

Cancer Survivorship Research Among Ethnic Minority and Medically Underserved Groups

Noreen M. Aziz, MD, PhD, MPH, and Julia H. Rowland, PhD

Purpose/Objectives: To review the current state of knowledge about the impact of cancer on ethnoculturally diverse and medically underserved survivors.

Data Sources: MEDLINE®, CancerLit, and PsychLit searches from 1966–present were conducted to locate articles about survivorship outcomes among minority and underserved populations.

Data Synthesis: 65 articles were identified and grouped into one of four content areas: physiologic; psychosocial; health services, patterns of care, and quality of care; and health-promoting behaviors and lifestyles.

Conclusions: Despite limited information, researchers found a consistent theme: the need to recognize and address the socioeconomic and cultural variables that affect adaptation to and survival from cancer among diverse groups of survivors.

Implications for Nursing: The researchers found specific variations in risk for, response to, and recovery from cancer that provide direction for changes in nursing practice that may reduce the burden of cancer in these often vulnerable populations.

Key Points . . .

- Survivorship research focuses on the physiologic, psychosocial, and economic sequelae of cancer and its treatment and issues related to healthcare delivery, access, and follow-up care.
- Many of these outcomes are under-researched for cancer survivors in general, particularly for under-researched cancer sites and ethnocultural or medically underserved populations.
- Provocative findings from the few studies exploring physiologic and psychosocial sequelae among cancer survivors need further, rigorous examination and assessment.
- A better understanding of the impact of healthcare delivery and access (system-driven factors) and cultural appropriateness and acceptance of care (patient-driven factors) on survivorship outcomes among ethnoculturally diverse and medically underserved populations clearly is needed.

Since the “war on cancer” was launched in 1971, the number of people living with a history of cancer has grown steadily. More than 8.9 million cancer survivors are estimated to live in the United States (Rowland, Aziz, Tesaro, & Feuer, 2001). Once deadly, cancer has become a curable disease for many and a chronic illness for most. With continued advances in early detection and effective treatment, along with an aging population, the number of individuals living years beyond cancer diagnosis can be expected to continue to grow well into the new millennium.

Despite the current optimistic outlook for most individuals diagnosed with cancer, a closer examination of the literature and of statistical trends indicates that the benefits of current knowledge about state-of-the-art cancer care are not shared equally by all members of U.S. society (President’s Cancer Panel, 1998). The five-year relative survival rate for all cancers among all races is about 62%, reflecting an increase from 49% in 1974–1976 and 51% in 1980–1982. However, when the statistics are broken down by race, significant differences are observed across ethnic minority and medically underserved populations with respect to the risk of developing and dying from cancer. For example, for all cancer sites combined, African Americans are more likely to develop and die from cancer than people of any other racial or ethnic group. They also are at greater risk of dying of the four most

common types of cancer (i.e., breast, prostate, colon, and lung) than members of any other minority group (American Cancer Society [ACS], 2002).

These cancer statistics notwithstanding, the outlook for minority survivors of cancer is far from grim. Incidence and mortality rates for all cancers combined decreased more among African American men than any other racial or ethnic group from 1992–1998. Additionally, cancer incidence rates have decreased by 2% per year among Hispanics, 1.7% per year among African Americans, and 1.2% per year among Caucasians and remained relatively stable among American Indians/Native Alaskans and Asian/Pacific Islanders (ACS, 2002). Similarly, mortality rates for all sites have decreased annually by 1.3% among African Americans, 1.2% among Asian/Pacific Islanders, 1.1% among Caucasians, and 0.9% among Hispanics and is leveling off for American Indians/Native Alaskans (ACS). Although healthcare professionals should keep in mind

Noreen M. Aziz, MD, PhD, MPH, is the program director, and Julia H. Rowland, PhD, is the director of the Office of Cancer Survivorship, both at the National Cancer Institute, National Institutes of Health, U.S. Department of Health and Human Services, in Bethesda, MD. (Submitted February 2002. Accepted for publication March 6, 2002.)

Digital Object Identifier: 10.1188/02.ONF.789-801

that comparisons of cancer rates between racial and ethnic groups should be interpreted with caution given the potential for misclassification of race on medical records, death certificates, and the census, the decreased mortality rates support the fact that the population of survivors of cancer is growing across all racial and ethnic categories.

The sizeable population of survivors presents many important questions related to patients' treatment decision making, quality of care, long-term follow-up, physical health after cancer treatment, and quality of life (QOL). As patients with cancer survive longer, a variety of long-term and late effects of cancer diagnosis and treatment are being observed, some of which are debilitating and others potentially life-threatening. Despite the health-limiting impact these cancer-related effects may have, many remain poorly documented or understood.

This is especially true for survivors belonging to ethnocultural minority and medically underserved groups. More research clearly is needed on the identification, prevention, treatment, and care of the broad spectrum of conditions experienced by survivors in general and minority survivors in particular.

Various studies have reported that ethnicity is an important prognostic factor. However, the independent effect of ethnicity on survival still is being evaluated. Some studies suggest that socioeconomic status may be a more critical determinant than ethnicity or race. Some argue that the lower overall or disease-free survival rates of people in minority and medically underserved populations are a consequence of, or compounded by, the effects of low income and less education. Poorer and less educated patients with cancer often have inadequate access to care, adverse prognostic factors at diagnosis (e.g., advanced disease stage), suboptimal treatment, inadequate follow-up care and monitoring, and poorer overall health status as a result of comorbidities or lifestyle (Aziz et al., 1999; Eyre & Feldman, 1998; Kagawa-Singer, 1995; Kaur, 1996; Lyman et al., 1997; Trock, 1996). Cultural beliefs and attitudes may further contribute to the survival disadvantage among patients belonging to ethnocultural minority and medically underserved groups. In one study of predominantly African American women with breast cancer, researchers found that women's beliefs about illness were significant predictors of late stage at diagnosis. These beliefs included convictions such as air causes cancer to spread, the devil can cause a person to get cancer, women who have breast surgery no longer are attractive to men, and chiropractic is an effective treatment for breast cancer (Lannin et al., 1998). The impact of cultural beliefs, mores, and norms on the quality of a person's survivorship experience is virtually unexplored.

Understanding of the causes of differences in cancer incidence and mortality among diverse populations is growing rapidly. Less clear, however, is what impact diagnosis and treatment have on those who continue to survive and live with their disease. This is particularly true for ethnically diverse groups. To better appreciate where the gaps in knowledge regarding the burden of cancer lie, and before any truly valid strategies can be developed to ameliorate potentially negative outcomes, researchers must

- Describe the survivorship experience for survivors belonging to ethnic minority and underserved groups
- Elucidate the ethnocultural context of survivorship
- Assess the similarities and differences in the survivorship

experience across ethnic minority and underserved groups and Caucasian populations

- Develop an understanding of the impact that cultural, socioeconomic, and institutional barriers have on the length and quality of cancer survivorship.

As a first step in this process, the researchers undertook an evaluation of the current state of knowledge about survivorship outcomes for this diverse population. The remainder of this article presents the results of a review of the research literature addressing cancer survivorship outcomes among ethnocultural minority and medically underserved survivors.

Process

General Approach

The researchers conducted a MEDLINE® search going back to 1966 using the keywords "cancer survivorship or cancer survivors" and "ethnic, cultural, minority, or medically underserved." The search then was expanded to use various combinations of terms, such as cancer and survivors and minority or ethnic or ethnocultural or medically underserved and one or more of the following terms: late effects, morbidity, QOL, health-related QOL, follow-up care, health services, patterns of care, post-treatment, health beliefs, health promotion, and lifestyle. Additional search terms included African American, Hispanic, Latina, Caucasian, research, and instruments. A second search, with identical timeframe and terms, was performed using CancerLit. The researchers perused the reference lists for each article identified through the MEDLINE and CancerLit searches for additional published studies. The searches requested articles published only in English.

Definition of Survivorship and Survivorship Research

For the purposes of this analysis, "survivorship" studies included only those that addressed outcomes in the cancer continuum beyond primary diagnosis and treatment. "Cancer survivorship research" was defined as encompassing the physiologic, psychosocial, and economic sequelae of cancer diagnosis and treatment among both pediatric and adult survivors of cancer and their family members. It also included issues related to healthcare delivery, access, and follow-up care.

Inclusion Criteria for Articles

To be included in this review, a study had to involve participants who were diagnosed with cancer and an adequate number of survivors belonging to one or more ethnocultural or medically underserved group to permit subgroup comparisons.

Exclusion Criteria for Articles

Articles were excluded from consideration if they did not contain adequate numbers of minority participants to elicit meaningful comparisons or did not address survivorship research domains as defined. Also excluded from the review were abstracts, theses, and dissertations.

For this article, the authors used the terms minority, ethnoculturally diverse, and medically underserved to broadly refer to cancer survivor populations. By including the term medically underserved, the authors were able to incorporate comments about the few articles retrieved that examined the rural cancer survivor population, a group that also included Caucasians.

Literature Review

The search process identified 65 research articles, which were reviewed and categorized into the following domains.

- Physiologic
- Psychosocial
- Health services, patterns of care, and quality of care
- Health-promoting behaviors and lifestyles

These outcomes of cancer diagnosis or treatment represent key survivorship research domains.

Physical Sequelae of Cancer Diagnosis and Treatment

Only five of the identified papers addressed the impact of cancer and its treatment on physiologic late or long-term effects and physical outcomes among survivors belonging to ethnocultural minority or medically underserved groups. The most significant of the articles is the Prostate Cancer Outcomes Study (PCOS), initiated in 1994 by the National Cancer Institute to examine patterns of cancer care and the effects of initial treatments on health-related QOL outcomes in a large population-based cohort of patients newly diagnosed with prostate cancer. Information about initial treatments was collected primarily from medical records, including inpatient and outpatient sources. Treatment information also was collected through a self-administered patient survey designed primarily to ascertain information about health-related QOL. Because of the number of African American and Hispanic men involved, PCOS investigators were able to examine a number of ethnic differences in outcomes in the sample of about 3,533 survivors of prostate cancer (Potosky et al., 1999).

While examining the effects of external-beam radiotherapy for prostate cancer in the PCOS population-based cohort, the researchers found no differences between ethnic groups in outcomes, such as sexual function (the most adversely affected QOL domain) and bowel function (Hamilton et al., 2001); both groups of men demonstrated significant levels of impairment in these health-related QOL domains.

Results of another study, which focused on outcomes of surgical treatment for prostate cancer, indicated that sexual and urinary function following prostatectomy vary with age. Men younger than 60 reported better potency ($p < 0.001$) and men 75–79 years old reported the highest level of incontinence ($p = 0.03$) 18 months or more after radical prostatectomy. However, sexual function for all ages also varied by race; 38% of black men reported firm erections 18 months or more after radical prostatectomy compared to only 26% of Hispanic and 21% of Caucasian men ($p = 0.001$) (Stanford et al., 2000).

An important limitation to the interpretation of these results is the possibility of bias caused by potential differences in respondents versus nonrespondents during different phases of the study. Response rates were lower among older men, Hispanics, and African Americans. Those responding to the six-month but not the 24-month survey were more likely to be older, Hispanic, and African American and more likely to have unknown or lower incomes than those responding to all of the surveys. Trends indicated that later nonrespondents may have had poorer function at baseline and slightly larger declines in function at six months after diagnosis than those who continued with the study (Hamilton et al., 2001). Thus, results of the study could have underestimated the functional losses resulting from therapy and masked or skewed ethnic differences in outcomes.

In another study that specifically examined racial differences in prostate cancer outcomes, demographic, clinical, and health-related QOL data about African American and Caucasian patients were compared just after treatment and one year post-treatment (Lubeck et al., 2001). African American patients were younger and had lower incomes and education levels than Caucasian patients. After the researchers controlled for age, education, and income differences, African American patients generally had worse clinical characteristics at presentation and lower baseline health-related QOL scores in most generic and disease-specific categories. The only exception was scores for sexual function, which were higher for African American patients at treatment. Health-related QOL improved over time for both groups. However, African American patients had slower rates of improvement for general health, bodily pain, physical function, role function, disease-related worry, and bowel function, but higher (i.e., better) sexual function. These data indicate that significant differences exist between African American and Caucasian patients with prostate cancer with respect to clinical presentation, sociodemographic characteristics, and health-related QOL and that these health-related QOL differences persist after treatment.

Late treatment-related toxicity among survivors of childhood cancer is another important area of inquiry. Anthracyclines, potent cytotoxic agents used to treat a variety of common malignancies, carry an attendant risk of cardiotoxicity. For some treated patients, anthracyclines affect the cardiac muscle itself, resulting in cardiomyopathy. Because the malignancies for which this class of drugs is used affect all age ranges, a broad population of patients may be at risk for development of heart disease. The type and degree of cardiomyopathy and the time at which the condition occurs (i.e., during or after treatment) have been shown to depend on individual risk factors, such as age. In their review article, Grenier and Lipshultz (1998) found that African American survivors of childhood cancer may be at increased risk of early cardiotoxicity (i.e., occurring during or within a year of completion of treatment). Whether this excess cardiotoxic risk also may affect African American survivors of adult cancers treated with anthracyclines is unclear.

Finally, Deimling, Schaefer, Kahana, and Bowman (in press) recently examined differences between African American and Caucasian ($n = 180$) older adults (58 years or older) who were long-term survivors of cancer (five years or more since primary cancer diagnosis) with respect to reported health problems, illness symptoms, functional difficulties, health worries and concerns, and overall perceptions of health. Their results, controlled for cancer and treatment factors, showed that African American survivors experienced poorer functional health after cancer, perhaps related to more extensive treatment and, thus, higher functional disability. Interestingly, African American survivors did not report significantly more symptoms attributed to cancer or its treatment. They did, however, report consistently higher levels of health-related conditions, such as comorbidities and decreased physical functioning, thereby increasing general health vulnerability. Finally, older African American survivors in the study reported less concern about recurrence or second cancers compared to Caucasians. Thus, older African American long-term survivors may have diverse healthcare needs, requiring follow-up care and surveillance for physical signs and symptoms, comorbidities, and screening for second cancers (i.e., primary, secondary, and tertiary prevention).

Psychosocial and Quality-of-Life Sequelae

No other site of cancer has been studied more extensively with respect to psychosocial impact than breast cancer. Literature searches in this category produce hundreds of reports. However, surprisingly few studies have examined differences in psychosocial or QOL outcomes among women from diverse backgrounds. Fewer still have examined the psychosocial impact of other cancers on these groups of survivors.

Psychosocial outcomes: In one of 25 studies in this area, Ashing-Giwa, Ganz, and Petersen (1999) asked 278 survivors of breast cancer (117 African American and 161 Caucasian) after treatment to describe the health-related QOL of long-term survivors and to examine the role of ethnicity on well-being. Initial univariate evaluation of the Cancer Rehabilitation and Evaluation System (CARES) Short Form and the Rand Short Form-36 Health Perceptions Scale suggested potential ethnicity-related differences in health-related QOL. However, ethnicity-related differences did not remain significant in the final predictive multivariate model, which included general health perception, life stress, income, partnership status, and comorbid conditions. Survivors who had better health perceptions, lower life stress, partners, higher incomes, higher educational levels, fewer other medical conditions, and shared living situations (i.e., did not live alone) reported better health-related QOL. Results of this study indicated that, overall, survivors of breast cancer reported favorable health-related QOL and that differences in health-related QOL outcomes are attributable to socioeconomic and life-burden factors, not ethnicity. An important caveat to these results may be the overall participation rate of 54%, in which only 44% of African Americans and 65% of Caucasians responded. Study participants consisted of a convenience sample drawn from a prior sample of a statewide, population-based tumor registry.

In another study of a tri-ethnic sample of 223 survivors of breast cancer, researchers examined a range of concerns that could affect well-being and adaptation. They reported that Hispanic women had stronger concerns related to recurrence, pain, death, harm from adjuvant treatment, and bills compared to Caucasian and African American survivors. Among all women, life, pain, and sexuality concerns predicted emotional and psychosocial disruption, and life and pain concerns predicted social disruption (Spencer et al., 1999). In a comparative interview study of 41 African American and 61 Caucasian survivors of breast cancer, Bourjolly, Kerson, and Nuamah (1999) found that African American women reported greater difficulty in social functioning, especially with regard to the resumption of household activities. In another comparative study, Rodrigue (1997) found no racial differences between African American and Caucasian survivors in global psychological adjustment, depression, anxiety, or healthcare satisfaction. Rodrigue did, however, find racial differences in factors that might influence long-term adjustment and health concerns or perceptions.

Other studies examining these issues are largely exploratory in nature. One of the larger studies (N = 98), conducted by Northouse et al. (1999) on African American survivors of breast cancer, found fairly high health-related QOL and low symptom distress in the sample, although energy loss, sleep disturbances, and pain were reported frequently and current concerns mediated by appraisal were associated indirectly with health-related QOL.

Body image, social support, health activism, menopause, and learning to live with a chronic illness were the five themes

related to adaptation that emerged from a focus group study (N = 24) of African American survivors of breast cancer (Wilmoth & Sanders, 2001). Two issues identified by group members as specific challenges for women of color were finding prostheses that matched their skin tones and obtaining referral to culturally relevant support groups.

In narrative accounts of experiences with breast cancer (N = 23), other African American women voiced the following themes.

- Breast cancer is a Caucasian woman's disease.
- Cancer is caused by repeated traumatic heartbreak.
- A lack of social support and understanding exists for the unique experiences of African American survivors of breast cancer (Moore, 2001).

Another study exploring the impact of breast cancer on Asian American women (N = 18 Chinese Americans, 15 Japanese Americans, and 13 Anglo Americans) found that Asian American women sought professional assistance for psychosocial problems at a significantly lower rate than Anglo women. Asian American women reported using different modes of help-seeking behavior for emotional concerns and receiving different sources of social support than Caucasian women. Although the numbers were too small to examine these effects, the authors emphasized the need for further research to explore these differences. Although hypothesized by the authors as a potential difference between ethnic groups, somatization did not appear to be a dominant form of symptom presentation for Asian American women regardless of level of acculturation. Results of the study suggest that differences may exist in the physical, emotional, and social impact of the breast cancer experience between Asian American women and Caucasian women and that subtle differences may exist within ethnic categories (e.g., between Chinese American and Japanese American women) (Kagawa-Singer, Wellisch, & Durvasula, 1997).

A multisite study examined psychological outcomes, specifically focusing on emotional or mood state, of young adult survivors of childhood acute lymphoblastic leukemia (ALL) compared to sibling controls. The study also sought to identify vulnerable subgroups at highest risk for negative mood (Zeltzer et al., 1997). The population consisted of 580 adult survivors treated for ALL before the age of 20 and 396 sibling controls. Results, based on structured telephone interviews and the Profile of Moods State (POMS), showed that survivors had higher total mood disturbance scores, indicating greater negative mood compared to sibling controls ($p < 0.01$). They also reported significantly more tension, depression, anger, and confusion, but not more fatigue or less vigor. Importantly, female, minority, and unemployed survivors reported the highest total mood disturbances. The significantly increased negative mood in survivors was not accounted for by differences in energy levels and, therefore, was unlikely to be the result of current illness.

One way that ethnicity, culture, and medically underserved status may confer an effect on outcomes is through differential beliefs and experiences of individuals in these diverse groups. For example, as noted previously, convictions about causes of cancer or efficacy of cancer treatments may lead to delays in diagnosis or refusal of care that may directly affect survival (Lannin et al., 1998). In a previously cited study, PCOS investigators raised concerns about the role of culture in men's reporting of symptomatology (Potosky et al., 1999).

Findings in the study were based on self-reporting, not objective measures, of symptoms and function. Cultural stigma around deficits in sexual performance could lead subsets of men to underreport problems when they occur.

Sex-related research in young, healthy populations has shown that cultural values associated with ethnicity influence sexual functioning. To explore the role of culture on sexual adaptation in women, Wyatt et al. (1998) examined ethnic differences in sexual socialization and attitudes, sexual history and current practices, and effects of treatment among survivors of breast cancer. The researchers interviewed 74 African American and 75 Caucasian women face-to-face regarding details about their psychosexual development, sexual beliefs and practices, and current adjustment to breast cancer. Few differences were found between the two ethnic groups, which were drawn from a sample of predominantly well-educated, high-income, highly functional women. However, African American women were significantly less likely to be comfortable with and to practice oral sex, self-touching, and masturbation, and Caucasian women were more likely to report that breast cancer had a negative impact on their sex lives. As the authors pointed out, these findings have specific implications for rehabilitative interventions for these different populations of women.

Another study examined the role of prior trauma on psychosocial adaptation of 160 women treated for early-stage, node-negative breast cancer (Green et al., 2000). Exposure to earlier life-threatening events was found to be a significant predictor of development of later cancer-related post-traumatic distress. The researchers theorized that, to the extent that exposure to assault and violence may be higher in some minority and low-income groups, individuals with these backgrounds may be at higher risk for difficulties in coping when cancer is diagnosed.

A study by Germino et al. (1998) explored the concept of uncertainty among African American and Caucasian survivors of prostate cancer. The study addressed two overarching areas.

- The relationship between uncertainty and family coping, psychological adjustment to illness, and spiritual factors
- Similarities and differences in patterns of relationships between patients and their family caregivers among Caucasians and African Americans

For the African American and Caucasian groups, greater degrees of uncertainty were correlated with less positive feelings about treatment and were inversely related to positive feelings about patients' recovery. For both groups of patients and for Caucasian family caregivers, uncertainty was inversely correlated to the quality of the domestic environment and also to psychological distress in both groups of patients and caregivers. For Caucasian patients and their family members, higher levels of uncertainty were related to the importance of God and to lower scores on adult role behavior (e.g., shopping, running errands) and for Caucasian family members alone to less active problem-solving and less perceived social support. The findings of this complex exploratory study draw attention to the role that cultural factors may play in survivors' and family members' responses to illness and the possibility that ethnic differences exist regarding the relationship of uncertainty to a number of QOL and coping variables.

The study by Germino et al. (1998) was one of few that attempted to explore the impact of spirituality on psychosocial outcomes among ethnically diverse survivors of cancer. A

recent review suggested that African American and Hispanic patients with cancer are more religious, recognize more spiritual needs, and benefit more from religious coping strategies than do Caucasian Americans (Taylor, 2001). African American patients with breast cancer have been found to rely on religion as a coping resource more so than Caucasian women (Bourjolly, 1998). Among African American patients with cancer, religious activity is related to lower levels of depressive symptomatology (Musick, Koenig, Hays, & Cohen, 1998). Some investigators have suggested that the greater existential needs of African Americans compared to Caucasians, including fears related to cancer, may reflect a tendency toward hopelessness, social isolation, and the belief that cancer is an inescapable death sentence (Moadel et al., 1999).

Finally, in an earlier study that compared religiousness between Caucasian and Hispanic patients with breast cancer, investigators reported that intrinsic and extrinsic religiousness did not predict existential well-being or hope among Hispanic patients. However, intrinsic religiousness was associated with religious and total spiritual well-being among this group of patients. In comparison, the authors found intrinsic religiousness to be associated with spiritual well-being and hope among Caucasian patients (Mickley & Soeken, 1993).

Cancer survivors, irrespective of ethnocultural background, suffer some unique consequences of cancer diagnosis when they live in rural areas. Koopman et al. (2001) studied survivors of breast cancer who lived in rural areas and found that even though women experienced considerable distress and reported a high level of helplessness and hopelessness in coping with their diagnosis, this was not reflected as a general mood disturbance (using the POMS). Other investigators have noted that significant issues articulated by rural survivors include worries about how partners and family members will cope during absences for treatment, the burden of running farms or property alone, and the financial strain of transportation and healthcare costs (McGrath et al., 1999). In a study examining the impact of cancer on a population of rural cancer survivors, investigators found that women reported relationship problems and lack of support more often than men, men perceived job security to be threatened more so than women, male and female survivors were equally likely to report feeling alone and isolated, and female survivors and male caregivers reported concerns about healthcare interactions more often than male survivors and female caregivers (Burman & Weinert, 1997). Thus, concerns of rural survivors and caregivers may differ by gender, and interventions may need to address interpersonal issues, such as the impact of illness on families and larger social networks (Lancee et al., 1994). In a study of interventions by Sandgren, McCaul, King, O'Donnell, and Foreman (2000), most rural patients with breast cancer reported that they were comfortable and felt better with telephone-administered cognitive behavioral therapy interventions. However, outcome data from the study showed that the intervention produced only modest benefits. For rural families with children who had survived cancer, the experience has been reported as fraught with challenges secondary to distance from cancer centers (Scott-Findlay & Chalmers, 2001). Additionally, parents and teachers in rural areas ($n = 20$) reported poorer social competence among child survivors compared to an age- and gender-matched control group ($n = 40$). Parents reported more behavioral problems, and teachers focused more on poorer school performance

(Olson, Boyle, Evans, & Zug, 1993). A need to educate practitioners caring for rural patients with cancer has been emphasized by others (McGrath, 2001).

Social support and support groups: The importance of social support in mediating health states in general—and cancer outcomes in particular—is a fast-growing area of research. A consistent finding is that good social support significantly reduces the risk and adverse impact of illness (Berkman & Syme, 1979; Cohen & Syme, 1985; Helgeson, Cohen, & Frits, 1998; Presberg & Levenson, 1993; Wortman, 1984). Some data suggest that this finding is true for diverse groups of survivors of cancer. This paper reviews six relevant articles.

A study examining the relationship between perceptions of social support and adjustment to breast cancer among 100 medically underserved African American women found poorer perception of social support to be associated with poor adjustment to cancer diagnosis and mastectomy (Beder, 1995). In another study assessing the relationship between coping strategies and survival among African American ($n = 442$) and Caucasian ($n = 405$) patients with breast cancer, investigators found that emotion-focused coping strategies were significantly associated with survival (i.e., the expression of emotion was associated positively with survival). When considered jointly with presence or absence of perceived emotional support, women who reported low levels of both emotional expression and perceived emotional support experienced poorer survival than women who reported high levels of both. Similar risk relations were observed for African Americans and Caucasians with early- and late-stage disease (Reynolds et al., 2000).

In their survey study, Guidry, Aday, Zhang, and Winn (1997) examined the role of informal and formal social support networks in mitigating barriers to treatment for 593 Caucasian, African American, and Hispanic patients with cancer. Individuals belonging to all racial and ethnic groups reported that formal support groups provided emotional assistance. For minorities, support groups helped in terms of continuation of treatment. Informal social support networks were reported as more helpful for African Americans and Hispanics compared to Caucasians. Koopman et al. (2001) similarly found considerable variability in the kinds of social support that rural women believed offered them the greatest comfort. Both spiritual and church groups and family support were rated as highly as general cancer support groups.

Wellisch et al. (1999) examined the nature of social support for 46 Asian American and Caucasian women after breast cancer treatment. Caucasian women indicated a greater need for social support than women in either of the two Asian American comparison groups (Japanese American and Chinese American) in 66% of the categories. No differences were found among the three ethnic groups in terms of receipt of emotional or tangible social support. However, the network size and composition differed significantly in 83% of the categories between the Anglo group and at least one of the Asian groups. In addition, differences were noted in network size, mode, and perceived adequacy of social support. Such findings may have implications for the design of culturally based clinical practice (Wellisch et al.).

In addition to providing vital information, cancer support groups often serve as critical sources of social support for survivors, particularly in cases where it may be lacking. Results of studies of mostly Caucasian survivors of cancer support the notion that support groups exert a positive impact on patients

with cancer and their caregivers. (Gregoire, Kalogeropoulos, & Corcos, 1997). Two meta-analyses demonstrated that participation in cancer support groups also may improve outcomes (Devine & Westlake, 1995; Meyer & Mark, 1995).

This review identified no studies that explored or described the effectiveness of support group interventions in mediating health outcomes for ethnically diverse survivors of cancer. In a thoughtful review of this issue, Barg and Gullatte (2001) suggested that faith-based cancer support groups may address the needs of African American patients and survivors by offering support and education within a spiritually based context. They also suggested that effective support groups are those that are congruent with the values and beliefs of a group's members. Two significant barriers to support group access in minority and underserved populations are availability of programs and awareness of service. Guidry et al. (1997) found that healthcare providers do not offer information about support groups to patients with cancer at the time of diagnosis and, thus, may need to be educated about the potential benefits of such groups.

Culturally relevant psychosocial assessment tools: One of the challenges to the examination of ethnocultural differences in cancer survivorship is having the right measurement tools and questions to capture these differences. The increasing diversity of the U.S. population has drawn attention to the need for the development of QOL assessment tools that are appropriate for special populations, including Hispanic Americans, Asian-Pacific Islanders, and Native Americans. Hispanics are one of the fastest growing of these special populations. This group includes people who have lived in the United States for many generations, as well as recent immigrants. Both language and culture are important to consider when developing QOL tools for diverse subpopulations. This search found five studies that addressed culturally relevant development of instruments and tools. One study designed to develop a Spanish translation of CARES encountered a number of methodologic problems not described previously, including the need for idiomatic translations, the target population's lack of familiarity with questionnaires, and low acculturation and literacy rates in the target sample, which included Hispanic patients with cancer in the southwestern United States (Canales, Ganz, & Coscarelli, 1995). The investigators noted that cultural mores and beliefs of subpopulations must be examined and the findings disseminated so that investigators can take them into account when developing culturally relevant instruments. That theme was echoed in the prevention literature (Phillips, Cohen, & Moses, 1999). Others have recommended the use of multisite and multicultural teams to conduct research with multicultural foci. They make the case that such teamwork should facilitate development of collaborative professional groups, sharing of resources, and data collection culminating in research proposals relevant to the study of cancer outcomes in multicultural populations (Grant et al., 1998).

Selecting culturally appropriate methods for obtaining data from minority populations is extremely important. Naranjo & Dirksen (1998) explored this issue within the Hispanic population and reported that useful strategies for recruitment included emphasis on the importance of the study and the option of meeting with other members of the community in a group. Reasons people refused to participate included fear of loss of healthcare benefits (exposure), negative responses of family members, and worry about reexperiencing distress related to

cancer diagnosis (Naranjo & Dirksen). The investigators noted that special attention to culturally relevant barriers to study entry may be needed to increase research study accrual in ethnically diverse samples.

Investigators also have suggested that researchers developing tools consider conducting separate analyses on different racial or ethnic subgroups in their study populations to determine whether common sets of factors or scales are available for further analysis (Ford, Havstad, & Kart, 2001). An example of this type of study examined the structure and reliability of the European Organization of Research and Treatment of Cancers Quality of Life Questionnaire (EORTC QLQ-C30). This instrument, designed for use in international clinical trials, is translated into more than a dozen languages. Ford, Havstad, and Kart found that seven of the nine scales showed good reliability for both African Americans and Caucasians (Cronbach's $\alpha > 0.75$). In contrast, the cognitive functioning scale had a reliability coefficient of only 0.69 for African Americans and 0.40 for Caucasians, and the nausea and vomiting scale had a reliability coefficient of only 0.49 for African Americans and 0.51 for Caucasians. Thus, even though overall reliabilities of seven of the scales showed good fit, many of the item-to-scale correlations did not. In another study, investigators translated six instruments, including the brief COPE (i.e., an inventory of coping responses with many distinct scales), Center for Epidemiological Studies–Depression, and abbreviated POMS, into Spanish and found comparable alpha reliabilities and correlations above 0.72 between the English and Spanish versions (Perczek, Carver, Price, & Pozo-Kaderman, 2000). A more complex approach may be needed to ensure cross-cultural validity of instruments. Cella et al. (1998) utilized a successful process involving an iterative forward-backward-forward sequence of item translation, expert bilingual and bicultural advisor review, pretesting in native Spanish-speaking oncology populations, and further expert advisory input to achieve semantic, content, and technical equivalence between the Spanish- and English-speaking versions of their Functional Assessment of Cancer Therapy (FACT) Instrument and five disease-specific subscales.

Health Services, Patterns of Care, and Quality of Care

The second largest area of research generated by the literature search looked at the broad category of patterns of care. Eighteen studies fell under this general category. Studies to date indicate that a number of healthcare variables at diagnosis may affect survival and survivorship. Poor survival of African American patients with breast cancer may be related to advanced stage and younger age at presentation (Baquet & Commiskey, 2000; El-Tamer, Homel, & Wait, 1999; Perkins, Cooksley, & Cox, 1996). Even after adjustment for socioeconomic variables, survival differences diminish but do not disappear, possibly because of residual differences in healthcare access, biology, or health and lifestyle behaviors. Ethnic differences also have been observed in stage at diagnosis among women with similar healthcare access predating breast cancer diagnosis (Yood et al., 1999). However, in a study that compared African American and Caucasian patients belonging to health maintenance organizations and diagnosed with localized breast carcinoma, similar survival outcomes and benefits from systemic chemotherapy were observed. This may have been a function of better access to care combined with provi-

sion of a complement of treatment options (Dignam, Redmond, Fisher, Costantino, & Edwards, 1997; Velanovich et al., 1999; Wojcik, Spinks, & Optenberg, 1998). Similarly, a study of patterns of care in radiation oncology found that although African American and Hispanic men with prostate cancer presented for therapy at a later stage than Caucasians, the treatment they received was of comparable quality (Zietman, Moughan, Owen, & Hanks, 2001). The presence and type of health insurance may be an important determinant of cancer stage at diagnosis. In their descriptive study, Roetzheim et al. (1999) found that non-Hispanic African American patients were more likely to be diagnosed with late-stage breast and prostate cancers than non-Hispanic Caucasians, and Hispanic patients were more likely to be diagnosed with late-stage breast cancer but less likely to be diagnosed with late-stage prostate cancer. People lacking health insurance and those insured by Medicaid are more likely to be diagnosed with late-stage cancer at diverse sites. The authors emphasized that efforts to improve access to cancer screenings are particularly warranted for these groups.

Barriers to cancer treatment and, logically, to appropriate follow-up care include both system-driven and patient-driven factors. Guidry, Aday, Zhang, and Winn (1998a) looked at the prevalence of barriers to cancer treatment, such as insurance coverage, indirect costs (transportation, lodging, and work days lost), and direct costs of care, for Caucasian, African American, and Hispanic patients with cancer. The study elucidated a number of different patterns by ethnic group. Specific insurance premium-related barriers with regard to maintaining and affording coverage were more prevalent for African Americans. Hispanics were less likely to have insurance coverage; however, more African Americans than Caucasians and Hispanics reported being denied insurance coverage when they changed jobs. Minorities, particularly Hispanics, were more likely to have experienced cost-related barriers associated with medications, diagnostic tests, and hospitalizations. In addition, Hispanics had significant out-of-pocket costs for cancer treatment.

These data largely reflect the potentially limiting effect that health insurance and out-of-pocket costs may have on diagnosis and access to active cancer treatments for minority populations. Less clear is the continued experience that these groups have in regard to coverage for and access to maintenance drugs and care or follow-up visits once treatment ends. Given the lower reimbursement rates for such visits, differences in coverage and access likely are even greater among ethnically diverse groups in the post-treatment period. The issue is compounded by confusion generated by differing recommendations from various national organizations and little empirical evidence of benefit from intense post-treatment surveillance. A study describing the use of post-treatment surveillance guidelines for colorectal cancer found that Caucasian survivors were more likely than minority survivors to receive carcinoembryonic antigen testing and to undergo colon examination. The study also found that the likelihood of both tests increased as median household incomes, reflected by residential zip codes, increased (Lafata, Johnson, Ben-Menachem, & Morlock, 2001).

A number of studies have reported systematic differences between diverse ethnic groups in the pattern of cancer treatments received. Many studies have documented that where people live affects the care they receive, which, in turn, may

affect survivorship outcomes (Nattinger, Gottlieb, Veum, Yahnke, & Goodwin, 1992). Individuals in rural areas and different geographic parts of the country do not receive what might be considered state-of-the-science care. By contrast, those proximate to major cancer centers or large volume cancer practices fare better (Farrow, Hunt, & Samet, 1992). However, care in defined regions may further differ for ethnoculturally diverse groups. Kagawa-Singer et al. (1997) found significantly lower rates of use of both breast-conserving and adjuvant therapy among Asian American survivors of breast cancer compared to Caucasian survivors. In another large follow-up study of survivors of breast cancer 1–5 years after treatment in one of two major metropolitan areas (Los Angeles, CA, or Washington, DC), African American women were significantly more likely to have received a mastectomy than their Caucasian or other non-Caucasian counterparts. They also were less likely to have undergone subsequent breast reconstruction (Rowland et al., 2000). Whether these differences in patterns of care reflect poorer candidacy for conservation, physician bias in recommendation or delivery of care, lack of access or awareness about surgical options, women's personal or cultural fears or beliefs about specific cancer treatments, or, as is most likely, some combination of these factors is unclear.

Observational studies indicate that African American patients with prostate cancer are less likely to receive definitive therapy (Horner, 1998). This pattern of care appears to be attributable primarily to the later clinical stage of disease at presentation. Socioeconomic considerations such as access to care (e.g., ability to pay) appear to play a lesser role. Future research should focus on the reasons for detection at a later clinical stage and, therefore, worse prognosis. However, uncertainties surrounding treatment also have given rise to variable practice styles. This is well illustrated by the considerable variations in the use of therapies for clinically localized prostate cancer across the United States and in different racial groups (Potosky et al., 1999; Zietman et al., 2001). As mentioned previously, other important patient-related factors that affect care, such as preferences for certain therapies, have not been well studied; consequently, the explanation for racial variations in use of therapies for this disease is unclear.

A better appreciation of how treatment decisions are made is critical because these choices will affect the QOL and survival of men treated. Investigators have reported that younger patients in ethnically diverse groups may elect to undergo radical prostatectomy rather than watchful waiting. Yan, Carvalho, Catalona, and Young (2000) found that for every five-year decrease in age, the odds of choosing radical prostatectomy versus watchful waiting increased proportionally. A similar pattern was observed with prostate-specific antigen (PSA) levels such that the odds for choosing radical prostatectomy versus watchful waiting increased with every 1 ng increase in PSA. Non-African American patients were more than four times more likely to select radical prostatectomy than watchful waiting.

Some studies have examined sources that minority patients with cancer use to obtain information regarding their treatment options and side effects, looking for the major predictors that facilitate use of information. In a survey administered to a representative sample of 593 patients with cancer in Texas (65% response rate), patients reported that providers, such as physicians and nurses, were the most helpful sources of information. Caucasian patients tended to use books and reference materials

more heavily to gather additional information regarding treatment; African American patients relied on pamphlets and television. Educational level appeared to have a major influence on African American patients' use of printed materials. These results support the important role that providers, including nurses, play in influencing patients' treatment decisions. They also highlight the fact that the most effective ways to communicate with patients with cancer may be different for patients from different ethnic and racial backgrounds. Such findings have important implications for the future development of patient-education materials and cancer-control initiatives targeting ethnic minorities (Guidry, Aday, Zhang, & Winn, 1998b).

In a follow-up interview study involving 1,928 adults who had survived childhood cancer, an investigative team explored factors related to the lack of awareness or failure to acknowledge the adults' earlier cancer diagnoses (Byrne, Lewis, Halamek, Connelly, & Mulvihill, 1989). Fourteen percent of the survivors of malignancies at sites other than the central nervous system said that they had not had cancer. This proportion differed according to type of tumor and treatment, the level of their fathers' education, the year of diagnosis, the center where the tumor was diagnosed, and, unexpectedly, race. Among survivors who knew that they had had cancer, however, most (81%) correctly identified the type of treatment they had received. These results suggest that healthcare providers should be aware that a substantial proportion of long-term survivors of childhood cancer may not reveal a history of cancer and treatment; therefore, clues to the cause of a new presenting condition may be missed. This may be especially true for non-Caucasian survivors of pediatric cancer (Byrne et al.).

Finally, two studies examined the use of complementary and alternative therapies by diverse populations of survivors. In one, investigators found that both the alternative therapies used and the factors influencing choice of therapy varied by ethnicity among women with breast cancer. African American women used spiritual healing most often, Chinese American women used herbal remedies most frequently, Hispanic women tended to use dietary therapies, and Caucasian women used dietary and physical methods (e.g., massage, acupuncture) (Lee, Lin, Wrensch, Adler, & Eisenberg, 2000). The second study found that more African American than Hispanic or non-Hispanic Caucasian patients with early-stage breast cancer used herbal therapies and spiritual healing. This pattern of use was not related to women's expectations of recurrence, dissatisfaction with medical care, or concerns about the consequences of chemotherapy, but rather to their expectations that these practices might increase the potential benefit of cancer-related treatment (Alferi, Antoni, Ironson, Kilbourn, & Carver, 2001). Given the rising prevalence and popularity of complementary and alternative treatment strategies and their potential for harm or benefit, providers should actively elicit this information from patients (Penson, Castro, Seiden, Chabner, & Lynch, 2001).

Health-Promoting Behaviors and Lifestyles

A number of lifestyle factors are known to increase individuals' risk of developing cancer, including tobacco use, alcohol consumption, sexual activity, and exposure to environmental toxins. Less clear is whether changing these factors after diagnosis will alter cancer outcomes in terms of disease-free or overall survival, preventing or ameliorating long-term

or late effects, or comorbidities. Research on the impact of these lifestyle factors on ethnic or cultural groups is virtually nonexistent. Only six articles provided insight into this general area.

Patients with cancer who belong to ethnocultural minority subgroups with low levels of literacy or education face a number of obstacles to learning about their illness. They sometimes receive overly complex information at inappropriate times. Avoidance as a way of coping and lack of comprehension are additional barriers to adequate healthcare knowledge. The lack of correlation between educational level and reading ability results in some patients receiving materials beyond their level of comprehension. The minority patients in one study wanted "all available information," desired participation in care decisions, and preferred personal interactive learning but were limited because their reading abilities were below the seventh- or eighth- grade level (Foltz & Sullivan, 1996).

Some research has suggested that behavioral risk factors, such as lower levels of physical activity and higher prevalence of severe obesity among African American women, may play an important role in explaining their relative disadvantage in stage of breast cancer at diagnosis (Jones, Kasi, Curnen, Owens, & Dubrow, 1997). Associations between body mass index (BMI), reproductive factors, and breast cancer also need to be examined. One study reported that, among postmenopausal African American women, cases had significantly lower weight and BMI levels than controls (Adams-Campbell et al., 1996). Age at first pregnancy and parity also were significantly lower among postmenopausal cases than their controls. Early age at menarche was the only reproductive factor that was an independent predictor of BMI for both pre- and postmenopausal African American women, irrespective of breast cancer status. These findings suggest the need to consider reproductive factors, particularly age at menarche, as covariates in future studies examining the role of weight, physical activity, and cancer outcomes. In another study examining cigarette smoking among patients in a cancer center, African American men comprised the highest percentage of current smokers, and both African American men and women had the lowest percentage of quitters (Spitz, Fueger, Eriksen, & Newell, 1988).

Models of health behavior provide the conceptual bases for the majority of breast cancer screening intervention studies. For the most part, these models were not designed for and have not been tested adequately with ethnically diverse populations and survivors of cancer (Ashing-Giwa, 1999). An article reviewing the evidence on five risk behaviors (i.e., cigarette smoking, dietary intake, being overweight, limited exercise, and alcohol consumption) among African Americans, Asian/Pacific Islanders, Latinos, and Native Americans observed that little evidence supported that these high-risk behaviors are any more or less significant as contributors to chronic disease risk in any ethnic group. Nevertheless, the limited information available, especially for Asian/Pacific Islanders and Native Americans, suggests that significant within- and between-group differences might exist in the prevalence of these behaviors. Some of the ethnic group differences in morbidity and mortality for chronic diseases likely are partly attributable to differences in behavioral risk profiles. Limited basic health behavior information on most ethnic minority groups delays the development of effective health-

promotion interventions (Myers, Kagawa-Singer, Kuman-yika, Lex, & Markides, 1995).

Discussion and Recommendations

The researchers undertook a detailed review of the extant literature describing cancer survivorship outcomes (e.g., physiologic, psychosocial), health services and quality of care, and health-promoting behaviors and lifestyles among survivors belonging to ethnoculturally diverse and medically underserved groups in an effort to understand the similarities and differences in the survivorship experiences of different ethnic groups and examine the potential role of ethnicity in influencing the quality and length of survival from cancer. The disturbingly few studies that were identified emphasized the significant lack of knowledge in this critical area. The information that this small body of research provided was spread across a number of survivorship domains. However, some potentially important findings were found across all of the selected survivorship outcome categories.

The present review revealed that, to date, research examining ethnic or minority differences in cancer survivorship outcomes is limited largely to epidemiologic analyses of differences in cancer risk and survival. Little effort has been made to explore how risk of development, diagnosis, treatment, and death affect individuals living with the disease. This represents a wide open area for inquiry. The few studies that have examined the physiologic and psychosocial sequelae of cancer and its treatment among diverse populations of cancer survivors are provocative.

The majority of modern cancer treatments carry substantial risks of adverse long-term (i.e., persistent or chronic) or late (i.e., delayed) effects. A body of evidence supports the presence of adverse late effects, such as neurocognitive problems, premature menopause, cardiac dysfunction, sexual impairment, chronic fatigue and pain syndromes, and second malignancies, among survivors of adult and childhood cancer (Aziz, 2002). One-fourth of late deaths of survivors of childhood cancer during the extended survivorship period, when the chances of primary disease recurrence are negligible, can be attributed to treatment-related effects, such as second cancer or cardiac dysfunction (Sklar, 1999). The vast majority of these findings are from research studies conducted on predominantly Caucasian survivors of cancer. The prevalence and incidence of these or other long-term and late effects of cancer treatment remain largely understudied for survivors belonging to ethnocultural minority or medically underserved groups.

Given this background and the growing population of ethnically diverse survivors expected to live years after diagnosis, exploring these patterns of illness and treatment-related long-term or late effects is critical. Evidence that African American survivors of childhood cancer treated with doxorubicin-based chemotherapy are at greater risk for early cardiotoxicity (Grenier & Lipschultz, 1998) should be explored further. Important challenges are examination of long-term and late effects among adult and pediatric survivors of understudied cancer sites (e.g., colorectal, lung), identification of those at increased risk for complications of treatment, and interventions to reduce that risk (e.g., use of cardioprotective agents during chemotherapy). Furthermore, studies must examine the role of comorbidities in the development of late effects among older survivors.

In addition, evidence that specific psychosocial outcomes, such as coping and sexual dysfunction, may vary by race (Wyatt et al., 1998) should be explored. The finding that breast and prostate cancers may have a less negative impact on sexual function among African American than Caucasian survivors (Lubeck et al., 2001; Stanford et al., 2000; Wyatt et al.), yet exert a heavier emotional toll (Beder, 1995; Germino et al., 1998), emphasizes the need to be aware that responses to illness are not uniform across ethnic groups. Several studies suggested that variations among ethnic groups in prior experience, social mores, and cultural beliefs can affect survival. The influence of family members and patterns of coping, such as use of spiritual communities, also may represent factors that distinguish outcomes across groups.

Sociocultural and behavioral factors play an important part in patient decision-making, adherence to treatments, outcomes, and willingness to adopt appropriate surveillance and health-maintenance behaviors post-treatment (Compas, Keefe, Haaga, Leitenberg, & Williams, 1998). Interventions to maximize patient engagement in and benefit from cancer treatments are growing rapidly (Devine & Westlake, 1995; Meyer & Mark, 1995). However, little is known about who needs what types of interventions and when. Few studies have explored the potentially unique intervention needs and responses of diverse and underserved survivor populations. For example, the finding that female, minority, and unemployed survivors may be at greatest risk for emotional sequelae indicates that targeted, preventive interventions may be needed to meet the needs of women with these characteristics (Zeltzer et al., 1997).

Examining factors that promote resilience and optimal well-being in minority survivors and their families is important. Studies are needed that examine the types of interventions (e.g., medical, behavioral, educational, psychosocial) that are effective in reducing cancer-related symptoms among minorities, as well as interventions that improve survivors' and family members' health, psychosocial functioning, and economic well-being. Toward this end, screening tools must be developed and tested to accurately identify individuals at high risk for poor physiologic, psychosocial, or behavioral outcomes (Meyerowitz, Richardson, Hudson, & Leedham, 1998).

Another theme identified in this review was the need to better understand the impact that the healthcare system itself and access to medical care have on survivorship outcomes for diverse ethnocultural groups and those who tend to be underserved by such structures and their delivery (e.g., the elderly, those with low incomes and low educational levels, geographically remote groups). Although little is known in general about the pattern of follow-up care received by people with a history of cancer, this knowledge deficit is particularly acute for these populations. Few guidelines exist for the delivery of follow-up cancer care and surveillance, who should provide or pay for such care, and where this care is best offered (e.g., at major cancer clinics or centers, community sites, physician offices or practices). Use of specially trained nurse practitioners and primary care physicians may be a cost-effective way to provide knowledgeable medical surveillance. The work of Guidry et al. (1998a) stressed the importance of nonclinical, financial factors that serve as barriers to optimal treatment and follow-up care of patients with cancer. Out-of-pocket costs, such as babysitting, meals, transportation, and missed days of work, may be particularly burdensome for some minority populations. Consequently, assessing for potential barriers to care early in the course of illness and

across the cancer trajectory—and connecting survivors to available resources to minimize these barriers—may be as effective a strategy for reducing cancer morbidity as provision of some drugs.

In a related vein, the influence that other post-treatment health behaviors (e.g., receipt of care for other chronic medical conditions) and lifestyle factors (e.g., dietary practices, smoking, alcohol consumption, sun exposure, exercise) have on the physical status and QOL of all survivors is not fully appreciated yet. Indeed, the healthcare industry has focused so narrowly on helping patients with cancer become survivors that it only has just begun to articulate what life is like for individuals living beyond treatment. Current data suggest that increased risk for cancer in some minority populations may be explained in part by poorer health status (e.g., obesity, exposure to work-related toxins) or behaviors that increase cancer risk (e.g., smoking, alcohol use) (Committee on Health and Behavior, 2001). If these conditions and practices continue after cancer diagnosis, this could lead to increased risk for morbidity and mortality. Nurses long have played a central role in the delivery of cancer prevention and control initiatives (e.g., cancer awareness, screening, and outreach). However, studies have not fully explored nurses' role in and the expected impact on the reduction of the cancer burden by facilitating access to or delivering health-promoting education and interventions to vulnerable populations of survivors.

The articles reviewed also highlighted a number of methodologic problems that limit the current ability to obtain information about and interpret survivorship outcomes of ethnically diverse and medically underserved survivors. Chief among these is the need for more studies with sufficient statistical power to yield comparative results. To rectify this situation, investigators should augment study populations by using larger sample sizes, targeted minority recruitment efforts, stratified designs, or some combination of the above. Further, reaching these populations, as several investigators pointed out, may require special measures. Investigators wishing to work with these populations must develop culturally sensitive approaches if they are to successfully address unique barriers to study participation.

Understanding the important questions to ask and how to ask them also is important. Although a number of well-constructed and validated measures now exist for evaluating the health-related QOL of patients diagnosed and in active treatment for cancer, few measures have been designed to study individuals beyond the acute phase of illness (e.g., more than six months post-treatment). As reflected in this review, even fewer measures are culturally relevant and of sufficient sensitivity to identify differences in diffuse subsets of survivors. Earlier work in instrument development relied heavily on educated responses from Caucasians. The standard approach involved paper-and-pencil measures often informed by or supplemented with focus groups. Many investigators pointed out that this approach may be insufficient to capture concerns and needs of those in minority settings. Most investigators working with minority populations stated that investment or "buy in" from the community, use of respected leaders, and participatory involvement of minority members in all phases of the process are key to the success of any research enterprise in such communities (Grant et al., 1998; Naranjo & Dirksen, 1998).

In *The Unequal Burden of Cancer*, a report released in January 1999, the Institute of Medicine noted that survivors of can-

cer are the most underutilized resource in the war on cancer (Haynes & Smedley, 1999). This is especially true for ethnic minorities and medically underserved populations. According to that report, minority survivors of cancer are aware of the lack of services and information that might assist them in dealing with not only the acute stages of treatment for cancer, but also the multitude of issues that are raised during survivorship. The limitation of the current research is that it often fails to ask the very individuals whom it seeks to help how it might do so.

This review made clear that researchers must move away from simplistic models to those that better capture the rich complexity of factors that affect people, their care, and the environments in which they live. A good example of this is the growing understanding that race often may be a proxy for myriad social risk factors (e.g., lower education levels and incomes) that are more critical to survival and survivorship than ethnicity or skin color. Adoption of a mediational framework that links ethnicity and cancer outcomes through socioeconomic status, knowledge, attitudes, and access to medical care may be particularly meaningful (Meyerowitz et al., 1998). Such a framework may offer the best hope for identifying areas where clinical, behavioral, and educational interventions could alter the burden of disease dramatically.

A final observation made in this study is the need to train clinicians and researchers to work with these special populations of survivors. A number of studies identified unique cultural norms and mores shared by specific minority groups that can affect care and outcomes. Clinicians should be aware of these when treating patients and following and educating survivors about life after cancer. Researchers may benefit from knowledge gleaned by their social scientist colleagues (e.g., sociologists, anthropologists, linguists) about the use of different strategies for data collection and analysis. This may lead to more reliance on narrative and qualitative approaches to information gathering than the strictly quantitative approaches that have dominated the field of cancer outcomes research thus far. Recruiting minority researchers and clinicians into this larger field of work also is critical.

This review's search process may have underestimated the number of published articles relevant to cancer survivorship outcomes among ethnocultural minority and medically underserved populations. The peculiarities of individual search engines and the key words and codes under which databases

archive research articles may have contributed to this limitation. However, every effort was made to search with various combinations and permutations of survivorship outcome-relevant keywords. Reference lists of primary articles also were perused to identify additional sources. Future reviews addressing this issue should be careful to include "survivorship" as a keyword.

The glaring lack of knowledge about the health-related and QOL outcomes of minority and medically underserved survivors of cancer represents a clear challenge—but one with exciting opportunity and growth. With the establishment in 1996 of the Office of Cancer Survivorship (OCS), the National Cancer Institute (NCI) made a formal commitment to better understand and meet the unique needs of this growing population, one whose very existence is a testament to the many advancements in diagnosing and treating cancer. The most recent initiative advanced by OCS was a supplement to cancer centers to fund pilot research addressing survivorship issues for minority and medically underserved survivors and their family members. This mechanism funded six investigators, and nine other full-scale research studies funded by OCS also are conducting survivorship research targeting ethnoculturally diverse and medically underserved populations. Issues being investigated include the interrelationship of cognition, emotion, biologic processes, and physical health; the impact of survivorship on families; differences in long-term QOL and predictors for recurrence; and the prevalence of long-term effects of cancer. Two additional activities within NCI also will serve to advance the understanding of the needs of these understudied communities. These include the establishment of the Center for the Reduction of Cancer Health Disparities, headed by Harold Freeman, MD, and the creation of the Special Populations Network, which consists of 18 centers around the country examining cancer and control activities in specific minority or rural populations. Finally, "Quality of Cancer Care" and "Reducing Cancer-Related Health Disparities" are two key NCI research priorities highlighted in the bypass budget documents for fiscal years 2002 and 2003. Their prominent placement in NCI's mission ensures that resources and initiatives will continue to make rapid inroads in understanding and addressing the health and well-being of all survivors of cancer.

Author Contact: Noreen M. Aziz, MD, PhD, MPH, can be reached at na45f@nih.gov, with copy to editor at rose_mary@earthlink.net.

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