



# Survey of young women with breast cancer to identify rates of fertility preservation (FP) discussion and barriers to FP care

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## Abstract

**Purpose** To identify the proportion of reproductive age women with breast cancer that engaged in a fertility preservation discussion and reproductive endocrinology and infertility (REI) consultation.

**Methods** This cross-sectional survey recruited women 18–42 years who were diagnosed with breast cancer from 2006 to 2016 by phone or email and asked them to complete an online survey. Demographic characteristics, barriers to FP, utilization of FP consultation, and FP procedures (oocyte and embryo cryopreservation) were analyzed.

**Results** A majority of women (64%) did not have FP discussed by any provider. Older women and those who were parents at the time of diagnosis were less likely to engage in a FP discussion. However, there were no significant differences in partner status or cancer stage between women with or without FP discussions. Of the women who desired future children prior to the cancer diagnosis, 93% received chemotherapy; however, only 34% of these women had a consultation with an REI. The most common reasons for declining FP consultation were already having their desired number of children (41%), financial barriers (14%), and concern about delaying cancer treatment and cancer recurrence (12%). Forty percent of women who desired future children and met with an REI pursued FP procedures.

**Conclusion** Younger women were more likely to receive FP counseling. FP consultations and procedures were low even in women who desired future fertility, with the predominant barriers being cost, fears concerning a delay in cancer treatment, and future cancer recurrence.

**Keywords** Breast cancer · Fertility preservation · Assisted reproductive technology · Oncofertility

## Introduction

Breast cancer is the most common cancer of reproductive age women. Five percent of breast cancer diagnoses are among women under the age of 40 with 50% of these women diagnosed with early-stage disease. Although survival rates are improving and 5-year survival rates now exceed 80% in early-stage disease [1, 2], reproductive age women with breast cancer are at risk for infertility after chemotherapeutic and hormonal treatments. Although the reported ranges of infertility in breast cancer survivors vary depending on age at diagnosis and chemotherapy dose, the incidence of infertility can be as high as 80% [3–5]. Despite the risk of infertility, most women do not pursue fertility preservation (FP) procedures prior to cancer treatment [6].

The American Society of Clinical Oncology and the American Society of Reproductive Medicine recommend that women diagnosed with cancer during their

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reproductive years should undergo counseling regarding the impact of cancer treatments on fertility, the options of fertility preservation, and be offered referrals to reproductive endocrinology and infertility (REI) specialists (“Fertility preservation in patients undergoing gonadotoxic therapy or gonadectomy: a committee opinion,” 2019; [7]). It is well established that cryopreservation of embryos and, more recently oocytes [8], is feasible and safe options for women of reproductive age facing potentially gonadotoxic treatment who wish to have genetically related children in the future. These procedures do not affect cancer prognosis or disease-free survival and can be completed in a 2–3-week time period [9]. Loss of fertility can have significant long-term psychological consequences, and women who do not receive FP counseling are at risk for reduced quality of life compared to those having a FP consultation [10]. Referral to a REI specifically for a FP consultation has been shown to improve quality of life and decrease regret [10] more than counseling by an oncologist or other provider even without undergoing a FP procedure. However, rates of REI referral remain low at 5–31% [11–14].

Many barriers to REI consultations and FP procedures have been documented including lack of a partner, fear regarding cancer progression or delay in treatment, cost of an IVF cycle, lack of counseling at a time when fertility preservation decisions must be made, and poor understanding of fertility preservation options [15, 16]. Limitations of prior studies evaluating the incidence of referrals and REI consultations include as follows: heterogenous populations studied with multiple cancer types, the use of claims databases where referral rates cannot always be assessed, and heterogeneity in health care systems (i.e., studies from Europe or Canada) [6, 17]. Therefore, to increase REI referral rates for patients who desire parenthood, we must determine FP counseling, REI consultation rates, and barriers to care allowing us to design specific interventions targeting the most common barriers for the breast cancer patient population. The primary objective of this study was to identify the proportion of reproductive age women with breast cancer that engaged in a fertility preservation discussion and REI consultation among women that had the desire to be parents at some point in their life. The secondary objective was to identify the barriers to fertility preservation and identify characteristics among those who did and did not have a FP discussion.

## Methods

We performed a cross-sectional survey using a breast cancer registry at an academic Breast Health clinic in Rhode Island. All study procedures were approved by the institutional IRB.

## Participants

Women 18–42 years old at time of breast cancer diagnosis of stage 1 or greater were contacted between 9/2019 and 1/2021 and asked to complete an online survey designed to assess socio demographic, medical history, and FP discussions at the time of cancer diagnosis. The women were diagnosed with breast cancer from 2006 to 2016. All women were contacted up to three times by phone to invite them to complete the survey. If email addresses were accessible, an email invitation was also sent. Those who did not reply within 1 week of the first email were sent up to the 3 email reminders 1 week apart. After 3 telephone and 3 emails, women were no longer contacted. The survey was emailed to participants through REDCap (Research Electronic Data Capture), a secure, web-based application designed to support data capture for research studies.

## Survey

The survey was designed and evaluated by our research team who had content knowledge and expertise in survey methodology. It was tested with medical and non-medical individuals to ensure that the questions were at an appropriate reading and comprehension level (supplementary fig. I). The final survey included questions regarding desire for future children at time of diagnosis, past obstetric history, cancer type and treatment, fertility preservation discussions and procedures such as oocyte and embryo cryopreservation, post-treatment pregnancies, and demographic characteristics. We used the following question “Have you ever had a desire to become a parent?” to identify patients who would be more likely to desire REI consultation. Subsequent questions about the desire for children, fertility preservation, and pregnancy were shown only to participants who responded affirmatively to this question. The survey was only available in English.

## Data analysis

Having had a FP discussion was determined by positive endorsement to the question “At the time of your breast cancer diagnosis, did you discuss fertility preservation with any of your medical team?” Demographic and cancer-specific questions were summarized by frequencies and proportions and compared between groups with and without FP discussions by Fisher’s exact test. The distribution of patients with previous children vs. those without previous children, as well as those who desired more children vs. those that did not, was also compared by FP discussion group using Fisher’s exact test. The percentage of patients who had an

REI consultation was evaluated in three separate groups (those that desired future children before cancer diagnosis, those that did not, and those that were unsure). The type of provider who engaged in a FP discussion and patient reasons for declining REI consultation and procedures were evaluated. A patient was able to select more than one provider type or more than one reason for declining. Therefore, responses were not mutually exclusive. Two-tailed  $p$ -values were reported with  $p < 0.05$  considered statistically significant. Analysis was performed with SAS 9.4 (SAS Institute, Cary NC).

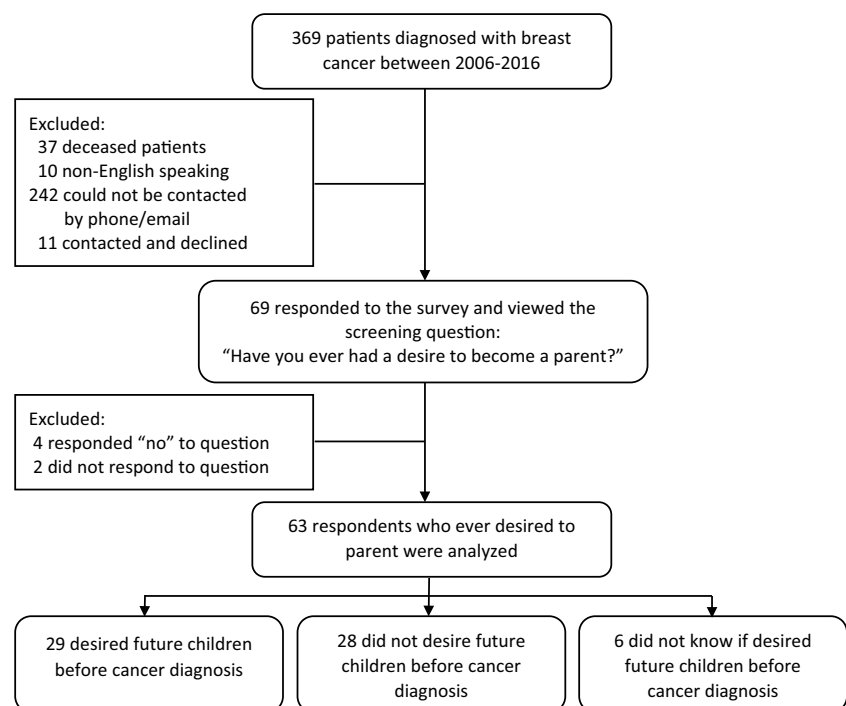
## Results

There were 369 women with newly diagnosed breast cancer in the cancer registry. Of these, 37 were deceased and 10 were non-English speaking so were excluded. In total, 322 women were approached by either a phone call and/or email. Eighty women were successfully contacted and 69 (86%) chose to participate. Of the 69 who completed the survey, 63 (91%) responded yes to the question “Have you ever had the desire to become a parent?” and were included in this analysis. The majority of all women in the analytic sample ( $n=46$ , 73%) had children at the time of diagnosis, 29 (46%) desired future children prior to diagnosis, and 6 (10%) were unsure (Fig. 1). Forty-four women (70%) were between 35 and 42 years old, 56 (89%) were partnered, 54 (86%) Caucasian, 51 (84%) were stage 1 or 2, and 54 (86%) had chemotherapy as part of their breast cancer treatment.

Forty women (64%) did not have a FP discussion with any provider during their cancer diagnosis. Two women who left the question blank were counted as not having a discussion. Women having FP discussions were more likely to be younger compared to women who did not have FP discussions ( $p = 0.0004$ ). The majority of women who were not counseled regarding FP ( $n=34$ , 87%) were in the older 35–42-year-old age category (Table 1). Women having FP discussions were much less likely to be parents compared to those who did not have discussions (48% vs. 88%,  $p=0.001$ ). Other demographics including race/ethnicity, education, and financial status did not differ significantly between groups (Table 1). Most women in both groups were diagnosed at stage 1 or 2 and the majority of women received chemotherapy as part of their treatment (Table 1). While not statistically significantly different, 96% of women having FP discussions received chemotherapy compared to only 80% of women who did not have FP discussions. There were no differences in hormonal therapy or stage of diagnosis between women with or without FP discussions (Table 1). FP was discussed by breast surgeons ( $n=16$ , 70%), by medical oncologists ( $n=16$ , 70%), and by OB/GYN or primary care providers ( $n=7$ , 30%).

Women who had a FP discussion were more likely to desire future children than those that did not have a discussion ( $n=17$ , 74%) vs. ( $n=12$ , 30%) (Table 2). However, only in multiparous women was there a difference in desire for additional children between women with and without FP discussions. All nulliparous women who did not desire future children ( $n=3$ ; 100%) had FP discussions in comparison to

**Fig. 1** Participant flow chart. Desire for future children before cancer diagnosis included becoming a parent for respondents without children and having additional children for respondents who were already parents



**Table 1** Patient demographics and fertility preservation discussions in patients who ever desired to be parents ( $n = 63$ )

| Variable  | Data are $n$ (column %)          |                                      | $p$ -value |
|---|----------------------------------|--------------------------------------|------------|
|   | Fertility preservation discussed | Fertility preservation not discussed |            |
| Total   | 23 (36.5)                        | 40 (63.5)                            | --         |
| Age at diagnosis (y) <sup>1</sup>                         |                                  |                                      |            |
| 18–34   | 13 (56.5)                        | 5 (12.8)                             | 0.0004     |
| 35–42   | 10 (43.5)                        | 34 (87.2)                            |            |
| Race/ethnicity  |                                  |                                      |            |
| White   | 16 (69.6)                        | 34 (85.0)                            | 0.46       |
| Black   | 2 (8.7)                          | 2 (5.0)                              |            |
| Other   | 1 (4.4)                          | 1 (2.5)                              |            |
| More than one race  | 1 (4.4)                          | 1 (2.5)                              |            |
| Hispanic/Latina <sup>2</sup>                              | 3 (13.0)                         | 1 (2.5)                              |            |
| Choose not to answer                                      | 0 (0)                            | 1 (2.5)                              |            |
| Education   |                                  |                                      |            |
| High school degree/GED                                    | 1 (4.4)                          | 4 (10.0)                             | 0.46       |
| Vocational school/Some college                            | 5 (21.7)                         | 3 (7.5)                              |            |
| College degree  | 9 (39.1)                         | 17 (42.5)                            |            |
| Graduate degree   | 8 (34.8)                         | 16 (40.0)                            |            |
| Household financial status                                |                                  |                                      |            |
| Not enough to pay some bills no matter how hard you tried | 7 (30.4)                         | 9 (22.5)                             | 0.58       |
| Enough to pay bills, but had to cut back                  | 5 (21.7)                         | 7 (17.5)                             |            |
| Enough to pay bills without cutting back, but no extras   | 4 (17.4)                         | 7 (17.5)                             |            |
| Enough money for extras                                   | 6 (26.1)                         | 14 (35.0)                            |            |
| Don't know  | 1 (4.4)                          | 0 (0)                                |            |
| Choose not to answer                                      | 0 (0)                            | 3 (7.5)                              |            |
| Partner at time of diagnosis <sup>3</sup>                 |                                  |                                      |            |
| Yes   | 21 (91.3)                        | 35 (89.7)                            | 1.00       |
| No  | 2 (8.7)                          | 4 (10.3)                             |            |
| Parent at time of diagnosis                               |                                  |                                      |            |
| Yes   | 11 (47.8)                        | 35 (87.5)                            | 0.001      |
| No  | 12 (52.2)                        | 5 (12.5)                             |            |
| Stage   |                                  |                                      |            |
| I   | 8 (34.8)                         | 13 (32.5)                            | 0.90       |
| II  | 11 (47.8)                        | 19 (47.5)                            |            |
| III   | 4 (17.4)                         | 5 (12.5)                             |            |
| IV  | 0                                | 1 (2.5)                              |            |
| Don't know  | 0                                | 2 (5.0)                              |            |
| Chemotherapy  |                                  |                                      |            |
| Yes   | 22 (95.7)                        | 32 (80.0)                            | 0.14       |
| No  | 1 (4.4)                          | 8 (20.0)                             |            |
| Anti-estrogen   |                                  |                                      |            |
| Yes   | 12 (52.2)                        | 24 (60.0)                            | 0.20       |
| No  | 9 (39.1)                         | 16 (40.0)                            |            |
| Don't know  | 2 (8.7)                          | 0 (0)                                |            |
| No chemo or anti-estrogen <sup>4</sup>                    |                                  |                                      |            |
| Yes   | 0 (0)                            | 2 (5.0)                              | 0.54       |
| No  | 21 (100)                         | 38 (95.0)                            |            |

Fisher's exact test was used for all comparisons

<sup>1</sup>One response of "choose not to answer" was excluded

<sup>2</sup>Participants reporting Hispanic/Latina ethnicity, regardless of reported race, were included in this category

<sup>3</sup>One missing response was excluded

<sup>4</sup>Two responses of "Don't know" were excluded

**Table 2** Parenting plans by parenting status at time of cancer diagnosis and fertility preservation discussions (*n* = 63)

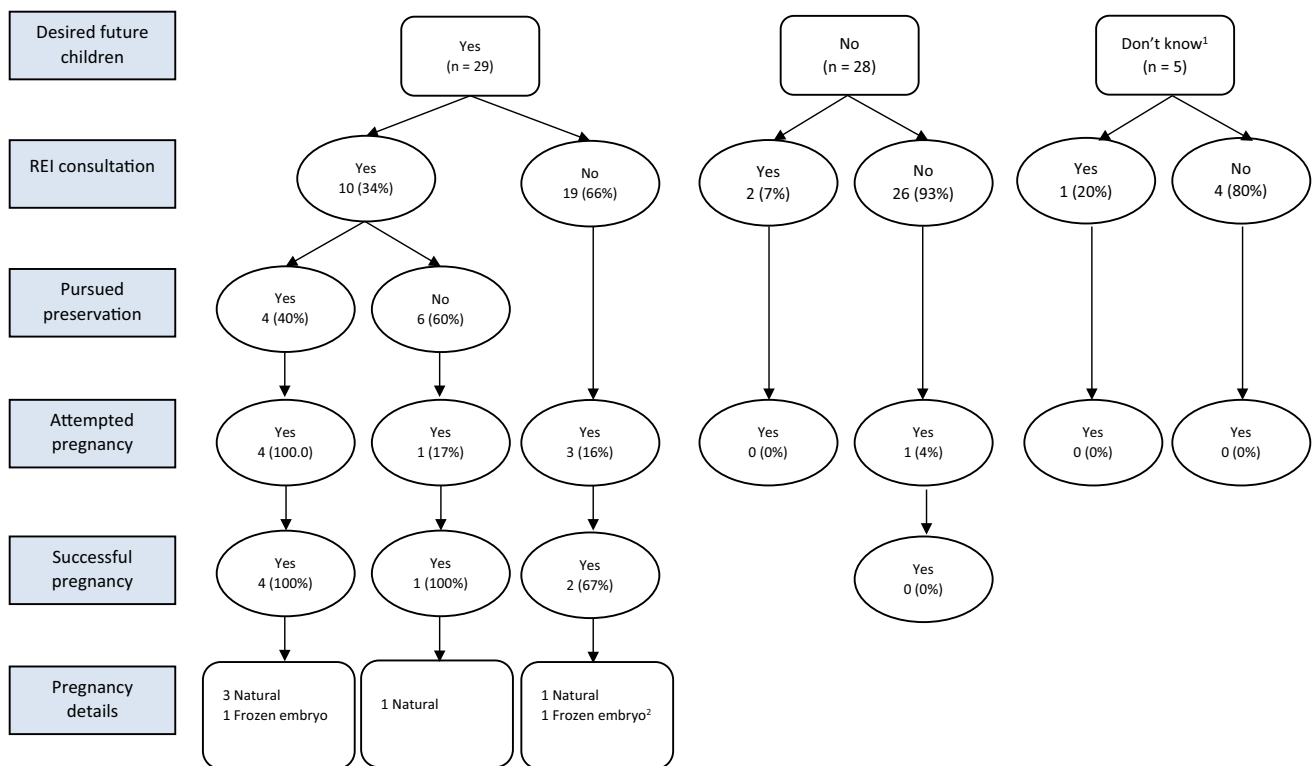
| Variable  | Total     | Data are <i>n</i> (column %)     |                                      | <i>p</i> -value |
|---|-----------|----------------------------------|--------------------------------------|-----------------|
|   |           | Fertility preservation discussed | Fertility preservation not discussed |                 |
| All patients  | 63        | 23 (36.5)                        | 40 (63.5)                            |                 |
| Desired children (or more children) prior to diagnosis        | 29 (46.0) | 17 (73.9)                        | 12 (30.0)                            | 0.002           |
| Did not desire children (or more children) prior to diagnosis | 28 (44.4) | 4 (17.4)                         | 24 (60.0)                            |                 |
| Don't know  | 6 (9.5)   | 2 (8.7)                          | 4 (10.0)                             |                 |
| Total with previous children                                  | 46        |                                  |                                      |                 |
| Considering additional children prior to diagnosis            | 17 (37.0) | 9 (81.8)                         | 8 (22.9)                             | 0.0006          |
| Did not desire additional children prior to diagnosis         | 25 (54.4) | 1 (9.1)                          | 24 (68.6)                            |                 |
| Don't know  | 4 (8.7)   | 1 (9.1)                          | 3 (8.6)                              |                 |
| Total without previous children                               | 17        |                                  |                                      |                 |
| Desired children prior to diagnosis                           | 12 (70.6) | 8 (66.7)                         | 4 (80.0)                             | 0.55            |
| Did not desire children prior to diagnosis                    | 3 (17.6)  | 3 (25.0)                         | 0 (0)                                |                 |
| Don't know  | 2 (11.8)  | 1 (8.3)                          | 1 (20.0)                             |                 |

Fisher's exact test was used for all comparisons

only 1 (4%) of multiparous women who did not desire future children having FP discussions (Table 2).

In our study population, 23 (37%) of women received FP discussions from a non-REI provider with 13 (57%) of those women who had discussions then pursuing REI

consultations. Yet, of those women who desired future children, a higher proportion (*n*=17, 59%) had FP discussions, with 10 (59%) of these women having an REI consultation (Table 2 and Fig. 2). Of those women who desired future children and consulted with a REI, 4 (40%) pursued oocyte



**Fig. 2** Reproductive endocrinologist fertility preservation consultations and pregnancies by desire for children at time of breast cancer diagnosis. REI, reproductive endocrinologist. <sup>1</sup>One patient attempted

pregnancy but did not answer the REI consultation question. <sup>2</sup>Embryo frozen after cancer treatment

or embryo cryopreservation prior to chemotherapy treatment. Although 28 (44%) women stated they did not want future children, 2 (7%) of that group consulted with a REI specialist. Moreover, 1 (20%) woman who was unsure about future children consulted with a REI specialist. However, none of the women in the latter two groups pursued FP procedures prior to treatment (Fig. 2).

Pregnancy outcomes after cancer treatment were also evaluated. Only 9 (14%) women attempted pregnancy after treatment, with 7 (78%) conceiving and having a clinical pregnancy. The majority of women ( $n=5$ , 71%) conceived naturally with 2 (29%) utilizing frozen embryos (Fig. 2). One of the embryos was frozen before cancer treatment and the other at the time of infertility diagnosis (Fig. 2). In the group that pursued a FP procedure, 1 (25%) attempted pregnancy with a previously frozen embryo and had a successful live birth. The other 3 (75%) attempted pregnancy and were able to conceive naturally without the use of their previously frozen gametes (Fig. 2).

The most common reasons for declining FP REI referrals or procedures were already having the desired number of children ( $n=24$ , 41%), financial barriers ( $n=8$ , 14%), concern about delaying cancer treatment or cancer recurrence ( $n=7$ , 12%), and did not know the option was available ( $n=6$ , 10%). FP clinic located too far away was not selected as a barrier to seeking FP consultation and care by any participants.

There was a higher proportion of FP discussions and REI consultations for the 29 women who desired children or future children in the 2013–2016 time period compared to the 2005–2012 time period. The 2013 time point was selected because oocyte cryopreservation became non experimental that year. There were 12 (71%) vs. 5 (42%) FP discussions and 9 (53%) vs. 1 (8%) REI consultations, respectively in the later vs earlier time period. All 4 women who pursued FP procedures were in the 2013–2016 time period.

## Discussion

In this retrospective survey study of breast cancer survivors aged 18–42 at diagnosis, we found that only 37% of women who answered they “ever had the desire to become a parent” had fertility preservation (FP) discussions during their cancer diagnosis. Additionally, 20% of all women pursued an REI consultation. However, of those women who desired future fertility, a higher proportion (59%) had FP discussions with non REI providers. Women ages 35 and older were less likely to receive FP discussions from non REI providers than those under 35 years.

The low FP procedure utilization in our study (6%) is overall consistent with the literature; however, REI consultations and FP discussions were higher than noted in some

previous studies [6, 18]. In a population-based retrospective study of reproductive age patients with breast cancer, Korkidakis et al. found using ICD-9 codes that only 4% women with breast cancer were referred to a gynecologist between cancer diagnosis and initiation of chemotherapy to discuss FP options, which is substantially lower than the 20% of women who consulted with a REI specialist in our study. Korkidakis et al. also found that older women (30 and above), and those with advanced disease were less likely to receive FP referrals [11]. Similarly, we found that older women (35 and over) were less likely to receive FP counseling; however, we did not find a difference by disease status. Similarly, Selter et al. found that national FP consultation rates after cancer diagnosis were only 3%, with FP procedure utilization of only 2% [6]. Selter et al. and Korkidakis et al. evaluated claims from insurance providers and therefore were unable to evaluate FP discussions that may have occurred at the oncologists or surgeon office.

The reason for the higher than previously reported FP discussions and REI consultations could be related to the institution where the women were evaluated. These women were recruited from a breast health center within a women’s hospital, which has a dedicated weekly breast multidisciplinary tumor board where newly diagnosed patients are presented in a prospective fashion to render treatment recommendations including identifying patients qualifying for FP discussion.

Nulliparous women were more likely than multiparous women to have FP discussions even if they did not desire future children. This finding is consistent with other reports. A large Swedish nationwide cohort study of 1275 women investigated the long-term reproductive outcomes of women with breast cancer receiving FP compared to those with breast cancer but without history of FP [19]. They found that a higher proportion of women who had undergone FP were nulliparous compared to the group that had not undergone FP. Contradictory to another study, whom found higher educational levels in women with FP compared to those without FP counseling [20], we found no significant difference between women with lower education levels and lower household financial status being less likely to engage in a FP discussion than those with higher education levels and financial status (Table 1). Future studies should evaluate whether socioeconomic status impacts FP counseling and referral.

We also found that a small percentage of women who did not desire future children at the time of breast cancer diagnosis (7%) consulted with an REI and attempted (4%) a future pregnancy. This is consistent with Di Mattea et al. who also showed that 2% of women who stated they did not want future children at the time of cancer treatment conceived within 5 years of treatment [21]. Therefore, the desire to become a parent can change during and after cancer



treatment. Consistent with the current guidelines [22], FP counseling should be encouraged regardless of women's current desires or previous deliveries.

Barriers to FP procedures have previously been reported including lack of and/or poor timing of counseling, fear concerning the perceived risks of pursuing FP treatment, lack of referral due to perceived assumptions made by the oncology care team, "survival mode"/overwhelmed, personal situation (i.e., unpartnered), and cost [15]. We found that after already having the desired number of children (41%), financial constraints were the second most common reasons for not pursuing FP procedures (14%), followed by worry about delaying cancer treating or increasing the chance of cancer recurrence (12%). Ten percent of women stated they were not even aware of any fertility preservation options. These statistics reemphasize the importance of FP counseling early in the process, allowing women to make informed decisions regarding FP procedures.

The strengths of this study include that we assessed FP counseling rates in one type of cancer population more suited for FP instead of using a heterogeneous sample. Breast cancer is the most common cancer in women of reproductive age and these women have more opportunities for FP counseling (i.e., at diagnosis, before surgery, and after surgery prior to chemotherapy.) This is unlike some other types of cancer such as leukemia for which there is urgent need to start chemotherapy and little time for FP referrals and procedures. FP options for breast cancer patients include oocyte and embryo cryopreservation, ovarian tissue cryopreservation (OTC), and ovarian suppression with GnRH analogs. Both oocyte and embryo cryopreservation are considered the gold standard procedures for fertility preservation in breast cancer patients with the highest success rates for subsequent pregnancy. The process involves stimulation of the ovaries with injectable gonadotropins for approximately 14 days and subsequently retrieving oocytes under anesthesia. Patients are able to start quickly and at any point in their menstrual cycle. If embryos are to be cryopreserved, the oocytes are inseminated with partner sperm the day of the retrieval and cultured in the lab for 2–6 days prior to freezing. In patients who are unpartnered or want to preserve reproductive autonomy, oocytes are frozen the day of the retrieval. During stimulation letrozole, an oral aromatase inhibitor is taken in conjunction with the injectable hormones to lower peripheral estrogen to physiologic levels, reducing the theoretical risk of cancer progression [23]. Furthermore, data shows that disease-free survival and mortality is not impacted by oocyte or embryo cryopreservation [24, 25]. Although pregnancy data from cancer patients is limited, age-based success rates from the infertile population is used to counsel patients regarding future live birth rates. Patients under 35, 35–37, 38–40, and 41–42 have the respective per IVF cycle live birth rates based on 2020 national US data:

55%, 40%, 26%, 13% [26]. In vitro maturation (IVM) is a modification of standard ovarian stimulation where there is less medication and/or days of stimulation prior to retrieval and the oocytes retrieved are more likely to be immature. The oocytes are matured in the lab and either inseminated or cryopreserved once they reach maturity. Success rates with IVM are significantly lower than conventional ovarian stimulation, but may be used for patients who lack time to undergo the full 2 weeks of stimulation or are concerned with hormonal stimulation [27]. Limitations to access include cost and patient's fear of delaying chemotherapy. Unfortunately, the cost of a fertility preservation cycle if not covered by health insurance is prohibitive for most patients and on average, can be over \$10,000–15,000 per cycle, with many patients needing more than one cycle [28]. Additionally chemotherapy may be delayed by an average of 6 days, but this has not been shown to impact cancer treatment and prognosis [24].

Other FP options include ovarian tissue cryopreservation (OTC) and gonadotropin-releasing hormone analogs (GnRH). In OTC, a laparoscopic surgery with a unilateral oophorectomy or biopsy is performed to cryopreserve ovarian tissue which contains oocytes which can be later transplanted back into the pelvis. This technique is no longer considered experimental and can be used in patients who are prepubertal or do not have the 2 weeks to undergo oocyte or embryo cryopreservation before starting chemotherapy. The pregnancy rate was reported at 29% and live-birth rate 23% in 111 patients who underwent transplant by a network of five major European centers [29]. Transplantation of ovarian tissue in breast cancer patients and specifically BRCA mutation carriers should be handled with caution as these patients are at higher risk of concurrent ovarian cancer and breast cancer. If ovarian cancer cells are present in the cryopreserved and thawed tissue, there is a potential for reseeding of ovarian tumors into the pelvis. Additionally these patients are at higher risk of ovarian cancer in the future.

Randomized control trials in breast cancer patients treated with chemotherapy have demonstrated return of menstrual function and ovulation more likely in patients who were given GnRH analogs compared to those who were not. Pregnancy and fertility data is more controversial as many studies lack long-term follow-up and enough data on the number of women attempting pregnancy [30, 31]. Nonetheless, GnRH analogs can be offered alongside other established methods of fertility preservation, but should not be offered in replacement of other procedures.

The limitations of this study include the potential for recall bias and selection bias. Some women may not remember whether they had FP counseling given the long period between cancer diagnosis and survey administration, ranging from 3 to 15 years. Women may have also been more likely to complete the survey if they became infertile or regret not having

counseling, which could overestimate the proportion of those without FP counseling. Additionally, we did not ask questions about other medical comorbidities at the time of breast cancer diagnosis. Therefore, we cannot confirm if our population is healthier than those that did not respond to the survey. However, the demographics (Table 1) show both early and late stage breast cancer patients, reflecting a heterogeneous population not limited to those with early stage disease.

The fertility preservation insurance mandate became a law in 2017 in Rhode Island. All Rhode Island commercial insurers are required to cover FP consultations and procedures. Therefore, although there will still be cost barriers because Medicaid and federal plans are excluded from the mandate, the survey results may have been different if repeated in more recent years where financial restrictions were less likely to play a role in counseling and selection of FP procedures. However, most states do not have an insurance mandate and the barriers we report are generalizable to the majority of those states.

In conclusion, our study supports the literature that FP counseling, referral to REI specialists, and utilization of FP procedures remain low in women of childbearing age with breast cancer. FP consultations and procedures are low even in women who desired future fertility with the predominant barriers being cost and fears concerning a delay in cancer treatment or future cancer recurrence. Future work on interventions aimed at increasing referrals for FP at the time of cancer diagnosis and throughout treatment is needed. Future work on interventions aimed at increasing referrals for FP at the time of cancer diagnosis and throughout treatment is needed. Examples of interventions currently being trialed include: online decision aids, EMR systems with prompts reminding providers to offer referrals, and dedicated FP nurse navigators that can support patients through the process from referral to FP treatment [15, 32, 33, 34, 36].

**Supplementary Information** The online version contains supplementary material available at <https://doi.org/10.1007/s10815-023-02850-8>.

**Author contribution** All authors contributed to the study conception and design. Material preparation, data collection, and analysis were performed by May-Tal Sauerbrun-Cutler, Olivia Recabo, and Christina Raker. The first draft of the manuscript was written by May-Tal Sauerbrun-Cutler and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

## Declarations

**Conflict of interest** The authors declare no competing interests.

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