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Field Testing of ICD-11 Proposals for Female Sexual Dysfunctions in India: Cognitive Interviews with Patients

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Background. Women's experiences of female sexual difficulties are shaped by cultural expectations.

Aim of the study. To investigate the cultural validity and clinical utility of the classification of female sexual dysfunctions (FSD) in the International Classification of Diseases - 11th Revision (ICD-11) among Indian Women.

Methods. A purposive sample of 22 married women with probable sexual problems underwent cognitive interviews that were conducted using a semi-structured guide. The interviews were transcribed and analyzed qualitatively to help establish the content and cultural validity of the ICD-11 classification of FSD.

Results. Most participants had limited knowledge of the sexual act, felt unskilled in sex, and were led by their husbands in sexual matters. Many participants reported problems related to sexual dysfunction and sexual pain-penetration. Many participants with sexual pain–penetration issues and some with low sexual desire considered these symptoms to be problematic; however, this was rarely the case with the absence or lack of sexual arousal and orgasm. The application of the 'independent focus of clinical attention' requirement for diagnosis reduced cases by half for Hypoactive Sexual Desire Disorder (HSDD) and almost eliminated all cases of Female Sexual Arousal Dysfunction (FSAD) and Anorgasmia. Hence, this requirement was moved from essential (required) features to 'additional features' of the final ICD-11 sexual dysfunction guidelines.

Conclusion. Advancement toward a more precise nomenclature and classification system of FSD will facilitate better diagnosis which will ultimately lead to improved care for women with sexual dysfunction.

Key Words: Sexual dysfunctions, Psychological, Sexuality, Classification, International Classification of Diseases, Developing countries.

Introduction

The Eleventh Revision of the *International Classification of Diseases and Related Health Problems* (ICD-11) was approved by the World Health Assembly in May 2019. Reporting of health information by WHO member states using the ICD-11 as a framework will begin in 2022. The ICD-11 has created a separate chapter on conditions related to sexual health that integrates sexual dysfunctions from the ICD-10 chapters on mental health and behavioural disorders and diseases of the genitourinary system (1). Sexual dysfunctions are described as clinically significant disturbances in a person's ability to respond sexually or experience sexual pleasure regardless of the presumed cause. Sexual dysfunctions are classified by phases, including desire, arousal, and orgasmic dysfunctions, and apply to both women and men unless there are distinct clinical presentations (e.g. female sexual arousal dysfunction, erectile dysfunction, and ejaculatory dysfunction) (2). The chapter also includes a separate

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grouping of sexual pain disorders, including sexual pain-penetration disorder.

Epidemiological studies suggest that female sexual dysfunction (FSD) is common. A consensus statement from the fourth International Consultation on Sexual Medicine (ICSM) in 2015 asserted that the prevalence of women's sexual complaints regardless of age is around 40–50% (3). However, not all women experiencing sexual problems are distressed by it. For example, a survey of US women aged 30–70 years found that though 36.2% of women experienced low sexual desire, only 8.3% met the DSM-IV criteria for hypoactive sexual desire disorder (i.e. low sexual desire and clinical distress) (4). The PRESIDE study (Prevalence of Female Sexual Problems Associated with Distress and Determinants of Treatment Seeking) of 50,001 US women confirmed these findings in reporting a prevalence of 8.9% (18–44 years), 12.3% (45–64 years), and 7.4% (65 years and older) for hypoactive sexual desire disorder (HSDD) in different age groups (5). The estimated prevalence for pain-penetration complaints is also high and affects about a quarter of women (6).

Laumann EO, et al. (7) had classified countries as belonging to gender equal (mostly Western European and non-European English speaking developed nations) and male-centered (mostly Mediterranean and Asian) regimes based on cluster analysis of data on cross-national variation of various aspects of sexual well-being drawn from the Global Study of Sexual Attitudes and Behaviors that was conducted in 29 countries (7). According to a meta analysis of prevalence studies on FSD, the global prevalence of these dysfunctions was estimated at 41%; with the prevalence in 'male centred' regimes being similar to that in 'gender equal' regime (8). Prevalence rates similar to global figures of FSD have also been reported in surveys of clinical populations in India (9–11). It has also been shown that these problems have a negative impact on women's interpersonal relationships and quality of life even in Asian countries (11–13). However, there is a much lower rate of treatment seeking and treatment adherence for female sexual problems in Asian countries even when services are available (9,14–17). This could be because many women with sexual problems may see their sexual experiences as a natural process of life, or as issues related to social or marital role (e.g., role of a wife to please her husband) rather than as a medical one (17–19).

Diagnosis of FSD can be contentious due to concerns that human experiences considered ''normal'' are being redefined as ''medical problems'' instead of being seen as variations of women's sexual experiences (17,20). People may perceive and understand sexuality differently. Qualitative studies show that women's experiences of female sexual difficulties are shaped by cultural expectations. For example, Nicolson and Burr reported that many women viewed female orgasm essentially as an action through which male sexual fulfilment was to be achieved (21). Kaler found that a group of American women with vulvar pain saw their inability to perform penetrative intercourse as a personal defect (22). Bellamy et al stated that contextual issues, particularly partners and relationships, determine how women understand their sexual problems and how they respond to such problems (23). And, Muhamad et al reported that Malay women understood sexuality in terms of intimacy within marriage and as linked to meanings attributed to procreation (19).

Women of different ethnic backgrounds demonstrate different patterns of sexual dysfunction, suggesting a role for cultural factors in their presentation (24). Some studies from Asian countries have suggested lower rates of sexual problems, subjective sexual arousal and pleasure from genital stimulation in Asian women as compared to their western counterparts (25,26). Unlike their western counterparts, Asian women also tended to present more with somatic complaints, suggesting a need to be alert to local idioms of distress (27).

The ICD-11 was developed with the goal to enhance clinical utility, provide clearly organized and consistent information across disorders, and yet be flexible enough to allow for cultural variations (1). In many low- and middle-income countries, challenges in identification (and treatment) of FSD include women's, caregivers'/partners' and clinicians' discomfort with the topic, reproduction-focused cultures, inadequate clinician training, and limited available time to elicit an in-depth sexual history (12,18,28). There is thus a need for field testing the ICD-11 classification of FSD in women of low- and middle-income countries to assess its cultural validity (to avoid medicalization of normal human sexual response and experience) and utility.

Methodology

The present study was conducted at All India Institute of Medical Sciences (AIIMS) in New Delhi and employed a cross-sectional observational design drawing on a purposive sample of 22 women (recruited from January 2017–July 2018). The participants were recruited through referral from various sources: sex and marital clinics, gynaecology outpatient department (OPD), psychiatry OPD, and patients known to professionals and health workers from other departments and snowball sampling (referral by women known to have FSD). The inclusion criteria were: female gender, acknowledgement of sexual complaints during clinical assessment, age 18 years or older, and ability to comprehend and speak in Hindi. Participants not providing informed consent, and those with clinical diagnoses that would have interfered with their ability to comprehend and participate in the interview were excluded. Fifteen participants were referred from Gynaecology OPD, 5 from Psychiatry OPD and 2 from Dermatology OPD. Nine participants referred from Gynaecology OPD were seeking treatment for infertility, 2 for pregnancy loss, 2 for

gynaecological problems and 2 for sexual problems. Both participants referred from Dermatology OPD, were seeking treatment for pain related to sex. Four participants referred from Psychiatry were seeking treatment for other psychiatric conditions and one was a wife of a person having sexual problems. All participants were in the reproductive age group (23–42 years; average: 31.5 ± 5.4) and all were married. There were 19 Hindu and 3 Muslim participants. Fourteen participants were homemakers, 6 were skilled workers and 2 were mid-level executives. Ten participants had graduate or higher degrees, 10 had completed high school or undergraduate courses, and 2 had not completed secondary schooling. All of them were articulate in Hindi.

Each participant underwent a cognitive interview. The purpose of cognitive interviews was to help establish the content and cultural validity of the ICD-11 classification of female sexual dysfunctions. The cognitive interviews were conducted using a semi-structured interview guide that included questions on the type of sexual problems experienced, associated distress, impact on life, reporting of sexual issues to partners and/or significant others; reporting of sexual issues to service providers, and treatment seeking. Interviews were conducted in respectful, professional, and confidential manner in spaces that offered privacy. The author (SP), who is a trained clinical psychologist, underwent one-day training in the study protocol, which included familiarization with the ICD-11 FSD diagnostic guidelines and its comparison with ICD-10 guidelines (2 h), familiarization with the study protocol including the interview methods (2 h) and supervised interviews with 2 FSD patients referred from Psychiatry OPD (3 hours). The participants were asked the same questions that were to be used for the actual interviews. The researcher observed and took notes during the session and had access to the ICD-11 FSD diagnostic guidelines. The fact that the interviewer was a married (many participants enquired about it) lady helped as she was seen as someone who would be able to understand the issues that the participants experienced. The interviewer had to take an active stance in asking questions because respondents were hesitant in talking about sexuality and often lacked words to discuss issues related to sexuality and intimacy. A direct manner often helped participants open up and talk more frankly about sexual issues. Sometimes technical words had to be used, in such situations their lay definitions were provided, and the participant was allowed time to use and practice it in her own head and in conversation with the interviewer before going further with the interview. Sometimes question was prefaced by the interviewer talking of experiences of women in general before asking about the participant's personal experience; or stating something factual followed by a question about person's own experience. Topics were introduced starting with general questions about sexual matters and then moving to specific questions to elicit more detailed information about the person. Towards the end, information was provided and issues raised by the participants about sexual dysfunction were clarified. Treatment for sexual dysfunctionwas offered to those who wanted it.

Comments on classificatory issues were based on descriptive statistics. For qualitative analysis, the interviews were transcribed in full. Pseudonyms were used to maintain confidentiality. The transcripts were read and reread several times and potential emergent codes were identified. The process of transcribing and coding was done by the second author (SP). Then codes were combined and adjusted with reference to field notes; and the magnitude and interaction of codes were highlighted. The next step involved axial coding, where different codes were combined and adjusted to precise themes within and across participants' narratives. This was followed by discussion among Indian authors and revision of themes to ensure integration into detailed descriptions.

The AIIMS ethics committee evaluated the protocol. The participants provided written informed consent. Research officers were trained extensively to conduct the interviews and had experience in evaluating this population.

Approach to Violence and Vulnerability (and Consent Process)

To ensure safety of respondents (and the research team), respondents who volunteered to come to the clinic on being referred by a trusted other (health professional, friend) only were approached. Their relatives (including spouses) were not informed of the nature of the study, unless expressly told by the respondent. The interview guide did not contain questions on violence that could negatively alert their family members (including spouses) about the research. However, the respondents were queried about any risk of violence and explained that the participation in the research is voluntary and they could withdraw if participation entailed risk. Their confidentiality was ensured to support women's safety and data quality by interviewing them separately in safe private spaces. The interviewer (SP) is a clinical psychologist who is trained to handle distress caused by participation in the research. There was a possibility to refer women requesting assistance to available institutional services and sources of support (AIIMS is a tertiary care centre with a well functioning medical social service unit with collaborative support in government and non-government sectors). Researchers and donors will help ensure that their findings are properly interpreted and used to advance policy and intervention development.

Results

Context

In general, participants had a ''male-centred'' stance towards sexuality. Most stated that they engaged in sexual

behaviour mainly based on a desire to comply with partner wishes. When entering into the marital relationship, participants reported a pressure to perform their duty as a wife, but preparations in terms of sexual knowledge were minimal; as a result, most participants did not know what to do, felt unskilled in sex, and had no idea whom to ask to teach and guide them. Some participants were uncomfortable with sexuality because it was seen as a taboo: something 'bad or dirty'. Four participants said that they felt uncomfortable or averse even to marital sex because they feared it as they had heard that sex was associated with pain and bleeding.

Reporting

The reporting of sexual difficulties is an involved process; the women had to decide whether they should report to their husband, sister/mother or sister-in-law/mother-in-law, or to a health worker/professional. One participant chose not to report about her sexual problems to her husband; and many only reported partially due to fear of being misunderstood. Participants talked to their husbands if they had issues in relation to absence/reduction of desire or 'sexual pain–penetration' mostly to explain their need to avoid sexual activity. Partial reporting was common, e.g. communicating about the lack of desire but not about 'not achieving' orgasm. Participants didn't talk about sexual pain if it was mild. Reporting to in-laws was sometimes necessary, e.g. if there were problems in relation to conceiving, or when they were seen as gatekeepers for help/health services. Reporting to health professionals (usually gynaecologists) would occur in response to specific enquiry, e.g. during assessment of infertility, or when a deep sense of trust developed. All participants reported that the (research) interview was the first time that they had talked about their sexual difficulties in detail.

Language

There are no Hindi terms or phrases for certain body parts or phenomena related to sexuality, e.g. orgasm or vulva. The Hindi term for clitoris ('bhagshef') is not understood even by people proficient in Hindi. Most participants used English words for body parts and processes and phenomena related to sex though they were more articulate in Hindi as compared to English. When Hindi terms related to sexuality were used by interviewers, they were not understood by most participants (e.g. 'kaamottejna/uttejna' [arousal], 'chiknai' [lubrication]. Some Hindi phrases did not convey the desired meaning, e.g. 'yoni ka soojna' [vulvovaginal swelling] and led to misinterpretation (vaginal swelling due to illness). Therefore, simpler/colloquial approximations ('geela hona' [wetness] for lubrication, 'sambandh' [relationship] for sexual intercourse) and line diagrams (for anatomical parts like clitoris) had to be used (after obtaining permission to show diagrams) to facilitate understanding. Some participants had very limited vocabulary for sexual/genital issues owing perhaps to their traditional backgrounds, and used very broad approximations like 'nichla hissa' [lower part] for referring to genitalia.

Phenomena

Problems in Relation to Sexual Desire

There were 26 references to 'no' or 'low' desire for sex. There were 8 references for a lifelong problem related to desire and 15 references for acquired problems. A participant stated that she did not want to get married (but had to under family pressure), and that she did not feel attached to her husband.

P 11: ''Shaadi ko 3 saal ho gaye hain, par 'sex' ki ichcha nahi karti''. (We have been married for 3 years, but there is no desire for sex).

Three participants reported situational problems. One of them reported that she had spontaneous desire but she felt no desire for sex when her husband approached her. She had had to abort after the death of her first husband and was forced to remarry She reported that she felt no attachment to her second husband and did not feel like engaging in sex with him.

P 9: ''Pehley husband ki death ke baad bachche ka 'abortion' kara diya tha aur ab doosri shaadi kara di hai. Doosre pati ke saath koi lagaav mehsoos nahi hota aur jab bhi vo paas aate hain toh sambandh ki ichha nahi karti.''

(After the death of my 1st husband, I was made to abort my child and I was forced to re-marry. I don't feel any attachment to my second husband and I feel no desire for 'relation' when he comes close).

A few participants reported that they were unable to sustain desire during sexual intercourse either due to their preoccupation with 'conceiving' or daily concerns. One participant would lose her desire when lubrication started because she equated it to 'white discharge' due to 'infection.'

P 19: ''Par kuch samay se 'penetrative sex' mein bhi beech mein iccha nahi rehti, kyun ki dhyan iss baat par chala jata hai ki 'baby conceive' nahi kar sakte toh kya fayda''

(Sometimes even during penetrative sex, the desire wanes because the mind gets diverted to the thought 'if I can't conceive a baby, what's the point of it').

Problems in Relation to Arousal

There were 23 references to problems in relation to arousal. These were mostly related to lack of lubrication and lack of subjective excitement. Even on direct enquiry, most participants reported that they had not paid attention to vulvovaginal swelling or non-genital arousal. Most participants were not aware that non genital arousal (e.g. changes in rate of breathing or heart rate) was a part of sexual arousal. One

participant expressed that she could not make out whether the increase in her heart rate and breathing was due to anxiety or arousal.

P 14: ''Dryness ki wajah se 'sex' ke dauraan dard hota hai, baaki sharer mein bhi koi 'response' nahi hota, koshish ke baad bhi 'excitement' nahi hota''.

(The dryness leads to pain during sex, there is no response in the rest of the body, there is no excitement even after trying).

Most participants with sexual arousal problems also had difficulties in other sexual areas, such as sexual desire and sexual pain-penetration.

P 5: ''Shaadi ke shuru se hi geelepan mein kami hai. Geelapan nahi hone ki vajah se jo dard hota hai uss se sambandh banane mein pareshani hoti hai.''

(Since the beginning of the marriage, there has been less lubrication. The pain due to lack of lubrication leads to difficulty in 'making relation').

Problems in Relation to Orgasm

There was no spontaneous reporting of the problemin this category. One participant stated that she was not aware of the existence of such an experience as she had neither felt it nor heard about it. Most participants did not expect to have orgasm as a part of the sexual intercourse because they could not ask their husbands to pleasure them beyond their own needs. Eight participants reported that they had never experienced an orgasm from penetrative sex; while 2 reported acquired problem with a new partner.

P 21: ''Sukoon ka anubhav kabhi nahi hua jaise baaki mahilain batati hain; mujhe nahi samajh mein aata ki wo kya hota hai, relate nahi kar paati hoon''

(I have not experienced 'relaxation' like that reported by other women; I am unable to understand what it is; I am unable to relate to it.)

Problems in Relation to Sexual Pain-penetration

Sixteen respondents reported difficulty with penetration, vulvovaginal pain during intercourse, or fear and anxiety regarding sexual pain or penetration. Two participants reported lifelong difficulty with penetration. One of these participants reported a fear of penetration due to commonly held beliefs related to bleeding and pain when the hymen breaks. The couple had avoided penetrative sex throughout the 7 years of their marriage. They came to the medical centre for help with conceiving.

P 17: ''Sambandh banana mein dikkat aati hai. Hum dusre tarikon se enjoy karte hain. Lekin ab bachcha chahiye, issliye aaye hain. 'Gyne' examination ke liye jaati hoon aur instruments dikhtey hain toh dard hone ka darr lagta hai, bechaini hoti hai aur examination nahi karva paati hoon.''

(There is problem in 'making relation.' We 'enjoy' by other methods. However, now we want a child, so we have come. When I go for gynaecological examination and see the instruments, I fear pain and feel restless and I am quite unable to face the examination).

P 5: ''Shadi ke turant baad 'intercourse' mein bahut dard hua toh main darr gayi aur ab jab bhi try karte hain toh mein darr jati hoon aur pair nahi kholti, mujhe geelapan nahi lagta issliye mujhe lagta hai ki dard hoga.''

(Soon after the wedding, I felt much pain during intercourse and I got so scared that whenever he tries it, I get scared and don't open my legs, I don't feel any wetness and thus I feel that it will hurt.)

Other Symptoms

Three participants reported pain in the abdomen area either during or after sexual intercourse. One respondent reported pain starting immediately after sex which remained for about a day. One of them reported that along with abdominal pain she also felt a decrease in appetite and dryness of mouth for about a day.

Clinical or Existential Distress

Some participants considered their sexual problems per se as distressing and in need of correction. Many participants with sexual pain−penetration issues and some with low sexual desire found these symptoms distressing. The absence or lack of sexual arousal and orgasm were rarely reported as distressing.

Sexual distress was expressed in various ways. These included guilt about sexual difficulties ('feel bad as despite effort made by my husband I don't feel excited'), stress about sex ('it was not there earlier, why now,' 'I have fear and anxiety about the act,' 'fear sex due to pain,' 'I am becoming irritable (because of it)'), feeling of sexual inadequacy ('I dislike my body'), embarrassment about sexual problems ('other women do not have such issues, why me'), and dissatisfaction with sex life ('we are not getting time to resolve the issues and both of us are unsatisfied'). The impact of sexual problem on interpersonal relations (less emotional involvement; arguments, verbal and physical violence); partner (distress, increased drinking), and ability to conceive (9 participants) were also distressing.

Other participants considered sexual problems as a part of life that would become all right if life circumstances changed. The lack of or absence of sexual desire was attributed to 'I was not ready for the marriage,' 'having a busy lifestyle,' 'distance-relationship: partner living away due to his job,' 'family completed,' 'having discrepancy in desire,' 'absence of bonding,' 'interpersonal problems,' 'worries about other problems,' 'worries about sexual infections,' 'worries about infertility,' and 'lack of comfort and privacy.' Some found their partner's insistence on sex distressing. The absence of or reduction in sexual arousal and orgasm were attributed to 'inadequate stimulation,'

owing mostly to a perception among the couple that 'woman are passive partners,' 'relationship factors: absence of emotional connection with husband,' and lack of comfort and privacy.

Distress can also be gauged from efforts at help seeking. Some participants had tried home remedies (such as use of massage oil or herbs); or had approached health professionals for associated conditions like 'white discharge,' urinary tract infection, lower abdominal pain, and particularly for infertility; and some had approached doctors for sexual problems like sexual pain or lack of lubrication. Some participants had thought about treatment but did not take it because of lack of awareness ('didn't know that lack of wetness can be treated by doctors') or hesitation in approaching health facilities due to embarrassment or lack of partner/family support. On the other hand, some participants did not take treatment because sexual problems were not seen as a health issue ('husband said: what will a doctor do about this'); or because the problems was seen as situational (I don't want to 'make a relationship' because he is so abusive when he is drunk') or time-limited ('it will go away').

Diagnoses

Hypoactive Sexual Desire Dysfunction (HSDD)

Of the 15 participants who mentioned problems with sexual desire, 11 reported reduction/absence of spontaneous desire, 10 reported reduction/absence of responsive desire, and 9 reported an inability to sustain desire (Table 1). Only 5 participants reported symptoms in all three domains of hypoactive sexual desire dysfunction: reduction/absence of spontaneous desire, reduction/absence of responsive desire, and inability to sustain desire; and there were at least 2 women who reported symptoms in only one of these domains. The presence of any of these three domains can count towards the diagnosis of HSDD based on ICD-11 diagnostic guidelines. More than 80% of participants reported that the symptoms were persistent or occurred frequently over months. Between half and two-thirds of participants avoided sex because of these symptoms demonstrating an impact on behaviour. Almost two thirds of participants with hypoactive sexual desire were bothered by their symptoms; and about the same proportion had communicated their symptoms to their partner or significant others or to care providers. While almost all participants with reduction/absence of spontaneous desire communicated their symptoms to their partneror significant others or care providers, only about half of those with reduction/absence of responsive desire or inability to sustain desire did so.

Participants were considered to have a probable diagnosis of HSDD if they: a) had persistent and/or frequent symptoms, b) were bothered by their symptoms and c) had communicated the symptoms to their partner or significant others or care providers. Almost half of participants with hypoactive sexual desire had probable HSDD. About two-fifths of the participants had sought or had accepted treatment on it being offered for the hypoactive sexual desire symptoms. Participants with reduction/absence of spontaneous desire (almost half) were more likely to do so. A definite diagnosis of HSDD was made for just over a quarter of the participants because the draft ICD-11 guidelines for HSDD required that the hypoactive sexual desire symptoms should be an 'independent focus of clinical attention' (Table 1).

Female Sexual Arousal Dysfunction (FSAD)

Eighteen participants reported absence or marked reduction in sexual arousal. Of these, 17 reported reduction in genital response, 6 reductions in non-genital response and 12 reductions in subjective response (Table 2). The presence of any of these three domains can count towards the diagnosis of FSAD based on ICD-11 diagnostic guidelines. More than three-fourths of participants reported that the symptoms were persistent or occurred frequently over months. Almost two-fifths of the participants avoided sex because of these symptoms. About half of the participants were bothered by the reduction in their sexual response; while two-

Table 1. Hypoactive Sexual Desire Dysfunction (HSDD)

	Reduction of spontaneous desire	Reduction of responsive desire	Inability to sustain desire	Hypoactive sexual desire
Symptoms reported	11	10	9	15
Persistent and/or frequent symptoms	9	10	8	12
Avoidance of sex	7	7	5	9
Bothered by symptoms	7	7	7	11
Symptoms communicated to partner/significant other/care provider	10	6	4	11
Probable diagnosis	5	5	3	7
Sought/accepted offered treatment	5	1	2	6
Definite diagnosis	3	1	2	4

Table 2. Female sexual arousal dysfunction (FSAD)

	Reduction in genital response	Reduction in non-genital responses	Reduction in subjective response	Reduction in sexual arousal
Symptoms reported	17	6	12	18
Persistent and/or frequent symptoms	14	5	9	14
Avoidance of sex	6	0	5	7
Bothered by symptoms	8	3	6	8
Symptoms communicated to partner/significant other/care provider	9	3	6	11
Probable diagnosis	6	2	3	6
Sought/accepted offered treatment	4	0	0	4
Definite diagnosis	1	0	0	1

thirds had communicated their symptoms to their partner or significant others or care providers.

One-third of participants with reduction in sexual arousal had probable diagnosis of FSAD. About one-fifths of the participants had sought or had accepted treatment on it being offered for the sexual arousal symptoms. No participants with reduction in non-genital or subjective arousal had done so. A definite diagnosis of FSAD was judged to be present in just one participant because only one case met the 'independent focus of clinical attention' requirement.

Anorgasmia

Ten participants reported absence or marked infrequency of the orgasm experience. Most participants were unable to comment on intensity of orgasmic sensations. Most participants stated that anorgasmia was persistent and/or occurred frequently over months. Only two-fifths of participants each, stated that it had led to avoidance of sexual activity, or that they were bothered by its non-occurrence, or that they had communicated about it to their partners or significant others or care providers. Probable diagnosis of anorgasmia was judged to be present in only 1 participant. No participant had sought or had accepted treatment on it being offered for anorgasmia. No participant was judged to have a definite diagnosis of anorgasmia because of the inability to meet the 'independent focus of clinical attention' requirement (Table 3).

Sexual Pain-Penetration Disorder (SPPD)

Sixteen participants reported issues related to sexual pain or penetration, of which 12 reported difficulties with penetration, 7 had vulvovaginal or pelvic pain during penetration, and 9 had fear or anxiety about vulvovaginal or pelvic pain related to penetration. Only 2 participants reported symptoms in all three domains of sexual pain-penetration disorder, and there was at least one woman who reported the presence of symptoms in only one of these domains. The presence of any of these three domains can count towards the diagnosis of SPPD based on ICD-11 diagnostic guidelines. More than 80% of participants reported that the symptoms were persistent or occurred frequently over months. However, this was not the case with vulvovaginal or pelvic pain during penetration, with less than half of participants reporting the occurrence of persistent and/or frequent symptoms. A similar pattern was seen with avoidance of sexual activities, personal distress regarding sexual pain-penetration symptoms, and reporting it to their partner or significant others or care providers. As a result, a diagnosis of SPPD was judged to be present in more than four-fifths of the participants reporting these symptoms; however, less than half of participants with vulvovaginal or pelvic pain during penetration seemed to have a diagnosis of SPPD; as the clause ''independent focus of clinical attention'' is not required for the diagnosis of SPPD. About one-third to half of the participants with symptoms in different domains of SPPD had sought or had accepted treatment on it being offered for the sexual pain-penetration symptoms (Table 4).

Table 5 lists the probable and definite diagnoses of participants. Probable diagnosis was given if the condition met all requirements for the diagnosis, except for the diagnostic element ''independent focus of clinical attention'' in the case of sexual dysfunctions (HSDD, FSAD and Anorgasmia). This diagnostic element was not required for SPPD, so probable and definite diagnoses have the same numbers. The application of the ''independent focus of clinical attention'' requirement reduced cases by about

Table 3. Anorgasmia

	Anorgasmia
Symptoms reported	10
Persistent and/or frequent symptoms	9
Avoidance of sex	4
Bothered by symptoms	4
Symptoms communicated to partner/significant other/care provider	4
Probable diagnosis	1
Sought/accepted offered treatment	0
Definite diagnosis	0

Table 4. Sexual pain-penetration disorder

	Difficulties with penetration	Vulvovaginal or pelvic pain during penetration	Fear or anxiety about vulvovaginal or pelvic pain related to penetration	Sexual pain-penetration difficulties
Symptoms reported	12	7	9	16
Persistent and/or frequent symptoms	11	3	8	13
Avoidance of sex	11	3	8	13
Bothered by symptoms	12	3	8	14
Symptoms communicated to partner/ significant other/care provider	11	3	8	13
Diagnosis[a]	10	3	8	12
Sought/accepted offered treatment	6	2	3	7

[a]Diagnosis does not require the diagnostic element ''independent focus of clinical attention''.

two-thirds. Anorgasmia was an uncommon diagnosis and FSAD usually occurred as comorbidity.

Discussion and Conclusions

The reticence in talking about sexuality in India was similar to that seen in women from 'male-centred' regimes or ethnic minorities in gender-equal regime (18,19,29–33). Shyness was common among women in the study, and even when they wished emotional intimacy, they found it difficult to talk about sex, even with their husbands. In interviews they often did not have the words to discuss sexual intimacy and sexual pleasure (19,34). Yet, many participants reported problems with spontaneous desire, responsive desire, sustaining desire, vulvovaginal lubrication, subjective arousal, infrequency of orgasm, penetration-pain, and fear or anxiety about pain related to penetration. Few participants were aware of problems in arousal in terms of engorgement or sensitivity of the genitalia, non-genital response, and intensity or timing of orgasm. Flore has pointed out that there is a gradual intensification of the medical gaze towards amounts and degrees of sexual functioning and sexual appetites, which, in addition to pathologizing these phenomena, invite the patient to develop greater awareness of his/her sexual self (and that of the partner's) in order to provide an account of his/her body's and mind's receptivity and reactions (35). By participating in the diagnostic process, e.g. through the articulation of personal distress around sexual dysfunction, the patient also co-creates the diagnosis. Thus, classifications have come to have a pedagogic function as patients learn that certain sexual behaviours (or their lack) are beneficial or pathological. One expects, with greater spread of knowledge of FSD (e.g. through internet), more problems in relation to FSD would come to women's awareness and be acknowledged.

Table 5. Diagnosis of female sexual disorders

	Probable	Definite
According to diagnostic category		
HSDD	7	4
FSAD	6	1
Anorgasmia	1	0
SPPD	12	12
	Comorbidity among Probable Diagnoses	Comorbidity among Definite Diagnoses
Only HSDD	2	1
Only FSAD	1	0
Only SPPD	6	9
HSDD + SPPD	2	2
FSAD + SPPD	1	0
HSDD + FSAD + SPPD	3	1
FSAD + Anorgasmia + SPPD	1	0

It is evident that many participants were raised in accordance with traditional cultural norms to engage in sexual interactions within a marital relationship fulfilling a gendered set of marital obligations (e.g. sexual activity for women must be focused on procreation). These norms discouraged sexual autonomy and agency to make informed decisions about sexuality as seen in other 'male-centred' regimes or ethnic minorities in 'gender-equal' regime (13,19,28). It is difficult to diagnose HSDD if it results from desire discrepancy between partners (36) or FSAD or anorgasmia if sexual interactions are dictated by one member of a couple and/or accepted only in order to please one's sexual partner as the diagnostic requirement for these disorders 'despite adequate sexual desire and stimulation' is rarely met.

Marked distress is central to the diagnosis of sexual disorders. King M, et al. found a disjunction between the diagnostic conception of sexual dysfunction in ICD-10 and the woman's perception of a problem; though in general women who received ICD-10 sexual dysfunction diagnosis were more likely than other women to consider that they had a sexual problem and to report lower sexual satisfaction (37). In the present study, many participants with sexual pain–penetration issues and some with low sexual desire considered these symptoms to be problematic; however, this was rarely the case with the absence or lack of sexual arousal and orgasm. In a qualitative study, Bellamy G, et al. found that participants privileged penetrative sexual intercourse as 'real sex' and physical problems like bleeding

and pain as real problems (23). SPPD was probably perceived as a 'real' problem because it can preclude coitus and, consequently, spontaneous conception and is hence often the only FSD that is spontaneously identified and treated by Indian clinicians. King M, et al. had found that the agreement between the ICD-10 diagnosis and the woman's perception that she had any type of sexual problem was highest for non-organic dyspareunia (74%) and nonorganic vaginismus (77%) (37). Participants who did not consider sexual symptoms as problematic saw them as a part of life that would become all right if life circumstances changed or as relational (e.g. lack of agency) or social issues as was seen in other studies (17,19,21,37). In a study conducted in a general population from rural area in South India, Viswanathan S, et al. reported that though the prevalence of sexual dysfunction, based on the cut-off score on a screening questionnaire was 64.3%; only a minority of women considered it to be a problem (4.7%), or expressed dissatisfaction (5.8%) or sought medical help (2.5%) (17). The most common explanatory models offered for sexual problems included an unhappy marriage, stress and physical problems. The scale of differences in the rates of clinically significant distress between the study by Vishwanathan et al's study and the present study probably relate to differences in the setting (community versus tertiary care clinic) and nature of participants due to the study designs (random selection for a quantitative study versus purposive selection for a qualitative study) (17).

About half of participants with hypoactive sexual desire symptoms, one third with arousal symptoms, and one-tenth with orgasm related symptoms had probable diagnoses according to our operational definition for this study. The application of the 'independent focus of clinical attention' requirement reduced cases by half for HSDD and almost eliminated all cases of FSAD and Anorgasmia. The absence of this requirement meant that there was no reduction in cases of SPPD. In India, many women do not express distress about sexuality to others because it is not culturally sanctioned and most women have limited interpersonal control over their lives and are dependent on their husbands and other family members for health-related decision-making (38); hence the presence of this requirement ('independent focus of clinical attention') may be very restrictive. Low level of reporting and stringency of diagnostic criteria can lead to women in need of treatment not getting adequate care (39,40). Based on the data from the present ICD-11 field study, the 'independent focus of clinical attention'requirement has been removed from the essential (required) features of the final ICD-11 sexual dysfunction guidelines. It is now housed in 'additional features' where it serves to clarify that sexual dysfunctions can be diagnosed in the presence of medical/health conditions (e.g. diabetes mellitus, injuries, surgical treatments) that may contribute to the sexual dysfunction. In this context, the sexual dysfunction is regarded as an 'independent focus of clinical attention' in that assessment and treatment methods specific to sexual dysfunctions are being applied and it is not simply assumed that the sexual dysfunction will go away when the medical/health conditions is treated,or, in the cases of chronic health conditions, that one has simply to live with it. The Etiological Considerations Qualifier 'Associated with a medical condition, injury, or the effects of surgery or radiation treatment' should be used to clarify the relation between the two diagnoses.

The DSM-5 has integrated the dysfunctions of hypoactive sexual desire and female sexual arousal into female sexual interest and arousal disorder (FSIAD) (41). The ICD-11 (1) and the committee on the incidence and prevalence on sexual dysfunctions from the Fourth International Consultation on Sexual Medicine (ICSM) have maintained HSDD and FSAD as separate entities (3). The International Society for the Study of Women's Sexual Health (ISSWSH) considers HSDD, female genital arousal disorder (FGAD) and female cognitive arousal disorder (FCAD) as separate entities (42). In the context of 'male-centered' regimes, the present study best supports the distinction between HSDD and FGAD as participants were able to comment on problems related to these. Even if subjective problems of arousal relevant to FCAD were recognized by some women, most did not see them as pathological.

The major strength of this study is that it provides a conceptual lens toward better understanding of the phenomenon of FSD among Indian women. Participants were heterogeneous in many ways, including sexual dysfunction categories, other diagnostic categories and sociodemographic features. Efforts were undertaken to improve the credibility and dependability of research findings by employing rich data from in-depth and diagram-supported interviews. The exclusion of unmarried and divorced women; and recruitment from a single centre; limit the transferability of the study findings. Studies on sexuality in 'male-centres' regimes can be biased due to the patients' inclination to give socially desirable responses.

As in 'gender-equal' regime, many women in 'male-centered' regimes suffer with problematic sexual experiences that lead to significant emotional, physical and relational issues. And, some women are conscious of their sexual health needs and may seek treatment in the traditional or biomedical health sectors (18). For these women FSD are useful diagnostic categories that need to be treated. Advancement toward a more precise nomenclature and classification system of FSD will facilitate better diagnosis, research, and development and selection of treatments options, all of which will ultimately lead to superior care for women with sexual dysfunction.

Conflict of Interest

The authors declare no conflict of interest.

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