

Listening to Kansans: Qualitative Data to Inform Development of the Comprehensive Cancer Plan and KUSM-W Breast Cancer Survivorship Center

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Introduction

The Kansas Cancer Partnership (KCP) began their work in the summer of 1999 at the request of the Kansas Department of Health and Environment (KDHE). The mission of the partnership was to focus on the reduction of cancer incidence, morbidity, and mortality for all Kansans through research, prevention, early detection, treatment, recovery, and palliative care. The Partnership completed their first set of tasks by utilizing available data and identifying gaps in the data to describe the burden of cancer in Kansas.

Cancer is a major public health issue with an estimated 13,178 cases (age-adjusted rate: 457.67 per 100,000) for all cancer types in Kansas in 2006.¹ Of the 120,704 new cases of cancer reported in the Kansas Cancer Registry from 1997-2005, there were 20,211 cases of female breast cancer (16.7%).

In the winter of 2003-04, KDHE and the Partnership began development of the Kansas Comprehensive Cancer Plan. The first step was a "Listening Tour" in four communities across the state to compile opinions and preferences. The tour was formed to hear what Kansans believed were the most important priorities to impact positive cancer-related changes. To continue the cancer planning conversation with a specific focus on breast cancer, the Mid-Kansas Affiliate of Susan G. Komen for the Cure funded an additional focus group study in 2009 to document experiences and per-

ceptions about breast cancer survivorship and to outline the possibility for developing a survivorship center in Wichita for Kansas breast cancer survivors. The 2009 study utilized a series of focus groups with breast cancer survivors to gather information about patient experiences and preferences for survivorship care. Focus groups and surveys used to assess breast cancer issues and treatment needs previously have included quality of life², barriers to exercise³, cancer survivorship^{4,5}, coping skills⁶⁻⁸, massage therapy⁹, and satisfaction with care¹⁰.

Kansas Comprehensive Cancer Plan

Listening tour process. Four communities were identified to participate in the listening tour. Wichita and Kansas City were chosen to represent the two most populous areas of the state. To provide insight from rural communities, Parsons in southeast Kansas and Garden City in southwest Kansas also were selected. Some sites held two listening sessions and all recruited 15-20 participants per group. Sessions were scheduled so half were during the workday and the others were in the evening.

The listening tour was designed to understand and assess perceptions and beliefs of participants toward cancer from prevention through recovery or end-of-life. Researchers identified a protocol similar to that used by the State of Arizona¹¹ including a mailed survey associated with registration

to participate in a community session and community forums to inform the development of the Kansas Comprehensive Cancer Plan. The Arizona language and definitions were revised to be consistent with the language of the Kansas Cancer Partnership. Queries for the listening sessions were developed to allow for a mix of individual and group responses. Small group brainstorming provided lists of needed services and resources and the entire group voted on prioritization of the small group lists. Additionally, each small group was asked to discuss and agree on the “one thing” that would have the greatest impact on cancer prevention and control in Kansas. Each individual also gave a rating, on a 6-point Likert scale, for each of the five priority items based on importance and feasibility.

Seven community listening sessions were held between February 16 and March 16, 2004. All groups were moderated by the same facilitators using a standard script. The project was approved by a university institutional review board. Each participant gave written informed consent prior to beginning the focus group protocol. Participant names were kept anonymous; only aggregate data were reported.

The seven sessions each lasted approximately 1 hour and 30 minutes. Each session was audio-recorded. A summary was compiled for each listening session and presented in a stakeholder report to KDHE and the Kansas Cancer Partnership.

Participants. Results stemmed from comments made during the seven community listening sessions. Fifty-six subjects participated in the groups (male=14; female=42). The ages ranged from 21 to over 80 years old (most were 41-50 years). The participants equally represented the Kansas communities (urban=27; rural=29). The participants shared their reasons for participating in the

session, including: working as a health care professional (33), being a cancer survivor (17), being a family member (16) or friend (12) of a cancer survivor (16), being a family member (10) or friend (12) of a cancer victim, and other reasons (7). The participants represented various agencies and organizations, such as cancer education and support/advocacy groups, medical centers and clinics, foundations, hospice, health departments, schools, insurance, and cancer societies. The participants reported that their agencies or organizations offered many cancer-related services and resources (see Table 1).

Table 1. Agency/organization services and resources.

Types	#
Prevention programs	32
Early detection programs	32
Patient support programs	25
Advocacy and lobbying	13
Volunteers and staff	11
Treatment	10
Strategic planning and evaluation	9
Rehabilitation services	6
Palliative care	5
Research	1
Cancer education library	1
Surgical services	1

Definitions and themes. The facilitator provided a definition for each of the following terms: (1) prevention, (2) diagnosis and treatment, and (3) recovery or end-of-life needs. Then, the participants described the services and resources needed from the larger cancer community for each of the three areas.

Prevention was defined as, “*reduction of cancer incidence through risk factor reduction*”, “*includes education, skill*

development and/or environmental/policy changes related to behaviors such as tobacco use, diet, and physical activity”, and “prevention does not include screening or diagnostic testing”. Participants reported the need for (1) education, (2) dedicated facilities, (3) policy changes, and (4) organized leadership. A lack of education was described for environmental and chemical exposures which may cause cancers, stress reduction skills, training in prevention for health care providers, and for educational materials (e.g., printable materials and Public Service Announcements) in multiple languages. Participants thought that education at all levels (children, youth, and adults) was needed to describe the links between lifestyle behaviors and cancer and how behavior modification could be made (e.g., nutrition, physical activity, smoking cessation, and sun protection).

The groups discussed the need for dedicated facilities for cancer prevention in the virtual sense and within communities. At that time, there was no statewide website with hyperlinks to cancer prevention and lifestyle information. Participants said there was a lack of facilities in all communities to inform the general public of no-cost cancer prevention services (e.g., breast, cervical, prostate, skin, or oral). Additionally, groups thought there was a need to increase physical activity opportunities at the community level with greater access in the built environment.

Discussion led participants to voice needs for policy change and advocacy. Participants wanted smoking bans in public places, changes in school lunches to low-fat options with more fruits and vegetables, and increased testing of air and water for chemicals/toxins. Additionally, participants expressed that many insurance plans do not pay for cancer prevention activities. Participants reported a lack of organized advocacy in Kansas related to environmental

policies and cancer. The groups discussed wanting increased involvement of community leaders, especially ethnic leaders, in issues of cancer prevention.

The facilitator defined diagnosis and treatment as *“timely disease detection through screening and other testing procedures, followed by prompt delivery of the best available therapeutics (including surgery, radiation, and/or chemotherapy)”*. To answer the question about what diagnosis and treatment services and resources were needed from the larger cancer community, participants reported (1) better screening guidelines, (2) education and training for physicians, (3) information on clinical trials, (4) increased access to existing services, and (5) a better referral system. Participants reported the current screening guidelines were *“inconsistent”* and discriminatory toward patient age.

The groups discussed inadequate procedures and systems in physician offices. Clinics lacked early detection services for a variety of cancers (e.g., skin cancer screening and mole mapping and oral cancer screenings by dentists). Participants thought that Kansas needs health care providers who are more involved in the continuum of care for cancer patients. Physicians needed an increased knowledge of signs, symptoms, and screening guidelines, as well as more thorough training on clinical breast examination and teaching patients how to do self-exams. Additionally, clinicians would benefit from education on providing patients with culturally appropriate materials.

Participants of the listening sessions perceived a lack of information and support for using alternative medicine as options for treatment. Additionally, there was a lack of knowledge regarding information on cancer clinical trials, including availability, location, and insurance coverage for participation. For those who have participated in cancer research and new

programs, participants wanted speedier reports from KDHE and others on the efficacy and effectiveness of the programs.

All of the groups discussed lack of access to cancer services and resources throughout Kansas. Specifically, participants discussed deficits in resources for the uninsured, underinsured, illegal aliens, and rural communities. Participants discussed needed services on behalf of these patients, such as transportation, child care, translators, psychosocial care, and insurance coverage. The groups discussed solutions to access problems, including advanced technology for rural areas, referral networks, one-stop facilities for diagnosis, surgery, and treatment staffed with local physician experts in rural Kansas. Additionally, participants discussed the need for a “*patient navigator*” or case management system to act as a guide or flow-chart for patients needing resources for care.

When discussing cancer, the facilitator defined recovery as “*the psychosocial and economic re-integration of person with cancer back into normal life following treatment*”. Examples of recovery services might include support groups, economic support, re-training and rehabilitation, and supported medical leave. End-of-life needs were defined as “*those services and resources needed by the cancer victim and their family to prepare for and/or adjust to the end of life*”. Themes from the discussion of recovery and end-of-life services needed from the larger cancer community included: (1) a cancer resource repository, (2) various support services, (3) financial and insurance related changes, (3) physician training, and (4) education.

Participants described the need for “*cancer resources repositories*” that could take the form of patient navigators or case managers, community “*banks*” for wigs or prostheses, and a website with information on services, support groups, important

phone numbers, and educational materials for cancer patients, families, and caregivers in Kansas. The focus groups voiced concerns of existing needs for families and caregivers in terms of counseling, skill development, planning services (financial, estate, and end-of-life issues), and support groups. Cancer survivors needed in-home support such as caregiving services, supplemental income, spirituality assistance, and support groups.

Various needs were discussed in relationship to insurance coverage. Participants advocated for changes in disability coverage, expanding automatic qualifications for Medicaid services under the Federal Treatment Act¹², and universal health care coverage. Participants thought more education was needed in human resource departments to help cancer patients know and plan for when their health insurance would not cover a service, and/or how to address insurance concerns when a cancer survivor switched employers or insurance (i.e., personnel sensitivity training to cancer issues). Participants also thought that financial support was needed to help patients pay for re-training and recovery services (e.g., nutrition, physical and/or occupational therapy, and psychotherapy).

Training and education were discussed as ways to address some recovery and end-of-life issues. Participants thought that physicians lacked awareness and training in palliative care. Additionally, participants believed physicians needed to be better at fully disclosing the known side effects of treatment, including the psychosocial effects. The groups believed that their communities would benefit from accurate cancer-related education (“*cancer is not contagious*”), cultural issues of hospice care, and research on “*chemo-brain*” (the mental cloudiness associated with chemotherapy).

Priority items and perceived feasibility scores. After the three lists of items were

compiled from the small group discussions, each participant placed five dots on the items they considered to be the most important. They were instructed to first review responses from all three of the question categories (prevention, diagnosis and treatment, and recovery and end-of-life), then select the five items they felt should be top priorities for the Kansas Comprehensive Cancer Plan. Each participant could use multiple dots for one item or vote for up to five different items. When all the voting was complete, votes were tallied and the top priorities were posted and read by the facilitator. Next, participants scored each of the group's five priorities for feasibility, using a 4-point Likert-type scale where 1 = very feasible, 2 = somewhat feasible, 3 = not very feasible, and 4 = not feasible at all. When scoring feasibility, participants were cautioned not to worry about "who" would be responsible for the selected priority or "how" they would get it done.

The priority items were defined separately for each listening session (see Table 2). The priority themes determined by the participants included: (1) funding, (2) policy changes, (3) services and resources, and (4) education. Many participants voted for items that would offer funding through insurance and/or reimbursements for cancer prevention education and screening for all types of cancers. The groups were interested in subsidizing benefits for the medically underserved. Feasibility scores rated the funding priorities as somewhat (2.0) to not very (3.0) feasible. Two groups asked for free screenings to be provided at special events and thought that this was a very (1.0) feasible idea. Still other groups opted for policy changes to benefit cancer victims as an option to finding funding agencies. One of the priority policy ideas was implementing universal health care coverage that would cover affordable and accessible care for all stages of cancer. Another idea

that made the priority list was to expedite Social Security disability payments so patients can receive their financial support and avoid losing their homes and other assets.

One of the groups in rural western Kansas was interested in increasing air and water testing around the local cattle feedlots to control for chemicals and toxic pollution. Participants thought that environmental testing was somewhat (2.0) feasible, however, they did not think that the other policy changes were very feasible with average scores near 3.0.

Another set of identified priorities across the listening groups were cancer services and resources. Participants in five sessions voted a patient navigator system as a top five priority and rated it as somewhat (2.0) feasible. A patient navigator system was described as an organized way of identifying services, resources, and information to help patients and families access needed health care appropriate to their language and geographical situation. Other priority ideas rated as very (1.0) to somewhat (2.0) feasible included increasing physical activity options in communities' built environments and support groups that provide prevention education. Less feasible (> 2.0) priority ideas included offering transportation for patients to get to services, and a one-stop facility in rural Kansas to provide consistent cancer care from diagnosis to treatment.

All education priorities were rated as very (1.0) to somewhat (2.0) feasible to implement in Kansas. Two of the identified priorities would provide information either via a statewide website with links for cancer prevention, treatment options, and alert reminders for screening appointments, or via a flowchart of options and resources to describe diagnosis and treatment options with specific channels for Medicare, Medicaid, privately insured, and uninsured patients.

Table 2. Priority items with average feasibility scores by session site.

Priority Items	Garden						
	Wichita		City		Kansas	Johnson	
	A	B	A	B	City	County	
Patient navigator system		1.7	1.3		1.7	2.7	1.4
Funding for cancer screenings	1.5	2.9					1.3
Prevention education			1.3			1.8	
Email reminder for screening appointment	1.0						
Statewide cancer website	1.0						
Support groups	1.0						
Flowchart for steps in diagnosis, treatment, and resources	1.3						
Free cancer screening events	1.5						1.1
Cancer education for medical students		1.0					
Health education in schools		1.7					
Expedite Social Security funding for disability coverage		2.6					
One-stop facility for rural Kansas (diagnosis to treatment)			2.5				
Expand Kansas Treatment Act			2.1				
Test air/water for pollutants			1.9				
Nutrition education				1.0			
Increased physical activity options				1.5			
Employer support for patients/families				2.0			
Stress reduction education				1.5			
Universal health care coverage							2.9
Available/affordable care for all stages							1.9
Funding for medically underserved (from prevention to treatment)						2.7	
Transportation services for patients						2.7	
Education on hospice and end-of-life care						1.7	
Increase public awareness and education					1.3		

Note: Feasibility rated on 4-point Likert-type scale (1 = very feasible to 4 = not feasible at all)

Other groups voted for age-appropriate cancer public awareness messages and health education in schools and at work-sites. One group identified stress reduction training as a top priority, while another wanted to see improved employer support for cancer patients and families. Another top priority was voiced for educating medical students specifically on cancer

prevention, diagnosis, and symptom management, including end-of-life and hospice care education for all medical care providers.

The “One Thing” for greatest impact in Kansas. Participants were asked to identify as a group, the one thing they would change to improve cancer prevention and control in Kansas. The facilitator asked them to make

their choice without worry about money, political will, or “how” it will be accomplished. Overall the participants identified five changes that would make the greatest impacts, listed below in the participant’s original wording:

1. Universal access to screening, diagnosis, and care.
2. Universal health coverage beginning with education, prevention measures, early detection, treatment options, and recovery resources available for everyone.
3. All people will access preventive services that are available and follow through with any care necessary. We want to make Kansas 100% healthy!
4. Health insurance includes preventive coverage with incentives for healthy lifestyle.
5. Cancer education for all. Lifestyle and risk factor education for kids through schools; parent education on lifestyle and risk factors; physician skill development to counsel patients about lifestyle issues; and social marketing.

Informing the Kansas Cancer Partnership. A final report of the listening tour sessions on the comprehensive cancer plan was synthesized and delivered to stakeholders (i.e., Kansas Cancer Partnership and KDHE). The information was used to inform development of the Kansas Comprehensive Cancer Plan with strategies to address each of the areas that were discussed in the community forums. The top priorities identified by the community forum participants were integrated into the plan with strategies for achievement of those priorities identified. The Task Groups that implemented the plan reported their progress on implementation and successes to the Kansas Cancer Partnership (KCP) semi-annually. The plan currently is being updated by the KCP membership.

Breast Cancer Survivors’ Focus Groups

Focus group process. The Mid-Kansas Affiliate of Susan G. Komen for the Cure, sponsor of the focus group research, identified the site for two focus groups and recruited 10-15 participants per group from central Kansas communities as far north as Salina and as far south as Arkansas City. Both focus groups were held on Saturdays and included lunch and gifts from Komen.

This project was designed to explore the participants’ experiences and perceptions of breast cancer survivorship and to dream a little about how similar experiences might be improved for those survivors who will follow. Researchers developed the protocol script to have two discussion phases. Phase I was a set of discussion queries to ask about treatment experiences: how treatment ended, the first three months following completion of treatment, the experience from end of treatment until the present, and challenges faced in returning to work. In phase II, participants divided up into small groups to brainstorm what an ideal support system for survivorship could look like.

Two focus group sessions were held in January 2009. All groups were moderated by the same facilitators using a standard script. Each participant gave written informed consent prior to beginning the focus group protocol. Participant names were kept anonymous, only aggregate data were reported. The two sessions each lasted approximately three hours. A co-facilitator took notes and another recorded discussions on flip charts. A summary was compiled for each listening session and presented in a stakeholder report to the Mid-Kansas Affiliate of Susan G. Komen for the Cure.

Participants. Results stemmed from comments made during the two focus group sessions. Eleven subjects participated in the groups (male=1; female=10). The participants represented the central part of Kansas (Reno, Saline, Sedgwick, and Sumner

counties) with the majority being diagnosed (54%) and treated (64%) in Wichita. The participants were breast cancer survivors diagnosed between 1981 and 2007.

Phase I themes. After introductions, the facilitator asked the participants to describe each of three phases of their lives: before cancer, during cancer treatment, and cancer survivorship following treatment. The majority of participants described their lives prior to breast cancer as “good”, “great”, “active”, and “living life to fullest”. One participant described the year prior as “extremely depressing” after having lost three grandchildren. Some of the participants remember being “clueless” or “uneducated” about breast cancer or feeling like it was not a concern for them.

When participants described their life during cancer treatment, they used words such as “stressful”, “terrified”, “numb”, “angry”, and “anxious and panicked”. Physically, the participants remembered it being “worse than awful” or reported they “blocked it out”. They commented that this time in their life could be classified as “surreal and challenging”, “isolated”, and a “struggle with growth”. One participant recalled it was “my hardest journey”.

Finally, the participants described their survivorship journey in a few words. Some participants declared they are “still scared every day”, “just glad I’m done”, and “didn’t think I’d live this long”. Others used more positive words to describe their current life as “wonderful”, “enriched”, “thankful”, “peaceful”, and a “blessing in disguise”. In this phase of life, survivors described that they have: “lots left to do and to live for”, “whole new appreciation for life”, “survived treatment so I can survive anything”, and are “able to focus on me”.

The facilitator asked the participants to expand on their experiences in more detail. Participants had both positive and negative responses to how their oncologists directly

impacted their experiences. One participant was complimentary of the nursing staff, “especially those who were also survivors”. Another participant described the importance of participating in the decisions and giving input into the plan that the oncologist and staff had laid out.

Of the negative experiences that were discussed, the majority of participants said the problems were in communication. One participant felt like they “talked at me, not to me”. Some participants described the lack of communication around everything but radiation and drugs: “there was no discussion on diet or exercise” and “there are tons of mental health issues... but no one deals with them”. Another said the “family doctor and surgeon didn’t talk - they assumed the other one was referring me”, which resulted in delayed treatment for a year after her mastectomy.

Participants reported that their oncologists could have provided more information to improve their experiences with side effects, prevention of side effects, diet during chemotherapy, affects associated with menopause, and fertility issues. Some discussion also focused on the need for properly informing the husbands and families who have a lot of “misinformation”. Family members also needed support and counseling. As one person said, “Cancer is very hard on a marriage and marriage counseling is essential to get through it”. Participants also wanted the oncologists to “offer clinical trials and explain why each is a good choice or not”, but most importantly to let the patient decide for themselves. Most participants determined that it was actually a nurse who told them the most about the clinical trials.

When participants were asked to recount the events surrounding the end of their cancer treatments, they told of receiving balloons and certificates from the oncology staff, but receiving very little instruction

other than “*to come back in three months for follow-up*”. Survivors thought that the experiences could have been better by having received a clinical plan for survivorship, a patient navigator for continued services and support, access to additional health professionals, and insurance information. Some participants thought that having a clinical plan for survivorship would help them “*to track ongoing tests, screens, scans they should have and on what schedule*”, to help “*the family practice physician [to be] kept in the loop*”, and to aid with “*life skills follow-up*”. A patient navigator to help through treatment would be more beneficial if the navigator continued through survivorship, especially to guide access to diet, exercise, and mental health professionals.

Participants discussed the period following the completion of their treatment until the time of the focus group. About half reported that their family physician did not ask about their cancer: “*they treat it as though that is in a separate compartment of their lives*”. The other half reported very supportive family physicians who monitored their cancer, referred them to their oncologists regularly, and provided emotional support. Many expressed concerns that their family physicians did not have access to the most current treatment information and they had to educate the physicians about their treatment.

The majority of participants reported that family and friends were the primary community resources used after their treatment. Over half of the participants had attended a support group one or more times, but the reactions were mixed as some had negative experiences that simply increased their fear and anxiety. Many mentioned the value of social groups of survivors that formed just to have fun and support one another and not to discuss cancer per se, similar to the “*camaraderie that developed*

in waiting rooms”. The internet was both helpful and scary because “*there is too much information*” and “*you don’t know what to believe*”. None of the participants reported using the www.cancerkansas.org official website. The participants thought something was needed to help people develop the skills to maintain relationships with cancer survivors throughout their treatment because of challenges with friends and family who “*disappear*” because they do not know how to talk to them.

Finally, participants discussed the challenges they faced when returning to work. In one group, most of the participants continued to work throughout treatment and had no adverse issues to report. One participant said she did this because it was “*important to her mental health*”. In the other group, some reported having supportive employers who would visit them in the hospital, while others remembered being told to come back to work the day after their surgery.

Insurance problems were the biggest issue reported. Some participants saw rising costs up to “*\$5000 in two years*” or were dropped from insurance because the cancer was “*pre-existing*”. One participant who was unable to return to work reported trying to get diagnosis and treatment services as an uninsured patient.

The problems with insurance generated a discussion of the ethical issues of not providing health care for all people. There was a universal need among the participants for help understanding their insurance relative to cancer and how to manage their health care costs.

Phase II dreams. After the discussion questions, participants formed into small groups. Groups were given 20 minutes to discuss and use markers to draw their responses to the question, “*If money was no object, what would a support system for breast cancer survivorship look like if we*

get it right?" Participants were instructed to think about all aspects of their own survivorship to respond to the question and to dream big.

After discussion, the entire group shared the features of their ideal survivorship support system. A number of themes repeated among the small groups in both focus groups:

1. A comprehensive survivorship plan with each individual using a multi-disciplinary group. The plan included exercise, diet, emotional health, and screening and follow-up plans. An annual visit to the center to develop and/or update your survivorship plan – in person, by phone, or by Skype for I-chat for rural survivors.
2. A patient navigator to assist both during treatment and throughout the survivorship journey, making the necessary connections for survivors.
3. A team approach with a trainer or physical therapist to design and teach exercise programs specific to needs, a registered dietitian to provide counseling and teach meal planning and healthy cooking, and a body image consultant to assist with prostheses, bras, swimwear, and reconstruction decisions.
4. Counseling for survivors, family, and friends as couples, individuals, and groups; access to other survivors for discussions.
5. Access to educational resources, including literature, lectures, web-resources, DVDs, and group discussions on a variety of topical areas with trained staff to assist them with information about:
 - a) long- and short-term side effects of treatment;
 - b) risk and prevention of recurrence;
 - c) breast cancer management classes, like diabetes management classes;

- d) internet connections to the center for survivors in rural areas;
 - e) internet connections to the center for family physicians in rural areas for consultation and continuing medical education;
 - f) menopause;
 - g) Facebook and MySpace chat rooms.
6. Social work assistance for issues related to finances, insurance, employment, end-of-life care, and legal rights.
 7. An exchange closet with items to share, such as wigs.
 8. Metabolism and hormonal assessment and treatment, including fertility survival and menopause.
 9. Support for survivors in rural areas, including tele-medicine.

Additionally, some groups requested spa amenities, on-site mammography, on-site pharmacy, cafeteria, alternative medicine options, and screening reminders.

Discussion

A qualitative method was chosen to extend the understanding of breast cancer survivors in Kansas through a deep, rich textual description of participant comments. All focus groups expressed consensus on topics such as physical benefits, reduced stress and anxiety, personal control over their choice to participate, and renewed sense of respect and dignity. A particularly valuable finding is the clear indication of the need for treatment that allows the patient a sense of “control” and “empowerment” and the need for ongoing support throughout survivorship.

Implications

These focus groups served as a preliminary indicator for the experiences of cancer patients. While many gaps were identified, an important potential avenue for intervention was indicated.

References

- ¹ Lai SM. Kansas Cancer Registry multiple year report: Cancer incidence and mortality in Kansas, 1997-2005. Kansas City, KS: University of Kansas Medical Center, August 2008. Accessed at: <http://www2.kumc.edu/kcr/AnnualReport/MultiYear9705%20Modified%20SG%201008.pdf>.
- ² Grunfeld E, Urquhart R, Mykhalovskiy E, et al. Toward population-based indicators of quality end-of-life care: Testing stakeholder agreement. *Cancer* 2008; 112:2301-2308.
- ³ Courneya KS, McKenzie DC, Reid RD, et al. Barriers to supervised exercise training in a randomized controlled trial of breast cancer patients receiving chemotherapy. *Ann Behav Med* 2008; 35:116-122.
- ⁴ Emslie C, Whyte F, Campbell A, et al. 'I wouldn't have been interested in just sitting round a table talking about cancer'; exploring the experiences of women with breast cancer in a group exercise trial. *Health Educ Res* 2007; 22:827-838.
- ⁵ Kooken WC, Haase JE, Russell KM. "I've been through something": Poetic explorations of African American women's cancer survivorship. *West J Nurs Res* 2007; 29:896-919.
- ⁶ Hilton BA. Family communication patterns in coping with early breast cancer. *West J Nurs Res* 1994; 16:366-388.
- ⁷ Manne SL, Sabbioni M, Bovbjerg DH, Jacobsen PB, Taylor KL, Redd WH. Coping with chemotherapy for breast cancer. *J Behav Med* 1994; 17:41-55.
- ⁸ Ptacek JT, Ptacek JJ, Dodge KL. Coping with breast cancer from the perspectives of husbands and wives. *J Psychosoc Oncol* 1994; 12:47-72.
- ⁹ Chesser A, Hart TA, Wetta-Hall R, et al. Breast cancer survivors' messages about the use of massage therapy. *KS J Med* 2009; 3:2-12.
- ¹⁰ Defossez G, Mathoulin-Pelissier S, Ingrand I, et al. Satisfaction with care among patients with non-metastatic breast cancer: Development and first steps of validation of the REPERES-60 questionnaire. *BMC Cancer* 2007; 7:129.
- ¹¹ Arizona Department of Health Services. The Arizona Comprehensive Cancer Control Plan. Phoenix, AZ: Arizona Department of Health Services, 2005. Accessed at <http://www.azcancercontrol.gov/pdf/cancercontrolplan.pdf>.
- ¹² Kansas Department of Health and Environment. Early Detection Works: Kansas Breast & Cervical Cancer Screening Program. Policy & Procedures Manual. Topeka, KS: Kansas Department of Health and Environment, August 2009. Available at <http://www.kdheks.gov/edw/download/programmanual.pdf>.

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