Sexual Function, Activity, and Satisfaction among Women Receiving Maintenance Hemodialysis

Maria K. Mor,[*†] Mary Ann Sevick,[‡] Anne Marie Shields,[*] Jamie A. Green,[§] Paul M. Palevsky,[‖¶] Robert M. Arnold,**[††] Michael J. Fine,*** and Steven D. Weisbord*[‖¶]

Summary

Background and objectives Past studies that demonstrated that sexual dysfunction is common among women receiving chronic hemodialysis did not distinguish sexual dysfunction/difficulty from sexual inactivity. This study sought to differentiate these in order to elucidate the prevalence of true "sexual dysfunction" in this population.

Design, setting, participants, & measurements As part of a clinical trial of symptom management strategies in patients receiving chronic hemodialysis, female sexual function was prospectively assessed monthly for 6 months and quarterly thereafter using the Female Sexual Function Index, to which questions were added differentiating sexual dysfunction/difficulty from sexual inactivity. Beginning in month 7, patients were asked three questions about sexual activity, difficulty, and satisfaction monthly.

Results Of the women enrolled in the clinical trial,125 participants completed 1721 assessments between 2009 and 2011. Scores on 574 of 643 (89%) quarterly Female Sexual Function Index assessments were consistent with sexual dysfunction, due largely to sexual inactivity, which was reported on 525 (82%) quarterly assessments. When reported (n=1663), the most frequently described reasons for sexual inactivity were lack of interest in sex (n=715; 43%) and lack of a partner (n=647; 39%), but rarely sexual difficulty (n=36; 2%). When reported (n=1582), women were moderately to very satisfied with their sexual life on 1020 (64%) assessments and on 513 of 671 (76%) assessments in which lack of interest was cited as a reason for sexual inactivity. Women indicated an interest in learning about the causes of and treatment for sexual dysfunction on just 5% of all assessments.

Conclusions Although many women receiving chronic hemodialysis are sexually inactive, few describe sexual difficulty. Most, including those with a lack of interest in sex, are satisfied with their sexual life and few wish to learn about treatment options. These findings suggest that true sexual dysfunction is uncommon in this population and that treatment opportunities are rare.

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*Center for Health Equity Research and Promotion, Veterans Affairs Pittsburgh Healthcare System, Pittsburgh, Pennsylvania; †Department of Biostatistics, Graduate School of Public Health, University of Pittsburgh, Pittsburgh, Pennsylvania; ‡Department of Population Health, New York University School of Medicine, New York, New York; §Nephrology Department, Geisinger Medical Center, Danville, Pennsylvania; ‖Renal Section, Medicine Service Line, Veterans Affairs Pittsburgh Healthcare System, Pittsburgh, Pennsylvania; ¶Renal-Electrolyte Division, Department of Medicine, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania; and **Divisions of General Internal Medicine and ††Palliative Care, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania

Correspondence: Dr. Steven D. Weisbord, Renal Section, Medicine Service Line, Veterans Affairs Pittsburgh Healthcare System, 7E Room 120, 111F-U, Pittsburgh, PA 15240. Email: weisbordsd@upmc.edu

Introduction

Patients treated with chronic hemodialysis experience a multitude of physical and emotional symptoms, many of which are associated with impairments in health-related quality of life (1–7). Fatigue, pain, depression, and difficulty with sleep are among the most common symptoms in this population (8–12). Studies suggest that sexual dysfunction is also highly prevalent, with ≥80% of men receiving maintenance dialysis therapy reporting the presence of erectile dysfunction (5,13–19). Recent studies report that a large proportion of women on chronic dialysis experience sexual dysfunction (14,17,20,21). In 2010, Seethala *et al.* surveyed 66 women receiving chronic dialysis and found that 53 (80%) had sexual dysfunction (17). Another recent cross-sectional study of 659 women receiving chronic hemodialysis reported that 555 participants (84%) had sexual dysfunction (21).

These two studies and others measured sexual function with the Female Sexual Function Index (FSFI), a 19-item questionnaire that evaluates six discrete domains of sexual function (17,20–24). Despite its widespread use, the scoring scheme of the FSFI does not effectively distinguish sexual inactivity from sexual dysfunction; all sexually inactive women who complete the FSFI have scores indicating the presence of sexual dysfunction (25). However, patients may be sexually inactive for reasons unrelated to sexual dysfunction. Therefore, the prevalence of true "sexual dysfunction" (*i.e.,* related to sexual difficulty) among women on chronic dialysis is not known. Moreover, the FSFI does not assess patients' interest in learning about causes of and treatments for sexual difficulty. Our study aim was to assess sexual function, activity, and satisfaction among women receiving chronic hemodialysis using a modified version of the FSFI that distinguishes between sexual dysfunction and lack of sexual activity, evaluates reasons women are not sexually active, and assesses their interest in learning about causes of and treatments for sexual difficulties.

Materials and Methods

Patient Population

This study includes data collected from women who participated in the Symptom Management Involving End-Stage Renal Disease (SMILE) trial. SMILE was a randomized, multicenter, clinical trial comparing two strategies for the management of pain, depression, and sexual dysfunction (principally erectile dysfunction) in patients dependent on chronic hemodialysis (26,27). We recruited patients from nine outpatient dialysis units in and around Pittsburgh, Pennsylvania, between January 2009 and January 2010, and followed participants for up to 24 months. Patients were included if they were aged >17 years, were cognitively intact, spoke English, and were receiving chronic, thrice-weekly, in-center hemodialysis. Patients were excluded if they were being evaluated for living donor kidney transplant and/or considering change of treatment modality to peritoneal dialysis. The SMILE study was approved by the institutional review boards of the University of Pittsburgh, Veterans Affairs Pittsburgh Healthcare System, and the Western Institutional Review Board. All patients provided consent to participate.

Demographic and Clinical Data Collection

After enrollment, we interviewed patients and reviewed medical records to evaluate their demographics and clinical characteristics, including dialysis vintage, type of vascular access, and comorbid illnesses burden based on the Charlson Comorbidity Index. We also abstracted patients' most recent laboratory values (*e.g.*, hemoglobin; serum calcium, phosphorous, albumin, and intact parathyroid hormone concentrations, and Kt/V and urea reduction ratio) from the dialysis chart. We assessed patients' health-related quality of life using the Short Form 12 (SF-12) on a quarterly basis and depression using the Patient Health Questionnaire 9 (PHQ-9) on a monthly basis.

Assessment of Female Sexual Function

The FSFI is composed of 19 items that assess a woman's sexual desire, arousal, lubrication, orgasm, satisfaction, and pain over the prior 4 weeks. A summary score is generated that ranges from 2 to 36, with a value <26.55 denoting the presence of sexual dysfunction. The first two items on the FSFI inquire about sexual interest/desire. Fifteen of the remaining 17 items focus on other domains of sexual function with the option for patients to respond that they were not sexually active or did not attempt intercourse. Such responses are assigned a score of 0 for that item. Thus, women who report that they were not sexually active have low summary FSFI scores and are labeled as having sexual dysfunction.

To distinguish between sexual dysfunction and sexual inactivity and to elucidate the reasons for sexual inactivity in this study, we modified the FSFI. Specifically, we left unchanged the initial two questions that inquire about sexual interest/desire and added a new question asking patients whether they had been sexually active during the past 4 weeks. Patients who responded that they had not been sexually active during this time frame were instructed to skip the next 15 questions inquiring about various aspects of sexual function and answer the remaining 2 questions about satisfaction with their sexual life and with their relationship with their partner. For this latter question, we included an additional response option of "not applicable/no partner." Finally, we added three new items to the end of the questionnaire asking patients if and why they were not sexually active, whether they were experiencing any sexual difficulty, and whether they were interested in learning about possible causes of and treatment options for sexual difficult (Supplemental Appendix 1).

After patients began to report survey fatigue from needing to complete the modified FSFI every month, we changed the study protocol so that after month 6, women would complete the modified FSFI on a quarterly basis and would answer a three-question survey about their sexual activity, difficulty, and satisfaction during intervening months (Figure 1 and Supplemental Appendix 2).

Statistical Analyses

We describe baseline demographic characteristics, clinical variables, and survey responses using frequencies and/or proportions for discrete variables and medians and interquartile ranges (IQRs) for continuous variables. We report FSFI summary scores based on the assessments with the modified questionnaire. To compute summary FSFI scores from data from the modified FSFI, we used the original scoring scheme in which women who indicated that they were not sexually active over the preceding 4 weeks were assigned scores of 0 on the 15 items that include the response option of "not sexually active or did not attempt intercourse." We present data on patients' sexual activity (and reasons for inactivity), difficulty, satisfaction, and interest in learning about causes and treatments based on all (modified FSFI and three-item monthly) assessments. We also describe the results at the patient level by aggregating data over all of the assessments completed by each participant. For these patient-level analyses, we report the frequency and

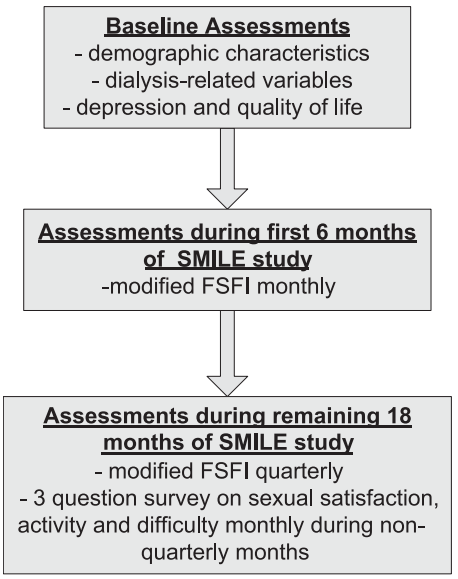

Figure 1. | **Study assessments**. SMILE, Symptom Management Involving End-Stage Renal Disease trial; FSFI, Female Sexual Function Index.

proportion of women who ever responded affirmatively to survey items at any assessment. To describe patients' overall sexual satisfaction, we report mean scores on the question "Over the past 4 weeks, how satisfied have you been with your overall sexual life," which includes five response options on a Likert scale ranging from very satisfied (score of 5) to very dissatisfied (score of 1).

We tested for differences in demographic and clinical characteristics, baseline depression and quality of life scores, and monthly responses on survey items related to sexual satisfaction between women who ever reported being sexually active at any study assessment and those who reported not being sexually active at any assessment. We used Fisher's exact tests for discrete variables with nominal or two response options, Cochran–Mantel–Haenszel tests for trend for discrete variables with ordinal response options (level of education, Charlson Comorbidity Index score, and mean overall sexual satisfaction) and Wilcoxon rank-sum tests for continuous outcomes. In addition, we used Wilcoxon rank-sum tests to compare the differences in depression and quality of life scores between women who were sexually active and had sexual dysfunction based on FSFI summary scores <26.55 and women who were sexually active and had no sexual dysfunction based on FSFI summary scores ≥26.55. We computed *P* values using two-tailed tests and considered a level of 0.05 to represent statistical significance. We conducted all analyses using SAS 9.3 software (SAS Institute Inc., Cary, NC).

Results

Patient Characteristics, Assessments, and Quarterly FSFI Scores

There were 127 women enrolled in the SMILE study; 2 died or withdrew before data collection, resulting in a population of 125 women who are included in this analysis. The median age of participants was 64 years (IQR, 56, 73), 40% were African American, and 40% were married or living with a partner (Table 1). Patients completed a median of 14 total (modified FSFI and monthly three-item) assessments (IQR, 7, 21). Two patients did not complete the FSFI but provided data on the monthly three-item questionnaire. The median FSFI score was 3.6 (IQR, 3.2, 5.4). Summary FSFI scores on 89% of assessments were <26.55. However, of 169 FSFI assessments in which women reported being sexually active, summary scores were <26.55 on only 72 (43%). Of the 123 patients with completed FSFI assessments, 118 (96%) had a summary score <26.55 on at least one assessment.

Table 1. Baseline patient characteristics

Characteristic	All Women (*n*=125)
Age (yr)	64 (56, 73)
African-American race	50 (40)
Education	
Less than high school	20 (16)
High school equivalent	41 (33)
More than high school	64 (51)
Income ($/yr)	
<30,000	71 (57)
≥30,000	30 (24)
Unknown	24 (19)
Employed	9 (7)
Married or living with partner	50 (40)
Years on dialysis	2.2 (0.9, 4.6)
Dialysis schedule (MWF)	77 (62)
Dialysis access (catheter)	37 (30)
CCI score	
1–2	24 (19)
3–4	52 (42)
≥5	49 (39)
Laboratory values	
Hemoglobin (g/dl)	11.6 (10.9, 12.1)
Albumin (g/dl)	3.8 (3.5, 4.0)
Calcium (mg/dl)	8.9 (8.5, 9.3)
Phosphorous (mg/dl)	5.2 (4.5, 6.5)
iPTH (pg/mL)	253 (148, 402)
Kt/V	1.6 (1.4, 1.7)
PHQ-9[a]	4 (2, 10)
SF-12[b]	
Mental composite summary score	50 (40, 59)
Physical composite summary score	34 (26, 42)

Data are presented as *n* (%) or median (interquartile range). Data on age, marital status, albumin, and PHQ-9 are each missing for one woman, years on dialysis for two women, the SF-12 composites for three women, and iPTH for nine women. MWF, Monday Wednesday Friday; CCI, Charlson Comorbidity Index; iPTH, intact parathyroid hormone; PHQ-9, Patient Health Questionnaire 9; SF-12, Short Form 12.
[a]PHQ-9 score >9 consistent with depression.
[b]Mean composite scores for the SF-12 in the general population = 50; lower scores denote lower health-related quality of life.

Sexual Activity, Satisfaction, Difficulty, and Interest in Causes and Treatments

On 81% of all assessments, women reported that they were not sexually active (Table 2). The primary reasons cited for sexual inactivity were lack of interest (43%) and lack of a partner (39%). Women reported sexual difficulty as a cause for sexual inactivity on only 2% of assessments. On 64% of assessments, women reported being moderately to very satisfied with their sexual life, whereas they described being moderately to very dissatisfied on 19% of assessments (Table 2). On 76% of assessments in which lack of interest was cited as a reason for sexual inactivity, patients reported being moderately to very satisfied with their sexual life. Of the 102 women who reported that lack of interest in sex was a reason for sexual inactivity, 76 (75%) described being moderately to very satisfied with their sexual life compared with 11 (52%) of the 21 women who did not report that lack of interest in sex was a reason for sexual inactivity (*P*=0.02 for trend). Women reported experiencing sexual difficulty on 11% of assessments, whereas they described an interest in learning about causes of or treatment options for sexual difficulty on just 5% of assessments.

Comparisons of Sexually Active and Sexually Inactive Women

Forty-five women (36%) reported being sexually active on at least one assessment, whereas 80 (64%) reported never

Table 2. Sexual activity and satisfaction

Characteristic	Assessments (*n*=1721)	Women[a] (*n*=125)
Sexually inactive[b]	1380 (81)	120 (96)
Reasons for sexual inactivity[c]		
Experiencing sexual difficulty	36 (2)	16 (13)
Lack of interest	715 (43)	103 (82)
No partner	647 (39)	83 (66)
Partner not interested or able	132 (8)	27 (22)
Illness/injury	37 (2)	20 (16)
Other	36 (2)	19 (15)
Overall sexual satisfaction[d]		
Very satisfied	811 (51)	52 (42)
Moderately satisfied	209 (13)	35 (28)
About equally satisfied/dissatisfied	253 (16)	21 (17)
Moderately dissatisfied	131 (8)	9 (7)
Very dissatisfied	178 (11)	6 (5)

Data are presented as *n* (%).
[a]Data reflect the *n* (%) of women ever reporting the characteristic with the exception of overall sexual satisfaction, which is the summary of the mean response for each woman.
[b]Sexual activity data are missing from 18 assessments.
[c]Data do not sum to 100% due to the option for women to select more than one reason for sexual inactivity and the selection of no reason for sexual inactivity by most sexually active women. Data on reasons for sexual inactivity are missing from 40 assessments on which women who reported being sexually inactive as well as the 18 assessments that were missing answers on sexual activity.
[d]Percentages do not sum to 100 due to rounding. Data on overall sexual satisfaction were missing on 139 assessments, including all assessments completed by two women.

being sexually active during the study. Compared with patients who reported being sexually active, women who reported never being sexually active during the study were older (66 versus 59 years, $P<0.001$) and were somewhat less likely to be married or living with a partner (35% versus 49%, $P=0.18$). There were no baseline difference in median depression scores (4 versus 4, $P=0.99$) or median SF-12 physical component summary scores (34 versus 33, $P=0.60$) between women who were not sexually active during the study compared with sexually active women. Women who were never sexually active had somewhat higher median baseline SF-12 mental component summary scores than women who reported being sexually active (52 versus 46, $P=0.08$). There was no difference ($P=0.32$) in overall sexual satisfaction, with 58 women (75%) who were never sexually active reporting being moderately to very satisfied compared with 29 women (64%) who were sexually active (Table 3).

In addition, for the 169 assessments in which patients reported being sexually active, women who had FSFI-defined sexual dysfunction (summary score <26.55) reported similar quality of life and depression scores as women who did not have FSFI-defined sexual dysfunction (median SF-12 physical component summary score of 35 versus 38, $P=0.74$; median SF-12 mental component summary score of 50 versus 51, $P=0.79$; median PHQ-9 score of 4 versus 4, $P=0.59$). Conversely, on these 169 assessments, women who had FSFI-defined sexual dysfunction were less likely to be moderately to very satisfied with their sexual life than women without FSFI-defined sexual dysfunction (35% versus 89%, $P<0.001$) (Figure 2).

Discussion

Although many women receiving chronic dialysis have FSFI scores consistent with sexual dysfunction, this is due to the high prevalence of sexual inactivity in this patient population. Very few women on chronic hemodialysis, including those who are not sexually active, report sexual difficulty or dissatisfaction with their sexual life. A very small minority is interested in learning about causes of or treatment options for sexual difficulty.

Similar to past studies, a large majority of our patients had FSFI summary scores consistent with sexual dysfunction. However, this observation reflects the high prevalence of sexual inactivity, not true sexual dysfunction. Many women in our study reported being sexually inactive, yet few cited sexual difficulty as a cause. Much more commonly, patients reported that lack of a partner or lack of interest in sex explained their sexual inactivity. Although lack of interest could certainly be a manifestation of sexual dysfunction, this did not appear to be true in our study, because most women who reported a lack of interest in sex were moderately to very satisfied with their sexual life. Among the minority of women on chronic hemodialysis who are sexually active, less than half appear to have sexual dysfunction. This subgroup of patients is more likely to be dissatisfied with their overall sexual function. These findings indicate that the FSFI should not be used as a screening tool in women on chronic dialysis. Renal providers and clinical researchers seeking to screen their patients for female sexual dysfunction should use a modified version of the FSFI (or an alternative questionnaire) that effectively differentiates between sexual inactivity and dysfunction.

Most women on chronic dialysis, including those who are not sexually active, are satisfied with their sexual life. This observation is consistent with the findings of past studies. Ferenidou *et al.* enrolled 164 women from the general medical population and administered the FSFI as well as the Symptom Checklist of Sexual Function, a questionnaire that measures self-perception of sexual function (28). The investigators reported that approximately half of study participants had FSFI-defined sexual dysfunction, yet >80% were satisfied with their sexual function. Strippoli *et al.* administered the FSFI to 659 women receiving chronic hemodialysis and found that of the six FSFI-defined domains of sexual function, satisfaction was the least impaired (median score 3.6; range, 0.8–6.0) (21). Collectively, these findings suggest that sexual inactivity and FSFI-defined sexual dysfunction do not necessarily translate into sexual dissatisfaction among women on chronic dialysis.

Among sexually active women, the presence of sexual dysfunction was associated with lower overall satisfaction but not with depression or lower quality of life. These findings conflict with some, but not all prior studies. In the study by Strippoli *et al.*, women with sexual dysfunction,

Table 3. Comparisons of sexually active and sexually inactive women

Characteristic	Ever Sexually Active (n=45)[a]	Never Sexually Active (n=80)[a]	P Value
Age (yr)	59 (49, 65)	66 (59, 77)	<0.001
African-American race	17 (38)	33 (41)	0.85
Education			0.59
Less than high school	5 (11)	15 (19)	
High school equivalent	17 (38)	24 (30)	
More than high school	23 (51)	41 (51)	
Income ($/yr)			0.77
<30,000	27 (60)	44 (55)	
≥30,000	11 (24)	19 (24)	
Unknown	7 (16)	17 (21)	
Employed	3 (7)	6 (8)	1.00
Married or living with partner	22 (49)	28 (35)	0.18
Years on dialysis	1.8 (0.9, 4.8)	2.3 (0.9, 4.5)	0.85
Dialysis schedule (MWF)	26 (58)	51 (64)	0.57
Dialysis access (catheter)	15 (33)	22 (28)	0.54
CCI score			0.84
1–2	8 (18)	16 (20)	
3–4	19 (42)	33 (41)	
≥5	18 (40)	31 (39)	
Laboratory values			
Hemoglobin (g/dl)	11.7 (11.0, 12.2)	11.5 (10.8, 12.1)	0.19
Albumin (g/dl)	3.8 (3.7, 4.0)	3.8 (3.5, 4.0)	0.26
Calcium (mg/dl)	8.9 (8.5, 9.4)	9.0 (8.6, 9.3)	0.82
Phosphorous (mg/dl)	5.2 (4.7, 6.7)	5.3 (4.5, 6.5)	0.55
iPTH (pg/ml)	235 (129, 440)	271 (175, 390)	0.51
Kt/V	1.5 (1.4, 1.7)	1.6 (1.4, 1.8)	0.40
SF-12[b]			
Mental composite summary score	46 (36, 58)	52 (43, 60)	0.08
Physical composite summary score	33 (26, 41)	34 (26, 42)	0.60
PHQ-9[b]	4 (2, 11)	4 (3, 9)	0.99
Overall sexual satisfaction			0.32
Very satisfied	14 (31)	38 (49)	
Moderately satisfied	15 (33)	20 (26)	
About equally satisfied/dissatisfied	11 (24)	10 (13)	
Moderately dissatisfied	4 (9)	5 (6)	
Very dissatisfied	1 (2)	5 (6)	

Data are presented as n (%) or median (interquartile range). Among women ever sexually active, data are missing from one woman for age and PHQ-9, from two women for years on dialysis and the SF-12 composites; and from three women for iPTH. For women never sexually active, data are missing from one woman for marital status, albumin, and the SF-12 composites, from two women for overall sexual satisfaction, and from six women for iPTH. MWF, Monday Wednesday Friday; CCI, Charlson Comorbidity Index; iPTH, intact parathyroid hormone; SF-12, Short Form 12; PHQ-9, Patient Health Questionnaire 9.

[a]Ever sexually active or never sexually active denotes sexual activity during the study period.

[b]Data reflect baseline values.

including those who were sexually active, were more likely to have depression (21). In a study of 578 Taiwanese women on chronic hemodialysis, Peng *et al.* found that sexual dysfunction was associated with decrements in multiple domains of quality of life as measured by the Short Form 36 (14). In contrast, Seethala *et al.* found no association of sexual dysfunction with depression or quality of life (17). Although varying methods used to assess these health-related domains and differences in patient populations may account for these conflicting findings, the results of this study suggest that sexual inactivity and sexual dysfunction among sexually active women are not associated with impairments in physical or psychologic well-being in the dialysis population.

Our study builds upon past research by describing women's interest in understanding the causes of and treatment options for sexual dysfunction. Unlike phosphodiesterase-5 inhibitors for the treatment of erectile dysfunction, there are no easily administered and effective treatment interventions for most forms of female sexual dysfunction in dialysis patients (16,29). Nonetheless, screening for female sexual dysfunction could potentially be justified if women were eager to understand the cause(s) of this problem and pursue available treatment options. Our findings suggest that this is not the case. Very few women in our study indicated an interest in understanding the causes of and treatment options for sexual difficulty. This finding, coupled with the observation that most women on chronic dialysis

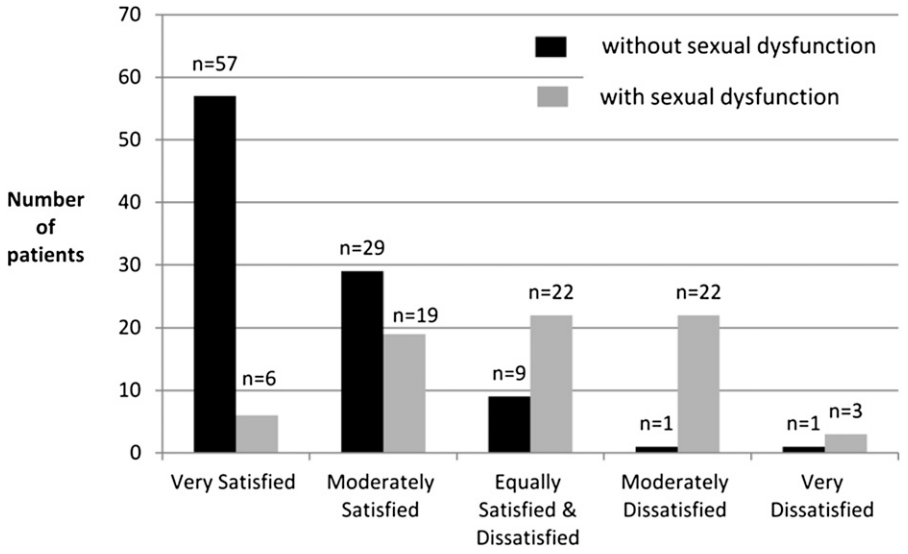

Figure 2. | **Comparison of overall satisfaction among sexually active women with and without sexual dysfunction**.

are satisfied with their sexual life, argues against routine screening for female sexual dysfunction in the dialysis setting.

It is interesting to compare certain of our findings with those in patients without ESRD. In a study of older community-dwelling women, Trompeter *et al.* reported that approximately 50% were sexually inactive based on a one-time assessment of sexual function (30). Among these women, 47% were living with a partner. Comparatively, 64% of our patients reported never being sexually active during the course of our study; just 35% of these participants were living with a partner. However, a considerably greater proportion of sexually inactive women in our study (75%) reported being moderately or very satisfied with their sexual life compared with sexually inactive women in the non-ESRD cohort (49%). Similarly, Baser *et al.* administered the FSFI to female cancer survivors, focusing on sexually active women (31). Approximately 50% of female cancer survivors were moderately to very satisfied with their overall sexual life, whereas 64% of sexually active women in our study reported being moderately to very satisfied with their overall sexual life. These findings seem to suggest that women on chronic dialysis, independent of sexual activity, may be particularly satisfied with their overall sexual life. Whether this could relate to demographic and/or clinical differences across patient groups, differing expectations based on underlying comorbid illness burden, or unique aspects of the dialysis experience is not clear.

Our study has certain limitations. First, our study population was composed of patients from a single geographic area who were participating in a clinical trial and may not be generalizable to the broader population of women on chronic dialysis. Second, although the median age of our patients (64 years) is not significantly different from the average age of the overall population of women receiving hemodialysis (61 years), our study population generally consisted of older women. Therefore, our findings may not be generalizable to younger dialysis patients, who may have different expectations and views regarding their sexuality and sexual life. Third, although the modified FSFI and monthly three-question survey have face validity, they were not formally validated before use in this study. Fourth, it is possible that patients' sexual function may have been influenced by their participation in a trial comparing symptom management interventions. We believe this to be unlikely because the treatment interventions for sexual dysfunction in the SMILE trial were focused on men with erectile dysfunction. Female participants in the higher-intensity intervention arm who had sexual dysfunction were offered the opportunity to be referred to a gynecologist, yet only two patients selected this option and only one patient received treatment for problems with lubrication. Finally, we adjusted the survey administration schedule subsequent to the start of the study. However, we believe that this change improved the quality and validity of our data.

In conclusion, true sexual dysfunction among women on chronic hemodialysis, particularly older patients, is considerably less common than previously reported. Differentiating sexual dysfunction from sexual inactivity is essential, because many women on chronic hemodialysis are not sexually active, but do not appear to be bothered by this. These findings suggest that efforts to assess and treat sexual dysfunction among women on dialysis may require one-on-one discussions between renal providers and patients to identify those women who truly suffer from this problem and wish to consider treatment.

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Disclosures

None.

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See related editorial, "Sexual Inactivity among Hemodialysis Patients: The Patients' Perspective," on pages 6–7.