

# Communication Difficulties and the Experience of Loneliness in Patients With Cancer Dealing With Fertility Issues: A Qualitative Study

Joline Goossens, MSc, RM, Ilse Delbaere, PhD, MSc, RM, Dimitri Beeckman, PhD, MSc, RN, Sofie Verhaeghe, PhD, MSc, RN, and Ann Van Hecke, PhD, MSc, RN

Cancer treatment can affect a patient's fertility (Diedrich, Fauser, & Devroey, 2011; Matthews et al., 2012), but its impact is difficult to predict because of a variety of factors related to the patient, disease, and therapy (Ajala, Rafi, Larsen-Disney, & Howell, 2010; Diedrich et al., 2011; Matthews et al., 2012). Fertility preservation includes medical and surgical treatments to decrease the impact of cancer therapy on future fertility (Matthews et al., 2012). The treatments can be offered to patients of reproductive age who are at risk for fertility problems, but they do not ensure a successful pregnancy. Therefore, uncertainty about future fertility and parenthood remains for many patients with cancer.

As the number of young cancer survivors increases, cancer survival cannot be the only focus within cancer care (Herbst et al., 2006; Howlader et al., 2012). Long-term quality-of-life issues, such as future fertility and parenthood, deserve attention (Valdivieso, Kujawa, Jones, & Baker, 2012).

Several studies have revealed that fertility and biologic parenthood are major issues for patients with cancer in the reproductive years and particularly for those with a desire to have children (Lee et al., 2006; Quinn, Murphy, Wang, Sawczyn, & Knapp, 2013). Previous studies have found that impaired fertility from cancer treatment has a negative impact on quality of life for cancer survivors. The psychological impact of cancer-related infertility is comprised of emotional distress, reproductive concerns, loss of identity, depression, and grief (Carter et al., 2005, 2010; Gorman, Bailey, Pierce, & Su, 2012; Perz, Ussher, & Gilbert, 2014). Infertility can also place strain on couples' relationships (Penrose, Beatty, Mattiske, & Koczwara, 2013; Perz et al., 2014). Single cancer survivors with the potential for fertility problems may experience difficulties in starting new relationships because of past rejection or the fear of being rejected by a potential partner (Zebrack, Casillas, Nohr, Adams, & Zeltzer, 2004).

**Purpose/Objectives:** To explore communication difficulties and the experience of loneliness among patients with cancer dealing with fertility issues.

**Design:** Qualitative study based on grounded theory principles.

**Setting:** One university hospital and two general hospitals in Flanders, Belgium.

**Sample:** 21 female and 7 male patients with cancer with potential fertility problems as a result of treatment.

**Methods:** Grounded theory approach using the constant comparison method; data collection (semistructured face-to-face interviews) and analysis occurred simultaneously.

**Findings:** Loneliness was a central theme in the experience of potential fertility loss among patients with cancer. Feelings of loneliness resulted from communication difficulties between the patient and members of his or her social environment or healthcare professionals because of several underlying processes and influencing factors.

**Conclusions:** Loneliness was a strong and common feeling among patients with cancer. Patients, members of their social environment, and healthcare professionals experienced difficulties in communicating about fertility in the context of cancer, leading to patients' feelings of loneliness.

**Implications for Nursing:** Healthcare professionals must be attentive to signs indicating loneliness regarding fertility concerns, and they should provide adequate information and appropriate guidance to support patients. Professionals need further training to improve knowledge and skills.

**Key Words:** oncofertility; cancer; infertility; loneliness; communication; qualitative research

ONF, 42(1), 34–43. doi: 10.1188/15.ONF.34-43

Oncofertility is a relatively new field of medicine that bridges the fields of oncology and reproductive medicine (Woodruff, 2010). Despite growing interest in the psychosocial aspects of oncofertility, gaps in research remain. To the authors' knowledge, extensive studies exploring the experience, psychosocial impact, and underlying processes of fertility problems among patients with cancer regardless of gender, cancer type, and illness trajectory are limited.

The purpose of this article is to describe a deeper understanding of the underlying processes and influencing factors of communication difficulties and the experience of loneliness among patients with cancer who are dealing with fertility issues. This study is part of a larger research project that explored the experience of patients with cancer who were confronted with their potential loss of fertility; the project also investigated their information and guidance needs. A qualitative research design was used in the current study, which gave researchers the ability to explore this sensitive subject in detail.

## Methods

A qualitative approach based on the principles of grounded theory (Glaser & Strauss, 1967) was chosen to explore the experience of fertility issues among patients with cancer in the main research project. During the analysis, the experience of loneliness emerged as a core theme. The constant comparison method of analysis was used so that data collection and analysis occurred simultaneously. New participants were selected through theoretical sampling, and data collection continued until data saturation was reached.

## Participants

From March 2012 to July 2013, patients with cancer were recruited from one university hospital, Ghent University Hospital, and two general hospitals, Saint Lucas and Saint Jan general hospitals, all in Flanders, Belgium. The hospitals' ethics committees approved the study. The inclusion criteria for this study consisted of a diagnosis or history of cancer, an age of 15–45 years at the time of diagnosis, cancer treatment with potentially gonadotoxic therapy, a good prognosis with disease-free survival, and fluency in Dutch. Survivors of childhood cancer were excluded. A healthcare professional who had direct patient contact with potential participants was appointed in each hospital. If a patient met the inclusion criteria, the designated professional contacted the main researcher of the study to verify whether the patient was eligible for inclusion. At the study's start, all patients who met the inclusion criteria were recruited. As the study progressed and insights emerged from data analysis, theoretical sampling was used. Results indicated that some patients with cancer find it more difficult to cope with fertility loss and the decision-making process regarding fertility preservation. To gain further insight into these processes and experiences, patients who were more likely to experience difficulties regarding aspects of fertility in the context of cancer (i.e., female; aged 25 years or younger; oocyte, embryo, or ovarian tissue cryopreservation; and patient refusal or medical contraindication

to preserve fertility) were selected. The designated professional asked permission for the researcher to contact the patients, and all except two agreed to be contacted. After receiving approval, the researcher called patients individually to provide extensive information about the study's aim and procedures. Patients were asked to participate in a face-to-face interview and allowed to choose the location and date. All (N = 28) agreed to participate in the study. A signed, written informed consent was obtained from all participants before the start of the interview.

During the course of the study, 29 semistructured interviews were conducted with 28 participants. One

**Table 1. Sample Characteristics (N = 28)**

Characteristic	$\bar{X}$	SD	Range
Age at diagnosis (years)	27.9	6.4	13–41
Time since diagnosis (years)	2.5	3.1	0–11
Characteristic	n		
<b>Gender</b>			
Female	21		
Male	7		
<b>Profession</b>			
White-collar worker	20		
Student	4		
Unemployed	3		
Blue-collar worker	1		
<b>Partner</b>			
Yes	23		
No	5		
<b>Children</b>			
No	22		
Yes	6		
<b>Cancer type</b>			
Breast cancer	9		
Lymphoma	6		
Testicular cancer	6		
Cervical cancer	2		
Brain tumor	1		
Dysgerminoma	1		
Hydatidiform mole	1		
Renal cell cancer	1		
Sarcoma	1		
<b>Illness trajectory</b>			
Treatment	7		
Follow-up	20		
Palliative	1		
<b>Fertility preservation</b>			
No	15		
Yes	13		
<b>Desire for children</b>			
Future	15		
Current	5		
Doubtful	3		
No	3		
Fulfilled	2		

*Note.* Two patients did not fully meet the inclusion criteria because one was a childhood cancer survivor and the other was in a palliative stage, but the research team included their interviews in the analysis to enrich the constant comparison method.

participant was interviewed twice: once at the start of cancer treatment and again after completing therapy. Of the participants, 21 were women and 7 were men, and they ranged in age from 19–44 years, with an average age of 30 years (see Table 1). Thirteen patients had preserved their fertility. The majority of the participants had a future ( $n = 15$ ) or current ( $n = 5$ ) desire for children at the time of the interview. Unintentionally, one interview took place with a participant who had been diagnosed with childhood cancer, and another interview involved a participant in a palliative stage. The research team decided to include these interviews because they allowed for the refining and strengthening of findings, which enriched the constant comparison method of analysis. The different cancer history and prognosis were taken into account in the analytic process.

## Data Collection

Semistructured face-to-face interviews were conducted using an interview guide. The guide was developed through a review of the literature. Topics included the experience of potential fertility loss and related emotions, the decision-making process regarding fertility preservation, fertility-related information and guidance needs, and the role of healthcare professionals. Each interview began with the same broad, open-ended question to invite participants to tell their story: “Could you tell me more about your experience with the subject of fertility and cancer?” During the process of data collection and analysis, the interview guide was adapted on the basis of new insights. As a result, two topics were added to the guide: the meaning of fertility and fertility loss, and the role of the social environment. As new insights emerged and the interview guide was refined, the interviewing style evolved from loosely structured in the beginning to more structured by the end. Interviews lasted, on average, 77 minutes (range = 31–116 minutes).

Twenty interviews were conducted by the main researcher, and nine were conducted by another researcher who was also involved in the data analysis. Twenty-eight interviews took place at participant homes, and one took place in an interview room at Ghent University Hospital. All interviews were audio recorded and fully transcribed by an experienced transcriptionist. The transcriptions of the first five interviews were verified by the researcher who conducted the interviews. The remaining transcripts were double-checked only if the transcriptionist experienced difficulties in understanding words or sentences from the audio recording.

## Data Analysis

The constant comparison method of analysis was used. This method involves a cyclic process in which

newly collected data are compared with previously emerged insights (Glaser & Strauss, 1967). All interviews were read several times to develop an overall picture of the situation and to grasp details. The transcripts were imported into NVivo 10 qualitative data analysis software and were coded. Themes and subthemes were constructed by studying the transcripts and codes. The findings were validated by researcher triangulation; two researchers followed the constant comparison process closely. Each researcher individually read 12 transcripts, identified and checked codes, and discussed themes and meanings. Halfway through the study, two other senior researchers and two oncology professionals (an advanced nurse practitioner and an oncopsychologist) joined the analytic discussion with the other researchers. All read a different transcript that was selected randomly by one researcher before discussing their findings and interpretations with one another. This analysis resulted in seven core themes related to fertility and cancer: (a) the meaning of fertility and fertility preservation, (b) hope and uncertainty, (c) coping with potential fertility loss, (d) the decision-making process regarding fertility preservation, (e) information and guidance needs, (f) the role of the social environment, and (g) loneliness. Loneliness was the central theme of several interviews. This theme became evident as data were collected and analyzed for the main study. The insights regarding the experience of loneliness and other central themes guided further data collection for the main research project. Data saturation was reached for all themes except those concerning the meaning of fertility and fertility preservation and the decision-making process regarding fertility preservation because of time restrictions.

## Findings

Loneliness was expressed in most interviews and was a central theme in the experience of potential fertility loss among patients with cancer regardless of age, gender, or overall social support. Even participants who stated that they had support during cancer treatment expressed feelings of loneliness concerning fertility issues. Although some participants used the terms *loneliness* or *feeling alone* when discussing their experiences with potential fertility loss, most used the phrase “being on your own.” In particular, patients who experienced multiple fertility concerns and found it hard to cope with those worries felt alone in confronting potential fertility loss. A 32-year-old woman with lymphoma said,

Eventually, you are on your own. You have to bear it. You have to cope with it. You have to. . . . It feels good to talk about it, yes. . . . But, for me, it is something I have to undergo and I have to learn to live with.

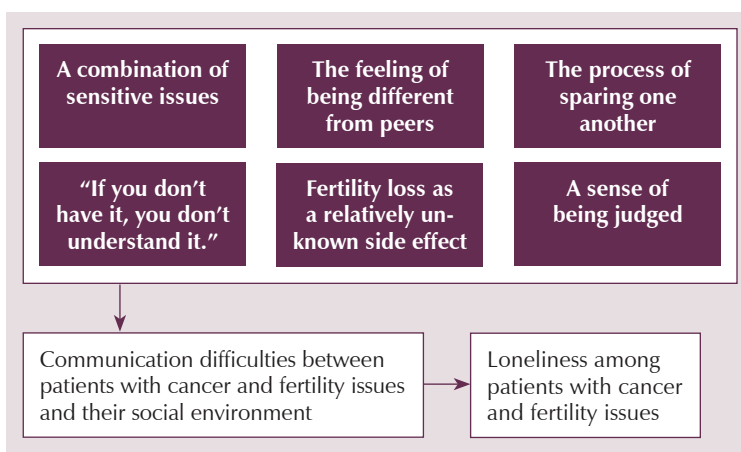
Participants experienced loneliness regarding fertility issues throughout different stages of the illness trajectory. For example, several participants felt lonely in the decision-making process regarding fertility preservation during the diagnostic phase, and some kept struggling with fertility concerns throughout the treatment and follow-up phases. Several participants found it difficult to discuss fertility concerns with their loved ones and tried to cope with them alone. Some participants experienced a distancing or a breakup in relationships involving themselves and significant others, family members, or friends. A 28-year-old woman with breast cancer said,

I decided to get a divorce . . . because that [fertility] was difficult to talk about. . . . We had a different point of view. [I received little] support as well in that difficult period, or he supported me, but I did not understand his support.

Loneliness regarding fertility concerns in the context of cancer was often a consequence of difficult communication between participants and others. Participant narratives revealed that they and significant others or healthcare professionals avoided discussing fertility and cancer. Avoidance also manifested in more subtle ways. Some patients talked about fertility with people in their social environment but on a practical or superficial level. A 28-year-old woman with breast cancer said, "That [conversation about fertility and fertility preservation with parents] was just the practical side: 'They are going to operate [on] me, and during that operation, they are going to remove ovarian tissue . . . just in case.'"

Participants experienced internal resistance and resistance from others about discussing fertility issues. Several processes and factors hindered communication between the participant and individuals in his or her social environment or healthcare professionals, leading to feelings of loneliness among patients with cancer dealing with fertility issues. A 29-year-old woman with breast cancer said,

When I hear people talk [about having children], I think, "Yes, it is a matter of course for all of you and no problem." . . . That carelessness about that theme . . . is something, yes. . . . You can tell people about it, but if you don't have it, you don't understand it. . . . I also notice that when I am sitting in the waiting room before radiotherapy. Last week, [I was] with three other women, also with breast cancer. You say one word, and you understand each other. That is, of course, something you do not have with other people. So, yes . . . sometimes I feel a bit lonely.



**Figure 1. Conceptual Model of Communication Difficulties and Loneliness Between Patients With Cancer and Fertility Issues and Their Social Environment**

A 19-year-old woman with renal cell cancer said,

Sometimes I think to myself, "Come on. How can you cope with all of that on your own?" Sometimes I am very silent in class, and they [fellow students], of course, don't know what I am thinking about. Sometimes I am thinking about my disease [cancer] . . . and that I am unable to have children. If I think about that . . . [then] I become silent in class. [Fellow students say,] "What is it? What is it?" and, "Tell me. Tell me." No, I cannot tell them. . . . Sometimes I have a really rough time, and sometimes I do not even think about it. But sometimes, if I do think about it, it is really difficult for me. I am someone who is hiding a lot of feelings inside.

### Communication Difficulties Between Patients and Their Social Environment

Data analysis revealed different underlying processes and influencing factors that contribute to communication difficulties regarding fertility in the context of cancer: a combination of sensitive issues, the feeling of being different from peers, the process of sparing one another, the inability of family members and others to understand the experiences of participants, fertility loss being a relatively unknown side effect of cancer treatment, and a sense of being judged (see Figure 1).

**A combination of sensitive issues:** Participants described fertility as an intimate issue, comparable to sexuality, which was often discussed only in a safe and confidential atmosphere. Cancer, particularly for young participants, was also a sensitive topic because it is associated with terrible suffering and death. Having cancer and fertility problems, which is a combination of sensitive issues, led to avoidance. A 28-year-old woman with breast cancer said, "Cancer in younger people,



that seems to be taboo . . . and then the fertility aspect on top, yes, that is an even bigger taboo."

**The feeling of being different from peers:** Participants reported that having a family with children is considered to be standard and normal in society. Participants who were in their 20s or 30s, a stage of life where having children is considered to be a logical next step, felt the pressure to fulfill this social norm. They often were confronted with this norm indirectly (e.g., by peers who had or were expecting a child) and directly (e.g., "When will you start a family?" "Why do you not have children?"). A 32-year-old woman with lymphoma said,

I work in the neonatology unit, and then they [parents of admitted infants] ask, "How many children do you have?" [I respond,] "None." Yes, that is normal for those to ask. . . . [They ask,] "And how come [you do not have children]?" Then I reply, "Oh, madam, we still have time." That is none of their business. Those are daily questions at work.

Patients with cancer often considered themselves as not meeting the norm or standard. They believed that being healthy, fertile, and having children was a certainty, but, because they had cancer, these aspects of life could no longer be taken for granted. As a result, participants felt different from their peers. These feelings often led to distance between participants and others, resulting in little or no communication about fertility and parenthood.

Several participants indicated that peer support groups were helpful in the process of coping with cancer. In these groups, participants met others going through similar circumstances, which often made them feel comfortable, safe, and more willing to share their feelings and experiences. However, most of the other patients with cancer in the peer support groups were older and had fulfilled their desire for children. As a result, participants with fertility concerns differentiated themselves from other patients with cancer, leading to insufficient peer support regarding fertility issues. A 28-year-old woman with breast cancer said,

I attended several lectures [for fellow patients and organized by peer support groups]. That was beneficial for me because I saw a lot of similarities [among our stories]. But, again, they all have a fulfilled desire for children. So that topic [fertility] was not addressed.

**The process of sparing one another:** Sparing one another can be defined as a person's avoiding an emotionally difficult subject through silence or a solely positive approach with the aim of protecting himself or herself or others against extra harm. Participants and their family members protected one another by avoiding discussion about fertility.

Patients spared others for several reasons. They felt that talking about a topic as difficult as fertility could cause extra worries aside from the daily stress that family members already experience when confronted with a relative with cancer. A 19-year-old woman with renal cell cancer said, "I will not cry on my mother's shoulder and say, 'Oh, mummy, I am unable to have children,' because I know that will hurt my mother. I am more concerned about my mother's, father's, and brothers' feelings." This desire to protect others was particularly true for participants who felt supported in their cancer trajectory; they did not want to overburden their family members. Participants also believed that others could not cope with negative emotions and presumed that their family members would feel uncomfortable or experience difficulties in adopting a supportive attitude toward the patient on this subject.

Participants also spared themselves for different reasons. Talking about potential fertility loss was difficult and could be burdensome. A 19-year-old woman with renal cell cancer said, "I did not want to talk [about potential fertility loss] with my psychologist. . . . I did not want to talk about it again because then I become a bit angry . . . angry because of it." Patients with cancer may not want to be pitied by others for having potential fertility problems. Some participants also felt as though they were unable to initiate a discourse about fertility problems or were uncomfortable discussing them.

Participants believed that people in their social environment spared them for three reasons. First, family members were afraid to hurt, confront, or emotionally overload them while they were already in the midst of a difficult period. A 23-year-old woman with sarcoma said,

I told him [patient's spouse], "Why do you not open up to me?" He has a good friend with whom he talks a lot, but he finds it really hard to open up to me. He said, "You already feel poorly, so I do not want you to know that I feel bad [about the fertility loss]. I have also cried about it, about the fertility [loss], but I just do not tell you."

Second, difficult issues were not addressed by people in participants' social environment to ensure that participants maintained a positive and empowered attitude during treatment. They did not want to waste energy on perceived side issues such as fertility. Third, fertility issues were not mentioned by family members out of ignorance and fear. Talking about fertility issues may cause participants to experience emotions with which people in the social environment were not able to cope.

Participants also believed that their loved ones spared themselves. For a spouse, a participant's infertility implied a potential loss of becoming a parent. People in the immediate social environment also

protected themselves because it was too emotional for them to talk about. A 28-year-old woman with breast cancer said,

We already had a discussion about children formerly. My husband was like, “We . . . [have been] married for so long, and everyone in our social environment has children, and I want children as well.” But I was not ready to have children. So now I think he finds it difficult to talk about it because it already was a difficult issue for him.

**“If you don’t have it, you don’t understand it”:**

Although people in the social environment could be understanding and empathetic, they did not know how it felt to be confronted with cancer and cancer-related infertility unless they had experienced it firsthand. Participants assumed that family members could not understand what they had to endure; therefore, they did not try to explain. A 36-year-old woman with breast cancer said,

I think a lot of people would have a negative attitude [toward postponing cancer treatment for fertility preservation], especially my parents. They focus on a complete recovery, and they are like, “Do not think about that [fertility].” If I told them [about postponing treatment], I think they would be angry because I would delay everything and increase the risk of metastasis.

**Fertility loss as a relatively unknown side effect:** In contrast to well-known side effects of cancer therapy, such as nausea, hair loss, and fatigue, the risk of impaired fertility was relatively unknown. Family members were often unaware of the impact of cancer treatment on fertility, the possibility of preserving fertility, and the complexity of that technique. As a result, participants found it difficult to explain or talk about these issues with people in their social environment. A 25-year-old woman with breast cancer said, “If you think about chemotherapy, the first thing you think

about [is that] you will lose your hair, [and] you will be nauseous. . . . Yes, that is the typical image we have of chemotherapy, and the rest . . . not really.”

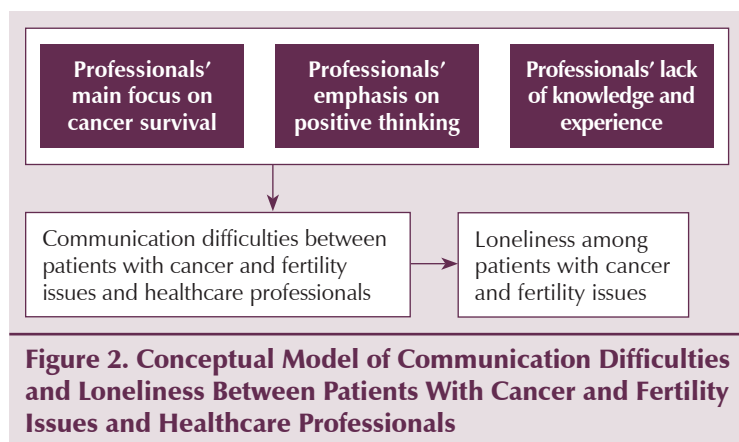
**A sense of being judged:** Some patients experienced criticism and insensitive remarks from family members regarding fertility issues. Patients often felt judged about fertility-related decisions, such as postponing their cancer treatment to preserve fertility or deciding to remain childless. Participants tried to avoid the judgment of others through silence or by changing the subject. A 29-year-old woman with breast cancer said,

[When people ask if I have or want children], then I tell them what the doctors told me. Most of the time, I also tell them that [fertility] is no . . . matter of course for us and that we are considering a life without children. That often leads to lack of understanding. For a lot of people of our age, having children is the greatest thing in life. And if you do not have children, you cannot imagine how that feels. I think that is very rude. Some people make such insensitive comments about it.

## Communication Difficulties Between Patients and Healthcare Professionals

Communication difficulties regarding the fertility aspect of cancer treatment also existed between participants and healthcare professionals. Several factors impeded patient-caregiver communication about fertility issues: a main focus on cancer survival, an emphasis on positive thinking, and a lack of knowledge and experience regarding oncofertility care by healthcare professionals (see Figure 2).

**A main focus on cancer survival:** Participants had the impression that survival was the primary focus of healthcare professionals because scarce attention was paid to the impact of cancer treatment on fertility. Participants often complained about the lack of information regarding fertility and cancer by healthcare professionals. Several participants received little or no information about the impact of treatment on fertility or the possibility of preserving fertility. Sometimes they had to introduce the topic themselves. Participants believed that fertility issues were considered by healthcare professionals to be a low priority and a future problem. Participants also felt that healthcare professionals assumed that patients thought about fertility as a side issue. The life-threatening character of cancer seemed more predominant for healthcare professionals. As a result, participants were reluctant to talk about fertility issues with their healthcare professionals, which led to silence about fertility in the



context of their cancer. A 32-year-old man with a brain tumor said,

The doctors were like, "Are you really thinking about that [fertility] right now?" They found it really strange. They focused more on the fact [of], "How can we make sure that T. survives as long as possible?" I think they had other priorities.

**An emphasis on positive thinking:** Participant narratives revealed that healthcare professionals wanted patients with cancer to have a positive and empowered attitude, which could help them during treatment. A negative attitude may hinder survival. Participants felt that healthcare professionals avoided matters that could dishearten patients with cancer and evoke negative emotions, such as a conversation about potential fertility loss. A 44-year-old woman with breast cancer said,

They [healthcare providers] never talked about it in depth. It was always like, "First, take care of yourself, and do not worry about that. Use all your energy to cure, and later we can focus on the subject [of] children."

**A lack of knowledge and experience:** Patients had the impression that professionals were not familiar with oncofertility care, resulting in fragmentation of care. The care provided by oncology healthcare professionals was mainly focused on cancer, and if patients wanted information or guidance regarding their fertility, they were referred to a fertility specialist. A 32-year-old man with testicular cancer said,

I wanted to ask information about sperm cryopreservation, but he [the urologist] stood up constantly. I did not like that. I believe I asked, "Where can I preserve sperm?" . . . He responded, "Go to the gynecology ward." I found that really odd. . . . It meant that I could not count on him.

Participants perceived the information and guidance provided by fertility healthcare professionals to be too one-sided and focused only on fertility issues. Participants viewed this fragmented care as a shortcoming because they did not consider themselves to be a typical fertility patient. They believed fertility healthcare professionals were unfamiliar with cancer and cancer care, which made it difficult for participants to talk about fertility issues in the context of cancer.

## Discussion

Loneliness regarding fertility concerns in the context of cancer was a strong and common feeling among participants. Research on the experience of cancer reveals that having cancer or being a cancer survivor can be a lonely experience (Rokach, 2003; Sevil, Ertem, Kavlak, & Coban, 2006; Wells & Kelly, 2008; Zhang & Siminoff,

2003). Loneliness is also a dominant feeling in patients with fertility problems (Hinton, Kurinczuk, & Ziebland, 2010). Because loneliness is present in patients with cancer and patients with fertility problems, the fact that patients diagnosed with cancer and confronted with fertility issues are also expressing feelings of loneliness is unsurprising. However, the experience of loneliness regarding fertility and cancer seems more complex among these patients because more factors and underlying processes are involved.

Results of this study indicate that feelings of loneliness were the result of communication difficulties between the participant and significant others or healthcare professionals regarding cancer and fertility. Wells and Kelly (2008) argued that society lacks openness regarding cancer and the impact on the patient, and silence remains. In patients with fertility problems, Allison (2011) attributed elements of isolation and loneliness to a lack of openness regarding the topic of infertility.

Several underlying processes and influencing factors were associated with difficult communication about fertility issues among participants, people in their social environments, and healthcare professionals. Participants and their family members experienced communication difficulties stemming from a number of factors. Previous studies involving patients with cancer and patients with infertility revealed similar findings. For example, the desire of patients and people in their social environment to spare one another is also found in literature on avoidance of communication in patients with cancer (Zhang & Siminoff, 2003) and in patients with fertility problems (Allison, 2011; Imeson & McMurray, 1996; Kirkman, 2001). A study by Crawshaw (2013) investigated the impact of social influences on male cancer survivors' fertility-related experiences. Similar to the current study's findings, results indicated that some patients were not being open about their fertility issues to appear normal and to avoid social rejection and associated stigma. Feeling different from peers is also described in several studies exploring the experiences of patients with fertility problems. Reproduction and having an ideal family is the societal norm, which creates social pressure to have children. Failure to fulfill this norm leads to social stigma and silence, causing loneliness (Allison, 2011; Imeson & McMurray, 1996).

Of note, the attitude and skills of healthcare professionals had an influence on the communication process and feelings of loneliness in patients with cancer. Participants felt reluctant to talk about fertility issues with their healthcare professionals as a result of professionals' emphasis on positive thinking, one-sided focus on cancer survival, and lack of knowledge and experience regarding oncofertility care. To the authors' knowledge,



this is the first study that extensively describes the underlying processes of communication difficulties between young patients with cancer who were receiving potentially gonadotoxic therapy and cancer, fertility, and oncofertility healthcare professionals, as well as the association between communication difficulties and loneliness.

## Limitations

This qualitative study does not claim to be representative of all patients with cancer. The majority of participants were women. Findings indicated that the decision-making process regarding fertility preservation was more complex for women than for men. As a result, more interviews with women took place to investigate the process in depth. The majority of participants were interviewed during the follow-up phase. Although designated healthcare professionals were asked to inform patients about the study during the diagnostic phase, no participants in this phase were recruited. Healthcare professionals may have found it inappropriate to inform patients in the diagnostic phase, which is characterized by overwhelming feelings, an excess of information, and numerous medical consultations (Gardino & Emanuel, 2010; Kessels, 2003; Patterson, Millar, Desille, & McDonald, 2012). Socioeconomic status was derived from the profession or education of the participant, the participant's vocabulary and grammar, and the location of the interview. Other socioeconomic data, such as household income, was not requested, but the majority of participants seemed to be members of the middle class.

Although only Dutch-speaking patients in Flanders, Belgium, were interviewed, the authors believe that the study's findings can be generalized to a broader population of patients with cancer with potential fertility problems. These findings refer to the general human experiences of patients with cancer who are dealing with fertility issues.

## Implications for Nursing

Oncofertility is a relatively new field in cancer care (Woodruff, 2010). Results from the current study indicate a lack of knowledge and skills among healthcare professionals regarding oncofertility and suggest that healthcare professionals need further training to provide adequate care for patients with cancer who are facing potential fertility problems.

Oncofertility integrates two separate specialties: oncology and reproductive medicine (Woodruff, 2010). However, participants in this study reported that oncology care and fertility care were provided separately and independently from each other, leading to fragmentation. A multidisciplinary approach may reduce fragmented

care. Based on the results of the main qualitative research project (Goossens et al., 2013) and a mixed-methods systematic review regarding fertility-related information (Goossens et al., 2014), the following recommendations to improve multidisciplinary collaboration between oncology and fertility healthcare professionals could be formulated: (a) coordinate care between oncology and reproductive medicine units, (b) create a shared vision regarding fertility preservation in patients with cancer, (c) establish agreements on referral and oncofertility care, (d) regularly schedule interdisciplinary team meetings, (e) maintain comprehensive and clear medical records, (f) inform all healthcare professionals about fertility-related decisions and procedures, and (g) designate a contact person in each unit.

Nurses and other healthcare professionals must be attentive to signs indicating loneliness regarding fertility concerns, and they should provide adequate information and appropriate guidance to support patients. Guidance should include providing psychological support about cancer and fertility, starting a conversation about fertility in the context of cancer, listening to patients' experiences, and exploring patient support systems, such as significant others, family members, and friends. Further research with a focus on the extent and consequences of fertility-related loneliness, patients at risk, and methods to prevent and decrease loneliness because of fertility loss in the context of cancer could help to gain more insight regarding the topic.

This study's findings suggest that peer support groups are helpful in the process of coping with cancer, but that they are insufficient regarding fertility issues because typically most patients are older and have already fulfilled their desire for children. Peer support groups for younger patients with cancer who are in the same stage of life could be helpful for patients dealing with cancer and fertility issues. Peer-to-peer support (also known as the *buddy system*) is a support system where a patient monitors and supports another patient. Several studies revealed that the buddy system is helpful and appreciated in patient groups (Burrage & Demi, 2003; Preyde & Ardal, 2003; Sattoe, Jedeloo, & van Staa, 2013).

Future research on the role of online peer support groups and the buddy system among patients with cancer dealing with fertility issues would be useful. Additional research is also needed concerning the role of the patient's social environment. Many participants in the current study reported that significant others, family members, and friends experienced difficulties in discussing fertility issues. Assessing the experience and needs of members of the patient's social environment and investigating how healthcare providers can support communication and involvement of those members would be worthwhile endeavors that may result in improvement of the patient's support system.



## Knowledge Translation

Communication difficulties between the patient with cancer and members of his or her social environment or healthcare professionals can result in feelings of loneliness.

Information and support provided by healthcare professionals seem to have an important impact on the communication process and on the experience of patients with cancer dealing with fertility issues.

A multidisciplinary approach may reduce fragmented care and improve the quality of oncofertility care.

## Conclusion

The current study provides insights into the underlying processes and influencing factors of communication difficulties and the experience of loneliness among patients with cancer who are dealing with fertility issues. These findings suggest that loneliness is a strong and common feeling among patients. Loneliness is the consequence of communication difficulties between the

patient and members of his or her social environment or healthcare professionals. Information and support provided by healthcare professionals seem to have an important impact on the communication process and experience of patients with cancer who are dealing with fertility issues. A multidisciplinary approach in oncofertility care is necessary to provide adequate care to patients with cancer who face potential fertility problems.

*The authors gratefully acknowledge the participants who were willing to share their time and stories.*

Joline Goossens, MSc, RM, is a doctoral student, Ilse Delbaere, PhD, MSc, RM, is a postdoctoral assistant, Dimitri Beeckman, PhD, MSc, RN, is a professor, Sofie Verhaeghe, PhD, MSc, RN, is a professor and head of the University Centre for Nursing and Midwifery, and Ann Van Hecke, PhD, MSc, RN, is a professor, all in the Department of Public Health at Ghent University in Belgium. This study was funded by the Flemish League Against Cancer. Goossens can be reached at [jolgoossens@ugent.be](mailto:jolgoossens@ugent.be), with copy to editor at [ONFEditor@ons.org](mailto:ONFEditor@ons.org). (Submitted March 2014. Accepted for publication August 12, 2014.)

## References

- Ajala, T., Rafi, J., Larsen-Disney, P., & Howell, R. (2010). Fertility preservation for cancer patients: A review. *Obstetrics and Gynecology International*, 2010, 160386. doi:10.1155/2010/160386
- Allison, J. (2011). Conceiving silence: Infertility as discursive contradiction in Ireland. *Medical Anthropology Quarterly*, 25, 1–21. doi:10.1111/j.1548-1387.2010.01123.x
- Burrage, J., & Demi, A. (2003). Buddy programs for people infected with HIV. *Journal of the Association of Nurses in AIDS Care*, 14, 52–62. doi:10.1177/1055329002239190
- Carter, J., Raviv, L., Applegarth, L., Ford, J.S., Josephs, L., Grill, E., . . . Barakat, R.R. (2010). A cross-sectional study of the psychosexual impact of cancer-related infertility in women: Third-party reproductive assistance. *Journal of Cancer Survivorship*, 4, 236–246. doi:10.1007/s11764-010-0121-2
- Carter, J., Rowland, K., Chi, D., Brown, C., Abu-Rustum, N., Castiel, M., & Barakat, R. (2005). Gynecologic cancer treatment and the impact of cancer-related infertility. *Gynecologic Oncology*, 97, 90–95. doi:10.1016/j.ygyno.2004.12.019
- Crawshaw, M. (2013). Male coping with cancer-fertility issues: Putting the 'social' into biopsychosocial approaches. *Reproductive BioMedicine Online*, 27, 261–270. doi:10.1016/j.rbmo.2013.04.017
- Diedrich, K., Fauser, B.C., & Devroey, P. (2011). Cancer and fertility: Strategies to preserve fertility. *Reproductive BioMedicine Online*, 22, 232–248. doi:10.1016/j.rbmo.2010.11.001
- Gardino, S.L., & Emanuel, L.L. (2010). Choosing life when facing death: Understanding fertility preservation decision-making for cancer patients. *Cancer Treatment and Research*, 156, 447–458. doi:10.1007/978-1-4419-6518-9\_34
- Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.
- Goossens, J., Delbaere, I., Decoene, E., Soetens, J., Grypdonck, M., Verhaeghe, S., & Van Hecke, A. (2013). *[Fertility and cancer. Guide for caregivers: Insights and recommendations]*. Retrieved from <https://biblio.ugent.be/input/download?func=downloadFile&recordId=4287906&fileId=4287939>
- Goossens, J., Delbaere, I., Van Lancker, A., Beeckman, D., Verhaeghe, S., & Van Hecke, A. (2014). Cancer patients' and professional caregivers' needs, preferences and factors associated with receiving and providing fertility-related information: A mixed-methods systematic review. *International Journal of Nursing Studies*, 51, 300–319. doi:10.1016/j.ijnurstu.2013.06.015
- Gorman, J.R., Bailey, S., Pierce, J.P., & Su, H.I. (2012). How do you feel about fertility and parenthood? The voices of young female cancer survivors. *Journal of Cancer Survivorship*, 6, 200–209. doi:10.1007/s11764-011-0211-9
- Herbst, R.S., Bajorin, D.F., Bleiberg, H., Blum, D., Hao, D., Johnson, B.E., . . . Mayer, R.J. (2006). Clinical cancer advances 2005: Major research advances in cancer treatment, prevention, and screening—A report from the American Society of Clinical Oncology. *Journal of Clinical Oncology*, 24, 190–205. doi:10.1200/JCO.2005.04.8678
- Hinton, L., Kurinczuk, J.J., & Ziebland, S. (2010). Infertility; isolation and the Internet: A qualitative interview study. *Patient Education and Counseling*, 81, 436–441. doi:10.1016/j.pec.2010.09.023
- Howlander, N., Noone, A.M., Krapcho, M., Neyman, N., Aminou, R., Waldron, W., . . . Cronin, K.A. (Eds.). (2012). *SEER cancer statistics review, 1975–2009 (Vintage 2009 populations)*. Retrieved from [http://seer.cancer.gov/csr/1975\\_2009\\_pops09](http://seer.cancer.gov/csr/1975_2009_pops09)
- Imeson, M., & McMurray, A. (1996). Couples' experiences of infertility: A phenomenological study. *Journal of Advanced Nursing*, 24, 1014–1022. doi:10.1111/j.1365-2648.1996.tb02938.x
- Kessels, R.P.C. (2003). Patients' memory for medical information. *Journal of the Royal Society of Medicine*, 96, 219–222. doi:10.1258/jrsm.96.5.219
- Kirkman, M. (2001). Thinking of something to say: Public and private narratives of infertility. *Health Care for Women International*, 22, 523–535. doi:10.1080/07399330127193
- Lee, S.J., Schover, L.R., Partridge, A.H., Patrizio, P., Wallace, W.H., Hagerty, K., . . . Oktay, K. (2006). American Society of Clinical Oncology recommendations on fertility preservation in cancer patients. *Journal of Clinical Oncology*, 24, 2917–2931. doi:10.1200/JCO.2006.06.5888
- Matthews, M.L., Hurst, B.S., Marshburn, P.B., Usadi, R.S., Papadakis, M.A., & Sarantou, T. (2012). Cancer, fertility preservation, and

- future pregnancy: A comprehensive review. *Obstetrics and Gynecology International*, 2012, 953937. doi:10.1155/2012/953937
- Patterson, P., Millar, B., Desille, N., & McDonald, F. (2012). The unmet needs of emerging adults with a cancer diagnosis: A qualitative study. *Cancer Nursing*, 35, E32–E40. doi:10.1097/NCC.0b013e31822d9105
- Penrose, R., Beatty, L., Mattiske, J., & Koczwara, B. (2013). The psychosocial impact of cancer-related infertility on women: A review and comparison. *Clinical Journal of Oncology Nursing*, 17, 188–193. doi:10.1188/13.CJON.188-193
- Perz, J., Ussher, J., & Gilbert, E. (2014). Loss, uncertainty, or acceptance: Subjective experience of changes to fertility after breast cancer. *European Journal of Cancer Care*, 23, 514–522. doi:10.1111/ecc.12165
- Preyde, M., & Ardal, F. (2003). Effectiveness of a parent “buddy” program for mothers of very preterm infants in a neonatal intensive care unit. *Canadian Medical Association Journal*, 168, 969–973.
- Quinn, G.P., Murphy, D., Wang, H., Sawczyn, K.K., & Knapp, C. (2013). Having cancer does not change wanting a baby: Healthy adolescent girls’ perceptions of cancer-related infertility. *Journal of Adolescent Health*, 52, 164–169. doi:10.1016/j.jadohealth.2012.05.011
- Rokach, A. (2003). Causes of loneliness of those afflicted with life-threatening illnesses. *Social Behavior and Personality*, 31, 663–674. doi:10.2224/sbp.2003.31.7.663
- Sattoe, J.N., Jedeloo, S., & van Staa, A. (2013). Effective peer-to-peer support for young people with end-stage renal disease: A mixed methods evaluation of Camp COOL. *BMC Nephrology*, 14, 279. doi:10.1186/1471-2369-14-279
- Sevil, U., Ertem, G., Kavlak, O., & Coban, A. (2006). The loneliness level of patients with gynecological cancer. *International Journal of Gynecological Cancer*, 16, 472–477. doi:10.1111/j.1525-1438.2006.00516.x
- Valdivieso, M., Kujawa, A.M., Jones, T., & Baker, L.H. (2012). Cancer survivors in the United States: A review of the literature and a call to action. *International Journal of Medical Sciences*, 9, 163–173. doi:10.7150/ijms.3827
- Wells, M., & Kelly, D. (2008). The loneliness of cancer. *European Journal of Oncology Nursing*, 12, 410–411. doi:10.1016/j.ejon.2008.11.003
- Woodruff, T.K. (2010). The Oncofertility Consortium—Addressing fertility in young people with cancer. *Nature Reviews. Clinical Oncology*, 7, 466–475. doi:10.1038/nrclinonc.2010.81
- Zebrack, B.J., Casillas, J., Nohr, L., Adams, H., & Zeltzer, L.K. (2004). Fertility issues for young adult survivors of childhood cancer. *Psycho-Oncology*, 13, 689–699. doi:10.1002/pon.784
- Zhang, A.Y., & Siminoff, L.A. (2003). Silence and cancer: Why do families and patients fail to communicate? *Health Communication*, 15, 415–429. doi:10.1207/S15327027HC1504\_03