Attitudes and perceptions towards fertility preservation among cancer survivor partners

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ABSTRACT

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

Methods: Partners (n = 50) of cancer survivors and fighters were recruited to take an online survey through nine cancer support organizations. Cancer survivors and fighters were invited to share the link with their partner. Survey question themes included attitudes towards FP, partner perceptions of the level of influence they have on the patient's decision to pursue FP, and partner perspectives of the different factors that play a role in their decision to engage in FP.

***Results*:** Almost all (98%) of partners thought FP 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 information about the patient's FP options. Half of partners (52%) felt they received enough FP information and the majority of partners (66%) were interested in learning more about FP. Eighty-three percent of partners said that the patient discussed the option of FP with them before making a decision. When asked what factors would play a role in the decision to pursue or not to pursue FP, partners said that desire for future children (86%) and safety of FP timing with cancer (81%) were the most influential factors.

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

BACKGROUND

Approximately 1.69 million new cancer diagnoses are expected to occur in the United States in the year 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 of the side effects of chemotherapy, radiation, or surgery includes compromised fertility.[3,4] For example, following cancer treatments, men may develop impaired sperm production, and women may experience premature ovarian failure.[5] In 2013, the American Society of Clinical Oncology (ASCO) updated their guidelines to recommend that health care providers should discuss fertility preservation (FP) with all cancer patients of reproductive age and refer to reproductive specialists if the patient expresses interest.[6]

FP options are continually developing and improving. For males, the ideal method is sperm banking. Experimental methods include testicular tissue freezing and testicular shielding.[7] For females, the most successful current options include embryo and oocyte freezing. Ovarian tissue cryopreservation is considered experimental. Additional alterative options include ovarian transposition and ovarian suppression.[8,9] A discussion of FP between a patient and their physician also is recommended to include the availability of alternative family-building options, which includes the use of donor sperm, donor eggs, donor embryos, surrogacy, or adoption.[10-12] The expansion of available options for cancer patients has allowed patients the choice to preserve their fertility in unique situations where the possibility may not have existed in the past.

While the field of oncofertility is growing, further research and development 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.[13] In contrast, financial reasons, lack of information, and fear of surviving the cancer often prevents patients from pursuing FP.[13-15] Although the ASCO guidelines recommend oncologists to inform all patients about the chance of infertility due to their cancer or its 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 oncologist's lack of knowledge, patient attributes such as cultural or religious, and lack of time due to stage of cancer.[16,17]

To further complicate the process, the health care provider and patient are not the sole persons involved in a FP discussion. Patient partners may also play an important role in the decision-making process. Tschudin *et al.* (2010) established that approximately 80% of young female cancer patients have partners.[18] Additional literature shows that partners often attend medical visits and provide support and comfort to patients.[19] Health care providers report that fertility is an important concern to partners, in addition to patients.[20] 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 the ethical complexity of FP.[21] 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.

METHODS

Sample

The study was approved by the Institutional Review Board (IRB) at 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 weblink to an online survey were posted on the organizations' social media websites. Participants were recruited between September 2016 and January 2017. A reminder post was sent out approximately one month after the initial post. Cancer survivors and fighters were invited to share the link with their partner. Those who were invited to participate in the study needed to meet the following criteria:

1) Their partner was diagnosed with cancer between the ages of 18-50
2) Their partner had or will have chemotherapy and/or radiation as part of their treatment
3) They can read English

As an incentive for participation, all participants were given the opportunity to enter a raffle with the chance to receive one of ten $25 visa gift cards.

Instrumentation

The survey instrument was developed based on published literature and clinical experience (Appendix).[22] Survey questions had overarching themes of assessing partner attitudes regarding FP, assessing partner perceptions of the level of influence they have on the patients' decisions to pursue FP, and exploration of partner perspectives of the different factors that play a role in their decision to engage in FP. Demographic questions including relationship type and status, desire for biological children, partner cancer information, age, income, religion, race, gender, health insurance status, and residence location. The survey consisted of 22 questions and 14 demographic questions.

Data Analysis

Following survey closure, the data from the survey was compiled, coded, and analyzed using SPSS software. Responses were not required for each question in the survey to be included in the analysis. Descriptive statistics, including frequencies, means, medians, and percentage of respondents, were calculated for each individual survey 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 if there were any significant associations between responses. P-value equal or less than .05 was considered significant.

RESULTS

The final study sample consisted of 39 partners who completed the survey, and 11 partners who partially completed the survey. The majority of partners were male (65%), Caucasian (87%), had been in a relationship over 5 years (64%), and made greater than $100,000 in household annual income (Table 1). Partners stated that fifteen (65%) female patients were treated at a university hospital, and 8 (67%) male patients were treated at a community or private hospital (Figure 1). Of partners with a household income of $75,000 - $250,000 or more, 21 (100%) patients were on private or no insurance. Of partners with a household income of $0 - $75,000, 13 (72%) patients were on private or no insurance and 5 (28%) were on Medicaid.

Forty-one (82%) of 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 the diagnosis of cancer. The mean age of partners was 34 years old, with an age range of 23-53 years. The range of the patient's age at the time of diagnosis was 21-48 years. The majority of partners 24 (62%) reported they did not have children, although 19 of these 24 (79%) individuals reported they want biological children. An even higher percentage of partners age 35 years and younger reported they want biological children (84%) (Figure 2). Of partners who had children, 5 (36%)

Catherine A Wicklund 3/4/2017 10:57 AM
Comment [1]: Fifty partners completed part or all of the survey?

Catherine A Wicklund 3/4/2017 10:58 AM
Comment [2]: Not sure I like this reference to them as the patient. Hmmmm.. these are participants and they are making comments about their partners who have cancer. But not sure there is any other way to do this…

wanted more biological children, 1 (7%) wanted to adopt more children, and 8 (57%) had completed family planning.

Partner Attitudes Towards Family Building Options

Partners were surveyed on their attitudes towards alternative family building options, including FP, adoption, use of egg donors, and use of sperm donors. Almost all partners reported that FP (98%) and adoption (92%) are acceptable family building options. While the majority of partners (84%) reported that the use of an egg donor is an acceptable family building option, it was noted that a greater portion of male partners found egg donation acceptable than female partners (88% vs 77%). Similarly, while the majority of partners (82%) reported that the use of a sperm donor is an acceptable family building option, a greater portion of male partners found sperm donation acceptable than female partners (88% vs 69%).

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 the information received regarding FP was adequate. In this study, 75% of participants reported they had received information about FP (Table 2). It was noted that slightly more male partners than female partners indicated the patient had received FP information (90% vs 80%) (Figure 3B). Additionally, the majority of male partners (75%) received information about the patient's FP options, while only 3

female partners (38%) reported they received information about the patient's FP options. More partners indicated they received FP information if the patient was diagnosed after 2012 vs. when the patient was diagnosed prior to 2012 (67% vs 43). Additionally, more patients felt they received adequate information regarding FP after 2012 compared to those prior to 2012 (56% vs 43%). There was no statistically significant difference identified regarding the receipt of FP information among individuals with respect to annual income or type of health insurance.

Several factors were identified, of which, partners were more likely to have received FP information. These factors included presence at the patient's treatment options discussion with their health care provider and relationship status at the time of the cancer diagnosis. Partners who were not present at the time the patient discussed treatment options with their health care provider 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 (Figure 4). Among married couples, 13 (93%) partners were present at the time the patient's health care provider discussed treatment options, and 10 (91%) partners said that the patient discussed the FP decision with them. Among all partners, 19 (83%) partners said the patient discussed the option of FP with them before making a decision.

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Comment [3]: What comparison is this p value referring to?

Among study participants, 56% of partners pursued FP. Of the 9 partners who were in a committed relationship, 3 (33%) partners said the patient chose to pursue FP. Of the 6

partners who were engaged, 5 (83%) partners said the patient chose to pursue FP. Of the 15 partners who were married, 9 (60%) partners said the patient chose to pursue FP.

All partners reported that they felt involved in the decision-making process to pursue or not to pursue FP, 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 a minimal desire to influence the patient's decision to pursue FP, 5 (26%) had some desire, and 10 (53%) had a strong desire to influence the patient's decision to pursue FP (Table 3).

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Comment [4]: 13 out of how many?

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 to influence FP decision-making) with regards to their decision to pursue or not pursue FP. The majority of partners responded that desire for future children (86%) and safety of FP timing with starting cancer treatment (81%) plays a large role in the decision to pursue or not to pursue FP, and that religion (81%) and moral beliefs (81%) largely does not play a role. Other influential factors that play a role include fear of partner's cancer recurring (76%), concern for partner's survival (74%), and stress of cancer diagnosis (70%). Additionally, 62% of partners indicated that cost was a factor in the decision to pursue FP, although more so for female than male partners (75% vs. 58%, respectively) (Figure 5). Of partners who reported that the patient chose to pursue

FP, the desire for future children (89%) was the most influential factor in the decision. For those who did not pursue FP, safety of FP timing with cancer (89%) and concern for partner's survival (89%) were the most influential factors in the decision. No statistical significance was identified among partner's responses with regards 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 reported they felt strong influence in the decision of whether or not to pursue FP and the majority had 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 studies 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.[22] In another study, 77% of partners said they received sufficient information about treatment for the patient.[23] It is well accepted that partners are involved in the cancer treatment decisions, and this study supports their additional involvement in FP discussions and decision-making.

An overall positive attitude towards FP as a family building option was expected in this study given the literature supports FP favorability among cancer survivors. For example, Ehrbar et al (2016) found that cancer patients had an overall positive attitude towards FP, and that all cancer patients should be given the opportunity to pursue FP.[24] Additionally, individuals with interest in or experience with FP may have been more inclined to participate, thus results may be biased towards FP favorability. Interestingly, this study also identified an overall positive attitude towards adoption among participants. Existing literature suggests adoption may be a more favorable family building option among cancer survivors in general. A recent study compared adoption considerations between young female cancer survivors and women of the same age in the general population, and found that 81.6% of female cancer survivors said they would consider adoption compared to 40.3% of women in the general population.[11] This study also identified a greater percentage of those who thought the use of egg and sperm donor were acceptable compared to previous studies done on the general population and infertile couples.[25,26] This may suggest that partners attitudes towards family building options are influenced by the cancer diagnosis and/or the possibility (rather than diagnosis) of subsequent infertility.

Almost all partners reported that the patient shared FP information with them. This finding may suggest that patients want to include and involve the partner in the FP decision-making process. In addition, 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. Badr (2016) discusses that involving partners in the FP process has the potential to change the dynamics and complexity of the FP discussions between patient and healthcare provider.[21] 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.

Previous studies report that FP information is being provided to most cancer patients by their health care provider.[27] Likewise, in this study, the majority of partners reported that the patient received FP information from their health care provider. This study did not see an effect on receipt of FP information based on a patient's income or type of health insurance. This may suggest continual improvement in patient access to FP information and health care providers following FP guidelines; however, receiving FP information and/or consultation is not the same as pursuing FP. This could suggest an increased referral rate to FP consults, but not necessarily the support to actually pursue FP. Additional research is needed to determine if increased FP information and consultation has led to an uptake of FP procedures, and what, if any, barriers remain.

Interestingly, more patients took steps in this study to preserve their fertility compared to previous studies.[15,28] This may be due to participation bias, as individuals aware of FP may have been more likely to participate. In addition, the study population may have had more experience with FP given that the average age of cancer diagnosis was 30 years and most participants reported they did not have children and strongly desired biological children.

Previous patient literature states that female patients are more likely to receive information about FP than men.[17] This study, which had an equal number of male and female participants, found that the majority of both male and female patients received FP information. This finding may suggest that discussion of FP rates for male patients are improving. However, 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 male partners are included in the FP discussions with female patients more 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.

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Comment [5]: This says that more men received info than women, but the next sentence says that this is consistent with females getting more info.

Overall, patients shared FP information with both female and male partners. While we do not know what their discussions entailed, this study's findings suggest that communication is occurring regardless of reported sex. This study also saw that the majority of 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 for the patient.

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 novel 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.[29] Health care providers should continue to encourage partners to participate in medical treatment discussions, including the FP discussion and decision-making process.

While relationship status doesn't necessarily indicate the level of commitment, partners in more committed relationships were more often present at treatment options discussions and more often involved in the FP discussion. Specifically, married couples were more likely to be present and participate in the FP decision compared to other relationship statuses. This finding could suggest that a partner may be more or less

involved in the cancer and FP decision-making process depending on their relationship status.

When distributed by relationship status at the time of cancer diagnosis, this study found the largest percentage of patients who chose to pursue FP were engaged. This may be because engaged couples often haven't started a family compared to married couples, and couples in a committed relationship might not be at a point in their relationship to discuss future children. In addition, the only relationship status of which partners stated that they did not know if the patient chose to pursue FP were those in a committed relationship, further indicating that these partners may not have been as involved in the FP discussion and decision-making process.

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.[30] 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.[31] 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, the least influential factors were religion and moral beliefs. Ehrbar (2016) found that those who were against FP had ethical and religious reservations.[24] In our study sample, almost all partners thought FP was an acceptable family building option. This suggests that our study might be biased towards those who would not have ethical or religious reservations towards FP.

Of partners that said the patient pursued FP, the most influential factors that played a role in the decision to pursue FP were desire for future children and safety of FP timing with starting cancer treatment. Of partners that said the patient did not pursue FP, safety of FP timing with cancer and concern for partner's survival were the most influential factors. These findings are consistent with previous studies assessing factors influencing patients to pursue or not to pursue FP.[13,15]

In this study population, the most influential factors in the decision to pursue or not to pursue FP are equally important to both male and female partners. However, more male partners listed fear of cancer reoccurring and stress of cancer diagnosis as influential factors than females. Males may have a greater fear of losing their partner and raising children on their own compared to females. We also saw that more female partners

listed cost as an influential factor compared to male partners. Bann *et al* (2015) found that among men and women who did not pursue FP, male patients listed cost as the biggest reason and female patients listed not enough time.[28] While consistent with this study, this finding was unexpected in our study, as male FP is more affordable and a more simple process compared to female FP. However, there are additional downstream costs associated with male FP, such as intrauterine insemination or *in vitro* fertilization (IVF), which might explain this finding.

There were no differences in the way partners ranked factors known to influence FP decisions when distributed by cancer stage, treatment location, and income. Disease status is significant in the literature, and often influences a health care provider when discussing FP options.[32] Our study may suggest improvement in access to FP discussions and consultation regardless of cancer stage, in addition to income and treatment location.

LIMITATIONS AND FUTURE DIRECTIONS

While results of this pilot study may not be generalized, they do 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. Limitations of this study included the predominant Caucasian participants of a high socioeconomic group. 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. No previous studies have attempted to survey partners of cancer patients on their attitudes and perceptions towards FP. No divorced couples participated in this study, which may be due to lack of communication between a cancer survivor and their former spouse. This may have biased our sample towards those who are currently still in a relationship or on good terms with their partner. In addition, 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.

As this was a pilot study, there are many avenues of future research to identify the needs of both patients and partners in accessing FP information and services. Next steps may involve a qualitative study interviewing couples regarding their discussions about FP, access to FP, and interactions with the patient's health care provider. Studying health care providers' experience working with partners would also give us insight into health care providers' barriers to including partners in the discussions. Also, access to FP for patients and partners by hospital type, as well as what type of information is being given to a partner by the health care provider would further guide the oncofertility communication process. This study's findings, along with future research, could be integrated into an FP educational tool for health care providers to use when discussing FP with patients and their partners.

CONCLUSIONS

This study is the first to assess partner attitudes and perspectives towards FP and the perceived influence a partner has on the patient during the FP decision-making process. 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 the FP discussions as well as the need for future research assessing the role of the partner in FP decision-making.

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AUTHOR DISCLOSURE STATEMENT

No competing financial interests exist.

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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.

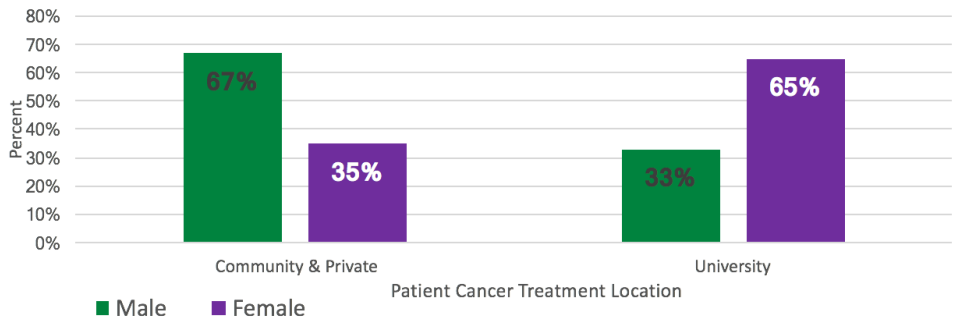

Figure 1. Partner reported treatment location of patients distributed by patient gender.

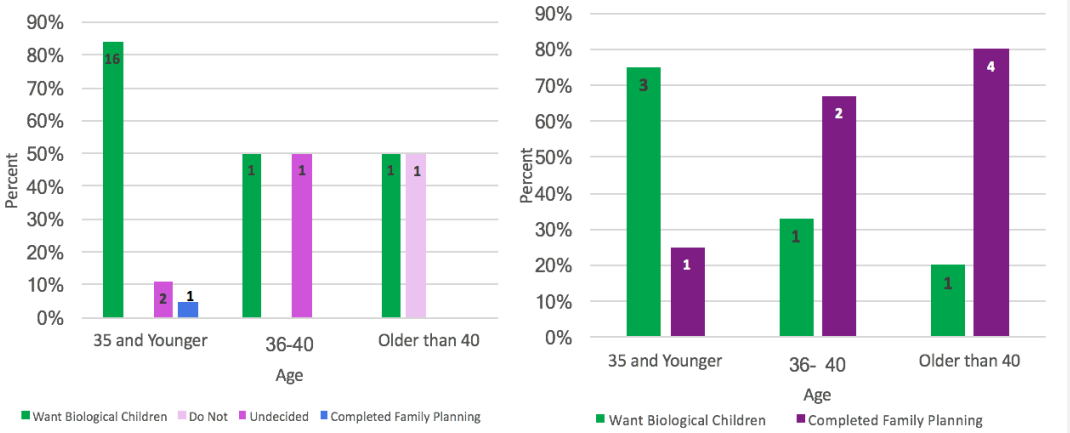

Figure 2. Partner distribution of family building by age (A) Partners who do not have children distributed by age and desire to have biological children. (B) Partners who already have children distributed by age and desire for more biological children.

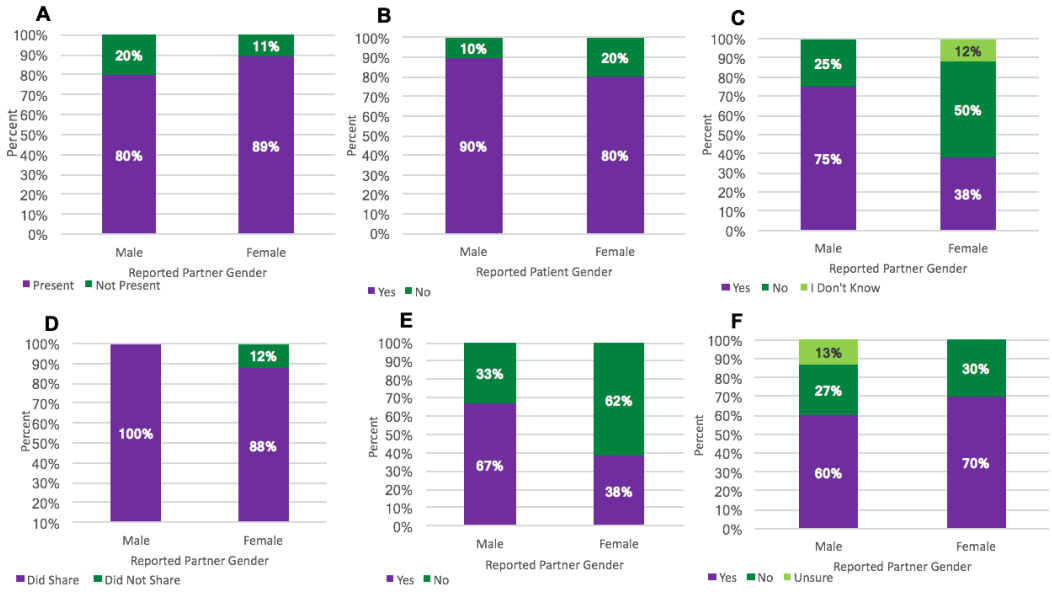

Figure 3. Partner's experience with FP and the decision-making process by reported gender. (A) Present at treatment options discussion. (B) Patient received FP information. (C) Partner received FP information. (D) Patient shared FP information with their partner. (E) If partner felt they received enough FP information. (F) If partner was interested to learn more about FP.

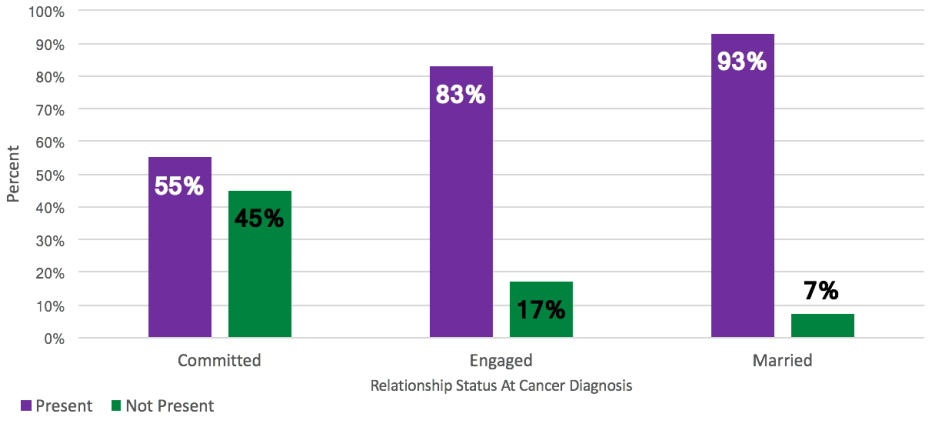

Figure 4. Partner's presence at the patient's treatment options discussion with their health care provider distributed by relationship status at the time of the cancer diagnosis.

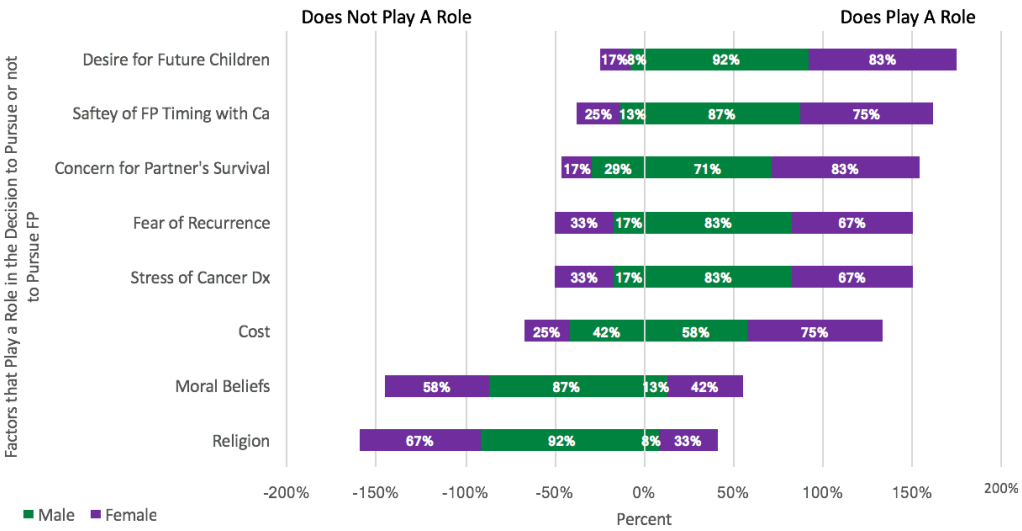

Figure 5. Factors that play a role in the partner's decision to pursue or not to pursue FP distributed by reported partner gender.
Legends: Ca = cancer, Dx = diagnosis, FP = fertility preservation

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 <u>your partner</u> receive information about fertility preservation from a health care provider?
    - Yes
    - No
    - I don't know / I don't remember

7. Did <u>you</u> 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

- 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
1	2	3	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
1	2	3	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
1	2	3	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	O1	O2	O3	O4
Stress of Cancer Diagnosis	O1	O2	O3	O4
Safety of Fertility Preservation Timing with Cancer	O1	O2	O3	O4
Fear of Partner's Cancer Reoccurring	O1	O2	O3	O4
Desire for Future Children	O1	O2	O3	O4
Religion	O1	O2	O3	O4
Moral Beliefs	O1	O2	O3	O4
Cost	O1	O2	O3	O4

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?
   - O Caucasian
   - O American Indian or Alaskan Native
   - O African American
   - O Asian
   - O Native Hawaiian or Other Pacific Islander
   - O 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?
   - O 0-6 months

- >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