

Attitudes and perceptions towards fertility preservation among cancer survivor partners

Kendra Frome¹, BS, Allison Goetsch^{2,3}, MS, Catherine A Wicklund⁴, MS, Christina G Hutten Selkirk⁵, MS, and Teresa K Woodruff⁶, PhD

¹ Center for Genetic Medicine, Northwestern University, 645 N. Michigan Ave., Chicago, IL, 60611, USA

E-mail: kendrafrome2017@u.northwestern.edu

Phone number: 541-979-5591

² Ann & Robert H. Lurie Children's Hospital, Chicago, IL, USA

E-mail: AGoetsch@luriechildrens.org

³ Department of Pediatrics, Northwestern University Feinberg School of Medicine, Chicago, IL, USA

⁴ Graduate Program in Genetic Counseling, Northwestern University, Feinberg School of Medicine, Chicago, IL, USA

E-mail: c-wicklund@northwestern.edu

⁵ Center for Medical Genetics, NorthShore University HealthSystem, Chicago, IL, USA

E-mail: CSelkirk@northshore.org

⁶ Department of Obstetrics and Gynecology, Northwestern University Feinberg School of Medicine, 303 E. Superior St, Lurie 10-231, Chicago, IL, USA

E-mail: tkw@northwestern.edu

PARTNER'S FERTILITY PRESERVATION ATTITUDES

KEY POINTS

Question: What are the attitudes and perspectives of cancer survivor partners towards fertility preservation?

Findings: Almost all (98%) of partners thought fertility preservation was an acceptable family building option. All partners were involved in the fertility preservation decision-making process and 83% of partners said the patient discussed the option of fertility preservation with them before making a decision.

Meaning: Partners play an active role in the fertility preservation decision-making and should be involved in this process.

ABSTRACT

Importance: Fertility preservation attitudes and perceptions have been widely studied among male and female cancer survivors as well as oncologists and reproductive specialists. Currently there is little information available on the perceptions and attitudes of partners on fertility preservation and cancer.

Objective: To investigate attitudes and perceptions towards fertility preservation among cancer survivor partners, as well as evaluate partner influence and additional factors that impact FP decision-making.

Design: Cancer survivors and fighters were invited to share a survey link with their partner. Survey questions included attitudes towards fertility preservation, partner perceptions of the level of influence they have on the patient's decision to pursue fertility preservation, and partner perspectives of the different factors that play a role in their decision to engage in fertility preservation.

Setting: Population-based.

Participants: Partners (n = 50) of cancer survivors and fighters were recruited to take an online survey through nine cancer support organizations.

Main Outcomes: The primary study outcome was to assess partner attitudes towards fertility preservation, perceived level of influence on the patient's decision to pursue fertility preservation, and factors that play a role in their decision to engage in fertility preservation.

Results: Almost all (98%) partners thought fertility preservation was an acceptable family building option. Seventy-seven percent of partners were present at the time of the patient's treatment options discussion, and 66% of partners said that they received

PARTNER'S FERTILITY PRESERVATION ATTITUDES

information about the patient's fertility preservation options. Half (52%) felt they received enough fertility preservation information and the majority (66%) were interested in learning more about fertility preservation. Eighty-three percent of partners said that the patient discussed the option of fertility preservation with them prior to decision-making. When asked what factors would play a role in the decision to pursue or not to pursue fertility preservation, partners said that desire for future children (86%) and safety of fertility preservation timing with cancer (81%) were most influential.

Conclusion: Partners play an active role in the fertility preservation decision-making process. Our findings support the involvement and participation of partners in fertility preservation discussions.

BACKGROUND

Approximately 1.69 million new cancer diagnoses are expected to occur in the United States in 2017.¹ Of those diagnoses, 10% will occur in individuals under the age of 45.² Improvements in early detection and treatment of cancer have increased survival rates, shifting focus to post-cancer quality of life. One side effect of chemotherapy, radiation, or surgery includes compromised fertility.^{3,4}

For males, the most mature FP technology is sperm banking. Experimental methods include testicular tissue freezing and testicular shielding.⁵ For females, the most successful options include embryo and oocyte freezing. Ovarian tissue cryopreservation is considered experimental. Additional options include ovarian transposition and ovarian suppression.^{6,7} Discussions of FP between patients and their physicians is recommended to include the availability of alternative family-building options, such as the use of donor sperm, donor eggs, donor embryos, surrogacy, or adoption.⁸⁻¹⁰ The expansion of options for cancer patients has allowed patients the choice to preserve their fertility in unique situations when it had not existed previously.

While the field of oncofertility is growing, further research is needed to aid both health care providers and patients in the discussion and consideration of FP. Hershberger *et al.* (2016) interviewed young women post-cancer diagnosis as to why they accept or decline FP and found that a strong desire for motherhood and family influence motivates patients to pursue FP.¹¹ In contrast, financial reasons, lack of information, and

PARTNER'S FERTILITY PRESERVATION ATTITUDES

fear of surviving cancer often prevents patients from pursuing FP.¹¹⁻¹³ Although the ASCO guidelines recommend oncologists to inform all patients about the chance of infertility due to their cancer or treatment, studies have found that only about 50-80% of oncologists initiate this discussion. The main barriers to FP discussions among oncologists and cancer patients include oncologists' lack of knowledge, patient attributes such as culture or religion, and lack of time due to stage of cancer.^{14,15}

To further complicate the process, the health care provider and patient are not the sole persons involved in FP discussions. Patient partners may also play a role in the decision-making process. Tschudin *et al.* (2010) established that approximately 80% of young female cancer patients have partners.¹⁶ Additional literature shows that partners often attend medical visits and provide support to patients.¹⁷ Health care providers report that fertility is an important concern to partners, in addition to patients.¹⁸ Several factors have been suggested by Badr (2016) that complicate the oncofertility communication process between patient and partner, including differing values and opinions regarding FP and its ethical complexity.¹⁹ The purpose of this study is to clarify partner perspectives regarding FP and to evaluate their perceived influence on patients during the FP decision-making process. This is the first to assess partner attitudes in the FP setting.

METHODS

Target Population

The study was approved by the Institutional Review Board of Northwestern University. Participants were recruited through nine cancer support organizations, including: Stupid Cancer, Imerman's Angels, the Oncofertility Consortium, I Have Lynch Syndrome, The Licorice Project, No Stomach For Cancer, Stupid Dumb Breast Cancer, Twist Out Cancer, and Young Survival Coalition. Text and a weblink to an online survey were posted on the organizations' social media websites. Participants were recruited between September 2016 and January 2017. A reminder was posted approximately one month after the initial post. Cancer survivors and fighters were invited to share the link with their partner. For the purpose of this study, 'patient' refers to individuals who were diagnosed/treated with cancer and 'partner' refers to individuals who identify as a participant in the patient's life. Male or female patients and partners were eligible for the study with no exclusion of same sex partners. Those who were invited to participate in the study needed to meet the following criteria: 1) patients were diagnosed with cancer between the ages of 18-50; 2) The patient had or will have chemotherapy and/or radiation as part of their treatment (if patients had neither chemotherapy or radiation, partners were able to answer questions regarding attitudes towards FP, factors that would influence their decision to pursue or not to pursue FP, and demographics); 3) participants can read English.

Instrumentation

PARTNER'S FERTILITY PRESERVATION ATTITUDES

The survey instrument was developed based on published literature and clinical experience (Appendix).²⁰ Survey questions assessed partner attitudes regarding FP, partner perceptions of the level of influence they have on the patients' decisions to pursue FP, and partner perspectives of the different factors that play a role in their decision to engage in FP. The survey consisted of 22 questions and 14 demographic questions.

Data Analysis

Data was compiled, coded, and analyzed using SPSS software. Responses were not required for each question to be included in the analyses. Descriptive statistics, including frequencies, means, medians, and percentage of respondents, were calculated for each question. Chi-square statistics (or Fisher's exact test) were used to compare categorical variables and Mann-Whitney and Kruskal Wallis tests were used to compare ordinal variables to determine any significant associations between responses. P-value equal or less than .05 was considered significant.

RESULTS

The study sample consisted of 39 partners who completed the survey and 11 partners who partially completed the survey. The majority of partners were male 24 (65%), Caucasian 34 (87%), had been in a relationship over 5 years 25 (64%), and made

greater than \$100,000 in household annual income (Table 1). Partners stated that 15 (65%) out of 23 female patients were treated at a university hospital, and 8 (67%) out of 12 male patients were treated at a community or private hospital. Of partners with a household income of \$75,000 - \$250,000 or more, 20 (95%) patients had private insurance and 1 (5%) had Medicaid coverage or no insurance. Of partners with a household income of \$0 - \$75,000, 13 (72%) patients had private insurance and 5 (28%) had Medicaid coverage or no insurance.

Forty-one (82%) partners reported that the patient had chemotherapy and/or radiation as part of their treatment, and 37 (74%) reported that they were in a relationship with the patient at the time of cancer diagnosis. Mean age of partners was 34 years old, with a range of 23-53 years. The range of the patient's age at the time of diagnosis was 21-48 years. Most partners 24 (62%) reported they did not have children, although 19 of these 24 (79%) individuals reported they want biological children. Sixteen out of 19 (84%) partners aged 35 years and younger reported they want biological children. Of the 12 partners who had children, 5 (36%) wanted more biological children, 1 (7%) wanted to adopt more children, and 8 (57%) had completed family planning.

Partner Attitudes Towards Family Building Options

All 50 partners were surveyed on their attitudes towards alternative family building options, including fertility preservation (FP), adoption, use of egg donors, and sperm donors. Almost all partners reported that FP 48 (98%) and adoption 45 (92%) are

PARTNER'S FERTILITY PRESERVATION ATTITUDES

acceptable family building options. While the majority of partners 41 (84%) reported that using an egg donor is an acceptable family building option, it was noted that 21 out of 24 (88%) male partners found egg donation acceptable compared to 10 out of 13 (77%) female partners. Similarly, while the majority of partners 40 (82%) reported that the use of sperm donor is an acceptable family building option, 21 out of 24 (88%) male partners found sperm donation acceptable compared to 9 out of 13 (69%) female partners.

The Decision-Making Process of Fertility Preservation Between Patient and Partner

Partners were surveyed on whether they and their partner, the patient, received FP information and whether information received was adequate. In this study, 15 of 23 (65%) participants reported they had received information about FP (Table 2). Slightly more male partners (9 of 10, 90%) than female partners (12 of 15, 80%) indicated the patient had received FP information (Figure 1B). Additionally, 9 of 12 (75%) male partners received information about the patient's FP options, while only 3 of 8 (38%) female partners received information about the patient's FP options. There was no statistically significant difference regarding the receipt of FP information among individuals with respect to annual income or type of health insurance.

Partner receipt of FP information was found to be associated with two factors: (1) presence at the patient's treatment options discussion with their health care provider, and (2) relationship status at the time of the cancer diagnosis. Partners not present at

the time of treatment options discussion were significantly less likely to receive FP information (p-value = .039). The more committed the relationship, the more likely the partner was to be present at this appointment and the more likely the partner had discussed FP options with the patient prior to decision-making. Among 14 married couples, 93% of partners were present at the time the patient's health care provider discussed treatment options, and 91% said that the patient discussed the FP decision with them. Among partners who said the patient received FP information, 19 of 23 (83%) said the patient discussed the option of FP with them before making a decision.

All partners who said the patient discussed the option of FP with them before making a decision reported feeling involved in the decision-making process, and 13 (75%) out of 16 partners felt they had a strong influence on the patient's decision to pursue or not to pursue FP. In addition, 4 (21%) partners had minimal desire to influence the patient's decision to pursue FP, 5 (26%) had some desire, and 10 (53%) had strong desire to influence the patient's decision to pursue FP (Table 3).

Factors that Influence a Partner to Pursue or Not to Pursue FP

Partners were asked to rate the influence of different factors (previously reported in the literature) with regard to their decision to pursue or not pursue FP. Of 42 partners, the majority responded that desire for future children 36 (86%) and safety of FP timing with starting cancer treatment 34 (81%) play large roles in the decision to pursue or not to pursue FP, while religion 34 (81%) and moral beliefs 34 (81%) largely does not play a

PARTNER'S FERTILITY PRESERVATION ATTITUDES

role. Other influential factors include fear of partner's cancer recurring 31 of 41 (76%), concern for partner's survival 31 (74%), and stress of cancer diagnosis 30 (70%). Additionally, 26 (62%) partners indicated that cost was a factor in the decision to pursue FP, although more so for female (9 of 12, 75%) than male partners (14 of 24, 58%) (Figure 2). Of partners who reported that the patient chose to pursue FP, the desire for future children 16 of 18 (89%) was the most influential factor in the decision. For those who did not pursue FP, safety of FP timing with cancer 8 of 9 (89%) and concern for partner's survival 8 of 9 (89%) were the most influential factors in the decision. No statistical significance was identified among partner's responses with regard to the patient's cancer stage, treatment location, or income.

DISCUSSION

There is a gap in the current oncofertility literature concerning partner attitudes and perspectives towards fertility preservation and the perceived influence a partner has on the patient during the FP decision-making process. This study established that partners play an active role in the FP process, and have a desire to be involved in FP decision-making. Partners are generally present at the time of cancer treatment discussion and receive FP information. Almost all partners reported that the patient shared the FP information and they felt involved in the FP decision-making process. Additionally, partners felt they strongly influence the decision of whether or not to pursue FP and the majority had either some or strong desire to influence the patient's FP decision. These results are the first to identify the involvement of partners in FP decision-making and

provide insights into the incorporation of partners in oncofertility discussions between health care providers and patients.

The study findings are consistent with previous reports assessing partner's influence on cancer patients' decisions regarding treatment. Srirangam *et al* (2003) found that only 48% of partners were present at the time the diagnosis of cancer was given, but that 74% of partners accompanied the patient to subsequent visits.²⁰ In another study, 77% of partners said they received sufficient information about treatment for the patient.²¹ It is well accepted that partners are involved in the cancer treatment decisions, and our study supports their additional involvement in FP discussions and decision-making.

Almost all partners reported that the patient shared FP information with them, which may suggest that patients want to include and involve partners in the FP decision-making process. However, only half of partners felt they received enough information about FP, and two-thirds reported they would have been interested to learn more about FP. While partners are generally receiving FP information, it is unclear what information they are receiving and whether or not the information is adequate to facilitate decision-making. Health care providers should continue to develop educational tools and resources to not only provide appropriate FP information and guidance for the patient, but also for the partner.

More male partners of female cancer patients received FP information compared to female partners of male cancer patients in this study. This finding may suggest that

PARTNER'S FERTILITY PRESERVATION ATTITUDES

male partners are included in the FP discussions with female patients more often than female partners are being included in male patient FP discussions. Additional research is needed regarding the differences of receipt of FP information among the sexes and the role of the partner.

Overall, patients shared FP information with both female and male partners. While we do not know what their discussions entailed, our findings suggest that communication is occurring regardless of reported sex. However, more male partners felt they received enough FP information compared to female partners. The female FP process is more complicated and time consuming than male FP and typically requires more detailed conversations and evaluation, which may explain why more male partners felt they received enough information compared to female partners. It is important to note that both female and male partners would have liked to learn more about FP, which suggests that overall partners are interested in FP options.

Attendance of partners at cancer patient medical appointments may be an important step towards increased involvement of partners in the FP decision-making process. Partners in this study were significantly less likely to receive FP information if they were not present at the patient's treatment options discussion. This finding may suggest that physicians include partners in the FP discussion if they are present, and possibly encourage partners to be involved. It also may suggest that it is important for partners to be present in the session in order to receive FP information. In one study, 80% of partners who had direct contact with the provider reported they were encouraged to

participate in decisions regarding the patient's cancer care.²² Health care providers should continue to encourage patients to bring their partner to visits and encourage partners to participate in medical treatment discussions, including the FP discussion and decision-making process. A separate FP follow-up visit for the couple may also increase FP discussions and help facilitate decision-making.

All partners in this study felt involved in the FP decision-making process. This finding is consistent with previous studies assessing partners' involvement in the treatment decision-making process.²³ The majority of partners felt they had a strong influence on the patient's decision to pursue or not to pursue FP and had a desire to influence the patient's FP decision. Laidsaar-Powell (2013) found that 55-60% of companions of cancer patients had a preference to be involved in the decision-making process regarding treatment, but 40% of companions deliberately avoided influencing the patient's final decision.²⁴ The findings of this study may differ from previous studies due to the nature of the FP decision involving both the patient, the partner, and their possible future children.

The strongest influential factor in the decision to pursue or not to pursue FP for partners was the desire for future children and safety of FP timing with initiating cancer treatment. These results are consistent with patient literature. In one study, patients seen for FP consultation reported their desire to have a child and the amount of time needed for FP were the most influential factors in their decision to pursue FP.¹⁵ In this study population, the most influential factors in the decision to pursue or not to pursue

PARTNER'S FERTILITY PRESERVATION ATTITUDES

FP are equally important to both male and female partners. However, more male than female partners listed fear of cancer reoccurring and stress of cancer diagnosis as influential factors. Males may have a greater fear of losing their partner and raising children on their own compared to females.

Limitations of this study include the predominantly Caucasian participants of high socioeconomic status. Additionally, invitations to participate in the survey were primarily sent to patients who were then asked to pass the survey on to their partner, which may have accounted for the sample size. However, this study was successful in reaching partners despite these limitations. The authors note that in the first month of data collection there was an error in the survey that excluded participants who had a diagnosis of cancer after 1998. This error was identified and corrected, and was reposted on the organization's social media websites. While results of this study may not be generalized, they highlight the importance of involving partners in FP discussions and decision-making, as well as the need for future research assessing the role of the partner in this setting. No previous studies have attempted to survey partners of cancer patients on their attitudes and perceptions towards FP.

CONCLUSIONS

While cancer is experienced by an individual and fertility preservation can be done autonomously, many young cancer patients are in partnered relationships. This study is the first to assess the attitudes and perspectives of those towards FP. Partners were

found to be actively involved in the FP discussion and decision-making process both with the patient's health care providers and with the patient. Our findings support the involvement and participation of partners in FP discussions as well as the value of counseling for both partners about FP.

ACKNOWLEDGEMENTS

The authors would like to thank the study participants for their involvement; the support organizations that shared this study with their members; Kristen Smith for her assistance and input; and Northwestern University's Graduate Program in Genetic Counseling for their support. This work was supported by the Center for Reproductive Health After Disease (P50HD076188) from the National Institutes of Health National Center for Translational Research in Reproduction and Infertility (NCTRI).

AUTHOR DISCLOSURE STATEMENT

No competing financial interests exist.

REFERENCES

1. Cancer Facts & Figures 2017. American Cancer Society. Atlanta: American Cancer Society; 2017.
2. NCCN Clinical Practice Guidelines in Oncology: Adolescent and Young Adult (AYA) Oncology. *National Comprehensive Cancer Network*. 2016.
https://www.nccn.org/professionals/physician_gls/pdf/aya.pdf. Accessed January 5, 2017.
3. Jeruss JS, Woodruff TK. Preservation of fertility in patients with cancer. *N Engl J Med*. 2009;360(9):902-11.
4. De Vos M, Smits J, Woodruff TK. Fertility preservation in women with cancer. *The Lancet*. 2014;384(9950):1302-10.
5. Hermann BP, Sukhwani M, Winkler F, et al. Spermatogonial stem cell transplantation into rhesus testes regenerates spermatogenesis producing functional sperm. *Cell Stem Cell*. 2012;11(5):715-26.
6. Practice Committee of American Society for Reproductive Medicine. Ovarian tissue cryopreservation: a committee opinion. *Fertil Steril*. 2014;101(5):1237-43.
7. Loren AW, Mangu PB, Beck LN, et al. Fertility preservations for patients with cancer: American Society of Clinical Oncology clinical practice guideline update. *J Clin Oncol*. 2013;31(19): 2500-11.
8. Gardino SL, Russell AE, Woodruff TK. Adoption after cancer: adoption agency attitudes and perspectives on the potential to parent post-cancer. *Cancer Treat Res*. 2010;156:153-170.

9. Gorman JR, Whitcomb BW, Standridge D, et al. Adoption considerations and concerns among young adult female cancer survivors. *J Cancer Surviv*, 2017;11:149-57.
10. Third-party reproduction. *American Society for Reproductive Medicine*. 2012. http://www.reproductivefacts.org/BOOKLET_Third-party_Reproduction/. Accessed February 27, 2017.
11. Hershberger PE, Sipsma H, Finnegan L, Hirshfeld-Cytron J. Reasons why young women accept or decline fertility preservation after cancer diagnosis. *J Obstet Gynecol Neonatal Nurs*. 2016;45:123-34.
12. Mersereau JE, Goodman LR, Deal AM, et al. (2013). To preserve or not to preserve: how difficult is the decision about fertility preservation? *Cancer*. 2013;119:4044-50.
13. Kim J, Deal AM, Balthazar U, et al. Fertility preservation consultation for women with cancer: are we helping patients make high-quality decisions? *Reprod Biomed Online*. 2013;27:96-103.
14. Knapp CA, Quinn GP. Healthcare provider perspectives on fertility preservation for cancer patients. *Cancer Treat Res*. 2010;156: 391-401.
15. Salsman JM, Yanez B, Smith KN, et al. Documentation of fertility preservation discussions for young adults with cancer: examining compliance with treatment guidelines. *J Natl Compr Canc Netw*. 2016;14(3):301-9.
16. Tschudin S, Bunting L, Abraham J, et al. Correlates of fertility issues in an internet survey of cancer survivors. *J Psychosom Obstet Gynaecol*. 2010;31(3):150-7.

PARTNER'S FERTILITY PRESERVATION ATTITUDES

17. Davison JB, Gleave ME, Goldenberg SL, et al. Assessing information and decision preferences of men with prostate cancer and their partners. *Cancer Nurs.* 2002;25(1):42-49.
18. Ussher JM, Cummings J, Dryden A, Perz J. Talking about fertility in the context of cancer: health care professional perspectives. *Eur J Cancer Care (Engl).* 2015;25:99-111.
19. Badr, H. The importance of actively involving partners in oncofertility discussions. *Future Oncol.* 2016;12(14):1679-82.
20. Srirangam SJ, Pearson E, Grose C, et al. Partner's influence on patient preference for treatment in early prostate cancer. *BJU Int.* 2003;92:365-9.
21. Lillie SE, Janz NK, Friese CR, et al. Racial and ethnic variation in partner perspectives about the breast cancer treatment decision-making experience. *Oncol Nurs Forum.* 2014;41(1):13-20.
22. Zeliadt SB, Penson DF, Moinpour CM, et al. Provider and partner interactions in the treatment decision-making process for newly diagnosed localized prostate cancer. *BJU Int.* 2011;108(6):851-7.
23. Yen-Chi LL, McFall SL, Byrd TL, et al. Is "active surveillance" an acceptable alternative? A qualitative study of couples' decision making about early-stage, localized prostate cancer. *Narrat Inq Bioeth.* 2016; 6(1):51-61.
24. Laidsaar-Powell RC, Butow PN, Bu S, et al. Physician-patient-companion communication and decision making: a systematic review of triadic medical consultations. *Patient Educ Couns.* 2013; 91(1):3-13.

TABLES & FIGURES

TABLE 1. PARTNER DEMOGRAPHICS		
Demographic Information		N (%) or Mean
Gender		
	Male	24 (65%)
	Female	13 (35%)
Partner Age at Time of Diagnosis		34.31
Patient Age		30.19
Race		
	Caucasian	34 (87%)
	American Indian/Alaskan Native	1 (3%)
	Asian	2 (5%)
	Other	2 (5%)
Relationship Status at Time of Cancer Diagnosis		
	In a committed relationship	9 (28%)
	Engaged	6 (19%)
	Married	15 (47%)
	Other	2 (6%)
Length of Relationship		
	> 6 months - 1 yr	2 (5%)
	>1-3 yrs	5 (13%)
	> 3-5 yrs	7 (18%)
	>5-10 yrs	9 (23%)
	>10 + yrs	16 (41%)
Children		
	Yes	15 (38%)
	No	24 (62%)
Income		
	\$0 - \$25,000	5 (13%)
	>\$25,000-\$50,000	4 (10%)
	>\$50,000 - \$75,000	9 (23%)
	>\$75,000 - \$100,000	6 (15%)
	>\$100,000 - \$250,000	14 (36%)
	>\$250,000 +	1 (3%)
Patient's Health Insurance		
	No Insurance	1 (3%)
	Private Health Insurance	33 (84%)
	Medicaid	5 (13%)
Patient's Location of Cancer Treatment		
	Community Hospital	6 (16%)
	Private Hospital	11 (29%)
	University Hospital	21 (55%)
Patient's Stage of Cancer Diagnosis		
	Stage 2	13 (34%)
	Stage 3	15 (39%)
	Stage 4	3 (8%)
	Unknown	1 (3%)
	Not yet determined/In progress	1 (3%)
	I don't know	5 (13%)

Table 1. Demographic factors of partners and patients as reported by the partner.

TABLE 2. PARTNER'S EXPERIENCE WITH
FERTILITY PRESERVATION (FP)

Partner's Involvement	N (%)
Partner Present at Treatment Options Discussion	
Yes	24 (77%)
No	7 (23%)
Patient Received FP Information	
Yes	24 (75%)
No	7 (25%)
Partner Received FP Information	
Yes	15 (65%)
No	7 (30%)
I Don't Know / I Don't Remember	1 (4%)
Patient Shared FP Information with Partner	
Yes	22 (96%)
No	1 (4%)
Did Partner Receive Enough FP Information	
Yes	12 (52%)
No	11 (48%)
Partner Interested in Learning More About FP	
Yes	21 (66%)
No	9 (28%)
Unsure	2 (6%)
Patient Pursued FP	
Yes	18 (56%)
No	13 (41%)
I Don't Know / I Don't Remember	1 (3%)

Table 2. Partner and patient's experience with FP as reported by the partner.

TABLE 3. PARTNER'S PERCEIVED
INFLUENCE ON PATIENT'S FP DECISION

Partner's Influence	N (%)
Did Partner Discuss FP Before Making Decision	
Yes	19 (83%)
No	4 (17%)
How Involved Partner Felt in Decision-Making Process	
No Involvement	0 (0%)
Minimal Involvement	0 (0%)
Some Involvement	4 (24%)
Strong Involvement	13 (76%)
How Much Influence Partner Had on Patient in Decision-Making Process	
No Influence	0 (0%)
Minimal Influence	1 (6%)
Some Influence	3 (19%)
Strong Influence	12 (75%)
How Much Desire to Influence Patient's Decision	
No Desire	0 (0%)
Minimal Desire	4 (21%)
Some Desire	5 (26%)
Strong Desire	10 (53%)

Table 3. Partner's responses to the level of influence and involvement they felt they had in the FP decision-making process.

PARTNER'S FERTILITY PRESERVATION ATTITUDES

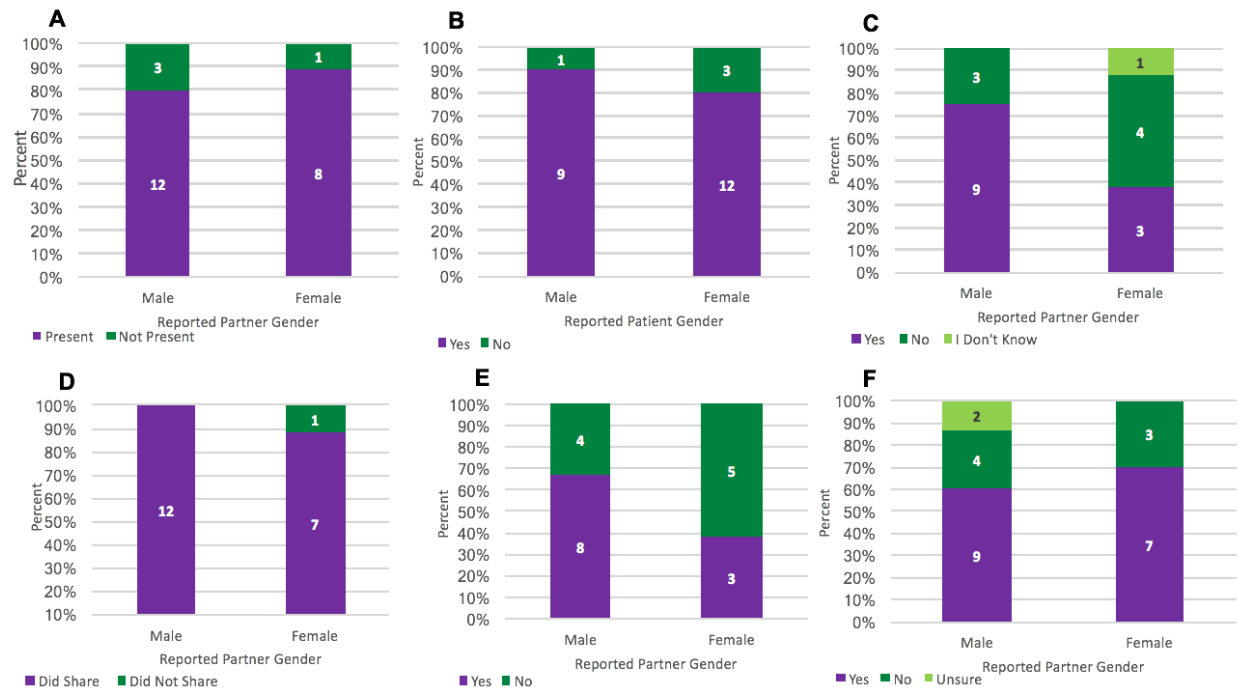


Figure 1. Partner's experience with FP and the decision-making process by reported gender. (A) Present at treatment options discussion. (B) Patient received FP information. (C) Partner received FP information. (D) Patient shared FP information with their partner. (E) If partner felt they received enough FP information. (F) If partner was interested to learn more about FP.

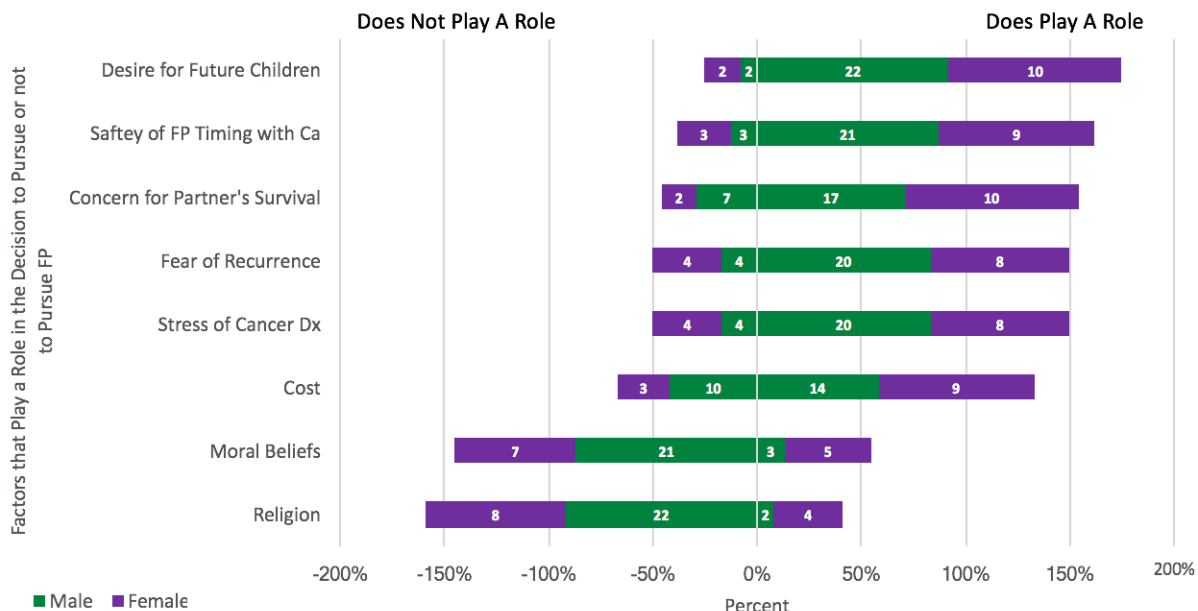


Figure 2. Factors that play a role in the partner’s decision to pursue or not to pursue FP distributed by reported partner gender.
 Legends: Ca = cancer, Dx = diagnosis, FP = fertility preservation

APPENDIX

Survey

What is Fertility Preservation?

Fertility Preservation is the process of protecting fertility (or ability to have biological children). Certain diseases or disease treatments may lead to infertility. There are different medical procedures that preserve fertility, such as sperm banking, embryo banking, egg banking, and ovarian tissue banking.

Sperm Banking is the collection and freezing of sperm for future use.

Embryo Banking is the collection of eggs that are then fertilized in a lab with sperm and frozen for future use. The process of embryo banking involves about two weeks of hormone medications and an outpatient egg retrieval.

Egg Banking is the collection of eggs that are frozen for future use. The process of egg banking involves about two weeks of hormone medication and an outpatient egg retrieval. This option was experimental until 2012.

Ovarian Tissue Banking is the collection of ovarian tissue that is frozen for future use. This experimental process involves a surgery where an entire ovary or portion of an ovary is removed and then processed in a lab and frozen. The freezing of ovarian tissue and the use of this tissue in the future is still experimental.

Partner is a significant other, spouse, girlfriend, or boyfriend.

Please answer the following when thinking about your partner's first cancer diagnosis:

Did your partner have chemotherapy and/or radiation as part of their treatment or will your partner have chemotherapy and/or radiation?

- Yes
- No

Were you in a relationship with your partner when they received their diagnosis of cancer?

- Yes
- No

Section 1

1. At what age was your partner first told about their cancer diagnosis?
2. What year was your partner first diagnosed with cancer?
3. Were you present at the time the healthcare provider discussed treatment options with your partner?
 - Yes
 - No

4. What was your relationship status with your partner at the time of their cancer diagnosis?
 - In a casual dating relationship
 - In a committed dating relationship
 - Engaged
 - Married
 - Widowed
 - Separated
 - Divorced
 - Other (Fill in the blank)
5. What is your current relationship status with your partner?
 - No longer together
 - In a casual dating relationship
 - In a committed dating relationship
 - Engaged
 - Married
 - Widowed
 - Separated
 - Divorced
 - Other (Fill in the blank)
6. Did your partner receive information about fertility preservation from a health care provider?
 - Yes
 - No
 - I don't know / I don't remember
7. Did you receive information about your partner's fertility preservation options from their health care provider?
 - Yes
 - No
 - I don't know / I don't remember
8. Did your partner share the information they received about fertility preservation from their health care provider with you?
 - Yes
 - No
 - I don't remember
9. Do you feel that you received enough information about fertility preservation?
 - Yes
 - No
 - I don't know / I don't remember
10. Would you have been interested to learn more about your partner's fertility options?
 - Yes
 - No
 - Unsure
11. Did your partner choose to pursue fertility preservation?
 - Yes
 - No
 - I don't know/I don't remember
12. In general, do you think fertility preservation is an acceptable family building option for individuals with a cancer diagnosis?
 - Yes

PARTNER'S FERTILITY PRESERVATION ATTITUDES

- No
- Why not?

13. Do you think that adoption is an acceptable family building option for individuals with a cancer diagnosis?

- Yes
- No
- Why not?

14. Do you think that using an egg donor (getting eggs from someone you know or someone you don't know to attempt to initiate a pregnancy) is an acceptable family building option for individuals with a cancer diagnosis or with a cancer history?

- Yes
- No
- Why not?

15. Do you think that using a sperm donor (getting sperm from someone you know or someone you don't know to attempt to initiate a pregnancy) is an acceptable family building option for individuals with a cancer diagnosis or with a cancer history?

- Yes
- No
- Why not?

Section 2

16. Did your partner discuss the option of fertility preservation with you before making a decision?

- Yes
- No

17. How involved did you feel during the decision-making process regarding fertility preservation?

- | | | | |
|-------------------------|-------------------------|-------------------------|-------------------------|
| No
Involvement | Minimal
Involvement | Some
Involvement | Strong
Involvement |
| <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 |

18. In **your** opinion, how much influence do you feel that you had on your partner's decision to pursue or not to pursue fertility preservation?

- | | | | |
|-------------------------|-------------------------|-------------------------|-------------------------|
| No
Influence | Minimal
Influence | Some
Influence | Strong
Influence |
| <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 |

19. How much desire did you have/would you have had to influence your partner's decision to pursue or not to pursue fertility preservation?

- | | | | |
|-------------------------|-------------------------|-------------------------|-------------------------|
| No Desire | Minimal
Desire | Some Desire | Strong Desire |
| <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 |

Section 3

20. On a scale from 1 to 4, with 1 being strongly does not play a role and 4 being strongly plays a role, which of these factors would/will/did play a role for you in deciding to pursue or not pursue fertility preservation?

	Strongly Does Not Play a Role	Somewhat Does Not Play a Role	Somewhat Plays a Role	Strongly Plays a Role
Concern for Partner's Survival	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Stress of Cancer Diagnosis	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Safety of Fertility Preservation Timing with Cancer	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Fear of Partner's Cancer Reoccurring	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Desire for Future Children	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Religion	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Moral Beliefs	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Cost	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4

21. Are there any other factors that influenced/would influence your decision to pursue or not to pursue fertility preservation?

22. General Comments:

Demographic Information

1. What is your age?
2. What is your race?
 - Caucasian
 - American Indian or Alaskan Native
 - African American
 - Asian
 - Native Hawaiian or Other Pacific Islander
 - Other
3. What gender do you identify with?
4. What gender does your partner identify with?
5. How long have you been/were you in a relationship with your partner?
 - 0-6 months

PARTNER'S FERTILITY PRESERVATION ATTITUDES

- >6 months – 1 year
 - >1 -3 years
 - >3-5 years
 - >5 -10 years
 - >10 years
6. Do you have children?
- Yes
 - No
7. Do you want more children? (Select All)
- I want more biological children
 - I want to adopt more children
 - I want to use a donor to have more children
 - I have completed family planning/building
8. Do you want biological children?
- Yes
 - No
 - Undecided
 - I have completed family planning/building
9. What is your partner's health insurance status?
- My partner does not have health insurance
 - My partner is on private health insurance
 - My partner is on Medicaid or Medicaid managed care
10. What is your household income?
- \$0-\$25,000
 - >\$25,000-\$50,000
 - >\$50,000-\$75,000
 - >\$75,000- \$100,000
 - >\$100,000 - \$250,000
 - >\$250,000 +
11. What type of location do you live in?
- Urban
 - Rural
 - Suburban
12. Where did your partner receive their cancer treatment, or where are they currently receiving their cancer treatment?
- Community Hospital
 - Private Hospital
 - University Hospital
13. What type of cancer did/does your partner have?
14. What stage of cancer was your partner diagnosed with?
- Abnormal cells are present but have not spread to nearby tissue
 - Cancer is limited to the place where it started, with no sign that it has spread
 - Cancer has spread to nearby lymph nodes, tissues, or organs
 - Cancer has spread to distant parts of the body (common sites cancer may spread are lung, liver, brain, bone, etc.)
 - Unknown- there is not enough information to determine
 - Not yet determined /In progress
 - I don't know/I don't remember