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A pilot study to examine patient awareness and provider discussion of the impact of cancer treatment on fertility in a registry-based sample of African American women with breast cancer

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Abstract

Purpose—Fertility is a concern for many cancer patients diagnosed during their reproductive years. Although African American women are more likely to be diagnosed with early breast cancer (i.e., ≤age 40), little is known about patient awareness of or provider discussion related to fertility in this group. We examined African American women's awareness of the possible impact of cancer treatment on fertility.

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Methods—In a cross-sectional survey of African American women with early-onset breast cancer, demographic and clinical variables were compared with patient awareness and physician discussion of potential fertility loss.

Results—For women in our sample (N=48), 45.8% reported being aware of the potential impact of cancer treatment on fertility, and 56.3% reported that their providers discussed fertility with them. Bivariate analyses demonstrated that awareness was significantly higher in women diagnosed at age ≤45 ($p<0.05$), who were nulliparous ($p<0.01$), or who did not have tubal ligation ($p<0.001$). Provider discussion was more often reported by patients who were diagnosed in stages 2/3 ($p<0.05$) and had no children ($p<0.01$).

Conclusion—Study results suggest potential health disparities in reproductive health among early-onset breast cancer patients and demonstrate missed clinical opportunities to provide information about fertility that may impact long-term quality of life in early-onset African American breast cancer patients.

Keywords

Breast cancer; African American; Cancer registry; Fertility awareness

Introduction

African American (AA) women bear a disproportionate burden of early-onset breast cancer diagnosed at age <40 [1]. Specifically, the incidence rate for breast cancer <40 is higher in African American women (15.5 per 100,000) compared to White women (13.1 per 100,000). While treatment advances have led to survival improvements for AA women [2, 3], many younger breast cancer patients face unique survivorship issues that may manifest in greater psychological morbidity and poorer quality of life than older breast cancer survivors [4–8]. Fertility has been identified as a leading concern among breast cancer patients diagnosed during their reproductive years [9]. Estimated infertility risks for women treated with adjuvant breast cancer therapy for 6 weeks with the most commonly used chemotherapy regimens is >80% for pre-menopausal women aged 40, 20–80% for women aged 30–39, and <20% for women under 30 [10]. Thus, the optimal time for breast cancer patients and oncology care providers to discuss fertility-related concerns is prior to the initiation of chemotherapy [11].

While a few studies have examined breast cancer patient awareness and provider discussion of fertility issues [9, 12, 13], there is little or no representation of AA breast cancer patients' experiences. Given that AA women are more likely to be diagnosed with early-onset breast cancer [14] that may coincide with their childbearing years (e.g., in their 30s and 40s), it is important to better understand whether they are informed about the possible impact of cancer treatment on fertility. To examine this issue, as part of a larger study examining the role of genetic factors in early-onset breast cancer among AA women [15], we assessed patient-reported awareness and provider discussion of the impact of cancer treatment on fertility among AA breast cancer patients.

Method

Participant recruitment

Details about participant recruitment are presented in detail in a previously published paper [15]. Briefly, eligible patients were AA women diagnosed with invasive breast cancer ≤age 50 between the years of 2005–2006 residing in one of four Florida counties. Upon approval of the Institutional Review Boards of the University of South Florida and the Florida Department of Health, recruitment took place between February 4, 2008 and April 30, 2009.

Sociodemographic and clinical characteristics

Sociodemographic and clinical characteristics obtained from the Florida State Cancer Registry or medical records review included: age at diagnosis (≤45, >46), stage of breast cancer at diagnosis (1, 2/3, 4, other (unknown/unstaged)), histological subtype (ductal, lobular, mixed, and other), cancer treatment (chemotherapy alone or in combination with additional treatment, treatment excluding chemotherapy, and no treatment), primary payor at diagnosis (private insurance, public insurance, no insurance, and other), county of residence at the time of diagnosis (Broward, Hillsborough, Pinellas, and Polk), and country of origin (USA, other). Additional data collected via self-report questionnaire included: marital status (married or living as married, other), number of children (none, ≥one), hysterectomy (yes, no), tubal ligation (yes, no), educational status (high school or less, vocational school and some college, college graduate and beyond, and attended school in another country), and household income prior to breast cancer diagnosis (<25,000, ≥ 25,000–<50,000, and ≥50,000).

Awareness and discussion of fertility preservation

Participants were asked to respond (yes, no) to the following two questions: (1) “Were you aware that some treatments you may have received for breast cancer may lead to loss of your future ability to have children?” and (2) “Did your doctor ever discuss the possibility that treatment for breast cancer may lead to loss of your future ability to have children?”

Data analysis

Data were summarized using descriptive statistics. Chi-square tests for equal proportions or exact tests were used to compare sociodemographic and clinical characteristics between those who responded affirmatively to the questions regarding awareness and provider discussion of the impact of cancer treatment on fertility and those who responded negatively. All analyses were performed using SAS version 9.1. For all analyses, statistical significance was defined at the conventional 95% level ($\alpha=0.05$, two-tailed).

Results

Of the 209 individuals identified through the cancer registry, 82 were reached by telephone and/or mail and informed about the study, and 48 ultimately participated. Comparisons of demographic and clinical variables from cancer registry data suggest study participants and non-participants were similar [15].

As shown in Table 1, the majority of the participants were age ≤45 (63%) and married (48%). Eighty-five percent had a ductal histologic subtype, and 75% had private insurance at the time of diagnosis. Those who indicated they were aware of the possible impact of cancer treatment on fertility were younger (age ≤45; $p=0.017$), had no children ($p=0.007$), or had not undergone tubal ligation ($p<0.001$; Table 1). Women diagnosed in stages 2/3 ($p=0.037$) or who had no children ($p=0.018$) were more likely to report provider discussion of the impact of cancer treatment on fertility (Table 2).

Discussion

Long-term survivorship concerns have become increasingly salient for women with early-onset breast cancer. Awareness and discussion of fertility implications of breast cancer treatment prior to the initiation of chemotherapy are likely two key antecedent factors to ensure women select treatment options that coincide with their future desires for biological family building [9, 13]. For AA females, who are more likely to be diagnosed with early-onset breast cancer [16], patient awareness and patient-provider discussion of treatment-associated infertility risk may be particularly critical to informed decision making and patient satisfaction.

As in previous studies on this topic [12, 17, 18], our findings suggest that a substantial proportion of breast cancer patients were unaware of the impact of breast cancer treatment on fertility. However, awareness in our study was higher in certain subgroups including those who were diagnosed ≤age 45, had no children, or had not undergone tubal ligation. These findings are consistent with those of previous studies suggest women diagnosed with breast cancer with fertility concerns are younger (at age of onset) [9, 19, 20], have had fewer pregnancies and live births [9, 19, 20], and have not undergone tubal ligation [9]. These characteristics likely represent a subset of women with breast cancer for whom fertility is a relevant issue. It is possible that higher levels of awareness reflect higher rates of information-seeking on this topic. Results from a recent study of female cancer patients (N=41) surveyed prior to an initial fertility preservation consultation suggest pre-visit knowledge was higher in women who conducted research before consultation or had personal (self, family, or friends) experiences with infertility [12].

With regard to provider discussion of fertility implications, 56% of the participants reported that providers discussed the potential impact of treatment on future fertility. Similar to studies of primarily Caucasian women, 34% to 72% of breast cancer patients reported provider discussion about fertility, with provider discussion reported more often by younger females and those who had no children [9, 13]. Thus, our findings as well as other studies suggest oncology care providers may selectively initiate discussion of fertility based on patient reproductive characteristics. However, it is also possible that patients with more fertility concerns (e.g., those with no children) may be more likely to initiate and/or recall this conversation compared to those for whom this issue was not a priority.

This study provides important information about patient awareness and provider communication regarding the possible impact of breast cancer treatment on fertility among a sample of AA breast cancer patients. However, these findings must be considered in light of certain limitations. The overall number of participants was small and raises concerns about the generalizability of this sample to other AA breast cancer survivors. However, comparisons of our study sample to all patients identified as eligible for the parent study showed no significant differences in demographic and clinical characteristics [15]. Additionally, participants completed the study questionnaire (including questions regarding fertility) on an average of 2.5 years from diagnosis (data not shown). As a result, these findings may be subject to recall bias. Issues of awareness and provider communication were assessed using two single-item measures. Thus, we were unable to explore the important nuances of the cognitive, affective, behavioral, and communicative factors that may accompany the discussion of fertility, such as the amount and type of information presented or whether referral to a reproductive endocrinologist or other fertility specialist was made. Most importantly, patient childbearing plans should be assessed by and fertility options should be discussed with providers prior to treatment decisions. Patients who may be unsure whether they desire children post-treatment should still be advised of infertility options. Prior research suggests that neither definite plans for future child-rearing nor current relationship status reliably predict patient desire to explore fertility preservation options [21]. Given the importance of infertility risk awareness prior to treatment selection, future studies examining nuances of patient knowledge and provider communication should also assess fertility plans and preservation options with all patients of childbearing age prior to treatment decisions. It is important to note that our study was conducted prior to the dissemination of clinical guidelines issued by the American Society of Clinical Oncology (ASCO) in 2006 which underscores the oncologists' role in initiating dialogue about fertility implications of treatment with patients of childbearing age [10, 22]. It is possible that provider discussion and, consequently, patient awareness will increase as more providers become aware of and incorporate these guidelines into their clinical practice. However, the present study provides a comparison for studies conducted after dissemination of ASCO guidelines.

Our study indicates that approximately one half of AA women diagnosed with invasive breast cancer at age ≤50 were unaware of and reported no discussion with their providers of fertility risk associated with treatment options. Since the time of our study, at least two interventions have been published in the peer review literature focused on addressing fertility concerns specific to breast cancer survivors. The first is an internet-based tool designed to provide reproductive health and fertility education to patients [23, 24]. The second is a peer counseling (phone or in-person) and workbook specifically developed for AA women [16]. While both studies showed improvements in knowledge and positive impact on psychosocial functioning, their efficacy was demonstrated in samples where the majority of women had completed their breast cancer treatment [16, 24]. We were unable to identify any tools specifically focusing on the narrow window of opportunity from diagnosis to the initiation of chemotherapy, when patients have the most options to preserve fertility [25]. Missed clinical opportunities to promote informed decision making and enhance patient satisfaction and quality of life outcomes among younger AA breast cancer patients may persist in the absence of patient-focused tools and provider training to improve fertility-related communication with breast cancer patients at or near the time of diagnosis.

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Table 1

Demographic and clinical variables stratified by patient awareness of impact of cancer treatment on fertility (N= 48)

Clinical and demographic variables	***n***	**Patient awareness of infertility risk**		***p* value**
	Total (*N*= 48)	**Yes (*n*=22)**[a]	**No (*n*=26)**[a]	
Age at Diagnosis				0.017
≤45	30	18 (60%)	12 (40%)	
>46	18	4 (22.2%)	14 (77.8%)	
Stage at diagnosis				ns
Stage 1	23	9 (39.1%)	14 (60.9%)	
Stage 2/3	23	13 (56.5%)	10 (43.5%)	
Other (unknown/unstaged)	2	0	2 (100%)	
Histologic subtype				ns
Ductal	41	18 (43.9%)	23 (56.1%)	
Lobular	3	2 (66.7%)	1 (50%)	
Mixed[b]	2	1 (50%)	1(50%)	
Other[c]	2	1 (50%)	1 (50%)	
Treatment received				ns
No treatment	5	2 (40%)	3 (60%)	
Treatment(s) including chemo	23	14 (60.9%)	9 (39.1%)	
Treatment(s) excluding chemo	20	6 (30%)	14 (70%)	
Primary payor at diagnosis				ns
Private insurance	36	16 (44.4%)	20 (55.6%)	
Public insurance	5	2 (40%)	3 (60%)	
No insurance	4	3 (75%)	1 (25%)	
Other	3	1 (33.3%)	2 (66.7%)	
County of diagnosis				ns
Broward	24	10 (41.7%)	14 (58.3%)	
Hillsborough	15	8 (53.3%)	7 (46.7%)	
Pinellas	7	4 (57.1%)	3 (42.9%)	
Polk	2	0	2 (100%)	
Country of origin				ns
USA	33	15 (45.5%)	18 (54.5%)	
Other	15	7 (46.7%)	8 (53.3%)	
Last grade or school-level completed				ns
High school or less	8	3 (37.5%)	5 (62.5%)	
Vocational school and some college	15	5 (33.3%)	10 (66.7%)	
College graduate and beyond	22	11 (50%)	11 (50%)	
Attended school in another country	3	3 (100%)	0	
Total household income prior to diagnosis				ns
<25,000	11	4 (36.4%)	7 (63.6%)	

Clinical and demographic variables	***n*** **Total (*N*= 48)**	**Patient awareness of infertility risk** **Yes (*n*=22)[a]**	 **No (*n*=26)[a]**	***p* value**
≥25,000–<50,000	14	7 (50%)	7 (50%)	
≥50,000	18	8 (44.4%)	10 (55.6%)	
Refused to answer	5	3 (60%)	2 (40%)	
Marital status				ns
Married (including common law)	23	11 (47.8%)	12 (52.2%)	
Other[d]	25	11 (44%)	14 (56%)	
Number of children				0.007
None	3	3 (100%)	0	
≥One	38	14 (36.8%)	24 (63.2%)	
Refused to answer	7	5 (71.4%)	2 (28.6%)	
Hysterectomy				ns
Yes	14	3 (21.4%)	11 (78.6%)	
No	34	19 (55.9%)	15 (44.1%)	
Tubal ligation				<0.001
Yes	20	3 (15%)	17 (85%)	
No	28	19 (67.9%)	9 (32.1%)	

[a] Percentages based on row totals

[b] Mixed includes mixed infiltrating ductal with lobular of other carcinoma

[c] Other includes other histologic subtypes and carcinoma, not otherwise specified

[d] Includes single, divorced, and widowed

Table 2

Demographic and clinical variables stratified by provider discussion of impact of cancer treatment on fertility (*N*= 48)

Clinical and demographic variables	***n***	**Patient–provider discussion of infertility risk**		***p* value**
	Total (*N*=48)	**Yes (*n*=27)**[a]	**No (*n*=21)**[a]	
Age at diagnosis				ns
≤45	30	19 (63.3%)	11 (36.7%)	
>46	18	8 (44.4%)	10 (55.6%)	
Stage at diagnosis				0.037
Stage 1	23	9 (39.1%)	14 (60.9%)	
Stage 2/3	23	17 (73.9%)	6 (26.1%)	
Other (unknown/unstaged)	2	1 (50%)	1 (50%)	
Histologic subtype				ns
Ductal	41	22 (53.7%)	19 (46.3%)	
Lobular	3	2 (66.7%)	1 (33.3%)	
Mixed[b]	2	1 (50%)	1 (50%)	
Other[c]	2	2 (100%)	0	
Treatment received (*n* =45)				ns
No treatment	5	3 (60%)	2 (40%)	
Treatment(s) including chemo	23	14 (60.9%)	9 (39.1%)	
Treatment(s) excluding chemo	20	10 (50%)	10 (50%)	
Primary payor at diagnosis				ns
Private Insurance	36	20 (55.6%)	16 (44.4%)	
Public Insurance	5	4 (80%)	1 (20%)	
No Insurance	4	2 (50%)	2 (50%)	
Other	3	1 (33.3%)	2 (66.7%)	
County of diagnosis				ns
Broward	24	14 (58.3%)	10 (41.7%)	
Hillsborough	15	9 (60%)	6 (40%)	
Pinellas	7	4 (57.1%)	3 (42.9%)	
Polk	2	0	2 (100%)	
Country of origin				ns
USA	33	20 (60.6%)	13 (39.4%)	
Other	15	7 (46.7%)	8 (53.3%)	
Last grade or school-level completed				ns
High school or less	8	5 (62.5%)	3 (37.5%)	
Vocational school and some college	15	9 (60%)	6 (40%)	
College graduate and beyond	22	12 (54.5%)	10 (45.5%)	
Attended school in another country	3	1 (33.3%)	2 (66.7%)	
Total household income prior to diagnosis				ns
<25,000	11	8 (72.7%)	3 (27.3%)	

Clinical and demographic variables	***n*** Total (N=48)	**Patient–provider discussion of infertility risk** Yes (n=27)[a]	No (n=21)[a]	***p* value**
≥25,000–<50,000	14	6 (42.9%)	8 (57.1%)	
≥50,000	18	9 (50%)	9 (50%)	
Refused to answer	5	4 (80%)	1 (20%)	
Marital status				ns
Married (including common law)	23	11 (47.8%)	12 (52.2%)	
Other[d]	25	16 (64%)	9 (36%)	
Number of children				0.004
None	3	3 (100%)	0	
≥One	38	17 (44.7%)	21 (55.3%)	
Refused to answer	7	7 (100%)	0	
Hysterectomy				ns
Yes	14	6 (42.9%)	8 (57.1%)	
No	34	21 (61.8%)	13 (38.2%)	
Tubal ligation				ns
Yes	20	8 (40%)	12 (60%)	
No	28	19 (67.9%)	9 (32.1%)	

[a] Percentages based on row totals

[b] Mixed includes mixed infiltrating ductal with lobular of other carcinoma

[c] Other includes other histologic subtypes and carcinoma, not otherwise specified

[d] Includes single, divorced, and widowed