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Identifying cancer patients with greater need for information about sexual issues

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ABSTRACT

Purpose: The aim of the research was to identify cancer patients who may have a greater need about sexuality-related information. The study explored the association between sexuality-related information need and socio-demographic factors, cancer type, types of cancer treatment, experienced adverse effects on sexuality, and changes experienced in relationships.

Methods and sample: This study used a survey design. Questionnaires were distributed and completed by 505 patients, with a diversity of cancer diagnoses, treated at a university hospital in Finland in 2009 and 2010. Information needs were rated using the international and well validated Information Needs Questionnaire (INQ). Sosiodemographic factors, cancer type, treatments, experienced adverse effects on sexuality and changed experienced in relationships were measured by using another questionnaire.

Key results: Those patients with experiences of functional problems or other adverse effects on sexuality due to cancer or treatment found sexuality related information more important than those with no experiences of adverse effects on sexuality. Patients with experiences of weakened relationships due to cancer had greater information needs than those with experiences of strengthened relationships or no changes in relationships due to cancer.

Conclusions: Cancer patients should be asked whether cancer or treatment has caused problems in their sexuality and possible relationships. Patients who experience problems in their sexuality or relationships should be provided an opportunity to discuss the issues. The whole oncology team have a role to play in patient sexuality guidance. The items on the INQ could be used as a reference tool for exploring patients' information needs.

Introduction

Sexuality influences quality of life and has biological, psychological, social and ethical as well as cultural dimensions (WHO, 2008). It is known, that cancer and its treatments affect sexuality in many ways. Having cancer can impact on the sexuality of the patient and his/her partner regardless of the type of cancer or the type of treatment (Hordern and Street, 2007). Treatment can cause functional as well as emotional problems (Oskay et al., 2011). Particular psychosocial factors affecting sexuality are changes in appearance and in self-image, and the life-threatening disease itself (Fobair et al., 2006; Park et al., 2009). Cancer survivors can suffer from loss of sexual desire, functional problems and sexual dissatisfaction. Functional problems are common after treatments both men (e.g. erectile dysfunction, problems with orgasm and ejaculation) and women (e.g. vaginal dryness, dyspareunia, problems with achieving orgasm). (Carmack Taylor et al., 2004; Bodurka and Sun, 2006; Cesaretti et al., 2007; Lindau et al., 2007; Reese et al., 2009.)

The disease can have long-term effects on relationships and the way partners feel about each other. Changes in sexuality can also weaken or worsen relationships if partners are reluctant to discuss problems openly (Badr and Taylor, 2009). Alternatively, a diagnosis of cancer may also have a strengthening or improving effect on relationships (Sheppard and Ely, 2008).

It has been shown that patients require information on sexuality issues (Stead et al., 2003; Fobair et al., 2006; Rasmusson and

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Thome, 2008; Knight and Latini, 2009), but perceive that access to such information is inadequate (Burt et al., 2005; Davison et al., 2007). Patients and their spouses require practical advice and emotional support to cope with intimate sexual changes, altered self-image, and the disease itself (Rasmusson and Thome, 2008; Sheppard and Ely, 2008; Hawkins et al., 2009).

Patients expect health care professionals to initiate discussion on sexual issues (Hordern and Street, 2007) but this rarely happens (Burt et al., 2005; Davison et al., 2007). This can be due to lack of training, time, private location, or to the sensitive nature of the issue and reluctance to discuss sexuality-related issues with patients may also be caused by professionals' attitudes to sexuality (Hautamäki et al., 2007; Kotronoulas et al., 2009; Park et al., 2009; Cleary and Hegarty, 2011). In general, the effects of the disease and treatment on sexuality are discussed if the patient initiates the discussion. (Hautamäki et al., 2007; Kotronoulas et al., 2009; Park et al., 2009.)

In several studies, sexuality-related information needs have been reported as less important than other information needs (Luker et al., 1995; Luker et al., 1996; Degner et al., 1997; Wallberg et al., 2000; Beaver and Booth, 2007). However, most of these studies were based on female samples with breast cancer. Prostate cancer patients have been found to rank sexuality-related information as more of a priority, ranked fifth in importance out of nine items of information (Davison et al., 2002). Age has been shown to be a significant factor in regard to information needs. Compared with older patients, sexuality-related information was considered more important by women with breast cancer aged under 51 years (Degner et al., 1997; Wallberg et al., 2000), and by men with prostate cancer aged under 66 years (Davison et al., 2002). Type of cancer has also been shown to have an impact on men's sexuality-related information needs. Men with genital cancer have considered sexuality-related information more important than men with non-genital cancer diseases (Jonker-Pool et al., 2004). In different cultures, cancer patients can rate the importance of sexuality-related information in different ways (Gopal et al., 2005).

This study aims to complement the information provided by previous research on factors that influence sexuality-related information needs.

Aims

The aim of the research was to identify cancer patients who may have a greater need about sexuality-related information. Our findings may help health professionals in oncology to identify the situations where patients find sexuality-related issues important and target professionals limited resources to meet this specific information need for those most likely to benefit from that intervention.

The research questions are:

1. Is there an association between patient socio-demographic factors, cancer type and treatment to the importance of sexuality-related information?
2. Is sexuality-related information more important to those patients who have experienced adverse effects on sexuality due to cancer?
3. Do experienced changes in relationships have an association with the importance of sexuality-related information?

Methods

This study involved a cross sectional survey design and the administration of a self completed postal questionnaire.

Sample

The sample for this study included patients admitted to the Tampere University Hospital, Finland, with a cancer disease during the period of October 2009 to March 2010. The participants were being treated at oncology, gynaecology, urology and gastroenterology wards and clinics. Eligibility criteria included 1) diagnosed with cancer, 2) minimum age of 18 years, 3) ability to complete questionnaires independently. Members of staff were informed of the aim of the study and the implementation of data collection. Nurses provided eligible patients with verbal and written information about the study, the voluntary nature of participation and confidentiality issues.

Ethical considerations

The research complies with the Declaration of Helsinki (1964) ethical guidelines for medical research. Patients were asked whether they would like to participate in the study. It was carefully explained that participating or not participating would have no impact on the treatment received. Patients attending hospital for the first time were not approached as this was thought to be intrusive as anxiety levels were assumed to be high. Patients whose physical or mental condition indicated that they would not be able to take part were excluded on the advice of health care professionals. Patients signed a written consent form indicating their willingness to participate. Patients filled in the questionnaire either in hospital or at home, and returned the questionnaires directly to the researcher in postage-paid and addressed envelopes. The results were handled with confidentiality throughout the research process and reported in such a way that it was impossible to recognise the respondents. The research was approved of by the ethics committee of the Tampere University Hospital in 2009.

Measures

Information needs questionnaire

Priority information needs were investigated using a measure devised by Lesley F. Degner (Information Needs Questionnaire, INQ). The INQ was originally designed to measure priority information needs of breast cancer patients (Luker et al., 1995, 1996; Degner et al., 1997; Wallberg et al., 2000), but has been successfully used to measure priority information needs of patients diagnosed with colorectal, gynaecological and prostate cancer (Beaver et al., 1999; Beaver and Booth, 2007; Davison et al., 2002). The INQ consists of nine information needs items (Box 1.)

Questionnaire about sosio-deomographic data and sexual adverse effects caused by cancer or treatments

A Questionnaire pre-tested on cancer patients ($n = 292$) during 2001 to 2003 (Kellokumpu-Lehtinen et al., 2003) was used in the study. Socio-demographic and treatment data were collected on gender, age, education, relationship status, type of cancer, treatment, time from diagnosis, and whether treatment was in progress or completed. Participants were also asked to assess any changes that had taken place with regard to sexuality and relationships, as well as any sexual problems they experienced before and after developing cancer.

Participants were asked to assess on a scale of 1 to 5 (1 = very few and 5 = very many) whether they had had any problems related to sexual dysfunction before developing cancer. They were asked to repeat the same assessment for the time after developing cancer. Participants were also asked to use the same scale to assess