
11 Measuring Sexual Quality of Life

Ten Recommendations for Health Psychologists

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Over the past 20 years, sexual quality of life has become of increasing interest to psychologists studying quality of life with ill and/or aging populations. As people are living longer with chronic illnesses, the maintenance of sexual health has become a topic of concern and an essential domain of overall quality of life (QoL; see Arrington, Cofrancesco, & Wu, 2004). This concern has mainly focused on the retention of sexual function after diagnosis and treatment. At the same time, the parameters of the definition of sexual function have been dramatically affected by the rapid development of new treatment techniques and pharmaceutical interventions aimed to treat sexual dysfunction. Together, this interest in maintaining patients' sexual health and testing new sexual function interventions in patient populations has generated a great deal of empirical research in a relatively short period of time. For example, from 1980 to 1989, only 607 articles were published on sexual function, sexual dysfunction, and sexual health. This number grew to 1,428 articles from 1990 to 1999. By the turn of the 21st century, we see this number jump to 5,202 articles published from 2000 to 2009—a nearly ninefold increase over two decades. This emerging 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 function commonly used in research settings are sufficient to describe the range and scope of sexual quality of life (SQoL) experienced by both men and women, especially those who are ill, recovering from illness, or living with a chronic illness.

This chapter offers 10 suggestions to help guide researchers in this burgeoning area of study. The recommendations include measurement as well as research design considerations in order to help enrich researchers' understanding of the psychological qualities of sexual quality of life as experienced across diverse populations who are coping with aging and/or conditions of illness, and perhaps treatment. Although there are a number of resources from a psychometric viewpoint that can help guide researchers as they choose among the various scales that are currently available to measure sexual health and function (Barton, Wilwerding, Carpenter, & Loprinzi, 2004; Berman, Berman, Zierak, & Marley, 2002; Corona, Jannini, & Maggi, 2006; Meston & Derogatis, 2002; Rosen, 2002), this chapter has a more targeted objective: to help researchers capture important and often underexplored aspects of sexual quality of life in their own work, whether they are designing new measurement techniques or using previously validated scales. The aim of this chapter is to raise issues about the conceptualization of sexual quality of life that will inform measurement so that research findings can be increasingly applicable to men and women 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 quality of life and ignoring the wide array of sexual expressions that patients experience.

SEXUAL QUALITY OF LIFE AND ILLNESS

For the purposes of this discussion, sexual quality of life is defined as encompassing multiple dimensions that an individual may associate with a healthy and pleasurable sexual life. These include sexual responses, cognitions, and attitudes, as well as dimensions related to intimate relationships and a sense of one's physical body as capable and entitled to experiencing sexual sensations. The physiological dimension of sexual response, and genital response in particular, has often dominated sexual function research. Research on sexuality in illness settings is often characterized by its interest in negative sexual outcomes with a focus on the potential loss of genital response (i.e., erection or lubrication) before or during sexual activity. This extreme focus on the genitals has in large part been a consequence of the changes that have been observed in patients' bodies wrought by illness and its treatments. For example, the research in cancer has consistently found that surgery, radiation, and chemotherapy result in dramatic changes to patients' genitals and, as a result, to their genital and sexual response. For women, these changes may include vaginal stenosis, atrophy and irritation of the mucosa, and inadequate lubrication (Crane & Skibber, 2003; Havenga, Maas, DeRuiter, Welvaart, & Trimbos, 2000; Killackey, 2000; Pocard et al., 2002). For men, these changes may include loss of erectile rigidity, ejaculatory dysfunction, and urinary and bowel dysfunction (Litwin et al., 1998; Schover et al., 2002). Research on these outcomes is essential to help patients and their doctors prepare for the possibility of short- and/or long-term impaired sexual functioning. However, though genital and physiological functioning remain essential components of sexual quality of life, it is important to recognize additional SQoL dimensions, including the psychological, relational, and social contexts in which sexual responsiveness exists. These additional dimensions include addressing sexual activities other than penile-vaginal intercourse, the role of altered body image (not limited to illnesses that affect genital function or appearance), and the effect of gender norms on determinations of what counts as a "successful" sexual activity.

The focus on the physiology of sexual response is in large part a consequence of the model of the human sexual response cycle proposed by Masters and Johnson more than 40 years ago (Masters & Johnson, 1966, 1970). Masters and Johnson's model has remained the most common method to describe the expectation of how a human anticipates and resolves a sexual experience. This model has been the basis for a number of scales used to assess sexual health (Andersen & Cyranowski, 1994; Andersen, Cyranowski, & Espindle, 1999; Rosen et al., 2000; Rosen et al., 1997) and still largely determines the model by which normal sexual responsiveness is assessed. Masters and Johnson's four-phase cycle (excitement, plateau, orgasm, and resolution) has had enormous staying power, in part, because this model guided the development of diagnostic criteria for sexual dysfunction as described in the *Diagnostic and Statistical Manual* (DSM IV; APA, 1994; also DSM IV-TR; APA, 2000), which has been used to guide clinical practice in the United States.

Although this model has come under scrutiny in recent years, particularly in terms of defining female sexual response (Basson, 2000; Kaschak & Tiefer, 2001; Tiefer, 1996, 2004), a detailed discussion of the critiques of the human sexual response is beyond the scope of this chapter. What is important to note is how critiques of "normal sexual response" have in many ways paralleled developments within the research on illness and sexuality. Both of these groups have recently begun to encourage health researchers to look beyond long established models of sexual health and to define "normal" sexuality as more varied than a simple linear progression from desire to activity to orgasm. The challenge remains how best to approach understanding the diverse sexual lives among people facing illness, the changes that illnesses and their treatments bring, and ultimately how sexual well-being is affected by these changes.

For patients and people living with illness, sexual quality of life has been a relatively recent addition to the list of activities that are assumed to be important in research on health-related quality of

life (Basson, 2007). For example, in cancer research, sexual health has been shown to play an important role in survivorship trajectories (Gotay & Muroaka, 1998; Hordern, 1999, 2000; NCI, 2004) and is repeatedly cited by patients as an important aspect of their lives they fear will diminish when ill (Yost & Cella, 2003). Research in this area extends to individuals who are coping with sexual outcomes that are a result of office procedures (Inna, Phianmongkhol, & Charoenkwan, 2009), chronic illness (Schmidt, Hofmann, Niederwieser, Kapfhammer, & Bonelli, 2005; Schover & Jensen, 1988), and end-of-life issues (Lemieux, Kaiser, Pereira, & Meadows, 2004; Stausmire, 2004). However, some diseases and some disease sites—for example, breast and prostate cancer—have been more frequently investigated for potential negative sexual outcomes, creating an uneven set of studies in the field of illness and sexuality. AQ1
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Several factors influence how easily and automatically a disease is associated with potential negative sexual quality of life. Whereas, on the one hand, certain diseases are seen as inherently damaging to sexuality because of the proximity to sexual organs (e.g., gynecological cancers; Gamel, Hengeveld, & Davis, 2000), other diseases are less frequently associated with sexual outcomes and may be more frequently overlooked (e.g., rheumatoid diseases; for exceptions, see Majerovitz & Revenson, 1994; Schmidt et al., 2005; van Berlo et al., 2007). Some treatment regimens are seen as directly damaging sexual function, for example, prostate surgery's effect on erectile function or chemotherapy's impact on vaginal lubrication (e.g., Schover et al. 2002), whereas others may negatively impact sexual relationships through more indirect routes. For example, such physical changes as the presence of a stoma after colorectal cancer surgery may affect a patient's body image, which may also create threats to sexual identity and self-esteem, personal control over bodily functions, and ultimately negatively affect intimacy with a partner (Sprangers, Taal, Aaronson, & te Velde, 1995).

In addition, some disease sites are associated with more subtle aspects of sexuality, including feeling a loss of masculinity or femininity as a result of diagnoses or treatment. This result might include, for example, the incapacity to perform penetrative sex with a partner or the loss of a woman's breasts as a result of mastectomy (Fergus, Gray, & Fitch, 2002; Lund-Nielsen, 2005; Oliffe, 2005). The close association between sexual organs and gender ideals within sexual relationships encourages researchers, patients, and their partners who fall within these disease categories to consider sexual function and adjustment issues as primary issues. At the same time, individuals who have illnesses that do not involve sexual organs may not be counseled to guard against these effects (e.g., kidney or liver disease; Sorrell & Brown, 2006). In sum, whereas concerns of sexual organs, sexual identity, and intimate relationships may inherently be of interest to patients and their families regardless of their disease, disease site, or treatment regimen, the research on these issues has concentrated on a much smaller and specific set of patients.

This uneven attention to sexuality concerns has important outcomes: It can dramatically influence the frequency with which doctors question their patients about their sexual health. For example, in a survey of rheumatologists, only 12% of patients were screened for sexual activity (Britto, Rosenthal, Taylor, & Passo, 2000, cited in Tristano, 2009). Reasons offered by rheumatologists for this low screening pattern rate were time constraints, discomfort with the subject, and ambivalence about whether such screening is in their domain. The degree to which an illness is associated with potential negative SQoL outcomes influences the amount of information available for patients and doctors alike, as well as the quality research on that disease and its treatments.

One small indication of this uneven level of interest in sexual health across disease types can be seen in how major U.S. foundations, dedicated to supporting funding, research, and patient education, address the issue of sexual health. A quick scan of the foundations' Web sites, including the American Cancer Society, the Multiple Sclerosis Foundation, the Arthritis Foundation, and the Cardiovascular Disease Foundation, demonstrated the enormous variability in the amount of SQoL information provided by these foundations. For example, the American Cancer Society's Web site includes 25 Web pages about sexual health and intimate relationships, for a total of 32,792 words on the subject. In comparison, the Arthritis Foundation's Web site includes two

pages, for a total of 691 words on the subject. Neither the American College of Rheumatology Research and Education Foundation Web site nor the Cardiovascular Disease Foundation Web site includes any information at all pertaining to sexual health. Although this varying amount of Web site information is one, albeit limited, indicator of the varying level of attention that a topic receives, it demonstrates that sexual quality of life is viewed as more salient within certain disease types than others.

Finally, the saliency of the association between sexual health and an illness may influence patient and partner assumptions and expectations about changes in sexual function caused by or attributed to the illness. In research with ill participants, sexual dysfunction can be traced to many possible different sources, including aging, illness effects, and treatment effects, as well as surgery and/or medication and any combination of these. This complex set of etiologies for sexual dysfunction sets sexuality research with ill populations apart from sexuality research with healthy people, where the origin of sexual problems is often treated as emerging from purely psychological causes within the person or relational issues (see Heiman, 2002). This complex set of co-occurring factors means that health psychologists working on sexuality not only can improve quality of life among patients and their partners but also must define sexual health in a way that addresses an enormous diversity of human experience.

At the same time, the complexity that health psychologists must deal with has the potential to shape the field of sexuality research more broadly. Individuals throughout the life span are contending with multiple influences on their sexuality, changes in their body as a result of illness and/or aging, and an evolving set of concerns relating to their sexual lives. Health psychologists are in the unique position to theorize and empirically observe this complex set of factors in their research and contribute to the emerging body of research on sexual quality of life for all individuals.

DEFINING AND MEASURING SEXUAL QUALITY OF LIFE

Quality-of-life research among people facing serious physical illness has grown tremendously over the last 20 years. The best exemplar is in the area of cancer, where new treatments and longer survivorship trajectories have encouraged the development of scales and interventions aimed to improve aspects of a cancer survivor's life (Bottomley, 2002; Fortune-Greeley et al., 2009; Jeffery et al., 2009; Penson, Wenzel, Vergote, & Cella, 2006). Within this larger body of quality-of-life research lies the domain of sexual quality of life.

AQ3 A number of self-report instruments to assess quality of life have been developed and validated in diverse populations. In some instruments, sexual function subscales are one domain within the larger construct of quality of life. Other instruments include sexual health items in disease- or site-specific modules (e.g., EORTC QLQ 30 core questionnaire and breast cancer module QLQ-BR23; Aaronson et al., 1993; Sprangers et al., 1996; and the FACT-G and FACT-B; Cella et al., 1993; Sprangers, Cull, Groenvold, Bjordal, Balzeby, & Aaronson, 1998; Brady et al., 1997). In these QoL measures, items tapping sexual desire and satisfaction have provided researchers with ways to track the effects of treatment effects (e.g., Robinson, Saliken, Donnelly, Barnes, & Guyn, 2000), develop psychosocial interventions (see Stanton, 2006, for discussion), and measure change over time (e.g., change from end of treatment to 12 months post-treatment; Jensen et al., 2003). These types of data have been essential in helping guide interventions, increase patient education, and have provided both patients and providers with enormous insight into how sexual quality of life is affected by illness.

These disease- and disease site-specific measures have, however, been limited in how much detail they can include for each dimension for QoL, usually including at most three to five items to measure sexual well-being and often only one item pertaining to sexual quality of life. These targeted QoL sexual function subscales lend themselves to reducing patient burden and increasing clinical efficacy, but they reduce the ability for such psychological concepts as sexual adjustment and adaption to illness to be understood more broadly.

In addition to scales that have been developed to study specific diseases and disease sites, there have also been scales used to study sexual function that, though not developed specifically to study patients with physical illnesses, have been taken up enthusiastically by researchers studying ill populations (e.g., Derogatis, 1997; Taylor, Rosen, Leiblum, 1994). Two scales that are most commonly used by health psychologists are the International Index of Erectile Function (IIEF; Rosen et al., 1997) and the Female Sexual Function Index (FSFI; Rosen et al., 2000). These instruments are used widely in clinical, psychological, and pharmaceutical research and have become the gold standard for research on sexual function in clinical samples of all types. As an indicator of the popularity of these two measures, according to the ISI Web of Science (searched in January 2010), the IIEF has been cited 1,311 times since its publication in 1997 and the FSFI has been cited 481 times since its publication in 2000.

I will not review measures of sexual function here, as a number of others have done this (see Arrington et al., 2004; Corona et al., 2006; Cull, 1992; Daker-White, 2002; Jeffery et al., 2009; Jones, 2002; Meston & Derogatis, 2002; Rosen, 2002; West, Vinikoor, & Zolnoun, 2004). The available measures of *sexual function* make enormous contributions to the understanding of many aspects of sexual outcomes but are less effective in assessing *sexual quality of life*, a broader construct that requires attention to an individual's psychological, relational, and physical well-being, in addition to characteristics of sexual health that currently fall outside the scope of sexual function definitions (see DSM IV and IV-TR).

As a step toward theorizing this construct more broadly, I will discuss three central issues when designing research on sexual quality of life: measurement and operationalization decisions, definitions of sex in research settings, and issues of research design in studies of medical populations. My hope is that these recommendations encourage health psychologists to remain attentive to issues of sexuality as they affect adjustment to illness and reveal the psychological mechanisms underlying sexual well-being that are currently understudied and/or not yet well understood. Because the chapter focuses on definitional and measurement issues, I will not review needs assessments or clinical interventions (see Lenahan, 2004, for discussion of sexual health issues across variety of chronic illnesses; see also Andersen, 2002; Andersen, Shelby, & Golden-Kreutz, 2007). Nor do I discuss the etiology of or sexual sequelae of medical disorders (for discussion, see Basson & Schultz, 2007; Bhasin, Enzlin, Coviello, & Basson, 2007; Clayton & Ramamurthy, 2008; Rees, Fowler, & Maas, 2007). I have also limited this discussion to physical illnesses and have therefore not included discussion of mental illness and sexuality (see Zemishlany & Weizman, 2008). Finally, while I am addressing these recommendations to researchers studying sexuality in the medical context, I am not proposing a general theoretical model to address SQoL issues across all chronic illnesses (see Verschuren, Enzlin, Dijkstra, Geertzen, & Dekker, 2010, for discussion of a generic conceptual framework for studying chronic disease and sexuality).

With an eye on the wide spectrum of research issues that health psychologists contend with in designing research, the 10 recommendations are grouped into three broad areas of interest. The first group of recommendations concern measurement issues that researchers face when evaluating sexual quality of life. The recommendations included in this group address measurement from a both a broader theoretical perspective (e.g., the role of gender socialization), as well as from a traditional psychometric perspective (e.g., issues of construct equivalency). The second group of recommendations concerns the definition of terms in sexuality research. By evaluating the consequences of limiting which activities and behaviors are included within the parameters of research on sexual health, these recommendations encourage investigators to expand the definition of what "counts" as sex. Finally, the third group of recommendations concern research design decisions that an investigator makes about how a study will be conducted and what kinds of questions will be answered by these designs (e.g., using a cross-sectional vs. longitudinal design). While these 10 recommendations do not address every aspect of the research process, each is designed to address important decisions that health psychologists face when designing research to study sexuality quality of life in illness contexts.

TEN RECOMMENDATIONS FOR MEASURING SEXUAL QUALITY OF LIFE AMONG PEOPLE FACING MEDICAL ILLNESS

1. ACKNOWLEDGE THE ROLE OF GENDER SOCIALIZATION IN SEXUAL APPRAISALS

Many research findings regarding sexual outcomes are interpreted as the result of simple sex differences (i.e., men and women rate their level of sexual satisfaction differently). However, an alternative perspective emphasizes the impact of gender role socialization when understanding why men and women do this. In an *American Psychologist* review on men, masculinity, and help seeking, Addis and Mahalik (2003) defined the gender role socialization perspective as follows: "Role socialization paradigms begin with the assumption that men and women learn gendered attitudes and behaviors from cultural values, norms, and ideologies about what it means to be men and women" (p. 7). Expanding on this definition, 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, through both verbal and nonverbal cues, that expressions of nurturance and warmth are highly valued, whereas 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 (see McClelland, in press, for discussion of gendered development of sexual expectations).

Researchers have argued that the sexual domain is one of the most powerful areas in which men and women feel pressure to enact gender roles (Sanchez, Crocker, & Bioke, 2005). Although there is a history of documenting gender differences in sexual outcomes and attitudes (Kinsey, Pomeroy, & Martin 1948; Kinsey, Pomeroy, Martin, & Gebhard, 1953; Oliver & Hyde, 1993; Peterson & Hyde, 2010), research on the mechanisms of what links gender socialization with sexual outcomes is much more recent. For example, Kiefer and Sanchez (2007) found that gender norm conformity affected sexual passivity, which was, in turn, associated with women's reduced rates of sexual arousal, sexual function, and sexual satisfaction. In addition, research has demonstrated links between gender conformity and increased rates of consenting to unwanted sex with male partners (Bay-Cheng & Eliseo-Arras, 2008) and lower rates of sexual pleasure (Sanchez et al., 2005). In their research on sexual compliance in heterosexual relationships, Impett and Peplau (2003) articulated how gender norms affected what men and women prioritized when they evaluated their level of sexual satisfaction.

Unfortunately, much of the research on gender socialization has remained outside the scope of the literature on sexual adaptation and medical illness, but this is beginning to change. For example, in a study of women diagnosed with vulvodynia (i.e., vulval pain and vulval vestibulitis), Marriott and Thompson (2008) found that women prioritized their male partner's sexual enjoyment to the extent that they often participated in sexual activities they found extremely painful. As one woman stated, "He used to say, am I hurting you? And I used to say no, and clench my teeth and think, actually I'm in agony here" (p. 251). In a related body of research, investigators have looked extensively at the impact of breast cancer on women's sense of femininity, body image, and intimate relationships with partners (Avis, Crawford, & Manuel, 2004; Pikler & Winterowd, 2003). In interviews with 40 individuals who had been treated with surgery for a variety of chronic illnesses, Manderson (1999) found that women were more self-conscious of their general appearance than the men in the sample and reported feeling less desirable because of changes in body parts beyond just their sexual organs.

Men experience the negative effects of gender norms on their sexual health as well. Schover et al. (2004) developed the Erectile Dysfunction Help-Seeking model in order to measure how traditional masculine attitudes about sex could inhibit help-seeking behavior; men with prostate cancer who held more traditional beliefs about sex and gender roles were less likely to seek medical help for erectile dysfunction. In an interview study of low-income Latino and African American men,

Maliski, Rivera, Connor, Lopez, and Litwin (2008) found participants struggled to maintain a masculine image of themselves during treatment for prostate cancer and its sequelae and in particular, they struggled with the loss of ideal male sexual performance. Participants discussed what it meant to “not being able to be united with my wife,” and a fear of losing the partner because of the inability to have an erection (p. 1614). Interestingly, participants also revealed that when they were with other male friends, they talked as if they were still sexually active when, in fact, they were not. The authors conclude, “By doing this, men were able to maintain a public masculine image consistent with the image they perceived others to hold” (p. 1614), a finding that highlights the often powerful and sometimes restrictive role that gender socialization can have in individuals’ lives.

Gender norms not only influence individuals’ sexual health outcomes but also can inhibit the quality of data that researchers collect by overdetermining what participants report in research settings. In a cognitive debriefing study designed to assess how respondents interpret the meaning of scale items, McCabe et al. (2009) 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.

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When asking participants to recall the quality, frequency, or evaluation of their sexual experiences and/or relationships, researchers often forget that these responses are highly influenced by social norms. For example, in an experimental study examining how research conditions affect men’s and women’s reported rates of sexual experiences and attitudes, investigators examined how responses to sex questions varied over three conditions (Alexander & Fisher, 2003). In one condition, the respondents believed their answers were anonymous; in a second condition, respondents believed their responses might be seen by a peer; in a third condition, respondents answered while they were attached to a nonfunctioning polygraph (known as the bogus pipeline methodology). With each level of exposure, women’s responses varied more than did men’s. For example, more women reported masturbating and viewing erotica when attached to the polygraph than when responding in the anonymous condition. The authors conclude that “reports of sex differences based on self-reports may reflect conformity to normative expectations for men and women rather than actual differences in behavior” (2003, p. 33). These findings, and studies that have replicated them (e.g., Fisher, 2007, 2009; Lucas & Parkhill, 2009), make clear the challenge involved in designing studies that both prioritize the individuals’ experience through the use of self-report measures and at the same time account for the (often unconscious) role that social norms play when participants decide how comfortable they are expressing aspects of their sexual experience and behaviors.

Taking this complex range of factors into account is not a simple or easy task. First, sexual quality of life should be measured independently for men and women. Sexual experiences are unique experiences for men and women both physiologically and socially, unlike fatigue, for example. Ignoring the uniquely gendered conditions of sexuality means that investigators risk obscuring these conditions and missing important elements of patients’ lives. This means using measures that are gender specific or tailoring items so they tap the experience of sexual quality of life specifically for men and women in one’s population of interest.

Second, SQoL scales should measure gender norms. As Range and Jenkins (2010) argued in their comprehensive analysis of gender theories, “If and when gender differences occur, the causal mechanism may not be biological sex, but instead one or more social or psychological correlates such as gender schema that might mediate or moderate effects otherwise misattributed to biological sex” (“Introduction,” para. 18). There are a number of scales that have been developed in other fields for use with other samples that could easily be adapted to suit research with ill populations. These measures include gender ideology scales (Levant & Richmond, 2007; Levant, Richmond, Cook, House, & Aupont, 2007; Thompson & Pleck, 1986; Tolman & Porche, 2000), measures of sexual self-concept (Rostosky, Dekhtyar, Cupp, & Anderman, 2008), and measures of sexual subjectivity (Horne & Zimmer-Gembeck, 2006).

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 and 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.” 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. These could be used as potential covariates, enabling investigators to understand the role of gender socialization as it interacts with SQoL outcomes.

2. EVALUATE CONSTRUCT EQUIVALENCY WHEN ASSESSING GROUP DIFFERENCES

When measuring sexual responsiveness and other qualities of an individual’s sexual life, as with any topic, researchers must decide on the best way to operationalize their construct of interest (Cronbach & Meehl, 1955; Machado & Silva, 2007). When health psychologists include SQoL items in a study, there is often an interest in examining group differences in terms of such attributes as gender, age, or experimental condition (as in a clinical trial). Construct equivalency is especially important when making group comparisons to ensure that the same experience (physical sensation, genital response, emotion, etc.) is being evaluated. In this discussion, I will use gender as an exemplar of issues that arise when making group comparisons and the problems that arise when using operationalizations of sexual experiences that may not be equivalent for men and women. However, it is important to keep in mind that construct equivalency is an issue for all types of research that investigate group comparisons. The choices we make in terms of operationalizing psychological constructs are some of the most important decisions we make as researchers—and some of the most difficult.

In sexual function research, investigators have often operationalized function using observable behaviors that allow participants to report on their genital response. For example, such physical factors as dyspareunia (pain on intercourse) or failure to maintain an erection are examined as similar types of physical sexual experiences that allow researchers to understand important aspects of genital health (Aaronson et al., 1993). However, taking a closer look at issues of construct equivalency, we might ask: Is the experience of erection difficulty the same (or similar enough) to the experience of dyspareunia that ratings on these items can be effectively compared? There are a number of related questions that are pertinent: Are the two physical experiences psychologically similar? What kinds of unstated assumptions are implied in these experiences? Looking more closely at a specific measure, the colorectal cancer supplement of the EORTC (CRC-38) includes five items that directly assess sexual quality of life. Three items are designed to be answered by both men and women and concern sexual interest, activity, and satisfaction. In addition, two items are gender specific: Men are asked if they had “difficulty getting or maintain an erection” and if they had a “problem with ejaculation.” Women are asked if they had “a dry vagina during intercourse” and if they had “pain during intercourse” (Aaronson et al., 1993). Taking up the question of construct equivalency, one should ask whether men’s ability to maintain an erection and women’s rate of pain with intercourse are equivalent, particularly when they will be compared with t-tests to document sex differences.

I would argue that the constructs underlying these gender-specific items are, in fact, not equivalent. As a result, this is not an effective way of comparing male and female sexual function. Historical perceptions of male and female sexuality (and the various stigmas attached particularly to female sexuality; see McClelland, in press, for discussion) can be observed in the assumptions that male sexual response is the norm. This implicit belief can be seen in such statements by researchers as “The simple endpoints equivalent to potency and ejaculation in men are not available [in women]” (Banerjee, 1999, p. 1901). As a result, researchers have often limited their assessment of female sexual function to measures of pain during intercourse (just as they often limit the assessment of male sexual function to erectile function). These implicit associations have resulted in defining

female sexual health as the absence of pain and men's sexual health as the presence of pleasure. It is by examining these unstated assumptions inherent in construct equivalency questions that one is able to see how discrepant these measures have become.

Solving issues of construct equivalency is not simple. Given the recommendation made earlier about the benefits of gender-specific items when assessing sexual quality of life, researchers who want to make group comparisons are faced with a difficult challenge. A first step is to examine how participants interpret and experience items. For example, in a recent study (Flynn et al., 2010), the investigators found that when they asked participants across a variety of group differences (gender, cancer site, and cancer stage) what sexual health meant to them, they found that though 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" ("Results," para. 12). Findings such as this should encourage researchers to examine the range of definitions that participants bring to the construct of sexual activity. More important, this type of research question also presents an opportunity for health researchers to inform sexuality research more broadly about the diversity of sexual experiences that individuals imagine as relevant to their sexual quality of life. A second recommendation is to examine the unstated assumptions when making group comparisons, for example, ensuring that items measuring pleasure and pain are compared with like items when comparing the sexual well-being of men and women.

3. INCLUDE BODY IMAGE AS A DIMENSION OF SEXUAL QUALITY OF LIFE

How medical illness and/or treatment affect body image is a very popular area of research (Andersen & LeGrand, 1991), particularly for studies of women and research on illnesses that affect what are often considered the "sexual organs" (breasts, uterus, cervix, ovaries; for exception, see Syrjala et al., 1998, for discussion of bone marrow transplant patients). However, body image is often conceptualized and measured as separate from sexual quality of life. In other words, it may be measured, but it is not necessarily analyzed along with those items measuring sexual function. 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 also analyze the body image data for its associations with sexual function (e.g., Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998).

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, Hendren and colleagues (2005) examined sexual function after treatment for rectal cancer and asked participants, a sample of men and women, if they had been embarrassed about or 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 (Andersen, Woods, & Copeland, 1997; Scott, Halford, & Ward, 2004; Yurek, Farrar, & Andersen, 2000) highlight that body image is not a domain limited to women, nor is it limited to illnesses that affect sexual organs, and 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, body image concerns were mentioned in each of the 16 focus groups (Flynn et al., 2010). Moreover, body image concerns negatively affected sexual function and intimacy with partners. Participants named common changes as important to their sexual well-being, including scarring, treatment-related hair loss, and weight gain. Women, more than men, described feeling sexually attractive as important to their sexual motivation. Men described the negative effects of weight gain and such treatment outcomes as colostomy bags as important in how sexually attractive they felt.

Researchers are advised to examine body image and sexuality as related domains. In doing so, they might include such measurement strategies as including body image scores within QoL scales

or creating subscale scores. Body image scores should be used as both predictors and outcomes of sexual quality of life. To do this, one should avoid such general items 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 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 because this approach may overly determine what researchers learn about men’s experience of body image and sexual well-being. Women are often asked about femininity concerns in breast cancer research, but concerns about how individuals’ masculinity and femininity concerns affect sexual quality of life should be extended to all illnesses and to studies with men as well. It is important to examine mechanisms that link body image and sexual quality of life to address important questions: Is sexual quality of life driven by self-perceptions or by partner perceptions of attractiveness? What relational qualities help to support experiences of positive body image? How do men experience changes to their bodies, especially in illness contexts where the physical is salient in a new way? Qualitative studies of women with breast cancer have identified a wide range of issues related to one’s body and bodily integrity. Wilmoth (2001), for example, found that participants described their sexual health in terms of missing parts of their bodies as a result of surgery; loss of menstruation and associations with aging; loss of sexual sensations, including arousal and libido; and an altered sense of womanhood. Thus, it is important to create definitions of sexual quality of life and genital responsiveness that are linked with psychological and physiological constructs.

Items that address the links between body image and sexual quality of life include those that inquire about participants’ level of comfort being naked or their interest in physical contact more generally. These items 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”), 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.

4. MEASURE THE IMPORTANCE OF SEX FOR INDIVIDUALS

Although many researchers have argued that sexuality is an essential aspect of quality of life (e.g., Arrington et al., 2004), sexual experiences and/or feelings may not be equally important for everyone. With this idea in mind, researchers should consider including measures that allow for varied levels of importance attached to the sexual domain. Not everyone will be bothered by diminished sexual function; this response may be a result of an individual’s history of unsatisfying or perhaps traumatic sexual experiences, as well as a result of physical changes because of aging or illness that make sexual contact uncomfortable or painful. For example, Lindau et al. (2007), noted that “women were more likely than men to rate sex as an unimportant part of life and to report lack of pleasure with sex” (p. 772). The fact that some individuals experience varying levels of investment in the sexual domain suggests that researchers should consider sexual activities, behaviors, and interactions in the context of the importance that individuals place on them. Without attention to overall importance of sexual experiences, researchers are at risk of conflating the lack of sexual activity with sexual dysfunction among participants who report no sexual activity or sexual desire. By including the concept of importance, it is easier to tease apart the motivation behind this reported lack of sexual activity or desire.

This idea of importance has more recently been developed in sex researchers’ recommendations to measure levels of distress as a necessary component of a diagnosis of sexual dysfunction (Bancroft, Loftus, & Long, 2003; Derogatis, Rosen, Leiblum, Burnett, & Heiman, 2002). Bancroft et al. (2003) found that a significant portion of women in heterosexual relationships who reported

high levels of sexual dysfunction were not distressed by their dysfunction. A similar finding was reported in a study of men treated for prostate cancer who reported that although their sexual function was poor, “they had adjusted to the change and were not terribly bothered, especially if they believed they were cured of the cancer” (Litwin et al., 1998, p. 1008). Given these findings, the role of importance in the sexual domain and its potential associations with bother and distress are worth investigating.

Raphael, Rukholm, Brown, Hill-Bailey, & Donato (1996) have developed a quality-of-life measure that blends how important a domain is to the individual with how satisfied he or she is in this domain. This model holds enormous potential for measuring how two dimensions are related. As the investigators explained, “Importance scores serve as a weight for converting satisfaction scores into quality of life (QoL) scores” (Raphael et al., 1996, p. 368). For example, a low satisfaction score weighted by a high importance score results in a low QoL score. This kind of weighting would allow for the separate domains within quality of life to be differentially important and to examine which domains individuals emphasize throughout their lives and at what stages of the illness trajectory.

Similarly, Avis and colleagues (1996) developed a scale that tapped perception of importance as well as satisfaction in their Multidimensional Index of Life Quality. The authors describe how during the scale development phase, they had created QoL scores that were weighted by each participant’s importance ratings of each QoL domain. While Avis and her colleagues found that the importance-weighted measures did not increase the accuracy of satisfaction scores (and were subsequently dropped from analyses), I argue that the practice of measuring importance may hold more promise for research in a domain where variability in importance has already been demonstrated. In a recent national study, Waite, Laumann, Das, and Schumm (2009) found that nearly one quarter of women (24.0%) ages 57–64 responded that sex was “not at all important” when asked how important a part of the participant’s life sex was. In this study, the prevalence of reporting the low importance of sex increased with women’s age (34.9% in ages 65–74; 52.3% in ages 75–85). For men, this rate was much lower, ranging from 6.2% in ages 57–64, to 14.1% in ages 65–74, and to 25.9% in ages 75–85.

Given that Waite et al. (2009) do not report on the health status of this sample, generalizability to patients living with illness is not immediately possible. Nevertheless, these findings demonstrate that there is enormous variability in how individuals rate the importance of sex. Including items that can measure attitudes toward intercourse, sexual behaviors more broadly, or even thinking about sex, would provide an important frame through which to analyze such other SQoL items as frequency of orgasm and genital function. Taking up the model that Avis and her colleagues presented, researchers are encouraged to create importance-weighted sexual domain scores that account for individuals who report low SQoL and low importance. Analyses with importance-weighted scores may offer insight into individuals and groups that are qualitatively different than those who report, for example, a low SQoL score with high importance.

It is important to note that data reflecting low importance of sex should not be confused with how much men and women like sexual activity or how one gender is inclined toward sex more than the other. Instead, data on importance tell us something about the quality of sexual experiences that men and women imagine when asked to evaluate the relative importance of sex in their lives. Low importance in the sexual domain is not a necessarily dysfunctional, nor is it a “natural” outcome or a gendered one. Because the etiology of sex may be complex for some individuals, researchers are encouraged to investigate not only the range of importance that individuals may attach to sex but also the history and genealogy of these attitudes.

5. DO NOT IGNORE DATA FROM PARTICIPANTS WHO ARE “NOT SEXUALLY ACTIVE”

Many sexual function measures 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). The language of “sexual activity” privileges sexual behaviors over sexual intimacy, physical

closeness, and nonactivity-based sexuality, including sexual daydreams, masturbation, and fantasies (Wilson, 2010). In just one example of this type of skip pattern, it is possible to see how those participants who have not been sexually active are not asked to provide any further data regarding their sexual well-being: "The first two questions asked if [the participants] were in an intimate relationship and if they were sexually active." If these two questions were answered yes, "participants were asked to complete the seven remaining [sexual function] questions" (Barber, Visco, Wyman, Fantl, & Bump, 2002, p. 292).

Such items and skip patterns as these limit SQoL data to only those participants who are both partnered and recently sexually active. More important, this conditional pattern unnecessarily eliminates data on individuals who fall outside these categories. In some cases, researchers will ask the participant to note such reasons for sexual inactivity as "too tired" or "no current partner" (Barber et al., 2002; Basson et al., 2004). 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 quality of life is experienced by individuals who are not currently sexually partnered but are 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 (Meyerowitz, Desmond, & Rowland, 1999).

Researchers are encouraged not to confine their samples only to those individuals who are partnered and/or who are currently sexually active. Although this type of skip pattern is often used to ensure that research sample participants share basic characteristics, the cost in terms of lost information is too great. By eliminating responses of participants who are nonpartnered or nonactive, researchers are at risk of missing important issues and ignoring subpopulations who fall outside these parameters. One suggestion is to collect SQoL data that do require participants be sexually active but nevertheless inquires about dimensions of their sexual well-being. This assessment 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," "I'm too tired"). These types of items expand the potential for research samples to be included in SQoL research but also allow researchers to investigate a much larger range of factors when individuals are asked to reflect on their sexual quality of life.

6. WIDEN THE SCOPE OF INQUIRY TO EXAMINE NONPARTNERED SEXUAL BEHAVIORS

Put simply, individuals outside of relationships still experience SQoL issues. When evaluating sexual quality of life, researchers consistently miss nonpartnered sexual experiences if items ask only about intercourse or ask nonpartnered individuals to skip items concerning sexuality. In addition to retaining in their samples those participants who may not be sexually active, researchers should also consider sexual quality outside relationships. Although many researchers have assumed that sexuality is a dyadic process, individuals are, in fact, born with and develop sexuality regardless of whether they ever experience partnered sex (Pluhar, 2007; Tolman & Szalacha, 1999). Research on sexuality within illness should allow for SQoL appraisals across a wide range of sexual expressions, including when alone, with a regular partner, or across multiple partners (Bocking & Coleman, 2002; Das, 2007).

By linking assessments of sexual function with relational status, researchers may not be accurately capturing nonpartnered 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, results 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 but remains quite high into old age.

Nonpartnered 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 may also signal an important point for clinical intervention, one that does not require the patient to contend with such issues as attractiveness to a partner, adequate genital response, and potentially new physical limitations resulting from the illness or its treatment. In sum, researchers should consider not restricting data collection or analysis to only those individuals who report being partnered. To the contrary, researchers may want to widen the definition of sexual activity to include nonpartnered activities.

7. CONSIDER ASSESSING NONPENETRATIVE SEX IN ADDITION TO INTERCOURSE

In addition to expanding definitions of sex to include masturbation and other sexual behaviors that do not require a sexual partner, it is also imperative to expand definitions to include sexual behaviors that are not limited to vaginal-penile intercourse. Sexual function is only one dimension of sexuality and intimacy (Gamel, Hengeveld, & Davis, 2000), yet sexuality is often equated singularly with and measured as sexual intercourse (Bruner & Boyd, 1999). 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 women's 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 nonheterosexual participants and/or those individuals who are not engaging in heterosexual intercourse (Schneidewind-Skibbe, Hayes, Koochaki, Meyer, & Dennerstein, 2008).

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 United States. Men and women reported high rates of oral sex and masturbation in the previous year: In the study, 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 one quarter of the sample participants rated their health status as poor or fair. Arthritis, diabetes, and hypertension were reported by approximately one half of the respondents, 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 nongenital sexual expression (“e.g., cuddling, hugging, kissing”). The authors offered a number of interpretations of this finding. One interpretation was that this response did not mean that women wanted to avoid intercourse; instead, it meant that the respondents 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 nonpenetrative sex more enjoyable, a finding that has been replicated in a variety of studies over the years. For example, in a 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 (Conway-Turner, 1992). Studies consistently show that vaginal dryness as a result of menopause is a significant factor in sexual (dis)satisfaction (e.g., Tomic et al., 2006). Because dyspareunia and

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vaginal dryness are frequent outcomes of many medications and surgery, as well as a common menopausal symptom, it is important to consider nonpenetrative sexual expression when measuring sexual quality of life.

Finally, Barsky, Friedman, and Rosen (2006) described the importance of flexibility when coping with long-term sexual dysfunction. The authors argue that individuals with chronic illness best cope by shifting their cognitive and behavioral ideals of what constitutes sexual functioning. This strategy used by the chronically ill might include shifting from intercourse as the only way to be intimate with a partner, for example, 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 (Potts, 2000; Potts, Grace, Gavey, & Vares, 2004). Perhaps even more important, this focus on penetration may obscure such aspects of male sexual well-being as diminished desire and low motivation for sexual activity (Meuleman & van Lankveld, 2005). For all these reasons, researchers should consider the widest possible array of sexual behaviors, including, but not limited to, sexual intercourse. This expanded definition not only would include men and women who do not engage in heterosexual intercourse but also would better represent the range of sexual behaviors that individuals engage in over the course of their lifetime.

8. AVOID ATTRIBUTION ERRORS THAT OCCUR WHEN PREMORBID SEXUAL HEALTH IS NOT ASSESSED

Because a diagnosis of a serious medical illness is often sudden and unpredictable, few studies can assess premorbid levels of sexual activity, function, importance, and distress. As a result, researchers often attribute the lack of sexual activity or dysfunction postdiagnosis exclusively to the patient's illness without explicit data on change over time.

Most researchers evaluate premorbid sexual health some time after the diagnosis is made or treatment has begun. Although there are many problems with this approach (see later), even retrospective data may contribute important information. Items asking people to report on their sex life before the illness allow for the evaluation of perceived changes in sexuality following diagnosis. Although these perceptions may be retrospectively flawed, they allow for the patient to evaluate the changes instead of assuming perfect health and function prior to illness (see Bruner et al., 1998, for examples of retrospective items). This approach is essential if researchers are to avoid falsely attributing declining sexual quality of life to illness when sexual activity may have been infrequent or even absent prior to illness. For example, Dennerstein and Leher (2004) found that when assessing current levels of sexual functioning in middle-aged women, "premorbid functioning [had] a major and essential effect, compared with concomitant cross factors" (p. 180), including change in partner status and feelings for one's partner.

The issue of retrospective data collection, that is, comparing "before surgery" with "after surgery," presents a potential, but not ideal, first step. Hendren and colleagues (2005) assessed sexual dysfunction retrospectively in a sample of men and women who had been treated for rectal cancer. Because the researchers chose not to exclude patients based on preexisting sexual inactivity or dysfunction (exclusions that bias results toward higher rates of sexual function), the researchers were able to make a number of within-group comparisons based on surgery type, recent sexual activity, and pre- and postoperative sexual function. In fact, 35% of men and 47% of women reported they had experienced sexual problems prior to cancer treatment. In terms of investigating the effects of surgery, their decision to measure presurgical sexual dysfunction allowed the authors to exclude participants who reported dysfunction symptoms prior to treatment in order to examine the specific effects of cancer treatment.

Researchers are encouraged to use validated measures of sexual quality of life that include retrospective items that ask participants to reflect specifically on the role of their illness on their own sexual health. This specificity is needed not only to disentangle premorbid sexual dysfunction from illness-related dysfunction but also to disentangle the potential influence of a partner's illness or the effects of the participant's illness on a partner. One example of a scale that includes an assessment of premorbid sexual quality of life is the Psychosocial Adjustment to Illness Scale (PAIS; Derogatis & Lopez, 1983), which was designed to measure changes an individual experiences as a result of illness. The sexual function subscale has six items that ask the participant to reflect on changes in their sexual interest, satisfaction, and relationship since becoming ill (e.g., "Sometimes when people are ill they report a loss of interest in sexual activities. Have you experienced less sexual interest since your illness?"). A small cross-sectional study of patients with advanced heart failure using the PAIS found that one quarter of the participants reported little or no change in the frequency of sexual activity and one half reported minimal changes in their sexual satisfaction since their illness (Jaarsma, Dracup, Walden, & Stevenson, 1996). In order to tease apart the effects of illness and and/or treatment from preexisting sexual quality of life, researchers are encouraged to include measures that enable participants to reflect on the changes they perceive in their own sexual well-being.

9. EXAMINE THE REEMERGENCE OF SEXUAL QUALITY OF LIFE OVER TIME

The role of time and change over time is essential and not yet well understood in studies of sexual quality of life (Talcott et al., 2003). Change over time is even more salient for people living with a medical illness. When does sexual function return? Does sexual quality of life precede sexual function? If so, under what conditions? And what form does it take? Most studies have looked at relatively short periods after diagnosis or treatment. As a result, the reemergence of physical intimacy and characteristics of the psychological adjustment period are not well understood. Research questions addressing change over time require not only longitudinal research designs but also measures that are sensitive enough to pick up on early SQoL indicators, including the experience of physical intimacy, masturbation, sexual thoughts, and anticipation of sexual activities. For example, Andersen et al. (1997) examined the influence of sexual self-schemas in a sample of women with gynecological cancer and found that a positive self-schema predicted higher rates of sexual responsiveness, including desire, excitement, orgasm, and resolution. Andersen (1999) has suggested that those with positive sexual schemas are better able to adjust to illness and make the necessary changes to their cognitive schemas and sexual behaviors that allow for the experience of pleasure to reemerge.

Researchers are encouraged to measure sexual quality of life over time using longitudinal designs, but perhaps more important, also to assess the emergence of sexual quality of life using measures that assess not only functionality but also the emergence of sexual feelings and fantasy that may or may not be accompanied by sexual behaviors. An example of a measure that assesses these more subtle changes in sexual quality of life over time is the Short Personal Experiences Questionnaire (Dennerstein, Anderson-Hunt, & Dudley, 2002; Dennerstein & Lehert, 2004). Items include, for example, "Give an approximate estimate of how many times you have had sexual thoughts or fantasies (e.g., daydreams) during the last month." This assessment of sexual thoughts may be more accessible to patients at early stages of recovery than assessments of sexual desire or libido, which may be perceived to be too closely related to sexual activities. Patients who are nervously anticipating and/or coping with sexual changes as a result of illness may be relieved to see that resuming normal sexual activities (i.e., intercourse) is not the only threshold to cross in order to be considered healthy, sexually active, or functional. Earlier and more subtle thresholds of sexual characteristics and feelings may offer considerable comfort and information on the way to recovering or adapting to illness.

In addition to including measures that assess early (re)emergence of sexual quality of life, researchers are encouraged to include repeated measures in order to understand the patterns of adjustment over time, including the variation of trajectories that individuals experience (Hegelson,

Snyder, & Seltman, 2004). An important point, which is reflected in the foregoing recommendations, is that in their longitudinal designs, researchers need to consider strongly the definitions used to determine when individuals “resume sexual activity.” As I argued earlier in this discussion, limiting the definition of successful and functional sex to intercourse results in a tremendous loss of data on individuals, the diversity of their lives, and the wide variety of sexual experiences, thoughts, and relationships that individuals—especially those who are adapting or recovering from illness—might include in their definition of a healthy and vibrant sexual life.

10. EVALUATE THE PSYCHOLOGICAL CONTEXTS OF SEXUAL QUALITY OF LIFE

As discussed in the foregoing recommendation, there is more to sexual quality of life than genital response. There are many contexts in which sexual quality of life flourishes, but one of the most important is the psychological health and well-being of an individual. Andersen (1985) was one of the first health psychologists to find that having a more negative self-view predicted greater sexual morbidity after cancer than having a positive self-view, a finding that has been replicated in many studies over the last 25 years (Andersen et al., 1997; Andersen, Woods, & Cyranowski, 1994). Psychological correlates may impair sexual functioning through perceptual changes in the sexual self (Cyranowski & Andersen, 2000). A patient’s self-esteem can potentially be eroded by physical changes resulting from treatment, cosmetic issues, and loss of functional ability, as well as numerous other changes after illness. In turn, the loss of self-esteem can adversely affect sexual response. In addition, stress and depression have been shown to predict decreased sexual response (Brassil & Keller, 2002; Wilmoth & Spinelli, 2000).

There has been a long history of examining the relationship between anxiety and negative sexual outcomes (Beck, 1967; Fenichel, 1945; Kaplan, 1974, 1979; Wolpe, 1958). This relationship has been more recently explored by researchers at the Kinsey Institute; they have consistently found a strong link between such negative mood states as depression and anxiety and subsequent decreased sexual interest (Bancroft & Janssen, 2000; Lykins, Janssen, & Graham, 2006). For medical populations, negative mood states might be triggered by not only life events and daily stress but also thoughts of expected pain and discomfort, anticipation of sexual distress, or anxiety that may be related to genital function or an altered body image.

Lindau et al. (2007) found that anxiety and avoidance were important factors affecting the sexual health of individuals in three illness groups—arthritis, diabetes, and hypertension—and that negative psychological responses varied across both gender and illness type. Women in the arthritis group reported significantly higher rates of anxiety about sexual performance than did men (odds ratios of 1.26 for women vs. 0.78 for men); whereas the reverse was seen in the diabetes group, where men were more anxious than women (odds ratios of 1.20 for men vs. 0.86 for women). In the hypertension group, both men and women reported approximately equal levels of anxiety about sexual performance. These findings demonstrate the role that psychological conditions can have on sexual quality of life. Similarly, in their recommendations for studying sexual dysfunction in men, Lue et al. (2004) emphasized the importance of anxiety, depression, and self-esteem in evaluations of men’s sexual health. They also highlighted the role of expectations and their potential underlying role in sexual disappointment, which may affect sexual satisfaction and an individual’s intimate relationships. More broadly, it is clear that negative psychological experiences, including but not limited to depression, anxiety, and low self-esteem, play important and often understudied roles in individuals’ experiences of sexual quality of life, particularly for those who are recovering or adapting to illness.

CONCLUSION

Sexual quality of life is an area that is becoming more important within the literature on adaptation to medical illness. Thus, it is important to think about measurement issues in terms of construct

validity and appropriate measurement tools (Basson, 2000; Basson et al., 2004; Kaschak & Tiefer, 2001; McClelland, in press; Moynihan, 2003; Tiefer, 1996, 2004). Definitions of sexual function have become increasingly controversial in the role that for-profit companies have had in the development of clinical and pharmaceutical interventions to treat male and female sexual dysfunction (see Moynihan, 2003). As this controversy around definitions continues to develop, health psychologists will be faced with a set of difficult but important questions: Is sexual health the same as genital functioning? Can I measure men's and women's sexual health using the same items? Is there a short scale I can use in my study that will help me understand the relationship between sexual health and overall well-being? What is the best way for me to evaluate an intervention aimed to help patients' sexual and relational health? The 10 recommendations provided in this chapter offer a starting point for health psychologists to navigate these questions and choose (or adapt) the most appropriate measure to answer these questions. In turn, doing this will help to ensure that the data we collect is not only representative of patients' lives but also attentive to diverse sexual experiences.

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