

VI. PROGRAMS, POLICIES, AND INFRASTRUCTURE

A. Goals

This section describes prioritized needs and recommended strategies for programs, policies, and infrastructure at national, state, and community levels to advance cancer survivorship within public health settings. Goals include the following:

- Develop a continuum of health programs and services that addresses both cancer treatment needs and primary, secondary, and tertiary prevention of additional health concerns for cancer survivors.
- Enhance supportive policies that establish an environment to comprehensively address cancer survivorship issues.
- Establish a system of services that enhances and creates partnerships among public and private health agencies.

Programs, policies, and infrastructure are means for effecting change and are defined here and in Section II.C. as follows:

Programs

Programs are the actual implementation of specific interventions at the national, state, and community levels to address a public health problem (NAAP, 1999). Medical, psychosocial, legal, and financial issues could be addressed by programs that are comprehensive in scope and encompass care for each stage of cancer survivorship.

Policies

Policies include legislation, regulations, ordinances, guidelines, and norms that establish an environment conducive to program implementation and other changes specific to survivorship (NAAP, 1999). These policies may be implemented at the national, state, organizational, and community levels in an effort to advance public health.

Infrastructure

Infrastructure is comprised of the basic resources and facilities in place to address survivorship and includes components of the health care and public health systems, such as state and local health departments, and the services and programs they provide. Effective infrastructure is required to operate and manage effective programs. As our health care system continues to evolve, delivery of quality care becomes more complex. Relationships among the public and private sectors, individual practitioners and managed care organizations,

and voluntary health organizations directly influence access to care and provision of clinical and community services (NAAP, 1999).

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

B. Prioritized Needs and Suggested Strategies

It is through programs, policies, and infrastructure that public health can effect change in terms of the delivery of services for cancer survivors. Survivorship initiatives could be embedded in all services related to the continuum of care, including cancer prevention, screening and early detection, diagnosis and treatment, rehabilitation, and palliative and end-of-life care. These programs may be offered through a variety of sources, such as comprehensive cancer centers, advocacy organizations, or community-based organizations (Tesauro et al., 2002). Policies may be implemented at the national, state, and community levels to create an environment supportive of advancing cancer survivorship in the realm of public health. An example of an existing policy that is relevant to cancer survivorship is the Cancer Survivors' Bill of Rights© (Spingarn, 1999). The Bill was written by a cancer survivor for cancer survivors and denotes the shift in a survivor's role from passive patienthood to proactivity (Leigh & Stovall, 1998). This document serves as an example of how an advocacy organization can advance policy in the realm of cancer survivorship.

Exploring ways that public health policy can be developed to address the needs of cancer survivors is an important next step in action planning. To ensure that cancer survivorship innovations reach the people who need them most, states, territories, and tribal organizations need to build and maintain appropriate infrastructure. Sufficient scientific and programmatic infrastructure will enable health agencies to build the necessary coalitions and partnerships to translate research into public health programs, practices, and services for cancer survivors. CCC Programs (see Section I.D.) hold promise as the foundation for developing this infrastructure specific to cancer prevention and control.

I. Develop, test, maintain, and promote patient navigation or case management programs that facilitate optimum care.

Patient navigation is a tool that can be used to ensure that survivors understand their care and their process of care and enhance the delivery of optimum care. In these programs, health professionals or highly trained patient liaison representatives coordinate health care

for patients and assist them in navigating the health care system. This need is discussed in detail in Section III.

2. Develop and disseminate public education programs that empower survivors to make informed decisions.

No one medical answer is right for everyone. Cancer survivors are faced with extremely difficult medical decisions at each stage of living with, through, and beyond cancer. This need is presented in Section III.

3. Identify and implement programs proven to be effective (i.e., best practices).

In the public health field, “best practices” refer to programs that have been identified as effective through a standardized process using commonly agreed-upon criteria for rating their success (USDHHS, 2003). These programs have been shown to be successful through measurable outcomes. Efforts are under way within public health to systematically identify these programs and disseminate them to a broader audience for replication (USDHHS, 2003). Within the realm of cancer survivorship, there is much to learn about the best practices of programs that address needs for people living with, through, and beyond cancer. Specific strategies to achieve the goal of identifying and disseminating best practices for cancer survivorship include the following:

- Establish quantifiable criteria to determine which programs are among the best practices for addressing cancer survivor needs.
- Identify best practices based on agreed-upon criteria and rank order programs accordingly.
- Identify gaps in survivorship research and provide funding to test new models and approaches.
- Establish a “clearinghouse” of information (e.g., **Cancer Control PLANET**, CIS) using existing mechanisms for those programs identified as best practices.
- Promote this “clearinghouse” and otherwise disseminate information to programs, survivors, health care providers, and others. Use this clearinghouse to connect survivors to resources specific to their needs.

4. Implement evidence-based cancer plans that include all stages of cancer survivorship.

Through the CDC’s funding of CCC Programs (see Section I.D.), states are developing cancer control plans to comprehensively address

this disease. States launched these Programs in collaboration with private and not-for-profit entities to assure appropriate expertise and to maximize the impact of limited resources on cancer control efforts. Public health agencies are using this support to establish broad-based cancer coalitions, assess the burden of cancer, determine priorities for cancer prevention and control, and develop and implement comprehensive plans. Through these and other activities, work is under way to identify those efforts that are grounded in sound scientific knowledge, or are “evidence based.” Evidence-based efforts in public health rely on a rigorous process where strategies to address a health issue are assessed to identify those with the highest quality scientific evidence of successful outcomes. Too often, rigorous evidence is lacking upon which to recommend strategies and interventions to address important goals and objectives. Most states have included issues related to cancer survivorship in their plans but have not necessarily included efforts that are evidence-based or that address needs for each stage of living with, through, and beyond cancer. There is a need to identify evidence-based initiatives that can be systematically incorporated into state cancer control efforts. The following strategies provide specific guidance to meet this need:

- Identify key leaders and experts in cancer survivorship in every state (especially survivors) to create a network of individuals to ensure that survivorship issues are being addressed through each cancer plan.
- Educate those involved in planning and developing state cancer plans on the importance of and issues related to cancer survivorship.
- Evaluate survivorship programs and publish and disseminate results.
- Link CCC Program and other funding so that cancer plans are required to comprehensively address survivorship.

5. Establish clinical practice guidelines for each stage of cancer survivorship.

Clinical practice guidelines are defined by the IOM as “...systematically developed statements to assist practitioner and patient decisions for specific clinical circumstances” (IOM, 1992). These guidelines summarize the collective research on outcomes pertaining to one disease. This need is presented in detail in Section III.

6. Promote policy changes that support addressing cancer as a long-term, chronic disease.

Historically, cancer was a disease that people often did not survive (see Section I.A.). Health care focused on making the patient comfortable during the last stages of cancer progression; few treatment options were available. Now, many more treatment options are available, and people survive with cancer for many years. The medical model tends to focus more on cancer survivors during their “acute” stages of cancer and less on the “extended” and “permanent” stages (Mullan, 1985) and not on post-treatment or long-term issues. Policies need to effectively address cancer survivorship for all those living with, through, and beyond cancer. Strategies for effecting this change include the following:

- Develop and disseminate public education materials to educate policy makers, health professionals, and survivors on the stages of cancer survivorship.
- Encourage insurance carriers and health plan administrators to provide for post-treatment and long-term follow-up services for cancer survivors.
- Address the terminology used in various settings, such as in formal policy and the media, at health care organizations and among providers and insurance agencies, to modify policies to better reflect the stages of cancer survivorship.

7. Develop infrastructure to obtain quality data on all cancer management activities to support programmatic action.

A great deal is unknown about cancer survivorship, particularly in terms of the long-term effects of cancer diagnosis and treatment. For that reason, much work needs to be done to create comprehensive databases to collect information on survivors and conduct research on issues related to survivorship. This need is discussed in detail in Section III.

Section VI Summary: Programs, Policies, and Infrastructure

1. Develop, test, maintain, and promote patient navigation or case management programs that facilitate optimum care.
2. Develop and disseminate public education programs that empower survivors to make informed decisions.
3. Identify and implement programs proven to be effective (i.e., best practices).
4. Implement evidence-based cancer plans that include all stages of cancer survivorship.
5. Establish clinical practice guidelines for each stage of cancer survivorship.
6. Promote policy changes that support addressing cancer as a long-term, chronic disease.
7. Develop infrastructure to obtain quality data on all cancer management activities to support programmatic action.

Bart, Cancer Survivor



“Survivorship has given me a more complete sense of the gift of life.”