

Female urinary incontinence

Impact on sexual life and psychosocial wellbeing in patients and partners, and patient-reported outcome after surgery

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Umeå 2012

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ISBN: 978-91-7459-393-8
ISSN: 0346-6612
E-version version available at <http://umu.diva-portal.org/>
Printed by: Print & Media, Umeå University
Umeå, Sweden 2012

*To Emma, Johan
and Yngve*

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Abstract

Background: Urinary incontinence (UI) and urgency are common conditions and can have a profound influence on many aspects of life. Approximately one in four women has UI and one in ten has daily symptoms. Knowledge is lacking, however, on the impact of UI and urgency on the lives of affected women and their partners and on the situation of women with urinary leakage one year postoperatively.

Aims: To study the consequences of female UI and urgency for patients and their partners on quality of life (QoL), the partner relationship, and their sexual lives. Also to evaluate the success rates of three operation methods: tension-free vaginal tape (TVT), tension-free vaginal tape-obturator (TVT-O), and transobturator tape (TOT) for stress urinary incontinence (SUI), with a particular focus on women who still have urinary leakage one year after surgery.

Methods: Women seeking healthcare for UI and/or urgency and their partners were invited to answer questionnaires. The women completed disease-specific questionnaires and both the women (n = 206) and their partners (n = 109) answered questions about their psychosocial situation, partner relationship, and sexual life. Patient-reported outcomes one year after surgery with TVT, TVT-O, or TOT (n = 3334) were derived from the Swedish National Quality Register for Gynaecological Surgery.

Results: Most of the women reported that their urinary problems negatively affected their physical activities, and almost half reported negative consequences for their social life. Women aged 25–49 years were less satisfied with their psychological health, sexual life, and leisure than women aged 50–74 years. One third of both the women and their partners (all the partners were men) experienced a negative impact on their relationship, and sexual life was negatively affected in almost half of the women and one in five of their men. Coital incontinence was reported in one third of the women. Most of their men did not consider this a problem, but the majority of the affected women did.

Satisfaction with outcome of the operation did not differ between TVT, TVT-O, and TOT, but TVT showed a higher success rate for SUI than TOT did. Higher age, higher body mass index, a diagnosis of mixed urinary incontinence, and a history of urinary leakage in combination with urgency each constitute a risk for a lower operation success rate. After one year, 29% of the women still had some form of UI, but half of these were satisfied with

the outcome and most reported fewer negative impacts on family, social, working, and sexual life than before the operation.

Conclusions: Female UI and/or urgency impaired QoL, particularly in young women, and had negative effects on partner relationships and on some partners' lives. Sexual life was also affected, more often in women with UI and/or urgency than in their partners. At one-year follow-up after surgery, about one third of the women still had some form of UI, but the negative impact on their lives was reduced. A challenge for health care professionals is to initiate a dialogue with women with urinary symptoms about sexual function and what surgery can realistically be expected to accomplish.

Abbreviations

ADL	activities of daily living
ASA	American Society of Anesthesiologists
BFLUTS	Bristol Female Lower Urinary Tract Symptoms questionnaire
BFLUTS-SF	Bristol Female Lower Urinary Tract Symptoms – Short Form
BMI	body mass index
CI	confidence interval
DO	detrusor overactivity
FSD	female sexual dysfunction
FSFI	Female Sexual Function Index
Gynop	Swedish National Quality Register for Gynecological Surgery
HRQL	health-related quality of life
HRT	hormone replacement therapy
ICS	International Continence Society
IIQ	Incontinence Impact Questionnaire
KHQ	King's Health Questionnaire
LUTS	lower urinary tract symptoms
MUI	mixed urinary incontinence
OAB	overactive bladder
OR	odds ratio
PISQ	Pelvic Organ Prolapse/Urinary Incontinence Sexual Questionnaire
QoL	quality of life
SF 36	Short Form 36 Health Survey
SIFO	Swedish Institute for Public Opinion Research
SUI	stress urinary incontinence
TOT	transobturator tape
TVT	tension-free vaginal tape
TVT-O	tension-free vaginal tape-obturator
UI	urinary incontinence
UUI	urge urinary incontinence
WHO	World Health Organization

Sammanfattning på svenska

Bakgrund

Urininkontinens är ett mycket vanligt problem bland kvinnor. Tidigare studier har visat att ungefär var fjärde kvinna drabbas av någon form av urinläckage och var tionde kvinna har dagliga besvär. Den vanligaste typen av urininkontinens är *ansträngningsinkontinens*, vilket innebär att man läcker urin i samband med att buktrycket ökar vid fysisk ansträngning som till exempel hopp, tunga lyft eller vid hosta och nysning. Ungefär hälften av alla kvinnor med urininkontinens har ansträngningsinkontinens. *Trängningsinkontinens* innebär att urinläckaget föregås av en stark känsla av att vara kissnödig som är svår att motstå. Vid *blandinkontinens* finns symtom på både ansträngningsinkontinens och trängningsinkontinens. *Urinträngningar* innebär en stark känsla av att vara kissnödig som är svår att motstå men leder inte till urinläckage. Dessa trängningsbesvär förekommer vanligtvis i kombination med att man kissar ofta och även nattetid. Trängningsinkontinens och urinträngningar benämns ibland *överaktiv blåsa*.

Den vanligaste behandlingsformen som rekommenderas vid urininkontinens är bäckenbottenträning. Förändringar som viktnedgång vid övervikt eller minskning av överdrivet vätskeintag kan också ha en positiv effekt. Urinträngningar och trängningsläckage kan minska med hjälp av blåsträning, vilket innebär att man försöker hålla emot vid en urinträngning och på så sätt ökar blåsans kapacitet. Blåsträning kan kombineras med mediciner som har en avslappnande effekt på urinblåsans muskulatur. När menstruationerna upphör kan slemhinnorna i såväl vagina som urinrör och urinblåsa bli tunna och sköra, vilket i sin tur kan förorsaka urinträngningar. Lokal östrogenbehandling kan i dessa fall minska besvären.

Vid ansträngningsinkontinens, där bäckenbottenträning inte gett tillräcklig effekt kan kirurgisk behandling hjälpa. De vanligaste operationsmetoderna är tension-free vaginal tape (TVT), tension-free vaginal tape-obturator (TVT-O) eller transobturator tape (TOT). Operationerna utförs oftast polikliniskt och i lokalbedövning. Ett litet snitt görs mitt under urinröret i främre vaginalväggen och två små snitt ovanför blygdbenet eller i ljumskarna (beroende på operationsmetod). Med hjälp av speciella instrument sätts därefter ett syntetband på plats. Detta band fungerar som ett stöd till urinröret och förstärker dess stängningsmekanism genom att förhindra att urinröret sjunker ned när buktrycket ökar vid ansträngning.

Mål

Syftet med våra studier har varit att undersöka hur urininkontinens och urinträngningar påverkar kvinnans, och även hennes partners, tillvaro när det gäller livskvalitet, psykosocial situation, parrelation och sexualliv. Ytterligare mål har varit att undersöka kvinnors bedömning av operationsresultatet och dess inverkan på livssituationen ett år efter att de har opererats för ansträngningsinkontinens.

Metod

En enkätstudie genomfördes bland kvinnor i åldern 25-74 år som sökte sjukvård och träffade uroterapeut på grund av besvär med urininkontinens och/eller urinträngningar. Om kvinnan hade en partner ombads hon även att förmedla en enkät till sin partner angående parrelation, sexualliv och psykosocial situation. För att utvärdera resultaten av de tre olika inkontinensoperationerna som nämnts ovan användes data från det svenska nationella kvalitetsregistret för gynekologiska operationer (Gynop-registret). Där registrerar den opererande läkaren exempelvis information om patientens eventuella andra sjukdomar, typ av operationsmetod och om det har uppstått komplikationer i samband med operationen. I registret finns också kvinnans enkätsvar om hur urininkontinensen har påverkat olika områden i hennes liv före operationen samt hennes svar ett år efter.

Resultat

I enkätstudien deltog 206 kvinnor, 170 hade en partner (alla partners var män) och 109 av dessa svarade på enkäten. Av de 109 paren var 99 sexuellt aktiva. Majoriteten av kvinnorna ansåg att deras urininkontinens och/eller urinträngningar påverkade deras fysiska aktiviteter på ett negativt sätt, och hälften angav också negativa konsekvenser för deras sociala liv. De yngre kvinnorna (25-49 år) var mindre nöjda med sin psykiska hälsa, sitt sexualliv och sin fritid än de äldre (50-74 år), och jämfört med de yngre männen var de yngre kvinnorna mindre tillfreds med sin fysiska hälsa. De yngre kvinnorna var också mindre tillfreds med sitt sexualliv, sin fritid och livet som helhet jämfört med motsvarande åldersgrupp i den senaste nationella populationsbaserade studien om sexualliv och hälsa i Sverige ("Sex i Sverige").

Bland de 109 paren angav 1/3 av både kvinnorna och deras partners en negativ påverkan på deras parrelation, och ännu fler uppgav negativa konsekvenser för parets gemensamma aktiviteter. Var femte kvinna och man upplevde att kroppskontakten (närhet, intimitet och värme) hade minskat på grund av kvinnans urinproblem. Det var fler kvinnor och män i den yngre

åldersgruppen som upplevde att kroppskontakten hade minskat jämfört med de i den äldre gruppen. Bland de sexuellt aktiva beskrev var annan kvinna och var femte man en negativ påverkan även på sexuallivet. Dessa kvinnor var oroliga för att läcka urin vid sexuell aktivitet, kände sig mindre attraktiva och var rädda för att lukta illa. De flesta av männen var dock inte oroliga för att kvinnan skulle läcka vid sex. Drygt en tredjedel av alla kvinnor hade urinläckage vid sexuell aktivitet. Majoriteten av deras män tyckte inte att det var ett problem, men de flesta av kvinnorna ansåg det.

Av de 3334 kvinnor som hade opererats för ansträngningsinkontinens var 2/3 mycket nöjda med resultatet vid 1-års uppföljningen. Andelen nöjda var lika stor oavsett operationsmetod, detta trots att något fler kvinnor blev botade med TVT jämfört med TOT. Risken för att ha kvar ett visst urinläckage efter operationen visade sig öka med stigande ålder, ökande BMI eller om kvinnan, förutom ansträngningsinkontinens, även hade trängningsinkontinens före ingreppet. Sammantaget uppgav 29 % av kvinnorna att de fortfarande läckte urin minst 1-3 gånger per månad ett år efter operationen. Hos dessa kvinnor hade dock både antalet läckagetillfällen och läckagemängden minskat. De rapporterade också en betydande minskning avseende läckagets negativa påverkan på familjeliv, socialt liv, arbetsliv och sexualliv jämfört med före operationen. Trots ett kvarvarande urinläckage var hälften av dessa kvinnor ändå nöjda med operationsresultatet.

Sammanfattning

Urininkontinens och/eller urinträngningar försämrar livskvaliteten för kvinnor, främst hos de yngre. Urinbesvären kan också ha negativ påverkan på parrelationen och partners tillvaro. Även sexuallivet påverkas negativt, oftare bland kvinnorna än bland männen. Majoriteten av kvinnorna med urinläckage vid sexuell aktivitet anser att detta är ett problem, de flesta av deras män delar inte den uppfattningen. Många kvinnor blir botade från sin ansträngningsinkontinens med operation och är mycket nöjda med resultatet. Stigande ålder, ökande BMI och blandinkontinens minskar emellertid chansen att bli kontinent. Ett år efter operationen har cirka 1/3 fortfarande kvar någon form av urinläckage. Bland dessa kvinnor har dock urinläckagens negativa effekt på livskvaliteten minskat och hälften av dem är nöjda med operationsresultatet.

Original papers

- I. Nilsson M, Lalos A, Lalos O. **The impact of female urinary incontinence and urgency on quality of life and partner relationship.** *Neurourol Urodyn.* 2009 Nov;28(8):976-81.

- II. Nilsson M, Lalos O, Lindkvist H, Lalos A. **How do urinary incontinence and urgency affect women's sexual life?** *Acta Obstet Gynecol Scand.* 2011 Jun;90(6):621-8.

- III. Nilsson M, Lalos O, Lindkvist H, Lalos A. **Impact of female urinary incontinence and urgency on women's and their partners' sexual life.** *Neurourol Urodyn.* 2011 Sep;30(7):1276-80.

- IV. Nilsson M, Lalos O, Lindkvist H, Löfgren M, Lalos A. **Female urinary incontinence: patient-reported outcomes one-year after mid-urethral sling operations.** Accepted for publication 2012-03-04. *Int Urogynecol J.*

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Introduction

Urinary incontinence (UI) and urgency are common conditions in women. During my years as a urotherapist several women have shared their stories with me – stories of the burden of living with UI and/or urgency. This experience roused my interest in exploring scientifically how women and their partners are affected by women’s urinary symptoms. Little is known about the quality of life, partner relationships, and sexual lives of women who suffer from UI and/or urgency (and their partners) in the context of living as a couple. Knowledge is also lacking about the lives of women who continue to have UI after surgery for UI.

Definitions

The concept of quality of life (QoL) in this thesis is related to the World Health Organization (WHO) definition of health as a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity [1]. International experts have stated that health-related QoL measurements should include physical, mental/psychological, and social health [2]. Sexual health is commonly described as a state of physical, mental, and social well-being in relation to sexuality [3].

The International Continence Society (ICS) is an organization with a global health focus that works through education and research to improve QoL in people with urinary, bowel, and pelvic floor disorders. The ICS Standardisation Sub-committee has defined UI as any involuntary leakage of urine [4]. The type of urine leakage is classified according to what is reported by the woman (symptoms), what is observed by the clinician (signs), and what is shown in urodynamic studies. The different types of urinary symptoms discussed in this thesis are defined by the ICS as:

Stress urinary incontinence (SUI). Involuntary leakage on effort, exertion, sneezing, or coughing.

Urge urinary incontinence (UUI). Involuntary leakage accompanied by or immediately preceded by urgency.

Mixed urinary incontinence (MUI). Involuntary leakage associated with both urgency and exertion, effort, sneezing, or coughing.

Urgency. A sudden compelling desire to pass urine that is difficult to defer.

Overactive Bladder (OAB). Urgency, with or without urge incontinence, usually accompanied by frequency and nocturia.

Detrusor overactivity (DO). A urodynamic observation characterised by involuntary detrusor contractions during the filling phase, which may be spontaneous or provoked.

In general, lower urinary tract symptoms (LUTS) are classified as storage, voiding, or post-micturition symptoms, and UI and urgency belong to the class of storage symptoms. Neurologic conditions and fistulas can also cause urinary incontinence, but these are not discussed in this thesis.

Prevalence and incidence

The prevalence range of UI is wide, mainly due to differences in methods of data collection, definitions of UI, and study populations. For middle-aged or older women, prevalence estimates are 25–45% for any UI and 5–15% for daily incontinence [5]. In an epidemiological survey in which 80% of the women in the community participated, the prevalence of any urinary incontinence was 25%, and 7% had moderate to severe incontinence that was bothersome. Half had symptoms of SUI, 11% had symptoms of UUI, 36% had symptoms of MUI, and the prevalence of UI was seen gradually to increase with age [6]. The proportion of women with SUI has been reported to decrease with age and the proportions of those with MUI and UUI to increase with age [7]. In a cohort study of 1274 continent women, 40% reported new onset of UI over a 10-year period, and during a four-year follow-up of 337 of these women, one third reported persistent UI [8]. Coyne et al. reported a prevalence of coital incontinence in 2% of women in an internet-based population study [9].

Among the very few studies that incorporated more than one country, some reported differences between European countries. The prevalence of UI was higher in France, Germany, and the United Kingdom (41–44%) and lower in Spain (23%) [10], and less impact of UI on QoL was found in the Netherlands than in 14 other European countries [11]. No obvious explanation for these discrepancies was established. In a study from the United States of women with various racial origins Hispanic women had the highest prevalence of UI, followed by Caucasian, African-American, and Asian-American women [12]. In contrast, Waetjen et al. found that Hispanic women had the lowest prevalence of UI, but also that Caucasian women's risk of UI was higher than that of African-American or Asian-American women [13]. In developing countries, practically no population-based prevalence studies on UI have been performed [5].

Although UI is a prevalent condition, a Swedish study reported that only 14% of affected women sought help [14], and a U.S. study reported 38% [14, 15]. Fear of humiliation [14], perceived severity of the condition [16], and low

QoL scores [14, 15] may contribute to whether or not women seek help for UI.

Evaluation of urinary symptoms

Women presenting with urinary symptoms require a basic examination to eliminate other causes of the urinary symptoms and to establish the type of incontinence in order to provide appropriate treatment.

A medical history is taken first and should include pattern, frequency, and severity of the urinary symptoms, co-existing diseases, current medication, gynaecological history, bowel function, sexual function, and impact on QoL. Height and weight should be recorded for calculation of body mass index (BMI). Self-reported height and weight tend to lead to underestimated values at the high end of the BMI scale and overestimated values at the low end. However, more than 80% of BMIs calculated from self-reported height and weight are within two units of the measured BMI [17].

Urinary analysis (dipstick, and urinary culture if required) should be performed to screen for urinary infection, and post-void residual urine should be measured to evaluate emptying ability. Post-void residual urine volumes measured with catheterisation and with portable ultrasound scanners are found to be in a good agreement [18-20].

Gynaecological examination is also required to evaluate potential vaginal atrophy, prolapse, myoma, cysts, or other palpable resistances. A cough stress test can be conducted to visualise urinary leakage and is suggested to be more reliable than the 24-hour pad test to detect SUI [21]. Pelvic floor muscle function, including strength, displacement, and duration of the contraction, should be assessed by palpation.

Frequency/volume charts recording volume voided and time of each micturition, preferably over 48 hours, provide reliable data of urine volume/24 hours, frequency, mean voided volume, maximum voided volume, and nocturia [22, 23]. These values can indicate urgency when the mean voided volumes are low, frequency is high, and maximum voided volume is low. However, the parameter found to discriminate between SUI and UUI may be micturition at night [24].

Urine loss can be objectively quantified with pad-weighing tests. In the 48-hour test, reflecting leakage during daily activities, the woman weighs pads before and after use [25-28]. There are also 1-hour tests that follow a scheme

of fluid intake and physical exercise, but those are more suitable for the evaluation of SUI [29].

Urodynamic tests such as filling cystometry with flow measurement can be used to investigate the bladder's function during filling, storage, and emptying phases, but they are usually not performed in a standard investigation. Ultrasound can also be used to image leakage from and movement of the bladder, but it is not yet recommended for routine clinical practice [30].

Risk factors for urinary incontinence

Age, obesity, and parity are well-known risk factors for UI [31]. Women with vaginal delivery are at even greater risk of UI [32] and SUI [33] than those who have a Caesarean section. There also seems to be a genetic component; sisters and daughters of women with SUI are at greater risk than first-degree relatives of continent women [34, 35]. Oral oestrogen treatment with conjugated equine oestrogen alone or in combination with medroxyprogesterone acetate has also been suggested to increase the risk for SUI in women aged 55 and older [36]. Chronic cough, previous hysterectomy, depression [31, 37-41], diabetes [13], and constipation [42, 43] are other suggested risk factors for UI.

Treatment

Methods to treat UI and urgency are in continuous development, and the most common are listed below. The choice of treatment depends upon the type and severity of the urinary symptoms, and the patient should be offered information and discussion about the pros and cons of different treatment options.

Pelvic floor muscle training is recommended as first-line therapy in women with stress, urge, or mixed urinary incontinence [44]. Short-term cure rates in SUI assessed as < 2 g of leakage on pad testing vary between 35% and 80%, but the training requires proper instruction and close follow-up to be effective [45].

Behavioural changes such as reduction of excessive fluid or caffeine intake, dietary changes to reduce constipation, smoking cessation to reduce coughing, etc., may be required to reduce associated symptoms of UI and urgency [46]. Weight loss in overweight and obese women can also cure or improve UI [47, 48]. Improvement of UI may be seen after weight loss of 5% to 10% of body weight [47]. Bladder training is a behavioural modification technique in which time between voiding is gradually increased to increase

both bladder capacity and the patient's confidence in controlling bladder function [49].

Electrical stimulation given with vaginal and/or anal transducer can be used to reinforce existing inhibitory reflexes in the vaginal and anal regions to relax the bladder and reduce UUI [50-52]. However, results regarding long-term outcome are contradictory [50, 52].

Local oestrogen treatment can reduce urgency in cases with co-existing urogenital atrophy [53]. However, treatment with oral oestrogen has been suggested to be a risk factor for SUI, at least in women age 55 and older [36]. The effects of oral oestrogen on urge incontinence, and on incontinence in women under 55 years of age, is less clear [36]. Oestrogen combined with progestin has also been found to worsen urinary incontinence [36, 54] and to increase the risk for SUI and UUI [55], but only conjugated equine oestrogen and medroxyprogesterone acetate were used in these studies.

Duloxetine is a serotonin-noradrenalin reuptake inhibitor for treatment of SUI [56]. The tonus in the urethra sphincter is suggested to increase with this treatment, resulting in a decrease of stress-induced leakages. However, nausea is a common side effect and about one in eight women discontinue the medication.

Anticholinergic medications (darifenacin, fesoterodine, oxybutynin, solifenacin, and tolterodine) have a positive effect on UUI, MUI, and urgency by reducing frequency and urgency and prolonging the time between urge and void, but they have side effects such as dry mouth and constipation. Therapy combining anticholinergics and bladder training is more effective than medication or bladder training alone [57].

Surgical procedures for UI were first developed in the mid-19th century. In 1914, Dr Kelly published a manuscript describing an operative procedure for the treatment of SUI by plicating the 'relaxed tissues at the vesical neck' with interrupted mattress sutures [58]. Many surgical procedures have been used since then, but for more than a decade minimally invasive mid-urethral sling methods have become standard surgical treatments for SUI (Figure 1). These treatments are based on the theory that the female urethra closes at the level of the midurethra and this function fails in women with SUI. Lack of support of the mid-urethra from the pubo-urethral ligaments, the suburethral vaginal wall, and the pubococcygeus muscles causes the urethral closure mechanism to fail under increased abdominal pressure and cause urinary leakage [59-61]. The technique of retropubic tension-free vaginal tape (TVT) was first described in 1996 and is still the most common surgical

treatment [62]. Transobturator tape (TOT), which is inserted outside-in through the thigh folds and the obturator foramen into the vagina, was introduced in 2001 [63, 64], and tension-free vaginal tape-obturator (TVT-O), inserted inside-out via the vagina through the obturator foramen and the thigh folds, was introduced in 2003 [65].

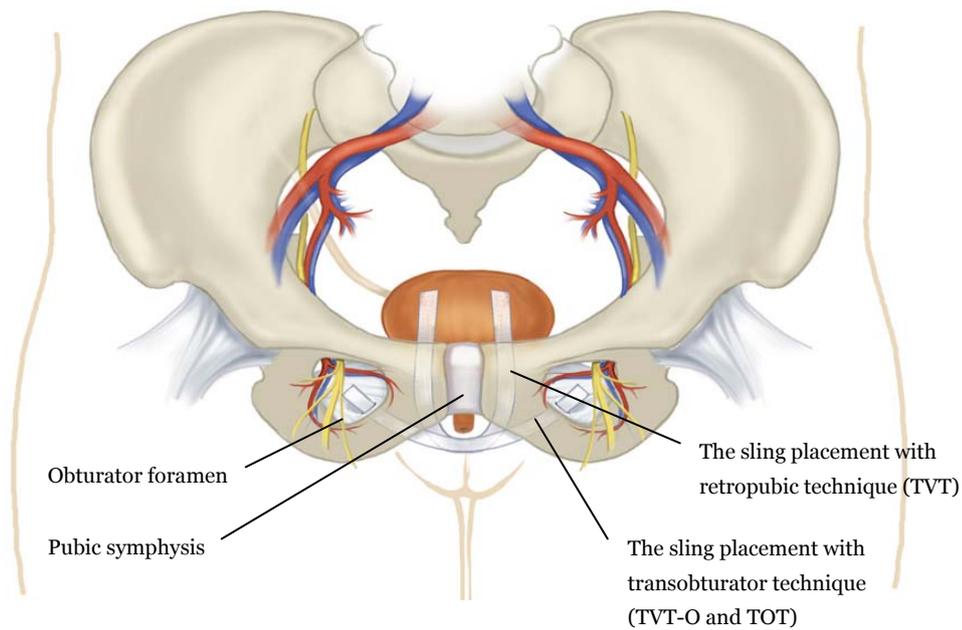


Figure 1. Placement of mid-urethral slings, with permission from the copyright holder

Other methods are used to treat SUI, e.g. single-incision mini-sling operations, but they are reported to have lower patient-reported and objective cure rates and higher reoperation rates for SUI than standard midurethral sling procedures [66]. New adjustable mini-slings are also in use, but more research is essential before their implementation in clinical practice [67]. Other alternatives for the treatment of SUI are peri-urethral or transurethral injections of bulking agents, but these methods also have lower cure rates than standard surgery [68]. For treatment of UUI and urgency, acupuncture may be another option [69], and a new drug, a β_3 -adrenoceptor agonist (mirabegron) has been developed but is not yet available in Sweden [70, 71]. Intra-detrusor injections of onabotulinumtoxinA (botox) have been

tried in idiopathic OAB patients who have not had an adequate effect from first-line pharmacotherapy [72]; however, further investigations are needed of their effectiveness and complications.

Sexual function and dysfunction

Women's sexual function may be affected by several factors, including whether or not they have a partner, the quality of the partner relationship, and the partner's sexual function. Hormonal and physical changes can influence sexual function, as can psychological and social factors. The report of the International Consensus Development Conference on Female Sexual Dysfunction classified female sexual dysfunction (FSD) into sexual desire disorders, sexual arousal disorders, orgasmic disorders, and sexual pain disorders, and emphasized the importance of including personal distress [73]. Population studies, however, have often reported the prevalence of FSD, but not whether the women consider the dysfunction a problem [74]. In a review, Hayes et al. reported a broad range of prevalence estimates of sexual dysfunction: desire difficulty (2.5–54.8%), arousal difficulty (2.6–31.2%), orgasm difficulty (3.1–28.6%), and sexual pain (3.1–20.3%). Studies that investigated sexual distress indicated that only some women were distressed by their sexual difficulties: desire difficulty (35–52%), arousal difficulty (33–45%), and orgasm difficulty (21–67%) [75]. Sexual function seems to decline with age, e.g. there is a decrease in desire, frequency of orgasm, and sexual intercourse, however FSD is reported to change little with age [76]. For example, in a population study that reported low sexual desire in 11% in women aged 20–29 years and 53% in women aged 60–70 years, 65% of the younger women with low desire were distressed by their lack of desire, but only 22% of the older women were [77].

Questionnaires regarding quality of life and sexual function

Questionnaires are useful for evaluating the symptoms and impact on QoL of a medical condition. They also make it possible to measure changes in symptoms over time and impact after treatment.

Two types of questionnaires measure QoL: generic and condition-specific. Generic questionnaires are designed to measure health in general populations rather than in people with a medical condition, e.g. the Short Form 36 Health Survey (SF 36) [78, 79] and the Nottingham Health Profile [80]. Such questionnaires are relatively insensitive in measuring the effect of urinary symptoms on QoL or improvement of urinary symptoms after treatment [81, 82]. Therefore, a number of condition specific questionnaires have been developed to assess UI and its impact on QoL. Examples of questionnaires highly recommended (grade A) by the Fourth International

Consultation on Incontinence [83] for evaluating the impact of urinary incontinence on QoL are the King's Health Questionnaire (KHQ) [84] for both women and men and the Incontinence Impact Questionnaire (IIQ) [85] for women. The Bristol Female Lower Urinary Tract Symptoms questionnaire (BFLUTS) [86] and the Bristol Female Lower Urinary Tract Symptoms-Short Form (BFLUTS-SF) are highly recommended for assessing both urinary symptoms and health-related QoL in women [87].

For evaluation of sexual function and health in women with urinary symptoms, the ICIQ-FLUTSsex (one of the modules in BFLUTS) [86] and the Pelvic Organ Prolapse/Urinary Incontinence Sexual Questionnaire (PISQ) [88] are highly recommended (grade A) and the Female Sexual Function Index (FSFI) [89] is recommended (grade B).

Sex in Sweden

The latest population-based Swedish survey of sexuality and health, *Sex in Sweden*, was carried out at the request of the National Institute of Public Health [90]. Data were collected by SIFO (The Swedish Institute for Public Opinion Research) through interviews and questionnaires during January to October 1996. In total, 5250 persons living in Sweden were contacted. The selection was random and representative of the Swedish population at the time between the ages of 18 and 74 years. Those who were blind, deaf, mute, or non-Swedish speakers, and those whose address was unknown were excluded from the study. In total, 2810 participated in the survey, for a response rate of 59%. The most common reasons for not participating were related to the sensitivity and subject of the study [90].

Test interviews of the questionnaire

Volunteer participants underwent a test interview using the questionnaire's oral and written parts. Discussion of unclear points and formulations with the interviewees helped refine the wording of the questions, and after additional input from SIFO, the questionnaire was finalised. Field trials were carried out, one with a deliberately larger proportion of older participants and one with people with homosexual experiences. These trials led to a shortening of the questionnaire without removing any key areas.

Failure analysis and external validity of the data

A failure analysis showed that the response rate decreased with increasing age. The geographic spread of respondents in the study reflected the country as a whole. The material contains information on infertility that corresponds well with other studies in the Western world, and the experiences of paying

for sexual services was found to be at almost same level as in Finland. The failure analysis revealed no systematic differences other than age.

Generalizability

The study sample was a representative survey of the Swedish population, however older people, particularly women, were underrepresented. The truthfulness of the responses was considered to be high and responses within the same individual and between men and women had high correlation. The research group's view was that the data was valid and, except for the age distribution - generalizable to the population as a whole [90].

The Swedish National Quality Register for Gynaecological Surgery

In 1993–1994 the Swedish Society of Obstetrics and Gynaecology and the National Board of Health and Welfare requested a national registry for endoscopic operations, which was begun as The Swedish National Quality Register for Gynaecological Surgery (Gynop-register). The Gynop-register was finally established in 1997 to evaluate objective and subjective data for hysterectomy on benign indication, adnexal surgery, and endometrial ablation. Since 2006 urinary incontinence and prolapse surgery have been included. The main aim of the Gynop-register is to provide departments with cost-effective tools for the continuous monitoring of quality efforts over time and in comparison with other departments. A further aim is to provide data for research on medical interventions and outcomes in accordance with SFS 2008:335 [91]. Several studies have been published from various branches of the register [92-97], but none to date from the incontinence branch. To assess the proportion of potential patients who were registered during 2007–2010, the Gynop-register offered all departments performing gynaecological surgery who were affiliated to the Gynop-register an inspection; 15 departments accepted and the mean proportion of patients included in the register was found to be 96%.

Collection of objective and subjective register data

At decision for incontinence surgery the patient answers a questionnaire (postal or internet-based) about socio-demographic data and health status and a validated, disease-specific questionnaire to measure severity of symptoms and QoL [98]. The physician completes a preoperative form containing the patient's history and the results of her physical and gynaecological examination. Directly after surgery the physician completes the perioperative form containing surgery data. The postoperative form is completed by the physician after discharge and contains the sequence of events during hospital stay. Two months after surgery the patient completes

a follow-up questionnaire with general and medical questions, and questions about well-being, surgery-related complications, recovery, and improvement. At one-year follow-up the patient receives a similar questionnaire with questions about UI, QoL, and sexual life identical to those asked preoperatively. Two reminders of the follow-up questionnaires are sent when necessary and the answers on the follow-up questionnaires are assessed by a physician. The questionnaires were validated in collaboration with the Department of Applied Educational Science at Umeå University, Sweden, and a study evaluating patients' acceptance of questionnaires as a means of collecting information showed high acceptance [99]. The questionnaires can be viewed at: <http://www.gynop.org/english/about/about.htm> [100].

Coverage of the Gynop-register

The total number of mid-urethral sling operations during 2010 registered in the Swedish official register for inpatient [101] and outpatient surgery [102] was 2438 compared with 1894 in the Gynop-register. This gives a coverage rate of 78% for the Gynop-register. However, not all patients are registered in the national official register, and particularly not in the outpatient part. Therefore, about 3000 mid-urethral sling operations could be estimated to be performed in Sweden per year. Based on the population in the catchment area for the 39 departments participating in the Gynop-register, it is estimated that 60% of the total number of mid-urethral sling operations performed in Sweden is registered in the Gynop-register. The geographic coverage area extends from Ystad in the south to Sunderbyn in the north, but does not include the Stockholm area, parts of the southern healthcare region, and parts of the Uppsala/Örebro healthcare region.

Aims

The overall aim of this thesis were to study the consequences of female UI and urgency in patients and their partners on quality of life, partner relationships, and sexual life. Furthermore, to evaluate three operation methods (TVT, TVT-O, and TOT) for SUI for their success rates, and to examine quality of life among women who still have urinary leakage one year after surgery.

More specific questions were:

- Do female UI and/or urgency affect women's and their partners' quality of life and partner relationship? Are there any differences in different age groups? Are there any differences compared with corresponding age-groups in a Swedish national population-based study? (Paper I)
- Does female UI and/or urgency affect women's sexual life? How common is urinary leakage during sexual activity? What factors may correlate with sexual desire and satisfaction with sexual life in women with UI and urgency? (Paper II)
- Do female UI and/or urgency affect women's and their partners' sexual life? Are there concordances of answers within couples? (Paper III)
- What are the patient-reported outcomes 12 months after surgery with TVT, TVT-O, or TOT? Are different domains of life affected in women who still have urinary leakage 12 months after surgery? (Paper IV)

Materials and methods

Ethics

The questionnaire study was approved by The Regional Ethical Review Board in Umeå, Sweden (Dnr 01-179 2003-06-16). All women gave their informed consent in writing and the data were analysed confidentially. The Regional Ethical Review Board in Umeå, Sweden, also approved the register-study (Dnr. 08-076M 2008-09-10, Dnr 2011-245-32M 2011-08-09)

The questions regarding sexuality could be sensitive for some participants, and to avoid privacy violations various measures were taken. All women received both oral and written information on the study's purpose and execution, and assurance that their responses could not be identified. The women were also asked whether she would consent to her partner participating in the study. If the woman gave her consent, she brought written information, the current questionnaire, and a return envelope to her partner. Voluntary participation in the study was emphasized, orally and in writing, as was the woman's immunity from any adverse consequence if she refused participation. The urotherapists had space and time available for women or their partners who felt the need to talk about their situation and their feelings after completion of the survey. If participants expressed a need for specific psychosocial interventions, sexual counselling, or psychotherapy, such contacts would be mediated.

Papers I–III

During a period of 2.5 years all women aged 18–74 years with UI and/or urgency who consulted a urotherapist at the Department of Gynaecology, University Hospital, Umeå, Sweden and three other outpatient clinics in the same region were asked to participate in the study. A standardized clinical evaluation including medical history, frequency-volume charts, residual urine, urine analysis, and vaginal examination were carried out. The women completed the BFLUTS questionnaire and a questionnaire concerning actual and previous diseases and demographics (Appendix). They were also asked to complete a semi-structured questionnaire regarding psychosocial situation, partner relationship, and sexuality (Appendix). In addition, those who had a partner were asked to distribute a similar questionnaire along with an information letter and a stamped envelope to their partners.

Exclusion criteria were urinary retention, polydypsia, pregnancy, untreated diabetes mellitus, malignancy, and serious heart, liver, nervous system, urological, and mental diseases. In addition, women who had been treated

for UI and/or urgency in the preceding year and women who did not understand Swedish were not included in the study. The inclusion of women with UI and/or urgency and their partners in the questionnaire study are displayed in Figure 2. According to exclusion criteria, six women were excluded for polydypsia, three for neurological disease, and two for urinary retention. The 36 women who did not have a partner are not included this thesis.

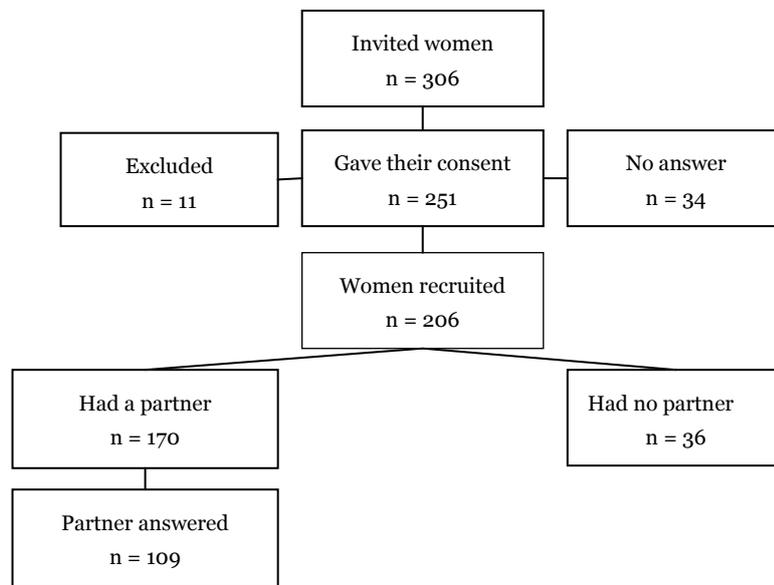


Figure 2. Inclusion of women with UI and /or urgency and their partners in the questionnaire study

Questionnaires about partner relationship and sexual life

No suitable questionnaires regarding partner relationships, psychosocial situation, or sexual life in women with UI or urgency and their partners were available, so we constructed an appropriate questionnaire. Half of the questions were identical to the questions used in the latest Swedish national population-based study on sexuality and health in women and men [90]. Two new questions were added regarding leakage during sexual activity, while the rest derived from a study of psychosexual and social consequences in women with gynaecological cancer and their partners [103]. The questions

about sexuality included sexual desire, vaginal lubrication, painful intercourse, incontinence during sexual activity, and overall satisfaction with sexual life. Several of the questions were open-ended in order to allow the use of respondents' own expressions in illustrative quotations.

Two sexologists, two gynaecologists, three nurses, and five senior researchers judged the relevance of the questions. The comprehensibility of the questionnaire was then tested on 10 women and 8 men. The questions were considered relevant and easy to understand and minor linguistic corrections were made.

The BFLUTS questionnaire

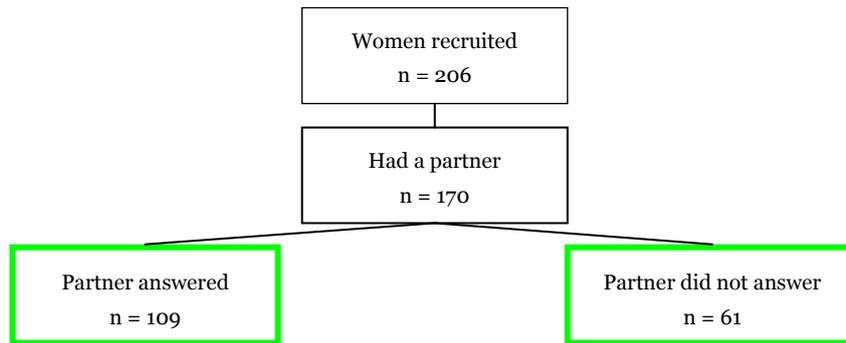
The BFLUTS questionnaire was developed in the United Kingdom to assess female lower urinary tract symptoms, particularly urinary incontinence and health-related QoL. The items address urinary leakage, storage phase, voiding phase, aspects of QoL, and sexual function. Each item is followed by a question about the perceived severity or frequency of the event. Construct validity was found to be good when comparing responses between a control group of women and a group of female patients. Criterion validity, as tested against frequency/volume charts and pad-test data was acceptable. The reliability was good; a Cronbach's alpha of 0.78 indicated that the symptom questions had acceptable internal consistency, while stability was excellent, with 78% of symptoms and problems answered identically on two occasions [86]. BFLUTS was one of the questionnaires recommended by the Second International Consultation on Incontinence [104]. The Swedish version of BFLUTS used in our studies was translated by a pharmaceutical company.

Paper IV

Between January 2006 and April 2010, 39 of 57 departments performing incontinence surgery in Sweden reported their objective and subjective data to the Gynop register, and that data was used in paper IV. Exclusion criteria were fecal incontinence, incontinence surgery combined with other gynecological operation, neurological disease, and other severe systemic diseases classified as grade III (grade I=completely healthy, grade II=mild systemic disease, and grade III=severe systemic disease) according to the American Society of Anesthesiologists (ASA) Physical Status Classification System. The data on the diagnosis SUI or MUI, grade of ASA, and type of sling-operation were collected from forms completed by the surgeon. All other data in this study derived from pre- and postoperative questionnaires completed by the patients. At follow-up, the women were asked about their degree of satisfaction with the operation, and offered the options of "very satisfied", "satisfied", "neither satisfied nor dissatisfied", "dissatisfied", and

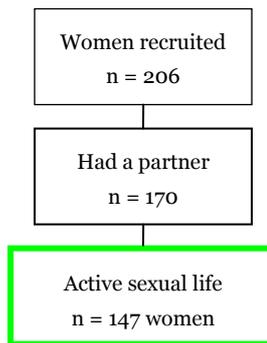
“very dissatisfied”. The women were also asked if they still had urinary leakage: “never”, “seldom”, “1–3 times a month”, “1–3 times a week”, and “daily”. A woman was defined as having UI after operation if she reported urinary leakage 1–3 times a month or more.

Subjects in paper I



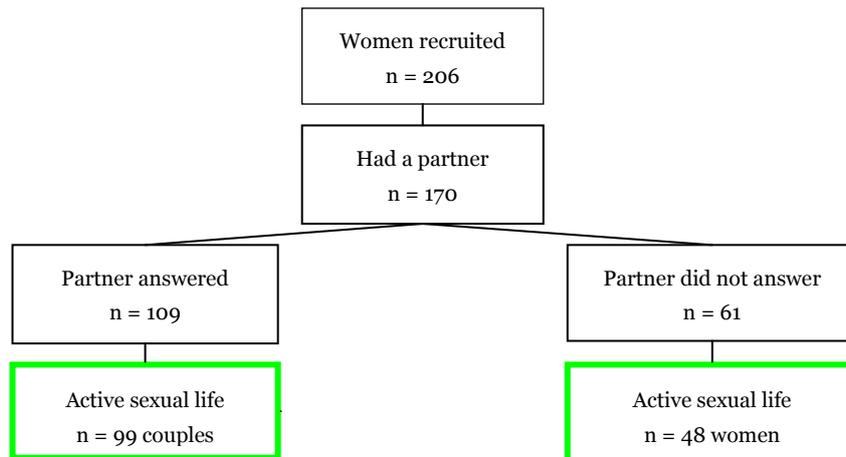
Paper I reports data from 109 couples and 61 women whose partners did not participate in the study. All partners were men. Data from the Swedish population study “Sex in Sweden” made possible comparisons with corresponding age groups regarding satisfaction with life in general, partner relationships, and other aspects of life. For these analyses the women were grouped according to age as younger (25–49 years) or older (50–74 years) and the men as younger (25–49 years) or older group aged 50–78 years. Comparisons were also made between women who had a partner who participated in the study and the women who had a partner who did not.

Subjects in paper II



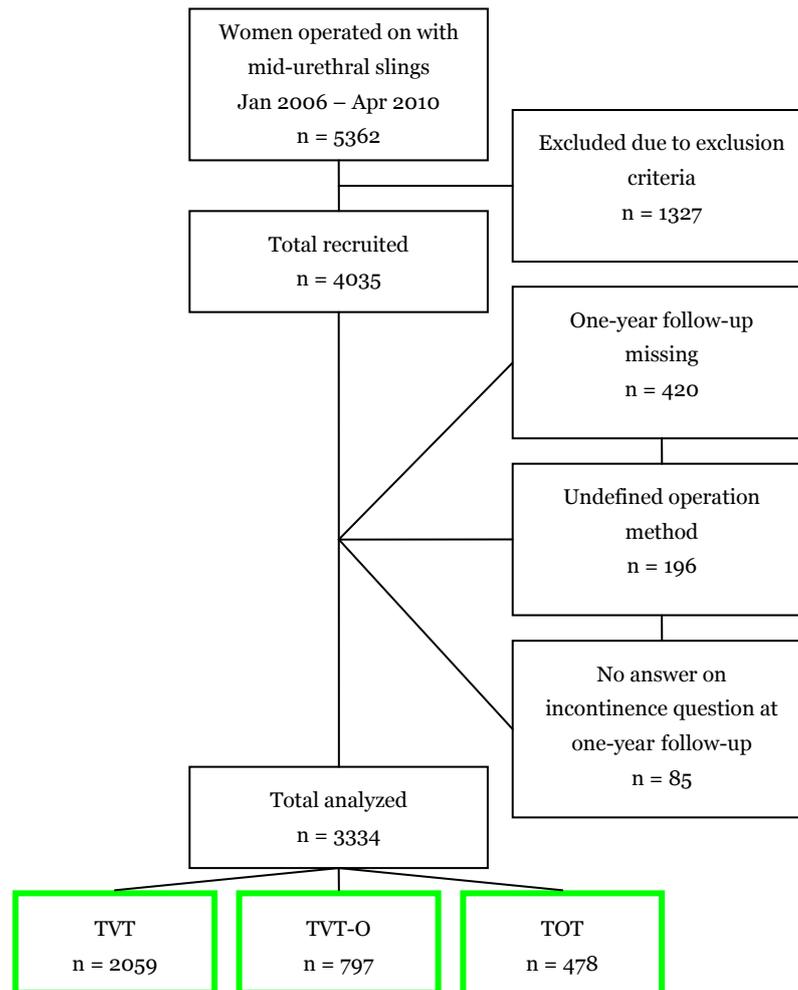
In paper II, 147 sexually active women in stable partner relationships, were studied. To explore the interaction of factors other than UI or urgency with sexual desire and satisfaction with sexual life we studied the significance of age, diagnostic group, BMI, somatic health, psychological health, attractiveness, quality of partner relationship, vaginal lubrication, painful intercourse, orgasmic ability, partner's health, worry about odour, worry about urinary leakage, and urinary leakage during sexual activity.

Subjects in paper III



Paper III focuses on the 99 couples with an active sexual life. Comparisons were also made with the 48 women who were sexually active and whose partners did not participate in the study. Comparisons between the groups of men and women were also made. The concordance of the answers within the couples was analysed, and we studied whether there were any differences between the three groups of women with SUI, UUI/urgency, and MUI.

Subjects in paper IV



In paper IV data from women who underwent surgery for SUI with TVT, TVT-O, or TOT from January 2006 to April 2010 and had completed questionnaires from the Gynop-register before and one year after surgery were analysed. Women who had incontinence surgery combined with prolapse operation (n = 159), hysterectomy (n = 32), or other major surgery (n = 8) were excluded, as were women with neurological disease (n = 90) and women who had not answered the question about disease (n = 178). Women with other severe systemic diseases (n = 189) classified as ASA grade

III were not included. Finally, women with faecal incontinence (n = 382) and women who had not answered the question about faecal incontinence (n = 289) were excluded.

Statistics

Categorical variables were compared between groups using the Chi-square test. Analysis of variance was used to test whether the mean age and mean BMI were equal in the different diagnostic groups (paper II, IV). A significance level of 0.05 was used throughout the testing, and the Holm-Bonferroni method was used to correct for multiple testing.

For all the questions, responses such as “all the time,” “nearly all the time,” and “quite often” or “sometimes” “often” and “always” or “very unsatisfying,” “unsatisfying,” and “rather unsatisfying,” were considered indicative of a negative effect of symptoms or circumstances and were dichotomized as such for the current analyses in paper II and III.

In paper II a multiple logistic regression analysis for each of the two dependent variables, sexual desire and satisfaction with sexual life, was performed to test which factors were significant. The incomplete answers were also examined, and we did not detect any systematic pattern. The odds ratios and p-values for each factor included in the final analyses are reported. None of the analyses had more than about 8% missing values.

To test whether the answers to the questions were concordant within the couples, Cohen’s Kappa was used in paper III. In paper IV, binary logistic regression analysis was used to test for differences in outcomes between operation methods and to adjust for baseline differences in the operation groups. SPSS versions 16 and 18 and Minitab versions 15 and 16 statistical packages were used for the analyses.

Results

Quality of life and partner relationship (Paper I)

Most of the couples in the study were married and had long-lasting relationships (Table 1). Almost all the women (95%) reported that their UI and/or urgency had a negative impact on their lives. Of the 109 women, 43% had SUI, 24% had UUI/urgency, and 33% had MUI. The majority of the women, 83%, considered that their urinary symptoms affected their physical activities negatively, 43% reported negative consequences on their social lives, and 46% avoided places where a toilet was not available.

Table 1. Age, civil status, and length of the partner relationship in women (n = 109) with UI and/or urgency and their male partners (n = 109)

Age, years		
Women: mean–median, range	52–52	25–74
Men: mean–median, range	55–54	27–78
Civil status % (n)		
Married	78	(85)
Cohabiting	17	(19)
Stable relationship/not cohabiting	5	(5)
Length of the relationship % (n)		
> 5 years	89	(97)
≤ 5 years	11	(12)

The majority of the couples had open communications about their partner relationship, the woman's urinary problems, and their sexual life (Table 2). Thirty-eight percent of the women and 32% of their partners reported a negative impact on their relationship. The couple's joint activities were affected according to 47% of the women and 36% of the men. This is exemplified by the quotations from two men one woman:

Men

- She does not want or does not dare to go to the cinema or to do other fun things. She is not always in the best mood.
- She is not willing to join in when the children and I play football or run around and are rowdy.

Woman

- I get furious and sad when I have urine leakage. I lose interest and joy in whatever we do.

Twenty percent of the women and 16% of their partners felt the woman's urinary problems exerted a harmful influence on physical proximity, intimacy, affection, and warmth. The influence was worse in younger women and men than in the older groups ($p = 0.003$ and 0.010 , respectively).

Table 2. Openness between mates in the couple (n = 109)

	Women % (n)	Men % (n)
Openness about the partner relationship		
Yes, totally	73 (80/109)	80 (86/108)
Yes, partially	25 (27/109)	18 (19/108)
No	2 (2/109)	2 (3/108)
Openness about the woman's urinary problems		
Yes, totally	72 (78/109)	80 (87/109)
Yes, partially	26 (29/109)	17 (19/109)
No	2 (2/109)	3 (3/109)
Openness about sexual life		
Yes, totally	63 (68/108)	72 (79/109)
Yes, partially	33 (36/108)	22 (24/109)
No	4 (4/108)	6 (6/109)

Women aged 25–49 were less satisfied than those aged 50–74 with their psychological health ($p = 0.002$), sexual life ($p = 0.000$), leisure ($p = 0.002$), and financial situation ($p = 0.000$). Men aged 25–49 years were less satisfied with their life as a whole ($p = 0.007$), psychological health ($p = 0.005$), partner relationship ($p = 0.001$), family life ($p = 0.001$), contacts with friends ($p = 0.001$), and vocation ($p = 0.004$) than older men (aged 50–78 years).

Compared with women and men in the corresponding age groups in the Swedish national population-based study (Table 3 and 4), young women with UI and/or urgency were less satisfied with their sexual life ($p = 0.000$), activities of daily living ($p = 0.000$), leisure ($p = 0.004$), and life as a whole ($p = 0.007$), and the young men were less satisfied with contacts with friends ($p = 0.005$) and life as a whole ($p = 0.000$). Overall, the women in the national population-based study were more satisfied with their psychological

($p = 0.000$) and somatic health ($p = 0.000$) than the women with urinary problems.

Table 3. Proportions of those “very satisfied/satisfied” with life in general and within different domains of life in women with urinary incontinence and/or urgency compared with women from the Swedish population survey

	Women Incontinence survey		Women Swedish population survey		p-value
	25–49 years	50–74 years	25–49 years	50–74 years	
	% (n)	% (n)	% (n)	% (n)	
Sex life	30 (13/44)	55 (34/62)	58 (395/677)	50 (198/395)	0.000 ^a
Partner relationship	75 (33/44)	87 (55/63)	78 (452/576)	81 (272/337)	0.005 ^b
Family life	75 (33/44)	90 (57/63)	83 (534/643)	85 (319/376)	ns
Activities of daily life	85 (37/44)	93 (58/62)	97 (685/703)	94 (388/411)	0.000 ^a
Contacts	50 (22/44)	70 (44/63)	66 (464/704)	75 (307/412)	ns
Leisure	30 (13/44)	61 (38/63)	52 (365/700)	66 (268/409)	0.004 ^a
Life as a whole	50 (22/44)	70 (45/63)	69 (489/705)	72 (298/412)	0.007 ^a

^a Younger women compared with the corresponding cohort in the Swedish population survey

^b Older women compared with the corresponding cohort in the Swedish population survey

Table 4. Proportions of those “very satisfied/satisfied” with life in general and within different domains of life in men with a partner with urinary incontinence and/or urgency compared with men from the Swedish population survey

	Men Incontinence survey		Men Swedish population survey		p-value
	25–49 years	50–74 years	25–49 years	50–74 years	
	% (n)	% (n)	% (n)	% (n)	
Sex life	36 (12/33)	61 (44/72)	56 (422/760)	54 (247/453)	ns
Partner relationship	63 (22/35)	90 (66/73)	77 (478/622)	86 (320/371)	ns
Family life	66 (23/35)	92 (67/73)	77 (513/662)	88 (347/395)	ns
Activities of daily life	94 (33/35)	93 (68/73)	95 (722/763)	90 (410/455)	ns
Contacts	31 (11/35)	65 (47/72)	55 (424/764)	71 (323/455)	0.005 ^a
Leisure	44 (15/34)	66 (48/73)	53 (402/762)	70 (316/454)	ns
Life as a whole	44 (15/34)	71 (52/73)	69 (528/764)	74 (338/455)	0.000 ^a

^a Younger men compared with the corresponding cohort in the Swedish population survey

Women who had a non-participating partner

Women who had a partner who participated in the study (n = 109) were more able (p = 0.002) to communicate openly with their partner about their UI or urgency than those with a non-participating partner (n = 61). More women with non-participating partners reported a harmful influence on physical proximity, intimacy, affection, and warmth (p = 0.005). No further differences were found between these two groups of women.

Women's sexual life (Paper II)

Of the 147 women, 44% had SUI, 33% MUI, and 23% OAB. There were no significant differences in the background data for age and BMI between the three groups. The vast majority, 86%, considered sexuality to be fairly or very important in their lives. Urinary leakage during sexual activity was sometimes or always experienced by 34%, most commonly during penetration and/or orgasm. All women had had intercourse during the preceding 12 months and 86% of these during the preceding month. Sexual life was adversely affected by UI or urgency in 53% of the women, and 46% of those thought that this was a problem. One in two were worried about urinary leakage during intercourse, 68% worried about odour, and 63% felt unattractive. Nineteen percent of the women felt sexual desire often, 62% felt desire sometimes, and 19% felt sexual desire seldom or never. Furthermore, 16% were very satisfied with their sexual life, 28% were satisfied, 34% rather satisfied, 11% rather unsatisfied, 7% unsatisfied, and 4% very unsatisfied. Fifteen percent of the women were dissatisfied with their psychological health, 30% with their somatic health, and 5% with their partner relationship. Additionally, 31% had insufficient vaginal lubrication, 18% experienced painful intercourse, 30% had difficulties reaching orgasm, and 20% had a partner with a disease that affected their sexual life.

Among women with decreased sexual desire there was a correlation with insufficient vaginal lubrication, unsatisfactory psychological health, and partners' ill health (Table 5). Dissatisfaction with sexual life was strongly correlated with unsatisfactory psychological health, orgasmic disability, and worry about urinary leakage during intercourse (Table 6).

Table 5. Factors affecting sexual desire in women with OAB (n = 33), MUI (n = 48), and SUI (n = 62)

	Odds ratio (n = 136) ^a	95% CI	p-value
Insufficient vaginal lubrication			
No ^b	1		
Yes	0.193	0.074–0.506	0.001
Psychological health			
Satisfied	1		
Not satisfied	0.269	0.083–0.869	0.028
Healthy partner			
No	1		
Yes	0.332	0.118–0.930	0.036

^a The number of individuals included in this analysis is less than the number of individuals in the study. Because of missing values, not all individuals are included in the final analyses.

^b 'No' includes responses of fairly rarely, almost never, and never

Table 6. Factors affecting satisfaction with sexual life in women with OAB (n = 32), MUI (n = 47), and SUI (n = 60)

	Odds ratio (n = 138) ^a	95% CI	p-value
Psychological health			
Satisfied	1		
Not satisfied	0.158	0.051–0.491	0.001
Difficulties achieving orgasm			
No ^b	1		
Yes	0.226	0.089–0.573	0.002
Worry about urinary leakage during sexual activity			
No	1		
Yes	0.340	0.132–0.874	0.025

^a The number of individuals included in this analysis is less than the number of individuals in the study. Because of missing values, not all individuals are included in the final analyses.

^b 'No' includes responses of fairly rarely, almost never, and never

Couple's sexual life (Paper III)

In total, 99 couples had an active sexual life. Among both men and women 21% were unsatisfied with their sexual life; however the great majority, 95%, was satisfied with their partner relationship. Men felt sexual desire more often than women ($p = 0.000$) and 81% of men and 72% of women reported having open communication about the woman's urinary problems. Concerning their sexual life, 75% of the men and 64% of the women communicated openly, and 22% of the men and 43% of the women reported that the woman's urinary problems impaired their sexual life ($p = 0.002$). These negative effects are illustrated by the following quotations from two men and two women:

Men

- She doesn't feel at ease with herself because of her problems with her bladder. This affects me too, of course.
- Sometimes she lacks desire or has to go to the loo. She can't really relax and enjoy.

Women

- I feel dirty, uneasy, and disgusting.
- Our sex-life doesn't work. I can never relax, because then I leak. We have to interrupt because I must go to the toilet, and yet I still leak.

Worry about leaking urine during sexual activity was expressed by 49% of women. However, most of their partners, 94%, did not share the woman's anxiety ($p = 0.000$). Women with MUI ($p = 0.003$) were more likely to be worried about having urinary leakage during sexual activity than women with SUI or UUI and/or urgency. Fewer men (23%) than women (39%) reported that the woman had urinary leakage during sexual activity. This was a problem for 35% of these men and for 84% of the women ($p = 0.000$). In 22% of the couples, there was a need for information or advice concerning sexual life related to the woman's urinary disorder. In testing whether or not the answers within the couples were in concordance, the only non-significant result was whether or not urinary leakage during sexual activity was a problem ($p = 0.484$). In addition, there was only slight concordance regarding worry about leakage and moderate concordance about urinary leakage having a negative impact on sexual life.

Women who had a non-participating partner

Among the women who had a non-participating partner (n = 61) 79% were sexually active (n = 48). Background data of women did not differ between those who had or did not have a participating partner. However, women with a non-participating partner were found to communicate less openly about their urinary problems with their partner than women whose partners participated in the study (p = 0.007). This is illustrated by the statements from two of these 48 women:

Women

- I myself have not told him about my leakage during intercourse.
- It is hard to put it into words. You don't feel fresh and you feel unattractive in a way.... It is hard to describe why and to get an understanding man. Instead he gets surly...and distant....

Among those whose partners did not participate, the length of the relationship was significantly shorter (p = 0.004) and fewer were married compared with women with a participating partner (p = 0.036). No other significant differences were found.

Patient-reported outcome after surgery (Paper IV)

At 12-month follow-up 67% of the TVT patients (n = 2059), 62% of the TVT-O patients (n = 797), and 61% of the TOT patients (n = 478) were very satisfied with the result of the operation. Demographic data is shown in Table 7. In total, 65% of 3254 (missing cases = 80) women had had coitus within three months previous to surgery and 31% of them reported coital incontinence preoperatively. After binary logistic regression analysis adjusting for baseline differences with respect to age, BMI, type of incontinence symptoms, previous hysterectomy, previous incontinence surgery, and oestrogen treatment, there were no significant differences in the proportion of women who were very satisfied with the result of the operation, regardless operation method. The chance of being very satisfied with the operation decreased with increasing age (p < 0.001), higher BMI (p < 0.001), and preoperative urinary leakage in combination with urgency once a day or more (p = 0.008).

Table 7. Demographic information by treatment group (n = 3334)

	TVT (n = 2059) ^a	TVT-O (n = 797) ^a	TOT (n = 478) ^a	p-value
Age (years), mean	55	56.5	55.7	0.004 ^b
BMI (kg/m ²)	26.30	27.22	26.56	0.000 ^b 0.012 ^c
Diagnosis				
SUI	1673 (82%)	600 (77%)	389 (84%)	
MUI	367 (18%)	177 (23%)	73 (16%)	0.006 ^b 0.002 ^c
Patient-reported symptoms of UUI	1491 (75%)	615 (80%)	356 (77%)	0.000 ^b

^a Some women did not answer all the questions, so the number of responses varies

^b TVT versus TVT-O

^c TVT-O versus TOT

After binary logistic regression analysis adjusting for baseline differences there were fewer women with urinary leakage at follow-up in the TVT group than in the TOT group ($p = 0.032$), the odds were 36% higher to become continent after TVT. The odds of having urinary leakage after surgery increased 19% with every 10 years of age ($p = 0.002$) and 30% when BMI increased by 5 kg/m² ($p < 0.001$). Preoperative diagnosis of MUI and urinary leakage in combination with urgency once a day or more preoperatively also increased the risk ($p < 0.001$, respectively) of postoperative urinary leakage.

Women who still had urinary leakage at the 12-month follow-up

At the 12-month follow-up, 29% (n = 977) still had some form of urinary leakage 1 to 3 times a month or more with a distribution per operation type of TVT 27%, TVT-O 34%, and TOT 33%. The negative impact of UI on family, social, working, and sexual life expressed preoperatively decreased in all these domains postoperatively ($p < 0.001$). There was a significant decrease in the amount of leakage and the number of episodes of both SUI and UUI ($p < 0.001$, respectively). There was also a significant decline in how often the women avoided activities due to fear of urinary leakage and avoidance of places without an available toilet ($p < 0.001$).

In the group of women who still had some form of urinary leakage at follow-up, 40% of those sexually active reported preoperative coital incontinence. At follow-up, 63% in this group reported a cure of coital incontinence. In total, 56% of the women with any urinary leakage postoperatively were

“satisfied” or “very satisfied” with the result of surgery one year postoperatively, compared with 98% in the group with no remaining urinary leakage (Figures 3 and 4).

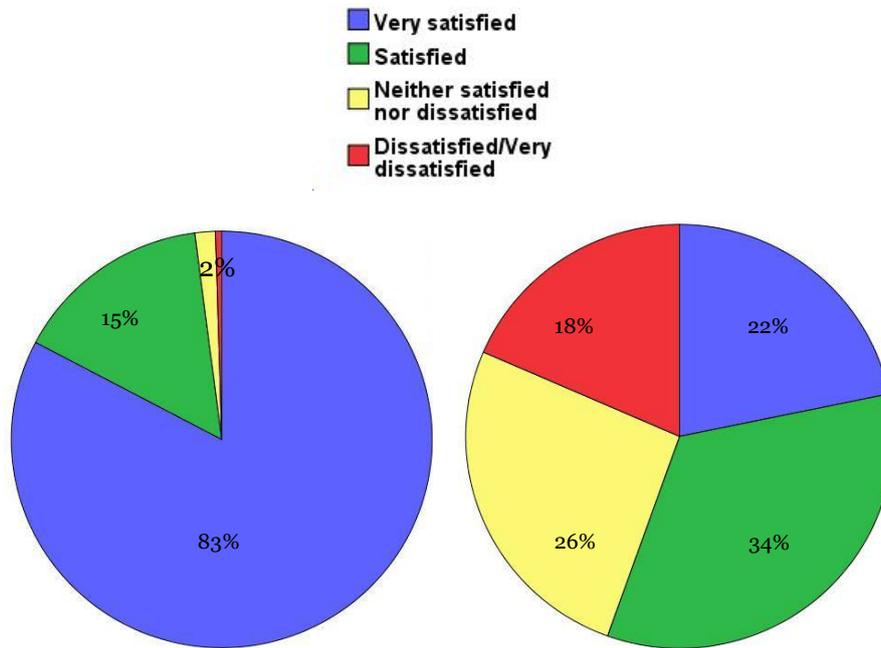


Figure 3. Satisfaction with the result of the operation in women (n = 2297) who are cured at the 12-month follow-up (60 missing cases)

Figure 4. Satisfaction with the result of the operation in women (n = 941) who still have urinary leakage at the 12-month follow-up (36 missing cases)

Discussion

This thesis contributes new information mainly through its evaluation of and attention to the effect of UI and urgency on affected women's partners and on the women's lives as part of a couple. Little is known about the QoL, partner relationships, and sexual lives of the partners of women who suffer from UI or urgency or of the impact of UI and urgency in younger women compared with older. The study emerging from the incontinence part of the Gynop-register is also the first from this branch of the register, and the focus on women who still had some form of urinary leakage at 12 months follow-up is also a new contribution.

Quality of life and partner relationship

Studies of the impact of female urinary disorders on their partners' lives are extremely rare. Several have, however, reported a negative impact on QoL in women with UI [11, 105-110], and urgency has seemed to be more distressing than the incontinence itself [111]. The women in our study reported a negative impact on their physical activities and social lives due to their urinary symptoms and nearly half avoided places where a toilet was not available (paper I). It seems reasonable to believe that restrictions in a woman's everyday life due to a urinary disorder also have some impact on those nearest to them. The partner relationship was adversely affected according to about one third of both the women in the present study and their male partners; even more women and partners experienced a negative effect on their joint activities. These findings are supported by a study on women with SUI or DO that reported a negative impact on joint activities, physical contact, and marital relationships [112], and in a qualitative study that found that OAB affected the lives of OAB patients' family members (daughters or partners) and limited their joint activities [113].

Impact of UI and urgency on young couples

Age-related differences were found in both women and men (paper I). Young women were less satisfied with their leisure and financial situations than older women, and young men were less satisfied with their lives, partner relationships, family lives, and contacts with friends than older men. These differences are in line with a Swedish population study [90], in which both men and women aged 25–49 years were less content in all these domains than older respondents. The young women and men in our study were also less satisfied with their psychological health than older women and men, a difference not seen in the population study, and the young women and men were less satisfied with life as a whole than the women and men in the

corresponding age groups in the population study. The young women in our study were also less satisfied with activities of daily life and leisure than women of similar age in the national study.

Physical proximity decreased due to the woman's UI or urgency in one fifth of the couples and this decrease was more common in younger couples (paper I). Although the woman is the primary sufferer of urinary symptoms, her partner is also affected. This can impose considerable stress on the marital relationship, especially in young couples. A previous study even found that having an incontinent wife puts a man at greater risk of developing depressive symptoms [41]. The negative impact of UI and urgency on physical activities, social life, partner relationships, and joint activities may exert a greater pressure on younger families, who often have a stressful life situation, and then probably contribute to a greater dissatisfaction with life. This is in line with a study that showed that younger women aged 20–45 years with active lives and symptoms of urgency, frequency, and UUI had negative effects that disrupted and restricted their activities [114]. Others have also reported that younger women are more bothered by their symptoms than older women [110, 115]. Current stereotypical images of a modern woman as young, fresh, stylish, active, and capable can contribute even more to the burden of women with female UI and urgency.

The only difference between younger women and younger men in the present study was that the women were less satisfied with their somatic health than the young men, which was hardly surprising since the women were suffering from their urinary symptoms.

Sexual life in women

Sexuality is a complex and challenging area to explore and many factors may interact with sexual functioning. Earlier studies have shown that few gynaecological patients self-report sexual disturbances [116, 117] and few are asked about their sexual life [118]. Salonia et al. found that 74% of women with UI and/or LUTS in a urologic clinic had never been asked about their sexual lives or sexual activity [119]. In a recent study, Bekker et al. reported that women with UI had lower overall sexual function and more avoidance behaviour than those without UI [120]. Others have also reported the negative impact of UI and urgency on women's sexual life [106, 121] and the relation of lower QoL to sexual dysfunction in women with SUI [122]. Thus, sexual function is a relevant and important issue for women suffering from UI and/or urgency, and more knowledge can help health-care professionals better meet the needs of their patients.

Factors interacting with sexual life in women

Worry about urinary leakage during sexual activity

Half of the women reported that their sexual lives were more or less ruined due to their UI and/or urgency (paper II). They worried about urinary leakage during sexual activity and about odour, and they felt unattractive. Their worry about urinary leakage during sexual activity correlated with their dissatisfaction with sexual life. This is supported by Kizilkaya et al., who reported a connection between urinary leakage during sexual activity and dissatisfaction with sexual life, and argued that worry about leakage during sexual activity leads to low sexual desire or deferral of intercourse [123]. An earlier study of women with SUI showed an increase in sexual desire in both women and their male partners one year after the woman's operation for SUI, although the frequency of intercourse did not increase [124].

Orgasm, vaginal lubrication, and pain during intercourse

Thirty percent of the women in our study had difficulties achieving orgasm, which correlated with dissatisfaction with sexual life (paper II). One explanation for their difficulties with orgasm might be that they could not relax and enjoy sex; as one woman said, "... I find it hard to let myself go, worrying about leakage." Or as Salonia et al. reported, for women with SUI "sexual fantasies were frequently associated with the fear of having an UI episode during intimacy, thus resulting in sexual anxiety" [119].

There are several reasons for insufficient vaginal lubrication, including menopause or lack of arousal. It seems reasonable that women who seldom felt sexual desire had insufficient vaginal lubrication (paper II). Lack of vaginal lubrication might also, however, be a consequence of impaired self image or fear of urinary leakage during sex. Interestingly, pain during sexual intercourse did not correlate significantly with sexual desire or satisfaction with sexual life in our study. This is in line with another study that reported lower FSFI scores (worse symptoms) in women with UI than in controls, except in the domains of pain and lubrication [125]. Considerably more women in our study reported having insufficient vaginal lubrication than having pain. Most women with pain also had insufficient vaginal lubrication, which may explain why the pain-factor did not become significant – or was it just that the other factors were more important? Among women participating in a health-screening project, 22% reported desire disorders, 35% arousal disorders, 39% orgasmic problems, and 12.8% pain disorder. Pain disorder was most common in women aged 20–39 years (22.9%), and

decreased to 14.8% in women aged 60–69 years [126]. The distress of the disorders, however, was not assessed.

Psychological health

Unsatisfying psychological health was correlated with both decreased sexual desire and dissatisfaction with sexual life (paper II). Earlier studies have found that UI and urgency have a negative impact on psychological health [108, 112] and that MUI and UUI have a greater impact on mental health than SUI [127]. There are also reports of more depression among women with UI [37-41], but its cause is still undetermined. Another study, however, found no association in women between UI and depression [128].

Age

When exploring the correlation of different factors to female sexual desire and satisfaction with sexual life, age did not turn out to be significant (paper II). However, when comparing different age groups, as in paper I, women aged 25–49 years were less satisfied with their sexual life than older women (aged 50–74 years). In the Swedish population study, women younger than 50 years were more satisfied with their sexual lives whilst women over 50 years became less satisfied with their sexual lives as their age increased [90]. Nevertheless, the young women in our study were less satisfied with their sexual lives than women of the same age group in the population study. However, there was no difference in satisfaction with sexual life between the older women in paper I and the older women in the population study. The stigma for younger women of having a disorder often associated with being old may contribute to their dissatisfaction with their sexual life.

Sexual life in couples

In paper III, focused on the couples' sex lives, the great majority of both women and men considered sexuality to be somewhat or very important in their lives. This view was shared by 77% of the women and 86% of the men in the Swedish population study [90]. Overall, there was no difference in satisfaction with sexual life between the men in our study (paper I) and the men in the Swedish population study. In contrast, Bekker et al. found that men with a partner with UI had more erectile problems and were less satisfied with their sexual lives than men with continent partners [120]. In paper III we showed that sexual life was negatively impacted by the woman's UI and/or urgency according to about 20% of the men and twice as many of the women. Responses to the open-ended questions indicated that this negative impact was experienced differently by men and by women. The men did not seem to be disturbed by the woman's urinary leakage or by her frequent need to go to toilet. They seemed more concerned about the overall

negative impact of the urinary disorder on the woman's general wellbeing. In contrast, several women used strong negative language, describing themselves as disgusting, smelly, and worthless. Such self-deprecation together with the women's worry about urinary leakage during sexual activity make the negative impact on their sexual lives understandable. This is supported by a qualitative study, showing that OAB with or without UI had a profound impact on the sexual health of women, associated with a loss of self-confidence and self-image [129].

Urinary leakage during sexual activity

Of the women reported in paper III, 39% had urinary leakage during sexual activity. Others have reported similar numbers [130-132], however, the prevalence of urinary incontinence during sexual activity in clinical samples varies from 10% to 56% [133]. It has been suggested that urinary leakage is more likely to be related to vaginal penetration in women with SUI and to orgasm in women with DO [134, 135]. Among women in our study, leakage during sexual activity was most common during penetration and/or orgasm (paper II); however, we could not detect any differences between the diagnostic groups. This is in line with other researchers who could not detect any correlation between urodynamic diagnosis and leakage during orgasm or penetration [130, 136]. In a recent study with a large sample, in which 60% of women with UI reported urinary leakage during intercourse, different urodynamic diagnoses did not correlate to sexual function or to urinary leakage during penetration or orgasm [137]. Thus, the pathophysiological mechanisms behind female incontinence during intercourse remain unclear.

Only 22 of 38 men were aware of their partner's urinary leakage during sexual activity (paper III). The majority of the men who knew that their partner had urinary leakage during sexual activity did not consider the leakage to be a problem, but the majority of the women did. Despite this negative impact (mainly from the women's point of view), most of the couples were satisfied with their sexual lives. The fact that they had long-lasting relationships and were satisfied with their partner relationship probably contributed to their positive assessment of sexual life in general. On the whole, the concordance of answers within the couples was good. The only question for which men's and women's answers diverged notably was whether or not urinary leakage during sexual activity was a problem. The impairment of women's/couples' sexual lives may be assumed to be even worse in new or temporary relationships. This reasoning is supported by a qualitative study of women with OAB in which the single women expressed reluctance to begin a new relationship due to their OAB symptoms [129].

Need for information and advice

Information and advice concerning sexual life due to the woman's UI and urgency were needed and welcomed by some of the women and their men (paper III). The mates were generally content with their partner relationship, but it is not unreasonable to suppose that in poorer relationships the need for professional support might be greater. Healthcare professionals need to be aware of the fact that not only their female patient, but also her partner, may need support related to the women's UI. Some studies have concluded that negative dimensions of marital functions influence patients' health outcomes negatively [138, 139], and one report suggested that patients' physiological systems are directly affected by the emotional climate in the family and that family members' responses to the patient's disease and its management affect patients' self-care behaviours [140]. There are no similar studies on urinary disorders, but one can hypothesize that it might be helpful to involve partners in the management of patients whose treatment for UI and urgency symptoms may require a regime of behaviour changes, training programmes, and perhaps life-long medication.

Women who had a non-participating partner

Women with partners who did not participate in the study reported that they communicated less openly about their urinary problems with their partner (paper I). In another study comparisons between women with UI and their male partners showed that the women had more difficulty than their partners with communicating about sexual life and sensuality [120]. Perhaps this difficulty in communication meant that some of the women in the present study were also reluctant to deliver the questionnaire to their partner?

Patient-reported outcomes after TVT, TVT-O, and TOT

About two thirds of the women were "very satisfied" with the result of the operation (paper IV), although most studies report higher subjective cure rates than we found [141-145]. In our study a woman was defined as having UI after operation if she reported urinary leakage one to three times a month or more. The definition of cure varies in different studies, which may be one explanation of the divergent results. The present study reflects a common clinical situation in a heterogeneous group of women treated by a mix of experienced and inexperienced surgeons, which could explain our lower satisfaction rates. However, in a similar study from Norway 75% to 83% of the women were "very satisfied" with the result of their TVT, TVT-O, or TOT operation [146]. In our study, the options for satisfaction were "satisfied" and "very satisfied" and in the Norwegian study, the options were "some satisfaction" and "very satisfied". If "satisfied" and "very satisfied" responses

are combined in the present study, the results are similar to those of the Norwegian study. Thus, the different choice of words may explain the discrepancy. Differences could also be explained by the fact that the women in our study were slightly older.

There were fewer women with urinary leakage at follow-up in the TVT group than in the TOT group, yet there was no difference in satisfaction with the operation between these groups. This is in line with a review in which Novara et al. reported slightly higher objective cure rates for the retropubic technique than for TOT, although the subjective cure rates were similar [147]. Another study reported an objective cure rate of more than 70% after TVT and TVT-O, but only 61% of those patients were satisfied [148]. Conversely, in a meta-analysis comparing TVT, TVT-O, and TOT at 1 to 44 months follow-up, no significant differences in subjective and objective cure rates were found [149]. This demonstrates the complexity of evaluating and interpreting outcomes.

BMI as a risk factor

BMI was shown to be one of the risk factors for an unsuccessful result of operation (paper IV). Increasing BMI was associated with higher risks of UI and of not being “very satisfied” with the operation result at the 12-month follow-up. Noblett et al. found a strong correlation between intra-abdominal pressure and BMI and suggested that obesity may stress the pelvic floor and, thus, support the belief that obesity is a common factor in the development of SUI [150]. This seems to be a plausible explanation for our findings. There are, however, conflicting reports regarding cure rates after mid-urethral slings in obese women. In a study in women operated upon with either the retropubic or the transobturator technique, BMI did not influence the outcome [151]. Furthermore, TVT was not found to be less effective in women with BMI ≥ 30 kg/m² than in women with BMI < 30 kg/m² [152], but the follow-up time was short. Yet another study reported no differences in subjective improvement after TVT comparing normal weight, overweight, and obese women [153]. In contrast, in a large sample with a long-term follow-up (mean 5.7 years) after TVT, cure rate was found to be lower in women with BMI ≥ 35 kg/m² than in those with normal weight [154].

Age as a risk factor

Age was also shown to be a risk factor for UI, with increasing age associated with a higher risk of having UI or not being “very satisfied” with the operation result at follow-up (paper IV). This is supported by other researchers. For example, Hellberg et al. found lower cure rates after TVT in women older than 75 years than in younger women. Interestingly, women

older than 75 years had lower urethral closure pressure preoperatively but their urethral closure pressure was not correlated with their cure rate [154]. Rechberger et al. found age to be an independent risk factor for failure in women operated with retropubic or transobturator technique [151]. MUI and UUI are reported to increase with increasing age [7] and this might be one reason for lower success rates in older women.

Symptoms of urge incontinence as a risk factor

The risk of postoperative urinary leakage increased with the preoperative diagnosis of MUI and with preoperative urinary leakage in combination with urgency once a day or more (paper IV). Mid-urethral slings are designed to cure SUI, but there was a significant decrease in leakage and number of episodes not only of SUI but also of UUI. Because we did not have urodynamic diagnoses of the patients, the number of DO is unknown, but the majority of women reported both stress- and urge-induced leakage preoperatively. Only about one fifth were diagnosed with MUI. The women may have found it difficult to distinguish between different types of leakage, or the symptoms of UUI may have different causes. Studies have shown that urethral relaxation precedes bladder contraction in about 40% of women with detrusor instability and in other cases bladder contraction precedes any change in urethral pressure [155, 156]. In an effort to develop an empirically derived definition of MUI for use in research on incontinence outcomes, it was found that the proportion of women with MUI varied from 8% to 93% depending on the definition [157].

Impact of urinary leakage on QoL at follow-up

The negative impact of UI on family, social, and working life expressed preoperatively decreased in all these domains one year postoperatively, despite some remaining urinary leakage. This decline is probably due to the reduction in urge and stress incontinence episodes as well as the amount of leakage after surgery. This reasoning is in line with other studies reporting that the more severe the UI, the more harmful its effect on QoL [11, 108]. In the group of women with some remaining postoperative leakage, the negative impact of UI on sexual life had decreased significantly at follow-up, and coital incontinence was cured in 63% of women who had this symptom preoperatively (paper IV). Although coital incontinence was cured and the negative impact of UI on sexual life was decreased, it remains unclear whether women's overall satisfaction with sexual life was influenced. The effect of mid-urethral slings on sexual life has shown divergent results. Some report a negative impact [158, 159], some no significant change [160-162], and some a significant improvement [163-165]. However, it has previously been reported that women with coital incontinence had worse QoL scores

than women without coital incontinence in women with UI and/or OAB [132]. Thus, one can assume that the cure of coital incontinence should have a positive effect on overall QoL.

Methodological considerations

The questionnaires

Earlier studies have shown that questionnaires seem to provide more anonymity for reporting personal and sensitive information than interviews. Studies evaluating the quality of data from mailed questionnaires and telephone interviews showed a greater willingness to answer sensitive questions in mailed questionnaires [166, 167]. Thus, we considered the use of questionnaires a suitable approach. No appropriate questionnaires were available, however, that dealt with the partner relationships, psychosocial situations, and sexual lives of women with UI and/or urgency and their partners. Therefore, we constructed our own questionnaire incorporating questions from the Swedish population study, taken out of that larger context, which might cause some bias. Using the population from the Swedish population study, however, allowed us to make comparisons with a representative Swedish reference group.

The BFLUTS questionnaire we used was translated by a pharmaceutical company. In a later Swedish study the BFLUTS questionnaire was translated into Swedish and retranslated with only minor differences adjusted by a person with English as native language [168]. Although the original version has shown good validity and acceptable reliability, the Swedish version has not been tested for validity and reliability. However, we had previously used the BFLUTS questionnaire in a randomized placebo-controlled clinical trial [169] and found that the patients had no problems understanding and answering the questions.

Subjects in papers I–III

In papers I–III, 13% of the women ($n = 34$) did not answer the questionnaire although they had given their informed consent to participate in the study. The mean and median ages of the non-responders were 52 years and 50 years, respectively. The reason for this drop-out is not known. All the women in the questionnaire study (papers I–III) had contacted health care because of their UI or urgency. To what degree they were representative of all women with UI or urgency is debatable. The literature offers various reasons, but no consensus, for why or why not women seek health care for their urinary problems, e.g. fear of humiliation, embarrassment, perceived severity of the condition, or low QoL score. Also, women who did not understand Swedish

were not included and all who were included were Caucasians, therefore culture differences were not considered.

One of the aims of the questionnaire study was to increase understanding of the effects of female UI and urgency in the context of their living as part of a couple. Because the women's partners were not patients, their participation in the questionnaire study of the impact of female UI and urgency on the couples' lives depended exclusively on the primary assistance of the women themselves. Therefore, it is impossible to know how many women actually gave the questionnaire to their partner, and this sample of men and couples is likely affected by selection bias. Nevertheless, these men remain of great interest since they are 109 men who represent partners of patients with UI and urgency.

Excluded and missing subjects in paper IV

The exclusion of patients with coexisting faecal incontinence, severe disease, or concurrent gynaecological surgery may be important. The group of excluded women was older than the included group (table 8) and more affected by concurrent disease (74%) than the studied group (63%), thus their exclusion could falsely favour success rates. Based on earlier reports of the impact of faecal incontinence [170], prolapse [171, 172], and severe systemic diseases [173] on QoL, women with these conditions were excluded to avoid interference of these aspects on women's QoL and sexual lives. The women who had not answered the questionnaire at the 12-month follow-up or whose operation method was undefined were slightly younger (table 8) than the studied group and had the same degree of concurrent disease (62%) as the studied group. We have no reason to expect that the women with missing answers differed from those we studied.

Table 8. Age and BMI in excluded, missing, and studied groups in paper IV

	Excluded group (n = 1327)	Missing group (n = 701)	Studied group (n = 3334)
Age (years)			
mean (median, range)	59.3 (60, 20–92)	54.8 (53, 23–94)	55.5 (55, 23–89)
BMI (kg/m ²)			
mean (median, range)	27.6 (26.8, 16–47)	26.9 (26.1, 19–44)	26.6 (25.9, 17–48)

Strengths and limitations paper IV

The strengths of paper IV are the large number of patients and all the information gained from the patient-reported outcomes. The study reflects a clinical situation including a broad spectrum of surgeons and patients of all ages. One limitation is that it was not a randomized study; the choice of sling procedure was left to the individual clinician, which may have caused uneven distribution (e.g. if one method was preferred over another for obese or other groups of women). Furthermore, the operation groups were not matched, although discrepancies were adjusted for. On the other hand, in randomized trials, only selected surgeons participate, which may result in expert bias, which is not a risk in this study. Due to the lack of objective cure measurements, the results depend solely on subjective outcomes. In addition, the follow-up time was 12 months; a longer follow-up time would be desirable.

Suggested revision of questions in the Gynop-register

The questions in the Gynop-register about whether sexual life and other QoL issues were affected by the woman's UI were designed to be answered postoperatively only by women who still had some urinary leakage. It was therefore not possible to study the effect of the surgery on these parameters in the whole group of women who underwent surgery for UI. A revision of these questions has started to enable the monitoring of sexual life and other QoL aspects in the whole group of women undergoing surgery for UI. The specific question regarding sexual pain is already asked of all women before and after operation, however, it needs to be revised.

Future perspectives

The results of this thesis indicate that there is still a lack of knowledge in several areas of female UI and urgency that need to be explored further. UI and urgency, for example, were found to have a more profound effect on young women and their partners than older women and their partners. That finding will be important to study further in larger groups. In addition, the lack of information about the impact of UI and urgency on the lives of single women and homosexual couples is a shortcoming that needs attention.

Some of the patients and their partners expressed a need for information and advice about their sexual lives in the context of the woman's UI and/or urgency. A qualitative study to determine the appropriate and most helpful type or content of information and advice for patients and their partners would therefore be enlightening. It would be very gratifying to explore the involvement of partners in the management of patients with UI and urgency, which can require a regime including behaviour changes, training

programmes, and sometimes life-long medication. It would also be of interest to elucidate any effects of treatment of UI and urgency on a couple's relationship and sexual life.

Many women with SUI are cured after incontinence surgery and the negative impact of UI on their sexual life is then eliminated. But does the cure of UI and coital incontinence alter their overall satisfaction with their sexual life? And what about the group of women we excluded from the register study: do their results differ from the women who were included?

Information via the internet about diseases and conditions is timely, and instructions for self-treatment of UI are accessible and can be helpful. However, the pros and cons of efforts to streamline health care for this condition need to be explored to avoid backlashes and errors in this relatively neglected group of women. General knowledge about urinary symptoms can of course increase with web-based information, but does this knowledge really lead to improvements for the individual with urinary symptoms, or are we at risk of making incontinence to an even more hidden problem than it already is? Is there a risk that women will blame themselves if they fail with self-care and thus, through embarrassment and avoidance of health care, miss another treatment they may need? The availability and patients' use of information on the internet needs to be scientifically evaluated.

In times of limited healthcare resources efforts must be made to identify the most cost-effective level of care. Therefore, it is essential to evaluate not only the outcomes of treatment, but also the current state of knowledge in health care professionals concerning female UI and urgency.

General conclusions

- Female UI and urgency impair QoL in both younger and older women, although younger women seem most affected. UI and urgency also have negative effects on women's partner relationships and their partner's lives. It is essential that health care providers learn more about the impacts of UI and urgency in order to meet the needs of patients and their partners.
- Sexual life in many women, especially younger women, and also some of their male partners is negatively affected by the woman's UI and/or urgency.
- One third of women with UI and/or urgency experience urinary leakage during sexual activity. Few men are worried about their female partner leaking urine during sexual activity; most men do not consider this a problem, but the majority of the women do.
- Overall, answers within the couples have high concordance.
- Patient satisfaction with the result of the operation does not differ between TVT, TVT-O, and TOT, although TVT has a higher success rate than TOT.
- Despite urinary leakage one year postoperatively, half of the women are satisfied with the result of the operation, and the negative effects of UI on their QoL and sexual lives have decreased.
- Older women and women with a high BMI, a diagnosis of MUI, or a history of urinary leakage in combination with urgency are at risk for lower rates of successful operation. It is a challenge, therefore, to inform patients adequately about what surgery can and cannot accomplish in order to give them realistic expectations.

Increased knowledge and insight about the complexity of living with female UI and/or urgency, both before and after treatment, for both the women and their partners could lead to improved information and better care for these groups of patients.

Acknowledgements

I would like first to thank all the women and men who generously contributed to these studies by answering all of our questions.

I would also like to express my sincere gratitude to:

Professor **Ann Lalos**, my supervisor. With your scientific expertise, accuracy, and friendship you supported me, led me forward, and kept me on the straight and narrow path of science. It has been a joy to work with you and your guidance made this thesis possible.

Professor Emeritus **Othon Lalos**, my co supervisor and mentor. You led me into urogynecology. Without you, I would never have become a urotherapist – and certainly not a PhD student! You have generously shared your clinical experience and your scientific knowledge with me.

Senior Lecturer **Håkan Lindkvist**, my co supervisor. Through your skill and your patience with statistical issues, you taught me a great deal and contributed a lot to this thesis. Thank you for your friendship and for being there to support me.

Mats Löfgren, co-writer. Your kind support and valuable insights into the Gynop-register made paper IV possible.

Lena Broddeskog, Mona Degerman, Margareta Holmberg, and Lena Karlsson, my urotherapist colleagues. Your help with collecting material for papers I–III was invaluable.

Sigrid Nyberg, my colleague, for careful reading and valuable input, for scientific discussions, for sharing bad times and good times, your support means a lot to me. Thanks for being my friend!

Mojgan Pakbaz, for reading and commenting on my thesis, for friendship and many happy talks about dresses and other important issues.

Birgitta Renström, for always giving me a helping hand with data support and for helping me when I was fiddling with fitting the thesis into the template. You have kindly saved my day several times!

Per-Åke Holmgren, Elisabeth Ekholm and Karin Svensson, former and present Heads of the Department of Obstetrics and Gynaecology. Thank you for supporting my scientific work and for allowing me the time to carry it out.

Erika Timby, Helena Hedberg and Margareta Persson, for your encouragement and valuable tips.

Birgit Ericson and **Carina Jonsson**, for many pleasant talks and moments, and for your practical help during the preparation of this thesis.

Ann-Kristin Norberg, for kindly doing parts of the clinical work, which gave me time to work on the thesis.

All staff at the clinical and scientific divisions of the Department of Obstetrics and Gynaecology for your friendly interest.

Emma and **Johan**, my children (although you are grown up now). You both make me so proud and happy, I am grateful that I am your mother. Special thanks to you, Emma, for reading and commenting on the texts in the thesis and cheering me up!

Yngve, my love since we were teenagers and my very best friend. Thank you for always believing in me, not only during this time, but always. Thank you for being there for me, for all of your care, for all of the delicious meals, and for handling so much of the housecleaning and everything else that needed to be done.

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Appendix

Frågeformulär (förutom BFLUTS) använda i artikel I-III

1. Hur lång är du? cm
2. Hur mycket väger du? kg
3. Röker du? Nej Ja, hur många cigaretter/dag? st
- 4a. Hur många koppar kaffe dricker du normalt per dag? st
- b. Hur många koppar te dricker du normalt per dag? st

5. Har du genomgått någon av dessa operationer och i så fall när?

- Framfallsoperation. Nej Ja, år
- Operation för urinläckage. Nej Ja, år
- Opererat bort livmodern. Nej Ja, år
- Opererat bort äggstockarna. Nej Ja, år
- Annan operation i magen/underlivet, vilken?År

6. Lider du just nu av någon/några av nedanstående sjukdomar/besvär?

- Diabetes Nej Ja
- Hjärtsjukdom Nej Ja
- Lungsjukdom Nej Ja
- Neurologisk sjukdom Nej Ja
- Förstoppning Nej Ja
- Diarréer Nej Ja
- Analinkontinens Nej Ja
- Annat, vad?

7a. Har du haft urinvägsinfektion som krävt behandling?

- Nej Ja, 1 ggr Ja, 2 eller flera ggr Ja, har kronisk infektion (mer än 3ggr/år)

b. Om ja på fråga 7 a) När hade du urinvägsinfektionen/erna?

- Som barn (0 - 12 år) Nej Ja
- Som tonåring (13 - 19år) Nej Ja
- Som vuxen (20 år -) Nej Ja
- Senaste året Nej Ja

8. Besväras du av urinträngningar (= ett starkt och svårkontrollerbart behov av att behöva kissa)?

- Nej Ja, måttliga, sedan hur länge? Ja, starka, sedan hur länge?

9a. Besväras du av urinläckage (= ofrivillig urinavgång)?

Nej Ja, sedan hur länge?

Om du svarat Nej på fråga 9 a), gå vidare till fråga nr 10

b. Om ja på fråga 9 a): När inträffar detta?

I samband med urinträngningar

(en stark känsla av att behöva kissa) Nej Ja

Vid hosta/skratt och liknande Nej Ja

Vid fysisk ansträngning som t ex

tunga lyft, gymnastik Nej Ja

Vid vila Nej Ja

Annat tillfälle, när?

c. Om ja på fråga 9 a):Använder du inkontinensskydd (binda, trosskydd)?

Nej Ja, vilken sort?Antal skydd/dygn?

10. Beskriv, med egna ord, hur du upplever dina problem med blåsan och vad som är mest besvärande

11. Hur ofta har du under de senaste fyra veckorna pga. dina blåsbesvär

	Aldrig	sällan	ibland	ofta	alltid
a. känt oro för att lukta illa?	<input type="checkbox"/>				
b. känt dig mindre attraktiv?	<input type="checkbox"/>				
c. varit orolig för att andra ska upptäcka dina besvär?	<input type="checkbox"/>				
d. känt oro för att det skulle bli fläckar hemma hos andra eller på jobbet?	<input type="checkbox"/>				
e. behövt byta kläder?	<input type="checkbox"/>				

12. Har dina menstruationer upphört?

Nej Ja, sedan hur länge?antal år

13. Besväras du nu för tiden av någon/något av nedanstående?

a. Svette

Nej Ja mycket, sedan hur länge? Ja måttligt, sedan hur länge?

b. Blodvullningar?

Nej Ja mycket, sedan hur länge? Ja måttligt, sedan hur länge?

c. Torra och/eller sköra slemhinnor i underlivet?

Nej Ja mycket, sedan hur länge? Ja måttligt, sedan hur länge?

14a. Använder du någon medicin som innehåller kvinnligt hormon?

Nej Ja

b. Om ja på fråga 14 a): Vad?

- östroge-tabletter p-piller
östrogeplåster slidkräm
östrogensalva slidpiller
gulkroppshormon (progesteron)
annat, vad?.....

15. Använder du andra mediciner?

Nej Ja, vilka?

16. Har du varit gravid?

Nej Ja, hur många gånger?

Om du svarat Nej på fråga nr 16, gå vidare till fråga nr 20

17. Om ja på fråga 16): Har du fött barn?

Nej Ja, ett Ja, två Ja, tre Ja, fyra eller fler

Om du svarat Nej på fråga nr 17, gå vidare till fråga nr 20

18. Hur gammal var du när du födde ditt första barn?år

19a. På vilket sätt är du förlöst?

Kejsarsnitt.....antal gånger Vaginalt (genom slidan).....antal gånger

Om du är förlöst vaginalt:

fick du stora bristningar? Nej Ja
användes sugklocka? Nej Ja
användes tång? Nej Ja
vägde barnet mer än fyra kg? Nej Ja

20. Vad har du för utbildning? Tänk på den högsta utbildningen du genomfört!

- Ej genomgått obligatorisk skola
Obligatorisk skola (folkskola, enhetsskola, grundskola)
Påbyggnadsskola med praktisk inriktning (yrkesskola, lärlingsutbildning, 2-årig gymnasieskola)
Påbyggnadsskola med teoretisk inriktning (realskola, flickskola, folkhögskola, gymnasium)
Universitet eller högskola
Annan utbildning. Vilken?

21. Vilken är din nuvarande huvudsakliga sysselsättning?

- Förvärvsarbete, heltid som:
- Förvärvsarbete, deltid som:
- Hemarbetande
- Studerande , till:
- Arbetslös
- Folkpensionär
- Sjukpensionär, helt
- Sjukpensionär, delvis
- Sjukskriven f n, annars:
- Annat:

Om du inte har ett förvärvsarbete, gå till fråga 25

22a. Påverkar dina problem med blåsan ditt förvärvsarbete?

- Nej, inte alls
- Ja, mycket
- Ja, något

Om ja, kan du beskriva hur?

Påverkar ditt förvärvsarbete dina problem med blåsan?

- Nej, inte alls
- Ja, mycket
- Ja, något

Om ja, kan du beskriva hur ?

23a. Kan du gå på toaletten när du vill när du arbetar?

- Ja
- Nej, p g a

b. Om nej; är detta ett problem för dig?

- Nej, inget problem
- Ja, ett litet problem
- Ja, ett ganska stort problem
- Ja, ett stort problem

24. Har du varit sjukskriven pga. dina problem med blåsan under det senaste året?

- Nej
- Ja, hur många dagar?

25. Är det något du vill kommentera eller förklara så gör det gärna här:

Frågeformulär om parrelation och sexualliv

Formuleringarna i partners formulär presenteras här inom parentes.

1. Civilstånd:

- gift
- sambo
- stadigt förhållande men ej sambo
- ensamstående, gå vidare till fråga nr 12

2. Sedan hur lång tid har du detta förhållande?

- mindre än 6 månader
- 6-12 mån
- 1-5 år
- 6-10 år
- 11 år eller mer

3. Är parförhållandet med en kvinna eller man? (frågan ställdes endast till patienten)

- kvinna
- man

4. Kan du och din partner prata öppet och rakt med varandra om ert förhållande?

- ja, helt
- ja, delvis
- nej

5. Brukar din partner visa värme/tillgivenhet gentemot dig?

- ja, ofta
- ja, ibland
- nej

6. Har du och/eller din partner under det senaste året på allvar diskuterat att gå ifrån varandra?

- nej
- ja

7. Påverkas ert parförhållande negativt på något sätt av dina (din partners) besvär med urinblåsan?

- nej, inte alls
- ja, något
- ja, mycket

Om ja, kan du beskriva hur?.....

8. Kan du och din partner prata öppet och rakt om innebörden av dina (hennes) besvär med urinblåsan?

- ja, helt
- ja, delvis
- nej

9. Påverkas era gemensamma aktiviteter (ex. fritidsaktiviteter, semesterresor,) negativt av dina (din partners) besvär med urinblåsan?

- nej, inte alls
- ja, något
- ja, mycket

Om ja, kan du beskriva hur?.....

10. Tycker du att kroppskontakten (närhet, intimitet, tillgivenhet och värme) mellan dig och din partner har förändrats sedan du (hon) fick besvär med urinblåsan?

- ökat
- minskat
- ingen skillnad

11. Kan du och din partner prata öppet och rakt om ert sexuella samliv?

- ja, helt
- ja, delvis
- nej

12. Hur ofta känner du sexuell lust?

- aldrig
- sällan
- ibland
- ofta

13a. Om du jämför din sexuella lust idag med tiden innan du (din partner) fick besvär med urinblåsan, är den då

- mycket större
- något större
- oförändrad
- något mindre
- mycket mindre

b. Om lusten har förändrats, är det ett problem för dig?

- nej, inget problem
- ja, ett litet problem
- ja, ett ganska stort problem
- ja, ett stort problem

I samband med samlag och som en del av ett samlag kan människor göra olika saker. När du svarar på dessa frågor ber vi dig således tänka på att för många människor innebär samlag även annat än enbart en mans penis i en kvinnas slida.

Med **samlag** menar vi när två personer är sexuellt tillsammans (har sex).

14a. Det händer att samlaget är förenat med smärta i könsorganen.

Har detta förekommit i ditt sexualliv under de senaste 12 månaderna?

- har ej haft samlag senaste 12 månaderna
- hela tiden
- nästan hela tiden
- ganska ofta
- ganska sällan
- nästan aldrig
- aldrig

b. Har detta varit ett problem i ditt sexualliv under de senaste 12 månaderna?

- har ej haft samlag senaste 12 månaderna
- hela tiden
- nästan hela tiden
- ganska ofta
- ganska sällan
- nästan aldrig
- aldrig

15a. Det händer att kvinnan har svårt att få utlösning/orgasm.

Har detta förekommit i ditt sexualliv under de senaste 12 månaderna?

- har ej haft samlag senaste 12 månaderna
- hela tiden
- nästan hela tiden
- ganska ofta
- ganska sällan
- nästan aldrig
- aldrig

b. Har detta varit ett problem i ditt sexualliv under de senaste 12 månaderna?

- har ej haft samlag senaste 12 månaderna
- hela tiden
- nästan hela tiden
- ganska ofta
- ganska sällan

nästan aldrig

aldrig

16a. Har din orgasmförmåga förändrats på grund av dina (din partners) besvär med urinblåsan?

nej

ja, ökat

ja, minskat

ja, upphört

vet inte

b. Om orgasmförmågan har förändrats på grund av dina (din partners) blåsbesvär, är detta ett problem för dig?

nej, inget problem

ja, ett litet problem

ja, ett ganska stort problem

ja, ett stort problem

17a. Det händer att kvinnans slida inte blir tillräckligt fuktig.

Har detta förekommit i ditt sexualliv under de senaste 12 månaderna?

har ej haft samlag med penis i slidan senaste 12 månaderna

hela tiden

nästan hela tiden

ganska ofta

ganska sällan

nästan aldrig

aldrig

b. Har detta varit ett problem i ditt sexualliv under de senaste 12 månaderna

har ej haft samlag med penis i slidan senaste 12 månaderna

hela tiden

nästan hela tiden

ganska ofta

ganska sällan

nästan aldrig

aldrig

18a. Det händer att samlag inte leder till utlösning för mannen.

Har detta förekommit i ditt sexualliv under de senaste 12 månaderna?

har ej haft samlag senaste 12 månaderna

hela tiden

nästan hela tiden

- ganska ofta
- ganska sällan
- nästan aldrig
- aldrig
- inte aktuellt med en man i mitt sexualliv (svarsalt. endast till kvinnan)

b. Har detta varit ett problem i ditt sexualliv under de senaste 12 månaderna?

- har ej haft samlag senaste 12 månaderna
- hela tiden
- nästan hela tiden
- ganska ofta
- ganska sällan
- nästan aldrig
- aldrig
- inte aktuellt med en man i mitt sexualliv (svarsalt. endast till kvinnan)

19. Människor kan ha olika uppfattning om hur viktig sexualiteten är. Hur viktig är sexualiteten i ditt liv?

- inte alls viktig
- ganska oviktig
- varken eller
- ganska viktig
- mycket viktig

20. Påverkas ditt sexualliv negativt av några besvär eller sjukdomar som du har?

- nej, inte alls
- ja, något
- ja, mycket

Om ja, av vad?.....

21. Påverkas det sexuella samlivet negativt av sjukdom eller besvär som din partner har?

- har inte stadigvarande partner (svarsalt. endast till kvinnan)
- nej, inte alls
- ja, något
- ja, mycket

Om ja, av vad?.....

22. Påverkas ditt sexualliv negativt på grund av dina (din partners) besvär med urinblåsan?

- nej, inte alls
- ja, något
- ja, mycket

Om ja, kan du beskriva hur?

23. Känner du, på grund av dina (din partners) besvär med urinblåsan, ett behov av information och råd när det gäller ditt sexualliv?

- nej
- ja, ett visst behov
- ja, ett stort behov
- tveksam, vet ej

24. Känner du oro för att (din partner ska) läcka urin under samlag?

- har aldrig samlag
- nej, aldrig
- ja, ibland
- ja, ofta
- ja, alltid

25a. Händer det att du (din partner) läcker urin i samband med samlag?

- har aldrig samlag
- nej, aldrig
- ja, ibland
- ja, ofta
- ja, alltid

b. Om ja på fråga 25a) är det ett problem för dig?

- nej, inget problem
- ja, ett litet problem
- ja, ett ganska stort problem
- ja, ett stort problem

c. Om ja på fråga 25a) när läcker du (din partner) urin (mer än ett kryss kan väljas)?

- vid förspel
- vid clitorisstimulering
- vid orgasm
- vid penetration (penis i slidan)
- annat, vad?

d. Om ja på fråga 25a) brukar du vidta några åtgärder för att minska risken för urinläckage?

nej

ja, vad?.....

26. Hur många gånger har du haft samlag under de senaste 30 dagarna?

Tänk på de senaste 30 dagarna även om de inte varit typiska för dig!

.....ggr

27. Hur ofta brukade du vanligtvis ha samlag innan du (din partner) fick besvär med urinblåsan?

Tänk på året innan du fick besvär med urinblåsan.

.....ggr / vecka ggr / mån ggr / år aldrig

28. Hur ofta har du vanligtvis samlag nu för tiden?

.....ggr / vecka ggr / mån ggr / år aldrig

29. Hur ofta skulle du vilja ha samlag?

.....ggr / vecka ggr / mån ggr / år aldrig

30. Hur många gånger har du onanerat de senaste 30 dagarna? Tänk på de senaste 30 dagarna även om de inte varit typiska för dig!

31. Hur värderar du ditt sexualliv som helhet? Tycker du att det är

mycket tillfredsställande

ganska tillfredsställande

varken tillfredsställande eller otillfredsställande

ganska otillfredsställande

mycket otillfredsställande

Nu följer ett antal frågor om hur tillfreds du är med olika aspekter av ditt liv samt därefter ytterligare frågor om din aktuella situation.

32. För var och en av dessa frågor vill vi att du ringar in en siffra från 1 till 6, där 1 betyder mycket otillfredsställande och 6 mycket tillfredsställande.

1 = mycket otillfredsställande

2 = otillfredsställande

3 = ganska otillfredsställande

4 = ganska tillfredsställande

5 = tillfredsställande

6 = mycket tillfredsställande

Livet är i allmänhet	1	2	3	4	5	6
Yrkes-/sysselsättnings- situationen är	1	2	3	4	5	6
Ekonomi är	1	2	3	4	5	6
Fritidssituationen är	1	2	3	4	5	6
Kontakterna med vänner och bekanta är	1	2	3	4	5	6
Sexuallivet är	1	2	3	4	5	6
Förmågan att klara mig själv (gäller klädsel, tvätt/bad, gångförmåga o dyl.) är	1	2	3	4	5	6
Familjelivet är	1	2	3	4	5	6
Parförhållandet är	1	2	3	4	5	6
Kroppsliga hälsan är	1	2	3	4	5	6
Psykiska hälsan är	1	2	3	4	5	6

Är det något du vill kommentera eller förklara så gör det gärna här: