-advocacy skills and improves health outcomes. Second, the framework helps healthcare providers to understand that the patient's emotional health is integral to the delivery of healthcare services and to patient-centered care.

The proposed framework's rationale is that consideration of the emotional health of patients with a chronic disease will improve health promotion services.

A disease can be either acute or chronic. Acute diseases are those that come on quickly but last for a short time, usually less than three months. These diseases tend to have severe signs and symptoms that eventually fade [12]. Examples of acute diseases are influenza, measles and the seasonal flu.

There is more than one definition of chronic disease. In light of the multiple definitions, this paper limits the definition of a *chronic disease* to one that begins slowly and lasts for longer than three months [12]. Included in this definition is the recognition that a chronic disease requires ongoing medical attention. Chronic diseases generally cannot be cured, but they are not immediately fatal. Examples of chronic diseases are asthma, type 2 diabetes, heart disease, and multiple sclerosis.

Some patients have a chronic disease that persists not just for months but for years. Signs and symptoms may never fade. Chronic diseases may begin suddenly and present severe signs and symptoms such as asthma, or they may begin gradually and present mild signs and symptoms such as certain skin cancers. There may be periods of remission, during which the patient feels free of disease but is aware that the signs and symptoms or its potential for recurrence or exacerbation remain [13]. There may be no relief as the disease progresses, causing severe disabilities such as with multiple sclerosis or even death such as with amyotrophic lateral sclerosis (ALS). Many chronic diseases are long-standing and forever alter normal physiological functioning [13].

IV. PSYCHOLOGICAL TEMPLATE

The *Psychological Template* is a set of questions for thinking about the emotional health of patients [13]. The template is a guide for evaluating and understanding the ways in which a patient emotionally responds to having a chronic disease [13]. The questions are designed for adaptation or adjustment by healthcare providers from multiple disciplines and orientations. Providers from disciplines other than psychology or psychiatry can add to or reframe the questions for use within their theoretical systems [13]. The *Psychological Template's* design adds to the discipline of health promotion because of its focus on the emotional health of patients with chronic diseases.

For purposes of the proposed health promotion framework, the *Psychological Template's* five questions have been reframed from the original wording. The original wording is as follows [13]: How does the person manage reality? How does the person manage anxiety? How does the person manage relationships? How does the person manage cognition? What is the person's mastery-competence level?

These five questions have been reframed as well as an additional question has been added to address the emotional health of patients with a chronic disease. The reframed questions are as follows: How does the patient(s) manage and express their fear? How does the patient(s) manage and express their anger? How does the patient(s) manage and express their sadness or sorrow? Does the patient(s) experience joy? Does the patient(s) experience compassion for self and for others? Does the patient(s) trust their healthcare provider(s)?

World Academy of Science, Engineering and Technology
International Journal of Medical and Health Sciences
Vol:11, No:11, 2017

In the development of health promotion strategies at the secondary and tertiary levels for patients with a chronic disease, consideration should be given to how patients' answers these six questions. This consideration is straightforward for the experienced healthcare provider. For example, if working with recently diagnosed type 2 diabetic patients, a provider can assess emotional health based on a patient's verbal responses as well as non-verbal cues. Less experienced providers may work harder in determining the patient's emotional health, particularly with nonverbal cues. For instance, a patient may initially express their fear or sadness as anger or may be unwilling to initially express their feelings.

V. Examples of Health Promotion Strategies

Following are examples of health promotion strategies that focus on emotional health. These health promotion strategies are of use when providing patient-centered healthcare services. Some strategies require adjustment or reframing based on a patient's emotional health as well as the type of relationship the patient has with their provider.

1. *Understand physical and emotional experiences of the patient*. You do not need to have clinical training, but it is important to have some medical knowledge about the patient's chronic disease [12], [13]. The medical knowledge helps in assessing and understanding the patient's emotional health. General medical knowledge concerning a specific chronic disease can be accessed via a reliable and valid website such as UpToDate © and/or a government websites such as Medline Plus, Centers for Disease Control (CDC) or World Health Organization (WHO). Medical knowledge that represents a more personal experience can be gained by health promotion strategies that facilitate small group discussion in a supportive and non-judgmental environment. This type of environment allows opportunities for patients to identify and to honestly discuss physical and emotional experiences related to having a chronic disease.

2. *Assess patients' ability to cope with having a chronic disease*. The patient's ability to cope with the challenges caused by having a chronic disease impacts their emotional health [13]. If a patient has coping skills that allows for self-advocacy then not only will their emotional health improve but also the health outcomes [12]. An example of a health promotion strategy is identifying coping and self-advocacy skills that a patient with a chronic disease can practice and use.

3. *Offer a menu of strategies that meet the emotional needs of patients*. Each patient experiences a chronic disease in their own and unique way. In addition, it is not unusual for a patient to have more than one chronic disease that puts additional demands on their emotional health. For instance, a patient with type 2 diabetes is also at risk to have atherosclerosis. If this is the case then the patient's emotional health can become stretched or over-burden in response to managing two chronic diseases at the same time. Accordingly, health promotion strategies need to be flexible enough in their design to address the often multiple emotional needs of each patient. Do not assume that "one-size" fits all when it comes to health promotion strategies for patients with a chronic disease. Stress management strategies may be emotionally beneficial with one group of patients while self-advocacy strategies may be more emotionally beneficial for others.

4. *Referral to support groups and community services*. Support groups and community service referrals are integral to providing healthcare to chronic care patients. Some patients with a chronic disease may need additional services that go beyond what health promotion strategies can provide. Examples of some of these community services include but are not limited to English as a Second Language (ESL) interpreters, housing, transportation, disability support services, and home healthcare.
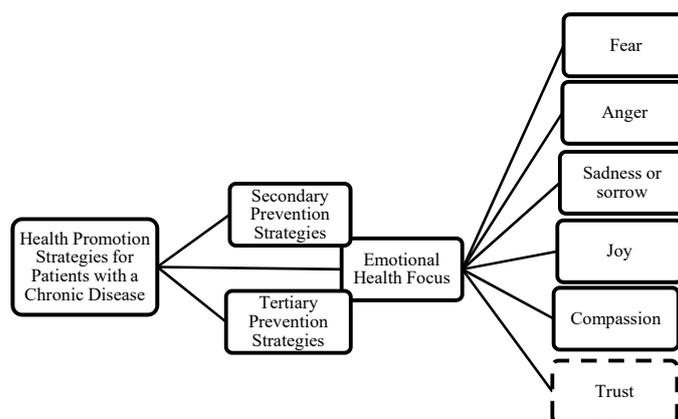

Fig. 1 Health Promotion Framework for Patients with a Chronic Disease

5. *Address the emotional issues related to progressive chronic diseases*. Some chronic diseases are progressive meaning that the disease's signs and symptoms usually get more difficult to manage overtime [12]. Progressive chronic diseases such as Alzheimer's disease can often lead to uncertainty, disability and death. Fear about the

World Academy of Science, Engineering and Technology
International Journal of Medical and Health Sciences
Vol:11, No:11, 2017

future can be heightened when those with a progressive disease find that they can no longer perform daily activities such as walking or eating or climb stairs [13]. To ignore or to pretend that these fears are non- existent in patients can undermine health promotion efforts.

In summary, having a chronic disease is a distinctive emotional experience for many patients. This emotional experience is one where the five basic emotions of fear, anger, sadness, joy, and compassion along with trust are often expressed in new and unique ways. In response, a health promotion framework requires an emotional health focus (see Fig. 1). By adding an emotional health focus to health promotion then secondary and tertiary prevention strategies become more patient-centered. These strategies go beyond addressing a patient's physical (signs and symptoms) experiences to helping patients identify and express their emotions in constructive ways. Once a patient with a chronic disease learns to express their emotions in constructive ways then access to quality health care improves as well as health outcomes.

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