



Unmet informational and supportive care needs of patients with muscle invasive bladder cancer: A systematic review of the evidence[☆]



C. Paterson^{a,*}, B.T. Jensen^b, J.B. Jensen^b, G. Nabi^c

^a School of Nursing and Midwifery, Robert Gordon University, Garthdee, Aberdeen, United Kingdom

^b Department of Urology, Aarhus University Hospital, Denmark

^c Department of Urology, Division of Cancer, Academic Urology, University of Dundee, United Kingdom

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ABSTRACT

Background: Little is known about the unmet supportive care needs of patients affected by muscle invasive bladder cancer (MIBC). We set out to determine the different domains of unmet supportive care needs for patients affected by MIBC.

Literature Search: A systematic review was conducted according to the PRISMA Statement Guidelines. A sensitive search was performed in electronic databases (DARE, Cochrane, MEDLINE, BNI, PsychINFO, EMBASE and CIHAHL) from the earliest date available to January 2017.

Data Evaluation: 1405 references were retrieved, 8 articles met the eligibility criteria and were appraised and ranked by strength using the levels of evidence.

Synthesis: Individual unmet needs were classified into the following domains: patient-clinician communication, daily living needs, health system/information needs, practical needs, family-related needs, social needs, psychological needs, physical needs and intimacy needs. Patients reported high unmet needs at diagnosis and into survivorship.

Conclusions: This review contributes to a greater understanding of the unmet supportive care needs of patients affected by MIBC. Findings reflect a paucity of research, but existing studies indicated needs commonly 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 patients evolve over time.

1. Introduction

Bladder cancer (BC) is a prevalent and expensive malignancy to manage in contemporary healthcare (Jensen et al., 2014; Johnson et al., 2015; Sonpavde et al., 2015). BC represents a significant cause of cancer morbidity and mortality and is the ninth most common cancer diagnosed worldwide (Burger et al., 2013).

The current standard of care for muscle invasive bladder cancer (MIBC) and high-risk non-muscle invasive bladder cancer (NMIBC) is radical cystectomy (RC) with lymphadenectomy, followed by an incontinent diversion or continent diversion (continent cutaneous pouch or orthotopic neobladder) (Lee et al., 2014; Parekh and Donat, 2007). Different options of urinary diversions are associated with individual challenges, complications, unique psychological burden, that can result in profound decrements in quality of life (Mak et al., 2016; Messer et al., 2014; Mohamed et al., 2014; Perlis et al., 2014). Additionally,

neoadjuvant chemotherapy is recommended to improve survival outcomes (Witjes et al., 2014), with emerging usage of adjuvant chemotherapy (Cognetti et al., 2012). Chemotherapy is associated with toxicities that can result in exacerbated symptomatology and can negatively impact upon quality of life (Perlis et al., 2014). Bladder cancer provides a powerful, yet understudied example of the impact that a cancer diagnosis and its associated treatments may have on patients emotional, physical, functional and social adjustments (Feuerstein et al., 2015; Gopalakrishna et al., 2016; Heyes et al., 2016; Mohamed et al., 2014). Given the substantial burden of this disease on patients, assessing patients unmet supportive care needs are important to inform and tailor resources and professional practices to address the needs of patients more effectively (Edmondson et al., 2017; Quale et al., 2015).

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

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* Corresponding author. School of Nursing and Midwifery, Robert Gordon University, Garthdee, Aberdeen AB10 7QG, United Kingdom.

E-mail address: c.paterson15@rgu.ac.uk (C. Paterson).

during diagnosis, treatment, or follow-up phases including issues of health promotion and prevention, survivorship, palliation and bereavement (Paterson et al., 2015). Little is known about the unmet supportive care needs of patients affected by BC, and the areas in which they most require assistance (Feuerstein et al., 2015; Heyes et al., 2014). This systematic review will address the following research questions:

1. What are the different domains of unmet supportive care needs of people affected by bladder cancer?
2. What are the most frequently reported individual domains of unmet need in the current available literature?

2. Methods

The review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2015).

2.1. Search strategy

The following electronic databases were searched: DARE, Cochrane, MEDLINE, BNI, PsychINFO, and EMBASE from earliest date available to January 2017, 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.

Inclusion criteria

- Studies investigating the unmet/supportive care needs of patients with MIBC
- Qualitative and quantitative methods irrespective of research design
- Studies published in the English language
- Studies conducted with adults (≥ 18 years old)

Exclusion criteria

- 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.

2.2. Study selection and data extraction

Following de-duplication, two review authors (CP and BJ) independently screened all titles and abstracts of the identified records for eligibility based on the inclusion/exclusion criteria. The full-text of all potentially eligible records were retrieved and screened independently by (CP and BJ) using a standardised form. Any disagreements were resolved by discussion or by consulting a third review author (GN). A standardised data extraction form was developed and piloted before its use. In the case of incomplete reported data within the included studies, the study authors were contacted.

Data extraction included the 'characteristics of the included studies' table which encompassed the following: study design; countries and institutions where the data were collected; dates defining start and end of patient recruitment and follow-up; whether there was an *a priori* protocol or analysis plan; participant demographic and clinical characteristics; unmet supportive care needs; the numbers of participants who were included in the study; losses and exclusions of participants, with reasons; description of interventions; study funding sources; ethical approval; and power calculation.

2.3. Evidence synthesis

The review used a narrative synthesis and tabulation of primary research studies to generate broad findings and conclusions. More specifically, the narrative synthesis undertook the following steps: data reduction (sub-group classification based on the levels of evidence and the research questions), data comparison (iterative process of making comparisons and identifying relationships) and finally, conclusion and verification (Whittemore and Knafl, 2005). This approach has been used before in several cancer care reviews (Paterson and Nabi, 2017; Paterson et al., 2015).

2.4. Quality appraisal

Methodological quality evaluation was conducted using two quality appraisal tools which enabled a plethora of methodologies to be evaluated. The quality appraisal tools have been used before in a variety of cancer systematic reviews (Paterson and Nabi, 2017; Paterson et al., 2015). The quantitative appraisal tool assessed a range of designs which included: RCT's, non-RCT, cohort, case-control, observational studies (for example, multiple time series, case studies, cross-sectional designs) and were classified as "good", "fair" and "poor" according to the criteria specific to each study design. The quantitative appraisal tool consisted of 18 items and three levels of quality assessment: good (2), fair (1), and poor (0). Some items in the quantitative assessment tool were only relevant to RCT's; therefore a "non-applicable" item option was available for other research designs. Scores across the items were summed to create a quality score and represented as a percentage to account for any non-applicable items. The qualitative appraisal tool had 15 items and three levels of quality assessment ranging from (2–0) and represented as a percentage score.

2.5. Operational definition of domains of need

Individual supportive care needs were classified into eleven primary domains of need based upon current literature (Mohamed et al., 2014; Perlis et al., 2014) and clinical expertise. Specifically, the domains included physical, psychosocial/emotional, family-related, social, interpersonal/intimacy, practical, daily living, spiritual/existential, health system/information, patient-clinician communication, and cognitive needs. See Table 2 for classification of supportive care needs domains as informed by the Supportive Care Needs Framework (Fitch, 2008) and the current definition of "supportive care needs" (Hui, 2014).

2.6. Findings

2.6.1. Search results

Of the 1405 publications retrieved from the search 1138 were excluded following the application of the inclusion/exclusion criteria, see Fig. 1. This left 18 publications reviewed in full, 10 articles were excluded (Bayar et al., 2008; Chawla and Arora, 2013; Cherrier et al., 2013; Karvinen et al., 2007; Lester, 2012; Månsson et al., 1998; Modh et al., 2014; Shih and Porter, 2011; Weinstein Dunn, 2015; Williams-Cox, 2004) with reasons because they did not meet the inclusion criteria, see Fig. 1. This left 8 articles which fully met the inclusion criteria, of which two articles reported on the same study (Mohamed et al., 2014, 2016). In total, there were 6 exploratory qualitative studies (Ali and Khalil, 1989; Cerruto et al., 2014; Fitch et al., 2010; Månsson et al., 1991; Mohamed et al., 2014, 2016; Nordström et al., 1992; Perlis et al., 2014) and one feasibility RCT study (Ali and Khalil, 1989) see Table 3 for an overview of the studies included (Supplementary Table 5 contains full data extraction of primary studies). This is a relatively small number of publications and underscores the importance of taking stock of the evidence to understanding the supportive care needs of patients affected by bladder cancer.

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