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Cancer and sexual health: The continuum of care

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PART II

THE PATIENT AND THEIR PARTNER

Chapter 4: Sexual healthcare for intimate partners of people with cancer: information and communication needs

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Introduction

Cancer and its treatment can negatively affect sexuality and intimacy, resulting in a decreased quality of life of patients with cancer (1-4). Sexual changes can start at diagnostic stage and are likely continue in long-term survival (1). Besides negative impact on patients sexuality and intimacy, most partners of patients with cancer report a negative impact on their sexuality and intimacy (5-10). Partners mark changes in their sexual relationship and a decreased frequency of sexual activity and intimacy. Previous studies identified the following reasons: the impact of cancer on self-image of the patient, physical changes, adverse effects of cancer treatment (e.g. pain, fatigue) and repositioning their partners as asexual (5, 7, 11). Consequently, partners report feelings of frustration, sadness and deterioration of their intimate relationship (11, 12). Nevertheless, an intimate relationship during cancer treatment and survivorship is important since it is associated with better psychosocial outcomes in both cancer patients and partners (13, 14).

Partners of patients with cancer experience communication with a care provider about sexuality and intimacy as unhelpful (9). They report a lack of advice and information regarding sexuality and intimacy issues (5, 9, 11, 12). They want a better insight in the sexual side effects and support on maintaining intimacy (5, 7, 15). Existing studies highlight the importance of involvement of the partner in communication about sexuality and intimacy with healthcare providers and providing them accurate information and include advice in supportive care for partners (5, 9, 11, 12, 16).

Little is known on partners' needs and preferences regarding communication about sexuality and intimacy. Moreover, to our knowledge, no recent studies have identified partners who are likely to be more in need of information. The aims of this study are to: 1) identify aspects that are associated with partners' sexuality and intimacy, 2) identify partners' characteristics that are associated with need for information, and 3) investigate partners' preferences for communication regarding sexuality and intimacy.

Methods

Study design

The survey was initiated by The Dutch Federation of Cancer Patient Organizations (NFK). Partners of patients with cancer were recruited via patients with cancer. First, the patients with cancer were recruited via different ways: an email to members of eight cancer patients organizations in the Netherlands, a call at the newsletters and website and of the NFK and allied cancer patient organizations, and via social media. By doing so, cancer patients and partners who were not a member of one of the cancer organizations were also able to react. The results of survey among cancer patients are out of the scope of this manuscript and are described elsewhere (17). The survey was open in March 2017. Responding cancer patients were requested to fill out the email address of their partner, if they wished their partner to receive the questionnaire of the current study. A different questionnaire was sent to the partners. Due to privacy reasons, it was not possible to relate the questionnaire of the cancer patients to the questionnaire of their partner. No reminder was sent. No data of the non-responders are available. There were no restrictions based on age, cancer diagnosis type or time since diagnosis. Sample size of the study could not be calculated due to the lack of previous and similar studies or surveys.

Questionnaire:

There was no validated questionnaire available. The questionnaire was conducted by the NFK in cooperation with the Leiden University Medical Center (LUMC) and patients advocates and their partners, based on the literature. The used questionnaire was based on questionnaires used in previous research of the LUMC. Items were based on expert opinions and literature (17-20). Patient advocates and partners were involved in the development of the questionnaire.

The questionnaire consists of 28 questions (see Appendix 4) including the following issues: demographics, concerns with sexuality and intimacy, information needs, and their suggestions to enhance communication regarding sexuality and intimacy with healthcare providers.

Statistics

Analysis were performed using IBM SPSS statistics 25. Descriptive statistics were used to analyse demographic information. Cancer types of the partners of the respondents which were less than 5% of the total amount were combined in "other". The independent sample T-test was used to calculate differences of numeric variables. Bivariate associations were tested with Pearson's chi-square test. For predication of the probability of the need of information a binary logistic regression was performed with need for information as dependent variable. Covariates which were included are: gender, age (divided by the median), disease stage, reported effect of cancer on sexuality, treatment modalities and time since diagnosis (less than 2 years, 3 till 5 years, 6 till 10 years and more than 10 years). Backward selection based on Wald tests was used. Types of information which were < 10% of the total amount were not displayed in Table 1. Missing data (questions which were not completed) was not added within the percentage; number (n) is mentioned to define. Statistical significant was considered if P- values were <0.05.

Privacy & ethics

The data was collected and stored by the NFK. Authorized staff members of the NFK and one staff member of the LUMC and author (LA) had access to the data. Questionnaires were collected anonymously and cannot be linked to the respondents. This was verified by a privacy staff member of the NFK.

The Medical Ethics Committee of the LUMC was consulted in order to verify whether ethical approval was necessary. Since the survey was initiated and conducted by the NFK, the respondents could not be identified and the participation was voluntarily and anonymous, the Medical Ethics Committee declared that no formal ethical approval was needed (protocol number G19.052). The current study was a continuation of a study among cancer patients and considered by the ethical committee at the same time with the same protocol number(17).

Results

In total, 564 partners of patients with cancer were invited to participate. 230 partners filled out the questionnaire, resulting in a response rate of 40%. **Table 1** presents the characteristics of the respondents. Of them, 66.3% (n=129) were female and 43.7% (n=100) were male. Female respondents (mean age 64.1, SD 9.9) were older than male

respondents (mean age 58.8, SD 10.4) ($p < 0.001$). The majority of their partners had limited disease ($n=151$, 79.0%) and had undergone surgery ($n=157$, 68.3%).

Aspects associated with partners' sexuality and intimacy

Slightly more than half of the participants ($n=127$, 55.9%) stated that the cancer had negatively their sexuality and intimacy. Significantly more women ($n=82$, 64.6%) than men ($n=45$, 45.0%) reported this negative impact ($p < 0.01$). Three-quarter ($n=47$, 74.6%) of the partners of prostate cancer patients, 57.1% ($n=32$) of the partners of breast cancer patients and 56.5% ($n=29$) of the partners of patients with gastro-intestinal cancer reported a negative impact (**Table 1**).

Partners of patients who underwent external beam therapy ($n=50$, 65%) reported more negative impact on sexuality and intimacy in comparison with partners of patients without external beam therapy ($n=26$, 26%; $p < 0.01$). Hormonal therapy was also associated with a negative impact on partners' sexuality and intimacy (hormonal therapy vs no hormonal therapy; $n=38$, 70% vs $n=86$, 51%, $p=0.01$). Age, stage of disease, surgery, chemotherapy and internal beam therapy were not significantly associated with greater negative impact on sexuality and intimacy (p -value ranges from 0.06 to 0.7; **Table 1**).

Characteristics associated with need for information

A majority of the respondents ($n=137$, 59.6%) reported a need for information (**Table 1**). Respondents who reported a negative impact of cancer on their sexuality and intimacy were more in need of information ($p < 0.01$). Age, gender, stage of disease, time from diagnosis and type of treatment were not related to a higher need for information (p -value ranges from 0.4 to 0.7; **Table 1**).

Table 1:
 Characteristics of the respondents
 Self-reported negative impact of the respondents
 Self-reported need for information of the respondents

	Participants n (%)	Negative impact n(%)	Need for information n(%)
All	230 (100)	127 (55.9)	137 (59.6)
Gender			
Female	129 (56.1)	82 (65.1)	78 (60.5)
Male	100 (43.4)	45 (45.0)	58 (58.0)
Missing	1 (0.4)		
Age (years)	Median 64 (20-84)		
< 50	24 (10.5)	7 (29.2)	12 (50.0)
50 – 70	153 (66.5)	93 (61.6)	98 (64.1)
> 70	53 (23.0)	27 (51.9)	27 (50.9)
Cancer type*			
Prostate	66 (28.7)	47 (74.6)	45 (68.2)
Breast	56 (24.3)	32 (57.1)	40 (71.4)
Gastro-intestinal	46 (20.0)	29 (56.5)	28 (60.9)
Other	34 (14.8)	18 (52.9)	17 (50.0)
Unknown	36 (15.7)	8 (22.2)	14 (38.9)
Time since diagnosis			
≤ 2 year	51 (27.9)	35 (71.4)	36 (70.0)
3-5 year	72 (39.3)	46 (64.8)	48 (66.7)
6-10 year	39 (21.3)	21 (53.8)	21 (53.8)
> 10 year	21 (11.5)	17 (53.8)	18 (56.3)
Stage of cancer			
Limited	151 (79.0)	59 (39.9)	97 (64.2)
Metastatic	38 (21.0)	10 (26.3)	24 (63.2)
Treatment*			
Surgery	157 (68.3)	93 (60.4)	98 (62.4)
External beam therapy	91 (39.6)	65 (71.4)	58 (63.7)
Chemotherapy	80 (34.8)	49 (61.3)	52 (65.0)
Hormonal therapy	54 (23.5)	38 (70.3)	36 (66.7)
Internal beam therapy	20 (8.7)	14 (70)	14 (70)

* Multiple answers possible

Preferences for communication

When facing sexuality and intimacy problems, most respondents (n=88, 69.3%) discussed the problems with their partner. A minority (n=12, 9.4%) talked to their healthcare provider about the problems or searched for information themselves (n=15, 11.8%).

Participants, who stated to have a need for information, were asked about their ideas to enhance communication with the healthcare provider about sexuality and intimacy. The majority of the partners (71.5%, n=98) suggest that a healthcare professional should provide information regarding sexuality and intimacy systematically. Half of the respondents (n=72, 52.6%) suggested that the healthcare professionals should be actively involved them in discussing sexuality and intimacy. Less partners were interested in an accessible referral to a sexologist to discuss sexuality and intimacy issues due to cancer (n=44, 32.1%).

Next, participants were requested what kind of information would be helpful for them. **Table 2** displays the need for kind of information per gender, age and cancer type. Slightly more than half of all responding partners preferred practical advice regarding sexuality and intimacy (n=76, 55%). Experiences from others (n=64, 46.7%), practical information (etiology, prevalence) (n=60, 43.8%) and information specific for partners (n=60, 43.8%) were next most mentioned. Significantly more men than women were in need of practical advice and information for partners (p=0.04, p=0.03).

Table 2: Kind of information required*

	Practical advice n(%)	Experiences from others n(%)	Practical information n(%)	Information for partners n(%)	None n(%)
Gender					
Female	41 (31.8)	35 (27.1)	31 (24.0)	28 (21.7)	51 (39.5)
Male	35 (35.0)	29 (29.0)	28 (28.0)	32 (32.0)	42 (42.0)
Age					
< 50 years	6 (25.0)	7 (29.2)	6 (25.0)	6 (25.0)	12 (50.0)
50 – 70 years	58 (37.9)	47 (30.7)	41 (26.8)	44 (28.8)	55 (35.9)
> 70 years	12 (22.6)	10 (18.9)	13 (24.5)	10 (18.9)	26 (49.1)
Cancer type					
Breast	25 (55.3)	21 (62.5)	22 (39.3)	24 (42.9)	16 (28.6)
Prostate	23 (66.2)	41 (64.6)	15 (21.5)	19 (29.2)	21 (31.8)
Gastro-intestinal	16 (34.8)	12 (26.1)	12 (26.1)	6 (13.0)	18 (39.1)

* answers to the question “What kind of information regarding intimacy and sexuality do you prefer?”; multiple answers possible

Discussion

This study supports previous research that highlights the need for adequate information regarding sexuality and intimacy for partners of patients with cancer. More than half of the respondents stated that cancer had negatively affect their sexuality and intimacy. Female gender, external beam therapy and hormonal therapy were associated with a higher negative impact. Except a self-reported negative impact of cancer, no characteristics were determinants for a higher need for sexuality related information. Partners prefer to receive information from a healthcare professional and were most interested in information consisting of practical advice and experiences from others.

Younger age and male gender were identified to be related to a higher need of information regarding sexuality and intimacy in patients with cancer (9, 21, 22). In our study, age and gender were not associated with the need for information regarding sexuality and intimacy. Also type of partners' treatment was not related to a higher need of information. This finding suggests that the need of information of the respondents is independent of characteristics (age, gender, treatment) of their partners with cancer. Therefore, it might be difficult to identify partners have a higher need for information. Both partners of a person with reproductive cancer and nonreproductive cancer are known to experience an impact on sexuality (5). This highlight the need to acknowledge sexual concerns of all partners of a someone with cancer. Moreover, partners of patients with cancer may experience feelings of shame and guilt regarding their sexual desires and they feel sexual needs are inappropriate (5). Hence, they might be less likely to report a need for support and information regarding sexuality and intimacy. It can be argued that information should be easily accessible and actively provided to partners, as they indicate in this survey. As the need for information is obvious both for partners and cancer patients, this aspect of treatment seems to be neglected in daily practice.

Current literature revealed that partners are not satisfied with the information and support regarding sexuality and intimacy (9). Our findings suggest that partners of patients with cancer are in need of practical advice regarding sexuality and intimacy and experiences from others. Suitable information with respect to sexuality and intimacy for partners can be helpful to prepare partners for sexual side effects and create realistic expectations about sexual function after cancer (12). Lack of knowledge regarding sexual side effects can lead to unmet sexual needs, which can negatively influence quality of life and may result in lower levels of relationship satisfaction (23-25). Moreover, knowledge on sexual side effects will foster communication about sexuality and intimacy within medical practice. Open communication about sexuality and intimacy may results in better coping with sexual problems (24, 26, 27).

Patients with cancer reported to prefer their partners to be involved in communication regarding sexuality and intimacy and sexual recovery with a healthcare provider, and so do their partners (12). In accordance with our study, in current medical practice, a discussion about sexuality and intimacy with a healthcare provider does not take place for most cancer patients and partners due to mismatched expectations or barriers by healthcare professionals or patients to bring up the subject (4, 5, 9, 18, 28). Therefore, it is recommended that information regarding sexuality and intimacy is also widely available independent of healthcare providers.

Strength of this study is a larger sample size than existing studies regarding our topic (5, 9, 11, 20, 21). However, a sample size calculation could not be calculated beforehand. More research among partners is needed in order to strengthen our findings. Another strength is the participation of partners from patients with diverse cancer types. A number of limitations need to be considered. First, a non-validated questionnaire was used. There were no questions on the duration of the relationship, ethnic and religious aspects, which might influence the negative impact on sexuality and the need for information. Both may be incorporated in future research.

The response rate might have caused nonresponse bias. Our response rate is slightly higher in comparison with surveys about sexuality among partners of patients with cancer (9). Besides, selection bias might have occurred. Not all cancer types were represented in this study. The reported negative effect of cancer on sexuality and intimacy was lower in our study (55.9%) than reported in literature (69-78%) (5, 6). This may be due to the lack of partners of patients with gynecologic cancer, who are known to report a high negative impact on sexuality and intimacy (7, 29). However, there was a good spread across gender and treatment modalities. Moreover, the sample size was larger in contrast with previous studies investigating cancer and sexuality and intimacy among partners (5-9).

Besides, recall bias might have occurred. Sexuality and intimacy problems are known to be a late effect of cancer and are likely to continue during long-term survival (1). According to our survey, partners of cancer patients are mostly affected in the first five years after diagnosis. Following on from this, the need for information was also highest in the first five years. However, some partners describe sexuality and intimacy as a nonissue during treatment (7). In time, people want life after treatment to return to as normal as possible again and may have more attention for sexuality and intimacy. They need to find a new approach to sexuality and intimacy. During this phase, information regarding sexuality and intimacy might be also important. This supports our findings that half of the partners stated a need for information more than ten years after diagnosis.

Further research could focus on the role of different psychological factors in information need regarding sexuality and intimacy in partners. Moreover, future research could include a longitudinal prospective study to evaluate information for partners per type of cancer. The results of this survey were used for the development of a website with information for partners of cancer patients about cancer and sexuality and intimacy (www.kankerenseks.nl).

Conclusion

In conclusion, our findings underscore that information regarding sexuality and intimacy for partners of patients with cancer is important with the limited majority of partners. Partners prefer to receive information regarding sexuality and intimacy from a healthcare provider as routine care. Information should include practical advice and experiences from others. Suitable information, adjusted to partners' social and cognitive condition, may support partners and patients to cope with changed sexuality and intimacy after cancer and is important to be included in supportive cancer care.

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