

Social support has long been recognized as an important component of physical and emotional health. Countless positive health outcomes from weight loss (Kubota, Nagata, Sugiyama et al., 2008) to better coping with drug addiction (Yan, Liu, Zeng, et al., 2008) have been associated with having strong social support networks. In terms of cancer, individuals that perceive high social support and positive coping strategies feel better adjusted to their cancer when compared to those with perceptions of low social support and negative coping strategies (Söllner, Zschocke, Zingg-Schir, et al., 1999). In this article, we look at one instance of social support in terms of health – the role of families in the social support networks of younger women (18 - 40) with breast cancer. Although breast cancer more typically affects women who are older, there has been greater awareness to younger women facing the disease in recent years. Younger women facing breast cancer are doing so during a time in their lives when most adults finish their education, decide on a career path, establish lifelong romantic partnerships, and become parents. Family networks and resources are an important way younger women with cancer deal with their diagnosis, cope with cancer treatment, and prepare for a life after cancer.

In this article, we explore how forty younger women with breast cancer draw on social support from their families. By using in-depth interviews, we focus on the lived experience of family social support from the perspectives of the women themselves. In their narratives, women describe many important forms of family social support including emotional, tangible, informational, and, what we term, experiential. We also find that while family support is a vital resource these women rely on as they cope with a potentially life threatening and a life altering condition, family relationships and support can also be sources of tension and stress as well.

### **Younger Women with Breast Cancer**

Breast cancer is the most common cancer to affect women over their lifetime; women have a 1 in 8 risk of developing breast cancer (NCI, 2006). Although the likelihood of a woman developing breast cancer increases greatly as a woman ages, approximately 1 out of 3 women are premenopausal when they are diagnosed (Jemal, Thomas, Murray et al., 2003). More than 11,000 women under 40 years of age will be diagnosed this year alone and 1 out of every 229 women between the ages 30 and 39 will be diagnosed within the next 10 years (Young Survivor's Coalition, 2007).

## Theoretical Background

Social relationships and support play a crucial role in the experiences of those with breast cancer; support from intimate others and friends reinforces one's acceptance of a changed body, encourages a peaceful relation with one's self, and helps (re)create a unified mind and body (Ucok, 2005). Social support and social networks have also been found to be related to favorable health outcomes in those with breast cancer including reduced mortality (Kroenke, Kubzansky, Schernhammer et al., 2006; Reynolds, Boyd, Blacklow, et al., 1994). Furthermore, breast cancer patients often feel an eagerness to discuss their experiences in the hopes of seeking meaning from breast cancer as a life-threatening illness, as concerns of life and death, purpose, and future plans seem ever present as a part of their post-treatment anxiety (Ferrell, 1998).

Although some research has examined the importance of social support in the lives of cancer patients, most research in this area tends to be quantitative analyses, which tend to overshadow important aspects of the experiences of those facing cancer (For exceptions, see Chantler et al., 2005; Vickberg, 2003). For example, Sammarco (2001) finds that for younger women with breast cancer, perceived social support is associated with increased quality of life, particularly in their socioeconomic, familial, and psychological/spiritual areas of life. Such quantitative approaches effectively establish links between social support and a particular outcome (e.g., quality of life), but these studies can overlook the voices of women themselves and the nuances in how they perceive and draw on family support as they cope with breast cancer. In drawing on in-depth interviews, we consider how women themselves define their family and the creative ways that family resources and support networks are invoked as they cope with breast cancer diagnosis and treatment.

A key component of a social support system is the network of relationships within the support system (Bloom, Stewart, Johnston et al., 2001). Since family is so central to the women's narratives in our study, we focus primarily on family networks of social support. In addition to relational ties, a social support system has functional aspects as well. In terms of cancer, researchers have looked at three primary functional forms of social support: tangible, informational, and emotional (Bloom, Stewart, Johnston, et al. 2001; Chantler, Podbilewicz-Schuller & Mortimer, 2005). Tangible (or instrumental) support "refers to specific resources that others may provide the individual, such as a loan of money, a ride to a medical community or child care" (Bloom, Stewart,

Johnston et al., 2001: 1514). In a study of younger women with breast cancer, Chantler, Podbilewicz-Schuller, and Mortimer (2005) found that tangible supports provided a way for those going through cancer to feel more in control of their treatment, relieved anxiety, and made them feel more informed about their disease. Informational support refers to “the provision of knowledge relevant to the particular situation that individual is experiencing” (Bloom, Stewart, Johnston et al. 2001: 1514), such as a husband looking up information regarding a particular treatment on the Internet for his wife. Chantler, Podbilewicz-Schuller and Mortimer (2005) found that informational support from their physicians relieved stress for those going through breast cancer and assured patients that their life was in “good hands.” Emotional support could be thought of as support that makes the individual feel better, more secure, or better understood (Chantler, Podbilewicz-Schuller & Mortimer, 2005).

We build on this research area that has looked at social support and health outcomes by drawing on in-depth interview data to understand how women in our study experience family social support. We also find that multiple and distinct, though interrelated, forms of social support exist: tangible, informational, and emotional. This typology of social support forms commonly referred to in research on social support and health is not meant to be exhaustive, but other possible forms of social support are often not explored. In our grounded theory approach (see Methods), we find an additional arena of social support present in many of these women’s lives – experiential support. In brief, experiential support arises from a connection with a person who has experienced a similar health trauma.

Despite the clear importance of family support, we also find that one’s family can also be a source of strain. As the women in our study discussed their family support networks, many also mentioned moments of tension as a result of their family relationships or attempts by family members to be supportive. Although the focus in much research on cancer has looked at how social support (or lack thereof) can be related to a particular health outcome, researchers have begun to consider how intimate relationships can be a source of tension as well (e.g., Manne, Ostroff, & Sherman, 2003; Vickberg, 2003). For example, Chantler, Podbilewicz-Schuller and Mortimer (2005) conclude that family and friends can be agents of stress, particularly to women 6-12 month post-therapy, as family members’ fears of a patient’s breast cancer returning often evoke fears within the cancer patient of subjecting the family to further trauma. Many patients in this study also felt that their partners/spouses treated

them as if they were fragile or dying by avoiding or having awkward emotional interactions.

## **Methods**

### **Sample Recruitment**

This data is part of a larger project looking at the psychosocial impact of cancer on younger women's fertility and family goals. The primary data for this article comes from in-depth interviews with 39 women who were diagnosed with breast cancer under 40<sup>1</sup> years of age. The women were solicited through advertisements distributed by breast cancer advocacy, charitable, and support group organizations. Organizations that agreed to help recruit included an advertisement in their newsletter or sent the ad electronically through an email newsletter or list serve. Postings were also put on message boards aimed on several of these organizations' websites.<sup>2</sup>

### **Sample Characteristics**

Table 1 shows the breakdown of key characteristics of the sample. At the time of their interviews, the age range of the sample was from 27 to 44 years of age with a mean age of 35.3 years. Also, 80% of the sample were diagnosed within the past 3 years, several of whom being initially diagnosed within months of the study. Many of the women were still actively receiving treatments such as chemotherapy and radiation at the time of their interview and all of the women were still within the 5-year recurrence window with most still receiving follow-up care. Additionally, 62.5% of the women are currently married/partnered and 10% are engaged to be married. Further, 40% of the sample has children. Aside from one woman with a stepchild and another woman with an adult foster child with whom she maintains a close, parental-style relationship, the women in this study have biological children and most of the children are under 10 years of age.

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<sup>1</sup> The operationalization of "young" or "younger" varies greatly in research on women with breast cancer. Some studies have age ranges up to 50 or 51 years of age (see Bloom, Stewart, Johnston et al. 2001; Sammarco, 2001). We chose the age range of 18-40 because this study is part of a larger research agenda on the impact of cancer on fertility, family goals, and relationships. Although some do become parents (either with biological children or through other means) after 40, most adults become first time parents by 40 (Child Trends, 2002); and between ages 18 and 40 is when most adults form long-term partnerships and marry (U.S. Census, 2005).

<sup>2</sup> We were initially concerned that the resulting sample would be much more politicized than younger women with breast cancer in general or would only include women who utilize support networks through advocacy organizations as their primary means of social and emotional support. To explore this possibility, we specifically asked women about the level of their participation in breast cancer advocacy and support groups and organizations. We found that few women in our sample could be classified as highly involved in such networks or groups. Since being involved in the cyber community regarding breast cancer (such as joining an email list from an advocacy group or occasionally checking a message board) involves minimal, if any, commitment, we do not think the sample over represents those who are very immersed in the breast cancer community. Also, in some cases, the respondent had no involvement in the advocacy organization, but rather a friend or family member forwarded the advertisement onto them.

**[Table 1 about here.]**

As shown in Table 1, the resulting is also highly educated (87.5% having at least a college degree), mostly Caucasian, non-Hispanic (82.5%), and most have professional or white-collar jobs (including several teachers, doctors, and engineers). All but one respondent has health insurance, almost all having private health insurance through their employers, with most of those insured describing their coverage as extensive.

As described above our main recruitment tool was the Internet. Those who have home Internet access may be of higher socioeconomic status in general and those who access the Internet through their jobs may be more likely to have white-collar and professional jobs. Our resulting middle to upper-middle class sample supports research on the “digital divide” that has found lower income and racial/ethnic minority groups may have less access to such electronic resources and when they do have access may use the internet and related resources in a different way (such as for entertainment rather than information gathering or social support) (For further discussion see Author 2007b; Gibbons, 2005; Kreps, 2006; Neuhauser & Kreps, 2003).

**Interview Procedures**

In-depth phone interviews were conducted with respondents. Prior to the interview, respondents were read a statement of informed consent before agreeing to participate in the study using an IRB approved protocol. Interview questions were open-ended and included topics regarding initial diagnosis, family background, treatment concerns, and family interactions during that time period. The interview schedule remained flexible – meaning that women’s narratives drove the interviewing process to accommodate their unique experiences and perspectives. Most interviews lasted approximately 60 minutes.

**Analysis and Coding**

We took a grounded theory approach to the data. Although we did find support for the various forms of social support that have been documented in other research on breast cancer (such as tangible support), we did not go into the data analysis with preconceived notions or seeking to document that certain forms of social support do or do not exist. Rather, we allowed the themes discussed below to emerge from the women’s narratives themselves.

Interviews were fully transcribed and analyzed in the qualitative analysis program HyperResearch.

Interviews were initially coded with very general open codes indicating family support and definitions of family (meaning who does the respondent feel is part of their family). After establishing that family was central to their support networks and that there was variation in how women experienced their families during this time, more detailed, or axial codes, were developed to identify the breadth and diversity of how family is used (e.g., tangible support acts, unsupportive family moments, family history of breast cancer etc.).

Our intent is not to have a nationally representative sample of younger women with breast cancer. Rather, we look at a narrow range of women experiencing breast cancer with similar demographic characteristics to explore their experiences in regards to family and breast cancer. Thus, in some sense we “control” for other sources of possible variation in their experiences – primarily race/ethnicity and socioeconomic status. Although there is diversity in how the women in our study draw on and use family resources, our sample size did allow us to reach “conceptual saturation” (Strauss & Corbin, 1998.)

### **Findings – How Women with Breast Cancer Experience their Family Support**

Our sample provides an interesting place from which to look more broadly at how family support and resources fits into one’s diagnosis, treatment, and recovery from a major – and potentially life threatening – health crisis. Family social support was central to all of these women’s narratives about their breast cancer experiences. Moreover, support resources outside of family and friends may be more limited for these younger women facing breast cancer. Those with a history breast cancer are some of the most vocal and involved in terms of advocacy, but arenas for formalized support (e.g., specialized advocacy organizations and support groups) for younger women may be less developed than they are for older women. Younger women have unique concerns related to their age and life stage (like potentially fertility damaging cancer treatments, see Author, 2007a) and often face very different prognosis than older women because of the different effects breast cancer may have with age (de la Rochefordiere, 1993).<sup>3</sup>

Although advocacy and support groups have called greater attention to the unique issues (such as fertility impairment) that affect younger women in recent years, such support resources for younger women are still more limited. Many women in our study felt that support groups were not very helpful because often the other

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<sup>3</sup> Some research even suggests that those under 45 develop more aggressive forms of breast cancer, respond less well to treatment, and have higher rates of recurrence than their older counterparts (*Science Daily*, 2008).

members were considerably older. For example, Allison, a 28-year-old married project associate with one child, feels isolated in her support group because most of the members are older with different concerns and experiences:

*Allison: I recently have started going to support groups, probably about a month ago. . . I don't really feel comfortable with them because they're all 50 and 60 year-old women. They're not exactly in my time. They don't have children who are young, they're not my age. They don't have the same things. They're treatment was different than mine was because they were diagnosed 10-15 years ago. Things like that. So I don't lean on them as much as I would if they were my own age.*

Understanding how family support networks work for most people facing a chronic or life-threatening health issue is important, but for younger women with breast cancer these familial forms of support may take on even an enhanced significance.

### **Who is your family?**

We employ a very loose definition of family in this research. Respondents were asked about how specific groups (namely partner, parents, and children) were part of their experiences, but most questions spoke in terms of family generally, allowing the women to create a definition of who is, in fact, their family. While this sample is very similar in terms of race/ethnicity and socioeconomic background, two distinct definitions of family arose as age and relationship status varied. For those who were younger and/or not in committed partner relationships, family most commonly meant parents and to a somewhat less extent, siblings. Kari Anne, a 33-year-old marketing specialist diagnosed a year and a half ago, is single with no children. She defines her family support network in terms of parents and siblings:

*Interviewer: So who would did you turn to for support during your diagnosis?*

*Kari Anne: My friends and my family.*

*Interviewer: Which family members exactly?*

*Kari Anne: My parents and my siblings.*

Married or partnered women were more likely to exclusively mention their partner as their primary support network. Cora, a 31-year-old married television writer, was diagnosed two years ago. Although she mentions other family members, it is her husband that she sees as her primary family support system:

*Interviewer: So who would did you turn to for support during your diagnosis?*

*Cora: My husband, my close friends, my family . . . . my husband was the number one go to person.*

Parents, partners, and to a lesser extent, siblings were mentioned as those who provided the most support, but other extended family members were at times included as well such as grandparents and aunts. Other sources of support, including support groups, co-workers and friends, were cited as well as important instruments for coping with their breast cancer, but the women in our study most often discussed their “family” as their most central support system.

### **Forms of Family Social Support**

#### **Family as Emotional Support**

One key variant of family social support is emotional. Emotional support is “the perceived availability of thoughtful, caring individuals to whom one can share one’s innermost thoughts and feelings” (Bloom, Stewart, Johnston, et al. 2001: 1516) and/or that one is valued and loved (1514). In respondents’ narratives, this idea of being cared for came through in two main elements: (1) being able to talk to someone, and (2) someone physically “being there.”

Not surprisingly, being able to talk to someone about their concerns, fears, and even treatment options was very important and perhaps the most common way in which emotional support was described. Donalyn, a 34-year-old diagnosed over four years ago, described her husband as being the person that she was able to talk to about everything that was going on, “*Interviewer: And what did you discuss with your husband? Donalyn: Just my pains, my fears, would my cancer come back, would I ever get my period back.*” Dorothy, a 33-year-old married teacher with two children, discussed with her husband her fears regarding her health and their future, “*I discussed our future, my concerns that I might die from this, about raising our children, him raising our children alone, how we were going to get through this. . . .*”

In addition to discussing their apprehensions and hopes, the idea of having family members around – physically present – was important emotional support as well. Kari Anne turned to her parents when she needed to talk, but her siblings provided emotional support in a different way – by being physically present to just “*hang out*” during her treatments:

***Kari Anne: I guess, you know, with my parents, I discussed treatment decisions or more, you know, talked to them about it. . . . My siblings, I think it was more just about the emotional support, something to hang out with. . . . It wasn’t really about talking about anything or more just like being together.***



Having family members being physically present allowed respondents to feel they were not going through the experience alone and that people in their lives were committed to seeing them through this healthcare crisis.

Rhonda, a 38-year-old currently single scientist, believed that her former partner, Selma, was fully committed to her as she went through treatment because Selma was physically present at her sessions:

***Rhonda: To my partner, to my friends, to my family. I had a really big, strong, wonderful support group – support network that I turned to. . . My partner, at the time, came to all of my treatments and was there for all my doctor’s appointments and helped me through everything. That was a really great support.***

For Jasmine, a 33-year-old physician in a long-term relationship, the physical presence of her parents and siblings was an indicator that she felt she had their emotional support:

***Jasmine: What issues did I discuss with my parents? My treatment options, where I would move to during my treatments. When I was initially diagnosed I was in this really dark, dank, moldy apartment and we didn’t think it was a good idea for me to stay there during the therapy. So we talked about where I should live. Things like that. I think a lot of the support that I got from them was during my surgery, during my chemotherapy when they were physically there just helping take care of me. And my brother too.***

### **Family as Tangible Support**

Jasmine took comfort in having family (and some friends) be there for all of her appointments. In fact, as she became more comfortable with her chemo sessions, she felt she needed fewer people coming along.

Jasmine’s experiences also underscore the idea that support can mean more than emotional comfort and feelings of security. Respondents relied heavily on tangible shows of support from family members such as cleaning, being driven to and from appointments, or bringing over food while they were going through their treatment. For Jasmine, having a family member there during chemo was not only emotionally supportive, but also represented how family members provided needed tangible assistance including physically taking care of her during chemo and helping her work through practical issues like where she should live during her treatment. Similarly, Jenna, a 32-year-old single mom with one child who is soon to be married again, relied heavily on the day-to-day help from her mother as she coped with her diagnosis and treatment:

***Interviewer: And what did you discuss with your mother during your diagnosis?***

***Jenna: Just about taking care of my son and who was going to help me with that and what kind of arrangements I needed to make for him. Also, day-to-day living. They helped me out with my finances a great deal.***

Another vital type of tangible support many women mentioned was having family members being a

second set of “ears” at medical appointments to make sure that all of the information about treatment options, diagnosis, prognosis etc. would be remembered. As expressed by Jocelyn, a 39-year-old married accountant, a second set of ears was vital because she believed, like other women in the study, that her ability to take in information had been impaired:

**Jocelyn:** *If it was just like a checkup, I would have always one to go with me just – whether it was because I couldn’t drive, I would just get too nauseous and they would put me – all those kind of medications made me la-la-la. So partly because I couldn’t drive and I wanted always somebody to be there to have an extra set of ears. Or maybe the doctor would ask me something and I would forget about and they would go, “Wait a minute. What about this?” So I liked having another person being there. If it was something about like results of tests or anything like that, I always had my husband and another friend. My husband and I there to listen and my friend to take notes.*

Similarly for Carrie, a 40-year-old African American teacher, her mother and husband were supportive in part by being the ones who were essentially listening to all of the information from her healthcare team.

**Carrie:** *My husband went to every single appointment and my mother went to about half.*

**Interviewer:** *Why did you have them come?*

**Carrie:** *I needed them there for support, to hear what the doctors were saying because, at first, I was so emotional, I’m not so sure I was even listening. So I needed them to at least be supportive and get the information that I might miss.*

This listening role of family members that respondents relied on was by no means a passive role. Women relied on their family members to be their advocates as well. Research on cancer more generally has found that, particularly when the patient is a child, family members can serve as advocates for those going through cancer. Women in our study described family members taking on this advocate role by asking questions, speaking up to doctors, and making sure that they were getting the best treatment possible. Donalyn, mentioned above, relied on her brother and husband to be good listeners, but also to take on an active role by asking questions:

**Donalyn:** *I know that my first visit with my surgical oncologist, my husband and my brother both went, and we were there for probably an hour and a half and they both came with a whole bunch of questions . . .*

Megan, a 38-year-old unemployed teacher, had her husband with her for medical appointments in part because she was too emotionally upset to take in everything, but also because what was happening with her cancer impacted their life together:

**Interviewer:** *Did anyone go with you to doctor’s appointments or treatment?*

**Megan:** *My husband.*

**Interviewer:** *And why was that?*

**Megan:** *Because it’s a big decision for both of us. It affects us both. And also to make sure that we were getting all the information. As the one who was directly affected, sometimes I get upset or I can’t hear*

***everything that they're saying. I just tune out at a certain point. And also to have somebody who could also be aggressive.***

But Megan also knew how important it was to have someone with her who could be “***aggressive***” because her own sister and mother had both survived breast cancer. She saw first hand how important pushy family members could be in ensuring getting the best treatment available. Her husband was able to also to take on this aggressive role for her:

***Megan: After working with my sister and her cancer, found that usually, for her, she was always really trying to please her doctors and stuff so needed a third party like me or my other sister, she was not married, to make sure that we're asking all the questions and we're kind of pushing. Because we found that she didn't really want to [ask questions] and it was easier to have another person. So, my husband kind of supported that role. So when there was a question I didn't want to ask, or I was afraid to ask, then he would go ahead and make sure it got asked and something would follow through, and he also took notes.***

### **Family as Informational & Experiential Support**

Informational support refers to others being able to provide needed facts and information in the health care process (e.g., the contact information for an oncologist). For the women in our study, family members often looked up information on the Internet, came prepared with questions to medical appointments, and Megan even consulted with her sister's oncologist in another state. But Megan's experiences bring up a unique way that the younger women with cancer in this study were able to draw on family resources— the experience and insights of family members who have gone through breast cancer themselves. Although most cases of breast cancer do not have hereditary links, many families have faced a breast cancer diagnosis because women, in general, have a 1 in 8 risk of developing breast cancer in their lifetime (NCI, 2006).

For several women in this study, experiential support from a family member with a history of breast cancer was central to their narratives in how they coped with their own cancer. Megan described herself as being “***really involved***” in her sister's cancer and knew in part what to expect when she was diagnosed. Ellen, a 26-year-old researcher, has been diagnosed with breast cancer twice, both at 23 and 25. At the time of her diagnosis, she considered her mother and sister as her main support network, but Ellen feels she leaned more on her mother, Pamela, because like herself, Pamela was also diagnosed when she was a mother with young children:

***Ellen: Well, my mom more than my sister because my mom is a breast cancer survivor. . . I would kind of bouncing ideas off of her head about whether do you really think it's safe if I don't do chemo. It was less, you know, more about asking her advice and kind of hearing myself talk and wanting to get her opinion on things. At the end of the day, I listened to my doctors, but the emotional thing, I***

*talk to her . . .*

As a young single mother who is getting remarried soon, Ellen also drew on her experiences as a child watching Pamela go through cancer as she cares for her own daughter. Ellen recalls not being ***“told [about the cancer] and having lots of questions and being very scared and being very confused as a child.”*** To ensure that her daughter did not experience the same confusion and fear based on her own childhood experiences, Ellen made sure to let her young daughter know what was going on, ***“And I said, ‘There were these things growing in mommy’s breast and they were bad and they were going to take them out and they were going to put me in a machine and they were going to make sure that they didn’t grow back.’”*** Ellen also brought her daughter along on some appointments so her daughter would have a sense of what was going on with her treatment.

Kayla, a married housewife with two stepchildren, leaned on her grandmother more than other female relatives because her grandmother had gone through breast cancer herself, ***“My grandmother was actually diagnosed with it so her and I discussed what she went through emotionally and physically. And she I guess basically warned me or forewarned me what I would possibly go through although bodies are different.”***

However, even when family members themselves have had breast cancer, experiential support was not guaranteed. Some women in the study had mothers or other female relatives who were diagnosed with breast cancer much later in life. Like many of their views of more formalized support groups, respondents did not necessarily feel comforted by their mother’s experiences and insights which were seen as very different or even outdated from what they were experiencing. Jessica, a 37-year-old married professor and mother of two, felt greater emotional support from a friend about her own age, also with children and a similar type of breast cancer even though her mother is also a breast cancer survivor.

***Jessica: [M]y mother came to Texas, although she was sort of less emotional support then actual, you know, she came and helped with my four-year-old. I also have a very close friend in town who was a year younger than me with metastatic breast cancer and two small children. So, you know, she was obviously somebody I knew already and had watched go through chemo and everything.***

Jessica’s mother was diagnosed post-menopause and did not have to go through radiation or chemotherapy both of which can impair fertility, something that Jessica is very concerned about.

This type of experiential support was found for a few respondents in more traditional support group settings. Most women in the study did not turn to support groups, and those who did often felt little in common

with the other members because of age differences as expressed by Allison above. Those who were more satisfied with their support group experience were those who found organizations that specifically catered to younger women with breast cancer. Dorothy, a 33-year-old married mother of two, was diagnosed with breast cancer two years ago when she was pregnant with her second child. Part of her support network included a “mentor” from an advocacy group that pairs up women with cancer with someone who has been through a similar experience. Dorothy’s mentor herself had also had breast cancer while pregnant. Dorothy expressed turning to her mentor even more often than her husband, whom Donna describes as supportive as well; in part because her mentor shared insights into what it is like to have breast cancer while pregnant:

***Interviewer: So who would did you turn to for support during your diagnosis?***

***Dorothy: My mentor. My mentor. And my husband. I talked to him, but mostly my mentor. I talked about everything with her. Any concern I had, questions, you know, I grilled her about her story and what happened with her and how her children are doing.***

Marianne, a married 35-year-old yoga instructor and mother of two, described her husband as her main support system: “***My husband kind of does everything with me. He’s my big support.***” But, like Dorothy, it was her mentor who could really understand what she was going through and could provide assurance by example that everything would be okay:

***Marianne: The “Moms with Cancer” [name of organization changed] mentor was a big help to me because it was just nice to have somebody say, “Yeah, I went through chemo when I was pregnant and my baby is fine.” . . . I was really looking for like peer age group, and not even that, but just a young mother’s, I was really looking for that. . . .***

Experiential support does not replace other forms of support, but rather supplements others forms of social support that respondents take comfort in from their families. For some, experiential support came from a family member and for others a friend or mentor was able to provide a type of support not present in their family.

### **Family as a Source of Tension**

While all of the women spoke of their families providing support – emotional, tangible, informational and/or experiential, there were also sources of tension and concern that are important to highlight because it shows the complexity of family relationships in providing support in the face of a medical crisis. Since many of the women are caregivers or in long-term partnerships, many were concerned about the impact of their decisions and cancer on their children and about living up to their caregiver roles (particularly for the mothers in this

group). For Marianne, the need to act as a mother to her four-year-old daughter while undergoing chemotherapy provided a difficult challenge. She remembers that instead of staying in bed on days after treatments, she would often be with her daughter regardless of the possible health consequences.

***Marianne: I couldn't pick her up. After each surgery I couldn't pick her up at all and I couldn't pick her up when I was in chemo. So that was what was most difficult at her young age...I told her 'Mommy has an "owie" in her breast and that the doctors are going to take it out and that I just won't be able to do a lot.' So that was the most difficult at her young age, just that I couldn't deal with a lot.***

It is these types of situations that add to the stress of mothers coping with breast cancer; the need to be physically available and, as shown with Ellen above, to explain their cancer in ways that their children can understand.

Another area of tension arose around the issue of having future biological children. The issue of potential fertility damage due to cancer treatment (radiation and chemotherapy) has become a more discussed issue in recent years by both support organizations and within the medical field (see Author, 2007a). As women contemplate having (more) children many are concerned about bringing a child into the world because of the possibility of themselves not surviving or the fear that a pregnancy could compromise their health or their child's (also see Siegel, Gorey, & Gluhoski, 1997). Such concerns play out in these women's relationships with their partners— even those relationships that the respondents consider to be generally supportive.

Although their survival is the first priority on everyone's list, respondents realize that their cancer and choices are impacting their partners' lives as well. As shown above, Marianne relied on her husband to help understand all of the information given by her doctor not only for emotional and tangible support, but also because ***"It affects us both."*** Marianne, at 35 years old, is also concerned that possible tension may arise in their relationship when they think about having additional biological children because of her treatment history as well as her age.

Catherine, a married 27-year-old chemical engineer, does not have children. It is unclear if her ability to have children has been compromised from her cancer treatments, but she often worries about what will happen if she and her husband are not able to conceive because they had always talked about having children before they turned thirty:

***Catherine: It kind of knocks you off the path that you were on and it has an impact on your relationship. . . I***

***don't know. I just felt like I, you know, I couldn't give him what he would want from me. He wanted to have a child too, so it kind of just made me feel like I couldn't provide for him what he wanted.***

Although Catherine describes her husband as generally supportive, the stress of her illness and the possibility of them not being able to have a biological child have caused them at times to take out their frustrations on one another. According to her, ***"It constantly seemed like we were so angry and we kind of were taking it out on each other."*** She says now they are now trying to work through these issues and have considered adoption if they are unable to have biological children of their own.

This tension regarding future children is not limited to partner relationships; parental relationships can experience strain on this front as well. Many women felt that their parents did not care if they had biological children of their own – particularly if they already had children or if their sibling already had children. But others suspected that their parents did want (additional) grandchildren, and for some it was a cause of reflection as they thought about their future. Angela, a 40-year-old divorced teacher with no children, believes her age and her cancer both are concerns for her parents:

***Angela: Oh, yes. They would love to have grandchildren. . . neither one of my sisters have children either. I would love to have given my parents grandchildren. They would have been great grandparents. . . I know that my mom has mourned with me that she doesn't have grandchildren. . . And my dad hasn't, as much, expressed a desire for grandchildren, but I know he's – he just doesn't talk about it as much, but that would be something he wanted.***

Though Angela expresses that this issue is one that deeply affects her parents, it does not appear that the situation has become contentious between her parents and herself, but rather it is another source of concern for Angela as she copes with her illness.

However, a few women expressed that this issue has in fact caused tension with their parents. LaTisha, a single 32-year-old Ph.D. student, also had lymphoma as a child. She describes having a strict Protestant upbringing where it was assumed that she would have children and that being a young mother was desirable, as most of her relatives had done. LaTisha feels her relationship with her mother is strained in part due to with her mother's desire for her to have children:

***LaTisha: It's been not great. Like I said, I have an older brother and he didn't have any of his own children. His wife has a child from when she was married before and so there was already this pressure on me to be the one that's going to carry on the family line. And then cancer, I think, just made it – heightened it, because I mean there was still the expectation that I was going to have a kid, but then there was the understanding that it may be that much difficult, but it's worth the effort to have the kid. So, yeah, it's been – I've talked to my mom some about not bringing it up as much and she says she doesn't bring it up as much, but she does it – she***

*actually does, just in a different way. She talks about, my mom was a twin sister, so she'll talk about her twin sister's grandkids and, oh, wasn't it great, you know, and, oh, I wish, you know, I saw them do this and it's her own jealousy of not having her own grandkids, but she kind of projects it on to me.*

This tension or concern regarding parents' desires for grandchildren can also have the opposite effect where parents voice their desire for their daughter *not* to have biological children. Some parents, like Jocelyn's who always wanted grandchildren, may noticeably stop mentioning grandchildren after their diagnosis because of the perceived potential impact on their daughter's well being. Ellen describes how the topic of her having additional children has caused tension within her family with her stepmother having made several "*nasty*" comments about how her becoming pregnant may not be possible or may be risky due to her history of cancer. And Donalyn's parents have made their concerns known about her potentially using an egg donor so she and her husband can conceive their first child because they think it may negatively impact her health:

*Donalyn: They don't want me to become an egg donor recipient because they feel that – and they feel that me getting pregnant on my own would make my cancer come back just because of all the estrogen and progesterone. They're kind of nervous about me becoming pregnant, with the fear of having my cancer come back.*

### **Conclusions and Future Research Directions**

This is an exploratory study exploring how younger women diagnosed with breast cancer deal with their diagnosis, treatment, and life after cancer, and how they are supported during this time through social support networks. Although support is found outside of their families (friends, healthcare workers, and even coworkers), family member support was central to these younger women's narratives of their experience as someone with breast cancer. A limit of our sample is that our respondents are largely homogenous in terms of race/ethnicity, socioeconomic, and health insurance status. Several studies have found that there are differences in the risk of younger women developing breast cancer across socioeconomic and racial/ethnic groups and that there are vast inequalities in health outcomes (including mortality rates) across these groups as well (Chlebowski, Chen, Anderson et al., 2005). Furthermore, cultural and community differences in terms of the importance of extended family networks and the role of community or church groups when an individual becomes chronically ill may alter how younger women facing breast cancer find and draw on support networks within and outside of their



families. So in order to more fully understand how younger women more generally deal with a cancer diagnosis and draw on available social support a more diverse sample is needed.

A strength of looking at this type narrative data is that we were not only able to more deeply understand these women's inner worlds, but also to see the complexity of their family relationships and support networks that may be missed when looking at scales and survey instruments that have investigated how social support forms are related to health outcomes. By looking at the "thick description" (Geertz, 1973) of how women describe their family support networks, we found that how one defines family can vary, social support comes in many and overlapping forms, and while family is more often a source of strength, it can also be a source of tension and concern as well.

In this study, we have uncovered several themes that future researchers should explore when examining the interaction of families and an individual's health status and issues that healthcare/social workers who work with younger women with breast cancer should be attuned to. Most of the instances where women discussed moments of stress and concern over family relationships centered on their future plans or ability to have biological children (and most felt that this topic was not sufficiently addressed by their healthcare team either). This study is a part of a larger research agenda on fertility, family plans and cancer, so the women we interviewed may have been drawn to our study wanting to discuss such issues. But other research on cancer more generally has found that concerns over having children is a main issue for many with cancer (Loscalzo & Clark, 2007). Researchers and healthcare workers should be aware how this issue can cause tension within familial relationships with parents as well as partners and is a source of concern for those who are single, partnered, parents, and non-parents alike.

This study also highlights that family support can come from many sources – partners, parents, foster children, aunts, and siblings. While women in this study are adults and most are partnered, many are single and with changing patterns of adulthood (see Arnett, 2007), many younger adults today are delaying forming permanent or long-term relationships or starting their own families so connections to family members outside of partners including parents and siblings as sources of support may be very pronounced. Those who work with younger adults should be aware that the term "family" will take on different connotations – for some it will mean

a partner and their children whereas for others parents and siblings are the core of their familial support network.

This study also raises the potential importance of experiential supports for those facing chronic healthcare issues. Most research on social support and health outcomes has looked at variants of social support including emotional, tangible, and informational. We propose experiential support as a type of support not fully captured by these other concepts and is characterized by having ties to someone who has been through the similar ordeal and who can provide information, insights, and hope. More than simply providing information about their illness, experiential support creates a bond of two people going through something most other people have not experienced and perhaps cannot fully understand because of their outsider status. For those in this study, experiential support came mostly from other women who faced not just breast cancer but who experienced it at a similar life stage and age. The younger women in our study are facing a diagnosis whereby they are not an “average” case. They are younger than most who are diagnosed with breast cancer and are often facing issues that those who are diagnosed at a later life stage may not contend with such as their ability to become a parent. Moreover, these women may feel distant from their healthy counterparts who are also getting married and forming families but who have not faced a life altering and potentially life threatening health issue. Pamela, a 39-year-old single woman, recalled that while friends were an important source of her emotional support, a close friend stopped contact because she “*couldn’t deal with it.*” LaTisha, the 32-year-old who had lymphoma as a child, described feeling somewhat disconnected from her own family because they have not faced cancer. While perhaps more extreme examples, they underscore how great this experiential gap can be and how it can impact otherwise close relationships. Finding specialized and formalized forms of support that address their special concerns can be difficult for younger women with breast cancer. But even among family and friends who are providing other forms of emotional or practical support, an experiential gap can exist.

Experiential support as a type of social support is clearly not restricted to family networks as shown in the experiences of Dorothy and Marianne, but is one key arena where experiential support may arise. Researchers and those who work with individuals with serious illnesses should explore the importance of experiential support for health outcomes and quality of life after a serious health diagnosis. How important is it for those facing a serious health issue to be able to lean on those who have gone through a similar diagnosis at similar time in their

lives? Do experiential support networks become more important when more traditional forms of support are harder to come by? Is experiential support more important when someone is facing a rare disorder (such as a man facing breast cancer), a stigmatized health status (a person dealing with schizophrenia), or an atypical diagnosis (like a young woman having breast cancer)? Our intent in this article is to begin to explore the ways that younger women with breast cancer draw on family and social support networks as they cope with their diagnosis, treatment, and life after cancer. Experiential support networks were invaluable resources for several women in this study and exploring this concept is important to understand more fully understand the breadth of social support resources that are available to those facing a healthcare crisis.

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<b>Table 1.</b>	
<b>Sample Characteristics</b>	
(n=40)	
<b>Race/Ethnicity</b>	
% Caucasian, Non-Hispanic	82.5%
% Caucasian, Hispanic	5.0%
% African American	7.5%
% Asian	5.0%
<b>Educational Attainment</b>	
% College Degree	87.5%
<b>Family Status</b>	
% Married/Partnered**	62.5%
% Engaged to be married	10.0%
% with Children (including foster and step children)	40.0%
<b>Mean Age at time of interview</b>	35.3
<b>Age Range at time of interview</b>	27 - 44
<b>Time Since Diagnosis</b>	
% less than 3 years	80.0%
% 4 - 5 years	20.0%
<b>Age Range at time of diagnosis</b>	23 - 40
<b>% Uninsured</b>	2.5%
**Includes one woman in a 15 year long committed partnership and one woman in a common law marriage.	

