**Abstract:**

Three main treatments are offered to men with localised prostate cancer (PCa); active monitoring, radiotherapy and prostatectomy. The aim of this research was to explore the role of body image in treatment decision making and post treatment regret following prostatectomy for localised PCa. Data was collected via nine semi-structured interviews. Interviews underwent thematic analysis. Four themes developed: 1) need to prolong life, 2) loss of function and self, 3) post-surgery effects on body image and confidence, 4) coping strategies.

Participants revealed that loss of erectile function following surgery resulted in reduced self-confidence, and changes in their perception of their body.

**Keywords:**

Body image, prostatectomy, prostate cancer, treatment decision.

**Key points:**

1. After prostatectomy men can have body image issues that are not always visible to anyone other than themselves.

2. Body image change had a minimal effect on the development of treatment decision regret

3. Post treatment regret identified by men following prostatectomy was due to physical side- effects such as erectile dysfunction incontinence

4. Treatment decisions were influenced by previous contact with others who had, previous forms of cancer treatment, and the long term outcomes that men perceived were related to their treatments.

**Reflective questions:**

1. Think about how your role as a nurse might influence how patients relate to you.
2. Consider how you would deal with a patient who expressed a concern about a change in their body image following treatment.
3. Think about how a nurse can tap into the multi-disciplinary team to support a patient with treatment regret.

**Introduction**

Approximately 47,000 men in the UK are diagnosed with prostate cancer (PCa) every year (Prostate Cancer Research UK. 2017). PCa is formed by uncontrolled division of cells within the prostate gland that produces swelling which is known as adenocarcinoma (Persad et al.2013). Risk factors for PCa include age, ethnicity, hereditary, genes and lifestyle (Persad et al. 2013).

Treatment for PCa may vary depending on personal preferences and clinical factors. Clinical factors include the size of tumour, the grading of the tumour on both the Magnetic Resonance Imaging (MRI) scan and biopsies, and risk of spread (NICE 2019). Men with PCa that is still contained within the prostate capsule are offered three treatment options; radical prostatectomy, active surveillance, and radiotherapy. The research presented in this paper focuses on prostatectomy as sole treatment option. The aim was to explore whether known side effects of prostatectomy impact on body image, and their role in men’s treatment decision and post treatment regret.

**Radical prostatectomy**

Prostatectomy involves removing the whole prostate capsule using a surgical procedure (laparoscopically (keyhole), robotic assisted or open surgery). Irrespective of the surgical approach used, post-treatment side-effects for surgery are similar, and these include urinary incontinence and erectile dysfunction (NICE 2019).

It has been documented in literature how incontinence and erectile dysfunction after surgery affects quality of life (Levinson et al. 2011; Christie et al. 2015), however one specific element with limited research is the impact of prostatectomy on men’s body image.

**What is Body Image?**

Fobair et al. (2006) defined body image as a mental picture of one's body, and an attitude towards physical self, state of health, wholeness, normal function and sexuality. White (2000) argues that in oncology populations, alteration to particularly symbolic parts of the body may lead to a greater disturbance in body image. This ~~can be~~ is directly related to the penis which can be identified as a bodily signifier and providing a distinction from femininity (Oliffe 2005). An alteration in the form and function of this organ may have a significant impact on one's body image and concept of self (Cash 2004; Fobair et al 2006; Hopwood 2001).

## Body image and prostatectomy

PCa treatments can have side effects such sexual dysfunction, erectile dysfunction, bowel and urinary incontinence (Manne et al. 2010). These side effects have been found to affect men's confidence, sexuality and their self-esteem (Manne et al. 2010), thereby affecting their body image (Hopwood, 2001). Regardless of the surgical approach used to remove the prostate gland for PCa 5% to 48% of men develop urinary incontinence caused by damage to the urinary sphincter during the removal of the prostate gland (Adamakis et al. 2013). Only 27% of men return to their baseline erectile function (Levinson et al. 2011) and the majority fail to have sufficient erection for penetrative sex due to intraoperative trauma on the sexual nerves, venous leakage and arterial insufficiency (Salonia et al. 2012; Tal et al. 2009). More visibly, penile shortening and penile deformity due to prostatectomy surgery can result in body image issues (Benson et al. 2009).

Studies using self-administered questionnaires find that men who have had a prostatectomy reported perceived penile shortening (Carlsson et al. 2012; Frey et al. 2014; Parekhet al*.* 2013). However, it was not reported in these studies as to whether the perceived penile shortening affected their body image.

Nelson et al. (2010) used self-reported questionnaires with 183 men before surgery and up to 24 months post-surgery, to determine whether 'sexual bother' increases following prostatectomy. Diminished erection post-surgery was associated with shame and embarrassment, and reduction of happiness. Using self-report questionnaires in this study failed to capture the lived experiences of men who experience sexual problems following surgery.

In a qualitative study by Wellam et al. (2010) loss of penile length was reported as unimportant, but men reported fear of failing to perform sexually which affected their masculinity. Although this was a qualitative study it had a focused outcome on penile shortening which is only one of the problems that may be experienced by men after prostatectomy. Dismissing penile shortening as an insignificant problem inhibits exploration of the wider effects that stems from perceived penile reduction and its impact on body image.

Hedestig et al. *~~et al~~*~~.~~ (2005) reported body image issues that affected men after surgery for PCa, but how prior knowledge of body image changes might have affected the patient’s treatment choices, and whether the changes experienced resulted in post treatment regret, have yet to be investigated.

## Body image, decision making and post treatment regret

Treatment decision making for PCa, with the curative element and convenience of treatment has been reported to influence men's choice of surgery (Anandadas et al.2011). However, the possible role of body image-related issues in men’s decision making about treatment has not yet been examined. The present study sought to explore whether known side effects impact on body image and influenced men’s treatment decision before choosing surgery as PCa treatment.

Post treatment regret associated with treatment choices has been linked to uncertainty of disease progression (Gwede et al. 2005; O’Connor et al. 2001). Unfavourable outcomes may lead one to believe that another decision might have been preferable (Christie et al. 2015). Regret following prostatectomy has been associated with poor quality of life due to incontinence and erectile dysfunction (Lee *~~et al~~*~~.~~ et al. 2015 and Lin, 2011).

At the time of writing, it is not known whether treatment decision is influenced by possible body image-related issues following surgical removal of the prostate for PCa.

**Methodology**

A qualitative descriptive ~~study was undertaken.~~ method was used to answer the research question and meet the aims and objectives of the study.

Research question:

What is the role of body image in treatment decision making and post treatment regret in men following prostatectomy for localised prostate cancer?

Aims:

* To explore the role of body image during treatment decision period.
* To understand whether men with prostate cancer identify body image change as a factor in post-treatment regrets.

Objective:

* To explore using semi-structured interviews, the role of body image in decision making when men who have been diagnosed with PCa chose surgery, and whether body image alteration plays any part in post treatment regret.

**Ethics**

Ethical approval was sought from the South West-Central Bristol Research Ethics Committee (REC: ethics ID 246944). Written consent was obtained before interviews. Provided in the patient information sheet was the contact details of support services that participants could contact if they were distressed after their interview.

**Research Team and Reflectivity**

The first author (CS) undertook the semi-structured interviews. CS is a urology research nurse with more than 5 years of working with ~~prostate cancer men~~ men with prostate cancer who were the population of interest in this project. The research was undertaken as partial fulfilment for CS’s Masters of Research (MRes). The second author (SH) is a Health Psychologist (DHealthPsych), and researcher (PhD). Both researchers are female, SH has extensive experience in undertaking qualitative research, while CS undertook qualitative training as part of her MRes.

**Participants**

Invitation letters were sent to thirty-eight ~~patients~~ men who had prostatectomy from November 2014 - November 2017 at Southmead Hospital, North Bristol NHS Trust,and who satisfied the study inclusion criteria (Figure 1). This represented the total population available within the timeframe. Fourteen men returned reply slips and were invited for interviews and nine men were subsequently available for interview.

[Insert Figure 1 here]

**Study design**

Semi-structured interviews were conducted on nine men. ~~undertaken using phenomenology as an underpinning framework.~~ Interviews were undertaken either face to face, or over the telephone (n=1) where a physical meeting could not be arranged with the participant. Where data was collected face-to-face some were undertaken in the participant home (n=1), while others were undertaken in a clinic setting (n=7). The location was chosen by the participant, and only the participant and interviewer were present, with field notes being taken to supplement audio recording. Table 1 provides demographic information of the participants. All participants were heterosexual and sexually active prior to their prostatectomy.

[Insert Table 1 here]

**~~Study design~~**

~~Semi-structured interviews were undertaken following an~~ An interview guide developed from previous prostate cancer studies (Harrington et al. 2009; Haliloglu et al.2007) was followed during the interviews. The interview ~~schedule~~ guide was piloted with members of a public patient involvement panel. Each participant was interviewed once and interviews wereaudio recorded and transcribed verbatim. All people who volunteered were interviewed, there were no new codes identified through ongoing analysis after 9 interviews.

**Analysis**

Transcriptions were outsourced to university credited transcriber. Once received from the transcriber the transcriptions were read whilst the researcher was listening to the recording to ensure accuracy in the written record. When transcriptions were approved as true record the researcher read and re-read them whilst listening to the recording to enable immersion in the data. Interviews were analysed thematically with the identification of commonalities, shared meaning and shared experiences across the data set (Braunand Clarke 2006). Analysis followed the six steps outlined by Braun and Clarke (2006).

1. Familiarise yourself with your data
2. Generate initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

At steps 1-5 analysis was reviewed by the second author. Any disagreements about the codes and themes were discussed and fed into the next stage of the analysis. CS’s academic supervisor reviewed and undertook theme checking. Mindmaps based on the data were created to support the analytic process, as suggested by Braun and Clarke (2006), during the deriving of the themes.

The consolidated criteria for reporting qualitative research (COREQ) 32-item checklist (Tong et al. 2007) was used to ensure trustworthiness in the findings.

**Results**

~~No statistical difference that was found on time from treatment or age between the men who participated in the study and none responders.~~ The average time of interviews was twenty-eight minutes (ranging from 16 to 43 minutes). They were four main themes from this study which included: need to prolong life, post-surgery effects on body image, loss of function and self and coping strategies.

**Theme 1: The need to prolong life**

During the interviews it became clear that body image did not play any role in treatment decision. However, the need to prolong life and survive the cancer was voiced as a major influence of treatment choice. Fear of disease progression was expressed and surgery was seen to be the only way to remove this fear, cure cancer and prolong life:

 *“I didn’t want the risk of anything coming back. I was scared; I was not a happy bunny. I just wanted this all over and done with, so I decided just get it out”* Bill.

*“No because you have sex or you die. Do you understand me”* Tom.

Surgery was ~~seen as the only~~ reviewed as a treatment that could prolong life compared to other PCa treatments in view of their friends and family’s experiences of PCa treatments:

*“I have a friend who’s dying of prostate cancer at present and I’ve been aware of that for the last six and a half years. He’s done very well but he is now in the later stages and it’s pretty … he’s got bone metastases so he’s in a fairly painful position. So I was very well aware of what the implications were if one left it. So my decision, which was my own decision, was ‘I’ll have it out’* Rob

Men felt that having surgery would remove cancer therefore removing the possibility of death. Unlike other options such as radiotherapy and hormones, surgery was considered as a curative treatment with minimum side effects according to experiences of friends.

**Theme 2: Post surgery side-effects on body image**

Although body image did not explicitly play a role in treatment decision making, body image problems defined as a mental picture of one’s body and an attitude about the physical self (Fobair et al 2006), were evident in negative post treatment experiences such as incontinence and sexual problems.

Incontinence

In some cases the interviewee had unrealistic expectations about the amount of time that would be required to regain bladder control:

*“I don’t know I… I was frustrated with myself because things weren’t going as fast as I … so it was myself but worried as well really. Worried that perhaps this is going to go on for longer than I thought. Because I had it in my head, within a week … but of course it was about a month by the time … it must have been about a month/six weeks I suppose before I was finished using the pads in the pants.”* Mike.

Although incontinence was a problem one man focused on the alternative of still having cancer and the risk of death, so he considered incontinence and the wearing of a pad was a small price to pay for life:

*“No because my main concern was longevity and life. If you’re unfortunate enough to have to wear a pad for the rest of your life so be it, but it’s better to be alive wearing a pad if you need to rather than be dead in the grave”* Ken.

Being incontinent as a man was expressed unequivocally as negative:

*“I was very conscious of it* [the Pad], *particularly going to a gents’ toilet, I used to go into the cubicles."* Eddy

Sexual problems

Altered erectile function left one man feeling inadequate as he felt he was now unable to fulfil his duty as a husband in their sexual relationship:

 *“If my wife maybe felt a bit like she wanted sex I can’t give it to her in a response that we would have had before. So I know ..she loves me dearly but from a sexual point of view she can’t get what she wants anymore if she wanted it. Because I wouldn’t be readily there for her ..It’s just that I haven’t got the tools to finish the job off, so to speak.”* Ken.

**Theme 3: Loss of function and self**

Regardless of men reporting no treatment regret, there was an overwhelming sense of loss of function and loss of self. Loss of erection was discussed by all participants during their interviews. Three men talked about a trade-off between having an erection and being alive.

 *“I’m fine, I’m just glad to be here. That’s the way I have to look at it. I’m here, I’m alive, I can go out and ride a motorbike, I can do everything I want to do. I can still work and I’m happy to just be here.”* Bill.

In amongst the interviews, two men expressed how unhappy they felt with their altered sense of self and their manhood. Erections played a big role in self-identification for Ken and Eddy:

*“That’s part of being a man. It must be like a woman if she’s got to have her breast removed. Very similar thing I would imagine. You’ve got a woman with a lovely pair of breasts and maybe she enjoys showing them off, then all of a sudden take them away and how’s she going to feel. She can’t show … she might enjoy showing her breasts off a little bit and now she hasn’t got any breasts to show off. So her confidence will go”* Ken.

**Theme 4: Coping strategies**

Various ways of coping such as re-evaluation of life, exercises, downward social comparison and age were talked about.

Re-evaluating what was important to them and their families and being alive was enough to enable them to cope with erectile dysfunction:

 *“I can’t get an erection. ..Put it this way, if I hadn’t have had that operation I could have been dead ..”* Ross.

Downward social comparison was used as a way of coping with their situation:

*“… we can’t have penetrative sex so what we can do ..also grateful for what we have got now because my brother...he couldn’t have nerve-sparing surgery so I know what the option is.”* Alex.

Distraction was a way that one man and his wife managed to cope with erectile dysfunction:

*“..Me more so and I actually take part in various events as well like running and obstacle races, that sort of thing. … that’s something we do together, which is nice and we do like going away to various motor sport events, music concerts, that sort of thing, so we have quite an active life … I think if we were sat here all the time then perhaps it might be more of a thing that we’d have to have a coping mechanism than not.”* Mike.

Men’s perception of age and what they considered normal body changes helped them cope with erectile dysfunction. They used their present age to almost justify erectile dysfunction:

*“Again, I’m 72 and so it’s not something that rules my life and never has”* Rob.

*“not being able to have sex is not good...it’s not ideal but I’m 57...”* Bill.

**Discussion**

The aim of this research was to explore the role of body image in treatment decision making and post treatment regret following prostatectomy for localised PCa. Data was collected via nine semi-structured interviews. Interviews ~~underwent~~ were analysed using ~~3)~~ thematic analysis. Four themes developed: 1) need to prolong life, 2) loss of function and self, 3) post-surgery effects on body image and confidence, 4) coping strategies.

Men in this study reported that body image, as defined by Fobair et al (2006), did not influence decision making process, but curing cancer and prolongation of life was a priority in spite of the side effects caused by surgery. This was consistent with the findings by Hopfgarten et al (2006) and Seigel et al (2001) who reported the willingness of men to accept long term erectile dysfunction if there was any chance of prolonging life. Further investigation is required to understand the pattern of acceptable side-effects of treatment or disease progression for men who choose active surveillance or radiotherapy, and if any biological factors such as age, or ethnicity affect treatmentchoice and the relationship to body image and regret.

Findings of the current study support that of Haliloglu et al (2007) and Harrington et al (2009) where men reported that loss of erection resulted in alteration to self-identification, and therefore body image.

Downward comparison was reported as being used as a coping strategy in the current study. Comparing oneself against a less fortunate other has been found to fulfil emotional needs by increasing self-esteem in cancer patients (Taylor and Lobel 1989; Carmack Taylor et al. 2007). This strategy has been discussed in breast and general cancer studies before, but appears to be new to a prostate cohort. These benefits seem to be especially pronounced for people who are low in self-esteem and who are strongly disposed to make social comparisons (Carmack Taylor et al. 2007). This social reframing may also promote positive psychological change (also called post-traumatic growth), which may be directly related to the physical trauma of prostate cancer, but could also be enhanced by social support in the form of family and friends, or through greater spirituality (Walsh et al. 2018).

A direct question about post treatment regret was asked during interviews. All participants reported that given the same situation, they would have surgery again even with the sexual/urinary problems they were experiencing. This contradicts the findings from previous prostate cancer studies following surgery (Lin 2011; Morris et al 2015), where post- treatment regret was attributed to sexual/urinary problems post prostatectomy.

A note of caution regarding the generalisability of this small sample should be made. The sample of nine men was almost all white except for one man who was Asian and this might have influenced the results. It is known that ethnicity is a risk factor for prostate cancer, with Afro-Caribbean men being disproportionately represented. A purposeful sample of the black and Asian minority might be valuable in order to understand their perspective on issues around body image following prostate cancer treatments. The age of men interviewed men ranged from 57 to 76 years old. Most men who experience PCa under the age of 50 are from black origins (Hosain et al. 2012), and further work is needed to unpick how ethnicity and age may interact with treatment choice ~~as a whole~~ and regret. ~~specifically, and~~ Also assess the relationship between ethnicity and age with changes in body image. However, the sample was representative of men who have PCa in published studies, and suggests that although not generalizable, the findings from this study could be compared to the wider UK PCa patient cohort represented in research.

**Limitations**

There are some limitations to this study one being ~~A~~ ~~limitation to the study may also be~~ that all participants had received their treatment from one NHS hospital, and therefore had similar service experiences. Their overall hospital experience may have influenced the way they felt about the decision they made, which could be associated with the lack of regret on treatment decision. Although there are treatment guidelines in place, it would be optimal to investigate experiences across treatment providers to understand if this is a factor in the subsequent opinions and feelings of the men being treated. It would also be beneficial to investigate the post-treatment support provided by different primary and secondary medical services, and which of these have been accessed by participants.

The other limitation that might have influenced the results is that prostatectomy is definitive once done some of the side effects cannot be reversed. Comparing prostatectomy to brachytherapy side- effects that has been reported to have less psychological trauma as the can be resolved with a year of having treatment.

**Conclusion**

Body image was not explicitly identified by men as a factor that was thought of during treatment decision making.

The interviews revealed that treatment decision making was influenced by family and friends’ experience of cancer in general including PCa and the quest to seek a cure and prolongation of life. Participants did not readily identify with body image as an explanatory point of reference but reported a strong sense of personal change in sexual/bladder function and sense of loss of self within these changes, which are factors of body image as defined by Fobair et al (2006). Prostatectomy leaves very little in terms of visible scars but interviews revealed invisible body image changes negatively affected men’s perception. Men developed coping strategies that enabled them to cope with erectile dysfunction following surgery and included re-evaluating what was important in their lives.

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