



Universiteit
Leiden
The Netherlands

Sexual health care in prostate cancer for men and their partners

Grondhuis Palacios, L.A.

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Part V

Summary and perspectives

Chapter 9



General discussion,
future perspectives and conclusion

GENERAL DISCUSSION

Prostate cancer (PCa) has a five-year survival rate of nearly 90% (1). For a long time, the focus in research was on survival. However, with the rapid development of several types of treatment and early PCa screening, survival rates have increased over the past years (2). As a consequence, the focus in research has shifted from quantity of life to quality of life (3). Maintaining an optimal quality of life, of which sexual health is an essential part, is important; especially since sexual dysfunction (SD) is one of the most prevalent side effects of PCa treatment (4). Therefore, the aim of this thesis was to investigate current sexual health care in PCa from different perspectives: men, their partners, and healthcare professionals (HCP).

Chapter 2 aimed to assess current sexual health care and satisfaction regarding SD treatment options. Additionally, this chapter also aimed to determine which HCP and what timing is considered most suitable according to men when addressing sexual health after PCa treatment. If given the option, a standard consultation with a urologist-sexologist after treatment was preferred by 75% of men. About 40 percent of men favored a sexologist or an oncology nurse as most desired HCP to consult sexual matters with. Stroberg et al. analyzed the long-term results when providing sexual health care by a clinical sexologist for men after radical prostatectomy (5). Men in their study were followed up to 7 years after surgery and received combined penile and sexual rehabilitation from a clinical sexologist in the first year after surgery with the aim to establish gratifying sexual health, regardless of penile function. Men were evaluated during follow-up at one, three, and six years postoperative. After one year, 67% reported their sexual life as satisfactory (ranging from rather satisfactory or satisfactory to very satisfactory) and 62% found it acceptable when compared to their sexual life prior to surgery.

Erectile dysfunction (ED) is a common side effect after PCa treatment and so it becomes of the utmost importance to provide adequate sexual health care after treatment.

Chapter 2 also showed that only a third of men (31%) dealing with ED was offered a consultation with a specialized HCP, such as a sexologist. Fourteen percent of participating men reported that they had never been offered an ED treatment option. This study also displayed that men who were offered treatment for ED, were only partially satisfied (31%) or not satisfied at all (26%). These findings are in line with a cross-sectional study performed in the United Kingdom; Dyer et. al explored how ED in patients with PCa was managed in clinical practice (6). They used the perspective of men and HCPs (i.e., general practitioners, practice nurses, urologists, and urology clinical care nurse specialists). The authors showed that 52% of participating men were

inquired by their HCP about ED within three months after treatment and that two-fifths (40%) indicated to have been offered ED treatment within three months and a smaller group of 19% were offered ED treatment within four to six months. Still, 22% of men reported they were not offered any ED treatment at all. In addition, half of men (51%) who used an ED treatment (mostly consisting of PDE-5 inhibitors and vacuum erection device) was not content with the treatment and 17% of men was unsure.

Chapter 3 evaluated possible discrepancies between expectations and experiences of men regarding sexual side effects after PCa treatment. A third of men (33%) who reported to have experienced sexual side effects after treatment, indicated that their sexual functioning was lower than expected based on the received information prior to their treatment. Likewise, sexual side effects were more often reported by men who in their opinion received insufficient information compared to men who received sufficient information (61% vs 23%, $p < .001$). This study may tell us that information provision given to men who are going to be treated for PCa, does not reflect the experienced sexual side effects and therefore, unsatisfaction concerning information provision exists. These findings are confirmed in a Dutch cross-sectional study concerning satisfaction with information provision in PCa (7). Lamers et al. found that a third of participating men (34%) was dissatisfied with information provision. Around a quarter (27%) wanted to have received more information and 4% less information. Moreover, a qualitative study performed by Chen et al. among men with different PCa stages reported that men often felt lack of information provision regarding side effects of treatment, such as incontinence and ED (8). Importance of suitable information provision in oncology patients is a finding affirmed by Husson et al.; patients who declared to have received adequate information, had a significantly greater understanding of their disease than patients who declared to have not received adequate information (9).

In addition, **Chapter 3** analyzed if these discrepancies were related to demographic characteristics, type of hospital or clinical characteristics (i.e., comorbidity, tumor stage, PSA level, Gleason grading and type of treatment). Demographic characteristics, type of hospital or comorbidity were not related to discrepancies between expected and experienced sexual side effects. However, tumor stage and PSA level were significantly associated with discrepancies between expectations and experiences. Sexual side effects were more often experienced as worse than expected in men with local tumors compared to men with regional or distant tumors ($p = .005$). Men who experienced sexual side effects worse than expected had a significantly lower PSA level at diagnosis (17.4 vs 33.3 ng/mL, $p = .046$). PSA level and Gleason grading were not significantly associated with age ($p = .075$). Yet, younger men were diagnosed more often with a local tumor ($p = .018$). Alemozaffar et al. described that high PSA levels may – in

some cases – indicate a more extensive form of PCa or a larger prostate which may lead to a worse sexual outcome regarding ED when treated surgically or with external radiotherapy (10). In general, these treatments – next to active surveillance – are offered when diagnosed with a local stage tumor or when PSA levels are low at diagnosis. It is plausible to believe that, in those cases, surgical treatment will be explained as probably more nerve sparing when compared to a treatment of a more extensive form of PCa or that radiation treatment solely will lead to less sexual side effects since it concerns a local tumor and/or a smaller prostate size. Reasonably, a local stage tumor or low PSA levels may rise the expectation of a less extensive form of PCa leading to the expectation of less severe sexual side effects when treated with active surveillance, radical prostatectomy or with radiation treatment. Therefore, men with a local stage tumor or a low PSA level at diagnosis and men who are treated with radical prostatectomy or with radiation treatment, may experience a greater discrepancy regarding their expectations and experiences when it comes to sexual side effects.

Furthermore, **Chapter 3** also aimed to investigate if certain factors of obtained information, such as provider and/or method of information provision, were related to discrepancies between patients' expectations and sexual side effects. Men who used written information material reported their sexual side effects less often worse than expected than men who had used other sources of information (18% vs 47%, $p < .001$). Men who used web-based information (41%) experienced sexual side effects more often as worse than expected than men who used other sources of information ($p = .110$). Several studies showed that information through the Internet about PCa is of poor quality and that its reliability remains disputable (11, 12). However, in our study men did not indicate which websites they consulted. Accordingly, it is difficult to state whether this finding in our study is sufficiently reliable. Nevertheless, web-based material about treatment and treatment-related side effects should be of a good quality and if possible, checked or even provided by HCPs to their patients to guarantee reliable sources.

In **Chapter 4** current information provision was analyzed through an evaluation of Dutch written information materials. Content of written information material provided by urology and radiotherapy departments was analyzed together with the availability of sexual health care. The results showed that urology departments provided brochures in which sexual health was discussed more often than radiotherapy departments. In addition, sexual counseling was also more frequently provided by urology departments than by radiotherapy departments. A study carried out by Choi et al. studied the content of information materials related to PCa and SD in urology practices and others, such as oncology and internal medicine practices (13). About half of the studied materials

(49%) coming from urology practices discussed treatment-related side effects whilst materials coming from the other practices did not discuss this subject. Furthermore, potential alterations in sexual function after surgery were more frequently addressed than after radiation treatment. In line with our study, urology departments paid more attention to sexual side effects around PCa than other medical departments. Considering that the first consultations are mostly provided by a urologist, it becomes plausible that information materials coming from urology departments are more extensive. Notwithstanding, **Chapter 4** described that SD was not addressed routinely and that available treatments methods for ED were discussed in half of the brochures. Oppositely, Choi et al. showed treatment methods for ED were considered in 13% of the studied materials (13).

Written information materials need further melioration and the importance that men attach to written information materials may not be underestimated. Sharpley et al. analyzed preferences for information regarding type of information, its value, and their preferred format among breast and PCa patients (14). The doctor interview was the most preferred future format of patient information, followed by an information booklet. Both sources were well ahead of other information formats, like the educational video, individual training, or a guided tour. Similar to these results, Preyde et al. analyzed different types of desired supportive care and the majority of participating men preferred information from a website (40%), via written handouts (32%), and through additional consultations with their physician (27%) (15). Since written information material is highly valued, quality of written information materials should live up to a certain standard. In **Chapter 4** a standard as to content of written information material was designed in the form of a checklist. This checklist contained several subjects, among others to address sexual health, to discuss the impact of ED, treatments for ED, and to disclose the impact of alterations in sexual health for partners and romantic relationship together with the availability of sexual health care.

More than two-thirds of participating men (68%) indicated that involvement of their partners is essential when sexual health is discussed during consultations (**Chapter 2**). The results demonstrated in **Chapter 5** showed us that 44% of the partners of men with an increase in erectile complaints after treatment, found it slightly difficult to deal with sexual side effects and 19% found it moderate to very difficult. About 75% of partners of men with PCa experience a deterioration in their sex life after treatment (16). Although it is known that sexual side effects have important consequences for partners, partners often feel disregarded during consultations between men and their HCPs (17, 18). In **Chapter 5** partners rated the severity of the experienced sexual problems. Moderate to severe sexual problems were reported by 73% of partners of

men treated with laparoscopic radical prostatectomy (LRP) and by 80% of partners of men treated with intensity modulated radiotherapy (IMRT). Less sexual problems were experienced by partners of men treated with a combination of IMRT and hormone therapy (HT), namely 49%. Men treated with HT are usually older and will generally have a higher comorbidity level than men treated with the intent of curative therapies, such as LRP (19). Consequently, partners of men treated with HT are mostly older and may therefore be presumably less sexually active than younger partners due to peri- or post-menopausal factors (20).

Furthermore, in our study 43 men (29%) indicated that they did not experience an increase in ED after treatment. Remarkably, 26% of the partners of these men, still indicated to experience sexual problems. Even though most men and partners experienced no impact of treatment-related sexual side effects on their relationship (respectively 59% and 63%), still a third of the couples (34%) reported to have encountered a negative impact on their relationship. Occasionally, women may attenuate sexual problems to not pressure their spouses in case of sexual health issues, especially when caused by a disease (21). In case men and their partners fail to communicate adequately, marital dissatisfaction may occur together with a deterioration in their intimate relationship (22). Accordingly, it becomes crucial to address both issues; not only ED, yet also the intimate relationship between men and their partners without neglecting the partners' sexuality.

Chapter 6 described sexual health care in PCa from the perspective of HCPs; the findings indicated that urology residents experience a lack of knowledge and competence. Almost 60% of the residents reported that they did not receive sexual health training during their career and 48% reported to have limited level of knowledge regarding sexual health. Fifty-five percent of the urology residents did not feel competent enough to treat SD after PCa treatment. Based on these results, it would be plausible to think that additional sexual health training would enhance the level of knowledge and competence to treat men experiencing SD after PCa treatment. A German study performed by Schloegl et al. analyzed education in sexual medicine amongst urology residents, urologists, and andrologists (23). They found that the majority of the physicians reported that they had attended training during their residency regarding SD; the two most attended trainings concerned sexuality after surgery (77%) and ED (75%). However, 44% of the young physicians still declared insufficient training as a barrier to address sexual health issues. Although 905 questionnaires were used for the German study, the authors displayed to have a response rate of 16%. This low response rate could be explained, according to the authors, due to lack of an honorarium or a personal reminder. In addition, the overall results may represent an overestimation of the average practice of German

urology residents, urologists, and andrologists since it is most likely that participating physicians have a greater interest in this topic. Considering this potential overestimation and the finding that young physicians still experience insufficient training as a barrier to discuss altered sexual health, it becomes disputable if additional training would be a great contributing factor for urology residents to feel more competent to discuss sexual health issues. Yet, **Chapter 6** showed that lack of knowledge, competence, and time is an important problem according to urology residents. Jonsdottir et al. performed a study where a sexual health care educational intervention was investigated among oncology healthcare professionals (24). The educational intervention consisted among other of staff training, workshops, and sexual counselling services provided by a specialized nurse hired for the project. Improvements in sexual health care practice were described, e.g. inquiring patients about sexual health issues and referring them to other professionals. However, barriers to discuss sexual health issues with patients remained. Although the barrier of 'lack of training' decreased over time, the barrier 'difficult issue to discuss' and the barrier 'lack of time' increased during the study. The authors considered that prior to enhancing educational interventions for physicians, awareness of their own personal barriers to discuss sexual health issues should be explored. In addition, the authors also acknowledged that not all physicians can or are willing to gain further competence in sexual health care (24). Altogether, the aforesaid emphasizes that enhancing education standards for HCPs involved in PCa treatment is certainly an important matter in need of further improvement. Yet, focus on personal reasons of HCPs to not be able to gain improvement in providing sexual health care should take place prior to enhancement of education and training.

Still, aside from lack of knowledge and competence, lack of time was in our study also indicated as an important barrier to discuss sexual health routinely as described in **Chapter 6**. To address sexual health routinely, participating residents stated that support from nurses would be helpful. However, nurses should also feel competent enough to discuss sexual concerns and should have sufficient knowledge to provide additional information regarding treatment-related SD. Previous studies have shown that nurses, like physicians, do also not feel competent and that lack of training is encountered as one of the main barriers to not discuss sexual health in oncology consultations routinely (25, 26). Despite, the study by Krouwel et al. showed that great part of participating nurses do feel responsible to discuss sexual health with their patients (25). Regardless of the approach, HCPs – especially when involved in PCa treatment – are presumed to have sufficient knowledge of the underlying etiology and treatment of ED.

In **Chapter 7** of this thesis, the effect of a symposium on sexual health care in PCa among HCPs was investigated, mostly among nurses. HCPs indicated that SD was

significantly discussed more often by participants after the symposium than prior to the symposium, and that awareness was increased. Most HCPs preferred written information materials or a website with adequate information provision as tools to help them discuss sexual health routinely with their patients during consultations. However, the level of knowledge, competence, and referral rate after the symposium did not significantly change according to the HCPs. A study performed by Sung et al. analyzed the impact of a four-week training program for nurses (a total of 16 hours) concerning sexual health care using a control group (27). They discovered that although knowledge concerning sexual health care increased in the experimental group, self-efficacy did not change significantly. Notwithstanding, great part of participating nurses felt responsible to help patients with alterations in their sexual health, yet lack of training was perceived as one of the main barriers. These results emphasize what we discussed in **Chapter 6**; nurses who work in sexual health care feel responsible to discuss sexual health issues. However, they do not always have sufficient knowledge and competence and so, there exists an unmet need regarding training and education.

In **Chapter 8**, a Letter to the Editor was written as a response to an article written by Kristufkova et al (28). Although sexual health training is considered a crucial part of the specialty training, this article displayed an insufficiency concerning sexual health education and training among other European urology residents. Yet, management of outpatient clinics and availability of referral options for men with SD after PCa treatment and their partners are aspects that need melioration as well. A study performed by Hanly et al. showed that men treated for PCa would profit from adequate referrals for sexual health counseling (29). Participants in this study were part of a PCa support group and they indicated that if referral would have taken place earlier in the process, it would have helped them in better understanding of treatment procedures and treatment-related side effects. Hence, the importance of adequate referral options arises together with optimal management in outpatient clinics.

Clinical implications

As described in the aforementioned chapters of this thesis, further education, and training for HCPs in SD after PCa treatment is essential to establish adequate sexual health care for men and their partners. Nevertheless, personal reasons of HCPs to not be able to gain improvement in providing sexual health care should be explored prior to enhancement of education and training. Likewise, this thesis also underlines the importance of adequate information provision and referral options. In addition to consultations with physicians and/or nurses, various types of information provision should be adapted or developed in order to meet the diverse preferences of men and their partners. Based on the results of this thesis and theses of colleagues, a website

called 'Sick and Sex' was created by a group of medical advisers. This website provides accessible information on sexual health, intimacy, and relationships for anyone facing an illness or a disease. Besides PCa, several other illnesses and diseases are addressed providing information in terms of written information, illustrative images, informative video materials, blogs, news, and podcasts. As for PCa, the website comprises information about the most common sexual side effects per type of treatment and additional information in the form of articles, digital brochures, links to other websites for further information, and recommendations for referral to a preferred type of HCP. Additionally, the website provides informative videos concerning the various types of treatment for ED and a page per type of ED treatment containing specific instructions for men to learn how to use ED medication or devices. Moreover, informative videos for partners of men with PCa were made in cooperation with the Dutch Prostate Cancer Foundation. One of the videos was based on subjects which were discussed during a gathering with partners of men with PCa organized by our researchers and the Dutch Prostate Cancer Foundation. The video addresses topics of interest when it comes to cancer and intimacy, such as diminished libido, ED, feelings of insecurity, fatigue, and embarrassment. In addition, a podcast produced by two urologist-sexologists was released recently. This podcast comprises additional information concerning sexuality and PCa and it includes interviews with patients who share their experiences. Overall, a beneficial addition as to current information provision around PCa treatment and provision of sexual health care with the focus on both men and their partners regarding the physical as well as the emotional aspect. These types of information materials, in addition to sexual healthcare consultations, may provide the adequate guidance for men with PCa and their partners when dealing with alterations in sexual health after PCa diagnosis and treatment.

FUTURE PERSPECTIVES

Undoubtedly, further research on how to effectively support patients during the disease and treatment trajectory should be performed. It appears that – based on the results of this thesis – both a medical as well as a psychosocial perspective should be included in clinical practice. In order to carry out this approach, development of a program should be established by a specialized team consisting of urologists, oncology nurses, psychologists, and sexologists. The program could consist out of scheduled consultations with a urologist(-sexologist) and an oncology nurse in the first phase of diagnosis and treatment to discuss sexual health. Along these scheduled consultations, separate consultations with a (specialized) oncology nurse would be a plausible option to provide men and their partner sufficient time and space to – in case of need of men and/or their partner – to deliberate sexual matters. Further in time, oncology

nurses should be able to refer men and their partners to a urologist(-sexologist) to discuss sexual health treatment concerning the medical aspect and to a sexologist for the psychosocial aspect of treatment-related sexual side effects. In case further guidance is needed, referral to a psychologist should take place. Furthermore, this program should be implemented on national level and considered as the new standard for men and their partners around PCa diagnosis, treatment, and follow-up. Taking in consideration the financial aspect; current sexual health therapy is not covered by the Dutch insurance. The aim would be to provide a certain number of sexual health counseling sessions after oncological treatment and to be covered by the insurance companies as a standardized element of the treatment trajectory.

Future research should also include a broader palette regarding sexual orientation and gender identity. This thesis focused primarily on heterosexual men and their partners and had to exclude homosexual partners due to the small number of participants. Therefore, other sexual orientations have been underrepresented and further research regarding a larger spectrum of sexual orientations should be established. Moreover, cultural differences exist implying a different view on gender and sexuality. In addition, men without partners were also underexposed in this thesis. Consequently, further research should be conducted in order to properly adapt information provision and sexual health treatments. The results of this thesis may serve as a fundamental element to improve future sexual health care in PCa for men, partners, and HCPs.

CONCLUSION

This thesis shows that current sexual health care has not yet succeeded to guide men and their partners sufficiently and in an adequate manner when it comes to dealing with the consequences of PCa diagnosis and treatment. The majority of men need a standardized consultation with a specialized HCP, such as a urologist-sexologist, to discuss sexual health issues preferably within three months after their treatment. Regarding information provision on treatment-related sexual side effects given prior to PCa treatment, insufficient information is provided. Although current written information provision coming from urology departments discusses sexual health more often than radiotherapy departments; SD is still not routinely addressed. ED treatment only appears in half of the brochures and the impact on partners is barely mentioned. Most men prefer their partners to be present when sexual health is discussed during consultations around PCa treatment. However, focus during consultations is mostly on men while most of the partners experience difficulties dealing with sexual side effects after PCa treatment. Besides, an important part of the couples encounter a negative impact on their relationship. Regarding HCPs, urology residents experience a lack of

knowledge and competence to treat SD after PCa treatment and an unmet need exists for additional education and training. Furthermore, insufficient time during consultations was also indicated as a barrier to address sexual health routinely. Therefore, urology residents reported that aid from a nurse would be helpful as well as further information provision. Yet, like urology residents, nurses do not feel capable to discuss sexual health; lack of competence and training was experienced as a main barrier as well. A symposium on sexual health care in PCa – attended by mostly nurses – led to an increase of awareness to discuss SD more often during consultations. Nevertheless, level of knowledge, competence, and referral rate did not alter after the symposium. In case HCPs feel lack of knowledge, competence, time or tools to discuss sexual health after PCa treatment, referral to a specialized HCP should occur; according to the needs and preferences of men and their partners. However, management of outpatient clinics and availability of referral options are still in need of melioration.

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