

The Unmet Needs of Cancer Survivors in New Jersey: A Dialogue for Action



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Long-term survivorship after cancer is now a reality for millions of Americans and more than 375,000 New Jersey citizens. Forty percent of Americans will be diagnosed with cancer at some point in their lifespan and sixty percent or more of these individuals will live many years with this disease. More than one in four hundred people are long term survivors of childhood cancer. Cancer is slowly being recognized as a chronic disease with long term consequences for many.

Meeting the complex medical, psychological, social, and spiritual needs of this growing population presents a significant challenge to the healthcare community and survivors themselves. It is becoming increasingly evident that cancer survivors face numerous long-term affects from their disease, and its treatment. Many of these problems are poorly understood and often left unaddressed. This interactive public forum was designed to listen to the major concerns of survivors and then use these findings to develop a framework for action so that New Jersey can begin to better address the unmet needs of cancer survivors.

Choosing To Thrive Through a Cancer Diagnosis

Selected key points of the keynote address by:

DonnaLyn Giegerich, MBA, CIC, RYT

Motivational Speaker – Health/Life Advocate – Entrepreneur
Founder/Co-Owner, Heritage Benefits Group, LLC

Four key areas of recovery:

*Be a leader in laughter for yourself, your loved ones,
and your medical/support team.*

Honor yourself

*Ask for help. The resources are endless!
Stay active, move your body, mind, and spirit.
Expect good things, keep learning, be grateful and never give up!
Continue living with a passion, whatever that might be for you.*

Help others

It is in giving ourselves that we become rich. Share your gifts!

Make use of your health team

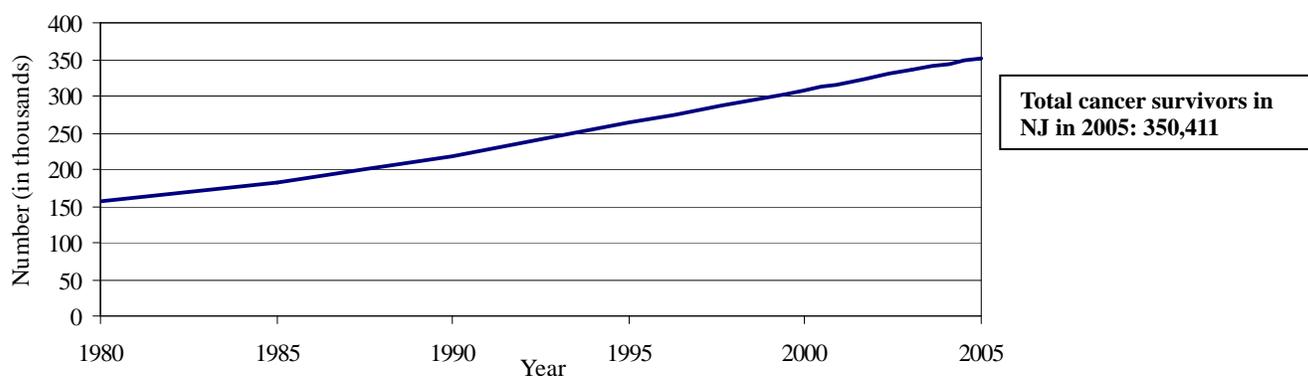
*Explore complimentary medicine.
Honor your doctors and caretakers with your appreciation.
You're not the only one suffering.*

Cancer Survivorship in New Jersey

Five year survival rates for most common cancers are presented below. New Jersey five-year relative survival rates vary greatly depending on type of cancer, sex, race, age, and stage at diagnosis. Overall, five-year relative survival rates improved during the past 20 years, especially for cancers diagnosed at the local and regional stages. New Jersey rates are similar to national trends. However, disparities in cancer survival continue to exist between blacks and whites and, to a lesser extent, between men and women.

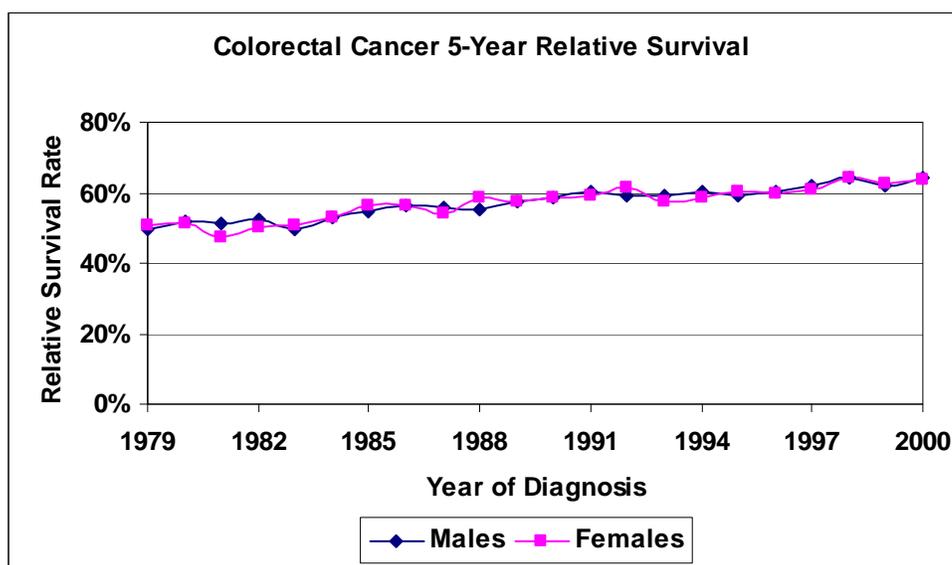
The Cancer Epidemiology Services (CES) Program is in the New Jersey Department of Health and Senior Services and is comprised of the New Jersey State Cancer Registry that houses more than 1.1 million cancer records (since 1979) and the Cancer Surveillance Program that monitors cancer trends in New Jersey, promotes cancer research, responds to cancer concerns, educates the public about cancer, provides data for cancer control and prevention and shares/compares cancer data with other states and the U.S.

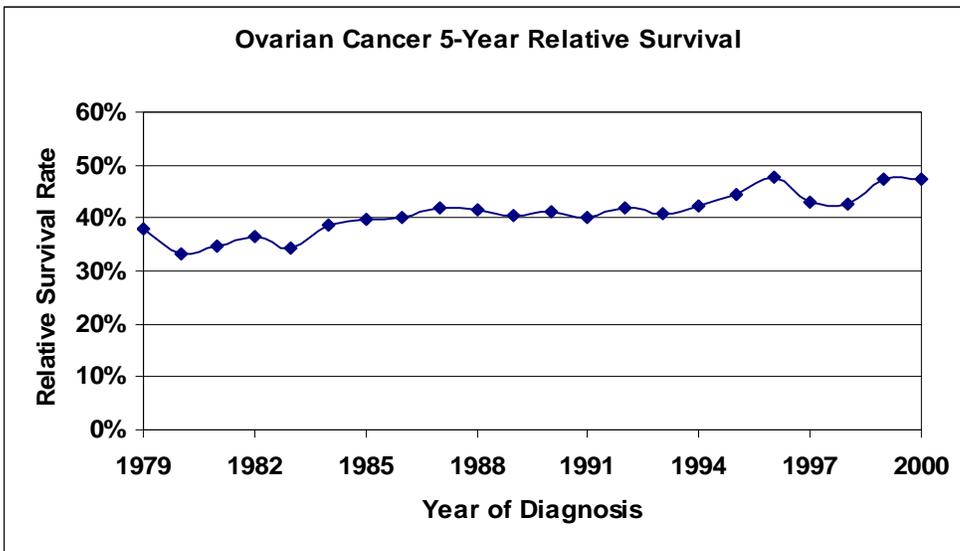
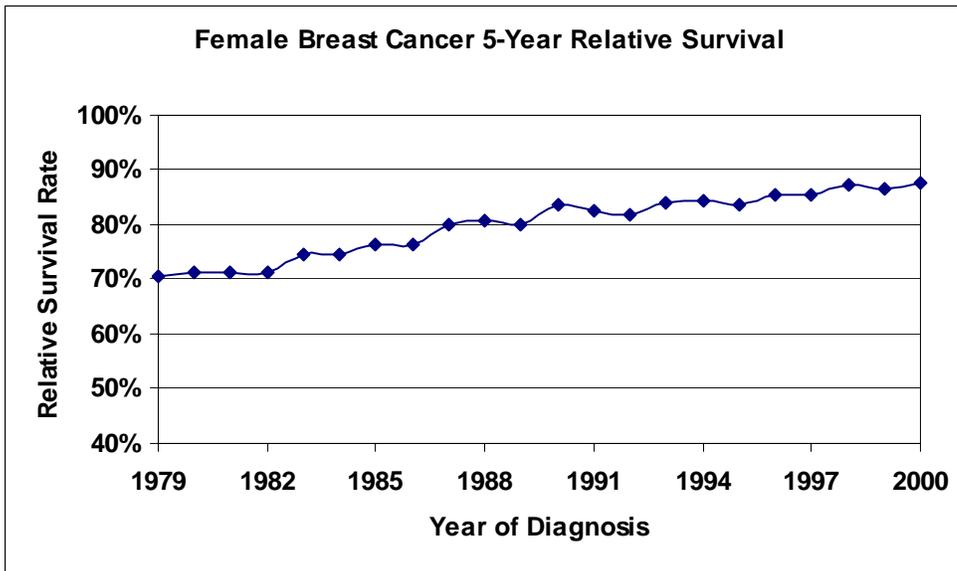
**Estimated Number of Cancer Survivors in New Jersey
from 1980 to 2005**



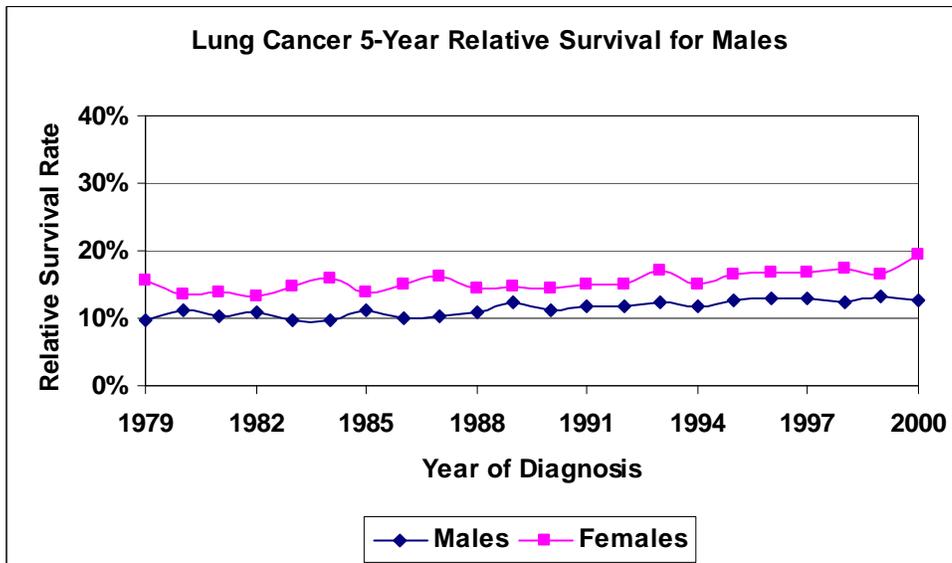
Source: New Jersey State Cancer Registry, Cancer Epidemiology Services, NJDHSS. May 2008

**Five-Year Survival Rates by Common Cancers and Year of Diagnosis
New Jersey, 1979-2000**

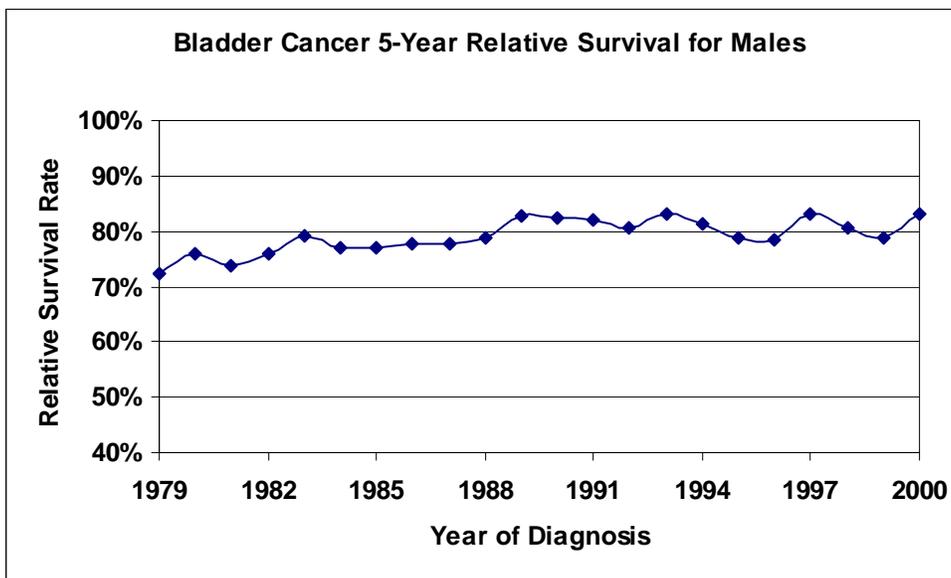
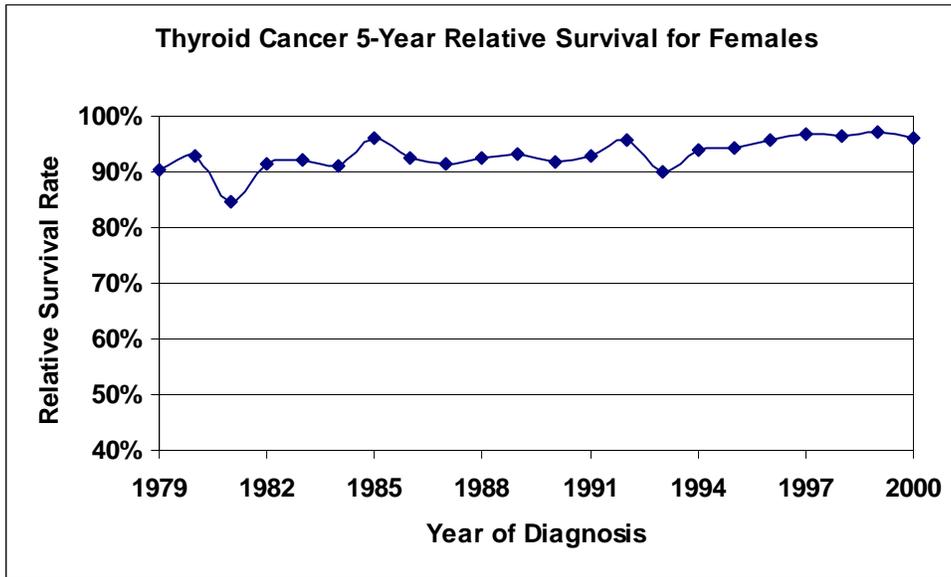


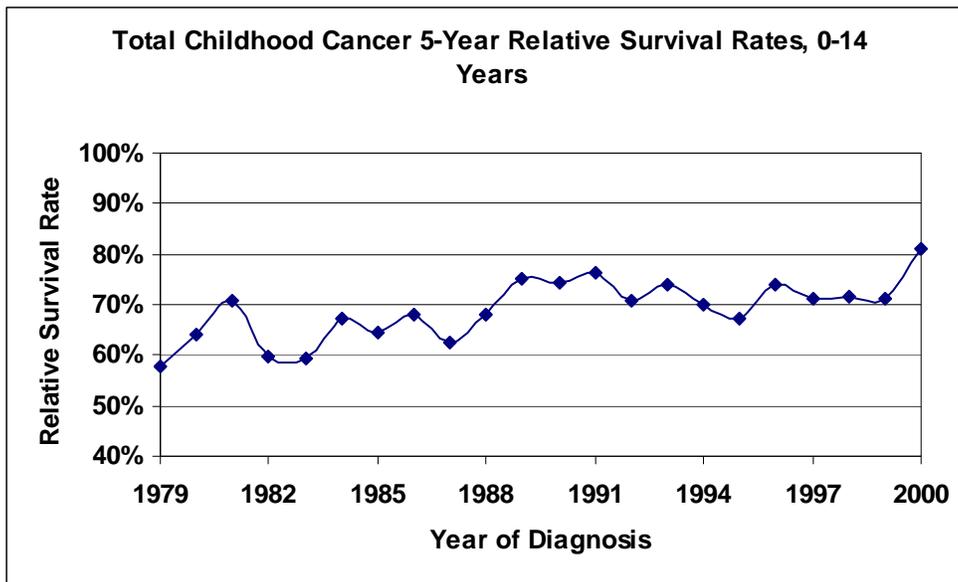


Five-Year Survival Rates by Common Cancers and Year of Diagnosis

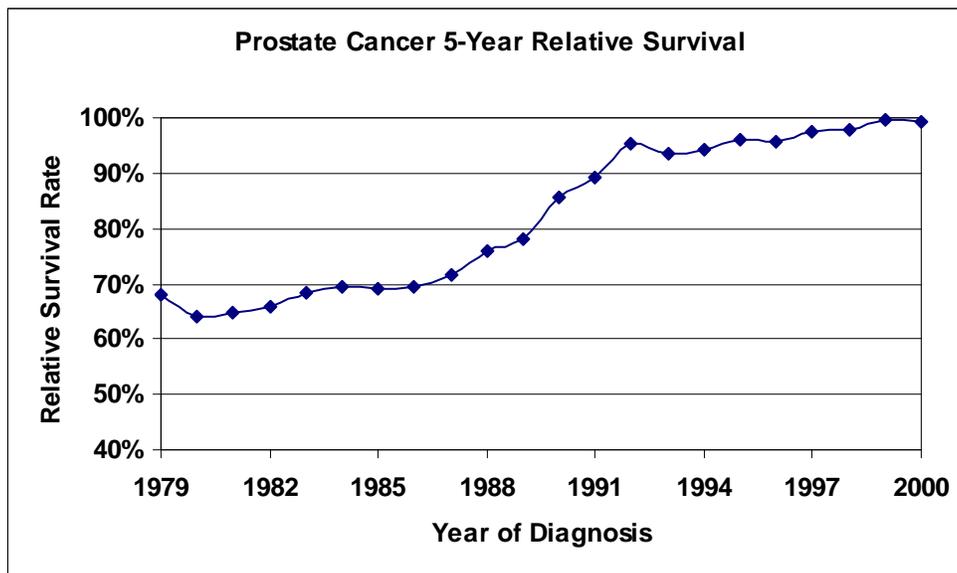


**Five-Year Survival Rates by Common Cancers and Year of Diagnosis
New Jersey, 1979-2000**



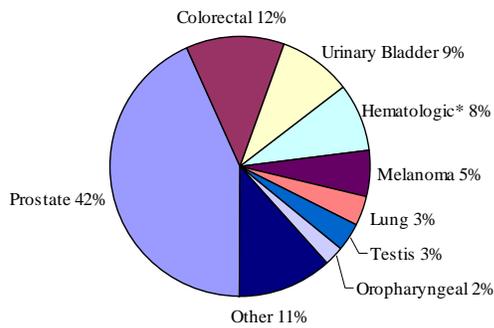


Source: New Jersey State Cancer Registry, Epidemiology Services, NJDHSS. September 2008.



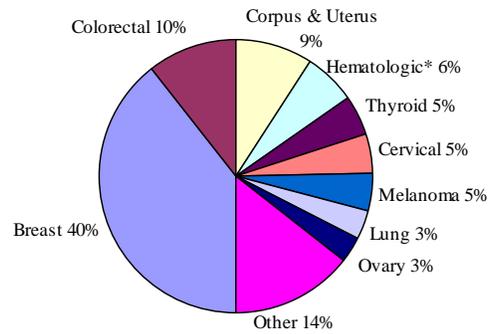
Cancer Survivorship Distribution by Sex

Distribution of Male Cancer Survivors in New Jersey, 2005
Total male cancer survivors: 157,411



* Includes Non-Hodgkin lymphoma, Hodgkin lymphoma and leukemia.
 Source: New Jersey State Cancer Registry, Cancer Epidemiology Services, NJDHSS. May 2008

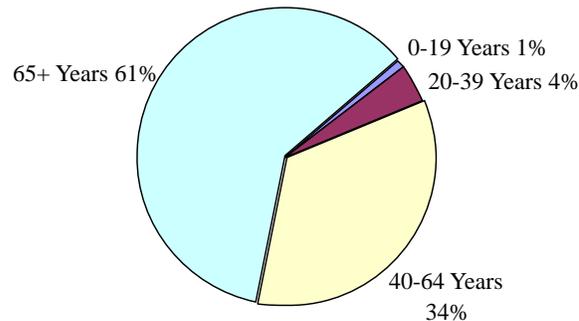
Distribution of Female Cancer Survivors in New Jersey, 2005
Total female cancer survivors: 193,000



* includes Non-Hodgkin lymphoma, Hodgkin lymphoma and leukemia.
 source: New Jersey State Cancer Registry, Cancer Epidemiology Services, NJDHSS. May 2008

Distribution of Total Cancer Survivors by Age in New Jersey, 2005

The majority of cancer survivors are older adults



Source: New Jersey State Cancer Registry, Cancer Epidemiology Services, NJDHSS. May 2008

Special Thanks to Xiaoling Niu, MS, Research Scientist, Cancer Epidemiology Services, New Jersey Department of Health and Senior Services for her work on these graphs.

Physical Effects in Cancer Survivors

Regina S. Cunningham, PhD, RN, AOCN

Chief Nursing Officer, The Cancer Institute of New Jersey
UMDNJ-Robert Wood Johnson Medical School

While advances in cancer treatments have prolonged survival, the quality of life after cancer is not always as good as we might hope. Lingering effects of both the disease and treatment can haunt cancer survivors long after they have completed therapy.

The physical effects of cancer and cancer treatment are diverse and complex. They depend on the specific disease as well as the type and dose of therapy. Complicating this is the fact that most cancer patients receive multiple types of cancer therapy, such as radiation, surgery, and chemotherapy, increasing the likelihood of long-term problems. New developments in cancer treatment further complicate this scenario.

Physical Functioning

Many adult survivors report that they have not fully regained their pre-cancer levels of physical functioning or engagement in social, work, or leisure activities. Fatigue, one of the most common symptoms experienced by patients while they are receiving treatment, often continues long after treatment has subsided; this effect has been inadequately studied in adult survivors of pediatric and adolescent cancer.

Heart and Lung Functioning

Certain types of chemotherapy can effect the functioning of the heart leading to cardiomyopathy (a weakening of the heart muscle) or an irregular heart beat. Anthracyclines are strong and effective drugs used in the treatment of many types of cancers. They have improved survival rates but their use is associated with toxic effects on the heart, such as abnormalities in heart size and function, as well as heart failure.

Trastuzumab or herceptin, a biological therapy used to treat certain types of breast cancer, is also associated with a specific type of cardiac dysfunction, differing from anthracycline-induced myocardial damage.

Testicular cancer is one of the most common cancers affecting young men. Cisplatin-based, combination chemotherapy is largely responsible for long-term survival of these men; however, it also may be responsible for the cardiac problems seen in long-term survivors. Cisplatin-based chemotherapy has direct and indirect effects on the cardiovascular system and impacts cardiac risk factors that increase chances of developing atherosclerosis. In addition, long-term survivors who have received this type of therapy have a high occurrence of obesity, lipid abnormalities, and hypertension.

Radiation therapy can also cause problems with the heart that include weakening of the muscle, narrowing of the cardiac vessels, and an irregular heart rate.

Lung toxicity can be seen in patients after they receive specific types of chemotherapy or radiation therapy. These toxicities can include irritation or hardening of the lung tissue, making breathing more difficult.

Reproductive Issues

Treatment with radiation therapy or chemotherapy may have adverse effects on fertility. Chemotherapy is associated with changes in libido, sexual and reproductive function. Many patients experience premature menopause as a result of cancer treatment; this is often associated with a number of physical symptoms such as flushing, vaginal dryness, and insomnia, that can be very distressing to patients. Early menopause can also lead to osteoporosis and an increased risk for bone injury.

Other Physical Effects

Other long term effects cancer survivors experience are numbness related to nerve damage, weakness, pain, swelling in the arm after surgical intervention, problems with cognitive function, and weight gain.

What should survivors do to manage these physical effects?

At the completion of treatment, survivors should be provided with a summary that outlines the type and dose of treatment they received and what specific monitoring (if any) is required. This is sometimes called a Survivor Care Plan and it is an important part of the health record. This information can be shared with other providers including Primary Care Physicians, so that they know what to expect and what kinds of tests to order. Survivors should be diligent about their ongoing care and know that the follow-up for cancer is a life long effort. As the transition to the survivorship phase of care is made, survivors should learn more about healthy lifestyle behaviors such as diet and exercise which can be helpful in keeping them in the best physical shape possible for their specific situation.

Addressing the Psychosocial Needs in Cancer Care

Kathleen Neville, PhD, R.N.

Professor of Nursing, Kean University, Union, NJ

In the latest Institute of Medicine (IOM) report (2008), *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, a committee on psychosocial services to cancer patients/families convened to study the delivery of psychosocial services needed by individuals with cancer and their families in community settings and to describe barriers to psychosocial services. It is now recognized that good quality care encompasses acknowledgement, treatment and management of psychosocial problems for individuals and their family members facing cancer. This current IOM report addressed that cancer care is often incomplete and that many people report that their cancer care needs are not being met. Most significantly, patients report dissatisfaction with the amount and type of information they are given about their diagnosis, prognosis, available treatments, and ways to manage their illness and health. Furthermore, this information is not conveyed in ways that allow patients and their family members to easily understand and take action. Also, individuals with cancer reported that their care providers do not understand their psychosocial needs, do not consider psychosocial support an important part of their care, are unaware of psychosocial health care resources, and do not make referrals for supportive services when required.

In the IOM Report, patients with cancer identified a number of other problems that affected their health care and recovery and included:

- a. poor communication with physicians (15% of U.S. households affected by cancer report leaving a doctor's office without getting answers)
- b. lack of knowledge about their illness and its management
- c. lack of transportation
- d. financial problems
- e. lack of health insurance.

Strengths in practice were identified. A shared vision to improve practice, patient care tools, resources, and effective services exists in cancer care settings.

Effective communication between patients, care providers and family members is essential for sharing needed information and quality cancer care. It is important to recognize the difficulty of such communication, as denial, protectiveness, and informational preferences often dictate communication patterns between patients, family members and health care providers. The IOM report identified the need to strengthen the patient side of the patient-provider partnership through additional patient and family education. Fear, anxiety, uncertainty, depression as well as other psychosocial problems common to the cancer experience can be better managed through effective communication.

Attending to psychosocial needs should be a central part of quality cancer care. All parts of the health care system that are involved in cancer care should definitely include attention to the psychosocial needs into their policies, practices and standards addressing clinical health care, aiming to ensure the provision of psychosocial health services to all patients and families who need them.

Sexuality and Cancer Survivorship

Lynne Kolton Schneider, PhD

Board Certified Sexuality Counselor
Flanders, NJ

Our sexuality is affected by many different variables: our background, ethnicity, religion, age, life experiences, and the like. These factors can dictate when we have sex, with whom, how often, in what positions, when we can't have sex – even who should be pleased first.

It is a gross understatement that adding a diagnosis of cancer complicates our sexuality. Some cancers can directly compromise sexuality – while others may have an indirect influence. This depends upon what organs and functions are affected by the cancer. Cancer treatments can also have an indirect impact – causing fatigue, bruising, pain, fragility; musculoskeletal aches and pains; hair loss, scarring, disfigurement, nausea/stomach problems, weight loss or gain; or hygiene issues. In addition to the direct consequences of the cancer and treatments on sexual functioning, there is the emotional baggage accompanying a diagnosis of cancer: that for some reason your body has betrayed you. Some people interpret a diagnosis of cancer as indication of wrongdoing in their past – how can you enjoy sex if you have done something so horrific so as to be diagnosed with cancer? Other people are concerned about the changes to their body image – and, depending upon where the cancer was diagnosed, may no longer see themselves as “sexual beings.” Finally, the reality of cancer survivorship is that during the initial stages (and often longer), all of your energy is focused on

surviving – and not necessarily on living each day to the fullest extent possible.

How can you bring a healthy sex life back into your world despite a diagnosis of cancer? First and foremost, initiate an open dialogue with your clinicians about how your specific cancer and your treatments should realistically affect your sexuality. Ask your clinicians for suggestions to integrate sex back into your life. They may suggest prescriptions (such as PDE-5 inhibitors such as Viagra, Cialis or Levitra) or prosthetic devices (pumps), or even over-the-counter agents (vaginal lubricants, massage oils or painkillers such as anti-inflammatories) to improve your ability to have sexual activity. They might also ask about your current lifestyle and make suggestions for easy changes – switching from evening, when you are exhausted, to early morning; switching sexual positions; scheduling intercourse or other sexual activity.

It is imperative that you open a dialogue with your partner. You might want to speak with a counselor or therapist who has expertise in this field. Both you and your partner need to be open about your fears, your concerns, and your desires. You may be overly aware of the changes to your physical appearance; whereas your partner is just so glad you are alive and able to be intimate. Establish realistic goals – having intercourse three times a day, hanging from the chandelier, may no longer be within your energy level. Maybe now you aim for once a week, lying in bed, in the morning when you are well rested. Finally: take it slowly. Laugh. Don't get discouraged – as long as you keep trying.

Spirituality and Cancer Survivorship

Chaplain Kava Schafer, M. Div, MA in Holistic Spirituality,

Certified Spiritual Director

Chaplain of the Bone Marrow Transplant Unit at the Hospital of the
University of Pennsylvania Medical Center

Living with cancer carries a serious existential weight for many people. As human beings, we all have values and belief systems that will respond in a variety of ways to the challenges of living with cancer. The cancer diagnosis and subsequent treatments evoke a spectrum of questions about the meaning and purpose of one's life. Through examination and evaluation, there is always the potential for discovery of new purpose and new meaning for many people, but there is also the potential for struggle and despair. When we are in the realm of values and meaning-making, we are also in the landscape of religion and spirituality.

We are in a spiritual place when we begin to ask what it is that enlivens us, what it is that makes us feel whole. Each person will have a different response and many people will identify the core animation as a connection with God or a divine presence, and will seek connection through religious beliefs and practices. Yet there are many people who do not express this center of aliveness in evident religious ways or have a belief at all in God. Those people may still identify themselves as spiritual. Why this is so important is that this individual inner place of ultimate meaning has great influence over outcomes, decision-making, and one's capacity to manage the unpredictable changes of cancer.

A person who is religious may find an encompassing support in their faith, but there are those who struggle with these value questions in a religious way that reflects some break with what had once brought satisfaction in the past. Sometimes struggle takes the form of anger at God or a haunting feeling that one is being punished through illness for something done or not done. The possibility for spiritual struggle exists as well for the non-religious person who may also grapple with questions of

meaning and purpose. For them, an inward examination of their cancer journey may lead to a renewed sense of purpose and meaning about life or a sense of bleakness and unfairness over suffering. Either way, there are many instances of cancer survivors expressing unmet spiritual needs that go to the very heart of their existence.

What can professional caregivers do? They can assist by learning to ask people what is of ultimate importance to them. With this knowledge of their core values, they have more information for assessment of their spiritual health. As the relationship grows, they can learn to listen intently for signs of this struggle or distress in our conversations. Deep listening is essential as not all people can put words to their experiences; art, music, other kinds of non-verbal expression may serve some people better. There are many possible practices which may assist the expression of spiritual experience and growth, including meditation, Reiki, and yoga. These are just a few examples of practices that fully integrate the connection between body, mind, and spirit.

The prospect of mortality unleashes deep life examination. Shock over diagnosis may upend everything perceived to be stable (hopefully, this is temporary), but the necessity to face uncertainty remains strong. There are questions about identity as one begins to deal with the limitations that often arise through illness. Loss of independence, the fear of being a burden, and the impact of vulnerability now come into clearer focus. It is important to stress the prevalence of the grief-work which seems to accompany the transition from health to a different way of living after diagnosis. This is real, and it is important work to grieve, but often grieving is interpreted as negative and people are encouraged to bypass this part of the process.

Another factor to consider is the traumatic nature of the cancer experience itself. The diagnosis, the multiple treatments that may or may not lead to a series of hospitalizations, the possibility of physical pain, and the emotional and spiritual pain that emerges when one's life feels under threat add up to a traumatic experience. It is very important for this stress to be alleviated or dealt with in life-enhancing ways so the burden does not begin to impact one's ability to heal. The whole person gets cancer, and that, by implication, suggests a holistic response to surviving cancer.

Employment, Insurance and Financial Issues

Barbara Hoffman, J.D.

Founding Chair, National Coalition on Cancer Survivorship
Legal Research & Writing Faculty, Rutgers University School of Law, Newark, NJ

The employment, insurance, and financial concerns of cancer survivors have changed significantly during the past generation. With improving survival rates, new legal rights, and a wide variety of resources that address the quality of life of cancer survivors, survivors now have new opportunities to advocate for their employment, insurance, and financial needs.

Most adults who are employed when they are diagnosed with cancer are able to continue to work during or after treatment. Although employers generally treat survivors fairly at work, a small minority of survivors face discrimination because of their cancer. Because most Americans obtain health insurance through work, maintaining employment can be critical to having sufficient health insurance to pay for treatment.

Two federal laws protect cancer survivors at work. The Americans with Disabilities Act (ADA) prohibits employers with at least 15 workers from discriminating against a person because he or she has a disability. The definition of disability covers most, but not all, cancer survivors. The ADA:

- Prevents disabled employees or a family member with a disability from being treated differently. So, for example, an employer cannot refuse to hire a person solely because he or she is still in cancer treatment. Similarly, an employer cannot demote an employee because he or she takes time off to care for a spouse who has cancer.
- Prohibits an employer from asking job applicants detailed questions about their medical history until they have been offered the job. Only then can the employer ask applicants to complete a medical form for insurance and safety purposes. At that time, survivors should fill out a medical questionnaire honestly.
- Requires employers to offer reasonable accommodations. These would be relatively inexpensive and safe ways, such as a change in job duties or flex time, to help employees return to work or perform a new job. Although the ADA does not require employers to offer health insurance, if they do, they must do so fairly and base any difference in coverage on actuarial data, not stereotypes.

The ADA is enforced by the Equal Employment Opportunities Commission. The EEOC settles most complaints. Only a small number actually end up in court.

Every state has a law similar to the ADA. The New Jersey Law Against Discrimination prohibits all employers from discriminating against cancer survivors who are capable of performing their jobs.

Additionally, the federal Family and Medical Leave Act requires any employer with at least 50 workers to provide up to 12 weeks of unpaid medical leave to care for oneself, spouse or child with a "serious health condition," which in most cases includes cancer. These 12 weeks, which the employee can take all at once or over time, are often enough time to recover from surgery and to adjust to treatment. While on leave, the employee is still entitled to medical benefits. Employees who return from leave are entitled to their previous job or an equivalent one. Under federal law, employers may, but do not have to, provide paid leave. Beginning in July, 2009, New Jersey will be one of the few states that will require large employers to provide paid medical leave for employees to take care of an ill dependent.

In May 2009, the federal Genetic Information Nondiscrimination Act will prohibit employers and health insurance providers from discriminating based on genetic information. The 1996 New Jersey Genetic Privacy Act also provides strong insurance and employment protections from discrimination based on genetic information.

Cancer survivors who have health insurance are entitled to all of the rights described in their policies. In addition to these rights, a growing, but still insufficient, patchwork of state and federal laws offer cancer survivors very limited remedies to barriers to securing adequate health insurance.

Major Concerns of Cancer Survivors: Setting a Research Agenda

Dr. Barbara Rabinowitz then led an interactive session among audience members to identify some of the major unmet needs of cancer survivors so that New Jersey could begin to set an agenda for action and help lay the groundwork for a strategic approach at a state level. Issues were discussed by major categories including physical effects, psychosocial concerns, sexuality, spirituality and employment/insurance/financial issues so that all who collaborated on this endeavor, as well as the breadth of constituents involved in cancer care throughout New Jersey, might lend their expertise and resources in a collaborative effort to address these critical points.

The following were identified at critical priorities that require action:

Education is essential to deal with the following issues:

- Survivor education is needed on a wide spectrum of issues
- Provider education is needed on a wide spectrum of issues
- Resource Guides and Websites with local information are needed. Updated and current information on available supportive resources are hard to locate and often too general to be of any real value

Special supportive services are required during critical transition points in a survivorship.

These include:

- Diagnosis
- Completion of treatment,
- Five - ten years after treatment,
- Reoccurrence/Relapse,
- End of Life and Hospice.

Best Practices do not exist for such services because research is still required. Areas of greatest concern include:

- Role of health care providers throughout the continuum of survivorship
- Additional tools and supportive services that may be required include survivorship plans, QOL assessment tools, etc.

Additional issues that require research include:

- Quality of life- is the cure worse than the disease?
- Long term effects and outcomes
- Cancer as a chronic disease
- Models of Psychosocial Support
- Appropriate response at transition points

Employment Issues continue even though laws exist to protect survivors. These include:

- Reintegration after long gaps out of work is a major problem.
- Pre-existing conditions – How do we handle this information?
- Insurance and managed care issues must be addressed.

Health Providers are often unable to advise or help with many of the psychosocial, sexual, spiritual, cultural or financial concerns of survivors and steps to deal with these gaps include the need to:

- Be more culturally sensitive.
- Listen and communicate.
- Respond to all aspects of patient needs.
- Help navigate patients through the health care system.

End of life care remains a concern of survivors. It's not the fear of death but the fear of dying that is a major concern. Steps should be taken including:

- Identifying gaps in how we provide this end of life care and provide services to support patients better.
- Finding better ways to help patient and family members make decisions?
- Assuring that there is no disruption in care while transiting to hospice care?
- Moving patients earlier into end of life care and hospice
- Providing resources to allow patients to make informed decisions?

Cancer is a disease that affects everyone, especially caregivers and family members. Issues to be addressed include:

- Communicating with family members
- Dealing with your children
- Understanding how cancer affects the patients and family dynamics
- Providing special resources for caregivers and family members

Survivorship means looking at the whole person. Addressing all the needs and personalizing approaches is essential:

- All aspects of survivorship need to be dealt with – psychosocial, sexuality, spirituality issues as well as physical problems.
- Routine survivorship care must be provided throughout the lifespan of the survivor.
- Advocates are needed for those who can't speak for themselves– many do not have the skills or the confidence to continuously fight the system.
- Many cannot get access to quality care – A quality chasm exists and must be addressed.
- Many patients are alone and do not have caregivers to share burden. Support systems are needed.

In closing, Dr. Rabinowitz thanked the sponsors, partners and audience for sharing their time, energy and passion during the evening and congratulated them on their openness and honesty. She noted that the urgent needs raised by the audience would require a “roll up your sleeves” commitment by all who contributed to the success of this program. She charged the participants with mobilizing and organizing their talents, skills and determination to accept responsibility for developing each area of need into workable action agendas in the coming months.

As a result of this program, major sponsors and partners are collaborating on a strategic planning Cancer Survivorship Summit in fall of 2009 to take the issues identified at the public forum to the next level: A Statewide Action Plan for Cancer Survivorship.

*Program Partners:
American Cancer Society, Eastern Division*

CancerCare New Jersey

Gilda's Club, Northern New Jersey

Leukemia & Lymphoma Society, Northern New Jersey

Leukemia & Lymphoma Society, Southern New Jersey

New Jersey Department of Health & Senior Services:

- *NJ Cancer Education & Early Detection Program*
- *Office of Cancer Control & Prevention*
- *Office of Cancer Epidemiology Services*

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Sisters Network of Central New Jersey, Inc.

South Jersey Breast Cancer Coalition, Inc.

The Wellness Community of Central New Jersey

Young Survival Coalition, Northern New Jersey