

Patient perspectives on quality of life after penile cancer

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ABSTRACT

INTRODUCTION: Penile cancer (PC) is a rare, but ominous disease. In 50-60% of squamous cell carcinomas of the penis, human papilloma virus infection, particularly with types 16 and 18, is part of the pathogenesis. Depending on cancer invasiveness, PC is treated with local resection of the glans and partial or total penectomy. This quality of life (QoL) study aimed at obtaining in-depth knowledge about patients' experiences with PC.

MATERIAL AND METHODS: A literature study was carried out to identify relevant topics for a semi-structured interview. Qualitative interviews with four former PC patients were transcribed verbatim and analysed using a medical anthropological approach. The analysis focused on the ways patients frame their disease experiences and relate the physical, sexual and emotional disease impact.

RESULTS: Varying degrees of amputation affected the participants' sexual capabilities. Still, three participants (aged 66-72 years) said that their partner relationships were not negatively affected by the disease. In contrast, the impact on sexual function and self-esteem had been devastating to the fourth participant (aged 44 years) who was single and worried about the disease impeding his chance of finding love in life. For all participants, having had a potentially fatal disease put the physical disease impact into perspective.

CONCLUSIONS: PC may greatly impact the psycho-sexual QoL of PC patients, particularly at a younger age and depending on their partnership status. Disease impact appears to be related to age, overall life situation and the cancer experience.

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Penile cancer (PC) is a relatively rare, but highly distressing disease. PC accounts for approximately 0.9% of male cancers in the developed world. Squamous cell carcinoma of the penis (pSCC) accounts for 95% of penile malignancies. In Denmark, the incidence is 0.8/100,000 per year – with a mean age of 65 years at diagnosis [1, 2].

Early childhood circumcision protects against pSCC. Non-retractile foreskin (phimosis) and poor genital hygiene are important risk factors for pSCC. Human papilloma virus (HPV) infection is part of the pathogenesis in 50-60% of pSCC patients, with HPV 16 and 18 (and sec-

ondarily 6/11) being the genotypes most commonly detected in PC tumours [3, 4]. Aetiological similarities have been found with SCC of the head and neck, the female genitalia, and the anal canal [5].

The primary lesion localizes mainly to the prepuce and the glans [6]. The paramount route of penile cancer dissemination is via the lymphatic vessels to the inguinal lymph nodes, typically presenting as palpable inguinal lymphadenopathy. 30-45% of men presenting with pSCC have lymph node metastases at the time of diagnosis. Such metastases predict a poor prognosis [7, 8]. Surgery is recommended for the treatment of primary PC. Superficial pSCC can be treated by local resection of the glans, whereas more invasive tumours require partial or total penectomy.

In addition to the worries related to any cancer, this particular location and the treatment of this cancer instinctively appear as a severe strike on a man's sexual capability and sense of masculinity. Hence, some recent studies have focused on penile preserving techniques and reconstructive surgery to reduce the assumed psycho-sexual morbidity associated with treatment [9, 10]. The present study aimed at examining patients' perspectives on the impact of PC and its treatment on relevant aspects of their quality of life (QoL).

MATERIAL AND METHODS

A literature study revealed only few quantitative studies of QoL in PC patients. None of these used a disease-specific standardised tool, but showed that PC and its treatment may, indeed, affect patients' physical, emotional and sexual well-being [11-16]. This formed the basis of a semi-structured interview guide aiming to examine how patients weigh and relate these factors to each other. Qualitative interviews with four former PC patients aimed at obtaining in-depth knowledge about their experiences with PC and the consequences of treatment. The interviews were transcribed verbatim and analysed using a narrative medical anthropological approach focusing on the ways patients frame their disease experiences [17].

The participants were recruited via the Department of Urology, Aarhus University Hospital, one of two specialised penile cancer treatment centres in Denmark, and one via a general practitioner (GP) and sexologist in

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Penile tumour on the left side of the glans involving the corona glandis. Histopathological tumour growth into the corpus spongiosum without urethral involvement (T2).

Copenhagen, Denmark. Patients were eligible if they had completed treatment for PC at least six months earlier and had no significant co-morbidity. No personal information about the participants was passed on to the authors, and their anonymity was safeguarded throughout. All participants gave informed consent and the study did not require ethics committee approval.

Trial registration: not relevant.

RESULTS

The participants' mean age at the time of diagnosis was 58.5 years (Table 1). No participants knew their HPV status, and because their disease perceptions were central to the study, such data were not subsequently collected. No participants were smokers at the time of the inter-

views. Three out of four participants had phimosis at the time of diagnosis. Two said it had developed during previous years. The first cancer symptoms were bleeding from the meatus, malaise and lumps on the glans penis which the participants perceived to be caused by infections. One participant sought immediate medical attention, while the rest delayed for 1½-24 months. This delay was mostly explained as disregard, a hope it would heal spontaneously and, in one case, embarrassment with regard to talking with the GP about it. Once the GP was consulted, the patients were referred to a specialized hospital department within 1-12 weeks, sometimes via private specialists.

Patients' perceptions of the penile cancer diagnosis and treatment

To all participants, the PC diagnosis came as a shock. Besides occasional spurs of fear, three (males no. 2-4) had, nevertheless, been confident throughout that they would survive this cancer. All put great trust in the medical specialists and only one (male no. 4) discussed treatment with his doctors. No participants knew or had asked about the causes of this disease. The three older participants (males no. 1-3) described their course of treatment as uncomplicated and effective though male no. 2 still had minor wound healing problems. In contrast, male no. 4 underwent four surgery sessions within six months which was very upsetting – especially the need for partial penectomy. Subsequent complications with a closing urinary tract were painful as was the futile attempt to widen it through surgery and self-catheterization. He considered the end cosmetic result to be much worse than if the initial glansectomy had been effective.

TABLE 1

Participant characteristics.

Participant	Age at time of interview, yrs	Age at diagnosis, yrs	First symptoms	Time span between first symptoms and first medical appointment	Treatment for penile cancer
Male no. 1	69	67	Fatigue, malaise, small lump on the glans penis	Immediate	Total glansectomy with preservation of foreskin, removal of lymph nodes in 2 groin, 6 chemotherapy treatments and 32 radiation treatments
Male no. 2	66	63	Lump under the foreskin believed to be an infection (phimosis)	Approx. 2 yrs	Local resection (removal of approx. 1/4 of the glans) Subsequent laser treatment due to poor wound healing
Male no. 3	72	64	Increasing bleeding from the meatus, seeming infection under the foreskin (phimosis)	12-18 months	Partial penectomy Years later a few lymph nodes were surgically removed from 1 groin due to suspicion of metastasis (which turned out to be unfounded)
Male no. 4	44	40	Lump under the foreskin believed to be an infection (phimosis)	6 weeks	4 operations within ½ yr: 1. Glansectomy (with reconstruction of foreskin using skin from the thighs of which some was kept for later use) and removal of lymph nodes in both groins 2. No lymph node metastasis, but removal of another 1½ cm of the penis needed (partial penectomy) 3. Surgery to prevent a developing closure of the urinary tract due to scar tissue (failed) 4. Plastic surgery to prevent closure of the urinary tract (succeeded)

Physical disease impact

At the time of the interviews, all participants had terminated treatment and followed their regular controls. None of them had pain or troubles urinating, which they needed to do sitting down, however. Males no. 1 and no. 4 said their overall physical condition was poorer than before, though the latter remains professionally active. The three older participants retired before diagnosis.

The impact of penile cancer on partner relationships and sex life

The various degrees of amputation affected the participants' sexual capabilities. Still, there were important differences between the three older men and the younger male (male no. 4). Male no. 1 had been married for over 40 years, while males no. 2 and no. 3 had had lady friends since the death of their former spouses. None of these mature relationships were negatively affected by the PC. The older men said that coitus had become less integral to intimacy while companionship, care and caresses meant more. Two already had some erectile dysfunction before the PC, so the adaptation required after penile surgery and its impact on their sensitivity and capability was less sudden to them. Males no. 2 and no. 3 said that their relationships were closer now owing to the course of disease and the support they had received from their partners.

In contrast, the impact on sexual function had been devastating to the younger patient (male no. 4). At the time of diagnosis, he had just met a woman and had no children. She left him shortly after and since then, he never managed to enter a relationship. At the time of the study, he longed for love in his life, but feared he might never achieve it. He was concerned that he might repulse or scare women away due to his partial penile amputation.

Psychological disease impact

Male no. 4 only told one woman about his PC and felt that it had scared her off. At the time of the study, he felt different and was occupied by a sense of loss of manhood. This greatly impacted his courage to seek a new partner and his overall emotional well-being. One of his main difficulties had been to accept that he sometimes longed for the care he had received at hospital. The course of treatment had been dreadful, but at the same time, he was cared for like never since.

Male no. 4 said he never feared that the cancer would kill him, but worried about how it would change his quality of life – which it definitely had. The three older men all experienced great support, in particular, from their partners. They also had children and grandchildren who took up much of their time. Still, male no.



FACTS

Changes in sexual intimacy in mature relationships

"Sex has changed a bit. Before it was fantastic, now it's different. You do what you can. We mostly cuddle and caress each other. My [penile] sensitivity is gone and I have difficulties getting or holding an erection, so that [coitus] has come to an end. She's not so interested anymore either, and the same actually goes for me. But our relationship has become stronger. We kiss and hug and hold each other. It fits with where we are now. We've moved closer and even though it's not a sex life like before, it's become more delicate in a nice way – the way old people might do it" (male no. 3).

Penectomy may cause fear of rejection and lost opportunities of finding love

"It's hard for me to bring it [the penectomy] up with a woman. I'm afraid to be rejected because of it. I think timing is decisive when it comes to sharing that information. At least that's what I tell myself. If I tell it too early, it might repulse her from even wanting to find out whether it's a problem at all. But if I take too long, she might say that I could have bloody well told her before we got that far. I imagine that I have a very narrow window that I might not be able to find. But I would really like to have someone to share my life with and I still hope to find that love. But my thoughts around it make it difficult for me" (male no. 4).

Anxiety following penile cancer

"The psychological reaction hasn't come until recently. At night, I get stomach aches. I think it is psychological because I have been prescribed some calming pills and when I take them, I calm down. I'm afraid it [cancer of some kind] comes back. The closer I get to the controls every three months, the worse it gets. ... I also get very tired and I've got trouble breathing. Even when I get up in the morning, I feel I can't breathe and have to go outside. Then all of a sudden, it goes away again. I'm wondering if that's also psychological. One night, I went to an after-hours doctor who examined me, but concluded there was nothing wrong with me. But if it stings somewhere, I start thinking it might have something to do with that [cancer]" (male no. 1).

1 had developed panic attacks manifesting as stomach aches and troubles breathing. He had received several medical examinations before it was concluded that the symptoms were related to anxiety of a cancer relapse rather than any physical problems themselves.

Patient rehabilitation needs

No participants had been offered any kind of rehabilitation. Males no. 1 and no. 4 would have appreciated professional help to get back into physical shape; male no. 4 sought psychological counselling on a private basis. Males no. 2 and no. 3 mainly coped thanks to the support of their partners and faith in the medical specialists. All participants said it had been important to be met with empathy and consideration by healthcare professionals.

DISCUSSION

The penis is both a cultural and an individual symbol of masculinity, potency and fertility. As such, it may be integral to male self-perception and it is to be expected that penile disease may affect a patient's QoL. This has led some urologists to explore less radical operating techniques and a few others to examine QoL in PC pa-

tients [11-16]. A disease-specific quantitative tool has yet to be developed, however. Two studies interviewed patients [11, 14], but the present study is the first to examine the physical and psycho-sexual QoL impact of PC using qualitative research methods to gain a deeper understanding of select patients' disease experiences. It is, however, a limitation that the study did not include a wider spectrum of participants with respect to age, ethnicity and civil status. Also, as is always the case with qualitative studies that include only few participants, the results can be generalized only analytically, not statistically.

This study indicates that differences in patients' age may affect the QoL impact of PC. In our participants, higher age was associated with mature partner relationships, having children and grandchildren and being retired. This all influenced coping with PC and the consequences of its treatment. The three older males (no. 1-3) all had partners and it should be noted that their sexual expectations and priorities had reportedly changed even before the PC diagnosis. In contrast, the partial penectomy and subsequent lack of capacity to perform coitus was important to male no. 4 and the derived impact on his prospects of finding love and companionship were decisive to the QoL effects of the condition.

While one study has shown that having a good partner relationship plays a decisive role in maintaining sexual QoL after PC [12], others have suggested important negative QoL effects of amputation on sexual function – deteriorating with more radical surgery – partnership and psychological well-being [11, 13, 14]. As the present study suggests, the participant selection is critical to grasp the nuances to the role of sexuality on QoL. This study shows that death too was perceived differently by the older men than by male no. 4. Males no.1-3 had experienced death at close hand as two had lost their wives to cancer; they knew that most of their lives lay behind them. Having survived PC meant relatively more than their sexual deficiencies. This is in accordance with a study of the QoL impact of prostate cancer which suggests that the life-saving nature of treatment mitigates concerns about erectile function [18]. Patients' age and overall life situation was thus central to their assessments of their QoL following PC.

It is likely that HPV vaccination is effective in preventing HPV-associated penile tumours [19], but in Denmark, male HPV vaccination awaits the recommendation of the European Medicines Agency (EMA). In PC, attention is paid to less invasive treatment options for select patients with the added advantages of preservation of body image and improved QoL. It has also been suggested that surgeons become experienced in reconstructive techniques and genital surgery as a whole, rather than in oncology alone [9, 10]. Some patients may

be involved in the choice of treatment and, as we have shown, the patient's life situation may play a considerable role in setting his priorities. Finally, this study confirms that some negative effects can be mitigated by post-treatment psycho-sexual and physical rehabilitation [20].

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