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# Editor's Note



## **Breast Cancer Survivorship**

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This issue of the Kansas Journal of Medicine (KJM) focuses on the subject of breast cancer survivorship. Breast cancer survivorship plays an integral role in the breast cancer care continuum. Survivorship care planning from the time of diagnosis allows health care professionals to provide a variety of services to women at all stages of breast cancer diagnosis and treatment. Survivorship care offers services from a multi-disciplinary medical team that includes primary care physicians, medical oncologists, endocrinologists, dietitians, clinical psychologists, and other health care professionals. Patients receive physical examinations, genetic counseling, cardiology assessments, diet, exercise programs, and fertility preservation. Two breast cancer survivorship centers have been created in Kansas; one in Kansas City and one in Wichita. These Centers seek to fill the unmet needs of breast cancer survivors by focusing on the physical and emotional needs of breast cancer survivors, family, and friends. The research studies presented in this issue report on multiple focus groups with breast cancer survivors and individuals involved in breast cancer care. The focus groups clearly indicated several psychosocial issues associated with diagnosis and treatment that need to be addressed to ensure an optimal outcome. As survivorship care is enhanced in Kansas, these studies point a clear direction for moving forward.

## Breast Cancer Survivors' Messages about the Use of Massage Therapy

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### Abstract

**Background.** The purpose of this study was to explore qualitative comments about massage therapy (MT) from breast cancer survivors. Patients suffering from cancer commonly use complementary alternative therapies for treatment and recovery, including massage therapy. Quantitative studies have shown that MT may reduce distress and enhance symptom control in cancer patients.

**Methods.** Four focus groups were conducted. Specific queries were identified for the group discussions to include: (1) prior massage experiences, (2) research study enrollment process, (3) MT intervention, and (4) the impact of MT. Participants also completed a 14-question survey, answering with forced-choice responses and ranking responses utilizing a four point Likert scale.

**Results.** Themes emerged from the analysis including physical and mental benefits of MT, control of decision-making during treatment, and positive implications of non-invasive treatment.

**Conclusions.** Efforts should be directed toward treatment that allows patients a sense of "control" and "empowerment." *KJM 2009; 3(1):2-12.*

### Introduction

Breast cancer is a major public health issue with an estimated 212,920 new cases and 40,970 deaths in the US for 2006.<sup>1</sup> Of new cancer diagnoses among women, one-third are breast cancer with 80% of breast cancer patients having a 5-year minimum survival prognosis and localized breast cancer patients having a 98% survival rate for a minimum of 5 years.<sup>2</sup>

Several studies reported using massage in addition to other medical treatments for breast cancer patients (see Table 1). Study population prevalence of women participating in massage therapy ranged from 5.2% to 28% with an all-cancer survivor population-based prevalence of 11.2%.<sup>3</sup> There is a positive correlation between survival of breast cancer and the completion of the full treatment regimen of chemotherapy.<sup>4,5</sup> Therefore, alternative or

complementary therapies that ameliorate the side effects of cancer treatment protocols should be investigated.

The American Cancer Society (ACS) strives to gain a better understanding of the causes underlying behavioral change of treatment protocols for breast cancer patients.<sup>1</sup> Using massage therapy (MT) to improve the psychological outlook of breast cancer patients may boost immune response, thereby ameliorating their perceptions of side effects caused by treatment and improving nausea<sup>6-8</sup>, pain<sup>7-10</sup>, sleep<sup>11</sup>, anxiety<sup>9,10,12</sup>, and aspects of quality of life<sup>10,13,14</sup>. In a 2002 study, women with breast cancer who received three 45-minute massages per week for five weeks had improved moods with decreased stress, anxiety, and anger after the first and last massage.<sup>11</sup> Additionally, cancer patients

who received massage with aromatherapy reported a statistically significant reduction in stress and a statistically significant improvement in cancer-related symptoms and quality of life.<sup>11,15</sup>

Focus groups and surveys used to assess breast cancer issues and treatment needs have previously included quality of life<sup>16</sup>, barriers to exercise<sup>17</sup>, cancer survivorship<sup>18,19</sup>, coping skills<sup>20-22</sup>, and satisfaction of care<sup>23</sup>. A recent analysis found gaps in several key research categories including pathophysiology, detection, treatment, pre-

vention, and psychosocial aspects of breast cancer.<sup>24</sup> However, focus group research studies involving complementary and alternative medicine (CAM) are few.<sup>25-29</sup>

The present study utilized a series of focus groups with breast cancer patients to gather information about patient experiences with massage therapy (MT). Interview questions were constructed through the theoretical underpinnings of information seeking<sup>30-33</sup> and decision-making<sup>26, 34-37</sup> for patients undergoing breast cancer treatment.

Table 1. Pattern of massage therapy use in research with breast cancer patients.

Author/Year/Country	Type of CAM	Prevalence
Crocetti et al., 1998, Italy <sup>38</sup>	Manual healing (massage)	16%
Burstein et al., 1999, USA <sup>39</sup>	Massage	5.2%
Vandecreek et al., 1999, USA <sup>40</sup>	Massage	10%
Boon et al., 2000, Canada <sup>41</sup>	Body work used at least once (reiki, massage, therapeutic touch)	14.1%
Gotay and Dumitriu, 2000, USA <sup>42</sup>	Massage	20.8%
Lee et al., 2000, USA <sup>43</sup>	Physical healing methods (including massage)	14.2% overall (7% blacks, 12% Chinese, 17% Latino, 21% white)
Rees et al., 2000, UK <sup>44</sup>	Massage	13.9%
Alferi et al., 2001, USA <sup>45</sup>	Massage/body work	11%
Lengacher et al., 2002, USA <sup>46</sup>	Massage used at least once	27%
Shen et al., 2002, USA <sup>47</sup>	Massage	28%
Nagel et al., 2004, Germany <sup>48</sup>	Massage included as "Other CAM types"	6%
Buettner et al., 2006, USA <sup>49</sup>	Massage used for any reason (i.e., wellness, bodily pain)	23%
Helyer et al., 2006, Canada <sup>50</sup>	Massage	26%
Lengacher et al., 2006, USA <sup>51</sup>	Massage (a traditional and ethnic medicine category)	25%
Molassiotis et al., 2006, European countries <sup>52</sup>	Massage	12.7% pre-cancer 15% since diagnosis
Boon et al., 2007, Canada <sup>53</sup>	Massage	9.8%

## Methods

Massage therapy pilot program. Fifty-one women who were undergoing breast cancer treatment, lived within a 100-mile radius of a regional cancer center, and had a physician referral for participation, were recruited for an MT pilot program. The MT process was explained to the patient and usual MT protocols were followed.<sup>54</sup> The patients indicated their willingness to participate in research and were selected as a convenience sample. Patients were excluded if they had contraindications to massage therapy, including: active skin rash, open cutaneous lesions, current diagnosis of venous thrombosis or symptomatic varicosity, untreated anemia (hemoglobin level less than 8 mg/dl), or current touch therapy. The pilot study was conducted for five weeks in 2006. The focus groups were held March-April 2007.

Focus group study. All surviving patient participants utilizing MT as a part of treatment were invited to attend the focus group discussions. Four focus groups were conducted with 21 volunteering participants in an urban Kansas county.

The study design emphasized the contribution from respondents to assess utilizing MT as a type of CAM and as a part of the treatment regimen for breast cancer patients at a regional medical cancer center. This research study was designed to better understand and assess changes in perceptions and beliefs of participants toward MT, and the impact the therapy may have had on side effects of breast cancer treatment, functional status, and quality of life. Researchers identified specific queries not examined previously in qualitative studies about MT, including (1) prior massage experiences, (2) research study enrollment process, (3) MT intervention, and (4) the impact of MT.

Study approval was granted by a university institutional review board. Each

participant gave written informed consent prior to beginning the focus group protocol. The four sessions each lasted approximately 90 minutes. The sessions were held at the same location and audio-recorded.

Participant survey. Subjects completed a 14-question survey, answering with forced-choice responses, and ranking responses utilizing a 4-point Likert scale. The survey collected quantitative data to corroborate the verbal comments and ensure convergent validation. Questions included a brief description of cancer diagnosis, date of original diagnosis, identification of other CAM therapies used, rating of the overall MT experience, possibility of recommending MT to other cancer patients, and demographic information.

All groups were moderated by the same professional female facilitator, who had 19 years of experience in qualitative research for health communication. The facilitator used a standard script for each meeting. She introduced two terms at the beginning of each session to create a common definition throughout the discussion. The facilitator defined complementary alternatives as, "Encompasses both the use of natural healthcare products (including herbs, homeopathy, and nutritional supplements) and the process of seeking health advice from individuals who are not generally considered conventional health care professionals (i.e., herbalists, homeopaths, naturopathic practitioners, and acupuncturists)." Quality of life was defined as, "The overall enjoyment of life." As terms were introduced, the facilitator asked participants if they understood the terms and concepts. Definitions were given when participants requested clarification.

Faculty members from the Department of Preventive Medicine and Public Health at the University of Kansas School of Medicine-Wichita conducted interviews,

transcribed comments, and subsequently analyzed the data. In addition to the moderator, another researcher was present during focus group sessions to take notes.

Immediately after each focus group session ended, the moderators convened to review the findings and assure that all key points were captured in writing. Then, they listened to the audiotape of each session, read transcripts, identified conclusions, and grouped the findings into categories for analysis. A summary was compiled for each focus group.

Data analysis. Questionnaire data from participant surveys were analyzed using SPSS 14.0 software (SPSS, Inc., Chicago, IL). The digital recordings were transcribed to text and uploaded to Ethnograph 5.0 (Qualis Research, Colorado Springs, CO), a professional qualitative software program for data-making. Unitizing the data occurred on a series of levels: by physical group (focus group session), by content (discussion question asked), by respondent, and by context (stated positively or negatively). The moderators cut full quotes that concisely summarized thoughts from the transcript and used them to describe themes.

After all transcripts were unitized, they were compared for themes within discussion questions and across groups. Similarity of consensus norms across sites implied validity of findings. A final analysis assessing convergence and divergence of themes across the groups was assembled. Similarities and differences between special populations were described based on differences between focus group consensus findings and discussion results when stratified by groups. Triangulation of qualitative and quantitative responses were categorized and compared to strengthen validity and reliability of the study.

## Results

Results stemmed from comments made during the focus group sessions and responses from the survey demographic questions. All focus group sessions were held after the completion of the MT intervention. All of the participants who completed the intervention and chose to be a part of the focus group study were included.

Participant demographics. Twenty-one female subjects participated in the focus groups. The majority classified themselves as Caucasian (86%), married (62%), between 50-59 years old (48%), college educated (48%), from an urban area (38%), and earning an annual income between \$20,000 and \$40,000 (33%; Table 2). The participants shared similar demographics to the deceased participants from the Massage Therapy Pilot Program.

The majority (91%) of participants reported using CAM with traditional cancer treatments. Some women (10%) reported using up to six different types of CAM. The most common types (excluding MT) were spiritual and religious practices (71%) and vitamins (57%; Table 3). The participants listed their cancer diagnoses as infiltrating ductal carcinoma (52.4%), metastatic breast cancer (23.8%), lobular carcinoma (5%), or inflammatory breast cancer (5%). Several participants (14.3%) indicated they were diagnosed with more than one type of breast cancer. Time since diagnosis ranged from 6 months to 8 years (mean = 2.8 years).

Previous massage experience. The facilitator began each focus group by asking about previous experience with massage. A majority (61.9%) of participants responded that they had received some type of massage prior to this research program, usually one or two MT sessions received 3 to 25 years prior to this study. When asked about the

type of massage they had received, the techniques were distinguished by using the terminology “regular,” “light,” and “hard” massages. Some participants expressed pain associated with prior massages; as one participant said, “Of course it felt good at the time but the very next day, boy I was really in a different kind of pain.”

Table 2. Demographics of focus group participants (n=20).

<b>Characteristic</b>	<b>%</b>
Gender (Female)	100
<b>Race</b>	
Caucasian	85.7
Hispanic	4.8
Other	4.8
More than one race	4.8
<b>Marital Status</b>	
Married	61.9
Divorced	14.3
Single	14.3
Separated	4.8
Widowed	4.8
<b>Age</b>	
< 40 years of age	4.8
40-49 years	28.6
50-59 years	47.6
> 60 years	19.0
<b>Education Level</b>	
Some College	47.6
Graduated College	38.1
Graduate School	14.3
<b>Area of Residence</b>	
Urban	38.1
Suburban	28.6
Small town	23.8
Rural	9.5
<b>Annual Income</b>	
< \$20,000	4.8
\$20,000 - \$40,000	33.3
\$40,000 - \$60,000	23.8
\$60,000 - \$80,000	19.0
> \$80,000	9.5
No response	9.6

Table 3. Complementary alternatives utilized in addition to MT.

<b>Types</b>	<b>%</b>
Spiritual / Religious	71.4
Vitamins	57.1
Supplements	33.3
Herbs	14.3
Meditation	14.3
Exercise	14.3
Yoga/ Pilates	4.8
Visualization	4.8
Chiropractic manipulation	4.8
Special diets	4.8

*Note:* No participants indicated using homeopathic medicine, traditional Chinese medicine, Reiki therapy, or acupuncture.

When asked their opinion of MT prior to participation in this program, participants expressed a variety of perceptions. Two overarching previous opinions were based on (1) the positive effects of massage, including feeling pampered and being relaxed and (2) negative preconceived ideas that massage was “for the wealthy,” “wasn’t for me,” and “wasn’t used for anything medically”. Although some of the participants previously had encountered negative or painful massages or had negative preconceived ideas related to massage, all were willing to try massage for this study.

**MT enrollment process.** The participants reported learning about the MT study mainly through word-of-mouth from clinic nurses, staff, and other study patients. The enrollment process was described as being “simple,” not requiring extensive permissions or paperwork. Choosing to participate in the focus group usually was based on previous knowledge or perceptions of massage benefits, while others joined because the program was free and they qualified, as well as, they would do “anything to help” and participation “couldn’t hurt”. One woman described her decision as being based on feeling more

normal because the massages are “something open to everybody, anybody can go in and get a massage.” Another survivor reported that she chose to participate in the pilot MT study because of the “powerful incentive to know that I could be a part of something on a global scale every woman or male...could benefit from.”

Comments from participants indicated that nurses were more likely than physicians to discuss MT or other CAM therapies due to the nurses' frequent interaction with the cancer patients. Participants' descriptions of discussions with physicians about CAM and MT were mixed: “[I] made a point of telling him,” and “he said anything that makes you feel good, I am for it”. Some participants were unable or unwilling to discuss their involvement in the MT study with their physicians because of a lack of personal rapport and conflicting information about CAM options. One woman described her hesitation as being related to “this is unfamiliar ground, you don't really know what to say, and I don't want to bother people [with questions].”

Experience with the MT intervention. All focus group participants (100%) rated their experience with MT as “very good” on a 4-point Likert scale. When asked to rate if they would recommend MT to other women undergoing breast cancer, all of the participants indicated they would recommend or highly recommend MT. Participants in every group described a continued interest in learning more about MT and the results of current research.

Participants across the focus groups called for therapy sessions to be longer in length and more frequent. One participant said the half-hour sessions were not “adequate time to really appreciate the massage and what it did for you and how it made you feel. It worked, but an hour, I think, is more beneficial.” All the women (100%) agreed that the sessions should be

one hour in length, but did not agree on the number and frequency of the sessions. When asked, “How often the participants would want to do MT in the future?”, 95% responded that they would want to continue with MT at a frequency of daily (14.3%), weekly (42.9%), monthly (33.3%), and every six months (4.8%). One focus group participant (4.8%) indicated that she would not want to participate in MT again; the participant gave no clarification or further explanation.

Focus group themes. When further probed about the MT intervention, four major themes emerged across the four sessions. Participants commonly described: (1) the perceived physiological and (2) psychological benefits, (3) the ability to be “in control” of part of their treatment, and (4) the nonclinical feel of MT.

Physiological benefits. Throughout the focus groups, the medical benefits of MT were discussed extensively by the participants. Responses centered on the relaxation of the body that resulted in the following benefits: reduced tension in muscles, relieved pain, increased strength and energy, and improved sleeping patterns. The majority of participants (66.7%) credited MT with easing the side effects of their treatment. In general, the opinions of the therapy were directed at a positive healing process with one respondent stating that her “body works better” after MT.

Psychological benefits. The majority of participants discussed how MT benefited them psychologically by reducing stress, clearing their minds, and generating a positive feeling of self and circumstances. One participant stated that MT helped her to persevere through her traditional medical treatments because the therapy allowed the “worry to go out of [her] mind” and another commented that the clinic “is not a place I really want to go again, but I do because the massages are more important than the reason



I was here". Many participants spoke about how MT made them feel respected as a person, with 52.4% reporting the therapeutic touch helped them to reconnect with themselves and 71.4% felt support during the therapy. One woman discussed why she recommends MT to others:

"It does make a difference in your mentality, how you perceive you are still a person, it hasn't taken over everything in your body... you aren't just a statistic, you aren't just another medical patient, you are actually still a person and you have feelings. And it makes you relax and accept the fight that you have to give."

Empowerment. Another benefit of study participation was that the participants were able to "own" their decision to participate. Unlike many other decisions that doctors and specialists recommend after a cancer diagnosis (e.g., radiation, chemotherapy, and medication), MT often was reported as "something I could choose to do" and the information learned during the sessions was "something you can manage within your own control". One participant described her decision as one that "allowed me to do something for myself that I felt good about without someone invading my body with stuff I wasn't sure about. It's real positive...I felt it was caring for myself in a different way." Empowerment gave many of the women a positive event to look forward to and commonly was described as the catalyst for helping a survivor follow through on the difficult traditional medical treatments, as one woman said "it made me feel more determined to fight it".

Nonclinical therapy. Due to the invasive nature of treating breast cancer with radiation and chemotherapy, the women mentioned how quickly a breast cancer patient must lose her modesty. The overall consensus was that with MT, women were not treated as just another patient, but were

"dignified" and "respected". One woman remembered a chemotherapy visit as:

"They put me in there with a man... this is a man that doesn't know me, and here I am... I don't have a breast anymore, but what I have I would like to keep it not exposed... it is kind of undignified...you are all laid up there, they come have a peek... it was not dignified."

MT was classified by many as nonclinical; participants described the touch as concentrating more holistically on the person and not invasively on the disease. Common responses about the kind of touch during MT were, "it wasn't medical, they weren't doing a procedure to you or sticking you or cutting you or hooking you up, so it was different" and "[MT] is a healthy touch, it is a healing touch".

Impact of MT. Participants described MT as a way to help them complete the cancer treatment, indicating it was an important component of their treatment regimen with terms like "one big package," and "just one of the therapies available." Respondents described their continuation of MT as a part of their personal treatment program and several of them recalled experiencing "trauma" at the end of the MT study. One participant said she continued MT after the study ended "to get through the breaking away from the treatment...eased me out of it", while others expressed a need to continue because "it still hurts" and because "chemotherapy has continued".

Most participants indicated a desire to continue with MT after their breast cancer treatment, but some reported that they lacked the financial resources to continue paying for additional sessions. When asked if insurance should cover MT for cancer patients, all participants responded, "Yes!" Participants were adamant in the responses such as, "they give you all kind of drugs for everything...and there has got to be a limit"

and others indicated a strong desire to lobby insurance companies.

### Discussion

There were several limitations to this study as well as areas of opportunity for future research. Although funding was extended to the assessment of MT as a CAM treatment option, it would have been valuable to have a larger number of participants in the pilot study and the focus groups. Also, while the participant characteristics in the study population were variable, the demographics may not generalize. Future studies should focus on recruiting more minority participants to ensure the cultural competency of responses for breast cancer patients. Additionally, future studies could include an assessment of provider perceptions of MT as a variable for patient acceptance. Another area for future research is a similar study that utilizes a control group not participating in CAM or MT to confirm the reliability and validity of the responses. Future studies also should investigate patient issues surrounding personal control, empowerment, and trust with the therapist.

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A qualitative method was chosen to extend the understanding of MT for breast cancer survivors 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 was the clear indication of a need for treatment that allows the patient a sense of “control” and “empowerment”.

### Implications

These focus groups served as a preliminary indicator for the affects of MT on breast cancer patients. While many gaps were identified, an important potential avenue for intervention was indicated. Participants placed trust in the massage therapist who provided massages for this program. By identifying trusted, qualified massage therapists within a local or state-level community, health care providers can ensure that these therapists are a part of the cancer treatment plan.

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**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.<sup>1</sup> 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 life<sup>2</sup>, barriers to exercise<sup>3</sup>, cancer survivorship<sup>4,5</sup>, coping skills<sup>6-8</sup>, massage therapy<sup>9</sup>, and satisfaction with care<sup>10</sup>.

### 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 Arizona<sup>11</sup> 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 Act<sup>12</sup>, 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 City	Johnson County	Parsons
	A	B	A	B			
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](http://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.

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