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Patients' Perception of Patient–Provider Communication in Fertility Preservation Decision Making Among Young Women With Cancer: A Qualitative Study

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Abstract

Fertility preservation (FP) for patients with cancer is an emerging field. With the advancement of technology, patients may face a complex decision-making process about whether to preserve fertility. The purpose of this article is to explore how young women with cancer perceive patient–provider communication in FP decision making. In this study, 25 women between the ages of 18 and 39 were interviewed retrospectively. They were interviewed one time to learn about their decision-making process related to FP. Results of this analysis indicate that patients seek support and involvement from providers throughout the process of decision making. They prefer providers to be directive when referring to the fertility clinic. Later in the process, they expect a supportive style of communication from providers. Patient-accessible language, supportive and reassuring styles of communication, and an existing relationship with providers may enhance well-being of the patients.

Keywords

fertility preservation, patient–provider communication, fertility decision making

Introduction

In 2010, an estimated one and a half million new cancer cases were diagnosed (American Cancer Society, 2010). Among those newly diagnosed, approximately 10% were younger than 45 years (Jensen, Morbeck, & Coddington, 2011). Thus, there are large numbers of cancer patients who are of or approaching childbearing age. Every year in Canada and the United States, about 26,000 adolescents and young adults (AYA) between ages 15 and 29 years are diagnosed with cancer (Tonorezos & Oeffinger, 2011). Although the majority of AYA cancer patients will survive their primary cancer, many will develop other serious health problems (Tonorezos & Oeffinger, 2011). Young adults with cancer in one study indicated infertility problems to be a significant health issue leading to poor psychosocial outcomes (Schwartz et al., 2010).

Fertility preservation (FP) is one of the answers to this problem apart from adopting or opting to remain childless (Schover, Rybicki, Martin, & Bringelsen, (1999). FP includes methods and efforts to maintain the ability of a person to reproduce even after natural or other illness-related fertility loss (Coyne, Kader, & Agarwal, 2010). Modern technological advancements have made FP a feasible option for cancer patients to have biological children in the future. To advance FP technology as a viable option for young cancer patients, the American Society of Clinical Oncology in June 2006 published guidelines for oncologists to address FP while providing treatment and counseling for cancer patients (Lee et al., 2006). These guidelines recommend discussing infertility as a side effect of cancer treatment and providing FP as an option. Providers are advised to apply their clinical judgment and discuss the possibility of fertility damage or loss at the earliest possible opportunity (Lee et al., 2006).

Studies indicate that communication between patients and health care professionals has a profound effect on patients' outcomes and behavior (Stewart, 1995). Effective communication reduces patients' suffering and anxiety during treatment (Fellowes, Wilkinson, & Moore, 2004). Patients seek a trusting relationship balancing the provider's role as an expert and as a partner in decision making (Epstein, 2006). Patient–provider communication is crucial in providing FP services to patients.

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Patient–Provider Communication

There are a number of challenges in discussing FP with young cancer patients. Barriers identified in FP are (a) physician factors that contribute to communication issues with FP discussion (e.g., awareness and sense of comfort in discussing issues, perceptions of the treatment-related priority), (b) parental factors (e.g., receptiveness and cultural background of the patients' parents), (c) patient factors (e.g., receptiveness and age), and (d) institutional factors like referral sites and practice guidelines (Vadaparampil, Quinn, King, Wilson, & Nieder, 2008). Oncologists and other cancer care professionals face challenges in discussing FP and helping patients in FP decision making. Cancer remains a highly delicate subject, and discussing it with young adults may incorporate added challenges like lack of awareness about specific psychosocial complications of this age group (Quinn, Vadaparampil, Bell-Ellison, Gwede, & Albrecht, 2008). Discussing fertility options with patients is difficult for health care professionals unless they work in reproductive health (Schover, Rybicki, Martin, & Bringelsen, 1999). Oncologists and other physicians may focus on treating malignancy and survivorship rather than discussing FP (Patrizio, Butts, & Caplan, 2005). Physicians may also have serious concerns about potential delays in cancer treatment necessary for FP procedures (Vadaparampil, Quinn, King, Wilson, & Nieder, 2008).

Most of the past research on FP communication is from the provider's perspective (Vadaparampil, Quinn, Lancaster, et al., 2008). Previous studies have highlighted the importance of patient–provider communication in patients with cancer; however, young patient's informational needs are still not adequately met (Quinn & Vadaparampil, 2009; Zebrack, 2008). In this qualitative study, we further explore the communication needs of the patients at various stages of treatment.

The purpose of this study is to gain an understanding of the communication process that occurs between young adult women with cancer and health care professionals (including nurses, oncologists, social workers, and other clinic staff) during the time women are making decisions about FP. In particular, this analysis documents patients' viewpoints on three sets of interactions with health care professionals, and identifies factors that lead to positive or negative experiences among patients. These interactions are (a) first discussion of fertility compromise and fertility issues, (b) first appointment at the fertility clinic, and (c) subsequent discussion about fertility with health care professionals.

Method

Study Design

As part of a larger research study (Block, Frohnmayer, Jivanjee, & Brandon Hayes-Lattin, 2012) designed to gain understanding of the FP decision-making processes of young adults, a focused qualitative analysis was completed to explore and describe women's experiences of interactions with health care professionals. This study represents a secondary analysis of the data collected for the primary study. While the data collection for the larger study is described below, the data analysis process and the results presented here are specific to FP communication. Secondary data analysis of existing data was approved by the medical institute IRB in which data were collected. Approval also ensured that the objectives of the secondary analysis corresponded with the objectives of the original study for which participant consents were obtained.

Sample and Setting

Participants. Qualitative interviews were conducted with 25 participants recruited at the oncology center of a large teaching hospital. Although eligibility criteria for study participants included being a woman between ages 15 and 39 at the time of interview and aware of potential fertility compromise due to cancer treatment, the actual sample had patients in 18 to 38 age range. These interviews were done retrospectively with the patients. Data are generated from only one interview with the patients. Patients were paid US$30 and the interviews were 60-min long. Twenty-three participants were Caucasian, 1 was Hispanic, and 1 was African American. Diagnoses included the following: leukemia, Hodgkin's lymphoma, breast cancer, sarcoma, colorectal cancer, adrenal cortical carcinoma, cholangiocarcinoma, and multiple myeloma. Five participants (19%) had children prior to their initial cancer diagnosis and 1 had a baby between first treatment and relapse. Eighteen (69%) participants opted for a consultation appointment with reproductive endocrinologist and 10 (39%) of those women pursued or planned to pursue FP. Eight women opted out of the consultation.

Setting. The research setting was an academic medical institution in the northwest of the United States. This institution has an adolescent and young adult oncology program designed to provide consultation services and research opportunities for patients with cancer between 15 and 39 years old. This program has done extensive outreach and education within the hospital and clinics.

A typical clinical flow of FP treatment includes multiple interactions with health care professionals that can be grouped into three sets. The first set is when a patient learns about her fertility compromise and available options to protect her fertility. This communication may be with an oncologist, nurse, or any provider who first discussed fertility compromise with the patient. The second set is when a patient has a scheduled consultation with a fertility specialist. This set includes communication with fertility specialists, who may be nurses and doctors at the fertility clinic. The third set of interaction is after the first appointment at the fertility clinic when the patient may consult with various

health care professionals while engaged in the decision-making process. This includes communication with the primary health care providers, nurses, gynecologists, or other providers with whom patients initiated conversations for advice on fertility. Considering the clinical flow of FP treatment, this article examines patient–provider communication grouped into these three sets of interaction.

Data Collection

In-person interviews with participants were done in a private setting. Interviews included questions on the patients' experiences of first finding out about the potential compromise to their fertility and the subsequent consultation experiences with their oncologists and fertility specialists. Examples of the questions include,

> Tell me the story of your diagnosis and finding out that your cancer treatment might affect your ability to have children. How did you find out about fertility consultation services for people with cancer? What was helpful about the consultation? What was not helpful?

Interviews were conducted after at least the first set of communication when patients were informed about fertility compromise. Some patients opted to move on to the first fertility consultation and discussed the second and third sets of FP communication during the interview.

The interview schedule contained questions beyond the scope of this project and only data related to patient–provider communication were included in this analysis. All the interviews were recorded, transcribed, and uploaded in the NVIVO software package to support qualitative data analysis.

Data Analysis

Straus and Corbin's (1990) open-coding method of data analysis was used to identify themes. Because the researcher was involved in thematic analysis of data for the larger study, she had already reviewed the data prior to this analysis. New codes were created in NVIVO relevant to this analysis and sections of the interviews beyond the scope of this project were disregarded. After reviewing and open-coding eight interviews, the researcher developed a codebook to identify basic themes and their relationships to one another. This codebook was not a set of rigid codes but a fluid document responsive to new codes and relationships that emerged during later coding of the interviews. Once all codes were identified, all of the interviews were revisited and recoded. The inductive method of data analysis was used. Themes and subthemes emerged from the data through reading and re-reading multiple times. While analyzing the themes, the number of cases represented within each theme was noted. Wherever possible, participants' own words were used to label styles to stay close to the original transcripts or they were labeled based on a communication literature review and peer debriefing with other members of the research team.

Data analysis was guided by the specific objective of identifying any text related to major aspects of provider–patient communication and what meaning patients assigned to the communication. The communication style was named according to what best described the style, and at times was labeled using the words of patients. Patient's state of mind was examined as it is believed to affect her satisfaction with the providers' communication style (Ben-Sira, 1980). Any communication relevant to the patient describing her mental state was categorized as state of mind.

Results

Based on the clinical flow of FP treatment, responses were classified into three sets of communication with the provider.

1. First was the discussion of cancer treatment's effects on fertility and FP. In this set of communications, patients reported their experience of finding out about the possibility of fertility compromise due to cancer treatment. Communication centered on the risks associated with cancer treatments and also the various fertility options available to the patient. Major themes that evolved during this stage were the *patient's state of mind, providers' characteristics* (gender, occupation), and *communication styles*. Similar themes were then explored in the next two sets of communication. Patients discussed their providers' communication style along with the providers' characteristics; hence providers' gender and profession were noted in the transcripts.
2. Second was the initial appointment at the fertility clinic. This included patients talking about their initial appointments after referral from another provider. Major themes identified in this stage were *patient's state of mind, provider's communication style*, and *information (clarity and adequacy)* provided to the patients. Because this study was done in one clinic, characteristics of the fertility consultants were not noteworthy as most patients were attended by same consultants. Patients focused more on the information provided to them.
3. Third was a subsequent discussion about FP options. During the subsequent discussions about FP with a provider stage, patients discussed their conversation with providers after the initial appointments to reach a decision about FP. Major themes that emerged were *patient's state of mind, provider's characteristics, provider's communication style, and relationship with provider.* As at this stage patients went back to the providers with whom they were comfortable, a new theme of previous relationship with providers emerged.

First Discussions of Fertility Compromise and Preservation

The major themes were the patient's state of mind and the communication style of the provider. The gender and profession of the provider were extracted from the transcripts as mentioned by the patients during the interview.

Provider's Communication Styles

The three provider communication styles identified were directive, indifferent, and supportive.

Directive. Style was categorized as directive if providers offered direction on next steps and the directions were followed. A directive style was noted when health care professionals provided a clear line of action with some assertiveness to comply. Some patients (n = 5) felt their providers had a directive approach. For example,

> She was sort of the guiding force, like these are the things that we would recommend. I can make the appointments for you and you can just kind of coast along and just attend them. You drive the bus and I'll just sit in the back is kind of how it went.

Supportive. Supportive style meant when patients were proactively provided information and emotional help.

Only two patients felt the professional's style was supportive. These patients appreciated provider's initiative in providing FP information and were interested in their overall well-being. For example, one of the patients said,

> She even specifically told me, I'm going to tell you about this because you are probably not going to have a lot of doctors that this is a concern for them. I want you to know before you go through anything, because you are a young adult and this kind of stuff. She just said, you at least need to know that this is something you could potentially have to deal with in the future.

Your situation, you decide/indifferent. However, some patients (n = 4) felt that the professionals' style was indifferent. Here the provider presented the facts to the patient and left it up to her to decide without offering details or showing interest in the patient as an individual. For example, "I'm not the person going through this situation, so decide what you need to decide," basically. He is like, "it is a low risk but I don't want to say that and have something happen."

Patient's State of Mind During the First FP Discussion

A reflection reported by some patients (n = 5) was that fertility news came embedded with other information and in itself was not the top priority, "I was just so overwhelmed with everything else. At that point it wasn't a real concern. I hadn't thought about it a lot. I was mainly focused on getting through the whole [treatment]."

However, others (n = 4) mentioned their disappointment and feelings of sadness upon hearing the news of fertility compromise. One of the patients said, "When they told me I couldn't have any more kids, I kind of felt like, of course, kind of crappy. Well, it was kind of taken away, if I did want that option."

While describing their feelings, participants also recalled their thoughts about having kids. For a few patients, this was the first time they seriously thought about having children as they were young:

> I'm not sure that I knew how to feel about it at the time, because we weren't sure at the time whether we wanted to have children or not. It felt like we were kind of having to make a split-second decision on something that we had thought we had a number of years to figure out.

Provider's Characteristics

The first person to inform participants about fertility compromise varied in gender and professional role. Patients' experience of first learning about FP was from a nurse, social worker, or oncologist. Most often this information was provided by the treating oncologist (n = 8). A few patients also found out from their nurse (n = 3) and others from a social worker, surgeon, or a doctor other than the treating oncologist. For example, one woman was told about FP by another doctor rounding on her floor the first night she was in the hospital.

In this sample, female health care professionals (n = 11) and male providers (n = 10) discussed fertility issues with patients. The gender of the health care professional who informed the remaining four participants is unknown.

First Appointment at the Fertility Clinic

At this stage of the clinical workflow, in addition to patient's state of mind and provider's style, themes around the information provided to patients were identified. It is at this stage that patients were provided their first consultation with a fertility expert and received FP information. Participants discussed their views on the adequacy and clarity of information provided to them.

Provider's Communication Style

Three major styles identified were directive, supportive, and indifferent (see Table 1).

Directive. Patients mostly talked about the conversations with their fertility specialist. Some patients found the provider's style directive (n = 7), when they assertively

Table 1. Chart Indicating Patient's Preference for Communication Styles During Various Stages in the Clinic.

	Communication style		
Stages	Directive	Supportive	Indifference
First fertility discussion	Most preferred	Preferred	Least preferred
First appointment at the fertility clinic	Preferred	Preferred	Least preferred
Subsequent discussions	unclear from data	Most preferred	Least preferred

recommended the FP option that the patients should opt for. As one of the patients expressed, "As much as he went over all this stuff, he gave us these options and basically said you probably want to do one of these two and I would recommend this one."

Supportive. Only two patients found their providers' style supportive and comforting. One participant liked this style because the provider took a holistic approach, considering the life situation of the patient and her interests. The patient said,

> The consultation was just really reassuring. It was kind of awkward because it was with my dad and it is a place where people go to have babies and stuff . . . I don't think anything wrong happened from it at all, because it (a) gave me an option and (b) he gave me really good advice that my oncologist agreed with, with the birth control.

Your situation, you decide/indifferent. Some of the patients (n = 4) felt that providers were not as involved as they wanted them to be. Hence, they perceived the providers to be very impersonal:

> All of those thing(s) is a lot (information provided at the first appointment with FP specialist). Then, again, that is their job. I just kind of felt like they . . . for something like that I would want to be able to build a relationship with a doctor and come up with some personalized plans. I didn't necessarily have that feeling from the first visit.

Patient's State of Mind

Patients talked about how they felt before and during their first appointment at the clinic. As some patients were in the process of cancer treatment, they felt confused and disoriented. As one of them said, "I have such bad memory. You have given me the chemo."

One of the patients felt that along with chemotherapy and radiation, going for another appointment for fertility consultation was a lot.

Mostly patients thought about their current life status and how appropriate fertility options were for them:

> I went in there. It was definitely overwhelming, like listening to it, because at that point in time I was just like, I don't want kids. I had to make the decision if I wanted to have that chance within a couple of hours. I was like . . .

For other patients, having information about FP was important to make the right decision. FP was like an insurance policy for the patients, if their situation improved in future. As one woman said,

> So I guess I kind of knew that there is a potential that maybe there is nothing they can do for me, I guess. But I guess I just kind of always felt that things are in the works, and, again, I don't want that opportunity to pass at that point.

Information

Some participants felt the information was too much and at times overwhelming. Patients felt too many choices and lack of a definite line of treatment left them scared or stressed.

> [My doctor] is like, this is relatively a new thing and I'm just like, I don't know if I want to try it. I don't really want to be a guinea pig. So, yeah, we did have the information and way too much more, or maybe we didn't actually get any of it. It didn't sink in. It was so out there and we were just like, we just sat in this room for an hour, and oh, my gosh.

Some patients expected the conversation about the cost of FP to be more explicit as pricing was one of the major deciding factors for them.

> There was sort of this vagueness about pricing and how much it was going to be. I always felt like I had to inquire, well, how much is that procedure going to be and how much is this bit and what is it going to look like all together. That was sort of this gray area. She kept saying, oh, you have to ask at the desk. That is a huge part of my decision making, how much is this going to cost me.

Although most of the patients felt they got sufficient information at their appointment in the fertility clinic, a few suggested that pamphlet information with pricing was their best guiding tool in decision making.

> I don't know if I learned it from [my doctor/the fertility specialist]. I think just reading stuff, because they were almost like do the research things, like . . . like mice or rats or whatever. I don't want to do that stuff. It was mostly reading the pamphlets and stuff like that.

The content of information for the most part was comprehensible; a few patients felt they were provided with unnecessary information on current research and it was difficult to

understand. Due to the research-oriented language in the information provided, participants could not appreciate various FP options available to them.

> When I listened to the doctor talk about all the studies and things, I don't know if I would have chosen a different option because I really didn't understand the different options. But I would have appreciated the time to step back and go, okay, this is this. I can do this and this will happen.

Subsequent Discussions

These results refer to the time beyond the first appointment at the fertility clinic after patients were given information about FP. Patients discussed their feelings about the fertility clinic and experiences with the providers who helped them think through their decision. Patients' recollections beyond their appointments with fertility specialists are captured in this section. It is an important phase where patients' are thinking through the decision and have described how discussions with various providers helped them through the process. *Patient's relationship with the professional* was an emergent theme at this stage of the clinical workflow. Patients discussed their existing rapport with the provider to whom they returned for subsequent discussions. Two other themes were *provider's style* and *patient's state of mind*.

Provider's style

Directive. Some patients (n = 8) described the provider's style as directive in this phase. Most of the patients who reported the style as directive said that they were told to adopt a particular method of FP. As one patient said,

> He said you definitely don't want to wait until you go through your first round of chemo because the chance of damaging your tissues or different things likes that or just the possibility of there being more of an issue with fertility later on. He goes it is best to go in and actually preserve that ovary now before you even start your first round of chemo.

Supportive. About a quarter of participants (n = 6) reported that their providers were supportive with their decision-making process. Patients approached their fertility specialist, primary care physician, social worker, or nurse depending on with whom they had a rapport and what conversations they remembered. Most patients talked about the providers who discussed their problems with them versus those who just provided them information. As one patient mentioned,

> She was just so positive and just, like I said, gave me enough clinical information and statistics but didn't overwhelm me with it. She sat down with a diagram. She wrote out what my treatment plan was going to look like, really took time with me. Not that this other surgeon has not done that, but he just doesn't have the same, it is just not the same approach.

Two patients described instances when the provider was being supportive and reassuring. One of them described her health care professional as a mentor. For example, "I definitely was a decision maker. I knew what I wanted to do and how to do it. But I always, at the same time, I always looked at them as being a mentor. They have been through this."

Your situation, you decide/indifferent. A quarter of the patients (n = 6) reported providers as being indifferent and not relating to their problem. As one of the patients said,

> Yeah, and I think he might be a little surprised by my having not decided yet. I said to him, when I saw him a few weeks ago, he was like, oh, have you decided. I said, you know, I really haven't decided. He kind of joked and said, well, you can decide up until you're in the prep, right before your anesthesia. You can decide . . . And that made me feel a little abandoned by him, as far as like, this is your decision, just let me know and I'll do whatever you want me to do. I don't know, it feels like of lonely.

A couple of patients felt that they were being pushed from provider to provider with no one taking the responsibility or helping them make a decision.

Patient's State of Mind Before Subsequent Discussions With Providers

After their first appointment some patients felt stressed, overwhelmed, and scared about the procedure. One of them said, "I remember just being really scared and paranoid and just really thinking what am I getting myself into, like if this isn't going to work, then is it really worth it."

Another patient said, "It is too much. It is too much. It is too much information. It is too much emotionally and it is hard to remember why I decided certain things."

However, a few others felt confident and satisfied with the decision they made. Patients also described their difficult situation about choosing between starting cancer treatment right away and waiting to complete FP treatment before beginning their cancer treatment.

Provider Characteristics and Their Relationship With the Providers

All the participants who talked about subsequent discussions (n = 7) with health care professionals approached a female provider, of whom three were nurses, two social workers, and two doctors.

Some participants explicitly expressed their comfort with female providers as they understood them better:

> I have my oncologist who is a female—I say that only because I do think that that kind of weighs into their ability to relate to this decision. We have been talking a lot over the course of the last several months. I'm still undecided as to what to do.

Two participants discussed their relationship and comfort with providers. Both indicated that an existing relationship made them feel comfortable talking to the provider.

> With my primary care . . . now I would have called my gyno [gynecologist] because I know her really well and I have a really good relationship with her now. I would ask her what she would do. When you go from no medical history, I didn't have anybody that I could trust that was a professional. Now I have my psychologist, my primary care, two oncologists, my naturopath. I have people that I always know that I can go to.

Discussion

This study reveals new insights into patient–provider communication during fertility decision-making processes. Overall it provides patients' perspectives on communication with providers while making a FP decision.

Provider's Style of Communication

Comparing all three sets of communications, the directive style was preferred by patients during the first discussion where providers emphasized the importance of a first consultation. The least preferred style was that of indifference. However, during the first fertility consultation, patients liked a supportive style where their current life situation was included in the discussion along with information on FP procedures. It is important to discuss patient's current life situation including relationship status and to provide advice regarding procedures for exclusive egg preservation or zygote preservation. Supportive style was preferred again during subsequent discussions as patients liked longer discussions to reach a decision on FP. Results indicated that some patients perceived directive styles as positive. A number of previous studies of adults report that cancer patients vary substantially in their preference for participation in decision making (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Degner & Sloan, 1992; Gattellari, Butow, Tattersall, Dunn, & MacLeod, 1999). In fact, in one study, the physician's recommendation was a strong predictor of whether a patient opted for FP (Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002). Although these studies are not specifically done with AYA populations, similar results emerged in the current article where participants demonstrated appreciation for the directive style of the professionals. One plausible explanation for favoring directive styles may be the need for clear directions from health care providers when patients felt overwhelmed with information. A recent study on pretreatment counseling for FP showed higher satisfaction among patients counseled by both oncologists and fertility specialists rather than by only oncologists (Letourneau et al., 2010). This study highlights preference for directive style, especially when it meant insisting on fertility clinic consultations, as it may lead to counseling sessions with both oncologists and fertility specialists and more informed basis of decision making.

Indifference on the part of providers while communicating was mostly unacceptable. Patients expressed discomfort when providers ended conversations by detaching themselves from patients and leaving the entire ownership of the decision to them. A study of women with breast cancer showed that patients have emotional needs and seek reassurance from their health care professionals (Bakker, Fitch, Gray, Reed, & Bennett, 2000). Affective communication showing understanding of a patient's life situation and building trust are important for patient satisfaction (Bakker et al., 2000). Hence, an indifferent, detached communication style is the least preferred style.

At first appointment in the clinic, patients expressed their stress and fear about the procedure. Anxiety before a medical procedure is common among patients (Kindler, Szirt, Sommer, Häusler, & Langewitz, 2005). A study of preoperative patient–provider communication suggests that having patient-centered conversations where focus is on psychosocial issues with discussions surrounding emotions before operations helps reduce anxiety among patients (Kindler et al., 2004). Although hospitals and clinics are resource and time-constrained, results indicate that there is a need for fertility counseling services to provide information about the procedures.

Information. There is no one consistent source of FP information for the patients. Patients heard about this service through different providers (nurses, oncologists, and others).

Feeling overwhelmed with information may imply that patients felt inundated with too much information along with the cancer diagnosis and treatment discussion. Feelings of sadness may emerge from the feeling of loss of an important organ function. Providers while communicating to the patients about possible fertility loss should be responsive to a patient's individual state of mind to ease them through the process of decision making about FP. Information on the pamphlet provided was useful for the patients.

Most of the patients liked when providers gave them a list of options but strongly recommended the one they thought best suited to them. Hence, they found a directive style to be useful at this stage. Along with clear recommendation of the FP method to be used, discussions with the provider around the patient's life stage and situation helped patients make their choices. This analysis suggests that patients were more satisfied when provider–patient communication went beyond medical facts, and related to the patient's current life situation.

Patient's State of Mind

Through the stages of communication, the patient's state of mind changed depending on the information she received. In the reflection of the first discussion about fertility, patients

focused on their reaction to the news of fertility compromise, including feeling overwhelmed with information and disappointment. Some patients reported how first consultation with a fertility specialist helped them start thinking about having children in the future. In the subsequent discussions set, patients started considering the possible options discussed in the fertility consultation and felt stressed about the procedure itself. Others felt relieved after making a decision about FP. Some of the patients in this study were either in the process of cancer treatment or treated for a relapse at the time of the study. Results indicate that within the context of many other life-changing decisions, FP was one more important decision to be made. Although for patients the outcome of their chemotherapy could not be accurately predicted, they went for their fertility appointment with the mind-set that having information was important and FP may be helpful in future.

Providers' Characteristics

Patients encountered various providers through their FP decision-making process. There was no consistency observed across the three sets of communication as to who provided information initially about fertility and to whom patients went back for subsequent discussions. Throughout the three sets of communication, these data reflect a lack of one point person to whom patients returned after consultation with other providers.

The participants in the present study offer important insights into their preferences for communication styles and services from providers. This insight could assist in the development of strategies for communication in this field, including tailoring communication styles to meet the needs of young adult patients. Patients reported feeling most comfortable with female health care professionals in discussing FP and they preferred to return to them for further consultation. As gender comparison was not the focus of this analysis, this study cannot endorse a preference for female providers. But the fact that patients found it meaningful enough to discuss in the interview reflects for this sample of patients that female providers do approach fertility discussion with appreciated sensitivity. Previous relationships with health care professionals helped patients think through their decisions. It is difficult for patients to establish a relationship with oncologists or surgeons in the short period between diagnosis and treatment. One study shows that as primary care provider, the gynecologist may interact with patients throughout the cancer care continuum, and this puts gynecologists in a unique position to join the onco-fertility team in providing young cancer patients with needed support (Duncan, Jozefik, Kim, Hirshfeld-Cytron, & Woodruff, 2011). For patients who have an ongoing relationship with their gynecologist, it may be useful to involve them in FP discussions.

It is evident from the results that most patients heard about their potential fertility compromise from their oncologist. But the information also came from various other sources, including nurses, social workers, and other professionals. It may be beneficial to involve other health care professionals in the process of providing FP information. Streamlining the process of FP treatment may avoid unnecessary delay in starting the treatment, for example, setting a standard protocol for informing patients about FP and timely referrals to social workers and the fertility clinic.

Limitations

This was an exploratory study and results obtained from this study may help generate research questions for future studies. However, due to the small and nondiverse sample, generalizability of the data to wider population may not be possible.

Secondary data analysis of the qualitative interviews can pose certain limitations. These limitations may include lack of knowledge of the context of the primary study and insensitivity to the data (Hinds, Vogel, & Clarke-Steffen, 1997). However, as the researcher was involved with the primary data analysis, the researcher is familiar with the data and context in this case. Questions in the interview schedule were not written to generate data regarding communication with providers specifically, which may limit the extent to which these patterns were discussed explicitly with participants.

Data were collected retrospectively from the patients; hence, there may be some recall biases. However, the purpose of the article was to capture the feelings about the conversation and what exactly stayed with participants from the communication rather than the exact content of the communication, and thus captures the long-term impact of patient–provider communication on the patients.

Due to single interviews with the patients, there is an absence of data triangulation. This limitation was compensated with the review of other qualitative and quantitative research studies to observe if similar findings were found by other research groups.

This analysis may incorporate the researcher's biases such as gender bias as the researcher is a woman who may approach fertility from a different perspective than men. Peer debriefing was done to include views of other researchers and diminish the personal biases of the researcher.

Research and Practice Implications

Practice Implications

FP advice to young adult patients must be delivered in a patient-centered manner. FP discussion with an appointed provider who may be with the patient throughout the decision-making process may lessen the feeling of abandonment.

A dedicated social worker or nurse trained specially in the FP field may provide this supportive role during the procedure. More involvement of providers with whom patients have an existing relationship in the onco-fertility team may improve the patient's satisfaction with the decision-making process.

Complicated language may be a barrier to patients' ease of decision making. FP information should be in a language accessible to the patients. Fertility consultation may be supported by the provision of pamphlets with FP information to take home. Presentation of FP information needs further attention.

Other studies on guidelines for communication on cancer diagnosis, treatment, and implications of treatment should be derived from patient-based data rather than be limited only to clinical opinion (P. N. Butow et al., 1996). Hence, when discussing risk to fertility, health care professionals need to account for the patient's state of mind rather than relying solely on their own clinical judgment.

Research Implications

This study addresses patient's perceptions of communication styles. Future research may focus on finding more about communication content, timing, and who should provide this information.

Content of information. This article emphasizes the importance of patient-centered communication of information. The content and mode (flyers, posters, FP awareness campaign, etc.) of information dissemination can be researched further to increase awareness. More studies on FP communication studying the impact of an FP awareness campaign may be useful.

Who should provide information? Findings from this analysis state that FP information was provided to the patients by various providers. Although most patients got information from their oncologists, others were informed by nurses, social workers, and other health care providers. Patients also discussed the gender of the provider who first discussed FP with them. There are unanswered questions about whose responsibility it is to discuss it first. Research should determine who along the cancer treatment continuum is the best person to discuss FP with patients?

Conclusion

Findings from this study indicate that it is essential to acknowledge that the FP process is complicated and patients look for more support than is currently provided to them. Directive style of communication, considering patient's status and state of mind during initial phase of information provision may improve the patient's experience of the fertility decision-making process. Later as patients progress in the FP decision-making process, providers' supportive style of communication may lead to higher satisfaction among the patients. Enhancing the quality of support to patients through effective patient–provider communication should be a priority for health care providers. Women undergoing cancer treatment face immense stress of treatment and decision making. The provider's role is not to merely provide information but to support her through the process of decision making. Understanding this communication process and responding to the needs of the patients will empower women to make the fertility choices that are right for them.

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