Quality of life, voiding and sexual function of penile cancer patients: DaPeCa-10—a cross-sectional questionnaire survey

Jakob Kristian Jakobsen1 | Christian Møbjerg Sørensen1 | Kim Predbjørn Krarup2 | Jørgen Bjerggaard Jensen1,3

1Department of Urology, Aarhus University Hospital, Aarhus, Denmark
2Department of Urology, Rigshospitalet, Copenhagen University Hospital, Copenhagen, Denmark
3Department of Clinical Medicine, Aarhus University, Aarhus, Denmark

Correspondence
Jakob Kristian Jakobsen, Department of Urology, Aarhus University Hospital, Palle Juul Jensens Boulevard 35, 8200 Aarhus N, Denmark.
Email: jkjjakobsen@gmail.com

Abstract
Objectives: To assess prevalence of voiding and sexual symptoms and quality of life in penile cancer patients.

Methods: From 1 January 2013 to 31 December 2015, we approached three separate groups of Danish penile cancer patients and asked them to complete a face-validated questionnaire at diagnosis (Group 1), after 1 year (Group 2) and after 2 years (Group 3). We analysed symptom prevalence and bother and quality of life items and explored differences between groups.

Results: In total, we analysed 157 questionnaires. The response rates at diagnosis, after 1 year and after 2 years were 29%, 46% and 30%. The pad use ($p=0.001$) and occurrence of nocturia twice a night or more ($p=0.006$) was significantly decreasing 2 years after treatment. There was an increasing trend in sexual thoughts and importance of sexuality from 1 to 2 years after treatment, but the proportion of patients reporting a frequency of orgasm at more than once in the past 6 months was significantly decreasing after treatment ($p=0.03$). Likewise, the trend for erectile dysfunction worsened after treatment with 49% of patients reporting an erection never sufficient for intercourse at diagnosis increasing to 62% after 1 year and 69% after 2 years. We observed trends towards lower self-esteem with increasingly mutilating treatment.

Conclusion: Pad use, nocturia and frequency of orgasm were significantly reduced after penile cancer treatment. We observed trends towards lower self-esteem with increasingly mutilating treatment and increase in erectile dysfunction after treatment.

Keywords
penile cancer, quality of life, sexual life, voiding symptoms

1 | INTRODUCTION

Among a multitude of morphs in penile cancer, especially tumours at the external urethral orifice, larger glans involving or eroding lesions and tumours presenting with the clinical picture of complete phimosis may all cause voiding symptoms. Following resection involving the external urethral orifice and distal urethra, glansectomy, partial penectomy and total penectomy surgeons will perform a reconstruction...
of the urethral orifice, which in turn may lead to a new perception of voiding and varying challenges with urine stream control and need for urinary aids.

Many treatments of penile cancer may affect penile sensibility, reduce sensible areas, introduce deformity and reduce length. Some of these changes may inflict sexual challenges on patients, and in some cases, the sum of changes caused by disease and treatment may affect quality of life.\(^1\)–\(^5\)

Even if a cancer is perceived life-changing and body-image-altering, a number of human psychological defence mechanisms and survival instincts prevail in the dominating narrative of many patients, who mobilize remarkable coping strategies and thrive against difficult odds.\(^3\)–\(^6\)

Few studies have focused on differences at different time points in aspects of quality of life, voiding symptoms and sexual function after treatment for penile cancer.\(^7\) Such data may be useful in the planning of cancer rehabilitation and might guide the focus and themes of the clinical follow-up.

In this study we assess quality of life, voiding and sexual function related to three different points in time: at diagnosis, after 1 year and after 2 years. We assess outcomes related to type of treatment, and we compare Danish penile cancer patients with healthy Scandinavian men. This study is among the first to focus on quality of life and sexuality in penile cancer at different time points in the clinical trajectory.

### 2 | METHODS

We conducted a questionnaire survey among Danish penile cancer patients from 1 January 2013 to 31 December 2015 in connection with inpatient treatment and outpatient follow-up. The study was prospectively designed as a two-centre, three-time point cross-sectional questionnaire-based survey in penile cancer patients. All patients were treated and followed up at the only two Danish urology departments treating penile cancer with curative intent. Questionnaires were handed out, introduced and collected as a part of everyday clinical practice by health professionals involved in the clinical trajectory. There was no dedicated study specific organization.

We approached patients if they were newly diagnosed (Group 1) if they attended a 1-year follow-up visit in our outpatient clinics (Group 2) or if they attended a 2-year follow-up visit (Group 3) during the study period. Patients registered to have accepted participation but failing to return the questionnaire received an identical questionnaire, a pre-stamped envelope and a reminding letter per mail 1 month after inclusion. We excluded patients who failed to respond to first and second invitation to participate.

To assess response rates, we retrospectively extracted the patterns of referral to the two specialized centres treating penile cancer with a curative intent in Denmark from the Danish National Penile Cancer Database.

### 2.1 | Questionnaire

The questionnaire queried patients on a wide range of issues with focus on demographic data, psychological aspects of life, voiding symptoms and sexual experiences and symptoms. We developed the study specific questionnaire from a combination of validated questionnaires and a series of purpose-built single questions. We translated into Danish and adapted for penile cancer patients the validated Scandinavian Prostate Cancer Group Study Number 4 (SPCG-4) Questionnaire.\(^10\) The SPCG-4 Questionnaire is partly based on other validated tools and two psychometric tests such as Spielberger’s Trait measure from the State–Trait Anxiety Inventory\(^11\) and the Centre for Epidemiological Studies Measure of Depression.\(^12\) The psychological symptoms (anxiety, depressed mood), sense of well-being and quality of life were assessed on 7-point visual digital scales. We assessed the resulting penile cancer questionnaire for face validity in a pilot project with six patients. Because the pilot project only led to minor non-significant changes to the original questionnaire, we included these six patients in the study cohort. We considered responders sexually active if they had engaged in any form of sexual stimulation or intercourse 6 months prior to responding to the questionnaire.

### 2.2 | Comparison

We compared score prevalence between groups of penile cancer patients according to time of completion of the questionnaire and according to the type of treatment received.

### 2.3 | Statistics

We ensured that data were discrete and independent by only considering one response per patient. In 27 patients responding more than once, we only considered their latest response. We compared age between groups by ANOVA and differences between groups of other demographic and clinical variables by nonparametric tests. For statistical analysis we used Stata Statistical Software: Release 13, TX: StataCorp. We considered a p-value of 0.05 or less statistically significant.

### 2.4 | Sexological counselling

Coinciding with study initiation, we decided to offer all penile cancer patients free in-hospital post-operative sexological counselling by a specially trained nurse as a standard of care. Thus, all study participants were offered post-operative sexological counselling.

### 3 | RESULTS

The response rate of the questionnaires in Groups 1, 2 and 3 were 51/173 (29%), 69/151 (46%) and 37/122 (30%) (Figure 1). In total, we...
analysed 157 questionnaires from individual patients. Only two responses were collected following a reminding letter. The mean age of responders at the time of responding was 70.3 years in Group 1, 67.2 years in Group 2 and 66.4 years in Group 3 (Table 1). We recruited 145 patients (92%) in Centre 1.

### 3.1 Symptoms and distress associated with urinary functions in penile cancer patient groups

At the current group sizes, we found few differences in symptom prevalence or bother scores between penile cancer patient groups.
There was a significant difference in the self-reported occurrence of nocturia 24/51 (47%) in Group 1, 33/68 (49%) in Group 2 and 8/36 (22%) in Group 3, \( p = 0.006 \). Treatment significantly reduced the need for pad use from 14/50 (28%) in Group 1 to 5/68 (7%) and 2/36 (6%) in Groups 2 and 3, \( p = 0.001 \).

There was a trend towards increased voiding frequency 6/51 (12%) in Group 1 to 13/67 (19%) and 12/36 (33%) in Groups 2 and 3, \( p = 0.15 \).

### 3.2 Symptoms and distress associated with sexual functions in penile cancer patient groups

Trends towards increasing occurrence of sexual thoughts from first (69%) to second year (80%) after diagnosis \( (p = 0.40) \) and an increase in attributing moderate or great importance to sexuality from first (29%) to second year (42%) after diagnosis \( (p = 0.76) \) did not reach statistical significance. This was also true for the trend of increasing...

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**TABLE 1** Patient characteristics for three groups of Danish penile cancer patients responding to a validated quality of life questionnaire at diagnosis (Group 1), after 1 year (Group 2) and after 2 years or more (Group 3)

| Variable                        | Group 1 (n = 51) | Group 2 (n = 69) | Group 3 (n = 37) |
|---------------------------------|-----------------|-----------------|-----------------|
| Age, years                      |                 |                 |                 |
| Mean                            | 70.3            | 67.4            | 66.4            |
| Median                          | 71.3            | 69.0            | 68.3            |
| Range                           | 43.6–91.7       | 46.9–92.5       | 41.2–87.2       |
| Body mass index (BMI) kg/m²      |                 |                 |                 |
| Mean                            | 28.8            | 27.4            | 26.5            |
| Median                          | 27.8            | 26.7            | 26.1            |
| Range                           | 23.1–40.8       | 19.6–41.7       | 19.7–42.9       |
| Marital status, n (%)           |                 |                 |                 |
| Married or cohabiting           | 38 (74)         | 50 (73)         | 24 (65)         |
| Living alone without a partner   | 8 (16)          | 12 (17)         | 7 (19)          |
| Living alone, but has a partner  | 4 (8)           | 4 (6)           | 4 (11)          |
| Widower                          | 1 (2)           | 3 (4)           | 2 (5)           |
| Educational level               |                 |                 |                 |
| Compulsory school only           | 29 (57)         | 44 (64)         | 25 (68)         |
| Upper secondary school           | 8 (16)          | 16 (23)         | 7 (19)          |
| Higher education                 | 14 (27)         | 9 (13)          | 5 (13)          |
| Source of income                 |                 |                 |                 |
| Employed                        | 16 (31)         | 16 (23)         | 13 (35)         |
| Unemployed/looking for a job     | 0               | 2 (3)           | 0               |
| Sickness pension/sickness benefit| 2 (4)           | 5 (7)           | 3 (8)           |
| Retired/pension benefit          | 33 (65)         | 46 (67)         | 21 (57)         |
| Performance status\(^a\)        |                 |                 |                 |
| 0                               | 32 (63)         | 45 (65)         | 25 (68)         |
| 1                               | 16 (31)         | 20 (29)         | 9 (24)          |
| 2                               | 2 (4)           | 4 (6)           | 2 (5)           |
| 3                               | 1 (2)           | 0               | 0               |
| 4                               | 0               | 0               | 1 (3)           |
| Type of treatment                |                 |                 |                 |
| Local resection and/or laser     | -               | 35 (51)         | 18 (49)         |
| Partial penectomy                | -               | 20 (29)         | 14 (38)         |
| Total Penectomy                  | -               | 14 (20)         | 5 (13)          |
| Treatment Centre 1/2             | 39/12           | 69/0            | 37/0            |

\(^a\)Performance status according to the Eastern Cooperative Oncology Group: 0 = fully active, able to carry on all pre-disease performance without restriction, 1 = restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, for example, light house work and office work, 2 = ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours, 3 = capable of only limited self-care; confined to bed or chair more than 50% of waking hours, 4 = completely disabled; cannot carry on any self-care; totally confined to bed or chair.
erectile dysfunction 25/51 (49%) in Group 1 to 42/68 (62%) and 25/37 (69%) in Groups 2 and 3, \( p = 0.30 \). The frequency of orgasm was reported with a significant decline in the number of responders having more than one orgasm 6 months prior to responding 29/50 (58%) in Group 1 to 30/68 (44%) and 11/33 (33%) in Groups 2 and 3, \( p = 0.03 \). The fraction of responders reporting that sexuality is a

| Variable                                      | Outcome definition                                      | Group 1 \( n = 51 \) | Group 2 \( n = 69 \) | Group 3 \( n = 37 \) | \( p \)-value
|----------------------------------------------|--------------------------------------------------------|----------------------|----------------------|----------------------|----------------------|
| Desire                                        |                                                        |                      |                      |                      |                      |
| Sexual thoughts                              | Occurrence more than once a month                       | 40/52 (78%)          | 47/68 (69%)          | 28/35 (80%)          | 0.40                |
| Importance of sexuality                      | Moderate or great importance                           | 18/51 (35%)          | 20/68 (29%)          | 15/36 (42%)          | 0.76                |
| Sexuality part of one's manhood              | Yes                                                    | 35/51 (69%)          | 48/68 (71%)          | 27/35 (77%)          | 0.17                |
| Ability to sexually satisfy partner          | Seldom or never                                         | 32/47 (68%)          | 44/65 (68%)          | 22/32 (69%)          | 0.38                |
| Distress from decreased sexual ability       | Moderate to great distress                              | 18/51 (35%)          | 27/66 (41%)          | 13/33 (39%)          | 0.90                |
| Penile stiffness                             |                                                        |                      |                      |                      |                      |
| Erectile function                            | Never sufficient for intercourse                        | 25/51 (49%)          | 42/68 (62%)          | 24/35 (69%)          | 0.30                |
| At awakening                                 | Never sufficient for intercourse                        | 29/51 (57%)          | 45/68 (66%)          | 25/37 (68%)          | 0.25                |
| Intercourse                                  |                                                        |                      |                      |                      |                      |
| Frequency of intercourse                     | More than once in past 6 months                        | 19/51 (37%)          | 23/68 (34%)          | 11/35 (31%)          | 0.44                |
| Distress from decreased frequency           | Moderate to great distress                              | 10/51 (20%)          | 18/67 (27%)          | 9/32 (28%)           | 0.81                |
| Orgasm                                       |                                                        |                      |                      |                      |                      |
| Frequency of orgasm                          | More than once in past 6 months                        | 29/50 (58%)          | 30/68 (44%)          | 11/33 (33%)          | 0.03\(^b\)          |
| Urinary emptying symptoms                   |                                                        |                      |                      |                      |                      |
| Weak stream                                  | More than half of all occasions                        | 17/51 (33%)          | 15/66 (23%)          | 11/35 (31%)          | 0.29                |
| Feeling of incomplete emptying              | More than half of all occasions                        | 4/51 (8%)            | 15/66 (22%)          | 9/36 (25%)           | 0.39                |
| Frequent voiding, interval <2 h              | More than half of all occasions                        | 6/51 (12%)           | 13/67 (19%)          | 12/36 (33%)          | 0.15                |
| Difficulty to start voiding                 | More than half of all occasions                        | 4/51 (8%)            | 4/67 (6%)            | 4/36 (11%)           | 0.12                |
| Urinary storing symptoms                    |                                                        |                      |                      |                      |                      |
| Nocturia                                     | Occurrence twice a night or more                       | 24/51 (47%)          | 33/68 (49%)          | 8/36 (22%)           | 0.006\(^b\)         |
| Urgency                                      | Occurrence once a day or more                          | 2/51 (4%)            | 5/68 (7%)            | 2/36 (6%)            | 0.56                |
| Distress from voiding problems              | Moderate or great distress                              | 6/51 (12%)           | 4/69 (6%)            | 5/35 (14%)           | 0.90                |
| Urinary leakage                              |                                                        |                      |                      |                      |                      |
| Urinary leakage in daytime                  | Occurrence once a week or more                         | 7/51 (14%)           | 6/68 (9%)            | 2/36 (6%)            | 0.33                |
| Urinary leakage in daytime                  | Occurrence once a day or more                          | 0/51                 | 2/68 (3%)            | 1/36 (3%)            | 0.33                |
| Regular dependence on some form of protective aid against urinary leakage | Pad, yes                                               | 14/50 (28%)          | 5/68 (7%)            | 2/36 (6%)            | 0.001\(^b\)         |
|                                              | Diaper, yes                                            | 1/48 (2%)            | 2/65 (3%)            | 2/32 (6%)            | 0.34                |
|                                              | Urisheath, yes                                         | 1/48 (2%)            | 2/65 (3%)            | 2/32 (6%)            | 0.34                |
|                                              | Other aid, yes                                         | 0/47                 | 1/65 (2%)            | 0/30                 | 0.87                |

Notes: Data are \( n/N \) (%) where \( N \) is the total number of patients responding to a given question. For each question, some men did not respond.

\(^a\)Non-parametric test for trend across groups.

\(^b\)Significant result.
part of one’s manhood displayed a trend in increasing score with time from diagnosis 35/51 (69%) in Group 1 to 48/68 (71%) and 27/35 (77%) in Groups 2 and 3, $p = 0.17$.

### 3.3 Comparison of psychological symptoms between penile cancer groups

Table 3 summarizes comparison of penile cancer patient responses to psychological questionnaire items. At the current study size, we observed no significant psychometrical score differences between groups. Trends towards a declining fraction of patients scoring ‘high’ in perceived quality of life, sense of meaningfulness, physical coping, physical well-being and self-esteem during the preceding 6 months were not significant ($p = 0.61$, $p = 0.57$, $p = 0.14$, $p = 0.40$ and $p = 0.17$).

### 3.4 Comparison of psychological symptoms between treated penile cancer groups

Table 4 summarizes comparison of treated penile cancer patient responses according to treatment type. At the current study size, we observed no significant score differences between patients treated with distinct types of treatment. Pooling data for patients from Group 2 and 3 and allocating patients into broader treatment categories ‘local treatment’ and ‘penectomy’ did not change this finding. Trends towards less self-esteem in patients subjected to more mutilating treatment were seen in both Groups 2 and 3 but did not reach statistical significance.

### 3.5 Sexological counselling

Four out of 157 (2.5%) men accepted the free offer of in-hospital post-operative sexological counselling during the study period either as a solo counselling session or as a couple counselling session with a partner. Further two patients received self-paid counselling in an out-of-hospital setting, one by a private practice clinical sexologist and one by a psychologist.

### 4 DISCUSSION

This study is among the first to investigate symptoms and distress associated with sexual and urinary functions and psychological domains in penile cancer patients with data from different time points in the clinical trajectory. In this large questionnaire survey, we found several interesting trends and some noteworthy findings that enable us to increase the level of detail in preoperative patient information and counselling. During the study, we learned important aspects about collecting patient reported outcome measures from penile cancer patients and about offering sexological counselling to penile cancer patients that will allow us to pursue these factors in future studies and daily practice.

When asking penile cancer patients at diagnosis, 29/50 (58%) reported more than one orgasm, and 19/51 (37%) reported more than intercourse in the 6 months preceding the diagnosis. In other words, many penile cancer patients are still sexually active even in the last months before diagnosis. Penile cancer treatment, however, significantly reduces the proportion of responders having more than one orgasm in the preceding 6 months 1 year after treatment 30/68 (44%) and 2 years after treatment 11/33 (33%), $p = 0.03$. This is in line with previous studies on the subject.

Although illness and treatment affect sexuality, some patients continue an active sex life after surgery with reports of more than one intercourse in the preceding 6 months from 23/68 (34%) 1 year after treatment and 11/35 (31%) 2 years after treatment.

Oozing and bleeding from cancerous lesions and occasional urinary dribbling because phimosis may cause penile cancer patients to use pads, which was the case for 22% of patients at diagnosis. After 1 and 2 years, this figure declined dramatically to 7% and 6%, $p = 0.006$. As treatment removes oozing lesions and resolves phimosis, this finding is not surprising but nonetheless an important aspect in preoperative reassurance of patients.

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**Table 3** Occurrence and intensity of psychological symptoms for Danish penile cancer patients responding to a validated questionnaire

| Variable                  | Group 1 (n = 51) | Group 2 (n = 69) | Group 3 (n = 37) | p-value\(^a\) |
|---------------------------|------------------|------------------|------------------|---------------|
| Quality of life (high)    | 31/51 (61%)      | 37/67 (55%)      | 15/34 (44%)      | 0.61          |
| Sense of meaningfulness (high) | 30/51 (59%)      | 40/67 (60%)      | 18/35 (51%)      | 0.57          |
| Physical coping (high)    | 32/51 (63%)      | 39/67 (58%)      | 16/35 (46%)      | 0.14          |
| Depressed mood (moderate or high) | 20/51 (39%)      | 37/69 (54%)      | 17/36 (47%)      | 0.36          |
| Anxiety (moderate or high) | 25/51 (49%)      | 39/69 (57%)      | 15/36 (42%)      | 0.51          |
| Psychological well-being (high) | 25/51 (49%) | 36/69 (52%) | 17/36 (46%) | 0.61 |
| Physical well-being (high) | 32/51 (63%)      | 38/68 (56%)      | 18/36 (50%)      | 0.40          |
| Self-esteem (high)        | 30/51 (59%)      | 38/68 (56%)      | 15/37 (41%)      | 0.17          |

Notes: Data are n/N (%) where N is the total number of patients responding to a given question. For each question, some men did not respond.

\(^a\)Non-parametric test for trend across groups.
The implementation of several items from the SPCG-4 questionnaire in our penile cancer questionnaire allows us to compare our findings to a large control cohort of cancer-free Scandinavian men from the SPCG-4 study.

We find a significant difference between the proportion of responders scoring the importance of sexuality as moderate or great with 53/155 (34%) of penile cancer patients versus 118/204 (58%) in the SPCG-4 control group. There was a significant difference between the proportion of responders reporting a frequency of intercourse at more than once in past 6 months, 53/155 (34%) of penile cancer responses versus 106/200 (53%) control group responses, \( p = 0.02 \). Significantly larger proportion of penile cancer patient responses scored anxiety as moderate or high compared with the SPCG-4 control group responses: 79/156 (51%) versus 68/208 (33%), \( p = 0.02 \).

There was no difference in scores for depressed mood, well-being, quality of life and sense of meaningfulness.

During the study period, only 40% of penile cancer patients accepted the offer of in-hospital post-operative sexual counselling. This was surprising, as we expected a larger group of men to accept the offer of in-hospital post-operative sexual counselling. The hesitance of men to accept this offer might have to do with the setting of a busy and sometimes hectic outpatient clinic environment in which they were invited. This environment could discourage patients from engaging in discussions of existential, sexual and emotional aspects of the disease and treatment. Most patients accepting the offer did so at a later time point after diagnosis and treatment, which might indirectly point to the fact that men might not be ready to engage in discussion and counselling of the sociological aspect of the disease at this early time point.

### Limitations and strengths

This study has a number of limitations. Due to small sample size and low response rate, we cannot claim to have established insights about penile cancer patients in general. A major limitation is inherent in all penile cancer studies, the small cohort size. Our response rates at 29%, 46% and 30% in the three approached groups of the questionnaire remained low despite reminder letters mailed to non-responders. In a Dutch quality of life and sexuality questionnaire study among penile cancer patients, they reached a response rate above 60 with a questionnaire with fewer items than in the current study.

| Variable                        | Group 2 \( n = 69 \) | Group 3 \( n = 37 \) |
|---------------------------------|----------------------|----------------------|
| Sense of meaningfulness (high)  | 21/33 (67%)          | 10/17 (59%)          |
| Physical coping (high)          | 21/33 (67%)          | 9/17 (53%)           |
| Depressed mood (moderate or high)| 16/35 (46%)         | 9/18 (50%)           |
| Anxiety (moderate or high)      | 19/35 (54%)          | 7/18 (39%)           |
| Psychological well-being (high) | 18/35 (51%)          | 9/18 (50%)           |
| Physical well-being (high)      | 21/35 (60%)          | 9/19 (53%)           |
| Self-esteem (high)              | 21/35 (60%)          | 9/19 (47%)           |

Notes: Data are \( n/N(\%) \) where \( N \) is the total number of patients responding to a given question. For each question, some men did not respond.

*Non-parametric test for trend across groups.

We find a significant difference between the proportion of responders scoring the importance of sexuality as moderate or great with 53/155 (34%) of penile cancer patients versus 118/200 (53%) control group responses. There was a significant difference between the proportion of responders reporting a frequency of intercourse at more than once in past 6 months, 53/155 (34%) of penile cancer responses versus 68/200 (33%), \( p = 0.02 \). There was no difference in scores for depressed mood, well-being, quality of life and sense of meaningfulness.

### TABLE 4 Occurrence and intensity of symptoms for treated Danish penile cancer patients from Groups 2 and 3 analysed per type of treatment

| Variable                        | Group 2 \( n = 69 \) | Group 3 \( n = 37 \) |
|---------------------------------|----------------------|----------------------|
| Sense of meaningfulness (high)  | 21/33 (67%)          | 10/17 (59%)          |
| Physical coping (high)          | 21/33 (67%)          | 9/17 (53%)           |
| Depressed mood (moderate or high)| 16/35 (46%)         | 9/18 (50%)           |
| Anxiety (moderate or high)      | 19/35 (54%)          | 7/18 (39%)           |
| Psychological well-being (high) | 18/35 (51%)          | 9/18 (50%)           |
| Physical well-being (high)      | 21/35 (60%)          | 9/19 (53%)           |
| Self-esteem (high)              | 21/35 (60%)          | 9/19 (47%)           |

Notes: Data are \( n/N(\%) \) where \( N \) is the total number of patients responding to a given question. For each question, some men did not respond.

*Non-parametric test for trend across groups.
We tried to run this study along with normal outpatient activities in two busy university clinic settings without dedicated study staff. Some of our approached and non-responding patients may have been discouraged to participate due to the substantial number of items in our questionnaire. One obvious way to approach this challenge may be to markedly reduce the number of items. Future attempts to collect patient reported outcome measures should focus on fewer items and either be integrated in obligatory electronic logistic procedures connected to the outpatient clinic routine or have dedicated data collection staff (or both) to ease participation and increase response rates. Nevertheless, penile cancer is a rare disease, and in fact, this is one of the larger series published on the subject. Our cohort represents national data with responders from both treating centres in Denmark that limits selection bias. However, we do see some indirect signs of selection bias in the dataset in our counterintuitive age distribution between Groups 1, 2 and 3, where one would expect the age to increase with time after diagnosis, the distribution of responders in our study is opposite, with more young patients participating in the group 2 years after treatment. We interpret this as a selection bias of the health professionals enrolling patients for Groups 2 and 3 in the study being more likely to invite younger patients than older patients. Only few patients were recruited from Centre 2. Because we have no questionnaire from non-responders, we have no way to compare base line characteristics from patient responses, but we are able to indirectly draw some conclusions from our knowledge of the penile cancer cohort as a whole. Our responders have a higher mean age at 70.3 years, 67.4 years and 66.4 years compared with our general penile patient cohort at 66.1 years, which indicates that a larger proportion of the younger patients declined to participate in the current questionnaire study. We speculate that this might have skewed our data in the direction of less dramatic differences between scores, because it is our experience from a previous single patient interview study and from our daily practice that younger patients seems to worry more about consequences of disease and treatment than older patients. If we look at other baseline parameters and compare our responders to our penile cancer cohort as a whole, we find no difference in cohabitation, education level and source of income.

Nearly 60% of responding penile cancer patients are sexually active at diagnosis. Pad use, nocturia and frequency of orgasm were significantly reduced after penile cancer treatment. We observed trends towards lower self-esteem with increasingly mutilating treatment and decline in erectile function after treatment. Only few patients accepted our free offer of in-hospital post-operative sexological counselling. We need to improve recruitment logistics and increase response rates in future studies to further explore the patient perspective in this rare disease.

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CONFLICT OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

ETHICS STATEMENT

We received approval of the research protocol by the Institutional Reviewer Board. We conducted the study in accordance with Danish law and rules and regulations from regional authorities. The study received permission from the Danish Data Protection Agency, file number 1-16-02-95-1-3. All patients consented to participate.

AUTHOR CONTRIBUTIONS

Study concept and design: Jørgen B. Jensen and Jakob K. Jakobsen. Data Collection: Kim P. Krarup, Christian M. Sørensen, Jørgen B. Jensen and Jakob K. Jakobsen. Analysis and interpretation of data: Christian M. Sørensen and Jakob K. Jakobsen. Drafting of the Manuscript: Jakob K. Jakobsen. Critical revision of the manuscript for important intellectual content: Kim P. Krarup, Christian M. Sørensen, Jørgen B. Jensen and Jakob K. Jakobsen. Statistical Analysis: Jakob K. Jakobsen. Study Supervision: Jørgen B. Jensen.

ORCID

Jakob Kristian Jakobsen https://orcid.org/0000-0003-1629-7411

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SUPPORTING INFORMATION
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