37
SEXUAL HEALTH

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The maintenance of sexual health has become a topic of concern and an essential domain in studies of overall quality of life (Flynn et al., 2016). Sexual health includes well-being across several domains, including physical, psychological, and social well-being, as well as factors related to one's identities and relationships (Rohleder & Flowers, 2018). These elements have historically been left outside of health psychology's investigations, which have focused largely on genital function and sexual dysfunction. While others have usefully discussed measurement resources from a psychometric point of view (e.g., Fisher et al., 2016a, 2016b), this chapter aims to expand the methodological possibilities when defining and assessing sexual health. The recommendations include measurement as well as research design considerations to help enrich researchers' understanding of the psychological qualities of sexual health as experienced across diverse populations who might be coping with aging, illness, and/or treatment.

Health psychology's focus on genital health as the major component of sexual health has, in large part, been due to the changes that have been observed in patients' bodies wrought by illness and its treatments. Breast cancer treatments, for example, have been shown to have a substantial negative impact on women's sexual health (Carter, Goldfrank, & Schover, 2011; DeSimone et al., 2014; Emilee, Ussher, & Perz, 2010). This body of research has undoubtedly helped to guide clinical interventions and to increase quality of life for patients and their intimate partners. However, questions remain as to whether definitions and operationalizations of sexual health commonly used in research settings are sufficient to describe the range and scope of sexual health experienced by both men and women, especially those who are ill, recovering from illness, or living with a chronic illness (Basson, 2007).

For example, Flynn and colleagues (2010) found that when they asked women and men diagnosed with cancer what sexual health meant to them, they found that while genitals were important to participants, they were not the only thing that was important. Some participants had broadened the conceptualization of sexuality to include intimacy in the absence of any sexual activity. For example, one participant with prostate cancer said, "We didn't have intercourse, but we hugged and you go down the street and you hold hands . . . this way, you're having sex all the time" (p. 383). Findings such as this should encourage researchers to examine the range of definitions that participants bring to the construct of sexual activity and sexual health.

This chapter discusses five central issues when designing research on sexual health: (1) gender socialization, (2) body image, (3) non-partnered sexuality, (4) non-penetrative sexual behaviors, and (5) including data from participants that are not "sexually active." My hope is that these

recommendations encourage psychologists to remain attentive to wide range of sexualities and relationships as they investigate adjustment to illness and the psychological characteristics of sexual health.

Assess the Role of Gender Socialization

Sexual health outcomes are often interpreted as the result of simple sex differences (i.e., men and women rate their level of sexual satisfaction differently). An alternate perspective emphasizes the impact of gender role socialization when understanding why men and women do this. Range and Jenkins (2010) defined gender socialization as the process by which women and men learn that certain feelings, thoughts, and behaviors are appropriate depending on gender. For example, women are commonly taught, via both verbal and non-verbal cues, that expressions of nurturance and warmth are highly valued, while men are commonly instructed that these same expressions are negatively valued. These messages coalesce and, over the life course, these gendering practices result in men and women developing varied expectations concerning sexual norms, relationships, and experiences (McClelland, 2017).

The sexual domain is one of the most powerful areas in which men and women feel pressure to enact gender roles. Although there is a history of documenting gender differences in sexual outcomes and attitudes (Petersen & Hyde, 2010), research on the mechanisms of what links gender socialization with sexual health outcomes is much more recent. For example, Kiefer and Sanchez (2007) found that gender norm conformity affected sexual passivity which, in turn, was associated with women's reduced rates of sexual arousal, sexual function, and sexual satisfaction. In research about gender norms and sexual activity, researchers have begun to document how women with sexual difficulties engage in sexual activity for a number of reasons, including the pursuit of intimacy, to please their partner, and to fulfill obligations perceived to be inherent in romantic relationships. This form of "sexual labor" as it pairs with gender socialization is an important component of sexual health. Norms may coalesce, for example, in internally and/or externally experienced pressures to be sexually active even when one does not want to, desires to be a "normal" person, and perhaps, even, when someone experiences tremendous pain during sexual activity (McClelland, 2017; see also Braksmajer, 2017; Marriott & Thompson, 2008).

Not only do gender norms influence individuals' sexual health outcomes, they can also inhibit the quality of data that researchers collect by over-determining what participants report in research settings. In a cognitive debriefing study designed to assess how respondents interpret the meaning of scale items, McCabe, Tanner, and Heiman (2010) found that participants' responses to questions about sex often conformed to gender norms, even though their own personal descriptions of sexual experiences and relationships often contradicted these same gender norms. In other words, there is a strong pull for participants to endorse traditional gender norms for both themselves and their partners when asked about sex and sexuality in research settings.

There are a number of scales that have been developed in other fields for use with other samples that could be adapted to suit research with ill populations. The Female Sexual Subjectivity Inventory is a good example of a scale developed to measure the relationship between gender and sex. Sexual subjectivity is defined as the perception of pleasure from the body and the experience of being sexual (Horne & Zimmer-Gembeck, 2006) and is a concept that is relevant to all ages, genders, and across the continuum of health and illness. Sample items include, "I think it is important for a sexual partner to consider my sexual pleasure" and "My sexual behavior and experiences are not something I spend time thinking about." In addition, scales that measure gender beliefs would allow investigators to understand how social and sexual norms have been internalized by research participants and how these subsequently affect sexual attitudes and beliefs (e.g., Levant, Richmond, Cook, House, & Aupont, 2007; Rostosky, Dekhtyar, Cupp, & Anderman, 2008). These measures could be used as

potential covariates, enabling investigators to understand the role of gender socialization as it interacts with sexual health outcomes.

Include Body Image as a Dimension of Sexual Health

Body image is a popular area of research, particularly for studies of women and research on illnesses that affect what are often considered the "sexual organs" (breasts, uterus, cervix, ovaries). Research on female sexual function and breast cancer has continuously been interested in the role of body image; researchers not only regularly include body image measures, but they also analyze the body image data for its associations with sexual function (e.g., Boquiren et al., 2016). Distress about appearance concerns (e.g., hair loss, scars, weight gain, and lymphedema) have all been found to be sources of frustration and embarrassment and have negatively impacted sexual health and body image has been found to be an important predictor of psychosocial outcomes in women with in situ breast cancer—and that these predictors have also differed for women across racial and ethnic identities (e.g., Buki, Reich, & Lehardy, 2016; Patel-Kerai, Harcourt, Rumsey, Naqvi, & White, 2017).

Studies that have conceptually linked the domains of sex and body image have produced compelling findings that challenge assumptions concerning the parameters of sexual function. For example, in a sample of men and women, Hendren and colleagues (2005) examined sexual function after treatment for rectal cancer and asked participants if they had been embarrassed/ashamed of their body or reluctant to have sex because they felt their body was undesirable. Similar proportions of men (22%) and women (18%) reported this was true. This finding and others like it (e.g., Fingeret et al., 2012) highlight that body image is not a domain limited to women, nor is it limited to illnesses that affect sexual organs. Perhaps most importantly, it draws attention to the important psychological link between body image and sexual feelings.

In a focus group study of men and women with different stages of cancer and cancer sites, participants consistently discussed body image concerns and negative effects on sexual function and intimacy with partners (Flynn et al., 2010). Both men and women—across racial and ethnic identities—described the negative effects of weight gain and treatment outcomes such as colostomy bags as important in how sexually attractive they felt. One male participant, for example, noted how he felt affected by his colostomy bag and how his body image suffered as a result: "Now, I could stand naked, and women could come in here and look at me, and they'd run out the door. You have that body image." Importantly, all gender and racial groups, described how weight gain impacted their feelings of sexual attractiveness.

With these findings in mind, researchers are advised to examine body image and sexuality as related domains. This might include measurement strategies such as including body image scores within quality of life scales or creating sub-scale scores. Body image scores should be used as both predictors and outcomes of sexual health. To do this one should avoid general items such as "Have you felt physically less attractive as a result of your disease or treatment," or "Have you been dissatisfied with your body?" (Aaronson et al., 1993). Instead, consider using items and methods that are more equipped to collect multiple ways that patients may be psychologically and physiologically imagining their (often altered) body image. In addition, researchers are advised to avoid items that may unconsciously link body image and femininity, as this may overly determine what researchers learn about men's experience of body image and sexual well-being. Women are often asked about femininity concerns, but concerns about how individuals' masculinity and femininity concerns affect sexual health are not limited to women or their body's appearance.

It is important to examine mechanisms that link body image and sexual health, to address questions such as: Is sexual health driven by self- or partner-perceptions of attractiveness? What relational qualities help to support experiences of positive body image? How do men experience changes to their bodies and what parts of their bodies do they feel most affect their sexual well-being?

Qualitative studies of women with breast cancer have identified a wide range of issues related to one's body and bodily integrity. Parton, Ussher, and Perz (2016), for example, found that participants described their post-cancer bodies in terms of abjection and "beyond abnormality," which included associations with aging, loss of control, loss of sexual sensations including arousal and libido, and an altered sense of womanhood. Thus, it is important to create definitions of sexual health and genital responsiveness that are linked with psychological and physiological constructs.

Items that address the links between body image and sexual health include those that inquire about participants' level of comfort being naked or their interest in physical contact more generally. These include, "I avoid close contact such as hugging," "I am satisfied with the shape of my body," and "I feel that part of me must remain hidden" (Body Image After Breast Cancer Questionnaire; Baxter et al., 2006). In addition, items that assess participants' evaluations of how they feel about their bodies (e.g., "I like the appearance of my body"), which when measured alongside sexual outcomes, would allow researchers to understand potential mechanisms that link how individuals feel about their bodies and the kinds of sexual thoughts, behaviors, and outcomes that result.

Include Non-Partnered Sexual Behaviors

Many researchers assumed that sexuality only occurs within partnered contexts; however, individuals are born with and develop sexuality regardless of whether they ever experience partnered sex (Pluhar, 2007). Put simply, individuals outside of relationships still experience sexual health (and sexual health concerns). When evaluating sexual health, non-partnered sexual experiences are consistently missed if items ask only about intercourse or ask non-partnered individuals to skip items concerning sexuality entirely. Research on sexuality within illness should allow for sexual health appraisals across a wide range of sexual expressions including when alone, with a regular partner, or across multiple partners.

By linking assessments of sexual function with relational status, researchers may be missing non-partnered sexual behaviors, particularly in the aging populations who are more likely to have a medical illness (Stanton, Revenson, & Tennen, 2007). For example, in a nationally representative sample of masturbation rates for women ranged from 31.6% in the younger group (57–64 years old) to 16.4% in the older group (75–85 years old) and for men, from 63.4% in the younger group (57–64 years old) to 27.9% in the older group (75–85 years old; Lindau et al., 2007). These data illustrate that although the frequency of masturbation decreases with age, it does not disappear and remains quite high into old age.

Non-partnered sexual behaviors may also be important indicators for patients who are recovering or coping with medical illness and its treatment. Sexual feelings or behaviors when alone may be an early indicator of the (re)emergence of sexual feelings, for example, after surgery. They also may signal an important point for clinical intervention—one that does not require the patient to contend with issues such as attractiveness to a partner, adequate genital response, and potentially new physical limitations due to the illness or its treatment. In sum, researchers should not restrict data collection or analysis to only those individuals who report being partnered and, in fact, may want to widen the definition of sexual activity to include non-partnered activities.

Assess Non-Penetrative Sex

Patients who want to remain sexually active and/or intimate, but who do not desire or are not capable of sexual intercourse, are nevertheless deserving of—and desirous of—information about sexual health. Sexual function is only one dimension of sexuality and intimacy, yet sexuality is often equated singularly with and measured as penetrative sexual intercourse (e.g., Rosen et al., 2000). One of the most common trends in this field has been the use of heterosexual intercourse as the primary

benchmark for sexual function. For example, the FSFI (the current gold standard for assessing female sexual function) includes three items about vaginal penetration and four items that ask about vaginal lubrication—a physiological response that is assessed in order to inquire about the ability to have penetrative sex. The conceptual conflation of sex, vaginal intercourse, and sexual function results in less knowledge about the range of sexual behaviors that participants engage in, as well as limiting the generalizability of research findings for LGBTQ participants and/or those individuals who are not engaging in heterosexual intercourse (Lisy, Peters, Schofield, & Jefford, 2018).

Lindau et al. (2007) found a wide variety of sexual activities reported in their nationally representative study of older adults 57–85 years old in the U.S. Men and women reported high rates of oral sex and masturbation in the previous year: 58% of the younger group (57–64 years old) and 31% of the older group (75–85 years old) reported participating in oral sex in the previous year. These rates of sexual activity outside of vaginal-penile intercourse should alert researchers to include measures that are not solely focused on penetrative sex. While not all the participants in this sample were coping with the effects of illness, approximately a quarter of the sample rated their health status as poor or fair. Approximately half of the respondents reported arthritis, diabetes, and hypertension, suggesting that the data from this study have important implications for researchers working with ill and aging populations.

Mansfield, Koch, and Voda (1998) found that one-fifth of their sample of midlife women reported an increased desire for non-genital sexual expression ("e.g., cuddling, hugging, kissing"). The authors offered a number of interpretations of this finding. One interpretation was that this did not mean that women wanted to avoid intercourse, but instead, wanted to increase their responsiveness to intercourse (i.e., through foreplay) or increase their ability to orgasm more readily. This finding also suggests that women may find non-penetrative sex more enjoyable—a finding that has been replicated in a variety of studies over the years. For example, in Conway-Turner's (1992) study of African-American women over 60, women expressed a great deal of interest and pleasure from various forms of sexual expression, but reported low interest and enjoyment of intercourse. This early finding has been replicated across many other samples (e.g., DeLamater, 2012; McHugh & Interligi, 2015). Studies also consistently show that vaginal dryness due to menopause is a significant factor in sexual (dis) satisfaction (e.g., Ambler, Bieber, & Diamond, 2012). As dyspareunia and vaginal dryness are frequent outcomes of many medications and surgery, as well as a common menopausal symptom, it is essential to consider non-penetrative sexual expression when measuring sexual health.

Finally, individuals with chronic illness have been found to better cope by shifting their cognitive and behavioral ideals of what constitutes sexual functioning (Gauvin & Pukall, 2017). This might include shifting from intercourse as the only way to be intimate with a partner, to engaging in oral sex as an alternative. This same type of flexibility needs to be reflected in measures that do not solely measure a male patient's ability to penetrate his partner or a female patient's ability to receive penetration. Researchers have argued that our culture's prioritizing of the erect penis above and beyond the experience of sexual pleasure places men (and their partners) in a position of caring more about the function of the penis and less about the pleasure that the penis is capable of (Ussher, Perz, Gilbert, Wong, & Hobbs, 2012). Perhaps even more importantly, this focus on penetration may obscure aspects of male sexual well-being such as diminished desire and low motivation for sexual activity (Meuleman & van Lankveld, 2005). For all of these reasons, researchers should consider the widest possible array of sexual behaviors including, but not limited to, sexual intercourse. Not only would this expanded definition include people who do not engage in heterosexual intercourse, but also it better represents the range of sexual behaviors that individuals engage in over the course of their lifetime.

In sum, two recommendations stand out: One, researchers should include and develop new definitions of sex and sexuality that extend beyond intercourse (McClelland, Holland, & Griggs, 2015). Two, practitioners in clinical settings need to support sexual health by offering a broad set of

information sources and providing support that extends beyond intercourse-related sexual activities and helps patients, both with and without partners, to develop strategies for feeling and sharing sexual intimacy and pleasure (Flynn et al., 2012; McClelland, 2016; Sporn et al., 2015).

Include Data From Participants Who Are Not Sexually Active

Sexual function measures often include a skip pattern where participants are asked whether they are partnered and/or whether they have been sexually active during a recent period (e.g., during the past month). Skip patterns often seek to create homogenous samples, but often do so at the expense of understanding more nuanced definitions of what sexual health may entail for a wide variety of individuals. For example, only those participants that answer "yes" to being in an intimate relationship and to being sexually active are asked to complete the sexual function questions (e.g., Barber, Visco, Wyman, Fantl, & Bump, 2002, p. 292). As a result, participants who are single, not partnered, not engaging in intercourse, but may be engaging in other kinds of sexual experiences alone or with partners, are not asked to provide data regarding their sexual well-being.

The concern is that the language of "sexual activity" privileges sexual behaviors over sexual intimacy, physical closeness, and non-activity based sexuality, including sexual daydreams, masturbation, and fantasies (Wilson, 2010). More importantly, this conditional pattern unnecessarily eliminates data on individuals who may be experiencing their sexual health, but not imagined within the definition of "being sexually active." In some cases, researchers will ask the participant to note reasons for sexual inactivity, such as "too tired" or "no current partner" (e.g., Barber et al., 2002). Although these additional data shed light on the relational contexts of the people answering the questions, they do not shed sufficient light on how sexual health is experienced by individuals who are not currently sexually partnered, but still sexually active and/or may be sexual, but without participating in sexual activities. These types of assessments may be particularly limiting for people who still are adjusting to their illness and may be learning to cope with a new form and idea of what "sexual" means in a newly altered body. Asking only about sexual behavior or sexual activities allows fewer opportunities to understand how patients adjust to illness and the effects of illness on their bodies and their intimate relationships.

Researchers are encouraged not to confine their samples to only those individuals who are partnered and/or who are currently sexually active. While this type of skip pattern is often used to ensure that a research sample shares basic characteristics, the cost in terms of lost information is too great. By eliminating responses of participants who are non-partnered or non-active, researchers are at risk of missing important issues and ignoring sub-populations who fall outside of these parameters. One suggestion is to collect sexual health data that does require participants be sexually *active*, but nevertheless inquires about dimensions of their sexual well-being. This includes items that inquire about sexual thoughts or fantasies (e.g., Changes in Sexual Functioning Questionnaire; Clayton, McGarvey, & Clavet, 1997). A second suggestion is to collect data on the criteria individuals use to decide if they want to be sexual alone or with a partner (i.e., sexual motivations), as well as the psychological, physiological, or relational barriers they believe stand in their way of feeling or enacting sexual expression (e.g., "my partner's health is poor," "too tired"). These types of items expand the potential for research samples to be included in sexual health research, but also allow researchers to investigate a much larger range of factors when individuals are asked to reflect on their sexual health.

Conclusion

This chapter aims to inform how psychologists conceptualize and assess sexual health in an effort to ensure that results can be applicable to people of all ages, in various types of intimate relationships, and with varying degrees of sexual interactions. Without attention to these definitional issues,

researchers run the risk of missing important characteristics of sexual health and ignoring the wide array of sexual expressions that individuals express and experience. This chapter contributes to the growing body of research (e.g., Wallner & Griggs, 2018) that draws attention to the ways that medicine and health psychology routinely ignore how experiences are dependent on a person's gender, race, class, and sexuality and, as a result, too often ignores those that fall outside of expected norms. Researchers must, as a minimum, examine the assumptions they are making about how people live, love, and share their lives with others on the way to making claims about what is normal, healthy, and desirable.

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