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What are the unmet supportive care needs of men affected by penile cancer? A systematic review of the empirical evidence.

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Introduction

Globally, penile cancer is an uncommon malignancy with reported incidence of 0.84 cases per 100,000 in globally (Sewell et al., 2015, Cardona and García-Perdomo, 2018). In contrast, the incidence is significantly higher in developing countries that are affected by economic disparity such as Brazil, India and African nations who have the highest reported incidence with rates as high as 6% of malignant neoplasms (Vieira et al., 2020). Penile cancer affects men over 18 years of age with the mean age of 55 years at the time of diagnosis. There is a range of treatment modalities for penile cancer depending on the stage of disease. The primary treatment for penile cancer is surgery, although in the case of precancerous changes or early stage malignancies, minimally invasive treatments such as topical chemotherapy with imiquimod or 5-fluorouracil (5-FU), laser therapy or brachytherapy may be applicable (Hakenberg et al., 2018). Surgical treatment involves the removal of the primary tumour lesion with or without performing inguinal and pelvic lymphadenectomy, depending on clinical indications or the histopathology. Surgical intervention includes the resection of the primary lesion by circumcision, glansectomy, a partial penectomy or a total penectomy amputation of the penis, (Hakenberg et al., 2018).

All treatments can be disfiguring and can have a profound negative impact on the patient's sexual function, quality of life (QOL), social interactions, self-image and self-esteem (Maddineni et al., 2009). Different modalities of treatment are associated with their own individual challenges for patients, complications, unique psychological burden, and unmet supportive care needs (Leem and Klaassen, 2018). A recent qualitative study identified that men and their loved ones affected by penile cancer can grapple with a range of needs which were inadequately addressed in routine care delivery with their urologist. Some men articulated that they had suicidal feelings following surgery, marital problems, sexual concerns, and practical issues around changes with urination (Gordon et al., 2017). Supportive care is defined as a person-centered 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., 2018). Little is known about the unmet supportive care needs experienced by patients and their loved ones affected by penile cancer, and the areas in which they most require assistance (Bullen et al., 2009). Individual supportive care needs can be classified into eleven primary domains of need (Paterson et al., 2015, Paterson et al., 2018) based upon domains of need in the literature (Maddineni et al., 2009) 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. The classification of supportive care needs domains are informed by the Supportive Care Needs Framework (Aranda and Yates, 2009). See **Table 1** for supportive care needs classification.

An existing systematic review (Maddineni et al., 2009), identified that 50% of men affected by penile cancer experienced psychological problems, 40% reported a negative impact on quality of life, and 70% of patients experienced difficulties with sexual function. Their review included only 128 patients, from 6 studies, of which 5 studies contained retrospective data and one study collected prospective data on erectile function only. This review does not identify the lived experienced of penile cancer, the impact that penile cancer can have on loved ones, or, importantly, the areas of unmet supportive care needs in care delivery. Gaining more knowledge of the experiences of men and their loved ones affected by penile cancer will provide important insights for healthcare providers to create a holistic model of care and clinical practice guidelines. Therefore, this systematic review will address the following clinically focused research questions:

1. What are the different domains of unmet supportive care needs of men and their loved ones affected by penile cancer?
2. What are the most frequently reported individual domains of unmet need in the current available literature?

Methods

This review was conducted using the systematic review methodology recommended by the European Association of Urology (Knoll et al., 2018) for clinical guidelines practice and the Preferred Reporting for Systematic Reviews (Moher et al., 2009). We published our review protocol in the International Prospective Register of Systematic Reviews, Prospero, available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018102376.

Eligibility Criteria

Types of studies

- We included qualitative and quantitative methods irrespective of research design.
- We excluded case reports, commentaries, editorials, and studies where unmet supportive care needs were not reported.

Types of participants

- We included adult men (≥18 years of age) with a confirmed histological diagnosis of penile cancer and their partners.
- All stages of disease and treatment modalities were included
- We excluded studies conducted with patients with mixed cancer groups, except when a separate sub-group analyses of only penile cancer patients were reported.

Types of Outcomes measures

The primary outcome of this review was non-oncological outcomes related to:

- Unmet supportive care needs (e.g. the Supportive Care Needs Survey (Boyes et al., 2009) and qualitative experiences.

Literature Search

The CINAHL, MEDLINE, PsychINFO, Embase, Cochrane Central Register of Controlled Trials (CCTR) and the Cochrane Database of Systematic Reviews (CDSR) databases and clinicaltrial.gov were searched for all relevant publications (date cut off 1990 to April 2020, limited to English language). Key words (penis cancer, penile neoplasms, unmet needs, health care need, patient care, psychological assessment) were mapped to each electronic database using the appropriate MeSH term, or used free search terms. The search architecture used a wide range of keywords and free text items to increase the sensitivity and specificity of the searches (see **Supplementary file 1**). Additional searches were performed in Index to Theses, Google Scholar, and Google. The references of relevant systematic reviews and original articles included in this current review were screened for studies potentially meeting our inclusion criteria.

Data collection and analysis

Selection of studies

Following de-duplication, four review authors (MB, BJ, CP, CP) independently screened the titles and abstracts of the identified records for eligibility. The full text of all potentially eligible records were retrieved and screened independently by the four reviewers using a standardised form, linking together multiple records of the same study in the process. Any disagreements were resolved by discussion.

Data extraction and management

All four review authors (CP, CP, MB, BJ) independently extracted the outcome data and compared for accuracy. Any disagreements were resolved by discussion. A standardised data extraction form was developed and piloted among the reviewers prior to its use. The extracted data included 'characteristics of included studies' (study design; countries and institutions where the data were collected; 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).

Assessment of risk of bias in included studies

Quality assessment of individual research studies were undertaken using two quality appraisal tools, one for studies reporting qualitative data (Shaw et al., 2009) and one for studies reporting quantitative data and have been used in a series of reviews. These tools were developed as part of a Health Technology Assessment Integrative Review (Shaw et al., 2009) and have been used in previous cancer care systematic integrative review publications (Paterson et al., 2018, Paterson et al., 2015). The quantitative appraisal tool assessed a range of designs including: RCT’s, non-randomized controlled studies, cohort, case-control, other observational studies (for example, interrupted time series, case series, cross-sectional designs) and were classified as “low”, “unclear” and “high” risk according to the criteria specific to each study design. Some items in the quantitative assessment tool are only relevant to RCT’s; therefore a “non-applicable” item option was available for other research designs. The qualitative appraisal tool has 15 items and three levels of quality assessment ranging from two to zero (see **supplementary Tables 2**).

Data synthesis

We used narrative synthesis approach to summarise the evidence. This involved tabulation of primary research studies, identifying similarities and differences within and between studies, and seeking explanations for these differences (Centre for Reviews and Dissemination, 2009). We undertook the following steps: data reduction and sub-group classification based on levels of evidence (Department of Health, 2001) and the review questions, narrative data comparison (iterative process of making comparisons and identifying relationships) and finally, drawing conclusions (Whittemore and Knafl, 2005). The level of evidence was categorised by typologies of supporting evidence identified by the

Department of Health in the National Service Framework, United Kingdom see **Table 2** (Department of Health, 2001).

Results

Search Results

Of the 1725 retrieved from the search, 1662 articles were excluded following the application of the inclusion and exclusion criteria during the title and abstract screening, see **Figure 1**. In total, 62 full-text publications were reviewed in full and 45 were excluded with reasons and 18 articles were included, reporting the results from 17 studies in the final review (Kieffer et al., 2014, Soh et al., 2014, Sosnowski et al., 2016, Wan et al., 2018, Windahl et al., 2004, Witty et al., 2013, Mortensen and Jakobsen, 2013, Skeppner and Fugl-Meyer, 2015, Skeppner et al., 2008, Opjordsmoen et al., 1994, Bhat et al., 2018, Bullen et al., 2010, Drager et al., 2017, Delaunay et al., 2014, Ficarra et al., 2000, Gordon et al., 2017, Bullen et al., 2009, D'Ancona et al., 1997, Bullen et al., 2010, Bullen et al., 2009). There was a range of study designs across the 17 included studies which underscores that this is a developing evidence base and these included: qualitative (n7) and survey (n10), see **Table 3**. The studies were conducted in a range of countries namely: Brazil (n1), India (n1), United Kingdom (n2), Germany (n1), France (n1), France/Spain (n1), Italy (n1), USA (n1), Denmark (n2), Norway (n1), Sweden (n3), Poland (n1), and China (n1). The sample sizes varied from n4 to n90 with a total sample size of n469 across the studies. Most of the participants in the included studies were married, over 50 years of age, and received heterogeneous therapies from minimally invasive therapy to total penectomy, see **supplementary Table 3**.

Quality Appraisal

The methodological quality assessment of the primary studies was conducted in parallel with the data extraction, **Table 4**. There are a number of shortcomings across the studies which included small sample sizes (Drager et al., 2017, Delaunay et al., 2014, Ficarra et al., 2000, Opjordsmoen et al., 1994, Sosnowski et al., 2016, Wan et al., 2018) lack of transparency in qualitative methodology (Mortensen and Jakobsen, 2013, Bhat et al., 2018, Ficarra et al., 2000) and limited reporting of the clinical and demographic characteristics across the study participants.

Frequency of supportive care needs documented in the literature

In descending order of the frequency of supportive care needs reported in the reviewed studies: intimacy/interpersonal needs (16/17), psychological emotional needs (14/17), physical needs (12/17), family related needs (7/17), health system information needs (7/17), social needs (5/17), daily living needs (3/17), patient/clinician communication (3/17), spiritual needs (3/17), practical needs (2/17), see **Table 5.**

Evidence of Unmet Supportive Care Needs by Domain

Men reported that the impact of penile cancer surgery affected physical, psychological, and sexual well-being with each facet impacting and being intertwined with the other at varying degrees. Thus, indicating the complexity of needs for men pre-surgery, during post-surgical care and into survivorship. The results are structured by the domains used in the supportive care needs classification (outlined in **Table 6**).

Interpersonal/Intimacy Needs

The devastating impact that a new diagnosis of penile cancer and related treatments was identified as a clinically significant theme across many of the studies related to unmet intimacy needs. Several studies identified that participants reported that their relationship with their partners was affected by sexual dissatisfaction (Bhat et al., 2018, Delaunay et al., 2014, Ficarra et al., 2000, Skeppner and Fugl-Meyer, 2015, Skeppner et al., 2008, Sosnowski et al., 2016, Wan et al., 2018). Moreover, in one study, 90% of the participants experienced anxiety in relation to their sexual performance (Bhat et al., 2018). Concerns about sexual performance affected both married and single men. Married men expressed long term concerns about satisfying their partners (Witty et al., 2013), and unmarried men avoided new relationships out of fear of ridicule, rejection (Bullen et al., 2010, Bullen et al., 2009) and perceptions that the scar would repulse women (Bullen et al., 2010, Bullen et al., 2009, Mortensen and Jakobsen, 2013). Studies illuminated frustrations due to an inability to achieve orgasm (Bullen et al., 2010, Bullen et al., 2009), which for some resulted in marital problems (Gordon et al., 2017, Opjordsmoen et al., 1994). Due to inevitable consequences of total penectomy, men expressed that they felt deprived of a sex life and considered this to be an aspect of life that is genuine and very natural (Gordon et al., 2017). Furthermore, sexual urges after total penectomy contributed to a disconnect between the sensory self and the physical self for some men (Witty et al., 2013). Men reported sexual distress in multiple areas related to sexual interest, quality of erections, early ejaculation and dyspareunia which was persistent following treatment (Windahl et al., 2004). Despite a range of complex concerns and sexual needs for men and their loved ones following treatment, little or no support was provided in care delivery in some of the narratives (Bullen et al., 2010, Bullen et al., 2009).

Psychological/Emotional Needs

The profound psychological impact of penile cancer and its associated treatments was evident across most (14/17) of the included studies. Men articulated concerns related to their ability to disclose their penile cancer diagnosis to family and friends (Gordon et al., 2017) due to feelings of embarrassment. Patients experienced difficulties in coping with the fear of dying (D'Ancona et al., 1997), the impact of mutilation and associated lack of sexual pleasure (D'Ancona et al., 1997), altered perceptions of masculinity (Bhat et al., 2018, Bullen et al., 2010, Bullen et al., 2009, Mortensen and Jakobsen, 2013), embarrassment and stigma (Bullen et al., 2010, Bullen et al., 2009, Gordon et al., 2017), altered body image (Kieffer et al., 2014), feelings of sorrow, anxiety and sadness (Drager et al., 2017, Gordon et al., 2017, Skeppner et al., 2008, Witty et al., 2013), shock (Gordon et al., 2017), fear (Gordon et al., 2017), denial (Gordon et al., 2017) and reduced self-esteem (Sosnowski et al., 2016). One study identified that some men developed panic attacks which manifested in stomach aches and breathing difficulties (Mortensen and Jakobsen, 2013). Other men experienced social phobia and post-traumatic stress disorders with subsequent alcohol abuse (Opjordsmoen et al., 1994). Major depression was associated with complete sexual dysfunction for some men (Opjordsmoen et al., 1994, Windahl et al., 2004). Men articulated fear related to the physical scar which made them worry that their cancer had returned (Witty et al., 2013). Across several studies patients reported feeling very scared and experienced multiple episodes of feeling suicidal (Gordon et al., 2017), anxiety and depression with the need for psychosocial interventions but they did not receive any help or the necessary referrals (Drager et al., 2017, Ficarra et al., 2000, Mortensen and Jakobsen, 2013, Witty et al., 2013). Moreover, loved ones also reported being at risk of anxiety at the time of their partners diagnosis and into the survivorship journey (12 months later) (Skeppner and Fugl-Meyer, 2015) suggesting the need for appropriate on-going support as a couple. The need for psychosocial interventions for couples was echoed elsewhere as men talked about grappling with severe mood swings which was damaging and had a negative impact on their relationship with their partners (Witty et al., 2013). Finally, men reported a lack of information prior to surgery which affected their emotional well-being post treatment and beyond (Witty et al., 2013).

Physical Needs

The physical impact of treatment varied considerably across the included studies. Twelve studies (Bullen et al., 2009, D'Ancona et al., 1997, Delaunay et al., 2014, Drager et al., 2017, Ficarra et al., 2000, Gordon et al., 2017, Kieffer et al., 2014, Mortensen and Jakobsen, 2013, Skeppner and Fugl-Meyer, 2015, Sosnowski et al., 2016, Wan et al., 2018, Witty et al., 2013), identified the unmet physical needs of men affected by penile cancer. The physical difficulties were far ranging and included: discomfort and difficulties urinating (D'Ancona et al., 1997, Drager et al., 2017, Gordon et al., 2017, Kieffer et al., 2014, Mortensen and Jakobsen, 2013, Wan et al., 2018, Witty et al., 2013) problems with sleeping and reduced physical strength (Bullen et al., 2010, Bullen et al., 2009), limitations in mobility (Drager et al., 2017, Witty et al., 2013), genital pain (Delaunay et al., 2014, Drager et al., 2017, Mortensen and Jakobsen, 2013, Skeppner and Fugl-Meyer, 2015), exhaustion (Drager et al., 2017, Witty et al., 2013), changes in sensation of the penile gland (Delaunay et al., 2014, Skeppner and Fugl-Meyer, 2015), altered penile appearance (Delaunay et al., 2014), frequent bleeding and meatal stenosis (Delaunay et al., 2014), reduced general state of health (Ficarra et al., 2000, Mortensen and Jakobsen, 2013, Sosnowski et al., 2016), penile swelling and itching (Gordon et al., 2017), erectile dysfunction (Gordon et al., 2017), retarded ejaculation/anejaculation (Skeppner and Fugl-Meyer, 2015), concerns related to lymphoedema due to lymph node dissection (Witty et al., 2013) and post-surgical infections which inhibited men from moving on emotionally and physically (Witty et al., 2013).

Family Related Needs

The impact of penile cancer had a profound negative impact on the family unit. Concerns were shared across several studies related to young men who were diagnosed with penile cancer and the implications for having children (Bullen et al., 2010, Bullen et al., 2009, Mortensen and Jakobsen, 2013). Other men spoke about the difficulties in maintaining their role as a husband, lover and father. In one study, the partners articulated their own unmet needs in coping with their husband’s diagnosis (Gordon et al., 2017) and suggested that partners needs were not being addressed in care provision. Evidence has acknowledged that penile cancer profoundly affected the dyadic processes of couples’ adjustment and related communication together (Skeppner and Fugl-Meyer, 2015). Some individuals experienced communication breakdown, and martial crisis after treatment (Opjordsmoen et al., 1994). Some men subsequently divorced due to problems after therapy (Opjordsmoen et al., 1994), but other contextual factors which might have affected marriage breakdown for these couples were not clear. Elsewhere, wives of men affected by penile cancer “understood and accepted” sexual dysfunction as an inevitable consequence of treatment (Soh et al., 2014). Moreover, men viewed the support from their wives as an important factor with coping with the impact of surgery (Witty et al., 2013).

Health System/Information Needs

A central theme resonated in relation to inadequate informational support and provision. Men articulated that they felt “poorly informed” in relation to the consequence of treatment on quality of life, sexuality, with a general lack of information across the cancer trajectory (Delaunay et al., 2014, Witty et al., 2013). Patients shared their concerns and frustrations regarding a perceived lack of the doctor’s knowledge and ability to provide a timely and accurate cancer diagnosis, as some men were misdiagnosed for many months (Gordon et al., 2017, Mortensen and Jakobsen, 2013). Others described a fragmented care pathway with little or no access to supportive care or rehabilitation (Mortensen and Jakobsen, 2013) within their healthcare system (Gordon et al., 2017). Other challenges were in relation to public health and the need to raise the profile of awareness of the early signs and symptoms of penile cancer. Some men delayed seeking medical attention by one-and-a-half years to two years due to a lack of knowledge and feelings of embarrassment (Mortensen and Jakobsen, 2013, Skeppner et al., 2008). Men articulated that they would have benefited greatly from counselling and psychosocial services within their healthcare system, but these were never offered (Witty et al., 2013).

Social Needs

Men voiced a reduced level of social functioning (Sosnowski et al., 2016). Following treatment some men experienced low confidence levels and struggling to interact with others in social circles (Witty et al., 2013). The impact of an altered body image inhibited some men participating in social activities which involved wearing shorts due to the belief that they perceived the public would see that they have had a penectomy (Witty et al., 2013). Some other men's narratives indicated that they needed access to cubicles to sit to urinate, and urination was helped by aids such as funnels (Witty et al., 2013).

Daily Living Needs

Men experienced a restriction on their daily lives when out in public due to urination challenges post treatment (Bullen et al., 2010, Bullen et al., 2009, Kieffer et al., 2014, Witty et al., 2013). Men needed public access to disabled toilets when away from home (Witty et al., 2013, Bullen et al., 2010, Bullen et al., 2009) which was problematic at times. Men also articulated daily living concerns due to inability to work and remain the status of the "breadwinner" (Bullen et al., 2010, Bullen et al., 2009).

Patient-Clinician Information Needs

Across the included studies several highlighted critical short-comings and limitations in routine service delivery in relation to support, information and access to rehabilitation (Bullen et al., 2010, Bullen et al., 2009, Witty et al., 2013). Men articulated a lack of self-management advice from healthcare professionals in relation to sexuality and learning to cope with new ways of urination post-treatment (Bullen et al., 2010, Bullen et al., 2009). Noteworthy, across all the studies none of the participants referred to having access to specialist nurses at diagnosis, during treatment or into survivorship. Furthermore, some men reported a lack of person-centered care with a lack of trust and compassion from their treating clinician (Gordon et al., 2017). This illuminates some fundamental elements of care provision that needs addressing in clinical practice to improve patient care and experience.

Spiritual Needs

Men experienced existential threat (Mortensen and Jakobsen, 2013) accompanied by feelings of shock, disbelief, fear and disappear (Bullen et al., 2010, Bullen et al., 2009). The diagnosis of penile cancer and its associated treatments (Gordon et al., 2017) challenged men's' manhood with multiple accounts of suicidal ideation. Several men expressed to have lost faith at some point during the sickness trajectory (Gordon et al., 2017).

Practical Needs

Following treatment men reported practical needs related to urination and mobility (Bullen et al., 2010, Bullen et al., 2009, Witty et al., 2013). Men reported that urination was helped by using aids, such as funnels, re-training themselves in self-management behaviours, including sitting down to urinate and accessing a cubical. These strategies were important to reduce spraying and dribbling of urine down their legs.

Cognitive Needs

None of the included studies provided accounts of cognitive needs of men affected by penile cancer.

Partners

Across the included studies only two studies included partners (Bhat et al., 2018, Skeppner and Fugl-Meyer, 2015) which limits understanding of the unmet supportive care need domains from the partners perspective. Bhat and colleagues identified that in all patients the relationship with their partners was affected by sexual dissatisfaction with 90% of the men reported anxiety about their sexual performance. Moreover, partners reported being at risk of anxiety at the time of their partners diagnosis and into the survivorship journey (12 months later) (Skeppner and Fugl-Meyer, 2015) suggesting the need for appropriate on-going support as a couple. Cancer affected the dyadic processes of the couple's adjustment and reduced communication together (Skeppner and Fugl-Meyer, 2015). Moreover, where partners accompanied the men during their interviews, they expressed their need to share their own perspectives on the experience of penile cancer but these accounts were not reported (Gordon et al., 2017).

Discussion

The rarity of penile cancer represents a significant challenge to the patient, partner and healthcare professional, at each step along the cancer care continuum, from diagnosis to treatment and into survivorship. Undisputedly, given the severity of treatment options and associated consequences of urinary and sexual dysfunction, coupled with psychological effects and altered perceptions of masculinity, identifying the unmet supportive care needs of patients and their loved ones affected by penile cancer is paramount to inform service delivery. This systematic review has made an important clinical contribution by informing multidisciplinary healthcare professionals about the complex person-centred supportive care needs in this relatively small patient population.

The problems for men and their partners affected by penile cancer were diverse and complex which requires a sensitive and compassionate approach to the provision of necessary services. Many men shared in their narratives that they “sat” on their symptoms for many months, if not years, before seeking medical attention due to a lack of general knowledge about the early signs and symptoms of penile cancer, and feelings of embarrassment. Some men also shared their frustrations and anger that they had been misdiagnosed, or outright dismissed, by medical staff which led to a delay in receiving their cancer diagnosis and subsequent treatment. Penile cancer is a rare condition that very few healthcare professionals will ever encounter excluding the Urologists or healthcare professionals based in supra-regional centres (Vanthoor et al., 2019). Therefore, greater attention is needed to raise the profile of this condition. We can learn from the successful strategies from our prostate and breast cancer campaigners historically.

This systematic review of the unmet needs of men and their loved ones affected by penile cancer, not unsurprisingly, revealed a profound negative psychological impact and a lack of support provided to them in care provision. Distress was experienced along a continuum ranging from normal feelings of vulnerability, sadness and fear because of a cancer diagnosis, to overwhelming episodes of suicidal tendencies, deep depression and anxiety in several other studies. Evidence has clearly identified that coping strategies can help to manage the psychological and physical stressors associated with cancer and treatment (Paterson et al., 2013). Broadly, coping is defined as cognitive and/or behavioural attempts to manage situations that are appraised as stressful to an individual. The transactional process of stress and coping theory (Folkman and Lazarus, 1984) details the central importance of support (informational, emotional, practical) on improving quality of life outcomes for people affected by cancer. Based on the findings of this systematic review, there is a notable lack of literature investigating whether support (informational, emotional and practical) moderates or mediates the relationship between coping and distress for men affected by penile cancer. Future studies should also examine predictor variables such as education, socio-economic status, employment, and clinical variables across various coping strategies to help stratify those at risk of distress. This review has demonstrated that couples affected by penile cancer are required to cope and adjust in every aspect of their lives. Given the under-recognition of psychological needs of men and their partners, we recommend the routine use of patient-reported Holistic Need Assessments (Biddle et al., 2016) in clinical practice to identify patients at risk to enable “timely referrals” for psychosocial care. Successful integration of standardized and validated holistic needs assessments has been well established in other tumor groups, including other urological cancers (Howell et al., 2015, Primeau et al., 2017).

Of all the urogenital cancers, the one that most obviously jeopardizes sexual function is penile cancer. Several studies identified that healthcare providers failed to initiate conversations about the impact of treatment on sexuality and relationships, rehabilitation and “individual identities”. Developing survivorship care programs to address areas of unmet needs might incorporate existing theoretical concepts of masculinity (Alexis and Worsley, 2018) to support men to adapt and re-construct their own ideas of self and sexuality. Masculinity was a prominent theme in the patient voices across the included studies. Moreover, we recommend a multidisciplinary follow-up with psychologists trained in sex therapy to be considered in the prehabilitation phase of treatment decision-making to help patients and their partners to discuss their feelings around intimacy and sexual well-being. The clinical need for developing shared interventions for couples was evidenced in this systematic review, but of note, only two studies (Bhat et al., 2018, Skeppner and Fugl-Meyer, 2015) included partners. In 21st century healthcare, we acknowledge that cancer not only affects the person who is diagnosed with cancer but also their family/loved ones (Berg and Upchurch, 2007). Thus, future research is needed to further explore the needs and preferences for support from the partners’ perspective. Moreover, men’s and their partners’ narratives identified that they experienced shock from seeing the results of the surgery which results in a negative impact on sexual well-being. We therefore need to develop and evaluate pre-surgical interventions and patient counselling to foster realistic expectations for the couple about recovery and the impact on broader aspects of quality of life. Currently there is no penile cancer specific quality of life (QOL) instrument with demonstrated reliability and validity to assess changes in QOL over time. Therefore, a further recommendation is that future research should focus on developing an instrument for research and clinical use in practice.

Limitations

One of the major challenges of this review was combining heterogeneous study designs and methodologies, and our findings are constrained due to the methodological limitations of the primary studies included. We excluded case reports as defined as a singular report on one individual patient which might have missed experiential accounts in the literature. Furthermore, we included qualitative and quantitative studies to elicit how unmet needs were expressed by the participants without being necessarily assessed as a primary objective in the included studies, which may have introduced bias. We included international literature which was a strength to understand the experience of unmet supportive care needs of men and their loved one affected by penile cancer globally. Given the relatively small numbers of participants included in this review we were not able to identify any discernible trends in unmet needs internationally based on treatments types or other clinical subgroupings. Despite the limitations, the review team followed a rigorous and transparent review methodology and reporting based upon the PRIMSA to promote re-producibility. This review has enabled a broad summary of the evidence which has importantly provided some clinical practice recommendations and facilitated refinement of the future research directions.

Conclusion

This systematic review underscores the need for clinical service reconfiguration internationally to develop new approaches and standardized ways to identify and address the profound unmet supportive care needs of men and their partners affected by penile cancer. What is clear from this review is that we need interdisciplinary clinicals team (specialist nurses, psychologists, urologists, plastic surgeons and sex therapists) working together to promote a person-centered model of rehabilitative care from diagnosis and into survivorship. Future research recommendations include the need for a consensus approach given the challenges of higher quality studies in the context of rare diseases.

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Table 1. Classification of the supportive care needs.

Domain of need	**Definition**
Physical needs	Experience of physical symptoms such as fatigue, pain, management of bladder voiding, 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/economic 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 2. Evidence categories used by the Department of Health in the National Service Framework.

Typologies of supporting evidence
A1 Systematic reviews, which include at least one randomized control trial (RCT), e.g. systematic reviews from Cochrane. A2 Other systematic and high-quality reviews. B1 Individual RCTs. B2 Individual non-randomized, experimental/interventional studies. B3 Individual well-designed non-experimental studies, controlling statistically if appropriate. Includes case control, longitudinal, cohort, matched pairs or cross-sectional random sample methodologies, and well-designed qualitative studies, well-designed analytical studies including secondary analysis. C1 Descriptive and other research or evaluations not in B (e.g. convenience samples). C2 Case studies and examples of good practice. D Summary review articles and discussions of relevant literature and conference proceedings not otherwise classified.

Table 3. Overview of the included studies.

Author and Year	Purpose	Setting	Country	Sample size	Sampling	Response Rate	Attrition	Design	Time points	Data collection tools
Bhat et al. (2018)	To evaluate sexuality in men and their partners affected by penile carcinoma	General Hospital, Honovar, Karnataka State, Rangadorai Memorial Hospital, TSS Shripad Hedge Kadave Institute of Medical Sciences	India	N = 12 and N = 12 partners	Convenience	Not reported.	N/A	Cross-sectional survey	1 (6 years after the surgery)	SFQ. Qualitative interview design is not reported.
Bullen et al. (2009), reporting the same study as Bullen et al., 2010	To examine the experiences of penile surgery for men affected by penile carcinoma.	Large District General Hospital	United Kingdom	N = 9	Purposive sample	47%	N/A	Cross-sectional qualitative	1 (>18 months after surgery and <5 years after surgery)	Semi-structured interviews with 6–8 questions, audio taped and transcribed verbatim

Bullen et al. (2009), reporting the same study as Bullen et al., 2010	To examine the experiences of penile surgery for men affected by penile carcinoma.	Large District General Hospital	United Kingdom	N = 9	Purposive sample	47%	N/A	Cross-sectional qualitative	1 (>18 months after surgery and <5 years after surgery)	Semi-structured interviews with 6–8 questions, audio taped and transcribed verbatim
D'Ancona et al. (1997)	To investigate the impact of partial penectomy on the quality of life	Universitidade Estadual de Campinas	Brazil	N = 14	Convenience	87.5%	N/A	Cross-sectional survey	1 (11.5 months, range 6–72 months since treatment)	Semi-structured interview and 4 standardized questionnaires (QSFQ, SPQ, GHQ-12, HADS). No details reported for the qualitative component.
Drager et al. (2017)	To examine psychosocial distress and psychosocial need for patients	University Hospital	Germany	N = 40	Convenience	100%	N/A	Cross-sectional survey	1 (prior to surgery at time of preadmission)	NCCN-DT, HIS

	affected by penile carcinoma									
Delaunay et al., 2014	To evaluate the sexual function and behaviour after brachytherapy for penile carcinoma	Large District General Hospital	Spain/France	N = 19	Convenience	90%	N/A	Cross-sectional survey	1 (12.8–189.8 months after treatment)	BASIC IDEA, IIEF
Ficarra et al. (2000)	To evaluate health and psychological well-being in a group of 155 patients after surgery for urological malignant neoplasms (n16 penile cancer data reported separately)	University Hospital	Italy	N = 16	Convenience	Not reported.	N/A	Cross-sectional survey	1 (average of 69 months after treatment)	ECOG, GHQ, HADS. Interviews. No details provided on the qualitative component of the study.
Gordon et al., 2017	To explore men's and their family's experiences of healthcare	Comprehensive Cancer Centre, University Hospital	USA	N = 13	Purposive Sampling	Not reported	none	Cross-sectional qualitative	1 (>3 months after diagnosis)	Face to face semi-structured interview, 45–60 min.

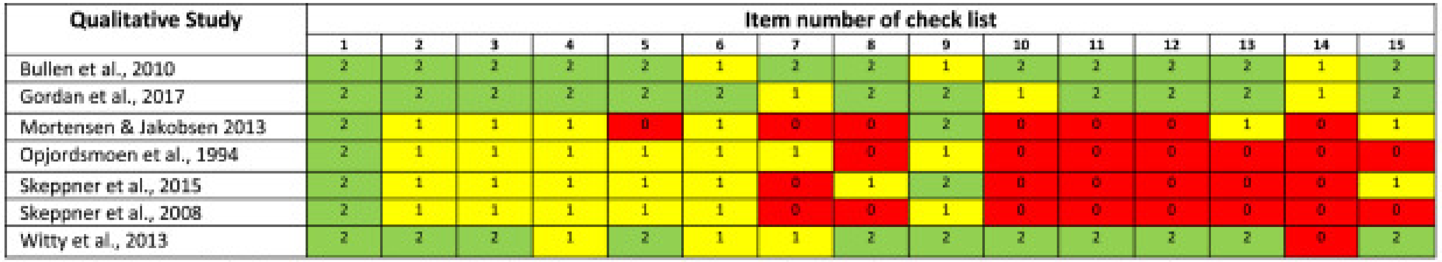
	in the context of penile carcinoma									
Kieffer et al. (2014)	To evaluate sexuality, HRQoL and concerns in men affected by penile cancer	1 tertiary cancer centre	Denmark	N = 90	Convenience	61%	N/A	Cross-sectional survey	1 (mean time since surgery 3.9 years, 0.1–6.8 years)	IIEF-15; SF-36, IOC
Mortensen and Jakobsen, 2013	To explore men's experience of penile cancer.	3 settings: Hospital, GP and sexologists.	Denmark	N = 4	Cross-sectional qualitative	Not reported	N/A	Cross-sectional qualitative	1 (within 6 months of treatment)	Semi-structured interviews. Duration of the interview not reported.
Opjordsmoen et al. (1994)	To evaluate sexuality after treatment of penile cancer	1 tertiary cancer centre	Norway	N = 28	Convenience	93.3%	N/A	Cross-sectional qualitative	1 (80, 11–225 months post treatment)	One-to-one interviews and the following questionnaires: PAIS, GHQ, EORTC QLQ C-30.
Skeppner et al., 2015	To describe the dyadic sexual well-being and quality of life satisfaction	1 tertiary cancer centre	Sweden	N = 29 couples for all three interviews time points	Convenience	Not reported	83% at baseline, 71% at the end of study	Cross-sectional qualitative	3 (before surgery, at 6 and 12 months post treatment)	Semi-structured Interviews. LiSat-11, HADS, IIEF-5.

	before and one year after organ-sparing laser treatment for penile carcionoma.									
Skeppner et al. (2008)	To describe the effect of laser treatment on sexual activity and life satisfaction.	1 tertiary cancer centre	Sweden	N = 46	Convenience	79%	N/A	Cross-sectional qualitative	1 (mean 4.5, 66 months to 15 years post treatment)	Interviews (lasted 1 h) and questionnaires. Unreported questionnaire (containing questions on initial symptoms, treatment seeking, sexual function/dysfunction and sexual activity) and LISat-11
Soh et al. (2014)	To assess sexual function and behaviours of men affected by penile cancer	2 tertiary hospitals in France.	France	N = 19 patients and N = 19 age-matched controls	Pair-matched controls	95%	N/A	Cross-sectional survey	1 (survey conducted 2010, time since treatment not reported)	IIEF-15; Questionnaire developed for the study using the BASIC IDEA grid - reliability and

										validity not reported.
Sosnowski et al., 2016	To evaluate sexuality, HRQoL and concerns of men affected by penile cancer	1 tertiary cancer centre	Poland	N = 10	Convenience	91%	N/A	Cross-sectional survey	1 (16, range 7–49 months post treatment)	EORTC-C30, SES, CMNI, IIEF-15, IPSS
Wan et al. (2018)	To prospectively evaluate self-esteem and relationships, HRQoL in men affected by penile cancer	1 tertiary cancer centre	China	N = 15	Convenience	Not reported	N/A	Prospective longitudinal survey	2 (Time 1 4 weeks before surgery; Time 2 6 months after surgery)	IIEF-15, SEAR, EDITS
Windahl et al. (2004)	To explore sexual function, satisfaction and cosmetic results for men affected by penile cancer	1 tertiary cancer centre	Sweden	N = 46	Convenience	79%	N/A	Cross-sectional survey	1 (median 3 years, 6 months to 15 years post treatment)	IIEF, LiSat-11, Questionnaire Perceived Cosmetic Results - reliability and validity not reported.

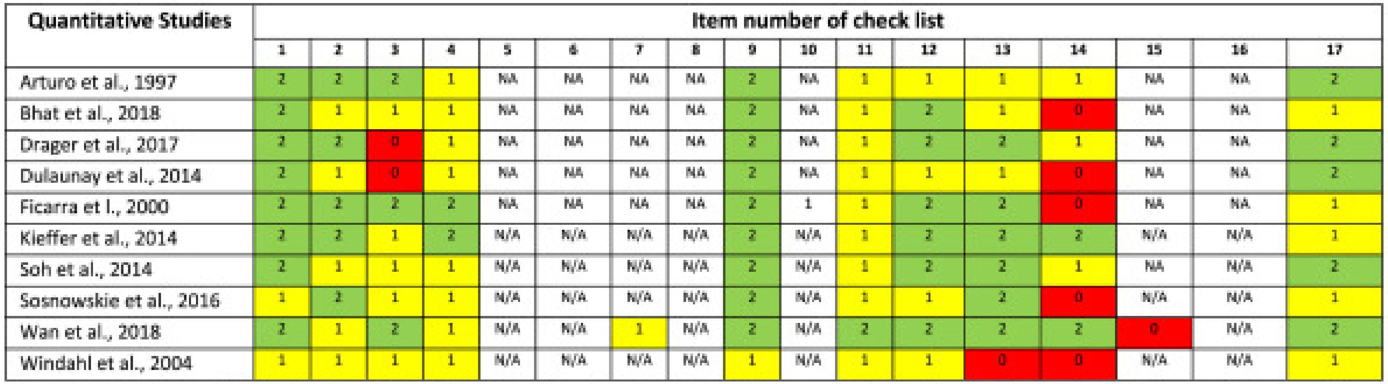
Witty et al. (2013)	To explore men's experiences of living with penile cancer.	9 multidisciplinary healthcare teams in England and Wales	United Kingdom	N = 28	Purposive sampling with maximum variation	Not reported	1 men withdrew consent at transcript checking stage	Cross-sectional qualitative study	1 (median 3, 0–15 years post treatment)	n28 qualitative interviews (37 min–2 h 17 min, average interview was 66 min)

Table 4. Quality appraisal of primary studies



Qualitative Study	Item number of check list														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Bullen et al., 2010	2	2	2	2	2	1	2	2	1	2	2	2	2	1	2
Gordan et al., 2017	2	2	2	2	2	2	1	2	2	1	2	2	2	1	2
Mortensen & Jakobsen 2013	2	1	1	1	0	1	0	0	2	0	0	0	1	0	1
Opjordsmoen et al., 1994	2	1	1	1	1	1	1	0	1	0	0	0	0	0	0
Skeppner et al., 2015	2	1	1	1	1	1	0	1	2	0	0	0	0	0	1
Skeppner et al., 2008	2	1	1	1	1	1	0	0	1	0	0	0	0	0	0
Witty et al., 2013	2	2	2	1	2	1	1	2	2	2	2	2	2	0	2

Item number check list key*: 1 research question clearly described, 2 qualitative method appropriate, 3 setting/context clearly described, 4 sampling strategy clearly described, 5 sampling method likely to recruit all relevant cases, 6 characteristics of the sample provided, 7 rationale of sample size given, 8 methods of data collection clearly described, 9 method of data collection appropriate for research question and paradigm, 10 has researcher verified data (e.g. by triangulation), 11 data analysis methods clearly described, 12 data analysis methods appropriate, 13 competing accounts/deviant data taken into account, 14 to what extend is the researcher reflective, 15 interpretations and conclusions supported by the data.



Quantitative Studies	Item number of check list																
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Arturo et al., 1997	2	2	2	1	NA	NA	NA	NA	2	NA	1	1	1	1	NA	NA	2
Bhat et al., 2018	2	1	1	1	NA	NA	NA	NA	2	NA	1	2	1	0	NA	NA	1
Drager et al., 2017	2	2	0	1	NA	NA	NA	NA	2	NA	1	2	2	1	NA	NA	2
Dulaunay et al., 2014	2	1	0	1	NA	NA	NA	NA	2	NA	1	1	1	0	NA	NA	2
Ficarra et l., 2000	2	2	2	2	NA	NA	NA	NA	2	1	1	2	2	0	NA	NA	1
Kieffer et al., 2014	2	2	1	2	N/A	N/A	N/A	N/A	2	N/A	1	2	2	2	N/A	N/A	1
Soh et al., 2014	2	1	1	1	N/A	N/A	N/A	N/A	2	N/A	1	2	2	1	NA	N/A	2
Sosnowskie et al., 2016	1	2	1	1	N/A	N/A	N/A	N/A	2	N/A	1	1	2	0	N/A	N/A	1
Wan et al., 2018	2	1	2	1	N/A	N/A	1	N/A	2	N/A	2	2	2	2	0	N/A	2
Windahl et al., 2004	1	1	1	1	N/A	N/A	N/A	N/A	1	N/A	1	1	0	0	N/A	N/A	1

Item number check list key*: 1 is the hypothesis/aim/objective clearly described, 2 is the study design well described and appropriate, 3 method of patient/control group selection clearly described, 4 characteristics of the patient/control group clearly described, 5 were patients randomised to the intervention group, 6 was randomisation/allocation concealed, 7 characteristics of patients lost to follow-up clearly described, 8 intervention clearly described, 9 main outcome measures clearly described, 10 was an attempted made to blind those measuring the primary outcome of the intervention, 11 population characteristics adequately described and controlled, 12 main findings clearly described, 13 methods of analysis appropriately and clearly described, 14 estimates of variance reported for main results, 15 analyses adjusted for different lengths of follow-up, 16 data analysed according to intention to treat principle, 17 conclusions supported by the results

*Three levels of assessment quality scores

🟩 Low risk of bias (2)
🟨 Unclear risk of bias (1)
🟥 High risk of bias (0)

Table 5. Frequency of unmet needs by domain.

Study	Cognitive Need	Physical Needs	Psychological/ Emotional Needs	Family Related Needs	Social Needs	Interpersonal/ Intimacy Needs	Practical Needs	Daily Living Needs	Spiritual Needs	Health System/ Information Needs	Patient-Clinician Communication	Number of domains explored within each study
Arturo et al., 1997 (Brazil)	-	✓	✓	-	✓	-	-	-	-	-	-	3
Bhat et al. (2018) (India)	-	-	✓	-	-	✓	-	-	✓	-	-	3
Bullen et al. (2009), 2010 (UK)	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10
Drager et al. (2017) (Germany)	-	✓	✓	-	-	✓	-	-	-	✓	-	4
Delaunay et al., 2014 (Spain/France)	-	✓	-	-	-	✓	-	-	-	✓	-	3
Ficarra et al. (2000) (Italy)	-	✓	✓	-	-	✓	-	-	-	-	-	3
Gordon et al., 2017 (USA)	-	✓	✓	✓	✓	✓	-	-	✓	✓	✓	8
Kieffer et al. (2014) (Denmark)	-	✓	✓	-	-	✓	-	✓	-	-	-	4

Mortensen and Jakobsen (2013) (Denmark)	-	✓	✓	✓	-	✓	-	-	-	✓	-	5
Opjordsmoen et al. (1994) (Norway)	-	-	✓	✓	-	✓	-	-	-	-	-	3
Skeppner et al., 2015 (Sweden)	-	✓	✓	✓	-	✓	-	-	-	-	-	4
Skeppner et al. (2008) (Sweden)	-	-	✓	-	-	✓	✓	-	-	✓	-	4
Soh et al. (2014) (France)	-	-	-	✓	-	✓	-	-	-	-	-	2
Sosnowski et al., 2016 (Poland)	-	✓	✓	-	✓	✓	-	-	-	-	-	4
Wan et al. (2018) (China)	-	✓	-	-	-	✓	-	-	-	-	-	2
Windahl et al. (2004) (Sweden)	-	-	✓	-	-	✓	-	-	-	-	-	2
Witty et al. (2013) (UK)	-	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	9
Number of domains explored across all studies	0	12	14	7	5	16	2	3	3	7	3	

Table 6. Unmet supportive care needs.

Author and Year	Physical Needs	Psychological/Emotional Needs	Cognitive Needs	Patient-Clinician Information Needs	Health System/Information Needs	Spiritual Needs/Existential	Daily Living Needs	Interpersonal/intimacy Needs	Practical Needs	Family Related Needs	Social Needs
Bhat et al. (2018)	Not reported.	Sexual interest was less in partners of patients with the partial penectomy. Masculine image was intact with those with partial and lost in those with total penectomy	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	In all patients the relationship with their partners was affected by sexual dissatisfaction. 90% of the patients had anxiety about their performance.	Not reported.	Not reported.	Not reported.
Bullen et al. (2009): reporting same results as	Reduced physical strength and inability to work and participate in exercise. The physical consequences of surgery for sexual and urinary function was life changing. Difficulties with sleeping.	Men noted change in sense of masculinity. Profound psychological impact of a cancer diagnosis and implications of having surgery. When seeking support men were faced with the dilemma for keeping the diagnosis a secret due to embarrassment and stigma.	Not reported.	Limitations noted in rehabilitation and patients express that this was a trial and error process. Lack of advice on how to cope with the sexuality and urination.	Lack of awareness of the implications of surgery and lack of counselling about the inability to have penetrative sex. Missed and incorrect diagnosis	Existential threat and concerns of feelings of shock and disbelief accompanied with feelings of fear and disappear.	Men required to sit down to urinate due to inability to control urine flow. This leads to concerns about restroom use (cleanliness, embarrassment). Patients reported inability to return to work, maintain their status as “breadwinner"	Married men expressed long term concerns about satisfying partner, unmarried men avoided new relationships out of fear of ridicule and rejection. Majority of men reported friendships and relationships were damaged or lost. One wife was noted to cry and state “what have they done” when viewing the surgical results for the first time. Men and partners report frustration because of inability to achieve orgasm and the inability to do anything about it.	Men expressed difficulty with walking.	Implications of having children. Challenges of maintaining roles as husband, lover and father.	Some men expressed they no longer participate in sports or drinking activities with social groups. Need to avoid communal showers/changing rooms.
D'Ancona et al., 1997	Discomfort of having to sit down during urination.	The impact of diagnosis and treatment resulted fears of mutilation and a lack of sexual pleasure. Fear of dying and the consequences for the family. Significant anxiety of depression was reported (HADS).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	2 patients out of 14 reported being a little unsatisfied with their job as well as having financial difficulties, both of which became worse after surgery.

Drager et al. (2017)	Difficulties with urination, limitations in mobility and pain and exhaustion.	42.5% of the men reported a need for psychosocial help. Patients reported sorrow, anxiety and sadness.	Not reported.	Not reported.	Patients reported increased psychological distress and need for psychosocial care	Not reported.	Not reported.	16% reported sexual dysfunction needs.	Not reported.	Not reported.	Not reported.
Dulaunay et al. (2014)	Needs related to changes in sensations of the gland, discomfort/pain, altered appearance, frequent bleeding and rate of meatal stenosis was 21.1%.	Not reported.	Not reported.	Not reported.	Men report being “poorly informed” regarding consequences of penile brachytherapy on sexuality and a general lack of information.	Not reported.	Not reported.	Some men reported being unsatisfied with sexual life.	Not reported.	Not reported.	Not reported.
Ficarra et al. (2000)	General state of health was impaired in 37.5% of patients undergoing partial penectomy which was statistically significant (p = 0.008) compared to controls (non-malignant BHP surgical patients).	Depression was observed in 6.8% of patients undergoing partial penectomy. Pathological levels of anxiety was reported in 31% of patients undergoing partial penectomy.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Altered function and ability in sexual activity and performance.	Not reported.	Not reported.	Not reported.
Gordon et al., 2017	Urination and side effects which included: lack of control urination, swelling, itching; and erectile dysfunction.	Concerns related to the ability to disclose diagnosis to family and friends. Barriers related to fear of stigmatisation and embarrassment; psychological distress in coping with the emotional turmoil including shock-anxiety -anger-fear-denial. Men expressed being very scared and multiple episodes of feeling suicidal.	Not reported.	A lack of trust and dissatisfaction with trajectory of diagnosis to treatment. Lack of professional help with changes in sexual life and physical function. Lack of compassion.	Lack of doctor's knowledge and ability to provide timely and accurate diagnosis. No access to supportive care.	Challenges to manhood, acceptance and multiple accounts of suicidal ideation. Several men have lost faith at some point during the sickness trajectory.	Not reported.	Several men expressed that penile cancer resulted in marital problems. Lack of support from partners, wives not visiting in hospital after surgery. Men felt that treatment ruined their sex life. They were being deprived of something genuine and very natural, sex life.	Not reported.	The spouses that accompanied the patients in the interviews expressed their own needs and impact of penile cancer.	Fear of creating a mess when using other people's toilet.
Kieffer et al. (2014)	The most frequently reported reasons for leakage included spraying urine flow n (NR) (35%) and that the penile was too short n (NR) (35%). Approximately, a quarter of the men reported having to sit while	Men who underwent partial penectomy reported significantly more appearance concerns than men treated by penile sparing surgery p = .008). Patients reported worry.	Not reported.	Not reported.	Not reported.	Not reported.	Patients treated by partial penectomy reported more concerns with life interferences than men treated with penile sparing surgery	No significant differences observed for erectile function, sexual desire, intercourse satisfaction or over satisfaction between both treatment groups P > .05. A significant difference was observed in	Not reported.	Not reported.	Not reported.

	urinating because of the perineal urethrostomy.						p = .032. Details of the specific areas of life interferences were not reported.	orgasmic function in favour of the penile sparing patient group p = .033.			
Mortensen & Jakobsen (2013)	Complications with closed urinary tracts was painful and men reported of being upset to perform self-catheterisation. General decline in physical function. Challenges with sitting down to urinate.	Loss of masculinity. Some men develop panic attacks manifesting as stomach aches and breathing difficulties. Unmanaged anxiety issues.	Not reported	Not reported	Most of the participants delayed seeking medical attention by 1.5–2 years due to feelings of embarrassment. None of the participants were offered any form of rehabilitation.	Fear of dying.	Not reported	None of the mature relationship experience an impact on the sex life that was of adversely affected on the relationship due to being older. Younger single men reported profound problems with trying to meet partners due to embarrassment and perceived sharing the diagnosis would scare or repulse women.	Not reported	Implications for having a family for younger men reported as an issue.	Not reported
Opjordsmoen et al. (1994)	Not reported.	Men experienced social phobia and post-traumatic stress disorder, alcohol abuse. Major depression was associated with complete non-sexual function.	Not reported	Not reported.	Not reported	Not reported	Not reported	Problems with erection, changes in ability to having sex. Changes in relationships and distressed partner relationships.	Not reported	Men reported problems with marriage and martial crisis after treatment. Some men subsequently divorced due to problems after therapy.	Not reported
Skeppner et al., 2015	Half of the men reported genital sexual pain, decreased sensitivity of the penis, retarded ejaculation/anejaculation.	Anxiety was present in partners at baseline and 12 months follow-up. Difficulties in shared coping processes and strategies.	Not reported	Not reported.	Not reported	Not reported	Not reported	Couples reported withdrawal in sexual activity due to penile cancer and its treatment. All couples reported low sexual satisfaction.	Not reported	Cancer affected the dyadic processes of the couple's adjustment and reduced communication together.	Not reported.
Skeppner et al.,. (2008)	Not reported.	Reduced psychological well-being.	Not reported.	Not reported.	Delay in seeking medical attention from initial symptoms more than 6 months.	Not reported.	Not reported	Dissatisfaction with sexual life.	Reduced satisfaction with economic provision. Further explanation not provided.	Not reported.	Not reported.

Soh et al. (2014)	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	No patients reported that they felt a loss of manliness or were worried about sexual performance. (n2) Patients reported a loss of sexual desire, (n7) reported a low or very low desire.	Not reported	(n14) declared their partners “understood and accepted” their sexual dysfunction; (n1) wife was “disappointed with sexual dysfunction”, (n3) she “did not express any opinion concerning sexuality and (n1) wife expressed “wishes I recovered my sexual performance".	Not reported
Sosnowski et al., 2016	Physical function median was reduced at 70 (EORTC)	Patients reported reduced self-esteem median 75%, ranged 67%–87%. Patients reported reduced emotional functioning.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Majority of the patients did not experience orgasm and ejaculation during sexual activity. Sexual relations with a partner were defined as very unsatisfactory, however, one patient described relations as very “rewarding".	Not reported.	Not reported.	Patients reported reduced social functioning..
Wan et al. (2018)	n15 all reported being able to micturate while standing, no cystitis or incontinence. n1 man reported spraying of urine while micturating.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Patients reported decrements in sexual relationships and confident levels prior to surgery. However, a statistically significant improvement in these both domains were reported at 6 months. However, orgasmic function decreased after surgery.	Not reported.	Not reported.	Not reported.
Windahl et al. (2004)	Not reported.	Decreases in sexual desire and interest were related to psychological needs.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Patients reported distress in sexual interest (n7), distress in quality of erections	Not reported.	Not reported.	Not reported.

								(n2), distress in early ejaculation (n1) and distress caused by dyspareunia (n6). Distress in these domains were persistent following treatment. Painful intercourse caused distress.			
Witty et al. (2013)	Difficulties with urinary function, spraying and inconsistent flow. One man had an urostomy which he considered to be messy and impractical. Post-surgical men experienced infection which inhibited them from moving on emotionally and physically. Loss of mobility and lethargic after treatment. Other health concerns included lymphoedema because of lymph node removal.	The physical scaring made men worried if their cancer had returned over time. Men talked about experiencing depression after the trauma of the operation. Men talked about feelings of loss, low and anxious, and having mood swings which was damaging relationships with partners. Some men reported feeling “emasculated” and not feeling like a “man” due to a disconnect in self-image.	Not reported.	Some men reported being poorly counselled about the extent of the surgery and completed shocked when he seen the results.	Some men reported that counselling and psychosexual services were not offered to them, but they would have found this helpful. Some men also reported a lack of information about what to expect after surgery.	Not reported.	Men needed public access to disabled toilets when away from home, which could be problematic at times.	Men expressed that their own lack of sexual gratification was less of a concern than feelings of being unable to satisfy their partner. Men expressed that they were denying wives/partners sexual satisfaction for what they deserved. Sexual urges after total penectomy contributed to a disconnection between sensory self and physical self. Other men were able to maintain a sex life, but it was “different” but still enjoyable.	Men reported urination was helped by aids, such as a funell, practicing using the toilet and having to re-train themselves. Men found it easier to sit down. Men needed access to a cubical to sit down.	Support from wives and partners was frequently referenced as an important factor in coping with the impact of surgery. Men did not feel able to share their diagnosis beyond their immediate family due to embarrassment and privacy as reasons.	Some men reported about experiencing low confidence and struggling to interact with others. It inhibited social activities which involved wearing shorts due to the believe that people would see that patients have had a penectomy.

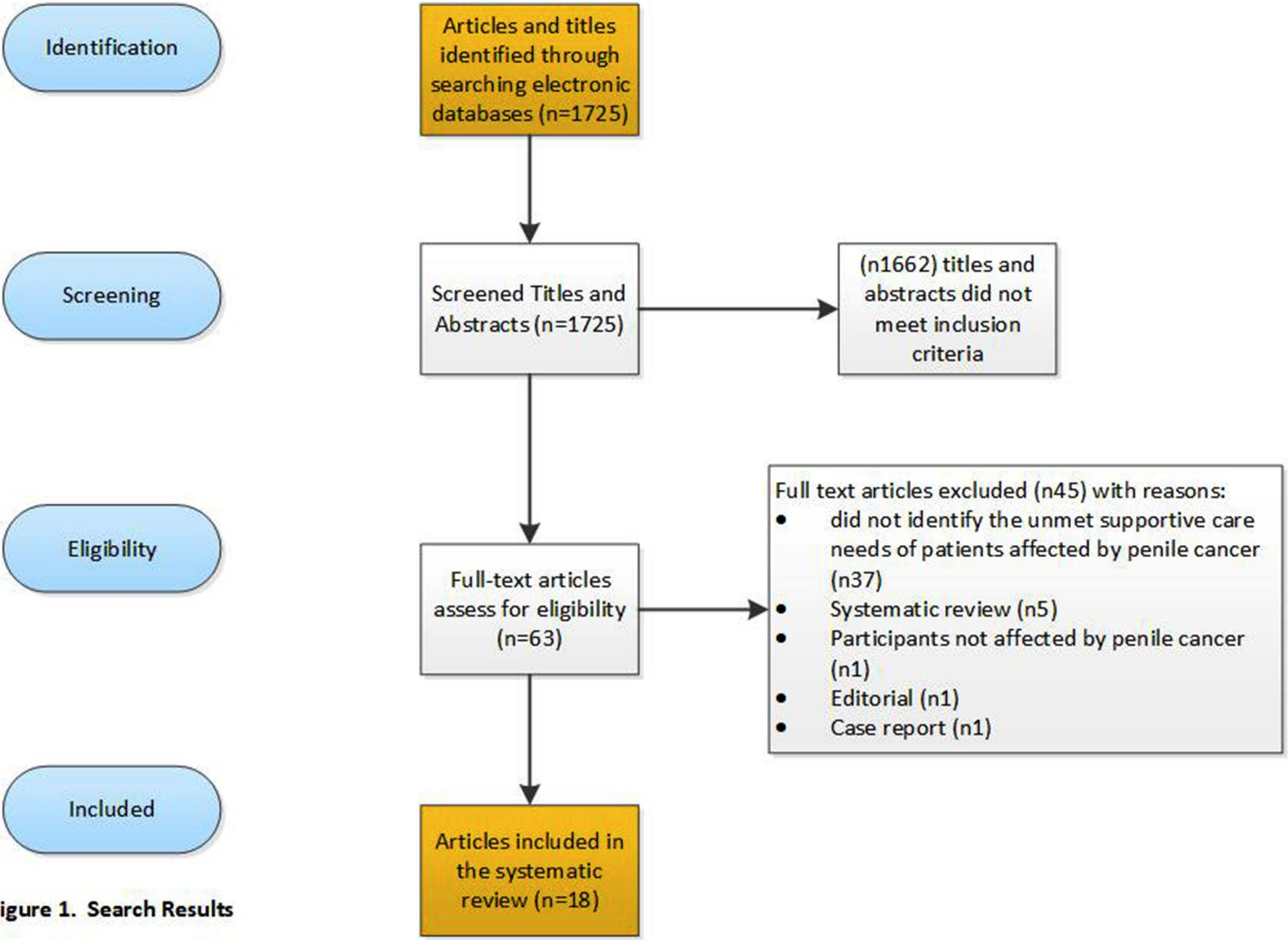


Figure 1. Search Results

Supplementary File 1. Literature Search Strategy

Electronic databases	Search Strings
Cochrane (CCTR and CDSR) Medline EMBASE PsychINFO (via OvidSP)	1 exp penis cancer/ or exp Penile Neoplasms/
	2 ((penile or penis) adj5 (cancer* or carcin* or malig* or tumor* or tumour* or neoplas* or SCC)).tw,kw.
	3 or/1-2
	4 ((unmet or care or healthcare or live) adj5 (need or needs or experience*)).tw,kw.
	5 ((support* or physical or psycholog* or emotion* or family or social or Psychosocial or psyhological or interpresonal or intima* or pratical or daily or spirtual or existential or patient* or caregiver* or physician* or clinician* or partner or spouser* or health system or information or cognitive or spiritual) adj5 (need or needs or experience*)).tw,kw.
	6 exp health care need/
	7 exp "health services needs and demand"/ or exp needs assessment/
	8 exp Needs Assessment/
	9 (need* adj3 assess*).tw,kw.
	10 or/4-9
	11 exp patient care management/ or exp Patient Care/
	12 (((health or medical or patient* or medical or nursing or home) adj3 care adj3 (team* or management or plan or planning or bundles)) or interdisciplinary health team*).tw,kw.
	13 (patient adj3 (centre* or center* or focuse*) adj3 (care or nursing)).tw,kw.
	14 exp Patient Care Bundles/ or exp care bundle/ or exp progressive patient care/ or exp home care/
	15 (patient care bundles or healthcare bundles or respite care).tw,kw.
	16 exp social support/ or exp caregiver support/ or exp Financial Support/ or exp Training Support/
	17 ((social or traning or educatiaon* or financial or nutritional or emotion* or family or Psychosocial or psyhological or interpresonal or intima* or pratical or daily or spirtual or existential or patient* or caregiver* or partner or spouser* or employment or decision) adj5 support*).tw,kw.
	18 exp nutritional support/
	19 exp Employment, Supported/ or supported employment/
	20 exp decision support techniques/ or exp decision support system/
	21 exp health care delivery/
	22 exp health care planning/
	23 supportive care.tw,kw.
	24 exp Behavioral Symptoms/
	25 (behavior* adj3 symptom*).tw,kw.
	26 exp emotional disorder/
	27 (symptom* adj3 control*).tw,kw.
	28 exp Communication/ or exp interpersonal communication/
	29 (information or communication*).tw,kw.
	30 exp Spiritual Therapies/
	31 ((spiritual adj3 (healing* or therap*)) or spirituality).tw,kw.
	32 exp Palliative Care/ or exp palliative therapy/
	33 palliative.tw,kw.
	34 or/11-33
	35 exp "Surveys and Questionnaires"/ or exp questionnaire/ or exp health survey/ or exp health care survey/
	36 (index orindexes or scales or scale or survey* or questionnaire* or self-report* or specific module or tool or tools or instructment* or checklist or check list).tw.
	37 exp "Quality of Life"/
	38 ((life adj2 (quality or qualities)) or QoL or HRQOL or well-being or "SWB").tw,kw.
	39 exp nutrition assessment/ or exp Symptom Assessment/ or exp Nursing Assessment/ or exp functional status assessment/ or "quality of life assessment"/

	40 exp psychologic assessment/ or exp family assessment/ or exp patient assessment/ or exp personality assessment/ or exp health impact assessment/ 41 exp medical assessment/ or exp behavior assessment/ or exp anxiety assessment/ or exp outcome assessment/ or exp geriatric assessment/ 42 exp clinical assessment/ or functional assessment/ or disease assessment/ or mental disease assessment/ or pain assessment/ 43 exp "outcome and process assessment (health care)"/ 44 ((functional or nutrition or symptom* or nursing or psychologic* or family or patient* or personality or health impact or medical or behavior or anxiety or outcome* or geriatric or clinical or functional or disease or mental or pain or self or programe or programme) adj3 (assessed or assessment* or evaluation or evaluated)).tw,kw. 45 exp Self-Evaluation Programs/ or exp evaluation studies/ or exp evaluation study/ 46 (validity or validation or validated or inventory or interview* or focus group*).tw,kw. 47 exp checklist/ or exp focus groups/ or exp interviews as topic/ or exp interview/ 48 exp Clinical Audit/ 49 audit.tw,kw. 50 or/35-49 51 exp Attitude to Health/ or exp patient attitude/ 52 ((patient* adj3 (attitude* or acceptance or satisfact* or perception*)) or attitudes to health).tw,kw. 53 exp qualitative research/ 54 ((qualitative or narrative) adj3 (research or study or analy*)).tw,kw. 55 or/51-54 56 3 and 10 57 3 and 34 58 3 and 50 59 3 and 55 60 or/56-59 61 limit 60 to yr="1990 -current" 62 (exp animals/ or exp animal/ or exp nonhuman/ or exp animal experiment/ or animal model/ or animal tissue/ or non human/ or (rat or rats or mice or mouse or swine or porcine or murine or sheep or lambs or pigs or piglets or rabbit or rabbits or cat or cats or dog or dogs or cattle or bovine or monkey or monkeys or trout or marmoset$1).ti.) not (humans/ or human/ or human experiment/ or (human* or men or women or patients or subjects).tw.) 63 case report/ or case reports/ or (case report or case series).ti. 64 note/ or editorial/ or letter/ or Comment/ or news/ 65 conference abstract.pt. or Congresses as Topic/ or Conference Review.pt. or "Journal: Conference Abstract".pt. 66 (child/ or Pediatrics/ or Adolescent/ or Infant/ or adolescence/ or newborn/ or (baby or babies or child or children or pediatric* or paediatric* or peadiatric* or infant* or infancy or neonat* or newborn* or new born* or kid or kids or adolescen* or preschool or pre-school or toddler*).ti.) not (adult/ or aged/ or (aged or adult* or elder* or senior* or men or women).tw.) 67 or/62-66 68 61 not 67 69 limit 68 to english language [Limit not valid in CDSR; records were retained] 70 remove duplicates from 69
CINAHL	S7 S1 OR S4 Limiters - English Language Narrow by Subject Age: - aged, 80 & over Narrow by Subject Age: - aged: 65+ years Narrow by Subject Age: - middle aged: 45-64 years Narrow by Subject Age: - adult: 19-44 years Narrow by Subject Age: - all adult Search modes - Boolean/Phrase S6 S1 OR S4 Limiters - English Language S5 S1 OR S4 Search modes - Boolean/Phrase S4 S2 AND S3

	S3 TI (cancer* or carcin* or malig* or tumor* or tumour* or neoplas* or SCC) OR AB (cancer* or carcin* or malig* or tumor* or tumour* or neoplas* or SCC) S2 TI (penile or penis) OR AB (penile or penis) S1 (MH "Penile Neoplasms")

Quality assessment for qualitative studies (Shaw et al., 2009)

Criteria		Yes (2/good)	Partial (1/fair)	No (0/poor)	score
Study aims & context					
1.	Is the research question sufficiently described?	Research question clearly identified by the end of the research process, if not at the outset.	Research question or objective is vaguely/incompletely reported.	Question or objective is not reported, *or* is incomprehensible.	
2.	Is qualitative method appropriate?	Qualitative method is appropriate for the aims and the qualitative framework is identified and justified.	Qualitative method appropriate but the methodological framework unclear or not adequately justified.	Qualitative methods inappropriate for the aims.	
3.	Is the *setting/context clearly described?	*Context/setting is clearly described, permitting the reader to relate the findings to other settings.	The context/setting is partially described.	The context/setting is not described.	
Sampling					
4.	Is the sampling strategy clearly described?	Sampling strategy & rationale clearly described and justified.	Sampling strategy not clearly described *or* is not fully justified.	Sampling not described.	
5.	Is sampling method likely to recruit all relevant cases? (purposive, theoretical sampling)	Sample includes the full range of relevant, possible cases (more than simple convenience sample) permitting conceptual (rather than statistical) generalisations.	Sampling was purposive but does not include the full range of possible cases.	No attempt made to sample purposively or theoretically, *or* sampling strategy not described.	
6.	Are relevant characteristics of sample given?	Relevant details of the characteristics of sample given.	Incomplete details of sample characteristics given.	No details of sample characteristics given.	
7.	Is rationale for sample size (e.g data saturation) given?	Gives rationale for termination of data collection e.g. data saturation.	Reasons for sample size implied *or* no firm rationale.	No reason given for sample size.	
Data collection					
8.	Are method of data collection clearly described?	Data collection methods are systematic and clearly described allowing an audit trail such that procedures could be replicated.	Data collection methods not clearly described. Difficult to determine if systematic or replicable.	Data collection procedures are not described.	
9.	Is method of data collection appropriate for research question and paradigm?	Data collection methods are appropriate for the research aims and the methodological and analytical framework.	The appropriateness of data collection methods are unclear.	Data collection inappropriate for the aims and methodological framework.	
10	Has the researcher verified the data (e.g. by triangulation)?	More than one method of data collection carried out *or* more than one analyst involved, *or* other methods of verification employed (e.g. member checking or line of questioning during interview).	Unclear whether triangulation or other types of verification used.	No triangulation or other methods of verification described.	

Data analysis					**Score**
11	Are data analysis methods clearly described?	Systematic analytic method clearly described such that procedures could be replicated.	Analytic methods not clearly described.	Analytic methods not described.	

Criteria		**Yes** **(2/good)**	**Partial** **(1/fair)**	**No** **(0/poor)**	
12	Are data analysis methods appropriate?	Analytic methods seem appropriate & are well-described.	Analytic methods only partially described and/or some concerns about appropriateness.	Analytic methods not described and/or appropriate.	
13	Are competing accounts/deviant data taken into account?	Account given of negative or deviant cases in the analysis.	Analysis of deviant or negative cases not clearly described.	No account given of negative or deviant cases.	
Reflexivity					
14	To what extent is the researcher reflective?	The researcher explicitly assessed the likely impact of their own personal characteristics and the methods used on the data obtained.	Possible sources of influence on the data obtained were mentioned, but the likely impact of the influence was not discussed.	No evidence of reflexivity in the report.	
Conclusions					
15	Are the interpretations and conclusions supported by the data?	The interpretations are clearly described and supported by the data and are evidenced by sufficient participant quotes.	The conclusions are unclear or only partially supported by the data, *or* there is insufficient raw data to support conclusions.	Conclusions are not identified *or* are felt not to be supported by the data *or* conclusions are absent.	

Quantitative quality assessment checklist

Quality Assessment Quantitative Studies

Criteria		Yes (2/good)	Partial (1/fair)	No (0/poor)	N/A	Score
Study aims						
1.	Is the hypothesis/aim/objective of the study clearly & sufficiently described?	Easily identified in introduction/method. Specifies: purpose, subjects/target population, and specific interventions/ associations under investigation.	Vague/incomplete reporting *or* some info has to be gathered from parts of the paper other than intro/background/ objective section.	Question or objective not reported/ incomprehensible.		
Study design & sample characteristics						
2.	Is the study design well described & appropriate? *(If study question not given, infer from conclusions).*	Design easily identified, well described and appropriate.	Design and/or study question not clearly described, *or* design only partially addresses study question.	Design does not answer study question *or* design is poorly described.		
3.	Is the method of patient/control group selection described and appropriate?	Described and appropriate. Inclusion/exclusion criteria described and defined.	Selection methods (and inclusion/exclusion criteria) not completely described, but no obvious inappropriateness. *Or* selection strategy likely introduces bias but not enough to seriously distort results.	No information/ inappropriate information provided *or* selection bias which likely distorts results.		
4.	Are the characteristics of patient/control group(s) clearly described (i.e. age range, health characteristic/s)?	Sufficient relevant demographic information. Reproducible criteria used to categorise participants clearly defined.	Poorly defined criteria *or* incomplete demographic information.	No baseline/demographic info provided.		
5.	Were patients/participants randomised to intervention groups?	*If randomisation appropriate:* Evidence of randomisation with a description of the method used (e.g. random number tables, block design).	Randomisation mentioned but method is not (i.e. may be possible that randomisation not true).	Random allocation not mentioned although it would have been feasible and appropriate (and possible done).	Study has no control group i.e. observational/ surveys/case-control. *Or* adequate justification for non randomisation. given.	

6.	*For RCT's only:* Was randomisation/allocation concealed from patients?	Evidence the next allocation was concealed from both parties (recruiter and patient/carer) at the point of consent (e.g. remote randomisation).	Allocation concealment reported but not described.	Allocation concealment would have been possible (and was possibly done) but not reported.	Allocation concealment not possible due to study design (e.g. cluster randomised trial).	
7.	Have the characteristics of patients lost to follow-up been described?	Losses adequately reported & not likely to affect results.	Losses not well reported, but small & not likely to affect results.	No information *or* losses large and likely to affect results.	No patients lost to follow-up.	
8.	Are intervention(s) clearly described?	Defined and reproducible.	Partially defined, but insufficient detail to reproduce design.	Not described.	Not possible/ appropriate – e.g. observational	
9.	Are the main outcomes to be measured clearly described in the introduction/method?	Defined and measured according to reproducible criteria.	Definition leaves room for subjectivity, *or* not sure (i.e. not reported in detail, but probably acceptable). *Or* precise definition(s) are missing, but no evidence of major problems. *Or* instrument/mode of assessment(s) not reported.	Main outcomes first mentioned in results section. *Or* measures not defined/inconsistent/ poorly defined.		
10	If possible, was an attempt made to blind those measuring the main outcomes of the intervention?	Assessor blind to intervention/study group.	Inadequate blinding: i.e. assessor may have been aware of group participant assigned to.	No attempt made to blind assessor.	Not possible/ appropriate – e.g. observational/ before & after study.	
11	Are population characteristics (if measured & described) controlled for and adequately described?	Appropriate control at design/analysis stage *or* randomised study with comparable baseline characteristics.	Incomplete control/ description. *Or* not considered but unlikely to seriously influence results.	Not controlled for and likely to seriously influence results.		
12	Are the main findings clearly described?	Simple outcome data (e.g. mean/prevalence) reported for all major findings.	Incomplete or inappropriate descriptive statistics.	No/inadequate descriptive statistics.		
13	Are methods of analysis adequately described	Described and appropriate.	Not reported but probably appropriate *or* some tests	Methods not described and cannot be determined.		

	and appropriate?		appropriate, some not.			
14	Are estimates of variance reported for the main results?	Appropriate estimates provided (SD/SE, confidence intervals).	Undefined *or* estimates provided for some but not all outcomes.	No information.		
15	In trials/cohort studies, do analyses adjust for different lengths of follow-up, or in case-control studies, is the time between intervention and outcome the same for cases/controls?	Different lengths of follow-up adjusted for (e.g. survival analysis) and adequately described.	Different lengths of follow-up probably adjusted for but not adequately described.	Differences in follow-up ignored.	Cross-sectional design *or* same length of follow-up.	
16	If appropriate, were data analysed according to ITT (intention to treat) principle?	All participant data analysed regardless of adherence to protocol or continuation in trial.	Attempt made to analyse data according to ITT principle, but inappropriate method *or* some participants not included.	No attempt made to carry out ITT analysis.	Design not appropriate for ITT (e.g. cross-sectional data).	
17	Are the conclusions supported by the results?	All conclusions supported by data.	Some of the major conclusions are supported by the data; some are not. *Or* speculative interpretations are not indicated as such.	None/few of major conclusions supported by the data.		

SHAW, C., MCNAMARA, R., ABRAMS, K., CANNINGS-JOHN, R. L., HOOD, K., LONGO, M., MYLES, S., O'MAHONY, M. S., ROE, B. & WILLIAMS, K. 2009. Systematic review of respite care in the frail elderly. *Health Technology Assessment,* 13**,** 1-246.

Supplementary 3 Clinical and demographic characteristics of the included participants

Author and Year	Age (years)	Marital status	Ethnicity	Education level	Cancer stage	Treatment
Bhat et al., 2018	Median 51.8 (38-74) Partners median 37.9 (26-55)	Not reported	Not reported	Not reported	Not reported	n2 total penectomy; n10 partial penectomy
Bullen et al., 2009: reporting same study as Bullen et al., 2010	Median 62.5 (50-76)	n7 married, n1 single, n1 separated	Not reported	Not reported	Not reported	n7 total penectomy; n2 partial penectomy
D'Ancona et al., 1997	median 50.5 (37-70)	All married and living with their partners.	Not reported	Average schooling 2.8 years (median 3 years). n=4 patients were illiterate, n=1 <4 y schooling	T1 n=1; T2 n=8; T3 n=5	Radical or modified lymphadenectomy was performed in n11. N3 treatment modality missing. No further date reported.
Drager et al., 2017	Mean 64 (SD 13.6, 31-88)	Not reported	Not reported	Not reported	Not reported	Partial penectomy n28, total penectomy n1, chemotherapy n11
Dulaunay et al., 2014	Mean 73.2 (SD not reported, 45-89)	n19 married or in a couple	Not reported	Not reported	Not reported.	n19 penile brachytherapy
Ficarra et al., 2000	Mean 63.0 (SD not reported)	Not reported	Not reported	Not reported	Not reported	n16 Partial penectomy
Gordan et al., 2017	Mean 62.2 (SD 10.9, 41-85)	Married n9, separated n1, widowed n1, divorced n1.	39% white, 15% Asian, 15% Black, 31% Hispanic	62% High School, 38% University Degree	Not reported	n10 partial penectomy, n2 excision, n1 total penectomy
Kieffer et al., 2014	n54 penile sparing surgery 61.8 (SD 12.4); n36 partial penectomy 70.9 (SD 8.7), p<0.001	Married n75, single n15	86% Caucasian	Primary/middle school n7 (7.8%), Occupational high school n38 (42.2%), College preparatory high school n8 (8.9%), College University n37 (41.1%)	Not reported.	Penile sparing n54, partial penectomy n36, lymphadenectomy n25, no further treatment data reported.
Mortensen et al., 2013	Mean 58.5 (SD not reported)	n1 married, n2 in a relationship and n1 single.	Not reported	Not reported	Not reported	n2 glansectomy, n2 partial penectomy
Opjordsmoen et al., 1994	Mean 57 years, (range 28-75)	n26 married, n3 single, n1 divorced (after treatment).	Not reported	Not reported	Tis: n3, Tis 1 n22, Tis 2 n2, Tis 3 n1, Tis 4 n1, Tis X n1. N category: N0 n26, N1-2 n4.	Local incision/laser beam n 5, radiotherapy n12, partial penectomy n9, total penectomy n4.
Skeppner et al., 2015	Mean 60 (range 37-73) and partners mean 57 years (range 30-72)	All in a steady relationship (median relationship time 29 (1-54) years	Not reported	Not reported	pT1 n12, and G2 n14, n2 missing data	n26 organ sparing laser treatment of the penis, n2 laser treatment and total penectomy.
Skeppner et al., 2008	Median 63.5 (range 34-90).	Married n=34, Single with a steady partner (n2), single n= 10.	Not reported	Not reported	CIS n13, T1 n14, T2 n19. Tumor grade: Ca in situ n16, G1 n=6, G2 n12, G3 n2.	Lymph node dissection n16, chemotherapy n1, radiotherapy n1, relapse n8. No further data reported.
Soh et al., 2014	n19 patients 73.2 (SD 11.7); control (n19) controls 70.0 (SD 10.5), p<.0381	Patients in couple (n19); Control in couple (n16), single (n3), p<.05	All participants Caucasian	Not reported.	n19 patients T1 well differentiated tumour <20mm, no lymph nodes; (n19) controls no diagnosis of cancer	n19 Low dose rate PB with Iridium-192
Sosnowskie et al., 2016	60 years, 35 to 74 years	Married 60%; single 40%	Not reported.	Education basic n5 (50%); higher education n5 (50%), no further classifications reported.	pT1b n4; pT2 n3; pT3 n3;	n10 total penectomy
Wan et al., 2018	n7 (wide local excisions) 60.7 (SD 10, 45-72); n8 (partial penectomy) 62 (SD 9.7, 44-74 years), P>.05	n15 married (100%)	Not reported.	Not reported.	n3 Tis; n1 Ta; n8 T1; n3 T2	n7 wide local excisions; n8 partial penectomies
Windahl et al., 2004	Not reported.	n31 in relationship; n10 single at time of study	Not reported.	Not reported.	Tis-T2, GI-II tumours less 3cm in diameter. No further details reported.	n31 men treated by laser therapy
Witty et al., 2013	63 years (range 41-82 years) at diagnosis and 67 (range 48-83 years) at time of interview.	n17 married/relationship; n11 single	n27 white; n1 asian	Not reported.	Not reported.	All men treated by surgical intervention ranging from circumcision to total penectomy. Not specific details reported.