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Title Page

Title

Promoting sexual well-being for men and their partners affected by Prostate Cancer

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Abstract

Objectives: To present an overview of the issues related to the sexual well-being of people affected by PCa and their partners and propose ways to manage and address these by oncology nurses and the wider multi-disciplinary team.

Data Sources: Electronic databases such as PubMed and Cinahl were used to retrieve relevant literature published between 2010-2020.

Conclusion: Sexual well-being in patients with PCa and their partners is multifaceted, comprising physical, emotional, social and cultural aspects.

Implications for Nursing Practice: A combination of pharmacological and non-pharmacological interventions together with enhanced communication can be successful in providing culturally competent, person-centered care by oncology nurses and the wider multi-disciplinary team.

Keywords: sexual well-being, prostate cancer, partners, nursing competencies

Introduction

Worldwide trends on the incidence and mortality for prostate cancer (PCa) indicate a continuous rise, making it the second most common type of cancer in men after lung cancer^{1,2}. Despite these negative trends, the progress of diagnostics and treatment options for this population had a significant positive effect on patient survivorship; more men now live beyond 5-years from diagnosis, facing the long-term effects of cancer and its treatment. Literature has well documented the level of unmet supportive care needs in this population, ranging from fear of cancer recurrence and future uncertainty, to urinary incontinence and affected interpersonal relationships^{3,4}. Sexual wellbeing, an important aspect quality of life, has been identified as key area of unmet need for patients with PCa⁵⁻⁷.

Current treatment options for PCa can have different adverse effects on a person's sexuality. The majority of patients report some level of erectile dysfunction (ED) after surgery, radiotherapy and/or brachytherapy^{8,9}. Hormone treatments affect testosterone levels, thus affecting libido as well as erections¹⁰. Other equally affected components of the sexual function include orgasm and ejaculation. Consequently, disrupted sexual function contributes to altered body image, self-esteem, and sense of masculinity and can result in poor communication directly affecting partner relationships^{6,11,12}.

Although affected sexual function has been well researched within the bio-physical domain, its wider impact on the psycho-emotional and socio-cultural life domains has only received interest in the past decade¹⁰. Adopting the World Health Organisation's (WHO)¹³ position that sexuality is instilled in human identity, this article will present an overview of the issues pertinent to the sexual well-being of people affected by PCa and their partners and will consider ways to manage and address these by oncology nurses and the wider multi-disciplinary team.

Living with and beyond impaired sexuality

The diverse issues that men with PCa experience relating to the normal sexual response (libido, erection, ejaculation and orgasm) are usually explored as side effects of specific treatment modalities, such as radical prostatectomy, brachytherapy and androgen deprivation therapy (ADT). For example, loss of libido is very common in men who receive ADT¹², while ED is affecting as many as 77% of those who undergo radical prostatectomy¹⁴ and 60% of patients receiving radiation therapy¹⁵. Similarly, radical prostatectomy can cause changes in orgasm in one fifth of patients¹², while men who are treated with radiotherapy can experience anejaculation ("dry orgasms")¹⁶. Penile deformities and urinary incontinence are also common after surgery and/ or radiotherapy¹⁷. Of note, the literature on sexual well-being in PCa tends to focus primarily on survivorship care rather than the direct impact of

active treatment. This comes as no surprise; when the priorities in the initial stages of the cancer trajectory tend to focus on life preservation, sexual concerns move to the background. However, such issues and their effects will resurface later on when individuals will start to seek ways to return to normality.

The psychological impact of sexual dysfunction on patients and their partners can manifest itself earlier on, during treatment and can have an adverse effect on the couple's relationship¹⁸. For many men ED can create psychosexual distress as it is experienced as loss of what was previously considered a normal part of sexual intercourse¹⁹. For instance, a man's body image that is affected due to hormone treatment that causes gynaecomastia can threaten male identity and masculinity²⁰. In a recent review, the loss experienced by men with PCa placed them in a more vulnerable place as they struggled to maintain socio-cultural norms related to male identity²⁰. In fact, it is because of these norms that patients have communication difficulties not only with health professionals, but also within their marital relationships, which can exacerbate distress and can further hinder help-seeking behaviours⁵.

Gay and Bisexual men

Researchers have primarily focused on the experiences and ways to address the needs of heterosexual men with prostate cancer. It is only in the past decade that experiences of gay and bisexual men with prostate cancer have been explored^{8,21}. Despite evidence showing similar prevalence for PCa in this group, gay and bisexual men report poorer sexual function and quality of life²². The greater unmet supportive care needs of this group²³ may be due to the fact that the majority of rehabilitation services are built around the needs of heterosexual men²². A recent qualitative meta-synthesis of experiential data indicates that, for gay men, sexual function has a different relational meaning, with the emphasis placed on penile function²⁴. As a result, ED can affect significantly intimate relationships in a different way compared to heterosexual men²⁴. Beliefs relating to inability to sustain an erection can lead to a feeling of not being desirable and threaten the relationship with the partner. In fact, relaxing existing relationships and allowing partners to seek sexual intimacy elsewhere was seen as a coping strategy for gay men²⁴. Other research has suggested that practices like role reversal (i.e. going from being the active partner to the receptive one) is less considered as an option to cope with ED, since the variety of sexual practices may differ in gay men compared to straight men²⁵. These factors can have a debilitating impact on masculine identity as well as psycho-emotional well-being: threatened "sexual disqualification"¹⁹ can increase feelings of isolation and increase psychological distress^{25,26}.

Besides the physical factors that impact on the sexual well-being of this group, there are socio-cultural factors that play an important role on the overall well-being, some of which may inadvertently affect

rehabilitation and consequently sexual function²⁷. Gay and bisexual men often go unnoticed by health professionals due to pre-assumptions rooting in heterosexual norms^{24,28}. It is common that the support network for this group is not the biological family, but rather friends or what has been defined as a “chosen family”²⁹. Evidence suggests that the different types of social support required for this group are not always offered, which can in turn have adverse effects on patient outcomes³⁰.

The partner

Cancer’s impact on family members has been well established in the literature. However, contrary to the indirect effect it can pose for most other cancers, partners of patients with PCa are directly affected¹⁸. The reported increased psychological distress has been attributed to a decline in satisfaction from the relationship and an affected sexual function^{31,32}. This chain of effects - affected sexual life, leading to lower quality of life and eventually affected marital relationship – links closely to the way couples choose to communicate their concerns³³. According to Manne et al.¹⁸ both patients and their partners choose to avoid discussions related to sexual concerns, irrespective of the differing reasons for each group. A more recent review further explains that holding back emotions and thoughts not only was a coping mechanism for the couple, but also a means to maintain continuity in the relationship³³. Researchers identified that a double act of protection is taking place: patients’ act was driven by fears of not meeting expectations, while that of partners’ was driven by fears of making patients feel inadequate to meet their sexual needs³³.

In order to adapt to the new reality of PCa patients and their partners go through key processes to accommodate their experiences; some authors define them as “grief, restructuring and rehabilitation”³⁴ and others as “cultivating connection vs disengaging” and “accepting change vs seeking continuity”³³. At different points in the cancer trajectory, couples employ different strategies: before surgery, experiences of anticipatory grief regarding future expectations on their sexual life are common and after surgery, frustration, anger and eventually adapting to the new reality are reported³⁵. Consequently, partners are equally affected and when designing interventions addressing their needs has to be taken into consideration. With evidence pointing out that all domains of need are equally affected (biological, psychological and social), interventions should encompass more holistic approaches that take into account the persons’ place within the relationship as well as how they are processing grief³⁵. This is further explored below.

Enhancing sexual well-being in prostate cancer

Evidence based interventions

A number of pharmacological and non-pharmacological interventions have been tested in order to address impaired sexual function in patients with PCa and their partners. Pharmacological interventions focus mainly on penile rehabilitation, i.e. the use of medication or pharmacological devices after PCa treatment to improve erectile function recovery. Oral phosphodiesterase type 5 (PDE5) inhibitors are offered as standard of care targeting cavernous nerves after radical prostatectomy³⁶. However, only 12-17% of men will respond within 6 months post surgery³⁷. The debate on the timing, dose and duration of penile rehabilitation protocols is ongoing³⁶, with the majority of the evidence pointing to starting as soon as possible after surgery to prevent irreversible damage to the structure of erectile tissue³⁸. Another treatment option for patients with non-nerve sparing includes intracavernosal injections with vasoactive agents (i.e. alprostadil); again this strategy requires clinicians to consider carefully the timing of administration as it has been associated with painful erections³⁹. Other interventions such as vacuum erectile devices and penile implants are also proposed with varied efficacy results³⁸.

Due to the varying results of pharmacological treatment to address ED as well as the recognition that impaired sexual wellbeing spans over a spectrum of domains, experts now advocate taking into account psycho-emotional needs in favour of a more holistic and effective sexual rehabilitation for this population that also includes partners^{6,14,36,40}. Psychosocial interventions have been introduced to attempt to address the needs of prostate cancer survivors and their partners in addressing intimacy and relationship factors⁴¹. These interventions either combine or focus exclusively on psycho-education, psycho-sexual counselling, cognitive behavioural therapy, information provision, additional peer and/or marital support⁶. Demonstrated positive outcomes of these approaches include stress reduction, increased levels of relationship satisfaction and a better understanding of the sexual rehabilitation process with a more realistic future outlook^{18,42-44}. Methodological limitations when testing these interventions include varied and relatively small samples, different delivery modes (face-to-face vs telephone conversations vs online webinars) and the variable duration of the offered intervention (ranging from a limited number of hours to 10 weekly sessions). These issues point to a more cautious interpretation of the level of effectiveness¹⁷.

More recently, researchers investigated whether patients and their partners would benefit equally from psychosocial interventions^{6,17,37}. Nelson et al.³⁷ highlight that while men with PCa may find more beneficial education about pharmacological interventions, partners find more useful interventions targeting relationships. Nevertheless, when asked to identify the key elements in interventions, both

patients and their partners expressed the need for more information early on, regarding the physical and emotional impact of treatment on sexual function, as well as future rehabilitation options⁶. Moreover, introduction of mindfulness and acceptance based interventions in the care of this group has also been proposed to enhance patient/ partner experience¹⁷. Experts agree that future interventions should be grounded on theoretical models when trying to address previous methodological limitations^{12,35,37,45}.

The role of communication and culture

In advocating effective, person-centered care to patients with PCa that minimises health inequalities, communication needs to have a pivotal role. The benefits of effective communication within the wider cancer care context have been highlighted, including increased patient satisfaction and psychological well-being and improved health outcomes⁴⁶. As a result, communication skills competencies feature in many guideline and policy documents as a means to support and enhance informed decision-making^{47,48}.

Communication in the context of sexual health care for PCa remains a challenging topic. A recent study in this population reveals that issues around the timing of conversations, the lack of tailored information to the specific needs, and addressing the psychology of sexual intercourse are key in successfully addressing these needs⁴⁶. Indeed, deciding when it is appropriate to discuss issues relating to sexuality and sexual functioning has been identified as a challenge that oncology nurses and other health professional face in the wider cancer population⁴⁹. Perhaps identifying that this is an important aspect that can be further explored later on is the optimum approach for the initial stages of PCa treatment, with more emphasis being placed in the psycho-emotional domain and the role of the person within the relationship. These aspects can be further explored and addressed in follow-up consultations at post-treatment. In all, maintaining a balance between the medical jargon of sexual intercourse and the psychosocial impact of deprived sexual function is necessary⁴⁶.

Alongside communication, cultural competency has been identified as another key element of providing sexual health care within a cancer context⁴⁹. Cultural competency refers to health professionals' principles, practices and attitudes that facilitate them to provide effective, cross-cultural care⁵⁰. A culturally competent workforce has the potential to cultivate an environment where patients with PCa, their partners and significant others feel valued and included in their care, thus improving care experiences across the cancer trajectory^{46,51}.

In multi-cultural societies, there is a requirement to provide culturally sensitive training on communication skills. Taking into consideration the societal meanings attributed to sexuality, as well as variations within specific groups, should be factored within any continuing professional

development programme⁴⁹. However, raising cultural awareness of oncology nurses needs to include not only existing cultural and religious diversity, but also groups like gay and bisexual men. Due to dominant heterosexual societal norms, health services require transition to best supportive models of sexual well-being for gay and bisexual men²⁸. Identifying the different needs of the varied support network of this population should be a priority²⁹. Adopting a welcoming and inclusive language that is gender neutral and free of assumptions promotes trust and enhances the therapeutic relationship among patients, partners and health professionals⁵⁰.

Sexual health care competency and the multidisciplinary team

Currently, different initiatives encourage the inclusion of sexual health care in the management of patients with PCa and offer recommendations on the level of support required^{47,52,53}. The sexual recovery process can be complex, requiring addressing interactions between biological, psychological and social factors and therefore requires a multidisciplinary approach to successfully address the needs of the patient in a holistic way^{54,55}. In order to deal with the ever-changing healthcare landscape, the multidisciplinary team must increase their skills and advance their practice to include a consultancy role to assist in meeting the needs of men with PCa and sexual health care needs⁷. Theoretical frameworks are currently available that propose a varying level of knowledge and expertise (entry or champion) with the potential for further career development⁴⁹. Using a biopsychosocial framework to guide consultations around sexual implications of treatment, oncology and urology nurses are pivotal in supporting patients and their partners through the cancer trajectory^{12,55}. More expertise in the area of sexual health care can be offered by advanced practice nurses to assess, diagnose, educate and manage specific sexual health issues for men³. Researchers propose tailored information to patient need, offering clear advice on the potential long-term effects of treatment and providing specialist care, such as erectile dysfunction clinics⁴⁵.

The inclusion of assessment in the context of a holistic supportive care needs evaluation can provide the space and opportunity to make the topic of sexuality part of the conversation, and facilitate future discussions for patients and their partners^{45,49}. This should adopt tailored and culturally sensitive language to enable a safe environment that will promote informed decision-making. As part of this assessment, screening for distress and psychosocial needs at diagnosis throughout and after treatment completion can assist in identifying individuals with higher need for support and make referrals for psychosexual counselling to clinical psychologists⁴. Similarly, the provision of information should be offered in a timely manner, ideally prior to treatment initiation and help set realistic expectations for the rehabilitation stage^{6,55}. Within this discussion, identifying a person's relationship values can help eliminate assumptions and enable the provision of culturally competent care⁵⁶.

Conclusion

Sexual well-being in patients with PCa and their partners is multifaceted, comprising physical, emotional, social and cultural aspects. Sexual health deficits can be personal and interpersonal, persistent and pervasive. Promoting sexual well-being in the context of PCa should be a key component of person-centred care, and a goal for oncology nurses and the wider multidisciplinary team to strive to achieve.

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