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Advocacy: The Cornerstone of Cancer Survivorship

PURPOSE: This article describes a cancer-related advocacy skill set that can be acquired through a learning process.

OVERVIEW: Cancer survivorship is a process rather than a stage or time point, and it involves a continuum of events from diagnosis onward. There exists little consensus about what underlying processes explain different levels of long term functioning, but skills necessary for positive adaptation to cancer have been identified from both the professional literature and from the rich experiences of cancer survivors.

CLINICAL IMPLICATIONS: Healthcare practitioners need to be more creative and assertive in fostering consumer empowerment and should incorporate advocacy training into care plans. Strategies that emphasize personal competency and increase self-advocacy capabilities enable patients to make the best possible decisions for themselves regarding their cancer care. In addition, oncology practitioners must become informed advocacy partners with their patients in the public debate about healthcare and cancer care delivery.

KEY TERMS: advocacy; cancer survivorship; empowerment; self-efficacy; skills training; quality of life

Approximately 10 million persons in the United States live with a cancer history. Of these, it is estimated that 7 million have survived 5 years or more.¹ However, in no way can statistics measure the physical and psychological trauma of cancer or how people with cancer continue to function within their family, workplace, or society. Regardless of the type of cancer or the effects of treatment, all those diagnosed with cancer must manage the enduring and complex ways in which cancer transforms the self and everyday life.

The diagnosis and treatment of cancer means the interruption of normal life and career. For a time, the future is foreshortened, reduced to the period between treatments or between episodes of the disease.² Frustration and disappointment may occur as a result of the nonlinear quality of healing. Despite these obstacles, people do adapt to cancer as an illness; they become cancer survivors.

Cancer survivorship is a term used to represent the state of living with the challenges of the cancer experience. Mullan described cancer survivorship as the "act of living on."³ Carter⁴ used the term "going through" and identified a sense of movement through phases. Leigh⁵ summarized the cancer survivorship concept as "a continual, ongoing process rather than as a stage or component of survival," and as "the experience of living with, through or beyond cancer." Survivorship is not only about long-term survival or cure; rather, a person with cancer is a survivor from the time of diagnosis through the remainder of life.⁶ It is a dynamic concept that avoids erecting unnecessary and inaccurate boundaries in the lives of persons with cancer. The prominence of cancer in the life of an individual depends on the illness, its treatment, and its progression or resolution.

Empowering the Cancer Survivor

The Cancer Survivorship Movement

The significance of the cancer survivorship movement should be considered from several perspectives. These include not only the professional perspectives of clinicians and cancer researchers, but also the rich experiences of cancer survivors themselves.

Advances in the diagnosis and treatment of cancer during the past decade led more people to look forward to longer, productive lives. As a natural outgrowth, the peer-support and advocacy movement for cancer survivors began to gather momentum throughout the country during the 1980s. In 1988 "*A Cancer Survivors Bill of Rights*," written by Natalie Davis Spingarn was published by the American Cancer Society.⁷

Recognition of the efforts of cancer survivors was

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emphasized in the report titled "*Measures of Progress Against Cancer*," which was released by the National Cancer Institute in 1994. The report noted that the last decade (1982-1992) had seen a growth of a consumer movement to "advocate for research, healthcare, and social reform on behalf of cancer survivors."⁸ The changing semantics of cancer terminology is a good indicator of the impact that the survivorship movement is having on redefining the perceptions and parameters of cancer.⁹ One of the most significant contributions has been to decrease the social stigma attached to cancer as an illness, and to dispel the myths about cancer. For example, even in the research literature, the phrase "cancer victim" is being replaced by the survivorship terminology, "cancer survivor." The increasing visibility and viability of the survivorship movement belies the still frequently held myth of cancer as a "death sentence." These may seem small points, but the act of defining is also an act of empowerment.

Empowerment refers to any process whereby individuals increase their capacity to influence other people and organizations that affect their lives.¹⁰ As such, empowerment is an important concept in the survivorship movement. Empowerment assumes that individuals typically understand their own needs better than others do, and that it is optimal for individuals to have the greatest possible control in determining various aspects of their lives¹¹ and in making their own informed decisions about healthful living and restorative actions that will shape the quality of their lives.¹² Spingarn¹³ noted that "a revolution in attitudes has finally reached once passive patients. Civil rights, women's rights, consumers' rights, human rights, growing interest in and candor about medical matters and preventive health care—all these have helped empower survivors, giving them the feeling that they can have at least a hand in their own destiny."

A Theory of Cancer Survivorship

Although numerous authors and studies have been able to identify or predict salient factors associated with positive adjustment after cancer,^{14,15} the scientific study of long-term survivors as a separate cohort is a relatively new research focus.^{16,17} As a result, there exists little consensus about what underlying processes explain different levels of long-term psychosocial functioning. Several assumptions derived from literature written by cancer survivors and research into cancer-related quality of life outcomes form the basis for a theory of cancer survivorship.^{14,16,18,19} Existing information suggests that a critical task of the recovery process is for cancer survivors to regain a sense of control over their lives. Other challenges of the cancer experience include: continuing personal growth,^{5,20-23} engaging in medical consumerism;^{13,24-26} maximizing choices;^{3,27} problem solving creatively;²⁸⁻³⁰ maintaining a positive and hopeful future outlook;³¹⁻³⁵ and advocating for self and others.^{7,9,36-39}

Numerous conclusions can be drawn from these challenges. First, survivorship is a dynamic concept that involves a continuum of events from the time of diagnosis onward.^{3,5} Second, although each person's cancer is indi-

vidual and unique, survivorship issues have commonalities that cross the boundaries of disease.⁴⁰ Third, skills necessary for positive adaptation to cancer have been identified in the literature and from the cancer survivorship movement. Finally, survivors must be self-advocates and should be viewed as partners in making decisions about their medical, social, and vocational well-being.

Specifically, we suggest that successful adaptation to cancer involves learning basic advocacy skills that will enhance the survivor's sense of empowerment and that can be applied throughout the cancer experience. This skill set applies to all types and stages of cancer, and is neither gender nor age specific. Although an impact on longevity is not postulated here, there should be a positive impact on several quality of life domains.

The Advocacy Skill Set

The advocacy approach emphasizes a competency model of survivorship that focuses on building skills and coping strategies as a way of preventing or overcoming psychosocial limitations and promoting expectations for effective living.^{30,41} Cancer survivors experience a sequence of crises for which habitual problem solving activities are not adequate and which do not lead to the previously achieved balanced state. Cancer may be an anomic situation for a significant number of persons. Anomia, as defined by Maher,² is "a temporary state of mind occasioned by a sudden alteration in one's life situation, and characterized by confusion and anxiety, uncertainty, loss of purpose, and a sense of separateness from one's usual social support system."

The concept of crisis is useful for adaptation to cancer both in terms of situational requirements and the various phases over time of the mobilization of resources.⁴² The tasks facing the individual, as well as the strategies selected for attempted management of these tasks, become important parts of the process of resolving crises. These tasks and strategies, such as seeking information or support, can be incorporated into a concept of skills training.

Support for skills training comes from a variety of professional perspectives including education, psychology, sociology, and social work.⁴³ McFall⁴⁴ distinguishes between competence and skills with the latter term referring to the specific underlying component processes that enable a person to perform in a manner that has been identified as competent. Skills are task-specific and are acquired through a learning process.

The importance of cancer survivorship skills training becomes apparent when one considers the complexities of the cancer experience. Cancer-related skills training involves a synthesis of several strategies that emphasize competency and that develop or enhance self-advocacy capabilities. From the psychosocial research literature and from the educational materials developed by cancer survivorship groups, four interrelated skills can be identified as essential to the advocacy skills model: 1) information-seeking skills;^{26,46,47} 2) communication skills;^{3,39,45,48,49} 3) problem-solving skills;^{3,10,26,37,50,51,52} and 4) negotiation skills.^{28,49,53}

Information-Seeking Skills Training

The informational needs of cancer survivors are many, and may change over time. Initially persons with cancer need information about cancer in general and about their own diagnosis,²⁷ about their treatment regimen and side effects, and about ways to cope with the acute phase of their illness.^{22,30} Later they need education about physical and psychosocial sequelae of the cancer experience, how to shift from a patient identity to the survivor role,²¹ and how to live with uncertainty while maintaining a positive future orientation.³⁴

Some survivors will need to address their uncertain future in the context of having exhausted treatment options for their cancer. This may occur as a result of conscientious decision making, or by having to face the limitations of current medicine's ability to treat their disease effectively. In either case, survivors need to be able to avail themselves of the kind of special guidance and support that is often more difficult to quantify; this includes being able to access information easily about how to live out the remainder of their lives. The survivorship journey often is physically and emotionally more painful at this juncture, and information about palliative treatments, hospice care, and spiritual counseling are necessary to optimize the quality of the remainder of life.

Information seeking is a form of medical consumerism. It involves asking questions, getting answers, gathering and storing data, and accessing resources. Cancer survivorship rests on the premise that information is strength, and when persons are faced with a cancer-related crisis or situation, they may not have adequate information for decision making. In fact, they simply may not know what questions to ask. To address these issues, some informational resources now exist. Examples are: *Charting the Journey: An Almanac of Practical Resources for Cancer Survivors*,³ *Facing Forward: A Guide for Cancer Patients*,⁵⁴ *The Cancer Patient's Information Binder*,⁵⁵ *Choices: Realistic Alternatives in Cancer Treatment*,²⁷ *Teamwork: The Cancer Patient's Guide to Talking with Your Doctor*,⁴⁸ and *Choices in Healing: Integrating the Best of Conventional and Complementary Approaches in Cancer*.⁵⁶

Cancer survivors also may be unfamiliar with existing informational resources such as clearinghouses, or may be unskilled in accessing existing information data bases (such as the telephone information services of the American Cancer Society or the National Cancer Institute), or in finding a peer support organization. While the training for and development of information-seeking skills appear straightforward, they also involve communication skills and negotiation.

Communication Skills Training

Communication is a complex concept that includes facets such as information, rapport, situational, interpersonal and emotional factors, understanding, willingness, ability, and trust.⁴⁵ In the medical encounter, the practitioner and the patient must share responsibility for interaction

and outcome. There should be equity, reciprocity, and mutuality of hope and goals. Passivity is no longer considered desirable in healthcare; it has been replaced by active patienthood¹³ and a mutual participation model, whereby both the patient and the healthcare professional have input into care decisions.⁵⁷

There exists a large literature on effective communication skills, many of which are applicable to encounters between patients and healthcare professionals. Using the physician-patient exchange, Moore²⁵ described barriers to communication, such as lack of privacy and use of medical jargon, and detailed suggestions for overcoming these obstacles. Solutions included preparing questions before the appointment, asking for explanations in familiar terms, rephrasing the doctor's answer, taking along a family member, and tape recording the session. Other interventions for enhancing communication skills include listening techniques, identifying nonverbal clues, assertiveness training, and problem-solving and negotiation skills.

Problem-Solving Skills Training

Problem-solving skills are especially useful in crisis situations. The primary purpose of a problem-solving strategy is not so much to train the person to become a better problem solver, but to teach the individual to think through more carefully what otherwise might appear as a situation with no apparent resolution.^{3,10} The problem-solving process includes process definition and formulation, generation of alternatives, decision making, taking action, and verification.

Problem-solving skills training may work best with a combination of methods including modeling⁵⁸ and role playing. Modeling is a form of observational learning that refers to the process by which the behavior of one individual or group acts as a stimulus for similar thoughts, attitudes and behavior on the part of another individual. It is considered an effective technique for persons of all ages and with many different problems. Role playing is a widely used form of simulation and offers the advantage of efficiency and flexibility. Role playing situations may be hypothetical or drawn from real life situations. Role playing generally is used for practice, not insight. For cancer survivors, role playing may be a useful technique for learning how to better interact with the healthcare team and to acquire needed information and support.

Negotiation Skills Training

A cancer diagnosis can have an impact on access to employment, insurance, and financial support. Therefore, some survivors must advocate not only for appropriate medical care, but also for their legal rights. Job discrimination affects many persons with a history of cancer and may result in "job-lock"—the inability to leave a job due to the risk of losing insurance, pension and other benefits. Cancer survivors can be taught to fight back against discrimination.^{28,53} Self-advocacy in the occupational sector often involves negotiation. Survivors may need to negotiate for

accommodations and vocational rehabilitation. They also may need to learn to negotiate the legal system.^{27,28,53,59}

Many other issues may require negotiation. For example, conflict may arise in the practitioner-survivor relationship.²⁵ Some theorists suggest that conflict is inherent and that conflict resolution through the process of negotiation is a critical part of any helping relationship.⁶⁰ Effective communication, resourcefulness, open-mindedness, and understanding alternative positions are central to all negotiation efforts.⁶¹

Cancer-Related Advocacy

In the classic sense, advocacy means summoning to one's assistance, calling to one's aid, or defending. Kohnke⁶² has proposed a useful definition of advocacy in healthcare: "Advocacy is the act of informing and supporting persons so that they can make the best decisions possible for themselves."

The skills training identified is an example of how healthcare professionals can be advocates for their patients. However, in cancer survivorship, advocacy is too important to be left solely to the health care professionals. As Gray³⁶ notes: "... medical language is insufficient for mapping cancer experience, and ... there are some insights about cancer care that can only come from the patient's perspective, i.e., from the inside out." Cancer survivors must become strong self-advocates. In fact, cancer survivors contend that frequently it is through self-advocacy and personal empowerment that other identified needs (for information, intervention, and support) are met. Speaking up for what one needs when faced with a diagnosis of cancer and knowing how to communicate those needs to family, friends, and caregivers is the first step in self-advocacy. For the person living with cancer, advocacy must become a life-long process.

The Advocacy Continuum

In cancer survivorship, advocacy is a continuum. It may begin at the personal level, but as the survivorship trajectory changes, self-advocacy efforts may broaden to encompass first group or organizational advocacy and later may move to public advocacy efforts.

Personal Advocacy

At diagnosis and during intensive cancer treatment, self-advocacy is a way of taking charge in an otherwise portentous environment of diagnostic tests, surgery, radiation, chemotherapy, and doctors' offices. From arming oneself with good information about their diagnosis, to seeking second opinions, to locating resources for identifying and obtaining support, to knowing how to ask the right questions—people with cancer can become self-efficacious. Personal empowerment can mean the difference between maintaining a positive future outlook and enhancing quality

of life or feeling helpless and less certain of the desirability of survival.^{32,33}

The 1 to 5 years after a cancer diagnosis is a time of reentry and reevaluation of one's life. It is during this time that cancer survivors realize that their lives will never be the same.²¹ Family and friends cannot understand why survivors are not happy simply to be alive, and support systems that were in place during the acute stage may diminish or disappear. It is at this point that many survivors seek out other survivors with whom they can identify.

This life transformation, whether at age 25 or 65, calls for another type of self-advocacy. With the underlying idea that they "want to give something back," in gratitude for their survival, many survivors seek out avenues to share their experience with others.⁶³ This shared knowledge, the idea that information is powerful—the veteran helping the rookie notion—is what the survivorship movement is largely about. When occurring in the context of a self-help group or within a professionally facilitated support group, this structured transmission of wisdom from a more seasoned survivor to the newcomer provides a strong foundation for people who have had cancer to play a more proactive role in making myriad decisions that will follow them the rest of their lives.

Advocacy for Others

Having been successful in exchanging information with others who share a cancer experience, survivors can extend their advocacy efforts to the larger community. Through networking with other persons in their area, survivors can learn more about specific issues (e.g., sexuality, infertility, job discrimination, insurance access, or reimbursement problems). Armed once again with valuable information, cancer survivors can go on to tell others of their shared experiences and advocate for changes that can have a broad impact on survivorship.

One of the easiest and most satisfying ways to advocate for others is to speak at the local community level—to church and civic groups, to medical students and physicians, oncology nurses, social workers, and others—to educate them about the complex interpersonal and psychosocial issues that dominate survivors' lives after a diagnosis of cancer. This public speaking becomes a testimony that affirms one's survival, defies the myths and stigmas about cancer that are still much in evidence in our society, and perhaps reaches others who are silently struggling with similar issues.

Public Interest Advocacy

The exponential growth of the survivorship movement increasingly is realized by the many long-term survivors who go on to become professional survivor advocates. These individuals have taken their learned experiences from diagnosis, through treatment and recovery, and become advocates participating in the national cancer survivorship movement. Particularly notable among them are those who have effected change in public policy including

appropriations for cancer research;⁸ those who have pressed for more survivorship research; those who have given public witness testimony at both the local and federal levels of government;³⁶ and those who have contributed to the body of knowledge about living a better quality of life after a diagnosis of cancer, either through professional journals^{16,18} or the popular press.^{24,29} By telling "one's story," including print and broadcast media, the net is cast much wider. Advocacy training for media relations is a burgeoning field of interest among consumer groups today and provides yet another avenue for survivors to "testify" about their experiences.

As people with a history of cancer recount their stories in the community and to the media, they become recognized experts on the compelling issues that have impacted their lives and the lives of the community of survivors with whom they have become involved.³⁸ Depending on one's vocation, avocation, or other life circumstances, the interest one takes in sharing this experience is limited only by the desire to speak up—whether it is survivor-to-survivor, in support groups, in the workplace, before state legislators, or to Congress. Advocacy is an invaluable skill set that can empower persons with cancer and can maximize the quality of their own survival as well as that of others.⁶³

Implications for Practice

Healthcare practitioners traditionally have assumed broad responsibility in the care of their patients with cancer. The continuum of care spans diagnosing; delivering physical care and treatments; educating patients and family members about cancer; assessing psychosocial strengths and referring for needed services; offering emotional support and assisting patients to maintain a positive future outlook; and advocating at various levels of intervention on behalf of the patient or the family. In addition, many health providers have long recognized and encouraged patients' rights and generally have welcomed the idea of patient-practitioner teamwork into hospitals and outpatient oncology settings. Yet, changes in healthcare—such as shortened lengths of hospital stays, increased ambulatory and home care services, more complex and restrictive insurance coverage, and limited access to oncology specialists—require that patients become even more empowered, and that healthcare practitioners become more creative and assertive in fostering consumer empowerment.⁶⁴

Health providers can enhance empowerment by incorporating advocacy skills training into the care continuum. Cancer-related skills training is based on strategies that emphasize personal competency and that increase self-advocacy capabilities so that patients can make the best possible decisions and choices for themselves and for their cancer care.

The basic advocacy skill set includes information-seeking skills, communication skills, problem-solving skills, and negotiation skills. This training can be delivered in a variety of ways: through patient education materials; by interactive computer programs; as part of support group programs; as the focus of community oncology conferences; or during one-to-one interventions.

Providing advocacy training for patients is an essential beginning. The next step is systems advocacy. Oncology practitioners will need to become informed advocacy partners with their patients in the public debate about the delivery of healthcare in general, and cancer care in particular.

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