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## **Executive summary**

### **Background**

Prostate cancer is the most common male cancer and second most common cause of cancer death in men in the Western world. Compared to other prostate cancer treatments trials report worse urinary incontinence (UI) and sexual function and similar bowel function among men with prostate specific antigen detected prostate cancer who underwent radicalized prostatectomy (RP).

### **Objective**

To identify men's perceptions of the impact of the physical consequences of a RP on their quality of life.

### **Inclusion criteria**

The review included:

#### *Types of participants*

Men of all ages and nationalities who had RP as treatment for all stages of prostate cancer.

#### *Phenomena of interest*

This review considered studies that investigated:

- The physical consequences of RP and its impact on quality of life and life experience as identified by the men
- The psychosocial implications of the identified physical consequences of RP as identified by the men

#### *Context*

Any setting where the topic was addressed with participants meeting the inclusion criteria.

#### *Types of studies*

The review considered studies that focused on qualitative data including, but not limited to phenomenology, grounded theory, ethnography and action research. Studies were included if they reported results relating to one or more of the phenomena of interest. Studies not written in English were excluded.

### **Search strategy**

The search strategy aimed to find published studies from six databases from database inception to November 2017.

### **Methodological quality**

Methodological quality of studies was independently assessed by two reviewers using standardized the Joanna Briggs Institute QARI critical appraisal instrument.

### **Data collection**

The standardized Joanna Briggs Institute QARI data extraction tool were used.

### **Data synthesis**

A meta-aggregation was undertaken and the final synthesis of the findings was reached through discussion. Results are presented as five aggregated qualitative syntheses.

### **Results**

Nineteen qualitative studies were included in the review. The five aggregated syntheses were:

1. Urinary incontinence is a significant problem for which men feel ill prepared, UI causes feelings of powerlessness and negatively impacts on social life and life experience. Healthcare professionals should understand the impact and consequence of UI and implement support interventions to ensure that the negative impact on life experience is minimized.
2. Erectile Dysfunction (ED) has the greatest impact on men post radicalized prostatectomy, affecting sexuality and masculinity and causing anxiety, loss and grief.
3. Acceptance of the side-effects of RP was demonstrated in a number of ways, reconciliation, adaptation and compensation for being rid of the cancer.
4. The impact of ED on relationships. Whilst ED can have a negative impact on relationships, an altered sexual relationship could still be enjoyable, physical and emotional support from partners was considered important.
5. Physical and psychosocial support are perceived to be essential for men to deal with the physical impact of RP on their quality of life.

### **Conclusions**

Urinary incontinence and ED are significant side-effects of RP which have a negative impact on men's quality of life for which they feel ill prepared, physical and psychosocial support is essential.

### **Table 1: ConQual summary of findings table**

Systematic review title: men's perceptions of the impact of the physical consequences of a radical prostatectomy on their quality of life: a qualitative systematic review  
Population: men of all ages and all nationalities who have undergone a RP as treatment for prostate cancer

Phenomena of interest: the physical consequences of RP and its impact on quality of life and life experience as identified by the men and the psychosocial implications of the identified physical consequences of a RP as identified by the men

Context: all settings where this topic has been addressed with participants meeting the inclusion criteria. This included, but was not limited to, outpatient clinics, community clinics, men's homes or support group locations

Synthesized Finding	Type of research	Dependability	Credibility	ConQual score
Urinary incontinence is a significant problem for which men feel ill prepared	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Low
The impact of ED on men post RP	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Low
Acceptance of the side effects	Qualitative	No change	Downgrade 1 level**	Moderate
The impact of erectile dysfunction on relationships	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Low
Physical and psychosocial support are perceived to be essential for men to deal with the physical impact of RP on their quality of life	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Low

\* Downgraded one level due to common dependability issue across include primary studies (the majority of studies had no statement locating the researcher and no acknowledgment of their influence on the research)

\*\* Downgraded one level due to a mix of unequivocal and credible finding

## Research Question

What are men's perceptions of the impact of the physical consequences of a RP on their quality of life?

## Background

Prostate cancer is the most common male cancer and second most common cause of cancer death in men in the Western world.<sup>1</sup> The quality of life of men with prostate cancer can be negatively affected by the various treatments available to them.<sup>2</sup> The three most common contemporary methods of treatment are active monitoring, radical radiotherapy with hormone treatment and RP.<sup>3,4</sup> Radical Prostatectomy predominates as the primary treatment approach for prostate cancer in a number of countries including Australia and North America,<sup>5,6</sup> and involves the complete removal of the prostate, seminal vesicles and surrounding tissues.<sup>7</sup>

Post-operative complications commonly occur and the literature reports issues concerning bladder, bowel and sexual dysfunction.<sup>8</sup> Each of these can be categorized as a physical consequence of the surgery and for RP such complications are urinary,<sup>9,10</sup> and fecal incontinence (FI)<sup>11</sup> as well as sexual dysfunction.<sup>9</sup> Compared to the other treatments of active surveillance and radiotherapy, many trials report worse UI and sexual function and similar bowel function among men with prostate specific antigen detected prostate cancer who underwent RP.<sup>3,12-14</sup> These physical consequences of surgery are intrinsically connected to psychosocial implications for the patient and are associated with significantly reduced quality of life or life experience.<sup>7,15</sup>

Urinary incontinence is a problem for at least 50% of men who undergo RP and this can have a negative effect on their post-operative quality of life.<sup>7,9-10,15</sup> Men can experience negative feelings about dealing with indwelling catheters and UI at home and report anxiety, fear and embarrassment,<sup>16</sup> as well as a loss of a sense of control, depression and decreased social interactions.<sup>10</sup> Fecal incontinence is also reported to have a significant impact upon men's self-confidence, personal image and social life.<sup>7,11</sup>

Sexual dysfunction following a RP encompasses several physical issues including erectile Dysfunction (ED) and impotence,<sup>17,18</sup> which is one of the most common quality of life concerns of men post RP.<sup>19,20</sup> A number of psychological and relationship implications have been

highlighted,<sup>21</sup> and many men do not know where to turn to for help.<sup>20</sup> A less common physical issue following RP is penile length shortening (PLS).<sup>22</sup> Yu-ko et al.<sup>22</sup> suggest that from the viewpoint of society and its preoccupation with penile size that a physical reduction in penile length size following RP can negatively affect psychological well-being. A recent review of the experiences of men after any prostate cancer treatment found that men across numerous studies all reported lost or diminished masculinity. This was linked to depression, embarrassment, decreased self-worth and fear of being stigmatized.<sup>23</sup>

An important clinical implication for understanding men's perceptions of the physical and psychosocial consequences of a RP is that healthcare professionals working with these men can assist them in considering and discussing issues such as masculinity, ED and incontinence pre and post treatment thereby increasing men's understanding, and adaptation post-operatively.<sup>24-25</sup>

A national survey of cancer patients conducted in the United Kingdom (UK) in 1999/2000 identified that patients with prostate cancer often had a worse experience of supportive care than those patients diagnosed with and treated for other cancers.<sup>26</sup> A second survey, conducted following the implementation of the NHS Cancer Plan,<sup>27</sup> a programme outlining the UK government's intentions to reform cancer care, was cohesive with the results of the 1999/2000 survey and identified only the smallest improvement in the provision of care for patients with prostate cancer.<sup>28</sup> A more recent survey,<sup>29</sup> identified improvement in the patient's perception of their experience of prostate cancer care. Even so, the care of people suffering from prostate cancer fell behind several other cancer groups (breast, lung and colorectal) on multiple elements of the survey including definitive explanations of the potential side-effects of treatment thereby identifying scope for improvement in care provision. The National Institute for Health and Care Excellence guidelines for prostate cancer,<sup>30</sup> emphasizes the pivotal role of communication between healthcare professionals and men with prostate cancer. One of their key priorities being the healthcare professionals' role in providing evidence based advice regarding the potential side-effects of prostate cancer treatment and subsequent support that takes into account quality of life implications for these men.

Treatment such as a RP, which has negative physical and psychosocial consequences, which can potentially impact upon men's future quality of life means it is increasingly becoming an important topic. Willener and Hantikainen<sup>31</sup> suggest that improving quality of life should be the ultimate aim of any healthcare treatment or intervention and the patient's experience of the treatment is paramount to this. In order to provide high quality care, healthcare professionals need to improve understanding of the physical and psychosocial implications of a RP from the

men's perspective.<sup>16</sup> An improved understanding of the men's perspective of these physical consequences could potentially enhance the value and impact of support provided.

The underpinning concept in this proposed review is to explore the repercussions on lifestyle and associated psychosocial impact that the physical consequences outlined have on men, following a RP. By identifying and exploring issues that affect men's quality of life, an opportunity is created to talk about problems, discuss information and ultimately improve the men's ongoing life experience. Nurses provide a vital role in ensuring that men are adequately prepared for a RP and the potential post-operative quality of life implications.<sup>20</sup> Without an in-depth knowledge and understanding of men's experience post RP there is a risk that health professionals may be unable to provide the comprehensive support and information that is vital to men post-operatively.

Numerous qualitative studies have been published exploring men's experiences of post RP surgery<sup>19-20, 25, 32-37</sup> and also from the point of view of their spouses.<sup>8, 38-39</sup> Previous qualitative reviews in this area are very limited and a search of the JBI Library, Cochrane, CINAHL and PROSPERO revealed one narrative review and one meta –synthesis of men's experiences after prostatectomy.<sup>16, 40</sup> The majority of systematic reviews which have been conducted are quantitative and have investigated health related quality of life following RP.<sup>7, 15</sup> and the effectiveness of psychoeducational interventions on urinary and FI and ED in men over 50 years and older after prostatectomy for prostate cancer in comparison to usual care.<sup>41</sup>

A systematic review exploring the findings of studies that specifically discuss the impact of the physical consequences of a RP on their life experience/quality of life is essential to assist healthcare professionals in achieving this goal in future practice. To date no such systematic review has been conducted. The objectives, inclusion criteria and methods of analysis for this review were specified in advance and documented in a protocol.<sup>42</sup>

### **Keywords**

Radical prostatectomy; incontinence; erectile dysfunction; quality of life, sexuality

### **Review objective**

The objective of this review was to identify men's perceptions of the impact of the physical consequences of a RP on their quality of life.

### **Inclusion criteria**

### ***Types of participants***

This review considered studies that included:

Men of all ages and all nationalities who have undergone a RP as treatment for all stages of prostate cancer.

The following were excluded

Studies that focused on men undergoing prostatectomy for reasons other than cancer.

Studies that focused on men receiving treatment other than RP for prostate cancer. This may include, but is not exclusive to radiotherapy, hormone therapy and watchful waiting.

Studies that focused only on the perspectives of family members.

### ***Phenomena of interest***

This review considered studies that investigated:

- The physical consequences of RP and its impact on quality of life and life experience as identified by the men
- The psychosocial implications of the identified physical consequences of a RP as identified by the men

### ***Context***

This review considered all settings where this topic has been addressed with participants meeting the inclusion criteria. This included, but was not limited to, outpatient clinics, community clinics, men's homes or support group locations.

### ***Types of studies***

The review considered studies that focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography and action research. Studies were included if they reported results relating to one or more of the phenomena of interest.

Studies not written in English were excluded.

### ***Search strategy***

The search strategy aimed to find published literature only. A three-step search strategy was utilized in this review. An initial limited search of MEDLINE and CINAHL was undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe articles. Initial keywords used were: 'Radical prostatectomy'; prostatectomy; incontinence; masculinity; 'emotional well-being'; continence; 'erectile dysfunction'; 'Men's health'; impotence; sexuality; 'Quality of life'; 'QoL'; Experience\*



A second search using all identified keywords and index terms was undertaken across all the following databases:

Web of Science;

PsycINFO, MEDLINE and EMBASE (via OVID platform);

CINAHL (via the EBSCO platform);

British Nursing Index (via the ProQuest platform).

The search strategy for all of the databases are included in Appendix I.

Thirdly, the reference list of all identified reports and articles was searched for additional studies. Studies published in English from inception of databases to November 2017 were considered for inclusion in this review. The most recent copies of the journals European Journal of Oncology Nursing and Cancer Nursing were hand searched between to ensure that any current relevant papers that may not be indexed in the major databases were located.

## **Method of the review**

### **Assessment of methodological quality**

Qualitative papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using Joanna Briggs Institute Qualitative Assessment and Review Instrument.<sup>43</sup> Any disagreements that arose between the reviewers were resolved through discussion, or with a third reviewer.

### **Data extraction**

Qualitative data was extracted from papers included in the review using the standardized data extraction tool from JBI-SUMARI by two independent reviewers.<sup>44</sup> The data extracted included specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives.

### **Data synthesis**

Qualitative research findings were pooled using the JBI method of meta-synthesis. This involved the aggregation or synthesis of findings to generate a set of statements that represented that aggregation, through assembling the findings rated according to their quality, and categorizing these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis in order to produce a single comprehensive set of

synthesized findings that could be used as a basis for evidence-based practice. The synthesized findings were drafted by the primary reviewer then discussed with the second author for validation. All analytic data within the paper that met the objectives of the review was considered as findings. These were identified through repeated reading of the results sections within the included papers. Categories were developed based on similarity in wording and concepts, descriptions were drafted by the primary reviewer then discussed with the second author for validation. The same process was then repeated to create the synthesized findings.

### **Assessing confidence**

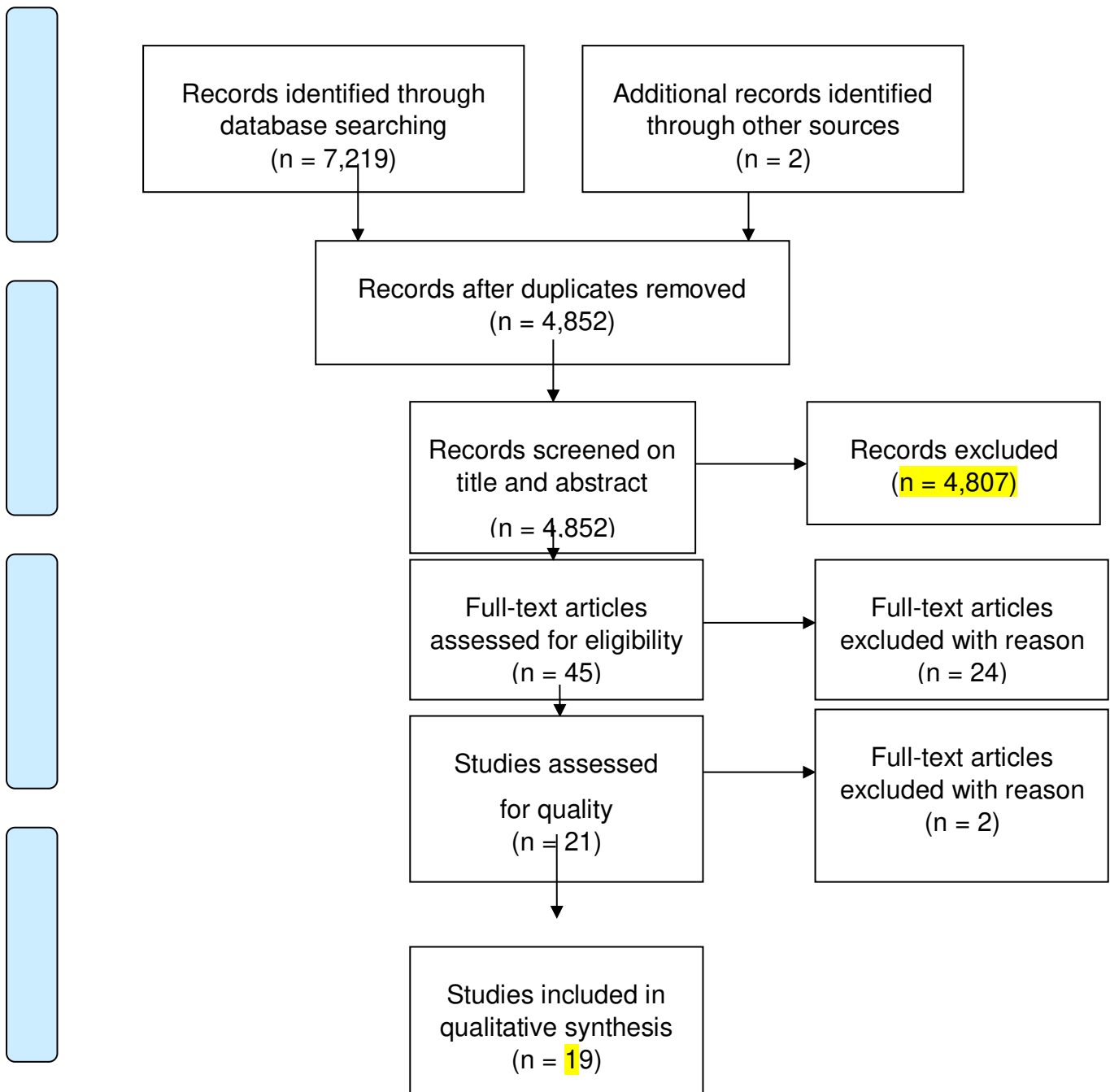
The final synthesized findings were graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings table.<sup>45</sup>

## **Results**

### ***Description of studies***

There were 7,219 citations identified as being potentially relevant to the review. After the duplicates had been removed the titles and abstracts of 4,852 records were reviewed. Based on the study eligibility criteria. 4,807 citations deemed not relevant. Forty five full text articles were retrieved and reviewed against the eligibility criteria using a screening tool designed specifically for the study. Those studies that did not meet the inclusion criteria are listed in Appendix II. All qualitative studies that met the inclusion criteria went forward to critical appraisal. Two qualitative studies were excluded after critical appraisal (Appendix III). A total of 19 qualitative studies were assessed as suitable for inclusion in the review (Figure 1). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist has been followed for the reporting of this review.<sup>46</sup>

Figure 1: Flowchart of the search and study selection process



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

A table detailing characteristics of the included studies is shown in Appendix IV.

### *Study design*

Sixteen were qualitative descriptive, approach,<sup>8, 19-20, 22, 24-25, 32-33 35-37, 39, 47-50</sup> one was an ethnographic study<sup>51</sup> and two used mixed methods.<sup>52, 53</sup>

### *Country of origin*

Six studies were undertaken in Canada,<sup>20, 22, 32-33, 35, 48</sup> two in the USA,<sup>52, 53</sup> two in the UK,<sup>24, 49</sup> two in Australia,<sup>36, 51</sup> one in Brazil,<sup>47</sup> one in Turkey,<sup>25</sup> one in Sweden,<sup>39</sup> one in Ireland,<sup>19</sup> one in Israel,<sup>50</sup> one in Switzerland,<sup>8</sup> and one in Denmark.<sup>37</sup>

### *Recruitment*

In six of the studies participants had been recruited as part of larger studies.<sup>20, 35, 48, 51-53</sup> For the remaining studies participants were recruited from pre-admission clinic,<sup>32</sup> urology departments at one hospital,<sup>24-25, 33, 47, 50</sup> urology departments at two hospitals,<sup>49</sup> prostate cancer support groups,<sup>19, 22</sup> sexological counselling service,<sup>37</sup> or from a cancer registry database.<sup>36</sup> Two studies just stated that participants were recruited from one local hospital<sup>35</sup> or two local hospitals.<sup>8</sup>

### *Participants*

Fifteen studies focused on the men alone.<sup>19-20, 22, 24-25, 32-33, 35-37, 39, 47, 49-51</sup> Four studies included partners,<sup>8, 48, 52-53</sup> and for the purpose of the review data was only extracted that related to the men themselves. One of these included heterosexual couples only,<sup>8</sup> one focused on gay couples only,<sup>48</sup> one study included seven heterosexual and one same-sex partnership,<sup>52</sup> one included one gay couple and twenty seven heterosexual couples.<sup>42</sup> The study conducted by Wittman et al.<sup>53</sup> drew their participants from the twenty eight couples included in the study by Wittman et al.<sup>52</sup> The age range of the participants, where stated varied from 46 years<sup>20</sup> to 80 years.<sup>49</sup>

### *Stage of cancer*

Stage of cancer was recorded across ten studies,<sup>8, 24-25, 32, 35, 39, 49-50, 52-53</sup> four included patients with only stage 0 – early stage tumors,<sup>32, 35, 39, 49</sup> three with stage I – localized tumors only<sup>8, 24, 50</sup> one with stage 2 – advanced tumors<sup>25</sup> and two that included both patients with localized and advanced tumors.<sup>52, 53</sup>

### *Data collection*

For the qualitative descriptive studies all data were collected through interviews and in some studies focus groups,<sup>20, 36</sup> or reflective diaries<sup>22</sup> were also conducted. The ethnographic study collected data through participant observation, field notes and semi-structured interviews.<sup>51</sup> Two studies collected interview data at multiple time points.<sup>32, 48</sup> Hartman et al.<sup>48</sup> collected data between; 3-6 months, 2-15 months and 21-24 months post-surgery and Burt et al.<sup>32</sup> collected data at day 2, 7, 21 and 120 days post discharge for all 17 participants and then collected data at 12 months post discharge with a subset of 5 participants who were selected for their reflective ability.

Data was collected for the remaining studies at one time point. For the majority of studies the time period for collecting the data after surgery had taken place ranged from 1 month<sup>8</sup> to 28 months.<sup>20</sup> The average time for collecting data was provided for five of these studies (mean of 14.3 months,<sup>52</sup> 17.32 months,<sup>20</sup> 21 months,<sup>51</sup> 26 months,<sup>39</sup> and median of 8 weeks.<sup>20</sup> Two studies interviewed some patients in the sample more than 3 years after surgery had taken place.<sup>19, 47</sup> In the study by de Moraes Lopes,<sup>47</sup> one patient who had UI for 12 years was interviewed 25 years post-surgery. The time period for collecting data was not specified for two studies.<sup>22, 33</sup>

### *Data analysis*

For the qualitative descriptive studies data was analyzed using a variety of approaches which included the use of an analysis grid,<sup>32</sup> content and or thematic analysis,<sup>19,-20, 33, 35-36, 39, 47, 50, 53</sup> Foucauldian discourse analysis,<sup>24</sup> through phenomenological methodology,<sup>37, 48, 49</sup> or using a grounded theory approach,<sup>8, 22, 52</sup> The ethnographic study<sup>51</sup> collected analyzed data through the use of a social constructionist gendered framework.

## **Methodological quality**

When a study met a criterion for inclusion (for example; 10 items for qualitative studies) a score of 1 was given. Where a particular point for inclusion was regarded as “unclear” it was given a score of 0. Where a particular point for inclusion was regarded as “not applicable” this point was subtracted from the total score. All included studies were assessed using this method and their overall critical appraisal scores presented. Studies were excluded if they scored below 5 using this approach.

Nineteen studies were included in the final synthesis and scored between 5 and 10 against the ten critical appraisal questions applicable to qualitative studies. For the study that scored 5, it was unclear as to whether there was congruity between the research methodology and the representation and analysis of data. There was no statement locating the researcher culturally or theoretically and the influence of the researcher wasn't addressed. There were no details of ethical considerations and their own conclusions did not flow from the analysis. For the remaining studies only four<sup>24, 35, 39, 51</sup> provided a clear statement locating the researcher culturally or theoretically and there was insufficient data to provide an answer to this question for a further study.<sup>50</sup> Hartman et al.<sup>48</sup> discussed the influence of the researcher on the research or vice-versa and there was insufficient data to provide an answer to this question for a further two studies.<sup>24, 36</sup> The critical appraisal scores are outlined below (Table 2).

**Table 2: Critical appraisal scores for qualitative studies**

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score
Burt et al 2005 <sup>32</sup>	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9/10
Butler et al 2001 <sup>33</sup>	Y	Y	U	Y	Y	N	N	Y	N	N	5/10
de Moraes Lopes et al 2012 <sup>47</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8/10
Eliat-Tsanani et al 2013 <sup>50</sup>	Y	N	Y	Y	Y	N	N	Y	Y	Y	7/10
Gannon et al 2010 <sup>24</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y	9/10
Hartman et al 2014 <sup>48</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8/10
Hedestig et al 2005 <sup>39</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Iyigun et al 2009 <sup>25</sup>	Y	Y	Y	Y	Y	N	U	Y	Y	Y	8/10
Milne et al 2008 <sup>20</sup>	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9/10
Moore and Estey 1999 <sup>35</sup>	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	9/10
O'Shaughnessy and Laws 2009 <sup>36</sup>	Y	Y	Y	Y	Y	N	U	Y	Y	Y	8/10
Oliffe 2005 <sup>51</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Petry et al 2004 <sup>8</sup>	Y	Y	Y	Y	Y	U	U	Y	Y	Y	8/10
Waller and Pattison 2013 <sup>49</sup>	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9/10
Walsh and Hegarty 2010 <sup>19</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8/10
Wittmann et al 2014 <sup>52</sup>	Y	Y	Y	Y	Y	U	U	Y	Y	Y	8/10
Wittmann et al 2015 <sup>53</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8/10
Yu Ko et al 2010 <sup>22</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Laursen 2017 <sup>37</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10

Y=Yes, N=No, UC=Unclear

## Findings of the review

## Meta-synthesis

In order to identify men’s perceptions of the impact of the physical consequences of a RP on their quality of life a total of two hundred and thirty nine findings from nineteen qualitative studies were extracted and aggregated to form twenty categories. The illustrations for each of these findings can be found in Appendix V. Findings were categorized as follows:

Unequivocal (U): evidence beyond reasonable doubt, which may include findings that are matter of fact, directly reported / observed and not open to challenge (one hundred and ninety nine findings).

Credible (C): related to those findings that are, albeit interpretation, plausible in light of the data and theoretical framework. They can be logically inferred from the data. Because the findings are essentially interpretative they can be challenged (Forty findings)

Unsupported (Un): is when the findings are not supported by the data. (thirty two). The unsupported findings were extracted but not included in the final synthesis

The twenty categories were further synthesized in a meta-synthesis which yielded 5 synthesized findings (Tables 3-7).

**Table 3: Meta synthesized finding 1: Urinary incontinence is a significant problem for which men feel ill prepared**

<b>Category 5:</b>
<b>Urinary incontinence identified as a significant problem: men felt emotionally unprepared</b>
<b>Findings</b>
<ol style="list-style-type: none"> <li>1. Participants expressed hatred of the catheter and referred to it repeatedly as the worst part of the prostatectomy experience (U)(HD).<sup>32</sup></li> <li>2. Reactions ranged from feeling optimistic about its (incontinence) temporary nature to frustration and embarrassment for which the men described themselves as emotionally unprepared (U)(HD).<sup>32</sup></li> <li>3. Feelings of helplessness permeated the speech of the interviewees (U)(MD)<sup>47</sup></li> <li>4. More than one man described the operation itself as a non-event compared to the ongoing incontinence. The unexpected persistence of incontinence played heavily on the man's psyche (U)(MD).<sup>36</sup></li> <li>5. For another man ongoing incontinence resulted in considerable anxiety causing him to question his decision to have surgery (U)(MD).<sup>36</sup></li> </ol>

6. The sensory experience of catheterization was for some the single biggest postoperative issue (U)(HD).<sup>20</sup>
7. Participants generally expected to experience some incontinence but were generally shocked by the severity (U)(HD).<sup>20</sup>
8. Most participants (57.1%) felt uncomfortable with the long-term use of a urinary catheter after surgery (U)(MD).<sup>25</sup>
9. Most participants (71.4%) stated that they had felt anxious regarding going home with the urinary catheter as they were afraid of bleeding or infection (U)(MD).<sup>25</sup>
10. The volume of UI after the catheter had been removed was high for some participants (13.3%) (U)(MD).<sup>25</sup>
11. Most participants (73.3%) indicated that they did not know they would be incontinent after the surgery and that this was as second shock to them, following the initial shock of the diagnosis of cancer (U)(MD).<sup>25</sup>
12. Some participants (20%) described incontinence as the worst thing that could happen to a man and related a feeling of loss of control (U)(MD).<sup>25</sup>
13. Participants indicated that they were trying to cope using a variety of different methods and that they had not consulted physicians or nurses on the matter (U)(MD).<sup>25</sup>
14. The level of urinary incontinence following removal of the catheter came as a surprise to a number of men (U)(MD).<sup>19</sup>
15. Urinary incontinence emerged as a major concern (C)(MD).<sup>19</sup>
16. Men stated they were unprepared for urine by-passing the catheter, haematuria, or the signs of a urinary tract infection (U)(HD).<sup>35</sup>
17. The degree of UI immediately after catheter removal was a shock to all men (U)(HD).<sup>35</sup>
18. Men had no knowledge about incontinence pads – where to go, what to use or the amount of heavy leakage they would have for several days after catheter removal (U)(HD).<sup>35</sup>
19. All men needed reassurance that they would improve and that most men regain continence after a RP (C)(HD).<sup>35</sup>
20. After surgery, dealing with incontinence became the first priority and erectile dysfunction was less important (U)(MD).<sup>11</sup>
21. Pads were handed to the man by nurses in most cases at discharge or after removal of the catheter, but usually they did not fit and the participants had to seek other options (U)(MD)<sup>11</sup>



22. Those who were not continent on removal of the catheter, incontinence came as a shock (U)(HD).<sup>49</sup>
23. Men felt their physical experience of regaining continence exceeded their expectations but that psychological recovery was more challenging (U)(HD).<sup>49</sup>

**Category 8:**

**Urinary incontinence had a direct, negative impact on men's feelings, social life and life experience and led to feelings of powerlessness**

**Findings**

24. Respondents stated that they maintained the desire for physical intimacy, which created even more frustration when they found themselves being unable to remain continent during intimacy or generate and maintain an erection (U)(MD).<sup>47</sup>
25. Respondents described a "leaking body" associated with loss of bladder control (U)(MD).<sup>47</sup>
26. Participant narratives also revealed feelings of powerlessness because the UI impaired multiple aspects of their lifestyle (U)(MD).<sup>47</sup>
27. Experiences with urinary incontinence and ED generated fear of disappointing not only their partner, but also family, friends and themselves (C)(MD).<sup>47</sup>
28. Participants described numerous other losses in their daily lives due to UI (C)(MD).<sup>47</sup>
29. Incontinence and ED signaled a body that had become limited and finite (U)(MD).<sup>47</sup>
30. The men in this study perceived incontinence to be a social impropriety: losing control over the retention of urine was seen as a disrespect to others who witnessed the problem (U)(MD).<sup>36</sup>
31. There was an over-riding sense that pad usage meant accepting the UI, and negatively impacted self-esteem (U)(HD).<sup>20</sup>
32. More than half of the participants (60%) stated that incontinence had significantly limited their social life (U)(MD).<sup>25</sup>
33. Some participants (13.3%) stated that they were embarrassed when family members witnessed their incontinence or thought they would be embarrassed in such a case (U)(MD).<sup>25</sup>
34. For some participants (20%) as they got used to their UI they returned to their normal social life (U)(MD).<sup>25</sup>

35. Some of the participants (26.6%) stated that incontinence prevented them from completing religious rituals (U)(MD).<sup>25</sup>
36. More than a third of the participants (35.7%) stated that they did not try sexual intercourse because of fears that their UI would bother their wives (U)(MD).<sup>25</sup>
37. Urinary incontinence often resulted in a need to wear absorbent pads on a daily basis as a precaution against urine leakage despite the pads. Described living a normal social life as something almost impossible to do (U)(HD).<sup>39</sup>
38. Some men were disappointed with the outcome of their RP (U)(HD).<sup>35</sup>
39. By 3 months post RP 20 out of 63 participants had a small amount of leakage and still required a pad 'just in case' – this is when ED became a bigger issue (C)(HD).<sup>35</sup>
40. Men had concerns about the use of protective pads (C)(MD).<sup>33</sup>
41. Men reported issues around incontinence and body image (U)(MD).<sup>33</sup>
42. Men reported being very self-conscious around wives when they had the catheter (C)(MD).<sup>33</sup>
43. Recovery from surgery as well as having an indwelling catheter restricted physical activity (C)(MD).<sup>33</sup>
44. Social activities were restricted due to a fear of UI (U)(MD).<sup>33</sup>
45. Urinary incontinence was reported by all participants to one degree or another and was described as a very difficult complication (U)(MD).<sup>50</sup>
46. The loss of urinary control and the need for pads or diapers caused a feeling of impotence, shame and discomfort (U)(MD).<sup>50</sup>
47. For other men, incontinence signified old age (U)(HD).<sup>49</sup>
48. Disclosure was limited to medical facts, with men preferring to keep their emotions about cancer and incontinence private, even from friends and family (U)(HD).<sup>49</sup>
49. The physical and emotional aspects of incontinence frequently compromised intimate personal relationships (U)(HD).<sup>49</sup>
50. One couple struggled with unresolved incontinence (U)(MD).<sup>52</sup>

**Category 11:**

**Determination to accept UI regain control and not let it impact upon life experience**

**Findings**

51. This (fear of incontinence) motivated them to do pelvic floor muscle exercises to regain continence (C)(HD).<sup>32</sup>
52. Participants noted that caffeine and beer exacerbated leaking, although some were unwilling to avoid these (C)(HD).<sup>32</sup>
53. Most refused to let incontinence slow them down (C)(HD).<sup>20</sup>
54. Although bothered by the unpredictable nature of their UI, all had adopted coping strategies to minimize impact (C)(HD).<sup>20</sup>
55. Most men avoided the use of incontinence pads (C)(HD).<sup>20</sup>
56. Consistent with their reluctance to accept UI, men were particularly motivated to perform pelvic floor muscle exercise (C)(HD).<sup>20</sup>
57. Some participants acted on physician's advice regarding UI and regained total control by 1 month after surgery (C)(MD).<sup>25</sup>
58. To maintain control over the leakage of urine (C)(HD).<sup>39</sup>
59. Being comfortable and safe including feeling dry, prepared and not fearing accidents facilitated men's sense of control and success. This success was required in order for them to resume their social activities, such as going out, walking, hiking, and work (U)(MD).<sup>11</sup>
60. Information-gathering was regarded as a vital part of pre-operative preparation (C)(HD).<sup>49</sup>
61. Those who were able to discuss their incontinence experiences tended to use humor as a coping mechanism (U)(HD).<sup>49</sup>
62. Fear of ongoing incontinence motivated all men to develop coping strategies to deal with incontinence. The most frequent techniques to prevent incontinence were vigilance and controlled toileting. Vigilance involved recognizing altered warning signs of a full bladder (U)(HD).<sup>49</sup>
63. Successful incontinence management meant being able to confidently deal with incontinence episodes without others noticing. This often included partners (U)(HD).<sup>49</sup>
64. Some men preferred to rely on maintaining strict personal hygiene and wearing dark clothes to deal with episodes of incontinence (U)(HD).<sup>49</sup>

Insert tables 4-7 around here

**Table 3: Meta synthesized finding 1: Urinary incontinence is a significant problem for which men feel ill prepared**

<p><b>Category 5:</b></p> <p><b>Urinary incontinence identified as a significant problem: men felt emotionally unprepared</b></p>
<p><b>Findings</b></p> <ol style="list-style-type: none"> <li>1. Participants expressed hatred of the catheter and referred to it repeatedly as the worst part of the prostatectomy experience (U)(HD).<sup>32</sup></li> <li>2. Reactions ranged from feeling optimistic about its (incontinence) temporary nature to frustration and embarrassment for which the men described themselves as emotionally unprepared (U)(HD).<sup>32</sup></li> <li>3. Feelings of helplessness permeated the speech of the interviewees (U)(MD).<sup>47</sup></li> <li>4. More than one man described the operation itself as a non-event compared to the ongoing incontinence. The unexpected persistence of incontinence played heavily on the man's psyche (U)(MD).<sup>36</sup></li> <li>5. For another man ongoing incontinence resulted in considerable anxiety causing him to question his decision to have surgery (U)(MD).<sup>36</sup></li> <li>6. The sensory experience of catheterization was for some the single biggest postoperative issue (U)(HD).<sup>20</sup></li> <li>7. Participants generally expected to experience some incontinence but were generally shocked by the severity (U)(HD).<sup>20</sup></li> <li>8. Most participants (57.1%) felt uncomfortable with the long-term use of a urinary catheter after surgery (U)(MD).<sup>25</sup></li> <li>9. Most participants (71.4%) stated that they had felt anxious regarding going home with the urinary catheter as they were afraid of bleeding or infection (U)(MD).<sup>25</sup></li> <li>10. The volume of UI after the catheter had been removed was high for some participants (13.3%) (U)(MD).<sup>25</sup></li> <li>11. Most participants (73.3%) indicated that they did not know they would be incontinent after the surgery and that this was as second shock to them, following the initial shock of the diagnosis of cancer (U)(MD).<sup>25</sup></li> </ol>

12. Some participants (20%) described incontinence as the worst thing that could happen to a man and related a feeling of loss of control (U)(MD).<sup>25</sup>
13. Participants indicated that they were trying to cope using a variety of different methods and that they had not consulted physicians or nurses on the matter (U)(MD).<sup>25</sup>
14. The level of urinary incontinence following removal of the catheter came as a surprise to a number of men (U)(MD).<sup>19</sup>
15. Urinary incontinence emerged as a major concern (C)(MD).<sup>19</sup>
16. Men stated they were unprepared for urine by-passing the catheter, haematuria, or the signs of a urinary tract infection (U)(HD).<sup>35</sup>
17. The degree of UI immediately after catheter removal was a shock to all men (U)(HD).<sup>35</sup>
18. Men had no knowledge about incontinence pads – where to go, what to use or the amount of heavy leakage they would have for several days after catheter removal (U)(HD).<sup>35</sup>
19. All men needed reassurance that they would improve and that most men regain continence after a RP (C)(HD).<sup>35</sup>
20. After surgery, dealing with incontinence became the first priority and erectile dysfunction was less important (U)(MD).<sup>11</sup>
21. Pads were handed to the man by nurses in most cases at discharge or after removal of the catheter, but usually they did not fit and the participants had to seek other options (U)(MD)<sup>11</sup>
22. Those who were not continent on removal of the catheter, incontinence came as a shock (U)(HD).<sup>49</sup>
23. Men felt their physical experience of regaining continence exceeded their expectations but that psychological recovery was more challenging (U)(HD).<sup>49</sup>

**Category 8:**

**Urinary incontinence had a direct, negative impact on men’s feelings, social life and life experience and led to feelings of powerlessness**

**Findings**

24. Respondents stated that they maintained the desire for physical intimacy, which created even more frustration when they found themselves being unable to remain continent during intimacy or generate and maintain an erection (U)(MD).<sup>47</sup>
25. Respondents described a “leaking body” associated with loss of bladder control (U)(MD).<sup>47</sup>
26. Participant narratives also revealed feelings of powerlessness because the UI impaired multiple aspects of their lifestyle (U)(MD).<sup>47</sup>
27. Experiences with urinary incontinence and ED generated fear of disappointing not only their partner, but also family, friends and themselves (C)(MD).<sup>47</sup>
28. Participants described numerous other losses in their daily lives due to UI (C)(MD).<sup>47</sup>
29. Incontinence and ED signaled a body that had become limited and finite (U)(MD).<sup>47</sup>
30. The men in this study perceived incontinence to be a social impropriety: losing control over the retention of urine was seen as a disrespect to others who witnessed the problem (U)(MD).<sup>36</sup>
31. There was an over-riding sense that pad usage meant accepting the UI, and negatively impacted self-esteem (U)(HD).<sup>20</sup>
32. More than half of the participants (60%) stated that incontinence had significantly limited their social life (U)(MD).<sup>25</sup>
33. Some participants (13.3%) stated that they were embarrassed when family members witnessed their incontinence or thought they would be embarrassed in such a case (U)(MD).<sup>25</sup>
34. For some participants (20%) as they got used to their UI they returned to their normal social life (U)(MD).<sup>25</sup>
35. Some of the participants (26.6%) stated that incontinence prevented them from completing religious rituals (U)(MD).<sup>25</sup>
36. More than a third of the participants (35.7%) stated that they did not try sexual intercourse because of fears that their UI would bother their wives (U)(MD).<sup>25</sup>
37. Urinary incontinence often resulted in a need to wear absorbent pads on a daily basis as a precaution against urine leakage despite the pads. Described living a normal social life as something almost impossible to do (U)(HD).<sup>39</sup>
38. Some men were disappointed with the outcome of their RP (U)(HD).<sup>35</sup>

39. By 3 months post RP 20 out of 63 participants had a small amount of leakage and still required a pad 'just in case' – this is when ED became a bigger issue (C)(HD).<sup>35</sup>
40. Men had concerns about the use of protective pads (C)(MD).<sup>33</sup>
41. Men reported issues around incontinence and body image (U)(MD).<sup>33</sup>
42. Men reported being very self-conscious around wives when they had the catheter (C)(MD).<sup>33</sup>
43. Recovery from surgery as well as having an indwelling catheter restricted physical activity (C)(MD).<sup>33</sup>
44. Social activities were restricted due to a fear of UI (U)(MD).<sup>33</sup>
45. Urinary incontinence was reported by all participants to one degree or another and was described as a very difficult complication (U)(MD).<sup>50</sup>
46. The loss of urinary control and the need for pads or diapers caused a feeling of impotence, shame and discomfort (U)(MD).<sup>50</sup>
47. For other men, incontinence signified old age (U)(HD).<sup>49</sup>
48. Disclosure was limited to medical facts, with men preferring to keep their emotions about cancer and incontinence private, even from friends and family (U)(HD).<sup>49</sup>
49. The physical and emotional aspects of incontinence frequently compromised intimate personal relationships (U)(HD).<sup>49</sup>
50. One couple struggled with unresolved incontinence (U)(MD).<sup>52</sup>

**Category 11:**

**Determination to accept UI regain control and not let it impact upon life experience**

**Findings**

51. This (fear of incontinence) motivated them to do pelvic floor muscle exercises to regain continence (C)(HD).<sup>32</sup>
52. Participants noted that caffeine and beer exacerbated leaking, although some were unwilling to avoid these (C)(HD).<sup>32</sup>
53. Most refused to let incontinence slow them down (C)(HD).<sup>20</sup>
54. Although bothered by the unpredictable nature of their UI, all had adopted coping strategies to minimize impact (C)(HD).<sup>20</sup>

<p>55. Most men avoided the use of incontinence pads (C)(HD).<sup>20</sup></p> <p>56. Consistent with their reluctance to accept UI, men were particularly motivated to perform pelvic floor muscle exercise (C)(HD).<sup>20</sup></p> <p>57. Some participants acted on physician’s advice regarding UI and regained total control by 1 month after surgery (C)(MD).<sup>25</sup></p> <p>58. To maintain control over the leakage of urine (C)(HD).<sup>39</sup></p> <p>59. Being comfortable and safe including feeling dry, prepared and not fearing accidents facilitated men’s sense of control and success. This success was required in order for them to resume their social activities, such as going out, walking, hiking, and work (U)(MD).<sup>11</sup></p> <p>60. Information-gathering was regarded as a vital part of pre-operative preparation (C)(HD).<sup>49</sup></p> <p>61. Those who were able to discuss their incontinence experiences tended to use humor as a coping mechanism (U)(HD).<sup>49</sup></p> <p>62. Fear of ongoing incontinence motivated all men to develop coping strategies to deal with incontinence. The most frequent techniques to prevent incontinence were vigilance and controlled toileting. Vigilance involved recognizing altered warning signs of a full bladder (U)(HD).<sup>49</sup></p> <p>63. Successful incontinence management meant being able to confidently deal with incontinence episodes without others noticing. This often included partners (U)(HD).<sup>49</sup></p> <p>64. Some men preferred to rely on maintaining strict personal hygiene and wearing dark clothes to deal with episodes of incontinence (U)(HD).<sup>49</sup></p>
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**Table 3: Meta synthesized finding 1: Urinary incontinence is a significant problem for which men feel ill prepared**

<p><b>Category 5:</b></p> <p><b>Urinary incontinence identified as a significant problem: men felt emotionally unprepared</b></p>
<p><b>Findings</b></p>
<p>1. Participants expressed hatred of the catheter and referred to it repeatedly as the worst part of the prostatectomy experience (U)(HD).<sup>32</sup></p>



2. Reactions ranged from feeling optimistic about its (incontinence) temporary nature to frustration and embarrassment for which the men described themselves as emotionally unprepared (U)(HD).<sup>32</sup>
3. Feelings of helplessness permeated the speech of the interviewees (U)(MD).<sup>47</sup>
4. More than one man described the operation itself as a non-event compared to the ongoing incontinence. The unexpected persistence of incontinence played heavily on the man's psyche (U)(MD).<sup>36</sup>
5. For another man ongoing incontinence resulted in considerable anxiety causing him to question his decision to have surgery (U)(MD).<sup>36</sup>
6. The sensory experience of catheterization was for some the single biggest postoperative issue (U)(HD).<sup>20</sup>
7. Participants generally expected to experience some incontinence but were generally shocked by the severity (U)(HD).<sup>20</sup>
8. Most participants (57.1%) felt uncomfortable with the long-term use of a urinary catheter after surgery (U)(MD).<sup>25</sup>
9. Most participants (71.4%) stated that they had felt anxious regarding going home with the urinary catheter as they were afraid of bleeding or infection (U)(MD).<sup>25</sup>
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13. Participants indicated that they were trying to cope using a variety of different methods and that they had not consulted physicians or nurses on the matter (U)(MD).<sup>25</sup>
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16. Men stated they were unprepared for urine by-passing the catheter, haematuria, or the signs of a urinary tract infection (U)(HD).<sup>35</sup>

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19. All men needed reassurance that they would improve and that most men regain continence after a RP (C)(HD).<sup>35</sup>
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21. Pads were handed to the man by nurses in most cases at discharge or after removal of the catheter, but usually they did not fit and the participants had to seek other options (U)(MD)<sup>11</sup>
22. Those who were not continent on removal of the catheter, incontinence came as a shock (U)(HD).<sup>49</sup>
23. Men felt their physical experience of regaining continence exceeded their expectations but that psychological recovery was more challenging (U)(HD).<sup>49</sup>

**Category 8:**

**Urinary incontinence had a direct, negative impact on men’s feelings, social life and life experience and led to feelings of powerlessness**

**Findings**

24. Respondents stated that they maintained the desire for physical intimacy, which created even more frustration when they found themselves being unable to remain continent during intimacy or generate and maintain an erection (U)(MD).<sup>47</sup>
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43. Recovery from surgery as well as having an indwelling catheter restricted physical activity (C)(MD).<sup>33</sup>
44. Social activities were restricted due to a fear of UI (U)(MD).<sup>33</sup>
45. Urinary incontinence was reported by all participants to one degree or another and was described as a very difficult complication (U)(MD).<sup>50</sup>

46. The loss of urinary control and the need for pads or diapers caused a feeling of impotence, shame and discomfort (U)(MD).<sup>50</sup>
47. For other men, incontinence signified old age (U)(HD).<sup>49</sup>
48. Disclosure was limited to medical facts, with men preferring to keep their emotions about cancer and incontinence private, even from friends and family (U)(HD).<sup>49</sup>
49. The physical and emotional aspects of incontinence frequently compromised intimate personal relationships (U)(HD).<sup>49</sup>
50. One couple struggled with unresolved incontinence (U)(MD).<sup>52</sup>

**Category 11:**

**Determination to accept UI regain control and not let it impact upon life experience**

**Findings**

51. This (fear of incontinence) motivated them to do pelvic floor muscle exercises to regain continence (C)(HD).<sup>32</sup>
52. Participants noted that caffeine and beer exacerbated leaking, although some were unwilling to avoid these (C)(HD).<sup>32</sup>
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64. Some men preferred to rely on maintaining strict personal hygiene and wearing dark clothes to deal with episodes of incontinence (U)(HD).<sup>49</sup>

Key: C: Credible; ED: erectile dysfunction; HD: High Dependability; MD: Moderate Dependability; RALP: robotic-assisted laparoscopic prostatectomy; RP: radical prostatectomy; UI: urinary Incontinence; U: Unequivocal

### ***Assessing Confidence***

The ConQual approach<sup>45</sup> was applied to rate the quality and confidence of each of the synthesized findings produced in this review. This process involved considering both the dependability and credibility of the findings present in each synthesis statement. All qualitative studies start with a ranking of 'high' on a scale of high, moderate, low to very low and are then downgraded based on their dependability and credibility. Dependability was established by rating each included study using five questions (Q2, Q3, Q4, Q6 and Q7) from the JBI QARI. Scores of four or five suggest a high level of dependability. Fifty five percent of studies included in this review scored three and received a moderate dependability rating. This was because there was no statement locating the researcher theoretically, and the influence of the researcher on the research was not addressed. This influenced the final level of dependability for each synthesis statement, four out of the five syntheses were ranked as having a moderate level of dependability.

Credibility was established by evaluating the congruency between the author's interpretation and the supporting data. In this project, the findings within each synthesized finding were a combination of unequivocal and credible findings. Therefore, the credibility of the synthesized findings in this study have been downgraded from a high level of credibility to a moderate level. A high level of credibility would have required the presence of only unequivocal findings.

Finally, a ConQual score was assigned to each of the synthesized findings and is presented in the summary of findings table (Table 1). Each synthesis statement is initially assumed to be of high quality and then downgraded for any credibility and/or dependability rating less than high. In this case, four of the five syntheses were downgraded two levels.

### **Synthesis 1: Urinary incontinence is a significant problem for which men feel ill prepared**

A total of sixty four findings from thirteen studies,<sup>8, 19, 20, 22, 25, 32, 34, 36, 39, 47, 49, 50, 52</sup> formed the three categories synthesized into synthesis one. This synthesis revealed that UI is a significant problem for which men feel ill prepared. Urinary incontinence causes feelings of powerlessness and negatively impacts on social life and life experience. Healthcare professionals should understand the impact and consequence of UI and implement support interventions to ensure that the negative impact on life experience is minimized.

#### **Category 5: Urinary incontinence identified as a significant problem – men felt emotionally unprepared**

The shock men felt by the severity of the incontinence and how emotionally unprepared they felt was identified in nine studies.<sup>8, 19, 20, 25, 32, 35, 36, 47, 49</sup> Some men felt uncomfortable with the long-term use of a catheter after surgery and were afraid of bleeding and infection,<sup>25</sup> and others hated it and described it as the worse part of the prostatectomy experience,<sup>32</sup> The incontinence that occurred on removal of the catheter came as a shock,<sup>19, 20, 25, 35, 49</sup> and the unexpected persistence of UI played heavily on their minds.<sup>36</sup> Experiencing UI was for some the single biggest postoperative issue,<sup>20</sup> which was their first priority after surgery<sup>8</sup> causing the men considerable anxiety,<sup>36</sup> feelings of helplessness<sup>47</sup> and a loss of control.<sup>25</sup> The men's reactions varied from optimism that the UI was temporary to embarrassment and frustration and a fear that UI would be an on-going issue.<sup>32</sup>

Men felt their physical experience of regaining continence exceeded their expectations but that psychological recovery was more challenging,<sup>49</sup> and needed reassurance that they would improve.<sup>35</sup> They tried to cope using a variety of different methods but did not speak to their

healthcare team about the issue.<sup>25</sup> Some men were given incontinence pads on discharge that were not always suitable<sup>8</sup> whereas others had no knowledge about incontinence pads including where to get them.<sup>35</sup>

Category 8: Urinary incontinence had a direct, negative impact on men's feelings, social life and life experience and led to feelings of powerlessness

Urinary incontinence was frequently linked by men with a direct, negative impact on their quality of life and life experience. The feeling of powerlessness and the direct impact on multiple aspects of the men's lifestyle was identified in eleven studies.<sup>8, 20, 22, 25, 32, 34, 36, 47, 49-51</sup>

Urinary incontinence was a disappointing outcome for most men with both the loss of urinary control and the need for pads or diapers which caused a feeling of feeling of impotence, shame and discomfort.<sup>50</sup> Unresolved UI had an impact on sexual relationships,<sup>52</sup> some men reported issues around body image,<sup>20</sup> which frequently compromised intimate personal relationships and made them feel childlike.<sup>49</sup> Some men, however viewed UI as a part of the aging process.<sup>49</sup>

The men described numerous losses in their daily lives,<sup>47</sup> with UI restricting physical<sup>33, 47</sup> and social activity<sup>25, 33, 36, 47</sup> and affecting physical relations with their partners,<sup>25, 33, 49</sup> Men made associations between UI and an inability to enjoy life as they used to, resulting in a feeling of powerlessness about the impact of UI and its contribution to impairing multiple aspects of their lifestyles.<sup>47</sup>

Men in a study conducted in Turkey stated that UI had negative connotations when undertaking the prayer ritual and it prevented many from attending the mosque.<sup>25</sup> This was particularly significant given the cultural aspect of this study. Urinary incontinence often resulted in a need to wear absorbent pads on a daily basis as a precaution against urine leakage.<sup>35,39</sup> Men had concerns about wearing incontinence pads and some thought that wearing them meant accepting UI which in turn negatively impacted their self-esteem.<sup>20</sup> Men were embarrassed when family members witnessed UI,<sup>25</sup> and they preferred to keep their thoughts and emotions about incontinence private.<sup>49</sup>

Category 11: Determination to accept urinary incontinence, regain control and not let it impact upon life experience

A determination to cope with the impact of UI was noted in six papers.<sup>8, 20, 25, 32, 39, 49</sup> Although the men were affected by UI, for some their optimism was evident and they developed coping strategies that contributed to their ability to lead a normal life,<sup>8,49</sup> refusing to let incontinence slow them down.<sup>20, 32</sup>

The unpredictable nature of UI and the fear of ongoing UI motivated men to develop a variety of strategies to deal with it,<sup>8, 20, 32, 49</sup> including performing pelvic floor exercises, avoiding caffeine and alcohol,<sup>20, 32</sup> and vigilance and controlled toileting.<sup>49</sup> Knowing what to expect helped them to prepare and information gathering pre-operatively was a vital part of this.<sup>49</sup> For some men successful incontinence management meant being able to confidently deal with incontinence episodes without others noticing, through strategies including maintenance of strict personal hygiene and wearing dark clothes,<sup>49</sup> some men preferred not to use incontinence pads.<sup>20</sup> For some being comfortable and safe, including feeling dry, was essential to resume normal social activity.<sup>8</sup> Some adapted to their UI and returned to their normal social life.<sup>25, 39</sup>

Gaining control of the new life situation and adapting to methods of controlling the UI that had the least impact and alteration to life experience<sup>39</sup> was identified as a significant aspect of the post RP process. Acting on their physician's advice some men regained total control of continence one month post-op.<sup>25</sup>

### **Synthesis 2: The impact of ED on men post RP**

A total of fifty three findings from seventeen studies,<sup>8, 19, 20, 24, 25, 32, 33, 36-37, 39, 51, 42, 47-50, 52</sup> formed the three categories synthesized into synthesis two. This synthesis revealed that ED has the greatest impact on men post RP. Erectile dysfunction affects sexuality and masculinity and causes anxiety, loss and grief, but there was also hope and determination that erectile function would return

Category 2: Erectile dysfunction was a major concern causing anxiety and uncertainty but there was also hope and determination that erectile function would return

Whilst ED was identified in seventeen studies, category 2 included fourteen studies,<sup>8, 19, 20, 25, 32, 33-34, 37, 39, 51, 53, 47-48, 52</sup> which discussed the overall impact of ED. For those diagnosed earlier in life ED had been a concern before and after their decision to have surgery.<sup>36</sup> Once the men had got their urinary function under control they began to face the issue of their sexual function.<sup>8</sup> Erectile function was reduced after surgery<sup>48</sup> and men considered ED to have a greater impact than other side-effects of RP,<sup>33</sup> causing anxiety<sup>20</sup> and uncertainty.<sup>8</sup> Men's sexual life was negatively affected following the RP,<sup>25, 51</sup> and adjusting to sexual dysfunction was difficult to accept and cope with.<sup>19, 20, 25, 37</sup> The ability to achieve erection was a major concern post RP.<sup>33</sup> The re-establishment of erectile function was a significant aspect of many participants' recoveries<sup>51</sup> but there was hope,<sup>8, 25, 32, 47</sup> and determination<sup>51</sup> that it would return, some perceived ED as a harbinger of the multiple losses associated with aging, taking sex



away from them.<sup>47</sup> Men retained their sexual desire post RP,<sup>33, 52</sup> but experienced a marked change in sexual experience and such losses in sexual function led to feelings of grief.<sup>19, 39, 53, 52</sup>

#### Category 10: Negative impact of ED on sexuality and masculinity

The specific impact of ED on men's sexuality and masculinity was addressed in ten studies.<sup>19, 24, 36-37, 39, 47, 49, 50-52</sup> The men noted that the psychological impact of RP on their sexuality,<sup>49, 51</sup> caused more concern than the physical impact,<sup>49</sup> as the art of penetrative sexual activity was considered key to sexual identity,<sup>23, 36, 39</sup> with its absence expressed as detracting from manliness.<sup>37, 39</sup> There was a reduction or total loss of sexual function following surgery.<sup>50</sup> This inability to engage in sexual relationships impacted on their sexuality,<sup>36</sup> and their ability to function as a man,<sup>50</sup> and they were worried about their partners satisfaction because of a lack of sexual performance.<sup>37, 52</sup> Men expressed a loss of identity as a man,<sup>19, 37, 50</sup> which changed their self-esteem,<sup>39, 50</sup> was linked to an altered sense of self<sup>36</sup> and saw their bodies as deficient.<sup>47</sup> This loss of identity led to a new-found sense of vulnerability and with it the avoidance of social situations.<sup>24</sup> Masculinity was also threatened as they became dependent on friends or family and felt they lost their roles as provider/protector.<sup>49</sup>

#### Category 17: Treatment regret

Only two findings from two papers identified regret related to ED.<sup>36, 48</sup> As the long term consequences of surgical morbidity became a daily experience there was a re-evaluation of their decision to be treated,<sup>36</sup> and men questioned whether the benefit of cancer free status was worth the loss of sexual function.<sup>48</sup>

### **Synthesis 3: Acceptance of side effects**

A total of forty five findings across fifteen studies<sup>8, 19, 20, 22, 24-25, 33, 36, 39, 47-52</sup> formed the five categories synthesized into synthesis three. Acceptance of PLS, loss of sexual function, ED, UI after having a RP was demonstrated in several ways, reconciliation, adaptation and compensation for being rid of the cancer. Some men felt that the change in sexual function was natural and would have occurred anyway with their advancing age.

#### Category 1: No perceived alteration in masculinity as a result of PLS

Penile length shortening was discussed in two studies.<sup>22, 51</sup> One study<sup>22</sup> specifically focused on PLS, none of the men perceived this to be an issue, as without sexual function PLS was seen to be irrelevant and was accepted. Only one other study<sup>51</sup> mentioned PLS, with the men stating that it was an unexpected bi-product of treatment.

Category 3: Acceptance of an inability to engage in sexual intimacy in the same way as before the surgery

Acceptance that the way in which the men engaged in sexual intimacy had changed was discussed in five studies,<sup>8, 19, 22, 37, 48</sup> It was acknowledged that sexual activity as they had known it previously was no longer possible<sup>22</sup> and that there was a decrease in sexual interest,<sup>48</sup> but relationships changed to accommodate the ability to engage in sexual intimacy.<sup>22, 48</sup> Adaptation took place, with acceptance of the change,<sup>19</sup> and belief that even permanent ED would not impact on their relationships.<sup>8</sup>

Category 4: Urinary incontinence and ED were compensated for by the men having rid themselves of cancer

Four studies<sup>20, 22, 48, 49</sup> discussed how the side-effects of RP were viewed as a trade-off for getting rid of the cancer with some men selecting robotic-assisted laparoscopic prostatectomy (RALP) over open and laparoscopic techniques due to their belief that incontinence would be temporary.<sup>49</sup> Some saw this as a positive trade-off,<sup>20, 22</sup> re-evaluating the importance of sex in their lives,<sup>48</sup> and emphasized that regardless of the UI and ED what really mattered was that the cancer was gone.<sup>20</sup>

Category 15: Becoming reconciled to a new life experience

Seven studies discussed how living in the present and prioritizing, taking care of their new life was important.<sup>20, 24, 33, 36, 39, 47, 48</sup> Men felt it important to inform their family and friends about their illness, reminding themselves that the operation means being cured and looking forward to a cancer free life.<sup>39</sup> Not all felt that the experience of prostate cancer treatment had effected their quality of life.<sup>33</sup> Some men however, reported conflicted feelings associated with their functional impairment<sup>47</sup> as they wondered whether the changes were permanent.<sup>48</sup>

Men adapted to a new life situation as alternatives to penetrative sex were sought.<sup>24</sup> An overwhelming need was felt to regain control of their daily lives by returning to pre-operative activities.<sup>20</sup> Resuming usual activity was a pivotal part of recovery,<sup>48</sup> by finding activities that enabled them to focus in the present and by prioritizing things which would enhance their quality of life.<sup>39</sup>

Category 16: Acceptance that change in sexual function was natural and age dependent

A particular finding in nine studies<sup>8, 20, 24-25, 33, 48, 50-52</sup> was that loss of sexual function was inevitable and associated with age, as well as the surgery. Men rationalized that it was natural that sexual relations would decrease at their age,<sup>24, 50</sup> and that it wasn't a concern at their stage of life.<sup>8, 48</sup> It was presented as a developmentally normative experience,<sup>51</sup> part of the

process of getting older<sup>52</sup> and related to time of life rather than just the cancer.<sup>33</sup> Whilst some accepted it others hoped things would get better and sought solutions,<sup>25</sup> noting frustration and disappointment at the changes in sexual function.<sup>50</sup> Some had purposefully resigned themselves to their condition following brief unsuccessful trials with medication, one because he was too embarrassed to raise the topic and another because of his advancing age.<sup>20</sup>

#### **Synthesis 4: The impact of ED on relationships**

A total of nineteen findings from ten studies,<sup>20, 25, 32, 35, 37, 39, 48, 50-52</sup> formed the two categories synthesized into synthesis four. This synthesis revealed the impact of ED on relationships. Men's relationships were affected post RP, communication and support from partners was essential and different ways of establishing a sexual relationship were identified. Whilst ED can have a negative impact on relationships, an altered sexual relationship could still be enjoyable, men were often reluctant to communicate their worries.

Category 7: Erectile Dysfunction and its associated emotions generally had a negative impact on relationships.

For the majority of men the impact of losing sexual function had a negative impact on relationships, this was explored in nine studies.<sup>20, 25, 32, 33, 35, 37, 48, 50, 52</sup> For some this included the breakdown of a relationship,<sup>50</sup> depression,<sup>20</sup> conflict<sup>33</sup> and difficulty in adjusting.<sup>35, 37</sup> Communication about sexual needs was important but often neglected<sup>52</sup> and lapses in communication challenged their ability to successfully manage sexual dysfunction.<sup>48</sup> For some men the overall quality of their relationships with their partners were strengthened,<sup>33</sup> some men commented that their partners were supportive and understanding about ED<sup>32</sup>. Other men wished that their partners would be aware of their needs.<sup>52</sup>

Category 9: Importance of re-establishing an altered sexual relationship that could still be enjoyable despite erectile dysfunction

The importance of re-establishing a sexual relationship that did not involve penetrative sex was identified as a significant aspect of recovery in four studies.<sup>22, 48, 51-52</sup> This included touch and the importance of intimacy without penetration,<sup>51</sup> using a variety of methods to increase functioning and obtain sexual gratification and coping strategies to strengthen the relationship in other ways.<sup>48</sup> Whilst erectile function was still valued, the men noted that other things in life deserved greater attention than grieving for its loss,<sup>22</sup> sexual relationships were recovered in other ways.<sup>52</sup> This included for example, placing an increased importance on intimacy, specifically verbal and nonverbal communication, as a means through which they could continue to connect as a couple in light of post-RP sexual disturbances.<sup>48</sup>

### **Synthesis 5: Physical and psychosocial support are perceived to be essential for men to deal with the physical impact of RP on their quality of life**

A total of fifty eight findings from fifteen studies formed the seven categories synthesized into synthesis five.<sup>8, 19, 20, 24- 25, 32-33, 36, 39, 48-53</sup> This synthesis revealed that both physical and psychosocial support are perceived to be essential for men to deal with the physical impact of RP on their quality of life.

#### Category 6: Inadequacy of pre and post-operative information

The general inadequacy of pre and post-operative information was addressed in five studies and it was evident that men felt ill prepared for the physical impact of RP.<sup>19, 25, 33, 39, 49</sup>

Men stressed the importance of information provision by HCP's.<sup>19</sup> Whilst some men liked receiving written pre-operative information, the majority felt overwhelmed by both the content and volume received.<sup>49</sup> Lack of recollection, inadequate or untimely pre-operative information left some participants ill prepared to deal with the consequences of surgery.<sup>49</sup> All of the men in this study felt that accurate, detailed and honest information was lacking concerning the practical and emotional side of dealing with incontinence.<sup>49</sup>

Participants in one study who had obtained information from healthcare staff during the 3 month post-operative period about UI felt more comfortable afterwards and were satisfied, however nearly half the participants in the same study stated that they had not received information from the healthcare staff.<sup>25</sup> Most men did not understand the relationship between doing exercise and decreasing incontinence, only a small number of men received information about performing pelvic exercises and some men believed they had received misinformation about experiencing incontinence.<sup>33</sup> In the same study<sup>33</sup> sexual functioning was discussed pre-operatively with the urologist, but men had mixed feelings about attending a sexual dysfunction clinic post-operatively. Men felt frustration and irritation that the follow-ups had not been scheduled according to plan.<sup>39</sup>

#### Category 12: The need for physical and psychosocial support interventions

A number of support interventions were identified in seven studies<sup>8, 19, 20, 25, 32, 39, 50</sup> that enabled the men to cope, this included support from the urologist, HCPs and in one study, regular phone calls from the research interviewer.<sup>32</sup>

Men were uniform in their view that they needed some form of support, but had varied experiences of the level of support provided from HCPs, they expressed their views as to the attributes of a HCP that would be able to provide the best support.<sup>19</sup> One study identified how

men wanted to share their problems with health care staff and wanted help from them but were too embarrassed to ask for it.<sup>25</sup>

Men expressed that incontinence strategies were not taught systematically by the healthcare providers.<sup>8</sup> One man felt that whilst he had learned to live with ED he would have valued increased input from HCP's in relation to methods of dealing with it.<sup>19</sup> Varied sources of support were sought throughout postoperative recovery periods,<sup>20</sup> some men felt that there was a need for information, but not support, although a good relationship with the urologist was described as a form of support.<sup>50</sup> The men described striving for a sense of security when visiting the hospital for check-ups.<sup>39</sup>

#### Category 13: Importance of physical and emotional support from partners and/or families

Five studies emphasized the importance of support from partners.<sup>9, 25, 39, 52, 53</sup>

Some of the men differed in their need for support from spouses and family<sup>19</sup> but others saw their partners as providing emotional support, help with frustration, sexual availability, and assistance with appointments.<sup>52</sup> Partners played a positive role in both sexual recovery and in coping.<sup>53</sup> The partner's own sexual interest was a key to successful recovery of their sexual relationship, and talking about sex, including about their worries, with their partner resulted in greater emotional intimacy as well as in a better sexual relationship, all men wished that their partners would be interested in their recovery of erectile function and seven patients saw partners as critical to the recovery of erectile function.<sup>52</sup> Some participants (46.6%) emphasized the importance of their partners' physical and emotional support in coping with UI.<sup>25</sup> However, participants in one study,<sup>39</sup> noted a reluctance to share innermost thoughts as a self-chosen strategy for managing, and didn't want to worry their families.

#### Category 14: Thoughts about the future were associated with anxiety, worry and a sense of vulnerability

Three studies<sup>24, 33, 39</sup> discussed men's concerns about their future. The cancer experience had altered men's view of life.<sup>33</sup> Thoughts about the future were associated with a growing worry, anxiety, or sadness<sup>39</sup> and with this came an increased sense of vigilance and attention to self.<sup>24</sup>

#### Category 18: Ambivalence about using pro-erectile aids with their partners

Seven studies identified that the participants felt unhappy or frustrated about using sexual aids.<sup>19, 32, 36, 48, 51-53</sup>

All of the men were offered medication to assist sexual function, which was only one way of addressing sexuality needs, and did not necessarily address their needs.<sup>32</sup> For many the use

of sexual aids was a feature of their experience.<sup>19</sup> Most felt that pro-erectile medication and side effect-related interruptions transformed after RP sexual activity from an organic, intimate endeavor to a planned and dispassionate event.<sup>48</sup> The lack of ability to attain a spontaneous erection was described by one man as resembling a comedy character developed by Rolf Harris called Jake-the peg (a three legged man).<sup>36</sup> Most participants tried various aids to regain potency including the VED, Viagra and/or injections but simultaneously disclaimed their reliance on penetrative sex and eventually abandoned the aids due to the artificial nature, ineffectiveness and lack of spontaneity in achieving, maintaining and using their erection.<sup>51</sup> For some men, dislike of pro-erectile aids was a barrier to sexual activity.<sup>52</sup>

#### Category 19: Altered body image and altered self

The impact of the surgery on body image and reduced physical strength was highlighted in two studies.<sup>36,39</sup> The surgery had an impact on men's body image<sup>36</sup> and well being for the men meant maintaining physical strength.<sup>39</sup>

#### Category 20: Peer support

The experience of peer support varied significantly and was explored in four studies.<sup>19, 32, 39, 49</sup> The men expressed a need to communicate with other prostate cancer patients<sup>39</sup> and peer support (in terms of support provided by other men who have been through prostate cancer and treatment themselves) emerged as the type of support perceived as most important.<sup>19</sup> Several kept in touch with their hospital roommate, comparing recovery stories and offering support during the postoperative period.<sup>32</sup>

However men's experiences varied significantly.<sup>19</sup> One man felt that he did not need support from peers in the form of organized support groups feeling that his family provided all the support necessary.<sup>19</sup> Men also sought alternative sources of information from peers and the internet and stated that they gained support from online prostate cancer forums and buddying systems with a friend or family member who had previously undergone RALP.<sup>49</sup>

### **Discussion**

The overall objective of this systematic review was to synthesize the best available evidence on men's perceptions of the impact of the physical consequences of a RP on their quality of life. Nineteen research papers were included which yielded 239 findings that led to 20 categories and five synthesized statements. The synthesized findings form the bases for recommendations for practice, education and research. The results of the Conqual criteria<sup>45</sup> determining dependability were considered in conjunction with the criteria determining the

credibility and level of evidence for four of the synthesized findings were rated as low and one as moderate.

Overall this systematic review has demonstrated that the post-operative complications of UI and ED that occur after a RP are significant side-effects of RP which have a negative impact on men's quality of life for which they feel ill prepared. This review also showed that both physical and psychosocial support is essential. Although the background literature also identified FI as a potential consequence of RP,<sup>16</sup> this was not an issue that was identified as in any of the included studies of this review.

Synthesis one demonstrates that UI is a significant problem for which men feel ill prepared, particularly at the point of catheter removal when the extent of the incontinence was a shock. For many this caused feelings of powerlessness and negatively impacted on social life and life experience. This is in keeping with previous findings from a small integrated literature review<sup>16</sup> that also found that men felt unprepared for UI after catheter removal and that they experienced a limited social life as a consequence. The narrative overview of quality of life after a RP also documented that UI can influence men's social relationships after an RP.<sup>15</sup>

This review found that ED has a significant impact on men's life experience post RP as shown in synthesis 2, affecting sexuality and masculinity. It was found that sexuality issues became more distressing as recovery progressed and men had very strong emotions of and causing anxiety, loss and grief when talking about the subject,<sup>32, 35-36, 51, 52.</sup> Hartman et al<sup>48</sup> questioned whether the benefit of cancer free status was worth the loss of sexual function. This evidence is intrinsically linked with the work of Gannon et al<sup>24</sup> who realized the significance of understanding ED and its potential impact on men's physical and psychological wellbeing. The issue of masculinity was prominent in the findings of this review whereby the men viewed sexual dysfunction as a direct challenge to their masculinity.<sup>19, 24, 36, 39, 49-50</sup> Contrastingly, one study<sup>22</sup> found men did not perceive a reduction in their individual perception of masculinity, this study was however, focused on one side effect, that of PLS. A number of men were able to reconcile the loss of sexual function by accepting it as part of the process of getting older,<sup>19, 24, 33, 48, 50, 52</sup> related to time of life rather than the effect of RP.

It was shown through synthesis 3 that despite the often negative implications of UI and ED post RP, men recognized the need for adaptation and in some cases had adjusted their lifestyle accordingly. Acceptance of PLS, loss of sexual intimacy, ED and UI after RP was demonstrated in a number of ways and included reconciliation, adaptation and compensation

for being rid of the cancer. Some men felt that the change in sexual function as a result of ED was natural and would have occurred anyway with their advancing age and that it was not necessarily related to the cancer. Thinking of it in these terms help the men to accept their loss of sexual function. This agrees with Chambers et al.<sup>23</sup> in their review of the experiences of men after any type of prostate cancer treatment who also found that men used age as a reference point to normalize or accept their experience. The findings of this review, significantly link adaptation and acceptance with an understanding by the men that they can never return to their pre-cancer lifestyle.<sup>22, 36, 48, 51</sup> This is cohesive with the work of Gannon et al.<sup>24</sup> who demonstrated that by developing knowledge of their perceptions of the physical consequences of a RP, appropriate support can be provided to improve men's understanding and subsequent ability to accept and adapt to a potentially changed life experience.

The impact of RP on men's relationships with their partners post RP was the essence of synthesis four. This synthesis highlighted both the negative impact ED could have on relationships with a reluctance to communicate thoughts and worries to partners, but also the importance of identifying different ways of establishing a sexual relationship that could still be enjoyable despite ED. A previous review suggested that the change of sexual ability and quality for men post RP may have an impact on the partner who do not want to "initiate sexual activity because of the possible failure".<sup>10(p.148)</sup>

In the context of impact on the men's relationships it was identified through synthesis five that physical and emotional support from their partners was considered essential, alongside communication. Milne et al.<sup>20</sup> concluded that the impact that ED has for men is not always reflected by their partners. Although the men often referred to their partner as being understanding,<sup>25, 32, 39, 52</sup> ED was often the source of arguments, exacerbated by a lack of communication in relationships.<sup>19, 39</sup>

Synthesis five identified that support was perceived by the men to be essential to enable them to deal with the physical impact of RP on their quality of life. This included physical support such as provision of suitable continence equipment and identification of appropriate erectile aids, pre and post-operative advice from healthcare professionals and the importance of psychological support from partners, friends and peers. Sometimes this was forthcoming, but for some men this was lacking with the result that thoughts about their future were associated with anxiety, worry and vulnerability. However, it was also noted that some men didn't want support. Professional guidance was perceived by the men to be essential to cope with the impact of the physical consequence of a RP, however this support was often inadequate and men were embarrassed to ask for help. Lassen et al.<sup>41</sup> in their review of the effect of



psychoeducational interventions for physical impairments following RP suggest that post prostatectomy psychoeducational interventions should become incorporated into nursing discharge planning. In this review, five of the included studies<sup>25, 32, 35, 49, 51</sup> identified a deficiency in the level and quality of pre-operative preparation and post-operative support provided. Kirschner-Hermanns<sup>7</sup> highlights that counseling for men undergoing an RP both pre and post-operatively and providing appropriate sexual aids are important to improve quality of life for this population group. Recommendations from the review by Liatsikos et al.<sup>15</sup> suggests that “meticulous” counselling should be offered prior to surgery and before informed consent is given with regards to the potential morbidity associated with the operation and recommends that partners should be involved in this process.

### **Limitations**

The major limitation across the included studies was the varying period of time that had elapsed since RP surgery had taken place. Some men were interviewed within a short period of time post RP and would therefore not have experienced the long term effects of the physical complications, or be able to fully evaluate the impact of these complications on their quality of life. However, inclusion of this wide variety of studies did highlight the impact of the more immediate physical consequences, including the UI that men experienced on urinary catheter removal for which they were clearly not prepared and caused significant distress. In other studies men were interviewed between 18 months and 25 years post RP, and it was evident that as time progressed ED became more of a problem than UI.

Only three of the studies stated the sexual orientation of the participants, this review may not therefore capture the specific impact of RP on the quality of life of homosexual and bisexual men. Only English language studies were included in the review and while specific cultural experiences were addressed in some studies, the review may not have captured further specific ethical and cultural issues.

The qualitative studies included in this review varied in methodological quality, which impacts on the overall results and conclusions. The majority of studies did not present a statement locating the researcher culturally or theoretically and/or the influence of the researcher on the research and vice versa was generally not addressed. This is an important issue as both Hedestig et al.<sup>39</sup> and Waller and Pattison<sup>49</sup> acknowledge that if the researcher is female this can influence what participants chose to divulge during the interview. Ten studies were downgraded for dependability from high to moderate quality using the ConQual approach.<sup>45</sup> The dependability of the majority of findings within four of the five syntheses were of moderate

quality leading to the overall dependability of the each synthesized findings to be ranked as moderate. All of the synthesized findings were then downgraded one level due the mix of unequivocal and credible findings. As a result of this process the overall quality of all of the majority of synthesized findings by using the ConQual approach were low.

## **Conclusions**

The findings from this review sought to identify men's perceptions of the impact of the physical consequences of RP on their quality of life. The review has shown that UI and ED are significant problems for which men feel ill prepared. Loss of sexual function in particular caused anxiety, loss and grief with the psychological impact of ED of more concern than the physical impact. Men are often reluctant to discuss their emotions and therefore the need to create suitable opportunities for them to express their feelings in conjunction with appropriate evidence based emotional support and advice is pivotal to the development of support interventions. In some cases the men were able to demonstrate successful adaptation and become reconciled to a new life experience. Without an in depth understanding of the physical consequences of RP and the impact this can have both physically and psychologically, healthcare professionals are limited in their ability to provide the high level of individualized support these men require.

A recent study<sup>3</sup> that reported 10 year outcomes following treatment for prostate cancer concluded that

'men with newly diagnosed, localized prostate cancer need to consider the critical trade-off between the short-term and long-term effects of radical treatments on urinary, bowel, and sexual function and the higher risks of disease progression with active monitoring, as well as the effects of each of these options on quality of life'.<sup>3 (p.1423)</sup>

This review highlights the importance of men being made aware of the impact the physical effects that RP can have on their quality of life and that those who select RP as a treatment strategy must be provided with appropriate information and support from healthcare professionals.

## **Implications for practice**

The meta-aggregated syntheses on men's perceptions of the impact of the physical consequences of a RP on their quality of life derived a set of recommendations that are useful for clinical practice and for the men faced with treatment choices for prostate cancer. The recommendations have been graded according to the JBI grades of recommendations.<sup>54</sup>

From synthesis 1 we recommend that:

- Healthcare professionals should implement support interventions and advise on appropriate continence support devices to minimize the negative impact of UI on men who have undergone an RP. This should include preparing men for the physical and psychosocial impact of being discharged with a urinary catheter and the impact of urinary catheter removal (Grade B).

From synthesis 2 we recommend that:

- Healthcare professionals strive to develop an understanding of the issues ED causes, both physically and psychologically for the men and ensure men are made aware of the impact ED can have on both sexuality and masculinity (Grade B).

From synthesis 3 we recommend that:

- Healthcare professionals should use the knowledge of how individuals accept and adapt to their new situation to inform and develop advice and support interventions for men who are undergoing an RP (Grade B).

From synthesis 4 we recommend that:

- Men and their partners should be made aware of the potential implications of RP on their relationships and supported to develop coping strategies (Grade B).

From synthesis 5 we recommend that:

- Healthcare professionals need to ensure adequate pre and post-operative support interventions are in place and that discussions about the physical consequences of an RP are instigated pre-operatively with the men and their partners (Grade B).
- Healthcare professionals should ensure that men know where to turn to for help and should prepare them for both the immediate and long-term physical consequences of RP, thereby maximizing the benefit that support interventions will have for all men post RP (Grade B).

### **Implications for research**

Further high quality qualitative research is required to determine for which men RP would be the most suitable treatment option and to identify effective strategies to support those men who select to undergo RP. There is also a need for further qualitative research to be undertaken which addresses ethical and cultural issues and for more research that addresses the quality of life for homosexual and bisexual men.

### **Conflicts of interest**

The authors have no conflicts of interest to declare

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## Appendix I: Search Strategies

### Database: EMBASE <1947November 2017>

- 1 (radical adj1 prostatectomy).ti,ab.
- 2 exp Prostatectomy/
- 3 exp Erectile Dysfunction/
- 4 (erectile adj1 dysfunction).ti,ab.
- 5 exp Fecal Incontinence/ or exp Urinary Incontinence/
- 6 incontinence.ti,ab.
- 7 exp Men's Health/
- 8 impotence.ti,ab.
- 9 exp Sexuality/
- 10 sex.ti,ab.
- 11 exp Sexual Dysfunctions, Psychological/
- 12 (f?ecal adj1 incontinence).ti,ab.
- 13 (urinary adj1 incontinence).ti,ab.
- 14 masculinity.ti,ab.
- 15 penile length shortening.ti,ab.
- 16 (negative adj1 consequences).ti,ab.
- 17 (emotional adj1 well?being).ti,ab.
- 18 (psychological adj1 well?being).ti,ab.
- 19 exp Adaptation, Psychological/
- 20 psychological well?being.ti,ab.
- 21 (psychological adj1 adaptation).ti,ab.
- 22 exp Stress, Psychological/
- 23 (emotional adj1 adjustment).ti,ab.
- 24 (psychosocial adj1 issues).ti,ab.
- 25 QOL.ti,ab.
- 26 experience\$.ti,ab.
- 27 perspective\$.ti,ab.
- 28 perception\$.ti,ab.
- 29 feeling\$.ti,ab.
- 30 (quality adj2 life).ti,ab.
- 31 ((prostate adj1 cancer) and surgery).ti,ab.
- 32 post?prostatectomy.ti,ab.
- 33 (prostate adj1 cancer).ti,ab.
- 34 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24

- 35 1 or 2 or 31 or 32 or 33
- 36 25 or 26 or 27 or 28 or 29 or 30
- 37 34 and 35 and 36
- 38 limit 38 to english language

**Database: Ovid MEDLINE(R) <1946 to November 2017>**

- 1 (radical adj1 prostatectomy).ti,ab.
- 2 exp Prostatectomy/
- 3 exp Erectile Dysfunction/
- 4 (erectile adj1 dysfunction).ti,ab.
- 5 exp Fecal Incontinence/ or exp Urinary Incontinence/
- 6 incontinence.ti,ab.
- 7 exp Men's Health/
- 8 impotence.ti,ab.
- 9 exp Sexuality/
- 10 sex.ti,ab.
- 11 exp Sexual Dysfunctions, Psychological/
- 12 (f?ecal adj1 incontinence).ti,ab.
- 13 (urinary adj1 incontinence).ti,ab.
- 14 masculinity.ti,ab.
- 15 penile length shortening.ti,ab.
- 16 (negative adj1 consequences).ti,ab.
- 17 (emotional adj1 well?being).ti,ab.
- 18 (psychological adj1 well?being).ti,ab.
- 19 exp Adaptation, Psychological/
- 20 psychological well?being.ti,ab.
- 21 (psychological adj1 adaptation).ti,ab.
- 22 exp Stress, Psychological/
- 23 (emotional adj1 adjustment).ti,ab.
- 24 (psychosocial adj1 issues).ti,ab.
- 25 QOL.ti,ab.
- 26 experience\$.ti,ab.
- 27 perspective\$.ti,ab.
- 28 perception\$.ti,ab.
- 29 feeling\$.ti,ab.
- 30 (quality adj2 life).ti,ab.
- 31 ((prostate adj1 cancer) and surgery).ti,ab.

- 32 post?prostatectomy.ti,ab.
- 33 (prostate adj1 cancer).ti,ab.
- 34 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
- 35 1 or 2 or 31 or 32 or 33
- 36 25 or 26 or 27 or 28 or 29 or 30
- 37 34 and 35 and 36
- 38 limit 38 to english language

**Database: PsycINFO <1806 to November 2017>**

- 1 (radical adj1 prostatectomy).ti,ab.
- 2 exp Erectile Dysfunction/ (
- 3 (erectile adj1 dysfunction).ti,ab.
- 4 exp Fecal Incontinence/ or exp Urinary Incontinence/ (
- 5 incontinence.ti,ab.
- 6 impotence.ti,ab.
- 7 exp Sexuality/
- 8 sex.ti,ab.
- 9 (f?ecal adj1 incontinence).ti,ab.
- 10 (urinary adj1 incontinence).ti,ab.
- 11 masculinity.ti,ab.
- 12 penile length shortening.ti,ab.
- 13 (negative adj1 consequences).ti,ab.
- 14 (emotional adj1 well?being).ti,ab.
- 15 (psychological adj1 well?being).ti,ab.
- 16 psychological well?being.ti,ab.
- 17 (psychological adj1 adaptation).ti,ab.
- 18 (emotional adj1 adjustment).ti,ab.
- 19 (psychosocial adj1 issues).ti,ab.
- 20 QOL.ti,ab.
- 21 experience\$.ti,ab.
- 22 perspective\$.ti,ab.
- 23 perception\$.ti,ab.
- 24 feeling\$.ti,ab.
- 25 (quality adj2 life).ti,ab.
- 26 ((prostate adj1 cancer) and surgery).ti,ab

- 27 post?prostatectomy.ti,ab.
- 28 (prostate adj1 cancer).ti,ab.
- 29 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20
- 30 1 or 2 or 26 or 27 or 28
- 31 21 or 22 or 23 or 24 or 25
- 32 29 and 30 and 31
- 33 limit 39 to english language

**Database: British Nursing Index <inception to November 2017>**

- S1.....all (radical prostatectomy)
- S2.....all (prostatectomy)
- S3.....S1 OR S2
- S4.....su.Exact ("incontinence")
- S5 all (incontinence)
- S6 all (masculinity)
- S7 all (emotional well being)
- S8 all (adaptation)
- S9 all (continence)
- S10 all (erectile dysfunction)
- S11 all (mens health)
- S12 all (impotence)
- S13 su.Exact ("sexuality")
- S14 all (sexuality)
- S15 S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14
- S16 su.Exact ("health and quality of life" OR "health & quality of life")
- S17 all (quality of life)
- S18 all (qol)
- S19 all (experience\*)
- S20 S16 OR S17 OR S18 OR S19
- S21 S3 AND S15 AND S20

**Database: CINAHL <inception-November 2017>**

- S1.....(MH "prostatectomy, Radical")
- S2.....radical prostatectomy
- S3.....(MH "prostatectomy")
- S4.....prostatectomy
- S5 S1 OR S2 OR S3 OR S4
- S6 (MH "incontinence")
- S7 incontinence
- S8 masculinity
- S9 (MH "psychological well-being")
- S10 emotional well being
- S11 (MH "Adaptation psychological+") OR (MH "Adaptation physiological")
- S12 adaptation
- S13 continence
- S14 (MH "impotence") OR (MH "sexual dysfunction, Male")
- S15 erectile dysfunction
- S16 (MH "mens health")
- S17 mens health
- S18 (MH "impotence")
- S19 impotence
- S20 (MH "sexual dysfunction, male+") OR (MH "sexuality+")
- S21 sexuality
- S22 S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16  
OR S17 OR S18 OR S19 OR S20 OR S21
- S23 (MH "quality of life+")
- S24 quality of life
- S25 qol
- S26 (MH "life experiences+")
- S27 experience\*
- S28 S23 OR S24 OR S25 OR S26 OR S27
- S29 S5 AND S22 AND S28 Limiters –English Language

**Database: Web of Science <inception-November 2017>**

- 1 Topic = (radical prostatectomy)
- 2 Topic = (prostatectomy)
- 3 1 OR 2
- 4 Topic = (incontinence)

- 5 Topic = (masculinity)
- 6 Topic = (emotional well being)
- 7 Topic = (adaptation)
- 8 Topic = (continence)
- 9 Topic = (erectile dysfunction)
- 10 Topic = (mens health)
- 11 Topic = (impotence)
- 12 Topic = (sexuality)
- 13 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12
- 14 Topic = (quality of life)
- 15 Topic = (qol)
- 16 Topic = (experience\*)
- 17 14 OR 15 OR 16
- 18 17 AND 13 AND 3
- 19 17 AND 18 AND 19 Refined by: Languages = (English)

**Appendix II: Studies excluded on screening after reading full papers**

<p>Bokhour BG, Clark JA, Inui TS, Silliman RA and Talcott JA. Sexuality after treatment for early prostate cancer: Exploring the meanings of "Erectile Dysfunction" J Gen Intern Med. 2001; 16(10): 649-55.</p>	<p>Study results doesn't distinguish between treatments</p>
<p>Butler L, Downe-Wamboldt B, Marsh S, Bell D and Jarvi K. 2000. Behind the scenes: partners' perceptions of quality of life post radical prostatectomy. Urol Nurs. 2000: 20(4): 254-8.</p>	<p>Spouses/partners views only</p>
<p>Butler L. Review of prostate tales: Men's experiences with prostate cancer. Int J Men's Health, 2003; 2(2): 165-6.</p>	<p>Book review</p>
<p>Carlson LE, Ottenbreit N, St. Pierre M and Bultz, BD. Partner understanding of the breast and prostate cancer experience. Cancer Nurs. 2001; 24(3): 231-9.</p>	<p>Spouses/partners views only</p>
<p>Chambers SK, Chung E, Wittert G, Hyde MK. Erectile dysfunction, masculinity, and psychosocial outcomes: a review of the experiences of men after prostate cancer treatment.  Trans Androl Urol. 2017: 6(1): 60-68</p>	<p>Review</p>
<p>Dowswell G, Ismail T, Greenfield S, Clifford S, Hancock B and Wilson S. Men's experience of erectile dysfunction after treatment for colorectal cancer: Qualitative interview study. BMJ, 2011; 343(7831): 982.</p>	<p>Colorectal cancer patients only</p>
<p>Evertsen JM and Wolkenstein AS. Female partners of patients after surgical prostate cancer treatment: interactions with physicians and support needs. BMC Fam Pract. 2010: 11: 19.</p>	<p>Spouses/partners views only</p>
<p>Fergus KD, Gray RE and Fitch MI. Sexual dysfunction and the preservation of manhood: Experiences of men with prostate cancer. J Health Psychol. 2002: 7(3): 303-16.</p>	<p>Study results doesn't distinguish between treatments</p>



<p>Grimsbø GH, Finset A and Ruland CM. Left hanging in the air: experiences of living with cancer as expressed through e-mail communications with oncology nurses. <i>Cancer Nurs.</i> 2011; 34(2): 107-16.</p>	<p>General cancer (breast and prostate) patient experiences</p>
<p>Hanly N, Mireskandari S and Juraskova, I. The struggle towards 'the New Normal': a qualitative insight into psychosexual adjustment to prostate cancer. <i>BMC Urology.</i> 2014; 14: 56.</p>	<p>Study results doesn't distinguish between treatments</p>
<p>Hayder D. The effects of urinary incontinence on sexuality: seeking an intimate partnership. <i>J Wound Ostomy Continence Nurs.</i> 2012. 39(5): 539-44.</p>	<p>Urinary incontinence in general and no mention of prostate cancer</p>
<p>Korfage IJ, Hak T, de Koning HJ and Essink-Bot M. Patients' perceptions of the side-effects of prostate cancer treatment -- a qualitative interview study. <i>Soc Sci Med.</i> 2006; 63(4): 911-19.</p>	<p>Study results doesn't distinguish between treatments</p>
<p>Maliski SL, Rivera S, Connor S, Lopez G and Litwin MS. Renegotiating masculine identity after prostate cancer treatment. <i>Qual Health Res.</i> 2008; 18(12): 1609-20.</p>	<p>Study results doesn't distinguish between treatments</p>
<p>O'Connell B, Baker L and Munro I. The nature and impact of incontinence in men who have undergone prostate surgery and implications for nursing practice. <i>Contem Nurse,</i> 2007; 24(1): 65-78.</p>	<p>Quantitative study</p>
<p>Oliffe, J and Thorne S. Men, masculinities, and prostate cancer: Australian and Canadian patient perspectives of communication with Male physicians. <i>Qual Health Res,</i> 2007; 17(2): 149-61.</p>	<p>Study results doesn't distinguish between treatments</p>
<p>O'Shaughnessy PK, Ireland C, Pelentsov L, Thomas, LA and Esterman AJ. Impaired sexual function and prostate cancer: a mixed method investigation into the experiences of men and their partners. <i>J Clin Nurs.</i> 2013; 22(23-24): 3492-3502.</p>	<p>Study results doesn't distinguish between treatments</p>
<p>Powel LL, and Clark JA. The value of the marginalia as an adjunct to structured questionnaires: experiences of men</p>	<p>Focus of the research is on the value of adding an</p>

<p>after prostate cancer surgery. Qual Life Res: 2005; 14(3): 827-835</p>	<p>open ended response to a structured questionnaire</p>
<p>Phillips C, Gray RE, Fitch MI, Labrecque M, Fergus K and Klotz, L. Early post surgery experience of prostate cancer patients and spouses. Cancer Prac. 2000; 8(4): 165-71.</p>	<p>Study results doesn't distinguish between patients and their spouses/partners</p>
<p>Rivers BM, August EM, Gwede CK, Hart A, Donovan KA, Pow-Sang JM, et al. Psychosocial issues related to sexual functioning among African-American prostate cancer survivors and their spouses. Psychooncology. 2011; 20(1): 106-10.</p>	<p>Study results doesn't distinguish between treatments</p>
<p>Wassersug RJ, Westle A, Dowsett GW. Men's Sexual and Relational Adaptations to Erectile Dysfunction After Prostate Cancer Treatment. Int J Sex Health. 2017; 29(1): 69-79</p>	<p>Study results doesn't distinguish between treatments</p>
<p>Wegner R. Deciding on radical prostatectomy: A patient's perspective. Sem Urol Onol. 2000; 18(3): 192-9</p>	<p>Personal experience – not research</p>
<p>Wootten AC, Abbott JM, Osborne D., Austin D, Klein B, Costello AJ, et al. The impact of prostate cancer on partners: A qualitative exploration. Psychooncology. 2014; 23(11): 1252-58.</p>	<p>Spouses/partners views only</p>
<p>Xiaojing, F, Heyes S and King L. Men's experiences of urinary incontinence after prostatectomy. Cancer Nurs Prac. 2012; 11(9): 29-34.</p>	<p>Review article</p>
<p>Xu J, Dailey RK, Eggly S, Neale AV, Schwartz KL. Men's perspectives on selecting their prostate cancer treatment. J Natl Med Assoc, 2011;103(6):468-478.</p>	<p>Study is about pre-treatment decision making</p>

**Appendix III: Studies excluded after critical appraisal**

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score
Ojdeby et al. 1996	N	N	N	U	N	N	N	N	N	Y	1/10
Splenger 1983	Y	U	Y	U	U	N	N	N	N	N	2/10

Y=Yes, N=NO, U=Unclear

**Ojdeby et al. 1996:** Urinary incontinence and sexual impotence after RP

Ojdeby G, Claezon A, Brekkan E, Häggman M, Norlén BJ. Urinary incontinence and sexual impotence after RP. Scand J Urol Nephrol.1996;30(6):473-7.

This study is not seeking to explore the experiences / perspective of participants but in contrast seeking to discuss numbers and statistics evident in the study aim and number of participants. Given the size of the study and the aim it is questionable whether interviews are an appropriate data collection method and perhaps a quantitative approach would have been more suitable. No direct quotations are used when discussion the findings, only numbers of participants. There is no evidence of how the data was analyzed and whether the categories were derived from the data or were pre-determined.

**Splengler 1983:** RP and sexuality

Spengler A. RP and sexuality. Sexuality Disability. 1983;6(1)155–166.

A qualitative approach is appropriate when looking at life experience however the aim of the study is unclear. Interviews are utilized as a method of data collection however during data analysis no direct quotations are used to substantiate findings and it is unclear as to how the data has been analyzed. Although a thematic discussion is apparent there is no clarity regarding how the themes were derived. No mention is made of ethical approval.

**Appendix IV: Included studies table**

Author, Year Country Aim	Recruitment and Participant details	Study design Methodology Data analysis
<p><b>Burt et al. 2004</b><sup>32</sup></p> <p>Canada</p> <p>To explore men’s experiences after RP and whether they perceived their pre-operative teaching adequately prepared them for postoperative recovery</p>	<p><u>Recruitment</u>                      Pre-admission clinic from one hospital</p> <p><u>Participants</u>                      17 men who spoke and read English</p> <p><u>Age (years)</u>                      Range 55 to 70</p> <p><u>Sexual orientation</u>                      Not stated</p> <p><u>Type of surgery</u>                      RP</p> <p><u>Stage of cancer</u>                      Early stage prostate cancer</p>	<p><u>Study design</u>                      Qualitative descriptive study</p> <p><u>Methods</u>                      Telephone interviews (semi – structured) (n=12) conducted at day 2, 7, 21 and 120 days post discharge                      Face to face interviews (n=5)</p> <p><u>Time since surgery</u>                      Day 2, 7, 21 and 120 days post discharge                      12 months with a subset of 5</p> <p><u>Data analysis</u>                      Analysis grid</p>

<p><b>Butler et al. 2001</b><sup>33</sup></p> <p>Canada</p> <p>To explore the meaning and effect of UI and impotence on the quality of life for men with prostate cancer</p>	<p><u>Setting</u></p> <p>Urology follow up clinics at the one hospital</p> <p><u>Participants</u></p> <p>21 men (73% RR) and their partners</p> <p><u>Age (years)</u></p> <p>47 to 73</p> <p>Average 62 years</p> <p><u>Sexual orientation</u></p> <p>Most had been married to the same partner for an average of 34 years (range 6 months to 54 years)</p> <p><u>Type of surgery</u></p> <p>RP</p> <p><u>Stage of cancer</u></p> <p>Not stated</p>	<p><u>Study design</u></p> <p>Qualitative descriptive study</p> <p><u>Methods</u></p> <p>Interviews (semi-structured)</p> <p><u>Time since surgery</u></p> <p>Not stated</p> <p><u>Data analysis</u></p> <p>Content analysis</p>
<p><b>de Moraes Lopes et al. 2012</b><sup>47</sup></p> <p>South Eastern Brazil</p>	<p><u>Setting</u></p> <p>Urology clinic between Sep 2007 and Feb 2009 at one hospital</p>	<p><u>Study design</u></p> <p>Qualitative descriptive study</p>

<p>To explore the psychosocial meaning and repercussions on lifestyle associated with ED and UI in men following RP</p>	<p><u>Participants</u> 10 males receiving treatment for UI</p> <p><u>Age (years)</u> 48 to 74</p> <p><u>Sexual orientation</u> 7 married, 2 in stable relationships and 1 divorced – ranging from 1 year 6 months to 25 years post-operatively</p> <p><u>Type of surgery</u> RP</p> <p><u>Stage of cancer</u> Not stated</p>	<p><u>Methods</u> Interviews (semi-structured)</p> <p><u>Time since surgery</u> 1 year 6 months to 8 years with the exception of one participant 25 years (who had UI for 12 years)</p> <p><u>Data analysis</u> Content qualitative analysis techniques</p>
<p><b>Iyigun et al. 2011<sup>25</sup></b> Turkey</p> <p>To define the experiences and perceptions of Turkish men who have undergone an RP and to</p>	<p><u>Setting</u> Urology department of one military medical hospital between Jan 2006 and April 2007</p> <p><u>Participants</u></p>	<p><u>Study design</u> Qualitative descriptive study</p> <p><u>Methods</u> Interviews (semi-structured)</p>

<p>determine the views and suggestions of men who had undergone RP as to their discharge training content</p>	<p>15 men who could read and understand Turkish</p> <p><u>Age</u> Mean 62.60 ± 6.86</p> <p><u>Sexual orientation</u> All married</p> <p><u>Type of surgery</u> RP</p> <p><u>Stage of cancer</u> Tumor stage 2a (6.6%), Tumor stage 2c (40%), Tumor stage 3b (33.4%), Tumor stage 3c (20%)</p>	<p><u>Time since surgery</u> First 3 months after surgery</p> <p><u>Data analysis</u> Analyzed according to phenomenological methodology</p>
<p><b>Hedestig et al. 2005<sup>39</sup></b> Sweden</p> <p>To illuminate the experience of living after RP for localized prostate cancer</p>	<p><u>Setting</u> Selected from a database of registration of prostate cancer patients in Northern Sweden</p> <p><u>Participants</u> 10 men</p>	<p><u>Study design</u> Qualitative descriptive study</p> <p><u>Methods</u> Interviews (semi-structured)</p> <p><u>Time since surgery</u></p>

	<p><u>Age (years)</u> Range 61-69 (Inclusion criteria men had to be between 60 and 69)</p> <p><u>Sexual orientation</u> All married</p> <p><u>Type of surgery</u> RP</p> <p><u>Stage of cancer</u> Early stage prostate cancer</p>	<p>The patients had to have had RP more than six months but not more than three years, previously. Actual range 12 to 34 months (Mean 26.1)</p> <p><u>Data analysis</u> Content analysis</p>
<p><b>Milne et al. 2008<sup>20</sup></b> Canada</p> <p>To explore what men experience post laparoscopic RP and how adequately their pre and post-operative needs are met</p>	<p><u>Setting</u> Via third-party contact from the treatment and control arms of a RCT. Men who were not part of the trial were also invited to participate via letters mailed from surgeons' offices</p> <p><u>Participants</u> 19 men</p>	<p><u>Study design</u> Qualitative descriptive study</p> <p><u>Methods</u> Interviews (loosely structured) (n=5) Focus groups (three focus group n=3, 5 ad 6 members)</p> <p><u>Time since surgery</u> Undergone RP in last 3 years Range 5-28 months</p>



	<p><u>Age (years)</u> Range 46 to 76 Mean 61.9</p> <p><u>Sexual orientation</u> All married, lived with their spouses</p> <p><u>Type of surgery</u> Laparoscopic RP</p> <p><u>Stage of cancer</u> Not stated</p>	<p>Mean 17.63</p> <p><u>Data analysis</u> Content and thematically analyzed</p>
<p><b>Moore and Estey 1999<sup>35</sup></b> Canada</p> <p>To determine the views and suggestions of men who had undergone RP as to their discharge training content</p>	<p><u>Recruitment</u> Two university-affiliated hospitals between Dec 1995 and Jan 1997. During this time 180 radical retro-pubic prostatectomies were performed.</p> <p><u>Participants</u> 63 men who described UI as being a problem to them met the eligibility criteria of being 4 weeks post RP, had no neurological deficits which would interfere with bladder</p>	<p><u>Study design</u> Qualitative descriptive design – part of a larger study</p> <p><u>Methods</u> Interviews (semi-structured)</p> <p><u>Time since surgery</u> Median time 8 weeks. Range 5 to 38 weeks</p> <p><u>Data analysis</u> Comparison of cases to identify common themes</p>

	<p>control and were within 2 hours driving distance of the study centre and were continent of urine prior to the RP. All agreed to take part</p> <p><u>Age (years)</u> Mean 67</p> <p><u>Sexual orientation</u> All married</p> <p><u>Type of surgery</u> Radical retro-pubic prostatectomy</p> <p><u>Stage of cancer</u> Early stage prostate cancer</p>	
<p><b>Oliffe 2005<sup>51</sup></b> Australia</p> <p>To explore participants' experiences of impotence following prostatectomy</p>	<p><u>Recruitment</u> Fieldwork was conducted at monthly meetings of two Melbourne-based prostate cancer support groups (PCSGs) over 6 months. Thirty-five participants were recruited for the larger study, however early in the analysis it was identified that</p>	<p><u>Study design</u> Ethnographic study</p> <p><u>Methods</u> Participant observation Field notes Interviews (semi-structured)</p>

	<p>participants treated exclusively with prostatectomy had specific experiences that were not shared by men who had undertaken other treatments. The RP procedures were conducted between 1995 and 2001</p> <p><u>Participants</u> 15 Anglo-Australian men (originating from English, Welsh, Scottish or Irish background and at least 2nd generation Australian).</p> <p><u>Age (years)</u> Range 46 to 74 Mean 57.06±6.68</p> <p><u>Sexual orientation</u> Heterosexual with a current female partner. Years with current partner 2 to 53, mean 27.6±12.99</p> <p><u>Type of surgery</u> RP</p>	<p><u>Time since surgery</u> Average time 21 months</p> <p><u>Data analysis</u> Social constructionist gendered framework</p>
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	<p><u>Stage of cancer</u> Not stated</p>	
<p><b>O'Shaughnessy and Laws 2010<sup>36</sup></b> Australia</p> <p>To describe men's long term recovery following prostatectomy for the purpose of identifying the effects of unresolved post surgical morbidity</p>	<p><u>Recruitment</u> Not stated</p> <p><u>Participants</u> 11 men</p> <p><u>Age (years)</u> Not stated</p> <p><u>Sexual orientation</u> Not specified but during the interviews one man identified that he was homosexual</p> <p><u>Type of surgery</u> RP</p> <p><u>Stage of cancer</u> Not stated</p>	<p><u>Study design</u> Qualitative descriptive study</p> <p><u>Methods</u> Interviews (semi- structured)(n=3) Two focus groups (n=8)</p> <p><u>Time since surgery</u> More than 6 months</p> <p><u>Data analysis</u> Content analysis</p>
<p><b>Walsh and Hegarty 2010<sup>19</sup></b> Ireland</p>	<p><u>Recruitment</u> Prostate cancer support group</p>	<p><u>Study design</u> Qualitative descriptive study</p>

<p>To provide a retrospective view of men's experiences of the prostate cancer treatment journey from initial diagnosis through to completion of their surgery and beyond</p>	<p>Volunteer sampling</p> <p><u>Participants</u> 8 men</p> <p><u>Age (years)</u> Not stated</p> <p><u>Sexual Orientation</u> Not stated</p> <p><u>Type of surgery</u> RP</p> <p><u>Stage of cancer</u> Not stated</p>	<p><u>Methods</u> Interviews (semi-structured) Reflective diaries</p> <p><u>Time since surgery</u> 14 months to 15 years</p> <p><u>Data analysis</u> Qualitative thematic content analysis</p>
<p><b>Yu Ko et al. 2010<sup>22</sup></b> Canada</p> <p>To provide an account of patients' perceptions and responses to living with penile length shortening after RP</p>	<p><u>Recruitment</u> Via open invitations at meetings held at the local prostate cancer support group, and by the posting of a recruitment advert in the group's newsletter</p> <p><u>Participants</u></p>	<p><u>Study design</u> Qualitative descriptive study</p> <p><u>Methods</u> Interviews (semi-structured)</p> <p><u>Time since surgery</u></p>

	<p>6 men (data saturation was achieved by the 5th participant)</p> <p>Inclusion criteria was the perception of penile length loss at least one year after undergoing RP, irrespective of stage of cancer at time of diagnosis or whether participants received other treatments for prostate cancer</p> <p><u>Age (years)</u> Range 58–77 Mean age 64.7</p> <p><u>Sexual Orientation</u> Five of them were married and lived with their spouses, whereas one of them was divorced and lived alone</p> <p><u>Type of surgery</u> RP</p> <p><u>Stage of cancer</u> Not stated</p>	<p>Not stated</p> <p><u>Data analysis</u> Grounded theory approach to qualitative research, so data analysis occurred simultaneously with data collection</p>
<p><b>Eilat-Tsanani et al. 2013<sup>50</sup></b></p>	<p><u>Recruitment</u></p>	<p><u>Study design</u></p>

<p>Israel</p> <p>To describe the outcomes of RP as perceived by the patients, and their ways of coping with them</p>	<p>Urology department at one hospital</p> <p><u>Participants</u> 22 Jewish men</p> <p><u>Age (years)</u> Range 60–81 Average age was 73</p> <p><u>Sexual Orientation</u> Were married (n=16), living with partner (n=1) or divorced 5)</p> <p><u>Type of surgery</u> RP</p> <p><u>Stage of cancer</u> Localized</p>	<p>Qualitative descriptive study</p> <p><u>Methods</u> Interviews (semi-structured)</p> <p><u>Time since surgery</u> 1 year</p> <p><u>Data analysis</u> Content analysis</p>
<p><b>Gannon et al. 2010<sup>24</sup></b></p> <p>UK</p> <p>To investigate how men</p>	<p><u>Recruitment</u> Urology department at one hospital</p> <p><u>Participants</u> 7 men</p>	<p><u>Study design</u> Qualitative descriptive study</p> <p><u>Methods</u> Interviews (semi-structured)</p>

<p>attempt to construct and re-construct masculinity</p>	<p>Eight were interviewed although data from one was not used as the cancer had returned and he was undergoing further treatment</p> <p><u>Age (years)</u> Range 58-70</p> <p><u>Sexual Orientation</u> All of the men were heterosexual, 5 were married or had a partner</p> <p><u>Type of surgery</u> RP</p> <p><u>Stage of cancer</u> Localized</p>	<p><u>Time since surgery</u> Range 7-15 months</p> <p><u>Data analysis</u> Foucauldian Discourse Analysis</p>
<p><b>Hartman et al. 2014<sup>48</sup></b> Canada</p> <p>To enhance understanding of gay couple's experience with sexual dysfunction after RP</p>	<p><u>Recruitment</u> Selected from a sample of 25 couples who participated in a longitudinal investigation at one hospital, between 2007 and 2009.</p> <p><u>Participants</u></p>	<p><u>Study design</u> Qualitative descriptive study</p> <p><u>Methods</u> Interviews (semi-structured) 3–6 months, 2–15 months, and 21–24 months</p>



	<p>3 men and their partners who had reported sexual dysfunction as a result of the surgery</p> <p><u>Age (years)</u> 52, 58 and 62</p> <p><u>Sexual Orientation</u> Homosexual</p> <p><u>Type of surgery</u> RP</p> <p><u>Stage of cancer</u> Not stated</p>	<p><u>Time since surgery</u> Average 12.9, 12.65, 14.42 months</p> <p><u>Data analysis</u> Interpretive phenomenological analysis</p>
<p><b>Petry et al. 2004<sup>8</sup></b> Switzerland</p> <p>To explore the responses and experiences of a sample of Swiss men after RP and their intimate partners</p>	<p><u>Recruitment</u> From across two hospitals</p> <p><u>Participants</u> Ten men and their female partners One participant, initially recruited, dropped out because of language difficulties</p> <p><u>Age (years)</u></p>	<p><u>Study design</u> Qualitative descriptive study</p> <p><u>Methods</u> Interviews (semi-structured)</p> <p><u>Time since surgery</u> Within 4–8 weeks (n=9) Within 12 weeks (n=1)</p>

	<p>Mean 64.6</p> <p><u>Sexual Orientation</u> Homosexual</p> <p><u>Type of surgery</u> RP</p> <p><u>Stage of cancer</u> Localized</p>	<p><u>Data analysis</u> Constant comparative method of grounded theory</p>
<p><b>Waller and Pattison 2013<sup>49</sup></b> London</p> <p>To understand how men interpret their experiences of regaining continence following robotic-assisted laparoscopic prostatectomy</p>	<p><u>Recruitment</u> From one hospital between July 2010 until December 2010 at three month follow up appointment (n=83). 15 met inclusion criteria which were locally confined, tumor stage 1, tumor stage 2a, b or c prostate cancer, Self-defined as continent of urine, surgery with past 12-16 weeks.</p> <p><u>Participants</u> 7 men</p> <p><u>Age (years)</u></p>	<p><u>Study design</u> Qualitative descriptive study</p> <p><u>Methods</u> Interviews (semi-structured)</p> <p><u>Time since surgery</u> 13-16 weeks</p> <p><u>Data analysis</u> Framework approach founded on hermeneutic Heideggerian Phenomenological principles</p>

	<p>Range 57-71</p> <p><u>Sexual Orientation</u> 5 married, 1 divorced, 1 not disclosed</p> <p><u>Type of surgery</u> Robotic-assisted laparoscopic prostatectomy</p> <p><u>Stage of cancer</u> Early stage of prostate cancer</p>	
<p><b>Wittmann et al. 2014<sup>52</sup></b> USA</p> <p>To understand patients' and partners' perceptions on the role of the partner in couples' sexual recovery</p>	<p><u>Recruitment</u> By contacting participants from a previous study on barriers to couples' sexual recovery after surgery for prostate cancer (n=28)</p> <p><u>Participants</u> 10 men and 9 partners (Eight couples and three individuals took part in interviews)</p> <p><u>Age (years)</u> Mean age was 62.2<sub>+4.4</sub></p>	<p><u>Study design</u> Qualitative descriptive study</p> <p><u>Methods</u> Interviews (semi structured)</p> <p><u>Time since surgery</u> Range 6-24 months Mean 14.3 months</p> <p><u>Data analysis</u> Grounded theory iterative process</p>

	<p><u>Sexual Orientation</u> Seven heterosexual and one same-sex partnership. Two married patients and one female partner participated alone</p> <p><u>Type of surgery</u> Surgery (no further details) The patient with aggressive prostate cancer required additional radiation treatment. The extent of his disease required partial nerve-sparing surgery and resulted in impotence</p> <p><u>Stage of cancer</u> Localized One patient's had aggressive prostate cancer</p>	
<p><b>Wittmann et al. 2015<sup>53</sup></b> USA</p> <p>To examine a proposed biopsychosocial conceptual model of couples' sexual recovery that included functional, psychological,</p>	<p><u>Recruitment</u> By contacting participants by telephone from a previous study on barriers to couples' sexual recovery after surgery for prostate cancer (n=28/108). 20 couples returned after surgery</p>	<p><u>Study design</u> Exploratory mixed methods with qualitative results presented separately</p> <p><u>Methods</u> Interviews (semi-structured)</p>

<p>and relational aspects of sexuality, surgery-related sexual losses, and grief and mourning as recovery process</p>	<p><u>Participants</u> 20 men and their partners</p> <p><u>Age (years)</u> Mean 60.2</p> <p><u>Sexual Orientation</u> 19 heterosexual and 1 same-sex couple</p> <p><u>Type of surgery</u> Robotic-assisted RP. Two patients' more aggressive cancer necessitated a wider resection of the neurovascular bundles and adjuvant radiation treatment, resulting in more nerve damage</p> <p><u>Stage of cancer</u> Tumor Stage 1c (n=17), Tumor Stage 2a (n=11), Tumor Stage 2b (n=1)</p>	<p><u>Time since surgery</u> 3 months</p> <p><u>Data analysis</u> Constant comparative thematic analysis</p>
<p>Laursen 2017<sup>37</sup> Denmark</p>	<p><u>Recruitment</u> Recruited from a sexological counselling service, in a university hospital.</p>	<p><u>Study design</u> Qualitative descriptive</p>

<p>To elucidate the effect of surgical treatment for prostate cancer on men's sexuality</p>	<p><u>Participants</u> Four men</p> <p><u>Age (years)</u> Age 55-68 years</p> <p><u>Sexual orientation</u> Heterosexual</p> <p><u>Type of surgery</u> Not stated, just that it was surgical treatment</p> <p><u>Stage of cancer</u> Not stated</p>	<p><u>Methods</u> Interviews (semi-structured)</p> <p><u>Time since surgery</u> Not stated</p> <p><u>Data analysis</u> Phenomenological-hermeneutic frame of understanding</p>
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Key: ED – Erectile Dysfunction; RCT – Randomized controlled trial; RP: Radical Prostatectomy; RR – Response Rate; UI – Urinary incontinence

## Appendix V: Extracted qualitative findings

### Paper 1: Yu Ko et al. 2010<sup>22</sup>

The purpose of this study was to provide an account of patients' perceptions and responses to living with penile length shortening (PLS) after RP. The study took place in Canada and was designed as a substantive theory type of grounded theory research. The study included a convenience sample of six participants who perceived that they had PLS at least one year after RP, irrespective of whether they received other treatments. None of the participants reported that they were able to achieve proper erections that allowed them to engage in penetrative sex. Five had occasional or minor urinary symptoms, no bowel symptoms were reported. The central theme emerging was that of 'resignation' as a situation of acceptance and co-existence with the cancer. Four of the six participants stated that they were not informed of the possibility of PLS at the time of surgery, however the issue of PLS was considered unimportant by the men and they did not feel it impacted on their masculinity.

Data were presented across three themes and data which were relevant to the post-surgery experience of the men were extracted from within the three themes: unaltered masculinity, the unimportance of PLS, and, ED as a speed bump.

#### *Theme: Unaltered masculinity*

**Finding 1 (F1):** None of the men perceived changes in their own evaluation of masculinity after noticing PLS post-RP (U)

Illustration 1: "I feel about normal. I'd say I match up with most men, I'm not very athletic, but I can do a lot of things that other people do, and get along. I don't feel unmanly or not a man". <sup>22(p.163)</sup>

**Finding 2 (F2):** There is some ambivalence in how men evaluate their own masculinity in light of the presence of ED with regard to PLS and ED (U)

Illustration 2: "I don't think the size of my penis bothers me that much, whether I'm manly or not. I guess what bothers you is that you're unable to perform with a woman". <sup>22(p.163)</sup>

#### *Theme: The unimportance of PLS*

**Finding 3 (F3):** None of the men were concerned with that they perceived to be a shorter penis following RP (U)

Illustration 3: “The size [of the penis]... doesn’t mean much if you’re not trying to get blood into it to get an erection... it’s just there to empty the bladder. As far as using it for sexual purposes... I just lost interest in that”.<sup>22(p.163)</sup>

**Finding 4 (F4):** Men felt that the effects of RP were acknowledged and accepted by their significant others, further justifying their own perception that the shortening of their penis was unimportant (U)

Illustration 4: “We have discussed sex, of course. there is uh. accept[ance] of what has happened to me and the size of it now. I don’t think she’s thinking much about it per se. sex in her eyes has diminished and she’s accepted that. we just feel that the penis is not used for intercourse anymore. so the size doesn’t really matter to me or to my partner, I think”.<sup>22(p.163)</sup>

**Finding 5 (F5):** The shortening of the penis was seen as only one item in package of accepted side-effects associated with treatment for prostate cancer (U)

Illustration 5: “You know, [the penis] shrank considerably. And I have to say I wasn’t somehow, terribly surprised. Uh nobody told me that it would, I have to say that nobody advised that at all. But I have to say that I wasn’t surprised that it did happen. I’m not sure why, it didn’t surprise me. Um up until recently, as well, I have some problems. because of shrinkage, and because of what turned out to be a bit of scar tissue, you know post surgery. I had trouble sort of standing and peeing normally. if you combine the small penis with the fact that I didn’t have a very sort of normal stream. I simply could not stand and pee. I had to sit. But, for the most part, I have to say. I have much, more important things to worry about than the size of my penis”.<sup>22(p.163)</sup>

*Theme: Erectile dysfunction as a speed bump*

**Finding 6 (F6):** The return of erectile function was seen by all participants as the single event that would improve satisfaction with penile function. Yet, they acknowledged that sexual intimacy as they had known it was no longer possible (U)

Illustration 6: “as you get older, sex doesn’t mean as much, although it is important there is no argue[ment] with that and it makes one feel good after having sexual intercourse. But after the surgery, well. that was gone and as time moved on, surprisingly, I kind of accepted it. it’s not easy, but I just accepted it. I guess my desire [for sex] too lessened and lessened I guess from the surgery. or not having sex and not being able to get an erection well, it kind of fades away, the interest”.<sup>22(p.163)</sup>



**Finding 7 (F7):** Erectile Dysfunction is a condition that deprived them (men) of pleasures in the intimacy, but reasoned that there are also other issues in life that deserved greater attention than the grieving of such loss (U)

Illustration 7: “I guess a guy always dreams or thinks about having sex again, but, you know, as time goes on. I have been involved in other things. It’s not as important as it was like five years ago. But as far as my relationship with my wife, uh. I feel we’re just as close, for sure. In the relationship you know you don’t get the feelings of the sexual satisfaction of having intercourse, but that’s something you just live with”.<sup>22(p.163)</sup>

**Finding 8 (F8):** Participants agreed that the loss of erectile function was greatly missed, but it was compensated by the chance of ridding oneself of cancer (U)

Illustration 8: “erectile firmness would be one problem, but other than that it’s not a big thing to worry about. because that’s all you’ve lost, and I guess there’s been men around that probably lost erectile hardness maybe younger”.<sup>22(p.163)</sup>

## **Paper 2: Burt et al. 2005<sup>32</sup>**

The aim of this qualitative descriptive study was to explore men’s experiences after RP and their individually identified post-operative needs. Multiple semi-structured telephone interviews were conducted at days 2, 7, 21 and 120 days post-operatively with 17 participants from one hospital in Canada, who were approached and agreed to participate pre-operatively, this was followed by a single in depth face to face interview 12 months post-operatively with a subset of 5 men. The telephone interviews consisted of an unstructured first phase where the participant was encouraged to discuss his experience, followed by specific questions. The researchers concluded that the area of sexuality and erectile function provided severe challenges and distress for the participants with the effect on their self-images profound, although their distress with the catheter was expressed more vehemently. Sexuality issues became more disturbing as recovery progressed; the researchers noted that had they not opened the discussions about sexuality the men would not have mentioned it. All participants expressed concern and hope that sexual function would come back, whilst downplaying the absence of erectile function. The participants noted that the telephone calls with the researcher were valued as a means of additional support during the various stages of recovery.

Data were presented across seven themes and data which were relevant to the post-surgery experience of the men were extracted from within four of the seven themes: living with the catheter, incontinence, support and sexuality issues. Data were not extracted from the three

themes unrelated to the review objectives: the decision about surgery, pre and post-operative information and exercise and its impact upon recovery which related to the immediate post-operative period and did not provide any relevant data.

*Theme: Living with the catheter*

**Finding 9 (F9):** Participants expressed hatred of the catheter and referred to it repeatedly as the worst part of the prostatectomy experience (U)

Illustration 1: “I could not wait to get that catheter out. I hated that thing! I could have handled the operation but the catheter was a terrible thing – the worst thing about the whole experience!”<sup>32(p.886)</sup>

**Finding 10 (F10):** Participants described the support they received during this time from the interviewer as essential to their coping with the catheter and its effects (C)

Illustration 2: “Through their regular conversations with her, they gained reassurance that their recovery was progressing normally and that the pain and discomfort they experienced was not an indication of some serious complication of the surgery”.<sup>32(p.886)</sup>

*Theme: Incontinence*

**Finding 11 (F11):** Reactions ranged from feeling optimistic about its (*incontinence*) temporary nature to frustration and embarrassment for which the men described themselves as emotionally unprepared (U)

Illustration 3: “I still have problems with leaking, especially when I am cold or tired. I hate it when I leak; it makes me mad. It’s an embarrassment, and demoralizing too”.<sup>31(p.886)</sup>

**Finding 12 (F12):** This (fear of incontinence) motivated them to do pelvic floor muscle exercises to regain continence (C)

Illustration 4: “The younger participants, who experienced little leaking and regained continence quickly, asserted that their age, physical condition and pelvic floor muscle exercises were factors in the early return of continence”.<sup>32(p.887)</sup>

**Finding 13 (F13):** Participants noted that caffeine and beer exacerbated leaking, although some were unwilling to avoid these (C)

Illustration 5: “One described coffee with his friends as important to his social life and physical recovery, despite being detrimental to continence”.<sup>32(p.887)</sup>

*Theme: Support*

**Finding 14 (F14):** Several kept in touch with their hospital roommate, comparing recovery stories and offering support during the postoperative period (U)

Illustration 6: “It’s really helpful if you’ve got a buddy when you’re going into these things, particularly if you can talk to somebody that has had a similar experience. You’re never going to have identical experiences, but someone who knows what it’s like can point out a few things”.<sup>32(p.887)</sup>

*Theme: Sexuality issues*

*Burt et al.*<sup>32</sup> note that the segments of the interviews about sexuality were extraordinarily difficult to analyze because they were contradictory whilst also being quite pervasive and clearly of importance to the participants. Even when the men had initiated the discussion and indicated verbally that erectile dysfunction was extremely distressing to them, there was incongruity between the content and the emotional tone of their verbalizations.

**Finding 15 (F15):** All of the men were offered medication to assist sexual function, which is only one way of addressing sexuality needs, and did not necessarily address their needs (U)

Illustration 7: “Viagra helps – without it I wouldn’t be able to have an erection at all. There’s a difference though; I don’t feel as inclined toward sex as before”.<sup>32(p.888)</sup>

**Finding 16 (F16):** Participants were open and frank about the impact altered sexual function had upon their relationship with their partners, whom they described almost universally as supportive and understanding about ED (U)

Illustration 8: “I can still get an erection, but my penis is not really hard, so intercourse is difficult. I tried Viagra and injections – they didn’t work. The loss of spontaneity in our sex life is really frustrating and a letdown; you have to plan for sex and then you’re not even sure if it is going to work. It’s affected our relationship because sex was an important part of our marriage; it feels as if something is missing, even though she doesn’t complain I feel like the cause of the problem”.<sup>32(p.888)</sup>

**Finding 17 (F17):** Although some men downplayed the absence of erectile function, all expressed concern and maintained hope that it would come back (U)

Illustration 9: “I worry about erections because I still feel young; it bothers me that I might not be able to have them again, even though I don’t have a wife or a girlfriend”.<sup>32(p.888)</sup>

### **Paper 3: de Moraes Lopes et al. 2012<sup>47</sup>**

This clinical qualitative interpretive study was conducted in Brazil and included single face to face semi-structured interviews with 10 men who underwent RP, with the aim of exploring the psychosocial meaning and repercussions on lifestyle associated with ED and UI following RP. Recruitment continued until data saturation was reached. All men had received treatment for UI in a public urology clinic, duration since RP surgery varied from 18 months to 25 years. Results revealed that a diagnosis of prostate cancer and the UI and ED associated with RP creates feelings of physical devitalization, ED was not just a physical symptom but a significant psychosocial burden that elicits feelings of powerlessness and significant emotional distress.

Data were presented across three themes and data which were relevant to the post-surgery experience of the men were extracted from within the three themes: sexuality called into question, a body without governance and experiencing loss.

*Theme: Sexuality called into question*

**Finding 18 (F18):** Feelings of helplessness permeated the speech of the interviewees (U)

Illustration 1: "I cannot have physical relations with my wife when my penis is dripping urine... I feel so ashamed... I turn my back... It is horrible, so I no longer want it...I'm ashamed of staying in bed and trying to penetrate my wife when I cannot".<sup>47(p.91)</sup>

**Finding 19 (F19):** Respondents reported perceptions of a deficient body because of their inability to engage in sexual relationships with their partners (C)

Illustration 2: "When the contact starts, with love, with empathy, it is not just sex. But where the ending is in the sex, then it does not even start...Actually I'm talking with some sadness, but its what's inside my soul. There is no other way, this is what I'm feeling, that's right, it won't go away".<sup>47(p.91)</sup>

**Finding 20 (F20):** Respondents stated that they maintained the desire for physical intimacy, which created even more frustration when they found themselves being unable to remain continent during intimacy or generate and maintain an erection (U)

Illustration 3: "Then I talked to her...Now I can't control my bladder, you are 15 years younger than me, so if you need another partner we will talk, we will think of something, I will do anything".<sup>47(p.91)</sup>

*Theme: A body without governance*

**Finding 21 (F21):** Respondents described a “leaking body” associated with loss of bladder control (U)

Illustration 4: “The hard part is that you feel the leaking, you cannot go out. Depending on the place I don’t even go because I have to change the diaper all the time”.<sup>43(p.92)</sup>

**Finding 22 (F22):** Participant narratives also revealed feelings of powerlessness because the UI impaired multiple aspects of their lifestyle (U)

Illustration 5: “It’s as if I have no use anymore, that’s not the case, it is not... I deprive myself, I do not want people to be concerned about me. Damn! From what it was”.<sup>47(p.92)</sup>

**Finding 23 (F23):** Experiences with urinary incontinence and ED generated fear of disappointing not only their partner, but also family, friends and themselves (C)

Illustration 6: “It [prostate cancer] totally changed my life; I used to play sports... liked to play ball, swim... [now] because I have to wear diaper, I’ll need a bag, the urine collector you know, it is never really safe”.<sup>47(p.92)</sup>

**Finding 24 (F24):** Participants described numerous other losses in their daily lives due to UI (C)

Illustration 7: “Life has become really boring... I’m living, I’m shuffling along but it’s not easy”.<sup>47(p.92)</sup>

*Theme: Experiencing loss*

**Finding 25 (F25):** Incontinence and ED signaled a body that had become limited and finite (U)

Illustration 8: “I live with my third wife...I always did my part, now this surgery it’s very difficult for me to have... intercourse, I lose control of urine. I feel so ashamed...I cuddle with my wife but I know I will not proceed”.<sup>47(p.92)</sup>

**Finding 26 (F26):** Even though men reported finding ways to cope with their UI and ED, they also reported conflicted feelings associated with their functional impairment (U)

Illustration 9: “No, nothing is normal....I do not hide anything...I don’t care. There are a lot of people having this, right? Why can’t I have it? I am not different from anybody else. I am not ashamed”.<sup>47(p.93)</sup>

**Finding 27 (F27):** Men perceived UI and ED following RP as a harbinger of the multiple losses associated with aging (U)

Illustration 10: “It takes sex away for the rest of my life... I was still an active man despite my age”.<sup>47(p.93)</sup>

#### **Paper 4: Oliffe 2005<sup>51</sup>**

Data from 15 participants who had a RP were abstracted and analyzed from a larger ethnographic study of 35 Australian participants who had undertaken other treatments for prostate cancer as early in the analysis it was noted that men treated exclusively with RP had specific experiences not shared with the other participants. Data were collected through individual in-depth semi-structured interviews, participant observation and field notes. The researchers concluded that prior to RP the risk of ED was insignificant in comparison to surviving the cancer, most of the men redefined their masculinity and sexuality post RP, age, long-term relationships an illness contributed to an acceptance from participants and willingness to live with ED.

Data were presented across three broad themes, data which were relevant to the post-surgery experience of the men were extracted from within two of the themes: acute recovery and reactions to impotence. Data were not extracted from the one theme unrelated to the review objectives: anticipation to impotence.

*Theme: Acute recovery: the shortened penis*

**Finding 28 (F28)** Some understood that their penis size reduction was due to the mechanism of surgery. However it was an unexpected bi-product of their treatment (U)

Illustration 1: “It is no real concern. It is just the way it is. I am told if and when it does become erect it would be the same size as it would have been anyway so that doesn’t that is not an issue”.<sup>51(p.2253)</sup>

*Theme: Acute recovery: the loss of potency*

**Finding 29 (F29):** Many emotive changes and challenges accompanied loss of potency (U)

Illustration 2: Arthur noted a loss of “that sense of potency... which would not rely on one being erect, it was a sense of being a man” He was having “very black experiences”, felt old, “like a 90-year-old man”, “worthless” and kept himself “invisible”.<sup>51(p.2254)</sup>

**Finding 30 (F30):** In the moments, months and years following prostatectomy, the re-establishment of erectile function was a significant aspect of many participants’ recoveries (U)

Illustration 3: “Anyone can close their eyes and put a blind fold on for 24 hours and get some appreciation of what it’s like to be blind. Not of the permanent loss but some appreciation of the hassles. If you were potent you can’t be impotent. You can’t experience it”.<sup>51(p.2254)</sup>

**Finding 31 (F31):** Most participants were less explicit than Arthur in their reliance on penetrative sex, but were nonetheless committed to re-establishing potency following surgery (U)

Illustration 4: “Patrick stated “In the last few years we haven’t been particularly sexually active anyway, but I would like to think that is something that you don’t close the book on”.<sup>51(p.2254)</sup>

*Theme: Reactions to impotence: treatment of the erectile dysfunction*

**Finding 32 (F32):** Most participants tried various aids to regain potency.

Illustration 5: “Ben recalled his experience of the VED: Well, you have a highly inflated penis. Unfortunately it’s all volume, no rigidity. It is normal erect size, but frightfully red looking and it is quite painful, but all of that would be okay if you had a degree of rigidity, so the truth is it has not allowed us to have penetrative sex. It is not rigid enough to do that”.<sup>51(p.2255)</sup>

**Finding 33 (F33):** Some participants pursued ways to re-establish erectile function but simultaneously disclaimed their reliance on penetrative sex (U)

Illustration 6: Clark described his libido, “Sometimes there’s an urge like it would be good and then it’s gone”. He suggested it was like giving up smoking; eventually “you don’t worry about it for three or four days a week, two weeks”. Despite a lack of desire, Clark decided to try the injection to restore his erection because “it’s a masculine thing that you expect to be able to do”.<sup>51(p.2255)</sup>

*Theme: Redefined masculinity: reactions to impotence*

**Finding 34 (F34):** Many participants initially used treatments to restore their potency but eventually abandoned them due to the artificial nature, ineffectiveness and lack of spontaneity in achieving, maintaining and using their erection (U)

Illustration 7: “We didn’t know how difficult the alternatives were going to be, the artificial, just wasn’t worth it, it had to be natural or not at all, we are probably better mates than lovers, we enjoy each other’s company, and do a lot of stuff together. go out to restaurants, just the two of us and sit and talk, we get on really well together”.<sup>51(p.2255)</sup>

**Finding 35 (F35):** As some participants grew older, their long-term relationships were less reliant on penetrative sex, and when impotence occurred it was accepted without trying medical treatments (U)

Illustration 8: “We have had our children, they have grown up and gone, we have grandchildren, we are older and we realize it, now we have moved onto the next stage of our lives, this involves smelling the flowers and friendship with each other and companionship and sharing of interests, and sex is not needed in this relationship”.<sup>51(p.2255)</sup>

**Finding 36 (F36):** Some participants described changes to specific erectile, penetrative and climactic sexual functions following prostatectomy and some components of sexual performance were maintained, whilst others were lost (U)

Illustration 9: “Having sexual relations, in so far as I could without getting an erection, with a lot of oral sex from both perspectives, and caressing. It is a fairly satisfying sex life, but different in the fact that you can’t penetrate”.<sup>51(p.2256)</sup>

Theme: *Reactions to impotence: the re-erected penis*

**Finding 37 (F37):** Arthur tried the VED and Viagra without success, but got an erection following the injection (U)

Illustration 10: “He recalled quickly making his way home from the surgery, where the injection had been administered, and described how the “weight of blood in [his] penis was terrific”.<sup>51(p.2256)</sup>

**Finding 38 (F38):** Determination to regain potency (U)

Illustration 11: “Similarly Ernie explained that sexually, he was “getting towards normal”, but in the interim he used Viagra and was “performing like the old days” which helped him “feel like a man”.<sup>51(p.2256)</sup>

### **Paper 5: O'Shaughnessy and Laws 2010<sup>36</sup>**

The aim of this study was to describe men’s long term recovery following RP with the purpose of identifying the effects of unresolved post-surgical morbidity. Data were collected from focus groups and individual interviews from 11 participants who had undergone an RP more than 6 months prior to the study which took place in Australia. Three men took part in individual interviews and 8 men took part in the focus groups. Individual interviews preceded the focus groups due to the inability of some participants to attend, these then contributed to defining the questioning for the focus groups. The authors’ conclusions indicated that many men appeared unaware of the long term consequences of the surgery and felt that their fears could have been reduced if there had been more support available and they were better informed about the potential implications of the RP. Coping with ED and UI was a major concern for most men and negatively impacted upon their quality of life. Some men looked for coping



methods but many found long term UI and ED insurmountable and were now seeking the empathy of partners.

Data were presented across three themes, data which were relevant to the post-surgery experience of the men were extracted from within each theme: incontinence: in the medium-long term, sexual health and altered body image an altered self. However, data related specifically to surgical scars under the theme altered body image an altered self were not extracted as they did not relate to the review objectives

*Theme: Incontinence: in the medium-long term*

**Finding 39 (F39):** More than one man described the operation itself as a non-event compared to the ongoing incontinence. The unexpected persistence of incontinence played heavily on the man's psyche (U)

Illustration 1: "it was distressing me quite a bit, the continence side of it, to the point where I would occasionally think to myself, 'why the hell did I bother with this operation, why didn't I just let it go, and when things happen, things happen, you know!'"<sup>36(p.102)</sup>

**Finding 40 (F40):** For another man ongoing incontinence resulted in considerable anxiety causing him to question his decision to have surgery (U)

Illustration 2: "you know, it has made me think, would I really, if I was faced with that again, would I still make the same decision? I am not sure".<sup>36(p.102)</sup>

**Finding 41 (F41):** The men in this study perceived incontinence to be a social impropriety: losing control over the retention of urine was seen as a disrespect to others who witnessed the problem (U)

Illustration 3: "A couple of weeks ago I was on holidays and we stayed at a friends place and I wet the bed. It was the first time I have ever done it since I was a toddler. I had that dream where you are having a wee and all of a sudden you wake up and you are doing it. The wife said it was quite warm actually. It was embarrassing, because it could have happened at a motel, but it happened at a friend's place and I wet the bed".<sup>36(p.102)</sup>

*Theme: Sexual health*

**Finding 42 (F42):** As the long term consequences of surgical morbidity became a daily experience there was a re-evaluation of their decision to be treated (U)

Illustration 4: "It was a pretty tough decision. Especially, like the incontinence kind of side of things. It's the two things you really don't want to think about isn't it. Like being impotent and

being incontinent, it's like the two, but then again you don't want cancer either kind of thing".<sup>36(p.102)</sup>

**Finding 43 (F43):** For the men diagnosed earlier in life the risk of ED weighed heavily on their minds before and after their decision to have surgery (U)

Illustration 5: "it's a pretty tough decision to make. I was like fifty at the time, and still sexually active and stuff".<sup>36(p.103)</sup>

**Finding 44 (F44):** Emotional adaptation to changes in sexual function and a level of acceptance (U)

Illustration 6: "What happened to men is I don't think about sex anymore, I don't think about cancer, I don't think about sex".<sup>36(p.104)</sup>

*Theme: Altered Body Image and Altered Self*

**Finding 45 (F45):** Overt discussions on the impact of surgery on the men's body image were readily revealed (U)

Illustration 7: "Just after the operation, like, I had five holes, scars and holes, and I didn't really feel like I was very sexually attractive. The one thing was, I didn't really want to uncover my body, like going to the swimming pool, and things like that. I didn't really want to do that".<sup>36(p.104)</sup>

**Finding 46 (F46):** Most men identified the state of erectility of their penis as an altered body image linked to a sense of altered self (U)

Illustration 8: One reported his erectile dysfunction to his urologist in the following terms. "I am going to sue you boy; before the operation, I could hang a bloody work boot on it, now it's only a rubber thong on a good day".<sup>36(p.104)</sup>

**Finding 47 (F47):** An inability to sustain an erection effected sexuality (U)

Illustration 9: A man who informed the group that he was gay explained "I notice not having an erection. Yeah, it like affects the pleasure of sexual encounters and that, it takes away my confidence".<sup>36(p.104)</sup>

**Finding 48 (F48):** The lack of ability to attain a spontaneous erection was described by one man of a comedy character developed by Rolf Harris called Jake-the peg (a three legged man) (U)

Illustration 10: The metaphor of a three legged man refers to the penis as a middle leg. "I don't think I will ever look like Rolf Harris again", "I have chosen to go with other options than tablets

and injections. The tablets didn't work very well'. 'I think in time it might come good or better. Otherwise I will look at the options".<sup>36(p.105)</sup>

**Finding 49 (F49):** Another man spoke more frankly about his altered body image (U)

Illustration 11: Another man spoke more frankly about his altered body image. "Masturbating with a limp dick isn't that much fun, with due respect, you know the maleness of having firm penis in your hand when you're masturbating gives you more enjoyment".<sup>36(p.105)</sup>

**Paper 6: Milne et al. 2010<sup>20</sup>**

This study investigated the experience of men following laparoscopic RP (LRP), a less invasive surgical option than the open retropubic approach. Data were collected using a qualitative descriptive method that combined individual (n=5) and three focus group interviews (n=3, 5 and 6), individual interviews were conducted first to inform the topic area. The study was conducted in Canada and included 19 participants, all married men, who had undergone LRP during the previous 3 year period. The major issue for participants was ED with most experiencing some degree of ED and uncertain where to turn for help. Most were not prepared for the post-operative challenges associated with early mobilization, gas pains, bladder symptoms and UI following catheter removal. Results suggested an important role for nurses in ensuring that men who choose LRP are adequately informed and prepared for potential post-operative experiences.

Data were presented across eight themes and data which were relevant to the post-surgery experience of the men were extracted from five of eight themes: the sensory experience of catheterization, coping with incontinence, is sex important, you've got to push yourself, having someone there and entering a life of uncertainty. Data were not extracted from the three themes unrelated to the review objectives: backgrounding oneself (as this focused on information about the condition and treatment options), the benefit of early discharge, and unexpected signs and symptoms.

*Theme: The sensory experience of catheterization*

**Finding 50 (F50):** The sensory experience of catheterization was for some the single biggest postoperative issue (U)

Illustration 1: "They have to find a better method. This whole thing would have been a piece of cake without the catheter".<sup>20(p.770)</sup>

*Theme: Coping with incontinence*

**Finding 51 (F51):** Participants generally expected to experience some incontinence but were generally shocked by the severity (U)

Illustration 2: “It was not very good for about the first six weeks, that’s for sure. I had some real bad episodes, really bad, where I had a stressed day and I couldn’t get to the washroom and that kind of thing happened a few times where I just filled my pad to the max and I was leaking down my pants”.<sup>20(p.770)</sup>

**Finding 52 (F52):** Most refused to let incontinence slow them down (C)

Illustration 3: “They travelled to California and Vancouver, resumed golf games and went heli-hiking during their initial 6-week recovery period’ always ensuring they had the proper supplies”.<sup>20(p.770)</sup>

**Finding 53 (F53):** Although bothered by the unpredictable nature of their UI, all had adopted coping strategies to minimize impact (C)

Illustration 4: “One man had engineered his own penile clamp out of polyethylene pipe and rubber bands; others became diligent about the timing of their voids and/or wore only dark clothing”.<sup>20(p.770)</sup>

**Finding 54 (F54):** Most men avoided the use of incontinence pads (C)

Illustration 5: “They complained about the fit of the pads and created their own solutions by cutting their wives pads in half or inserting toilet tissue in their underpants”.<sup>20(p.770)</sup>

**Finding 55 (F55):** There was an over-riding sense that pad usage meant accepting the UI, and negatively impacted self-esteem (U)

Illustration 6: “People already feel uncomfortable and unhappy by the situation and the clothing and the devices that are being offered are so pathetic looking that it makes you even feel worse”.<sup>20(p.770)</sup>

**Finding 56 (F56):** Consistent with their reluctance to accept UI, men were particularly motivated to perform pelvic floor muscle exercise (C)

Illustration 7: “One had purposefully not entered a randomized controlled trial on the topic because he might have been assigned to the control rather than the treatment arm. Men who were in the study had initially performed their exercises one–three times a day and all but one had “religiously” maintained at least a portion of their original routines. Most credited pelvic floor muscle exercise with their improved bladder control”.<sup>20(p.770)</sup>

*Theme: Is sex important?*

**Finding 57 (F57):** Erectile dysfunction was a common topic of discussion and the most lingering source of anxiety among participants (C)

Illustration 8: "Participants all reported diminished ability to achieve or maintain an erection".<sup>20(p.770)</sup>

**Finding 58 (F58):** Some had purposefully resigned themselves to their condition following brief unsuccessful trials with medication, one because he was too embarrassed to raise the topic and another because of his advancing age (U)

Illustration 9: "Either I don't remember or they didn't tell me about the nerves being cut but I'm not worrying too much about it I'll be 70 this month and it would be nice, sure, but I'm going to put my mind at ease and not going to worry about it".<sup>20(p.770)</sup>

**Finding 59 (F59):** Most men acknowledged that sex was an important part of their lives and were not willing to accept their dysfunction (U)

Illustration 10: "sex is 10% of your marriage if it's fine and it's a hundred percent of your marriage if it's not fine".<sup>20(p.770)</sup>

**Finding 60 (F60):** Another man who was 2 years postoperative remarked that he was often depressed and that his ED had severely impacted his marriage (U)

Illustration 11: "The problem is that I still have the desire, all the pent up emotion and can't do a thing about it even with the needle, I'll maybe get a 2 or a 3 out of 10, like it will just be semi-flaccid sort of thing, and it just, you know,... it makes me angry".<sup>20(p.770)</sup>

**Finding 61 (F61):** Participants appeared to need professional guidance to cope with the impact of ED and to pursue a wider range of therapy (C)

Illustration 12: "They emphasized the importance of including spouses in counselling / intervention because women have a different perspective on ED. Whereas men link sexual performance to self-esteem, they noted, women focus on the importance of health and living cancer-free".<sup>20(p.770)</sup>

*Theme: You've got to push yourself*

**Finding 62 (F62):** An overwhelming need was felt to regain control of their daily lives by returning to pre-operative activities (U)

Illustration 13: "You have got to get up and push yourself".<sup>20(p.771)</sup>

Theme: *Having someone there*

**Finding 63 (F63):** Varied sources of support were sought throughout postoperative recovery periods (U)

Illustration 14: "Sometimes I think you just get spooked, or you're confused or worried... and it's just great to have someone to talk to, to reassure you".<sup>20(p.771)</sup>

Theme: *Entering a life of uncertainty*

**Finding 64 (F64):** Overwhelming emphasis that regardless of the degree of their UI and ED, what really mattered was that the cancer had gone (U)

Illustration 15: "Who the hell cares about incontinence when you're 28 kilometres on foot in the mountains fishing world class trout".<sup>20(p.771)</sup>

### **Paper 7: Iyigun et al. 2011<sup>25</sup>**

Thirteen participants, all married took part in this study conducted in Turkey. A descriptive phenomenological approach was taken using semi-structured interviews, the first part involved demographic data and the second part open-ended questions exploring the problems and emotions experienced by the participants following ED and the effects on their daily lives. Also addressed were areas in which the participants lacked information when they were discharged. Key areas identified were emotions regarding living with the urinary catheter, the emotions, loss of self-control and impact on social lives and religious rituals associated with living with UI, with many participants feeling ill informed about UI prior to surgery. Whilst ED was viewed as a negative factor most participants stated that it did not negatively impact upon their relationship with their partner, younger participants saw ED as a more serious problem and hoped they would regain erectile function.

Data were presented as themes within four categories: experiences regarding the urinary catheter at home, experiences regarding UI, *sexual experience* and experiences of being informed. Data which were relevant to post-surgery experience of the men were extracted from within each theme.

*Category 1 Experiences regarding the urinary catheter at home*

*Theme 1: Emotions regarding living with the urinary catheter*

**Finding 65 (F65):** Most participants (57.1%) felt uncomfortable with the long-term use of a urinary catheter after surgery (U)

Illustration 1: "It is difficult but has to be put up with as part of the treatment. You have to stay home when you have a urinary bag, and it is for a long time as well".<sup>25(p.104)</sup>

**Finding 66 (F66):** Most participants (71.4%) stated that they had felt anxious regarding going home with the urinary catheter as they were afraid of bleeding or infection (U)

Illustration 2: "I heard from other patients that the urinary catheter causes infection at home, and that is why I did not want to go home, the catheter seems to cause infection, I thought 'did it stay too long or should it have been exchanged during that period'".<sup>25(p.104)</sup>

*Theme 2: Medical problems related to the urinary catheter have not been extracted as these were not relevant to the objectives of the review.*

### *Category 2 Experiences regarding UI*

#### *Theme 1: Emotions related to UI*

**Finding 67 (F67):** Some participants acted on physician's advice regarding UI and regained total control by 1 month after surgery (C)

Illustration 3: "Some of the participants (13.3%) who knew that they would suffer from UI and that this would continue for some time stated that they did not see this as a problem and had acted on their physician's advice. These participants stated they had regained total control between the end of Postoperative Week 1 and Month 1".<sup>25(p.104)</sup>

**Finding 68 (F68):** The volume of UI after the catheter had been removed was high for some participants (13.3%) (U)

Illustration 4: "We had gone to the hospital to have the catheter removed, and I told my wife we should go for a walk in Kizilay (a crowded city center) when it was removed, as we had been staying at home all this time. My pants got all wet in the middle of the road, and I was very embarrassed. I would have taken precautions if I knew it would be this much".<sup>25(p.104)</sup>

**Finding 69 (F69):** Most participants (73.3%) indicated that they did not know they would be incontinent after the surgery and that this was as second shock to them, following the initial shock of the diagnosis of cancer (U)

Illustration 5: "My cancer was discovered by chance with the prostate specific antigen result; they told me I was going to undergo surgery. I was shocked, I didn't expect this at all, now this situation (incontinence) was a second shock for me. Believe me, this is the worst part. I didn't expect this at all, no this situation (incontinence) was a second shock for me, believe me this is the worst part".<sup>25(p.104)</sup>

**Finding 70 (F70):** Some participants (20%) described incontinence as the worst thing that could happen to a man and related a feeling of loss of control (U)

Illustration 6: “It is the worst thing that can happen to someone, I feel awful when it happens, I can’t control my feelings sometimes and even cry occasionally”.<sup>25(p.104)</sup>

**Finding 71 (F71):** Some participants (13.3%) stated that they were embarrassed when family members witnessed their incontinence or thought they would be embarrassed in such a case (U)

Illustration 7: “It was a very heavy burden for me for my pants to become wet in front of my child, my wife, my son-in-law; I can say I felt terribly embarrassed, the feeling just can't be described”.<sup>25(p.104)</sup>

#### *Theme 2: Effect of UI on social life*

**Finding 72 (F72):** More than half of the participants (60%) stated that incontinence had significantly limited their social life (U)

Illustration 8: “I can't go out because I am not sure whether I will always find a place to urinate? You first check to see if there is a toilet when you go to a place. And the smell makes you terribly uncomfortable among others”.<sup>25(p.104)</sup>

**Finding 73 (F73):** For some participants (20%) as they got used to their UI they returned to their normal social life (U)

Illustration 9: “We weren't able to accept guests for a month or two, and I could not go to anyone as I was constantly keeping the toilet in mind. I put the toilet paper in my pocket and took precautions before going out. I limited the time and wanted to go back home as soon as possible. It's gradually decreasing, and I am looking forward”.<sup>25(p.105)</sup>

#### *Theme 3: Effect of social life on religious rituals*

**Finding 74 (F74):** Some of the participants (26.6%) stated that incontinence prevented them from completing religious rituals (U)

Illustration 10: “I perform the prayer ritual, and I continue although the pads are wet, but I can't go to the mosque as I suffer from incontinence while bending, and I suffered so much incontinence while sacrificing the sheep during the Religious Holiday of Sacrifice that I found myself in a very difficult situation”.<sup>25(p.105)</sup>

#### *Theme 4: Coping with incontinence*

**Finding 75 (F75):** Participants indicated that they were trying to cope using a variety of different methods and that they had not consulted physicians or nurses on the matter (U)



Illustration 11: "I use a female pad; I hear there are also pads for men, but we don't know these. I am a very fastidious person, but we can only find primitive solutions".<sup>24(p.105)</sup>

**Finding 76 (F76):** Some participants (46.6%) emphasized the importance of their physical and emotional support in coping with UI (U)

Illustration 12: "... my wife is always with me, my biggest support".<sup>25(p.105)</sup>

### *Category 3 Sexual experience*

#### *Theme 1: Emotions regarding the loss of sexual function*

**Finding 77 (F77):** All participants except one stated that their sexual life had been negatively affected following RP (U)

Illustration 13: It is difficult as a man, of course, I asked whether this was the end of my sex life. The physician said no, but I believe it is".<sup>25(p.105)</sup>

**Finding 78 (F78):** Most of the participants (64.3%) defined this problem as something that was difficult to accept and cope with and felt that they were too young for this negative effect on their sexual life (U)

Illustration 14: "I am not old; I read from books that sexuality can continue until 90 years old. This situation really affected me".<sup>25(p.105)</sup>

**Finding 79 (F79):** Some participants (28.5%) felt that ED was a result of their treatment and was something that they should accept (U)

Illustration 15: "We are like eunuchs in the Ottoman period; we sleep like brother and sister with my wife. We have eight children anyway, and I am at a certain age, it is enough if God gives us health".<sup>25(p.105)</sup>

**Finding 80 (F80):** Participants also stated that they carried hope that their sexual functions would eventually return to normal (U)

Illustration 16: "Sexuality is very important of course. They told me there would be such a problem. I feel very little at the moment; I hope it will improve in time. One can put up with a lot when death is a possibility".<sup>25(p.105)</sup>

#### *Theme 2: Effect of ED on married life*

**Finding 81 (F81):** Most participants (64.3%) stated that their wives had been very understanding regarding the negative impact of ED on sex life, and this was not a major problem for their relationships (U)

Illustration 17: "I have a very good relationship with my wife; our love is limitless. We talk all the time, and we have had no problems. My wife is 56 years old. We have been married for 40 years. It would not be a problem for us even if this problem never resolved. My wife is still young but understanding".<sup>25(p.105)</sup>

**Finding 82 (F82):** Some participants (28.6%) said that their wives were even happy that they had lost their sexual function, but it was an important problem for them and that they continued to seek a solution (U)

Illustration 18: "My wife is old too anyway. She was even happy. The frequency had decreased anyway, but it would be good for me even if it were only once in a while. The physicians had said that a rod could be placed. My wife doesn't want it anyway. We are also elderly, and this is the way it will be from now on".<sup>25(p.105/6)</sup>

**Finding 83 (F83):** One participant said he was agitated due to losing of sexual function and that it had affected his relationship with his wife negatively and caused arguments. He was hoping that things would get better (U)

Illustration 19: "My sex life is over. I talk to some patients; they say it is not over, but it is. I am going to use medication and hope it will be better. I constantly have rows with my wife as I am irritable (he gets tearful as he talks)".<sup>25(p.106)</sup>

### *Theme 3: Effects of UI on sexual life*

**Finding 84 (F84):** More than a third of the participants (35.7%) stated that they did not try sexual intercourse because of fears that their UI would bother their wives (U)

Illustration 20: "My wife said that my health was important and that I did not need to use medication for sexuality. I also worried about bothering my wife due to my incontinence. I am trying to save myself. Sexuality takes second place".<sup>25(p.106)</sup>

### *Category 4 Experiences of being informed*

#### *Theme 1: Perceptions of regarding information received from the physician or nurse*

**Finding 85 (F85):** Some participants (46.7%) stated that they had not received information from the healthcare staff during this period (U)

Illustration 21: "I did not trust them as they did not tell me I would have incontinence when they removed the catheter at the hospital and I did not call them after I went home. I did the research myself and found a condom catheter and underwear pads, and I now use these".<sup>25(p.106)</sup>

**Finding 86 (F86):** Some participants (40%) stated that they wanted to share their problems with the healthcare staff and wished to obtain help from them, but they were too embarrassed to talk to them (U)

Illustration 22: “Erectile dysfunction is not something men desire. If there is a treatment that will not cause problems, I would like to use it. It is degrading for a man to completely lose sexual function, but it is more valuable to stay alive. I would still prefer to have a sex life though. However, I couldn't ask my physician as I thought he would think such a problem as unimportant and think badly for me for making this a problem”.<sup>25(p.106)</sup>

**Findings 87 (F87):** Participants (13.3%) who had obtained information from the healthcare staff felt more comfortable afterward and were satisfied (U)

Illustration 23: “We obtained pads from the clinic on the advice of the head nurse; she made me somewhat more comfortable”.<sup>25(p.106)</sup>

*Category 3, Theme 2: Views regarding the content of the discharge training findings, were presented in a numerical list with no supportive qualitative data and have therefore not been extracted.*

#### **Paper 8: Hedestig et al. 2005<sup>39</sup>**

This study conducted in Sweden included ten participants who were all married and retired and between 6 months and 3 years post-operatively. The aim of the study was to illuminate the experience of living after RP through a qualitative phenomenological approach using narrative interviews conducted in the men's home.

Data were extracted from all four themes: 'living as a changed man' as a consequence of side-effects such as UI and ED; 'striving to gain a sense of control' of the declining body and disease progression; 'managing a new life situation' disclosing to others, planning for the future and managing worry and anxiety; finally 'striving to become reconciled in a new life situation' living in the present, believing that they had been cured and prioritizing things which enhanced their quality of life.

*Theme: Becoming a changed man*

**Finding 88 (F88):** Losing their erectile function, radically changed their sex life, which gave them a sense of grief (C)

Illustration 1: “To teach oneself to accept this situation, even if life is not as one had imagined – that is the art of being human”.<sup>39(p.681)</sup>

**Finding 89 (F89):** A waning ability to gain an erection and a consequently altered sex life were expressed as detracting from manliness (U)

Illustration 2: “Most of the men said they did not feel like “a whole man”. Other expressions the men used were, “half human”, “a weak man”, “cut down”, and “mutilated”.<sup>39(p.681)</sup>

**Finding 90 (F90):** The “mutilation” was described as having changed the men’s self-esteem, bringing a sense of not being a complete man when comparing current experiences with life before treatment (U)

Illustration 3: One man said, “I feel, well, [like] a man who is mutilated. I’m only a half human because the desire and the ability for sexual activity is lost”.<sup>39(p.681)</sup>

**Finding 91 (F91):** Urinary incontinence often resulted in a need to wear absorbent pads on a daily basis as a precaution against urine leakage despite the pads. Described living a normal social life as something almost impossible to do (U)

Illustration 4: “I am cut down... A large part of my life has disappeared, and I also have to wear absorbent pads and change my clothes often every day”.<sup>39(p.682)</sup>

**Finding 92 (F92):** Wellbeing for the men meant maintaining physical strength. Waning physical strength was seen as a loss and was experienced with grief (U)

Illustration 5: “I am not as I used to be, I can’t go at it as before”.<sup>39(p.682)</sup>

*Theme: Striving to gain a sense of control in a new situation*

**Finding 93 (F93):** To maintain control over the leakage of urine (C)

Illustration 6: “the men focused on the consumption of drinks, the frequency of lavatory visits, how they were dressed when going outside in cold weather, and how to avoid situations of stress and activities which they would worsen their incontinence”.<sup>39(p.682)</sup>

**Finding 94 (F94):** The men expressed a need to communicate with other prostate cancer patients (U)

Illustration 7: “From my brother (he had been operated for prostate cancer before me), I got a lot of information before my own surgical treatment. I am grateful to him. I have also spoken to a friend who has been surgically treated. It’s important to have someone to compare my own situation with”.<sup>39(p.682)</sup>

**Finding 95 (F95):** Frustration and irritation that the follow-ups had not been scheduled according to plan (U)

Illustration 8: 'My first follow-up was after 3 months; after that, they came with 6-month intervals. These 6 months become 7 and I felt that that wasn't good for me, because I need to feel secure. The regularity for me means security'.<sup>39(p.682)</sup>

*Theme: Managing a new life situation*

**Finding 96 (F96):** Men expressed it as important to inform their family and friends about their illness (U)

Illustration 9: "Once I'd had this big operation and managed it, it was a pleasure to inform others about what had happened".<sup>39(p.682)</sup>

**Finding 97 (F97):** For most men, thoughts about the future were associated with a growing worry, anxiety, or sadness (C)

Illustration 10: "The future is behind me".<sup>369p.683)</sup>

**Finding 98 (F98):** Most men expressed the desire and hopes for a cancer-free life (U)

Illustration 11: "I know my situation and I'm adapting to it. The illness is a reality and I can't change anything about that, but I distance myself from it. I take each day as it comes".<sup>39(p.683)</sup>

**Finding 99 (F99):** Most of the participants kept their innermost thoughts to themselves as a self-chosen strategy for managing (U)

Illustration 12: "Even though I have a family, I will keep some thoughts to myself; that's my own private space".<sup>39(p.683)</sup>

**Finding 100 (F100):** The men's strategy for coping with worry and anxiety was to find activities with a new focus in the present (C)

Illustration 13: "Examples of such activities were being in nature, listening to, or making music, working with something, starting a new hobby, and socializing".<sup>39(p.683)</sup>

**Finding 101 (F101):** Spending time alone and not thinking about the illness was another strategy for managing anxiety (U)

Illustration 14: "Walking in the forest is music for my soul. When I was told that I had cancer I went to the sea to go ice-fishing. That diverts one's thoughts. Walking quietly in the forest...then there will be order in my mind... a relaxation".<sup>39(p.683)</sup>

*Theme: Striving to become reconciled in a new life situation*

**Finding 102 (F102)** Striving to live in the present (U)

Illustration 15: “To live in the present and take care of my own life is very important to me”.<sup>39(p.683)</sup>

**Finding 103 (F103):** Striving for a sense of security when visiting the hospital for checkups (U)

Illustration 16: “It’s always better to be able to speak with a person who has been involved in my treatment all the time. When I meet a new physician I never know perhaps he’s coming with new ideas. No, I have more confidence if I see the same physician. I am better known by him and it’s easier for me to speak”.<sup>39(p.683)</sup>

**Finding 104 (F104):** To prioritize things which would enhance the quality of life (U)

Illustration 17: “After the operation I don’t take life for granted. To be able to stand on my own legs and go out, for example, is important. Playing golf has taught me a lot about life. Life isn’t always smooth, and it happens differently from what we want as humans”.<sup>39(p.683)</sup>

### **Paper 9: Walsh and Hegarty 2010<sup>19</sup>**

The aim of this study was to provide a retrospective view of men’s experience 15 years or less post RP from initial diagnosis to post surgery and beyond. Time since surgery varied from 14 months to 15 years, data were extracted related to experiences post RP. A qualitative design was employed; eight men participated in the study conducted in Ireland, semi-structured interviews were conducted in a place of each person’s choosing. The most overriding concern identified was ED which each man experienced, along with the level of UI. The importance of being equipped with information and the need for increased information by HCPs was a recurrent theme.

Data were presented across six broad themes, data which were relevant to the post-surgery experience of the men were extracted from within four of the themes: support, the importance of information, defining moments and primary concerns. Data were not extracted from the three themes unrelated to the review objectives: the process of diagnosis, normalization and survival.

#### *Theme Support*

##### *Sub theme: Perceived need for support*

**Finding 105 (F105):** Men in this study were uniform in their view that men need some form of support (U)

Illustration 1: “If there was support I’d have been much better. I had nobody to talk to. It was a year after the operation before I had the support group people to talk to”.<sup>19(p.129)</sup>

*Sub theme: Type of support*

**Finding 106 (F106):** Peer support (in terms of support provided by other men who have been through prostate cancer and treatment themselves) emerged as the type of support perceived as most important (U)

Illustration 2: “No one can talk about the patient’s experiences only the patient”.<sup>19(p.129)</sup>

**Finding 107 (F107):** Men’s experiences of peer support varied significantly (U)

Illustration 3: One of the men spoke with praise regarding his consultant who had put him in touch with a support group. “.so I rang this man and met him and he was very helpful because he talked me right through the operation and what would happen afterwards. It kind of prepares you to some extent”.<sup>19(p.129)</sup>

Illustration 4: Another spoke with sadness with regard to the lack of information available to men concerning support groups. “I was really really down around February after the operation. No one said there’s a group of men out there who have been through it and they are available to speak to. That would be a great help”.<sup>19(p.129)</sup>

**Finding 108 (F108):** Just one man felt that he did not need support from peers in the form of organized support groups feeling that his family provided all the support necessary (C)

Illustration 5: stating that support groups just “weren’t his thing”.<sup>19(p.129)</sup>

**Finding 109 (F109):** As regards support from HCP’s men had varied experiences of the level of support provided (U)

Illustration 6: “We got tremendous support from the staff in the hospital. I was kind of reassured by this man (*the consultant*) that he was capable, knew what he was doing and easy to talk to”.<sup>19(p.129)</sup>

Illustration 7: “There was nobody here I could talk to about it”.<sup>19(p.129)</sup>

**Finding 110 (F110):** Men expressed their views as to the attributes of a HCP that would be able to provide the best support (U)

Illustration 8: “I think it would have to be a very special person to talk about these things”. They’d have to have a great understanding themselves and none of that word taboo or any of these things. Twould be quite normal like”.<sup>19(p.129)</sup>

**Finding 111 (F111):** Men differed in their need for support from spouses and family (C)

Illustration 9: “ah my wife; one doesn’t like to worry her about it”.<sup>19(p.130)</sup>

*Data were not extracted with regard to keeping the diagnosis from friends*

*Theme: Information*

*Sub theme: The seeking of information: data were not extracted from this sub theme as it was related to treatment choices*

*Sub theme: Importance of being equipped with information*

**Finding 112 (F112):** Importance of being equipped with information (U)

Illustration 10: “forewarned is forearmed”.<sup>19(p.130)</sup>

*Sub theme: The need for increased information provision by HCP’s*

**Finding 113 (F113):** Men also however stressed the importance of information provision by HCP’s (U)

Illustration 11: “I asked my doctor was there any leaflets and he said he couldn’t supply me with any”.<sup>19(p.130)</sup>

*Theme: Defining moments*

*Data not extracted from the subthemes: The day men received their diagnosis. The day men were called for surgery*

*Subtheme: The day the urinary catheter was removed (Quotes concerned with the physical sensation associated with removal, psychological reactions and what removal of the catheter represented for men were not extracted)*

**Finding 114 (F114):** The level of urinary incontinence following removal of the catheter came as a surprise to a number of men (U)

Illustration 12: “I had a lot of problems afterwards you know with passing water and for a long time I suffered a lot of incontinence. I wasn’t told to expect that....you know I often think that the people who operate on you have never had prostate cancer and they don’t know what happens afterwards”.<sup>19(p.130)</sup>

*Theme: Primary concerns*

*Subtheme: Erectile dysfunction*

**Finding 115 (F115):** The overriding most common concern was the whole area of ED (U)

Illustration 13: “There is only one long lasting effect that I am aware of at the moment – there is absolutely no sign of an erection at all, absolutely dead”.<sup>19(p.130)</sup>



**Finding 116 (F116):** For some adjusting to sexual dysfunction was very difficult (U)

Illustration 14: “I would have been very concerned that time about like would ya ever get back an erection like after this operation. I mean men can’t kill dinosaurs today but this thing of having penetrative sex that is important to a man. And that would have probably been the biggest concern leading up to the operation and after it as well”.<sup>19(p.131)</sup>

**Finding 117 (F117):** Another of the men aligned his loss of sexual function with a loss in his sense of identity as a man (U)

Illustration 15: “I mean, well I felt anyway I’m going in a whole man and not coming out a whole man”.<sup>19(p.131)</sup>

**Finding 118 (F118):** Others meanwhile looked upon this loss of sexual function with acceptance (U)

Illustration 16: “At this stage of my life ya know I’m not that worried so that wasn’t a bother ya know... He was prepared to prescribe this or that or the other for the sexual function but I really told him look I’m not interested. We didn’t go into medications because I didn’t want to know, it’s not the same I suppose but we can live with it and we’re happy enough”.<sup>19(p.131/2)</sup>

**Finding 119 (F119):** Although this man has learned to live with ED he would have valued increased input from HCP’s in relation to methods of dealing with it (U)

Illustration 17: “ED is something that no one not even the consultants want to talk about. Of course I wanted to but it didn’t happen and no one ever said to me there’s medication there, there’s counselling there”.<sup>19(p.132)</sup>

**Finding 120 (F120):** For many the use of sexual aids was a feature of their experience (U)

Illustration 18: “Now as it happened they prescribed a tablet for me afterwards and as it happens that side of it isn’t working too bad. For a long time there was none but gradually with the tablet we’ve had a sexual relationship since. Now without the tablet it wouldn’t work really”.<sup>19(p.132)</sup>

*Theme: Urinary incontinence*

**Finding 121 (F121):** Urinary incontinence emerged as a major concern (C)

Illustration 19: “a twenty-four seven 365 day a year problem”.<sup>19(p.132)</sup>

*No data were extracted from the subtheme survival*

### **Paper 10: Moore and Estey 2005<sup>35</sup>**

This study was conducted in Canada and used a descriptive exploratory approach to explore the concerns of men with UI in the early weeks of recovery after RP. This was part of a larger study evaluating effectiveness of intensive physiotherapy for UI, informal semi-structured interviews were conducted in the subject's home with their spouse present. 63 participants with a mean age of 67, who were 5-38 weeks post-surgery, participated. All of whom were experiencing UI. The experiences post RP were stressful and affected their quality of life, a perceived lack of information and support from HCPs made the experience frustrating and stressful. Concerns were categorized into pre and post-operative concerns.

Data were presented across two broad categories: pre-operative concerns and post-operative concerns. Data were extracted for post-operative concerns only, this included four themes: I didn't know what to expect, the worst day of my life, no one told us where to go and buy diapers and I've lost my manhood.

*Theme: I didn't know what to expect*

**Finding 122 (F122):** Men stated they were unprepared for urine by-passing the catheter, haematuria, or the signs of a urinary tract infection (U)

Illustration 1: "The day of the catheter removal was described as the "worst day of my life"; "never knew it would be like this".<sup>35(p.1125)</sup>

*Theme: The worst day of my life*

**Finding 123 (F123)** The degree of UI immediately after catheter removal was a shock to all men (U)

Illustration 2: "I think he told me about incontinence but I didn't know he meant this".<sup>35(p.1125)</sup>

*Theme: No-one told us where to go to buy diapers*

**Finding 124 (F124):** Men had no knowledge about incontinence pads – where to go, what to use or the amount of heavy leakage they would have for several days after catheter removal (U)

Illustration 3: "I was crying, sitting at the kitchen table while my wife washed all my clothes. No one told us where to go and buy diapers. If I had known it would be like this. I wouldn't have done it. They probably don't tell you because you change your mind [and not have surgery]".<sup>35(p.1125)</sup>

**Finding 125 (F125):** All men needed reassurance that they would improve and that most men regain continence after a RP (C)

Illustration 4: “One man needed a lot of reassurance because “the guys at church said I shouldn’t have had surgery”.<sup>35(p.1125)</sup>

**Finding 126 (F126):** Some men were disappointed with the outcome of their RP (U)

Illustration 5: “I know all about Kegel exercises. The only problem is that they no longer work for me. Thank heavens I am retiring soon. I don’t know if my students can smell me or not, but I certainly can...I find the whole thing extremely embarrassing”.<sup>35(p.1125)</sup>

**Finding 127 (F127):** By 3 months post RP 20 out of 63 participants had a small amount of leakage and still required a pad ‘just in case’ – this is when ED became a bigger issue (C)

Illustration 6: These men had adjusted to the inconvenience of occasional leakage. They were ready to get on with life; but ED interfered”.<sup>35(p.1125)</sup>

*I’ve lost my manhood*

**Finding 128 (F128):** Participants who had been sexually active pre operatively found it very hard to adjust to ED (U)

Illustration 7: “The doctor told me not to get despondent but it’s hard not to get frustrated”.<sup>35(p.1125)</sup>

### **Paper 11: Butler et al. 2001<sup>33</sup>**

The aim of this study conducted in Canada was to explore the meaning and effect of UI and impotence on the quality of life for men with prostate cancer. The Cancer Recovery model, which is based on the assumption that the chronicity of cancer is a function of recovery as well as illness, guided the study. The participants included 21 men and their partners, the men were between the ages of 47-73 years and most had been married to the same partner for an average of 34 years (range 6 months-54 years) and had undergone an RP. Data were collected using semi-structured interviews using a specifically developed guide based on a previous pilot study conducted with the local prostate information group, most FAQs reported by urologists and a literature review. The focus was on UI and sexuality. The study identified indicators for QOL for men who have had an RP, including the need for information to facilitate self-care at home following surgery and the availability of community resources that should be included in discharge teaching plans.

Data were presented across six theme and the data which were relevant to the post-surgery experience of the men were extracted from within three of the themes: urinary incontinence and sexual relationships, effects of a RP on quality of life. Data were not extracted from three themes unrelated to the objectives of the review: the diagnosis of prostate cancer, sources of information for decision making, acquiring medical information.

*Theme: Urinary incontinence*

**Finding 129 (F129):** Men had concerns about the use of protective pads (C)

Illustration 1: "Men reported the use of protective pads as an area of concern particularly related to size, cost, length of time required, and perceived visibility (N=17, 81%)".<sup>33(p.285)</sup>

**Finding 130 (F130):** Men reported issues around incontinence and body image (U)

Illustration 2: "Well, yeah. I thought some people were looking at me with a big bulge in my pants or something. It's embarrassing; you know, you are a little self-conscious about it. I would think, gee. I wonder if they could smell it".<sup>33(p.285)</sup>

**Finding 131 (F131):** Only a small number of men received information about performing pelvic exercises (C)

Illustration 3: "Only six men reported that they had received information about performing pelvic exercises".<sup>33(p.285)</sup>

**Finding 132 (F132):** Most men did not understand the relationship between doing exercise and decreasing incontinence (C)

Illustration 4: Just half of the men were actually performing the exercises (N=11, 52%), which was often initiated after a discussion with other men who had similar experiences".<sup>33(p.285)</sup>

**Finding 133 (F133):** Some men believed they had received misinformation about experiencing incontinence (C)

Illustration 5: "Seven (33%) men believed they had received misinformation about experiencing incontinence mainly related to the frequency and severity of loss of urinary control".<sup>33(p.285)</sup>

*Theme: Sexual relationships*

**Finding 134 (F134):** The ability to achieve an erection was a major concern for the participants postoperatively (C)

Illustration 6: “Four men stated their sexual relationship was "gone" (19%), while one man experienced no change in erectile functioning”.<sup>33(p.285)</sup>

**Finding 135 (F135):** The men described feelings and sensations concerning sexuality (C)

Illustration 7: “few men also talked about their own feelings of desire remaining the same and of orgasm being the same (N=3,14%), However, the sensation of ejaculating was described as either lost or causing them unanticipated concern (N=6, 29%)”.<sup>33(p.285)</sup>

**Finding 136 (F136):** Men reported being very self-conscious around wives when they had the catheter (C)

Illustration 8: “Three men also described the period of time when they had the catheter as being very self-conscious around their wife, particularly in relation to sleeping arrangements. One man stated that he and his wife have continued to maintain separate rooms since his operation”.<sup>33(p.285)</sup>

**Finding 137 (F137):** Sexual functioning was discussed pre-operatively with the urologist but men had mixed feelings about attending a sexual dysfunction clinic post-operatively (C)

Illustration 9 “Two men stated that they initiated the discussion about a referral with the urologist, while others had mixed responses concerning attendance at the clinic”.<sup>33(p.286)</sup>

Theme: *Effects of a RP on quality of life*

**Finding 138 (F138):** Men frequently described the cancer experience as altering their view of life (C)

Illustration 10: “Men frequently described the cancer experience as altering their view of life based on the uncertainty of cancer, the likelihood of a recurrence, and fear of having cancer (N=12, 57%)”.<sup>33(p.286)</sup>

**Finding 139 (F139):** Recovery from surgery as well as having an indwelling catheter restricted physical activity (C)

Illustration 11: “Recovery from the surgery, as well as having an indwelling catheter restricted physical activity (N=10, 48%)”.<sup>33(p.286)</sup>

**Finding 140 (F141):** Social activities were restricted due to a fear of UI (U)

Illustration 12: “Well, yeah, because I wouldn't go any place, or stay any length of time if I didn't have access to a washroom”.<sup>33(p.286)</sup>

**Finding 141 (F141):** Some men did not feel that their experience of prostate cancer and its treatment had effected their QOL (C)

Illustration 13: “Five men believed that their experience with prostate cancer and its treatment had no effect on their quality of life (24%)”.<sup>33(p.286)</sup>

**Finding 142 (F142):** For the majority of men the overall quality of their relationships with their partners did not change, for some there was conflict and for others it has been strengthened (C)

Illustration 14: “When asked about the overall quality of their relationship with their partner, eight men stated there was no change, two felt there was some conflict as a result of their illness, and two believed the quality of their relationship had been strengthened by this experience (38%, 9.5%, 9.5% respectively)”.<sup>33(p.286)</sup>

**Finding 143 (F143):** Some participants felt changes in their relationship were not necessarily related to the cancer (C)

Illustration 15: “Five men stated that given their age and the number of years they had been together with their wives, they expected changes, and did not believe they were necessarily related to the cancer but to the time in their life (24%)”.<sup>33(p.286)</sup>

#### **Paper 12: Eilat-Tsanani et al. 2013<sup>50</sup>**

The aim of this study was to describe the outcomes of RP as described by the patients and their ways of coping with them. The study included 22 men who underwent RP in a medium sized community hospital in Northern Israel. Data were collected through semi-structured interviews conducted in the patients’ homes using a questionnaire with open-ended questions. Recurrent themes included the outcomes of surgery: coping with the physical effects of UI and loss of sexual function, implications for marital relationships and the lack of need for psychological support.

Data were presented across five themes and data which were relevant to the post-surgery experience of the men were extracted from within two of the themes: the outcomes of surgery-coping with the physical effects, the lack of need for psychological support. Data were not extracted from two themes which were not relevant to the objectives of the review: the perception of the disease and its treatment, the importance of surgery and the surgeon as a support.

*Theme: The outcomes of surgery: Coping with the physical effects*

*Subtheme: Urinary incontinence*

**Finding 144 (F144):** Urinary incontinence was reported by all participants to one degree or another (U)

Illustration 1: "Since the surgery I need to go to the bathroom often and also wet myself".<sup>44(p.154)</sup>

**Finding 145 (F145):** The loss of urinary control and the need for pads or diapers caused a feeling of impotence, shame and discomfort (U)

Illustration 2: "Because of that I prefer not to go anywhere, because of the shame and the fear that I will wet myself".<sup>50(p.155)</sup>

*Theme: The outcomes of surgery: Coping with the physical effects*

*Subtheme: Sexual function*

**Finding 146 (F146):** All participants cited a reduction in or total loss of sexual function following surgery (U)

Illustration 3: "I maintain a romantic relationship with intimate contact even though I don't have an erection, but somehow we've managed without it... there simply is no erection..."<sup>50(p.155)</sup>

**Finding 147 (F147):** The loss of sexual function led to impaired self-esteem and a feeling of guilt because of the inability to function as a male (U)

Illustration 4: "This situation in which there is no sexual satisfaction and there is lack of full control of urination is enough to cause a normal person to feel angry at himself, at the environment, and at everyone".<sup>50(p.155)</sup>

**Finding 148 (F148):** There was a feeling of frustration and disappointment, while on the other a sense of consolation in the fact that some of the changes were natural and age-dependent (U)

Illustration 5: "...I took it relatively well because I had surgery at the age of 79, so I figure that my capacity is decreased because of my age as well".<sup>50(p.155)</sup>

**Finding 149 (F149):** The doctors played a role in the patients' acceptance of the situation (U)

Illustration 6: "The doctors told me that the percentage of men who have sexual relations at this age is low, so if I succeed I am in relatively good shape".<sup>50(p.155)</sup>

*Theme: The outcomes of surgery: coping with the physical effects*

*Subtheme: Implications for marital relationships*

**Finding 150 (F150):** In describing their partners' attitudes they mentioned an understanding based on years of good relations (U)

Illustration 7: "We have been together for over 50 years so things like that don't matter today, and everything is as usual".<sup>50(p.155)</sup>

**Finding 151 (F1521):** At the same time they described relationships that were affected negatively by the impaired sexual capacity (U)

Illustration 8: "I can say that it affects me more than her, with the fact that I cause the lack I also feel the lack. I have very strong guilt feelings that I can't give her satisfaction and feel satisfaction myself".<sup>50(p.155)</sup>

*Theme: The lack of need for psychological support*

**Finding 152 (F152):** There is a need for information, but not support (U)

Illustration 9: "I am a member of Hosen (a support group for cancer patients). I get material from them and I have the opportunity to go to meetings, but I don't need to".<sup>50(p.155)</sup>

**Finding 153 (F153):** The patients said that everything was fine, but the investigators suspected the opposite (U)

Illustration 10: "I'm sad, you know, only because I can't do things I could before... but I get the situation.... I'm in worse shape and become more tired. There is nothing you can do about it I convince myself. When I see the others, there are younger people in a worse state than me. I ... I'm not depressed, I don't suffer from depression".<sup>50(p.155)</sup>

**Finding 154 (F154)** A good relationship with the urologist is also a form of support (U)

Illustration 11: "No. I'm not interested in talking with anyone about this. Visiting the doctor is good enough for me. If something is wrong he will let me know. I feel healthy and good".<sup>50(p.155)</sup>

### **Paper 13 Gannon et al. 2010<sup>24</sup>**

This qualitative study aimed to investigate how men attempt to construct and re-construct masculinity following RP for prostate cancer. Data were included from seven heterosexual men who had been treated for localized prostate cancer with RP were recruited through the urology department of a large teaching hospital in London, UK. The men were interviewed on the hospital premises, interviews were guided by a semi-structured interview schedule and analyzed using Foucauldian Discourse Analysis (FDA). Penetrative sex was constructed as central to a masculine identity, but inability to achieve this was normalized in terms of the ageing process. Stereotypically masculine qualities of emotional control and rationality were



drawn on in describing their reaction to the diagnosis and treatment of cancer but they also experienced a new-found sense of physical vulnerability.

Participants drew upon four main discourses when discussing the impact of surgical treatment on their sense of masculinity: masculine identity and sexual activity, ED as a normative experience, mental resilience, vulnerability and caution. Data were not extracted from mental resilience as this discourse related to cancer diagnosis.

*Discourse: Masculine identity and sexual activity*

**Finding 155 (F155):** A capacity for penetrative sexual activity was presented as central to masculine identity (U)

Illustration 1: "It is very important to me. As a man you see....I have been doing this thing all my life before and now all of the sudden because of the surgery.... started to come off. Whether you have a woman beside you or not as a man you must be active but you don't know when. Being a man means that sexually you must be active..... nothing so important apart from that".<sup>24(p.260)</sup>

**Finding 156 (F156):** The absence of an ability to have spontaneous erections is presented as depriving the man of his sexual purpose (U)

Illustration 2: "as a sexual partner I have no function now. At present at least. I have been prescribed Viagra but I won't use it".<sup>24(p.260)</sup>

**Finding 157 (F157):** The ability to be sexually active was a central aspect of (his) identity and when this was lost the identity became challenged to the extent that certain social situations were avoided (U)

Illustration 3: "Because I know I can't do it and I feel inadequate....I am not the same I used to be. I can't perform so I don't go to places where I may meet people....I won't go out socially. I have a lot of friends and I have been invited to go to parties and I said no....which I would have never said before, because I am not sexually active. My social life has changed because of you know.... I can't do it anymore and I won't be able to stay the night".<sup>24(p.261)</sup>

**Finding 158 (F158):** Some men drew on alternatives to penetrative sex as a way of constructing a masculine gender identity (U)

Illustration 4: "I don't feel any less of a man (because of ED) because obviously it depends on your partner. There are other ways of pleasing a woman apart from actually entering her. You can use your tongue or use your hands.... or that sort of thing. So if you are satisfying her

then your feedback would be that you are still capable of giving her pleasure and I always felt that if you can give somebody pleasure in the relationship then you know that is where you masculinity comes not from the fact ..... boom bang boom bang thank you ma'am sort of thing".<sup>24(p.261)</sup>

*Discourse: Normalizing impotence*

**Finding 159 (F159):** This man accounts for absence of erections using two strategies: in the medium term by an appeal to expert knowledge (the doctor) relating to the effects of surgery, and in the longer term to unspecified sources of information that emphasize the natural process of aging (U)

Illustration 5: "The area where I have a problem, although it is not a practical problem because I haven't got a partner, is the erectile side. I haven't had an erection since the operation at all. The documentation my doctor gave me... gave me the impression I would be lucky if I got anything much before a year after the operation. It can be.... well depends on age as much. The older you are... the erectile side as I understand it tends to drop off anyway".<sup>24(p.261)</sup>

**Finding 160 (F160):** In addition to age other factors were also called upon to explain the inability to achieve an erection (U)

Illustration 6: "I haven't had an erection for some time..... -even before I had the operation ... around 5 years...because we both work and as you get older you get more tired..... and all those other things that we do".<sup>24(p.261)</sup>

**Finding 161 (F161):** The construction of impotence as a normative experience as men age can be problematic (U)

Illustration 7: "I don't bother with it. I can't so I just don't bother. And my wife understands so there is no problem with it. I am 62 years of age I am not a teenage boy you know..... I don't worry about it and I don't let it become a problem. That is the only thing that it has daunted me since the operation. And it is not in me to take this or take that. I just don't want to take Viagra to have sex. I want to have sex naturally.... why do I have to do that?"<sup>24(p.261)</sup>

*Discourse: Vulnerability and caution*

**Finding 162 (F162):** One characteristic of hegemonic masculinity is physical dominance. For some men this construction was challenged by a new-found sense of vulnerability following their illness and treatment (U)

Illustration 8: "I used to play a lot of rugby and that sort of thing when I was younger so physical confrontation is part of that game and obviously that can sometimes spill out to life outside the

game of rugby. You know bangs and somebody bangs into you. This sort of thing...without looking for fights if you know what I mean. I suppose it is in the back of my mind I feel slightly more vulnerable than I would have done before the operation possibly... suspect that if I have an argument I would be less aggressive in the argument. Generally I don't get into arguments but you know it would be at the back of my mind that I may be more vulnerable and therefore I would be more careful in how aggressive I was. You know... I stand my ground but I just would be a little bit more wary as to how far I push that situation if I happen to defend that area".<sup>24(p.262)</sup>

**Finding 163 (F163):** Another consequence of this sense of vulnerability is increased vigilance and attention to the self (U)

Illustration 9: "Because I am alone now I try to take a good care of myself. When you are alone you should know how to take care of yourself because you are alone. If anything goes wrong, there is nobody to help so you must be on your guard all the time... more than you would like".<sup>24(p.262)</sup>

**Finding 164 (F164):** As with the mental resilience discourse the vulnerability discourse offers the opportunity for the enactment of male characteristics, such as control (U)

Illustration 10: "that caution in the physical side is governed by the psychological side. My mind tells me.... pulls me back from doing things I would normally do. Although I know I am not doing them because of physical condition.... as I said the mind and the body work together".<sup>24(p.262)</sup>

#### **Paper 14 Hartman et al. 2014<sup>48</sup>**

This exploratory study examined the experience of three gay couples managing sexual dysfunction as a result of undergoing a RP. Semi-structured interviews were conducted as part of a larger study at an urban hospital in Toronto, Ontario, Canada. Interview transcripts were analyzed using interpretative phenomenological analysis. All couples, regardless of their level of sexual functioning, highlighted the need for more extensive programming related to sexual rehabilitation.

Data were presented across three themes and eighteen subthemes and data which were relevant to the post-surgery experience of the men were extracted from within the three themes and eighteen subthemes: acknowledging change in sexual experience (libido, erectile function, sexual activity, orgasmic function), accommodating change in sexual experience (strategies: emphasizing intimacy, embracing plan B, focus on the other; barriers: side-effect

concerns, loss of naturalness, communication breakdown, failure to initiate, trial and failure, partner confounds), strategies for accommodation and accepting change in sexual experience indicators: emphasizing health, age attributions, finding a new normal; barriers to acceptance: uncertain outcomes, treatment regrets. Data was presented from the perspective of the patient and their partner. Only data related to the patient experience was extracted.

*Theme: Acknowledging change in sexual experience*

*Subtheme: Libido*

**Finding 165 (F165):** An overall decrease in sexual interest after RP was noted (U)

Illustration 1: “you have no drive, you have no interest, in fact it’s almost as if you’ve been castrated”.<sup>48(p.242)</sup>

*Subtheme: Erectile function*

**Finding 166 (F166):** The patients also described reduced erectile functioning after surgery (U)

Illustration 2: “they aren’t hard, they aren’t full, they aren’t important. They never have been important in my life; I’m not a penetrator so an erection wasn’t necessary”.<sup>48(p.242)</sup>

*Subtheme: Sexual activity*

**Finding 167 (F167):** The couples also encountered a reduced capacity for sexual activity after RP (U)

Illustration 3: “not like it was before the surgery. You know the marathons of seven hours of going at it, they’re long gone”.<sup>48(p.242)</sup>

*Subtheme: Orgasmic function*

**Finding 168 (F168):** The patients reported changes in their physiological response to sexual stimulation after RP (U)

Illustration 4: “The sensation of orgasm is less, and the pleasuring part is at the less intensity, there’s no two ways about it”.<sup>48(p.242)</sup>

*Theme: Accommodating change in sexual experience*

*Subtheme: Strategies for accommodation – Emphasizing Intimacy (Verbal and non verbal)*

**Finding 169 (F169):** Participants placed an increased importance on intimacy, specifically verbal and nonverbal communication, as a means through which they could continue to connect as a couple in light of post–RP sexual disturbances (U)

Illustration 5: “I emphasize open and honest communications, people talk to each other they’re saying what the other party wants to hear, but I really think you have to express your true

feelings so that the other person in your life really understands what you're going through".<sup>48(p.243)</sup>

*Sub-theme: Embracing Plan B – Erectile aids and open relationships*

**Finding 170 (F170):** Couples used a number of methods to achieve increased functioning and obtain sexual gratification in light of RP–related sexual dysfunction (U)

Illustration 6: Viagra, it helps for sure, because the sex that we have is somewhat similar to the sex we were having before where it's penetrative and it's me who's doing the penetration".<sup>48(p.243)</sup>

*Sub-theme: Focus on the other*

*Data not extracted from this sub theme as this is related to the partners experience*

*Theme: Barriers to accommodation*

*Sub-theme: Side-effect concerns*

*Data not extracted from this sub theme as this is related to the partners experience*

*Sub-theme: Loss of naturalness*

**Finding 171 (F171):** Pro–erectile medication and side effect–related interruptions transformed after RP sexual activity from an organic, intimate endeavor to a planned and dispassionate event (U)

Illustration 7: "If the scheduling is such, it's because of the meds, you know, you have to sort of say, okay, we're going to be doing this, so therefore you have to you know set yourself up for it".<sup>48(p.244)</sup>

*Sub-theme: Communication breakdown*

**Finding 172 (F172):** All couples inevitably experienced communication lapses that challenged their ability to successfully manage sexual dysfunction (U)

Illustration 8: "I'm not going to, you know, rehash the whole thing and make [Partner 3] more upset and it just makes me more upset".<sup>48(p.245)</sup>

*Sub-theme: Failure to initiate*

**Finding 173 (F173):** Participants acknowledged interruptions in initiation behaviors after RP (U)

Illustration 9: "An erection would be the trigger and then from there you physically make motions that we're going to have sex, [.....] that is less so now".<sup>48(p.245)</sup>

*Sub-theme: Trial and failure*

**Finding 174 (F174):** (Patient 3) failed to notice any improvement in his erections when he used pro-erectile agents such as Viagra and Cialis (U)

Illustration 10: “We both knew that I was going to take it [.....] And just nothing would happen, and it just puts me deeper and deeper [into] depression”.<sup>48(p.245)</sup>

*Sub-theme: Partner confounds*

*Data not extracted from this sub theme as this is related to the partners experience*

*Theme: Accepting change in sexual experience*

*Sub-theme: Emphasizing health*

**Finding 175 (F175):** Their primary concern after RP was their continued health and appreciation for their after RP cancer-free status caused them to reevaluate the importance of sex in their lives (U)

Illustration 11: “I just want to know I’m healthy and I continue to be healthy and that’s my main concern”.<sup>48(p.246)</sup>

*Sub-theme: Age attributions*

**Finding 176 (F176):** Attributing their sexual experience changes partly to advancing age (U)

Illustration 12: I’m a half century old and you know like seems like the normal kind of trajectory that sex is less important and I think that was happening even pre-surgery and I feel like, you know, to a certain degree that what post-surgery is part and parcel of the aging process”.<sup>48(p.246)</sup>

*Sub-theme: Finding a new normal*

*Data not extracted from this sub theme as this is related to the partners experience*

*Theme: Barriers to acceptance*

*Sub-theme: Uncertain outcomes*

**Finding 177 (F177):** They were unsure whether these functional changes (lack of erectile function) were permanent or whether they should still anticipate some improvement (U)

Illustration 13: “I guess basically what we are doing is we will just wait and see and we’ll get to see this erectile dysfunction specialist in October and then we’ll see what he says”.<sup>48(p.247)</sup>

*Sub-theme: Treatment regrets*

**Finding 178 (F178):** Treatment regrets, questioning whether the benefit of after RP cancer-free status was worth the cost of sexual dysfunction (U)

Illustration 14: “Well, to put it in to plain words, I think if I had to do this all over again, I would just roll the dice and say no to surgery. That’s just the way I feel right now”.<sup>48(p.247)</sup>

### **Paper 15 Petry et al. 2004<sup>8</sup>**

The purpose of this cross-sectional qualitative study was to explore the responses and experiences of a sample of Swiss men after RP and their intimate partners. Interviews were conducted with 10 couples between 4- 12 weeks after surgery and analyzed using a constant comparative method. Private interviews were conducted in the participants’ homes. Men focused on regaining control over their lives, urinary and erectile function.

Data were presented across two categories, data which were relevant to the post-surgery experience of the men were extracted from within one of the categories: Men - regaining control with the sub categories of: setting priorities, managing UI and dealing with sexual activity. Data were extracted from ‘Being there,’ which related to experience of their wives.

*Category: Men: regaining control*

*Sub-category: Setting priorities*

*Quotes relating to managing the managing the diagnosis were not extracted as did not relate to the objectives of the review*

**Finding 179 (F179):** After surgery, dealing with incontinence became the first priority and ED was less important (U)

Illustration 1: “Yes, it is like priorities, at the moment incontinence is my priority, if that is o.k., then I’ll deal with the other (erectile function)”.<sup>8(p.509)</sup>

*Sub-category: Managing urinary incontinence*

**Finding 180 (F180):** Incontinence strategies were not taught systematically by the healthcare providers (U)

Illustration 1: “I talked to my primary physician about it and he suggested Kegel exercise. I’m doing that now for a month....”.<sup>8(p.509)</sup>

**Finding 181 (F181):** Pads were handed to the man by nurses in most cases at discharge or after removal of the catheter, but usually they did not fit and the participants had to seek other options (U)

Illustration 2: “They gave us some, but they were much too big, so we went to get others”.<sup>8(p.509)</sup>

**Finding 182 (F182):** Being comfortable and safe including feeling dry, prepared and not fearing accidents facilitated men's sense of control and success. This success was required in order for them to resume their social activities, such as going out, walking, hiking, and work (U)

Illustration 3: "When I know I am going out, like tonight, I anticipate that I will have a little alcohol and mineral water. So I know one pad will be enough. Or when I go to the city, I take one extra with me and after two hours I go to the toilet to change it. I can predict that".<sup>8(p.509)</sup>

*Sub-category: Dealing with sexual activity*

**Finding 183 (F183):** With progress in control over urinary function the men started to face the issue of sexual function (C)

Illustration 4: "Some participants (n=4) spoke openly and spontaneously about how they thought about and dealt with erectile dysfunction. Others displaying hesitancy to talk about this issue".<sup>8(p.509)</sup>

**Finding 184 (F184):** None of the men within 4–8 weeks after surgery were able to achieve an erection. Although there was concern whether "it" (*sexual function*) will ever return, most of them thought it was too early to know for sure (U)

Illustration 5: "It is too early, I am already happy that everything else went well, that things are developing well, that is most important right now".<sup>8(p.509)</sup>

**Finding 185 (F185):** Men remained hopeful that the ability of erectile function would return naturally after several months, but fearing that it may be permanent, a burdensome uncertainty (U)

Illustration 6: "Well the impotence, I mean it is a kind of burden psychologically, I mean. That is a point where I hope that it will come back".<sup>8(p.509)</sup>

**Finding 186 (F186):** One approach to deal with ED was placing it in the context of age, health and relationship (U)

Illustration 7: "We are at a certain age, you look at it differently".<sup>8(p.509)</sup>

Illustration 8: Being comfortable and safe including feeling dry, prepared and not fearing accidents facilitated men's sense of control and success. This success was required in order for them to resume their social activities, such as going out, walking, hiking, and work".<sup>8(p.509)</sup>

Illustration 9: "We have touched, caressed, and kissed each other; that is still the same and we can develop that further".<sup>8(p.509)</sup>



**Finding 187 (F187):** Most men believed that even permanent impotence would not have an impact on their relationships with their wives (U)

Illustration 10: “I don’t think that our relationship would suffer or my wife would cheat on me because of this”.<sup>8(p.509)</sup>

### **Paper 16 Waller and Pattison 2013<sup>49</sup>**

This was a qualitative descriptive study, the stated aim of which was to understand how men interpret their experiences of regaining continence following robotic-assisted laparoscopic prostatectomy (RALP), an innovative surgical technique intended to minimize the risk of long-term postoperative UI in localized prostate cancer. Data were generated through in-depth face to face semi-structured interviews, with 7 men who had undergone RALP for early stage prostate cancer at one hospital site in the UK and who were all self-defined as continent of urine. Interviews took place between 13-16 weeks post-surgery. Data were analyzed using a framework approach founded on hermeneutic phenomenological principles. Data were extracted from all four themes: ‘what was forecast’, ‘after sales service’, ‘new plumbing’ and ‘sense of self’.

Data were presented across four themes, data which were relevant to the post-surgery experience of the men were extracted from within all of the themes: what was forecast, after sales services, new plumbing, sense of self.

*Theme: What was forecast (Men’s expectations)*

*Sub theme: Treatment decision making*

**Finding 188 (F188):** Whilst incontinence was viewed as a trade-off, these men selected RALP over open and laparoscopic techniques due to their belief that it would be temporary (U)

Illustration 1: “I’m willing to put up with incontinence knowing that I haven’t got that disease in my body ... I think that sort of evened it up...because I did lose a mate with cancer...err 2 years ago...and I actually saw the road he went down and I’m thankful that all the incontinence I went through, which was nothing [in comparison with disease progression] Thank God...”<sup>49(p.371)</sup>

*Sub theme: Pre-operative information needs*

**Finding 189 (F189):** Information-gathering was regarded as a vital part of pre-operative preparation (C)

Illustration 2: “Three participants explained that knowing what to expect pre-operatively and being shown preventative techniques of how to improve incontinence made the occurrence of

postoperative incontinence seem less worrying. This preparation enabled them to regain a sense of control and normality over their lives”.<sup>49(p.371)</sup>

**Finding 190 (F190):** Lack of recollection, inadequate or untimely pre-operative information left some participants ill prepared to deal with the consequences of surgery (U)

Illustration 3: “I think I got a lot of information before the operation started, but on this specific issue [incontinence] it was just one of the things that was mentioned in passing that it would take some time [to regain continence] but you would be ok. So that’s the kind of headline you get and then...they give you some exercises you have to do, which should accelerate everything... but you’re half listening because that’s not your primary concern at that stage....you’re not ready to hear that information...it’s the impending operation that you worry about. But when the thing comes off [catheter] you are totally out of control”.<sup>49(p.371)</sup>

**Finding 191 (F191):** Whilst some men liked receiving written pre-operative information, the majority felt overwhelmed by both its content and the volume received (U)

Illustration 4: “I found it quite forbidding.....so I adopted a bit of an ostrich sort of attitude.....head went into the sand....I didn’t want all the detail...but I was sort of sneaking glimpses of it rather than sitting comfortably in the chair and reading it from A-Z “.<sup>49(p.371)</sup>

**Finding 192 (F192):** Alternative sources of information from peers and the internet were sometimes sought (U)

Illustration 5: “People who have been through it sound more convincing and can tell you in a non-technical way, which makes it sound more normal”.<sup>49(p.372)</sup>

*Theme: After-sales service (Post-RALP care)*

*Quotes relating to after-sales service (related to men’s interpretations and descriptions of their post-RALP care) were not extracted as did not relate to the objectives of the review*

*Theme: New plumbing (Regaining urinary continence)*

*Sub-theme: Catheter removal*

**Finding 193 (F193):** Those who were not continent on removal of the catheter, incontinence came as a shock (U)

Illustration 6: “I had absolutely no control so as I was standing there you could feel it dribbling...dribbling...dribbling”.<sup>49(p.372)</sup>

**Finding 194 (F194):** For other men, incontinence signified old age (U)

Illustration 7: “A new stage of life... Its sort of that one that Shakespeare talks about...the seven ages of man. Well it’s one of the later stages...sans teeth, sans everything”.<sup>49(p.372)</sup>

*Sub-theme: Regaining urinary control*

**Finding 195 (F195):** Those who were able to discuss their incontinence experiences tended to use humor as a coping mechanism (U)

Illustration 8: “I said [to my friends] I will be hanging around Mothercare...that’s the way I cope with it...I make a joke of it myself. I didn’t make a joke about cancer or anything cos that’s nothing to joke about...The after effects with the nappies and all that...Yeah I thought right I am going to cope with it, I am going to have a laugh with them”.<sup>49(p.372)</sup>

**Finding 196 (F196):** Men felt their physical experience of regaining continence exceeded their expectations but that psychological recovery was more challenging (U)

Illustration 9: “Physically less stressful than I thought it would be...mentally, a bit more stressful than I thought it would be”.<sup>49(p.373)</sup>

*Sub-theme: Being prepared*

**Finding 197 (F197):** Fear of ongoing incontinence motivated all men to develop coping strategies to deal with incontinence. The most frequent techniques to prevent incontinence were vigilance and controlled toileting. Vigilance involved recognizing altered warning signs of a full bladder (U)

Illustration 10: “My body chose a different alarm system...the only sensation I got...instead of my bladder feeling full and needing to go [and urinate] was the end of my penis ached”.<sup>49(p.373)</sup>

**Finding 198 (F198):** Successful incontinence management meant being able to confidently deal with incontinence episodes without others noticing. This often included partners (U)

Illustration 11: “My wife knew [about incontinence] we’d discussed it so between the two of us we knew what was going on...and I was glad she didn’t make a song and a dance about it...she left me to get on with it”.<sup>49(p.373)</sup>

**Finding 199 (F199):** Some men preferred to rely on maintaining strict personal hygiene and wearing dark clothes to deal with episodes of incontinence (U)

Illustration 12: “There’s no question of me padding up for it [incontinence]...in fact it made me change my pattern of washing... I certainly started to wash thoroughly every day, all around the inside of my legs...I made sure I always wore clean underwear every day”.<sup>49(p.373)</sup>

*Theme: sense of self (Psychological impact of RALP)*

*Sub-theme: Diagnosis*

*Quotes relating to diagnosis were not extracted as did not relate to the objectives of the review*

*Sub-theme: Disclosure*

**Finding 200 (F200):** Disclosure was limited to medical facts, with men preferring to keep their emotions about cancer and incontinence private, even from friends and family (U)

Illustration 13: "This macho thing you hold inside you...you do hold [your emotions] inside you...I've had tears...I've had tears you know when I've been on me own...and I've started to think about what's happened".<sup>49(p.373)</sup>

**Finding 201 (F201):** Being dependent on friends or family also threatened their masculinity, particularly with a change in social roles and women taking on their provider/protector role (U)

Illustration 14: "Seeing your wife walking up the road with shopping and you're walking behind...it made me feel inferior...weak and...bloody awful. You know it made me feel, what have you come to where you've got to walk along [behind your wife]. What will it be next? Sticks? Arched back? Little mobile? It made me feel like that I'd got nowhere".<sup>49(p.373)</sup>

**Finding 202 (F202):** The ability to resume usual activities was viewed by men as a sign of regaining control over their lives and was a pivotal part of their psychological recovery (U)

Illustration 15: "I wanted to get back on my feet as quickly as possible, again part of the psychology because I feel staying at home and not moving around, meant that somehow there was something seriously wrong about me...as a mature man".<sup>49(p.374)</sup>

*Sub-theme: Intimacy*

**Finding 203 (F203):** The physical and emotional aspects of incontinence frequently compromised intimate personal relationships (U)

Illustration 16: "Unusually for me I went into a very heavy sleep and I didn't wake up to go to the toilet... for anyone of any age that's pretty distressing... but as an adult it's [continence] very important...we all want to be normal. It's very much a pride thing with me...I thought the worst was over...she [wife] wondered why the washing machine was churning away at the crack of dawn...I didn't even tell my wife...it's just the way I am".<sup>49(p.374)</sup>

**Finding 204 (F204):** The psychological as opposed to the physical impact of RALP on their sexuality caused the greatest concern (U)

Illustration 17: “You start thinking about sexuality and sex itself and what it means to you...that it’s not as big as maybe psychologically you make it out to be...but it does make a difference in your perception of yourself as a man...maybe not correctly...but psychologically”.<sup>49(p.374)</sup>

*Sub-theme: Physical and emotional support*

**Finding 205 (F205):** Men also gained support from online prostate cancer forums and buddying systems with a friend or family member who had previously undergone RALP (U)

Illustration 18: “[Men] are embarrassed to talk about the pads; embarrassed to talk about wetting the bed; embarrassed to talk about a lot of things...A support group would probably make me feel a bit more inferior to myself...I’d be thinking, why do I need a support group? I can handle this myself...and I have done...I think that would have made me feel worse...I could handle this myself, make me a stronger person”.<sup>49(p.374)</sup>

### **Paper 17: Wittmann et al. 2014<sup>52</sup>**

The aim of this mixed methods qualitative descriptive study conducted in the USA was to understand patients’ and partners’ perceptions on the role of the partner in couples’ sexual recovery. Data were generated through semi-structured interviews, with participants interviewed separately, and analyzed through a grounded theory iterative process. Participants were recruited from a previous study on barriers to couples’ sexual recovery after surgery for prostate cancer and included ten men, 9 men were heterosexual and married and one man was in a same sex relationship. Nine men had erectile dysfunction, one had residual urinary incontinence.

For the purpose of this systematic review data were extracted related to the patients’ perceptions only. Data were presented across three themes, data which were relevant to the post-surgery experience of the men were extracted from within two of the themes, couples’ perceptions of the overall sexual recovery of the couple at the time of the study, patients’ perception of the importance of partners’ emotional and logistical support as well as interest in sex. Data were not extracted from one theme: partners’ desire to be fully supportive of the men, but finding their role complicated and sometimes difficult to fulfill.

*Theme: Couples’ overall sexual recovery at the time of the study*

*Sub-theme: Erectile function*

**Finding 206 (F206):** Most were ambivalent about using pro-erectile aids (U)

Illustration 1: "I used the pump for the first three months as part of that process of rehab, and it's such a pain to go through all that assembly and disassembly, and it's just too much monkey motion for me".<sup>52(p.2511)</sup>

*Sub-theme: Attitudes to erections*

**Finding 207 (F207):** Patients continued to value erectile function above all, but one couple expanded their love-making repertoire (U)

Illustration 2: "We do more stroking; more exploring of the body, other parts of the body"....<sup>52(p.2511)</sup>

**Finding 208 (F208):** His partner became more sexually expressive which was very stimulating to him (U)

Illustration 3: "I think she's more, a little more wilder than she used to be".<sup>52(p.2511)</sup>

**Finding 209 (F209)** Some men coped with erection loss by conflating it with aging (U)

Illustration 4: "it's almost, you know, like an old convertible that you once had and it's also a process of getting older...so I think you have to kind of live with that and just you have to make light of it"...<sup>52(p.2511)</sup>

*Sub-theme: Menopause*

*Data not extracted as not relevant to the objectives of the review*

*Sub-theme: Changes in sexual relationships*

**Finding 210 (F210):** All men retained sexual desire but acknowledged reduced post-prostatectomy frequency of sexual activity and feelings of grief about sexual losses (U)

Illustration 5: "I am disappointed...disappointed, from the sexual side of it".<sup>52(p.2512)</sup>

**Finding 211 (F211):** Others worried about sexual performance and partner satisfaction (U)

Illustration 6: "It's the part of the fear of trying you know, what if it doesn't work...you worry about, are you satisfying your partner?"<sup>52(p.2512)</sup>

*Theme: Recovery of sexual relationship*

**Finding 212 (F212):** Four of the patients reported having recovered or recovering their sexual relationships (U)

Illustration 7: "I think we're pretty close to coming back full circle"....<sup>52(p.2512)</sup>

**Finding 213 (F213):** Nearly all patients thought that communication about sexual needs was important but undeveloped in their relationships (U)

Illustration 8: “She’ll say.... I thought about it a couple of hours ago but you were gone...and that’s why I never have sex with you...”<sup>52(p.2512)</sup>

**Finding 214 (F214):** One couple struggled with unresolved incontinence (U)

Illustration 9: “Well, she states that’s the only reason she tried twice...because of urine everywhere, all over the bed”<sup>52(p.2512)</sup>

*Theme: Patients’ perception of the importance of partners’ emotional and logistical support as well as interest in sex*

**Finding 215 (F215):** They saw partners as providing emotional support, help with frustration, sexual availability, and assistance with appointments (U)

Illustration 10: “Well, I mean I think she’s instrumental in my recovery and the rapidity in which that activity has been restored”, or “Yeah,...she noticed that I was more irritable, then I went on this sleep apnea thing.... C-PAP machine, so that seems to be helping with that, but I also went to counseling, um, (and) went on the Prozac”<sup>52(p.2512)</sup>

**Finding 216 (F216):** Patients did not expect a role for their partners in erection recovery (U)

Illustration 11: “Well, I don’t think she could help my recovery; it was something I would have to (do)”<sup>52(p.2512)</sup>

**Finding 217 (F217):** All men wished that their partners would be interested in their recovery of erectile function (U)

Illustration 12: “I just don’t see much interest, period”<sup>52(p.2512)</sup>

**Finding 218 (F218):** In the patients’ minds, the partner’s own sexual interest was a key to successful recovery of their sexual relationship (U)

Illustration 13: “Whenever we were involved, she was really interested in it”<sup>52(p.2512)</sup>

**Finding 219 (F219):** Talking about sex, including about their worries, with their partner resulted in greater emotional intimacy as well as in a better sexual relationship (U)

Illustration 14: “It’s more of a deeper...it’s more than just an orgasm, it’s...our relationship is better”<sup>52(p.2512)</sup>

**Finding 220 (F220):** Patients wished for a partner who enjoyed sex, and some wished for partners’ awareness of their needs, the ability to gently take sexual initiative (U)

Illustration 19: “Someone who could bring me out, make me better understand my fears, and also one, once you did get in the sex act, be willing to do whatever it took to really turn me on”.<sup>52(p.2512/3)</sup>

*Theme: Partners’ desire to be fully supportive of the men, but finding their role complicated and sometimes difficult to fulfill*

*Data not extracted as not relevant to the objectives of the review*

### **Paper 18 Wittmann et al. 2015<sup>53</sup>**

This mixed methods study examined a proposed bio psychosocial conceptual model of couples’ sexual recovery that included functional, psychological, and relational aspects of sexuality, surgery-related sexual losses, and grief and mourning as recovery process. Participants were recruited from the same previous study as Wittman et al.<sup>52</sup> The study sample included 20 men who chose robotic-assisted RP as primary prostate cancer treatment in a Midwestern academic cancer center in the USA and their partners, 19 heterosexual and 1 same-sex couple. Sexual function was assessed with a quantitative outcome measures and experiences of sexual recovery was explored through one-hour couple interviews which were followed by brief individual interviews pre-operatively and 3 months post-operatively. For the purpose of this systematic review only the interview data were used, data were extracted related to the patients’ perceptions post-operatively only.

Data for the post-operative experiences were related to the biopsychosocial model of sexuality and were presented across seven themes. Data which were relevant to the post-surgery experience of the men were extracted from within all of the themes: bio: functional sexual losses, bio: sexuality now, psycho: ambiguous loss and grief, social: couple’ coping (positive), social: couples’ coping (negative), social: partner’s role in sexual recovery, psycho: definitions of sexual recovery. The themes and quotes were presented within a table with no further description provided so the findings reflect this presentation

*Theme: Bio: functional losses*

#### **Finding 221 (F221): Functional losses (U)**

Illustration 1: “And plus my orgasms are diminished I can’t get an erection and I can’t have an orgasm”.<sup>53(p.498)</sup>



*Theme: Bio:*

**Finding 222 (F222):** Sexuality now (U)

Illustration 2: “There is a response but it’s not, probably not what I would say is enough for penetration”.<sup>53 (p.498)</sup>

*Theme: Psycho:*

**Finding 223 (F223):** Ambiguous loss and grief (U)

Illustration 3: “It’s a part of my being that has changed . . . this is something that is life changing”.<sup>53 (p.498)</sup>

*Theme: Social*

**Finding 224 (F224):** Couples’ coping— positive (U)

Illustration 4: “In that sense the quality is improved. And I think you focus more on your partner than you did in the past”.<sup>53 (p.498)</sup>

*Theme: Social*

**Finding 225 (F225):** Couples’ coping – negative (C)

Illustration 5: “The electric pump device I find sort of alienating it’s you know it’s mechanical and rigid and kind of aggressive”.<sup>53 (p.498)</sup>

*Theme: Social*

**Finding 226 (F226):** Partner’s role in sexual recovery (U)

Illustration 6: “She knows what I need and so she’s going to give that and she knows that I need someone to lean on, someone to be strong while I’m having my fearful time.... I would count on her to do that”.<sup>53 (p.498)</sup>

*Theme: Definition of sexual recovery*

**Finding 227 (F227):** Definition of sexual recovery (U)

Illustration 7: “I wish I could be totally confident that I’d be able not have to worry about anything, just be myself”.<sup>53 (p.498)</sup>

**Paper 20: Laursen 2017<sup>37</sup> (37)**

In this descriptive qualitative study the author utilized a phenomenological-hermeneutic frame of understanding to elucidate the effect of surgery for prostate cancer on men’s sexuality. Data were collected through interviews, only four heterosexual men were included

in the study, all recruited from a sexological counselling service, undertaken by nurses, in a hospital in Denmark.

Data were presented in four overarching themes: lack of control, sense of self, intimate relations and redefining sexuality. Findings were extracted from within each theme using both units of significance related to each theme, which the author presented as a table, and further verbatim data as presented by the study author within each theme, as units of significance were not provided for all the themes.

*Theme: Lack of control*

**Finding 228 (F228):** The men said that it was a problem that sex was no longer spontaneous (U)

Illustration 1: “We have never talked about our sex life, so it seems odd to have to ask, ‘Is it now?’ Because then I need to go and inject myself [uses medicine for erection] – no, that’s really weird”.<sup>37(p.122)</sup>

*Theme: Sense of self*

**Finding 229 (F229):** Being a man and feeling like a man is very close connected to the ability of having a penis and being able to have an erection (U)

Illustration 3: “When I looked down at my willy, and it’d disappeared – it looked as if the catheter tube was coming directly out of a hole in the stomach, and I thought, ‘What the heck – did they cut it off? I nearly panicked’”.<sup>37(p.122)</sup>

**Finding 230 (F230):** Male identity defined by sexual performance (U)

Illustration 4: “I have used my sexuality – that is, I’ve used sex to prove my manhood. With my wife, but also with other women”.<sup>37(p.122)</sup>

*Theme: Intimate relations*

**Finding 231 (F231):** The erectile dysfunction affects their identity as men which again affects their role in relation to other people (U)

Illustration 5: “I’m almost at a point where I can’t bother talking to other women. Even if my thoughts are the same, I’m not the man I used to be. I feel inferior – I’m thinking, “You couldn’t even do it if you got the chance’”.<sup>37(p.122)</sup>

**Finding 232 (F232):** Realising their inability to complete sexual intercourse was deeply frustrating to the men, and they found that it was constantly on their minds (U)

Illustration 6: “It’s always there, at the back of your head; you never forget it. My sex drive is the same, but I just can’t get it up. You know, you can’t just forget about your sex life”.<sup>37(p.123)</sup>

**Finding 233 (F233):** Some of the men worried that their erectile dysfunction would prompt their wives to look for a new partner (U)

Illustration 7: “Sometimes I worry that she is deceiving me – whether she’s longing for someone who’s got it”.<sup>37(p.123)</sup>

**Finding 234 (F234):** The erectile dysfunction made the men feel uncertain in their relation with their spouses. Because of the men’s inability to perform sexually, they held their spouses at a distance and vice versa (U)

Illustration 8: “I feel bad about giving her a hug, because, you know I can’t get it up and then, when I get around to doing it [hug her], I can sense her freezing because she knows I’m impotent, and she doesn’t want to make me feel bad – it’s rather a mess, really”.<sup>37(p.123)</sup>

**Finding 235 (F235):** The men said that in some cases they sensed that their spouses avoided hugging and touching them (U)

Illustration 9: “Without her saying anything, I sensed that she was sort of thinking ...well, what’s the point – you can’t go through with it anyway”.<sup>37(p.123)</sup>

**Finding 236 (F236):** No longer able to enjoy the intimacy and closeness that sexual intercourse gives, the couple had a sense of a big loss, which left both parties grieving (C)

Illustration 10: “I have been distressed about it. I think we are missing out on something very important in our lives and I realized my wife felt the same way”.<sup>37(p.123)</sup>

**Finding 237 (F237):** Some of the men had experienced that their situation had affected the relationship to other men (U)

Illustration 11: “I don’t talk to other men about it [his impotence]. I’m ashamed about it ...I feel inferior, not as manly”.<sup>37(p.142)</sup>

*Theme: Redefining sexuality*

**Finding 238 (F238):** Some couples were successful in replacing their former sex life with petting and closeness. Being able to talk about problems in the relationship had had a positive effect (U)

Illustration 12: “We also do a lot of touching, for example lying belly-to-back – it feels very sexual without actual intercourse but it’s very loving and reassuring. Also, you know, taking

care to give a hug during the day – that does mean a lot. I guess that’s a common experience”.<sup>37(p.124)</sup>

**Finding 239 (F239):** The men stressed that sex is not just about having sexual intercourse (U)

Illustration 12: “Sex – there’s many things to it, you might say. To me, sex is not only about sleeping together. It’s just as much about feeling masculine and being able to see oneself as a man”.<sup>37(p.124)</sup>

### **Categories based on extracted findings**

Findings identified during the extraction of data, were examined for similarity in meaning, leading to the development of categories. These categories were then aggregated into synthesized findings which could be used as a basis for recommendations for practice

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**Table 1: ConQual summary of findings table**

Systematic review title: men’s perceptions of the impact of the physical consequences of a radical prostatectomy on their quality of life: a qualitative systematic review

Population: men of all ages and all nationalities who have undergone a RP as treatment for prostate cancer

Phenomena of interest: the physical consequences of RP and its impact on quality of life and life experience as identified by the men and the psychosocial implications of the identified physical consequences of a RP as identified by the men

Context: all settings where this topic has been addressed with participants meeting the inclusion criteria. This included, but was not limited to, outpatient clinics, community clinics, men's homes or support group locations

Synthesized Finding	Type of research	Dependability	Credibility	ConQual score
Urinary incontinence is a significant problem for which men feel ill prepared	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Low
The impact of ED on men post RP	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Low
Acceptance of the side effects	Qualitative	No change	Downgrade 1 level**	Moderate
The impact of erectile dysfunction on relationships	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Low
Physical and psychosocial support are perceived to be essential for men to deal with the physical impact of RP on their quality of life	Qualitative	Downgrade 1 level*	Downgrade 1 level**	Low

\* Downgraded one level due to common dependability issue across include primary studies (the majority of studies had no statement locating the researcher and no acknowledgment of their influence on the research)

\*\* Downgraded one level due to a mix of unequivocal and credible findings

**Table 2: Critical appraisal scores for qualitative studies**

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score
Burt et al 2005 <sup>32</sup>	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9/10
Butler et al 2001 <sup>33</sup>	Y	Y	U	Y	Y	N	N	Y	N	N	5/10
de Moraes Lopes et al 2012 <sup>47</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8/10
Eliat-Tsanani et al 2013 <sup>50</sup>	Y	N	Y	Y	Y	N	N	Y	Y	Y	7/10
Gannon et al 2010 <sup>24</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y	9/10
Hartman et al 2014 <sup>48</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8/10
Hedestig et al 2005 <sup>39</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Iyigun et al 2009 <sup>25</sup>	Y	Y	Y	Y	Y	N	U	Y	Y	Y	8/10
Milne et al 2008 <sup>20</sup>	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9/10
Moore and Estey 1999 <sup>35</sup>	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	9/10
O'Shaughnessy and Laws 2009 <sup>36</sup>	Y	Y	Y	Y	Y	N	U	Y	Y	Y	8/10
Oliffe 2005 <sup>51</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Petry et al 2004 <sup>8</sup>	Y	Y	Y	Y	Y	U	U	Y	Y	Y	8/10
Waller and Pattison 2013 <sup>49</sup>	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9/10
Walsh and Hegarty 2010 <sup>19</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8/10
Wittmann et al 2014 <sup>52</sup>	Y	Y	Y	Y	Y	U	U	Y	Y	Y	8/10
Wittmann et al 2015 <sup>53</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8/10
Yu Ko et al 2010 <sup>22</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Laursen 2017 <sup>37</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10

Y=Yes, N=No, UC=Unclear

**Table 3: Meta synthesized finding 1: Urinary incontinence is a significant problem for which men feel ill prepared**

<p><b>Category 5:</b></p> <p><b>Urinary incontinence identified as a significant problem: men felt emotionally unprepared</b></p>
<p><b>Findings</b></p>
<ol style="list-style-type: none"> <li>1. Participants expressed hatred of the catheter and referred to it repeatedly as the worst part of the prostatectomy experience (U)(HD).<sup>32</sup></li> <li>2. Reactions ranged from feeling optimistic about its (incontinence) temporary nature to frustration and embarrassment for which the men described themselves as emotionally unprepared (U)(HD).<sup>32</sup></li> <li>3. Feelings of helplessness permeated the speech of the interviewees (U)(MD).<sup>47</sup></li> <li>4. More than one man described the operation itself as a non-event compared to the ongoing incontinence. The unexpected persistence of incontinence played heavily on the man's psyche (U)(MD).<sup>36</sup></li> <li>5. For another man ongoing incontinence resulted in considerable anxiety causing him to question his decision to have surgery (U)(MD).<sup>36</sup></li> <li>6. The sensory experience of catheterization was for some the single biggest postoperative issue (U)(HD).<sup>20</sup></li> <li>7. Participants generally expected to experience some incontinence but were generally shocked by the severity (U)(HD).<sup>20</sup></li> <li>8. Most participants (57.1%) felt uncomfortable with the long-term use of a urinary catheter after surgery (U)(MD).<sup>25</sup></li> <li>9. Most participants (71.4%) stated that they had felt anxious regarding going home with the urinary catheter as they were afraid of bleeding or infection (U)(MD).<sup>25</sup></li> <li>10. The volume of UI after the catheter had been removed was high for some participants (13.3%) (U)(MD).<sup>25</sup></li> <li>11. Most participants (73.3%) indicated that they did not know they would be incontinent after the surgery and that this was as second shock to them, following the initial shock of the diagnosis of cancer (U)(MD).<sup>25</sup></li> <li>12. Some participants (20%) described incontinence as the worst thing that could happen to a man and related a feeling of loss of control (U)(MD).<sup>25</sup></li> <li>13. Participants indicated that they were trying to cope using a variety of different methods and that they had not consulted physicians or nurses on the matter (U)(MD).<sup>25</sup></li> </ol>

14. The level of urinary incontinence following removal of the catheter came as a surprise to a number of men (U)(MD).<sup>19</sup>
15. Urinary incontinence emerged as a major concern (C)(MD).<sup>19</sup>
16. Men stated they were unprepared for urine by-passing the catheter, haematuria, or the signs of a urinary tract infection (U)(HD).<sup>35</sup>
17. The degree of UI immediately after catheter removal was a shock to all men (U)(HD).<sup>35</sup>
18. Men had no knowledge about incontinence pads – where to go, what to use or the amount of heavy leakage they would have for several days after catheter removal (U)(HD).<sup>35</sup>
19. All men needed reassurance that they would improve and that most men regain continence after a RP (C)(HD).<sup>35</sup>
20. After surgery, dealing with incontinence became the first priority and erectile dysfunction was less important (U)(MD).<sup>11</sup>
21. Pads were handed to the man by nurses in most cases at discharge or after removal of the catheter, but usually they did not fit and the participants had to seek other options (U)(MD)<sup>11</sup>
22. Those who were not continent on removal of the catheter, incontinence came as a shock (U)(HD).<sup>49</sup>
23. Men felt their physical experience of regaining continence exceeded their expectations but that psychological recovery was more challenging (U)(HD).<sup>49</sup>

**Category 8:**

**Urinary incontinence had a direct, negative impact on men’s feelings, social life and life experience and led to feelings of powerlessness**

**Findings**

24. Respondents stated that they maintained the desire for physical intimacy, which created even more frustration when they found themselves being unable to remain continent during intimacy or generate and maintain an erection (U)(MD).<sup>47</sup>
25. Respondents described a “leaking body” associated with loss of bladder control (U)(MD).<sup>47</sup>
26. Participant narratives also revealed feelings of powerlessness because the UI impaired multiple aspects of their lifestyle (U)(MD).<sup>47</sup>
27. Experiences with urinary incontinence and ED generated fear of disappointing not only their partner, but also family, friends and themselves (C)(MD).<sup>47</sup>
28. Participants described numerous other losses in their daily lives due to UI (C)(MD).<sup>47</sup>
29. Incontinence and ED signaled a body that had become limited and finite (U)(MD).<sup>47</sup>



30. The men in this study perceived incontinence to be a social impropriety: losing control over the retention of urine was seen as a disrespect to others who witnessed the problem (U)(MD).<sup>36</sup>
31. There was an over-riding sense that pad usage meant accepting the UI, and negatively impacted self-esteem (U)(HD).<sup>20</sup>
32. More than half of the participants (60%) stated that incontinence had significantly limited their social life (U)(MD).<sup>25</sup>
33. Some participants (13.3%) stated that they were embarrassed when family members witnessed their incontinence or thought they would be embarrassed in such a case (U)(MD).<sup>25</sup>
34. For some participants (20%) as they got used to their UI they returned to their normal social life (U)(MD).<sup>25</sup>
35. Some of the participants (26.6%) stated that incontinence prevented them from completing religious rituals (U)(MD).<sup>25</sup>
36. More than a third of the participants (35.7%) stated that they did not try sexual intercourse because of fears that their UI would bother their wives (U)(MD).<sup>25</sup>
37. Urinary incontinence often resulted in a need to wear absorbent pads on a daily basis as a precaution against urine leakage despite the pads. Described living a normal social life as something almost impossible to do (U)(HD).<sup>39</sup>
38. Some men were disappointed with the outcome of their RP (U)(HD).<sup>35</sup>
39. By 3 months post RP 20 out of 63 participants had a small amount of leakage and still required a pad 'just in case' – this is when ED became a bigger issue (C)(HD).<sup>35</sup>
40. Men had concerns about the use of protective pads (C)(MD).<sup>33</sup>
41. Men reported issues around incontinence and body image (U)(MD).<sup>33</sup>
42. Men reported being very self-conscious around wives when they had the catheter (C)(MD).<sup>33</sup>
43. Recovery from surgery as well as having an indwelling catheter restricted physical activity (C)(MD).<sup>33</sup>
44. Social activities were restricted due to a fear of UI (U)(MD).<sup>33</sup>
45. Urinary incontinence was reported by all participants to one degree or another and was described as a very difficult complication (U)(MD).<sup>50</sup>
46. The loss of urinary control and the need for pads or diapers caused a feeling of impotence, shame and discomfort (U)(MD).<sup>50</sup>
47. For other men, incontinence signified old age (U)(HD).<sup>49</sup>
48. Disclosure was limited to medical facts, with men preferring to keep their emotions about cancer and incontinence private, even from friends and family (U)(HD).<sup>49</sup>

49. The physical and emotional aspects of incontinence frequently compromised intimate personal relationships (U)(HD).<sup>49</sup>
50. One couple struggled with unresolved incontinence (U)(MD).<sup>52</sup>

**Category 11:**

**Determination to accept UI regain control and not let it impact upon life experience**

**Findings**

51. This (fear of incontinence) motivated them to do pelvic floor muscle exercises to regain continence (C)(HD).<sup>32</sup>
52. Participants noted that caffeine and beer exacerbated leaking, although some were unwilling to avoid these (C)(HD).<sup>32</sup>
53. Most refused to let incontinence slow them down (C)(HD).<sup>20</sup>
54. Although bothered by the unpredictable nature of their UI, all had adopted coping strategies to minimize impact (C)(HD).<sup>20</sup>
55. Most men avoided the use of incontinence pads (C)(HD).<sup>20</sup>
56. Consistent with their reluctance to accept UI, men were particularly motivated to perform pelvic floor muscle exercise (C)(HD).<sup>20</sup>
57. Some participants acted on physician's advice regarding UI and regained total control by 1 month after surgery (C)(MD).<sup>25</sup>
58. To maintain control over the leakage of urine (C)(HD).<sup>39</sup>
59. Being comfortable and safe including feeling dry, prepared and not fearing accidents facilitated men's sense of control and success. This success was required in order for them to resume their social activities, such as going out, walking, hiking, and work (U)(MD).<sup>11</sup>
60. Information-gathering was regarded as a vital part of pre-operative preparation (C)(HD).<sup>49</sup>
61. Those who were able to discuss their incontinence experiences tended to use humor as a coping mechanism (U)(HD).<sup>49</sup>
62. Fear of ongoing incontinence motivated all men to develop coping strategies to deal with incontinence. The most frequent techniques to prevent incontinence were vigilance and controlled toileting. Vigilance involved recognizing altered warning signs of a full bladder (U)(HD).<sup>49</sup>
63. Successful incontinence management meant being able to confidently deal with incontinence episodes without others noticing. This often included partners (U)(HD).<sup>49</sup>
64. Some men preferred to rely on maintaining strict personal hygiene and wearing dark clothes to deal with episodes of incontinence (U)(HD).<sup>49</sup>

Key: C: Credible; ED: erectile dysfunction; HD: High Dependability; MD: Moderate Dependability; RALP: robotic-assisted laparoscopic prostatectomy; RP: radical prostatectomy; UI: urinary Incontinence; U: Unequivocal

**Table 4: Meta synthesized finding 2: The impact of ED on men post RP**

<p><b>Category 2:</b>  <b>Erectile dysfunction was a major concern causing anxiety and uncertainty but there was also hope and determination that erectile function would return</b></p>
<p><b>Findings</b></p>
<ol style="list-style-type: none"> <li>1. The men said that it was a problem that sex was no longer spontaneous (U)(H).<sup>37</sup></li> <li>2. Being a man and feeling like a man is very close connected to the ability of having a penis and being able to have an erection (U)(H).<sup>37</sup></li> <li>3. Realising their inability to complete sexual intercourse was deeply frustrating to the men, and they found that it was constantly on their minds (U)(H).<sup>37</sup></li> <li>4. Although some men downplayed the absence of erectile function, all expressed concern and maintained hope that it would come back (U)(HD).<sup>32</sup></li> <li>5. Men perceived UI and erectile dysfunction following RP as a harbinger of the multiple losses associated with aging (U)(MD).<sup>47</sup></li> <li>6. In the moments, months and years following prostatectomy, the re-establishment of erectile function was a significant aspect of many participants' recoveries (U)(HD).<sup>51</sup></li> <li>7. Most participants were less explicit than Arthur in their reliance on penetrative sex, but were nonetheless committed to re-establishing potency following surgery (U)(HD).<sup>51</sup></li> <li>8. Determination to regain potency (U)(HD).<sup>51</sup></li> <li>9. For the men diagnosed earlier in life the risk of erectile dysfunction weighed heavily on their minds before and after their decision to have surgery (U)(MD).<sup>36</sup></li> <li>10. Erectile dysfunction was a common topic of discussion and the most lingering source of anxiety among participants (C)(HD).<sup>20</sup></li> <li>11. Most men acknowledged that sex was an important part of their lives and were not willing to accept their dysfunction (U)(HD).<sup>20</sup></li> <li>12. All participants except one stated that their sexual life had been negatively affected following RP (U)(MD).<sup>25</sup></li> <li>13. Most of the participants (64.3%) defined this problem as something that was difficult to accept and cope with and felt that they were too young for this negative effect on their sexual life (U)(MD).<sup>25</sup></li> <li>14. Participants also stated that they carried hope that their sexual functions would eventually return to normal (U)(MD).<sup>25</sup></li> <li>15. Losing their erectile function, radically changed their sex life, which gave them a sense of grief (C)(HD).<sup>39</sup></li> <li>16. The overriding most common concern was the whole area of ED (U)(MD).<sup>19</sup></li> </ol>

17. For some adjusting to sexual dysfunction was very difficult (U)(MD).<sup>19</sup>
18. The ability to achieve an erection was a major concern for the participants postoperatively (C)(MD).<sup>33</sup>
19. The men described feelings and sensations concerning sexuality (C)(MD).<sup>33</sup>
20. The patients also described reduced erectile functioning after surgery (U)(MD).<sup>48</sup>
21. With progress in control over urinary function the men started to face the issue of sexual function (C)(MD).<sup>11</sup>
22. None of the men within 4–8 weeks after surgery were able to achieve an erection. Although there was concern whether “it” (sexual function) will ever return, most of them thought it was too early to know for sure (U)(MD).<sup>11</sup>
23. Men remained hopeful that the ability of erectile function would return naturally after several months, but fearing that it may be permanent, a burdensome uncertainty (U)(MD).<sup>11</sup>
24. All men retained sexual desire but acknowledged reduced post-prostatectomy frequency of sexual activity and feelings of grief about sexual losses (U)(MD).<sup>52</sup>
25. Functional losses (U)(MD).<sup>53</sup>
26. Sexuality now (U)(MD).<sup>53</sup>
27. Ambiguous loss and grief (U)(MD).<sup>53</sup>
28. Definition of sexual recovery (U)(MD).<sup>53</sup>

**Category 10: Negative impact of ED on sexuality and masculinity**

**Findings**

29. Male identity defined by sexual performance (U)(H).<sup>37</sup>
30. The erectile dysfunction affects their identity as men which again affects their role in relation to other people (U)(H).<sup>37</sup>
31. Some of the men worried that their erectile dysfunction would prompt their wives to look for a new partner (U)(H).<sup>37</sup>
32. Some of the men had experienced that their situation had affected the relationship to other men (U) (H).<sup>37</sup>
33. The men stressed that sex is not just about having sexual intercourse (U)(H).<sup>37</sup>
34. Respondents reported perceptions of a deficient body because of their inability to engage in sexual relationships with their partners (C)(MD).<sup>47</sup>
35. Many emotive changes and challenges accompanied loss of potency (U)(HD).<sup>51</sup>
36. Most men identified the state of erectility of their penis as an altered body image linked to a sense of altered self (U)(MD).<sup>36</sup>
37. An inability to sustain an erection effected sexuality (U)(MD).<sup>36</sup>
38. Another man spoke more frankly about his altered body image (U)(MD).<sup>36</sup>

39. A waning ability to gain an erection and a consequently altered sex life were expressed as detracting from manliness (U)(HD).<sup>39</sup>
40. The “mutilation” was described as having changed the men’s self-esteem, bringing a sense of not being a complete man when comparing current experiences with life before treatment (U)(HD).<sup>39</sup>
41. Another of the men aligned his loss of sexual function with a loss in his sense of identity as a man (U)(MD).<sup>19</sup>
42. All participants cited a reduction in or total loss of sexual function following surgery (U)(MD).<sup>50</sup>
43. The loss of sexual function led to impaired self-esteem and a feeling of guilt because of the inability to function as a male (U)(MD).<sup>50</sup>
44. A capacity for penetrative sexual activity was presented as central to masculine identity (U)(HD).<sup>24</sup>
45. The absence of an ability to have spontaneous erections is presented as depriving the man of his sexual purpose (U)(HD).<sup>24</sup>
46. The ability to be sexually active was a central aspect of (his) identity and when this was lost the identity became challenged to the extent that certain social situations were avoided (U)(HD).<sup>24</sup>
47. One characteristic of hegemonic masculinity is physical dominance. For some men this construction was challenged by a new-found sense of vulnerability following their illness and treatment (U)(HD).<sup>24</sup>
48. As with the mental resilience discourse the vulnerability discourse offers the opportunity for the enactment of male characteristics, such as control (U)(HD).<sup>24</sup>
49. Being dependent on friends or family also threatened their masculinity, particularly with a change in social roles and women taking on their provider/protector role (U)(HD).<sup>49</sup>
50. The psychological as opposed to the physical impact of RALP on their sexuality caused the greatest concern (U)(HD).<sup>49</sup>
51. Others worried about sexual performance and partner satisfaction (U)(MD).<sup>52</sup>

**Category 19:**

**Altered body image and altered self**

**Findings**

52. As the long term consequences of surgical morbidity became a daily experience there was a re-evaluation of their decision to be treated (U)(MD).<sup>36</sup>

53. Treatment regrets, questioning whether the benefit of after RP cancer-free status was worth the cost of sexual dysfunction (U)(MD).<sup>48</sup>

Key: C: Credible; ED: erectile dysfunction; HD: High Dependability; MD: Moderate Dependability; RALP: robotic-assisted laparoscopic prostatectomy; RP: radical prostatectomy; UI: urinary Incontinence; U: Unequivocal

**Table 5: Meta synthesized finding 4: The impact of ED on relationships**

<p><b>Category 7: Erectile Dysfunction and its associated emotions generally had a negative impact on relationships</b></p>
<p><b>Findings</b></p>
<ol style="list-style-type: none"> <li>1. The erectile dysfunction made the men feel uncertain in their relation with their spouses. Because of the men's inability to perform sexually, they held their spouses at a distance and vice versa (U)(H).<sup>37</sup></li> <li>2. The men said that in some cases they sensed that their spouses avoided hugging and touching them (U)(H).<sup>37</sup></li> <li>3. No longer able to enjoy the intimacy and closeness that sexual intercourse gives, the couple had a sense of a big loss, which left both parties grieving (C)(H).<sup>37</sup></li> <li>4. Participants were open and frank about the impact altered sexual function had upon their relationship with their partners, whom they described almost universally as supportive and understanding about erectile dysfunction (U)(HD).<sup>32</sup></li> <li>5. Another man who was 2 years postoperative remarked that he was often depressed and that his erectile dysfunction had severely impacted his marriage (U)(HD).<sup>20</sup></li> <li>6. Most participants (64.3%) stated that their wives had been very understanding regarding the negative impact of ED on sex life, and this was not a major problem for their relationships (U)(MD).<sup>25</sup></li> <li>7. Participants who had been sexually active pre operatively found it very hard to adjust to ED (U)(HD).<sup>35</sup></li> <li>8. For the majority of men the overall quality of their relationships with their partners did not change, for some there was conflict and for others it has been strengthened (C)(MD).<sup>33</sup></li> <li>9. At the same time they described relationships that were affected negatively by the impaired sexual capacity (U)(MD).<sup>50</sup></li> <li>10. All couples inevitably experienced communication lapses that challenged their ability to successfully manage sexual dysfunction (U)(MD).<sup>48</sup></li> <li>11. Participants acknowledged interruptions in initiation behaviors after radical prostatectomy (U)(MD).<sup>48</sup></li> <li>12. Nearly all patients thought that communication about sexual needs was important but undeveloped in their relationships (U)(MD).<sup>52</sup></li> </ol>
<p><b>Category 9: Importance of re-establishing an altered sexual relationship that could still be enjoyable despite erectile dysfunction</b></p>
<p><b>Findings</b></p>
<ol style="list-style-type: none"> <li>13. Erectile Dysfunction is a condition that deprived them (men) of pleasures in the intimacy, but reasoned that there are also other issues in life that deserved greater attention than the grieving of such loss (U)(HD).<sup>22</sup></li> </ol>



14. Some participants described changes to specific erectile, penetrative and climactic sexual functions following prostatectomy and some components of sexual performance were maintained, whilst others were lost (U)(HD).<sup>51</sup>
15. Participants placed an increased importance on intimacy, specifically verbal and nonverbal communication, as a means through which they could continue to connect as a couple in light of post-radical prostatectomy sexual disturbances (U)(MD).<sup>48</sup>
16. Couples used a number of methods to achieve increased functioning and obtain sexual gratification in light of radical prostatectomy-related sexual dysfunction (U)(MD).<sup>48</sup>
17. Patients continued to value erectile function above all, but one couple expanded their love-making repertoire (U)(MD).<sup>52</sup>
18. His partner became more sexually expressive which was very stimulating to him (U)(MD).<sup>52</sup>
19. Four of the patients reported having recovered or recovering their sexual relationships (U)(MD).<sup>52</sup>

Key: C: Credible; ED: erectile dysfunction; HD: High Dependability; MD: Moderate Dependability; RALP: robotic-assisted laparoscopic prostatectomy; RP: radical prostatectomy; UI: urinary Incontinence; U: Unequivocal

**Table 6: Meta synthesized finding 4: The impact of ED on relationships**

<p><b>Category 7: Erectile Dysfunction and its associated emotions generally had a negative impact on relationships</b></p>
<p><b>Findings</b></p>
<ol style="list-style-type: none"> <li>1. The erectile dysfunction made the men feel uncertain in their relation with their spouses. Because of the men's inability to perform sexually, they held their spouses at a distance and vice versa (U)(H).<sup>37</sup></li> <li>2. The men said that in some cases they sensed that their spouses avoided hugging and touching them (U)(H).<sup>37</sup></li> <li>3. No longer able to enjoy the intimacy and closeness that sexual intercourse gives, the couple had a sense of a big loss, which left both parties grieving (C)(H).<sup>37</sup></li> <li>4. Participants were open and frank about the impact altered sexual function had upon their relationship with their partners, whom they described almost universally as supportive and understanding about erectile dysfunction (U)(HD).<sup>32</sup></li> <li>5. Another man who was 2 years postoperative remarked that he was often depressed and that his erectile dysfunction had severely impacted his marriage (U)(HD).<sup>20</sup></li> <li>6. Most participants (64.3%) stated that their wives had been very understanding regarding the negative impact of ED on sex life, and this was not a major problem for their relationships (U)(MD).<sup>25</sup></li> <li>7. Participants who had been sexually active pre operatively found it very hard to adjust to ED (U)(HD).<sup>35</sup></li> <li>8. For the majority of men the overall quality of their relationships with their partners did not change, for some there was conflict and for others it has been strengthened (C)(MD).<sup>33</sup></li> <li>9. At the same time they described relationships that were affected negatively by the impaired sexual capacity (U)(MD).<sup>50</sup></li> <li>10. All couples inevitably experienced communication lapses that challenged their ability to successfully manage sexual dysfunction (U)(MD).<sup>48</sup></li> <li>11. Participants acknowledged interruptions in initiation behaviors after radical prostatectomy (U)(MD).<sup>48</sup></li> <li>12. Nearly all patients thought that communication about sexual needs was important but undeveloped in their relationships (U)(MD).<sup>52</sup></li> </ol>
<p><b>Category 9: Importance of re-establishing an altered sexual relationship that could still be enjoyable despite erectile dysfunction</b></p>
<p><b>Findings</b></p>
<ol style="list-style-type: none"> <li>13. Erectile Dysfunction is a condition that deprived them (men) of pleasures in the intimacy, but reasoned that there are also other issues in life that deserved greater attention than the grieving of such loss (U)(HD).<sup>22</sup></li> </ol>

14. Some participants described changes to specific erectile, penetrative and climactic sexual functions following prostatectomy and some components of sexual performance were maintained, whilst others were lost (U)(HD).<sup>51</sup>
15. Participants placed an increased importance on intimacy, specifically verbal and nonverbal communication, as a means through which they could continue to connect as a couple in light of post-radical prostatectomy sexual disturbances (U)(MD).<sup>48</sup>
16. Couples used a number of methods to achieve increased functioning and obtain sexual gratification in light of radical prostatectomy-related sexual dysfunction (U)(MD).<sup>48</sup>
17. Patients continued to value erectile function above all, but one couple expanded their love-making repertoire (U)(MD).<sup>52</sup>
18. His partner became more sexually expressive which was very stimulating to him (U)(MD).<sup>52</sup>
19. Four of the patients reported having recovered or recovering their sexual relationships (U)(MD).<sup>52</sup>

Key: C: Credible; ED: erectile dysfunction; HD: High Dependability; MD: Moderate Dependability; RALP: robotic-assisted laparoscopic prostatectomy; RP: radical prostatectomy; UI: urinary Incontinence; U: Unequivocal

**Table 7: Meta synthesized finding 5: Physical and psychosocial support are perceived to be essential for men to deal with the physical impact of RP on their quality of life**

<p><b>Category 6: Inadequacy of pre and post-operative information</b></p>
<p><b>Findings</b></p>
<p>Some participants (49.7%) stated that they had not received information from the health care staff during this period (U)(MD).<sup>25</sup></p> <p>Participants (13.3%) who had obtained information from the health care staff felt more comfortable afterward and were satisfied (U)(MD).<sup>25</sup></p> <p>Frustration and irritation that the follow-ups had not been scheduled according to plan (U)(HD).<sup>39</sup></p> <p>Importance of being equipped with information (U)(MD).<sup>19</sup></p> <p>Men also however stressed the importance of information provision by HCP's (U)(MD).<sup>19</sup></p> <p>Only a small number of men received information about performing pelvic exercises (C)(MD).<sup>33</sup></p> <p>Most men did not understand the relationship between doing exercise and decreasing incontinence (C)(MD).<sup>33</sup></p> <p>Some men believed they had received misinformation about experiencing incontinence (C)(MD).<sup>33</sup></p> <p>Sexual functioning was discussed pre-operatively with the urologist but men had mixed feelings about attending a sexual dysfunction clinic post-operatively (C)(MD).<sup>33</sup></p> <p>Lack of recollection, inadequate or untimely pre-operative information left some participants ill prepared to deal with the consequences of surgery (U)(HD).<sup>49</sup></p> <p>Whilst some men liked receiving written preoperative information, the majority felt overwhelmed by both its content and the volume received (U)(HD).<sup>49</sup></p>
<p><b>Category 12: The need for physical and psychosocial support interventions</b></p>
<p><b>Findings</b></p>
<p>Some participants (40%) stated that they wanted to share their problems with the health care staff and wished to obtain help from them, but they were too embarrassed to talk to them (U)(MD).<sup>25</sup></p> <p>Participants described the support they received during this time from the interviewer as essential to their coping with the catheter and its effects (C)(HD).<sup>32</sup></p> <p>Participants appeared to need professional guidance to cope with the impact of ED and to pursue a wider range of therapy (C)(HD).<sup>20</sup></p> <p>Varied sources of support were sought throughout postoperative recovery periods (U)(HD).<sup>20</sup></p>

Participants (13.3%) who had obtained information from the health care staff felt more comfortable afterward and were satisfied (U)(HD).<sup>25</sup>

Striving for a sense of security when visiting the hospital for checkups (U)(HD).<sup>39</sup>

Men in this study were uniform in their view that men need some form of support (U)(MD).<sup>19</sup>

As regards support from HCP's men had varied experiences of the level of support provided (U)(MD).<sup>19</sup>

Men expressed their views as to the attributes of a HCP that would be able to provide the best support (U)(MD).<sup>19</sup>

Although this man has learned to live with ED he would have valued increased input from HCP's in relation to methods of dealing with it (U)(MD).<sup>19</sup>

There is a need for information, but not support (U)(MD).<sup>50</sup>

The patients said that everything was fine, but the investigators suspected the opposite (U)(MD).<sup>50</sup>

A good relationship with the urologist is also a form of support (U)(MD).<sup>50</sup>

Incontinence strategies were not taught systematically by the health care providers (U)(MD).<sup>11</sup>

**Category 13: Importance of physical and emotional support from partners**

**Findings**

Most of the participants kept their innermost thoughts to themselves as a self-chosen strategy for managing (U)(HD).<sup>39</sup>

Some participants (49.6%) emphasized the importance of their physical and emotional support in coping with UI (U)(MD).<sup>25</sup>

Men differed in their need for support from spouses and family (C)(MD).<sup>19</sup>

They saw partners as providing emotional support, help with frustration, sexual availability, and assistance with appointments (U)(MD).<sup>52</sup>

Two patients did not expect a role for their partners in erection recovery (U)(MD).<sup>52</sup>

All men wished that their partners would be interested in their recovery of erectile function (U)(MD).<sup>52</sup>

In the patients' minds, the partner's own sexual interest was a key to successful recovery of their sexual relationship (U)(MD).<sup>52</sup>

Talking about sex, including about their worries, with their partner resulted in greater emotional intimacy as well as in a better sexual relationship (U)(MD).<sup>52</sup>

Couples' coping— positive (U)(MD).<sup>53</sup>

Partner's role in sexual recovery (U)(MD). <sup>53</sup>
<b>Category 14:</b>
<b>Thoughts about the future were associated with anxiety, worry and a sense of vulnerability</b>
<b>Findings</b>
<p>For most men, thoughts about the future were associated with a growing worry, anxiety, or sadness (C)(HD).<sup>39</sup></p> <p>Men frequently described the cancer experience as altering their view of life (C)(MD).<sup>33</sup></p> <p>Another consequence of this sense of vulnerability is increased vigilance and attention to the self (U)(HD).<sup>24</sup></p>
<b>Category 18:</b>
<b>Ambivalence about using pro-erectile aids with their partners</b>
<b>Findings</b>
<p>All of the men were offered medication to assist sexual function, which is only one way of addressing sexuality needs, and did not necessarily address their needs (Unequivocal) (High Dependability).<sup>31</sup></p> <p>Most participants tried various aids to regain potency including the VED, Viagra and/or injections (Unequivocal) (High Dependability).<sup>41</sup></p> <p>Some participants pursued ways to re-establish erectile function but simultaneously disclaimed their reliance on penetrative sex (Unequivocal) (High Dependability).<sup>41</sup></p> <p>Many participants initially used treatments to restore their potency but eventually abandoned them due to the artificial nature, ineffectiveness and lack of spontaneity in achieving, maintaining and using their erection (Unequivocal) (High Dependability).<sup>41</sup></p> <p>Arthur tried the VED and Viagra without success, but got an erection following the injection (U)(HD).<sup>51</sup></p> <p>The lack of ability to attain a spontaneous erection was described by one man of a comedy character developed by Rolf Harris called Jake-the peg (a three legged man) (U)(MD).<sup>36</sup></p> <p>For many the use of sexual aids was a feature of their experience (U)(MD).<sup>19</sup></p> <p>Pro-erectile medication and side effect-related interruptions transformed after radical prostatectomy sexual activity from an organic, intimate endeavor to a planned and dispassionate event (U)(MD).<sup>48</sup></p> <p>(Patient 3) failed to notice any improvement in his erections when he used pro-erectile agents such as Viagra and Cialis (U)(MD).<sup>48</sup></p> <p>Most were ambivalent about using pro-erectile aids (U)(MD).<sup>52</sup></p>

Couples' coping – negative (C)(MD). <sup>53</sup>
<b>Category 19:</b> <b>Altered body image and altered self</b>
<b>Findings</b>
Overt discussions on the impact of surgery on the men's body image were readily revealed (U)(MD). <sup>36</sup>  Wellbeing for the men meant maintaining physical strength. Waning physical strength was seen as a loss and was experienced with grief (U)(HD). <sup>39</sup>
<b>Category 20:</b> <b>Peer support</b>
<b>Findings</b>
Several kept in touch with their hospital roommate, comparing recovery stories and offering support during the postoperative period (U)(HD). <sup>32</sup>  The men expressed a need to communicate with other prostate cancer patients (U)(HD). <sup>39</sup>  Peer support (in terms of support provided by other men who have been through prostate cancer and treatment themselves) emerged as the type of support perceived as most important (U)(MD). <sup>19</sup>  As regards the perceived availability of peer support however men's experiences varied significantly (U)(MD). <sup>19</sup>  Just one man felt that he did not need support from peers in the form of organized support groups feeling that his family provided all the support necessary (C)(MD). <sup>19</sup>  Alternative sources of information from peers and the internet were sometimes sought (U)(HD). <sup>49</sup>  Men also gained support from online prostate cancer forums and buddying systems with a friend or family member who had previously undergone RALP (U)(HD). <sup>49</sup>

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Figure 1: Flowchart of the search and study selection process

