An Innovative Path to Improving Cancer Care in Indian Country

LINDA BURHANSSTIPANOV, DRPH[a]
ALISA GILBERT[b]
KHARI LAMARCA, MA, MPH[c]
LINDA U. KREBS, RN, PHD, AOCN[d]

SYNOPSIS

The Native American Cancer Survivors' Support Network is an innovative public health program designed to improve survival from cancer and the quality of life after a cancer diagnosis for American Indians, Alaska Natives, and Canadian Aboriginal patients and their loved ones. The Network, initiated in 1999, now has more than 300 survivors enrolled as members. This article briefly describes the process that led to its formation and preliminary findings, primarily for breast cancer survivors, of ongoing qualitative and quantitative research. Network data show patterns of cancer care that are partially responsible for poor survivorship outcomes.

---

[a] Native American Cancer Research, Pine, CO

[b] National Native American Cancer Survivors' Support Network and Native American Cancer Research–Anchorage Satellite Location, Anchorage, AK

[c] Native American Cancer Research–Portland Satellite Location, Portland, OR

[d] University of Colorado School of Nursing, Denver, CO

Address correspondence to Linda Burhansstipanov, DrPH, Native American Cancer Research, 3022 S. Nova Rd., Pine, CO 80470; tel. 303-838-9359; fax 303-838-7629; e-mail <natamlb@aol.com>.

The Native American Cancer Survivors' Support Network was initiated in response to the experiences of approximately 40 Native American cancer patients living on the North American continent. The Network, formed in 1999, now has more than 300 survivors enrolled as members. This article briefly describes the process that led to its formation and preliminary findings, primarily related to breast cancer survivors, of ongoing qualitative and quantitative research based on Social Networking theory and participatory research methods.

The Network implementation is in the third year of a five-year developmental project. The project addresses support issues for those dealing with cancer to learn more about how cancer is affecting Native communities. Initially, the intended population was Native American breast cancer patients ages 20 and older living anywhere on the North American continent. With the support of the Mayo Clinic's Spirit of E.A.G.L.E.S. initiative, the Network is expanding to be inclusive of all cancer sites and supportive to people of both genders and all ages.

The Network is supported by the Susan G. Komen Breast Cancer Foundation, the Department of Defense, the Mayo Clinic's Spirit of E.A.G.L.E.S. initiative, Native American Cancer Initiatives, and the California Community Foundation.

NATIVE AMERICAN CANCER DATA

Although cancer incidence is decreasing among white ethnic groups, it continues to increase among the American Indian and Alaska Native (AI/AN) population of the US.[1–4] Native Americans with cancer continue to have the poorest survivorship five years after diagnosis when compared with other minority, poor, and medically underserved populations.[1–4]

In the last half of the 20th century, cancer became the leading cause of death for Alaska Native women, and the second leading cause of death for Alaska Native men.[5–7] Cancer is the third leading cause of death for American Indians and Alaska Natives of all ages,[8] and the second leading cause of death for both male and female American Indians older than age 45.[5] Cancer incidence rates that previously were reported to be lower in American Indian and Alaska Natives than in other populations have been shown to be increasing in the past 20 years.[9] Indeed, in 1977–1983, incidence rates among Alaska Natives exceeded those for other racial/ethnic groups except African Americans for most cancer sites.[2,10–12] Similarly, cancer rates have increased for Canadian bands in the last 30 years.[1,10] Relative five-year survival for American Indians, based on data for American Indian residents of New Mexico and Arizona, is among the poorest of any racial group in the US.[13] Even those cancers diagnosed at early stages result in poorer survival for American Indians in the Southwest than for non-Indian peoples in the Southwest.[14] Although cancer incidence and mortality rates are lower among American Indians living in Arizona and New Mexico than among Natives living in other regions of the county, even in the Southwest the "burden of cancer" appears to be high.[15,16]

CANCER COPING SKILLS

Coping with cancer has been defined as a process by which individuals adapt to the vast array of demands inherent in the diagnosis of cancer rather than to the diagnosis itself.[17] Skills needed to facilitate coping include those related to controlling stress, minimizing stress or suffering, surviving, adapting, maintaining self-esteem, and maintaining equilibrium in relation to the diagnosis.[18–20] Cancer survivors deal with the physical, social, cultural, and psychological implications of diagnosis, treatment, rehabilitation, and survival, and many find meaning both in having cancer and in being a survivor. Physical and social implications include alternations in sexuality and body image, the need for long-term symptom management, role changes, family concerns, and workplace issues.[21–25] Cultural factors include beliefs and practices that can significantly influence how an individual copes with, understands, and responds to the cancer experience.[26] Anger, anxiety, depression, despair, sadness, rationalization, numbness, and sense of loss are among the emotional reactions noted to occur.[27,28] Additional concerns of the survivor include social and conversational isolation, concerns about self-disclosure and rejection, survivor guilt, the resurfacing of emotions at times of testing or specific anniversary dates, and varying degrees of fear and grief.[29,30]

Every aspect of life, including one's relationships, attitudes, and feelings, is affected by the cancer diagnosis and its treatment and subsequently impact the ability to survive.[31] Kramer explains that treatment and adherence to treatment plans are affected by such social factors as access to health care, institutionalized racism, poverty, and the structure of social services.[32]

Adjustment to cancer is rarely easy.[33] For cancer patients, survival usually includes living with uncertainty, a continuing sense of vulnerability, and the desire to support and give back to others coping with the same stresses.[34] The ability to overcome these stresses and move to a level of readiness to perceive oneself as a survivor is an important transition in the recovery process. The information gleaned from each step of the cancer journey has a potential impact on the next step, and what assists one individual on her or his journey is often of benefit to the next. Wyatt, Kurtz, and Liken's qualitative study of breast cancer survivors found that participants had to "tell their stories" from the beginning of their experiences with cancer.[35] The researchers concluded that the ability to put these experiences into a life context were important components of quality of life and long-term survival.

Social support from friends, family members, and others; the ability to manage physical compromise; the availability of resources to manage symptoms and side effects of disease and treatment; the ability to cope with the gap between expected and experienced well-being; and the ability to integrate the cancer experience into one's life appear to be integral to survival.[23,35–39] Springer showed that surviving breast cancer is a unique experience for each woman.[39] In particular, this author noted that surviving involves varying combinations of praying and having faith, fighting for survival, obtaining support from caring relatives, believing all will be well, keeping going, empowering one's self, allowing family to help, having good health care providers and facilities, gaining knowledge and information, being positive, recognizing that there is life after breast cancer, helping others, and realizing that having breast cancer is a transforming experience.

As noted, social support has been identified as one of the primary components of survival. The amount and quality of social support has been shown to affect survival in women with breast cancer.[40] Funch and Marshall noted that women with breast cancer who had little or no social support had significantly poorer average survival than those who felt supported.[41] Similarly, Weisman and Worden, in their classic analysis of cancer death, implicated poor social support as a component in poorer survival.[42] The importance of social support was reiterated by Ferrell et al. in their study of 687 cancer survivors, 43% with breast cancer.[43]

Finding meaning in both the cancer diagnosis and in one's ability to survive cancer also plays an important role in recovery for many cancer patients.[44–46] Leigh suggested that the meaning of having cancer evolves from one's individual interpretation of disease, treatment, and survival and can be associated with growth and new knowledge about life.[22] Many emerge from the cancer experience with an improved perspective on life and death, acceptance of future uncertainty, and an appreciation for life.[47] O'Connor, Wicker, and Germino investigated the process of the patient's search for the meaning of having cancer in 50 cancer patients.[48] Respondents stated that in order to find personal meaning, a patient needs to understand the personal significance of the cancer diagnosis, to be able to look at the consequences of that diagnosis, to review her or his life and then restructure and revalue it following the diagnosis, to learn to live with cancer, and to gain hope for survival. Faith and social support were noted to be important elements necessary for the patient to carry out the process of finding meaning.

Dumas noted that breast cancer survivors seem to be drawn together by a spiritual thread that not only supports and validates each woman's feelings but also provides hope for the future.[31] Thus, while believing in survival does not promise survival, it does enhance quality of life and provide purpose and meaning, and appears to be essential to living whatever life can be experienced after cancer. In surviving cancer, one grows emotionally and spiritually. Relationships take on new value, and the survivor gains a stronger sense of herself/himself and how she/he would like her/his life to be. For many people, surviving means finding the meaning in the experience of having cancer through helping other people deal with the terrifying reality of this disease. It becomes important to define one's role or mission in life and to do something positive for the world.[27] Having a reason for living, helping others, and giving back to society help to define the experience and assist in the coping process.[22,44,47,49]

EVOLUTION OF THE NETWORK

Initial steps

In the mid-1990s, Native American cancer patients requested information, resources and support from Native American Cancer Research for a multitude of cancer care–related needs that were not being met by their local tribal programs. Native American Cancer Research is a Native-owned and operated nonprofit corporation; its mission is to reduce Native American cancer incidence and mortality and to improve quantity and quality of life during and following a cancer experience.

Approximately 40 intertribal Native cancer survivors from throughout North America became the "community of survivors" who provided direction regarding the type of program they wanted and needed. This "community of survivors" desired to have direct and ongoing participation in the development and implementation of an infrastructure that would provide the information, resources, and support they believed was needed to help Native American cancer patients cope with the cancer experience. Thus a participatory research methodology, also known as community-driven research, was adopted for use in the development of a national support network for Native American cancer survivors and their loved ones. This methodology views community members as shareholders or equal partners and not simply as "participants" in a study and allows for full participation in all aspects of project development, implementation, and evaluation.[50–56] This methodology continues to be used in the research activities of the Network.

Development of the infrastructure of the Network began in 1994, while implementation began in 1999 and is ongoing.

Intertribal working groups and focus groups

Initially, focus groups were conducted with Native American cancer survivors to help determine how a national network that would provide support or access to services not available at the local level could be implemented. Focus groups had previously been used to assist with the development and refinement of educational strategies and resources in other Native American cancer projects.[57–59] These focus groups allowed the participants to talk in their own words about their experiences with cancer, using their own categories and/or conceptualizations.[60,61] Additionally, the participants had the opportunity to hear about the experiences of others in the group, and were able to respond to comments and topics that were brought up by others during group discussions. Focus groups of survivors have continued to provide guidance for the development and refinement of the Network.

Ten focus groups and five working groups were convened with Native American cancer survivors across the US from 1994 through 1999. Four training workshops were held for Natives who were conducting cancer programs in Indian country; participants included survivors, program directors, and providers. Additionally, approximately 75 informal one-on-one interviews were conducted on all aspects of the organization and format of the Network. These survivors were very specific about what they believed would and would not be beneficial in a survivors' network. For example, due to dissatisfaction with and distrust of local referral procedures or care policies and to avoid local tribal politics from interfering with cancer support or care, survivors mandated that no Indian Health Service (IHS) or tribal clinic would be used as a base for the project. The Figure gives examples of features that the survivors did and did not want incorporated within the overall design of the national network.

Figure. Selected recommendations by Native breast cancer survivors for the organization of the Native American Cancer Survivors' Support Network

What is needed?

- Native American leadership, preferably a Native cancer survivor
- Social, spiritual, emotional, mental, physical support for (*a*) the Native cancer patient and (*b*) the loved ones of the cancer patient
- One-on-one support (face-to-face preferred, but if not feasible, phone support acceptable but help needed, e.g., pre-paid long-distance calling cards)
- Native-specific cancer survivor support resources using testimonials/story-telling format
- Support programs that integrate cultural components (e.g., traditional Indian medicine, selected ceremonies)
- Access to high quality cancer care services
- Timely referral to cancer care
- Ability of family members to accompany patient to cancer care
- Access to second opinions and choice of cancer treatment options
- Culturally specific cancer support information for Native children diagnosed with cancer
- Support mechanism for family members who are unable to accompany patient to treatment facility
- Culturally specific local Native American cancer/chronic disease support groups

What should be avoided?

- IHS or tribally controlled support programs (politics interfere with program implementation and maintenance)
- Use of local tribal authorities (to prevent loss of confidentiality due to small communities)
- Implementation of cancer support groups based on non-Native model
- Use of IHS-contracted health services for cancer care

PURPOSE AND ORGANIZATION OF THE NETWORK

The purpose of the Network is to improve survival from cancer and overall quality of life after being diagnosed with cancer for both the patient and her or his loved ones.

Native cancer patients or the loved ones of cancer patients connect with the Network through self-referral, provider referral, and/or community member referral. The bulk of referrals are from community members and Native American organizations.

The Network has three arms: Service Users, Contributing to Native Knowledge, and Loved Ones. The Service Users arm is for those who are in the midst of a cancer diagnosis and/or treatment and need support, information, and services. Contributing to Native Knowledge is for those who have completed treatment and/or are willing to take part in a survey to assist with the development of a database that can provide information to other cancer survivors. Finally, Loved Ones are those who are providing cancer support to family members and need information and social support.

Within these arms, the following services, resources, and materials are provided:

Support materials. When the Network receives a referral form, the patient is called and the informed consent process is implemented. The patient is then mailed Native-specific cancer support print and video materials. Since many patients do not have telephones in their homes, or do not have long distance service, prepaid long distance calling cards are also provided.

Before the Network was formed, this component was already in process through alternative funding. By the time the Network was implemented, such culturally specific materials had been refined and pretested and were available for distribution.

One-on-one support. Alisa Gilbert, the Director of the Network, either personally provides the one-on-one support for the patients or assigns another survivor to be the support contact. Almost all support is provided over the telephone; thus, the network is not limited by the availability of local Native cancer patients.

Assistance in obtaining quality cancer care. Patients are provided information on where and how to obtain quality care. Advice is offered to those who have received inappropriate care; for example, when a patient has had lumpectomy without radiation, the patient and family are educated about the importance of adjuvant therapy with lumpectomy to reduce the likelihood of recurrence.

Assistance in obtaining other needed services. Patients have many diverse needs in addition to cancer care. All requests are documented by the Network Director, who has assumed the leadership role in helping patients and family members obtain the necessary services. The problems addressed are quite diverse, from insufficient food in the household while the patient is undergoing cancer treatment to needs related to care for comorbidity, e.g., diabetes. The Director and Network staff take primary responsibility for these referrals and follow-up.

Survey. For those survivors who have completed their treatment and are willing to share their experiences to benefit others, a telephone appointment is scheduled to administer the survey. This determines which "arm" of the Network he or she wishes to participate in.

RESEARCH ON NATIVE AMERICANS' EXPERIENCES WITH CANCER CARE

As previously noted, the purpose of the Network is to improve survival from cancer and quality of life after being diagnosed with cancer for both the patient and the patient's loved ones. To address this purpose, the Network is undertaking participatory research that has the following objectives: (*a*) to identify and recruit Native American cancer patients into the survivors' network and database with the support of key Native American cancer leaders from geographically diverse regions of the country; and (*b*) to use the survivors database to determine patterns of disease and patterns of care experienced by Native American cancer survivors.

Methodology: development of the survivors' database

Native-specific information about the cancer experience is a major component of the Network, and preliminary findings from this programmatic component are the focus of this paper. Since there is a dearth of accurate information about Native American cancer survivorship, a database was needed so that more could be learned about the patterns of care and patterns of disease experienced by Natives. A survey instrument was developed and piloted and is administered to patients by trained interviewers to learn more about their cancer experiences. Cancer-related medical records are also requested to validate histologic grade and diagnostic staging information.

The data collection instrument. After a thorough review of available instruments, including a review of these instruments with members of the community, it became evident that no one instrument could be used to adequately and accurately collect the data desired from the survivors. Of major importance, none alone was culturally acceptable to the survivors. However, the following instruments were able to be used as a basis for a culturally competent survivors' survey:

- CARES-SF
- CES-D Scale
- COPE
- FACT Spirituality Subscale, Version 3
- FACT-G, Version 4
- FACT/GOG-NTX, Version 4
- Impact of Event Scale
- Integrative Cancer Experience Scale
- ISEL Short Form
- Qualitative Survivorship Questions
- Quality of Life of Female Cancer Survivors Diagnosed During Childbearing Years
- QOL-CSH
- Self-Efficacy Measure
- Sexual Activity Questionnaire
- SF-36 Health Survey

More details on these instruments are available from the present authors on request.

Through the participatory research methodology, 13 versions of the survey instrument were retested using one-on-one interviews and focus groups. This survey instrument was specific to breast cancer; another version that addresses all cancers is in development.

The refined survey instrument addresses the following areas:

- Demographics (e.g., tribal affiliation, age, access to health care)
- Social network (e.g., with whom does she or he discuss cancer)
- Emotional well-being (e.g., "I had crying spells")
- Physical well-being (e.g., "I felt that I could physically do things for myself")
- Spiritual well-being (e.g., "I took part in healing or cleansing ceremonies")
- Reactions to cancer treatment (e.g., "I found that cancer or its treatments interfered with my ability to work")
- Health care (e.g., "I felt that the doctors clearly explained what they were doing to me")
- Social support (e.g., "I felt comfortable talking with my close friends about my cancer diagnosis"; "My family or friend(s) helped me by doing my grocery shopping for me")
- Financial (e.g., "How were you able to pay for your cancer care medical bills?")
- Sexuality (e.g., "My partner and I are getting along as well as we usually do")
- Prior to diagnosis (e.g., "Prior to your diagnosis, how long had it been since you had seen a doctor?")
- Diagnosis (e.g., "Who told your family about your cancer diagnosis?")
- Diagnosis: medical tests and initial treatment (e.g., "Where was the biopsy or FNA performed?")
- Treatment (e.g., "Did you take part in traditional Indian or spiritual ceremony prior to your medical treatment?")
- Surgery (e.g., "Was 'lumpectomy' an option for your cancer diagnosis?")
- Breast reconstruction (e.g., "What type of breast reconstruction did you have?")
- Chemotherapy (e.g. "Did you continue to work or do your normal daily activities while you were receiving your chemotherapy?")
- Radiation (e.g., "What side effects did you experience from the radiation therapy?")
- Cancer care and clinical care trials (e.g., "Did your provider inform you of any cancer care trials for which you were eligible?")
- Financial (e.g., "How were you able to provide for the special needs [e.g., school books for your children] for your family during your treatment and recovery from cancer?")
- Sexuality and intimacy (e.g., "How did you make yourself feel more feminine during your cancer treatment and recovery?")

Preliminary findings

More than 300 native survivors are enrolled in the Network. Approximately 240 of these are breast cancer survivors. This revised breast cancer survey instrument was administered to 200 breast cancer patients enrolled in the "Contributing to Native Knowledge" arm of the Network in 1999–2001. Selected findings from the quantitative survey are described here.

Self-administration of survey tools was seen as unacceptable by those who participated in the focus groups and interviews,[62] so the survey was administered over the phone by a trained Native interviewer. Most surveys were administered through at least two phone appointments; the questions required an average of two hours to complete.

Relationship between quality of care and insurance. Findings included:

1. Fewer than one-third of the Native breast cancer survivors had health insurance.
2. High quality cancer care was obtained by those with private health insurance. Most of those without health insurance used tribal or IHS-contracted health services. None of the latter group had access to a second opinion for their diagnosis.
3. Only one of the women who used IHS-contracted health services was offered breast-conserving surgery (lumpectomy with radiation), and none was offered tamoxifen until the latter part of 2000.
4. Only one woman had the benefit of sentinel node biopsy.
5. Native breast cancer patients in some regions had not received quality cancer care; no established treatment protocols were followed, and no follow-up recommendations were sent back to the woman's home village.
6. The average interval from the time of diagnosis (i.e., biopsy) to initiation of treatment was three to six months. In some geographic regions, the average was six to nine months.
7. For those women who received screening from the 12 Centers for Disease Control and Prevention (CDC) American Indian/Alaska Native Breast and Cervical Cancer Early Detection Programs, the tribal programs provided assistance in accessing treatment. Clearly those patients working directly with the 12 CDC programs benefited from this national program.

Clinical trials information and/or referrals. Based on preliminary information from the Network members, Fewer than 10 of the 240 enrolled breast cancer survivors interviewed had ever heard of a clinical trial. If information was provided, it was not understood. This is not unique to Native patients.[63] It is easy to criticize health care providers for not giving patients information, but providing information about clinical trials requires dedicated time and effort on the part of both providers and patients due to the complexity of the clinical trials process.

There are many issues involved with recruitment of members of minority groups and women to clinical trials.[64–66] A series of inter-tribal focus groups were conducted during the latter part of 2000 and early 2001, supported by a grant from the Cancer League of Colorado. In discussions of clinical trials during these groups, a number of issues were raised. Among those who had heard of clinical trials, almost all were aware only of treatment trials. Many providers, as well as patients, do not understand the different types of trials or the phases of trials. The jargon used in clinical trials is daunting to many patients, and the emotional reaction of a newly diagnosed cancer patient is likely to affect comprehension. Patients become nervous when they hear that the clinical trial is "research" or that they will be "randomly assigned" to intervention or control groups. They fear being a guinea pig and fear being given a "sugar pill" rather than the recommended treatment. Additionally, patients do not understand eligibility criteria that can exclude them from participation even when they want to take part.

From the Network's perspective, clinical trials are viewed as a way to help patients access standard quality cancer care, which many currently are not receiving. It is important for Native patients, as well as other medically underserved and poor patients, to be provided with clear understandable information about treatment trials and other types of clinical trials. Currently, educational workshops on clinical trials are being designed and pretested with members of the Network.

Effectiveness of the Network. Of the 240 breast cancer patients, 230 are still surviving as of November 2001. Five-year relative survival was close to 90% for those who had been working with the Network's Director ($n = 85$), while the NCI SEER data cite a five-year relative survival of approximately 48% for Native Americans, the poorest of any "racial" group.[13] While this is only a small sample of Native American women with breast cancer, based on the preliminary data it appears that the Network's efforts to help the women find better care and/or broader care is having a beneficial impact on their survival.

In conclusion, the Network is an innovative, community-based program that is gradually improving the quality of information and cultural relevance of information received by Native American cancer patients. Preliminary data indicate that there are likely to be unique patterns of cancer care experienced by Native cancer patients (e.g., half of the women in the Network sample were diagnosed with breast cancer at an age younger than 50, compared to only one-quarter of white women[67–73]). As noted, few of the survivors enrolled in the Network had access to clinical trials that can assist the patient to attain standard cancer treatment.

Those who wish additional information about the Network can call its toll-free number: 800-315-8848.

REFERENCES

1. Horm JW, Devesa SS, Burhansstipanov L. Cancer incidence, mortality, and survival among racial and ethnic minority groups in the United States. In: Schottenfeld D, Fraumeni JF Jr, editors. Cancer epidemiology and prevention. New York: Oxford University Press; 1996.
2. Lanier AP, Kelly J, Smith B, Amadon C, Harpster A, Peters H, et al. Cancer in the Alaska Native population: Eskimo, Aleut, and Indian incidence and trends 1969–1988. Anchorage: Alaska Area Native Health Service; 1993 Dec.
3. Burhansstipanov L, Hampton JW, Tenney MT. American Indian and Alaska Native cancer data issues. Am Indian Culture and Res J: 1999;23:217-41.
4. Burhansstipanov L, Olsen S. Cancer prevention and early detection in American Indian and Alaska Native populations. In: Frank-Stromborg M, Olsen, SJ, editors. Cancer prevention in diverse populations: cultural implications for the multi-disciplinary team. St. Louis: Oncology Nursing Society/Mosby. In press 2001.
5. Cobb N, Paisano RE. Cancer mortality among American Indians and Alaska Natives in the United States: regional differences in Indian health, 1989–1993. Rockville (MD): Indian Health Service; 1997. IHS Pub. No. 97-615-23.
6. Department of Health and Human Services (US). Healthy people 2010: understanding and improving health. Washington: DHHS; 2000.
7. Burhansstipanov L. Cancer: a growing problem among American Indians and Alaska Natives. In: Dixon M, Roubideaux Y, editors. Promises to keep. Washington: American Public Health Association; 2001.
8. Department of Health and Human Services (US), Indian Health Services, Office of Planning, Evaluation and Legislation. Regional differences in indian health: 1997. Rockville, (MD): Indian Health Service; 1997.
9. Cobb N, Paisano RE. Patterns of cancer mortality among Native Americans. Cancer 1998;83:2377-83.
10. Lanier AP, Bulkow LR, Ireland B. Cancer in Alaska Indians, Eskimos, and Aleuts, 1969–83: implications of etiology and control. Pub Health Rep 1989;104:658-64.
11. National Cancer Institute (US). Appendix A. In: NCI. Report of the Special Action Committee, 1992: program initiatives related to minorities, the underserved and persons aged 65 and over. Washington: Government Printing Office; 1992.
12. Lanier AP, Kelly J, Smith B, Amadon C, Harpster A, Peters H, et al. Cancer in Alaska Natives: a twenty-five year report 1969–1993: incidence and mortality. Anchorage: Alaska Area Native Health Service; 1996 Aug.
13. National Cancer Institute (US). Appendix C. In: NCI. Report of the Special Action Committee, 1992: program initiatives related to minorities, the underserved and persons aged 65 and over. Washington: Government Printing Office; 1992.
14. Samet JM, Key CR, Hunt WC, Goodwin JS. Survival of American Indian and Hispanic cancer patients in New Mexico and Arizona, 1969–82. J Natl Cancer Inst 1987;79:3:457-563.
15. Gilliland FD, Hunt WC, Key CR. Trends in the survival of American Indian, Hispanic, and non-Hispanic white cancer patients in New Mexico and Arizona, 1969–1994. Cancer 1998;82:1769-83.
16. Galloway JM, Goldberg BW, Alpert JS. Primary care of Native American patients: diagnosis, therapy, and epidemiology. Boston: Butterworth and Heinemann; 1999.
17. Woods N, Lewis F, Ellison E. Living with cancer: family experiences. Cancer Nurs 1989;12:28-33.
18. Dow KH. The enduring seasons of survival. Oncol Nurs Forum 1990;17:511-16.
19. Grant M, Padilla G, editors. Cancer nursing research: a practical approach. Norwalk (CT): Appleton and Lange; 1990.
20. Rowland JH. Interpersonal resources: Coping. In: Holland JC, Rowland JH, editors. Handbook of psychooncology. New York: Oxford; 1989. p. 44-57.
21. Holland JC. Cancer's psychological challenges. Sci Am 1996;275:158-61.
22. Leigh S. Myths, monsters, and magic: personal perspectives and professional challenges of survival. Oncol Nurs Forum 1992;19:1475-80.
23. Leigh SA, Willimans JE Jr, Stoval E. Survivorship: from the moment of diagnosis. Cancer 1998;83(8 Suppl): 1710-13.
24. McCaffrey D, Loescher LJ. Surviving breast cancer: long-term effects. Innovations Oncol Nurs 1990;6(3):2-3,14.
25. Payne DK, Sullivan MD, Massie MJ. Women's psychological reactions to breast cancer. Semin Oncol 1996; 23(Suppl 2):89-97.
26. Kagawa-Singer M. Socioeconomic and cultural influences on cancer care of women. Semin Oncol Nurs 1995;11:109-19.
27. Cederberg D, Davidson D, Edwards J, Hebestreit C, Lambert B, Langer A, et al. Breast cancer: let me check my schedule! Vancouver (WA): Innovative Medical Education Consortium; 1994.
28. McGinn KA, Haylock PJ. Women's cancers. Alameda (CA): Hunter House; 1993.
29. McCaffrey D. Life after cancer: the continuum of care evolves. Innovations Oncol Nurs 1990;6(3):1,15.
30. Krebs LU. Recreating harmony: stories of Native American women surviving breast cancer [dissertation]. Denver (CO): University of Colorado; 1997.
31. Dumas MAS. What it's like to belong to the cancer club. Am J Nurs 1996:96:4:40-2.

32. Kramer BJ. American Indian families and home care: macro social and cultural considerations. Alaska Med 1995;37;4;139-44.
33. Schain WS, d'Angelo TM, Dunn ME, Lichter AS, Pierce LJ. Mastectomy versus conservative surgery and radiation therapy. Cancer 1994:73:1221-8.
34. Shanfield S. On surviving cancer: psychological considerations. Compr Psychiatry 1980;21:128-34.
35. Wyatt G, Kurtz ME, Liken M. Breast cancer survivors: an exploration of quality of life issues. Cancer Nurs 1993; 16:440-8.
36. Ferrans CD. Quality of life through the eyes of survivors of breast cancer. Oncol Nurs Forum 1994:21:1645-50.
37. Barsevick AM, Much J, Sweeney C. Psychosocial responses to cancer. In: Yarbro CH, Forgge MH, Goodman M, Groenwald SD, editors. Cancer nursing: principles and practice. 5th ed. Boston (MA): Jones and Bartlett; 1993. p. 484-95.
38. Nessim S, Ellis J. Cancervive. Boston (MA): Houghton, Mifflin; 1991.
39. Springer M. A tribe of warrior women. Birmingham (AL): Crane Hill; 1996.
40. Rowland JH. Interpersonal resources: social support. In: Holland JC, Rowland JH, editors. Handbook of psychooncology. New York: Oxform; 1989. p. 58-71.
41. Funch DP, Marshall J. The role of stress, social, and age in survival from breast cancer. J Psychosom Res 1983; 27:77-83.
42. Weisman AD, Worden JW. Psychosocial analysis of cancer deaths. Omega 1975;6:61-75.
43. Ferrell BR, Dow KH, Leigh S, Ly J, Gulase Karam P. Quality of life in long-terms cancer survivors. Oncol Nurs Forum 1995;22:915-22.
44. Ferrell BR, Taylor EJ, Sattler GR, Fowler M, Cheyney BL. Searching for the meaning of pain. Cancer Practice 1993;1:185-94.
45. Fife B. The conceptualization of meaning of illness. Soc Sci Med 1994;38:309-16.
46. Fife BL, Taylor EJ. Introduction. Semin Oncol Nurs 1995;11:1-2.
47. Dow KW. A review of late effects of cancer in women. Semin Oncol Nurs 1995;11:128-36.
48. O'Connor AP, Wicker CA, Germino BB. Understanding the cancer patient's search for meaning. Cancer Nurs 1990:13:167-75.
49. Eick-Swigart J. What cancer means to me. Semin Oncol Nurs 1995;11:41-42.
50. Cornwall A, Jewkes R. What is participatory research? Soc Sci Med 1995;41:1667-76.
51. Davis SM, Reid R. Practicing participatory research in American Indian communities. Am J Clin Nutr 1999; 69(4 Suppl):755-9.
52. Foster MW, Sharp RR, Freeman WL, Chino M, Bernsten D, Carter TH. The role of community review in evaluating the risks of human genetic variation research. Am J Hum Genet 1999;64:1719-27.
53. Herbert CP. Community-based research as a tool for empowerment: the Haida Gwaii diabetes project example. Can J Public Health 1996;87(2):109-12.
54. Macaulay AC, Delormier T, McComber AM, Cross EJ, Potvin LP, Paradis G, et al. Participatory research with native community of Kahnawake creates innovative code of research ethics. Can J Public Health 1998;89:2:105-8.
55. Segal-Matsunaga D, Enos R, Gotay CC, Banner RO, DeCambra H, Hammond OW, et al. Participatory research in a Native Hawaiian community: the Wai'anae Cancer Research Project. Cancer 1996;78(7 Suppl):1582-6.
56. Wallerstein N, Bernstein E. Introduction to community empowerment, participatory education, and health. Health Educ Q 1994:21:141-8.
57. Dignan MB, Michielutte R, Sharp PC, Bahnson J, Young L, Beal P. The role of focus groups in health education for cervical cancer among minority women. J Community Health 1990;15:369-75.
58. Morgan DL, Designing focus group research. In: Stewart M, et al., editors. Tools for primary care research. Newbury Park (CA): Sage; 1992.
59. Morgan DL, editor. Successful focus groups: advancing the state of the art. Newbury Park (CA): Sage; 1993.
60. Strickland CJ. Conducting focus groups cross-culturally: experiences with Pacific Northwest Indian people. Public Health Nurs 1999;16:190-6.
61. Strickland CJ. The importance of qualitative research in addressing cultural relevance: expreiences from research with Pacific Northwest Indian tribes. Health Care Women Int 1999:20:517-25.
62. Burhansstipanov L, Hollow W. Native American cultural aspects of nursing oncology care. Semin Oncol Nurs 2001;17:206-19.
63. Brawley O. Recruitment of minorities into clinical trials. In: National Cancer Advisory Board, editors. Conference summary: recruitment and retention of minority participants in clinical cancer research. Bethesda (MD): National Institutes of Health (US), National Cancer Institute; 1996. NIH Pub. No. 96-4182. p. 3-10.
64. Underwood SM. Minorities, women, and clinical cancer research: the charge, promise, and challenge. Ann Epidemiol 2000;10(8 Suppl):3-12.
65. McCaskill-Stevens W, Pinto H, Marcus AC, Comis R, Morgan R, Plomer K, Schoentgen S. Recruiting minority cancer patients into cancer clinical trials: a pilot project involving the Eastern Cooperative Oncology Group and the National Medical Association. J Clin Oncol 1999;17:1029-39.
66. Burhansstipanov L. Overcoming psycho-social barriers to Native American cancer screening research. In: National Cancer Advisory Board, editors. Conference summary: recruitment and retention of minority participants in clinical cancer research. Bethesda (MD): National Institutes of Health (US), National Cancer Institute; 1996. NIH Pub. No. 96-4182. p. 40-42.
67. National Cancer Institute (US). Report of the International Workshop on Screening for Breast Cancer; February 24–25, 1993. Bethesda (MD): NCI; 1994.

68. National Cancer Institute (US). Cancer.gov. Breast cancer home page. PDQ screening for breast cancer screening/detection–health professionals. Available from: URL: http://cancernet.nci.nih.gov/cancer_types/breast_cancer.shtml
69. Harras A, Edwards BK, Blot WJ, Ries LAG. Cancer rates and risks. Bethesda (MD): National Cancer Institute (US); 1996. NIH Pub. No. 96-691.
70. Wingo PA, Ries LAG, Rosenberg HM, Miller DS, Edwards BK. Cancer incidence and mortality, 1973–1995: a report card for the United States. Cancer 1998;82:1197-1207.
71. NCI Fact Sheet 5.28 [cited 2002 Jan 29]. Available from: URL: http://cis.nci.nih.gov/fact/5_28.htm
72. Feuer EJ, Wun LM. DEVCAN: probability of developing or dying of cancer. Version 4.0. Bethesda (MD): National Cancer Institute (US); 1999.
73. MEDLINEplus health information. Medical encylopedia. Breast cancer. Causes and risks [cited 2002 Jan 29]. Available from: URL: http://www.nlm.nih.gov/medlineplus/ency/article/000913.htm#causesandrisk