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

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**Recommended Citation**

Hyde, M. K., Newton, R., Galvao, D. A., Gardiner, R., Occhipinti, S., Lowe, A., Wittert, G. A., & Chambers, S. K. (2017). Men’s help-seeking in the first year after diagnosis of localised prostate cancer. DOI: [https://doi.org/10.1111/ecc.12497](https://doi.org/10.1111/ecc.12497)

10.1111/ecc.12497

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This journal article is available at Research Online: https://ro.ecu.edu.au/ecuworkspost2013/2531
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 ≤ 0.03), less well educated (P ≤ 0.04) and more depressed (P ≤ 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 ≤ 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.

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).

Proportionally, 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 \(z = 0.85\), bowel \(z = 0.87\), sexual \(z = 0.89\) and hormonal \(z = 0.69\) 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 \(z = 0.73\), depression \(z = 0.86\) and somatization \(z = 0.67\) and a Global Severity Index [GSI] \(z = 0.88\] assessed psychological distress [Derosgatis & 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
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 ≥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 ≥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 |
| 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 |
| Having 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 |

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Table 2. Continued

| Supportive care needs*† | Some need % | No need or need satisfied % | Low need % | Moderate-high need % |
|------------------------|-------------|----------------------------|------------|---------------------|
| Feeling that 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).

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 (ORPsychological 0.09, CI 0.02–0.51; ORHealthSystInfo 0.06, CI 0.01–0.64) and increased depression symptoms (ORPsychological 0.71, CI 0.57–0.87; ORHealthSystInfo 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

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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* |
|----------------------------------------|----------|--------------------------------|--------------------|-----------------------------|--------------|-------------------------------|
| Factors                                | OR [CI 95%] | P                          | OR [CI 95%] | P                          | OR [CI 95%] | P                          | OR [CI 95%] | P                          |
| Age (years)                            | 0.96 [0.91–1.01] | 0.14                      | 0.92 [0.89–0.96] | <0.001                      | 0.92 [0.88–0.96] | <0.001                      | 0.97 [0.93–1.01] | 0.12                      |
| Education                              |          |                             |                    |                             |              |                              |              |                            |
| University/college                     | 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                       |
| 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                       |
| 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                       |
| 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                       |
| ADT                                    |          |                             |                    |                             |              |                              |              |                            |
| Absence                                | Ref.     |                             | Ref.              |                             |              |                              |              |                            |
| Presence                               | 0.53 [0.21–1.35] | 0.18                       | 2.29 [1.13–4.65] | 0.02                       | 1.52 [0.75–3.11] | 0.25                       | 2.15 [1.05–4.39] | 0.04                       |
| BSI-18                                 |          |                             |                    |                             |              |                              |              |                            |
| Somatisation                           | 1.28 [0.96–1.97] | 0.10                       | 1.24 [1.05–1.48] | 0.01                       | 1.09 [1.03–1.54] | 0.005                      | 1.09 [0.93–1.28] | 0.27                       |
| Depression                             | 0.98 [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                       |
| Anxiety                                | 1.44 [1.00–2.08] | 0.05                       | 1.17 [0.97–1.40] | 0.10                       | 1.08 [0.89–1.30] | 0.44                       | 1.20 [1.01–1.43] | 0.04                       |
| EPIC                                   |          |                             |                    |                             |              |                              |              |                            |
| Urinary                                | 0.98 [0.95–1.01] | 0.17                       | 0.98 [0.96–1.00] | 0.02                       | 1.00 [0.98–1.02] | 0.68                       | 0.97 [0.96–0.99] | 0.006                      |
| Bowel                                  | 0.96 [0.90–1.03] | 0.30                       | 0.95 [0.92–0.99] | 0.01                       | 0.98 [0.94–1.01] | 0.19                       | 0.99 [0.96–1.02] | 0.56                       |
| Sexual                                 | 0.97 [0.96–0.99] | <0.001                     | 1.00 [0.99–1.02] | 0.61                       | 0.99 [0.97–1.00] | 0.01                       | 0.98 [0.97–1.00] | 0.007                      |

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.
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 4. Resources and sources of support accessed since diagnosis [N = 331]

| Help accessed                  | %  |
|-------------------------------|----|
| Resources                     |    |
| Brochures or books from doctor| 77.6|
| Internet                      | 52.6|
| Brochures or books from family/friends | 7.3 |
| Library                       | 2.7 |
| Sources of support            |    |
| 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 |
Table 5. Factors associated with help-seeking for unmet supportive care needs in men with prostate cancer

| Supportive care needs | 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] |
|-----------------------|--------------------|------------------------------------------|-----------------------------|--------------------------------------|--------------------------|---------------------------------------|
| **Age (years)**       | 0.94 (0.89–0.99)   | 0.88 (0.80–0.98)                          | 0.92 (0.85–1.01)            | 0.91 (0.83–1.00)                     | 0.95 (0.88–1.03)         | 0.92 (0.86–0.99)                       |
| **Education**         |                    |                                          |                             |                                      |                          |                                       |
| University/college    | Ref.               | Ref.                                     | Ref.                        | Ref.                                 | Ref.                     | Ref.                                  |
| Trade/technical       | 0.38 (0.13–1.14)   | 0.58 (0.11–2.93)                          | 0.66 (0.15–2.89)            | 0.43 (0.07–2.69)                     | 0.69 (0.17–2.80)         | 0.31 (0.08–1.27)                       |
| High school           | 0.25 (0.09–0.74)   | 0.67 (0.12–3.74)                          | 0.68 (0.16–2.84)            | 0.28 (0.04–1.73)                     | 0.24 (0.07–0.90)         | 0.32 (0.08–1.28)                       |
| Primary school        | 0.07 (0.02–0.28)   | < 0.001                                  | 0.09 (0.02–0.51)            | 0.06 (0.01–0.64)                     | 0.10 (0.02–0.57)         | 0.08 (0.02–0.42)                       |
| Months since dx       | 0.92 (0.76–1.10)   | 0.99 (0.74–1.32)                          | 0.98 (0.75–1.28)            | 0.74 (0.53–1.05)                     | 0.72 (0.53–0.97)         | 0.96 (0.77–1.21)                       |
| ADT                   |                    |                                          |                             |                                      |                          |                                       |
| Absence               | Ref.               | Ref.                                     | Ref.                        | Ref.                                 | Ref.                     | Ref.                                  |
| Presence              | 0.82 (0.34–2.01)   | 0.85 (0.22–3.19)                          | 0.49 (0.14–1.76)            | 0.98 (0.21–4.65)                     | 0.42 (0.12–1.50)         | 0.92 (0.29–2.90)                       |
| BSI-18                |                    |                                          |                             |                                      |                          |                                       |
| Somatisation          | 1.11 (0.90–1.36)   | 1.23 (0.89–1.70)                          | 1.08 (0.83–1.42)            | 1.35 (0.92–1.97)                     | 1.04 (0.75–1.44)         | 1.17 (0.89–1.54)                       |
| Depression            | 0.83 (0.70–0.98)   | 0.93 (0.74–1.17)                          | 0.71 (0.57–0.87)            | 0.77 (0.60–1.00)                     | 0.81 (0.66–1.00)         | 0.83 (0.68–1.00)                       |
| Anxiety               | 1.09 (0.86–1.40)   | 0.88 (0.64–1.22)                          | 1.28 (0.91–1.80)            | 1.23 (0.86–1.78)                     | 1.10 (0.81–1.50)         | 1.07 (0.81–1.41)                       |
| EPIC                  |                    |                                          |                             |                                      |                          |                                       |
| Urinary               | 1.00 (0.97–1.02)   | 1.02 (0.98–1.05)                          | 1.00 (0.96–1.03)            | 1.01 (0.98–1.05)                     | 0.99 (0.96–1.03)         | 1.00 (0.97–1.03)                       |
| Bowel                 | 0.97 (0.93–1.02)   | 0.99 (0.94–1.04)                          | 0.98 (0.92–1.03)            | 0.99 (0.94–1.06)                     | 0.93 (0.87–1.00)         | 1.00 (0.95–1.04)                       |
| Sexual                | 1.00 (0.98–1.02)   | 1.00 (0.97–1.04)                          | 0.98 (0.96–1.01)            | 1.00 (0.96–1.04)                     | 1.03 (1.00–1.06)         | 1.01 (0.98–1.03)                       |

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.

ACKNOWLEDGEMENTS

This project was funded by Cancer Australia and beyond-blue [ID APP1008320]. SKC had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. The sponsors did not participate in the design or conduct of the study; collection, management, analysis and interpretation of the data; or in the preparation, review or approval of the manuscript. DAG is funded by a Movember New Directions Development Award from Prostate Cancer Foundation of Australia and Cancer Council Western Australia Research Fellowship. SKC is an Australian Research Council Future Fellow; and AG by a Cancer Institute NSW grant. We gratefully acknowledge the support of the Urological Society of Australia and New Zealand; of Mr Bill McHugh, Mr Spence Broughton and Mr Peter Dorman as consumer advisors; and of Ms Brigid Hanley and Ms Sylvia Burns as prostate cancer nurse advisors in the undertaking of this research. We also thank and acknowledge Ms Anna Stiller for research assistance.

CONFLICT OF INTEREST

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

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