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REVIEW ARTICLE

Survivorship Perspectives and Advocacy

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ABSTRACT

From the moment of diagnosis, a cancer survivor faces serious life-altering decisions. Survivors who are informed about their options and who feel they have personal control over decision making generally perceive a higher quality of life than those who feel less informed and less in control. Health care providers are in a unique position to define a survivor's cancer care and to guide a survivor through treatment and post-treatment care. By implementing survivorship care plans and directing their patients to survivorship resources, health care providers can advocate for survivors and teach them to be effective self-advocates.

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A BRIEF HISTORY OF CANCER ADVOCACY

The dictionary definition of advocacy is active support, which includes directly representing, defending, intervening, or recommending a course of action.[1] For cancer survivors, the need for advocacy is nearly limitless. As Cokie Roberts once said, "advocacy is everything."[2]

The concept of advocacy for cancer survivors began in the cancer peer support community and later was embraced by professionally led organizations.[3] For example, in 1970, parents of children who had cancer founded the Candlelighters Childhood Cancer Foundation to advocate on behalf of pediatric survivors and their families. In 1977, the American Cancer Society, which had previously ventured into national health advocacy by taking a public policy stand against tobacco use, promoted I Can Cope, an education and support program developed by Judi Johnson. Nancy Brinker founded the Susan G. Komen Breast Cancer Foundation in 1982 in memory of her sister, who died from breast cancer. Like Candlelighters, Komen provided not only education and support, but advocated for survivors' access to quality cancer care. In 1991, the National Breast Cancer Coalition was created primarily to lobby for funding for breast cancer research and subsequently became the most visible national group dedicated to the eradication of breast cancer. Six years later, Lance Armstrong started the Lance Armstrong Foundation to advocate for survivors of all types of cancer.

Although the words survivor, survivorship, and advocacy are now widely used in professional and consumer cancer settings, these terms were not associated with cancer until the National Coalition for Cancer Survivorship (NCCS) changed the lexicon of the cancer experience. In 1986, representatives from 20 organizations founded NCCS to advocate on behalf of cancer survivors. The founders of NCCS concluded that persons diagnosed with cancer should be allowed to call themselves survivors from the moment of diagnosis and for the balance of their lives. This definition also included the survivor's family, friends, health care professionals, and care givers. NCCS embraced this broader definition to recognize that the impact of a person's cancer did not begin and end within a rigid 5-year period. Surviving cancer entailed "a continual, ongoing process," a holistic "experience of living with, through, or beyond cancer."[4] From its nascent beginnings until today, NCCS has convened groups that share its vision of assuring an informed, patient-centered voice is at the center of all aspects of cancer care and support. In 1992, NCCS convened seven other cancer support and advocacy organizations to create the Cancer Leadership Council, now a forum of 30 national cancer organizations that meets monthly to learn about and advocate for issues related to quality cancer care. NCCS's advocacy was instrumental in the creation of the Office of Cancer Survivorship at the National Cancer Institute in 1996.

The following year the National Cancer Policy Board was established within the National Academy of Sciences, Institute of Medicine (IOM). The National Cancer Policy Board issued a series of reports on quality cancer care and on childhood and adult cancer survivorship.[5-7] These reports, based on the rigorous processes and respected methodology used by the IOM of researching, analyzing, and reviewing existing data, provide the primary evidence base to move the field of quality cancer care and survivorship into the mainstream.

In 2005, the American Society of Clinical Oncology (ASCO) and NCCS partnered to create the

Cancer Quality Alliance (CQA). Created in the image of the Cancer Leadership Council, the CQA was formed to bring together diverse stakeholders, including governmental and nongovernmental stakeholders from within and outside of oncology. The goal of the CQA is to foster collaboration to address the challenges of defining, measuring, and implementing high quality care in oncology.

THE NEED FOR CANCER ADVOCACY

From the moment of diagnosis, a cancer survivor faces serious life-altering decisions. Our complex and inefficient health care delivery system further compromises survivors' abilities to make critical treatment, financial, and personal decisions, as well as their abilities to understand and weigh their health care providers' recommendations.[8] Survivors who are informed about their options and who feel they have personal control over decision making generally perceive a higher quality of life than those who feel less informed and less in control.[9] Any model for cancer advocacy must give providers effective communication tools to address survivors' questions and their need for empowerment.[8]

TYPES OF CANCER ADVOCACY

Clark and Stovall identified a three-part advocacy continuum: national advocacy, community advocacy, and personal advocacy.[10] These three stages form a pyramid of advocacy. Though relatively few in number, national advocates who are at the top of the pyramid, cannot exist without the support of community advocates, who in turn rest on the foundation of the more than 10 million cancer survivors.

Personal advocacy or self advocacy arises from being an informed health care consumer. Personal advocacy involves collecting accurate medical information, seeking second opinions, locating and accessing support resources, asking questions and insisting on clear answers, and fighting for individual financial, insurance, employment, and privacy rights. Community advocacy is a transitional advocacy that provides veteran survivors an opportunity to help the newly diagnosed. Community advocacy can include participation in support groups, speaking publicly about survivorship issues, and community-based fundraising. National advocacy entails influencing public policy decisions involving cancer care. For example, NCCS[11] and the American Cancer Society[12] provide online information and links for survivors to learn about and participate in national public policy.

CANCER ADVOCACY ISSUES

The relatively new field of cancer survivorship recognizes that, in seeking optimal cancer care, survivors struggle to balance their medical, personal, and financial needs.[13] Proximate to diagnosis, survivors focus on the medical consequences of cancer, such as choosing health care providers, choosing among types of treatment, and obtaining quality cancer care. However, cancer subsequently affects the quality of life of everyone it touches. Although studies vary in how to assess cancer survivors' quality of life, the fact that cancer has a significant psychosocial impact on survivors and their families is unchallenged.[7] Ferrell and Grant's model of the quality of life of cancer survivors organizes these concerns into physical, social, psychological, and spiritual issues (Table 1).[14]

The IOM report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, embraced patient advocacy and survivorship guidelines developed by the Association of Community Cancer Centers. These guidelines suggest that survivorship resources should address at least five areas of concern to cancer survivors: access to information about cancer prevention, early detection, genetics, disease treatment, symptom management, and psychosocial, spiritual, and financial concerns; information about local, regional, and national resources regarding cancer, cancer care, research, advocacy, and survivorship; access to onsite, online, or telephone support groups; information about specific survivorship issues, such as employment rights, insurance coverage, late and long-term effects of disease and treatment, advance directives, living will, durable power of attorney, estate planning, options for recurrent disease management, and end-of-life care planning; and programmatic opportunities to participate with the care team to develop community outreach education and support programs for quality cancer care in the community and to educate professional staff about the cancer experience.

Survivorship research has identified four interrelated skills that are integral to effective advocacy: information-seeking skills, communication skills, problem-solving skills, and negotiation skills.[15,16] With

Table 1. Quality of Life Model Applied to Cancer Survivors

Physical well-being and symptoms
Functional activities
Strength/fatigue
Sleep and rest
Overall physical health
Fertility
Pain
Psychological well-being
Control
Anxiety
Depression
Enjoyment/leisure
Fear of recurrence
Cognition/attention
Distress of diagnosis and control of treatment
Social well-being
Family distress
Roles and relationships
Affection/sexual function
Appearance
Enjoyment
Isolation
Finances
Work
Spiritual well-being
Meaning of illness
Religiosity
Transcendence
Hope
Uncertainty
Inner strength

NOTE. Reprinted from Hewitt et al with permission.[14]

these skills, survivors can better access, understand, and use survivorship resources.

THE CHANGING ROLE OF PROVIDERS IN CANCER ADVOCACY

The relationship between providers of oncology care and their patients is in transition. Traditionally, few health care providers devoted significant resources to patient advocacy. Most providers have little time for any patient-related care other than traditional medical treatment. Insurers seldom reimburse for giving psychosocial support, answering patients' questions, and reviewing long-term and late effects of treatment. Most physicians, nurses, and other cancer care providers have not had formal education, training, and continuing medical education on how to advocate for their patients. Only recently have some medical schools begun to incorporate cancer survivorship into their curricula.

Moreover, survivors historically saw themselves as passive patients instead of as active health care consumers.[17] However, in the past generation the rise of advocacy in civil, human, women's, and consumer rights has empowered cancer survivors to demand a voice in choosing their treatment to improve their quality of life. The proliferation of consumer health-related information has transformed the doctor-patient relationship and given survivors the means to become informed participants in their own health care. Although a growing number of survivors now expect patient advocacy to be the norm of patient care, and most patients want to discuss the effects of cancer on the nonmedical aspects of their lives, only a minority of patients have these discussions with their oncologists.[18]

Information is the key to successful advocacy. Like general patient advocacy, cancer care has witnessed a sea change in the exchange of information between physicians and their patients during the last few decades. In the 1960s, few physicians in the United States disclosed a cancer diagnosis to their patients.[19,20] By 1977, 97% of physicians informed their patients of their diagnosis.[19,21]

Because quality of life affects not only the psychosocial health of survivors but their medical health as well, it has become an important factor in cancer treatment.[22] The 2006 IOM report identified four essential components of survivorship care: prevention, surveillance, intervention, and coordination.[7] Of the report's 10 recommendations

Table 2. National Cancer Survivorship Organizations

Organization	Type of Service Provided
American Cancer Society 1599 Clifton Road NE Atlanta,GA 30329-4251 (800) ACS-2345 www.cancer.org	Publications, counseling, financial assistance, and public education programs
Association of Cancer Online Resources www.acor.org	Information, education, and online group discussion and peer support
Cancer Care Inc 275 Seventh Avenue New York, NY 10001 (800) 813-HOPE www.cancercare.org	Staffed by oncology social workers and other professionals, Cancer Care provides counseling, education, referrals, publications, and financial assistance
Cancer Hope Network Two North Road Chester, NJ 07930 877-HOPENET www.cancerhopenetwork.org	One-on-one peer support
Cancer Survivors Project www.cancersurvivorsproject.org	Information on physiological and psychosocial late effects, preventive care, and long-term follow-up
Gilda's Club 322 Eighth Ave, Suite 1402 New York, NY 10001 (917) 305-1200 www.gildasclub.org	Education and support groups
Lance Armstrong Foundation PO Box 161150 Austin, TX 78716-1150 (512) 236-882 www.laf.org www.livestrong.org	The Lance Armstrong Foundation seeks to promote the optimal physical, psychological, social recovery, and care of cancer survivors and their loved ones through education, community programs, national advocacy, and research grants; the Lance Armstrong Foundation's project Live Strong provides quality of life information on post-treatment and long-term issues for cancer survivors and their caregivers
NCCS 1010 Wayne Ave, 7th Floor Silver Spring, MD 20910 (877) 622-7937 www.canceradvocacy.org	NCCS is the only survivor-led organization working exclusively on behalf of all cancer survivors; NCCS's mission is to ensure quality cancer care for all Americans; NCCS provides education resources and publications, such as *A Cancer Survivor's Almanac: Charting Your Journey*[25]*; programs include the Cancer Survival Toolbox, a comprehensive audio program designed to help cancer survivors and caregivers gain practical skills to deal with the diagnosis, treatment, and challenges of cancer*
The Wellness Community 919 18th St NW, Suite 54 Washington, DC 20006 (888) 793-WELL www.thewellnesscommunity.org	Support and education online and in person in 22 cities

NOTE. Data adapted from Hewitt et al.[7]
Abbreviation: NCCS, National Coalition for Cancer Survivorship.

Table 3. Cancer-Related Legal and Financial Support

Organization	Type of Service Provided
Equal Employment Opportunity Commission 1801 L Street NW, Room 9405 Washington, DC 20507 (800) 668-4000 (to locate regional office) (800) 669-3362 (for information) www.eeoc.gov	Information on how to enforce rights under the Americans with Disabilities Act; the Equal Employment Opportunity Commission provides the name and phone number of the state agency that enforces each state employment discrimination laws
National Association of Insurance Commissioners 2301 McGee Street, Suite 800 Kansas City, MO 64108-2662 (816) 842-3600 www.naic.org	Access to the consumer publication, *A Shopper's Guide to Long-Term Care Insurance*[26]
Pension and Welfare Benefits Administration United States Department of Labor (866) 444-3272 www.dol/gov/ebsa	Information on pension and insurance rights under COBRA

Abbreviation: COBRA, Consolidated Omnibus Budget Reconciliation Act.

on how to improve survivors' medical and psychosocial care, four require direct involvement by a member of the oncology team: (1) health care providers, patient advocates, and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care; (2) patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This "Survivorship Care Plan" should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third-party payers of health care; (3) health care providers should use systematically developed, evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined, and new evidence-based guidelines should be developed through public- and private-sector partnerships; and (4) employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors with short-term and long-term limitations in ability to work.

The second of these recommendations—provision of a cancer survivorship care plan—holds the most promise for establishing a systematic means of enhancing communication between providers and patients. A comprehensive care plan would summarize five types of information recommended by the President's Cancer Panel in 2004 needed to plan the survivor's long-term care: cancer type, treatments received, and their potential consequences; specific information about the timing and content of recommended follow-ups; recommendations regarding preventive practices and how to maintain health and well-being; information on legal protections regarding employment and access to health insurance; and the availability of psychosocial services in the community.[7]

The plan serves the dual purpose of providing a systematic way for physicians to convey information to their patients and of providing a comprehensive, personal education and care plan to survivors.

Table 4. Examples of Information on Cancer Survivorship

Audio
- Cancer Survival Toolbox. An audio resource program. National Coalition for Cancer Survivorship (NCCS), Oncology Nursing Society, Association of Oncology Social Work, National Association of Social Workers. Also in Spanish and Chinese. Available at 877-TOOLS-4-U.

Print
- Facing Forward-Life After Cancer Treatment, National Cancer Institute (NCI, 2002). Also in Spanish. Available from the National Cancer Institute. Booklet.
- Cure Magazine. Quarterly. www.curetoday.com, 800-210-CURE. Magazine.
- A Cancer Survivor's Almanac, Charting Your Journey, Hoffman, B, ed. (Wiley 2004). Available from NCCS, www.canceradvocacy.org. 888-650-9127. Book.

Internet
- Cancer: Keys to Survivorship, webcasts of live teleconferences, NCCS and The Leukemia & Lymphoma Society, www.canceradvocacy.org
- Cancer Survivors Network, American Cancer Society, www.cancer.org
- LIVESTRONG, Lance Armstrong Foundation, livestrong.org
- People Living With Cancer, American Society of Clinical Oncology, plwc.org

Radio
- The Group Room, syndicated live cancer talk radio show, produced by Vital Options International, www.vitaloptions.org

Telephone
- American Cancer Society, National Cancer Information Center, 800-ACS-2345
- Cancer Information Service, National Cancer Institute, 800-4-CANCER
- CancerCare, 800-813-HOPE

NOTE. Reprinted from Hewitt et al with permission.[7]

Although providers should give some of the information in the care plan to their patients during treatment, most doctor-patient communication during treatment focuses on acute treatment issues. Therefore, providers should discuss the care plan during a formal discharge consultation when survivors can better assess the long-term consequences of their cancer.[7] Depending on the individual survivor's circumstances, any knowledgeable member of the health care team (for example, the oncologist, oncology nurse, oncology social worker, or primary care physician) could explain the care plan to the survivor. The health care team's preparation and presentation of the plan should be reimbursed as necessary medical care, and indeed, like traditional preventative medical care, may be a cost efficient means of mitigating future medical and psychosocial costs.

The 2006 IOM report provides examples of survivorship plan models for breast, prostate, and colorectal cancer, and for Hodgkin's disease. The ASCO Survivorship Task Force, which was established in December 2004 by then ASCO president David Johnson, MD, is providing direction for increased efforts after the release of the 2006 IOM Report. ASCO is working with NCCS, professional organizations, and government agencies to act on the 10 recommendations set forth in the report, most notably, the development and implementation of survivorship care plans.

Oncologists should capitalize on what Ganz refers to as the "teachable moment" that survivorship care provides.[23] Ganz noted that oncologists are in a unique position to define a survivor's cancer care and guide a survivor through the expected stages of initial curative-intent therapy. She wrote: "Whether such ongoing care will be the responsibility of the oncologist or the primary care physician is not the main issue; however, oncologists must provide guidance and leadership in this area, because they are the most knowledgeable member of the health care team in understanding the potential exposures associated with cancer treatments and the potential for late effects."[23]

CANCER SURVIVORSHIP RESOURCES

Because survivors can obtain information through a wide variety of sources, one of the most important advocacy services oncologists can provide is to point their patients to appropriate resources. At diagnosis, survivors tend to focus on pretreatment considerations, such as long-term fertility after treatment, careful planning of radiation therapy to avoid damage to normal tissues, and genetic testing and counseling.[24] Subsequently, survivors search for answers to the types of questions that arise during treatment, such as paying for care, mitigating adverse effects of treatment, locating support, resolving employment problems, and arranging transportation. At the conclusion of treatment, other issues may arise, such as the need for follow-up treatment, warning signs of late effects, and end-of-life concerns. At each stage of survivorship, health care providers can help their patients understand these issues and make decisions by guiding them to resources that provide answers and support.

A wealth of information on psychosocial resources is now available to cancer survivors. Though most national and community organizations address a specific cancer, such as breast cancer, several advocacy organizations address issues common to most survivors. The 2006 IOM report highlighted some of the most highly-respected organizations (Table 2). Each of these organizations offers extensive lists of more specific resources.

In addition to these private resources, public agencies can help cancer survivors with employment and insurance concerns (Table 3).

The 2006 IOM report also noted that survivorship information is available in a wide variety of formats (audio, video, print, Web, radio, and telephone). Examples of these resources are listed in Table 4. Many of the resources, such as the Cancer Survival Toolbox and the National Cancer Institute booklet, Facing Forward, are free. Oncologists, especially those in major cancer centers, could provide print or audio information during initial diagnosis. Resources are developed and changed daily. The national resources listed in Tables 2, 3, and 4 are sufficient for some survivors, but may merely be the starting point for others. Providers should also be aware of local and regional resources, lists of which can be obtained from local cancer organizations, regional offices of national organizations, such as the American Cancer Society, community cancer centers, and state and county agencies. Moreover, information and support related to specific cancers is available from national and local organizations that serve survivors of one type of cancer, such as breast, prostate, or pediatric cancer.

Quality cancer care necessitates a multidisciplinary team approach because it involves a complete person, not merely affected cells. Survivors must have access not only to physicians, but to experts in nursing, social work, psychology, rehabilitation, and genetic counseling before, during, and after treatment.[7] As dual advocates, providers should guide their patients as they negotiate the journey of selecting, receiving, and financing treatment, and they should encourage their patients to become self-advocates. Through effective communication and sharing resources with their patients, health care providers can support their patients through their cancer experience so that they are no longer lost in transition.

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