original contribution

# Looking Through the Lens of a Family Planner to Prioritize Reproductive Health Among Women With Cancer

Jessica M. Madrigal, MS[1,2]; Mokshasree Atluri, DO[1,3]; Erika K. Radeke, MS[1]; and Ashlesha Patel, MD, MPH[1,4]

**QUESTION ASKED:** What does comprehensive assessment of the reproductive health goals among women newly diagnosed with cancer look like?

**SUMMARY ANSWER:** Reproductive life planning among newly diagnosed premenopausal women must include a thorough discussion about fertility interest, reproductive health preservation, sexual health, and contraceptive options. The family planning quotient/reproductive life index tool helps women talk to their provider about their reproductive goals.

**WHAT WE DID:** We developed and evaluated a tool with a family planning algorithm to provide women with cancer with tailored family planning counseling and an effective method to track reproductive life goals before cancer treatment.

**WHAT WE FOUND:** The use of a family planning and reproductive life tool to facilitate discussion regarding fertility preservation and effective contraception between a patient with cancer and her medical team is useful in the patient care setting.

**BIAS, CONFOUNDING FACTOR(S):** Our study has a small sample size and was conducted within a health system that serves female patients with cancer who are primarily Hispanic or African American, have low incomes, and are un- or underinsured.

**REAL-LIFE IMPLICATIONS:** Our tool has direct relevance for oncology providers who screen and treat female patients of reproductive age. Reproductive life planning conversations must be a priority among patients who may be pregnant (or trying to become pregnant) before diagnosis as well as with those who desire to become pregnant after treatment has ended. The tool can be used by women with cancer to guide discussions with their multidisciplinary care team to ensure information about fertility risks and preservation is received before treatment.

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CARE DELIVERY

original contribution

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abstract

**PURPOSE** Prioritization of cancer treatment initiation in women of reproductive age may underscore potential implications on reproductive health. This study describes a family planning quotient (FPQ) and reproductive life index (RepLI) tool designed to help providers to discuss effectively reproductive health with women with cancer.

**METHODS** We tailored the FPQ/RepLI tool for patients with cancer after development in the family planning setting and piloted it with 36 oncology patients referred to our family planning clinic. Each patient completed the FPQ/RepLI with a health educator or medical student and then met with a physician to create a reproductive life plan. A subsample evaluated the tool by rating satisfaction using a Likert scale. Summary statistics were calculated overall and by childbearing status.

**RESULTS** Of the 36 women, 22 did not desire additional children and received contraception. One third (n = 14) had not completed childbearing, four of whom continued with fertility preservation counseling. Women who desired childbearing were less likely to already have children ($P = .02$), and more than one half were using long-term contraception. All agreed that the FPQ/RepLI helped them to talk to their provider about their reproductive goals. Only 44.4% agreed that their oncologist knew how many children they desired, and 88.9% found the tool helpful and would use it for future tracking of their reproductive goals.

**CONCLUSION** The FPQ/RepLI is useful for assessing the reproductive health of young women with a new cancer diagnosis, understanding desires of future childbearing, and providing effective contraception. We recommend the incorporation of this tool into practice to better understand patients' reproductive needs.

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## INTRODUCTION

Reproductive health is a critical facet of cancer survivorship in women.[1-3] Of the estimated 852,630 incident cancers in females in 2017, breast, lung and bronchus, and colorectum were the most common,[4] and approximately 10% occurred in women younger than 45 years of age.[5] Priorities in cancer care focus on rapid initiation of treatment[6]; however, addressing reproductive health issues related to sexuality after diagnosis, loss of fertility, endocrine disruption, and exposure to teratogenic treatment in the short window between diagnosis and treatment is also important to ensure optimal quality of life, particularly among women who desire to have children in the future.

Recent advancements in cancer detection and treatment have led to increased survival. Survivorship care plans have emerged from ASCO and the American Cancer Society,[7,8] but few specifically address women's reproductive health. Despite evidence that oncologists cite lack of knowledge as a reason for not having conversations about reproductive health with female patients,[9,10] few tools specific to reproductive health are available to facilitate this conversation in the clinical setting. Decision aids that contain information about cancer, female fertility, and available fertility options have been used,[11-14] but these tools must go beyond fertility and expand in scope to ensure that premenopausal women with cancer are fully informed about all aspects of sexual and reproductive health before treatment.

Previous studies have suggested that young women with cancer do not receive the information they need about risks to fertility and fertility preservation options,[15-19] which indicates that this discussion is not going beyond simply asking a patient whether she wants any more children and/or that oncologists are

ASSOCIATED CONTENT

Appendix

Author affiliations and support information (if applicable) appear at the end of this article.

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not having these discussions with patients newly diagnosed with cancer. Without standardized tools to guide oncology providers, comprehensive assessment of reproductive health goals and contraceptive options may be neglected or forgotten before treatment, which may be especially true for lesbian women. To our knowledge, no template exists for this purpose.

The purpose of this study was to describe the family planning quotient (FPQ) and reproductive life index (RepLI) tool we developed for use in an oncology setting. A secondary aim was to examine the usefulness of this tool to assess contraceptive needs and fertility goals among women with cancer.

## METHODS

In 2015, members of the Division of Family Planning in the Department of Obstetrics and Gynecology of the Cook County Health and Hospitals System began a project with the Division of Hematology/Oncology to standardize family planning referrals for women of reproductive age and any sexual orientation who present to the oncology department. This project aimed to educate and provide women with the proper contraception to meet their needs and address the need to discuss each woman's perspective with regard to potential desires for pregnancy after cancer. Our goal was to use our existing family planning algorithm to provide women with cancer with tailored family planning counseling and an effective method to track reproductive life goals.

### FPQ/RepLI Standardized Tool

The FPQ/RepLI tool originally was designed for use with family planning patients to help patients and providers to visualize the patient's reproductive goals, contraceptive history, and gestational history.[20] In the family planning setting, a nurse, medical assistant, medical student, or health educator completes the tool with the patient, and the responses are given to the provider for further discussion with the patient. The same can be done in the oncology setting. For oncology, we tailored the tool by adding a section on fertility preservation and cancer treatment options. As shown in Figure 1, the first section covers the FPQ, which is derived from the number of children in the patient's family at the time divided by the number of children desired. The FPQ is plotted on a graph with the children desired on the *x*-axis and the current children on the *y*-axis. If the number of children a patient has is less than the number she desires, the point stays in the green zone, which indicates a future desire for children. If a patient has the number of children desired, the point falls on the blue line. If the current number of children is more than desired, the point falls into the purple zone.

The FPQ algorithm (Fig 1) was designed to help women to achieve their reproductive life goals. The algorithm complements the FPQ by guiding the patient to a contraceptive method that suits her current needs. By using the algorithm with the current medical eligibility criteria guidelines,[21] the provider can discuss available contraceptive options to ensure that the patient's reproductive goals are met. In general, the goal is to have an FPQ of 1, which indicates equality between the patient's reproductive desires and her current reproductive history. An FPQ greater than 1 indicates a need for long-term contraception to prevent additional pregnancies when no pregnancy is desired among women who have sex with men. Recommendations for long-term contraception should follow medical eligibility criteria[21] and may include a tier 1 method,[22] which includes long-acting reversible contraception methods, such as a copper intrauterine device (IUD). For a woman with cancer, the need for effective contraception goes beyond the goal of reproductive balance. Evaluation of pregnancy before and during cancer treatment is important in preventing fetal anomalies as a result of unintended concomitant pregnancy during cancer treatment.

For a woman with an FPQ less than 1, the oncology tool indicates a need to consult with reproductive endocrinology for fertility preservation counseling and assessment. This consultation ensures that fertility preservation methods are discussed before the start of any cancer treatment and is important for all women who may desire children in the future, including lesbian women. For a woman who is pregnant at the time of cancer diagnosis, a discussion with the obstetrics and gynecology team is indicated to consider the desire to continue or terminate the pregnancy before or in conjunction with the discussion of cancer treatment options.

The second page of the template presents the RepLI as shown in Figure 2. The graph at the top of the page is used to record FPQs, pregnancy-related interventions and outcomes, and a patient-determined ideal childbearing window. The primary left *y*-axis represents the FPQ, and the secondary right *y*-axis represents the frequency of other pregnancy-related losses and interruptions. Both axes share a common *x*-axis of time. Thus, a graph that plots a woman's FPQ longitudinally allows for a simple and accessible visual guide for this conversation. The key shows symbols for various pregnancy-related outcomes. The first four symbols (intended live birth, unintended live birth, adoption, and stepchild) represent events that affect the FPQ and are thus plotted along the FPQ line. The next five (child death, miscarriage, stillbirth, ectopic or tubal pregnancy, and elective abortion) do not affect the FPQ but are relevant pieces of reproductive history that are tracked along the secondary *y*-axis. The chart at the bottom of the second page is used to track various elements of a patient's cancer treatment history as well as previous and present fertility preservation or treatment methods (Fig 2). The chart also includes menstrual history, partner status, and contraceptive history. In general, contraceptives are categorized by efficacy as tier 1, 2, or 3 methods.[22] Tier 1 methods

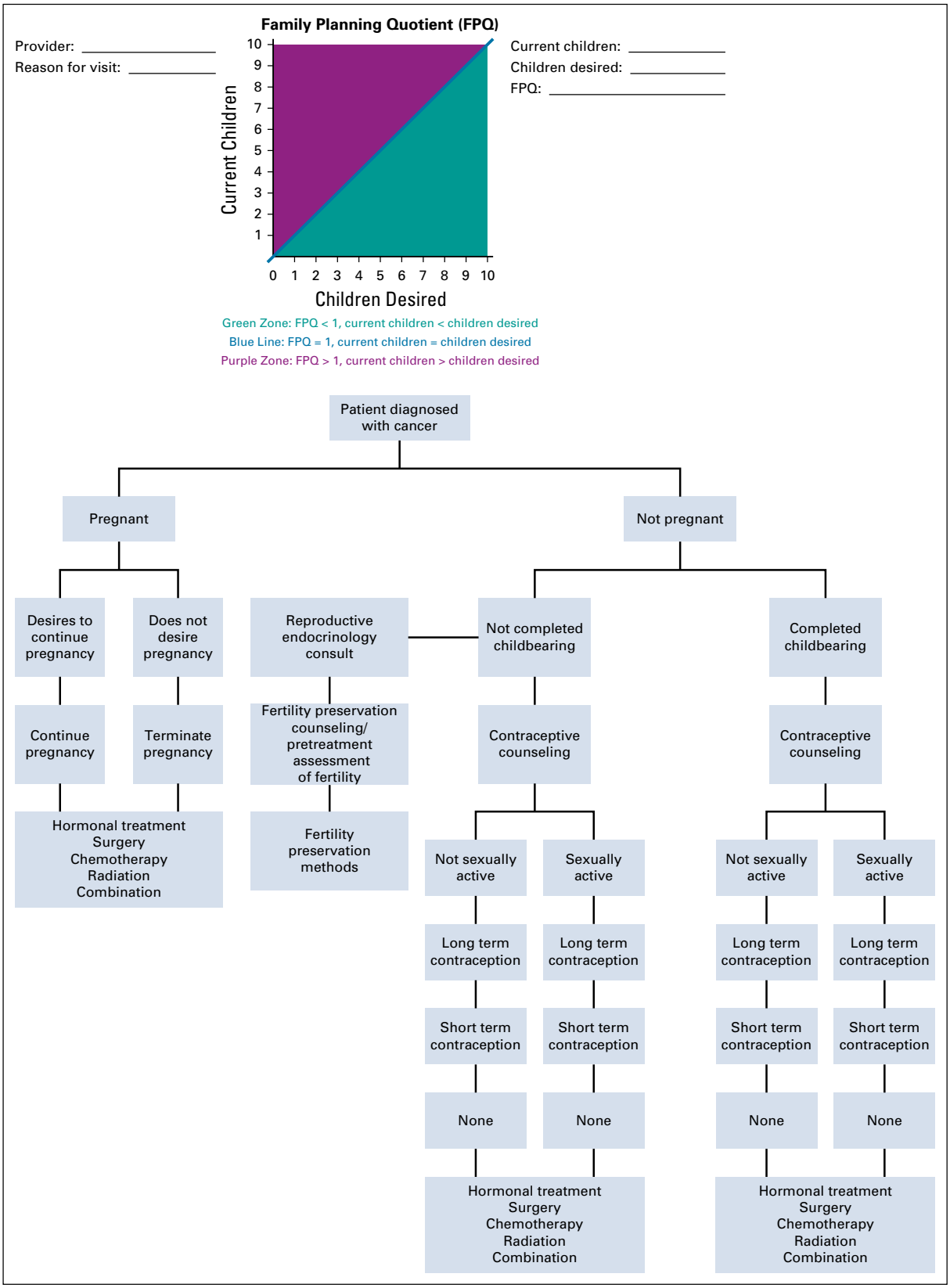


**FIG 1.** Family planning quotient (FPQ) portion of the FPQ/reproductive life index tool.

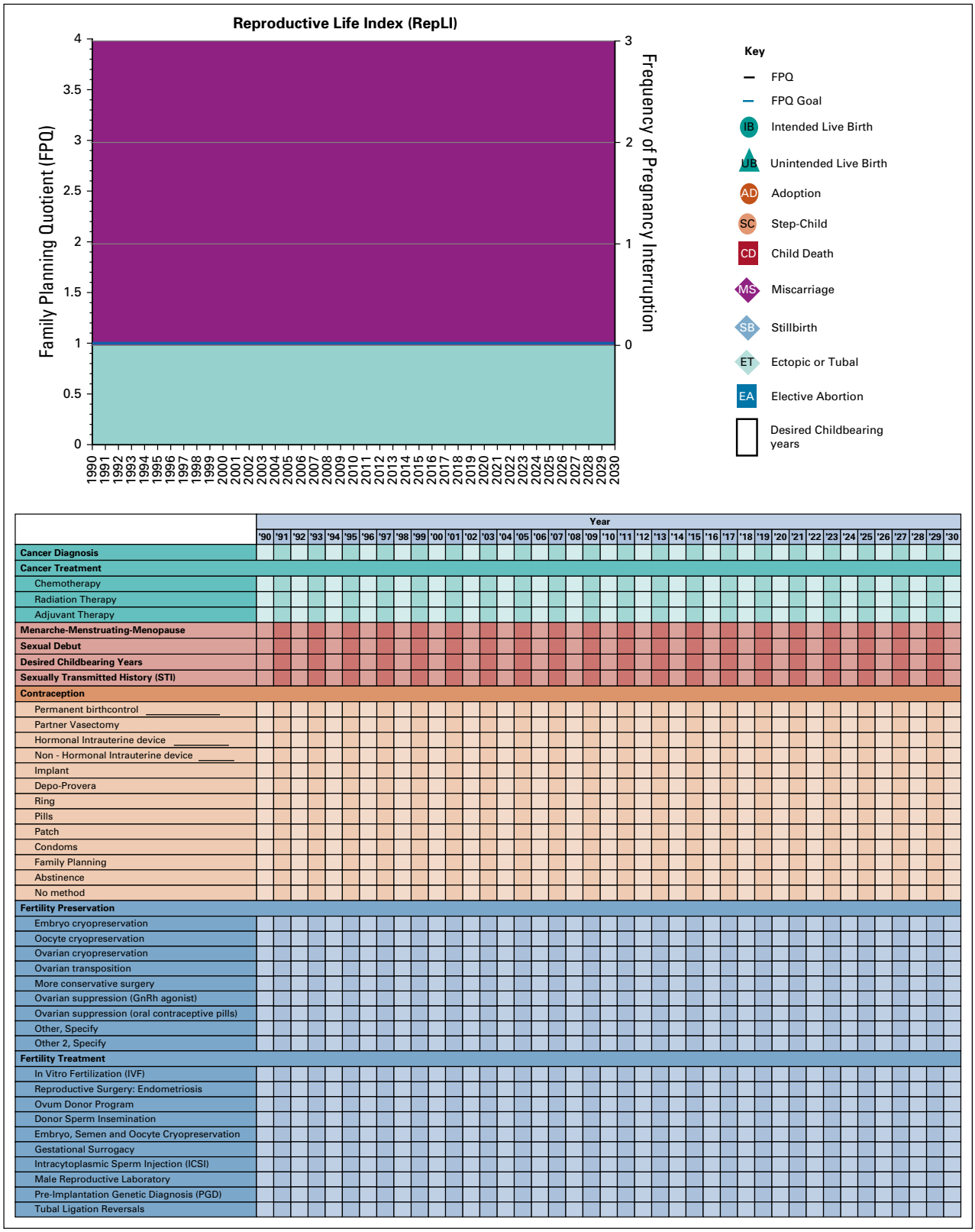


**FIG 2.** Reproductive life index (RepLI) portion of the family planning quotient (FPQ)/RepLI tool. GnRh, gonadotropin-releasing hormone; STI, sexually transmitted infection.

include hormonal implant, IUD, female sterilization, and vasectomy. Tier 2 methods include the vaginal ring, pills, patches, and injectables. Tier 3 methods include condoms, diaphragms, sponges, spermicides, fertility awareness, and withdrawal.

### Patient Experience

We conducted a pilot study to test the oncology FPQ/RepLI tool with 36 women of reproductive age (younger than 50 years) from July 2015 through January 2017 who were diagnosed in the oncology department and referred to the family planning department. Women met with a health educator and completed the adapted FPQ/RepLI to create a reproductive life plan. They next met with a physician to implement a plan in accordance with their reproductive goals.

At the time of the family planning visit, women completed a short survey of demographic characteristics, such as ethnicity, educational attainment, income, and relationship status. Information about childbearing desire, sexual activity, number of children, contraception use, and fertility preservation were collected as part of the reproductive health discussion using the FPQ/RepLI tool. Women evaluated the FPQ/RepLI tool by rating their response to seven statements as strongly agree, agree, neither agree nor disagree, disagree, or strongly disagree. The statements were as follows: this tool helped me to think about my own personal goals; this tool helped me to communicate my own personal goals to my provider; I had thought about my reproductive life plan prior to today's visit; I had discussed my reproductive life plans with my doctor prior to today's visit; before today's visit, my doctor knew how many children I wanted; before today's visit, my doctor knew when I wanted to have additional children, if desired; and overall, this tool is helpful and I would use it to track my reproductive health goals. Space was available to write in suggestions to improve the tool. This study was approved by the Cook County Health and Hospitals System institutional review board and was conducted in accordance with the Declaration of Helsinki.

### Statistical Analysis

Means and standard deviations were calculated for age. Frequencies and proportions were calculated for all categorical characteristics. Differences in the proportion of women who had completed childbearing compared with women who desired childbearing were evaluated using the *t* test for age and $\chi^2$ tests for categorical variables. $P < .05$ was considered statistically significant. Evaluation information was summarized as the proportion of women who selected strongly agree or agree for each statement compared with the proportion of women who selected neither agree nor disagree, disagree, or strongly disagree. Data analysis was conducted using SAS 9.4 software (SAS Institute, Cary, NC).

## RESULTS

Overall, 36 women were referred to family planning and completed the FPQ/RepLI tool during the study period. None of the women were pregnant at the time of the family planning visit (Fig 3). Fourteen indicated that they had not completed childbearing, and 100% were referred to Northwestern University's Oncofertility Consortium for counseling. Of these women, 12 (85.7%) had an FPQ of less than 1 and two (14.3%) had an FPQ of greater than 1. Of note, at the time of the oncology encounter, two women who were previously satisfied with the size of their family (FPQ greater than 1) did not want to consider their childbearing to be complete when faced with a cancer diagnosis that could affect their fertility. Neither woman was sure how many more children she wanted. One of the two went on to pursue fertility counseling. Overall, four (28.6%) of the 14 women presented for fertility preservation counseling before beginning their cancer treatment. During contraception counseling, 11 women (78.6%) reported being sexually active and three (21.4%) were not. Of the sexually active women, five (45.4%) chose reversible long-term contraception, and four (36.4%) chose short-term contraception.

Among the 22 women who had completed childbearing at the time of study initiation, 20 (91%) had an FPQ of 1 and two (9%) had an FPQ greater than 1. Twenty women (90.9%) were sexually active and two (9.1%) were not. The majority (n = 15; 68.2%) chose long-term contraception (IUD or hormonal implant), six of whom opted for a permanent option (sterilization). One woman who reported her childbearing status as complete at the time of the visit also desired to learn more about fertility preservation. Overall, the majority (77.8%) underwent a combination of chemotherapy plus radiation, surgery, or hormonal therapy for treatment.

As shown in Appendix Table A1 (online only), at the time of the family planning visit, the average age was 34.1 years (standard deviation, 7.8 years), and most women were married or had a partner (58.3%). Those who desired childbearing were less likely to already have children at the time of their diagnosis ($P = .02$) compared with women who had completed childbearing.

Overall, nine women (25.0%) participated in the evaluation of the FPQ/RepLI tool. All agreed that the tool helped them to think and talk to their provider about their personal goals. All indicated that they had thought about their reproductive life plan and discussed the plan with their physician before their family planning visit. Only 44.4% agreed that their oncologist knew how many children they desired before the visit where the tool was used, and 28.6% indicated that their physician understood the time period in which they desired children. The majority of women (88.9%) indicated that they found the tool helpful and would use it in the future to track their reproductive goals.

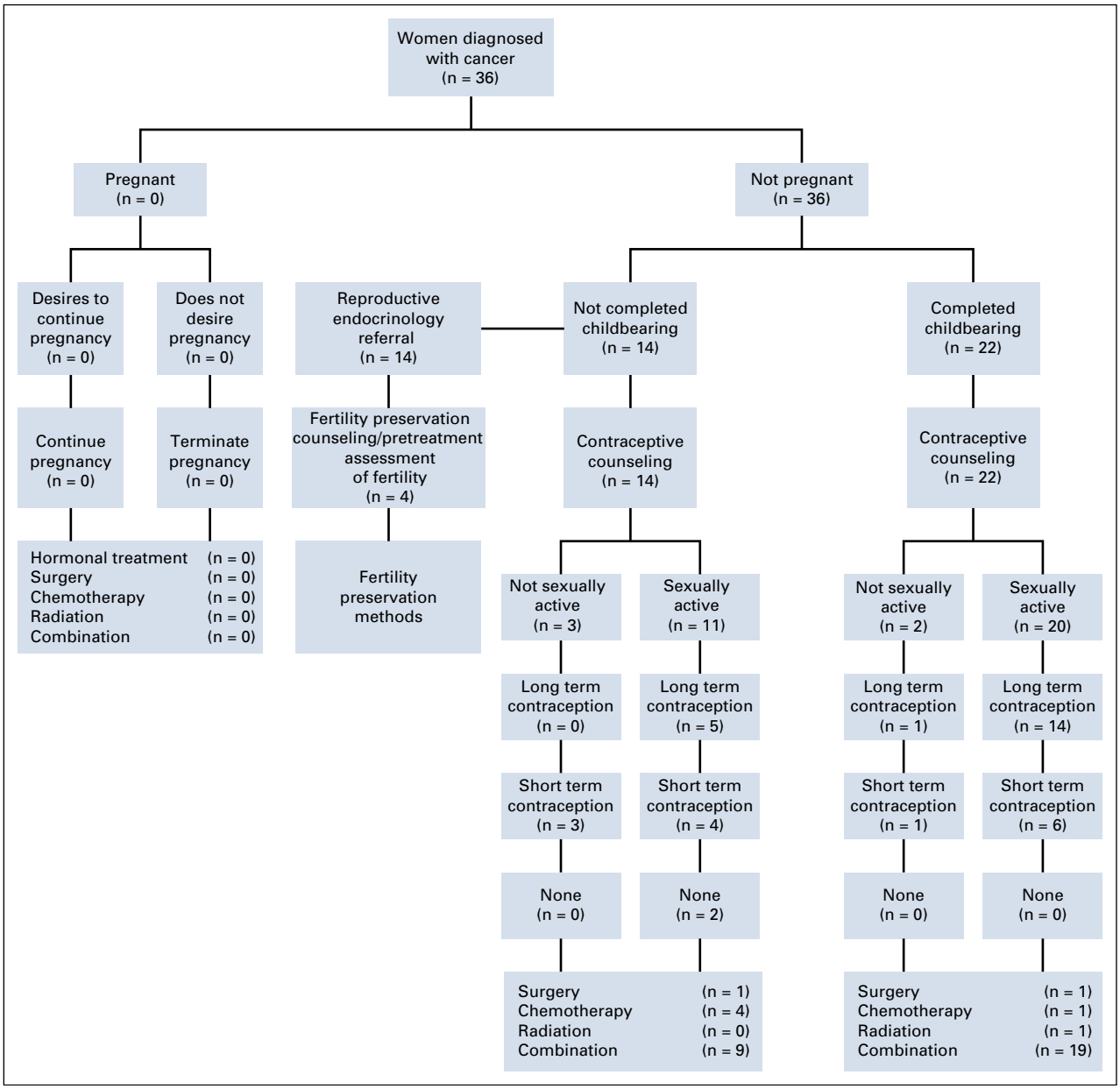


**FIG 3.** Description of participant flow during the pilot study, beginning with cancer diagnosis through treatment.

## DISCUSSION

Many studies have revealed that young women are concerned about their fertility and sexual health before and after cancer treatment.[23-25] Consistent with our prior work,[1,2,26] the current study suggests that use of a family planning and reproductive life tool to facilitate the discussion between a patient and her medical team is useful. The FPQ/RepLI tool is applicable to the growing number of women who survive cancer diagnosed during their reproductive years, can supplement the oncologist's role in patients' reproductive care, and may help to bridge the gap between oncologic and reproductive health care.

The oncologist plays a key role in the fertility care of young patients with cancer[27] but often is limited by insufficient fertility treatment resources. Oncologists also may have limited time with the patient, which is further complicated by hesitancy to discuss fertility or limited knowledge of family planning practices.[10] In an ongoing multicenter study of family planning in the cancer setting in which we have been participating (ClinicalTrials.gov identifier: NCT01806129), it has been challenging to overcome feelings of reluctance among oncologists to facilitate conversations about reproductive health and family planning among women with newly diagnosed cancer. A national assessment of fertility preservation services found that most fertility centers operate with insufficient resources and support for patients,[28] despite guidelines that call for prioritization of fertility preservation discussion and referral.[29] Limitations to fertility treatment

options are especially relevant at institutions that deliver services to minorities or underserved communities,[30,31] where fertility preservation resources are costly[32] and may not be available onsite. Despite these barriers, we observed a need for fertility preservation consultation among the women in the current study who desired children.

In an ongoing study in our oncology clinic, physicians have been receptive to referring their patients to an in-clinic health educator to discuss the FPQ/RepLI during patient visits. Also suitable for oncology practices, to have a nurse, medical assistant, or medical student discuss the tool before the patient meets with the oncologist. In consideration of the history of hesitation and discomfort in leading a discussion about fertility and reproduction in an oncology setting, a referral to a family planning practice alleviates the need for oncologists to be fully educated on the tiers of contraceptive methods and creates a multidisciplinary care team between oncology and family planning practices. We plan to survey our oncologists to assess their interest and concerns about using the FPQ/RepLI tool in oncology practice.

With emphasis frequently on the preservation of fertility before cancer care, discussion about contraception and the possibility of pregnancy before or during treatment must become part of the conversation health care staff has with the patient and must include female patients of any sexual orientation. In the current study, results indicate that only a minority of women believed that their current medical oncology team was knowledgeable about women's family planning desires, and all agreed that the tool helped them during their oncology visit. When faced with a situation where treatment may affect future childbearing, two of our patients indicated that the number of children they currently had in their family was more than they had previously imagined (FPQ greater than 1), yet they did not want to be categorized as childbearing complete. Neither woman was sure about how many (if any) additional children she desired, which adds to existing evidence[33] that coming to an absolute decision about the number of biological children one desires is not easy and that this decision may change over time, especially in a situation where life-saving treatment may prevent future childbearing.

This study has direct relevance for women who may be pregnant (or trying to become pregnant) before diagnosis as well as for those who survive cancer and desire to become pregnant afterward. Research has demonstrated the need for a thorough discussion about fertility interest, reproductive health preservation, sexual health, and contraceptive options among newly diagnosed premenopausal women,[1,34-37] yet a prior study showed less than one half of US oncologists follow the ASCO guidelines[38] that support the provision of information about fertility preservation to all patients of reproductive age.[10]

Sexuality is a component of reproductive health that has direct implications for women with cancer and should be considered just as important as oncofertility and oncocontraception.[39-42] Approximately two thirds of the patients in our sample had completed childbearing at the time of our study, and the majority were sexually active. The FPQ/RepLI tool can help a provider to become familiar with sexuality and contraceptive methods, and our findings complement previous research findings of the need to broaden the scope of reproductive health to include sexuality and contraception.[25,43] A prior study of 107 women of reproductive age with a recent cancer diagnosis found that just four were using an IUD for contraception.[44] This is a stark contrast to the 19 women (52.8%) who were using tier 1 methods in the current study. We attribute the high use of tier 1 methods in our setting to the family planning referral and use of the FPQ/RepLI tool.

Despite the small sample size, our study provides insights into the needs of a primarily minority, low-income, un- or underinsured population of female patients with cancer, and adds to the paucity of literature previously cited by ASCO.[45] Our future directions include continued investigation and evaluation of the FPQ/RepLI algorithm and subsequent referral patterns through the aforementioned clinical trial.

In conclusion, we provide a useful tool to prioritize reproductive health conversations between women with cancer and their medical providers. We recommend a multidisciplinary approach that involves oncologic and family planning staff to understand the patient's reproductive needs and to address her goals effectively.


## AFFILIATIONS

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST AND DATA AVAILABILITY STATEMENT

Disclosures provided by the authors and data availability statement (if applicable) are available with this article at DOI https://doi.org/10.1200/JOP.18.00429.

AUTHOR CONTRIBUTIONS

**Conception and design:** Erika K. Radeke, Ashlesha Patel
**Administrative support:** Erika K. Radeke
**Collection and assembly of data:** Jessica M. Madrigal, Mokshasree Atluri
**Data analysis and interpretation:** All authors
**Manuscript writing:** All authors

**Final approval of manuscript:** All authors
**Accountable for all aspects of the work:** All authors

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## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

**Looking Through the Lens of a Family Planner to Prioritize Reproductive Health Among Women With Cancer**

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## APPENDIX

**TABLE A1.** Demographics of Female Oncology Patients Who Attended Family Planning Visits Overall and by Childbearing Status

| Demographic | Overall, No. (%) | Desire Childbearing, No. (%) | Completed Childbearing, No. (%) | *P* |
|---|---|---|---|---|
| No. of patients | 36 | 14 | 22 | |
| Age at diagnosis, years | | | | .001 |
| Mean | 34.1 | 28.4 | 37.7 | |
| Range | 17-47 | 17-37 | 25-47 | |
| Standard deviation | 7.8 | 6.5 | 6.2 | |
| Marital status at diagnosis | | | | .8 |
| Married/partnered | 21 (58.3) | 8 (38.1) | 13 (61.9) | |
| Single | 11 (30.6) | 5 (45.6) | 6 (54.6) | |
| Divorced/separated | 4 (11.1) | 1 (25.0) | 3 (75.0) | |
| Ethnicity | | | | .4 |
| Non-Hispanic black | 9 (25.0) | 5 (55.6) | 4 (44.4) | |
| Hispanic | 22 (61.1) | 8 (36.4) | 14 (63.6) | |
| Other* | 5 (13.9) | 1 (20.0) | 4 (80.0) | |
| No. of children at diagnosis | | | | .02 |
| 0 | 9 (25.0) | 6 (66.7) | 3 (33.3) | |
| 1 | 6 (16.7) | 4 (66.7) | 2 (33.3) | |
| ≥ 2 | 21 (58.3) | 4 (19.1) | 17 (80.9) | |
| No. of additional children desired | | | | < .001 |
| 0 | 22 (61.1) | 0 (0.0) | 22 (100.0) | |
| 1 | 6 (16.7) | 6 (100.0) | 0 (0.0) | |
| ≥ 2 | 6 (16.7) | 6 (100.0) | 0 (0.0) | |
| Not sure | 2 (5.6) | 2 (100.0) | 0 (0.0) | |
| Family planning quotient | | | | < .001 |
| < 1 | 12 (33.3) | 12 (100.0) | 0 (0.0) | |
| 1 | 20 (56.7) | 0 (0.0) | 20 (100.0) | |
| >1 | 4 (11.1) | 2 (50.0) | 2 (50.0) | |
| Sexually active | | | | .3 |
| Yes | 31 (86.1) | 11 (35.5) | 20 (64.5) | |
| No | 5 (13.4) | 3 (60.0) | 2 (40.0) | |
| No. of family planning visits | | | | .2 |
| 1 | 23 (63.9) | 7 (30.4) | 16 (69.6) | |
| 2-3 | 13 (36.1) | 7 (53.9) | 6 (46.2) | |
| Contraception use at initial family planning visit† | | | | .05 |
| Tier 1 | 19 (52.8) | 4 (21.1) | 15 (78.9) | |
| Tier 2 | 4 (11.1) | 3 (75.0) | 1 (25.0) | |
| Tier 3 | 13 (36.1) | 7 (50.0) | 6 (46.2) | |
| Time between diagnosis and family planning visit | | | | .8 |
| 4 weeks | 4 (11.1) | 1 (25.0) | 3 (75.0) | |
| 5 weeks to 6 months | 8 (22.2) | 4 (50.0) | 4 (50.0) | |
| 6 months to 1 year | 2 (5.6) | 1 (50.0) | 1 (50.0) | |
| ≥ 1 year | 22 (61.1) | 8 (36.4) | 14 (63.6) | |

(continued on following page)

**TABLE A1.** Demographics of Female Oncology Patients Who Attended Family Planning Visits Overall and by Childbearing Status (continued)

| Demographic | Overall, No. (%) | Desire Childbearing, No. (%) | Completed Childbearing, No. (%) | *P* |
|---|---|---|---|---|
| Interested in fertility preservation | | | | .04 |
| Yes | 5 (13.9) | 4 (80.0) | 1 (20.0) | |
| No | 31 (86.1) | 10 (32.3) | 21 (67.7) | |
| Cancer type | | | | .05 |
| Breast | 27 (75.0) | 8 (29.6) | 19 (70.4) | |
| Other‡ | 9 (25.0) | 6 (66.7) | 3 (33.3) | |

*Non-Hispanic white (n = 1) and Asian/Pacific Islander (n = 4).

†Tier 1 methods include hormonal implant, intrauterine device, female sterilization, and vasectomy. Tier 2 methods include the vaginal ring, pills, patches, and injectables. Tier 3 methods include condoms, diaphragms, sponges, spermicides, fertility awareness, and withdrawal.

‡Other includes lymphoma (n = 2), ovarian cancer (n = 2), gestational trophoblastic neoplasia (n = 2), nasal carcinoma (n = 1), rectal adenoma (n = 1), and nasopharyngeal cancer (n = 1).