European Journal of Oncology Nursing 17 (2013) 661–667

Contents lists available at SciVerse ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

The impact of surgical treatment for penile cancer – Patients' perspectives

Karl Witty [a,*], Peter Branney [b], Julie Evans [c], Kate Bullen [d], Alan White [a], Ian Eardley [e]

[a] Centre for Men's Health, Leeds Metropolitan University, UK
[b] School of Social, Psychological & Communication Sciences, Leeds Metropolitan University, UK
[c] Health Experiences Research Group, University of Oxford, UK
[d] Department of Psychology, Aberystwyth University, UK
[e] Pyrah Department of Urology, Leeds Teaching Hospitals NHS Trust, UK

Keywords:
Cancer
Penile neoplasms
Men
Qualitative research
Patient experience
Healthtalkonline

ABSTRACT

Purpose of the research: 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.

Methods and sample: The study used a narrative history design in which data were collected using one-on-one semi-structured interviews. Maximum variation sampling was used to acquire the widest possible range of experiences. Twenty-seven interviews of around one hour were conducted with men with an average age of 63 years at diagnosis (range = 41–82). The data were analysed using constant comparison analysis.

Key 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.

Conclusion: 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 lives, 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.

Introduction

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-flurouracil 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,

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* Corresponding author. Centre for Men's Health, Faculty of Health and Social Sciences, Leeds Metropolitan University, Queen Square House, 80 Woodhouse Lane, Leeds LS2 8NU, UK. Tel.: +44 113 8121968.

E-mail address: k.witty@leedsmet.ac.uk (K. Witty).

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http://dx.doi.org/10.1016/j.ejon.2013.06.004

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 2 cm 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 is 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). 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 onwards[1] 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 well-being.

Participants

Twenty-eight men were recruited and interviewed; one man withdrew at the transcript checking stage. Interviews lasted between 37 min and 2 h 17 min. The average duration of interviews was 66 min. 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 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.

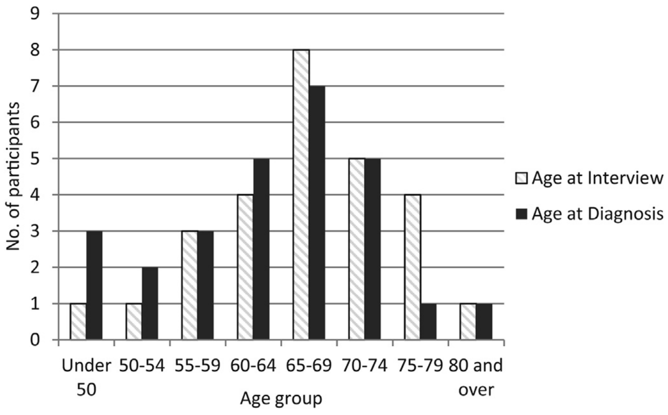

Fig. 1. Age distribution of men at interview and diagnosis.

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[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.