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Tailoring Cancer Education and Support Programs for Low-Income, Primarily African American Cancer Survivors

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Almost 12 million Americans to date are living with a diagnosis of cancer (Altekruse et al., 2010); of them, more than 65% have survived for more than five years (Jemal et al., 2009). As the population continues to age and treatment outcomes improve, the numbers of Americans with cancer and long-term survivors are expected to increase. However, gains in survival have been uneven; the five-year survival rates for minorities are lower than the rates observed in the Caucasian population (Jemal et al., 2009).

Public health efforts to better understand and improve the survivorship experience in minority populations are critical. Initiatives tailored to survivor needs must be developed, implemented, and evaluated. Accordingly, leaders in addressing the cancer survivorship experience have collaborated to develop the *National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* (Lance Armstrong Foundation & Centers for Disease Control and Prevention, 2004). The plan identifies a comprehensive set of priorities for cancer survivorship, which includes ensuring effective support programs and education for cancer survivors.

Despite the availability of many cancer survivorship educational materials and resources, research on the usefulness of those materials to survivors is limited. In particular, whether available materials or programs have met survivor needs and improved quality of life generally has not been evaluated rigorously. Gaps in the understanding of survivorship resources are pervasive, particularly for minorities and the medically underserved.

The American Cancer Society (ACS) is a leader in the development of cancer survivorship resources such as

Purpose/Objectives: To identify the information and stress-management topics of most interest to low-income, predominantly African American cancer survivors.

Research Approach: Descriptive, cross sectional.

Setting: Outpatient oncology clinic in a public hospital in Birmingham, Alabama.

Participants: 25 patients with cancer; 12 were men, 22 were African Americans, and 16 had a 12th-grade education or less.

Methodologic Approach: Patients ranked potential topics to be included in an educational curriculum.

Main Research Variables: Quantitative rankings of information and stress-management priorities.

Findings: Learning about cancer, understanding cancer treatments, relieving cancer pain, and keeping well in mind and body were the most highly ranked topics among those offered within the American Cancer Society's I Can Cope curriculum, which also included supportive topics such as mobilizing social support. The preferred stress-management topics were humor therapy, music therapy, meditation, and relaxation; lower-ranked topics included pet therapy and art as therapy.

Conclusions: Cancer survivors appear most interested in topics specific to their illness and treatment versus supportive topics. Stress management also received high rankings.

Interpretation: Nurses have a key role in providing patient education and support. Tailoring education programs may better target specific needs and improve the quality of cancer care of underserved patients.

I Can Cope, a basic cancer information program for survivors and their families. The program (a formal curriculum aimed at addressing knowledge, beliefs, and attitudes, as well as developing skills important to cancer survivorship) was developed in 1977 by two nurses in

response to the information needs of their patients with cancer. The pilot program was funded by the Minnesota division of ACS. In 1978, the concept and work were presented at the annual Oncology Nursing Society Congress and were well received by the attendees. In 1979, I Can Cope officially became an ACS program.

Despite its long history, I Can Cope has few published evaluations. In one study, 78% of I Can Cope participants indicated that their expectations of the program were met (Diekmann, 1988). However, a gap exists in the understanding of I Can Cope's value among diverse cancer survivors. Given its origin in Minnesota at a time when census indicated that Caucasians comprised 97% of the population (Gibson & Jung, 2002), the patients who inspired I Can Cope probably were not minorities. Therefore, the content of the classes may not resonate with diverse populations. In addition, I Can Cope attendees have been fairly homogenous with regard to race or ethnicity. For example, in a national ACS evaluation of I Can Cope programs, only 3% of the participant sample providing an evaluation of the program were African Americans. Attendees also tend to have greater financial means. Of those providing an evaluation of the program, almost 50% of participants had an income higher than \$30,000 and 17% had a family income of \$50,000 or more (McMillan, Tittle, & Hill, 1993). For the continuous quality improvement of cancer survivorship resources, initiatives should engage diverse populations in the delivery and evaluation of cancer support programs.

To address this knowledge gap, the authors conducted a randomized, controlled trial to evaluate the efficacy of I Can Cope in meeting the information needs of cancer survivors. As a first step in designing the intervention, the authors conducted an informational needs assessment among low-income, primarily African American cancer survivors. This article describes the outcome of that assessment.

The current study sought to identify the I Can Cope and stress-management topics of most interest to low-income, primarily African American cancer survivors in treatment or follow-up at a local publically funded hospital. Results were intended to guide delivery of topics to a population of a similar demographic. The study was approved by the university and hospital institutional review boards.

Methods

Sample and Setting

Participants in the study were recruited as a convenience sample (N = 25) from the outpatient oncology clinic in a hospital provid-

ing care primarily to low-income residents of Jefferson County, AL. The sociodemographic characteristics of Jefferson County are noteworthy. An estimated 41% of residents report their race as African American, in contrast to 12% in the total U.S. population. Many residents are economically challenged. Although the average percentage of Jefferson County families living below poverty level is similar to the 10% national rate, almost 20% of African American families in the county are below the poverty level (U.S. Census Bureau, 2009). The high cancer rates in Jefferson County (National Cancer Institute, 2009) and the demographic characteristics of its residents highlight the significance of the current study.

Cancer survivors who were aged 19 years or older, were experiencing their first primary cancer diagnosis, and were receiving or had completed treatment were invited to participate in the informational needs assessment. Because patients with a cancer recurrence may have markedly different understanding and needs than patients experiencing cancer for the first time, patients with recurrent or second primary cancers were excluded from the study, as were patients with a poor prognosis (i.e., an expected life span of six months or less). The charge nurse referred potential participants to study recruiters.

Table 1. Rankings of I Can Cope Topics

Topic	Rank					Total
	1	2	3	4	5	
Learning about cancer	10	3	2	–	2	70
Understanding cancer treatments	2	10	2	1	2	60
Keeping well in mind and body	3	3	3	2	2	42
Relieving cancer pain	3	1	2	4	2	35
Managing effects of illness and treatment	2	1	4	3	2	34
Communicating concerns and feelings	2	1	3	4	1	32
Nutrition during cancer treatment	1	2	2	4	2	29
Taking charge of money matters	1	1	3	–	2	20
Managing cancer-related fatigue	–	2	1	2	4	19
Nutrition after cancer treatment	–	1	2	3	3	19
Exploring self-esteem and intimacy	1	–	1	–	3	11
Mobilizing resources and support	–	–	–	2	–	4

N = 25

Note. Patients were asked to choose the topics in which they were interested and then rank the top five, with 1 reflecting their highest rating. Rankings then were reverse scored (i.e., a topic ranked as 1 was assigned a value of 5). The total rank value for each topic equaled the sum of the number of patients multiplied by the rank across all 5 categories for that topic.

Informational Needs Assessment

This descriptive, cross-sectional study took place within the oncology clinic during a regularly scheduled visit. Participants agreeing to complete the needs assessment received a brief description of each I Can Cope topic, identified the topics of interest to them, and rank ordered their top five. Participants also ranked stress-management topics from a separate list of topics and descriptions generated by the investigative team and by colleagues within the education outreach section of a comprehensive cancer center. Care was taken to include general stress-reduction techniques that might be of interest to cancer survivors but did not include cancer-specific information.

To identify the topics of greatest interest, the ranks were calculated as follows. Participants rank ordered their top five, with 1 reflecting their highest rating. Rankings then were reverse scored (i.e., a topic ranked as 1 was assigned a value of 5). The total rank value for each topic equaled the sum of the number of patients multiplied by the rank across all five categories. Participants also indicated their preferred time for the intervention (day and time of day), preferred location of the sessions (e.g., community, hospital, university), and any potential logistic challenges (e.g., transportation, child or older adult care needed).

Results

Descriptive statistics were calculated to characterize the study sample. Twenty-five patients were recruited from the oncology clinic to participate in the survey. The majority of the patients were aged 50–69 years, 9 were married or partnered, 12 were men, 22 were African American, and 16 had a 12th-grade education or less. None was employed. Based on their assessment, the highest-ranked I Can Cope topics were learning about cancer, understanding cancer treatments, keeping well in mind and body, and relieving cancer pain (see Table 1). The highest-ranked stress-management topics were humor therapy, music therapy, relaxation, and meditation (see Table 2). With regard to potential barriers to participation, about half indicated they would need assistance with transportation. No respondents reported a need for child care or older adult care. Participants preferred daytime offerings for the program and desired the intervention to be delivered on a weekday and in the hospital or university setting (versus a community setting).

Discussion

Consistent with the Institute of Medicine position put forth in *The Unequal Burden of Cancer: Confronting Racial and Ethnic Disparities in Health Care*, quality survivorship care for racial or ethnic minorities and the medi-

Table 2. Ranking of Stress-Management Topics

Topic	Rank					Total
	1	2	3	4	5	
Humor therapy	13	2	2	1	3	84
Music therapy	5	11	2	3	1	82
Relaxation	2	5	7	5	2	63
Meditation	–	3	6	4	6	40
Massage therapy	4	1	3	1	3	38
Art as therapy	–	–	3	7	3	26
Dance therapy	–	2	2	3	3	23
Pet therapy	1	1	2	1	3	20

N = 25

Note. Patients were asked to choose the topics in which they were interested and then rank the top five, with 1 reflecting their highest rating. Rankings then were reverse scored (i.e., a topic ranked as 1 was assigned a value of 5). The total rank value for each topic equaled the sum of the number of patients multiplied by the rank across all 5 categories for that topic.

cally underserved requires a patient-centered approach (Smedley, Stith, & Nelson, 1999). As such, the current authors engaged a low-income, predominantly African American group of cancer survivors in the selection of topics to be offered in this randomized, controlled trial evaluation of ACS's I Can Cope program. The results of the needs assessment suggest that low-income, minority patients are interested in general basic information about cancer (i.e., about the disease process, treatments, and managing side effects as opposed to mobilizing resources and support). Because the stress-management topics were ranked highly, the current study also suggests great interest in alternative topics. To the authors' knowledge, this is the first study to use a quantitative needs assessment to measure the interests of low-income African American patients for nontraditional cancer survivor information.

The current study had two limitations. First, I Can Cope is a general cancer survivorship program (i.e., not specific to one type of cancer), so the needs assessment engaged survivors with varying cancer types. However, the authors did not document participants' specific cancers. As such, whether the cancer profile of the sample reflects the cancer survivor population at the county hospital is not known. Second, the small sample size limits the generalizability of the findings.

Nonetheless, this informational needs assessment has several strengths. Consistent with the recommendation from the National Action Plan for Cancer Survivorship to disseminate educational programs to cancer survivors (Lance Armstrong Foundation & Centers for Disease

Control and Prevention, 2004), the current research has brought I Can Cope to a county hospital and engaged a population typically not reflected in the programs. In addition, conducting the needs assessment to tailor the content of I Can Cope interventions reflects an innovation; I Can Cope program facilitators typically determine the topics to be delivered without input from participants.

Nursing Implications

For nurses, who increasingly will become involved in survivorship care (Haylock, Mitchell, Cox, Temple, & Curtiss, 2007), understanding patient educational priorities will shape how care is delivered and resources are allocated. Patient education should begin with an assessment of patient-centered educational goals. Although the biomedical framework suggests a focus on cancer-specific topics, the current study's results suggest that African American cancer survivors also are very interested in stress-management topics. In the healthcare system, supportive topics such as stress management often are overshadowed by immediate medical concerns. Therefore, nurses are charged with developing clinical tools that allow for the ongoing assessment of patient educational priorities and preferences, as well as creating an environment in which patients feel supported to express interest in nontraditional support needs.

The current study's findings also challenge healthcare providers to think differently about how to allocate patient education resources. I Can Cope is structured such that each of the topics stands alone as a separate class. In other words, each topic is given equal weight. However, many topics received very low rankings. Engaging nurses, other healthcare professionals, or invited speakers in the delivery of the information for the low-ranked topics in a face-to-face meeting may not be cost effective. The allocation of healthcare resources should reflect patient needs and interests. Overall, the current program of research to assess the information needs of low-income, minority cancer survivors and the authors' effort to evaluate the efficacy of a national program developed by nurses has great potential to improve the cancer survivorship experience for a vulnerable population. Future research should include assessing the impact of I Can Cope on various outcomes (e.g., adherence to treatment, patient activa-

tion to assume greater responsibility for their health, satisfaction with care). Additional studies also should determine whether a cultural adaptation of I Can Cope is indicated. For example, in a review of culturally appropriate health education for patients with type II diabetes, those receiving the cultural intervention had better glycemic control and knowledge than patients receiving usual care (Hawthorne, Robles, Cannings-John, & Edwards, 2008). A culturally appropriate I Can Cope program may improve outcomes for racial and ethnic minorities. The current project and similar future clinical and research efforts ultimately will contribute to the continuous quality improvement of cancer survivorship resources, particularly for those who are minority or low income.

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Digital Object Identifier: 10.1188/11.ONF.E55-E59

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