Challenges having conversations about sexuality in ambulatory settings: Part I—Patient perspectives

by Margaret I. Fitch, Gerry Beaudoin and Beverley Johnson

Abstract

Introduction: *A cancer diagnosis and treatment can have a significant impact on an individual's quality of life. In particular, body image and sexuality can be compromised. However, there is increasing evidence that conversations about these consequences are not happening often between cancer patients and their health care providers. This is especially the case in busy ambulatory settings.*

Purpose: *This study was undertaken to explore the perspectives of cancer patients concerning the conversations that happen about sexuality following a cancer diagnosis in daily practice. There was a desire to understand more about the barriers that exist with regards to having this type of conversation.*

Methods: *Thirty-two cancer patients participated in interviews that explored their experiences with having conversations about sexuality. Transcripts of the interviews were subjected to a standard qualitative content and theme analysis.*

Findings: *Patients described many changes in their bodies following cancer treatment that had the potential to impact on sexuality, but actual concerns or problems about sexuality were highly individualized. Few had had conversations about sexuality with their health care providers. Most thought it was the responsibility of the cancer care team to "open the door" to the topic area.*

Conclusion: *The results support the idea that few conversations are taking place between cancer patients and their providers about sexuality. Innovative approaches are required to better meet patient needs.*

A diagnosis of cancer and its treatment can have a significant impact on an individual's quality of life (Tierney, 2008). Not only are there physical consequences, but there are emotional, psychosocial, spiritual, and practical consequences, as well. In particular, body changes and alterations in bodily functions can influence body image, self-esteem, fertility, and sexual functioning (Reese, 2011; Tan, Waidman, & Bostick, 2002). Sexuality is an important aspect of quality of life (Shell, 2002) and a central aspect of being human (WHO, 2002). Providing person centred or whole person cancer care includes attention to sexuality (Institute of Medicine, 2007) and is cited as an important dimension of quality cancer care (Institute of Medicine, 2001).

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However, studies about patient needs reveal sexuality concerns frequently remain unmet (Harrison, Young, Price, Butow, & Solomon, 2009). Patients have reported that these concerns are not always attended to during their visits with physicians and nurses (Fitch, Deane, & Howell, 2003; Hughes, 2000; Lindau, Surawska, Paice, & Baron, 2011; Penson, Gallangher, Gioiella, Wallace, Borden, Duska, et al., 2000). Health care professionals may be aware of the needs cancer patients have regarding sexual concerns, but it would appear discussion about sexuality may not be happening within daily practice. It remains unclear what is interfering with the necessary dialogue between cancer care providers and their patients.

Purpose

This study was undertaken to gain an increased understanding about the dialogue between cancer care professionals and cancer patients regarding the topic of sexuality. There is limited evidence to describe the barriers that exist which limit this dialogue, or how the barriers may be overcome in a busy ambulatory care setting. Ultimately, the work was undertaken to provide a foundation or basis for improving the care of cancer patients who have difficulties concerning sexuality related to their disease and treatment.

The study gathered views from both patients and health care professionals. This article focuses on the perspectives of the patients. The views of the health care providers will be reported in a separate article.

Background

In Canada, approximately 177,800 individuals are diagnosed with cancer annually (Canadian Cancer Society, 2011). This number is expected to increase by 50% by the year 2020 (International Union Against Cancer, n.d.; World Health Organization, n.d.). The impact of cancer treatment on individuals has been well documented and presents a clear picture of physical, psychosocial, emotional, and practical consequences (Fitch, Page, & Porter, 2008; Harrison, Young, Price, Butow, & Solomon, 2009). With advances in screening and treatment resulting in an ever increasing number of individuals who survive after treatment (Sun, Chapman, Gordon, Sivaramakrishna, Link, & Fish, 2002), the emphasis on survivorship and rehabilitation is more pressing than ever (Braude, Macdonald, & Chasen, 2008).

According to the World Health Organization, sexuality is a central aspect of being human throughout life (WHO, 2002). Sexuality is a multidimensional issue and involves physical, psychological, interpersonal and behavioural dimensions (Hughes, 2000). Expressed through various avenues, it concerns giving and receiving sexual pleasure and is associated with belonging and acceptance by another (Shell, 2002). Identity, self-image, and esteem are integral to sexuality (National Council on Aging, 1998).

Over the past decade, the literature describing the impact of cancer and its treatment on sexuality has grown considerably (Hordern, 2008; Mercadante, Vitrano, & Catania, 2010; Reese, 2011). From early publications regarding breast (Meyerowitz, Desmond, Rowland, Wyatt, & Ganz, 1999) and gynecologic patients (Andersen, Woods, & Copeland, 1997), the literature has expanded to now include other cancer groups such as lung (Reese, Shelby, & Abernethy, 2011), gastro-intestinal (Reese, Shelby, Keefe, Porter, & Abernethy, 2010), bladder (Fitch, Miller, Sharir, & McAndrew, 2010), hematology (Yi & Syrjala, 2009) and prostate (Latini, Hart, Coon, & Knight, 2009). Whereas much of the early work focused on sexual dysfunction and the physical changes following treatment, more publications now embrace a broader conceptualization of sexuality including body image, self-esteem, roles and relationships.

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The specific impact of cancer and its treatment on sexuality is closely aligned to the location of cancer and the nature of the treatment and can include loss of desire, erectile disorder, orgasmic dysfunction, and decreased sexual activity (Avis & Deimling, 2008; Eton & Lepore, 2002; Harrison et al., 2009; Jonker-Pool et al., 2001; Lockwood-Rayerman, 2006). There is a growing recognition that all modes of treatment have the potential to influence sexuality (Mercadante, Vitrano, & Catania, 2010) and the impact may be felt at any point along the cancer journey (Brearley, Stamataki, Addington-Hall, Foster, Hodges, Jarrett, et al., 2011), including with advanced and palliative stages (Redelman, 2008; Stausmire, 2004). Sexual concerns have been associated with higher symptom distress (Reese, 2011; Sarna, 1993) and have been reported by 10% to 90% of cancer survivors at some point during or following treatment depending upon the disease site, sex, and treatment type (Jeffry, 2001; Syrjala et al., 2000). Given this reality, clinicians caring for patients with all types of cancer ought to be taking issues of sexuality into consideration in their daily practice.

Unfortunately, there is a growing evidence from both quantitative and qualitative studies, that cancer patients have unmet sexuality needs. Following a review of 94 articles assessing supportive care needs of cancer patients, Harrison et al. (2009), described unmet sexuality needs for patients in treatment (49%–63%) and in the follow-up or survivor phase (33%–34%). The level of unmet sexuality need in cancer populations suggests the idea that conversations about the topic are not part of routine daily practice. Several studies have made similar observations (Fitch, Deane, & Howell, 2003; Hughes, 2000; Penson, Gallangher, Gioiella, Wallace, Borden, Duska, et al., 2000), but have not investigated barriers to holding these conversations, especially in ambulatory clinic settings. Therefore, our work was undertaken to explore the perspectives of both patients and health care providers about holding conversations concerning sexuality in the daily practice of ambulatory cancer care. In particular, we wanted to understand about the barriers that exist to having these conversations and how they might be overcome. This article will focus on the perspectives of the patients.

Methods

Design

The study utilized a qualitative descriptive design. Participants engaged in an in-depth semi-structured interview, on one occasion, with a skilled qualitative interviewer. The interview focused on discussing the participants' perspectives about having conversations with their cancer care providers regarding sexuality. The study protocol was approved by the ethics committee of the hospital prior to initiation of the study.

Table 1: Selected demographic characteristics of patient participants

Demographic Items	Male (n=14)	Female (n=18)
Average age in years	58.2	58.9
Age range in years	34–80	28–73
Number married or living common-law	16	9
Number with college or university education	8	12
Working at time of interview	5	6
On work leave at time of interview	3	5
Disease sites represented	colon, head & neck, kidney, liver, prostate	bladder, breast, colon, gynecologic, lung
Time since diagnosis (range in years)	1.25–13	1–10
Number with metastatic spread diagnosed	3	2

Sample accrual

Accrual for this study utilized a purposive, convenience approach. Nursing and social work staff members were asked to identify individuals on their caseloads who had a definitive diagnosis of cancer, were over the age of 18 years, could understand and speak English, were at least one year post-diagnosis, and were capable of talking about their cancer experiences. Staff members contacted the individuals and informed them generally about the study. The names of those who agreed to hear more about the study were passed onto the project assistant. The assistant then spoke with the individual and informed the person about the study objectives and participation requirements. Those who consented to participate engaged in one interview conducted in person by an individual skilled in qualitative interviewing. The interviews lasted between 30 and 90 minutes, although most were about an hour. All were audio-taped.

Interview guide

The interview guide was developed for the purposes of this study. The questions were open-ended yet designed to elicit patients' perspectives regarding the conversations about sexuality they had had with their health care providers in an ambulatory clinic setting. The initial question asked the individual to describe their experience with diagnosis and treatment. This information provided a context for the interview. The second question asked the participant to describe any changes they experienced related to sexuality because of the cancer and its treatment. The term sexuality was not defined for the participant by the interviewer. The changes identified were left for the participant to select and describe. Once this perspective was understood, the interviewer asked about concerns or distress related to the identified changes and whether there had been any conversation about specific concerns with health care providers. Subsequently, questions were posed to explore the patients' perspectives regarding why conversations did or did not occur on the part of the patient, as well as the health care provider. The interview concluded with a question asking the participant about recommendations for the cancer centre regarding care for patients with sexual concerns arising from their cancer and treatment.

Analysis

The interviews were transcribed verbatim and subjected to a standard content and thematic analysis (Denzin & Lincoln, 2000). The authors read through the transcripts independently making marginal notes about the content. Following a discussion about their impressions of the interview data, they created content category codes and definitions. The entire set of transcripts was coded according to the content categories by one individual. Subsequently, review of the coded data by the authors allowed comparison across participants' responses and identification of common perspectives. These common perspectives are reported as themes in the findings section below.

Findings

Sample characteristics

A total of 32 individuals participated in the interviews (see Table 1). The sample included men (44%) and women (56%), of whom 69% were married. The group ranged in age from 28 to 80 years and 63% had college or university education. Approximately one-third was working at the time of the interview. The participants reflected a range of disease type groups (e.g., breast, gynecologic, colon) and time since diagnosis (1 to 13 years). All had had surgery and either chemotherapy, radiation, or a combination of both chemotherapy and radiation. Five had been diagnosed with metastatic disease.

Themes

Five themes emerged from the analysis of these interview transcripts. Each will be described below with illustrative quotes from the participants. Following the themes, the recommendations patients wanted to share with health care providers will be described.

Theme 1: Cancer and its treatment create changes in a person's body, how the body works, and how a person feels about his or her body.

Without exception, all of the participants described changes in their bodies following the diagnosis of cancer and the treatment. No one was untouched regardless of disease site. The specific changes were linked to the type of cancer, its location, and the nature of treatment. For example, those who had had colon cancer described having a colostomy and experiencing weight changes, while those with prostate cancer talked about incontinence and impotence. Surgery often meant a loss of a body part (e.g., breast) while radiation and chemotherapy contributed to changes such as fatigue, menopause, appearance, and nausea and vomiting.

Theme 2: Whether or not the bodily changes experienced by cancer patients have an impact on sexuality varies and is linked to personal factors.

The participants described a range of bodily changes they had experienced that they thought influenced sexuality. Of note, sexuality itself was not defined by the interviewer, but the participants clearly differentiated between intimate physical relations (sex) and the relationship with their partners. For example, *"…even though we have less activity, the relationship is strong and there are no changes there" (#7)* or *"…there is a strain in the relationship, she does not really understand why I cannot have sex like I used to."(#1)*

Some changes, such as loss of a breast, having a colostomy, or being unable to achieve an erection, were readily described as having a direct impact on sexuality. In the words of one man:

My sex drive is not anywhere near what it used to be. I'd say maybe 15% or 20% of what it used to be… It happened over time… but it did seem to happen very quickly. Now I'm finding that I'm having erectile dysfunction as well… with just the colostomy I was able to maintain some level of intimacy… but at this point, since the removal of my colon, I have not been able to achieve an erection. I have a very difficult time getting an erection. I just don't get one anymore. (#33)

However, other changes, such as alterations in appearance because of weight change (loss or gain) or hair loss, and side effects of fatigue, nausea and vomiting, and rash were also described as having the potential to have an impact on sexual matters. Following breast surgery and chemotherapy that induced menopause, one woman said,

My image of myself has really changed. I can't stand the way I look right now and so that reflects on my desirability. I just feel totally unattractive. I think sometimes I look as bad as I feel… I can't wear the clothes I want and I have more or less stopped caring how I look to others. I just don't care about sex—no desire and even less response. (#4)

As participants described the bodily changes they had experienced, they spoke about the impact and meaning of the changes for themselves. The meaning was linked to their ideas about sexuality and its relative importance to them. Meaning was clearly a result of unique personal perspectives. As one woman described, *"I have always been really flat-chested and my breasts really did not mean much to me. Being without a breast is not an issue."(#26)*

On the other hand, as one gentleman described, *"I cannot be intimate any more and that is hard. I guess you could say that it does make me feel less of a man, you know." (#31)*

As participants reflected upon why the changes had not had an impact for them personally they described where sexuality fit into their lives at this point in time as a key reason. Some felt the primary priority for them was to be treated and do whatever needed to be done to achieve a cure, and that sexuality had almost been set aside. Others spoke of getting older and not being as interested in sex in general. Others found the overwhelming nature of side effects precluded any attention to sexual matters. The following examples illustrate these perspectives.

…losing two breasts doesn't seem like a big deal in the grand picture, it really doesn't… once you get your head beyond all the bad news and statistics and do what you have to do, well, I don't think of myself any differently even though I have no breasts. I don't think of myself as less of a woman or as any less desirable. (#6)

…I am just so glad to be alive that I don't care at this point. I'm just so thankful that I'm alive and able to do things. So, it doesn't bother me [not to have sex]. (#25)

It's like it's not that important. I can't believe I'm saying this, but it's really not that important to me. Twenty years ago, if anybody had said that to me I'd figure that they were, well, they'd lost their head. I used to really, really like it. (#2)

There's nothing you can do about your sex life [as you get older]. That's, in my case, the end of it. So, you just have to live with it. (#30)

I was in extreme pain. My sexual health was not a concern to me at that point. I was far more concerned about the pain and dealing with that. (#33)

Theme 3: Whether or not the impact of cancer treatment on sexuality becomes a problem is highly individualized.

Not every participant who described an impact on their sexuality following cancer treatment thought it was a problem. Whether the impact on sexuality was considered a problem by the individual was, to a great extent, a matter of their particular situation or context. The actual change, the meaning of that change, its impact, and what is considered important to the individual contributed to whether or not a problem emerged for that person. All elements had to be considered together. Even then, not everyone openly acknowledged a problem existed and, would seek assistance for it. The following examples illustrate the complexity and range of the individual situations.

I am not comfortable with my body. I think it is disgusting. No boobs and I look like the Pillsbury Doughboy. I look at others and think they are so lucky to have boobs… now I feel, well, just old. And that's hard to deal with, because I'm not. Somewhere inside here, I'm not old. My body just doesn't work that way right now… and that's really depressing and frustrating. I get angry. (#8)

My husband just did not understand what was happening to me and why I was not interested in sex anymore. He just didn't get it and wouldn't talk about it at all. I felt I was letting him down, but at the same time I was angry with him. I was so angry. (#11)

Having a catheter in, well, it makes [intimate relations] zero to start with. That doesn't come out. It stays there. I asked my wife if she would like me to do anything for her or to her, and she said no. But she's never been crazy about it anyway, so that makes it a lot easier. I used to want it every day and she'd want it once a month! (laughs) So, this might be a blessing in disguise. (#2)

To me, it really isn't sensible to be so upset about that kind of thing… I know we are all different though. Maybe if I was younger or more concerned about sex, or thinking about getting into another relationship… But it isn't really a concern for me quite frankly. I mean I'm living and that's what's important to me. (#20)

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Additionally, participants described different approaches to dealing with the strains in their relationships and the challenges about engaging in the physical act of intercourse. For some of the physical challenges (i.e., dry vagina, impotence, etc.) participants were apt to seek assistance from others, including health care providers. Dealing with the strains in their relationships was described in terms of something they believed they ought to work out, to a greater or lesser degree, on their own. As one participant described, *"I think our relationship got stronger, but we had to work at it, mostly because of me and how I am. I was sort of running around for awhile after the diagnosis." (#27)* Another stated, "*…couples really need to talk about these issues." (#1)*

Theme 4: Very few patients had conversations about sexuality with the health care providers.

Only a few of the participants could recall having conversations about anything related to sexuality with their health care providers. When they occurred these conversations were brief and, for the most part, before surgery or focused on symptoms (i.e., pain, dry vagina). Topics of intimacy or personal relationships were not part of the conversations. One woman described her experience as follows:

I asked my gynecologist before and after surgery, then mentioned [trouble with having intimate relationships] at the first visit at the cancer centre to the oncologist, and then with a resident in the family practice unit. And no one ever followed up with me… I was disappointed that nobody went any further. (#1)

A few participants recalled having conversations, before the final decision regarding treatment was made, about body changes to expect following cancer treatment. Otherwise, no one recalled health care professionals raising direct questions about sexuality during and after treatment. Participants recalled conversations about pain, hair loss, and vaginal dryness, but no one inquired how the person was feeling emotionally about their situation or how the changes were affecting their personal relationships.

Most individuals indicated they would talk about the topic if it had been raised by the health care provider. In the words of one woman, *"If they had initiated it, I would have felt more inclined to talk about it". (#26)* If the professional asked, they thought this would indicate an interest and a willingness to listen. However, they also thought there was a patient responsibility to tell the health

Table 2: Patient perspective on why patients do not raise sexual issues to cancer care providers

Reason cited	Example of quote
Feeling embarrassment/ uncomfortable	*…some patients are very introverted. Very, very quiet. Maybe they would feel intimidated or at least very uncomfortable (#16).* *People vary in their comfort level with this topic, especially older folks or ones from other cultures; there could be religious reasons why it is not discussed. (#26)*
Topic is a taboo subject	*You know, I am 73, and this is hard to talk about. It is a taboo subject for me. (#11)* *It's not something you really want to ask anybody about. (#3)* *Some cultures are more private than others and this is something we wouldn't talk about, especially someone who is not of the same cultural background. (#14)*
Topic is a private/ personal matter	*This is something personal. I never thought to raise it with the doctor or nurse. It is personal…you have to be really close to a person before you talk about this...it is something you solve yourself. (#17)* *I am a very private person and keep things like this to myself. (#13)* *It's not important for me to bring it up. There's a whole range of things, a whole lot of different stuff that's more part of my own sex life. (#3)*
Topic is not a priority	*I don't think they'd be comfortable, you know. The main concern is for your health and there's so many other things to think about. Some patients are nauseous or, you know, tired, or have mouth sores and all the other side effects, all the other physical issues that can come out. So, I think, it's a matter of priority, and age, and how sexual they are. (#3)* *It's not really a priority for me any more. It would have been when I was younger. (#2)* *I want to kill this thing first. I will deal with the other issues later. (#27)*
Lack of privacy in clinic environment	*I did not want to talk about any of my own personal things with strangers, especially in a public place. (#21)* *You need privacy to talk about this and it is just too crowded at the clinic. (#31)*
Perception health care provider is not interested in this topic	*Really, they are only interested in the cancer…they are not worried about body image, I don't think. (#16)* *…well it seems to me that it would be the last thing they would think about. (#6)*
Perception the health care provider does not have time	*…like for nurses, they are busy, you know. They're coming around, setting up IV's, and they've got more to do. They're always on the go. They don't have time to stay and talk with you. (#16)*
Perception that health care provider is not trained/ qualified in this topic	*The doctors don't understand, so it is no use talking to them… and the nurses really can't help. (#17)*
No expectation that health care provider would be responsible for dealing with this matter	*Why would she [cancer doctor] want to know about my sex life? (#13)* *I would not expect them to talk with me about this topic…not qualified in my opinion and probably not comfortable. (#23)*
No feeling of rapport or trust with provider	*You need a close relationship with the doctor to bring this up. Like the family doctor who knows you for a long time. (#10)* *You need to have a good rapport with them before you can discuss this. It is a hard topic to talk about. (#13)*

professional about any problems or concerns. One man stated,*"If there is a problem, you should tell the doctor. After all, you're the only one who knows how you feel. The doctor is not a mind reader. You know your body and how it feels and how it is reacting." (#19)*

Most patients, if they did have a concern or problem, thought they would be more likely to raise it with their family physician or the oncology nurse because of the relationship they had with these individuals. In the words of one participant, *"You have to have a rapport to talk about this, so they [family doctor/nurse] know you". (#15)* Several participants actually raised the question of whether the providers at a cancer centre were prepared to deal with this topic or were even supposed to deal with it.

Theme 5: Having a conversation with a health care professional about a problem concerning sexuality depends on various factors.

The participants in this study emphasized that sexual concerns are present following cancer treatment and do need to be discussed, to a greater or lesser degree, based on the individual. They felt conversations about sexuality during cancer need to be held in terms of what is comfortable for the individual, to help the person prepare for what to expect, and to deal with any changes that do occur. However, they thought there were many reasons why these conversations are not taking place that are related to the patients themselves and the health care providers.

Almost all of the participants mentioned the embarrassing nature of the conversation and the perception that the health care professionals did not have time for these conversations as barriers to patients raising the topic. In essence they "*…did not want to bother the busy doctors and nurses…". (#32)* by initiating the conversation. Specifically, patients could feel embarrassment or discomfort with the topic; a lack of privacy in the clinical setting; a lack of rapport with the health care professional; or perceived lack of time, interest or qualification on the part of the health professional. Table 2 presents quotes supporting these viewpoints. Overall, they emphasize that these types of conversations require time and sensitivity.

Participants also indentified why they thought health care providers were not engaging in dialogue about sexuality topics. Being too busy, being uninterested in the topic, and not being trained in the area were suggested as reasons. Additionally, the embarrassing nature of the topic could also be an influencing factor. Table 3 presents quotes to support these observations.

Patient recommendations to health care providers

The primary recommendation to health care providers by these participants emerged from the perspective that sexuality ought to be discussed. Overall, the patient participants thought health care providers ought to open the conversations about sexuality, raise questions about how the person is managing, and let the individual know that it is alright to talk about difficulties related to sexuality. One participant indicated, *"There's a whole big area that's not being looked after, not covered…". (#18)*

Not all participants agreed that the discussion should be held with the cancer care providers; some thought the conversation ought to be with the family physician who knows them better as a person. However, the participants agreed that the providers ought to be raising the issue. In the words of one woman: *"They're the ones who should approach the situation first. Put it out on the table. Say, 'okay, do you have any concerns about your body?'". (#16)*

Overall the participants thought the issue should be raised as part of the routine care or regular procedures. It could be raised in conversation or through using a questionnaire. They thought the cancer care providers ought to be informing the patients about the possibility of treatment having an impact on sexuality before treatment begins, not just talk about the treatment side effects.

Participants also thought that health care providers ought to be checking with patients over the course of their treatment about the impact of side effects on sexuality. By asking the question, a signal is given to patients that it is acceptable to talk about the topic.

Table 3: Patient perspective on why cancer care providers do not raise sexual issues with patients

Reason cited	Example of quote
Feeling embarrassment/ uncomfortable	*They may be inhibited discussing sex. (#9)* *It is a sensitive topic and it can be hard to bring it up and talk about it. (#12)* *I guess it depends on how shy they are, their experience with talking, their own body image, their own comfort with the topic, if they are embarrassed about it. (#22)*
Not in their job description	*I really wonder if it is part of their job description – is it? Are they supposed to be doing it? (#26)* *I am not certain if it is their job to be dealing with this. (#12)* *Doctors have certain bedside manners; nurses sort of build relationships. So the nurses are the ones that sort of talk to us and sort of sit with us a bit longer. Doctors are sort of the type where you just sit there and just say "okay, this is the problem and here I'll send you to these people". (#5)*
Does not have time	*…really think they just look after the physical stuff and I mean they look busy enough…they never ask you how you are doing…the nurses are running around all over the place and have even less time than the doctors…everybody's rushing all the time. (#18)* *They are just all so dreadfully busy. I would not want to cause them more concern with too many complaints. (#22)* *To be honest, I don't think they have the time. They just go from one patient to the next…so they don't ask. (#27)*
Does not see matter as important/ priority	*I really wonder if they see it as important in light of the life and death issues they are dealing with every day. (#12)* *They all have a full caseload and don't have time to sit and talk with you. They have other priorities, like the treatment and chemo. (#23)* *The doctor is just there for treatments and doesn't care about whatever you're talking about, sexual issues or body image. (#24)*
Is not qualified to deal with this topic	*The oncologists don't have time to get into that, and besides, they're probably not even trained for that, you know. (#18)* *Does the oncologist even know what to do about this? (#2)* *Staff need to know how to raise the issues and have the conversation. They need to be trained in the topic. (#23)*

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Participants also emphasized that health care providers need to be clear regarding what they are comfortable talking about and when they need to make an appropriate referral to other providers. As one individual stated, "*They do not have to deal with it if they are not comfortable or trained in this area, but they could tell us who is and how to contact them". (#29)*

Although this topic should be approached in conversation, the participants also thought there needed to be written resources available. Having videos, a specially trained counsellor, and group teaching sessions were also suggested.

Discussion

This study was undertaken to describe the perspectives of cancer patients regarding having conversations with cancer care providers about sexuality. Participants reflected a range of cancer sites and treatment types, ages and genders. Without exception, all experienced bodily changes after treatment. However, whether or not the changes had an impact on their sexuality and, if there had been an impact, whether they considered the impact to be a concern or problem, was an individual matter. It is important for clinicians to recognize that patients in all disease site groups could be at risk for experiencing concerns about sexuality. However, an individualized assessment and discussion is required to clearly determine if there is an issue to be resolved and if the patient actually wants assistance with it. Previous research has shown that not all patients will desire assistance for a given problem despite feeling emotional distress about it (Steele & Fitch, 2008). The desire for assistance is an individualized matter.

For the most part, participants had a broad conceptualization of sexuality that included body image, self-esteem, and relationships. Of note, these participants were clear about there being a difference between personal relationships and intimacy (physical intercourse). Their descriptions about the impact of changes resulting from treatment made a distinction between these two aspects of sexuality. They acknowledged an individual could experience a strengthening in personal relationship (i.e., feeling closer emotionally) yet deterioration in intimacy (i.e., loss of desire, inability to achieve orgasm). Their perspectives emphasized the idea that conversations with health care professionals often did not extend to these deeper dimensions, but stopped short at discussions about side effects of treatment. This left the patient not truly appreciating the potential for a side effect to have an impact on personal relationships or intimacy. It also created a sense that the health care professional did not wish to talk about the more deeply personal topics.

The results concerning the infrequent nature of conversations about sexuality are disappointing. However, they are not entirely surprising given that holding a conversation about changes in sexuality and intimacy has been reported by other investigators as an infrequent practice among health care professionals and their cancer patients (Hughes, 2000; Lindau, Surawska, Paice, & Baron, 2011; Penson, Gallangher, Gioiella, Wallace, Borden, Duska, et al., 2000). Patients in this study were able to share perspectives about the barriers to having more intimate types of conversations. However, they also thought these barriers needed to be overcome. Patients ought to have information about the potential impact of treatment on sexuality and the available resources. Overall, they shared the perspective that the physician and nurse team ought to raise the topic (i.e., open the door in the conversation) to signal that it is acceptable to discuss sexual concerns. They agreed that specific health care professionals who are not comfortable or prepared to provide assistance ought to refer to a service or individual who can help. In essence, the participants thought that patients ought to be given the opportunity to talk and to know what choices are available to resolve problems that might arise.

Of interest, participants saw nurses and social workers as the health care professionals with whom they were more likely to raise the topic of sexuality at a cancer centre. This was especially the case if the concern was about personal relationships, body image, self-esteem, or intimacy. Family physicians were most likely to be the ones with whom they would raise the topic otherwise. Having a relationship and rapport with the individual practitioner was a major facilitator to raising this sensitive topic.

Implications for practice

The implications for clinical practice emerge directly from the perspectives shared by the participants in this study. First, there needs to be a standard of care implemented or expected where all patients are given information about the possible alterations in sexuality and the opportunity to discuss this topic. Second, those who would benefit from additional intervention ought to be identified and have the choice to pursue additional care. This implies the following specific suggestions could be implemented by oncology nurses:

- Open the communication by introducing the topic about the bodily changes that occur with cancer and its treatment and how these changes might influence sexuality (be explicit about including personal relationships and intimacy)
- Let the patient know early in the course of the cancer experience about possible changes in sexuality and that resources are available to help should an issue arise
- Check with the person over the course of the treatment interval and during follow-up appointments about whether there are difficulties related to sexual matters (can use a checklist or standard questionnaire)
- Have information resources (i.e., brochures, books, videos) available about the impact of cancer treatment on sexuality and encourage patients to use them; include information from other patients' experiences
- Provide access to experts who can help with sexuality difficulties for patients who are experiencing them and refer in a timely manner.

Implementation of these ideas assumes a level of skill and comfort in the topic of sexuality and a degree of preparation on the part of cancer care providers. Access to education and skill development about talking about sexuality may need to be facilitated for staff nurses. One recently developed on-line resource is the IPODE Sexuality Program (IPODE, 2008). Further elaboration of the necessary education may emerge from the companion study of health care provider perspectives (Fitch, Beaudoin, & Johnson, 2011). Models for including sexuality information in routine practice have been described by Anne Katz (2005).

These recommendations also imply the need to develop referral pathways and partnerships with service providers who are not necessarily within cancer programs. Referral pathways to counsellors and sex therapists may need to be organized to facilitate timely referral.

Future efforts are needed to design and utilize standardized approaches in clinical practice to identify those individuals who would benefit from additional intervention. The approaches need to be short and easily applied in busy clinical settings. Although the actual identification of an issue can occur during a short clinical exchange, a lengthier conversation and assessment may need to be organized in a less clinical setting beyond the appointment time.

Future efforts are also needed to develop appropriate patient education resources for this topic area. The participants in this study described the need for easily understandable pamphlets or documents outlining expected changes in sexuality and available resources. These could be shared with patients by oncology nurses as a routine aspect of care. It would help to signal an openness to talk about the topic.

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