



Identifying the unmet supportive care needs of men living with and beyond prostate cancer: A systematic review



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A B S T R A C T

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Purpose: Men affected by prostate cancer are a patient population in need of on-going person-centred supportive care. Our aim was to synthesise current available evidence with regard to the unmet supportive care needs of men living with and beyond prostate cancer.

Methods: A systematic review was conducted according to the PRISMA Statement Guidelines. Electronic databases (DARE, Cochrane MEDLINE, BNI, PsychINFO, EMBASE and CINAHL) were searched to identify studies employing qualitative and/or quantitative methods. Methodological evaluation was conducted, and findings were integrated in a narrative synthesis.

Results: 7521 references were retrieved, 17 articles met the eligibility criteria. Individual needs were classified into the following domains: social needs (2/17: 11.8%), spiritual needs (4/7: 23.5%), practical needs (4/17: 23.5%), daily living needs (5/17: 29.4%), patient-clinician communication (5/17: 29.4%), family-related needs (7/17: 41.2%), physical needs (8/17: 47.1%), psychological emotional needs (9/17: 52.9%), interpersonal/intimacy needs (11/17: 64.7%) and health system/Information needs (13/17: 76.5%).

Conclusions: This systematic review has identified that men can experience a range of unmet supportive care needs with the most frequently reported being needs related to intimacy, informational, physical and psychological needs. Despite the emerging evidence-base, the current within study limitations precludes our understanding about how the needs of men evolve over time from diagnosis to living with and beyond prostate cancer. Whether demographic or clinical variables play a moderating role, only remains to be addressed in future studies. This review has made an important contribution by informing clinicians about the complex unmet supportive care needs of men affected by this disease.

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Introduction

Prostate cancer is a significant health burden in Europe and is now the most prevalent type of cancer in men in developed countries (excluding non-melanoma skin cancer) (Jemal et al., 2011). Since the emergence of the Prostate Specific Antigen Test (PSA) in the 1980's, the rate of prostate cancer diagnosis increased considerably. As the number of men diagnosed with prostate cancer continues to rise, as a consequence, more men will receive treatment and subsequently face the physical and psychological after effects of therapy (Prabhu et al., 2014). The follow-up after treatment for prostate cancer is necessary to monitor progression

of the disease or to detect recurrence, assess any adverse effects of treatment and to offer supportive care for any physical or psychosocial needs (Vieira et al., 2014). Up until now, the follow-up care for patients with prostate cancer after treatment has been traditionally led by secondary care. However, as the number of men living with and beyond prostate cancer increases (Røder et al., 2014), currently 250,000 men affected by this disease in the UK (Prostate Cancer UK, 2014), alternative models of follow-up care are being considered (Cowie et al., 2012; Ream et al., 2009; Vieira et al., 2014). Moreover, guidance from the National Institute for Clinical Excellence recommends that for patients undergoing active surveillance or watchful waiting, and for those patients with a stable PSA after at least 2 years who have had no significant treatment complications to consider follow-up outside of the hospital (for example, in primary care) (NICE, 2014). However, there is a dearth

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of evidence on the optimum delivery of supportive care for men affected by this disease (O'Brien et al., 2010).

In the UK, the Improving Outcomes Strategy for Cancer (Department of Health, 2013) recognises that not enough attention has been given to the long-term consequences of a cancer diagnosis, the need to maximise service delivery for the ever increasing number of individuals surviving the disease, or how to enable individuals to return to active lives following the completion of initial cancer treatment. The Survivorship Initiative has set out to understand the needs of those living with cancer and to develop models of care that meet their needs, with the goal being to support cancer survivors to live as healthy and active a life as possible, for as long as possible (Davies and Batehup, 2009; Richards et al., 2011).

Supportive care is a person-centred approach to the provision of the necessary services for those living with or affected by cancer to meet their informational, spiritual, emotional, social, or physical needs during diagnosis, treatment, or follow-up phases including issues of health promotion and prevention, survivorship, palliation and bereavement (Carter et al., 2014; Hui, 2014; Rittenberg et al., 2010). Whilst the physical and psychological sequelae of prostate cancer and its associated treatments have been well-documented (e.g. urinary, bowel, and sexual dysfunction, pain, fatigue, spinal cord compression, hot flashes, difficulties with self-image and masculinities) little is known about men's perceptions about the impact of these on their lives, and the areas in which they most require assistance (Hashine et al., 2014; Prabhu et al., 2014; van Tol-Geerdink et al., 2013; Waller and Pattison, 2013). One approach to quality of life evaluation that assesses supportive care requirements is needs assessment (Bonevski et al., 2000).

Supportive care needs can be defined as requirements for care arising during treatment and illness to manage symptoms and side-effects, enable adaption and coping, optimise understanding and informed decision-making, and minimise decrements in functioning (Ream et al., 2008). Therefore, identifying and addressing such needs for men affected by prostate cancer can prevent patient distress, improve quality of life and improve overall satisfaction with care (Carter et al., 2011), whilst reducing healthcare utilisation and costs (Brown et al., 2001).

There is evidence acknowledging that current care delivery is failing to provide a person-centred follow-up in this patient group (Richards et al., 2011) as men have voiced a number of unmet needs including: unmet informational needs (Carter et al., 2011; Cockle-Hearne et al., 2013, 2012), enduring urological symptoms (Steginga et al., 2001), psychological problems (O'Brien et al., 2010; Ream et al., 2008) and sexual needs (Carter et al., 2011; Mason, 2008). In an era of limited healthcare resources it is a prerequisite to understand the evidence in relation to the unmet supportive care needs of service users to enable resources to be effectively targeted, with the ultimate goal of optimising the quality of care, and patients' quality of life (Richards et al., 2011).

Therefore the aim of this systematic review was to synthesise current available evidence with regards to the unmet supportive care needs of men living with and beyond prostate cancer, driven by the following research questions:

1. What is the current evidence with regards to the different domains of unmet supportive care needs in men living with prostate cancer?
2. What are the most frequently reported individual domains of unmet need in the current available literature?

Methods

This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-

Analyses (PRISMA) guidelines published in 2009 (Moher et al., 2009).

Search strategy

The following electronic databases were searched: DARE, Cochrane, MEDLINE, BNI, PsychINFO, and EMBASE following a two-step systematic search strategy to identify studies adopting a qualitative and/or quantitative methodology. The search architecture used a wide range of keywords and free text items to increase the sensitivity and inclusiveness of the searches (see Table 1).

Inclusion and exclusion criteria were applied to all records identified. The electronic searches began on 15th September 2014 and concluded on the 15th of October 2014. All records were managed using the software package Endnote X4. The following pre-selection criteria were applied to all records.

Inclusion Criteria

- Studies investigating the unmet/supportive care needs of men with prostate cancer irrespective of disease stage, treatment modality, or time since diagnosis
- Qualitative and quantitative methods irrespective of research design
- Studies published in the English language
- Studies conducted with adults (≥ 18 years old)
- Studies published in peer-reviewed journals between 1990 and 2014

Exclusion Criteria

- Studies testing the psychometric properties of Supportive Care Needs Questionnaires.
- Studies where unmet/supportive care needs were not explicitly reported.
- Studies conducted with patients with mixed cancer groups, except when separate sub-group analyses were reported.

Study selection and data extraction procedures

The publications (titles and abstracts) were reviewed independently by members of the research team using a pro forma checklist to make decisions to include or not to include studies, based on the inclusion/exclusion criteria. All articles which met the inclusion criteria were retrieved in full-text. Any disagreements were resolved through discussion. Data extraction tables were specifically developed for this review, pilot tested on three randomly selected studies of the final sample, and subsequently refined as necessary (Centre for Reviews and Dissemination, 2008; The Cochrane Collaboration, 2009). One author extracted data from the final sample of studies. The included studies were subject to a quality appraisal conducted by the review team to inform the suitability of each individual study in the results synthesis based upon methodological quality.

Quality appraisal

Methodological quality evaluation was conducted using the two quality appraisal tools, one quantitative appraisal tool and one qualitative appraisal tool (Shaw et al., 2009) which enabled a plethora of methodologies to be evaluated. The quality appraisal tools have been used in a variety of systematic reviews, including prostate cancer (Paterson et al., in press, 2013). The quantitative appraisal tool assessed a range of designs including: RCT's, non-RCT, cohort, case-control, observational (for example, multiple

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