Hovedoppgave

NTNU
Norges teknisk-naturvitenskapelige universitet
Fakultet for medisin og helsevitenskap
Institutt for samfunnsmedisin og sykepleie

Silje Kristine Sveen Ulven

Pelvic floor disorders and impact on sexual function in sexually active women and non-sexually active women

Hovedoppgave i Medisin
Veileder: Signe Nilssen Stafne
Medveileder: Susan Saga

Januar 2022

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Kunnskap for en bedre verden

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Forord

Denne hovedoppgaven ble utført ved Institutt for samfunnsmedisin og sykepleie (ISM) ved Norges teknisk-naturvitenskapelige universitet (NTNU) under forskningsterminen IIIA på medisinstudiet. Arbeidet strakte seg fra august 2021 til desember 2021.

Oppgaven har gått ut på å undersøke seksualfunksjonen hos kvinner med bekkenbunnslidelser. Oppgaven er skrevet på engelsk i artikkelformat. Dette er et videre arbeid på den norske oversettelsen og valideringen av PISQ-IR ledet av Susan Saga i samarbeid med Signe Nilssen Stafne og Tone Prøsch-Bilden. Datainnsamlingen i valideringsstudien er avsluttet ved St. Olavs Hospital Trondheim Universitetssykehus, men pågår fortsatt ved Universitetssykehuset i Nord-Norge.

Jeg ønsker å rette en stor takk til hovedveileder, Signe Nilssen Stafne, for støttende, inspirerende og kunnskapsrik veiledning gjennom hele prosessen. Hun har bidratt med et godt arbeidsmiljø, oppmuntring, tålmodighet og imøtekommenhet under hele arbeidet. Jeg vil også rette stor takk til biveileder Susan Saga som har bidratt med god hjelp, statistikk-kunnskap og gode diskusjoner.

Takk til gynekologisk og kirurgisk poliklinikk på St. Olavs Hospital Trondheim Universitetssykehus som har bidratt med utdeling av spørreskjemaene.

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Silje Kristine Sveen Ulven

Stud.med.

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Abbreviations

AI: Anal incontinence

CI: Confidence interval

CRADI-8: Colorectal Anal Distress Inventory-8

ICIQ-UI SF: International Consultation on Incontinence Questionnaire-UI Short Form

NSA: Not sexually active

PFD: Pelvic floor disorder

PFDI-20: The Pelvic Floor Distress Inventory Questionnaire-20

PISQ-IR: The Pelvic Organ Prolapse Incontinence Sexual Questionnaire, IUGA-Revised

POP: Pelvic Organ Prolapse

POPDI-6: Pelvic Organ Prolapse Distress-6

SA: Sexually active

SD: Standard deviation

St. Marks: St. Marks incontinence score

UDI-6: Urinary Distress Inventory-6

UI: Urinary incontinence

Domain specific subscales:

AO: Arousal/orgasm

CI: Condition impact

CS: Condition-specific

D: Sexual desire

GQ: Global quality

PR: Partner-related

Abstract

Background: Pelvic floor disorders such as urinary-, anal incontinence and pelvic organ prolapse are common and often associated with reduced quality of life and impaired sexual function. The Pelvic Organ Prolapse Incontinence Sexual Questionnaire, IUGA-Revised (PISQ-IR) has been validated to measure sexual function in women with pelvic floor disorders.

Aim of the study: The overall aim of this study is to describe how a population of Norwegian women with pelvic floor disorders perceive their sexual function. More specific, we want to describe 1) which factors are associated with not being sexually active and 2) which factors are negatively associated with sexual function in sexually active women with pelvic floor disorders.

Methods: This is a secondary descriptive analysis of data collected during the validation of the Norwegian translation of PISQ-IR. Non-pregnant women with symptoms of pelvic floor disorders who were referred to the gynecological/surgical outpatient clinic at St. Olavs Hospital, Trondheim University Hospital were invited to participate in the study. Participants were categorized as sexually active or not sexually active based on self-report, and completed PISQ-IR, in addition symptom specific pelvic floor disorder scoring tools (ICIQ-UI-SF, St. Marks and PFDI-20).

Results: Of 132 patients, 94 (71%) women reported being sexually active (with or without a partner), and 38 (29%) reported not being sexually active. Not sexually active women were older ($p<0.001$), more menopausal ($p=0.001$), had higher BMI ($p=0.041$), a shorter duration of symptom debut ($p=0.009$) and reported a higher level of POP distress ($p=0.047$). Furthermore, multivariable logistic regression analysis demonstrated that being menopausal was associated with not being sexually active (OR 4.3 [95% CI: 1.7, 10.6], $p=0.002$). In sexually active women, a multivariable linear regression analysis demonstrated that colorectal distress was associated with reduced sexual function, (PISQ-IR total score), of which sexual function was reduced by 0.18 points for each point on CRADI-8.

Conclusions: Menopause was associated with not being sexually active. For sexually active women, only colorectal distress was associated with negative impact on sexual function.

Introduction:

More than one-third of middle aged women report at least one pelvic floor disorder (PFD) (1). The most common types of PFD are urinary incontinence (UI), anal incontinence (AI) and pelvic organ prolapse (POP). UI is defined as “any complaint of involuntary loss of urine” (2). The overall prevalence in women is 25% (3). AI is defined as “the involuntary loss of flatus, liquid or stool that is a social or hygienic problem” (4). The prevalence of AI in the female population is 19% (5). POP is defined as the descent of the posterior or anterior vaginal wall, the vault of the vagina or the uterus (cervix). The symptoms most often occur when the prolapse is at a level or further down than the hymen, and often cause nonspecific symptoms such as vaginal bulging, back pain, pelvic pressure or increased feeling of heaviness (6). Anatomical prolapse is diagnosed in up to 50% of parous women, of which 20% report symptoms (7).

UI, AI and POP often occur concomitantly, and these PFD both share and have unique risk factors (8). Pregnancy and childbirth are established risk factors, possibly due to pregnancy-related mechanical and hormonal changes, and delivery-related damage to the pelvic floor muscles, connective tissue and nerves (9). In particular multiparity, vaginal delivery, instrumental delivery and childbirth trauma are the main causes of UI, AI and POP. PFD as symptom of obstetric injury can occur both immediately after childbirth and in some cases after a latent period. This delay may be due to hormonal changes after menopause and poorer pelvic floor function (10). Obesity, increasing age, menopause, and smoking also appear to be common risk factors for PFD (11). Increased intraabdominal pressure such as chronic cough, constipation and heavy lifting are common causes for UI and POP (11, 12).

PFD is associated with a considerable reduction in women´s psychological, social and sexual function (11). The impact on sexual function is less studied, however, UI is found to impact different sexual domains, such as desire, pain and orgasm, loss of self-confidence and even abandonment of sexual intercourse (13), while AI is associated with shame, anxiety, depression (14) and higher rates of poorer sexual function (15). POP can impact sexual function in terms of loss of self-confidence, abandonment of sexual intercourse, pain during intercourse and difficulties relating to partner (13).

Sexual health is according to the World Health Organization defined as “a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity” (16). Sexual functioning is defined as “absence of difficulty moving through the stages of sexual desire, arousal, and orgasm, as well as subjective satisfaction with the frequency and outcome of individual and partnered sexual behavior” (17). Thus, sexual function is complex and female sexual dysfunction consists of physiological, anatomical, psychological and social-interpersonal components. The most commonly used definition of female sexual dysfunction includes ”persistent reduction in sexual desire and arousal, difficulty in achieving an orgasm or feeling of pain during intercourse” (18). Although sexual activity differs between populations, the number of women experiencing sexual dysfunctions is high (19). In a recent review paper, the prevalence of sexual dysfunction was reported to be 30-50% in the general female population, respective 50-83% in women with PFD (11). In one study, as many as 64% of women referred to an urogynecological department reported sexual dysfunction (20).

Women's sexuality has recently emerged as an important issue after years of neglect (18). Further, knowledge on how women with PFD perceive their sexual function is scarce. Verbeek et al. (11) concluded that most studies to this date have focused on anatomic rather than functional outcomes, and that there is urgent need for further research on the effects of treatment for PFD on sexual function. However, a symptom specific valid and reliable questionnaire is essential to explore this. In 2013 the International Urogynecological Association developed The Pelvic Organ Prolapse Incontinence Sexual Questionnaire, IUGA-Revised (PISQ-IR) (21), which is a 20-condition specific validated self-reported questionnaire. The PISQ-IR addresses both women who consider themselves as sexually active (with or without a partner) and not sexually active. In 2020, PISQ-IR was translated into Norwegian and is now in the process of being validated in the Norwegian female population.

This is a planned secondary study. The overall aim is to describe how a population of Norwegian women with PFD perceive their sexual function. More specific, we want to describe 1) which factors are associated with not being sexually active and 2) which factors are negatively associated with sexual function in sexually active women with PFD.

Method:

Participants & study design:

This is a secondary and descriptive analysis of data collected during validation of the Norwegian translation of The Pelvic Organ Prolapse Incontinence Sexual Questionnaire, IUGA-Revised (PISQ-IR) (21). Recruitment period were June 2020 to June 2021. Eligible study participants were non-pregnant women >18 years, able to read Norwegian and with symptoms of UI, AI or POP referred to the gynecological or surgical outpatient clinic at St. Olavs Hospital, Trondheim University Hospital. Women with vulvodynia, painful bladder syndrome or chronic pelvic pain for longer than six months were excluded. An invitation to participate (Appendix 1) and the questionnaire (Appendix 2) were sent to eligible women with a prepaid envelope along with the letter of appointment for first hospital visit.

Outcome variables:

The primary outcome was sexual function assessed with The Pelvic Organ Prolapse Incontinence Sexual Questionnaire, IUGA-Revised (PISQ-IR) (22). PISQ-IR is a 20-condition specific validated assessment instrument developed in 2013 by the International Urogynecological Association(21). The revised version is based on a multicultural framework and provides a reliable instrument for use in many cultures. PISQ-IR was translated from English to Norwegian through several steps: The first step involved translation of the questionnaire by a bilingual translator from English to Norwegian. The second step involved testing for comprehensibility, readability and equivalence through cognitive interviews with 10 women with PFD recruited from pelvic floor training classes in the physiotherapy department at the hospital. Third, opinions from multidisciplinary clinical PFD experts were obtained (One urogynecologist, one nurse, two physiotherapists and a sexologist). Fourth, another 10 cognitive interviews were conducted with women with PFD in order to test comprehensibility, readability and equivalence once again. Between step 2 and step 4, discrepancies were identified and amended. Fifth, once the final wording was established for each question, another independent bilingual translator translated the questionnaire back into English. Sixth, the IUGA Translation Working Group reviewed and approved this version of the questionnaire. The Norwegian translation is in process of being validated for psychometric properties for the Norwegian female population.

Through PISQ-IR, respondents define themselves as not sexually active (NSA) or sexually active (SA). The NSA is further divided into four domain-specific subscales, while there are six domain-specific subscales for SA (23) (Table 1). The domains for NSA include condition-specific (NSA-CS), partner-related (NSA-PR), condition impact (NSA-CI) and global quality (NSA-GQ). Domains for SA women include arousal/orgasm (SA-AO), condition-specific (SA-CS), global quality (SA-GQ), partner-related (SA-PR), sexual desire (SA-D) and condition impact (SA-CI).

Table 1. *PISQ-IR domain-specific subscales with related questions*

NSA – not sexually active		**SA – sexually active**	
Domain	***Related questions***	***Domain***	***Related questions***
CS: Condition-specific reasons for not being active	Q2c: Condition impact Q2d: Other health reason Q2e: Pain	AO: Assessment of arousal, orgasm	Q7: Sexually aroused Q8a: Fulfilled Q10: Orgasm intensity Q11: Pain
PR: Partner-related reasons for not being active	Q2a: No partner Q2b: No interest	PR: Assessment of partner-related impacts	Q13: Lack desire Q14a: Desire Q14b: Frequency
GQ: Global quality rating of sexual quality	Q4a: Satisfaction Q4b: Adequacy Q5a: Frustration Q6: Bothersome	CS: Assessment of condition specific impacts on activity	Q8b: Shame Q8c: Fear Q9: UI/FI with activity
CI: Condition impact on sexual quality	Q3: Fear Q5b: Inferior Q5c: Angry	GQ: Global quality rating of sexual quality	Q19a: Satisfaction Q19b: Adequate Q19c: Confidence Q20a: Frustration
		CI: Condition-specific impact on sexual quality	Q18: CS fear restrict Q20b: Inferior Q20c: Embarrassed Q20d: Angry
		D: Assessment of sexual desire	Q15: Wanting more Q16: Frequency desire Q17: Rate desire

As recommended, a transformed sum method were used to score the PISQ-IR domain-specific sub-scales (23). Each domain gives a score between 0-100. In the NSA-group, a higher score indicates a poorer sexual function, while in SA, a higher score indicates a better sexual function.

Explanatory variables were symptoms and severity of PFD and demographic data. UI was assessed using the International Consultation on Incontinence Questionnaire-UI Short Form (ICIQ-UI SF), an outcome measure developed to assess prevalence, severity, impact on quality of life and type of leakage. The short form has demonstrated satisfactory validity, reliability and sensitivity (24). ICIQ-UI SF gives a score between 0-21, where a higher score indicates more severe symptoms. Symptoms severity was categorized into "slight" (1-5 points), "moderate" (6-12 points), "severe" (13-18 points) and "very severe" (19-21 points) (25). Severity of AI was assessed with the widely used St. Marks incontinence score (26). The St. Marks score assesses frequency of stool and gas leakage, impact on daily life, urgency, pad use and use of constipating medication. The St. Marks score gives a score between 0-24 with higher scores indicating more symptoms. The severity of symptoms was graded according to clinical relevance: "no AI" (0-3 points), "mild/moderate" (4-8 points), "severe" (≥9 points) (27). The Pelvic Floor Distress Inventory Questionnaire-20 (PFDI-20) (28) was used to assess pelvic floor distress. PFDI-20 consists of 3 scales: Pelvic Organ Prolapse Distress-6 (POPDI-6), Colorectal Anal Distress Inventory-8 (CRADI-8) and Urinary Distress Inventory-6 (UDI- 6). Each scale gives a score between 0-100, and the PFDI-20 gives a score between 0-300. The higher the score, the more severe the distress (28, 29).

Patient demographic variables (age, height, weight, menopause, parity, previous surgery for PFD and previous / ongoing conservative treatment for PFD) and presence of selected diseases (diabetes, neurological disease and depression) was collected according to the IUGA-recommended international protocol for the translation and validation of the original English version of the PISQ-IR (www.iuga.org/?page=pisqir) with some adaptations.

Statistics:

Statistical analyzes were performed using SPSS version 27. Descriptive statistics for continuous variables are presented with mean, standard deviation (SD) and range. Categorical variables are presented as frequencies and percentages. The independent-samples T-test were performed to compare the continuous variables and the Chi-squared test was performed to compare differences between categorical variables.

We explored risk factors associated with being NSA using a multivariable logistic regression analysis. Variables with p-value <0.20 in univariable analyses were included in the multivariable analysis. None of the variables in the multivariable logistic regression model were highly correlated (VIF <2.0). Effect estimates are presented as odds ratio (OR) with 95% confidence interval (CI). P-value less than 0.05 was considered statistically significant.

Multivariable linear regression was conducted to predict and understand the effect variables based on the six PISQ-IR domains [arousal/orgasm (SA-AO), condition-specific (SA-CS), global quality (SA-GQ), partner-related (SA-PR), sexual desire (SA-D) and condition impact (SA-CI)] and the total score of PISQ-IR as "sexual function". Different multivariable regression models were explored using forward selection and the F-test to measure change. The independent variables were entered one by one. Variables significantly associated with the effect variable in bivariate regression were considered as candidates for the multivariable regression model. R^2 was used to assess how well the predictors in the chosen model explained the dependent variable. Missing data was replaced with means. Predictor variables were age, BMI, pelvic floor symptom debut, POPDI-6, CRADI-8 and UDI-6. Examination of normal distribution and linearity in effect- and predictor variables were satisfactory.

Ethical considerations:

The study was approved by The Norwegian Regional Committee for Medical and Health Research Ethics (REK sør-øst D 95426). All data is collected anonymously, and descriptive data is compared on a group level.

Results:

The questionnaire was sent to 498 patients. 162 patients returned the questionnaire, of which 23 were excluded. Further, 7 women were excluded due to incomplete data. In total 132 women were included in the present analysis (Figure 1).

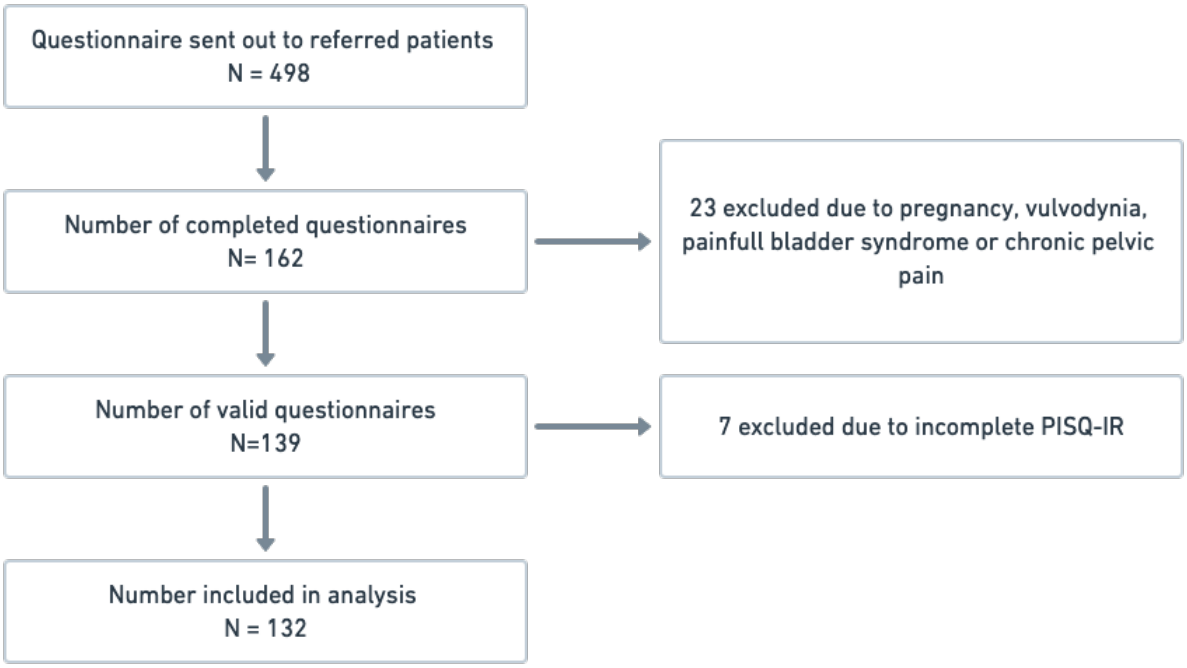

***Figure I**: Flow-chart of patient inclusion.*

Of these, 94 (71%) women reported being SA (with or without a partner) and 38 (29%) reported being NSA. NSA women were older, more were menopausal, had higher BMI and a trend of shorter duration of symptom debut compared to SA women (Table 2). Prevalence and severity of UI and AI, and level of colorectal-anal and urinary distress were comparable between SA and NSA women. NSA women reported higher level of POP distress (Table 2).

***Table 2**. Characteristics of study population (N=132).*

	Not sexually active N=38	**Sexually active** N=94	p-value
Age (y)	60.6 ± 12.9 [34,78]	51.1 ± 12.0 [25, 76]	<0.001
BMI (kg/m^2)	27.8 ± 6.1 [13.8, 42.6]	25.7 ± 4.3 [19.2, 41.8]	0.041
Menopause	30 (79%)	44 (48%)	0.001
Parity			0.877
0	2 (5%)	7 (7%)	
1	6 (16%)	13 (14%)	
≥2	30 (79%)	74 (79%)	
PFD symptom debut			0.009
<6 months	4 (11%)	3 (3%)	
6-12 months	9 (24%)	5 (5%)	
1-5 years	14 (37%)	42 (46%)	
6-10 years	6 (16%)	19 (21%)	
>10 years	5 (13%)	23 (25%)	
Previous surgery for PFD	13 (36%)	20 (22%)	0.109
Previous/ongoing conservative treatment for PFD	24 (67%)	74 (82%)	0.058
Other diseases*	13 (35%)	26 (28%)	0.442
Previously sought professional help for sexual dysfunction (n/N)	0/22	2/92	NA
Pelvic floor symptoms			
ICIQ-UI SF severity levels			0.716
Urinary continent	6 (16%)	20 (21%)	
Slight UI	5 (14 %)	13 (14%)	
Moderate UI	15 (41%)	40 (43%)	
Severe UI	10 (27%)	16 (17%)	
Very severe UI	1 (3%)	5 (5%)	
ICIQ-UI SF**	10.2 ± 4.4 [3, 20]	10.1 ± 4.7 [2, 21]	0.887
St.Marks severity levels			0.205
Anal continent	14 (40%)	51 (55%)	
Moderate AI	11 (31%)	17 (19%)	
Severe AI	10 (29%)	24 (26%)	
St.Marks index***	9.1 ± 3.8 [4, 18]	10.5 ± 4.9 [4, 20]	0.239

PFDI-20	106.1 ± 49.8 [33.3, 216.7]	92.5 ± 48.6 [10, 256.3]	0.152
POPDI-6	36.4 ± 24.3 [0, 91.7]	27.6 ± 22.1 [0, 87.5]	0.047
CRADI-8	30.0 ± 22.6 [0, 78.1]	28.3 ± 22.6 [0, 93.8]	0.699
UDI-6	40.5 ± 23.1 [0, 95.8]	46.6 ± 23.7 [0, 100]	0.390

Data are presented as mean ± standard deviation [range] or n (%).

*diseases that can lead to UI / AI / POP such as diabetes, neurological disease, depression, use of antidepressants and previous radiation therapy of the pelvis

**calculated for women reporting ICIQ-UI SF ≥1

***calculated for women reporting St.Marks ≥4

Domain-specific sub-scales and total scores of PISQ-IR in NSA and SA women are presented in Table 3.

***Table 3**. PISQ-IR scoring – reported as transformed score in a 0-100 range.*

	Not sexually active*	**Sexually active****
	N=38	N=94
Condition specific	45.9 ± 37.7 [31, 61] N=27	80 ± 22 [76, 84] N=94
Partner-related	29 ± 30.4 [CI 18, 40] N=31	77 ± 20 [73, 82] N=83
Global quality	49.5 ± 28.3 [40, 59] N=38	53 ± 27 [47, 58] N=94
Condition Impact	51.9 ± 27.0 [43, 61] N=35	69 ± 31 [63, 75] N=94
Assessment of arousal/orgasm	NA	64 ± 18 [60, 67] N=94
Desire	NA	47 ± 18 [43, 51] N=94
Total	46 ± 24 [38, 54]	63 ± 16 [60, 67]

Data are presented as mean ± standard deviation [range]

*Higher score indicates a higher impact on sexual function

**Higher score indicates better sexual function

When assessing factors associated with being NSA, age, menopausal status and POPDI-6 showed a significance level lower than 0.2 in the univariable logistic regression analyses and were included in the multivariable analysis. In the multivariable logistic regression analyses only menopausal status was significantly associated with being NSA (OR 4.3; 95% CI: 1.7, 10.6) (Table 4).

Table 4. *Multivariable logistic regression analysis of factors associated with not being sexually active (N=38).*

	Univariable			**Multivariable**	
	OR [95% CI]	p-value		OR [95% CI]	p-value
BMI	1.1 [1.0, 1.2]	0.046		1.1 [1.0, 1.2]	0.057
Menopausal	4.1 [1.7, 9.8]	0.002		4.3 [1.7, 10.6]	0.002
POPDI-6	1.1 [1.0, 1.1]	0.086		1.1 [1.0, 1.1]	0.102

Multivariable linear regression analysis was performed to study associations between sexual function and the predictor variables age, BMI, duration of PFD, POP, colo-rectal distress and urinary distress (Table 5).

Table 5. *Multivariable linear regression models of sexual function (PISQ-IR total score) and domain-specific sub-scales of factors associated with being sexually active (N=94)**

Independent variable / Dependent	**PISQ-IR** Sexual function total score	**SA-AO** Arousal/orgasm	**SA-PR** Partner related	**SA-CS** Condition specific	**SA-GQ** Global quality	**SA-CI** Condition impact	**SA-D** Desire
Age [95% CI]	-0.04 [-0.21, 0.13]	-0.14 [-0.34, 0.06]	-0.17 [-0.38, 0.05]	0.19 [-0.03, 0.41]	-0.06 [-0.37, 0.25]	0.19 [-0.15, 0.53]	-0.11 [-0.32, 0.10]
BMI [95% CI]	0.11 [-0.35, 0.57]	0.18 [-0.35, 0.70]	0.02 [-0.55, 0.58]	-0.08 [-0.67, 0.51]	-0.13 [-0.96, 0.70]	0.29 [-0.62, 1.19]	0.29 [-0.27, 0.85]
Duration of PFD [95% CI]	0.28 [-1.78, 2.33]	0,50 [-1.84, 2.83]	1.63 [-0.91, 4.17]	-2.29 [-4.90, 0.37]	0.67 [-3.06, 4.39]	1.24 [-2.82, 5.30]	-0.58 [-3.07, 1.90]
POPDI-6 [95% CI]	-0.02 [-0.13, 0.08]	-0.02 [-0.14, 0.10]	-0.02 [-0.14, 0.11]	-0.003 [-0.14, 0.13]	0.02 [-0.16, 0.21]	-0.14 [-0.35, 0.06]	0.001 [-0.13, 0.13]
CRADI-8 [95% CI]	-0,18** [-0.29, -0.08]	-0.18** [-0.29, -0.06]	-0.16** [-0.29, -0.04]	-0.24** [-0.38, -0.11]	-0.20** [-0.39, -0.01]	-0.25** [-0.45, -0.04]	0.08 [-0.20, 0.05]
UDI-6 [95% CI]	-0.03 [-0.13, 0.08]	-0.03 [-0.14, 0.09]	0.1 [-0.03, 0.23]	-0.19** [-0.32, -0.06]	0.09 [-0.09, 0.28]	-0.11 [-0.32, 0.09]	-0.02 [-0.14, 0.10]
Overall regression statistics							
R^2	0.12	0.10	0.09	0.23	0.20	0.12	0.18
F (6,125) =	2.72 p =0.016	2.34 p=0.036	2.05 p=0.64	6.24 p<0.001	0.86 p=0,53	2.70 p=0.017	0.71 P=0.641

* Missing values were replaced with mean.

**p<0.05

Significant regression equations were found for PISQ-IR total score, SA-AO, SA-PR, SA-CS and SA-CI. Respondents' sexual function (PISQ-IR total score) was reduced by 0.18 points for each point on the colorectal distress scale, when adjusted for other factors. Thus, only colorectal problems were significantly correlated with sexual function and analyzes of the subscales showed the same tendency; when a multivariate linear regression analysis was performed to predict different parts of the sexual function of women with pelvic floor dysfunctions (assessment of the subscales SA-AO, SA-PR, SA-CS, SA-GQ and SA-CI) based on their age, BMI, duration of pelvic floor dysfunction, prolapse problems, colorectal distress and urinary incontinence, only colorectal distress was significantly associated with the dependent variable. The exception was SA-CS which also demonstrated a significant association with urinary distress.

Discussion:

In this descriptive study, NSA women were older, more were menopausal, had higher BMI and a trend of shorter duration of symptom debut compared to SA women. After adjusting for potential confounders, menopausal women were more than four times likely to be NSA compared to premenopausal women. In SA women only colorectal distress were negatively associated with sexual function.

Our findings indicate that being menopausal is strongly associated with being NSA. After adjusting for potential confounders, menopausal women were more than four times likely to be NSA compared to premenopausal women. This is supported by a review of Nappi & Lachowsky (30) who found that female sexual dysfunction is prevalent during and beyond menopause as a consequence of hormonal changes, with lowered levels of oestradiol having a destructive effect on arousal, desire, pleasure, orgasm and sexual functioning (30). However, negative impact of menopause on sexual function differed across studies depending on sample size, design and hormonal status. With increasing age, more women are likely to be menopausal, and our results suggest that both the natural aging and the hormonal change as a consequence of aging are the main reasons why women are NSA. Our results also showed that NSA-women had higher BMI, but this was not significant in the multivariable analysis. However, BMI is a common risk factor for PFD, and it might be a cause for the condition, but not the reason for abstaining from sexual activity itself.

One interesting finding in our study was a trend of shorter duration of PFD symptoms in NSA-women compared to SA-women. Among NSA women, 35% reported symptoms less than 12 months compared to 8% among SA women. The mean time for diagnosis has been reported to be almost two and a half years for women after symptom debut of PFD (31), which shows that many women have symptoms for a long time before seeking help. For women who reported symptoms, but did not seek help, the main problem was the perception that PFD is a normal part of aging. Other barriers are that they feel their condition is not serious enough, self-managing their symptom and embarrassment (32). Unfortunately, the trend could not be further explored due to low number NSA-respondents and low statistical power. Further, no previous literature has been found to support our findings of duration with symptoms and not being sexually active. However, it might be that women with new symptoms choose to refrain from sexual activity because they are not familiar with their

symptoms yet, and therefore do not feel comfortable with sexual activity. They may be afraid of leakage during sexual activity, pain, fear of doing something wrong, embarrassment or lack of understanding from their partner. Another theory is that even though the mean age of NSA women were higher than SA women, the range was wide, including women of reproductive age. Since recent delivery was not an exclusion criteria, some in this group may be postpartum women with recent onset of symptoms following childbirth. This is a period in which many women choose to abstain from sexual activity regardless of symptom severity, and it is difficult to say whether it is the condition or the postpartum period that were the cause.

In our study, only POP distress was higher, and no difference in levels of urinary and colorectal distress were found between NSA and SA women. Neither the total PFDI score was different, thus, having a combination of PFDs did not affect whether women were sexually active or not. According to the review by Verbeek and Hayward (11), 30% were sexually inactive due to POP. The reason for the reduction in women's sexuality is complex and multifactorial. Discomfort associated with POP, fear of making the prolapse worse and a reduced genital sensation was reported as reasons. In addition, many women were bothered by embarrassment, worry about the appearance of the vagina and worries about the partner's satisfaction (11). A study by Lowder et al. (33) also showed that several women with POP reported that they completely avoid sexual intercourse and physical intimacy. One woman said "*I am not in the mood for intimacy of any kind because I think this prolapse is gross and it is always on my mind*" (33). This underlines the theory that there is a lot of shame and embarrassment associated with the condition, and that the quality of life for women living with POP is significantly reduced. For women with POP, pessary is a possible conservative treatment. According to a review by Rantell (34), pessaries can be an effective treatment, and have been shown to increase sexual function in women. However, the use of pessaries requires good guidance on what to expect and how to deal with certain situations. We do not have any information about use of pessary in our population. Further, we did not have enough statistical power to explore subgroups of UI, and the impact on sexual function. Neither do we have data on coital leakage. We have chosen to use urinary-/colorectal distress in the analysis, as this will include more symptoms and not only presence or absence of incontinence.

In this population, 71% of the respondents define themselves as SA, either alone or with a partner. Among SA women only colorectal distress was found to be negatively associated

with sexual function when looking at the total score. For every point they received on the CRADI-8 scale, sexual function was reduced by 0.18 points, when adjusted for other factors. Pauls et al. (15) assessed sexual function in women with AI using PISQ-IR and found that women with AI were as likely as those without AI to be sexual active, but poorer sexual function than women without AI. The theory in Pauls et al. (15) study as to why it does not influence the amount of sexual activity is that women adapt a coping strategy, to reduce the impact of AI on daily activities.

The same weak negative association between colorectal distress and sexual function was found in the different domains of arousal (SA-AO), partner-related (SA-PR), global quality (SA-GQ), condition-specific impact on sexual quality (SA-CI) and condition-specific impact on activity (SA-CS). Each sexual function domain was reduced by 0.16-0.25 points for every point they received on CRADI-8. This means that women who have colorectal distress are less sexually aroused, less satisfied, having less intense orgasms and pain during intercourse with a linear relationship between symptom severity and impact. In comparison, Pauls et al. (15) also found that the SA-CS and SA-GQ domains were worse in women with AI. In a logistic regression model, Pauls found that for SA-CS significantly predicted a low score when adjusting for other confounding factors. This supports our result that colorectal distress is negatively associated with sexual function. Similarly was found for the association between urinary distress and the SA-CS domain, with condition-specific impact reduced by 0.19 for each point they received at UDI-6. This domain includes questions about whether they feel worried or ashamed during sexual activity, and if they experience urinary or anal leakage during sexual activity.

Although the results did not reach statistical significance ($p=0.058$), there was a trend that more SA women reported previous or ongoing conservative treatment. This may be explained with SA women have had the symptoms longer than NSA women. One of these conservative treatments are pelvic floor exercises. A study by Kanter et al (35) concluded that a strong pelvic floor is associated with higher rates of sexual activity, in addition to scoring higher on the domain SA-CI and SA-D. It has been reported that the most common factors that lead to reduced sexual experience are concerns about the image of their vagina for women with POP, incontinence in women with UI, fear of soiling for those with AI and dyspareunia (11). Pelvic floor exercise has level A evidence and is recommended as first line treatment in women with UI and POP (36, 37). Although less studied, pelvic floor exercise is also recommended for

women with AI (38). Besides improving PFD, pelvic floor might improve sexual function. It is therefore important that both symptoms and sexual function are evaluated before and after treatment.

Between group comparisons (NSA vs. SA) is not possible since they are differently scored. The higher the score among those who define themselves as NSA, the more negative impact on sexual function. Higher scores in those who are SA are positively directed, hence indicate better sexual function. Regarding the domain-specific subscales of NSA women in our study, the condition impact domain (NSA-CI) had the highest score and thus most impacted. This compares to findings in an Arab study using PISQ-IR to study NSA women (39). In the global quality (NSA-GQ) domain, on the other hand, French women (40) score approximately the same as Norwegian women. We observe through NSA-PR that partner-related problems are not the main negative effect on sexual inactivity for Norwegian women. This is different from the findings in German women (41). In the German study NSA-PR was the domain with the greatest impact on women that are NSA. For SA women in our study, it is especially the domains of desire (SA-D) and global quality (SA-GQ) that is impacted, with SA-D having the lowest score. This is supported by other studies (39-41), suggesting that having PFD negatively impact sexual desire. Other negative factors associated with the sexual function of SA women are seen in the domain SA-GQ, where women's experience is that their sex life is unsatisfactory, and that they feel frustrated and not confident. The same results can be found in French and Arab (39, 40) women.

The number of studies using PISQ-IR so far are relatively small, thus limiting the external validity. Also, cultural differences make it difficult to compare results between countries. As in the Arabic study (39), they had to make cultural adjustments, including that all sexual activity was in the context of husband-wife relationships. In a study by Nicolosi et al. (42) it was shown that there are large differences between continents, such as the lack of interest in sex varied between 34% in Southeast Asia to 17% in Northern Europe. The prevalence of pain during intercourse and inability to orgasm was also different between Northern Europe and Southeast Asia. A review by Nappi et al. (43) found that female sexual dysfunction is multidimensional and varies across a life span. They noted that there were very few results worldwide, and most of the data was not truly representative for a large population. But they estimated that about 40-50% of women report at least one symptom of sexual dysfunction. Thus, there is a great need for more research in this area.

Only 2 out of 132 women in our study has sought professional help for sexual dysfunction. Both women were SA. This is a very small percentage and shows that patients may be embarrassed to request help. This is worrying, especially since SA women have had a longer duration of symptoms than NSA women. But we do not know if the symptoms have affected sexual function as long as symptom onset. To address the complexity of female sexual function, health care professionals can contribute to improve the patients sexuality by asking them about their sexual life (18). Since sexual function is such an important part of quality of life, it is very important that it receives greater attention. A review (30) emphasized the importance of giving women an opportunity to talk about their sexual problems as a fundamental part of health care. But many women appreciate that the health workers ask questions, as it is not certain that the women are willing to start this conversation. It is important to ask during consultation, and not only after surgery or conservative treatment. However it is essential to educate health care professionals on how to talk about sexual function, and to figure out why they are hesitant to ask their patients (18). It is important to be sensitive to the impact of emotionally charged questions and words, to look for cues that may signalize discomfort, and explain why you ask those questions (18).

The strength of this study is the use of a condition specific questionnaire, and that data are collected anonymously. The study contributes to a field where there is little knowledge about how women with PFD perceive their sexual function, and uses a new instrument (PISQ-IR) that is validated and intended to assess sexual function. Another strength is that the study covers a large age group from 25-78 years, and this gives a good external validity. Even though the number of NSA is small, it is likely that the result is valid for the rest of the population that has PFD, because of the large age variation.

However, the study has some limitations. The overall number (N=132) included in this study is small, especially the number of NSA (N=38). The small number of NSA affected our ability to do exploratory analyzes. To be able to perform multiple linear regression in SA women, missing data was replaced with mean instead of deletion due to the small sample. By replacing missing data with means, variance is reduced and thereby introducing a bias to our model (44). We have no knowledge about the patients who did not respond; whether they are the youngest/oldest patients or have less/more advanced symptoms. Sexual function is also an area that is still surrounded with taboo(45), and some are probably not comfortable answering

the questions. One major limitation is that we do not know how women without PFD report their sexual function. In other words, we do not know whether the groups with UI, AI and POP differ from healthy women in terms of sexual function. The questionnaire itself was long, and fatigue was observed in answering the PISQ-IR (the last section in the questionnaire) among some of the patients. A weakness is also that the Norwegian validation of PISQ-IR has not been completed as of today, although it has been through a thorough translation process from the original English version to Norwegian.

Conclusion:

In this study assessing the association between PFD and sexual function among Norwegian women we found that NSA women were older, more were menopause, had higher BMI and shorter duration of symptoms than SA women. Menopausal women were four times more likely to be NSA. NSA women also reported higher levels of POP distress than SA women. The condition-impact domain was most impacted.

Among SA women, Colorectal distress was the only factor negatively associated with sexual function. Colorectal distress was also negatively associated with the domains SA-AO, SA-PR, SA-GQ, SA-CI and SA-CS. This implies that SA women with colorectal distress may experience being less sexually aroused, less satisfied, having less intense orgasms or pain during intercourse.

Quality of Life is significantly affected by sexual function. There is a great need for more research on how women with PFD perceive their sexual function, and whether sexual function is improved by conservative and surgical treatment. It is also very important that health workers address sexual function during consultation.

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Appendix 1 *– Invitation to participate*

NTNU Kunnskap for en bedre verden | UNIVERSITETSSYKEHUSET NORD-NORGE | ST. OLAVS HOSPITAL UNIVERSITETSSYKEHUSET I TRONDHEIM

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

SEKSUALFUNKSJON HOS KVINNER MED UNDERLIVSFREMFALL, URIN- ELLER AVFØRINGSLEKKASJE – OVERSETTING OG TESTING AV SPØRRESKJEMAET PISQ-IR

Dette er et spørsmål til deg om å delta i en forskningsstudie om seksualitet ved dysfunksjoner i bekkenbunnen, som underlivsprolaps, urin- eller avføringslekkasje. Dysfunksjoner i bekkenbunnen berører mange kvinner. Det er derfor behov for mer kunnskap om temaet, slik at behandlingstilbudet kan bli bedre i fremtiden. I denne studien vil vi teste et internasjonalt spørreskjema vedrørende seksualfunksjon hos kvinner med dysfunksjoner i bekkenbunnen. I dette spørreskjemaet innebærer seksuell aktivitet, aktivitet som er både med og uten partner. Seksualfunksjonen er en del av livet enten vi opplever oss selv som seksuelt aktive eller ikke – og vi håper derfor at du vil delta i denne studien! Mer spesifikt vil vi invitere deg som:

- er over 18 år og som er i stand til å samtykke til å delta i studien
- er i stand til å fylle ut det vedlagte spørreskjemaet på egen hånd
- ikke er gravid
- er i stand til å lese, skrive og forstå norsk
- har underlivsfremfall, urininkontinens, avføringsinkontinens (eller en kombinasjon av disse)

Du blir spurt om å delta fordi du er henvist til St. Olavs hospital for utredning og behandling av underlivsfremfall, urin- eller avføringslekkasje. Alle som blir invitert til å delta i forskningsprosjektet er identifisert i samarbeid med St. Olavs hospital. Ansvarlig for forskningsprosjektet er Norges teknisk-naturvitenskapelige universitet (NTNU).

HVA INNEBÆRER PROSJEKTET?

Deltagelse i studien innebærer at du fyller ut det vedlagte spørreskjemaet og poster det i den ferdig frankerte konvolutten. Spørreskjemaet er oversatt til norsk og inneholder spørsmål om din helsetilstand og seksualfunksjon.

Vi vet at spørsmål om seksualfunksjon kan oppleves som vanskelige å svare på fordi dette er et intimt og privat tema. Fordi vi også vet at dette er problem mange kvinner har, er det viktig å forbedre behandlingen av dysfunksjoner i bekkenbunnen. Spørreskjemaet som du blir bedt om å fylle ut kan være en måte å forbedre behandlingen i fremtiden. Gjennom å samle inn riktig informasjon om kvinnenes problemer, er det enklere å gi riktig behandling. I tillegg kan spørreskjemaet brukes i forskning for å skaffe nye kunnskaper om problemene. Resultatene fra undersøkelsen vil bli brukt i vitenskapelige publikasjoner.

MULIGE FORDELER OG ULEMPER

Studien innebærer ingen ulemper for deg annet enn å sette av den tiden det tar å fylle ut spørreskjemaet.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Ved å fylle ut spørreskjemaet og sende det tilbake i den ferdig frankerte konvolutten er dette å anse som at du samtykker til å delta i studien. Når skjemaet er sendt inn, er det ikke lenger mulig å trekke seg fra undersøkelsen fordi vi ikke er i stand til å identifisere ditt spørreskjema. Dersom du ikke ønsker å delta i studien vil ikke dette ha noen konsekvenser for din videre behandling. Dersom du har spørsmål til prosjektet, kan du kontakte Susan Saga, Førsteamanuensis ved Institutt for samfunnsmedisin og sykepleie, NTNU, på telefon 73 41 21 62 eller email susan.saga@ntnu.no.

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. Data vil bli slettet når datainnsamlingen avsluttes, senest ved utgangen av 2021. Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte.

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, REK 95426.

Appendix 2: *PISQ-IR questionnaire – Norwegian version*

PISQ-IR:
Spørreskjema om seksualfunksjon ved fremfall av underlivsorganer, urin- og/eller avføringsinkontinens

I dette spørreskjemaet innebærer seksuell aktivitet, aktivitet alene eller med partner

Spm 1 Hvilken av følgende beskrivelser synes du passer best på deg:

Seksuelt aktiv med eller uten partner	□ →	Gå videre til Spm 7 (del 2)
Ikke seksuelt aktiv i det hele tatt	□ →	Fortsett med Spm 2 (del 1)

Del 1: Spørsmål til personer som ikke er seksuelt aktive

Spm 2 Her er en liste med mulige grunner til at du ikke er seksuelt aktiv. Angi hvor enig eller uenig du er i at dette er grunner til at du ikke er seksuelt aktiv.

		Svært enig	Ganske enig	Ganske uenig	Svært uenig
a.	Ingen partner	□[1]	□[2]	□[3]	□[4]
b.	Ingen interesse	□[1]	□[2]	□[3]	□[4]
c.	Har problemer med blære eller tarm (urin- eller avføringsinkontinens) eller fremfall (utbuling eller følelse av utbuling i skjeden)	□[1]	□[2]	□[3]	□[4]
d.	Fordi jeg har andre helseproblemer	□[1]	□[2]	□[3]	□[4]
e.	Smerter	□[1]	□[2]	□[3]	□[4]

Spm 3 Hvor mye har frykten for urin- og/eller avføringslekkasje og/eller utbuling i skjeden (på grunn av fremfall av blære, endetarm eller livmor) å si for at du unngår eller begrenser din seksuelle aktivitet?

□[1] Ikke noe å si i det hele tatt
□[2] Litt
□[3] Noe
□[4] Mye

Spm 4 Sett en ring rundt det tallet mellom 1 og 5 som best beskriver hva du mener om sexlivet ditt (sett en ring for hver av punktene a-b).

a.	Fornøyd	1	2	3	4	5	Misfornøyd
b.	Tilfredsstillende	1	2	3	4	5	Utilfredsstillende

Spm 5 Angi hvor enig eller uenig du er i hver av følgende påstander:

		Svært enig	Ganske enig	Ganske uenig	Svært uenig
a.	Jeg føler meg frustrert over sexlivet mitt	□[1]	□[2]	□[3]	□[4]
b.	Jeg føler meg seksuelt utilstrekkelig på grunn av inkontinens og/eller fremfall	□[1]	□[2]	□[3]	□[4]
c.	Jeg føler meg sint på grunn av den betydningen inkontinensen og/eller fremfallet har for sexlivet mitt	□[1]	□[2]	□[3]	□[4]

Spm 6 I det store og hele, hvor vanskelig er det for deg at du ikke er seksuelt aktiv?

□[1] Ikke i det hele tatt
□[2] Litt
□[3] Noe
□[4] Mye

Slutt på spørsmål til personer som ikke er seksuelt aktive

Del 2: Spørsmål til personer som er seksuelt aktive (med eller uten partner)

Resten av spørsmålene i undersøkelsen gjelder et tema som sjelden berøres i slike undersøkelser. Vennligst svar så tydelig og ærlig du kan.

Spm 7 Hvor ofte blir du tent (fysisk opphisset eller kåt) ved seksuell aktivitet?
□[1] Aldri
□[2] Sjelden
□[3] Av og til
□[4] Vanligvis
□[5] Alltid

Spm 8 Når du er involvert i seksuell aktivitet, hvor ofte føler du deg:

		Aldri	**Sjelden**	**Av og til**	**Vanligvis**	**Nesten alltid**
a.	Tilfreds	□[1]	□[2]	□[3]	□[4]	□[5]
b.	Skamfull	□[1]	□[2]	□[3]	□[4]	□[5]
c.	Bekymret/engstelig	□[1]	□[2]	□[3]	□[4]	□[5]

Spm 9 Hvor ofte lekker du urin og/eller avføring i forbindelse med ulike typer seksuell aktivitet (med eller uten partner)?
□[1] Aldri
□[2] Sjelden
□[3] Av og til
□[4] Vanligvis
□[5] Alltid

Spm 10 Sammenlignet med orgasmer du tidligere har hatt, hvor intense er orgasmene dine nå?
□[1] Mye mindre intense
□[2] Mindre intense
□[3] Like intense
□[4] Mer intense
□[5] Mye mer intense

Spm 11 Hvor ofte har du smerter under samleie? (Hvis du ikke har samleie, setter du et kryss i denne ruten □ og fortsetter med neste spørsmål.)
□[1] Aldri
□[2] Sjelden
□[3] Av og til
□[4] Vanligvis
□[5] Alltid

Spm 12 Har du en seksualpartner?
1 □ Ja → Fortsett med Spm 13
2 □ Nei → Gå videre til Spm 15

Spm 13 Hvor ofte har partneren din et problem (manglende tenning, begjær, ereksjon osv.) som begrenser den seksuelle aktiviteten for deg?

□[1] Hele tiden
□[2] Mesteparten av tiden
□[3] En del av tiden
□[4] Nesten aldri/Sjelden

Spm 14

	Svært positiv	**Ganske positiv**	**Ganske negativ**	**Svært negativ**
a. Rent generelt, vil du si at **partneren din** har en positiv eller negativ **innvirkning** på ditt seksuelle begjær?	□[1]	□[2]	□[3]	□[4]
b. Rent generelt, vil du si at **partneren din** har en positiv eller negativ innvirkning på **hyppigheten** av din seksuelle aktivitet?	□[1]	□[2]	□[3]	□[4]

Spm 15 Ved seksuell aktivitet, hvor ofte føler du at du vil ha mer?

□[1] Aldri
□[2] Sjelden
□[3] Av og til
□[4] Vanligvis
□[5] Alltid

Spm 16 Hvor ofte har du et seksuelt begjær? Dette kan inkludere at du har lyst på sex, har seksuelle tanker eller fantasier.

□[1] En eller flere ganger daglig
□[2] En eller flere ganger i uken
□[3] En eller flere ganger i måneden
□[4] Mindre enn en gang i måneden
□[5] Aldri

Spm 17 Hvordan vil du rangere ditt seksuelle begjær eller din seksuelle interesse?

□[1] Svært høyt
□[2] Høyt
□[3] Middels
□[4] Lavt
□[5] Svært lavt eller ikke-eksisterende

Spm 18 Hvor mye har frykten for lekkasje av urin, avføring og/eller fremfall (utbuling i skjeden) å si for at du unngår seksuell aktivitet?

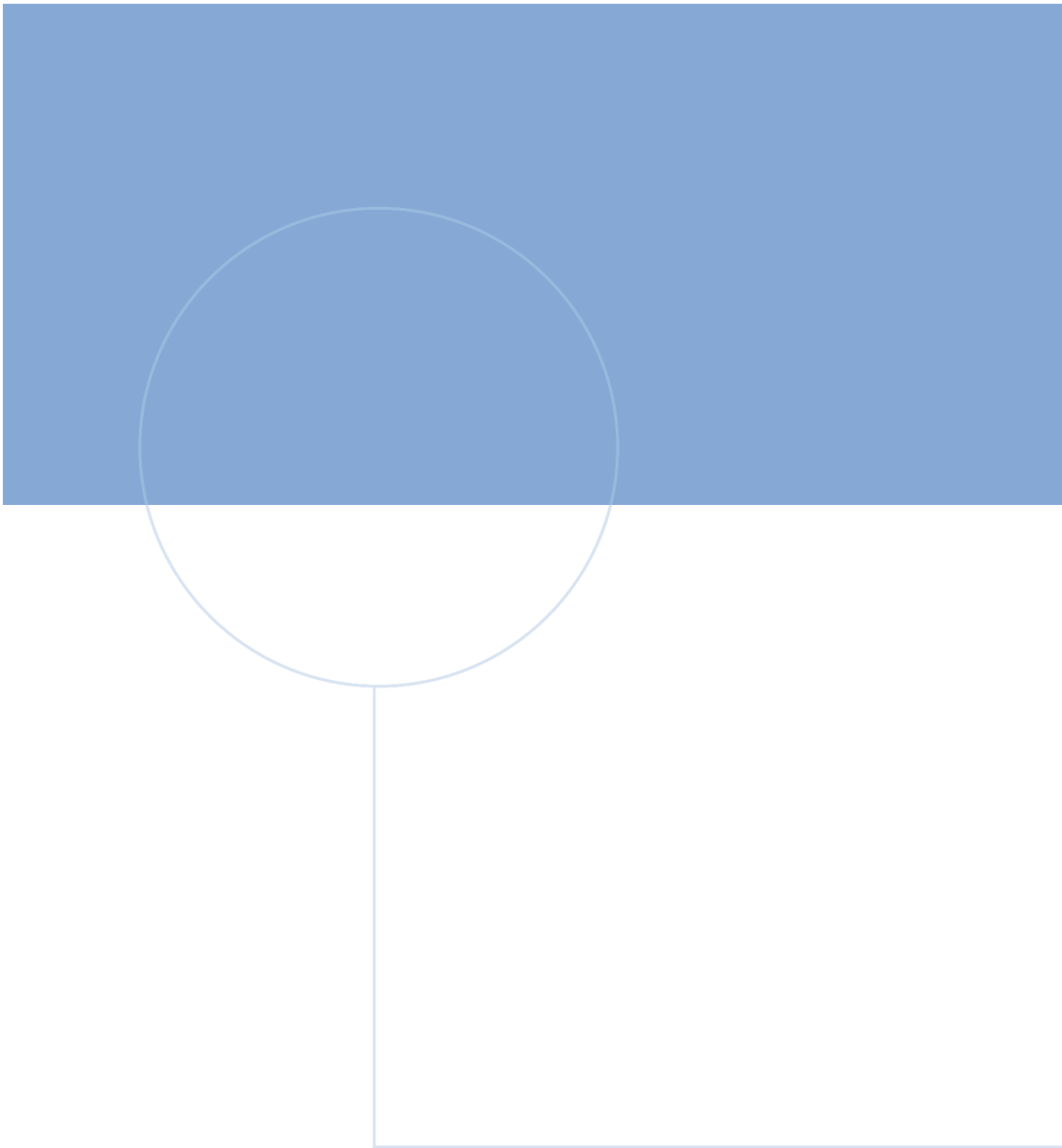
□[1] Ikke i det hele tatt
□[2] Litt
□[3] Noe
□[4] Mye

Spm4|19 Sett ring rundt det tallet mellom 1 og 5 som best beskriver din opplevelse av sexlivet ditt (sett en ring for hver av punktene a-c).

a.	Fornøyd	1	2	3	4	5	Misfornøyd
b.	Tilfredsstillende	1	2	3	4	5	Utilfredsstillende
c.	Selvsikker	1	2	3	4	5	Ikke selvsikker

Spm 20 Angi hvor enig eller uenig du er i hver av følgende påstander:

		Svært enig	**Ganske enig**	**Ganske uenig**	**Svært uenig**
a.	Jeg føler meg frustrert over sexlivet mitt	□[1]	□[2]	□[3]	□[4]
b.	Jeg føler meg seksuelt utilstrekkelig på grunn av inkontinens og/eller fremfall	□[1]	□[2]	□[3]	□[4]
c.	Jeg er flau over sexlivet mitt	□[1]	□[2]	□[3]	□[4]
d.	Jeg føler meg sint på grunn av den betydningen inkontinensen og/eller fremfallet har for sexlivet mitt	□[1]	□[2]	□[3]	□[4]



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