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# Validity of self-reported fertility-threatening cancer treatments in female young adult cancer survivors

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## Abstract

**Purpose—**Detailed cancer treatment information is important to fertility and pregnancy care of female young adult cancer survivors. Accuracy of self-report of treatments that impact fertility and pregnancy is unknown. This study assessed agreement between self-report and medical records on receipt of fertility-threatening treatments.

**Methods—**A national cohort study of female young adult cancer survivors reported cancer treatments via web-based questionnaires. Primary cancer treatment records were abstracted. Self-reported exposure to fertility-threatening therapies (alkylating chemotherapy, stem cell transplant, pelvic radiation, hysterectomy and/or oophorectomy) was compared to medical records. Logistic

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*Conflict of Interest:* Samantha C Roberts, Amber Knight, Brian W. Whitcomb, Jessica R. Gorman, Andrew C. Dietz, and H. Irene Su declare that they have no conflict of interest.

*Ethical approval:* All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

*Informed Consent:* Informed consent was obtained from all individual participants included in the study.

regression models estimated odds ratios (OR) for characteristics associated with inaccurate self-report of fertility-threatening therapies.

**Results—**The study included 101 survivors (mean age 28.2, SD 6.3). Lymphoma (33%), breast cancer (26%) and gynecologic cancers (10%) were the most common cancers. Accuracy of self-report was 68% for alkylating chemotherapy and 92–97% for radiation, surgery and transplant. Significant proportions of survivors who were treated with transplant (8/13, 62%), alkylating chemotherapy (18/43, 42%), pelvic radiation (4/13, 31%), or hysterectomy and/or oophorectomy (3/13, 23%) did not report undergoing these therapies. In adjusted analysis, age ≤ 25 at diagnosis (OR 3.4, 95% CI 1.3–8.7) and recurrence (OR 6.0, 95% CI 1.5–24.4) were related to inaccurate self-report.

**Conclusions—**Female young adult cancer survivors have limited recall of fertility-threatening cancer treatment exposures. Reproductive health providers and researchers who need this information may require primary medical records or treatment summaries.

**Implications for Cancer Survivors—**Additional patient education regarding treatment-related reproductive risks is needed to facilitate patient engagement in survivorship.

### Keywords

cancer survivorship; cancer treatment; fertility; medical records; pregnancy; self-report; young adults

## Introduction

In the United States, more than 35,000 adolescent and young adult women aged 15 to 39 years are diagnosed with cancer annually [1]. Advances in cancer treatment have resulted in higher survival rates of, more than 80% at 5 years, allowing young cancer survivors to consider long-term fertility and parenthood [2].

Cancer treatments can differentially impact fertility and pregnancy. Chemotherapy, particularly alkylating agents, and pelvic radiation are toxic to the finite oocyte pool, leading to premature ovarian aging, infertility and early menopause [3–5]. Pelvic radiation can also damage uterine myometrium and vascular supply, resulting in higher risks of miscarriage and preterm delivery [6]. Finally, surgical resection of reproductive organs directly impacts using autologous oocytes and/or carrying a pregnancy. As part of patient education and informed decision making, oncology providers should address fertility threats with reproductive-aged women facing these cancer treatments [7, 8]. Beyond informing fertility preservation decisions *prior to* cancer treatment, fertility preservation counseling provides highly relevant information for young survivors who are *post-treatment* and considering pregnancy. To date, rates of fertility preservation counseling remain modest [9, 10].

Detailed cancer treatment information is important to the fertility and pregnancy care of female young adult survivors. While primary medical records provide the most accurate treatment details, complete records are not always available at consults with reproductive healthcare providers or to researchers conducting studies related to cancer treatment risks, leaving patients to provide self-reported cancer treatment information.

The accuracy of self-report of fertility-threatening cancer treatments is unknown. Several studies have examined the validity of self-reported cancer and treatment characteristics in young adults with cancer, none on self-report of treatments that impact fertility and pregnancy. These studies generally show high agreement between self-report and medical record or cancer registry data on diagnosis and general treatment categories, e.g. receipt of any chemotherapy [11, 12, 13]. However, self-report tends to be less accurate for more detailed information including type of chemotherapy, e.g. anthracyclines; such details are central to counseling and studying treatment-related reproductive risks [11, 14, 15].

This study compared self-report with primary medical record information on fertility-threatening treatment exposures in female young adult cancer survivors. The primary fertility-threatening treatment exposures included alkylating chemotherapy, pelvic radiation, pelvic surgery, and hematopoietic stem cell transplantation. We hypothesized that self-reported cancer diagnosis and fertility-threatening treatments would be in agreement with medical records. Secondarily, the study examined factors associated with inaccurate self-report. We hypothesized that younger age at diagnosis, fewer years of attained education and cancer recurrence and/or second cancers would be associated with less accuracy.

## Materials and Methods

### Participants

Study participants were recruited from the Fertility Information Research Study (FIRST), an ongoing prospective cohort study examining the impact of cancer and cancer treatments on reproductive health. FIRST participants are female, between the ages of 18 and 44, and have a history of cancer or cancer treatments as a child or young adult. Participant are being recruited from 44 states in the United States through a variety of sources, including referral from 6 fertility preservation programs that participate in the National Physicians Cooperative of the Oncofertility Consortium (27%) and young adult cancer advocacy groups via social media (73%) [16, 17].

FIRST participants were eligible for the current study if they completed an online questionnaire and returned written consents for medical record release (n=149). Upon receipt of written consent, study staff contacted the participants' medical, radiation, and/or surgical oncologist's medical record departments via telephone and faxed HIPAA forms and medical record requests to acquire primary treatment records. Each location was contacted up to 3 times. Primary medical records were successfully obtained for 101 (68%) survivors, who were then eligible to be included in this analysis. Baseline characteristics of participants in the current study were compared with FIRST cohort members whose records were not obtained to assess potential selection bias, and no differences were observed (data not shown). The Institutional Review Board of the University of California, San Diego approved this research protocol, and all participants gave written informed consent.

### Study Procedures

The study questionnaire asked for participant self-report of demographics, cancer diagnosis, and cancer treatments. For cancer diagnosis and stage or risk group, all participants were

asked to select from a list of cancer types as well as stages and risk stratification appropriate for each diagnosis. To determine which cancer treatments they received, participants were asked to select all of the cancer treatments they received from the following options: “surgery to remove tumor”, “radiation”, “chemotherapy”, “hormonal treatments such as tamoxifen or aromatase inhibitors (Arimidex®, Femara®)”, “bone marrow or stem cell transplant”, “did not receive treatment”, and/or “don’t know”.

Participants who chose chemotherapy, radiation, or surgery were required to complete follow up questions. For chemotherapy, participants were asked to indicate all treatments that they received by selecting from a list of historical and contemporary chemotherapy regimens or individual chemotherapy agents tailored to their cancer type. These options included: 1) chemotherapy regimen acronyms with the generic and brand names for each drug within the regimen listed; 2) single chemotherapy agents with their generic and brand name; and 3) an “other” option to write in additional chemotherapy. Chemotherapy treatment options were derived from the National Comprehensive Cancer Network treatment guidelines [18]. A screen shot of the chemotherapy options provided for breast cancer survivors is depicted in the Appendix. For radiation, participants were asked: ‘On what part of the body did you have radiation?’ and were then given a list of body parts to choose from. For pelvic surgery, participants were asked if they had their uterus removed, as well as if they had one or both ovaries removed. For stem cell transplant, participants were asked if they had undergone a bone marrow transplant. For all questions, participants also had the option of selecting “other” and writing in a response. Participants could, but were not reminded to, use prior records to complete the questionnaire.

Structured medical record abstraction, supervised by two investigators (ACD, HIS), was conducted by one investigator (AK) following training. Twenty percent of record abstractions were checked for accuracy by ACD and HIS. Primary oncology medical records were abstracted for cancer diagnosis, stage, chemotherapy regimen, alkylating chemotherapy, pelvic radiation, and stem cell therapy. Alkylating chemotherapy included the following agents: cyclophosphamide, ifosfamide, cisplatin, carboplatin, oxaliplatin, carmustine, lomustine, dacarbazine, and procarbazine.

Self-report was compared to medical record data. Treatment exposures of interest were receipt of alkylating chemotherapy, pelvic radiation, uterine and/or ovarian surgery, and stem cell transplants. A participant with medical record documentation of at least one of these four exposures was considered to have undergone fertility-threatening cancer treatment. Participants who reported a treatment exposure that was also documented in their medical records were deemed to be accurate. Similarly, participants who did not identify a treatment by self-report and did not have the treatments documented in their medical records were deemed to be accurate. Discrepant self-report and medical record data were considered inaccurate. To be considered accurate in overall reporting of fertility-threatening therapies, participants had to correctly self-report all treatments documented in their medical records.

## Statistical Methods

Descriptive characteristics were summarized using frequencies for categorical variables and mean and standard deviation, or median and range for continuous variables, as appropriate.

Using medical record data as the gold standard, proportion correct, sensitivity, specificity, positive predictive values (PPV), and negative predictive values (NPV) were calculated for self-report of treatment exposures.

Using Fisher's exact and Student's t-test, baseline characteristics were compared by accuracy of self-report of fertility-threatening cancer treatments. Characteristics that were significant in the bivariable analysis were used in logistic regression models to estimate the odds ratio (OR) for characteristics associated with overall inaccurate self-report of fertility-threatening cancer treatment. Two-tailed p-values of $\leq 0.05$ were considered significant. All analyses were performed using SAS statistical software version 9.4 (Cary, NC).

## Results

Between May 2011 and February 2013, 101 participants met the inclusion criteria. Table 1 shows participant characteristics. Mean age at cancer diagnosis was 28.2 (standard deviation [SD] 6.3) years, and mean age at enrollment was 31.8 (SD 5.4) years. Median years since cancer diagnosis was 2.4 (inter-quartile range [IQR] 1.2–4.4). Most participants completed higher education and reported white race. Lymphoma was the most common self-reported cancer type (33%), followed by breast cancer (26%), and uterine or ovarian cancer (10%). When compared to medical record data, 98 participants (98%) correctly reported their cancer type.

According to medical records, 58 participants (59%) underwent at least one fertility-threatening treatment. In the cohort, 43 participants (43%) received alkylating chemotherapy, 13 (13%) received pelvic radiation, 13 (13%) underwent uterine and/or ovarian surgery, and 13 (13%) underwent stem cell transplant.

Table 2 depicts the accuracy, sensitivity, specificity, and positive and negative predictive values for self-reported fertility-threatening cancer treatments when compared to medical records. For alkylating chemotherapy, 69 (68%) participants were accurate in self-report. Among 43 survivors who received alkylating chemotherapy, 25 correctly reported exposure (i.e., sensitivity = 58%), whereas among 58 survivors who did not receive alkylating chemotherapy, 44 correctly did not report exposure (i.e., specificity = 78%). Ninety-two percent of participants were accurate in self-report for pelvic radiation. Among 13 survivors who received pelvic radiation, 9 correctly reported exposure (i.e., sensitivity = 69%) and among the larger group of 88 survivors who did not receive pelvic radiation, 84 were accurate in self-report (i.e., specificity = 95%). Accuracy was high for both pelvic surgery (97%) and stem cell transplant (92%). A total of 13 survivors underwent hysterectomy and/or oophorectomy of whom 10 correctly reported their surgery (i.e., sensitivity = 77%). Although sensitivity for self-report of stem cell transplant was only 38% (5/13), specificity was 100% for both pelvic surgery (88/88) and transplant (88/88).

Overall, self-report of fertility-threatening therapy exposure was in complete agreement with medical record data in only 58 of 101 participants (57%). Younger age at cancer diagnosis, younger age at enrollment, cancer recurrence and cancer diagnosis were associated with inaccurate reporting of fertility-threatening cancer treatment exposures. These characteristics

were considered in multivariable logistic regression models (Table 3). Compared to survivors of other cancer types, lymphoma survivors were more likely to inaccurately report their fertility-threating treatments. For these models, cancer diagnosis was collapsed as lymphoma versus other cancers. Because age at enrollment and age at cancer diagnosis were highly correlated and the latter was of greater interest, age at enrollment was not considered in multivariable models. In models adjusting for age at diagnosis, race, and cancer type, the odds of inaccurate reporting was 3.4 (95% CI 1.3–8.7) times higher for women diagnosed when they were younger than age 25, compared to women diagnosed when they were age 25 or older. In addition, survivors who experienced a cancer recurrence had a 6.0 (95% CI 1.5–24.4) times higher odds of inaccurate reporting compared to survivors who did not have a cancer recurrence.

## Discussion

We assessed whether reproductive-aged female cancer survivors provide accurate self-report of prior fertility-threatening cancer treatments. Specifically, we compared self-report of chemotherapy incorporating alkylating agents, stem cell transplants, radiation to the pelvis, and uterine and/or ovarian surgery to data abstracted from primary cancer treatment medical records. For treatments known to adversely impact fertility, accuracy of self-report when compared to medical records was high for transplant, radiation and surgery and more modest for alkylating chemotherapy. However, among survivors with exposure to these fertility-threatening therapies, significant proportions did not report undergoing them. Fertility and pregnancy risks differ by cancer treatment exposures, therefore, reproductive health providers should not solely rely on survivors' self-reported treatment data when developing clinical management plans. For researchers studying reproductive risks of cancer treatments in young female cancer survivors, self-report will result in substantial misclassification and potential bias to study findings.

In this study, accuracy of recall was consistent with prior reports on cancer diagnosis and treatment details. From the Childhood Cancer Survivor Study (CCSS), a high proportion (91%) of adult survivors of childhood cancer reported their diagnosis accurately, similar to our data. The CCSS and other studies also observed that additional cancer details were less reliable via self-report [11]. For example, a population-based breast cancer family registry of breast cancer survivors reported 62% agreement on stage of diagnosis [12]. Another study of breast and colorectal cancer survivors demonstrated that 40% of breast cancer survivors and 65% of colorectal cancer survivors were unable to identify stage of disease [14]. Among breast cancer survivors, self-report is reliable for chemotherapy, i.e. yes or no, but less reliable for chemotherapy regimen [15]. Taken together, significant discrepancies between medical records and self-report occur when detailed cancer treatment information is required. When clinical care or research depends on ascertaining such details, cancer treatment summaries or primary medical records become vital documents for survivors and their providers. As well, processes to facilitate communicating this information and patient-specific risks between primary oncologists and specialists such as fertility physicians are needed.

The motivation for the current study was that detailed cancer treatment information is relevant to reproductive health. Overall, specificities of self-report on fertility-threatening treatments were higher than sensitivities, meaning that participants were better at recalling not receiving these treatments than at recalling receiving these treatments. Of concern is the finding that only 57% of participants were able to correctly recall all treatments that confer reproductive risk. For each of the four types of exposures, significant proportions of survivors who had documented exposure (23–62%) did not report receiving them. This finding was surprising given that treatments such as hysterectomy are large procedures. Interestingly, only 5 of 13 who received stem-cell therapy correctly reported undergoing transplant. Of 8 participants who did not self-report undergoing transplant, despite having medical record documentation of treatment, 7 had undergone an autologous transplant and may not have considered their treatment a transplant. As the questionnaire asked participants if they had received “bone marrow or stem cell transplant”, the wording of this treatment option may have contributed to the low sensitivity of recall if patients did not understand that an autologous transplant is also considered a transplant. Because preparation for autologous transplants also requires gonadotoxic chemotherapy, by self-report, these participants would not have been identified as having a fertility-threatening exposure if they were queried on receiving “bone marrow or stem cell transplant”. Educating patients about reproductive risks related to their treatments may help to improve recall and engage them in follow-up care. As treatment summaries and survivorship care plans evolve, one potential solution to explore would be to denote which therapies put fertility at risk within these documents.

In our cohort, younger age at diagnosis and recurrence were related to inaccurate reporting. The adolescent and young adult survivor population is of particular interest because they face developmental challenges that may impact their ability for valid self-report, compared with women who are older at cancer diagnosis [19]. While breast cancer survivors can report breast surgery, chemotherapy, radiation and hormone therapy with a high degree of agreement, childhood cancer survivors were shown to have important knowledge deficits regarding their diagnosis and treatment [15, 11]. Cancer recurrence has been shown to be a risk factor for inaccurate treatment reporting in patients with breast cancer in previous studies, and our study is consistent with this finding [12, 13]. In light of the growing population of young adults with cancer and increasing complexity of cancer treatments, we advocate for oncology providers to generate treatment summaries and for young adults survivors to acquire them as documents of personal health information for their future providers.

Generalizability is a limitation of the study, as our study included highly educated young women with access to the Internet and an interest in future fertility after cancer. We speculate that self-report may be even less accurate in a broader population of adolescent and young adult survivors. The absolute rates of pelvic surgery, pelvic radiation and stem cell transplant were low, limiting the precision of our reported sensitivities. Additionally, sample size and variability in demographic characteristics limited the assessment of factors related to accuracy. We did not observe time since diagnosis and accuracy, but this may be limited by our cohort’s short time since cancer diagnosis. Obtaining primary medical records was also a challenge; we also noted discrepancies between primary treatment records and subsequent physician notes. Therefore, abstraction utilized only primary surgical and

pathology reports, treatment summaries and documentation by primary treatment providers. Finally, while primary treatment records appeared to be complete, it is possible that some participants were misclassified as having false positive reporting if their medical records were indeed incomplete. This misclassification risk is likely low, as medical record review of cancer treatments, e.g. chemotherapy regimens, type of surgery, location of chemotherapy, were consistent with known treatments for individual cancer diagnoses.

We conclude that while accuracy of self-reported fertility-threatening treatments was generally high, many female young adult cancer survivors are not able to report all of their fertility-threatening cancer treatment exposures. Health care providers and researchers should not rely on self-report alone to counsel these young patients regarding fertility, and treatment summaries should be requested. We encourage oncology providers to educate patients and supply them with treatment summaries so that they have the necessary information available for health care providers.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## Appendix

A screen shot of the chemotherapy options on the questionnaire for breast cancer survivors.

## References

1. Waimey KE, Smith BM, Confino R, Jeruss JS, Pavone ME. Understanding Fertility in Young Female Cancer Patients. J Womens Health (Larchmt). 2015; 24(10):812–8. DOI: 10.1089/jwh.2015.5194 [PubMed: 26075731]
2. Ward E, American Cancer Society National Vice President IRAG; DeSantis C, American Cancer Society Epidemiologist SaHSRAG; Robbins A, American Cancer Society Director SaHSRAG. et al. Childhood and adolescent cancer statistics, 2014. CA: A Cancer Journal for Clinicians. 2016; 64(2): 83–103. DOI: 10.3322/caac.21219
3. Schover LR, Rybicki LA, Martin BA, Bringelsen KA. Having children after cancer. A pilot survey of survivors' attitudes and experiences. Cancer. 1999; 86(4):697–709. [PubMed: 10440699]
4. Partridge AH, Ruddy KJ. Fertility and adjuvant treatment in young women with breast cancer. Breast. 2007; 16(Suppl 2):S175–81. DOI: 10.1016/j.breast.2007.07.029 [PubMed: 17804236]
5. Barton SE, Najita JS, Ginsburg ES, Leisenring WM, Stovall M, Weathers RE, et al. Infertility, infertility treatment, and achievement of pregnancy in female survivors of childhood cancer: a report from the Childhood Cancer Survivor Study cohort. Lancet Oncol. 2013; 14(9):873–81. DOI: 10.1016/s1470-2045(13)70251-1 [PubMed: 23856401]
6. Critchley HO, Wallace WH. Impact of cancer treatment on uterine function. J Natl Cancer Inst Monogr. 2005; 34:64–8. DOI: 10.1093/jncimonographs/lgi022

7. Practice Committee of American Society for Reproductive Medicine. Fertility preservation in patients undergoing gonadotoxic therapy or gonadectomy: a committee opinion. Fertil Steril. 2013; 100(5):1214–23. DOI: 10.1016/j.fertnstert.2013.08.012 [PubMed: 24011612]

8. Lee SJ, Schover LR, Partridge AH, Patrizio P, Wallace WH, Hagerty K, et al. American Society of Clinical Oncology Recommendations on fertility preservation in cancer patients. Guideline Summary. 2006; doi: 10.1200/JOP.2.3.143

9. Quinn GP, Block RG, Clayman ML, Kelvin J, Arvey SR, Lee JH, et al. If you did not document it, it did not happen: rates of documentation of discussion of infertility risk in adolescent and young adult oncology patients' medical records. J Oncol Pract. 2015; 11(2):137–44. DOI: 10.1200/jop.2014.000786 [PubMed: 25549654]

10. Letourneau JM, Ebbel EE, Katz PP, Katz A, Ai WZ, Chien AJ, et al. Pretreatment fertility counseling and fertility preservation improve quality of life in reproductive age women with cancer. Cancer. 2012; 118(6):1710–7. DOI: 10.1002/cncr.26459 [PubMed: 21887678]

11. Kadan-Lottick NS, Robison LL, Gurney JG, Neglia JP, Yasui Y, Hayashi R, et al. Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. JAMA. 2002; 287(14):1832–9. [PubMed: 11939869]

12. Phillips KA, Milne RL, Buys S, Friedlander ML, Ward JH, McCredie MR, et al. Agreement between self-reported breast cancer treatment and medical records in a population-based Breast Cancer Family Registry. J Clin Oncol. 2005; 23(21):4679–86. DOI: 10.1200/jco.2005.03.002 [PubMed: 15851764]

13. Liu Y, Diamant AL, Thind A, Maly RC. Validity of self-reports of breast cancer treatment in low-income, medically underserved women with breast cancer. Breast Cancer Res Treat. 2010; 119(3): 745–51. DOI: 10.1007/s10549-009-0447-5 [PubMed: 19551500]

14. Nissen MJ, Tsai ML, Blaes AH, Swenson KK. Breast and colorectal cancer survivors' knowledge about their diagnosis and treatment. J Cancer Surviv. 2012; 6(1):20–32. DOI: 10.1007/s11764-011-0189-3 [PubMed: 21735277]

15. Maunsell E, Drolet M, Ouhoummane N, Robert J. Breast cancer survivors accurately reported key treatment and prognostic characteristics. J Clin Epidemiol. 2005; 58(4):364–9. DOI: 10.1016/j.jclinepi.2004.09.005 [PubMed: 15862722]

16. Gorman JR, Roberts SC, Dominick SA, Malcarne VL, Dietz AC, Su HI. A diversified recruitment approach incorporating social media leads to research participation among young adult-aged female cancer survivors. J Adolesc Young Adult Oncol. 2014; 3(2):59–65. DOI: 10.1089/jayao.2013.0031 [PubMed: 24940529]

17. Mersereau JE, Goodman LR, Deal AM, Gorman JR, Whitcomb BW, Su HI. To preserve or not to preserve how difficult is the decision about fertility preservation? Cancer. 2013; 119(22):4044–50. DOI: 10.1002/cncr.28317 [PubMed: 24037854]

18. National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology. 2016. http://www.nccn.org/professionals/physician_gls/f_guidelines.asp

19. Prasad PK, Hardy KK, Zhang N, Edelstein K, Srivastava D, Zeltzer L, et al. Psychosocial and neurocognitive outcomes in adult survivors of adolescent and early young adult cancer: a report from the childhood cancer survivor study. 2015; doi: 10.1200/JCO.2014.57.7528

**Table 1**

Participant characteristics and their association with accuracy of self-report for receiving fertility-threatening cancer treatments

| | Overall n (%) N=101 | Accurate n (%) N=58 | Inaccurate n (%) N=43 | p-value |
|---|---|---|---|---|
| Age at study enrollment, mean [SD] | 31.8 [5.4] | 32.9 [5.4] | 30.2 [4.9] | 0.01 |
| White Race | 86 (86.0) | 52 (91.2) | 34 (79.1) | 0.08 |
| Hispanic/Latina | 9 (8.9) | 3 (5.2) | 6 (14.0) | 0.17 |
| Education | | | | 0.52 |
| Did not graduate from college | 11 (11.5) | 5 (8.9) | 6 (15.0) | |
| College or post graduate degree | 85 (88.5) | 51 (91.1) | 34 (85.0) | |
| Employment | | | | 0.58 |
| Full time | 44 (43.6) | 25 (43.1) | 19 (44.2) | |
| Part time | 14 (13.9) | 8 (13.8) | 6 (14.0) | |
| Unemployed | 31 (30.7) | 16 (27.6) | 15 (34.9) | |
| Prefer not to answer | 12 (11.9) | 9 (15.5) | 3 (7.0) | |
| BMI | | | | 0.61 |
| <25 | 58 (57.4) | 32 (55.2) | 26 (60.4) | |
| 25–29.9 | 16 (15.8) | 11 (19.0) | 5 (11.6) | |
| ≥ 30 | 27 (26.7) | 15 (25.9) | 12 (27.9) | |
| ≥ 1 Comorbid medical conditions | 68 (67.3) | 41 (70.7) | 27 (62.8) | 0.40 |
| Age at cancer diagnosis, mean [SD] | 28.2 [6.3] | 29.5 [6.5] | 26.5 [5.6] | 0.02 |
| Years since cancer diagnosis, median [IQR] | 2.4 [1.2–4.4] | 2.2 [1.1–3.9] | 2.5 [1.2–4.8] | 0.51 |
| Cancer type | | | | 0.02 |
| Breast | 26 (25.7) | 21 (36.2) | 5 (11.6) | |
| Lymphoma | 33 (32.7) | 12 (20.7) | 21 (48.8) | |
| Leukemia/Blood | 8 (7.9) | 5 (8.6) | 3 (7.0) | |
| Thyroid | 2 (2.0) | 1 (1.7) | 1 (2.3) | |
| Gynecologic | 10 (9.9) | 7 (12.1) | 3 (7.0) | |
| Other | 22 (21.8) | 12 (20.6) | 10 (23.3) | |
| Cancer recurrence | 15 (4.9) | 3 (5.2) | 12 (27.9) | <0.01 |
| Self-report of: | | | | |
| Alkylating chemotherapy | 39 (38.6) | 20 (34.5) | 19 (44.2) | 0.32 |
| Pelvic Radiation | 13 (12.9) | 6 (10.3) | 7 (16.3) | 0.38 |
| Hysterectomy and/or oophorectomy | 10 (9.9) | 6 (10.3) | 4 (9.3) | 0.99 |
| Stem Cell transplant | 5 (5.0) | 3 (5.2) | 2 (4.7) | 0.99 |
| Number of self-reported fertility-threatening cancer treatments | | | | 0.36 |
| 0 treatments | 42 (41.6) | 27 (46.6) | 15 (34.9) | |
| 1 treatment | 52 (51.5) | 27 (46.6) | 25 (58.1) | |
| 2 treatments | 6(5.9) | 4 (6.9) | 2 (4.7) | |
| 3 treatments | 1 (1.0) | 0(0.0) | 1 (2.3) | |

Note: Due to missing data, some variables do not add up to 101.

SD=standard deviation; IQR=inter-quartile range

**Table 2**

Accuracy, sensitivity, specificity, and predictive values for self-reported fertility-threatening cancer treatments. % (N)

| | Alkylating Chemotherapy | Pelvic Radiation | Hysterectomy and/or oophorectomy | Stem Cell Transplant |
|---|---|---|---|---|
| **Accuracy** | 68% (69) | 92% (93) | 97% (98) | 92% (93) |
| **Sensitivity** | 58% (25/43) | 69% (9/13) | 77% (10/13) | 38% (5/13) |
| **Specificity** | 76% (44/58) | 95% (84/88) | 100% (88/88) | 100% (88/88) |
| **Positive Predictive Value** | 64% (25/39) | 69% (9/13) | 100% (10/10) | 100% (5/5) |
| **Negative Predictive Value** | 71% (44/62) | 95% (84/88) | 97% (88/91) | 92% (88/96) |

## Table 3

Unadjusted and adjusted logistic regression models of participant characteristics associated with inaccuracy in self-report of fertility-threatening cancer treatments

| | Unadjusted | | Adjusted | |
|---|---|---|---|---|
| | **OR (95 %CI)** | **p-value** | **OR (95 %CI)** | **p-value** |
| **Age at cancer diagnosis** | | | | |
| **< 25** | 2.5 (1.1–5.9) | 0.04 | 3.4 (1.3–8.7) | 0.01 |
| **≥ 25** | ref | | ref | |
| **Age at study enrollment** | | | | |
| **< 32** | 2.5 (1.1–5.6) | 0.03 | – | – |
| **≥ 32** | ref | | | |
| **Race** | | | | |
| **White** | 2.8 (0.85–8.9) | 0.09 | 2.6 (0.75–9.3) | 0.13 |
| **Non-White** | ref | | ref | |
| **Cancer Type** | | | | |
| **Lymphoma** | 3.7 (1.5–8.8) | 0.004 | 2.0 (0.77–5.3) | 0.16 |
| **Other cancer types** | ref | | ref | |
| **Cancer recurrence** | | | | |
| **Yes** | 7.1 (1.9–27.1) | 0.004 | 6.0 (1.5–24.4) | 0.01 |
| **No** | ref | | ref | |