

Quality of life in penile carcinoma patients – post-total penectomy

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Introduction Total amputation, as a treatment for advanced penile cancer, significantly debilitates the patient's quality of life and sexual function. The aim of the study was to assess the quality of life in patients who had undergone total penectomy.

Material and methods The questionnaires EORTC QLQ C-30, SES, CMNI, and a modified IIEF-15 questionnaire, were sent to 11 patients.

Results A total of 10 patients returned the questionnaires completed. The results of the overall quality of life, the median result in individual domains, as assessed by the EORT QLQ C-30 questionnaire, were clearly lower than the reference results. There were statistically significant differences in the results of the QLQ C-30, concerning the role-functioning domain in relation to age ($p = 0.008$) and education ($p = 0.032$), in the domain of emotional functioning in relation to education ($p = 0.008$) and in the domains of physical functioning in relation to the partner relationship ($p = 0.032$). A significant number of patients were sexually inactive. Sexual activity as defined by touching the area of the pubic symphysis at the scars of the penis, touching and fondling perianal areas or the scrotum and watching things/people that cause excitement was observed in 2/10, 1/10 and 2/10 of patients respectively. In 5/6 of these patients, partnership relationships did not deteriorate, including one patient for whom the relationship actually improved.

Conclusions The results obtained indicate that total amputation of the penis significantly affects one's sex life and overall quality of life. However, this does not have negative implications in terms of partnership relations, self-assessment or the evaluation of masculinity.

Key Words: Quality of Life (QoL) ↔ Health Related Quality of Life (HRQoL) ↔ penile cancer
↔ total penile amputation

INTRODUCTION

Penile cancer is a rare malignancy (0.58/100.000 men) in the developed countries [1]. In the authors' own country, with its population of 36 million, 232 new cases and 89 new deaths were recorded in 2010 [2]. These rates are comparable with those recorded elsewhere in Western Europe, but much lower than in Africa, South America and Asia [3]. The primary treatment for penile cancer is surgery, although

in the case of precancerous changes or in cancer detected at an early stage, minimally invasive clinical methods such as superficial chemotherapy, laser therapy or brachytherapy may be applicable [4]. Surgical treatment involves the removal of the primary tumor lesion with or without performing inguinal lymphadenectomy, depending on clinical indications or the histopathology of the original change. The surgical procedure involves removing the change itself, that is, the re-sectioning of the lesion, circumcision,

glansectomy and the partial – or total – amputation of the penis, subsequently forming an exit for the urethra into the perineum [5].

Guided by experience and/or intuition alone, each urologist describes the total amputation of the penis as a most debilitating procedure, which clearly adversely affects the patient's quality of life, particularly one's sex life. The quantity and quality of data available in the medical literature to substantiate such predictions is scarce, which significantly limits the quality of the publication. However, one should bear in mind that penile carcinoma is a rare disease and there is only a limited pool of patients available for clinical research. For this reason, there are no standardised research tools for the evaluation of subsequent quality of life. Various tools are used and they are often not validated, making comparison of any results difficult. Due to the limitations presented above, the study of the disease should be carried out solely in specialist reference hospitals. This would give easier access to a larger number of patients, thereby facilitating prospective research [6].

MATERIAL AND METHODS

The study included patients treated during the period 06.2007 to 06.2013 at the Uro-oncology Department, Memorial Cancer Centre, Warsaw, Poland – all underwent total amputation with perineal urethrostomy. All treatments were carried out by a team of urologists experienced in this practice. Simultaneous inguinal lymphadenectomy, along with surgery of the penis did not disqualify the patient from taking part in the study. The study was carried out with the consent of the local Bioethics Committee (KB-411-3-13). Prior to the study, all patients consented by signing the patients' 'Informed Consent' form. All patients received anonymous questionnaires during the period 06–07.2014. For the assessment of the quality of life, cancer-specific instruments were used as a major research tool together with modular questionnaires assessing some selected aspects of the quality of life. Rated parameters were taken into account such as age, education, place of residence, employment status, marital status and partnership relations for which the author developed the question: "How would you rate satisfaction in your relationship with your partner: 1 – not at all satisfactory, 2 – almost satisfactory, 3 – satisfactory on average, 4 – very satisfactory".

For an overall assessment of the quality of life, the "European Organisations for Research and the Treatment of Cancer (EORTC) -QLQ-C30 v 3.0" questionnaire was used [8]. Modular questionnaires were used as tools to assess self-esteem, the patient's sexual life, masculinity and symptoms associ-

ated with the lower urinary tract. The level of the self-rated questionnaire was assessed with the help of the "Rosenberg Self-Esteem Scale (SES)" [9]. The scale consists of 10 statements regarding positive or negative conscious attitudes to the inner self and the emotions, associated with cognitive opinions about oneself. The maximum possible score is 100%. The percentage score was arbitrarily categorised into five groups from very low self-esteem to very high self-esteem. For the assessment of a patient's compliance or non-compliance with masculinity standards, the "Conformity to Masculine Norms Inventory (CMNI)" questionnaire was used [10, 11]. The questionnaire consists of 22 questions reflecting 11 domains of the *id* in the perception of masculinity norms, in areas such as indomitability (or the unwillingness to be beaten), emotional control, risk-taking, violence, control of women, domination, the 'playboy behaviour' independence, the over-riding importance of work, disdain for homosexuality and the pursuit of status. Each question has four answers on a scale from 0 to 4 points (from strongly disagree – 0 points to strongly agree – 4 points). The results were arbitrarily divided into five ranges from very low compliance to very high compliance. In order to assess the sexual sphere, a modification of the "International Index of Erectile Function (IIEF-15)" was developed [12, 13].

Based on conversations between the cancer survivors and urologists experienced in this area, 'sexual activity' was defined, for the purpose of this study, as the stimulation of selected parts of the patient's body, visual stimulation providing sexual satisfaction as well as contact with the so-called 'open field', and about which the patients were prompted to comment, personally. Manual stimulation was defined as the touching or fondling, 'inter alia', of such areas as the pubic symphysis, anus, scrotum, testes or nipples. The so-called 'open field' in the questionnaire was left to allow inclusion of other areas, the touching of which is identified with 'sexual activity'. In the next question, the duration (in minutes) of a single 'sexual activity' was evaluated.

The next question came from the *IIEF-15* questionnaire – from question 7 to question 15 – and related to the respective domains of satisfaction obtained from 'sexual activity'. The term 'sexual intercourse' was replaced by the term 'sexual activity'. All answers to the questions were to reflect the patient's status in the last 6 months. In order to assess the symptoms associated with the lower urinary tract (LUTS), the "International Prostate Symptom Score (IPSS)" questionnaire was used [14, 15].

The Mann-Whitney U test was used in order to compare the results obtained from the individual ques-

tionnaires with respect to age, education, size of city, employment status, satisfaction in the relationship with a partner and marital status. A significance level of $p < 0.05$ was assumed.

RESULTS

Of the 24 patients who underwent total amputation of the penis, between 01.2009 and 08.2013, 13 patients died due to progression of the original disease. The remaining 11 patients were sent questionnaires in October 2013 concerning their quality of life. Of this group, responses from 10 patients were obtained and subjected to further analysis.

Table 1 shows the socio-demographic data obtained. The average age of the patients was 60 years, with ages ranging from 35 to 74 years and the median being 60.5 years. The median time elapsed from the treatment to the present investigation was

16 months (range from 7 to 49 months). All patients identified their sexual orientation as heterosexual. Table 2 presents the patients' clinical and pathological characteristics. Within the group of patients (6 ptn) remaining in the same relationship, at the time of surgery, 4 patients reported no deterioration in their personal relationship, whereas in one case, the relationship actually improved. Among all patients after surgery, 2/10 patients established new partnerships, while two-thirds remained with the same partner. The median result of the SES self-assessment questionnaire was 75%, but ranged, however, from 67% to 87%. None of the patients defined self-esteem as being very low or low. The average level of self-esteem was shown, in 1/10 of the patients, to be high and very high, with scores of 90% and 100%, respectively. The median result for compliance with masculinity norms – 'the CMNI questionnaire' – was 88% and ranged from 81% to 100%. Compliance with standards of masculinity was very high in all patients (30% of patients – high compliance; 70% of patients – very high compliance). All patients described moderate LUTS symptoms. The median result for the IPSS questionnaire was 12.5 points, ranging from 11 to 18 points.

The majority of patients responded to the question regarding their sexual life, by saying that they were not sexually active; these patients did not respond to specific questions. Two patients defined touching the pubic symphysis area, at the scars of the penis, as sexual activity. In addition, one of these patients defined sexual activity as manual stimulation, such as touching and fondling, around the anus, the scrotum, and the breasts. In two other patients from this group, sexual activity meant visual stimulation

Table 1. Socio-demographic data

	(%) of patients
Education	
Basic	50%
Higher	50%
Place of residence	
Village	20%
Town	80%
Employment status	
Employed	30%
Unemployed	70%
Marital status at the time of diagnosis	
Single	40%
In relationship	60%

Table 2. Patient's clinico-pathological characteristics

	Date of surgery (month.year)	Age on the day of surgery (years)	T stage	G stage	N stage	Supplementary proceedings
1	07.2009	74	pT2	1	LND not carried out	Unavailable
2	02.2010	61	pT1b	1	pN0	Unavailable
3	11.2011-	61	pT1b	2	pN0	Unavailable
4	03.2012	68	pT2	1	pN2	Plastic surgery of the urethral meatus on the perineum, no adjuvant systemic therapy
5	07.2012	35	pT1b	2	pN0	Unavailable
6	11.2012	58	pT3	3	pN3	No complementary systemic therapy/RTH
7	11.2012	64	pT1b	1	LND not carried out	Unavailable
8	02.2013	60	pT3	2	pN3	CHTH, RTH in the groin area
9	04.2012 05.2012	55	pT3	2	pN3	Due to the general state, no possibility of a supplementary CHTH
10	04.2013	58	pT2	2	pN0	Narrowing of the plastic coil on the crotch x2

LND – superficial inguinal lymphadenectomy and a deep one on both sides

– watching things/people that cause sexual excitement. None of the patients answered the question: “I experience sexual activity in a different way – please indicate how?” (this question was left blank). Responses to questions from the original IIEF-15 questionnaire – wherein the phrase ‘sexual intercourse’ was modified to ‘sexual activity’ – represent significant disturbances in sexual life. Most patients did not experience orgasm and ejaculation during ‘sexual activity’. Sexual relations with a partner were defined as very unsatisfactory by the majority of patients; however, one patient described these relations as ‘very rewarding’. The median for the domain of the global health status / *QoL* EORTC C-30 questionnaire was 50. The median results for other domains of the questionnaire, as well as the results of the reference EORTC Quality of Life Group for the relevant cancer [16], are presented in Table 4. Statistical analysis of the results obtained from the individual questionnaires, with respect to age, education, place of residence, employment status, partner relationship and marital status, revealed some important relationships. Statistically significant differences were found in the results of the QLQ C-30 questionnaire relating to the role-function domain, in relation to age ($p = 0.008$) and level of education ($p = 0.032$); then in the QLQ C-30 questionnaire, relating to the domains of emotional function, in relation to education level ($p = 0.008$) and finally in the QLQ C-30 questionnaire relating to the domains of physical functioning *vis-à-vis* partnership relationships ($p = 0.032$)

DISCUSSION

Long-term survival in patients after penile cancer treatment may be associated with sexual dysfunction, voiding and cosmetic problems, penile appearance, all of which may adversely affect the patient’s quality of life [17, 18]. In particular, this applies to the most debilitating method of treatment which is total amputation of the penis [19]. A systematic review of the literature by Meddineny et al. on the quality of life, *vis-à-vis* psychosexual and psychosocial terms, in patients with penile cancer, subjected to different treatment methods, including total amputation of the penis, revealed only 6 related studies [6]. The above-cited authors showed that the treatment of penile cancer has a negative impact on the well-being of up to 40% of patients and that the more disabling the treatment, the more likely it is to impair patient well-being. The authors also point out that in these 6 studies, 13 different, quantitative tools were used to assess psychological well-being, *QoL* and sexual function.

A significant problem is the lack of standardised research tools for assessing *QoL* in this group of patients. Most of the research studies have used data collected retrospectively from a small group of patients in single medical centres using different measurement methods. One of the most common tools used in the HR*QoL* assessment of cancer patients is the EORTC - QLQ C-30 questionnaire. Many uro-oncological research studies have used this tool under the assumption that assessing the quality

Table 3. The median result for individual domains of the QLQ C-30 questionnaire and the results of the reference EORTC Quality of Life Group for the relevant cancer [16]

	Global health status / <i>QoL</i> (median)	Physical functioning (median)	Role functioning (median)	Emotional functioning (median)	Cognitive functioning (median)	Social functioning (median)
Authors' own study	50.0	70.0	83.3	70.8	83.3	75.0
Scott N.W. (all cancers, male) [16]	66.7	86.7	83.3	75	83.3	83.3
Scott N.W. (genitourinary cancers) [16]	66.7	N/A	66.7	83.3	100.0	83.3
Scott N.W. (general population) [16]	75	100	100	83.3	100.0	100

Table 4. Research tool used to assess the sexual and overall quality of life in patients undergoing total amputation of the penis

	Global health status / <i>QoL</i> (median)	Physical functioning (median)	Role functioning (median)	Emotional functioning (median)	Cognitive functioning (median)	Social functioning (median)
Authors' own study	50.0	70.0	83.3	70.8	83.3	75.0
Scott N.W. (all cancers, male) [16]	66.7	86.7	83.3	75	83.3	83.3
Scott N.W. (genitourinary cancers) [16]	66.7	N/A	66.7	83.3	100.0	83.3
Scott N.W. (general population) [16]	75	100	100	83.3	100.0	100

of life is one of the main reasons for using this tool [20, 21, 22]. The EORTC group was developed to measure disease and treatment-related *QoL* issues relevant to selected uro-oncological diseases, such as cancers of the prostate, bladder and testis, not covered by the EORTC QLQ-C30 [22–25]. However, a module dedicated to patients with cancer of the penis has not been developed as of yet.

In our study, the median global health assessment/quality of life in the EORTC QLQ-C30 questionnaire was lower than in the general population and in genitourinary cancer patients [16]. In addition, the median of all five functioning domains, including physical functioning, role functioning, emotional functioning, cognitive functioning, and social functioning, were lower compared to general population reference values [16]. In the domain of physical functioning, the median result in patients after complete amputation of the penis, was also lower than in the male population suffering from various other cancers, including bladder cancer. A statistically significant difference was observed in the score of physical functioning in relation to partnership relations. This suggests that patients, who were more satisfied with their relationship with a partner, evaluated their physical functioning more highly. The median results among respondents for the role functioning domain was higher than in the population of genitourinary cancer patients and bladder-cancer patients. It was noted, however, that there is a statistically significant correlation between age ($p = 0.008$) and education ($p = 0.032$). Younger and better-educated patients rated their functioning lower. In reference to this observation, it should be noted that the average age for disease onset in our study group was 60, which could have resulted in the higher scores observed in the role-functioning domain. In our study, the median result for the emotional functioning domain, for patients undergoing total amputation of the penis, was lower than in the population of patients with various cancers and bladder-cancer. A statistically significant difference was observed in the score of emotional functioning in relation to education ($p = 0.008$). The more educated patients assigned a lower score to this aspect, which also included their subjective evaluation. In connection with the results obtained on the overall quality of life, measured by the EORTC C-30 questionnaire, it is advisable to take, under special psychological care, those patients who are not in a satisfactory relationship with their partner and also younger and highly-educated patients. Should these patients be placed under such special care, there could well be a lesser decline in *QoL* after surgery.

Of all urogenital cancers, penile carcinoma is the cancer, which most evidently jeopardises sexual func-

tion. It seems that the sex life of patients undergoing total amputation will suffer the greatest as it is the most debilitating of surgical procedures. In the questionnaire conducted by Opjordsmonem et al. in which they asked doctors for their views on sexual activity among patients undergoing total amputation of the penis, sexual interest in these patients was assessed as severely reduced [26]. Ficarra et al. showed that patients had moderate sexual function scores with a mean of 2.1 (4 = best function; 0 = worst function) across all treatment groups, but those patients who had undergone more radical treatment had lower scores (1.3 and 1.0 for partial and total penectomy, respectively) [27].

Although the EORTC QLQ-C30 is a psychometrically robust HRQOL measuring tool for the generic cancer population, it is not aimed at detecting specific HRQOL aspects related to different carcinomas, such as sexual function and urinary problems. So far, a questionnaire, specific for penile cancer, which deals with these aspects of quality of life, has not been developed. In evaluating the sexual sphere, most authors have used a variety of research tools and self-developed questionnaires [19, 26, 28–31] (Table 4).

To date, no specific tool facilitating the analysis of sexual function in patients undergoing total amputation of the penis has been developed. The IIEF-15 questionnaire seems to be a valuable tool for assessing the domain of sexual life. It has been used, *inter alia*, to evaluate the *QoL* of patients after, organ-sparing surgery, partial amputation and laser treatment [31–34]. In order to assess sexual life, the present authors have developed their own tool, which is a modification of the IIEF-15 questionnaire. In the interest of presenting the issue better, the patients were asked to define ‘sexual activity’. Most responded that they did not engage in any sexual activity. Attention should be drawn to the fact that the average age of the patients, which was 60, could have affected the results of the evaluation of the sexual sphere. Similar conclusions have been drawn by Opjordsmoean et al., who analysed four patients after complete amputation of the penis [19, 26]. To evaluate the sphere of sexual life, the above-mentioned authors applied, at the time of surgery, a global score of overall sexual function. Patients assessed their sexual function as severely reduced. In another study conducted qualitatively, patients indicated that their condition would have had a greater impact on their sexual function and quality of life, had they been younger [30]. However, this correlation is not obvious, as evidenced by one of the patient’s responses in this study: “I think one’s sex life changes as you get older anyway. It has probably had a marginal

effect but it's very slight. I think there's far more to being a human being and far more to being a man than just simply being dependent on a penis." In our study, both sexual activity and sexual desire were evaluated more critically by the patients. Using the same tool, namely the IIEF-15 questionnaire, different results were obtained when examining patients after partial amputation of the penis, where dysfunction concerning sexual desire was assessed as mild. Such discrepancies among patients, after total and partial amputation of the penis, are most likely caused by the more debilitating scope of the operation, which may have a significant impact on the change in the patient's understanding of oneself, their masculinity and sexual desires [30]. It should also be noted that if a man is willing to put some effort into his sex life, pleasure is possible after amputation of the penis. Total penectomy patients report that stimulation of their remaining genital tissue, including the 'mons pubis', healed surgical site, perineum and scrotum, produces an orgasm. The patients in our study regarded their sexual activity similarly. Touching the area of the pubic symphysis at the site of the scar or the perianal scrotum, or breast stimulation was, for them, equivalent to sexual activity. Another form of arousal was visual stimulation. Although most patients did not undertake any sexual activities and evaluated their sexual relations with their partner as very unsatisfactory, it should be noted that the overall relationship, for most patients, was good, since 85% of the patients claimed that the relationship with their partner had not deteriorated, while one patient found that his relationship with his partner had actually improved. Moreover, it is an interesting fact that despite the total amputation of the penis, 2/10 of patients, who were single at the time of the surgery, established new partnerships post-operatively. The authors have no data as to the period of time, which had elapsed between surgery and the formation of new relationship. The above data suggests that in selected patients, the impairment of the sexual domain does not necessarily have a negative impact on the overall relationship with a partner. Those patients who undertook sexual activities were satisfied to varying degrees. Justification can be found in the study by Wittly et al., in which several patients said that their own lack of sexual gratification was less of a concern than were their feelings of being unable to satisfy their partner. One of the patients said: "Me and my wife never make love anymore; it's her I feel sorry for really" [30].

An important issue raised by many studies carried out in patients with cancer of the penis after radical surgery, is the concept of 'masculinity' [18, 30, 31, 35].

Masculinity is a socially-constructed expectation that embraces a set of norms and behaviours that are expected to be exhibited by men. These norms and beliefs can be influenced by environmental factors, as well as by social and cultural beliefs. Men not complying with these expectations have been viewed as subordinate and weak [36]. Of the many expectations of a masculine man, his sexual prowess and his ability to satisfy a partner are crucial qualities [52, 53]. Illness can reduce a man's status in masculine hierarchies, shift his power relations with women and raise his self-doubts about his own masculinity. This study made use of the CMNI which has been psychometrically tested [10]. Despite the use of severely debilitating treatment in all patients, compliance with the standard of masculinity was high or very high. The impact on masculinity has also been studied in patients after partial amputation of the penis and the conclusions drawn were convergent. Some aspects of sexuality, such as masculine self-image and the relationship with one's partner, remained basically unchanged [37]. Other authors have presented different results indicating that masculinity was rated below the norm.

An important element of *QoL* is emotional function and social self-esteem and, in turn, self-esteem which has a significant effect on these parameters. Rosenberg et al., demonstrated a correlation between low self-esteem and depression [9]. The above-mentioned author pointed out that the feeling of being of lesser value is a characteristic symptom of neuroses. The present authors used a simple, self-assessment scale (SES), in evaluating a positive or negative attitude towards the *id* in their own study. No patient defined his self-esteem as low, while 9/10 of patients defined their level of self-esteem as high. Perhaps a significant impact on such high self-esteem was the fact that more than three-quarters of patients reported that the relationship with their partner, with had been already established at the time of cancer diagnosis, had not deteriorated. Two patients from the whole group established new relationships with a partner after surgery, which could also prove the significance of high, self-definition as being 'good enough' for formation of new partnerships, quite regardless of the total amputation of the penis. Similar conclusions were drawn by Kieffer et al. in a study where, among those patients studied, most remained in partnered relationships while subject to different methods of penile cancer treatment [31]. The results of this paper showed no significant differences in overall sexual satisfaction. The present author emphasises that the overall positive results with regard to HRQOL and survival issues, partly reflect that having a 'good' relationship was reported

to be an important, protective factor against feelings of anxiety after surgery. The positive effect of a partner on sexual rehabilitation has been emphasised in other studies involving uro-oncological patients [20, 21, 38]. In the study by Bullen et al. the centrality of wives or female partners, in providing support, was a key finding [18]. The data suggested that rehabilitation was possible for men in strong, supportive relationships, which provided reassurance of a continued, albeit re-constructed, masculine role. Conversely, for those without this support, successful rehabilitation was less likely.

The appropriate time period that should elapse from the performance of penis surgery to conducting the *QoL* assessment has not been clearly defined. Bullen et al. evaluated an adaptation period of a minimum of 18 months, post-surgery, within the range from 18 months to 5 years [29]. In the present study, the time to conduct this study was similar, at 16 months. However, the current study is not devoid of limitations. The number of patients in the present study was small and any comparison with other studies must be made with caution. It should be appreciated, however, that penile cancer is a rare malignancy and the group under investigation is significantly large, compared to previous studies in which a group of four patients, following total amputation, was surveyed with respect to an assessment of their quality of life and sexuality [18, 19, 28]. It must be noted that when researching rare conditions, the sampling rationale is reversed; rather than aiming to recruit a sufficient number of participants to achieve data saturation, the goal should be to work out how best to use the information gathered, given recruitment limitations. We should assume that the lack of a control group was a drawback to our study. Even though sexual impairment after penile amputation is self-

evident, other known circumstantial changes related to oncologic surgery may also play a role [39]. One undoubted drawback of our study is its retrospective nature. Supplementing this study with a *QoL* assessment, before surgery, could extend the possibilities for data analysis and increase credibility of the results, especially in the sexual sphere.

CONCLUSIONS

It should be emphasised that our study is the first survey dedicated entirely to patients having undergone complete amputation of the penis. By developing our own assessment tools of the sexual sphere, as well using other, recognised research tools relating to *QoL*, it was possible to study patients precisely. The results obtained indicate that total amputation of the penis significantly affects the sexual sphere of life as well as the overall quality of life. However, it should be noted that this does not have negative implications in terms of partnership relations, self-assessment or the evaluation of masculinity. The results obtained indicate the need for further exploration of this issue to determine coping strategies for patients. It is important that psychologists, trained in sex therapy and other dedicated specialists, begin working with the patient while treatment is being decided. Future studies on large and perhaps international samples, a prospective research design, standardised measurement tools and normative comparison groups can help to further clarify the problem of the *Quality of Life* and the sexual sphere in patients after total amputation of the penis and the perceived needs of men with penile cancer.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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