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**Link to publisher's version:** <https://doi.org/10.1111/ijun.12106>

**Citation:** Branney P, Witty K, Braybrook D et al (2016) Mortality and sexuality after diagnosis of penile cancer: a participative study. *International Journal of Urological Nursing*. 10(3): 137-145.

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This is the peer reviewed version of the following article: Branney P, Witty K, Braybrook D et al (2016) Mortality and sexuality after diagnosis of penile cancer: a participative study. *International Journal of Urological Nursing*. 10(3): 137-145, which has been published in final form at <https://doi.org/10.1111/ijun.12106>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving.

**Full Title:** Mortality and sexuality after diagnosis of penile cancer: a participative study

**Running Head:** Mortality, sexuality and penile cancer

### **Abstract**

**Objectives:** Survival for penile cancer is high but treatment can have a long-term detrimental effect on urological function and quality of life. Due to its rarity, it is difficult to include men with penile cancer in research about their condition. The aim of this study was to identify aspects of their diagnosis and treatment that they would want explored in penile cancer research.

**Design:** The study employed a participative, mixed-qualitative-methods design; it utilised focus groups and patient-conducted interviews, combined into a one-day 'pilot workshop'. The data were analysed using framework analysis.

**Results:** 'Early signs and seeking help', 'disclosure of a 'personal' cancer' and 'urological (dys)function' emerged as three key themes.

**Conclusions:** Men with penile cancer want research about their condition to explore early signs and helping seeking, disclosure of a 'personal' cancer and urological (dys)function. Research could use methodologies that include consideration of the chronological narrative of the experiences of men with penile cancer, which could be applied in clinical practice by integrating opportunities to explore specific aspects of their experiences at appropriate times along the care pathway.

## **Introduction**

Whilst the aim of care for penile cancer is to provide a cure while maintaining the anatomical function of the penis, the standard treatment is surgical excision of the primary tumour (and a margin of normal penile tissue) (Pizzocaro et al., 2010), which means that sexual and urinary functioning can be impaired. Approximately 80% of those with early stage disease survive beyond five years (Pizzocaro et al., 2010) and up to two third report impaired sexual functioning (Maddineni, Lau, & Sangar, 2009). There is evidence of reduced quality of life in up to 40% of patients (Maddineni et al., 2009), whilst one clinic found signs of psychiatric morbidity and post-traumatic stress in almost half of a sample of patients (Ficarra et al., 1999). Nevertheless, there is evidence to suggest that some patients are still able to achieve sexual satisfaction despite impaired functioning (Maddineni et al., 2009). Indeed, rather than experiencing dramatic alteration to their sense of masculinity, men report subtle and insidious changes (Bullen, Edwards, Marke, & Matthews, 2009). While the effects on sexual functioning and masculinity may be unsurprising, these findings highlight that the experiences of men with penile cancer are complex and require in-depth exploration if we are to develop treatment, rehabilitation and support that meets patients' needs.

As penile cancer is rare in Western populations (Pizzocaro et al., 2010), including men who have been treated for penile cancer in research about their condition remains a challenge. Patient involvement in research provides information (Jackson, 1999; Rydin & Pennington, 2000), encourages creativity and innovation (Involve, 2005), and improves the quality of decision making (Johnson, Lilja, & Ashby, 2001). While it is common to include one or two patients in advisory or steering groups across the life of a study, there is scope to include larger numbers in shorter elements nested within a trial.

## ***Aim***

The present study was a one-day pilot workshop nested within the Patients' Experiences of Penile Cancer study (PEPC; Branney, Witty, & Eardley, 2011). The workshop complemented the PEPC advisory group, which required a greater time commitment. The workshop preceded the main phase of PEPC, which comprised audio-visual narrative interviews conducted with men across the UK about their experiences of diagnosis and treatment. The aim of the pilot workshop was to identify aspects of patients' diagnosis and treatment that they believe warrants further exploration in penile cancer research. This will be outlined in this paper while also considering the usefulness of the pilot for patient and public involvement.

## **Methods**

### ***Design***

The study adopted a participative, mixed-qualitative-methods design combined into a one-day 'pilot workshop'. Focus groups and interviews were employed. In the focus groups, participants designed a one-on-one semi-structured interview schedule. Each focus group had an experienced qualitative researcher (the facilitator; PB and KW) who was there to help clarify the aims of the study, and the potential advantages and disadvantages of different aspects of interview technique. The small group format of the focus groups meant that participants could discuss potential interview questions with others who had personal experience of the diagnosis and treatment of penile cancer. Group interaction encouraged a range of interview questions and variety of views about them.

At the end of the discussion each focus group had created an interview schedule, which was subsequently piloted in participant-conducted one-on-one semi-structured interviews. The interview replicated the design used in the main phase of PEPC and gave participants an opportunity, after constructing an interview schedule, to experience (as an interviewer or interviewee) the conduct of such research. While the interviews would help to identify key issues, their primary aim was to ensure that the pilot workshop was a two-way process in which participants could also learn about the process of conducting interview-based research.

The one-day format was designed to facilitate patients' short but intense involvement in the development of a study about their experiences. The one-day design also meant that a variety of men who had been diagnosed with penile cancer could be involved in designing the study. Additionally, as a participative workshop running on a single day, the focus groups allowed time for participants to work together, getting to know each other and build rapport, before the one-on-one interviews.

### ***Sample & Recruitment***

While the aim of a sampling strategy for qualitative health research is usually to ensure that the analysis can reach saturation, we would argue that rare conditions require a different approach. Instead, we have to work out how many participants it is possible to recruit given practical limitations, and consider what we can achieve from that data. We aimed to recruit a maximum variation (Marshall, 1996) sample of 5 to 10 men diagnosed and treated for penile cancer. The intention of this recruitment strategy was to include the widest possible range of experiences in terms of age, type of treatment and time since treatment. Nevertheless, the sampling would be limited by the variety of participants available and interested in the study.

The minimum age for inclusion was 16 years due to legal requirements for signing consent forms, but in practice penile cancer is unlikely under 40 years of age. As

many people take a partner, family member or friend with them to healthcare visits, the workshop incorporated companions in discussions running parallel to the focus groups and participant-conducted interviews. This meant that everyone attending the workshop (except the research team) had been directly or indirectly affected by penile cancer. Nevertheless, the focus of this paper is on men with penile cancer, so we will exclude the data from the companions and explore this elsewhere.

Participants were recruited through a single UK supranetwork multidisciplinary team (Sn-MDT; National Institute for Clinical Excellence, 2002) specialising in penile cancer, covering a population of >4 million and seeing >30 new cases annually. A clinician asked patients if they would talk to a researcher about a study and if they were interested sent them to a clinic room where they could speak to the researcher (PB or KW). Recruiting 5 to 10 participants would have meant that it was possible to conduct two focus groups (A & B), and then have participants interview someone from another group (A interview B, or A interviewed by B) and produce up to 5 interviews (assuming N=10).

### ***Analysis***

Qualitative analysis often aims to inductively identify analytical categories from the data, but the design of this study meant that participants created the key questions (in the form of the interview schedules). Indeed, inductive qualitative approaches engender an analytic scepticism about the talk of the participants (Gondolf, 2000) whereas a deductive approach would mean that we could stick close to the concerns participants highlighted in the interview schedules. Consequently, we applied the five stages of framework analysis (Pope, Ziebland, & Mays, 2000); i) familiarisation, ii) identifying a thematic framework, iii) indexing, iv) charting, v) mapping and interpretation. The analysis was conducted by PB and checked by KW, both of whom were at the pilot-workshop.

The interview schedules were used as the framework (stage ii) from which to deductively index or code all data from the respective focus group according to whether it related to one or more of the 'frames'. Subsequently, the two framework analyses were combined and rearranged to identify similarities and differences between the focus groups (charting, stage iii). The charting stages allowed for the integration of the two sets of initial findings, identifying larger themes while still staying close to participants' concerns. The participant-conducted interviews were analysed to further identify any aspects that elucidated or challenged the themes identified in the focus groups. In the final stage of mapping and interpretation, the data was brought together to identify the key issues and their interconnections.

### ***Research Governance***

Ethical approval was given by South Yorkshire Research Ethics Committee: an organisation independent of the researchers whose working practices are established by the National Health Service (NHS) Patient Safety Agency.

Participants chose whether they were to be identified by their first name or a pseudonym. There was a multi-stage informed consent process. Signed informed consent was taken at the start of the workshop, when the researchers discussed anonymity and confidentiality, giving practical examples and explaining their limitations. Furthermore, access to toilet and changing facilities had been agreed with participants beforehand and they were free to use these at any time.

### ***Procedure***

During registration, two experienced researchers (PB & KW), a junior researcher (DB) and a research administrator welcomed participants, talked through the day and completed consent forms (see Figure 1). First, there was the introduction in which the researchers described the research topic and explained how qualitative interviews were conducted, including how audio and video recording equipment was used. As none of the participants knew each other, they were asked to sit at one of two tables, which subsequently made up the two focus groups. The focus groups were audio recorded and the researchers kept a list of questions raised during the discussion to help construct the interview schedule. This was followed by audio and video participant-conducted interviews in which they could try out the research methodology that was to be used in the main phase of PEPC. See Figure 1 for the workshop schedule, which was sent to participants before the event. As well as the focus groups and interviews, there was time (during registration, the introduction and subsequent breaks) for the participants to learn about the day, ask questions, and build rapport.

### **Results**

#### ***Describing the Sample***

Ten men attended the workshop (primary participants), three of whom were accompanied by their wife (companions). As would be expected, most participants were over 55 years old (see Table 1); a single man attending was under the age of 50, although a second had received his diagnosis when under 50. Seven of the ten men lived with their wife/partner and the remaining three were widowed and/or single. All men described themselves as White British and heterosexual. Six participants reported that their primary treatment was a glansctomy (see Table 1). The sample included one each with glans resurfacing, a total penectomy and radiotherapy as the primary treatment and one where it was unknown. Seven were treated after the 2002 publication of UK standards of care for penile cancer, which restricted surgical procedures and postoperative care to named hospitals within a Sn-MDT (National Institute for Clinical Excellence, 2002).

#### ***Interview Schedules***

Two focus groups were conducted and each created an interview schedule (Table 2). Focus Group A wanted to start the interview by ensuring that their participant

was comfortable and by explaining the process of the interview, which is in their preamble. This is a standard but unspoken part of interviewing technique and can signal the transition from the initial introduction (meeting, saying hello, etc.) to the start of the interview (usually when the recording device is switched on). Focus Group A also used the preamble to clarify how the participant would like to refer to the penis, so that the researcher and participant would establish what terms to use and hopefully dispel discomfort about referring to urological functioning. Focus Group B used the term 'waterworks' in question 3 to refer to both sexual and urinary functioning.

Using the interview schedules as the framework for the analysis of the focus groups, 'early signs and seeking help', 'disclosure of a 'personal' cancer', and 'urological (dys)function' emerged as three main themes.

### ***Early Signs and Seeking Help***

Participants recalled a lack of engagement akin to avoidance or delay in help-seeking after noticing a lump or wart on their penis (Table 3). Tom calls this 'sticking my head in the sand' (Group A) and for several men, gender (being male) was mobilised to explain avoidance. Women were cast as experienced users of healthcare services who had been socialised to adopt a functional help-seeking style. As is seen in GP surgeries (Seymour-Smith, Wetherell, & Phoenix, 2002), men conceded control of the initial diagnostic stage to others, in particular to female companions, who were used to legitimise help-seeking. Participants spoke of feeling a helpless inevitability about what was to come, fearing the loss of their penis and conscious of their mortality (Table 3). When the point of diagnosis was reached this led to an eruption of fear and a shift in temporal perspective, from the long to the short-term, as they faced their mortality. Early physical signs and, particularly, the moment of 'diagnosis', led to a process of problem-focused and systematic information seeking.

### ***Disclosure of a 'Personal' Cancer***

The penis and the tumour was seen as personal, and participants talked about their embarrassment should others learn of their cancer and associated treatment. As such, attempts to limit disclosure – for example, to only family – was part of a need for privacy that was maintained by a fear of what others might think. Participants did note that the anatomical location of their cancer meant that it largely remained invisible to others, which had some advantages for maintaining privacy

In some cases, disclosure to the family and partner was seen as automatic or 'obvious' because they were kept up-to-date with medical appointments (Table 4). Other participants elected to keep appointments private until a definitive diagnosis was reached, protecting family and their partner from potentially unnecessary anxiety. Financial and practical considerations were paramount; some talked about making plans to "make sure there was a foundation" (Tom, Group A). Categories of

people to whom they would disclose their diagnosis related to levels of perceived responsibility, with the “immediate family” and their partner of primary concern, followed by extended family, colleagues at work, neighbours, and friends (John, Group B).

Nevertheless, there were practical limits to non-disclosure, such as their avoidance of urinals in public toilets or overnight hospital appointments when colleagues, neighbours, etc. might notice their absence. Participants managed disclosure, tailoring the information given to different people. Saying that their cancer was ‘down there’ was a way of providing a vague location while closing off further discussion (Table 4).

### ***Urological (Dys)Function***

Participants indicated that fears about urination arose soon after diagnosis, when treatment plans had been considered. Wearing a catheter post-operatively was considered worse than the operation to excise the tumour (see Table 5). Catheters presented multiple practical problems, including the logistics of supply, wearing/changing bags and sleeping. For some, urinary problems diminished as they recovered from surgery. Indeed, the removal of the post-surgical catheter was talked about as if it was a rite of passage: they had to prove themselves by urinating three times before they could go home/the district nurse would leave them, symbolising their recovery and self-control (over urination).

In response to the issue of sexual function, for Tom (Group A), the ability to maintain a sex life was “the most obvious” day-to-day issue for men with penile cancer. Participants noted that it would be difficult to discuss sex in interviews and, as mentioned, this was also evident in the focus groups, where discussion focused on elaborating difficulties with urination over those with sexual function.

### **Discussion**

The aim of this study was to identify those quality-of-life aspects of diagnosis and treatment that men with penile cancer thought most affected them, and thus which they would want explored in further research. Utilising a participative, mixed-qualitative-methods design, the study found three key themes; ‘early signs and seeking help’, ‘disclosure of a ‘personal’ cancer’ and ‘urological (dys)function’. That urological (dys)functioning should be a theme is unsurprising and is the primary concern of the quality-of-life research on penile cancer (Maddineni et al., 2009). Echoing Bullen et al’s findings, this theme shows how participant’s sense of masculinity (Connell, 2005) is a complex interplay of the *symbolism* of social practices (such as what using or not using a urinal means) and the *real* effects of the body. Participants’ talked of what they *imagined* others might think of them even when their penis was hidden by their clothing (Lacan, 1997[1953-54]).

Combined, the three themes can be read as a chronological narrative of patients' experiences of penile cancer; the story starts with noticing symptoms, then moves from the responses to receiving a diagnosis to disclosure to family, neighbours and colleagues, and finally moves onto dealing with the effects of treatment. The themes from Bullen et al.'s study in Wales (Bullen, Edwards, et al., 2009) can also be read together as a sequential story over time; 'grappling with [the] reality' of symptoms and diagnosis, 'learning to cope' with the challenges of seeking support, whether to disclose and changes to sexual and urinary functioning. In penile cancer trials, it is likely that researchers will turn to psychometric measures to quantify differences in quality of life between treatments. What this research shows is that future research should explore quality of life up to and beyond treatment. This could be done by interviewing a sub-sample of participants in each treatment arm of a trial, using patients' stories to complement the quality of life and survival outcomes.

The chronological narrative supports patient-focused models of care. Bullen et al.'s research (Bullen, Edwards, Marke, & Mathews, 2008; Bullen, Edwards, et al., 2009; Bullen, Matthews, Edwards, & Marke, 2009) suggests that the problem-focused responses to diagnosis evident in both this and the Welsh study (Bullen, Edwards, et al., 2009) are an attempt to regain control when faced with their mortality. Additionally, Bullen et al. (Bullen, Edwards, et al., 2009) found that men with penile cancer talked of receiving emotional and practical support from others, which means that disclosure may be one means to dealing with their diagnosis. Throughout the cancer journey, a patient-focused approach could explore the impact of diagnosis and treatment and how, through disclosure, patients can seek support from others.

This study recruited a maximum variation sample to ensure that the widest possible range of experiences were included. None of the participants had undergone laser therapy and they were of limited ethnic diversity. Further research could attempt to include the views of wider groups of men with penile cancer. Notwithstanding the limits to generalisability, these findings should be considered alongside other sources of information, such as health policy or service changes, while also including patients and the public in future studies. In terms of the topics discussed by participants, there was a notable lack of discussion of sex in the theme of urological (dys)function given that most participants had their primary tumour surgically excised. The sample may have underrepresented those for whom treatment has devastating effects on sexual function. Alternatively, the group format may have discouraged participants from discussing sexual intimacy and intercourse: individual research designs such as one-on-one interviews may prove more fruitful for this topic. Additionally, the one-day design may have meant that participants lacked the rapport and trust necessary for them to share aspects of their sexuality, thus longer-term approaches may allow this to develop.

## **Conclusion**

The one-day workshop design is useful as a participative model of research where patients can contribute to and learn about interview research concerning their condition. Men with penile cancer want research about their condition to explore early signs and helping seeking, disclosure of a 'personal' cancer and urological (dys)function. This can be done through the idea of the patient-journey, using research methodologies that include consideration of the sequential narrative of their diagnosis and treatment. These findings can be applied in practice by integrating opportunities, at appropriate times, within the care pathway to explore the impact of a) diagnosis and b) treatment, and c) prompting patients' to consider how they can use disclosure of their condition to seek support from others.

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