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

Krouwel, E.M.

Chapter 8

Written information material and availability of sexual health care for men experiencing sexual dysfunction after prostate cancer treatment: An evaluation of Dutch urology and radiotherapy departments

L.A. Grondhuis Palacios, E.M. Krouwel, M. Duijn, B.L. den Oudsten, M.E.M. den Ouden, H. Putter, R.C.M. Pelger, H.W. Elzevier

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INTRODUCTION

Prostate cancer is one of the most common malignancies among men. Approximately 11,000 new cases are diagnosed in the Netherlands each year (Netherlands Comprehensive Cancer Organisation (IKNL), 2016). Due to early screening for prostate-specific antigen (PSA) and improved treatment results, the 5-year survival rate extends up to 88% (Netherlands Comprehensive Cancer Organisation (IKNL), 2014). Treatment options differ according to disease stage and patient's preference. Depending on Gleason score, tumour volume and PSA level, patients with localised disease (stage T1c–T2c, N0, M0) are eligible for active surveillance, radical prostatectomy (RP), external beam radiotherapy (EBRT) or brachytherapy (BT) (Heidenreich et al., 2014). In case of extensive disease, eligible treatment consists of androgen deprivation therapy (ADT), implicating bilateral orchiectomy, luteinising hormone-releasing hormone agonists, antagonists or anti-androgens (Heidenreich et al., 2014; White et al., 2015).

Sexual dysfunction (SD), in particular erectile dysfunction (ED), is in addition to incontinence one of the most common side effects of prostate cancer treatment (Potosky et al., 2004). Additional sexual side effects include decreased libido, orgasm impairment and diminished ejaculation or anejaculation (Chung & Brock, 2013). After RP (laparoscopic, open procedure or robot-assisted) rate of ED varies between 25% and 90%, up to 64% after EBRT and 50% after BT depending on, for example, erectile function prior to treatment (Chung & Brock, 2013; Merrick et al., 2005; Tutolo et al., 2012). Erectile function is affected in up to 85% of patients receiving ADT (White et al., 2015).

Disease recurrence has the primary focus during follow-up consultations rather than the impact of treatment-related side effects, such as SD. Evidence has shown that SD fundamentally affects the quality of life and romantic relationship between patient and partner. The disease itself and coping with its consequences is considered as a "relationship disease," as partners may experience psychosocial issues as well, resulting in decrease in quality of life (Garos, Kluck, & Aronoff, 2007; Meyer, Gillatt, Lockyer, & Macdonagh, 2003). In a cohort of 165 partners of men with prostate cancer, significant more distress was reported by partners, implicating the necessity to discuss an altered sexual function after prostate cancer treatment and importance of extensive and comprehensive information material for both patients and partners (Eton, Lepore, & Helgeson, 2005; Knight & Latini, 2009). Nevertheless, the content of written information material regarding sexuality throughout prostate cancer treatment has not been investigated previously.

Besides adequate information material, sexual health care becomes utterly relevant when it comes to guidance in altered sexuality after treatment. Several ED treatment options are available, such as PDE5 inhibitors, intraurethral prostaglandins, penile injection therapy or vacuum devices (Megas et al., 2013). Despite this availability, treatment should also focus on the psychological aspect of altered intimacy between patient and partner. Thereupon, psychosexual support can be implemented when changes in the relationship are experienced

by men with prostate cancer and their partners, meaning both aspects of SD treatment are essential and should be available at departments within corresponding hospital or clinic. As such, knowledge about reference possibilities for corresponding departments would be convenient in case specialised sexual health care is needed.

The aim was to evaluate the content of written information material concerning sexual side effects provided to men with prostate cancer throughout treatment by Dutch urology and radiotherapy departments. In addition, the availability of sexual health care for patients experiencing treatment-related SD was investigated.

METHODS

Study design

A cross-sectional survey was conducted among Dutch urology and radiotherapy departments to evaluate the content of written information material for men with prostate cancer provided throughout RP, BT, EBRT or hormone therapy treatment. Also, the availability of sexual health care was evaluated for men experiencing SD after treatment. Data were collected by administering short interviews by phone or email along with collecting and scoring of written information material on content regarding sexual health after prostate cancer treatment provided by Dutch urology and radiotherapy departments.

Data collection

All Dutch urological outpatient clinics (n = 88), radiotherapy departments (n = 14) and independent radiotherapy clinics (n = 6) were primarily contacted by phone. Hospitals or clinics were excluded in case of unavailability of RP, BT or EBRT treatment (n = 37). From May 2015 until July 2015 all eligible hospitals and/or clinics (n = 71) were approached telephonically to participate in our survey, in which anonymity was ensured. A questionnaire developed by the authors was administered by phone or sent by email after telephonic inquiry (Appendix A). Main topics included type and timing of information material provision, available ED treatment options and knowledge concerning referral possibilities. Furthermore, participating departments were asked to send all available brochures regarding prostate cancer treatment by mail. After two weeks, non-responders were contacted by phone or a reminder was sent by email, depending on the initial approach. A second reminder by phone or email was performed after four weeks. Received written information material was collected as well as brochures presented on their websites, prior to permission of the concerning department to download and print their information material. If permission was not received, brochures of unwilling departments were not collected despite the availability of information material online.

Appendix A. Questionnaire administered among urology and radiotherapy departments.

1. Do you provide information material regarding treatment and its side effects to men who will undergo prostate cancer treatment?
2. What type of information material does it concern?
3. Do patients receive information material routinely or is it provided upon request?
4. Who is responsible for the provision of information material to patients?
5. Which treatment options are available at your hospital or clinic?
6. Does the department provide pre-treatment nurse consultations where sexual health is discussed in context of informed consent?
7. Does the department provide sexual health care for patients experiencing altered sexuality after prostate cancer treatment?
8. Do you know where patients are referred to when altered sexuality is experienced after prostate cancer treatment?
9. Is your department able to send us available written information material regarding prostate cancer treatment?

Categorisation and scoring

Collected written information material was reviewed and scored for content by two independent researchers according to in advance determined categories, mainly concerning in to what extent SD after prostate cancer treatment and ED treatment options are discussed (all categories are displayed in detail in Table 1). A third independent researcher checked the agreeability of the first scoring researchers. If agreement was not obtained on independent items, deliberation took place until agreement was achieved. Each category was scored on a scale from 1 to 3 regarding quantity of information on sexuality: (1) extensive amount of information, (2) moderate amount of information and (3) little or no information. Accordingly, points credited to each category were summed leading to a total score per brochure. Written information material containing information about different types of treatments was grouped in category "general information material". In case participating departments had sent multiple brochures, written information material was categorised regarding type of treatment. If various departments provided identical information material, brochures were analysed separately.

Statistic methods

Data analysis was performed using spss Statistics Version 23 (SPSS Inc., Chicago, IL, USA). Descriptive statistics and frequency analyses were used to calculate the results of administered interviews and the scored content of received written information material. Differences between specific answers and scoring results of information material categorisation were identified using Pearson's Chi-Square test, Fisher's Exact test and Cochrane-Armitage Trend test. Statistical significance was defined as $p < .05$.

Table 1. Categories and corresponding score of written information material content

Sexual side effects resulting from treatment are discussed	**Score**
Yes, discussed in separate chapter	1
Yes, discussed in side effects section	2
Not discussed	3
Influence of treatment on erectile function is described	
Yes, described and statistics are presented	1
Yes, described although statistics are not presented	2
Not described	3
Influence of treatment on ejaculation is described	
Yes, described and aetiology is discussed	1
Yes, described although aetiology is not discussed	2
Not described	3
Aetiology of SD subsequent to treatment is discussed	
Yes, both mental and physical causes are discussed	1
Yes, although only physical causes are discussed	2
No description	3
Information concerning several types of ED treatment options	
Yes, information is given and examples are listed	1
Yes, information is given although advice is not presented	2
No information is given	3
Information concerning SD and its possible effect on relationship	
Yes, information is given and advice is presented	1
Yes, information is given although advice is not presented	2
No information	3
Partner is mentioned in context of intimacy and sexuality	
Yes, partner is mentioned and specific information is given	1
Yes, partner is mentioned although specific information is not given	2
Not mentioned	3
Mention of sexual counselling and provision of contact details	
Yes, mentioned and contact details are given	1
Yes, mentioned although contact details are not given	2
Not mentioned	3

Ethical considerations

Official approval was received by local Research Ethics Committee of the Department of Urology of Leiden University Medical Center. Participation was voluntary and results were analysed anonymously.

RESULTS

Participating clinics

Out of 71 eligible departments, a total of 49 departments consisting of 34 urology departments and 15 radiotherapy departments agreed to participate, resulting in a response rate of 69.0%. Thirty-two departments completed the questionnaire by phone and 17 by email. Thirty-two urology departments and 14 radiotherapy departments conceded to send their written information material. However, a small part of written information material never arrived despite sending was confirmed by concerning departments (n = 4). A total of 59 written items were received corresponding to 42 participating departments.

Questionnaires

To the question whether written information material was provided to patients throughout prostate cancer treatment, all participating departments (n = 49) answered positively. Brochures as information material were provided most frequently (Table **2**). Although not significant, urology departments (39.1%) had, in comparison to radiotherapy departments (8.7%), more brochures available regarding sexuality throughout prostate cancer treatment (p = .197, Fisher's Exact test). Pre-treatment nurse consultation, where sexuality is specifically discussed as a part of informed consent, was found to be more available at urology than radiotherapy departments (p < .01, Pearson's Chi-Square test).

Urology departments had more sexual counselling possibilities for patients experiencing SD after treatment in comparison to radiotherapy departments (p < .05, Fisher's Exact test). In case of absence of sexual health care within the corresponding department, all participating urology departments were aware of external referral possibilities (both within hospital or clinic and external location) for patients experiencing SD. Of all participating radiotherapy departments, 66.7% were aware of referral possibilities. Urology departments referred patients more frequently to a medical sexologist as to radiotherapy departments (p < .001, Fisher's Exact test), whereas radiotherapy departments referred patients more often to a urologist than urology departments (p < .01, Fisher's Exact test). A significant majority of all participating departments had referral possibilities for patients within their own hospital or clinic (p < .02, Likelihood Ratio), particularly departments of academic and top clinical hospitals (p < .001, Linear-by-linear Association). Three urology departments had both sexual counselling within the corresponding department as well as possibilities to refer patients to an external location.

Table 2. Results of administered questionnaires concerning sexual health care provision

Characteristics	Urology (n = 34) *n (%)*	Radiotherapy (n = 15) *n (%)*	*p-value*
Availability of treatment-specific information material[a]	73 (76.0)	23 (24.0)	
Brochures	32 (43.8)	14 (60.9)	*NS*[b]
Prostate cancer guidebook	4 (24.7)	3 (13.0)	*NS*[b]
Website information material	9 (12.3)	6 (26.1)	*NS*[c]
Personal patient information file	9 (12.3)	-	*<.05*[b]
Other	5 (6.8)	-	*NS*[b]
Availability of general information material	18 (52.9)	4 (26.7)	*NS*[b]
Brochures created by corresponding hospital or clinic	5 (27.8)	-	*NS*[b]
Dutch Cancer Society (KWF)	9 (50.0)	2 (50.0)	*NS*[b]
'Cancer and sexuality'	4 (22.2)	2 (50.0)	*NS*[b]
Pre-treatment nurse consultation[d]	31 (91.2)	8 (53.3)	*<0.01*[c]
Availability of sexual counselling within department	14 (41.2)	1 (6.7)	*<.05*[b]
Physician	8 (57.1)	1 (100.0)	*NS*[b]
Nurse/nurse practitioner	6 (17.6)	-	*NS*[b]
Referral possibility known	34 (100.0)	10 (66.7)	*<.001*[c]
Within hospital/clinic	23 (67.6)	9 (90.0)	*NS*[c]
Sexologist	17 (73.9)	2 (22.2)	*<.05*[B]
Urologist	3 (13.0)	6 (66.7)	*<.01*[b]
Psychologist	4 (17.4)	-	*NS*[d]
Other	3 (13.0)[e]	2 (22.2)[e]	*NS*[b]
External location	14 (41.2)	1 (90.0)	*NS*[b]
Sexologist	12 (85.7)	-	*NS*[b]
Psychologist	1 (7.1)	-	*NS*[b]
Other	2 (14.3)[e]	1 (100.0)[e]	*NS*[b]

NS: Not significant

a) Some departments provided multiple brochures

b) Fisher's exact test

c) Pearson's chi square test

d) Consultation in which sexuality is specifically addressed as a part of informed consent

e) Including (one) urologist-sexologist

Comparison of written information material among departments

A significant difference was found between urology and radiotherapy departments regarding the content of written information material when it comes to treatment-related SD. Urology departments provided more extensive information material in comparison to radiotherapy departments ($p < .05$, Cochrane-Armitage Trend test). Further categories of received information material are displayed in Table 3. Moreover, significant more extensive information was found in brochures concerning sexual side effects throughout RP than brochures concerning sexual side effects around BT and EBRT ($p < .05$, Cochrane-Armitage Trend test).

Table 3. Categories of content regarding received written information material

Information material	**Urology (n = 38)** *n (%)*	**Radiotherapy (n = 21)** *n (%)*	*p-value*
Discussing sexuality	37 (97.4)	15 (71.4)	*<.01*[a]
Separate chapter	23 (62.2)	9 (60.0)	
Appointed among side effects	14 (37.8)	6 (40.0)	
Discussing impact of treatment on erectile function	36 (94.7)	11 (52.4)	*<.001*[a]
Percentages named	13 (36.1)	4 (36.4)	
No percentages named	23 (63.9)	7 (63.6)	
Discussing impact of treatment on ejaculation	28 (73.7)	6 (28.6)	*<.001*[a]
Cause named	15 (53.6)	2 (33.3)	
No cause named	13 (46.4)	4 (66.7)	
Discussing aetiology of SD	28 (73.7)	7 (33.3)	*<.01*[a]
Physical and mental causes	11 (39.3)	5 (71.4)	
Physical causes only	17 (60.7)	2 (28.6)	
Discussing treatment options for erectile dysfunction (ED)	20 (52.6)	2 (9.5)	*<.01*[b]
Examples named	12 (60.0)	1 (50.0)	
No examples named	8 (40.0)	1 (50.0)	
Discussing impact of SD on relationship	8 (21.1)	2 (9.5)	*NS*[b]
Named options for help	6 (75.0)	2 (100.0)	
Named no options for help	2(25.0)	-	
Partner mentioned in the context of intimacy and sexuality	10 (26.3)	5 (23.8)	*NS*[a]
Specific partner information	-	-	
Partner mentioned only	10 (100.0)	5 (100.0)	
In case of questions about sexuality	18 (47.4)	8 (38.1)	*NS*[a]
Contact person with details named	1 (5.6)	1 (12.5)	
Contact person named without details	17 (94.4)	7 (87.5)	
Amount of information			
Extensive (10 – 14 points)	10 (26.3)	2 (9.5)	*<.05*[c]
Moderate (15 – 20 points)	21 (55.3)	9 (42.9)	
Little or no (21 – 25 points)	7 (18.4)	10 (47.6)	

NS: Not significant

a) Pearson's Chi-square test

b) Fisher's exact test

c) Cochrane-Armitage trend test

With regard to the influence of SD to the romantic relationship and intimacy between patient and partner, 21.1% of urology departments and less than 10.0% of radiotherapy departments discussed this subject in written information material. Around one-fourth of urology and radiotherapy departments (respectively 26.3% and 23.8%) mentioned partners of men with

prostate cancer. However, none of them provided specific information for partners regarding the impact of SD on the romantic relationship and intimacy.

DISCUSSION

Key results

This study shows that treatment-related SD is discussed into highly varying degrees in written information material coming from Dutch urology and radiotherapy departments. Furthermore, it shows that sexual health care is currently not available in every hospital or clinic where prostate cancer is treated.

Although all participating departments provide written information material, it appears that sexuality is discussed more frequently and more extensively in written information material coming from urology departments in comparison to radiotherapy departments. Thereby, all brochures contain more extensive information concerning altered sexuality after RP compared with altered sexuality after BT and/or EBRT. Although ED rate is higher after RP in comparison to after BT and/or EBRT, the possibility of SD as a result of radiation therapy is still highly present. Availability of ED treatment options is mentioned in only half of written information material, whereas in even fewer brochures examples of ED treatment options are specified. Partners of men with prostate cancer are not extensively mentioned in written information material, although impact of SD on the romantic relationship between patient and partner is well known (Letts, Tamlyn, & Byers, 2010).

The availability of sexual health care varies among Dutch urology and radiotherapy departments. Moreover, referral systems of various hospitals are not organised in a similar way when it comes to men experiencing treatment-related SD. Urology departments dispose of more sexual counselling in order to treat ED than radiotherapy departments. If sexual counselling is not available in their own hospital or clinic, all urology departments know where to refer patients in comparison to only half of all radiotherapy departments. Likewise, urology departments provide pre-nurse consultation where sexuality and treatment-related SD is discussed more often than radiotherapy departments.

Comparison with literature

This study is the first to investigate the content of written information material concerning intimacy and sexuality provided to men undergoing prostate cancer treatment. However, a few studies investigated the general content of written information material regarding prostate cancer treatment. Rees, Ford, and Sheard (2003) reported poor quality of written information material in general. Unfortunately, the content concerning sexuality in particular, was not mentioned in this study. Walling, Maliski, Bogorad, and Litwin (2004) described insufficient and inaccurate written information material concerning treatment management and disease-

related symptoms. Seventy-nine per cent of brochures regarding RP were reported to mention impotence. Nevertheless, only 18% of all brochures provided specific information concerning this topic. Weintraub, Maliski, Fink, Choe, and Litwin (2004) evaluated written information material through the Suitability Assessment of Materials (SAM) rating scale. SAM is an instrument to measure suitability in terms of content, literacy demand, graphics and layout (Doak, Doak, & Root, 1996). Written information material investigated in this study scored poorly on content and self-efficacy and did not include sexuality as a specific topic.

Krouwel et al. (2015) investigated the role of radiation oncologists concerning the discussion of sexual function after (pelvic) radiation. Out of 119 participating radiation oncologists, 29.2% reported the referring physician as responsible for informing patients regarding possible treatment-related sexual side effects. Additionally, 13.8% of radiotherapists stated treatment-related SD should be discussed and treated by concerning general practitioner. Thus, radiotherapy departments are aware of SD due to treatment, however, it is unclear who is responsible for discussing sexual function after radiation.

Interpretation

An apparent need of information material concerning SD after treatment is evidently present among men treated for prostate cancer. The majority of the group of men studied by Crowley et al. (2015) stated that more extensive information concerning sexuality and intimacy issues throughout treatment would have been appreciated. More than half of these men (57%) were anxious whether they would be able to sexually satisfy their partners after treatment, and if these consequences would have an impact on the romantic relationship (46%). Role of partners regarding intimacy and sexuality is hardly mentioned in studied written information material. Nevertheless, partners indeed report an unmet need for information concerning altered intimacy between them and their partner (Adams, Boulton, & Watson, 2009). Partners of men with prostate cancer indicate information regarding sexuality as excessively important (Rees, Sheard, & Echlin, 2003). Furthermore, partners require to be involved in health care issues of their spouses and are willing to participate in sexual health counselling if necessary (Garos et al., 2007).

Prostate cancer treatment and its sexual side effects also affect a partners' quality of life severely (Eisemann, Waldmann, Rohde, & Katalinic, 2014). Moreover, research has found partners to suffer more frequently from depressive symptoms, are often sexually dissatisfied and experience less communication with respect to sexuality with their partner after treatment (Garos et al., 2007).

Sexual side effects are often not addressed by physicians or oncology nurses during follow-up consultations (Hordern & Street, 2007; Krouwel et al., 2015). Moreover, research has shown that patients forget 40% to 80% of the information which is verbally given by physicians or other health care providers during consultation (Kessels, 2003). Accordingly, the essence of written information provision around sexuality during informed consent was reported by 61%

of men with prostate cancer studied by Feldman-Stewart et al. (2000). Thence providing additional information material becomes of great importance. Written information material is the most preferred source of information by patients when it comes to sensitive topics as sexuality and intimacy issues (Davison, Keyes, Elliott, Berkowitz, & Goldenberg, 2004). Physicians are thus more likely to provide written information material such as brochures, guidebooks or useful website addresses along with informed consent. These sources are most frequently used as additional information material concerning information provision around prostate cancer treatment (Ramsey et al., 2009).

Clinical implications

The content of written information material among Dutch urology and radiotherapy departments should be equivalent regarding altered sexuality throughout treatment. Consequently, additional information for partners should be available since it evidently lacks in current information provision. Unfortunately, current written information provision is entirely subjected to whether a hospital or clinic is willing to provide information about altered sexuality throughout prostate cancer treatment. Hence, it is of great importance to provide adequate information for optimal coping with eventual upcoming sexual side effects.

At present, no uniform standard exists stating the most important topics which should be discussed in written information material for men undergoing prostate cancer treatment. Since written information material currently provided does not address sexuality routinely and the impact to the relationship is hardly mentioned, it is highly relevant to assemble a list of standard topics essential to men with prostate cancer and their partners regarding treatment-related SD. Based on our results, a list was established enclosing important matters that need to be discussed (Figure 1). In this respect, by implementing these topics in future patient written information material, men with prostate cancer and their partners could be optimally informed concerning sexual side effects that may emerge after treatment.

Not only can ED treatment options be further specified, but sexual counselling possibilities can be determined as well. Moreover, a uniform standard concerning topics for written information material can help to not only distribute an extensive and comprehensive brochure for men with prostate cancer, but to their partners as well. Specific information for partners can be determined as well as sexual health care possibilities when altered sexuality and impact to the relationship is experienced.

Referral possibilities could be further specified for concerning urology and above all radiotherapy departments, as knowledge regarding sexual health care within corresponding hospital or clinic was not present among many participating departments. Available sexual counselling possibilities should be familiar among departments where men with prostate cancer are treated in order to provide adequate health care. If sexual counselling is not available within the corresponding department, knowledge of referral possibilities elsewhere is of great importance.

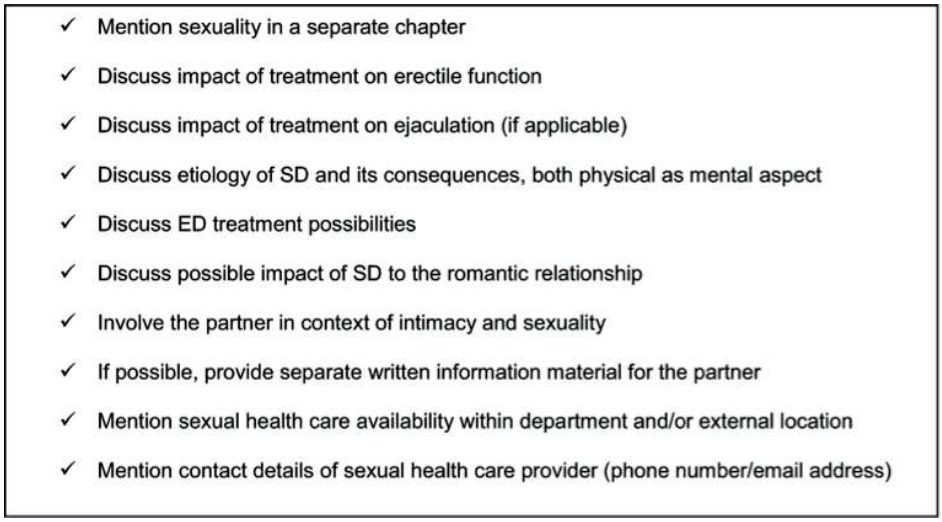

Fig 1. Recommended checklist regarding the content of written information material provided to men with prostate cancer concerning treatment-related SD.

Strengths and limitations

One of the main strengths of this study was the high response rate, both in completed questionnaires and received brochures. Almost 70% of all eligible urology and radiotherapy departments participated in this study; so a reasonable impression is obtained when it comes to information provision around sexuality throughout prostate cancer treatment in the Netherlands. Furthermore, all written information material was scored by two individual, objective researchers and in case no agreement was achieved, a third researcher scored written information material and discussed the scores until an agreement was conceived by any means. Hence, objective scoring was performed to prevent bias concerning the analysis of provided written information material.

There are a few limitations to this study that should be discussed. Several hospitals were interviewed by telephone leading to participants doubting about anonymity, although anonymity was guaranteed explicitly. Also, a few participants who already gave permission to participate and questionnaires were sent to, indicated lack of time to complete the questionnaires. Further reasons for not completing the questionnaire could be a lack of knowledge or little affinity concerning sexual health care within corresponding department leading to non-response bias. Besides, it remains uncertain as to which extent the content of brochures from departments which refused to participate in this study varied. In addition, it is possible that the concerning person who completed the questionnaire is better or worse informed when it comes to availability of sexual health care as to other health care professionals coming from the same department. It is rather plausible this contributes to an unreliable reflection of overall knowledge of concerning department leading to information bias. However, several attempts

were made by the researchers to reach the health care professional with sufficient knowledge regarding this subject.

We did not investigate which type of information (i.e. written, E-health, nurse consultation, etc.) or which specific content regarding sexuality is considered to be important by patients. Consequently, future research is recommended concerning information needs from the patients' point of view. Accordingly, the content of information material concerning sexuality after prostate cancer treatment can be adjusted to the needs of patients and their partners.

CONCLUSION

Treatment-related SD is not routinely mentioned in written information material provided by Dutch urology and radiotherapy departments. Little information is available concerning the patient's partner in context of intimacy and sexual health. No information was available regarding the impact of SD on the romantic relationship between patient and partner.

Consequently, it is recommended to establish a standard regarding the content of written information material in order to provide material of high-quality, extensive and comprehensive information.

Sexual health care is not available at every hospital or clinic where prostate cancer is treated. Furthermore, radiotherapy departments spent less attention to sexual side effects. Hence, it is recommended for radiotherapy departments to enhance their awareness of detecting sexual health issues and subsequently, increase their knowledge regarding sexual counselling referral possibilities.

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