INTERNATIONAL PERSPECTIVES

Holding conversations with cancer patients about sexuality: Perspectives from Canadian and African healthcare professionals

by Johanna Maree and Margaret I Fitch

ABSTRACT

Cancer treatment can have a significant impact on an individual’s sexuality. However, cancer survivors are reporting that very few healthcare professionals are talking with them about the topic. This work was undertaken to gain an increased understanding about the dialogue between cancer care professionals and cancer patients regarding the topic of sexuality. It was anticipated the effort would allow the identification of barriers that could limit dialogue between patients and healthcare providers, as well as offer insight regarding how to overcome such barriers in busy clinical settings. A Canadian sample of 34 healthcare professionals were interviewed and 27 African nurses engaged in a focus group discussion. A content analysis revealed similarities in terms of personal discomfort with the topic and feeling unprepared to discuss it with patients. There were notable differences between the two samples in terms of the barriers related to culture and tradition. African nurses reported significant cultural barriers, stigma and discrimination influencing conversations about sexuality with cancer patients in contrast to their Canadian counterparts.

INTRODUCTION

Cancer treatment can have a significant impact on an individual’s quality of life. There are multiple physical, emotional, psychosocial, spiritual, and practical changes following a diagnosis and treatment of cancer (Fitch, Page & Porter, 2008; Katz, 2016). In particular, body changes and alterations in bodily functions can have an influence on an individual’s body image, self-esteem, fertility, and sexual functioning. In short, one’s sexuality can be compromised.

Sexuality is an important aspect of quality of life and a central aspect of being human (World Health Organization, 2002; Shell, 2002). Defined broadly, sexuality encompasses identity, gender roles and orientation, erosexism, pleasure, and intimacy (Bober & Varela, 2012; Park, Norris & Bober, 2009). For many, it is vital to their self-identity and sense of personal integrity which sustains adaptability and resilience, thus enabling the ability to cope (Redelman, 2008). Sexual interest varies widely from person to person and is influenced by age, relationships, illness and life circumstances (Bianchi, 2018).

There is a growing body of literature describing the impact of cancer on sexuality (Bedell et al., 2017; Hordern, 2008; Jackson, Wardle, Steptoe, & Fisher, 2016; Rossen, Pedersen, Zachariae, & von der Maas, 2012). Much of the early writing focused on mechanistic aspects of physical dysfunction that were the consequence of physical changes post treatment. However, there is a growing understanding of the subjective meaning of sexuality and deeper understanding of the complexities of sexuality during illness (Perz et al., 2014; Ussher et al., 2015; Varela, Zhou, & Bober, 2013). From early writings that focused primarily on breast (Meyerowitz, Desmond, Rowland, Wyatt, & Ganz, 1999) and gynecological populations (Andersen, Woods, & Copeland, 1997), the literature has expanded to include a variety of other populations (Fitch, Miller, Sharir, & McAndrew, 2010; Mercadante, Vitrano, & Catania, 2010; Reese, Shelby, & Abernethy, 2011; Reese, Shelby, Keefe, Porter, & Abernethy, 2010) and the impact of sexuality changes following cancer on quality of life (Tierney, 2008).

Whole-person care means paying attention to all aspects of a person, including issues of sexuality (Institute of Medicine, 2007). However, sexuality needs frequently remain unmet and result in heightened emotional distress (Harrison, Young, Price, Butow, & Solomon, 2009; Jackson et al., 2016; Reese, Bober & Daly, 2017). Patients have reported their concerns about sexuality as not always addressed during their visits with physicians and nurses (Fitch, Beaudoin, Johnson, 2013; Lindau 2011). The evidence is growing that conversations about these specific consequences are not happening often between cancer patients and healthcare providers, especially in busy ambulatory settings (Candoza et al., 2016; Katz, 2005; Reese et al. 2017) despite the evidence that patients want the discussion to occur (Flynn et al., 2012; Park, Norris & Bober, 2009).

PURPOSE

This work was undertaken to gain an increased understanding about the dialogue between cancer care professionals and cancer patients regarding the topic of sexuality. It was anticipated the effort would allow the identification of barriers that could limit dialogue between patients and healthcare providers, as well as offer insight regarding how to overcome such barriers in busy clinical settings. Focal points in Canada

ABOUT THE AUTHORS

Johanna Maree, RN, PhD, Department of Nursing Education, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

Margaret I. Fitch, RN, PhD, L Bloomberg Faculty of Nursing, University of Toronto, Toronto, Canada
and Zimbabwe allowed the topic to be explored in two distinct geographical situations.

**METHODS**

The initiative utilized a qualitative descriptive design given the exploratory nature of the work and the desire to garner perspectives on the topic. In Canada, individual in-depth semi-structured interviews were held with healthcare providers while in Zimbabwe, a focus group approach was used.

**RECRUITMENT AND DATA COLLECTION**

In Canada, a purposive, convenience sampling approach was utilized to accrue participants at a comprehensive outpatient clinic. Following an announcement that the study was open, the research assistant approached clinical staff members in each disease site group who were available and interested in the study. Accrual continued until there were individuals in the sample who cared for a cross-section of cancer types and modalities. Individuals who agreed to participate underwent one semi-structured interview (between 45 and 80 minutes) with the research coordinator skilled in qualitative methods. The interview guide was developed for the purposes of the study and elicited responses about several topics: whether conversations about sexuality occurred within their clinical practice, what was seen as a sexuality issue (the definition of sexuality was not shared ahead of time), the obstacles to holding conversations with patients, and what they thought would be solutions to overcome the obstacles. The interviews were audiotaped and transcribed verbatim.

In Zimbabwe, healthcare providers attending a cancer education course were invited to participate in a session focused on sexuality and cancer. The session began with a short presentation about cancer and sexuality. Subsequently, small groups of participants (4–5) discussed the following question together: what are the barriers to having conversations with cancer patients and families about sexuality in your clinical setting? The group members wrote notes regarding their discussions on large newsprint pages, as well as provided verbal reports to the entire group. A note-taker recorded the verbal reports and the subsequent group discussion. The large group discussion focused on identifying solutions to the identified barriers. The entire session took an hour to complete. Both authors facilitated the session.

**ANALYSIS**

The verbatim transcripts from Canadian participants were subjected to a standardized content analysis (Denzin & Lincoln, 2000) once all the interviews had occurred. The transcripts were read through in their entirety while making marginal notes about the content. Following a discussion about impressions of the interview data, content category codes and definitions were created. The entire set of transcripts were then coded according to the content categories by one individual (MF). Subsequently, review of the coded data by two Canadian colleagues with expertise in the field and the primary author allowed comparison across participants’ responses and identification of common perspectives or themes. These common perspectives were identified prior to the analysis of the African data.

All of the notes from the African session were also subject to a similar content analysis process of the notes was completed and salient themes identified. The notes were reviewed in their entirety prior to devising coding categories. All notes were coded by one author (MF) using the coding categories and salient perspectives or themes were isolated. These perspectives were reviewed by the co-author who had co-facilitated the session and resides in Africa. Similarities and differences between the two datasets were then identified and form the basis for the results reported below.

**RESULT**

**Sample**

The Canadian sample (N=34) consisted of nurses (n=12), oncologists (n=11), social workers (n=6) and radiation therapists (n=5). Although the individuals within the sample may only have provided care for patients in three or four disease sites, collectively across the sample all cancer types were reflected. The African sample of 27 consisted of nurses (n=22) and radiology/registry (n=5). All practitioners in both samples were experienced in caring for cancer patients.

**Themes**

Six themes emerged from the analysis of the interviews with a good deal of similarity across the two samples. Each will be described briefly below and illustrative quotes can be seen in Tables 1 and 2.

- The extent of the impact cancer and cancer treatment can have on a person’s sexuality varies by the site of the cancer.
- Sexuality is not perceived as a priority for cancer patients, especially during diagnosis and treatment.

Most participants held the perspective that sexuality was not a priority for patients during the diagnosis and treatment stages of their cancer experience. They believed that patients were too anxious about their diagnosis, feeling too unwell, and caught up in dealing with symptoms during treatment to be concerned about sexuality. Additionally, they believed the topic is not a priority for healthcare professionals during that time, as well. The professionals are focused on organizing the diagnostic tests, making certain the correct diagnosis is made, and orchestrating the treatments. The time is a very busy one and the increasing number of patients who require care precludes much conversation about a topic that is not perceived as important at that time.
Sexuality is not perceived as a priority for cancer patients, especially during diagnosis and treatment.

If sexuality is going to be a concern for cancer patients, it will occur after treatment is finished.

Conversations about sexuality occur most often in the context of informed consent discussion prior to surgery or treatment or if the patient raises a specific question.

If cancer patients have difficulties or concerns about sexuality, they will ask questions or tell the health professional.

<table>
<thead>
<tr>
<th>Table 1: Themes about cancer and sexuality</th>
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<tbody>
<tr>
<td>Themes regarding Sexuality and Cancer Patients</td>
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<tr>
<td>The extent of the impact cancer and cancer treatment can have on a person’s sexuality varies by the site of the cancer.</td>
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Participants held the perspectives that patients would be more focused on sexuality following their cancer treatment, once they had returned home and were trying to carry on with their normal lives. For some, they would be able to manage and there would be no concerns about their intimate relationship. However, if the individual was going to experience difficulty regarding sexual issues and become distressed about the situation, this would emerge following treatment.

Conversations about sexuality occur most often in the context of informed consent discussion prior to surgery or treatment or if the patient raises a specific question.

One consistency in practice regarding conversations about sexuality across the two samples occurred with regards to the informed consent processes prior to cancer treatment. For some cancer surgeries in particular (i.e., gynecological, prostate), informed consent conversations included mention of topics such as libido, dryness of the vagina, and impotence. These conversations however, did not necessarily include a great deal of depth concerning what these changes would mean in terms of the daily impact or coping with the changes. Participants also mentioned that conversations about this impact could occur if the patient raised questions or was experiencing difficulties that they asked the healthcare professional about.

If cancer patients have difficulties or concerns about sexuality, they will ask questions or tell the health professional.

Canadian participants held the perspective that patients would raise the issue of sexuality and ask questions if
### Table 2: Themes regarding barriers to having conversations about sexuality with cancer patients and potential solutions

<table>
<thead>
<tr>
<th>Perspectives about having a conversation regarding sexuality</th>
<th>Canadian health care professionals</th>
<th>African health care professionals</th>
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<tbody>
<tr>
<td><strong>Perspectives described</strong></td>
<td>Examples of comments</td>
<td>Examples of comments</td>
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<tr>
<td>Why cancer patients find it difficult to talk about sexual concerns.</td>
<td>The following factors were named: age, culture, personal topic, embarrassment, gender, language, being overwhelmed from the cancer, trust and rapport with the professional, time, sexual orientation, relationship between partners, perceived role of professional.</td>
<td>The following factors were emphasized: Culture/tradition Religion Topic is a taboo one Lack of knowledge and skill and language regarding the topic Time/workload Lack of privacy Shame and fear Embarrassment Age, gender Attitude Relationship with partner.</td>
</tr>
<tr>
<td>Why health care professionals find it difficult to talk about sexual concerns.</td>
<td>The following factors were named: Time, patient load, clinic flow, priority efforts are on disease care, personal comfort, lack of training and experience, privacy in the clinic, perceived role, incentive.</td>
<td>Lack of knowledge by medical practitioners themselves that these issues need to be addressed.</td>
</tr>
<tr>
<td>Suggestions for managing conversations about sexual matters with cancer patients</td>
<td>Set a standard of care that all patients are informed about the impact of cancer treatment on sexuality. Ensure information is about side effects and the impact on various aspects of sexuality. Basic assessment of patients ought to include questions about sexual concerns and whether the person wants help with them. Staff ought to check in with patients on a regular basis about whether sexual concerns have changed. Include educational resources about sexuality for patients in the clinics. Hold staff accountable for focusing on sexuality as a routine part of their practice. Offer staff training programs on sexuality (assessment and interventions) Develop a list of resources so that referrals can be made appropriately.</td>
<td>Have someone from same cultural group talk with patient. Put posters on the wall of clinic. Have someone who is same gender and age talk with patient. Hold classes with same age groups and one gender. Emphasize health in conversations. Use an education approach. Offer staff training programs.</td>
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</tbody>
</table>
they were experiencing difficulties and many waited for this to happen rather than initiating an exploration about the topic. However, the African participants thought patients were not as likely to raise the issues, even if they were experiencing difficulties. The primary reason for this would be the embarrassment and shame they would feel about what they were experiencing. Often, in Africa, sexual issues were thought to be the result of infidelity and associated with prostitution. Additionally, there is a large degree of mistrust of healthcare professionals regarding privacy; patients worry that if they tell healthcare professionals about the sexual issues, the healthcare professionals will tell other people.

There are many factors that influence whether or not conversations about sexuality take place.

All shared the perspective that having a conversation about sexuality was difficult for both healthcare professionals and for patients and was influenced by many factors (See Table 2). It was clear that individual healthcare professionals’ practices concerning conversations about sexuality varied considerably and were closely linked with individuals’ personal comfort with the topic, philosophy of care, perception of role, and preparation concerning the topic area (including education, skill training, and confidence). Very few had had any formal education in the topic of sexuality. Additionally, no one described policy or explicitly stated expectations about how this topic was to be handled in their clinical setting.

A major difference in the barriers to having conversations about sexuality between the two settings concerned the influence of culture and tradition. Although Canadian participants cited culture as a factor, African participants placed considerably greater emphasis on the influences of traditional practices, religion, and the widely shared public perception that talking about sexual topics was a taboo. Fear of being shamed and stigmatized was a strong influence on African patients; participants thought the patients would opt to remain silent in light of this fear rather than talk about needing assistance with sexual concerns.

Potential Solutions

Participants all expressed the viewpoint that there ought to be conversations about sexuality with cancer patients and opportunity to discuss the details about how changes could impact them personally. They also described a variety of approaches that could be used for patient and family education. However, they were also very clear about the idea of needing to tailor the approaches for the culture and local sensitivities, as well as for gender, age, and language. Setting clear expectations for practice was also described as an important solution. Staff members need to be clear about their roles and what is expected of them regarding holding conversations about sexuality.

DISCUSSION

This work was undertaken to learn more about the barriers to having conversations with cancer patients regarding sexuality. Given the nature of cancer treatment, there can be changes with all types of cancer that would have an impact on an individual’s sexuality. However, sexuality is not a topic that is discussed frequently with all cancer patients (Candoza et al., 2016; Katz, 2005; Reese et al. 2017).

There was similarity among the perspectives held by the participants in Canada and Africa about the importance of the topic and the factors that could influence whether or not conversations took place. Personal and work settings factors were described as influencing these conversations. In particular, practitioners felt a lack of preparation to engage in the conversation and the busy nature of practice environments and lack of privacy thwarted their intention to talk with patients about such a sensitive topic. There would seem to be improvements needed in educational preparation and role expectations. Setting standards for patient care and for role performance of healthcare professionals related to holding conversations about sexuality would be useful to clarify expectations. Models for these types of examples are available (CANO/ACIO, 2006; CAPO, 2012) although these would need to be adapted for local settings.

The notion of talking with patients about sexuality has been explored in North American settings and revealed that patients do want to talk about it (Fitch, Beaudoin & Johnson, 2013; Flynn et al., 2012; Park, Norris & Bober, 2009). However, in many instances, patients are expecting healthcare professionals to raise the issue and open the conversation (Bianchi, 2018); at the very least, healthcare professionals ought to tell them it is alright to raise any concerns they have. It would be important to explore this issue directly with patients in Africa to determine the appetite for actually holding conversations, and preferences for approaching it, given the large index of cultural taboo and restriction surrounding the topic.

REFERENCES


Canadian Association of Psychosocial Oncology (2012). Emotional Facts of Life with Cancer. Available at www.capo.ca


