

V. COMMUNICATION, EDUCATION, AND TRAINING

A. Goals

The ever-growing population of cancer survivors requires new information that affects not only survivors and their families but also health care providers and the public at large. These needs can be met through effective communication, education, and training efforts aimed at increasing awareness of cancer survivorship issues. These issues include the importance of effective prevention or management of secondary health concerns, appropriate management of cancer, ability to maintain adequate health coverage, adequate post-treatment care, and quality-of-life strategies for those at all stages of cancer survivorship. Goals in communication, education, and training include the following:

- Structure existing and develop new messages about cancer survivorship to reach three broad audiences: the public, cancer survivors, and health care providers.
- Tailor the content and delivery of these existing and/or developed messages for subgroups (e.g., culturally diverse groups, various health care professionals) within each of the three main audiences.
- Use factual, consistent, culturally appropriate language and information.

For the purposes of cancer survivorship, the topic areas are defined here and in Section II as follows:

Communication with the Public

Communication with the general public and policy or decision makers about the issues surrounding cancer survivorship aims to create a societal understanding and acceptance of the growing population of cancer survivors and the issues they face.

Survivor Education

Education of cancer survivors includes provision of information tailored to the particular stage of survivorship. Such educational interventions may be most appropriate during the first 5 years after diagnosis as this is the time when many of the challenges associated with the adjustment to survivorship occur (Mullan, 1984).

Provider Training

Health care provider training aims to ensure that providers are aware of the medical and other special needs of cancer survivors so they can

offer the spectrum of services available to enhance quality of life throughout survivorship and refer survivors to these services as appropriate.

Prioritized needs for these components and suggested strategies for addressing them are presented in the following section.

B. Prioritized Needs and Suggested Strategies

One aim of communication with the public is to dispel the myth that cancer is an inevitably disabling or fatal disease (Leigh & Clark, 1998). This misconception may lead to fear and discrimination that creates a difficult environment for survivors. For example, 25% of cancer survivors experience some form of employment discrimination based on their medical history (Hoffman, 1991). This may come in the form of demotions, reduction or elimination of benefits, or may manifest itself in communications or relationships with coworkers (Hoffman, 1991).

The goal of communication with the public about cancer survivorship is to create societal understanding and acceptance of issues affecting survivors. Those developing public education campaigns need to take into account variations in messages and materials relating to cancer survivorship among different segments of the population. Organizations and agencies that disseminate information about cancer survivorship could partner together in these efforts to leverage resources and ensure the consistent and efficient delivery of cancer survivorship information.

Although communication with the general public regarding cancer survivorship issues is important, cancer survivors and their families need specific information. Survivors' educational needs vary depending on their stage of survivorship. Potential areas to be addressed in survivor-focused education include issues surrounding medical care after treatment, both for the first 5 years after diagnosis and the need for long-term care and/or prevention; prevention of secondary cancers and other health concerns; physical aftereffects and complications of cancer and cancer treatment; psychological and social effects of cancer diagnosis and treatment; and practical matters, such as employment and insurance coverage. An example of educational materials designed to address such issues is the Facing Forward Series, a three-part series published by NCI, designed to educate and empower cancer survivors as they face the challenges associated with life after cancer treatment. Other publications, including numerous books, such as Lance Armstrong's *It's Not About*

the Bike (Armstrong & Jenkins, 2001), provide insight into the personal side of the experience of survivorship.

Health care providers play an important role in the care of cancer survivors, not only by providing diagnostic and treatment services but also by referring survivors to services that address physical, psychosocial, and economic needs throughout the span of survivorship. In many cases, however, providers may be unaware of survivors' specific needs and how they might play a role in facilitating access to services to meet these needs. Support and education program providers need to communicate with health care providers to ensure that survivors are receiving referrals to services designed to enhance quality of life throughout the stages of cancer survivorship and address their specific needs and issues in a timely manner.

1. Develop strategies to educate the public that cancer is a chronic disease that people can and do survive.

Despite significant reductions in cancer-related mortality, myths and misinformation about a cancer diagnosis persist (e.g., "diagnosis of cancer means certain death" as in Section I.C.). Accurate, culturally appropriate information is needed to counteract these misconceptions and increase understanding and acceptance of issues affecting cancer survivors. Key strategies for addressing this need include the following:

- Convene a Task Force to identify existing educational information, and encourage partnerships to avoid duplication of efforts in developing new educational materials.
- Enhance a centralized information resource center, such as a clearinghouse (e.g., print, on-line), to provide access to consistent, scientifically valid, culturally appropriate health communication information.
- Promote the centralized information resource through a variety of media, including public service announcements for television, print, and the Internet.
- Promote the concept of survivorship as a chronic condition that people can live with and not necessarily die from.

2. Educate policy- and decision-makers about the role and value of long-term follow-up care, addressing quality-of-life issues and legal needs, and ensuring access to clinical trials and ancillary services for cancer survivors.

Acknowledgment and understanding of the long-term effects of cancer can enable survivors, caregivers, and health care providers to anticipate and deal with these effects. Increased understanding may

also enable enactment of appropriate policies to ensure that survivors receive needed follow-up care. Well-informed policy and decision makers can advocate for changes in and funding of services and additional research in these areas. Key strategies for addressing this need include the following:

- Identify potential policy and decision makers and establish mechanisms to educate them on survivorship issues.
- Catalogue and characterize existing policies in order to identify gaps in survivor needs to address.
- Identify partnerships with those with an interest in national and/or state policies.
- Develop and implement specific strategies to educate each identified policy and decision maker group (e.g., legislators; local, state, and national regulators; health service administrators; advocacy groups; community-based organizations; health-related industries; insurance industry; pharmaceutical industry).

3. Empower survivors with advocacy skills.

Cancer survivors are faced with extremely difficult medical decisions at each stage of living with, through, and beyond cancer. Because medical decisions are such an important component to ongoing improvement of quality of life among cancer survivors, the topic of “informed decision making” is presented in detail in the cross-cutting section (Section III).

4. Develop, test, maintain, and promote patient navigation systems for people living with cancer.

Patient navigation systems attempt to provide a mechanism to enhance the delivery of optimum care. This need is also summarized in Section III.

5. Teach survivors how to access and evaluate available information.

Cancer-related information is available from a multitude of organizations. However, this information may be inconsistent in the message content, culturally inappropriate, and/or difficult to access. A system to evaluate the validity of available cancer survivorship information is needed that can be linked to other, reliable information sources. Key strategies for addressing this need include the following:

- Develop a standardized system to assess the adequacy of available survivorship information.

- Develop resources to assist survivors in assessing survivorship information in a variety of formats (e.g., CD-ROM, pamphlets, Web pages, video).
- Disseminate the above-mentioned resources through a variety of distribution points (e.g., medical offices, cultural or faith-based community organizations, support groups, national and local associations) and through a centralized database that can be linked to other sources of reliable information.
- Provide technical assistance to groups whose materials do not meet the established evaluation criteria (i.e., do not maintain scientific validity) and enhance the quality of materials/products.

6. Educate health care providers about cancer survivorship issues from diagnosis through long-term treatment effects and end-of-life care.

Health care providers include all clinical, community, and public health professionals who potentially affect the health and well-being of people living with cancer. Although the specific message will vary for different types of providers, all should understand the impact a cancer diagnosis has on quality of life, the common myths and misperceptions about cancer and accurate information to dispel them, prevention strategies for secondary illnesses, appropriate management strategies, referral sources (i.e., where and when to refer), sources of support, and long-term treatment effects and end-of-life care. Key strategies for addressing this need among providers include the following:

- Establish educational forums on survivorship in partnership with professional organizations.
- Educate health professionals and para-professionals in local medical communities through grand rounds, tumor board meetings, and other venues.
- Partner with advocacy groups to visit community practices and observe/educate local providers about implications of and opportunities for improving quality of life.
- Incorporate survivorship curricula into professional/para-professional training programs.
- Develop continuing education training in survivorship to deliver to a variety of health care professionals (e.g., internists, nurses).

Section V Summary:

Communication, Education, and Training

1. Develop strategies to educate the public that cancer is a chronic disease people can and do survive.
2. Educate policy- and decision-makers about the role and value of long-term follow-up care, addressing quality-of-life issues and legal needs, and ensuring access to clinical trials and ancillary services for cancer survivors.
3. Empower survivors with advocacy skills.
4. Develop, test, maintain, and promote patient navigation systems for people living with cancer.
5. Teach survivors how to access and evaluate available information.
6. Educate health care providers about cancer survivorship issues from diagnosis through long-term treatment effects and end-of-life care.

Mason, Wilms' Tumor Survivor



“Survivorship has shown me that cancer was really hard, but it was something I just had to go through.”