



LEEDS
BECKETT
UNIVERSITY

Citation:

Witty, K and Branney, P and Evans, J and Bullen, K and White, A and Eardley, I (2013) The impact of surgical treatment for penile cancer – patients' perspectives. *European journal of oncology nursing : the official journal of European Oncology Nursing Society*, 17 (5). 661 - 667. ISSN 1462-3889 DOI: <https://doi.org/10.1016/j.ejon.2013.06.004>

Link to Leeds Beckett Repository record:

<https://eprints.leedsbeckett.ac.uk/id/eprint/249/>

Document Version:

Article (Accepted Version)

The aim of the Leeds Beckett Repository is to provide open access to our research, as required by funder policies and permitted by publishers and copyright law.

The Leeds Beckett repository holds a wide range of publications, each of which has been checked for copyright and the relevant embargo period has been applied by the Research Services team.

We operate on a standard take-down policy. If you are the author or publisher of an output and you would like it removed from the repository, please [contact us](#) and we will investigate on a case-by-case basis.

Each thesis in the repository has been cleared where necessary by the author for third party copyright. If you would like a thesis to be removed from the repository or believe there is an issue with copyright, please contact us on openaccess@leedsbeckett.ac.uk and we will investigate on a case-by-case basis.

Title: The Impact of Surgical Treatment for Penile Cancer – Patients’ Perspectives

Authors: Karl Witty¹, Peter Branney², Julie Evans³, Kate Bullen⁴, Alan White¹, Ian Eardley⁵

1 Centre for Men’s Health, Leeds Metropolitan University, UK

2 School of Social, Psychological & Communication Sciences, Leeds Metropolitan University, UK

3. Health Experiences Research Group, University of Oxford, UK

4. Department of Psychology, Aberystwyth University, UK

5. Pyrah Department of Urology, Leeds Teaching Hospitals NHS Trust, UK

Corresponding Author:

Karl Witty,
Centre for Men's Health,
Faculty of Health and Social Sciences,
Leeds Metropolitan University,
Queen Square House,
80 Woodhouse Lane,
Leeds,
LS2 8NU
UK

k.witty@leedsmet.ac.uk.

Tel: (+44)113 8121968

Abstract

Purpose: Penile cancer is a rare but highly treatable condition. Whilst over 80% survive for over five years, treatment can have a significant impact on quality of life. There has been little research conducted to date on men's experiences of treatment for penile cancer; The Patients Experiences of Penile Cancer study (PEPC) aimed to redress this shortfall by exploring men's experiences of surgical treatment for penile cancer.

Method: Data were collected using two methods; an initial narrative oral history followed by a semi-structured interview. Maximum variation sampling was used to acquire the widest possible range of experiences. Twenty-seven interviews were conducted with men with an average age of 63 years at diagnosis (range = 41 – 82). The data were analysed using constant comparison analysis.

Results: The physical impact of surgery was inter-connected with broader events in the lives of the men experiencing treatment. These experiences cover urinary function, sexual function and sexual relationships, healing and recovery, masculinity, mental well-being, coping and support.

Conclusions: A key area for the development of care is to devise and evaluate procedures for ensuring that men are well-informed about the extent and potential consequences of their treatment. Men's experiences of penile cancer surgery will be informed by a complex web interlaced with their broader life making it difficult for health professionals to judge how surgery will impact on a men presenting to them. Further research is required to ascertain the most appropriate strategies for rehabilitation of men experiencing penile cancer surgery.

Background

More than 95% of malignant diseases of the penis are squamous cell cancers (SCC). A few (less than 5%) have other morphology including melanoma, adenocarcinoma and basal cell carcinoma (Pizzocaro et al., 2010). Penile cancer is rare in Western populations. Incidence rates in Europe and the United States are less than 1 in 100,000 men (Pizzocaro et al., 2010). In the UK, approximately 500 men are diagnosed with penile cancer each year (Macmillan Cancer Support, 2013), which represents less than 1% of new cancer registrations annually (Branney et al., 2011). Some authors (Pizzocaro et al., 2010, Bullen et al., 2009) suggest that incidence is higher in areas of South America, Africa and Asia. Robust evidence on aetiology is limited, but risk factors include older age, cigarette smoking, presence of human papillomavirus (HPV), lichen sclerosus, balanitis xerotica obliterans (BXO), and phimosis (Blanco-Yarosh, 2007, Pizzocaro et al., 2010, Pow-Sang et al., 2010, Yagnik, 2009). There is a lower incidence of penile cancer in men who have been circumcised as a child, which suggests that this may be a protective factor (Pizzocaro et al., 2010, Pow-Sang et al., 2010).

A range of treatments are available for localised, early stage penile cancers, including laser therapy, glans resurfacing and topical 5-fluorouracil therapy (Maddineni et al., 2009). Depending on the size and location of the tumour, advanced stage cancers are treated with technically uncomplicated (Bullen et al., 2010) surgical procedures; either a circumcision, local excision of the tumour, glansectomy (removal of the glans), or partial or total penectomy (removal of the penis). Treatment guidance recommends preservation of as much of the penis whenever possible although it is still necessary to remove a margin of normal penile tissue (Pizzocaro et al., 2010, Hegarty et al., 2008). Traditionally, a margin of at least 2cm of normal tissue be removed (Hegarty et al., 2008, Branney et al., 2011) although some studies suggest that more conservative surgery may be safe in the treatment of localised penile cancer (Smith et al., 2007, Minhas et al., 2005). Chemotherapy and radiotherapy are restricted to adjuvant use or palliative treatment of extensive disease (Branney et al., 2011). Lymph node removal is commonly performed separately to the main surgery, subject to staging (Pizzocaro et al., 2010). Survival rates in the UK are high, with more than 80% of men presenting early stage cancer living beyond five years (Branney et al., 2011).

In the UK, management of cases of penile cancer is undertaken within supra-regional specialist multi-disciplinary penile cancer networks covering a population of three million and seeing at least 25 new patients per annum (Hegarty et al., 2008). Whilst effective, surgical treatments may have a profound impact on form and function of the penis (Branney et al., 2011, Maddineni et al., 2009), which in turn can impact on self-image and mental well-being (Romero et al., 2005, Ficarra et al., 2000, Bullen et al., 2010).

Research exploring the impact of penile cancer treatment are limited in scope, depth and quality (Maddineni et al., 2009). The vast majority of studies have utilised psychometric measures to examine psychological well-being, quality of life and sexual function (see Maddineni et al., 2009). Additionally, men with penile cancer have reported that they want research to explore the whole patient journey, which means we have to go beyond a limited focus on sexual and urinary function (Branney et al., under review-b). With the exception of a study in Wales (Bullen et al., 2010), there is a dearth of research using designs that allow for the in-depth exploration of men's experiences of treatment for penile cancer, particularly in relation to their sense of masculinity. It is unsurprising

therefore that treatment guidelines merely state that “psychological support is very important” (Pizzocaro et al., 2010) with nothing about how this could be achieved.

Aim

The patients’ experiences of penile cancer (PEPC) study comprised audio-visual narrative interviews with men diagnosed with penile cancer from across the UK. The aim of this paper is to explore these men’s experiences of surgical treatment for penile cancer and identify those aspects that they think impact on their quality of life.

Methods

Design

PEPC used a one-on-one narrative interview design, because it would allow us to explore each patient’s ‘oral histories’ (Herxheimer et al., 2000) of their experiences of penile cancer from pre-diagnosis onwards¹ rather than what clinicians or researchers thought was important. Data was collected using a single semi-structured interview of around an hour, which gave participant’s the time and freedom to explore what was important to them while avoiding the potential intrusion of multiple contacts with the study.

Recruitment and Sampling

The inclusion of a broad sample is vital to represent the many different ways that health issues affect peoples’ lives. We therefore used purposive sampling to aim for maximum variation in the sample, to include people whose experience of penile cancer might be considered ‘typical’ and those with more unusual experiences (Coyne 1997). We included adults from various social backgrounds and geographical locations, of different age groups at diagnosis, who had different treatments and were at varying stages of treatment or follow-up at interview. Access to participants was achieved through collaboration with consultants working within nine multi-disciplinary teams distributed across England and Wales. All men who had been diagnosed and treated for penile cancer were eligible for inclusion in the study. A small number of men presented strong, anxieties about participating in the study during first contact with the research team, these men were advised not proceed to interview out of a concern for their wellbeing.

Participants

Twenty-eight men were recruited and interviewed; one man withdrew at the transcript checking stage. Interviews lasted between 37 minutes and 2 hours 17 minutes. The average duration of interviews was 66 minutes. All men had undergone surgery, ranging from circumcision to total penectomy. Additional treatments included lymphadenectomy, radiotherapy or Interferon Alpha. Two men engaged with counselling services; another man received a consultation for psychosexual therapy. Seventeen of the men declared themselves as either being married or currently in a

¹ Further analyses and extracts from the interviews can be found at www.healthtalkonline.org/Cancer/Penile_Cancer (formerly DIPEX), an award-winning resource, which currently covers over 70 health conditions and issues.

relationship at the time of interview. The mean age at diagnosis was 63 years (range = 41 – 82) and at the interview it was 67 years old (range = 48-83) (see Fig. 1). Twenty six of the 27 were White, one man was Asian. Men were on average 3 years post-surgery (range = 0 - 15 years).

Procedure/Interview

The first question on the interview schedule was *'Please describe your experience of illness, from the point at which you first suspected that there may be something wrong'*. With this question men were encouraged to position their illness within the context of their wider lives, allowing *them* to set the agenda of the interview and enabling them to describe the impact of the illness on *their own* lives. Digital recording equipment was used to capture data. Men were given the choice of having their interview recorded using a digital audio recorder or additionally using a video camera.

On completion of the oral history, the interviewer asked each man supplementary questions to gain further insight into key issues and to seek clarification on elements of the narrative. Construction of supplementary questions was informed by findings from a participative one-day pilot workshop (Branney et al., under review-b). Topics covered included help seeking, diagnosis, treatment, information and support and impact of the illness and treatment. All interviews were conducted by the same male researcher (KW) over an eleven month period between December 2010 and November 2011. All interviews took place in the men's home, with the exception of two interviews, which were held in community settings.

Analysis

All interviews were transcribed verbatim from a digital audio file, checked by the researcher and sent to the participant for further checking and feedback, including any sections that they wanted omitted. A qualitative interpretive approach was adopted in analysis of data.

A thematic analysis was conducted using the constant comparative method (Glaser and Strauss, 1967). A researcher (KW) began analysis of transcripts as soon as the first interviews were completed. Categories for coding were identified from the researcher's own knowledge of the men's experiences of illness, reviewing the literature and the first few interviews as the analysis progressed, and as unanticipated themes emerged additional categories were added. This approach, where the researchers begin with some knowledge of the likely themes to emerge, is recognised as a modified form of grounded theory research (Cutcliffe, 2005). Coding was conducted using qualitative analysis software, this software enabled the research team to generate links between sections of data, record memos and efficiently manage data. When coding was complete, the researcher examined the data under each category noting down each issue raised and the ID of each interviewee on a piece of paper 'OSOP' ('one sheet of paper') analysis. Axial coding was then used to group issues raised under broader themes and identify deviant cases (Ziebland and McPherson, 2006).

Two researchers (KW & PB) wrote up each OSOP analysis as a distinct paper called a 'topic summary'. Each topic summary was checked for completeness by a 3rd researcher (JE) familiar with all the data. As the researchers talked to clarify and amend themes and discuss their progress, the process was iterative and produced 24 topic summaries, which are all available at healthtalkonline.org. This paper focuses on those themes about the impact of surgery.

Ethical Considerations

The methods used in this and all healthtalkonline studies have been approved by Berkshire Research Ethics Committee (Ref: 12/SC/0495). Informed written consent was obtained from all participants. Participants chose to use their first name or a pseudonym. All data that was potentially identifying, such as hospital names, key locations and health professionals, were anonymised and stored on a secure server.

Fig. 1 Age distribution of men at diagnosis and interview.

Results

The impact of surgery on men's lives varied considerably, informed by multiple aspects of their lives. The talk of impact was overlaid with an idealised version of masculinity of stoicism, independence and resilience. For the purpose of reporting, themes are presented as discrete categories, with the impact of surgery on urinary and sexual function reported first and subsequently contextualised within the impact of surgery on the broader lives of men. Such categorisation is, however, somewhat artificial as within the context of the lives of men experiencing treatment, physical impact of surgery was often inter-connected with broader aspects of the lives of men, for example relationship status, age and social support. All quotes are presented alongside the participant's first name or pseudonym, age group at diagnosis and relationship status at the interview. One person chose neither their first name nor a pseudonym and is therefore referred to by an interview reference number.

Urinary function

Surgical removal of the primary tumour can affect the flow of urine from the penis. This can be temporary, improving as the penis heals, or may be chronic. Some men receiving surgery experienced urinary spray and inconsistent flow. A number of men talked about practising using the toilet and re-training themselves. Urination aids, such as a funnel, helped to assist urination. After surgery, several men found it easier to urinate sitting down. Other men receiving a partial penectomy or a total penectomy, required further corrective procedures such as a meatotomy or a meatoplasty to improve the flow of urine and regain adequate urinary function. Men receiving a total penectomy will have their urethra diverted to another location in the body. In this study, Michael reported preferring a new urethra between the anus and testicles (a perineostomy) to one attached to a bag on the abdomen (an ileal conduit urinary diversion), which he considered to be messy and impractical.

For some men, changes to urinary function, resulting from surgery, appeared to impact on their engagement with the wider world. They reported that they wanted toilet facilities when away from the home where they could sit down to urinate. For Paul, embarrassment was also a factor, fearing that other men would become suspicious should they see him struggling to use a urinal in a public toilet; in order to prevent this happening he used a cubicle. Some men reported using toilets for the

disabled, which provided them with greater access to appropriate facilities when away from the home.

"I can still kind of stand there like any normal man and urinate, it's just that if I'm out in public places I feel like when you're struggling to try and find yourself, to urinate, you know you think all the guys are looking at you and thinking, you know, 'what's the matter with him' kind of thing. That was why I hid myself away in a cubicle. Just out of sheer embarrassment."

Paul, 55-59, single

Sexual function and sexual relationships

The impact surgery had on men's sexual function appeared to vary considerably. Participants talked about diagnosis, relationship status, and procedure performed influencing their experiences. In particular, some men said that had they been younger when diagnosed, the condition would have had a greater impact on their sexual function and quality of life.

"I mean sex is what you make it, if you know what I mean, and at our age it isn't the important thing it was when you're young. When you first get married it seems to be the most important thing of your life but you get older and it doesn't take on that mantle so much."

Frosty, 65-69, married

Several participants were able to resume an active sex life after a period of recovery. For these men, intercourse was 'different', but still enjoyable. Tim felt intercourse was less satisfying than before the operation. Nevertheless, he said that his sex life had been reinvigorated through experimentation, which had developed from the re-evaluation of his sexual relationship with his wife.

"My wife and I, have both got used to the actual intercourse not being as, as satisfying as it was for either of us, but, with a bit of imagination you can make up in other ways... I think we still have fulfilling sex. My wife said actually the first time we tried it after the operation, she said, 'Oh it's like being a teenager again' [chuckles]. So yeah, it can have its plus [points]"

Tim, 50-54, married

Several men pointed out that their own lack of sexual gratification was less of a concern than feelings of being unable to satisfy their partner. Simon, who received a total penectomy indicated that the cessation of intercourse that followed his surgery left him feeling as though he was denying his wife the sexual satisfaction she deserved.

"Me and my wife never make love anymore; it's her I feel sorry for really"

Simon, 60-64, married

Few men in the PEPC study discussed the impact of treatment on libido, but for those who did, libido was an important aspect of their narrative. For Mark, sexual urges, after a total penectomy appeared to contribute to a disconnection between his sensory self and his physical self.

"Just because I don't have a penis, I still have sexual feelings... I still feel like I can get an erection. Obviously I can't because I haven't got a penis"

Mark, under 50, single

Healing and recovery

Post-surgical rehabilitation could be complicated by infection. For some men experiencing infection, this prevented them from moving forward physically and emotionally. Other men found that they lacked visible scars and the healing enabled them to regain 'ownership' of their penis.

"The scarring appeared to be getting bigger and I then became fairly highly concerned. I was then concerned, you know, 'has the cancer come back?' 'Was it not successful?' and all these thoughts go through your mind."

Tom, 65-69, married

Several men talked about a loss of mobility and feeling lethargic after treatment. However, many of the men interviewed had experienced other health concerns, and several had experienced lymphoedema as a consequence of lymph node removal related to their cancer. For these men, it was often difficult to differentiate the effects of other health conditions, or the effects of ageing, from those of the treatment for penile cancer.

Masculinity

Men sometimes talked about feeling 'emasculated' and losing their 'manhood'. Paul said that he had lost the confidence to approach potential sexual partners and that he felt different from what he thought was the masculine norm. For Mark, feelings of emasculation appeared to be informed by changes to his body image and a disconnection between self-image and the masculine ideal; sexual functioning appeared to be less important. Mark went on to link plans of reconstruction of his penis to regaining a masculine body image.

"I don't feel a proper man. I feel completely emasculated and it's difficult to explain but I still have a problem wearing shorts, because, I think that people know. And it's silly I know, but I think that people will look and realise that I haven't got a penis."

Mark, under 50, single

In contrast, other participants said that their surgery had either fleeting or negligible consequences for their masculinity. For these men, their advanced age and, in some cases, being widowed meant that sexual function lacked importance for their sense of being a man.

"I think sex life changes as you get older anyway and it's probably had a marginal effect but it's very slight. I think there's far more to being a human being and far more to being a man than just simply being dependent on a penis."

David, 65-69, married

Mental Well-being

Participants talked about a broad range of emotional responses to their surgery, from depression to relief. Immediately after surgery, some participants' penis was bandaged and catheterised, which meant they had a period when they were unable to see the consequence. The removal of bandages and the sight of their penis was met with shock, relief and/or joy. The severity of the surgery, how informed they felt about the treatment and their expectations of the end-result were all talked about as aspects of their emotional response. For men like Les, a positive response to seeing the results of the surgery appeared to be mediated by a general positive outlook on life, encapsulated in his focus on the preservation of function rather than cosmetic appearance. Simon felt uninformed about the extent of his surgery and while he ultimately accepts the consequences ('that's the way it was done') he was completely shocked when he saw the results.

"I was really chuffed, you know [laughs] I'm going to be alive, it's not killed me, I've beaten this thing and to have sort of survived cancer if you like, it still works, it doesn't look the best [but] it performs when it has to do."

Les, married, under 50

"That was a shock. Yeah, I wasn't expecting it to be just like that, because I was expecting just a bit cutting off and send me away, you know what I mean. I think that were a bit rash, just to do it like, just to do it like that, you know. But, that's the way it was done."

Simon, 60-64, married

Two men talked about experiencing depression after what was for them the initial trauma of the operation. They talked about having feelings of loss, which they felt combined with their long recovery periods in the onset of their depression. Participants talked about how feeling low and anxious would have implications for how they engaged with others. John reported having mood swings, which he felt were damaging his relationship with his wife. Others talked about getting angry quicker than before surgery, experiencing low confidence and struggling to interact with others.

Coping and Support

Accepting change, adopting a positive life view, looking to the future, rather than dwelling on the past, were all felt by men to be protective factors against mental and emotional ill health over the longer term. Humour was also employed as a means of mitigating feelings of embarrassment and awkwardness experienced by men and others. Narratives appeared to be overlaid with hegemonic male discourse, with stoicism and emphasis on personal resilience often making it difficult to establish the meaning of these strategies to men using them. For many men humour, forward thinking and acceptance appeared to act as both a constructive way of coping but also as a means of disassociating themselves from the experience.

The support of wives and partners was frequently referenced as an important factor in coping with the impact of surgery. Men who presented themselves as coping well with the impact of surgery on their mental health and wellbeing often reported strong social support from their partner, wife, friends and family. Men in relationships commonly reported the importance of gaining acceptance of bodily change from wives and partners, brought about by an open disclosure. For some men this acceptance and the reassurances provided by intimate partners, helped strengthen their relationship.

Many did not feel able to share their diagnosis with people beyond their immediate family, with men citing embarrassment and privacy as reasons. For men such as Jim telling others was, in itself, a valuable coping strategy.

"I've sort of shared this problem with family and friends. It's not a taboo subject. It's been kept in the open, which I think, if I'd lost a foot that would obvious... I felt better for it I'm sure. It's been accepted. And therefore I feel fine with it."

Jim, 55-59, in a relationship

Some men accessed Professional support in the form of counselling or psychosexual therapy. Mark talked about how counselling sessions helped support his rehabilitation.

"Me opening up to her has made me feel markedly better. It didn't happen overnight. It didn't happen straight away. The first time I went to her, I nearly did the box of Kleenex out. But, the next time I wasn't as bad."

Mark, single, under 50

Some men reported that counselling and psychosexual services were not offered to them by health professionals after receiving surgery, a number of whom stated they would have found them helpful. However, a greater number of men said that such services were unsuitable for them. One man suggested that there were people in greater need of such services than he was, whilst Simon, said the best strategy was just to get on with life.

"I think you could get some [counselling]. There's plenty of information about it, but I haven't done. To me it's just done, just get on with it, because you know, there's not much you can do about it now is there? I don't think anyway."

Simon, 60-64, married

Discussion

The aim of this study was to gain a greater insight into the impact of penile cancer surgery on men's physical and mental health and wellbeing and broader quality of life. While all men in the study had been successfully treated for penile cancer, with a range of different procedures, the price of surgery for these men was commonly a change to the form and function of the penis. The physical impact of treatment varied considerably and, possibly of greater importance, so did the meaning which these changes had in the lives of men experiencing them, a point neglected in existing literature (Branney et al., under review-a). Results from this study have shown that impact is rarely felt in relation to a single facet of a man's life. Men reported surgery affecting sexual, physical and psychological wellbeing with each facet informing aspects of others to varying degrees, thus indicating the complexity of men's pre and post-surgery care.

Much of the research on the impact of penile cancer surgery is focused on a single, discrete issue with which a man must contend after penile cancer surgery; commonly men's sexual function, neglecting the broader impact of surgery on men's lives. What the literature does show us is that many men treated for penile cancer are likely to experience changes in their sexual function, ability to engage in regular sexual intercourse (Romero et al., 2005) and following this achieve sexual satisfaction. Broadly speaking more radical surgery will have the greatest impact on men's sexual lives (Opjordsmoen and Fosså, 1994). However, research on penile cancer has provided conflicting evidence on the impact of such sexual impairment on men's mental health and wellbeing. A Norwegian study of men successfully treated with a range of procedures for penile cancer found no significant associations between mental symptoms and sexual function (Opjordsmoen and Fosså, 1994); and a Brazilian study of quality of life after partial penectomy found no evidence of anxiety and depression in participants (D'Ancona et al., 1997). Contrasting this, Ficarra et al's. cross-sectional study of health and psychological well-being in patients who experienced surgery for urological malignant neoplasms found patients receiving more mutilating treatments were most likely to have impairment of their general state of health and psychological well-being compared to controls (Ficarra et al., 2000, Maddineni et al., 2009). Some indication has been provided on the importance of context when looking at men's impaired sexual function, highlighting the role of methods used, culture and education as potentially contributing to the differences in research findings such as those referenced above (Romero et al., 2005, D'Ancona et al., 1997). Whilst acknowledging the diversity of male experience across cultures, the current findings and the Welsh study (Bullen et al., 2010) show variation in men's experience within a relatively homogenised

cultural context, introducing concepts beyond the scope of existing quantitative research on the topic.

Research has shown that men diagnosed with penile cancer are more likely to focus on the immediate treatment of the disease and may defer considering the implications of that treatment on their physiology and psychology (Bullen et al., 2010). Further to this, Ficarra et al. noted that the accuracy of information given to men before treatment and their subsequent expectation of the impact of the surgery can influence management of the disease (Ficarra et al., 2000). The interplay of these findings within the context of men within our study may go some way to explain why several men reacted with shock at seeing results of the surgery. We therefore need to develop and evaluate pre-surgical procedures to find those that best ensure that men with penile cancer are aware of the implications of surgery including realistic expectations about recovery and the impact on their broader life.

Within the current study, older men commonly stated that the treatment would have had a greater impact on them if they had received the diagnosis as a younger man. Although important, age was however, just one factor which appeared to influence impact and great variation in men's experience was also found within age groups. Bullen et al's study (Bullen et al., 2010) reported similar findings with not only age but also life experience referenced as helping men cope with the impact of treatment.

In line with previous studies (Bullen et al., 2010, Bullen et al., 2009, D'Ancona et al., 1997), the acceptance and support from wives and partners was found to be an integral part of coping with the impact of the surgery and regaining quality of life. Providing such support undoubtedly places great stresses upon intimate partners, meaning they may also require help to manage the impact of penile cancer surgery on themselves and their relationship.

Supporting findings from Bullen et al. (Bullen et al., 2010), men's narratives in our study were interlaced with a hegemonic discourse of a stoic and independent masculinity that emphasised robustness and resiliency in the face of health scares. In many instances this demonstration of 'maleness' appeared to mediate men's reporting of the impact of surgery on their psychology. This reticence undoubtedly represents a challenge to those providing psychological therapies.

Methodological considerations

The methodology employed in this and all healthtalkonline studies has been designed with the intention of using the same degree of rigour in the collection and analysis of the data as is expected in the presentation of evidence-based health information (Ziebland and Herxheimer, 2008). The methods have been developed and refined over 13 years and have been replicated in over 70 studies of health-related conditions and illnesses which are all available on www.healthtalkonline.org. Healthtalkonline studies are recommended in the NHS Evidence Process and Methods manual (National Institute for Health and Clinical Excellence, 2012) as trusted, evidence-based sources of patient, user and carer experiences of health and illness.

The studies use qualitative interview methods, which are widely regarded as the most appropriate method for collecting and understanding 'patients' experiences'. Healthtalkonline projects reflect

what is important to people facing different health conditions and also harness the appeal of patients' experiences to impart accurate, useful information to the public, patients and health professionals.

This study utilised maximum variation sampling and achieved diversity in terms of age and types of treatment. Nevertheless, the sample was relatively small, predominately White, with an under-representation from non-white backgrounds and lower socio-economic levels. Additionally, medical and nursing members of the study advisory panel noted that our sample lacked participants with conservative, organ preserving treatments compared to their clinical practice. Whilst acknowledging this deficiency, the study does offer the largest and most diverse qualitative dataset of men's experiences of penile cancer known to the team. Future studies should attempt to employ recruitment procedures that overcome the difficulties of recruiting from these groups and ensure they are represented within study samples.

It must be noted that when researching rare conditions, the sampling rationale is reversed; rather than aiming to recruit sufficient participants to achieve data saturation, the aim is to work out how best to use the information gathered given the limitations to recruitment (Branney et al., under review-b).

Conclusions

Men's experiences of surgery for penile cancer represent a complex web interlaced with their broader life. While it would be difficult to provide care that leaves all men with satisfactory experiences, this research shows that ensuring that men are well-informed about the extent and potential consequences of their treatment is a key area for development. Rehabilitation may be aided by the inclusion of partners, family or friends although their wellbeing would need to be incorporated into any such procedures.

Implications for Nursing

Penile Cancer is a rare condition that few nurses outside of specialist units will encounter however; it is likely that community nurses or practitioners in sexual health clinics may be the first contact for men with worrying symptoms. Should a diagnosis of penile cancer subsequently be made, nurses will adopt a key role in supporting men through treatment and post-discharge aftercare. Alongside routine tasks of post-operative care (such as assessment of the wound for infection; checking for urinary retention and fluid retention in the legs if lymph nodes have also been excised) nurses caring for men treated for penile cancer face the additional challenge of helping them cope with the potential impact of penile surgery on, sexual relationships mental wellbeing and their sense of masculinity.

Nurses in urology clinics and wards need to be aware of the difficulty men face in coming to terms with the potentially debilitating effects of penile cancer, but also to avoid assuming the worst as some men do accept their condition. Each case needs to be managed through a careful assessment of the patient, using screening tools, communication and rapport building strategies and an on-going evaluation of the effectiveness of the care delivered. Psychosexual guidance may be required by the men and their partners to be able to cope with a partial or total excision of the penis, therefore

practitioners should not only provide information on appropriate services available to patients and their partners, but also ensure that reluctance to attend these services is sensitively challenged.

References

- BLANCO-YAROSH, M. 2007. Penile cancer: an overview. *Urologic Nursing*, 27, 5.
- BRANNEY, P., RAINE, G., WITTY, K., BRAYBROOK, D., BULLEN, K., WHITE, A. & EARDLEY, I. under review-a. Sexual function after treatment for penile cancer: a systematic research review of qualitative research of patients' experiences.
- BRANNEY, P., WITTY, K., BRAYBROOK, D., BULLEN, K. & EARDLEY, I. under review-b. Men with penile cancer want quality-of-life research to explore the patient journey with some consideration to humour: a participative one-day pilot workshop study.
- BRANNEY, P., WITTY, K. & EARDLEY, I. 2011. Patients' experiences of penile cancer. *European Urology*, 59, 959-61.
- BULLEN, K., EDWARDS, S., MARKE, V. & MATTHEWS, S. 2010. Looking past the obvious: experiences of altered masculinity in penile cancer. *Psycho-Oncology*, 19, 933-940.
- BULLEN, K., MATTHEWS, S., EDWARDS, S. & MARKE, V. 2009. Exploring men's experiences of penile cancer surgery to improve rehabilitation. *Nursing Times*, 105, 5.
- CUTCLIFFE, J. R. 2005. Adapt or adopt: developing and transgressing the methodological boundaries of grounded theory. *Journal of Advanced Nursing*, 51, 421-428.
- D'ANCONA, C. A. L., BOTEGA, N. J., MORAES, C. D., LAVOURA JR, N. D. S., SANTOS, J. K. & NETTO JR, N. R. 1997. Quality of life after partial penectomy for penile carcinoma. *Urology*, 50, 593-596.
- FICARRA, V., RIGHETTI, R., D'AMICO, A., PILLONI, S., BALZARRO, M., SCHIAVONE, D., MALOSSINI, G. & MOBILIO, G. 2000. General State of Health and Psychological Well-Being in Patients after Surgery for Urological Malignant Neoplasms. *Urologia Internationalis*, 65, 130-134.
- GLASER, B. G. & STRAUSS, A. L. 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Chicago, Aldine.
- HEGARTY, P. K., REES, R. W., BORLEY, N. C., RALPH, D. J. & MINHAS, S. 2008. Contemporary management of penile cancer. *BJU International*, 102, 928-932.
- HERXHEIMER, A., MCPHERSON, A., MILLER, R., SHEPPERD, S., YAPHE, J. & ZIEBLAND, S. 2000. Database of patients' experiences (DIPEX): a multi-media approach to sharing experiences and information. *The Lancet*, 355, 1540-1543.
- MACMILLAN CANCER SUPPORT. 2013. *Penile cancer (cancer of the penis)* [Online]. Available: <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Penis/Penilecancer.aspx> [Accessed February 2013].
- MADDINENI, S., LAU, M. & SANGAR, V. 2009. Identifying the needs of penile cancer sufferers: A systematic review of the quality of life, psychosexual and psychosocial literature in penile cancer. *BMC Urology*, 9, 8.
- MINHAS, S., KAYES, O., HEGARTY, P., KUMAR, P., FREEMAN, A. & RALPH, D. 2005. What surgical resection margins are required to achieve oncological control in men with primary penile cancer? *BJU International*, 96, 1040-3.
- NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE. 2012. *NHS Evidence Process and Methods Manual* [Online]. Available: <http://www.evidence.nhs.uk/nhs-evidence-content/process-and-methods-manual> [Accessed].
- OPJORDSMOEN, S. & FOSSÅ, S. D. 1994. Quality of life in patients treated for penile cancer. A follow-up study. *British Journal of Urology*, 74, 652-657.
- PIZZOCARO, G., ALGABA, F., SOLSONA, E., TANA, S., VAN DER POEL, H., WATKIN, N. & HORENBLAS, S. 2010. Guidelines on Penile Cancer.
- POW-SANG, M. R., FERREIRA, U., POW-SANG, J. M., NARDI, A. C. & DESTEFANO, V. 2010. Epidemiology and Natural History of Penile Cancer. *Urology*, 76, S2-S6.
- ROMERO, F. R., RICHTER PEREIRA DOS SANTOS ROMERO, K., DE MATTOS, M. A. E., CAMARGO GARCIA, C. R., DE CARVALHO FERNANDES, R. & CARDENUTO PEREZ, M. D. 2005. Sexual function after partial penectomy for penile cancer. *Urology*, 66, 1292-1295.

- SMITH, Y., HADWAY, P., BIEDRZYCKI, O., PERRY, M. J., CORBISHLEY, C. & WATKIN, N. A. 2007. Reconstructive surgery for invasive squamous carcinoma of the glans penis. *European Urology*, 52, 1179-85.
- YAGNIK, V. 2009. Carcinoma of the penis. Report of three cases and review of literature. *The Internet Journal of Surgery*, 20.
- ZIEBLAND, S. & HERXHEIMER, A. 2008. How patients' experiences contribute to decision making: illustrations from DIPEX (personal experiences of health and illness). *Journal of Nursing Management*, 16, 433-439.
- ZIEBLAND, S. & MCPHERSON, A. 2006. Making sense of qualitative data analysis: an introduction with illustrations from DIPEX (personal experiences of health and illness). *Medical Education*, 40, 405-14.