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Sexuality in Intimate Partners of People with Cancer: Information and Communication Needs: A Brief Communication

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ABSTRACT

Partners of patients with cancer report a negative impact on their sexuality and intimacy and experience a lack of information. Little is known about partners' information needs regarding sexuality and intimacy. The study was conducted with 230 partners of patients with cancer using a questionnaire. 56% stated that cancer had negatively affected their sexuality and intimacy. 60% percent reported a need for information. Except a self-reported negative impact of cancer, no characteristics were associated with a higher need for sexuality related information. Partners prefer information that includes practical advice and experiences from others. It is recommended to provide patients and their partner's information on sexuality and intimacy within routine treatment.

Introduction

Cancer and its treatment can negatively affect sexuality and intimacy, resulting in a decreased quality of life of patients with cancer (Ben Charif et al., 2016a, 2016b; Bober and Varela 2012; Ussher, Perz, Gilbert, & Australian Cancer and Sexuality Study Team, 2015). Most partners of patients with cancer report a negative impact on their sexuality and intimacy as well (Garos, Kluck, & Aronoff, 2007; Gilbert, Perz, & Ussher, 2016; Hawkins et al., 2009; Lehto, Aromaa, & Tammela, 2018; Miaja, Platas, & Martinez-Cannon, 2017; Oldertroen Solli, de Boer, Solbraekke, & Thoresen, 2019). 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 (Gilbert, Ussher, & Hawkins, 2009; Hawkins et al., 2009; Oldertroen Solli et al., 2019).

Existing studies highlight the importance of involvement of the partner in communication about sexuality and intimacy with healthcare professionals and providing them accurate information and include advice in supportive care for partners (Gilbert et al., 2009, 2016; Hawkins et al.,

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2009; Mehta et al., 2019; Vermeer, Bakker, Kenter, Stiggelbout, & Ter Kuile, 2016). Partners experience a lack of support, advice and information regarding sexuality and intimacy (Gilbert et al., 2016; Hautamaki-Lamminen, Lipiainen, Beaver, Lehto, & Kellokumpu-Lehtinen, 2013; Hawkins et al., 2009). To our knowledge, no recent studies have identified partners who are likely to be more in need of information. Besides, little is known on partners' needs and preferences regarding communication about sexuality and intimacy. The aims of this study are to: (1) identify partners' characteristics that are associated with need for information, and (2) investigate partners' preferences on communication regarding sexuality and intimacy.

Materials and methods

The survey was initiated by The Dutch Federation of Cancer Patient Organizations (NFK). This study is part of a broader study including cancer patients and their partners. First, 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 the website of the NFK and allied cancer patient organizations, and via social media. The results of survey among cancer patients are out of the scope of this manuscript and are described elsewhere (Albers et al., 2020).

Questionnaire

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 and expert opinions (Albers et al., 2020; Grondhuis Palacios et al., 2018; Krouwel et al. 2019; Nicolai et al., 2014). Patient advocates and partners were involved in the development of the questionnaire and tested the questionnaire with regard to spelling, lay-out, relevance and structure. The questionnaire consists of 28 questions including the following issues: demographics, concerns regarding sexuality and intimacy, information needs, and their suggestions to enhance communication regarding sexuality and intimacy with healthcare professionals.

Statistics

Analysis was performed using IBM SPSS statistics 25. Descriptive statistics were used to analyze demographic information. The independent sample T-test was used to calculate differences in age between females and males. 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. Backward selection based on Wald tests was used. Statistical significant was considered if p -values were <0.05 .

Privacy and ethics

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 part of a broader study with cancer patients and therefore and considered by the ethical committee at the same time with one protocol number (Albers et al., 2020).

Table 1. Characteristics of the all participants.

	Participants <i>n</i> (%)	Need for information <i>n</i> (%)
All	230 (100)	137 (59.6)
Gender		
Female	129 (56.1)	78 (60.5)
Male	100 (43.4)	58 (58.0)
Missing	1 (0.4)	
Age (years)	Median 64 (20-84)	
<50	24 (10.5)	12 (50.0)
50–70	153 (66.5)	98 (64.1)
>70	53 (23.0)	27 (50.9)
Cancer type*		
Prostate	66 (28.7)	45 (68.2)
Breast	56 (24.3)	40 (71.4)
Gastro-intestinal	46 (20.0)	28 (60.9)
Other	34 (14.8)	17 (50.0)
Not specified	36 (15.7)	14 (38.9)
Time since diagnosis		
≤2 year	51 (27.9)	36 (70.0)
3-5 year	72 (39.3)	48 (66.7)
6-10 year	39 (21.3)	21 (53.8)
>10 year	21 (11.5)	18 (56.3)
Stage of cancer		
Limited	151 (79.0)	97 (64.2)
Metastatic	38 (21.0)	24 (63.2)
Treatment*		
Surgery	157 (68.3)	98 (62.4)
External beam therapy	91 (39.6)	58 (63.7)
Chemotherapy	80 (34.8)	52 (65.0)
Hormonal therapy	54 (23.5)	36 (66.7)
Internal beam therapy	20 (8.7)	14 (70)

Self-reported need for information of the participants.

*Multiple answers possible.

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.

Characteristics associated with need for information

A majority of the respondents ($n = 137$, 59.6%) reported a need for information (Table 1). In a logistic regression, respondents, males as well as females, who reported a negative impact of cancer on their sexuality and intimacy were more in need of information ($p < 0.01$). Age, stage of disease, time from diagnosis and type of treatment were not related to a higher need for information (Table 2; p -value ranges from 0.07 to 1).

Preferences on 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 professional 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 professional 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 ($n = 72$,

Table 2. Factors associated with a higher need for information regarding sexuality.

Male Female						
Variable	B*	S.E.*	p value	B*	S.E.*	p value
Age (≥ 65 years)	-1.1	0.7	0.3	-0.1	0.64	0.2
Stage of disease	-0.2	0.9	0.1	0.9	0.5	0.8
Negative impact on sexuality	-2.5	0.7	<0.001	-1.5	0.5	0.003
<i>Time from diagnosis</i>						
< 2 years			1			0.4
2–5 years	-0.05	0.8	1	0.4	0.7	0.6
6–10 years	-0.05	1	1	0.9	0.7	0.2
>10 years	0.4	1.2	0.8	1	0.7	0.2
<i>Treatment</i>						
Surgery	0.6	1.1	0.6	-0.1	0.6	0.9
External beam therapy	1.3	0.7	0.07	-0.4	0.5	0.5
Internal beam therapy	-0.4	1.2	0.8	-0.4	0.8	0.6
Chemotherapy	-0.5	0.7	0.5	-0.2	0.6	1

*B = regression coefficient, SE = standard error.

Table 3. Kind of information required*.

	Practical advice <i>n</i> (%)	Experiences from others <i>n</i> (%)	Practical information <i>n</i> (%)	Information for partners <i>n</i> (%)	None <i>n</i> (%)
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.

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 3 displays the need for kind of information per gender, age and cancer type. Significantly more men than women were in need of practical advice ($p = 0.04$).

Discussion

This study supports previous research that highlights the need for adequate information regarding sexuality and intimacy for partners of patients with cancer. Except a self-reported negative impact of cancer, no characteristics (age, gender, stage of disease, time from diagnosis and type of treatment) were associated with 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.

In previous research among cancer patients, younger age and male gender were identified to be associated with a higher need for information regarding sexuality and intimacy (Davison et al., 2002; Gilbert et al., 2016; Sporn et al., 2015). In our study, age and gender were not associated with the higher need, nor was the type of partners' treatment. The need of information may independent of characteristics (age, gender, treatment) of their partners with cancer. This highlights

the need to acknowledge sexual concerns of all partners of a someone with cancer. Literature reveals that partners of patients with cancer may experience feelings of shame and guilt regarding their sexual desires and they feel sexual needs are inappropriate (Hawkins et al., 2009). 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.

Current literature revealed that the majority of partners were not satisfied with the information and support regarding sexuality and intimacy (Gilbert et al., 2016). Current 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 (Mehta et al., 2019). 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 (Acquati et al., 2018; Dobinson et al., 2016; Park & Hwang 2012).

Patients with cancer reported to prefer their partners to be involved in communication regarding sexuality and intimacy and sexual recovery with a healthcare professional, and so do their partners (Mehta et al., 2019). In accordance with our study, in current medical practice, a discussion about sexuality and intimacy with a healthcare professional does not take place for most cancer patients and partners. This might be due to mismatched expectations or barriers by healthcare professionals or patients to bring up the subject (Ben Charif et al., 2016a; Gilbert et al., 2016; Hawkins et al., 2009; Hordern & Street 2007; Krouwel et al. 2019). Therefore, it is recommended that information regarding sexuality and intimacy is also widely available independent of healthcare professional.

Strength of this study is a larger sample size than existing studies regarding our topic (Davison et al., 2002; Gilbert et al., 2009, 2016; Grondhuis Palacios et al., 2018; Hawkins et al., 2009). A number of limitations need to be considered. No data was collected on sexual orientation (heterosexual, gay, lesbian), duration of the relationship, ethnical and religious aspects, which might influence the negative impact on sexuality and the need of information. 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 (Gilbert et al., 2016). Selection bias might have occurred. 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 (Bober & Varela 2012). 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 (Oldertroen Solli et al., 2019). 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.

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 professional as routine care. Information should include practical advice and experiences from others. Suitable information, adjusted to partner's 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.

Disclosure statement

The authors declare that they have no conflict of interest.

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