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Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses

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A B S T R A C T

Purpose: In most types of cancer, the disease and its treatment can result in altered sexual function (SF). Oncology nurses are strategically placed to address SF since they have frequent patient interaction. Our aim was to establish their knowledge about and attitudes to SF in oncology care and identify their perceived barriers to addressing the subject.
Methods: A 37-item questionnaire was administered during the 2012 Dutch Oncology Nursing Congress and mailed to 241 Dutch oncology nursing departments.
Results: The majority of 477 nurses (87.6%) agreed that discussing SF is their responsibility. Discussing SF routinely is performed by 33.4% of these nurses, consultations mainly consisted of mentioning treatment side-effects affecting SF (71.3%). There were significant differences depending on experience, knowledge, age, academic degree and department policy. Nurses ≤44 years old ($p < 0.001$), with <10 years oncology experience ($p = 0.001$), insufficient knowledge ($p < 0.001$), no academic degree ($p < 0.001$), and in whose department policy was lacking or inadequate ($p < 0.001$), were less comfortable discussing SF. Barriers included lack of training, presence of a third party and no angle or motive for initiating discussion.
Conclusions: Findings suggest oncology nurses consider counselling on sexual issues to be an important responsibility, in line with discussing other side-effects caused by the disease or its treatment. Nevertheless, cancer patients may not routinely be receiving a sexual health evaluation by oncology nurses. Results emphasize the potential benefit of providing knowledge, including practical training and a complete department protocol.

Introduction

For most types of cancer, regardless of the patient's age or relationship status, the disease and its treatment can lead to a deterioration in sexual health (Baker et al., 2005; Beckjord et al., 2011; Den Oudsten et al., 2012; Galbraith and Crighton, 2008; Hughes, 2008; Lange et al., 2009; Sadovsky et al., 2010; Wright et al., 2002). The World Health Organisation has addressed sexual health as an integral aspect of wellbeing, defined as 'a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence' (World Health Organization, 2006). Sexual health cannot be defined without considering sexuality, partially defined as 'a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction' (World Health Organization, 2006). Satisfactory sexual function (SF) (i.e. sexual health despite the presence of disease) is considered to make an important contribution to the quality of life of cancer patients (Flynn et al., 2011; Krebs, 2008; Stead et al., 2003). The disease, however, frequently interferes with SF, leading to sexual dysfunction (SD). With rising long-term survival-rates for cancer, quality of life, including sexual health, is becoming increasingly significant.

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For instance, a reasonable SF provides the patient with the ability to participate in intimate relationships and accordingly assimilate the rehabilitation of self-esteem and physical body function.

Causes of a deterioration in SF in cancer patients are often physically and mentally ambiguous. Surgery, chemotherapy, hormonal agents, radiation therapy, intrinsic disease and psychological disease-related or body image factors may all contribute to a decrease in SF. Despite the fact that it is considered important by both patients and health professionals, patients and survivors have indicated that SF is frequently not addressed by oncology health care providers and an unmet need for information exists (Flynn et al., 2012). According to multifarious studies, compromising data on self-reported practice attitudes and observed practice attitudes, discussing SF with patients is not routinely performed by multidisciplinary oncology health care providers (Flynn et al., 2012; Gamel et al., 1995; Hautamaki et al., 2007; Hordern and Street, 2007; Julien et al., 2010; Kotronoulas et al., 2009; Lavin and Hyde, 2006; Nakopoulou et al., 2009; Olsson et al., 2012; Oskay et al., 2014; Stead et al., 2003; White et al., 2011; Zeng et al., 2011).

Oncology nurses are in a strategic position to be able to address SF, since they have frequent contact with patients when they can provide medical and emotional support for issues of concern during illness, treatment and recovery. Consequently, they are able to identify changes and provide information about the effect of the disease and its treatment on SF. The Oncology Nursing Society (USA) stated in 1979 that sexual health is an integral aspect of quality care in outcome standards for cancer nursing practice (Valencius et al., 1980). The first Dutch national guideline on SF was accepted by the Comprehensive Cancer Centre of the Netherlands (IKNL) in 2006, describing the important position of the oncology nurse in diagnosing and intervening in cancer-related SD (Integraal Kankercentrum Nederland, 2006).

Although discussing SF is officially stated as an important component of oncology nursing practice worldwide, many nurses experience barriers in actually discussing psychological or physiological aspects of SF. Barriers identified in previous publications involved factors like incorrect assumptions regarding sexual issues, discomfort, lack of knowledge (Kotronoulas et al., 2009), 'it is not my responsibility', embarrassment (Stead et al., 2003), patients do not expect nurses to discuss sexual concerns, confidence (Julien et al., 2010), lack of training, difficult to bring up the subject and lack of time (Hautamaki et al., 2007). Furthermore, it was shown that cancer patients, who themselves had to initiate discussion with an oncology professional about SF, already experienced significantly greater SD than those who did not bring up the subject (Flynn et al., 2012). The fact that routine nursing practice currently neglects addressing SF is emphasized by patients who state that more attention should be paid to SD (Hill et al., 2011; Hordern and Street, 2007; Stead et al., 2003). While health care professionals do little to address SF (Bekker et al., 2009, 2011; Nicolai et al., 2013; Saunamaki et al., 2010), patients with all types of cancer are willing to talk about their sex lives and the impact of the disease on their SF (Ananth et al., 2003; Hill et al., 2011). For over thirty years, international nursing and treatment guidelines have highlighted the importance of discussing SF and providing additional information. In their daily practice, however, nurses often avoid responding or fail to respond to patients' sexual concerns. Considering the incidence, the influence on quality of life and the patients' need to discuss the impact of disease on SF, there is much room for improvement in sexual health care provision in oncology departments.

Our aim was to investigate nurses' knowledge about and opinions on the responsibility for addressing SF in oncology treatment settings in The Netherlands, as well as looking at their attitudes to the subject and identifying what they consider as barriers to addressing it. In addition, the possible wish of oncology nurses for supplementary education and practical training in counselling on sexual matters was investigated. Several previous studies have recommended future research using a larger sample, in order to have a more representative overview. Since conflicting findings have been reported worldwide and as the studies performed have been mostly qualitative, based on a single centre and relatively small samples, we considered it essential to investigate the Dutch nurses' attitudes and practice behaviour in a nationwide quantitative study design (Kotronoulas et al., 2009). We postulated that most Dutch oncology nurses are aware of the possible impact of cancer diagnosis and treatment on SF, but they do not routinely take a sexual history because of difficulties in bringing the subject up and stereotypical assumptions about sexuality in the face of cancer. This study was performed as part of an extensive study on possible omissions regarding attention paid to SF in oncology care, in order to develop sexual health care solutions for cancer patients in future.

Methods

Study design

Data for this cross-sectional survey were collected using a questionnaire. The sample consisted of Dutch nurses involved with oncology patients working in various departments in several clinical settings. Our sampling strategy aimed to be representative with regard to tumour site, employment setting, level of education, years of oncology experience, type of hospital, age and gender.

Instrument design and development

The established Sexuality Attitudes and Beliefs Survey (SABS) assesses nurses' attitudes to and views on human sexuality with 12 items presented in a Likert-type format (1–6 levels of agreement) (Reynolds and Magnan, 2005). In order to acquire extensive information on all relevant factors covering the aim of this study, not included in the SABS, it was decided to design a more comprehensive questionnaire. The current questionnaire design does, however, comprise items addressed in the SABS. The 37-item questionnaire was developed by the corresponding author (E.M.K.) in cooperation with an expert-panel, consisting of an experienced sexology researcher (M.P.J.N.), a urologist–sexologist (H.W.E.), a professor of oncology (S.O.) and an oncology research nurse (A.Q.M.J.v.S) (Appendix 1). A literature review was conducted to find other surveys in the field of nursing and sexuality, in order to merge all relevant items, barriers and what was not yet known. The design made use of previous surveys among health care providers (Bekker et al., 2011; Nicolai et al., 2013), studies which measured adequately attitudes regarding sexuality. After the initial instrument design, the authors individually scored all items for content validity. Items scored as non-essential by multiple authors were removed. The pilot questionnaire was reviewed by 10 anonymous oncology nurses from the LUMC (Leiden University Medical Centre) and modified using their feedback. In the pilot, the questionnaire was tested for length, layout, linguistic inaccuracies, identification of problematic questions, advice on content, whether response choices were appropriate and whether respondents followed directions. On the basis of the pilot, irrelevant questions were removed and minor linguistic changes and question order modifications made.

The final version comprised a demographic sheet and Likert-scale items (ranging from 1 to 5 levels of agreement) measuring practices, attitudes, content of sexual counselling, responsibility, need for education and barriers regarding discussing SF and fertility