

Cancer Survivorship in the Adult: An Annotated Bibliography

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This annotated bibliography was developed to complement and extend the material on cancer survivorship presented in the *State of the Science on Nursing Approaches to Managing Late and Long-Term Sequelae of Cancer and Cancer Treatment*, and to provide readers seeking additional information with selected topics in cancer survivorship. The citations were identified through computerized searches of CINAHL and MEDLINE encompassing the period from January 2000 through June 2005, using the following search terms: “cancer” in combination with “survivorship,” “survivors,” or “late effects of treatment.” In CINAHL, these search strategies resulted in 627 citations, and in MEDLINE they produced 1,788 citations. The abstracts of these citations were reviewed, and articles reporting survivorship issues in adolescents and adults were included. Papers excluded from this bibliography included: articles focused on survivorship issues following childhood cancer treatment; unpublished dissertations, theses, and reports; and papers addressing specific topics already covered in this issue (for example, osteoporosis in cancer survivors, fatigue, and family and psychosocial issues). The remaining citations were grouped thematically and briefly annotated. The most recent or most comprehensive reviews, and reports thought to offer a unique perspective were retained.

TABLE OF CONTENTS

Late Effects—Epidemiology	e2
Older Adult Survivors	e5
Health Disparities	e5
Advocacy	e6
Employment and Vocational Function	e8
Genetics	e10
Management of Specific Survivor Symptoms and Syndromes	e10
Research Agenda—Challenges and Opportunities	e12
Rehabilitation	e13
Post-Treatment Risk Reduction, Surveillance, Primary Care	e14
Exercise	e16
Complementary Therapies	e18
Nutrition	e19

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LATE EFFECTS—EPIDEMIOLOGY

Baker F, et al. Health-related quality of life of cancer and noncancer patients in Medicare managed care. *Cancer* 2003;97(3):674-81.

This study compares the quality of life of more than 20,000 Medicare beneficiaries diagnosed with cancer and a frequency age-matched sample of noncancer patients. The results suggest that cancer has a negative effect on health-related quality of life, one that cannot be attributed to the simple effects of age, since frequency age-matched cancer survivors had significantly lower scores ($p < 0.001$) on all subscales and summary scores of the Medical Outcomes Study Short Form-36 (SF-36). To gauge the clinical significance of these differences in SF-36 scores, the researchers examined effect sizes. Undergoing treatment for lung carcinoma only or for more than one type of cancer had the most negative effect on quality of life. Although the authors acknowledge the limitations in using the SF-36 as a measure of quality of life in patients with cancer, these study results offer useful data for developing cancer policy and for planning and evaluating clinical services.

Baker KS, et al. Late effects in survivors of chronic myeloid leukemia treated with hematopoietic cell transplantation: results from the Bone Marrow Transplant Survivor Study. *Blood* 2004;104(6):1898-906.

Researchers analyzed the medical late effects in 248 survivors who had received an allogeneic (sibling or unrelated donor) ($n=220$) or autologous ($n=28$) stem cell transplant in treatment of chronic myelogenous leukemia (CML) and had survived at least two years, comparing these individuals to 317 siblings. Compared with their healthy siblings, these transplant survivors were at higher risk for developing ocular, oral health, endocrine, gastrointestinal, musculoskeletal, neurosensory, and neuromotor impairments, although many of these complications are not potentially life threatening and can be addressed with medical intervention. Chronic graft-versus-host disease (a complication of allogeneic transplant in which the donor immune system recognizes the recipient's tissues as foreign and mounts an immunologic response that results in oral, ocular, pulmonary, integumentary, musculoskeletal, and gastrointestinal sequelae, as well as compromised immune function) was the most important predictor of adverse long-term effects and poor overall health, and was associated with a higher risk of hypothyroidism; osteoporosis; and cardiopulmonary, neurosensory, and neuromotor impairments. Nevertheless, nearly 80% of the CML survivors in this study rated their health as "excellent," "very good," or "good," indicating that allogeneic stem cell transplantation is a treatment option that offers patients long-term benefit.

Cancer survivorship—United States, 1971-2001. *MMWR Morb Mortal Wkly Rep* 2004;53(24):526-9.

This report summarizes the results of a National Cancer Institute (NCI) and Centers for

Disease Control and Prevention (CDC) study of the prevalence of cancer survivors from 1971 to 2001 Using incidence and follow-up data from the registries in the Surveillance, Epidemiology, and End Results (SEER) Program, the study found that the number of persons living with cancer has steadily increased during the last three decades, from 3 million in 1971 (1.5% of the population) to 9.8 million (3.5% of the population) in 2001. In 2001, an estimated 60% of all cancers occurred among persons age 65 years or older; this age group represents 61% of all cancer survivors. The growing population of survivors, particularly older adult cancer survivors, make it increasingly urgent for researchers to develop a better understanding of their physical and psychosocial experience, and for clinicians to develop evidence-based programs to promote their health and well-being.

Gleeson HK, Shalet SM. Endocrine complications of neoplastic diseases in children and adolescents. *Curr Opin Pediatr* 2001;13(4):346-51.

Endocrine and metabolic consequences of cancer treatment are common and may affect the life of the adolescent patient both immediately after treatment and in later years. The literature review focuses on the areas of growth hormone deficiency, cardiovascular risk factors, osteopenia, thyroid problems, and gonadal damage resulting in infertility. Recommendations are presented for prevention, screening, and management of gonadal dysfunction, infertility, hypothyroidism; consideration is also given to the use of growth hormone replacement and gonadotropin-releasing hormone analogues in pediatric and adolescent survivors who have undergone cranial radiation or total body irradiation.

Ivantes CA, et al. Hepatitis C virus in long-term bone marrow transplant survivors. *Bone Marrow Transplant* 2004;33(12):1181-5.

Hepatitis C virus (HCV) infection is a complication of transfusion support given during and following hematopoietic stem cell transplantation (HSCT) and may affect the long-term outcome for these patients. This study examines the prevalence of HCV antibody positivity in a sample of 80 HSCT recipients who were alive 10 or more years after bone marrow transplant, defining the annual progression rate of hepatic fibrosis, and identifying cases of cirrhosis among those who were positive for HCV antibody. A total of 39 individuals (48.8%) in the study sample were positive for the HCV antibody, one was indeterminate, and 40 (50%) were negative for it. Hepatic fibrosis was diagnosed in 10 patients (25.6%), and three (13.6%) already had cirrhosis. These results have implications for monitoring cancer survivors who have received transfusion support, and underscore the importance of prompt initiation of treatment in survivors with transfusion-associated HCV infection.

Ness KK, et al. Prevalence of the metabolic syndrome in relation to self-reported cancer history. *Ann Epidemiol* 2005;15(3):202-6.

This study estimates the prevalence of metabolic syndrome in persons with a history of cancer from a sample of more than 12,000 adults, comparing that to the prevalence in

persons without a history of cancer, and adjusting for race and ethnicity, educational level, income, and smoking status. The prevalence of metabolic syndrome was 258 per 1,000 persons for those with a cancer history and 184 per 1,000 persons among those without, resulting in a prevalence difference of 74 per 1,000 persons (95% confidence interval, 38–110). The prevalence difference was highest among those age 40 to 49 years (112 per 1,000 persons) and 50 to 59 years (73 per 1,000 persons). In patients who were younger (18–39 years) and older (60 years), those without a history of cancer had a higher prevalence of metabolic syndrome than did those with cancer history. The authors speculate that the unusual results in these groups may be attributed to therapy-associated weight loss and lipid changes in the elderly, and to the rarity of cancer history in young adults. Although further population-based research is needed, these study results are consistent with the premise that cancer or its treatment may be a risk factor for metabolic syndrome.

Nord C, et al. Self-reported health and use of health care services in long-term cancer survivors. *Int J Cancer* 2005;114(2):307-16.

This Norwegian study compares the use of health care services, the prevalence of common health problems, and the self-report of unfavorable lifestyle parameters among 815 cancer (testicular, prostate, breast, gynecologic, hematologic, and colorectal) survivors identified from a registry with a matched sample of individuals without cancer history. Cancer survivors displayed more adverse health conditions (osteoporosis, hypertension, gastrointestinal complaints, hypothyroidism, and cerebrovascular episodes), and there was an increased risk of perceiving poor health after a history of cancer, regardless of the duration of survival after diagnosis. Controlling for other common health problems and unfavorable lifestyle parameters, cancer survivors were also found to use health care services and receive social welfare benefits more often than did the individuals in the control group. These results support the need for epidemiologic research to explore the reasons, including the influence of psychosocial variables and symptom distress, for perceived poor health and increased use of health care services in cancer survivors.

Schultz PN, et al. Health profiles in 5,836 long-term cancer survivors. *Int J Cancer* 2003;104(4):488-95.

Researchers described the self-reported health status of a group of 583 cancer survivors who had a mean interval since diagnosis of 18 years. Although the group reported generally good health, individuals identified multiple enduring medical problems, including osteoporosis, thyroid, heart and lung problems, as well as memory loss, hearing loss, and cataracts, attributable to their cancer diagnosis or treatment. Survivors were most likely to report cancer-related health problems 5–10 years after diagnosis. Younger survivors and men were more likely to report that cancer had negatively affected their health, and there was a high predominance of health effects observed in patients who were Hodgkin disease survivors.

Yabroff KR, et al. Burden of illness in cancer survivors: findings from a population-based national sample. *J Natl Cancer Inst* 2004;96(17):1322-30.

This study was conducted to estimate the burden of illness in cancer survivors using a national, population-based sample of 1,823 cancer survivors and 5,469 age-, gender-, and educational attainment-matched control participants. Across multiple measures of burden of illness and health status, cancer survivors had poorer health outcomes when compared to similar individuals without cancer. Even after controlling for the influence of smoking and ethnicity, cancer survivors were more likely to have multiple comorbid conditions and to report higher levels of lost productivity, fair or poor health, and the need for help with activities of daily living. These effects were consistent across tumor sites and were observed in patients who were between two and 11 years postdiagnosis. Study results suggest that the productivity costs due to morbidity and the intangible burden of illness associated with cancer are substantial even among those who have survived well beyond five years following diagnosis. These estimates of lost productivity in cancer survivors, when combined with estimates of mortality costs, lost productivity among caregivers, and direct costs of cancer care suggest that the burden of illness associated with cancer is substantial even in long-term survivors.

OLDER ADULT SURVIVORS

Garman KS, et al. Function in elderly cancer survivors depends on comorbidities. *J Gerontol A Biol Sci Med Sci* 2003;58(12):M1119-M1124.

The authors investigate the association between comorbidity and functional status in 376 elderly cancer survivors, controlling for age, race, gender, educational attainment, marital status, depression, cognitive status, and duration of cancer survivorship. In the older cancer survivor, regardless of the length of time since cancer diagnosis, the presence of comorbidity (self-reported stroke, diabetes, hypertension, and myocardial infarction) rather than the history of cancer correlates with impaired functional status.

HEALTH DISPARITIES

Ashing-Giwa KT. Can a culturally responsive model for research design bring us closer to addressing participation disparities? Lessons learned from cancer survivorship studies. *Ethn Dis* 2005;15(1):130-7.

This paper examines research participation disparities through the lens of the “Culturally Responsive Model for Research Design.” The implications of the model for defining the research aims; specifying the methods, procedures, and instruments; collecting the data; and interpreting and disseminating the findings are thoughtfully considered. Ethnic minorities are overrepresented in cancer burden, yet underrepresented in cancer research. This paper offers a model for designing culturally responsive research, and has implications for increasing ethnic minority participation in cancer research.

ADVOCACY

Gomez EG, McHale M. The advocacy needs of patients with cancer and cancer survivors. In: Gomez EG, Gullatte M, editors. *Advocacy in health care: teaching patients, caregivers, and professionals*. Pittsburgh, PA: Oncology Nursing Society; 2002. p. 9-13.

This chapter offers a basic introduction to the advocacy needs of patients with cancer and cancer survivors, and describes how health care professionals can help patients to protect their rights and support effective advocacy. The authors give an overview of legislation and position papers developed to protect individuals against employment and insurance discrimination, promote rehabilitation, and ensure access to ongoing quality cancer care. Contact information for agencies that provide employment advocacy resources for cancer survivors is offered, including resources for filing employment complaints.

Hoffman B. Cancer survivors' employment and insurance rights: a primer for oncologists. *Oncology (Williston Park)* 1999;13(6):841-6.

This article reviews the problems faced by cancer survivors in securing and maintaining access to adequate employment and health insurance, summarizes federal and state legislation relevant to this issue, and recommends specific and practical strategies to address this important aspect of survivorship.

Koyani S. Patients resources: cancer survivorship information resources from the US government. *Cancer Pract* 1999;7(3):154-6.

The authors compile a list of electronic, print, and telephone resources that may be useful to health professionals in their work with cancer survivors and families. A helpful two-page table provides contact information for United States government agencies that offer information and education resources for cancer survivors and professionals.

Levy J. Financial assistance from national organizations for cancer survivors. *Cancer Pract* 2002;10(1):48-52.

This brief publication gives an overview of the financial support resources, pharmaceutical assistance, support for transportation and lodging, and fundraising guidance provided by voluntary organizations, private industry, and selected public and governmental programs for individuals who are uninsured or have low incomes. Information is available by directly contacting organizations and on their Web sites. Some organizations provide financial assistance or other benefits directly to patients, while others offer information, coordination of benefits, case management, and advocacy. Although stipends are often small relative to need, many organizations can also help to find services at reduced cost and can direct clients to new community resources.

O'Hair D, et al. Cancer survivorship and agency model: implications for patient choice, decision making, and influence. *Health Commun* 2003;15(2):193-202.

This paper describes an organizational model of patient communication as well as theoretically derived strategies that may help cancer survivors to take greater control of the decision-making process related to their treatment and care following diagnosis. The Cancer Survivorship and Agency Model (CSAM) may also generate ideas for theoretically based applied research and novel clinical approaches related to postdiagnostic cancer communication and agency issues, such as uncertainty, advocacy, empowerment, voice, and decision making.

Plymale MA, et al. Cancer survivors as standardized patients: an innovative program integrating cancer survivors into structured clinical teaching. *J Cancer Educ* 1999;14(2):67-71.

The practice of incorporating cancer survivors as standardized patients in structured clinical teaching for health care professions is described and evaluated. Skill development stations related to breast cancer, head and neck cancer, and cancer pain management were staffed by a faculty member and a cancer survivor. Students had the opportunity to develop skills in assessment and intervention with patients in relation to such topics as a cancer-positive biopsy, treatment options, posttreatment follow-up, reconstruction options, and pharmacologic management of pain. Cancer survivors, faculty members, residents, and medical students all considered the participation of survivors in clinical teaching to be beneficial. This report offers an innovative model for expanding the role of cancer survivors in the education of health care professionals.

Tesauro GM, et al. Survivorship resources for post-treatment cancer survivors. *Cancer Pract* 2002;10(6):277-83.

Researchers conducted a survey of the range of services and resources provided by NCI-designated comprehensive cancer clinics to posttreatment cancer survivors based on interviews with cancer center representatives and an examination of their Web sites. The most frequently identified services integrated the needs of survivors at all stages of the illness continuum, including counseling, support groups for patients and families, peer-based support programs, genetic testing and counseling, pain management, lymphedema management, insurance and financial counseling, complementary therapy, smoking cessation, nutrition and dietary counseling, physical activity programs, fatigue management, information about coping with disability, chaplaincy services, and celebration of survivors' day. More than 75% of the centers reported that they offered one or more services developed specifically to meet the needs of posttreatment survivors and their families, including school-reentry programs, long-term and late effects follow-up clinics, and reproductive and sexuality counseling centers. The study results can be used to create bench marks for assessing individual centers and to improve programs offered to cancer survivors.

Walsh-Burke K, Marcusen C. Self-advocacy training for cancer survivors. The Cancer Survival Toolbox. *Cancer Pract* 1999;7(6):297-301.

The authors evaluate a self-advocacy training program, the Cancer Survival Toolbox, developed through the collaboration of the National Coalition of Cancer Survivorship, the Association of Oncology Social Work, and the Oncology Nursing Society. The material was pilot tested with groups of cancer survivors on both East and West coasts, and with representatives of 15 national cancer organizations. Data from the pilot groups indicate that the program improves self-advocacy skills, specifically communication, information seeking, problem solving, decision making, and negotiating. Qualitative evaluation supports a conclusion that the teaching materials are both easy to use and relevant. At the Web site (www.cancersurvivaltoolbox.org), the Toolbox can be read or listened to in English and in Spanish. Chinese transcripts are also available at the Web site. The materials are available free of charge.

EMPLOYMENT AND VOCATIONAL FUNCTION

Bradley CJ, Bednarek HL. Employment patterns of long-term cancer survivors. *Psychooncology* 2002;11(3):188-98.

The authors examine employment patterns of 253 long-term cancer survivors. Of those working at the time of initial diagnosis, 67% were employed five to seven years later. Of those who had to reduce their work schedules because they were undergoing treatment, 80% returned to their former schedules and almost all patients reported that their employers were willing to accommodate their needs during treatment. Only 16 participants indicated that their family members had altered their work schedules after their diagnosis. Individuals who stopped working did so because they retired (54%), were in poor health or disabled (24%), quit (4%), cited other reasons (9%), or their business closed (9%). Many employed survivors worked in excess of 40 hours per week, although about 10% reported that they had at least one limitation that was imposed by their illness or treatment, particularly in relation to performing manual labor. Future research is needed to examine the extent to which continued employment is necessary for access to employer-sponsored health insurance and treatment, to replace income lost during treatment, or to cover expenses and protect against financial uncertainties of survivorship. Other considerations include psychological reasons for continued employment, such as empowerment and the ability to maintain a sense of control.

Feuerstein M. Cancer survivorship and work. *J Occup Rehabil* 2005;15(1):1-2.

Much of the knowledge and many of the skills in the area of musculoskeletal disorders and work disability can be applied to achieve greater understanding and develop model programs to address the area of cancer survivorship and work. The author issues a call for researchers and clinicians who are focused on the prevention, evaluation, and rehabilitation of work disability—and thereby well equipped with theories, approaches,

and perspectives on this important problem—to turn their attention to improving the occupational functioning of cancer survivors.

Short PF, et al. Employment pathways in a large cohort of adult cancer survivors. *Cancer* 2005;103(6):1292-301.

This study reports employment- and work-related disability in a cohort of 1,433 cancer survivors who were one to five years after diagnosis and who were working at the time of their diagnosis. Three-quarters of those individuals who had stopped working during treatment returned to work within the first year afterward. Of the survivors who quit working following their diagnosis and treatment, more than one-half did so within the first year. Using life-table analysis, the researchers project that 13% of all survivors who are working at diagnosis will quit for cancer-related reasons in the first four years of survivorship. Survivors of central nervous system, head and neck, and stage IV blood and lymphatic malignancies had the highest adjusted risk of disability or of quitting work. Cancer survivors with other chronic health conditions were more likely to report work disabilities and were more likely to quit work for cancer-related reasons. Survivors in more physically demanding jobs had higher disability rates, but were no more likely to quit work, and those survivors with a higher educational level were less likely to quit working than were those with lower educational attainment. Supportive care directed towards symptom management, rehabilitation, and accommodation of disabilities, particularly in those survivors at highest risk, will promote optimal occupational function in cancer survivors.

Spelten ER, et al. Factors reported to influence the return to work of cancer survivors: a literature review. *Psychooncology* 2002;11(2):124-31.

A systematic review examines the rate of return to work and the factors associated with return to work in cancer survivors, as reported in 14 studies published from 1985–1999. The rate of return to work ranged from 30% to 93%, with wide variation in the factors affecting return to work. Factors that were negatively associated with a return to work included: a nonsupportive work environment, manual labor employment, work posing physical demands, and having head and neck cancer. Coworkers' positive attitudes and flexibility regarding work hours or amount of work was positively associated with return to work. Longitudinal studies are needed to establish the relative importance of factors associated with return to work and to evaluate model programs that optimize the vocational functioning of cancer survivors.

Taskila-Brandt T, et al. The impact of education and occupation on the employment status of cancer survivors. *Eur J Cancer* 2004;40(16):2488-93.

This paper reports a population-based study of 12,542 new cases of cancer in Finnish or Swedish individuals who were 15–60 years of age at the time of diagnosis. Two to three years after diagnosis, cancer survivors had a 9% lower employment rate than their cancer-free, gender- and age-matched referents. As in other studies, education level and

occupation modified the effect of cancer on employment, with individuals of lower educational attainment having a higher probability of being employed compared to those with higher educational attainment. There may be more opportunities for individuals of higher educational attainment to access prolonged medical leave or to return to work part-time. Survivors working in agricultural, forestry, fishing, transport, communication, manufacturing, or service industries were 18% to 20% less likely to be employed. The difference in employment rate between cancer survivors and their age- and gender-matched referents was largest in lung cancer, leukemia, stomach cancer, and cancers of the nervous system, requiring further studies on whether return to work is also dependent on factors such as prognosis and posttreatment adverse effects, such as fatigue.

GENETICS

Jacobs LA, Giarelli E. A model of survivorship in cancer genetic care. *Semin Oncol Nurs* 2004;20(3):196-202.

This paper offers a model of survivorship that encompasses the unique needs of patients and families with heritable cancer. Recommendations for treatment, surveillance, and follow-up care for those who have undergone hereditary cancer risk assessment and counseling and are mutation carriers or at high genetic risk are discussed.

MANAGEMENT OF SPECIFIC SURVIVOR SYMPTOMS AND SYNDROMES

Armer JM. The problem of post-breast cancer lymphedema: impact and measurement issues. *Cancer Invest* 2005;23(1):76-83.

Lymphedema can have an impact on daily activities and quality of life in cancer survivors. However, the measurement and quantification of lymphedema has been problematic, resulting in a widely varying reported incidence of this problem among women treated with surgery and radiation for breast cancer. Through increased measurement accuracy, lymphedema incidence and prevalence following treatment can be better understood and more informed decisions about risk factors, prevention and treatment approaches, and recovery may be made. This paper provides recommendations for measurement and quantification of lymphedema, assessment of the symptom experience, and database development that offers a foundation for intervention studies.

Davidson JR, et al. Nonpharmacologic group treatment of insomnia: a preliminary study with cancer survivors. *Psychooncology* 2001;10(5):389-97.

This paper reports a single-arm pilot study of the feasibility and initial efficacy of a sleep therapy program in cancer survivors with insomnia. The six-session group program included stimulus-control therapy, relaxation training, and other strategies aimed at

consolidating sleep and reducing cognitive–emotional arousal. Although limited by small sample size (n=12), a high nonparticipation rate, and by the absence of a comparison group and random assignment, results suggest that the intervention improved total sleep time, sleep efficiency, and sleep quality, as well as reducing fatigue and improving functional status. This intervention merits further study to maximize treatment efficiency and identify those patients who are best suited to participate in this type of intervention. If further research confirms these results, dissemination of the findings to family practice care providers, who are often the practitioners consulted about sleep difficulties by survivors, is indicated.

Eversley R, et al. Post-treatment symptoms among ethnic minority breast cancer survivors. *Oncol Nurs Forum* 2005;32(2):250-6.

This is the first study designed to explore racial and ethnic differences in the incidence and intensity of fatigue, pain, depression, and lymphedema among white, African American, and Latina women who have undergone surgical and postsurgical treatment for breast cancer. The investigators observed an increased rate of posttreatment symptoms experienced by low-income and Latina women. These disparities among breast cancer survivors may result from lack of information regarding therapeutic interventions, inability to afford rehabilitative therapies, language barriers, or lack of information about how to effectively communicate with health care providers. To address the symptom experience of an ethnically inclusive group of breast cancer survivors, a need exists for the development, testing, and translation into practice of affordable, linguistic, and culturally appropriate symptom-management interventions.

McDougall GJ, Jr. Memory improvement program for elderly cancer survivors. *Geriatr Nurs* 2001;22(4):185-90.

Maintaining cognitive capacity is necessary for independent functioning and for satisfactory quality of life. This pilot study tests the feasibility and effectiveness of an intervention designed to improve memory performance and self-efficacy in a group of older adult cancer survivors and those with other chronic conditions. The eight-session intervention was delivered over four weeks and emphasized health promotion, everyday memory (remembering names, appointments, news articles, and faces), memory strategy use, and becoming more realistic and less fearful about cognitive aging. Although limited by the small sample size of cancer survivors (n=11) and the absence of a control group, the study provides new preliminary evidence that older adult cancer survivors experience improvements in short-term memory as a result of intervention, although the responses of a group of older adults to training varies depending on their health status.

Nuver J, et al. The metabolic syndrome in long-term cancer survivors, an important target for secondary preventive measures. *Cancer Treat Rev* 2002;28(4):195-214.

This review examines the association between metabolic syndrome (central obesity, atherogenic dyslipidemia, hypertension, insulin resistance or glucose intolerance,

prothrombotic state, and proinflammatory state) and treatment-related complications in cancer survivors. The data concerning the association between hormonal (testosterone, estrogen, and growth hormone) deficiencies, hypothyroidism, hypomagnesemia, endothelial dysfunction, and metabolic syndrome are considered; these disorders are regularly reported following curative cancer treatment and could be important etiologic factors in the development of metabolic syndrome. Secondary prevention measures (including hormonal supplementation, treatment of therapy-related endothelial dysfunction, and magnesium supplementation) for patients at highest risk for the development of metabolic syndrome are discussed, and the importance of screening for the signs and symptoms of metabolic syndrome and of implementing treatment in a timely manner are emphasized.

Steineck G, et al. Symptom documentation in cancer survivors as a basis for therapy modifications. *Acta Oncol* 2002;41(3):244-52.

In order to suggest therapy modifications aimed at diminishing the risk of therapy-induced distress in cancer survivors, data is needed to relate details of therapy to the experience of long-term symptoms. However, no specific measure has been developed to assess the symptom experience during long-term follow-up in patients who have completed radiation therapy. This paper describes the development of a preliminary psychometric evaluation to measure the occurrence, intensity, and duration of various long-term symptoms in patients who have completed radiation therapy. A unique strength of the paper is its focus on the conceptual issues underlying the measurement of symptoms and their consequences for functional status, and the authors' consideration of the validity challenges in measuring these issues in cancer survivors.

RESEARCH AGENDA—CHALLENGES AND OPPORTUNITIES

Aziz NM, Rowland JH. Trends and advances in cancer survivorship research: challenge and opportunity. *Semin Radiat Oncol* 2003;13(3):248-66.

This comprehensive state of the science paper, authored by senior scientists affiliated with the NCI's Office of Cancer Survivorship, offers a comprehensive and evidence-based treatment of the topic of cancer survivorship. The authors examine definitional issues relevant to cancer survivorship, offer an overview of the physiologic and medical sequelae of cancer diagnosis and treatment, provide recommendations for surveillance, and trace the evolution of cancer survivorship research from a medical deficit-dysfunction model to one that considers survivorship from a multidimensional, biopsychosocial wellness perspective. Using prevalence data that offers a profile of cancer survivors, the authors identify priority research needs and issues for long-term cancer survivors, outlining the areas of research that should be emphasized and providing examples of potential research questions.

Ganz PA. Why and how to study the fate of cancer survivors: observations from the clinic and the research laboratory. *Eur J Cancer* 2003;39(15):2136-41.

This paper presents evidence supporting the importance of studying health outcomes in cancer survivors, including the increasing incidence of cancer, the growing number of cancer survivors, the paucity of information about the late effects of therapy and their interaction with underlying comorbid conditions, and the need for evidence-based treatment decision-making and long-term monitoring guidelines. The author underscores the need to develop long-term outcome studies that begin at cancer treatment inception and examines challenges in identifying cancer survivors, limiting nonparticipant bias, and gauging late effects, given the continued evolution in therapeutic approaches. Possible solutions are offered to the challenge of recruiting cancer survivors to studies that can obtain the most comprehensive data on outcomes, and that can link current health status to details of past medical treatment.

Pakilit AT, et al. Making effective use of tumor registries for cancer survivorship research. *Cancer* 2001;92(5):1305-14.

Research models that promote the identification and recruitment of cancer survivors to studies are urgently needed. This report describes one such model, the use of hospital cancer registries, to recruit samples of cancer survivors and examines the outcomes, opportunities, and limitations associated with this approach. Enhancements for future studies that may increase the yield from registry recruitment are discussed.

REHABILITATION

Cheville AL. Cancer rehabilitation. *Semin Oncol* 2005;32(2):219-24.

The author presents evidence supporting three conclusions: cancer patients are highly distressed by the loss of functional independence; cancer-related functional impairments and the associated economic burden are likely to increase in coming decades; and rehabilitative interventions have the potential to improve function and quality of life in patients with cancer. The widely accepted schema for the formulation of restorative, supportive, preventive, and palliative rehabilitation goals is described and oncology-specific examples of each category are offered. Using illustrations from clinical practice, the author redefines functional goals that may be anticipated at each stage in the cancer trajectory, including cancer survivorship, and describes critical rehabilitative issues.

Gerber LH. Cancer rehabilitation into the future. *Cancer* 2001;92(4 Suppl):975-9.

This paper offers context and direction for the important role of rehabilitative interventions in cancer care. The author emphasizes the range and complexity of functional problems that present during and following cancer treatment, and underscores the importance of rehabilitation professionals as members of the treatment team. There is an urgent need for cross training of oncology and rehabilitation professionals in

intervention techniques that support patients in their ability to reach functional independence; to manage symptoms such as pain, fatigue and weakness; and to maintain quality of life. Additional research is needed to determine which rehabilitative interventions are most effective in restoring functional capacity and performance, as well as to identify by what mechanisms they work, in which cancer survivors they work, and at what time in survivors' illness trajectory.

POST-TREATMENT RISK REDUCTION, SURVEILLANCE, PRIMARY CARE

Elston Lafata J, et al. Routine surveillance care after cancer treatment with curative intent. *Med Care* 2005;43(6):592-9.

The surveillance care received by 500 adult cancer survivors diagnosed with breast, colorectal, endometrial, lung, or prostate cancer and treated with curative intent is compared to consensus guidelines concerning routine surveillance care for recurrence and metastasis. All study participants had health insurance, and most patients received the recommended minimum number of physical examinations after treatment as well as the recommended testing for local recurrence. However, less than two-thirds of colorectal cancer patients received recommended colon examinations in the initial year after treatment, and less than 20% received recommended metastatic disease testing within the initial 18 months following treatment. Among colorectal, lung, and prostate cancer patients who received recommended initial local recurrence testing, repeat testing tended to occur more frequently than recommended. The use of testing for metastatic disease that is not recommended in guidelines was also commonplace among this subset of cancer survivors. Study results suggest that there is wide variation in the patterns of surveillance care, including both underuse and overuse relative to guideline recommendations. Regrettably, the study did not evaluate differences in surveillance care use by race, gender, socioeconomic status, and other patient characteristics. It is likely that patterns of surveillance care would be different in patients who were uninsured. These findings point to the need for further research to explore the clinical reasons for these practice variations, determine whether there are racial and other disparities, and to examine the health and economic implications of variations in the use of surveillance care for cancer survivors.

Kuhn KG, et al. Evaluation and outcome of behavioural changes in the rehabilitation of cancer patients: a review. *Eur J Cancer* 2005;41(2):216-24.

This paper reviews the evidence base for interventions for cancer survivors focused on changing known risk factors for cancer recurrence and improving physical well-being. Twenty-seven clinical trials of intervention programs that address exercise, smoking cessation, alcohol consumption, diet, and the use of sunscreens were examined in this nonquantitative metaanalysis. Many of the studies were flawed by small sample size and difficulty in validating outcomes, making it difficult to conclude that specific approaches

to cancer risk reduction should be a component of the rehabilitation of all cancer patients. The authors suggest design modifications for future studies that may enhance the observed effects of preventive health behavior changes on patient outcomes. The design modifications include selection of study participants on whom the greatest impact could be made and the provision of booster interventions to support the maintenance of healthy behavior changes.

Lindsey AM, et al. Cancer risk-reduction behaviors of breast cancer survivors. *West J Nurs Res* 2004;26(8):872-90.

This study used secondary data analysis to examine a sample of 37 postmenopausal women who have survived breast cancer and determines the extent to which they have adopted healthy nutritional and physical activity behaviors (diet emphasizing healthful foods with an emphasis on plant sources, limited alcohol intake, physically active lifestyle, and maintenance of a healthy weight) recommended in American Cancer Society (ACS) guidelines. Findings indicate that breast cancer survivors may not fully adhere to guidelines for cancer risk reduction or prevention of other chronic diseases, specifically with regard to intake of vegetables, fiber, saturated fat, and whole grain products. The mean body mass index for the group was 27.1 (range of 19 to 36.2), reflecting that the group was overweight. The women in this sample did not exercise on most days of the week, as recommended by the ACS guidelines. Further study is necessary to determine if a customized nutritional and physical activity intervention may be of benefit to breast cancer survivors in implementing the ACS recommendations for diet and activity.

Pinto BM, et al. Health behavior changes after a cancer diagnosis: what do we know and where do we go from here? *Ann Behav Med* 2000;22(1):38-52.

Changing unhealthy behaviors such as smoking, poor diet, and sedentary lifestyle among individuals who have been diagnosed with cancer may help to reduce cancer treatment sequelae; prevent cancer recurrence; increase survival; reduce risk for other common diseases such as cardiovascular disease, obesity, and hypertension; and improve quality of life. This review paper examines studies of the prevalence of unhealthy behaviors (smoking, poor nutrient composition in the diet, and sedentary behavior) among those diagnosed with cancer and reviews interventions that have targeted these risk behaviors. The authors suggest guidelines for implementing cognitive-behavioral smoking cessation interventions, dietary counseling to reduce the percentage of fat in the diet, and exercise programs and offers directions for designing research studies in this area.

Sunga AY, et al. Care of cancer survivors. *Am Fam Physician* 2005;71(4):699-706.

This review summarizes recommendations for primary care and periodic surveillance in cancer survivors, focusing on risk factors for and signs and symptoms of disease recurrence. Development of secondary primary malignancies and medical, developmental, and psychological problems resulting from cancer therapy, genetic

predisposition to cancer, and other risk factors is also addressed. The review incorporates recommendations concerning preventive health practices and the importance of body image and sexuality concerns. Specific guidance for periodic surveillance (interval history, physical examination, laboratory tests, and diagnostic procedures) in survivors of breast, colorectal, and prostate cancer is offered.

EXERCISE

Burnham TR, Wilcox A. Effects of exercise on physiological and psychological variables in cancer survivors. *Med Sci Sports Exerc* 2002;34(12):1863-7.

The study examines the effect of two levels of aerobic exercise on physiologic and psychological function in patients who are rehabilitating from cancer treatment. Study and control group participants were matched for aerobic capacity and quality of life at study onset. Low- and moderate-intensity aerobic exercise programs were equally effective in improving both physiologic function (aerobic capacity, lower body flexibility, and body fat) and psychological well-being (quality of life, energy, fatigue, and anxiety). Although more study is needed to evaluate the effectiveness of this program over a longer period of time and with a more varied sample, results suggest that aerobic exercise may be a beneficial and well-tolerated component of any cancer rehabilitation process.

Courneya KS, et al. Exercise issues in older cancer survivors. *Crit Rev Oncol Hematol* 2004;51(3):249-61.

The potential role of physical exercise in attenuating the effects of cancer and its treatments in older survivors is reviewed in this paper. After describing the effects of aging on physical and mental health, the authors summarize the effects of cancer and its treatments on older survivors. Although no studies have been conducted on the effects of exercise training in cancer survivors older than 65 years, drawing on the compelling evidence of the benefits of exercise in cancer survivors in general and evidence that exercise benefits older adults, the authors suggest that exercise has the potential to be beneficial for older adult survivors when delivered in accordance with the American College of Sports Medicine's guidelines for exercise in older adults. An agenda for research concerning exercise in older cancer survivors is offered.

Jones LW, et al. Effects of an oncologist's recommendation to exercise on self-reported exercise behavior in newly diagnosed breast cancer survivors: a single-blind, randomized controlled trial. *Ann Behav Med* 2004;28(2):105-13.

This study compared the effects of two oncologist-based interventions (recommendation only, and recommendation plus referral to an exercise program) on self-reported exercise behavior and other relevant outcomes in women attending a consultation about

commencing adjuvant treatment for newly diagnosed breast cancer. Results showed that a very brief recommendation of exercise may be as influential in changing behavior among breast cancer survivors as more intensive intervention protocols. Based on the study findings, it may be beneficial to reinforce the exercise recommendation in follow-up appointments to achieve prolonged behavior change. Further research is indicated to determine the components and timing of interventions by the oncology care team in order to promote exercise in cancer survivors.

McTiernan A. Physical activity after cancer: physiologic outcomes. *Cancer Invest* 2004;22(1):68-81.

This paper synthesizes the current state of knowledge regarding the physiologic effects, short- and long-term physiologic outcomes, and potential risks of exercise in patients who are recovering from cancer. The benefits of physical activity include improvement in physical functioning, fitness, strength, and flexibility; reduced fatigue and lymphedema; optimization of body composition (adiposity and muscle mass); and possible improvements in immune function, cognitive function, and sleep. The evidence linking physical activity with decreased risks of cardiovascular disease, cerebrovascular disease, diabetes, and new primary cancers such as colorectal and breast cancer is examined, and the possible impact of physical activity on prognosis through a beneficial effect on biomarkers and energy balance is considered.

Schmitz KH, et al. Controlled physical activity trials in cancer survivors: a systematic review and meta-analysis. *Cancer Epidemiol Biomarkers Prev* 2005;14(7):1588-95.

This qualitative and quantitative review examines the evidence that physical activity interventions, alone or combined with diet modification, are effective in helping cancer survivors improve their psychosocial or physiologic outcomes. A secondary purpose of the review was to examine the potential for injuries and other adverse effects from these interventions. Results show a moderate to large positive effect of physical activity on cardiorespiratory fitness and vitality. There are other outcomes (body image, lymphedema, fatigue, quality of life, and multiple constructs of mental health) for which significant weighted mean effect sizes from physical activity interventions were noted. Although encouraging, the magnitude of these effect sizes (ranging from 0.01 to 1.64) must be interpreted with caution until additional studies are conducted to confirm or refute these preliminary findings.

Schwartz AL. Physical activity after a cancer diagnosis: psychosocial outcomes. *Cancer Invest* 2004;22(1):82-92.

The psychosocial effects of physical activity during and following cancer treatment are systematically examined in this paper, differentiating what is known about the outcomes of physical activity in those survivors who are actively receiving treatment and in those who have completed treatment. The impact of physical activity on physical, emotional

and social function; fatigue, depression, and anxiety; self-esteem; body image; quality of life; and symptom distress are considered. The limitations of previous research are discussed, and the author outlines the many questions that remain unanswered about the psychosocial outcomes of exercise in cancer survivors. The discussion includes psychosocial determinants of physical activity, adherence to physical activity interventions, and considerations related to activity and inactivity in pediatric cancer survivors.

COMPLEMENTARY THERAPIES

Greenlee H, et al. Supplement use among cancer survivors in the Vitamins and Lifestyle (VITAL) study cohort. *J Altern Complement Med* 2004;10(4):660-6.

The authors describe the use of specific supplements by 10,857 cancer survivors, ages 50 to 75 years, compared to their use by cancer-free controls. Cancer survivors' supplement use was comparable to that of cancer-free controls, when controlling for age, gender, race and ethnicity, and education, although the cancer survivors chose to take different supplements than did those without cancer. The association of 11 specific cancers with high use of multivitamins, vitamins, and mineral and herbal supplements was examined in analyses adjusted for gender, age, education, race and ethnicity, and comorbidity. After applying a correction factor to limit a spurious result based solely on the fact that many tests for association were conducted, the following associations were still significant: cranberry pills with bladder cancer (odds ratio 3.44, 95% confidence interval 1.86–6.35), vitamin A with colon cancer (odds ratio 1.59, 95% confidence interval 1.31–1.92), soy with prostate cancer (odds ratio 1.99, 95% confidence interval 1.38–2.87), and saw palmetto with prostate cancer (odds ratio 0.40, 95% confidence interval 0.31–0.50). Additional research in cancer subpopulations is needed to assess the safety and efficacy of these specific supplements.

McDavid K, et al. Vitamin/mineral supplementation among cancer survivors: 1987 and 1992 National Health Interview Surveys. *Nutr Cancer* 2001;41(1-2):29-32.

This study reports gender-specific proportions (adjusted for age, race and ethnicity, education, smoking status, and poverty index) for the use of multivitamins; vitamins A, C, and E; and calcium in a sample of 689 individuals who had survived five years or more after the diagnosis of a cancer other than nonmelanoma skin cancer, and in a sample of persons reporting no history of cancer. Supplement use was similar in survivors and persons reporting no history of cancer, with most people in both populations taking multivitamins and about one-half taking vitamin C. Among survivors, calcium use was significantly higher among women than men, and vitamin A use was higher among men than women. A slightly higher proportion of men who were cancer survivors were taking vitamin E, compared to males with no history of cancer. Although the study sample was too small to test for differences between male and female survivors and did not permit examination of supplement use by cancer site, these nationally representative population

estimates suggest that persons who have survived cancer and those who report that they never had the disease do not differ appreciably in their use of vitamin and mineral supplements.

NUTRITION

Brown JK, et al. Nutrition and physical activity during and after cancer treatment: an American Cancer Society guide for informed choices. *CA Cancer J Clin* 2003;53(5):268-91.

This comprehensive report summarizes the findings of a group of experts in nutrition, physical activity, and cancer, convened by the American Cancer Society. Tables of evidence summarize and grade the collective scientific research to determine likelihood of benefits versus harms related to nutrition (including supplements, food safety, alcohol consumption, intake of fresh fruits and vegetables, nutrient composition, food selection, and maintaining a health body weight) and physical activity for persons who have recovered after treatment, and offer specific guidance for breast, colorectal, lung, and prostate cancer survivors. This report provides clinicians and survivors with state of the science information to guide clinical practice and suggests several priority areas for further research.

Maskarinec G, et al. Dietary changes among cancer survivors. *Eur J Cancer Care (Engl)* 2001;10(1):12-20.

This qualitative study explored the patterns of and motivation for dietary changes among 143 cancer survivors. Most of the reported dietary changes were in accord with current nutritional recommendations, such as decreasing meat and fat intake and increasing the consumption of vegetables and fruits. However, all 69 patients who had changed their diet also used some form of herbal or vitamin supplements or other complementary therapies (average 4.5 different complementary modalities), such as meditation, that have unproven effects. The major themes for changing diet were hopes that nutrition would increase well-being, maintain health, and prevent cancer recurrence; these hopes were based on the beliefs that the consumption of foods that cause or prevent cancer should be avoided or increased. Other reasons for diet changes included a desire to take greater control and a desire to follow advice. This study offers important insight into the reasons that patients may change their diet, and suggests that the transition to cancer survivorship offers an important 'teachable' moment in which health care providers can educate survivors about a healthy diet and other self-care measures to enhance well-being.