

**Understanding the Lived Experiences of People with Sexual Difficulties Resulting from
Using and Discontinuing Antidepressants**

Emily Rice

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Supervisor: Dr. Peggy J. Kleinplatz

Faculty of Education

University of Ottawa

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Abstract

Many studies have demonstrated that antidepressants can cause a variety of side effects, including sexual difficulties. These sexual difficulties can persist after discontinuation of antidepressants – a condition known as post-SSRI sexual dysfunction (PSSD). Researchers have found that prescribers are not informing their patients of the sexual side effects of antidepressants and PSSD. The purpose of this study was to explore the lived experiences of those who have experienced sexual difficulties as a result of using and withdrawing from antidepressants. Ten (10) participants were recruited through a patient advocacy group, the Canadian PSSD Society, to participate in individual semi-structured interviews. The results were analyzed using descriptive phenomenological analysis. Eight themes and corresponding subthemes emerged to describe participants' experiences with PSSD. The findings indicate that people with PSSD can undergo psychological, physical and sexual effects of withdrawal that cause suffering, hopelessness and alienation. In addition, the findings suggest that there was a lack of understanding, awareness, informed consent or acceptance among healthcare providers about PSSD, which (1) compounded the suffering, trauma, hopelessness and alienation that people with PSSD experience about their condition and (2) contributed to an overall lack of trust in physicians and/or medicine in general and therefore reliance on oneself to find relief from the symptoms of PSSD.

Keywords: selective serotonin reuptake inhibitors (SSRIs), serotonin-norepinephrine reuptake inhibitors (SNRIs), sexual dysfunction, SSRI-induced sexual dysfunction, iatrogenic sexual difficulties, post-SSRI sexual dysfunction (PSSD), SSRI deprescription, prescriber education, depression, phenomenology

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Understanding the Lived Experiences of People with Sexual Difficulties Resulting from Using and Discontinuing Antidepressants

Introduction

Many individuals who are experiencing symptoms of depression reach out to their primary healthcare professional(s) (e.g., family doctor, nurse practitioner, psychiatrist, psychologist or therapist, among others) for treatment options to relieve their symptoms. In the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (*DSM-5*), the symptoms of depression are listed as follows: depressed mood; significantly decreased interest or pleasure in all or almost all activities; significant weight loss or gain; increase or decrease in appetite; insomnia or hypersomnia; observable psychomotor agitation or retardation; feelings of worthlessness; excessive or inappropriate guilt; decreased ability to think, concentrate or make decisions; and thoughts of death, suicidal ideation, plan for suicide or suicidal attempt(s) (American Psychiatric Association [APA], 2013, pp. 160-161).

Antidepressants are pharmacological interventions considered to be a primary treatment for depression and depressive symptoms (Kennedy et al., 2016). It has been well documented that using antidepressants can cause sexual difficulties (e.g., decreased libido, erectile dysfunction, anorgasmia and genital numbness, among others; Bly et al., 2013; Clayton et al., 2016; Jacobsen et al., 2015; Khazaie et al., 2015; Kronstein et al., 2015; Serretti & Chiesa, 2009). However, the prevalence antidepressant-induced sexual dysfunction remains unclear (Bala et al., 2018). It is estimated that 25% to 85% of selective-serotonin reuptake inhibitor (SSRI) users experience treatment-induced sexual dysfunction (Jacobsen et al., 2015). Healy (2019) found that almost 100% of SSRI users experience genital sensory changes within 30 minutes of consumption. Another study reported that 5% to 15% of SSRI/serotonin

norepinephrine reuptake inhibitor (SNRI) users developed treatment-induced sexual dysfunction (Bahrnick, 2006). Researchers have found that when antidepressants are prescribed, people are rarely warned about the sexual side effects that antidepressants can cause (Bahrnick & Harris, 2009; Healy et al., 2019; Higgins et al., 2006).

Prescription practices have relied on the assumption that those who develop sexual difficulties as a result of using antidepressants will no longer experience sexual difficulties once they stop taking the antidepressant (Bahrnick, 2008). However, studies have found that individuals can continue to experience lingering sexual difficulties after they have stopped taking the antidepressant, a condition now referred to as post-SSRI sexual dysfunction (PSSD; Bahrnick, 2006; Bahrnick, 2008; Bala et al., 2018; Ben-Sheetrit et al., 2015; Csoka et al., 2008; Healy, 2019; Healy et al., 2018a; Healy et al., 2018b; Healy et al., 2019). There is emerging evidence that PSSD may persist for months (Csoka et al., 2008) or indefinitely (Bahrnick & Harris, 2009) following the cessation of the antidepressant. Studies have found that participants who identify as having PSSD report that they were not informed in advance about the sexual difficulties that could occur or persist after discontinuing the antidepressant (Healy et al., 2019; Stinson, 2013). The prevalence of PSSD remains unclear due to underreporting and lack of awareness about this condition (Bala et al., 2018; Healy, 2019).

In order to inform patients about the side effects of discontinuing antidepressants, prescribers also need to be aware of *deprescribing* practices. Deprescribing is the process of decreasing and/or stopping medications that are no longer needed or are causing harm (Farrell & Mangin, 2018; Farrell et al., 2019; Turner et al., 2018). It is also important for prescribers to tell their patients how long they should be taking the antidepressants as this informs the deprescribing process. Some researchers suggest that current deprescribing regimens contribute

to the severity of the withdrawal symptoms and that tapering antidepressants more slowly may be beneficial in reducing the withdrawal symptoms, including PSSD (Horowitz & Taylor, 2019). Horowitz and Taylor (2019) suggest that current deprescribing regimens need to be re-evaluated to reduce the harm to patients who are withdrawing from antidepressants. For the purposes of this study, the term “prescribers” can refer to physicians, nurse-practitioners and pharmacists. The 10 participants in this study spoke primarily about their relationships with physicians but occasionally also mentioned pharmacists and therapists.

Informed consent consists of healthcare professionals providing sufficient information about a treatment so that patients can make an informed decision about whether to accept or reject a particular treatment (Bahrnick & Harris, 2009). Informed consent is an essential aspect of creating trust in the physician-patient relationship and an essential part of ethical healthcare practice (Bahrnick & Harris, 2009). Therefore, it is necessary to understand why patients with iatrogenic sexual difficulties and PSSD are rarely informed of these effects in advance.

Healthy sexual functioning is a fundamental aspect of overall health (Stevenson, 2004). Many individuals who use antidepressants have not been informed about the possible sexual difficulties that result from using and discontinuing antidepressants. It is necessary to listen to these individuals so that they have the opportunity to share their stories. In this study, I intend to explicate the experiences of 10 individuals to readers who are unaware of antidepressant-induced sexual difficulties/PSSD and to future patients who might consider antidepressants as a treatment option.

In the Literature Review, I summarize previous studies related to sexual difficulties resulting from using and discontinuing antidepressants and the lack of informed consent about these difficulties when prescribed these medications. First, I describe sexual dysfunctions and the

etiology of sexual dysfunctions. Next, I provide a history of antidepressants and their rise in use. Then, I outline reports of antidepressant-induced sexual side effects. I also describe the history of PSSD. Then, I outline potential barriers that physicians face (1) when discussing sexual functioning with patients and (2) when prescribing and deprescribing medication. I also examine how these barriers may lead to physicians failing to disclose sexual side effects and withdrawal effects when prescribing and deprescribing antidepressants. I summarize two qualitative studies that explored individuals' experiences with PSSD. Finally, I provide the purpose statement and justification for this study along with the main research question.

In the Methods section I outline the methods used to conduct this study. This section includes a description of descriptive phenomenology and why this method of research was chosen. I outline the participant recruitment process and the interview prompts that were used to elicit participants' experiences. Finally, I outline the data analysis procedure and theme development.

In the Results section I summarize participants' characteristics and information about the antidepressants that participants used. I outline and describe the main themes and subthemes that emerged to describe participants' experiences. The descriptions are accompanied by direct quotes (i.e., rich text) from participants to illustrate their experiences.

In the Discussion section I discuss the results of this study along with contributions to the literature, clinical implications, limitations, strengths, directions for future research and the conclusion.

Literature Review

Sexual Dysfunction

In the *DSM-5*, sexual dysfunction is described as “a clinically significant disturbance in a person’s ability to respond sexually or to experience sexual pleasure” (APA, 2013, p. 423), including difficulties in experiencing sexual desire, sexual arousal and/or orgasm. In the *DSM-5*, the following sexual dysfunctions are identified: delayed ejaculation, erectile disorder (i.e., erectile dysfunction), female orgasmic disorder (i.e., female anorgasmia), female sexual interest/arousal disorder, genito-pelvic pain/penetration disorder, male hypoactive sexual desire disorder, premature (early) ejaculation, substance/medication-induced sexual dysfunction, other specified sexual dysfunction and unspecified sexual dysfunction (APA, 2013).

Causes of Sexual Dysfunction.

In the *DSM-5*, it is suggested that the following factors can impede sexual functioning: (1) partner factors (e.g., partner’s sexual problems); (2) relationship factors (e.g., discrepancies in desire for sexual activity); (3) individual vulnerability factors (e.g., poor body image), psychiatric comorbidity (e.g., depression) or stressors (e.g., job loss); (4) cultural or religious factors (e.g., attitudes towards sexuality); and (5) medical factors relevant to prognosis, course or treatment (e.g., antidepressants; APA, 2013, p. 423). It is important to note that a combination of these factors can induce sexual dysfunction. For the purposes of this study, I will be looking at medication-induced sexual dysfunction caused by antidepressants.

Antidepressants

Antidepressants are a group of medications that were developed with the hope of alleviating symptoms of depression as a result of the monoamine hypothesis of depression. This hypothesis suggests that depression is the result of decreased concentrations of serotonin,

norepinephrine and dopamine (Bunney & Davis, 1965; Delgado, 2000; Hirschfield, 2000) and that an increase in these neurotransmitters may reverse the symptoms of depression.

Antidepressants have been empirically validated as successful treatments for many with depression (Hillhouse & Porter, 2015).

Over the decades, drug manufacturers have created different chemical compositions of antidepressants. The different classes of antidepressants are as follows: Selective serotonin reuptake inhibitors (SSRIs); serotonin and norepinephrine reuptake inhibitors (SNRIs); tricyclic antidepressants (TCAs); monoamine oxidase inhibitors (MAOIs); noradrenergic and specific serotonergic antidepressants (NaSSAs); and norepinephrine and dopamine reuptake inhibitors (NDRIs) (Jain, 2004). Please see Appendix A for a complete list of the antidepressants that participants in this study used and their mechanisms of action. The term “antidepressant” will be used when discussing this medication in general. Specific classes of antidepressants will be referred to when applicable.

The Rise of Antidepressant Use

Initially, antidepressants were seen predominantly as a psychopharmacological treatment for depression; however, antidepressants are now prescribed for various psychological and other disorders such as generalized anxiety disorder, panic disorder, social phobia, obsessive-compulsive disorder, bulimia, premenstrual dysphoric disorder, posttraumatic stress disorder, peri- and post-menopausal hot flashes, chronic fatigue syndrome, chronic pain syndromes, premature ejaculation and paraphilias (Bahrnick, 2008). As of 2009, antidepressants were the most commonly prescribed medication in the United States (Bahrnick, 2009). As of 2006, approximately 1 in 8 Americans had used an SSRI or SNRI in the past 10 years (Bahrnick, 2008;

Bahrack & Harris, 2009; Bala et al., 2018; Raz, 2006). Furthermore, there was a 64% increase in the use of antidepressants in the United States between 1999 and 2014 (Winerman, 2017).

Efficacy of Antidepressants

Despite the efficacy of antidepressants for some individuals, recent studies have found that the monoamine hypothesis of depression does not sufficiently explain the root causes of depression (Hillhouse & Porter, 2015). The monoamine hypothesis of depression posits that depression is caused by low levels of serotonin, dopamine and/or norepinephrine (Delgado, 2000). Evidence comes from studies that have found that for those diagnosed with Major Depressive Disorder (MDD; depression), 34% to 64% of patients do not respond to antidepressant treatment and are classified as having “treatment-resistant depression” (Fava & Davidson, 1996; Fava, 2003). There is growing concern that antidepressants are over- or misprescribed, which may ultimately leave patients with more negative side effects than when they sought out treatment (Franki, 2019; McCartney, 2014). Other successful treatment options for depression, such as exercise and psychotherapy, have been identified and empirically validated for individuals who may not respond to medication or for those who do not wish to take medication (Casacalenda et al., 2002; Cuijpers et al., 2008, 2013a,b; Cooney et al., 2013; Huhn et al., 2014; Imel et al., 2008; Khan et al., 2012; Kirsch et al., 2008; Spielmans et al., 2011; Sugarman et al., 2014; Turner et al., 2008).

Side Effects of Antidepressants

Even though antidepressants are a favoured treatment option, there are many side effects to consider when taking these medications. Severe side effects include visual impairment, suicidal ideation, seizures, stroke and hearing loss; moderate symptoms include impotence, migraines, psychosis, vaginal bleeding and hallucinations; and mild symptoms include insomnia,

nausea, libido decrease, orgasm dysfunction and pelvic pain, among others (Physicians' Desk Reference, 2017). In the *Compendium of Pharmaceuticals and Specialities (CPS)*, the following symptoms are listed as occurring in at least 1% of patients who use SSRIs/SNRIs: dry mouth, dizziness, rash, excessive sweating, diarrhea, arthralgia, rhinitis, sexual dysfunction and incontinence, among others (Canadian Pharmacists Association, 2020).

Sexual Side Effects of Antidepressants

SSRIs and SNRIs have been associated with higher levels of sexual dysfunction when compared to TCAs and MAOIs (Balon, 2006; Clayton & Montejo, 2006). Some sexual side effects of SSRIs/SNRIs are outlined in both the *Physicians' Desk Reference* and the *CPS* as moderate, mild or rarely occurring. Other studies have found more detailed reports of the sexual side effects of SSRI/SNRI use such as: genital numbness, genital irritability, delayed ejaculation, delayed orgasm, muted orgasm, loss of libido, anorgasmia, loss of pleasurable sensation, difficulty maintaining an erection and problems with lubrication (Bahrack & Harris, 2009; Healy, 2019).

Studies have also found that SSRIs have a negative impact on reproductive health and fertility among men (Safarinejad, 2008; Tanrikut et al., 2010). Safarinejad (2008) compared 74 depressed men taking one of the following five SSRIs: fluoxetine, paroxetine, citalopram or sertraline for at least 6 months to a control group comprised of 44 men who were not taking SSRIs. The men taking SSRIs had significantly lower sperm motility, sperm count, sperm density, higher DNA fragmentation and poorer sperm size and shape (Safarinejad, 2008). Safarinejad (2008) also found that there was a positive relationship between the duration of time the men had been taking the SSRI and the abnormality of their sperm. Tanrikut and colleagues (2010) looked specifically at paroxetine's effects on sperm in a sample of 35 men. The

researchers found that there was significant damage to the sperm's DNA integrity after exposure to paroxetine for five weeks (Tanrikut et al., 2010). In some cases, the DNA fragmentation was enough for the man to be considered infertile (Tanrikut et al., 2010). In addition, Milosavljević and colleagues (2019) found that escitalopram and paroxetine might interfere in fallopian tube functioning in women, which has the potential to render them infertile.

Post-SSRI Sexual Dysfunction (PSSD)

In 2006, reports began to emerge about sexual dysfunctions lasting after discontinuation of SSRIs, a condition which has since been termed post-SSRI sexual dysfunction (PSSD; Bahrack, 2006). Since then, researchers have found that PSSD does not only arise from SSRIs but can also arise from discontinuing any serotonin reuptake inhibiting (SRI) medication (e.g., SNRIs, SRI tricyclic antidepressants; Healy et al., 2022). Reports have continued to arise about lingering sexual dysfunction following cessation of SSRIs (Bahrack, 2008; Bala et al., 2018; Ben-Sheetrit et al., 2015; Healy, 2019; Healy et al., 2019). The prevalence of PSSD is still unknown due to underreporting and a lack of awareness about this condition (Bala et al., 2018; Healy, 2019). PSSD symptoms are generally the same as those for antidepressant-induced sexual dysfunction and include, but are not limited to, genital anesthesia, weak or anhedonic orgasm, decreased sexual desire, erectile dysfunction, premature ejaculation, problems with vaginal lubrication and nipple insensitivity (Bala et al., 2018). It is estimated that PSSD can persist for decades (Healy et al., 2018a, 2018b). PSSD has been found to occur after a few doses or after years of exposure in all ages, ethnic groups and in men and women (Healy et al., 2018a).

Informed Consent

Researchers have found that when antidepressants are prescribed, people are rarely informed in advance about the sexual difficulties that can occur while taking the medication or

persist after stopping the medication (Bahrnick & Harris, 2009; Healy et al., 2019; Higgins et al., 2006; Stinson, 2013). Informed consent consists of healthcare professionals providing sufficient information about a treatment so that patients can make an informed decision about whether to accept or reject a particular treatment (Bahrnick & Harris, 2009). Informed consent is an essential aspect of creating trust in the physician-patient relationship and an essential part of ethical healthcare practice (Bahrnick & Harris, 2009). By failing to provide informed consent, the prescriber dismisses the patient's autonomy and values and may prescribe a treatment that causes more harm than good. In the next section, I will explore why patients with iatrogenic sexual difficulties and PSSD are rarely informed of these effects in advance.

Barriers to Prescriber-Patient Education about Sexual Functioning

Researchers have noted the importance of clinicians evaluating, understanding and communicating about sexual problems to patients (Higgins et al., 2006; Higgins et al., 2008; Quinn et al., 2011; Stevenson, 2004; Urry et al., 2019). Healthy sexual functioning is a fundamental aspect of overall health. Despite the fact that health professionals agree with this statement, studies have found that health professionals face barriers when it comes to talking to their patients about sexual health and functioning (Higgins et al., 2006; Higgins et al., 2008; Quinn et al., 2011; Stevenson, 2004; Urry et al., 2019).

Barriers to Information and Skills

First, many health professionals lack the information and awareness about iatrogenic sexual difficulties and PSSD. It has been well documented that when compared to independent studies and clinical testimonies, premarket studies (i.e., clinical testing of a drug before it is made available to the public) of treatment-emergent side effects of antidepressants have underestimated the prevalence of antidepressant-induced sexual difficulties (Bahrnick & Harris,

2009; Bly et al., 2013; Clayton et al., 2016; Jacobsen et al., 2015; Khazaie et al., 2015; Kronstein et al., 2015; Montejo et al., 2001; Serretti & Chiesa, 2009; Zajecka et al., 1997).

Landén and colleagues (2005) suggest that the discrepancy in incidence reporting has to do with the questioning methods researchers and clinicians use when evaluating side effects of a medication. More specifically, during clinical trials, the researchers usually ask about treatment-emergent side effects in an open-ended manner (Landén et al., 2005). For example, they may ask, “Have you felt different in any way since starting the new treatment/since the last visit?” (Landén et al., 2005, p. 100). The purpose of evaluating symptoms this way is to prevent the patient from responding in a biased manner (i.e., discussing symptoms that are neither there nor significant; Landén et al., 2005). Landén and colleagues (2005) have highlighted that sexual topics are generally seen as private and can be difficult or embarrassing for patients to discuss openly. If patients and healthcare providers are both uncomfortable talking about sexual functioning, then it is understandable that sexual difficulties go unreported and are, therefore, underestimated.

Landén and colleagues (2005) believe that patients would be more forthcoming about treatment-emergent sexual difficulties if they were questioned directly about any sexual side effects. To test this theory, the researchers conducted a study that evaluated sexual side effect reporting in response to direct questioning versus non-direct questioning for those using an SSRI (Landén et al., 2005). These researchers found that participants reported more sexual dysfunction in response to direct questioning (41%) when compared to non-direct questioning (6%) ($p < .001$; Landén et al., 2005). The researchers concluded that open-ended questioning may not be a sufficient method for evaluating treatment-emergent sexual side effects given the sensitivity surrounding sexual topics. Another study found that when evaluating treatment-emergent side

effects, nurses used direct focused questions but adopted a vague questioning style when sexual side effects were a possibility (Higgins et al., 2006). It is counterproductive to evaluate sexual side effects in a less direct manner when more direct questioning is normally used. Landén and colleagues (2005) recommend that future drug evaluation should include open-ended questioning to be followed by direct questioning about treatment-emergent side effects to ensure more accurate estimation of the incidence of sexual side effects.

Many studies have concluded that healthcare professionals do not discuss PSSD with their patients because they believe it is a rare occurrence (Higgins et al., 2006; Higgins et al., 2008; Urry et al., 2019). More specifically, studies have found that psychiatrists (Osvath et al., 2003), primary care physicians (Hu et al., 2004) and psychiatric nurses (Higgins et al., 2006) underestimate PSSD due to a lack of awareness. If there is a lack of awareness of PSSD among health care professionals, then their patients will not be informed about PSSD.

Health professionals lack the knowledge and skills about how to talk to their patients about sexual health in general. Many medical training programs in North America do not provide physicians with the necessary skills or knowledge for talking about sexual health problems with their patients (Stevenson, 2004). Studies have found that nurses, psychiatrists and psychologists do not discuss sexual health with their patients because they do not feel that they have sufficient education and guidance about how to talk with patients about sexual health and functioning (Higgins et al., 2006; Higgins et al., 2008; Quinn et al., 2011; Stevenson, 2004; Urry et al., 2019). More specifically, the nurses felt as though they did not have adequate role models when it came to talking about sexual topics with their patients (Higgins et al., 2008). This lack of education and guidance can perpetuate the notion among healthcare providers that it is not their responsibility to initiate conversations about sexual functioning with their patients (Higgins et

al., 2006; Quinn et al., 2011; Stevenson, 2004; Urry et al., 2019). In addition, physicians have stated that they do not feel comfortable talking about sex with their patients because it is too biopsychosocially complex (Stevenson, 2004). That is, physicians feel that sexual problems are too psychological to be addressed in a medical context (Stevenson, 2004). In summary, there is evidence that health professionals are not informed and trained adequately to engage in matters related to sexual health and functioning with their patients.

Barriers to Motivation

The following section will outline barriers to motivation that mental health professionals face when it comes to talking with their patients about sexual health and functioning. Along with the rest of North American society, mental health professionals are raised to view sex in a certain way. As children, parents and caregivers generally speak about sex conservatively and associate it with “negativity, taboo, privatization, sin, shame and embarrassment” (Higgins et al., 2008, p. 310). In school, sex is taught through clinical, anatomical, physiological and reproductive lenses (Higgins et al., 2008). Sex is also portrayed as negative in the education system because discussions about sex are centered around sexually transmitted infections and unplanned pregnancies. This negative attitude towards sex is solidified in practice for mental health professionals by virtue of a lack of role models who talk about sex openly and positively with their patients (Higgins et al., 2008). Higgins and colleagues (2008) refer to this phenomenon as “weaving the veil” that hides sexual topics. Mental health professionals assert that they do not talk to their patients about sex because these discussions are associated with vulnerability, embarrassment, taboo and difficulty (Higgins et al., 2006; Quinn et al., 2011; Urry et al., 2019). It is reasonable to see how holding these attitudes about sex could impinge upon motivation to talk with patients about sex.

Another motivational barrier that prevents health professionals from talking to their patients about sexual health is that sexual functioning is not seen as a priority when it comes to patients' overall health (Higgins et al., 2006; Quinn et al., 2011; Stevenson, 2004; Urry et al., 2019). More specifically, Higgins and colleagues (2006) found that nurses often worked from "a hierarchy of prioritization" where "sexual side effects were always at the bottom" of the hierarchy (p. 439). Nurses reported that this prioritization resulted from viewing their patients as "non sexual" beings (Higgins et al., 2006, p. 439). It is likely that this view of patients and sex also stems from the aforementioned sociocultural attitudes and decreases motivation and confidence to talk about sexual side effects with patients.

One other obstacle that health professionals face when it comes to talking to patients about sexual side effects is that discussing such matters is not seen as pragmatic (Higgins et al., 2006; Quinn et al., 2011; Stevenson, 2004; Urry et al., 2019). Some health professionals say that sexual problems take too much time to explain and that it is difficult to find the right time to bring up sexual topics (Stevenson, 2004). Some say that there are more important things to talk about than sex, (e.g., drug or alcohol abuse, hygiene and money management) especially in public systems (Urry et al., 2019). In addition, some assert that it is not appropriate to start a conversation about sex in certain contexts, such as during cognitive or crisis assessments (Urry et al., 2019). Finally, Higgins and colleagues (2006) found that many of the nurses in their study did not disclose sexual side effects of medications to their patients because they were afraid that this would lead to non-compliance with the medication, which would not be pragmatic. Support for this expectation came from the notion that the nurses themselves would not be willing to take the medication if it meant that they would experience sexual difficulties (Higgins et al., 2006). In order to justify withholding information about sexual side effects, the nurses indicated that they

were acting on the principle of beneficence and believed that not disclosing these side effects was acting in the best interests of the mental health of their patients (Higgins et al., 2006). They believed that their actions were ethical in that they had therapeutic intent (Higgins et al., 2006). If health professionals believe that talking about sexual side effects with their patients is inefficient or could lead to medication non-compliance, then health professionals are less motivated to disclose these side effects with their patients.

Overall, the literature supports the notion that health professionals lack the knowledge, skills and motivation to discuss sexual topics, including iatrogenic sexual difficulties and PSSD, with their patients. It has been suggested that health professionals who are failing to disclose sexual side effects of medications may be engaging in a form of “covert coercion” to encourage patients to comply with a treatment plan (Bahrack & Harris, 2009; Higgins et al., 2006, p. 443). These health professionals are not obtaining informed consent from their patients for the prescribed treatment (Bahrack & Harris, 2009; Higgins et al., 2006).

Furthermore, many studies have found that patients were unsatisfied with the information they received from their prescribers about the sexual side effects of their medications (Happell et al., 2004; Healy et al., 2019; Higgins et al., 2006). Not only does this lack of information lead to lack of trust towards physicians, but it can also result in treatment failure or noncompliance (Stevenson, 2004). Some health professionals, including psychologists and sexologists, are pushing for reform in training about sexuality for health professionals (Higgins et al., 2006; Quinn et al., 2011; Stevenson, 2004; Urry et al., 2019). Some health professionals have acknowledged that there was a gap in their knowledge and that they could better address sexual health in their practice (Quinn et al., 2011; Urry et al., 2019). One additional barrier facing health

professionals face when talking to their patients specifically about PSSD is the lack of knowledge and training about deprescribing medications.

Deprescribing

The idea of deprescribing medication as a means to minimize polypharmacy and improve quality of life is growing in importance (Farrell et al., 2018). Deprescribing involves stopping or decreasing the dose of medications that are no longer useful, needed or causing harm (Farrell & Mangin, 2018; Farrell et al., 2019; Turner et al., 2018). Part of the process of deprescribing can include recommending nonpharmacological interventions such as exercise, dietary changes and psychotherapy, among others (Farrell et al., 2019). The ultimate goal of deprescribing is to improve patient outcomes (Farrell & Mangin, 2018; Farrell et al., 2019; Turner et al., 2018). It is believed that the development of a safe deprescribing regimen for SSRIs could help reduce the side effects that accompany SSRI use and withdrawal, including sexual side effects (Canadian Pharmacists Association, 2020; Horowitz & Taylor, 2019; Taylor et al., 2013).

Deprescribing SSRIs

It has been well-established that abrupt discontinuation of SSRIs causes unpleasant physiological symptoms (Fava et al., 2015; Renoir, 2013; van Geffen et al., 2005; Wilson & Lader, 2015). This phenomenon has since been termed SSRI withdrawal syndrome. Symptoms of this syndrome include numbness, irritability, insomnia, headache, dizziness, confusion and nausea, among others (Horowitz & Taylor, 2019). Since the discovery of this syndrome, researchers have been investigating whether certain deprescribing practices will help reduce the symptoms of SSRI withdrawal (Fava et al., 2015; Renoir, 2013; van Geffen et al., 2005; Wilson & Lader, 2015).

The National Institute for Care and Excellence (NICE), the British Association for Psychopharmacology, the Monthly Index of Medical Specialties and UpToDate all recommend tapering SSRIs with linear reductions for periods between two to four weeks to help reduce withdrawal symptoms (Horowitz & Taylor, 2019). However, randomized studies have shown that when compared to those who stopped taking SSRIs immediately, those who tapered for two weeks demonstrated no or minimal decreases in severity of withdrawal symptoms (Baldwin et al., 2006; Montgomery et al., 2004; Tint et al., 2008). Therefore, longer tapering guidelines may help minimize withdrawal symptoms. This is based on an understanding that the biological systems that are affected by SSRIs need significantly more time to adapt when the SSRIs are withdrawn to help reduce the severity of symptoms (Cleare et al., 2015; Haddad & Anderson, 2007; Phelps, 2011). It is recommended that SSRIs are reduced at smaller dosages over extended periods of time (i.e., months not weeks) to give the biological systems time to adapt (Horowitz & Taylor, 2019). Furthermore, given that every person is different and is on different types and doses of SSRIs, it is recommended that the tapering regimen be personalized and adjusted as necessary for each person (Horowitz & Taylor, 2019). It is important to note that the aforementioned studies that have evaluated symptoms of SSRI withdrawal syndrome have not focused on sexual side effects of SSRI withdrawal. However, one review found that dose reduction of SSRIs may help reduce sexual side effects while on the medication, which is also listed in the *CPS* drug monograph for SSRIs (Canadian Pharmacists Association, 2020; Taylor et al., 2013).

Given that the sexual side effects of SSRIs also result from interactions between SSRIs and biological systems, it is possible that symptoms of PSSD could also be reduced by tapering SSRIs or antidepressants in general more slowly and for longer periods of time. It is imperative

that prescribers understand and discuss safe deprescribing practices with patients who are using antidepressants to help prevent PSSD and SSRI withdrawal syndrome. In summary, guidelines for antidepressant deprescription should include recommendations for deprescribing that ameliorate SSRI withdrawal syndrome and possible PSSD.

Barriers to Deprescribing

Just as there are obstacles to talking about sexual functioning with patients, there are obstacles to discussing deprescribing and effects of withdrawal with patients. Clinicians and patients have observed the following barriers to deprescribing: “Prescriber self-efficacy, difficulty communicating the reasons for deprescribing to patients, patient awareness regarding the need to deprescribe” (Anderson et al., 2014; Reeve et al., 2013; Turner et al., 2016; Turner et al., 2018, p. 688) and the expectation that patients will receive a prescription from a physician as opposed to a recommendation to deprescribe (Raman-Wilms et al., 2019). In addition, there are financial incentives and business motives from the pharmaceutical industry which influence the development of prescribing policies and practices and thereby also impede deprescribing practices (Conklin et al., 2019). Overall, these incentives have promoted a culture of prescribing without deprescribing in Western society. It is suggested that improving education surrounding prescribing and deprescribing could help mitigate these barriers (Raman-Wilms et al., 2019).

Raman-Wilms and colleagues (2019) discovered a lack of education surrounding prescribing following discussion groups with pharmacists, physicians, health professional educators and medical students. These healthcare professionals agreed that prescribing was taught as a technical skill, which involves memorizing procedures and drugs that should and should not be prescribed, as opposed to a clinical skill, which involves critical and holistic thinking and shared decision-making about what is best for the patient (Raman-Wilms, 2019).

One participant recalled that side effects and drug interaction are the only things to consider when prescribing medications. In addition, participants reported that they are not often taught about how to communicate the duration of a prescription. Participants also described the importance of language when it comes to prescribing medication. They found that the word “need” is used when it comes to prescribing medication (i.e., “you need this medication”). Participants proposed that a more appropriate way to communicate with patients is to explain potential benefits and risks of the medication. Using the word “need” perpetuates the idea that medication is necessary and that there are no other treatment options. Moreover, participants reported that nonpharmacological treatment options are often not addressed in their education, which may also explain the belief that medications are necessary treatment options. Finally, participants reported that prescribing skills are not formally assessed in the curricula for health professionals in Canada. Participants explained that this lack of assessment perpetuates the idea that learning proper prescribing/deprescribing skills is not important and casts doubts onto the competency of prescribers and the information patients are receiving when deciding on treatment options. The lack of education surrounding deprescribing means that prescribers may not have the necessary information to provide to their patients so they can make informed decisions about treatment. Next, I will examine two studies that have examined the lived experiences of people with PSSD.

Patient Experiences

The following two qualitative studies examined the experiences of people with PSSD. Stinson (2013) looked at how individuals with PSSD make meaning from their experience, how PSSD has changed their identities and how therapists could help them. Following the analysis of interviews with nine individuals experiencing PSSD, Stinson (2013) found the following eight

themes: Participants experienced “difficult emotions, varied coping strategies, negative impacts on romantic relationships, changed identity, changed attitude towards sex, problems with medical providers, mixed feelings about SSRIs and a desire for collaborative healthcare” (p. 75).

More recently, Healy and colleagues (2019) specifically examined patients’ experiences of interacting with healthcare professionals about PSSD. The researchers interviewed 62 participants with PSSD and found that participants perceived a lack of awareness and knowledge about PSSD among their healthcare providers. In addition, participants felt that they were not being listened to by their healthcare providers and received insensitive responses and suggestions to return to medication from their healthcare providers (Healy et al., 2019). Many healthcare professionals had negative responses when participants brought in published medical literature about PSSD (Healy et al., 2019). These invalidating and unhelpful responses towards PSSD has left patients feeling angry, insulted, frustrated and helpless. Many said that they no longer mention PSSD to their healthcare providers (Healy et al., 2019).

Summary

It is clear that the lack of information, skills and motivation healthcare professionals have about discussing sexual side effects of antidepressants, PSSD and deprescribing with patients is having negative effects on patient outcomes, their sense of identity, their attitudes towards sex and their relationships with healthcare providers. Overall, the problem of prescriber willingness and ability to discuss naturally or otherwise occurring sexual problems and deprescribing practices with their patients cannot simply be solved by knowing that these problems exist. There needs to be a paradigm shift in the way society views sexuality and deprescribing in order to make a difference. In order for this paradigm shift to occur, more research needs to be conducted to shed light on the experiences of those suffering from PSSD (Stinson, 2013).

Current Study

Purpose Statement

There is still much research to be conducted to explain the experiences of antidepressant-induced sexual dysfunction and PSSD in order for them to become recognized disorders that are widely known and discussed. Furthermore, it has been recommended that future studies focus on understanding patient experiences when interacting with their prescribers to help break down barriers to discussing sexual functioning and deprescribing (Healy et al., 2019; Stinson, 2013; Thompson et al., 2019).

Therefore, the purpose of this phenomenological study is to explore the lived experiences of those with sexual difficulties resulting from using and discontinuing antidepressants. More specifically, this study explores the prescriber-patient interaction when an antidepressant is prescribed, what patients are told about how long they will be on the antidepressant and plans for discontinuation, the experience of being on an antidepressant, the experience of stopping an antidepressant and the experience of PSSD.

Research Question

The central question investigated in this study is as follows: What is the lived experience of those who have undergone sexual difficulties as a result of using and discontinuing antidepressants?

Methods

Research Design

Descriptive Phenomenology

Descriptive phenomenology was used as the methodological framework for this study (Husserl, 1970; Lavery, 2003; Lopez & Willis, 2004). At its core, phenomenology is the study of lived experience (Polkinghorne, 1989). When employing phenomenology as a research method, the researcher seeks to understand participant experiences with a particular phenomenon. In this case, the phenomenon is having an antidepressant prescribed, being on an antidepressant, coming off of an antidepressant, PSSD and experiences with healthcare professionals throughout this process. Phenomenological studies traditionally conduct in-depth interviews to collect participants' subjective, lived experience with the phenomenon (Lopez & Willis, 2004). The narratives are then transcribed, reviewed and analyzed by the researcher in attempt to understand participants' experiences (Lopez & Willis, 2004).

Proponents of descriptive phenomenology believe that there are common elements among all individuals experiencing a particular phenomenon. These elements are also known as universal essences or eidetic structures, which are generally presented as themes (Lopez & Willis, 2004; Natanson, 1973). Therefore, the purpose of descriptive phenomenological studies is to attempt to uncover and describe the common structures or essences of participants' experiences with a particular phenomenon (Polkinghorne, 1983). This consists of the researcher reviewing and analyzing participants' narratives many times in an iterative process (Lavery, 2003; Lopez & Willis, 2004). Direct quotes from the transcripts are then presented as support for the emerging themes. (The process of uncovering emerging themes for this study will be outlined in more detail in the theme development section).

Descriptive phenomenologists believe that it is crucial to try to achieve transcendental subjectivity or remain as unbiased as possible throughout the research process (Husserl, 1970; Lavery, 2003). The purpose of this is to allow the essence or structure of the participants' experience to emerge with minimal influence from the researcher (Lavery, 2003; Lopez & Willis, 2004; Natanson, 1973). In an attempt to achieve transcendental subjectivity, the researcher constantly and consciously assesses and sheds preconceptions and personal biases about the phenomenon throughout theme development (Lavery, 2003; Lopez & Willis, 2004). This process is referred to as bracketing or epoche (Natanson, 1973). To check and reduce biases in this study, the researcher uncovered the emerging themes collaboratively with other experts in this field as outlined by VanKaam (1966). Finally, in an attempt to achieve confirmability of the results (Lincoln & Guba, 1985), the emerging themes were reviewed by other experts who were blind to the theme development process. (The processes of collaborative bracketing and blind reviewing will be outlined in more detail in the theme development section).

Little is known or understood about people who develop PSSD. It is essential to gain a better understanding of what these individuals experience to create more awareness of this condition. Therefore, descriptive phenomenology is an appropriate methodological approach for this study because it offers an open and exploratory approach to understanding individuals' experiences. Descriptive phenomenology has also been shown to be useful in understanding patient experiences in health sciences and psychology (Beck, 1992; Cheung & Hocking, 2004; Hilton & Henderson, 2003; Kanaskie & Loeb, 2014; Lopez & Willis, 2004; Midtgaard et al., 2007; Schumacher et al., 2012; Sundler et al., 2019). For example, phenomenology has been used to uncover peoples' experiences with sexual difficulties, optimal sexual experiences, other health conditions and treatment options (Kleinplatz et al., 2013; Marriott & Thompson, 2008).

Participants

Following approval from the thesis committee and the Research Ethics Board of the University of Ottawa, a sample of 10 key informants experiencing post-antidepressant sexual dysfunction were recruited to participate in this study. The Canadian PSSD Society (formerly known as PSSD Canada), a patient-advocacy group, contacted the Optimal Sexual Experiences (OSE) Research Team because they wanted experiences with PSSD to be studied empirically. The Canadian PSSD Society agreed to advertise this study through their website for participant recruitment. The researcher emailed the recruitment statement (see Appendix A) to the Canadian PSSD Society and it was then posted to their website. In order to participate in this study, participants had to meet the following inclusion criteria: Participants needed to be (1) 18 years of age or older, (2) have experienced or be experiencing sexual side effects following the use and/or discontinuation of an antidepressant, (3) willing to have their interview audio-recorded for data analysis purposes and (4) able to describe their experiences sufficiently in English. A total of 10 volunteers were recruited through The Canadian PSSD Society patient-advocacy group to participate in this study. This sample size is consistent with recommendations from the literature. Polkinghorne (1989) recommends 5 to 25 participants and Dukes (1984) recommends 3 to 10 participants for phenomenological studies. A smaller sample size is recommended for phenomenological studies because of the detailed and time-intensive analysis required to describe the experiences of the participants (Polkinghorne, 1989).

Materials and Measures

This study required a computer or mobile device and an Internet connection to conduct the interviews. With informed consent, an audio-recording device was used to record the interviews to ensure accurate transcription and theme development. Finally, the participant

characteristics (see Appendix B) and semi-structured interview prompts (see Appendix C) were used during the interview to collect the necessary information from participants.

Participant Characteristics

The primary purpose of gathering the participants' characteristics was to gather background information from participants to get a better picture of the participant sample as a whole. Participants were asked to provide their age, sex/gender, race/ethnicity, education level, sexual orientation, relationship status and geographic location. Transcripts were de-identified to maintain confidentiality.

Interview Prompts

The semi-structured, in-depth interview was chosen as the method for collecting data because these interviews are considered to be an optimal way to understand individuals' lived experiences, which is the purpose of phenomenological research (Laverty, 2003; Lopez & Willis, 2004; McCracken, 1988; Polkinghorne, 1983). The semi-structured interview protocol consisted of open-ended questions created by the researcher (e.g., What was your experience of having an antidepressant prescribed to you?). This style of interviewing is in line with descriptive phenomenology because asking open-ended questions allows the researcher to remain open to and reflective of participants' experiences (Laverty, 2003; Lopez & Willis, 2004; Sundler et al., 2019). This style of questioning also reduces the researcher's bias in the interview process and allows participants to share their experiences more fully (Sundler et al., 2019). The questions were designed to invite participants to talk openly about their experiences with having an antidepressant prescribed to them, what they were told about how long they would be on the antidepressant and plans for discontinuation, their experiences while using the antidepressant, how they stopped using the drugs, sexual effects and their experiences with healthcare

professionals throughout this process. The researcher used additional prompts as needed to help participants clarify or elaborate on their experiences or to articulate their experiences and reflections more deeply.

Procedure

The following protocol was approved by the Research Ethics Board at the University of Ottawa in February, 2021. Semi-structured interviews were conducted by the researcher, Emily Rice B.Sc., between March and June, 2021. At the time of the study, the researcher was a female graduate student with previous training in descriptive phenomenological research methodology through a qualitative research class and as part of the OSE Research Team. The interviews were conducted using a version of Zoom that is compliant with the Personal Health Information Protection Act (PHIPA) and were audio-recorded with informed consent. All participants chose their own pseudonym to protect confidentiality. Participants were given the informed consent form (see Appendix D) to review before the interview. At the beginning of each interview, the researcher reviewed the informed consent form verbally with the participant. Each participant was given the opportunity to ask questions about the study and the informed consent form before proceeding with the interview. After receiving informed consent from each participant to participate in and audio-record the interviews, the interviewer proceeded with asking about participant characteristics and then interview prompts. Interviews ranged between 42 min and 125 min in duration ($\bar{x} = 74$ min).

Theme Development

Each interview was transcribed verbatim by the researcher. The transcripts included verbal and non-verbal behaviour and emotion (e.g., pauses, laughter, crying). All identifying information except for the sex/gender of participants was removed from the transcripts. Eight

team members from the OSE Research Team of the University of Ottawa participated in uncovering and developing the themes. Members of the OSE Research Team are all licensed mental health professionals or graduate students under their supervision with a particular interest in sexuality research and/or the treatment of sexual difficulties. These team members also have previous experience with descriptive phenomenology.

This collaborative form of research is one of the ways to establish transcendental subjectivity in descriptive phenomenological research (Lavery, 2003). This study specifically utilized the research process outlined by VanKaam (1966) where the researcher and the other experts (1) collaboratively review each other's themes of the transcripts, (2) discuss emerging themes until consensus is reached, (3) write out the description or an initial list of themes that emerged, (4) apply the themes to other participants and (5) collaboratively revise again until consensus is reached about the final list of themes that fully, accurately and faithfully capture the participants' experiences. A total of eight members from the research team (including the researcher and the thesis supervisor) took part in developing the themes. Six members (including the researcher and the thesis supervisor) uncovered and developed the themes. In an attempt to establish confirmability, the remaining two members were blind to developing the themes and revised and refined the themes at the final stage of development.

Initially, the researcher read and re-read all of the transcripts several times to get a general feel of the narratives. The researcher then distributed the de-identified transcripts to the other five team members. Next, the researcher along with the other five team members independently read the first transcript several times to identify emerging themes from each unit in the transcript. The six team members then met to compare their prospective themes from each unit. The team members asked each other questions and discussed and returned to the data itself

until a consensus was reached for each unit. The team members repeated this process for the first six transcripts. This first stage of theme development was completed over the course of 12 meetings (24 hours).

During the next stage, the team members independently began to identify which of the prospective themes appeared together from the first six transcripts. The members then read transcripts seven and eight to determine whether the emerging themes captured these participants' experiences as well. Over the course of the next eight meetings (16 hours), the themes were refined collaboratively until consensus was reached and an initial list of emerging themes was developed.

When necessary, the team members also pointed out when particular comments were thought to be stemming from a place of bias. When this happened, the team members self-reflected and talked with one another. The discussion continued until consensus was reached. If the comment was considered to come from a place of bias, it was re-evaluated in this iterative process by looking, again, at the transcripts. This iterative process served to reduce bias and allowed the themes of participants' experiences to emerge.

In the final stage of theme development, the remaining two team members who had remained blind to theme development thus far were given the last two de-identified transcripts and the initial list of emerging themes. These two team members read and re-read transcripts 9 and 10 to evaluate whether the initial, emerging themes captured fully participants' experiences. The purpose of this final review process was to (1) attempt to establish confirmability (Lincoln & Guba, 1985) (2) identify any other biases or blind spots during theme development and (3) help the other team members revise and refine their understanding of the themes and bring participants' experiences into clearer focus. These two team members then brought their

comments and questions about the themes to the other six team members who had helped to refine the descriptions of the experiences that were common and unique among participants. Over the next three meetings (4.5 hours), these comments and questions about the themes were discussed among all eight team members until consensus was reached and the final list of themes emerged.

The team members had a total of 23 collaborative meetings (44.5 hours). The entire process from reading the transcripts for the first time to the development of the final list of emerging themes was collaborative and iterative. The collaborative component of developing the themes allowed the team members to share and question each other's understanding of participants' experiences to minimize biases. The iterative development moved continuously back and forth from viewing each part of participants' experiences in relation to the whole and the whole experience in relation to each part. For example, while developing themes, the team members looked for connections among the prospective themes to see which ones appeared together. Then while evaluating and refining the themes, the team members referred back to the themes and direct transcript quotations to ensure that the themes were qualitatively different from each other. This collaborative and iterative process was rigorous to ensure that the team members had captured participants' experiences fully, accurately and faithfully.

This collaborative theme development process has been conducted in previous studies by the OSE Research Team (Kleinplatz & Ménard, 2007; Kleinplatz, Ménard, Paradis et al., 2009; Kleinplatz, Ménard, Paquet et al., 2009; Kleinplatz et al., 2013; Ménard et al., 2015; etc.). The collaborative theme development process in all of these previous studies required considerable discussion and the constant iterative process of returning to the data, discussion and further refinement until consensus was achieved. This study in which the same process was used was

distinctive as compared to these previous studies from the same research team. Much to our surprise, the themes emerged so readily and conspicuously that we arrived at consensus from the outset without the need for prolonged discussion. The themes that emerged in the data from this study were unusually transparent and stark. Each of the research team members remarked that compared to their previous experiences in conducting precisely this type of data analysis, their experiences in studying this data were eerily similar in that sense, unique.

Results

Participants

A total of 10 participants were recruited internationally from Europe, Asia and North America through the Canadian PSSD Society patient-advocacy group website. Participant characteristics are presented in aggregate form. Participant's life stories, in particular in relation to their use of antidepressants and PSSD experiences, made them readily identifiable even while using pseudonyms. As such, in consultation with the research team and the ethics application, the determination was made to err on the side of caution and to protect the identity of the participants by using their words without the pseudonyms. This deliberately makes it harder for the reader to know whose voices are heard while reading the results. The reader should be informed however, that representative quotes from each participant are sprinkled in more or less equal proportions throughout this thesis.

The final sample included five women and five men ranging in age from 24 to 75 years of age ($\bar{x} = 38$). Nine participants identified as White and one identified as South Asian. The participants resided in North America ($n = 6$), Europe ($n = 2$) and Asia ($n = 2$). Participants had completed high school ($n = 1$), part of a bachelor's degree ($n = 1$), a bachelor's degree ($n = 5$) or a postgraduate degree ($n = 3$). At the time of the interview participants worked in retail ($n = 2$), business or finance ($n = 2$), education ($n = 1$), law ($n = 1$) or cargo transportation ($n = 1$) while others were unemployed ($n = 2$) or retired ($n = 1$). Participants self-identified as straight ($n = 7$) and lesbian and/or bisexual ($n = 3$). At the time of the interview, six of the participants were single and four of the participants were in relationships. For those in relationships, the average length of their current relationship was 4.5 years. Of the participants who were single, the

average length of their previous relationship was 2.4 years. One person reported never having been in a relationship.

Prior to having had an antidepressant prescribed, the participants were seeking help for various concerns including depression, anxiety, social anxiety, obsessive compulsive disorder (OCD), eating disorders, thoughts of suicide, life transition stress and relationship stress. Some physicians recommended antidepressants while some participants asked their physicians for antidepressants. The antidepressants were prescribed to participants by their general practitioners or their psychiatrists. None of the participants reported experiencing sexual difficulties prior to using antidepressant. The antidepressants that were prescribed were as follows: Fluoxetine (SSRI), sertraline (SSRI), bupropion (NDRI), paroxetine (SSRI), venlafaxine (SNRI), escitalopram (SSRI), mirtazapine (NaSSA), clomipramine (TCA), imipramine (TCA) and citalopram (SSRI). Participants reported that anywhere from one to four different antidepressants were prescribed over the course of treatment. Participants had used antidepressants ranging in duration from 3 days to 5 years or more. All of the participants decided to stop using antidepressants because of the side effects they had experienced. At the time of the interviews, participants had been experiencing PSSD anywhere from 5 months to 25 years ($\bar{x} = 7.8$ years).

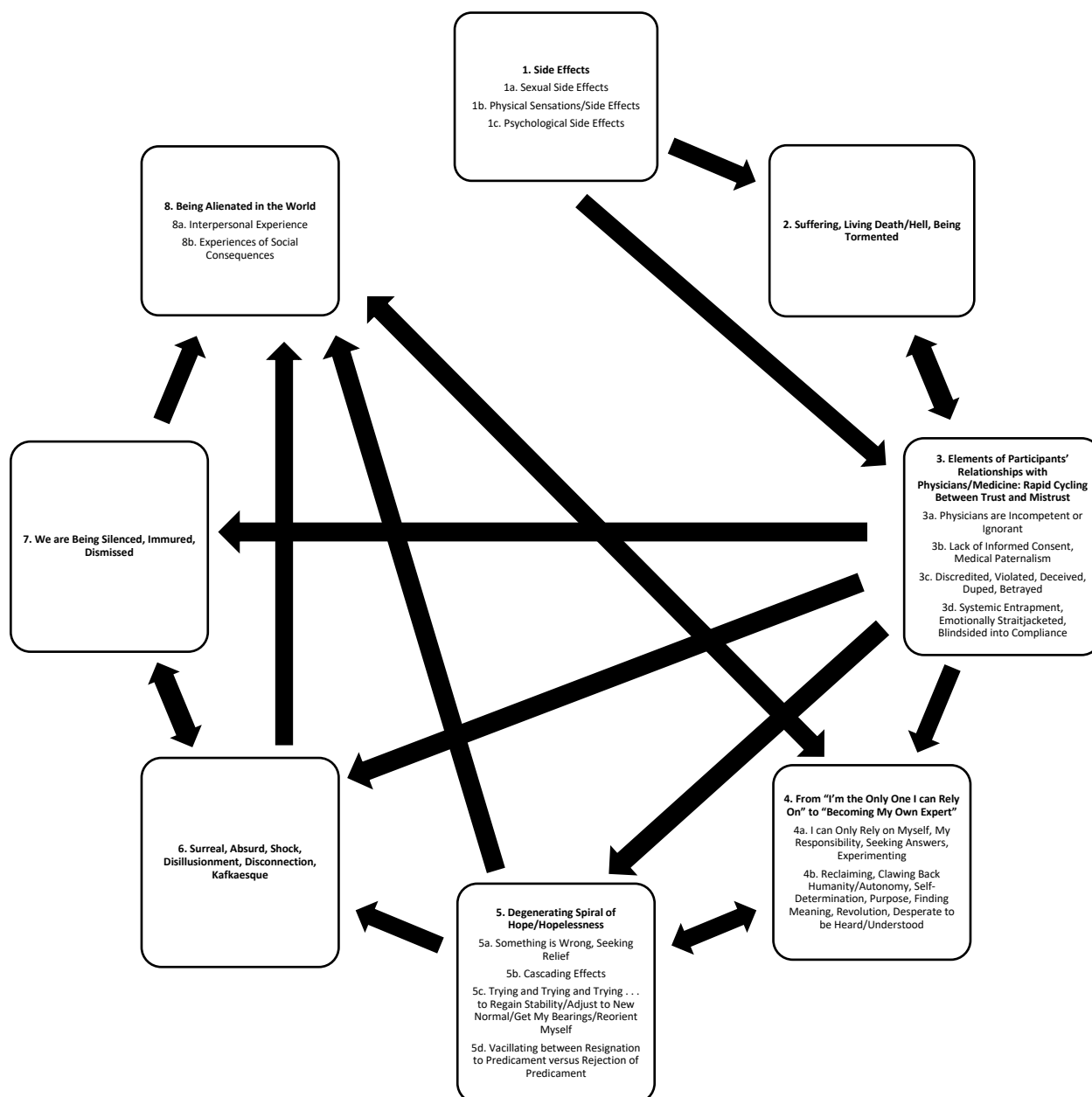
Themes and Subthemes: Introductory Summary

Descriptive phenomenology was used to uncover and develop the themes and subthemes that described participants' experiences with the following: having an antidepressant prescribed, using and discontinuing antidepressants, PSSD and healthcare professionals throughout this process. In descriptive phenomenological research, the names of the themes typically consist of more than one word or descriptor to fully capture all of the elements of each theme (Mahrer,

2004; Mahrer & Boulet, 1999). In this study, eight major themes emerged and are outlined in the figure below.

Figure 1

Themes and Subthemes



Note: Arrows indicate the impact of one theme on another.

Presentation of results includes describing each theme and subtheme and using direct quotations from the transcripts to illustrate the themes and subthemes. Presentation of the themes and subthemes along with rich text from the transcripts is provided below. Square brackets within the quotes indicate that words were removed for length or to maintain anonymity.

1. Side Effects

All of the participants experienced side effects as a result of using antidepressants and/or effects after withdrawing from antidepressants. Three different subthemes of side effects emerged: sexual, physical and psychological.

1a. Sexual Side Effects. Participants reported the following sexual side effects from using and/or discontinuing antidepressants: genital shrinkage/changes, semen changes, erectile dysfunction, anhedonic or pleasureless orgasm, loss of nocturnal penile tumescence, genital numbness and menstrual changes. Participants also described loss of sexual desire, arousal, sexual fantasy and sexual pleasure. A male participant described the changes in his genitals after using antidepressants: “The skin of my genitals got scaly. These dark veins appeared where I had never seen and just a total, like, an engine seizing up. I can't even describe it and it was, like, horrifying, uh, from the Wellbutrin.” A female participant described her experience of sexual response and arousal before and after using an antidepressant:

So, my experience before this was that, um, kind of sex or masturbation would lead to, like, a warm feeling, um, and there wasn't any of that. There was no kind of build-up of tension, which normally ends in an orgasm. It was very flat and I think the best way I can think to describe it to someone would be that it was, like, trying to give yourself an orgasm by touching your elbow. Like, just no connection to [pauses] my previous experience would be that sex would lead to feelings in, like, my stomach, my legs

[pauses] and my brain and there was nothing like that at all. It was just very, very flat and completely apparent that there was none of the build-up of tension that you need to reach an orgasm.

Another participant described his experience of anhedonic orgasm after withdrawing from antidepressants: “Uh, climax for me is about as exciting as popping pimple. You know, there's a little spurt but there are no stars bursting in the sky and meteors flying around.” A female participant described the degeneration of her sexual symptoms in the first few days of taking the antidepressant:

And on the second day [pauses] that I took it, um, I was masturbating and I had an orgasm but the orgasm felt really, really weird. I felt very, like, [pauses] I just felt very drugged. It was a really weird experience and . . . I felt, like, it was going away, like, I felt it, like, that it was distanced if that makes sense but it was still [pauses] it still felt like an orgasm But just far away and drugged . . . and then on the third day, um, I noticed . . . that my genitals were numb.

Finally, another female participant described the degeneration of her sexuality and the loss of feeling in her body and genitals after withdrawing from antidepressants:

I was waiting for my libido to pick up again and it just seemed to be getting slowly worse over the next couple of weeks and I thought it was just withdrawal. But then about two-and-a-half to three weeks after stopping the medication, I woke up one morning and *all* sexual sensation was gone from my body and I knew as soon as I opened my eyes something is horribly wrong [pauses] and just something was deeply, deeply altered about me from the second I opened my eyes that morning. Um, [pauses] my skin had a vague numbness to it, there was, like, no pleasurable sensitivity anywhere on my body.

Any erogenous zone just felt like dead flesh and it's like my clitoris is gone like I can't even feel it there [pauses] and when I touch it, it just feels like touching a calloused knuckle, like there's no feeling.

1b. Physical Sensations/Side Effects. Participants reported the following physical side effects from using and/or withdrawing from antidepressants: numbness in the skin and limbs; diminished fine motor skills (e.g., writing and drawing); brain and body zaps, restless legs, akathisia, weakness in limbs, chronic fatigue, insomnia, hair loss, pressure in the head, tinnitus and chronic pain. A male participant reflected on his diminished ability to draw while using antidepressants:

And even, like, [pauses] even the raw artistic talent itself aside from the creative thinking aspect even just like the ability to draw [pauses] like, the [pauses] just, like, [pauses] just a mechanical aspect of the artistic talent was diminished.

Another participant described the chronic fatigue that she experienced after withdrawing from antidepressants:

The fatigue was so bad that, uh, besides I went to work, I was just lying in my bed all weekend, um, every day, I could do nothing So I was so weak that, uh, even brushing my teeth or washing my hair or just showering would take all of the energy out of me, so that was, uh, horrible.

1c. Psychological Side Effects. Participants reported the following psychological side effects from using and/or discontinuing antidepressants: loss of creativity and imagination, anhedonia, loss of emotional range, emotional numbness or blunting, depersonalization, loss of empathy, intrusive thoughts, suicidal ideation, cognitive fog, memory loss, cognitive decline, difficulty concentrating, loss of motivation, loss of romantic feelings and loss of desire to

connect with others. One participant described his experience of depersonalization and diminished senses after discontinuing antidepressants:

It's just like this depersonalization I mean and again, it's nothing I ever experienced before where I just feel like I'm watching someone else's movie and it's this [pauses] it's a chemical thing. Even the way light reflects on things I can see, like, it's just like it's impossible to describe but it's almost like there's this layer of removal. I don't know. I can't describe it but it's like this detachment from my sort of immediate reality basically and even my sense of smell is pretty much, not gone, but I really can't smell the atmosphere. Um, like, things are just turned off in a sense.

Another male participant reflected on his diminished ability to feel happiness after withdrawing from antidepressants: "I noticed from the memory that I have of myself before that there was peaks of [pauses] there were just emotional peaks in like joy and happiness peaks that I just have not since experienced ever again." The same participant described his emotional numbness and inability to cry while using an antidepressant:

I was, uh, in [a life-threatening event] where, um, a bunch of my friends got injured, [some people died]. I managed to get out of the way of it and was safe, like, [pauses] but I had no emotion to it. Like, I couldn't cry. Um, to me, it was just like oh, oh yeah, whatever. Um, yeah so it was just it kinda [pauses] that's where I was kind of like, hmm, something's not right here, you know. Like, I thought about it. I'm like I wanna cry but I can't cry. Um, it felt like [pauses] it just made me numb to the experience.

Another participant described the range of psychological side effects she experienced after withdrawing from antidepressants:

I started to experience, uh, very severe, uh, cognitive symptoms and by that I would say it was, uh, in the level of like Alzheimer's or dementia type symptoms Cognitively I declined very severely. So I, uh, wanted to read, for example, uh, emails in my workplace. I read, uh, one row and, uh, I couldn't, uh, I couldn't just, uh, capture what was in the email. So I read it a second time, a third time, a fourth time and my cognitive symptoms, my brain fog, it was so bad, I couldn't, uh, [pauses] interpret what was, uh, written Not to mention that, uh, because of the emotional, uh, anesthesia, what I like to call, I completely lost my ambitions, my motivations.

She also explained the loss of romantic feelings and desire to connect with others:

PSSD is not only a physical thing but, uh, some kind [pauses] or somehow, uh, it took away the feeling that I [pauses] how I am feeling when I am in love. So it took away that feeling of love, attachment, uh, desire, uh, mentally and emotionally also, not only, uh, physically.

Finally, another participant described the disturbing intrusive thoughts that he experienced after withdrawing from antidepressants:

All of a sudden, I'm getting these weird intrusive thoughts like, um, mass shootings 'cause that was a very typical [pauses] at the time there was [pauses] that seemed to be a hot topic issue. [Pauses] So I don't know if that was just me thinking like that because it was, um, every week there was, uh, a mass shooting but I remember being in a department store being like, huh, this might be, you know [pauses] like, whoa, whoa, where are these thoughts coming from? Um, it was pretty intense.

2. Suffering, Living Death/Hell, Being Tormented

It is necessary to differentiate between the side effects and the suffering that was experienced as a result of the side effects. Many participants used phrases such as “living utter hell,” “zombie state,” “lobotomized,” “inhuman,” “waking death,” “horrifying,” “nightmare,” “hopeless” or feeling “like a ghost” to describe their physical or mental state as a result of using and discontinuing antidepressants. One participant described the darkness and despair that he felt after withdrawing from antidepressants:

I fell into the blackest [pauses] and I can't even describe this mental state that I was in just [pauses] to call it depression is not even [pauses] depression would be like a picnic in a sunny park. I mean this was like a complete blackness of reality and fortunately, I just had the presence of mind to realize was just with, well they call it discontinuation syndrome, but it's basically a chemical withdrawal and if I didn't have that presence of mind, I'm certain I probably would have killed myself. I think someone with less self-awareness would have.

Another participant described the suffering she experienced as a result of the effects of withdrawal on cognition:

But it was pure suffering to be honest, uh, without, uh, brain, without motivation, without feeling emotions, without feeling, uh, regard of anything you do and without the ability of multitasking what I had previously, uh, with, uh, very severe brain fog, uh, what, um, often resulted [pauses] even in addition problems that, uh, I was so bad every day that I can't really describe. So [pauses] it was horrible.

One participant explained that after withdrawing from antidepressants, he felt that he was in an anhedonic, survival state:

I mean there's depression and then there's just like anhedonia or if there's even another word that's even worse than anhedonia [pauses] where it's just like my brain is shut off every day, uh, and just like doing the baseline [pauses] survival.

Similarly, another participant described the unbearable state she was living in after withdrawing from antidepressants: "I can't live a life where I'm like [pauses] yeah, where I'm just trying [laughs] to survive like that's really what I feel like I'm doing right now."

Other participants felt tormented or consumed by their side effects. A male participant described his desperation to escape the side effects that he was experiencing, which resulted in thoughts of suicide:

Then I started getting [pauses] thoughts of suicide where I'm like I just want this to go away I want [pauses] I can't handle this feeling anymore, um, the whole desperate [pauses] waking up feeling like that, feeling like just there's no hope, there's nothing to live for, um, every day is a grey day just [pauses] yeah, it's an awful feeling. I know like when I hear about people that have committed suicide, I *know* what they experienced leading up to the point that they did it.

Another participant explained that the sexual side effects she experienced caused such distress that she attempted suicide twice because she did not know what else to do:

I was utterly distressed. Like the side effects was very distressing for me the sexual side effects . . . it came to a head, um, nine months after the appearance of the sexual symptoms. I was like, I can't do this anymore [pauses] and, um, I had like a bad interaction with my, uh, male partner . . ., uh, he tried to have sex with me and I couldn't feel *anything at all*. It was just really upsetting for me and I was just like crying while we were trying to have sex and I was just like I can't do this. And I, um, [sounds tearful,

choking up] I pretty much spontaneously tried to hang myself in my dorm room. . . . Um, so after I had reached this breaking point where I spontaneously tried to hang myself in my dorm room [laughs] as well as a different incident close by a few months later where I tried to suffocate myself with a plastic bag, both of which were unlikely to work, you know, I just kind of reached a breaking point and impulsively tried something I was determined to get off of everything at any cost. I was like even if I die from trying to get off or because I kill myself or because of mental illness or whatever I just literally don't care anymore. Like my life isn't worth living. I'll pay any cost to try to escape this.

Another female participant described feeling that PSSD had taken over her life and her conversations with her boyfriend:

I'm really sick of talking about it at this point. I don't want to talk about anymore. It's annoying [laughs] I just want it to be done I'm just like working really hard on trying to get [to] a place where this isn't controlling me.

Finally, some participants suffered because the side effects resulted in a profound loss of sense of self. For example, a female participant reflected on her loss of sexuality:

I feel like I have the same level of sexuality as an 80-year-old woman, you know, I'm [young] and I just I don't think anyone should kind of underestimate how much you get from your own sexual pleasure and I don't get any of that.

The same participant reflected on how her loss of sexuality had changed her perception of self:

“It's changed who I like [pauses] who I am and how am I supposed to move on from that?”

3. Elements of Participants' Relationships with Physicians/Medicine: Rapid Cycling Between Trust and Mistrust

This theme includes a description of the participants' experiences with their physicians and the field of medicine when participants were seeking help for the side effects of antidepressants and the effects of withdrawal from antidepressants. The four subthemes are as follows:

- 3a. Physicians are Incompetent or Ignorant
- 3b. Lack of Informed Consent, Medical Paternalism
- 3c. Discredited, Violated, Deceived, Duped, Betrayed
- 3d. Systemic Entrapment, Emotionally Straitjacketed, Blindsided into Compliance

Each of the subthemes includes a description of an element of the participant-physician relationship that led to participants' cycling between trust and mistrust. Before looking more specifically at each of the four subthemes, I have outlined the general narrative of participants' interactions with their physicians from the time that antidepressants were prescribed to the time when participants consulted their physicians about PSSD.

The participants sought out help from their physicians at least three times. First, participants sought out help for their presenting concerns. Next, participants sought out help for the side effects of the antidepressants. Lastly, participants sought out help for the effects of withdrawing from the antidepressants. All of the participants initially trusted their physicians to help them with their presenting concerns. Participants trusted that their physicians had their best interests at heart and that they were being offered the appropriate treatment. When seeking help for their presenting concerns, some of the participants indicated that their physicians recommended non-pharmaceutical treatment options like "talk therapy" (i.e., psychotherapy) or

cognitive behavioural therapy in addition to antidepressants. Some of the participants reported that their physicians did not disclose any potential side effects of the medications nor did they describe the purpose of the medications. Other participants explained that their physicians or pharmacists disclosed side effects such as dizziness, headaches, nausea or digestive upset. One participant said that she was warned by her pharmacist not to drink alcohol while taking the medication. Two of the participants reported that their physicians explained that their “mental health concerns” were caused by a serotonin imbalance in their brains and that the antidepressants would rectify those imbalances. Otherwise, participants were not told the purpose of the medication or how the medication worked. None of the participants were warned in advance that these medications could cause sexual difficulties during use or thereafter. None of the participants were told how long they could expect to take the medications. Some of the participants were told to take the medications for two weeks and then come back for a follow-up to see if dose adjustments were required.

From 24 hours to 1 month after starting the antidepressants, participants became aware of sexual side effects. Participants trusted that their physicians would be able to understand or resolve the side effects, so participants reported their side effects to their physicians and asked for help. Participants received various responses from their physicians or pharmacists. Some participants reported that their prescribers dismissed the side effects or denied that the medications caused the side effects. Other participants said that their physicians were unaware that antidepressants could cause sexual side effects. Participants reported that these prescribers said they could not help or referred participants to other physicians or healthcare providers. As a result of the side effects, participants reported that some of the physicians and pharmacists recommended changing the dose of the medication or trying a different antidepressant. Some

participants reported that the prescribers acknowledged that sexual side effects could emerge but were rare and tried to reassure participants that the side effects were temporary and would diminish or go away following discontinuation of the antidepressant. Some participants stopped taking the antidepressants in attempts to regain their sexual functioning. Other participants felt reassured and tried the alternate antidepressants in attempts to regain their sexual functioning.

Eventually, participants who had continued with antidepressant treatment realized that their sexual side effects were not diminishing or they underwent other adverse side effects and decided to try withdrawing from the medication. Some participants reduced the medication themselves while others consulted their physicians for tapering assistance. The reported tapering protocol was to decrease the dose over a time span which varied from two weeks to one month. Some participants found that this deprescribing advice caused worsened effects and participants decided to reduce more slowly. None of the participants were given advance warning that these medications could cause long-term or permanent sexual difficulties following withdrawal of the medication. In fact, participants had been told the opposite i.e., that their sexual side effects would go away once they stopped taking the antidepressants.

From 24 hours to a few weeks after stopping or reducing the antidepressants, all of the participants began experiencing effects of withdrawal that were the same as or worse than the side effects of the antidepressants. Participants went back to their initial prescribers and other healthcare providers (e.g., general practitioners, pharmacists, nurse practitioners, psychiatrists, urologists, gynaecologists, endocrinologists, psychotherapists and sex therapists) to try to receive support for the side effects of withdrawal. Participants received the same responses as when they consulted their physicians about the side effects that emerged while using the antidepressant: dismissal or denial of the effects, reassurance that these effects would diminish or

recommendations for other antidepressant or psychotropic medications to relieve the effects. At this point, participants were told that their sexual effects were actually symptoms of their mental health concerns re-emerging and not effects of withdrawing from antidepressants. Some of these participants continued to trust their physicians and tried other antidepressants to try to resolve their sexual symptoms.

Participants' sexual symptoms were not diminishing. Participants questioned whether their physicians were able or willing to help. Participants felt trapped in the medical relationship and in the medical system because their physicians were not willing to accept their experiences and only offered more of the same treatment.

Many participants also began to investigate what was happening by themselves. In their search, all of the participants found websites, scholarly articles and/or online forums or support groups for people experiencing withdrawal from antidepressants, antidepressant-induced sexual dysfunction and/or PSSD. Eventually, all of the participants realized that it was the medication and/or withdrawing from the medication that was causing the side effects. Many participants brought scholarly articles to their physicians to show them the research but the physicians dismissed these articles, too. Overall, participants continuously received the same messages from their physicians: Your side effects are not significant, your side effects are "in your head" or are not possible, your side effects will diminish, your side effects are real but we do not know how to help you, or your side effects are the result of your mental health deteriorating so you need more psychotropic medications.

The emerging narrative is of the participants' cycling between trusting and mistrusting physicians and/or the medical system as they experienced sexual difficulties resulting from using and discontinuing antidepressants. This experience left participants feeling that (1) their

prescribers were ignorant or incompetent about the side effects of the medications or (2) that the medication had been prescribed without participants' informed consent as to medication side effects, (3) participants had been betrayed or violated by their physicians and/or (4) participants were trapped into receiving treatment from the medical system with no real support or understanding from this system. These four subthemes are characteristic of participants' relationships with their physicians/medicine during this experience, which ultimately led to a breakdown of trust.

3a. Physicians are Incompetent or Ignorant. After reflecting on their experiences, participants felt that their physicians were incompetent or ignorant about the sexual side effects of antidepressants and about how and when to prescribe and deprescribe these medications. A female participant recounted her experience of telling her physician about the sexual side effects she experienced after taking antidepressants:

Called the doctor the next day [pauses] freaking out. Told her about my numb genitals [laughs] and [pauses] she [pauses] said that she had never, like, heard of that before and she's heard of, like, having, like, lower libido on the pills, um, but that was it and that I need to go to a gynecologist 'cause, like, she can't help me.

Another participant reflected on physicians' lack of understanding about how to prescribe and deprescribe antidepressants and the side effects that they can cause:

I believe most of the doctors are completely unaware that those psychiatric drugs have, uh, withdrawal effects, uh, they need to be tapered and I think [pauses] I believe most of the doctors are unaware of it. So they should, uh, know this that these have a dependency on the nervous system and they should [pauses] they should tell their patients about that [pauses] not to wean off abruptly but, uh, tapered slowly to come off Nowadays

doctors are prescribing psychiatric drugs way more, way more than before and, um, many people are having many symptoms having those medications and I think [pauses] doctors should, uh, learn about those psychiatric medications more and [pauses] the effects on the patients of those drugs more.

Other participants felt that their physicians did not understand what was causing their distress or that they did not do an appropriate assessment of their distress, which led to antidepressants being misprescribed. One participant explained that she was misdiagnosed with depression, which then led to antidepressants being prescribed. Other participants explained that their physicians had told them that their depression was caused by a serotonin imbalance in their brains and that antidepressants would correct those imbalances. Through their own reading, participants discovered that this serotonin imbalance theory has been questioned. A female participant reflected on psychiatrists' lack of understanding of what happens to the brain when people are depressed or on antidepressants:

What I've learned is that nobody knows what's going on in your brain . . . from these drugs at all, like, um, [pauses] yeah, I've talked to so many psychiatrists at this point [laughs]. Another one told me that, um, oh, like, it's, you know, depression is because of the chemical imbalance in your brain and [pauses] but I've read studies on that, too, now and I know that's not true either and that psychiatrists actually don't know.

Other participants who had sought support for relationship and life adjustment stressors felt that their distress was “medicalized” or considered “abnormal,” which was what led to antidepressants being prescribed. Looking back on their experiences, these participants felt that their distress had been normal under the circumstances and wished that their physicians had normalized their distress and offered non-pharmaceutical support options (e.g., exercise, diet

changes, “talk therapy”, adjustment help and LGBTQ+ resources) prior to prescribing antidepressants. A female participant reflected on how she felt about having antidepressants prescribed following a break-up:

So, she just prescribed something to a problem, which was a fully life-related problem. It was, uh, for a normal, uh, situation when a person would feel sad and stressed. Uh, it was not necessary, um, to prescribe these drugs to me.

Similarly, other participants felt that their physicians did not gather enough information about other factors in their lives (e.g., family and romantic relationships) to understand fully why they were feeling depressed or suicidal in the first place. Participants felt that their physicians jumped to antidepressants being prescribed:

Um, in retrospect, I honestly think that [sighs], you know, that aspect not being explored was part of why I *was* put on drugs is nobody asked me, you know, what is your relationships like and how do you feel about them before I was handed an antidepressant prescription. It was just [pauses] I was handed an antidepressant prescription as a knee jerk response to hearing that I was suicidal [pauses] without them asking like why or, you know, what kind of thoughts or experiences accompany those kind of thoughts? It was just like [pauses] it was like a robotic response. It was like suicidal, antidepressants.

These participants observed a lack of understanding, awareness and knowledge about the sexual side effects of these medications and about how and when to prescribe and de-prescribe these medications. That, in turn, led to distrust between participants and their physicians and/or the medical system. Participants concluded that, for the sake of future patients, physicians should become informed about antidepressant prescribing and de-prescribing practices and the sexual side effects.

3b. Lack of Informed Consent, Medical Paternalism. None of the participants were warned in advance about sexual side effects that could develop while using antidepressants or about the sexual side effects that could persist after discontinuing use of antidepressants. As a result, all of the participants began using antidepressants without informed consent. There were some cases where participants discovered that their physicians knew about certain side effects but had not disclosed that information before participants started taking the medication.

One participant explained her interaction with her physician when antidepressants were prescribed:

She didn't tell me how long I should take the medication [sighs] and the tone around it was casual. Like the tone was always [pauses] not [pauses] there wasn't any gravity to it, you know? There wasn't any sense that these were heavy duty medications It didn't feel like a big deal there was *absolutely* no mention of sexual side effects It was a noticeable difference in how my body functioned and it was *the most* noticeable difference out of all the side effects and she hadn't said anything about it. That should have tipped me off that this person didn't know what she was doing or didn't have my best interests at heart.

Another participant reflected on the necessity of making informed decisions about medical treatments and the lack of informed consent in psychiatry:

You know, in every single area of medicine, there is something called informed consent, like you did to me, right? So you gonna do a cancer treatment that is quite aggressive. They gonna [pauses] you gonna be informed about what happened to you, OK? With your body. You can have a wise decision about do it or not do it. Maybe you just decide OK I'm fine. I'm not gonna do it. In psychiatry, there is no informed consent I'm

not saying antidepressants are bad, alright? They helped me. The first time they really helped me. This time, they really destroyed me. So I am [pauses] you have [pauses] you are having two possibilities, OK? But they destroy you, they are going to destroy you really, really, really bad and people need to know, need to decide. It's that simple.

The lack of informed consent left participants feeling that they had not been able to choose a treatment option that would be best for their overall health and wellbeing. Participants felt that the physicians had not taken their values and life perspectives into consideration when making treatment decisions. Participants valued their emotional expression, cognitive function and sexuality and explained that if they had known that antidepressants could have a negative impact on these aspects of their lives, they would have sought alternative treatments.

Participants felt that there had been a deliberate lack of informed consent or that their physicians had engaged in medical paternalism when prescribing these medications. Participants speculated about why their physicians did not disclose certain side effects. Participants suggested that their physicians had been corrupted by the pharmaceutical industry such that antidepressants would be prescribed whenever possible for financial gain. Other participants suggested that their physicians were uncomfortable talking about sexual functioning and/or felt that sexual functioning was irrelevant. Some participants thought that their physicians were afraid to disclose the sexual side effects because physicians feared that patients' knowledge of these side effects would lead to non-compliance with treatment. Finally, other participants suggested that physicians were too invested in the medical model of mental illness and believed that antidepressants were the only treatment option.

A female participant explained her thoughts on how physicians weigh patient well-being versus pharmaceutical profits when making decisions about prescribing of antidepressants:

I've researched a little bit into like the pharmaceutical industry and their relationship to medical training and medical doctors. I think patients' well-being is a very low second priority to making money for these companies.

Another participant felt that physicians do not disclose side effects out of concern that patients would refuse to take antidepressants:

This is why doctors don't say anything. You say to a patient, OK, you gonna take this, you gonna be cured of your depression, of your low mood but you have 5% chances that you develop a sexual side effect that can affect you for years or even decades [laughs]. So everyone, absolutely everyone will stand up and go out of the [pauses] doctor's office. Straight away. Straight away!

Another participant reflected on her physicians' negative attitudes towards sex and discomfort regarding talking about sexual and relational well-being:

I think it was really scandalizing the way that, uh, my sexuality was considered irrelevant by healthcare and therapeutic professionals. Like in retrospect I took on all this blame for their discomfort with the situation and their unwillingness to talk about [sex].

Participants felt that their physicians had not taken their patients' values and well-being into consideration when antidepressants were prescribed. As a result, they felt that the physicians engaged in medical paternalism and antidepressants were prescribed without informed consent. Overall, this contributed to distrust in the medical system.

3c. Discredited, Violated, Deceived, Duped, Betrayed. Once the participants concluded that they had not been informed about the potential side effects or that their physicians would engage in medical paternalism; participants felt discredited, violated, deceived, duped and betrayed by their physicians and/or medicine in general. Participants had been told that these

medications were the only solutions or the best solutions but participants ended up suffering more than they had been before taking antidepressants. A male participant reflected on his feelings towards his physicians after he experienced sexual side effects that he was told would not happen:

So, they prescribed me mirtazapine. It's another [pauses] another, um, uh, antidepressant that's supposed to not have *any* sexual side effects. After, uh, we can say after withdrawal [pauses] make me impotent, absolutely impotent. That's the truth, the reality And that's, consider myself, after what happened to me criminal! That's criminal is the word what has happened to me They have stole me 3 years of my life. Without my permission. No one even mentioned this could happen.

Another participant described when she caught her psychiatrist in a lie:

I talked to a psychiatrist and she was very rude [laughs] and she told me, um, it was impossible [pauses] *at all* for this to happen, for sexual side effects to persist. She was like the drug is out of your system by now. Um, so [pauses] like you can't have any problems, um, it's not the drugs. And I told her, no, I know that they can do this and then she goes, OK fine they can, um, it's only for people that have been on them for years. You were on them for three days. Um, [pauses] which was really upsetting because, first of all, in the beginning, she told me like that it couldn't happen at all and when I pushed her and told her that I know that it can happen, she admitted that she knew that it could happen I feel like they're lying to everybody [voice quivers] and, like, how can you lie about the risks? Like it's not even [pauses] and not even telling me, oh yeah, that could be a risk, sorry that this happened to you kind of a thing. Like, they're just denying it a lot of the times.

Many participants said that they would never trust psychiatrists after this experience. Some participants said that they would never trust any physicians, again.

3d. Systemic Entrapment, Emotionally Straightjacketed, Blindsided into Compliance. Participants felt that their concerns were pathologized by their physicians. Participants were told simply that antidepressants were the treatment. In addition, their withdrawal symptoms were explained as symptoms of their presenting problems re-emerging because they had stopped using antidepressants. Therefore, the physicians recommended that participants resume using antidepressants. Participants felt that their physicians were not willing to see that the medication and withdrawal from the medication were causing emotional, cognitive, physical and sexual side effects. Participants also concluded that their physicians did not understand that these effects were contributing to the decline of the participants' mental health. Participants were now trapped in a system in which antidepressants were seen as the cure but were, in fact, the culprits. A female participant explained that she had been coerced into compliance to start taking antidepressants by her physician:

Like, I just felt like in the context of the situation the prescriber clearly wants me to take the drug and thinks that it will do me good or wants it to do me good regardless of if it actually will. And, um, it's not a neutral choice in that situation where you're being told that you have something wrong with your brain. It's like, OK if you were told that you had a life-threatening bacterial infection and you're being offered antibiotics who would say no? I just don't feel like there's a real choice in that situation.

Another participant explained his interaction with his physician when he tried to get help for his effects of withdrawal:

Um, so I went back to my doctor, I can't remember the timeline, maybe three to six months, explained to him what was happening and he goes, OK, I think that's probably [pauses] you're experiencing underlying depression. I'm like, OK, maybe? I don't know I'm like, I feel good other than no libido, um, life's good. I can go out and enjoy stuff. I don't have that hopeless desperation feeling just no sex drive, no ability to get an erection or whatever. Um, so he's like, OK, well we'll try a different antidepressant. I'm like, OK I don't think it's underlying depression but OK it's, you know, I trust my doctor and OK.

Another participant described how her physician refused to offer any other treatment options besides antidepressants when she was experiencing depression as a result of withdrawing from antidepressants:

Um, yes, so I, um, did suffer a period of quite severe depression [a few years] ago, um, I went to the GP, um, and they offered me, um, antidepressants again and I tried to kind of open a conversation with them about, um, what options would be available other than an SSRI. And I suggested some medications that I'd kind of read about online, um, but their willing to kind of believe, I suppose, what I was telling them was almost zero, um, which obviously was quite an upsetting experience. I was kind of suicidal and they wouldn't offer me anything [pauses] that wasn't this pill and as far as I was concerned like if my sexual and cognitive problems got any worse [sighs] my life would be, like, fairly low in quality.

Participants realized that their reports of their experiences were not accepted by their physicians. Participants felt that their physicians were trapped in the belief that antidepressants would cure all of the participants' problems. Participants reported losing trust in the medical system as a result of these experiences. Participants were desperate to be believed and

understood, so they took it upon themselves to try to understand what had happened to them and figure out how they could resolve their symptoms.

4. From “I’m the Only One I Can Rely On” to “Becoming My Own Expert”

Following the breakdown of trust with physicians and/or medicine, the participants resorted to relying on themselves to try to resolve their side effects. In this process, many of the participants felt that they had to become their own experts on their minds and bodies.

4a. I Can Only Rely On Myself, My Responsibility, Seeking Answers, Experimenting. The participants eventually decided that they could only rely on and trust themselves to try to fix what they had undergone because they were not getting the support that they needed from the medical system. A participant explains:

You have to do research. No one is going to help you but there are a lot of help on Internet with other people in the situation and you have to teach [pauses] you have to try stuff, OK, and see how it works.

Another participant explained the responsibility she felt to learn about medications on her own because of the lack of trust she had in the pharmaceutical industry:

I won’t have any trust in the pharmaceutical industry and pharmaceuticals, uh, even if, uh, anyone, any doctor would prescribe me anything, I would research it like crazy because my life probably depends on it so yeah, I have to.

Participants sought out and found online forums and support groups for people experiencing iatrogenic sexual side effects and/or PSSD. Finding these support groups validated the participants’ experiences. Through their Internet exploration, participants also found treatment suggestions and at-home remedies. Participants began the process of experimenting to try to reverse-engineer their symptoms. For example, participants tried different diets, fasting,

herbal supplements, going back on a low dose of antidepressants and tapering off more slowly, hormone therapies and using vibrators, among other methods, to try to enhance sexual response. A male participant described his experience of trying to understand his sexual difficulties and trying to recover his sexual:

I've kept a spreadsheet in Excel every single day for [a few years] how many hours of sleep I get, everything I eat, anything I consume in terms of alcohol or not, supplements that I've experimented with, all over the counter, some I guess not over the counter, um, and there's just no rhyme or reason.

Another participant described the various medical examinations and treatments that she tried in an attempt to alleviate her symptoms:

So, after all, um, I went to very [pauses] to a lot of examinations in the past, uh, several years [pauses], uh, because, uh, these symptoms were very, very long-lasting. Mm, of course I did many, uh, lab tests, uh, MRIs, mm, hormonal tests, all you can think about and research to an average person like me So, uh, [pauses] after many, many tests and many, many doctors, I saw a psychiatrist, I don't know, 4 times after that or 5 times So for example, I tried hyperbaric chambers, uh, with high levels of oxygen to regenerate the brain cells. Hmm, of course, maybe I could do more sessions but I did 11 sessions and I didn't notice a difference. Um, many, many supplements and herbs that I tried.

Many participants also sought out peer-reviewed articles in order to understand the electrobiology and neurobiology of sexual response and how serotonin plays a role in sexual response. Participants found studies that demonstrated that antidepressants can cause sexual difficulties. This was also how many of the participants became aware of the term PSSD. That is,

these participants were experimenting on themselves and trying to understand what their bodies had undergone after taking antidepressants.

4b. Reclaiming, Clawing Back Humanity/Autonomy, Self-Determination, Purpose, Finding Meaning, Revolution, Desperate to Be Heard/Understood. Throughout the process of information seeking and experimenting, many of the participants reached a point where they became their own experts and reclaimed their sense of autonomy and self-determination after feeling trapped in the medical system. Participants began to understand that their symptoms were iatrogenic – not psychological. Participants concluded that physicians were wrong. Many participants began to reflect on their sexual functioning before antidepressants were prescribed to them and realized that even though they were dealing with psychological problems, their sexual functioning had not been affected prior to being medicated:

The second time I was in the hospital I talked to another psychiatrist. He was nicer but he was still telling [pauses], like, basically trying to tell me that it was all stress. Everybody was telling me that I was just stressed that [pauses] once I calmed down, that I could feel my sexual pleasure again. Um, [pauses] that's not true [laughs] because stress doesn't give you numb [pauses] genitals. Um, [pauses] I've been stressed [pauses] like I was stressed before. I was depressed before. I've never had any kind of problem with sexual response.

That's never, never been an issue.

Participants came to the conclusion that they knew their minds and bodies better than anyone else and that no one could tell them that what they were experiencing was not real. Participants reported that they would decide for themselves what treatment options would be best. As one participant explained, “These doctors are undermining people but then you realize it’s not in your head because you know your sexuality better than anyone.” Another participant explained

her realizations about the harm that the antidepressants were causing to her and her decision to quit them:

I lived with drug induced suicidal ideations for, you know, four years, five years and no prescriber ever deduced that the medication was causing that effect. I'm the one that did and I quit all my psychiatric drugs against medical advice and [pauses] because of a series of events that taught me that these drugs are doing me harm and I'm done and I don't care what anybody thinks about my decision to quit.

Many of the participants concluded that there were systemic problems in the healthcare system that prevented people from receiving the care they needed. Participants began to advocate for audits of antidepressants; for transparency about how side effects are reported; for more education among physicians about psychological problems and how to conduct assessments of individuals struggling with psychological distress; awareness of the side effects of antidepressants and for sexual well-being to be taken seriously by health professionals. A male participant explained his attempts to understand how adverse effects of medications are reported and the lack of clarity about the circumstances in which a medication would be removed from the market:

I'm trying to understand how, if someone's experiencing these side effects, how it gets on the radar of Health Canada and then from there how it gets brought out to the masses or to the general public [pauses] that's a big thing. [Pauses], um, I've gone onto the adverse effects page of Health Canada and it's like OK yeah, it is getting reported to them but how is it? And how many adverse effects does it take to get a medication [pauses] to have it really called or to have it, uh, audited or reviewed to a point where it's like OK this medication is screwing up peoples' lives it needs to come off the market?

Another participant advocated for more awareness about drug-induced suicidality and suicidality as a result of PSSD:

Also, I definitely wish there was more publicity on the fact that people with post-SSRI sexual dysfunction often kill themselves and that should be a critical issue in the field of mental and medical health is that it should never, should never be an acceptable outcome that someone that comes for help gets pushed to a place where they *kill* themselves like and I would love it if the therapy profession knew more about psychiatric drug side effects. Like if therapists could identify drug-induced suicidality, you could literally save lives.

Some participants tried to find meaning or purpose in response to what they had undergone. For example, some participants tried to find a higher understanding of themselves, formed or joined advocacy groups, tried to adapt or cope with their symptoms, tried to develop their own theories about what causes PSSD or spread awareness to prevent this from happening to others. One participant explains his experience with finding meaning in what he had undergone:

I basically found, uh, you know, I don't want it [pauses] I don't [pauses] I hesitate to say like my God of my understanding but I came into my own in terms of just [pauses] I don't know a belief system and acceptance of, you know, my higher [pauses] which is so interesting that's part of AA. It's like a cardinal aspect of AA where they just would drill it into it [pauses] you must [pauses] even if you're like an atheist whatever like you need to find some like higher something. Obviously, I didn't go to AA, I just kind of [pauses] it's just interesting that naturally I gravitated [pauses] I mean if I didn't find that, I think I would've just maybe ended it [pauses] to be honest with you and, uh, I guess I just kind

of found this hope and this belief that, you know, there was some maybe greater purpose to my life and I just got really spiritual and I guess found a belief in God as would fit [pauses] as fits me.

Participants expressed a desire to share their stories. This was reflected in the process of providing the interviews for this study. All of the participants were grateful to have an outlet to share their narratives and saw participating as a way to spread awareness about what they had experienced and hoped to generate more research about PSSD.

5. Degenerating Spiral of Hope/Hopelessness

Participants experienced a degenerating spiral from hope to hopelessness as they tried to find support for their symptoms. The following four subthemes emerged as sequential steps that participants went through more than once as part of this degenerating spiral:

5a. Something is Wrong, Seeking Relief

5b. Cascading Effects

5c. Trying and Trying and Trying . . . to Regain Stability, Adjust to New Normal, Get My Bearings, Reorient Myself

5d. Vacillating between Resignation to Predicament versus Rejection of Predicament

5a. Something is Wrong, Seeking Relief. As previously described, participants initially sought help for various concerns including depression, anxiety, social anxiety, OCD, eating disorders, thoughts of suicide, relationship distress, financial distress and stress brought on by life transitions. Participants turned to their physicians for help and antidepressants were quickly prescribed.

Participants sought out help again when they underwent side effects from using antidepressants. Some participants went back to their physicians for help and were told to

withdraw from the medication. Other participants stopped using the antidepressants without consulting their physicians because they had been told that the side effects would go away once they stopped using the medications.

Participants continued to seek out help when they experienced effects of withdrawing from antidepressants. Some of the participants continued to return to their physicians or other health care providers for assistance. Other participants turned to the Internet for help where they found support groups and peer-reviewed studies that acknowledged and validated their experiences and offered alternate treatment options. These participants had some hope for relief from their symptoms after consulting with their physicians, again, or after learning from others' experiences.

5b. Cascading Effects. After starting the medication, the participants encountered various side effects that compounded the symptoms that they were already experiencing. A male participant explained that even after his presenting problems faded, he was still left with the side effects from the SSRI that was prescribed to him:

I was on [the SSRI] for about two years and I finally was over my relationship, the bad relationship, the break up relationship, um, I was in a good place financially, got myself out of debt, had some money in the bank, um, but the big thing . . . the big issue was the side effects. Sleeping all day, or, you know, sleeping and waking up still tired and then going back to bed kind of thing after sleeping 12 hours, um, and then, again, yeah, not . . . erectile dysfunction was really frustrating.

After coming off of the antidepressants, the pattern continued. Participants reported that they underwent a withdrawal period in which the side effects persisted or worsened. Some participants reported temporary relief from the side effects after withdrawing but then waking up

one morning with worsened side effects that gradually increased. A male participant explained his withdrawal from an antidepressant:

And then there was one day where I'm like . . . can masturbate again, so you know, masturbated, had a pleasurable orgasm, climax, um, still had a high sex drive or whatever. I'm like, OK, perfect, you know. I felt back to normal . . . Felt great, everything was . . . I felt, you know, OK, I'm at a good spot in my life again, perfect, back to normal, pre-antidepressants everything like that and then one day, um, it was like I went to bed, um, and it was almost like something switched off in my body just like a light switch. Uh, woke up the next morning and had erectile dysfunction again. I'm like, OK, weird, you know. Started experiencing that again, um, but still had a sex drive, still desired sex, still, um, had the urges to cuddle, you know, those kind of feelings in that sense . . . And then it just started going downhill from that point, um, my erections never came back, um, and my desire for sex, my libido, slowly started to decline to a point where there was nothing there.

Similarly, all other participants reported that the effects of withdrawal remained the same or became worse than the side effects that they experienced while taking the medication.

Participants' friends, families or physicians told them to be patient and that the effects of withdrawal might take some time to dissipate.

After trying other antidepressants or alternate treatments, participants continued to experience the same or worsened side effects. Some participants reported experiencing temporary relief from these alternatives but eventually, their side effects would return. At this point, some of the participants continued to seek out and try multiple treatment options. These participants went through a cycle of finding a treatment, hoping for relief, not receiving that

relief for a sustained period of time, trying to cope with their new realities and then feeling hopeless and resigned to their new realities, multiple times. Each time participants tried new treatments and went through this cycle, they felt increasingly hopeless about ever getting better.

Participants reported that what they were experiencing at the time of the interview was far worse than what they had experienced prior to using antidepressants. Participants explained that the side effects of using or withdrawing from antidepressants caused break-ups or relationship distress, changes in education plans or jobs, anxiety, panic, low self-esteem, depression, isolation or thoughts of suicide. In addition, participants reported frustration, hopelessness, loneliness and/or isolation as a result of how they were treated by their healthcare providers. One participant reported being diagnosed with post-traumatic stress disorder (PTSD) as a result of how she was treated by her healthcare providers. Another participant reported that he had recovered and regained sexual functioning slowly after three years of living with PSSD. However, he continued to be stigmatized by friends and family about his condition and lives with fear about his sexual functioning. These cascading and consuming side effects that stemmed from using antidepressants contributed to the hopelessness that participants felt about their lives and about eventual, sustained improvement. A female participant explained her experience of feeling hopeless as a result of the cascading effects: “And then [the next month] came and I started feeling like . . . I started feeling suicidal because I was like I'm ruined and what . . . like I don't know what happened to me.” Another female participant described how her side effects and the effects of withdrawal affected other aspects of her life:

After 9 months of this, uh, hell I would say, mm, I still live with this, uh, symptoms and, uh, I lost my job as well because, uh, I couldn't perform at all. I just, uh, totally disintegrated because of this, because of the cognitive symptoms. Not to mention that, uh,

because of the emotional, uh, anesthesia, what I like to call, I completely lost my ambitions, my motivations [pauses] it took away my future, my desires in my life and also my motivations in my life because, um, I can't really imagine life, uh, lived alone. So [pauses] and, uh, this illness, uh, completely [pauses] causes me to not being able to look for a new relationship.

5c. Trying and Trying and Trying . . . to Regain Stability, Adjust to New Normal, Get My Bearings, Reorient Myself. Participants tried to adjust to their side effects from using antidepressants. Participants were told that the side effects they experienced while on the medication would go away once they stopped the medication. As a result, these participants thought that they would only have to reorient themselves for the short-term.

The pattern continued when participants withdrew from antidepressants. With some hope and reassurance that the effects of withdrawal would diminish, participants tried to cope with the effects as part of their lives. One participant explained that he used distraction from his side effects as a way to cope: “Yeah, it was, uh, in that timeline I just kind of distracted myself with work, um, working long hours all that, always keeping busy, trying to keep my mind occupied.” Another participant explained that she was constantly monitoring her sexual response to see if there were improvements after withdrawing from the antidepressant: “So after this happened, I started like [pauses] like trying to masturbate and touch myself like constantly to see if I could feel anything.”

5d. Vacillating between Resignation to Predicament versus Rejection of Predicament. Eventually, the side effects from using antidepressants became too much for the participants. They vacillated between resigning to their new reality with the side effects and

rejecting their new reality. At this point, participants sought relief from the side effects of the medication that was supposed to help them.

The pattern continued when participants withdrew from antidepressants. Eventually, participants realized that the effects of withdrawal were not diminishing and felt hopeless, again, about ever returning to the baseline functioning they had known prior to having started antidepressants. A male participant explained that he waited for four years with no change to his symptoms:

I was 100% med free for you . . . for good four years thinking, OK, this is what my body needed to finally get back to normal but it never did . . . it just did not improve the slightest bit it just always stayed numb, that no desire for sex, no nocturnal erections, nothing like that.

The participants, again, vacillated between resigning to the effects and refusing to endure these effects, in which case, they would eventually decide to seek out support again.

At the time of the interviews, the participants were at various stages in this degenerating spiral. Some were trying new treatment options and were hopeful for recovery. Other participants explained that they were in a state of vacillating between resignation and rejection about what they had undergone. Some participants were actively trying to raise awareness about PSSD or contacting physicians and researchers for support. A male participant described the vacillation between hope and hopelessness about his condition:

I guess for a lot of years I had hope. Like for literally since I first started Googling around [10 years ago] [pauses] I guess I really had hope that I can somehow reverse engineer or get to the bottom of this thing and it would fluctuate, right? I have like these windows of fervent, diligent effort. I put all my time and focus into reading all these studies and I say,

oh this could be the path, this could be the path and then I go on the forums and see that everyone had already thought of this or tried it and didn't have any solutions and then I kind of just get hopeless and just, again, I can't take this anymore . . . need . . . I need to just back away. If I read another one of these studies, I'm just gonna go nuts. So kind of vacillating between like having hope and like putting all my time and energy into it and then just being like I can't look at this anymore and just trying to make the most of my life.

Another participant expressed a similar experience:

And then in [that next month], um, [pauses] I was trying to, like, get my . . . I was trying to accept it. I was like, OK, like, if I can't feel anything, um, like, that doesn't mean that I can't have a relationship. It doesn't mean that I can't, like, have a life. Like, I can still, like please my partner, um, [pauses] and then my mouth randomly got super, super dry, my lips got super, super dry. Like something I had never experienced before and then I freaked out and I was like I'm broken. Like I can't have any kind of sex ever again [laughs]. Um, so that means I can't get married and I can't do this and that. My life is ruined and I am ruined and I have to like struggle every day . . . I mean I still hope it isn't permanent but honestly at this point I've lost hope.

Participants experienced this degenerating spiral of hope and hopelessness as they tried to find relief from their symptoms. Participants reported feeling that their efforts of trying to get better had diminishing returns. In the process of trying to get better, participants' symptoms actually became worse and affected multiple aspects of their lives. In addition, the participants' reported feeling dismissed and discredited by physicians, which added to the hopelessness and suffering that they experienced.

6. Surreal, Absurd, Shock, Disillusionment, Disconnection, Kafkaesque

The participants were not informed about the side effects that they experienced. As such, they felt betrayed, trapped and blindsided by the medical system. Participants were left questioning themselves, their experiences and their realities. Participants noticed a contradiction between what they were experiencing and what they were told they were experiencing. They reported feeling that they were left to try to make sense of their situation. At some point throughout this experience, all of the participants asked themselves, “What is happening to me?” or “Why did this happen to me?” A female participant reflected on the state of shock she felt when her physician told her that her side effects were not possible:

I think it's one thing to like be experiencing it but to have somebody that is supposed to know about this [laughs] tell you that it's not possible that's like [pauses] and then I just feel helpless and like who can help me? Who can like [pauses] how are they telling me this isn't real? Um, [laughs] and it just makes it all feel so much more like, I don't know, it's some kind of nightmare, you know? . . . It's, um, [pauses] yeah, so it's just completely a different kind of trauma to be told that it's not real and to not be believed [pauses] because then what do you do? Like who's gonna believe you? Like who's [pauses] how are you gonna get any kind of help? Um, [voice quivers, pauses] yeah [sniffs].

A female participant reflected on the absurdity of the contradiction between the dangers of antidepressants and how commonly they are prescribed:

I feel beyond any doubt at all that my brain has been permanently changed and I just can't understand how a medication that is classed as being so safe and that is so commonly distributed can have potential to do this.

A male participant reflected on the contradiction among physicians about whether PSSD is real:

There is a resolution of the European Medical Agency inquiries only, so. But see, people argue that so I don't see the point [pauses]. So the European Medical Agency is the top doctors at Europe. So if they're saying this is happening, this is happening! There is no more questioning, more argument and I know from all the, of course, we have a [social media] group and there, doctors carry on this believing and say, no that's not true. What?! Still! I don't see that as a good practice especially now when there is a resolution. And the thing is that it's gonna be on the leaflets that [pauses] I know psychiatrists quite well and they gonna carry on not mentioning nothing of that to patients. If you read the leaflet, we're gonna have the opportunity to choose and be knowledgeable on that but they, I know them quite well, they're gonna carry on not talking about side effects in any way, you understand?

As a result of the trauma of being lied to and not understood, participants were left with uncertainty about whom to trust or about how to move forward with their lives.

7. We are Being Silenced, Immured, Dismissed

The participants felt that they were having to manage their side effects and they were fighting to be believed by their physicians. When participants confronted their physicians about their side effects, the messages they reported receiving were: Your side effects are not significant, your side effects are “in your head” or are not possible, your side effects will diminish and your sexual functioning is not significant. A male participant explained his experience of trying to be understood by his physician:

I'm kinda [sighs] getting frustrated with it because nothing's being done to recognize it or, um, [pauses] you go to a doctor [pauses] the biggest thing I'm finding with healthcare

professionals [pauses] and I believe the fact that they just gaslight you right away to say, no, that these drugs are safe, um, or dismiss you and like, no they don't they [pauses] what you experience is mental, um, maybe go see a, uh, sex therapist, um, it's just [pauses] it's like, *no, listen*. It seems like no one wants to listen [pauses] to it [pauses] listen to us suffer.

Another participant explained how her male therapist dismissed her sexual symptoms:

And the therapist at the, um, residential facility I went to also told me [pauses] don't you think that you're putting too much value onto this? Like, you're putting too much onto [pauses] like, you're too freaked out about it. Like, you can't orgasm, so what? But he didn't say those exact words, like the, "so what" part but he did say [laughs] I think, like, [pauses] don't you think that you're putting too much value on this. [Pauses], um, [pauses] and that's what everybody was telling me. They were like, so you can't orgasm anymore, so what.

A male participant reflected on the dismissal that he experienced when he tried show his physicians evidence that SSRIs affect sexual functioning:

I literally brought the studies to doctors, gone to psychiatrists and said, don't tell me it's all in my head, here's the stack of peer-reviewed studies of SSRIs and what they affect [pauses] and electrobiology of sexuality [pauses] like I said earlier ion channels, the synapses, everything and I'll bring this to a psychiatrist, not this whole stack but the very key [pauses] the key ones and they'll [pauses] one of them literally just said, oh you shouldn't read that. That was his answer.

A male participant reflected on the powerlessness he felt because of how his physician viewed patients with psychological problems:

But the problem is they can [pauses] no one can speak up about the damage, never, OK? So that's why what you're doing today is really, really important [pauses] because you shouldn't forget about this issue, people taking their lives. Not because they're not happy with their lives, they're not happy with themselves, they're having, um, it's like, uh, they have a problem, really. It's because they're going through this, they don't know how to get out and they decide to [pauses] and I am the same thing because I went through that No one wants to know about our lives. Doctor ask symptoms We are people with, um, psychological problems. So only for that [pauses] sometimes we are disbelieved.

Another participant explained how her health professionals failed to recognize that it was the iatrogenic sexual dysfunction contributing to her psychological distress:

My deterioration was just kind of seen as, oh well, [pauses] you know, this person is mentally ill. That's just what mentally ill people do is mentally ill stuff and it was kind of like there was no recognition of the correlation between being prescribed this medication, the side effects that I had and my life just deteriorating to a point where, you know, somebody that was a, uh, [coughs, pauses] an athlete, full ride scholarship winner, a straight-A student, someone that was, um, fit and relatively thin, in shape, fashionable, dating people, having friends, deteriorated to this point where I was, like, almost obese and no friends and not going to classes and, um, at *no* point did I feel like the prescriber or the therapist acknowledged that the sexual functioning deteriorating was the reason for that, in my view. It was just kind of seen as, oh, this brain disorder of depression is worsening.

A female participant reflected on how she felt silenced and dismissed by her physician:

So, some of them are so arrogant that, uh, for example, I went to a psychiatrist, uh, to ask for some, uh, emotional help when I went to the lawyer and I want to start the legal action and, uh, they didn't even let me tell, uh, my story, what happened to me. They always, uh, just interrupted me, uh, saying that, uh, you can't prove it, you can't prove it. It was not even, uh, interested to hear that, uh, the drugs she's prescribing every day what kind of damage they do [pauses], uh, and did to me. Uh, she didn't even want to read about that and that's a very bad, very big problem because, mm, it is not only the case that she is not interested in my life and me, OK, I can deal with that but she will prescribe the same drug without any consideration to them.

Finally, the same participant reflected on the powerlessness she felt when trying take legal action against her physician and the pharmaceutical industry:

I tried to take legal action as well against her and against the pharmaceutical company. Unfortunately, it was not, uh, successful because, uh, because, uh, of corruption actually. So yeah. There was, mm, [pauses] so I got a lawyer and, uh, [pauses], uh, the lawyer has, of course, some, uh, doctor some doctors, uh, who are working, uh, to her, uh, by deciding whether, uh, the damage could be from the drug or not. Uh, informally they told me and my lawyer that yes, this can be from the drug but, uh, they also said that, uh, in a, uh, tribune or a lawsuit, they would say no. So this is how corrupt the system is.

Participants perceived that their physicians and the medical and legal systems were silencing them. Participants concluded that they had no voice and no power to escape what had happened to them. They were not just *feeling* silenced, immured and dismissed – they were also *being* silenced, immured and dismissed.

8. Being Alienated in the World

The participants also reflected on how their relationships with friends, family and significant others were affected by the sexual side effects from the antidepressants. Participants described their interactions with friends, family and significant others in the first subtheme. In the second subtheme, participants described their experiences of the social consequences that resulted from the sexual difficulties and interpersonal experiences. These subthemes encapsulate the broader experience of being alienated in the world.

8a. Interpersonal Experience. Many of the participants turned to friends, family or significant others for support while experiencing the side effects from using and discontinuing antidepressants. In some cases, there was a cycle of interaction between participants and their families and friends. First, participants' reported that their social support dismissed or did not believe the side effects. Then, after participants continued to talk about their side effects, their social supports would try to reassure or placate them. Eventually, some of the participants' families and friends would grudgingly believe them. In other cases, participants' social supports were not able to believe or understand what was happening to them and ended up leaving them, bullying them or alienating them. A female participant explained what it was like when she first told her parents about the side effects she was experiencing:

I told my parents what happened about this, um, you know, like I got this thing and I'm numb [pauses, takes a shaky breath] and they were telling me to like calm down like it's been [pauses] it hasn't been long, it was like a few days maybe a week, like it's not going to be permanent for you, um, just give it time, it's gonna go away, this drug is still in your system.

Another participant recalled that his family initially did not believe him and then eventually began to believe his experience:

I went right to my parents 'cause it seemed pretty odd . . . I knew it had to be the drugs and went to my parents and said, oh it's just like illogical, there's no way that drugs can do this Um, and now they finally kind of [pauses], uh, have come around [pauses] so the point being that like even my own family just like doesn't believe it, doesn't want to hear about it.

Finally, another participant explained the bullying, stigmatization and rejection that he experienced from friends and family because of the side effects he was experiencing:

It has created [pauses] a lot of stigma on top of me that probably, well, I'm telling you, some people of my family are not gonna talk to me anymore the rest of my life. Some friends are gone for the rest of my life I mean, um, [pauses] this, uh, person with my family [pauses] this person from my family that I'm telling you that told me you are done, you are over. So your life is over. So was telling me like throw [pauses] throw yourself from a bridge or something like that.

As a result of the sexual side effects, many of the participants felt that they were now unable to have intimate and sexual relationships with others or actively avoided having these relationships. Some participants explained that PSSD was the demise of their relationships. A female participant explained her experiences of trying to be in sexual, romantic relationships with PSSD:

Um I've been in a number of relationships that have all been one or two or three years, um, and I have ended all of those, um, because I really just feel it's so hard to have a kind of deep, romantic connection with someone when just [pauses] I just feel completely

unsexual, asexual, um, [pauses] I think [pauses, sighs] I think, you know, your friends
[pauses] your relationships just become a friendship

Some of the participants were in sexual relationships at the time of the interview. These participants explained that PSSD was a source of frustration in their relationships. A male participant explained the sexual desire discrepancy in his relationship:

It's hard to be in a relationship when you have a partner that has a very high sex drive. They're climbing on you, um, and again I can use the [pauses] excuse like, oh, I'm tired, I'm busy or she knows I'm on the meds so I can use that as an excuse to like, yeah they've screwed up my sex drive and all this but I can tell she's getting frustrated with it . . . I cannot, um, [pauses] pleasure her or I can't be on that level and it's frustrating because I feel like I'm letting her down, um, and then it is taking her [pauses] it is taking a toll on her mental health as well.

Participants who were single found that friends and family members questioned their relationship and family status. A male participant explained the interpersonal interactions he experienced:

Um and in that time, you know, gone to a few of my friends' weddings as a groomsman and you know, hearing stories like, well when are you gonna get a girlfriend? Or when are you gonna have kids? Or what, you know, when's your turn? Or, you know, those kind of questions and, um, just yeah it was pretty hard time.

Three of the men who participated in this study also explained that sometimes friends or family members questioned their sexuality as a result of their single relationship status.

8b. Experience of Social Consequences. As a result of the sexual side effects and these interpersonal experiences, participants reported feeling rejected, lonely, stigmatized, abnormal,

not belonging, insecure, deprived of human connection and ashamed. A female participant explained the isolation she felt as a result of her interpersonal experiences:

Like my life became smaller and smaller Like I wouldn't hang out with friends because it's normal for [people in their 20s] to talk about sex and dating and I would just hear people talk about having sex and get so upset and have to leave and I just became extremely isolated.

In addition, participants felt as though they were missing out socially or that their social development had been stunted. As a result, many participants expressed fear or concern about their futures as social beings and whether they would be able to find a partner, get married and have children. A male participant explains his fear of loneliness as a result of being at a different social stage than his friends:

But socially it's just, you know, it's definitely getting worse with age, right? All my friends are married, they have kids it's like, what am I doing? And you're basically out of the loop I'm really kind of worried about, am I just going to be some like lonely old person with no one 'cause the friendships or [pauses] it's hard to sustain any real relationships, friendships or otherwise when you're just not on the same, uh, page, you know? If you're not in the same stage as people.

This theme includes a description of the social consequences of PSSD and how emotional, sexual and romantic feelings are crucial for developing and maintaining relationships, belonging and being human and how the deprivation of these feelings causes alienation and isolation.

Discussion

The purpose of this study was to explore the lived experiences of individuals with sexual side effects resulting from using and/or withdrawing from antidepressants. More specifically, this study explored the experience of using antidepressants, the experience of withdrawing from antidepressants, the experience of persistent sexual difficulties after withdrawing from antidepressants and the experience of the physician-patient relationship.

The meaning of participants' experiences will be highlighted in the discussion. First, participants' experiences of using and withdrawing from antidepressants and the experience of persistent sexual difficulties after withdrawing from antidepressants will be discussed. Then, participants' experiences of the physician-patient relationship will be discussed. Finally, a discussion of contributions to the literature, clinical implications, limitations, strengths and directions for future research will be provided.

Experience of Using and Withdrawing from Antidepressants and Persistent Sexual Difficulties

The current study found that participants experienced suffering, hopelessness and alienation as a result of the adverse sexual, psychological and physical effects of using and withdrawing from antidepressants. Participants in this study described these adverse sexual and emotional effects (e.g., loss of empathy or blunted emotions) as leading to relationship distress or rupture; isolation and alienation from friends and family; bullying; doubts about getting married and having children; and feelings of loneliness, insecurity, sadness, sorrow, hopelessness, suicidality, anxiety and panic. Participants also indicated that the adverse cognitive and physical effects created circumstances in which participants had to quit their jobs, drop out of school or change their careers. These losses, too, contributed to subsequent suffering, anxiety, suicidal

ideation and poorer quality of life. Some participants reported that they had attempted suicide as a result of the persistent sexual difficulties or knew others who had completed suicide as a result of the persistent sexual difficulties. The persistent and, in some cases worsened, effects of withdrawal left participants feeling that they were in perpetual survival mode in which they were simultaneously in states of desperation and despair about getting better, sexually and otherwise. The side effects and adverse effects of withdrawal from antidepressants created far more distress and suffering for participants than what they had experienced at the outset.

Moreover, their loss of sexuality or sexual functioning resulted in a loss of sexual vitality; sense of self; identity; humanity; belonging or connection with self and others; and a feared loss of sexuality for the future. Participants felt ashamed or horrified at themselves as a result of their loss of sexuality or as a result of the adverse sexual effects. These feelings led to avoidance or anxiety about engaging in or talking about sex. Participants explained that having sex or talking about sex is important when connecting with people and is an important part of personal and interpersonal development. Therefore, participants described feeling left out when friends and family talked about sex or relationships. Participants felt stuck while their friends were moving on to new stages in life such as getting married and having children. Some participants in relationships felt that their low or lost sexual desire was causing distress in the relationship and for their partners. Some participants did not feel comfortable disclosing their sexual difficulties to their partners. Some participants in the current study felt that they may no longer be able to experience attachment or relationships as a result of their loss of sexuality. These losses also contributed to the suffering, hopelessness and alienation that participants experienced. For these participants, loss of sexuality was also experienced as loss of self, connection and development.

Trauma Response

Participants were seeking help from medical professionals and were ultimately harmed. Participants were not informed about the side effects and effects of withdrawal that they experienced. The side effects and effects of withdrawal themselves were traumatizing per se. Then, when participants explained the harm that they were experiencing, they were dismissed, discredited and silenced by their physicians, friends and families. As described in the Results, this discrediting, silencing and gaslighting of participants' experiences was also traumatic, specifically: Participants questioned their realities; doubted themselves; experienced a surreal interpersonal environment, felt trapped in the medical relationship or into taking more antidepressants; and felt that they could only rely on themselves to resolve their symptoms. Gaslighting is "a type of psychological abuse aimed at making victims seem or feel 'crazy,' creating a 'surreal' interpersonal environment" (Sweet, 2019, p. 851). Participants noticed a contradiction between what they were experiencing and what they were told they were experiencing and were left to try to make sense of their situations on their own. Participants' trauma exacerbated the alienation and suffering that they were already experiencing and left them feeling uncertain about whom to trust or about how to move forward with their lives. It is important to note that most participants interacted with their healthcare providers multiple times and were invalidated *repeatedly* and dismissed, which reinforced their trauma. Not only did participants undergo pervasive, protracted and adverse effects of withdrawal, but the lack of understanding and awareness of these effects of withdrawal further traumatized participants.

Experience of the Physician-Patient Relationship

Participants felt that their physicians were incompetent or ignorant about how to assess psychological problems; prescribe/deprescribe antidepressants appropriately; and about

iatrogenic psychological distress/sexual dysfunction, SSRI withdrawal syndrome and the persistent sexual difficulties of withdrawing from these drugs. Participants felt that their physicians failed to obtain informed consent and engaged in medical paternalism when antidepressants were initially prescribed. Participants felt that they had become entrapped in a system wherein their physicians refused to see the damage that the antidepressants were causing. Finally, participants felt that they could not speak up about their experiences with the persistent sexual difficulties or that physicians and/or the field of medicine at large was trying silence or dismiss participants' experiences with the persistent sexual difficulties.

As a result, participants lost trust in their physicians, psychiatry and/or the field of medicine. Without the support of physicians, participants explained that they relied on themselves or formed/turned to online communities for help. Finally, participants felt that the dismissal and lack of understanding that they received from their physicians compounded the hopelessness, shock, disillusionment and sense of surreal experience in relation to the persistent sexual difficulties. Overall, when interacting with their physicians or other healthcare providers, participants felt discredited, violated, disillusioned, betrayed, blindsided, gaslighted, silenced and dismissed. As a result, participants were desperate to be heard and understood and felt that they had to reclaim autonomy over their bodies, minds and medical decisions.

Discussion of Literature

The Pervasive Consequences of Using and/or Withdrawing from Antidepressants

Participants in this study explained that the side effects and effects of withdrawing from antidepressants caused more distress than they had experienced before treatment. This phenomenon is known as cascade iatrogenesis or “a serial development of multiple medical complications that can be set in motion by a seemingly innocuous first event” (Cosci &

Chouinard, 2020; Thornlow et al., 2009, p. 1528). This phenomenon has been found to occur when using or withdrawing from psychotropic medications (e.g., antidepressants, benzodiazepines, ketamine, antipsychotics; Cosci & Chouinard, 2020; Thornlow et al., 2009). The findings of the meta-analysis conducted by Cosci and Chouinard (2020) suggest that using antidepressants “may increase chronicity, vulnerability to depressive disorders and comorbidity” (p. 299). In addition, this phenomenon can lead to dependency on antidepressants or other psychotropic medications because these medications continue to be prescribed for the cascading effects (Cosci & Chouinard, 2020).

Antidepressants and Addiction

As a result of the symptoms of withdrawing from SSRIs/SNRIs, researchers argue that SSRIs/SNRIs could be considered addictive substances or as having an associated physical dependency (Balon et al., 2019; Cosci & Chouinard, 2020). Cosci and Chouinard (2020) conducted a meta-analysis to identify withdrawal syndromes following discontinuation of psychotropic medications. The findings indicate that anywhere from 27% to 86% ($\mu = 56\%$) of people who withdraw from antidepressants will experience symptoms of withdrawal (Cosci & Chouinard, 2020). Horowitz and Taylor (2022) explain that effects of withdrawal persist after the drug is discontinued and no longer circulating in the blood stream because the brain has adapted to or become dependent on the use of antidepressants. Effects of withdrawal manifest as a result of the brain no longer receiving the anticipated drug (Horowitz & Taylor, 2022). The *DSM-5* identifies the following substances as addictive and having an associated dependency and withdrawal disorder: Alcohol; caffeine; cannabis; opioids; sedatives, hypnotics or anxiolytics; stimulants or tobacco (APA, 2013, p. 583). The *DSM-5* specifies another diagnosis called other (or unknown) substance withdrawal (APA, 2013, p. 583). The diagnostic criteria are as follows:

(A) Cessation of (or reduction in) use of a substance that has been heavy and prolonged, (B) the development of a substance-specific syndrome shortly after the cessation of (or reduction in) substance use, (C) the substance-specific syndrome causes clinically significant distress or impairment in social, occupational or other important areas of functioning, (D) the symptoms are not attributable to another medical condition and are not better explained by another mental disorder, including withdrawal from another substance, (E) the substance involved cannot be classified under any of the other substance categories or is unknown (APA, 2013, p. 583).

There is debate about whether SSRIs and SNRIs along with other psychotropic medications could be considered addictive (Balon et al., 2019; Cosci & Chouinard, 2020). Researchers have found that some psychotropic medications such as benzodiazepines and ketamine are addictive (Cosci & Chouinard, 2020). Based on the results of the current and previous studies, it could be argued that withdrawal from SSRIs and SNRIs meets most if not all of the diagnostic criteria listed above.

The first criterion is debatable as some participants in the current study identified symptoms of withdrawal after low doses or brief use of the SSRI/SNRI (e.g., one pill). SSRI-withdrawal syndrome has been identified, which meets the second criterion (Horowitz & Taylor, 2019). Participants in the current study and in previous studies (Healy et al., 2019; Stinson, 2013) have identified that the symptoms of withdrawal cause significant distress or impairment in social and/or occupational functioning. Participants in the current study and in previous studies (Healy et al., 2019; Stinson, 2013) also underwent several diagnostic tests which determined that symptoms were not caused by another medical condition. The common belief among medical professionals is that symptoms of withdrawal from SSRIs/SNRIs are actually the

re-emergence of mental illness because the drugs have been discontinued. However, researchers have identified specific symptoms or diagnostic criteria of SSRI-withdrawal syndrome (Horowitz & Taylor, 2019) and PSSD (Healy et al., 2022) which are specific to drug withdrawal and would not occur as a result of mental illness. For example, “an enduring change in somatic (tactile) or erogenous (sexual) genital sensation after treatment stops” (Healy et al., 2022, p. 68). Finally, SSRIs and SNRIs are not classified under the current substance categories.

Cosci and Chouinard (2020) argue that researchers should continue to evaluate whether SSRIs and SNRIs should be considered addictive substances. However, it has been suggested that individuals who take psychotropic medications under medical supervision do not meet the criterion for withdrawal (APA, 2013; Balon et al., 2019). Cosci and Chouinard (2020) also found that current diagnostic criteria for substance-induced disorders and withdrawal are “inadequate to assess psychotropic medication withdrawal because they do not take into account the issue of iatrogenic comorbidity” (pp. 299-300; Fava & Rafanelli, 2019). Cosci and Chouinard (2020) argue, “there is also reluctance toward accepting that psychoactive drugs can cause withdrawal” (p. 300). Finally, another problem that was identified in the literature review is that PSSD goes under-reported because clinicians do not pay attention to sexual symptoms and there is a lack of research in general about PSSD (Patacchini & Cosci, 2020). One could argue that participants in the current study were experiencing a substance-induced disorder and withdrawal and were not being validated or receiving the help they needed. These studies suggest that PSSD has not been recognized or accepted as a substance-induced disorder because (1) symptoms are caused by a psychotropic, medically supervised drug; (2) there is a lack of research on the subject and (3) there is a lack of attention placed on sexual dysfunction in medical/psychiatric settings.

The Pervasive Consequences of the Persistent Sexual Difficulties

The effects of withdrawing from antidepressants caused many difficulties for participants. However, the loss of sexual functioning alone had pervasive consequences for participants. Previous studies have also identified the devastating and far-reaching consequences of losing sexual functioning and/or living with sexual difficulties. Similar to the current study, Stinson (2013) found that participants with PSSD experienced relationship distress, hopelessness, shame, changed identity, isolation and despair as a result of sexual dysfunction. Participants in both this study and the current study also avoided sex or relationships altogether because they felt as though the loss of sexuality meant that they were no longer able to share a “core human experience” with others (Stinson, 2013, p. 98). Humans are designed for connection and attachment, which can be facilitated by sex (Carter, 1998). Therefore, the loss of sex can be seen as a loss of an integral part of the human experience.

Marriott and Thompson (2008) explored the experiences of women living with vulvar pain. As a result of this sexual difficulty, participants felt ashamed, less feminine, a loss of self and avoidant of sexual activity and/or relationships (Marriott & Thompson, 2008). The researchers concluded that the theme of loss was evident among these women (i.e., loss of sexuality, loss of self and loss of future self) and that this needs to be considered when helping these women therapeutically (Marriott & Thompson, 2008).

Finally, Albaugh and colleagues (2017) looked at the experiences of men with sexual dysfunction following prostate cancer treatment and their partners. Similar themes and feelings were found, which included relationship distress, loss, grief, frustration, depression, anxiety and suicidal ideation as a result of sexual dysfunction (Albaugh et al., 2017). The researchers found

that the loss of sexual functioning has the potential to “change the very lens with which men and their partners view and experience their whole existence” (Albaugh et al., 2017, p. 5).

There are many, compounding effects of withdrawing from antidepressants that cause a variety of issues. However, these studies have found that the loss of sexuality per se has pervasive effects. Participants in the current study felt that this potential loss should be understood and considered by physicians when weighing treatment options.

Literature on the Physician-Patient Relationship among People with PSSD

Participants in the current study experienced a lack of understanding, awareness, informed consent or acceptance among healthcare providers about the persistent sexual difficulties of withdrawing from antidepressants. These experiences (1) compounded the suffering, trauma, hopelessness and alienation that participants experienced about their condition, (2) contributed to an overall lack of trust in physicians and/or medicine in general and (3) contributed to increased reliance on oneself to find relief from the symptoms of withdrawal. Many of these results are supported by findings from previous qualitative studies. Healy and colleagues (2019) and Stinson (2013) found that patients regard their physicians as incompetent or ignorant about the sexual side effects of antidepressants and PSSD. Previous studies, mentioned in the introductory literature review, found that there is a lack of awareness of iatrogenic psychological distress and sexual dysfunction, SSRI withdrawal syndrome and PSSD among health professionals (Bahrack, 2008; Bala et al., 2018; Healy, 2019). The failure to obtain informed consent and the resulting feelings of betrayal experienced by these participants is also supported by findings in studies conducted by Healy and colleagues (2019) and Stinson (2013). These studies also found that patients received skeptical responses about PSSD from their

physicians, which contributed to the sense of being invalidated and the hopelessness and stress of trying to get better.

Some findings emerged in this study which warrant further attention. Participant interviews offered insights about what was unhelpful in the relationships between patients and physicians. Generally, these thoughts were as follows: Physicians adhere to the medical model of mental illness; physicians engaged in medical paternalism or did not obtain informed consent when prescribing antidepressants; physicians gaslight patients' experiences with using and withdrawing from antidepressants and the persistent sexual difficulties of withdrawing from antidepressants; physicians do not want to hear about suffering caused by antidepressants; and physicians do not believe in, let alone have an understanding of the pervasive consequences of the persistent sexual difficulties.

Physicians Adhere to the Medical Model of Mental Illness

Participants in the current study felt that their physicians assessed, diagnosed and treated their psychological distress based on the medical model of mental illness. The medical model of mental illness suggests that psychological problems are the result of biological processes in the brain and require biological treatment (Fuller, 2017). More specifically, some participants were told that their psychological distress was the result of a serotonin or "chemical" imbalance in their brains and that antidepressants would help correct that imbalance. This serotonin imbalance theory of depression has persisted for decades among physicians and the general public and continues to justify the use of SSRIs as a treatment for depression (Moncrieff et al., 2022; Pescosolido et al., 2010; Pilkington et al., 2013; Read et al., 2020).

Some participants reported feeling "euphoric," emotionally blunted or calmer when they first started using antidepressants, which was initially perceived as helpful for their

psychological distress. However, with the exception of one participant, none of the participants felt that using antidepressants helped with their initial psychological distress long-term. Participants did their own research and found studies which suggested that depression is not caused by a serotonin imbalance.

For example, a recent meta-analysis by Moncrieff and colleagues (2022), suggest that there is no consistent evidence to support the notion that serotonin is associated with depression nor that lower serotonin levels cause depression. Another review found that there was no clinically significant improvement in depressive symptoms among people who used SSRIs when compared to those who used placebos (Kirsch et al., 2008). Researchers suggest that people who do report feeling better or less depressed after using SSRIs may be experiencing the placebo effect or the emotionally blunting effects of SSRIs (Jakobsen et al, 2020; Moncrieff & Cohen, 2006).

It is important to note that physicians prescribe antidepressants for a variety of reasons and illnesses besides depression. Therefore, it is also necessary to evaluate the efficacy of these drugs in these other contexts. However, participants in the current study felt that their distress had been assessed and treated based on the medical model. Looking back, participants explained that their distress was rooted in psychological and social factors (e.g., financial stress, relationship distress, life transitions), which their physicians did not ask about. Participants felt that medical treatment and their persistent sexual difficulties could have been avoided if their distress had been assessed and treated in terms of psychological and social experiences.

There is some literature to support this idea. Researchers explain that diagnosing and treating psychological problems based on the medical model can lead to overmedicalization, over-prescription of psychotropic medications and adds to the power imbalance in the patient-

physician relationship (Huda, 2021; Johnstone, 2020). Overmedicalization and over-prescription can be harmful because patients can then experience iatrogenic harm that is worse than the initial distress (Treadwell & McCartney, 2016). This is precisely what participants in the current study described.

Medical Paternalism and Lack of Informed Consent

Participants in the current study also felt that their physicians assessed and treated psychological distress based on their understanding of psychological distress and not the participants' understanding of their distress. Participants felt that their life experiences and values were not taken into consideration by their physicians when assessing distress and offering treatment options. Participants explained that their sexuality was important to them and had they known about these potential side effects and effects of withdrawal, they would not have taken the medication. Participants also explained that the diagnosis/prescription process was completed in a single 15-20-minute meeting. They felt that this was not enough time to evaluate life experience and values comprehensively when deciding on treatment options.

Medical paternalism is an approach to the physician-patient relationship wherein physicians make decisions based on what they determine is the best care for their patients as opposed to patients determining what is the best care for themselves (Lepping & Raveesh, 2016; Murgic et al., 2015). Physicians who practice primarily from the paternalistic perspective may be violating their patients' autonomy in making decisions about treatment options (Washington, 2018). This approach also has the potential to further the power imbalance between patients and physicians because physicians may not consider patients as equals in the decision-making process (Lepping & Raveesh, 2016). Finally, this approach can cause physicians to omit certain information about the proposed treatment (e.g., side effects) if they feel that this would

compromise patient compliance (Higgins et al., 2006; Valenti et al., 2015). In doing so, physicians fail to obtain informed consent from their patients about the treatment. This hierarchical relationship with its attendant consequences was experienced by the participants in the current study.

Participants in the current study also explained that they felt that they were not taken seriously because of their psychological problems, which led to over-prescription. There is literature to support this experience. Washington (2018) and Valenti and colleagues (2015) explain that medical paternalism among psychiatrists or physicians treating patients with psychological problems can be especially dangerous because people with psychological problems can be stereotyped as being deviant, in need of fixing or unable to make treatment decisions altogether. Therefore, participants in the current study, along with clinicians and researchers, are advocating for a more egalitarian partnership between physicians and patients where physicians consider and respect patients' contexts and values when formulating diagnoses and making treatment decisions (Fulford & Van Staden, 2013). This practice involves a more individualized and contextualized approach to patient care.

Gaslighting and Systemic Entrapment

Sebring (2021) and Sweet (2019) argue that gaslighting results from the larger sociological context of Western society which is rooted in power imbalances and inequities (e.g., colonialism, capitalism, classism, sexism and racism, among others). Sebring (2021) discusses gaslighting in the medical context. Medical gaslighting results from the power imbalances in paternalistic physician-patient relationships which value "biomedical expertise over lived experience" (Sebring, 2021, p. 1952). The power imbalance in the paternalistic perspective comes from the ideology that science and medicine are "the ultimate source of objective,

indisputable knowledge and truth” (Sebring, 2021, p. 1957). As a result, paternalistic physicians believe that their knowledge is final, which leaves no room for the perspectives of patients.

Participants reported that some of their physicians did not believe or had never heard that using antidepressants could cause sexual difficulties. However, researchers have found that participants without depressive symptoms and without previous sexual dysfunction experienced sexual difficulties after using SSRIs (Nafziger et al., 1999; Waldinger et al., 1998). Since these findings, many studies have confirmed that individuals with depression can experience sexual difficulties from SSRI or SNRI use alone (Bly et al., 2013; Clayton et al., 2016; Jacobsen et al., 2015; Khazaie et al., 2015; Kronstein et al., 2015; Serretti & Chiesa, 2009). Finally, antidepressants are commonly prescribed for those with paraphilias to help decrease sexual arousal and for premature ejaculation (PE) to delay ejaculation (Arafa & Shamloul, 2006; Assalian, 1988; Kafka, 1996; Safarinejad, 2007; Safarinejad & Hosseini, 2006; Shindel et al., 2007; Waldinger et al., 1994; Waldinger et al., 1998; Waldinger, 2007).

Participants also reported that their physicians did not believe or had not heard that withdrawing from antidepressants could cause protracted sexual difficulties. There is a lack of consensus among healthcare professionals about whether PSSD is an actual condition. It is not a recognized condition in North America. PSSD has only been recognized by the European Medicines Agency. A common assumption among healthcare providers is that any sexual difficulties that arise while using an antidepressant will stop once treatment is stopped (Bahrack, 2008). Another assumption is that the symptoms of withdrawal from antidepressants are actually a recurrence of the initial psychological concern, which can lead to protracted antidepressant treatment (Horowitz & Taylor, 2019).

These assumptions along with the underreporting and lack of awareness of PSSD could lead to a lack of acceptance and understanding of this condition in the medical community. Besides the growing number of studies identifying PSSD, a study conducted by Safarinejad in 2007 confirmed that there are protracted sexual effects of withdrawing from antidepressants when looking to treat PE. Safarinejad (2007) found that those with PE have indicated that the sexual side effects induced by SSRI/SNRI use (i.e., decreased sexual arousal and delayed ejaculation) persist after stopping the antidepressant. Thus, using these drugs becomes an effective long-term treatment for those with PE.

Another concern is that the biological mechanisms underlying PSSD are still debated (Csoka et al., 2008; Healy, 2019). The proposed hypotheses are that SSRIs cause long-term physical and/or epigenetic changes which (1) affect the concentration of neurotransmitters and/or hormones responsible for sexual response, (2) cause a decrease in physical reactivity to stimuli and/or (3) cause desensitization and downregulation of serotonin receptors in the body (Csoka et al., 2008; Healy, 2019). However, more research is needed to find the definitive causes of PSSD.

Participants felt that their experiences were gaslighted because of their physicians' lack of acceptance and understanding of iatrogenic sexual difficulties. Participants felt that their physicians were relying on their own expertise or assumptions and failed to listen to and accept the participants' experiences. Participants had also found similar studies to those discussed above and some even brought these studies to their physicians and were still dismissed. Participants were left wondering why their physicians had failed to see or accept this research. Besides that, even if physicians did not understand what was going on for participants or were unaware of these conditions, participants' experiences and suffering was real and they deserved to be validated and understood in their experiences by their physicians.

The lack of awareness of the persistent sexual difficulties that can accompany withdrawing from antidepressants is dangerous because physicians and other healthcare providers may continue to dismiss patients' sexual difficulties as psychological and prescribe antidepressants for their patients' symptoms. This could leave patients trapped in a system where (1) antidepressants are seen as the solution but are actually the problem and (2) where physicians continue to believe that their current knowledge is correct and fail to acknowledge the patients' experience.

Silencing People who are Living with Persistent Sexual Difficulties of Withdrawing from Antidepressants

Sexual wellbeing is seen as a critical aspect of overall health and wellbeing but that importance is not reflected in practice (Higgins et al., 2006; Higgins et al., 2008; Quinn et al., 2011; Stevenson, 2004; Urry et al., 2019) and was not reflected in this study. When participants did go to their therapists or physicians to disclose their sexual difficulties or dysfunctions, participants were told "it's not that big of a deal," "get over it," "so what" or "we can't do anything about it," or "that's not possible." Participants also reported that physicians did not recognize the link between the deterioration of their psychological distress and the sexual dysfunction (i.e., that the sexual dysfunction was causing psychological distress). Participants felt that their sexual distress was not seen as important when compared to their mental illness. Previous studies discussed in the literature review found that healthcare providers can place sexual functioning on the bottom of the hierarchy when evaluating patients' distress and treatment options (Higgins et al., 2006; Quinn et al., 2011; Stevenson, 2004; Urry et al., 2019). Participants explained that their sexual difficulties were critical issues that needed to be resolved immediately but felt that their sexuality was being silenced by physicians.

Contributions to the Literature

There are few studies that have explored the lived experiences of people with PSSD and the causes and potential treatments for PSSD. PSSD is not recognized globally as a disorder. The European Medicines Agency is the only medical agency that has recognized PSSD (Reisman, 2020). The current study allowed participants to tell their experiences so that they might be shared with those who are unaware of these persistent sexual difficulties or struggling with PSSD. By continuing to share their experiences with the persistent sexual difficulties of withdrawing from antidepressants, their hope was that this condition will become recognized and lead to more research surrounding the causes and potential treatments for this condition. Participants in this study emphasized the lack of awareness of this condition and the culture of silence and dismissal that still exists around sexual wellbeing, iatrogenic sexual difficulties and PSSD in the medical community. This study can help to break the silence and stigma that surrounds PSSD and iatrogenic sexual difficulties.

Clinical Implications

The participants in this study emphasized (1) the suffering that they experienced as a result of PSSD and (2) the paternalistic, silencing, unhelpful and harmful interactions with their physicians over the course of treatment. The results indicate that physicians and other healthcare providers (i.e., therapists, prescribers, pharmacists, mental health professionals, sexual health professionals, etc.) need to be aware of the pervasive effects of PSSD. The results also indicate that the loss of one's sexuality is serious and needs to be considered as such by all healthcare providers. In addition, when it comes to assessing and helping people with mental illness and/or PSSD, there should be more emphasis on lived experience as opposed to only medical expertise. This includes assessing psychological and social factors that are contributing to a patient's

psychological distress; understanding how sexual difficulties contribute to psychological and social distress, normalizing and validating distress; understanding the patient's values and how those values might be in conflict with the physician's values and treatment plan; and creating a more egalitarian physician-patient relationship.

Findings from this study suggest that physicians and other healthcare providers would benefit from more or better education and training about comprehensive approaches to clinical care. Key topics may include: how to obtain informed consent; how to assess and talk about sexual wellbeing and functioning with patients and clients; empathy, active listening and understanding patients' lived experiences; egalitarian physician-patient relationships; evaluation of whether antidepressants are the best form of treatment; prescription and deprescription of antidepressants; how dismissing patients' concerns affects them; overmedicalization; iatrogenic difficulties (including psychological, physical and sexual); and PSSD. A few participants specifically stated that they wished that their healthcare providers (including psychotherapists and social workers) had been more aware of iatrogenic suicidality because this may have prevented prolonged use of antidepressants. In addition, participants explained that if their therapists had better training in suicide assessment and safety planning, then participants may not have been referred to a physician where they were then prescribed antidepressants.

Such comprehensive assessments of patients' psychological distress will require physicians to plan for longer appointment times to fully assess their patients' psychological distress, which is not the norm for physicians (Huda, 2021). Moreover, physicians are in high demand and are pushed to see as many patients as possible, which result in assessing patient concerns in a short amount of time (Huda, 2021). Therefore, this problem stems from a systemic

issue in healthcare where physicians and other prescribers are understaffed, overworked and have limited time to speak with their patients (Huda, 2021).

In addition, some of the interventions listed above (e.g., assessing psychological and social factors that are contributing to a patient's psychological distress; normalizing and validating distress; understanding the patient's values and lived experiences; empathy; and active listening) are the foundations of psychotherapy. Mental health professionals such as psychologists, psychotherapists and social workers have been trained in psychotherapy. Therefore, physicians may not be most suited to be the first point of contact for people with psychological distress, especially if the physician in question has not undergone psychotherapy training. Healthcare providers who have specialized psychotherapy training may be better suited as the first point of contact for people with psychological distress. The obstacle to implementing this recommendation is that mental health professionals in North America are not publicly funded and consequently are not accessible to everyone.

Some participants recommended more collaboration among healthcare professionals. For example, therapists could act as advocates for client and inform their clients' physicians of any medication side effects or effects of withdrawal. However, permission to disclose this information would need to be given by clients and therapists would need to be aware of iatrogenic psychological, physical and sexual difficulties. This advocacy could help individuals with PSSD feel less alone and more supported.

Participants in this study suggest that therapists who are aware of PSSD and who have experience in helping people with grief, sexual dysfunction, loss and trauma may be helpful for people who are currently experiencing PSSD. Couples/sex therapists may also be helpful for couples dealing with PSSD. This has shown to be helpful and a necessary part of the healing

process for patients dealing with sexual dysfunction after prostate cancer treatment (Albaugh et al., 2017).

Finally, if patients still choose to use antidepressants after being informed of the potential side effects and effects of withdrawal, then there needs to be an initial assessment of sexual functioning and sexual functioning should continue to be monitored while using and withdrawing from the antidepressant.

Limitations

Although this study provided some novel insights into the experiences of people with PSSD, it is important to note that there are some limitations of this study. First, the 10 participants were highly selected. They were recruited through a PSSD patient advocacy group after having experienced PSSD. Second, the majority of the people who participated in this study resided in North America and identified as White. Therefore, the results of this study may not be representative of people in different cultures. Finally, it is important to note that the experts who contributed to the theme development process were all a part of the same research group. Therefore, it is possible that the experts shared similar perspectives about the study, leading to bias in the results.

Strengths

The current study also has some strengths. The sample size of this study allows for transferability of the findings. The theme development was rigorous and iterative and in line with descriptive phenomenological research. Theme development was conducted using multiple experts in the field in attempt to establish transcendental subjectivity (Laverly, 2003; VanKaam, 1966). All of the eight experts had conducted research and/or worked in areas related to sexuality using a phenomenological lens. All experts had at least a bachelor's degree in psychology. One

also had a degree in phenomenology. Six of the experts are mental health professionals. Six of the experts had history in conducting this form of descriptive phenomenology in previous projects of the OSE Research Team. The two experts who participated as blind raters have been members of the research team for over 10 years, have multiple graduate degrees (including in psychology) and have extensive experience using this methodology. Neither of these individuals is the thesis supervisor.

More specifically, this study utilized the research process outlined by VanKaam (1966) where the researcher and the other experts (1) collaboratively reviewed each other's themes of the transcripts, (2) discussed emerging themes until consensus was reached, (3) wrote out the description or an initial list of themes that emerged, (4) applied the themes to other participants and (5) collaboratively revised again until consensus was reached about the final list of themes that fully, accurately and faithfully capture the participants' experiences. In an attempt to achieve confirmability of the results (Lincoln & Guba, 1985), the emerging themes were reviewed by other experts who were blind to the theme development process. Finally, this study was focused on lived experiences and was developed because there was a group of people who were asking to be studied. Therefore, this study was based on the needs and wants of participants as opposed to being based on the needs and wants of the researcher.

Directions for Future Research

Based on the results of this study, future research should attempt to prevent PSSD, as well as continue to investigate the physiological mechanisms of PSSD, prevalence of PSSD, risk factors for PSSD, treatments for PSSD and how antidepressants affect sexual response in general. Researchers could also examine different tapering schedules and whether these affect prevalence, timing or severity of PSSD. In addition, researchers should continue to investigate

the barriers that physicians face when informing their patients about the sexual side effects and effects of withdrawal from all medications, including antidepressants and how to mitigate these barriers. Finally, based on the increase in reports of iatrogenic harm and questionable efficacy, future research should continue to examine the balance of positive and negative effects to inform both patients and their prescribers in the shared decision-making process for treatment initiation and discontinuation. In Canada, patients suffering from PSSD can take action, in theory, and report these adverse effects to Health Canada as per Vanessa's law. It can be difficult for clinicians to ascertain the exact causality of symptoms. However, patients should be encouraged to ask their healthcare provider(s) to make a report to Health Canada under Vanessa's law (Government of Canada, 2014).

Conclusion

In summary, these findings indicate that people with PSSD can undergo psychological, physical and sexual effects of withdrawal that cause suffering, trauma, hopelessness and alienation. In addition, the findings suggest that loss of sexuality alone causes psychological and social distress that needs to be taken seriously by healthcare professionals. Moreover, these findings indicate that there is a lack of understanding, awareness, informed consent or acceptance among healthcare providers about PSSD, which (1) can compound the suffering, trauma, hopelessness and alienation that people with PSSD experience about their condition, (2) can contribute to an overall lack of trust in physicians and/or medicine in general and (3) can contribute to increased reliance on oneself to find relief from the symptoms of PSSD.

Participants in this study are asking for more research to understand the causes and potential treatments of this condition and for more understanding, awareness, informed consent and

acceptance of PSSD among all healthcare providers so that fewer patients in the future will be put in this position.

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Appendix A

Antidepressants Used by Participants in this Study and Mechanisms of Action

Antidepressant	Class/Mechanism of Action
Bupropion (Wellbutrin®)	NDRI
Citalopram (Celexa®)	SSRI
Clomipramine (Anafranil®)	TCA
Escitalopram (Lexapro®/Cipralex®)	SSRI
Fluoxetine (Prozac®)	SSRI
Imipramine (Tofranil®)	TCA
Mirtazapine (Remeron®)	NaSSAs
Paroxetine (Paxil®)	SSRI
Sertraline (Zoloft®)	SSRI
Venlafaxine (Effexor®)	SNRI

Note: This table has been adapted from Kennedy and colleagues (2016).

Appendix B

Participant Recruitment Statement

My name is Emily Rice and I am a graduate student at the University of Ottawa in the M.A. Counselling Psychology program in the Faculty of Education. I am currently recruiting participants for my Master's thesis project under the supervision of Dr. Peggy J. Kleinplatz, Professor, Faculty of Medicine and cross-appointed to the Faculty of Education, University of Ottawa. The purpose of my study is to explore the lived experiences of those who have experienced sexual difficulties as a result of antidepressant use and/or discontinuation. Participation in this study will consist of completing a telephone or video interview with the researcher (Emily Rice) for approximately 90 minutes. During this interview, participants will be asked to reflect on their experiences of being prescribed an antidepressant, what they were told about how long they will be on the antidepressant and plans for discontinuation, of being on an antidepressant, of stopping an antidepressant and their experiences with PSSD. In order to be eligible for participation, participants must be (1) 18 years of age or older, (2) have experienced or are experiencing sexual side effects following the use and/or discontinuation of an antidepressant, (3) willing to have their interview audio-recorded for data analysis purposes and (4) able to describe their experiences sufficiently in English. The hope is that this study will raise awareness of post-antidepressant sexual dysfunction and prescription practices and give voice to those who have experienced post-antidepressant sexual dysfunction.

If you meet the above criteria and are interested in participating in this study or have any questions about the study, please contact me by email or by phone. You can also contact Dr. Peggy J. Kleinplatz at (613) 563-0846, Monday–Friday, noon–5:00 PM EST. Should you have any additional concerns, please contact the Protocol Officer for Ethics in Research, University of

Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, tel.: (613) 562-5387 or ethics@uottawa.ca. Your participation is greatly appreciated!

Appendix C

Participant Characteristics

1. How old are you?
2. What is your sex/gender?
3. What is your race/ethnicity?
4. What is the highest level of education you have completed?
5. What kind of work do you do?
6. What is your sexual orientation?
7. What is your relationship status?
8. How long have you been in your current or most recent relationship?
9. Which country do you live in?

Appendix D

Interview Prompts

1. How did you come to receive a prescription for antidepressants? What was going on in your life that led to visiting your healthcare professional and receiving a prescription for antidepressants?
2. When you first went to visit your healthcare professional, what did you talk about? What did your healthcare professional say to you?
 - a. What treatment options did s/he provide?
3. What was your experience of having an antidepressant prescribed to you?
 - a. What antidepressant(s) were prescribed to you?
 - b. What was(were) the dose(s) of your antidepressant(s)?
 - c. What did the prescriber tell you about the purpose of the medication?
 - d. What did the prescriber tell you about the prescribed dosage(s)?
 - e. What did the prescriber tell you about how long you should take the medication?
 - f. What did the prescriber tell you about possible side effects?
 - g. What did the prescriber tell you about how to deal with possible side effects?
 - h. What did the prescriber tell you about follow-up that s/he could offer?
 - i. What did the prescriber tell you about the plan for when/how you would stop taking the medication?
4. What was your experience of starting the antidepressant?
 - a. What happened when your first started taking the antidepressant?
 - b. Did you experience any benefit from using the antidepressant?
 - c. Was there any change in your symptoms? If so, please describe the change(s).

- d. Did you experience sexual difficulty(ies) while using antidepressants? If so, please describe the difficulty(ies).
 - e. If you experienced sexual difficulty(ies), did you seek professional help about these symptoms? If so, please describe that experience.
 - f. Approximately how long were you taking the antidepressant(s)?
5. What was your experience of stopping the antidepressant?
 - a. How did you come to stop taking the medication?
 - b. Did you seek out professional help to stop the medication?
 - c. What symptoms did you experience after stopping the medication?
 - d. Did you seek professional help about these difficulties? If so, please describe that experience.
6. What has been your experience with PSSD?
 - a. Approximately how long have you been experiencing PSSD?
 - b. How has PSSD affected your life overall?
 - c. How has PSSD affected your intimate/sexual relationships?
 - d. How has PSSD affected your relationships with healthcare professionals? Have you sought professional help for PSSD?
7. Was there ever a period while taking the antidepressant or since stopping the antidepressant where you did not experience sexual difficulties? If so, please describe this period.
8. How was your sex life before you began taking antidepressants?
9. What would you have liked to have known about the sexual side effects of using and stopping antidepressants before they were prescribed to you?

10. How do you feel that healthcare professionals can improve their conversations with patients about sexual side effects of medications and about deprescribing medications?
11. Is there anything else that I have not asked you about that you feel is important for me to know?

Appendix E

Informed Consent Form

Title of Study: Understanding the Lived Experiences of Sexual Difficulties Resulting from Antidepressant Use and/or Discontinuation

Principal Investigator: Emily E. Rice
Graduate Student, Faculty of Education
University of Ottawa
Ottawa, ON

Supervisor: Dr. Peggy J. Kleinplatz
Professor, Faculty of Medicine and Faculty of Education
University of Ottawa
Ottawa, ON

Invitation to Participate: I am invited to participate in the abovementioned research study conducted by Emily E. Rice to complete her Master's thesis under the supervision of Dr. Peggy J. Kleinplatz. This research study is funded by the Social Sciences and Humanities Research Council (SSHRC) of Canada.

Purpose of the Study: The purpose of the study is to explore the lived experiences of those who have experienced sexual difficulties as a result of antidepressant discontinuation and/or use. More specifically, this study will examine the experiences of being prescribed an antidepressant, what participants are told about how long they will be on the antidepressant and plans for discontinuation, of being on the antidepressant, of stopping the antidepressant and experiences with post-antidepressant sexual difficulties.

Participation: My participation will consist essentially of completing a telephone or video interview with the researcher for approximately 90 minutes during which I will be asked to reflect on my experiences of being prescribed an antidepressant, of being on an antidepressant, of stopping an antidepressant, my experiences with PSSD and what all of these experiences mean to me. I will also be asked to provide some basic demographic information at the beginning of the interview. I am aware that the interview will be audio-recorded for data analysis purposes. I do not have to answer any questions that I do not want to answer. The interview has been scheduled for a time that is convenient for me.

Risks: By participating in this study, I am aware that I will be volunteering some personal information. Given the nature of this research, there is a risk that I will feel emotional discomfort before, during or after the interview. I have received assurance from the researcher that every effort will be made to minimize these risks. As such, I know that I am free to refuse to answer any questions that may cause such discomfort and I know that any information collected from me during the interview will be kept confidential and anonymous. Furthermore, if I do feel any emotional discomfort, I know that I may find support on the PSSD Canada website:

<https://pssdcanada.squarespace.com/>

Benefits: This research is not specifically designed to benefit participants. However, the hope is that this will be an opportunity for participants to share their stories and shed light on this condition.

Anonymity: I have received assurance from the researcher that the information I will share will remain anonymous. Anonymity will be protected in the following manner: I have been asked to provide a pseudonym to ensure that any information I disclose remains anonymous during data analysis and for publication purposes.

Confidentiality: I have received assurance from the researcher that the information I will share will remain strictly confidential and will be used solely for the purposes of this research. The only people who will have access to the research data (i.e., the interview transcripts) are the researcher, Emily E. Rice and the Supervisor, Dr. Peggy J. Kleinplatz. Members of the Optimal Sexual Experiences Research Team will see only de-identified transcripts for data analysis purposes. I understand that the members of the Optimal Sexual Experiences Research Team are either graduate students or mental health professionals. I understand that the contents will be used only for data analysis purposes and that some direct quotations from my interview may be cited in the final research paper and future publication. Any identifying information, such as my real name and contact information (i.e., email address and/or telephone number) will be known only to the researcher. Finally, in order to minimize the risk of security breaches and to help ensure my confidentiality it is recommended that I use standard safety measures such as signing out of my account, closing my browser and locking my screen or device when I have completed the interview.

Conservation of data: Any information taken and printed from the questionnaires will be kept in a locked filing cabinet in the office of Dr. Peggy J. Kleinplatz of the University of Ottawa for a period of 5 years at which time, they will be destroyed. All electronic data (i.e., the interview transcript, a copy of the consent form and the audio-recording of the interview) will be kept on the password-protected computer of the researcher in password-protected files for a period of 5 years before deleting.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of

withdrawal will not be used for the study. It will be conserved and destroyed/deleted in the same manner as described above.

Acceptance: I, (*Name of participant*) agree to participate in the above research study conducted by Emily E. Rice of the Faculty of Education, University of Ottawa, whose research is under the supervision of Dr. Peggy J. Kleinplatz.

If I have any questions about the study, I may contact the researcher or her supervisor.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, tel.: (613) 562-5387 or ethics@uottawa.ca

There are two copies of the consent form, one of which is mine to keep.

Participant's signature:

Date:

Researcher's signature:

Date: