Brief Report

Penile cancer awareness and knowledge among adult patients in an ambulatory urology clinic

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Abstract: Penile cancer (PeCa) is a rare urologic malignancy in the United States, and public awareness remains low. In this brief report, we design and execute a survey to evaluate knowledge and awareness of PeCa focusing on general PeCa knowledge, treatment options, and willingness to recommend a preventative intervention. Study participants were recruited with a study flyer from the waiting room of two Los Angeles community-based urology clinics. All patients were English-speaking and over 18 years old. Study recruitment took place from October 2021 to June 2022 and 83 participants were included. The majority of respondents were men (90%) and white (87%), with a mean age 63 years. Ninety-eight percent of respondents reported either knowing "nothing" or "a little" about PeCa; 69% of respondents did not know a person could get cancer on the penis. Knowledge of risk factors for PeCa was particularly poor, with respect to phimosis (5% correctly identified this as a risk factor), balanitis (28%), and human papilloma virus (HPV) (44%). The majority of respondents, however, reported that they would recommend administration of an HPV vaccine for the prevention of PeCa (89%) once informed of HPV as a risk factor. Our findings underscore the lack of knowledge and awareness of PeCa, which may contribute to future delays in care.

Keywords: Penile cancer (PeCa); survey; ambulatory clinic; knowledge gap

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Introduction

Penile cancer (PeCa) represents a rare and potentially devastating urologic malignancy. In the United States (U.S.), the incidence is less than 1 per 100,000 men, with just over 2,000 cases and 450 deaths attributed to the disease reported annually (1). PeCa is a significantly more common malignancy in the developing world due to factors such as limited access to healthcare, poor hygiene practices, high rates of human papilloma virus (HPV) infection, and other intersectional factors (2). We have made significant improvements in prevention, diagnosis, and treatment substantially improving PeCa outcomes in the last three decades, especially with respect to organ-sparing approaches, radiation therapy, and sentinel lymph node biopsy (3). This has been further examined through limited yet focused research as it pertains to HPV, improved treatment options, and the role of socioeconomic status in diagnosis and treatment. The majority of epidemiological data of PeCa comes from North America & Europe, despite

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the highest rates of PeCa occurring in South America and parts of Africa (4). To date, no study has specifically evaluated PeCa awareness among patients in an ambulatory urology clinic setting, with much of the literature asserting low awareness impacts prevention, diagnosis, and treatment. This study aims to address this gap and provide valuable insights into patient knowledge and attitudes in this unique context. The impact that awareness of other cancers has on attitudes towards screening and treatment has been well-documented for many other cancers including breast, cervical, and prostate cancer (5-7). Unfortunately, many patients report delays in seeking medical attention for PeCa due to fear, stigma, shame, and lack of awareness of the disease (8). In this report, we survey individuals presenting to a general urology clinic to query knowledge of PeCa, treatment modalities, and preventative measures. The article is presented in accordance with the SURGE reporting checklist (available at https://tau.amegroups.com/article/view/10.21037/tau-2025-41/rc).

Methods

The study questionnaire was designed using an iterative process involving our multidisciplinary research team. We first constructed a process map to ensure the survey would be focused on our study aims: general PeCa knowledge (relative incidence, risk factors, respondents' self-reported knowledge level, etc.), treatment options, and willingness to recommend a preventative intervention (the HPV vaccine). These categories were based on similar endpoints used in other studies that looked to quantify awareness of other types of cancer (9,10). The questionnaire was trialed among a group of urologists and medical researchers in the University of California, Los Angeles (UCLA) Department of Urology. The questionnaire was initially drafted by one urology attending (N.M.D.), one urology resident (E.L.W.), and two urology researchers at UCLA (E.P. and K.C.W.). The draft was then reviewed by two additional urology faculty members, who provided feedback. Following their input, the questionnaire underwent one round of revisions before being finalized by the original drafting team (N.M.D., E.L.W., E.P., and K.C.W.). The pilot questionnaire was not formally tested on patients; instead, it was iteratively refined (two iterations total) within the team to ensure clarity and relevance to the study objectives. Edits to the questionnaire were made to improve clarity and brevity following feedback after administration of the pilot questionnaire. Average completion time was under 5 minutes during pilot testing. Similar methodologies for construction of questionnaires have been previously validated (11). Once a consensus was reached, the final questionnaire was designed in Qualtrics (Seattle, WA, USA).

Study participants were passively recruited with a study flyer from the waiting room of two urology clinics in Burbank, CA and Santa Clarita, CA. There was no restriction for participation other than being English speaking and over 18 years old. Participants were excluded if they did not respond to any penile-cancer related questions in the survey (e.g., respondent stopped during demographic survey questions).

This study was conducted in accordance with the Declaration of Helsinki and its subsequent amendments, and was approved by the institutional review board of our institution, David Geffen School of Medicine, University of California, Los Angeles (IRB#21-001134). The study was open for recruitment from 09/2021 to 07/2022. All participants provided written informed consent prior to their inclusion in the study. For participants who were unable to provide written consent, consent was obtained from a legally authorized representative.

Given limitations associated with our sample size, only descriptive statistics were performed on the data. Missing data are noted in the tables, where applicable.

Results

A total of 88 participants started the survey; of these, 5 only responded to all or some of the demographic questions and stopped prior to the PeCa portion of the survey and were therefore excluded. Eighty-three participants were included in this study. The majority were men (90%) and white (87%), with a mean age 63 years. Most participants had a high income with 73% earning above $70,000 annually. Over 50% of participants received health insurance through their employer and 95% reported seeing a primary care provider regularly. *Table 1* outlines participant demographic information in greater detail.

Self-rated knowledge of PeCa was low, with 98% of participants reporting either knowing nothing (73/83) or a little (8/83). This is consistent with other answers to the survey as 69% of participants did not know a person could get cancer on the penis prior to starting the survey. Forty percent of participants did not know if PeCa would be fatal, while 4% believed it was probably or definitely not fatal. Most participants (83%) were able to identify a lump or growth on the penis as a potential symptom of PeCa;

Table 1 Demographic characteristics of participants (n=83)

Characteristics	Value
Age (years)	63±13 (28–86)
Male	75 [90]
Race[†]	
White/Caucasian	72 [87]
Black/African American	3 [4]
Asian	8 [10]
Other	3 [4]
Hispanic/LatinX ethnicity	12 [14]
Marital status	
Never married, no partner	11 [13]
Never married, partnered	4 [5]
Married	61 [73]
Widowed	1 [1]
Divorced	4 [5]
Other	2 [2]
Insurance[†]	
Through employer	49 [59]
Self-insured/exchange	5 [6]
Medicare	32 [39]
Tricare/Veterans administration	1 [1]
Other	13 [16]
Household income (U.S. dollars per year)	
<50,000	6 [7]
50,000–70,000	9 [11]
>70,000–100,000	17 [20]
>100,000	44 [53]
Education	
High school/GED	8 [10]
Some college	20 [24]
Associate's degree	2 [2]
Bachelor's degree	28 [34]
Master's degree	14 [17]
Professional degree (JD, MD)	6 [7]
Doctorate (PhD)	1 [1]
Trade	4 [5]
Primary care physician	79 [95]
Personal cancer history	36 [43]
Family cancer history	69 [83]
Known anyone with penile cancer	3 [4]
Circumcised (of men)	64 [81]

Data are presented as mean ± SD (range) or n [%]. Race: three individuals selected more than one option for the race category. Latinx: one person did not respond. Insurance: nobody selected Medicaid or Indian Health Service. No respondents answered Native American/Alaska Native or prefer not to say for race. For household income, 7 participants (8%) chose not to report their income, resulting in 76 total responses for this item. [†], respondents could select all that apply for race and insurance coverage so percentages may not add up to 100. GED, General Educational Development, equivalent to high school diploma; JD, Juris Doctor; MD, Doctor of Medicine; PhD, Doctor of Philosophy; SD, standard deviation.

however, 51% of the responses included incorrect symptoms of PeCa including: a lump on the testicle and blood in the urine. It is important to note that participants were asked to identify typical symptoms of PeCa, rather than potential symptoms, to focus on common early presentations. Late-stage symptoms, such as hematuria, were not the intended focus of this question. *Figure 1* demonstrates the frequency of correctly and incorrectly identified symptoms of penis cancer. Respondents consistently reported having either no knowledge, or demonstrated incorrect beliefs about risk factors, treatments, and outcomes related to PeCa. Knowledge of risk factors for PeCa was particularly poor, with respect to phimosis (5% correctly identified this as a risk factor), balanitis (28%), and HPV (44%). Despite poor self-assessed knowledge of the link between HPV and the development of PeCa, a majority of respondents indicated they would recommend the HPV vaccine if it were proven to definitively prevent PeCa (89%). *Table 2* outlines these findings in greater detail. The Centers for Disease Control and Prevention (CDC) currently recommends routine HPV vaccination for individuals aged 11–12 years, with catch-up vaccination available up to age 26 years. In 2018, the U.S. Food and Drug Administration (FDA) expanded approval of the HPV vaccine to include individuals aged 27 through 45 years, recognizing its potential to prevent HPV-related diseases, including cancers. Recent discussions have explored further expanding HPV vaccination efforts

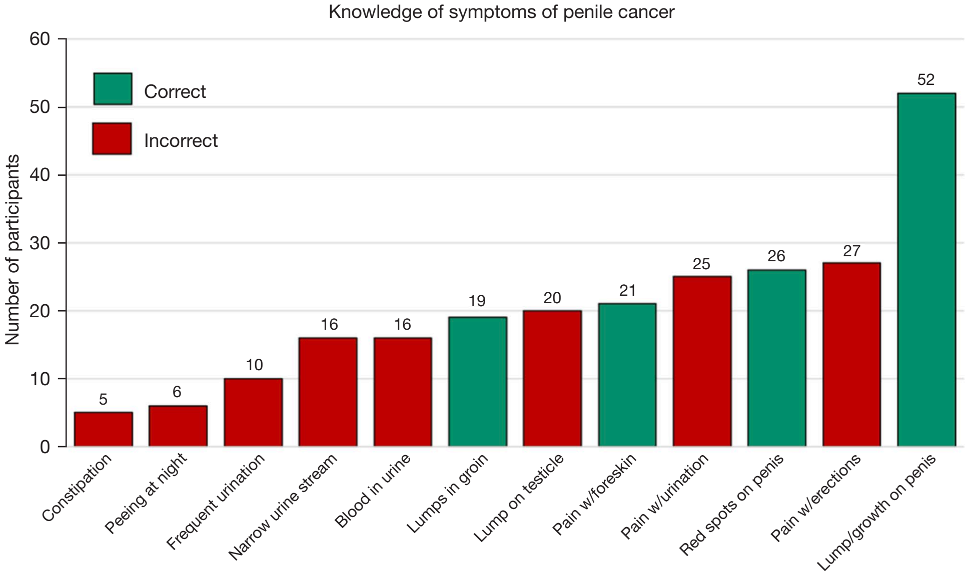

Figure 1 Knowledge of symptoms of penile cancer among participants.

to older populations and high-risk groups, as well as integrating HPV-related cancer prevention into broader public health initiatives (12,13).

Discussion

This study is the first to assess PeCa awareness in an ambulatory urology clinic setting. Our findings confirm that even among a relatively well-educated, higher-income population with good access to healthcare, awareness of PeCa remains extremely low. Most participants were unaware that PeCa exists, had limited understanding of its risk factors, and demonstrated misconceptions about symptoms and outcomes. Despite these gaps in knowledge, there was strong recognition of HPV vaccination being an important preventative factor.

Men with PeCa often experience a delay obtaining appropriate medical attention, and hence often experience delays in diagnosis and treatment. This delay can be compounded in the setting of poor understanding of the aggressive natural history of this disease. Moreover, no screening guidelines exist for PeCa in the U.S. The bottleneck to the knowledge in this group regarding PeCa likely did not stem from their lack of faith in preventative medicine, as 95% of this group reported to see their PCP regularly.

It is well-documented in the literature that low socioeconomic status and other intersectional factors such as black race, Hispanic ethnicity, nonmetropolitan area, lack of insurance, never being married OR being divorced, are associated with worse clinical factors of PeCa like advanced stage, treatment delay and poor overall survival (14-16). Our findings show that even without many of these intersectional factors, the public consciousness and understanding of PeCa may not be as robust as that of other conditions. There is likely significant room for improvement in building awareness for this condition throughout a wide cross-section of society.

Formalized educational interventions and preventive counseling for PeCa remain limited. Unlike other cancers with established awareness initiatives, PeCa lacks integration into public health strategies, and no dedicated screening or prevention programs exist. Despite known risk factors—including HPV infection, poor hygiene, phimosis, and smoking—public education remains scarce, especially among those with low healthcare access, high HPV prevalence, and lower socioeconomic status.

Some PeCa awareness campaigns have emerged but remain small in scale and not necessarily focused on high-risk populations. The United Kingdom (UK)-based charity Orchid launched the #InDenial campaign to educate men and healthcare providers about risk factors, symptoms, and early detection (17). Similarly, the "Ignore It" video, developed by eUROGEN and the European Association of Urology, emphasizes the dangers of ignoring symptoms and highlights rising PeCa rates in the UK (18).

Table 2 Knowledge of penile cancer

Question	Answer option	Correct answers, $n_{correct}/n_{selections}$	Correct answers, $n_{correct}/n_{participants}$	Incorrect answers, $n_{correct}/n_{selections}$	Don't know, $n_{Don't\ know}/n_{participants}$	No response, n
Which body parts are affected in penile cancer?†	Penis skin	32/206 (16%)	32/83 (39%)	–	49/83 (59%)	0
	Prostate, bladder, scrotum, urethra	–	–	125/206 (61%)	–	–
Which doctor should a person with penile cancer see?†	Urologist	71/152 (47%)	71/83 (86%)	–	5/83 (6%)	5
	Primary care	39/152 (26%)	39/83 (47%)	–	–	–
	Oncologist	29/152 (19%)	29/83 (35%)	–	–	–
	Gynecologist, proctologist, general surgeon, nephrologist	–	–	8/152 (5%)	–	–
What are typical symptoms of penile cancer?†	Spots on penis	26/243 (11%)	26/63 (41%)	–	NR	20
	Lump/growth on penis	52/243 (21%)	52/63 (83%)	–	–	–
	Pain with foreskin retraction	21/243 (9%)	21/63 (33%)	–	–	–
	Lump in groin	19/243 (8%)	19/63 (30%)	–	–	–
	Lump on testicle, blood in urine, pain with urination, pain with erections, nocturia, constipation, narrow urine stream, frequent urination	–	–	125/243 (51%)	–	–
Risk factors?†	Smoking	12/181 (12%)	12/61 (34%)	–	NR	22
	Obesity	11/181 (6%)	11/61 (18%)	–	–	–
	STI	23/181 (13%)	23/61 (38%)	–	–	–
	Foreskin infections	17/181 (9%)	17/61 (28%)	–	–	–
	HPV	27/181 (15%)	27/61 (44%)	–	–	–
	Not being circumcised	6/181 (3%)	6/61 (10%)	–	–	–
	Unable to retract foreskin	3/181 (2%)	3/61 (5%)	–	–	–
	Poor foreskin hygiene	9/181 (5%)	9/61 (15%)	–	–	–
	Family history of cancer, chemical exposures	–	–	64/181 (35%)	–	–
Possible treatments?†	Removal of part of penis	32/168 (19%)	32/62 (52%)	–	NR	21
	Removal of all of penis	9/168 (5%)	9/62 (15%)	–	–	–
	Chemotherapy	49/168 (29%)	49/62 (79%)	–	–	–
	Radiation	45/168 (27%)	45/62 (73%)	–	–	–
	Circumcision	7/168 (4%)	7/62 (11%)	–	–	–
	Removal of lymph nodes	12/168 (7%)	12/62 (19%)	–	–	–
	Shaving of penis skin	14/168 (8%)	14/62 (23%)	–	–	–
Penile cancer prevalence?	Uncommon	55/83 (66%)	–	–	NR	0
	Common	–	–	28/83 (34%)	–	–

Table 2 (*continued*)

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Question	Answer option	Correct answers, $n_{correct}/n_{selections}$	Correct answers, $n_{correct}/n_{participants}$	Incorrect answers, $n_{correct}/n_{selections}$	Don't know, $n_{Don't\ know}/n_{participants}$	No response, n
Penile cancer transmissible?	Probably not	30/83 (36%)	–	–	41/83 (49%)	0
	Definitely not	9/83 (11%)	–	–	–	–
	Probably, definitely	–	–	2/83 (2%)	–	–
Rate of growth	Fast growing	1/83 (1%)	–	–	76/83 (92%)	0
	Slow growing	–	–	6/83 (7%)	–	–
Could someone die from penile cancer?	Probably yes	39/81 (48%)	–	–	32/81 (40%)	2
	Definitely yes	7/81 (9%)	–	–	–	–
	Probably no, definitely no	–	–	3/81 (4%)	–	–
Types of cancer related to HPV exposure[†]	Penis	42/212 (20%)	42/57 (74%)	–	NR	26
	Cervical	37/212 (17%)	37/57 (65%)	–	–	–
	Throat	18/212 (8%)	18/57 (32%)	–	–	–
	Anal	21/212 (10%)	21/57 (37%)	–	–	–
	Testicle, bladder, prostate, ovarian, colon	–	–	94/212 (44%)	–	–
Recommend an HPV vaccine if it could definitely prevent penile cancer	Probably yes	23/76 (30%)	–	–	NR	7
	Definitely yes	45/76 (59%)	–	–	–	–
	Probably no, definitely no	–	–	8/76 (11%)	–	–

[†], indicates that participants can select more than one answer. Some questions allowed multiple responses, resulting in a total response count exceeding the number of participants (n=83). NR: no response was recorded, as this was not an option. HPV, human papilloma virus; STI, sexually transmitted infection.

Existing cancer prevention models could inform PeCa education efforts. HPV vaccination programs, proven to reduce cervical and oropharyngeal cancers, should be expanded to high-risk male populations (19). STI clinics offer opportunities to integrate PeCa education into routine counseling, particularly for patients with HPV or Human immunodeficiency virus (HIV). Smoking cessation programs, which have successfully reduced lung and oral cancer rates, could incorporate PeCa risk messaging, as seen in anti-smoking campaigns linking tobacco use to bladder cancer. Additionally, circumcision, known to reduce PeCa risk, has been promoted for HIV prevention and could serve as a cost-effective educational strategy in regions with limited HPV vaccine access (20).

Our findings reveal significant gaps in PeCa awareness, even among individuals with regular healthcare access, mirroring knowledge deficits seen in other cancers before targeted awareness efforts. For example, in a study in India, over 50% of school teachers lacked knowledge of cervical cancer symptoms and screening, while a breast cancer study among college teachers found that fewer than 20% practiced regular breast self-examinations (BSE) due to lack of awareness (5,6). Similarly, an Australian prostate cancer study found low awareness of risk factors and screening, particularly in rural populations, leading to delays in care (7). A lack of GP-driven conversations and inconsistent screening recommendations contributed to these knowledge gaps. Unlike prostate cancer, which benefits from primary care discussions, PeCa is rarely addressed in provider-patient interactions, exacerbating diagnostic delays.

While breast, cervical, and prostate cancer awareness campaigns have successfully improved knowledge and screening rates, no comparable large-scale initiatives exist for PeCa. Minimal public discourse, limited provider emphasis, and a lack of standardized education efforts likely contribute to persistent knowledge gaps and diagnostic delays. Given the success of structured community-based cancer education programs, implementing similar public health outreach, digital awareness campaigns, and primary care education initiatives could help bridge this gap.

Our findings are aligned with previous investigations. In an interview study among eleven PeCa survivors in the UK, none had knowledge of the disease prior to their own diagnosis (21). In the same study, these individuals acknowledged feeling as if their general practitioners were also poorly informed on PeCa, "*There is nothing out there in the media about it, my doctor is awful, and this is one of the issues we talked about before, that local GPs don't know what's going on.*"

Several prospective studies underscore the importance of knowledge of PeCa in the timely self-referral to a medical profession. In one study of 59 PeCa patients in a Swedish university hospital, the majority of patients (65%) delayed medical evaluation for over 6 months after noting suspicious penile lesions (commonly erythema, rash, and eczema) (22). The most common reason for delaying care was embarrassment (39%), followed by: lack of knowledge, belief in spontaneous resolution, fear of severe illness, and believing the symptoms were not severe. In another prospective study in a population of men in China, 254 PeCa patients completed questionnaires regarding their diagnosis and treatment (23). The majority delayed seeking medical care after first noting a change in their penis (45% >3 months, 24% >6 months) with belief in spontaneous remission (27%), embarrassment (23%) and not feeling the symptoms were serious (19%) as the primary justification for delay. In both of these studies, presentation with erythema or eczema was associated with delays in seeking medical attention. Although virtually no screening/counseling guidelines are present around PeCa in the U.S., the results from this study could support exploring the impact of a conversation between PCPs and high-risk men (with phimosis, HPV, HIV, lack of circumcision etc.). Further studies would need to be conducted to operationalize the impact of making patients (especially with risk factors) more cognizant of PeCa.

Notable limitations of our study are worth mentioning. We present data from a single-center setting with a narrow population of a convenience sample (people in the waiting room of a urology clinic), which may certainly limit generalizability. Our study population consisted primarily of middle- to high-income, insured individuals, a demographic that does not represent the highest-risk groups for PeCa. Prior studies have shown that lower socioeconomic status, lack of healthcare access, and certain environmental exposures increase PeCa risk, and our findings may not generalize to these populations. Our study does not assess whether awareness of PeCa differs in these higher-risk regions compared to lower-risk populations. Future investigations should evaluate how awareness varies across different geographic, socioeconomic, and environmental contexts to better inform targeted education efforts. Future investigations may benefit from a multi-center study design with a more diverse and abundant population of respondents. Our target recruitment of 100 respondents was more challenging than anticipated and ultimately only 83 participants were included in the study. Factors related to poor accrual include poor efficacy of passive flyers in the waiting room, lack of dedicated research coordinator for study recruitment, and competing interests in the clinical setting (e.g., active urologic issues being addressed during their visit).

Conclusions

This study reveals significant gaps in knowledge among a well-educated, predominantly White, higher-income population with good access to care. Most participants lacked awareness of PeCa, its risk factors, and its potential symptoms, though respondents indicated support for HPV vaccination when presented with the premise that it could definitively prevent PeCa. These findings highlight a critical need for targeted educational interventions to increase public and provider awareness of PeCa, especially in populations with identifiable risk factors. Addressing these knowledge gaps may improve early detection and reduce delays in diagnosis and treatment, which are often exacerbated by fear and misinformation. Future studies should explore the efficacy of educational interventions and preventative counseling in high-risk populations, as well as the integration of PeCa awareness into broader health promotion strategies. Multicenter and more demographically diverse studies will further enhance our understanding of these barriers and inform strategies to promote timely care and improve outcomes for this malignancy.

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Footnote

Reporting Checklist: The authors have completed the SURGE reporting checklist. Available at https://tau.amegroups.com/article/view/10.21037/tau-2025-41/rc

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