Surviving Cancer or Other Serious Illness: A Review of Individual and Community Resources

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ABSTRACT In order to provide appropriate individual and community support for cancer survivors, there is a great need to better understand how people who have survived cancer or other serious illness adapt positively to health challenges and to identify effective approaches for helping people cope with health challenges over their lifetime. Studies have identified a number of personal factors that are associated with resilience, increased quality of life, and positive adaptation to illness. Of particular interest is the ability of individuals to survive or even thrive despite an adverse event, as influenced by both individual factors such as resiliency and external factors like social support. The experience of having a potentially life-threatening illness can lead to positive adaptation and increased ability to thrive despite difficult circumstances. The cancer survivorship movement and the cancer community in general provide important resources for improving quality of life and alleviating human suffering and distress among patients and survivors and for adding personal meaning and hope to people’s lives. (CA Cancer J Clin 2007;58:60–64.) © American Cancer Society, Inc., 2008.
following the diagnosis of invasive cancer. About 14% of these survivors of cancer had their disease diagnosed at least 20 years previously. In recent years, an estimated 64.9% of US adults diagnosed with cancer could expect to live at least 5 years.

Some side effects of cancer therapy can persist for long periods of time. The chronic and delayed effects of cancer treatment vary by diagnosis, treatment, coexisting health conditions, and other factors. Common side effects of cancer treatment, even after a year since diagnosis, include fatigue, loss of strength, difficulty sleeping, and sexual dysfunction. There may also be adverse affects on cognition. Appropriate follow-up care for survivors of cancer, for which clinicians have a key role to play, includes medical surveillance to detect recurrences or secondary cancers, monitoring to identify and address potential late effects of cancer treatment, advice about risk reduction, and assessment of cancer risk among biological family members. The potential late effects of cancer treatment can include second malignancies or other chronic conditions affecting physical and emotional well-being.

COPING STRATEGIES AND RESILIENCY AMONG CANCER PATIENTS AND SURVIVORS

There is a large and growing literature on strategies used by people to cope with cancer and other potentially life-threatening illness. Cancer patients and survivors may face a variety of situations, including painful or frightening symptoms, uncertainty about their prognosis, and changes in social relationships. Coping strategies employed by cancer patients are similar to those employed by people with other difficult life events. Coping strategies or styles are sometimes categorized by researchers as active versus avoidant, although such categorizations are likely to be overly simplistic and not capture the full range of coping strategies employed by people over time. Active coping refers to strategies whereby persons accept the issue at hand and actively attempt to deal with it through problem solving, planning, and seeking emotional support. For example, someone may try to learn more about the problem or talk with friends and family. Avoidant coping, which includes denial, refers to strategies whereby persons avoid facing an issue by mentally or physically distancing themselves from it. For example, someone may get busy with other things and avoid thinking about the situation. Dunkel-Schetter et al identified several patterns of coping in a sample of 603 cancer patients, including “seeking or using social support,” “focusing on the positive,” “distancing,” and cognitive and behavioral patterns of “escape-avoidance.” When faced with a difficult situation, people often search for meaning in adversity and draw on their personal values and beliefs. Cancer patients and survivors have been shown to use a large repertoire of important strategies to cope with different aspects of their illness and treatment. Coping strategies are not isolated phenomena, but rather complex, dynamic processes that change over time and which are related to other personal characteristics and aspects of the social environment.

Following cancer treatment, some people do not remain focused on being a cancer survivor, but rather focus on other pressing life concerns or experiences. Hopefulness and optimism are important mediators of coping and resiliency to illness. Several studies have shown that there are important connections between hopefulness, coping, resilience, and adaptation to illness. In these studies, measures of hopefulness have been found to be positively associated with indices of life satisfaction and well-being. Among women with breast cancer, for example, optimism is associated with short- and longer-term emotional well-being. Hopefulness is an important part of some positive coping strategies that people may use to tolerate or minimize stressful events. On the other hand, people who lack hope may be more likely to use negative coping strategies (for example, alcohol abuse or overeating) to alleviate stressful circumstances.

Survivors show resilience when they recover or even thrive in the face of adversity. The psychological concept of resilience focuses on the ability of individuals to survive or even thrive despite an adverse event and incorporates both individual traits, such as hardiness, and external factors, such as social support. As Rowland and Baker noted, many cancer survivors manifest remarkable resilience in the face of illness, despite experiencing difficult or catastrophic life events.
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ENHANCED QUALITY OF LIFE AND POSITIVE ADAPTATION TO SERIOUS ILLNESS

Persons living after a diagnosis of a potentially life-threatening illness such as cancer often have psychological concerns such as fear of progression of their illness, disability, or premature death.7,18 Numerous studies have found psychological difficulties among many cancer survivors, such as fear of cancer recurrence or cancer anxiety.19–21 For many survivors, concerns about the potential for disease recurrence or progression are neither unexpected nor unreasonable. However, studies have shown that levels of psychological distress vary, and not all survivors experience unusual fear or anxiety.4,21 This variation is likely to be partly explained by interindividual variation in personality traits, coping strategies, and resiliency. In addition, the experience of having a potentially life-threatening illness can make some problems, aggravations, or sources of stress seem less important or worrisome.

Survivors often want to know what they can do to reduce their chance of having a recurrence or worsening of their illness and how to improve their overall physical and psychological health. Engaging in behaviors such as physical activity, avoidance of cigarette smoking and heavy alcohol consumption, eating a healthy diet (for example, a diet low in fat and high in fruits and vegetables), and learning stress-reduction techniques can offer survivors of cancer or other serious illnesses some control over their health and lessen their fear of disease recurrence or progression.1 Advice given to survivors of cancer by their health care providers can guide and reinforce such efforts. Getting adequate rest, learning how to effectively deal with psychological stress, and paying attention to the spiritual aspects of life can also be beneficial.

Studies of cancer patients have shown that religion and spirituality are positively associated with better physical and mental health outcomes (for example, lower levels of depression, anxiety, and pain) and that coping strategies may mediate the relationship between spirituality and greater well-being.22–25 As noted by Canada et al.:3

...studies suggest that religion/spirituality resources may serve multiple functions in long-term adjustment to cancer such as maintaining confidence, providing a sense of meaning or purpose, giving comfort, reducing emotional distress, increasing inner peace, engendering a positive attitude toward life, and offering protection against end-of-life despair. Spiritual well-being, particularly a sense of meaning and peace, has been associated with an ability of cancer patients to continue to enjoy life despite high levels of pain or fatigue.

People who have survived a potentially life-threatening illness may reflect on the meaning of their life experiences and draw strength from spirituality and enhanced relationships with others.26 Dealing with cancer or other serious illness can remind people of what they believe should be their top priorities and what they feel matters most in life (for example, helping others and having positive relationships with other people).

The positive responses that people may show to adverse events have sometimes been referred to as thriving or post-traumatic growth. Such favorable responses include positive mental, physical, or social outcomes.16,27 Although the experience of having a potentially life-threatening illness taxes an individual’s resilience and ability to cope, it can also lead to positive adaptation and increased ability to thrive despite difficult circumstances. When people experience great difficulties, their usual coping mechanisms may break down and prompt them to look at life in new ways and to reevaluate their life goals and priorities.11,12 Everyone has interests, ambitions, hopes, and dreams, but people often go through life with many aspects of their life “on automatic” in terms of habitual patterns of behavior and ways of thinking. Anecdotal information suggests that when faced with diagnosis of a potentially life-threatening illness and the treatment and survivorship experiences that follow, people may develop a more intentional way of living that more clearly focuses on their goals, priorities, and hopes. Persons who have survived cancer, for example, may gain a clearer or more focused understanding of their values, what they really love to do, and what they are most passionate about.

Relationships with other people are also apt to change due to severe illness. Following a diagnosis of a potentially life-threatening illness such as cancer, people often reach out to caregivers, family, and friends and draw on their existing sources of social support or develop new sources of support. Sources of social support include family...
members, caregivers, friends, neighbors, coworkers, clergy, and patient support groups. Social support and social connectedness have been shown to improve patient outcomes and to enhance overall health and quality of life. Support groups and group therapy have been shown to provide psychological benefits for patients with cancer or other serious illness. Through support groups and community-based organizations, many cancer survivors encourage each other, teach other cancer patients how to survive and fare well, and help those who are burdened by cancer. Anecdotal information and narrative accounts illustrate that many people who have survived a potentially life-threatening illness enjoy greater social connectedness and sense of belonging to a community, although additional scientific evidence from longitudinal studies would be helpful to clarify the mechanisms for this phenomenon. Scientific studies have shown that a sizeable proportion of persons who experience serious illness report increased quality of life and other positive life changes following their experience. As Aspinwall and MacNamara observed:

It is now a common finding that large proportions of people who have experienced cancer and other life-threatening illnesses appear to find benefit in the experience, reporting such positive outcomes as improved quality of life, better interpersonal relationships, and changes in values and priorities (e.g., a greater appreciation of each day, changes in spirituality) as a result of their experience. Such changes have been reported by 30–90% of most samples studied across a wide range of adverse events and have been variously termed cognitive adaptation, personal or posttraumatic growth...

A learning process occurs as people deal with being diagnosed with a serious illness, treatment for their condition, and experiences that occur afterward. Although additional research is needed, it seems plausible that survivors of a potentially life-threatening illness are apt to be much more familiar with how to navigate the medical system, what to expect during an event such as a hospitalization or diagnostic workup, and how to communicate their needs and concerns to health care providers. For example, people who have had the experience of receiving chemotherapy or extensive surgery may gain important insights into what to anticipate during similar circumstances, what types of financial and emotional concerns are apt to arise and how to deal with them, and how to successfully get through similar ordeals while maximizing quality of life. As a result, many survivors have an important role to play in providing social support, practical guidance, and other assistance for friends, family members, or in the broader community.

THE ROLE OF COMMUNITIES AND EXTENDED SOCIAL NETWORKS

The social context in which persons live out their lives following a diagnosis of a potentially life-threatening illness such as cancer is also important. In addition to individual traits, external factors such as social support provided by others also promote coping and resilience. When faced with pain, grief, or fear of premature death, people reach out to others for support and are reminded of how interconnected we are with others. Community norms and resources and the common understanding of life's challenges and responsibilities provide support for people who are dealing with a potentially life-threatening illness or who are caring for someone who is ill. Resiliency can be conceptualized not only in terms of individual resiliency or coping strategies, but also in terms of the resilience of extended family networks and community resilience. Some communities or networks of persons may be more resilient and capable of responding positively to adverse events than others due to differences in community resources, infrastructure, or social and cultural factors. Extended family networks contribute importantly to the resiliency of many societies. People who are resilient and employ positive coping strategies are apt to do better when faced with a serious illness, and this may be particularly true of people who are members of resilient communities or networks of persons. Multilevel analyses and studies of contextual effects are needed to test this and related research hypotheses, however.

CONCLUSION

The cancer survivorship movement in the United States and other countries, which has drawn attention to the needs and concerns of cancer survivors and led to new resources and programs for cancer patients and survivors, is an important example of how communities, institutions, and organizations can help individuals cope
with serious illness. A variety of resources and programs for female and male cancer survivors have been developed or envisioned, including existing or proposed programs for those who are in different life stages or are from different socioeconomic or cultural backgrounds. Evaluative studies would be helpful to identify resources and programs that are most likely to benefit cancer survivors, including helping survivors to positively adapt to their circumstances. Other areas for further research identified in this review include the need for longitudinal studies to clarify the mechanisms by which people who have survived a potentially life-threatening illness may enjoy greater social connectedness and sense of belonging to a community, research into patients’ communication of their needs and concerns to health care providers, and multilevel analyses of possible interactions between community resources and individual factors such as positive coping strategies.

The presence of highly active and visible communities of survivors creates a social environment where individual cancer survivors and caregivers are more apt to think of themselves in a positive light as survivors. When people see themselves as part of an energetic, compassionate, and important social movement or community of survivors, their relationships, expectations, and perspectives are likely positively influenced. The strength of survivors to endure adversity may also be augmented by their social network, environment, and access to community resources. The cancer survivorship movement and the cancer community in general (for example, survivors, caregivers, clergy, volunteers, advocates, health care providers, researchers, and program support staff) provide important resources for improving quality of life and alleviating human suffering and distress among patients and survivors and for adding personal meaning and hope to people’s lives.

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