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Breast Cancer Survivors' Messages

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. 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.

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%. There is a positive correlation between survival of breast cancer and the completion of the full treatment regimen of chemotherapy. 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.1 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 nausea⁶⁻⁸, pain⁷⁻¹⁰, sleep¹¹, anxiety^{9,10,12}, and aspects of quality of life^{10,13,14}. 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. 11 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. 11,15

Focus groups and surveys used to assess breast cancer issues and treatment needs have previously included quality of life¹⁶, barriers to exercise¹⁷, cancer survivorship^{18,19}, coping skills²⁰⁻²², and satisfaction of care²³. A recent analysis found gaps in several key research categories including pathophysiology, detection, treatment, pre-

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

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 ³⁰⁻³³ and decision-making ^{26, 34-37} 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 ³⁸	Manual healing (massage)	16%
Burstein et al., 1999, USA ³⁹	Massage	5.2%
Vandecreek et al., 1999, USA ⁴⁰	Massage	10%
Boon et al., 2000, Canada ⁴¹	Body work used at least once (reiki, massage, therapeutic touch)	14.1%
Gotay and Dumitriu, 2000, USA ⁴²	Massage	20.8%
Lee et al., 2000, USA ⁴³	Physical healing methods (including massage)	14.2% overall (7% blacks, 12% Chinese, 17% Latino, 21% white)
Rees et al., 2000, UK ⁴⁴	Massage	13.9%
Alferi et al., 2001, USA ⁴⁵	Massage/body work	11%
Lengacher et al., 2002, USA ⁴⁶	Massage used at least once	27%
Shen et al., 2002, USA ⁴⁷	Massage	28%
Nagel et al., 2004, Germany ⁴⁸	Massage included as "Other CAM types"	6%
Buettner et al., 2006, USA ⁴⁹	Massage used for any reason (i.e., wellness, bodily pain)	23%
Helyer et al., 2006, Canada ⁵⁰	Massage	26%
Lengacher et al., 2006, USA ⁵¹	Massage (a traditional and ethnic medicine category)	25%
Molassiotis et al., 2006,	Massage	12.7% pre-cancer
European countries ⁵²	-	15% since diagnosis
Boon et al., 2007, Canada ⁵³	Massage	9.8%

Methods

Massage therapy pilot program. Fiftyone 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.⁵⁴ 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 symptomatic or 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 changes and assess 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 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 A final analysis validity of findings. 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%), metastasic 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).

Characteristic	%
Gender (Female)	100
Race	
Caucasian	85.7
Hispanic	4.8
Other	4.8
More than one race	4.8
Marital Status	
Married	61.9
Divorced	14.3
Single	14.3
Separated	4.8
Widowed	4.8
Age	
< 40 years of age	4.8
40-49 years	28.6
50-59 years	47.6
> 60 years	19.0
Education Level	
Some College	47.6
Graduated College	38.1
Graduate School	14.3
Area of Residence	
Urban	38.1
Suburban	28.6
Small town	23.8
Rural	9.5
Annual Income	
< \$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.

Types	%
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 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. enrollment process was described as being "simple," requiring extensive not 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 discussed extensively by 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 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 statelevel community, health care providers can ensure that these therapists are a part of the cancer treatment plan.

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