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Prevalence and possible predictors of sexual dysfunction and self-reported needs related to the sexual life of advanced cancer patients

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Abstract (252 words)

Background: Sexual dysfunction and problems are common late effects after treatment of cancer. However, little is known about the prevalence and risk factors for sexual dysfunction in patients with advanced cancer. The aim of this study was to investigate the prevalence and predictors of sexual problems and needs in a large sample of Danish patients with advanced cancer.

Methodology: The data derived from a representative cross-sectional study of patients with advanced cancer. Patients who had been in contact with one of 54 hospital departments were invited to fill out a questionnaire on symptoms and problems. Five items asked about sexuality. Ordinal logistic regression was used to identify variables associated with sexual functioning in explorative analyses.

Results: A total of 1,447 patients completed the questionnaire and of those, 961 patients (66%) completed the sexuality items. More than half of the patients (60%) had not been sexually active within the previous month, despite a high prevalence of desire for sexual intimacy (62%). More than half of the patients (57 %) experienced that their physical condition or treatment had impaired their sex life. Of those, 52% experienced an unmet need for help with sexual problems from the health care system. Older patients were less likely to report sexual problems than younger patients. Having prostate or gynecologic cancer was associated with the feeling that one's sexual life was negatively influenced.

Conclusion: Sexual problems are common among patients with advanced cancer and should be addressed by the health care system.

Introduction

Sexual dysfunctions, problems and limitations are common late effects of cancer and affect both sexes [1-5]. Sexual dysfunction represents a broad concept, including several possible definitions and underlying causes related to the patient such as emotional and physical changes and an altered partner relationship after cancer treatment [6].

The prevalence of sexual dysfunction in cancer patients varies depending on patient group, measurement, and definitions. In a review by Andersen et al, the overall prevalence was estimated to range between 20-90 % across different cancer diagnoses, stage, and treatment [2]. In a review of women with diverse types of cancer, the prevalence ranged between 25 % and 94 % [6]. Often, research in sexual dysfunction or problems is focused on cancer sites affecting the genitals including prostate and breast [7]. Sexual complaints are very common among these patients [1] and sexual impairments often persist among survivors [8].

Few studies have investigated sexual dysfunction in patients with advanced cancer. And few studies (if any) have investigated sexual problems in large samples of patients with diverse types of advanced cancer also including patients with less common cancer diagnoses. Patients with advanced cancer are diverse and little is known about the prevalence and severity of sexual dysfunction in this group and whether suffering from sexual dysfunction is more common in certain clinical populations. Knowledge of associations between sociodemographic and clinical variables and sexual problems and needs may help targeting future interventions addressing sexual dysfunction in

advanced cancer patients.

The aim of this study was to investigate the prevalence of sexual problems in a large national sample of cancer patients with advanced cancer. Further, we aimed to investigate sociodemographic and clinical variables possible associations between sexual problems and the patients need for help from the health care system in an explorative design. The study was part of a larger study of symptoms and problems in a national representative sample of patients with advanced cancer. Parts of the study have been reported elsewhere [9-12].

Method

Patients

Data derived from a nationwide, representative, cross-sectional study of advanced cancer patients [9, 10]. Three regions in Denmark were selected based on their geographic and socio-demographic representation, and all hospital departments treating cancer patients in these regions were invited to participate. A random subset was selected among patients who a) were ≥ 18 years of age, b) lived in one of three hospital regions, c) had been in contact with one of the hospital departments from the region within the previous year, d) had cancer (solid tumors or lymphomas stage III or IV according to the American Joint Committee on Cancer (AJCC) staging manual [13]; cancer in the central nervous system, small-cell lung cancer in any stage, or leukemia), e) spoke Danish, and f) did not have cognitive impairment or psychiatric comorbidity. A sample of patients was included based on their date of birth. However, to obtain a

relevant number of patients from the smaller departments these were oversampled compared to the two larger regional oncological departments. Eligible patients received a questionnaire and a letter including informed consent by mail.

Clinical information about the patient's diagnosis, time since diagnosis, cancer stage, treatment and type of last contact with the hospital was extracted from their medical records. Information on marital status, education, and number of children was obtained from the patients in the questionnaire.

The study was approved by the local ethics committee (01-116/03 and 11-143/03) and took place from October 2004 to January 2006. The inclusion of patients has been described previously [10-12].

Questionnaire

The questionnaire consisted of 60 items assessing patients' symptoms, problems and needs [9, 10, 14]. Five items assessing the patients' sexuality and potential sexual problems were developed for this study. The items were validated in a mixed methods study using a combined qualitative and quantitative approach to ensure that the patient's understanding and interpretation of the questions and response categories corresponded to the researcher's intention [21]. The five items are depicted in Table 2. The first three questions had a timeframe of one month and asked the patient 1) to what degree he/she had been sexually active, 2) if he/she had desired sexual intimacy and 3) if his/her illness/treatment had complicated his/her sexual life. The fourth question had a timeframe of one week and asked 4) if his/her sexual difficulties had been a problem for

him/her in the past week. These four questions were scored on a 4-point Likert-scale where 1 = not at all, 2 = a little, 3 = quite a bit, 4 = very much. The fifth item was labeled the 'felt need' item and included four sub-items. First, patients were asked if they had had problems with their sexual life (sub-item 1). Second, they were asked if they had received help and/or treatment from the health care services for their problems with their sexual life (yes/no) (sub-item 2). Finally, if they had received help, they were asked to indicate if the help was adequate (adequate/partly inadequate or inadequate) (sub-item 3). If the patient indicated that he/she had not received help they were asked if they were interested in help and/or treatment if possible (yes/no) (sub-item 4).

For analytical purposes, the 'felt need' item was categorized into four outcomes: a) '*no problem*' defined as those who indicated not having problems with sexuality, b) '*met need*' was defined as those who had received adequate help for their problems, c) '*unmet need*' was defined as those indicating that they had not received any help or received partly inadequate/inadequate help, while d) '*no wish*' was defined as those who did not wish any help with their sexual problems. These four outcomes were also used to create a dichotomized variable where an unmet need corresponded to outcome c ('unmet need'), and not having an unmet need corresponded to the three other outcomes (outcomes a, b, and d).

(Figure 1 around here)

Statistics

The analyses were performed using SAS statistical software version 9.4. The patients who answered at least the first sexuality item (participants) and patients who participated in the survey but did not answer the first sexuality item (non-participants) were compared using chi-squared tests.

For each outcome (being sexually active, desire for sexual intimacy, physical condition complicated sexual life, difficulties with sexual life a problem, and unmet need for help) univariate logistic regressions were made with the potentially explanatory variables. The variables tested were age group, sex, cancer diagnosis, stage, treatment status, type of last contact with the hospital, time since diagnosis, marital status, education, and children.

The explanatory variables that were significant in the univariate analysis ($p < 0.05$) were entered into a multivariate ordinal logistic regression model to identify the predictive variables of each outcome. In the multivariate regression we used a stepwise procedure with an exclusion criterion of $p > 0.05$.

Results

Participants

A total of 1,447 patients participated in the survey (response rate 67%). Of those, 961 patients (66%) completed the first sexuality item (41 % of eligible patients).

Characteristics of participants compared to non-participants are given in Table 1.

Patients who completed the sexuality items were more often of male sex, aged below

60, were more often off-treatment, had a higher education (a theoretical education of three years or more), and were more often married or cohabiting. Further, the distribution of cancer diagnoses differed between participants and non-participants.

(Table 1 around here)

Prevalence

More than half of the responding patients (60%) had not been sexually active within the previous month while 62% expressed a desire for some degree of sexual intimacy. More than half (58 %) had experienced that their physical condition or treatment had complicated their sexual lives, and 54% of the patients responded that difficulties with their sexual life had been a problem for them within the previous week (Table 2).

(Table 2 around here)

Of the 1,447 patients, 801 (55%) completed the *felt need* item. Of these, 396 (49%) indicated that they had problem(s) with sexuality, 32 (4%) indicated that their need for help was met, 208 (26%) had an 'unmet need' for help, 134 (17%) had 'no wish' for help, and 22 (3%) did not fully answer the questions (not shown in table).

Regression analysis

For the outcome *being sexually active*, the following variables were significant in the univariate analysis: age, diagnosis, treatment, contact type, cancer stage, marital status

and education level. The multivariate model showed that age above 80, a diagnosis of multiple myeloma, being divorced, unmarried, or widowed was associated with not being sexually active (Table 3).

In relation to *lack of desire for sexual intimacy*, the following variables were significant in the univariate analysis: age, diagnosis, sex, treatment, contact type, cancer stage, marital status, children and education level. The multivariate regression analyses showed that patients aged above 70 and females were more likely to lack desire for sexual intimacy (Table 3).

For the item measuring if *physical condition or treatment had complicated sexual life*, age, diagnosis, sex, treatment, cancer stage and marital status were significant in the univariate analysis. The multivariate model showed that patients aged below 70 and patients with prostate or gynecologic cancer and in active treatment had a significantly higher odds of feeling that their sex life was complicated by their physical condition or treatment (Table 3).

For the item measuring if *difficulties with sexual life had been a problem*, age, diagnosis, sex, treatment, contact type, cancer stage, marital status, children and education level were significant in the univariate analysis. The multivariate model showed that patients with prostate-, bladder-, gynecological-, lung cancer or multiple myeloma or patients who had recently been hospitalized were more likely to experience that sexual difficulties were a problem (Table 3).

Finally, regarding experiencing an *unmet need related to sexual problems*, diagnosis and sex were significant in the univariate analysis. The multivariate analysis showed that an unmet need was more likely among patients with gynecologic cancer and patients of male sex (Table 3).

(Table 3 around here)

Discussion

The present study reported on sexual problems in a large cross-sectional cohort of patients with advanced cancer and constitutes an explorative sub-analysis of a larger study [9]. Only 40% of the patients were sexually active although the majority felt a need for sexual intimacy. In accordance with the literature, the patients experienced that their physical condition or treatment complicated their sex life [1-5]. Previous studies have mainly addressed sexual dysfunction after treatment of early stage cancer and consistently reported that sexual problems were not addressed properly during follow-up [1, 4, 5, 8, 15-20]. An important finding in the present study is that patients with advanced cancer also report a desire for sexual intimacy, a high prevalence of sexual problems, and an unmet need for support concerning their sexual problems from the health care systems. This is a reminder that sexual problems during survivorship are also important for patients with advanced cancer and deserve more attention in the health care system.

In the present study older age was associated with being less sexually active and having less desire for sexual intimacy whereas younger age was associated with a higher risk of feeling that one's sexual life had been complicated by physical condition and treatment. This is consistent with the literature showing that ageing is associated with decreased sexual activity [21]. However, importantly, age was not a predictor of having an unmet need for help with sexual problems. Thus, it is important to emphasize that the results presented here should not be translated into a reluctant attitude towards communicating with elderly cancer patients about potential sexual dysfunction following cancer and its treatment.

A diagnosis of prostate or gynecologic cancer was associated with experiencing that disease and treatment had complicated sex-life, experiencing difficulties with sex life to be a problem and gynecological cancer was also associated with having an unmet need for help. Many previous studies have reported decreased sexual desire among gynecologic and prostate cancer survivors [1, 7, 14]. Erectile dysfunction following treatment for prostate cancer and decreased vaginal elasticity, dyspareunia, and lack of lubrication following pelvic radiotherapy are common sexual dysfunctions. This may prompt patients to cease sexual activities, despite their sexual desire being intact [22]. The present study underlines the importance of addressing sexuality and potential sexual problems in patients treated for genital cancer. Our study also confirms earlier findings that gynecological cancer patients have unmet needs related to help with sexual problems [5, 9, 15]. However, the present study also demonstrates that patients with other diagnoses may experience similar sexual difficulties that need to be addressed

accordingly, e.g. patients with many different forms of cancer were more likely to experience difficulties with sex life to be a problem.

Males were more likely to experience a need for help and females were more likely to experience lack of desire for sexual intimacy. This underscores that both genders may have supportive needs in this area as also reported in other studies[8]. Interestingly, the variable ‘time since diagnoses’ was not significant in the univariate-analysis. However, based on the questions posed in the present study we do not know if the nature of sexual dysfunction changes over time. It is possible that the overall prevalence of problems stays the same because new challenges arises and may substitute old ones.

We found a high proportion of patients with an unmet need for help. This underlines that patients with sexual dysfunction would like the assistance and support from the health care system regarding their sexual problems. The findings that patients do not receive sufficient help and information from their medical providers are consistent with the literature [1, 4, 5, 8, 15-20]. Several reasons could be discussed: medical providers may not be confident addressing issues related to sexuality [20, 23] and may hesitate to refer the patient to sexual specialist care [8]. Further, the health care staff may overlook the problems of the patients, because patients and their partners self-silence to cope with the situation [15]. Finally, specialist sexual care may also be a limited resource. These barriers to the recognition and treatment of sexual problems are not easily overcome. However, as the sexual lives of patients are closely connected to the patient’s psychological well-being and quality of life [3], the health care system would be well

advised to be proactive in their handling of sexual problems. This could be done by carrying out systematic assessment of sexual functioning before and after the cancer treatment, via courses in sexology for the health care staff, and through improved possibility to refer patients for counselling if severe sexual problems are identified.

A limitation in the present study is that the data was obtained in 2004-2006. However, the relationship between sexual desire and sexual distress is not likely to change much over time, nor are the predictors of sexual problems. Further, our findings are consistent with newer research showing that a great amount of cancer patients are suffering from sexual dysfunction [1]. The primary study had a participation rate of 61%. However, not all participants responded to the items on sexuality. This led to a comparatively low participation rate of 41% in this study. The participation rate obtained is likely to represent what can be expected when approaching advanced cancer patients with poor performance. Significant differences were identified between participants and non-participants. This may compromise the representativity of our findings. It is most likely that our results represent the outcome of the patients with the best performance while those with poor performance may be under-represented. Our results regarding sexual problems may thus be underestimated.

Conclusion

Patients with advanced cancer reported a high prevalence of sexual dysfunction and unmet needs related to their sex life. Our results underline the obligation for the health

care system to address and handle sexual problems during cancer survivorship independent of cancer diagnosis and stage.

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