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Cancer and sexual health: The continuum of care

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PART I

THE PATIENT

Chapter 2: Discussing sexuality in cancer care:
towards personalized information for cancer patients and
survivors

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Introduction

The negative impact of cancer and cancer treatment on patients' sexuality is widely known(1-4). Cancer patients can experience sexuality related issues regardless of cancer type or treatment(5-7). Prevalence of sexuality related issues due to cancer is high and is reported up to 90% in some gynecologic cancers(8). The etiology of sexuality related issues in cancer patients is multifactorial(9). The cancer itself, cancer treatment, as well as psychological factors can contribute to the issues(8).

Sexuality related issues can arise by start of treatment and are likely to extend years after primary treatment(2, 10). Sexuality is considered an important quality of life concern by many cancer patients and survivors(11, 12). Since prognosis for cancer gets, attention directed towards the late effects of treatment and quality of life concerns is getting more important. An opportunity to discuss sexuality during the treatment process is important(4). Before treatment, cancer patients and physicians should be aware of potential sexual side effects of treatment. During treatment and follow-up communication is essential to identify and treat sexual problems(2, 10, 13). Most health care providers see sexuality as an important topic that need to be discussed(6, 14, 15). However, communication between patients and health care providers about sexuality is challenging and seems not enough imbedded in daily oncological practice yet(13, 15-19). Many barriers of health care professionals to initiate the discussion are described, like lack of time and lack of training(13, 20-24). Consequently, many cancer patients may experience unmet sexual health needs. Previous studies focused on the assessment of patients reported rates of communication about sexuality with health care providers and patients' experience with the communication. These studies reveal that cancer patients and survivors are not satisfied with current communication and the existing information regarding sexuality. The studies highlight the need for improvement of information about sexuality for cancer patients(17-19, 25-29). However, it is known that not all patients have the same need for information regarding sexuality(30). To our knowledge, only a few recent studies have examined which patients have a greater need for information about sexuality(16, 30). Moreover, preferences for kind of information might be personal and differ between cancer types.

Taking this in mind, personalized information for cancer patients and survivors is needed. The aims of the current study were to identify in a large sample of cancer patients what substantive information patients and survivors preferred to receive, their ideas on how to improve communication regarding sexuality, and to identify patients groups who are more in need of sexuality-related information.

Methods

Study population and procedure

The study was conducted by The Dutch Federation of Cancer Patient Organizations (NFK) and the Leiden University Medical Center (LUMC), the Netherlands. The NFK is the Dutch umbrella organization for cancer patient organizations. The NFK and the cancer patient organizations work together to promote important and relevant themes. Besides, they ask for attention for underexposed themes. Sexuality was considered as an underexposed theme in cancer care. This questionnaire survey was initiated by the NFK.

The questionnaire was sent to cancer patients and survivors of eight cancer patient organizations as well as patients in the patient panel of the NFK. The questionnaire was also open for cancer patients who were not a member of one of the organizations. The participants were recruited via the following channels: email to members, NFK website, NFK newsletter, websites and newsletters of the cancer patient organizations, and social media. The questionnaire was distributed in March 2017 and open for two weeks. Due to the wide distribution of the questionnaire, it was not possible to know a actual reach and response rate.

Questionnaire:

The questionnaires for the survey were developed by the NFK in collaboration with patients advocates and the department of Urology and department of Biomedical Data Sciences at the LUMC since no validated questionnaire for the aim of the study was available. Structure and design of the questionnaires were derived from questionnaires used in previous studies performed by the LUMC to evaluate sexual health care, with items based on issues identified by the authors and in literature(21, 23, 31, 32). Patient advocates' knowledge and experiences played a key role in matching the questionnaires to patients' needs and perspective.

The questionnaire contains 28 questions (see Appendix 2) assessing topics such as demographic factors, issues with sexuality after cancer, information needs regarding sexuality, and their ideas to improve communication about sexuality with a health care provider.

Privacy

All data were stored securely and only authorized employees of the NFK and a researcher of the LUMC had access to the data. No personal information of participants was collected. Questionnaires couldn't be traced back to the participants. This was confirmed by the privacy coordinator of the NFK.

Data-analysis

All data were analysed using IBM SPSS statistics 23. Demographic information and responses to the survey were analysed using descriptive statistics. Bladder cancer and kidney cancer and cancer of the male external genitalia were merged to “Urological cancer”. Type of cancers which were < 5% of the total group were merged to “other”. These included endocrine, haematological, lung, bone, head neck and skin malignancies. Difference in age between male and female was calculated using the independent sample T-test. Bivariate associations were calculated using the Pearson's chi-square test. Binary logistic regression model was used to predict the probability of needing information. Need for information was the dependent variable. The following covariates were included in the model: age (younger vs older, divided according to the median), gender (male vs. female), stage of disease (local vs. metastatic), relationship (no vs. yes), self-reported negative impact on sexuality (no vs. yes), time from diagnosis (<2 years, 3-5 years, 6-10 years, > 10 years), treatment modalities (all: no vs yes): surgery, external beam therapy, internal beam therapy, hormonal therapy, chemotherapy, immunotherapy. For the binary logistic regression stratified for type of cancer only the significant variables were presented. “Other” malignancies were not included in the model since this is a mix of 6 different malignancies. The models were built using backward selection based on Wald tests. Outcomes were considered statistically significant if the two-sided P- values were <0.05.

Ethics

The Medical Ethics Committee of the LUMC was consulted in order to verify whether ethical approval was necessary. Since the survey was initiated by the NFK in such a manner that the respondents could not be identified and participation was anonymous and fully voluntarily the Committee declared that no formal ethical approval was needed (protocol number G19.052).

Results

In total, 2657 (ex)cancer patients participated in the study. Half of the respondents was male (45%). Men (mean age 66.6 years, SD 10.3) were significant older than women (mean age 54.0 years, SD 11.4) ($p < 0.001$, CI 95% 11.7-13.4, SE 0.4). The majority of respondents (89%) was in a relationship. Of all men, 44% ($n=523$) had prostate cancer. Of all women, 63% ($n=902$) had breast cancer. Of all respondents, 67% ($n=1767$) reported a negative impact of cancer on their sexuality. All characteristics are presented in **Table 1**.

Table 1: Patients characteristics (n=2657)

* Multiple answers possible

	Participants n (%)
Gender	
Male	1193 (45)
Female	1444 (55)
Age (years)	Median 61 (19-94 years)
Relationship status	
Not in a relationship	267 (11)
In a relationship	2221 (89)
Time since diagnosis	
≤ 2 year	530 (23)
3-5 year	736 (32)
6-10 year	556 (24)
> 10 year	471 (21)
Type of cancer*	
Breast	905 (34)
Prostate	531 (20)
Gastro-intestinal	455 (17)
Urological	172 (7)
Gynecological	135 (5)
Other	260 (10)
Stage of cancer	
Local disease	1708 (74)
Metastatic disease	477 (20)
Treatment*	
No treatment	29 (1)
Surgery	1954 (74)
External beam therapy	1205 (45)
Internal beam therapy	172 (7)
Hormonal therapy	791 (49)
Chemotherapy	1073 (40)
Immunotherapy	186 (7)
Self-reported negative impact of cancer on sexuality	
Yes	1767 (67)
No	884 (33)

Factors associated with a higher need for information

Of the respondents, 65% (n=1721) reported a need for information regarding sexuality. Patients with gynaecological cancer reported the highest need (n=113, 84%), followed by patients with prostate cancer (n=383, 72%), see **Figure 1**. Of the patients diagnosed with cancer less than two years as well as patients who were diagnosed 3-5 years ago, in both groups 71% reported a need for information (resp. n=377 and n=522). In patients who were diagnosed 6-10 years ago, 69% (n=384) reported a need, and a need was reported by 57% (n=269) in patient who were diagnosed more than 10 years ago.

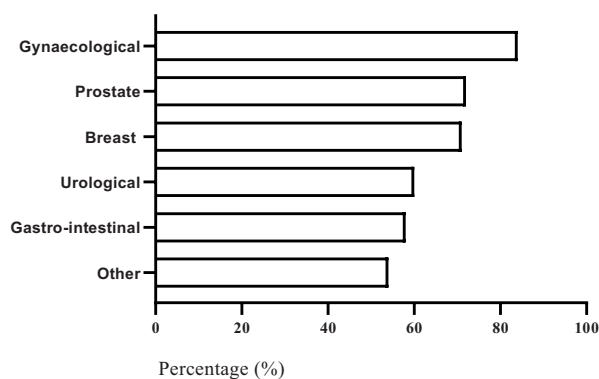


Figure 1: Percentage of patients who reported to have a need for information regarding sexuality

The need for information was significantly higher in patients from 61 years and younger ($p < 0.001$), patients with a self-reported negative impact of cancer on sexuality ($p < 0.001$) and patients who were diagnosed less than two years ago ($p = 0.04$). The need for information significantly declined after 10 years after diagnosis ($p = 0.02$).

No differences in need for information according to gender, relationship status, stage of disease or treatment were found, see **Table 2**. **Table 3** shows that the need for information stratified for type of cancer. In contrast to the analyses with all respondents, the information need did not differ according to age in patients with a gynaecologic cancer. The information need in patient with prostate cancer was higher in patient who had surgery ($p = 0.02$) and patient with a local stage of disease (< 0.01).

Table 2: Factors associated with a higher need for information

Variable	B*	S.E.*	P Value
Age (≥ 62 years)	-.9	.1	<0.001
Gender	-.1	.1	0.6
Stage of disease	-.1	.1	0.3
Relationship	.2	.2	0.3
Negative impact on sexuality	1.6	.1	<0.001
Time from diagnosis			
< 2 years			0.04
2-5 years	.007	.1	0.9
6-10 years	-.07	.2	0.7
> 10 years	-.4	.2	0.02
Treatment			
Surgery	.01	.2	0.9
External beam therapy	.2	.1	0.2
Internal beam therapy	-.2	.2	0.4
Hormonal therapy	-.1	.1	0.6
Chemotherapy	-.1	.1	0.4
Immunotherapy	.2	.2	0.4

*B = regression coefficient, SE = standard error

Table 3: Factors associated with a higher need for information according to type of cancer

Variable	B*	S.E.*	P Value
Breast			
Age (≥ 54 years)	-4	.2	0.04
Negative impact on sexuality (no vs. yes)	1.9	.2	<0.01
Prostate			
Age (≥ 70 years)	-1	.2	< 0.01
Negative impact on sexuality	.9	.3	< 0.01
Surgery (no vs. yes)	.5	.2	0.02
Stage of disease (local vs. metastatic)	-.9	.2	< 0.01
Gastro-intestinal			
Age (≥ 68 years)	-.6	.2	< 0.01
Negative impact on sexuality	1.5	.2	< 0.01
Urological			
Age (≥ 68 years)	-1.7	.4	<0.01
Negative impact on sexuality	.9	.4	0.03
Gynaecological cancer			
Negative impact on sexuality	1.5	.7	0.02

*B = regression coefficient, SE = standard error

What do they need?

Respondents, who reported a need for information regarding sexuality were asked what kind of information they prefer to receive. **Table 4** presents the scores of the need of specific kind of information. Patients do prefer to receive several types of information. Most mentioned were practical tips (n=1048, 60%), practical information (etiology, prevalence) (n=1018, 59%) and experiences from others (n=943, 54%).

Respondents, who reported a need for information, were asked how health care professionals could improve communication around sexuality. More than half of all respondents (64%, n=1101) suggested that it would be of help to improve the communication about sexuality with their care providers if the care providers give information systematically and if health care providers initiate the subject (34%, n=578). A third of the respondents (34%, n=591) would like to have the opportunity to get a referral to a sexologist. Active involvement of the partner when discussing the subject was suggested by 45% (n=657) of the respondents in a relationship.

Table 4: Kind of information patients prefer to receive

	All	Breast	Prostate	Urological	Gastro-intestinal	Gynaecological
Total	1721 (100)*	643 (100)	383 (100)	104 (100)	262 (100)	113 (100)
Practical tips	1048 (60)	519 (81)	258 (68)	67 (64)	150 (57)	71 (63)
Practical information	1018 (59)	456 (71)	198 (52)	49 (47)	142 (54)	71 (63)
Experiences from others	943 (54)	352 (55)	215 (56)	60 (58)	126 (48)	71 (63)
Information for partners	647 (37)	270 (42)	153 (40)	34 (33)	79 (30)	39 (35)
Contact with other cancer patients	298 (17)	112 (17)	61 (16)	18 (17)	38 (15)	23 (20)
Referral to a professional	281 (16)	97 (15)	70 (18)	22 (21)	49 (19)	19 (17)
Information video	141 (8)	30 (5)	58 (15)	12 (12)	24 (9)	7 (6)
Information for care providers	130 (8)	61 (10)	23 (6)	5 (5)	11 (4)	12 (11)

* Patients, out of all respondents, who reported to be in need of information regarding sexuality

Discussion

The aim of this study was to examine what kind of sexuality-related information cancer patients need, their ideas on how to improve communication regarding sexuality, and to identify groups who are likely to be more in need of information. It shows that cancer patients reported to be in need of different kind of information regarding sexuality. Respondents preferred practical tips and practical information regarding sexuality. Respondents emphasized the importance of care providers to provide information regarding sexuality as standard care. The study highlighted factors associated with a higher need for information regarding sexuality in terms of age, self-reported negative impact of cancer on sexuality and time from diagnosis.

Based on earlier research, patients experience unmet needs regarding sexual health care, including a lack of information and communication with health care providers about sexuality(17-19, 25-29). As respondents of the current survey recommended to health care providers, providing information regarding sexuality as standard care might create an opening for discussing sexuality and may therefore be used to enhance communication about sexuality (25, 33, 34). The availability of accurate information regarding sexuality might be helpful for health care providers to initiate a discussion. Some of health care providers' barriers for not initiating the topic, like lack of training in sexual issues or lack of resources, could be reduced if information is available. According to our survey, information should contain at least practical tips and information regarding sexuality to meet with patients' preferences. However, given the distribution of preferences of patients regarding kind of information, it would be ideal to provide multiform information.

In our survey 35% of the respondents reported to feel no need for information regarding sexuality. This percentage is in concordance with the literature(28, 35). Since sexuality is considered as a sensitive and private subject, it might be important to be aware of patients who are more likely to be in need. Age is one predictive factor in regard to information need.

According to the literature, in our survey younger patients reported a higher information need(18, 36). Younger patients are likely to have more sexual activity and therefore a higher need for information. However, age is not a defining factor since sexual activity continues to an old age and sexuality in older patients cannot be neglected (7, 16, 37, 38). Previous literature reported a higher percentage of men to discuss sexuality with a health care provider, suggesting a higher information need in men(16, 17, 30). However, the present study suggests that the need for information regarding sexuality does not differ between gender. Study results also suggest a higher need in patients diagnosed less than two years ago. Information should be provided actively to patients during this period. The need for information regarding sexuality declines significantly 10 year after diagnosis. However, 57% of the respondents who were diagnosed more than 10 years ago still reported a need for information. This indicates a role for information regarding sexuality in long time follow-up. Sexual issues can remain long time after diagnosis and not all cancer patients might be in follow-up when they face sexuality issues(10). Therefore, it is recommended to embed practical tips and information regarding sexuality not only in standard care and follow-up care but also make sure it is widely available and easily accessible online.

Our findings can contribute to the development and implementation of information to better inform and support cancer patient and survivors about sexuality issues. Unlike previous research, the current study assessed what kind of information patients with different kind of cancer prefer. This may contribute to more personalized information for cancer patients and survivors. The results of this study resulted in a Dutch website about cancer and sexuality with practical tips, practical information and experiences from others divided by cancer type (www.kankerenseks.nl).

Strengths of this study are the large sample size and the inclusion of patients with different cancer types and different times from diagnosis. Some limitations need to be considered. First, the study design was cross-sectional. The respondents were mainly recruited via the NFK and related patient organisations. It is unknown if the respondents are a representative sample of all cancer patients. Patient who have unmet sexual health care needs might more likely to respond. However, the need for information regarding sexuality in our study was comparable with previous literature(28, 35).

Second, level of education was not included in our questionnaire. A higher education level has shown to be associated with a higher health literacy and a better capability to assert needs(18, 39). Moreover, it can be argued that level of education may have an impact on preferences regarding kind of information(40). In general, members of patient organizations have a higher level of education than the population of cancer patients. Therefore, our results might not be generalizable for all cancer patients and patients' level of education should be incorporated in further research. Finally, recall bias might have occurred since a self-reported questionnaire was used. The majority of respondents was diagnosed more than two years ago. Experiences of respondents diagnosed some time ago are important to this study because sexual issues can remain in long term survival. Further research could focus on longitudinal evaluation of information designed according to patients' preferences.

Conclusion

According to these findings it can be concluded that cancer patient prefer different types of information about cancer induced sexuality issues. Most preferred information were practical tips and information, regardless of cancer type. (Ex)cancer patients prefer to get standard information provided by their health care providers. Patients' age, self-reported negative impact on sexuality and time from diagnosis (< 2 years) were related with a higher need of information regarding sexuality. Results might be useful for developing suitable information regarding sexuality for cancer patients in the future.

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