Differences in health care professionals' and cancer patients' views on sexual health issues

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Succinct key points:

- Previous studies have shown that cancer and its treatment affect sexual health
- Patients and health care professionals have different views of sexual health issues and rarely address sexual health issues
- Validated sexual health measures may facilitate physician-patient communication
- The EORTC Sexual Health Questionnaire (EORTC SHQ-22) can be used to identify sexual health problems in research and clinical practice

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Background

Cancer patients and survivors may experience a broad range of sexual problems as a result of diagnosis and treatment [1-2]. These sexual problems can develop across the entire disease and treatment trajectory and persist into survivorship thereby negatively affecting quality of life (QoL)[3]. Despite a prevalence of up to 85%, sexual problems are often underestimated and not identified during routine clinic appointments [4]. Though health care professionals (HCPs) seem to be aware of sexual dysfunction as a major health concern related to cancer, they often feel uncomfortable in discussing sexual issues with their patients due to a lack of training, lack of time, their own attitude, and perceived patient embarrassment [5]. It is not known if patients and HCPs share views of the relative importance of sexual health problems after cancer treatment. Understanding of which sexual health issues patients and/or HCPs identify as clinically relevant and important is essential for improved communication between both parties. During the development of the European Organization for Research and Treatment of Cancer - Sexual Health Questionnaire (EORTC SHQ-22), we identified essential sexual health issues and aimed to compare patient and HCPs views of the relevance and importance of sexual health issues to form the questionnaire design.

Methods

The EORTC Quality of Life Group is developing a multilingual, self-report measure to assess treatment-related sexual health issues of cancer patients and survivors following the EORTC guidelines [6]. The developmental stages of the EORTC SHQ-22 have been described previously [7]. This project has been conducted in a multicultural setting including 12 countries (Austria, Belgium, Croatia, France, Germany, Greece, Italy, NL, Poland, Spain, Taiwan, UK). For the purpose of this communication, a review of the literature identified sexual health issues relevant and important to male and female cancer patients and cancer survivors. An 'issues list' was generated with 52 issues.

Participants

Health care professional eligibility: any discipline; specialized in oncology; at least six months experience in cancer care. Patient eligibility: histologically confirmed cancer diagnosis; any cancer site and stage; any time point on treatment including follow up; no cognitive impairments; 18 years of age or above; and written informed consent.

Procedure and Assessments

Patients were recruited in hospitals during and after treatment in inpatient and outpatient clinics. They were asked to rate each of the 52 sexual health issues for relevance and importance using a 4-point Likert scale (1=not relevant to 4=very relevant). HCPs with expertise in oncology at each hospital were asked to evaluate the issue list in exactly the same way. The sexual health issues were categorized in 13 areas: sexual activities, issues related to the sexual response cycle, side-effects influencing sexual activities, intimacy, fear related to sexual activities, communication/relationship issues, distress related to sexuality, sexual health care needs, male sexual health issues, and female sexual health issues. The protocol was approved by the local ethical committees according to the national requirements of the participating institutions.

Statistical Analysis

Descriptive statistics were used to describe the general characteristics of the samples. The difference in mean scores between the HCPs and patients and between male and female patients was investigated using an independent two-sample t-test. Effect size (Eta^2) was calculated with $Eta^2 > 0.14$ indicating strong, $Eta^2 > 0.06$ moderate, and $Eta^2 < 0.06$ weak effects.

Results

One-hundred and seven patients (62% females; 38% males) with different sites and stages of cancer and 83 HCPs with different professional backgrounds participated in the study. Sociodemographic and clinical characteristics for the patient sample are shown in Table 1. The HCPs sample consisted of radiation oncologists (24%), surgical gynecologic oncologists (23%); psycho-oncologists (21%); other oncologic surgeons (13%), medical oncologists (6%), oncology nurses (5%); and other professions (8%). HCPs showed mean scores >2 in the majority of issues related to sexual activity, sexual desire, orgasm, side effects influencing sexual activities, intimacy, fear related to sexual activities, communication/relationship issues, distress related to sexuality, sexual health care needs, males sexual health issues, and female health issues. Patients scored only six issues as 'relevant' or 'very relevant' (mean >2). These were 'satisfaction with the frequency of having an active sexual life', 'importance of having an active sex life', 'the level of emotional intimacy', 'satisfaction with the level of affection or intimacy', 'satisfaction with partner communication', and 'general sexual satisfaction'. Female cancer patients rated the relevance of six issues significantly higher than male patients. These were 'reasons for being sexual inactive', 'level of hesitation to initiate sexual activities', ' hair loss affecting sexual response, 'scarring/organ loss affecting sexual response', 'level of pain during/after sexual activity', and 'fear that sex will be painful'. Comparison of mean

relevance ratings showed significant differences in more than 50% of the issues. Of the 52 sexual health issues, HCPs provided significantly higher mean scores ($p<0.001$) for 32 issues compared to the patient scores. The relevance of all issues concerning treatment side effects influencing sexual activities, fear related to sexual activities and sexual health care needs was rated significantly higher by HCPs compared to patients. In addition, all gender specific sexual health issues were considered significantly more relevant by HCPs than by patients except 'level of confidence in getting and keeping an erection'. This was true also for the communication/relationship issues except 'satisfaction with partner communication'. Finally, HCPs relevance ratings for the three issues related to orgasm, reasons for being sexually inactive, distress caused by decreased libido, satisfaction with the level of sexual arousal, general sexual satisfaction, and distress due to sexual dysfunctions significantly exceeded patient ratings. We found strong effect sizes for 22 issues (Eta^2 >0.14) and moderate for 10 issues (Eta^2 >0.06). The profile of HCPs and patients' mean ratings are shown in Figure 1.

Discussion

Despite extensive reporting of the causal association between cancer treatment and sexual problems, patient's sexual health needs are frequently neglected in health care [4,5]. Although sexual health is not routinely discussed we found that HCPs consistently rated the relevance of more than two thirds of sexual health issues higher than the patients. There seems to be a gap between acknowledging the importance of sexual health issues and actually discussing these issues with patients. HCPs often feel uncomfortable in discussing sexual issues with their patients due to a lack of training, lack of time, discomfort and embarrassment [4,5]. Similar barriers also exist in the communication of information on fertility preservation with young cancer patients [8].

In this study the different views of HCPs and patients is to be expected given that patients are reflecting on the relevance of the issues to their own experience and HCPs are reflecting on the relevance of the issues to the target patient population. Furthermore, the majority of patients were undergoing active treatment, a time point within the disease trajectory where other QoL issues rather than sexual health issues might be prioritized by patients. Our results showed that during active treatment only two sexual health issues were rated higher by patients than by HCPs. After completion of treatment sexual health issues became more relevant. It seems that patient ratings of importance and relevance of sexual health issues are time dependent.

Based on the results of this study, we conclude that HCPs should be aware of sexual health as a subject that has to be actively addressed across the entire treatment trajectory, extending long beyond the completion of cancer treatment. This is in line with the recently established clinical

practice guidelines of the American Society of Clinical Oncology regarding interventions to improve sexual function in patients with cancer [9]. An accurate assessment of sexual health issues can contribute to individualized and improved patient care. For screening and assessment of sexual health problems the EORTC SHQ-22 may facilitate the discussion on this sensitive topic.

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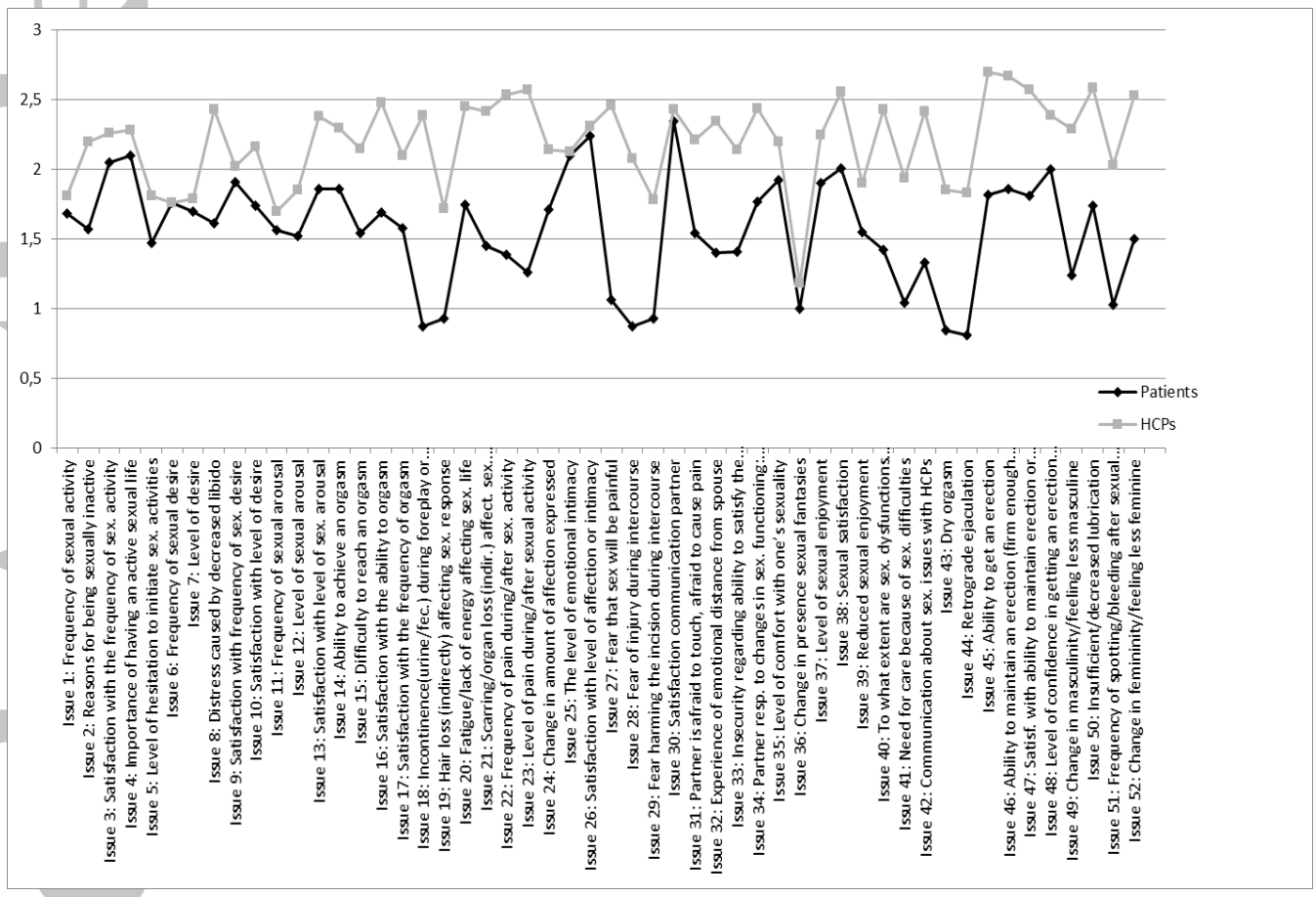
Table 1: Sociodemographic and clinical characteristics of the patient sample (N=107)

	N	%
Gender		
Female	66	62
Male	41	38
Age		
20-35 years	3	3
36-50 years	31	29
51-65 years	54	50
66-85 years	17	16
Missing	2	2
Sexual partner		
Yes	90	84
No	15	14
Missing	2	2
Cancer Site		
Breast	43	41
Colorectal	17	16
Head/Neck	14	13
Gynecologic	12	11
Prostate/Testicular	11	10
Lung	5	5
Other sites	4	4
Treatment		
Surgery	76	71
Radiation therapy	66	62
Chemotherapy	62	60
Anti-hormonal therapy	28	26
Others	5	5
Treatment status		
Active treatment	72	67
Treatment completed	34	32
Missing	1	1

Figure 1. Profile of health care professionals (HCPs) and patients ratings*



*Mean scores of relevance ratings