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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 of 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.

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 symptomology 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 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?

Methods

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

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.

Study Selection and Data Extraction

Following de-duplication, two review authors (CP and BT) independently screened the 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 two review authors (CP and BT) 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 from studies, the study authors were contacted.

Data extraction included the 'characteristics of the included studies' table which encompassed the 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.

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 levels of evidence and the review questions), data comparison (iterative process of making comparisons and identifying relationships) and finally, conclusion and verification (checked primary data sources for accuracy and confirmability) (Whittemore and Knafl, 2005). This approach has been used in several cancer care reviews (Paterson and Nabi, 2016; Paterson et al., 2015).

Quality Appraisal

Methodological quality evaluation was conducted using two quality appraisal tools, one quantitative appraisal tool and one qualitative appraisal tool which enabled a plethora of methodologies to be evaluated. The quality appraisal tools have been used in a variety of cancer systematic reviews (Paterson and Nabi, 2016; Paterson et al., 2015). The quantitative appraisal tool assessed a range of designs which included: RCT's, non-RCT, cohort, case-control, observational (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 to 0) and represented as a percentage score.

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 include 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, informed by the Supportive Care Needs Framework (Fitch, 2008) and the current definition of “supportive care needs” (Hui, 2014).

Findings

Search Results

Of the 1405 publications retrieved from the search 1138 were excluded following the application of the inclusion/exclusion criteria, see **Figure 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 **Figure 1**. This left 8 articles which fully met the inclusion criteria, of which two articles reported on the same study (Mohamed et al., 2014; Mohamed et al., 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; Mohamed et al., 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.

Methodological Appraisal

The methodological quality assessment of the retained studies was performed in parallel with the data extraction see **Table 4**. Overall the methodological quality of the included studies varied from 50% to 80.0%, with a median score of 58.5% (IQR 16.5% range 51.8% to 68.3%) was yielded. The studies were conducted in a variety of countries including the following: Canada (n=2), USA (n=2), Sweden (n=2), Egypt (n=1) and Italy (n=1). The sample sizes ranged from n=20 to n=30 with a total sample of n= 260 across all studies. All of the included studies in this review were cross-sectional and therefore, very little is known about how supportive care needs change over time.

Evidence of unmet supportive care need by domain

Physical Needs

Seven studies (Ali and Khalil, 1989; Cerruto et al., 2014; Fitch et al., 2010; Månsson et al., 1991; Mohamed et al., 2014; Mohamed et al., 2016; Perlis et al., 2014) described unmet physical needs of patients affected by bladder cancer. These included difficulties with urinary function (incontinence associated with urinary diversion, frequent stoma bad emptying, skin irritation, urinary mucus, foul urinary odour, pelvic and stoma pain) (Ali and Khalil, 1989; Cerruto et al., 2014; Mohamed et al., 2016; Perlis et al., 2014), sexual function (erectile dysfunction, decreased sexual satisfaction, decreased clitoral sensation, loss of ability to please partners, vaginal dryness, and pain during intercourse) (Cerruto et al., 2014; Perlis et al., 2014), and bowel problems particularly for those treated by radiotherapy (defecation urgency, loose stool and incontinence, bloody stools, spasms, excess gas, and nausea) (Perlis et al., 2014). Moreover, carers of patients with bladder cancer have unknown supportive care needs, as patients can depend on their BC caregiver for support and stoma plate attachment following post-surgery and into survivorship (Cerruto et al., 2014; Mohamed et al., 2016). Across all the studies patients found the experience of coping with the stoma appliance frustrating and debilitating, with a lack of information and education, suggesting a higher need for support and access to stoma care nurses (Mohamed et al., 2014; Mohamed et al., 2016).

Psychological/emotional Needs

Emotional needs were consistently reported across seven studies (Ali and Khalil, 1989; Fitch et al., 2010; Månsson et al., 1991; Mohamed et al., 2014; Mohamed et al., 2016; Nordström et al., 1992; Perlis et al., 2014). Patients experienced anxiety and depression before treatment and into survivorship (Mohamed et al., 2016; Perlis et al., 2014), with 33.3% of patient reported feeling severely depressed but did not receive an appropriate referral for care (Mohamed et al., 2014). Patients often reported feelings of uncertainty about the future (Ali and Khalil, 1989; Månsson et al., 1991; Mohamed et al., 2014; Mohamed et al., 2016; Perlis et al., 2014), fear of the cancer returning or spreading (Månsson et al., 1991; Mohamed et al., 2014; Perlis et al., 2014), frightened, sadness, guilt, distress and avoiding planning for the future (Ali and Khalil, 1989) and concerns about the worries of those close to them (Ali and Khalil, 1989; Cerruto et al., 2014).

Family related Needs

The family dynamic was affected because of bladder cancer and its associated treatments. Several studies reported the BC caregiver as a central support for the patient's stoma management (Ali and Khalil, 1989; Cerruto et al., 2014). Family caregivers often felt unprepared for the cancer experience, limited knowledge about cancer and associated treatments, and received little guidance on how to support and care for the patient during and following treatment, which altered relationships (Perlis et al., 2014). Patients often worry about the burden of care of loved ones (Perlis et al., 2014).

Social Needs

Patients experienced that due to living with a decreased functional ability this significantly reduced their social activities (Perlis et al., 2014). Urinary symptoms and incontinence associated with unintentional stoma plate detachment had a negative effect on patient's social needs as they could no longer participate in sporting activities, hobbies, travel limitations, or going to the theatre/cinema (Ali and Khalil, 1989; Mohamed et al., 2016; Nordström et al., 1992). A common theme was the enduring consequence of the constant fear of accidental leakage on their daily social activities (Mohamed et al., 2014). Some experienced a sense of loneliness, social isolation and feelings of abandonment (Ali and Khalil, 1989; Perlis et al., 2014).

Interpersonal/Intimacy Needs

Unmet intimacy-related needs were a common theme featured across all the studies (Ali and Khalil, 1989; Cerruto et al., 2014; Fitch et al., 2010; Månsson et al., 1991; Mohamed et al., 2014; Mohamed et al., 2016; Nordström et al., 1992; Perlis et al., 2014). The consequences of sexual dysfunction affected emotional outcome (Fitch et al., 2010), satisfaction with sexual experience due to a loss of sensation (Perlis et al., 2014), disintegration of marital relationships (Ali and Khalil, 1989) and some patients voiced that often sexuality related needs were often poorly explored within clinical consultations, if explored at all (Fitch et al., 2010; Mohamed et al., 2016).

Practical/Daily Living Needs

Daily living needs was found to be intrinsically linked to the continence diversion. Patients spoke about the difficulties of returning to work (Perlis et al., 2014), unable to perform normal daily activities (Ali and Khalil, 1989), practical issues of the cost of the stoma appliances (Ali and Khalil, 1989; Mohamed et al., 2016) and where to source stoma products from (Ali and Khalil, 1989). Patients identified concern in relation to the financial burden experienced as a result of living with a long-term

disability, unemployment and for some, expensive medical cost associated with treatments, and insurance (Ali and Khalil, 1989; Mohamed et al., 2016; Perlis et al., 2014).

Health System/Clinician-Patient Communication Needs

There were several unmet information needs identified across the reviewed studies at diagnosis, post treatment and into survivorship (Mohamed et al., 2014; Mohamed et al., 2016). Patients voiced concerns about a lack of understanding and discussion about the treatment options available to them and the consequence of treatments (Fitch et al., 2010; Månsson et al., 1991; Mohamed et al., 2014). In one study, of the information that patients received from their healthcare professionals, 56.7% found it insufficient (Mohamed et al., 2016). A common theme was that patients felt that they would have benefited from receiving information on pre and post-operative self-management, finances, medical insurance and recovery process (Fitch et al., 2010; Månsson et al., 1991; Mohamed et al., 2014).

Patients experienced that the focus of their consultation with their clinician was targeted on the physical aspects and cancer surveillance, rather than dealing with the psychological consequences of sexual dysfunction (Fitch et al., 2010) and providing emotional support (Mohamed et al., 2016). Patients experienced not having the opportunity to discuss concerns about changes in body function and sexuality/body image during consultations (Cerruto et al., 2014; Fitch et al., 2010; Mohamed et al., 2014; Mohamed et al., 2016). Moreover, patients reported a lack of adequate training and support in the management of the continence diversion appliances. One study identified 53.3% of patients reported having support from a stoma care nurse, of which 30% were not satisfied with the care provided to them to support their own self-manage of their condition (Mohamed et al., 2014).

Frequency of supportive care needs documented in the literature

In ascending order of the frequency of needs reported in the reviewed studies: patient-clinician communication (4/8), daily living needs (4/8), health system/Information needs (5/8), practical needs (5/8), family-related needs (5/8), social needs (6/8), psychological emotional needs (7/8), physical needs (7/8), interpersonal/intimacy needs (8/8), see **Table 4**.

Discussion

MIBC presents challenges to both the patient and the family caregiver at each step along the cancer continuum, from diagnosis to treatment and into survivorship. Given the gravity of treatment and associated consequence of urinary diversion on patient's quality of life, this systematic review set out to identify the unmet supportive care needs of patients affected by bladder cancer, and to identify the most frequently reported unmet needs in the literature to inform service delivery. This systematic review has made an important contribution by informing healthcare professionals about the complex person-centred supportive care needs of patients and their BC caregivers.

To date, there is a dearth of research examining the unmet informational, supportive care needs and psychological adjustments for patients with BC. Patients continue to experience a range of unmet supportive care needs with the most frequently reported in the literature related to interpersonal/intimacy, psychological/emotional and physical needs.

Some patients reported unmet sexual needs which were infrequently explored in clinical consultations, embarrassment, and a lack of supported self-management advice (Ali and Khalil, 1989; Cerruto et al., 2014; Fitch et al., 2010; Månsson et al., 1991; Mohamed et al., 2014; Mohamed et al., 2016; Nordström et al., 1992; Perlis et al., 2014). Given the increasing incidence and survival of patients, it is timely and appropriate to develop family-relational-psychosexual interventions for couples to address areas of unmet needs. Furthermore, consistent provision of specialist nurses is needed across the care pathway, with training to address sexual and psychological needs as a priority for enhancing supportive care (Mohamed et al., 2014).

A further common theme across the included studies was the informational concerns and dissatisfaction with the information provided (Fitch et al., 2010; Månsson et al., 1991; Mohamed et al., 2014; Mohamed et al., 2016). This is a major area of concern particularly when providing information about the options of urinary diversion procedures, critical treatment decisions and planning how the family will cope post-operatively after surgery. Providing clear and accurate written information as well as open-communication is crucial, particularly for pre-operative counselling to support a patient's choice of urinary diversion, and associated impact on quality of life and sexual function.

Severe psychosocial problems have been reported after major extirpative cancer surgery that involves construction of new excretory pathways for urinary and faeces. Unmet psychological and emotional needs were identified across a range of studies (Ali and Khalil, 1989; Fitch et al., 2010; Månsson et al., 1991; Mohamed et al., 2014; Mohamed et al., 2016; Nordström et al., 1992; Perlis et al., 2014).

Patients experienced anxiety and depression before treatment and into survivorship (Mohamed et al., 2016; Perlis et al., 2014) , and noteworthy one study (Mohamed et al., 2014) identified that 33.3% of patient reported feeling severely depressed but did not receive an appropriate referral for care. Patients recalled that the early post-operative months were very difficult, and experiencing feelings of uncertainty about the future (Ali and Khalil, 1989; Månsson et al., 1991; Mohamed et al., 2014; Mohamed et al., 2016; Perlis et al., 2014), fear of the cancer returning or spreading (Månsson et al., 1991; Mohamed et al., 2014; Perlis et al., 2014), fear, sadness, guilt, distress and avoiding planning for the future (Ali and Khalil, 1989). Patients were also worried about family members (Ali and Khalil, 1989; Cerruto et al., 2014).

Several definitions of the concept of body image exist, but most commonly used, is defined as, “the picture of our own body which we form in our minds, that is to say, the way which the body appears to ourselves” (Cohen, 1991). Body image disturbance was common reported across the studies, disfigurement leading to low self-esteem, and difficulty in forming relationships, and females considered more significant than males (Ali and Khalil, 1989; Månsson et al., 1991; Mohamed et al., 2014; Mohamed et al., 2016; Perlis et al., 2014). One women articulated her experience as “*not in a million years would I let anyone close to me with this stoma and bag, oh and my stomach [the scar], I am disgusting*” (Fitch et al., 2010), for some the impact clearly substantial.

There was wide heterogeneity across the studies in this review and identified several important gaps. First off, all the studies that have been conducted to date are cross-sectional; hence our knowledge base is limited to a “snap-shot”. It would be of interest to guide future research to explore how patients’ needs change over the cancer care continuum, and during times of disease recurrence/progression. Moreover, it would be also of interest to examine how potential complications based on a validated grading system, such as Clavien-Dindo classification, affect unmet needs. To the best of our knowledge, no study has examined the determinates of psychological adjustment and the needs of BC caregivers across various types of urinary diversions.

Due to the identified unmet needs of patients affected by MIBC there is a strong need for consistent and clear communication and information between the healthcare provider and patient/caregiver. To overcome and address unmet needs, literature supports the use of patient reported outcomes (PROMs) in routine clinical practice (Greenhalgh et al., 2005; Paterson and Nabi, 2016; Paterson et al., 2015) which permits a systematic and “real time” assessment of person-centred supportive care needs, to enable interventions to be appropriately targeted. Existing models of consultation in cancer care might help address the needs of patients affected by MIBC (Paterson and Nabi, 2016). Evidence acknowledges that using PROMs in clinical consultations, can enhance communication between the

patient and the healthcare professional, patients can experience greater satisfaction with care, enable an opportunity for tailored self-management advice, and promote targeted and better management of side-effects in line with patient need (Mohamed et al., 2012).

There are several important clinical implications for this review. Regardless of clinical characteristics and time since treatment across the reviewed studies, patients have reported a range unmet supportive care needs. Investing time, holistic assessment and using effective interpersonal communication to deliver supportive care is a central message to all healthcare professionals. This review suggests that greater attention should be focused on the side-effects that patients are embarrassed and reticent to discuss, perhaps due to the stigma associated with them.

Review strengths and limitations

One of the major challenges of this review was combining heterogeneous methodologies, and our findings are constrained due to the methodological limitations of the studies included. The review only included articles in the English language, and as such, it may limit the understanding globally. Despite this limitation the review team follow-up a rigorous and transparent review methodology based upon the PRIMSA guidelines (Moher et al., 2015) to promote reproducibility. This review has enabled a broad summary of the evidence which has facilitated refinement of future research directions.

Conclusion

This systematic review contributes towards the understanding of unmet supportive care needs of patients affected by MIBC. The current with-in study limitations preclude our understanding about how the needs of BC patients evolve over time from diagnosis, to treatment and into survivorship. Future studies should employ a prospective longitudinal design to assess how needs change from diagnosis, treatment and into survivorship.

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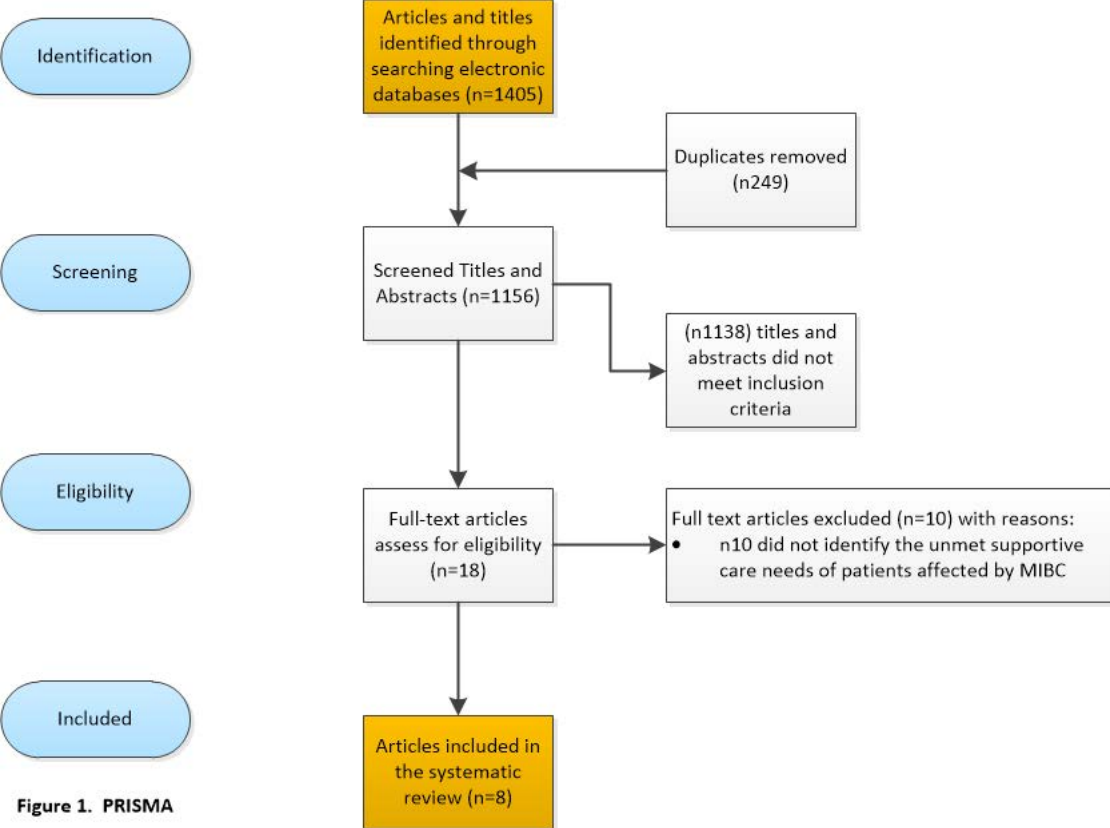


Figure 1. PRISMA

Table 1. Electronic database searched and search terms used^a

Electronic databases	Search Terms
DARE Cochrane Medline EMBASE CINAHL PsychINFO	<p>Step 1: Studies employing a quantitative methodology</p> <ol style="list-style-type: none"> 1. "(MH "Patient Care Team") OR (MH "Patient Care Planning") OR (MH "Patient Care Bundles") OR (MH "Patient Care") OR "patient care" OR (MH "Patient-Centered Care") OR (MH "Progressive Patient Care") OR (MH "Patient Care Management") OR (MH "Continuity of Patient Care") OR (MH "Respite Care") OR (MH "Social Support") OR (MH "Training Support") OR (MH "Financial Support") OR (MH "Nutritional Support") OR (MH "Employment, Supported") OR (MH "Decision Support Techniques") OR (MH "Subacute Care") OR (MH "Ambulatory Care") OR (MH "Health Planning Support") OR "supportive care" OR (MH "Behavioral Symptoms") OR (MH "Symptom Assessment") OR (MH "Affective Symptoms") OR "symptom control" OR (MH "Lower Urinary Tract Symptoms") OR (MH "Urinary Diversion") OR (MH "Urinary Catheters") OR (MH "Urinary Catheterization") OR (MH "Urinary Retention") OR (MH "Urinary Incontinence") OR (MH "Urinary Bladder") OR "urinary symptoms" OR (MH "Signs and Symptoms, Digestive") OR (MH "Sexual Dysfunction, Physiological") OR (MH "Sexual Dysfunctions, Psychological") OR (MH "Depression") OR (MH "Anxiety") OR (MH "Sexuality") OR (MH "Erectile Dysfunction") OR "sexual dysfunction" OR (MH "Information Literacy") OR "information needs" OR (MH "Needs Assessment") OR (MH "Spiritual Therapies") OR (MH "Spirituality") OR "spiritual needs" OR (MH "Pain") OR "pain" OR (MH "Pain Measurement") OR (MH "Palliative Care") OR (MH "Hospice and Palliative Care Nursing") OR "palliative" 2. "unmet needs" OR (MH "Care needs") OR (MP "Patient\$ need\$") OR (MP "Needs Assessment") OR (MP "Family Need\$") OR (MP "Caregiv\$ need\$") OR (MP "Supportive care needs") 3. 1 or 2 4. "(MH "Questionnaires") OR "questionnair\$" OR "tool\$" OR "Scale" OR "instrument" OR (MH "Needs Assessment") OR (MH "Nutrition Assessment") OR (MH "Symptom Assessment") OR (MH "Nursing Assessment") OR (MH "Geriatric Assessment") OR (MH "Patient Outcome Assessment") OR (MH "Health Impact Assessment") OR (MH "Process Assessment (Health Care)") OR (MH "Outcome Assessment (Health Care)") OR "assessment" OR (MH "Self-Evaluation Programs") OR (MH "Evaluation Studies") OR "evaluation" OR "validity" OR "inventory" OR "index" OR (MH "Checklist") OR "checklist" OR (MH "Nutrition Surveys") OR (MH "Health Care Surveys") OR (MH "Health Surveys") OR "survey" OR (MH "Longitudinal Studies") OR (MH "Diet Surveys") OR (MH "Nursing Audit") OR (MH "Clinical Audit") OR "audit measure" 5. "(MH "bladder Neoplasms") OR "bladder cancer" 6. 3 and 4 and 5 <p>Step 2: Studies employing a qualitative methodology</p> <ol style="list-style-type: none"> 1. "(MH "Patient Care Team") OR (MH "Patient Care Planning") OR (MH "Patient Care Bundles") OR (MH "Patient Care") OR "patient care" OR (MH "Patient-Centered Care") OR (MH "Progressive Patient Care") OR (MH "Patient Care Management") OR (MH "Continuity of Patient Care") OR (MH "Respite Care") OR (MH "Social Support") OR (MH "Training Support") OR (MH "Financial Support") OR (MH "Nutritional Support") OR (MH "Employment, Supported") OR (MH "Decision Support Techniques") OR (MH "Subacute Care") OR (MH "Ambulatory Care") OR (MH "Health Planning Support") OR "supportive care" OR (MH "Behavioral Symptoms") OR (MH "Symptom Assessment") OR (MH "Affective Symptoms") OR "symptom control" OR (MH "Lower Urinary Tract Symptoms") OR (MH "Urinary Diversion") OR (MH "Urinary Catheters") OR (MH "Urinary Catheterization") OR (MH "Urinary Retention") OR (MH "Urinary Incontinence") OR (MH "Urinary Bladder") OR "urinary symptoms" OR (MH "Signs and Symptoms, Digestive") OR (MH "Sexual Dysfunction, Physiological") OR (MH "Sexual Dysfunctions, Psychological") OR (MH "Depression") OR (MH "Anxiety") OR (MH "Sexuality") OR (MH "Erectile Dysfunction") OR "sexual dysfunction" OR (MH "Information Literacy") OR "information needs" OR (MH "Needs Assessment") OR (MH "Spiritual Therapies") OR (MH "Spirituality") OR "spiritual needs" OR (MH "Pain") OR "pain" OR (MH "Pain Measurement") OR (MH "Palliative Care") OR (MH "Hospice and Palliative Care Nursing") OR "palliative" 2. "unmet needs" OR (MH "Care needs") OR (MP "Patient\$ need\$") OR (MP "Needs Assessment") OR (MP "Family Need\$") OR (MP "Caregiv\$ need\$") OR (MP "Supportive care needs") 3. 1 or 2 4. "(MP "Constant Comparison Method") OR (MP "Content Analysis") OR (MP "Discourse Analysis") OR (MP "Ethnographic Research") OR "Exp Patient Attitudes" OR "Exp Patient Perceptions" OR (MP "Focus Groups") OR (MP "Interview\$") OR (MP "Field Stud\$") OR (MP "Phenomenology") OR "Phenomenological Research" OR "Purposive Sample" OR (MP "Qualitative Research") OR "Theoretical Sample" OR (MP "Observational Research") OR (MP "Ethnonursing Research") OR "Open-Ended" OR (MP "Theoretical Saturation") OR (MP "Themes") OR (MP "Thematic") OR "Narrative Anaylsis" OR "Narrativ\$" OR "Lived Experience" OR (MP "Grounded Theory") OR "Semi-structur\$" 5. "(MH "Bladder Neoplasms") OR "Bladder cancer" 6. 3 and 4 and 5

^aSearch strategy as conducted in Medline©

Table 2. Classification of the 11 domains of supportive care needs

Domain of need	Definition
Physical Needs	Experience of physical symptoms such as fatigue, urinary symptoms, bowel symptoms, pain, management of incontinent diversion, etc.
Psychological/emotional needs	Experience of psychological/emotional symptoms such as anxiety, depression, worry, despair, fear, etc.
Family-related needs	Experience of fears/concerns for the family, dysfunctional relationships, etc.
Social Needs	Experience of reduced social support, social isolation, loneliness, etc.
Interpersonal/Intimacy needs	Experience of difficulties with self-image and masculinities, reduced libido, sexual dysfunction, compromised intimacy with partner, fertility, etc
Practical Needs	Situations of transportation, out-of-hours access to healthcare, financial support, etc
Daily Living Needs	Experience of restriction in daily living tasks such as exercise, housekeeping, etc
Spiritual/Existential Needs	Existential concerns such as fear of death, death and dying, fears regarding after life, etc
Health System/Information	Experience of a lack of information, uncertainty of follow-up care, lack of information in relation to treatment and diagnosis, etc
Patient-Clinician Communication Needs	Quality of communication between patients and healthcare professionals, satisfaction with care, shared decision-making, etc
Cognitive Needs	Experience of cognitive impairments, memory loss, etc.

Table 3. Basic characteristics and main findings including domains of commonly reported unmet supportive care needs items of qualitative studies (n=8) included in the literature review

Author (year published) and country	Study participants and treatment	Methodology	Summary of findings and domains of supportive care needs
Mohamed et al., (2016) ^a USA	30 patients Ileal conduit 15 patients (50%), Continent reservoir 2 patients (6.7%), Neobladder 13 patients (43.3%), Adjuvant/Neoadjuvant chemotherapy 11 patients (36.7%)	Cross-sectional qualitative study, 60 minute semi-structured (9 in person, 21 telephone) <i>Time since diagnosis:</i> 0-6 months 3 (10%), 6-12 months 7 (23.3%), 12-18 months 6 (20%), 18+ months 14 (46.7%)	<i>Informational Needs:</i> Unmet informational needs at diagnosis, post treatment and into survivorship. Lack of support for treatment decisions at diagnosis. Lack of information on side-effects of treatments. <i>Psycho-social Needs:</i> Unmet supportive care for managing depression and anxiety before treatment. Coping with the uncertainty of future. <i>Physical Needs:</i> Coping difficulties with incontinence, and sexual dysfunction after surgery. Difficulties with self-management.
Perlis et al., (2014) Canada	12 healthcare professionals with expertise in bladder cancer and 47 patients affected by bladder cancer NMIBC 10 (21.3%), MIBC 36 (76.6%), Radical cystectomy 22 (46.8%), Trimodality treatment (radiation) 10 (21.3%), Metastatic disease 4 (8.5%)	Scoping literature search 20 papers on health related quality of life, and focus groups 12 healthcare professionals with expertise in bladder cancer (2 focus groups) 47 patients affected by bladder cancer (4 focus groups) <i>Time since diagnosis:</i> not reported.	<i>Urinary problems:</i> Night time frequency associated with chemotherapy or orthotropic bladder. Urinary incontinence associated with urinary constructions, and foul urinary odour. Frequent stoma bag emptying, skin irritation, urinary mucous, stoma problems. Pelvic/stoma pain. Associated fatigue and tiredness. <i>Bowel problems:</i> particularly for treated with radiotherapy, defecation urgency, loose stool and incontinence. Bloody stools, bowel spasms, constipation, excess gas, faecal leakage, faecal urgency, nausea. <i>Sexual Problems:</i> sexual dysfunction, poor quality erections for men, women report decreased sexual satisfaction due to devascularised neurovascular bundles and decreased clitoral sensation due to urethral dissection. Loss of ability to be intimate, loss of ability to please partner, vaginal dryness or other problems with pain with intercourse. Decreased libido. <i>Impaired body image:</i> distress about change in body image can interfere with daily activities. Embarrassment about the visibility of stoma appliances, surgical scars and hernias. Patients affected by advanced stage disease, body image can be altered due to weight loss and alopecia from chemotherapy. <i>Psychological Problems:</i> coping with fear of recurrence, anxiety and depression. Sadness, guilt, distress, avoiding planning for the future. <i>Social problems:</i> Feeling of abandonment, altered relationships with friends and family, social isolation, limitations with hobbies, travel limitations, unfit for returning to work, embarrassment to expose body in public, burden of care on loved ones.
Mohamed et al., (2014) ^b USA	30 patients Ileal conduit 15 (50%), Continent reservoir 2 (23.3%), Neobladder 13 (43.3%), Adjuvant/neoadjuvant chemotherapy 12 (40%).	Cross-sectional qualitative study <i>Number of months diagnosis-interview:</i> 0-6 6 patients (10%), 6-12 7 patients (23.3%), 13-18 6 patients (20%), 18+ 14 patients (46.7%)	<i>Unmet needs at diagnosis:</i> Lack of understanding of treatment options and potential side effects. 56.7% found the information received from clinical was insufficient. More information on pre-operative self-care, finances and medical insurance, and healing process. Concerns about survival, pain, body image and decreased sexual function after surgery. 33.3% of patients reported feeling severely depressed at diagnosis and did not receive a referral for care. <i>Unmet needs Postoperatively:</i> 50% of patients reported difficult with recovery and 46.7% reported problems due to medical complications (urinary infections, incisional hernias, deep vein thrombosis, kidney problems). Grappling with

			<p>incontinence major concern for patient treated with a neobladder, lack of urine control and leakage reported by patients treated by ileal conduit. Information needs related to recovery and self-management. Patient reported a lack of adequate training on stomal appliances and catheters (i.e. stoma pouch changing, tailoring, cleaning and emptying and choice of appliances). 53.3% reported support from nurse, but 30% were not satisfied with the support given.</p> <p><i>Unmet needs during survivorship:</i> unable to resume usual physical or social activities. Problems with sexual function. Men reported erectile dysfunction and low libido. Women reported vaginal dryness, pain during intercourse, lost desire for sex due to changes in body image and presence of stoma. Difficulties with changes in body image. Feeling of depression. Worry about the future and fear of cancer recurrence. Concerns about age related problems with decreases in manual dexterity and vision for managing the stoma appliance.</p>
Cerruto et al., (2014) Italy	30 patients Treatment modalities not reported	<p>Cross-sectional qualitative study. Semi-structured interviews.</p> <p><i>Time since surgery:</i> 2- 30 years (mean 7 years)</p>	<p><i>Unmet needs at - 1 - year post surgery:</i> poor sleep, difficult to manage the urostomy, dependent on other people, perceptions of worse quality of life than before surgery.</p> <p><i>3-year post surgery:</i> severe limitations on daily activities, drastic worsening on dependence on partners in managing the ostomy (change and cleaning), strong and constant concerns of the urinary stoma leaks, frequent and unintentional plate detachment, urine smell, lack of sexual relationships, giving up social activities to go out (due to incontinence).</p> <p><i>5-year post surgery:</i> greater degree of independence (or less dependence) by partner in the management of the stoma, fear of leakage and unintentional plate detachment, but patients learned strategies to manage.</p> <p><i>7-year post surgery:</i> Lack of sexual activity because of fear of plate detachment leakage. Possible problems of stoma hernias, urinary tract infections, stoma obstruction.</p> <p><i>7>greater post surgery:</i> developed long coexistence with stoma, patient's no longer fear plate detachment. Patients and partners work together for correct appliance placement. Absence of sexual relationships and lack of sexual activity persists.</p>
Fitch et al., (2010) Canada	22 patients Ileal conduit 10, Neobladder 12	<p>Cross-sectional qualitative study. Semi-structured interviews.</p> <p><i>Time since surgery:</i> 12-36 months since surgery.</p>	<p><i>Lack of knowledge about bladder cancer:</i> lack of knowledge about bladder cancer and its associated risks. Patients reported that they believed this delayed their bladder cancer diagnosis. Lack of information about the urinary diversion options.</p> <p><i>Urinary incontinence:</i> coping with the pouching system frustrating and challenging problem. Lack of advice and instruction. Limited knowledge of community healthcare professional of appliances made the time of post-operative recovery difficult.</p> <p><i>Changes in body image and function:</i> Coping with changes appear to be link to age, life experience, and personal comfort with body image prior to surgery. "not in a million years would I let anyone close to me with this stoma and bag, oh and my stomach, I am disgusting".</p> <p><i>Sexual dysfunction:</i> Pain during intercourse and problems with urinary incontinence during intercourse.</p> <p><i>Patient-clinician communication:</i> Lack of understand and information about the various surgical options and the impact on the person as a result of changes in body function. Not having the opportunity to discuss concerns about</p>

			changes in body image and sexuality changes. Not enough information about post-operative information and what to expect. Patients lacked information on diet progression, care of wounds, infections, homecare, follow-up care plans and cancer surveillance.
Nordstrom et al., (1992) Sweden	66 patients Ileal conduit for bladder cancer 44 patients, and 22 patients for bladder dysfunction.	Cross-sectional qualitative study. Semi-structured interviews. <i>Time since surgery:</i> 3-14 years (mean 7 years).	<i>Psychosocial Adjustment:</i> Fear of accidental leakage or fear of leakage and factors related to altered body image. Fears of collecting device visible through clothing. <i>Sexual dysfunction:</i> Loss of ability to achieve an erection. <i>Social problems:</i> Problems with fear of leakage (curtailed going on domestic travel, overnight visits, foreign travels and cinema or going to theatre).
Mansson et al., (1991) Sweden	32 patients Ileal conduit 20 patients, Neobladder 12 patients	Cross-sectional qualitative study. Semi-structured interviews. <i>Time since surgery:</i> 1-10 (mean of 5 years)	<i>Informational Needs:</i> Lack of information about the consequences of sexual function following surgery. Not all treatment options discussed. <i>Psychological problems:</i> fear of death and dying. Feelings of complete isolation, frightened, irritable, nervousness, feelings of living on "borrowed time". <i>Adjustment to stoma:</i> patients report feelings of being disturbed, problems with incontinence. Reduced self-esteem. <i>Sexual dysfunction:</i> problems with erections and unable to achieve orgasm. <i>Patient-clinician communication:</i> patients felt unable to discuss fears and anxiety with their doctors. Lack of emotional support
Ali et al., (1989) Egypt.	30 patients Bladder cancer all planned urinary diversion. No further clinical information reported.	30 (15 in each group experimental and control group) Questionnaires and semi-structured interview. <i>Time since diagnosis:</i> not reported.	<i>Psychological Problems:</i> coping with fear of recurrence and spread, anxiety and depression. Sadness, guilt, distress, avoiding planning for the future. Insecure, doubt that all the tumour is removed. Treatment for palliative or cure. <i>Mutilation and body image distortion:</i> Disfigurement, general look, passage of urine, body invasion by surgical procedure, odor, width of stoma, site and look for the stoma. <i>Social problems:</i> unable to carry on normal activities, concerns of who would look after family if died, loss of friends. <i>Sexual problems:</i> loss of marital relationships. <i>Daily living problems:</i> Cost of buying the stoma application, and where to get supply from.

Table 4. Quality appraisal of primary studies

Qualitative Article	Item number of checklist															Summary Score (%)		
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15			
Mohamed et al., (2016) ^a	2	1	1	0	2	2	1	2	2	1	1	2	1	0	1	63.3%, 19/30		
Perlis et al., (2014)	1	2	1	1	1	2	1	1	2	2	1	1	1	0	2	63.3%, 19/30		
Mohamed et al., (2014) ^b	2	2	1	1	2	2	1	2	2	2	2	1	1	0	1	73.3 %, 22/30		
Nordstrom et al., (1992)	1	1	1	1	1	1	0	1	2	2	1	1	1	0	1	50.0 %, 15/30		
Fitch et al., (2010)	1	2	1	1	1	1	0	1	2	1	1	1	1	1	1	53.3 %, 16/30		
Mansson et al., (1991)	1	2	1	1	1	1	0	1	2	1	1	1	1	0	1	50.3 %, 15/30		
Cerruto et al., (2014)	2	2	1	2	2	1	1	2	2	1	2	2	1	1	2	80.0 %, 24/30		
Quantitative Studies	Item number of checklist															Summary Score (%)		
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15		16	17
Ali et al., (1989)	1	1	1	1	1	N/A	0	1	1	2	N/A	1	1	1	2	N/A	N/A	53.8%, 14/26

Table 5 (supplementary). Data extraction of primary studies

Author (Year)	Purpose and Context	Methods	Participant Characteristics	Quality Appraisal Score, limitations.
Mohamed et al., (2016) ^a	Purpose: explore the unmet informational needs and supportive care needs of patients with muscle invasive bladder cancer Setting: no data provided Country: USA	Sample Size: n=30 Sampling: Convenience Response Rate: 54.3% Attrition: N/A Design: Cross-sectional qualitative study Time Points: 1 Data Collection: 60 minute semi-structured (n9 in person, n21 telephone) Outcomes: unmet information and supportive care needs	Demographic: Age: 67 (SD 8.9, 52-82) years; Gender: Male n22 (73.3%), Female n8 (26.7%), Marital Status: Single n2 (6.7%), Married/Partner n=27 (90%), Divorced n1 (3.3%) Ethnic Origin: White n30 (100%). Employment: Employed n10 (33.3%), Retired n3 (10%), Unknown n17 (56.7%) Clinical: Cancer stage: Not reported Time since diagnosis: 0-6 months n3 (10%), 6-12 months n7 (23.3%), 12-18 months n6 (20%), 18+ months n14 (46.7%) Treatment: Ileal conduit n15 (50%), Continent reservoir n2 (6.7%), Neobladder n13 (43.3%), Adjuvant/Neoadjuvant chemotherapy n11 (36.7%),	63.3%. No diversity of ethnicity. Due to cross-sectional design limited understanding of supportive care needs over time. No measure of self-efficacy or Clavien-Dindo classification of complications and potential influences on supportive care needs. Retrospective memory recall bias.
Perlis et al., (2014)	Purpose: Develop a conceptual framework of quality of life for patient affected by bladder cancer Setting: no data provided Country: Canada	Sample Size: n20 papers, and 2 focus groups Sampling: structure literature search, n12 healthcare professionals with expertise in bladder cancer (2 focus groups, n47 patients affected by bladder cancer (4 focus groups) Response Rate: no reported. Attrition: N/A Design: Sequential design of structure literature review and focus groups. Cross-sectional. Time Points: 1 Data Collection: Focus groups Outcomes: unmet information and supportive care needs	Demographic: Age: 66 (62-76) years, Gender: Female n13 (27.6%), Male 34 (72.3%), Marital Status: Single n3 (6.4%), Married n33 (70.2%), Divorced n2 (4.2%), Widow n3 (6,4), Ethnicity: Black n1 (2.1%), Middle Eastern n2 (4.2%), White n38 (80.8%). Clinical: NMIBC n10 (21.3%), MIBC n36 (76.6%), Radical cystectomy n22 (46.8%), Trimodality treatment (radiation) n10 (21.3%), Metastatic disease (n4 (8.5%)	63.3% Due to cross-sectional design limited understanding of supportive care needs over time. Limited detail on the structure review methodology, unclear if PRIMA was followed.
Mohamed et al., (2014) ^b	Purpose: Determine the unmet supportive care needs of bladder cancer patients Setting: Department of Urology, Mount Sinai (December 2011 to September 2012). Country: USA	Sample Size: n30 Sampling: Convenience Response Rate: 54.3%. Attrition: N/A. Design: Cross-sectional qualitative study Time Points: 1 Data Collection: semi-structure interview. Outcomes: Unmet supportive care needs.	Demographic: Age 67 years, Gender: Men n22 (73.3%), Female n8 (26.7%), Marital Status: Married n27 (90%), Single n2 (6.6), Divorced n1 (3.3%). Ethnicity: White n30 (100%) Clinical: Ileal conduit n15 (50%), Continent reservoir n2 (23.3%), Neobladder n13 (43.3%), Adjuvant/neoadjuvant chemotherapy n12 (40%). Number of months diagnosis-interview: 0-6 n6 (10%), 6-12 n7 (23.3%), 13-18 n6 (20%), 18+ n14 (46.7%)	73.3% Selection bias is possible. Change over time was not assessed due to the cross sectional design. The transferability of the findings is limited due to the sample being biased in favour of Caucasian men. Memory recall bias.
Cerruto et al., (2014)	Purpose: to explore unmet supportive care needs Setting: No data provided. Country: Italy	Sample Size: n30 Sampling: Convenience Response Rate: Not reported. Attrition: N/A Design: Cross-sectional qualitative study. Time Points: 1 Data Collection: Semi-structured interviews Outcomes: supportive care needs	Demographic: Age: 76.4 years (SD 7.4), Gender: Male n17, female n13, Time since surgery: 2- 30 years (mean 7 years)	80.0% Selection bias is possible. Change over time was not assessed due to the cross sectional design. Memory recall bias. No measure of self-efficacy or Clavien-Dindo classification of complications and potential influences on supportive care needs
Fitch et al., (2010)	Purpose: Impact of treatment for bladder cancer, experience of	Sample Size: n22 Sampling: Convenience Response Rate: Not reported.	Demographic: Age: 44-85 years, Gender: Male n13, female n9, Marital status: Married n12, Widow n3, Divorced n5, Single n2 Clinical: Ileal conduit n10, Neobladder n13	53.3%

	care Setting: No data provided. Country: Canada	Attrition: N/A Design: Cross-sectional qualitative study. Time Points: 1 Data Collection: Semi-structured interviews Outcomes: Unmet supportive care needs	Time since surgery: 12-36 months since surgery.	Selection bias is possible. Change over time was not assessed due to the cross sectional design. No measure of self-efficacy or Clavien-Dindo classification of complications and potential influences on supportive care needs
Nordstrom et al., (1992)	Purpose: Impact of treatment for bladder cancer on health status Setting: Stoma Care Unit Sodersjukhuset. Country: Sweden	Sample Size: n66 Sampling: Convenience Response Rate: Not reported. Attrition: N/A Design: Cross-sectional qualitative study. Time Points: 1 Data Collection: Semi-structured interviews Outcomes: Quality of life. Nottingham Health Index	Demographic: Age: 20-76 years (mean 55 years), Gender: Male n40, female n26 Clinical: Ileal conduit for bladder cancer n44, and n22 for bladder dysfunction. Time since surgery: 3-14 years (mean 7 years).	50% Selection bias is possible. Change over time was not assessed due to the cross sectional design. No measure of self-efficacy or Clavien-Dindo classification of complications and potential influences on supportive care needs.
Mansson et al., (1991)	Purpose: Impact of treatment for bladder cancer, experience of care Setting: No data provided. Country: Sweden	Sample Size: n32 Sampling: Convenience Response Rate: Not reported. Attrition: N/A Design: Cross-sectional qualitative study. Time Points: 1 Data Collection: Semi-structured interviews Outcomes: supportive care needs	Demographic: Age: 46-79 years (mean 60 years), Gender: Male n28, female n6, Marital status: Married n12, Widow n3, Divorced n5, Single n2 Clinical: Ileal conduit n20, Neobladder n12 Time since surgery: 1-10 (mean of 5 years)	50.3% Selection bias is possible. Change over time was not assessed due to the cross sectional design. No measure of self-efficacy or Clavien-Dindo classification of complications and potential influences on supportive care needs
Ali et al., (1989)	Purpose: Determine the effect of a psychoeducational intervention to address unmet needs Setting: National Cancer Institute Cairo. Country: Egypt.	Sample Size: n30 (15 in each group experimental and control group) Sampling: Convenience Response Rate: Not reported. Attrition: Not reported. Design: Pre-test, post-test control group design Time Points: 3 rd day post operatively and the day of discharge. Data Collection: questionnaires and semi-structure interview. Outcomes: Anxiety State Trait self-report measure (STAI), qualitative verbatim.	Demographic: Intervention group: Age 45 years (SD 5.9), Gender: Men n11 (73%), Female n4 (27%), Marital Status: Married n14 (93%), single n1 (7%). Control group: Age: 45 years (SD 4.4), Gender: Men n12 (80%), Female n3 (20%), Marital Status: Married n13 (86%), Single n1 (7%), Widow n1 (7%). Clinical: Bladder cancer all planned urinary diversion. Cancer stage or grade not reported.	53.8% No measure of self-efficacy or Clavien-Dindo classification of complications and potential influences on supportive care needs. Limited date on the supportive care needs over time.