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Prostatectomy for People with Prostate Cancer: A Rapid Qualitative Review

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Context and Policy Issues

Radical prostatectomy is a procedure where the entire prostate is surgically removed for the treatment of prostate cancer. Open and minimally invasive (i.e., laparoscopic and robotic) surgical techniques can be used to perform radical prostatectomy. Open surgical techniques are most widely available and involve accessing the prostate gland by making a single incision in the abdomen, typically four to five inches in length.[1] Laparoscopic surgical techniques involve making four or five small incisions through which specialized surgical instruments and a video camera are passed to access the prostate gland.[2] Some specialists have described the laparoscopic technique as challenging and requiring expertise and experience that is not available everywhere.[2] Robotic surgical techniques build off laparoscopic techniques and involve the robotic control of surgical instruments. Like laparoscopic techniques, they require expertise and experience, but also access to robotic surgical devices.

Typically, open prostatectomy is a two- to four-hour surgery with a minimum stay of around one to three days, depending on the health care institution and patient and provider factors.[1] Patients typically leave with a catheter, which must stay in for a minimum seven days, and are advised to do no major activities for around six weeks. Laparoscopic and robotic prostatectomy surgeries may take longer to perform (typically four to seven hours) and as such may require patients to be under general anesthetic for longer. However, they may reduce the lengths of stay, length of catherization, and length of time in which strenuous activity is to be avoided.[3]

The purpose of this report is to describe the experiences and perspectives of people with prostate cancer, their partners or spouses, and their health care providers on prostatectomy, with attention to differences in experiences with and perspectives on the type of surgical technique.

Research Questions

Two sets of research questions guided this review:

1. How do people with prostate cancer experience prostatectomy? What are their expectations of and perspectives on prostatectomy? What are their experiences and those of their partners or spouses relating to decision-making, surgery, recovery and long-term impact of prostatectomy on their lives?
2. How do health care providers who care for people with prostate cancer understand and perceive prostatectomy? What are their experiences and expectations of decision-making, surgery, recovery and long-term impact of prostatectomy on their patients' lives?

Key Findings

A total of 38 publications were included in this review that investigated how people with prostate cancer perceived and experienced prostatectomy. No studies investigated health care providers' views on and experiences with prostatectomy.

A diagnosis of prostate cancer raised difficult emotions for people diagnosed and their partners, who then sought information from a variety of sources. They particularly turned to those with experience with prostate cancer, but above all valued their specialists' recommendations in informing their treatment decision.

People with prostate cancer saw radical prostatectomy as a way to 'get the cancer out' quickly and effectively. They appreciated that they would receive more information on their cancer after surgery, and that it left other treatment options open.

The transition from hospital to home was difficult for many people who underwent prostatectomy as they struggled emotionally and physically, particularly with having an indwelling catheter and experiencing incontinence upon its removal.

While there was limited information on experiences of radical prostatectomy by type of surgical technique, people who had chosen laparoscopic prostatectomy as their treatment described pre-surgery that they appreciated the minimal invasiveness of the procedure. However, after surgery, some were surprised by the level of pain and discomfort they experienced post-operation. People who had undergone prostatectomy done with minimally invasive surgical techniques wished to stay in hospital longer and found themselves unprepared to be discharged to home.

People who had undergone a prostatectomy struggled with the long-term impact of urinary incontinence and erectile dysfunction, which affected their sense of self, their relationships with their partners, and their ability to engage socially. Despite this, people sought to find a new normal afterwards and tried to return to routines, and physical, social and work activities as quickly as possible.

Methods

Literature Search Methods

A limited literature search was conducted by an information specialist on key resources including MEDLINE, CINAHL, and Scopus. The search strategy was comprised of both controlled vocabulary, such as the National Library of Medicine's MeSH (Medical Subject Headings), and keywords. The main search concept was prostatectomy. Search filters were applied to limit retrieval to qualitative studies. Where possible, retrieval was limited to the human population. The search was also limited to English language documents published between January 1, 1999 and September 26, 2019.

Selection Criteria and Methods

One reviewer screened citations and selected studies. In the first level of screening, titles and abstracts were reviewed and potentially relevant articles were retrieved and assessed for inclusion. The final selection of full-text articles was based on the inclusion criteria presented in Table 1.

Table 1: Inclusion Criteria

Sample	Q1: People receiving or having received a prostatectomy for prostate cancer at any stage or severity Q2: Health care providers who provide care for people with prostate cancer undergoing a prostatectomy
Phenomenon of Interest	Prostatectomy, using a robotic, laparoscopic, or open technique, as compared to each other or other interventions
Design	Any qualitative design using qualitative data collection and analysis methods
Evaluation	Q1: From a patient's perspective, issues emerging from the literature that relate to the research questions, including but not limited to perspectives on, expectations of, and experiences with prostatectomy in general and in comparison, to each technique. As appropriate, differences will be explored by patient characteristics including, for example: • age, • severity of condition, • by different geographies (i.e., urban, rural, remote), • typically marginalized or vulnerable populations (e.g., immigrants/refugees; Indigenous Peoples; lesbian, gay, bisexual, transgender, queer, two-spirited, and other persons) Q2: From a health care provider's perspective, issues emerging from the literature that relate to the research questions, including but not limited to perspectives on, expectations of, and experiences with caring for people with prostate cancer. As appropriate, differences will be explored by provider's characteristics, including for example, geography or setting.
Research type	Primary qualitative studies, qualitative evidence syntheses

Exclusion Criteria

Articles were excluded if they did not meet the inclusion criteria outlined in Table 1, were duplicate publications reporting on the same data and same findings or were published prior to 1999.

Critical Appraisal of Individual Studies

One reviewer assessed quality in terms of the credibility, trustworthiness and transferability of the included publications. For primary qualitative publications, the assessment used the ten items from the Critical Appraisal Skills Programme (CASP) Qualitative Checklist.[4] In the absence of an established qualitative metasynthesis critical appraisal tool, qualitative systematic reviews and metasyntheses were assessed using the four components of CERQual from GRADE-CERQual.[5] These four components mapped closely onto to the principles of credibility, trustworthiness and transferability. Results of the critical appraisal were used to understand the methodological and conceptual limitations of the included publications in specific relation to this review. In particular, the critical appraisal contributed to the analysis by identifying the limits of transferability of the results of included publications to this review.

Data Analysis

A framework analysis was used to organize and analyze results of the included publications.[6] The a priori framework consisted of orienting concepts identified through project scoping, which included reading background materials on prostatectomy and the issues related people's experiences of undergoing treatment. Concepts in the initial framework related to treatment decision-making for people with prostate cancer, perspectives, expectations and views on surgery and types of surgery, and experiences of undergoing surgery and recovery.

One reviewer conducted the analysis. Included primary publications were read and re-read to identify key findings and concepts that mapped onto concepts in the initial framework, which was then modified as new concepts emerged. During the reading and re-reading of studies, memos were made, noting details and observations about the study's methodology, findings, and interpretations, and connections to other studies and concepts in the framework. Publications were imported into NVivo 11[7] and descriptive codes were applied to help sort codes and data. Using these techniques, concepts and data were re-ordered and organized into thematic categories. During the analysis, issues with transferability and the results of the critical appraisal were reflected on to aid with interpretation. Analysis continued until themes were described and supported by data from the included publications. Once the analysis was stable and key findings well-described, the included qualitative syntheses were read. The findings of these reviews were read and compared to identify any gaps or alternative interpretations for the analysis. The objective of the analysis was to describe how people with prostate cancer perceive, decide on, and experience prostatectomy, and how differences in types of surgical techniques are perceived and experienced.

Summary of Evidence

Quantity of Research Available

A total of 854 citations were identified in the literature search. Following screening of titles and abstracts, 760 citations were excluded and 94 potentially relevant reports from the electronic search were retrieved for full-text review. Of these potentially relevant articles, 56 were excluded and 33 primary research reports and five qualitative metasyntheses, for a total of 38 publications, met the inclusion criteria and were included in this report. Appendix 1 presents the PRISMA[8] flowchart of the study selection process.

Summary of Study Characteristics

Details regarding the characteristics of included publications are provided in Appendix 2 and Appendix 3, and characteristics of the participants of included primary studies are provided in Appendix 4.

Study Design and Data Collection

The five included syntheses each used a different study design: one used meta-aggregation,[9] one used qualitative meta-synthesis,[10] another used meta-study,[11] and one each used thematic analysis[12] and meta-ethnography.[13]

Of the primary research publications, 15 studies reported on in 19 publications did not specify the study design used.[14-31] Six used phenomenology as their study design,[32-37] five

studies reported on in six publications used grounded theory,[38-41] and two studies used qualitative description as their study design.[42,43]

Twenty-four studies reported on in 28 publications used interviews as the method of data collection.[14-16,18,21-41,43,44] One study used focus groups,[17] and three studies used both focus groups and interviews.[19,42,45] One study used public social media posts.[20]

Twenty-four publications reporting 23 studies collected data from participants post-prostatectomy.[15,17-19,21-24,30-39,42-45] Four publications reported data collection as occurring before treatment.[14,16,25,41] Two studies reported in five publications collected data before and after prostatectomy.[20,26-29]

Country of Origin

Two of the included syntheses were from the UK,[9,13] and one each from Canada,[10] Korea,[11] and Australia.[12]

Twelve primary research publications reporting on seven studies were from Canada.[16,18,26-29,31,33,38,39,42,46] Nine publications were from the United States,[17,21,22,25,30,35,40,41,44] three were from Australia,[14,19,45] and two were from the UK.[20,34] One each was from Finland,[15] Denmark,[32] Sweden,[37] Ireland,[43] Israel,[23] Turkey,[36] and Brazil.[24]

Patient Population and Interventions

All 33 primary research studies included people with prostate cancer. Nine publications from six studies also included people with prostate cancer and their partners.[19,22,26-29,33,47] Three studies included men who had sex with men and had undergone prostatectomy.[18,33,44]

Six studies included people who were newly diagnosed and in the process of making a treatment decision for their prostate cancer of which prostatectomy was an option.[14,16,20,21,25,41] The participants of 23 publications reporting on 19 studies had a prostatectomy using an unspecified surgical technique.[15,17,18,22-24,26-34,36,38,39,43-46] Three studies included a portion of people who had a prostatectomy using robotic or laparoscopic surgery;[14,19,21] one study included people who had laparoscopic prostatectomy only[42] and another included those who had robotic prostatectomy only.[34]

Summary of Critical Appraisal

Overall, the included publications were assessed to be of high quality. Details of the critical appraisal can be found in Appendix 4 and Appendix 5.

Two key issues affected the transferability of the included studies to the current review. First, many studies were focused on treatment decision-making or on post-surgery issues with incontinence or sexual dysfunction. This means that studies reported little on participants' experiences of surgery per se. A second and related issue was the timing of data collection. Participants who had surgery many years ago are likely to have a different perspective on their experience than they would have if interviewed closer to their surgery. As the focus of this review was on experiences of surgery, studies that included the perspectives of these participants were focused on issues of survivorship as opposed to active treatment, and thus less relevant to this review.

Summary of Findings

The experiences of people with prostate cancer and their partners

Amidst the emotional turmoil caused by a diagnosis of prostate cancer, people sought information from many sources, particularly those with experience with prostate cancer, and valued their specialists' recommendations

People with newly diagnosed prostate cancer found their normal state of affairs disrupted. The diagnosis of prostate cancer triggered feelings of anxiety and fear, with people with prostate cancer and their partners worrying about the impact of the disease and its treatment upon their future.[16,19,25,28,30] Cancer, as a disease, evoked fears of it spreading and of death,[30,34,37] with some describing feeling they had "been handed a death sentence".[30] Even when they understood their cancer to be slow-growing, people with prostate cancer sought to move quickly through the decision-making process in fear that their tumour would grow or spread.[16,20,21,23,25] As one participant described it, "[y]ou don't wait once you know you got cancer – if you can get rid of it…They wanted to give me two weeks to think about it, but I didn't want to do that."[25]

Many of the participants had more than one treatment option (e.g., external beam radiation, radiation seed therapy) and found themselves immersed in gathering information to inform themselves and their partners about treatment options.[11,16,25,28,30,35,39] People with prostate cancer sought information from multiple sources.[10,16,25,30,31,35,43] One wife whose husband had been diagnosed with prostate cancer said: "[w]e decided that knowledge is power, so we made a concerted effort to find out everything. We used the Internet, we used the Cancer Society, we used the library."[28]

People turned to the personal experiences of friends, family and others in their social network who had undergone treatment for prostate cancer for information.[10,13,20,25,30,31,41,42,48] Negative stories discouraged people from choosing those treatment options that others had undergone and had poor experiences with (either through the long-term effects of treatment or of cancer reoccurrence).[16,20,25] For example, one participant described choosing radiation therapy because: "[my brother] had his whole prostate removed fourteen years ago, and it's come back because he thought, they thought, they got it all, but obviously they missed a cell."[16] Similarly, positive experiences were cited as rationales for choosing the same option.[16,20,25]

Practical considerations around the logistics of treatment also figured into treatment decision-making. These related to the amount of time treatment would require, the disruption in their lives and their work, and the need for travel.[16,20,39] The amount of time played out as worries about finances, as either undergoing or recovering from treatment meant being potentially unable to work,[16,20,39] Additionally, in the case of treatments that were only available in other larger specialist centres, people with prostate cancer considered that they would have to travel frequently or arrange for a short-term stay.[16,20]

People with prostate cancer described how doctors' recommendations played a critical role in their treatment decision-making.[10,13,14,16,20,23,25,28,40,41,43] Sometimes this was expressed as belief or faith in their doctor, with patients deferring to their specialist's opinion.[10,14,16,20,23,25,40] In other cases, patients sought their doctors' opinion to affirm their choice as the right one.[16,28,41] As one patient put it, "[i]t all comes back to this doctor, you know, and depending on what he has to say and I'm sure he'll have his point of view on what I should do."[16] Once their decisions were made, people tended not to seek second

options or discuss treatment options with another physician.[25,41]

For many, partners were an important source of support, but people with prostate cancer varied in the ways they relied on or engaged their partners, particularly in decision-making.[13,14,16,19,40] Some relied heavily on their partners' opinions on treatment, while others made the decision themselves and received support in terms of emotional presence. One participant described: "I've discussed it with my wife and my daughter and they both feel that I should have the prostate out, but . . . at the end of the day, it's my final decision".[14] Not everyone sought support from family and friends, and some participants chose to keep the diagnosis to themselves.[16] At the same time, partners of those diagnosed found themselves reaching to others for emotional support.[13,16]

In some accounts of their treatment decision-making, people with prostate cancer and their partners appeared to minimize or downplay worries about side effects such as erectile dysfunction and urinary incontinence.[11,14,16,25,34,37,39,41] Instead, the fear of cancer and its ability to spread and the risk of death drove decision-making. As one participant described it, "[side effects] are not important compared to dying. So you know, the rest of it is immaterial. If I have to wear Depends [incontinence underwear] the rest of my life, then so be it."[25]

Those who chose radical prostatectomy valued the ability to 'get the cancer out' quickly and saw it as a definitive therapy that gave them more information on their cancer and left other treatment options open

When choosing a treatment option, people with prostate cancer expressed divergent and strong views about surgery. Those who chose surgery perceived it as a definitive and concrete treatment that could be undergone quickly. The idea of "get it out, get it over, get on with it" was repeatedly expressed in a number of ways by those who chose it, drawing attention to the ways in which it was seen as quick and efficient way of addressing their cancer and enabling them to move on.[14,16,20,21,23,25,31,40,41]

The perception of prostatectomy as a concrete and definitive treatment was founded in two interrelated ideas. First, the successful removal of their tumour was seen as eliminating their cancer,[14,16,20,21,23,25,39,41,43] as expressed by one participant: "[m]y thinking at the time was that basically, if I had the surgery it's out, it's gone and I do not have to worry about it coming back at least in that area or that type of cancer."[16] Second, people found reassurance in the additional information about their cancer that they could receive after surgery, including reducing worries about cancer spread.[16,20,25,39] "If you get the surgery, then they will examine the prostate when it is out and they will know where the cancer was and that there was zero chance of it metastasizing or that there was some,, but you'll have some more data."[25] If these results came back that their cancer had not spread, people who had undergone prostatectomy felt reassured that their cancer was cured.[16,20,25] If not, having a prostatectomy left other treatment options open, whereas choosing first-line radiation therapy foreclosed the possibility of having prostate surgery later.[16,20,25,28,31,39]

People expected that after prostatectomy, they would be able to "get on with it" and that they would be able to have their lives return to(ward) normal.[14,16,20,25] As one participant noted, "I want to get this over with and get back to working and go on with my life. This [prostatectomy] seems to me the quickest and best situation to do that."[16] However, the ability of surgery to be a way to get back to normal was balanced with the disruption it would entail. One person who was still working described how, "with surgery, I was

expected to rest for about three months before I could fully get back to work. That's too long to be without income."[39] For others, practical considerations and ready access to prostatectomy compared to other forms of treatment (which would have required additional travel) played into the ability to return to normal.[16,41]

Those who declined surgery and chose other treatment options described viewing surgery as "drastic" and "extreme" and instead saw other options as less invasive.[14,16,25,28] Surgery evoked graphic descriptions, such as those from one person who chose radiation therapy:

> … the actual surgery… they open you up and go in and cut away the prostate and the testicle or whatever and hopefully they get it all and put you back on the table. They actually set your guts out on the table as I understand it… You can get screwed up pretty bad with any surgery where you go under a general anesthesia."[25]

It also seemed that patients noted that they were concerned about erectile function and urinary continence when expressing an aversion to surgery,[16,25] drawing attention to the personalized nature of balancing benefits and risks in treatment decision-making.

The transition from hospital to home was difficult for many people who underwent prostatectomy as they struggled emotionally and physically, particularly with having an indwelling catheter and the experience of being incontinent

Those did not know of the recovery process or what to expect post-surgery found themselves ill-prepared upon retuning home.[11,12,28,29,36] People who underwent laparoscopic or robotic radical prostatectomy did not want to be discharged early, as they described feeling emotionally unprepared to return home.[34,42]

Some expressed that the reason for early discharge was solely due to financial concerns, not patient well-being:

> "[t]his is all about money. This has nothing to do with treatment. This is all about how long they're going to keep you in hospital. You're all plugged up; you're getting spasms. You're going to end up in the hospital and it's going to cost them probably twice as much.[42]

Post-surgery, people struggled with getting out of bed, walking, abdominal gas, and their first bowel movement.[34,42] One person described how he became impacted: "I thought, well, it's a little bit of pain, you've got to suck it up. And at the end, I couldn't even get off the floor... they shouldn't have let you out of the hospital until you have had a bowel movement."[42]

Others were surprised by the degree of pain they experienced after undergoing laparoscopic prostatectomy: '[i]t hurt more than I thought it would. You know, I thought, oh he'll just take it out. It didn't occur to me there'd be, you know, any particular discomfort."[42] Back home, people who had a prostatectomy and their partners found themselves unsure and unsettled when faced with side effects or unexpected experiences.

A key challenge of the post-surgery recovery period was the experience of leaving hospital with an indwelling urinary catheter.[9,12,31,34-36,42,43] For some, having the catheter in for the days and weeks after surgery was the worst part of their prostatectomy, as put by one participant: ''They have to find a better method. This whole thing would have been a piece of cake without the catheter.''[42] When catheterized, people found themselves stressed about and embarrassed by urinary leakage, feared pulling it out, and were challenged by

bladders spasms they found difficult to control.[35,36] Others worried about infection and pain and struggled to care for it at home.

The removal of the catheter was a significant experience for many people post-surgery as they were not prepared for the experience of being incontinent immediately upon its removal.[9,12,31,35,36,42,43] People described not having incontinence pads with them at their doctors appointment, and the embarrassment that came with wetting themselves.[35,36] As people struggled to cope physically with their incontinence, they also struggled emotionally with embarrassment, shock, and feelings of depression.[11,35,36] In some cases, this led to irritability post-surgery in people who were recovering, which partners had to navigate.[29] In addition to helping their partners who had surgery recovery and tend to their physical needs, spouses played an important role by offering emotional support to their partners, while at the same time continuing to have ensure their own emotional support needs were met.[29]

People who had undergone a prostatectomy struggled with the long-term impact of urinary incontinence and erectile dysfunction which affected their sense of self, their relationships, and their ability to engage socially

Urinary incontinence disrupted the emotional, physical, and social lives of the people who experienced after their prostatectomy.[9,11,12,23,24,34,36,37,42,45] For some, experience of having no or minimal bladder control invaded all aspects of their lives and was devastating.[23,24,34,36,37,42,45] For men who had undergone the procedure, they confronted societal ideals of what it meant to be a man,[45] and described feeling like a child.[37]

One participant described his experience as such: “[i]t 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.”[36] Often, in response to fear, embarrassment and shame, they found themselves retreating from social activities, sports, clubs, and religious activities:[23,24,34,36] “[T]he hard part is that you feel the leaking, you cannot go out. Depending on the place, I don’t even go because you have to change the diaper all the time.”[24] Using incontinence pads felt to some as resigning to their lack of bladder control, and was not seen as a positive solution: ‘‘[p]eople 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.’’[34,42] Some developed other coping strategies, including using homemade penile clamps, developing routines around the timing of drinking and using the bathroom, and wearing dark pants.[34,36,42] Oftentimes urinary incontinence and sexual dysfunction went hand in hand, as people found that sexual arousal decreased their level of bladder control, and as such, incontinence became an obstacle for engaging in sexual activity.[18,24,44]

Prior to and immediately after surgery, people who chose prostatectomy did not focus on concerns with the ability to be sexually active or erectile function. It was only as they recovered, that these perspectives came to the fore. People who suffered from erectile dysfunction (either complete or partial) found themselves navigating their insecurities, sense of self, their ability to engage in sexual activities and expression, and their relationships.[9,11,12,18,31-33,44,45]

Erectile dysfunction was felt as a challenge to men’s masculinity, to their sense of self, and they described feeling that they were ‘less of a man’.[32,45] As one participant described it: “[s]ex – 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."[32] Similarly, one asked: "[w]hen do I get to be a husband again?"[26]

The sense of being unable to perform, for those who were married or in a long-term relationship, added stress to their relations and raised insecurities.[9,11,12,17,31,32] Partners often offered reassurance that sex did not matter so much as having their partner alive, put by one wife as: "we discussed it and both came to the conclusion that if we never have sex again, it's probably better than being dead".[28] The length of couples' relationships was consistently referred to as a factor in dealing with the changes:[15,37,41 9,11-13] One wife said, "I told him we'd be alright. I told him 'honey, we've been married 47 years… you're here, that's what matters."[41] However, partners walked an uneasy line between being accepting and being afraid of appearing disinterested or offending.

With erectile dysfunction, sex was no longer being impromptu or spontaneous, and instead became a space loaded with expectations, emotions, and erectile aids (e.g., vacuum pumps, injections, pills).[18,32,33,43-45] While some couples found success with these aids, many felt otherwise: "[w]ith the pump, you sort of felt like crying when it was over. You felt, I don't know, that maybe it's not the right way of doing it. It didn't have any normality to it."[26]

Exploring sexuality beyond intercourse or using aids was easier for those couples that had done so previously in their relationship.[26] For some, this opened up new space: "[y]ou're able to experiment. If you were ashamed or you couldn't talk about it with your partner, then I think you would back off. But we talk about it and joke about it and treat it lightly."[26] Similarly, those who were able to talk about it as a couple described finding ways of being close and intimate.[19,22,32] However, for many, talking about erectile dysfunction and sex was shrouded in shame and discomfort.[18,33]

Men who had sex with men faced unique challenges relating to erectile function. The lack of ejaculate[18,44] and inability to give or receive anal sex post-surgery were difficult changes. One participant describe now he could no longer participate in insertive anal sex: "I was a top. I am a top, I guess. I have been very sexually active my entire life, and it was very important to me. Losing it was just devastating."[44] Throughout their recovery, men who had sex with men were provided information that was geared for heterosexuals: "My GP knew that I was gay. I'm not sure if that information filtered through to the urologist. I don't remember specifically telling him, but I may have. But there was never any discussion about homosexual sex, that's for sure."[18]

Some people expressed regret about their decision to have a prostatectomy, either because they felt they had not been informed or that they were not prepared to experience erectile dysfunction.[26,33,37] One patient recounted: "I'm not if they had said, 'Oh, and by the way, if you decide to have the operation now, there's a high probability that your sex life is going down the drain.' I'm not sure what decision I would have made."[26] Decision regret was also expressed by those who experienced long-term urinary incontinence: "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!"[45]

Others seemed to feel that the loss of erectile function was natural and linked to both partners aging.[9,15,22,24,31,33,34 ,36,37] One participant said: "…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".[23,41] Similarly, a reduction in their sex life was seen as natural as women experienced menopause and reduced desire for sex.[22]

Prostatectomy resulted in shortened penile length for some, however in general, this did not appear to be experienced as disruptive to one's sense of self as compared to erectile dysfunction and urinary incontinence.[32,44]

People who underwent prostatectomy sought to find a new normal afterwards and tried to return to routines, and physical, social and work activities as quickly as possible

As many people chose to undergo prostatectomy because they saw it as offering a quick and effective way to have live return to normal, and post-surgery, many worked to see that expectation through.[11,17,19,29,30,34,42]

In the recovery period immediately following surgery, people pushed themselves to get back to normal to their usual routines, attending social events and outings, exercising, and returning to work.[28,29] A sense of masculinity was associated with such return to normalcy, as people sought to be productive, and saw their worth as tied up in male roles as provider.[38]

As they resumed living their lives and became preoccupied with concerns about work, family responsibilities and attending to crises in the lives of their families and friends, they had to find room for the lingering effects of cancer and surgery.[19,28,43] In general, people who had prostatectomy limited sharing the information in part to keep life 'normal'.[27,28,43] Similarly, responses to questions about the impact of prostate cancer on their lives many times appeared to downplay the impact of the disease and surgery: "I don't like to look at it as a big deal. It's just something that happens in your life."[28] However, others became passionate about sharing their experiences with prostate cancer and its treatment and educating others.[27,42]

Limitations

No studies from the perspectives of health care providers were found. As such, this review suffers from the limitation that it does not provide evidence on health care providers' views of prostatectomy. Few of the included studies reported which type of surgical technique participants had undergone, and only two studies reported specifically on the experiences of a specific surgical technique. As a result, this review provides limited information about the experiences and perspectives of people undergoing prostatectomy by type of surgical technique.

Conclusions and Implications for Decision or Policy Making

This review used a framework analysis to synthesize the results of 38 included publications and described how people with prostate cancer decide to undergo radical prostatectomy and their experiences post-surgery. Upon diagnosis, people with prostate cancer and their partners sought information from a variety of sources to understand their treatment options. The experiences of family, friends, and people in their social network who had prostate cancer were particularly important as a source of information, but above all, people with prostate cancer relied on the opinions of their specialists to confirm or decide on their treatment. Prostatectomy was viewed as an expedient and thorough treatment for prostate cancer, with successful tumor removal often viewed as indicating a cure. People with

prostate cancer and their partners focused on the importance of getting the cancer out and on extending life than on side effects, which many who chose prostatectomy appeared to minimize in their decision-making. In the immediate post-surgery period, people who had undergone prostatectomy struggled with the indwelling catheter and urinary incontinence. In the long-term, changes in erectile function and urinary incontinence left people who had had prostatectomy struggling with their masculinity, sense of self and ability to be social.

No information was available on health care providers' perspectives on or experiences with prostatectomy for prostate cancer.

This review provides limited information on experiences of radical prostatectomy by type of surgical technique. In the one study on laparoscopic prostatectomy, people who had chosen laparoscopic prostatectomy as their treatment described pre-surgery that they appreciated the minimal invasiveness of the procedure. However, after surgery, some were surprised by the level of pain and discomfort they experienced post-operation. Shorter hospital stays were not universally viewed as a benefit by patients who had just undergone surgery. This suggests that it is possible that those who choose surgery may not have a strong preference about type of surgical procedures. Those who declined surgery as an option because of its invasiveness may be more open to minimally invasive procedures.

Given that people expect prostatectomy to be effective at removing cancer, differences in clinical effectiveness by surgical technique would likely influence people's treatment decision-making. Post-surgery, having an indwelling catheter, experiencing urinary incontinence, and having erectile dysfunction were all described as having an impact on people's emotional, psychological and social well-being. Surgical techniques that minimize the length of having an indwelling catheter, and the risk of urinary incontinence and erectile dysfunction, are likely to be appreciated.

Practical considerations such as the need to travel for treatment figured into treatment decisions. People with prostate cancer may vary in their ability and desire to travel to larger specialist centres for treatment as it may disrupt their ability to work and stay close to their partners and families. The findings of this review identified several opportunities to ensure appropriate patient education for treatment decision-making and recovery. The substantial impact of urinary incontinence and erectile dysfunction on people who undergo prostatectomy and their patterns and the potential for decision regret highlight the need to ensure consistent information is given about different treatment options. Similarly, patient education about the post-surgery recovery period may help to support the transition from hospital to home and reduce worries about side effects. Information about erectile dysfunction should be appropriate for men who have sex with men as well as men who have sex for women.

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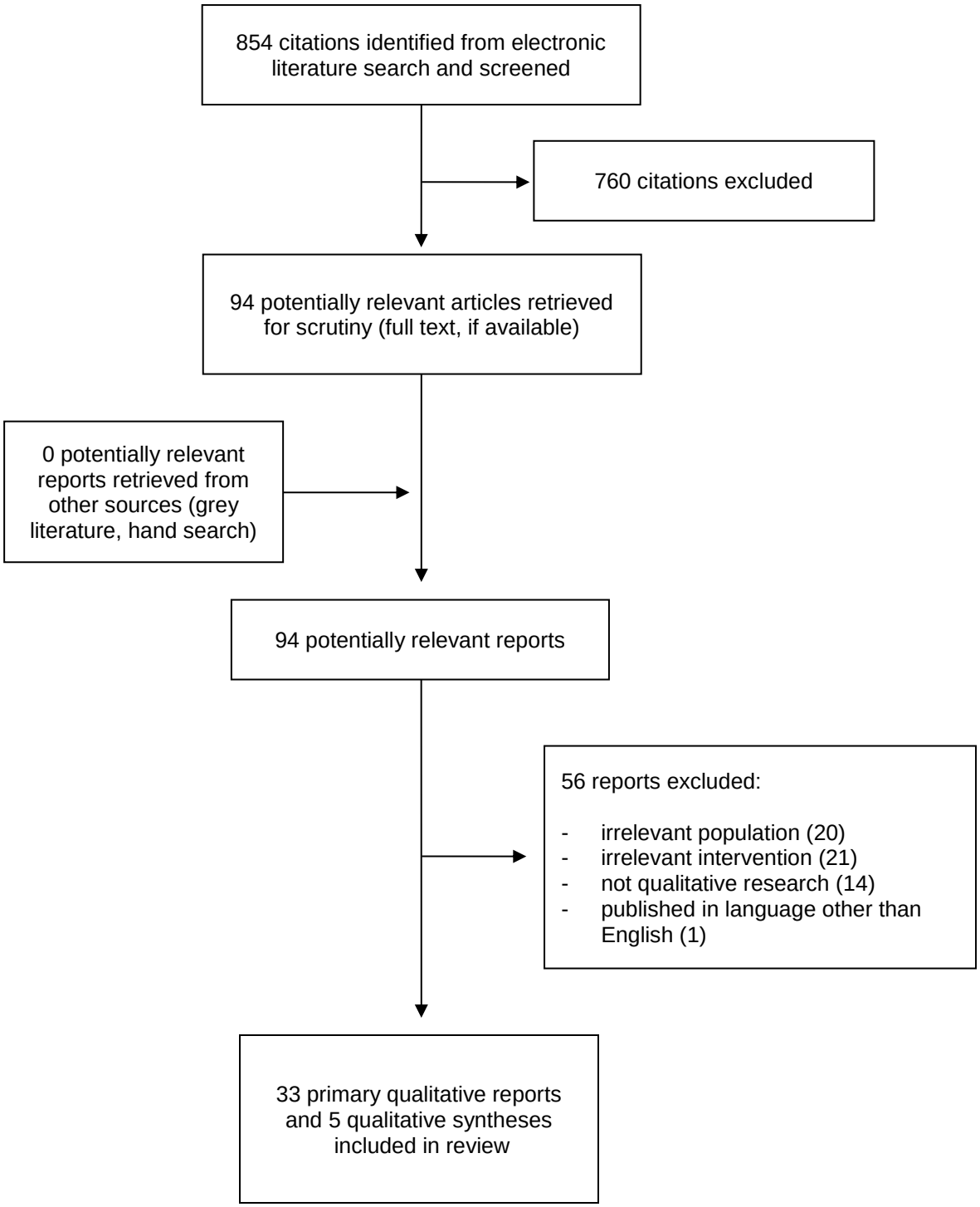
Appendix 1: Selection of Included Studies



Appendix 2: Characteristics of Included Publications

Table 2: Characteristics of Included Studies

First Author, Publication Year, Country	Study Design	Study Objectives	Sample Size	Inclusion Criteria	Data Collection
Smith, 2019, Australia[14]	NS	To explore men's understanding of and preferences for robotic prostatectomy versus radiotherapy as treatment options for their prostate cancer	25 patients	Patients with newly diagnosed localized prostate cancer whose treatment options were robotic prostatectomy or radiotherapy	Semi-structured interviews before and/or after treatment decision-making
Yu Ko, 2019, Canada[38,39]	Grounded theory	To understand the relationship between work, prostate cancer screening and the decision to undergo prostatectomy	24 patients	Patients who were employed and who had radical prostatectomy for prostate cancer in the last 36 months	In-depth interviews within 36 months of surgery
Pietiä, 2018, Finland[15]	NS	To describe the narrative practices men use to make sense of and articulate their liminal state after having radical prostate cancer treatment	22 patients	Patients attending a 12-month follow-up visit after undergoing prostatectomy for prostate cancer	In-depth interviews 12 months after radical prostatectomy
Thera, 2018, Canada[16]	NS	To understand how patients with prostate cancer experience shared decision-making and nurse navigators	11 patients	Patients with newly diagnosed localized prostate cancer who had been seen by a nurse navigator and were in the process of making treatment decisions	Semi-structured interviews prior to treatment
Imm, 2017, USA[17]	NS	To understand the experiences of African American men's prostate cancer survivorship	12 patients	Patients who underwent radical prostatectomy for prostate cancer	Focus groups after treatment

First Author, Publication Year, Country	Study Design	Study Objectives	Sample Size	Inclusion Criteria	Data Collection
Schantz Laursen, 2017, Denmark[32]	Phenomenology	To explore the impact of prostatectomy for prostate cancer on men's sexuality	4 patients	Patients attending a sexology clinic who were experiencing sexual dysfunction post-prostatectomy and were in a stable heterosexual relationship	In-depth interviews after surgery
Rosser, 2016, USA[44]	Grounded theory	To understand the effects of radical prostatectomy on sexual function and behavior of gay and bisexual men	19 people attending a prostate cancer support group	People attending a support group for gay and bisexual survivors of prostate cancer	In-depth interviews 1-5 years post-surgery
Lee, 2015, Canada[18]	NS	To understand the sexual concerns of men who have sex with men after being treated for prostate cancer	16 people attending a prostate cancer support group	Men who have sex with men who were treated for non-metastatic prostate and were less than 75 years of age	Semi-structured interviews 2-18 years after treatment
O'Shaughnessy, 2015, Australia[19]	NS	To explore the psychological, emotional and spiritual burden of prostate cancer on men and their partners	30 participants (21 men, 9 women)	People who had undergone a treatment for prostate cancer and were in a long-term relationship	In-depth interviews with couples and focus groups after treatment
Hartman, 2014, Canada[33]	Phenomenology	To explore gay couples' experiences with sexual dysfunction after radical prostatectomy	3 couples	People who had undergone a radical prostatectomy, reported sexual dysfunction and had an intimate partner who consented to participate	Semi-structured interviews at 3-6 months, 12-15 month, and 21-24 months after surgery
Sillence, 2014, UK[20]	NS	To explore the decision-making process and treatment choices patients	137 online messages	Online posts about patients with prostate cancers treatment	Sampling of threads and posts of patients that related to

First Author, Publication Year, Country	Study Design	Study Objectives	Sample Size	Inclusion Criteria	Data Collection
		are making and disclosing to peers in online forums		decision-making made on public online forums	treatment decision-making
Volk, 2014, USA[21]	NS	To explore patients' understandings of active surveillance and treatment decisions	30 patients	Patients with localized prostate cancer who had 6-18 month prior chosen either treatment or active surveillance	In-depth telephone interviews 6-18 months post-treatment decision
Wittmann, 2014, USA[22]	NS	To explore the role of partners in post-prostatectomy sexual recovery	10 people with prostate cancer and 9 partners	Patients with localized prostate cancer who had chosen prostatectomy and whose partners consented to participate	In-depth interviews of individuals 6-24 months after surgery
Eilat-Tsanan, 2013, Israel[23]	NS	To describe the outcomes of prostatectomy from patients' perspectives and how they coped with them	22 patients	Patients with localized prostate cancer who had underwent radical prostatectomy in the preceding 12 months	In-depth interviews 12 months after surgery
Waller, 2013, UK[34]	Phenomenology	To understand how men interpret their experiences of regaining continence following robotic-assisted laparoscopic prostatectomy	7 patients	Patients with early-stage prostate cancer who underwent robotic-assisted laparoscopic prostatectomy and self-described as incontinent	In-depth interviews three months after surgery
de Moraes Lopes, 2012, Brazil[24]	NS	To describe the impact of erectile dysfunction and urinary incontinence on men following radical proctectomy	10 patients	Patients who had undergone radical prostatectomy for prostate cancer	Semi-structured interviews post-surgery (between 18 months and 25 years)
Krumwiede, 2012, USA[35]	Phenomenology	To understand the lived experience or	10 patients	NS	In-depth interviews with patients "a few

First Author, Publication Year, Country	Study Design	Study Objectives	Sample Size	Inclusion Criteria	Data Collection
		people with prostate cancer			months" to five years after surgery
Iyigun, 2011, Turkey[36]	Phenomenology	To define the experiences and perceptions of Turkish men who have undergone RP and to explore the views and suggestions of men who had undergone RP as to their discharge training content	15 patients	Patients who had undergone radical prostatectomy for prostate cancer more than three months ago	In-depth interviews around 3 months after surgery
Walsh, 2010, Ireland[43]	Qualitative descriptive	To describe the experiences of men who had undergone radical prostatectomy	8 people attending a prostate cancer support group	People attending a support group for prostate cancer who had undergone radical prostatectomy for localized prostate cancer	In-depth interviews 18 months-15 years post-surgery
Yu Ko, 2010, Canada[46]	Grounded theory	To explore patients' perceptions and responses to penile shortening post-radical prostatectomy	11 patients	Patients who perceived penile length loss at least one year after undergoing radical prostatectomy	In-depth interviews one year after surgery
O'Shaughnessy, 2009, Australia[45]	NS	To understand the long-term experiences of men who had undergone prostatectomy	11 patients	People who had a prostatectomy more than six months prior	In-depth interviews and focus group after surgery
Milne, 2008, Canada[42]	Qualitative descriptive	To understand the experiences of men after laparoscopic radical prostatectomy and how well their pre- and post-operative needs were being met	10 patients	Participants enrolled in a randomized control trial who underwent laparoscopic radical prostatectomy for prostate cancer in the previous three years	In-depth interview and focus groups after surgery
Denberg, 2006, US[25]	NS	To understand the factors that	20 patients	Patients with newly diagnosed	In-depth interviews

First Author, Publication Year, Country	Study Design	Study Objectives	Sample Size	Inclusion Criteria	Data Collection
		influence patients' treatment decision-making and treatment preferences		localized prostate cancer who had not yet made their treatment decision	within a week of patients' first treatment discussion
Walton, 2004, USA[40]	Grounded theory	To discover what spirituality means for men with prostate cancer and how it influences their treatment	11 patients	Patients who were admitted to hospital post-radical prostatectomy	In-depth interviews several days after radical prostatectomy
Gray, 2002, Canada[26-28] Philips, 2000[29]	NS	To describe men's experiences of disclosing their diagnosis, and of their treatment, and its' impact on their spouses	34 couples	Patients with prostate cancer who were married or cohabiting with a partner and who had chosen prostatectomy	In-depth interviews with couples and separately at three points in time: pre-surgery, 8-10 weeks post-surgery, and 11-13 months post-surgery
Maliski, 2002, USA[30]	NS	To understand couples' experiences of diagnosis of prostate cancer to post-prostatectomy	20 couples	People who had prostatectomy for prostate cancer more than three months ago and their partners	In-depth interviews with couples as individuals between 3-10 months after prostatectomy
Berterö 2001, Sweden[37]	Phenomenology	To describe the impact of prostate cancer and its treatment on patients	10 patients	Patients who had been treated for prostate more than 18 months prior	In-depth interviews more than 18 months after surgery
Butler, 2001, Canada[31]	NS	To explore the meaning of urinary incontinence and impotence in men with prostate cancer	21 patients	Patients who had been treated with radical prostatectomy	Semi-structure interviews after treatment
O'Rourke,1999, USA[41]	Grounded theory	To understand the treatment decision-making process amongst couples	18 couples (36 individuals)	Patients with newly diagnosed prostate cancer	In-depth interviews with couples together and separately prior to treatment decision-making

NS = not specified

Appendix 3: Characteristics of Included Qualitative Syntheses

Table 3: Characteristics of Included Qualitative Syntheses

Author, Year, Country	Review Objective	Synthesis Method	Inclusion Criteria	Number of Included Studies
Carrier, 2018, UK[9]	To identify men's perceptions of the impact of the physical consequences of a radical prostatectomy on their quality of life	Systematic review and meta-aggregation	• English-language full-text publications published by November 2017 • Primary qualitative research on men who had undergone prostatectomy	19 studies
Kandasamy, 2017, Canada[10]	To describe how patients diagnosed with prostate cancer use information in their treatment decision-making	Systematic review and integrative qualitative meta-synthesis	• English-language full-text publications Studies published between January 1, 2010, and June 23, 2016 (no theses) • Primary qualitative empirical research (using any descriptive or interpretive qualitative methodology, including the qualitative component of mixed-methods studies) Studies involving adult men (> 18 years of age) with experience with prostate cancer • Research conducted in Canada, the United States, Australia, New Zealand, the United Kingdom (i.e., comparable to the Ontario context) • Studies addressing men's experiences of treatment decision-making	29 studies
Kong, 2017, Korea[11]	To synthesize existing qualitative studies that explored men's experiences after prostatectomy	Meta-study	• Published primary research report • Targeted men with prostate cancer	15 studies

Author, Year, Country	Review Objective	Synthesis Method	Inclusion Criteria	Number of Included Studies
			• Focused on men's experiences after prostatectomy • Used appropriate qualitative research methods or mixed methods • Reported qualitative research data • Stated explicit study aims • Publication type: journal • Published in English • Published from earliest year to 2016	
Xiaojing, 2012, Australia[12]	To explore men's experiences of urinary incontinence post-prostatectomy	Thematic analysis	• Qualitative research, full text available, published from 1999 to current • Men who had prostatectomy including radical prostatectomy, laparoscopic radical prostatectomy or unidentified method of prostatectomy • Men's experience, perception or perspectives about urinary incontinence postprostatectomy	12 studies
Schumm, 2012, UK[13]	To describe the influences on couples' treatment decision-making for prostate cancer	Meta-ethnography	• Published studies that used qualitative methods and contained data that explored any aspect of prostate cancer treatment decision-making from the perspective of couples (patient and their partner)	14 studies

+ = yes; - = no

Appendix 4: Characteristics of Study Participants

Table 4: Characteristics of Study Participants

First Author, Publication Year, Country	Sample Size	Age Range in Years	Details on Condition; Treatment Received
Smith, 2019, Australia[14]	24 patients	52-76	Newly diagnosed localized prostate cancer; 68% chose robotic prostatectomy
Yu Ko, 2018, 2019 Canada[38,39]*	24 patients	44-75	Prostate cancer; radical prostatectomy
Pietilä, 2018, Finland[15]	22 patients	56–71	Prostate cancer; radical prostatectomy
Thera, 2018, Canada[16]	11 patients	51-71	Newly diagnosed localized prostate cancer; no treatment decision yet made
Imm, 2017, USA[17]	12 patients	49-79 (at diagnosis)	Prostate cancer; radical prostatectomy
Schantz Laursen, 2017, Denmark[32]	4 patients	55-68	Prostate cancer; prostatectomy
Rosser, 2016, USA[44]	19 patients	48-72	Prostate cancer; radical prostatectomy
Lee, 2015, Canada[18]	16 patients	55-61	Localized prostate cancer; 63% had prostatectomy
O'Shaughnessy, 2015, Australia [19]	21 patients 9 partners	59-84 patients 51-72 partners	Prostate cancer; 57% had open prostatectomy, 24% had robotic prostatectomy
Hartman, 2014, Canada[33]	3 couples	52-64 patients 40-42 partners	Prostate cancer; radical prostatectomy
Sillence, 2014, UK[20]	NA	NA	Prostate cancer; during treatment decision-making
Volk, 2014, USA[21]	30 patients	45-72	Localized prostate cancer; of the treatment group (n=15) 8 chose robotic or open prostatectomy
Wittmann, 2014, USA[22]	10 patients and 9 partners	62 (mean) patients 58 partners	Localized prostate cancer; prostatectomy
Eilat-Tsanan, 2013, Israel[23]	22 patients	60-81	Localized prostate cancer; radical prostatectomy
Waller, 2013, UK[34]	7 patients	51-80	Early-stage prostate cancer; robotic radical prostatectomy
de Moraes Lopes, 2012, Brazil[24]	10 patients	48-74	Prostate cancer; radical prostatectomy
Krumwiede, 2012, USA[35]	10 patients	62–70	Prostate cancer; 50% had open radical prostatectomy and 40% had robotic radical prostatectomy
Iyigun, 2011, Turkey[36]	15 patients	62.6 mean	Prostate cancer; radical prostatectomy
Walsh, 2010, Ireland[43]	8 patients	NS	Localized prostate cancer; radical prostatectomy
Yu Ko, 2010, Canada[46]	6 patients	58-77	Prostate cancer; radical prostatectomy

First Author, Publication Year, Country	Sample Size	Age Range in Years	Details on Condition; Treatment Received
O'Shaughnessy, 2009, Australia[45]	11 patients	NS	Prostate cancer; prostatectomy
Milne, 2008, Canada[42]	19 patients	46–76	Prostate cancer; laparoscopic radical prostatectomy
Denberg, 2006, UK[25]	20 patients	53-80	Newly diagnosed localized prostate cancer; 35% chose to undergo radical prostatectomy
Walton, 2004, USA[40]	11 patients	54-71	Prostate cancer; radical prostatectomy
Gray, 2002, Canada*[26-28] Philips, 2000[29]	34 couples	50-68 (patients) 42-72 (spouses)	Prostate cancer; prostatectomy
Maliski, 2002, USA[30]	20 couples	51-71 (patients) 28-70 (spouses)	Prostate cancer; prostatectomy
Berterö 2001, Sweden[37]	10 patients	63-76	Prostate cancer; 60% underwent prostatectomy
Butler, 2001, Canada[31]	21 patients	47-73	Prostate cancer; radical prostatectomy
O'Rourke,1999, USA[41]	18 patients and their spouses	52-78 (patients) 49-74 (spouses)	Stage I-II prostate cancer; 67% underwent radical prostatectomy

NS = not specified; NA = not applicable

* = multiple publications from the same study but reporting different results (not duplicates)

Appendix 5: Critical Appraisal of Included Primary Publications

Table 5: Critical Appraisal of Included Publications Using CASP Qualitative Checklist[4]

First Author, Year	Clear statement of the aims of the research?	Qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participants been adequately considered?	Ethical issues been taken into consider-ation?	Data analysis sufficiently rigorous?	Clear statement of findings?	Relevant to the current review?
Smith, 2019[14]	+	+	+	+	+	+	+	+	+	+
Yu Ko, 2019[38]	+	+	+	+	+	+	+	+	+	-
Pietilä, 2018[15]	+	+	+	+	+	+	+	+	+	-
Thera, 2018[16]	+	+	+	+	+	+	+	+	+	+
Yu Ko, 2018[39]	+	+	+	+	+	+	+	+	+	+
Imm, 2017[17]	+	+	+	+	+	-	+	-	+	-
Schantz Laursen, 2017[32]	+	+	+	+	+	+	+	+	+	+
Rosser, 2016[44]	+	+	+	+	+	+	+	+	+	+
Lee, 2015[18]	+	+	+	+	+	+	+	+	+	+
O'Shaughnessy, 2015[19]	+	+	+	+	+	+	+	+	+	-
Hartman, 2014[33]	+	+	+	-	+	+	+	-	+	-
Sillence, 2014[20]	+	+	+	+	-	+	+	-	-	+
Volk, 2014[21]	+	+	-	-	-	-	+	-	+	-
Wittmann, 2014[22]	+	+	-	-	+	+	+	-	+	-
Eilat-Tsanan, 2013[23]	+	+	+	+	+	+	+	+	+	+
Waller, 2013[34]	+	+	+	+	+	+	+	+	+	+
de Moraes Lopes, 2012[24]	+	+	-	-	+	+	+	+	+	-
Krumwiede, 2012[35]	+	+	+	-	+	+	+	+	+	-
Iyigun, 2011[36]	+	+	+	+	+	+	+	+	+	+
Walsh, 2010[43]	+	+	+	+	-	+	+	+	+	+
Yu Ko, 2010[46]	+	+	+	+	-	+	+	+	+	+
O'Shaughnessy, 2009[45]	+	+	+	+	+	+	+	+	+	+
Milne, 2008[42]	+	+	+	+	-	+	+	+	+	+
Denberg, 2006[25]	+	+	+	+	+	-	+	+	+	+

First Author, Year	Clear statement of the aims of the research?	Qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participants been adequately considered?	Ethical issues been taken into consider-ation?	Data analysis sufficiently rigorous?	Clear statement of findings?	Relevant to the current review?
Walton, 2004[40]	+	+	+	+	+	+	-	+	-	-
Gray, 2002[26]	+	+	+	+	+	+	+	+	+	+
Maliski, 2002[30]	+	+	+	+	-	-	+	+	+	+
Berterö, 2001[37]	+	+	+	+	-	-	+	+	+	-
Butler, 2001[31]	+	+	-	-	+	-	+	-	+	+
Gray, 2000[27]	+	+	+	+	+	+	+	+	+	-
Gray, 2000[28]	+	+	+	+	+	+	+	+	-	+
Philips, 2000[29]	+	+	+	+	+	+	+	+	+	+
O'Rourke,1999[41]	+	+	+	+	+	+	+	+	-	+

+ = yes; - = no

Appendix 6: Critical Appraisal of Included Qualitative Syntheses

Table 6: Critical Appraisal of Included Qualitative Syntheses Using CERQual Components[5]

Author, Year, Country	No Substantial Methodological Limitations	Relevant	Coherent	Adequate
Carrier, 2018, UK[9]	+	+	+	+
Kandasamy, 2017, Canada[10]	+	+	+	+
Kong, 2017, Korea[11]	+	+	+	+
Xiaojing, 2012, Australia[12]	+	+	+	+
Schumm, 2012, UK[13]	+	+	+	+

+ = yes; - = no