Exploring men’s experiences of penile cancer surgery to improve rehabilitation

This qualitative study examined men’s experiences of penile cancer surgery with the aim of improving the rehabilitation process.

**BACKGROUND**

Cancer of the penis is a rare diagnosis in the northern hemisphere (one per 100,000 people), although its incidence is far higher in countries such as Brazil (50 per 100,000) (Goodman et al, 2007; D’Ancona et al, 1997). Penile cancer represents 20–30% of all male cancers in Asia, Africa and South America (Stotts, 2004) and is a considerable challenge for countries in the developing world (Misra et al, 2004).

Aetiological factors are thought to include poor hygiene and the presence of the human papilloma virus (HPV). Circumcision appears to afford protection exposure by reducing irritants beneath the foreskin (Stotts, 2004). Although penile cancer is predominantly a disease of older men, the age range of those affected is wide, with 22% of patients being under 40 years. Many report still being sexually active before presentation.

Confusion and ignorance affect the diagnosis. Patients’ embarrassment and healthcare professionals’ lack of recognition frequently result in late presentation.

The treatment of choice that maximises the chance of cure is surgery; the extent of surgery is dictated by disease stage. With early presentation, conservative surgery is possible, maintaining both function and cosmetic appearance. However, more advanced disease requires invasive intervention to maximise chances of survival. For the majority of men, surgery results in either partial or total penectomy with regional lymph node excision in those with evidence of disease in the inguinal region(s).

The experience of men with penile cancer has been little investigated to date and is limited to quantitative studies using standardised quality-of-life instruments. What such studies cannot reveal is the

**PRACTICE POINTS**

- The physical and psychological consequences of penile cancer surgery present challenges for patients, families and healthcare professionals.
- A perceived key oversight in the rehabilitation process was practical, basic advice on how to manage urination after partial or total penectomy. Addressing the most appropriate ways of dealing with this from a patient-centred perspective is essential for successful rehabilitation.
- Sexual functioning was also problematic, especially for men who still experienced desire but were unable to achieve what they considered to be a satisfactory sexual outcome. Where men are sexually active within a stable relationship, working with the couple is important.
- A more difficult challenge to address with single men is overcoming fears of rejection and increasing self-esteem, which may support them as they develop relationships.
- A particularly important finding was the central role that wives/female partners have in providing support for participants. However, for men without intimate relationships, a strong source of support essential for successful rehabilitation was missing.
- This finding suggests a potential vulnerability for certain patients with penile cancer, which needs to be considered at initial presentation and during follow-up.
- This study also highlights the value of a mixed-gender research team, particularly during the analysis stage. The male researcher was able to provide insights into the world of masculinity unavailable to female team members.

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**Background** Penile cancer is an uncommon but serious cancer; in the UK 50% of patients undergo partial or complete penectomy resulting in far-reaching consequences.

**Aim** To examine the impact of penectomy for men and make recommendations for rehabilitation and patient/carer support services.

**Method** A small-scale qualitative study using interpretative phenomenological analysis (IPA) was carried out. A purposive sample of men with penile cancer (n=9) at least 18 months post surgery were recruited. A male researcher interviewed them.

**Results** Key themes were: the cancer journey; support and relationships; life stage and life review; and masculinity and self-image.

**Conclusion** It is not unexpected to find that men should have changed life experiences following penile cancer surgery. However, the far-reaching and insidious nature of post-treatment changes reported here have implications for clinical practice and show that there is a need for further research in this area.
A detailed case study of a man with complex problems following surgery for penile cancer, identifying a considerable impact on body image. Ficarra et al (2000) reported significantly increased levels of anxiety and depression in patients with penile cancer compared with controls.

Opjordsmoen et al (1994) argued that the preservation of sexual function should be a major therapeutic aim. This was further reinforced by Romero et al (2005), who found that, even with partial penectomy, only 33% of men maintained the frequency of preoperative sexual intercourse, mainly due to feelings of shame because of small penis size and the absence of the glans penis. The limited research suggests that although post-surgical physical recovery may be relatively straightforward, the psychological impact of penile cancer and its treatment deserve further study. It is not unreasonable to speculate that penectomy will affect men’s perceptions of themselves and many aspects of their daily lives.

AIM

The study’s overall purpose was to examine the consequences of penile cancer surgery for men and make recommendations for rehabilitation and patient/carer support services.

METHOD

To explore the experience of penile cancer, we chose a qualitative research method – interpretative phenomenological analysis (IPA). This method captures subjective perceptions of events rather than objective statements (Smith et al, 2006; Howes et al, 2005; Jarman et al, 2005; Smith and Osborn, 2003).

A mixed-sex research group was convened with a male researcher acting as interviewer. The rationale for this was the possibility that a man could provide masculine insights into the world of male ‘culture’ unavailable to women, thus enhancing methodological rigour.

Participants

A specialist urology nurse from the urology department of a large district general hospital recruited a purposive sample of men at least 18 months post-surgery (n=9, average age=62.5, range=50–76 years). Participants were recruited until the sample size was achieved. Refusals were accepted and reasons not pursued on ethical grounds. All were white Caucasian native English speakers with no serious concurrent psychological or physical illnesses. Social class was not recorded in this sample. Table 1, p22, outlines participants’ characteristics.

Data collection

After positive university and NHS research ethics committee reviews, potential participants received invitation letters, detailed information sheets and consent forms. Participants were interviewed individually in the urology department. Semi-structured interviews of 6–8 questions provided opportunities for them to relate...
their experiences of penile cancer, for example: ‘In what ways has your life changed since your diagnosis?’ The interviews (approximately one hour) were audiotaped and transcribed verbatim.

Analysis
Transcript analysis was completed in stages (Smith and Osborn, 2003). Each researcher conducted stage 1 independently. The first transcript was read several times to develop familiarity with the text and salient passages were noted on the script. Emergent themes were grouped into clusters; the central focus was on meaning rather than frequency. The same process was repeated for each transcript.

Comparison across transcripts generated lists of preliminary themes, with common themes developed from group analysis sessions (stage 2). During stage 3, we produced definitive themes and identified examples to illustrate them.

RESULTS
Four main themes emerged from the subjective experiences of this group of men with penile cancer (see Box 1). Participants are identified as 1–9.

The cancer journey
Four distinct phases can be identified in the cancer journey: presentation; diagnosis; treatment; and rehabilitation. If recurrence occurs, the cycle may be repeated. These phases were clearly seen in the narratives.

The majority of participants had an extended pre-presentation phase – often of many years – which was characterised by increasingly unpleasant symptoms often associated with misdiagnosis or outright dismissal by medical staff. Participant 8 reported: ‘I spent a month with toilet tissue wrapped around my penis to stop the bleeding… I was in a terrible mess.’

In contrast to the delay before diagnosis, confirmation of penile cancer led to rapid treatment. As is common in cancer diagnoses, participants spoke of feelings of shock and disbelief when told they had cancer, feelings that were often accompanied by fear and despair. For example, participant 9 said: ‘He looked me in the face and said “you have got cancer”. I just broke down and I don’t know what he was talking about ‘cos when you mention cancer, well you have got six weeks to live.’

Initially, men were concerned with the issue of survival rather than the implications of surgery on the penis. They were matter of fact. For example, participant 8 said: ‘If they do not amputate this penis you are dead, alright, so you have two choices: you live or you die. I said: “Cut it off”’. The consequences of surgery for sexual and urinary functions slowly started to emerge for participants. The realisation of a changed life was reflected in comments such as: ‘It hadn’t crossed my mind of the physical impact that it might have, you know, on our married life essentially’ (participant 3). Participant 5 commented on the difficulties of urination: ‘Before, you could hold something and all of a sudden I had nothing to hold on to.’

Central to adaptation was the extent of surgery. In general, conservative surgery led to preserved function. Sadly, for those who had more advanced disease on presentation, conservative surgery and reconstruction were not options, leaving patients with an altered appearance, reduced function and the realisation of a changed reality.

Support and relationships
The theme of support and relationships with partners, children and friends, together with professional support, was common throughout the narratives. The importance of partners’ acceptance and understanding was central. During the immediate treatment period, men turned to wives, ex-wives or girlfriends for emotional and practical support: ‘Without her, I don’t know where I would be’ (participant 2).

When seeking support, men were faced with a dilemma – they could either keep their diagnosis a secret, shared only with their partners, or they could adopt the more risky strategy of being honest. Participant 2 explained the situation, saying: ‘You wouldn’t tell them that perhaps they were going to cut off my penis.’

An alternative strategy was to develop a ‘cover story’ of half-truths, which participant 9 described as ‘misdirection’. This allowed men to receive support as a ‘cancer patient’ without compromising their self-esteem.

The reasons for non-disclosure varied from embarrassment and the use of acceptable vocabulary when telling women, to fear of ridicule and perceptions of sexual incompetence and threatened masculinity when speaking to other men.

Men’s help-seeking behaviour is influenced by their perceptions of masculinity (Mansfield et al, 2003). It was notable that, in terms of reporting responses to treatment and in seeking help, responding in a male-appropriate manner appeared important.

Men spoke of ‘facing up to’ their diagnosis and ‘getting on with it’, reflecting stereotypical reactions of male stoicism and strength. Image maintenance was essential and was seen in the projection of the self as the strong masculine ‘coper’. Participant 4 said: ‘You know I could sit in the corner… and cry all the time, but, what hell good [would] that do! You [have] got to face it and get out and mow the lawn.’

Participants commented on the support of fellow patients with penile cancer,

TABLE 1. DESCRIPTIVE STATISTICS OF PARTICIPANTS AT TIME OF INTERVIEW

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Marital status</th>
<th>Operation</th>
<th>Time since surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>67</td>
<td>Married</td>
<td>Partial</td>
<td>5 years</td>
</tr>
<tr>
<td>2</td>
<td>68</td>
<td>Married</td>
<td>Partial</td>
<td>2 years</td>
</tr>
<tr>
<td>3</td>
<td>60</td>
<td>Married</td>
<td>Partial</td>
<td>&lt;2 years</td>
</tr>
<tr>
<td>4</td>
<td>68</td>
<td>Married</td>
<td>Total</td>
<td>2 years</td>
</tr>
<tr>
<td>5</td>
<td>50</td>
<td>Single</td>
<td>Total</td>
<td>3 years</td>
</tr>
<tr>
<td>6</td>
<td>56</td>
<td>Separated</td>
<td>Partial</td>
<td>&lt;2 years</td>
</tr>
<tr>
<td>7</td>
<td>76</td>
<td>Married</td>
<td>Partial</td>
<td>2 years</td>
</tr>
<tr>
<td>8</td>
<td>60</td>
<td>Married</td>
<td>Partial</td>
<td>2 years</td>
</tr>
<tr>
<td>9</td>
<td>58</td>
<td>Married</td>
<td>Partial</td>
<td>3 years</td>
</tr>
</tbody>
</table>
particularly regarding how to deal with daily practicalities such as urination. Participant 9 observed: ‘I think that he appreciated it because he was asking me: what [had] they done, what’s happening, how do you feel, and how are you walking?’

It could be argued that, in supporting others as an ‘expert’, participants were able to reassert a degree of control over their situation, simultaneously investing it with meaning and maintaining a positive self-image.

Both men in supportive relationships and those who were not had concerns about the effect of their cancer and treatment on the future. While men were anxious about recurrence, they were also apprehensive about the effect on intimate sexual relationships.

This differed between married and unmarried men. For some married men, not being able to sexually ‘satisfy’ their wife was an issue and they commented on whether their wives would seek out other men.

For unmarried men, the problem of how to form new relationships was acute, with men worried about both penile appearance and function. The main concerns were about ridicule and rejection, fears that were overcome by avoiding new relationships.

Participant 6 said: ‘I don’t think that would satisfy a woman. I wouldn’t have thought so at least.’ These responses have implications not only for rehabilitation and a return to normal life, albeit a changed one, but also provide insights into how the men viewed themselves.

**Life stage and life review**

Another source of support for men was their individual life experiences and life stage. Central to life-stage themes were comments on the threats to masculine identity, the difficulties for forming relationships and the implications for having children.

How the situation could have been worse was a recurrent theme. The men commonly reported that, while their situation was difficult, it would have been far worse if they:

- Were younger;
- Were not in an established relationship;
- Had not had a previous sex life;
- Had not had children.

The extent of surgery was also a negative comparator.

The narratives provided a strong sense of the need to survive for most participants, with downward comparison a useful way of helping to reconcile their changed circumstances.

Position in the life stage and earlier experience allowed men to draw on strategies previously developed to cope with difficulties. Participants cited a range of previous life events and experiences that ‘tempered’ them so they could deal with the challenges of penile cancer (see Box 2).

For participant 3, there were benefits in being older and having had more life experience: ‘I am certainly stronger now than I was 12 years ago.’

Allied to life stage was the importance of maintaining existing roles such as those of husband, lover and father.

For a minority of men, the inability to continue aspects of function associated with their lives before their cancer diagnosis (such as playing sports and spending time drinking) provided opportunities to develop and deepen relationships with family members such as wives, children and grandchildren. For a few men, a consequence of diagnosis and treatment was increased intimacy in their roles of husband and parent.

However, the majority reported the opposite – possibly those who had more fragile or less well-established relationships before diagnosis – with friendships and intimate relationships damaged or lost.

Participant 8 said: ‘I may have a girlfriend if my wife does split, if she does go, which I think she will. I may have a friend but it would be totally… a platonic relationship.’

In terms of life stage, the younger the man, the greater the sense of loss and disruption. This finding was seen in younger men and older participants speculated this to be the case.

**Masculinity and self-image**

Although when questioned directly, the majority of participants denied feeling ‘less of a man’ after a total or partial penectomy, responses to other questions revealed that surgery resulted in changes to both feelings of masculinity and perceptions of self and body image.

Participant 8 said that ‘…it took a lot of accepting. It took a lot of accepting to think that I was going to lose my manhood… then it starts to dawn on you then: you are no longer… you’re half a man.’

Changes in appearance affected the masculine roles of ‘lover’ and being ‘one of the boys’.

Regarding the role of ‘lover’, some men in established relationships spoke of initial reticence in showing the surgical site to their partners. They talked about the immediate shock and dismay that both they and their partners experienced.

Participant 9 reported his wife’s response to his surgery as follows: ‘My wife was concerned and she wanted to see what they had done, but I didn’t want to show her. I had seen it to a point but I couldn’t look down there because I was afraid to a point… but when she saw it she broke down and her words were, “Oh God what have they done! What have they done!”’

For men without partners, changed appearance was a major concern and a potential barrier to seeking new relationships. Participant 6, a single man, spoke of his fears of rejection: ‘I think I could handle it but in the back of my mind, or maybe in the forefront or my mind at the time, would be rejection, yes? How would I handle it?’

Sexual competence and the ability to achieve orgasm were major concerns and were related to the extent of surgery. For some men, although orgasm was unachievable, libido was unaffected, leading to frustration for them and their partners: ‘I can’t do nothing about it, and my wife feels what is the point of trying because you can’t do nothing anyway. So she is frustrated as much as me… you are going so far and then you have to stop because you can’t go no further’ (participant 9).

The effect of changed appearance and being considered as different was also seen in the avoidance of communal showers/changing rooms. Men were shy about their changed shape and apprehensive about other men’s reactions. For example, participant 1 said: ‘…would that bloke be looking at me?’

Changes in appearance, together with the need to modify ways of urination, had
implications for social activities and behaviour in men’s lavatories, as participant 8 said: ‘You have got to sit down to pee. You know you can’t pee standing up because you soak your trousers.’

An additional aspect of the disease and treatment was reduced physical strength and changes in ability to work and participate in exercise. However, continuing in work was limited not just by physical changes; it was also limited by psychological factors such as coping. Men were determined to portray themselves as fit, strong and capable before surgery and found their changed, more vulnerable status difficult to adjust to after treatment, as participant 9 reported: ‘I have always been a working bloke… and now you know that has gone…. Where I walked for miles for no problem, I am chugging around town like an old-age pensioner if you like.’

Not being part of male culture, a fear of loss of control and an increased sense of dependence and vulnerability contributed to a sense of altered masculine image.

DISCUSSION

The study’s overall purpose was to examine the experience and consequences of penile cancer surgery for men and make recommendations for rehabilitation and patient/carer support services.

Shock, disbelief and fear of death were common post-diagnosis responses. The most dominant cause was having ‘cancer’ rather than the site of the disease.

These narratives demonstrated the lack of awareness of penile cancer not only by participants but also by medical staff. Many men suffered considerable difficulties before diagnosis, with some misdiagnosed before a final diagnosis was made.

The cancer journey started in earnest after diagnosis with a rapid treatment process that both reassured and frightened participants. Implications, both physical and psychological, were secondary; the need to deal with the cancer was imperative.

However, post-surgery, the consequences for urinary and sexual functioning and the reality of a changed life became apparent.

Four main themes were identified as men strove to deal with the realities of diagnosis and treatment and its implications for all aspects of functioning in a masculine environment.

Qualitative studies are not without their limitations; they can provide only information about the reality of the specific participants at a particular moment in time.

However, general applicability is not the aim of methods such as IPA; ‘getting under the skin’ of the participant experience is. The value of using a qualitative method can be seen in the detailed ‘teasing out’ of events.

Although Ficarra et al (2000) and Romero et al (2005) reported changes in mood and sexual functioning in men with penile cancer, these studies are limited as they cannot identify the reasons for such changes and their nature.

This current study provides insight into participants’ lived experience. It shows that, while superficially the men appeared to be – and in many respects were – dealing with their changed circumstances, to do so they had to adjust to significant changes in every aspect of their lives. All participants had to reconfigure their role as men in an entirely different way post surgery, ranging from how they urinated to their diverse roles in the family and society.

CONCLUSION

Although uncommon, penile cancer is a diagnosis with profound implications for both men and their families.

The men’s narratives in this study reflected the major life changes this diagnosis brings. Participants reported an altered sense of masculinity and male functioning across all areas of daily life. Changes ranged from the most basic such as urination to subtle social interactions with different groups of people.

The narratives provide a sense of a group of men with complex problems that need sensitive and appropriate support. Developing the ability to provide that support requires further studies to understand how best to rehabilitate patients with penile cancer and maintain their quality of life.

Arguably, the extensive literature on post-mastectomy rehabilitation may provide insights into how to support men post penectomy. However, such parallels should be treated cautiously as men’s approach to health and illness is different from that of women (Mansfield et al, 2003).

Further research will support the development of rehabilitation interventions that are responsive to men’s needs post penectomy and sensitive to the totemic and symbolic importance of the penis for masculinity. We are involved in a larger-scale, multi-site study using mixed research methods, based on the initial findings from this study.

REFERENCES


