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13. ABSTRACT *(Maximum 200 words)*

Breast cancer survivors wishing to have a child must contemplate the relative risks and benefits of pregnancy after treatment. Through indepth interviews with 51 women off treatment for at least six months, the perceived deterrents and incentives to childbearing following breast cancer were explored. Principal deterrents were: (1) the fear of a recurrence; (2) the fear of birth defects because of the treatments received; (3) the fear that their child would have a greater susceptibility to cancer; and, (4) the concern that caring for a child would be too stressful. Principal incentives were: (1) having a baby is a cherished part of a life plan; (2) the belief that having a child is life affirming; (3) the belief that having a child will promote feeling normal again; (4) the wish to please a husband; and (5) the belief that having a child would enhance quality of life. Additionally, other social, medical and interpersonal factors appeared to influence a woman's decision about childbearing. These included: (1) whether the woman already had a child of her own; (2) time off treatment; (3) marital status; (4) age; (5) her physician's opinion; and (6) her husband's desire for a child. These findings illustrate the potential value of family planning issues to women's perceived quality of life following breast cancer.

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Karolynn Siegel 4/24/97

PI - Signature Date

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I. Introduction

A. Nature of the Problem

Approximately 25% of all women diagnosed with breast cancer will be premenopausal and approximately 7% of these will go on to have one or more pregnancies following treatment [6]. Of central concern from a medical perspective is whether pregnancy-induced hormonal changes will stimulate the growth of metastatic deposits, increasing the probability of a recurrence. To date, the preponderance of available data suggests that pregnancy following a successfully treated breast cancer does not alter the outcome of the treated tumor, especially if the woman waits at least 6 months to conceive. This has been found to be true whether overall survival is considered for all breast cancer patients or for subgroups of patients who are at various stages of disease [2,4,5,7,15,20,22,24,29]. Some research has even suggested that pregnancy or multiple pregnancies after treatment for breast cancer may have a "protective" effect on prognosis [3,4,5,23,26]. However, there are limitations associated with these studies [29]. At the present time, it is generally recommended that women delay childbearing for at least 2-3 years following treatment termination, not because of any presumed adverse effect of the pregnancy on the malignancy, but rather to allow the period of the greatest risk of recurrence to pass [7,8,16,17].

As the trend toward first pregnancies at an older age continues, growing numbers of young women diagnosed with breast cancer who may not yet have had a child or feel that they had not yet completed their desired family, may be confronted with the decision of whether to attempt conception following treatment. Five-year relative survival from breast cancer, across all stages, for women under age 45 is now 80.1% for White women and 63.3% for Black women [17]. Thus a substantial majority of women have a good prognosis which would presumably support a desire to consider pregnancy.

B. Background

Despite the obvious importance of the issue of childbearing to women, we were unable at the time of the original grant application to locate any studies in the literature that focused specifically on childbearing decision-making following treatment for breast cancer or more generally for any cancer in adulthood. (One study of decisions concerning marriage and family planning among childhood cancer survivors was located [30]). Since that time, two related psychosocial reports by another investigator have been published [9,10]. One of these [9] directly addresses the issue of pregnancy decision-making following treatment for breast cancer. Qualitative interviews were conducted with a small sample of women who had had children following breast cancer (n=16). The investigator found that three themes were most prominent in women's reasons for deciding to become pregnant after cancer; (1) having children was a cherished goal; (2) desire for a sense of normalcy; and (3) reconnecting with others (e.g., peers). Despite ultimately successful pregnancies, these women did report that at the time of their decision-making and during pregnancy they worried about: (1) having a normal pregnancy; (2) delivering a healthy infant; (3) fears about recurrence; (4) effective surveillance during pregnancy; and (5) concerns about breast feeding. When the meaning of having children after breast cancer was explored, several themes were again prominent: (1) their children helped direct their attention outward and not inward at their health problems; (2) their children directed their attention toward the future; (2) having children fostered their recovery by giving them a reason to live and look forward to the future; and (3) having children made them feel complete. While based on a small sample, the findings illustrated the central importance of family issues to women's perceived quality of life following breast cancer.

The general literature on family planning decision-making is primarily focused on family size and contraceptive use and is of limited relevance to understanding childbearing decision-making in the context of cancer survivorship [e.g., 14]. The literature of closest relevance seems to relate to reproductive decision-making among parents seeking genetic counseling [11,18,19,25]. This literature seems to suggest that crucial common factors in reproductive decision-making are often the individuals' perceptions of their ability to cope with or manage the consequences should the worst possible outcome occur, and the diffusion of decision-making responsibility to others [18, 19]. Among families with women who perceive themselves at risk for ovarian or breast cancer, this literature also notes a lack of interest in making reproductive decisions which might reduce the number of female offspring potentially at risk. Richards [25] observes, "There appears to be a widespread belief that there is a kind of destiny that they will produce children and among them daughters who, like them, will be prone to cancers" (p. 574).

Because having children and family life is a central quality of life issue for most women, it is important to understand more about how women make this important decision. What factors do they weigh in deciding? To date, however, there has been little empirical investigation of this or any other factors in women's decision making. It has been observed that if having a child was a life goal before diagnosis, it will probably remain one [1].

C. Study Objectives and Method of Approach

Study Objectives. We studied the childbearing decision-making of women previously treated for breast cancer with the goal of learning more about the factors that influence their choices about attempting conception after breast cancer. A total of 51 women (43 non-Hispanic White and 8 Black women) who were previously treated for breast cancer were interviewed.

Using qualitative research methods, unstructured interview data was gathered and analyzed to generate a provisional model of the decision-making process that can be tested and refined in subsequent research. The principal research issues of interest were:

1. What do women perceive as the potential medical, social and psychological risks of childbearing following treatment for breast cancer?

2. What do women perceive as the potential medical, social and psychological benefits of having a child following treatment for breast cancer?

3. What are women's sources of information about potential risks and benefits and how satisfied are they with each source?

4. Have these women sought or been offered any kind of counseling regarding reproductive decision-making?

5. What are the implications of the findings for developing counseling programs for women who are considering conception following treatment for breast cancer?

Methods of Approach. We relied exclusively on qualitative data gathering and data analytic techniques. A qualitative methodology was chosen to enable us to understand the social context of women's decision-making. That is, we assumed that the choices women make are not merely the outcome of some rational process of weighing perceived costs and benefits. Rather, their decisions take place in the context of the values, norms and expectations of their social and reference groups which a qualitative methodology permitted us to explore. We also adopted a qualitative approach because of the dearth of information available on the issues of interest coupled with the very limited relevance of existing theories/models of family planning. We believe this kind of study is an essential preliminary step to developing meaningful theory-driven psychosocial research on the issues of childbearing among women previously treated for cancer. Further, qualitative research on reproductive decision-making in families seeking genetic counseling "highlights the importance of recognizing parent's perceptions of their situation to understand how their deliberations are structured and how factual information influences their ultimate choices" [19]. Such insights can most effectively be gained through a qualitative methodology.

We applied precepts of grounded theory, as explicated by Glaser and Strauss [12]. However, because of difficulties experienced in locating eligible cases, we were not able to employ the principles of theoretical sampling consistently. To do so would have required a considerably larger pool of eligible potential participants from which to select study cases than were able to be identified despite extensive effort to locate possible cases. Further, because of the difficulty not only in locating but also recruiting eligible black cases, it was not possible to meaningfully hypothesize about the influence of race on pregnancy decision-making. Due to the limitations these conditions imposed on the application of grounded theory methods, this approach was complemented with other qualitative strategies (e.g., thematic content analysis).

II. Body

A. Study Methods

Eligibility. To be eligible for the study, a woman had to: 1) have completed treatment for breast cancer at least 6 months earlier; 2) have believed that she retained the capacity to bear a child either through natural conception or with the assistance of reproductive technologies (e.g., the use of an egg donor or in vitro fertilization); 3) have been ≤45 years of age; 4) was currently actively considering the question of whether to have or not have a (another) child or have completed that decision-making process within the past three years; 5) was currently living in the greater New York City metropolitan area (i.e., approximately a 50 mile radius of Manhattan); and 6) was White non-Hispanic or Black. Marital status was not part of the eligibility criteria.

The eligibility criteria described above reflect three modifications made to the original protocol. Throughout the early accrual period, we had experienced a great deal of difficulty locating and accruing eligible African-American women into the study, despite targeted recruitment efforts (see **Recruitment** below). As a result, the eligibility criteria were modified in an effort to facilitate accrual, especially of minority Black women. Permission for these changes was given by both the Army and the Institution Review Board at Memorial Sloan-Kettering Cancer Center (MSKCC). The modifications made were:

1. We removed a requirement that a woman evidence no indications of menopause and instead stipulated that any woman who believed that she maintained the capacity to conceive a child naturally or through the use of reproductive technologies was included.

2. We relaxed the eligibility requirements to permit inclusion not just of native-born women of African-American extraction, but of any Black woman (e.g., Caribbean) previously treated for breast cancer who met other eligibility requirements.

3. We amended the eligibility criteria to include women who had actively made the decision whether to become pregnant post-treatment for breast cancer, if that decision was made no more than three years prior to being screened for eligibility. In the original protocol eligibility was restricted to women who were currently actively considering whether to become pregnant or not.

Recruitment. Various sources were used for the recruitment of potential study participants. Because of concerns about patient confidentiality, we did not ask organizations that assisted us in recruitment to provide us with names and addresses. Rather, we asked them to review their patient/client files and send a flyer describing the study to potentially eligible women. In the flyer women were invited to self-refer if they wished to learn more about the research or participate. Cancer Care, and the New York offices of the American Cancer Society (ACS) have cooperated and contacted their clients who were likely to meet study eligibility requirements for our study. Several hundred letters were mailed out by these two organizations to potentially eligible clients. In addition, we telephoned a large number of breast cancer support groups for survivors identified either from a list provided by the National Alliance of Breast Cancer Organizations (NABCO) or from contacts with hospitals throughout the tri-state area. Group leaders were similarly asked to provide flyers to their members. Another recruitment source was MSKCC's own patient population. After receiving permission from physicians at MSKCC, we also used the hospital data base to identify potentially eligible women and contacted them by mail with information about the study and how to contact us if they were interested in participating in the study.

We found that even when women were determined to be eligible, there was emotional resistance to participating in the study. Childbearing and the possible loss of the opportunity to have children is obviously a very emotion-laden issue for young women. Because the study was not an intervention (i.e., we were not offering counseling about the risks or safety of childbearing after breast cancer), we sensed that some women were reluctant to risk the distress they feared might be invoked by having to discuss their sense of loss of the opportunity to have a child or their fears of recurrence that dissuaded them from attempting to become pregnant.

Accrual of African-American or Black women continued to be especially difficult even after the eligibility criteria was expanded (see **Eligibility**). We identified a local chapter of an African-American breast cancer survivors network (i.e., Sisters) and provided them with study flyers. We contacted medical and surgical oncologists serving women in areas of the metropolitan region having large numbers of women of color. Interested physicians were provided with a copy of the IRB protocol, consent form, and flyers for distribution to potentially eligible women. We placed an advertisement in the New York Amsterdam News and The City Sun (two New York City based Black newspapers) informing readers of the study's existence, eligibility requirements, and how to contact us regarding participation. Additionally, we hired as a consultant a female African-American social worker from Cancer Care, a well-recognized social service agency, to do a second mailing to potentially eligible clients and follow up with a telephone call to offer information and answer questions about the study. Cumulatively, these efforts yielded only 14 eligible black women, of whom 8 participated in the study.

As our extensive efforts to recruit an adequate number of Black women proved unsuccessful, we achieved our target total sample size of women by accruing additional White women. While we originally had hoped to over-represent Black women with breast cancer (from New York City and Long Island) in the study, it was only possible to represent them in approximate proportion to their numbers (i.e., 10-15%).

Screening. Women interested in participating in the study contacted us by calling a dedicated telephone number. At this initial contact, a potential participant was screened by a research staff member to determine whether she was eligible for participation. If the respondent met all eligibility criteria, an appointment was scheduled for the interview.

Interviewing. During Year 1, an interview guide for the study was developed (see Appendix D). Further modifications occurred in the course of the interviewing when topics of potential theoretical importance have emerged from the data that had not been anticipated. We also hired and trained the (female) interviewers in Year 1. Training consisted of both instruction in general interviewing techniques and conducting mock interviews that were critiqued.

Before each interview, informed consent was obtained from all participants and each woman was given a signed copy of the informed consent document. Potential risks and benefits of study participation were described in the document. Prospective participants were also assured that their refusal to participate or their dropping out of the study at any point would have no adverse consequences for their future medical or psychosocial care.

Each participant was individually interviewed once face-to-face for approximately two hours. The interview consisted of two parts, an interviewer-administered questionnaire, given during the first half hour, and a focused, unstructured interview lasting approximately one and a half hours. All interviewers were women.

The interviewer-administered questionnaire contained items eliciting standard sociodemographic data (e.g., race/ethnicity, marital status, age, education, occupation, religion, etc.) and relevant medical data (e.g., the participant's child-bearing history, length of time off treatment, stage of treated disease and treatment history). Focused, unstructured individual interviews was the primary data-gathering technique. Unstructured focused interviews involve specific procedures and techniques that maximize completeness, validity and reliability of the data. Unstructured interviewing techniques have the unique ability to elicit the respondent's own frame of reference. We drew heavily on the interviewing techniques outlined in Merton et al.'s manual [21] and also built on the Principal Investigator's work on combining psychodynamic (unstructured and nondirective) and structured interviewing techniques [13].

Interviews were audiotaped to permit transcription for analysis. Printed transcripts and associated word processing files are kept in a locked file in the research offices of the Principal Investigator and had no identifying information on them. Identifying information has not and will not be used in any research reports, publications or written presentations.

Computer-Assisted Qualitative Analysis. ZyINDEX, a software program for text retrieval and qualitative data analysis was used to assist in the analysis of the narrative interview data. It permits all instances of text relating to a particular issue or problem to be efficiently located, excerpted, and stored in a newly created topic file. This excerpted textual material can be further searched for subcodes or even specific words or combination of words. Topic file material can then be subjected to thematic analysis. ZyINDEX also produces a lexicon, an alphabetical listing with frequency counts, that can be organized by words, phrases, or synonymous phrases by case, designated subgroups and for the total data file. These lexicons create independent criteria for evaluating the importance of themes and the ability of the coding scheme to efficiently represent the major concerns discussed in the accounts.

B. Description of Cases Collected

Eighty-one women were screened for participation in the study. Of these, 51 completed the study, 9 were found to be eligible for interview but declined to participate, and 21 were ineligible.

Table 1 provides basic demographic data regarding study participants. Of the 51 women interviewed, 84% were (non-Hispanic) White and 16% were African-American. The average age of women participating in the study was 35.5 (SD=4.9 years). While 18% of participants were 24-30 years of age, 31% were 31-35, 33% were 36-40, and 18% were 41-44. Sixty-seven percent of the women were married at the time of the interview, an additional 27% were single and had never been married and 6% were divorced. A third of the respondents (33%) were Roman Catholic, 28% were Jewish, 27% were Protestants, 4% specified other, and 8% reported no religion.

Respondents were, for the most part, well educated. Three-fourths (75%) of the sample graduated from college (25% had a graduate or professional degree). All of the respondents graduated from high school. Over two-thirds of the women (71%) were employed at the time of the interview with 49% of all women were employed full-time. Of the fifteen women who were not working at the time of the interview, five (33%) were not working because of their breast cancer and/or its treatment. The median household income reported by respondents was $64,061. Regarding household income, only 6% of the sample reported it to be less than $25,000, 27% reported it to be between $25,000 and $49,999, 31% reported it to be between $50,000 and $74,999, 10% reported it to be between $75,000 and $99,999, and 26% reported it to be $100,000 or more.

Over half of the women in the sample (55%) reported that they had no children living in their household at the time of the interview while 29% reported one child living with them, 14% reported two children living with them, and 2% reported three children residing with them. The mean number of children in the household among women who reported having at least one child in the household was 1.4 (SD=0.7).

Relevant medical data obtained from the respondents are presented in Table 2. The average length of time since they were first diagnosed with breast cancer was 33.0 months (SD=23.3 months), with 67% reporting diagnosis within the past three years and 18% reporting their first diagnosis of cancer more than five years prior to the interview. Fifty women reported that at the time of their first diagnosis, only one breast was affected, while one woman had cancer in both breasts. Twenty-six percent of the women reported they had Stage I disease at the time of their diagnosis, compared to 32% who reported having Stage II disease and 10% who reported having Stage III disease. Nearly a third of the women (32%) reported either not knowing or uncertainty about the stage of their disease at the time of their diagnosis. Forty-five percent of the respondents describe their current health as "Excellent", while another 41% describe it as "Good". Only six of the women describe their current health as "Fair" (12%) or "Poor" (2%).

As shown on Table 3, 43% of the women reported never having been pregnant prior to their cancer diagnosis while another 22% reported one pregnancy, 19% reported two pregnancies, 6% reported three, 8% reported four, and 2% reported five. Among the 57% of all women who reported at least one pregnancy prior to their cancer diagnosis, the mean number of pregnancies was 1.2 (SD=1.4). Thirty-seven percent of all women reported at least one live birth prior to diagnosis, while 28% reported terminating at least one pregnancy by abortion and 16% reported at least one stillbirth or miscarriage during the same period. Nine women in the sample had been pregnant a total of 12 times since their diagnosis. Two of the pregnancies were current at the time of the interview. Of the other 10 pregnancies, 4 resulted in live births of healthy children, 4 were terminated pregnancies, 1 was a stillbirth, and 1 was a miscarriage.

C. Study Results

I. Perceived risks of becoming pregnant

Several themes were prevalent in the women's narratives regarding perceived deterrents to attempting pregnancy. These related primarily to risks or dangers they perceived to be associated with having a child. Associated with these perceived risks were various negative emotions --typically guilt or conflict -- that the women experienced when they contemplated having a child after cancer.

1. The fear of a recurrence of their disease. As with most cancer survivor populations [28], the fear of a recurrence of their disease was prevalent among the women in our sample. Some women specifically worried that the hormonal changes brought about by pregnancy could stimulate a recurrence of their cancer. Typically these were women who had been told their tumor was estrogen receptor positive. One woman said:

> I've heard of cancer...being kind of jump-started by pregnancy because of hormonal changes. And sometimes you think breast cancer, ovarian cancer, you know, whatever is hormonally related ... That's really it. And you think to yourself, 'Am I really clean?' Because if I get pregnant, and if I'm not, stuff happens.

Given the possibility they perceived that pregnancy might lead to a recurrence and premature death, women wondered if it was morally right to bring a child into the world. Further, they felt there was something patently illogical in risking one's life to have a child one might then not be alive to raise. As one woman said, "Where's the sense in having a child you won't be here to care for."

Others simply feared that their disease might return after the child was born, although they did not assume their pregnancy would necessarily be implicated. Under either circumstance, the women believed that if their disease recurred their prognosis would be significantly poorer than at their initial diagnosis, and their likelihood of becoming ill or even dying would be considerably enhanced. One woman remarked:

> I've been mostly reassured that pregnancy couldn't initiate a recurrence. But then I feel like, well no one knows for sure ... I guess the main risk I think about is recurrence and, you know, I don't survive it and die, and then my kids are left without a mother.

Even if their disease recurred and they did not die, some women felt that it would be a significant burden to a young child to have a seriously ill mother. A few had had a mother who had been very sick with breast cancer or another chronic illness when they were a child and still felt the emotional and psychological impact of that situation. One woman whose mother was ill when she was young recalled:

> I knew from my mother that I was left alone ... Emotionally she didn't want to leave me alone, but I was physically, I was left alone as a child. My sister was in school and my mother was at the doctor's. I had to go with her. And even as a small child I felt I was taking care of her. I think that's the worst thing in the world for a child.

Several women, who at the time of their diagnosis had a child old enough to understand that their mother was seriously ill, felt that the experience had been an emotionally trying and difficult one for the child. For example, one women who already had two children at the time of her diagnosis, felt that the stresses of her illness and treatment had had a negative impact on them and decided she would not want to take the chance of having another child, having a recurrence, and putting that child through the same ordeal. Another said: "I worry about them [my child and my husband] seeing me suffer...I'll suffer quietly, but still, I don't want someone else to suffer because of my suffering." Still another woman said:

> It is devastating to a child to lose a mother. So, you know, I think that when it came down to it [becoming pregnant], no matter what my spiritual attitude is toward it, I guess I would probably feel pretty guilty if I had a child and the child was young and I died from cancer knowing when I conceived the child that there was that possibility.

For those women who had already had a child before their diagnosis, there was also the feeling that it was not fair to that child to do something that might jeopardize their survival and lead that child to experience a profound loss. While these women may have always wished to have more children, they acknowledged that they should "count their blessings" that they had already had a child by the time they were diagnosed with breast cancer. One mother of two children born before her diagnosis, who had decided not to try to become pregnant again after breast cancer, explained her choice by saying:

> Just the thought, because it's not known and the possibility exists that it can

> shorten my life for this to recur. It's not fair to my children, you know, or to me. Being their mother, that's more important than anything. Like I said, if the situation were to exist that I didn't have children, that would be a different-- the answers would be different.

Although some were confident that their husband or family would step in and ensure that the child's emotional and practical needs were met if they died, a few still believed that the child would suffer not having its biological mother. As one woman who knew her husband and family would be there for her children if she died expressed it, "No body, no matter what, would care for them like I would." She felt that the loss of the special love and attachment a biological mother has with her child could never be replaced.

While these women did not doubt that they had much love to offer, they questioned whether trying to have a child of their own would be a selfish act, which although meeting their own needs, might bring a child into a situation that was less than desirable. Some wondered if they were being immature or stubborn to cling to their desire for a baby of their own. A woman who had decided not to try to become pregnant after breast cancer said:

> I mean the idea of having and abandoning the child... would just be unthinkable to me...I certainly didn't want to bring into the world a child without a parent. I mean that to me is just too difficult for the child. Even if my need was so great to have the child.

2. **The fear that their child might have a birth defect because of the chemotherapy or radiation they had received.** Some women worried that there might be toxic residues in their bodies of the chemotherapeutic agents they had received as treatment for their disease and these could cause fetal abnormalities. One woman commented: "What if the child is deformed because of the chemotherapy. Although my organs are apparently fine, you know, they did a lot of tests. But I keep thinking, 'What if the child is deformed.'" Another woman remarked:

> My concern was the chemotherapy... It wasn't so much the breast cancer itself, as it was the chemicals that may be deposited in the body and it triggers off something else that may trigger off something with the baby. You know what I'm saying?

Most who held this fear felt this risk could be minimized or eliminated by postponing childbearing a number of years to allow the opportunity for their bodies to be completely purged of these chemicals. However, if the woman was already in her late thirties or early forties, waiting a few years seemed for some a luxury that they feared their "biological clock" would not allow. A couple of these women also expressed that because the risks of birth defects increase with age for women in general, to wait a period of years before conceiving might carry its own risks.

Women who had received radiation were generally somewhat more optimistic that the radiation had been effectively targeted to avoid exposure of their eggs, but a couple still worried about the possibility that their eggs had been damaged and there might be a greater risk the child would be born with some disability. A related fear of women was whether they would have a healthy pregnancy given their previous exposure to toxins and radiation. A couple worried that they might be at increased risk for a miscarriage which they anticipated would be devastating given the intense longing they experienced to have a child.

3. The fear that their child would be born with a greater susceptibility to cancer. Women worried both specifically about the possibility of having a daughter who was likely to develop breast cancer as an adult, but also more generally about whether their child might be more likely to be born with cancer or to develop childhood cancer. Those who expressed this fear also worried that having a child might be a selfish or immoral act. One woman said: "You don't want to bring a baby into the world that you know somewhere down the line, it's going to have to suffer. That's not right, if you know it."

A few women who felt that their diagnosis and treatment had been particularly distressing and that they had suffered a great deal, related that they were concerned that if they had a daughter, she might be doomed to endure the same physical and emotional pain someday. One women remarked:

> I think, 'Oh you're just being selfish to want to have children. What's it gonna mean for the child. The child's gonna grow up and have breast cancer. You're going to give all this pain to another human being.'

Other women adopted a more optimistic attitude saying that by the time their daughters were grown there might be a cure, or at least a way to diagnose breast cancer very early. Barring such advances, they believed that at least their daughter would have the advantage of being educated about the disease and know how to ensure that it was detected very early. While most women admitted that certainly it was distressing to think if they had a daughter she might one day develop breast cancer, almost all said this by itself would not deter them.

Several women worried about genetically passing on a general susceptibility to cancer to a male or female offspring. Several believed that their child might be born with cancer if any undetected cancer cells were still lurking in their bodies during their pregnancy. Again, concerns about whether it was fair or morally right to put a child at risk for a terrible life-threatening illness were expressed. Others felt that while the child might not be born with cancer, he/she would have a greater propensity to develop a childhood cancer because of some presumably genetic predisposition that would be inherited.

4. **The concern that caring for a child would be too stressful.** Some women expressed concern that caring for a baby or young child would be very physically demanding. While a few women worried whether such demands would be good for their overall health,

most were concerned about whether they would have the energy to provide the level of care and involvement they would want to provide to their child. One woman who already had a child at the time of her diagnosis and was undecided about whether to attempt to become pregnant again feared the physical demands of pregnancy. She said:

> Well the risks of having another one are I mean, I guess making demands on my body when my body might need all its resources just to stay healthy ... I just might not be physically and mentally up to the demands I would have to face ...I would worry that I would feel so tired and so pulled in different directions that it would be detrimental to my health. And I am pretty protective of myself these days. So that I see as a risk.

These fears were especially prevalent among those who felt that they had not regained their pre-illness level of energy and found they continue to fatigue easily. As one woman said: "I'm not sure that I have enough energy to mother a child...You know, I want to have a baby that doesn't have, that you are too tired to play with or anything like that."

One women worried about the long-term effects of all the chemotherapy she had received on her body. She commented:

> ... five, ten years down the line what is my health going to be like...All the drugs that went through my liver and my kidneys, my body. What kind of effect, what kind of shortness of life they're causing my organs.

II. Perceived benefits of becoming pregnant

Despite the potential risks women perceived to be associated with becoming pregnant after breast cancer, they also believed important gains could be realized. The incentives were both those that most women in general see for having a child and some that were more specifically related to their illness experience.

1. Having a baby is a cherished part of a life plan. Most women reported that they had grown up always wanting to have a child or family of their own. For most, this was an important part of their life plan that they were committed to trying to actualize. It was a dream or goal that they were very emotionally invested in realizing. One woman who admitted fearing the possibility of a recurrence if she became pregnant nevertheless said:

> The benefits to me emotionally outweigh the risks to have like a future with a child or a family that you have always wanted. So that seems to me like you can't have anything more. That is the ultimate to me.

When asked what losses she felt she would experience if she decided not to become pregnant in the future, this woman said: "A very unsatisfying life. Unfulfilled ... I think that I would feel a loss if I didn't become a mother naturally. I always wanted to see their hands, their face, the future of your family."

Many felt that breast cancer had robbed them of a great deal including physical attractiveness, self-esteem and a sense of security and confidence about the future. Some felt more insecure in their relationships with men (if unmarried), in their marriages, and in their jobs and careers. The further loss of an opportunity to have a child of their own was something they resisted strongly. One woman commented:

> There were so many events in my life that were things that happened that were blocks and were obstacles; a situation or a person or something trying to hold me back or hold me down. A female thing. ... And its sort of like this final thing [having a baby] that maybe I do feel I do have control over, you know. That I don't, I don't want someone to tell me 'No.'

2. Having a baby is life affirming. A related theme to the to the previous one was that having a child is life affirming. It would be a way of saying, "I'm here to stay. I have a job to do to raise this child and I'll be here to do it." It was also a way of saying they believed in their future. While most women felt they were strongly motivated to stay well, a few also expressed that they believed that having a child to raise would be an extraordinarily powerful motivator to stay healthy and alive, to have a strong will to live. A child, some said, would give them more hope and optimism about the future. One woman said:

> Having a child forces you to focus on the day to day and there is a normal sense of joy. The day to day is good in the sense that even though I am not obsessed on the fact that I've had cancer, I think there is still a presence there. But day to day existence with a child, although a lot of work, is a joy and it is life affirming. It's like saying the doctors have said I'm okay. I'm going to go back to life.

3. The belief that having a child will promote a feeling of normalcy. Women diagnosed with breast cancer often experience an abrupt sense of discontinuity with the past. Their lives seem jolted and thrown off course. Some spoke about feeling different or set apart from their peers. They felt that having a child would return them to the world of the healthy, the living. As one woman put it, when you have a child "you're back in life again."

Many women spoke of how they and their husband were already making plans to have a child when they were diagnosed and about how their peers and siblings were already having children. Some felt left behind because of their illness. They weren't doing the things that were developmentally normative, such as starting a family in one's thirties. A few believed that having a child would help them restore a sense of normalcy in their lives. One woman said:

> I see it as getting on with my life, and not letting the breast cancer hold me back or rob me. I suppose you could say having a normal life. And I see

having children as part of a normal married life.

Women spoke too of how having a baby would affirm their normalcy as women and restore their sense of normal femininity and sexuality. Having a baby, they believed, would also make them feel that they were no less a woman despite their disease. It would signal to themselves an others that, as one woman said, they could still function as a woman, even without their breasts. Another woman talked about how she felt when her breast cancer doctor had asked her if she was planning to have any more children. She reported that she was delighted that he asked her the question, because it signified to her that he still viewed her as a vibrant, well-functioning woman. Still, another commented: "It reinforces the fact that you are still a woman ... They just took away part of your body... but it [having a baby] just reinforces the fact that you are still a woman. You can still perform."

Despite positive changes in women's self-concept and enlarged opportunities for achievement brought about by the women's liberation movement, the ability to bear a child is still very important to many women's feminine identity and sense of self-worth. Women admitted that their self-view and confidence about themselves as attractive, desirable women had already been dealt a blow by their breast cancer and the deformity some believed resulted. To also lose their opportunity to bear a child was a further insult some were unwilling to endure.

One woman described her reaction when her physician talked about also removing her ovaries as a further precaution against the spread of her cancer. She recalled:

> At one point, one doctor had discussed removing my ovaries and it was like 'No way. I've lost a breast; you're not taking those too...If you are going to start taking things from me that are important to my womanhood, then I just can't deal with it...I'm going to hold on and protect as long as I can the fertility that I do have.

Another said, that having a child would allow her to say to the world: "Hey I can still do that. I'm still a woman, you know. And I think that's an issue. I think your sexuality is a big issue, a very big issue actually."

4. **The wish to give her husband something that would make him very happy**. A final theme that emerged, but with considerably less frequency was the desire to have a baby for one's husband. However, this was in no case a primary motive. These women expressed that they knew that their husbands very much wanted a child and that they wanted to be able to give it to them. Women spoke of how enduring the diagnosis and treatment experience together had forged a special bond and sense of closeness between them and their husband. This bond, together with the gratitude they felt for all the support their husbands had offered them, fueled their desire to have a child together. One recounted that after her breast cancer, her husband had always said that it was up to her if they would have children. He had repeatedly reassured her that whatever decision she made about having children would be fine

with him. She had believed that it really did not matter to him if they did not have a child. She recalled how bad she felt one day when finally one day he said: "You know, I'm starting to feel old. It would be nice to have a child."

If couples talked about having a child or having another child before the disease and the woman knew this was something her husband was looking forward to, she wished to be able to give him a child. She did not want him to have to miss out on having a child because of her illness.

Some women felt that having children was something they and their spouses both expected in their marriage; in a sense it was something they had contracted for going into the marriage. One woman related an incident that she still recalled as very painful over two and a half years later. As her husband was wheeling her out of the hospital following her breast surgery, he saw another man wheeling out his wife with a newborn baby. He said: "That's the only reason I thought I would ever be in the hospital, to check you out from having a baby, Here I am checking you out for a mastectomy." This woman spoke about how bad she felt, both for her husband and for herself, when he made that remark.

5. The belief that having a child would improve their quality of life. For the most part, women were not counting on a baby to make them happy. They realized that that had to come from within themselves. Still they expected that having a child would bring certain pleasure into their lives. One woman remarked:

> I think I might be very happy having a child...And that it might, probably would, add a great deal to my life. Now I look at my friends who have children, and I see that it adds lots of hassles, but it adds lots of joys. I can see the pleasure that they're getting in between the hassles. And I can see the gratifying aspects of it very easily.

Another woman who did go on to have a baby after breast cancer said: "To me and [her husband] it's just something that we always wanted and something that is very special to us. And it has a lot of meaning to us. And it just, you know, makes each day a little more special."

III. Women's sources of information about potential risks and benefits.

Women relied primarily on the opinions of the physicians who had cared for them to evaluate the potential risks of conception after treatment for breast cancer. Many sought more than one opinion. Thus a woman might ask both her surgeon and her oncologist to advise her on the risk or safety of pregnancy. Some women also sought the opinion of their gynecologist with whom they often had a long standing and trusting relationship. Women were sometimes dismayed by the fact that the opinions they received from different doctors were not consistent, leaving them confused and uncertain how to proceed. They were also frustrated by the ambiguity that seemed to exist about the risks they would be facing by having a child after cancer. They wanted their physician to be able to give them a precise and firm estimate of the probability that a pregnancy might lead, for example, to a recurrence of their disease. In most cases, the physician admitted they could not do so. While they often expressed their own clinical opinion on the matter, many physicians acknowledged that not enough research had been done on the risks of pregnancy after breast cancer to predict the outcome with any certainty. Because there was no definitive information that enabled women to quantify the potential risks, some found themselves ruminating about the safety of pregnancy and were locked in indecision about whether to proceed with trying to conceive.

A small proportion of women also sought out "popular" books on breast cancer written by physicians, such as Dr. Susan Love. These physician-authors were regarded as having considerable clinical experience with women with the disease and thus valuable opinions.

IV. Counseling regarding reproductive decision-making.

A couple of the women had undergone testing for the genetic susceptibility for breast-ovarian cancer. While such information has implications for the risk of transmitting susceptibility to a female offspring, none spoke of seeing a genetic counselor for assessing the risks of having a child with an increased risk of breast or other kind of cancer. Some did, however, have a family history of breast cancer and recognized that a female child might quite probably face the threat of the disease someday.

None of the women had yet seen a fertility expert either. However, a few who were still in the 2-5 year waiting period that their doctor had recommended observing before attempting conception, indicated that they might do so at a later time, closer to the time when they would actually begin to attempt conception.

Several women did report that they had spoken with a therapist regarding their feelings and thoughts about having a child after breast cancer. Typically, the therapist was helping them adjust to their illness and was not sought out explicitly for advice or counseling regarding pregnancy. Rather, this was one of many issues raised as part of the women's process of coming to terms with the implications of her illness.

Finally, none of the woman reported seeking the counsel of a minister, priest, rabbi or other religious figure to aid in their decision-making about child-bearing.

V. Implications of the findings for developing counseling programs for women who are considering pregnancy following treatment for breast cancer

When asked what would have been useful to them as they went through the decision-making process, almost all study participants said they needed more information. Women wished that a doctor or nurse had taken the time to sit down with them and discuss the matter of pregnancy after breast cancer directly. They wanted their doctors to tell them what was actually known about the risks of becoming pregnant after breast cancer. They also wanted their doctors to inquire about how important the idea of having a child was to them and their partners.

The data suggest that if the physician is perceived as avoiding discussion of the issue of pregnancy, women may interpret this as a negation of her femininity or as a sign that the physician believes her prognosis is poor. What many of the women would like physicians to understand that, as one woman expressed, "... the pregnancy thing is not just a medical issue. It's an emotional issue too." As much as women want a frank discussion with their doctors about the potential risks associated with pregnancy after breast cancer, they also want their doctors to understand that this is not an issue that can always be decided on a purely rational or statistical basis. Having a child of one's own, having a family life, and completing a life plan are goals that hold tremendous emotional meaning for most women and that does not change because they had breast cancer. If anything, this desire may become even stronger. A discussion at the time of treatment initiation about a woman's desire for a future pregnancy is also necessary as certain chemotherapeutic agents may induce ovarian failure, and a woman needs to weigh the risks when making treatment decisions [27].

The above findings are reported in our paper "Pregnancy Decision-Making Among Women Previously Treated for Breast Cancer" which has been accepted for publication in the Journal of Psychosocial Oncology (see Appendix A).

D. Provisional Decision-Making Model

A variety of factors influenced women's decision about whether to attempt conception following breast cancer. In Figure 1, the principal sets of factors are depicted.

1. Perceived Risks: We have already discussed above what women viewed as the principal risks or having a baby after breast cancer. These were: (1) the fear of a recurrence of their disease; (2) the fear that their child might have a birth defect because of the chemotherapy or radiation they had received; (3) the fear that their child would be born with a greater susceptibility to cancer; and, (4) the concern that caring for a child would be too stressful.

2. Perceived Benefits: Also discussed above were the principal perceived benefits of pregnancy. These were: (1) having a baby is a cherished part of a life plan; (2) the belief that having a child is life affirming; (3) the belief that having a child will promote a feeling of normalcy again; (4) the wish to give their husband something that would make him very happy; and (5) the belief that having a child will enhance their quality of life.

3. Social and Medical Characteristics: A number of structural factors appeared to impinge on women's decision-making about childbearing after breast cancer.

a. Prior Births. Whether the woman already had a child of her own (born before her diagnosis) was often a factor in her decision-making. For those who did, this circumstance tended to enter into their consideration in two ways. Among women who believed that pregnancy might stimulate a recurrence of their disease, there was the feeling that they should not take such a risk because of the responsibility they had to their child to do everything possible to maximize their health and chance of survival. These women felt that it would be selfish or irresponsible to possibly jeopardize their health by having another child which could cause them to become ill again, and this time with a poorer prognosis. These women felt that they should "count their blessings" that they already did have a child and did not have to expose themselves to the potential risks of pregnancy after cancer to experience the joys of being a mother.

On the other hand, some women who had one child at the time of their diagnosis spoke of the wish to give that child a sibling. They felt that a sibling would greatly enrich the child's life emotionally, while others felt less secure of their own survival and wanted to provide their child with "more family" in case they should die.

Among women who did not already have children at the time of their diagnosis, there was a willingness to accept the risks of pregnancy to have a baby of their own. Their desire to fulfill their long-standing goal of being a mother remained strong despite their illness, and in some cases may even have been reinforced by it for the reasons discussed above -- e.g., a child was seen as life affirming, a child would facilitate a return to normalcy. Some women felt that while their illness had caused them many kinds of loss, relinquishing their dream of being a mother or having a family of their own were losses that they would not easily accept.

b. Time Off Treatment: There was a tendency for women to become increasingly comfortable with considering pregnancy as longer stretches of time since the end of their treatment passed. Many women had been told by their physicians to wait a period of time, usually 2 to 5 years, before attempting conception. As they approached or reached that point in their recovery, many seemed to achieve some sense of psychological security or even optimism that their disease was gone and the risk to their future health of conception at this time was probably small. A number of women seemed to imbue the specific interval to wait suggested by their physician with almost magical significance, as if they would be safe as soon as they traversed the end point of that period. Others, who may have sought more than one physician's opinion, recognized after having received varying suggestions about a prudent waiting period that there was a certain degree of arbitrariness in physicians's recommendations.

c. Marital Status: Most single women expressed considerable reluctance about having a child without a spouse. Clearly, for them the concerns about what would happen to that child if their disease recurred and they were unable to provide adequate care loomed large. A couple of women felt that having to go through the diagnosis and treatment of their disease the first time was especially difficult without the support of a spouse, even when family supports were available. The thought of having to face recurrence alone and with a child seemed a daunting prospect to entertain. They had to think too of what it would be like for their child if they died and the child had no father. When a satisfying solution to the problem of who would become the child's guardian was not readily available, the decision to go forward with pregnancy seemed hard to justify.

Yet, while these women were reticent to consider single motherhood, they also worried given their illness, and the disfigurement they felt they experienced, that they might not be able to find a partner who accepted and valued them and would want to start a family. If not, they would have to reconsider single parenthood.

d. Age: Age was another consideration is women's decision's about childbearing. Some women who were already in their late thirties or early forties at the time of their diagnosis felt that they were perhaps already too old to attempt pregnancy, or certainly would be if they adhered to their doctor's directive to wait a period of years before attempting to become pregnant. Some also expressed the concern that they would not have the energy or stamina to undertake the rigors of caring for a young child. This seemed to be attributed to both their age and the fatigue or loss of energy that they had experienced since treatment.

4. Interpersonal Influences

There were two principal interpersonal sources of influence that women spoke of in discussing their decision-making about becoming pregnant after cancer -- their physicians and, if married, their husbands.

a. Physician's Opinions: Most women who contemplated the possibility of becoming pregnant sought the opinion of their physician about the possible risks of such a course of action. Women generally reported that the issue of the risks or safety of pregnancy had to be raised by them with their physicians. Few doctors took the initiative to bring it up themselves. When raised early in the disease course (i.e., before or during treatment), physicians tend to encourage women to hold the issue in abeyance until they were through with treatment. Some physicians were unequivocally opposed to the woman becoming pregnant, feeling that this would almost certainly increase her risk of recurrence. Other physicians were willing to support the idea, or at least not oppose it, if the woman was willing to wait 2-5 years after treatment, through the period when the risk of recurrence was greatest. One white woman recalled that while one of her doctors told her that she could go ahead with her plans to get pregnant, he mentioned the paucity of research data and the possibility of recurrence. She recounted:

> ... there was a period of time where I really didn't bring it up, but now I felt like I got past a certain amount of time, and I bring it up more. And ah, she (Oncologist) actually ah, seems favorable towards me ah, having children. Or a child. And ah, my surgeon ah, the one I saw after my original surgeon, my second surgeon, now my third, ah, he actually kind of did a statistical thing and he was the one I mentioned before who said, 'well, after two years, you know, recurrences usually occur within two years, and your risks go down,' and he

> said, 'Sure, go ahead,' you know, 'Go ahead now. You can start having a child now.' I said, 'well, OK, but that's great, but I'm not -- I'm still gonna wait. I'm not ready yet.' So actually it surprised me. I didn't expect him to say that. ...Yeah, and ah he said something which kind of, gave me kind of doubt. I mean he said, again, you know, everyone said there's really no studies on it. They have really nothing. Well, there have been studies but not ah, good statistical quality. I mean not enough women and they really haven't followed ah, any women, you know, maybe who have gotten pregnant to see what has happened to them. Ah, but he said, 'well, you know, the reason we're so concerned is that if there is any ah, like residual cancer cells in your body, that by getting pregnant, because your hormone levels change, and you know, it could create,' you know, I don't know -- your estrogen, progesterone -- 'whatever changes, it could stimulate growth of cancer that has, you know, just been in your body but has been dormant.' And he said, 'But, you know, if that happens, you know, you can look at it as you're only ah, speeding up the inevitable.' So you could take that, you could take that, you know, well, it's gonna happen anyway, so might as well have a child. You know.

While most respected their doctors' expert advice, they were sometimes dismayed to learn that different physicians they consulted held quite divergent positions on the question of probable risks associated with conception after breast cancer. One white woman described her dilemma when faced with various physician opinions with respect to childbearing after breast cancer. She said:

> Ah, one of them was an oncologist that I ah, you know, got as a referral. And went to see for an opinion. Ah, he was actually the oldest doctor that I saw. He was the most adamant about how this was a terrible idea. And I should never do this. Ah, and the gynecologist that I now see, ah, we only talked about this like in passing. And she said that she thought it was a bad idea. Ah, and all the other doctors have told me, 'I don't know if this is a good idea or not.' So I've got two definite 'no's,' and a whole bunch of, 'we don't know about this.' Ah, a couple of times I've been told, 'wait two years.' Well, I mean, you know, I don't know how many -- how many more years, even if this is an issue, I don't know how many more years I have. So two years is kind of, you know, is kind of a difficult thing. So ah, I'm I'm kind of up in the air. Also I mean if there's a chance of a recurrence, if there's a chance that I won't be healthy, or a chance that having a pregnancy would increase my chance of having cancer again, I don't know if I should do this to -- to the child. I mean I'd want to be around, and I'd want to be healthy, especially if I'm a single parent. So ah, that's the biggest question for me.

The quality of their relationship with their physician tended to influence the weight they attached to the physician's opinion. Obviously too, when the physician's opinion supported their own predilections they were inclined to embrace that opinion. Some women who wished to have a child sought out a physician who would support that decision if their own surgeon or oncologist did not.

b. Husband's Desires: Most married women and their spouses had discussed the question of having a child following her illness. Many husbands appeared to defer to the wife on this matter, apparently feeling that because there might potentially be risks to the woman's life associated with the choice to become pregnant, it ultimately had to be her own decision. When the husband did have an opinion, the women typically reported that her husband's attitudes on the matter of pregnancy were strongly influenced by her doctor's opinion. That is, the husbands feelings tended to follow the doctor advice on this issue. If the doctor felt pregnancy was probably safe for the woman, the husband supported the idea. On the other hand, if the doctor felt it was unsafe, the husband tended to be opposed, or at least more resistent to the possibility. In some cases allying themselves with the physician seemed to represent an attempt on the part of the husband to diffuse responsibility for their position and any attendant consequences of such a course of action.

Additional findings are reported in two appended papers: "Unique Stressors of Unmarried Women with Breast Cancer" (see Appendix B), which has been accepted for publication in the Journal of Psychosocial Oncology; and "Breast Cancer: Age-Related Distress" (see Appendix C), submitted to Social Science and Medicine.

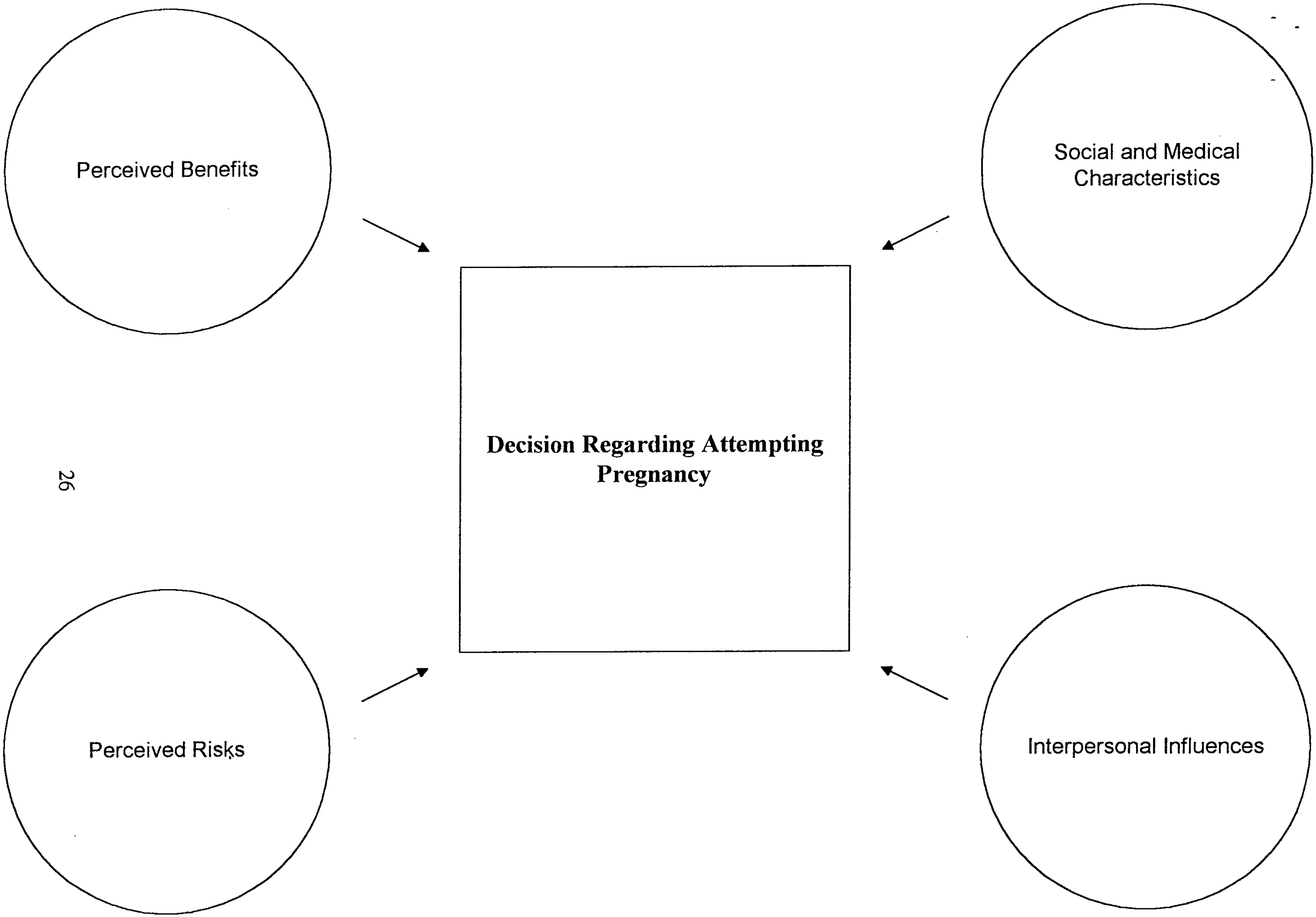

Figure 1 - Factors Influencing Pregnancy Decision-Making After Breast Cancer

Table 1. **Sociodemographic Characteristics of Study Participants (n=51).**

	Percent
Race	
White non-Hispanic	84
African-American	16
Age	
27-30	18
31-35	31
36-40	33
41-44	18
Mean	35.5
(SD)	(4.9)
Marital Status	
Married	67
Divorced	6
Never Married	27
Religion	
Roman Catholic	33
Jewish	28
Protestant	27
Other	4
None	8
Educational Attainment	
High School Grad	2
Some College/	18
Associate's Degree/Technical School	12
Bachelor's Degree	43
Graduate or Professional Degree	25
Employment Status	
Employed	71
Not Employed	29

Table 1. Sociodemographic Characteristics of Study Participants (n=51) -- Continued.

	Percent
Household Income	
< \$25,000	6
\$25,000 - \$49,999	27
\$50,000 - \$74,999	31
\$75,000 - \$99,999	10
≥ \$100,000	26
Median	\$64,061
Number of Respondent's Children Living in Household	
0	55
1	29
2	14
3	2
Mean[a]	1.4
(SD)	(0.7)

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[a] -- Restricted to women with children in their household (n=23)

Table 2. Medical Information Regarding Study Participants (n=51).

	Percent
<u>Length of Time Since Diagnosis (in months)</u>	
Mean	33.0
(SD)	(23.3)
<u>Reported stage of cancer at diagnosis</u>	
Stage I	26
Stage II	32
Stage III	10
Don't know/Uncertain	32
<u>Self-Evaluation of Health</u>	
Excellent	45
Good	41
Fair	12
Poor	2

Table 3. Pre-Diagnosis Pregnancy History of Study Participants (n=51).

	Percent
Reported number of pregnancies	
None	43
One	22
Two	19
Three	6
Four	8
Five	2
Mean[a]	1.2
(SD)	(1.4)
% Reporting at Least One:	
Live Birth	37
Abortion	28
Still Birth/Miscarriage	16

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[a] -- **Restricted to women who have ever been pregnant (n=29).**

III. References

1. Accola KM, Sommerfeld DP. (1979). Helping people with cancer consider parenthood. Am J Nurs, 79, 1580-1583.
2. Ariel IM, Kempner R. (1989). The prognosis of patients who become pregnant after mastectomy for breast cancer. Int Surg, 74, 185-187.
3. Clark RM, Chua T. (1989). Breast cancer and pregnancy: The ultimate challenge. Clin Oncol, 1, 11-18.
4. Clark RM, Reid JM. (1978). Carcinoma of the breast in pregnancy and lactation. Int J Radiat Oncol Biol Phys, 4, 693-698.
5. Cooper D, Butterfield J. (1970). Pregnancy subsequent to mastectomy for cancer of the breast, Ann Surg, 171, 429-433.
6. Danforth DN. (1991). How subsequent pregnancy affects outcome in women with a prior breast cancer, Oncology, 5, 23-35.
7. Danforth DN Jr, Lippman ME. (1988). Surgical treatment of breast cancer. In: ME Lippman, AS Lichter, DN Danforth Jr (Eds.), Diagnosis and management of breast cancer, pp. 95-154. Philadelphia: WB Saunders.
8. Donegan WL. (1977). Breast cancer and pregnancy. Obstet Gynecol, 50, 244-252.
9. Dow KH. (1994) Having children after breast cancer. Cancer Pract, 2, 407-413.
10. Dow KH, Harris JR, Callista Roy. (1994). Pregnancy after breast-conserving surgery and radiation therapy for breast cancer. JNCI Monographs,16, 131-137.
11. Frets PG, Duivenvoorden HJ, Verhage F, Peters-Romeyn BMT, Niermeijer MF. (1991). Analysis of problems in making the reproductive decision after genetic counselling. J Med Genet, 28, 194-200.
12. Glaser BG, Strauss AL. (1967). The discovery of the grounded theory. Chicago: Adline.
13. Hendin H, Siegel K. (1981). Psychodynamic and structured interviewing: A synthesis. Comp Psychiatry, 22, 153-61.
14. Hofferth SL. (1983). Childbearing decision making and family well-being: A dynamic sequential model. Am Sociol Rev, 48, 533-545.
15. Holleb AI, Farrow JH. (1962). The relation of carcinoma of the breast and pregnancy in 283 patients. Surg Gynecol Obstet, 115, 65-71.
16. Kitchen RB, McLennan R. (1987). Breast cancer and pregnancy. Med J Austral, 147, 337-339.
17. Kosary Cl, Ries LAG, Miller BA, Hankey BF, Harras A, Edwards BK (eds). (1995). SEER Cancer Statistics Review: 1973-1992, Tables and Graphs, National Cancer Institute. NIH Pub. No. 96-2789. Bethesda, MD.
18. Lippman-Hand A, Fraser FC. (1979). Genetic counselling--the post-counselling period. I. Patients' perceptions of uncertainty. Am J Med Genet, 4, 51-71.
19. Lippman-Hand A, Fraser FC. (1979). Genetic counselling--the post-counselling period. II. Making reproductive choices. Am J Med Genet, 4, 73-87.
20. Malamos NA, Stathopoulos GP, Keramopoulos A, Papadiamantis J, Vassilaros S. (1996). Pregnancy and offspring after the appearance of breast cancer. Oncology, 53, 471-475.

21. Merton RK, Fiske M, Kendall P. (1956). The focused interview: A manual and procedures. Glencoe, IL: The Free Press.
22. Mignot L, Morvan F, Sarrazin D, et al. (1986). Breast carcinoma and subsequent pregnancy. Proc Am Soc Clin Oncol, 5, 57-61.
23. Peters M. (1968). The effect of pregnancy in breast cancer. In Foresy APM, Kuckler PB (eds.) Prognostic Factors in Breast Cancer, Baltimore: Williams and Wilkins.
24. Riberio GG, Palmer MK. (1977). Breast carcinoma associated with pregnancy: A clinician's dilemma. BMJ, 2, 1524-1527.
25. Richards MPM. (1993). The new genetics: Some issues for social scientist. Sociol Health and Illness, 15, 567-586.
26. Rissaner PM. (1969). Pregnancy following treatment of mammary carcinoma. Acta Radiol Ther Phys Biol, 8, 415-422.
27. Siegel K, Christ GH. (1989). Hodgkin's disease survivorship: Psychosocial consequences. In: MJ Lacher, JR Redman (Eds.), The Consequences of Survival (pp. 383-399). Philadelphia: Lea & Febiger.
28. Surbone A, Petrek JA. (1997). Childbearing issues in breast carcinoma survivors. Cancer, 79, 1271-1278.
29. Sutton R, Buzdar AU, Hortobagyi GN. (1990). Pregnancy and offspring after adjuvant chemotherapy in breast cancer patients, Cancer, 65, 847-850.
30. Teeter MA, Holmes GE, Holmes FF, Baker AB. (1987). Decisions about marriage and family among survivors of childhood cancer. J Psychosoc Oncol, 5, 59-68.

IV. APPENDIX A

Pregnancy Decision-Making Among Women Previously Treated for Breast Cancer

(Proprietary Material)

Pregnancy Decision-Making Among Women Previously Treated for Breast Cancer

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Abstract

As the rate of first and subsequent births among women 35-45 continues to rise [U.S. Bureau of the Census, 1995], a growing number of women diagnosed with breast cancer who have not yet had a child, or who feel they have not achieved their desired family size, will be confronted with having to decide whether to attempt pregnancy after treatment for their disease. Through indepth focused interviews with 50 women who completed treatment for breast cancer at least 6 months earlier, the perceived deterrents and incentives to having a child following breast cancer were explored. The principal deterrents identified were: (1) the fear of a recurrence of their disease; (2) the fear that their child might have a birth defect because of the chemotherapy or radiation they had received; (3) the fear that their child would be born with a greater susceptibility to cancer; and, (4) the concern that caring for a child would be too stressful. The principal incentives discerned were: (1) having a baby is a cherished part of a life plan; (2) the belief that having a child is life affirming; (3) the belief that having a child will promote a feeling of normalcy again; (4) the wish to give their husband something that would make him very happy; and (5) the belief that having a child will enhance their quality of life.

As the rate of first and subsequent births among women 35-45 continues to rise [U.S. Bureau of the Census, 1995], a growing number of women diagnosed with breast cancer who have not yet had a child, or who feel they have not achieved their desired family size, will be confronted with having to decide whether to attempt pregnancy after treatment for their disease. Available data indicate that approximately 7% of women diagnosed with breast cancer premenopausally go on to have one or more children following treatment [Danforth, 1991].

Five-year relative survival from breast cancer, across all stages, for women under age 45 is now 76.8% for White women and 59.9% for Black women [Miller, Reis, Hankey, Kosary, and Edwards, 1992]. Thus, a substantial majority of women have a good prognosis which would presumably support a desire to attempt conception. Still, of central concern from a medical perspective is whether pregnancy-induced hormonal changes will stimulate the growth of metastatic deposits, increasing the probability of a recurrence. To date, the preponderance of available data, although primarily retrospective, suggests that pregnancy following a successfully treated breast cancer does not alter the outcome of the treated tumor, especially if the woman waits at least 6 months to conceive. This has been found to be true whether overall survival is considered for all breast cancer patients or for subgroups of patients who are at various stages of disease [Ariel and Kempner, 1989; Clark and Reid, 1978; Cooper and Butterfield, 1970; Danforth and Lippman, 1988; Holleb and Farrow, 1962; Mignot, Morvan, and Sarrazin, 1986; Riberio and Palmer, 1977; Sutton, Buzdar, and Hortobagyi, 1990]. Some research has even suggested that pregnancy or multiple pregnancies after treatment for breast cancer may have a "protective" effect [Clark and Chua, 1989; Clark and Reid, 1978; Cooper and Butterfield, 1970; Peters, 1968; Rissanen, 1969].

Still, in the absence of good prospective studies on the impact of a subsequent pregnancy, if any, on recurrence and survival of women with breast cancer, there continues to be considerable uncertainty about whether there are risks associated with pregnancy and if so, their magnitude. How women with breast cancer make their decisions about childbearing in this context of ambiguity has received little empirical investigation to date.

We could find only one study in the literature which directly addressed the issue of pregnancy decision-making following treatment for breast cancer. In this investigation [Dow, 1994], qualitative interviews were conducted with a small sample of women (n=16) who had had children following breast cancer. The investigator found that three themes were most prominent in women's reasons for deciding to become pregnant after cancer; (1) having children was a cherished goal; (2) desire for a sense of normalcy; and (3) reconnection with others (e.g., peers). Despite ultimately successful pregnancies, these women did report that at the time of their decision-making and during pregnancy they worried about: (1) having a normal pregnancy; (2) delivering a healthy infant; (3) fears about recurrence; (4) effective medical surveillance during pregnancy; and (5) concerns about breast feeding.

When the meaning of having children after breast cancer was explored, several themes were again prominent: (1) their children helped direct their attention outward and not inward at their health problems; (2) their children directed their attention toward the future; (3) having children fostered their recovery by giving them a reason to live and look forward to the future; and (4) having children made them feel complete. While based on a small sample, the findings illustrate the central importance of family issues to women's perceived quality of life following breast cancer.

In an anecdotal report on considering parenthood after cancer, Accola and Sommerfeld [1979] identified the possible mutagenic or teratogenic effects of chemotherapeutic agents as a salient concern of cancer survivors. While male cancer patients have the option of banking sperm before beginning treatment, no comparable opportunity exists for women patients.

Evidence that the concerns of cancer survivors about the risks of conception to either themselves and/or their offspring may often deter them becoming biological parents is available. For example, a study of decisions about marriage and pregnancy among 263 male and female survivors of childhood cancer (n=263 survivors) [Teeter, Holmes, Holmes, and Baker, 1987] found that while infertility problems were no more frequent among survivors than their sibling controls, the former were significantly more likely to have decided to have fewer or no children. Analysis of this data aggregated with that from several other sites participating in a multisite collaborative investigation (n=2506 survivors), similarly found that while 44.4% of child and adolescent cancer survivors had not become pregnant, the comparable figure among sibling controls was only 29.3% [Byrne et al., 1985]. They also observed a greater risk among childhood and adolescent cancer survivors of what they termed "subfertility" -- defined as the individual being pregnant no more than once.

In another report [Dow, Harris and Roy, 1994], 23 women who had had a pregnancy following breast cancer and 4 who subsequently adopted a child were compared with a sample of 23 breast cancer patients with no subsequent pregnancies. The comparison group was matched for age, stage of disease (i.e., tumor size and number of lymph nodes involved), and time from treatment completion to onset of a full-term pregnancy. Data from a subsample of women who completed measures of perceived quality of life and psychosocial adjustment revealed no significant group differences.

Because having children is a central quality of life issue for most women, it is important to understand more about how they strive to make this important decision in a context of limited information and ambiguity. To investigate this problem, we conducted indepth interviews with 50 women previously treated for breast cancer. A central objective of the study was to explore what women perceived as the possible risks and expected benefits of having a baby after breast cancer. The study was intended to be exploratory given the relative dearth of information about the problem of interest. The intent was to generate insights into the varied factors that influenced their decision-making around pregnancy. The principal findings concerning this issue are presented below.

Methods

To be eligible for inclusion in the study sample women must had to: (1) have completed treatment for breast cancer at least six months earlier; (2) currently be 45 or younger; (3) be a non-Hispanic white or non-Hispanic Black; (4) be currently actively deciding whether to attempt pregnancy or have actively consider it and made a decision within the past three years; and (5) believe that they still had the capacity to become pregnant. With respect to the last criterion, we had originally intended to require that women have no perimenopausal or menopausal symptoms. However, many of the women who contacted us who had had chemotherapy and were not currently menstruating or menstruating only irregularly, indicated that they were unsure if they were menopausal or if their periods would eventually return. Their physicians typically expressed similar uncertainty. In addition, many of the women were taking tamoxifen. Because some of the side-effects of this drug (e.g., hot flashes, irregular menstrual periods) can mimic symptoms of menopause [National Cancer Institute, 1994], these women were also uncertain about their menopausal status. For these reasons, we simply required that women believed that they still had the capacity to become pregnant or would have that capacity when their periods resumed.

Women were recruited with the assistance of organizations such as Share, the American Cancer Society, and Cancer Care who informed potentially eligible members or clients of our study and gave them information to permit them to self-refer. These procedures protected the confidentiality of the women. Several women were also recruited from the patient population at the investigators' own institution. In total 50 women were interviewed. Of these, 42 were White and 8 were Black.

Women in our sample ranged in age from 22 to 44 at the time of their diagnosis, with a mean age of 33.4. The time since their diagnosis ranged from 8 months to 8 years with a mean of 33 months. At the time of the interview 66% were married, 6% were divorced, and 28% were single and had never been married. Eight women in the sample had been pregnant a total of 11 times since their diagnosis. Two of the pregnancies were current at the time of the interview. Of the other 9 pregnancies, 4 resulted in live births of healthy children, 4 were terminated pregnancies and 1 was a still birth. All of the women disease had been confined to the breast or regional lymph nodes. Four of the women had experienced a recurrence of their disease.

All participants completed an indepth interview that lasted two hours on average. While there was a standard set of questions we sought to cover with each woman, participants were also encouraged to bring up anything they felt might be relevant to understanding their attempt to come to a decision on the matter of becoming pregnant. We also probed about issues that came up spontaneously in the women's accounts of their experiences that we felt might have relevance to their decision-making. With the exception of some items intended to obtain personal background and medical information, all of the questions were open-ended and women were encouraged to be as expansive with their answers as they could.

All interviews were audiotaped and transcribed for analysis. ZY-Index a text-based software program designed to facilitate the analysis of qualitative data was used to retrieve materials from the interviews likely to be relevant to understanding the women's perceptions of the risks and benefits of attempting pregnancy after treatment for breast cancer. Relevant material was located by both excerpting responses to related questions contained in the interview guide, as well as by searching the womens' narratives for terms likely to be embedded in relevant text (e.g., "risk", "danger", "fear", "desire", "safe"). All relevant material was extracted and subjected to a content analysis in an effort to identify the principal themes in the women's narratives.

Results

Deterrents to becoming pregnant

Several themes were prevalent in the women's narratives regarding perceived deterrents to attempting pregnancy. These related primarily to risks or dangers they perceived to be associated with having a child. Associated with these perceived risks were various negative emotional responses --typically guilt or conflict -- that the women experienced when they contemplated having a child after cancer.

1. The fear of a recurrence of their disease. As with most cancer survivor populations [Siegel and Christ, 1989], the fear of a recurrence of their disease was prevalent among the women in our sample. Some women specifically worried that the hormonal changes brought about by pregnancy could stimulate a recurrence of their cancer. Typically these were women who had been told their tumor was estrogen receptor positive. One woman said:

> I've heard of cancer...being kind of jump-started by pregnancy because of hormonal changes. And sometimes you think breast cancer, ovarian cancer, you know, whatever is hormonally related ... That's really it. And you think to yourself, 'Am I really clean? Because if I get pregnant, and if I'm not, stuff happens'.

Given the possibility they perceived that pregnancy might lead to a recurrence and premature death, women wondered if it was morally right to bring a child into the world. Further, they felt there was something patently illogical in risking one's life to have a child one might then not be alive to raise. As one woman said, "Where's the sense in having a child you won't be here to care for."

Others simply feared that their disease might return after the child was born, although they did not assume their pregnancy would necessarily be implicated. Under either circumstance, the women believed that their disease recurred their prognosis would be significantly poorer than at their initial diagnosis, and their likelihood of becoming ill or even dying would be considerably enhanced. One woman remarked:

> I've been mostly reassured that pregnancy couldn't initiate a recurrence. But then I feel like, well no one knows for sure ... I guess the main risk I think about is recurrence and, you know, I don't survive it and die, and then my kids are left without a mother.

Even if their disease recurred and they did not die, some women felt that it would be a significant burden to a young child to have a seriously ill mother. A few had had a mother who had been very sick with breast cancer or another chronic illness when they were a child and still felt the emotional and psychological impact of that situation. One woman whose mother was ill when she was young recalled:

> I knew from my mother that I was left alone ... Emotionally she didn't want to leave me alone, but I was physically, I was left alone as a child. My sister was in school and my mother was at the doctor's. I had to go with her. And even as a small child I felt I was taking care of her. I think that's the worst thing in the world for a child.

Several women, who at the time of their diagnosis had a child old enough to understand that their mother was seriously ill, felt that the experience had been an emotionally trying and difficult one for the child. For example, one women who already had two children at the time of her diagnosis, felt that the stresses of her illness and treatment had had a negative impact on them and decided she would not want to take the chance of having another child, having a recurrence, and putting that child through the same ordeal. Another said: "I worry about them [my child and my husband] seeing me suffer...I'll suffer quietly, but still, I don't want someone else to suffer because of my suffering." Still another woman said:

> It is devastating to a child to lose a mother. So, you know, I think that when it came down to it [becoming pregnant], no matter what my spiritual attitude is toward it, I guess I would probably feel pretty guilty if I had a child and the child was young and I died from cancer knowing when I conceived the child that there was that possibility.

For those women who had already had a child before their diagnosis, there was also the feeling that it was not fair to that child to do something that might jeopardize their survival and lead that child to experience a profound loss. While these women may have always wished to have more children, they acknowledged that they should "count their blessings" that they had already had a child by the time they were diagnosed with breast cancer. One mother of two children born before her diagnosis, who had decided not to try to become pregnant again after breast cancer, explained her choice by saying:

> Just the thought, because it's not known and the possibility exists that it can shorten my life for this to recur. It's not fair to my children, you know, or to me. Being their mother, that's more important than anything. Like I said, if the situation were to exist that I didn't have children, that would be a different-- the answers would be different.

Although some were confident that their husband or family would step in and ensure that the child's emotional and practical needs were met if they died, a few still believed that the child would suffer not having its biological mother. As one woman who knew her husband and family would be there for her children if she died expressed it, "No body, no matter what, would care for them like I would." She felt that the loss of the special love and attachment a biological mother has with her child could never be replaced.

While these women did not doubt that they had much love to offer, they questioned whether trying to have a child of their own would be a selfish act, which although meeting their own needs, might bring a child into a situation that was less than desirable. Some wondered if they were they being immature or stubborn to cling to their desire for a baby of their own. A woman who had decided not to try to become pregnant after breast cancer said:

> I mean the idea of having and abandoning the child... would just be unthinkable to me...I certainly didn't want to bring into the world a child without a parent. I mean that to me is just too difficult for the child. Even if my need was so great to have the child.

2. The fear that their child might have a birth defect because of the chemotherapy or

radiation they had received. Some women worried that there might be toxic residues in their bodies of the chemotherapeutic agents they had received as treatment for their disease and these could cause fetal abnormalities. One woman commented: "What if the child is deformed because of the chemotherapy. Although my organs are apparently fine, you know, they did a lot of tests. But I keep thinking, 'What if the child is deformed.'" Another woman remarked:

> My concern was the chemotherapy... It wasn't so much the breast cancer itself, as it was the chemicals that may be deposited in the body and it triggers off something else that may trigger off something with the baby. You know what I'm saying? .

Most who held this fear felt this risk could be minimized or eliminated by postponing childbearing a number of years to allow the opportunity for their bodies to be completely purged of these chemicals. However, if the woman was already in her late thirties or early forties, waiting a few years seemed for some a luxury that they feared their "biological clock" would not allow. A couple of these women also expressed that because the risks of birth defects increase with age for women in general, to wait a period of years before conceiving might carry its own risks.

Women who had received radiation were generally somewhat more optimistic that the radiation had been effectively targeted to avoid exposure of their eggs, but a couple still worried about the possibility that their eggs had been damaged and there might be a greater risk the child would be born with some disability. A related fear of women was whether they would have a healthy pregnancy given their previous exposure to toxins and radiation. A couple worried that they might be at increased risk for a miscarriage which they anticipated would be devastating given the intense longing they experienced to have a child.

3. The fear that their child would be born with a greater susceptibility to cancer. Women worried both specifically about the possibility of having a daughter who was likely to develop breast cancer as an adult, but also more generally about whether their child might be more likely to be born with cancer or to develop childhood cancer. Those who expressed this fear also worried that having a child might be a selfish or immoral act. One woman said: "You don't want to bring a baby into the world that you know somewhere down the line, it's going to have to suffer. That's not right, if you know it."

A few women who felt that their diagnosis and treatment had been particularly distressing and that they had suffered a great deal, related that they were concerned that if they had a daughter, she might be doomed to endure the same physical and emotional pain someday. One women remarked:

> I think, 'Oh you're just being selfish to want to have children. What's it gonna mean for the child. The child's gonna grow up and have breast cancer. You're going to give all this pain to another human being'.

Other women adopted a more optimistic attitude saying that by the time their daughters were grown there might be a cure, or at least a way to diagnose breast cancer very early. Barring such advances, they believed that at least their daughter would have the advantage of being educated about the disease and know how to ensure that it was detected very early. While most women admitted that certainly it was distressing to think if they had a daughter she might one day develop breast cancer, almost all said this by itself would not deter them.

Several women worried about genetically passing on a general susceptibility to cancer to a male or female offspring. Several believed that their child might be born with cancer if any undetected cancer cells were still lurking in their bodies during their pregnancy. Again, concerns about whether it was fair or morally right to put a child at risk for a terrible life-threatening illness were expressed. Others felt that while the child might not be born with cancer, he/she would have a greater propensity to develop a childhood cancer because of some presumably genetic predisposition that would be inherited.

4. **The concern that caring for a child would be too stressful.** Some women expressed concern that caring for a baby or young child would be very physically demanding. While a few women worried whether such demands would be good for their overall health, most were concerned about whether they

would have the energy to provide the level of care and involvement they would want to provide to their child. One woman who already had a child at the time of her diagnosis and was undecided about whether to attempt to become pregnant again feared the physical demands of pregnancy. She said:

> Well the risks of having another one are I mean, I guess making demands on my body when my body might need all its resources just to stay healthy ... I just might not be physically and mentally up to the demands I would have to face ...I would worry that I would feel so tired and so pulled in different directions that it would be detrimental to my health. And I am pretty protective of myself these days. So that I see as a risk.

These fears were especially prevalent among those who felt that they had not regained their pre-illness level of energy and found they continue to fatigue easily. As one woman said: "I'm not sure that I have enough energy to mother a child...You know, I want to have a baby that doesn't have, that you are too tired to play with or anything like that."

One women worried about the long-term effects of all the chemotherapy she had received on her body. She commented:

> ... five, ten years down the line what is my health going to be like...All the drugs that went through my liver and my kidneys, my body. What kind of effect, what kind of shortness of life they're causing my organs.

Incentives to becoming pregnant

Despite the potential risks women perceived to be associated with becoming pregnant after breast cancer, they also saw important gains that could be realized. The incentives were both those that most women in general see for having a child and some that were more specifically related to their illness experience.

1. Having a baby is a cherished part of a life plan. Most women reported that they had grown up always wanting to have a child or family of their own. For most, this was an important part of their life plan that they were committed to trying to actualize. It was a dream or goal that they were very emotionally invested in realizing. One woman who admitted fearing the possibility of a recurrence if she became pregnant nevertheless said:

> The benefits to me emotionally outweigh the risks to have like a future with a child or a family that you have always wanted. So that seems to me like you can't have anything more. That is the ultimate to me.

When asked what loses she felt she would experience if she decided not to become pregnant in the future, this woman said: "A very unsatisfying life. Unfulfilled ... I think that I would feel a loss if I didn't become a mother naturally. I always wanted to see their hands, their face, the future of your family."

Many felt that breast cancer had robbed them of a great deal including physical attractiveness, self-esteem and a sense of security and confidence about the future. Some felt more insecure in their relationships with men (if unmarried), in their marriages, and in their jobs and careers. The further loss of an opportunity to have a child of their own was something they resisted strongly. One woman commented:

> There were so many events in my life that were things that happened that were blocks and were obstacles; a situation or a person or something trying to hold me back or hold me down. A female thing. ... And its sort of like this final thing [having a baby] that maybe I do feel I do have control over, you know. That I don't, I don't want someone to tell me 'No'.

2. Having a baby is life affirming. A related theme to the to the previous one was that having a child is life affirming. It would be a way of saying, "I'm here to stay. I have a job to do to raise this child and I'll be here to do it." It was also a way of saying they believed in their future. While most women felt they were strongly motivated to stay well, a few also expressed that they believed that having a child to raise would be an extraordinarily powerful motivator to stay healthy and alive, to have a strong will to live. A child, some said, would give them more hope and optimism about the future. One woman said:

> Having a child forces you to focus on the day to day and there is a normal sense of joy. The day to day is good in the sense that even though I am not obsessed on the fact that I've had cancer, I think there is still a presence there. But day to day existence with a child, although a lot of work, is a joy and it is life affirming. It's like saying the doctors have said I'm okay. I'm going to go back to life.

3. The belief that having a child will promote a feeling of normalcy. Women diagnosed with breast cancer often experience an abrupt sense of discontinuity with the past. Their lives seem jolted and thrown off course. Some spoke about feeling different or set apart from their peers. They felt that having a child would return them to the world of the healthy, the living. As one woman put it, when you have a child "you're back in life again."

Many women spoke of how they and their husband were already making plans to have a child when they were diagnosed and about how their peers and siblings were already having children. Some felt left behind because of their illness. They weren't doing the things that were developmentally normative, such as starting a family in one's thirties. A few believed that having a child would help them restore a sense of normalcy in their lives. One woman said:

> I see it as getting on with my life, and not letting the breast cancer hold me back or rob me. I suppose you could say having a normal life. And I see having children as part of a normal married life.

Women spoke too of how having a baby would affirm their normalcy as women and restore their sense of normal femininity and sexuality. Having a baby, they believed, would also make them feel that they were no less a woman despite their disease. It would signal to themselves an others that, as one woman said, they could still function as a woman, even without their breasts. Another woman talked about how she felt when her breast cancer doctor had asked her if she was planning to have any more children. She reported that she was delighted that he asked her the question, because it signified to her that he still viewed her as a vibrant, well-functioning woman. Another commented: "It reinforces the fact that you are still a woman ... They just took away part of your body... but it [having a baby] just reinforces the fact that you are still a woman. You can still perform."

Despite positive changes in women's self-concept and enlarged opportunities for achievement brought about by the women's liberation movement, the ability to bear a child is still very important to many women's feminine identity and sense of self-worth. Women admitted that their self-view and confidence about themselves as attractive, desirable women had already been dealt a blow by their breast cancer and the deformity some believed resulted. To also lose their opportunity to bear a child was a further insult some were unwilling to endure.

One woman described her reaction when her physician talked about also removing her ovaries as a further precaution against the spread of her cancer. She recalled:

> At one point, one doctor had discussed removing my ovaries and it was like 'No way. I've lost a breast; you're not taking those too...If you are going to start taking things from me that are important to my womanhood, then I just can't deal with it...I'm going to hold on and protect as long as I can the fertility that I do have.

Another said, that having a child would allow her to say to the world: "Hey I can still do that. I'm still a woman, you know. And I think that's an issue. I think your sexuality is a big issue, a very big issue actually."

4. **The wish to give her husband something that would make him very happy**. A final theme that emerged, but with considerably less frequency was the desire to have a baby for one's husband. However, this was in no case a primary motive. These women expressed that they knew that their husbands very much wanted a child and that they wanted to be able to give it to them. Women spoke of how enduring the diagnosis and treatment experience together had forged a special bond and sense of closeness between them and their husband. This bond, together with the gratitude they felt for all the

support their husbands had offered them, fueled their desire to have a child together. One recounted that after her breast cancer, her husband had always said that it was up to her if they would have children. He had repeatedly reassured her that whatever decision she made about having children would be fine with him. She had believed that it really did not matter to him if they did not have a child. She recalled how bad she felt one day when finally one day he said: "You know, I'm starting to feel old. It would be nice to have a child."

If couples talked about having a child or having another child before the disease and the woman knew this was something her husband was looking forward to, she wished to be able to give him a child. She did not want him to have to miss out on having a child because of her illness.

Some women felt that having children was something they and their spouses both expected in their marriage; in a sense it was something they had contracted for going into the marriage. One woman related an incident that she still recalled as very painful over two and a half years later. As her husband wheeling her out of the hospital following her breast surgery, he saw another man wheeling out his wife with a newborn baby. He said: "That's the only reason I thought I would ever be in the hospital, to check you out from having a baby, Here I am checking you out for a mastectomy." This woman spoke about how bad she felt, both for her husband and for herself, when he made that remark.

5. The belief that having a child would improve their quality of life. For the most part, women were not counting on a baby to make them happy. They realized that that had to come from within themselves. Still they expected that having a child would bring certain pleasure into their life. One woman remarked:

> I think I might be very happy having a child...And that it might, probably would, add a great deal to my life. Now I look at my friends who have children, and I see that it adds lots of hassles, but it adds lots of joys. I can see the pleasure that they're getting in between the hassles. And I can see the gratifying aspects of it very easily.

Another woman who did go on to have a baby after breast cancer said: "To me and [her husband] it's just something that we always wanted and something that is very special to us. And it has a lot of meaning to us. And it just, you know, makes each day a little more special."

Discussion

The findings from our sample of women, most of whom were contemplating pregnancy after breast cancer but had not yet attempted conception, closely parallel those described by Dow [1994] who interviewed women who had already had children following breast cancer. Most prominent among the motivating factors was that having a child and a family life were a long cherished aspects of many of the women's life plans and a deeply felt desire that was not diminished by their breast cancer. As Accola and Sommerfeld [1979] observed about couples in which one partner had cancer, "If having children was one of the couple's goals before such a diagnosis, it will probably remain a goal afterward" (p. 1581). Still, some women decided not to act on their strong desire to have a child of their own because of concerns about their own health or that of the child. Although these women believed that it was medically prudent for them to relinquish the goal of becoming pregnant, and even recognized that they would likely be anxious about recurrence if they conceived, the sense of loss that they felt was still profound and readily apparent in their expressed affect during the interviews. The symbolic meanings attached to becoming pregnant were also evident in the women's accounts. Being able to have a baby meant that one was still a vital functioning woman. It could blunt the feeling that one had suffered a loss of femininity. Having a child would represent a kind of reclaiming of one's body by showing that it could produce something beautiful and valued, rather than harbor something feared and destructive.

Most prevalent in the womens' narratives as a deterrent to pregnancy were fears of recurrence. Women struggled to try to evaluate the magnitude of the increased risk for recurrence that having a child would represent. Because there was no information that enabled them to quantify this risk, some found themselves ruminating about the risks or safety of pregnancy and were locked in indecision about whether to proceed with trying to conceive. Women who already had one or more children before breast cancer clearly found it harder to justify taking a possibly serious health risk by becoming pregnant than did childless women. As more time elapsed since the completion of treatment, women's confidence that could stay healthy typically grew and they were more willing to consider becoming pregnant or plan a time to start trying to conceive.

Women generally found that the issue of pregnancy had to be raised by them. Few doctors took the initiative to bring it up themselves. When the topic was discussed, some physicians were unequivocally opposed to the woman becoming pregnant, feeling that this would almost certainly increase her risk of recurrence. Other physicians were willing to support the idea, or at least not oppose it, if the woman was willing to wait 2-5 years after treatment, through the period when the risk of recurrence was greatest.

It should also be noted that single women survivors faced some additional issues that complicated the decision-making process. Most of these women expressed reluctance about considering having a child without a spouse. Clearly for them the concerns about what would happen to that child if their disease recurred and they were unable to provide adequate care loomed large. A couple of women felt that having to go through the diagnosis and treatment of their disease the first time was especially difficult without the support of a spouse, even when family supports were available. The thought of facing recurrence alone and with a child seemed a daunting prospect to entertain. They had to think of what their child would experience if they died and the child had no father. When a satisfying solution to the guardianship issue was not readily available, the decision to go forward with pregnancy seemed hard to justify. While these women were reluctant to consider single motherhood, they also worried whether they would find a partner who accepted them and would want to start a family given their illness history, and their perceived disfigurement.

When asked what would have been useful to them as they went through the decision-making process, almost all study participants said more information. Women wished that a doctor or nurse had taken the time to sit down with them and discuss the matter directly. They wanted their doctors to tell them what was actually known about the risks of becoming pregnant after breast cancer. They also wanted their doctors to inquire how important the idea of having a child was to them and their partners. The data suggest that if the physician is perceived as avoiding discussion of the issue of pregnancy, women may be interpret this as a negation of her femininity or as a sign that the physician believes her prognosis is poor.

What many of the women would like physicians to understand that, as one woman expressed, "... the pregnancy thing is not just a medical issue. It's an emotional issue too." There may be potential risks associated with pregnancy after breast cancer and women want their doctors to discuss those with them. However, they also want their doctors to understand that this is not an issue that can always be decided on a purely rational or statistical basis. Having a child of one's own, having a family life, and completing a life plan are goals that hold tremendous emotional meaning for most women and that does not change because they had breast cancer. If anything, this desire may become even stronger.

References

Accola KM, Sommerfeld DP. (1979). Helping people with cancer consider parenthood. American Journal of Nursing, 79, 1580-1583.

Ariel, I.M., & Kempner, R. (1989). The prognosis of patients who become pregnant after mastectomy for breast cancer. International Surgery, 74, 185-187.

Byrne, J., Mulvilhill, J.J., Abbott, S.C., Connelly ,R.R., Hanson, M.R., Hassinger, D.D., Naughton, A.D.F., Gurgin, V., Holmes, F.F., Holmes, G.F., Latourette, H.B., Weyer, P.J., Meigs, J.W., Teta, M.J., Strong, L.C., & Cook, J.A. [1985]. Risk of infertility among survivors of childhood and adolescent cancer, American Journal of Human Genetics, 19:423-430.

Clark, R.M., & Chua, T. (1989). Breast cancer and pregnancy: The ultimate challenge. Clinical Oncology, 1, 11-18.

Clark, R.M., & Reid, J.M. (1978). Carcinoma of the breast in pregnancy and lactation. International Journal of Radiation Oncology, Biology, Physics, 4, 693-698.

Cooper, D., & Butterfield, J. (1970). Pregnancy subsequent to mastectomy for cancer of the breast, Annals of Surgery, 171, 429-433.

Danforth, D.N. (1991). How subsequent pregnancy affects outcome in women with a prior breast cancer, Oncology, 5, 23-35.

Danforth, D.N. Jr, & Lippman, M.E. (1988). Surgical treatment of breast cancer. In: ME Lippman, AS Lichter, DN Danforth Jr (Eds.), Diagnosis and management of breast cancer, pp. 95-154. Philadelphia: WB Saunders.

Dow, K.H. (1994) Having children after breast cancer. Cancer Practice, 2, 407-413.

Dow, K.H., Harris, J.R., & Callista, R. (1994). Pregnancy after breast-conserving surgery and radiation therapy for breast cancer. Journal of the National Cancer Institute Monographs,16, 131-137.

Hendin, H., & Siegel, K. (1981). Psychodynamic and structured interviewing: A synthesis. Comparative Psychiatry, 22, 153-61.

Hofferth, S.L. (1983). Childbearing decision making and family well-being: A dynamic sequential model. American Sociological Review, 48, 533-545.

Holleb, A.I., & Farrow, J.H. (1962). The relation of carcinoma of the breast and pregnancy in 283 patients. Surgery, Gynecology and Obstetrics, 115, 65-71.

Mignot, L., Morvan, F., Sarrazin, D., et al. (1986). Breast carcinoma and subsequent pregnancy. Proceedings of the American Society of Clinical Oncology, 5, 57-61.

Miller, B.A., Ries, L.A.G., Hankey, B.F., Kosary, C.L., & Edwards, B.K. (eds). (1992). Cancer Statistics Review: 1973-1989, National Cancer Institute. NIH Pub. No. 92-2789.

National Cancer Institute (1994) Cancer facts: Questions and answers about tamoxifen.

Peters, M. (1968). The effect of pregnancy in breast cancer. In A.P.M. Foresy, P.B. Kuckler (Eds.), p. 65-80. Prognostic factors in breast cancer. Baltimore: Williams and Wilkins.

Riberio, G.G., & Palmer, M.K. (1977). Breast carcinoma associated with pregnancy: A clinician's dilemma. British Medical Journal, 2, 1524-1527.

Rissanen, P.M. (1969). Pregnancy following treatment of mammary carcinoma. Acta Radiologica Therapy Physics and Biology, 8, 415-422.

Siegel, K., & Christ, G. (1989). Psychosocial consequences of long-term survival of Hodgkin's disease. In: J. Redman, M. Lacher (Eds). Hodgkin's disease: The consequences of survival. Philadelphia PA, Lea and Febiger.

Sutton, R., Buzdar, A.U., & Hortobagyi, G.N. (1990). Pregnancy and offspring after adjuvant chemotherapy in breast cancer patients, Cancer, 65, 847-850.

Teeter, M.A., Holmes, G.E., Holmes, F.F., & Baker, A.B. (1987). Decisions about marriage and family among survivors of childhood cancer. Journal of Psychosocial Oncology, 5, 59-68.

U.S. Bureau of the Census, Statistical Abstract of the United States: 1995. (115th edition.) Washinghton, D.C.

IV. APPENDIX B

Unique Stressors of Unmarried Women with Breast Cancer

(Proprietary Material)

Unique Stressors of Unmarried Women with Breast Cancer

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Abstract

Although marital status may be a significant variable in determining adjustment to breast cancer, limited empirical research has addressed the unique challenges of single women with this illness. As part of a study examining pregnancy decision-making following breast cancer, 16 unmarried women participated in in-depth interviews. They described five principal stressors associated with being an unmarried breast cancer survivor: pessimism regarding future relationships, fears about disclosing their illness to partners, negative body image and impaired sexuality, pain of rejection by partners, and a sense of isolation and inadequate support. These findings suggest that unmarried women with breast cancer may be a vulnerable subpopulation of women with the disease who may benefit from psychosocial interventions tailored to their particular concerns.

Single women with breast cancer may face particular stressors. For example, they might face difficulties in the realms of actual or anticipated rejection, perceived desirability, and social support. As part of a study of pregnancy decision-making following breast cancer, 16 single women were interviewed. Almost all of the single women discussed how their marital status influenced their cancer experience. Below is a description of the principal themes uncovered in their narratives which may help elucidate the unique stressors faced by single women with breast cancer.

The Influence of Marital Status on Adjustment to Breast Cancer

Limited attention has been paid to marital status as a determinant of breast cancer adjustment. Some researchers have found that single women with breast cancer have a better psychological outcome (Pistrang and Barker, 1995; Dean, 1987). However, Cella (1987) reviewed work which found that cancer patients without a significant loved one were at increased risk for distress. Schover (1994) noted that concerns about sexuality and fears of rejection may be particularly prominent among unmarried women with breast cancer. These women face the unique stressor of telling new partners about their illness and revealing their altered body.

However, none of the work cited above studied marital status as the variable of primary interest. Further, no previous work has examined the issues unmarried women face in coping with this illness. Thus, little is known about the specific stressors and challenges of single women with breast cancer. Below we will describe themes uncovered during interviews with 16 unmarried women diagnosed with breast cancer in order to illuminate some of the unique stressors they face.

Method

To be eligible for the study from which the data are drawn, women had to: 1) have completed all breast cancer treatment at least six months previously; 2) currently be 45 or younger; 3) be white (non-Hispanic) or black (non-Hispanic); 4) be actively deciding whether to become pregnant or to have made a decision about this issue in the previous three years; and 5) believe they had the ability to become pregnant. Several prominent cancer organizations, including the American Cancer Society, Share, and Cancer Care, assisted with recruitment. These organizations notified their clients about the project and provided them with contact information to self-refer. In addition, several women were recruited through our own institution.

Study participants met with an interviewer once. After informed consent was obtained, they completed a questionnaire which elicited sociodemographic and medical information and then participated in an in-depth, unstructured interview which typically lasted two hours. Women were also encouraged to provide any information about their illness experience that might be helpful in understanding their adaptation to their disease. All interviews were audiotaped, transcribed, and relevant information about marital status extracted and content analyzed.

Sample Characteristics

The mean age at diagnosis of the 16 women included in this report was 33.5 (range = 22 to 42). The mean time since diagnosis was 37 months (range = 8 months to 8 years). The majority of the participants were white (n=12) and the remainder were African-American (n=4). Most were diagnosed as stage 1 (19%) or stage 2 (56%). Thirteen of the women had never been married and three were divorced. The sample was well educated: 25% had some college, 44% had a bachelor's degree, 6% completed technical school, and 25% had a graduate or professional degree. Diverse religious affiliations were represented in the sample: 19% were Protestant, 19% were Jewish, 31% were Catholic, 13% were of some other denomination, and 19% indicated they had no religious identification.

RESULTS

Five principal themes emerged from a thematic analysis of the womens' interviews. These were: pessimism regarding future relationships, fear about disclosing, negative body image and impaired sexuality, pain of rejection, and a sense of isolation and inadequate support.

Pessimism about finding a satisfying long-term relationship

The issue of dating was of utmost concern to the participants. Women feared they would be unable to attain a long-term committed relationship. They also appeared to believe that the number of suitable partners available to them was more limited because of their illness. These assumptions of diminished possibilities were due to two limiting factors: some women viewed themselves as more selective now while others expected that men would find them less appealing. Several expressed apprehension that they would ever find an accepting partner. One women discussed her reluctance to break up with her current boyfriend, despite her dissatisfaction. She stated: "What are my guarantees of finding another person that's equally supportive, because he's been here through all this illness...it's hard to guarantee another such helpful soul. That's kind of scary." Another woman described an experience of becoming more selective and thus, more uncertain that she could find a suitable partner. She noted: "I thought I can teach somebody how to be with me or how to deal with this...I'm not sure I can. I'm not sure I want to help somebody grow up...I'm not sure I have the stamina for it." She added: "...as a result of having breast cancer...I really feel a lot more selective about men and who I would want to have a long term relationship with."

Other women spoke of how their chances of finding a compatible partner might be diminished because of their illness and its ramifications. One thought her illness might make her less appealing. She commented:

> I don't form good relationships very easily so I kind of feel like there is another strike against me... (breast cancer is) another negative, as far as getting married and having a long-term relationship. It's another issue I would have to go through in a relationship and it's like my salability.

<u>Fears about disclosing their illness</u>

Women struggled with when and how to share information about their cancer experience with partners. For several participants, discomfort about discussing their cancer and a fear of rejection led to an avoidance of new relationships. One stated:

> I don't know when you've become intimate enough with a person to tell them. Do you tell them on the first date, do you tell them on the tenth date... A friend keeps on telling me there are men out there that are wonderful. I thought I had wonderful (with ex-boyfriend who left her after she was diagnosed). We had made a lot of commitments and promises together and wonderful turned out to be a pretty sour apple. So, how do I know to trust somebody else.

Other women noted similar concerns about disclosure. One wondered how sharing information about her illness would influence the development of a relationship:

> When do you tell them? Obviously you don't tell them on the first date because you don't know if it was this (the cancer) or if they didn't care for you (that led to the relationship not lasting). So there are a lot of other things that come up with this, being single.

Another woman said she was "...afraid to start a new relationship because of the thought of..how do you explain all these years, the last few years to a new person?" She described her reluctance to end her current dissatisfying relationship because of fears of having to disclose her illness to a new partner. She said:

> The thought of saying "good-bye" to him and having to explain to a whole new being -- relationships are hard enough to start this day and age, under normal circumstances, but how do you explain to a whole new person that there's a real big chunk of me that's not here anymore. That scares me. So I think that's the hardest part of being a young person with cancer...to be a single woman and be in that position and have had breast cancer with the results I did....to have a chunk missing ...the thought of starting a new relationship to me is overwhelmingly frightening.

Negative body image and impaired sexuality

The breast cancer experience also appeared to influence how many of the single women viewed their bodies and their sexuality. For those subjects who lost a breast, their disfigurement appeared to negatively affect their view of themselves as sexually desirable.

Consequently, they were more likely to avoid a sexual relationship due to fear of rejection. One woman discussed how these issues led to the dissolving of a relationship:

> I was trying to fight this disease and yet I didn't feel very attractive. And he had some physical needs... I wasn't even in no shape or form even thinking along those lines. I was trying to deal with the fact of losing a breast and how I felt going through chemo...so it was easier, I guess, for him just to leave.

This woman also discussed how her views about her desirability and attractiveness had changed because of her illness:

> Sometimes I guess I just don't feel sexy. I used to feel I could wear some things that I can't wear now. It took me for the longest time to think I could even wear a bathing suit, but I got that behind me. It's been so long, I don't know what it feels like to be sexy...there's not been anyone I've met that has made me feel that way, either.

When discussing the possibility of sexual activity she stated: "Now I would never meet somebody and have a physical relationship, after three dates with them ... maybe before I would. But now I wouldn't do that." She explained her hesitancy about sexual relationships:

> That person would have to be really special for me to share that kind of intimacy with, especially because it's hard enough to date as it is, but yet to explain to somebody...I have had eight operations. I do have scars, you can tell that. As good as plastic surgery can be, they'll never be the same. And so that's difficult...when and if it happens, that'll be a difficult thing.

Another woman also spoke about the changes in her appearance and how it might affect her chances of forming a relationship:

> Getting the breast cancer it was like "Great! This (her breasts) is like one part of my body that I really could look at and love" and my boyfriend always said it and every man I ever dated always said that I had great breasts and I'm like "They are gone, they are only half there." So I don't feel that secure. I have a lot of problem with going out and dating.

Fears of rejection from partners

Another issue for participants was actual or expected rejection from partners due to their illness. Both women who had been with their partners for many years and women who were involved with new relationships experienced losses.

Several women in relationships at the time of diagnosis described their experiences of rejection from their partners. One woman described the actions of her partner of a year whose wife had died from cancer: "He said he couldn't go through it again for another person because it was so emotional with her, but he stuck by me until I started chemo. Then he left." Although she viewed him as helpful initially because of his prior experience, he was unable to sustain his support. She added:

> He explained to me so many things that his wife had, that she went through and he told me why I had to go through it and he said, "The only thing is, I'm not going to stay with you for so long because I can't go through it again. I had a hard enough time going through it with her."

Another woman described how her relationship of eight years ended following her diagnosis of cancer. She stated:

> He was kind of there (after her diagnosis) for about two months and then he couldn't handle it anymore, he left. He was around in the beginning and then he got scared....Whether or not our kids would be born normal and the fact that he was a physician and knew that I needed to wait a few years in the best interest of myself and children. He didn't know if he could handle it.

Another woman described her eight month relationship with her current boyfriend, which she thought might soon end. She stated:

> (boyfriend) thought of my breast cancer as something really in the past. And he was finding out that it wasn't in the past. I mean, even if I didn't have a recurrence, it was a big part of my life and my consciousness and it was real. The risks were real. But I think it's (boyfriend's concerns) still with him and he began to pull away...We talked about it and he told me how scared he was and how he had called the American Cancer Society and asked them what my chances were. That really upset me, the whole thing. We have talked about getting married, but I'm not sure he can handle this. It brings up the idea that someone really smart thinks I'm a bad risk... it took away (my) confidence in his ability to handle it.

She later added:

> (boyfriend) asked me earlier on about what my chances were... and the numbers are not that good. They're just not that good. I said it basically like "If the numbers aren't good, then you're going to leave me?" Like there is something too creepy about this for me. It just doesn't seem good. Because

> then I have to worry about him leaving me...there is just something in here that just seems so calculating. If he loves me, is there really a decision to be made?... the whole thing kind of pains me.

Others described relationships that ended quickly after their diagnosis or when they revealed their cancer history to a new potential partner. One woman stated:

> When (ex-boyfriend) took me home from the hospital, it was just like he couldn't handle it. He said he couldn't get attached to me again. It was too hard. So I was dealing with that emotionally...We don't choose to see each other as friends now, I think it's just too hard. If I see him on the street, he's happy to see me, I'm happy to see him, but he's afraid to make that next step.

Another woman described a potential relationship which ended because of her illness:

> I felt that if I was close enough to him to be fooling around with him on the couch, I was close enough to him to tell him what I had gone through. And after telling him... he told me that he felt a little weird about it and that he wasn't really sure if he could continue dating me...I realized that he was in fact pulling away. He said, "Well, I have a couple of fears... number one, I'm afraid that I'll fall in love with you and you'll die. Number two, I'm afraid I'll fall in love with you, want to marry you, have children with you, and then our children will have possible risk for breast cancer. Number three, I'm afraid of what I'll think when I finally see your body."... So he was totally in a very very different place than I needed someone to be. And then we just very very quickly grew apart.

Sense of isolation and inadequate support from others

Several subjects described the difficulty of going through treatment without the support of a partner, missing both practical help and emotional support. They described an experience of feeling alone and a longing for a close companion and confidant. When asked about the most difficult aspect of having breast cancer as a young woman, one participant responded: "probably being single...being home alone at night, not being in a relationship or not having that other person to make decisions with you. I felt that I did miss that at that time." Another woman stated: "going through chemo, living alone, it's very difficult." She further noted: "the thing that was difficult with the surgery is I was a voice. I was solely a voice. That no one saw me day to day, how I lived...that was tough."

One woman described the difficulties of going through treatment without a significant other. She stated:

> It's been a rough road. At times, I really wish there was somebody else there, just not only for hugs and companionship and sharing part of the sorrow...I think it also would be when I want to escape, when I really want to escape from the bills, the collectors --- just having to do all the paperwork. I just sometimes wish there was a person that would just take over and do it for me.... in all aspects, I'd say I think it's ten times more difficult for someone who is a single person than it is for somebody who has someone. Even if they're not emotionally there, they're still physically there. It's very lonely, and it's very scary. And it's very difficult.

She related a particular instance when she wanted the support of a partner: "All my bills keep coming back unapproved. And I keep on fighting with Social Security...this is when I wish I had somebody to take all that other stuff so I can deal with just getting well."

Discussion

The challenges confronted by the study participants as single women were striking. The five themes described above --- pessimism regarding a long-term relationship, fear regarding disclosing to partners, negative body image and impaired sexuality, fear of rejection, and a sense of isolation and lack of help from others --- all highlight how interpersonal functioning and psychosocial adjustment may be affected by breast cancer in single women. The women described altered views of themselves, negative interactions, and pessimistic expectations about relationships. Subsequently, they were often fearful and avoidant of new partners and commitments.

Relationship issues were a salient and emotional concern for these women. Many reported disturbing instances of rejection by close partners early in their illness when their support needs were great. The women also discussed current stressors in the interpersonal realm including negative views of their desirability, fears of disclosing their illness history to new partners, experiences of loneliness, and a reluctance to leave dissatisfying relationships due to fears of not finding another accepting partner. They believed that the stigma of a cancer diagnosis, in addition to their disfigurement, significantly compromised their chances for a committed relationship. Holding negative views of themselves and potential partners may have contributed to diminished relationship expectations. Even women who had boyfriends were unsure that these relationships would become more serious, due to their illness. The perceived permanence of these stressors was noteworthy. A profound sense of hopelessness pervaded these womens' interviews.

As noted above, the data was obtained from a study of pregnancy decision-making and not on single women with breast cancer. Thus, limited information was available on the issue of being unmarried with breast cancer. Therefore, this paper represents only an initial effort to describe the salient sources of psychosocial distress for single women with breast cancer. Future empirical work should examine marital status as a primary predictor of adjustment.

Finally, developing strategies to assist single women in managing these stressors may be beneficial. For example, some women may be helped by skills training which focuses on how to disclose one's medical history to new partners. Other women may benefit from a targeted intervention for improving body image and increasing comfort with sexuality. Hopefully the issues outlined here will spark further interest in this topic and future research can study the adaptive problems of this population in greater depth.

References

Cella, D.F. (1987). Cancer survival: Psychosocial and public issues. Cancer Investigations, 5, 59-67.

Dean, C. (1987). Psychiatric morbidity following mastectomy: Preoperative predictors and types of illness. Journal of Psychosomatic Research, 31, 385-392.

Pistrang, N., & Barker, C. (1995). The partner relationship in psychological response to breast cancer. Social Science and Medicine, 40, 789-797.

Schover, L.R. (1994). Sexuality and body image in younger women with breast cancer. Journal of the National Cancer Institute Monographs, 16, 177-182.

IV. APPENDIX C

Breast Cancer: Age-Related Distress

(Proprietary Material)

Proprietary Material

Breast Cancer: Age-Related Distress

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Key Words: Breast Cancer, Age, Psychosocial Distress, Qualitative Research, Young Women

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Abstract

Available evidence suggests that younger women diagnosed with breast cancer may be at increased risk for poor psychosocial outcomes. However, limited work has examined the mechanisms for why younger women may have poorer adjustment. As part of a study examining pregnancy decision making following breast cancer, 34 women aged 35 or younger participated in unstructured interviews. Many spoke of the unique issues associated with being a young woman diagnosed with breast cancer. The predominant stressors they described included: coping with the untimeliness of the diagnosis, concerns about the impact of the illness on their husbands, sadness about lost childbearing ability, feeling different and isolated, uncertainty about their future, and concerns about their children. A theme of altered belief systems, about themselves and the world, ran throughout their narratives of the adaptive challenges their illness posed for them.

Introduction

A diagnosis of breast cancer constitutes a profound psychological insult for any woman. For younger women, however, who may perceive themselves to be in the prime of their life and are actively engaged in career building and family planning, the diagnosis can be a particularly disorganizing event, unlike anything that they ever experienced. At a time in life when possibilities typically seem almost endless, a diagnosis of cancer seems to impose abrupt and severe limitations on what one can envision as future opportunities (Siegel & Christ, 1989). A diagnosis of breast cancer may also be especially distressing for young women because it may significantly challenge their fundamental belief systems. In particular, young women may hold self-protective beliefs about themselves and the world that are fundamentally challenged following the diagnosis.

While only a limited number of reported studies have examined the importance of age at diagnosis as a variable in explaining psychosocial adjustment to the disease, the clear weight of evidence from this research suggests that younger women with the disease experience more adaptational difficulties than older women (Jamison, Wellisch, & Pasnau, 1978; Vinokur, Threatt, Vinokur-Kaplan, & Stariano, 1990; Northouse & Swain, 1987; Northouse, 1994; Ganz, Lee, Sim, Polinsky & Schag, 1992; Mor, Malin & Allen, 1994; Hughson, Cooper, McArdles, & Smith, 1988; Penman et al., 1986). Significant age differences, supporting poorer adjustment among younger breast cancer patients, have been detected on a wide range of diverse outcome measures including: rates of seeking psychiatric assistance after mastectomy (Jamison et al., 1978), impact of mastectomy on sexuality (Jamison et al., 1978; Hughson et al., 1988; Penman et al., 1986 Shover, 1994), global mental health (Vinokur et al., 1990; Northouse and Swain, 1987; Northouse, 1994; Hughson et al., 1988; Ganz et al., 1992), overall adjustment (Jamison et al., 1978; Ganz et al., 1992), financial well-being (Mor et al., 1994), depression (Hughson et al., 1988), anxiety (Hughson et al., 1988), changed routines (Mor et al., 1994; Hughson et al., 1988; Penman et al., 1986), self-view (Penman et al., 1986), and impaired relationships (Penman et al., 1986; Hughson et al., 1988; Ganz et al., 1992). Confidence in the frequently observed direct association between age and psychosocial adjustment is strengthened by the fact that the timing of assessments varied considerably across studies, ranging from post-biopsy but pre-surgery (Northouse, 1994) to more than 22 months after mastectomy (Jamison et al., 1978).

While the preponderance of evidence does suggests that younger age is associated with poorer adjustment to breast cancer, almost nothing is known about the particular adjustment of women 35 and under as few published studies have made (or permit from the data reported) direct comparisons of these women with older ones. Yet, there are clear theoretical and practical grounds for hypothesizing that women aged 35 and younger confront different adaptive challenges than older women with the disease and may experience unique vulnerability factors.

Adult developmental theory (Erikson, 1963; Levinson, Darrow, Klein, Levinson & McKee,1978; Levinson, 1996; Gould, 1972; Neugarten, 1968; Valliant & Milofky, 1980; Lowenthal, Thurber & Chiriboga, 1975) suggests that a variety of developmental tasks characterize different stages of the adult life cycle. Several significant tasks for younger women are likely to be affected by a diagnosis of breast cancer. For example, women of this age are beginning to merge their identity with a significant other and make long-term commitments. In addition, procreation usually occurs at this time. Breast cancer at this age may impair the formation or continuation of intimate relationships when the disease and its treatment produce concerns about physical attractiveness or desirability as a life partner. These concerns may be particularly intense for women who feel disfigured by the disease, fear that conception may increase the risk of recurrence, or for whom fertility has been compromised or lost as a result of treatment.

Although developmental issues have received some attention in the clinical and anecdotal literature on breast cancer (Rowland, 1989; Siegel & Christ, 1989), they have received little empirical investigation (Dow, 1994; Dow, Harris, & Roy, 1994; Siegel, Gorey & Gluhoski, in press). Thus, little is currently known about how having breast cancer complicates the accomplishment of normative developmental tasks of younger women. As part of a study of pregnancy decision-making among women previously treated for breast cancer, 34 women aged 35 and younger were interviewed using unstructured interviewing techniques. Although the main focus of the study was pregnancy decision-making, most younger women spontaneously volunteered information on the impact of having cancer at a young age and how their reactions to the disease and illness experiences were influenced by their relative youthfulness. Below we discuss the age-related themes that emerged from the women's interviews.

Methods

To be eligible for participation in the study, potential subjects were required to: 1) have completed all treatment for their breast cancer at least six months previously; 2) currently be 45 or younger; 3) be white (non-Hispanic) or black (non-Hispanic); 4) be actively deciding whether or not to become pregnant or to have made a decision about this issue in the past three years; and 5) believe that they had the ability to become pregnant.

Although many of the potential participants had received chemotherapy and were not menstruating regularly, they were unsure if they were menopausal. Their doctors also expressed uncertainty about their fertility status. Because of these factors, it was only necessary that the women believe that they could conceive in order to be included in the study.

Several prominent cancer organizations, including Share, the American Cancer Society, and Cancer Care, assisted with recruitment for the study. These organizations notified their clients about our study and provided them with contact information to self-refer. Thus, the confidentiality of the women was preserved. Several subjects were recruited through our own institution as well.

Study participants met with an interviewer once. After obtaining informed consent, the interviewer administered a questionnaire designed to elicit relevant sociodemographic and medical information. Immediately following this, the respondent participated in an indepth interview, typically lasting two hours. The interview schedule contained a series of open-ended items to which women were encouraged to provide expansive responses. Similarly, they were encouraged to volunteer any additional information about their illness and treatment-related experiences that might be helpful in understanding their adaptation to their illness. All interviews were audiotaped and transcribed. Using ZY-Index, a text based software program for qualitative analysis, relevant information was extracted and content analyzed.

Sample Characteristics

The mean age at diagnosis of the 34 subjects included in this report was 30.6 (range= 22 to 35). The mean time since their diagnosis was 38 months (range=13 months to 8 years). The large majority of the women were white (85%); the remainder (15%) were black. Most of the subjects were diagnosed as stage 1 (24%) or stage 2 (36%). None of the women showed evidence of metastatic disease. At the time they were interviewed, 65% were married, 6% were divorced, and 29% had never been married. The majority of the sample was well educated: only 3% had a high school degree or less, 18% had some college, 9% had an associates degree, 41% graduated college, 8% completed technical school, and 21% had a graduate or professional degree. A variety of religious affiliations was represented in our sample: 24% were Protestant, 27% were Jewish, 32% were Catholic, 5% reported another religious affiliation, while 12% stated that they had no religion.

Findings

Overall, most of the young women described experiences and emotions similar to those suggested in the clinical and anecdotal literature. Prominent themes included their reactions to the diagnosis, their feelings about the impact of the illness on their partner and their relationship with them, the loss of childbearing ability, a sense of isolation, uncertainty about the future, and anxiety about the impact of the illness on their children. Each of these adjustment issues, exemplified by quotes from the womens' interviews, will be elaborated below.

Reactions to the Untimely Diagnosis. Although disbelief is a common initial reaction among women who receive a diagnosis of breast cancer, this reaction may be more enduring among young women because the diagnosis was so untimely. Those women in our sample who did not have a family history of breast cancer and, therefore, did not perceive themselves as at-risk for the disease were completely stunned by the diagnosis. However, even women with a family history were surprised that they had gotten the disease at such a young age. In a few instances, women who had received reassurances that their breast lump was unlikely to be cancerous because of their youthfulness, reported a heightened sense of shock and disbelief upon receiving the diagnosis. One woman, who was 31 at diagnosis, captured these issues when she described her reaction upon hearing that she had breast cancer:

> I was totally shocked. Everyone sort of led me to believe that this was not gonna be anything. It was probably benign if it was anything - that I was too young to have anything happen to me. So I was absolutely not prepared.

For most of the women, their diagnosis of breast cancer was the first time they were forced to confront their mortality. The realization that their life could be cut short was terrifying and disorganizing because it was so unexpected. They were unprepared to cope with the realization that they had a life-threatening illness. The diagnosis imbued subjects with a novel sense of vulnerability as they faced a challenge for which they had no prior experience. One women commented: "My thing was, 'Damned, I can die from this.' Who thinks about dying at the age of 31? Comes back to that same question. You're at that age. Who thinks about dying at 31?"

Others who had been conscientious about maintaining good health habits described an experience of feeling betrayed by their bodies. They believed that they were taking good care of themselves by eating healthy foods and exercising regularly, and thus viewed the diagnosis as undeserved and unfair. Their self-view was changed by the diagnosis. As one woman commented:

> My whole life, even as a young girl, I've always thought of myself as healthy and strong. Coming down with breast cancer, it kills that. As much as I still want to believe and think of myself as being that way, it kills it. I started saying to myself, "Well, what's wrong with me. What's wrong with my body that this is happening to me. Why can't I be like a normal person."

Many women also expressed a sense of injustice upon learning of the diagnosis. One woman described her reaction as: "Very angry, very confused. Why me? Because I was only 30 years old at the time." Another women thought her young age was a protective factor and was shocked to be diagnosed: "I felt that I was very young. I was 32. I was 32 years old. I didn't think that [cancer] was a possibility."

Women largely saw the unfairness of the diagnosis in terms of the missed opportunities having breast cancer at a young age might cause. One woman stated:

> It would be different [if older when diagnosed] because I would say I lived my life

> already. At least I could look back on my life and say my kids are grown. I might have accepted it differently than now because I'm younger and I'd like to see -- there's a lot in my life I haven't done yet and I would love to see my kid get married. Give me the first grandkid, you know stuff like that. Like everybody looks forward for. So that makes a difference.

Guilt Related to the Impact of the Illness on One's Partner . Many women spoke of the tremendous emotional and practical support they had received from their husbands at diagnosis and throughout treatment. One woman succinctly summarized the husband's role during this time: "[husband] is the forgotten one in the whole thing kind of because I crash after dinner. He's got to put the kids to bed. Cleans dishes. Still do some work. Take off time when he can."

Although the women were grateful for this support, they expressed guilt about the toll of the cancer experience on their partners and marriage. One subject, newly married when diagnosed, discussed her sense of injustice in this domain: "My relationship with my husband - not being married that long - I felt we were still supposed to (be) enjoying our newly wedded bliss. We were only married a few months." This subject also stated: "I felt that he was being cheated of a healthy, young wife. Everything got put on hold."

Another woman, whose cancer was also diagnosed within a few months of marriage, felt that she and her husband were deprived of a blissful or carefree first year of marriage. She commented:

> My being sick sort of just made our first year of marriage so odd. Certainly it was

> not what either of us had anticipated. Married three months and all of the sudden I'm in the hospital for a week - and I spent all of Thanksgiving in the hospital getting IV antibiotics - it wasn't normal - it wasn't what we expected - it wasn't right. And I think part of our problem is simply that we didn't get that first year of just playing, you know, let's go somewhere for the weekend - let's go do whatever we want.

One woman described a poignant interaction with her husband, early in her cancer experience, which captured the sadness and guilt she felt about how her illness forced her husband to shift his focus away from the usual things young husbands might typically contemplate. She stated:

> ... when (husband) checked me out of the hospital for my mastectomy, he goes, "There was a young man getting his wife out from having a child." He goes, "That's the only reason I thought I would be in the hospital, to check you out from having a baby. Here I was checking you out for a mastectomy." I just felt so horrible for him, and for me.

Other women reported similar feelings. One noted:

> I feel bad sometimes that I might have disappointed him. The breast cancer was probably beyond my control but you still feel like you've sort of failed him if he wanted to have more than one child, and you couldn't produce more than one, or because of circumstances, you chose not to.

Women were also worried about their husbands' reactions and ability to cope with the illness. Several felt a sense of responsibility and need to protect their partner. One woman stated: "The worst of it is if I do pass away, I'm leaving (husband) with young children. I don't know how he would be able to handle it, so I have a lot of concerns for him, too." She added: "I was worried because I think I make more money than (husband) does. Who's gonna help him pay the mortgage? And his mother will have to come live with us."

Lost Opportunities for Childbearing. Another domain of the women's lives affected by the illness was childbearing. When conception discouraged by their physician or their fear of recurrence dissuaded them from considering pregnancy, the women felt a great sadness at this profound loss and also guilty over not being able to fulfill the couple's dreams for a child of their own. They spoke movingly about the profound sense of loss they experienced in this area. One woman who had been actively planning and desiring children before her diagnosis stated:

> I can't have children. I've been married for seven and a half years. This is the place that I was at in my life, and it was just cut short. That was it. Everything was stopped. I mean obviously I've got this fear of death now that I did not have. But now I have this, but I can't have children, and I never used to operate that way.

She also noted:

> Everything [before the cancer diagnosis] I was doing was getting ready for children. You know, I had planned out how long I wanted to stay at work. He would have the sick time to be out. Savings. Getting my husband's career on path because he was out of work at the time. You know, everything I was doing

was gearing up to, "Ok, now I can become pregnant."

Another woman also reported on the loss she felt for herself and her husband: "When I had the breast cancer, I was thinking, 'Oh, no, it's not fair. I never even got to that stage (childbearing) of my life. I never even got a chance to experience that, for us to experience that together.'"

Another participant, who deeply desired to have children, described her conflict in receiving treatment that might prolong her life but destroy her dream of having a baby. As she was going through treatment-induced menopause, she recalled crying to her doctor and telling him, "Maybe we should stop the chemotherapy because I want to have children."

For others, this issue was particularly sensitive because their peers were beginning to have children. Seeing their friends' joy added to their sense of loss and sense of being different. A woman who reported difficulty seeing her friends reach this developmental milestone stated: "Several [friends] had children, or are having children. [best friend now pregnant] - I was really happy for her, but I was also sad for myself."

Several other women were struck by the unfairness of their inability to have children and the discontinuity the illness had introduced into their life plans. One woman said: "It's [inability to have more children] just like symbolic of - of an interruption in my life - in my life's plans. And it's a very poignant sort of symbolism."

One woman, who believed she had always safeguarded her health and fertility to prepare for motherhood, spoke of her sense of unfairness over losing the opportunity to have a child of her own, due to breast cancer. She said:

> ...(cancer has) taken away my right as a female. It's taken away something that I have every right to, that I have safe guarded, that I have been careful not to use IUDs. I've taken good care of myself. I haven't done any weird or mind expanding drugs. I've been really careful about my health, both mentally and physically so that I could be a good mother some day. And they've taken that away from me, whoever "they" is. Somewhere out there maybe there is a brilliant little Chinese girl who now can grow up to be President, if I go and I get her, but it won't be the same.

<u>Feeling Different and Isolated</u>. A significant theme uncovered in the womens' narratives was a sense of isolation and of being different from other women because of their illness experience. Some felt a sense of isolation because they did not know others in their age group facing similar issues and adaptive challenges. In these cases, the cancer diagnosis evoked an anomic situation in which the normative expectations were unclear, as no one in their peer group had undergone a similar event. They also felt different from the older women with breast cancer they encountered because these women were typically in long standing marriages and had raised their families. Thus, they had different concerns from young women with the disease. Subsequently, some of the study participants believed that no one could understand their issues. Several women in our interviews discussed this consequence of their cancer experience. One woman noted:

> You do feel very isolated and alone having been so young and that feeling that there is no one out there who has gone through the same kind of situation to sit down and talk to. There was literally not one person I could, although I had asked my doctor for phone numbers of some of the people that maybe I could speak to but I never got them.

Several women specifically spoke of their experiences of going to support groups and their reactions to being the youngest one in the group. Instead of gaining a sense of normality and an opportunity for mutual support from participation, their belief that they were alone only increased. One woman, who was 29 at diagnosis, explained her disappointment with her participation by saying:

> You still feel like you are so alone. I went to a couple support classes, but they were so sad and depressing, I stopped going. But I found out that there was nobody my age out there. All the women that had it were like 50 or 60. Nobody my age and nobody wanted children, like I did...And it was like really nobody to talk to.

Another woman who was 30 at diagnosis, shared:

> The first group I went to, there were older women and we definitely weren't dealing with the same issues. Like at that point, I was really wanting to know how this was going to affect my chances of having a child, and all these women had already had kids a long time ago.

A fourth woman, who was 31 at diagnosis, noted:

> I was in a group where I was the youngest. I was single. All these women are probably fifteen years my senior, and we're talking about menopause and vaginal dryness. And I'm sitting there going: "These (issues) don't affect me right now." And I found them to be extremely self-absorbed in the fact that they couldn't look at (me) and say, "Wow. I've had 30 years beyond you. How scared you must be."

Still another participant, who was only 27 when diagnosed with breast cancer, explained her reluctance to attend a breast cancer support group by saying:

> One reason why I never went to a group is because I feel that I would be so much younger than most women with breast cancer. All along, I think I felt my case is a little different because most women are over 40 anyway who have it. And I kind of feel it's not the same thing. They wouldn't really understand what it's like to be just newly married and experience this and go through those doubts about your husband, your sex life, your future, having kids, whatever. So at the time, I never wanted to go because I felt they wouldn't be able to understand.

This same woman later stated:

> I felt that like these were older people (the people who go to support groups). And they wouldn't be going through these issues of a younger person - starting a new job, marriage, pregnancy, financial - because it's not like you have a savings like a 50 year old person who gets breast cancer, or a 60 year old. By then they've got some savings, so they can deal with this.

Several women also focused on how they were different from other women their age. They noted that their experiences were not typical for their age cohort. For example, one woman stated: "I don't think other young people understand it. I feel like I'm on speaking terms with my mortality and it's not abstract to me. People my age aren't like that."

Another young woman observed: "The average 34 year old woman is not undergoing chemotherapy and worrying about things like this. She's having children, she's developing her career, she's decorating her house."

Uncertainty about the Future. Another issue which led to significant distress for our subjects was a sense of uncertainty and unpredictability about their future. Many mentioned that the diagnosis altered their world view and vision of their life plans. One woman noted how quickly the diagnosis altered her life: "In one second, your whole life changes. Your vision of yourself and your life and your family's life, it just changes in one second. That's all it takes."

Having their expectations for the future called into question produced anxiety, sadness, and anger for some of the women. They spoke of their fears of missed opportunities. They previously had many dreams for the future and expected that these goals would be met. They had looked forward to developmental milestones, such as having a baby. Their illness forced them to recognize these prior goals might not be able to be realized. Several of them discussed these concerns in their interviews.

One woman spoke of how her sense of security about the future had been shaken by having cancer: "But it was just very, very hard to feel like am I really going to have a good, healthy, happy life." Another said: "I've also realized that nothing is for certain. Nothing is guaranteed. Marriage (and) health. And you want those things to be guaranteed. You want to say this marriage is going to last. I'm never going to be sick again. I guess I'm still sort of reeling from the fact that who the heck knows."

Another summarized both the sense of unfairness she experienced as well as how her life course seemed dramatically altered by her diagnosis:

> I felt cheated because of just being married - not having had kids yet. I thought of our future. No point in thinking much further than today, you know, at this point. Everything changed so fast. Life just turned around and just took such a sharp turn from where I was expecting.

Issues about Children. One of the areas of greatest concern for our participants was their children. The young age of our subjects' children, typically toddlers or pre-adolescent at the time of the mother's diagnosis, seemed to be at the source of much of the mothers' worries. Women expressed concerns in three domains because their children were so young: a) fear and sadness that they might not live to see the children reach adulthood; b) anxiety about suitable caretakers if they should become increasingly ill or die; and c) the challenge of trying to minimize the daily impact on their children of the illness.

Several mothers spoke painfully about fearing death because it would mean missing their childrens' developmental milestones. For these women, the possibility of not being able to see their children into young adulthood was a particularly poignant source of distress. Although currently off treatment and presumably healthy, the fear of recurrence was prevalent. One woman said: "Once in a while it (fear of recurrence) creeps up on me. And I think about it and I say, 'I'm not going to be here to see my sons bar mitzvahed and stuff.' You know, it's scary. You know, I maybe have a tear in my eye at the time." Another described her pain when thinking about her mortality: "I thought of my children, and I thought I was not going to see them grow up because at that point I didn't know anyone who had breast cancer and survived...I almost passed out."

Another prominent issue regarding children was the concern mothers in the sample expressed about the adequacy of the love and care their children would receive if they should die. One talked about her anxiety regarding who would care for her children should she die: "My initial reaction was, 'I think I'm gonna die.' It was just like, 'Who's gonna take care of the children?'" She also expressed concern that "Nobody, no matter what, would care for them like I would."

Other women expressed similar fears. One stated: "What if I have a recurrence? And you know, I don't survive it. And I die. And my kids are left without a mother. That's something I think about a lot." Another mother of a seven year old son noted:

> My mother died when I was very young. And I was more or less, I was an only child. That was one of the biggest blows to me, when I was diagnosed with this was that I could see what happened to me happen to him. He was going to relive

> what I went through, and that was horrendous.

The subjects also described the emotional and practical impact of the illness on their children. They spoke of the need to conceal their own anxiety and distress and to maintain a facade of normalcy in order to avoid worrying their children. They also discussed how they strove to manage the demands of the illness in a way that would limit the disruption of the children's usual activities and routines. One woman spoke of her concerns about her five year old daughter:

> You can't live thinking, "This is going to come back, what am I going to do?" Because I have a five year old child, and if I'm going to be like that, neurotic and worried, what kind of a life is she gonna have? I don't want her to look back, should I die when she's seven, and say, 'Oh, until seven years, she was neurotic, but dying.' I want her to think I'm just like everybody else.

Another woman related an exchange she and her husband had about their four year old daughter who confided in her father that she worried very much about her mother. The subject recalled her conversation with her husband: "... he told me when I came in and he said 'Your daughter is worried about you, that is too much for her to be carrying'. I said, 'Because she saw what I went through. Because if I was lying down with a headache, she comes and lies down beside me. (She says) 'Let me rub it for you.' You know, so I worry.'"

A third mother also expressed guilt over the pain her illness may have caused her young daughter, remembering the pain she felt, even as an adult, when her father was ill. She recalled:

> My father was ill when I was in my late 20's and that seemed terrible. That was really painful. I think as a parent you try so hard to protect your children from difficulty of pain, the idea of being the author of your own child's pain is too painful to bear.

Others also spoke of their efforts to maintain a functioning household while hiding their distress:

> I was like, "You can't let your kids see this." You don't want to be sitting in your house saying, "Oh, my God, I think I'm going to die" and you got your kids looking you in your face. You don't want that to happen. So you gotta be strong. You put on this big old shield and say "Everything is alright. Let me just cook dinner. Let me just wash the clothes. Let me help you with your homework." I went through the motions, I was like a robot. I did things because I had to. Every day you have to get up, you have to go to work, you have to send your kids to school. The kids have to be picked up. Dinner has to be made. The uniforms have to be pressed. You do things because you have to. You have to keep that every day life going on.

An additional participant discussed her medical treatment (i.e., doctor's visits, reconstruction work) in terms of how it could interfere with her childrens' activities:

> ...I didn't want it to interfere with the summer activities, like taking the kids to the pool, and being in a bathing suit. I don't want it to affect, not when I'm doing something electively, I don't want it to intentionally interfere with my children's

summer, summer sports and things like that.

Discussion

The findings reported above substantiate observations reported in the clinical and anecdotal literature that young women with breast cancer face unique challenges that may interfere with their adjustment to the illness. The young women in our study did not perceive themselves to be vulnerable to breast cancer, at least not at such a young age. Their belief systems were not constructed to accommodate such an event. A significant adpative task they faced was to rework their assumptions about themselves and the world to incorporate their experiences as a young adult with a life-threatening illness. For example, many of the interviews revealed a prior sense of invulnerability which was shattered by their diagnosis. The illness was distressing in part because it led them to view themselves as vulnerable and capable of being harmed. Further, because of their youth and place in the life cycle, the women felt the illness limited future options. Some were bitter because of their feeling that it was unjust they had to confront issues of mortality and disability at such a young age.

The stressors most frequently identified by subjects included coping with the untimeliness of the illness, the impact of the illness experience on their husbands, sadness about lost opportunities for childbearing, feeling different and isolated, an expectation of future uncertainty and unpredictability, and concerns about their children. Typically, feelings of anger sadness, guilt and anxiety accompanied their issues. Most of these issues are unique to young women, but to date have received little attention in the literature.

An overarching theme which ran through many of the stressors described by the women was the untimeliness of the event. Life events typically occur within a basic sequence. Subsequently, "out of phase" unexpected life events, like the diagnosis of a life-threatening illness in young adulthood, may be associated with poorer adjustment because they are not anticipated and, therefore, may be more practically and emotionally disruptive (Lazarus and DeLongis, 1983; Filipp, 1992).

Younger women with breast cancer may also be more adversely impacted by their illness because they may be considerably less experienced at negotiating complex health care systems. Further, probably having experienced generally good or excellent health prior to their diagnosis, they may take more time to accept their diagnosis and effectively adjust to the sick role. The spouses of young married patients may also be less available than the partners of older patients to offer emotional and practical support because of the other role demands they face (Mor et al., 1994; Northouse, 1994).

Another prevalent theme in our subjects' narratives was concern about the impact of their illness experience on their husbands. Although almost all the married women in our sample perceived their husbands as extremely supportive, they often felt guilty about the dependency their illness had imposed on them and the resulting additional responsibilities and burdens their husbands had to assume. Some saw their husbands struggling to take on roles they sometimes felt ill equipped to handle (e.g., child care, cooking). Thus, receiving their partner's help was a bittersweet experience for some participants: while they appreciated the support, they felt guilty that it was necessary. Some women in our study expressed guilt and despair at the feared loss of opportunity to realize individual or couple goals, such as having a child or owning a home. These feelings were often accompanied by anger at the seeming unfairness of their situation.

One issue particularly associated with a sense of injustice was childbearing. Women who were discouraged from becoming pregnant by their physicians or whose fear of recurrence caused them to decide against becoming pregnant, spoke of the sadness and anger they experienced due to their inability to have a child of their own. It appeared that this issue was difficult for several reasons: it required an altering of personal goals, represented an unfulfilled developmental task, and marked these women as different from their peers. Even if some women retained the ability to conceive, their doctors may have advised against it. Furthermore, some women were confused or unsure about the consequences of pregnancy after breast cancer, which only heightened their distress. Bearing children is a core aspect of feminine identity, and one for which many women plan their entire lives. Being stripped of this opportunity may radically alter a woman's self-view and may account for the sadness our subjects experienced in this domain.

The data suggest that loneliness and a sense of being different may be significant issues faced by young women with breast cancer. Because a diagnosis of breast cancer is not common for young women, the women were frequently without peer role models who could guide them through this stressor. Our participants revealed that they viewed themselves as different from their "healthy" peers, as well as from older women with breast cancer and frequently reported feelings of isolation. It appeared that these young women with breast cancer believed that they were without a cohort group to whom they could truly relate. Although they shared an age group with other young women, they felt different because of their disease and its sequelae.

Conversely, while they shared an illness with older women, they perceived their challenges and struggles to be different. If they did not know other young women with the illness, their sense of isolation was even more pronounced.

Many of our subjects also spoke of a new self-view they developed as a result of being a young woman with breast cancer. Since their diagnosis and treatment they perceived themselves as "different" or "abnormal." Associated with this new self-view was the belief, "I'm alone and no one understands me." These beliefs were contrary to their previous views and often quite distressing.

Several other issues women discussed can be viewed as relating to the loss of their future dreams. Prior to their cancer diagnosis, these women had a healthy lifestyle and were confident that they would live a normal life span and be able to achieve family and career goals. However, the diagnosis interjected uncertainty into their lives and plans. They now experienced sadness and disappointment as they relinquished prior plans and strove to develop acceptable, alternative goals.

The young women in our study were forced to confront their mortality prematurely and modify their life goals. They now viewed themselves as flawed and unsafe. This new self-view may have been associated with a heightened sense of insecurity about their future. Although older women with breast cancer may also view the future as uncertain, they have had the advantage of more time and opportunity to fulfill particular goals. Our participants had a distinct disadvantage in that more opportunities may have been potentially cut off to them.

Acknowledging these lost opportunities may have contributed to a belief that the world is not just. The women reported that they viewed the future with caution, having learned that their plans could be altered instantaneously without reason.

The most poignant moments in the interviews occurred when the mothers in the sample spoke about their children. For women diagnosed with breast cancer who already had young children, the responsibilities of parenting continued despite new illness-related demands. Additional worries, including what would happen to the children if she dies and what and how to tell them about the diagnosis, prognosis, and the impact of treatments may also have interfered with the women's adjustment to their illness. Other mothers in our sample worried about the psychological impact of their illness on their children and strove to maintain a sense of normalcy in the household. Some reported feelings of guilt due to seeing that children were worried about the mother's well-being.

The majority of mothers in the sample lived in fear that they would not see their children reach young adulthood. This is an issue not shared by older women with breast cancer whose children have already passed significant developmental milestones. In addition, subjects' realization that they might not see their children grow up countered the typical assumption of young women that they will be available to raise and nurture their children. Those who believed that they might die, leaving their children at a vulnerable age without adequate support and care, experienced guilt and anxiety.

Because of the young age of their children, the women in our study had more responsibilities than older women might have. Typically patient role responsibilities were added to those of worker, spouse and mother. For some participants, their ability to fulfill usual duties was compromised due to the demands and sequelae of treatment (e.g., fatigue). Still some felt inhibited from expressing their distress around their children in order to preserve a sense of normalcy. They also felt guilty in many cases about their inability to fulfill family responsibilities to the standards they set for themselves. They worried too about the burden this placed on their husbands and children.

Overall, the women's narratives suggest that their diagnosis of breast cancer may have altered several of their basic assumptions about themselves and their world. Many women alluded to a sense of invulnerability prior to the diagnosis. They believed that they were protected from illness because of their youthfulness and healthy lifestyle. The illness brought a painful realization that they were vulnerable and mortal.

Feminine identity was another aspect of self-view significantly affected by the illness in several ways. In particular, the actual or feared loss of fertility most likely affected subjects' self-view as a normal, functioning woman. While most may have taken their femininity for granted before their illness, this self-view was strongly challenged for those who felt significantly disfigured by the disease or who believed that they were now unable to have a child of their own. In addition, they may have believed that they were less capable of fulfilling their roles as wife and mother. All of these domains are critical aspects of feminine identity. Our subjects noted modifications in all of these areas.

Subjects' views of the world may also have been altered by having breast cancer at a young age. Many now viewed the world as unjust or unfair. These beliefs resulted in feelings of anger and a sense of being cheated for many of the participants. Others came to view the world as unsafe, a view which may be associated with fear, hypervigilance, and cautiousness. Some of the women's responses suggested a view of the world as unpredictable and uncertain. Such a view may have interfered with goal-directed behavior and may have left them with a sense of chaos and anxiety. Finally, other women appeared to be in flux about how the experience influenced their view of the world. Some of these women gave responses suggesting a search for meaning and understanding (e.g., asking "Why me?"), but it appeared that they had not yet integrated the experience in a coherent world view.

As noted above, the interviews discussed here were part of a study focusing on pregnancy decision-making following breast cancer. Although the subsample of women participants reported on here were atypically young, the interviews did not focus on this aspect of their cancer experience. Yet these women spontaneously volunteered comments about how their youthfulness had influenced their reactions to cancer. As a result, multiple age effects were discernable from their narratives. It's likely that an investigation more specifically focused on young age at diagnosis would uncover still other stressors not described in the interviews. Future research should focus on this variable specifically so that the unique stressors and developmental issues for young women with breast cancer can be more fully scrutinized. Furthermore, subsequent work should compare cohorts of younger and older breast cancer patients so that the mechanisms which put younger women at higher risk for poor outcome could be identified.

In conclusion, the data suggest that young women and their families may have unmet needs and may require unique kinds of assistance to effectively cope with their illness and its sequelae. In particular, young women would benefit from counseling concerning what is and is not known about possible risks associated with childbearing after breast cancer. In addition, those with young children would benefit from guidance concerning how to communicate with young children about the illness and what to share with children about the illness and prognosis. In addition, the husbands of these young patients should not be overlooked. They also need education and support about the illness and its psychosocial consequences for patients and family members.

References

Dow K.H. (1994) Having children after breast cancer. Cancer Practice, 2, 407-413.

Dow K.H., Harris J.R., Roy C. (1994) Pregnancy after breast-conserving surgery and radiation therapy for breast cancer. Journal of the National Cancer Institute Monographs, 16, 131-137.

Erikson E.H. (1963) Childhood and Society. New York: WW Norton and Company.

Filipp S.H. (1992) Could it be worse? The diagnosis of cancer as a prototype of traumatic life events. In Montada L., Filipp S.H., & Lerner M.J. (eds.), Life Crises and Experiences of Loss in Adulthood (pp. 23-36). New Jersey: Lawrence Erlbaum Associates.

Ganz P.A., Lee J.J., Sim M.S., Polinsky M.L. & Schag C.A. (1992) Exploring the influence of multiple variables on the relationship of age to quality of life in women with breast cancer. Journal of Clinical Epidemiology, 45, 473-485.

Gould R.L. (1972) The phases of adult life: A study of developmental psychology. American Journal of Psychiatry, 129, 521-531.

Hughson A.V.M., Cooper A.F., McArdles C.S. & Smith D.C. (1988) Psychosocial consequences of mastectomy: Levels of morbidity and associated factors. Journal of

Psychosomatic Research, 32, 383-391.

Jamison K.I., Wellisch D.K. & Pasnau R.O. (1978) Psychological aspects of mastectomy: I. The woman's perspective. American Journal of Psychiatry, 135, 432-436.

Lazarus R.S. & DeLongis A. (1983) Psychological stress and coping in aging. American Psychologist, 38, 245-254.

Levinson D.J. (1996) The Seasons of A Woman's Life. New York: Alfred A. Knopf.

Levinson D.J., Darrow C.N., Klein E.B., Levinson M.H. & McKee B. (1978) The Seasons of A Man's Life. New York: Alfred A. Knopf.

Lowenthal M.F., Thurber M. & Chiriboga D. (1975) Four Stages of Life: A Comparison of Men and Women Facing Transitions. San Francisco: Jossey Bass.

Mor V., Malin M. & Allen S. (1994) Age differences in the psychosocial problems encountered by breast cancer patients. Journal of the National Cancer Institute, 16, 191- 197.

Neugarten B.L. (1968) Adult personality: Toward a psychology of the life cycle. In B.L. Neugarten (ed.), Middle Age and Aging. Chicago: University of Chicago Press.

Northouse L.L. (1994) Breast cancer in younger women: Effects on interpersonal and family relations. Journal of the National Cancer Institute, 16, 183-190.

Northouse L.L. & Swain M.A. (1987) Adjustment of patients and husbands to the initial impact of breast cancer. Nursing Research, 36, 221-225.

Penman D.T, Bloom J.R, Fotopoulos S., Cook M.R., Holland J.C., Gates C., et al. (1986) The impact of mastectomy on self-concept and social functioning: A combined cross-sectional and longitudinal study with comparison groups. Women and Health, 11, 101- 130.

Rowland J.H. (1989) Developmental stage and adaptation. In J.C. Holland and J.H. Rowland (Eds.), Handbook of Psychooncology . New York: Oxford University Press.

Schover L.R. (1994) Sexuality and body image in younger women with breast cancer. Journal of the National Cancer Institute, 16, 177-182.

Siegel K. & Christ G.H. (1989) Hodgkin's disease survivorship: Psychosocial consequences. In Lacher M.L. & Redman J.R. (eds.), Hodgkin's Disease: The Consequences of Survival. Philadelphia: Lea and Febiger.

Siegel K., Gorey E. & Gluhoski V. (in press) Pregnancy decision-making among women previously treated for breast cancer. Journal of Psychsocial Oncology.

Valliant G.E. & Milofsky E. (1980) Natural history of male psychological health: IX, Empirical evidence for Erikson's model of the life cycle. American Journal of Psychiatry, 137, 1346-1359.

Vinokur A.D., Threatt B.A., Vinokur-Kaplan D. & Satariano W.A. (1990) The process of recovery from breast cancer for younger and older patients. Cancer, 65, 1242-1254.

IV. APPENDIX D

INTERVIEW GUIDE

(Proprietary Material)

ID ______ ______ ______

CHILDBEARING DECISION-MAKING AMONG WOMEN PREVIOUSLY TREATED FOR BREAST CANCER

BACKGROUND AND MEDICAL HISTORY QUESTIONNAIRE (Revised 10/18/95)

Date: __/__/__ WBMO WBDA WBYR

Interviewer I.D.: ___ WBINTID

To begin with, I would like to ask you some brief questions about your treatment for breast cancer. Some of these questions may not relate to your circumstances, but we need to ask these questions of everyone in the study.

1. When were you first diagnosed with breast cancer? WB1MO WB1DA WB1YR

____/____/____

2. Which breast was affected? WB2

Right	1
Left	2
Both (Ask subsequent questions separately for each site)	3

3 Where did you receive your treatment for breast cancer, at what hospital or clinic? [IF MORE THAN ONE LOCATION, RECORD ALL PLACES R. MENTIONS.] WB3LOC1 WB3LOC2 WB3LOC3

____

____

____

4 What surgical procedure did you have at that time for breast cancer. . . WB4R

Right Breast

Lumpectomy (removal of the lump only)	1
Wide excision (removal of the lump and an area of surrounding breast tissue)	2
Lumpectomy and lymph node dissection	3
Modified mastectomy, also called simple or total mastectomy (removal of the lump and all the breast tissue)	4
Modified radical mastectomy (removal of the lump and all the breast tissue, some lymph nodes and the lining of the chest muscles)	5
Radical mastectomy (removal of the lump, all breast tissue, all lymph nodes and some muscle	6

WB4L

Left Breast

Lumpectomy (removal of the lump only)	1
Wide excision (removal of the lump and an area of surrounding breast tissue)	2
Lumpectomy and lymph node dissection	3
Modified mastectomy, also called simple or total mastectomy (removal of the lump and all the breast tissue)	4
Modified radical mastectomy (removal of the lump and all the breast tissue, some lymph nodes and the lining of the chest muscles)	5
Radical mastectomy (removal of the lump, all breast tissue and some muscle)	6

5. When was this surgery? WB5RMO

WB5RDA
WB5RYR
WB5LMO
WB5LDA
WB5LYR

Right Breast _____/_____/_____

Left Breast _____/_____/_____

6. At the time of your initial surgery for breast cancer were the lymph nodes under the arm surgically removed? WB6R

Right Breast

Yes	1	[ASK A]
No	2	[GO TO Q. 7]

A. Were any of the lymph nodes removed from under your right arm found to contain cancer cells? WB6RA

Yes	1
No	2

Left Breast — WB6L

Yes	1	[ASK A]
No	2	[GO TO Q. 7]

A. Were any of the lymph nodes removed from under your left arm found to contain cancer cells? — WB6LA

Yes	1
No	2

7. To your knowledge, at the time of the initial diagnosis, had the breast cancer spread to other parts of your body? — WB7

Yes	1	[ASK A]
No	2	[GO TO Q. 8]

A. What other parts of your body had the breast cancer spread to? — WB7A1 WB7A2

____

8. Do you know what stage of breast cancer you had at the time of your diagnosis? — WB8

Stage I	1
Stage II	2
Stage III	3
Stage IV	4
Other (RECORD VERBATIM________________)	5
DON'T KNOW	8

9. Did you receive chemotherapy treatment for the breast cancer? — WB9

Yes	1	[ASK A - B]
No	2	[GO TO Q. 10]

A. When did the chemotherapy treatment begin? [IF R. HAS HAD MULTIPLE COURSES OF CHEMOTHERAPY, RECORD DATE OF FIRST CHEMOTHERAPY TREATMENT.] — WB9AMO WB9ADA WB9AYR

____/____/____

B. When did the chemotherapy treatment end? [IF R. HAS HAD MULTIPLE COURSES OF CHEMOTHERAPY, RECORD DATE OF LAST CHEMOTHERAPY TREATMENT FOR BREAST CANCER.] — WB9BMO WB9BDA WB9BYR

____/____/____

10. Did you receive radiation treatment for the breast cancer? WB10

Yes . . . . 1 [ASK A - B]
No . . . . 2 [GO TO Q. 11]

A. When did the radiation treatment begin? [IF R. HAS HAD MULTIPLE COURSES OF RADIATION TREATMENT, RECORD DATE OF FIRST RADIATION TREATMENT FOR BREAST CANCER.]
WB10AMO
WB10ADA
WB10AYR

____/____/____

B. When did the radiation treatment end? [IF R. HAS HAD MULTIPLE COURSES OF RADIATION TREATMENT, RECORD DATE OF LAST RADIATION TREATMENT FOR BREAST CANCER.]
WB10BMO
WB10BDA
WB10BYR

____/____/____

11. Have your ever taken any hormonal therapy (Tamoxifen (Nolvadex) pills) as part of your treatment for breast cancer? WB11

Yes . . . . 1 [ASK A - B]
No . . . . 2 [GO TO Q. 12]

A. When did you begin taking it?
WB11AMO
WB11ADA
WB11AYR

____/____/____

B. Are you still taking it? WB11BMO

Yes . . . . 1 [GO TO Q. 12]
No . . . . 2 [ASK C - D]

C. When did you stop?
WB11CMO
WB11CDA
WB11CYR

____/____/____

D. Why did you stop?
WB11DRS1
WB11DRS2

____

12. Since your initial diagnosis and treatment for breast cancer, have you had a recurrence of breast cancer or any other type of cancer in any part of your body? WB12

Yes . . . . 1 [ASK A]
No 2

A. 1. Specify part of body__________________________ WB12A1

2. Specify when this occurred _____/_____/_____ WB12A2MO WB12A2DA WB12A2YR

Ask: Was this a spread of the initial breast cancer or a new unrelated cancer?

Spread of the initial cancer (recurrence) 3 WB12ASPR
A new unrelated cancer (Specify type__________________)4 WB12ASPT
Don't know 5

Ask: What type of treatment have you received for this (recurrence/new) cancer?

Specify treatment(s): 6
- Surgery . . . . a WB12A6A
- Chemotherapy . . . . b WB12A6B
- Radiation . . . . c WB12A6C
- Hormonal (Tamoxifen (Nolvadex)) . . . . d WB12A6D

No treatment received . . . . 7 [GO TO Q. 13] WB12A7

Ask: When did you last receive treatment for this (recurrence) cancer?

Specify date _____/_____/_____ 8 WB12A8MO WB12A8DA WB12A8YR

Now I have a few questions about yourself and your health which we are asking all participants so that we will be able to describe the sample of women who are participating in the study. These questions will just take a few minutes to answer.

13. What age were you on your last birthday? WB13

____
AGE IN YEARS

14. What is the highest grade in school you have completed? WB14

8th grade or less 1
Some high school 2
High school grad or GED 3
Some college 4
Associate's degree 5
Bachelor's degree 6
Technical school 7
Graduate or professional degree 8
Refused 9

15. Currently, are you . . . WB15

Working full-time	1	[ASK D-E]
Working part-time	2	[ASK D-E]
Working free-lance	3	[ASK D-E]
In school and working	4	[ASK D-E]
In school and not working	5	[ASK A-D]
Not working	6	[ASK A-D]

A. Are you not working because of an illness-related condition? WB15A

Yes	1	[ASK B]
No	2	[ASK C]

B. Is this condition related to the breast cancer or its treatment? WB15B

Yes	1
No	2

C. Have you ever been employed? WB15C

Yes	1	[ASK D]
No	2	[GO TO Q. 14]

D. What kind of work (do/did) you do? What type of business (is/was) that? WB15D

JOB TITLE

JOB RESPONSIBILITIES OR TASKS

TYPE OF BUSINESS/WORKPLACE

E. CURRENTLY WORKING: How many hours do you usually work in a week? WB15E

HOURS

16. What is your religion? WB16

Protestant, no denomination specified	1
Baptist	2
Methodist	3
Lutheran	4
Presbyterian	5
Episcopalian	6
Adventist	7
Jewish (i.e., Orthodox, Conservative, Reform)	8
Roman Catholic	9
Greek or Russian Orthodox	10
Eastern religions, not specified below	11
Islamic	12
Muslim	13
Hindu	14
Other [SPECIFY] ____________________	15
Doesn't have a religion	16

17. Were you born in the United States? WB17

Yes	1
No (specify country of birth)	2

____

18. What is your current marital status? Are you . . . WB18

Legally married	1	[ASK A]
Living with a partner	2	[ASK A]
Separated	3	[GO TO Q. 19]
Divorced	4	[GO TO Q. 19]
Widowed	5	[GO TO Q. 19]
Never married	6	[GO TO Q. 19]
IF VOLUNTEERED, DO NOT READ: Common law marriage	7	[ASK A]

A. How long have you been (married/living together)? WB18A

____
NUMBER OF YEARS

20. Prior to your diagnosis and treatment for breast cancer, how many times had you become pregnant? WB20NUM

Number of times pregnant ________
[If none, GO TO Q. 21]

Can you tell me for each pregnancy, starting with the first, what was the outcome?

Circle one:	Still birth	Live birth	Miscarriage	Abortion	
1st Pregnancy	1	2	3	4	WB20P1
2nd Pregnancy	1	2	3	4	WB20P2
3rd Pregnancy	1	2	3	4	WB20P3
4th Pregnancy	1	2	3	4	WB20P4
5th Pregnancy	1	2	3	4	WB20P5
6th Pregnancy	1	2	3	4	WB20P6

21. After your diagnosis and treatment for breast cancer, how many times have you become pregnant? WP21NUM

Number of times pregnant ________
[If none, GO TO Q. 22]

Can you tell me for each pregnancy, starting with the first, what was the outcome?

Circle one:	Still birth	Live birth	Miscarriage	Abortion	
1st Pregnancy	1	2	3	4	WB21P1
2nd Pregnancy	1	2	3	4	WB21P2
3rd Pregnancy	1	2	3	4	WB21P3

22. In the year preceding your diagnosis of breast cancer did you use any form of birth control? WB22

Yes (specify method ____________________) 1
No 2

23. Since your diagnosis of breast cancer have your used any form of birth control? WB23

Yes (specify method ____________________) 1
No 2

24. Are you currently using a form of birth control?

WB24

Yes (specify method ______________________) 1
No 2

[If birth control method has changed, probe to find out why]

25. Who lives in your household with you? [If lives alone, GO TO Q. 26]

Could you please tell me what their relationship is to you (i.e., mother, father, husband, daughter, etc.)?

[If son or daughter, ask: What was his/her age on his/her last birthday?]

RELATIONSHIP TO R.	M	F	Age of Child
Person 1: ______________________	1	2	________
Person 2: ______________________	1	2	________
Person 3: ______________________	1	2	________
Person 4: ______________________	1	2	________
Person 5: ______________________	1	2	________
Person 6: ______________________	1	2	________
Person 7: ______________________	1	2	________
Person 8: ______________________	1	2	________

WB25REL1
WB25SEX1
WB25AGE1
WB25REL2
WB25SEX2
WB25AGE2
WB25REL3
WB25SEX3
WB25AGE3
WB25REL4
WB25SEX4
WB25AGE4
WB25REL5
WB25SEX5
WB25AGE5
WB25REL6
WB25SEX6
WB25AGE6
WB25REL7
WB25SEX7
WB25AGE7
WB25REL8
WB25SEX8
WB25AGE8

26. What is the total yearly income of your household? That is, what is the total combined income of all persons living in your household?

WB26

Under $5,000	1
$5,000 - $9,999	2
$10,000 - $14,999	3
$15,000 - $19,999	4
$20,000 - $24,999	5
$25,000 - $34,999	6
$35,000 - $49,999	7
$50,000 - $74,999	8
$75,000 - $99,999	9
$100,000 or over	10
Refused	98

27. What kind of health insurance, if any, do you have? WB27

Medicaid	1
Disability	2
Self-paid insurance plan	3
THROUGH JOB Private insurance co. (e.g., Blue Cross)	4
THROUGH JOB Hmo or managed care (e.g., HIP)	5
Other [SPECIFY]____________	6
No coverage	7

28. How would you rate your health at this time, would you say your health is . . . WB28

Excellent	1
Good	2
Fair	3
Poor	4

29. Prior to your diagnosis of breast cancer, did you have any ongoing health problems (e.g., heart problems, arthritis, asthma, etc.) which limited your energy, endurance or activities? WB29

Yes	1	[ASK A]
No	2	[ASK B]

A. What were they? (PROBE: Anything else?) WB29A1 WB29A2 WB29A3

____

____

B. Currently do you have any ongoing health problems (e.g., heart problems, arthritis, asthma, etc.) which limit your energy, endurance or activities? WB29B

Yes	1	[ASK C]
No	2	

C. What are they? (PROBE: Anything else?) WB29C1 WB29C2 WB29C3

____

____

QUESTIONS TO BE ASKED OF ALL WOMEN

30. Can you tell me a little bit about the circumstances that led up to your being diagnosed with breast cancer. How did you discover there was a problem (e.g., felt a lump, mammogram)? WB30

31. Prior to your diagnosis had you, for any reason, considered yourself to be at particular risk for breast cancer? (**If yes, ask:** Why did you feel that way (e.g., family history, prior suspicious mammogram?) WB31

32. What was your initial reaction to hearing the diagnosis of breast cancer? By initial I mean in the first few weeks. WB32

33. What did your doctor tell you about the stage of your disease at the time of your diagnosis? (Try to get a sense about how advanced the doctor told her the cancer was.) WB33

34. What did your doctor initially tell you about the prognosis of your disease or how effective treatment was likely to be? WB34

35. You've already told me a little about the treatments you underwent for you breast cancer. Can you tell me if you experienced any complications associated with the treatments (e.g., infections, toxic side-effects of chemotherapy)? WB35

36. Do you have any lasting medical problems as a result of the treatment you underwent for your breast cancer? Probe: (e.g., fatigue, swollen arm on the affected side, loss of arm strength or range of motion, scarring from surgery or radiation). WB36

37. Did you have or consider reconstructive surgery? (If yes, ask: Was your choice of reconstructive surgical procedure(s) influenced by you desire to become pregnant in the future? (i.e., some doctors do not recommend using abdominal tissue if pregnancy is planned) WB37

38. At the completion of your treatment for breast cancer, what did your doctor tell you about the status of your disease (e.g., cured, in remission)? WB38

39. Do you think there are things a woman can do to try to prevent a recurrence of breast cancer? WB39

40. How much control do you think you personally have over whether you will stay cancer free in the future? WB40

41. How much do you worry about the possibility of your breast cancer recurring? (Try to get some sense of the magnitude of R's worry) WB41

42.	How often do thoughts about the possibility of recurrence come into your mind? (Follow up with: Are there circumstances that particularly evoke worry about recurrence?)	WB42
42a.	What has been the most difficult aspect of having breast cancer as a young women? (**Probe** to find out what has been the most difficult thing for her to cope with and how she would compare her experience as a young women to an older woman)	WB42a
43.	As you entered adulthood, how important in your life was the idea of having children?	WB43
44.	Prior to your diagnosis of breast cancer, were you contemplating having a child (another child)? (**If yes, ask:** Why at that time, did you feel you might want to have (a child/another child?) (**If no, ask:** Why at that time, did you feel you didn't want to have (a child/another child?)	WB44
45.	How likely do you think it is that you would have tried to become pregnant (pregnant again) if you had <u>not</u> been diagnosed with breast cancer.	WB45
46.	How about since your diagnosis and treatment? Have your thoughts or feelings about whether to try to become pregnant and have (a child/another child) changed in any way? (**If yes, ask:** How have your thoughts and feelings about becoming pregnant changed? Why do think your feelings changed in this way?)	WB46
47.	Do you believe that your treatment for breast cancer in any way changed your ability to become pregnant?	WB47
47a.	What has been the pattern of your menstrual periods since breast cancer treatment? (**Probe** to determine changes in frequency and duration). Is this pattern of menstruation a change from before your breast cancer treatment? (**If yes, probe** to find out the nature of the change and **ASK** How do you interpret this change? (i.e., onset of menopause, menopause, or lingering treatment effect)). **ASK** How do you feel about this change?	WB47a
48.	Did you ever consult a fertility counselor about the probabilities of becoming pregnant after breast cancer? (**If yes, probe** to find out who they consulted and how satisfied or dissatisfied they were with the counseling.)	WB48
49.	Did you ever consider, or would you consider, the use of some reproductive technologies such as using a donor egg or surrogate mother to carry your child? (**If no, ask:** Why not?)	WB49
50.	Since your breast cancer have you undergone any kind of medical evaluation or assessment of your fertility?	WB50

51. (FOR THOSE WHO HAD CHEMOTHERAPY) Did a doctor ever discuss with you the possibility that your treatment for breast cancer might in any way make it more difficult or impossible for you to become pregnant? (**If yes, ask:** What exactly did he/she tell you? How did what he/she told you make you feel?) WB51

52. Did you ever discuss with any doctor or other health care professional any questions you had about the idea of trying to become pregnant following breast cancer? WB52

    If yes, ask: Who did you consult; was it the doctor who treated you for the breast cancer or some one else? (e.g., R's internist or gynecologist)

    What questions did you raise and what exactly were you told? (If more than one doctor or health care professional was consulted, find out what each told R).

    How did you feel about this information? (Probe to learn did R accept it/question it; did it upset R/reassure her. Was she satisfied with the information she received or not).

    If no, ask: Why haven't you discussed this issue with a doctor or other health professional?

53. (IF R DID NOT SEEK A MEDICAL OPINION, ASK:) Did the doctor who treated your breast cancer or any other doctor ever volunteer an opinion to you regarding whether there were or were not any health risks associated with trying to become pregnant after breast cancer?) (**If yes, probe** to find out what they told respondent and respondent's reaction to what she was told.) WB53

54. Did you ever see a genetic counselor to determine if you had a female child if she might be more susceptible to breast cancer? (**If yes, probe** to find out what information they were given and how satisfied or dissatisfied they were with the counseling.) WB54

55. Did you ever seek medical information on pregnancy after breast cancer from a source other than a doctor or other health care professional, for example books, medical journals? (**If yes, ask:** From where have you tried to get information? (Probe: For each source find out what she learned, and how satisfied or dissatisfied she was with this source of information?) WB55

56. Did you ever seek counseling from a psychologist or other mental health professional in trying to clarify your feelings and motivations about having a child after breast cancer? (**If yes, probe** to find out who they consulted and how satisfied or dissatisfied they were with the counseling.) WB56

57. (FOR WOMEN WHO HAVE DECIDED TO BECOME PREGNANT ASK): Are you currently trying to become pregnant or are you planning to try in the future?) WB57

DIRECTIONS FOR INTERVIEWER

IF RESPONDENT,

Has decided not to try to become pregnant [GO TO PAGE **15**]
Has decided to try to become pregnant, and is actively trying [GO TO PAGE **18**]
Is undecided [GO TO PAGE **21**]
Has decided to try to become pregnant, but plans to wait some period before trying [GO TO PAGE **24**]

IF R HAS DECIDED NOT TO TRY TO BECOME PREGNANT

58. Can you tell me a why have you decided not to try to become pregnant following your breast cancer. (Try to encourage Respondent to be expansive on this issue. Get all her reasons. Keep asking "Any other reasons?" We want to understand her decision-making process.) WB58

59. (After R has responded, probe specifically about the following, if not already mentioned, SAY): I want to ask you about some reasons other women have offered for deciding to become or not become pregnant after cancer. Can you tell me if any of these thoughts entered into your own decision-making. WB59

    - worry about whether your disease might recur and you would be unable to care for a child.
    - worry about the possibility that a female child might grow up to have the disease.
    - worry that caring for a child might be stressful and detrimental to your health.
    - worry that you may not have a normal baby because of the effects of Radiation therapy or Chemotherapy on your baby.
    - the thought that it might be selfish, given possible uncertainty about your future health.
    - the thought that there might be some health benefits to becoming pregnant.
    - the thought that having a child would make you happier or improve your quality of life.
    - the thought that having a child is something that is life affirming and gives you hope and optimism about the future.
    - the thought that having a child would help you start to feel normal again after breast cancer.
    - the thought that there were any health risks to becoming pregnant.

60. Can you think of any other potential benefits, risks, advantages or disadvantages you considered in making your decision? WB60

61. Do you feel any sense of loss over your decision not to have a child/another child following your breast cancer? WB61

62. Was age a factor, in any way, in your decision? (**If yes, ask:** In what way?) WB62

63. Do you feel that because of your age there may be a limited period in which you have a reasonable chance of becoming pregnant. (**If yes, ask:** What is that time period?) WB63

64. (IF MARRIED OR LIVING WITH A PARTNER) Since your breast cancer, have you and your husband/partner ever discussed whether you would try to become pregnant? WB64

If yes, ask: What have been his thoughts and feelings about this matter?

Do you think that prior to your diagnosis that he felt differently about your becoming pregnant?

On what points have you two agreed or disagreed regarding this matter?

Has this matter, to any extent, been a source of marital strain or conflict for you?

Has this been a particularly difficult topic to discuss because it raises so many questions about what the future may hold?

Have you and your husband/partner discussed what would happen in the worst case scenario, if you had a child and afterwards became terminally ill?

To what extent have his feelings influenced your own feelings on this issue?

If no, ask: Why haven't you discussed this issue with your husband/partner?

Do you think he knows what you are thinking or feeling about having a child?

65. Did you discuss your thoughts about getting pregnant following breast cancer with any other family members or friends? WB65

If yes, ask: Who did you discuss it with? (If not mentioned, ask specifically about mother, father, mother-in-law, father in-law and brother(s), sister(s), close friend(s)).

(FOR EACH PERSON NAMED ASK): What were their thoughts or feelings about the matter? (Probe to understand how supportive/nonsupportive they and others mentioned were of R's decision/position).

If no, ask: Why haven't you discussed this issue with any other family members or friends?

66. Did you discuss your thoughts about getting pregnant following breast cancer with a member of the clergy (e.g., priest, Rabbi, minister)? WB66

If yes, ask: Who did you discuss it with?

(FOR EACH PERSON NAMED ASK): What were their thoughts or feelings about the matter? (Probe to understand how supportive/nonsupportive they were of R's decision/position).

67. What person or persons do you feel have been most influential in your decision? (For each person mentioned, probe to find out why this person(s) opinion(s) has been so important to R's decision.) WB67

68. (FOR THOSE WHO HAVE CHILDREN): Has the fact that you already have a child/children influenced your thoughts or feelings about whether to try to become pregnant since your diagnosis of breast cancer? WB68

69. (FOR THOSE WHO DO NOT HAVE A CHILD): Has the fact that you do not have a child influenced your thoughts or feelings about whether to try to become pregnant since your diagnosis of breast cancer? WB69

70. Do you feel there is a possibility that you might, in the future, change your mind about getting pregnant? WB70

71. How do you feel about your decision? Are you comfortable with it, or do you still sometimes wonder if it's the right one? (Try to determine if R seems ambivalent or unresolved about her decision). WB71

72. Is there anything you can think of that would cause you to change your mind or reconsider your decision? WB72

73. Since your breast cancer, have you ever or would you ever consider adoption as an alternative to having your own child? (**If no, ask:** Why not?) WB73

74. Is there anything else, we haven't discussed, that you feel has been a factor in your decision-making about becoming pregnant following breast cancer? WB74

75. What kinds of services or information do you think would be helpful for women like yourself who have had breast cancer and are considering pregnancy? WB75

IF R HAS DECIDED TO TRY TO BECOME PREGNANT OR IF CURRENTLY PREGNANT

76. Can you tell me why you have decided to try to become pregnant following your breast cancer. (Try to encourage Respondent to be expansive on this issue. Get all her reasons. Ask "Any other reasons" We want to try to understand Respondent's decision-making process). WB76

77. (After R has responded, probe specifically about the following, if not already mentioned, SAY): I want to ask you about some reasons other women have offered for deciding to become or not become pregnant after cancer. Can you tell me if any of these thoughts entered into your own decision-making. WB77

    -- the thought that there might be some health benefits to becoming pregnant.
    -- the thought that having a child would make you happier or improve your quality of life.
    -- the thought that having a child is something that is life affirming and gives you hope and optimism about the future.
    -- the though that having a child would help you start to feel normal again after breast cancer
    -- the thought that having a child is something you want to do for your husband or family.
    -- worry about whether your disease might recur and you would be unable to care for a child.
    -- worry that you may not have a normal baby because of the effects of Radiation Therapy or Chemotherapy on your baby.
    -- worry about the possibility that a female child might grow up to have the disease.
    -- worry that caring for a child might be stressful and detrimental to your health.
    -- the thought that it might be selfish, given possible uncertainty about your future health.

78. Can you think of any other potential benefits, risks, advantages or disadvantages you considered in making your decision? WB78

79. Was age a factor, in any way, in your decision? (**If yes, ask:** In what way?) WB79

80. Do you feel that because of your age there may be a limited period in which you have a reasonable chance of becoming pregnant. (**If yes, ask:** What is that time period?) WB80

81. (IF MARRIED OR LIVING WITH A PARTNER) Since your breast cancer, have you and your husband/partner ever discussed whether you would try to become pregnant? WB81

If yes, ask: What have been his thoughts and feelings about this matter?

Do you think that prior to your diagnosis that he felt differently about your becoming pregnant?

On what points have you two agreed or disagreed regarding this matter?

Has this matter, to any extent, been a source of marital strain or conflict for you?

Has this been a particularly difficult topic to discuss because it raises so many questions about what the future may hold?

To what extent have his feelings influenced your own feelings on this issue?

Have you and your husband/partner discussed what would happen in the worst case scenario, if you had a child and afterwards became terminally ill?

If no, ask: Why haven't you discussed this issue with your husband/partner?

Do you think he knows what you are thinking or feeling about having a child?

82. Have you discussed your thoughts about getting pregnant following breast cancer with any other family members or friends? WB82

If yes, ask: Who did you discuss it with? (If not mentioned ask specifically about mother, father, mother-in-law, father-in-law and brother(s), sister(s), close friend(s)).

FOR EACH PERSON NAMED ASK: What were their thoughts or feelings about the matter? (Probe to understand how supportive/nonsupportive others were of R's decision).

If no, ask: Why haven't you discussed this issue with family members or friends?

83. Did you discuss your thoughts about getting pregnant following breast cancer with a member of the clergy (e.g., priest, Rabbi, minister)? WB83

If yes, ask: Who did you discuss it with?

(FOR EACH PERSON NAMED ASK): What were their thoughts or feelings about the matter? (Probe to understand how supportive/nonsupportive they were of R's decision/position).

84. What person or persons do you feel have been most influential in your decision? (For each person mentioned, probe to find out why this person(s) opinion(s) has been so important to R's decision.) WB84

85.	(FOR THOSE WHO HAVE CHILDREN ASK): Has the fact that you already have a child/children influenced your thoughts or feelings about whether to try to become pregnant since your diagnosis of breast cancer?	WB85
86.	(FOR THOSE WHO DO NOT HAVE A CHILD): Has the fact that you do not have a child influenced your thoughts or feelings about whether to try to become pregnant since your diagnosis of breast cancer?	WB86
87.	How do you feel about your decision to try to have a child? Are you comfortable with it, or do you still wonder if it's the right one? (Try to determine if R seems ambivalent or unresolved about her decision).	WB87
88.	Is there anything you can think of that would cause you to change your mind and 7econsider your decision?	WB88
89.	(FOR THOSE WHO ARE NOT CURRENTLY PREGNANT ASK): Do you feel that you might change your mind in the future.	WB89
90.	(FOR THOSE WHO ARE CURRENTLY PREGNANT ASK): Was this pregnancy planned? (**If no, ask:** Had you considered terminating this pregnancy? **If no, ask:** Why not?) (**If yes, ask:** Why?)	WB90
91.	If you were unable to become pregnant, do you think that you would consider adoption as an alternative. (**If not, ask:** Why not?)	WB91
92.	Is there anything else, we haven't discussed, that you feel has been a factor in your decision-making about becoming pregnant following breast cancer.	WB92
93.	What kinds of services or information do you think would be helpful for women like yourself who have had breast cancer and are considering pregnancy?	WB93

IF R IS UNDECIDED

94. As you try to decide whether or not to try to become pregnant, what do you see as the potential risks and benefits of each alternative choice. Let's start with becoming pregnant now, since your breast cancer. What possible risks and benefits do you see of such a choice? WB94

95. What about choosing not to become pregnant. What potential loses or risks and benefits do you see associated with such a choice? WB95

96. (After R has responded, probe specifically about the following, if not already mentioned, SAY): I want to ask you about some reasons other women have offered for deciding to become or not become pregnant after cancer. Can you tell me if any of these reasons entered into your own decision-making. WB96

    -- the thought that there might be some health benefits to becoming pregnant.
    -- the thought that having a child would make you happier or improve your quality of life.
    -- the thought that having a child is something that is life affirming and gives you hope and optimism about the future.
    -- the though that having a child would help you start to feel normal again after breast cancer.
    -- the thought that having a child is something you want to do for your husband or family.
    -- worry about whether your disease might recur and you would be unable to care for a child.
    -- worry about the possibility that a female child might grow up to have the disease.
    -- worry that you may not have a normal baby because of the effects of Radiation Therapy or Chemotherapy on your baby.
    -- worry that caring for a child might be stressful and detrimental to your health.
    -- the thought that it might be selfish, given possible uncertainty about your future health.

97. Can you think of any other potential benefits, risks, advantages or disadvantages you considered in making your decision? WB97

98. Is age a factor, in any way, in your remaining undecided? (**If yes, ask:** In what way?) WB98

99. Do you feel that because of your age there may be a limited period in which you have a reasonable chance of becoming pregnant. (**If yes, ask:** What is that time period?) WB99

100. (IF MARRIED OR LIVING WITH A PARTNER) Since your breast cancer, have you and your husband/partner ever discussed whether you would try to become pregnant? WB100

If yes, ask: What have been his thoughts and feelings about this matter?

Do you think that prior to your diagnosis that he felt differently about your becoming pregnant?

On what points have you two agreed or disagreed regarding this matter?

Has this matter, to any extent, been a source of marital strain or conflict for you?

Has this been a particularly difficult topic to discuss because it raises so many questions about what the future may hold?

Have you and your husband/partner discussed what would happen in the worst case scenario, if you had a child and afterwards became terminally ill?

To what extent have his feelings influenced your own feelings on this issue?

If no, ask: Why haven't you discussed this issue with your husband/partner?

Do you think he knows what you are thinking or feeling about having a child?

101. Did you discuss your thoughts about getting pregnant following breast cancer with any other family members or friends? WB101

If yes, ask: Who did you discuss it with? (If not mentioned ask specifically about mother, father, mother-in-law, father-in-law and brother(s), sister(s), close friend(s)).

FOR EACH PERSON NAMED ASK: What were their thoughts or feelings about the matter? (Probe to understand how what their position is on the matter; how much they try to influence R's decision).

If no, ask: Why haven't you discussed this issue with family members or friends?

102. Did you discuss your thoughts about getting pregnant following breast cancer with a member of the clergy (e.g., priest, Rabbi, minister)? WB102

If yes, ask: Who did you discuss it with?

(FOR EACH PERSON NAMED ASK): What were their thoughts or feelings about the matter? (Probe to understand how supportive/nonsupportive they were of R's decision/position).

103. What person or persons do you feel will be most influential in your ultimate decision? (For each person mentioned, probe to find out why this person(s) opinion(s) has been WB103

so important to R's decision.)

104.	(FOR THOSE WHO HAVE CHILDREN): Has the fact that you already have a child/children influenced your thoughts or feelings about whether to try to become pregnant since your diagnosis of breast cancer?	WB104
105.	(FOR THOSE WHO DO NOT HAVE A CHILD): Has the fact that you do not have a child influenced your thoughts or feelings about whether to try to become pregnant since your diagnosis of breast cancer?	WB105
106.	If you ultimately decide to become pregnant but are unsuccessful, would you consider adoption? (**If no, ask:** Why not?)	WB106
107.	Is there anything else, we haven't discussed, that you fell has been a factor in your decision-making about becoming pregnant following breast cancer?	WB107
108.	What kinds of services or information do you think would be helpful for women like yourself who have had breast cancer and are considering pregnancy?	WB108

IF R HAS DECIDED TO TRY TO BECOME PREGNANT
BUT IS DELAYING TRYING

109. Can you tell me why you have decided to wait to try to become pregnant following your breast cancer. (Try to encourage Respondent to be expansive on this issue. Get all her reasons. Ask "Any other reasons" We want to try to understand Respondent's decision-making process). WB109

110. (After R has responded, probe specifically about the following, if not already mentioned, SAY): I want to ask you about some reasons other women have offered for deciding to become or not become pregnant after cancer. Can you tell me if any of these thoughts entered into your own decision-making. WB110

-- the thought that there might be some health benefits to becoming pregnant.
-- the thought that having a child would make you happier or improve your quality of life.
-- the thought that having a child is something that is life affirming and gives you hope and optimism about the future.
-- the thought that having a child would help you to feel normal again after breast cancer.
-- the thought that having a child is something you want to do for your husband or family.
-- worry about whether your disease might recur and you would be unable to care for a child.
-- worry about the possibility that a female child might grow up to have the disease
-- worry that you may not have a normal baby because of the effects of Radiation Therapy or Chemotherapy on your baby.
-- worry that caring for a child might be stressful and detrimental to your health.
-- the thought that it might be selfish, given possible uncertainty about your future health.

111. Can you think of any other potential benefits, risks, advantages or disadvantages you considered in making your decision? WB111

112. Was age a factor, in any way, in your decision? (**If yes, ask:** In what way?) WB112

113. Do you feel that because of your age there may be a limited period in which you have a reasonable chance of becoming pregnant. (**If yes, ask:** What is that time period?) WB113

114. (IF MARRIED OR LIVING WITH A PARTNER) Since your breast cancer, have you and your husband/partner ever discussed whether you would try to become pregnant WB114

If yes, ask: What have been his thoughts and feelings about this matter?

Do you think that prior to your diagnosis that he felt differently about your becoming pregnant?

On what points have you two agreed or disagreed regarding this matter?

Has this matter, to any extent, been a source of marital strain or conflict for you?

Has this been a particularly difficult topic to discuss because it raises so many questions about what the future may hold?

To what extent have his feelings influenced your own feelings on this issue.

Have you and your husband/partner discussed what would happen in the worst case scenario, if you had a child and afterwards became terminally ill?

If no, ask: Why haven't you discussed this issue with your husband/partner?

Do you think he knows what you are thinking or feeling about having a child?

115. Have you discussed your thoughts about getting pregnant following breast cancer with any other family members or friends? WB115

If yes, ask: Who did you discuss it with? (If not mentioned ask specifically about mother, father, mother-in-law, father-in-law and brother(s), sister(s), close friend(s)).

FOR EACH PERSON NAMED ASK: What were their thoughts or feelings about the matter? (Probe to understand how supportive/nonsupportive others were of R's decision).

If no, ask: Why haven't you discussed this issue with family members or friends?

116. Did you discuss your thoughts about getting pregnant following breast cancer with a member of the clergy (e.g., priest, Rabbi, minister)? WB116

If yes, ask: Who did you discuss it with?

(FOR EACH PERSON NAMED ASK): What were their thoughts or feelings about the matter? (Probe to understand how supportive/nonsupportive they were of R's decision/position).

117. What person or persons do you feel have been most influential in your decision? (For each person mentioned, probe to find out why this person(s) opinion(s) has been so important to R's decision.) WB117

118. (FOR THOSE WHO HAVE CHILDREN ASK): Has the fact that you already have a child/children influenced your thoughts or feelings about whether to try to become pregnant since your diagnosis of breast cancer? (Probe to find out if her having a child/children is a factor in her decision to delay a future pregnancy)	WB118
119. (FOR THOSE WHO DO NOT HAVE A CHILD): Has the fact that you do not have a child influenced your thoughts or feelings about whether to try to become pregnant since your diagnosis of breast cancer?	WB119
120. How do you feel about your decision? Are you comfortable with it, or do you still wonder if it's the right one? (Try to determine if R seems ambivalent or unresolved about her decision).	WB120
121. Do you think you might change your mind in the future?	WB121
122. If you were unable to become pregnant, do you think that you would consider adoption as an alternative. (**If not, ask:** Why not?)	WB122
123. Is there anything else, we haven't discussed, that you feel has been a factor in your decision-making about becoming pregnant following breast cancer?	WB123
124. What kinds of services or information do you think would be helpful for women like yourself who have had breast cancer and are considering pregnancy?	WB124

CLOSING STATEMENT

We have talked a lot about a very important subject. Before ending, I'd like to invite you to make a brief closing statement about your experience of considering pregnancy after having breast cancer. Do you have any other thoughts to share before we end?

Thank you for your participation in this study.

INTERVIEWER NOTES AND COMMENTS:

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Siegel K, Gorey E, Gluhoski V. (in press) Pregnancy decision-making among women previously treated for breast cancer. Journal of Psychosocial Oncology.

Gluhoski VL, Siegel K, Gorey E. (in press) Unique stressors of unmarried women with breast cancer. Journal of Psychosocial Oncology.

Siegel K, Gluhoski V, Gorey E. Breast cancer: Age-related distress. Submitted for consideration for publication. Social Science and Medicine.

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REPLY TO
ATTENTION OF:

MCMR-RMI-S (70-1y) 10 Aug 98

MEMORANDUM FOR Administrator, Defense Technical Information Center, ATTN: DTIC-OCP, Fort Belvoir, VA 22060-6218

SUBJECT: Request Change in Distribution Statement

1. The U.S. Army Medical Research and Materiel Command has reexamined the need for the limitation assigned to technical reports written for the following contracts. Request the limited distribution statement for these contracts be changed to "Approved for public release; distribution unlimited." These reports should be released to the National Technical Information Service.

Contract Number	Accession Document Number
DAMD17-91-C-1020	ADB187724 + ✓
DAMD17-92-C-2053	ADB196427 +
DAMD17-94-C-4022	ADB190750 +
DAMD17-94-C-4023	ADB188373 +
DAMD17-94-C-4027	ADB196161 + ✓
DAMD17-94-C-4029	ADB190899 +
DAMD17-94-C-4039	ADB188023 +
DAMD17-94-C-4024	ADB189184 +
DAMD17-94-C-4026	ADB187918 +
~~DAMD17-94-J-4250~~	~~ADB221970~~
~~DAMD17-94-J-4250~~	~~ADB230700~~
DAMD17-96-1-6241	x ADB233224
DAMD17-96-1-6241	ADB218632 ✓
DAMD17-94-J-4496	x ADB225269
DAMD17-94-J-4392	ADB225308 ✓
DAMD17-94-J-4455	ADB225784 ✓
DAMD17-94-J-4309	ADB228198
DAMD17-91-C-1135	ADB233658
DAMD17-94-J-4038	ADB232313
DAMD17-94-J-4073	ADB222794
DAMD17-94-J-4131	ADB219168
DAMD17-94-J-4159	ADB232305
MIPR· 95MM5535	ADB232218
95MM5605	ADB233374
95MM5673	ADB226037

2. Point of contact for this request is Ms. Judy Pawlus at DSN 343-7322 or email: judy_pawlus@ftdetrck-ccmail.army.mil.

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