Published in final edited form as:

J Sex Med. 2017 November ; 14(11): 1327–1335. doi:10.1016/j.jsxm.2017.09.009.

Patients' Conceptions of Terms Related to Sexual Interest, Desire, and Arousal

John D. DeLamater, PhD¹, Kevin P. Weinfurt, PhD^{2,3}, and Kathryn E. Flynn, PhD⁴

¹Department of Sociology, University of Wisconsin, Madison, WI, USA

²Department of Psychiatry and Behavioral Sciences, Duke University School of Medicine, Durham, NC, USA

³Duke Clinical Research Institute, Duke University School of Medicine, Durham, NC, USA

⁴Center for Patient Care and Outcomes Research, Medical College of Wisconsin, Milwaukee, WI, USA

Abstract

Background—Measurement of sexual function typically utilizes self-report, which, in order to work as intended, must use language that is understood consistently by diverse respondents. Commonly used measures employ multiple terms, primarily (sexual) interest, desire, and arousal, that may not be understood in the same way by lay people and professionals.

Aim—To inform self-reported measurement efforts for both research and clinical settings by examining how U.S. men and women recruited from a healthcare setting understand and interpret different terms.

Methods—We conducted 10 focus groups in XXXXX (N=57). Discussions were audio recorded and transcribed, and the content of the discussions was systematically analyzed in 2 phases of coding by the research team, facilitated by Nvivo qualitative analysis software.

Outcomes—Patient focus group discussions about the meanings and connotations of multiple terms related to sexual function, especially interest, desire, and arousal.

Results—Five of the groups included male participants and five included female participants. Participants characterized (sexual) interest as a cognitive phenomenon and a situational response to a specific person. Similarly, they characterized (sexual) desire as a situational, person-specific experience with some support for it as a cognitive phenomenon but more support for it as a physical phenomenon. In contrast, participants characterized sexual arousal as a physical phenomenon, occurring in response to physical or visual stimulation and not related to a specific person.

Corresponding author: kflynn@mcw.edu.

Conflict of Interest: "None"

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Clinical Implications—These results can help us understand how lay people are using and responding to these terms when they are used in clinical and research settings.

Strengths & Limitations—Patient participants in these groups were diverse with respect to age, gender, sexual orientation, and health, with the potential to voice diverse perspectives on sexual functioning; however the sample was limited to a single city in the southeastern United States.

Conclusion—The meanings of interest, desire, and arousal were defined, compared, and contrasted in the context of patient focus groups. Qualitative coding revealed that interest was considered the most “cognitive”, arousal the most “physical”, and desire somewhere in between.

INTRODUCTION

Measurement of sexual function typically utilizes self-report, which, in order to work as intended, must use language that is understood consistently by diverse respondents. There are several terms related to aspects of sexual functioning that are commonly used in research and clinical practice—primarily (sexual) *desire*, (lack of) *sexual interest*, and (sexual) *arousal* or *subjective* (sexual) *arousal* (Table 1). Sexual desire is generally discussed as a motivational state and widely associated with the work of Kaplan.¹ Sexual arousal was identified by Masters and Johnson² as a set of physiological processes associated with sexual activity; later work documented a subjective component in arousal.³ Sexual interest refers to cognitive phenomena such as thoughts or fantasies about engaging in sexual activity, but it has also been paired with both arousal⁴ and desire.⁵

How distinct these terms are from each other remains a matter of debate, as evidenced by continued professional disagreements about terminology, including the replacement of Hypoactive Sexual Desire Disorder (HSDD) and Female Sexual Arousal Disorder (FSAD) with Female Sexual Interest and Arousal Disorder (FSIAD) in the DSM-5^{6,7}, the subsequent backlash to these changes⁸ for women and the retention of HSDD for men,⁹ and the sometimes inconsistent factor structures observed in different populations based on psychometric evaluations of self-report measures.^{10–12}

As Table 1 shows, major self-report measures of sexual (dys)function used in both research and clinical practice have approached these domains and terms in different ways, sometimes combining terms (e.g., “sexual desire or interest” and “sexually aroused (turned on)”). This raises the question of how research participants and clinical patients interpret these terms. A few qualitative studies have addressed this question. Graham et al. conducted 9 focus groups with a diverse sample of 80 women, asking them what cues they associated with sexual arousal, and to describe and differentiate between “sexual interest” and “sexual arousal”.¹³ Janssen et al. replicated this research using 6 focus groups with 50 primarily heterosexual men.¹⁴ In describing the research, the authors of both of these studies seem to use the terms interest and desire synonymously. Results indicated that both men and women had difficulty distinguishing between the concepts of interest/desire and arousal, and respondents associated a wide variety of physical, cognitive/emotional, and behavioral cues with sexual arousal. Mitchell et al. conducted 32 interviews with men and women in England to understand how they defined desire and arousal. They found that, if prompted to do so, most

participants would attempt to distinguish between desire and arousal, but the task was difficult and no clear and consistent definitions were used by the participants.¹⁵

These previous studies focused on the concepts of interest/desire and arousal. It is important to ask whether the terms interest and desire are seen as different from each other, especially as at least one commonly used self-report measure couples these terms. Moreover, these three previous studies used non-patient samples, and it is useful for both research and clinical care to demonstrate how people who interact with the health care system interpret these terms. Previous work has used qualitative methods to examine lay people's definitions and conceptualization of other terms related to sexual function and sexual activity, including at least one study that used focus groups to define sexual pleasure,²¹ and others that explored definitions of sexual satisfaction²² and sexual abstinence/having sex.²³ In this study we describe what multiple terms mean to men and women, primarily focusing on the more commonly used terms of interest, desire, and arousal, using data collected during focus groups with patients recruited from a healthcare setting in the southeastern United States.

METHODS

Recruitment

Eligible participants were aged 18 years or older, were able to speak English, and were either sexually active or, if not sexually active, they self-reported having interest in sexual activity. We recruited participants via flyers posted in XXXXX clinics and affiliated health centers, on the university's research studies website, and in-person through clinic staff. Approval from the treating physician was obtained prior to approaching patients in-person.

Procedure

We organized a total of 10 in-person focus groups. Participants in each group were of the same gender. They also shared in common a health-related characteristic or trait, namely self-identification as a sexual minority, older age (65+), or a self-reported diagnosis of heart failure/diabetes or depression/anxiety. All focus groups were audio-recorded and transcribed. Participants were informed of the management of the recordings, confidentiality procedures, destruction of the audio files following verification of the transcripts, and that reports would present aggregated information or associate quotations with a pseudonym. Participants were compensated \$75. The institutional review board of the XXXXXX approved the study and all participants provided written consent. The institutional review board at XXXXXX approved the current analysis of the data.

Focus group sessions lasted about 90 minutes. Professional focus group moderators of the same gender as participants led discussions by following a semistructured guide developed by a multidisciplinary domain committee. The guide was based on 1) a previous guide used in focus groups with patients with cancer,²⁴ 2) literature review, 3) input from telephone discussions with a convenience sample of physicians, advanced practice providers, and nurses (15 providers in 6 discussions) who specialized in treating patients with heart failure, diabetes, anxiety, or depression, or sexual dysfunction,¹⁸ and 4) input from a telephone

discussion with a convenience sample of experts in sex research and measurement of sexual function (2 experts).

The discussion guide addressed: 1) the scope and importance of physical intimacy and sexuality, including how health affects peoples' sex lives; 2) how physical symptoms affect distinct aspects of sexual response; 3) a discussion of the meanings and connotations of the terms interest, desire, arousal, turned on, excited, and horny; 4) how psychosocial symptoms affect intimate relationships and sexual function and satisfaction; and 5) the meaning of a satisfying sex life and how health affects satisfaction with sex life. Questions from the discussion guide related to #3 (the topic of this analysis) are shown in Table 2.

A member of the research team (XX) observed all groups and produced summaries of the themes covered as well as reported on the tone or energy of the group, distinctive qualities of the group or particular members, and nonverbal and group dynamics. Members of the research team (XX and XX) met regularly and reviewed these summaries with an independent auditor to determine whether any focus group should be repeated or new groups added to achieve data saturation. We found no new themes after 8 focus groups with sexual minorities and patients with targeted health conditions, suggesting that we had achieved data saturation. However, we felt that older people were insufficiently represented in these groups so held 2 additional groups with adults aged 65 and older.

Sample Characteristics

The sample was 53 percent women (Table 3). Participants' average age was 50, with a range of 23 to 77. By race/ethnicity, the sample was diverse, with about 40 percent white and 58 percent black. The mode for education was some college/technical degree. There was also diversity in sexual orientation, with 14 percent of the participants self-identifying as lesbian or gay and another 16 percent as bisexual. This diversity should provide multiple perspectives on sexual interest, desire, and arousal.

Analysis

The primary goal of the original research was to update a conceptual measurement model, which had been developed based on extant literature and focus groups with patients with cancer,^{24–26} and which would be used to guide item content coverage for the PROMIS Sexual Function and Satisfaction measure version 2.0.¹⁸ Thus, the original analysis was conducted with the goal of refining item content for a self-report measure. The current research presents a new, more detailed analysis than was conducted during the original analysis, focused on elucidating the meaning of key terms to the participants in the focus groups. Our systematic coding procedure was guided by principles as outlined by Saldaña²⁷ and are described in detail below.

Per our discussion guide, each focus group was asked what each of the key terms meant and what they thought of when they heard the term. In a first round of coding, the first author (XX) and a research assistant coded (using the label “terms”) all sections of the transcripts that referred to the characteristics that participants associated with or thought of in response to each term. Then, in a second round of focused coding, two authors (XX and XX) and the research assistant read two of the original transcripts independently, flagging all comments

by participants' that revealed their interpretation of or emotional reaction to the key terms. The team met, discussed, and refined our initial impressions. The research assistant then codified our discussion into an initial coding manual. We read two additional transcripts and coded them using the initial manual. The first author (XX) and the research assistant met and discussed the coding of each transcript. Disagreements led to refining category definitions, the addition of categories, and additional discussion with the senior author (XX). This resulted in the final coding manual, which included 14 attributes that participants associated with one or more of the key terms. The assistant then coded all 10 transcripts according to the final manual facilitated by Nvivo qualitative software. Throughout the coding process, the assistant discussed instances of ambiguity with the first author. Using Nvivo queries, we identified every comment by a participant that implicated each of the key terms and the code(s)/attribute(s) associated with the comment. We then assessed the relative frequency of the attributes associated with each term.

We report first on our analysis of participants' comments made in response to the moderator's questions; participants quoted are identified by a pseudonym and initials identifying the focus group that they were part of. We use pseudonyms to identify speakers so that the comments made by the same person can easily be identified across the analysis. We subsequently consider what participants said in response to the moderator's questions about the differences between the terms. Given our interest in identifying the meaning associated with each of the three terms, we looked for attributes on which people's statements about these terms varied. We analyzed the patterns of application of the attributes to elucidate how the focus group participants understood the meaning of each of the terms.

RESULTS

The final coding manual contained 14 attributes. They are outlined in Table 4, which lists the attributes and indicates which ones were evident in the participants' comments about each of the three key terms found in many self-report measures: "interest," "arousal," and "desire."

Definitions and Connotations of Key Terms

Interest—Models of sexual functioning vary in the emphasis placed on cognitive/mental aspects versus physical aspects of sexuality.^{2,28–30} The results from these focus groups indicate that participants discussed interest exclusively as a cognitive phenomenon. Such comments were made in seven of the ten groups. For example, one man said, "for me, it all begins with interest ... it all develops as a thought in my mind." (Leo, MD). No participant mentioned any physical manifestations of interest. Participants In five groups referred to interest as person-specific, i.e., related to or occurring in response to a specific person, as opposed to something elicited by several persons or members of a category (e.g., "Hot men/women/persons"). In response to the question "How would you define interest?" Madeleine replied, "Is he who you want?" (65+W). Consistent with the perception that it is person-specific, participants in five groups also referred to interest as situational rather than as a cross-situational trait. Asked how she would respond to an advance by a man, Evelyn said, "depends on how he come after me, you know?" (65+W).

Participants in five groups considered interest a positive experience. Asked if interest is “a good thing or a bad thing,” Shirley replied “I think it’s a good thing.... When I get there, I like that feeling” (MD-W). Participants in two groups made negative comments about interest. Asked if there are times when interest is not good, Gabriel replied, “[when] there are extenuating circumstances where you can’t – you know [perform]” (GB). One of the 14 attributes mentioned by participants was a sense of wanting or needing to have sex. Only one woman mentioned this in discussing the characteristics of interest, Maya, who said “wanting it” (MDW).

Arousal—As evidenced by attributes often included in self-report measures shown in Table 1, some conceptual models draw a sharp distinction between interest/desire and arousal. Our analysis provides insight into whether lay persons think of interest (on its own, not coupled with desire) and arousal as distinctly different or not. Whereas participants in the focus groups characterized interest as cognitive or mental and not physical, persons in five groups associated arousal with physical phenomena. Maria said, “Arousal is definitely ... more physical” (MDW). Alexander said, “you feel it in your body” (HFD). Two of the 14 dimensional codes referred to potential sources of interest/arousal/desire: direct physical stimulation or a visual stimulus. None of the participants mentioned either of these in relation to interest. In contrast, in discussing arousal, members of three groups said it is a response to physical stimulation. Asked what effects your level of arousal, Dorothy said “it depends on where he knows to touch and everything” (65+W). Participants in two groups mentioned visual stimulation. Alexander said, “And here comes this gorgeous thing on TV, and you’re sitting there and you’re watching her, and she’s doing different things and you start getting aroused” (MDM).

Whereas persons in five of the groups described interest as person-specific, only one participant characterized arousal as person-specific. Asked if members of the group had had problems with getting aroused, Roxanne replied, “It depends on the [other] person” (LB). Whereas participants in four of the five male groups referred to interest as situation specific, none of the men characterized arousal that way, suggesting they experience it as a more generalized phenomenon.

Desire—In discussing desire, women in one of the groups characterized it as cognitive. Zora said, “desire is sort of like thinking about it [sex]” (LB). One man associated desire with memories of past good times with his wife of 38 years. Asked if desire was physical, he replied, “No, it’s probably more of a mental emotion” (Joseph, HFD). Participants in five groups characterized desire as person specific. William stated, “you have a desire for a person,” and went on to say that if that person “wasn’t what you expected,” you would lose the desire (65+M). Leo described desire as having an aspect of fantasy, “I desire the perfect person” (GB). When a moderator paraphrased a discussion saying “so you have the desire if the person [is] the right person,” Evelyn replied “Right” (65+W). Participants in two groups referred to desire as situational. For example Arthur, discussing moving into a new relationship, said, “she was the type that she can go two months without it.... And I kind of adapted to it” (HFD). Another of the 14 attributes is that the phenomenon being discussed can be turned on or off. This was only mentioned in discussions of desire, by participants in

two groups, both comprised of women. Jane described desiring a man, but “then he says one thing that tees you off,” and the desire is turned off (65+W). This seems somewhat similar to William’s remark about person-specific desire above.

The other dimension that was voiced only in discussions of desire was remarks about desire in relation to sexual performance or behavior. None of the participants mentioned performance in relation to either interest or arousal. Participants in two groups composed of men mentioned the relationship between desire and performance. Scott said, “if you have to say “I’m sorry, honey,” more than once ... the desire ... goes” (HFD2).

Similarities and Differences Among Terms

After being asked to define each term, each focus group was also asked whether each of a series of terms was the same as or different from the other terms. In most of the 10 groups, the facilitator specifically asked about similarities and differences among the following five terms: (sexual) interest, (sexual) arousal, (sexual) desire, horny, and turned on. The term excited was also presented in half of the groups. Individual participants would reply, and often other participants would agree or disagree with them. However, not all members of a group stated an opinion. Based on responses to the questions of whether the terms were similar or different, focus group participants identified two distinct (underlying) processes. A majority of the judgments grouped interest and desire as similar, and aroused, excited, horny, and turned on as similar.

Arousal/Horny/Turned on were more likely to be characterized as physical. James said “arousal is ... more of like a bodily thing” (MDM). Harper said, “To me, ‘aroused goes with ‘horny’, it’s your body’s internal desire to want to have sex” (D). Participants also associated these three terms with hormones. Edith, discussing a decline in her arousal/excitement with age, said “You just don’t have that hormone anymore” (65+W). Male participants discussed these terms in association with experiencing erections. The moderator asked what it means to ask if you are aroused? Gabriel replied, “Is there blood entering your penis right now?” (GB). In discussing the difference between arousal and desire, Arthur said “even though I got an erection, even though it’s hard, but, hey, I really don’t want to have sex with you” (HFD1). Note that Arthur’s comment indicates that desire is person specific whereas arousal is not. Finally, these terms were associated with wanting/needing to have sex. Discussing the similarity of aroused and turned on, Gabriel said, “Like, when you’re turned on, you’re turned on and that switch is not coming back down” (GB).

Interest and desire were more likely to be characterized as positive. Virginia said, “the desire that you have for your mate would go hand in hand with interest ... wanting to please your husband” (HF). They were also characterized as situation-specific. Alexander stated, “Desire-to me, really, I mean interest ... you can cut that off in a heartbeat.” (MDM) Also, they were perceived as affected by sexual performance. Arthur said, “If I open my eyes and look at her and she’s looking like - - you know, like it ain’t good ... I’m done, you know?” (HFD1). Some participants perceived desire and interest as different from each other. Margaret said desire “seems like a more physical thing than interest” (65+W). A related characterization was that desire reflects a stronger motivation to engage in sexual activity. Toni said, “I look at interest as being a want and desire ... maybe a need” (D).

DISCUSSION

The participants in this research, men and women aged 23 to 77 recruited from a healthcare setting, described their understandings and interpretations of multiple terms, including (sexual) interest, desire, and arousal. The definitions and connotations associated with these terms voiced by participants were not universally held. However, a number of themes did emerge across the groups. In general, participants characterized (sexual) interest as a cognitive phenomenon and a situational response to a specific person. Similarly, they characterized (sexual) desire as a situational, person-specific experience, though less often characterized it as mental/cognitive. In addition, some participants stated that desire can be turned on or off by interactional events, such as a partner saying the wrong thing, touching in the wrong place, or looking dissatisfied with the sexual interaction. In that sense, desire or lack thereof is related to sexual performance. In contrast, they characterized sexual arousal as a physical phenomenon. It occurs in response to physical or visual stimulation and is not related to a specific person.

When asked whether the key terms were similar or different, participant's responses reflected the themes identified above. More groups and participants within groups thought interest was different from desire rather than the two being the same. Comparing interest and desire, some respondents said desire is more physical and stronger than interest. Arousal, horny, and turned on were characterized as similar and seen as related to physical responses, especially erections (among men). Some respondents associated these terms with wanting or needing to have sex.

Our results differ in some ways from those reported by previous qualitative studies of lay understandings of these terms.^{13–15} These three previous studies reported that their participants had difficulty distinguishing between interest/desire and arousal, yet our participants generally responded with specifics when asked what each term meant, as many of the quotes demonstrate. The previous studies found that participants associated a diverse set of physical, cognitive and behavioral cues with “sexual arousal.” In total, our respondents also identified a diverse set of cues, but when asked to compare, for example interest and arousal, they were able to differentiate them. There are multiple possible reasons for these differences. First, specific methods varied somewhat across the studies. None of the previous studies asked about all of the terms that our study included, nor did any ask specifically about differences between interest and desire. Mitchell et al. conducted individual interviews in the UK, whereas the Graham et al. and Janssen et al. studies used focus groups in the US, as did we. We noted instances where a comment by one participant would trigger a discussion that drew in others, an element missing in the interview setting. Moreover, the previous U.S.-based focus group studies recruited participants from a Midwestern university town, whereas our participants were recruited through a large medical center in the Southeast. There may be regional differences in language use and/or differences between community samples and those recruited from a healthcare setting.

Professional communities develop a language for communication about the topics at the core of their professional work. Such a language includes specific terms to refer to the elements or entities that they manipulate, whether symbols, objects, or aspects of persons, and these

terms are defined in certain ways for their purposes. When professionals interact with non-professionals, these terms or concepts often need to be translated or restated in language understandable to non-professionals. Our focus in this paper was non-professionals' understanding of key terms related to sexual interest, desire, and arousal. Some researchers want to craft theoretical models that draw conceptual distinctions among certain aspects of sexual experiences such as these. However, there are limitations to how well the theoretical constructs can be operationalized in measures when lay people do not honor the same conceptual distinctions in their own use of key terms. Some lay conceptions are exemplified by the participants in our focus groups. Also users of self-report measures that include these terms either individually or in various combinations should consider the understandings of the participants or patients being assessed.

Limitations

The data we analyzed are from focus groups. The sample of participants in these groups was diverse and has the potential to voice diverse perspectives on sexual functioning; however the sample was limited to a single city in the U.S. The moderators generally worked to ensure that every member participated. The transcripts suggest that most participants felt free to express their views. There are numerous instances where one participant disagreed with another. We believe that the discussions reflected the views of the participants. However, there may have been instances where an individual respondent did not share a dissenting perspective.

The participants were primarily recruited from pools of persons with diagnoses of particular health conditions, and additional groups were held with older adults and sexual minorities. A few participants reported that their illness had effected their experience of interest, arousal, and/or desire, but there was no evidence of a general effect of illness on the participants' remarks.

Conclusion

Among a diverse sample of men and women recruited from a U.S. health system, lay definitions of the terms interest, desire, and arousal were elicited. Qualitative coding revealed that interest was considered the most "cognitive", arousal the most "physical", and desire somewhere in between. While self-report measures have coupled the terms interest and desire, lay people in our sample did not consider them synonyms. These results can help us understand how lay people are using and responding to these terms when they are used in clinical and research settings.

Acknowledgments

Helen Powling, BA, University of Wisconsin provided research assistance. Members of the PROMIS Sexual Function Domain Group provided helpful feedback on an earlier version of this work.

References

1. Kaplan, HS. Disorders of Sexual Desire. New York: Simon and Schuster; 1979.
2. Masters, WH., Johnson, VE. Human Sexual Response. Toronto; New York: Bantam Books; 1966.

3. Heiman JR. A psychophysiological exploration of sexual arousal patterns in females and males. *Psychophysiology*. 1977; 14(3):266–274. [PubMed: 854556]
4. Basson R. On the definition of female sexual interest/arousal disorder. *Arch Sex Behav*. 2014; 43(7): 1225–1226. [PubMed: 24938589]
5. Regan PC, Atkins L. Sex differences and similarities in frequency and intensity of sexual desire. *Soc Behav Personal*. 2006; 34(1):95–101.
6. Brotto LA. The DSM diagnostic criteria for hypoactive sexual desire disorder in women. *Archives of Sexual Behavior*. 2009; 39(2):221–239.
7. Brotto LA, Graham CA, Binik YM, Segraves RT, Zucker KJ. Should Sexual Desire and Arousal Disorders in Women Be Merged? A Response to DeRogatis, Clayton, Rosen, Sand, and Pyke (2010). *Archives of Sexual Behavior*. 2011; 40(2):221–225.
8. Parish SJ, Goldstein AT, Goldstein SW, et al. Toward a More Evidence-Based Nosology and Nomenclature for Female Sexual Dysfunctions-Part II. *J Sex Med*. 2016; 13(12):1888–1906. [PubMed: 27843072]
9. Brotto LA. The DSM diagnostic criteria for Hypoactive Sexual Desire Disorder in men. *J Sex Med*. 2010; 7(6):2015–2030. [PubMed: 20929517]
10. Rosen R, Brown C, Heiman J, et al. The Female Sexual Function Index (FSFI): a multidimensional self-report instrument for the assessment of female sexual function. *J Sex Marital Ther*. 2000; 26(2):191–208. [PubMed: 10782451]
11. Rosen RC, Cappelleri JC, Gendrano N III. The International Index of Erectile Function (IIEF): a state-of-the-science review. *Int J Impot Res*. 2002; 14(4):226–244. [PubMed: 12152111]
12. Rosen RC, Riley A, Wagner G, Osterloh IH, Kirkpatrick J, Mishra A. The international index of erectile function (IIEF): a multidimensional scale for assessment of erectile dysfunction. *Urology*. 1997; 49(6):822–830. [PubMed: 9187685]
13. Graham CA, Sanders SA, Milhausen RR, McBride KR. Turning on and turning off: a focus group study of the factors that affect women's sexual arousal. *Arch Sex Behav*. 2004; 33(6):527–538. [PubMed: 15483367]
14. Janssen E, McBride KR, Yarber W, Hill BJ, Butler SM. Factors that influence sexual arousal in men: a focus group study. *Archives of Sexual Behavior*. 2008; 37(2):252–265. [PubMed: 18040768]
15. Mitchell KR, Wellings KA, Graham C. How do men and women define sexual desire and sexual arousal? *J Sex Marital Ther*. 2014; 40(1):17–32. [PubMed: 23819590]
16. McGahuey CA, Gelenberg AJ, Laukes CA, et al. The Arizona Sexual Experience Scale (ASEX): reliability and validity. *J Sex Marital Ther*. 2000; 26(1):25–40. [PubMed: 10693114]
17. Stewart, AL., Ware, JE. Measuring functioning and well-being: The Medical Outcomes Study approach. Durham, NC: Duke University Press; 1992.
18. Weinfurt KP, Lin L, Bruner DW, et al. Development and Initial Validation of the PROMIS((R)) Sexual Function and Satisfaction Measures Version 2.0. *J Sex Med*. 2015; 12(9):1961–1974. [PubMed: 26346418]
19. Derogatis LR, Rosen R, Leiblum S, Burnett A, Heiman J. The Female Sexual Distress Scale (FSDS): initial validation of a standardized scale for assessment of sexually related personal distress in women. *J Sex Marital Ther*. 2002; 28(4):317–330. [PubMed: 12082670]
20. Wei JT, Dunn RL, Litwin MS, Sandler HM, Sanda MG. Development and validation of the expanded prostate cancer index composite (EPIC) for comprehensive assessment of health-related quality of life in men with prostate cancer. *Urology*. 2000; 56(6):899–905. [PubMed: 11113727]
21. Goldey KL, Posh AR, Bell SN, van Anders SM. Defining Pleasure: A Focus Group Study of Solitary and Partnered Sexual Pleasure in Queer and Heterosexual Women. *Arch Sex Behav*. 2016; 45(8):2137–2154. [PubMed: 27007471]
22. Pascoal PM, de Narciso IS, Pereira NM. What is sexual satisfaction? Thematic analysis of lay people's definitions. *J Sex Res*. 2014; 51(1):22–30. [PubMed: 24070214]
23. Byers ES, Henderson J, Hobson KM. University students' definitions of sexual abstinence and having sex. *Arch Sex Behav*. 2009; 38(5):665–674. [PubMed: 18204893]

24. Flynn KE, Jeffery DD, Keefe FJ, et al. Sexual functioning along the cancer continuum: focus group results from the Patient-Reported Outcomes Measurement Information System (PROMIS(R)). *Psychooncology*. 2011; 20(4):378–386. [PubMed: 20878833]
25. Fortune-Greeley AK, Flynn KE, Jeffery DD, et al. Using cognitive interviews to evaluate items for measuring sexual functioning across cancer populations: improvements and remaining challenges. *Qual Life Res*. 2009; 18(8):1085–1093. [PubMed: 19672697]
26. Jeffery DD, Tzeng JP, Keefe FJ, et al. Initial report of the cancer Patient-Reported Outcomes Measurement Information System (PROMIS) sexual function committee: review of sexual function measures and domains used in oncology. *Cancer*. 2009; 115(6):1142–1153. [PubMed: 19195044]
27. Saldaña, J. *The Coding Manual for Qualitative Researchers*. Sage; 2009.
28. Basson R. The female sexual response: a different model. *J Sex Marital Ther*. 2000; 26(1):51–65. [PubMed: 10693116]
29. Basson R. Human sexual response. *Handb Clin Neurol*. 2015; 130:11–18. [PubMed: 26003236]
30. Rosen RC, Barsky JL. Normal sexual response in women. *Obstet Gynecol Clin North Am*. 2006; 33(4):515–526. [PubMed: 17116497]

Table 1

Terms used in selected self-administered self-report measures for women and men

Women	Men
Instrument - Domain(s) <i>Item Wording</i>	Instrument - Domain(s) <i>Item Wording</i>
ASEX-Female¹⁶ - Drive "sex drive" ASEX-Female¹⁶ - Arousal "sexually aroused (turned on)"	ASEX-Male¹⁶ - Drive "sex drive" ASEX-Male¹⁶ - Arousal "sexually aroused (turned on)"
MOS¹⁷ - Sexual Problems "lack of sexual interest" "difficulty in becoming sexually aroused"	MOS - Sexual Problems "lack of sexual interest" "difficulty in becoming sexually aroused"
PROMIS SexFS¹⁸ - Interest in Sexual Activity "interest in sexual activity" "want to have sexual activity"	PROMIS SexFS - Interest in Sexual Activity "interest in sexual activity" "want to have sexual activity"
FSDS¹⁹ - Sexual Distress "Low sexual desire"	--
FSFI¹⁰ - Desire "sexual desire or interest" FSFI - Arousal "sexually aroused ('turned on')" "arousal (excitement)"	--
--	EPIC²⁰ - Sexual Function "sexual desire"
--	IIEF¹² - Sexual Desire "sexual desire"

Abbreviations: ASEX, Arizona Sexual Experienced Scale; EPIC, Expanded Prostate Cancer Index Composite; FSDS, Female Sexual Distress Screener; FSFI, Female Sexual Function Index; IIEF, International Index of Erectile Function; MOS, Medical Outcomes Study; PROMIS SexFS, Patient Reported Outcomes Measurement Information System Sexual Function and Satisfaction

Table 2

Questions from Focus Group Discussion Guide Regarding Terminology

Moderator wrote terms on a white board in the room:	
Interest	
Desire	
Turned on	
Excited	
Horny	
Aroused	
1.	What does [term] mean to you?
2.	What are the connotations of [term]?
3.	Is [term] different from the other terms?
4.	Is [term] a good thing for you? / Is it always a good thing?
5.	Is there any time [term] is not good / unwelcome?
6.	What affects your [term] in sexual activity?
7.	How has [health condition] or its treatments affected your [term] in sexual activity?

Table 3

Characteristics of Focus Group Participants (n=57)

Characteristic	Total (n = 57)	Men (n = 27)	Women (n = 30)
Age, mean (range)	50 (23–77)	53 (31–77)	47 (23–74)
Hispanic or Latino ethnicity, No. (%)	3 (5.0)	2 (7.4)	1 (3.3)
Race, No. (%)			
Black/African American	33 (57.9)	16 (59.3)	17 (56.7)
White	22 (38.6)	10 (37.0)	12 (40.0)
Asian	2 (3.5)	1 (4.0)	1 (3.3)
Education, No. (%)			
Less than high school	6 (10.5)	5 (19.1)	1 (3.3)
High school grad/GED	9 (15.8)	4 (15.1)	5 (16.7)
Some college/technical degree	21 (36.8)	9 (33.3)	12 (40.0)
College degree	11 (19.3)	5 (19.1)	6 (20.0)
Advanced degree	8 (14.0)	3 (11.1)	5 (16.7)
Sexual orientation, No. (%)			
Lesbian or gay	8 (14.0)	4 (15.1)	4 (13.3)
Heterosexual or straight	38 (66.7)	19 (70.3)	19 (63.3)
Bisexual	9 (15.8)	3 (11.1)	6 (20.0)
Health conditions *			
High blood pressure, No. (%)	24 (42.1)	14 (52.5)	10 (33.3)
Heart failure, No. (%)	11 (19.3)	9 (33.3)	2 (6.7)
Diabetes, No. (%)	22 (38.6)	12 (44.4)	10 (33.3)
Depression, No. (%)	27 (47.4)	15 (55.5)	12 (40.0)
Anxiety, No. (%)	23 (40.4)	13 (48.1)	10 (33.3)
Other health condition(s), No. (%)	29 (50.9)	16 (59.3)	13 (43.3)
Use of prescription medication(s), No. (%)	14 (24.6)	6 (22.2)	9 (30.0)
Self-reported general health status, No. (%)			
Excellent	3 (5.3)	1 (4.0)	2 (6.7)
Very good	15 (26.3)	6 (22.2)	9 (30.0)
Good	22 (38.6)	9 (33.3)	13 (43.3)
Fair	10 (17.5)	8 (30.3)	2 (6.7)
Poor	3 (5.3)	2 (7.4)	1 (3.3)

* Many participants reported more than one health condition, 11 (19%) reported no health conditions

Table 4

Attributes Associated with Terms During Focus Groups, Overall and By Group (k = 10, n = 57)

	WOMEN						MEN				
Group	Heart Failure (HF)	Diabetes (D)	Mood Disorders (MD-W)	Lesbian / Bisexual (LB)	Age 65+ (65+W)	Heart Failure / Diabetes 1 (HFD1)	Heart Failure / Diabetes 2 (HFD2)	Mood Disorders (MD-M)	Gay / Bisexual (GB)	Age 65+ (65+M)	# of FGs
Total # of participants	2	5	10	6	7	4	6	6	3	8	10
Interest											
Person specific				1	2			1	1	1	5
Situational					1	1		1	2	1	5
Cognitive/mental	1		1		1	1	2	1		2	7
Physical											0
Positive	2	2	2		1				2		5
Negative					1						1
Wanting sex/need			1								1
Performance						1	1				2
Arousal											
Person specific				1	1						2
Cognitive/mental						2					1
Physical (incl. association with erection)			1			2		2	2		4
Scientific					1						1
Response to external stimulation - physical				2	1	1					3
Response to external stimulation - visual						2		2			2
Situational						2					1
Desire											
Person-specific					2			1	1	1	4
Physical				1	2						2
Situation specific					1	1					2
Strong(er)	1			2					1		3
Cognitive/mental							2				1
Want/need sex		1		1					3		3

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Group	WOMEN					MEN					# of FGs
	Heart Failure (HF)	Diabetes (D)	Mood Disorders (MD-W)	Lesbian / Bisexual (LB)	Age 65+ (65+W)	Heart Failure / Diabetes 1 (HFD1)	Heart Failure / Diabetes 2 (HFD2)	Mood Disorders (MD-M)	Gay / Bisexual (GB)	Age 65+ (65+M)	
Turn on/off				1	2						2
Related to performance								1			2
Comparisons of Terms											
Interest same as desire		1	1					1	1		4
Interest different from desire	1	2	2		1			1	1		7
Arousal same as desire		2	1					1	1		4
Arousal different from desire											0
Arousal same as turned on		2	1			1					3
Arousal diff. from turned on											0
Desire same as turned on					1				1		3
Desire diff from turned on	1										0
Desire same as horny										1	2