European Journal of Oncology Nursing 30 (2017) 48-58

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Routes to diagnosis for men with prostate cancer: men's cultural beliefs about how changes to their bodies and symptoms influence help-seeking actions. A narrative review of the literature



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ARTICLE INFO

Article history: Received 7 April 2017 Received in revised form 16 June 2017 Accepted 21 June 2017

Keywords: Men Prostate cancer Beliefs Appraisal Help-seeking Ethnicity Culture

ABSTRACT

Purpose: To examine the findings of existing studies in relation to men's cultural beliefs about changes to their bodies relevant to prostate cancer and how these affect interpretation of bodily changes and help-seeking actions.

Method: We undertook a narrative review of studies conducted from 2004 to 2017 in 6 databases that highlighted men's beliefs and help-seeking actions for bodily changes suggestive of prostate cancer.

Results: Eighteen (18) studies reflecting men from various ethnicities and nationalities were included. The belief that blood and painful urination were warning signs to seek medical help delayed help-seeking among men compared to men that did not experience these symptoms. The belief that urinary symptoms such as dribbling, cystitis and urinary hesitancy were transient and related to ageing, normality and infection significantly delayed symptom appraisal and help-seeking. Men also held the belief that sexual changes, such as impotence and ejaculation dysfunction were private, embarrassing and a taboo. These beliefs impeded timely help-seeking. Cultural beliefs, spirituality and the role of wives/partners were significant for men to help appraise symptoms as requiring medical attention thus sanctioning the need for help-seeking.

Conclusions: This review underscores a critical need for further empirical research into men's beliefs about bodily changes relevant to prostate health and how these beliefs affect their interpretation of symptoms and subsequent help-seeking actions.

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1. Introduction

Prostate cancer is the second most common cancer in men and the fifth leading cause of cancer death globally (Globocan, 2012). Unlike other cancers, prostate cancer can be slowly progressive and indolent but also aggressive and so it is difficult to determine the nature of the disease through symptoms until it reaches an advanced stage (Esserman et al., 2014). Global variation in survival between countries is often attributed to the availability of prostate specific antigen (PSA) screening programmes and access to health resources. Evidence of these differences is suggested from migrant studies where individuals moving from a country of low health care provision to that of higher provision have better survival (Moten

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et al., 2014). This may not be the only factor as how men interpret and appraise symptoms and seek help may be different across countries and ethnic groups. A recent independent global online and telephone survey conducted among 867 men with advanced prostate disease and 360 care givers in ten countries from France, Germany, Japan, Italy, Netherlands, Singapore, Spain, Taiwan, UK and USA showed that 68% of men ignored symptoms of advanced prostate cancer, manifested as bone and body pains, numbness and weakness, which significantly delayed help-seeking (The International Prostate Cancer Coalition, 2016). Men from higher risk groups for prostate cancer are those with a family history and from Black African or Caribbean origin (Lloyd et al., 2015). The aforementioned men have a tendency to present to emergency services when symptoms of prostate cancer have reached a stage where they are debilitating and life threatening (Mayer et al., 2011). Understanding the cultural beliefs and perceptions of how men interpret, appraise and seek help is important for understanding factors that impact on risk.



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While there has been considerable research globally on prostate cancer screening among various populations (Lane et al., 2010; Mulhem et al., 2015) and on the general impact of prostate cancer on the health and wellbeing of men and their families (Lim et al., 2013), there remain critical gaps in the research evidence on how to help men recognise symptoms earlier. A recent metasynthesis of qualitative studies on ethnicity and prostate cancer experience highlighted three specific features in health perceptions: the healthcare provider relationship, spirituality and living on for others (Rivas et al., 2016). This review focuses on studies of men's cultural beliefs and ethnic populations, and asks do these themes impact on help-seeking and are Black and Minority Ethnic (BME) groups different to other groups of men who are diagnosed with prostate cancer? This narrative review examines both qualitative and quantitative studies asking the question: how do men's beliefs related to bodily changes including symptom appraisal of prostate cancer affect their interpretation and help-seeking actions, especially from culturally diverse groups.

1.1. Definitions, scope and study aims

Beliefs are socially constructed by individuals in relation to the environment and culture, which are adapted depending on situations and relationships (Radley and Billig, 1996). A disturbance in the body triggers beliefs that are embedded within cultural expectations that enable individuals to interpret these changes as normal or requiring medical attention (Bury, 1982; Radley, 1994). As such, the aim of this review is to explore men's beliefs in relation to symptom appraisal for bodily changes suggestive of prostate cancer and how these affect their help-seeking behaviours and actions. Comparison of cultural and ethnicity differences in help-seeking behaviours are explored across these studies. The pre-diagnosis phase takes into account symptom appraisal and help-seeking. In this review, symptom appraisal is defined as the detection of bodily change(s), attribution to an organ or disease/illness and interpretation/perceptions as needing medical help (Scott et al., 2013). Help-seeking is defined as a decision to seek medical help, schedule an appointment and discuss health concerns/bodily changes with a Health Care Provider (HCP) (Scott et al., 2013).

2. Methods

2.1. Search strategy

Searches were completed using appropriate MESH terms, keywords and subject headings on each abstract. Boolean operators were utilized to capture studies as per eligibility criteria. References cited on papers that met the inclusion criteria were explored for potential inclusion in the review (see Fig. 1). All papers from searches were uploaded into Refworks and EPPI reviewer 4 software. Papers were screened for duplicates and for eligibility. Initially, papers were scanned by looking at the title and abstracts; and subsequently by reading the full text of the article. All three authors studied and discussed articles included for the review. Studies were critiqued using the respective critical appraisal tools and evaluative tool for mixed methods studies as highlighted in the Appendices and presented using The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) tool as seen in Fig. 2. Data were extracted from individual papers and tabulated in accordance to the research question.

3. Results

A total of 18 articles that met the criteria for the review were included (see Table 1). These consisted of 9 qualitative studies

Databases used for narrative review	
CINAHL FULL TEXT	
PsychArticles	
PsychINFO	
MEDLINE	
Psychology & Behavioural Sciences	
PROQUEST	

Inclusion criteria	Exclusion criteria
Studies conducted 2004-2017	Studies prior to 2004
Men from all ethnic groups and	Men with other cancers, partners and
nationalities with self-reported beliefs	health professionals beliefs
related to symptom(s) of prostate	
cancer, including BPH and prostatitis	
Studies with available abstracts	Studies with no abstracts
Studies in English Language	Studies in non English Language

Fig. 1. Outlines the databases and eligibility criteria for the review.

(Anderson et al., 2013; Blocker et al., 2006; Hale et al., 2007; Matthew et al., 2011; Nanton and Dale, 2011; Ng et al., 2013; O'Brien et al., 2005; Shaw et al., 2008; Taghipour et al., 2010), 5 quantitative studies (Apostolidis et al., 2009; Gülpinar et al., 2011; Metcalfe et al., 2008; Shabsigh et al., 2004; Whitaker et al., 2014) and 4 studies that utilized mixed-methods (Emery et al., 2013; Ertel et al., 2016; Place et al., 2011; Sarma et al., 2008). The methodological framework utilized for qualitative studies consisted of interpretive phenomenology, thematic analysis and grounded theory; in which face-to-face and telephone interviews and focus groups were conducted. The quantitative studies utilized largescale surveys, population based cohorts, epidemiological interviews and self-administered questionnaires. The critical appraisal and evaluative tools for mixed methods scoring systems (see supplementary materials) highlighted studies in the review as good or fair. Sample sizes ranged from 7 to 55 men for qualitative studies; 239-1958 for quantitative studies and mixed studies ranged from 14 to 165 men. Of the 18 studies included in the review, 8 were conducted in the UK (Anderson et al., 2013; Metcalfe et al., 2008; Whitaker et al., 2014; O'Brien et al., 2005; Nanton and Dale, 2011; Shaw et al., 2008; Place et al., 2011; Hale et al., 2007), 2 were conducted in the USA (Blocker et al., 2006; Sarma et al., 2008) 1 in the Caribbean (Ng et al., 2013), 1 study in Australia (Emery et al., 2013), 1 in Turkey (Gülpinar et al., 2011), 1 in Iran (Taghipour et al., 2010), 1 in Greece (Apostolidis et al., 2009), 1 in Canada (Matthew et al., 2011) and 2 were conducted in multiple countries (Shabsigh et al., 2004; Ertel et al., 2016). The men were representative of African, Afro-Caribbean, White Caucasian, and Asian ethnicity. Some studies did not identify the ethnicity of the research participants. The ages of men ranged from 20 to 91 years comprising of men who were diagnosed with prostate cancer, benign prostatic hyperplasia (BPH), enlarged prostate and lower urinary tract disorders. Some men were not diagnosed with any prostatic diseases (Blocker et al., 2006; Matthew et al., 2011; Whitaker et al., 2014; Sarma et al., 2008). However, self-reported symptoms relevant to these diseases or conditions were evident. Four studies included women (Blocker et al., 2006; Ng et al., 2013; Whitaker et al., 2014; Shaw et al., 2008), nevertheless, only men's accounts were considered for the review. The populations were representative of diverse ethnic groupings, however, beliefs identified were not contextualized from a cultural perspective. This review will explore beliefs about bodily changes as it pertains to ethnic groups from the studies.

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