



Analysis of Survivorship Components  
in Selected State Cancer Plans

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Prepared by:

Marice Reyes  
University of Nebraska Law Student Volunteer  
Nebraska C.A.R.E.S.

## EXECUTIVE SUMMARY

Cancer is the second leading cause of death in the United States. However, advancements in medical technology allow for early detection and effective treatment, which continue to increase the number of cancer survivors. According to the National Cancer Institute, in 2002 10.1 million Americans were alive who had been diagnosed with cancer. In fact, of those 10.1 million people, more than 715,000 had been diagnosed over 27 years earlier. It is clear that survivorship is an area of importance when addressing the impacts of cancer.

An analysis of 23 cancer control state plans revealed that the term survivorship has numerous meanings. Thus, this report begins by highlighting various perspectives as to what survivorship actually encompasses. Most define survivorship as a continual process that affects a cancer patient's quality of life.

Next, this report focuses on five major areas of survivorship, including physical, psychological, social, spiritual, and economic well-being. The majority of state plans recognized these subject matters as central to understanding cancer survivorship.

Further analysis of state plans uncovered additional topics of considerable importance. These topics include access to care, environmental influences, complimentary and alternative therapies, legislative support, continued education of health care providers, accreditation of hospital cancer programs, self-advocacy training, childhood survivorship, research and clinical trials, and data management. While these matters were not addressed by all state plans it was evident that such topics carry much weight when trying to improve cancer survivorship.

Overall, cancer survivorship presents a broad area of issues to be addressed with equal importance. The goal of this report is to help familiarize the reader with such issues and gain a better understanding of cancer survivorship.

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## **SURVIVORSHIP REPORT**

### **Introduction**

Twenty-three cancer control state plans were reviewed for content concerning survivorship. As presented in the following sections, there was much variation yet significant consistency in themes regarding survivorship.

### **Defining Survivorship**

The majority of state plans began by defining survivorship. Most states deferred to certain cancer organizations that have already established a definition. Two frequently used organizations were the National Coalition for Cancer Survivorship (NCCS) and the Lance Armstrong Foundation (LAF). The NCCS defined survivorship as:

The experience of living with, through, or beyond cancer. It is a continual, ongoing process that begins at the moment of diagnosis and continues for the remainder of life; composed of stages or phases of survival.<sup>AZ</sup>

The LAF went further by expanding on the three stages of living “with,” “through,” and “beyond” cancer.

Living “with” cancer is the experience of receiving a cancer diagnosis and any treatment that may follow. Living “through” cancer refers to the extended state following treatment, which includes the time when the person has completed treatment and/or is in remission. Living “beyond” cancer is the post-treatment and long-term survivorship stage, including the time when the “activity of the disease or likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested.”<sup>AL,TX</sup>

Some state plans not only defined survivorship, but also clarified past misconceptions about what it means to be a cancer survivor. In the beginning, a cancer survivor meant someone who suffered the loss of a loved one to cancer. The definition then evolved when physicians began to use such terminology to describe a person who had survived at least five years following diagnosis.<sup>TX</sup> Now numerous states and organizations like the LAF and National Cancer Institute

(NCI) are utilizing NCCS' definition of someone living with, through, or beyond cancer from the moment of diagnosis.<sup>MD</sup> The common misperception that cancer survival only begins once a person is in remission is being replaced by the idea that cancer survival really begins the day of diagnosis and a few state plans are making it a point to communicate this change to its readers.<sup>NC</sup>

Some states discussed survivorship under the bigger umbrella of quality of life. The definition given to quality of life varied among states. For example, Arizona defined quality of life as:

A general sense of well-being that encompasses multiple dimensions of a person's life, which includes physical, psychological, social, and spiritual well-being as well as financial security.

Tennessee used a more comprehensive definition:

Quality of life is the subjective experience of individual cancer survivors and all those affected, including family, friends, and caregivers, throughout the remainder of their lives. This involvement includes physical, psychological, social, and spiritual well-being resulting from a cancer diagnosis and subsequent treatment.

Another variation came from New Mexico, which included factors that influence quality of life:

Quality of life is a concept that encompasses spiritual, psychological, emotional, financial and physical well-being. It is influenced by age, sex, sexual orientation, urban/rural location, socioeconomic status, level of education, immigration status, culture, and access to health care.

Other states have turned to Healthy People 2010, which defined quality of life as:

A general sense of happiness and satisfaction with our lives and environment. Health-related quality of life reflects a personal sense of physical and mental health and the ability to react to factors in the physical and social environments.

Overall, the state plans commonly defined quality of life as encompassing the areas of physical, psychological, social, spiritual, and financial well-being. These areas identified within the

concept of quality of life correlate with areas that impact survivorship as indicated in other state plans.

### **Issues in Survivorship**

When addressing survivorship, the majority of state plans identified five areas of concern: physical, psychological, social, spiritual, and economic well-being.

#### **Physical**

Many state plans recognized that cancer patients not only cope with the physical symptoms of cancer itself, but with the effects of treatment as well. Such symptoms may occur as chronic or acute physical problems during and after treatment. Most state plans included a non-exhaustive list of symptoms, such as pain, fatigue, hair loss, weight loss, appetite change, nausea, vomiting, shortness of breath, and mental confusion. Arizona's Comprehensive Cancer Control Plan grouped physical risks and effects into system-specific effects, i.e., urologic, gastrointestinal, sexual/reproductive, and musculoskeletal effects of treatment.

Only a few state plans addressed the problem of patients being unaware that reproductive challenges are a risk associated with cancer treatment. The Texas Cancer Plan states that “[m]en and women of reproductive age and parents of pediatric patients are often not informed of the risks associated with cancer treatment or the opportunities for preserving reproductive capacity.” Certain cancer treatments can cause sterility, impotence, testicular atrophy, premature menopause, and other changes that can affect an individual's ability to reproduce. The risk of reproductive change is one area that is not always addressed in state plans, but should be.

One area that is commonly addressed by state plans is pain management, particularly through palliative therapy. Cancer pain is a significant problem for many patients and it is well

recognized that palliative therapy should be available from the time of diagnosis to end of life care.<sup>IN</sup> According to the North Carolina state plan, a cancer patient's desire for pain relief extends beyond mere control to the need of being able to care for and enjoy their own family, go to work, and pursue other interests. Pain management is seen as such a significant issue in North Carolina that a Cancer Pain Advisory Committee was formed and held responsible for developing and implementing a plan of action to meet the state's pain control goals and objectives.

Certain state plans also addressed barriers to palliative care. Some barriers include inadequate training of health care professionals in symptom management, lack of information resources for patients, lack of insurance reimbursement, and lack of understanding patients' fear of addiction and loss of control.<sup>CA, NC</sup> In an effort to address these barriers the National Consensus Project for Quality Palliative Care released the *Clinical Practice Guidelines for Quality Palliative Care* in 2004.<sup>AZ</sup> While recognizing barriers and developing guidelines to improve the status of palliative care is encouraging, many states emphasized that much work is still needed in the area of cancer pain management.

Another issue touched upon by state plans regarding physical impacts on survivorship was cosmetic change, from excessive weight loss and hair loss to amputations and reconstructive surgery.<sup>AZ, TX</sup> Such alterations in appearance, while physical, are felt on a psychological level as well.

### **Psychological**

Many state plans stressed that the moment an individual is diagnosed with cancer they begin to experience a wide range of feelings. Such feelings can include shock, fear, anger, anxiety, stress, as well as hopefulness and optimism.<sup>MD, AZ</sup>

While it is recognized that such feelings can be debilitating and even lead to other health problems like clinical depression, many patients are still reluctant to communicate their feelings to their physicians or other medical practitioners.<sup>MD, AZ</sup> Maryland's state plan suggested that this reluctance may stem from the stigma of seeking mental health care or the mere fact that cancer patients are not aware that counseling services exist. Even if more health care providers knew of their patients' needs, they may not direct their patients to the appropriate support services. This is because many health care professionals are skeptical about the usefulness of psychosocial services or are not adequately trained to recognize that their patients are in need of psychiatric help.<sup>MD</sup> Furthermore, such services are commonly not covered by insurance, which adds another barrier to receiving the quality cancer care that patients deserve.

Despite these challenges, numerous state plans acknowledged that psychosocial support services are beneficial and can enhance quality of life. Such services can help the cancer patient, as well as family and friends, to understand the physical and emotional changes they are experiencing and ultimately alleviate some of the anxiety and stress associated with such change. Cancer patients can even choose the appropriate setting in which to receive psychological and psychosocial support services, i.e., support groups, one-on-one programs, or even electronically-based support groups.<sup>MD</sup> Thus, while cancer patients may experience negative psychological changes there are available means to develop renewed meaning to their lives and place more value on their relationships with friends and family.

### **Social**

Most, if not all, state plans addressed how the effects of cancer are not limited to the cancer patient, but also extend to friends and family. The stresses and anxiety of living with cancer may inhibit interactions between cancer survivors and others. This limited interaction is

enhanced by the fact that the concerns and feelings of a survivor are different from those experienced by their friends and family. As a result, many relationships are strained and may become less authentic.<sup>AZ</sup>

The loss of autonomy is another issue frequently touched upon by state plans. Being diagnosed with cancer poses many challenges when trying to carry on with employment or normal daily activities. Survivors now find themselves dependent on others because of the limitations imposed by cancer and the effects of its treatment. Life as they once knew it is interrupted to the extent that their sense of social well-being or self-worth is diminished.<sup>AZ</sup> This is an area in which psychosocial support services can help cancer patients adjust to their new roles in the family and workplace as well as assist in the re-establishment of autonomy.

### **Spiritual**

Another common area of survivorship is spirituality. Many state plans recognized that cancer not only affects the body, but the soul as well. However, the impact of spirituality will depend upon the culture and ethnicity of the cancer survivor since beliefs and value systems vary accordingly.<sup>AZ, TX</sup>

Spirituality is sometimes seen as a coping mechanism by cancer patients. Being diagnosed with a serious illness can incite a renewed faith or deeper connection to religion, which patients use to help accept and overcome their diagnosis. In fact, Arizona's state plan reported that 77% of hospital inpatients felt that physicians should consider patients' spiritual needs, while 37% felt religious needs should be addressed more frequently by their physicians.

However, the Texas state plan also mentioned that while some turn to faith for support, others may feel that their faith is being tested. Some cancer patients may even become angry and

feel that their cancer diagnosis is a punishment. Being a cancer survivor may even cause guilt, where one may ask, “Why am I the one to survive?” or “What is the meaning of my life now?”<sup>TX</sup>

Regardless of its impact, states across the nation have accepted that spirituality does play a role in a life filled with uncertainty and fear of recurrence or death.

### **Economic**

The large cost of cancer treatment was a major area of concern when state plans addressed the economic impact of survivorship. This financial burden can worsen because of loss of employment. Most state plans touched upon the fact that some cancer patients lose their jobs or are forced into early retirement due to the effects of treatment.<sup>TX</sup> Those that try to find new employment are often met with discriminatory results. Moreover, North Carolina’s state plan revealed “that approximately 90% of cancer survivors returning to the job market encounter discrimination when trying to find employment.”<sup>NC</sup>

Even if cancer survivors are able to keep their jobs they may still face challenges when reentering the workforce. One study in Maryland’s state plan reported that breast cancer survivors returning to work would face problems like demotion, unwanted changes in tasks, problems with employer/co-workers, personal changes in attitudes toward work, and diminished physical capacity. Despite these issues, a cancer survivor may not change jobs for fear of losing health insurance or being unable to find other employment.

Even if cancer patients are able to retain their job and health insurance, out-of-pocket expenses can be a devastating financial burden as well. Such things as high deductibles and co-payments, transportation, child and elder care, home care expenses, and special foods or equipment can be very costly. One study that focused on patients receiving outpatient chemotherapy reported that transportation and food are the largest out-of-pocket expenses.<sup>MD</sup>

Another area of high cost is healthcare services that cancer patients need, but are not considered part of their treatment. For instance, mental health services, fertility treatment, and physical or occupational therapy may or may not be covered by health insurance.<sup>MD</sup> Thus, these treatments have the potential to add to the already heavy financial burden.

Notwithstanding socioeconomic status, financial difficulties will affect almost all families coping with cancer and its treatment. However, there are sources of relief that may help alleviate this incredible financial strain on families. One source is publicly funded aid, such as the Breast and Cervical Cancer Prevention and Treatment Act. West Virginia is one of few states that have implemented this Act. Another state effort to relieve financial burden is the James “Tiger” Morton Catastrophic Illness Commission, which was established by the state’s legislature in 1999. West Virginia provides some privately endowed options as well, such as the Cancer Alternative Screening and Support Indemnity Endowment Fund, also known as the CASSIE Fund. While these are great resources for cancer patients, it must be communicated that there are strict criteria to be met in order to be eligible for financial aid.

### **Other Areas of Survivorship**

Some areas addressed by state plans do not fall within the five main issues related to survivorship. The following sections highlight topics outside the areas of physical, psychological, social, spiritual, and economic impacts of survivorship, but were still commonly found in various state plans.

#### **Access to Care**

Access to proper health care is a topic emphasized by the majority of state plans. While differences in cancer status for different populations can be attributed to individual behaviors,

there are other factors that contribute to such disparities as well. Certain factors include literacy levels, geography, socioeconomic status, and race or ethnicity. The main idea is that because of such factors different groups have different access to particular goods and services, which ultimately affects quality of life. The Pennsylvania state plan has even defined dimensions of access:

**Availability**—The relationship of volume and type of existing services (and resources) to the number of clients and types of needs. Refers to the adequacy of the supply of providers, facilities and specialized programs and services.

**Accessibility**—The relationship between the location of supply and the location of clients, taking account of transportation resources, travel time, distance, and cost.

**Accommodations**—The relationship between the manner in which supply resources are organized to accept clients and the client’s ability to accommodate to these factors and the clients’ perception of their appropriateness.

**Affordability**—The relationship of prices, of services and providers’ insurance or deposit requirements to the client’s income, ability to pay, and existing health insurance.

**Acceptability**—The relationship of client’s attitudes toward provider personal characteristics and characteristics of the provider’s practice, as well as to provider attitudes about acceptable personal characteristics of clients.

One significant factor in determining access to quality cancer care is literacy. The Tennessee state plan defined “health literacy” as “encompassing the skills necessary to perform basic reading and numerical tasks for functioning in the healthcare environment and furthermore acting on health care information.”

Patients with low health literacy experience difficulties with written and oral communication, which in turn limits any understanding of cancer screening, symptoms, and treatment options.<sup>TN</sup> Such patients have a hard time understanding physician instructions, following through on medical care, and utilizing preventive health measures.<sup>PA</sup> In addition, there

is also limited comprehension of informed consent forms for procedures and clinical trials, which can affect quality of treatment.<sup>TN</sup>

Tennessee's state plan revealed that some studies indicate that health related materials could not be understood by most of the people for whom they are intended.<sup>TN</sup> Thus, even people who are well-educated and possess strong reading and writing skills may still encounter difficulties when trying to comprehend health information.

An additional factor leading to limited comprehension of health related materials is language. Many cancer patients are non-English speaking and need assistance in the translation of medical information given to them by medical professionals. However, this help is not always given to cancer patients.<sup>MD</sup> The result is a gap in the information exchange, which creates yet another barrier to quality cancer care.

Socioeconomic status is another barrier to accessible cancer care frequently found in state plans. A cancer patient's socioeconomic status plays a significant role in determining risk factors, screening prevalence, incidence, and mortality rates among racial and ethnic populations. Furthermore, studies have reported that socioeconomic status is a better predictor than race when calculating the likelihood of a group's access to education, health insurance, income level, and living conditions.<sup>TN</sup> Ultimately, a lower socioeconomic status gives rise to the economic complexities and attitudinal issues that underscore the lack of access to proper cancer treatments, such as pain management programs and hospice services.

Geography is another factor considered by states when determining the accessibility of quality cancer care. The National Cancer Advisory Board noted, "researchers can develop new cancer treatments, but they cannot guarantee people's access to these therapies."<sup>NC</sup> Geographic access involves forming a link between the cancer patient and health care provider. This

connection is formed when the patient actively seeks care from the provider. However, this connection is weakened as distance and travel times between patient and provider increase.<sup>NC</sup>

One instance in which this linkage may be weak is with patients in rural areas as opposed to patients in urban communities. This is one comparison that many state plans executed to determine geographic accessibility to cancer care in their state.

Public funding of health care in rural areas is less than the average for the United States as a whole and as a result, many rural hospitals are financially distressed. Such hospitals have fewer new technologies and resources to maintain continuity of care.<sup>NC</sup> Thus, rural cancer patients are forced to travel substantial distances to receive the treatment they need. Not only is this time consuming, but also adds more cost in terms of food, fuel, and lodging. These factors weigh against a patient's need for care and can ultimately lead to the undesirable choice of not obtaining treatment.

North Carolina's state plan also emphasized that other factors may be responsible for the urban-rural differential. These factors include lower incomes, greater poverty, lack of health insurance, and lesser educational attainment. These problems are especially prevalent in racial and ethnic populations and the rural elderly.<sup>NC</sup>

Being a member of a racial or ethnic population is a barrier in itself and is associated with the previously mentioned barriers to accessible cancer care. Moreover, limited access to such care contributes to the fact that racial and ethnic groups are underrepresented among cancer survivors.<sup>TN</sup>

### **Environmental Influences**

Despite the obvious importance of environmental influences in cancer diagnosis and treatment only a small number of state plans addressed this issue. The California state plan

began by defining “environment” according to the 2002 International Summit on Breast Cancer and the Environment. “Environment” was defined as including “...the totality of living and working conditions as well as the physical, biological, social and cultural responses to those conditions.”<sup>CA</sup> In our environment, whether at work, home or school, we encounter environmental carcinogens. The Environmental protection agency has created a list of suspected environmental carcinogens, including agents like arsenic, asbestos, benzene, beryllium, cadmium, nickel, radon, and vinyl chloride. These agents have been connected to cancers of the liver, bladder, skin, and lungs as well as mesothelioma, leukemia, and lymphoma.<sup>TN</sup>

In addition to environmental carcinogens there are other “environmental” influences that may increase cancer risk. For instance, occupations that are low in the corporate hierarchy may expose workers to occupational carcinogens. There is also the possibility that country of residence compared to country of origin may play a role in the predisposition to cancer. California’s state plan has recognized the need of additional studies in these areas.

### **Complimentary & Alternative Therapies**

A few state plans emphasized how complimentary and alternative therapies are starting to play a greater role in the treatment of cancer. Arizona’s state plan attributed the greater use of less conventional treatments to the dissatisfaction with traditional medicine, the accessibility of information on the Internet, and the need for some patients to be more autonomous in regards to medical decisions.

The National Center for Complementary and Alternative Medicine (NCCAM) is 1 of 27 institutes and centers that make up the National Institutes of Health (NIH). It is devoted to discovering complimentary and alternative healing practices through research, integration with conventional medical practices, and outreach efforts like conferences and educational programs.

The NCCAM defines complimentary and alternative medicine as “a group of diverse medical and health care products, practices, and systems that are not part of conventional medicine.”<sup>AZ</sup> Furthermore, the major types of complimentary and alternative medicine are divided into five categories:

- 1. Alternative Medical Systems**—built upon complete systems of theory and practice, and have often evolved apart from and earlier than the conventional medical approach used in the U.S. Examples include homeopathic medicine and Chinese medicine.
- 2. Mind-Body Interventions**—uses a variety of techniques designed to enhance the mind’s capacity to affect bodily function and symptoms. Examples include meditation, prayer, mental healing and creative outlets such as art, music, or dance.
- 3. Biologically Based Therapies**—use substances found in nature, such as herbs, foods, and vitamins. Examples include dietary supplements, herbal products, and the use of more unusual, not yet scientifically proven, therapies like using shark cartilage to treat cancer.
- 4. Manipulative and Body-Based Methods**—based on the manipulation and/or movement of one or more parts of the body. Examples include massage and chiropractic or osteopathic manipulation.
- 5. Energy Therapies**—involve the use of energy fields. Examples include Qi Gong, Reiki, and the use of electromagnetic fields.

Cancer patients who utilize complimentary and alternative therapies are aiming to prevent further illness, reduce stress, prevent or reduce side effects and symptoms, or control or cure disease.<sup>CO</sup>

Such therapies must be proven safe and effective before being adopted by conventional health care systems. Thus, Arizona’s state plan reported that the National Cancer Institute and NCCAM are currently sponsoring clinical trials to study the complementary and alternative therapies for the treatment of cancer.

### **Legislative Support**

Most state plans addressed the issue of legislative support, usually as a strategy to accomplish an objective or goal. California approached this topic in a more comprehensive

manner and discussed how to frame policy and legislative issues. The state must “declare how serious the cancer problem is, how serious we are to solve it, that there is something we can do about it, and that the resources to solve the problem are insufficient.”<sup>CA</sup> California is one state that has certainly seen success in this area with the 1988 Tobacco Tax Initiative (Proposition 99) and California smoke free workplace law, which also included bars.

Many state plan strategies focused on supporting legislation involving Medicare/Medicaid and expanding access to those who are uninsured or underinsured. For example, New Mexico’s state plan specifically addressed supporting legislation that would:

- raise Medicare reimbursement rates;
- expand Medicaid to provide increased cancer treatment coverage;
- expand the state’s Insurance Assistance Program to help low-income cancer patients maintain their medical insurance coverage;
- coordinate Supplemental Security Income and Social Security Disability with Medicaid to facilitate continuing coverage of medical treatment.

Overall, legislation initiatives were widely recognized as one avenue to address and achieve particular goals and objectives.

### **Education of Health Care Providers**

Most state plans touched upon the need to continue educating health care providers to ultimately achieve optimal cancer care. One particular area that needs to be addressed is being sensitive to psychosocial issues of cancer patients. It has been shown that continued education can increase the knowledge, confidence, and skills to manage such issues of cancer patients.<sup>MD</sup>

The Michigan state plan provided a more comprehensive list of areas that should be stressed when educating health care professionals. Michigan’s strategy options regarding professional education included the following:

- History should include psychological screening, social history, and sexual self-concept.
- Partners should be included in pre- and post-treatment assessment of patients' concerns.
- Individuals at high risk for chronic distress should be identified.
- All patients undergoing treatment for cervical cancer should be assessed for depression.
- Patients should be informed of disease and treatment in a manner that will instill the greatest degree of hope.
- Psychological interventions should be identified as reducers of distress during and immediately following gynecologic cancer treatment.
- Immediate and long-term psychological changes should be identified as possible motivations for complying with medical therapy, improving diet, exercising, adjusting, and possibly enhancing medical outcome.

To further improve the care given by health care providers, the Utah state plan suggested that these providers should know and implement the use of particular treatment standards. Two current standards of cancer care promoted by Utah were the National Comprehensive Cancer Professionals standard and the Physicians Data Query standard.

### **Accreditation of Hospital Cancer Programs**

The accreditation of hospital cancer programs was commonly mentioned as one method to improve access to cancer care. Hospitals with oncology programs can and should seek voluntary accreditation through the American College of Surgeons Commission on Cancer (ACoS CoC). Accreditation can be received in several categories, including Teaching Hospital Cancer Program, Community Hospital Comprehensive Cancer Program, and Community Hospital Cancer Program.<sup>NC</sup>

Some areas that the commission considers include institutional and programmatic resources, cancer committee leadership, cancer data management and registry operations, clinical

management, and community outreach. The *Cancer Program Standards 2004 Revised Edition* was released in March of 2006 and provides a comprehensive explanation of 36 different standards used to evaluate cancer programs. A complimentary electronic version is available at <http://www.facs.org/cancer/coc/cocprogramstandards.pdf>.

North Carolina and West Virginia included specific numbers of hospitals that are accredited or are pursuing accreditation in their respective state plans. Each state even provided a map to illustrate the insufficient number of accredited hospitals. North Carolina went even further and provided maps that displayed the location of accredited cancer centers and the estimated cancer prevalence throughout the state. Such maps are an excellent visual aid to demonstrate the disproportion between cancer patients and accredited hospitals.

### **Self-Advocacy Training**

While some state plans addressed the need to educate health care providers, other state plans emphasized the need to educate cancer patients. Cancer survivors should recognize the fact that they are their own best advocates. To be an advocate they need to know the specifics of their disease, the results of tests they have taken, and the details of their treatment. Patients may obtain such information by requesting a copy of their medical record, which may cost money and add to their financial burden. However, this information is crucial to understanding treatment and appropriate follow-up care. The North Carolina state plan emphasized the importance of exploring possibilities of obtaining medical records at no cost. In addition, cancer survivors have medical and legal rights of which they should be aware.<sup>NC</sup>

Furthermore, the Texas Cancer Plan revealed that the National Coalition for Cancer Survivorship offers self-advocacy training in the forms of audiotape, the Internet, and interactive group formats. Training focuses on essential skills as determined by a survey of cancer survivors

and oncology professionals. Such essential skills include communication, information-seeking, problem-solving, decision-making, and negotiating.<sup>TX</sup>

### **Childhood Survivorship**

A limited number of state plans made the distinction between adult survivorship and childhood survivorship. North Carolina did a particularly nice job of isolating childhood survivorship as an independent issue. The state plan emphasized that children diagnosed with cancer face a unique set of problems. Some physical problems that may occur include short stature, learning disabilities, infertility, heart failure, and second cancers. In addition to physical challenges, survivors of childhood cancer are confronted with the psychosocial issues of adjustment which continue as they grow older. These psychosocial issues may involve re-entering the classroom and evolve into concerns about marriage or job performance. Financial issues also arise when these individuals are no longer covered by their parent's insurance policy.

One tool designed to aid childhood survivorship is a transitional program, which combines pediatric and medical expertise.<sup>NC</sup> As childhood survivors of cancer grow older they eventually "graduate" to the care of a non-pediatric oncologist. Before this occurs, the survivor's treatment record and potential long-term problems should be reviewed with the family and patient. During this transitional period, correspondence between the pediatric oncologist and subsequent health care provider should address these same areas.

Long-term survivors of childhood cancer must continually keep watch for any late effects. This involves individualized laboratory tests and repetitive evaluations that occur yearly or every other year.

A recurrent tumor continues to be the greatest cause of death beyond five years from diagnosis.<sup>NC</sup> Thus, despite the fact that long-term survivors of childhood cancer are normally thought to be cured of primary malignancy, a potential recurrence should not be overlooked.

### **Research & Clinical Trials**

It is well accepted among numerous state plans that controlling cancer entails continued support for cancer research. California's state plan explained that cancer research entails a grand continuum. This continuum begins at the basic, molecular, and genetic level, but expands to epidemiologic and clinical research and spans even further into translational research, which concentrates on transferring current technology from the academic field to the communities of providers and consumers.

One particular area needing improvement is that of clinical trials. This type of research is one of the primary ways to discover new and better methods of preventing and treating cancer. The West Virginia state plan stressed the essential role of clinical trials in the testing of new drugs, alternative approaches to existing therapies, new combinations of treatments, and brand new methods like gene therapy. Not only are current questions being answered about cancer treatment, but future directions in cancer research are being suggested as well.

While state plans appreciate the value of conducting clinical trials, it is the participation factor that has proved problematic. Cancer patients who participate in this research have access to free treatment and are linked to potential support services. However, only a small fraction of the total number of cancer patients in the U.S. has enrolled in past clinical trials. The Indiana state plan identified certain factors as potential reasons for underutilization. Such factors included lack of physician and patient awareness of available clinical trials, lack of trust in the effectiveness of clinical trials, the perception that the clinical trial process is extremely

complicated, and lack of insurance coverage for routine patient care costs related to clinical trials.

West Virginia's state plan admitted having no hard data as to why only a small number of state residents enrolled in such research. However, the state plan still referred to anecdotal evidence to isolate possible reasons. One potentially significant reason was the fact that only four locations in West Virginia participated in clinical trials. Thus, extra costs associated with travel and lodging may have led to expenditures that potential participants could not afford. Other possible reasons included lack of physician awareness and knowledge of the clinical trial process and failure to present clinical trials as a treatment option to patients. Furthermore, the state plan suggested that patients are reluctant to leave the area or their current doctor.

There is also the possibility that certain cultural barriers inhibit enrollment in clinical trials. One study mentioned in Indiana's state plan found that the African-American community continue to distrust such research because of past research exploitation. Furthermore, certain minority populations are more comfortable with health care providers who are of similar ethnicity, or at least with providers who comprehend and appreciate their cultural background.<sup>IN</sup>

Some state plans hoped to find ways to increase minority enrollment in clinical trials as one means to increase overall participation. Other means, such as supporting policy changes in Medicare/Medicaid coverage of patient care costs associated with this type of research, may also improve utilization of clinical trials.

### **Data Management**

Data collection and management was generally broken down into two topics. The first being data management in relation to patient diagnosis and treatment and second, information use directed toward patient understanding of cancer and its treatment.

When state plans addressed the former, a statewide database was the primary tool for organizing and disseminating patient information. The Alabama state plan recognized the need for a statewide database to sustain a continuum of care for cancer patients. Information should be collected from the time of diagnosis through follow-up treatment and any care-related activities.

There are a number of positive aspects to creating and maintaining a statewide database, including the ability to identify the needs of individuals and groups of cancer patients, red flag any inconsistencies and inequities, map out geographic comparisons of service supply and demand, and ultimately become more effective in providing cancer care services across the state.<sup>AL</sup>

The second focal point of data management is directed toward a patient's understanding of cancer and its treatment. Not every cancer patient undergoes the same experience and thus, not every cancer patient has the same needs. To meet these individualized needs the Colorado state plan suggests the use of a centralized directory of services, from screening to end-of-life. This centralized source of information would include sources of "medical care, ancillary medical services, cancer rehabilitative services, psychological and emotional support, meals, transportation, hospice care, family/caregiver support and/or respite care, educational materials, and other services."<sup>CO</sup> Family members and friends of cancer patients could also utilize this service as a reference tool.

If patients continue to have difficulties using health care services, there are patient navigator programs being tested throughout the country that may help with this problem. As reported by the Arizona state plan, these programs provide patients with "patient navigators" whose job is to aid patients and their families through the health care system by helping them

obtain accurate information on diagnoses and treatment options, access to services, financial assistance, social support and religious counseling.

The majority of states acknowledged that collecting patient information for health care providers and disseminating information to patients and their families are two ways of improving quality of life for cancer patients.

### **Conclusion**

While no state plan was exactly the same certain issues were generally highlighted as having equal importance in the area of cancer survivorship. The five categories of physical, psychological, social, spiritual, and economic impacts of survivorship emerged as a common theme throughout numerous state plans. Overall, the majority of these plans recognized that cancer survivorship will continue to improve due to advancements in medication and treatment methods. Yet, it is also recognized that there is still much to be done in terms of access to quality care, physician and patient education, legislative support, cultural barriers to cancer care, continued research, and much more.

## STATE PLANS

- ◆ Alabama Comprehensive Cancer Control Plan
- ◆ Arizona Comprehensive Cancer Control Plan
- ◆ Arkansas Cancer Plan
- ◆ Comprehensive Cancer Control in California
- ◆ Colorado Cancer Plan
- ◆ Georgia Cancer Coalition Strategic Plan
- ◆ Illinois Comprehensive Cancer Control Plan
- ◆ Indiana Cancer Control Plan
- ◆ The Face of Cancer in Iowa
- ◆ Kansas Cancer Control Plan
- ◆ Maryland Comprehensive Cancer Control Plan
- ◆ Massachusetts Comprehensive Cancer Control Plan
- ◆ Michigan Cancer Consortium Initiative
- ◆ Nebraska Comprehensive Cancer Control State Plan
- ◆ New Mexico Cancer Plan
- ◆ North Carolina Cancer Control Plan
- ◆ Pennsylvania Comprehensive Cancer Control Plan
- ◆ Tennessee Comprehensive Cancer Control Plan
- ◆ Texas Cancer Plan
- ◆ Utah Cancer Plan
- ◆ Washington State Comprehensive Cancer Control Plan
- ◆ West Virginia Comprehensive Cancer Control Plan
- ◆ Wyoming Cancer Control Plan