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Toward theoretical understanding of the fertility preservation decision-making process: Examining information processing among young women with cancer

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Abstract

Background—Young women with cancer now face the complex decision about whether to undergo fertility preservation. Yet little is known about how these women process information involved in making this decision.

Objective—The purpose of this paper is to expand theoretical understanding of the decision-making process by examining aspects of information processing among young women diagnosed with cancer.

Methods—Using a grounded theory approach, 27 women with cancer participated in individual, semi-structured interviews. Data were coded and analyzed using constant-comparison techniques that were guided by five dimensions within the Contemplate phase of the decision-making process framework.

Results—In the first dimension, young women acquired information primarily from clinicians and Internet sources. Experiential information, often obtained from peers, occurred in the second dimension. Preferences and values were constructed in the third dimension as women acquired factual, moral, and ethical information. Women desired tailored, personalized information that was specific to their situation in the fourth dimension; however, women struggled with communicating these needs to clinicians. In the fifth dimension, women offered detailed descriptions of clinician behaviors that enhance or impede decisional debriefing.

Conclusion—Better understanding of theoretical underpinnings surrounding women's information processes can facilitate decision support and improve clinical care.

Keywords

Decision Theory; Information Seeking Behavior; Health Communication; Oncofertility; Survivorship; Young Adult Cancer

October 22, 2012 marked a new era for young women with cancer. Egg freezing, long considered an experimental procedure in the United States (US), moved from “experimental” to non-experimental and joined embryo freezing as an acceptable and recognized fertility preservation option available to postpubertal women diagnosed with cancer (American Society for Reproductive Medicine, 2012; Practice Committees of the American Society for Reproductive Medicine and the Society for Assisted Reproductive Technology, 2013). Although fertility preservation for postpubertal males has been successful and evolving since 1953 (Anger, Gilbert, & Goldstein, 2003; Bunge & Sherman, 1953), advances in female preservation have proven more difficult to achieve (Cobo & Diaz, 2011; Smith, Motta, & Serafini, 2011). In fact, it was only in 2006 that the American Society of Clinical Oncology (Lee et al., 2006) advised clinicians to inform patients of reproductive age about the potential loss of fertility associated with gonadotoxic cancer therapy, discuss basic questions about fertility preservation options, and refer interested patients to fertility preservation specialists.

Fertility preservation has been recently defined by the National Center for Biotechnology Information at the US National Library of Medicine (i.e., PubMed) (2012) as, “A method of providing future reproductive opportunities before a medical treatment with known risk of loss of fertility. Typically reproductive organs or tissues (e.g., sperm, egg, embryos and ovarian or testicular tissues) are cryopreserved for future use before the medical treatment (e.g., chemotherapy, radiation) begins.” The advances in female fertility preservation to establish options such as egg and embryo freezing are groundbreaking and if available previously, may have altered the opportunity for biological motherhood for many of the estimated 7,196,020 female cancer survivors who are 20 years-of-age or greater in the US alone (Siegel et al., 2012). The decision whether to undergo fertility preservation should ideally take place before the onset of cancer therapy; therefore, there is an urgent need for research to explore and explicate how nurses, physicians, and other clinicians can best assist women in the decision-making process regarding these complex fertility preservation options (Canada & Schover, 2005; Lamar & DeCherney, 2009; Peate, Meiser, Hickey, & Friedlander, 2009; Quinn et al., 2010). At the same time, there is a growing awareness and call for incorporating theoretical understanding and insight into how to help patients make personally relevant decisions that involve risk and uncertainty (Bekker, 2009; Elwyn, Stiel, Durand, & Boivin, 2011).

A critical component of assisting patients in the decision-making process is providing information about treatment options (International Patient Decision Aid Standards Collaboration, 2005). It has also been well documented that individuals diagnosed with cancer want and benefit from information, especially information related to treatment options (Chelf et al., 2001; O’Leary, Estabrooks, Olson, & Cumming, 2007; Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004; Stephens, Osowski, Fidale, & Spagnoli, 2008). Yet, many cancer patients report that they have not received adequate information about treatments or are overwhelmed by information and have difficulty determining what is accurate and what is relevant to them (Rozmovits & Ziebland, 2004; Skalla et al., 2004).

The information needs of young people with cancer and especially women may be even more acute. In a systematic review of 112 published articles to discern cancer patients’

information needs and sources from which they receive information, Rutten, Arora, Bakos, Aziz, and Rowland (2005) found that younger cancer patients tend to seek more information than older patients and the range of sources of information is also broader in younger patients. Rozmovits and Ziebland (2004) echoed these findings in their study examining the information needs of prostate and breast cancer patients and concluded that information support services often failed to meet the needs of young people with cancer and especially the needs of women.

Research in the evolving area of fertility preservation for young women with cancer indicates that only 34%–72% of women diagnosed with breast cancer discuss fertility related issues with their physician or other clinicians (Duffy, Allen, & Clark, 2005; Partridge et al., 2004; Thewes et al., 2005). Many women have also reported to investigators that although clinicians discussed fertility issues, their concerns were inadequately addressed (Duffy et al., 2005; Partridge et al., 2004). In a study that preceded the 2006 recommendations by the American Society of Clinical Oncology (Lee et al.), Quinn and colleagues (2007) completed in-depth interviews with 16 oncologists and found that while most oncologists discuss potential fertility loss secondary to cancer treatment, few provide women with information about preserving fertility. About two years following the release of the 2006 recommendations, Quinn and colleagues (2009) queried oncologists in a US national survey and concluded that less than half of oncologists were routinely referring patients who had questions about fertility to a fertility preservation specialist.

The need for knowledge and understanding about information processing surrounding fertility preservation for young women with cancer is not limited to the US. Young women with cancer in Australia also reported a lack of information and support for decisions surrounding fertility (Penrose, Beatty, Mattiske, & Koczwara, 2012) and Jukkala and colleagues (2010), in a sample comprised of young women from eight countries, found that most women self-identified as having limited knowledge about fertility preservation even though they were on average only 22 months postcancer diagnosis. Moreover, investigators in Australia found that among 111 young female breast cancer survivors *all* participants indicated that receiving information on fertility preservation options was important; 20% of the sample went on to indicate that fertility preservation information was very important and 63% indicated this information was extremely important (Peate et al., 2011). In Germany, Switzerland, and Austria a web-based survey is currently in progress to determine patient knowledge, attitudes, and intentions about fertility preservation among cancer patients (FertiPROTEKT, 2006). In addition, since 2007, the European Society of Human Reproduction and Embryology (2012) has convened a task force to address issues and concerns regarding fertility preservation in cancer patients.

In response to the multiple urgent needs, efforts to inform clinicians and aid patients in the decision-making process are underway. For example, the sequence of women's decision points surrounding fertility preservation in which clinicians can approach patients has been documented via a decision tree (Gardino, Jeruss, & Woodruff, 2010), and several decision support aids are in development (National Cancer Institute, 2011) or under evaluation (Meneses, McNees, Azuero, & Jukkala, 2010; Peate et al., 2012). Yet, there is little in-depth or theoretical understanding about information processing as it relates to young women's

decisions to accept or decline fertility preservation following a diagnosis of cancer. To address this gap, the purpose of this paper is to expand theoretical understanding of the decision-making process by examining aspects and insights related to information processing among a sample of young women diagnosed with cancer who have real-world experience in making a decision about fertility preservation.

Method

After obtaining Institutional Review Board approval to ensure ethical conduct of this grounded theory study, 27 female participants were recruited from two large university centers ($n = 7$) and the Internet ($n = 20$). Women were invited to participate in the study if they: (1) were diagnosed with cancer, (2) were eligible for fertility preservation, (3) had recently decided or were in the process of deciding whether to freeze eggs, embryos, or ovarian tissue. Each participant completed a semi-structured in-depth interview with the Principal Investigator (PI) (PEH), either by phone or e-mail. In this sample, 21 of the women opted to complete a phone interview that was digitally recorded and averaged about 59 minutes in length. The phone interviews were transcribed, checked for accuracy, and corrected as appropriate. Procedures for the e-mail interviews were developed after reviewing the scientific literature in the field including seminal articles by Hunt and McHale (2007) and Meho (2006) and incorporating insight derived from the PI's similar research (Hershberger et al., 2012). The e-mail interviews were conducted asynchronously through a series of back-and-forth e-mail cycles that averaged about 4 cycles between the PI and each individual participant. After completing the interview, each participant received a \$25 gift card that was mailed to her home address.

The interviews began with a broad question asking participants to think aloud or write about their decision-making experience surrounding fertility preservation. The findings delineating the women's responses that comprise their overall decision-making process framework are reported elsewhere (Hershberger, Finnegan, Pierce, & Scoccia, 2013). Because of the importance of information processing within the decision process and the limited knowledge in the field, the interview guide also included questions that centered around aspects of information processes that would address: (1) how women acquire information about fertility preservation, (2) what information do women desire, and (3) what insights do women have regarding information processing as they formulate a decision about fertility preservation following a diagnosis of cancer. Examples of these questions and probes can be found in Table 1.

During data collection, interview data were de-identified to ensure participant confidentiality. To facilitate retrieval and analysis, the data were entered into NVivo software (QSR International, Pty Ltd, Doncaster, Victoria, Australia). In keeping with the tenets of grounded theory, initial coding began shortly after the onset of data collection and eligibility criteria were added to include the principles of theoretical sampling (Charmaz, 2006; Glaser & Strauss, 1967; Morse, 2010). Initial coding, primarily completed through incident coding, was performed by the first and fourth authors (PEH & SL) and codes were linked directly to the raw data. Because a hallmark of grounded theory analysis is constant comparison (Charmaz, 2006; Glaser & Strauss, 1967), we performed an iterative analytical

thought process whereas emerging codes and sub-categories were constantly compared to other emerging codes and sub-categories and also to the five dimensions within the Contemplate phase of our previously discovered decision-making process framework (Hershberger et al., 2013). This framework emerged from our initial grounded theory analysis and is comprised of four main phases (Identify, Contemplate, Resolve, Engage) that women in this sample progressed through as they formulated a decision regarding fertility preservation (see Figure 1). In the Contemplate phase, five critical and interrelated dimensions that include (a) acquiring and integrating information, (b) incorporating prior experiences, (c) constructing and determining preferences and values, (d) considering contextual components, and (e) undergoing decisional debriefing occur whereby women actively formulate decision intent before moving into the next phase, Resolve. Because of the active processes involved in formulating decision intent that occur within the Contemplate phase, we incorporated the five interrelated dimensions within this phase into our constant-comparative analysis of information processing. Other nurse scientists have advocated for the elaboration of an inductively derived theory through linked grounded theory analyses (Olshansky, 1996) or have recommended continued analysis to clarify or refine concepts and statements within an existing theory to further theory development (Walker & Avant, 2011).

To enhance credibility, preliminary findings were evaluated and discussed with the multidisciplinary research team members and presented for audience review, a form of triangulation (Patton, 2002), at the 2012 World Congress on Controversies in Obstetrics, Gynecology and Infertility Conference in Lisbon, Portugal and at the 2013 Midwest Nursing Research Conference in Chicago, Illinois, USA. Analytic insight obtained from the multidisciplinary team provided additional depth and expertise from nursing, public health, and medicine and was incorporated into the final analysis. Audience review, obtained by feedback from the two groups of conference participants following the presentations, was confirmatory and supportive of the findings.

Results

Sample Characteristics

The sample included 27 young adult female participants, ages 19 to 40 years ($M = 28.7$ years), who lived in 15 different states and the District of Columbia. The women were highly educated, ranging from 12 to 17 or more years of education ($M = 15$ years), although one participant did not disclose this information. Household income was also high ($M = \$72,465$ US dollars). Participants were predominately White ($n = 21$) and employed full-time ($n = 16$); however, 9 participants were students. The women received a diagnosis of cancer between 1 to 16 months ($M = 5$ months) prior to participating in the interview. Cancer types included: breast ($n = 14$), Hodgkin's lymphoma ($n = 5$), ovarian ($n = 4$), leukemia ($n = 3$), non-Hodgkin's lymphoma ($n = 1$), and kidney ($n = 1$). One woman was diagnosed with two cancer types. Regarding the women's decision about whether to undergo fertility preservation, 13 women decided to accept egg and/or embryo preservation and 14 women declined fertility preservation.

Information Processing within the Contemplate Phase

The five dimensions within the Contemplate phase of the decision-making process framework emerged as categories that conceptualize information processing. To aid understanding of these complex processes and enhance trustworthiness, verbatim quotes are used below in the description of the five dimensions within the Contemplate phase. Participant names have been replaced by numeric codes to maintain confidentiality; however, women who accepted fertility preservation are coded with “[A]” and women who declined fertility preservation are coded with “[D]”. To provide additional insight and enhance understanding, sociodemographic information about the women depicted in the quotes can be found in Table 2.

Acquire and Integrate Information—In this dimension, women described how they acquired and began to integrate information about fertility preservation. Nurses and other healthcare clinicians (e.g., physicians, social workers) and other sources of information such as the Internet were beneficial; however, the women often reported multiple challenges to acquiring information. In particular, four of the women described situations where information about fertility preservation was not addressed by clinicians and most women reported that if it was addressed, the provision of information was inadequate. For example, Participant 9 [D] related this experience, “They had me running from department to department going through this test and that test, that test, that test, I had recommendations for everything that I needed -- except the fertility part.” Participant 15 [D] commented that fertility was the “red-headed stepchild of having cancer” in that clinicians were lax and avoided addressing fertility concerns. In a contrary case, one woman, Participant 2 [D], reported that she acquired information exclusively from her physicians and did not seek outside sources for additional information.

Several participants offered strategies that clinicians could implement that would be helpful in acquiring and integrating information. Participant 24 [D] described the benefits of having clinicians prepare an informational “binder.” She said, “The nurse that had been helping me along - and kind of been working with during the whole time, took us into a conference room. She had a binder with a whole bunch of [cancer] information in it about what I would be going through, pamphlets on support groups, pamphlets with websites, where to find information, just a whole bunch of stuff. And I just think that would have been a great time [to discuss fertility], because it didn’t come up.... And over the course of a week [I] went through everything in that binder, read everything, and, you know. And I still take it to every doctor appointment I have. I keep everything in there.” A similar suggestion was made by Participant 16 [D] who said: “I think that [fertility] should have been addressed from the outset, and you know ... it wouldn’t have hurt for them [clinicians] to put in, you know ... an information packet.”

Acquiring and integrating information from multiple clinicians also presented unique challenges for the women. Women described difficulty in processing information from a large cadre of clinicians. Participant 23 [A] wrote, “My oncologist advised me that future sterility was a possibility as a result of my treatment and then referred me to someone in the gynecology department; she made no mention that the purpose of this visit would be to

discuss fertility preservation options. I was completely shocked when the gynecologist suggested I look into my [fertility preservation] options.” In another poignant example that describes difficulties that women face navigating information from multiple clinicians, Participant 16 [D] said, “I had two very well-known medical professionals telling me completely opposite things. And I just, I had to put my faith in one or the other.”

Clinicians who were able to incorporate effective and efficient communication systems and strategies between multiple clinicians enhanced women’s abilities to obtain and integrate information. Participant 5 [A] wrote, “Having a program already organized to manage cancer patients seeking fertility preservation is really important ... and making it clear who the patient can contact with question[s] is helpful.”

All but two of the women (Participants 2 [D] and 19 [D]) searched the internet to acquire information or to confirm or supplement information provided by nurses and other clinicians. The 25 women who used the internet had mixed perceptions about whether the internet was helpful. Although some women found it helpful – and one young woman (Participant 20 [D]) even spoke fondly about her father who performed internet searches to obtain fertility preservation research articles for her – some women found the information confusing, questioned its reliability, or felt that information obtained from the internet escalated fears. Participant 8 [A] said, “I went on the internet, and I drove myself absolutely insane, and I was terrified.” Participant 15 [D] added, “A lot of what’s out there on the internet is difficult for someone to use. It’s a little overwhelming.” Participant 5 [A] wrote, “I was afraid to cold call the internet... because I was afraid of unreliable or incorrect information.” Important to note is that two women (Participants 6 [A] and 10 [D]) went to local bookstores in an attempt to supplement information obtained from their clinicians. Both women reported they found little information on fertility preservation and what little they did find was not relevant to them.

Incorporate Prior Experiences—In the second dimension, women reflected on their own personal experiences and also sought-out information from other young women’s experiences regarding fertility preservation. Many of the women seemed to crave information from other women, regardless of whether they accepted or declined fertility preservation. In fact, one participant (Participant 19 [D]) who was recruited on the internet, when asked directly if she sought information about fertility preservation on the internet replied, “I didn’t” but went on to describe how she used the internet for obtaining experiential information from other young women with cancer.

Most women were more direct in stating how experiential information was helpful. For example, Participant 20 [D] said, “People saying, ‘this is what I did and this is how it works’ and ‘this is my experience and this is how I made my decision.’” Participant 25 [A] said, “So I did my research, and you know, I did join the support group because I wanted to know from other women who you know, were going through the same thing or had went through [fertility preservation].” Participant 10 [D] stated, “I mean there is so much anguish and you know sadness and frustration for women my age who were trying to figure out what I am going to do...I wish they would incorporate that sort of, someone you could talk to when you are dealing with women who are diagnosed.”

Women also looked within themselves for insight about information obtained from prior experiences. Participant 1 [A] described how she integrated her friend's experience. She said, "I have friends who went through treatment for Hodgkin's lymphoma, and ... she wasn't able to undergo any fertility preservation measures and um, is now experiencing ovarian failure ... I feel like even though I knew her as a cancer survivor a few years before and I thought 'oh, that's so awful, I don't know how I would feel if that ever happened to me' and then it, it winds up happening to me. So I feel like, um, definitely knowing about her experience has, has fueled the fire a little bit more, you know, and determined that that wasn't going to be me."

Construct and Determine Preferences and Values—The information that women described as beneficial to constructing and determining preference and values, the third dimension, consisted of evaluating the pros and cons of fertility preservation as well as moral and ethical considerations. The types of information that was important to women included details pertaining to the medical procedures involved in fertility preservation treatment (e.g., medications, length of time to treatment, frequency of clinic visits, necessity for gamete manipulation) and information on treatment risks, benefits, success rates, and costs. Participant 13 [A] captured the sentiment of many of the women when she said succinctly that she wanted information to determine that, "I wasn't causing myself any harm" by optioning to undergo treatment. Participant 2 [D] offered this, "[Clinicians] had explained to me what research had been done, what had been successful, what the, the uh, success rates are of different types, of the different options. That was, that was, the most helpful [information], probably." Participant 1 [A] reiterated the importance of procedural information when she said, "I just didn't know what to expect and I was hoping that it would kind of be a quick, um, painless-not entirely painless-you know because I expected it would be some kind of surgical procedure."

As the women processed information, many expressed frustration about uncertain, conflicting, or unavailable information surrounding success rates, costs, and the potential increased risk of future cancer. Participant 23 [A] wrote, "My major concern in this area was the controversial link that some have reported between fertility treatments and breast cancer. I looked up scholarly articles concerning this topic, but the data are so conflicting that I could not get a good answer on this."

Constructing strong preferences or discerning values regarding treatment options was challenging for some women. Several women suggested that consultation with religious leaders could aid in preference and value formation or clarification. Participant 12 [D] recommended, "I would also encourage them [women] to talk to a clergyman or someone whose opinion they respect if they need some insight." Noteworthy is that as the women navigated this dimension they found themselves seeking information not only on egg and embryo preservation but also on a wide range of fertility options including adoption, foster-parenting, surrogacy, and emergent experimental options that protect rather than preserve fertility such as GnRH analog or antagonist treatments.

Consider Contextual Components—As women progressed through the decision-making process, they sought and desired tailored, personalized information that was context

specific to their situation. Participant 17 [A] reported, “Well, at least with my oncologist, she has never, she’s never sort of treated me like a, like a standard case.” In a contrary example, Participant 20 [D] said that while she was acquiring information about fertility preservation, she met with a reproductive endocrinologist who was unable or unwilling to provide information that was specific to her situation. In her words Participant 20 [D] said, “I mean, basically she said, your best option is to freeze an embryo because obviously we know that, we have evidence that that works. But her recommendation was like, go ask an ex-boyfriend to donate sperm to me, which I was like, that’s not an option. I’m very single and I’m not having an ex-boyfriend’s child! There’s a reason they are an ‘ex’. You know, and so it was, she really kind of, relied on that very first option, which wasn’t an option.”

Although women desired contextual information, they varied in their ability to articulate contextual needs. The ability of nurses and other clinicians to anticipate the need for contextual information by demonstrating sensitivity to subtle cues was particularly beneficial. For example, Participant 13 [A] who was diagnosed with breast cancer said, “When I met with my surgeon, one of my questions was like, you know, kind of after he’d told me about surgical options and then we’ll see about what further treatment you need...I asked him about breastfeeding ... So I think he, he quickly got that fertility was a concern of mine, and mentioned that there are options for fertility preservation.” In contrast, Participant 9 [D] reported the following experience when clinicians did not pick up on cues particular to her situation: “Because when I got the answer [from clinicians], ‘Well we don’t see many patients like you’ -- meaning that even if they are pre-menopausal the chances being thirty-six is ‘We assume you’ve already had a child or two -- it’s not going to be a big deal if we take away your fertility.’ Knock, Knock, Ding, Ding, Ding ... This is not acceptable. I have some concerns here and I want them addressed! Um, can you please help me? [pauses] And they didn’t.”

Undergo Decisional Debriefing—Women undergo decisional debriefing sessions in the fifth dimension where active information processing takes place with one or more individuals. The debriefing sessions aid women in the formulation or confirmation of their emerging decision intent regarding fertility preservation. Because the sessions include interaction with one or more individuals, the women offered detailed descriptions of behaviors, often of clinicians, that enhance or impede the debriefing sessions.

Behaviors that enhanced decisional debriefing include active listening and open, honest, non-judgmental communication where information is exchanged in an environment that promotes respect, empowerment, and the women’s comfort in discussing personal thoughts and emotions about fertility preservation. Participant 22 [D] wrote, “I absolutely love my oncologist. He has been by my side since day one. The reason why we get along so well is the way he treats me. He doesn’t dumb things down for me and he gives me power. He leaves every decision up to me. He tells me the truth about what is happening inside my body and doesn’t hide anything.” Participant 8 [A] said, “I just have this amazing team of doctors that I can talk to about everything.” Efforts to decrease stress and tension were also helpful and aided information processing. Participant 7 [A] offered, “Because when you’re all stressed out you can’t really think when people are asking you all these questions and

need an answer and they're just adding on the stress. So when she [physician] stayed calm and was friendly, it kind of left some of the tension, as least for me, you know."

Behaviors that impede decisional debriefing include those where clinicians are insensitive, judgmental, or perceived as having a hidden agenda that may be in conflict with the decision-making needs of the woman. Regarding insensitivity and judgment, Participant 3 [A] wrote that when she questioned her physician about egg preservation he responded, "That is a very expensive and still experimental idea" and then provided little information about fertility preservation. In another example, Participant 26 [D] admitted that she refused to attend a consultation appointment with her mother's long-time physician who had recently started to offer egg and embryo preservation because she feared "pressure" to accept treatment. Participant 26 [D] stated, "My mom actually set up a consultation with her [the physician], and I decided I didn't want to go to it at all because I was kind of afraid she [the physician] would try to pressure me into it."

Discussion

Among young adult women with cancer, the Contemplate phase of fertility decision making is a critical juncture for information processing. Our findings are the first to delineate how information processes occur within five integrated dimensions of the Contemplate phase within the decision-making process framework. The findings also illuminate how linked grounded theory analyses can further understanding of an emerging theory by demonstrating clinical application and value, a notion articulated by Olshansky (1996).

Noteworthy is that 85% of the sample ($n = 23$) reported that a discussion of fertility preservation had taken place with one or more of their clinicians. This increase from prior reported data of 34%–72% (Duffy et al., 2005; Partridge et al., 2004; Thewes et al., 2005) may indicate that clinical guidelines and educational efforts to address fertility concerns of young women with cancer are beginning to be more widely implemented. However, our findings are consistent with others in that women continue to report that information provided by clinicians is often inadequate (Duffy et al., 2005; Partridge et al., 2004). Our findings address the important gap in inadequacies within information processing in that we identify and describe in detail how women process information in a real-world context. Furthermore, use of the decision framework to breakdown women's informative processes highlights the importance of underlying mechanisms involved in clinician's consultations that can enhance women's decision making and addresses areas where information processing can be improved. Nurses and other clinicians that are aware of these findings can modify counseling or behaviors and work collaboratively to address these key findings. For example, in the *Contextual Components* dimension, women were often unable to verbalize concerns or formulate and ask important and targeted questions. Thus, using broad questions (e.g., "Do you have any specific questions about fertility preservation?") that may be appropriate in other contexts should be used judiciously as women may not be able to articulate their concerns regarding fertility preservation. When possible, information should be tailored to each woman's individual situation and delivered in a strong supportive manner with an awareness of anticipating women's needs and concerns. Another strategy would be to compile the women's suggestions into a handbook for clinicians on effective overall

strategies for facilitating this important decision (e.g., “Facilitating Behaviors” and “Impeding Behaviors”).

Women also reported a significant benefit to having an organized informational approach to fertility preservation across various specialty areas (e.g., oncology, reproductive endocrinology). Mounting evidence has indicated that young women with cancer are often overwhelmed by the healthcare system (Hershberger et al., 2013; Penrose et al., 2012; Quinn et al., 2010) and strategies to reduce cognitive burden and streamline care across specialties and systems could help women process information. A clinical strategy gaining momentum in cancer care is to incorporate patient navigators (Robinson-White, Conroy, Slavish, & Rosenzweig, 2010). Because of the complexity and time limits involved in fertility preservation decisions for women with cancer, a clinical strategy that includes a patient navigator who coordinates care between specialties may be beneficial. One patient navigator at a large fertility preservation center in the US has observed improved patient care by providing information about fertility preservation, assisting with appointments, aiding patients as they interface with the healthcare system, and providing counseling, when needed (Scott-Trainer, 2010).

A key finding was that the vast majority of young women used the Internet in addition to information obtained from nurses and physicians. Clinicians should consider supplying young women with recommended Internet websites to provide reliable information and facilitate information processing. Because we recruited women on the Internet, the sample may be biased toward Internet use; however, among the 7 women that were recruited at fertility clinics, 6 reported seeking information on the Internet. Other investigators have also found the Internet as a leading source of patient information for reproductive or fertility related information (Hammarberg et al., 2013; Kahlor & Mackert, 2009; Weissman, Gotlieb, Ward, Greenblatt, & Casper, 2000). Women in this study placed a high value on the experiences and opinions of other young women. When directing women to the Internet, nurses may want to recommend websites that incorporate patient stories. This approach could facilitate information processing within two dimensions of the Contemplate phase: *Incorporating Prior Experiences* and *Consider Contextual Components*. Another useful strategy may be for clinicians to invite women to discuss information they have found online. Such discussions could help to ensure that women have factually correct information. In addition, processing other patient stories may help women to understand the unique facets of their own situation and arrive at decisions that are best for each woman.

While the findings provide insight into strategies that clinicians at the individual level and across specialties can implement to facilitate information processing, there is also an implicit call for an integrated and collaborative interdisciplinary approach among nurses, physicians and other clinicians. Nurses that work to implement strategic and collaborative approaches with physicians and others would improve information processing for women. Developing transparent strategies for coordinating care such as assigning clinician roles for initiating and facilitating information processes would be helpful. One example that could take place in the *Acquire and Integrate Information* dimension would be to have one clinician (e.g., physician) responsible for the initial discussion of fertility preservation and a second clinician (e.g., nurse) responsible for providing follow-up information in a written format

such as a take home educational binder or notebook. In the *Decisional Debriefing* dimension, clinicians (e.g., social worker, nurse) could be responsible for carrying-out a decisional debriefing session where fertility preservation is discussed with attention to the woman's contextual and experiential concerns. Other investigators have identified the importance of collaboration (Canada & Schover, 2005; Penrose et al., 2012) and our findings extend this idea by highlighting the need for clinicians from all professions and disciplines to work strategically and collaboratively at multiple information processing points as women contemplate fertility preservation.

Although analysis of our data revealed thick descriptions of information processing and provided strategies that clinicians can implement to improve these processes, the findings should be interpreted with caution due to several limitations. The sample was predominately White and well educated and a study involving women situated in other socioeconomic and cultural backgrounds could yield different findings. At the time of data collection, egg freezing was considered experimental by the American Society for Reproductive Medicine. The change in experimental status may impact underlying mechanisms that take place within the *Construct and Determine Preferences and Values* dimension of the Contemplate phase as women consider the pros and cons of fertility preservation options. Research is emerging on the sociodemographic, clinical characteristics, and other factors that influence women's decisions about fertility preservation such as the labeling of procedures as experimental (Kim et al., 2012; Lawrenz, Jauckus, Kupka, Strowitzki, & von Wolff, 2011; Peddie, van Teijlingen, & Bhattacharya, 2005). Yet, the science of understanding how best to translate and aid preference formation in clinical care is challenging (Epstein & Peters, 2009; Llewellyn-Thomas, 2009) and there is also little understanding about how cancer patients value and weigh information obtained from a variety of sources (e.g., Internet, physicians, nurses) (Blank, Graves, Sepucha, & Llewellyn-Thomas, 2006). Our research highlights the need for future work in these important areas. What is clear from the women's experiences is the significant role that clinicians have in information processing for young women with cancer. A critical next step in research would be to examine clinicians' perceptions and insights from a wide range of disciplines and specialty areas. As knowledge and theoretical understanding in this area grow, clinicians and investigators who implement clinical strategies to improve information processing and decision support should do so under close examination as the field is novel and there is a growing awareness that young women with cancer have unique needs.

Despite the limitations, there are several strengths of the study. Foremost, we included the perceptions of women that accepted and declined fertility preservation, which allows for a wider breath of theoretical application. By implementing theoretical sampling, we were able to target and interview women with varying experiences surrounding information processing. The sample also mirrors nascent data in that most women interested in and choosing to undergo fertility preservation are diagnosed with breast cancer or lymphoma (Klock, Zhang, & Kazer, 2010; Lawrenz et al., 2011). Our sample also included the experiences of women from underrepresented cancer types for which there is a dearth of knowledge on fertility decisions (e.g., leukemia, ovarian). As more women survive cancer, the findings add much needed theoretical knowledge about information processing and

provide thick descriptions of how nurses, physicians, and other clinicians can facilitate these processes.

Conclusion

Increasingly women are faced with making lifesaving cancer treatment decisions and simultaneously they are asked to think about the potential consequences of cancer therapy on their future ability to have children. Our findings demonstrate that information processing can be broken down into five conceptual dimensions within the Contemplate phase of the decision-making process framework. In these dimensions, women contemplate and engage in information processing activities to formulate a decision about fertility preservation. There are multiple strategies that nurses and other clinicians can implement to aid young women as they acquire and process information. These include strategies for clinicians at the individual, intra-professional, and across specialty areas. Future research that explores the information processes of women from other socioeconomic and cultural contexts would add to theoretical understanding. Uncovering clinician's perceptions and examining and evaluating strategies that facilitate information processing and decision making would also be helpful to improving care for young women with cancer.

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Figure 1. Theoretical Framework of the Decision-Making Process of Young Adult Women with Cancer

From: "The Decision-Making Process of Young Adult Women with Cancer Who Considered Fertility Cryopreservation" by P.E. Hershberger, L. Finnegan, P.F. Pierce, and B. Scoccia, 2013, *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 42(1), 59–69. Copyright 2012 by Association of Women's Health, Obstetric and Neonatal Nurses. Reprinted with permission.

Table 1

Interview Guide: Examples of Questions and Probes

1	How did you learn about egg/embryo/uterine tissue freezing and who, if anyone, was involved in this learning process?
2	What information was helpful to you? And what information was not helpful to you?
3	In learning about egg/embryo/uterine tissue freezing did you seek-out information beyond the information that your doctor, nurse or other healthcare clinicians were giving you? If so, please let me know where you looked and what was helpful for you?
4	Was there information that you might have liked to know about regarding fertility freezing options but could not get answers for or was not available? If so, can you please tell me about this?
5	Can you tell me about ways that information about fertility freezing options was communicated or provided to you that were helpful? And ways of communicating or providing information that were not helpful?
6	Is there anything about your obtaining or understanding information about fertility preservation options that was or was not helpful to you that I have not asked about? If so, could you describe this to me?

Table 2

Sociodemographic Characteristics of Quoted Participants

Participant*	Age	Race & Ethnicity**	Marital Status	Cancer Type	Employment Status	Education (In Years)	Income Level
1 [A]	19	White	Living with Partner	Leukemia	Student	13	\$20,000–24,999
2 [D]	30	Black	Married	Breast	Full-time	16	\$100,000–124,999
3 [A]	27	White	Single	Ovarian	Part-time	14	\$4,999 or less
5 [A]	30	White	Married	Breast	Full-time	17+	\$50,000–54,999
6 [A]	30	White	Single	Breast	Full-time	16	\$45,000–49,999
7 [A]	23	White & Hispanic	Single	Leukemia	Student	13	\$5,000–9,999
8 [A]	37	White	Married	Ovarian	Full-time	16	\$150,000 or more
9 [D]	36	White	Married	Breast	Full-time	17+	\$70,000–74,999
10 [D]	34	Black	Married	Breast	Full-time	17+	\$90,000–94,999
12 [D]	40	Other & Hispanic	Married	Breast	Full-time	17+	\$110,000–129,999
13 [A]	35	White	Single	Breast	Full-time	17+	\$70,000–89,999
15 [D]	32	White	Married	Hodgkin's	Full-time	17+	\$50,000–69,999
16 [D]	27	White	Married	Breast	Full-time	17+	\$110,000–129,999
17 [A]	31	White	Married	Breast	Full-time	17+	\$70,000–89,999
19 [D]	25	White	Single	Ovarian	Student	15	\$50,000–69,999
20 [D]	29	White	Single	Hodgkin's	Full-time & Student	17+	\$50,000–69,999
22 [D]	21	White	Single	Ovarian	Student	14	\$50,000–69,999
23 [A]	23	White	Married	Hodgkin's & Kidney	Student	17+	\$50,000–69,999
24 [D]	24	White	Single	Breast	Student	17+	\$110,000–129,999
25 [A]	34	White	Married	Breast	Full-time	15	\$110,000–129,999
26 [D]	22	White	Single	Hodgkin's	Student	17+	\$130,000 or more

Notes:

* [A] = Accepted fertility preservation

[D] = Declined fertility preservation

** Ethnicity is "Hispanic" as when indicated or "Not Hispanic or Latino" when not indicated