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Sexual Desire, Distress, and Associated Factors in Premenopausal Women: Preliminary Findings from the Hypoactive Sexual Desire Disorder Registry for Women

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This article presents data from a validation sample of 390 premenopausal women clinically diagnosed with hypoactive sexual desire disorder (HSDD) enrolled in the HSDD Registry for Women. Participants completed validated measures of sexual distress (e.g., Female Sexual Distress Scale Revised, Question 13) and sexual function including desire (e.g., Female Sexual Function Index). Results showed that lower levels of desire in these women were associated with diminished sexual satisfaction, increased sexually related distress, and fatigue or stress in the women's lives. In addition, the level of distress related to sexual desire decreased with age. The authors conclude that even among women with clinically diagnosed HSDD, the level of sexually related distress varies with situational factors, such as stress and fatigue.

Two elements have come to define *hypoactive sexual desire disorder* (HSDD). In particular, these are decreased or absent sexual desire and distress related to this decrease or absence of desire. Several definitions of HSDD

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have been offered in recent years. According to the *Diagnostic and Statistical Manual of Mental Disorders* (4th edition, text revision; *DSM-IV-TR*), HSDD is the "persistent or recurrent deficiency (or absence) of sexual fantasies and desire for sexual activity, which causes marked distress or interpersonal difficulty, and which is not better accounted for by a medical, substance-related, psychiatric, or other sexual condition." (American Psychiatric Association, 2000, p. 541). A consensus panel of the American Foundation of Urologic Diseases (Basson et al., 2000) defined it similarly, as did a more recent consensus of the International Consultation on Sexual Medicine (Basson et al., 2004). According to this definition, *HSDD* is defined as "absence of sexual fantasies, thoughts, and/or desire for, or receptivity to, sexual activity, which causes personal distress."

Recent epidemiologic studies using validated measures of sexual function and sexual distress in women found that sexual distress and dissatisfaction with sex life are highly correlated in women with decreased sexual desire (Leiblum, Koochaki, Rodenberg, Barton, & Rosen, 2006; Rosen et al., 2009). The Women's International Study of Health and Sexuality found that women reporting decreased sexual desire were approximately 11 times more likely to feel dissatisfied with their sex lives and 2.5 times more likely to feel dissatisfied with their marriage or partner relationship than were women who did not have low desire and distress (Leiblum, Koochaki, Rodenberg, Barton, & Rosen, 2006). Similarly, The Boston Area Community Health study, a population-based random sample survey, reported a 38.4% prevalence rate of sexual problems among sexually active women, while 34.9% of participants with sexual problems also reported dissatisfaction with their overall sex lives. Age was strongly and positively associated with sexual problems as well as depression, sexual and physical abuse in adulthood, global mental health functioning, and alcohol use (Lutfey, Link, Rosen, Wiegel, & McKinlay, 2009).

Previous studies have examined correlates of sexual distress, but not the relationship between decreased desire and sexual distress. Results from a recent cross-sectional survey study of female adults in the United States (Prevalence of Female Sexual Problems Associated With Distress and Determinants of Treatment Seeking) showed that correlates of sexual distress include poor self-assessed health, low education level, current depression, anxiety, thyroid condition, and urinary incontinence (Shifren, Monz, Russo, Segreti, & Johannes, 2008). A national survey of women in the United States found that the best predictors of sexual distress were lack of emotional well-being and negative emotional feelings during sexual interaction with a partner (Bancroft, Loftus, & Long, 2003).

The present study aimed to identify the degree to which the two key diagnostic components of HSDD (decreased desire and personal distress) are correlated with each other in a sample of premenopausal women with clinically diagnosed HSDD. A secondary aim was to assess the relation of

other domains of sexual dysfunction (orgasmic dysfunction, overall dissatisfaction with sex life, arousal difficulties, lack of lubrication, and pain) with sexual distress and other relevant predictor variables in this diverse sample of women. We conducted multivariate analyses specifically to examine correlates of distress related to decreased sexual desire among our validation study sample of premenopausal women with HSDD.

METHODS

Study Design

A longitudinal, observational (i.e., noninterventional) registry study of women clinically diagnosed with HSDD, the HSDD Registry for Women, is currently under way at 18 clinical sites throughout the United States (Maserejian et al., 2010; Rosen, Connor, & Maserejian, 2010). All women in the Registry have a clinician-confirmed diagnosis of HSDD. Enrollment began on June 27, 2008, and as of June 15, 2009, a total of 400 premenopausal women were enrolled. Enrollment of approximately 1,000 premenopausal women with diagnosed HSDD at approximately 40 clinical sites is planned over a total of 24 months.

To be eligible to participate, women must be 18 years or older, and have a confirmed diagnosis of HSDD by a clinician within 3 months of enrollment. Confirmation of the diagnosis is determined by a validated instrument, the Decreased Sexual Desire Screener (Clayton et al., 2009), administered in-person by a site clinical investigator (primarily obstetric/gynecologists and sexual medicine experts). Investigators are selected on the basis of (a) their individual clinical and research experience in assessment and management of HSDD and (b) their willingness to use a standardized diagnostic approach. In addition, all site investigators and staff attend a standard in-person or Web-based training on the HSDD *DSM-IV-TR* diagnostic criteria captured by the DSDS. Women are excluded if they are participating in a clinical trial, have a chronic medical or psychiatric condition that may interfere with participation in the Registry in the opinion of the investigator, or are non–English-speaking. Women are recruited at clinic sites from current and new patient databases as well as local advertisements.

The Decreased Sexual Desire Screener used to confirm the clinician-based diagnosis of generalized, acquired HSDD is made up of five questions: the first four assess symptoms of HSDD and the fifth is a multi-item question to assist the clinician in the diagnosis of HSDD. The DSDS provides a diagnosis of primary HSDD, and does not exclude women with other female sexual disorders such as female arousal disorder or sexual pain that often occur as comorbidities, but it has the important capability of differential diagnosis, or ruling out diagnosis of other clinically relevant conditions. The DSDS was developed to provide both expert and nonexpert clinicians in the field of

sexual medicine with a validated brief, reliable, standardized diagnostic instrument for generalized acquired HSDD in women (Clayton et al., 2009). In a recent validation study at 27 sites in North America, the Decreased Sexual Desire Screener was administered to 263 women by a nonexpert clinician and compared the results to a standard diagnostic interview conducted by a clinician with expertise in sexual dysfunction. The majority of diagnoses by Decreased Sexual Desire Screener and standard diagnostic interview were the same in 85.2% of the women. The sensitivity and specificity of the Decreased Sexual Desire Screener were 84% and 88%, respectively (Clayton et al., 2009).

The Registry consists of both patient-based and clinician-based assessments. At baseline, all women complete a self-administered questionnaire consisting of validated measures of distress (Female Sexual Distress Scale-Revised [FSDS-R], Question 13) and sexual function and desire (Female Sexual Function Index) as well as a number of questions regarding biomedical and psychosocial functions. The self-administered questionnaire is completed at the clinical site on a secure Web site by means of a computer assisted self-administered interview or with paper-and-pencil if a computer is not available.

MEASURES

Female Sexual Function Index

The Female Sexual Function Index is a brief, validated 19-item self-report measure used for assessing female sexual function (Rosen et al., 2000) and consists of six domains: desire, arousal, lubrication, orgasm, satisfaction, and pain. Higher scores on the Female Sexual Function Index equate to better sexual function. The Index was developed in a validation study with a sample of 131 normal controls (*M* age = 40.5 years, *SD* = 12.98 years) and 128 age-matched subjects (*M* age = 39.7 years, *SD* = 13.15 years; Rosen et al., 2000). All subjects met *DSM-IV-TR* criteria for a clinical diagnosis of female sexual arousal disorder, whereas the controls reported no problems with sexual function, were sexually active and in a stable heterosexual relationship. Factor analyses established all six domains, and test–retest reliability of the measure was confirmed. The Female Sexual Function Index has also been shown to have discriminant validity, the ability of the measure to differentiate between patients with female sexual arousal disorder and controls, on each of the six domains of sexual function and the full scale score (Rosen et al., 2000).

A further validation study was performed in 71 women with female orgasmic disorder (*M* age = 29.4 years, *SD* = 8.76 years), 44 women with HSDD (*M* age = 33.0 years, *SD* = 10.42 years), and 71 controls (*M* age = 29.2 years, *SD* = 7.9 years; Meston, 2003). High internal consistency coefficients of .79 or higher were found for all of the domain scores among women

with female orgasmic disorder. High interitem correlations were also found for Female Sexual Function Index total scores among the three groups of women. Discriminant validity was confirmed (a) between women with female orgasmic disorder and controls and (b) between women with HSDD and controls (Meston, 2003). This study confirmed that the Female Sexual Function Index is a reliable and valid measure of sexual function in women with FOD (female orgasmic disorder) and HSDD, in addition to HSDD alone.

FSDS-R, Question 13

The FSDS-R is a revised version of the FSDS, a standardized, quantitative measure of sexually-related distress in women (Derogatis, Rosen, Leiblum, Burnett, & Heiman, 2002). The original FSDS 12-item scale has been shown to distinguish between women with sexual dysfunction and those without as well as able to measure sexually related personal distress in women with HSDD (Derogatis, Rosen, Leiblum, Burnett, & Heiman, 2002). The FSDS-R has the same questions as the FSDS does, with the exception of one additional question (Question 13), which asks women, "Are you bothered by low sexual desire?" reported on a 5-point Likert-type scale ranging from 0 (*never*) to 4 (*always*) (Derogatis, Clayton, Lewis-D'Agostino, Wunderlich, & Fu, 2008). Low desire-related personal distress with a recall period of one month at baseline is determined by the FSDS-R Question 13 in the HSDD Registry.

The FSDS-R was validated in a study of 261 women. Of these women, 138 (*M* age = 38.4 years) had a *DSM-IV-TR* diagnosis of HSDD, 48 (*M* age = 32.4 years) had another female sexual disorder, and 75 (*M* age = 34.7 years) had no female sexual disorder. The score for Question 13 differed significantly between women with HSDD and those with no female sexual disorder ($p < .001$). Good discriminant validity and test–retest reliability was confirmed for the FSDS-R Question 13 alone (Derogatis, Clayton, Lewis-D'Agostino, Wunderlich, & Fu, 2008).

Data Analysis

Baseline data were available for 400 premenopausal women enrolled in the Registry from June 27, 2008, to June 15, 2009. We excluded 10 premenopausal women from this analysis for not meeting the criteria for HSDD because of missing or incomplete data on level of distress as assessed by the FSDS-R Question 13 (i.e., reported "never" or "rarely" on FSDS-R Question 13), leaving 390 women for inclusion in the present analysis. The 390 women in this analysis were separated into three categories of sexual distress—*occasionally* ($n = 88$), *frequently* ($n = 219$), and *always* ($n = 83$)—on the basis of self-report responses to the FSDS-R Question 13. We calculated correlations between the Female Sexual Function Index domain and total scores for the total sample ($N = 390$). In secondary analyses,

we restricted the sample to the subset of women who were sexually active ($n = 337$, 89% of the total sample).

Summary measures (means, standard deviations, and ranges for continuous variables and number of responses and percentages for categorical variables) are reported for each variable overall and by frequency of distress. We used a multinomial generalized linear model with a cumulative logit link function to predict the frequency of distress (Agresti, 1990). We selected variables for the model on the basis of expected associations and associations reported in published data. We included these variables in the initial model, and we used backward selection to eliminate nonsignificant variables ($p > .05$). Last, we added variables back one at a time to come up with the final model. We performed all statistical analyses using SAS statistical software (Version 9.2).

RESULTS

Participant Characteristics

A summary of the characteristics of the participants included in these analyses are presented in Table 1. All women in the Registry, by necessity of the diagnostic inclusion criteria, experience sexually related distress; however, the frequency or intensity of distress may vary among women with HSDD and may vary within women over time. Of the 390 women in this analysis, 83 (21.3%) reported "always" feeling distressed by their decreased sexual desire, 219 (56.2%) reported "frequently" feeling distressed and 88 (22.6%) reported "occasionally" feeling distressed in the past month. Participants were between the ages of 18 and 55 years ($M = 35.8$ years, $SD = 8.7$ years). The majority of women were White (71.5%) with the next highest group being Black (14.4%). More than 80% of women reported being married or living with a partner, while 13.1% of women reported their relationship status as single. Most women reported being in a relationship for at least 1 year, with the largest group of women having been in a relationship for 10–20 years (29.2%), and more than half of the women having their sexual desire problem for 1–5 years. Age differences were apparent by the level of distress, displaying a pattern in which women in the occasional distress group were on average the oldest ($M = 38.0$ years, $SD = 9.4$ years), women in the frequently distressed group were on average younger ($M = 35.8$ years, $SD = 8.4$ years), and women in the always distressed group tended to be the youngest in our sample ($M = 33.5$ years, $SD = 8.4$ years).

Sexual Function and Distress Measures

Registry participants had low levels of overall sexual function (total Female Sexual Function Index score: $M = 16.4$, $SD = 6.3$). This mean total Female Sexual Function Index score is considerably lower than the validated

TABLE 1. Participant Characteristics From a Preliminary Sample ($N = 390$) of Premenopausal Women in the HSDD Registry for Women

	Sexual desire–related distress**			
	Total	Occasionally	Frequent	Always
n	390	88	219	83
Age, years				
Mean ± *SD*	35.8 ± 8.7	38.0 ± 9.4	35.8 ± 8.4	33.5 ± 8.4
Range	(18, 55)	(22, 55)	(19, 54)	(18, 52)
Race				
Hispanic	38 (9.7%)	9 (10.2%)	22 (10.1%)	7 (8.4%)
Black	56 (14.4%)	8 (9.1%)	29 (13.2%)	19 (22.9%)
Other	17 (4.4%)	3 (3.4%)	11 (5.0%)	3 (3.6%)
White	279 (71.5%)	68 (77.3%)	157 (71.7%)	54 (65.1%)
Marital status				
Married	239 (61.3%)	52 (59.1%)	137 (62.6%)	50 (60.2%)
Living with partner	74 (19.0%)	12 (13.6%)	46 (21.0%)	16 (19.3%)
Single, never married	51 (13.1%)	19 (21.6%)	21 (9.6%)	11 (13.3%)
Other	26 (6.7%)	5 (5.7%)	15 (6.9%)	17 (7.2%)
Duration of relationship				
Less than 1 year	22 (5.6%)	6 (6.8%)	9 (4.1%)	7 (8.4%)
1–5 years	107 (27.4%)	18 (20.5%)	64 (29.2%)	25 (30.1%)
5–9 years	89 (22.8%)	14 (15.9%)	51 (23.3%)	24 (28.9%)
10–20 years	114 (29.2%)	29 (33.0%)	65 (29.7%)	20 (24.1%)
>20 years	44 (11.3%)	13 (14.8%)	25 (11.4%)	6 (7.2%)
Not in a relationship	14 (3.6%)	8 (9.1%)	5 (2.3%)	1 (1.2%)
Duration of desire problem				
Less than 6 months	20 (5.1%)	2 (2.3%)	9 (4.1%)	9 (10.8%)
6–11 months	64 (16.4%)	11 (12.5%)	41 (18.7%)	12 (14.5%)
1–5 years	211 (54.1%)	49 (55.7%)	117 (53.4%)	45 (54.2%)
>5 years	95 (24.4%)	26 (29.6%)	52 (23.7%)	17 (20.5%)
Partner's desire now compared to in the past*				
Much lower/somewhat lower	97 (24.9%)	25 (28.4%)	58 (26.5%)	14 (16.9%)
Same level	189 (48.5%)	39 (44.3%)	107 (48.9%)	43 (51.8%)
Somewhat greater/much more	90 (23.1%)	16 (18.2%)	49 (22.4%)	25 (30.1%)
Not in a relationship	14 (3.6%)	8 (9.1%)	5 (2.3%)	1 (1.2%)
Reported stress or fatigue as contributors to HSDD				
Yes	254 (65.1%)	61 (69.3%)	153 (69.9%)	40 (48.2%)
No	136 (34.9%)	27 (30.7%)	66 (30.1%)	43 (51.8%)
Relationship happiness***				
Unhappy	111 (30.3%)	27 (30.7%)	66 (30.3%)	25 (30.1%)
Happy	106 (27.2%)	22 (25.0%)	57 (26.1%)	27 (32.5%)
Very happy	151 (38.8%)	31 (35.2%)	90 (41.3%)	30 (36.1%)
Not in a relationship	14 (3.6%)	8 (9.1%)	5 (2.3%)	1 (1.2%)
Self-assessment of health				
Excellent/very good	244 (62.6%)	51 (58.0%)	135 (61.6%)	58 (69.9%)
Good	122 (31.3%)	31 (35.2%)	69 (31.5%)	22 (26.5%)
Fair/poor	24 (6.1%)	6 (6.8%)	15 (6.8%)	3 (3.6%)
Ever used oral contraceptives				
Yes	111 (28.5%)	29 (33.0%)	62 (28.3%)	20 (24.1%)
No	279 (71.5%)	59 (67.1%)	157 (71.7%)	63 (75.9%)

Note. These interim data describe participants recruited from June 27, 2008, to June 15, 2009. Recruitment of additional participants is ongoing and will continue until 1,000 premenopausal women are enrolled. HSDD = hypoactive sexual desire disorder.

*Assessed by asking participants "How would you rate your partner's desire to have sex with you now compared to when you started your relationship?" with response options of (1) much lower desire now, (2) somewhat lower desire now, (3) same level of desire, (4) somewhat greater desire now and (5) much more desire now.

**Sexual desire–related distress is measured by the Female Sexual Distress Scale-Revised, Question 13.

***One woman did not answer this question.

TABLE 2. FSFI Scores and Correlations Between Sexual Desire–Related Distress and FSFI Scores From a Preliminary Sample ($N = 390$) of Premenopausal Women in the HSDD Registry for Women

	Sexual desire–related distress[§]				
n FSFI scores) (range)	Total 390 *(M ± SD)*	Occasionally 88 *(M ± SD)*	Frequent 219 *(M ± SD)*	Always 83 *(M ± SD)*	Total 390 Correlation coefficient
Desire (1–5)	2.0 ± 0.8	2.3 ± 0.8	1.9 ± 0.8	1.6 ± 0.7	–0.30
Arousal (0–5)	2.3 ± 1.2	2.6 ± 1.4	2.3 ± 1.1	1.9 ± 1.1	–0.21
Lubrication (0–5)	3.0 ± 1.7	3.2 ± 1.7	3.1 ± 1.6	2.4 ± 1.6	–0.17
Orgasm (0–5)	2.5 ± 1.7	3.0 ± 1.9	2.5 ± 1.6	2.0 ± 1.6	–0.20
Satisfaction* (1–5)	2.6 ± 1.2	2.9 ± 1.2	2.6 ± 1.2	2.2 ± 1.2	–0.19
Pain (0–5)	3.9 ± 2.2	3.9 ± 2.4	4.0 ± 2.1	3.8 ± 2.2	–0.01**
Total* (2–36)	16.4 ± 6.3	18.2 ± 7.0	16.5 ± 5.7	14.0 ± 6.2	–0.22

Note. Negative correlations are seen between the FSFI and the FSDS-R, Question 13. This is the result of FSFI scores increasing as sexual function improves, while FSDS-R, Question 13 score decreases as distress improves. These interim data describe participants recruited from June 27, 2008, to June 15, 2009. Recruitment of additional participants is ongoing and will continue until 1,000 premenopausal women are enrolled. HSDD = hypoactive sexual desire disorder; FSFI = Female Sexual Function Index; FSDS-R = Female Sexual Distress Scale-Revised.

*Information for the satisfaction domain was not available for 8 women.

**All correlations were statistically significant ($p < .05$) except for the correlation between pain and FSDS-R, Question 13 ($p = .86$).

[§]Measured by the FSDS-R, Question 13.

Female Sexual Function Index clinical cutoff of 26.5 for overall sexual dysfunction in women with HSDD and other sexual problems (Wiegel, Meston, & Rosen, 2005). Furthermore, the mean Female Sexual Function Index score for Registry participants is also lower than norms observed in the original validation sample, which included women with female sexual arousal disorder (reported total Female Sexual Function Index score: $M = 19.2$, $SD = 6.6$; (Rosen et al., 2000), as well as compared with a separate study of women with HSDD (reported total Female Sexual Function Index score: $M = 19.7$, $SD = 4.3$; Meston, 2003).

Table 2 presents the Female Sexual Function Index scores for women in the HSDD Registry separated by distress categories. As is evident, decreasing levels of desire are associated with increasing levels of distress. Table 2 also shows the Pearson correlations for these variables. Higher scores on the Female Sexual Function Index indicate better sexual functioning, whereas higher scores on the FSDS-R indicate increased distress. Therefore, negative correlations between the Female Sexual Function Index and the FSDS-R Question 13 were expected and are evident from the results. Moreover, we observed significant correlations with distress, with the exception of the sexual pain domain. In contrast with the other domains of sexual function, sexual pain scores were not correlated with distress in this sample of women with clinically diagnosed HSDD ($r = –0.01$, $p = .86$). Furthermore, the sexual

TABLE 3. Correlation Coefficients Between FSFI Total and Individual Sexual Function Domains From a Preliminary Sample ($N = 390$) of Premenopausal Women in the HSDD Registry for Women

Female Sexual Function Index domain	1	2	3	4	5	6	Total
1. Desire	1.00	0.49	0.32	0.27	0.37	0.14	0.48
2. Arousal		1.00	0.68	0.74	0.48	0.42	0.84
3. Lubrication			1.00	0.57	0.42	0.52	0.83
4. Orgasm				1.00	0.40	0.32	0.76
5. Satisfaction					1.00	0.31	0.65
6. Pain						1.00	0.71
Total							1.00

Note. These interim data describe participants recruited from June 27, 2008, to June 15, 2009. Recruitment of additional participants is ongoing and will continue until 1,000 premenopausal women are enrolled. HSDD = hypoactive sexual desire disorder.

desire domain scores had a moderate, significant correlation with distress ($r = –0.30$, $p < .001$), as predicted.

Correlations Among Sexual Function Domains

Table 3 summarizes the correlations between the Female Sexual Function Index total and individual domain scores. In this group of women with generalized, acquired HSDD, sexual function was impaired across multiple domains of sexual function. Results were similar in sensitivity analyses that excluded women who were sexually inactive according to their responses on the Female Sexual Function Index (data not shown).

Model-Building Results

The associations between sexual function domain scores and distress related to lack of desire are presented in Table 4. In these unadjusted bivariate models, each domain of sexual function, with the exception of sexual pain (dyspareunia), had a significant association with sexually related distress. Distress tended to be higher as sexual function domain scores decreased. However, when each domain was examined in a model controlling for the sexual desire domain score, the independent effects of other sexual function domains on distress were no longer statistically significant.

Table 5 shows the results of the full multivariate analysis modeling. The model demonstrated that for each one point increase in the Female Sexual Function Index desire score, women were about half as likely to report more frequent distress (OR = 0.45, 95% CI [0.34, 0.59], $p < .001$). Older premenopausal women were also less likely to report higher levels of distress. For each year increase of age, the risk of reporting more frequent distress decreases by about 5% (OR = 0.95, 95% CI [0.93, 0.98], $p < .001$).

TABLE 4. Bivariate Association Between Sexual Function Domains and Personal Distress Over Decreased Sexual Desire Among a Preliminary Sample (N = 390) of Premenopausal Women in the HSDD Registry for Women

Female Sexual Function Index domain	Unadjusted odds ratio (95% CI)	p
Desire	0.44 [0.34, 0.58]	<.001
Arousal	0.68 [0.57, 0.81]	<.001
Lubrication	0.81 [0.72, 0.92]	<.001
Orgasm	0.78 [0.70, 0.88]	<.001
Satisfaction	0.74 [0.62, 0.87]	<.001
Pain	0.99 [0.91, 1.09]	0.86

Note. These interim data describe participants recruited from June 27, 2008, to June 15, 2009. Recruitment of additional participants is ongoing and will continue until 1,000 premenopausal women are enrolled. HSDD = hypoactive sexual desire disorder.

Women who perceived that stress or fatigue contributed to their decreased desire were 47% less likely to report more frequent levels of sexual distress (OR = 0.53, 95% CI [0.35, 0.82], p = .004). The multivariate modeling also found that women who felt that their partner's level of sexual desire was greater now than in the past were more likely to report more frequent distress caused by low desire. In addition, women who reported ever using oral contraceptives were less likely to report frequent distress.

DISCUSSION

Current definitions of HSDD emphasize (a) diminished sexual desire, and (b) presence of related distress. In this preliminary sample of premenopausal women from the HSDD Registry for Women, we examined baseline associations between key sexual function variables and related distress measures. Given the importance of both components of diminished desire and related

TABLE 5. Multivariate Model Results of Factors Associated with Personal Distress Over Decreased Sexual Desire Among a Preliminary Sample (N = 390) of Premenopausal Women in the HSDD Registry for Women

Variable	Adjusted odds ratio (95% CI)	p
Female Sexual Function Index desire domain score	0.45 [0.34, 0.59]	<.001
Age	0.96 [0.93, 0.98]	<.001
Any stress or fatigue	0.54 [0.35, 0.82]	.004
Perceived partner desire	1.34 [1.11, 1.62]	.002
Ever use oral contraceptives	0.55 [0.34, 0.87]	.01

Note. These interim data describe participants recruited from June 27, 2008, to June 15, 2009. Recruitment of additional participants is ongoing and will continue until 1,000 premenopausal women are enrolled. HSDD = hypoactive sexual desire disorder.

distress in the diagnosis of HSDD, we aimed to increase understanding of the relative contributions of these different components.

Overall, our results showed that the sexual function and distress measures had low-to-moderate correlations with each other. Of note, the sexual desire domain and the sexual arousal domain scores had similar, moderate negative correlations with desire-related distress. In the unadjusted bivariate model, each domain of sexual function, with the exception of sexual pain (dyspareunia), was significantly associated with distress related to low desire. A lack of association with the pain domain may have resulted from the fact that most of these women with clinically diagnosed HSDD did not frequently experience sexual pain; furthermore, among the minority with coexisting sexual pain problems, there may have been less distress specifically due to desire, and more due to painful aspects of sex. Distress related specifically to sexual pain was not assessed in the HSDD Registry. Last, the correlations observed were almost identical regardless of whether sexually inactive women were included in the analysis.

Although only modest correlations were seen between separate measures of desire and distress, our multivariate analyses confirmed that low sexual desire is still the key determinant of distress frequency. The association between low desire and distress was highly significant in the multivariate model, and showed that for each unit increase in the desire domain score, women had half the odds of reporting frequent distress. Because lack of sexual desire is strongly associated with distress, our findings support the *DSM-IV-TR*-based definition of HSDD. These findings underscore the need for future research to include validated measures of low desire and desire-related distress for the diagnosis and definition of HSDD.

On the basis of our multivariate analyses, age, presence of other situational factors, such as stress or fatigue, and the perceived level of partner's sexual desire played a significant role in mediating distress. The potential effects of stress or fatigue could be explained by the fact that stress or fatigue factors may have caused some women as much or greater distress than HSDD, which may diminish a sense of distress as a result of lack of sexual desire. These interactions warrant further investigation. Baseline levels of sexual dysfunction (Female Sexual Function Index scores) and desire-related distress were similar in our study to levels of these measures in women with low desire and distress reported in other large-scale observational and psychometric studies, indicating that our results are potentially generalizable to the larger population of women with HSDD. As expected, the women in our HSDD Registry had low Female Sexual Function Index total scores ($M = 16.4$, $SD = 6.3$), low levels of sexual desire ($M = 2.0$, $SD = 0.8$), and the majority reported "frequent" to "always" experiencing personal distress related to their lack of desire. These findings are consistent with scores obtained from other samples of women with HSDD (Meston, 2003; Rosen, 2000). We also observed associations between the sexual desire and arousal domains, as in previous studies, supporting the proposed overlap of these two

primary sexual function domains in women. Similar findings were reported in the original validation study of the Female Sexual Function Index (Rosen et al., 2000), and in other more recent psychometric studies of sexual function and dysfunction in community-dwelling women (Meston, 2003; Wiegel et al., 2005). Our results were consistent whether sexually inactive women were included in the analyses, which addresses the critique that the Female Sexual Function Index may have scoring problems for sexually inactive women. In addition, using the FSDS-R Question 13 (Meyer-Bahlburg & Dolezal, 2007), results confirmed that these premenopausal participants in the HSDD Registry had frequent personal distress, with a mean of 3.0 ($SD = 0.7$). These results are similar to the results obtained in a recent validation study of the FSDS-R, in which the average score on FSDS-R Question 13 among women with HSDD was 3.1 ($SD = 0.8$; Derogatis et al., 2008).

A large sample of women ($n = 400$) participated in this validation study. The results were generally consistent across measures in our study, as well as in comparison with other recent, large-scale observational studies. This lends internal and external validity to the findings reported here. Longitudinal analyses in subsequent years on the full Registry sample will address the limitations of our cross-sectional design. The primary strength of this Registry sample is that all participants received a clinician-confirmed diagnosis according to standard *DSM-IV* criteria, and they were selected from a variety of clinical sources. Additional strengths of the study include the use of validated measures of sexual distress and sexual function, including desire, and the extremely limited exclusion criteria. Our sample is highly diverse and is designed to serve as a highly generalizable sample (i.e., high external validity) of premenopausal women with HSDD.

In this analysis, we attempted to delineate which factors are associated with distress over low desire in premenopausal women with HSDD. The implications of these findings for clinicians are worth noting. First, the co-occurrence of distress, low desire and lack of arousal is evident in our sample, and should be addressed by clinicians routinely in the evaluation and history taking of HSDD in women. Second, the strong influence of patient's age, ongoing stress or fatigue, the patient's perception of her partner's desire levels, and oral contraceptive use should be considered and evaluated in each case. Last, these findings provide strong support for the use of current measures of sexual distress and desire in the HSDD Registry and other large-scale studies of sexual dysfunction in women.

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