

Finding a Place for Hope in the Management of Chronic Illness

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Abstract

The current concept of hope used by most of the existing literature and within health care is generally future-oriented and curative focused. This pervasive idea of ‘hope for a cure’, though applicable to many illnesses, does not apply to patients with chronic, progressive, and debilitating diseases. In this paper, I present a detailed description of the hope strategies employed by chronic illness sufferers, and how these differ from traditional ideas of hope. I also describe how hope may be negatively affected during clinical encounters with physicians and our current symptom rating tools. Suggestions for moving towards a supportive clinical environment are given, highlighting the importance of finding hope, and health, within chronic illness.

Suffering from a critical illness, or being suddenly diagnosed with a life-threatening condition, represents a turning point in the lives of many patients. The moment of the injury or diagnosis becomes a focal point, suddenly dividing their existence into a healthy “before”, and an “after” marked with the hardships of striving to be healthy again. According to author, professor, and patient, Arthur W. Frank, this is “the experience of being taken to the threshold of life, from which you can see where your life would end.”¹ What happens to patients’ hope, as well as the importance of finding it again, when faced with loss and death in these situations is relatively well understood, but what if the onset of illness is not so sudden or severe? What if there is not one focal incident, but an accumulation of small losses with varying significance? What if a patient is faced, not with impending death, but with an uncertain future of increasing infirmity? This is the reality for many individuals living with chronic, progressive and debilitating illnesses such as rheumatoid arthritis or multiple sclerosis. As a chronic illness progresses, patients may “experience a crumbling away of their former self images without the simultaneous development of equally valued new ones.”² Over time, this can lead to diminished feelings of self-worth and self-confidence.

When dealing with chronic, progressive disease, patients face the challenge of learning to maintain their own sense of self, while functions that previously defined daily living slowly fade away. For many of these patients, losing the ability to walk, groom, or feed oneself is not only devastating, but also an injury to the hope for a full and satisfying life. Research has

shown that the intrusiveness of a chronic illness into the activities of daily living is a major factor in the psychosocial impact of the disease, with pain, physical disability and energy levels identified as major issues.³ The inability to complete the tasks of daily living has been directly correlated to feeling a loss of autonomy.⁴ Functionally, with a progressive disease, these patients have everything to lose and nothing to gain. Therefore, it is of critical importance to reflect on and consider challenges to hope in this context.

While there are many different definitions of hope, the one I am employing for this discussion is that provided by Farran et al.,⁵ that states:

“Hope constitutes an essential experience of the human condition. It functions as a way of feeling, a way of thinking, a way of behaving, and a way of relating to oneself and one’s world. Hope has the ability to be fluid in its expectations, and in the event that the desired object or outcome does not occur, hope can still be present.”

Hope has been empirically shown to have significant value in patient care, and is beneficial to coping, reducing psychological distress and improving quality of life.⁶ Specifically, hope has been shown to play a protective role against depression for seniors, whose symptoms of aging often mirror, or are compounded by, the progression of chronic disease.⁷ While the benefits of hope are fully appreciated in the literature, sources of hope have proven to be a much more complicated issue. For patients who have suffered a brain injury,

hope has been identified as originating in finding new perspectives, gaining a new lease on their second chance at life, and from success stories of recovery.⁸ For chronic illness sufferers, sources of hope may be quite different and varied. There are few, if any, success stories about living well with arthritis to guide the hope of an aging patient. Patients with chronic illness, therefore, may not fit into the general structure of a future-oriented, curative focused concept of hope used by most of the existing literature, and within healthcare. This approach to hope as a “prospective orientation towards future improvements” also pervades commonly used quantitative research tools, such as the Hope Scale and the Nowotny Hope Scale.⁹⁻¹¹ For patients whose hope is not future-oriented and does not involve a prospective cure, these scales may be misleading about a patient’s degree of hopefulness. Research has shown that this is the case, identifying as many as five distinct patterns of hope employed by sufferers of chronic illness.¹² These patterns were distributed around two axes, focused either on the future or the past as a source of hope, then on internal or external sources. For instance, one individual patient may find sources of hope primarily in the people surrounding them, or in thinking about goals for the future. In contrast, another may rely primarily on inner strength and meditating on past accomplishments to find sources of hope. These variations in hope strategies point to the differences that can exist amongst chronic illness patients, in comparison to sudden injury patients who remain primarily in the “future-oriented” end of the spectrum.⁹ It is important to understand the sources of hope and how they can vary amongst individuals if we wish to attend to hope among chronically ill patients.

In clinical encounters with patients, biomedical information often takes precedence over social/emotional content in the discussion of illness. However, biomedical concerns brought to the meeting by patients come with social/emotional components. These are almost equally valued as topics of discussion with the clinician. Despite this, psychosocial and emotional issues are discussed much less frequently than purely biomedical concerns.¹³ Amongst the emotional and psychosocial concerns is hope, as a topic that patients may be looking to the clinician to initiate. In particular, it is important to promote hope other than for a cure, as well as discussing and maintaining a broad spectrum of sources from which hope can be enhanced.¹³ This is especially relevant for chronic, progressive illness sufferers, who, as discussed above, utilize varied patterns and sources of hope.

Despite the patient’s desire to discuss and maintain hope in the clinical setting, the opposite may be occurring. In a study done by Fox, only 12% of patients suffering from chronic illness identified medical professionals as a source of hope. Even more disturbing is that 50% of respondents identified health professionals as having dashed their hopes completely.¹⁴ Knowing the benefits of hope, and how important it is to patients who are looking to clinicians for a discussion of more than just biomedical aspects of illness, these statistics become even more important. They show that on an emotional and psychosocial level, patients may not be getting what they need from their health care providers, which is not false hope, but an open honest discussion that includes hope, and an emphasis on the fact that they are not alone in facing chronic disease progression.

A recent study involving patients with multiple sclerosis indicates that, at diagnosis and with exacerbations in or a worsening of symptoms, these patients are most vulnerable to the possibility of hopelessness.¹⁵ Accordingly, these are key times to ask patients with chronic illnesses about what they may be most fearful of or concerned about, as well as what they are hoping for (or what is threatening their hope). Talking with patients about the possibilities for alternative ways to do some of their most cherished activities, finding new sources of purpose or meaning, and negotiating some of the limits imposed by their illness can provide opportunities for patients to share their feelings and, potentially, see their illness from another perspective. Referrals to other health professionals, such as occupational or physiotherapists, may also ensure that patients are provided with additional concrete suggestions/strategies for improved success with adapting to life with a chronic illness, something which can also contribute to hope.

A particular example in which hope can be injured, rather than fostered, in the clinical setting is when chronic illness patients are presented with a health assessment questionnaire. These forms instruct patients to grade themselves on how well they perform the functions of daily living, and may also require the patient to self-indicate the severity of their progressing disability. In a way, questionnaires like this bring functions that the patient has already lost to a painful focus. They also can cast a shadow on the future, indicating that the patient’s current abilities may not be available in the upcoming months or years. To illustrate living with a chronic, degenerative disease, Toombs says “the assumption ”I can do it again” can no longer be taken for granted by a person whose physical abilities are constantly diminishing.”¹⁶ This statement highlights

the particular challenges facing these patients for whom future-oriented sources of hope may not be valid. Future hope may also be diminished by seeing disease progression, as laid out in the assessment form, as an inevitable outcome. The questionnaire, unlike a discussion with a health care provider, cannot act in a dynamic or sensitive way towards the patient and their particular attitude towards disease progression.

This type of threat to hope in the clinical setting can be looked at as contributing to the phenomenon of “bruising.” A term coined by Wendy Edey of the Hope Foundation of Alberta, bruising refers to situations in which patients are continually bombarded with setbacks, without any appreciable reprieve. This may cause a patient to exhibit anger or withdrawal when asked to discuss their illness.¹⁷ The bruising phenomenon, therefore, is a significant detriment to the quality and effectiveness of the clinical encounter. In the context of chronic, progressive disease, each loss of function can be considered a bruise. Some may be large, some small, but with each new addition the overall effect of hopelessness is intensified. It is in various degrees of this state that patients are confronted with assessment questionnaires, which may function to decrease the patient’s level of hope even before the actual meeting with the clinician begins.

Hope in chronic illness is a varied and delicate thing. No two patients will experience hope in the same way, or look to the same places as sources of it. Therefore, it presents a unique challenge for healthcare professionals. How can hope be fostered in the clinical encounter, and more importantly, how do we ensure that an open, honest discussion about hope is available for all patients, especially those with chronic, progressive illness? In the clinical encounter, certain techniques have been suggested to augment hope in patients. Simple methods such as building management around the strengths of the patient, assisting in finding support (either spiritual or medical) groups if needed, and empowering patients by giving options for illness management, all increase hope.¹⁴ Another important topic to address in the patient-clinician interaction is that of uncertainty. One of the themes unearthed in a discourse on living with chronic illness done by Ohman et al. was that of “uneasiness and threats against life”, which shows how insecurities about the progression of chronic illness can be a source of fear for patients.

Being open and honest with patients by providing information about their illness, including clarifying what is or is not known about its progression, can help to balance their unease about the future with the

possibility of hope. Given that one aspect of finding or having hope involves being able to imagine a future in which one wants to participate, helping patients explore and reflect on the relative (un)certainly related to the progression of their symptoms can be helpful. This approach can help patients avoid losing hope as they “think the worst” about what their future may hold. At a minimum, this creates the opportunity to address any misunderstandings or misperceptions of what may happen that may be having a negative effect on the patient.¹⁸

Despite the many challenges facing chronic illness sufferers, there are ways in which health can be found within illness. Research has found that there are six main themes related to this: honoring the self, seeking and connecting with others, creating opportunities, celebrating life, transcending the self and acquiring a state of grace.¹⁹ For many patients, hope is the key that unlocks the ability to create opportunities, and to celebrate life despite the appearance or progression of a chronic illness. Therefore, it is vital that hope be a central part of the patient-health care provider interaction. This is not to say that it is the responsibility of the clinician to be a source of hope for each and every patient, but that it should be acceptable to talk about hope (or the lack thereof), and to critically appraise practices that are injurious to hope. Recognizing hope’s place in the management and experience of chronic illness will help to enhance the quality of the patient’s interaction with clinicians, as well as their ability to live fuller and more satisfying lives.

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