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# The impact of persistent sexual side effects of selective serotonin reuptake inhibitors after discontinuing treatment: a qualitative study

Rebecca Diane Stinson  
*University of Iowa*

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THE IMPACT OF PERSISTENT SEXUAL SIDE EFFECTS OF SELECTIVE  
SEROTONIN REUPTAKE INHIBITORS AFTER DISCONTINUING TREATMENT:  
A QUALITATIVE INVESTIGATION

by  
Rebecca Diane Stinson

A thesis submitted in partial fulfillment  
of the requirements for the Doctor of Philosophy degree  
in Psychological and Quantitative Foundations (Counseling Psychology)  
in the Graduate College of  
The University of Iowa

December 2013

Thesis Supervisor: Associate Professor Saba R. Ali

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Graduate College  
The University of Iowa  
Iowa City, Iowa

CERTIFICATE OF APPROVAL

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PH.D. THESIS

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This is to certify that the Ph.D. thesis of

Rebecca Diane Stinson

has been approved by the Examining Committee  
for the thesis requirement for the Doctor of Philosophy  
degree in Psychological and Quantitative Foundations (Counseling  
Psychology) at the December 2013 graduation.

Thesis Committee: \_\_\_\_\_  
Saba R. Ali, Thesis Supervisor

\_\_\_\_\_  
Elizabeth M. Altmaier

\_\_\_\_\_  
Audrey Bahrlick

\_\_\_\_\_  
William M. Liu

\_\_\_\_\_  
Anthony Paik

\_\_\_\_\_  
John S. Westefeld

To Ren. For being my rock on this wild ride.

In the beginning was sex and sex will be in the end...I maintain—and this is my thesis—that sex as a feature of man and society was always central and remains such.

Alexander Goldenweiser  
Sex and Primitive Society (1929)

## ACKNOWLEDGMENTS

First I would like to thank the participants of this research study for sharing their stories. Without their courage to give voice to such an intimate topic, this study could not have been completed. Second, I would like to thank my dissertation committee and advisor, Saba Ali, for providing feedback and guidance along the way. Third, I would like to thank my auditor, Lauren Levy, for her time and effort sorting through my data set and providing feedback beyond my expectations. I appreciated her enthusiasm for the project and willingness challenge my work. Finally, I would like to thank Dr. Audrey Bahrick for raising my awareness about PSSD and providing her support and expertise along the way.

## ABSTRACT

This dissertation details a qualitative study that examined nine individuals living with sexual side effects of SSRIs that had persisted after the discontinuation of pharmacological treatment (referred to as post-SSRI sexual dysfunction or PSSD). The investigation sought to answer the following research questions: (1) *How do individuals with persistent sexual side effects make sense of and meaning from their experience?*; (2) *How have these individuals' sense of self or identity changed over the course of their sexual difficulties?*; and (3) *What role could a counseling psychologist have had in helping the individual with his or her situation?* Using Interpretative Phenomenological Analysis methodology, eight themes emerged from the data including: (1) difficult emotional experiences; (2) varied coping strategies; (3) negative impact on romantic relationships; (4) changed identity; (5) changed attitude toward sex; (6) problems with medical providers; (7) mixed feelings about SSRIs; and (8) desire for collaborative healthcare. A review of relevant literature, a detailed explanation of the research methodology, a description of the results incorporating participant narratives, and a discussion of the results highlighting implications for counseling psychologists and limitations of the study are included in this dissertation.



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## CHAPTER 1

### INTRODUCTION

Antidepressants are some of the most widely prescribed medications on the market today. IMS Health (2012a) reported that ‘antidepressants’ (a category consisting of selective serotonin reuptake inhibitors [SSRIs] and serotonin-norepinephrine reuptake inhibitors [SNRIs] for their purposes) were the most commonly dispensed prescriptions in the United States in 2011. Over time the number of prescriptions dispensed for SSRIs and SNRIs has been steadily increasing. Likewise, the U.S. Department of Health and Human Services in conjunction with the Centers for Disease Control and Prevention (2004) found that adult SSRI use was almost six times greater between 1999-2000 than had been between 1988-1994. Olfson et al. (2002) found that individuals treated for depression were 4.8 times more likely to be prescribed an antidepressant in 1997 compared to 1987 and attributed the increase to SSRIs. They found that in 1997, the majority of people (58.3%) engaged in outpatient treatment for depression were prescribed an SSRI. As of 2009, three of the five most commonly dispensed psychotropic medications in the United States were SSRIs (Prozac®, Zoloft®, and Lexapro®) and accounted for 66.7 million prescriptions (Grohol, 2010).

Antidepressant use varies by demographic characteristics (Olfson & Marcus, 2009; Paulose-Ram, Safran, Jonas, Gu, & Orwig, 2007; Pratt, Brody, & Gu, 2011). Women are about twice as likely than men to take antidepressant medications. Also, individuals over the age of 40 are more likely than those under 40 years of age to take an antidepressant. When examining racial differences in antidepressant use, it has been found that non-Hispanic white people use antidepressant medications at about twice the

rate of black or Hispanic individuals. No difference was found between antidepressant use and income level, although those who are unemployed take antidepressants at higher rates than those who are employed.

The popularity of antidepressants is not isolated to the United States. Canada, too, has seen increasing rates. Antidepressant prescriptions increased by 353% between the years of 1981 and 2000 (Hemels, Koren, & Einarson, 2002). As of 2003 SSRIs made up 81% of the antidepressant market in Canada and accounted for 15.67 million prescriptions, an 80% increase from 1999 figures (IMS Health Canada, 2003). As of 2011, sales of SSRIs and SNRIs in the United States topped 11 billion dollars (IMS Health, 2012b).

Sexual side effects have accompanied antidepressant medications since their development in the 1950s. The first class of antidepressant medications, monoamine oxidase inhibitors (MAOIs), were linked to sexual dysfunction shortly after their release (e.g., Bennett, 1961) and all major classes of antidepressants introduced since that time—tricyclic antidepressants (TCAs), tetracyclic antidepressants (TeCAs), SSRIs, and SNRIs—have been implicated in the development of sexual side effects as well (see Margolese & Assalin, 1996 for a review). While different classes of antidepressant medications impact sexual functioning to varying degrees, it has been well documented that sexual side effects are common during the time in which individuals take them (see Ferguson, 2001; Lundberg & Biriell, 1998; Margolese & Assalin, 1996 for reviews). Given the widespread use of SSRIs specifically, psychologists should be well informed about this class of medication's sexual side effects. In fact, Cascade, Kalali, and Kennedy (2009) found that in a survey of approximately 700 patients, sexual functioning problems

were the most frequently cited side effect. Studies examining the sexual side effects of SSRIs have found prevalence rates between 16% and 80% depending upon methodology, sample used, and medications examined (e.g., Ashton, Hamer, & Rosen, 1997; Clayton et al., 2002; Landén, Högberg, & Thase, 2005; Montejo, Llorca, Izquierdo, & Rico-Villademoros, 2001; Montejo-Gonzalez et al., 1997; Serretti & Chiesa, 2009; Shen & Hsu, 1995; Zajecka, Mitchell, & Fawcett, 1997). Further review of this research is provided in chapter 2.

While concurrent sexual side effects are well documented in the literature, within the last five years case reports have been published indicating that for some individuals sexual side effects can persist for months or years after the discontinuation of SSRIs (Bolton, Sareen, & Reiss, 2006; Csoka, Bahrack, & Mehtonen, 2008; Csoka & Shipko, 2006; Kauffman & Murdock, 2007). With the large number of individuals taking SSRIs, close attention should be paid the possibility that these medications may have lasting impacts on sexual functioning. Given that sexual functioning and issues related to sexuality are within the scope of topics that may be the focus of clinical attention, psychologists need to pay attention to potential sexual side effects and be prepared to work with clients who report concurrent or persistent sexual dysfunction related to SSRI use.

Professional literature is beginning to emerge about sexual dysfunction that does not remit when SSRI medication is discontinued, partly in response to the increasing numbers of individuals living with persistent sexual side effects who are connecting with one another through informal means. For example, online consumer and support groups such as SSRIsex (<http://health.groups.yahoo.com/group/SSRIsex/>) are comprised of

thousands of individuals who report living with persistent sexual side effects and are aimed at mutual support and raising awareness about this problem. Also, case reports have been published by concerned clinicians who have worked with individuals experiencing persistent sexual side effects of SSRIs. While several publications aim to raise professional awareness about the problem (Bahrnick, 2006, 2008; Bahrnick & Harris, 2009; Kauffman, 2008), no empirical investigations addressing PSSD have been published. Given the calls for attention to the problem of PSSD and the minimal information available in the literature on this topic, the purpose of the current study is to explore PSSD and its psychological impact by interviewing individuals with persistent sexual side effects about their experiences.

The current study is designed to build upon case studies reporting PSSD. Although case studies are important for providing the professional community with documentation that SSRIs have the potential to affect individuals' sexual functioning beyond medication use, they do not explore the personal impact of persistent sexual side effects on psychological and interpersonal functioning. Bahrnick (2008) noted that individuals in PSSD-focused consumer groups often discuss the challenges of living with PSSD related to psychological well-being (e.g., intimacy, self-concept, quality of life); however, in-depth exploration of such issues in the literature is absent. The unique feature of this study is that it is a qualitative investigation of the experiences of individuals living with PSSD. Participants were interviewed about their experiences and the impact of persistent sexual dysfunction on their intra- and interpersonal lives. Results increase psychologists' understanding of the psychological ramifications of persistent sexual dysfunction as well as provide much needed information to better work with

clients living with PSSD as well as those who are taking, or thinking about taking, SSRI medications. Additionally, the results of the current study illuminate new directions for future research on PSSD.

This dissertation describes a qualitative research investigation using Interpretative Phenomenological Analysis (IPA; Smith, 1996; Smith, Flowers, & Larkin, 2009). IPA is a methodology used for studies seeking to understand how participants make sense of, and meaning from, major life experiences. IPA involves interviewing a small sample of participants using a semi-structured interview protocol. Each interview transcript is analyzed for emergent themes. The analyst always ensures themes are couched in participant narratives, but analysis involves the analyst trying to make sense of the participant trying to make sense of their experience. Hence, IPA is also interpretive as well as phenomenological. Once each transcript has been analyzed for emergent themes, the analyst looks for patterns across cases. The current study sought to address the following research questions:

1. How do individuals with persistent sexual side effects make sense of and meaning from their experience?
2. How have these individuals' sense of self or identity changed over the course of their sexual difficulties?
3. What role could a psychologist have had in helping the individual with their situation?

### **Summary**

In sum, the purpose of the current study is to explore the issue of post-SSRI sexual dysfunction — an area that is currently understudied. With SSRIs prescribed in



increasing numbers and uncertainty related to their long-term effects, the psychological impact of persistent sexual dysfunction beyond medication discontinuation is an area that psychologists should be invested in understanding more thoroughly. This dissertation consists of four additional chapters. In chapter two, a literature review is provided. First, sexual dysfunctions as described by the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV-TR; American Psychiatric Association, 2000) are presented. Second, more detailed information is provided about SSRIs including their history, indications for use, general and sexual side effects, and hypothesized mechanisms of change. Third, a review of the literature related to persistent sexual side effects associated with SSRI use is discussed. Fourth, literature related to the psychological impact of sexual dysfunctions is presented. Chapter three of this dissertation outlines Interpretative Phenomenological Analysis, the research methodology of the current study. First, IPA is introduced and explained. Second, the problem and research questions are provided. Third, data collection considerations are discussed. Fourth, data analysis and validity checks are overviewed. Chapter four provides a detailed summary of the results of this study. Using participant narratives drawn directly from their interviews, the eight emergent themes are described. In chapter five of this dissertation, a general discussion of the results is provided, specifically as it relates to the three main research questions of the study. Second, limitations of the current investigation are reviewed. Finally, future directions for research are presented.

### **List of Terms**

Terms for various constructs addressed in this dissertation are provided below:

**Genital Anesthesia:** Numb or nearly numb genitals that may respond to stimulation, but

without the corresponding subjective feelings of arousal.

**Monoamine Oxidase Inhibitors (MAOIs):** the first class of antidepressants to be developed and marketed to treat depression (mid 1950s). MAOIs treat depression by preventing monoamine oxidase from metabolizing norepinephrine, serotonin, and dopamine within the brain.

**Orgasmic Anhedonia:** Orgasm that is preceded by minimal levels of building arousal and is experienced as pleasureless or nearly pleasureless.

**Post-SSRI Sexual Dysfunction (PSSD):** sexual dysfunction that persists (potentially indefinitely) after the discontinuation of SSRI medications.

**Pre-market studies:** empirical investigations testing the efficacy of a given treatment/intervention before gaining FDA approval. For medications, pre-market studies are usually conducted by the pharmaceutical companies applying for FDA approval.

**Selective Serotonin Reuptake Inhibitors (SSRIs):** the fourth major class of antidepressants marketed to treat depression (late 1980s to today). While precise mechanisms differ for each SSRI, it is assumed that SSRIs generally work by blocking the reuptake of serotonin in the synapses of the brain, thus increasing levels of serotonin.

**Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs):** the most recent major class of antidepressants marketed to treat depression (mid 1990s). While the precise mechanisms of SNRIs remains unclear, it appears as though SNRIs inhibit the reuptake of both serotonin and norepinephrine.

**Sexual Dysfunction:** a disturbance in one or more processes that characterize the sexual response cycle or other sexual difficulties that negatively impact a person's sexual experience (e.g., pain, genital anesthesia).

**Sexual Response Cycle:** a response cycle broken down into four phases (described below). While it is widely assumed that each phase transitions into the next, in reality difficulties related to the phases of sexual response often coexist, suggesting the phases are not discrete entities and do not necessarily proceed sequentially.

*Desire/Libido* (Phase 1): an individual's subjective self-report of interest in sex or sexual stimuli (e.g., fantasies, thoughts, expressed interest in engaging in sexual activity).

*Arousal* (Phase 2): an individual's subjective self-report of sexual excitement as well as a physiological response to sexual stimuli involving engorgement of the genitals as the body prepares for sexual activity (erection for men, vaginal swelling/lubrication for women).

*Orgasm* (Phase 3): the "peak" of sexual pleasure, or climax, which then results in involuntary contractions of the perineal muscles in both sexes as well as ejaculation for men.

*Resolution* (Phase 4): a state of relatively low bodily tension and muscle relaxation as the body returns to its baseline levels (e.g., a drop in heart and respiratory rates, decreased genital vasocongestion and lubrication). This phase can last anywhere from a couple of minutes to days depending on gender, age, and physical health.

**Tetracyclic Antidepressants (TeCAs):** the third major class of antidepressants to be marketed to treat depression (1970s). TeCAs prevent neurotransmitters from binding with alpha-2 nerve cell receptors leading to increased serotonin and norepinephrine in the brain.

**Tricyclic Antidepressants (TCAs):** the second major class of antidepressants to be marketed to treat depression (late 1950s and early 1960s). TCAs treat depression

primarily by inhibiting the reuptake of norepinephrine and serotonin by brain cells, but also dopamine to a lesser degree.

## CHAPTER 2

### REVIEW OF THE LITERATURE

#### **Introduction**

Sexuality is an essential part of human existence and is sensitive to changes in our physical and emotional health. When individuals experience physical or mental distress, sexual functioning is often impacted. Additionally, sexual problems have been observed as side effects to many anti-depressant medications (e.g., Bennett, 1961; Corona et al., 2009; Margolese & Assalian, 1996; Masand & Gupta, 2002). While it has traditionally been assumed that sexual side effects will remit once an individual stops taking an SSRI medication (Balon, 2006; Gutierrez & Stimmel, 1999), within the past six years case reports have been published documenting sexual side effects persisting after the discontinuation of SSRI treatment (Bolton et al., 2006; Csoka et al., 2008; Csoka & Shipko, 2006; Kauffman & Murdock, 2007). While unacknowledged by the majority of SSRI manufacturers, Eli Lilly, which produces Prozac®, recently added a statement about the possibility of persistent sexual side effects in their medication disclosure packet (2011). The problem of persistent sexual side effects of SSRIs is the primary focus of the current study given it has only recently emerged in the literature and there is a dearth of research related to its impact on individuals living with it. The issue of persistent sexual side effects after the discontinuation of SSRIs is also referenced using the acronym "PSSD," which was first introduced into the literature by Bahrnick (2006) after people reporting PSSD and their allies began using the acronym on the online support community SSRIssex. Csoka, Bahrnick and Mehtonin (2008) subsequently suggested the

acronym PSSD be formally adopted by researchers in the literature. Thus, this dissertation will use the acronym PSSD to refer to post-SSRI sexual dysfunction.

Because relatively little is currently known about PSSD, this chapter will initially review literature regarding both sexual dysfunction and SSRIs. First, this chapter provides an overview of sexual dysfunctions from the perspective of the DSM-IV-TR (American Psychiatric Association, 2000). Second, SSRIs are described including their history, uses, general side effects, and sexual side effects. Third, the emerging literature on PSSD is reviewed with an emphasis on the need for more research. Fourth, what is currently known about the psychological impact of sexual dysfunction is discussed.

### **Sexual Dysfunction**

According to the DSM-IV-TR (American Psychiatric Association, 2000), sexual dysfunction is defined as “a disturbance in the processes that characterize the sexual response cycle or by pain associated with sexual intercourse” (p. 535). The DSM-IV-TR states that sexual dysfunction can occur at one or more phases of the sexual response cycle (for more detail on the phases of the sexual response cycle, see the List of Definitions in chapter one). The DSM-IV-TR outlines four major classifications of sexual dysfunction: (1) sexual desire disorders, (2) sexual arousal disorders, (3) orgasmic disorders, and (4) sexual pain disorders. While these classifications make clear demarcations between the disorders, it should be noted that diagnosis in one area is commonly associated with difficulties with, or another diagnosis in, other areas as well (American Psychiatric Association, 2000).

### **Sexual Desire Disorders**

The DSM-IV-TR outlines two sexual desire disorders. One, Hypoactive Sexual Desire Disorder (HSDD), is characterized by a deficiency or absence of sexual fantasies and desire for sexual activity. Often it is accompanied by problems with arousal and orgasm as well. The other sexual desire disorder, Sexual Aversion Disorder, is characterized by an aversion to and active avoidance of genital sexual contact with a partner.

### **Sexual Arousal Disorders**

The DSM-IV-TR outlines two sexual arousal disorders. One, Female Sexual Arousal Disorder, is characterized by “a persistent or recurrent inability to attain, or maintain until completion of sexual activity, an adequate lubrication-swelling response of sexual excitement” (p. 543). The DSM-IV-TR also states that Female Sexual Arousal Disorder often results in painful intercourse, sexual avoidance, and difficulties with sexual relationships. The other sexual arousal disorder, Male Erectile Disorder, is characterized by “a persistent or recurrent inability to attain, or to maintain until completion of the sexual activity, an adequate erection” (p. 545). Several forms of erectile dysfunction exist including (1) the inability to attain an erection from the outset of sexual activity, (2) the ability to attain an adequate erection at the outset but being unable to maintain it for penetration, (3) attaining and maintaining an erection for penetration, but losing the erection during intercourse, and (4) the ability to attain and maintain an erection during masturbatory activities, but an inability to experience an erection for intercourse.

## **Orgasmic Disorders**

Three orgasmic disorders are described in the DSM-IV-TR. Both Female Orgasmic Disorder and Male Orgasmic Disorder are characterized as “a persistent or recurrent delay in, or absence of, orgasm following a normal sexual excitement phase” (p. 547, 550). For women, orgasmic disorder is often lifelong rather than acquired. The DSM-IV-TR states that once a woman learns how to achieve orgasm, it is uncommon to lose that capacity unless something intervenes such as a traumatic sexual experience, a medical condition, or mood disorder. For men, the most common form involves being unable to reach orgasm during intercourse, but being able to ejaculate from manual or oral stimulation. Other men can reach orgasm through intercourse, but only after extended and concentrated non-coital stimulation. The third orgasmic disorder, Premature Ejaculation, is characterized by “the persistent or recurrent onset of orgasm and ejaculation with minimal sexual stimulation before, on, or shortly after penetration and before the person wishes it” (p. 552). While more often present in young men, premature ejaculation also depends on the novelty of the sexual partner or situation as well as recent frequency of sexual activity.

## **Sexual Pain Disorders**

Two sexual pain disorders are outlined in the DSM-IV-TR and include Dyspareunia and Vaginismus. Dyspareunia is characterized by “genital pain that is associated with sexual intercourse” (p. 554) and can occur before, during, or after sexual intercourse. Vaginismus is limited to women and is characterized by “the recurrent or persistent involuntary contraction of the perineal muscles surrounding the outer third of the vagina when vaginal penetration...is attempted” (p. 556). These contractions can



range anywhere from mild discomfort to so severe as to prevent penetration altogether.

### **Substance-Induced Sexual Dysfunction**

Also of relevance to the current study is substance-induced sexual dysfunction, which is diagnosed when dysfunction involving sexual desire, arousal, orgasm, or pain is present and the dysfunction can be fully explained by the direct physiological effects of a substance (e.g., medications). It is presumed that SSRI-induced sexual dysfunctions present similarly to the primary sexual dysfunctions explained above. The DSM-IV-TR notes, however, that if a sexual dysfunction persists for a substantial time period after discontinuation of the substance, it may have been better accounted for by a primary sexual dysfunction. Similarly, others authors state that true medication-induced sexual dysfunction resolves when the medication is decreased in dosage or discontinued altogether (Balon, 2006; Gutierrez & Stimmel, 1999)—a viewpoint that is directly challenged by case reports documenting PSSD (e.g, Bolton, Sareen, & Reiss, 2006; Csoka & Shipko, 2006) and recent SSRI medication inserts (Eli Lilly, 2011). Also, as Bahrack (2008) pointed out, it is an assumption that side effects will remit upon medication discontinuation because such an assertion is not grounded in any empirical data; the SSRI sexual side effects investigations have lacked long-term follow up assessment. This issue of sexual dysfunction persisting beyond SSRI treatment, and how it impacts individuals psychologically, is the focus of the current study.

### **Summary of Sexual Dysfunctions**

The previous section reviewed sexual dysfunctions as outlined by the DSM-IV-TR, which include sexual desire disorders, sexual arousal disorders, orgasmic disorders, sexual pain disorders and substance-induced sexual dysfunction. It is important for

psychologists to have a comprehensive understanding of sexual disorders as described by the DSM-IV-TR, especially when sexual problems are often associated with psychological disorders such as depression (Michael & O'Keane, 2000). Recent epidemiological literature suggests that there is a bidirectional relationship between depressive symptoms and sexual dysfunction in both men and women (Araujo, Durante, Feldman, Goldstein, & McKinlay, 1998; Atlantis & Sullivan, 2012; Hartmann, 2007; Kalmbach, Ciesla, Janata, & Kingsberg, 2012; Seidman 2002; Shabsigh, Zakaria, Anastasiadis, & Seidman, 2001). A frequently cited study from the large Massachusetts Male Aging epidemiological sample analyzed survey data of 1,265 men aged 40-70 who reported erectile dysfunction and depressive symptoms (Araujo et al., 1998). The researchers found moderate to complete erectile dysfunction to be 1.82 times more likely in those who reported depressive symptomology. However, the researchers suggested that the relationship between erectile dysfunction and depression is a bi-direction, mutually reinforcing relationship. That is, while depression may result in erectile dysfunction, erectile dysfunction likely also exacerbates depressive symptoms in men. Fabre and Smith (2012) had similar findings with a sample of 1,184 women, showing that as depression severity increased, so did severity of sexual dysfunction. Additionally, Atlantis and Sullivan (2012) performed a meta-analysis of epidemiological studies about the association between depression and sexual dysfunction. Statistically controlling from medication use, including antidepressants, the researchers concluded that individuals with depressive symptoms had a 50% - 70% increased risk for developing sexual dysfunction. Furthermore, individuals with sexual dysfunction had a 130% - 210% increased risk for

developing depression. While it is clear from recent research that sexual dysfunction is correlated with depression, the etiology of the relationship is still unclear.

It is also important for psychologists to have a clear understanding of sexual disorders given that sexual dysfunctions are a common side effect of anti-depressant medications, such as SSRIs (see Serretti & Chiesa, 2009 meta-analysis for a review). SSRIs and their sexual side effects will be discussed in much greater depth in the sections that follow; however, it is important to clarify that when determining whether an individual's PSSD is related to depression, a primary sexual dysfunction, or a persistent side effect to a SSRI medication, the type of sexual problem needs to be considered. As discussed by Bahrck (2006, 2008), two of the most common PSSD symptoms, genital anesthesia and orgasmic anhedonia, cannot be accounted for by either depression or DSM-IV-TR sexual dysfunctions.

The next section describes the use of SSRIs for the treatment of depression, the history of the medications, uses, and general side effects. Sexual side effects of SSRIs and resulting sexual dysfunctions of SSRIs are specifically discussed.

### **Selective Serotonin Reuptake Inhibitors**

The 1980s ushered in what author Edward Shorter (1997) has labeled the "Age of Prozac." The first SSRI indicated for the treatment of depression and marketed was indalpine (Upstène®; Carlsson & Wong, 1997), which was created in France in 1982. It achieved enormous sales worldwide except in the United States. Shortly thereafter, in 1983, a Swedish company released a second SSRI indicated for the treatment of depression, zimelidine (Normud®; Carlsson & Wong, 1997). Not long after zimelidine's release, it was banned worldwide due to serious and sometimes fatal cases of a

neurological disease, Guillain-Barré syndrome. In 1987, indalpine was pulled from the market as well due to concerns of potentially serious adverse side effects. That same year Eli Lilly's fluoxetine (Prozac®) was introduced in the United States, approved by the FDA to treat depression, and revolutionized the psychopharmacological treatment for depression in the United States.

Since the release of fluoxetine, a handful of other SSRIs have been developed to treat major depressive disorder by a variety of pharmaceutical companies. Sertraline (Zoloft®; Mylan Laboratories, Inc.) was FDA-approved in 1992, followed shortly by paroxetine (Paxil®; GlaxoSmithKline) in 1993, citalopram (Celexa®; Forest Laboratories, Inc.) in 1998, and escitalopram (Lexapro®; Forest Laboratories, Inc.) in 2002 (Appleton, 2004). Most recently, in 2011, vilazodone (Viibryd®; Forest Laboratories, Inc) was released on the U.S. market for the treatment of major depression. While another SSRI, fluvoxamine (Luvox®; Jazz Pharmaceuticals), has been released, its primary indication is for obsessive-compulsive disorder.

After their introduction, SSRIs quickly became the primary psychopharmacological treatment for depression (U.S Department of Health and Human Services, 2004). Due to reportedly offering clinical efficacy with fewer side effects, improved safety with overdose, fewer problems with drug interactions, and ease of dose regulation on the part of physicians compared with their predecessors (Nurnberg, 2001), prescribing rates of SSRIs have increased for both on- and off-label treatments. As a whole, SSRIs have become some of the most popularly prescribed psychotropic medications in the United States and around the world. In fact, of the top five most prescribed psychotropic medications in the United States in 2009, three of them were

SSRIs (Prozac®, Zoloft®, and Lexapro®) and account for 66.7 million prescriptions alone (Grohol, 2010). Approximately one out of every eight American adults has taken an SSRI or serotonin-norepinephrine reuptake inhibitor (SNRI) within the last decade (Raz, 2006).

Many clients with whom psychologists work have taken (or are currently taking) SSRIs given SSRIs are currently the medications of choice for a range of psychiatric and medical conditions (Nurnberg, 2001). Besides depressive disorders, SSRIs are FDA-approved and considered first line pharmacological treatments for anxiety disorders such as generalized anxiety disorder, obsessive compulsive disorder, panic disorder, post-traumatic stress disorder, and social phobia (Physicians' Desk Reference, 2009), as well as bulimia, pre-menstrual dysphoric disorder, and neuropathic pain. Also, while not specifically approved by the FDA or indicated for use by their manufacturers, SSRIs are prescribed off-label for treating conditions such as irritable bowel syndrome, migraine headaches, chronic fatigue syndrome, and premature ejaculation (Chen et al., 2006; Stone, Viera, & Parman, 2003). For some populations, off-label use has surpassed that of on-label use. For example, Chen and colleagues (2006) found that the majority of elderly Medicaid patients in Georgia using SSRIs are doing so for off-label purposes.

While regularly prescribed for a variety of conditions, SSRIs also have a significant number of side effects (Appleton, 2004; Physicians Desk Reference, 2009). According to the Physicians' Desk Reference (2009) serious side effects include, but are not limited to, severe allergic reactions resulting in difficulty breathing, tightness of the chest, or swelling of mouth, face, or tongue; bizarre behavior; chest pain; confusion; reduced concentration; reduced coordination; fainting; irregular heartbeat; fever or chills;

hallucinations; memory loss; increased agitation; panic attacks or severe anxiety; aggressive or hostile behavior; impulsive behavior; exaggerated feelings of well being (e.g., mania); seizures; renal impairment; worsening depression; and suicidal thoughts or attempts which Healy, Herxheimer, and Menkes (2006) hypothesize is secondary to akathisia, emotional blunting, or treatment-induced psychosis.

The general side effects considered less serious include, but are not limited to, nausea/vomiting; dizziness; fatigue; dry mouth; headache; diarrhea; nervousness; restlessness; weight gain; somnolence; tremors; anhedonia; vivid or strange dreams; paresthesia (i.e., feelings of “pins and needles”); pupil dilation/photosensitivity; and changes in appetite and sleep. Sexual side effects are also considered to be non-serious by the Physicians’ Desk Reference, although researchers have documented that sexual side effects are more distressing to patients and more prevalent than is commonly believed (Montejo et al., 2001; Zajecka et al., 1997) and that the possibility that sexual side effects might persist, even if only in a small number of individuals, raises complex informed consent issues (Bahrack & Harris, 2009).

### **Sexual Side Effects of SSRIs**

Sexual side effects have been associated with all SSRI medications, but reported in pre-market studies to be much less common than what has been found by subsequent research investigations (Serretti & Chiesa, 2009). Pre-market studies conducted by the manufacturers of SSRIs indicated that treatment-emergent sexual dysfunction occurs in < 2-16% of patients (Physicians’ Desk Reference, 2009); however, researchers attained these rates by relying on spontaneous reports of clients versus direct questioning (Balon, 2006). A brief review of a recent meta-analysis that follows, though, demonstrates that

consumers report rates at much higher levels. Because a thorough discussion of the extant literature related to this topic is beyond the scope of this paper, the reader is referred to Serretti and Chiesa's (2009) meta-analysis for scholarly references related to sexual side effects of SSRIs published over the past several decades.

Most reports related to rates of sexual side effects associated with SSRI use come from uncontrolled, non-randomized, open-label retrospective or cross-sectional studies which include a variety of antidepressants in their analyses (e.g., Balon, Yergani, Pohl, & Ramesh, 1993; Corona et al., 2009; Shen & Hsu, 1995). Because of each study's heterogeneity of sample size, medications examined, dosage levels, various participant diagnoses, length of treatment, and participant demographics, finding precise prevalence data has been nearly impossible. However, a recent meta-analysis (Serretti & Chiesa, 2009) examined the results of 44 studies between the years of 1985 and 2008 related to antidepressant-emergent sexual dysfunction. The 44 analyzed studies met inclusion criteria which consisted of: (1) directly investigating the sexual functioning of individuals taking antidepressants, (2) clearly stating that clinicians directly inquired about sexual dysfunction either through interview or questionnaire, (3) the use of monotherapy (except for one study that allowed simultaneous use of benzodiazapines), (4) including patients with no previous sexual dysfunction, (5) clearly providing data on individual medications, and (6) providing dichotomous variables for at least one outcome such as "total sexual dysfunction." The sample of studies that met inclusion criteria included retrospective, cross-sectional, open-label, and double-blind investigations with treatment durations usually lasting from 4-12 weeks in length. The researchers' primary outcome measure of the meta-analysis was rate of treatment-emergent sexual dysfunction, while

secondary outcome measures were rates of desire, arousal, and orgasm dysfunction individually.

In their analysis, Serretti and Chiesa (2009) found that, compared to placebo, SSRIs were associated with significantly higher rates of sexual dysfunction. In fact, of all antidepressants studied (N=17) across several classes of medications, sertraline, citalopram, paroxetine, and fluoxetine demonstrated some of the greatest total sexual dysfunction, with rates of 80.3%, 78.59%, 71.48%, and 70.6% respectively. Escitalopram (37.04%) ranked ninth out of seventeen. Similar results were found for the secondary outcome measures. For desire disorders, SSRIs topped the list again with citalopram (84.11% of men, 70.78% of women), paroxetine (73.65% and 72.89% respectively), fluoxetine (86.18% and 74.39% respectively), and sertraline (84.15% and 71.92% respectively) demonstrating highest rates. Escitalopram ranked sixteenth out of seventeen. For arousal disorders, SSRIs again caused the most dysfunction with citalopram, paroxetine, sertraline, and fluoxetine in the top five although data for men and women separately were provided only for paroxetine (64.51% and 83.96% respectively) and sertraline (67.05% and 82% respectively). Escitalopram ranked fourteenth of seventeen. Finally, regarding orgasmic difficulties, SSRIs again ranked at the top with all five SSRIs in the top eight positions. Although it was found that the SSRIs impact orgasmic functioning much more so than other classes of antidepressants, the gender breakdowns of difficulty with citalopram (74.05% of men, 39.47% of women), fluoxetine (77.23% and 40.56% respectively), paroxetine (80.23% and 44.84% respectively), and sertraline (71.64% and 44.22% respectively) show the SSRIs impair male orgasmic functioning at significantly higher rates than female orgasmic functioning.



Serretti and Chiesa's (2009) analysis uncovered several notable findings. First, all six SSRIs examined were associated with significantly higher rates of sexual dysfunction when compared with placebo; in fact, highest overall rates out of all medications were found with citalopram, fluoxetine, paroxetine, and sertraline. Second, all medications associated with overall sexual dysfunction were found to be associated with impaired desire, arousal, and orgasm functioning albeit to varying degrees. Third, based upon the investigations that sorted their data by gender, men appear to report greater difficulty with orgasm, women have greater difficulty with arousal, and both genders experiences very high rates of hypoactive sexual desire. Fourth, sexual dysfunction rates appear to systematically differ depending on the assessment measure used, suggesting varying sensitivity.

Nowhere does the effect of SSRIs on sexual functioning seem to receive more attention and appear more robust than in the treatment of premature ejaculation. Over the past five years, several researchers have used single- and double-blind, placebo-controlled investigations to establish treatment benefit from SSRIs. Sarafinejad and Hosseini's (2006) double-blind, randomized study of 51 married men with premature ejaculation (age 21-49) who were otherwise psychologically and physically healthy evaluated the efficacy of citalopram (20mg daily) in treating premature ejaculation over the course of a 12-week trial. They found that from the first week onward, the effect of citalopram differed significantly from placebo. The mean intravaginal ejaculatory latency time (IVELT; i.e., time between vaginal insertion and ejaculation) increased from 32 seconds to 268 seconds in the citalopram group while only a small increase (28 seconds to 38 seconds) was noted in the control group. Even after discontinuing citalopram, the

treatment group maintained increased IVELT three and six-months later (210 seconds and 198 seconds, respectively) compared to the control group (27 seconds and 25 seconds, respectfully).

Another study using escitalopram (Safarinejad, 2007) found similar results to Sarafinejad and Hosseini (2006). Two hundred and fifty-four married men with premature ejaculation (age 20-45) who were otherwise psychologically and physically healthy were randomized into either a treatment (escitalopram, 10mg daily) or control placebo group for a 12-week trial examining the efficacy of escitalopram for treating premature ejaculation. Beginning in second week, and continuing through the twelfth week, the treatment group demonstrated significantly longer IVELT (4.9-fold increase in duration versus 1.4-fold increase), which was maintained during three- and six-month follow-ups (3.7-fold vs. 1.2-fold and 3.1-fold and 1.3 fold, respectively).

Yet another study examining the efficacy of sertraline (50mg daily) for premature ejaculation found significant results (Arafa & Shamloul, 2006). In their single-blind, eight-week crossover study, 147 psychologically and physically healthy heterosexual men with premature ejaculation (IVELT < 120 seconds) were randomized into two groups. For four weeks Group 1 was the treatment group while Group 2 was the control, then the groups were switched for the final four weeks. Overall, 86% of their sample experienced a significant improvement in their scores on the Arabic Index of Premature Ejaculation after taking sertraline. Follow-up found that 66% of those who had improved ejaculation status during sertraline treatment had lost treatment gains within six months after the discontinuation of sertraline. The other 34% maintained their treatment gains. As argued by Bahrack (2008), such robust findings regarding the persistent effect of SSRIs

on the ejaculation latencies of otherwise healthy men (i.e., no simultaneous physical or psychological illness) strongly support the notion that sexual side effects can persist well beyond medication discontinuation.

In addition to the sexual side effects impacting the sexual response cycle, emerging research suggests that SSRIs also have the potential to impact reproductive health and decrease fertility (e.g., Safarinejad, 2008; Tanrikut, Feldman, Altemus, Paduch, & Schlegel, 2010). Tanrikut and Schlegel (2007) reported two case reports of men treated with SSRIs. One male, (age 44), taking citalopram for depression, underwent multiple semen analysis to explore his history of infertility. The analysis conducted while taking citalopram showed marked low sperm count and only 1% motility indicating poor sperm quality. One month after discontinuing his medication, all sperm parameters were within normal range. The second male (age 35), taking sertraline for depression, also underwent multiple semen analyses. While taking sertraline, results showed very low sperm count and no motile sperm. Three months after discontinuing sertraline, all sperm parameters were within normal range. Subsequent empirical research has supported Tanrikut and Schlegel's (2007) observations.

Safarinejad (2008) examined 74 fertile, depressed men who had been taking a variety of SSRIs (citalopram, escitalopram, fluoxetine, paroxetine, or sertraline) for at least six months. Compared to control group of 44 healthy fertile men, those taking SSRIs had significantly lower sperm counts, significantly lower sperm motility, lower sperm density, higher DNA fragmentation, and poorer sperm morphology (i.e., more defective in terms of size and shape). Safarinejad found that the longer a man had been taking an SSRI, the more abnormal his semen parameters. Additionally, Safarinejad

found that no one SSRI appeared to be more detrimental to semen parameters than another. Another research group (Tanrikut et al., 2010) examined only paroxetine's effect on sperm. In their sample of 35 healthy male volunteers, exposure to paroxetine over the course of five weeks had marked effects on their sperm's DNA integrity. While other parameters (count, motility, morphology) remained within normal limits, significant increases in DNA fragmentation were noted (13.8% to 30.3%). This is important to note given 30% is generally considered the "threshold" for infertility. The percentage of men with 30% or greater DNA fragmentation rose from 9.7% to 50% over the course of the five-week study. Also reported by their subjects was worsened erectile function (35%) and ejaculatory function (47%).

In sum, the extant literature related to sexual side effects during SSRI use demonstrates several major findings. First, SSRI use is associated with difficulties in at least three phases of the sexual response cycle (desire, arousal, and orgasm) and these difficulties can co-occur. Second, beyond phases of the sexual response cycle, SSRIs are associated with negative impact reproductive health. Third, prevalence rates of SSRI-induced sexual dysfunction appear to be higher than what was initially published by pre-market studies. Fourth, although some studies have found paroxetine to be more problematic for consumers, as a whole there are no substantial differences between SSRIs regarding their likelihood to cause sexual side effects. Fifth, when queried directly or systematically, individuals report substantially more sexual side effects compared to rates obtained by spontaneous report. And sixth, evidence from premature ejaculation studies lend credence to the notion that PSSD is not an anomaly.

There are several limitations of the research regarding sexual side effects of SSRIs. One major limitation of the research is that long-term follow-up with participants is not routinely completed. Studies, such as those reviewed above, only follow participants for a short time period while data is collected. As Bahrck (2008) has pointed out, neglecting long-term follow-up prohibits researchers from even documenting the possibility of persistent sexual side effects of SSRIs and therefore, the assumption that side effects cease once the medications are discontinued is not substantiated by any empirical data. Another limitation of the SSRI sexual side effects research is that the problem is only examined using quantitative methods, missing the phenomenological and psychological/emotional elements of this problem for individuals. Qualitative investigations may shed light on the nuanced experiences of individuals that report SSRI-related sexual dysfunction.

### **Proposed Mechanisms of SSRI-Induced Sexual Dysfunction**

As discussed by Gitlin (1994), SSRI-induced sexual dysfunction may be a consequence of several factors including: (1) their effect on specific parts of the central nervous system by altering concentrations of neurotransmitters at specific points; (2) altering neurotransmitter concentrations in the genital region; and (3) altering hormone levels that impact and alter sexual functioning in general. The following summary is adapted from Kelter, McAfee, and Taylor (2002) as well as Rosen, Lane, and Menza (1999). The reader is referred to these reviews for a more detailed discussion of neurobiology and the proposed mechanisms of SSRI-induced sexual dysfunction.

At the most basic level, SSRIs produce sexual side effects due to the fact that they all, to some degree, block the reuptake of serotonin (5-hydroxytryptamine [5-HT]).

Although SSRIs block reuptake of serotonin in the synapses immediately, increased serotonin levels occur primarily in areas containing the cell body and dendrite. As a consequence, autoreceptors (which tell the cell to slow the rate of serotonin synthesis) located in this area lose sensitivity. With desensitization, autoreceptors become unresponsive to serotonin and switch off the body's natural negative feedback system. Thus, neuronal activity is no longer inhibited by serotonin, leading to increased neuronal activity and greater release of serotonin at the axonal terminal. Based upon some research, it appears as though the stimulation of only a couple of post-synaptic receptors by serotonin (5-HT<sub>2</sub> and 5-HT<sub>3</sub>) bear responsibility for sexual side effects (Nelson, Shah, Welge, & Keck, 2001; Stahl, 2000). It should be noted, however, that changes most likely occur in the peripheral nervous system as well as given 95% of serotonin receptors reside outside of the brain (Meston & Frohlich, 2000).

Other authors (Kim & Dysken, 1991; Resnik & Ithman, 2008) also hypothesize that increases in serotonin may lead to diminished dopaminergic activity in the brain, which can negatively impact sexual functioning. Although most research related to dopamine's effect on sexual response has been conducted on animals (e.g., El-Din, Senbel, Daabees & Sharabi, 2007; Rampin, Jerome, & Suaudeau, 2003), some studies demonstrate that increased dopamine has been linked to increased sexual desire and erection in men. For example, dopamine agonists (like the antiparkinsonian medication levodopa) may lead to increased sexual desire and facilitate erection (Bowers, Van Woert, & Davis, 1971; O'Sullivan & Hughes, 1998). Alternately, dopamine antagonists (such as antipsychotic medications) have been reported to decrease desire as well as

impair erection in men and delay or inhibit orgasm in women (Bobes et al., 2003).

### **Managing Sexual Side Effects**

Several studies have found that healthy sexual functioning is important to those struggling with mental health concerns (Clayton et al., 2002; Williams et al., 2010). It would be erroneous for professionals to assume that a decrease or loss of sexual functioning is an acceptable trade-off for improved mental health. Sexual dysfunction related to psychotropic medication use is often an additional source of distress, impacting quality of life (Williams et al., 2010). Thus treatment-induced sexual dysfunction can lead to problems with treatment compliance (Gregorian, Golden, Bahce, Goodman, Kwong, & Khan, 2002; Rosenberg, Bleiberg, Koscis, & Gross, 2003).

There is no antidote or strategy that is reliably effective for reversing or relieving sexual side effects associated with SSRIs. However, a number of strategies have been proposed for managing sexual dysfunction present during SSRI use. Strategies include: (1) a ‘wait and see’ approach, (2) dose reductions, (3) drug holidays, (4) delaying intake, (5) switching to or adding another antidepressant, and (6) adding another non-antidepressant medication. This section will review the proposed methods more thoroughly, including empirical findings where available.

#### **The “Wait and See” Approach**

It is often suggested in clinical practice that adaptation to sexual side effects will occur when complaints are relatively mild and associated primarily with orgasmic difficulties. Thus, many professionals ask their clients to ‘wait and see’ if their sexual side effects resolve themselves within the first six months of beginning treatment. However, research shows that spontaneous remission of sexual side effects is uncommon.

Shen and Hsu's (1995) investigation revealed that only three of 35 cases (8.5%) of sexual side effects remitted spontaneously within three months of beginning treatment and all three were taking fluoxetine. Later investigations found similar results. Montejo-González and colleagues (1997) found that only 5.8% of participants experienced a complete remission of their sexual dysfunction by the end of the six-month study while 12.8% displayed moderate improvement. Alternately, 81.4% displayed no improvement at all. Another study by Montejo and colleagues (2001) found that only 9.7% of participants experienced total spontaneous remission of their sexual side effects at the end of the 6-month treatment while 11.2% experienced partial improvement. Alternately, 79.1% experienced no improvement. This evidence suggests that a 'wait and see' approach is not a practical strategy given a substantial number of clients may consider discontinuing treatment due to sexual side effects (Montejo et al., 2001). Finally, Haberfellner and Rittmannsberger (2004) found that of the 26 patients who developed SSRI-induced anorgasmia, only eight (30.8%) reported complete remission and four (15.4%) reported marked improvement (with more severe orgasm delay less likely to spontaneously remit).

### **Dose Reduction**

Given that some research has found sexual side effects to be dose related (Benazzi & Mazzoli, 1994; Herman et al., 1990; Montejo-Gonzalez et al., 1997; Zajecka et al., 1997), reducing a client's dose has the potential to alleviate their sexual side effects. Research has found that this is helpful for some clients (Montejo-González et al., 1997; Shen & Hsu, 1995). Of the nine participants (fluoxetine=5, paroxetine=4) in Shen and Hsu's study that experienced dose reductions, seven (fluoxetine=3; paroxetine=4)



experienced remission of sexual side effects while maintaining clinical benefit. In Montejo-González et al.'s investigation, 30 participants experienced a dose reduction of 50% (particular medications not disclosed). Of those 30 participants, 23 (73%) reported 'some' or 'quite a lot' of improvement.

### **Drug Holidays**

Investigating whether or not taking a drug holiday (i.e., suspending use for a specific period of time) lasting several days would improve sexual functioning without compromising clinical benefit has been the focus of some research. Rothschild (1995) found that of the 30 SSRI-using outpatients followed over the course of four weekend-long drug holidays, the majority experienced 'much' or 'very much' improved functioning related to libido and orgasm for at least half of the drug holidays. Significantly better results were found with paroxetine and sertraline compared with fluoxetine. Rothschild hypothesized this was due to the shorter half-lives of paroxetine and sertraline, although the placebo effect could not be ruled out. However, the potential for discontinuation symptoms to occur shortly after missing doses—especially for those SSRIs with shorter half-lives (Haddad, 2001; Shelton, 2006)—is a complicating factor for using this management method.

### **Delaying Intake**

For individuals and physicians concerned that skipping several days of medication may compromise clinical efficacy or initiate discontinuation effects, delaying intake of a daily dose until after sexual activity has been proposed as a possible alternative. Shen and Hsu (1995) followed some participants who did not take their medications within 24 hours of engaging in sexual activity, but took their dose afterward. The researchers

reported that several participants were successfully able to re-establish sexual functioning without compromising efficacy.

### **Switching Antidepressants**

Several studies have shown that switching clients to antidepressants less likely to cause sexual side effects or with less severe side effects can be a good strategy (e.g., Ashton & Rosen, 1998; Clayton et al., 2004; Walker et al., 1993; Montejo et al., 2001; Montejo-Gonzalez et al., 1997). For example, Montejo-Gonzalez and colleagues found that four of 13 participants (30.7%) switched to another SSRI and one of five participants (20%) switched to an atypical tricyclic antidepressant experienced partial remission in their symptoms. Alternately, 12 of 15 participants (80%) switched to an MAOI and three out of five (60%) switched to an atypical tricyclic antidepressant achieved complete remission (Montejo-Gonzalez et al., 1997). Researchers have also found that the atypical antidepressants bupropion (e.g., Ashton & Rosen, 1998; Clayton et al., 2004) and trazodone (e.g., Stryjer et al., 2009) are sometimes successful at alleviating SSRI-induced sexual dysfunction. The availability of this option may increase as other antidepressants associated with fewer sexual side effects are developed and/or become more widely available.

### **Adding a Pharmacological Antidote**

For those clients who are not interested in or do not respond well to the aforementioned strategies, adding a second medication such as Viagra® (e.g., Ashton, 1999; Shen, Urosevich, & Clayton, 1999), to serve as an antidote to their sexual dysfunction is another option. In sum, there is no consistently successful solution for alleviating SSRI-induced sexual dysfunction. However, some individuals are able to

alleviate their sexual dysfunction while taking SSRI medication. What remains unknown is the degree to which individuals return to baseline sexual functioning when sexual dysfunctions persist after SSRIs have been discontinued. It remains unknown the extent to which SSRI-induced sexual dysfunction persists after the discontinuation of treatment and what impact it has on individuals who may experience it. The following section overviews the emerging evidence of post-SSRI sexual dysfunction.

### **Persistent Sexual Side Effects After Discontinuation of SSRIs**

Persistent sexual side effects are those that do not remit after discontinuation of SSRI treatment and last from months to years (potentially indefinitely). Because empirical investigations examining the sexual side effects of SSRIs lack long-term follow up with participants, the incidence of persistent sexual side effects remains unknown. However, given there are online consumer support and discussion groups for those living with persistent sexual side effects, it is apparent that SSRIs can continue to have persistent effects months and years after discontinuation. One such group, highlighted by Bahrack (2008) and Csoka, Bahrack, and Mehtonen (2008), is called SSRIssex, which began in 2005 and had over 3200 members in October 2010 when it was accessed for the purposes of this dissertation ([http://health.groups.yahoo.com /group/SSRIssex](http://health.groups.yahoo.com/group/SSRIssex)). The foundational literature related to persistent sexual side effects is limited to eight publications at the current time (Bahrack, 2006, 2008; Bahrack & Harris, 2007; Bolton, Sareen, & Reiss, 2006; Csoka, Bahrack, & Mehtonen, 2008; Csoka & Shipko, 2006; Farnsworth & Dinsmore, 2009; Kauffman & Murdock, 2007) and will be briefly summarized below.

Bahrnick's (2006) initial publication raised concern about post-SSRI sexual dysfunction by examining published prevalence data related to sexual side effects of SSRIs and SNRIs. Bahrnick stated "our knowledge base is unintegrated, inadequate, and even inaccurate. ...we have barely begun to appreciate the pervasiveness and complexity of the impact on sexuality of these medications" (p. 2). She highlighted the typical dysfunctions often captured as side effects of SSRIs (e.g., low desire, anorgasmia), but also raised concern about symptoms that are qualitatively different than those typically classified as sexual dysfunctions, namely genital anesthesia (decreased genital sensation) and orgasmic anhedonia (pleasureless orgasm).

In a follow-up article, Bahrnick (2008) reviewed the emerging evidence for PSSD by documenting incidental and empirical research findings as well as those from the online consumer support group SSRIsex. Bahrnick indicated that based upon postings from the individuals belonging to the SSRIsex online community, it appears any and all SSRI-induced sexual side effects can continue after ending treatment. Based on the informal polls, it appears that most characteristic of the condition were reduced genital sensitivity/genital anesthesia, reduced intensity of orgasm, diminished libido, and erectile difficulties. While Bahrnick notes the polls conducted in these consumer groups are not scientific, they do capture qualitative information about the issue of persistent sexual side effects that is not available elsewhere. In Bahrnick's exploration of genital anesthesia and orgasmic anhedonia, concern was raised that current assessment inventories for sexual functioning are not adequately designed to gather sufficient information about changes in genital sensitivity or orgasmic intensity, particularly the severity of such problems. Additionally, Bahrnick noted that the fact that post-SSRI sexual dysfunction is not widely

recognized unwittingly leaves psychologists in a position that potentially harms clients long-term because they are unable to intervene on clients' behalf. Thus, she emphasized psychologists' obligation to inform clients regarding the possibility of sexual side effects should they consider taking SSRI medications as well as promote collaboration with clients and prescribers about medication issues.

An extension of the medication-related informed consent discussion is found in Bahrck and Harris's article (2009), which raised concern about the sexual side effects of SSRI medications, particularly those that persist after medication discontinuation. Given the dearth of research on PSSD and resulting limited relevant knowledge base, the authors emphasized that treating providers need to take great care when working with individuals who are considering taking or are taking SSRI medications. They encouraged psychologists to proactively and openly discuss sexual dysfunction and its possibility with clients who are considering SSRI treatment instead of assuming prescribing providers will provide full and comprehensive information and dialogue. They assert that doing so will promote collaboration with clients, will preserve the therapeutic alliance, and will help clients accurately interpret symptoms should sexual dysfunction arise. The authors also emphasized that psychologists should do their best to collaborate with their client's prescriber and advocate on their client's behalf for medication changes if necessary.

Farnsworth and Dinsmore (2009) documented the problems raised by patients reporting PSSD in a genitourinary clinic. The authors concluded that more novel approaches for treating PSSD are needed due to the complex nature of the sexual

dysfunction reported (e.g., peripheral nerve damage). Therefore, more novel treatments need to be studied to help with the multifaceted problem of PSSD.

Csoka and Shipko (2006) and Bahrlick (2008) have highlighted an incidental finding of evidence for PSSD in humans based upon a study conducted by Montejo and colleagues (1999). In their study of 111 participants, one treatment group of 47 people were switched from SSRIs to amineptine (a medication used to treat depression but not associated with sexual side effects), and reports of sexual side effects dropped from 100% to 55% after six months. Alternately, another treatment group of 38 people were switched to paroxetine, and reports dropped from 100% to 90% after six months. Thus, for the first group switched to a non-SSRI, 55% of them continued to experience sexual dysfunction initiated by an SSRI at least six months after discontinuing the medication. No more additional follow up was provided, so it remains unknown how many participants continued to experience side effects and for what duration.

Only within the last five years have formal, peer-reviewed case reports been published documenting the persistent sexual side effects of SSRIs after the discontinuation of treatment despite no known psychological/medical etiology for the continued effects. In particular, genital anesthesia and orgasmic anhedonia appear to be uniquely related to SSRI treatment—symptoms independent of depression itself (Bahrlick, 2006). Bahrlick (2008) notes that these effects are not often assessed in prevalence studies and are therefore underestimated. Often it requires talking with individuals to determine the nature and extent of their persistent sexual side effects.

Bolton, Sareen, and Reiss (2006) documented a case of a 26-year-old man who was prescribed sertraline for depression at 20 years old and within two weeks began

experiencing genital anesthesia, decreased libido, delayed orgasm and anorgasmia. When his depression and the sexual side effects did not improve within 4-5 months, sertraline was discontinued. Despite a clean bill of health by physicians and urological specialists, four years post-SSRI use, he was still experiencing genital anesthesia, decreased libido, and delayed orgasm although no medical etiology could be found. Six years post-SSRI use, genital anesthesia persisted as well as delayed ejaculation and orgasmic anhedonia.

Csoka and Shipko (2006) documented three cases of clients who experienced persistent sexual side effects after SSRI discontinuation. One was a man prescribed citalopram for depression at age 20 and began experiencing reduced libido and anorgasmia within the first month of treatment. While these side effects subsided after one month, by the end of two years on citalopram, he was again experiencing reduced libido and difficulty maintaining an erection although orgasmic functioning remained intact. Several months later, he reported a dramatically lowered libido and inability to maintain an erection although orgasm was possible with significant stimulation. At that time, citalopram was discontinued. Since that time, genital anesthesia and low libido have persisted despite repeated attempts for antidotes (e.g., bupropion). Another was a woman prescribed fluoxetine at age 27 for depression and anxiety and began experiencing anorgasmia, reduced genital and nipple sensitivity, and lack of libido within 3 days of initiating treatment. Fluoxetine was discontinued seven months later. Tactile sensitivity partially returned, and while her ability to experience orgasm returned, they were dramatically reduced in intensity. Her libido did not recover. Also highlighted was a man prescribed sertraline at age 30 for depression who began experiencing reduced libido, moderate erectile dysfunction, difficulty reaching orgasm, genital numbness, and

decreased ejaculatory volume within four to five days of beginning treatment. Sertraline was discontinued after five weeks due to the severity of sexual side effects. None of the sexual side effects subsided after discontinuing the SSRI.

Kauffman and Murdock (2007) documented a case of a woman prescribed citalopram at age 32 for depression who began experiencing genital anesthesia, reduced orgasmic intensity, low libido, and difficulty achieving orgasm within days of beginning treatment. She was switched to nefazodone, which is infrequently associated with sexual side effects, but her symptoms persisted. Antidotes of bupropion and sildenafil were tried, but with no success. Nefazodone was discontinued after 14 months once her depression had subsided. One year after discontinuation though, low libido, genital numbness, and orgasmic dysfunction persisted.

Finally, Csoka, Bahrck, and Mehtonen (2008) documented three cases of persistent sexual side effects of SSRIs. One was a man prescribed fluoxetine at age 18. Within four days he experienced impotence and ejaculation difficulties. Fluoxetine was discontinued four months after treatment began due to the sexual side effects and lack of clinical improvement. Ten years after discontinuation, he continued to experience erectile difficulties. Another client was a man prescribed citalopram at age 39. After beginning treatment, he experienced mild reduction in libido and orgasmic intensity as well as erectile difficulties. He remained on the medication for two years. After discontinuation he experienced persistent symptoms of low libido, difficulty achieving an erection, and declines in genital sensitivity that only worsened over time. Last, a man prescribed a variety of SSRIs beginning at the age of 23 experienced decreased genital sensitivity, anorgasmia, weak erections, and leakage of seminal fluid. Each switch to a different



SSRI provided no relief and the medications were discontinued after one year due to the sexual side effects. After discontinuation his erectile dysfunction resolved, but the other side effects have persisted.

The few existent case studies on PSSD, while important for highlighting this emerging problem, do have limitations. First, given such a small sample size, it is difficult to know the extent of this problem. With relatively few documented cases in the professional literature, skeptics are able to label these cases of PSSD as an anomaly rather than considering that they may reflect a truly problematic condition that affects many more people. Additionally, the published case studies only document the facts of PSSD (e.g., what medications were taken, what side effects occurred, what treatments were tried), ignoring the phenomenological experience of the individuals affected. The current study aims to address these limitations by interviewing multiple people who are living PSSD about their experiences.

In summary, these studies demonstrate that the conventional wisdom assuming that sexual side effects remit with the discontinuation of SSRIs may not be accurate. When compared to the amount of literature dedicated to sexual side effects concurrent with SSRI use, literature discussing persistent sexual side effects is sparse, consisting of case studies. While online communities of consumers experiencing persistent sexual side effects have emerged, their reports are anecdotal given the non-scientific nature of their internal polls and reports. Nevertheless, these anecdotal reports indicate that the psychological impact of PSSD is significant to some individuals and needs to be studied further given the complexity of the problem (Farnsworth & Dinsmore, 2009).

### **Psychological Impact of Sexual Dysfunction**

The goal of the current study is to investigate the psychological impact of PSSD, therefore a review of the literature on the psychological impact of sexual dysfunction is warranted. While the psychological impact specific to PSSD remains unstudied, there is limited existing research on the psychological effect of sexual dysfunction due to antidepressants and some existing research on how sexual dysfunction, in general, impacts individuals psychologically. This section reviews the relevant research on the psychological impact of sexual dysfunction, both induced by antidepressants and what has been found with affected individuals in general.

Only three empirical studies could be found in the literature that included information regarding the psychological impact of antidepressant-induced sexual dysfunction as part of broader prevalence studies (Corona et al., 2009; Williams et al., 2006; Williams, Edin, Hogue, Fehnel, & Baldwin, 2010). Corona and colleagues (2009) surveyed 2,040 depressed men who were beginning either SSRIs, non-SSRI antidepressants, or benzodiazepines. They found in their comparison across groups that those individuals who took SSRIs experienced more sexual side effects across all stages of the sexual response cycle, had poorer couple outcomes (e.g., less sexual satisfaction, lower frequency of sexual intimacy), and reported more performance anxiety and depressed mood after starting their medication.

In their initial quantitative study, Williams and colleagues (2006) surveyed 502 individuals in France and the United Kingdom (UK) who were diagnosed with depression and taking an SSRI or SNRI within the previous three months. The Medical Outcomes Study 12-Item Short Form Health Survey as well as questions developed by the research

team were used to gather information about mental indices. Response options were ‘not at all,’ ‘a little bit,’ ‘a good bit,’ and ‘a great deal.’ The majority of patients who were experiencing concomitant sexual dysfunction in both the French and UK sample indicated that the changes in their sexual functioning had negatively affected their self-esteem, romantic relationship, mood, and overall quality of life at least ‘a little bit’.

Specifically, 72.3% French and 60.8% UK participants reported at least ‘a little bit’ of negative effect on self-esteem. Seventy-nine point one percent and 66.6% respectively reported at least ‘a little bit’ of negative effect on their relationship. Seventy-eight point three percent and 66% respectively reported at least ‘a little bit’ of negative effect on their mood. Finally, 79.4% and 61.9% respectively reported a least ‘a little bit’ of negative effect on overall quality of life. The researchers’ follow-up quantitative study (Williams et al., 2010) surveyed 704 individuals in Germany, Spain, and The Netherlands who had recently begun taking SSRIs or SNRIs. Like the first investigation, those individuals who were experiencing concomitant sexual dysfunction with antidepressant use reported significantly poorer quality of life, self-esteem, mood, and romantic relationships than their counterparts who were not experiencing antidepressant-induced sexual dysfunction, although those from Spain and The Netherlands reported more distress than those in Germany. Specifically, 22.4% of Germans, 61.5% of Spaniards, and 34.5% of the Dutch reported at least ‘a little bit’ of negative effect on self-esteem.

Twenty-six point two percent, 59.3%, and 40.4% respectively reported at least ‘a little bit’ of negative effect on their relationship. Twenty-one point two percent, 62.7%, and 37.3% respectively reported at least ‘a little bit’ of a negative effect on their mood.

Finally, eighteen point four percent, 53.8%, and 34.1% respectively reported at least ‘a

little bit' of a negative effect on their overall quality of life. While these initial studies have begun exploring the psychological impact of antidepressant-induced sexual dysfunction, conclusions remain limited given a lack of breadth or depth of information.

The majority of research on the psychological impact of sexual dysfunction focuses on men with erectile dysfunction. Many studies examine the quality of life in men with erectile dysfunction in conjunction with a medical condition such as prostate cancer and diabetes mellitus (e.g., de Berardis et al., 2002; Fergus, Gray, & Fitch, 2002; Litwin et al., 1999; Penson et al., 2003a; Penson et al., 2003b). However, a few studies have been conducted using samples drawn from the general population. One quantitative study conducted by Guest and Das Gupta (2002) surveyed 939 men between the ages of 35 and 85 living with erectile dysfunction. They found that men less than 65 years old reported significantly poorer quality of life than age-matched men from a normal population. Also, a substantial minority (12% - 28% across all age ranges) believed their erectile difficulties were directly responsible for the dissolution of their last relationship. Additionally, 52% - 65% of single respondents stated their erectile dysfunction kept them from forming new relationships. Finally, men dealing with erectile dysfunctions reported experiencing significantly more depression and anxiety, although the researchers could not determine whether those were potential causes or effects of erectile dysfunction.

Another study (Litwin, Nied, & Dhanani, 1998) surveyed 57 men with erectile dysfunction between the ages of 55 and 66 using the RAND SF-36, which is a brief general measure of health-related quality of life. Results indicated that participants struggled to a greater degree with the emotional effects of erectile dysfunction compared to the physical effects. The participants' erectile dysfunction was associated to poorer

psychosocial functioning compared to an age-matched normal population, although specific details about ‘emotional effects’ and ‘poorer psychosocial functioning’ were not provided.

A more recent study by McCabe and Matic (2008) involved both men with erectile dysfunction and their partners when examining its impact on their romantic relationships. They surveyed 40 Australian men who were predominantly middle-class, Anglo-Saxon individuals who self-classified as having erectile dysfunction (mean age 62.8 years). The men’s female partners were also interviewed (mean age 54.2 years). The researchers used items from quantitative measures (e.g., items from the Self Esteem and Relationship Questionnaire, items from the World Health Organization Quality of Life Scales) and found that men with erectile dysfunction reported significantly poorer self-esteem, self-confidence, quality of life, and sexual satisfaction than their partners. Additionally, although most partners appeared to accept the decline of intercourse frequency and note that the erectile problems were not as important as other life issues, almost 25% reported "a level of unacceptance with the possibility that their sex life may be drastically diminished" (p. 58). The authors hypothesized that such unacceptance may lead to a deteriorated couple partnership. Partners also indicated that erectile dysfunction was a significant problem for their relationship, with 38% stating that, in some ways, erectile dysfunction had been 'devastating'. Likewise, Carroll and Bagley (1990) found in their quantitative study of 43 female partners (age <35 - 70 years) of men with erectile dysfunction that 49% felt their men were withdrawing from them as a result of their sexual difficulties, 41% of female partners indicated they felt ‘to blame’ for their male partner’s sexual dysfunction, and 31% reported clinically significant discord within their

sexual relationship. These studies demonstrate that sexual dysfunctions not only impact the individuals diagnosed, but can potentially negatively affect their partners and intimate relationships as well.

Finally, Mallis and colleagues (2006) found in their quantitative study of 69 men with erectile dysfunction (age 22 - 71 years) that these men had significantly lower satisfaction with their sex lives (especially those with moderate or severe erectile difficulties) as well as significantly lower overall satisfaction with life compared with normative data from a healthy control sample using the Life Satisfaction Index. No differences were found in their mental health status or general quality of life. However, the researchers found that men with erectile dysfunction showed significantly greater satisfaction in other life domains, particularly their financial status and recreation/leisure activities. The authors concluded that men with erectile dysfunction “gain more satisfaction from other domains of their life...[which] possibly reflects a coping pattern that helps compensate for ED patients’ low overall life satisfaction” (p. 448). This means that while sexual dysfunction can greatly affect someone’s life, it does not necessarily mean the negative repercussions are felt pervasively throughout other life domains.

In addition to empirical investigations examining erectile dysfunctions, there are some studies that explore the psychosocial impact of other sexual disorders. For example, a qualitative study conducted by Lavie and Willig (2005) studied the impact of anorgasmia on a sample of six women (age 20 to 26). They found that anorgasmia impacted participants’ interpersonal as well as intrapersonal quality of life. Five of the six participants stated that anorgasmia affected their self-confidence or self-image in that anorgasmia was viewed as a form of inferiority or personal defect. Most participants in

the study said that their anorgasmia upsets them greatly and occupies their thinking; all stated that they thought frequently about what was wrong with them. Additionally, participants reported being negatively affected by the social stigma associated with anorgasmic women (e.g., seen as frigid, cold, sexually frustrated). Participants also compared themselves to their peers who were orgasmic, thus reinforcing feelings of exclusion and inferiority. Interpersonally, all participants stated that their anorgasmia disturbed their partners and negatively impacted their relationships.

A more recent article published by Rosen and Althof (2008) reviewed literature related to the impact of premature ejaculation on psychological state, quality of life, and sexual relationships. Their review consisted of 11 studies published between 1997 and 2007 that included over 19,000 men (of which approximately 4,500 had premature ejaculation) and approximately 3,000 female partners. Of the seven studies that examined psychosocial effects, men with premature ejaculation reported significantly greater levels of distress compared to men without premature ejaculation, such as difficulty relaxing in sexual situations, greater anxiety about intercourse, depression, and embarrassment. Of the four studies that examined quality of life, men with premature ejaculation reported lower levels of intimacy (emotional, social, sexual, etc.), self-esteem, confidence, and satisfaction compared to men without premature ejaculation. Eight studies examined its effects on partner relationships and found a significantly greater proportion of men with premature ejaculation (as well as their partners) reported interpersonal difficulties compared to men without premature ejaculation. Men with premature ejaculation also reported lower confidence in their romantic relationship as well as greater avoidance of discussing sexual problems with their partners.

One quantitative study could be found specifically examining hypoactive sexual desire in women (Dennerstein, Koochaki, Barton, Graziottin, 2006). The sample consisted of 1,356 partnered women (age 20 - 70 years) residing in France, Germany, Italy, and the UK. The researchers found that women in the sample with hypoactive sexual desire disorder (N=119) were significantly more dissatisfied with their sex life, significantly more dissatisfied with their romantic relationship, and more likely to endorse negative emotions or psychological states than women with normal desire, such as unhappiness (86% v. 6% respectively), disappointment (72% v. 5%), inadequacy (71% v. 3%), sadness (72% v. 4%), frustration (68% v. 4%), and hopelessness (61% v. 3%). The most frequently endorsed statement regarding emotional state was 'letting my partner down' which the authors interpreted as an indication that these women were concerned about the negative effects of low desire on their intimate relationships.

A study by Marriott and Thompson (2008) examined the psychological ramifications of living with vulvar pain. Their qualitative investigation of eight women (age 18 to 41) found that vulvar pain impacted both intrapersonal and interpersonal quality of life. Besides painful intercourse, the participants reported: (1) a loss of sexual confidence, (2) disappointment with their bodies, (3) feelings of sexual inadequacy, (4) feelings of unfairness, humiliation, guilt, shame, failure, and personal responsibility related to their pain, (5) fear of infidelity due to partners feeling rejected or not getting sexual needs met, (6) avoidance of sex in order to avoid pain, and (7) unwillingness to develop potential romantic relationships so as to avoid having to disclose sexual difficulties. Some participants reported believing their vulvar pain would never improve and frustration at having their difficulties minimized or dismissed by medical



professionals. As a whole, vulvar pain greatly impacted their sexual identity and sense of femininity, although younger participants in their early to mid-twenties seemed to be especially upset by their pain given their internalized belief that young women ‘should’ be out having and enjoying sex.

Research examining the psychological impact of sexual dysfunctions suggests that individuals are greatly affected by sexual difficulties. However, the vast majority of studies neglect individuals that experience sexual dysfunction secondary to medication and few investigations qualitatively capture the experiences of participants. While it could be hypothesized that the psychological consequences of sexual dysfunction persisting from previous SSRI use is similar to sexual dysfunction stemming from current organic or medical causes, it remains unknown given there is no research examining the experiences of individuals with PSSD. It is possible that the psychological ramifications may differ for individuals whose sexual dysfunction is directly related to prior SSRI use.

### **Summary of Literature Review**

The preceding sections reviewed the research and literature related to (1) sexual dysfunctions, (2) the SSRIs and their concurrent sexual side effects, (3) the emerging evidence supporting the existence of PSSD and highlighting the paucity of empirical research specific to this topic, and (4) the psychological impact of primary sexual dysfunctions. Evidence exists documenting psychological distress related to sexual dysfunction, but a dearth of research about PSSD suggests the importance of investigating the psychological impact of persistent sexual side effects related to prior SSRI use. While one may assume sexual dysfunction associated with previous SSRI use has similar characteristics to that of sexual dysfunction associated with organic or

medical causes it remains unknown given there have been no studies conducted that ask individuals specifically about the psychological consequences of PSSD.

### **Purpose of the Present Study**

The purpose of the study detailed in this dissertation is to expand upon case reports of persistent sexual side effects related to previous SSRI use by exploring the phenomenological experience of individuals living with PSSD and ways they believe that psychologists may be able to assist individuals dealing with SSRI-related sexual dysfunction. As discussed previously, research suggests that sexual dysfunction greatly impacts psychological well-being. However, very little is known about how individuals living with persistent sexual side effects make sense of and meaning from their experiences.

## CHAPTER 3

### RESEARCH DESIGN AND METHODOLOGY

#### **Introduction**

Interpretative Phenomenological Analysis (IPA) was used to design and analyze data for the current study. Interpretative Phenomenological Analysis is a qualitative research methodology developed and established within the health psychology discipline (see Brocki & Wearden, 2006 for a review). IPA is increasingly being used as a qualitative approach to research in psychology. It was introduced by Smith (1996) and has been used in hundreds of studies examining people's experiences regarding health-related conditions, treatments, and decision-making. In general, IPA is concerned with the examination of how individuals make sense of major life experiences. Sexual dysfunction falls within the realm of health psychology, and IPA has been used previously to investigate individuals' experiences with genital abnormalities and sexual functioning difficulties (e.g., Chadwick, Liao, & Boyle, 2005; Lavie & Willig, 2005; Marriott & Thompson, 2008); thus, IPA was an appropriate methodology for examining people's experiences with medication-induced sexual dysfunction. Its developers (Smith, Flowers, & Larkin, 2009) firmly rooted IPA in three foundational pillars: phenomenology, hermeneutics, and idiography.

Approaching research from a phenomenological perspective, IPA concentrates on direct lived experience. Being phenomenological, IPA is particularly committed to exploring lived experiences on their own terms rather than viewing them in a predefined way. Interpretative Phenomenological Analysis holds that when people are actively engaged with recalling major experiences in their lives, they start to reflect on the

significance of what has happened cognitively, emotionally, and linguistically. It is the analyst's job to take the parts of an individual's recollections and discover, along with the person, the underlying common meaning of the experiences recounted.

Hermeneutics is the theory of interpretation. IPA holds that individuals try to make sense of what has happened to them. Thus, the experiences that individuals recount linguistically will reflect not only content, but also their attempts to make sense of their experience. However, sense- or meaning-making is rarely explicit. Thus, the researcher/analyst is trying to make sense of the individual trying to make sense of what has happened to them. And unlike other qualitative analysis methods that are linear and follow specific steps from start to finish, analysis in IPA is a process that moves through steps of analysis in a circular fashion, often requiring the analyst to revisit earlier steps as new results emerge from deeper analysis. The hermeneutic circle is concerned with the dynamic relationship between the part and the whole. To understand any given part, you look to the whole; to understand the whole, you look at its parts.

Idiography is concerned with the particular. Unlike most of psychology, which is nomothetic (i.e., aiming to discover general laws or principles), IPA is idiographic in that it seeks to discover particular processes. In IPA, idiography operates at two levels. First, there is a depth of understanding resulting from thorough and systematic analysis. Second, IPA focuses on how particular experiences have been understood by the individuals within a specific context. As said by Smith et al. (2009): “[IPA] is committed to the detailed examination of the particular case. It wants to know in detail what the experience for *this* person is like, what sense *this* particular person is making of what is happening to them” (p. 3).

Interpretative Phenomenological Analysis is a comprehensive and credible approach for analyzing qualitative research data. As a methodology, it has strong theoretical underpinnings, which help the analyst remain true to the framework of IPA and the analysis process. Also, IPA provides structure and direction regarding the tasks of each specific stage of data analysis. Four stages are used to standardize the research design of an IPA investigation: (1) defining aims and research questions, (2) data collection, (3) data analysis, and (4) compiling results and interpretation. Additional, detailed steps are part of the data analysis process (reviewed later in the chapter). The four stages as they relate to the current study are described in the sections that follow. A variety of researchers have expressed concern over the validity of results that emerge from qualitative investigations. The developers of IPA take these concerns seriously and require scientific rigor from analysts due to the complexity of data analysis. Not only do analysts continually revisit their raw data to ensure emergent themes are capturing the experiences of individual participants and interpretations are well-founded, Smith and colleagues (2009) also highly suggest the use of independent audits to increase the credibility of results. The process for this dissertation's analysis and independent audit will be reviewed later in this chapter.

### **Stage One: Defining Aims and Research Questions**

The typical aims of an IPA investigation involve developing understanding about a phenomenon by exploring people's lived experiences as well as their perceptions and views of the phenomenon and their experiences (Smith et al., 2009). Additionally, the IPA researcher is process-oriented and approaches the phenomenon with a sense of openness (Smith et al., 2009). The aim of the current study was to explore the

experiences and psychological reactions of individuals living with post-SSRI sexual dysfunction. The primary research questions of an IPA investigation (1) are targeted toward phenomenological material (i.e., people's understandings of their experiences), (2) are open-ended, (3) seek to explore rather than explain, and (4) focus on the meaning people make of specific events. Given this foundation, the current study sought to address the following research questions:

1. How do individuals with persistent sexual side effects make sense of and meaning from their experience?
2. How have these individuals' sense of self or identity changed over the course of their sexual difficulties?
3. What role could a mental health professional have had in helping these individuals with their situation?

### **Stage Two: Data Collection**

#### **The Sample**

Since IPA investigations examine very specific phenomena and seek to gain information about a specific experience, sample recruitment is very purposive, meaning participants are chosen based upon their inclusion in a particular, defined group rather than from a wider population (Smith & Osborn, 2007). Smith and colleagues (2009) note that samples are often obtained through referral, snowballing, and/or convenience methods. Additionally, sample sizes are small, ranging from one to 15 participants. The small sample size recommended by Smith and colleagues (2009) is due to the fact that IPA is primarily concerned with a detailed account of individual experience that requires extensive, time-intensive analyses. For this dissertation, individuals experiencing

persistent sexual side effects after discontinuing SSRI treatment were recruited for the sample.

Participants for the current study were recruited using both convenience and snowball sampling. The primary investigator solicited participants in the following ways: (1) publishing a newspaper advertisement in two local newspapers, (2) displaying advertisements in the public transit buses, (3) hanging flyers in public places and local businesses (e.g., libraries, coffee shops), (4) sending a recruitment email to all current students and staff at the university, and (5) contacting mental health providers in the area (e.g., community mental health centers, private practitioners) and requesting they hang a recruitment flyer in their waiting area. Additional participants were found through individuals passing along the recruitment information to other personal contacts who fit inclusion criteria.

The sample was selected based upon several inclusion criteria: participants must have been (1) experiencing persistent sexual side effects stemming from previous SSRI use, (2) at least 18 years old, (3) willing to be audio-recorded for data analysis purposes, (4) mentally stable enough to participate in an interview (e.g., no active psychosis), and (5) proficient with receptive and expressive English language skills.

A total of ten individuals participated in the study. However, one individual was dropped from analysis because she had only very recently discontinued SSRIs at the time of the interview and had recovered functioning when the principal investigator followed up with her two months after her interviews. Thus, the analysis and results of the current study are based upon nine individuals. The final sample included five women and four men ranging in age from 22 to 59 years of age. Participants self-identified as White (n =

7), Latina (n = 1), and biracial (n = 1). Seven participants identified as heterosexual, while two identified as gay men. Relationship statuses included married (n = 2), in a relationship (n = 3), and single/divorced/not dating (n = 4). All five SSRIs FDA-approved for the treatment of depression at the time of data collection were represented. Brief descriptions of each participant are provided below (see Table 1 for basic demographic information).

Casey was a 22-year-old single White female and a senior in college. She said she began taking an SSRI as a teenager when a psychiatrist prescribed Lexapro (escitalopram) for depression and anxiety. She indicated taking the medication for four years prior to discontinuing it due to symptom remission. At the time of her interview, Casey said she had stopped taking escitalopram about two months prior. She noted hypoactive sexual desire was the sexual side effect she experienced while taking escitalopram, which also continued to persist beyond medication discontinuation. Casey said that she attempted to date both while taking the SSRI and after its discontinuation, but found it difficult given men her age were interested in having an active sex life. Because of dating difficulties, she had chosen to focus her energies on school and extra-curricular activities. She characterized herself as being in "very good" health at the time of her interview.

Susan was a 59-year-old partnered biracial female. She indicated taking Prozac (fluoxetine) and Zoloft (sertraline) sequentially for symptoms of depression. She took fluoxetine for one month after it was prescribed by a family physician, but was switched to sertraline by a psychiatrist when her depression did not remit. She took SSRIs for a total of seven months prior to discontinuing the medications. She had been off of SSRI



**Table 1. Demographics for Participant Sample**

| Pseudonym | Age | Gender | Race/Ethnicity         | Sexual Orientation | Relationship Status | Post-SSRI Sexual Dysfunction          | SSRIs Taken   |
|-----------|-----|--------|------------------------|--------------------|---------------------|---------------------------------------|---------------|
| Casey     | 22  | Female | White                  | Heterosexual       | Single              | hypoactive desire                     | esc           |
| Susan     | 59  | Female | White/Pacific Islander | Heterosexual       | In a relationship   | hypoactive desire; anorgasmia         | flu; ser      |
| Sugar     | 34  | Female | White                  | Heterosexual       | Married             | hypoactive desire; genital anesthesia | ser           |
| Darcy     | 28  | Female | White                  | Heterosexual       | In a relationship   | hypoactive desire                     | esc           |
| E.B.      | 25  | Female | Latina                 | Heterosexual       | Married             | hypoactive desire; orgasmic anhedonia | esc; ser; flu |
| Tom       | 33  | Male   | White                  | Gay                | In a relationship   | ED; genital anesthesia                | flu; par; cit |
| Jim       | 34  | Male   | White                  | Heterosexual       | Divorced            | ED; anorgasmia                        | esc           |
| Austin    | 51  | Male   | White                  | Gay                | Single              | ED; orgasmic anhedonia                | par; ser; cit |
| Brian     | 27  | Male   | White                  | Heterosexual       | Single              | ED; genital anesthesia                | ser           |

Note: ED = erectile dysfunction; cit = citalopram; esc = escitalopram; flu = fluoxetine; par = paroxetine; ser = sertraline

medications for three years at the time of her interview. She noted in her interview that she is very sensitive to all forms of medication, so was unsurprised to have substantial side effects. She noted the primary sexual side effects while taking SSRIs were hypoactive sexual desire and anorgasmia, and both had persisted beyond medication discontinuation. She noted she and her partner had been together for 20 years, and while she denied concern that her PSSD would end the relationship she did note substantial distress (at least initially) on her partner's behalf. Susan indicated being in "fair" health at the time of her interview.

Sugar was a 34-year-old married White female. She stated her SSRIs were prescribed by a psychiatrist to treat posttraumatic stress disorder. She indicated taking Zoloft (sertraline) two separate times for a total of one and a half years prior to discontinuing medications a little over a year before her interview. She stated she stopped taking sertraline due to intolerable adverse reactions such as increased suicidal ideation in addition to substantial sexual side effects. She noted hypoactive sexual desire and genital anesthesia were the sexual side effects she experienced while taking sertraline, both of which had persisted beyond medication discontinuation. Otherwise, she characterized her health as "good." Sugar shared that she had made the decision not to tell her husband about her ongoing sexual difficulties in order to preserve her relationship.

Darcy was a 28-year-old partnered White female. She reported that her SSRIs were prescribed by a psychiatrist for symptoms of obsessive-compulsive disorder. She indicated taking Lexapro (escitalopram) for 20 months prior to discontinuing medication. At the time of her interview, she had been off of the medication for a little over four months. She stated escitalopram provided great relief from her symptoms, but said its use

also contributed to the break-up of her relationship. She shared that she and her boyfriend reconciled once she discontinued the medication. She noted hypoactive sexual desire was the sexual side effect she experienced while taking escitalopram, which also persisted after discontinuation. Otherwise, she characterized herself as being in "excellent" health.

E.B. was a 25-year-old married Latina female. She indicated taking Lexapro (escitalopram) initially for 8 months in the mid-2000s and later took Zoloft (sertraline) and Prozac (fluoxetine) concurrently for nine months between 2008-2009. She had ceased taking SSRIs approximately two years prior to her interview. She noted that her SSRIs were prescribed by her primary care physician for symptoms of depression. She noted that hypoactive sexual desire and orgasmic anhedonia were the primary sexual side effects she experienced while on SSRIs, both of which had persisted beyond medication discontinuation. She stated that she and her husband had had a long-distance relationship over the course of much of their relationship and married within the previous year. They had yet to consummate their marriage due to her low sexual desire. She said other than her PSSD symptoms, she was in "very good" health.

Tom was a 33-year-old partnered White male. He indicated taking Prozac (fluoxetine), Paxil (paroxetine), and Celexa (citalopram) "on and off" for 14 years beginning at age 17 due to distress related to his emerging gay male identity. At the time of his interview, he had been off of SSRI medications for a little over two years. Because his medication use spanned such a long length of time, the medications were prescribed by a variety of professionals including his pediatrician, followed by primary care providers, psychiatric nurse practitioners, and psychiatrists. He noted erectile dysfunction

and genital anesthesia were his primary PSSD symptoms. He characterized his health as generally "very good."

Jim was a 34-year-old divorced White male. He said his SSRIs were prescribed by primary care physician based upon the suggestion of a therapist. He indicated taking Lexapro (escitalopram) for one and a half years before discontinuing medications due to symptom remission. He had ceased taking escitalopram a little less than two years prior to his interview. He noted erectile dysfunction and anorgasmia were the sexual side effects most prominent while on medications. Erectile dysfunction and inconsistent orgasm were his primary PSSD symptoms. He characterized his health as "excellent."

Austin was a 51-year-old single White male. He indicated taking Paxil (paroxetine), Zoloft (sertraline), and Celexa (citalopram) at different times between the years of 2000 and 2010. He stated he was started on paroxetine by a nurse practitioner, but was switched to setraline due to adverse effects. He took sertraline for three years and was then switched to citalopram by a psychiatrist, which he took for a total of four years. He stated he was eventually allowed to discontinue his SSRI medication after years of asking his doctor to do so. At the time of his interview, he had been off of SSRI medication for about nine or ten months in his estimation. Austin noted orgasmic anhedonia and erectile dysfunction were his primary PSSD symptoms. He stated he was generally in "very good" health, however he had been diagnosed with cancer the week preceding his interview.

Brian was a 27-year-old single White male. He stated that a psychiatrist prescribed Zoloft (sertraline), which he took for nine months before discontinuing due to intolerable sexual side effects. He said that his doctor encouraged him to continue taking

the medication, but he decided to discontinue use anyway. At the time of his interview, he had been off of sertraline for three years and nine months. He noted genital anesthesia and erectile dysfunction were his primary sexual side effects while on sertraline, and both had continued beyond medication discontinuation. Besides PSSD symptoms, he characterized his health as "excellent." Although Brian wanted to be in a romantic relationship and highly valued having an intimate partner in his life, he found PSSD to be an insurmountable challenge when it came to dating and establishing relationships with women.

### **Data Collection**

Data was collected through two in-depth, individual, face-to-face interviews per participant conducted by the principal investigator. Each participant was invited to choose his or her own pseudonym to be attached to the interview data and protect privacy. The first interview was semi-structured and consisted of questions designed to allow participants to talk at length about their experiences. Smith and colleagues (2009) recommend an interview schedule between six and ten questions long as well as appropriate prompts to help participants articulate their experiences, views, and perceptions more deeply. Such an interview schedule allows appropriate guidance without too much structure. The interview protocol used for the current study is provided in Table 2. The second, follow-up interview had two main purposes: (1) it allowed participants to add to or expand upon his and her narrative from the first interview, and (2) it provided the principal investigator an opportunity to clarify parts of the participant's initial narrative that were vague or incomplete. Interview length ranged from 1.5 - 3 hours.

**Table 2.** Interview Protocol

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1. Could you tell me how you came to experience persistent sexual side effects related to SSRI medication?
  2. What side effects did you experience while on SSRI medication? Have they changed over time?
  3. Describe for me what it was like realizing your sexual functioning was not returning to normal after you discontinued your medication?
  4. Could you tell me what it has been like living with persistent sexual dysfunction?
  5. What impact do you think the persistent sexual side effects have had on your life?
  6. Do you believe your persistent sexual side effects have affected your sense of identity? If so, how?
  7. How do you think a mental health professional (psychologist, counselor, etc.) could have helped you with this situation?
  8. Would you say that you're a different person having gone through this experience? If so, how?
  9. Is there anything I haven't asked you about that you think is important for me to know?
-

Each interview was transcribed verbatim by the principal investigator. Transcripts noted not only verbal content, but also non-verbal behavior and emotion that emerged as part of the narratives (e.g., long pauses, tearfulness, laughter). As part of the data collection process, the principal investigator wrote field notes after each interview documenting (1) date, time, and place of the interview, (2) personal reactions to the participant and interview, (3) things that were observed regarding non-verbal behavior, (4) thoughts about the material that seemed of primary importance to the participant, and (5) thoughts and feelings related to the interaction in general.

### **Stage Three: Data Analysis**

Data analysis for IPA investigations consists of six steps (Smith et al., 2009). These six steps are detailed below. However, it should be remembered that these steps do not prescribe a linear, sequential process. The principal investigator consistently revisited earlier steps to re-evaluate interpretations and ensure accuracy in capturing the participants' lived experiences during the data analysis process.

#### **Step One: Reading and Re-reading**

This step requires the analyst to immerse themselves in the data. This includes reading not only the transcript multiple times, but also listening to the interview again to note vocal quality. Revisiting the data multiple times before analysis begins is done to ensure that the participant becomes the primary focus of the analysis. Another key reason for revisiting each interview/transcript multiple times is so the analyst can begin to see how different parts of the participant narrative fit together, or alternately, if different parts contradict each other.

**Step Two: Initial Noting**

This step involves examining language use and semantic content at a very broad, exploratory level. The analyst takes note of anything interesting within the transcript. This process allows the analyst to begin seeing how a participant talks about, understands, and thinks about an issue. At this point there are no rules regarding what gets commented upon and the analyst avoids breaking the text into ‘meaning’ units. In general, descriptive comments (i.e., describing the content of what the participant said), linguistic comments (i.e., exploring the specific use of language by the participant), and conceptual comments (i.e., questions raised by the participant data at a more abstract level) help give the analyst a good basis from which to begin further analysis. In doing initial noting, analysts usually begin to see more clearly things such as similarities and differences in participant stories as well as areas of repetition/emphasis. When noting, the analyst asks themselves what a particular word, phrase, or sentence means to them and also what it may mean for the participant.

**Step Three: Developing Emergent Themes**

This step shifts the analyst’s work from that involving the original transcript to the exploratory commenting created in the previous step. The main task involves attempting to create concise statements of what was important related to the various comments attached to parts of the transcript. Themes are typically expressed as phrases and capture the psychological essence of the piece. Statements need to contain enough specificity to remain grounded in the participant’s experience, but also be abstract enough to convey the analyst’s interpretation. Emergent themes should feel as though they have



captured and reflect an understanding of the participant and their experience. It is in this step that the hermeneutic circle becomes apparent: a part is interpreted in relation to the whole, and the whole is interpreted in relation to the part.

#### **Step Four: Searching for Connections Across Emergent Themes**

This step involves the analyst developing a chart, or map, of how they think the emergent themes fit together in order to showcase all of the most important or interesting aspects of the participant's account. Not all themes need to be incorporated into this stage of analysis; some can be discarded depending on the overall research question and its scope. While not constrained to the following techniques, some common ways of finding patterns and connections include: (1) Abstraction (i.e., identifying patterns between emergent themes and developing a 'super-ordinate' theme); (2) Subsumption (i.e., when an emergent theme becomes a super-ordinate theme because it helps bring together other related themes); (3) Polarization (i.e., examining the oppositional relationships between emergent themes to see if they provide a higher level of organizing); (4) Contextualization (i.e., connecting emergent themes by identifying similar contextual or narrative elements); (5) Numeration (i.e., reflects the frequency with which emergent themes appear throughout the transcript, thus the relative importance to the participant); (6) Function (i.e., seeing whether emergent themes reflect a specific function for the participant).

#### **Step Five: Moving to the Next Case**

This step involves moving onto each successive transcript and repeating the previous four steps. While the analyst will likely be influenced by previous findings, it is important to treat each transcript (i.e., participant narrative) as a unique and independent

data set.

### **Step Six: Looking for Patterns Across Cases**

This step involves looking for patterns across cases. This requires the analyst to examine the participants' charts/maps of thematic connections and question what connections exist across cases, which themes are most potent, and whether themes in one case can inform understanding in another. Here the analysis moves to a higher level as the analyst comes to recognize that some themes or super-ordinate themes particular to an individual also represent broader concepts that multiple cases share. The final results are often displayed in a table of themes. The table should capture the most important information to be shared about the participants' narratives.

For samples larger than six, it is also recommended that analysts somehow measure recurrence of super-ordinate themes across cases. While left up to the analyst to determine how to define recurrence, the developers of IPA (Smith et al, 2009) suggest that for a super-ordinate theme to be classified as recurrent it should be present in at least a third, if not half or more, of all participants. The principal investigator adhered to these guidelines. Thus, a super-ordinate theme in this dissertation was classified as recurrent if five or more participants provided responses that contributed to the theme.

### **Validity Checking**

Much like other qualitative research methods, IPA analysis is inevitably subjective—a fact that may raise concern about the validity of its results. Validity checks put in place for IPA investigations are designed to ensure the final analysis is credible, but do not demand an ultimate “true” account given analysis is couched in participant experience and subjected to the analyst's interpretation (Osborn & Smith, 1998).

However, Smith (1996) stressed the importance of demonstrating coherent and valid conclusions (e.g., conclusions that are consistent and can be justified through the data) in IPA research. In accordance with its developers and previous IPA investigations, two methods were used to increase the validity of analysis for the current study. The methods include participant verification and an independent audit.

### **Participant verification**

Inviting participants to be part of the validation process stays true to the goals of IPA in that it encourages the analyst to return, again and again, to the data in a cyclical process to ensure the results accurately reflect the experiences and emotions of participants. At the end of the second interview, the principal investigator invited each participant to be a part of the data analysis process by evaluating the analysis of their individual data and providing feedback about whether the emergent themes and connections across emergent themes appeared to credibly reflect their experience. Agreeing to participate in the participant verification process was not required, but encouraged. Six participants agreed to verify their individual analysis at the end of their second interviews. When the principal investigator followed up with the six individuals when individual analysis ended, only four participants continued to express interest. The principal investigator sent each participant's individual transcripts and analysis through certified mail. After two follow-up emails over the course of a month, only two participants ended up providing their feedback. One participant (Brian) felt as though the analysis of their data credibly captured their experience and had no additional feedback. The other participant (Jim) provided minor feedback/clarification about language and terminology, but provided no feedback that altered the analysis.

While it was disappointing that only two of the original six who had agreed to participate in the verification process completed the validity check, it was encouraging that both felt as though the analysis accurately captured their experience. There are several possibilities to account for the attrition of the other four participants. First, they simply may have lost interest in the project over time, particularly if other life demands were pressing. And second, perhaps the two individuals who received their individual transcripts and analysis were overwhelmed with the amount of information sent to them and did not have the time, energy, or emotional fortitude to confront the painful conversations and analysis for a second time.

### **Independent audit**

An independent audit (i.e. cross-validation) was conducted by an individual familiar with IPA analysis but not connected to the current study. The independent audit involved the auditor reviewing the entire data set and providing the analyst feedback regarding (1) units of the data related to how the participants understood, talked about, or thought about an issue that was missed or inappropriately used in subsequent steps of the analysis, (2) units of the data or analyst comments that were used to support one theme, but better supported another or seemed to capture an entirely new theme, (3) alternate ways of connecting emergent themes, (4) the classification of higher order concepts, and (5) any additional recommendations for establishing a more valid data set. To ensure a thorough independent audit, all transcripts, analyst notes/comments, and analysis charts were given to the auditor.

## **Interpretive Lens**

While it is not possible to conduct a completely unbiased investigation given each analyst interprets the data from a certain perspective, IPA, like other qualitative methods, encourages researchers to acknowledge what may introduce subjectivity during the data collection and analysis processes. Data analysis was conducted solely by the principal investigator (a 28-year-old, heterosexual, Caucasian American, married woman). Given her background working with individuals in a clinical capacity as well as her knowledge of sexual dysfunctions, the research investigation was undertaken with the following biases from the beginning: (1) PSSD does exist and is a legitimate areas of concern for individuals and professionals alike, (2) given the negative psychological impact of primary sexual dysfunction, sexual dysfunction due to secondary sources (e.g., medication) most likely results in distressing psychological consequences as well, especially if symptoms do not remit over time, and (3) clients often are not provided adequate informed consent regarding possible sexual side effects of SSRIs and the possible duration of such side effects. Acknowledging and bracketing biases (Fischer, 2009) is consistent with the IPA approach of the analyst continuously engaging in the hermeneutic circle of data analysis to ensure findings are rooted in participant experiences even with the introduction of the analyst's own assumptions or biases during the interpretation process.

A primary component of IPA investigations is discovering how individuals make sense of their experiences; however, as discussed previously in this chapter, analysis consists of the researchers trying to make sense of the participant trying to make sense of his or her experiences. Thus, analysts bring a lens through which they interpret data. The

principal investigator for this dissertation holds a very established feminist worldview, which impacts interpersonal interactions as well as interpretations of events/experiences in life. In addition to the influence of feminism within the context of personal life, it also greatly impacts professional activities and the way in which the principal investigator approaches clinical work and case conceptualization. Given the centrality of this feminist worldview, it is through this lens that the analyst most naturally conceptualized and interpreted the data.

There are two major viewpoints that have been discussed among feminists and within the literature that are of central importance to this dissertation and have heavily influenced the analyst's interpretation of the data. First is the feminist conviction that one's cultural environment influences gender role socialization and contributes to beliefs about gender and sexuality (e.g., what is and is not appropriate sexual behavior men and women; expectations for sexual performance). Although many forms of feminism exist, each acknowledges and emphasizes society's role in shaping attitudes, expectations, and behaviors. Specifically, feminists are attuned to the cultural attitudes and socialization experiences of men and women around sexuality that emanate from Western perspectives of sexuality (Caplan, 1987; Travis & White, 2000). Feminists have written about how "sexuality is conventionally singled out as a 'special' area of life: it has been variously romanticized and tabooed, seen as a threat to civilization or the route to social revolution, as a source of degradation and a means of personal growth" (Jackson & Scott, 1996, p. 26). Consequently, feminists have been actively discussing and writing about issues related to sexuality and Western medicine (McHugh, 2006; Mollenhauer, 2011). Mollenhauer (2011, p. 6) writes:

The overly genital focus of medical discourse ignores psychological and especially sociocultural factors that play an important role in sexual response. The diversity of human sexual experience is reduced to one narrow sexual script, and differences due to religion or socioeconomic status are treated as problematic or dysfunctional, since the human body is perceived as having one "natural" sexual process that maps onto all bodies. Moreover, although sex is generally considered to be something that happens between two people, medical discourse locates sexuality within the individual, ignoring relationship context; however, relationship problems are almost certain to affect sexual functioning in ways that medical approaches cannot treat.

Approaching analysis through a feminist lens, the analyst was particularly sensitive to participant references to gender and sexuality noting the ways in which participants made connections between gender and expectations about sexual behavior and their concerns with how Western medicine was approaching their experiences.

#### **Stage Four: Writing Results and Interpretation**

The results section of an IPA investigation has two purposes (Smith et al, 2009). First, it is to provide a detailed communication of the data, represented by extensive quotations of participant narratives. Second, it is to offer an interpretation of the data, conveying to readers the meaning of the data. Smith and colleagues (2009) state data can be represented in a concise summary table or figure, but is not necessary. Most important is the comprehensive inclusion of participant quotations to highlight themes.

For larger samples (more than six participants), Smith et al (2009) suggest paying particular attention to recurrent themes across cases without losing the individual experiences of respective participants. For such samples, the results section should demonstrate those themes that can be considered overall descriptors of the participants' shared experience, however the outlying individual(s) should not be forgotten. Their experience and narrative should be used to highlight the inherent contradictions and

complexities of human experiences. By doing so, the analyst does not ignore the "part-whole" hermeneutic of the investigation.

Even while writing the results section, the analyst may find him- or herself involved in the hermeneutic circle, returning to the raw data if it becomes apparent that some themes are more or less central to the story being conveyed. This process is central to interpretative analysis and ensures that the final results reflect the most important information possible.

### **The Process of the Current Investigation**

The idea for the current project came about after being taught about post-SSRI sexual dysfunction by a practicum instructor at a clinical setting early in my counseling psychology doctoral training. It was surprising, given the persistent nature of the problem, that little research had been conducted about PSSD beyond case reports. As conversations with this colleague progressed, we discussed how beneficial it would be to give individuals with PSSD a voice in the professional literature and document the psychological or emotional impact of the condition. The possibility of making a significant contribution to the literature by carrying out this project was really exciting, and I looked forward to designing and completing the study.

After contacting the moderators of two of the online support networks for individuals with PSSD (SSRIsex and PaxilProgress), I was given access to the forums and started looking through some of the online data (both non-scientific polls and individuals posts). Based upon this review, I determined that a phenomenologically-based methodology would best capture the lived experiences of the study's participants. As I began to research phenomenological research methods, I came across Interpretative



Phenomenological Analysis in the health psychology literature. This method was often used for individuals who had gone through a major change in health status and examined how individuals make meaning from their experience. I felt PSSD would fit this methodology well.

In formulating research questions to guide the investigation, it was natural to include one that echoed the ultimate aim of IPA studies: How do individuals with PSSD make sense of and meaning from their experience? Additionally, I wondered how PSSD affected identity given the centrality of sexuality to the human experience. Thus, the second research question sought to explore how the sense of self or identity changed over the course of sexual difficulties for individuals with PSSD. Finally, as a clinician, I was interested in finding out how a psychologist could have been helpful for individuals with PSSD. Therefore, three overarching research questions guided this investigation.

A major concern in developing this study was where I would find participants. Advertising locally was easy enough, but I was unsure of how many participants would emerge through local recruitment efforts. I contacted the moderators of the online support networks SSRIssex and PaxilProgress, and they were initially interested in the study and willing to post an advertisement for the study. However, when the advertisement was ready to be posted they were unwilling to do so. From my understanding, the moderators were suspicious that I was going to exploit this population for my own personal gain despite sincere efforts to convince them otherwise. Thus, recruitment was limited to local/regional sources and word of mouth. Ultimately, seven individuals who were local and three individuals from different parts of the country (California, Massachusetts, and New York) contacted me wanting to participate.

Interviews were conducted face-to-face rather than by phone or video conferencing, which helped create a richer data set. Being able to meet with them in person fostered the development of stronger rapport and allowed me to capture both the verbal and telling non-verbal components of their stories. Five out of the ten individuals expressed great enthusiasm for participating, noting the importance of sharing their stories. In fact, one participant who had recently been diagnosed with and started treatment for cancer refused to cancel his interviews because he thought it was so important to have the experiences of individuals with PSSD documented. In their final interviews all ten individuals thanked me for doing the study and expressed how nice it was to talk to someone about their experiences even if there was nothing I could do for them specifically to bring relief from symptoms. Three participants asked when this study would be published, and I had to explain that it would be published until after it was used to complete my graduate coursework.

I found all of the participants to be enjoyable to sit with and talk to. Initial interviews ranged in duration, with discussions lasting anywhere from 40 minutes to three hours. Participants also ranged in expressive affect. Some individuals were more restricted in their affect while others displayed a full-range of affect (e.g., crying, laughing). Participants were attentive to our discussions, thoughtful in their responses, and willing to expose vulnerabilities and fears related to their experiences with SSRIs and PSSD. At times it was difficult for me to witness the sadness of participants who broke down and cried while recounting their experiences because in the context I was a researcher and not a clinician. Yet I believe reflecting feeling and providing empathy instilled a sense of safety and allowed them to share more fully. While the second

interview with each participant did not introduce any substantial amount of additional data, it was important to have in place so I could clarify responses from the initial interview and probe deeper into areas that had been more vague.

Data analysis was a challenging process given I wanted to stay true to the data, but was also required to infer from participant responses what their interpretations were of their experiences. I frequently worked with the original transcripts right by my side and went back to the first-person accounts to ensure my interpretations were commensurate with the data. Because making sense of other people trying to make sense of their experiences is not a straightforward endeavor, I often found myself re-phrasing and re-wording my analysis. With each individual who read my results, I was forced to go back to the data and re-examine my analyses to justify my interpretations or consider alternate perspectives. The final results look very different from where I initially started, but they feel more accurate because of the hermeneutic circle. The field notes were referenced during analysis primarily for the purpose of accurately capturing participant affect and ensuring such inflections were included as important components of their narrative.

Reflecting upon the process of this study, I feel as though I learned something from each and every participant, which was rewarding and made the energy, time, and resources dedicated to the investigation worth it. It was an honor to be let into each individual's private experiences and I feel as though the same quality of data could not have been gleaned from a quantitative methodology. In a sense, there was also a social justice component to this investigation, because it allowed me to document their

experiences in their own words and provide a platform for their voices to be heard in the professional literature in a way that previously was unavailable.

### **Summary of Research Design and Methodology**

This chapter reviewed the methodology for the current investigation. Interpretative Phenomenological Analysis was explained. This was followed by the research questions designed to investigate the research problem. The sample, data collection, data analysis, interpretive lens, and the process of the current investigation were also reviewed.

## CHAPTER 4

### RESULTS

#### **Introduction**

This chapter includes a detailed report of the results of the data analysis for this study. Themes are provided along with illustrative quotes from participants. Both a summary table and written descriptions of the results are included. As discussed in Chapter 3, ten participants took part in this study; however one was dropped before analysis commenced. Thus, results are based upon responses from nine individuals. Based upon the data analysis (see Chapter 3 for methodology), eight primary themes emerged from the data. Themes included: (1) difficult emotional experiences, (2) varied coping strategies, (3) negative impact on romantic relationships, (4) changed identity, (5) changed attitude toward sex, (6) problems with medical providers, (7) mixed feelings about SSRIs, and (8) desire for collaborative health care. Themes one through six were determined to be recurrent based upon the frequency of thematic content discussed as well as the significance of the theme in participant narratives. See Table 3 for a summary table of thematic results. The remainder of this chapter is dedicated to a thorough description of emergent themes.

#### **Difficult Emotional Experiences**

Participant reflections on the impact of PSSD conveyed a deep sense that persistent sexual difficulties were having a deleterious emotional effect on their well-being. Negative emotions emerged from a shift in the way one conceptualized one's self after a loss of full sexual functioning (e.g., feeling broken) as well as from a perception that the loss of functioning changed their sense of belonging or connecting to others

**Table 3.** Summary of Emergent Themes

| Theme  | Theme Type | Central Meaning   |
|--|------------|---|
| <i>Difficult emotional experiences</i>           | Recurrent  | Negative emotions emerged in reaction to intrapersonal and interpersonal adjustments due to PSSD.   |
| <i>Varied coping strategies</i>                  | Recurrent  | Coping strategies ranged from avoidance to active intervention, which influenced adjustment to PSSD.  |
| <i>Negative impact on romantic relationships</i> | Recurrent  | PSSD was a barrier to emotional and physical intimacy in existing and new relationships.  |
| <i>Changed identity</i>                          | Recurrent  | PSSD led to a lost sense of sexual vitality. Men reported greater impact on sense of identity, perhaps due to cultural emphasis on masculinity and sexuality.                             |
| <i>Changed attitude toward sex</i>               | Recurrent  | Sexual intimacy was no longer an enjoyable, positive experience, but rather a source of disappointment, anxiety, and sadness.   |
| <i>Problems with medical providers</i>           | Recurrent  | Participants reported inadequate healthcare related to SSRIs and PSSD, including a lack of informed consent, non-collaborative care, and invalidation of concerns.                        |
| <i>Mixed feelings about SSRIs</i>                |            | Negative side effects of SSRIs were easily identified, however benefit from the medications was acknowledged by some participants.  |
| <i>Desire for collaborative health care</i>      |            | Participants viewed better health care to include informed consent, greater empathy, closer monitoring, education about medications, and more collaboration between healthcare providers. |

(e.g., feeling "left behind" by peers).

For these individuals a clear sense of loneliness and isolation developed with the onset of PSSD. Brian succinctly stated, "I feel like it's a lonely situation to have this condition because this is not something that you really talk about." Reflections of experience were rife with perceptions that they are alone with their problem and unable to connect with or make others truly understand what their experience is like. This sense of isolation was pervasive and referenced in relation to intimate partners, friends, medical providers, and family members. For example, Austin, who had actually tried to be open about his PSSD with people in his life, felt very misunderstood or unheard by people important to him:

I'd say one of the hardest things is the sense of alienation you feel from people you're close to who you'd confided in and you don't feel they really got it or can really remember it. It's like it sort of goes in one ear and out the other. They can't process it. ...I'm not wishing paraplegia on myself, I'm just saying if I was in a wheelchair, everybody would get it. What I have is this invisible thing that is next to impossible to explain to people including a lot of professionals. Including my former therapist, who is perfectly aware that SSRIs have sexual side effects. He just really couldn't get his head around it. And he would say things like 'Are you completely numb down there? Can you feel your penis at all?' And I'm like 'Yes.' 'Can you feel yourself peeing?' 'Yes, I can feel myself peeing. It actually feels better than ejaculating.' And he'd be like 'I just can't imagine that.' ...It makes it very hard. (Austin, 51 years old)

Like Austin, several other participants characterized PSSD as an invisible disability, which means it is less noticeable and more difficult for others to comprehend. While family and close peers may be drawn upon for support, individuals with PSSD are left feeling misunderstood. Even from medical and mental health professionals, who are supposed to provide support and empathy, individuals like Austin are met with responses that heighten a sense of detachment and isolation. Relationships with medical

professionals specifically will be addressed in greater depth in a theme later in this chapter.

Compounding the experience of loneliness and feeling misunderstood, PSSD also serves to set individuals apart from their peer group—almost as if being left behind. Tom, who identified as a gay man, discussed his sense of alienation from the gay community due to PSSD:

It really is very challenging when you're one label: gay. If you really identify with that community, and that whole label gravitates around sexuality, if somehow you're not on board it's very hard to hang onto the label. It's just very, very difficult. And sometimes you feel... I know I'm not artificially gay. I know I'm not a poser. But sometimes I feel very peripheral. (Tom, 33 years old)

Similarly, Darcy, who identified as heterosexual, felt on the periphery of her peer group of friends due to her PSSD:

I definitely feel a little left out, you know, when people are talking about sex. I don't feel always like I'm a part of, like, sexual life. I definitely sometimes have this weird outside feeling. (Darcy, 28 years old)

While difficult emotional experiences are often the result of feeling interpersonally alienated or isolated by PSSD, difficult emotions that are more intrapersonal in nature are of significant concern. Reflections of the emotional impact of PSSD encompassed negative emotional states such as feelings of despair, devastation, hopelessness, and shame. For example, Tom noted "There's been a lot of depression with the PSSD stuff. A lot of feeling helpless, a lot of feeling there's no way to fix this and I'm broken. More broken now than ever." Likewise, Sugar mentioned a documentary she had seen about female sexual dysfunction years prior to losing her own functioning and noted not really



grasping how desperate the women were to rid themselves of "brokenness" until she found herself in a similar position due to PSSD:

And to know that [my husband] is doing everything that should get me there and it won't happen...it makes me feel like a failure. Like I'm failing. ...It's like that show I told you about [featuring women with sexual dysfunction]. Those women were all failures in society. That's why everyone was trying to "fix" them. If [sexuality] wasn't an expectation, then nobody would care about "fixing" them. And so by not having [culturally normative sexual pleasure] it's like you need to be fixed. It's like you're broken. So it makes me feel like I'm broken. Like there's something wrong with me. (Sugar, 34 years old)

In addition to feeling as if she was broken and a failure, Sugar also touched on a very salient observation that these negative feelings can stem from societal expectations of active and pleasurable sexuality. Even though sexual intimacy is at its core a private event shared between individuals, we are all influenced by messages received from our broader culture dictating what is good/acceptable sexual behavior and what is considered bad/unacceptable. We internalize those messages and start comparing ourselves to those expectations. This notion was also evidenced in Brian's narrative, when he expressed his belief that no woman would ever want to be romantically involved with him because he does not have the ability to meet societal standards of adequate sexual performance for men:

People wonder, why have I been single for almost 5 years now in my 20s? It's not really natural. But [PSSD] is probably why. Not because I haven't had people interested. It's more like I stop [relationships] from developing because I guess I'm really afraid. I guess I have this fear of being rejected over this issue. It's humiliating enough as it is. To have to deal with [rejection] would be really difficult (*tearing up*). Being single with this...(*sighs*) It's not something I would wish on anyone I guess. (Brian, 27 years old)

Holding onto hope for symptom improvement was also important in the experience of PSSD, but not always for the better. Hope was a double-edge sword for individuals with PSSD; on one hand it provided a sense that they have a chance to recover functioning, but on the other hand it led to disappointment. Both Austin and Tom spoke at length about the mixed feelings that hope provides for individuals with PSSD, noting that it can keep one motivated to continue trying to find a cure, but also acknowledged the disappointment and feelings of stagnation and betrayal that can co-occur:

The problem with something like [PSSD] is it's much harder to be able to just move on. It's much harder. After I don't know how many years, if it hasn't gotten better I assume I will eventually emotionally adjust and just accept it's not gonna get better. But at this stage I have this tiny grain of hope that it could improve. And that's both a blessing and a curse. It's a blessing in that I have some hope so I'm not completely devastated about it. But it's a curse in that it's preventing me from getting to that stage of acceptance and moving on. I'm just not anywhere close to that yet (Austin, 51 years old)

If you have one sort of fluke [in symptom improvement]—the momentum that that can give you. It's also tricky, too, because you have this great flash of light and hope sort of recalibrates your motivation. But at the same time when that goes away it's that sort of perennial disappointment. That devastation. All I can think about is maybe, you know, having an Alzheimer's family member who you get used to them not knowing and then one day they know who you are and they're talking very lucidly and it's like 'Oh my gosh.' And the next thing they say is like 'Okay, they're not really there.' And it feels like a dirty trick. There's almost an element of cruelty. And then self-punishment or chastisement because I was foolish for thinking 'I got my hopes up again' so then you develop a personal culture of not getting your hopes up, of being skeptical. And that can totally work against something that might in fact really help. (Tom, 33 years old)

Embedded in participant reflections about the role of hope in living with PSSD was a sense of personal responsibility for the outcome. Holding onto a sense of hope did help individuals ward off feelings of pure devastation when confronted by the reality of PSSD, but self-blame emerged when outcomes were not ideal. This burden was evident in the

narratives of two female participants, Sugar and Susan, who had chosen to fake sexual functioning/pleasure in an attempt to preserve their relationships while holding out hope that sexual functioning would recover over time. While this strategy intended to protect male partners from distress, it put the burden of achieving a positive outcome on them personally and led to difficult emotions such as frustration and guilt when those positive outcomes did not occur. For example, Sugar shared a recent example of an interaction she had with her husband:

I felt really guilty last night 'cause when we made love and he actually said to me 'You know, it's amazing to me. I've had other partners in the past and I would just get tired of them and bored or just frustrated.' And he's like, 'With you it's so amazing. It's like the first time every time. I really feel that way.' And I was like... 'I love you.' ... Obviously we have that really nice connection between us so I know what he means, but I felt kind of guilty when he said that. 'Cause I thought, 'I wish I could say that too.' (Sugar, 34 years old)

While the majority of participants conveyed the sense that PSSD had caused substantial emotional distress, reflections from two participants suggested that minimal distress is possible even when confronted by PSSD. A core component was an eventual acceptance of the loss of functioning and situating the loss of functioning within their broader life contexts. For example, Jim shared:

Well, I'm an artist. So I think as a personality I'm prone towards making mistakes to know the effects, to experience them. And I paint about them (*laughs*) ... And I think that I tend to appreciate wisdom over naivety. And even as I feel a sense of failure or inability to [have sex], I appreciate having that just as another aspect of living. I'd trade it back probably. Maybe. I mean I don't know. It'd be nice if these side effects wore off for sure. To just have regular sex. But on the other hand, [erectile difficulties are] gonna happen eventually anyway, so maybe it just happened faster, you know? And I guess what I'm saying is for me, I'm a cataloguer of experience good and bad as an aspect of my profession. So I'm okay with it on that level. And I really

appreciate it actually. ...So yeah, I'm not altogether angry about it in any way. I'm accepting of it. (Jim, 34 years old)

For Jim, who came to view PSSD as a life experience to learn from and incorporate into his work as an artist, there was a sense of disappointment that accompanied the loss and willingness to welcome full functioning back if it ever returned; however, he did not internalize the loss like many other participants or view it as a major source of distress in his life. In fact, he was quite open and honest with sexual partners regarding the difficulties he experienced without apologizing for them or feeling shame.

What is evident in reflections about the emotional impact of PSSD is that the majority of individuals living with the condition suffer silently. It is not a condition that is visible to the outside world and easily comprehended. Thus, even if individuals attempt to share their experience or distress with others, they are often left feeling unheard or misunderstood. Additional distress emerges when individuals feel as though they no longer live up to normative expectations for adult sexuality. Participants spoke openly about the types of sexual experiences and romantic interactions they were supposed to be having, and not having those experiences left them feeling as if they had failed or they were irreparably broken. They compared themselves to cultural standards of normativity or others in their peer groups rather than trying to create individual definitions of 'successful' sexual interaction. For many, they held onto hope that PSSD would go away and they could pick up with interactions where they had left off. However, this mentality led to continued disappointment.

It was individuals who eventually came to accept PSSD and alter their relationship to sexuality that fared best emotionally. While this strategy had the best outcome, it was only one of several used by individuals to cope with PSSD.

### Varied Coping Strategies

When faced with PSSD, a condition unknown to the participants when they first started noticing persistent symptoms, participants were left to try to cope with their situations as best they could. With limited support, information or guidance, these individuals formulated and implemented a variety of coping strategies. While they were each making decisions perceived to be best for them and their life context at any given time, analysis of participant reflections demonstrated that some strategies were more effective at alleviating distress than others. Coping strategies ranged on a continuum from avoidance to active intervention, and some participants noted using strategies on different points of the continuum depending up how much time had elapsed living with PSSD as well as the situational context surrounding the use of each coping strategy.

Different forms of avoidance were pervasive for individuals trying to deal with PSSD. Additionally, avoidance strategies were used in multiple contexts and included the avoidance of talking about PSSD with loved ones, avoidance of new relationships, and avoidance of sexual intimacy with partners. Two women participants who were in committed relationships but struggling with hypoactive sexual desire chose to cope with PSSD by avoiding sexual activity. While their partners would periodically ask about resuming sexual relations or express the desire to be sexually intimate, neither party was active in making change toward re-establishing sexual intimacy. For example, in discussing her marriage E.B. shared:

We haven't slept together in a long time. It's been over a year. We just got married a few months ago and we still haven't slept together since we got married. ...And I was thinking about our type of relationship—if it's more like roommates. But I really don't think so. It's not like roommates. We really are a couple. The feelings are not platonic. They're romantic. It's just a different kind of relationship with no sex involved. We talk about it. And he

understands. We talk about it for a few minutes and then because we can't change it at that moment we turn our attention to something else. (E.B., 25 years old)

Based upon this narrative, E.B. would like to have an active sexual life with her husband and at another point in her interview she did state that "the desire to desire is there." However, E.B. and her husband were unsure of what to do about her lack of sexual desire. Because they did not have guidance as to what may possibly help, it was easier to distract away from a significant barrier in the relationship and focus on other life tasks like work. This strategy also serves to ward off feeling out of control of the situation and being forced to sit with the very difficult reality of PSSD.

For individuals not in relationships, avoidance of new romantic relationships was a very attractive option because it prevented the possibility of being rejected or questioned by a partner. Individuals like Casey had faced the hardship of rejection over sexual difficulties—she had lost several relationships due to her low desire. To prevent the pattern from continuing, she chose to focus instead on academics and extra-curriculars during her college experience. While she was disappointed by the reactions she received from college-aged men, no single participant was more distraught by the possibility of rejection or committed to avoiding new relationships than Brian. He was very emotional when discussing his desire for a romantic relationship as well as his perception that it would be too much heartbreak to pursue. From his perspective young women would not be interested in dating a man with sexual difficulties; thus, it was emotionally safer for him to avoid trying to establish a new relationship despite yearning for a romantic partner:

I do actually believe that there might be a woman who'd be willing to date me anyways and work with this problem. I just believe that it probably won't be *most* people so I'll probably have to go through a couple of very humiliating rejections before I find the right person. I know it's something I just have to do. I want that part of my life again. It's just... god, it's hard to have to go through that you know. (*tearing up*) It's hard enough to share it with people that are close friends. But in the middle of a developing relationship? Whew (*sighs deeply*). I don't want to deal with it. (Brian, 27 years old)

Brian was not the only one who felt talking about one's sexual difficulties with a partner may lead to negative outcomes. Two participants avoided telling their long-term partners altogether that they had ongoing struggles with PSSD. Both had mentioned their difficulties to their partners in passing, but were met with invalidating responses. Thus, they had decided it was best to stay silent and not burden their partners with something that could not be changed anyway:

Since I'm not feeling it anyway I might as well make him happy. That's kind of how I feel. If there was something he could do to help me then I would tell him. I guess that's part of why I don't want to talk to him about it because it's kind of this hopeless thing. I'm gonna tell you and you're gonna feel bad and then you're not gonna enjoy sex as much because you know I'm not feeling it. If I actually convinced him and found a way for him to understand, it would just be negative. Isn't it better that one of us enjoys it? ...Some forms of the truth just hurt. I kind of feel like this is one of those things. (Sugar, 34 years old)

With the relationship that I'm in now, it's working in large part because my partner, I think, assumes that things are better. I've clearly stopped seeming like I'm in a dark cloud of despair and so 'It's not something to worry about' [from his perspective] It doesn't concern him so much. It's not that it's not there. It's that I'm really dealing with it completely alone now and not verbalizing it. Because the burden is a little more familiar, a little more manageable. Maybe I've acquired better coping skills in the mean time. (Tom, 33 years old)

The alternative to avoidance-based coping strategies was active interventions targeted at fixing sexual difficulties. These interventions were almost exclusively used by

men in an attempt to restore sexual functioning and ranged from homegrown remedies found on the Internet to seeking the advice/help of physicians. Brian and Tom both had gone to great lengths to restore sexual functioning, with little long-term success:

I've tried Viagra. I've tried Muse. I've tried, um, various different supplements. I work out and I exercise a lot. And I think being healthy is one of the few things that I've read people say that actually helped them get over this. ...And so I figured 'Well, what do I have to lose?' So I've been weight training and exercising. It makes me feel healthier and more attractive, which I guess is a good thing, but it hasn't really fixed the problem at all. ...I've taken zinc trying to raise my testosterone 'cause I got tested at one point and the levels were somewhat low. I remember reading about a combination of testosterone and dopamine agonist, but I have a fear now of most all medications. (Brian, 27 years old)

It's actually been called the Goldstein Protocol: a combination Clomid or any kind of a testosterone enhancement with a dopamine agonist. ...I was trying to masturbate a week or so after starting the medication and there was again a very similar response that I had when I was on Wellbutrin originally. I was like "Woah! There's something here." ... It was really pretty fantastic. It did sort of wane. I don't know whether that's just habituating or my ability to sense the dramatic contrast shifted, but in any case it did something. So I stayed on that for a year. ...I was most happy to know that my body was still *capable* of something 'cause I had begun to wonder 'Did I kill the pleasure centers in my brain? Is it just gone? Like I'm never, ever gonna have another orgasm in my life because my brain is literally not capable of it?' So that was very, very reassuring. (Tom, 33 years old)

For men like Brian and Tom, there had to be a "fix" out there somewhere and they were committed to finding it. During their interviews, Brian, Tom, and Austin all referenced online networks of individuals (e.g., SSRISex, PaxilProgress) struggling with PSSD who share information about what has been helpful or not. While they recognized the danger of trusting and acting upon the self-report of strangers, the possibility that something, like the Goldstein Protocol, could actually be effective at alleviating PSSD was too hard to pass up at times. Tom had thrown himself into medical interventions in an attempt to restore functioning, whereas Brian and Austin were intrigued but hesitant to



do so given the fact that pharmacological intervention is what caused their PSSD in the first place. Rather, they chose to implement strategies with less risk (e.g., good diet, exercise, vitamins, etc.).

A third form of coping was evident in the reflections of over half of participants: trying to trust in time and believe that the human body is able to right itself. While Brian (who was a graduate student in biological sciences) was the only individual to reference neuroplasticity by name, it was alluded to time and again by individuals. For example, Sugar, who had chosen to stay silent about her PSSD, was holding out hope that her body would be able to mend itself sexually:

I noticed the other day that I did have a moment. It was almost like when you're trying to light a lighter and it won't come on. You're trying to light it and it won't come on and then all the sudden it flickers but goes off. I kind of felt that way sexually. We were making love and all the sudden I started feeling excited. And it was really weird because I had felt nothing and I had been numb and then all the sudden I was in the moment and I was like 'Wow I felt it.' And then it went away. So maybe there's hope that it will come back. Because my physical function is there, maybe the connectors will re-grow. Whatever was damaged. Maybe it's literally having to relearn it. It's almost like having physical therapy for sex or something. (Sugar, 34 years old)

The "flickers" of functioning referenced by individuals like Sugar and Tom helped ease some of the despair that so often accompanied PSSD. However, flickers of functioning also served to remind individuals of what they had lost and they continued to struggle greatly as discussed in the previous theme. Only by accepting the loss of full sexual functioning were individuals able to adapt and move forward in their lives and relationships without the level of suffering initially carried. Just as Jim had referenced the importance of acceptance highlighted in the previous theme, so too did Susan. She had been with her partner for decades, and although distress was present for both parties

when she lost sexual desire, over time they had come to recognize a change in health status was just a part of life when growing old with someone:

As far as my partner goes...I think he's finally gotten over [the loss of sexual intimacy]. It took him a long time to come to terms with it. You know, and the relationship moves on. But we were friends long before we were lovers. I think that's what has kept our relationship together. If our relationship was built on sex it wouldn't have lasted. But you work through it and work through growing old together and other things that go with it. (Susan, 59 years old)

The primary means of coping were related to behavior (either avoidance or intervention), but analysis also revealed that individuals turned to cognitive coping strategies when behavioral strategies failed to provide relief. For example, participant reflections revealed that they also try to cope with PSSD by thinking of ways their loss of functioning may have been beneficial rather than always ruminating about the negative. For example, Tom rationalized:

I tend to train myself to look at the other side of the coin, and perhaps having been fully sexually functioning, maybe I'd have been a complete whore. Maybe I'd be HIV positive today. Who knows where I could have ended up. I could have ended up in some fantastic, wonderful experiences meeting great people. There's sort of lamenting what could have been. But there is perhaps also being quite relieved at what could have been that didn't. (Tom, 33 years old)

In sum, a host of coping strategies were drawn upon in an attempt to manage the intra- and interpersonal difficulties associated with PSSD. The majority of individuals used more than one coping strategy depending upon the context or length of time they had been dealing with symptoms. Very few individuals were able to just sit with the experience of PSSD and accept it for what it is. More often, individuals felt driven to find a way to manage the discomfort associated with PSSD in some way, even if their

methods only partially alleviated distress or did so only for the short-term. For many, avoidance-based strategies were chosen and aimed at either protecting their own emotional well-being or that of their partners. Alternatively, action-oriented strategies were embraced by the majority of the men in an attempt to gain control over PSSD symptoms and re-establish full sexual functioning. When behavioral strategies did not prove fully effective, cognitive strategies were used in an attempt to reframe the PSSD experience. While the range of behavioral and cognitive strategies served to minimize PSSD-related distress, suffering only ceased for those individuals who accepted the condition, gave up struggling with it, and chose to move forward with PSSD.

### **Negative Impact on Romantic Relationships**

Because human sexuality is often an interpersonal endeavor, it was unsurprising to see in participant reflections that PSSD negatively influences intimate relationships. Individuals saw PSSD as a barrier that engendered emotional distance and physical discomfort within established relationships as well as a roadblock to forming new relationships. Whether discussing a partner's reaction to the loss of sexual functioning or the way one tried to handle the loss themselves considering the relational dynamics, it was evident that PSSD prevented relationships from carrying on unscathed.

Although PSSD symptoms technically only affect one individual, it was clear that the condition also affects partners and their interpretation of the sexual difficulties present within the couple. Both male and female participants shared that their partners often felt as though the sexual difficulties were their fault or somehow indicative of a lack of interest or love. In some cases, relationships ended because of such feelings, as experienced by Casey and Tom:

They felt like it was their fault, something they did. 'Cause it's hard to understand, you know? It's the pill that does that to you. [PSSD] made it harder because guys in their 20s are immature and so [sex] is a big basis of their relationships. So, [the relationships] didn't last probably because of that. And I tried as hard as I could to make that clear that it had nothing to do with them. (Casey, 22 years old)

It was a pretty big factor [in the dissolution of a relationship]. There's no real clear cut, you know, 'Okay we're splitting because of *this*.' But the sexuality component... And the tension that is there and the difficulty that it introduces and the resentment that crops up on both sides and the guilt that crops up on both sides. And the powerlessness. 'It's never enough.' I can't tell you how many times partners of mine have said 'I feel like I'm trying really hard and it's never enough.'...I mean the energy that it takes to tell somebody, 'It's not you. Trust me. It's not you.' And that alone is a little awkward. To tell somebody 'This is usual for me. This is something I've experienced with many other people.' (*laughs*) It's also kind of like saying 'This isn't special.' That dynamic certainly erodes everything else that might be right and good and strong. ...It doesn't really stand much of a chance. (Tom, 33 years old)

In the minds of several participants, if PSSD in particular had not been present their relationships would have stood a chance of surviving. Couples can work through the difficulties of many health-related illnesses, however PSSD seems uniquely different. Sexual and emotional intimacy is a core component of romantic relationship. If such intimacy disappears and partners cannot grasp what is going on when confronted by such a puzzling condition with an indefinite duration, it is understandable that they would see the difficulties as a reflection of poor match between partners and end the relationship.

For individuals experiencing PSSD who attempt to discuss their symptoms with sexual partners, it is not uncommon to be met with reactions of disbelief. This lack of empathy in turn engenders negative emotions toward partners and affects relationship dynamics. Feelings such as envy, resentment, and guilt build which further distances partners from one another. Tom and Austin, the two gay male participants, both spoke at

length about how partner reactions to their PSSD difficulties led to the development of negative emotions that continued to fester within the partnership and drive the couple apart:

And I have told [my current sexual partner], but he totally doesn't get it. Which in some ways I guess is good because he enjoys being in bed with me and he thinks it's awesome. Part of me is irritated because I'm like, 'I told you and you still think that that was much better for me than it could possibly have been.' And part of me doesn't want to keep drumming it in to him. Saying 'No. That really just didn't feel like much.' It's a sucky thing to tell a lover. And it's not his fault. It's no reflection on him in bed. It's this condition that I have which is an adverse reaction to drugs I was on over the course of 10 years. But I'm very conflicted because part of me feels like taking him by the shoulders and shaking him and saying 'I told you I don't really have orgasms. So yes, you saw that I ejaculated but no it wasn't that great. It couldn't have been.' Part of me is, like, just let him believe he made me feel good because he's super thrilled. And part of me feels envy. I feel resentment and envy. (Austin, 51 years old)

If anything those are the most difficult moments: the moments that I will have been crying in sex and not had a partner notice. Not have somebody see that I'm actually in a place of great pain because of what's happened. ...To actually be engaged in having sex with somebody else experiencing passion or being part of their pleasure, knowing that what I'm doing to them or with them is bringing them to a wonderful place of great pleasure and satisfaction, and not being able to go with them...It's very hard. And you can be sort of stoic about it and make it an act of generosity. [But] there does come a point where it breeds resentment. Even if they want to be supportive, even if they notice that things are bad for you. Then what happens is that they develop this avoidance stance, 'Well, we just won't have sex because it's an awful time every time.' So the degree to which they want to initiate something sort of stops. Then you just sort of go down divergent paths and it's very hard to maintain a partnership that way. (Tom, 33 years old)

If feelings such as envy and resentment are present, it is difficult to have a satisfying partnership. However, it was also evident that in relationships where envy and resentment were not present, PSSD still leads to a sense of having an incomplete relationship. This was particularly salient for individuals who were avoiding sex

altogether, such as E.B. and Susan. Susan, the woman who had been in a relationship for over twenty years succinctly stated, "We're just two people who live in a house. We're friends. Sure we kiss, that kind of thing. But as far as like sex? It's just nonexistent. I'm just not interested." Alternately, E.B. who was just embarking on her marriage, was more concerned about her loss of desire the lack of sexual intimacy, especially given they had had an active sex life prior to her SSRI use:

I guess I feel there's something missing in my relationship with my husband. We need more of the physical aspect. We have other ways of experiencing closeness, but I want everything. I want everything back the way it used to be. And I feel sort of abnormal. Because I know we're supposed to be having sex on a regular basis. That's what couples are supposed to do. And I would like to have the desire to do that again. But I don't have the desire and it's frustrating. (E.B., 25 years old)

Whereas Susan and her partner had weathered many years together and enjoyed a highly active sex life for many of those years, it was younger participants like E.B. and Darcy who expressed fear that PSSD would cause relationship complications unknown to sexually functioning couples. E.B. explained "It is going to be hard for me to conceive kids if I don't want to have sex. I want to have kids. That'll make it difficult." (E.B., 25 years old). Darcy who had initially lost the relationship with her boyfriend due to her changed personality while taking SSRIs, was already worrying about how her PSSD would influence the relationship if they did choose to get married now that they had reconciled:

[My boyfriend and I] were so happy to get back together. And now as we go forward we're talking about getting married. And I just feel like [my PSSD] is going to be this thing that follows us. Like I'm never going to... I get really worried that sex will always be a big deal for us—in a way that I didn't think would ever be a problem. (Darcy, 28 years old)

Even for individuals not in relationships, PSSD greatly influences thoughts about romantic relationships. Worries about attracting and keeping a partner are at the forefront of their minds. The reflections of single participants conveyed the hesitancy with which they thought about and approached new relationships because of the embarrassment and shame related to their PSSD. Thus, despite yearning for a committed long-term romantic relationship, PSSD was viewed as a barrier to achieving that goal. Dating can be difficult enough given the anxiety and potential rejection that comes with searching for a partner; the addition of indefinite sexual dysfunction was too much to face. Individuals like Casey, Brian and Austin, who had all lost relationships due to PSSD, were open about their hesitancy to enter the dating world given their PSSD. For example, Austin shared:

It's affected my marketability in the gay dating world. My confidence levels are shaky enough that I pass up potential encounters. Chances are they wouldn't lead to a relationship, but there's that possibility. It probably wouldn't. It would be a one time only thing, I'd never see him again, but there's always that tiny possibility that it could. (Austin, 51 years old)

With the exception of masturbatory activities, sexual intimacy takes place between individuals. It is inevitable that PSSD influences each partner individually as well as the dynamics between them. A partner has to live with PSSD just as the individual afflicted by symptoms does. Whether through direct loss of sexual intimacy as is the case for couples who cease sexual intimacy or through emotional distance that crops up with the introduction of negative feelings like resentment, both individuals of the dyad are affected by PSSD. The impact of PSSD on relationships is varied: some relationships are lost, some suffer silently, some move forward with the expectation of bumps along the way, some are never given a chance to begin. Whatever form it takes, it is undeniable that

PSSD negatively influences romantic relationships.

### **Changed Identity**

Beyond introducing negative emotions and complicating romantic relationships, for some participants PSSD led to struggles with identity as well. This was evident in the narratives of the men more so than the women. This is not to say that women were unaffected by PSSD; indeed, they often referred to a lost sense of sexual vitality and energy. However, their core identity did not seem as intimately tied to their sexuality as men. Regardless of gender differences, self-perceptions of sexual "being" changed because of PSSD.

With a loss of full sexual functioning came the loss of sexual vitality. Women gave voice to this changed sense of femininity and sexuality, which at times put them at odds with expectations for female sexuality. Both Darcy and Sugar spoke at length about the shift from engaging in full, active sex lives and enjoying male attention to something more resembling asexuality:

I can't really put my finger on it. It's almost like a spiritual weirdness. ...I don't feel like I'm a sexual person. I used to dress a lot more provocatively...It's not like I was super provocative or anything, but now I don't even want to wear a tank top. I don't really want any part of my boob to show. I just don't feel hot. Or like I want to be hot. I don't even want to talk about hotness. I feel like it's just made me look at the world now as a very desexualized place. ...I remember when I was younger just noticing guys. Not wanting to go talk to them or anything, but thinking 'That guy's hot.' Feeling, like, a sexual energy that I don't feel anymore. Um. And I think that's made my identity a little different. I feel like my identity now is very school marm-ish, like I don't want any shenanigans (*laughs*). Which is weird because my politics are not like that. That's not who I am. (Darcy, 28 years old)

It's affected my sense of identity a lot. I don't feel sexy as a woman. I always felt sexy. I noticed men would look at my breasts or something and I'd kind of like that in a way. It made me feel good and now I'm just like 'Ugh. Whatever.' ...Because sex is so important in our society right now, not having it makes me feel



like somehow I don't fit in or I'm old. 'Spinster' and those kind of words come out. (Sugar, 34 years old)

This loss of sexual energy was particularly salient for women, who often compared themselves to cultural references of female asexuality like "spinster" and "school marm." As Sugar alluded to, declining sexual activity is often associated with old age in our culture, and there is a clear negative connotation that accompanies such references. For women who were not "old" and had enjoyed years of sexual activity preceding PSSD, the energy shift that occurred due to PSSD was not congruent with their sense of identity. As Darcy stated, "That's not who I am."

Men seemed to reflect much more heavily what the loss of functioning has meant for their identities. Their masculine identities were jeopardized by PSSD. Men are inundated with cultural messages that equate manhood with sexual ability. Thus, when the ability to "perform" sexually disappears, it can drastically alter a man's perceptions of his masculinity, as evidenced by Brian's reflections:

[It's impacted my identity] in the respect that I don't feel as much of a man. I feel like I'm not able to function like I should be able to. So I feel like...not as much of a man. I mean a lot of our culture defines you as being a man by these [sexual performance] things. I try to not buy into that, but sometimes you feel... I used to feel very confident in my sexual abilities and now I don't. (Brian, 27 years old)

One participant, Tom, acknowledged that PSSD had caused him to reflect upon his sexual identity and corresponding affiliation with the gay male culture. He spoke to the intersections of his various identities, namely his gender, age, and sexual orientation. While PSSD had caused him to grapple with identity, it was ultimately strengthened:

[The gay community] is sadly an aesthetically driven, youth driven community. So as my youth account dries up (*laughs*) it becomes less and less critical that I have that sexual function. Not that I want to be a complete whore, but it's one of those things that you struggle with. ...[My gay male identity] has been a hard thing even to hang on to. In spite of all of this time where the ability to 'be gay' in a practical sense, in a behavioral sense [has been lost]...I'm still very much a gay man. I think the ability to have a visceral response—to feel totally goo-goo ga-ga over Justin Timberlake without a shirt on—I still know...I'm still very much in touch with that. That's what I'm connected to. It's not like I feel equally towards a naked female body as I do a naked male body. But I have kind of wrestled with 'Okay, then what does that make you? If you aren't sexual at all. Or if you're oddly sexual.' (*laughs*) And that's been interesting to pause and think about. ...And I think that that's interesting. It can't be ignored. ...If anything [PSSD has] served to more solidify my identity as a gay man. And maybe not necessarily a gay man in a sexual sense, but a gay man in a very global sense. It's made my identity more solid but also more idiosyncratic. I'm not just a gay man. I'm not just a 'this' or a 'that.' I'm THIS gay man (*pointing to self*). (Tom, 33 years old)

While the salience of certain identities shift based upon environmental context, it is clear that PSSD caused individuals to grapple with changed self-perceptions. There was a sense of sexual emptiness woven into the reflections of female participants, and they, more so than men, alluded to a loss of sexual vitality. Telling in Darcy's narrative was the fact that one's "politics" or views of sexuality did little to stop the change in self-perception brought on by PSSD. Alternately, men reflected upon sexual ability and what that has meant for identity. This focus on sexual ability is unsurprising given centrality of sexual ability in the lives and identities of American men. And for gay men, who interact within gay male culture where youth and virility reign supreme, the loss of sexual functioning can even cause them to call into question their sense of belonging.

### **Changed Attitude Toward Sex**

While perceptions of self shifted for individuals with PSSD so too did their perspective of sexual intimacy in general. They no longer related to sexual intimacy in

the same way they had done so before SSRI use. What was once an enjoyable, fulfilling act now was a source of disappointment. Participant reflections made clear that due to PSSD the meaning of sex has changed for them. These sentiments stemmed from altered physical sensations as well as a shift in how they think about sexual intimacy because of their PSSD.

Common in the narratives of women were references to "work" or "duty" when discussing the role that sex now plays in their lives. They disclosed that whereas sex was once something to enjoy and look forward to, it was now something to be surmounted. This was especially the case for women in long-term relationships who had experienced years of sexual satisfaction prior to PSSD. For Sugar in particular, who had enjoyed an extremely active sex life with her husband but was not upfront with him about her sexual difficulties, acts of sexual intimacy came to be something that she "dealt with" rather than enjoyed:

I used to have a really high sex drive. Even personally—not just with my partner. I would masturbate and feel sexual a lot. But [side effects] have almost completely changed the way that I feel. And I feel irritable about sex, which I've never felt that way before. ...I feel more irritable in general because I don't have that release. I don't have that enjoyment. ...It's something to deal with instead of something enjoyable. And that's the opposite of what it used to be for me. So it takes away one of my outlets of pleasure.  
(Sugar, 34 years old)

Besides sex for the sake of enjoyment and intimacy with a partner, viewing sex as something to be overcome and tolerated was echoed in the practical concerns of E.B., who was concerned about how she would ever get through the process of conceiving a child with her husband. They had been married several months and had never consummated their marriage given her lack of sex drive:

If it's so hard to get me in the mood, and if I need to be having sex on a regular basis in order to conceive...I just thought 'Oh, it's going to be such a chore. How am I going to sustain interest long enough to be able to get that going?' Yeah, it is totally a different attitude I had afterwards rather than before [taking the SSRI]. (E.B., 25 years old)

Beneath the message of sex being a 'duty' or 'chore' was the notion that because of their PSSD sex was not really worth the effort anymore. Individuals recognized they would not derive pleasure from the experience, thus it was preferable to avoid the inevitable disappointment and reminder of the loss. Whereas the act of sex had previously been equated with physical pleasure and positive emotions, it was now associated with a sense of emptiness and negative emotions. Both Tom and Sugar spoke to this changed reaction to physical intimacy with partners. In their view, sex has lost its allure:

There'd be times back in college, people would be trying to give me oral sex and I'd be like 'If that's good for you, keep going, but I don't even care.' If that's not telling that something's wrong...Whereas typically a guy my age would kill for any opportunity for a blow job, I'm kinda like 'Well, okay. Or pizza?' (*laughs*) Which is sad. And that's another part of it. (Tom, 33 years old)

I don't even like having intercourse really 'cause it feels invasive. Like putting in a tampon or something. I know that's awful to say. Not that I should compare my husband to a tampon. But what I mean is in that very functional non-arousing... For me, putting in a tampon isn't arousing. Just something's in you and it's functional and that's kind of how it feels. And I've never felt that way before. I always wanted him in me like he would be doing oral and I'd be like 'Come in me!' And I don't feel that way now. I'm like '*Ugh!*' (*exhaling with disgust*). And yesterday he was doing oral and I just wanted to push him away. (Sugar, 34 years old)

What appeared most difficult for participants to reconcile was the fact that sex plays an important role in the life of an adult and they were now missing out on that experience. Participants would repeatedly emphasize that they "want to want it" or "desire to desire," but despite those wishes enjoyment of sex simply was not happening.

Woven throughout individual reflections were reminiscence of the pleasure they had once derived from sexual activity before the start of their sexual dysfunction while on SSRIs. In their minds, sexual functioning had meant that they were "normal" and capable of experiencing the range of physical and emotional pleasure associated with intimacy. However, the loss of functioning caused sex to take on a different meaning for them. It was no longer a source of pleasure, but rather a reminder of their "abnormality" and inability to share in core human experience. This appeared especially salient for individuals in the prime of their sexual lives.

### **Problems with Medical Providers**

Participants' reflections on medical care lead to concern about their relationship with medical providers and conveyed the sense that they were not provided the care they needed or deserved. Participants often felt ignored, uncared for and disregarded in clinical settings. Additionally, they wondered why they were not provided proper informed consent regarding SSRIs, which compounded their sense of distrust and betrayal toward medical providers. Difficult relationships with providers were evident both while taking SSRIs as well as when reporting concerns of PSSD.

When participants raised concern about sexual side effects to their medical providers, more often than not they were met with invalidating responses that ignored or disregarded their concerns. The insensitivity of providers engendered high levels of frustration and resentment for participants. Often physicians attributed the concerns of sexual side effects to age, adjustment to medication, or psychological problems. Participants spoke at length about their emotionally distressing interactions with medical providers and how toxic such interactions were to establishing a collaborative, respectful

relationship:

I talked to the doctor about [my loss of desire]. And he said 'Well, your body's just adjusting to the new medication. Give it time. Everything will be okay.' Well, that was 5 years ago and I still have no interest in sex. ... And then I also get the whole 'Well, you're over 50 now.' And it's like 'Yeah. But still. So what?' I don't have to be like I was when I was 20, but still, I'd like a satisfying sex life. (Susan, 59 years old)

The majority of [doctors] said 'Oh, if you're having pleasureless orgasms it's depression because depression causes you not to have pleasure in things.' And I said 'No no no no. I know the feeling of being depressed and not having pleasure in the things you normally have pleasure in. I've had that. I've experienced that. This is not that symptom.' ... There are a lot of MDs who just don't listen...and you're not supposed to question them. The majority of the people I called were like 'No. It's the depression and if you're not on the drug it's not the drug. The symptom would have gone away as soon as you went off the drug.' Which I find very frustrating because these things may be rare, but just because the drug was approved by the FDA doesn't mean that it can't have a persistent side effect. (Austin, 51 years old)

I've gone to two different urologists and a men's health doctor who was not a urologist. I've gone to a couple different general practitioners. A few times I've brought [my PSSD] up with a general practitioner. They're ones that tend to really not know what they're doing. But one of the urologists even told me it's not possible. And I said 'How can you tell me what I'm experiencing is not possible?' Just because it's not common does not mean it's not possible. It's frustrating. ... As someone that's trained as a scientist, you're trained to take evidence as it comes. And I feel like doctors feel like they know everything already even though obviously that's not true and they tell you what is or is not possible. And you're like 'Well I know what I'm experiencing so you can't tell me it's not possible.' ... It's really incredibly frustrating. And I find it incredibly humiliating. And insulting. It's insulting to my intelligence. (Brian, 27 years old)

Evident in the narratives of Susan, Austin, and Brian is the perception that physicians are not willing to sit and really listen to what is going on with their patients and consider alternative explanations for someone's symptoms. Participants do not view their relationships with their providers as one that is collaborative; rather physicians situate themselves in positions of power and fall back on "expertise" in a way that is

dismissive of patients. And as emphasized by Brian, negative emotions build up to the point of complete exasperation.

Beyond disregarding the concerns of patients, prescribing physicians harmed relationships with their patients by shirking their responsibility to provide proper informed consent to pharmacological treatment. Astoundingly, eight out of nine participants expressed that no informed consent was provided before beginning SSRI medications. At the time of being prescribed medications, participants did not know any better than to trust their physicians. E.B. succinctly summed it up in her statement "[The prescriber] really didn't tell me anything. She said 'Just take these. These will make you feel better.' And that was it." In one case, Darcy's, the prescribing physician let her know there could be side effects, but did not continue with informed consent as they should have given her obsessive-compulsive diagnosis:

[Not knowing the side effects was] kind of my fault. Because I was in the throws of this thing. I was really just bad, anxious. ...[The prescriber] said 'Well I'm thinking Lexapro is a good drug for you.' And he said 'Do you want to know the side effects?' And I was like 'No.' And he was like 'Okay. Well if you do here's where you...' But for some reason he presented it to me like 'Do you want to know this?' and I, for some reason...I think because I thought I would just obsess about them, I said no.  
(Darcy, 28 years old)

Thus, although it was the doctor's duty to provide informed consent to pharmacological treatment, including information about adverse effects, Darcy blamed herself for her ignorance.

Compounding the sense of betrayal due to providers not fulfilling their professional obligation was the belief that knowing possible side effects could have prevented the difficulties of PSSD. In his reflections Austin explained that he stayed on his SSRI

medication much longer than he would have been willing to do if he had known potential side effects ahead of time:

Now I should also mention just to put it on the record that at no point ever, *ever* did any prescriber ever tell me about any side effects whatsoever, let alone sexual ones. Absolutely no one ever mentioned a single side effect. Never said 'If this happens to you, let me know.' About *anything*. It was really just 'Here's the prescription and if you don't start feeling better after such and such a time we can try a different drug.' They certainly never said 'If you start having sexual issues, let me know.' No one ever did that... And I think it could have changed things. I think that would have been a big enough red flag for me. I would have pushed harder at 'Let's get me off this drug. I want to taper off.' (Austin, 51 years old)

Neglecting informed consent and dismissing the concerns of patients did little to foster strong working relationships with patients. Given these poor interactions, individuals with PSSD are justifiably skeptical about reaching out for help from medical professionals in the future despite wanting help for their problems. Sugar, Brian, and Austin all spoke in detail about wanting help, but not trusting the judgment or credibility of medical providers anymore:

I'm skeptical. And concerned. And afraid that I'll build up my trust and take something and then I'll have another problem, but I need help. But the skeptical feelings I have right now are based on experiences unfortunately. So it's not unfounded. (Sugar, 34 years old)

I should probably try to see another doctor, but the fact that doctors are so insulting to me makes it really hard for me to go and see another doctor because every time I get really, really upset. I can't stand it. Even though I want to get help, it's just so frustrating and insulting, such a humiliating experience to go through that and have them say 'It's in your head.' And you've read enough and you're educated enough that they ought to take you seriously. The fact that they don't makes me not want to see another freaking doctor. ...It's hard for me to have faith in the medical system at this point. I've lost a lot of faith that I used to have. (Brian, 27 years old)



My new psychiatrist can't do the job he normally does with me because I keep saying 'No.' I don't know if this [PSSD] symptom is ever going to go away, but I don't want to decrease the chances of it going away by risking going on a drug that could do the same thing. And he suggested all sorts of things. ...I said 'Let me google it.' I've become a very different consumer. I'm much more skeptical. (Austin, 51 years old)

Within this thematic category there was one outlier, Jim. In the reflections of his experience with providers, he described good working relationships with professionals and noted benefit from medical and mental health treatment. Despite persistent sexual side effects, he was satisfied with his experience:

My memory is fuzzy as to whether or not my doctor verbally told me [about side effects]. I mean I did read through the stuff 'cause I'm not one to take a lot of medications. ...But I think she did. My rough memory is that I was told. I didn't know that [the sexual side effect] was coming, but when it came I wasn't, like, 'What's this?' And Lexapro was very helpful. I was going through a divorce and in retrospect I've suffered from depression for a long, long time. So Lexapro was a relief. The pressure had been lifted off my shoulders. I felt a big difference. The benefits I was receiving from Lexapro was worth that side effect. ...I feel like the Lexapro really helped me change my perspective in a way that's been somehow permanent. I went to therapy and pharmaceutical therapy and I've changed. I've changed quite a bit in terms of my outlook. And changed for the better. (Jim, 34 years old)

Jim's recollections demonstrate that not all prescribers are negligent to their duty of informed consent and choose to work collaboratively with patients. However, based upon this sample of participants with PSSD, it is more common for individuals to experience a power imbalance in relationships with their physicians. Thus, their voices are not heard and they are not provided the opportunity to make informed decisions about their care. Given these factors, it is unsurprising individuals are wary of trusting the professionals they may turn to in the future.

### **Mixed Feelings about SSRIs**

Analysis of participant narratives demonstrated that each individual had come to their own, unique conclusion about the payoff of SSRI intervention. Although the vast majority of individuals spoke to the damage SSRIs had caused in their lives, both physically and psychologically, it was striking to find that individuals with PSSD had varied opinions about SSRI medication. Each individual's experience of SSRI treatment had come to mean something different depending upon contextual factors such as the severity of the presenting problem, noticeable benefit from the medication, and reactions to healthcare providers. Some individuals despised SSRIs, some liked them a great deal, and others were more ambivalent.

Despite the drawbacks of sexual dysfunction, therapeutic effects of SSRI medication provided a welcome relief from distressing symptoms in the lives of some individuals. Both Jim and Casey expressed appreciation for SSRI interventions. As highlighted previously, Jim shared that escitalopram was helpful and provided relief from depressive symptoms. He likened it to having pressure lifted off his shoulders and felt that the "benefits I was receiving from Lexapro was worth that side effect." Likewise, Casey shared:

I was never told [hypoactive sexual desire] may be a side effect. But that didn't matter because I was happier in all the other aspects. If [low desire] was the one thing that's going to affect me a lot I'd rather be happier with less anxiety and depression. (Casey, 22 years old)

The sentiments of Jim and Casey demonstrate that for some, SSRIs provided enough relief from their presenting problem(s) to justify in their minds the continuation of treatment despite the fact they were simultaneously experiencing sexual side effects.

Alternately, for others who reacted negatively to the medications from the beginning, SSRIs have been conceptualized as the source of all their misfortune. In these cases, individuals expressed the wish that they had never started SSRIs and desire to take everything back, noting that psychotropic interventions made things worse in the long run. For example, Brian, who was put on SSRIs after the dissolution of a relationship and experienced so many difficult interactions with providers over the years, expressed his belief that SSRI intervention had negatively altered the course of his life:

I feel like the SSRIs definitely caused me a lot more problems than helped me. I don't think they ever helped me at all. I feel kind of betrayed that the family physician first of all didn't really warn me about any of this stuff and second of all, it was like 'Oh you're depressed. Let's give you this medication right now.'...In the long run I'm pretty sure I would have recovered from the break up and the different things that were going on right after college. I feel kind of betrayed by the whole thing. I shouldn't really have ever been prescribed them and now I have a major issue that I have to deal with that's bigger than the issue that I originally had. (Brian, 27 years old)

For Brian, this condition was something that happened *to* him based upon a lack of informed consent, not being invited to be a collaborator in his health care decisions, and the hasty decision to push an antidepressant over other alternatives. Others recognized how their decisions ultimately led to the difficulties they were now experiencing. While these individuals were not provided informed consent or invited to be active collaborators in their treatment planning, they acknowledged they had made decisions along the way based upon symptom relief that ultimately affected sexual functioning in a dramatic way. These individuals were more ambivalent about SSRIs given the contrast between welcomed symptom relief and the experience of substantial drawbacks of use. Darcy, who had struggled with obsessive-compulsive disorder and "decided" to forego informed

consent, expressed such views. Despite the relief she experienced while on escitalopram, she expressed wishing she had tried something else first:

If there were truly no side effects like they say there isn't with Lexapro, I would've stayed on it forever. There were times I was on it that I didn't even have health insurance. I was paying for it out of pocket. I was obsessed with that drug because the difference in the way I felt before I took it compared to after taking it was a complete 180. ...I was desperate to feel better. And it did make me feel better, but at the same time it just...It almost makes me feel like I was a drug addict. I wish sometimes that I had done more work or been more interested earlier on in a more holistic approach to dealing with some of this anxiety that threw me off in the first place. I'm sort of disappointed in myself that a clinical approach was the path I chose. (Darcy, 28 years old)

In sum, there were three general stances toward SSRI medication. First, despite the sexual side effects some individuals found the medication to be highly beneficial in treating their presenting problems and ultimately worth the adverse effects. Second, others reacted poorly to the medication from the beginning and felt as if the SSRIs ultimately caused more problems in the long run. Finally, others had more ambivalent attitudes toward SSRIs, having felt and appreciated relief from symptoms, but increasingly found it difficult to justify use when confronted with substantial sexual, physical, and emotional side effects.

In addition to sexual side effects, SSRI use introduced a host of other adverse effects for participants. Their reflections on the experience of taking SSRIs encompassed references to a variety of other side effects. Some of the side effects were minor and to be expected (e.g., headaches, nausea) while others were much more substantial in their impact. This was particularly true for experiences of emotional blunting/detachment and apathy. Notably, these emotional side effects appear to have a persistent quality as well. And much like reflections of sexual side effects, mixed feelings are involved with

emotional side effects. Jim found the emotional detachment that resulted from SSRI use to be a good thing, given it was extreme emotional intensity that had been the source of much of his distress to begin with:

I feel a lot less attached to everybody, to everything. Everything in my life. From the career to the people, um, family. Everything. And mostly I think that that's good because the attachments were what was the big problem. In terms of people, I can move on pretty quickly or I often don't even care whether I do things to hurt people in ways that I would have cared quite a bit about before. (Jim, 34 years old)

Emotional intensity was also something Sugar had been struggling with given her posttraumatic stress disorder diagnosis. However, unlike Jim, she eventually became quite concerned about the apathy and emotional blunting that accompanied SSRI use:

We talked [previously] about numbing. I think that was the thing that I loved the most about the Zoloft for a period of time. But then when I wanted to start regaining...a normal amount of feeling, that's when I noticed it. So it took a long time because I really liked being numb. It was such a wonderful change...That numbness was so welcome and so different for me. ...But [it became] really distressing. I just didn't care about anything. I didn't feel anything. ...I kind of still feel that way. I kind of feel detached. And that's not me at all. (Sugar, 34 years old)

Austin went so far as to posit that SSRIs, although helpful for treating his depression, only did so because they instilled a sense of emotional blunting and apathy. He had spoken at length in his interview about feeling "stuck" in life and wanting to work toward goals like investing in a new career path, beginning dating, etc. However, he expressed the feeling SSRIs were ultimately harmful because the emotional side effects kept him from wanting to move forward:

SSRIs definitely for me helped with the depression. There's just no question. If I am emotionally distressed, both anxiety and

depression, an SSRI will help with those. However, quite apart from the sexual issues, they have what I think is a very deleterious effect on me. They tend to flatten my affect a lot. ...And they make me very indifferent. Very amotivational. ...I think it's unfortunate in hindsight that I went on SSRIs at all because they had the opposite effect. I was really looking to get myself unstuck and looking to motivate myself. And the SSRIs essentially made me not care. ...Because while I was on the SSRIs I just didn't give a crap about anything. ...I remember talking to another friend. When I went on the Celexa he went on Lexapro at the same time. And we were both joking about it. We were both saying 'We may still be depressed, but we don't care.' ...And for much of the time I was on SSRIs I was not in talk therapy because I was just much less motivated to continue it. (Austin, 51 years old)

What was evident in the reflections of Sugar, Austin, and other participants was the concern that much like sexual side effects, SSRI use had introduced persistent emotional changes as well. While for some, like Jim and Casey, pharmacological treatment was deemed to be "worth it" given perceived benefit, the majority of individuals conveyed that such treatment had only introduced more difficulties.

### **Desire for Collaborative Healthcare**

Perhaps due in part to their difficult interactions with healthcare providers, participants provided several different recommendations for professionals who interact with individuals involved in pharmacotherapy. More than anything else, the necessity of proper informed consent to psychotropic medications was emphasized demonstrating the importance of such practice for patients. For example, Brian simply stated "I really think that the responsible thing that doctors need to do if they're gonna prescribe these drugs is to share the side effects." This sentiment was shared time and again by participants. Their reflections conveyed that it would have meant a lot to have someone sit down with them and really help them comprehend and weigh the decision they were making.

Beyond emphasizing the necessity of informed consent, other recommendations

were provided and seem well suited to psychologists. For example, Tom recommended if patients do choose to begin SSRI treatment, psychologists should be advocates for patients as part of an inter-disciplinary treatment team:

I do think there needs to be a collaborative effort on the part of primary physicians, the person who's writing for the drug, and the person doing the counseling if it's not the same individuals. They can't just pass hot potato and say 'I'm doing my job. I refer to specialists.' and expect that your consumer is an informed consumer and can say 'Something's not right.' Because they might not be able to identify that something's wrong. They may not know who to go to if something's not right. So you need to be prepared as a therapist. When somebody says they're having a medication problem, if that's not in your domain you need to make the phone call and say [to the prescribing professional] 'You should really schedule a meeting to meet with the patient about this medication because they're reporting this and it's concerning.'  
(Tom, 33 years old)

Thus, rather than leaving patients feeling alone with problems, psychologists can check in regularly with clients, get updates about concerns, and coordinate care to ensure the individual does not continue to struggle without having the issue addressed. This would have build a stronger alliance with clients and help counteract a sense of powerlessness on behalf of clients. Beyond collaborating with other treatment providers to coordinate care, it was also recommended that clients be asked regularly about any side effects they may be experiencing and track side effects. Given psychologists spend generally more time interacting with clients during visits compared to prescribing providers, they could be well-suited to this task:

[Providers should be] requiring journaling. Like, 'At least for the first month or so on a medication keep track of what you're experiencing. How does this make you feel? We know sexual side effects can be a problem, so here's a rubric, you don't have to invent it. Here you go. Here's all these things that maybe you don't want to talk about, but rate them.'  
(Tom, 33 years old)

Some individuals suggested in addition to encouraging clients to discuss and track side effects psychologists could help clients by providing psychoeducation about sexuality and relationships, the impact of SSRIs, and how to approach sexual side effects. For example, a common theme in Darcy's narrative was the impact of SSRI use and sexual side effects on her boyfriend and romantic relationship in general. She expressed having that additional information would have meant a lot to her:

I don't want to blame anyone for being a bad mental health professional, but I feel like if someone had said to me something like 'You know, sexuality is something that's really important in a relationship. If something feels off there are things you can do.' If someone had told me it takes work, or that it might take work after taking these drugs and that these are things to think about... Because I feel like I have felt a little bit of that stigma. I felt like, 'Maybe it means that [my boyfriend] and I aren't meant to be together or we're terribly incompatible' or whatever. And that's stuff I don't actually think is true. So maybe just a little bit of education at some point. You know, 'Your boyfriend might feel some things too. He might want to check out this book or talk to his therapist about how this might be...' I feel like as a couple we're only just now starting to be the type of couple that would even consider the other one's medical choices to be a big deal. And maybe if we had done that earlier we wouldn't have broken up. (Darcy, 28 years old)

For many, the impact of PSSD and the process of receiving help was an intensely emotional one. Participants like Tom emphasized the importance of health care providers providing empathic listening and validation of the struggle that comes with PSSD:

I cried at my first appointment with [my urologist] because he told me 'So what are you in here for?' and I just started with 'Well, I've taken an antidepressant...' And he stopped me and said 'You don't even have to finish. I know what you're gonna say.' And then he told me 'I'm not gonna write you for Viagra or anything because I know that it won't fix the problem.' Just to have a medical professional acknowledge that's not going to work (*laughs*) I was like 'Yes! Finally!' I mean the degree of healing to just meet with someone who heard you and who wasn't just looking in a sack of tricks for the best trick that they had so that they could appease their conscience and feel like they did the responsible thing... When in fact the responsible thing is to say 'I



don't really know. And I completely 100% agree that what you're experiencing is true. Maybe not the norm for all people who use these drugs, but it's definitely a problem and it's something that's going unaddressed, unacknowledged and needs to be.' (Tom, 33 years old)

In addition to emphasizing the value of having an understanding health care provider, Tom recommended that prescribing physicians consider promoting therapy before medication, noting that this would have been helpful for him when struggling with his sexual identity as a teenager:

I think it would have done me wonders to meet with someone who looked at my situation as something other than a pathology. And who understood that my depression was a very natural and rational response to my circumstances that I was experiencing. And the intervention that I needed was just a moment in time for somebody to say, 'Let's look at this through other ways. If religion is really the issue, we can work through that.' But instead 'Here's a sickness, here's a pill. There you go.' ...I think now, knowing what we know, being met with just 'Maybe you just need somebody to talk to. Maybe you need someone to show you there are other options and not look to medicine until we get to the point where there is no other option' and to try that. ...If somebody had told me there was a chance—I don't care if it was the slimmest decimal ever chance—if somebody had said 'There is a chance that this may flip that switch and shut off sex for you for good,' I would not have gone down that road. Never. It's just not something I would have wanted to risk. (Tom, 33 years old)

Several participants were unsure of how a mental health professional such as a psychologist would have been able to provide help or assistance with their PSSD concerns while others commented that mental health professionals would not have been helpful in solving the problem. Perhaps they were skeptical that relief could have been successful. However, in general the narratives of participants who offered recommendations reveal that psychologists could serve an important role in the healing process. Specifically, the main goal of a mental health intervention would be to stand

with patients as an ally and advocate while supporting patients through empathy and validation. Between advocacy, validation of concerns, psychoeducation, first-line psychotherapy, and intervention to help clients understand their medications and track side effects, psychologists have the opportunity to help clients feel that they are not alone in their struggles. This could do much for alleviating the sense of isolation, loneliness, betrayal, and "brokenness" that so many of the participants of this study referred to when describing their experiences with PSSD.

### **Summary of Results**

Data from nine participants was analyzed and a summary of their responses was provided in this chapter. The interviews were analyzed using Interpretative Phenomenological Analysis by the principal investigator. Eight themes were formed based upon participant responses. The themes were: (1) difficult emotional experiences, (2) varied coping strategies, (3) negative impact on romantic relationships, (4) changed identity, (5) changed attitude toward sex, (6) problems with medical providers, (7) mixed feelings about SSRIs, and (8) desire for collaborative health care. Common among themes were references to relationships with self, others, and cultural norms related to sex and gender. The experience of PSSD is both heavily intra- and interpersonal, affecting emotional state, identity, romantic relationships, and attitudes toward sex in general. Additionally, coping with and adjusting to the loss of sexual functioning was a mix of acceptance and struggle as individuals tried to figure out how to deal with PSSD and unhelpful healthcare. The discussion that follows will continue to explore the themes presented in this results chapter as they relate to the broader research questions of this investigation. Additionally, the specific role that counseling psychologists can play in

helping individuals considering pharmacological intervention or experiencing PSSD will be explored.

## CHAPTER 5 DISCUSSION

### **Introduction**

This dissertation has provided an overview of the literature on sexual side effects associated with SSRI use, both those that occur concurrently and more importantly for the purposes of the current study, emerging evidence that sexual side effects can persist after medication discontinuation. The qualitative methodology, Interpretative Phenomenological Analysis, which was used to gather, analyze and report data from nine participants was described. The study focused on three major research questions: 1) *How do individuals with persistent sexual side effects make sense of and meaning from their experience?* 2) *How have these individuals' sense of self or sexual identity changed over the course of their sexual difficulties?*, and 3) *What role could a psychologist have had in helping the individual with their situation?* This final chapter provides a discussion of results. Answers to the three overarching research questions gleaned from the results are explored. Additionally, implications for counseling psychologists are provided. Finally, limitations and directions for future research are discussed.

### **Making Sense of and Meaning from the Experience of PSSD**

The first research question asked how individuals with persistent sexual side effects make sense of and meaning from their experience. The prevailing message in participant interviews was that PSSD was difficult to make sense of and led to a struggle with acceptance. With the exception of two individuals, Jim and Susan, results demonstrated that participants consistently had difficulty making sense of their experience in a way that promoted adaptive functioning. Jim and Susan were able to

reframe the loss of sexual functioning as one more part of the human experience like anything else, which made the loss easier to accept and move forward with. Alternately, the others conveyed the notion that their loss of sexual functioning was an unnatural, senseless loss. In fact, there seemed to be present a belief that PSSD was something that happened to them due to neglectful medical providers that did not offer adequate patient-centered care. Positioning themselves as the injured party and fusing with that belief led to feelings of helplessness, hopelessness, and at times despair. What seemed to compound this sense of loss was that PSSD is an "invisible" condition (unlike paraplegia for example), which kept them from being fully able to express to others, including medical providers, what they were experiencing and having their experience validated by others.

In addition, the emotional struggles of many participants and the level of distress related to PSSD symptoms was a strong indicator of whether an individual had been able to make sense of his or her experience. Participants were unaware PSSD could result from SSRI use and there was ambiguity about how long they may have to deal with a loss of sexual functioning. For individuals who indicated considerable distress (e.g., feelings of hopelessness, despair), there was an additional level of suffering on top of the already painful realization that sexual functioning may not return. Thus, while individuals with PSSD report similar types of distress compared to people with sexual difficulties unassociated with SSRI use (e.g., strain on relationship; feeling broken), there appeared to be an additional sense of betrayal and disbelief for those with PSSD.

Viewing the results from a feminist lens, it is apparent that the majority of participants felt a lack of power and control over their current situation, but also dating

back to when they first began SSRI treatment. It was apparent that interactions with medical providers overwhelmingly left them feeling disempowered, unheard, and dismissed. However, to better understand the subjective experiences of participants' interactions with medical providers it is important to examine and critique traditional models of biomedical (i.e., allopathic) practice.

Their experiences are reflective of a long-standing "paternalistic model" of physician-patient interactions (Elwyn, Edwards, Kinnersley, 1999; Stevenson, Barry, Britten, Barber, & Bradley, 2000) in which medical doctors take the expert role and patients are passive recipients of the physician's authority rather than drawn upon to be collaborators in their own care. As reviewed in his book *Trusting Doctors: The Decline of Moral Authority in American Medicine*, Jonathan Imber (2008) stated:

For more than a century – from the 1860s to the 1970s – the American medical profession relied on a combination of commitment to rigorous training in medical science and a dedication to professional ethics that made it a revered and respected vocation. (p. xviii)

A characteristic of being 'revered and respected,' paternalistic doctor-patient relationships were typical in the 19th and 20th centuries, with distinct roles for each party; physicians dominated the interactions, controlling both access to information and prescribing treatment, while the patient was expected to be submissive and willing to obey and comply with their doctor's treatment decisions (Parsons, 1951 cited in Beisecker & Beisecker, 1993). From the paternalistic model it is thought that the physicians are more capable than patients in making medical decisions for several reasons including (1) professional expertise and experience, (2) more objective, rational thinking, and (3) the ability to consider both short- and long-term cost and benefits (see Beisecker &

Beisecker, 1993 for a historical review); thus, patients should obey doctors orders.

Implicit in this paternalistic arrangement is the fact that the physician controls all information about the patient's illness/condition and can choose whether or not to fully inform the patient and/or seek consent for treatment (Buchanan, 1978). When patients are put into this disempowering position, physicians can maintain their status and power in the relationship, dictating what is and is not considered important.

Because of the entrenched nature of the paternalistic physician-patient relationship, Imber (2008) stated there is a mistaken assumption that "trusting doctors [is] one of life's necessities" (p. xi). Therefore, patients can unwittingly agree to treatments that may not be in their best interest simply because they have been taught to trust and not question physicians' expertise. This blind trust is reflected in high ratings of trust toward physicians by the public despite the media's publicity of numerous stories of medical errors (Corrado, 2001). Thus, individuals like the participants of the current study may begin SSRIs because a medical expert said it would be helpful, and they trusted that their physicians were providing them optimal treatment.

However, if patients are feeling disempowered, dismissed, and unheard by their prescribing physicians they are not receiving adequate care, the physicians are ignoring their patient's rights to effective care (American Hospital Association, 1998) and patients remain ignorant about treatment options, the possible effects of pharmacological intervention, and how to redress their grievances. From a feminist perspective, all individuals no matter their background have a right to self-determination. The paternalistic model of healthcare serves to restrict such rights, which as the participants of this study have reported, can lead to subpar care and ultimately medical harm. Not

understanding what is happening or why it is happening only serves to increase negative emotions and leave patients grappling for answers and solutions on their own.

In response to the paternalistic status-quo of the medical system, the second wave of the women's movement during the 1960s and 1970s brought with it much criticism and analysis of the health system and ushered in the women's health movement of the 1970s and 1980s (see Scott, 1998 and Kuhlmann, 2009 for a review). As Scott succinctly stated, "feminist health activities have argued that orthodox biomedicine imposes passivity, ignorance, and powerlessness on patients, particularly on female and non-white patients" (pg. 195). As noted by Kuhlmann (2009), the groundbreaking *Our Bodies, Ourselves* (Boston Women's Health Book Collective, 1973) set the stage for consumers (female consumers in particular) to assume responsibility for their own healthcare information and intervention. Specifically, this movement promoted personal empowerment through self-help and consciousness-raising groups, public debate about topics that patients were previously infantilized about (e.g., reproductive rights), and access to comprehensive medical information through community-based women's health centers (see Kuhlmann, 2009 for a review). Scott (1998) argues an additional feminist alternative to the traditional biomedical model is homeopathy, which she asserts challenges the power imbalance typical of the doctor-patient interaction, neglect of the social and environmental concerns impacting patients, and trivialization of the patient's voice/knowledge within the doctor-patient interaction.

What was evident in the narrative of this dissertation's participants was the fact that their initial points of contact for their presenting concerns were with allopathic practitioners (i.e. trained medical doctors) whose training and professional judgment led



to the prescribing of medications as a first-line treatment rather than other less invasive options such as psychotherapy (for PTSD in Sugar's case for example) or a wait-and-see approach (for bereavement in Austin's case). Yet the vast majority of the participants found themselves in paternalistic doctor-patient relationships and either eventually gave up on the medical system completely (like Susan) or turned to other sources of consumer-created, self-help information like the SSRIsex online community.

The ways in which participants chose to cope with their PSSD was an indication of how they were trying to make sense of their experience, and some of the coping strategies provided both positive and negative consequences simultaneously. There seemed to be an either/or dichotomy between protecting the individual psyche vs. promoting healthy relational functioning (e.g., faking sexual functioning to preserve the relationship even if it bred resentment and guilt internally). In general, avoidance-based coping strategies prevented individuals from confronting the reality of their situation honestly, and thus stymied their ability to come to terms with and make sense of their PSSD experience. Alternately, coping strategies that required individuals to confront the reality of their situations (e.g., talking openly with partners) were much more likely to lead to acceptance of the change in health status and promote meaning making.

How participants reacted to and coped with PSSD also seemed to influence the emotional sequelae of the condition. Some coping strategies were adaptive and appeared to lessen distress related to PSSD, while others were avoidance-based which made things more problematic in the long-run by keeping people from reaching important goals (e.g., establishing a relationship, starting a family). Participants who fared better emotionally, such as Jim and Susan, were those who had accepted the fact that they lost sexual

functioning with no real justification for why, had created perspective on their PSSD experience, and moved forward focusing on other aspects of their lives. Unlike other participants who felt powerless and were caught up in the quest of needing or wishing their sexual problems to be 'fixed' both Jim and Susan felt personally empowered in a way that allowed them to decide for themselves to accept the limits of sexual functioning rather than continuing to negatively evaluate themselves against cultural messages of normative sexuality and conclude "I'm broken." Such individuals were open with others/partners about their difficulties and honest about the limitations of their sexual functioning. This communication with others about their struggles may have also assisted in the meaning-making process, because it allowed them to put PSSD in perspective when examining their life context as a whole.

The participants who reported distress related to PSSD seemed to be in a mode of self-protection or self-preservation. Some were actively involved in invasive treatments (i.e., The Goldstein Protocol) involving significant pharmacological interventions, while others were involved with rigorous vitamin regimens in an attempt to fix or resolve their PSSD. They were grasping to hope that PSSD symptoms would eventually resolve and thus not require them to confront the reality and subsequent consequences of a potentially indefinite loss of sexual functioning/pleasure. While holding out hope could be viewed as a good coping mechanism, it seemed to function as a double-edge sword in most cases. Hope provided a possibility of a better future, but it also led to "perennial disappointments" in the words of Tom. When revisiting the narratives of individuals who shared significant distress over their PSSD symptoms, the feminist phrase "the personal is political" (Enns, 2004) seemed salient. That is, American culture contains many

messages of 'appropriate' and 'normal' functioning. While often passed down by peers, family, and media these constricting messages are propagated by individuals and corporations that necessitate a reliance on 'appropriate' and 'normal' sexual functioning to maintain their power and/or economic privilege. Is the problem inherent in the individual and their sexual dysfunction or in the expectations of sexual functioning set forth by societal messages? Would individuals in this study be in so much distress if they were less reliant on these cultural messages about sexuality? As Enns (2004) stated:

If clients are encouraged to look exclusively inside themselves for clues about the origins and dynamics of their problems, they are also more inclined to blame themselves, and to respond by adjusting to or changing themselves to fit the circumstances around them. (p. 11)

### **Changes in Sense of Self or Identity**

The second research question asked how these individuals' sense of self or identity changed over the course of their sexual difficulties. While many participants were struggling to make sense of what had happened, it was clear that SSRI-related sexual dysfunction had a substantial impact on their sense of identity and how they carried themselves in the world.

For a handful of participants, the loss of sexual functioning appeared to end of a part of their lives—particularly in the way they related to others sexually. It was common for the women to use words like "spinster" and "school marm" to describe the loss of sexual energy that accompanied PSSD. Whereas they had once enjoyed flirting and drawing the attention of men, that sense of sexual vitality had vanished from their lives. They shared that they wanted no part in exchanges that prior to SSRI use they would have found exciting. This fact was particularly difficult to come to terms with for women

like Sugar and Darcy, whose politics and outlook on sexuality were progressive and sex-positive.

Whereas women more frequently spoke to a loss of sexual vitality or "being," men more explicitly made the connection between sexual dysfunction and a decreased sense of masculinity. Men, like Brian, referred to a decreased sense of masculinity because they could no longer sexually perform at a level that was perceived normative. This gender difference speaks to the influence of gender-based expectations around sexuality. Societal messages abound equating successful manhood with sexual performance, so when the ability to "perform" (e.g., maintain an erection, achieve orgasm) is lost it is unsurprising to see men's sense of masculinity falter (see Fergus et al., 2002 for similar results). This seemed especially true for the gay male participants, who frequently referenced the importance of youth and sexuality in the gay male culture. Tom and Austin noted in their narratives that PSSD was a dividing line between them and the rest of the gay male community. Without being able to participate fully in sex in a behavioral sense, gay men with PSSD end up feeling "peripheral," in the words of Tom. While Tom and Austin certainly still identified as gay men, there was a whole part of their pre-SSRI/PSSD lives that dropped away when they were no longer able to be "keep up" sexually with the rest of their gay male peers.

Age also appeared to be major factor when examining the impact of PSSD on identity. Younger participants in their "sexual prime" such as Brian, Casey, and Darcy expressed an additional level of identity-related distress due to the perception that sexuality and sexual intimacy is necessary for establishing a long-term committed relationship for individuals in their age group. Alternately, older participants such as

Susan and Austin spoke openly about how advanced age helped ease the burden of PSSD because sexuality was no longer as integral to their identity as it has been in earlier decades of their lives. While they both mentioned that having a satisfying sex life is important for people of any age, they explicitly made comments related to distress easing as time living with PSSD passed because sexual functioning and regular sexual activity was no longer a primary form of social capital and connection in their lives.

Overall, participants referenced the notion that sexuality is emphasized as a central part of one's identity. Not only is it often emphasized in more traditional ways (e.g., having children), but it is also reflective of the "sex sells" barrage of sex and sexuality messages targeted toward men and women by popular culture outlets in recent decades (McNair, 2002). In a feminist critique of popular culture, McNair (2002) states, "The less explicit forms of sexual imagery deployed by the advertising and fashion industries are charged with disseminating distorted and damaging views of both femininity and masculinity..." (p. 8). Consumers are taught that it is through their sexuality that they will be able to attract a mate, keep a mate, be successful, and have happiness. While one's sexuality *is* a component of one's identity, mainstream American culture does a disservice to idealize sexuality and de-emphasize the development of other important parts of identity. This sole focus on sexuality as identity is detrimental for individuals because it leaves them struggling when sexual functioning or sexuality suffers.

As reflected by the majority of participants, when sexual functioning is lost, one's perceived identity can be lost or re-evaluated. For example, Brian expressed the belief that being able to "perform" sexually is a primary component of one's manhood, so when

sexual functioning was lost, his sense of masculinity was called into question. With such an emphasis on sexuality and peak sexual performance, it is understandable that individuals feel a certain pressure to reclaim a level of functioning that was present prior to SSRI use. This is especially the case given the prominence of goal-directed sex in society, where "successful" sex is defined as being able to reach orgasm (especially for men). Without being provided any alternative frameworks for redefining "successful" sex and intimacy (i.e., open-ended sex encompassing sexual touching, oral sex, shared fantasies), individuals will continue to struggle reconciling their identity and sexual functioning.

There was an underlying message present in participant responses that they would be unwanted by partners if they admitted to "subpar" functioning. Several referenced the notion that partners *need* sex and deserve *good sex*, and if participants were unable to provide "good sex" their partners would find it elsewhere. However, none disclosed that they had actually confirmed this belief/fear with their partner; they had all come to this conclusion based upon what they learned about sex and relationships growing up from peers and other sources (TV, movies, magazines, etc.). One participant, Sugar, even referenced the documentary *Orgasm, Inc.* in emphasizing how important it was for women to be fully functional in a relationship for the benefit of both partners.

Results such as these are prime examples of the level of influence that our culture has on constructing norms/expectations for gender and sexuality as well as the pressure it places on individuals to conform to normative masculinity or femininity (Enns, 2004). If each person was left to their own devices to determine and create personal norms of sexual behavior beyond the influence of culture, the impact on sense of self or identity

may have produced very different results. However, culture does not leave much room for individual difference, instead promoting norms that individuals may or may not be able to achieve.

### **Recommendations for Professionals**

The third research question asked what role a psychologist could have had in helping individuals with PSSD. Participants provided many recommendations for professionals working with individuals who have taken, are taking, or are considering starting SSRI medications. In fact, this appeared to be an area of interviewing where participants were passionate about their responses—often due to discontent with their experiences with the health care system. First and foremost, participants recommended and emphasized that professionals not evade responsibility to provide clients complete informed consent to medications. Eight out of nine participants denied receiving adequate informed consent or any informed consent at all. Overwhelmingly they felt that their medical professionals had done them a disservice by not informing them about sexual side effects, because either (1) it would have impacted the individual's decision to begin the medication in the first place, or (2) they would not have been hesitant to report sexual difficulties had they known it was to be expected. Based upon participant narratives and extant literature, it is concerning that adequate informed consent procedures for medications is lacking (Happell, Manias, & Roper, 2004; Rutherford et al., 2007) and the possibility of sexual side effects (concurrent to use or persistent) is not routinely disclosed (Bahrack & Harris, 2009; Higgins, Barker, & Begley, 2006).

Beyond requiring better care from prescribing physicians it was also recommended that mental health professionals, such as psychologists, mention the

possibility of side effects to their clients, recommend they track side effects to bring to the attention of their prescriber, and be an active member of coordinating treatment for clients. While close collaboration with the prescriber may be difficult for providers who do not work in a setting in which the prescriber and mental health professional are colleagues and in frequent contact, participants said it would have made a big difference for them to have their health care providers working together in coordinating the best care possible. The importance of collaborative efforts on the part of providers is a sentiment echoed by Bahrack (2008) and Bahrack and Harris (2009) and such collaboration is recommended for psychologists by recent APA practice guidelines (American Psychological Association, 2011). Whether or not a psychologist collaborates with the prescribing provider, it would be wise for psychologists to ask clients taking SSRIs what they have been told about their use. Through this discussion it may become apparent that clients have not been properly informed and are unaware of possible adverse events. If this is the case, psychologists can provide what information they do know about SSRIs (e.g., sexual side effects are common) and encourage clients to request more comprehensive informed consent information from their prescribers. Psychologists are not in a position to provide medical informed consent procedures and should be wary of impeding upon the purview of the prescriber. Nevertheless, they have a role to play in educating clients and advocating for proper informed consent procedures.

Psychologists who practice in multidisciplinary treatment settings may have an advantage in helping to treat and advocate for PSSD-related issues. There are several benefits to serving clients in collaborative treatment settings. First, psychologists can provide thorough and comprehensive assessment of client concerns. Psychologists are



frequently afforded more time that the prescriber to spend with the client, allowing for the opportunity for increased depth in clinical interviews as well as opportunities for objective assessment measures. Sharing additional and accurate information can lead to more comprehensive treatment plans and adjustments to treatment plans if problems are reported (e.g., side effects to medications). Second, in multidisciplinary treatment settings there are fewer barriers to communication between providers. The providers of a particular client often know one another; they most likely have access to the same patient records, and can have face-to-face consultation in regular or arranged meetings. This close and uninhibited collaboration can streamline the sharing and accuracy of client information, leading to better care. With a complicated issue such as PSSD a streamlined process is likely beneficial for best care. Third, in collaborative healthcare settings prescribing and non-prescribing providers have the opportunity to provide education to one another either through formal (e.g., grand rounds, journal club) or informal (e.g., clinic listserv, conversation) means. These would be ideal settings for psychologists to advocate for clients experiencing PSSD. Many participants in this study emphasized the need for increased collaboration between treatment providers – specifically psychotherapists and prescribers. Multi-disciplinary settings may be the ideal setting to provide care for complex and less understood problems such as PSSD.

Participants also stressed the importance of clinicians really listening to and validating the concerns of their clients. The fact was repeatedly made that although some problems, like PSSD, may be rare, treatment providers should take the concerns of their clients seriously without dismissing them out of hand as impossible or "in your head." Even if there is nothing that a psychologist could do to treat the client's sexual

dysfunction, several participants noted that having a provider believe them, validate their concerns, and take their distress seriously provided a great sense of relief.

Another area where psychologists could intervene is in talking with clients openly about sexuality and how to manage sexual difficulties in a way that would promote the least amount of distress. Darcy, for one, mentioned that we have a myth in our society that sex and sexuality should come easily and therapists could help educate clients that this is not true, that many people have different sexual problems or struggles, and follow this education up by teaching communication strategies that clients can use with their partners or work with the couple together to navigate sexual intimacy in a way that accommodates one partner's sexual dysfunction. And for those individuals considering pharmacological treatment, it was recommended that mental health professionals talk with clients about the possible implications of their decision to take medications—not just for themselves, but also for their partner and the relationship as a whole. Based upon participant narratives, it is apparent that psychologists also have a role to play in educating clients about the link between sexual dysfunction and anxiety—particularly the notion that comfort with oneself and one's partner will increase the likelihood that a more positive sexual interaction will occur. This does not by any means mean that full sexual functioning would return in instances of greater comfort, but sexual interactions may be less distressing.

In addition to providing psychoeducation, it was also recommended that psychotherapy services be used before medications are started to treat the presenting problem(s) without the added risk of adverse side effects of psychotropic drugs. Several participants mentioned wishing they had been encouraged to give psychotherapy a

chance before taking medications. Looking back they realized that their concerns were normal developmental problems (e.g., end of a relationship, coming out/sexual identity concerns, grief and loss), which could have resolved solely with the help of a therapist. Prescribing providers and mental health professionals alike should be more forceful in recommending a course of psychotherapy be attempted prior to implementing psychopharmacological treatment, even if clients are in substantial distress at the time of their initial assessment.

### **Implications for Counseling Psychologists**

While all mental health professionals have a role to play in the care of individuals with PSSD, it is this author's opinion that counseling psychologists are particularly skilled to provide care for this population.

Division 17 of the American Psychological Association (known as the Society of Counseling Psychology), defines counseling psychology as a discipline aimed at "facilitating personal and interpersonal functioning across the life span" by attending to emotional, social, and health-related concerns among others (Society of Counseling Psychology, 2013). In addition, counseling psychology "encompasses a broad-range of culturally-sensitive practices that help people improve their well-being, alleviate distress and maladjustment, resolve crises, and increase their ability to function better in their lives" (Society of Counseling Psychology, 2013). Given this framework, counseling psychology is a specialty area of psychology that is well-suited to intervening with issues of physical illness (Altmaier, 1991; Altmaier & Johnson, 1992; Mrdjenovich & Moore, 2004). In fact, Division 17 has a section dedicated solely to the promotion of health

psychology and support of psychologists who participate in education, prevention, and intervention efforts related to health and wellness.

The principles of practice that counseling psychology emphasizes sets it apart from other psychology disciplines and fields within healthcare, and makes it uniquely situated to address the types of concerns raised by this study's participants. Briefly, the discipline of counseling psychology emphasizes the following in its approach to professional practice and intervention: (1) viewing individuals from a developmental perspective with a greater tendency toward normality versus pathology; (2) emphasizing primary prevention efforts; (3) encouraging active collaboration between clients and treatment providers; (4) providing appropriate psychoeducation to clients in order to aid understanding; (5) approaching intervention in a way that develops client strengths and promotes coping effectively; (6) integrating family and social/environmental components into treatment planning and intervention; and (7) remaining cognizant of cultural differences/diversity and mindful of how that may impact therapeutic relationships and intervention (Altmaier, 1991; Altmaier, Johnson, & Paulsen, 1998; Mrdjenovich & Moore, 2004). Given these pillars that provide the foundation of counseling psychology, it is undeniable that counseling psychologists are uniquely situated to work in a way that differs greatly from other health care providers.

Physicians and other allied health professions approach patient care from a biomedical perspective, often emphasizing rapid and active interventions (e.g., medications) with the intention to relieve distress quickly. As counseling psychologists, we are more thorough in our assessment of the patient, the environmental factors of the patient that either hinder or promote positive outcomes, and inclusion of the patient as an

active collaborator in their treatment planning (Altmaier, 1991; Altmaier et al., 1998).

Although we most certainly want our patients to feel better, we will weigh treatment options and take precautions to ensure the treatment implemented is appropriately suited to their needs and then monitor progress and outcomes closely (Altmaier, 1991).

The treatment approach emphasized in counseling psychology allows counseling psychologists to relate to patients in a manner radically different than other healthcare providers. Participants in this investigation spoke to the need of multidisciplinary teamwork for coordinating care and the desire to have someone advocating on their behalf. Since we are not trained from a biomedical model, counseling psychologists can be assets on multidisciplinary teams where we have greater liberty to emphasize important environmental factors that should be considered in treatment planning as well as question treatment options and offer alternatives. Also, with patient advocacy as part of our professional identity, we are uniquely situated to speak up and ensure client concerns are heard and considered rather than dismissed (Altmaier, 1991).

In reflecting upon their experiences, a handful of participants noted the presenting concerns that led pharmacological intervention were issues that should not have been pathologized (e.g., grief, loss of a relationship), but rather were normal, developmental concerns that everyone experiences at some point. Had a counseling psychologist been involved in their care when they first presented to their primary care physician, their concerns would not have been pathologized, but instead conceptualized as a normal reaction to distressing circumstances and perhaps they would have been provided a variety of treatment options that included psychotherapy as a first possibility.

A developmental perspective continues to be important even after PSSD begins. As demonstrated by participants, reactions to and concerns about PSSD were definitely connected to the developmental stage of participants. Some, like Brian and Casey, were single young adults in the phase of life focused on establishing intimacy and a romantic partnership, which was impacted by their PSSD. Others, like E.B., were partnered and looking toward starting a family, which was impacted by PSSD. And others, like Susan, were older and had primarily achieved what she had wanted regarding partnership and parenting, which made it easier for her to put PSSD in perspective related to broader health changes that come with aging. When working with individuals with PSSD, counseling psychologists would be mindful of the developmental stage of clients and tailor assessment and intervention appropriately.

Several recommendations made by participants involved the family system/partner relationship. Because we work from a more contextual framework that integrates components of the social system into interventions, counseling psychologists play an important role in providing such services. As professionals we are well-suited to the task of providing psychoeducation to individuals or couples about sexuality, the role that sexuality plays in fostering a healthy romantic relationship, how the treatment of one partner may affect relationship dynamics, as well as other possible treatment interventions available to an individual. Working from a biopsychosocial framework, there are many different types of intervention that counseling psychologists could appropriately provide to assist clients in making treatment decisions or better manage the treatment they have chosen to undertake.

Given counseling psychologists also look for individuals' strengths during assessment and treatment planning, much could be done in supportive counseling to help individuals with PSSD uncover what is going well or what has potential, rather than focusing solely on what has been lost. For example, if someone has no sexual desire, but still can find enjoyment being intimate with partners, that is a place to start. Several participants noted that the loss of full sexual functioning was devastating, but they still find ways to foster closeness and intimacy with partners even if it does not quite look like what they had before. With a loss so drastic that accompanies PSSD, it can become easy for individuals to forget to look for ways of focusing on what is going well or ways they could shift interaction to promote more effective coping. Counseling psychologists can help them gain this perspective.

Additionally, counseling psychologists remain cognizant of the cultural influences in people's lives. Many beliefs about sexuality and normative sexual practices are culturally based and influence individuals' behavior. For example, in this dissertation gender and sexual orientation were both discussed in relation to their impact on sexual behavior, sexual beliefs, and adjustment to PSSD. Such cultural influences are very important things to consider when working with individuals with PSSD because they highlight the individual differences that must be considered when planning and implementing intervention. While not highlighted in the results section, some participants noted the importance of race and ethnic membership on attitudes toward sexuality and sexual performance, especially for men. Cultural factors are very important things to consider when conducting an assessment of the problem as well as treatment planning and implementation. Many healthcare professionals trained from a biomedical model

may miss this important component, but counseling psychologists play an important role in ensuring culturally competent and appropriate services are provided.

Finally, counseling psychologists are in a unique position to help train healthcare providers to improve patient care (Altmaier, 1991). This can be done through teaching effective communication strategies (e.g., empathic listening, more accessible explanations of conditions and treatment options) and better interpersonal sensitivity including expressions of warmth and concern. Such training can occur on multidisciplinary teams that counseling psychologists are already a part of, or they can be exported to formal medical training programs in medical schools and other healthcare settings. Thus, counseling psychologists can play an integral role in shifting the relationship between medical providers and clients from one where the provider is in the position of power to one of 'mutual participation' and collaboration (Altmaier, 1991; Altmaier & Johnson, 1992). Thus, rather than always intervening at a client level, counseling psychologists are well-suited to helping physicians alter the way they interact with and care for clients presenting with chronic problems.

Given the patient-centered framework from which counseling psychologists work, one might begin to think that if psychologists had prescription privileges, many of the hardships individual clients encounter with SSRIs could be avoided. These individuals could have had a "one stop shop" to discuss their presenting concern, perhaps cease any medications they were on, or start medications and track use and side effect profiles carefully. However, it is this author's opinion that prescription authority for psychologists would not ameliorate the problem or ensure the same standard of care for clients.



The debate over prescription privileges intensified in 1995 when the American Psychological Association took an official position of support to pursue prescribing authority for appropriately trained professional psychologists (Gutierrez & Silk, 1998). As reviewed by Gutierrez and Silk (1998) and Long (2005), supporters of prescription authority assert that allowing psychologists to prescribe would (1) be a logical extension of our role in assessing behavior and intervening in behavior change efforts, (2) allow true professional autonomy, (3) promote cost-effectiveness of services, (4) be safer than having medications prescribed by primary care physicians who do not know and do not follow their clients as closely as psychologists, and (5) meet demand in underserved segments of the population. While the states of Louisiana and New Mexico, as well as the U.S. Territory of Guam, have passed prescription authority to psychologists with proper training, the vast majority of U.S. states continue to limit prescription authority to those in the medical field. For professionals who do not support prescription privileges for psychologists, the main concern is the "powerful seductiveness" of medications in that it is "easier and faster to turn to a prescription pad than to those behavioral and psychotherapeutic techniques that have been shown to be effective and more lasting, but which require more time and effort" (DeNelsky, 1996; 207). In other words, opponents fear prescription authority would change the practice of psychology from predominantly psychotherapy to pharmacotherapy. Additionally, opponents believe psychologists cannot become and remain experts in both psychological and biological assessment and interventions, which would impact graduate- and post-graduate education and training as well as continuing education as professionals (DeNelsky, 1996; Kingsbury, 1992).

The hesitation of this author to support prescription privileges is not unusual. As discussed by Hayes, Walser, and Bach (2002), dating back to 1996, private practitioners expressed substantial disinterest in pursuing prescription authority, primarily due to practical reasons such as training demands. In a meta-analysis of 16 studies examining opinion data about prescription privileges, Walters (2001) found an insignificant difference in rates of support and opposition among psychologists. Results of the meta-analysis also found that more psychologists supported prescription privileges theoretically versus being willing and motivated to actually pursue such authority themselves should the opportunity arise.

In sum, the central tenets that form the professional identity of counseling psychology are all applicable when working with individuals like those highlighted in this dissertation. We have a role to play prior to pharmacological intervention in thoroughly assessing a client and their presenting concerns and providing comprehensive treatment options, during pharmacological treatment in helping them track the effects of medication and interacting with prescribing providers in a manner that advocates for the needs of the client, and after pharmacological intervention, if PSSD occurs, to try to formulate a treatment plan that helps them cope effectively with the condition in a way that promotes adjustment to the change in health status. As non-prescribers (and collaborators) we also need to remain cognizant of the APA Practice Guidelines Regarding Psychologists' Involvement in Pharmacological Issues (2011), which among others, remind us to (1) seek consultation when necessary before making medication recommendations, (2) remain sensitive to the sociocultural characteristics of our clients which may impact pharmacotherapy, (3) obtain an appropriate level of knowledge about

the medications used to treat the psychological disorders and populations served, (4) be aware of potential adverse effects of psychotropic medications used by our clients, (5) openly discuss medication attitudes and adherences with clients, and (6) remain aware of the potential effects of marketing on treatment decisions made by clients and prescribers.

### **Limitations**

While this dissertation focused on a topic that up to this point has been understudied, it is not without limitations. First and foremost, the sample size was small. The results of this dissertation were based upon nine individuals, and although a small sample size was the goal of this project so as to make in-depth analysis of phenomenological experience possible, the results have limited generalizability because the nine participants enrolled in the study may not be representative of the general PSSD population. However, given the sample was made up of both male and female, younger and older, partnered and single, as well as gay and straight individuals, the range of experiences shared by participants provided a complex, varied data set to work with.

A second limitation of this dissertation is that, for those who were partnered, only the individual living with PSSD was interviewed. Although they provided in-depth responses related to the impact of PSSD on their relationships and how they interact with partners, it would have been a richer data set had the partners of individuals with PSSD be interviewed as well. However, this endeavor would have come with its own limitations: it would have excluded from the sample individuals with PSSD who were single. Additionally, as uncovered by this study, not all partners knew their spouse/partner was struggling with sexual difficulties. It would have been impossible to respect the wishes of such participants to keep their PSSD secret while at the same time

collecting data from their partners regarding how such sexual difficulties have impacted them and the relationship.

A third limitation is related to the participant verification validity checking process. Although six participants initially expressed interest in reading the results of their data analysis and providing feedback to ensure accuracy of interpretation, only two participants actually ended up providing feedback about their analysis. While an opportunity was lost to verify over half of the analysis with participants themselves, it was encouraging to see on the two responses that were received that the participants noted the individual analyses completely captured their experiences and conveyed their perspectives accurately. This suggests the principal researcher was using the methodology appropriately. Because of the level of accuracy confirmed by the two participants who read their individual analyses, it is assumed that the other seven participants, had they participated in the participant verification validity check, would have viewed their analyses as valid representations of their experiences as well.

A fourth limitation is related to accepting participant self-report without corroborating medical evidence. There were no medical evaluations or assessments as part of this study. The exact status of their sexual dysfunction was not measured and diagnosed. The medications they took, the dates they took them, and the dosages they reported were all retrospective accounts. There may be error in their self-report. Importantly, the principal investigator did not set out to "prove" that their ongoing sexual dysfunction is a direct result of the SSRI medications they took historically given that was not the aim of this study. For the current study, PSSD was treated much like chronic pain—it is a reality for individuals who have to live with it, even if medical professionals

cannot/do not prove its source. What mattered for the current study was that participants made the connection between their previous SSRI use and their persistent sexual dysfunction. If PSSD was how they interpreted their symptoms, then it did not matter for this study that it be medically proven that SSRIs were the root cause of their ongoing difficulties. Their narratives would reflect the psychological impact of PSSD anyway since that was the lens through which they were viewing their experiences.

### **Future Directions for Research**

Given research about PSSD is in its infancy, there are many exciting possibility for future research, both quantitative and qualitative in scope. Three such ideas are provided below.

First, based upon the results of this dissertation, it would be very intriguing to gather data from the partners of individuals living with PSSD. Such a study would provide them the opportunity to give voice to their own experiences trying to live with PSSD and what their reactions are to the condition. Given everyone interprets the world through their own lens, the interpretations of this study's participants may not accurately reflect the actual attitudes and responses of their partners. Gathering interview data from partners would also help researchers more fully understand the impact of PSSD on relationship dynamics.

Second, it would also be a worthy endeavor to investigate the benefits and drawbacks of the online support forums that exist for individuals living with PSSD. While the forums provide a space for individuals to share their stories, trade ideas, and support one another, many individuals seem to use the space as a place to fixate on the negative emotions related to PSSD (e.g., anger, shame, sadness) without trying to move

to a better place. While not highlighted in the results, two participants noted that such forums provide a sense of support, but also tend to draw people into a "black hole of despair."

Third, given the incidence of PSSD is unknown, a large, wide-scale survey of individuals who have taken SSRIs could provide the data needed to begin forming estimates of the rate of PSSD in the general population. Once general incidence rates are determined, more research focused on the PSSD rates of specific medications and specific side effects can be carried out. While such research would be a large task, based upon participant reflections it would be critical to do in order to get the attention of the pharmaceutical and medical communities.

Fourth, an incidental finding of this study was the fact that emotional side effects, particularly emotional blunting, appear to persist beyond SSRI discontinuation as well. A qualitative study documenting emotional side effects was uncovered in a literature search (Price, Cole, & Goodwin, 2009). The potentially persistent nature of emotional side effects is beyond the scope of this dissertation and indeed warrants further research.

### **Conclusion**

This dissertation aimed to explore three research questions: 1) *How do individuals with persistent sexual side effects make sense of and meaning from their experience?* 2) *How have these individuals' sense of self or identity changed over the course of their sexual difficulties?*, and 3) *What role could a psychologist have had in helping the individual with their situation?* To provide an argument for the research undertaken in this dissertation, a literature review of SSRIs, their side effects, the emergence of PSSD, and the psychological impact of sexual dysfunction was provided. A qualitative

methodology, Interpretative Phenomenological Analysis, was used to design and implement research procedures. Analysis of interviews conducted with nine participants experiencing PSSD resulted in eight themes. The themes were: (1) difficult emotional experiences, (2) varied coping strategies, (3) negative impact on romantic relationships, (4) changed identity, (5) changed attitude toward sex, (6) problems with medical providers, (7) mixed feelings about SSRIs, and (8) desire for collaborative health care. Themes were described and illustrated with participant quotes in the results section of this dissertation. The discussion revisited the three broad research questions and explored possible answers in light of the results of this study. Additionally, implications for counseling psychologists in working with this population were discussed. Finally, limitations and recommendations for future research were provided.

The research on and general understanding of PSSD remains limited and not well understood. Despite its limitations, the current study provided information that had not yet been published in the research literature. The study aimed to capture, beyond case reports, the experiences of people living with post-SSRI sexual dysfunction as well as the impact that PSSD has on their lives. Overall, the findings of this study provide evidence that PSSD can impact individuals with a history of SSRI use and has substantial psychological and interpersonal ramifications for individuals, both intra- and interpersonally. In sum, based upon the results of this investigation there does seem to be a connection between more adaptive coping strategies and better overall outcomes. For example, the ability to think existentially/make meaning out of this experience, spending time and energy developing other parts of identity, and communicating openly with a partner about difficulties to try to find a solution together seems to lead to greater

acceptance of the indefinite nature of PSSD and reduces negative emotions such as shame, resentment, and guilt.

It is hoped that this investigation will give voice to individuals experiencing PSSD and lead to improvements in health care around this issue as well as raise awareness of the problem and inspire researchers to continue investigating this condition. As Brian said at the end of his interviews, "I really think the only way we're going to get the medical community to [believe] is if you publish enough papers. If you publish enough papers maybe they'll believe that this problem exists. I really wish a doctor could hear me saying this."



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