

4· Patient Issues and Cancer Survivorship



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PATIENT ISSUES AND CANCER SURVIVORSHIP

Each person with a cancer diagnosis deals with many difficult issues that affect his or her life and chances for survival as well as the lives of loved ones. The issues confronting cancer patients cut across all diagnoses, cultures, demographics, and situations. This chapter identifies problems faced by cancer survivors in Maryland and recommends solutions.

THE TERM “CANCER SURVIVOR” refers to someone living with, through, or beyond cancer from the moment of diagnosis. 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:

- Access to care, information, and resources.
- Psychosocial issues.
- Long-term survivorship.
- Financial issues.

Throughout the chapter, recommendations for addressing these problem areas are targeted to both cancer survivors and healthcare providers. Empowering survivors is of utmost importance. In today’s health systems, survivors must be advocates for their own health and work together with healthcare providers throughout the cancer journey.

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Access to Care, Information, and Resources

Access to Cancer Care

ACCESSING LIFE-SAVING and evidence-based cancer care is a major concern to newly diagnosed cancer survivors and their families. There are several key questions that a newly diagnosed cancer survivor may want answers to:¹

- Who is the best medical professional to consult?
- What tests should I have?
- How can I manage my cancer treatment and its health effects?
- Which treatment options allow for the best preservation of fertility?
- What services are available to help me and my family deal with the disease?

Cancer patients often endure many health effects of cancer and its treatment including difficult symptoms, preventable conditions such as osteoporosis, and potentially lethal late effects such as heart failure. In addition to these health effects, cancer survivors are at risk for recurrence

of the same cancer and developing other forms of cancer.²

To ensure optimal treatment, minimize the health effects of treatment, and prevent future cancers, the Institute of Medicine (IOM) has developed a plan for four key aspects of survivorship care:

- Preventing and diagnosing new and recurring cancers.
- Ensuring surveillance of existing or new cancers.
- Developing a plan for addressing the negative effects of treatment.
- Creating a coordination plan ensuring the well being of cancer survivors.³

It is recommended that healthcare providers develop a survivorship care plan for each of their cancer patients. The plan should describe treatment and post-treatment care that includes:⁴

- Giving survivors a record of the cancer care services they have received, including screening and diagnostic tests, information about their cancer, type of treatment and its duration, and

Nutrition and Physical Activity for Cancer Survivors

The World Cancer Fund/American Institute for Cancer Research's Second Expert Report (2007) recommends that "All cancer survivors [should] receive nutritional care from an appropriately trained professional. If able to do so, and unless otherwise advised, [cancer survivors should] aim to follow the recommendations for diet, healthy weight, and physical activity."⁵

The nutritional recommendation for survivors is the same as the recommendation for improved health and fitness: eat plenty of fruits and vegetables, exercise, do not use tobacco, and limit alcohol consumption. The American Cancer Society recommends the following for cancer survivors; this combination of foods ensures intake of plenty of the vitamins and nutrients needed for a strong body:⁶

- Eat five or more servings of vegetables and fruits every day.
- Choose healthy fats, including omega-3 fatty acids, rather than saturated fats or trans fats.
- Select proteins that are low in saturated fat, such as fish, lean meats, eggs, nuts, seeds, and legumes.
- Opt for healthy sources of carbohydrates, such as whole grains, legumes, and fruits and vegetables.

Survivors should seek advice from their physicians for personal nutritional information especially in cases where treatment or cancer site may have resulted in dietary challenges, including those associated with digestion, chewing, taste, and bowel elimination.

Across all domains of cancer treatment and therapies, physical activity is recognized to have a positive impact on recovery of function and improved quality of life. A routine of physical activity during cancer treatment may reduce the negative effects of cancer treatment. For instance, exercise can decrease fatigue levels, improve bone mass, reduce pain, encourage return to prior level of functional activity, and may improve overall recovery.^{7,8,9,10,11,12,13} Physical activity also attenuates weight gain, a common side effect experienced after cancer treatment.^{14,15}

Due to many of the side effects associated with common cancer therapies, it is important to exercise caution with undertaking a physical activity program during and after treatment. Specific guidelines may assist the survivor in determining what type of physical activity intervention is best. This decision is optimally made in consultation with a knowledgeable healthcare provider.¹⁶

contact information of all physicians involved in their treatment.

- Giving survivors post-treatment standards of care that includes the health and personal effects of treatment, the possibility of recurrence, suggestions for healthy lifestyle (see text box, Nutrition and Physical Activity for Cancer Survivors, on page 2), and resources for supportive services (e.g., legal, financial, counseling).

In addition to treatments for cancer, many cancer survivors need access to other treatment services, such as mental health care. Approximately 10% to 25% of cancer survivors develop major depressive disorders, a rate that is four times higher than the general public. Other health problems cancer survivors may suffer from include sexual dysfunction, infertility, physical changes, and limitations in mobility, communication, and memory loss.¹⁷

Some of the barriers to healthcare that cancer survivors experience include a lack of or limited health insurance, coordinated care, and post-treatment care. Cancer survivors, even those with health insurance, may have difficulties paying for their treatments. According to a 2005 Institute of Medicine Report, 11% of cancer survivors under the age of 64 years in the United States are uninsured.¹⁸ While the percentage of cancer survivors in Maryland without health insurance is unknown, 12% of Marylanders reported being uninsured in 2008.¹⁹ Uninsured survivors mostly depend on government-run programs (Medicaid, Medicare) or private health agencies for treatment. See the Financial Issues section of this chapter for more information.

TERMS TO KNOW

Cancer survivor refers to someone living with, through, or beyond cancer from the moment of diagnosis. Because family members, friends, and caregivers are also impacted by the survivorship experience, they are included in this definition.

Access to Information and Resources

EACH CANCER PATIENT OR SURVIVOR is unique and has an individual learning and coping style. Some may want extensive disease, treatment, and resource information; others may want little or no information. It is critical that healthcare providers consider how active a role the patient wants to play in healthcare decision-making, in addition to considering the degree to which the patient desires information.

In addition, there is a need to overcome barriers to patients being able to receive and understand the information given to them. It can

Potential Survivorship Quality of Care Measures

PROCESSES OF CARE

- Provision of a survivorship care plan, a written post-treatment summary outlining the proposed follow-up plan.
- Assessment of psychosocial distress, referral to mental health providers.
- Assessment of employment, insurance, and financial issues, referral to rehabilitation and social work providers.
- Provision of written information on available community support services.

SCREENING GUIDELINES

- Adherence to evidence-based follow-up and surveillance guidelines, where available (e.g., annual mammography for breast cancer survivors; non-routine use of inappropriate follow-up scans and tests for breast cancer; follow-up colonoscopy for colorectal cancer survivors).

SURVIVORSHIP INTERVENTIONS

- Adherence to adjuvant therapy (e.g., hormonal therapy for breast cancer).
- Assessment and management of pain.
- When appropriate, referral to enterostomal care.
- When appropriate, referral for lymphedema management.
- When appropriate, assessment of sexual function and referral to sexuality counseling.
- When appropriate, referral to genetic counseling.
- Recommendation of exercise for fatigue.
- Smoking cessation counseling, if necessary.

SURVIVOR ASSESSMENTS OF CARE

- Ratings by survivors of their satisfaction with care, coordination of care, and quality of care.

Source: Institute of Medicine and National Research Council of the National Academies. "From Cancer Patient To Cancer Survivor: Lost in Transition." November 2005.

DID YOU KNOW?

The Institute of Medicine Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting reported that it is imperative to directly address a patient's psychosocial issues and needs in order to provide the most comprehensive cancer care.

sometimes be difficult for patients to receive and understand information pertaining to their cancer diagnosis, and there may be a need for education and assistance with the cancer decision-making process. This may be especially true for those at low levels of literacy proficiency. According to estimates from the 2003 National Assessment of Adult Literacy Survey (NAAL), 11% of Maryland adults lack basic prose literacy skills.²⁰

A new specialty—that of patient navigator—has emerged to increase patient access to information, resources, and care. Patient navigators are trained, culturally competent healthcare professionals who work with patients, families, physicians, and the healthcare system to ensure cancer patients' needs are appropriately and effectively addressed. The navigator's role is to ensure that individuals receive timely diagnosis and treatment, to advocate for the patient, and to teach the patient to advocate for him- or herself. The navigator may also coordinate doctors' visits, maintain telephone contact between patients and physicians, arrange rides to and from the hospital, help with insurance forms, and even suggest what to ask at future appointments.

In October 2005, the National Cancer Institute, with support from the American Cancer Society, awarded grants to nine academic research institutions to establish the Patient Navigator Research Program (PNRP). These institutions are charged with developing innovative patient navigator interventions to reduce or eliminate cancer health disparities and test their efficacy and cost-effectiveness. PNRP's overall aim is to decrease the time between a cancer-related abnormal finding, definitive diagnosis, and delivery of quality standard cancer care.

Psychosocial Issues

A cancer diagnosis automatically evokes 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 negative and positive psychosocial concerns that may arise are:²¹

Negative

- Fear of recurrence, concerns about future and death.
- Depression, sadness.
- Inability to make plans.
- Adjustment to physical compromise, health worries.
- Sense of loss for what might have been (e.g., loss of fertility).
- Uncertainty and heightened sense of vulnerability.
- Alterations in social support.
- Fears regarding accomplishment of adult developmental tasks.
- Existential and spiritual issues.
- Psychosocial reorientation.
- Sexuality, fertility, and intimate relationships.
- Concerns about parenting.
- Employment and insurance problems.
- Relationship with the treatment team.

Positive

- Feelings of gratitude and good fortune.
- Sense of self-esteem and mastery.

CANCER SURVIVORS deal with many stresses that could be partially or completely alleviated with the help of psychosocial support services, including support groups (either in-person or internet-based), mental health counseling, peer support networks, patient education conferences, and support from trained professionals.

Depending on the patient's needs, these services may be used alone or in combination. Support services may aid a cancer patient and his or her family in understanding changes in 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. In addition, participation in any psychosocial support services has been shown to reduce anxiety and depression and generally improve quality of life for cancer survivors.^{22,23,24}

One task for cancer survivors is to accept that life is different and to create normalcy both for themselves and their network of support.²⁵ This task is more manageable with the help of support staff who are trained in providing emotional and mental care to individuals who are learning to live with a chronic disease.

However, patients are often reluctant to communicate their psychological and emotional concerns to their physicians or other medical practitioners. In fact, the stigma associated with seeking and receiving counseling is one of the most common barriers for individuals with cancer to access mental health services.²⁶ Many individuals do not understand how mental health services may help them or the range of services that may be available. Early in the process of diagnosis, healthcare providers should inform patients that it is common to deal with depression and/or psychological distress at some point in the cancer journey and direct the patients to the help that is available.

Additional provider education may be necessary to give healthcare professionals the necessary understanding and appreciation of the cancer survivor's needs. Botti et al. reported that the high levels of stress associated with oncology nursing can be attributed to providing emotional support for patients and relieving the fears of their family members. Healthcare providers, particularly nurses, can benefit from psychosocial support training in order to enhance a cancer patient's outcome.²⁷ 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.^{28,29}

The healthcare community realizes the importance of integrating a patient's medical and psychosocial care. In fact, the IOM Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting reported that it is imperative to directly address a patient's psychosocial issues and needs in order to provide the most

comprehensive cancer care. The IOM Committee concluded:

“Addressing psychosocial needs should be an integral part of quality cancer care. All components of the health care system that are involved in cancer care should explicitly incorporate attention to psychosocial needs into their policies, practices, and standards addressing clinical medical practice. These policies, practices, and standards should be aimed at ensuring the provision of psychosocial health services to all patients who need them.”³⁰

Long-Term Survivorship

Survivorship is a relatively new term when discussing cancer. However, as advances in research are helping to slow the progress or impede recurrence of cancer, more and more individuals are living longer as survivors and living with high qualities of life.

WITH THIS TRANSITION to long-term survivorship new healthcare issues have emerged. Resources and support are necessary for long-term survivorship to help individuals adjust to life after cancer.

Oncologists and other healthcare providers should work to empower cancer survivors to be advocates of their own health through various methods including:

- Attending orientations offered at local treatment and infusion centers.
- Contacting patient navigators, social workers, or support staff to empower patients to take control of their own health.
- Using a journal or log to document doctor's visits, prescriptions, and blood work.
- Obtaining literature and other resources that give them suggestions on how to better communicate with their doctors.

Healthcare providers must also be educated about long-term survivorship issues such as cognitive deficiencies, secondary cancers, effects of some treatments on heart health, fertility problems, and others. Cancer treatment centers throughout the United States are looking at how best to address long-term survivorship. A good example is the University of Texas M.D. Anderson Cancer Center,

which has worked to develop a model for what happens after cancer is controlled.³¹

The IOM report, “From Cancer Patient to Cancer Survivor: Lost in Transition,”³² states that upon discharge from an oncologist, a plan should be developed to instruct any primary care provider on how to care for the patient based on the type of cancer diagnosis, treatment, and potential long-term health issues that may result from treatment. The implementation of such a plan could help educate healthcare providers on the need to refer their patients to other specialists.

In addition to addressing long-term health issues, other aspects of long-term cancer survivorship inclusive of the “whole person” should be supported, including issues of self-esteem, sexuality, employment, healthy eating/exercise, and others. One method of completely addressing long-term survivorship issues is to create clinics in Maryland for both childhood and adult cancer survivors.

Other members of the community who interact with cancer survivors should also be considered. An increased awareness among educators and community leaders about the specific physical, emotional, and cognitive needs of cancer survivors as well as the emotional needs of family members and caregivers is needed.

Financial Issues

A major area of concern for people affected by cancer relates to financial issues.

CANCER DIAGNOSIS, treatment, and survivorship care are expensive, even for those individuals with comprehensive health insurance coverage. Cancer brings about many questions, including:

- How will I pay for my treatment?
- Do I have health insurance? If I cannot work because of my cancer, how will that impact my coverage?
- How will I afford co-pays for doctors’ visits and medications?
- How will I get transportation to my treatment centers?

Federal Laws Providing Protection Against Work-Related Discrimination

- Americans with Disability Act (ADA)
- Family and Medical Leave Act (FMLA)
- Employee Retirement and Income Security Act
- Federal Rehabilitation Act

Source: Institute of Medicine and National Research Council of the National Academies. “From Cancer Patient To Cancer Survivor: Lost in Transition.” November 2005. (See source for details on federal laws.)

- How can I pay for child and/or elder care?
- Will I ever be able to go back to work?
Will I need a different job?
- How will I support myself or my family?

The National Institutes of Health (NIH) estimates that overall costs for cancer in 2010 at \$265.8 billion: \$102.8 billion for direct medical costs (total of all health expenditures), \$20.9 billion for indirect morbidity costs (cost of lost productivity due to illness), and \$140.1 billion for indirect mortality costs (cost of lost productivity due to premature death).³³

In addition to the direct cost of medical care and wages lost due to illness, the financial burden on cancer patients (those recently out of treatment and even long-term survivors) is exacerbated significantly by out-of-pocket expenses. Often even individuals and families with quality, comprehensive health insurance can be devastated by the expenses associated with high deductibles and co-payments, transportation, child and elder care, homecare expenses, special food or equipment, and compounded by lost wages.

Many cancer patients need health services that are not routinely considered part of their treatment. Most significant of these are mental health services.³⁴ Other services that cancer patients may need include fertility treatment, physical or occupational therapy, and integrative medicine therapies.

It is also important to consider the patient time costs associated with care, including time preparing for appointments, time spent in waiting rooms, and time recuperating at home from procedures, chemotherapy infusion, or radiation therapy.³⁵

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. Accommodations in the workplace as well as survivors' perceived notions of employer support or discrimination play a key role in survivors re-entering the workforce.³⁶ Much of the discrimination likely results from employers' lack of understanding of the variability in prognosis of the many cancer types, misconceptions about the productivity of cancer patients and survivors, and inability to provide flexibility in the work schedule, job sharing, or telecommuting.

Employers in Maryland must be educated on their employees' rights (see text box, Federal Laws Providing Protection Against Work-Related Discrimination, on page 6) as well as resources that they can use, such as Cancer and Careers' Managing Through Cancer program (www.cancerandcareers.org). Quality of life for the off-treatment or long-term survivor can be significantly impacted when he or she does not explore new and desired employment opportunities for fear of losing health insurance or discrimination.

Conclusion

To address cancer survivorship effectively and comprehensively, the Centers for Disease Control and Prevention, along with the Lance Armstrong Foundation, developed a National Action Plan for Cancer Survivorship.³⁷

THIS PLAN identifies 23 recommended needs, 18 of which are described as priority needs.

The following Goals, Objectives, and Strategies have been developed with attention to these priority needs, and specifically address the following five priorities:

- Develop strategies to educate the public that cancer is a chronic disease people can and do survive.
- Educate policy- and decision-makers about the role and value of providing 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.
- Empower survivors with advocacy skills.
- Educate healthcare providers about cancer survivorship from diagnosis through long-term treatment and end-of-life care.
- Educate decision-makers about economic and insurance barriers related to healthcare for cancer survivors.

GOALS - OBJECTIVES - STRATEGIES

GOAL

Enhance the quality of life of cancer survivors in Maryland through information and supportive services.

OBJECTIVE 1

By 2015, create an annual awareness campaign during the National Cancer Survivors Day to educate cancer survivors, the general public, policymakers, media, and healthcare providers about the needs of cancer survivors (including access to care, information and resources, psychosocial issues, long-term survivorship, and financial issues).

STRATEGIES

- 1 Develop awareness campaign publications (e.g., proclamation fact sheets on elements of a Survivorship Care Plan and advocacy skills for cancer survivors, press releases, and public service announcements).
- 2 Utilize existing partners and collaborate with local health departments, community health coalitions, support groups, and other community-based organizations to assist with the awareness campaign.
- 3 Host one statewide event during the National Cancer Survivors Day.
- 4 Post awareness publications on the Maryland Cancer Plan Web site: www.marylandcancerplan.org.

OBJECTIVE 2

By 2015, develop a Web-based resource guide in English and Spanish for cancer survivors seeking support groups, financial/legal services, and psychosocial support services at no cost.

STRATEGIES

- 1 Identify existing support groups and legal and counseling services available to cancer survivors at no cost. Include in the resource guide a brief summary of their services and contact information.
- 2 Utilize existing partners and collaborate with local health departments, community health coalitions, support groups, and other community-based organizations to assist with the distribution of the resource guide to local cancer care providers.
- 3 Post the resource guide on the Maryland Cancer Plan Web site: www.marylandcancerplan.org.

OBJECTIVE 3

By 2015, utilize the recommendations of the Institute of Medicine to develop and disseminate a fact sheet on elements of a Survivorship Care Plan for cancer survivors and healthcare providers.

STRATEGIES

- 1 Identify the necessary information and develop a fact sheet with the elements of a Survivorship Care Plan.
- 2 Utilize existing partners and collaborate with local health departments, community health coalitions, support groups, and other community-based organizations to assist with the dissemination of the elements of a Survivorship Care Plan to their respective cancer care providers.
- 3 Post the fact sheet on the Maryland Cancer Plan Web site: www.marylandcancerplan.org.

GOALS - OBJECTIVES - STRATEGIES

OBJECTIVE 4

By 2015, develop and disseminate materials to educate policy- and decision-makers, community leaders, and educators about the role and value of providing long-term care and support services to cancer survivors.

STRATEGIES

- 1 Identify the necessary long-term care and supportive services information and develop the materials.
- 2 Utilize existing partners and collaborate with local health departments, community health coalitions, support groups, and other community-based organizations to assist with the dissemination of the materials to their respective policy- and decision-makers, community leaders, and local educators.
- 3 Post the materials on the Maryland Cancer Plan Web site: www.marylandcancerplan.org.

OBJECTIVE 5

By 2015, develop and disseminate materials such as a financial resource manual, fact sheet, and PowerPoint slide presentation, to teach and empower cancer survivors the advocacy skills to protect their financial and legal rights at work and within the healthcare system.

STRATEGIES

- 1 Research and identify financial resources and state and federal laws that protect cancer survivors and include this information in the materials.
- 2 Utilize existing partners and collaborate with local health departments, community health coalitions, support groups, and other community-based organizations to distribute the materials.
- 3 Post the materials on the Maryland Cancer Plan Web site: www.marylandcancerplan.org.

OBJECTIVE 6

By 2015, create a workgroup to explore methods to educate decision-makers on, and reduce, the economic and insurance barriers related to healthcare for cancer survivors in Maryland.

STRATEGIES

- 1 Utilize existing partnerships to create a workgroup.
- 2 Research and explore methods such as implementing a "Maryland Supports Cancer Survivors" license plate program and drafting recommendations for insurers.

OBJECTIVE 7

By 2015, create a workgroup to explore the need for and feasibility of providing formal training and/or certification for healthcare providers in the area of cancer survivorship, including psychosocial issues.

STRATEGIES

- 1 Utilize existing partnerships to create a workgroup.

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