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# Men's help-seeking in the first year after diagnosis of localised prostate cancer

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**Men's help-seeking in the first year after diagnosis of localised prostate cancer**

This study describes sources of support utilised by men with localised prostate cancer in the first year after diagnosis and examines characteristics associated with help-seeking for men with unmet needs. A cross-sectional survey of 331 patients from a population-based sample who were in the first year after diagnosis ( $M = 9.6$ ,  $SD = 1.9$ ) was conducted to assess sources of support, unmet supportive care needs, domain-specific quality of life and psychological distress. Overall, 82% of men reported unmet supportive care needs. The top five needs were sexuality (58%); prostate cancer-specific (57%); psychological (47%); physical and daily living (41%); and health system and information (31%). Professional support was most often sought from doctors (51%). Across most domains, men who were older ( $P_s \leq 0.03$ ), less well educated ( $P_s \leq 0.04$ ) and more depressed ( $P_s \leq 0.05$ ) were less likely to seek help for unmet needs. Greater sexual help-seeking was related to better sexual function ( $P = 0.03$ ), higher education ( $P \leq 0.03$ ) and less depression ( $P = 0.05$ ). Unmet supportive care needs are highly prevalent after localised prostate cancer diagnosis with older age, lower education and higher depression apparent barriers to help-seeking. Interventions that link across medicine, nursing and community based peer support may be an accessible approach to meeting these needs. Clinical Trial Registry: Trial Registration: ACTRN12611000392965.

**Keywords:** prostate cancer, supportive care needs, help-seeking, survivorship.

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## INTRODUCTION

Globally, over 1 million new cases of prostate cancer were diagnosed in 2012 with 68% of these occurring in more developed countries (Ferlay *et al.* 2014). Prostate cancer incidence is highest in Australia/New Zealand, North America, Western and Northern Europe (age

standardised rates per 100 000 range from 85.0 to 111.6), with incidence expected to increase globally to 1.7 million cases in 2030 (Center *et al.* 2012; Ferlay *et al.* 2014). Survival rates for prostate cancer have increased in most countries in the past two decades (Allemani *et al.* 2015) such that in the UK, North America and Australia/New Zealand approximately 90% of men now survive their prostate cancer at least 5 years and >80% survive for 10 years or more (Australian Institute of Health and Welfare 2013; Cancer Research UK 2014; American Cancer Society 2015). Although many more men are surviving prostate cancer, they are living with high and persistent symptom burdens often not addressed in follow-up care (Smith *et al.* 2000; Bernat *et al.* 2015; Carlsson *et al.* 2015; Gavin *et al.* 2015). In a recent UK study, approximately one-third of men up to 2 years post-prostate cancer diagnosis reported concerns with sexual, urinary and bowel function (Watson *et al.* 2015) and there is evidence to suggest that these effects can persist for a decade or more (Bernat *et al.* 2015; Carlsson *et al.* 2015). As well, men who were younger or received multi-modal treatment including androgen deprivation therapy (ADT) experienced worse effects (Smith *et al.* 2007; Carlsson *et al.* 2015). In addition to substantial symptom burden, prostate cancer survivors' supportive care needs are frequently not met (Steginga *et al.* 2001; Lintz *et al.* 2003; Smith *et al.* 2007; Chambers *et al.* 2015a,b; Watson *et al.* 2015). Up to one half of men report ongoing unmet sexuality, psychological, and health system and information needs after prostate cancer treatment (Steginga *et al.* 2001; Lintz *et al.* 2003; Smith *et al.* 2007; Bernat *et al.* 2015; Watson *et al.* 2015).

Problematically, although prior studies suggest that men access health care services (Holden *et al.* 2005, 2006) at similar frequencies to women (Hourani *et al.* 2016), they often do not actively seek help (or receive treatment) for the full range of their concerns (Addis & Mahalik 2003; Shabsigh *et al.* 2004; Galdas *et al.* 2005; Steginga *et al.* 2008; Forsythe *et al.* 2013; Hyde *et al.* 2016; Yousaf *et al.* 2015) unless prompted to do so by a partner or a direct enquiry from a health professional (Holden *et al.* 2006). In particular, men with prostate cancer are less likely to discuss their social and emotional concerns with health care providers compared to women with breast cancer (Forsythe *et al.* 2013). Reasons for men's hesitancy to seek help may include under-reporting of emotional, physical or sexual concerns (Kunkel *et al.* 2000; Holden *et al.* 2006; Bernat *et al.* 2015; Yousaf *et al.* 2015); somatisation of mental health symptoms (Kockler & Heun 2002; Fiske *et al.*

2009); self-reliance and a desire to maintain a sense of normalcy (Gray *et al.* 2000; Yousaf *et al.* 2015); concerns about burdening others (Gray *et al.* 2000); discomfort or embarrassment (Yousaf *et al.* 2015); being less well educated or unaware (Dunn *et al.* 1999); and preference for self-management (Klafke *et al.* 2014). However, although recent studies have identified the symptom burden and supportive care needs of prostate cancer survivors and the factors that contribute to these (Smith *et al.* 2000; McDowell *et al.* 2010, 2011; Bernat *et al.* 2015; Gavin *et al.* 2015; Watson *et al.* 2015), patterns of help-seeking in this population to address unmet needs are less well described (Neese *et al.* 2003; Hyde *et al.* 2016). Rutten *et al.* (2005) propose that cancer patient's unmet needs and sources of support should be examined with specific reference to cancer survivorship stage (e.g., diagnosis, treatment, post-treatment) in order to be responsive to context. For prostate cancer survivors, unmet supportive care needs are highest close to the time of treatment (Smith *et al.* 2007; Harrison *et al.* 2009). Accordingly, we describe men's patterns of help-seeking in the first year after prostate cancer treatment, their unmet supportive care needs and from this examine factors related to help-seeking in the context of unmet need.

## METHODS

### Recruitment

Men who were diagnosed with localised prostate cancer in the state of Queensland, Australia were recruited between September 2011 and November 2012 via the Queensland Cancer Registry as part of a randomised controlled trial that is ongoing (Chambers *et al.* 2011; Galvão *et al.* 2015). Men were eligible for the trial if they had undergone/were undergoing prostate cancer treatment; could read and speak English; had no prior history of head injury, dementia or current psychiatric illness; had no concurrent cancer; and received clearance to participate from their physician. This study reports cross-sectional baseline data from a sub-group of men drawn from the larger population-based cohort who were in the first year after diagnosis and had received treatment. The study was approved by the Griffith University Human Research Ethics Committee and human research ethics committees of hospitals across Queensland. All participants provided written informed consent.

### Measures

Baseline assessment occurred via computer-assisted telephone interview using previously validated and reliable

self-report measures (Chambers *et al.* 2011; Galvão *et al.* 2015).

#### *Help-seeking and sources accessed*

Help-seeking for prostate cancer-related concerns since diagnosis was assessed using a self-report yes/no measure. Type of help sought was measured with a prompted list on which men indicated all resources (e.g. Internet, brochures/books) and sources of support (e.g. doctor, nurse/other health professional, family/friends, support group) they had accessed for their concerns since diagnosis (McDowell *et al.*, 2011; Hyde *et al.* 2016). An open-ended response option was provided for men to indicate if they had used a resource or source of support that was not listed.

#### *Unmet supportive care needs*

The Supportive Care Needs Survey Short Form-34 (SCNS-SF34) measured men's need for help across psychological, health systems and information, patient care and support, physical and daily living, and sexuality domains (Boyes *et al.* 2009). A previously validated eight-item prostate cancer-specific module was also included to assess urinary, bowel, hormone and masculinity-related sexuality (e.g. feeling like you've lost part of your manhood) needs (Steginga *et al.* 2001). Items were rated 1 (no need/not applicable), 2 (need was satisfied), 3 (low need), 4 (moderate need) or 5 (high need).

#### *Disease-specific quality of life*

The domain summary scores from the Expanded UCLA Prostate Index Composite (EPIC) was applied to measure disease-specific quality of life for urinary ( $\alpha = 0.85$ ), bowel ( $\alpha = 0.87$ ), sexual ( $\alpha = 0.89$ ) and hormonal ( $\alpha = 0.69$ ) function (Litwin *et al.* 1998; Wei *et al.* 2000). Scores for each domain were transformed to a 0–100 scale with higher scores indicating better functioning.

#### *Distress*

The Brief Symptom Inventory-18 (BSI-18) including subscales of anxiety ( $\alpha = 0.73$ ), depression ( $\alpha = 0.86$ ) and somatisation ( $\alpha = 0.67$ ) and a Global Severity Index (GSI) ( $\alpha = 0.88$ ) assessed psychological distress (Derogatis & Lopez 2000). Men reported the degree of distress experienced for each symptom in the week prior to assessment, scored 0 (not at all) to 4 (extremely), with higher scores indicating greater distress. Raw

scores were converted to standardised *t*-scores to identify men with clinically significant symptoms (Chambers *et al.* 2014). Consistent with previous studies of cancer patients, caseness was identified using a cut-off *t*-score  $\geq 57$  on the BSI-18 GSI or on at least two of the BSI-18 subscales (Zabora *et al.* 2001; Chambers *et al.* 2014).

#### **Statistical analysis**

Descriptive statistics were calculated for socio-demographic and treatment characteristics, and to describe psychological distress, disease-specific quality of life, unmet supportive care needs, help-seeking and sources of help accessed. For men who expressed some level of need (scored  $\geq 3$ ) overall and in each SCNS-SF34 domain (except patient care and support because too few men reported an unmet need on this domain), logistic regression was used to examine associations between help-seeking and the following variables: age, education, months since diagnosis, hormone treatment; BSI-18 somatic, depression, anxiety subscales; and EPIC urinary, bowel and sexual domain summary scores. The hormone summary score was not included in the analysis due to the small number of men who received ADT. Logistic regressions were also conducted to examine associations between the variables specified above and supportive care needs (except patient care and support).

## **RESULTS**

### **Recruitment and participant characteristics**

Initially, 1899 patients were identified as potentially eligible for the trial and of these, 1770 doctors were contacted for permission to recruit their patients of whom 88.4% ( $n = 1564$ ) gave consent to do so. Six hundred and seventy-nine of 1501 patients contacted agreed to participate, of which 463 met eligibility criteria, gave consent and completed baseline assessment (Galvão *et al.* 2015). Within this group, 331 patients were in the first year after diagnosis and had received treatment for localised prostate cancer. Analyses in this study are based on data from this sub-group of men.

Mean age of men was 64.5 years (median = 65.0; SD = 7.6). Most were in a relationship (86%), educated at university/college (25%) or trade/technical (38%) level, and just over half had an income  $\geq$  AUD \$60 000. Men were within the first 12 months of diagnosis (M = 9.6 months; median = 10.0; SD = 1.9). Men had received treatment approximately 6 months prior to the study (M = 6.4 months; median = 6.8; SD = 2.5), and

**Table 1.** Patient socio-demographic and treatment characteristics and EPIC domain summary scores ( $N = 331$ )

Characteristics	Mean (SD)/range or %
Age (years)	64.5 (7.6)/44–89
Education (highest level completed)	
University or college degree	25.4
Trade/technical certificate/diploma	38.4
Senior high school	10.0
Junior high school	19.9
Primary school	6.0
Did not complete primary school	0.3
Marital status	
Married	81.6
Defacto	3.9
Divorced/separated	4.5
Widowed	1.2
Single	8.8
Gross household income (AUD)	
< \$20 000	11.2
\$20 000 to \$39 999	23.0
\$40 000 to \$59 999	14.2
\$60 000 to \$79 999	12.7
\$80 000+	35.6
Don't know/unwilling to answer	3.3
Months since diagnosis	9.6 (1.9)/2.9–12.5
Months since treatment	6.4 (2.5)/0.1–11.3
Treatment received	
Radical prostatectomy	68.9
EBRT with ADT	13.0
EBRT without ADT	2.7
Brachytherapy with ADT	2.1
Brachytherapy without ADT	5.4
EBRT & Brachytherapy with ADT	1.5
ADT only	2.7
Other	3.6
EPIC domain summary scores	
Urinary	85.3 (15.6)
Bowel	93.1 (11.0)
Hormonal	80.6 (13.9)
Sexual	36.0 (22.6)

ADT, androgen deprivation therapy; AUD, Australian dollars; EBRT, external beam radiation therapy; EPIC, expanded prostate cancer incidence composite.

most (68%) were treated with radical prostatectomy (Table 1).

### Disease-specific quality of life

Table 1 reports EPIC domain summary scores and of these men reported few difficulties in the areas of urinary and bowel function and hormonal effects. By contrast, sexual function scores were lower. Specifically, 41% of men considered their sexual function to be a moderate/big problem in the month prior to baseline assessment; with 14.2% and 4.5% reporting urinary and bowel dysfunction, respectively, to be a moderate/big problem in the same time frame. Sixty-four men received ADT and of these approximately 10% identified hot flushes,

depression and body weight as a moderate/big problem. Lack of energy was a moderate/big problem for 22% of these men.

### Psychological distress

The standardised mean BSI GSI was 45.5 (SD = 8.5, range 36–72), with mean subscale scores of 47.4 for somatisation (SD = 6.8, range 42–81), 46.3 for depression (SD = 7.2, range 42–77) and 45.2 for anxiety (SD = 7.5, range 39–72). Forty-two men (12.7%) were identified as reaching high distress using the cut-off specified ( $t$ -score  $\geq 57$ ).

### Unmet supportive care needs

Overall, 82% of men had some (low, moderate or high) level of need across any supportive care need domains. Of these, over half had concerns about sexuality (58%) and prostate cancer-specific needs (57%) that were not addressed. Approximately, half reported psychological (47%) and physical and daily living (41%) needs, and less than one-third had health system and information (31%) or patient care and support (17%) needs. Moderate–high need was expressed most frequently on sexuality (40%) and prostate cancer-specific (34%) domains (Table 2). The top 10 items for which men reported moderate to high unmet needs are described in Table 2. Of these, sexuality needs caused the most concern or discomfort with approximately one-third of men reporting they needed help with changes in sexual feelings and relationships and their sense of masculinity (feeling like a man). Physical needs, particularly not being able to do things as before, lack of energy/tiredness, and urinary incontinence were moderate–high concerns for  $\geq 10\%$  of men. Men also expressed moderate–high need for help with their own (10%) or close others' (12%) psychological well-being, and their feelings of uncertainty about the future (9%). A moderate–high information need regarding being informed about things to do to get well was reported by 9% of men. Table 3 shows that men who experienced increased anxiety or somatic symptoms and were treated with ADT (vs. not treated) were more likely to express unmet supportive care needs across a range of need areas. Better outcomes on sexual, urinary and bowel domains and older age were associated with less unmet needs (Table 3). Education and months since diagnosis were not related to unmet needs.

### Help-seeking and sources of support accessed

Overall, 94% of men reported that they had accessed resources and/or support for their prostate cancer-related

**Table 2.** Supportive care needs domains and items (SCNS SF-34) (*N* = 331)

Supportive care needs*†	Some need %	No need or need satisfied %	Low need %	Moderate-high need %
Physical and daily living need	40.5	59.5	18.1	22.4
Not being able to do the things you used to do	24.8	75.2	10.3	14.5‡
Lack of energy/tiredness	24.8	75.2	14.8	10.0‡
Feeling unwell a lot of the time	8.7	91.3	3.0	5.7
Work around the home	8.5	91.5	4.9	3.6
Pain	6.6	93.4	3.0	3.6
Psychological need	47.1	52.9	23.0	24.1
Concerns about the worries of those close to you	23.0	77.0	11.2	11.8‡
Fears about the cancer spreading	21.5	78.5	12.7	8.8
Uncertainty about the future	21.1	78.9	12.1	9.0‡
Feeling down or depressed	17.5	82.5	7.3	10.2‡
Anxiety	15.7	84.3	7.3	8.4
Feelings of sadness	15.4	84.6	7.8	7.6
Worry that the results of treatment are beyond your control	14.2	85.8	7.3	6.9
Learning to feel in control of your situation	12.4	87.6	6.9	5.5
Feelings about death or dying	9.1	90.9	5.8	3.3
Keeping a positive outlook	8.2	91.8	3.9	4.3
Health system and information need	30.8	69.2	10.3	20.5
Being informed about things you can do to help yourself get well	14.5	85.5	5.5	9.0‡
Having one member of staff with whom you can talk to about all aspects of your condition, treatment and follow-up	13.0	87.0	4.5	8.5
Having access to professional counselling (e.g. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	10.9	89.1	4.5	6.4
Being given information (written, diagrams, drawings) about aspects of managing your illness and side effects at home	9.4	90.6	4.2	5.2
Being given explanations of those tests for which you would like explanations	9.1	90.9	3.6	5.5
Being adequately informed about cancer which is under control or diminishing	8.8	91.2	2.4	6.4
Being adequately informed about the benefits and side effects of treatments before you choose to have them	8.5	91.5	2.4	6.1
Being informed about your test results as soon as feasible	7.3	92.7	2.1	5.2
Being given written information about the important aspects of your care	5.8	94.2	1.6	4.2
Being treated like a person not just another case	5.7	94.3	1.8	3.9
Being treated in a hospital or clinic that is as physically pleasant as possible	3.6	96.4	2.1	1.5
Patient care and support need	16.7	83.3	6.7	10.0
Reassurance by medical staff that the way you feel is normal	8.5	91.5	4.3	4.2
More choice about which cancer specialists you see	6.4	93.6	1.8	4.6
More choice about which hospital you attend	6.1	93.9	2.1	4.0
Hospital staff attending promptly to your physical needs	5.4	94.6	2.7	2.7
Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	2.4	97.6	0.6	1.8
Sexuality need	58.0	42.0	17.8	40.2
Changes in sexual feelings	47.7	52.3	18.7	29.0‡
Changes in sexual relationships	41.4	58.6	13.0	28.4‡
To be given information about sexual relationships	19.9	80.1	9.0	10.9‡
Prostate cancer-specific need	57.4	42.6	23.0	34.4
Feeling like you've lost part of your manhood	38.1	61.9	16.0	22.1‡
Urinary incontinence	26.0	74.0	12.7	13.3‡
Problems with your bowel habits	11.5	88.5	4.8	6.7
Hot flushes§	6.9	93.1	3.1	3.8
Difficulties in passing urine	6.6	93.4	3.6	3.0

**Table 2.** *Continued*

Supportive care needs*†	Some need %	No need or need satisfied %	Low need %	Moderate–high need %
Feeling that what you say is not taken seriously by others	9.4	90.6	4.5	4.9
Feeling as if you are going through a change of life like women do‡	3.4	96.6	1.1	2.3
Feeling like you have lost the ability to be aggressive	2.4	97.6	1.2	1.2

\*Level of need for help in the last month.

†Need was scored 1–2 = no need/need satisfied, 3 = some need, 4–5 = moderate–high need.

‡Top 10 moderate–high supportive care need.

§ $n = 262$  (69 men receiving androgen deprivation therapy were excluded).

concerns. Excluding resources accessed, 79.5% reported seeking support while 20.5% did not access any form of support. Breaking this down further to examine seeking support from a health professional (doctor, nurse, counselling, or cancer helpline), 61% reported seeking support while 39% did not seek any support from health professional(s) for prostate cancer-related concerns. The most common resources accessed were brochures or books from the doctor (78%) and the Internet (53%). Sources of support most frequently accessed by men since their prostate cancer diagnosis were a doctor (51%) and family or friends (48%). Local nurse counsellors, cancer helpline, and counselling services and libraries were rarely accessed. While prostate cancer support group use was not high, it was substantially more than other types of counselling services (Table 4).

### Associations between help-seeking and unmet supportive care needs

Associations between socio-demographic and treatment characteristics, disease-specific quality of life, psychological distress, and help-seeking for men who had some level of need overall and on each supportive care needs domain were examined and results of the logistic regressions are displayed in Table 5. Men who expressed *some level of need overall* ( $n = 272$ ) were less likely to seek help if they were older (OR 0.94, CI 0.89–0.99), limited to high school (OR 0.25, CI 0.09–0.74) or primary school (OR 0.07, CI 0.02–0.28) level education and had increased depression symptoms (OR 0.83, CI 0.70–0.98). Being older (OR 0.88, CI 0.80–0.98) and those limited to primary school level education (OR 0.14, CI 0.02–0.90) were associated with a lower likelihood of seeking help for *physical and daily living needs*. Men who had *psychological or health system and information needs* were less likely to seek help if they had not progressed beyond primary school level education (OR<sub>Psychological</sub> 0.09, CI 0.02–0.51; OR<sub>HealthSystInfo</sub> 0.06, CI 0.01–0.64) and increased depression symptoms

(OR<sub>Psychological</sub> 0.71, CI 0.57–0.87; OR<sub>HealthSystInfo</sub> 0.77, CI 0.60–1.00). As well, there was a trend for older men with unmet health system and information needs to seek help less often (0.91, CI 0.83–1.00,  $P = 0.057$ ). Men with unmet *sexuality needs* were less likely to seek help if they were educated at high school (OR 0.24, CI 0.07–0.90) or primary school (OR 0.10, CI 0.02–0.57) level, more time had passed since diagnosis (OR 0.72, CI 0.53–0.97), they experienced more depression symptoms (OR 0.81, CI 0.66–1.00), and had better bowel function (OR 0.93, CI 0.87–1.00,  $P = 0.056$ ), with help-seeking also associated with better sexual function (OR 1.03, CI 1.00–1.06). Being older (OR 0.92, CI 0.86–0.99), educated not further than primary school level (OR 0.08, CI 0.02–0.42), and increased depression (OR 0.83, CI 0.68–1.00) were associated with less help-seeking for men with *prostate cancer-specific needs*.

### DISCUSSION

The present study confirms previous research over the past decade showing a high prevalence of unmet supportive care needs in men with localised prostate cancer (Steginga *et al.* 2001; Lintz *et al.* 2003; Smith *et al.* 2007; Watson *et al.* 2015). Hence, despite the development of clinical practice guidelines for men with prostate cancer (National Health and Medical Research Council 2003; American Urological Association 2007; Australian Cancer Network Management of Metastatic Prostate Cancer Working Party 2010; Parker *et al.* 2015) and generic guidelines for psychosocial care in oncology (National Comprehensive Cancer Network 2002; National Breast Cancer Centre and National Cancer Control Initiative 2003; Holland *et al.* 2011), the pattern of need is unremitting and sexuality needs in particular appear intransigent. These findings have implications moving forward given the recent focus on prostate cancer survivorship guidelines (Skolarus *et al.* 2014; Resnick *et al.* 2015) and the observation that knowing what might assist men and actually

**Table 3.** Factors associated with unmet supportive care needs in men with prostate cancer (N = 331)

Supportive care needs	Any need		Physical and daily living need		Psychological need		Health system and info need		Sexuality need		Prostate cancer-specific need*	
	OR	(CI 95%)	OR	(CI 95%)	OR	(CI 95%)	OR	(CI 95%)	OR	(CI 95%)	OR	(CI 95%)
Age (years)	0.96	(0.91–1.01)	0.14	0.98 (0.94–1.02)	0.24	<b>0.92 (0.89–0.96)</b>	< <b>0.001</b>	<b>0.95 (0.91–0.99)</b>	<b>0.02</b>	<b>0.92 (0.88–0.96)</b>	< <b>0.001</b>	0.97 (0.93–1.01)
Education												
University/college	Ref.		Ref.		Ref.		Ref.		Ref.		Ref.	
Trade/technical	0.90	(0.42–1.96)	0.79	1.22 (0.64–2.34)	0.54	0.67 (0.36–1.27)	0.22	1.67 (0.83–3.36)	0.15	0.97 (0.51–1.86)	0.92	0.62 (0.32–1.22)
High school	1.38	(0.59–3.22)	0.46	1.30 (0.66–2.59)	0.45	1.20 (0.62–2.31)	0.59	1.52 (0.72–3.21)	0.27	1.08 (0.55–2.13)	0.83	1.41 (0.70–2.84)
Primary school	1.28	(0.40–4.17)	0.69	1.06 (0.33–3.40)	0.92	1.98 (0.62–6.29)	0.25	1.28 (0.39–4.17)	0.69	1.27 (0.38–4.27)	0.70	2.27 (0.59–8.69)
Months since dx	1.09	(0.92–1.30)	0.32	0.95 (0.83–1.09)	0.50	0.98 (0.86–1.12)	0.80	1.07 (0.93–1.24)	0.35	1.13 (0.98–1.30)	0.08	1.06 (0.92–1.23)
ADT												
Absence	Ref.		Ref.		Ref.		Ref.		Ref.		Ref.	
Presence	0.53	(0.21–1.35)	0.18	<b>2.29 (1.13–4.65)</b>	<b>0.02</b>	1.52 (0.75–3.11)	0.25	<b>2.15 (1.05–4.39)</b>	<b>0.04</b>	<b>0.50 (0.25–1.01)</b>	<b>0.06</b>	<b>0.39 (0.18–0.86)</b>
BSI-18												
Somatization	1.28	(0.96–1.71)	0.10	<b>1.24 (1.05–1.48)</b>	<b>0.01</b>	<b>1.29 (1.08–1.54)</b>	<b>0.005</b>	1.09 (0.93–1.28)	0.27	0.89 (0.76–1.04)	0.14	1.08 (0.89–1.30)
Depression	0.93	(0.72–1.20)	0.56	1.02 (0.88–1.19)	0.80	1.09 (0.93–1.28)	0.30	0.96 (0.83–1.11)	0.59	1.00 (0.84–1.18)	0.97	1.01 (0.84–1.21)
Anxiety	<b>1.44 (1.00–2.08)</b>		<b>0.05</b>	1.17 (0.97–1.40)	0.10	1.08 (0.89–1.30)	0.44	<b>1.20 (1.01–1.43)</b>	<b>0.04</b>	1.18 (0.95–1.45)	0.13	1.24 (0.98–1.56)
EPIC												
Urinary	0.98	(0.95–1.01)	0.17	<b>0.98 (0.96–1.00)</b>	<b>0.02</b>	1.00 (0.98–1.02)	0.68	<b>0.97 (0.96–0.99)</b>	<b>0.006</b>	1.00 (0.98–1.02)	0.81	<b>0.95 (0.93–0.98)</b>
Bowel	0.96	(0.90–1.03)	0.30	<b>0.95 (0.92–0.99)</b>	<b>0.01</b>	0.98 (0.94–1.01)	0.19	0.99 (0.96–1.02)	0.56	0.97 (0.93–1.00)	0.07	<b>0.95 (0.91–1.00)</b>
Sexual	<b>0.97 (0.96–0.99)</b>	< <b>0.001</b>	< <b>0.001</b>	1.00 (0.99–1.02)	0.61	<b>0.99 (0.97–1.00)</b>	<b>0.01</b>	<b>0.98 (0.97–1.00)</b>	<b>0.007</b>	<b>0.96 (0.95–0.98)</b>	< <b>0.001</b>	< <b>0.001</b>

Ref., Reference; ADT, androgen deprivation therapy; dx, diagnosis.

\*The two items that could be confounded with side effects from androgen deprivation therapy were excluded from this scale for analysis (experiencing hot flushes, and going through a change of life like women do). Bolding in the table denotes a statistically significant result.

**Table 4.** Resources and sources of support accessed since diagnosis ( $N = 331$ )

Help accessed	%
<b>Resources</b>	
Brochures or books from doctor	77.6
Internet	52.6
Brochures or books from family/friends	7.3
Library	2.7
<b>Sources of support</b>	
Doctor	50.8
Family/friends	48.0
Nurse/Other health professional	17.8
Prostate cancer support group	7.9
Cancer Helpline	4.5
Counselling service	2.1
Local nurse counsellors	0.0

moving this into practice are different questions (Deane 2014).

In this regard, although men may access health care services and do so more frequently as they age, this may not equate to help-seeking for reproductive health concerns such as erectile dysfunction (Holden *et al.* 2005, 2006). In a population-based study of close to 6000 Australian men, 21% reported moderate to severe erectile dysfunction and of these 30% had spoken to a health professional about their condition, with this proportion decreasing by age (17% of men aged  $\geq 70$  years had discussed their concerns) (Holden *et al.* 2005, 2006). Prostate cancer survivors are also less likely to raise their concerns with health care providers (Forsythe *et al.* 2013), and in particular discuss sexual concerns much less frequently in follow-up care than concerns about urinary or bowel function (Watson *et al.* 2015). This creates a challenge for health professionals in terms of how to best identify men with unmet needs and provide accessible support. As well it indicates a need for health care professionals to initiate discussion with men about sexuality irrespective of whether sexual concerns are expressed (Holden *et al.* 2006; Forsythe *et al.* 2013). The top three sources of support accessed by men in the present study were the medical professional, nurse and to a lesser extent prostate cancer support groups. These three points of support may present as a triad that if well linked and resourced may have the greatest potential for making a difference in men's unmet needs after prostate cancer diagnosis and treatment. Family and friends as a preferred source of support may also help to promote men's awareness and encourage help-seeking from available health and supportive care services (Holden *et al.* 2006; Smith *et al.* 2006). As well, the high utilisation of the Internet points to this as a key resource that could be leveraged to improve access to self-management tools as well as professional support.

Men who were older, less well educated and more depressed were less likely to seek help despite having unmet needs for support. For age, this may relate to masculine values around stoicism and self-reliance that may be more strongly held by older men (Chambers *et al.* 2015a,b) and suggests the importance of continuing to understand the unique challenges faced by specific sub-groups of men. Level of education likely reflects health literacy that is especially problematic given low health literacy is also related to poorer health outcomes (DeWalt *et al.* 2004) and poorer use of health services (Berkman *et al.* 2011). For example, in a population-based study of Australian men, lower levels of functional health literacy were associated with obstructive sleep apnoea and comorbidities including sedentary lifestyle, depression and cardiovascular disease (Li *et al.* 2014). The relationship between higher depression and not seeking help speaks to the need for regular assessment of psychosocial needs (Forsythe *et al.* 2013) including systematic distress screening, rather than waiting for distressed men to self-present (Chambers *et al.* 2014). Finally, help-seeking was associated with better sexual function and this may reflect that men who sought help had better outcomes. Alternatively, it may suggest that men were more likely to seek support for sexuality needs if they had better sexual function. This latter interpretation is consistent with prior research suggesting severity of erectile dysfunction deters help-seeking such that sexuality interventions may require tailoring to sexual function (Hyde *et al.* 2016).

Strengths of this study include a large cohort of men drawn from a population-based cancer registry; the use of valid and reliable measures; and addressing the knowledge-gap regarding associations between supportive care needs and help-seeking. Limitations include the cross-sectional design which precludes inferences about causality, and retrospective self-report assessment of help-seeking. Longitudinal assessment of supportive care needs for men with localised and advanced prostate cancer and their patterns of help-seeking are a key focus for future research.

## CONCLUSION

The diagnosis and treatment of prostate cancer is followed by well-described supportive care needs that are frequently unmet and this was apparent in the current study, particularly for sexuality needs. Few men accessed the range of health professional and community support options available and men with greatest need were least likely to seek support. Older age, lower education, and depression are risk factors for men not seeking help. A new approach to

**Table 5.** Factors associated with help-seeking for unmet supportive care needs in men with prostate cancer

Supportive care needs Factors	Any need (n = 272)		Physical and daily living need (n = 134)		Psychological need (n = 156)		Health system and info need (n = 102)		Sexuality need (n = 192)		Prostate cancer-specific need* (n = 190)	
	OR [CI 95%]	P	OR [CI 95%]	P	OR [CI 95%]	P	OR [CI 95%]	P	OR [CI 95%]	P	OR [CI 95%]	P
Age (years)	<b>0.94 (0.89–0.99)</b>	<b>0.03</b>	<b>0.88 (0.80–0.98)</b>	<b>0.02</b>	0.92 (0.85–1.01)	0.10	<b>0.91 (0.83–1.00)</b>	<b>0.06</b>	0.95 (0.88–1.03)	0.20	<b>0.92 (0.86–0.99)</b>	<b>0.03</b>
Education	Ref.		Ref.		Ref.		Ref.		Ref.		Ref.	
University/college	0.38 (0.13–1.14)	0.09	0.58 (0.11–2.93)	0.51	0.66 (0.15–2.89)	0.58	0.43 (0.07–2.69)	0.37	0.69 (0.17–2.80)	0.61	0.31 (0.08–1.27)	0.10
Trade/technical	<b>0.25 (0.09–0.74)</b>	<b>0.01</b>	0.67 (0.12–3.74)	0.65	0.68 (0.16–2.84)	0.59	0.28 (0.04–1.73)	0.17	<b>0.24 (0.07–0.90)</b>	<b>0.03</b>	0.32 (0.08–1.28)	0.11
High school	<b>0.07 (0.02–0.28)</b>	< <b>0.001</b>	<b>0.14 (0.02–0.90)</b>	<b>0.04</b>	<b>0.09 (0.02–0.51)</b>	<b>0.007</b>	<b>0.06 (0.01–0.64)</b>	<b>0.02</b>	<b>0.10 (0.02–0.57)</b>	<b>0.009</b>	<b>0.08 (0.02–0.42)</b>	<b>0.003</b>
Primary school	0.92 (0.76–1.10)	0.36	0.99 (0.74–1.32)	0.95	0.98 (0.75–1.28)	0.88	0.74 (0.53–1.05)	0.09	<b>0.72 (0.53–0.97)</b>	<b>0.03</b>	0.96 (0.77–1.21)	0.75
Months since dx												
ADT	Ref.		Ref.		Ref.		Ref.		Ref.		Ref.	
Absence	0.82 (0.34–2.01)	0.67	0.85 (0.22–3.19)	0.80	0.49 (0.14–1.76)	0.27	0.98 (0.21–4.65)	0.98	0.42 (0.12–1.50)	0.18	0.92 (0.29–2.90)	0.88
Presence												
BSI-18												
Somatization	1.11 (0.90–1.36)	0.32	1.23 (0.89–1.70)	0.20	1.08 (0.83–1.42)	0.56	1.35 (0.92–1.97)	0.12	1.04 (0.75–1.44)	0.81	1.17 (0.89–1.54)	0.25
Depression	<b>0.83 (0.70–0.98)</b>	<b>0.03</b>	0.93 (0.74–1.17)	0.51	<b>0.71 (0.57–0.87)</b>	<b>0.001</b>	<b>0.77 (0.60–1.00)</b>	<b>0.05</b>	<b>0.81 (0.66–1.00)</b>	<b>0.05</b>	<b>0.83 (0.68–1.00)</b>	<b>0.05</b>
Anxiety	1.09 (0.86–1.40)	0.47	0.88 (0.64–1.22)	0.45	1.28 (0.91–1.80)	0.15	1.23 (0.86–1.78)	0.26	1.10 (0.81–1.50)	0.54	1.07 (0.81–1.41)	0.65
EPIC												
Urinary	1.00 (0.97–1.02)	0.82	1.02 (0.98–1.05)	0.35	1.00 (0.96–1.03)	0.81	1.01 (0.98–1.05)	0.47	0.99 (0.96–1.03)	0.72	1.00 (0.97–1.03)	0.93
Bowel	0.97 (0.93–1.02)	0.20	0.99 (0.94–1.04)	0.65	0.98 (0.92–1.03)	0.39	0.99 (0.94–1.06)	0.93	<b>0.93 (0.87–1.00)</b>	<b>0.06</b>	1.00 (0.95–1.04)	0.79
Sexual	1.00 (0.98–1.02)	0.94	1.00 (0.97–1.04)	0.93	0.98 (0.96–1.01)	0.26	1.00 (0.96–1.04)	0.97	<b>1.03 (1.00–1.06)</b>	<b>0.03</b>	1.01 (0.98–1.03)	0.53

Ref., Reference; ADT, androgen deprivation therapy; dx, diagnosis.

\*The two items that could be confounded with side effects from androgen deprivation therapy were excluded from this scale for analysis (experiencing hot flushes, and going through a change of life like women do). Bolding in the table denotes a statistically significant result.

supportive care for men with prostate cancer seems warranted that links across medicine, nursing and community-based peer support. Future research is needed to establish the optimal mode for intervening to reduce the morbidity associated with this disease.

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## CONFLICT OF INTEREST

The authors have no conflict of interest, including relevant financial interests, activities, relationships and affiliations to declare.

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