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Life satisfaction of patients with penile cancer

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ABSTRACT

INTRODUCTION. In penile cancer, both disease and treatment may be mutilating. We examined life satisfaction in three separate groups; at penile cancer diagnosis and one and two years later.

METHODS. From 1 January 2013 to 31 December 2015, Danish penile cancer patients completed the Life-Satisfaction Questionnaire-11 (LISAT-11) at diagnosis and after one year and after two years. Responders scored 11 domains of life on a six-point scale. We analysed the scores and compared scores with those of a Swedish control cohort from the literature with patients in the same age group.

RESULTS. A total of 157 individual penile cancer patients completed the LISAT-11 checklist at one point in the trajectory and were considered for this study. We observed trends towards less life satisfaction in the years after diagnosis and with increasingly mutilating surgical treatment. The differences were not statistically significant. A difference was observed between the proportion of responders scoring “satisfied” on activities of daily living between penile cancer patients and a healthy control cohort, with a higher score being recorded for the healthy controls. No other LISAT-11 domains were scored significantly different between penile cancer patients and controls.

CONCLUSIONS. Danish responders with penile cancer are less satisfied than a Swedish control cohort within the self-care domain.

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Penile cancer is rare with approximately 80 new invasive cases per year in Denmark. Since 2009, staging and treatment with curative intent has been centralised to two centres to consolidate service and offer a unified management nationwide [1].

Two reviews of quality of life and literature on psychosexual and psychosocial outcomes of penile cancer reported from primarily cross-sectional case control studies found that a number of aspects of life such as anxiety, feelings of pleasantness and relation with family and partner may be affected in penile cancer [2, 3].

The external genitals are a focus of sexual identity, and mutilating surgery may cause significant distress, whereas organ-sparing surgery and reconstruction positively influence quality of life [3]. Studies by Windahl et al. and Kieffer et al. point to the fact that the type of treatment may be an important defining factor when patients judge their sexual satisfaction and the consequences of disease and treatment [4, 5].

However, few studies have focused on life satisfaction at different time points in the clinical trajectory. This type of data may be useful in the planning of cancer rehabilitation and may potentially guide the focus and themes of clinical follow-up.

In the present study, we evaluated life satisfaction in a cross-sectional study design with three different groups responding at three different points in time; at diagnosis, after one year and after two years. We evaluated life satisfaction related to type of treatment, and we compared the life satisfaction of Danish penile cancer responders to that of two groups of healthy Scandinavians from the literature. To our knowledge, this study is the first to focus on life satisfaction in penile cancer at different time points in the clinical trajectory.

METHODS

The present study forms part of a larger questionnaire survey conducted among Danish penile cancer patients from 1 January 2013 to 31 December 2015 in connection with inpatient treatment and outpatient follow-up. Questionnaires were handed out, introduced and collected at the only two Danish urology departments treating penile cancer with curative intent; the Department of Urology, Aarhus University Hospital and the Department of Urology, Rigshospitalet, Copenhagen University Hospital. Patients were divided into three separate cohorts in relation to time of response. To analyse independent data between groups, only the latest response of patients responding more than once was considered.

Life satisfaction measurement

Life satisfaction was measured with the validated Life-Satisfaction Questionnaire-11 (LISAT-11). The current Danish version of the LISAT-11 was face validated on six patients. The LISAT-11 was completed by penile cancer patients at diagnosis, one year after diagnosis and two years (or more) after diagnosis. The LISAT-11 checklist covers 11 specific domains, see **Table S1**; https://ugeskriftet.dk/files/a05210379_-_supplementary.pdf The responder scores the domains on a six-point scale; from 1 = “very dissatisfying” to 6 = “very satisfying". For the analyses, the scores were dichotomized per domain into two outcome groups, scores 1-4 “not satisfied” and scores 5-6 “satisfied”.

Comparison

LISAT-11 scores were compared between groups of penile cancer patients according to time of completion of the questionnaire and according to the type of treatment received. Responders at diagnosis, after one year and after two years constituted Groups 1, 2 and 3, respectively. To compare the LISAT-11 scores to the scores of healthy Scandinavians, we chose a cohort from a recent Swedish study by Abzhandadze et al. [6] who had recruited patients from the same age group as the penile cancer responders. We extracted data for healthy controls from the published tables.

Statistics

Differences between groups in the demographic data were estimated by ANOVA and Kruskall tests, as appropriate. A p-value of 0.05 or less was considered statistically significant. For statistical analysis, we used Stata Statistical Software: Release 13, TX: Statacorp.

To minimise the effect of multiple testing with regard to LISAT-11 responses, we used a descriptive method for comparison by looking for overlap of the separate confidence intervals for the separate groups. Non-overlapping 95% confidence intervals (CI) indicated significant differences between groups.

Ethics

All patients consented to participating and the study was conducted in accordance with Danish law and provisions from the regional authorities. Permission was granted by the Danish Data Protection Agency, file number 1-16-02-95-13.

Trial registration: not relevant.

RESULTS

A total of 157 individual penile cancer patients completed the LISAT-11 checklist at one point in the trajectory and were considered for this study. We found no differences in LISAT-11 scores between penile cancer patient Groups 1, 2 and 3 with regards to age, marital status, level of education, source of income, Eastern Cooperative Oncology Group Performance Status and type of treatment (**Table 1**).

TABLE 1 Demographic and clinical data for three groups of Danish penile cancer patients completing the Life-Satisfaction Questionnaire (LISAT)-11 at diagnosis (Group 1) and after one year (Group 2) and after two years or more (Group 3).

	Group 1 (N_1 = 51)	Group 2 (N_2 = 69)	Group 3 (N_3 = 37)
Age, yrs, mean (range)	70.3 (43.6-91.7)	67.4 (46.9-92.5)	66.4 (41.2-87.2)
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, n (%)			
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, n (%)			
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], n (%)			
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, n (%)			
Local resection and/or laser	-	35 (51)	18 (49)
Partial penectomy	-	20 (29)	14 (38)
Total penectomy	-	14 (20)	5 (13)

a) Eastern Cooperative Oncology Group Performance Status.

Comparison of life satisfaction between penile cancer patient groups

At the current group sizes, no differences in LISAT-11 scores were found between penile cancer patient Groups 1, 2 and 3 (**Table 2**).

TABLE 2 Satisfaction with life according to the Life-Satisfaction Questionnaire (LISAT)-11. Proportions of individuals with ratings 5 = satisfying and 6 = very satisfying and the 95% confidence intervals (CI) shown for three groups of Danish penile cancer patients completing the LISAT-11 at diagnosis (Group 1) and after one year (Group 2) and after two years or more (Group 3), and for the Swedish control cohort.

	Proportion (95% CI)			
Satisfaction with	Group 1 Median age 70.3 yrs (N_1 = 51)	Group 2 Median age 69.0 yrs (N_2 = 69)	Group 3 Median age 68.3 yrs (N_3 = 37)	Swedish control cohort Median age 65 yrs (N_S = 246)
Life as a whole	0.80 (0.67-0.90)	0.70 (0.57-0.80)	0.65 (0.47-0.80)	0.80 (0.75-0.85)
Work situation	0.71 (0.56-0.83)	0.59 (0.47-0.71)	0.57 (0.39-0.73)	0.68 (0.62-0.74)
Financial situation	0.75 (0.60-0.86)	0.70 (0.57-0.80)	0.76 (0.59-0.88)	0.74 (0.68-0.79)
Leisure time	0.76 (0.63-0.87)	0.86 (0.75-0.93)	0.70 (0.53-0.84)	0.74 (0.68-0.79)
Contact with friends	0.82 (0.69-0.92)	0.74 (0.62-0.84)	0.76 (0.59-0.88)	0.70 (0.65-0.76)
Sexual life	0.29 (0.17-0.44)	0.26 (0.16-0.38)	0.30 (0.16-0.47)	0.42(0.36-0.49)
Activities of daily living	0.80 (0.67-0.90)[a]	0.84 (0.73-0.92)[a]	0.84 (0.68-0.94)	0.96 (0.93-0.98)
Family life	0.83 (0.73-0.91)	0.84 (0.73-0.92)[b]	0.88 (0.72-0.97)[b]	0.90 (0.86-0.94)
Partner relationship	0.81 (0.66-0.91)[c]	0.82 (0.69-0.91)[c]	0.76 (0.55-0.91)[c]	0.90 (0.86-0.94)
Somatic health	0.59 (0.44-0.72)	0.62 (0.50-0.74)	0.62 (0.45-0.78)	0.69 (0.63-0.74)
Psychological health	0.73 (0.58-0.84)	0.67 (0.54-0.78)	0.68 (0.50-0.82)	0.84 (0.68-0.79)

a) 95% CIs do not overlap between the penile cancer group and the control cohort around the same age.
b) 1 patient in Group 2 and 2 patients in Group 3 reported having no family.
c) 9 patients in Group 1 (18%), 13 patients in Group 2 (19%) and 11 patients in Group 3 (30%) reported having no partner.

Comparison of life satisfaction between penile cancer patients and the control cohort with patients around the same age

A difference was recorded between the proportion of responders scoring 5-6 for activities of daily living between penile cancer patient Groups 1 (0.80, 95% CI: 0.67-0.90) and 2 (0.84, 95% CI: 0.73-0.92) and the healthy control cohort around same age (0.96, 95% CI: 0.93-0.98) where a higher score was recorded for the healthy controls. No other LISAT-11 domains were scored differently between penile cancer patients and controls of the same age group (Table 2).

Comparison of life satisfaction between penile cancer patients, by treatment type

Table 3 summarises the life satisfaction scores in Group 2 and Group 3 by type of surgical penile cancer treatment. When comparing patients treated by local resection, partial penectomy and total penectomy, we observed trends towards a lower life satisfaction with increasingly mutilating surgical treatment, but at the current group sizes no significant differences in LISAT-11 scores were found between patients treated with different types of treatment.

TABLE 3 Satisfaction with life according to the Life-Satisfaction Questionnaire (LISAT)-11: analysed per type of treatment. Proportions of individuals with ratings 5 = satisfying and 6 = very satisfying and the 95% confidence intervals (CI) shown for two groups of Danish penile cancer patients completing the LISAT-11 one year after treatment of penile cancer (Group 2) and after two years or more (Group 3).

	Proportion (95% CI)					
	Group 2 (N_2 = 69)			Group 3 (N_3 = 37)		
Satisfaction with	local resection (n = 35)	partial penectomy (n = 20)	total penectomy (n = 14)	local resection (n = 18)	partial penectomy (n = 14)	total penectomy (n = 5)
Life as a whole	0.80 (0.63-0.91)	0.60 (0.36-0.81)	0.57 (0.29-0.82)	0.67 (0.41-0.87)	0.57 (0.29-0.82)	0.80 (0.28-0.99)
Work situation	0.60 (0.42-0.76)	0.60 (0.36-0.81)	0.57 (0.29-0.82)	0.50 (0.26-0.74)	0.57 (0.29-0.82)	0.80 (0.28-0.99)
Financial situation	0.71 (0.54-0.85)	0.65 (0.41-0.85)	0.71 (0.42-0.92)	0.72 (0.47-0.90)	0.79 (0.49-0.95)	0.80 (0.28-0.99)
Leisure time	0.86 (0.70-0.95)	0.60 (0.56-0.94)	0.93 (0.66-0.99)	0.72 (0.47-0.90)	0.64 (0.35-0.87)	0.80 (0.28-0.99)
Contact with friends	0.77 (0.60-0.90)	0.60 (0.36-0.81)	0.86 (0.57-0.98)	0.72 (0.47-0.90)	0.79 (0.49-0.95)	0.80 (0.28-0.99)
Sexual life	0.37 (0.21-0.55)	0.25 (0.09-0.49)	0 (0-0.23)	0.28 (0.10-0.53)	0.36 (0.13-0.65)	0.20 (0.01-0.72)
Activities of daily living	0.89 (0.73-0.97)	0.95 (0.75-0.99)	0.57 (0.29-0.82)	0.83 (0.59-0.96)	0.93 (0.66-0.99)	0.60 (0.15-0.95)
Family life	0.85 (0.68-0.95)	0.90 (0.68-0.99)	0.71 (0.42-0.92)	0.88 (0.62-0.98)	0.85 (0.55-0.98)	0.99 (0.40-0.99)
Partner relationship	0.88 (0.69-0.97)	0.82 (0.57-0.96)	0.69 (0.39-0.91)	0.83 (0.52-0.98)	0.73 (0.39-0.94)	0.50 (0.01-0.99)
Somatic health	0.69 (0.51-0.83)	0.60 (0.36-0.81)	0.50 (0.23-0.77)	0.72 (0.47-0.90)	0.64 (0.35-0.87)	0.20 (0.01-0.72)
Psychological health	0.69 (0.51-0.83)	0.65 (0.41-0.85)	0.64 (0.35-0.87)	0.67 (0.41-0.87)	0.64 (0.35-0.87)	0.80 (0.28-0.99)

DISCUSSION

To our knowledge, this study is the first to focus on life satisfaction in penile cancer at different time points in the clinical trajectory. We found no differences in the proportion of patients reporting scores 5-6 “satisfied” in any LISAT-11 domain between three separate groups of patients completing the LISAT-11 at diagnosis, after one year and after two years. The general picture of high life satisfaction scores was confirmed by comparing with a control cohort published by Abzhandadze et al., which approximately matches our penile cancer cohort with respect to age [6]. The penile cancer patients of our study reported life satisfaction scores that were in line with those of the control cohort around the same age within all domains, except for the self-care domain, where penile cancer patients reported lower scores than controls. However, the control cohort consisted of both men and women; and in the original LISAT-11 standardization, cohort gender differences were found within two domains; contacts with friends and acquaintances and ability to manage self-care [6, 7].

This may possibly indicate that even the lower score of the penile cancer patients in the domain self-care may be a result of the female contributors the self-care score in the control cohort of the same age group. On the other hand, the report of a lower degree of self-care by penile cancer patients may also be inherent to the disease entity. A lower degree of self-care is often associated with obesity and, in some cases, moderate- to high-risk obesity, where physical contact to the penis might be hampered by a large abdominal mass and visual inspection and the possibility to perform lower hygiene is challenged for the same reason. Indeed, in a previous publication, we documented that penile cancer patients have a higher BMI than age-matched controls [8].

Treatment type and life satisfaction

Even if the trend did not reach statistical significance at the current sample size, we observed a trend in the domains “life as a whole”, “sexual life” and “partner relationship” towards lower scores for more mutilating surgical treatment. These findings are in line with findings by Windahl et al. who found only minimal sexual consequences and little effect on sexual wellbeing in penile cancer patients treated with organ-sparing surgery with local resection and laser ablation [4]. Our observed trend also mirrors the data from Kieffer et al. who found that partial penectomy was associated with more problems with orgasm, body image and life interference [5].

Comparing findings from our current penile cancer survey with the significantly younger Swedish

standardisation cohort by Fugl-Meyer et al. [7] reveals differences in life satisfaction scores within the domains of "financial situation" and "leisure" with higher satisfaction scores being recorded for penile cancer patients. However, this finding is most likely a reproduction of the intrinsic positive effect of increasing age within these domains also found in the original Fugl-Meyer et al. LISAT-11 study [7]. The same interpretation for the reverse effect of increasing age may well be true for the significant difference between life satisfaction scores within the domains of "sexual life", "self-care", "physical health" and, for penile cancer patient Group 2, also "mental health" [7, 9]. In addition, the superior self-care satisfaction score of controls over penile cancer patients might also be driven by female responders in the standardisation cohort, considering the gender differences already discussed above [7]. This interpretation of the effect of age on life satisfaction scores is supported by the fact that the same score differences are not found when the comparison includes the cohort of matching age [6]. Moreover, this is in line with findings reported in a study conducted on a cohort of elderly by Wilhelmson et al. [10].

Limitations and strengths

The main limitation of this study was the small cohort size resulting in very wide confidence intervals in the subgroup analyses, leading to trends towards score differences rather than significant differences in statistical analysis. This may indirectly indicate that further patient inclusion might reveal actual differences, e.g., between treatment groups. At this point, this notion is speculative. However, penile cancer is a rare disease and, in fact, this is one of the largest series published on the topic. Our cohort represents national data with responders from both treating centres in Denmark, which limits potential selection bias.

The present study does not allow us to conclude on the life satisfaction of penile cancer patients in general, but only on the life satisfaction of responders, and we do not know if the patients with poor life satisfaction chose to refrain from participating in our questionnaire survey, thereby reducing possible differences between patients and controls. It seems counterintuitive that the mean age in Group 2 should be lower than in Group 1. Even in this case with no overlap between groups, one would expect the mean age to increase after diagnosis. This may indicate that younger patients are more likely to respond later in the trajectory, which, in turn, might provide part of the explanation for the absence of reported life satisfaction differences between the penile cancer groups. In the comparison between penile cancer patients and healthy cancer-free controls, a major limitation is the different nationalities of cases and controls, considering that national differences in life satisfaction were published and specifically taking to account that Danes have systematically reported higher scores than Swedes in nationwide surveys [11].

This may potentially introduce an underestimation of score differences between Danish cases and Swedish controls. However, several similarities exist in individuals' social capital, possibilities, safety net and financial situation among Scandinavian countries, and the comparison is considered reasonable [12].

Perspectives

Considering the present study size and wide confidence intervals of subgroups, we consider introducing continuous collection of patient-reported outcome measures including life satisfaction as an interesting parameter to learn from in future studies. This type of data may be useful in the planning of cancer rehabilitation and may possibly guide the focus and themes of clinical follow-up.

CONCLUSIONS

Danish responders with penile cancer were less satisfied than responders in a Swedish control cohort within the self-care domain. With the present study population and a three time point cross-sectional design, we observed

trends towards a lower life satisfaction in the years after diagnosis and with increasingly mutilating surgical treatment. The differences were not statistically significant.

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Kun hvis den medtages på tryk:

References can be found with the article at ugeskriftet.dk/dmj

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