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Reproductive and sexual health care in oncology: current practice and challenges

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Chapter 4

Sexual Concerns after (Pelvic) Radiotherapy: Is There Any Role for the Radiation Oncologist?

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INTRODUCTION

Cancer is a life-threatening disease, but because of expanding treatment options, it is turning into a condition with decreasing mortality. As patients live longer after diagnosis, attention for late effects of treatment and quality of life are of increasing importance, both during treatment and throughout survivorship [1]. A typical problem is that physicians and patients tend to concentrate on intensive medical treatment options and underestimate the late treatment-related adverse effects [2,3].

Radiotherapy (RT) is commonly used to treat cancer, whether as external-beam RT or brachytherapy. Specifically, pelvic RT for the treatment of uterine, cervical, bladder, prostatic, rectal, or anal cancer is known for its influence on sexual function, affecting both men and women [4,5]. Sexual dysfunction (SD) caused by pelvic RT originates from injury to organs, vessels, persistent inflammatory responses, hormonal deprivation, and psychologic responses, although the molecular etiology is not completely understood [6–13]. Tissue toxicity is depending on the accumulated radiation dose to the pelvic area [14–16]. Possible late effects of pelvic RT include pelvic fibrosis, resulting in endothelial damage, inflammation, ischemia, and eventually necrosis [17]. Vaginal discharge, skin erythema, and fatigue result in low scores of satisfaction with sexual function in women after pelvic RT [18–20]. Three years after RT for prostate cancer, 38% of pre-treatment potent men reported erectile dysfunction (ED), resulting in decreased satisfaction with sexual function [21]. Preoperative RT in primary rectal cancer has negative effects on sexual function in men and women [5]. RT on other areas of the body also has the ability to affect sexual function by inducing fatigue, psychosocial and emotional problems, sensory loss and reduced fertility [22], also breast radiation can have an impact on long-term cosmetic outcomes [23].

Despite the significant effect on sexual function, clinical assessment of treatment-induced SD following RT is an underexposed item during regular radiation oncologist consultations [24–26]. For this reason, patients should be actively informed on problems associated with radiation-induced SD and must be guided toward appropriate therapeutic options. To our knowledge, information concerning the attitude of radiation oncologists is barely available yet. So far, research focusing on radiation oncologists' attitudes regarding the provision of sexual counseling only involved a Chinese study [25]. However, the Global Survey of Sexual Attitudes and Behaviors revealed that women in East Asia were the least likely to talk to a doctor about their sexual issues (9% vs. 18–40% in non-Asian countries) [27]. For this reason, the Chinese survey might differ significantly from a non-Asian perspective.

As medical doctors are the major information source of treatment-induced morbidity and have a legal obligation to inform their patients on treatment-induced morbidity, investigating their current sexual counseling practices is of significant importance. By collecting data and demonstrating possible omissions, the development of a consistent and effective sexual health care counseling policy for patients receiving RT can be established. Aims The aim of this study was to investigate the attitude, knowledge, and barriers of Dutch radiation oncologists toward informing their patients on the possibility of treatment-induced SD. We also investigated the need for

training and perceptions concerning responsibility for addressing sexual issues, in order to clarify whether or not this is felt to be the radiation oncologist's responsibility. The data obtained could be used to adapt and develop educational training, guidelines and standard operating procedures regarding the counseling of cancer patients on treatment-induced sexual problems.

METHODS

Study Design

A cross-sectional postal survey was held among radiation oncologists and RT residents holding active practice in The Netherlands.

Cohort Identification and Survey Process

Questionnaires were sent to all radiation oncologists and RT residents (n = 234) who were member of the Dutch Association for Radiotherapy and Oncology (NVRO) at the time of Spring 2012. An information letter concerning the study and a postpaid return envelope were added, as well as an opt-out possibility. To facilitate the response rate, the initial mailing was followed by two reminders in August and November 2012. All data were collected anonymously in order to prevent a self-reporting bias.

Instrument Design and Development

Identified participants were sent a 28-item questionnaire developed by the authors, content based on questionnaires successfully used for similar studies among cardiologists, urologists, surgical oncologists and oncology nurses in the Netherlands [28–31]. A pilot study with 24 radiation oncologists was performed to evaluate the questions and adjust the questionnaire for the final survey according to the comments. As a result of the pilot study, questions on practice attitudes were separated for tumor-specific areas of specialization, and participants were given the opportunity to answer for two different areas of specialization.

Data Analysis

Quantitative data were analyzed using SPSS 20 (SPSS Inc., Chicago, IL, USA). The results were described using frequency distribution and descriptive statistics. Missing data (i.e., not completed questions) were not added with percentage calculations; n is always mentioned to clarify. Bivariate associations between demographic information and specific answers were made with Pearson's chi-squared test and Cochran-Armitage trend test.

Ethical Considerations

In The Netherlands, research that does not involve patients or interventions is not subject to approval from ethical boards. In previous research where nurses were the participants, the Medical

Ethics Committee was consulted in order to verify whether ethical approval was necessary. As the study did not concern any information recorded by the investigator in such a manner that subjects could be identified, directly or through identifiers linked to the subjects, and as it did not compromise the study participants' integrity, the Committee declared that no formal ethical approval was needed [32]. Participation was fully voluntarily and anonymous, an opt-out possibility was implemented.

Main Outcome Measures

- Demographic questions relating function, experience, gender, age, and focus areas. • Self-reported practice patterns regarding sexual counseling and providing information on sexuality.
- Opinion about responsibility for sexual counseling and referral behavior.
- Barriers toward assessing sexual health issues.
- Knowledge on sexual problems in reference to RT.
- Need for additional training.

RESULTS

Participants

Questionnaires were sent to 234 members of the NVRO. The final response rate was 54.6%, for further details on participation see Figure 1.

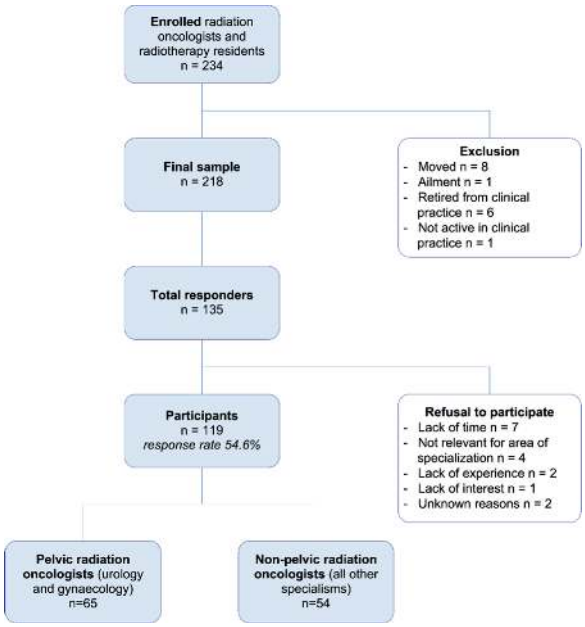

Fig. 1. Flow chart of the final participants.

Demographics of Respondents

Overall, there was an almost equivalent amount of men and women with a median age of 47 years. There was variation in experience, 52.9% of all respondents had over 15 years of experience in RT. All demographic information is displayed in Table 1.

Table 1. Demographic characteristics of the respondents (n = 119)

	n (%)
Age (years)	119 (100)
Median 47 years (range 26-66) m	
Mean 46.5 years (SD 8.9)	
Gender	
Male	58 (48.7)
Female	61 (51.3)
Function	
Radiation oncologist	116 (97.5)
Resident	3 (2.5)
Radiotherapy experience (years)	
<1	2 (1.7)
1–2	2 (1.7)
3-5	4 (3.4)
6-10	23 (19.3)
11-15	25 (21)
>15	63 (52.9)
Hospital type	
University hospital	60 (50.4)
District general teaching hospital	27 (22.7)
District general hospital	22 (18.5)
Categorical cancer hospital	4 (3.4)
University & district general hospital	3 (2.6)
Independent consultant	1 (0.8)
Not available	2 (1.7)

SD = standard deviation.

Practice Patterns

Data about practice attitudes regarding sexual function were separated according to area of specialization. Each radiation oncologist was able to provide answers for two areas of specialization and answer the questions for each type of patient. The results to the question "How often do you discuss sexual functioning of the patient?" are featured in Figure 2.

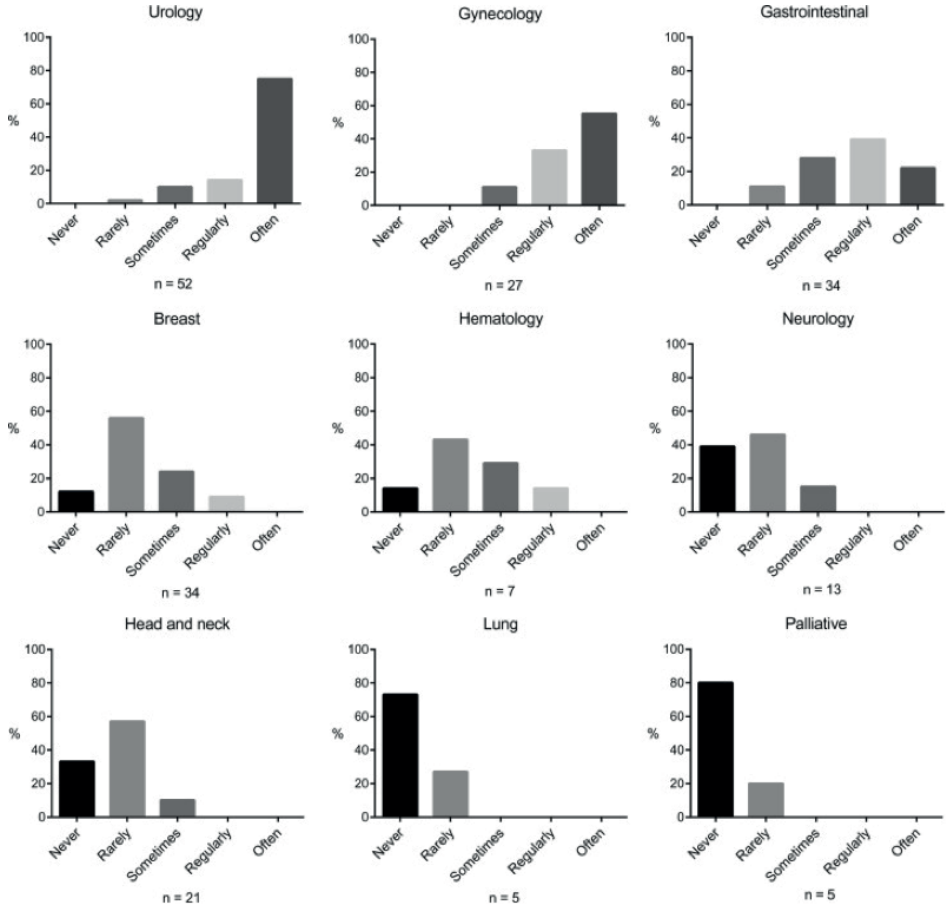

Fig. 2. Results to the question "How often do you discuss sexual functioning of the patient?," allocated for type of cancer.

According to the radiation oncologists involved with care for urology patients (n = 59), information about the risk for ED after prostatic RT is given regularly (16.9%) and often (81.3%). The majority declared to inform patients about the use of phosphodiesterase 5-inhibitors regularly (49.2%) and often (40.7%). A few radiation oncologists stated to rarely or never inform patients about erection medication (10.2%). Participants involved with gynecology patients (n = 27) gave information about sexual function after RT for cervical cancer rarely (n = 4, 14.8%) and regularly plus often (n = 23, 85.2%). Physicians involved with breast cancer patients (n = 48) provided information about sexuality in respect to breast radiation never (12.5%), rarely (50%), regularly (18.8%), and often (18.8%).

During conversations about sexual function, the partner was present in half of the cases (n = 32, 28.8%), more than half of the cases (n = 37, 33.3%) or almost always (n = 38, 34.2%). As for the question "How long does it take before treatment adverse effects to sexual function start to decrease?" 62.7% of the respondents (n = 69) stated from experience that adverse

effects from RT on sexual function remain forever. Forty-one responders estimated that sexual adverse effects remain for about 3–24 months (37.3%). The majority believed that women who underwent RT for cervical cancer often (82.5%, n = 94), regularly (14%, n = 16) and sometimes (3.5%, n = 4) experience sexual problems, after RT for breast cancer it was believed that women experience problems often (7%, n = 8), regularly (38.3%, n = 44), sometimes (36.5%, n = 42) and never/rarely (18.3%, n = 21).

Responsibility and Referring

Evaluation of treatment-induced SD is the responsibility of the radiation oncologist according to the majority of the respondents (n = 87, 75%). Remaining respondents considered neutral (n = 22, 19%) or disagreed having responsibility (n = 7, 6%). In the following question regarding responsibility of other health care providers (with a multiple answer possibility), a third of the respondents pointed at the referring specialist (e.g., the surgeon, urologist, gynecologist or oncologist) regarding responsibility for discussing SD (n = 40, 33.6%). A fifth considered the general practitioner responsible (n = 25, 21%). The primary responsibility of sexual counseling was separately analyzed among all pelvic radiation oncologists (n = 65, 54.6%), consisting of all radiation oncologists with urology and gynecology as their primary specialism. In this pelvic radiation group, the referring specialist (n = 19, 29.2%) and general practitioner (n = 9, 13.8%) were also felt to be responsible for addressing sexual functioning. Sixteen percent of respondents stated that the patient has its own responsibility to initiate discussion on SD.

To the question regarding patient referral in case of SD, 75.9% (n = 88) confirmed to have the possibility of referring their patients to an expert on this topic, 24.1% of the radiation oncologists (n = 28) was not familiar where to refer patients. The majority of the respondents indicated to be in need of a list with qualified sexual health care providers for referral (n = 84, 72.4%).

Barriers

The respondents were given a list of possible barriers for discussing SF, in order for them to indicate to which extent they agreed (Table 2). Radiation oncologists mentioned "patient is too ill" to discuss sexual issues as a major barrier (36.2%). The second barrier, to which 32.4% agreed, was "no angle or reason for asking." Other barriers were "advanced age of the patient" (27%), "culture/religion" (26.1%), "language/ethnicity" (24.5%), "sexuality is not a patient's concern" (23.9%), "patient doesn't bring up the subject" (20%), "lack of training" (19.3%), and "patient is not ready to discuss sexual functioning" (13.1%). The barriers that did not keep radiation oncologists from sexual counseling were all barriers regarding gender, "it's someone else's task" (2.6%), "age difference between you and the patient" (3.5%), "afraid to offend the patient"(3.5%), and embarrassment (5.3%). The results to the question concerning the provision of information about treatment-related SD in regard to the age of a patient are displayed in Figure 3.

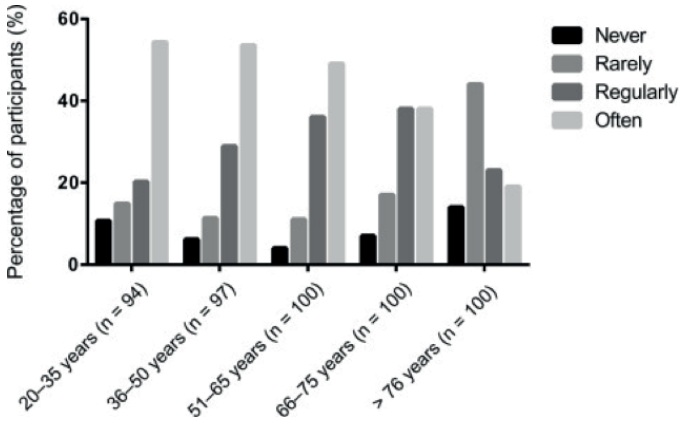

Fig. 3. How often do you discuss sexual concerns with patients in the following age categories?

Table 2. Barriers to sexual counseling; sorted from most agreed to least agreed

	Agree	**Partly agree/partly disagree**	**Disagree**
	n (%)	*n (%)*	*n (%)*
Patient is too ill	41 (36.2)	36 (31.9)	36 (31.9)
No angle or reason for asking	37 (32.4)	21 (18.4)	56 (49.2)
Advanced age of the patient	31 (27.0)	38 (33.0)	46 (40.0)
Culture/religion	30 (26.1)	32 (27.8)	53 (46.1)
Language/ethnicity	28 (24.5)	33 (29.0)	53 (46.5)
Sexuality is not a patient's concern	27 (23.9)	32 (28.3)	54 (47.8)
Patient doesn't bring up the subject	23 (20.0)	19 (16.5)	73 (63.5)
Lack of training	22 (19.3)	35 (30.7)	57 (50.0)
Patient is not ready to discuss sexual functioning	15 (13.1)	39 (33.9)	61 (53.0)
Presence of a third party	13 (11.3)	36 (31.3)	66 (57.4)
Lack of time	13 (11.3)	21 (18.3)	81 (70.4)
Sexuality is a private matter	12 (10.5)	15 (13.2)	87 (76.3)
Lack of knowledge	10 (8.8)	31 (27.2)	73 (64.0)
I feel uncomfortable	9 (7.9)	15 (13.2)	90 (78.9)
Embarrassment	6 (5.3)	14 (12.3)	94 (82.4)
Afraid to offend the patient	4 (3.5)	15 (13)	96 (83.3)
Age difference between you and patient	4 (3.5)	6 (5.2)	105 (91.3)
It's someone else's task	3 (2.6)	24 (20.9)	88 (76.5)
Patient is the opposite gender	2 (1.7)	5 (4.3)	108 (93.9)
Patient is the same gender	-	3 (2.6)	112 (97.4)

*For ease of presentation, results in response categories 'Strongly agree' and 'agree' have been merged, as have 'strongly disagree' and 'disagree'.

Knowledge and Training

To the question regarding knowledge, the majority of radiation oncologists stated to possess some knowledge concerning SD (n = 87, 67.2%), a quarter of all respondents stated to have sufficient knowledge on SD (n = 29, 25%) and the remaining respondents stated to have not much knowledge on SD (n = 9, 7.8%). Radiation oncologists under the age of 47, possessed less knowledge of SD in comparison to respondents of 47 years and older (P = 0.046). Gender did not influence the knowledge of SD (P = 0.513).

Of all responding radiation oncologists, 44.4% indicated to be in need of additional training regarding discussing sexuality with their patients (n = 50). Female respondents more often wished additional training than their male colleagues (55% vs. 33.9%, P = 0.023). Age (<47 vs ≥47 years) did not influence the wish for training (48.3% vs. 41.1%, P = 0.432). Almost all respondents agreed that sexual counseling should be a regular component of the radiation oncology residency (n = 110, 94%).

DISCUSSION

Key findings of this study are that radiation oncologists routinely discuss sexuality with their urology and gynecology patients, but not so consistently with their gastrointestinal-, breast-, and other cancer patients. The majority of radiation oncologists considered counseling on sexual functioning as part of their job, a third also pointed at the referring specialist as well as a fifth indicated that to be a responsibility of the general practitioner. More than half of the radiation oncologists indicated that radiation effects on sexual function usually persist forever. The majority of radiation oncologists stated to have some knowledge on treatment-related SD. Young radiation oncologists had less knowledge of the topic; illustrating experience might play a role in counseling. An important finding was that 44% of the respondents indicated that they would benefit from additional training regarding sexual counseling in radiation practice; female physicians indicated this wish more often than male physicians. Almost all respondents agreed that training in sexual counseling should be a regular part of RT residency. Barriers for sexual counseling included patient is too ill, no angle or reason for asking, advanced age, and culture or religion.

Comparison with Literature

To our knowledge, this survey was the first evaluation in Europe of radiation oncologists' attitudes and practice patterns regarding sexual health. In China, a similar evaluation was performed among radiation oncologists, also evaluating attitudes and behavior toward sexual issues of patients who received RT [25]. In line with our results, the radiation oncologists felt responsible for addressing the issue, nonetheless, dissimilar to our results they hardly addressed the issue spontaneously but only when the patient explicitly consulted them on this issue. The

majority of Chinese radiation oncologists expressed the need for training to enable them to provide guidance to patients, in the present study this was less than fifty percent. Wang et al. [25] found 41.7% of their surveyed radiation oncologists to be uncomfortable discussing sexual functioning with a patient, compared with 20% of the Dutch radiation oncologists, illustrating that the East Asian attitude regarding sexuality might differ from the non-Asian perspective.

In the United Kingdom, a survey among specialist gynecologic oncology nurses and an evaluation of the content of patient brochures showed a prominent lack of psychosexual content for example regarding vaginal dilatation in both clinical counseling and written materials [33]. Vaginal dilatation after pelvic radiation is recommended in order to maintain patency of the vagina. Although there is no reliable evidence on preventing stenosis, several reports suggest that women who dilate their vagina after RT reported and measured less stenosis [34]. Furthermore, a psycho-educational intervention is demonstrated to increase compliance of the use of vaginal dilatators compared with supplying information only [35]. As for Faithfull et al. their "information after pelvic radiation" survey, physicians rarely provided patient education in relation to sexual health advice and vaginal dilatation [33]. Patient education was considered a nursing or radiographer role; however, the physician was thought to be the one to evaluate on a patient's compliance regarding any intervention. Noteworthy, it appeared information was solely provided for gynecology patients, even though pelvic radiation therapy is also frequently used for the treatment of women with bladder, rectal and anal tumors.

The discrepancy between doctors' assumptions and the actual experienced complaints after receiving pelvic RT have also been emphasized in other reports, showing underreport of vaginal discomfort and underestimation of ED by physicians. In the United Kingdom, RT follow-up consultations were observed in order to determine the clinical assessment of treatment-induced female sexual difficulties [26]. Results showed acknowledgment by both patient and physician in the challenge of discussing sexual concerns. Barriers included the different priorities during consultations; like attention for possible recurrence of disease, lack of time, lack of expertise and lack of adequate referral pathways.

Vistad et al. compared physician-assessed morbidity (including vaginal discomfort) with reported symptoms from patients treated with RT for cervical cancer. Patient morbidity scores correlated poorly with data reported by physicians, confirming underreporting and underestimation of intestinal and bladder morbidity [24]. Vaginal discomfort was not compared with physician data; at follow-up only two-thirds of the patients were examined for vaginal symptoms, indicating the physician did not actively counsel at all.

Showalter et al. surveyed the estimation of 926 radiation oncologists on how often RT affected recovery of ED after radical prostatectomy. Significantly less radiation oncologists (47%) predicted a "major/total detrimental effect" to erectile function following RT in comparison with urologists (69%) [36]. With respect to patient-reported outcomes regarding RT for prostate cancer, the number of patients reporting inability to achieve an erection sufficient

for intercourse after 2 (60.8%), 5 (71.9%), and 15 years (93.9%) illustrates the underestimation of the radiation oncologists [37].

Clearly, the main barriers toward sexual counseling detected in the current survey can be opposed. The primary reason for not discussing sexual health "the patient is too ill" should be questioned, considering the body of evidence reporting on the importance of sexual function to the quality of life of patients with all sorts of cancer patients being in early as well as advanced stages. The second barrier, "no angle or reason for asking," can easily be tackled by the provision of practical training on how to address the subject. By providing informed consent and mentioning possible treatment-related SD, as well as additionally notifying that the patient should address any concerns, the key component of sexual health care has already been performed. The third barrier, advanced age of the patient, was also found in a recent survey among a group of surgical oncologists [31]. Apparently, physicians seem to consider that elderly patients are not sexually active anymore and the subject is consequently not relevant to discuss. This assumption might be rather incorrect; according to a study on the prevalence of sexual activity among 3005 adults of 57–85 years, a serious percentage of older adults is still sexually active [38], making this barrier defeasible.

Limitations

This study has a few limitations. We used a non-validated questionnaire, as there are no validated questionnaires available that assess the provision of sexual counseling by radiation oncologists. In order to explore the aim of the study, specific questions were required regarding sexual function in the face of radiation therapy. For this reason, we developed a particular questionnaire investigating the aims and influencing factors instead of using a validated, more general instrument. Nevertheless, the questionnaire was based on other surveys of the research group, which successfully assessed the provision of sexual counseling by several (oncology) health care providers [28–32]. As for an approximation toward validation, an extensive pilot study was performed and the instrument was adjusted because of the comments. Test–retest reproducibility of the questionnaire was not tested due to the anonymous design; therefore, nothing can be said about the reproducibility of the questionnaire. Another important limitation, which may have resulted in over- or underestimation, is that physician responses were self-reported. Attempts were made to reduce this bias by collecting the survey results anonymized.

The subdivisions by area of specialization resulted in small numbers of radiation oncologists in each group. For this reason, it was not possible to reflect on the relationship between frequency of counseling sexual function and demographic characteristics of the respondents. At the same time, because of the subdivisions we were able to produce a detailed insight in patient groups who might lack attention for SD following RT. Only three residents responded to the survey, which made it impossible to calculate differences in results between residents and radiation oncologists. Different treatment settings, knowing curative therapy, salvage therapy and palliative radiation, where not in particular assessed in this survey. As a result, nothing can

be concluded about the approach of radiation oncologists toward patients receiving a different type of treatment. The response rate was comparable with that of other postal questionnaires among physicians [39]. Nevertheless, nonrespondents may have different beliefs, attitudes and practice patterns than respondents, this may have caused a nonresponse bias and hence radiation oncologists may perform less or more active counseling for sexual problems after RT in daily practice.

CONCLUSIONS

Findings suggest that awareness of treatment induced SD is present among radiation oncologists, but responsibility for active counseling was not fully agreed on. Counseling on sexual function is routinely done in case of pelvic radiation therapy, but not consistent in case of gastrointestinal, breast and other cancers. According to the majority of the radiation oncologists, treatment-induced effects on sexual function are lasting forever. Radiation oncologists stated the preference for more detailed education about discussing SD in daily practice, and indicated that education about sexual issues should be a routine component of the residency in radiation oncology. A list for specialized referral regarding patients experiencing treatment-induced SD is requested.

Implications for Clinical Practice

In order to provide this component of care, radiation oncologists need to have good communication skills, an open and nonjudgmental approach, and knowledge of the potential consequences of radiation therapy on sexuality. Especially for gastrointestinal patients who possibly receive radiation on or close to the pelvic area, awareness should be improved among radiation oncologists. Both standard education within radiation oncology residency as additional education for practicing radiation oncologists are strongly recommended. Radiation oncologists who have the intention to integrate sexual health in their practice and would like to make use of a structured framework, could for example counsel with the widely used Permission (P), limited information (LI), specific suggestions (SS), and intensive therapy (IT) (PLISSIT) model [40]. Guidelines and standard operating procedures for radiation treatment should implement possible sexual side effects and the importance of addressing them as a part of informed consent and follow-up. Within the oncology team, clear appointments should be made regarding responsibility for addressing sexual issues with every patient before and during treatment. A list with specialized sexual health care providers should become available for referral of patients in need of specialized advice.

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