Providing psychosocial and psychosexual support to patients diagnosed with prostate cancer

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Declaration

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Contents

Thesis Summary

Prostate cancer is the most commonly diagnosed solid organ cancer in Australian men. A large majority receive a good prognosis and typically live at least five years post diagnosis. Though survivorship rate is high, quality of life is often significantly affected. Many men express unmet psychosocial and psychosexual needs post-diagnosis regardless of stage of cancer and treatment. Current literature suggests that general practitioners caring for men with prostate cancer typically focus on regaining biological function and capacity, often neglecting the psychosocial and psychosexual factors of holistic wellbeing. They report barriers including lack of knowledge in which to target supportive care and lack of time to fully explore patient needs. The aim of this thesis is to explore the impact of prostate cancer through a biopsychosocial lens, with a strong focus on highlighting psychological, social and sexual aspects and the need for these to be addressed throughout a patient's journey. It will also attempt to provide strategies for clinicians with which to initiate important conversations with their patients about these issues.

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Literature Review

Abstract

Prostate cancer is the most commonly diagnosed solid organ cancer in Australian men. Though survivorship rate is high for those diagnosed, quality of life is often significantly affected. Current literature suggests that general practitioners caring for men with prostate cancer often focus on regaining biological function and capacity, neglecting psycho-social-sexual factors. This literature review will provide an overview of prostate cancer and treatment pathways. It will also explore the impacts of prostate cancer through a biopsychosocial lens. It highlights the barriers that general practitioners face in relation to psycho-social-sexual concerns and why they need to consider utilising a biopsychosocial model of care.

Prostate Cancer

Prostate cancer (PCa) is the most commonly diagnosed solid organ cancer in Australian men (National Cancer Control Indicators (NCCI), 2018). One in six Australian men are at risk of developing it by age 85, with the mean age of diagnosis being 67.7 years (Australian Institute of Health and Welfare (AIHW), 2017). Currently, risk factors for the development of PCa include having a family history of breast, ovarian and prostate cancer, and age; the older the individual, the higher the risk (Perdana, Mochtar, Umbas, & Hamid, 2016). Fortunately, due to early detection, men have a 95% chance of surviving for at least five years (AIHW, 2017). Unfortunately PCa treatment can have long-term consequences that impact on quality of life (QoL) and cause significant psychological distress (Katz & Dizon, 2016).

In most situations, PCa grows slowly, improving prognoses if caught early. While early stage localised PCa is asymptomatic, some men may feel discomfort upon urination. If untreated, PCa can metastasise (i.e. spread to other parts of the body), resulting in a poorer prognosis. Screening for PCa may involve a prostate-specific antigen (PSA) test and/or digital rectal examination (Frydenberg, 2007)[1].

Classification

While PCa can be classified in several ways, this paper will focus on the four stages which relate to the cancer spread. The early stages of PCa (i.e. when still contained inside the prostate) are classified as stages 1-2 or localised PCa. Stage 3 or locally advanced PCa is when the cancer has moved to either the surrounding tissues or nearby organs such as the bladder, rectum or pelvic wall. If the cancer spreads to the lymph glands, bone or other

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[1] Please refer to Frydenberg (2007) for more information on performing a clinical assessment to diagnose PCa

distant areas of the body, this is known as metastatic cancer and is classed as stage 4 (Cancer Council, 2018).

Treatment pathways for PCa

Treatment for men diagnosed with PCa varies according to cancer stage, age and co-morbidities (National Comprehensive Cancer Network [NCCN], 2019). Grouped into active treatment and non-active management strategies (NCCN, 2019), the former results in more extreme physical side effects compared to the latter (Ávila et al., 2018). This is due to non-active management strategies such as active surveillance (AS) and watchful waiting (WW) being used to monitor cancer progression to relieve men from the physical side effects of active treatment (NCCN, 2019). AS is generally advised for men with low-risk, localised PCa (NCCN, 2019). Comparatively, WW is considered for older men where the cancer is unlikely to cause any problems in their lifetime, or co-morbid health conditions are present, that can impact on treatment (NCCN, 2019). However, both active treatment and non-active treatment strategies can have a psycho-social-sexual impact (Ávila et al., 2018; McIntosh, Opozda, Galvao, Chambers, & Short, 2019; Sciarra et al., 2018).

While there are many forms of active treatment for PCa, this review will focus specifically on prostatectomy, radiotherapy (external beam radiation [EBRT], and brachytherapy), and androgen deprivation therapy (ADT). It will examine the bio-psycho-social-sexual impact of these active treatment modalities and also AS and WW.

Biopsychosocial Model of Care

The biopsychosocial framework states that the biological, psychological and social aspects of an individual interacts dynamically, helping guiding health policy and support disease diagnoses (Engel, 1977). This framework is often used to direct research, practice and policy in the area of health psychology and provides a holistic approach to health care and wellbeing (Hatala, 2012). In the context of PCa, this model can be expanded to include the sexual and relational aspects of an individual (Katz & Dizon, 2016; Wittmann, Skolarus, & Montie, 2015). Physical, psychological, social and sexual impacts will be covered in more depth in this review.

Bio-psycho-social-sexual model of care for prostate cancer

Sexual health is multi-faceted and encompasses a biopsychosocial model of care (World Health Organization (WHO), 2002). Research into the sexual impact of PCa has often focused on impaired physiological function of the penis. Consequently, the focus of treatment for PCa survivors with erectile dysfunction tends towards medical interventions to achieve erections, either through medication, invasive surgery, or external penile pumps (Chung & Gillman, 2014). In 2499 PCa survivors, nearly three-quarters reported unresolved sexual problems five years after diagnosis (Darwish-Yassine, Berenji, & Wing, 2014). Additionally, the sexual impact of PCa does not just affect the individual but can impact on intimate partners (Collaço et al., 2018; Ramsey et al., 2013) and the dyadic alliance due to the interplay between intercourse and intimacy (Katz & Dizon, 2016). Thus, Wittmann, Skolarus and Montie (2015) suggest a paradigm shift from sole focus on regaining erectile function, to adopting a biopsychosocial model of sexuality, i.e. satisfaction with sex life. This does not reduce the importance of the physiological aspect of sexual functioning. However, it does encourage psychological and social input to achieve better sexual health outcomes.

Bio-psycho-social-sexual impact of PCa

The diagnosis and treatment of PCa have been shown to significantly impact men physiologically (Ávila et al., 2018; Lardas et al., 2017), psychologically (Maggi et al., 2019;

Punnen et al., 2013), sexually (Ávila et al., 2018) and socially/relationally (Elliott et al., 2010; Ettridge et al., 2018).

Physiological impact

PCa is typically asymptomatic, thus men are unlikely to experience great physical discomfort at diagnosis (NCCN, 2019). For men on non-active treatment strategies, no significant changes to urinary or bowel function a year after diagnosis were reported (Bellardita et al., 2015; Egger et al., 2018; Wilcox, Gilbourd, & Louie-Johnsun, 2014).

Conversely, active treatments inevitably lead to physical changes to the body, impacting urinary, bowel and erectile function in varying degrees, dependent on treatment (Lardas et al., 2017; Prostate Cancer Outcome Registry Australia and New Zealand (PCOR-ANZ), 2018). A recent meta-analysis of patient-reported outcomes indicated that those diagnosed with localised PCa had substandard QoL at an average 12-24 months after prostatectomy or radiotherapy [Ávila et al., 2018]). In general, prostatectomy has a larger urinary impact and higher levels of erectile dysfunction compared to radiotherapy, while EBRT had a greater impact on bowel function comparative to other treatments (Ávila et al., 2018; Lardas et al., 2017). Amongst active treatments, those treated with ADT alone are more severely impacted by physical side effects of treatment (Drummond et al., 2015; Punnen, Cowan, Chan, Carroll, & Cooperberg, 2015).

Longitudinal studies have shown that irrespective of active treatment modality, physiological impacts persist ten years post-treatment (Punnen et al., 2015; Resnick et al., 2013). While the largest difference in physical impact between modalities occurs within the first two years after treatment, this difference attenuated over time despite a mild decline from the third year (Punnen et al., 2015; Resnick et al., 2013).

Two longitudinal studies collected functional outcome data from men diagnosed with PCa (Punnen et al., 2015; Resnick et al., 2013). The Prostate Cancer Outcomes Study (PCOS) followed over three thousand American men. Of those, 1655 were diagnosed with localised PCa,treated with prostatectomy or radiotherapy, and completed QoL measures at 1, 2, 5 and 15 years after diagnosis (Resnick et al., 2013). Men's physiological function was shown to have declined at 15 years post diagnosis; however, there were no significant relative differences in urinary, bowel and sexual function across both treatment modalities (Resnick et al., 2013). The Cancer of Prostate Strategic Urologic Research Endeavor (CaPSURE) registry followed men diagnosed with localised cancer who received any form of primary treatment (Punnen et al., 2015). These men completed QoL measures at 2, 5 and 10 years and found that physical capacity attenuated after 10 years with ADT showing the largest physical decline. In both longitudinal studies, men on AS/WW were not physically impacted by their treatment.

Though men who underwent active treatment have worse physical outcomes compared to men on non-active treatment strategies, men diagnosed with PCa have worse functional outcomes when compared with the general population overall. A Swedish study that compared age-matched controls with men diagnosed with PCa found that those with PCa felt more negatively impacted by urinary, bowel and sexual concerns up to 12 years post-treatment (Carlsson et al., 2016). Many individuals with PCa reported experiencing erectile dysfunction or were sexually inactive, approximately 20% of participants receiving treatment reported urinary incontinence and14% reported bowel dysfunction (Carlsson et al., 2016). Men who received multiple treatments, either at the same or different times, were at higher risk of poor functional outcomes compared to men who underwent one form of treatment (Carlsson et al., 2016). Thus, the long-term physical impact of active PCa treatment can be significant and have a significant effect on depression, anxiety and psychological distress

(Maggi et al., 2019; Sciarra et al., 2018; Sharp, O'Leary, Kinnear, Gavin, & Drummond, 2016; van Stam et al., 2017).

Psychological impact

The psychological impact of PCa can be immense both at diagnosis (Dillard, Scherer, Ubel, Alexander, & Fagerlin, 2017; Seklehner et al., 2013) and after treatment (Maggi et al., 2019; Sciarra et al., 2018; Sharp et al., 2016). In particular, men often experience heightened anxiety while waiting for prostate biopsy results, with this discomfort peaking just before receiving a diagnosis (Dillard et al., 2017). Greater anxiety is felt when knowledge of treatment options and understanding of treatment side effects is low. This can have an effect on patient's decision making when it comes to deciding the type of treatment they would like to receive (Dillard et al., 2017). In these situations, where there is high anxiety and low knowledge, men typically choose surgery which can have adverse consequences to mental health post-treatment (Dillard et al., 2017).

Though men on AS generally have better functional outcomes and lower psychological impact compared to men on active treatment (Bellardita et al., 2015; Egger et al., 2018; Wilcox et al., 2014), distress can still occur when receiving diagnosis. Furthermore, psychological distress often acts as a barrier to seeking support, attending follow-up sessions and can lead to men opting to start active treatment despite no evidence of disease progression (Bellardita et al., 2015; Van Hemelrijck et al., 2019). This illustrates that psychological distress can have a significant impact on QoL.

While research is limited on the effect of WW on mental health, preliminary literature indicates that men on AS or WW have higher initial levels of distress and hyperarousal compared to those offered surgery or radiotherapy (Egger et al., 2018). Despite these differences, men on AS and WW have similar long-term functional and psychological outcomes when compared with men who have undergone active treatment (Bill-Axelson et al., 2013).

Functional outcomes for prostatectomy and radiotherapy (e.g. sexual, urinary and bowel outcomes) can increase risk of depression, anxiety and psychological distress. These effects are compounded when an individual undergoes more than one PCa treatment (Maggi et al., 2019; Sciarra et al., 2018; Sharp et al., 2016; van Stam et al., 2017). Tripp et al. (2017) found that in ADT, either as an adjuvant or as a monotherapy, depression scores increased and mental QoL decreased across a two years post-diagnosis. It can be postulated that this is due to the sexual impact of ADT which can increase depression and anxiety in this population. Furthermore, the urinary impact of ADT also correlates with psychological distress (Punnen et al., 2013). Psychological distress can prevent men from engaging in future follow-up and in rehabilitation after treatment (Johanes, Monoarfa, Ismail, & Umbas, 2013). This is a bidirectional process, as the functional outcomes can affect the mental state of the individual, which in turn can affect coping and recovery from functional side effects of treatment (Orom, Biddle, Underwood, & Nelson, 2018).

A major contributor to distress is expectations that individuals may have post-treatment (Maguire, Hanly, Drummond, Gavin, & Sharp, 2018). This may include functional treatment outcomes being worse than anticipated (Maguire et al., 2018), or concerns and worry associated with recurrence (Kong, Deatrick, & Bradway, 2017) impacting negatively on mental health. This illustrates the potential for psychosocial input early on in both non-active treatment strategies and active treatment.

Qualitative data suggest that the psychosexual impact of PCa treatments has a larger impact on men’s QoL than quantitative research indicates (Chapple & Ziebland, 2002; Letts, Tamlyn, & Byers, 2010; O’Brien et al., 2011). Moreover, sexual impact is a large factor in treatment decision-making (Christie, Sharpley, & Bitsika, 2015). Chapple and Ziebland (2002) reported that side effects of treatment such as urinary incontinence, erectile dysfunction, body feminisation, and decreased libido have a profound effect on sense of self and masculinity (Chambers, Chung, Wittert, & Hyde, 2017). Many men report withdrawing from any form of intimate activity with partners, thereby affecting their relationship, self-identity, and QoL (Letts et al., 2010). Furthermore, psychosexual problems can arise years after treatment and can have associated grief and loss feelings attached to changes in sexual functioning; this can lead to feelings of depression, irritability, anxiety, fear, worry, embarrassment and stress (O'Brien et al., 2011). Unfortunately, despite the distress that can be felt from loss of sexual function, there is a lack of psychosexual support from clinicians (Letts et al., 2010; O'Brien et al., 2011) and men often regret their treatment choice due to sexual outcomes (Christie et al., 2015). This signifies the multiple factors that can influence the psychological wellbeing of PCa survivors and the importance of psychological support throughout the cancer journey.

Sexual impact

Men experience many health-related adverse effects after treatment, however sexual dysfunction is the most commonly reported side effect (Carlsson et al., 2016; Resnick et al., 2013). These can include libido changes, erectile dysfunction, orgasm intensity change, penile shortening and/or curvature, pain during orgasm and reduced ejaculatory volume (Sanchez Varela, Zhou, & Bober, 2013). In fact, between 57-63% of men will not attain erectile functionality two years post-treatment which can cause significant distress (Alemozaffar et al., 2011). Men who have had a prostatectomy experience the largest negative change in physiological sexual function, followed closely by EBRT and ADT (Ávila et al., 2018; Lardas et al., 2017).

Unsurprisingly, due to the role that testosterone can play in regulating sexual arousal and libido, ADT in particular can have a major sexual impact on men who undergo this treatment (Mazzola & Mulhall, 2012). A cross-sectional study that surveyed men 2 to 18 years post-diagnosis for health-related QoL (stratified based on treatment received), found that men who had undergone ADT alone had a worse global QoL score compared to other treatments (Drummond et al., 2015). This was attributed to poorer urinary and sexual outcomes compared to other treatment modalities. Men over 70 years were also more likely to be on ADT monotherapy for localised PCa compared to younger men, highlighting the potential psycho-social-sexual consequences that may be experienced by this population group (de Camargo Cancela, Comber, & Sharp, 2013). Further illustrating the long-term impact that PCa can have on sexual wellbeing and the importance of supporting men throughout their cancer journey.

Impact on relationships

The importance of the dyadic relationship in relation to psychosexual care post-PCa treatment is becoming increasingly evident in the literature (Arrington, 2005; Letts et al., 2010). Partners (typically wives) are often quoted as the primary source of support for men with PCa, playing a fundamental role in supporting changes after PCa and facilitate recovery (Collaço et al., 2018). Unfortunately, due to the physical and psychological impacts of treatment for PCa, intimacy negatively impacted, which can lead to further distress for both parties (Tucker, Speer, & Peters, 2016). Surgery can negatively impact the dyadic partnership the most when compared with other treatment modalities (Ramsey et al., 2013). It is recommended that the partner be included in PCa-related medical consultations to empower the partner and patient (Collaço et al., 2018; Fode & Sønksen, 2014:King, 2015 #134; Perz, Ussher, & Gilbert, 2014).

Intimate relationships are not the only social aspect negatively impacted for men with PCa. One risk factor for worsening mental health in this population is social isolation (Ettridge et al., 2018). Many men report experiencing feelings of loneliness and social isolation due to a variety of factors including lack of readily available social support/contact, a reluctance to speak about their experiences stemming from embarrassment associated with a cancer diagnosis and the associated side effects of PCa, perceived withdrawal from others due to diagnosis, and being limited by physical and social consequences of treatment such as incontinence (Ettridge et al., 2018). Feeling socially isolated is especially prevalent for younger men and those who live alone with no family within close proximity (Ettridge et al., 2018).

Under-researched population groups

Despite the breadth of literature on the impacts of PCa and PCa treatment there are still gaps in the research. Participants in PCa research tend to be Caucasian (Dowsett, Prestage, Duncan, du Plooy, & Waling, 2015), heterosexual (Cathcart-Rake, 2018) men aged between 65 (Wennick, Jönsson, Bratt, & Stenzelius, 2017) and 80 years (Lardas et al., 2017), and with a long-term partner (Ettridge et al., 2018). Perhaps what is most lacking is research or data aggregation of the needs and the impact on minority populations, such as Aboriginal men (Cancer Australia, 2013), men in rural areas of Australia (Butow et al., 2012; Gunn, Turnbull, McWha, Davies, & Olver, 2013) and transgender women (Deebel et al., 2017). Furthermore, not all men who are diagnosed with PCa have a partner (Ettridge et al., 2018). Unfortunately, the research into the impact of cancer diagnosis and treatment on single men is limited despite emerging literature implying the elevated distress experienced regarding their sense of self and masculine identity (PCOR, 2018). Similarly, men under 65 years have reported that their needs are overlooked by health care professionals (HCPs) (Wennick et al., 2017).

Many studies have not differentiated the experiences and needs of men who identify as heterosexual and those who have sex with other men (MSM) (Tucker et al., 2016; Wassersug, Lyons, Duncan, Dowsett, & Pitts, 2013). Ussher et al. (2016) found that MSM experienced greater psychological distress, ejaculatory bother, lower masculine self-esteem, and greater dissatisfaction with treatment compared to heterosexual men. It is postulated that this is due to the different emphasis on functional sexual outcomes between the two groups, thus further illustrating the unique needs of MSM (McConkey & Holborn, 2018) and the potential impact psychosexual consequences can have on the dyadic alliance (Ussher et al., 2016). Further research is necessary to determine how best to support the MSM population.

Finally, research around QoL for patients diagnosed with metastatic PCa is limited (Holm, Doveson, Lindqvist, Wennman-Larsen, & Fransson, 2018). Holm et al. (2018) reported that men with metastatic PCa generally rated their QoL poorly compared to clinically significant values, indicating unmet physical and psychological needs. They recommended a palliative care approach that focuses on QoL and symptom relief as a possibility to giving these men the best support in their final years of life.

Supportive care needs of people diagnosed with PCa

Unmet supportive care needs

As previously discussed, men face many challenges at diagnosis and throughout their cancer journey. The impact that PCa can have on wellbeing can be hidden and immense (Armes et al., 2009; King et al., 2015; Paterson, Robertson, Smith, & Nabi, 2015; Watson et al., 2016). Men diagnosed with PCa frequently report unmet informational, psychosocial, and psychosexual needs (Goonewardene & Persad, 2015; Paterson et al., 2015). Informational needs include clarity regarding PSA testing, treatment types and associated side effects, psychological and long-term impacts of treatment, information for carers and partners, and local support access (Carter, Miller, Murphy, Payne, & Bryant-Lukosius, 2014; Paterson et al., 2015). Fear of recurrence and disease progression, and managing changes in sexual functioning/feelings and relationships are amongst the most commonly reported unmet needs for men after treatment (Watson et al., 2016). Overall, unmet supportive needs are higher in younger patients and patients receiving hormone therapy, whereas unmet sexuality needs were more prevalent in younger men who have regular partners when compared to other common cancer types (Armes et al., 2009).

Men have reported that peer support, whether from groups run by HCPs, individuals, religious groups and online communities, and support from partner, friends and families, are useful in meeting unmet needs (King et al., 2015). Unfortunately, King et al. (2015) found that men's supportive care needs were predominantly provided by informal networks of peer support, and formal support from HCPs was lacking. Reasons for this includes help-seeking behaviour in PCa survivors (Moreira Jr et al., 2005; Paterson et al., 2015; Roney & Kazer, 2015), barriers to adequate health care provision by HCPs (Dyer & das Nair, 2013; Ussher et al., 2013), and HCPs needing to deliver services within the bounds of the health care system (e.g. timing restrictions for each consult) (Dyer & das Nair, 2013; Neumann et al., 2011).

Good supportive care for men diagnosed with PCa requires a multidisciplinary team. Members can include the general practitioner (GP), medical oncologist, oncology/PCa nurse, pathologist, radiation oncologist, psychologist, social worker, physiotherapist and the urologist (Cancer Council, 2016). Best practice requires case management by the lead clinician, which can be the GP or the oncologist in charge of patient care (Cancer Council, 2016). Considering the GP's role in detection, monitoring PCa progression, and continual relationship with the patient, they are best placed to be the primary HCP of men diagnosed with PCa.

Help-seeking behaviour in survivors of PCa

Research indicates that men seek help differently compared to women (Smith, Braunack-Mayer, Wittert, & Warin, 2008). Smith et al. (2008) showed men in general practiced physical self-monitoring to determine whether they required further support. This paper identified four main factors that can influence help-seeking practices in men: 1) length of time required to rest and monitor dependent on the nature of the problem; 2) previous illness experiences; 3) impact on daily life; and, 4) perceived illness severity.

Psychosexual impact of PCa can greatly affect QoL in men if left unaddressed. Despite a willingness to discuss sexual concerns with their GP, older men with PCa generally wait for clinician initiation of this conversation (Farrell & Belza, 2012; Roney & Kazer, 2015). Moreira et al.'s (2005) study found that in their cohort, nearly half felt that GPs should initiate discussion about sexual health concerns during routine consultations, thus adding pressure on the provider to initiate. Unfortunately, men with PCa felt that their psychosexual needs were often overlooked or poorly explored within clinical consultations (Paterson et al., 2015).

Furthermore, for patients who did initiate conversation with their GPs, barriers were encountered. Patients reported a narrow focus on regaining physiological functioning (i.e. erectile functioning) without consideration of the emotional and relational impact of further medical intervention (Speer, Tucker, McPhillips, & Peters, 2017; Wentzell, 2017; Wittmann et al., 2015). Speer et al. (2017) reported that many patients received psychosexual information too early in their cancer journey, and that communication with their physicians might not have been individually tailored. Thus, leaving men feeling depersonalised and with the impression that doctors lacked empathy (King et al., 2015).

Psychosexual communication challenges for health care professionals

The role of PCa-specific HCPs' involvement is becoming crucial to managing side effects after treatment for PCa survivors (Grant, Economou, Ferrell, & Uman, 2012). Unfortunately, HCPs, including GPs, have varying levels of comfort when discussing the sexual health of their patients, despite perceiving sexual health as an important factor in overall cancer care (Greimel et al., 2018; Olsson, Berglund, Larsson, & Athlin, 2012; Ussher et al., 2013). Much research has attributed this to lack of professional training and knowledge, the provider's own bias towards talking about sexual health, and perceived patient embarrassment (Dyer & das Nair, 2013). Lack of knowledge and professional training is often cited as one of the most common barriers in initiating discussion which in turn influences comfort levels and fear of starting a conversation that may be awkward or embarrassing for patient and clinician (Dyer & das Nair, 2013; Ussher et al., 2013).

To address this barrier, Jonsdottir et al. (2016) ran a sexuality-based educational intervention in the hospital for nurses and physicians in medical, surgical and gynaecological oncology settings. An increase in confidence and knowledge was observed for those who attended. Despite not being statistically significant, HCPs who attended the workshops were more likely to initiate conversations with patients compared to those who did not. Unfortunately, it did not improve the overall frequency of sexual discussions with patients, indicating the potential influence of other factors.

Another barrier to discussing psychosexual problems with patients is the clinicians' personal discomfort; that is, fear of embarrassing the patient, discomfort at discussing the topic despite having the knowledge, and perceiving the topic as too personal to discuss (Dyer & das Nair, 2013; Ussher et al., 2013). Many health care professions perceive discussion of sexual health as the role of other clinicians (Olsson et al., 2012; Ussher et al., 2013). Unfortunately, this poses the problem that by positioning the discussion of sexuality as the responsibility of others, there is a greater risk of the patient's psychosexual needs being unmet. Sexual health is the responsibility of all health professionals (Olsson et al., 2012), including GPs.

Implicit biases and stereotypes can also influence when clinicians determine who and how to ask questions relating to the sexual wellbeing of an individual (Chapman, Kaatz, & Carnes, 2013; Lyons et al., 2017). For example, PCa predominately affects men over 65 years, and the incidence increases with age (Australian Institute of Health and Welfare (AIHW), 2017). Unfortunately, there is a common misconception that many older people are asexual or unwilling to discuss issues relating to sex (Lyons et al., 2017; Minichiello, Plummer, & Seal, 1996). This can lead to GPs overlooking what might be an important QoL area for men. Additionally, most resources and training that GPs receive tend to have a heteronormative focus which can force practitioners to feel uncomfortable discussing sexual health with men who identify as sexually diverse (Gianotten & Aars, 2018). This lack of discussion can potentially lead to poorer QoL outcomes (King et al., 2015; Speer et al., 2017).

The alliance between the patient and their medical and allied health team is important to improving QoL(Ernstmann, Weissbach, Herden, Winter, & Ansmann, 2017). Ernstmann, et al. (2017) found that patients had better QoL outcomes if supportive, devoted and participatory patient-physician communication over the course of treatment and at follow-up occurred. This is particularly important should the patient be on AS or post-treatment, as fear of recurrence and/or disease progression is a predictor of emotional distress in these circumstances (Armes et al., 2009). Thus, there is a need for physicians to ensure the patient is aware of signs of cancer recurrence without causing excessive distress or anxiety (Armes et al., 2009).

Limits of the health care system

Despite acknowledging the psychosexual needs of men around coping with uncertainty, sexual and relationship changes, HCPs commonly report limited time availability to discuss these issues in-depth with the patient and his family members (Carter et al., 2014; Dyer & das Nair, 2013). A standard GP consult is 15 minutes (Britt et al., 2016) which may not be sufficient in disseminating information adequately to patients (King et al., 2015). This can further add to feelings of incompetence and feeling rushed, which can affect patient-physician communication.

Challenges are also present in the health care system, whether public or private, in providing optimal cancer care. Neumann et al. (2011) compared patients who accessed a physician through either a public system or through private health insurance in The Netherlands. They found that patients perceived the private health physicians to be more empathetic and less stressed which can impact on care. Generalisation of this information to Australia may not be applicable due to the differences in health care systems. Further research is required to determine applicability to Australia.

Psychosexual support is recommended to occur from diagnosis, through to treatment and survivorship (King et al., 2015). Unfortunately, many patients will not have the same team of HCPs throughout their treatment journey (King et al., 2015; Paterson et al., 2015). Due to the lack of continuity of care, difficulties are found in establishing and building of relationships with doctors and nurses, thus reducing opportunity to disclose any sexual problems or concerns (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2011). GPs are generally a part of the patient’s cancer journey from diagnosis to survivorship. Consequently awareness of the psycho-social-sexual impact of PCa and how to provide support is necessary.

Conclusions

The psychosocial and psychosexual care of PCa survivors is a fast growing research area. It may be difficult for time-limited practitioners to keep up to date with the most current literature. Added to the complexity of patient support is the varying psychosocial and psychosexual care needs of patients. Such needs may potentially varying as a result of age at diagnosis (Ettridge et al., 2018), gender and sexual diversity (Ussher, Perz & Rosser, 2018), relationship status (Letts et al., 2010) and cultural status (Cancer Australia, 2013). Thus, a discussion paper which provides an overview of PCa and its impact on mental, social and sexual health, considering age, marital status, sexual status and cultural status is needed for GPs who may lack the knowledge and/or time. Such a paper would provide GPs with the opportunity to integrate themselves into PCa research or identify areas for professional development. This is especially pertinent to improving the QoL outcomes of patients diagnosed with PCa by addressing their unmet psychological, social and sexual needs.

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Providing psychosocial and psychosexual support to patients diagnosed with prostate cancer

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Abstract

Background

Prostate cancer is the most commonly diagnosed solid organ cancer among Australian men. Prostate cancer diagnosis and treatment can have an impact on patients physiologically, psychologically, socially and sexually with many men expressing unmet psychosocial and psychosexual needs post-diagnosis regardless of stage of cancer and treatment. General practitioners (GPs) find that they are unable to fully explore the psychosocial and psychosexual implications for patients diagnosed with prostate cancer due to a lack of time and feeling inadequately prepared to provide supportive care.

Objective

To equip GPs with the tools to provide psychosocial and psychosexual support for men diagnosed and treated for prostate cancer.

Discussion

GPs face a number of barriers to providing psychosocial and psychosexual support for patients diagnosed with prostate cancer. GPs support for patients with prostate cancer will benefit from employing a biopsychosocial model of care and by initiating these conversations with their patients.

While prostate cancer is the most commonly diagnosed solid organ cancer in Australian men, 95% of men diagnosed can typically live at least five years post diagnosis.[1] Generally, prostate cancer is slow growing and slow spreading. Early detection methods such as PSA screening and digital rectal examination can help to detect prostate cancer earlier, thus leading to treatment, before it metastasises to other areas of the body such as the lungs, bone and lymph nodes. For the purposes of this paper, the specific methods used for prostate cancer diagnosis will not be covered; if interested, please refer to Frydenberg.[2]

There are a few known risk factors for developing prostate cancer including having a family history of breast, ovarian or prostate cancer, and being aged 50 years or older.[3] Currently, the mean age at diagnosis for prostate cancer at 67.7 years.[1] With the life expectancy of Australian men on the rise,[4] more and more men are survivors of prostate cancer and living with the ongoing consequences of diagnosis and treatment. Prostate cancer can negatively impact men physiologically, psychologically, socially and sexually reducing quality of life.[5-7] Unfortunately, survivors find their psychosocial and psychosexual needs remain unmet, thereby affecting ongoing quality of life.[7, 8]

General practitioners (GPs) are well-placed to provide psychosocial and psychosexual support and link people diagnosed and treated with prostate cancer with allied health services.[9] However, research indicates that a number of barriers are faced by GPs when trying to facilitate psychosocial and psychosexual support for their patients. This includes feeling that they have a dearth of knowledge and/or training in psychosocial and psychosexual concerns, that they lack appropriate access to psychosocial and psychosexual resources and referral pathways,[10] and insufficient time during consultations to fully explore patient needs.[11] Furthermore, clinicians' personal discomfort has also been found to act as an additional barrier to talking about psychosexual concerns with a patient.[10,12]

Research has shown that patients who report having a supportive relationship with their clinicians have better quality of life outcomes. The patients felt that they were invited to participate and discuss their concerns with their doctor and were an active member of their care over the course of treatment and follow-up.[13] This article aims to provide an overview of the impact of prostate cancer, with a particular focus on the psychosocial and psychosexual effects of diagnosis and post-treatment. The second purpose is to provide tools and resources for GPs to increase knowledge, provide structure, and foster an ongoing supportive relationship with their patients to meet their psychosocial and psychosexual needs.

Impacts of prostate cancer

Prostate cancer diagnosis and treatments can have far-reaching consequences for men physiologically, psychologically, sexually and socially.[5,7,14] Treatment normally varies depending on the stage of the cancer as well as the age and medical co-morbidities of the individual.[15] Primary treatment pathways for prostate cancer include active treatments such as prostatectomy, radiotherapy and androgen deprivation therapy (ADT), and/or non-active treatment strategies such as active surveillance and watchful waiting. The goal of non-active treatment strategies is to monitor cancer growth through regular screening as well as to stop patients from undergoing active treatment when it may not be required as these may inadvertently lead to more severe consequences.[15]

The physiological impacts on urinary, bowel, sexual and hormonal functions are well documented for active treatment modalities. [5,16] Men have reported experiencing a variety of symptoms; including but not limited to urinary incontinence, urinary obstruction, bowel incontinence, sexual dysfunction, hot flushes and gynecomastia during treatment or post-treatment.[5,17] In many instances, clinicians typically focus on physiological recovery and wellbeing.[18,19] In many instances, patients frequently report unmet informational, psychosocial and psychosexual needs.[18] This only serves to highlight that the psychosocial and psychosexual impact of prostate cancer can have significant consequences on quality of life for individuals.[8,18]

Patients on non-active treatment strategies have better functional outcomes and fewer treatment-related negative psychological consequences compared to those patients on active treatment.[20-23]However, they often experience higher levels of distress and hyperarousal soon after diagnosis, compared to those who are offered surgery or radiotherapy.[22] This does not mean that they do not experience any psychological distress throughout their cancer journey. In fact, 12.8% of men on active surveillance will decide to start active treatment with no evidence of disease progression within five years from diagnosis[24] suggesting some psychological burden.[25] Research indicate that men feel anxiety and uncertainty while waiting for screening results. [26, McIntosh, Opozda, Galvao, Chambers, Short, *unpublished data*] This further illustrates the importance and the need for psychological input early for those on non-active management strategies to reduce men's distress.

Patients that have received some form of active treatment, may also experience psychological distress, depression and anxiety associated with their diagnosis and the consequences of treatment.[14,27,28] Patients are faced with concerns and worries associated with recurrence and/or disease progression, adjusting to life after receiving a cancer diagnosis, managing treatment side effects and the social consequences of diagnosis and treatment.[29-31] In particular, urinary incontinence, erectile dysfunction, body feminisation and decreased libido, have a profound effect on sense of self and masculinity in patients.[32] Some patients report later regret their treatment decision due to the development of urinary and sexual consequences of treatment.[33] Additionally, suicidal ideation is higher in men diagnosed with prostate cancer compared to the general population.[34] Men most at risk of suicidal ideation have greater reported symptom burden, poor physical and emotional functioning, and a higher frequency of pain occurrence.[35]

Sexual dysfunction is the most common side effect of active prostate cancer treatment[36,37] with 41% of Australian men reporting sexual problems after surgery, and 32% after radiotherapy.[38] These may include libido changes, erectile dysfunction, changes to orgasm intensity, penile shortening and/or curvature, pain during orgasm and reduced ejaculatory volume.[39] Almost two-thirds of men will not have full erectile functionality two years post-treatment which can cause significant distress.[40] However, improved sexual wellbeing for patients can go beyond recovery of erectile functionality; it also encompasses overall satisfaction with sex life that may or may not include functional recovery.[41] Psychosexual problems can arise years after treatment and can have associated grief and loss attached to changes in sexual functioning. Sexual difficulties may also result in feelings of depression, irritability, anxiety, fear, worry, embarrassment and stress illustrating the psychosexual impacts of prostate cancer.[29]

Prostate cancer can also impact upon the social identity of an individual. Patients who are diagnosed often report feeling socially and emotionally isolated from their partners and friends.[7] Their partners may consequently also have unmet psychosocial and psychosexual needs that are often not addressed during clinician consults.[42] Partners are frequently the emotional caregiver for patients as patients deal with the psychological impacts of receiving a prostate cancer diagnosis and treatment. Often partners feel unsupported by the health care system and struggle to cope. Partners also feel unprepared and not knowing how prostate cancer can have an impact on their relationship and can express grief and loss of sex and intimacy. Unfortunately, partners often report feeling overlooked and forgotten by clinicians in lieu of the patient’s needs even when they do have good experiences with health care professionals.[43] This is a problem as evidence suggests that the dyadic relationship is important to maintaining psychosocial and psychosexual care of patients.[44]

Additionally, patients withdraw or become more socially isolated from friends due to the physical and social consequences of their cancer treatment (e.g. if a man has incontinence, he might fear leaking in social situations and withdraw from activity). Men also report embarrassment at being associated with a prostate cancer diagnosis or feel that the people around them have withdrawn due to their diagnosis, resulting in a loss of social support.[7] Lack of social support is particularly prevalent in younger men (65 years and younger), older men (80 years and above) and for those who live alone with no family close by.[7,45]

Prostate cancer can cause physiological dysfunction, psychological and emotional distress, negatively effect on sexual wellbeing and cause social withdrawal and isolation. Unfortunately, men often report feeling that their concerns in these areas are not addressed adequately by health care professionals.[7] Considering the impact of psychosocial and psychosexual concerns on quality of life, patients might benefit from clinician’s exploration and support in these areas.

Practical Tips

To discuss patient’s psychosocial and psychosexual concerns, clinician’s should consider the following:

- Maintain a good relationship with patients and their partners as the relationship between clinician and patient can be a contributing factor to improving quality of life.[13]

- While many patients are often uncomfortable bringing up sexual concerns with their clinicians, patients report feeling generally comfortable speaking about these concerns if they are raised first by the health professional.[46]
- Ask about psychosocial and psychosexual concerns in a non-judgemental open-ended fashion to normalise patient experience (i.e. "Many patients who have had [treatment/diagnosis] have concerns about how it can affect your sexual function/intimate relationship. Is this something you would like to talk about?").[47]
- Choose an appropriate time in the patient's cancer journey to discuss psychosocial and psychosexual concerns and impacts. This will be explored in the article.
- Assess patient needs using screening tools before consultation can better direct consultations. These tools will be discussed later in the article.
- If possible, discuss with patients the possibility of scheduling a longer appointment when psychosocial or psychosexual concerns will be next addressed to provide sufficient time and space for clinicians to offer adequate support for patients.
- Some patients might prefer partner involvement early in the prostate cancer process to provide additional support for patients.[44]

If clinically appropriate, clinicians have many referral options to help patients when faced with their psychological, social or sexual concerns. These can include:

- Direct patients to the Cancer Council or Prostate Cancer Foundation – useful general information and information to available community peer support groups. More referral pathways are discussed at the end of this article.
- Referral to a community psychologist or counsellor under the Better Access Scheme.
- Engage with a prostate cancer nurse to answer any general questions about prostate cancer and address any psychosocial and psychosexual concerns.

When to provide psychosocial and psychosexual support

Psychosocial and psychosexual support is recommended to occur from diagnosis, through treatment and into survivorship.[8,48] Between the time of prostate biopsy and diagnosis, patients often report experiencing heightened anxiety.[26,49] Levels of anxiety can be attenuated by having more knowledge, i.e. by receiving appropriate and useful information patients will feel less anxiety about their diagnosis.[26] Unsurprisingly, heightened anxiety has an impact on information retention. This in turn, impacts upon their decision making with regards to their treatment. Thus, the timing of general prostate cancer information delivery from GPs is important.[50] It is best to provide information to resources for patients, such as the Cancer Council, and/or access to an allied health professional, such as a prostate cancer nurse, who can disseminate the information to the patient, between the time of biopsy, and returning to receive the diagnosis.[8] Furthermore, facilitation of psychological support for depression and anxiety management early on has additional benefits as it can increase patients' psychological resilience for the rest of their cancer journey.[51]

For patients on active surveillance or watchful waiting may report psychological distress whilst on this treatment, before they receive their prostate cancer test results. [McIntosh, et al., *unpublished data*] Clinicians should check in with patients at regular intervals, especially at important times, such as before the patients are due for their screening results, if they are not already connected with a psychologist or other supportive counselling services. This is so the patient feel supported, thus reducing psychological distress.

Functional outcomes of active treatments have a significant effect on depression, anxiety and psychological distress.[14,27] Functionality post-active treatment is generally at its poorest after three months.[52] Thus, three months can be considered another time point in which to check-in with patients about their psychosocial and psychosexual concerns.

Furthermore, it is considered by many men to be a good time to discuss the psychosocial and psychosexual impact of treatment-related side effects.[53]

Thus, the optimal times in which to check in with patients is around time of diagnosis and three months post-active treatment. However, every individual is different and will react and respond in different ways at different times. Checking in with patients at regular intervals (e.g. biannually to yearly) is important in supporting their quality of life and can foster goodwill between clinician and patient, thus strengthening the patient-clinician alliance and working to reduce the negative impact of treatment.[54]

Regardless of when the discussion takes place, one of the most important aspects is the therapeutic alliance between the clinician and the patient. Without a good rapport and a strong therapeutic alliance, it is unlikely that the patient will feel comfortable disclosing sensitive matters, and will be more reluctant to reach out for help.[13]

Practical Tips

In summary, psychosocial and psychosexual can be discussed:

- Just after their diagnosis,
- Between screening and receiving results,
- If patients have completed active treatment, 3 months post-treatment, and
- Every 6 to 12 months thereafter.

Use of psychosocial and psychosexual measures

Understandably, one of the most quoted limitations for GPs with regards to being able to ask questions about the psychosocial and psychosexual needs of their patients, is time.[11] The average GP consultation time is generally insufficient to address all relevant concerns a patient may have. Screening instruments, in particular patient-reported outcome measures, can be useful to help identify patient unmet needs and direct conversation during a consult.[55] Screening instruments can be completed patients when they check in before the consult.

Active prostate cancer treatment generally leads to specific urinary, sexual, bowel and hormonal changes that may cause psychological distress in patients.[14] Whereas non-active treatment strategies rarely lead to physical dysfunction, it can still have an impact on patient's psychological health.[22] Currently, there is no measure that fully captures all the issues that can arise for prostate cancer patients, thus, a wide range of validated measures is needed to provide to patients to assess their needs and in determining how to address them. The ones presented here have been selected for their brevity as to reduce physical and psychological burden to patients. Further, for their validity specific to prostate cancer. Utilising screening tools can also minimise the time that clinicians will need to review the answers given as to better refer patients to manage their psychosocial and psychosexual needs. These assessments should take patients no more than 10 minutes to complete per assessment and are freely available online. Some commonly used measures include but are not limited to, the following;

To assess functioning: Expanded Prostate Cancer Index Composite – Clinical Practice (EPIC-CP)

EPIC-CP contains 16 items in which it assesses functionality and amount of bother experienced in the past four weeks across four domains: urinary, bowel, sexual, and hormonal.[56] This has been validated in the prostate cancer population and is available in English, Korean, Portuguese and Spanish languages.

To assess quality of life: The Functional Assessment of Cancer Therapy – Prostate (FACT-P)

The FACT-P is a prostate-specific questionnaire that consists of 40 items in four quality of life domains; physical wellbeing, social/family wellbeing, emotional wellbeing, and functional wellbeing, with additional prostate cancer specific questions. The prostate cancer specific questions asked about an individual's sexual, urinary and bowel symptoms, pain and weight changes.[57] The FACT-P provides a good general overview of the impact that prostate cancer can have on the patient. It is a validated measure for use in the prostate cancer population and will be a useful clinical tool to monitor changes in quality of life domains for patients. It is available in 45 different languages.

To assess distress: the Distress Thermometer

The distress thermometer is a recommended measure that is used widely in research and clinical settings to detect clinically significant distress in cancer patients and has been validated in the prostate cancer population.[58,59] Unlike the other measures, the distress thermometer can be used for patients who had not yet undergone active treatment. It is a single page with a picture of a thermometer on one side for patients to indicate level of distress and a checklist covering psychosocial factors that might contribute to patient's distress. If the patient scores four or less after diagnosis, and three or less for assessments that is more than a year after diagnosis for psychological distress, they should be referred to a psychologist or a similar professional. Despite becoming less sensitive to markers of anxiety and depression a year post-diagnosis, the sensitivity of this measure is retained for psychological distress up to three years post-diagnosis.[59]

To assess anxiety and depression: Hospital Anxiety and Depression Scale (HADS)

HADS is a 14-item questionnaire that measures anxiety and depression in the medically ill.[60] HADS provides a number of statements (e.g. "I can sit at ease and feel relaxed") where patients are asked to report on a Likert scale (0-3) how they have been feeling in the past week. These statements are typically related to anxiety or depression. While it has been validated in the cancer population,[61] no research has been done on validating it in a prostate cancer population. However, it is used extensively in prostate cancer research. It has been validated in several different languages; Dutch, Spanish, Iranian, Portuguese, Cantonese and Greek.

To assess unmet needs: the Cancer Survivors' Unmet Needs (CaSUN)

The Cancer Survivors' Unmet Needs (CaSUN) assesses unmet supportive care needs of patients. Consisting of 41 items, it explores survivorship expectations and management of side effects, information, body changes, relationships, psychosocial and financial support, and the quality, participation and satisfaction with medical care.[62] These questions can open up discussion with patients on what unmet needs they have and determine how best to address those needs.[55] This measure has been validated in the oncology population[62] and is currently only available in English.

To assess social distress: Social Difficulties Inventory (SDI-21)

The social impact of prostate cancer is rarely explored adequately in screening tools. The Social Difficulties Inventory (SDI-21) focuses on social issues faced by cancer survivors and measures social distress.[63] It is a 21-item questionnaire with three subscales; 1) everyday living which covers areas such as independence and domestic chores, 2) financial concerns, and 3) the impact on self and others. The SDI-21 also asks about sexual matters and other more general social information. Though not validated in the prostate cancer population, it has been validated and used extensively in the clinical oncology cohort.[64,65] Free access to the tool can be gained through contacting the Patient Centred Outcomes Research Group, based in Leeds, UK.

Psychosocial and psychosexual interventions

The psychological wellbeing of patients diagnosed with prostate cancer varies widely between individuals and over time. There are a variety of factors that can influence an individual’s psychological growth or contribute to psychological distress. These factors can fall under two broad headings: cancer stress and burden, and resources. The various elements that can have an impact on cancer stress and burden include physical health and wellbeing, psychological wellbeing, interpersonal support, financial wellbeing and spiritual wellbeing. Conversely, resources that can influence psychological health include intrapersonal resources, i.e. resilience and coping mechanisms, interpersonal resources and access to quality informational resources. These types of resources are also required to be tangible and real to the patients.[66] Thus, for clinicians to impact psychological health of patients, they should address the factors that can contribute to psychological wellbeing and provide support where appropriate.

There are multiple components and modalities to provide psychosocial and psychosexual support to patients diagnosed with prostate cancer. These can be broken down to education (psychoeducation, psychosexual education, and prostate cancer education), communication between patient and their partner, patient and clinicians, peer support (i.e. support groups run by health care professionals or one-on-one), cognitive behavioural therapy, supporting patient’s decisions, relaxation techniques and supportive counselling.[67] In many cases, a combination of the different components offered appears to provide the best outcomes in regards to psychological distress, anxiety, depression, fatigue, and improved sexuality outcomes, and leads to better informed decision-making by increasing self-efficacy and confidence.[67,68] Still more work is required to test the efficacy of psychological interventions to improve partner distress. In fact, there is some evidence that couple-focused interventions can produce poorer outcomes for the partner's psychological wellbeing despite improving the patient's wellbeing.[67] More research is still required in couple-based interventions to improve both patient and partner's psychological and sexual health.

Psychological interventions have been shown to be effective in improving quality of life by reducing distress, increasing intimacy, and reducing anxiety and depression in patients diagnosed with prostate cancer.[67-69] In particular, there is strong evidence to suggest that quality of life is improved by psychological interventions targeting depressive symptoms related to adjustment post-prostate cancer treatment.[69] Additionally, improving psychological wellbeing can also have a positive impact on functional recovery post-treatment.[54] Please note that many of these studies were performed for patients who were diagnosed with localised prostate cancer.

Practical Tips

Psychosocial and psychosexual support for patients can take the following forms:

- Education (psychoeducation, psychosexual education, and prostate cancer education),
- Facilitating connections patients and their medical team, allied health team and social support network (e.g. peer support groups),
- Cognitive behaviour therapy,
- Relaxation techniques, and
- Providing supportive counselling and normalising their experiences.

These services can be provided by GPs, psychologists, social workers, nurses, and official organisational bodies such as the Cancer Council. For more psychosexual related concerns, it is possible to seek support from clinical sexologists as well.

Specific population needs

There are some specific considerations required for people who are gender and sexually diverse,[70,71] Aboriginal men and Torres Strait Islander men, men from culturally and linguistically diverse (CALD) backgrounds,[9] men who live in rural areas,[72] men who are single,[7] and men under 65 years[73] and older than 80 years.[16,29,45] This is due to each group having unique unmet psychosocial and psychosexual needs.[7,70] While each group will be discussed separately, clinicians should be aware of the potential intersectionality between them.

Gender and sexually diverse people

Prostate cancer affects all men equally, regardless of sexual orientation. However, much of the information and resources provided to men diagnosed tends to be focused toward heterosexual men forming an accessibility barrier for those men who identify as sexually diverse.[74] Unsurprisingly, research has found that men who are sexually diverse, have been found to experience greater psychological distress, ejaculatory bother, lower masculine self-esteem, and greater dissatisfaction with treatment when compared with heterosexual men. Given their different needs, alternative sexual emphasis is required when addressing them.[71]

Another often forgotten minority population are transgender women. The risk of prostate cancer in transgender women is dependent on when hormone therapy was initiated and whether they have had their prostate removed. In particular, the risk of a transgender woman being diagnosed with prostate cancer can be the equal to a cisgender male if they started hormone therapy after 50 years of age.[75] Clinicians need to be aware of the potential risk of being diagnosed with prostate cancer in transwomen, and the decision to perform screening should be made based on guidelines for cisgender men.[76] Recommendations for this group of individuals include lowering the upper limit of normal for a PSA test to 1.0 ng/ml for transgender women with low testosterone levels.[77]

Despite the growing presence of individuals who are gender and sexually diverse, many report fearing being stigmatised in the consulting room.[78] Gay patients often do not disclose their sexual orientation to their clinicians as they fear being judged and not feeling adequately supported psychologically. Furthermore, gay patients report feeling that their clinicians were embarrassed and sometimes lacked empathy.[74] This can greatly limit a clinician's ability to address the needs of prostate cancer survivors adequately as patients may not be forthcoming with their concerns.

Practical Tips

- Have space on the patient intake form for the individual to scribe their own gender and sexual preferences rather than having a prescribed assumption of gender or sexual identity can foster a sense of inclusion,
- Use of gender inclusive or gender-neutral language (e.g. gonads rather than testicles; partner rather than wife),
- Ask the patient for their name and pronouns, and actively using them, can make the patient feel validated in a setting in which they can often feel rejected and discriminated against,[79]
- For sexually diverse men, clinicians should be aware of the potential sexual impact that treatment can have which may be greater than heterosexual men. In particular, consideration of the importance of various sexual acts (e.g. prostate massage) and incorporate sexual scripts (e.g. the patient can be either a 'top', that is the one who

penetrates, or a ‘bottom’, the one who is penetrated). It is highly recommended that clinicians involve partners in these discussions.[80]

People from culturally and linguistically diverse (CALD) backgrounds/ Aboriginal and Torres Strait Islander people

Australia is a multicultural country with people from diverse cultural backgrounds. Unfortunately, not much research is available about unmet needs for men diagnosed with prostate cancer from CALD backgrounds. What is known is that cultural understanding and consideration is required to meet the needs of men from CALD backgrounds.[81] This may be particularly difficult where the patient’s English is limited. Further adding to the complexity, there can be differing perceptions of cancer and of the impacts of cancer between cultures (e.g. language may not have a word for cancer). This poses challenges when trying to impart important information to minimise distress.[9]

A more specific group of people within Australia are the Aboriginal and Torres Strait Islander population. Aboriginal and Torres Strait Islander people have a higher burden of cancer compared to the non-Indigenous Australian population.[82] For some Aboriginal men speaking about prostate cancer can be a taboo subject due to the sensitive nature of the region, and thus help-seeking is avoided.[83] In many instances, Aboriginal cultures have distinct gender lines (i.e. men’s business and women’s business) which can impart on care if clinicians are not aware of them. Some Aboriginal men will not engage with female clinicians about psychosocial and psychosexual impacts.[83,84] Furthermore, some Aboriginal cultures have close family connections and it may be appropriate to include family members in discussions around psychosocial and psychosexual care.[83] All these factors are important to consider when trying to provide optimal care for Aboriginal and Torres Strait Islander men diagnosed with prostate cancer.

Practical Tips

- Be aware of the gender lines within each culture. Many CALD men and Aboriginal and Torres Strait Islander men would feel more comfortable disclosing sensitive information to a male clinician,
- Offer to have family members and/or partners present during consults,
- Where appropriate, engage in a professional interpreter. If a face-to-face interpreter is not appropriate due to gender or confidentiality reasons (e.g. interpreter is known to the patient), then there are national telephone interpreter services,
- If needed, engage in continued professional development to increase cross-cultural/cultural competency.

Specifically for Aboriginal and Torres Strait Islander men:

- It takes time to engage with Aboriginal and Torres Strait Islander community and form good relationships with members of that community.[84]
- Provide a safe, confidential and comfortable environment for Aboriginal and Torres Strait Islander men to be able to disclose sensitive information. Having Aboriginal and/or Torres Strait Islander staff can help to foster the space.[45,84]

Men in rural and remote areas

People who live rurally often face unique challenges which may subsequently impact upon their survivorship. This is largely due to limited access to appropriate, local health care services and allied health support.[72] Patients who are diagnosed often either need to regularly travel into cities or stay in the city until treatment is completed. This not only can be geographically isolating but also have a financial impact, which can increase psychological and emotional distress.[72] In these situations, the alliance between patient and GPs, and between GPs and oncology specialists, is highly important and can enhance patients' treatment experiences.

Practical Tips

- Maintain a strong alliance between patient and GP, and between GPs and oncology specialists, as this is highly important for continuity of care for patients,
- Check in on patient's mental health regularly to catch any change,
- Connect with a mental health professional either locally, or in metropolitan areas via telehealth through the Better Access Scheme, when clinically appropriate.

People who are single

Patients who are single have unique considerations when compared to patients who have a partner. Patients who are single or living alone with no social supports close by are at greater risk of depression and suicidality compared to those who have a close social network or with a partner.[7,35] The functional impacts of prostate cancer can affect confidence and self-esteem in patients further isolating them.[29]

Practical Tips

- Connecting patients with peer support groups or online forums,
- Encourage social engagement where possible,
- Referral with a mental health professional can be beneficial to managing the negative psychosocial and psychosexual consequences of prostate cancer.[7]

Men under 65 years and older than 80 years

The average age of men diagnosed with prostate cancer is 67.7 years.[1] However, little consideration has been given to those who are under 65 years and those who are older than 80 years. In fact, men aged under 60 years and are over 80 years report higher levels of social distress due to unemployment, feeling socially and emotionally isolated, and for the older age group, having medical co-morbidities[73,85] illustrating the unique needs that may have been overlooked in the past.

For those who are in their 20s to 40s, the psychosocial and psychosexual impact can be felt differently when compared to those who are older. Many feel socially isolated from their peers as fewer in this age group who are diagnosed with prostate cancer. Younger men tend to not know other men in the same age group who have prostate cancer and they tend to be the outlier in peer support groups.[7] Furthermore, fertility concerns are most likely more prominent in this age group.[86] For many 65 years and under who are diagnosed, they feel that they were ‘paying the price for survival’ (i.e. living with the psychosexual consequences of the life sustaining treatments), sidestepped by clinicians when it comes to their fundamental needs (i.e. their needs were not prioritised by the health care system or society), and that they are living with an uncertain future.[73]

Conversely, for men aged over 80 years, they often report unmet psychosexual needs, especially those who placed greater importance on sexual activity and function.[29] Additionally, those in this age group may already have additional medical co-morbidities and functional and cognitive difficulties, adding to the complexity of providing psychosocial and psychosexual care.[82] It is recommended that people in this age group undergo a geriatric assessment[85] to determine whether comorbidities affect function, cognition, emotional status and social supports can influence treatment outcomes.[9]

Practical Tips

- Where clinically appropriate, a referral to a mental health professional through the Better Access Scheme can help with managing uncertainty, anxiety and loss of self-identity,

- Patients may not have a large support network and might need to be connected with support groups,[29]
- Initiate conversation with patients around psychosexual concerns and impacts after diagnosis but before treatment,
- For patients where fertility is a concern, open up discussion around fertility preservation options in an appointment after diagnosis.

Referral pathways

There are many ways in which a clinician can support their patient. Here is a list of potential referral pathways for patients, to assist with psycho-social-sexual concerns. These range from online resources and online forums, to phone and face-to-face consultations with specialist counsellors and psychologists.

Psycho-social-sexual/cancer support and information from official established bodies

- The Cancer Council offers telephone counselling with experienced nurses and access to support groups (www.cancer.org.au).
- The Prostate Cancer Foundation of Australia (www.prostate.org.au/) have resources for people diagnosed with prostate cancer and also offers locations for local community support groups as well as an online forum.
- A Touchy Subject (www.atouchysubject.com/) is the website by Victoria Cullen, a sexual recovery specialist. Her website includes access to webinars, videos and sexual rehabilitation products for men post-treatment.
- Referral to a community psychologist who specialise in cancer care and/or who have an understanding of prostate cancer difficulties. The Australian Psychology Society offer a

listing service to members in which consumers can search for a psychologist based on their needs and location (www.psychology.org.au/Find-a-Psychologist).

- For more specialised sexual health and sexuality counselling, the Society of Australian Sexologists has a listing of accredited sexologists in the community (www.societyaustraliansexologists.org.au/).

Online forums run by consumers for consumers

- Though not specific to prostate cancer, FrankTalk (www.franktalk.org/) is an online forum for men who suffer from erectile dysfunction, a common side effect of treatment, and other sexual issues.
- UsTOO (www.inspire.com/groups/us-too-prostate-cancer/?origin=freshen) is a part of an international online support forum called “Inspire”. This link is specific to prostate cancer.

General support

- For general counselling and support, you can direct men to MensLine Australia. They offer 24/7 telephone (1300 78 99 78) and online counselling (www.mensline.org.au/).
- Healthy Male (www.healthymale.org.au/) provides information and resources on male reproductive health accessible via their website.
- BeyondBlue offers information and support for depression, anxiety and related disorders. They offer 24/7 telephone support (1300 224 636) and also online chat (www.beyondblue.org.au/).
- Lifeline is the national suicide prevention and crisis line. They offer 24/7 telephone counselling support (13 11 14) and also online chat (https://www.lifeline.org.au/).

Key points

- While prostate cancer is the most commonly diagnosed solid organ cancer in Australian men, 95% of men survive at least five years post-diagnosis.
- Treatment often has negative impacts on the psychosocial and psychosexual wellbeing of men and men diagnosed with prostate cancer commonly report unmet informational, psychosocial and psychosexual needs.
- Key times to start psychosocial and/or psychosexual discussion is just after diagnosis and 3 months post-treatment. Support for men should continue through treatment and into survivorship.
- A strong therapeutic alliance is one of the most important aspects in supporting patients through their cancer journey and into survivorship as can increase quality of life for patients.
- Screening tools can be given to patients before consultations to maximise the time in consultation and direct discussion towards psychosocial and psychosexual concerns.
- Peer support and psychological intervention has been shown to be beneficial in managing the psychosocial and psychosexual impacts of prostate cancer treatment, and addressing unmet needs.
- Extra considerations should be made for patients who are gender and sexually diverse, Aboriginal and Torres Strait Islanders, men from culturally and linguistically diverse backgrounds, patients who are single and patients who are either younger than 65 years or older than 85 years of age as they may have different needs compared to the general population of men diagnosed with prostate cancer.

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3.1.6 Ethics

In keeping with international protocols and National Health and Medical Research Council (NHMRC) guidelines, all research papers reporting new research must be able to state that appropriate ethics approval was obtained before undertaking the study. All clinical trials must be registered. Ethics approval details must be described in the manuscript, and the human research ethics committee approval number or a copy of the approval certificate must be supplied (certificates should be uploaded with manuscript files at the manuscript submission stage and allocated the file type ‘Forms’).

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