Information needs in patients with bladder cancer undergoing radical cystectomy – A qualitative review with thematic synthesis

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ARTICLE INFO

Keywords:
Bladder cancer
Experiments
Information needs
Radical cystectomy
Self-care

ABSTRACT

Purpose: Worldwide, bladder cancer is the eleventh most common cancer. Self-care is significant after surgery and optimal information needs to be individualized. This will help the patient to understand and become involved in their own care. This study investigated experiences of information needs in patients with bladder cancer undergoing radical cystectomy.

Methods: A qualitative review study with a thematic synthesis according to the PRISMA Statement Guidelines was performed.

Results: Thirteen peer-reviewed original articles were included. This review highlighted that patients experienced unmet information needs about postoperative care and self-care. Patients also experienced receiving too much information in a limited time. This led to difficulties in understanding and processing the information. Patients also experienced limited information about sexual and psychological support and requested more information about physical activity.

Conclusion: Information is essential but needs to be adapted and based on person-centred care principles related to the patients’ needs and wishes. Unmet needs impact patients’ lives and are associated with misunderstandings and insecurity, which need to be considered in cancer nursing.

Clinical trial registration: The review was not registered.

1. Introduction

Bladder cancer is one of several diseases that affect the urinary tract and is mainly prevalent in the elderly population over the age of 70 (Burger et al., 2013; Pietzak et al., 2015). Bladder cancer occurs with different degrees of severity; in severe bladder cancer, the disease is treated by surgically removing the bladder, a procedure called radical cystectomy (DeGeorge et al., 2017; Witjes et al., 2021). Patients with bladder cancer undergoing radical cystectomy need to receive comprehensive information about the procedure to gain an understanding of what they will go through and why (Kappa et al., 2017). Previous research shows that patients find it difficult to generally remember all the information given during visits to receive health care. In addition, if the message and the information create anxiety, it is perceived as frightening, and this further affects what patients remember afterwards (Ormandy, 2011). Although bladder cancer has a high frequency in the population, knowledge is limited about the patient’s experiences and their perspective on the perioperative information given in the context of radical cystectomy (Edmondson et al., 2017).

Muscle-invasive bladder cancer is aggressive and shortening the investigation time to diagnosis is an important factor in being able to start treatment in a timely manner. Radical cystectomy is a treatment that significantly improves patient survival, but it involves the surgical removal of the bladder and the distal part of the ureter along with the nearby lymph nodes. In men, the prostate is also removed. In women, the uterus, ovaries, urethra, and vaginal top are removed, and the vagina is then reconstructed. A new urinary diversion is then constructed using the small intestine (Witjes et al., 2021). The most common bladder reconstruction is ileal conduit urinary diversion with urostomy. The urine will then be collected in an ostomy bag. Other types of urine diversion are continental reservoirs and orthotopic bladder substitutes. If these diversions are chosen, pure intermittent catheterization needs to be mastered to avoid residual urine, which can cause urinary tract infections and damage to the upper urinary tract. Since the surgery for
radical cystectomy is extensive and stressful for the patient, treatment decisions and the choice of urine diversion are based not only on tumour type but also on the patient’s general condition, age and other diseases. The surgery may be preceded by neoadjuvant chemotherapy (Witjes et al., 2021).

Prior to planned urological surgery for bladder cancer, patients often receive a lot of information at the same time (Roche and Jones, 2021). Information is a basic human need (Ormandy, 2011), but healthcare professionals need to have knowledge of what kind of information to give as well as what the patient needs to know (Roche and Jones, 2021). When information is taken in, physiological, cognitive, emotional, and psychological aspects need to interact (Ormandy, 2011). Cystectomy is a major operation that affects the patients’ continued daily lives in various ways. The information needs of these patients are significant and need to be considered to increase their sense of control. Satisfying the patient’s need for information increases the chance of success of the postoperative process (Patel and Dowse, 2015; van Stralen et al., 2020).

The information should help increase the patient’s safety and knowledge to continue living with their diagnosis and their changed body after surgery (Paterson et al., 2018). Healthcare professionals need to be aware that their patients’ ability to understand and absorb information depends on their level of health literacy (Mårtensson and Hensing, 2012). Thus, it needs to be adapted to the individual’s conditions and needs. The surgery involves changing the body, and the patient must learn to manage and care for these changes. Self-care will be a large part of the patient’s remaining life, where the goal is for the patient to become independent. Person-centred care is based on partnership and shared responsibility, and the information and education need to be personalized (Cronenwett et al., 2007; Renpenning and Taylor, 2003).

To address this unmet patient need, we investigated the experiences of patients with bladder cancer undergoing cystectomy.

2. Methods

A qualitative review study with a thematic synthesis according to the PRISMA Statement Guidelines was performed.

2.1. Literature search

The inclusion criteria were adult patients (>18 years old) with bladder cancer undergoing cystectomy. Peer-reviewed articles with qualitative or mixed methods, containing abstracts, available in full text and written in English, and published in a scientific journal between 2012 and 2021 were eligible. Data collection was carried out in three databases: CINAHL, PubMed and PsyInfo. A pilot search was conducted with the support of a librarian, and then specific keyword and search combinations were used to delineate the problem area. The search used both MeSH terms and a free text search. To create a structured and systematic search strategy, the SPICE framework was used (Booth, 2006).

- Setting (Context): Urological care
- Perspective: Patients with bladder cancer
- Intervention/Interest (Intervention): Information needs
- Comparison:
- Evaluation: Experiences of information needs

The keywords used were “Bladder cancer”, “Cystectomy”, “Information needs”, and “Qualitative research”.

Search blocks were created, and the Boolean operators OR and AND were used in the databases. References in the articles were checked to see if additional studies could be of relevance to the purpose. The search was conducted on 2021-10-28, with a combination of search words: Bladder cancer OR neoplasms OR bladder tumour; Information needs OR information use OR information seeking OR information behaviour; Cystectomy OR radical cystectomy; Qualitative research OR qualitative study OR qualitative methods OR interview

2.2. Study selection

A total of 591 studies were identified. After screening the title and abstract, 118 articles remained, and after full-text review, 13 studies were included; see the PRISMA flow chart in Fig. 1 (Page et al., 2021). The articles were assessed for quality according to CASP (Critical Appraisal Skill Programme, 2022). A study with ≥8 points was assessed as high quality, and a study with <5 points was assessed as low quality. A total of 13 studies were reviewed for quality, of which 12 had 10/10 points and 1 had 9/10 points according to CASP. All articles were thus judged to be of high quality, and no study was excluded due to low quality.

2.3. Data synthesis

The data analysis followed Thomas and Harden’s (2008) thematic synthesis process for qualitative studies. The analysis process consists of three stages, where the first step involves the encoding of text. In step two, the codes evolve further into describing themes. In the final stage, the descriptive themes are developed into analytical themes that represent new interpretations, explanations, and hypotheses of the results of the original studies.

The analysis began with the authors individually reading all of the studies, and the keywords were identified. Keywords were found in the results and in the abstract. The highlighted keywords were examined sentence by sentence to see their meaning and content. This is the key task in synthesizing. In this step, the authors were able to see if there were similar keywords in other studies, as they could be described with different words. Once this step was completed, the encoded texts were examined again to ensure nothing was missed. Similarities and differences in all codes were investigated.

In step two, the codes were grouped so that new overall codes emerged that summarized the underlying codes. The codes led to the formulation of descriptive themes. The results of the studies were summarized and described under the descriptive themes identified and then used to produce the analytical themes in the last step.

In the third (last) step, the authors made their own interpretations and drew their own conclusions based on the descriptive themes that emerged. Synthesis is a cyclical process that continues until no newer analytical themes arise. When the authors did not come up with more analytical themes, the synthesis was considered saturated. Examples of this process; Keyword “Different strategies to get more information”, Code “Other sources of information”, Descriptive theme “Strategies” and the Analytical theme “Dimensions of information”.

3. Results

The results are based on 13 studies conducted in the United States (n = 10), Belgium (n = 2), and Australia (n = 1). A total of 315 patients were included, and 65% (204) were male, with an age ranging from 41 to 89 years. The characteristics and main findings of each article are highlighted in Table 1.

From the thematic synthesizing, four analytical themes emerged: the dimensions of information, the emotional roller coaster through the trajectory of illness, the changed body and the importance of self-care to continued life. The results are presented below in chronological order.

3.1. Dimensions of information

The theme includes various reasons why patients are not able to
absorb and understand the information given during the perioperative process. The reasons for this can be seen from two different perspectives: patients and caregivers. These two perspectives conflict with each other, as the care situation is new for the patient and not for the staff. The theme is presented based on these dimensions of information: preoperative information, postoperative information and information associated with recovery.

3.1.1. Preoperative information

One reason why the patients had difficulty absorbing the preoperative information was that they had a lack of basic knowledge about bladder cancer and how the disease was treated (Wulff-Burchfield et al., 2021). The two most important reasons for patients to be able to absorb the information before or during treatments were that there was enough time set aside and that they felt confidence in the person who gave the information. Stress was a contributing factor to information not being able to be taken in (Heyes et al., 2020; Klein et al., 2021; Rammant et al., 2021), and the patient felt that there was no room to ask questions. This was a contributing factor to the patient’s lack of participation (Garg et al., 2018; Heyes et al., 2020). The consequence was that the patient felt that valuable information was missing regarding treatment choices, side effects, recovery time, and postoperative self-care (Mohamed et al., 2014).

The preoperative information needed to be given in plain language and be honest. For this to happen, the staff needed to understand what information was relevant to provide at the right time for the individual. When this did not occur, the patient’s information needs were not met (Garg et al., 2018; Heyes et al., 2020; Mohamed et al., 2014; Rammant et al., 2021; Smith et al., 2019). Alternative sources of information were used to create security and confidence and helped to fill the information gap and the unmet information needs (Klein et al., 2021; McMullen et al., 2019). One of the most significant alternative sources of information was lived experience from patients who had previously undergone cystectomy. The information they provided was perceived as more consistent and credible in comparison to the information given by health care staff that was abstractly experienced. The importance of health care staff knowing that information needed to come from different sources was crucial to meet the patients’ information needs. It provided a holistic perspective that led to patients feeling safe (McMullen et al., 2019; Rammant et al., 2021).

3.1.2. Postoperative information

The timing, quality and quantity of postoperative information laid the foundation for the patient’s continued information and learning needs and minimized the risk of misunderstandings (Garg et al., 2018; Heyes et al., 2020; Hockman et al., 2020; Rammant et al., 2021; Smith et al., 2019). One of the most critical elements of information sharing and teaching was that too much information was given at the same time (Rammant et al., 2021). Important information was at risk of drowning in the large volume that was given (Hockman et al., 2020; McMullen et al., 2019).

Fig. 1. PRISMA flow chart.
Table 1

<table>
<thead>
<tr>
<th>Author, Year, Country</th>
<th>Type of Study/ Methodological Orientation</th>
<th>Purpose</th>
<th>Sample Size (Bold text is the number of patients)</th>
<th>Major Findings</th>
<th>CASP Quality Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Garg et al. (2018) USA</td>
<td>Qualitative/Content Analysis</td>
<td>To understand patient experience, define care priorities, and identify targets for care improvement across the cancer continuum.</td>
<td>Total: n=20 &lt;br&gt; Female: n = 4 &lt;br&gt; Male: n = 16</td>
<td>Five primary themes emerged: access to care, provider characteristics and communication, quality of life, goals of care/influences on decision-making and role of social support. Timely access to care, honest and caring provider communication is important to cope emotionally with changes in urinary function.</td>
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<tr>
<td>Gupta et al. (2021) USA</td>
<td>Qualitative/Thematic analysis</td>
<td>To better understand the physical and psychosocial components of female sexual dysfunction among women undergoing radical cystectomy for bladder cancer</td>
<td>Total: n = 25 &lt;br&gt; Patients: n=22 &lt;br&gt; Female: n = 22 &lt;br&gt; Partner: n = 3</td>
<td>Major themes emerged in the interviews in both cohorts that included concerns about changes to body image, the psychosocial impact of the diagnosis and treatment, the impact of radical cystectomy on their sexual functions and inadequacies in provider-led sexual health counselling. There was no difference in older or younger regarding the desire to retain the option of sexual function.</td>
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</tr>
<tr>
<td>Heyes et al. (2020) Australian</td>
<td>Qualitative/Thematic Analysis</td>
<td>To gain an understanding of quality-of-life disruptions among both those diagnosed with bladder cancer and their supportive partners.</td>
<td>Total: n=20 &lt;br&gt; Patients: n=10 &lt;br&gt; Male: n = 8 &lt;br&gt; Partner: n = 10 &lt;br&gt; Female: n = 8 &lt;br&gt; Partner: n = 2</td>
<td>Four themes emerged: psychical responses, cognitive and emotional reactions, survival techniques and the importance of their partner’s support with acceptance, adaptation, surveillance, and treatment. Bladder cancer patients and their partner need more information from different parties regarding information about the cancer and the treatment and their sexual health and function post treatment.</td>
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<tr>
<td>Hockman et al. (2014) USA</td>
<td>Qualitative/Thematic Analysis</td>
<td>To evaluate patient satisfaction, with emphasis on preoperative education with radical cystectomy. To identify specific areas where improvements can be made.</td>
<td>Total: n=13 &lt;br&gt; Male: n = 11</td>
<td>Four themes emerged regarding patient satisfaction: Patient centered care, availability of care, preoperative preparation and quality of care. Patients rely on the staff, but they feel abandoned when the staff isn’t available. The patients feel that they get too much information. The use of medical language contributed to the fact that the patients did not understand the risks of the surgery.</td>
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<tr>
<td>Klein et al. (2021) USA</td>
<td>Qualitative/Thematic Analysis</td>
<td>To evaluate the perioperative decision-making process, postoperative decision regret and reflection on the peri-operative experience of patients undergoing radical cystectomy and urinary diversion through patient interviews.</td>
<td>Total: n=13 &lt;br&gt; Female: n = 3 &lt;br&gt; Male: n = 10</td>
<td>Patients are satisfied with the preoperative information. Problems that arise concerning the postoperative self-care may be due to insufficient information about the perioperative process.</td>
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<tr>
<td>McHullen et al. (2014) USA</td>
<td>Qualitative/Modified grounded Theory</td>
<td>To learn about patients’ experiences with treatment choice, surgical care, and recovery across health settings. Understanding patient experiences is essential to closing care gaps and developing patient-reported measures.</td>
<td>Total: n=63 &lt;br&gt; Patients: n=57 &lt;br&gt; Male: n = 39 &lt;br&gt; Caregivers: n = 5</td>
<td>Across both systems, patients described variable experiences in decision-making about their cystectomy and urinary diversion. Some felt overwhelmed by information; others felt poorly informed. Many found self-care equipment challenging when transitioning to home. The result also describes meaningful domains of patient experience with cystectomy and urinary diversion.</td>
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<tr>
<td>Mohamed et al. (2014) USA</td>
<td>Qualitative/Content analysis</td>
<td>Examining unmet patient needs along the illness trajectory.</td>
<td>Total: n=30 &lt;br&gt; Female: n = 8 &lt;br&gt; Male: n = 22</td>
<td>Unmet informational needs changes along the illness trajectory. At diagnosis, patients experience insufficient information about postoperative self-care &amp; recovery.</td>
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<td>Mohamed et al. (2016) USA</td>
<td>Mixed method/ Crystallization approach</td>
<td>Examining whether the unmet informational and supportive care needs of the patients with muscle-invasive bladder cancer vary by the patients’ age, sex, or individual treatment choices.</td>
<td>Total: n=43 &lt;br&gt; Female: n = 8 &lt;br&gt; Male: n = 22</td>
<td>Younger patients (&lt;65y) were less satisfied with the preoperative information and were more likely to report complications. More women than men reported difficulties with self-care, and they relied on themselves instead of spousal support. Up to 50% patients reported feeling depressed before or after treatment regardless of age, sex, or treatment choice.</td>
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<td>Total: n = 25 &lt;br&gt; Patients: n=22 &lt;br&gt; Female: n = 22 &lt;br&gt; Partner: n = 3</td>
<td>Major themes emerged in the interviews in both cohorts that included concerns about changes to body image, the psychosocial impact of the diagnosis and treatment, the impact of radical cystectomy on their sexual functions and inadequacies in provider-led sexual health counselling. There was no difference in older or younger regarding the desire to retain the option of sexual function.</td>
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The postoperative information needed to come from all of the different professional categories in the team, as the information content was adapted based on the different competencies (Hockman et al., 2020; Smith et al., 2019).

The information and education that was given needed to be processed and this could not be accelerated. To individualize self-care training, this aspect needs to be considered. The lack of information and education led to difficulties with self-care in the patients’ everyday lives (Heyes et al., 2020; Klein et al., 2021; McMullen et al., 2019; Mohamed et al., 2021).

### 3.1.3. Information related to recovery

The recovery was about the patient being able to return to a new normal life. The need for information during this phase varied depending on where in life the patient was (Mohamed et al., 2016). Relatives should be seen as an additional resource that has a positive role. 

### Table 1 (continued)

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<thead>
<tr>
<th>Author, Year, Country</th>
<th>Type of Study/Methodological Orientation</th>
<th>Purpose</th>
<th>Sample Size (Bold text is the number of patients)</th>
<th>Major Findings</th>
<th>CASP Quality Score</th>
</tr>
</thead>
</table>
| Mohamed et al. (2021) USA | Qualitative/Immersion/Crystallization | Examining patient and informal caregiver unmet needs to identify areas for targeted supportive care interventions and programs to enhance both patient and informal caregiver experience | **Patients:** n=30  
**Female:** n = 7  
**Male:** n = 23  
**Caregivers:** n = 13 | Patients have insufficient psychological preparation for ostomy surgeries. They don’t get enough hands-on-training on stoma care and the utility of stomal appliances. Unmet psychological needs related to depression, anxiety and distress caused by changes in body image and sexual, urinary and bowel function were also reported. The patients have a significant medical need in the acute postoperative period including pain, fatigue, sleep disturbance, inflammation and complications, which results in readmission to the hospital. Life is affected to a large extent by the surgery, both emotionally and in terms of lifestyle. | 5 |
| Rammant et al. (2019) Belgium | Qualitative/Content Analysis | To explore the determinants of physical activity in patients with bladder cancer before and after radical cystectomy. | **Total:** n=30  
**Female:** n = 8  
**Male:** n = 22 | The results show that patients are missing information about physical activity that promotes healing and recovery. Furthermore, it also showed that the medical staff does not provide information about what activities patients can do after the operation or which rehabilitation can strengthen their recovery. | 10 |
| Rammant et al. (2021) Belgium | Qualitative/Content Analysis | To explore patient perspectives of muscle-invasive bladder cancer on how the health care team and their social network can support them during their cancer trajectory. | **Total:** n=16  
**Female:** n = 7  
**Male:** n = 9 | Patients have different needs throughout the illness trajectory. Before diagnosis, the most important need was to get a quick appointment with a urologist. After diagnosis, prompt planning for treatment is important as it reduces the feeling of insecurity. The patients want the information to be sufficient and clear and that was important throughout the whole illness trajectory. Information about patient associations was important. | 10 |
| Smith et al. (2019) USA | Qualitative/Thematic Analysis | Examine which patient-reported factors were affected the most regarding the perioperative experience for the patient. | **Total:** n = 45  
**Patients:** n=15  
**Female:** n = 5  
**Male:** n = 10 | The need for information within this patient group is great. However, the patients have different needs about what the information should be. The preoperative information led to an overwhelmed patient because they couldn’t comprehend everything. To make it easier for the patient, it was important that the information was given step by step. Furthermore, the results showed that the patients didn’t have the right amount of information to understand the “normal” and the postoperative symptoms that they needed to seek health care for. There were also reports that they didn’t feel prepared for the ostomy care because when the education was provided, they felt overwhelmed. Patients also reported that they felt left out and forgotten about when their hospital stay was over. | 10 |
| Wulff-Burchfield et al. (2021) USA | Qualitative/Thematic Analysis | Examine the effect of the stoma “Bootcamp” to improve the patient’s and their relative’s urostomy awareness and coping ability. | **Total:** n = 37  
**Patients:** n=29  
**Female:** n = 7  
**Male:** n = 22 | The result is presented through 3 themes: patient and caregiver motivation to attend the program, attitudes towards ostomy and education. The results show that the patients and the caregivers had lack of knowledge, fear and concern about ostomy and care as motivation. The patient also had different attitudes towards the ostomy, from avoidance to acceptance. The ostomy bootcamp worked as a wakeup call for the patients and was an effective way to prepare the patients for the surgery. | 10 |
impact on recovery after cystectomy. They contributed to an increased sense of security, which reduced the risk of misunderstandings arising in connection with information sharing and education. Therefore, it is important to include them early during recovery (Heyes et al., 2020; Hockman et al., 2020). Patients’ information needs about physical activity were not met by the health care professionals, and they failed to inform them about its positive effects on recovery. Older patients in particular felt that this information need was not met, and they perceived that the health care staff had preconceived notions regarding older people’s exercise habits and levels of physical activity (Rammant et al., 2019).

3.2. Emotional roller coaster through the trajectory of the illness

The second analytical theme describes the emotional spectrum that patients undergo in the context of information being given throughout the course of care. A cancer diagnosis is mentally stressful for the individual, and the health care staff must see the whole person and support them throughout their lives. The creation of a trusting and confiding relationship provided the patient with security and reduced the patient’s anxiety (Heyes et al., 2020; Mohamed et al., 2021; Rammant et al., 2019). Younger patients felt that the health care system did not offer them psychological support; they chose instead to seek help on their own (Gupta et al., 2021; Mohamed et al., 2016; Rammant et al., 2021).

Patients with bladder cancer were given information with the aim of being prepared for cystectomy (Garg et al., 2018; Wulff-Burchfield et al., 2021), but they were overwhelmed by the amount of information given (Smith et al., 2019). The amount of information was perceived as frightening and contributed to their anxiety and fear (Heyes et al., 2020; Rammant et al., 2019; Smith et al., 2019; Wulff-Burchfield et al., 2021). This feeling of unease existed throughout the course of the disease but differed between younger and older individuals. Younger people worried about the future, and older people worried that ageing could contribute to a loss of physical function (Mohamed et al., 2016). Other emotions that characterized the course of the disease were loneliness, vulnerability, and the feeling of not being respected. This was experienced despite the patient having the support of partners or relatives (Heyes et al., 2020; Mohamed et al., 2021; Wulff-Burchfield et al., 2021). The health care staff had a great responsibility throughout the course of the disease in giving the patient security, reducing their anxiety, and facilitating their control of their situation. This gave the patient the tools to restore self-confidence (Heyes et al., 2020; Klein et al., 2021; McMullen et al., 2019).

After returning from the hospital, the patient felt that they were forgotten and abandoned, which contributed to increased worry, fear, and stress. They felt that they did not have control over their situation, the aids, or what possible complications could arise after surgery (Heyes et al., 2020; Klein et al., 2021; Smith et al., 2019). Other perceived emotions were shame and loneliness. Shame was experienced when the patient no longer had control over their urinary function and the risk of leakage that produced an unpleasant odour. This could lead to the patient isolating themselves and thus feeling lonely (Mohamed et al., 2016).

3.3. The changed body

This theme is about how patients adapt to their changed body and the changed bodily functions that the operation carries with it. This theme also describes what information is needed to facilitate the patient moving forward in their process of adapting and understanding their new self. The theme is presented in two parts, Body Image and Sexuality.

3.3.1. Body image

Undergoing cystectomy involves both external and internal bodily changes (McMullen et al., 2019). The largest external change was that the patient had a urostomy, while the internal changes affected the urinary and bowel function of the patient (Heyes et al., 2020; McMullen et al., 2019; Mohamed et al., 2016). A urostomy affects their entire life, and the new look needed to be accepted (Gupta et al., 2021; Mohamed et al., 2021). Having the bladder removed was seen as an invasion of privacy and hindered their acceptance of their new appearance (Garg et al., 2018). The patients felt that they lacked information and knowledge about urostomy, ostomy care and how they could continue to live their life after undergoing surgery (Garg et al., 2018; Gupta et al., 2021; Hockman et al., 2020; Klein et al., 2021; Mohamed et al., 2014, 2021; Rammant et al., 2021). The patients felt that the nursing professionals had encroached upon their personal sphere. This caused them difficulties in assimilating information and knowledge regarding stoma care (Garg et al., 2018; Hockman et al., 2020; Klein et al., 2021; Rammant et al., 2021; Wulff-Burchfield et al., 2021). Feelings of shame and embarrassment affected the patient’s ability to assimilate information and their ability to develop knowledge about ostomy management and continued life. The feelings arose because bladder cancer affected their intimate body parts and this could contribute to the patient alienating themselves from the new body part (Mohamed et al., 2021; Rammant et al., 2021; Wulff-Burchfield et al., 2021).

3.3.2. Sexuality

A major physical change that occurred in connection with cystectomy concerned sexual function. Sexuality is perceived as a difficult topic for patients to bring up with health care professionals, which contributes to the experience of a lack of information about how the surgery will affect the anatomy and cause possible sexual dysfunction (Gupta et al., 2021; Klein et al., 2021). The patients felt that it was the responsibility of health care professionals to raise the topic of sexuality; if this did not occur, further deficiencies arose, and patients lacked information on how they could be sexually active after surgery or what kind of support was available regarding assistive technology/aids after surgery (Gupta et al., 2021; Heyes et al., 2020; Klein et al., 2021; Mohamed et al., 2016). Healthcare professionals contribute to the unnecessary suffering of their patients and their partners when information about sexuality is not provided (Gupta et al., 2021; Heyes et al., 2020; Mohamed et al., 2014, 2021).

Elderly patients experienced that they did not receive any information about how to be sexual after surgery. They felt that health care professionals had preconceived notions about ageing and sexuality (Heyes et al., 2020). Women felt that they had not received information about how the surgery affected their sexuality and what that sexual dysfunction meant. Feelings of embarrassment and shamefulness and that it was not acceptable to talk about female sexuality made women seek information on the internet and from female patient associations instead of their healthcare providers (Gupta et al., 2021; Mohamed et al., 2014). Desire decreased due to sexual dysfunction, which further provoked feelings of shame and embarrassment (Gupta et al., 2021; Mohamed et al., 2021).

The men felt to a greater extent that they had received information about sexual dysfunction and what aids were available. Healthcare professionals were seen as a natural avenue for information gathering about their sexuality and their sexual dysfunction (Gupta et al., 2021; Mohamed et al., 2021). Their desire decreased due to the sexual dysfunction that arose. Their self-image was affected because of sexual dysfunction, and the men felt that they did not live up to the stereotypical image of being a man. This often led to the men preferring to abstain from sexual activity (Heyes et al., 2020; Mohamed et al., 2021).

3.4. The importance of self-care to continued life

The fourth analytical theme is about the patient’s prerequisites for a continued good life. This theme describes what patients need to learn to master and what adaptations they need to make to feel prepared for the situations that may arise in everyday life. This theme is divided into Self-Care and Physical Activity.
Patients who have undergone cystectomy need to adapt to their new life. The extent of these adaptations was often not perceived as graspable until the patient experienced it for real (Mohamed et al., 2021). The procedure and subsequent recovery were physically and mentally difficult for the patient. To manage this transition and relate to the new transformative situation, the patient needed to be motivated (Garg et al., 2018). Motivation increased if the patient felt that their information needs were met (Garg et al., 2018; Mohamed et al., 2021; Rammant et al., 2021; Wulff-Burchfield et al., 2021).

3.4.1. Self-care

Self-care has a significant role in the patient’s continued life after surgery, but becoming an expert in self-care required time. The time aspect needed to be accepted by both the patient and their relatives (McMullen et al., 2019). To live an independent and active life, the patient needs to have confidence in their ability to perform self-care (Klein et al., 2021; McMullen et al., 2019; Rammant et al., 2019; Smith et al., 2019). When this step failed, it affected the patient’s ability to perform self-care, and they did not know how to interpret their symptoms. This contributed to difficulties in knowing when to seek medical care. This then created anxiety and made the patient feel unready when returning home (Hockman et al., 2020; Klein et al., 2021; McMullen et al., 2019; Mohamed et al., 2021; Rammant et al., 2021; Smith et al., 2019).

The patients felt that they lacked strategies and solid advice to be able to sort out situations that could arise in everyday life since the information and especially the education had taken place at too fast a pace (Klein et al., 2021; McMullen et al., 2019; Mohamed et al., 2016, 2021; Rammant et al., 2021; Smith et al., 2019).

3.4.2. Physical activity

The concept of self-care also includes physical activity (Klein et al., 2021; Rammant et al., 2019). Patients experienced receiving only vague information about what rehabilitation could strengthen them after surgery and what activities should be avoided to reduce the risk of complications (Rammant et al., 2019). Again, elderly patients experienced preconceived notations. They did not receive information about exercise. The lack of information created fear within the patient, and they therefore avoided all physical activity (Klein et al., 2021; Rammant et al., 2019).

4. Discussion

The main results showed that patients with bladder cancer who had undergone cystectomy had a great need for information extending from the time of diagnosis to a long time after the surgery and their discharge from the hospital. The two most important reasons for patients to be able to assimilate the information are, according to the results of this review, that there was enough time set aside for education and that they had confidence in the person who gave the information. Trust and security need to be provided for patients. When this is achieved, the patients feel safe and can therefore absorb the information, and their information needs have been met (Gupta et al., 2021; Mohamed et al., 2016; Rammant et al., 2019).

The patient’s ability to take in information depends on what level of health literacy they possess. This is something that health care professionals need to be aware of in all encounters with patients (Nesari et al., 2019; Wijets et al., 2021).

Patients felt that information given by others who had undergone cystectomy was the most significant source of information. The information was then perceived as more consistent and credible. A patient who had previously undergone the procedure and has lived experience is therefore an important source of information and creates security and hope. In person-centred care, the patient’s story is described as a key concept and is one of the resources available in the patient’s life situation (Cronenwett et al., 2007). Health care professionals therefore need to have access to alternative credible sources of information, such as patients with lived experience and patient associations. To further strengthen person-centred care, health care professionals need to understand what information is relevant to provide at the right time.

The results showed that patients experienced concerns about their cancer diagnosis and the situation that arose after surgery. They experienced a lack of information that psychological support is available to reduce anxiety. Their concern had several components, but a large part concerned that the patient was no longer in control. Anxiety creates insecurity, which contributes to the difficulty of taking in the information given (Garg et al., 2018; McMullen et al., 2019; Rammant et al., 2021). Previous research shows that patients with a positive evaluation of social support appear to have a higher level of psychological well-being and lower levels of cognitive distress (Heyes and Bond, 2020).

Another aspect was time. The staff had only a certain amount of time set aside, and they did not consider that the information shared was new to the patient. This situation caused stress, which in turn created room for misunderstanding (Heyes et al., 2020; Rammant et al., 2019; Smith et al., 2019; Wulff-Burchfield et al., 2021). Unless the psychological strain and mental journey that the patient undergoes is recognized, the staff has failed to look after the whole person. This can affect the length of hospitalization and the patient’s ability to learn self-care. This can lead to unnecessary suffering for patients. By creating trusting care relationships and taking a holistic approach, anxiety can be reduced. Person-centred care can be seen as ethical and is one of six core competencies that specialist nurses specializing in surgical care should work towards (Cronenwett et al., 2007). The approach involves evaluating and using patients’ subjective experiences of their disease, regardless of their cognitive ability (Fazio et al., 2018), where the focus is the patient and not their illness (Edwardsson et al., 2010). Reasons why healthcare professionals fail to reduce anxiety and provide reassurance in situations of care may be that the information provided is standardized and not individualized. Standardized information is good in that it ensures that the content of what is needed to know is given. The quality of how the information is given certainly varies according to who gives it, where the healthcare staff’s experience and pedagogical knowledge are important. Person-centred care that is carried out together with the patient according to prerequisites and needs contributes to the preservation of integrity and dignity (Cronenwett et al., 2007).

Patients experienced a lack of information about the physical changes affecting their sexual function associated with cystectomy. They also lacked information on how they might be sexual after surgery (Gupta et al., 2021; Heyes et al., 2020; Huang et al., 2015; Klein et al., 2021; Mohamed et al., 2016). It is noteworthy that this topic is not addressed with patients, as it is a need like any other, since sexuality is part of being human (World Health Organization, 2017). One reason why that topic is not raised by health care professionals may be that conversations and information are perioperatively focused on cancer, survival, physical recovery, self-care, and mobilization to be able to cope with returning home. Sexual health has a holistic perspective that states that sexuality is important throughout life (World Health Organization, 2017). Society’s norms for female and male sexuality differ. Female sexuality is less openly talked about (Gupta et al., 2021; Mohamed et al., 2014, 2021). Differences in help and support between genders thus exist. Elderly patients do not receive information about sexuality. They feel that healthcare professionals do not understand elderly patients and their sexuality (Heyes et al., 2020). This issue needs to be raised among the staff. Sexual concerns contribute to suffering for both the patient and their partner, and it is important that the condition is assessed continuously during follow-up to be able to provide person-centred care and offer individual help (Cronenwett et al., 2007; World Health Organization, 2017).

Self-care is a prerequisite for the patient to be able to live independently and feel in control in their continued life (Repennig and Taylor,
Physical activity is part of self-care, and it contributes to faster recovery after surgery. Elderly patients received insufficient information about physical activity, and they felt that the reason was that the health care professionals had preconceived notions about their exercise habits (Klein et al., 2021; Ramman et al., 2019). These results showed once again that older people are discriminated against based on age. Older people are already a fragile group in society based on what ageing means for the body, which also affects their cognitive ability and their level of health literacy (Bozkurt and Demirci, 2019; Turkoglu et al., 2019). The lack of information has consequences, as patients have reduced opportunities for rehabilitation and recovery. This study has methodological aspects that may be considered. The inclusion criteria were articles published between 2012 and 2021, which may be interpreted as a limitation. However, its strength is the relatively new evidence summarized. The authors had the support of an experienced university librarian regarding keywords and search combinations to increase the search specificity. To carry out a structured literature review. Scand. J. Caring Sci. 26, 151–161. The quality appraisal of articles was carried out by all authors on the research team, which improved the strength of the study and increased the credibility of the study. The analysis was carried out according to Thomas & Harden’s thematic synthesis process for qualitative studies. The analysis aimed to provide an overall picture of the research area/topic of interest by compiling results from several qualitative studies into a new overall result (Thomas and Harden, 2008).

5. Conclusion

The results show that patients with bladder cancer feel that their information needs are not met, which can contribute to misunderstandings and insecurity. The main problem is that too much information is given all at once. To facilitate patient education, the information needs to be clear, given in plain language and, above all, be step-by-step and person-centred. Through this, the health care staff will contribute to patient security, which promotes the patient becoming independent in their self-care. Further research exploring information needs and female sexuality after cystectomy is important to obtain a deeper understanding and knowledge.

Declarations of competing interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Acknowledgements

We would like to thank the Department of Urology at Linköping University Hospital, who financially supported this study.

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