Penile Carcinoma
To all men

"Real knowledge is to know the extent of one’s ignorance”

Konfucius
Penile Carcinoma: 
From First Symptom to Sexual Function and Life Satisfaction Following Organ-Sparing Laser Treatment
Abstract


The overall aim of this thesis was to describe how patients with penile carcinoma experienced their symptoms, treatment seeking and the impact of the diagnosis and treatment on sexual function, sexual activity and life satisfaction. The thesis contains two studies of patients treated with organ-sparing laser therapy, a retrospective study (Papers II and III) of 46 patients treated between 1986-2000 and a prospective study (Papers I and IV) of 50 patients between 2005 and 2009 and additional 34 partners. In both studies face-to-face interviews were used with a structured questionnaire; and self-assessment instruments IIEF-5, LiSat-11, and HADS. An ad hoc comparator population of men aged 34–74 years from a nationally representative investigation of sexual life and life satisfaction in Swedes was chosen for some of the questions concerning sexuality and life satisfaction.

We found a delay of more than 6 months in 37% of the patients in the retrospective study and 65% of the patients in the prospective study. The single most important reason for patients’ delay was embarrassment. Nine patients had a doctors’ delay of more than 3 months from first special visit until diagnosis. Eight of these patients consulted dermatologists and were subjected to repeated biopsies, leaving premalignant results (I, II). All patients younger than 75 years (34/46) in the retrospective study reported that they were sexual active before treatment, 80% of these had resumed their activity by the time of the interview. Furthermore, except for satisfaction with somatic health, similar—or even higher—proportions of patients than comparators were satisfied with life as a whole and with other domains of life including satisfaction with sexual life (III). We found that 21/29 couples were sexually active with intercourse before treatment and 17 couples resumed their activity. Two items differed markedly from the comparators; considerably fewer patients were satisfied with their somatic health, and satisfaction with sexual life (at 12 months follow-up). Couples with an active partner-related sexuality at 12 months follow-up, reported coherence in high satisfaction with life as a whole (IV). In conclusion, patients with penile carcinoma delay for a long time after identifying symptoms before seeking contact with the health care system. This delay is mainly caused by embarrassment in describing the symptom to health care personnel and deficient knowledge about the disease. Organ-sparing technique offers good, satisfying cosmetic results and the possibility of maintaining sexual activity and function to a great extent.

Keywords: Penile carcinoma, Sexuality, Life satisfaction, Treatment-seeking, Sexual function, Sexual dysfunction, Delay, Organ-sparing.

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<tr>
<td>CO₂</td>
<td>Carbon dioxide</td>
</tr>
<tr>
<td>EAU</td>
<td>European Association of Urology</td>
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<td>ED</td>
<td>Erectile dysfunction</td>
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<td>ER</td>
<td>Retarded ejaculation</td>
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<td>Hospital Anxiety and Depression scale</td>
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<td>Human papilloma virus</td>
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<tr>
<td>ISSM</td>
<td>International Society of Sexual Medicine</td>
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<tr>
<td>Laser</td>
<td>Light amplification by stimulated emission of radiation</td>
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<td>LiSat-11</td>
<td>Life Satisfaction Checklist, eleven items version</td>
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<tr>
<td>Nd-YAG</td>
<td>Neodymium-doped yttrium aluminium garnet</td>
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<td>NPECR</td>
<td>National Penile Cancer Register</td>
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<tr>
<td>PE</td>
<td>Premature ejaculation</td>
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<tr>
<td>SHIM</td>
<td>Sexual Health Inventory for Men</td>
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<tr>
<td>STI</td>
<td>Sexually transmitted infections</td>
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<tr>
<td>TNM</td>
<td>Tumour node metastasis- classification system</td>
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<td>UICC</td>
<td>International Union Against Cancer Classification</td>
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INTRODUCTION

Organ-sparing treatment has been used more frequently in penile carcinoma in recent decades in an effort to preserve function and achieve a better cosmetic result for men with this rare malignancy, without compromising the long-term oncologic outcome. The technique with laser treatment for penile carcinoma has been used in Sweden since the beginning of the 1980s. However, knowledge is still deficient about the consequences of treatment on the sexuality and the extent to which a patient is able to maintain or restore his sexual function and the satisfaction with sexual life after treatment. The low incidence of penile carcinoma and ethical considerations make it more or less impossible to conduct randomized controlled trials involving different treatment modalities, such as an organ-sparing technique and partial amputation. Single-centre studies often cover several decades, with varying treatment techniques and sometimes even changed behaviour in the society making it difficult to evaluate both treatment results and side effects. Preservation of sexual function has been inconsistently reported and there is a lack of validated tools and questionnaires for evaluating the sexual outcome in patients with penile carcinoma. Almost all penile carcinomas are primarily located at the glans, sulcus, or prepuce and are therefore also visible to the patient every day. Despite this unavoidable physical signal, a lot of affected men delay for a considerably long time before seeking treatment.

My interest in this group of patients began in 1998, when I started my work as a medical social worker at the Department of Urology in Örebro University Hospital. I met patients who had been diagnosed with different urogenital cancers. Many of these patients suffered from side effects after surgery that affected their sexual function physically and causing psychological burden. These experiences nourished the thoughts that penile carcinoma might be the worst psychological threat for a man having a urogenital cancer diagnosis. Men with penile carcinoma were the only ones I met that had a visible location of their tumour and maybe the more obvious fear of losing the organ and/or sexual function because of the treatment. Questions also arose about why men with penile carcinoma had been found to delay seeking treatment and whether this possible fear influenced these men. Furthermore, the effects on sexual function of the organ-sparing laser technique had not previously been evaluated in Sweden, and I found it necessary to study the effects in order to increase knowledge about the patients’ perspective.

Therefore, is the main focus in this thesis is the patients’ experiences of symptoms and treatment-seeking, and their experiences after being treated.
with an organ-sparing technique for penile carcinoma, especially the impact on sexual function, activities, and life satisfaction. A further focus is on the partners’ perspective, which to my knowledge has never been evaluated.
BACKGROUND

Penile carcinoma

Incidence and risk factors
There is a worldwide geographic variation in incidence of penile carcinoma, and it is considered as a rare malignancy in western society. The highest incidence is reported from some areas of Asia, Africa and South-America where it constitutes up to 10% of all malignant diseases in men. The lowest incidence with less than 0.1 cases per 100,000 men/year have been reported from Israel. In Sweden, the annual incidence during the years 2000-2009 was 2.2 – 3.0/100,000, men/year including carcinoma in situ (Tis).

The aetiology of penile carcinoma are multifactorial. The association with human papilloma virus (HPV) types 16 and 18 are well documented. HPV has been detected in up to 82% of penile carcinoma specimens. Another risk factor is phimosis, and 25-75% of the patients have phimosis when diagnosed with penile carcinoma. Early neonatal circumcision has been found to reduce the risk of penile cancer. Other risk factors mentioned in the literature are tobacco smoking, poor genital hygiene, a sexual history of multiple partners and early age of first intercourse, and self-reported history of condyloma (3 to 5-fold increased risk of penile cancer). Additionally to the foregoing, also chronic inflammatory conditions, such as, balanoposthitis, lichen sclerosus et atrophicus (balanitis xerotica obliterans), and treatment with psoralene and ultraviolet A photochemotherapy have been reported to be associated with penile carcinoma.

Symptoms and staging
The presentation of penile carcinoma varies, but the most frequent location is on the glans, sulcus, or prepuce. The most common symptom recognized by the patient and/or the physician is erythema, erosion, superficial ulceration, or induration, not seldom hidden by phimosis. A biopsy from the affected area of the penis is needed to make an accurate diagnosis of cancer. The rareness of the disease could also make a problem for the pathologists with minor experience especially when distinguish the high-grade carcinomas from some of the differential diagnosis. Penile carcinoma can be preceded by premalignant lesions, and as many as 25% of dysplastic premalignant lesions (giant condylomas, Bowenoid papulosis) have been found to have been incorrectly diagnosed as benign, with a delay in treatment. This is also true for inflammatory conditions,
such as lichen sclerosus et atrophicus (balanitis xerotica obliterans). In fact, studies have shown the incidence of subsequent cancer with long-term follow-up to be between 3% and 9% of men with lichen sclerosus. In fact, studies have shown the incidence of subsequent cancer with long-term follow-up to be between 3% and 9% of men with lichen sclerosus\textsuperscript{24-25}. Carcinoma in situ, the earliest stage penile carcinoma will, when inadequately treated, progress to invasive carcinoma in about 10% to 33% of cases\textsuperscript{12, 26-29}. The common classification system for staging of the tumours, the TNM system, has been used during recent decades (UICC). It has also been revised 2009 and then been subject to discussion\textsuperscript{30-32}. For examples of tumours representing different tumour stages and a description of tumour stages Tis-T4, see pictures below\textsuperscript{1}.
**Treatment**

For decades the conventional treatment has been partial or total penectomy, giving excellent tumour control in low-stage disease, but at the same time a cosmetic and functional result that considerably affects sexual function and desire. Today, according to the 2009 EAU guidelines, at least the group of patients below 60 years of age should be offered organ-sparing treatment for preserved sexual function. These guidelines recommend penile-preserving treatment for primary lesion categories Tis and Ta-T2, G1-2 (T2 limited to glans), particularly for those patients who can guarantee to attend regular follow-up. Partial amputation is still recommended for the same tumour groups for those who cannot comply with regular follow-up.

The use of laser treatment in surgery for penile lesions was developed at the end of the 1970s. It was shown in small series that laser surgery controlled the local tumour as well as conventional surgery with the positive difference of better cosmetic and functional results. Laser treatment is today regarded as an appropriate choice as organ-sparing treatment for patients with low risk for inguinal metastases and disease progression. This technique has been evaluated in several studies showing good tumour control. Since 1986 the first line treatment for localized penile carcinoma staged Tis - pT2 at the Department of Urology in Örebro has been combined laser treatment using the carbon dioxide (CO2) laser and the neodymium-doped yttrium aluminium garnet (Nd:YAG) laser, simplified using the CO2 laser for excision of the tumour and the Nd:YAG laser for coagulation of the tumour bed.

However, the recurrence rate is higher with all type of organ-sparing treatment compared with radical treatment. The recurrence rate after organ-sparing treatment has been 29%, and after partial amputation 5%, in a two-centre analysis of 700 patients (Örebro University Hospital and The Netherlands Cancer Institute). When using combined laser treatment, the recurrence rate has been 19% in a sample with a mean follow-up of 60 months. However, despite the high number of local recurrences after penile-preserving treatment, they showed little impact on survival. The relatively high frequency of local recurrences after laser treatment requires patient self-examination for many years and a follow-up visit every 3 months during the first 2 years. One contributory factor in making the organ-sparing techniques possible is the development in surgical techniques. Recent studies argue that the previously suggested margins of 2 centimetres can safely be reduced to only a few millimetres.
Penile carcinoma in Sweden
Since 2000 there has been a National Penile Cancer Register (NPECR) whose purpose is to gather data and experiences about staging, treatment, and outcomes after treatment in penile carcinoma in Sweden, and also to evaluate adherence to guidelines. The median age among Swedish men diagnosed with penile carcinoma has been around 67 during the years 2000-2009. However, close to 30% in the Swedish material are younger than 60 years. Squamous cell carcinoma accounts for more than 95% of cases of penile carcinoma. Carcinoma in situ (Tis) is included in the Swedish penile cancer registration, but that is not always the case in other countries. In the years 2005-2009 the registered tumours in the Swedish material was distributed as follows in pTis to PT3; pTis occurred in 34% of cases, pT1 in 26%, pT2 in 20%, and pT3 in 10% of cases. In this register there are available data on system delay (but not patients’ delay), showing that the time interval between referral and first appointment varied geographically. The shortest time was found in the urban regions, where the time between referral to urologist and surgery ranged between 37 and 56 days. In Sweden during the years 2005-2009, 70% of the tumours were classified as pTis - pT2, and 50% were treated with organ-sparing treatment (local excision 35%, laser treatment 15%). Data from the NPECR show that during the years 2005-2009 the treatment of penile carcinoma in Sweden was spread among 26 hospitals, with only 4 of these performing more than 5 operations a year 39.
Treatment seeking and delay in cancer diagnosis

One of the main issues in this thesis is the pathway for men from the discovery of a symptom on the penis, something disturbing but unknown, until the diagnosis can be made. It is unavoidable that the process of cancer detection consists of several steps, involving both the individual’s perspective and the health care system’s. This issue has been studied by researchers over several decades, and both quantitative and qualitative studies have considered the question of why a person delay seeking medical care when having obvious symptoms of illness.

More than 70 years ago Pack and Gallo defined two types of delay, the time lag of more than 3 months defining patients’ delay and 1 month as an “adequate time for the physician to take appropriate action” known as doctors’ delay. These definitions are surprisingly still the most frequently used when studying delay in cancer diagnosis, even though the time thresholds were established arbitrarily. Previous research has revealed that 20-30% of the patients in all cancer types has been reporting more than 3 months delay in treatment seeking when experienced possible cancer symptoms. When measuring total delay, i.e. from the onset of symptoms to diagnosis there are studies suggesting that up to half of the delay is patient delay. The most common way to measure patients’ delay is ask the patients about when they first experienced the symptoms they thought were related to the cancer and when they first contacted health professionals.

Regardless of type of cancer and symptoms, when reviewing the literature, similarities have been found in delayed treatment-seeking, suggesting the main structure to two-sided, with, on one hand, recognition and interpretation of symptoms, and on the other hand, the patients’ gender and social context. When studying delay in patients with cancer diagnosis, the estimated delay could also be affected by how they legitimize the decision to seek care and also if there are known, established relationships between the specific symptoms and a diagnosis of severe illness and reasons for delay in presentation by patients with symptoms of cancer are multifactorial. Patient characteristics attributable to sociodemographic factors such as age, gender, and education have for decades been discussed as important factors causing a delay in treatment seeking. Psychological factors as denial and embarrassment are shown to be associated with the motivation for treatment and patients’ delay. It has been shown, that being worried, having fear, and being anxious could lead to both treatment seeking or delay, depending on the cause of the fear and how the individuals cope with it. In a review of the literature in qualitative research in patient delay in different cancer diagnoses, Smith et al. analysed the results...
and found strong similarities in the patients’ treatment-seeking experiences. Two main structures were recognition and interpretation of symptoms and fear of consultation. Fear could arise especially when symptoms affected a sensitive or sexual body area, and/or when patients had concerns about being seen as timewasters or as neurotic especially if they had mild symptoms. Fear might be the fear of something unknown, but it could also manifest sometimes as a fear of cancer connected with experiences of other cancer patients 51. The communication plays an important role in the treatment-seeking process. This process can be delayed because of the patients’ attitudes towards physicians, with some stating that they are hesitant to “bother” their GP, especially when they feel their symptoms are ambiguous 46. Concern over wasting the doctor’s time and feeling afraid of what the doctor might find were the most commonly endorsed emotional barriers to prompt help seeking in a study by Robb et al. 61.

**Doctors’ delay**

A lot of previous research has been done into different cancer malignancies and possible causes related to long doctors’ delay in different stages of the health care system and with inconsistent findings. A long doctors’ delay has been found to be associated with patients’ young age or old age, low education and being single status; and in other cancer studies no associations between age, marital status, and socioeconomic factors were reported 55, 62. A time lag might also be due to lack of resources or be of a more organizational nature, factors that could be difficult to analyse 63-64. These factors could include accessibility, staff’s knowledge and capacity, economic resources, and other kinds of organizational factors, and delays between primary health level and specialist care are common in several countries 65. The health care system might provide more or less access for the patients, causing some problems when comparing the times from appraisal of a symptom to diagnosis. One study tried to highlight this question by comparing the diagnostic pathways in the UK, the Netherlands, and Sweden. The results showed that patients in the UK had a significantly longer delay in secondary care, both from referral to first appointment, and in the next step, from first appointment to diagnosis; however, delays in Sweden and the Netherlands were comparable 66. A delayed referral from a general practitioner to a specialist has been found to be primarily related to misdiagnosis of a common symptom or to a problem in making a diagnosis at the first appointments 45, 57. Studies have shown that time to referral for cancer was increased among patients who consulted GPs frequently 56, 67.
**Symptoms and delay**

In the earlier stages of penile carcinoma there is a varied picture of symptoms, for example, erythema, erosion, superficial ulceration, or induration, and the most common location is on glans, sulcus, or prepuce. The symptom could also be hidden by a phimosis. These vague symptoms could also contribute to a possible prolonged delay. There will always be a passage of time between the time during which a change in the body’s appearance shows the patient that an illness is present and he will be in need of medical help. This picture is not specific for the debut of penile carcinoma. Symptoms of malignancy are sometimes complex and changeable, and it is therefore not always easy to point out when they start and when they should lead to treatment seeking. Bodily sensations do not necessarily have to start as symptoms of illness, but become so when they are retrospectively recalled as being the starting point. This process from the experience of a body sign of illness or something unknown until a person determines that it is a symptom that represents some condition they need to seek medical help for has been named “appraisal delay.” In a often cited study by Andersen et al. from 1995, it has been suggested that there is a delay in all patients between detecting cancer symptoms and deciding to seek medical help. The model suggests a stepwise process of treatment seeking combined with individual psychological processes: “appraisal delay, illness delay, behavioural delay, scheduling delay, and treatment delay.” Appraisal delay has been found to account for most of the delay, and it is understood that the psychological processes in this stage are important, but difficult to influence. They highlight the difficulty in interpreting bodily states when the symptoms are general or diffuse, in combination with the opinion that cancer is life-threatening and a low-probability disease which could be transferred to the situation of symptoms in penile carcinoma.

Interpretations of symptoms as normal and as “nothing serious”, and therefore not a reason for treatment seeking, are commonly reported. Fear associated with recognition of potential cancer symptoms has been found to be both a negative and a positive factor, influencing the decision-making process. Individuals differ in their perception of symptoms, some people have more symptoms than others and also differ in the sensation they experience from the same kind of symptom. More obvious symptoms such as pain and bleeding has been shown to fasten up the treatment seeking. For example, in bladder cancer patients, acute haematuria was a threatening symptom that prompted short delay. Symptoms that are mild or not felt to be serious have been found to delay treatment seeking. Treatment seeking for genital symptoms has been found to be associated with embarrassment.
Knowledge and delay

Insufficient knowledge in society of penile carcinoma as a cancer diagnosis, and of the varied symptoms one has to be observant about, could be one problem in this rare diagnosis. Familiarity with the symptoms of cancer and related knowledge trigger patients to seek medical consultation. To know whether something is wrong requires for a consciousness about body sensations and the body – one must be aware of what is normal to have the possibility of understanding if something is abnormal. Studies have shown that this problem based on deficient knowledge is more common in males than females. Lack of knowledge could lead to uncertainty associated with delayed treatment seeking. Studies in colorectal cancer patients have shown a long patients’ delay, which is partially explained by poor knowledge about symptoms. Knowledge about available treatment has been found to influence treatment seeking, and information in media has triggered treatment seeking. Hesitation because of well-known side-effects – especially those affecting sexual function, has also been discussed. In qualitative studies in testicular cancer and delay it has been shown that young men felt afraid that a diagnosis of testicular cancer would signal that they were lacking in masculinity. The impact of information has been studied in selected populations. A more prevalent self-examination and thereby shorter time lag between symptom recognition and treatment seeking have been showed in testicular cancer. One study examined the knowledge of testicular cancer and performance of testis self-examination in a group of men over two time periods, 20 years apart in the same institution, and found increased public awareness and self-examination over the years. Men who showed a higher knowledge score were more likely to perform diagnosis of testicular tumours, and the changes in patient awareness over time, showed that patient performance had improved over an 18-year study-period. The authors conclude that this is due to a combination of health education programmes.

Gender and delay

As the diagnosis indicate, penile carcinoma is a male malignancy, and therefore it is difficult to study and point out whether there are gender differences in this specific pathway of treatment seeking. Instead researchers are obliged to lean on knowledge in other malignancies when discussing whether the male patient has an increased risk for being exposed to a longer delay in the treatment seeking process.

There are findings suggesting a sex difference in treatment seeking behaviour among men and women. In a population-based study in Denmark, Pedersen et al. studied patients’ delay and social support, with a difference
between males and females in patients’ delay. Being in a relationship and receiving support from the partner were the two most important factors for decreased delay in men, and females reported more partner avoidance then males ⁸⁴. Several studies have reported passive detection behaviour and treatment seeking and less knowledge of cancer symptoms among men compared to women ⁷⁶, ⁷⁸, ⁸⁵-⁸⁸. Findings have shown that men consistently ignored symptoms and avoided seeking help from the health services, supported by a “wait and see” attitude, and that women appear to visit the health care service on a more regular basis than men ⁵¹, ⁸², ⁸⁶. The gender of the patient and/or physician when consulting the physician can have an impact on the communication about symptoms and thereby delay the total process ⁸⁹. In a Danish population-based study male cancer patients experienced a longer doctors’ delay than female patients when gender-specific cancers were excluded, and the authors suggest that the delay could have been a result of men disclaiming and downplaying the importance of their symptoms ⁴³. Men with testicular cancer have been found to hesitate because of the risk that their male image might be affected by treatment seeking. Reasons for the time lag were described as complex, involving a mixture of feelings, including fear of appearing weak or hypochondriac, feeling embarrassed, fear of appearing to lack in masculinity, and being afraid of the consequences of treatment ⁴⁷.

Social support and delay
Studies in prostate- and breast cancer patients have found that delay tends to become longer when a patient does not share his or her symptoms of illness with other people ⁵⁹, ⁹⁰. The partner’s worries have been found to hasten contact with the health care service ⁴⁸, ⁹¹-⁹². A stable social network and social support have been studied as factors that may stimulate an individual to seek medical advice because of an unexplained symptom and have an effect on reducing delay ⁵⁶, ⁵⁸, ⁹³. Women seem to have an important influence on the decisions of men to seek health care ⁹⁴. In a study on the impact of social networks on colorectal cancer screening men and women who were socially isolated, were equally less interested in fulfilling screening compared with individuals who were involved in social networks ⁹⁵.

Penile carcinoma and delay
Penile carcinoma has always been described in the literature as an illness with a long patients’ delay. Studies of delay in penile carcinoma follow a pattern of retrospectively evaluated cohorts, usually by evaluation of time lags documented in medical records. Because of the low incidence of penile carcinoma in western society, these retrospective studies encompass several
decades each. Findings from the beginning of the 20th century estimated the patient delay to be more than one year in 15–50% of the samples and the most quoted causative factors were embarrassment, fear, neglect, and ignorance, although these have not previously been studied in detail, as shown below 96-101. A common feature in these studies is the lack of interviews where the patients were asked to describe their symptoms and treatment seeking. The results are mainly based on the surgeons estimated time lag.

Dean et al. described as early as in 1935 the problems with long delay in penile carcinoma and concluded that about 1 year was lost between the appearance of the first symptom and the first visit to a physician, and that sometimes even more time was wasted because of inappropriate treatment 102. This finding were repeated in a retrospective Swedish study of 229 patients in 1958, with a delay of more than 1 year in 26% of the patients in both the group without metastases and the group with metastatic spread 100. In the same period, Buddington et al. presented data with more than 40% of the patients showing a delay of 3–12 months, and a fourth (27%), 1 to 5 years 103.

Further studies in penile carcinoma in the 1970s reported that half the patients delayed more than 1 year with penile symptoms 104, and in one study they noted that the survival was slightly less in the patients that had a delay of more than 1 year, although the difference was not statistically significant 98. Johnson et al. found in an American study of 153 patients with penile carcinoma a delay of more than 1 year in 84% and noted the need for earlier diagnosis 101. None of these authors reflected about possible factors that may have caused this delay, and this pattern continued in later research with two British studies, where Naryana et al. reported that up to 50% of the patients might have symptoms for more than 1 year, and Seyam et al. found a median delay of 1 year in a retrospective sample of 22 men 97, 99. Some older studies show that the difference in survival rates between patients who present early, and those who present later is negligible 100, 105 while other series show decreased survival with longer delay 98.

Recent studies reinforce earlier results. In a 2009 British study, Lucky et al. found a mean patients’ delay of nearly 6 months and a doctors’ delay in around 20% when referred to specialists other than urologists. The authors speculated that the major source of the patients’ delay resulted from the reluctance to seek medical advice 96. It has also been shown in a German study by Schlenker et al, that patients with local recurrence of penile carcinoma also hesitated to seek medical help which delayed their treatment 106.
Sexuality

Sexual health and sexual ill-health

The field of sexology has developed and changed throughout the 20th century. Initially the term sexuality derived from the Latin word sexus and was only used as “belonging to sex or gender”. It was in literature primarily used when describing plant life and then transferred to human beings and the aspect of reproduction 107. More than two hundred years ago, Carl von Linné 108 the pioneer in Sweden, besides teaching about the sexual life of plants and animals, also taught students about the sexual functions of human beings, including not only reproduction but also the aspect of sexual desire.

Sexuality is an integral part of our development through life. This complex phenomenon is defined by the World Health Organization (WHO) 109 as: “a central aspect of being human throughout life that encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors”. This definition teaches us to understand that sexuality is a vulnerable aspect of life and may be influenced when ill-health affects an individual, and moreover, that sexuality is not easily separated from other aspects of life.

Sexual health is a part of overall health and a life area affecting and affected by many other factors. Thus, WHO states that: “sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled” 109.

Sexual medicine/clinical sexology focuses on human sexual well-being from physiological, psychological, social, and cultural aspects. The goal is to support the individual with sexual problems to have a satisfying sexual life (and thereby a satisfying life situation). Studies on aetiology, risk factors, and treatment strategies have been highlighted, as have the importance of partner aspects, and not the least, associations with diseases,
disabilities, and medication. Sexual function and ability is viewed in relation to the person’s life situation in general, and sexual medicine/clinical sexology will thus, be multidisciplinary and multiprofessional. Diseases and various pharmacological and surgical treatments will often affect a patient’s sexual life. Some diseases are manifested directly as genital; others will affect sexual life indirectly. Specific symptoms, such as decreased desire, and erectile and ejaculatory dysfunctions, can be related to physiological pathology (often cardiovascular, neurological, endocrinological, and urological factors) while others are unspecific such as fatigue, decreased mobility, pain and changes in physical appearance. In clinical practice sexual dysfunctions are therefore, by and large, similar to other problems met in health care: adequate treatment demands examination and differential diagnosis.

Sexual dysfunctions – definitions and classification
The physiological model of the human response cycle, first described by Masters and Johnson 110 and later modified by Kaplan 111 has been the platform for the definitions of sexual dysfunctions. The definitions of sexual dysfunctions most frequently used are included in the diagnostic systems of the International Classifications of Diseases (ICD-10)112 and the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) 113. The former is mainly used in somatic care, and the latter in psychiatric/psychological care.

ICD-10 defines dysfunctions per se in relation a person’s ability to participate in sexual activities, categorized into organic (N-series) and non-organic (F-series) dysfunctions. However, several inconsistencies occur, and retarded ejaculation is, for example, not included. DSM-IV describes psychogenic sexual dysfunctions with one category defining dysfunctions per se and excludes causes due to medical and pharmacological condition. When combinations of psychological and somatic causes occur these are noted. The other category includes the dimension of personal problems – distress. Evaluation of the diagnosis will be made for ICD-11 and DSM-V. In clinical praxis the distressful dysfunction will, of course, be noticed as the important one, while in research, for example, when estimating risk-factors, dysfunction per se may be central.

Recommendations for (newer) definitions of sexual dysfunctions for men (Table 1) and women (Table 2) have been suggested by a WHO consultation group of experts 114. In this thesis the definitions of the different sexual dysfunctions are mainly in accordance with the definitions below, which to a great extent are equivalent to the phrasing in the epidemiologi-
cal investigation of sexual life in Sweden \textsuperscript{115}. Women’s sexual dysfunctions are mainly deliberations by the work of Basson et al. in 2003 \textsuperscript{116}.

Table 1 Definitions for sexual dysfunctions in men

<table>
<thead>
<tr>
<th>Dysfunction:</th>
<th>Definition:</th>
<th>Comment:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual interest/desire</td>
<td>Diminished or absent feeling of sexual interest or desire, absent sexual thoughts or fantasies and a lack of responsive desire.</td>
<td>Identical for men and women</td>
</tr>
<tr>
<td>Men Erectile dysfunction (ED)</td>
<td>The consistent or recurrent inability of a man to attain and/or maintain penile erection sufficient for sexual activity. A 3-months’ minimum duration is accepted for establishment of the diagnosis.</td>
<td>Sexual activity not exclusive intercourse</td>
</tr>
<tr>
<td>Premature ejaculation</td>
<td>Ejaculation which always or nearly always occurs prior to or within about a minute of vaginal penetration, and the inability to delay ejaculation on all or nearly all vaginal penetrations, and negative personal consequences such as distress, bother, frustration and/or the avoidance of sexual intimacy.</td>
<td>Defined according to ISSM (2007). Includes only vaginal penetration</td>
</tr>
<tr>
<td>Anejaculation</td>
<td>The absence of ejaculation during orgasm.</td>
<td>Retarded ejaculation could be defined as unwanted delay or absence of ejaculation during sexual activity</td>
</tr>
<tr>
<td>Orgasmic dysfunction (OD)</td>
<td>Inability to achieve an orgasm, markedly diminished intensity of orgasmic sensations or marked delay of orgasm during any kind of sexual stimulation</td>
<td>High sexual arousal is reported and OD can occur together with ejaculatory function</td>
</tr>
<tr>
<td>Dyspareunia</td>
<td>Persistent or recurrent pain during sexual activities.</td>
<td>Genital sexual pain</td>
</tr>
</tbody>
</table>

\textsc{Elisabeth Skeppner Penile Carcinoma} 1 25
Table 2 Definitions for sexual dysfunctions in women

<table>
<thead>
<tr>
<th>Dysfunction</th>
<th>Definition</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual interest/desire</td>
<td>Diminished or absent feeling of sexual interest or desire, absent sexual thoughts or fantasies and a lack of responsive desire.</td>
<td>Identical for men and women</td>
</tr>
<tr>
<td><strong>Women Genital sexual arousal dysfunction</strong></td>
<td>Absent or impaired genital sexual arousal. For women, self-report may include vulva swelling or vaginal lubrication from any type of sexual stimulation and reduced sexual sensation from caressing genitalia. Subjective sexual excitement still occurs from non-genital sexual stimuli.</td>
<td>Sexual arousal disorder for women is divided into three subtypes</td>
</tr>
<tr>
<td><strong>Subjective sexual arousal dysfunction</strong></td>
<td>Absence or markedly diminished feelings of sexual arousal (sexual excitement and sexual pleasure) from any type of genital stimulation. Vaginal lubrication or other signs of physical response still occur.</td>
<td></td>
</tr>
<tr>
<td><strong>Persistent genital arousal dysfunction</strong></td>
<td>Absence or markedly diminished feelings of sexual arousal (sexual excitement and sexual pleasure) from any type of genital stimulation as well as complaints of absent or impaired genital arousal.</td>
<td></td>
</tr>
<tr>
<td><strong>Orgasmic dysfunction</strong></td>
<td>Lack of orgasm, markedly diminished intensity of orgasmic sensations or markedly delay of orgasm from any kind of stimulation.</td>
<td>High sexual arousal</td>
</tr>
<tr>
<td><strong>Dyspareunia</strong></td>
<td>Persistent or recurrent pain with attempted or complete vaginal entry and/or penile vaginal intercourse.</td>
<td></td>
</tr>
<tr>
<td><strong>Vaginismus</strong></td>
<td>Persistent or recurrent difficulties of the woman to allow vaginal entry of a penis, a finger and/or any object, despite the women’s expressed wish to do so.</td>
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</table>
For research as well as clinical work different descriptors have been recommended for men and women with sexual dysfunctions. These are, mainly, classification and degree of distress (see below), and occurrence of dysfunctions: life-long or acquired, general or situational.

Classification of severity has been highlighted as well as the occurrence of distress due to sexual dysfunctions. This is not, at least when it comes to comparison between different populations, important. When measuring severity of dysfunctions, differences in scale grades vary in studies from two-graded scales (yes/no) to six-graded scales (never/hardly ever/rather rarely/rather often/always/nearly always). In the epidemiological investigation of sexual life in Sweden, psychometrically, a valid trichotomy has been used: no dysfunction (never), mild dysfunction (hardly ever, rather rarely), and manifest dysfunction (rather often, always, nearly always)\(^{117}\). In this thesis manifest dysfunction is regarded as a dysfunction *per se* and/or as distressing. Distress has been defined as “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively”\(^{118}\). This can also be true when it comes to coping with a sexual dysfunction, but it is not necessarily so. Thus, it is important to differentiate between a sexual dysfunction *per se* and a sexual distressful dysfunction. Rather great differences in prevalence between these two entities have also been found (see below “Epidemiology”). In patients with cancer, it has, moreover, been observed that distress results in other negative consequences, such as decrease in compliance with medical advice and worse global satisfaction with the health care service \(^{119,120}\). There is no reason to imagine that distress due to sexual dysfunction would be different. Female partners’ psychosocial distress and bother related to sexual changes in their husbands has been reported in couples after treatment for prostate cancer, and has also been more clearly expressed by the partners than by the patients \(^{121,122}\).

**Epidemiology of sexual dysfunction**

Knowledge of incidence and prevalence is important in understanding the burden of sexual dysfunction as well as in identifying risk factors for prevention efforts. There has been an increased interest in epidemiological studies of sexual functioning during the past decades. However, there are difficulties in comparing studies due to methodological differences (personal interviews, telephone interviews, questionnaires) and lack of consensus concerning definitions, classifications, and quantifications (how often does the dysfunction occur on a scale from always to sporadically) and time-frame (how long need a dysfunction be present to being classified as a dys-
Incidence
Relatively few studies (with evidence-based methods) of sexual dysfunctions among men have been published; in those that have erectile dysfunction is most often investigated in men 40 to 80 years old, showing that age-specific incidence rates increase with age. Notably, a Dutch study found men 70-78 years to have a high incidence (99/1000 men/year), but only half of them reported this as “clinically relevant”. In Finland the five-year incidence of decreased sexual desire was 6% for 18-24 year-olds, with an increase to 13% for 25-34 year-olds, 23% for 35-44 year olds, 45% for 45-54 year olds, 69% for 55-64 year olds, and 81% for 65-74 year olds. Rather similar numbers are found in the Swedish population.

Prevalence
Prevalence of sexual dysfunctions is, on the other hand, strongly reported in the literature, especially among men. Valid descriptive epidemiological data indicate that 40-45% of women and 20-30% of men have at least one manifest (occurring rather often/often/nearly always/always) sexual dysfunction. In Sweden 26% of sexually active men (18-74 years) have experienced sexual dysfunction during the previous year.

Decreased sexual interest is the most common/prevalent dysfunction for both genders. In different reports from around the world the prevalence of men’s desire/interest dysfunction has been reported to range from about 16% in the United States and Sweden up to 25-30% in Australia (among 16-59 year olds). Sexually active Swedish men 65-74 years old, have a decrease in their sexual interest, and 38% of these experience this dysfunction as a personal problem (distress).

Erectile dysfunction (ED) is the dysfunction with the strongest evidence-based prevalence data. A review of 59 studies (world-wide) was published in 2010. It has been estimated that manifest ED is below 10% up to the age of 50-55 years, followed by an increase to slightly over 50% in men 75 to 80 years old. In Sweden the prevalence is found to be 5% (18-74 years), following the international numbers with a marked increase after 65 years. A great majority (69%) found this dysfunction to be distressing. Manifest ED is reported to be significantly associated with decreased sexual interest,
premature and retarded ejaculation, and furthermore, with the female partners' sexual dysfunctions: decreased sexual interest, decreased vaginal lubrication, and orgasmic dysfunction \(^{130}\).

**Premature ejaculation** (PE) has in a global study been found to occur in 3-8% of men \(^{131}\). In Sweden the prevalence of manifest PE is 8-9% and almost 40% found it distressing. An increase is seen in men older than 65 years, but other studies have not found this age-dependency. There is a significant association with erectile dysfunction and decreased sexual interest and female orgasmic dysfunction \(^{128}\).

**Retarded ejaculation** (RE) is a rather rare dysfunction, and there are few prevalence studies with evidence-based methods including this disorder. Moreover, retarded ejaculation is often and wrongly classified as orgasmic dysfunction, globally, found in 1-3% of 40-50 year olds \(^{131}\). In Sweden manifest ER has been reported to occur in less than 3% of sexually active men 18-65 year old, and then increase to 10% in men 66-74 years old causing distress for 55% \(^{128}\). About a third of men with RE also reported decreased sexual interest, and nearly 60%, erectile dysfunction. Female partners to men with retarded ejaculation have been found to experience decreased sexual interest, insufficient vaginal lubrication, orgasmic dysfunction, and dyspareunia \(^{130}\).

**Risk factors for male sexual dysfunctions**

Risk factors for sexual dysfunction can be classified into health-related, psychological, social and cultural factors. Many studies have shown significant and close association with the individuals' experience of ill-health and, of course, to different somatic diseases or trauma affecting the cardiovascular system, the central nervous system, hormonal regulation and urological conditions. Psychological/psychiatric risk factors found are depression, including some antidepressants (especially SSRIs), and anxiety, emotional problems, stress, partner's sexual dysfunctions, unsatisfactory partner relationship, family life and life as a whole. Furthermore, socio-cultural risk factors include are having been sexually molested as a child or sexually abused during one’s life-time, being single, being an immigrant and smoking (Table 3) \(^{114}\). Sexual dysfunctions may not only be a consequence of disease or sexual side effects of different medications and treatments; they may diminish the compliance, if the patient is dissatisfied.
**Table 3** Common risk factors associated with sexual dysfunctions in men

<table>
<thead>
<tr>
<th>Risk factor</th>
<th>Low/decreased interest</th>
<th>Erectile dysfunction</th>
<th>Premature ejaculation</th>
<th>Delayed ejaculation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health related</strong></td>
<td></td>
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<tr>
<td>Endocrinological</td>
<td>X</td>
<td>X</td>
<td></td>
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<tr>
<td>Diabetes mellitus</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
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<tr>
<td>Neurological</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Urinary tract disease</td>
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<tr>
<td><strong>Psychologically related</strong></td>
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<tr>
<td>Emotional stress</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Depression (incl medication)</td>
<td></td>
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<tr>
<td>Anxiety</td>
<td>X</td>
<td>X</td>
<td></td>
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</tr>
<tr>
<td><strong>Socio-cultural related</strong></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Partner dysfunction</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Unsatisfactory relationship</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>X</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Immigrant</td>
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<tr>
<td>Sexually molested as child</td>
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</tr>
<tr>
<td>Smoking</td>
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</table>

**Higher age and sexuality**

Older men are in a particularly paradoxical situation, as they relatively more often have sexual dysfunctions and more than one dysfunction, but the majority are sexually active, have sexual thoughts and fantasies, and a positive view of sexuality. In the Swedish epidemiological study 128, it was found that 71% of men in the age group 66-74 years had been sexually active during the previous year; lower frequencies were found for those without a steady partner. As mentioned above, more than one dysfunction often occurs in one and the same person. The number of sexual dysfunction also increases with age; having 2-3 dysfunctions was reported in almost a quarter of the men 65-74 years of age as compared to 7% of those 50-65 years and 4% of 18-49 year olds 128.
Sexual fantasies can be looked upon as a sexual activity. More than 90% of the Swedish men 18 to 49 years old had such fantasies, whether they had a steady partner or not. In the age group 50 to 65 years about 80% fantasized, and in the oldest age-cohort about two thirds — but for these older men without a steady partner as many as 90% had sexual fantasies. Beckman et al. have in their longitudinal study of elderly Swedes (70 years old), followed during a period of 30 years, found that 95% of the men valued sexuality as a positive factor in life $^{132}$.

**Penile carcinoma and sexuality after treatment**

In this rare diagnosis, and at the same time in the vulnerable localization of the disease, post-treatment sexual function is the most obvious subjective outcome parameter to deal with when comparing organ-sparing treatment for penile carcinoma and partial or total penectomy.

Knowledge about sexual function and activities after treatment for penile carcinoma is deficient, and this subject has only been investigated in a few studies worldwide. Sexual outcomes after treatment for penile carcinoma has been investigated in Norway, Brazil, France, and Italy during the past decades $^{4-6,133-134}$.

In a 2009 review, Maddineni et al. examined the current literature and found these studies including a total of 128 patients with penile carcinoma and evaluating sexual function, quality of life, and sexual well-being after all common treatment modalities (partial amputation, laser therapy, glansectomy, local excision, radiotherapy). They concluded that the treatments in penile carcinoma negatively affected the patients’ well-being in about 40% of cases, resulting in psychiatric symptoms in half the group and a decreased sexual function in 75% of the patients $^3$. The lack of standardized and validated tools for assessing the sexual outcomes in this cancer diagnosis was also noted by the authors as a problem when evaluating this group of patients. In some other studies of penile carcinoma and treatment outcomes, sexual function receives a one-line mention and has not been studied as a specific outcome. For example, the surgeon has asked the patient before and after treatment if he has an erection satisfactory for intercourse.
Partial amputation and sexuality

Sexual interest, activities, and quality of life after partial amputation have been studied in Brazil by D’Ancona et al. and Romero et al., in two small groups of patients. These two studies showed somewhat conflicting data, especially on the outcomes focusing on self-image and relationship to the partner. Using semi-structured interviews and four standardized questionnaires for self-evaluation D’Ancona et al. found in 14 patients that the degree of sexual functioning, interest in sex, and sexual satisfaction was described as normal or just slightly decreased in 9 of the 14 patients. The authors concluded that the patients remained as they were before the surgery, concerning family life, interactions with other people, and areas of living conditions. Moreover, no signs of anxiety or depression were found according to the Hospital Anxiety and Depression Scale (HADS), and the patients reported that they had been able to maintain masculine self-image and relationship with the partner through-out the treatment process. In contrast to these findings, Romero et al. found, when evaluating 18 patients that had undergone partial penectomy, by using the International Index of Erectile Function (IIEF-15) written questionnaire and personal interviews addressing erectile function, orgasmic function, sexual desire, intercourse satisfaction, and overall satisfaction with sexual activity, that around half of the patients had an erection that allowed sexual intercourse. The main reason given for not resuming sexual intercourse in half of the sexually inactive patients was feelings of shame due to a small penis and the absence of the glans penis; the medium penile length after partial penectomy was 4 cm in the flaccid state. Surgical complications also compromised resumption of sexual activity after amputation. However, two thirds sustained the same frequency and level of sexual desire prior to surgery, and continued to experience ejaculation and orgasm every time they were sexually stimulated or had intercourse. All 18 patients reported that they were moderately or very satisfied with sexual function before treatment. Nevertheless, only one third maintained their preoperative frequency of sexual intercourse and were satisfied with their sexual relationships with their partners and their overall sex life. The overall satisfaction with sex life and relationship with the partner had decreased markedly. In conclusion, postoperative scores were statistically lower for all domains of sexual function after partial penectomy.

Quantitative studies in penile carcinoma, as described here, have reported changes in sexual functioning and psychological experiences, but the causes have not been deeper studied. In a small qualitative study among 9 men with penile cancer treated with partial or total penile amputation, the impact on quality of life and sexuality has been studied in some detail by...
Bullen et al. 135. These authors reported that penile amputation alters the
sense of masculinity, but that psychosexual adaptation was feasible for
men in strong and supportive relationships. Appearance, sexual function,
and self-image were affected after the amputation, and the patients had to
construct a new concept of masculinity, which was more easily done with
support from partners 135.

Different treatment techniques and sexuality
When evaluating sexual function in patients treated for penile carcinoma,
the possibility of having larger groups of patients treated with the same
method is unusual, and commonly the studies show a mixture of different
treatments. Opjordsmoen et al. investigated 30 patients treated with four
alternatives: laser beam treatment/local excision, radiotherapy, and partial
or total penectomy. This design affords just a handful of patients in each
treatment regime. The findings in this study focus on the organ-sparing
method with radiotherapy as the most gentle treatment in respect of the
patient’s sexual life, but these patients differed in being much younger than
the others, and therefore not easily comparable. In this study, the patients
who had undergone partial penectomy showed a reduction in sexual func-
tion almost as poor as the patients that had undergone total penectomy. It
is noteworthy that 7 of 30 would have retrospectively chosen a less inva-
sive treatment, if they had been able to keep their sexual function 133. In
another paper, Opjordsmoen discusses this problem with different trea-
tment regimes and highlights the question about the discrepancy between
the physicians’ judgement and the patients’ opinion about post-treatment
sexual function. When evaluating the sexual outcomes and the quality of
life among these patients, the physicians evaluated the patients’ sexuality,
especially those 12 patients treated with radiotherapy, as worse than the
patients did This group of patients were also about ten years younger than
the others, which may have influenced the judgement 6. In another study by
Ficarra of patients treated with partial amputation (n = 11) or radiotherapy
(n = 6), three quarters reported a sexual dysfunction, and moreover, one
quarter a high level of anxiety 134.

Organ-sparing techniques and sexuality
Radiotherapy is a one of the organ-sparing methods described as least
damaging in treating penile carcinoma, even if it has not been so frequently
used. Sexual function after this treatment has been evaluated by the pro-
viders, but the research suffers from the lack of systematic, patient-
reported outcomes about sexuality 136-138. In a Swedish study including 44
patients during the years 1960 to 1984, Modig et al. found preserved sexu-
al ability after radiation if patients had been sexually active prior to treatment, but unfortunately, the author did not report the number of subjects who were sexually active 139.

Crook et al. found in a Canadian study that, of 49 patients treated with brachytherapy (mean age 58 years), 27 were “sexually potent” and, resumed sexual activities after a few weeks, and 22 of them had an erection satisfactory for intercourse 140. Sexual outcomes after organ-sparing wide local excision and circumcision have been described in a Chinese study, assessed by IIEF-5 pre- and postoperatively, showing that 22 of 32 men reporting none to mild erectile dysfunction before surgery and 96% maintained their erectile function 141.

The patients’ goal of maintaining sexual function without compromising survival has prompted the development of new reconstructive techniques after treatment for penile carcinoma. This fact has also increased the focus on the importance of studying the sexual outcomes when introducing a new surgical technique. Glans resurfacing has become an area with the possibility to also recreate sexual function in partially amputated men. Evaluation of one series of 17 patients that underwent glans resurfacing, showed that 12 patients maintained sexual function but with reduced genital sensitivity and five patients reported complete sexual function and ability. These patients who underwent glans resurfacing also received the psychological benefit of an aesthetically appealing organ compared to being partial amputated 142. In another study evaluating a novel technique with the distal urethral reconstruction of the glans for penile carcinoma in 14 patients, 10 of the patients had erectile function at 1-year follow-up, and orgasmic and ejaculatory function did not significantly change in the periods before and after surgery 143.

Morelli et al. studied 15 patients that underwent glansectomy and reconstruction (mean age 51 years). All patients were sexually active before surgery, and at mean follow-up at three years all patients reported maintained sexual function with good vaginal penetration, orgasm, and ejaculation. All of them reported reduced glans sensitivity, but were able to maintain the orgasm and ejaculation due to the presence of the sensation coming from the tip of corpora cavernosa 144.

O’Kane has reported outcome data for 25 patients treated surgically with glansectomy and skin grafting in the United Kingdom. Only 11 patients could be evaluated regarding sexual outcome; 9 reported that they could achieve erection, and 6 were still sexually active 145. Veeratterapillay et al. recently presented data from 65 patients, where 85% reported achieving erections 1 year after glansectomy, glans relining, and distal penectomy with glans reconstruction, but again no validated questionnaire
was used to assess the postoperative outcomes \textsuperscript{146}. In a small study by Hatzichristou et al. \textsuperscript{7} patients showed adequate sexual function maintained after glansectomy \textsuperscript{147}.

The conclusion of this summary of studies in postoperative sexual outcomes after treatment for penile carcinoma is that organ-sparing treatment allows a better sexual function than penile amputation and must be considered whenever feasible. However, there is a lack of standardised tools for this group of patients.
Life satisfaction

In medical research it has become increasingly popular to characterize patients’ perceived adaptation to life prior to and after interventions. The term quality of life (QoL) is much used to gain clarity of this important outcome. As a concept QoL is, however, as pointed out many years ago, a vague and ethereal entity, which people talk about. The breadth of the term QoL has been emphasized by WHO. In fact there is no reasonably universal consensus on the definition.

The World Health Organization Quality of Life (WHOQoL) group defines QoL as “An individual’s perception of his or her position in life in the context of the culture and value system in which he or she lives and in relation to his or her goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s health, psychological state, level of independence, social relationships, and his or her relationships to salient features of his or her environment”.

Quality of life can be regarded not only as the degree of normal function of a human being (i.e. a normalizable/objectifiable concept) but also as the degree of personal satisfaction that an individual can derive from life (i.e. a subjective, not per se health-related, concept). From an action-theoretical perspective health is the ability to fulfil one’s goals, while satisfaction (as an emotion) arises as a consequence of goal fulfilment. Quality of life can be regarded as satisfaction with life as a whole and satisfaction with life as a psycho-social indicator. Low levels of satisfaction indicate aspiration — goal achievement gaps, which could be a sign of unsuccessful coping. From a psycho-social point of view a major goal of rehabilitation of patients met in health care is to secure or restore satisfaction with life.

Life satisfaction and the Swedish population

In a nationally representative population study of Swedish men and women (aged 18 to 74 years) life as a whole and 10 domains have been described using the Life Satisfaction, LiSat-11 checklist. In this thesis satisfaction with life is measured by the use of the LiSat-11 checklist, developed over more than 20 years, from LiSat-8 to LiSat-11, the numbers referring to actual items. The 10 domains are closeness (family life, partner relation, sexual life), leisure (leisure activities, contacts with friends and acquaintances), provision (vocation, economy), and health (somatic health, psychological health, personal activities of daily life (p-ADL)). This checklist has adequate psychometric properties concerning reliability, construct, and clinical validity.
Some main results are that, independent of gender, 70% were satisfied or very satisfied with life as a whole. Individuals who experienced good health had higher levels of satisfaction with life as a whole and with all 10 items, and good health was a positive predictor of satisfaction for all items, except partner relationship \(^{154}\). Furthermore, having a steady partner was positively associated with life as a whole and with all items except contacts with friends and acquaintances. In men, increasing age was significantly and positively associated with satisfaction with family life, vocation, and economy while somatic health and personal ADL were negatively correlated \(^{154}\).

The Life Satisfaction checklist has been used in different clienteles seen in somatic healthcare and rehabilitation, for example, in patients with neurological diseases/injuries \(^{155}\), severe multiple trauma \(^{156}\), severe pelvic fractures \(^{157}\), peripheral vascular disease \(^{158}\), and benign chronic pain \(^{159}\), and in vocational rehabilitees \(^{152,160}\). Some main results are that the experience of life as a whole as satisfying after severe diseases or trauma is uncommon/rare and several domains are often affected \(^{155-157}\).

In clinical practice the LiSat checklist can be used to identify domains important for the patients and thereby to direct the interventions and processes of rehabilitation, giving opportunities for follow-ups on an individual level. Eriksson et al \(^{161}\) found spouses of patients with acquired brain injury to have low levels of satisfaction with life as a whole, showing the need to acknowledge the couple’s perspective in healthcare. Also, dyadic satisfaction among stroke patients and their close ones was found to be rather low (40%) \(^{162}\).

**Life satisfaction, sexual life, and sexual dysfunctions**

The interplay between life satisfaction, sexual satisfaction and sexual dysfunctions has been epidemiologically investigated, including analytic epidemiology. Manif estly distressing sexual dysfunctions are risk factors for satisfaction with life as a whole for both men and women \(^{128}\).

Men with premature ejaculation have been found to experience a lower level of sexual satisfaction than men without this dysfunction and both rated fulfilling the partners’ needs as the aspect that had most impact on the overall sense of sexual satisfaction \(^{130,163}\). For both men and women, low level of satisfaction with partner relationship is 2-4 times more frequent if the male has decreased sexual interest and/or premature ejaculation, and low satisfaction with family life and with life as a whole is twice as common if he experiences decreased sexual interest. Sexual dysfunction is, thus, to a high degree a couple’s problem \(^{130}\).

Men in treatment for erectile dysfunction with prostaglandin E1 (Caverject™) have shown to be significantly less satisfied not only concerning
sexual life but also with partner relationship, family life and life as a whole compared to a control group; \textsuperscript{164} after treatment all domains and life as a whole were normalized. Gil et al. found that men successfully treated with sildenafil (Viagra\textsuperscript{TM}) were significantly more satisfied with all domains compared to pre-treatment \textsuperscript{165}. Moreover, men in successful oral treatment with tadalafil (Cialis\textsuperscript{TM}) in a study of more than 6500 men, have been found to follow the same pattern when used LiSat-8 \textsuperscript{166}, The International Index of Erectile Function, IIEF-5 \textsuperscript{167-168}, and Sexual Health Inventory for Men, SHIM \textsuperscript{169}. The researchers found a close convergence between these erectile function instruments and satisfaction with sexual life. They concluded that three subset of items – satisfaction with sexual life, partner relation and contacts – could validly substitute SHIM/IIEF-5 \textsuperscript{170}. 
RATIONALES FOR THE THESIS

There is a lack of knowledge regarding patients’ experiences of sexuality and life satisfaction after treatment for penile carcinoma, both in Sweden and globally, mainly because this is an uncommon disease in western societies. As a consequence there is also an insufficient knowledge in society and among health care providers. For decades it has been commonly thought that these men have a long delay in treatment seeking, and as discussed before, studies of penile carcinoma often have included small populations with a variety of treatment modalities, many spread over several decades, and therefore difficult to evaluate and compare.

Combined laser treatment (Nd:YAG and CO₂) has been used since the 1980s in Sweden. At the Department of Urology at Örebro University Hospital we have had the possibility of studying delay and the sexual outcomes in a group of patients with a uniform treatment modality, which provides the base for this thesis.

With both a retrospective view of the patients description about sexuality and life satisfaction several years after treatment, and a prospective view were we are able to follow the patients both pre- and post-treatment, completed with the partners’ perspective. This gives us a unique opportunity to get more insight and understanding of the patients pathway all the way from first symptom through treatment and during the rehabilitation of this malignancy.

There is also an intention to highlight the need of improved communication in health care services about the care of patients with urogenital malignancies, and especially with focus on the sexual rehabilitation.

Hopefully, increased knowledge of the patients’ and couples’ experiences in penile carcinoma should be of value for both newly diagnosed patients and their partners when seeking information about the outcomes after organ-sparing treatment, and also for clinicians in situations where appropriate treatment should be considered.
AIMS OF THE THESIS

This thesis has two main objectives. The first aim is to describe symptoms and treatment seeking among patients with penile carcinoma. The second aim is to examine to what extent sexual function and sexual activities are affected by the diagnosis and organ sparing laser treatment for penile carcinoma.

These overall aims have resulted in four papers with the following specific aims:

I  To get more insight into patients’ perception of initials symptoms, and factors associated with patients’ delay, and further, to assess whether and to what extent there is a doctors’ delay. We also wanted to evaluate whether tumour stage is associated with the delay.

II  To describe the prevalence of sexual dysfunction before and after laser treatment, investigate whether sexual satisfaction changed after laser treatment, compare sexual satisfaction of treated men to that of a representative sample of Swedish men, and evaluate patients’ experiences with the cosmetic results.

III  To describe the initial clinical symptoms of penile carcinoma, assess the time between initial symptoms and treatment seeking, and describe the effect of laser treatment of penile carcinoma on sexual activities and life satisfaction.

IV  To describe the couples’ sexual activities, sexual function, and life satisfaction before and after the mens’ diagnosis and organ-sparing treatment for penile carcinoma.
MATERIALS AND METHODS

This thesis contains two studies, one retrospective and one prospective. The used method is almost the same with face-to-face structured interviews. The interviewer presented the questions orally, along with the multiple-choice responses and filled in the participants’ declared answers. The participants’ themselves filled in the self-assessment questionnaires.

There are no validated instruments assessing outcomes in penile carcinoma, so a structured questionnaire was designed for this study added with three well-validated self-assessment questionnaires, The International Index of Erectile Function, IIEF-5\textsuperscript{167-168}, The Life-Satisfaction checklist, LiSat-11\textsuperscript{153, 165-166}, and The Hospital Anxiety and Depression Scale, HADS\textsuperscript{171}.

Most of the questions addressing sexual function, sexual activities and life satisfaction were extracted from a nationally representative study of sexual life) from which we had an ad hoc comparator population of all 935 men and 809 women, aged 34 to 74 years\textsuperscript{115, 153}.

Table 4  An overview of the used methods in the studies included in this thesis

<table>
<thead>
<tr>
<th>Retrospective study (Paper II and III)</th>
<th>Prospective study (Paper I and IV)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient interview</td>
<td>Patient interview</td>
</tr>
<tr>
<td>After treatment</td>
<td>Before treatment</td>
</tr>
<tr>
<td></td>
<td>After 6 months</td>
</tr>
<tr>
<td></td>
<td>After 12 months</td>
</tr>
<tr>
<td>Self-evaluation questionnaires</td>
<td>Self-evaluation questionnaires</td>
</tr>
<tr>
<td>IIEF-5 (10 pat with ED)</td>
<td>IIEF-5 (all patients)</td>
</tr>
<tr>
<td>LiSat-11 (all patients)</td>
<td>HADS (all patients and partners)</td>
</tr>
<tr>
<td></td>
<td>LiSat-1 (all patients and partners)</td>
</tr>
<tr>
<td></td>
<td>Data collected from medical records</td>
</tr>
</tbody>
</table>
Patients, retrospective study (Paper II and III)

A total of 67 patients were treated at the Department of Urology, Örebro University Hospital, Sweden, for penile carcinoma, using a combined carbon dioxide (CO$_2$) and neodymium (Nd :YAG) lasers, between 1986 and 2000. Of the 67 patients 58 were alive when the present retrospective interview study was initiated. All 58 men were identified by the urologist through the medical records system and contacted by telephone. During this initial contact, 46 patients (79%) agreed to be contacted by a researcher and were sent written patient information about the study. Twelve patients refused to participate in the study for unknown reasons, but there were no differences regarding tumour stage or grade, or cosmetic results (evaluated by the surgeon) compared to those participating in the study. The 46 patients that had accepted, were then contacted by telephone during a period of 6 months, asking them again about interest in participating. All 46 patients agreed (Table 5). All patients were considered to be tumour free at the time of the interview. Seven patients (15%) had a medical history of serious cardiovascular diseases (such as myocardial infarction, arrhythmia and cerebrovascular thrombosis). One had concomitant diabetes and 3 had been diagnosed with diabetes mellitus at the time of laser treatment. Thirty-six patients lived in a steady relationship. Five men had divorced and lived in new relationships, while 31 had the same partners as before the treatment. All men reported being heterosexual.

All the interviews were conducted at the outpatient departments of the hospitals in Sweden to which the patients primarily had been referred. Each interview lasted approximately 1 hour, and took place at a median of 3 years after the laser treatment (mean 4.5 years; range 6 months to 15 years).
Patients and partners, prospective study (Paper I and IV)

This study is a prospective, observational and longitudinal study with repeated measures at baseline (often 1 or 2 days before treatment), and at, 6 and 12 months after treatment. A total of 104 patients with localized penile carcinoma were referred to the Department of Urology, Örebro University Hospital, during the period May 2005 to April 2009. Exclusion criteria in this study were relapse after previous combined laser treatment and age over 74 years (the choice of excluding patients older than 74 was due to the age limit in the comparison group that were chosen for the questions about sexual activity). Twenty-two patients were excluded due to age, and 15 because they were referred for treatment of local recurrences. The remaining 67 patients were consecutively asked to participate in the study. Eight men were unwilling to participate, leaving 59 men for the final analyses. Some of the men gave as reasons for not participating being “too old to answer questions about sexuality” (n = 3) and “embarrassed answering questions about sexuality” (n = 2), while the rest declined without explanation.

Nine of the 59 men were judged to have tumour stage too advanced at the time of surgery and thus not be suited for organ-sparing therapy, and they underwent partial amputation. These men were also included in the
study, but are presented as a separate group when discussing symptoms and delay in Paper I. Fifty men had organ-sparing therapy with combined laser treatment (CO₂ and Nd:YAG) (Table 6).

Table 6  Patient- and tumour characteristics, prospective study, Paper I

<table>
<thead>
<tr>
<th></th>
<th>Patients Laser treatment n = 50</th>
<th>Patients Partial amputation n = 9</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>61,5 years (37 – 73)</td>
<td>61 years (47 - 69)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>40</td>
<td>6</td>
</tr>
<tr>
<td>Co-habitant</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Single, divorced or widowed</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td><strong>Tumour stage</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tis</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>T1</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>T2</td>
<td>12</td>
<td>2</td>
</tr>
<tr>
<td>T3</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Tumour grade</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tis</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>G1</td>
<td>13</td>
<td>1</td>
</tr>
<tr>
<td>G2</td>
<td>17</td>
<td>5</td>
</tr>
<tr>
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<td>5</td>
<td>3</td>
</tr>
</tbody>
</table>

In this prospective study we also included partners to the patients. The definition for partner is that they were living together or in a stable relation even if they were not living together. Thirty-four of 41 eligible partners (83%) to laser treated patients accepted participation and were interviewed at baseline, 31 at 6 months’ follow-up and 29 (71%) at 12 months’ follow-up. Two partners to partially amputated patients fulfilled all three interviews, but due to this low number, we have chosen not to publish the data from these interviews. Five partners declined during the follow-up period. One partner declined due to separation, one patient died, and the remaining three declined without explanation, leaving 29 couples fulfilling all three measuring points, with partners’ median age 57 years (range 30-72) (Figure 1 Flowchart). One couple lived in a homo-sexual relationship, which is why we use the term “partner” consistently in this paper.

The patients were referred to the Department of Urology in Örebro from 22 different hospitals around the middle and south of Sweden. After being
referred for the organ-sparing treatment, the patients were informed by the physician about the study both orally and through a written patient information letter, at the end of the first appointment at the Department of Urology in Örebro University Hospital. The patients were then asked about the willingness to participate in the study by the researcher (not involved in the surgery or clinical care), often the day before their surgery, and interviewed immediately if they accepted.

At the end of the interview the patients were asked for approval to contact their partner and discuss the partners’ own willingness to participate in the study, using the same method. Those patients who gave their permission got a letter with information to give to the partner, and the partners were then contacted by the researcher by telephone or asked in person about participation at the department the day before treatment.

The interview sessions were individual for patients and their partners and took place either at the university department or at the local hospital in the patient’s (and partner’s) home county.
Laser treated penile carcinoma

Patients

- Patients referred for treatment and filling inclusion criteria
  - n = 67
  - partners n = 47

  - Partial amputated patients, n = 9
  - Declined participation n = 8
  - Declined further participation without explanation n = 4
  - Died between interview II and III n = 1

Interview I
- baseline before or <1 week after treatment
  - n = 58
  - n = 50

  - Interview I
  - baseline before or <1 week after treatment
  - n = 34
  - n = 31

  - Interview II
  - 6 months after treatment
  - n = 46

  - Interview II
  - 6 months after treatment
  - n = 31

  - Interview III
  - 12 months after treatment
  - n = 45

  - Interview III
  - 12 months after treatment
  - n = 29

  - Died between interview II and III n = 1
  - Widow n = 1
  - Separated n = 1

29 couples participated through all interviews

Partners

- Partners referred to partial amputated patients, n = 6
  - n = 41

  - Declined participation
  - n = 7

  - Declined further participation without explanation n = 3

Interview I
- baseline before or <1 week after treatment
  - n = 58
  - n = 50

Interview II
- 6 months after treatment
  - n = 46

Interview III
- 12 months after treatment
  - n = 45

- 29 couples participated through all interviews

Patients referred for treatment and filling inclusion criteria
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- partners n = 47

Partners eligible for the study
- n = 41
- Declined participation
- n = 7
- Declined further participation without explanation n = 3

29 couples participated through all interviews

Laser treated penile carcinoma

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- 12 months after treatment
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- 29 couples participated through all interviews
Questionnaires

The questionnaires consisted of 55 questions in the retrospective study and 68 in the prospective. Both focused on specific outcomes in penile carcinoma, such as questions about symptoms, penile appearance, and urological rehabilitation, with additional questions about sexual activities, sexual function/dysfunction. The first half of the questionnaire contained questions about socio-demographic data, symptoms, treatment seeking, physical outcomes after treatment and cosmetic result and the remaining questions were about sexual function/dysfunction and sexual activities, drawn from the questionnaire in the sexual survey in Sweden. All patients were asked the same questions, in the same order by the same researcher.

Five questions in the questionnaire in the retrospective study were open-ended, and the rest closed-ended. The five open-ended questions were as follows:

1. (If you have had any surgery on the penis earlier in life) What kind of surgery did you have?
2. What type of symptom of illness was the first you recognized on your penis?
3. If you hesitated in taking the first contact with health care services, what do you think the main reason was?
4. (If your sexual desire changed after treatment) Which factor affected sexual desire the most?
5. (If you experienced the healing process after treatment as troublesome) In what way did you experience the treatment as troublesome?

These earlier open-ended questions about symptoms and reasons for delay were used as answering alternatives in the prospective study and all questions about sexuality were identical at all three measuring points. Those differing from baseline to follow-up were concerning the urological rehabilitation.

The rest of the questions were as follows:
One question concerned the passage of time from the patient’s awareness of symptom(s) until seeking medical attention. Possible answers were < 1 week, 1–4 weeks, 1–6 months, 7–12 months, and > 1 year.

We also asked whether the patients had previously been diagnosed with one or several sexual transmitted infections (STIs): gonorrhea, syphilis, chlamydia, genital herpes, condyloma, HIV, or other STI. Possible answers were yes, no, doubtful/not sure.

Sexual function/dysfunction: Participants were asked how often they experienced sexual desire, and the frequency options were often, occasional-
ly, rarely and never, and those giving the latter 2 answers were considered to experience a manifest dysfunction of sexual desire.

Other sexual function parameters addressed were sexual interest, erection, ejaculation (early and delayed), dyspareunia, female orgasmic function, female lubrication, and vaginismus (Table 7).

Table 7 Phrasing of statements addressing sexual abilities during the preceding 12 months. All statements were followed by the question: Has this happened in your sexual life during the last 12 months? and also when a manifest dysfunction occurred a following question; Has this been a problem for you (personal distress)?

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual interest (w or m)</td>
<td>It happens that people have periods of decreased interest in sex. Has this happened......</td>
<td>Has this been a problem for you?</td>
</tr>
<tr>
<td>Penile erection (m)</td>
<td>It happens that the man’s penis does not become rigid or gets flaccid during the intercourse. Has this ......</td>
<td>Has this been a problem for you?</td>
</tr>
<tr>
<td>Ejaculation (m)</td>
<td>Too early</td>
<td>Has this been a problem for you?</td>
</tr>
<tr>
<td></td>
<td>It happens that the man has ejaculation very shortly after intromission. Has this......</td>
<td>Has this been a problem for you?</td>
</tr>
<tr>
<td></td>
<td>Too late</td>
<td>Has this been a problem for you?</td>
</tr>
<tr>
<td></td>
<td>It happens that the man has difficulties in achieving ejaculation. Has this......</td>
<td>Has this been a problem for you?</td>
</tr>
<tr>
<td>Dyspareunia (m or w)</td>
<td>It happens that intercourse is associated with pain in the genital organs. Has this......</td>
<td>Has this been a problem for you?</td>
</tr>
<tr>
<td>Orgasm (w)</td>
<td>It happens that woman has difficulties to reach orgasm. Has this......</td>
<td>Has this been a problem for you?</td>
</tr>
<tr>
<td>Vaginal lubrication (w)</td>
<td>It happens that the woman’s vagina does become sufficiently wet during intercourse. Has this......</td>
<td>Has this been a problem for you?</td>
</tr>
<tr>
<td>Vaginismus (w)</td>
<td>It happens that the woman gets spasms in her vagina so that penile penetration is difficult or impossible. Has this......</td>
<td>Has this been a problem for you?</td>
</tr>
</tbody>
</table>
Using the questions given in Table 7, the level of each sexual function/dysfunction during the preceding 12 months was reported along a six-graded scale: never, hardly ever, quite rarely, quite often, nearly all the time, and all the time. A dysfunction that occurred quite often, nearly all the time or all the time was judged to be manifest dysfunction. If the dysfunction led to personal distress, the occurrence of personal distress was reported, using the same scale. The phrasings furthermore enabled the women to report their perception of the male partner’s abilities concerning erection and ejaculation. Likewise, the men could report their perceptions of the female partner’s vaginal lubrication, orgasm and the female occurrence of vaginismus. The first question in this section were: “It happens that people have periods of decreased interest in sex. Has this happened in your sexual life?” One possible answer was, “I have not had intercourse after the treatment,” and no further specific evaluation of sexual function/dysfunction was performed in participants who gave this answer. These questions were also extracted from the nationally representative survey of sexual life in Sweden.115

**Sexual activities:** Patients were asked if they had been sexually active before and if they had resumed sexual activities after treatment. Possible answers were < 1 week, 1–4 week, 1–12 months, > 1 year, and not resumed. Patients were also asked to specify the time since their most recent intercourse. Answering alternatives ranged from less than 24 hours ago to more than 10 years ago. Information about specific sexual activities was obtained by asking about the number of lifetime sexual partners, and sexual preference was investigated by a five-category question. Aspects of sexual repertoires were explored by questions about masturbation as a way of obtaining sexual satisfaction, and use of manual genital sexual stimulation/caressing and fellatio before treatment/after treatment. Possible answers were yes or no.

**Cosmetics:** One question addressing the perceived cosmetic results used a five-point Likert scale ranging from very satisfied to very dissatisfied.

**Sexual satisfaction:** The level of sexual satisfaction was assessed by a question derived from the LiSat-11 checklist (see below) How satisfying is your sexual life? The six levels of satisfaction were very satisfying, satisfying, rather satisfying, rather dissatisfying, dissatisfying, and very dissatisfying. Patients who answered very satisfying or satisfying were considered to have a high level of sexual satisfaction, while others were considered to have a low level.
Self-assessment questionnaires

The International Index of Erectile Function, IIEF-5 (Appendix 1)

Men who reported decreased erectile function after treatment in the retrospective study were asked to complete the erectile domain questions from the well-validated IIEF-15 instrument. This IIEF-5 is a short version of the IIEF-15 and well validated in men with ED. All men in the prospective study completed IIEF-5.

IIEF-5 consists of five questions and each IIEF-5 item is scored on a five-point ordinal scale where lower values represent poorer sexual function. The first question addresses confidence in the erectile function, questions 2-4 the actual erectile function capacity, and question 5, intercourse satisfaction. Thus, a response of 0 for a question is considered the least functional, whereas a response of 5 is considered the most functional. The possible scores for the IIEF-5 range from 1 to 25; a score above 21 was considered as normal erectile function and at or below this cut-off, ED. According to this scale, ED is classified into four categories based on IIEF-5 scores: severe 1-7, moderate 8-11, mild to moderate 12-16, mild 17-21, and no ED 22-25. There is an possible answer in four of the questions, no attempt to intercourse has occurred, which gives a risk for finding men in the “severe” classification, despite having an erectile function sufficient for intercourse. A low score may then be a consequence of a patient having no opportunity or lack of interest in sex, rather than ED per se.

The Life Satisfaction checklist, LiSat-11 (Appendix 2)

The LiSat-11 life-satisfaction checklist was used both in the retrospective and the prospective study. In this thesis satisfaction with life is defined as the degree to which an individual experiences himself as being able to attain his goals, using the LiSat-11 life-satisfaction checklist. LiSat-11 is a one-page, generic, 11-item questionnaire on life satisfaction. The first item characterizes satisfaction with life as a whole. The remaining items characterise satisfaction with ADL-capacity, physical health, psychological health, sexual life, partner relationship, family life, leisure, friends and acquaintances, work, and financial situation. Each item has six graded alternative answers: 1, very dissatisfied; 2, dissatisfied; 3, rather dissatisfied; 4, rather satisfied; 5, satisfied; 6, very satisfied. The instrument has been validated in a representative sample of Swedish men and women aged 18–74 years. It has adequate test–retest reliability, and discriminate, and specificity validities. The scale can validly be dichotomized into satisfied (answer alternatives 5 or 6) versus not satisfied (answer alternatives 1–4),
where being satisfied indicates that the individual is well adapted and has little or no gap between aspirations and goal achievement.

Among the 11 items in this generic self-assessment instrument, one item encompasses the subjective satisfaction with life as a whole, and the remaining 10 items form a stable factor construct with different domains of life. A health factor encompasses satisfaction with personal ADL, and somatic and psychological health. Satisfaction with the vocational and financial situation constitutes the provision factor, and a spare time factor includes satisfaction with leisure and with contacts with friends and acquaintances. A closeness factor consists of the items about satisfaction with sexual life, partner relationship, and family life.

The individuals indicate the subjective level of satisfaction for each of the 11 items on a six-point Likert scale with six levels of satisfaction: very satisfying, satisfying, rather satisfying, rather dissatisfying, dissatisfying, and very dissatisfying. Patients who answered very satisfying or satisfying were considered to have a high level of sexual satisfaction, while others were considered to have a low level.

As mentioned before, a survey of sexual life in Sweden was conducted in 1996, initiated and financed by the Swedish National Institute of Public Health. The LiSat-11 checklist was used in this survey, and population-based Swedish reference values for the social indicator LiSat-11 instrument were established.

With regard to analysing the responses from LiSat-11 earlier studies have shown the validity of dichotomizing the possible answers as satisfied (very satisfied and satisfied) and not satisfied (very dissatisfied, dissatisfied, rather dissatisfied, and rather satisfied).

The Hospital Anxiety and Depression Scale, HADS (Appendix 3)

The Hospital Anxiety and Depression Scale (HADS) is a valid, self-rating test for mood, screening for anxiety and depression. HADS is a 14-item questionnaire, and each item has a Likert response scale. Two scores are constructed by summation and often reported as HADS-A (level of anxiety) or HADS-D (level of depression). Seven questions each pertain to symptoms associated with anxiety or depression. Recommended cut-off points, from the original article by Zigmond and Snaith, are less than 8 in both sub-scales to be considered “normal”; scores between 8 and 10 are considered to be “border-line cases”, and in accordance with this a score greater than 10 on either of the sub-scales indicates the presence of psychological distress. It usually takes between 3-5 minutes to complete the HADS questionnaire.
HADS has been used by several researchers for assessing psychological distress in cancer patients as well as in primary care cases. It has been shown that the HADS gives clinically meaningful results as a psychological screening tool, in clinical group comparisons and in studies with several aspects of disease and quality of life. It is sensitive to change both during the course of the disease and in response to medical and psychological interventions.

Collection of data from medical records

To test for consistency of the patient’s perception regarding symptoms and delay, answers were compared with data extracted from the medical records. With informed consent from the patients, copies of their medical records from the referral urological departments around Sweden, and in step two also from medical records, from the first medical appointment, often from a general practitioner, were requisitioned.

We chose to define the different stages of delay from symptom to diagnosis and not to laser treatment, due to inclusion criteria that could include patients who had been treated with other modalities before referral to Örebro.

Delay was divided as follows:

Patients’ delay — the time interval between first awareness of a sign or symptoms involving the penis until the first contact with a health professional, typically a general practitioner (GP).

Doctors’ delay — Primary delay, GP delay the time interval from the first medical consultation until referral to hospital.

Doctors’ delay — Secondary delay, specialist delay this delay was subdivided into two parts: first, the time interval from the referral until the first specialist consultation, and second, the time between the first specialist consultation and a definitive cancer diagnosis.

Because of the intention to compare the patient-reported time lag we used the same intervals in the interviews and the collection of data from the medical records; < 3 months, 3-6 months, 6-12 months and > 1 year.
ETHICAL CONSIDERATIONS

The Regional Ethics Committee of Örebro University Hospital approved the study protocol in September 2000 for the retrospective study, (Papers II and III) and the prospective study (Papers I and IV) was approved by the Ethics Review Board in Uppsala (2005:112).

The patients, and in the prospective study also their partners, were given both written and oral information about the study and all participation was based on informed consent. Because of the law that governs the health care services in Sweden, there was an obligation to first ask the patients if we could contact their partners about participating in the study.

Questions concerning sexuality could be perceived as sensitive and embarrassing, due to their intimate nature. It is important to emphasize both that the patients and the partners exercised their own free will in agreeing to participate, and that, before deciding, they received written information that the study mainly focused on sexual function and activities after treatment. The interviews could perhaps affect both the communication about sexuality and the sexual activities of the couples when both were included in the study, an intervention that could be experienced as both positive and negative. When questions were raised linked to the researchers profession as a medical social worker, they were discussed, and patients and/or partners were counselled on how to cope with different needs or problematic situations and where to find further professional support at their own hospital clinics. At the end of the interviews they were also asked if they would prefer help in effectuating the contact or if they would be able to do it themselves. One patient and one couple got this further referral to professional support.

The prospective study took place only 1 or 2 days before surgery, and shortly after the men had been diagnosed with cancer. Consideration has been given to this problem, but it is unavoidable in clinical settings, when studying patients’ experiences in cancer care. Most of the patients commented at the second and third interviews, that they had experienced this intervention, rather, as positive instead. A long time had passed since treatment for some of the patients, when interviewed in the retrospective study. There could be both positive and negative aspects to discussing cancer diagnosis and treatment outcomes after several years. Hopefully, this question was considered by the patients themselves upon reading the written information before they accepted the invitation to participate.

In both the retrospective and the prospective studies the participants always had the opportunity to refuse to answer each single question, and to withdraw without further explanation which some of them actually did.
**DATA ANALYSIS**

This thesis is based on detailed structured interviews among a relatively small number of individuals. The number of subjects was generally stated in the results together with percentages to facilitate comparisons, and the small numbers allowed only for limited quantitative analyses.

The data, except information on age, were on an ordinal and nominal level, and did not show a normal distribution, and analyses were therefore based on non-parametrical methods. The LiSat-11 was dichotomized into “not satisfied” (categories 1-4) and “satisfied” (categories 5-6) \(^{153-154, 160}\).

The Mann-Whitney U test (MW) or, simple cross-tabulations with computations of chi-square and the Fisher exact probability test were used to detect differences between groups in Paper II and III. In Paper IV within-couple agreement concerning sexual activity, satisfaction with life as a whole, sexual life, and partner relationship was analysed using the Kappa coefficient for agreement (where values > 0.60 represented substantial to strong agreement) \(^{173}\). The non-parametric sign test was further used to test differences in medians in the distribution over time comparing satisfaction with sexual life at baseline and after 12 months.

We used the SPSS, version 14.0–17.0 software (SPSS Inc. Chicago, IL. USA) for statistical analyses. The confidence level was set to 0.05 in all analyses.
SUMMARY OF RESULTS

This thesis has two main objectives. The first aim is to describe symptoms and treatment seeking among patients with penile carcinoma. The second aim is to examine to what extent sexual function and sexual activities are affected by the diagnosis and organ-sparing laser treatment for penile carcinoma.

Both the 46 patients in the retrospective study (paper II and III) and the 50 patients (and the partners) in the prospective study (paper I and IV) were questioned about initial symptoms, and their estimated time frame between the first symptom and their first contact with health care and the time to diagnosis. Hence, the results in this thesis about symptoms and delay are shown with a summary of the results from both the retrospective and the prospective studies. Concerning sexual function and activities, these are separated due to the design, with Papers II and III showing the results from the patients’ viewpoint, and Paper IV the couples’ perspective (the papers are referred to in the text by their Roman numerals).

Initial symptoms and treatment seeking

Initial symptoms (I, III)

When evaluating initial symptoms and patients’ delay in the prospective study, only 48 patients are presented, because 2 patients denied any penile problem demanding medical attention. These 2 patients had phimosis, and the suspicion of penile tumour was not revealed until they were in need of bladder drainage in conjunction with treatment for another medical condition.

In the prospective study, 17/48, (35%) reported the initial symptoms to be erythema, rash, or eczema on the glans penis, and 14 patients (29%) experienced superficial fissures or ulceration.

For some of the patients in the retrospective study a long time had passed between the symptom appraisal, treatment, and interview, but despite this, almost all of them (98%) could recall their first symptom of penile carcinoma. Most reported symptoms were superficial ulceration and fissures, followed by induration of the glans penis.
Patients’ delay (I, III)
In total, 31 out of those 48 patients (65%) in the prospective study who were able to recall their symptoms and time lag, had a patients’ delay of more than 6 months. This delay was distributed across all pT stages, with a small, not statistically significant, predominance, for pT1 or pTis-tumours (23 of 31; 74%). Twenty-five of those 31 (81%) lived in a steady partner relationship.

The single most important reason for patients’ delay of more than 6 months was embarrassment in describing the problem to medical personnel by telephone or at consultation (14 of 31 patients; 45%). Among the remaining patients, the main reasons varied: lack of knowledge; a feeling that the symptoms would resolve spontaneously; fear of severe illness; or having no thought that the symptoms could be something severe, demanding health care.

Patients describing their first symptom as superficial fissure, ulceration, erythema, or eczema had both longer patients’ and longer doctors’ delay, compared with patients with clearer symptoms such as tumours and warts. Eleven of those 14 patients reporting ulceration (79%) and 13 of 17 (77%) reporting erythema/eczema had a delay of more than 6 months before their first medical consultation.

Thirty patients reported concomitant disease and regular health-care contacts, but still, 20 out of 30 (67%) delayed contacting a general practitioner (GP) for more than 6 months after symptom presentation.

We also studied the willingness of the men to share their penile problems with their partners. Eighteen patients having a partner awaited the cancer diagnosis or postponed the conversation until a point when it was impossible to hide the problem due to bleeding or pain. Eight of them had had symptoms for more than 1 year, which was confirmed by the partners in separate interviews. The men had lived together with their partners for a long time (median 39 years).

We found no statistically significant correlation between a long patients’ delay (> 6 months) and a high level of depression/anxiety (HADS), or with low satisfaction with life (LiSat-11).

Among the 46 patients interviewed in the retrospective study, patient’s delay in treatment seeking was less than 4 weeks for 11 of 46 (24%), whereas it was more than 6 months for 17 of 46 (37%). The length of delay was related to marital status: all 6 men who were single when symptoms first appeared delayed more than 6 mo, whereas only 15 of 40 married men delayed more than 6 months.
Doctors' delay (I)

Doctors' delay was divided in primary delay, “GP delay” and secondary delay, “specialist delay”.

The medical records show that 38 of 50 patients (76%) primarily contacted a GP due to their penile symptoms; 25 of these patients were referred to a urologist and 13 to a dermatologist. The reason for referral to a dermatologist was the presence of more unspecific symptoms, such as erythema or ulceration at the glans penis.

Twenty-nine patients out of 38 (76%) were referred immediately in the same day or week, but the remaining 9 patients had repeated contacts with the GP for 4-35 weeks (median 20 weeks) before referral to a specialist.

For 33 of the 38 patients (87%), referred by a GP to a specialist, the time interval between referral and the first specialist consultation was within 3 months, but for 5 patients (13%) the delay was 3-12 months. These 5 patients had pT stages pTis or pT1. Of the remaining 12 patients, 10 were already patients at a hospital clinic when they presented the current penile symptom, and 4 of them had more than 3 months’ delay between first examination by a specialist and the cancer diagnosis. Two patients contacted the emergency department due to severe phimosis and were later circumcised and diagnosed with penile carcinoma within 3 months.

Forty-one of 50 patients (82%) were diagnosed with penile carcinoma within 3 months from first specialist visit. In the remaining group with a delay of more than 3 months, 8 out of 9 patients consulted dermatologists, which led to repeated biopsies, leaving premalignant results. They had different topical treatments before being referred to a urologist for enlarged excision or biopsy resulting in malignant diagnosis. The time between the first specialist consultation and diagnosis was less than 1 week for 6 out of 9 patients who were partially amputated.

Sexuality (II, III)

Cosmetic result (II)

The cosmetic results in the retrospective study were regarded as satisfying/very satisfying by 36/46 of the patients (78%), and the remaining 22% were rather satisfied with the cosmetic result.

Sexual interest/desire dysfunctions (II)

When asked about changes in sexual interest, 8 out of the 46 patients reported experiencing manifest decreased sexual interest before treatment, and 6 experienced manifest decreased sexual interest after treatment. This
decreased sexual interest led to distress for 7 of 8 patients who experienced it before treatment and 4 of 6 patients who experienced it after treatment. Of the patients in the retrospective study 36/46 (78%) reported at the interview that they felt sexual desire often or sometimes, 37 (80%) patients reported unchanged sexual desire after treatment, 8 (17%) reported manifest decreased sexual desire and 1 reported increased sexual desire. This manifest decreased sexual desire was explained as being due to physical causes in 3 cases, psychological causes in 3, and causes related to the partner in 2 cases. The only patient who reported increased sexual desire had started a new partner relationship shortly after treatment.

**Erectile dysfunction (II)**

Manifest erectile dysfunction (ED) during intercourse was reported by 3 patients before treatment and by 6 after treatment. The reasons for the manifest erectile dysfunction varied, and were considered to be of mainly psychogenic origin in 2 of the 6 patients. ED led to distress in 2 patients before treatment and in 3 patients after treatment (see table). Ten patients (22%) reported a decrease in erectile function after treatment, 33 (72%) reported unaltered erectile function and 3 (6%) reported improved function. The 10 patients with decreased erectile function completed the erectile domain questions (IIEF-5). All of these patients had a steady partner relationship, while 6 reported no sexual activity, 1 was classified as having moderate ED according to IIEF severity classification and 3 had mild ED.

**Early/delayed ejaculation (II)**

Two patients reported early ejaculation, which normalized in 1 of them after treatment. In the other patient early ejaculation emerged after treatment. Neither of these 2 patients experienced early ejaculation as distressing. Three patients experienced delayed ejaculation after treatment. One of them had reported this before treatment. Delayed ejaculation was not reported to be distressing either before or after treatment.
Dyspareunia (II)

Manifest painful intercourse was experienced by 7 patients before treatment, causing distress in 6. Dyspareunia persisted after treatment in 1 patient and resolved in the remaining 6. Furthermore, 2 patients experienced dyspareunia only after treatment. Dyspareunia after treatment was distressing in all 3 patients.

Table 8 Patients with sexual dysfunctions and distress before and after treatment, and evaluable men (30/46 having had intercourse postoperatively) with no dysfunction postoperatively (II)

<table>
<thead>
<tr>
<th></th>
<th>No preoperative Dysfunction</th>
<th>No postoperative Dysfunction</th>
<th>No. no postoperative dysfunction (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual interest</td>
<td>8</td>
<td>6</td>
<td>24</td>
</tr>
<tr>
<td>Erection</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Early ejaculation</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Delayed ejaculation</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Dyspareunia</td>
<td>7</td>
<td>6</td>
<td>3</td>
</tr>
</tbody>
</table>

Sexual activities (III)

All patients younger than 75 years (34 men) reported that they had been sexually active before treatment, and 27 (80%) had resumed sexual activities at the time of the interview. This finding contrasts with 12 patients older than 75 years. In this age group the proportion was considerably lower immediately before the interview (3 of 6 patients who had been sexually active before treatment resumed sexual activity after treatment).

Six of the 46 patients were sexually inactive before and after treatment. An additional 10 had not resumed sexual activity when interviewed. Twenty-nine had had penetrative sexual intercourse during the 3 months prior to the interview, the majority of these within the previous 2 weeks. A slightly lower proportion of patients aged 34–74 years had had intercourse during the preceding 3 months compared with those in the same age range in the comparator group.

Younger age was significantly correlated with resuming/adding genital manual stimulation to the sexual repertoire (MW, z = 3.38, p = 0.001), whereas no such statistical significance emerged among the few who engaged in fellatio (MW, z = 1.868, p = 0.062). Masturbation was included in the sexual repertoire of 20 patients (43%) before treatment. Almost all (44 of 46) stated that the laser treatment did not affect their opinion re-
Sexual satisfaction (II)

Of the 46 patients 23 (50%) reported that they were satisfied or very satisfied with their sexual life at the time of the investigation. Furthermore, 33 (72%) considered their sexual life to be as good as they wanted.

Lifetime sexual partners and sexual transmitted infections (STIs) (III)

That the men in this sample had had more sexual partners and more STIs than Swedish men in general indicates that these variables may be risk factors for penile carcinoma. The sample is, however, too small to enable a definite conclusion. All patients had had at least one sexual partner during their life, and 23 (50%) had had 10 or more (range, 1–200). A considerably greater proportion of patients than comparators recalled having had more than 30 partners (Table 4). Furthermore, those who recalled that they had had (or possibly had had) at least one STI had significantly higher numbers of lifetime sexual partners (MW, z = −2.939, p = 0.003) than those who reported no history of STI. Thirteen (29%) recalled having had at least one STI. The most commonly reported STI was condyloma, followed by gonorrhoea. Most patients who reported having had an STI were younger than 74 years. Having a history of STI was clearly lower in the comparator group, with the exception of chlamydia infection. Indeed, the prevalence of a history of STI was approximately twice as high in the patient group, with the greatest difference concerning condyloma.

The couples’ sexuality (IV)

In this paper, data from 29 couples are described. The patients’ median age was 60 years (range 37-73), and their partners 57 years (range 30-72). Eight couples were retired; all others were vocationally active. The median duration of stable relationships was 29 years (range 1-54 years). There was a high level of co-morbidity in the studied couples (Table 9).
Table 9 Diagnosed comorbidity and score for anxiety and depression (HADS) in 29 patients treated for penile carcinoma, and their partners (IV)

<table>
<thead>
<tr>
<th>Diagnosed comorbidity</th>
<th>Patients at baseline</th>
<th>Patients at 12 months</th>
<th>Partners at baseline</th>
<th>Partners at 12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>10</td>
<td>11 (59%)</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Diabetes Mellitus</td>
<td>8</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>4</td>
<td>8</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Pain</td>
<td>3</td>
<td>3</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Anxiety (HADS)b</td>
<td>0</td>
<td>2</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Depression (HADS)b</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

a More than one diagnosis could be specified by individuals.  
b One partner declined self-assessment at baseline.

Overall, after the patients had been treated for penile carcinoma, the couples maintained a high level of satisfaction with their life as a whole and with the partner relationship.

Dyspareunia among the patients was reported equally frequently as a decreased sexual interest during the last year before treatment. Before treatment 21/29 (72%) of the couples reported that they were sexually active with intercourse; after 1 year that number decreased to 17/29 (59%). In 2 of the 4 couples who reported that they were not able to have intercourse at 12 months, the men had had total penectomy after the interview at 6 months due to relapse. They had both been able to have intercourse during the first months after laser treatment and before relapse. These patients had tumour stages pT2, G2 and G3 respectively.

Relatively few couples (41%) had an ongoing verbal mutual communication about their sexuality during the year after treatment.

**Life satisfaction (III, IV)**

In the retrospective material of 46 patients we found that patients’ satisfaction with life as a whole and with the two domains closeness and provision were equal to those of the general population (Table 10). Thus, post treatment aspirations for (intimate) life at home are generally met as adequately for the patients as for the Swedish male population, as are aspirations for provision.

Patients were more satisfied than comparators concerning both leisure items. In contrast, patients were markedly less satisfied with their somatic health and somewhat less satisfied with their psychological health. Cross-tabulations between resumption/not resumption of intercourse against all
(dichotomized) life satisfaction items showed that only the level of satisfaction with sexual life differed significantly: Those who had resumed sexual activity were more satisfied than those who had not. For all patients aged 34–90 years, chi2 was 15.71 (p < 0.0001), and for those aged 34–74 years, p = 0.003 (Fisher exact probability test).

Table 10 Satisfaction with life as a whole and with 10 domains of life in comparators and in 46 patients who received laser treatment for penile carcinoma (III)

<table>
<thead>
<tr>
<th>Satisfied with</th>
<th>Swedish men</th>
<th>All patients</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>34-74 years</td>
<td>34-90 years</td>
<td>34-74 years</td>
</tr>
<tr>
<td>Life as a whole</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closeness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual life***</td>
<td>527/925 (57%)</td>
<td>23/43 (54%)</td>
<td>19/33 (58%)</td>
</tr>
<tr>
<td>Partner relation*</td>
<td>675/826 (82%)</td>
<td>33/43 (77%)</td>
<td>26/31 (84%)</td>
</tr>
<tr>
<td>Family Life**</td>
<td>709/848 (84%)</td>
<td>36/46 (78%)</td>
<td>28/34 (82%)</td>
</tr>
<tr>
<td>Health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somatic</td>
<td>698/929 (75%)</td>
<td>26/46 (57%)</td>
<td>19/34 (56%)</td>
</tr>
<tr>
<td>Psychological</td>
<td>773/929 (83%)</td>
<td>35/46 (76%)</td>
<td>26/34 (76%)</td>
</tr>
<tr>
<td>(p) ADL</td>
<td>858/930 (92%)</td>
<td>42/46 (91%)</td>
<td>32/34 (94%)</td>
</tr>
<tr>
<td>Leisure</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leisure</td>
<td>566/927 (62%)</td>
<td>33/46 (72%)</td>
<td>25/34 (74%)</td>
</tr>
<tr>
<td>Contacts</td>
<td>587/931 (64%)</td>
<td>34/46 (74%)</td>
<td>25/34 (74%)</td>
</tr>
<tr>
<td>Provision</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vocation***</td>
<td>545/901 (61%)</td>
<td>30/45 (67%)</td>
<td>22/34 (65%)</td>
</tr>
<tr>
<td>Economy</td>
<td>459/926 (50%)</td>
<td>25/46 (54%)</td>
<td>17/34 (60%)</td>
</tr>
</tbody>
</table>

(P)ADL, personal activities of daily life. For comparison, patients aged 34–74 years are shown separately.
* Those with partner.
** Those with family.
*** Some patients did not respond this question

Couples with an active partner-related sexual life at follow-up showed a coherence in high satisfaction with life as a whole and sexual inactive couples showed coherence in being unsatisfied with their sexual life already at baseline, as well as at 12 months follow-up. Overall life satisfaction was found to be at par with the comparators in most of the domains of closeness, health, leisure and provision. Exceptions were somatic health and sexual life were patients differed and showed a lower satisfaction. The patients’ decreased satisfaction with sexual life was the most remarking difference between the perceived satisfaction with different domains of life, when comparing the both studies (Table 11).
Table 11 Satisfaction with life as a whole and with 10 domains of life in comparators and in 29 couples (patients treated with combined laser for penile carcinoma and their partners)(IV)

<table>
<thead>
<tr>
<th>Satisfied with</th>
<th>Patients At baseline</th>
<th>Patients After 12 months</th>
<th>Partners At baseline</th>
<th>Partners After 12 months</th>
<th>Swedish men 35-74 yr n=935</th>
<th>Swedish women 35-74 yr n= 809</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life as a whole</td>
<td>23/29 (79%)</td>
<td>22/29 (76%)</td>
<td>24/28 (86%)</td>
<td>24/29 (83%)</td>
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<td>9/28 (32%)*</td>
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<td>12/24 (50%)</td>
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<td>(P) ADL</td>
<td>25/29 (86%)</td>
<td>26/29 (90%)</td>
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*p = 0.039
GENERAL DISCUSSION

Reflection on the findings

Reflection on the findings in this thesis will focus on two aspects, the difficulties in the treatment seeking process with a genital malignancy and the importance of highlighting the sexual aspects, both before and after treatment for penile carcinoma. For the men in these studies, verbal communication about the symptoms has been difficult to handle both in the intimate communication with a partner, and when contacting health care services. We found a long patients’ delay from symptom to treatment seeking. Embarrassment has been a part of the delay. In the sexual rehabilitation after laser treatment we found only slight changes in the sexual activities, but with a short perspective of 1 year after, a relatively high proportion of men who were less satisfied with their sexual life. This finding will be a reminder of the importance of an invitation from health care personnel to discuss this area with the patient and his partner, and not only with respect to measuring the erectile function. To understand patient needs and desire for help, health care providers should assess current sexual health and patient perceptions of healthy sexuality. Potential barriers must be evaluated and addressed in an effort to increase effectiveness of distress screening and treatment interventions.

The retrospective study in this thesis is, up until now, the largest published study of sexual outcomes after laser treatment of penile carcinoma, and these findings have been emphasized in the European guidelines supporting the use of organ-sparing treatment for retaining sexuality when possible in tumours staged Tis-T2. Despite our findings, caution is warranted when generalizing the results from both the retrospective and the prospective study. The results are a description of patients’ and their partners’ experiences of sexual function after organ-sparing treatment with combined laser. A long time passed for several of the patients in the retrospective study between the treatment and the interview, which may have caused a recall bias, with interviews performed at a median of 3 years after the laser treatment (mean 4.5 years; range 6 months to 15 years).

Starting with the treatment-seeking process, this thesis confirms earlier findings regarding penile carcinoma as a disease heavily affected by long patients’ delay. Symptom appraisal and the pathway to treatment seeking are complex and well-studied problems in several cancer diagnoses. In spite of this, structuring the possible causes of delay and deciding where to start when studying delay is met with several difficulties. When does a bodily...
sensation become a symptom? The initial symptoms of penile carcinoma are described as varying and to a large extent among a lot of men, not perceived as something causing malignancy. Vague symptoms as erythema, ulceration, and eczema, as reported in both our studies, could possible further delay the diagnosis, because they are perceived from the men’s standpoint as non-dangerous. In our effort through interviews to elucidate the reasons behind the delay, we have found support for the description that this is largely caused by the embarrassment men feel while talking about symptoms localized to the genital organ, as discussed earlier in the literature of penile carcinoma, but not shown earlier in patient-reported outcomes. This finding is a well-known problem, giving a time lag in treatment seeking especially with tumours in genital organs as described in literature in other cancer diagnoses. However, other researchers have also been noticed a gender difference, with men down-playing and showing a more passive detection behaviour compared to women. When asking about the reasons for delay in our study almost half of the studied group did not identify the symptoms as something severe and they thought the symptoms would disappear spontaneously. Furthermore, in the prospective study we used self-assessment instruments, to evaluate whether if the patients were anxious and/or depressed and to evaluate the level of life satisfaction, but no statistically significant correlation was found between a long patients’ delay (>6 months) and a high level of depression/anxiety (HADS), or low satisfaction with life (LiSat-11). Factors such as age, gender, prior experience, education, attitudes to health services, and social network support, suggest that personal attributes may predispose individuals to seek care or not. These are factors that could not be easily changed and will probably remain, even if knowledge in society about penile carcinoma increases. Suffering from penile carcinoma, can be the ultimate threat of the masculinity realizing the risk of being amputated. It should be understandable that the fear of losing their sexual ability and masculinity in combination with the lack of knowledge could lead to denial of the problems, as has been shown, for example, in men with testicular cancer. We did not specifically ask the patients about their fear of losing their sexual ability, but a lot of the men interviewed made comments in this vein during the interviews, to emphasize other answers.

However, the low incidence of penile carcinoma in western countries may also contribute to prolonging the time lag until a definitive diagnosis is established. Most of the men in the prospective study have pointed out the lack of knowledge about penile carcinoma both among themselves and in society, and sometimes even in the medical context. The men have commented that this disadvantage, besides leading some to delay seeking
treatment also caused problems for them in communicating with their partners and relatives. It is remarkable that such a great proportion of the patients in our study who were living in steady partner relationships as 18 patients (45%), did not even discuss their symptoms with their partner until it was unavoidable. Prior to the laser treatment, less than half of the couples had had an ongoing verbal communication about their sexual life during the last year. There is also support for in other studies for the relation between difficulties in talking about health-related worries and a lack of relationship intimacy. The men are often left alone, sometimes with deficient information both from health care and from written information; compared to men with prostate cancer where information about the diagnosis and communication with members of cancer support groups are available. There is still a great need for discussion in society about penile problems. Public information and a general, increased openness about male health problems, such as has occurred in the last decade concerning prostate cancer, can slowly make men feel more comfortable in the treatment seeking process and might make them more confident when talking with both partners and health care personnel. In comments from patients outside the formal interviews, some of those living in rural areas where people are more familiar, found that this also was a barrier to seeking treatment, especially when the symptom were located at the genital organs. When the health care personnel were also their neighbours, the patients were more easily embarrassed. An increased knowledge in society about cancer symptoms might remedy and reduce this problem. Testis cancer is another urological cancer comparable to penile carcinoma as a cancer diagnosis with symptoms that are noticeable and can be detected by self-examination. Research in testis cancer has shown that information and campaigns about self-examination increase the knowledge among men and shorten the delay.

The majority of the patients in our study had no doctors’ delay, but a small group had been referred to a dermatologist, with a time lag before diagnosis. There seems to be an insufficient awareness of penile cancer, even among physicians treating lesions on the glans penis; perhaps because of the low incidence, there is also low likelihood than an individual physician would encounter a man with symptoms of penile carcinoma and recognize them as such. In our study we had 9 patients that were referred for laser treatment, but judged to have too advanced a tumour stage, and were partially amputated instead. Almost all of them were diagnosed with penile carcinoma within a week from the first contact with the health care service. We know that a long time had expired for these men between the first appraisal of the symptom and the health care contact, but we don’t know
if they had a longer delay from observation of the first symptom than men who had laser surgery, or if they had had more aggressive tumours from the start. Doctor’s delay could also be caused by difficulties in diagnostics, which points out the need for available guidelines for treatment. Effective use of guidelines and better access to diagnostic services has been called for in cancer care internationally 58. This need for guidelines has been observed in Sweden and the work has started during the last year to produce guidelines in diagnosis and treatment of penile carcinoma.

The advantageous cosmetic result in organ-sparing treatment for penile carcinoma, in contradistinction to the result after partial or total penectomy, has together with preserved sexual ability, been considered to be one of the most important outcomes for the men apart from the tumour control 7. The results in our material showed a clear tendency for the patients to be satisfied with the cosmetic result and to comment that this was important for being more comfortable in a sexual situation. The patients in the retrospective study reported resumption of their sexual activities to a large extent, but the possibility of recall bias must be kept in mind, as the interviews took place several years after treatment, and there is also lack of information about baseline sexual activities. One third of the patients in the retrospective study were not sexually active before treatment. This proportion was lower in the prospective study, with a fifth not being sexual active at baseline. In the retrospective study we had no information about the reasons for this inactivity, but when asked in the prospective study, the men gave varying explanations, such as the presence of concomitant disease (n = 5), symptoms attributed to penile carcinoma (n = 3) and partners’ level of sexual interest or sexual dysfunction (n = 2). Moreover, in the prospective study one third of the patients considered their decreased sexual activities, when followed up at 12 months, to be caused by the diagnosis per se as well as being an effect of treatment.

In the groups of patients studied in this thesis, both retrospectively and prospectively, there has been a relatively low incidence of manifest sexual dysfunctions after being treated with combined laser therapy. Despite this finding, around one third of the men (and their partners) reported a sexual dysfunction even before the treatment. This dysfunction could possible also reflect life before diagnosis, with a growing tumour that the man initially denied, but which had been causing him both decreased sexual interest and a lower grade of sexual activity. Knowledge about how male/female sexual dysfunctions influence each other suggests the importance of thinking in terms of partner relationship when evaluating sexual outcomes after treatment 179-180. This is also supported by epidemiological data showing that men’s sexual dysfunctions are closely coherent with women’s dysfunctions.
and vice versa. When studying the couples’ sexual dysfunctions, we found a relatively high level of both patients’ and partners’ showing decreased sexual interest both before and at 1 year of follow-up.

There is an obvious discrepancy regarding the physical consequences of having organ-sparing treatment versus amputation, even notable without studying the patients’ experiences. With partial amputation the ability of vaginal penetration will vary with the length of the remaining penis, and with total amputation there are other possibilities for experiencing orgasm. A group of 9 patients who were partially amputated and two of their partners were interviewed in our prospective study. It is a very small group of patients, and the result reveal only a narrow view of their situation, but we found that the 2 couples that were interviewed managed to have sexual intercourse after the partial amputation, and 3 more of the patients reported sexual satisfaction with masturbation. In organ-sparing techniques there seems more to be a question of the penile sensibility and the psychological impact of the treatment. With knowledge from other studies we know that there are multiple psychological or interpersonal factors that could possibly causes sexual dysfunction, such as depression, anxiety, and partner-related sexual dysfunction.

To get a better global understanding about how the diagnosis and the treatment of penile carcinoma possibly affects the men and their partners, it is important also to find out whether it affected not only their sexual health but also the rest of their life domains, and if it affected their global satisfaction with life. The couples studied showed a satisfaction with life as a whole to a great extent, with 76% of the patients and 83% of the partners reporting that they were satisfied compared to 70% in the Swedish comparator population of both men and women that was used in these studies. On the other hand, when examining their responses to questions about satisfaction with sexual life, we found a clear difference, in particular, between the patients’ description of life satisfaction, and those given by Swedish men. Satisfaction with sexual life among laser-treated men, decreased significantly, from 61% being satisfied before the treatment to 32% after 1 year, low result compared to the Swedish men (59%).

In the retrospective study a higher proportion of the men were satisfied with sexual life than in the prospective study. There are several possible reasons for this somewhat contradictory finding. One imaginable reason could be the time aspect. In the retrospective study the men were interviewed a considerably longer time after treatment, in median 3 years versus 1 year in the prospective study. It is well-known both clinically and from the literature that being affected with cancer also strengthens the individual and results in higher scores in studies on quality of life than before the
illness and treatment. The reverse result with decreased satisfaction with sexual life is shown only in the prospective study, and is notable as an indicator of a more complex process in the psychological part of rehabilitation among these men with penile carcinoma. The levels of sexual activity and sexual dysfunction are comparable in the two studies, but probably are not the single explanation for this decreased satisfaction with sexual life.

However, what seems clear is that all patients with low satisfaction with sexual life are those reporting not being sexual active. When studying sexual activity and function in men in the age span 34-74 years and median 64 years, we also had to take into account other possible factors that could affect their sexual function and evaluation of completed treatment. The prevalence of self-reported (using medication) concomitant illness, such as diabetes, cardiovascular disease and hypertension was relatively high in our prospective material. It is well-known that erectile dysfunction is one symptom that can both be caused by illness but also be a side-effect of the medical treatment. The occurrence of partners’ diagnosed comorbidity increased between baseline and the 12-month follow-up. This is in agreement with findings from a large Swedish cohort study of partners to persons diagnosed with cancer; during the first year after diagnosis the partners were found to be vulnerable to ill-health, especially concerning psychiatric, circulatory, and muscle diseases. Another aspect to consider when studying sexual function/dysfunction in this age-span is that decreased sexual desire and sexual function sometimes may be considered as a consequence of normal aging. In contradiction to this, sexual fantasies are commonly even in higher age, with 80% of Swedish men reporting having sexual fantasies in the age group of 50-65 years and in men between 66-74 years, two thirds. In another study of elderly Swedes, 70 years old, 95% of the men valued sexuality as a positive factor in life. Some of the patients were reflecting about this phenomena as having sexual fantasies giving a hope of more sexual satisfaction than they experienced. It is possible that the impact of the diagnosis and treatment on sexuality also may depend on the preoperative level of sexual desire and activities. This hypothesis has been studied in patients affected with prostate cancer, in an effort to analyse whether patients who had higher sexual desire experienced greater distress concerning their sexual dysfunction and the possibility of experiencing overall sexual problems postoperatively. These studies identified increased risk for distress among those who reported preoperative sexual problems, those who were sexually active before treatment and those who displayed neurotic personality traits. Another important finding is that the proportion of patients who experienced problems relevant to having impaired postoperative sexual function was...
significantly higher among preoperatively sexually active patients than those who had been inactive 185-186.

Dysfunction has to be related to function. When studying side effects of cancer treatment in those diagnosed with a genital malignancy, it is important to observe the patients’ sexual function before treatment, to be able to evaluate whether there is a dysfunction connected to the diagnosis and/or treatment. One has to be aware of this issue, both as one indicator of life satisfaction and rehabilitation and also as one factor when deciding appropriate treatment for each patient. When asking about the dysfunction and the level of distress, researchers and clinicians should be aware that the time elapsed since the dysfunction first occurred and the reason for the dysfunction could be factors that also affect the result. For example, a man suffering from erectile dysfunction because of diabetes for a long time before penile carcinoma diagnosis and treatment, may already have accepted the condition and oriented himself towards closeness with his partner without intercourse but a lot of caressing and sexual satisfaction with other techniques; in these circumstances, he may not experience the diagnosis and treatment of penile carcinoma as something threatening. On the other hand, a cosmetic change even without a functional change can have a high negative impact, with severe sexual dysfunction, if it affects a man in a period of his life in which he has a high level of sexual desire.

After diagnosis of penile carcinoma, eligible treatment is first determined by tumour stage and grade. As in all other malignancies the first priority when treating the penile tumour must be cancer eradication, and with modern techniques there are treatment options giving both oncological, cosmetic and sexually positive outcomes. In preoperative discussion with a patient, invasive treatment modalities with excellent tumour control and low risk of recurrence but worse impact on the male’s psychological health, have to be set against organ-sparing techniques such as laser therapy that carry a higher risk for recurrence and repeated treatment.

When taking care of this relatively small group of patients it should be easy to choose the treatment with the most optimal outcome for each patient, and the effort to preserve sexual function should be large in a sexually active man, regardless of whether he is living in a steady relationship or not. A preoperative interview about the individual’s sexual life will be indicative before the treatment decision; most preferably it should also include the partner, if any. The clinician’s knowledge about this disease and available treatment options, regardless of speciality, dermatology, urology or oncology, will affect the delay, offered treatment options, and outcomes. This dilemma has been studied by Harden et al. A number of urologists and oncologists saw four patient cases with penile carcinoma and were
asked their preferred treatment organ-sparing surgery, amputation or radiotherapy Urologists were inclined to choose surgery and oncologists radiotherapy 187. The doctors’ knowledge could also affect the results after treatment, as was shown in a Norwegian study where the surgeons judged the sexual outcomes as better than the patients did 6.

In both studies the use of current therapies such as the PDE-5 inhibitors sildenafil (Viagra®), tadalafil (Cialis®), vardenafil (Levitra®), and intracavernous injections (Caverject®), has been infrequent despite a relatively high incidence of erectile dysfunction among the patients. This finding confirms the necessity to discuss these issues at regular follow-up and the need of multidisciplinary teams to support the patients and couples in their sexual rehabilitation.

An organ-sparing approach is recommended in EAU guidelines for early stage penile cancer, and the functional outcome is an important measurement of organ-sparing techniques 1. As seen in the literature, organ-sparing treatment has improved and has been increasingly used in penile carcinoma over time 2, 35, 142. Retaining sexual function after penile carcinoma has become one of the goals when treating these men, at least in western society but there is still a lack of validated tools for patient-reported outcomes in this diagnosis.

Methodological strengths and limitations

The strengths of Papers I and IV are the prospective, longitudinal design and interviews with both the patients and their partners giving pre-and postoperative descriptions about experiences of symptoms, treatment seeking and treatment in penile carcinoma, and their sexual health. To our knowledge this is the first study in penile carcinoma where partners’ sexual function and activity also are described. The advantage of interviewing both the patient and his partner with the same questionnaire has earlier been identified as one form of internal validation process within the couple 188.

Furthermore, the use of a questionnaire designed exclusively for these studies and not externally validated is a limitation that has to be acknowledged. Because of the limited numbers of studies world-wide and the absence of an instrument made for patient- reported outcomes in penile carcinoma, we found no validated questionnaire. In the studies in this thesis we used face-to-face interviews with questionnaires designed especially for this evaluation. The first retrospective study encompassed a few open questions but mostly closed-ended questions and the prospective study involved only structured closed-ended questions. The multiple-choice alternatives in the prospective study in the questions encompassing initial symptoms and reasons for patients’ delay were derived from the descriptions given in the
Erectile function was evaluated with IIEF-5, but this questionnaire does not address issues regarding the overall perception of sexuality and life satisfaction. That is why we added other questions about erectile dysfunction and distress, trying to include the complexity of male sexuality. If man had not been sexually active over a long period, there is a risk that his perception of his erectile function might be lower than the actual function, resulting in a false low score in IIEF.

Methodological problems are more or less always inherent in sexual research, because it involves aspects of a most intimate character and could be perceived as infringing upon the individual’s integrity. This is also a factor that could decrease the participation rate. Therefore, it would be a strength if the interviewer were working daily practice with sexual issues, providing a open attitude and relaxed questioning about sexuality, but in the same time not involved in the clinical care, as in these studies.

There are only two ways of measuring patient-reported outcomes as in both our studies, using interviews, or mailed questionnaires. While interviews can be regarded as reliable, there is in the literature some doubt about the reliability of mailed questionnaires, mainly because they may be answered in consensus between partners. Such a questionnaire may also yield a relatively low response rate. However, it is also possible that interviews are particularly prone to social desirability bias, where the presence of an interviewer results in respondents being more likely to give answers that they think will be socially acceptable. Face-to-face methods has previously been used in several large studies in sexual research. The validity of self-reports of sexual behaviour has been discussed in sexual research. Privacy and embarrassment may be reasons for people to conceal their true sexual behaviour. Some people may under-report the level of activity and behaviour, and some may over-report.

Recalling past behaviour could be a problem in the retrospective study and it is well known and easy to understand that a shorter recall-period will result in more reliable self-reports of sexual behaviour, with one year as a commonly used period. The reliability of self-report is supported by high levels of agreement of sexual activity and behaviour between partners in studies of couples. When retrospectively asking about symptoms and delay, recall bias cannot be excluded, and the risk of methodological limitations regarding studies on patient delay is well-known.

retrospective study. For the questions concerning sexual activity we used earlier validated questions from the national investigation of sexual life and life satisfaction in Swedes aged 18–74 years, and the three self-assessment tools, IIEF-5, HADS, and LiSat-11, were also well-validated instruments.
Because the face-to-face interviews used in our study took on average 1 hour to complete, we had to consider a choice of self-assessment tools that both completed the information in the questionnaire and also were short enough. The three 1-paged, validated instruments we chose fulfilled the criteria. The LiSat-11 checklist was also chosen because of the possibility of analysing to what extent the group of patients that had received laser treatment were comparable with the Swedish male population in the national investigation.

The numbers of patients in both studies could be looked upon as a limitation. On the other hand, it is, to our knowledge one of the largest studies up to now, that describes outcomes after an organ-sparing method of treatment for localized penile carcinoma with a distribution over the three most common pT-stages and of the most commonly affected ages. A limitation also of Paper IV is the small sample of couples (n = 29) fulfilling all three interviews. Our conclusions should therefore be regarded with caution, and further confirmatory studies are needed. In infrequent diagnosis nation wide studies are therefore to be preferred when studying patient-reported outcomes.

Baseline data in the prospective study were in general collected 1 day before treatment. This was, of course, not optimal, because of the stressing situation for both the patients and their partners, but was almost impossible to avoid in this study, due to logistics whereby the patients were referred from other hospitals for specialist care. In cancer diagnoses, the possibility of finding an optimal measuring point is limited. In the retrospective study we asked the patients a long time after treatment about their sexual function and/or dysfunction before diagnosis/treatment, which makes it difficult to assess the real effect of a cancer diagnosis and treatment. In the prospective study we asked before treatment, even if they already have been affected by the diagnosis so the “real baseline” is difficult to define.

There were 5 partners (female) and 2 (one at baseline and another at 12 months) patients who did not complete the question about satisfaction with sexual life in the self-assessment instrument LiSat-11. They all explained this in the same way, stating that they did not want to assess whether they were or were not satisfied with sexual life. Instead they reported that their feeling about sexuality were totally neutral – neither positive or negative, but absent. When evaluating other questions about sexual activity, sexual function, and/or dysfunction, they all reported that they had no sexual activity, which was the only common denominator that emerged.
SUMMARY OF THE FINDINGS

Paper I.
A considerable proportion of the patients had a delay of more than 6 months, especially among cases with tumours staged Tis or pT1. This could be due to the insidious and unspecific initial, self-reported symptoms, such as erythema, rash, and eczema, and sometimes also due to a concomitant phimosis hiding the cancerous lesion. Psychological factors such as embarrassment and denial are also involved, as well as insufficient awareness or knowledge of the disease. The majority of the patients had no doctors’ delay, but a small group of patients had been referred to dermatologists, with a time lag to diagnosis.

Paper II.
All patients younger than 75 years were sexually active before the laser treatment, and almost all of them resumed their sexual activity. Erectile dysfunction, decreased sexual interest, and dyspareunia were the sexual dysfunctions causing some of the patients most distress, both before and after treatment. Overall, sexual function and sexual satisfaction were only marginally reduced after laser treatment of penile carcinoma, and the cosmetic results, judged by the patients themselves, were highly satisfactory. The men achieved the same level of satisfaction with sexual life as the general Swedish male population.

Paper III.
More than a third of the patients delayed their treatment seeking after symptom appraisal for a considerable long time and being in a steady relationship seemed to shorten the delay. After treatment, these men, as a group, achieved their goals in life concerning life as a whole and most domains of life at a level comparable to that of the general Swedish male population. One domain in which they failed to reach their goals to a significant extent was that of health. The fact that the men in this sample had had more sexual partners and more STIs than Swedish men in general may indicate that these variables are a risk factors for penile carcinoma.

Paper IV.
Couples having ongoing sexual activity before treatment resumed to a large extent their earlier sexual behaviour after treatment, with 17/21 couples being sexual active with intercourse. The couples showed a within agreement concerning both their presence/absence of penetrative intercourse, the
male erectile dysfunction and the female lubrication dysfunction after treatment. Eight of the studied couples were sexual inactive already several years before the diagnosis and laser treatment, and they did not resumed. Sexual dysfunctions were common among men, especially decreased sexual interest and dyspareunia and a fourth of the women had decreased vaginal lubrication before treatment. At follow-up increased sexual function were found with exception for erectile function and partner’s orgasm. Overall life satisfaction was found at par with the general population at most of the domains of closeness, health, leisure and provision. Exceptions were patients somatic health and at follow-up, sexual satisfaction.

Clinical implications and further research
This thesis has highlighted the problem of men feeling uncomfortable seeking help for a symptom localized to the penis and the importance of a focus on the patient’s sexual well-being after organ-sparing treatment for penile carcinoma. Simultaneously, penile carcinoma is a rare malignancy in Sweden, and there could be a problem in updating the knowledge and being able to offer the different treatment modalities guiding the patient to the best available treatment.

Helping men recognize sexuality as a concept much larger than erectile function is an important intervention. Sexual feelings, penile sensitivity, orgasm, and partnered intimacy (in many cases) are available, despite decreased erection. Creating an accepting health care environment for men’s vulnerability and feelings about loss of sexual function will help them approach mourning as the gateway to a new sexual adaptation, alone or with a partner. The communication in the relationship between partners about sexual issues related to cancer is also an area for development, and the treatment discussion and counselling in the time before treatment could be places to start with this.

To summarize, from both my clinical point of view and from these studies on the embarrassment men still might feel when talking about their genital organs in health care, we must take the first step and invite them and their partners to the discussion about this natural sphere of life, and especially when diagnosed with a genital malignancy where the treatment could affect the function. Establishment of men’s health support centre to provide men with both information and diagnosis should be a clinical area to build up. Having a telephone service where men could directly discuss their concerns with nurses trained in urological issues, and further, having access to information and examination within a urological specialist clinic, should be comfortable ways of meeting these needs of men in the health care system. To continue to educate health care professionals in sexual
medicine in order to better provide patients with genital malignancies with support and information is another important area for development.

To be affected by a rare malignancy is, in my opinion, very traumatizing situation. Most of the men had never heard of this diagnosis before they were affected. Some of them even lied to their relatives and friends and told about being affected by prostate cancer, instead, because it is more frequently occurring and more widely known in society, and nowadays not so embarrassing to talk about. Based on the experiences from this thesis and on meeting all these patients over several years, I hope the future will provide health care in penile carcinoma appropriate to the number of diagnoses adopting the model of the United Kingdom with just a few centres in the country providing a multidisciplinary team approach. The team should include urological surgeons, clinical oncologists, histopathologists, palliative care specialists, plastic surgeons, radiologists, nurse specialists, and medical social workers giving a holistic view in each case. Psychological support is very important for these patients. This type of organization in small, rare, diseases should create the possibility of offering the patient the best treatment modality according to clinical tumour stage, personal circumstances, and available treatment options, with as little morbidity as possible, as well as optimal possibilities for research. First, with that scenario we could present a health care service fulfilling the best criteria, in diagnoses, treatment and rehabilitation.

The increased possibilities of organ-sparing methods in treatment of penile carcinoma should open up opportunities for research in sexual outcomes, and from an international perspective it would strengthen the research if the data were comparable. A process has started in Sweden during the last year, focusing on the lack of patient-reported outcomes in the national cancer registers. Consistent with this discussion the National Penile Cancer Register in Sweden has started an initiative to measure patient-reported outcomes in sexuality, quality of life, and post-operative complications. Data from this register should offer the definitely best means for further research in this small diagnosis. As the next step in this research field an international research group with experience in penile carcinoma and skilled in studies with a focus on sexual outcomes would provide the possibility of working together to validate measuring tools especially for penile carcinoma. With this scenario it would be possible to study larger groups of patients with penile carcinoma and the outcomes after different treatment modalities, which in turn would give a better evidence-based care.
Sammanfattning på svenska
(Summary in Swedish)


Traditionellt sett har den vanligaste metoden för behandling av peniscancer varit partiell amputation vilket naturligtvis lett till en kraftig negativ påverkan på männens sexualliksidom. I de europeiska riktlinjerna, som även svensk urologisk förening anslutit sig till, har organbevarande metoder alltmer lyfts fram för behandling av peniscancer.


Det övergripande syftet med denna avhandling har varit att öka kunskapen om hur svenska män som genomgått organbevarande laserbehandling för peniscancer beskriver sina erfarenheter av symtom och vårdöknande, samt att studera om och i vilken utsträckning såväl diagnosen som behandling påverkar sexualitet och livstillförsäljelse.

Metoden har i båda studierna varit ”face-to-face” intervjuer med utgångspunkt i ett strukturerat frågeformulär omfattande cirka 70 frågor. En del av dessa är sjukdomsspecifika och konstruerade enbart för dessa studier. De frågor som berör sexualitet är till största delen tagna ur den senaste svenska sexualvanundersöknningen (1996). Dessa frågor har kompletterats med tre olika självskattningsskalor, LiSat-11 som mäter global och domänspecifik livstillfredsställelse, The International Index of Erectile Function (IIEF), som mäter förekomst av erektildysfunktion och The Hospital Anxiety and Depression Scale (HADS) som mäter förekomst av ångest och depression.

I delarbete I var syftet att beskriva patienternas upplevelse av symtom och vårdökande. Utslag, rodnad och eksem var vanligast (35 %) bland de symtom patienterna först uppmärksammade. ”Patient delay” var vanligt förkommande och 65 % av patienterna hade ett ”delay” på sex månader eller mer. Det fanns i denna grupp med längst delay en liten dominans (ej statistiskt signifikant) för de som klassificerades som carcinoma in situ och pT1 tumörer. Patienter med stabil partnerrelation hade inte kortare delay. Det vanligaste skälet till ”patient delay” var känslan av att det var genant att ringa och/eller ta personlig kontakt med sjukvården med ett symtom lokalisert till penis. De allra flesta (76 %) remitterades inom en vecka från primärvården till specialist när de tagit sin första vårdkontakt. Endast 9/50 hade en ”doktors delay” på mer än tre månader från första möte med specialist till diagnos. Att av dessa hade haft kontakt med hudklinik under denna tid, med upppepade biopsier som visat förändringar klassade som förstådier till cancer. I den lilla grupp av män som inte kunde laserbehandlas (beroende på för stor tumör) utan blev partiellt amputerade var tiden mellan första specialistkontakt och diagnos i 6/9 fall mindre än en vecka.

Syftet i delarbete II och III var att beskriva förekomsten av sexuell dysfunktion före och efter laserbehandling, undersöka om den sexuella tillfredsställelsen hade förändrats efter behandlingen och jämföra den sexuella tillfredsställelsen hos behandlade män med ett representativt urval av
svenska män samt även att utvärdera patienternas erfarenheter av det kosmetiska resultatet av behandlingen. Det kosmetiska resultatet med behandlingen upplevdes tillfredsställande, 78 % av patienterna uppgav att de var nöjda eller mycket nöjda. Beträffande den sexuella funktionen visade resultatet att 40/46 var sexuellt aktiva före laserbehandlingen och 30 (75 %) hade återupptagit sin sexuella aktivitet vid tiden för intervjun. Alla 34 patienter som var yngre än 75 år hade varit sexuellt aktiva före laserbehandlingen och 80 % av dessa återupptog sin sexuella aktivitet. Ofräknad erektionsförmåga efter behandling uppgavs av 72 % av männen. Den sexuella aktiviteten bedömdes utifrån tid sedan senaste samlag där 54 % av patienterna uppgav att de hade haft samlag under den senaste tvåveckors-perioden före intervjun och 78 % kände sexuell lust ibland eller ofta. De laserbehandlade patienterna hade även erfarenhet av ett större antal sexualpartners och högre prevalens av sexuellt överförbara infektioner (STI) jämfört med gruppen svenska män i åldern 34-74 år som redovisas i den svenska sexualvaneundersökningen. Efter laserbehandlingen förändrades det sexuella mönster i viss grad. Frekvensen av sexuellt smek och oralsex sjönk, men trots dessa förändringar upvisade patientgruppen en hög grad av tillfredsställelse när det gäller livet i allmänhet inklusive tillfredsställelse med sexuallivet (drygt hälften, 54 %) jämförbar med den övriga svenska manliga befolkningen i samma åldersgrupp.

I det fjärde och sista delarbetet (IV) har vi valt att beskriva sexualiteten hos de 29 par som deltog i alla tre mättillfällen. Åtta av paren hade inte varit sexuellt aktiva de senaste åren före behandling och återupptog inte heller sitt sexuella samliv. Av de 21 par som varit sexuellt aktiva med samlag före behandling så hade 17 återupptagit detta vid ettårsuppföljningen. Sexuell dysfunktion förekom redan före behandlingen och visade sig då främst i försämrat sexuellt intresse och smärta vid samlag hos männen, samt försämrad vaginal lubrikation hos kvinnorna. Det var en hög grad av samstämmighet i parens bedömning av sexuellt funktion/dysfunktion vad gällde förekomst av samlag, erektiel dysfunktion, fördröjd/utebliven ejakulation och bristande lubrikation. Par med ett aktivt sexuellt samliv hade en hög grad av tillfredsställelse vad gäller livet i allmänhet, men patienterna visade en lägre tillfredsställelse med sin somatiska hälsa och sexuallivet än jämförelsegruppen av svenska män från sexualvaneundersökningen. Studierna har gett en ökad kunskap om män med penis cancer som genomgått en organbevarande, kombinerad laser kirurgi. Vi har funnit en lång fördröjning mellan upptäckt av de första symtomen till vårdökande och studierna har visat att den viktigaste bakomliggande orsaken till detta är okunskap om sjukdomen och genansen i att söka för symtom lokalisera till könsorganet. Vi kunde i den retrospektiva studien se en liten tendens till att män som levde ensamma hade längre fördröjning i sitt vårdökande vilket inte upprepades i den prospektiva studien. Efter behandling har pati-
enterna i hög grad varit nöjda med det kosmetiska resultatet och kunnat återuppta tidigare sexuell aktivitet. Den försämrade tillfredsställelsen med sexuallivet hos den icke sexuellt aktiva gruppen kan eventuellt tolkas som ett resultat av behandlingen men ytterligare studier krävs för att kartlägga detta.
TACK (Acknowledgements in Swedish)

Allra först vill jag allra varmast tacka de patienter och deras partners som outtröttligt och tacksamt har låtit sig intervjuas. Det har varit ett privilegium att få möjlighet att möta er i en känslig period i ert liv med frågor inom ett område som ni tidigare inte verbaliserat tillsammans med många andra. Alla har ni uttryckt att detta varit viktigt för att öka kunskapen om en liten och okänd diagnos för att andra som kommer efter er skall ha bättre möjlighet till kunskap. Utan er hade denna avhandling inte varit möjlig!

Nästa tack går till alla andra som på olika sätt outtröttligt och med vänliga ord stöttat mig under denna forskarutbildning och detta så långsamt framskridande avhandlingsarbete och ett särskilt tack vill jag rikta till:


Torgny Windahl, min handledare, som väckte nyfikenheten när det gällde denna ovanliga cancerdiagnos. Det har varit många år av samarbete och jag är tacksam över att du orkat hanterat mina ”humörsvängningar”.

Kerstin Sjögren Fugl-Meyer, min handledare, med stor kunskap inom det sexualmedicinska området har du lotsat mig framåt. Trots dina ”tusen bollar i luften” har du alltid hjälpt mig ta ett steg till.

Swen-Olof Andersson, medförfattare och till stor del ”grovarbetare” som alltid outtröttligt funnits där och många gånger bidragit med de mest briljanta tankarna och formuleringarna genom åren.

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Anna Kagelind, min närmaste kuratorskollega och vän, som genom åren tålmodigt lyssnat på mina berättelser från forskningens värld samt periodvis även praktiskt tagit hand om mina patienter så att jag kunnat disponera lite mer tid till mina intervjuer och min utbildning.

Mina tidigare doktorandkollegor Gunnel Andersson och Renée Allvin, kloka, härliga kvinnor som numera är disputerade sedan flera år tillbaka - vänner och mina trösterskor när forskningen känts omöjlig!

Kuratorskollegorna på Universitetssjukhuset, speciellt då FoU-gruppen och Caisa Lindström, tidigare doktorandkollega och samtidig vän som delat allt onämnbart om forskarutbildningens våndor och vedermödor!

Kuratorskollegor inom urologiområdet i Sverige – de få och tappra som värnar detta område tillsammans med mig och då vill jag speciellt nämna Marie-Louise Liljergren och Lena Österman som alltid uppmuntrat mig och varit väldigt generösa med positiv feed-back.

Alla medarbetare på Urologkliniken vid Universitetssjukhuset i Örebro

Medarbetare på urologkliniker runt om i Sverige som vänligt tagit emot mig och ordnat med rum när jag kommit resande för att genomföra mina intervjuer. Ni har även varit intresserade genom åren när jag kommunicerat mina forskningsresultat och visat mig att det finns ett behov av kunskap om detta område vilket drivit mig framåt i de tyngsta perioderna.

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Vårdprogramgruppen i Nationella peniscancerregistret för den uppmärksamhet ni visar kommande patienter med peniscancer genom att lyfta fram resultaten från dessa svenska studier.
Katja Fall, min ”lots” inom statistikområdet.

Margareta Landin, min ”personal librarian” – som ofta fått rycka ut för en ”livräddning” i sista minuten – du har varit guld värd!

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Mina föräldrar Karin och Ernst samt min bror Lars med familj – ni befinner er långt ifrån den akademiska världen och i en helt annan livsmiljö, men jag känner ändå ett starkt stöd och att ni med varme uppmuntrat det jag gjort.

Till sist och den allra största, varmaste, innerligaste tacksamheten känner jag för min härliga familj; min man Gunnar samt mina barn Johan, Hanna och Fredrik som på sätt och vis fått leva med (och växa upp med) detta under så många år – ni har alltid visat och påmint mig om vad som är viktigast i livet.
REFERENCES


### FRÅGEFORMULÄR – SEXUELL FUNKTION MÄN

**Patientinstruktioner:**
Sexuell hälsa är en viktig del av en persons totala fysiska och psykiska välbefinnande. Sexuella problem är emellertid mycket vanliga i befolkningen. Erekptionsproblem hör till det mest vanliga, och är något som alla män kan drabbas av någon period i livet. Detta formulär är tänkt att vara en hjälp för Dig och Din läkare att tillsammans identifiera eventuella problem.

**IIEF-5 “ED-SCORE”**
Varje fråga har 5 svarsalternativ. Dessutom finns i de flesta fall ytterligare en kolumn med ett kryss (X) som du ringar in om frågan inte är relevant för Dig. Ringa in det svar som bäst beskriver din situation. Ringa endast in ett svarsalternativ per fråga.

<table>
<thead>
<tr>
<th>EREKTION</th>
<th>Mycket svag eller ingen alls</th>
<th>Svag</th>
<th>Måttlig</th>
<th>Stark</th>
<th>Mycket stark</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Hur uppskattar Du att din tilltro till att kunna få och behålla en erektion varit de senaste 6 månaderna?</td>
<td>Ingen sexuell aktivitet har förekommit</td>
<td>Nästan aldrig eller aldrig</td>
<td>Några få gånger (mycket färre än hälften av gångerna)</td>
<td>Ibland (ungefär hälften av gångerna)</td>
<td>De flesta gångerna (mycket mer än hälften av gångerna)</td>
</tr>
<tr>
<td>X</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TILLFREDSSTÄLLElse</th>
<th>Inga försök till samlag har förekommit</th>
<th>Mycket stora svårigheter</th>
<th>Stora svårigheter</th>
<th>Svårigheter</th>
<th>Vissa svårigheter</th>
<th>Inga svårigheter</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. När Du de senaste 6 månaderna försökt genomföra samlag, hur ofta har Du upplevt dem som tillfredsställande?</td>
<td>X</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>


**Total ED-poäng (fr 1–5):**
Here are a number of statements concerning how satisfied you are with different aspects of your life. For each of these statements please mark a number from 1 to 6 where 1 means very dissatisfying and 6 means very satisfying.

1= very dissatisfying  4=rather satisfying
2=dissatisfying          5=satisfying
3=rather dissatisfying   6=very satisfying

My life as a whole is  
My vocational situation is  
My financial situation is  
My leisure situation is  
My contact with friends and acquaintances is  
My sexual life is  
My ability to manage my self-care (dressing, hygiene, transfers etc) is  
My family life is  
My steady partner relationship is  
My physical health is  
My psychological health is  

The LiSat-11 checklist (in English translation) as used in the studies
Läs igenom varje påstående och ringa in det alternativ som bäst beskriver hur du har känt dig den senaste veckan. Fundera inte för länge över dina svar; din spontana reaktion inför varje påstående är förmodligen mer korrekt än ett svar som du tänkt på länge.

<table>
<thead>
<tr>
<th>Nr.</th>
<th>Påstående</th>
<th>Alternativ 0</th>
<th>Alternativ 1</th>
<th>Alternativ 2</th>
<th>Alternativ 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Jag känner mig spänd eller nervös:</td>
<td>3 Mestadels</td>
<td>2 Ofta</td>
<td>1 Av och till</td>
<td>0 Inte alls</td>
</tr>
<tr>
<td>2</td>
<td>Jag uppskattar fortfarande saker jag tidigare uppskattat:</td>
<td>0 Definitivt lika mycket</td>
<td>1 Inte lika mycket</td>
<td>2 Endast delvis</td>
<td>3 Nästan inte alls</td>
</tr>
<tr>
<td>3</td>
<td>Jag har en känsla av att något hemskt kommer att hända:</td>
<td>3 Mycket klart och obehagligt</td>
<td>2 Inte så starkt nu</td>
<td>1 Betydligt svagare nu</td>
<td>0 Inte alls</td>
</tr>
<tr>
<td>4</td>
<td>Jag kan skratta och se det roliga i saker och ting:</td>
<td>0 Lika ofta som tidigare</td>
<td>1 Inte lika ofta nu</td>
<td>2 Betydligt mer sällan nu</td>
<td>3 Aldrig</td>
</tr>
<tr>
<td>5</td>
<td>Jag bekymrar mig över saker:</td>
<td>3 Mestadels</td>
<td>2 Ganska ofta</td>
<td>1 Av och till</td>
<td>0 Någon enstaka gång</td>
</tr>
<tr>
<td>6</td>
<td>Jag känner mig på gott humör:</td>
<td>3 Aldrig</td>
<td>2 Sällan</td>
<td>1 Ibland</td>
<td>0 Mestadels</td>
</tr>
<tr>
<td>7</td>
<td>Jag kan sitta stilla och känna mig avslappnad:</td>
<td>0 Definitivt</td>
<td>1 Vanligtvis</td>
<td>2 Sällan</td>
<td>3 Aldrig</td>
</tr>
<tr>
<td>8</td>
<td>Allting känns trögtt:</td>
<td>3 Nästan alltid</td>
<td>2 Ofta</td>
<td>1 Ibland</td>
<td>0 Aldrig</td>
</tr>
</tbody>
</table>
9. Jag känner mig orolig, som om jag hade ”fjärilar” i magen:

0 Aldrig
1 Ibland
2 Ganska ofta
3 Väldigt ofta

10. Jag har tappat intresset för hur jag ser ut:

3 Fullständigt
2 Till stor del
1 Delvis
0 Inte alls

11. Jag känner mig rastlös:

3 Väldigt ofta
2 Ganska ofta
1 Sällan
0 Inte alls

12. Jag ser med glädje fram emot saker och ting:

0 Lika mycket som tidigare
1 Mindre än tidigare
2 Mycket mindre än tidigare
3 Knappast alls

13. Jag får plötsliga panikkänslor:

3 Väldigt ofta
2 Ganska ofta
1 Sällan
0 Aldrig

14. Jag kan uppskatta en god bok, ett TV- eller radioprogram:

0 Ofta
1 Ibland
2 Sällan
3 Mycket sällan

Poängen på frågorna med udda nummer (1 tom 13) visar totalpoängen för ångest. Poängen på frågorna med jämna nummer (2 tom 14) visar totalpoängen för depression. Lägg samman poängen från båda sidor av formuläret och ange summan för depression och ångest i respektive ruta.