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Sexuality and intimacy among people living with serious mental illnesses: Factors contributing to sexual activity

Kelsey A. Bonfils, MS[1,2], **Ruth L. Firmin, MS**[1,2], **Michelle P. Salyers, PhD**[1,2], and **Eric R. Wright, PhD**[3]

[1]Psychology Department, Indiana University-Purdue University Indianapolis, Indianapolis, Indiana

[2]ACT Center of Indiana, Indianapolis, Indiana

[3]Department of Sociology, Georgia State University

Abstract

Objective—Limited research has focused on sexuality for those diagnosed with a severe mental illness. We aimed to extend existing work by exploring relationships between mastery (perception of control of one's life and future), sexual self-esteem (perceptions of one's capacity to engage in healthy sexual behavior), sexual attitudes (permissive ideas about sexuality), and perceived importance of relationships/sexuality and number of sexual partners.

Methods—A secondary analysis of survey data from adult participants living with a severe mental illness (N=401) in the Indiana Mental Health Services and HIV-Risk Study (Perry & Wright, 2006) was conducted. Analysis of covariance (controlling for marital status) compared those with zero partners, one partner, or multiple partners over the past three months on the dependent variables of mastery, sexual self-esteem, sexual attitudes, and perceived importance.

Results—Participants with more permissive attitudes, greater perceived importance, and higher mastery were more likely to be sexually active with multiple partners. Self-esteem did not differentiate groups.

Conclusions and Implications for Practice—Given the key role of sexual satisfaction in quality of life and the high rates of sexual risk behavior in this population, it is important that clinicians systematically assess mastery, perceived importance, and attitudes about sexuality when working with consumers diagnosed with a severe mental illness. Individually tailoring existing interventions based on consumers' levels of mastery, related to self-efficacy for implementing changes in life, could improve long-term outcomes for these programs. Future research should examine other constructs that may account for more variance in sexual activity, such as perceptions of risk, intentions for sexual safety, or romantic relationship functioning.

Keywords

Severe mental illness; sexuality; sexual dysfunction; self-esteem; sexual attitudes; mastery

Please address correspondence to Kelsey A. Bonfils, 402 North Blackford Street, LD120A, Indianapolis, IN 46202. Phone: 317-274-6767. kbonfils@iupui.edu.

Sexual activity is an important aspect of life, yet is frequently overlooked by providers in treatment and conceptualizations of recovery for people who have been diagnosed with a mental illness (Higgins, Barker, & Begley, 2008; McCann, 2010; Quinn, Happell, & Browne, 2011). While providers have a difficult time addressing sexual health in general, stigma about mental illness may lead providers to see these individuals as asexual, or to view romantic relationships as inappropriate in this population (Walsh, McCann, Gilbody, & Hughes, 2014). Person-centered care has gained recognition and increased importance over the last decade in mental health care (National Research Council, 2006); in striving to improve delivery of person-centered care, greater knowledge of how yet-unstudied constructs such as mastery and self-esteem relate to sexuality and intimate relationships is needed for individuals diagnosed with a severe mental illness. Expanding research to include new constructs in this area has the potential to increase awareness and provide tools for providers in their endeavors to include sexuality in the assessment of each individual.

Studies of sexual activity in the general population indicate the vast majority of individuals engage in romantic relationships with a spouse, partner, or significant other for the majority of adult life. A national survey found that 88% of adults in the US reported having at least one sexual partner in the past year (Laumann, 1994). Other community surveys have reported 50-86% of adults were sexually active in the past month (Johannes & Avis, 1997; Lutfey, Link, Rosen, Wiegel, & McKinlay, 2009). Among people diagnosed with a severe mental illness, however, this pattern differs. A systematic review of 52 studies reported a weighted mean prevalence of 44.9% of individuals diagnosed with a severe mental illness as sexually active in the past three months (Meade & Sikkema, 2005). Further, adults in this population have high rates of sexual risk behaviors, such as multiple partners and involvement in the sex trade (e.g., see Meade & Sikkema, 2005; Perry & Wright, 2006), and are disproportionately infected with HIV/AIDS (Campos et al., 2008; Meade & Sikkema, 2007).

To explain these differences, some research suggests those diagnosed with a severe mental illness may face unique challenges relating to sex. For example, comparing women with schizophrenia to a control sample, women diagnosed with schizophrenia were more likely to have been sexually assaulted, have had more sexual partners, and experienced higher rates of unplanned pregnancy (Cogan, 1998). Further, those with greater substance use have been shown to be more likely to be sexually active, but also to be more likely to trade sex for money or other favors (Meade & Sikkema, 2007). Individuals in this population often also experience a lower sense of mastery (one's perception of oneself as in control of one's own successes and failures in life as opposed to perceiving life as fatalistically determined; Pearlin & Schooler, 1978) and related perceived quality of life (Hansson, 2006), which have been linked to lower self-esteem and lower marital satisfaction in the general population (Cassidy & Davies, 2003; Malcom, 1995). Having lower mastery and a more fatalistic view of the future has also been associated with increased sexual risk behavior in varied “at-risk” populations (Dixon, Saul, & Peters, 2010; Kelly et al., 1990; Loue, Cooper, Traore, & Fiedler, 2004; Somlai et al., 2000), but this association has yet to be tested in individuals diagnosed with a severe mental illness. At the relationship level, Perry and Wright (2006) reported that, compared to the general population, people diagnosed with a severe mental illness had less committed and intimate relationships. Other studies have found adults in this

population are also less likely to have long-term sexual partners or be married (Agerbo, Byrne, Eaton, & Mortensen, 2004). As would be expected, those who *are* in steady romantic relationships are more likely to be sexually active, but are also less likely to use condoms consistently (Meade & Sikkema, 2007).

Expanding upon differences in sexual activity, in-depth interviews touch on other areas of difficulty specific to people who have diagnosed with a mental illness. Participants in multiple studies have identified stigma as key in their sexual behavior, with greater stigmatizing experiences leading these individuals to feel they have little choice regarding sexual partners, and that they are unattractive and/or unappealing as a romantic partner because of their mental illness (Wainberg et al., 2007; E. R. Wright, Wright, Perry, & Foote-Ardah, 2007). Similar relationships have been demonstrated in quantitative studies, indicating increased exposure to sex-related or relationship stigma in this population is associated with increased sexual risk behaviors (Collins et al., 2008; Elkington et al., 2010).

The stigma attached to mental illness has also been linked to lowered self-esteem (Lysaker, Tsai, Yanos, & Roe, 2008; Ritsher & Phelan, 2004). Lowered self-esteem has, in turn, been linked with greater sexual risk behaviors in other “at risk” populations (Somlai et al., 2000; Sterk, Klein, & Elifson, 2005), but this association has yet to be examined for those who have been diagnosed with severe mental illnesses. Attitudes such as fear surrounding sexual activity can also impact behavior (E. R. Wright et al., 2007). For example, sexual knowledge, attitudes, and experiences among people diagnosed with a severe mental illness have been linked to sexual activity (Berman & Rozensky, 1984). This same study also reported that many experienced a conflict between their sex-related attitudes and behavior, producing an overall negative attitude regarding sex. More recently, others have found that sexual satisfaction in this population was related to individuals' overall self-esteem (Eklund & Östman, 2010). However, these important constructs have yet to be directly linked to sexual activity in people with severe mental illness.

Better understanding the perspectives of people diagnosed with a severe mental illness regarding sex can also inform services for this population. Although rates of sexual activity are significant, this is a frequently overlooked topic within mental health service systems. D. E. Wright (2006) reported that even among consumers who regularly see providers, conversations about sex are infrequent; the mental health nursing literature also speaks to this issue, acknowledging that these conversations happen far less often than desirable (Higgins et al., 2008; McCann, 2010; Quinn et al., 2011). Further, despite the development of numerous behavioral interventions designed to reduce sexual risk behavior (Walsh et al., 2014), these interventions have had mixed results, and have yet to see widespread dissemination (Meade & Sikkema, 2007). Although false ideas about the asexuality of those diagnosed with a severe mental illness have long existed in the mental health field (Test & Berlin, 1981; Walsh et al., 2014), research suggests the contrary—that these individuals perceive sex as an important area of life (McCann, 2010; Werner, 2012). Relatively little is known about the nature and extent of sexuality-related attitudes among those diagnosed with a severe mental illness (i.e., permissive versus conservative sexual ideas about things like pornography and sex outside of marriage). Thus, research is needed to understand the impact these attitudes have on behavior in this population.

When investigating perspectives of individuals diagnosed with a severe mental illness regarding their sexual activity, several variables seem particularly important. Our aim was to examine the number of sexual partners in our sample and how this relates to person-centered variables including mastery, sexual self-esteem, sexual attitudes, and perceived importance of relationships/sexuality. We hypothesized that better overall self-esteem, higher sexual self-esteem, and a greater sense of mastery would be positively related to number of sexual partners. However, given that having multiple sexual partners is generally considered risky sexual behavior, which has been associated with lower self-esteem and mastery (e.g., see Dixon et al., 2010; Sterk et al., 2005), there could be a curvilinear relationship between the number of sexual partners and self-esteem and mastery. Given past findings indicating those diagnosed with a severe mental illness find sex to be an important part of life (McCann, 2010; Werner, 2012), we further hypothesized that viewing sex with greater importance and having more permissive attitudes would be positively associated with number of partners.

Methods

Data for this study came from the Indiana Mental Health Services and HIV-Risk Study (Perry & Wright, 2006), which was designed to explore the extent and nature of sexuality and HIV-related services for consumers diagnosed with a severe mental illness in the public mental health system. The parent study recruited 401 adults receiving mental health services from two state hospitals and three community mental health centers. Participants had to be 18-60 years old, have a diagnosis of major depression, bipolar disorder, schizophrenia, schizoaffective, or other psychotic disorder, have been in psychiatric treatment for two years or longer (at least three months being at the current service site), and not be currently subject to criminal charges or be in jail. Random sampling was utilized at two community mental health centers, but all eligible consumers were invited to participate at the state hospitals and the remaining community mental health center. The participation rate across sites was 74%. Consenting consumers were interviewed using a mixture of Likert-style survey items and open-ended questions. Data collection concluded in 2001. For a more detailed description of the parent study, see Perry and Wright (2006).

Measures

Demographics & Sexual Activity—A large portion of the interview items reflected questions asked in the National Health and Social Life Survey (NHSLS; (Laumann, 1994), Detailed demographic information included age, race, marital status, gender, education, employment, income, and sexual orientation. Diagnosis and Global Assessment of Functioning (GAF) scores were collected via medical chart review. Questions were included to assess sexual activity over the past three months with male and/or female partners. For the purposes of these analyses, sexual activity was categorized as 0, 1, or multiple partners in the past 3 months (either male or female).

Sexual attitudes—Sixteen items were included to assess sexual attitudes with variable response options; items assessed individuals' thoughts about whether certain acts, such as sex before marriage or watching pornography, were morally right or wrong. Items did not ask whether an individual would or would not engage in an act him- or herself, but rather

whether they felt it was acceptable for others to engage in said act. Although all 16 items were administered to participants in both the NHSLS and the parent study, Laumann (1994) included only 9 items in analyses because of comparable response options and evidence in the NHSLS that respondents may have ambiguously interpreted the remaining 7 items. To remain consistent with the NHSLS, we used the same 9 items in our scale score. An example item reads, “What is your opinion about sexual relations between two adults of the same sex?” Items were dichotomized to reflect whether participants felt a certain act or idea was acceptable and summed to create a total score, with higher scores indicating more sexually permissive attitudes. Cronbach's alpha indicated an adequate level of internal consistency (alpha = .70).

Self-esteem—Both general self-esteem and sexual self-esteem were assessed. General self-esteem was measured with Rosenberg's 10-item self-esteem scale (Rosenberg, 1965). The items are summed to create a total score, with higher scores reflecting better self-esteem. This scale has been used successfully with samples of individuals diagnosed with severe mental illnesses in the past (e.g., Corrigan, Watson, & Barr, 2006; Torrey, Mueser, McHugo, & Drake, 2000). Internal consistency of the Rosenberg self-esteem scale was good (alpha = .83).

Sexual self-esteem was assessed using a modified short version of the multidimensional sexual self-concept questionnaire (MSSCQ; Snell Jr., 1998). Sexual self-esteem is defined for the purposes of this measurement tool as one's ability to positively evaluate one's capacity to engage in healthy sexual behavior, and to be able to enjoy this sexual behavior and obtain sexual satisfaction; feeling anxious, depressed, or scared about sexual behavior fall under this purview (Snell Jr., 1998). Twelve items were rated on a 5-point scale from “not at all” to “very much” (e.g., “I feel good about the way I express my own sexual needs and desires.”). The original MSSCQ has evidence of validity and good internal consistency, with all 20 subscales having alpha values above .70 (Snell Jr., 1998). Sexual self-esteem items for this study were averaged to produce a total score, with higher scores reflecting poorer sexual self-esteem. In the current sample, internal consistency was good (alpha = .81).

Mastery—Mastery, or the extent to which one views one's future as within one's own control as opposed to fatalistically determined, was assessed utilizing the scale developed by Pearlin and Schooler (1978). Seven Likert-type items are rated from 1, strongly agree, to 4, strongly disagree, e.g., “I often feel helpless in dealing with the problems of life.” Item scores are summed to create a total score with higher scores reflecting greater mastery. This scale has been used previously in samples of individuals diagnosed with a severe mental illness (E. R. Wright, Gronfein, & Owens, 2000). In the current sample, internal consistency was adequate (alpha = .70).

Importance—A scale of six items assessed participants' perceptions of the importance of intimate relationships/sexuality, rated from 1, strongly agree to 5, strongly disagree (e.g., “Having a relationship with someone is very important to me.”). Item scores are averaged to produce a total score, with higher scores reflecting a greater degree of importance. In this sample, Cronbach's alpha was .68.

Analyses

All analyses were conducted in SPSS version 20. Frequencies and exploratory statistics were examined for all variables and scales. Bivariate relationships between background variables and measures of self-esteem, attitudes, mastery, importance, and number of sexual partners were examined using Pearson's *R*, Spearman's rho, point-biserial correlations, and chi-square statistics. Differences between sexual activity groups were investigated in a series of analyses of covariance (ANCOVAs). In these analyses, participants' marital status (ever married vs. never married) was included as a covariate in order to parse apart the presence of a serious romantic partner from other sexually-relevant constructs. Tukey's post hoc tests were run to determine if levels of the independent variable (number of partners) significantly differed on each dependent variable. Alpha was set at $p < .05$ for all analyses.

Results

Nearly one third of the sample was sexually active over the past three months (29.9%). See Table 1 for background characteristics of the sample. Correlational associations between demographic characteristics and sexuality-related measures can be seen in Table 2. Number of sexual partners was significantly associated with younger age, having ever been married or cohabitating (including divorced individuals), higher functioning, more permissive sexual attitudes, and higher perceptions of relationships/sexuality as important. Number of sexual partners did not vary by diagnosis, $\chi^2(6) = 4.21$, $p = .649$.

See Table 3 for ANCOVA results. Post-hoc tests revealed that, when controlling for marital status, those with multiple partners over the past three months had a greater sense of mastery than those with zero ($p = .005$) or one partner ($p = .008$). Those with one ($p = .043$) or multiple partners ($p = .002$) also had more permissive sexual attitudes than those with zero partners. Regarding importance, those with one ($p = .003$) or multiple partners ($p < .001$) in the last three months considered sexuality/relationships more important than those with no partner. Neither self-esteem nor sexual self-esteem differed based on number of sexual partners in the past three months.

Discussion

Nearly one third of consumers had at least one sexual partner in the three-month period prior to the interview (29.9%), a level slightly lower than found in previous reviews (Meade & Sikkema, 2005), and substantially lower than levels found in the general population (e.g., Lutfey et al. (2009) found 50% of their community sample had been active in just the past four weeks). In support of our hypotheses, having more permissive sexual attitudes and perceiving sexuality and relationships as more important were related to increased sexual activity (with one or multiple partners compared to none) when controlling for marital status.

A greater sense of mastery, or the belief that one is in control of one's own life, was also related to sexual activity with multiple partners in the past three months. Although mastery has not been studied in the context of sexual activity for people who have been diagnosed with a mental illness, past research indicates that greater mastery is related to increased

condom usage and lower overall sexual risk among Puerto Rican women (Dixon et al., 2010; Loue et al., 2004); similar relationships have been found among disadvantaged inner-city women (Somlai et al., 2000), gay men (Kelly et al., 1990), and African American men (McKay, 1999). Interestingly, our findings indicate those with more than one partner over the past three months have greater mastery than those with zero or one partner when controlling for marital status. As a greater number of partners increases one's sexual risk, our findings are in contrast with past research indicating greater mastery tends to be associated with fewer sexual risk behaviors. But, we did not include other measures of sexual risk, such as condom use. In addition, it is possible that the nature of mental illness plays a role in our results; given the stigma often held by members of society against people who have been diagnosed with a mental illness, finding a sexual partner is more difficult for this population (Elkington et al., 2010; Wainberg et al., 2007; E. R. Wright et al., 2007). Thus, being able to find multiple partners in the span of three months may in fact contribute to these individuals having a greater sense of control in their lives.

Although self-esteem and sexual self-esteem were each related to mastery, neither was significantly related to number of sexual partners. Prior research in the general population has been mixed, with some reporting a significant association (Ethier et al., 2006; La Rocque & Cioe, 2011) and others showing self-esteem is not related to sexual behavior (Commendador, 2007; Robinson & Frank, 1994). Recent research has also reported an association between self-esteem and sexual activity in people with other chronic conditions, such as cerebral palsy (Wiegerink, Stam, Ketelaar, Cohen-Kettenis, & Roebroeck, 2012). Of interest, a qualitative study based on the same parent study (i.e., utilizing the same data from this study) found self-esteem frequently emerged in responses about sexuality provided by those who had not been sexually active in the last three months (E. R. Wright et al., 2007). That the present study did not find a similar association may indicate that quantitative measurements are not doing an adequate job in capturing aspects of self-esteem related to sexuality in this population; alternatively, qualitative questions may have lead participants to highlight self-esteem when it may not have in fact been the most salient aspect influencing sexual activity, as qualitative interviewing can vary based on interviewer characteristics and interviewing strategies (Charmaz, 2006). Future research should utilize mixed methods, which can offer benefits over either qualitative or quantitative methods alone (Johnson & Onwuegbuzie, 2004), to obtain a full picture of how self-esteem plays into sexuality in this population and to ascertain appropriate measurements for this construct going forward.

Overall, results suggest that self-esteem may not play a substantial role in whether or not an individual diagnosed with a severe mental illness is sexually active. Instead, a greater sense of control in one's life (mastery) and the relative importance of sexuality/relationships play a role in number of sexual partners in this population, as do sexual attitudes. Given that the rate of sexual activity in adults diagnosed with a severe mental illness is lower than those found for the general population (Meade & Sikkema, 2005; E. R. Wright et al., 2007), assessing these variables can provide important insight as to who maintains an active sexual life, and who may be more likely to have multiple sex partners, thereby increasing risk of contracting sexually transmitted infections (Meade & Sikkema, 2005). Furthermore, our results speak to the importance of going beyond background variables to obtain a thorough understanding of sexuality and the whole person in this population, enhancing our ability to

work within a person-centered framework of care (Institute of Medicine, 2001; National Research Council, 2006). Even when taking into account marital status, which gives one more ready access to a sexual partner, mastery, importance, and attitudes still influence a person's level of sexual activity; use of these variables in a holistic assessment may increase our ability to appropriately plan treatment and create opportunities to provide education regarding risks associated with some sexual behaviors.

Results from this study should be interpreted in light of some limitations. First, although much of our data was based on collection instruments used in the NHSLS (Laumann, 1994), some scale scores were assembled for this study (i.e., attitudes) that were used at the item-level in NHSLS analyses, and other scales had not been used previously in samples of individuals diagnosed with severe mental illnesses. Internal consistency was acceptable in this study, but other psychometric indices (e.g., test-retest stability) were not available. Although our study included either random sampling or population-based sampling, depending on recruitment site, exclusion criteria for this study may limit generalizability of results. Participants had been in treatment for at least two years at the time of interview, indicating these results may not generalize to the early psychosis population or to others early in the course of a mental illness. However, results of this study largely reflect participants with a chronic course of illness, with a large and relatively diverse sample. Further, data collection ended in 2001; although these data are dated, no study to our knowledge has since collected similar variables regarding sexuality in this population. Thus, our results still provide an important contribution to the literature.

Conclusions and Implications for Practice

This study provides insight as to what factors play a role in whether individuals diagnosed with a severe mental illness are sexually active, and, if so, their number of partners. Given the key role of sexual satisfaction in quality of life (Eklund & Östman, 2010) and the high rates of risky sexual behavior in this population (Meade & Sikkema, 2005), it is important that clinicians consider sexuality when working with consumers diagnosed with a severe mental illness. Based on our results, we recommend providers systematically assess consumers' sense of mastery as well as their attitudes toward sex and perception of its importance. On a grander scale, behavioral interventions designed to decrease risky sexual behavior may benefit from incorporating these concepts into curricula. Although most interventions show some improvement after consumers have completed the program, no intervention has shown continued improvements six months after termination of the program (Walsh et al., 2014). It is possible that providing individually-tailored information based on consumers' levels of mastery, which inherently influences one's world view and self-efficacy for implementing changes in life, could improve outcomes for these programs. Future research may integrate mastery into these programs and look for further variables that play a role in consumers' sexual activity and number of partners, such as perceptions of risk, intentions for sexual safety, or romantic relationship functioning.

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Table 1

Participant Demographics

	N (Percent)
Gender (female)	169 (42.1%)
Race	
White	257 (64.1%)
African American	117 (29.2%)
Other	25 (6.2%)
Marital Status	
Married or Cohabitating	43 (10.7%)
Divorced, Widowed, or Separated	100 (24.9%)
Never Married	258 (64.3%)
Education	
0-7 years	22 (5.5%)
8-11 years	151 (37.7%)
12 years or GED	136 (33.9%)
Some college or more	92 (22.9%)
Currently Employed	66 (16.5%)
Sexual Orientation	
Straight or Heterosexual	316 (78.8%)
Homosexual or Gay/Lesbian	11 (2.7%)
Bisexual	20 (5.0%)
Asexual	9 (2.2%)
Primary Diagnosis	
Schizophrenia/Schizoaffective	211 (52.6%)
Major Depression	40 (10.0%)
Bipolar Disorder	28 (7.0%)
Psychosis NOS	122 (30.4%)
Age (mean, SD)	39.6 (9.6)
Monthly Income	$535 ($443)
GAF Score	46.8 (14.3)
Sexually Active	122 (32.5%)

Note. GAF = Global Assessment of Functioning. All percentages are calculated for the full sample (N = 401); due to some missing data, percentages may not add up to 100.

Table 2

Bivariate Relationships

		1	2	3	4	5	6	7	8	9	10	11	12
1	Gender (female)	1											
2	Age	.05	1										
3	Race (black)	-.01	-.03	1									
4	Race (other)	.07	-.06	-.17**	1								
5	Marital status (ever married)	.28**	.35**	-.10*	-.04	1							
6	GAF	.19**	.10*	.09	-.10	.18**	1						
7	Self-esteem	-.07	-.13*	.02	.08	-.15**	.10*	1					
8	Mastery	-.06	-.21**	.01	-.02	-.06	.11*	.62**	1				
9	Sexual Attitudes	-.16**	-.03	.04	.03	-.07	.07	.00	-.01	1			
10	Sexual Self-esteem	.00	.02	-.04	.03	.01	-.08	-.34**	-.36**	-.05	1		
11	Sexual/relationship importance	-.14**	.08	.04	.09	.13**	.13**	.19*	.19**	.13*	-.04	1	
12	Number of sexual partners in last 3 months	.09	-.12*	.08	.10	.17**	.15**	-.03	.09	.16**	.00	.25**	1

Note. GAF = Global Assessment of Functioning.

* denotes significance at the level of $p<.05$;

** denotes significance at the level of $p<.01$.

Table 3

ANCOVA results

Variable	Zero partners in last 3 months mean (SD) (n = 281)	One partner in last 3 months (n = 90)	Multiple partners in last 3 months (n = 30)	Test of significance
Self-Esteem	29.2 (4.8)	28.4 (5.5)	29.6 (6.1)	$F(2,395) = 0.23$, $p = .792$
Mastery	18.9 (3.4)	18.7 (3.6)	20.8 (3.9)	$F(2,394) = 4.20$, $p = .016$
Sexual Attitudes	3.9 (2.4)	4.3 (2.2)	5.3 (2.2)	$F(2,395) = 6.26$, $p = .002$
Sexual Self-Esteem	1.6 (.8)	1.6 (.9)	1.6 (.9)	$F(2,381) = 0.05$, $p = .952$
Sexual/Relationship Importance	3.2 (.8)	3.5 (.7)	3.8 (.7)	$F(2,379) = 10.93$, $p < .001$

Note. All analyses were conducted controlling for marital status (never vs. ever married). Self-esteem, mastery, sexual attitudes, and sexual/relationship importance are all scored such that higher scores reflect greater presence of the construct. Higher scores for sexual self-esteem reflect poorer sexual self-esteem.