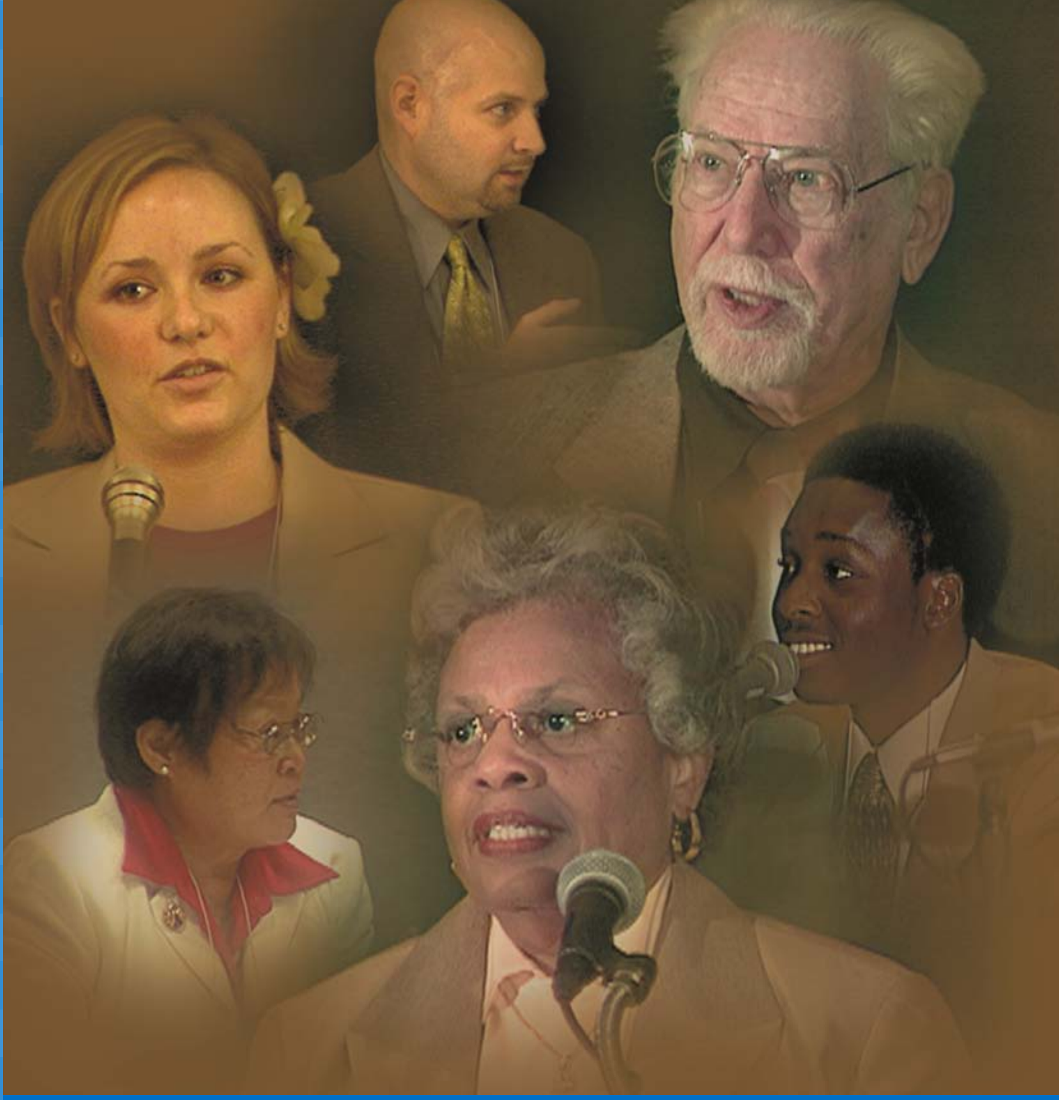


Living Beyond Cancer: Finding a New Balance

President's Cancer Panel
2003–2004 Annual Report

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health
National Cancer Institute

Living Beyond Cancer: Finding a New Balance

President's Cancer Panel
2003–2004 Annual Report

Prepared by:
Suzanne H. Reuben
for The President's Cancer Panel

May 2004

National Cancer Institute
National Institutes of Health
U.S. Department of Health and Human Services

This report is submitted to the President of the United States in fulfillment of the obligations of the President's Cancer Panel to appraise the National Cancer Program as established in accordance with the National Cancer Act of 1971 (P.L. 92-218), the Health Research Extension Act of 1987 (P.L. 99-158), the National Institutes of Health Revitalization Act of 1993 (P.L. 103-43), and Title V, Part A, Public Health Service Act (42 U.S.C. 281 *et seq.*).

The President's Cancer Panel

Chair:
LaSalle D. Leffall, Jr., M.D., F.A.C.S.
Charles R. Drew Professor of Surgery
Howard University College of Medicine
Washington, DC 20059

Members:
Lance Armstrong
Founder
Lance Armstrong Foundation
Austin, TX 78746

Margaret L. Kripke, Ph.D.
Executive Vice President and
Chief Academic Officer
The University of Texas M. D. Anderson Cancer Center
Houston, TX 77030

Printed May 2004
For further information on the President's Cancer Panel
or additional copies of this report, please contact:

Maureen O. Wilson, Ph.D.
Executive Secretary
President's Cancer Panel
31 Center Drive
Building 31, Room 3A18
Bethesda, MD 20892-2440
301-496-1148
pcp-r@mail.nih.gov

PRESIDENT'S CANCER PANEL

NATIONAL CANCER PROGRAM NATIONAL CANCER INSTITUTE NATIONAL INSTITUTES OF HEALTH
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

The President
The White House
Washington, DC 20500

Dear Mr. President:

Since passage of the National Cancer Act of 1971, scarcely imagined advances have been achieved in virtually every area of cancer research and cancer care. Earlier detection and better treatment of cancer are allowing more people across the country to live with and beyond the disease, rather than dying from it. The population of cancer survivors—now numbering nearly ten million Americans—is expected to increase dramatically as our population ages, and access to post-treatment care, needed ancillary services, and quality of life improvements have become major concerns.

Long-term and late effects of cancer or its treatment can occur many years after treatment ends. These effects include but are not limited to physical, psychological, and social issues. Physical side effects can include heart and other organ damage, infertility, second cancers, and cognitive dysfunction. Psychological and social issues following a cancer diagnosis can include depression, debilitating fear of relapse or a new cancer, employment problems, and difficulties with health, disability, and life insurance eligibility.

Oncology researchers are struggling to understand many of the unexpected effects of cancer treatment and continue to work to improve outcomes for patients. The President's Cancer Panel understands the need to continue research and inquiry into the needs and concerns of our Nation's growing population of cancer survivors. This understanding led the Panel to conduct a series of meetings focused on survivorship as it spans the life cycle. The Panel heard compelling testimony on the breadth and depth of survivorship issues from nearly 200 American and European survivors, caregivers, community advocates, providers, researchers, health systems specialists, and representatives from the insurance industry.

Mr. President, this report, together with a companion volume, ***Living Beyond Cancer: A European Dialogue***, presents the Panel's findings and recommended action steps to help alleviate the severe burdens experienced by cancer survivors and their families. The Panel appreciates your continued support of the National Cancer Program and urges you to act now on behalf of these courageous Americans as they strive to continue their contribution to our society.

Sincerely,

LaSalle D. Leffall Jr.

LaSalle D. Leffall, Jr., M.D., F.A.C.S.
Chairman

Lance Armstrong

Margaret Kripke

Margaret L. Kripke, Ph.D.

31 Center Drive ◆ Room 3A18 ◆ Bethesda, Maryland 20892-2440 ◆ Tel: 301-496-1148 ◆ Fax: 301-402-1508

Email: pcp-r@mail.nih.gov ◆ Web site: http://pcp.cancer.gov

Table of Contents

2003 Meeting Minutes available online at:

http://deainfo.nci.nih.gov/ADVISORY/pcp/minsmenu.htm

Executive Summary

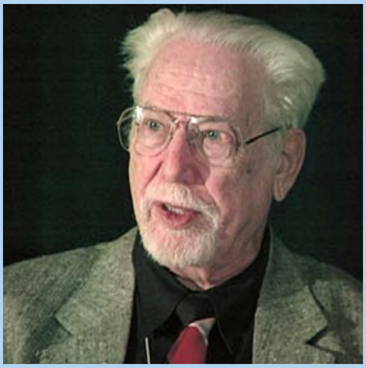
The end of cancer treatment is not the end of the cancer experience. As nearly 200 American and European cancer survivors, caregivers, health care providers, advocates, researchers, and others detailed in testimony provided to the President's Cancer Panel between May 2003 and January 2004, the end of treatment marks the beginning of a new phase of life: living *beyond* cancer. For the nearly ten million Americans now living with a cancer history, life after cancer means finding a new balance—one that celebrates the triumph and relief of completing treatment, recognizes changes or losses the disease has wrought, and assimilates revised perspectives, newfound strengths, and lingering uncertainties. Typically, few signposts exist to guide these highly personal journeys into a familiar but forever changed world.

Life after cancer treatment may hold diverse and often unexpected challenges. These challenges may be influenced by numerous factors, including the survivor's age at the time of diagnosis, the type and severity of both the cancer and its treatment, the duration of an individual's survival, financial and geographic access to needed follow-up care, employment and educational issues, information needs, and cultural, spiritual, literacy, and language differences. The impact of many of these factors, and the issues that arise from them, is magnified among many survivors from minority and other underserved populations.

Issues Affecting Cancer Survivors Across the Life Span

Both the testimony and additional data gathered suggested that several issues affect cancer survivors and their families regardless of whether the survivor was diagnosed as a child, an adolescent or young adult, in adulthood, or in older age:

- Many survivors leave treatment with neither adequate documentation of the care they received nor a written description of recommended follow-up care and resources for obtaining



“...being a cancer survivor is at the forefront of my self awareness. It enters into the conversations that I have with myself about what I want to do, how I want to spend money, how I want to spend time, my energy, all of that. Being a cancer survivor has added another dimension to my identity. I am a cancer survivor.”

Mortimer Brown, 80, colorectal cancer survivor diagnosed age 75, Florida

“There is also an inefficient and sub-optimized patient data collection system and storage, where every doc holds on to their own records about the patient, and the patient holds on to nothing. And yet every doc has to keep in sync with all the other docs sharing the responsibility for the care of that patient.”

Richard Migliori, physician and administrator, United Health Resources, Minnesota that care. The lack of a national electronic health record system is an impediment to continuity and quality of care for cancer survivors.

- Cancer survivors and their families need better information about existing laws and regulations that may protect their employment, insurance, and assets.
- Privacy provisions of the Health Insurance Portability and Accountability Act (HIPAA) are inhibiting needed research on survivor issues and blocking appropriate information sharing among providers and between providers and the patient's caregivers.
- Education about cancer, cancer treatment, and survivorship needs is inadequate. The general public, newly diagnosed patients and their caregivers, post-treatment survivors, and health care providers all have significant unmet information needs. Understanding of clinical trials also is limited among all of these groups.
- Many survivors, caregivers, and family members need, but are not receiving, psychosocial assistance and support, both during treatment and in the months and years that follow. Family caregivers increasingly are becoming medical care providers in the home, but are not receiving adequate training and ongoing support for this role.
- The risk of infertility associated with cancer treatment and opportunities for preserving reproductive capacity are not being conveyed fully to newly diagnosed cancer patients of reproductive age or to the parents of children diagnosed with cancer prior to selecting or initiating treatment. For many, access to available fertility preservation options is limited by cost.
- Existing insurance systems in the United States are a significant impediment to appropriate care for people with a cancer history. The link between employment and insurance particularly disadvantages cancer survivors, who risk losing both their employment and insurance during extensive treatment. Lower income, young adult, and near elderly survivors are particularly vulnerable to becoming uninsured. Coverage for psychosocial care and follow-up care is inadequate even under most comprehensive health plans or Medicare.

"...I found out that I could possibly do *in vitro* fertilization with a surrogate mother....Well, there is a $10,000 payment that you have to plunk down right from the beginning...I am thinking, 'I have a PPO [preferred provider organization]. There is going to be no problem.'...Well, I was denied because I was not married and I was already on a form of birth control—[a hysterectomy]....I look back and I think of so many things that I could have done to preserve my chance of biologically having a child of my own and I cry...no one told me these things."

Tamika Felder, 28, cervical cancer survivor diagnosed age 25, Maryland

"...right now my health insurance is $950 a month...it continues to go up every three months. So at the time in my life when I should be saving for retirement it is kind of hard to do when you are having to pay $1,000 a month for health insurance."

Gloria Jean Moore, 51, Hodgkin's lymphoma and breast cancer survivor diagnosed ages 27 and 50, Texas

In addition, testimony provided to the Panel highlighted important nuances of these cross-cutting issues, as well as additional issues, that are distinct to survivors diagnosed at different ages.

Survivors Diagnosed as Children

Speakers identified five issues of special importance to survivors diagnosed before age 15:

- Survivors of cancer diagnosed in childhood may need special assistance to re-enter the classroom setting successfully and may require accommodations to learning difficulties resulting from their disease or its treatment. Parents of these survivors may need help advocating for their children in the school system.
- Some survivors of childhood cancers have social development and psychosocial issues that require attention years after treatment ends. These issues may include depression, social problems due to missing typical childhood experiences, and difficulty integrating the cancer experience as a part of the individual's life.
- Many survivors of childhood cancers are not being transitioned appropriately from pediatric care to adult health care settings and receive inadequate assistance in coordinating their follow-up care. Issues include inadequate transfer of information between pediatric oncologists and primary care providers, particularly if the child received treatment away from home, and lack of understanding among primary care providers of the follow-up care needs of childhood cancer survivors.
- Caregivers and siblings of children with cancer have longer-term psychosocial needs that are not being met. Both parents and siblings are vulnerable to post-traumatic stress disorder. Support groups and services available during the treatment period are far less available post-treatment, particularly when the patient was treated away from home.
- Continued research is needed on the long-term effects of cancer treatment on survivors of pediatric cancers. Limited follow-up of pediatric patients, even those treated on clinical trials, is a major barrier to better understanding late treatment effects experienced by this population. Specialized late effects clinics may prove useful for addressing this issue, but require further development and evaluation.

"...the younger a child is when he receives radiation, the more damage he receives...[Adam] was unable to get his high school diploma because he didn't pass the math portion of the competency test. He took that test ten times from the 9th grade to the 12th grade. He missed it by five points. He passed the English portion, and he passed the computer portion...The diploma issue has been hard for him as far as finding a job...It is very frustrating as a parent to see your child struggling and to see him want to be productive and he is not being given an opportunity."

Pam Cox, mother of Adam Cox, 20, brain tumor survivor diagnosed age 3, North Carolina

"It is clear from the last 20 years that these little incremental, piecemeal things, Federal and State legislation —we're not going to have major, effective, across-the-board health insurance reform until the public really demands it..."

Barbara Hoffman, attorney and advocate, New Jersey

> “My concerns as a survivor have evolved the farther away I have gotten from treatment….During my treatment and for several years after…my primary concern was recurrence and, although I haven’t had any, I would be lying if I say that I don’t think about it all the time. [Now] I worry about secondary cancers…and problems due to my splenectomy… I am in premature menopause because of the high doses of chemotherapy I received, so I worry about osteoporosis, sexuality, cardiac problems, and yes, even wrinkles. I take hormone therapy but so little is known about young menopausal women that I can’t help but be concerned.”

Karen Dyer, 24, rhabdomyosarcoma survivor diagnosed age 15, New York

Survivors Diagnosed as Adolescents or Young Adults

In addition to concerns common to survivors of all ages, people diagnosed between the ages of 15 and 29 have other distinct needs:

- Adolescent and young adult cancer survivors—sometimes called the “orphaned cohort”—are a vastly understudied population. Because they often relocate to attend college or obtain employment, follow-up on this population has been particularly difficult.
- Diagnosis and treatment during this crucial developmental period often results in a range of psychosocial issues, including problems with depression, limited social skills, difficulty planning for the future and establishing independence, and coping with neurocognitive problems resulting from cancer treatment. Body image and fertility issues may be a significant impediment to developing intimate relationships.
- Similar to childhood cancer survivors, adolescents and young adults treated in the pediatric setting are not being transitioned effectively to care in the adult setting.
- Adolescent and young adult cancer survivors, particularly those with disabilities requiring accommodation, may find themselves at a disadvantage when competing for jobs, and may be starting adulthood burdened by significant treatment-related debt. In addition, once terminated from their parents’ health insurance policies, they are highly likely to become uninsured and lose access to follow-up care.

Survivors Diagnosed as Adults

Survivors diagnosed between the ages of 30 and 59 face three additional issues that affect their care, livelihood, and quality of life:

- Limited recommendations exist to guide the follow-up care of people with adult-onset cancers due to a lack of research evidence on post-treatment needs of this population. Lack of recommendations limits insurance reimbursement for care recommended by survivors’ physicians and presents a barrier to follow-up care.
- Cancer occurring during the prime and middle years of adulthood may seriously disrupt the survivor’s ability to carry out family, social, and work-related responsibilities, which can damage self-esteem. In particular, many survivors of this age

are responsible for caring for children and aging parents at the same time they are battling their cancer or its after-effects. Recognition of and intervention for issues related to sexuality and intimacy is a largely unmet need.

- Many survivors diagnosed in adulthood face major income losses that endanger the security of their families, particularly if a spouse also must reduce work hours to care for the patient. These losses may be temporary or permanent. Adult survivors typically are unable to obtain or increase life or disability insurance, and may have difficulty securing mortgages or loans.

Survivors Diagnosed as Older Adults

Those diagnosed at age 60 or older comprise the majority of cancer survivors. In addition to issues relevant across the life span, five key issues were identified:

- Many survivors 60 and older still need and want to work. Job loss, forced retirement due to cancer, and resulting loss of health benefits prior to Medicare eligibility are of major concern. Out-of-pocket health care costs are a significant burden for those on fixed incomes.
- Many older people with cancer also have one or more other chronic medical conditions (comorbidities). Such illnesses continue to be a barrier to clinical trials participation by older survivors and to the best standard care for many who are treated in community settings. Comorbidities may mask signs of recurrence or late effects of cancer treatment, and suspicious symptoms may be attributed both by the survivor and medical personnel to age-related conditions.
- Because older survivors rarely have been included in research, little is known about late and long-term effects in this population. Providers may be unaware of cancer screening and other follow-up care needed by these survivors, and lack of Medicare reimbursement for preventive care has hampered efforts to gather information about them.
- Many older cancer survivors lack adequate social and caregiver support. Health care providers often assume that the patient has a support system; in fact, many—particularly older women—live alone far from family members or are cared for by an elderly spouse who may have illnesses, limited mobility, or short-term memory problems. For those who no longer drive, lack of transportation limits access to medical care or support services.

"I cannot lower my premium with [my] current insurance company because of my history of cancer and I cannot change to another insurance because of the same reason. I am not yet 65 years old and I am in the middle class, middle income household. And so I am not eligible for either Medicare or Medicaid. What can we do? Who do we turn to? I survived the cancer but I cannot pay for necessary treatment post-chemo. I feel like I am being punished for surviving cancer."

Boonsee Yu, 57, colon cancer survivor diagnosed age 53, New York

"I am currently being treated as an outpatient. This has enabled me to continue working, a necessity for me because I am a single parent. I am also having to deal with other family issues—an aunt with Alzheimer's and an 83-year-old mother. Many adult survivors are part of that "sandwich generation" caring for both their own children and helping their aging parents."

Debra Thaler-DeMers, 49, oncology nurse, Hodgkin's lymphoma and breast cancer survivor diagnosed ages 25 and 45, California

"[For impotence] they have a vacuum pump and they have a prosthesis that you can insert surgically. There is a lot of different things....I was trying to do injections into the penis and I used to say to my wife, 'Now, I am going to go in the bathroom and I am going to inject myself. If you get a headache you are in big trouble.'...Even though the mechanical part of it worked, the psychological, emotional part never worked."

Emanuel Hamelburg, 63, prostate cancer survivor diagnosed ages 47 and 51, Massachusetts

"...all of the times that I went for the various examinations...I always was alone....I remember sitting one day waiting for the dye to go through my system and I am looking at everybody coming and going....Everybody had somebody and there I sat. I couldn't help it. I wept. I had nobody but I managed to make it through."

Grace Butler, 67, colorectal cancer survivor diagnosed age 63, Texas

- Intimacy and body image issues remain an important, though often unaddressed need among older cancer survivors.

The testimony received at these and previous Panel meetings provides a critical dimension to the growing body of knowledge about cancer and the needs of cancer survivors. These extraordinarily candid survivor accounts of life during and after treatment convey the qualitative experiences that place quantitative information in the very human context in which it must be evaluated. Likewise, the daily experiences of health professionals who provide care to people with cancer, their families, and their caregivers are rich reservoirs of front-line information on the poorly charted journey each diagnosed person must make to live with and beyond cancer. It is with this understanding and in this spirit that the Panel has developed this report and recommendations for legislators, policy makers, the scientific and medical communities, employers, insurers, advocates, and others whose actions can so greatly affect the quality of life of people with cancer and their loved ones.

Recommendations

Issues Affecting Survivors Across the Life Span

Treatment and Follow-up Care Information

1a. Upon discharge from cancer treatment, including treatment of recurrences, every patient should be given a record of all care received and important disease characteristics. This should include, at a minimum:

- Diagnostic tests performed and results.
- Tumor characteristics (e.g., site(s), stage and grade, hormonal status, marker information).
- Dates of treatment initiation and completion.
- Surgery, chemotherapy, radiotherapy, transplant, hormonal therapy, gene or other therapies provided, including agents used, treatment regimen, total dosage, identifying number and title of clinical trials (if any), indicators of treatment response, and toxicities experienced during treatment.
- Psychosocial, nutritional, and other supportive services provided.
- Full contact information on treating institutions and key individual providers.

1b. Upon discharge from cancer treatment, every patient should receive a follow-up care plan incorporating available evidence-based standards of care. This should include, at a minimum:

- A description of recommended cancer screening and other periodic testing and examinations, and the schedule on which they should be performed.
- Information on possible late and long-term effects of treatment and symptoms of such effects.
- Information on possible signs of recurrence and second tumors.
- Information on the possible future need for psychosocial support.
- Specific recommendations for healthy behaviors (e.g., diet, exercise, sunscreen use, virus protection, smoking cessation).
- Referrals to specific follow-up care providers, support groups, and/or the patient's primary care provider.
- A listing of cancer-related resources and information (Internet-based sources and telephone listings for major cancer support organizations).

1c. The Department of Health and Human Services (DHHS) should establish a consortium of public and private institutional and community health care providers and payors, patient advocates, and technology experts to develop a blueprint for functional, content, format, and technology standards for creating a nationwide electronic health records system.

Legal and Regulatory Protections

2. Procedures should be established within diverse patient care settings to better inform patients/survivors and their caregivers about available legal and regulatory protections and resources.

HIPAA Privacy and Insurance Portability Provisions

3a. The Institute of Medicine should be commissioned to evaluate the impact of HIPAA provisions and provide guidance to legislators on amendments needed to make this law better serve the interests of cancer survivors and others.

3b. HIPAA privacy provisions inhibiting the ability to track and collect data for research on cancer survivors should be re-evaluated.

Cancer-related Education and Information

4a. National public education efforts sponsored by coalitions of public and private cancer information and professional organizations and the media (e.g., film, television, print and broadcast news) should be undertaken to:

- Raise awareness of survivor experiences and capabilities, and of the continuing growth of the cancer survivor population. These efforts should seek to enhance understanding of the post-treatment experiences of cancer survivors of various ages and their loved ones and the need for lifelong follow-up care.
- Provide accurate information and enhance community trust about participation in clinical trials and raise awareness of the importance of trials in developing new and better cancer treatments and other cancer-related interventions.

4b. Existing online resources, including those of the National Cancer Institute (NCI), that provide information on clinical trials and facilitate patient-trial matching should be improved to help patients more easily find trials for which they may be eligible and to simplify the enrollment process.

4c. A central online information resource on scientific evidence about late and long-term effects of cancer and its treatment should be developed and maintained by a consortium of interested constituencies (NCI, American Cancer Society, American Society of Clinical Oncology, and others). The NCI Physician Data Query database may provide a model for this effort.

- Using their existing networks, cancer awareness, education, and advocacy organizations should take a major role in helping to collect and disseminate (e.g., through newsletters, lay educators, workshops, other outreach efforts) late effects information as it becomes available.
- Individual cancer survivors should be able to contribute to this database information about their own experiences with late effects.

4d. The potential role of specialized long-term follow-up clinics or departments within or operated by medical or cancer centers should be evaluated for their benefit as a central education resource for cancer survivors. Ideally, such programs should provide the most current information to survivors and their families about late and long-term effects of cancer and cancer treatment and on complementary and preventive strategies (e.g., nutrition, exercise, sunscreen use, virus protection, stress reduction) to promote wellness.

4e. Education about possible late effects of cancer treatment and survivorship needs should be part of the core curricula for health care providers in training, and a part of continuing education for primary care physicians, oncologists, and non-physician health care providers.

Psychosocial and Support Needs

5a. All survivors should be counseled about common psychosocial effects of cancer and cancer treatment and provided specific referrals to available support groups and services.

5b. A caregiver plan should be developed and reviewed with a survivor's caregiver(s) at the outset of cancer treatment. It should include, at a minimum:

- An assessment of the survivor's social and support systems.
- A description of elements of patient care for which the caregiver will be responsible. Caregivers should be provided adequate

and, as needed, ongoing hands-on training to perform these tasks.

- Telephone contacts and written information related to caregiver tasks.
- Referral to caregiver support groups or organizations either in the caregiver's local area or to national and online support services.

5c. Providers should include psychosocial services routinely as a part of comprehensive cancer treatment and follow-up care and should be knowledgeable about local resources for such care for patients/survivors, caregivers, and family members. In particular:

- The transition from active treatment to social reintegration is crucial and should receive specific attention in survivors' care.
- Primary and other health care providers should monitor caregivers, children, and siblings of survivors for signs of psychological distress both during the survivor's treatment and in the post-treatment period.

Fertility

6a. All people of reproductive age who are diagnosed with cancer should be given complete culture- and literacy-sensitive information, both verbally and in writing, about options for preserving fertility and on possible effects of treatment on pregnancy or offspring before cancer therapy is selected or initiated.

6b. Parents of young children diagnosed with cancer must be given full culture- and literacy-sensitive information, both verbally and in writing, on the possible impact on fertility of treatment options prior to selecting and initiating treatment. If the patient is too young to understand this information at the time of treatment, parents should be urged to share this information with the survivor at the earliest possible time.

6c. Further research should be conducted to determine what fertility preservation options are possible for children and young adolescent cancer patients.

6d. Fertility preservation procedures and infertility treatment services should be covered by health insurance for cancer patients/survivors whose fertility will be or has been damaged by cancer treatment.

Health Insurance

7a. The Federal Government should revive efforts to implement comprehensive health care reform.

7b. Adequate reimbursement for prosthetics must be provided and it must be recognized that:

- Many prostheses must be replaced periodically.
- Access to prostheses is an integral part of psychosocial care for cancer.

7c. Coverage should be provided routinely for psychosocial services for which there is evidence of benefit both during treatment and post-treatment as needed.

7d. Public and private insurers should provide reimbursement for risk assessments, surveillance, and other follow-up care for cancer survivors, including care provided by appropriately trained non-physician personnel.

7e. Existing follow-up care clinic models should be evaluated and compared to ascertain their impact on survivor outcomes and their cost effectiveness.

Issues of Cancer Survivors Diagnosed as Children

School Re-entry

8a. Qualified providers in the treatment setting should train and assist parents to assume their crucial roles in helping the child with cancer return to school and becoming an educator and advocate with individual teachers and the school system.

8b. Pediatric cancer centers should offer and promote teacher training as a part of their community outreach efforts to help ensure that the needs of pediatric cancer survivors returning to the classroom are met. Internet-based training modules also should be considered to extend the geographic reach of these training efforts. If possible, continuing education units (CEUs) should be provided to participating teachers.

8c. NCI and the Department of Education should explore collaborative opportunities to improve the classroom re-entry and reintegration of young people with cancer or other chronic or catastrophic illnesses (e.g., remote learning, teacher training).

Transition to Adult Care

9a. Centers that care for both children and adults with cancer should consider establishing a department or service specifically geared to provide for the needs of older children, adolescents, and young adults with cancer and to assist in their transition to adult care.

9b. As part of the process of transitioning survivors of childhood cancers into the adult care setting, information about young adult support groups, Internet sites, and other sources of information and support specific to this age group should be provided to survivors and their families. (See also Recommendations 1a and 1b.)

Psychosocial and Support Needs

10. Cancer care providers should inform families of cancer patients about supportive services, including special camps for families and siblings. (See also Recommendations 5a and 5c.)

Issues of Cancer Survivors Diagnosed as Adolescents or Young Adults

Surveillance and Research

11a. A working group comprised of representatives from public agencies and private organizations with established surveillance databases should be convened to determine what additional data collection, infrastructure, and related funding would be required to better capture treatment and survival data on adolescent and young adult cancer survivors.

11b. NCI and other cancer research sponsoring agencies should increase the priority of and funding for research on the issues of cancer survivors diagnosed as adolescents or young adults. Studies of biologic differences in cancer type and host factors, and of late effects of cancer and cancer treatment in this population should be emphasized to improve the knowledge base and inform the design of treatment, prevention, and quality of life interventions designed to benefit this population.

Psychosocial and Support Needs

12a. Family members, primary care providers, cancer specialists, and others who are close to or provide medical care to adolescent and young adult survivors should be made aware that depression, anxiety, or other psychosocial issues may affect the survivor long after treatment ends and should be instructed on how to intervene should the survivor experience such difficulties. (See also Recommendations 1b and 5a.)

12b. Adolescent and young adult survivors should be taught self-advocacy skills that may be needed to secure accommodations for learning differences resulting from cancer or its treatment. Physicians and other providers should act as advocates for survivors when necessary.

Issues of Cancer Survivors Diagnosed as Adults

Follow-up Care Recommendations

13. The American Society of Clinical Oncology, the American College of Surgeons, the American College of Radiology, and other major cancer clinician and research organizations should develop more complete recommendations to guide the post-treatment care of survivors of adult-onset cancers. These recommendations should be published and posted on a website and updated regularly to ensure that survivors, patient educators, providers, and insurers have access to them.

Issues of Cancer Survivors Diagnosed as Older Adults

Insurance

14. The Institute of Medicine or other independent body should undertake a periodic assessment of the impact of Medicare legislative changes on older cancer patients' access to care and other follow-up services.

Surveillance and Research

15. Public and privately sponsored research and surveillance on survivorship issues among people diagnosed with cancer in older adulthood should be increased significantly to address the information void on the needs of this population that will comprise an increasing percentage of people with cancer over the next several decades. (See also Recommendation 3b.)

Psychosocial and Support Needs

16. Health care providers must ascertain the strength of an older survivor's social and caregiver support system. This should be assessed at diagnosis, during treatment, and at intervals after treatment is completed. Oncology nurses, nurse practitioners, other advanced practice nurses, physician assistants, social workers, patient navigators, or other non-physician personnel may be best able to make these assessments and arrange assistance and services for survivors who lack adequate support.

17. Health care providers should not assume that older cancer survivors and their partners are uninterested in sexuality and intimacy. Survivors should be asked directly if they have concerns or are experiencing problems in this area and should receive appropriate referrals to address such issues.

Preface

The President's Cancer Panel, established by the National Cancer Act of 1971 (P.L. 92-218), is charged with identifying barriers to the optimal development and implementation of all aspects of the National Cancer Program. The Panel raises questions and explores issues chiefly, though not solely, by soliciting testimony from leaders in cancer-related medicine, academic research, industry, the advocacy community, and the public. At least annually, the Panel reports to the President its recommendations for removing identified barriers and addressing identified needs.

A recent Panel report, ***Voices of a Broken System: Real People, Real Problems***,[1] described difficulties experienced by Americans from all walks of life as they tried to access and pay for needed cancer screening, diagnostic, treatment, and supportive services. Some of the nearly 400 patients, caregivers, and health providers who testified at seven regional meetings also alluded to numerous issues that confront people after they have completed cancer treatment. This powerful testimony suggested the need to further explore survivorship concerns through a series of meetings focusing principally on the post-treatment period, with the issues of long-term survivors of particular interest.

Research to date suggests that many factors contribute to an individual's experience of cancer, its treatment, and its after-effects. One of these factors is the age at which a person is diagnosed. For this reason, the Panel took a life span approach to this meeting series, exploring at four meetings in the United States issues particularly affecting people diagnosed as children (ages 0–14 years), as adolescents or young adults (ages 15–29 years), as adults (ages 30–59 years), or as older adults (ages 60 years and older). The Panel also sought to identify issues common to survivors regardless of age or age at diagnosis.

In addition, an international meeting explored similarities and differences in the experiences of cancer survivors from a variety of European nations. The Panel invited 33 speakers from 14 countries to describe their personal experiences as cancer survivors or caregivers, and/or their work related to cancer surveillance, research, cancer treatment, or patient advocacy. In addition to learning about available services and support, the meeting explored differences within the European community and between Europe and the United States in societal attitudes and awareness concerning cancer. A key objective of the meeting was to learn about health services and survivorship activities in diverse European nations and health systems that might benefit survivors in this country. ***Living Beyond Cancer: A European Dialogue***, the Panel's report of the findings from this meeting, is provided in conjunction with this report, and also is available at: http://pcp.cancer.gov.

Each of the subsequent four meetings held in the United States consisted of invited testimony followed by an evening Town Hall at which broad input from the community was solicited. The 156 participants included survivors, caregivers, advocates, providers, insurers, Federal and State government employees, media representatives, and support organization representatives.

The recommendations contained in this report reflect the testimony provided at all five meetings that were conducted as indicated below:

May 27–28, 2003	*Living Beyond Cancer:* *A European Dialogue* Lisbon, Portugal
September 5, 2003	*Living Beyond Cancer: Survivorship Issues and Challenges Among Pediatric Cancer Survivors* Denver, Colorado
September 22, 2003	*Living Beyond Cancer: Challenges for Adolescent and Young Adult Cancer Survivors* Austin, Texas
November 4, 2003	*Living Beyond Cancer: Meeting the Challenges of Adult Cancer Survivors* Birmingham, Alabama
January 5, 2004	*Living Beyond Cancer: Meeting the Challenges of Older Adult Cancer Survivors* Philadelphia, Pennsylvania


President's
Cancer
Panel

Cancer Survivors and Survivorship—An Overview

As people emerge from the physical and emotional intensities of cancer treatment, they often find themselves in a world that is intimately familiar, yet forever changed from the one they inhabited prior to their diagnosis. Even as they triumph in having endured the rigors of treatment, virtually all also harbor some trepidation about what the future may bring. For most survivors and their loved ones, life after cancer involves finding a new equilibrium—a new balance. This report explores issues of survivors and survivorship, particularly those related to the life that lies beyond cancer treatment.

Who Is a Survivor?

Among health professionals, people with a cancer history, and the public, views differ as to when a person with cancer becomes a survivor. Many consider a person to be a survivor from the moment of diagnosis; in recent years, this view has become increasingly prevalent. Some, however, think that a person with a cancer diagnosis cannot be considered a survivor until he or she completes initial treatment. Others believe a person with cancer can be considered a survivor if he or she lives five years beyond diagnosis. Still others feel that survivorship begins at some other point after diagnosis or treatment, and some reject the term 'survivor' entirely, preferring to think of people with a cancer history as fighters, 'thrivers,' champions, patients, or simply as individuals who have had a life-threatening disease. A considerable number of people with a cancer history maintain that they will have survived cancer if they die from another cause.

The issues of living with and beyond cancer, however, begin at diagnosis and continue for the duration of a person's life, whether that life is measured in weeks, months, years, or decades. In the 1980s, a young physician diagnosed with cancer wrote about his experience.[2] He described three "seasons of survival," each marked by its own challenges and issues: *acute* survival, beginning at diagnosis and continuing through the end of treatment;

"…being a cancer survivor is at the forefront of my self awareness. It enters into the conversations that I have with myself about what I want to do, how I want to spend money, how I want to spend time, my energy, all of that. Being a cancer survivor has added another dimension to my identity. I am a cancer survivor."

Mortimer Brown, 80, colorectal cancer survivor diagnosed age 75, Florida *extended* survival that may begin at the conclusion of treatment and last until the risk of recurrence has decreased; and *permanent* survival, encompassing the duration of the survivor's life. This seminal paper is credited with being among the first public declarations that people with cancer were survivors rather than victims, and later giving credence to the idea that survivorship begins at the moment of diagnosis.

Some suggest that the weeks or months at the end of life comprise a distinct, additional phase of survival, characterized by the use of palliative care.[3] The goal in this phase is to achieve the best possible quality of life for patients and their families through pain and other symptom management, and by attending to psychological and spiritual needs.

In addition, several organizations have expanded the definition of 'survivor' to include others touched by the disease, including families, friends, and caregivers of a person with cancer. In this report, however, the term 'survivor' refers to any person who has ever had a cancer diagnosis, and the terms 'survivor' and 'patient' may be used interchangeably.

Survivors Now and in the Future—A Growing Population

Though cancer still takes more than a half million lives each year,[4] earlier detection and better treatments are enabling increasing numbers of people to live—and live longer—after a diagnosis of cancer. Whereas only three million people with a cancer history were alive in 1971, the population of survivors now approaches ten million—approximately three percent of the U.S. population.[5]

Cancer may never be vanquished entirely, but increasingly, cancer is becoming a chronic disease rather than a fatal one. Currently, the five-year relative survival rate[6] for all cancers combined is 63 percent.[7] Overall relative five-year survival for

Table 1

Period Estimates of Relative Survival Rates, By Cancer Site

	Relative Survival Rate, Percent (Standard Errors not shown)			
Cancer Site	**5 yrs**	**10 yrs**	**15 yrs**	**20 yrs**
Oral cavity and pharynx	56.7	44.2	37.5	33.0
Esophagus	14.2	7.9	7.7	5.4
Stomach	23.8	19.4	19.0	14.9
Colon	61.7	55.4	53.9	52.3
Rectum	62.6	55.2	51.8	49.2
Liver/intrahepatic bile duct	7.5	5.8	6.3	7.6
Pancreas	4.0	3.0	2.7	2.7
Larynx	68.8	56.7	45.8	37.8
Lung and bronchus	15.0	10.6	8.1	6.5
Melanoma	89.0	86.7	83.5	82.8
Breast	86.4	78.3	71.3	65.0
Cervix uteri	70.5	64.1	62.8	60.0
Corpus uteri and uterus, NOS	84.3	83.2	80.8	79.2
Ovary	55.0	49.3	49.9	49.6
Prostate	98.8	95.2	87.1	81.1
Testis	94.7	94.0	91.1	88.2
Urinary bladder	82.1	76.2	70.3	67.9
Kidney and renal pelvis	61.8	54.4	49.8	47.3
Brain and other nervous system	32.0	29.2	27.6	26.1
Thyroid	96.0	95.8	94.0	95.4
Hodgkin's lymphoma	85.1	79.8	73.8	67.1
Non-Hodgkin's lymphoma	57.8	46.3	38.3	34.3
Multiple myeloma	29.5	12.7	7.0	4.8
Leukemia	42.5	32.4	29.7	26.2

NOS = not otherwise specified

Adapted from: Brunner H, *Lancet* 2002;360:1131-1135, Table 4. Rates derived from SEER 1973-1998 database, both sexes,all racial/ethnic groups.

children with cancer is even higher, now 78 percent.[8] Survival rates for adults and children vary considerably depending on cancer type and stage at diagnosis, and survivors reaching the five year mark may be disease-free, in remission, or still undergoing treatment for their cancer. Five-year survival rates provide an indicator of progress against cancer, but are not useful for predicting individual prognosis, since they may not reflect trends toward more favorable stage at diagnosis or treatment advances in the most recent years, among other factors. Yet period estimates[9] of 5-, 10-, 15-, and 20-year relative survival (Table 1) suggest that a great number of people with a cancer diagnosis are surviving far longer than five years.[10] Recent data from the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) program indicate that nearly 1.4 million of the survivors living today were diagnosed more than 20 years ago.[11] A higher proportion of men are within five years of diagnosis, consistent with the larger number of males diagnosed annually with cancer. However, more women will live more than five years beyond diagnosis, due in part to a greater percentage of treatable cancers diagnosed among women, and women's overall survival advantage over men independent of a cancer history.[12]

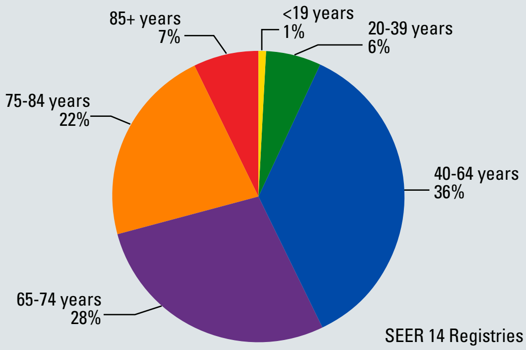
These statistics, though certainly encouraging when compared with earlier figures, also demonstrate that much remains to be done to minimize the national burden of cancer. In addition to continued research to strengthen our understanding of these diseases and develop new treatments and preventive interventions, improved access to quality care is needed across the cancer continuum. Specifically, serious survival disparities exist among diverse racial/ethnic and cultural minorities, low-income and many rural populations, and recent immigrants compared with national overall and disease-specific survival rates.[13,14] Many factors contribute to disparities—socioeconomic status; limited access to care and late diagnosis related to insurance status; geographic and transportation barriers; educational attainment and health

Figure 1

Source: U.S. Census Bureau, Current Population Reports P25-1104, 1993

Figure 2

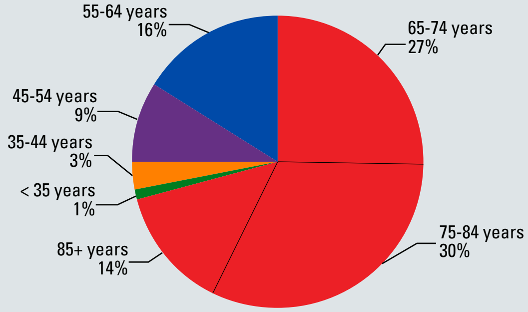
Age Distribution of Cancer Incidence, All Sites Combined, 1996–2000



SEER 14 Registries

Figure 3

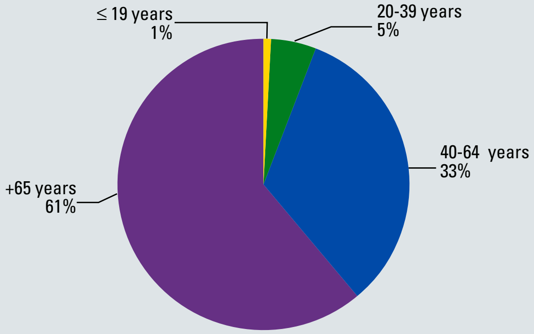
Age Distribution of Cancer Deaths, All Sites Combined, 1996–2000



NCI SEER Program Data, N=553,080

Figure 4

Estimated Percent of Persons Alive in the U.S. Diagnosed with Cancer in the Last 25 Years, By Current Age

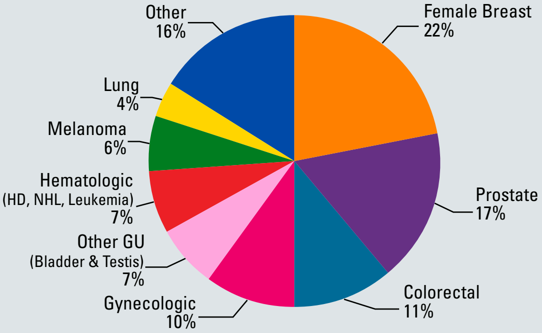


Invasive/1st Primary Cases Only, N=8.7 Million Survivors

Data Sources: November 2002 Submission. U.S. Estimated Prevalence counts were estimated by applying U.S. populations to SEER 9 Limited Duration Prevalence proportions. Populations from January 2000 were based on the average of the July 1999 and July 2000 population estimates from the U.S. Census Bureau

Figure 5

Estimated Percent of Persons Alive in the U.S. Diagnosed with Cancer, By Site



Invasive/1st Primary Cases Only, N=9.6 Million

Prevalance proportions based on the standard SEER 9 registries. Complete Prevalence estimated using the completeness index method (Capocaccia, et al. 1997; Merrill, et al. 2000). U.S. prevalence counts estimated by applying SEER prevalence proportions to the U.S. populations. No attempt was made to adjust for demographic differences between the U.S. and SEER other than age.

literacy levels; cultural and language differences; provider bias; and lifestyle, among others.[15,16,17] Disparities are particularly disturbing since research has shown that in many instances equal treatment yields equal outcome.[18]

For a number of years, overall mortality rates for all age groups and for most types of cancer have decreased slowly, while overall incidence has remained relatively stable.[19] Due to the aging of the population, this situation soon will change. Between 1946 and 1964, 75 million persons were born—the so-called "baby boom." Figure 1 (see p. 7) illustrates what has been termed the "rectangularization" of the historical age pyramid, with greater percentages of the population reaching older ages over the next few decades. These age shifts reflect life expectancy increases.

Currently, 57 percent of all cancer incidence (Figure 2) and 71 percent of all cancer deaths (Figure 3) occur in the 65 years and older age group. Figure 4 shows the age distribution of people currently living with a cancer history (cancer prevalence), while Figure 5 indicates the cancer diagnoses of these survivors.

As the population ages, and greater numbers of people reach and exceed the average age at which cancer is diagnosed (approximately 70 years of age), cancer incidence will begin to rise steadily and may double by 2050.[20] This trend is important not only as a human issue, but for the profound implications it holds for the U.S. health care system. Greater numbers of new cancer cases, combined with increasing cancer survival, will produce a rapidly expanding population that will require ongoing surveillance and specialized care over many years. Several trends raise serious concerns about the ability of the health care system to meet this challenge. Among these are the worsening nursing shortage, lack of adequate health insurance coverage, disincentives to entering a career in medicine (e.g., the high cost of training, static or shrinking physician incomes due to reimbursement policies, providers' professional quality of life issues), and the inability of many community institutional providers to acquire new treatment technologies and other infrastructure requiring capital investment.[21]

Efforts to Address Survivorship Issues Have Increased

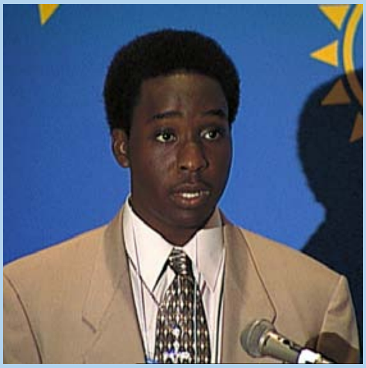
As the number of cancer survivors has grown, so has their involvement in advocating for their needs. Their individual and collective voices are being heard, and heightened awareness that survivors have ongoing health issues can be seen at all levels of government and the community.

At the Federal level, NCI has designated survivorship as one of several priority areas for research progress, and understanding and addressing survivorship concerns are integral to the Institute's stated goal to eliminate suffering and death due to cancer by 2015.[22] Though recognizing that cancer is unlikely to be eradicated by that date, the goal does reflect the ability of medicine to now alleviate suffering from cancer and help far more patients live with cancer as a chronic disease. NCI established its Office of Cancer Survivorship (OCS) in 1996 in direct response to the advocacy community's insistence that it was not enough for research to enable people to outlive their diagnosis, and that the role of research should extend to understanding the quality of the lives to which these survivors return. OCS's mandate is to improve the quality of life and length of survival for people diagnosed with cancer, and to improve the health-related quality of life for family members of survivors. The OCS research portfolio, which focuses on post-treatment outcomes, has nearly quadrupled in eight years, and a recent call for grant applications focused on longer-term survivors (those five or more years beyond diagnosis) yielded 125 applications. In addition, NCI's Director's Consumer Liaison Group (DCLG) and Consumer Advocates in Research and Related Activities (CARRA) program were established to promote ongoing involvement of and input from the survivor community.

Other National Institutes of Health (NIH) components also are involved in survivorship research. For example, NCI and the National Institute on Aging (NIA) have partnered to accelerate the pace of research on issues of cancer and various aspects of the aging process. Through this collaboration, as well as in efforts supported solely by NIA, numerous studies have been conducted or sponsored on diverse prevention and treatment issues, addressing cancer in the presence of multiple comorbidities (i.e., concomitant health conditions) and/or functional limitations, caregiver burden, and other areas. Other Federal research efforts and programs include activities related to survivorship. The Centers for Disease Control and Prevention (CDC), in addition to its other public health and research programs, partnered with the Lance Armstrong Foundation to develop a national action plan for advancing public health strategies related to survivorship. Other Federal activities include the Department of Defense (DoD) research and health care programs, and the health services and quality of care research of the Agency for Healthcare Research and Quality (AHRQ).

State level cancer control plans are at varying stages of development and implementation. Most of these plans focus principally on prevention and early detection, but some go beyond surveillance to address certain post-treatment survivorship concerns. In addition, several consortia of public, industry, and non-profit organizations have made recommendations for improving health system performance in survivorship-related areas such as cancer screening, pain management, and other quality of care issues.

Cancer-related advocacy has burgeoned in the past two decades. Numerous non-profit organizations have been established, some of which have developed into national voices for cancer advocacy in general or for constituencies concerned about specific types of cancer or patient groups. An ever-growing number of grassroots information, support, and advocacy groups are being formed across the country. Their members are articulate in expressing their needs and increasingly sophisticated about cancer-related science and the legislative process. A directory of many of these organizations can be found at the NCI Office of Liaison Activities website, http://la.cancer.gov/links.html.



"I love giving back and helping kids who might have similar emotional or physical problems to get them through their difficult times…I would say survivorship is about having hope and giving hope to others."

Malcolm Brewster, 16, brain tumor survivor diagnosed age 9, Maryland

"I owned a company, a manufacturing company, and I think I was a pretty good father just the same. I have five kids and eight grandchildren. I think I did a pretty good job, but looking back now I realize that all I was trying to do actually was earn enough money to get them all to go to college and it really didn't leave much time for other things. And one thing that cancer did for me is it put me into what I call a state of mindfulness…"

Emanuel Hamelburg, 63, prostate cancer survivor diagnosed ages 47 and 51, Massachusetts

What Post-treatment Issues May Cancer Survivors Face?

Contrary to what some may believe, the aftermath of cancer is not categorically negative. Many survivors report a new sense of personal power, a new spirituality, revised priorities in life that put relationships above career or material pursuits, and a greater sense of the preciousness of life. Many volunteer as support group leaders or peer counselors, cancer educators, and advocates, driven by a desire to help others with cancer travel a less rocky road and to "give back" to the community in gratitude for their own survival. For some, working to improve the lives of others with cancer has become a new career.

These important and usually unexpected gains notwithstanding, issues faced by survivors and their families are myriad. They may be categorized as follows:

Physiological Issues

Some survivors experience skin, hair, and other changes during and after treatment, though these usually are temporary. Individuals may face rehabilitative challenges related to amputations or ostomies. They may need to adapt to other physical changes from cancer or its treatment, such as changes in sensory, sexual, or reproductive function; chronic pain; chronic fatigue; compromised function of bodily organs; and neurocognitive dysfunctions. In addition, survivors may have other disfigurements or alterations in appearance (e.g., radiation tattoos, visible scars) that identify the person as a cancer patient and that may endure after treatment is completed. People who have been treated for cancer must live with the possibility of recurrence and many are at increased risk of a second malignancy. Survivors also have the challenge of securing adequate follow-up care and working with the health professionals providing that care.

Psychosocial Issues

These issues may include psychological adjustment to physical compromise; anxiety about and fear of recurrence or second cancers; reintegrating back into family, educational, work, and social environments; changes in social support and family roles; changed values; lingering anger, depression, or feelings of isolation; and continuing needs to communicate about the cancer experience (with family members, friends, coworkers, health professionals). Some survivors suffer poor self-esteem and body image disturbances. These difficulties may complicate challenges in establishing or re-establishing intimate relationships and in gaining or regaining their independence and self-sufficiency. Spirituality issues, which may vary significantly among different cultural and ethnic groups, may become more important in the survivor's life. These may include anger at God, loss of faith, finding faith, fatalism, and the notion of cancer as punishment. Survivors also must learn to live with the uncertainty that comes with cancer, and cope with their fear of death. In some cases, survivors are faced with accepting major alterations in personal, educational, career, or social goals.

Three out of every four American families will have at least one family member diagnosed with cancer.[23] Family members may have issues with which they struggle even after a loved one's treatment is over, such as ongoing family role changes, taking care of their own needs, maintaining open communication with the survivor, and fears that their own cancer risk may be higher than they had presumed.

Employment Issues

Some survivors still face the stigma of cancer in the workplace. They may be passed over for promotions for which they are qualified, be given reduced responsibilities or demoted, or may even lose their jobs. Survivors may have difficulty securing reasonable accommodations in their work schedule or responsibilities during or following treatment. Coworkers may believe the cancer survivor no longer can be counted on to handle heavy workloads. In addition, a cancer history may pose a barrier to being hired. Though some legal protections exist, workplace discrimination often is difficult to prove. Many survivors stay in

"I am a prostate cancer survivor of seven years. I consider myself an educator, a volunteer….This is a mission for me."

Jim West, 67, prostate cancer survivor diagnosed age 60, Florida

"…'survivorship' is an interesting word. I tend to say I am living with it because on melanoma there [are] no statistics at Stage 4 …that, you know, you go five years, well, hey, it is behind you now. That is not the case…the probability of it recurring can hang like a heavy smoke in your life…[but] I am ready to go whenever God calls me because I don't believe any of us leave one second before He calls us home, and I am very much at peace with that."

Tom Trotter, 53, melanoma survivor diagnosed age 40, California

“I don’t want to tell everyone I am a cancer survivor all the time because, for whatever reasons, they might put on me what their thoughts of that are, and you do have to think of discrimination in the back of your mind with work…because you don’t want to get passed over for promotion.”

Michael DiLorenzo, 32, non-Hodgkin’s lymphoma survivor diagnosed age 6, Pennsylvania

“…the hospital…continued to bill me for four years after I finished chemotherapy because they wanted more money over and above the fees they accepted from CHAMPUS [military health insurance] even though they agreed to them and…the insurance carrier…gladly accepted my $550 monthly premium but would not pay for the prosthetic breast I wanted because it exceeded the covered amount by $70.”

Susan Shinagawa, 46, breast cancer survivor diagnosed ages 34, 40, and 44, California

unsatisfactory or restrictive jobs to avoid losing insurance benefits (“job lock”), although legislation[24] has provided protection to some employees in this regard. Similarly, some survivors may stay in unhappy marriages to avoid losing insurance benefits they receive through a spouse’s employer.

Insurance Issues

In some cases, insurers do not pay claims as required under the policy. Insurance companies and managed care organizations may not keep pace with treatment advances, refusing to pay for treatment they deem experimental, although most insurers now pay for the usual patient care costs associated with participation in reputable clinical trials. Survivors who must pay the full premium to retain employer-sponsored coverage if they must leave their jobs and those who seek individual policies often find that even basic health coverage is unaffordable. Survivors may find it impossible to obtain life or disability insurance following a cancer diagnosis. Some cancer survivors, particularly those whose assets or income preclude Medicaid eligibility, cannot afford private insurance, or are too young for Medicare simply have no insurance at all and little or no access to care outside of the hospital emergency room.

Financial Issues

Many cancer survivors, even those with insurance, leave cancer treatment with heavy debts that may be made more burdensome if the individual’s (and/or caregiver’s) earning capacity has been or will be reduced. For those without insurance or resources, a cancer diagnosis can be financially devastating. As a result, some may defer needed follow-up care because of expense, or in the event of a recurrence, may make treatment decisions based on cost. Financial concerns may cause survivors to return to work too soon, and to work more hours or perform work tasks not advisable due to their health. Survivors have found they are unable to secure mortgage or other loans because of their cancer history, and both their own and family members’ career and educational goals may be compromised by financial burdens related to the cancer.

Legal Issues

Some of the issues above, such as employment discrimination, dealings with insurers, or breaches of patient information confidentiality, may give rise to legal issues. Many survivors are not aware of their legal rights, or need assistance in locating affordable, appropriate legal services.

As this overview illustrates, survivorship issues are many and complex, typically occurring in interrelated clusters that shift and change over the journey of life with and beyond cancer. Some of these issues are common among survivors regardless of age at diagnosis or years of survivorship, while others tend to be specific to those diagnosed at younger or older ages. It should be noted that no firm consensus exists in the medical or scientific communities as to cut-points for defining various age groups. For this inquiry into survivorship issues, the Panel used the following age range definitions:

Pediatric	0–14 years
Adolescent and Young Adult	15–29 years
Adult	30–59 years
Older Adult	60 years and older

The following sections describe key survivorship issues raised by the survivors, caregivers, providers, insurers, advocates, and others who provided testimony to the Panel, as well as information gathered prior and subsequent to the Panel's meetings.

"[My husband] decided to move on. I had three young children depending on me. There was no room for me to be sick but I didn't have a choice….The 'repo' man came to take our car. My son would hide it in the woods so I could have transportation. [My kids] did odd jobs so that I could have the gas money to go back and forth [to treatment]….I became so depressed until I just didn't want to live anymore…[my kids said,] 'You can't give up. You have come so far…Your doctors say they are going to help you. Let us help you.'…I am a cancer survivor because of the people reaching out to me [who] gave me some hope that I am somebody in God's eyesight. And that is what I am trying to do now…reaching out trying to help those that are in need…to let them know that someone out there cares for them, too."

Barbara Young, 50, breast and stomach cancer survivor diagnosed ages 34, 41, and 44, Mississippi

Issues Affecting Survivors Across the Life Span

Some survivorship issues are shared by survivors and their families regardless of the patient's age at diagnosis. These issues or problems may stem from the design and infrastructure of the health care system, provider issues, access to care (including availability, financial access, and continuity issues), information and education deficits, employment and insurance availability concerns, insurance claims and reimbursement issues, caregiver needs, and cultural differences. The testimony provided to the Panel emphasized seven cross-cutting issues of particular importance.

Many cancer survivors are leaving treatment without adequate documentation of care received and a written description of recommended follow-up care and available resources.

Treatment Summaries

To provide the most appropriate lifelong follow-up care to cancer survivors, health care providers must know what treatments and other care the survivor has received. Yet many patients are unable to provide this information, and information transfer between providers, particularly when treatment occurred many years ago, is often incomplete or not possible. Long-term survivors of pediatric- or adolescent-onset cancers are most likely to be affected by this problem. It is estimated that as many as one-fourth of pediatric cancer survivors may have incomplete knowledge of the treatments they received.[25] They may not have been old enough at diagnosis to understand details of their treatment or were not given this information by parents or other caregivers, who themselves may not have understood[26] or recorded important treatment information. Similarly, adult survivors of all ages may not remember or have recorded the details of all treatment or other care they received, or may not have wanted to know these details during treatment.

Numerous survivors and caregivers who testified underscored the need for a concise but detailed documentation of care received that they could share with physicians and others who provide the survivor's care over time. They emphasized that a survivor's full medical file can be quite thick and is unlikely to be read in detail by time-pressured physicians.

The Institute of Medicine (IOM)[27] has noted the need for such a treatment summary for pediatric cancer patients, but documentation of this information is equally important for survivors of all ages. In the near term, such a portable treatment record may need to be provided in the most commonly used electronic formats as well as in print, particularly for survivors in rural and frontier areas where computer resources may be scarce. In response to the IOM recommendation, members of the federally-supported Children's Oncology Group (COG) have developed a prototype cancer treatment summary that may provide a model for a similar summary for adults. The Lance Armstrong Foundation also has been working to develop templates to help cancer survivors collect their treatment information. Partnership with oncology and advanced practice nurses may prove essential to the success of these efforts, since these nurses likely will be responsible for completing the forms.

“…any time I have a new doctor they require that you fill out all your medical history and I tell them, ‘Do you have a CD-ROM?’ because…that’s how many files that I have for my medical history.”

Eric Rodriguez, 26, brain tumor survivor diagnosed age 14, Massachusetts

“I think survivors are asking for this now. They don’t know how to be well. They don’t know what exercise is healthy for them. Depending on whether we’ve had cardiotoxic drugs, we’ve had drugs that affect our lungs or, you know, you have amputations or whatever, what is healthy exercise for an individual? What is healthy nutrition for each one of us? What kind of coping skills would help us get by better?”

Susan Leigh, 56, Hodgkin’s lymphoma, breast, and bladder cancer survivor diagnosed ages 24, 43, and 48, Arizona

Follow-up Care Plans

In addition to lacking a record of the care they received, many survivors leave treatment without adequate information—or any information—about the follow-up care they should receive to monitor for recurrences or second malignancies, identify and address late effects of treatment, obtain referrals for needed psychosocial or supportive services, or obtain new information about their disease, treatment effects, and maintaining a healthy lifestyle (e.g., smoking, sun exposure, diet, exercise). The need for such a follow-up plan was described by both survivors and providers as an invaluable tool that would contribute to better quality of care and quality of life.

Electronic Health Record (EHR)

For more than a decade, efforts have been underway to encourage institutional and community practice health care providers to move from paper-based health record systems to electronic health record systems (EHRs).[28] In other major industries (e.g., airline, manufacturing, financial) the evidence is indisputable that widespread incorporation of electronic technologies to capture, access, and manage information and processes has led to efficiency improvements and operating cost reductions.

These same technologies, when applied to health record management and incorporated into health care systems, have enormous potential to ameliorate some of the treatment information capture and transfer problems now experienced by survivors, and to improve efficiency, quality of care, and patient safety. However, the transition to EHRs has been slower than anticipated,[29] though efforts continue to stimulate this transition.[30,31,32] A barrier to more rapid implementation has been the lack of standards for both the functions of an EHR system or the required software, but guidance in these areas recently has been provided as part of a larger patient safety study being conducted by the IOM.[33] Protecting the privacy of patient information has been another major concern.

Of the relatively few EHR systems that have been implemented, most have been limited to single hospital systems or insurers. Some of these have been large systems (e.g., Veterans Affairs’ VistA system), however, and patients who receive all of their care within such systems should therefore be spared some of the data capture and retrieval problems experienced by many cancer survivors and other patients.

A family physician testified on the positive impact an EHR could have on the continuity of follow-up care for cancer survivors rendered by primary care providers. He suggested that an electronic record should use a standard technology and be equipped with "just in time" education and decision-making assistance that would prompt the physician to ensure proper investigation of potential cancer-related health problems. The system also should link to relevant information resources and current treatment or surveillance guidelines. The speaker further recommended that a standardized EHR should be developed by a summit of experts and through public/private partnerships. The Department of Health and Human Services (DHHS) is moving to develop a standard similar to the Veterans Affairs' EHR that could be implemented in all Federal health programs, and has suggested that the agency might pay providers to implement the system, once developed.[34] It does not appear, however, that current efforts include broad representation of constitutent groups as suggested by the speaker.

The rapid pace of change in consumer information technology must be recognized in any efforts to develop a broadly implemented, patient- and provider-friendly, and flexible EHR. For example, current trends suggest that "flash memory," the data storage chips used in personal data/digital assistants (PDAs), digital cameras, and music players, will soon dominate as the media of choice for portable data and image storage, supplanting compact discs (CDs) and digital video discs (DVDs).[35] Moreover, the broad dissemination of information technologies tends to be quite uneven. Previous testimony provided to the Panel[36,37] demonstrated that providers in many parts of the country have at their disposal only limited and obsolete computer equipment, and are unlikely to have access to sophisticated systems or hand-held devices in the near future without funding support. Therefore, the affordability, availability, and longevity of any technology standard selected for EHRs will be important considerations.

Recommendations:

1a. Upon discharge from cancer treatment, including treatment of recurrences, every patient should be given a record of all care received and important disease characteristics. This should include, at a minimum:

- Diagnostic tests performed and results.
- Tumor characteristics (e.g., site(s), stage and grade, hormonal status, marker information).

"There is also an inefficient and sub-optimized patient data collection system and storage, where every doc holds on to their own records about the patient, and the patient holds on to nothing. And yet every doc has to keep in sync with all the other docs sharing the responsibility for the care of that patient."

Richard Migliori, physician and administrator, United Health Resources, Minnesota

"I was in the Air Force. And whatever people may think about the VA medical system generally,…I think I am an example of one of the things that they did right, because they had sort of an integrated system whereby everything that was being done for me would come up on the screen every time that a specialist would see me, the oncologist, my primary care doctor, and all of the other people that had some input into the final operation that took place."

Dorothy Saunders, kidney cancer survivor, Pennsylvania

“The EHR is not a panacea, but as a family physician, I am being asked to remain current in a lot of disease entities. I am being asked to remain current in post-treatment concerns, surveillance, and prevention guidelines. As a matter of fact, there are over 1,500 guidelines that I may have to interface with in a day…”

Warren Jones, family physician, Mississippi

“…cancer affects more than just a body. It affects a whole person, and it affects, therefore, our right to earn a living, our right to have a career, and our right to be financially independent.”

Barbara Hoffman, attorney and advocate, New Jersey

- Dates of treatment initiation and completion.
- Surgery, chemotherapy, radiotherapy, transplant, hormonal therapy, gene or other therapies provided, including agents used, treatment regimen, total dosage, identifying number and title of clinical trials (if any), indicators of treatment response, and toxicities experienced during treatment.
- Psychosocial, nutritional, and other supportive services provided.
- Full contact information on treating institutions and key individual providers.

1b. Upon discharge from cancer treatment, every patient should receive a follow-up care plan incorporating available evidence-based standards of care. This should include, at a minimum:

- A description of recommended cancer screening and other periodic testing and examinations, and the schedule on which they should be performed.
- Information on possible late and long-term effects of treatment and symptoms of such effects.
- Information on possible signs of recurrence and second tumors.
- Information on the possible future need for psychosocial support.
- Specific recommendations for healthy behaviors (e.g., diet, exercise, sunscreen use, virus protection, smoking cessation).
- Referrals to specific follow-up care providers, support groups, and/or the patient’s primary care provider.
- A listing of cancer-related resources and information (Internet-based sources and telephone listings for major cancer support organizations).

1c. The Department of Health and Human Services (DHHS) should establish a consortium of public and private institutional and community health care providers and payors, patient advocates, and technology experts to develop a blueprint for functional, content, format, and technology standards for creating a nationwide electronic health records system.

Cancer patients and their families need better information about the legal and regulatory protections available to them as cancer survivors.

The extent of employment discrimination against people with a cancer history has been difficult to quantify and has received little research attention. A 1991 study suggests that 25 percent of survivors experience some form of employment discrimination.[38] The testimony provided to the Panel indicates that some survivors still battle the stigma of cancer in the workplace, which may cause them to be passed over for promotion, demoted, given undesirable transfers, or fired. A cancer history can be a barrier to being hired,[39] and survivors are more likely to lose their jobs than non-survivors. Employers may have concerns about the survivor's productivity and potential absenteeism. Coworkers may doubt that the survivor will be able to handle his or her workload and that these responsibilities will then fall on other workers.[40]

Employment problems can threaten the survivor's ability to retain health insurance, result in the loss of income needed to pay for treatment and related costs, and cause a loss of self-esteem. Despite some legal protections, many survivors still stay in restrictive or otherwise unsatisfactory jobs for fear of losing their employer-sponsored health insurance. For some, disability and life insurance benefits also are at risk.

Over the past 30 years, laws have been enacted that provide limited employment and insurance protection for some workers or family members of workers with disabilities or serious illnesses. However, testimony provided to the Panel suggests that many survivors and their family members who may be protected under these laws may be unaware of the protections available to them. Briefly, the Federal laws of greatest importance for protecting survivors' employment rights are:

- **Americans with Disabilities Act of 1990 (ADA), P.L. 101-336.** Survivors who work for companies with 15 or more employees have some legal protections under the ADA that prohibit employers from treating a cancer survivor (or the family member caring for a survivor) differently from other employees. The ADA also requires employers to make reasonable accommodations to the survivor's work schedule, work environment, or duties, if needed.
- **Family Medical Leave Act of 1993 (FMLA), P.L. 103-3.** With passage of the FMLA, patients and individuals who care for a family member with cancer or another serious illness gained some long-needed job protections. Employers with at

"I have been turned down for a promotion for a job that I know I was more than qualified for…the reason was that 'you have been out of work too many days,' which was the year before when I was going through treatment. It didn't matter that I was covered under FMLA and was out due to surgery and chemotherapy. [But] that was not even a battle I wanted to fight at that time."

Tracy Cook-Brewton, 33, breast cancer survivor diagnosed age 27, North Carolina

"I believe it is important that the late-effects clinic be separate from the general pediatric oncology clinic, as its focus should be on the side effects of treatment instead of cancer itself. As more children survive cancer, the medical community has an obligation to follow our children through the months and years following the initial diagnosis and treatment."

Marilyn Eichner, mother of Danielle Eichner, 18, leukemia survivor diagnosed age 11, Maryland least 50 employees are required to provide up to 12 weeks of unpaid medical leave to care for a spouse, child, or oneself with a serious medical condition. The leave need not be taken all at once. The person on leave is still entitled to health benefits, and must be allowed to return to his or her job or an equivalent position.

- **Federal Rehabilitation Act of 1973, P.L. 93-112 (amended 1998).** This legislation bans certain public and private employers from discriminating on the basis of disability. Specifically, the legislation covers some employees not covered by the ADA, including employees of the executive branch of the Federal Government, employees of employers who receive Federal contracts and have fewer than 15 workers, and employees of employers who receive Federal financial assistance and have fewer than 15 workers.

According to a legal expert who testified on cancer survivors' employment, insurance, and financial issues, every State has a law that prohibits disability-based discrimination, and most apply to cancer-based discrimination. In some cases, State employment and insurance laws may provide additional or stronger protections for survivors than the provisions of Federal laws because they cover all employers, even those with only one or two workers. Such laws provide another safety net for survivors to help them keep the jobs they have, or to avoid discrimination when they are seeking a different job.

The same speaker indicated that far less progress has been made in securing survivors' rights to insurance than in safeguarding employment rights. Federal laws that affect insurance rights include:

- **Employee Retirement Income Security Act of 1974 (ERISA), P.L. 93-406.** ERISA sets minimum standards for most voluntarily established pension and health plans in private industry and is designed to provide protection for individuals in these plans. Health plans established or maintained by governmental entities or churches are not covered by ERISA. Among the plans subject to ERISA are large employer "self-insured" plans (i.e., health plans financed by employers who decide what will or will not be covered). ERISA stipulates, among many other provisions, that a person cannot be fired from his or her job solely because the employer thinks the individual's health care will cost too much and cause health insurance premiums to rise.
- **Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA), P.L. 99-272.** COBRA is the legislation that

"…sometimes the protection of privacy can be overreaching, and in fact may inhibit our ability to share information from one party to another on behalf of the patient's best outcome."

Michael Kanter, physician and administrator, Kaiser Permanente, California

"…the privacy regulations…are making it very difficult to care for patients as part of a family unit. Currently, when a family member calls the nursing station to see how their relative is doing, I cannot even confirm that their relative is a patient on the unit. This is affecting care."

Debra Thaler-DeMers, 49, oncology nurse, Hodgkin's lymphoma and breast cancer survivor diagnosed ages 25 and 45, California

enables a worker at a company of more than 20 employees who must leave his or her job, even for medical reasons, to continue participation in the employer's group health insurance plan. The employee must, however, pay the full monthly premium plus an administrative fee. For many, the cost of insurance under COBRA is unaffordable, particularly if the person is not working, or is working part-time. It usually is in an individual's interest to try to retain coverage if at all possible, since employer-sponsored group health plans typically have more robust benefits at a lower cost than an individual policy.

- **Health Insurance Portability and Accountability Act of 1996 (HIPAA), P.L. 104-191.** Under HIPAA's insurance portability provisions, employees must be allowed to join a group health plan without an exclusion or waiting period for coverage of pre-existing conditions as long as they have had continuous qualifying ("creditable") coverage without a break of longer than 63 days. Although HIPAA provides this protection for many employees, it does not guarantee that premiums will be affordable and does not provide coverage for the uninsured.

These laws affect survivors who are insured through employer-sponsored health plans. Most older survivors receive their health coverage through Medicare. It is unclear how recent changes in the Medicare legislation will affect coverage for cancer survivors over the next five to ten years. There are early indications that attempts to contain Medicare costs could restrict patient access to newer, sometimes experimental, anti-cancer agents that often are more expensive than older drugs but may represent a patient's best or only hope.[41] Some low-income patients are covered by Medicaid, under which coverage varies from state to state.

Though neither patients nor family members may be able to use information about employment and insurance protections immediately due to the stress of the diagnosis and the need to make treatment decisions, this information should be made available as early as possible. Many patients and caregivers will need this information to avoid insurance or job loss, and to secure needed job accommodations during the treatment period.

Recommendation

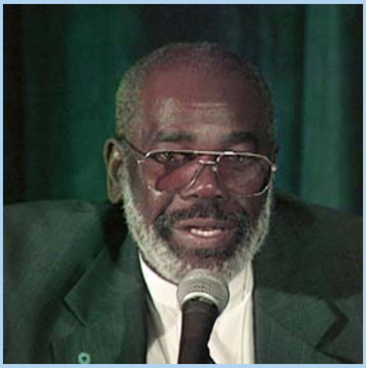
2. Procedures should be established within diverse patient care settings to better inform patients/survivors and their caregivers about available legal and regulatory protections and resources.

"...she didn't have any family so her friends were her support and her caregivers, but now with HIPAA...there is not an opportunity for those people to get information about that person's diagnosis...to get survivorship information...to get that person resources. The thing is that [survivors] don't always have the ability and the mental wherewithal to get it for themselves."

Anastasia Rodriguez, caregiver and friend, Alabama

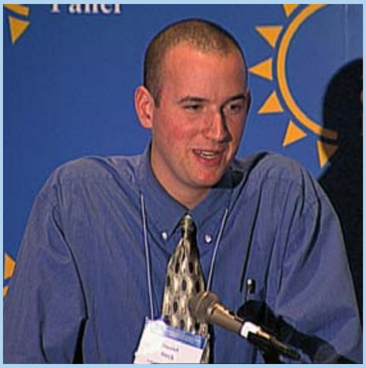
"Only 45.5 percent of Asian Pacific Island adult women in [the] U.S. have had a mammogram or clinical breast exam within the last two years. All this has to do with culture and beliefs. They are told that cancer is contagious, cancer is punishment, family comes first, hospital is for dying people. We need to reach out to these people and educate them about surviving cancer."

Boonsee Yu, 57, colorectal cancer survivor diagnosed age 54, New York



“Some of the literature [is]…above the reading ability of people in my community. I am now using four cassette tapes and two cassette recorders with a recording that I had done of one of my meetings and I give this to an individual and say, ‘Listen to it. If you have a question, give me a call.’ I have been doing this for about two months. I have had five calls…. Of those five, one individual has got tested and is afflicted with prostate cancer.”

Jim West, 67, prostate cancer survivor diagnosed age 60, Florida



“I do see my oncologist, but they have no information, and I have given them no information on the physical ailments that I am suffering from now that are a result, it is fair to say, of the bone marrow transplant and the leukemia.”

Daniel Sieck, 23, leukemia survivor diagnosed ages 11 and 15, Maryland

HIPAA medical privacy provisions are inhibiting research on survivors and blocking appropriate patient information sharing among providers, and between providers and the patient’s caregivers.

In addition to its provisions concerning the portability of health insurance, HIPAA also includes provisions intended to protect the privacy of patient information. These provisions, which took effect fully in April 2003, allow health care providers to share patient records for the purposes of treatment and other “health care operations” without obtaining explicit consent from patients. Some believe that the provisions, as written, allow inappropriately broad sharing of information by health plans, billing companies, drug companies, consultants, and lawyers for medical providers.

Patients are required to sign forms at providers’ offices acknowledging that they have been informed that the HIPAA privacy provisions are in force, but the forms may not indicate clearly that information can be shared without their specific consent, or with whom. Providers must, however, obtain consent from patients before they can disclose medical records in “nonroutine” cases. According to speakers at the Panel meetings, the privacy provisions appear to be having a number of unintended effects. For example, HIPAA provisions may inhibit research on survivors by limiting the ability of investigators to follow patients to ascertain late and long-term effects of treatment. Speakers stated that the provisions pose a barrier to evaluations of health care effectiveness and quality, and of the cost-effectiveness of preventive, treatment, and supportive interventions. In addition, providers attending the meeting maintained that the provisions hobble efforts of the medical and research communities to inform survivors of new information about treatment effects or changes in recommended follow-up or other interventions of potential benefit. Further, under the HIPAA provisions, providers may not discuss the medical situation or care of the patient/survivor with family members or caregivers unless specific permission has been granted. Many patients and families are unaware of this, and may not find out until they are unable to obtain information needed to assist in the survivor’s care. Current education about HIPAA does not adequately explain the risks and benefits of its privacy provisions and their implications for cancer survivors’ ongoing care.

Recommendations:

3a. The Institute of Medicine should be commissioned to evaluate the impact of HIPAA provisions and provide guidance to legislators on amendments needed to make this law better serve the interests of cancer survivors and others.

3b. HIPAA privacy provisions inhibiting the ability to track and collect research information on cancer survivors should be re-evaluated.

Education about cancer, its treatment, and survivorship needs is inadequate.

Throughout this meeting series, survivors, caregivers, providers, advocates, and others remarked that education about cancer in America is almost uniformly inadequate. Clearly, different audiences have different information needs, but education for the public, newly diagnosed patients and their caregivers, post-treatment survivors, and health care providers needs strengthening. In addition, improved information about clinical trials is needed to correct misconceptions about trials and encourage participation.

Public Education

A principal goal of public education about cancer is to dispel the myth that cancer is an inevitably disabling or fatal disease.[42] Speaker testimony indicated that public understanding of cancer and cancer survivors—while certainly improved due to media attention, the willingness of public figures to speak about their own cancer, and greater openness about cancer generally—still is limited by misconceptions and continuing myths that may lead to stigmatization of people with cancer. The prevalence of such misconceptions varies considerably among population subgroups, and tailored education is needed to reach people with diverse cultures, native languages, and levels of educational attainment.

It was suggested that cancer awareness and prevention education should start with schoolchildren, to dispel myths and fears concerning the disease, to encourage healthy lifestyles that may prevent future cancer, and to increase understanding and sensitivity to the experiences and needs of people with cancer. For example, a survivor who testified suggested that cancer could

"I know of no hospital or cancer program in the United States that has a public awareness program that tells the well elderly that they are at risk, that goes to them and says, 'Do you realize that 60 percent of all cancer occurs in your age group?' And when I say tailoring that kind of an approach, it also means looking at problems with hearing, with vision, looking at font size…and importantly, going to the community rather than expecting the elder person and their family to come to us."

Debi Boyle, oncology nurse, Arizona

be a subject for school essay contests (i.e., writing about a family member or friend with cancer); such an activity could be expected to cause students to seek factual information about cancer and perhaps become familiar with one or more cancer information or support organizations.

Speakers noted that media programming about cancer tends to focus on diagnosis and treatment, while longer-term issues of survivors seldom are addressed. Story lines, news, and documentary programming that focuses on survivorship issues could do much to show that people do survive and thrive productively after cancer, and to improve public understanding of survivor issues and experiences. Employers, it was further noted, would be an important segment of this audience.

Newly Diagnosed Patients and Caregivers

People newly diagnosed with cancer and the people who will care for them have a great need for understandable and accurate information about the disease and treatment options. Speakers maintained, and some research suggests,[43,44] that while patients who have a positive attitude and are active participants in their care may not live longer than those who are more negative or passive patients, their quality of life may be comparatively better.

Numerous speakers reported that when told their diagnosis, they comprehended little or nothing after hearing the words, "You have cancer." This highly common reaction points to the need to educate providers on how best to give patients important practical information early in the care process. An oncology nurse stated her belief that health professionals must be prepared to repeat important information frequently until the survivor and family are able absorb it. Other speakers mentioned the value of being matched from the outset with a navigator, social worker, cancer guide, or volunteer who has experienced a similar diagnosis to help collect and explain information and assist the patient and family in coping with the diagnosis and undertaking initial steps in the care process.

Information cited as critical for newly diagnosed patients and caregivers included:

- Potential long-term and late effects, including possible fertility damage (see Recommendations 6a-d), of various treatment options. This information should be provided before treatment is selected and initiated.
- Awareness that cancer is a family disease.

"…when you go to that oncologist's office, why is that not a warehouse of information in there? There should be all kinds of things physically in that office. All these printed materials we talk about—I see a pamphlet [here at this meeting] about things you should ask your doctor. Why isn't that in the oncologist's office?"

Stacy Gordon, breast cancer survivor diagnosed age 35, Alabama

"…if you are a 30-year-old with breast cancer, you are going to get your information on the Internet. You are going to know about clinical trials in an hour, whereas if you are an 84-year-old with breast cancer, you are not going to have access to that information."

Barbara Hoffman, attorney and advocate, New Jersey

- The legitimacy and appropriateness of psychosocial care for people with cancer and their families or caregivers.
- Sources of relevant cancer information, support groups, and organizations that provide supportive services.
- Information on available legal and regulatory protections related to health insurance, employment, and asset protection.

In providing this information and assistance, speakers noted the need to accommodate cultural, spiritual, educational, and language differences that may affect the patient's and family's acceptance and absorption of this crucial information. In addition, patients and caregivers of varying ages are likely to have different information-seeking patterns that must be accommodated. Patients also must be educated on how to find and evaluate information on the Internet.

Post-treatment Survivors

As treatment concludes, survivors of all ages must be helped to understand the need for lifelong care including surveillance for recurrences, second malignancies, and late effects of treatment, as well as regarding their possible need for psychosocial assistance in the future. In addition, survivors should be provided information on maintaining their health through lifestyle choices (e.g., exercise, diet, sunscreen use, virus protection, tobacco and alcohol use) and possibly through chemoprevention (e.g., supplements, proven chemopreventive agents).

Cancer care providers have an obligation to offer this information to patients leaving treatment (see Recommendation 1a). To assist them in fulfilling this obligation, age appropriate, and culture- and literacy- sensitive patient and caregiver education tools are needed to help equip survivors and their family/caregiver support systems to transition out of the treatment setting and become empowered to monitor and protect their ongoing health. For example, a community oncology practice in New Jersey is developing and will soon provide to each patient an updatable, loose leaf patient education notebook to help keep patients and families abreast of developments in follow-up and preventive care. Numerous survivors called for the development of Internet sites or other central information resources (e.g., 800 numbers, public libraries) where information about late effects of treatment and prevention information for survivors could be made available. Further, speakers suggested that long-term follow-up clinics, particularly those with a wellness focus, have the potential to be valuable centers of information for these purposes.

"…with some of the older patients, even when they are given the diagnosis, they are so afraid of disappointing their family, they go along with what somebody is telling them. So they need somebody else…to help navigate them through these channels."

Joanne Stetz, 65, nurse/educator, ovarian cancer survivor diagnosed ages 61 and 63, Pennsylvania

"[It] is so important to take an active role in this health care and your follow-up, and always be aware of treatment advances. I mean, once you are out that five years, don't stop looking into what is available."

Alisa Gilbert, 39, breast cancer survivor diagnosed age 31, Alaska

“…at the end of treatment [the doctor] said to me, ‘You are done.’ …I didn’t know which way to turn. I honestly didn’t. I mean, I felt like I had been cut loose from something. I had a treatment team—and then, ‘You are done.’ So I asked her, ‘Well, what am I now? What stage am I now? Am I cured?’ She said, ‘No.’ I asked, ‘Am I in remission?’ She said, ‘Yes, you are in remission. Come back in six months and let’s see if your cancer has recurred.’ That statement—I learned to hate it….I would have preferred if it had been said to me, ‘Let’s develop a survivorship plan…and in the process we might do an MRI or we might take some lab work but the purpose in coming back is, let’s see how your plan is working.’ That is a very different thought. That is a very different way of asking a person to come back…”

Grace Butler, 67, colon cancer survivor diagnosed age 63, Texas

Health Care Providers

Physicians, nurses, and other primary care providers need to be better informed on the need for long-term surveillance and signs and symptoms of late effects among cancer survivors. Late effects of cancer treatment may present in a variety of ways. Chief among these are: premature development of a normal age-related change, atypical presentation of a common medical problem, increased risk of developing certain common diseases and some rare diseases, and poor response to treatment that is usually effective. Late effects are influenced by the survivor’s age, pre-existing physiologic or psychological comorbidities, lifestyle, and developmental stage.

Primary care providers (e.g., family physicians, internists, physician assistants, nurse practitioners, and in some cases, gynecologists) frequently become the “medical home” (i.e., usual source of care) for survivors who have completed treatment. These providers need to be well-informed about possible late effects and new research findings about their manifestation and care. This information must be specific to survivors of various cancers who are of differing ages and have varying lengths of survival. Providers’ effectiveness in monitoring for and providing or arranging care for late effects may be facilitated by electronic health record systems as these are further developed. The role of primary care providers in education and surveillance is especially crucial for the population of survivors who are poor, less educated, and who lack access to information via the Internet. Trained community health or other lay educators also may have important roles to play in conveying information about possible late effects to survivors who may have infrequent contact with the health care system, such as those in culturally insular communities and those in rural, inner urban, and other isolated areas.

Among the more common physiologic effects of cancer treatment for which numerous speakers maintained that care often is inadequate, particularly post-treatment, are pain, fatigue, lymphedema,[45] and cognitive dysfunction (“chemo brain”).[46] Insufficient care, or lack of appropriate referrals, may result from failure to acknowledge these problems, minimization of problems, and failure to provide adequate medication. All of these problems are likely due in part to providers’ lack of information or misinformation about these common treatment effects.

Sexual side effects of treatment, including early menopause with accompanying symptoms such as hot flashes, loss of libido, impotence, and concerns about intimacy due to body image or other physical issues may affect adolescent, adult, and older adult survivors. Speakers noted that many providers are unaware of the prevalence of these side effects, in part because they do not ask about them and because survivors may hesitate to discuss them or believe they are a cost of surviving their cancer. Research has shown, for example, that prostate cancer survivors often hesitate to admit problems with impotence, loss of libido, or incontinence, and their health providers therefore may greatly underestimate the frequency of these treatment side effects.[47] An oncology nurse specializing in sexuality issues among survivors stressed that providers need to be the ones to bring up topics related to sexuality and intimacy, and should reassure patients that these are common difficulties that nearly always can be improved.

Speakers indicated that many providers still do not consider psychosocial support an integral component of quality cancer care, and may fail to recognize, adequately treat, or refer for depression, anger, and stress in cancer survivors, family members, or other caregivers. Provider understanding of cancer as a family disease that can have lasting effects on family roles and functioning, and the special needs of survivors' caregivers and siblings also appears to be limited.

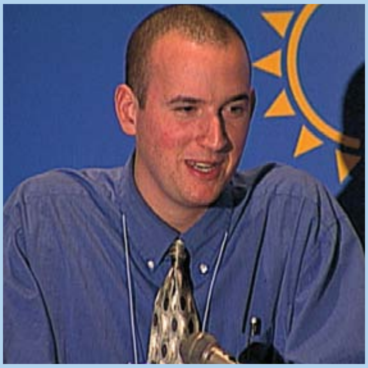
Further, health care providers need to be aware of late effects as they may be called upon to assist the survivor in combating stigma concerning cancer in the workplace and in educational settings. Finally, provider education about survivorship issues must extend to health care providers in training to ensure that the next generations of clinicians will be prepared to deliver the most appropriate care to the growing survivor population.

Clinical Trials Information

Currently, only three percent of adult cancer patients participate in clinical trials, while a large majority of children with cancer are treated on protocols. Oncologists who testified agreed that clinical trials participation needs to increase, but that not every patient needs to be on a clinical trial (e.g., patients with early stage disease for which standard treatment is effective). A trial may be appropriate for some patients as initial treatment, while for others a trial is most appropriate in the event of a recurrence or second cancer. However, a number of survivors reported that finding understandable information on trials was often difficult, and that many health care providers were unfamiliar with trials that might benefit their patients. The wife of a prostate cancer patient, who is a librarian and was actively involved in searching

"…with the partial support of the Texas Cancer Council, we have been involved in developing an Internet-based resource which keeps and generates individualized guidelines…that are updated periodically with any new information [on] new late effects or consequences of therapy or the disease, and which they can make available to their caregiver either by giving them access over the Internet or by printing out the actual information."

David Poplack, oncologist, Texas Children's Cancer Center, Texas



"I sort of feel like a 50-year-old man in a 23-year-old's body. I have high blood pressure, high cholesterol. I have got to do all the things as far as no sodium in my diet and all that kind of stuff, so I am dealing with those issues that, given my family history, I probably would have had to deal with anyway—but at a much younger age."

Daniel Sieck, 23, leukemia survivor diagnosed ages 11 and 15, Maryland for appropriate clinical trials for her husband, suggested that NCI should have dedicated staff assigned to continually update its clinical trials database. She believes the current approach, in which investigators voluntarily report ongoing trials to the database, results in an incomplete information source for both patients and providers.

In addition, survivors and providers emphasized that the public has not been educated adequately about the value of clinical trials. Many people still believe that a patient who enters a clinical trial may be randomized to receive only a placebo. The understanding that trials compare the best known standard treatment with one that may be as effective or more effective is not widespread. Nor does the public understand that patients receiving investigational treatments are immediately switched to the standard care arm of the study should their disease progress on the investigational agent. In addition, trial participation is hampered by public distrust—particularly among minorities—of both the government and the pharmaceutical industry. Recently, some doubt has been cast on the real benefit of trials to the majority of people who participate in them,[48] but the value of trials in finding more effective new treatments for future cancer patients is unquestioned. A speaker suggested that NCI should launch a national public education campaign focused on clinical trials; in fact, several national cancer advocacy organizations have conducted public education activities on this topic over the past few years.

“We have no guidelines to send those of us who are long-term survivors out back into the community no matter where we are going to be seen and the longer we survive, the more physicians we are going to see, the less access we have to our oncologists, and we really need to have something to take to the practitioners in the general community and to the specialists that we will be seeing throughout our lives….It is imperative for health care and oncology today to start developing these standards of care and these are actually being asked for by our primary care physicians in the community.”

Susan Leigh, 56, Hodgkin’s lymphoma, breast, and bladder cancer survivor diagnosed ages 24, 43, and 48, Arizona

Recommendations

4a. National public education efforts sponsored by coalitions of public and private cancer information and professional organizations and the media (e.g., film, television, print and broadcast news) should be undertaken to:

- Raise awareness of survivor experiences and capabilities, and of the continuing growth of the cancer survivor population. These efforts should seek to enhance understanding of the post-treatment experiences of cancer survivors of various ages and their loved ones and the need for lifelong follow-up care.
- Provide accurate information and enhance community trust about participation in clinical trials and raise awareness of the importance of trials in developing new and better cancer treatments and other cancer-related interventions.

4b. Existing online resources, including those of the National Cancer Institute (NCI), that provide information on clinical trials and facilitate patient-trial matching should be improved to help patients more easily find trials for which they may be eligible and to simplify the enrollment process.

4c. A central online information resource on scientific evidence about late and long-term effects of cancer and its treatment should be developed and maintained by a consortium of interested constituencies (NCI, American Cancer Society, American Society of Clinical Oncology, and others). The NCI Physician Data Query database may provide a model for this effort.

- Using their existing networks, cancer awareness, education, and advocacy organizations should take a major role in helping to collect and disseminate (e.g., through newsletters, lay educators, workshops, other outreach efforts) late effects information as it becomes available.
- Individual cancer survivors should be able to contribute to this database information about their own experiences with late effects.

4d. The potential role of specialized long-term follow-up clinics or departments within or operated by medical or cancer centers should be evaluated for their benefit as a central education resource for cancer survivors. Ideally, such programs should provide the most current information to survivors and their families about late and long-term effects of cancer and cancer treatment and on complementary and preventive strategies (e.g., nutrition, exercise, sunscreen use, virus protection, stress reduction) to promote wellness.

4e. Education about possible late effects of cancer treatment and survivorship needs should be part of the core curricula for health care providers in training, and a part of continuing education for primary care physicians, oncologists, and non-physician health care providers.

"…chronic pain is a silent epidemic ….We need programs and funding to train culturally competent pain management specialists to educate other medical providers about pain and to conduct more research on pain pathways and treating pain effectively…to examine the institutional, cultural, and individual barriers that preclude appropriate and timely pain management for people of color and those living in poverty…interventions to overcome those barriers…[and] the recruitment and retention of pain specialists who come from communities of color and poverty, which is critical to addressing these disparities."

Susan Shinagawa, 46, breast cancer survivor diagnosed ages 34, 40, and 44, California

"…having been in the Bronx for many years of my professional life, I always laugh at the [emphasis on the] Internet and the computer capabilities, when half my patients in the Bronx did not have a telephone."

Carolyn Runowicz, oncologist, Connecticut

“Greater standardization in terms of the presentation of the cancer trial information with maybe an advanced search engine would really help those of us who plow through that stuff.... What is there on the NCI website is good. It could be better.”

Tom Trotter, 53, metastatic melanoma survivor diagnosed age 40, California

“...you are re-establishing and redefining what normal is, because what you thought physically was normal for your body...your guidelines are no longer there. You have to really find them again, really find your feet. So, I think having psychiatric help if need be...no matter how wonderful a spouse has been, or a family member, you are alone with your disease, and you know, you have to work with that.”

Helen O’Grady, chronic myelogenous leukemia survivor, Pennsylvania

The psychosocial and support needs of many survivors, caregivers, and family members are not being met.

Speakers enumerated a wide range of unmet psychosocial needs of survivors, their caregivers, and family members:

Survivor Needs

Cancer survivors may confront a diverse array of psychosocial issues and these typically differ across the developmental continuum. The issues and needs of survivors diagnosed at ages 5, 15, and 50 years will almost certainly be different, but most cancer survivors will have some psychosocial concerns over the course of their lives after diagnosis. Like physiologic late effects, psychosocial effects of cancer and cancer treatment can have long latency periods. Lag time to symptoms varies significantly and may be measured in months or years, often influenced by the survivor’s cancer type, treatment, age, developmental stage, social environment, and other experiences.

Many survivors have significant difficulty with the transition from active treatment to reintegration into their family, social, and work lives. Many of the survivors who testified described depression, stress, and uncertainty that followed the end of treatment and for which they had no ready resources or referrals to help in making this transition. It was suggested that the immediate post-treatment period be considered a distinct phase of survivorship for which psychosocial and other services should be planned and in place. At the Panel’s meeting in Europe, speakers from three countries described formal transition programs for cancer patients finishing active treatment; a limited number of such transition programs appear to be in place at major cancer centers in the United States.

Family and Caregiver Needs

Numerous speakers stated that the psychological and emotional needs of family members of cancer survivors receive inadequate attention. Millions of family members are affected by the cancer of a loved one, and may themselves be at increased risk of the disease due to genetic heritage, lifestyle, and/or environmental exposures. Children of a parent or sibling with cancer may be fearful that the person with cancer will die; they also may be worried about their own cancer risk, but hesitant to discuss this for fear of creating additional burden on the family. As many as one-third of parents of children with cancer, particularly mothers, are affected by post-traumatic stress disorder even years after the child's treatment has ended.[49] Another study found that stress-response symptoms and anxiety/depression differed among children whose parent had cancer relative to the age and sex of the child and the gender of the parent; adolescent girls whose mothers had cancer were the most significantly distressed.[50]

Families may need to deal with temporary or permanent physical, cognitive, and/or spiritual changes in the survivor. For these reasons, family members need a better understanding of the physical and emotional processes of recovering from cancer and cancer treatment, both regardless of and specific to patient/survivor age. Of note, NCI's Office of Cancer Survivorship in 2003 identified family issues and needs as a priority area for survivorship research.[51]

Caregivers often are given neither sufficient information nor the support they need to carry out their roles. As cancer treatment increasingly is provided on an outpatient basis, greater home nursing responsibility is being placed on caregivers. Tasks may include ostomy and catheter care, wound dressing, administering injections, and monitoring medication dosages and schedules; some of these are tasks that not all nurses in hospital or physician office settings are authorized or trained to perform. These responsibilities often are accompanied by significant physical, mental/emotional, and economic (e.g., lost time from work, out-of-pocket costs of medical and other supplies) burdens on the family, particularly among family caregivers who provide the core of care for patients at the end of life.[52] Caregivers of all ages need resources for support, information, respite, and skills training.

A speaker noted that professional caregivers—physicians, nurses, and others—also can require psychosocial support. He stated that the pediatric oncologist who treated his daughter eventually left medicine, because it had become too painful emotionally to continue.

Provider Issues

Numerous survivors and caregivers who testified stated that many of their cancer care providers did not acknowledge, understand, or accommodate their psychosocial needs. Speakers reported that their providers often were unaware of available survivorship resources and/or did not provide referrals to those resources. This testimony is consistent with findings of a recent study designed to establish a baseline measure of oncology providers' awareness of and referral to survivor support programs. The

"…the siblings…they are always being shifted around—with their loss of control, their sense of normalcy. They don't really know what is going on. My brother didn't know whether he could catch it or not; my sister felt that she was just neglected. They are passed [around], from their first grade teacher taking them to the mall, to different people who say, 'Oh, well, we can watch them'…because my parents have to go to work; they have to be with me. What do you do with them? They don't want to spend all their time in the hospital."

Danielle Eichner, 18, leukemia survivor diagnosed age 11, Maryland

"You always wonder in the back of your mind what is coming up next. Something else might happen, or is bound to happen. Maybe a new side effect that has not even been seen before will come about through you, because that is a lot of what happened with me…"

Michael DiLorenzo, 32, non-Hodgkin's lymphoma survivor diagnosed age 6, Pennsylvania

"…it is a frightening thing to watch what chemo does to people in your family, and some of them live, and some of them don't….[As a caregiver] sometimes you end up being in the background, because I am not the spouse most of the time. I am the daughter, the niece, the sister. So I don't get all of the direct contact sometimes with the physician, even though in many instances I am the primary person that the family goes to.

I forget that I actually had thyroid cancer myself, because I had to downplay that, and [after all] it's supposed to be the easiest one to cure. But it was traumatic for me nevertheless…"

Rosalyn McPherson, caregiver, thyroid cancer survivor, Pennsylvania

researchers found that 70 percent of those surveyed had heard about ACS or NCI support and information programs, but less than 60 percent recommended these services or thought they were of benefit to patients.[53]

Recommendations

5a. All survivors should be counseled about common psychosocial effects of cancer and cancer treatment and provided specific referrals to available support groups and services.

5b. A caregiver plan should be developed and reviewed with a survivor's caregiver(s) at the outset of cancer treatment. It should include, at a minimum:

- An assessment of the survivor's social and support systems.
- A description of elements of patient care for which the caregiver will be responsible. Caregivers should be provided adequate and, as needed, ongoing hands-on training to perform these tasks.
- Telephone contacts and written information related to caregiver tasks.
- Referral to caregiver support groups or organizations either in the caregiver's local area or to national and online support services.

5c. Providers should include psychosocial services routinely as a part of comprehensive cancer treatment and follow-up care and should be knowledgeable about local resources for such care for patients/survivors, caregivers, and family members. In particular:

- The transition from active treatment to social reintegration is crucial and should receive specific attention in survivors' care.
- Primary and other health care providers should monitor caregivers, children, and siblings of survivors for signs of psychological distress both during the survivor's treatment and in the post-treatment period.

Infertility risks associated with cancer treatment and opportunities for preserving reproductive capacity are not being conveyed fully to newly diagnosed cancer patients or the parents of children with cancer prior to selecting or initiating treatment.

Preserving fertility is an important issue for cancer survivors diagnosed as children, adolescents, young adults, adults in their thirties, and less commonly, survivors (primarily men) in their forties or older.[54,55,56] Several speakers indicated that they had no idea that their treatment might have made them infertile (or would make pregnancy a high health risk) until years after treatment; in some cases, not until the survivor tried to become pregnant or father a child.

If the patient was quite young when diagnosed, information about loss of fertility may have been provided to the parents, but the future impact of infertility may have been minimized or outweighed by the primacy of saving the child's life. It appears that information on possible infertility may not always be conveyed by parents to childhood cancer survivors once they become old enough to understand this information. Speakers who were survivors of childhood cancers suggested that children are able to absorb such information at a younger age than parents or health care providers may imagine.

Currently, several options exist for fertility preservation.[57,58] Sperm and oocytes (including immature egg cells of young girls that are matured in the laboratory) can be frozen (cryopreservation). For patients with partners, embryo storage may be an option. Techniques for preserving ovarian function include ovarian tissue storage, surgically moving an ovary out of the radiation field, and transplanting ovarian tissue to another location in the body (e.g., forearm, abdomen). In certain cases, oral contraceptives or other drug treatments have helped protect fertility, though the exact mechanism of action is not well understood. Some of these procedures have better success rates than others, and some still may be considered experimental. The options available to any particular patient will depend on patient age; cancer type, severity, and location; and type of treatment needed. In some cases, cancer treatment cannot be delayed long enough to take advantage of some of these procedures (e.g., oocyte harvesting). It is important to note that children past the age of puberty when treated for cancer may be at greater risk for infertility than younger children.[59]

"…my family went through several emotional states. My mom went through a bit of depression for some time. My dad also had a bit of depression, so it was something that I noticed. They needed to talk to somebody, and I wish somebody would have talked to them at that time."

Alfredo Cerritos, 21, leukemia survivor diagnosed age 8, Maryland

"…sometimes you are so busy actually taking care of the emergency at the moment…that you are [not] able to even verbalize your needs and I think maybe it's part of the care provider's responsibility to acknowledge the fact that you are having a tough time as a caregiver and seeing that there is something, somewhere, that can just give you relief. Sometimes [it's enough] just having someone acknowledge the fact that you are having a hard time [even though] you are not the person with cancer."

Judy Lundgren, oncology nurse, Texas

Many private health plans do not provide coverage for any of these fertility preservation procedures, nor for the *in vitro* fertilization (IVF) or other infertility treatment services (i.e., assisted reproductive technologies) that may be necessary to enable women sterilized by their cancer treatment (or the spouses of men rendered sterile by treatment) to have a child using banked sperm or eggs. Nor are such services typically covered by publicly-funded health programs. Speakers who had experienced fertility problems, or were told before treatment that infertility was a likely outcome of treatment, stated that when they investigated options for preserving reproductive capacity, they found that these services were not covered by their insurance plan. In some cases, providers required thousands of dollars in payment prior to initiating care. For some of the adolescent or young adult survivors, these costs simply were not affordable. They expressed heartbreak and anger not only at losing their fertility, but at the realization that money was the barrier to their hope of having a family in the future.

Recommendations

6a. All people of reproductive age who are diagnosed with cancer should be given complete culture- and literacy-sensitive information, both verbally and in writing, about options for preserving fertility and on possible effects of treatment on pregnancy or offspring before cancer therapy is selected or initiated.

6b. Parents of young children diagnosed with cancer must be given full culture- and literacy-sensitive information, both verbally and in writing, on the possible impact on fertility of treatment options prior to selecting and initiating treatment. If the patient is too young to understand this information at the time of treatment, parents should be urged to share this information with the survivor at the earliest possible time.

6c. Further research should be conducted to determine what fertility preservation options are possible for children and young adolescent cancer patients.

6d. Fertility preservation procedures and infertility treatment services should be covered by health insurance for cancer patients/survivors whose fertility will be or has been damaged by cancer treatment.

“…radiation [destroyed] his pituitary gland, so he didn’t have the capacity to grow naturally. He was put on growth hormone injections, and this guy was quite brave to endure six nights a week of hormone injections—which I gave to him for a period of five years.”

Devarda Jones, mother of Malcolm Brewster, 16, brain tumor survivor diagnosed age 9, Maryland

“At the time of my first diagnosis I had not been married very long. I didn’t have any children and had not yet considered whether I wanted to have any children. No one ever mentioned to me that my treatment would induce menopause and that I would probably be infertile. It wasn’t until several months after my treatment was completed that I asked my oncologist when he thought I would start menstruating again…. I was very angry when I heard that I probably could not have children.”

Debra Thaler-DeMers, 49, oncology nurse, Hodgkin’s lymphoma and breast cancer survivor diagnosed ages 25 and 45, California

Existing health insurance systems in the United States are a significant impediment to appropriate care for people with a cancer history.

Unlike industrialized countries in Europe and elsewhere in the world, access to health insurance in the United States is highly dependent on employment status. Cancer survivors who must leave their jobs risk losing their health insurance unless they can afford to retain their employer-sponsored group health plan under COBRA provisions (see page 20), can retire with continued and affordable health benefits, or qualify for Medicare or Medicaid.

Lack of health insurance is a persistent and growing problem in the United States, though estimates of its magnitude vary. The U.S. Census Bureau estimates that 43.6 million people lacked health insurance at some point in 2002, up 5.7 percent from the previous year, with loss of employer-sponsored health coverage (particularly among men and non-parents) the principal cause.[60] This coverage loss occurred mainly among low-income adults, although higher income households also were affected.[61] Data from the Medical Expenditures Panel Survey (MEPS) indicate that in the first half of 2002, the most current period for which data are available,[62] an estimated 45.9 million non-elderly Americans (18.5 percent) were uninsured. A study tracking uninsurance rates longitudinally over the four-year period 1996–1999 shows that 85 million non-elderly adults (38 percent) were uninsured at some point during that period.[63]

Approximately 84 percent of the uninsured are workers and their dependents.[64] It is well documented that compared to people with health care coverage, the uninsured are less likely to visit a doctor, have a usual source of medical care, receive preventive services, or have a recommended test or prescription filled.[65,66,67]

Lower income working survivors who are too young to qualify for Medicare or make too much to qualify for Medicaid are particularly vulnerable to being uninsured or underinsured, as they may be unable to afford employer-sponsored health coverage even if it is offered, or may only be able to afford limited policies with high deductibles and copayments. A recent survey found that lack of prescription drug coverage is an important indicator of underinsurance.[68] Like the uninsured, insured non-elderly adults (aged 19–64 years) whose policies did not include prescription drug coverage were more likely to report not having

“…I thought that if I got pregnant in the first place, I had faced all the issues that there were regarding pregnancy and survivorship, but I was wrong…. I was five months pregnant and admitted to the hospital for pulmonary hypertension related to my [cancer] treatment….[I spent] the remainder of my pregnancy on oxygen and on strict bed rest…. Before [my son] was born, I had become pretty comfortable with my mortality and the possibility of death, but after he was born, I was suddenly terrified of dying, because he needed me, and he needed me to be alive….He is now five years old, and he is healthy—and I am healthy, too… yet I know I am maintaining a delicate balance, both physically and emotionally.”

Angie Farfan, 30, metastatic Ewing’s sarcoma survivor diagnosed ages 4, 10, and 14, Missouri a prescription filled due to cost, were more likely to skip recommended tests or follow-up care, and were more likely to forgo seeing a doctor when sick because of cost.

These patterns may have profound health and financial consequences for cancer survivors, who require lifelong follow-up care, access to diverse services across the cancer care continuum, and who may require medication on an ongoing basis. The health consequences of delaying or forgoing care or medication may include delayed diagnosis, worse outcomes, greater comorbidities, reduced quality of life, and decreased survival. In the event of a recurrence, second cancer, or other serious late effect of their treatment, uninsured and underinsured survivors and their families may face financial ruin.

Lack of insurance is particularly high among minorities: according to recent estimates, 38 percent of Latinos, 24 percent of African Americans, and 22 percent of Asian American/Pacific Islanders are uninsured, compared with 14 percent of non-Latino whites.[69] Young adults also are likely to lack health insurance.[70] Young cancer survivors with little work experience, particularly those with a disability that may affect their employability, are highly likely to be uninsured or underinsured.

Other trends are further cause for concern. Health insurance premiums increased 13.9 percent in 2003,[71] and an increasing percentage of health care costs are being shifted onto employees in the form of higher premium contributions, and higher deductibles and copayments (including multi-tiered prescription drug copayments). Recent research has demonstrated that increases in patient cost-sharing affect people with serious illnesses and low incomes the most.[72] Health benefit options are becoming less robust, even for those at large companies, where the number of covered workers also is dropping.[73] This trend is of particular concern due to the increasing reliance on technology-driven treatment advances that are expensive and that may well become unavailable except to those with the most comprehensive insurance or the ability to pay out-of-pocket. Thus, with regard to access to state-of-the-art cancer and other care, the divide between the health "haves" and "have-nots" can be expected to widen.

The insured and uninsured alike are drained by non-reimbursed costs of cancer. Medical costs may include expenses for follow-up care and testing, non-covered medications, supportive and complementary care services, compression garments needed to

"…the husbands, wives, parents are becoming the *de facto* nurses…not only is the cancer survivor not able to work but the family unit has to care for them at home and is not able to work effectively as well….So while in this country we tie insurance and health care payment to work there is a real lapse there and I think there needs to be some sort of addressing of that."

Christopher Turner, pediatric oncologist, Massachusetts

"…one of the first and main barriers [is that] the HMOs and insurance, in general, just will not recognize your follow-up needs unless, of course, you are symptomatic. In my case, if I were symptomatic, it would be a very big problem."

Octavio Zavala, 30, leukemia survivor diagnosed age 12, California control lymphedema, reconstructive surgery, and prosthetics (e.g., limbs, breast forms, wigs). Non-medical costs, such as for transportation to follow-up care appointments, child care, construction of ramps or other accessibility improvement measures, and other expenses further drain survivors' resources.

Existing health financing systems do not adequately recognize psychosocial support or risk assessment services as an appropriate part of comprehensive cancer care and do not adequately reimburse for the services of these providers, many of whom are non-physician medical and social service personnel. In addition to the hesitation to access psychological services due to the perceived stigma attached to doing so, some patients do not avail themselves of care for depression, family relationship problems, or other psychosocial needs due to lack of or limited insurance coverage for these services. Providers may be hamstrung in their ability to conduct assessments of psychosocial problems or make appropriate referrals for needed care for the same reason.

Speakers reported that reimbursement for follow-up services such as cardiac assessments is more difficult to secure the longer a survivor has been out of treatment. Often, the insurer does not recognize the possibility that symptoms related to organ system, neurologic, or other physical functions may be related to past cancer treatment the survivor received. Similarly, education and preventive services (e.g., weight control, nutritional counseling, smoking cessation) often are not reimbursed, but these will be increasingly important in efforts to stem the tide of cancer incidence and recurrence that is projected in the coming decades.

It was suggested that a program or package of services modeled on the cardiac rehabilitation services typically provided to people with heart disease should be developed and reimbursed for the post-treatment care of cancer survivors. Speakers acknowledged, however, that compared with cardiac rehabilitation, post-treatment follow-up for cancer survivors would be less uniform due to the many types of cancer and cancer treatment and could be needed over a longer period.

Numerous speakers discussed survivors' need for specialized long-term follow-up clinics or programs, either freestanding or located within cancer centers or other medical centers. Some such clinics currently exist within pediatric cancer centers, and nearly all are focused on long-term follow-up of survivors who were diagnosed as children. Similar programs, it was emphasized, are needed for those diagnosed as adolescents and in adulthood. Ideally, such clinics should go beyond monitoring for recurrence to assess changes in the individual's physical and

"…right now my health insurance is $950 a month…it continues to go up every three months, and that is with a $2,000 deductible, and then $10,000 out of cash payment before it pays the full amount. So at the time in my life when I should be saving for retirement it is kind of hard to do when you are having to pay $1,000 a month for health insurance—and that is for one month for one person."

Gloria Jean Moore, 51, Hodgkin's lymphoma and breast cancer survivor diagnosed ages 27 and 50, Texas

"Last year one of my patients was in the hospital receiving treatment when his employer informed him they were filing for bankruptcy and his insurance would expire at the end of the month. Rather than continue looking for clinical trials that might benefit him, he decided to go home with hospice care. He spent the last weeks of his life writing letters of recommendation for his coworkers and died before the month was up."

Debra Thaler-DeMers, 49, oncology nurse, Hodgkin's lymphoma and breast cancer survivor diagnosed ages 25 and 45, California

“I believe that the fact that I had excellent insurance benefits through my employer while my sister had no benefits through her employer contributed to the fact that I am alive today and she is not.”

Debra Thaler-DeMers, 49, oncology nurse, Hodgkin’s lymphoma and breast cancer survivor diagnosed ages 25 and 45, California

“…the American health care system is in need of fundamental change, not just tweaking… don’t throw more money at an under-performing system; fix the system.”

Richard Migliori, physician and administrator, United Health Resources, Minnesota

personal well-being, evaluate potential long-term effects of prior treatments, determine and address management issues including modifiable risk factors, and enhance overall quality of life. Though additional research is needed to identify the most effective approaches to providing this care, programs such as these have the potential to provide specialized care to survivors and to capitalize on opportunities for research on survivor issues. Insurance reimbursement for services provided in long-term follow-up clinics, including those rendered by non-physician personnel, is essential to the viability of any such programs.

It is widely acknowledged that the current health care system is broken.[74] Half of all personal bankruptcies are due to crushing medical debt.[75] Many, including health care providers in diverse settings, the IOM,[76] and a broad spectrum of the public[77] are calling for comprehensive rather than continued incremental changes in the way health care is provided and financed in this country.

Recommendations

7a. The Federal Government should revive efforts to implement comprehensive health care reform.

7b. Adequate reimbursement for prosthetics must be provided and it must be recognized that:

- Many prostheses must be replaced periodically.
- Access to prostheses is an integral part of psychosocial care for cancer.

7c. Coverage should be provided routinely for psychosocial services for which there is evidence of benefit both during cancer treatment and post-treatment as needed.

7d. Public and private insurers should provide reimbursement for risk assessments, surveillance, and other follow-up care for cancer survivors, including care provided by appropriately trained non-physician personnel.

7e. Existing follow-up care clinic models should be evaluated and compared to ascertain their impact on survivor outcomes and their cost effectiveness.

“Dieticians, social workers, chaplains, monks…psychologists, marriage counselors, family counseling, oncology counseling, sexual therapy, and my nurses need time to educate patients….I don’t know anybody covering those services. I don’t even know how to fill out a CPT [Current Procedural Terminology] code on them but they are vital and they are necessary to a patient’s quality [of life].”

Shelby Sanford, oncologist, Alabama

“Refusal by insurance companies to pay for necessary tests and treatments has had a financial impact on my family and me. Fear of losing health insurance has restricted my job choices and only through carefully navigating coverage rules have I been able to avoid pre-existing condition restrictions.”

Craig Lustig, 39, brain tumor survivor diagnosed age 27, Washington, DC

Issues of Cancer Survivors Diagnosed as Children

Childhood cancer is rare, but advances in treating these malignancies have yielded by far the most dramatic improvements in cancer survival. Thirty years ago, only 30 percent of children diagnosed with cancer survived into adulthood; today nearly 80 percent do so.[78] As of 1997, the most recent year for which data are available, there were an estimated 270,000 individuals of any age who had survived cancer diagnosed in childhood.[79] Of these people, approximately 95,000 were under age 20.[80]

Like adult-onset malignancies, childhood cancers are not a single disease, but a varied group of diseases. The most common forms of childhood cancer among those aged 0 to 14 years are: (1) leukemias, including acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (AML), (2) central nervous system (CNS), intracranial, and intraspinal cancers, (3) soft tissue sarcomas, (4) sympathetic nervous system tumors, (5) Wilms' tumor, rhabdoid and clear cell sarcomas, (6) germ cell, trophoblastic, and other gonadal cancers, and (7) Hodgkin's lymphoma.[81] Figure 6 (see p. 42) illustrates improvements in five-year relative survival rates for these and other cancers that typically occur in childhood.

The likelihood, type, and severity of late effects vary by the type and stage of disease, the age of the patient during treatment, and the nature and aggressiveness of the treatment regime. Some late effects of therapy experienced by children with cancer are temporary and resolve themselves. However, in many cases of childhood cancer, survival and cure come with a cost. As a result of the disease or its treatment, children may suffer a range of disabilities.[82,83] These include cognitive impairments such as learning disabilities, attention deficit hyperactivity disorder, developmental delays, mental retardation, and autism. Sensory impairments, including hearing loss and cataracts, can occur depending on the treatment received. Some children may suffer amputations that will compromise

"About two-thirds of children experience at least one late effect. Many of them are minor, and many of them are transitory, but about one-fourth experience a serious late effect that causes some limitation of how they can live or [produces] a life-threatening late effect. Late effects may emerge soon after therapy is completed or many years, or even sometimes decades, later…this creates problems with follow-up…"

Joseph Simone, pediatric oncologist, National Cancer Policy Board, Washington, DC

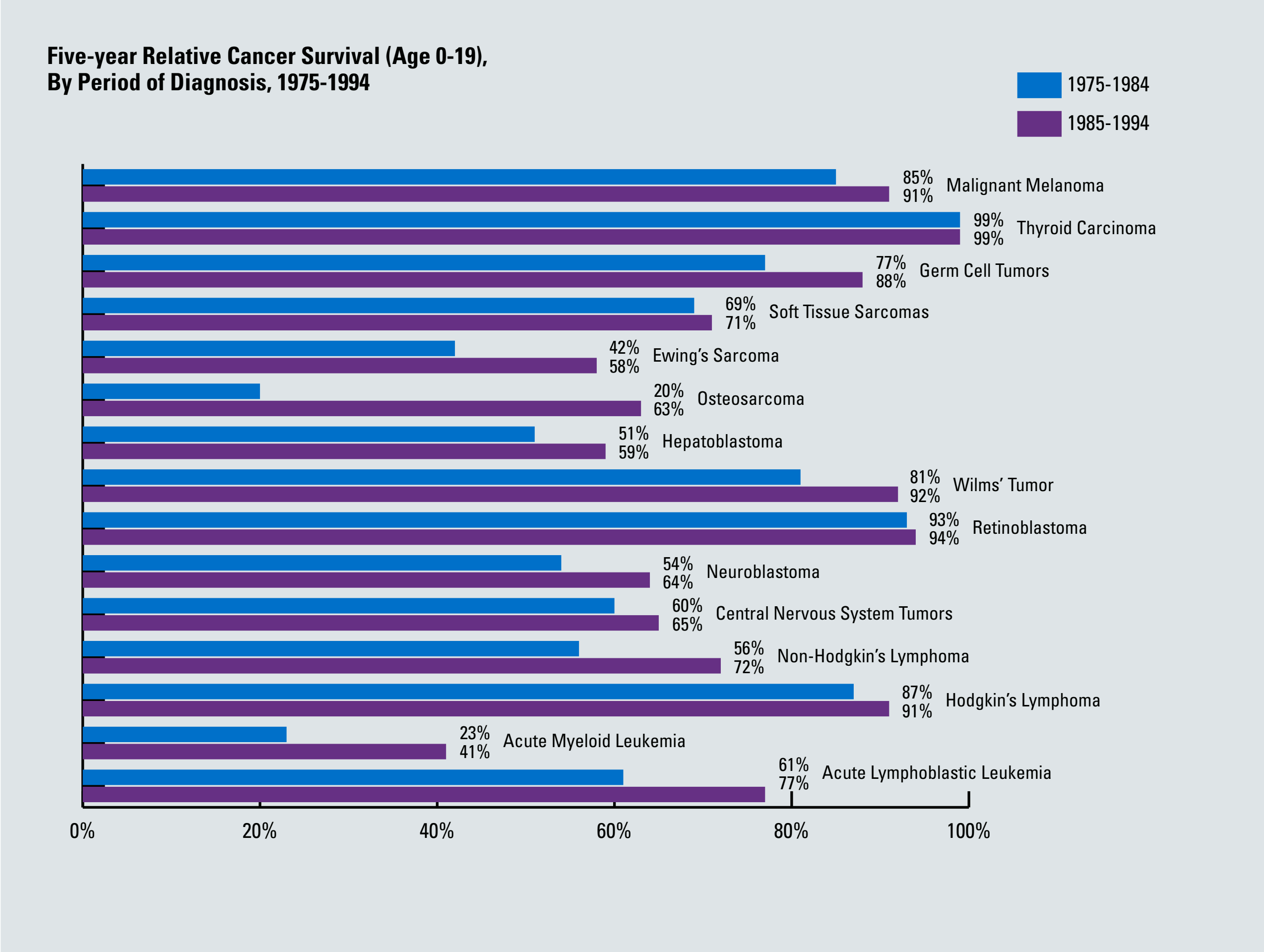
"At the age of eight, I didn't get to be a child as I should have been—like my sister was. I had to grow up very quickly mentally because I needed to understand what was going on with my body and why things were happening the way they were."

Aileen Delgado, 22, leukemia survivor diagnosed age 8, 10, and 12, New York their mobility. Other late effects of treatment can include heart, lung, thyroid, kidney, and other organ system dysfunctions; soft tissue or bone damage; overweight or obesity; and osteoporosis. Endocrine disturbances can result in delayed or arrested puberty, short stature, and reproductive problems. In addition, some of the late effects that become chronic problems may affect the progression of other diseases associated with aging, such as diabetes or hypertension.[84,85]

When a child is diagnosed with cancer, the entire family is thrown into crisis, and family dynamics may be permanently altered. Initially, parents may be struggling with the shock of the diagnosis and fears for their child's life; and may be consumed with trying to take in new information and make treatment decisions. Both the patient and siblings may exhibit behavior changes. During the treatment period and beyond, family roles may be altered; for example, the father and/or older children may be called upon to assume new household and childcare duties, a patient who is an older child may regress to a more dependent role as in earlier childhood, or may become mature beyond his or her years.

The recent IOM report, *Childhood Cancer Survivorship: Improving Care and Quality of Life*,[86] provides a comprehensive review of childhood cancer survivorship issues. Speakers at the Panel meetings touched upon many of the areas

Figure 6



Source: ACS, 2000. Data from the Surveillance, Epidemiology, and End Results Program (SEER), Division of Cancer Control and Population Sciences, National Cancer Institute. In: Hewitt, Weiner, and Simone, 2003.

discussed in that volume and elsewhere in the literature,[87,88] but particularly emphasized five issues of importance to this population of survivors.

Survivors of cancers diagnosed in childhood may need special assistance to re-enter the classroom setting successfully and may require accommodations to special learning needs resulting from their disease or its treatment.

Children who are being treated for cancer may be absent from school for weeks, months, even years at a time. Some survivors diagnosed in childhood receive treatment far from home and may all but lose contact with their friends. They may be returning to school without hair, or with amputations, scars, weight gain, or other visible signs that they have been sick. Upon their return, survivors who have been in such situations may need assistance with social reintegration into the classroom environment, and some will require special arrangements to accommodate temporary or permanent changes in their mobility, energy level, dietary or medication needs, or learning abilities.

Some survivors were fortunate to experience a smooth transition back to the classroom; other survivors of childhood cancers who provided testimony to the Panel described vividly the stress of returning to school. A brain tumor survivor recalls being teased continually because he was bald and had a prominent scar on his head. Others reported being unnecessarily restricted from activities or play with other children, which heightened their feelings of isolation and being different. For some, speaking to their classmates and teachers about cancer and their experience of it, though stressful, was empowering and helped them in the transition back to school. Another brain tumor survivor who testified was accompanied back to school by his art therapist, who helped him talk to his classmates and explain that he did not need any special treatment and was there to work hard.

Parents of pediatric cancer survivors had varied stories to tell. Both parents and survivors reported difficulties in finding suitable tutors to continue education during the treatment period. While the young survivors usually were not held back from progressing to the next grade in school, some felt they had not received an equivalent education and were therefore at a disadvantage academically upon returning to the classroom. Sometimes these disadvantages did not become apparent until years later when, for example, an inadequate foundation in

“…what made that transition smooth as well as an important part of my life was that my medical team came and talked to my class about reintroducing me into the classroom after I had been gone for a year…[but] it was difficult to convince the school that I needed special services….I was supposed to be well, but I was suffering all the effects from my treatment, which were undiagnosed.”

Coreen Oshiro, soft tissue sarcoma and secondary bone cancer diagnosed ages 2 and 11, California

“Adam never has been hyperactive, but his brain is hyperactive, and if you see an EEG [electroencephalogram] of his brain, the right side is just off the chart constantly. He has seizure activity all the time, but he has learned to function even with that interference. The way it was described to us is that it is like trying to read a book and listen to a really loud radio at the same time. You get a little bit out of both but not a whole lot out of either one.”

Pam Cox, mother of Adam Cox, 20, brain tumor survivor diagnosed age 3, North Carolina

“School was very, very rough for me because I was in a public school with hundreds of children. Hundreds of kids who were my age who didn’t understand why I didn’t have hair, why I had to miss school, why I couldn’t run as fast as they could, because I would get very tired….I would come home crying every day…”

Aileen Delgado, 22, leukemia survivor
diagnosed age 8, 10, and 12, New York

“…at school they treated me also like I was really fragile…I wasn’t allowed to go to recess. My teachers treated me differently. They would sometimes put me in a corner so that the kids wouldn’t pick on me, but that actually made me feel worse because I was being excluded from the group, and I think that also encouraged the kids to tease me a bit more. I was bald and I was fat because of the chemotherapy…”

Alfredo Cerritos, 21, leukemia survivor
diagnosed age 8, Maryland

middle school math skills made work at the high school or college level extremely difficult, even when the survivor had no learning disability.

The mother of a brain tumor survivor whose treatment resulted in significant learning problems voiced her frustrations in trying to work with a rigid school system that would not make accommodations to her son’s learning needs. She also described the frustration of her son, who narrowly missed earning a passing grade on his high school equivalency examination after taking the test numerous times. In his case, lack of a high school equivalency certificate prevented him from becoming employed and self-supporting, his most important goal.

Another parent of a brain tumor survivor stated that although her son has a good total IQ score, his visual spatial, fine motor, and information acquisition skills have been affected by his cancer—he is both gifted and in need of special education. The local school system does not recognize these problems as warranting special services. After countless attempts to secure help for their son, she and her husband, as well as their three other children, have taken on the job of home schooling him.

Conversely, another parent related that all of the teachers at her son’s school attended a training session at the center where her son was treated so that they could understand and provide for his needs upon his return to school. These testimonies illuminated how important it is for parents to be adequately prepared to advocate and intercede for their child who is returning to school after cancer treatment.

A leukemia survivor, now 18 years old, who was in treatment and out of school throughout the seventh and eighth grades, suggested that videoconferencing offers the possibility for young cancer survivors to keep up with their schoolwork and also retain some academic participation and social connection with the classroom environment.

Recommendations

8a. Qualified providers in the treatment setting should train and assist parents to assume their crucial roles in helping the child with cancer return to school and becoming an educator and advocate with individual teachers and the school system.

8b. Pediatric cancer centers should offer and promote teacher training as a part of their community outreach efforts to help ensure that the needs of pediatric cancer survivors returning to the classroom are met. Internet-based training modules also should be considered to extend the geographic reach of these training efforts. If possible, continuing education units (CEUs) should be provided to participating teachers.

8c. NCI and the Department of Education should explore collaborative opportunities to improve the classroom re-entry and reintegration of young people with cancer or other chronic or catastrophic illnesses (e.g., remote learning, teacher training).

Survivors of cancers diagnosed in childhood may have social development and psychosocial issues that require attention years after treatment ends.

For some survivors of childhood malignancies, cancer and its after-effects have always been a part of life. As one survivor of extensive treatment and several serious treatment-related conditions stated, *"I have never known otherwise: 'this is what's happening, this is what has to be done,' and you amend your life around that, which has its benefits, actually. Rather than being an adult or a young adult and having a certain lifestyle, and then…cancer comes in and explodes it, this way, I have been living with it basically since I can start remembering."*

Other survivors of childhood cancers may not feel the full impact of their experience until years after treatment ends. A survivor of non-Hodgkin's lymphoma diagnosed at age six, now 32, stated that once he reached adolescence, he rebelled against the constant concern with medical issues that had been the hallmark of his earlier years. In his twenties, he became convinced that he no longer needed doctors at all. It was a significant psychological jolt, therefore, when he experienced a serious late effect of his treatment.

It has been estimated that post-traumatic stress disorder may occur in as many as one-fifth of pediatric cancer survivors.[89] Data from the Childhood Cancer Survivor Study suggest that pediatric cancer survivors have lower rates of marriage and more interpersonal difficulties than the general population.[90]

Social development and psychosocial effects are highly varied in this population, and may be immediately evident or delayed. According to the mother of a brain tumor survivor, her (now nine-year-old) son's mild neurocognitive changes cause him to sometimes misinterpret the context of statements made by other children. She also noted that in the past year, he has had difficulty with assessing and integrating the place of cancer in his

"My whole life I have been described by others as wise and amazing and strong and heroic, and I believed it because it felt good to believe it. Then I started college…and for the first time, I was thrown into this whole huge melting pot of people who didn't really care about my story and didn't care what I had been through. They only knew that I was this girl with a limp….So I just tried to be like everyone else. But you can't stand at the brink of death and fight the way I had to fight and then just expect to be like everyone else."

Angie Farfan, 30, metastatic Ewing's sarcoma survivor diagnosed ages 4, 10, and 14, Missouri

“I’m in my third year of college, and I noticed that I actually do have problems learning…since they can’t actually diagnose if I do have or don’t have any disabilities because, as the doctors put it to me, they don’t know if I am at my full potential or if something actually affected my brain—the school will not give me any disability allowances or allow me to have extra time to finish my tests or exams or turn in my paperwork a little bit later than the other students [or]…have any services provided by the school.”

Alfredo Cerritos, 21, leukemia survivor diagnosed age 8, Maryland

“…I don’t think the teachers are educated enough, because once your treatment is over, it is not over for you, and you have all the late effects. And the teachers don’t know that, and they don’t know what to expect of you. They think you are back to normal…”

Danielle Eichner, 18, leukemia survivor diagnosed age 11, Maryland

life; he has experienced both sadness and anxiety. His mother feels that this is part of a normal grieving process for the losses he has suffered, but she recognizes that he remains at risk for future psychological problems.

Several survivors emphasized the value of special camps for cancer survivors and their families; after attending themselves during treatment, a number of those who spoke have since gone on to become volunteers and counselors at these camps. Helping other children and families still going through the treatment experience, they said, has helped them come to terms with their own cancer experiences.

Many survivors of childhood cancers are not being transitioned appropriately from pediatric to adult health care settings and receive inadequate assistance in coordinating their care.

Speakers described a lack of awareness among pediatricians, primary care physicians, internists, and other adult care providers about important differences in care provided to cancer survivors in pediatric and adult settings. In addition, adequate information on the prior treatment of childhood cancer survivors does not appear to be transferred consistently to the adult health providers who will take over care of the survivor. The likelihood of this problem is especially great when a young person receives treatment away from home. One survivor indicated that his pediatric oncologist was instrumental in helping him find an internist familiar with childhood cancer and possible late effects of cancer treatment. Although the speaker lives in a rural area more than an hour’s drive from the university cancer center where he was treated, he returns regularly to this internist; he was unable to find a local physician who understood his health issues related to his cancer treatment.

Other survivors of childhood cancer, now young adults, indicated that they are responsible for coordinating their care, and often must educate providers about their cancer history and late effects. This, they believe, should not be necessary.

The issue of transition from the pediatric to adult care setting also is germane to older adolescent cancer survivors (see page 56). It was suggested that providers with experience in caring for both pediatric and adult cancer survivors may be needed to effectively bridge the current gap between these care settings.

Recommendations

9a. Centers that care for both children and adults with cancer should consider establishing a department or service specifically geared to provide for the needs of older children, adolescents, and young adults with cancer and to assist in their transition to adult care.

9b. As part of the process of transitioning survivors of childhood cancers into the adult care setting, information about young adult support groups, Internet sites, and other sources of information and support specific to this age group should be provided to survivors and their families. (See also Recommendations 1a and 1b.)

The longer-term needs of caregivers and siblings of children with cancer are not being met.

Support groups and services tend to be robust during the treatment period, particularly for those patients treated at major pediatric cancer or academic medical centers. After treatment ends, however, such services may be less available, particularly when the patient and family have traveled to a center for treatment and return home when treatment ends. Parents of children with cancer are vulnerable to post-traumatic stress syndrome months or years after the child's treatment is over.[91] Similarly, siblings may continue to suffer fears and anxieties.[92] In addition, siblings often receive severely reduced levels of attention from parents for a considerable period of time while the sibling with cancer is in treatment. This imbalance may persist for months or years depending on the health status of the survivor and family dynamics. The effects of such situations on siblings may be profound.

Recommendation

10. Cancer care providers should inform families of cancer patients about supportive services, including special camps for families and siblings. (See also Recommendations 5a and 5c.)

"I missed my entire freshman year of high school as a result of what I went through…returning to school, I felt so lucky. I was feeling pretty good, glad to be back with my friends…but around the beginning of my senior year of high school, I started to feel down all the time…. I think that I was kind of struggling with the joy, obviously, and strength that you draw from being a survivor... then I guess I became conflicted because my life had changed, and I couldn't play sports. And I was actually on crutches most of the time during high school…after essentially failing out of college my freshman year at Kenyon [College], I came home and decided that it was time to emotionally reassess everything and really deal with what had happened…"

Daniel Sieck, 23, leukemia survivor diagnosed ages 11 and 15, Maryland

“[Pediatric oncologists] can educate the patients…and in their evaluation letters they can tell the primary care doctors, ‘look for XYZ in the future years,’ or something, because after you are out so many years for follow-up visits, and they don’t want to see you [in the pediatric setting] anymore because you are “clean,” you are going to go to that primary care doctor. So then, you’re not starting from zero with him; he has all your information from all those years, so there is a smoother transition of care.”

Michael DiLorenzo, 32, non-Hodgkin’s lymphoma survivor diagnosed age 6, Pennsylvania

Continued research is needed on the long-term effects of cancer treatment on pediatric cancer survivors.

Speakers at the Panel meetings, including representatives from the IOM study of childhood cancer survivors, the Children’s Oncology Group, and academic medical centers specializing in childhood cancer treatment underscored the need for continued research on the long-term effects of treatment on survivors of childhood cancers. The IOM has identified four broad research priorities:[93]

- Assess the prevalence and etiology of late effects.
- Test the potential for the reduction of late effects during treatment.
- Develop interventions to prevent or reduce late effects after treatment.
- Further improve quality care to ameliorate the consequences of late effects on individuals and families.

The limited follow-up of pediatric cancer patients is an important barrier to this research. Although most survivors of childhood cancers are treated on clinical trials, follow-up seldom continues for more than two years post-treatment. Late effects, however, may not arise until several years, or even decades later. Nor is follow-up provided in a systematic manner based on cancer type, stage, and treatment. Many patients who have traveled to cancer centers for treatment return to communities that lack health care providers familiar with late effects of cancer treatment, and may become lost to follow-up. Further, some survivors want to put the cancer experience behind them and may not be amenable to participation in survivorship studies. By one estimate, less than ten percent of survivors diagnosed before age 15 were being followed twenty years later.[94]

Several speakers believed that long-term survivorship clinics offer a locus for maintaining contact with and compiling information about the experiences of survivors of childhood cancers. Currently, most such clinics are located within pediatric cancer treatment centers, however, some patients resist coming back to the facility at which they were treated because of bad memories. Survivors who have become adults also indicated that returning to a pediatric facility can be uncomfortable—for example, a speaker commented that it was disconcerting to return for care to a place that is decorated with building blocks and cartoon characters. It was suggested that they might be more willing to attend a clinic located in a separate facility; such an option would be feasible in a major metropolitan area, but because of the small number of pediatric cancer survivors nationwide, would not likely be possible in more rural settings. The testimony suggested that no such facilities exist at this time.

Recommendation

See Recommendations 1c and 4c.

"I am followed by a pulmonologist, a cardiologist, a gynecologist, a prosthetist, and an oncologist; for every 'ist' doctor there is, I have one. And it's overwhelming and confusing because I coordinate all that care by myself—with the help of my friend who is a nurse specialist—but basically by myself. . . .every time I face a normal medical situation—like the kidney stone I had last year . . .I have to re-educate everybody on my issues, and it's almost like they don't believe me, I have to convince them."

Angie Farfan, 30, metastatic Ewing's sarcoma survivor diagnosed ages 4, 10, and 14, Missouri

"I noticed that after going to camp [for siblings of cancer patients] a few times, they stopped treating me like I was going to break. And it also helped them because at some points it seemed like I was getting all the attention, and they weren't getting any attention at all. . .having a week and a weekend set aside during the summer just for them, for siblings, it's pretty good."

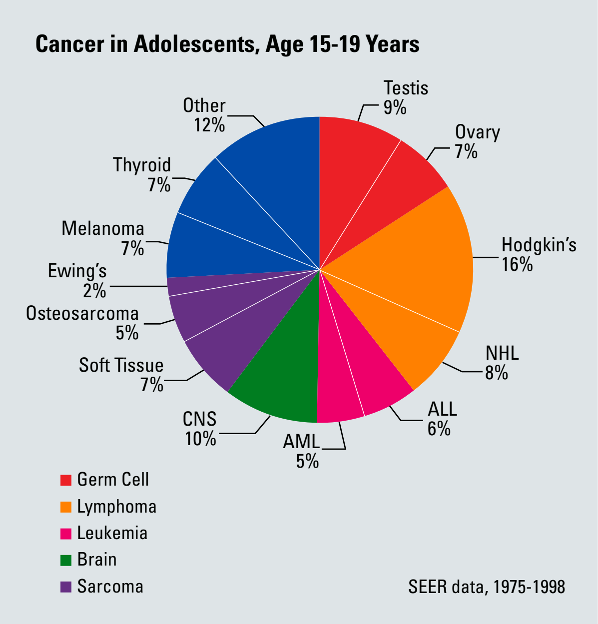
Alfredo Cerritos, 21, leukemia survivor diagnosed age 8, Maryland

Issues of Cancer Survivors Diagnosed as Adolescents or Young Adults

According to the recent IOM report on childhood cancer survivorship, approximately one-third of all patients with cancer under age 20 are diagnosed between the ages of 15 and 19.[95] In the age group 15 to 29, cancer diagnosis is 2.5 times more likely than among the under 15 age group.[96] Figures 7 and 8 illustrate the most common diagnoses among those aged 15 to 19 years, and among those 20 to 29 years of age. Some of the cancers occurring in people in their twenties, and sometimes in their thirties, are malignancies that most often occur in the pediatric population. An estimated 600,000 cancer survivors alive today were diagnosed between the ages of 15 and 29.[97]

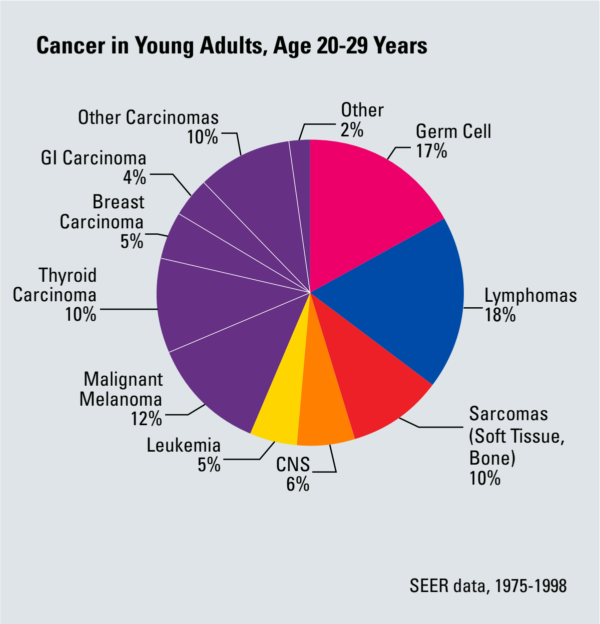
Cancer survival among children has increased dramatically since the 1970s, and steady increases in survival from many adult solid tumors have been achieved over the past 20 years. Yet survival among patients diagnosed as adolescents and young adults has not kept pace with progress in the younger and older age groups. Major factors contributing to this failure are a lack of knowledge about this age cohort, limited clinical trial participation, lack of follow-up, lack of health insurance among this age group, and lack of health professional education about cancer in and survivorship needs of this population. In addition, due to psychological and social factors, patients in this age range may be at higher risk of delayed diagnosis because they are hesitant to discuss their symptoms or seek medical attention.[98]

Figure 7

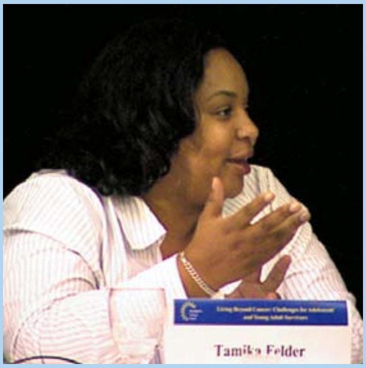

Cancer in Adolescents, Age 15-19 Years

SEER data, 1975-1998

Figure 8


Cancer in Young Adults, Age 20-29 Years

SEER data, 1975-1998



“I was diagnosed at the age of 25. It was the time in my life where I can simply describe it as just being glorious, you know… I had a bright future ahead of me and then all of a sudden—cancer.”

Tamika Felder, 28, cervical cancer survivor diagnosed age 25, Maryland

“…get your patient, friend, family, relative, whoever it is, and encourage them and force them if you need to, empower them, invigorate them to bring the information [about late effects] back to us because we really need it desperately.”

Archie Bleyer, oncologist, Texas

Some of the issues described by those who provided testimony are common to survivors of pediatric cancers and to adults. These are discussed above (Issues Affecting Survivors Across the Life Span); however, speakers emphasized four issues of special concern to survivors diagnosed between the ages of 15 and 29.

Adolescent and young adult cancer survivors are an understudied population.

Compared with other age groups, adolescents and young adults with cancer are a vastly understudied population, considered by some to be the “orphaned cohort.” Less than one percent of cancer-related citations in the National Library of Medicine’s PubMed database between 1993 and 2003 are specific to survivorship issues among the adolescent and young adult population.[99] Few studies are conducted that involve only survivors diagnosed as adolescents or young adults. Typically, they are included in larger studies that include those diagnosed in childhood, and data on adolescents and young adults in these studies often are not reported separately. As a result, relatively little is known about the survivorship needs and concerns of this population.

According to an oncologist specializing in the treatment of this age group, cancers that peak in incidence in the adolescent/young adult age group may have distinct biological differences compared with the disease of the same name that occurs in older persons. For example, melanoma that occurs in this age group does not appear to be related primarily to sun exposure, as is true in older adults. Studies are needed to identify biologic aspects of disease—including tumor characteristics and host factors—that may be unique to this age group. This knowledge would enable researchers to devise more effective treatment protocols for these patients.

Survivors diagnosed as adolescents and young adults are under-represented in treatment clinical trials. Trial participation is lowest among those aged 15 to 30 years, regardless of gender, race, or ethnicity, and this population is least likely to be referred to a tertiary care center. For most cancers, adolescents have better five-year survival outcomes when treated in a pediatric cancer center.[100,101] These findings suggest that decisions about treatment location should be made based on the nature of the disease rather than the age of the patient. However, some children’s hospitals do not accept patients over 16 years of age, and many will not take patients over age 21. Only 21 percent of patients diagnosed at ages 15 to 19 are treated at Children’s Oncology Group member institutions.[102]

Though reliable data are lacking, follow-up of adolescent and young adult patients appears to be even less consistent than among other age groups. Speakers stated that long-term surveillance of people diagnosed as adolescents or young adults is hampered by HIPAA privacy provisions that have erected information access barriers. Adolescent and young adult survivors who testified emphasized their interest in information related to their long-term health and well-being. They urged that patients be involved actively in their care during the treatment phase, and while recognizing that some survivors may shun ongoing involvement after completing treatment, maintained that most were eager for continued contact.

The infrastructure for maintaining contact with this population of survivors is largely lacking. It was suggested, however, that NCI's SEER cancer registry program, the CDC-supported National Program of Cancer Registries, the American College of Surgeons, and the Children's Oncology Group databases could be coordinated and expanded to include and follow every adolescent and young adult with cancer. The military and veterans health system databases also might be included in such an effort. Speakers agreed that additional funding would be required for such an initiative.

Recommendations

(See also Recommendation 3b.)

11a. A working group comprised of representatives from public agencies and private organizations with established surveillance databases should be convened to determine what additional data collection, infrastructure, and related funding would be required to better capture treatment and survival data on adolescent and young adult cancer survivors.

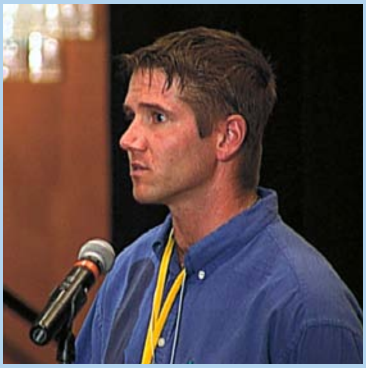
11b. NCI and other cancer research sponsoring agencies should increase the priority of and funding for research on the issues of cancer survivors diagnosed as adolescents or young adults. Studies of biologic differences in cancer type and host factors, and of late effects of cancer and cancer treatment in this population should be emphasized to improve the knowledge base and inform the design of treatment, prevention, and quality of life interventions designed to benefit this population.

"...college is an environment where independence, resourcefulness, and social skills are vital. I lacked them all and I was basically drowning....I managed to pull through and graduate, [but] it was all as a result of, kind of, the psychosocial stalling I experienced while I was on treatment [for over three years]."

Octavio Zavala, 30, leukemia survivor diagnosed age 12, California

"I wanted to be home for the football games, so they would give me three hours [of hydration] and we would drive home....[Afterward] I would drink as much water as possible, and drive all the way back and get hooked back up to hydration, because to me the most important thing was that my life remain the same...those bits of normalcy began to be what was keeping me alive..."

Amy Dilbeck, 23, osteogenic sarcoma survivor diagnosed age 15, California



“I was going through treatments at the age of, essentially, 13 to 18, the developmental years in my life. I really didn't understand the impact of what I went through until after I went through college and went for my master's degree…when I reflected on my life and realized that what I went through didn't make me who I am, but it had an incredible impact on my life…. I think it would have helped to actually have some type of—not necessarily support group, but literature, the Internet, anything to provide [information on] those long-term psychological effects…”

Sean Swarner, 30, Hodgkin's lymphoma and primitive neuroectodermal tumor (Askin's disease) survivor diagnosed ages 13 and 15, Colorado

“…I am only 28. I am uncertain about future relationships, being a single woman I don't know how —if I meet someone and I date, do I say, ‘Hi, I'm Tamika. I'm unable to have kids’?”

Tamika Felder, 28, cervical cancer survivor diagnosed age 25, Maryland

Adolescents and young adults with cancer have significant unmet psychosocial and educational needs.

Adolescents and young adults who are diagnosed with cancer typically face a loss of independence and disrupted plans and relationships at a stage in life during which establishing independence, relationships, and career choices are major developmental tasks. In addition, these survivors are taken away from their normal social milieu at a time when they should be learning social, coping, and negotiation skills critical to successful adult functioning. In this respect, their social development may be hindered, though neither the survivor, the family, nor health care providers may recognize or address these issues at the time.

Speakers described eloquently their struggles to retain aspects of normalcy in their lives during lengthy periods of treatment, and in the months and years that followed treatment. Some stated that their experiences had left them out of touch with issues important to their peers (e.g., entertainment, fashion) that they found superficial and unimportant by virtue of the suffering they had seen and experienced. Such differences sometimes made it particularly difficult to reintegrate into school environments. Other survivors described receiving extraordinary support and understanding from classmates and friends, which seemed to help despite still being acutely aware of differences in perspective and priorities.

Survivors who have short-term memory difficulties, information processing problems, or other learning changes or disabilities as a result of their cancer or its treatment may have significant difficulties upon returning to the classroom, whether in high school, college, or graduate educational settings. Particularly in the post-secondary setting, where parental intervention may be less likely, students may have difficulty advocating for accommodations in the use of instructional tools or assistance (e.g., note-takers) and in testing methods.

As with children, cancer treatment may arrest the physical growth of survivors diagnosed in adolescence, leaving them significantly shorter than their peers. Others may have to adjust to amputations, obvious scarring, or other physical changes that set them apart from peers at a time in life when body image is extremely important to most. A survivor of pediatric and adolescent Ewing's sarcoma admitted that she married someone she did not really love because he was a nice person who was willing to marry someone with only one leg. It was several years before she realized that she did not have to settle for an unfulfilling relationship simply because of her disability and ended the marriage.

Survivors in this age group also noted difficulties in dating and establishing relationships; specifically, when to tell a prospective mate about having had cancer and about any disabilities or adverse treatment effects (e.g., infertility, cardiac problems).

Several young survivors described anxiety, depression, and an inability to plan for the future following their cancer treatment, as well as feelings of isolation and survivor guilt (i.e., why did I survive when others I knew in treatment died?). In some cases, according to speakers, these problems did not arise until years after their treatment ended, because in their eagerness to resume their lives and schooling, they did not recognize or acknowledge their feelings. One speaker noted that it was not until he was foundering in college that he began to recognize his depression and anger at having had cancer as the root of his problems. However, even when they were aware of their depression or other problems, some of these speakers hesitated to join support groups or receive traditional psychotherapy. To paraphrase one survivor, *"I wanted to be socialized, not psychologized."* Several speakers indicated that they did not seek out a support group for young adult survivors for five or more years after their treatment ended. One young woman stated that although a post-treatment psychosocial program was available, she initially was too proud to take advantage of it. Others stated that for them, the best therapy was found in helping others.

Recommendations

12a. Family members, primary care providers, cancer specialists, and others who are close to or provide medical care to adolescent and young adult survivors should be made aware that depression, anxiety, or other psychosocial issues may affect the survivor long after treatment ends and should be instructed on how to intervene should the survivor experience such difficulties. (See also Recommendations 1b and 5a.)

12b. Adolescent and young adult survivors should be taught self-advocacy skills that may be needed to secure accommodations for learning differences resulting from cancer or its treatment. Physicians and other providers should act as advocates for survivors when necessary.

"It's 31 years later and I still don't have…a savings account. I think our sense of the future is very different."

Susan Leigh, 56, Hodgkin's lymphoma, breast, and bladder cancer survivor diagnosed ages 24, 43, and 48, Arizona

"I am currently applying to medical school but last year and even recently…it was hard for me to decide if that was the right decision to make. I mean, should I prepare as if I was going to live for only five years or 20 years?…medical training takes ten years and, you know, if I was only going to live five years, I would not have lived to actually become an active, practicing physician. To me it really didn't matter when I was going to die. I just wanted to make the most of the time that I had."

Michael Lin, 22, Hodgkin's lymphoma survivor diagnosed age 20, Missouri

“…I was in a pediatric hospital [but] they didn’t have radiation therapy machines big enough for a 15-year-old so I was then sent to… an adult hospital. And as a 15-year-old, I thought it was strange that I was next in line, if you will, ready to get zapped with 65-, 75-, and 80-year-old people who were going through radiation therapy.”

Eric Rodriguez, 26, brain survivor diagnosed age 14, Massachusetts

“I worry about losing my insurance, about not being able to afford follow-up care because the insurance system is so insane. What to tell my employers, if anything, how to find a new health care team if I move. These are among the things I worry about.”

Karen Dyer, 24, rhabdomyosarcoma survivor diagnosed age 15, New York

Like survivors of childhood cancers, survivors diagnosed as adolescents and young adults who are treated in the pediatric setting are not being transitioned appropriately to care in the adult setting.

Though this is particularly an issue for adolescents, some young adults are treated in pediatric facilities if their cancers are those that most often occur in younger people. At the point that young adults complete treatment, failure to communicate adequately to adult care providers who will take over the management of these patients is common. This situation is compounded by the fact that many young adult survivors complete treatment and move out of the area to attend college or take jobs. The result is that many young survivors “get lost” in the system and lost to systematic follow-up. This is an issue even for adolescents without special health issues.

The aunt of a 20-year-old diagnosed with Ewing’s sarcoma stated that although her nephew’s health plan sent him to a children’s hospital for treatment, the lack of coordination and difference in attitude toward care when he returned to the adult care setting was striking and unsettling. It was suggested that a medical specialty in adolescent and young adult oncology is needed so that these survivors can be served by health professionals who are knowledgeable about and attuned to their needs.

Recommendation

See Recommendation 10.

Adolescent and young adult cancer survivors have special employment and insurance issues and needs that require remedy.

Many survivors of adolescent and young adult cancers are likely to have limited work experience, compared not only with older persons, but also compared to peers, putting them at a disadvantage when seeking employment after treatment. This situation may be exacerbated if the survivor has a disability or other after-effect of cancer or cancer treatment that requires special accommodation in the workplace. Even without a condition requiring accommodations, young survivors seeking employment may experience discrimination in hiring if they reveal a cancer history.

Young adults have a high likelihood of becoming uninsured when they no longer are able to remain on their parents' health policy. Typically, young adults are dropped from their parents' health insurance policy when they become 19 years old unless they are full-time students, in which case coverage may continue until age 23. They also may be dropped from public insurance programs such as Medicaid and the State Children's Health Insurance Program (SCHIP) upon reaching age 19, or when they begin working and exceed the income ceiling of the program. According to U.S. Census Bureau statistics,[103] people 18 to 24 years old have the highest uninsurance rate—30 percent in 2002. Twelve percent of younger adolescents and children (0–18 years old) were uninsured, and a quarter of young adults over age 25 were uninsured in 2002. The population aged 13 to 29 also is least likely to be eligible for Supplemental Security Income (SSI) benefits due to a cancer diagnosis.[104] Lack of insurance is a major factor in the scant participation of young adults in clinical trials.

Without insurance, or adequate insurance, survivors may be unable to pay for needed follow-up care, and may forgo needed psychosocial assistance because it is not covered and too expensive to pay for out-of-pocket. Similarly, with both limited employment and lack of insurance (or inadequate insurance), survivors diagnosed in adolescence and young adulthood are unlikely to have the financial resources to travel to receive specialized care should the need arise. Ironically, a speaker who became employed at the hospital at which he had received his treatment could not get coverage for his follow-up care; though sympathetic to his problems, his employer could only advise him to try to work with the insurance company.

Young adults with cancer who are employed may experience "job lock;" feeling compelled to remain in an unsuitable job for fear of losing health benefits. This is particularly detrimental for people in this age group. Ideally, young adulthood is a time to try different jobs to find the work environment and duties that are a good fit with the individual's skills and interests.

If insured, survivors in this age group may be at a disadvantage in submitting health care claims paperwork and negotiating with insurers to ensure that claims are paid. During treatment, and perhaps for some time afterward, parents assumed these responsibilities for adolescent survivors. Speakers in this age group remarked on the difficulty they experienced as they began to assume control of insurance-related paperwork and managing their own care.

"It took me about another two years to finally get insurance and that was so difficult to do because it is just hard to be young, straight out of college, and get a job that will take you and insure you for medical reasons. And then you think, wow, I have insurance finally, and you realize that it doesn't matter because it's not going to get you what you need…

I still go back to Children's Hospital [for my long-term follow-up]… all they can really do is look at my charts and give me consultation services because I have to pay for things out-of-pocket there and I simply would not be able to afford to pay for ECHOs, MRIs, bone density scans…"

Octavio Zavala, 30, leukemia survivor diagnosed age 12, California

Young adults with cancer may leave treatment with significant debt due to non-covered cancer-related care that will be a burden as they attempt to establish themselves as self-supporting individuals. In addition, many adolescents and young adults with a cancer history will find it difficult or unaffordable to obtain life or disability insurance. For survivors starting families, this is a serious barrier to establishing family financial stability.

Recommendation

See Recommendation 7a.

"I started my own business… because I couldn't find employment due to my visual disability and my physical disability…[also] because of health insurance… once you get to a certain point in education, Social Security, social services doesn't help out. Once they see that you have an undergraduate degree or even a master's degree they think you are fine, you have no problem."

Eric Rodriguez, 26, brain tumor survivor diagnosed age 14, Massachusetts

"…I didn't have the support of a husband or someone else to carry that load. It was just me. I don't come from a wealthy family so I had to carry the load of all my bills and everything else."

Tamika Felder, 28, cervical cancer survivor diagnosed age 25, Maryland


President's
Cancer
Panel

Issues of Cancer Survivors Diagnosed as Adults

Nearly 40 percent of all cancers are diagnosed in people aged 30 to 59 years. The most common malignancies affecting this age cohort are cancers of the female breast, prostate, lung and bronchus, skin (melanoma), non-Hodgkin's lymphoma, and female genital system (cervix, corpus uteri, other uterine, ovary).[105]

Survivorship research grants focusing on adults (defined as those aged 40 to 64) make up 70 percent of the entire FY 2002 NIH survivorship research portfolio. Most of the research on this population has focused on breast cancer survivors, since breast cancer is the most common malignancy diagnosed in adult women. Intervention research, particularly addressing some aspect of psychological distress and sexual and reproductive issues, is heavily represented in the research portfolio to date.[106]

Testimony at the Panel's meetings emphasized three key areas of concern among survivors in this age group: lack of follow-up care guidelines, psychosocial needs of survivors, and employment and insurance concerns. Details of these concerns are discussed below, however, many of these issues in their broader sense also are common among survivors of other ages. For this reason, most of the recommendations related to the adult survivorship concerns described are found on pages 15–39, Issues Affecting Survivors Across the Life Span.

Limited recommendations exist to guide the follow-up care of people with adult-onset cancers.

Efforts have been underway for some time to develop long-term follow-up care guidelines for survivors of pediatric cancers, and such guidelines have only recently been published (http://www.childrensoncologygroup.org/disc/LE/default.htm). Far less, however, has been done to develop equivalent guidelines for adults, and limited recommendations exist to guide the follow-up care of those with adult-onset cancer. Those that exist (e.g., American Society of Clinical Oncology guidelines for breast,

> "…the number of adult cancer survivors is increasing, and that is especially true of the number of survivors who have received radiation and chemotherapy, and they have not really been studied in the way that the kids have been studied. So, many issues concerning adult survivors are largely still unknown, and need to be discovered."

Anna Meadows, oncologist, Pennsylvania colon, and prostate cancers) focus almost exclusively on monitoring for recurrence, but do not include guidance for monitoring for late effects of treatment or second cancers, principally because limited high quality evidence exists to support guideline development. Existing guidelines also do not address rehabilitation, psychosocial, or other possible survivor health issues.

While survivors and some providers who testified urged the development of comprehensive follow-up guidelines as a tool for improving quality of care, it also was noted that some providers may resist following guidelines if they believe that the best care for an individual patient differs from the guideline. Providers recognized, however, that their failure to follow a guideline could result in litigation at some point in the future. Lacking firm guidelines, they acknowledged that most providers practice "defensive medicine," sometimes ordering tests that may not be essential as insurance against making an error of omission.

As with children, lack of guidelines has affected the insurance reimbursement available for follow-up surveillance testing (e.g., cardiac testing for patients treated with adriamycin, pulmonary function testing for patients treated with bleomycin, periodic PET or other costly scans as recommended by the survivor's physician) or supportive care adult survivors may need, thus reducing access to this care for many. As with younger adults and uninsured adolescents, if follow-up care is not covered by insurance, some survivors delay or do not get recommended care.

Of note, in April 2002 a Conference on Guideline Standardization, supported by AHRQ, brought together experts in clinical practice guideline development, dissemination, and implementation to develop a core set of guideline components. These were documented in a guidelines checklist as a framework to support more comprehensive and consistent documentation of practice guidelines, and were reviewed favorably by multiple organizations active in guideline development.[107] This checklist may provide a framework for developing more complete recommendations for post-treatment care for this population of cancer survivors.

To help develop the necessary body of evidence concerning late and long-term effects experienced by adults, health care providers in the community need to ask patients with a history of adult-onset cancer about health problems they are experiencing that could be related to the cancer or its treatment.

"…it is important to have guidelines. It is important to have scientific rigor with those guidelines but it is really, really important to make sure that the person who is applying those guidelines to the care of their patient realizes they are sitting across from another human being and, in fact, they need to mitigate everything and the judgments have to be made in the context of what is happening with that person as well."

Alexander Hantel, oncologist, American Society of Clinical Oncology, Illinois

"I am currently being treated as an outpatient. This has enabled me to continue working, a necessity for me because I am a single parent. I am also having to deal with other family issues, an aunt with Alzheimer's and an 83-year-old mother. Many adult survivors are part of that "sandwich generation" caring for both their own children and helping their aging parents."

Debra Thaler-DeMers, 49, oncology nurse, Hodgkin's lymphoma and breast cancer survivor diagnosed ages 25 and 45, California

Recommendation

13. The American Society of Clinical Oncology, the American College of Surgeons, the American College of Radiology, NCI, and other major cancer clinician and research organizations should develop more complete recommendations to guide the post-treatment care of survivors of adult-onset cancers. These recommendations should be published and posted on a website and updated regularly to ensure that survivors, patient educators, providers, and insurers have access to them.

The special psychosocial needs of adult cancer survivors are not being met.

Cancer occurring during the prime and middle years of adulthood can seriously disrupt the survivor's ability to carry out his or her family and work-related responsibilities, often temporarily, but sometimes permanently. Many adults invest a great deal of their self-esteem in their ability to function effectively in multiple roles—parent, spouse/significant other, caregiver, financial provider, worker, and simply as an adult in society. Cancer can dramatically alter a person's vision of the future, calling into question not only one's mortality, but assuming survival, one's vitality and ability to fulfill these multiple roles and reach important life goals. Often, according to speakers, these concerns are not acknowledged by health care personnel, who may be focused solely on medical issues, and survivors may not know to whom they can turn to discuss such matters. Unaddressed, these issues may lead to depression, anxiety, stress, and loneliness.

A considerable number of adult cancer survivors are part of the so-called "sandwich generation"—adults who are caring for both children and aging parents. Though stressful even under favorable circumstances, cancer survivors in this situation may be under additional stress as they try to manage these responsibilities along with their own disease or late effects of treatment.

Several speakers whose cancers were diagnosed in adulthood spoke candidly about the impact of cancer on their intimate relationships, particularly difficulties with re-establishing intimacy within their marriages. Both men and women described loss of libido and concerns related to physical changes. Among men, impotence related to prostate cancer treatment was an important issue for which interventions exist but are less than satisfying. A survivor of two primary breast cancers and recurrent disease being treated for chronic pain stated that vaginal

"[For impotence] they have a vacuum pump and they have a prosthesis that you can insert surgically. There is a lot of different things....I was trying to do injections into the penis and I used to say to my wife, 'Now, I am going to go in the bathroom and I am going to inject myself. If you get a headache you are in big trouble.'...Even though the mechanical part of it worked, the psychological, emotional part never worked.

...loss of libido is really tough because, you know, I was very conscious of my wife and her needs...it was probably the most difficult side effect that I had to live with..."

Emanuel Hamelburg, 63, prostate cancer survivor diagnosed ages 47 and 51, Massachusetts atrophy, a side effect of extended opioid use, has prevented her from having intercourse with her husband for most of their marriage. A newly married survivor of Hodgkin's lymphoma indicated that although he said nothing to her, her husband was worried about the decline in their sex life during her treatment.

An oncology nurse noted the enormous unmet need for counseling and assistance to help survivors and their partners find ways to regain intimacy despite disabilities or other bodily changes—at a recent conference for survivors, she was asked to repeat her workshop on sexuality and fertility five times over a two-day period. Like adolescents and younger adults, adult survivors who are single face dilemmas related to forming new intimate relationships, particularly if they have sexual side effects of their treatment. For some adults in their thirties, fertility is still a major concern, and may be an issue for some into their forties.

Recommendation

See Recommendations 5c and 6a.

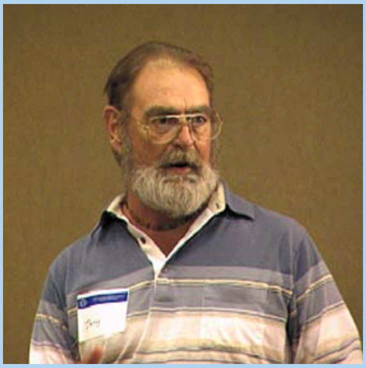
Adult cancer survivors have employment and insurance issues that require greater support.

In addition to needing to retain their own financial independence and stability, a large percentage of cancer survivors diagnosed between the ages of 30 and 59 have families to support. Even with job protections available under the Family Medical Leave Act (see page 19), survivors may suffer a major loss of income during extended treatment, and income may be further reduced if a working spouse must take time off or leave his/her job to care for the person with cancer. Financial stability may be further jeopardized if parents must incur new childcare or other non-medical expenses, and pay for non-covered costs of care both during and after treatment.

On returning to work after cancer treatment, some survivors may need alterations in their work schedule or duties, either temporarily or permanently, due to physical or cognitive disabilities. Such accommodations may be difficult to negotiate with some employers, who may be concerned that the survivor will not be able to carry the full responsibilities of the job or will be absent from work more than other employees. In fact, research indicates that most survivors do return to work and may have no greater absenteeism than employees without a cancer history.[108,109] Survivors may find they have to educate their employer about cancer and about survivors' work performance to overcome these obstacles.

"I was denied, flat out denied, disability coverage for any and all health reasons again based only on the fact that I am a cancer survivor. This leaves my family exposed… to potential financial ruin should I have a catastrophic recurrence of cancer or heart disease or anything simply because of my previous history with cancer even though I am a long-term survivor."

Matthew Bennett, 39, testicular cancer survivor diagnosed ages 30 and 31, Alabama



"Credit reports still from 13 years ago are on my credit [record]. I cannot get credit….We always believed we would rebound and pay off our debts but after losing my job here recently in 2002 we have had to file bankruptcy. We had no credit card debt, just every day bills…. No one is hiring a 60-year-old that you have to give extra training to because of short-term memory problems, other physical and mental problems showing up after the bone marrow transplant 14 years later."

Jerry Johnson, 60, Hodgkin's lymphoma and prostate cancer survivor diagnosed ages 46 and 57, Texas

Despite protections afforded some employees under ERISA and HIPAA, many survivors still stay in unsuitable jobs to avoid losing health benefits. Some employees also may have employer-sponsored disability and life insurance. These types of insurance generally are not portable (i.e., benefits would be lost upon leaving the employer), and would be virtually impossible for a person with a cancer history to replace through individual policies. New employers may or may not offer such coverages, and unlike group health plans governed by HIPAA provisions, submitting to a medical examination, providing a medical history, or enduring waiting periods may be required before the survivor would become eligible for benefits.

Adults who retire before they reach age 65 and become eligible for Medicare need to be aware of the accelerating trend toward reduction and elimination of retiree health benefits. Even the declining number of large employers that are retaining retiree benefits increasingly are eliminating premium subsidies (typically around 60 percent) and requiring retirees to shoulder the full cost themselves, which may prove unaffordable for many. A renowned health economist predicts that in 20 years, no company will offer retiree health care.[110]

Working women with health problems in the 55 to 64 year old age group are a particularly vulnerable group. They have been found to be more likely than younger workers to lack employment-based health insurance, to be uninsured, and to have insufficient income to purchase insurance.[111] Survivors in this age group who lose or must leave their jobs because of illness are too young to qualify for Medicare and may be at especially high risk of becoming uninsured.

Recommendation

See Recommendations 7a, 7b, and 7c.

"I cannot lower my premium with [my] current insurance company because of my history of cancer and I cannot change to another insurance because of the same reason. I am not yet 65 years old and I am in the middle class, middle income household. And so I am not eligible for either Medicare or Medicaid. What can we do? Who do we turn to? I survived the cancer but I cannot pay for necessary treatment post-chemo. I feel like I am being punished for surviving cancer."

Boonsee Yu, 57, colon cancer survivor diagnosed age 53, New York

"...unlike my first time around, [we had] 100 percent support from both my employer and my wife's employer helping us get through this. Not necessarily financially but we both were secure in the fact that we were not going to lose our jobs while we were off and I was trying to live. That makes a difference."

Matthew Bennett, 39, testicular cancer survivor diagnosed ages 30 and 31, Alabama

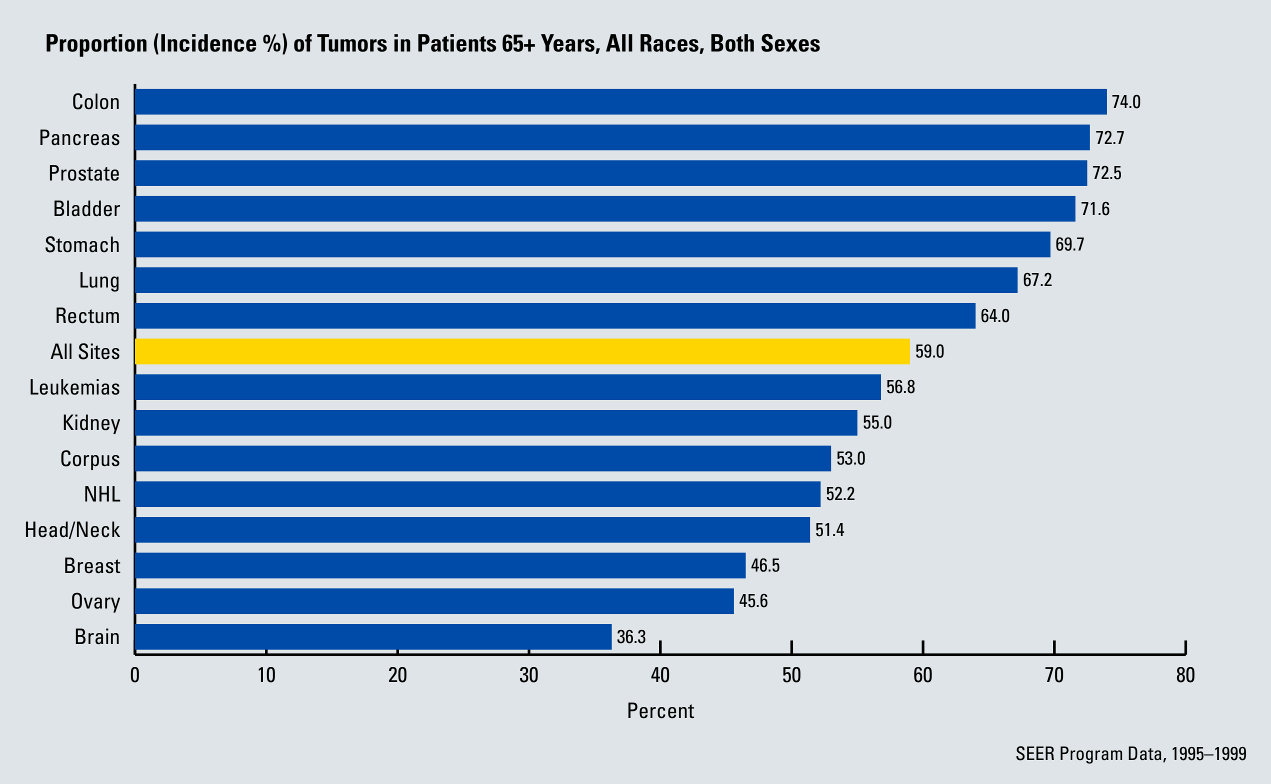
Issues of Cancer Survivors Diagnosed as Older Adults

Most of the major solid tumors primarily affect older people. Incidence of most cancers rises with age, and 59 percent of all cancers occur in those over age 65. As Figure 9 shows, for both sexes combined, people over age 65 account for two-thirds to three-fourths of colon, pancreas, prostate, bladder, stomach, lung, and rectal cancers.

Sixty-one (61) percent of cancer survivors alive today are over age 65. The current average ages of male and female cancer survivors are 69 and 64, respectively.[112] However, although older survivors comprise nearly two-thirds of all survivors, available information about their survival experiences is quite limited. Factors contributing to this deficit include comorbid conditions of older people that complicate treatment and have inhibited research in this population, explicit exclusion of older people from cancer clinical trials due to perceived risks, and research emphasis on younger age groups (particularly pediatrics) due in part to ageism.

At the Panel's meetings, this group of survivors expressed coping strategies and concerns not described by those in the younger age groups. For example, among some of the older individuals who spoke, there appeared to be a perspective

Figure 9



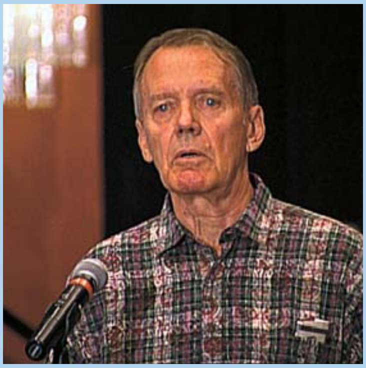
on life and on the cancer experience seemingly tempered by lifetimes that already had weathered some adversities and losses. Speakers noted the value of finding humor even in the cancer experience. One speaker stated that at the end of every meeting of his colon cancer support group (the "Semi-Colons"), each person is asked to tell a joke so that everyone leaves with a smile.

Like younger survivors, speakers in this age group spoke about their involvement in cancer education, awareness, and support activities following completion of their treatment. However, the greater level of interest and activity in the legislative process at State and Federal levels was notable in this group compared with others.

In addition, several older speakers expressed concern that they may have passed on a genetic predisposition to cancer to their offspring. This concern also was voiced by younger survivors who had children.

"What has cancer given me besides the unwanted side effects? Well, it has given me wavy hair…. You have got to find humor in everything that happens. If there is humor there, hold on to it."

Mary Jo Albee, 69, endometrial cancer survivor diagnosed age 68, Iowa



"When the surgeon told me that I had the cancer, I said, 'You know, that really doesn't bother me too much, because I'm 75 years old, and there are all kinds of diseases trying to get me in the next three years, so I'll just throw this in the bag with the others.'"

Dick Tenney, 77, gastrointestinal stromal tumor survivor diagnosed age 75, Colorado

Job loss, forced retirement, and loss of health benefits are significant concerns of older working cancer survivors.

Many survivors aged 60 and older are still working. Some may need or want to work, but may be forced into retirement by a cancer diagnosis. Speakers testified that they feared losing their incomes and their employer-sponsored health benefits as a result of having cancer. The loss of health benefits available while an individual is still employed can be a major issue both for older survivors, and for spouses who are themselves survivors, particularly when they are not yet eligible for Medicare. This vulnerable population may have great difficulty finding affordable insurance, or any insurance at all. As noted earlier, retiree benefits have been eroding steadily over the past 25 years,[113] and a recent survey of 400 large employers indicates that this trend will continue, with new retirees most affected.[114]

The majority of survivors who are diagnosed with cancer at age 65 or older will be covered by Medicare. It is unclear, however, what impact recent changes in the Medicare legislation will have in the coming years on cancer survivors in terms of payment for the range of services and medications they may need as part of their follow-up care. Reductions in coverage, increased premiums, or higher copayments may force some to forgo Part B (outpatient and all physician) coverage. Others who can afford Part B premiums may be unable to afford Medicare supplemental insurance (or a sufficiently robust supplemental policy), however, leaving them liable for considerable out-of-pocket expenses. Moreover, even those with Medicare and Medicare supplemental benefits are likely to sustain out-of-pocket health costs that can strain fixed income budgets and may cause survivors to decline care they cannot afford. Of the older survivors who testified, most had Medicare supplemental insurance that covered some of their expenses not reimbursable under Medicare. Even with supplemental coverage, however, some incurred substantial out-of-pocket costs that were difficult to manage.

Older survivors are not always eligible for Medicare. These include people who were subsistence farmers or fisherman, other self-employed individuals who did not pay enough into the Social Security system to qualify for benefits, and many immigrants. Some of these older survivors may qualify for Medicaid or other State level medical assistance programs. Others may have no health coverage at all; their access to follow-up testing and needed ancillary services is likely to be extremely limited.

An older lung cancer survivor who has exhausted most available treatment options noted that a medication approved by the Food and Drug Administration for colon cancer is expected to be tested in lung cancer, for which it appears promising. To receive the drug sooner outside of a trial, however, she would have to pay for it out-of-pocket at a cost of $2,000 per month. She is retired and on Medicare and cannot afford this cost. She recommended that new drugs and "off-label" uses of drugs be made more available to patients on fixed incomes through "compassionate use" programs of drug manufacturers.

Recommendation

See Recommendation 7a.

14. The Institute of Medicine or other independent body should undertake a periodic assessment of the impact of Medicare legislative changes on older cancer patients' access to care and other follow-up services.

Comorbidities remain a barrier to the most appropriate cancer care for many older people with cancer.

Older adult survivors are far more likely than younger persons to have one or more comorbidities (e.g., concomitant illnesses or health problems) that may affect their ability to obtain needed cancer-related care. Comorbidities (such as heart disease, hypertension, stroke, diabetes, arthritis, digestive problems,

"…if somebody becomes eligible for a Medicare supplement because they sign up for Medicare Part B, they have six months to enter the program without us ever asking a question about past or current health care history. If they wait longer than that, then it is like the person who decides to buy flood insurance when there is water in the basement. You can buy certain levels of protection, but you cannot get the whole thing because it would be unfair for those that have prepaid. It would also make it unaffordable for those who have prepaid, and it would encourage everybody to wait until the time that the flood has started.…Granted, with people who wait to the last minute, the benefit design may be narrow."

Richard Migliori, physician and administrator, United Resource Networks, Minnesota

“Compression hose [for lymphedema] was suggested by my local physician. I have not bought any. They are very expensive. My legs are two different sizes….I would have to buy either two pair—one of one size, and one for the other—or have them custom made, and this is over $100 a pair and they say you should have them new every six months because they lose their elasticity….The compression hose are not covered by Medicare nor by my supplemental insurance.”

Mary Jo Albee, 69, endometrial cancer survivor diagnosed age 68, Iowa

“…if we translate what has evolved successfully in the field of gerontology into oncology, it is the perfect arena for developing a true comprehensive team of individuals in geriatric care…[as well as] comprehensive geriatric assessment that addresses some of the functional disabilities up front before any kind of care decision-making is even made.”

Debi Boyle, oncology nurse, Arizona

Alzheimer’s disease or dementia) continue to be a barrier to treatment and prevention clinical trials participation for some older survivors. The historical routine exclusion of people older than 60 or 65 years from clinical trials has resulted in a dearth of research information about the treatment responses and cancer care needs of this population compared with younger age groups.

Encouragingly, one older survivor with a gynecologic cancer, who required heart bypass surgery before she could receive a hysterectomy to treat her cancer, reported that she subsequently was invited to participate in a combination chemotherapy trial. In her case, a significant comorbidity did not prove a barrier to trial participation. An oncologist noted that many comorbidities are becoming less of an issue than previously because advances in anesthesiology and the availability (at least in many major medical centers) of acute care intensivists (physicians specializing in critical care) are making it possible to better manage patients such that comorbid conditions do not pose a significant danger or complication to cancer treatment.

Comorbidities also are a significant issue for older survivors in that they may obscure symptoms of recurrence or late effects of treatment. Patients may attribute symptoms to an age-related condition and fail to seek medical care, thus delaying diagnosis. Similarly, primary care or other medical personnel may not associate symptoms with recurrence or late effects.

It was suggested that treatment protocols and clinical trials designed specifically for older people with cancer are needed to answer some of the questions about the effect of comorbidities on treatment response and the development of late effects in older survivors. Speakers noted, however, that special efforts will be needed to involve older patients in clinical trials; patients treated outside of major cancer centers may never be informed about available trials, and cultural sensitivity and proficiency will be needed to reach and encourage the participation of members of minority and other underserved populations. Further, a goal should be to improve the likelihood that older patients with comorbidities who do not participate in trials are receiving the best known standard care.

Recommendation

See Recommendation 15.

Information about cancer and cancer survivorship in older adults is extremely limited.

Several speakers noted the lack of information about older adult cancer survivors, particularly with regard to late effects of treatment and quality of life issues. Greater participation by older patients is needed not only in treatment trials, but in prevention and survivorship-specific studies.

Among the needs enumerated were: (1) developing tools to address and standardize evaluations of the elderly, including their functional status, psychosocial evaluation, laboratory testing (particularly with regard to pharmacogenetics), and examinations tailored to this age group; (2) defining survivorship issues specific to age and disease type compared with an age-matched control group with similar comorbidities, in order to determine if cancer has an impact independent of the aging process; (3) establishing databases of older adult cancer survivors and of caregivers for longitudinal study; (4) defining the age-associated factors that may exacerbate treatment toxicity and negatively impact survivorship; and (5) developing interventions (e.g., exercise, nutrition, social networks) to prevent or reduce the medical and psychosocial effects of cancer treatment in older patients.

Speakers further noted that elderly survivors five to ten years post-treatment may still be visiting their oncologist, but neither their oncologist nor their primary care provider may be knowledgeable about the long term effects of the treatment received, or about recommendations for colonoscopy, cardiac, PSA, or bone density testing in this age group of survivors based on their treatment. Providing such testing, and gathering information about the health of elderly survivors also is hampered by lack of reimbursement for preventive care by Medicare.

Recommendation

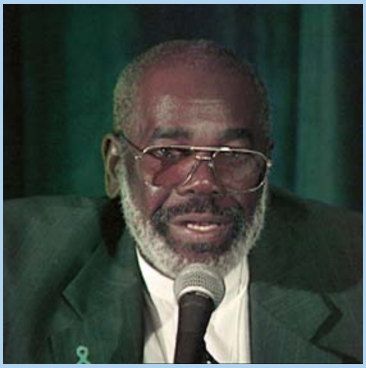
15. Public and privately sponsored research and surveillance on survivorship issues among people diagnosed with cancer in older adulthood should be increased significantly to address the information void on the needs of this population, who will comprise an increasing percentage of people with cancer over the next several decades. (See also Recommendation 3b.)

“There is also a problem of non-participant bias, so in the little literature…available, we are suffering from those participants who do not participate. And so, we may come to a conclusion, but it is like asking everybody at a meeting, ‘Is this a good time to have the meeting?’ and everyone at the meeting says yes. Well, if you ask those who did not make the meeting, the answer is no. And so, we have the same problem of non-participant [bias in] research, particularly in the elderly.”

Carolyn Runowicz, oncologist, Connecticut

“…the node in my neck became enlarged and paralyzed my left vocal cord…I still try and project my voice as well as I can. However, I was [no longer] able to be a sales person because people had problems listening to me and hearing me, especially when there was a noisy convention and we had many meetings like that we had to attend so I had to quit my job.”

Lois Zuspan, uterine and lung cancer survivor diagnosed 1983 and 2001, Alabama



“I was diagnosed at the age of 60. It was the first time in my life that I was going to face major treatment for any disease.… After surgery I found that I had a number of ailments…erectile dysfunction, and incontinence. I went into extreme deep depression. Single, living alone, did not know of a support group—so that tells you something about my early times as a survivor.”

Jim West, 67, prostate cancer survivor diagnosed age 60, Florida

“…all of the times that I went for the various examinations.…I always was alone.…I remember sitting one day waiting for the dye to go through my system and I am looking at everybody coming and going.…Everybody had somebody and there I sat. I couldn’t help it. I wept. I had nobody but I managed to make it through.”

Grace Butler, 67, colorectal cancer survivor diagnosed age 63, Texas

Many older cancer survivors lack adequate social and caregiver support.

Social support and caregiver issues are of special concern for this age group. Many older survivors live alone, particularly women. They may have difficulty in securing transportation to medical appointments and transportation issues may prevent them from participating in support groups from which they might benefit. Many people in this age group are not experienced at using computers or the Internet, and so may not be able to take advantage of available online support resources.

Many have adult children, but they may be unavailable to provide care, either because they live in another part of the country, or because they are overburdened with work and child care responsibilities. Some adult children of survivors may be caring for both parents with concurrent, but different illnesses. One older survivor stated that her only relative, her daughter, was so traumatized by her mother’s colon cancer diagnosis after her father’s death from the same disease that she was unable to be of any help to her. Speakers emphasized that health care providers often assume that the patient has a support system, and this may not be the case.

Many survivors are cared for by their elderly spouse/partner, who like other family caregivers, is likely to lack training to perform home nursing. However, older caregivers also may have comorbidities that include mobility, strength, or other physical limitations. They may no longer drive, or may have short-term memory deficits. Even those who are able to care for a spouse reported uncertainty and stress associated with the caregiver role. One speaker noted that she had to learn to give her husband injections and help him to care for his ostomy; she was fearful that her lack of competence could cause serious injury.

Recommendation

16. Health care providers must ascertain the strength of an older survivor’s social and caregiver support system. This should be assessed at diagnosis, during treatment, and at intervals after treatment is completed. Oncology nurses, nurse practitioners, other advanced practice nurses, physician assistants, social workers, patient navigators, or other non-physician personnel may be best able to make these assessments and arrange assistance and services for survivors who lack adequate support.

Intimacy and body image issues remain an important concern among older cancer survivors.

Survivors who testified stated that intimacy remains an important need in older age. Cancer and cancer treatment can have a severe impact on both intimacy and sexual function. For example, nearly two-thirds of prostate cancer survivors are 65 years of age and older; research indicates that sexual impairment may affect 60 to 80 percent of these men, depending on the type of therapy they received.[115] These survivors also are often affected by incontinence, which may cause embarrassment and be a barrier to intimacy. Other physical changes (e.g., loss of breast, scarring) likewise may affect body image and inhibit intimacy.

Recommendation

17. Health care providers should not assume that older cancer survivors and their partners are uninterested in sexuality and intimacy. Survivors should be asked directly if they have concerns or are experiencing problems in this area and should receive appropriate referrals to address such issues.

"...at the hospital the oncological nurse...came around and she did the [ostomy] preparation. She did the clean-up and I watched her. She never told me what the devil she was doing...she gave me some literature and I went home with this.... There was no hands-on education.... You have to have somebody there who will supervise you when you are doing it because it is a life-threatening condition. You could create another infection. God knows what you could bring about that will cause all kinds of troubles for him."

Marilyn Brown 78, wife of Mortimer Brown, 80, colorectal cancer survivor diagnosed age 75, Florida

"This year my wife and I, as I said, shall celebrate our 59th anniversary.... Cancer has tested that relationship as no other previous challenge....I felt shame about the body changes and certain other things and sure that these would be abhorrent to her, but she found it within herself to help with the procedures and to continue to share a passion—yes, continue—and somehow accommodate to my needs."

Mortimer Brown, 80, colorectal cancer survivor diagnosed age 75, Florida

Conclusion

The President's Cancer Panel believes strongly that the testimony received at these and previous meetings provides a critical dimension to the growing body of knowledge about cancer and the needs of cancer survivors. The testimonies of survivors are not merely "stories;" they are oral histories in the finest sense of that tradition—the qualitative experiences that put quantitative information in the very human context in which it must be evaluated. Likewise, the daily experiences of each health professional who provides care to people with cancer, their families, and their caregivers are rich reservoirs of front-line information on the poorly charted journey each diagnosed person must make to live with and beyond cancer. It is with this understanding and in this spirit that the Panel has developed this report and recommendations for legislators, policy makers, the scientific and medical communities, employers, insurers, advocates, and others whose actions can so greatly affect the quality of life of people with cancer and their loved ones.

References

1 Freeman HP, Reuben SH (ed.) *Voices of a Broken System: Real People, Real Problems*, President's Cancer Panel, Report of the Chairman, 2000–2001, National Institutes of Health, National Cancer Institute, NIH Publication No. 03-5301, December 2002.

2 Mullan F. Seasons of survival: reflections of a physician with cancer, *New England Journal of Medicine* 1985; 313:270-273.

3 Centers for Disease Control and Prevention, Lance Armstrong Foundation, RTI International. "Building Partnerships to Advance Cancer Survivorship and Public Health: Background Paper," May 2003, p.3.

4 American Cancer Society. *Cancer Facts and Figures, 2004*, American Cancer Society, Atlanta, GA, 2004, p. 4.

5 Ibid., p.1.

6 Relative survival rate is a specific measurement of survival calculated by adjusting the rate to eliminate all causes of death except cancer. It is the ratio of a cancer patient's chance of surviving a given time interval to that of an average person of the same age and sex (National Cancer Institute, Glossary of Statistical Terms). At: http://cancer.gov/statistics/glossary (accessed 2/17/04).

7 American Cancer Society. op. cit., p.2.

8 Reis LAG, Eisner MP, Kosary CL, Hankey BF, Miller BA, Clegg L, Edwards BK (eds.). *SEER Cancer Statistics Review, 1973–1999*, National Cancer Institute, Bethesda, MD, 2002.

9 Period survival is a more accurate estimate of current long-term survival than cohort survival. Cohort survival estimates are based on patients diagnosed many years ago while period survival considers patients diagnosed more recently and provides the opportunity to take into consideration improvements in treatment and outcomes of individuals diagnosed over time (Brenner and Hakulinen 2002; Brenner, Söderman, and Hakulinen 2002).

10 Brenner H. Long-term survival rates of cancer patients achieved by the end of the 20th century: a period analysis, *Lancet* 2002; 360:1131-1135.

11 National Cancer Institute. "Estimated US Cancer Prevalence Counts: Who Are Our Cancer Survivors?" Division of Cancer Control and Population Sciences, April 2003. At: http://dccps.nci.nih.gov/ocs/prevalence/index.html (accessed 2/3/2004).

12 US Department of Health and Human Services. *Cancer Survivorship: Moving Beyond Cure*, National Institutes of Health, National Cancer Institute, April 2003, p.9.

13 Trans-HHS Cancer Health Disparities Progress Review Group. *Making Health Disparities History*, US Department of Health and Human Services, March 2004. At: http://www.chdprg.omhrc.gov (accessed 3/25/04).

14 Smedley BD, Stith AY, Nelson AR (eds.). *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, Institute of Medicine, The National Academies Press, Washington, DC, 2003.

15 Trans-HHS Cancer Health Disparities Progress Review Group. op. cit.

16 Freeman HF, Reuben SH (ed.). op. cit.

17 Carlson MF, Blustein J. Access to care among vulnerable populations enrolled in commercial HMOs, *Journal of Health Care for the Poor and Underserved* 2003; 14(3):372-385.

18 Bach PB, Schrag D, Brawley OW, Calaznik A, Yakren S, Begg CR. Survival of blacks and whites after a cancer diagnosis, *Journal of the American Medical Association* 2002; 287(16):2106-2111.

19 Edwards BK, Howe HL, Ries LA, Thun MJ, Rosenberg HM, Yancik R, Wingo PA, Jemal A, Feigal EG. Annual report to the nation on the status of cancer, 1973–1999, featuring implications of age and aging on U.S. cancer burden, *Cancer* 2002; 94(10):2766-2792.

20 Ibid.

21 Freeman HF, Reuben SH (ed.). op. cit.

22 von Eschenbach AC. "Eliminating Suffering and Death from Cancer by 2015: What Should NCI Contribute to the Challenge Goal?" Director's Update, August 27, 2003. At: http://www.cancer.gov/directorscorner/directorsupdate-08-27-2003 (accessed 2/3/2004).

23 American Cancer Society. *Cancer Facts and Figures, 1996*, American Cancer Society, Atlanta, GA, 1996.

24 The Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191) improved the ability of some insured persons with health conditions to change jobs and retain health coverage for pre-existing conditions if individuals can document continuous "creditable coverage." However, those with a break in coverage of 63 days or longer are subject to a waiting period of up to one year for coverage of pre-existing conditions. In addition, the Act has other significant limitations; most importantly, it does nothing to ensure the affordability of health insurance or to provide coverage to the uninsured.

25 Kadan-Lottick NS, Robison LL, Gurney JG. Childhood cancer survivors' knowledge about their past diagnosis and treatment, *Journal of the American Medical Association* 2002; 2287:1832-1839.

26 Kodish E, Eder M, Noll RB, Ruccione K, Lange B, et al. Communication of randomization in childhood leukemia trials, *Journal of the American Medical Association*, 2004; 291:470-475.

27 Hewitt M, Weiner SL, Simone JV (eds.). *Childhood Cancer Survivorship: Improving Care and Quality of Life*, National Cancer Policy Board, Institute of Medicine, The National Academies Press, Washington, DC, 2003.

28 Dick RS, Steen EB (eds.). *The Computer-based Patient Record: An Essential Technology for Health Care*, Institute of Medicine, The National Academies Press, Washington, DC, 1991.

29 Institute of Medicine. *Key Capabilities of an Electronic Health Record System: Letter Report*, Committee on Data Standards for Patient Safety, Board on Health Services, The National Academies Press, Washington, DC, July 31, 2003.

30 The Kaiser Family Foundation. "Sen. Clinton Unveils Five-Part Health Plan That Would Increase Use of Technology," Daily Health Policy Report, January 13, 2004. At: http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=21653 (accessed 1/13/04).

31 The Kaiser Family Foundation. "WellPoint to Give Free, Discounted Handheld Devices, Computer Systems to Doctors as Way to Prevent Medical Errors," Daily Health Policy Report, January 15, 2004. At: http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=21702 (accessed 1/16/04).

32 Davis K. "Making Health Care Affordable for All Americans," Invited testimony before the Senate Committee on Health, Education, Labor, and Pensions hearing on "What's Driving Health Care Costs and the Uninsured?" Executive Summary, January 28, 2004. At: www.cmwf.org/programs/davis_senatehelptestimony_exsum_714.asp (accessed 1/28/2004).

33 Institute of Medicine. *Key Capabilities of an Electronic Health Record System: Letter Report*, op. cit.

34 Infohealth Management Corporation. *The Emerging Role of the Federal Government in Healthcare Information Technology*, September 2003.

35 Unsworth J. *Worldwide Flash Card Market History and Forecast Trends, 2001-2007: Market Analysis*, Gartner, Inc., August 29, 2003.

36 Freeman HP, Reuben SH (ed.). op. cit.

37 Reuben SH. *Facing Cancer in Indian Country: The Yakama Nation and Other Northwest Tribes*, 2002 Annual Report, The President's Cancer Panel, National Institutes of Health, National Cancer Institute, December 2003.

38 Hoffman B. Employment discrimination: another hurdle for cancer survivors, *Cancer Investigation* 1991; 9:589-595.

39 Yankelovich CS. Cerenex Survey on Cancer Patients in the Workplace: Breaking Down Discrimination Barriers. Unpublished.

40 Ibid.

41 Harris G. "Medicare Considers Curbs on Payment for Cancer Drugs," *The New York Times*, January 30, 2004.

42 Leigh SA, Clark EJ. Psychosocial aspects of cancer survivorship. In: Berger A, Portenoy RK, Weissman DE (eds.), Principles and Practice of Supportive Oncology, Lippincott-Raven, Philadelphia, PA, 1998, pp.909-917.

43 Dunkel-Schetter C, Feinstein LG, Taylor SE, Falke RL. Patterns of coping with cancer, *Health and Psychology* 1992; 11(2):79-87.

44 Petticrew M, Bell R, Hunter D. Influence of psychological coping on survival and recurrence in people with cancer: systematic review, *British Medical Journal* 2002; 325(7372):1066.

45 Paskett ED, Stark N. Lymphedema: knowledge, treatment, and impact among breast cancer survivors, *Breast Journal* 2000; 6(6):373-378.

46 Ahles TA, Saykin AJ, Furstenberg CT, et al. Neuropsychologic impact of standard-dose systemic chemotherapy in long-term survivors of breast cancer and lymphoma, *Journal of Clinical Oncology* 2002; 20:485-493.

47 Litwin MS, Lubeck DP, Henning JM, Carroll PR. Differences in urologist and patient assessments of health related quality of life in men with prostate cancer: results of the CAPSURE database, *Journal of Urology* 1998; 159:1988-1992.

48 Peppercorn JM, Weeks JC, Cook EF, Joffe S. Comparison of outcomes in cancer patients treated within and outside clinical trials: conceptual framework and structured review, *Lancet* 2004; 363:263-270.

49 Kazak AE. Effective psychosocial intervention for children with cancer and their families, *Medical Pediatric Oncology* 1999; 32:292-293.

50 Compas BE, Worsham NL, Epping-Jordan JE, Grant KE, Mireault G, Howell DC, Malcarne VL. When mom or dad has cancer: markers of psychological distress in cancer patients, spouses, and children, *Health and Psychology* 1994; 13(6):507-515.

51 US Department of Health and Human Services. op. cit., p.11.

52 Rabow MW, Hauser JM, Adams J. Supporting family caregivers at the end of life: “They don’t know what they don’t know,” *Journal of the American Medical Association*, 2004; 291:483-491.

53 Matthews BA, Baker F, Spillers RL. Healthcare professionals’ awareness of cancer support services, *Cancer Practice* 2002; 10(1):36-44.

54 Schover LR, Brey K, Lichtin A, Lipshultz LI, Jeha S. Knowledge and experience regarding cancer, infertility, and sperm banking in younger male survivors, *Journal of Clinical Oncology* 2002; 20(7):1880-1889.

55 Schover LR, Rybicki LA, Martin BA, Bringelsen, KA. Having children after cancer: a pilot survey of survivors attitudes and experiences, *Cancer* 1999; 86(4):697-709.

56 Keene N, Hobbie W, Ruccione K. Childhood Cancer Survivors: A Practical Guide to Your Future, O’Reilly and Associates, Inc., Sebastopol, CA, 2000, pp.85-95.

57 Johnson K. “Fertility-sparing CA treatments rarely discussed: women and girls either do not know of options or do not have time before cancer therapy,” *Medical Post* 2003; 39(19).

58 Posada MN, Kolp L, Garcia JE. Fertility options for female cancer patients: facts and fiction, *Fertility and Sterility* 2001; 75(4):647-653.

59 People Living With Cancer. PLWC Feature: Fertility and Cancer Treatment (Part I), People Living With Cancer Knowledge Center. At: http://www.plwc.org (accessed 12/16/03).

60 US Census Bureau. *Health Insurance Coverage in the United States: 2002*, US Department of Commerce, Washington, DC, September 2003.

61 Holahan J, Wang M. Changes in health insurance coverage during the economic downturn: 2000–2002, *Health Affairs*, Web Exclusive, January 28, 2004, W4-31 – W4-42. At: http://content.healthaffairs.org/cgi/content/full/hlthaff.w4.31v1/DC1 (accessed 4/12/04).

62 Rhoades JA, Cohen JW. The Uninsured in America—1996–2002 Estimates for the Civilian Noninstitutionalized Population Under Age 65, Statistical Brief #34, Medical Expenditure Panel Survey, Agency for Healthcare Research and Quality. At: http://www.meps.ahrq.gov/papers/st24/stat24.htm#Fig2 (accessed 2/23/04).

63 Short PF, Graefe DR, Schoen C. “Churn, Churn, Churn: How Instability of Health Insurance Shapes America’s Uninsured Problem,” Issue Brief, Task Force on the Future of Health Insurance, The Commonwealth Fund, November 2003.

64 Brown ER. Public Policies to Extend Health Care Coverage. In: Changing the U.S. Health Care System: Key Issues in Health Services Policy and Management, second edition, Jossey-Bass, 2001.

65 Taylor A, Cohen J, Machlin S. Being uninsured in 1996 compared to 1987: how has the experience of the uninsured changed over time? *Health Services Research* 2001; 36(6) Part II:16-31.

66 Weinick RM, Drilea SK. Usual sources of health care and barriers to care, 1996, *Statistical Bulletin* 1998; 79(1):11-17.

67 Kaiser Commission on Medicaid and the Uninsured. *The Uninsured: A Primer—Key Facts about Americans without Health Insurance*, The Kaiser Family Foundation, December 2003, Figure 5.

68 Schur CL, Doty MM, Berk ML. “Lack of Prescription Coverage Among the Under 65: A Symptom of Underinsurance,” Issue Brief, Task Force on the Future of Health Insurance, The Commonwealth Fund, February 2004.

69 Brown ER. op. cit.

70 US Census Bureau. op. cit.

71 Davis K. op. cit.

72 Trude S. “Patient Cost Sharing: How Much is Too Much?” Issue Brief No. 72, Center for Studying Health System Change, Washington, DC, December 2003.

73 Glied S, Lambrew JM, Little S. The Growing Share of Uninsured Workers Employed By Large Firms, The Commonwealth Fund, Publication #672, October 2003.

74 Freeman HF, Reuben SH (ed.). op. cit.

75 Warren E, Sullivan T, Jacoby MB. Medical problems and bankruptcy filings, *Norton’s Bankruptcy Adviser*, May 2000.

76 Committee on the Consequences of Uninsurance. *Insuring America’s Health: Principles and Recommendations*, Institute of Medicine, The National Academies Press, Washington, DC, 2004.

77 McInturff W, Greenberg S. AHA National and Selected Statewide Surveys, American Hospital Association, January 2004.

78 National Cancer Institute. *Young People with Cancer: A Handbook for Parents*, Publication No. 01-2378, 2001.

79 Hewitt M, Weiner SL, Simone JV (eds.). op. cit., p.31.

80 Ibid., p.29.

81 SEER 14 registry data, 1996–2000, using the SEER modified ICCC site recodes (for pediatric cancers) and SEER site recodes (including Kaposi’s sarcoma and mesothelioma) for all other age groups.

82 Hewitt M, Weiner SL, Simone JV (eds.). op. cit., Table 4.2, pp.55-56.

83 Hudson MM, Mertens AC, Yasui Y, Hobbie W, Chen H, et al. Health status of adult long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study, *Journal of the American Medical Association* 2003; 290(12):1583-1592.

84 Prasad VK, Lewis IJ, Aparicio SR, Heney D, et al. Progressive glomerular toxicity of ifosfamide in children, *Medical and Pediatric Oncology* 1996; 27(3):149-155.

85 Skinner R, Cotterill SJ, Stevens MC. Risk factors for nephrotoxicity after ifosfamide treatment in children: a USCCSG Late Effects Group study, United Kingdom Children's Cancer Study Group, *British Journal of Cancer* 2000; 82(10):1636-1645.

86 Hewitt M, Weiner SL, Simone JV (eds.). op. cit.

87 Meadows AT (ed.), Green DM, Oeffinger KC. Issues for Survivors of Pediatric Malignancy, Part I, *Current Problems in Cancer* 2003; 27:107-167.

88 Meadows AT (ed.) Current Problems in Cancer: Survivors of Childhood and Adolescent Cancer, *Current Problems in Cancer* 2003; 27:177-235.

89 Kazak AE. op. cit.

90 Rauck AM, Green DM, Yasui T, et al. Marriage in the survivors of childhood cancer: a preliminary description from the Childhood Cancer Survivor Study, *Medical and Pediatric Oncology* 1999; 33(1):60-63.

91 Kazak AE. op. cit.

92 Alderfer MA, Labay LE, Kazak AE. Brief report: does posttraumatic stress apply to siblings of childhood cancer survivors? *Journal of Pediatric Psychology* 2003; 28(4):281-286.

93 Hewitt M, Weiner SL, Simone JV (eds.). op. cit.

94 Children's Cancer Survivor Study data, courtesy of K. Oeffinger.

95 Hewitt M, Weiner SL, Simone JV (eds.). op. cit.

96 Ries LAG, Eisner MP, Kosary CL, Hankey BF, Miller BA, Clegg L, Mariotto A, Fay MP, Feuer EJ, Edwards BK (eds.). *SEER Cancer Statistics Review, 1975–2000*, National Cancer Institute, Bethesda, MD. At: http://seer.cancer.gov/csr/1975_2000, 2003 (accessed 3/11/04).

97 Bleyer WA. Presentation, "Survivorship Challenges among Cancer Patients Diagnosed at Age 15–29," Austin, TX, September 22, 2003.

98 Bleyer WA. Overview: cancer in older adolescents and young adults: epidemiology, diagnosis, treatment, survival, and importance of clinical trials, *Medical and Pediatric Oncology* 2002; 38:1-10.

99 Bleyer WA. Presentation, op. cit.

100 Rauck AM, Fremgen AM, Hutchison CL, et al. Adolescent cancers in the United States: A national cancer data base (NCDB) report, *Journal of Pediatric Hematology and Oncology* 1999; 21:310.

101 National Childhood Cancer Foundation. "James Nachman, M.D. Says Teenagers Should Receive Care from Pediatric Oncologist," National Childhood Cancer Foundation. At: http://www.nccf.org/researchers/jnach.asp (accessed 7/3/03).

102 Ibid.

103 US Census Bureau. op. cit.

104 Social Security Administration. Social Security Bulletin, 2002.

105 SEER 14 registry data, 1996–2000, using the SEER modified ICCC site recodes (for pediatric cancers) and SEER site recodes (including Kaposi's sarcoma and mesothelioma) for all other age groups.

106 Office of Cancer Survivorship. Chronic and Late Effects of Cancer and Its Treatment: Selected Research Findings from Investigators Funded on Grants Held by the Office of Cancer Survivorship, National Cancer Institute, NIH/DHHS, Bethesda, MD, August 4, 2003.

107 Shiffman RN, Shekelle P, Overhage JM, Slutsky J, Grimshaw J, Deshpande AM. Standardized reporting of clinical practice guidelines: A proposal from the Conference on Guideline Standardization. *Annals of Internal Medicine* 2003; 139(6):493-498.

108 Bradley CJ, Bednarek HL. Employment patterns of long-term cancer survivors, *Psycho-Oncology* 2002; (11):188-198.

109 Satariano WA, DeLorenze GN. The likelihood of returning to work after breast cancer, *Public Health Reports* 1996; 111(3):236-241.

110 Freudenheim M. "Companies Limit Health Coverage of Many Retirees," *The New York Times*, February 3, 2004.

111 Monheit AC, Visnes J, Eisenberg JM. Moving to Medicare: trends in health insurance status of near-elderly workers, 1987–1996, *Health Affairs*, 2001; March/April.

112 National Cancer Institute. "Estimated US Cancer Prevalence Counts: Who Are Our Cancer Survivors?" op. cit.

113 The Henry J. Kaiser Family Foundation and Health Research and Educational Trust. *Employer Health Benefits: 2003 Annual Survey*, Kaiser Family Foundation, Washington, DC, 2003.

114 McArdle FB, Neuman P, Kitchman M, Kirland K, Yamamoto D. Large firms retiree health benefits before Medicare reform, 2003 survey results. *Health Affairs*, Web Exclusive, January 14, 2004, W4-7 – W4-19. At: http://content.healthaffairs.org/cgi/content/full/hlthaff.w4.7v1/DC1 (accessed 1/30/04).

115 Potosky A, Legler J, Albertson P, et al. Health outcomes after prostatectomy or radiotherapy for prostate cancer: results for the Prostate Cancer Outcomes Study, *Journal of the National Cancer Institute* 2000; 92:1582-1592.

Appendix

President's Cancer Panel Survivorship Meetings

May 2003 – January 2004

Participant List

Participant	Meeting(s) Attended
Ms. Mary Jo Albee Community Representative Marshalltown, IA 50158	Philadelphia
Ms. Annica Andersson Community Representative 51161 Skene, Sweden	Lisbon
Mr. Lance Armstrong Member President's Cancer Panel Austin, TX 78746	Lisbon Denver Austin Birmingham
Mr. Matthew Bennett Community Representative Alabaster, AL 35007	Birmingham
Dr. Archie Bleyer Chair, Adolescent and Young Adult Committee Children's Oncology Group Director, Community Oncology Group The University of Texas M.D. Anderson Cancer Center Houston, TX 77030	Austin
Dr. Josep M. Borràs Director Institut Català d'Oncologia 08907 Barcelona, Spain	Lisbon
Dr. Andrew Bottomley Coordinator Quality of Life Unit European Organisation for Research and Treatment of Cancer B-1200 Brussels, Belgium	Lisbon

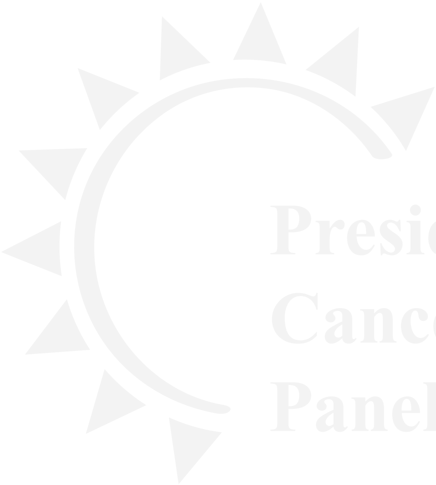
Participant	Meeting(s) Attended
Dr. Peter Boyle Director Division of Epidemiology and Biostatistics European Institute of Oncology 2014 Milan, Italy	Lisbon
Mr. Malcolm Brewster Community Representative Capitol Heights, MD 20743	Denver
Dr. Mortimer Brown Community Representative Lutz, FL 33549	Philadelphia
Dr. Marilyn Brown Community Representative Lutz, FL 33549	Philadelphia
Dr. Jan Buter Medical Oncologist VU Medical Centre 1081 Amsterdam, The Netherlands	Lisbon
Dr. Grace L. Butler Community Representative Pearland, TX 77584	Philadelphia
Ms. Ruth Campbell Head of Cancer Care Services Ulster Cancer Foundation BT9 6DX Belfast, Northern Ireland	Lisbon
Mr. Riccardo Capocaccia Department of Epidemiology and Biostatistics Istituto Superiore di Sanità 00161 Rome, Italy	Lisbon

Participant	Meeting(s) Attended
Mr. Alfredo Cerritos Community Representative Brookville, MD 20833	Denver
Dr. Michel Coleman Head of the Cancer and Public Health Unit London School of Hygiene and Tropical Medicine WC1E 7HT London, England	Lisbon
Ms. Tracy Cook-Brewton Community Representative Gastonia, NC 28056	Austin
Mr. Adam Cox Community Representative Asheville, NC 28806	Denver
Ms. Pam Cox Community Representative Asheville, NC 28806	Denver
Ms. Ulrika Botelho Cyrne Community Representative 1250-240 Lisbon, Portugal	Lisbon
Ms. Aileen Delgado Community Representative State College, PA 16803	Denver
Ms. Amy Dilbeck Community Representative Pasadena, CA 91101	Austin
Mr. Michael DiLorenzo Community Representative Martins Creek, PA 18063	Denver
Ms. Julia Doherty Health Care Consultant Washington, DC 20012	Lisbon
Ms. Karen Dyer Community Representative Pleasantville, NY 10570	Austin
Ms. Danielle Eichner Community Representative Rockville, MD 20853	Denver
Ms. Marilyn Eichner Community Representative Rockville, MD 20853	Denver
Ms. Angie Farfan Community Representative Jefferson City, MO 65101	Denver
Ms. Tamika Felder Community Representative Upper Marlboro, MD 20774	Austin
Dr. Harold P. Freeman Director The Ralph Lauren Center for Cancer Care and Prevention New York, NY 10035	Lisbon
Dr. Gemma Gatta Medical Doctor Division of Epidemiology Istituto Nazionale per lo Studio e la Cura dei Tumori I-20133 Milan, Italy	Lisbon
Ms. Alisa Gilbert Community Representative Anchorage, AK 99516	Birmingham
Mr. Emanuel Hamelburg Community Representative Stoughton, MA 02072	Birmingham
Dr. Alexander Hantel Member ASCO Breast Cancer Surveillance Expert Panel Naperville, IL 60540	Birmingham
Mr. Ambrose Heaney Community Representative Loughlinstown, County Dublin, The Republic of Ireland	Lisbon
Ms. Karen Lisa Hilsted Community Representative 2920 Charlottenlund, Denmark	Lisbon
Ms. Barbara Hoffman Founding Chair National Coalition for Cancer Survivorship Newark, NJ 08550	Philadelphia
Dr. Donal Hollywood Marie Curie Professor of Oncology Trinity College Dublin Dublin The Republic of Ireland	Lisbon
Dr. Patrick G. Johnston Professor of Oncology and Director of Cancer Research Belfast City Hospital BT9 7AB Belfast, Northern Ireland	Lisbon

Participant	Meeting(s) Attended
Ms. Devarda Jones Community Representative Capitol Heights, MD 20743	Denver
Dr. Warren Jones Associate Vice Chancellor for Multicultural Affairs The University of Mississippi Medical Center Ridgeland, MS 39157	Philadelphia
Ms. Daniela Kampmann Community Representative 44267 Dortmund, Germany	Lisbon
Dr. Michael Kanter Associate Medical Director for Quality and Clinical Analysis Kaiser Permanente Pasadena, CA 91188	Philadelphia
Dr. Basil Kasimis VA New Jersey Health Care System East Orange, NJ 07018	Philadelphia
Dr. Margaret Kripke Member President's Cancer Panel Houston, TX 77030	Lisbon Denver Austin Birmingham Philadelphia
Dr. LaSalle D. Leffall, Jr. Chairman President's Cancer Panel Washington, DC 20059	Lisbon Denver Austin Birmingham Philadelphia
Ms. Susan Leigh Community Representative Tucson, AZ 85739	Austin
Mr. Michael Lin Community Representative San Antonio, TX 78229	Austin
Ms. Elvira Lowe Community Representative BT8 8HR Belfast, Northern Ireland	Lisbon
Ms. Judy Lundgren President Oncology Nursing Society North Arlington, TX 76012	Birmingham
Mr. Craig Lustig Community Representative Washington, DC 20002	Austin
Dr. Luis d'Orey Manoel Surgeon Portuguese Institute of Oncology–Lisbon Center P-1099-023 Lisbon, Portugal	Lisbon
Dr. Sharad Mansukani Medical Officer, Special Assistant Centers for Medicare and Medicaid Services Baltimore, MD 21244	Philadelphia
Ms. Kathy Marsh Community Representative Lewiston, MI 49756	Austin
Dr. Riccardo Masetti Associate Professor of Surgery Catholic University of Rome 00168 Rome, Italy	Lisbon
Dr. Glen Mays Senior Health Researcher Mathematica Policy Research Center for Studying Health System Change Washington, DC 20024	Birmingham
Dr. Judith McNeill Head of Community Links Macmillan Cancer Relief SE1 7UQ London, England	Lisbon
Dr. Anna T. Meadows Oncologist Children's Hospital of Philadelphia Abramson Cancer Center Philadelphia, PA 19104	Philadelphia
Dr. Richard Migliori CEO United Resource Networks Golden Valley, MN 55427	Philadelphia
Ms. Marie-Agnès Moulin Community Representative St. Cloud, France	Lisbon
Ms. Coreen Oshiro Community Representative Thousand Oaks, CA 91360	Denver
Mr. Jørgen Petersen Community Representative Espergaerde, Denmark 3060	Lisbon

Participant	Meeting(s) Attended
Dr. Fenna Postma-Schuit Community Representative 1066 CX Amsterdam The Netherlands	Lisbon
Ms. Claudia Rodemers Community Representative 7018 Flims Waldhaus Switzerland	Lisbon
Mr. Eric Rodriguez Community Representative Middleboro, MA 02346	Austin
Dr. Julia Rowland Director Office of Cancer Survivorship National Cancer Institute Bethesda, MD 20892	Lisbon Denver Austin Birmingham Philadelphia
Dr. Carolyn Runowicz Director Oncology Signature Program & Women's Health Department of Obstetrics and Gynecology University of Connecticut Health Center Farmington, CT 06030	Philadelphia
Dr. Shelby Sanford Oncologist and CEO Southeast Cancer Network Tuscaloosa, AL 35475	Birmingham
Dr. Milena Sant Senior Researcher Epidemiology Unit Istituto Nazionale per lo Studio e la Cura dei Tumori I-20133 Milan, Italy	Lisbon
Mr. Dirk Schmidt Community Representative 01277 Dresden, Germany	Lisbon
Ms. Susan Shinagawa Community Representative Spring Valley, CA 91977	Birmingham
Mr. Daniel Sieck Community Representative Towson, MD 21204	Denver
Dr. Joseph Simone President Simone Consulting Company Dunwoody, GA 30338	Denver
Dr. Odd Søreide Professor, Chairman of the Board Norwegian Cancer Society 5021 Bergen, Norway	Lisbon
Ms. Pilar Suarez Community Representative 28220 Madrid, Spain	Lisbon
Ms. Debra Thaler-DeMers Board of Directors National Coalition for Cancer Survivorship San Jose, CA 95148	Birmingham
Mr. Antonio Toscano Community Representative 00146 Rome, Italy	Lisbon
Mr. Tom Trotter Community Representative San Diego, CA 92128	Birmingham
Dr. Christopher Turner Director Pediatric Neuro-Oncology Outcomes Research Dana-Farber Cancer Institute Boston, MA 02115	Birmingham
Dr. Georges Vlastos Attending Physician Geneva University Hospital 1211 Geneva, Switzerland	Lisbon
Mr. Steinar Krey Voll Community Representative 0172 Oslo, Norway	Lisbon
Dr. Andrew C. von Eschenbach Director National Cancer Institute Bethesda, MD 20892	Lisbon Denver Austin Philadelphia
Dr. Mads Utke Werner Director Center of Oncological Rehabilitation and Palliative Care University Hospital Department of Oncology Lund, Sweden	Lisbon

Participant	Meeting(s) Attended
Mr. Jim West Community Representative St. Petersburg, FL 33705	Philadelphia
Dr. Maureen Wilson Assistant Director National Cancer Institute Bethesda, MD 20892	Lisbon Denver Austin Birmingham Philadelphia
Dr. Catherine Woodman Community Representative Iowa City, IA 52240	Denver
Dr. Rosemary Yancik Health Science Administrator Geriatrics and Clinical Gerontology Program National Institute on Aging Bethesda, MD 20892	Philadelphia
Ms. Barbara Young Community Representative West, MS 39192	Birmingham
Dr. Boonsee Yu Community Representative East Northport, NY 11731	Birmingham
Mr. Octavio Zavala Community Representative Pasadena, CA 91105	Austin
Mr. Robert Zimmerman, Jr. Regional Director (Region 3) U.S. Department of Health and Human Services Philadelphia, PA 19106	Philadelphia



President's
Cancer
Panel


President's
Cancer
Panel


President's
Cancer
Panel

NATIONAL®
CANCER
INSTITUTE

Printed May 2004

P 7 7 7