

The Pink Ribbon

Issue 2 (October 2008)

Status Update: We Have Findings to Report!!!



**By Elise Radina, PhD, CFLE
(Principle Investigator)**

Thank you for taking part in the breast cancer survivorship projects focusing on quality of life and health information use.

These projects began at the University of Northern Iowa (UNI) in 2003. In 2005, I moved to Miami University (Ohio) when I took a new position as assistant professor. Since then, I have been busy training new student research team members, concluding data collection on several of these projects, entering into the realm of data analysis, and beginning new related projects. Before I tell you about these new projects, I would like to update you on what we have accomplished so far.

Since all four research projects were approved to begin enrolling participants in October 2004, we have been able to complete enrollment of participants in four of our studies. This is great news!!! We certainly appreciate the enthusiasm for our studies.

These four studies explored the impact of breast cancer diagnosis on daily functioning within family contexts. Ultimately we hope to use the information we gather to create educational programming that best meets the needs of the various family members.

Descriptions of the data analyses to date for these four studies are described here.

Study 1. Adult Children of Breast Cancer Survivors (2 papers)

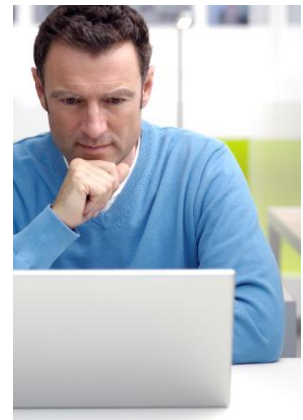
Perceived Changes in Family Quality of Life Following Mothers' Breast Cancer

Authors: M. Elise Radina, Katie A. Kuker, Jennifer L. Koenig, Jill McDonald, and Kathy Mujumdar

This study explores perceptions of changes in family quality of life among 18 adult children of breast cancer survivors who took part in in-depth interviews. The conceptualization of family quality of life focused on the following as they relate to participants' families of origin (i.e., themselves, their siblings, and their parents): areas of strength and challenge for families, the support the family and its members receive from others, the concerns of women, the health of family members, the experiences of siblings, the responsibilities taken on by family members, and concerns about the future. Findings indicated largely positive perceived changes in family of origin quality of life.

Adult Children of Breast Cancer Survivors: Encounters with Breast Cancer-related Information

Authors: M. Elise Radina, Kathy Mujumdar, Jill McDonald, Daniel R. Longo, and Jane M. Armer



Eighteen adult children participated in interviews about their encounters with health

information regarding their mothers' breast cancer. Findings indicated overwhelmingly that participants used the Internet to gather needed information. Their information seeking appeared to serve three purposes: 1) to expand and validate medical information provided by the physician regarding the mother's breast cancer diagnosis, treatment, and prognosis; 2) to provide themselves with comfort and reassurance by finding additional information on treatment options, prognosis, and survival; and 3) to provide their mothers and other family members with the information they needed to make informed decisions and be comforted and reassured themselves. Despite the central role of the Internet as an information source, participants noted that information found on the Internet was not always of high quality and therefore should be used with caution. We suggest that these findings should be used to develop health-based, and likely Internet-based, family life education programming geared toward the specific content of the information adult children of breast cancer patients need as well as the way they use the use Internet based information.

Study 2. Post-Breast Cancer Lymphedema (2 papers)

Breast Cancer-related Lymphoedema and Sexual Relationships in Mid and Later Life *(Journal of Lymphoedema)*

Authors: M. Elise Radina, Wendy, K. Watson, and Kandice Faubert

Women with breast cancer-related lymphoedema (LE) can experience physical, psychological, and sexual problems as a result of both physical limitations and appearance associated with this condition. One area in need of further investigation with regard to quality of life is the sexual relationships with intimate partners for women with LE. Participants were 11 women with LE. In-depth interviews were used to elicit participants' descriptions of quality of life with breast cancer-related LE, and in what ways breast cancer-related LE has

impacted their sexual relationships. Two predominant themes among the participants' responses were found: *Not Feeling Sexy Anymore* and *Changes in Intimate Relationships*. These findings show that breast cancer-related LE has an important and often negative influence on women's experiences of sexuality and intimacy. We recommend that family life educators and health care professional should use these findings to assist women with breast cancer-related LE in their intimate relationships following diagnosis.

Responding to limitations on family leisure participation: Breast cancer-related lymphedema *(Family Relations)*

Author: M. Elise Radina

Physical appearance and limitations created by post-breast cancer lymphedema (LE) affect quality of life in terms of social relationships. This study explored the impact on family relationships and functioning related to family leisure activities in the context of LE. The 27 participants ranged in age from 40-78 years (average=59.5 years). On average, participants were 5.7 years past their breast cancer diagnosis and 4 years past their diagnosis of LE. In-depth interviews were conducted with each participant. Findings highlighted participants' sense of cautiousness with leisure activities. They coped with this by either: a) stopping their participation in family leisure activities that might be dangerous or difficult for them, or b) making modifications in participation in order to continue their leisure time with their families.



Stopping participation meant missed opportunities for social interaction. These findings show that women with LE experience changes in familial relationships due to decreased ability to participate in family leisure. We offer specific suggestions for how family life educators and health care professionals can use these findings to assist women and their families in modifying leisure activities and/or exploring new activities to continue participation in family leisure.

Study 3. Breast Cancer Survivors (1 presentation)

Reliance on Medical Practitioners during Breast Cancer Treatment and Survivorship: Emotional versus Informational Support

Location: The 12th Annual College of Social and Behavioral Sciences Student Research Conference. Cedar Falls, IA.

Authors: Jennifer Koenig, Katie Kuker, Misty Erdahl, Stacie O'Connor, and M. Elise Radina

This study focused on the extent to which breast cancer survivors relied on medical personnel to provide them with support during and after their breast cancer diagnosis. Data included interviews with 13 participants regarding their degree of reliance on health practitioners, nurses, health care organizations, doctors, and oncologists during their treatment, diagnosis, and recovery for support and information. Findings included: 1) trust and reliance primarily on medical practitioners for information on diagnosis, treatment, and condition; 2) reliance on sources other than doctors, nurses, and oncologists for issues such as support and emotional well-being; 3) negative experiences with health practitioners that led to search for other sources of support and information; and 4) expressed need to share stories about experiences and personal health information with others. We suggest that these findings will help further researchers understand the different types of information seeking strategies, as well as the information needs of breast cancer patients and survivors.

Study 4. Partners/Spouses of Breast Cancer Survivors (1 presentation)

Partners of Breast Cancer Survivors: Social Support Needs and Resources

Location: The 12th Annual College of Social and Behavioral Sciences Student Research Conference. Cedar Falls, IA.

Authors: Katie Kuker, Misty Erdahl, Jennifer Koenig, Stacie O'Connor, and M. E. Radina

This study explored the experiences of long-term partners and spouses of breast cancer survivors. Previous research suggests that, for partners, the role of social support from sources other than the survivor herself is very important throughout the breast cancer experience. Specifically, the opportunity for partners to experience emotional closeness and discuss feelings with others is associated with a higher level of emotional adjustment following their partners'/wives' diagnosis and treatment. This support tends to also be linked to fewer health problems and physical symptoms that produce improved overall well-being. The present study is based on four case studies. The following sources of social support for partners were identified 1) patients/survivors, 2) parents/family of origin, 3) co-workers, and 4) adult children. Collectively these four cases contribute to our understanding of the sources of social support upon which partners may rely. This information can be used to create appropriate support systems consisting of patients/survivors, parents/family of origin, co-workers, and adult children to better fulfill the emotional and informational needs of the partner during this difficult time.

Thank you all for your participation in these studies and the referrals you have given us. We have heard numerous wonderful stories and we are looking forward to hearing more! So, keep reading to learn about our new studies and ways that you can help out.

More Participants Needed!!!!

New Study #1: Mothers of Daughters with Breast Cancer

This new project investigates perceived changes in family quality of life among mothers of breast cancer patients. Based on what I have learned in the previous four studies, I have designed this new study to explore the perspectives of mothers of breast cancer survivors. This study furthers the current line of research by providing an innovative multigenerational focus and thus acknowledging the complex constellation of family members who are likely to be affected by breast cancer and affording insight into the potentially unique perspective on breast cancer diagnosis among mothers of survivors. We are looking for participants whose daughters have been diagnosed with breast cancer and are now living as survivors. Just like the other studies, the interviews can be conducted over the phone or in-person. Unfortunately, due to funding restrictions, face-to-face interviews are limited to those who live in or near the Greater Cincinnati area. Interviews are either conducted by myself or trained, female, student research assistants. So far we have interviewed 10 moms. These interviews have been wonderfully helpful. We look forward to talking to as many as 20 more moms over the next year. Please contact me at radiname@muohio.edu or 513-529-3639 if you would like more information or are interested in participating. Also, please pass this newsletter on to someone who might be interested.

New Study #2: Lesbian Breast Cancer Survivors and Their Partners

This new project explores the experiences of lesbian breast cancer survivors and their partners with specific emphasis on experiences of interaction with health care providers, family/relationship quality of life, use of health information, methods of coping, and participation in decision making. In addition, for those breast cancer survivors who are now experiencing post-breast cancer lymphedema (the swelling in the arm, neck, or chest that can sometimes occur following breast cancer treatment), this study seeks understanding regarding the impact of this chronic illness on lesbian partners' well-being and perceived family/relationship quality of life. This project is a pilot study that will provide support for an external grant application, which will fund a full scale study (40+ participants). We are looking for at least 5 lesbian breast cancer survivors and 5 partners of lesbian breast cancer survivors, who may participate either as individuals or as couples. . Just like the other studies, the interviews can be conducted over the phone or in-person. Unfortunately, due to funding restrictions, face-to-face interviews are limited to those who live in or near the Greater Cincinnati area. Interviews are either conducted by myself, my colleague Dr. Kate Kovalanka, or trained, female, student research assistants. We will begin recruiting for this study in early 2009. If you would like more information or are interested in participating, please contact me at radiname@muohio.edu or 513-529-3639. Also, please pass this newsletter on to someone who might be interested.

Meet the Research Team Members

Dr. Elise Radina, CFLE is an Assistant Professor of Family Studies in the Department of Family Studies and Social Work at Miami University (Oxford, Ohio). Dr. Radina began her work on studying breast cancer survivorship within family and relationship contexts in 1999. She has published seven articles on her research and has made numerous presentations at national and international meetings. Each year, Dr. Radina chooses outstanding students to help in conducting this research. Below is an introduction to the members of this year's research team:

Amanda Ginter is a first-year master's student in Family and Child Studies. Amanda says, "I hope to one day work for a non-profit organization assisting lower income families. I'm so excited to be working with the breast cancer research team! The thing I like best is connecting with women on the team who share my same interests and passions."

Adrienne Cox is a senior Psychology major who is earning minors in Child Studies and Black World Studies. After graduation, Adrienne is planning to attend graduate school to become a school psychologist. About her work with the research team, she says, "I enjoy being a part of the team and learning about all the stories and experiences that the participants have had and knowing that what we put together could serve as a resource for them and others."

Brandi McLeish is a senior Family Studies major who is earning a minor in Child Studies. After graduation, Brandi would like to work for a non-profit. About her work with the research team she says, "I love being right in the thick of the research. It makes me feel like I can help to make a difference."

Carrie Zinck is a junior Family Studies major. She plans to continue her education after graduation, and hopes to become a school guidance counselor for high school students. Carrie says that her favorite part of this research team is being able to talk personally with the mothers of survivors.

Carlyn Richardson is a first-year master's student in Family and Child Studies. Her long term goal is to create culturally-based intervention programs and support networks for women with chronic illnesses and to bridge the health disparity gap among women and minorities. She says, "What I like most about this research is actually speaking to mothers and knowing that we are touching lives by hearing their needs."

Joy Miller is a junior majoring in Spanish and Social Work. Joy plans to be a clinical social worker in urban settings working with youth in bilingual communities. She says, "My favorite part of this research team is learning about individual lives that bring our study to life. Each person has their own unique history that deserves to be heard and it makes the time commitment worthwhile."

Kathleen Farrell is a senior Psychology major who is earning a minor in Women's Studies. After graduation, Kathleen is planning to attend graduate school to become a clinical psychologist. About her work with the research team she says, "I like getting to meet new people and hear different perspectives about the various topics. I think it helps me to keep an open mind, and appreciate other people's experiences."

News You Can Use: Breast Cancer Information

Check out these websites about breast cancer and breast cancer-related lymphedema:

- Susan G. Komen for the Cure, Greater Cincinnati Affiliate
 - www.komencincinnati.org
- The Breast Cancer Alliance of Greater Cincinnati
 - www.bcacincy.org
- University of Cincinnati College of Medicine, Breast Cancer Registry of Greater Cincinnati
 - www.eh.uc.edu/breastcancerregistry
- National Lymphedema Network
 - www.lymphnet.org
- Pink Ribbon Girls
 - www.pinkribbongirls.org
- Iowa Breast Cancer Edu-Action
 - www.iowabreastcancer.org
- Mothers Supporting Daughters with Breast Cancer
 - www.mothersdaughters.org
- Avon Crusade
 - www.avoncompany.com/women/avoncrusade
- 24 Hours of Booty
 - www.24hoursofbooty.org

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