Enhancing Life After Cancer in Diverse Communities

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BACKGROUND: Although large numbers of cancer survivors exist in every community, including minority communities, there is a significant gap in knowledge about best practices for these patients. METHODS: The Community Networks Program, funded by the National Cancer Institute Institute to Reduce Cancer Health Disparities, has developed and tested unique services for these communities. These programs have used community-based participatory research techniques under a framework of diffusion of innovation and communications theory. RESULTS: This article describes some specifically tailored interventions that may be useful to a wide range of providers working with the underserved. CONCLUSIONS: Enhancing life after cancer can be achieved in underserved communities by supplementing local resources. Cancer 2012;118:5366-73. © 2012 American Cancer Society.

KEYWORDS: community networks, cancer, quality of life, health disparities, palliative care, comprehensive cancer care, spirituality.

In the first (1982) edition of the classic text *Principles and Practice of Oncology*, Stephen Hersh’s chapter on psychosocial aspects of patients with cancer states that “most of the diseases called cancer fall into the category of chronic illness.”1 That statement remains true today. The chapter stands out as historic due to its premise that the treating physician should consider the whole cancer patient, not just the cancer.

This humanistic vision notwithstanding, more than 2 decades later, the 2005 Institute of Medicine report “From Cancer Patient to Cancer Survivor: Lost in Transition” painted an unsettling picture of how cancer care is being delivered.2 Patients are not receiving care that prepares them for, or supports them after, the end of cancer treatment. Few health care providers are familiar with the short- and long-term consequences of a cancer diagnosis and treatment, and there is a lack of clear evidence about what constitutes best practices in caring for patients with a history of cancer. This is especially true in underserved populations.

Cancer prevalence figures, the number of persons alive with a history of cancer, for the United States, have been growing at a rate of approximately 3% per year. This number is rapidly approaching 12 million, representing approximately 4% of the population.3 It is expected that the numbers of survivors will continue to climb,4,5 and given current demographic trends, the numbers of survivors from ethnoculturally diverse groups will also rise.

Treatment regimens are now more complex, the decisions regarding these are often complicated, and a growing proportion of cancer care is delivered in the outpatient setting. There is a greater need among families and survivors alike for help negotiating cancer journeys that may last years, decades, or even a lifetime. This reality has fueled the development of survivorship programs and the fast-moving field of cancer survivorship research.

Established in 1996, The Office of Cancer Survivorship at the National Cancer Institute (NCI) has seen an increase in the number and breadth of studies examining the trajectory of cancer survivors. The end of treatment does not mark the end of the cancer experience because as many survivors tell us, “It’s not over when it’s over.” Although some of cancer’s adverse effects disappear or are reversed soon after treatment stops (hair loss, anemia, mouth sores), others can persist over time (pain syndromes, sexual dysfunction, fatigue, memory problems) and still others may occur months or years later (eg, second cancers, cardiac dysfunction, osteoporosis). Survivors from different ethnic and cultural groups, geographic

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The authors thank Vicki Shea, research secretary, for her diligence in working with the authors to gather and submit this manuscript and associated paperwork to the journal. The authors also acknowledge The Community Networks Programs grantees, their colleagues and community partners, and most importantly the participants in these projects for whom this program was developed and without whom this effort would not have been possible.

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DOI: 10.1002/cncr.27491, Received: July 7, 2011; Revised: October 19, 2011; Accepted: November 10, 2011, Published online March 20, 2012 in Wiley Online Library (wileyonlinelibrary.com)
areas, or underserved communities may have very different survivorship experiences. For example, in one report at 2 years after treatment, African American prostate cancer survivors report lower satisfaction with the degree of overall treatment outcomes than white or other ethnic prostate cancer survivor groups.6 Another study found that low-income Hispanic breast cancer survivors report high levels of economic distress, which is negatively associated with quality-of-life outcomes.7 Others observed disparities in mental health outcomes between rural and nonrural cancer survivors.8 Research should address the factors that may lead to differential outcomes.

The NCI Community Networks Program (CNP) initiative looks at the whole continuum of cancer care. The NCI Center to Reduce Cancer Health Disparities funded 25 CNPs from 2005 to 2010 to develop community-based participatory research (CBPR) methods to reduce cancer health disparities.9 The basic principles of CBPR include a research approach that mandates a partnership between traditionally trained academic “experts” and members of a community, with all parties interested in addressing a common research problem. They draw on distinct sources of knowledge, such as academic, cultural, social, and/or historical, to enrich the process. In this paradigm, community members, who are highly valued partners, participate fully in the planning, development, implementation, evaluation, and dissemination of the research findings.

All of the funded CNPs developed programs addressing the needs of their unique populations and focused their attention on increasing awareness and access to care such as screening. Some of the CNPs developed and tested unique programs, materials, and services to improve survivorship; those CNPs were invited to contribute to this article.

We highlight CNPs (Table 1) whose outreach programs were based on innovation-diffusion theory.10 Their work enhanced cancer survivorship by increasing awareness and developing change agents and role models needed to effect change over the long term within communities of color. Their use of public health communications with strategic dissemination and evaluation of culturally relevant, accessible, and understandable health information advances the public health. The interesting activities that follow range from development of cancer survivor plans, Web-based survivor support, expressive writing for psychological support and spiritual conferences to palliative care training.

Table 1. Community Networks Programs With Outreach Based on Innovation-Diffusion Theory

<table>
<thead>
<tr>
<th>Program</th>
<th>Target Population</th>
<th>Intervention</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>'Imi Hale</td>
<td>Native Hawaiians</td>
<td>Program development</td>
<td>CSCP = Cancer survivor care plan</td>
</tr>
<tr>
<td>NACES</td>
<td>American Indians and Alaska Natives (nationally)</td>
<td>web-based survivor support</td>
<td>Quality of life analysis</td>
</tr>
<tr>
<td>AANCART</td>
<td>Asians (Chinese)</td>
<td>Expressive writing</td>
<td>JLA = Joy Luck Academy</td>
</tr>
<tr>
<td>SAICN</td>
<td>American Indians in the Southwest</td>
<td>Spiritual care conferences</td>
<td>Videos</td>
</tr>
<tr>
<td>SOE</td>
<td>Providers (nationally)</td>
<td>Palliative care training</td>
<td>Access to palliative care,</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>increased competence</td>
</tr>
</tbody>
</table>

AANCART indicates Asian American Network for Cancer Awareness Research and Training; 'Imi Hale, Native Hawaiian Community Networks Program; NACES, Native American Cancer Education for Survivors; SAICN, Southwest American Indian Collaborative Network; SOE, Spirit of EAGLES.

'Imi Hale–Native Hawaiian Cancer Network

'Imi Hale–Native Hawaiian Cancer Network (U01 CA114630) was established in 2000 by Papa Ola Lōkahi, a community organization in Hawaii dedicated to improving Native Hawaiian health.11 Similar to other CNPs, the program’s goal is to reduce cancer incidence and mortality in Hawaiians by: 1) promoting cancer awareness, 2) training minority researchers, and 3) facilitating research. 'Imi Hale recognizes the unique strengths and perspectives of community and academic partners who work together to articulate problems and develop and test solutions to address them. From the outset, Native Hawaiian cancer survivors have played a key role in setting the direction for 'Imi Hale and informing programs and research projects. For example, 45 survivors participated in kukakuka (Hawaiian for “talk story”) sessions to help the program set its research priorities.12 Others serve on Papa Ola Lōkahi’s Institutional Review Board and Community Advisory Committee, helping ensure that programs and research are meaningful and respectful of Native Hawaiian participants.13 Another 29 survivors, along with their family members, were involved in focus groups to help design a 48-hour training program to enhance the cancer patient navigation skills of outreach workers in Native Hawaiian communities, and some serve as faculty in this curriculum.14

Survivors play an important role in helping to pretest cancer education materials. They helped in the development and testing of a 5-booklet series on end-of-life care,15 as well as a booklet, Cancer Care Questions to Ask Your Provider, and in the production of television.
programs and public service announcements featuring Native Hawaiian cancer survivors, and a DVD. 'Imi Hale also supported the testing of 2 cancer screening interventions featuring Native Hawaiian cancer survivors as storytellers and educators, one to promote colorectal cancer and the other to promote breast cancer screening.14,15

An 'Imi Hale partner, The Queen’s Medical Center (endowed by Queen Emma Kaleleonalani) is the largest provider of cancer care in Hawaii and honors its mission to serve Native Hawaiians. The Queen’s Medical Center began its survivorship program in 2009. The program was initially piloted with breast cancer patients, but soon expanded to patients with prostate, lung, and colorectal cancer. As recommended by the Institute of Medicine’s “Lost in Transition” report,16 cancer survivors are provided with a cancer survivorship care plan that includes diagnosis and treatment summaries, a schedule of follow-up tests and appointments, contact information of providers, and educational information on side effects, community resources, and health promotion, such as cancer screening, smoking cessation, and physical activity. Patients are encouraged to give a copy of their cancer survivorship care plan to their primary care physician.

The Queen’s Medical Center also has a pain and palliative care department to work with patients to reduce pain and other cancer- or treatment-related symptoms. The department is a member of Kokua Mau (Hawaiian for “continuous care”), a statewide coalition to improve care for the dying, which helped pass the Physician Orders for Life-Sustaining Treatment (POLST) law in 2009. The department participates in clinical trials and sponsors research, for example the Comedy in Chemotherapy (COMIC) study to investigate the effects of humor on symptoms for patients receiving chemotherapy.

Native American Cancer Education for Survivors

The Mayo Clinic’s Spirit of EAGLES CNP subcontracted to Native American Cancer Research Corporation (NACR) to extend the Native American Cancer Education for Survivors (NACES) quality-of-life (QOL) study.17 The purpose of NACES is to improve the QOL of cancer patients by increasing knowledge and informed choice using innovative, tailored Web-based technology that is both culturally relevant and scientifically accurate. Native Patient Advocates (also called “Navigators”) help patients complete the 114-item QOL survey and access the survivorship information available on the Web site. NACES is organized as a QOL Tree with information that is interactive, culturally appropriate, written at reading grade levels 5 through 7 for most pages, and based on Native survivors sharing excerpts of their stories on videos integrated throughout the education materials.17

The original NACES survey and Web-based intervention was designed for breast cancer survivors and the findings were reported elsewhere.18 However, due to the severe lack of culturally appropriate survivorship information available for Native cancer survivors, the Native Patient Advocate Navigators and Web site immediately began receiving requests and input from survivors of cancers other than of the breast. As of January 2010, the NACES database included 596 Native American cancer patients (Table 2). There are more females than males, because the Web site started with the breast cancer focus only. Almost half (46.2%) lived on the reservation, 72.2% traveled more than 100 miles one way to access cancer care, and 50.9% traveled between 4 and 18 hours one way to get to help. Of note is the low level of education, which is one of several reasons why the NACES education intervention is so frequently accessed.

Table 2. NACES Survivors Demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number (N = 596)</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>486</td>
<td>82.2%</td>
</tr>
<tr>
<td>Male</td>
<td>105</td>
<td>17.8%</td>
</tr>
<tr>
<td>Year of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1970-1989</td>
<td>32</td>
<td>5.5%</td>
</tr>
<tr>
<td>1950-1969</td>
<td>282</td>
<td>48.5%</td>
</tr>
<tr>
<td>1940-1949</td>
<td>173</td>
<td>29.8%</td>
</tr>
<tr>
<td>1910-1939</td>
<td>94</td>
<td>16.2%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>148</td>
<td>27.0%</td>
</tr>
<tr>
<td>High school/graduate equivalency degree</td>
<td>162</td>
<td>29.5%</td>
</tr>
<tr>
<td>Technical/some college associates/bachelors/ masters/doctorate</td>
<td>152</td>
<td>27.7%</td>
</tr>
<tr>
<td>Associates/bachelors/ masters/doctorate</td>
<td>87</td>
<td>15.9%</td>
</tr>
<tr>
<td>Sexual orientationa</td>
<td>(n = 146)a</td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>121</td>
<td>82.9%</td>
</tr>
<tr>
<td>Gay, lesbian, transgendered, other</td>
<td>25</td>
<td>17.1%</td>
</tr>
</tbody>
</table>

NACES indicates Native American Cancer Education for Survivors.

a Sexual orientation item added in 2009, and thus fewer responses.
late effects from their cancer, including persistent fatigue, weakness, and difficulty concentrating.

**Asian American Network for Cancer Awareness Research and Training**

Historically, few studies focused on psychological needs of minority cancer survivors. Studies including sufficiently large samples from diverse groups to analyze effects separately are rare, a limitation often due to recruitment and methodological challenges. Fortunately, this picture is rapidly changing.19,20

Asian American Network for Cancer Awareness Research and Training (AANCART) investigators asked 19 Chinese breast cancer survivors with limited English proficiency to write about their deepest thoughts and feelings, their coping efforts, and positive thoughts and feelings regarding their experience with breast cancer.21 This expressive writing intervention was associated with long-term improvement of health. Investigators further explored unique needs of this population by analyzing written essays using content analysis. The essays consistently revealed that language barriers, lack of health insurance, and financial concerns often prevented patients from visiting doctors and may have contributed to delay in diagnosis and treatment. One survivor specifically mentioned the late diagnosis of her cancer, which might have resulted from lack of adequate communication. Cancer treatment created financial burdens and hardships, a finding that while not unique to Chinese breast cancer survivors, may be especially burdensome in this subset of women.

Similar to caucasian breast cancer survivors, Chinese cancer survivors in the United States revealed worries about cancer recurrence, fear of death, sadness about their scar, and loss of their breast. In addition, several needs that were particularly salient to Chinese cancer survivors were identified. Survivors reported that they were afraid of telling their family about their breast cancer because they did not want the family to carry the burden. They felt alienated from their friends and were afraid to tell their friends about their breast cancer because there remains a widely held belief in the Chinese culture that breast cancer is contagious. Participants also disclosed their fear of telling others about their cancer diagnosis and emotions in general, likely due to Chinese cultural norms of not disclosing emotions. Thus, breast cancer seems to bring these women a sense of isolation from their existing social network, and there was a shortage of other available social supports.

AANCART investigators and a local Chinese non-profit organization, the Herald Cancer Association, worked together to implement and evaluate a 10-week psychosocial and educational program named “Joy Luck Academy” (JLA) that was planned and implemented by a local Chinese nonprofit organization, the Herald Cancer Association. Upon finishing the program, a focus group was conducted to evaluate the needs of the women and the success of the program. Among all the educational sessions conducted, participants felt that the ones focusing on psychological adjustment and communication were the most useful. In addition, they felt the need for more information on sexual adjustment to breast cancer and on communication with their spouses. The feelings of isolation from friends and social network were again echoed among participants. Participants strongly felt the need to have a safe place to talk about their breast cancer and express their feelings. Two bilingual participants compared the JLA with mainstream support groups that they joined and reported feeling more comfortable with JLA because of a strong sense of belonging to the group. This study suggests the need to collaborate with local communities so that they can provide a safe and culturally familiar environment for minority cancer survivors and develop culturally tailored psychosocial interventions for their community members living with and beyond cancer.

**Southwest American Indian Collaborative Network**

An innovative spiritual care program for cancer patients developed at an Indian Health Service hospital, the Phoenix Indian Medical Center, was a collaborative effort involving partner organizations in the Southwest American Indian Collaborative Network (SAICN). The SAICN partnership included the Intertribal Council of Arizona, Incorporated; Arizona Cancer Center, University of Arizona; and the Phoenix Indian Medical Center. Addressing spiritual needs is an integral and expected aspect of care for American Indians and their families when healing for illnesses is sought. Long before the practice of Western or modern medicine, traditional American Indian practitioners approached their patients as whole persons for whom restoring health included restoration of spiritual well-being. Reliance on spirituality and interpersonal relationships between provider, patient, and families is an essential part of the provision of oncology care. The chaplain conducts advance directive and end-of-life discussions, and this requires utmost sensitivity and cultural awareness. Some patients, because of tribal and spiritual beliefs, regard direct discussions about negative information or death as having the potential to literally cause harm. The chaplain also consults with the traditional Indian practitioners who are members of the hospital’s Traditional Cultural Advocacy Committee.
to ensure that patients and families have access to their services, if requested, in matters involving traditional and/or ceremonial needs.

Oncology patients are honored by being presented with a Native handcrafted prayer shawl and an uplifting card at the initiation of chemotherapy. This simple gesture has a profound impact, because it symbolizes and honors the respect for spirituality and the importance of interpersonal relationships between the patient and his or her health care team.

Hospital chaplains and traditional Indian practitioners work closely with SAICN to hold spiritual care conferences promoting cancer spirituality, awareness, and education. Past conferences have addressed important topics such as grief and loss as experienced not only by individuals but also by the tribal community, and the importance of storytelling as a means of healing. One such conference, “Celebration and Ceremonies for Life’s Transitions: Implications for Cancer Care with American Indians,” had more than 200 participants.

To reach a wider audience about American Indian concerns, 2 educational videos were produced based on presentations and interactions at the conference. The first video, “Cancer Has Crept Among Us,” features the story of an American Indian cancer survivor and her family’s multiple experiences with cancer in a rural reservation community in northwestern Arizona. Her story highlights cancer care disparities that are often present in American Indian communities. The second video, “American Indian Attitudes and Values: An Integral Part of Cancer Care,” features interviews with American Indian cancer survivors, family members, community leaders, and health care providers on the importance of providing culturally and spiritually appropriate cancer care. The videos are available for viewing on the Inter Tribal Council of Arizona, Incorporated, Web site at http://www.itcaonline.com/saicn/Resources.html. An accompanying discussion booklet with questions based on the videos is currently being produced.

**Spirit of EAGLES CNP**

The goal of comprehensive palliative care programs, now considered standard-of-care for all acute care hospitals (www.capc.org), is to facilitate not only patient comfort and QOL, but patient autonomy, access to information, and choice. Unfortunately, many patients and families never access this important aspect of care. Minority patients, American Indians, and rural, underserved populations in particular, are unlikely to access palliative care programs. African Americans too are underrepresented in many areas of clinical investigation, including end-of-life care. The limited research done with communities of color indicates that even basic treatment such as optimal pain management is lacking. Racial and ethnic differences in the assessment and management of pain, including chronic pain, are an important part of palliative care and must be part of efforts to reduce disparities.

Although few studies have been conducted on pain management across racial and ethnic groups, communication between the patient and the provider may often be an issue in obtaining adequate pain relief. Patients may fail to accurately report the level of pain for various reasons, including the fact they do not believe that the pain can be relieved and they are afraid of potential addiction. Communication between provider, patient, and family is essential for ensuring optimal symptom management and respect for patient autonomy. Culturally respectful and specific materials about palliative care are essential, but are often lacking. Storytelling is often shown to be an effective method for eliciting more accurate information from patients. Clearly, research is needed in this area generally, but especially in minority and underserved populations, which suffer disproportionate cancer-related mortality.

Research supporting models of palliative care in underserved communities is desperately needed. An example of an innovative program is a train-the-trainer model using cultural adaptations to EPEC-O (Education in Palliative and End-of-Life Care for Oncology) developed within Indian Health Service in conjunction with the Spirit of EAGLES CNP. From 2006 to 2010, more than 120 interdisciplinary providers nominated from service units within the Indian Health Service have received culturally competent end-of-life care training and are now implementing local programs across the United States (Table 3). Other ethnic and racial minorities face daunting challenges in accessing palliative care and hospice. Overcoming disparities will require attention to this fundamental need for quality end-of-life care.

**DISCUSSION**

Communication theory explores how messages are created, transmitted, received, and assimilated. This theory applies to serious public health messages such as those addressed by the community networks programs highlighted here. Targeted messages at the group level and social marketing within the community can debunk misconceptions about cancer, increase support for services, and strengthen organizational relationships. Data from more recent studies of the well-being of long-term cancer survivors suggest that whereas most people report good health in general, a substantial proportion of survivors...
experience lasting physical, social, and economic consequences of their illness. A recent review calls for special attention given to older adults and minority long-term cancer survivors in monitoring cancer-related characteristics and comorbidities. Survivorship researchers recognize a consistent theme identifying the importance of addressing socioeconomic and cultural factors that may affect (positively or negatively) adaptation and survival among diverse populations of cancer survivors.

Although it is not realistic for any individual health care professional to be culturally competent in working with the multitude of ethnic groups found in the United States, she or he should learn about the predominant culture(s) in the area and act in ways that are culturally sensitive. One way to be respectful is to listen carefully, behavior that is highly regarded across cultures. Further, the health care professional must keep in mind that individuals within a social group may vary widely in their identification with their culture of origin and the degree to which their own actions approximate the cultural norms.

Community-based approaches can be applied to reduce health disparities and enhance survival after cancer in diverse populations. Lessons learned from the current programs include

1. Programs developed and evaluated with active community input are most successful.
2. Research on needs of patients after active cancer treatment can help providers plan appropriate after-care. Effective community-based programs can and should be disseminated.
3. Health educators should draw on the important traditions held by members of the population served. In fact, program planners would be wise to work with the community, especially elders, to incorporate these traditions into the plans they develop. The humanities in medicine include art, music, poetry, and storytelling.
4. Spirituality and social support are critically important issues in many cultural groups. These must be addressed in program planning, because issues such as acculturation and traditionalism may dramatically influence patient care across the survival continuum.
5. Palliative care training of providers is needed to upgrade quality of care across the cancer continuum. Pain control is typically inadequate across all patient populations and should be added as the so-called “5th vital sign.”

Table 4 shows elements for building survivorship programs for diverse groups.

**Conclusions**

Quality of life is an important outcome across the cancer trajectory but is especially important in tertiary care. The meaning of QOL may have different nuances in specific social and ethnic groups, but overall it refers to well-being in various domains of life, usually physical, emotional...
social, psychological, and spiritual. A recent publication on QOL research in Chinese breast cancer patients in Shanghai, China, showed that women with the highest tertile of social well-being had reduced mortality and relapse rates when support was provided in the first year after diagnosis.

The CNPs use CBPR principles to improve detection, treatment, and survival of diverse populations with cancer across the country. Quality of life from diagnosis through end of life is the ultimate goal. Cultural strengths exist in every community and enhance the success of these programs. In this article, we have highlighted projects developed by CNPs that aim to enhance life after cancer in diverse communities.

Around the world, for thousands of years, care of the sick regularly involved using a wide range of strategies—storytelling, spiritual care, music, ceremony—that were designed to meet the complex physical, spiritual, psychological, and social needs of individuals. Across cultures, illness, recovery, and death were seen as natural transitions in the circle of life, and ceremonies were created to help individuals and their loved ones make these transitions more comfortably. Through the NCI CNP programs, which are largely driven by community partners, many of these cultural strategies, including music, storytelling, and spirituality, are being valued. The human need for this type of attention during difficult transitions is universal. Only when programs meet these needs will we be able to say we have truly comprehensive cancer care.

FUNDING SOURCES

‘Imi Hale–Native Hawaiian Cancer Network is funded by National Institutes of Health (NIH) grant U01 CA114630. Mayo Clinic’s Spirit of EAGLES Community Network Program is funded by NIH grant U01 CA114609. Southwest American Indian Collaborative Network is funded by NIH grant U01 CA11469. Native American Cancer Education for Survivors is supported by Susan G. Komen for the Cure (POP0202135 and POP0503920) and NCI (R25 CA 101938 and NCI U01 CA 114609).

CONFLICT OF INTEREST DISCLOSURE

The authors made no disclosure.

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