



CHAPTER 4

PATIENT ISSUES AND CANCER SURVIVORSHIP

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PATIENT ISSUES AND CANCER SURVIVORSHIP

It is because so many people must deal with the challenge of facing a life threatening disease—cancer—that so many have worked so diligently to develop this cancer plan. We must never lose sight of the fact that the sole purpose of our research to find better ways to prevent, detect, and treat cancer is to promote patient care and to help those who face a cancer diagnosis. We must continually strive to improve the manner in which we deliver that care to the public. If the science is not translated into widespread patient care then the science becomes irrelevant.

No matter what the type of cancer, each person with a cancer diagnosis deals with a myriad of difficult issues that affect their lives, the lives of their loved ones, and their chances for survival. The issues that confront cancer patients cut across all diagnoses, all cultures, all demographics, and all situations. The goal of this chapter is to identify problems faced by cancer survivors in Maryland and to recommend solutions to those prob-

lems. This chapter defines “cancer survivor” as someone living with, through, or beyond cancer from the moment of diagnosis. This definition was first developed by the National Coalition for Cancer Survivorship,¹ and has been adopted by many organizations including the National Cancer Institute² and the Lance Armstrong Foundation.³ Because family members, friends, and caregivers are also impacted by the survivorship experience, they are included in this definition.

This chapter identifies four major problem areas faced by cancer survivors. They are:

- Access to information and resources
- Financial and legal issues
- Psychosocial issues
- Long-term survivorship

Because these areas of concern are multifaceted, complicated, overwhelming, and numerous, an ongoing Patient Issues and Cancer Survivorship Advisory Board should be formed to oversee the implementation of the recommendations within this chapter and to continue to examine the issues and expand upon the findings of the Patient Issues and Cancer Survivorship committee.

Access to Information and Resources

“You have cancer” is one of the most overwhelming and frightening phrases anyone can be confronted with. That phrase raises immediate and confusing questions such as:

- Whom should I call?
- Will I die?
- What kind of treatment should I have?
- What are my options?
- Should I get other opinions?
- Who will take care of me?
- Where do I get the information that I need to answer all of these concerns?

Unfortunately, it is often very difficult for patients to receive and understand information pertaining to their cancer diagnosis. There is a great need for education and assistance with the cancer decision-making process. According to the National Adult Literacy Survey (NALS), 21–23% of adults demonstrated literacy skills in the lowest level of proficiency (Level 1).⁴ Though many factors contribute to the large number of surveyed adults demonstrating the lowest proficiency level, it remains that many adults may lack the literacy and skills necessary to understand and make decisions about their health and well-being.^{5,6} In addition, the percentage of the population whose first language is not English is increasing; in Maryland in 2000, 12.9% of adults spoke a non-English language at home, up from 9% in 1990.^{7,8} Non-English speaking patients need assistance with information given to them by medical professionals, but this is not always afforded them.⁹

Patients with low literacy levels and who may not speak English are not the only ones who experience difficulty understanding medical information related to their cancer diagnosis and treatment. In one study of hospitalized cancer patients, 74% of patients reported that they would have liked more information about their future condition, and over 50% reported that they had unmet needs regarding information about their diagnosis, exams, and treatment.¹⁰ This gap in information may stem in part from communication problems between patients and medical staff, a barrier cited by the vast majority of cancer patients in another study sample.¹¹

Unmet needs for information and assistance in understanding one's own medical situation often lead the patient to non-adherence with the recommended treatment and follow-up. In addition, a lack of information and understanding contributes negatively to patients' quality of life and increases anxiety

about their condition.¹²

Various methods have been successfully utilized to assist cancer patients in receiving the information and educational assistance they need. Oftentimes health care providers do not have the time or expertise in all the areas that affect their patients and their families to provide them with the information and help that they require. Cancer information hotlines have been used on a national, state, and local basis for some time in an effort to supplement scanty information given to patients by health care providers. The American Cancer Society and the National Cancer Institute's Cancer Information Service (CIS) operate national hotlines and can provide patients with virtually unlimited cancer information and resources. The CIS collects data on the types of callers and reasons for calls to its hotline, and through evaluation efforts has confirmed the great "health education potential of telephone helplines."¹³

Another well-documented intervention for increasing access to information as well as patient adherence is the use of a patient navigator. A patient navigator, or case manager, is typically an outreach worker who monitors the patient's needs and ensures he or she receives appropriate care. Navigator systems were originally designed to aid in follow-up of abnormal screening results for breast and cervical cancers. However, the navigator concept is increasingly being expanded to include follow-up of abnormal results for screening tests performed for other cancer sites such as prostate and colorectal. In addition, navigator systems may well be used before any screening has occurred in an effort to reduce cancer risk behaviors and steer the patient into screening, as well as to guide the patient through treatment and the accompanying decision-making processes. For example, in one study of men in Georgia, receiving a client navigator intervention was one of the most important predictors of men participating in a free prostate cancer screening.¹⁴ In another study of medically underserved women with abnormal breast findings, 87.5% completed recommended breast biopsies when the patient navigator intervention was employed. Only 56.6% of patients received the recommended biopsy when they did not receive patient navigation.¹⁵

Regardless of the methods used to achieve awareness and strengthen education, the citizens of Maryland need readily available information in order to take charge of their health care needs in general as well as

their needs in relationship to cancer in particular. Not only should they be educated about preventative behaviors, available screenings, and signs and symptoms, they must be afforded easy access to timely information and resources for decision-making pertaining to diagnosis and treatment, financial and legal issues, psychosocial issues, and long-term survivorship. Comprehensive information on all possible treatment options, clinical trials, second opinions, repercussions of treatment and disease, and available support and resources should be readily available to all cancer patients and their loved ones.

Financial and Legal Issues

Another area of concern for people affected by cancer relates to financial and legal issues. Once medical decisions have been made and treatment has begun, there are many practical issues that must be addressed. A cancer diagnosis puts many stresses on a person beyond the physical. The process of treatment and recuperation is a very expensive one. More questions arise, such as:

- How will I pay for my treatment?
- Do I have health insurance coverage? Is it comprehensive? What about life insurance?
- How will I pay for co-pays and medications?
- How will I get transportation to my treatment centers?
- How will I pay for child care?
- Will I lose my job?
- Will I be able to go back to work? Will I need a different job?

The NIH estimates that overall costs for cancer in the year 2002 were \$171.6 billion: \$60.9 billion for direct medical costs (total of all health expenditures); \$15.5 billion for indirect morbidity costs (cost of lost productivity due to illness); and \$95.2 billion for indirect mortality costs (cost of lost productivity due to premature death).¹⁶

In addition to the direct cost of medical care and wages lost due to illness, the financial burden on cancer patients is exacerbated due to increased out-of-pocket expenses. Even those with insurance can be devastated by elevated expenses associated with high deductibles and co-payments, transportation, child and elder care, home care expenses, special foods or equipment, and

compounded by lost wages.^{17,18} One study found transportation and food to be the largest out-of-pocket expenses for patients receiving outpatient chemotherapy.¹⁹ With more and more health care being delivered on an outpatient basis, patients must routinely make arrangements for transportation to treatment. Transportation has been found to be a major barrier to receiving care, particularly for minority patients, and often causes some patients to forgo necessary cancer treatment.²⁰ This issue is of great importance in Maryland. During each of the seven comprehensive cancer control Town Hall Meetings held at various sites throughout Maryland during the summer of 2002, a lack of transportation was cited as a major barrier to accessing cancer services.²¹

In addition to the financial burden of medical care and associated out-of-pocket expenses, cancer survivors may experience long-term financial and legal difficulties stemming from disability and other problems associated with returning to work. Despite the fact that many states have an increased focus on vocational rehabilitation for cancer patients,²² “approximately 25% of Americans with a history of cancer experience disparate treatment in employment solely because of their medical histories.”²³ Much of the discrimination likely results from employers’ lack of understanding of the variability in prognosis of the many types of cancer and misconceptions about the productivity of cancer survivors in relation to other workers.^{24,25} In one study, problems reported by breast cancer survivors upon returning to work included job loss, demotion, unwanted changes in tasks, problems with the employer or co-workers, personal changes in attitudes to work, and diminished physical capacity.²⁶ While confronting all of these issues, the quality of life of a cancer survivor may be severely impacted when he or she does not change jobs because of the fear of losing his or her health insurance, of discrimination, or of the ability to obtain a new job.

Many cancer patients need health services that are not routinely considered part of their treatment, which is another aspect of the financial burden confronting cancer survivors. The most significant of these is the need for mental health services, which will be discussed in the next section. Other services that cancer patients may need include fertility treatment (or arrangement for sperm or egg storage) and physical or occupational therapy. Though cancer is commonly viewed as a disease of the elderly, increasing numbers of cancer patients are of child-bearing age. Cancer patients don’t always receive timely information regarding fertility

services thus many patients do not consider this factor as they make treatment decisions. In addition, fertility services can be very expensive and are not often covered by insurance, even for cancer survivors whose fertility may have been affected by necessary medical treatments. Physical and occupational therapy are more likely to be covered by insurance, but again, patients often do not receive appropriate and timely information regarding these services. In many cases, a referral is required for the therapy to be covered by the patient's insurance and this may present a barrier to the patient obtaining the therapy.

Lack of health insurance and other financial barriers may prevent Marylanders from receiving optimal cancer care.²⁷ The financial burden may cause cancer patients to face setbacks in treatment adherence, overall functioning capacity, and quality of life.²⁸ Regardless of socioeconomic status, almost all families confronted with cancer and its treatment will experience financial difficulties.²⁹ New and creative methods must be developed to reduce the devastating financial burden of cancer on Maryland families.

Psychosocial Issues

Along with a cancer diagnosis automatically comes a wide range of emotions including, but not limited to, fear, anger, depression, shock, confusion, and denial, as well as optimism and hopefulness. Some of the psychosocial concerns that arise are:

- Will my doctors understand my feelings and stresses?
- Will I die?
- Where can I get help dealing with my feelings? How will I pay for these services?
- How will I interact with my family, friends, and co-workers?
- How will I deal with losing my hair, or having scars or burns?
- How will I cope with side effects?
- Will I lose my independence?
- Will my cancer reoccur?

Cancer survivors deal with many stresses that could be partially or completely alleviated with the help of psychosocial support services, including support groups, mental health counseling, and the support of trained

professionals such as social workers, professional counselors, psychologists, and psychiatric nurses. These services may be used alone or in combination, depending on the patient's needs. These support services may aid a cancer patient and his or her family in understanding changes in family, social, work, and school relationships, changes in body image and physical capacity, emotions such as depression, anger, and fear, feelings associated with loss of control and independence, memory loss, and the cognitive effects of treatment and medication. Support services may be helpful in a variety of settings, including professionally led support groups, one-on-one peer support programs, patient education conferences, and even electronically-based support groups; participation in any of these support services has been shown to reduce anxiety and depression and generally improve quality of life for cancer survivors.^{30,31,32,33} Electronically-based support programs may be especially important for rural or other populations without access to in-person support groups.³⁴

Patients are often reluctant to communicate their psychological and emotional concerns to their physicians or other medical practitioners. This reluctance may stem from the stigma associated with seeking and receiving counseling, a lack of awareness of psychosocial support services, or many other factors. Many medical practitioners do not see their patients often throughout the treatment phase and therefore are not fully aware of the psychological stresses their patients are dealing with. In addition, health care providers are often accused of not being sensitive to the psychological needs of their patients. Further, some health care practitioners do not routinely refer their patients and their families to mental health professionals and services. One study found a direct correlation between the attitudes of health care providers toward cancer support services and referrals given to their patients for psychosocial support services.³⁵ The study suggests that assembling a concise directory of locally available resources and improving collaboration among agencies may help to improve provider referrals to support services.³⁶

Additional provider education may also be necessary to give health care professionals the necessary understanding and appreciation of the cancer survivor's needs. A curriculum entitled "Bearing Witness to Cancer" has been developed at Brown University's Department of Community Health.³⁷ The course explores the experiences and issues faced by people dealing with cancer using a biopsychosocial framework, and is open to students in a variety of disciplines

at various academic levels. In addition to instituting similar curricula in Maryland universities, educational offerings should be expanded for currently practicing health care providers. Barriers to providing psychosocial training for providers include the skepticism among health care professionals about its usefulness,³⁸ as well as the time required to provide effective psychosocial care.³⁹ While many providers, especially nurses, do acknowledge the importance of the psychosocial aspects of care, many do not express confidence and adequate skill level for delivering this type of care.⁴⁰ Various methods of continuing education have been shown to increase the confidence, knowledge, and skills of the participants in managing the psychosocial issues of cancer patients.^{41,42}

Certainly, specific “improvements are needed in recognizing mental health problems among cancer survivors and reducing barriers to psychosocial service use.”⁴³ Compared with individuals without a cancer history, cancer survivors reported significantly greater contact in the past year with a mental health provider.⁴⁴ However, many individuals do not understand how mental health services could help them, or the range of services that may be available to them. Also, there are stigmas attached to seeking and receiving mental health care among some cultures and populations. Patients may be embarrassed or fearful of seeking such help. Indeed, stigma is one of the most common barriers to accessing mental health services cited throughout scientific literature.⁴⁵ For those that do seek mental health services, access is restricted by the availability of trained providers. A survey of providers recently completed by the Maryland Mental Health Coalition found that over the last five years, 76% of those surveyed reported increased difficulty accessing mental health services for their clients and one third of the providers reported dropping services that they used to provide.⁴⁶ With resources and providers stretched so thin, the accessibility of mental health services for uninsured and underinsured cancer patients is likely even further reduced than for patients with private insurance.

All cancer survivors deserve to have attention paid to their psychological and emotional well-being. While the effect of psychosocial interventions on cancer survival has been disputed,^{47,48,49} the effect of these support services on the mood, perception of pain, and overall quality of life of cancer survivors is undeniable.^{50,51,52}

Long-Term Survivorship

With the progress and breakthroughs that research has brought to cancer treatment, more people are surviving cancer and living longer. With that development comes a responsibility to ensure that cancer survivors receive continuous and long-term care. There are many long-term effects of cancer and treatment that are of great concern and need to be addressed, such as:

- What are the long-term effects of cancer treatments?
- Will my cancer return or will I be diagnosed with other cancers?
- How will I deal with the long-term medical and emotional side effects of cancer?
- How will my family cope over the long term?
- Who will help me through fertility issues specific to cancer survivorship?
- How will I learn about genetic risks among my children or siblings?
- Will I be able to go back to work? Will I need retraining?
- Will educators understand the emotional, physical, and cognitive needs of student cancer survivors?

A survey conducted among cancer survivors at the M. D. Anderson Comprehensive Cancer Center at the University of Texas indicated that 34% of the participants felt that having cancer had affected their overall health.⁵³ However, long-term cancer survivorship is a relatively new area of study and little is known about adult survivors of cancer. There is a great need for further research into the effects of cancer and its treatment and the development of interventions to reduce these effects. In 1996, the National Cancer Institute established the Office of Cancer Survivorship to support and promote research that addresses the physical, psychological, social, and economic issues of pediatric and adult cancer survivors and their families.⁵⁴ Enhancing long-term follow-up and ensuring the continuum of care for cancer survivors is necessary to reduce premature mortality and diminished quality of life associated with cancer and its treatment. Establishing cancer survivorship clinics in Maryland, like the Life After Cancer Care program at the M. D. Anderson Comprehensive Cancer Center in Texas and the Living Well After Cancer program at the University of Pennsylvania Cancer Center, would greatly enhance access to long-term follow-up services and coordinated care for survivors.

Conclusion

More than 24,400 people will be diagnosed with cancer in Maryland in 2003.⁵⁵ Three out of four families will help care for a family member with cancer. Fortunately, the number of cancer survivors is growing daily, due to advances in cancer detection, early diagnosis, aggressive and effective treatments, enhanced rehabilitative and support interventions, and active screening and healthier lifestyles by survivors. It is imperative that we take our charge seriously to help ease the challenge of a cancer diagnosis among our citizens and improve the lives of cancer survivors.

The investigation of issues faced by cancer patients in Maryland has brought to light many areas of concern. We have a great opportunity now to learn from this investigation and to set in place strategies to better serve the citizens of this state. These strategies can in fact be utilized in communities all over the country.

The citizens of Maryland are fortunate to live in close proximity to many cancer centers, agencies, and research programs that are furthering the cause of improved cancer treatment and possible cancer cures. Because our state already has the infrastructure and human resources available, implementing the recommendations contained herein can be readily accomplished.



Patient Issues and Cancer Survivorship Goals, Objectives, and Strategies

Goal:

Enhance the quality of life for all cancer survivors in Maryland.

Target for Change

By 2008, establish a Patient Issues and Cancer Survivorship Advisory Board to continuously assess the needs of cancer survivors in Maryland and to make recommendations to address those needs.

Objective 1:

Enhance access to information and resources for Maryland cancer survivors, their friends, and families.

Strategies:

1. Establish and market a comprehensive cancer information clearinghouse in the form of a website plus a staffed, toll-free telephone number. This website should house all pertinent information relating to national, regional, and local resources for cancer survivors. Consider the Cancer Gateway of Texas⁵⁶ and other existing state cancer websites as models for the Maryland website.
2. Encourage oncologists to distribute copies of the National Cancer Institute publications “Facing Forward” and “Life After Cancer Treatment” to all patients.
3. Identify Patient Navigator tools and systems for use in Maryland to facilitate patient access to cancer information, screening, diagnosis, and treatment.
4. Develop and implement a multimedia public service campaign to empower the public to be informed, proactive consumers of health care and to ask their doctors about appropriate cancer prevention and screening.
5. Educate community leaders throughout Maryland about available cancer resources and involve community leaders in helping to raise public awareness of issues faced by cancer survivors.



Objective 2:

Reduce the financial burden on cancer survivors and their families.

Strategies:

1. Examine the cost of cancer services and develop a statewide financial aid system to help offset the expense of cancer diagnosis and treatment services.
2. Initiate a review of the Maryland Medicaid system with attention to cancer costs.
3. Provide tax credits for chronically ill citizens.
4. Establish a paid medical leave program based on the best practices of existing programs.
5. Modify existing or develop new policies to ensure that patients with managed care insurance may have lab work, scans, and tests performed (and covered by their carrier) at the centers where they are already being treated rather than being forced to travel to other facilities.
6. Develop user-friendly transportation assistance programs to help patients get to and from treatment and medical appointments, support groups, education sessions, and other support services. Coordinate with existing transportation services and consider incentives such as tax credits for companies donating transportation services for cancer patients.
7. Mandate insurance coverage for fertility benefits to cover fertility counseling, sperm banking, or egg harvesting and storage for those affected by cancer treatments or surgeries.
8. Develop methods to increase access to physical and occupational therapy services as well as mental health services for cancer survivors.
9. Develop employer-employee education programs to make the workplace comfortable for survivors as they deal with cancer.
10. Mandate that life insurance be portable when one leaves employment.
11. Expand and develop new educational efforts to make cancer survivors and their families aware of pharmaceutical assistance programs.
12. Expand insurance coverage for screening for cancer survivors, who are often at risk for secondary cancers and other physical problems.
13. Develop programs to make childcare, eldercare, homecare or respite care available while patients are undergoing treatment and follow-up.

Objective 3:

Ensure that all cancer survivors have access to psychosocial support services throughout all phases of their cancer experience.

Strategies:

1. Educate health care practitioners to be aware of, and sensitive to, the psychosocial needs of their patients. Educate providers about existing mental health services and other psychosocial support services for cancer survivors and the urgent need for increased numbers of timely referrals for mental health services.
2. Establish an annual conference sponsored by the Maryland Department of Health & Mental Hygiene, academic health centers, and Maryland professional organizations to address psychosocial issues of cancer survivors.



3. Expand continuing education offerings to provide training in oncology mental health for those both within and outside the oncology arena. Consider providing certification in this field on the state level to practitioners including nurses, licensed professional counselors, psychologists, psychiatrists, social workers, occupational and physical therapists, physicians, and other health care workers who complete a course and designated hours of practice in oncology mental health.
4. Implement curricula on the psychosocial issues related to cancer in all Maryland universities offering programs in the health and social work professions. Consider the current curriculum written by Margaret Wool, PhD, MSW, being taught at Brown University as a model.⁵⁷
5. Provide incentives for prospective students entering the mental health profession to specialize in oncology.
6. Design and launch a media campaign to educate the public about the psychosocial issues related to cancer and to raise awareness and knowledge of the support services available throughout the state.

Objective 4:

Address the needs of long-term cancer survivors in Maryland.

Strategies:

1. Encourage and provide funding for survivorship research.
2. Establish new and expand existing long-term survivorship clinics in Maryland for both childhood and adult cancer survivors. These clinics should be designed to follow survivors after treatment and to provide them with comprehensive care to address the unique needs of cancer survivors. The Living Well After Cancer program at the University of Pennsylvania Cancer Center and the Life After Cancer Care program at the M. D. Anderson Comprehensive Cancer Center in Texas may provide models for such clinics.
3. Educate oncologists and other health care providers about long-term survivorship issues. Providers should be encouraged to explain the long-term effects of the different treatment options available and help their patients make treatment decisions with regard to these long-term effects.
4. Educate oncologists about the need to refer their patients to neurologists, cardiologists, physical therapists, or other specialists as necessary for the management of long-term side effects.
5. Identify or create new programs to address occupational issues of cancer survivors such as job retraining and workplace reintegration.
6. Increase awareness among educators about the specific physical, emotional, and cognitive needs of student cancer survivors, and of the emotional needs of the family members of cancer survivors.

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