

**CHAPTER 5: Searching for Answers and Validation: Australian Women's Experiences of Coping with the Adverse Sexual Effects of Antidepressants.**

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## Chapter Overview

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As discussed in Chapter Four, the research identified four discrete but overlapping coping strategies namely i) *searching*; ii) *suffering in silence*; iii) *trying to resolve* and iv) *accepting what is*. This chapter explores and expands on one particular theme “searching” and provides and details the findings related to women’s experiences of searching for answers and validation relating to their concerns. Most women found that early interactions with GPs were inadequate, and therefore hindered their attempts to prepare for the sexual side effects and adopt strategies to move forward. As such, this chapter discusses and contextualises these particular findings for general practitioners (GPs).

## **Abstract**

Sexual difficulties relating to selective serotonin reuptake inhibitor (SSRI) medication have an impact on quality of life and are a common cause for non- adherence to medication. Whilst most research has focused on the prevalence and treatment of sexual difficulties relating to SSRIs, little is known about how individuals cope with the adverse sexual effects. This qualitative study, using Interpretive Phenomenological Analysis (IPA), investigated the experiences of ten Australian women currently coping with the adverse sexual effects of this antidepressant by conducting semi- structured interviews. This paper presents one major theme from the study and reports the findings specifically related to women's self-reported experiences of interacting with general practitioners (GPs) in their search for answers and validation of their concerns. Findings from the study add to the current literature by providing an insight into how interactions with GPs affect women's abilities to cope with adverse sexual effects. Empathic discussions and shared decision making between GPs and women can provide the opportunity to improve the management of the adverse sexual effects of SSRIs and may lead to improved outcomes for women.

### **What is known about this topic?**

Female sexual difficulties associated with selective serotonin reuptake inhibitors are well- documented but women's experiences of coping with such difficulties have not been explored.

### **What does this paper add?**

This study provides insight into how interactions with GPs affect women's abilities to cope with the adverse sexual effects of selective serotonin reuptake inhibitors, creating an opportunity to improve the management of sexual difficulties.

## Introduction

Antidepressant prescribing in Australia has increased substantially over the past decade. Despite controversy surrounding the influence of the pharmaceutical industry, adverse drug effects and questions about efficacy (Fournier et al., 2010; Spence, 2013), antidepressants have become the most commonly dispensed psychotropic medication in Australia (Stephenson, Karanges & McGregor, 2013). Selective serotonin reuptake inhibitors (SSRIs) are the most widely prescribed category of antidepressant, and according to Stephenson et al., their use doubled in Australia between 2000 and 2011. Whilst there have been calls to reconsider medication as a first line treatment for mental health problems (Carlat, 2010), an increasing reliance on medication and indeed, patient reluctance to discontinue medication for fear of relapse (Spence, 2013) have led to an increased focus on the management of adverse drug effects.

Although a number of adverse effects have been associated with SSRIs (Moret, Isaac & Briley, 2009), sexual difficulties remain an underestimated but important problem (Safarinejad, 2011). Concerns relating to quality of life and adherence to medication have prompted an emerging body of research into the sexual difficulties associated with this medication; such difficulties were the focus of a recent Cochrane review (Taylor et al., 2013). Given that women have higher levels of SSRI use (Hollingworth, Burgess & Whiteford, 2010), several studies have focused specifically on managing female sexual problems associated with the medication (Safarinejad, 2011; Zhang et al., 2010). Whilst such studies have identified a number of management and treatment strategies, the evidence to support these approaches is somewhat limited (Taylor et al., 2013).

Therefore, current attention has focused on strengthening the therapeutic alliance between GPs and the patient. Researchers have highlighted the importance of a patient-centred approach to the management of sexual difficulties, calling for GPs and mental health clinicians to inform patients about potential sexual problems (Kikuchi, Uchida, Suzuki, Watanabe & Kashima, 2011) and to encourage shared decision making with respect to the management of such difficulties (Quinn, Happell & Browne, 2011; van Servellen, Heise & Eiliis, 2011). Whilst attention has been

drawn to the importance of informed consent when prescribing medication and the adoption of a patient-centred model (Gopal et al., 2012; van Servellen et al., 2011), such approaches have not been widely adopted.

Indeed, research has shown that treatment emergent sexual problems are infrequently discussed by GP's and mental health clinicians; personal discomfort, lack of time or expertise, and the belief that treatment options are limited have been cited as prohibitive factors (Goldstein, Lines, Pyke & Scheld, 2009; Quinn et al., 2011; Shifren et al., 2009). In addition, Quinn et al. (2011) highlighted that fear of non-adherence has prompted the deliberate withholding of information about adverse sexual effects in spite of findings revealing such knowledge can actually improve adherence rates (Smith & Henderson, 2000). Furthermore, women have been reported as generally reluctant to seek help for sexual problems citing personal embarrassment, lack of time and perceptions that sexual problems are not taken seriously as reasons for this lack of disclosure (Macdowall et al., 2010; Shifren et al., 2009). Subsequently, it has been reported that women who are taking antidepressants have been unlikely to report such adverse effects (Kikuchi et al., 2011).

Although there is a growing body of research on the adverse sexual effects of SSRIs, there is a dearth of research on women's self-reported experiences of coping. The aim of our study was to complement existing research by using Interpretative Phenomenological Analysis (IPA) to explore the subjective experiences of coping with sexual difficulties amongst women who chose to continue on SSRIs despite adverse drug effects. Within the field of health psychology, IPA has been gaining attention as a flexible and inductive research approach which allows the researcher to move beyond a biomedical model of disease and illness to explore self-reported experiences and meanings that individuals assign to those experiences (Brocki & Weardon, 2006; Smith, Flowers & Larkin, 2009). To offer detailed, nuanced analyses of lived experience, IPA utilises an idiographic approach that focuses on the individual or specific situations either in a single case study or through a small number of participants (Larkin, Watts & Clifton, 2006). Unlike other qualitative approaches such as grounded theory which use larger sample sizes and seek to generate theory (Pringle, Drummond, Mc Lafferty & Hendry, 2011), the individual case is central to the inquiry in IPA. The overall analysis remains faithful to the individual through illustrating the particular lived experience of participants who

have recounted their experiences whilst also illustrating more generalised themes (Smith, Flowers & Larkin, 2009).

This paper presents one major theme from the study and reports the findings related to women's experiences of searching for answers and validation relating to their concerns. This paper adds to the current literature by bringing to light an increased understanding of how interactions with GPs influence women's abilities to cope with adverse sexual effects.

## Methods

Australian women were recruited to this study through homogeneous sampling and selection was based on the following inclusion criteria: heterosexual, under 45 years, in a relationship and currently taking SSRIs for depression and/or anxiety disorders. Participants for this study were recruited via a mental health website (depressionnet.com), social media sites and snowballing techniques (Liamputtong, 2013). As reported by Shifren et al., (2009), women have often been reluctant to seek help for sexual problems hence we did not recruit through health professionals or clinics. Participant details are provided in Table 1 (pseudonyms have been used to protect anonymity).

Table 1. Demographic information.

Name	Age	Diagnosis and SSRI	Length of time on SSRI	Relationship status	Education level
Alison	29	Mild depression (Escitalopram)	6 months	De Facto	Bachelor Degree
Charlotte	45	Severe depression (Sertraline)	13 years	Married	Postgraduate Diploma
Helen	23	Moderate depression (Escitalopram)	11 months	Married	Grade 12 completion
Julie	44	Severe depression (Fluoxetine)	7 years	Married	Postgraduate Degree
Lisa	44	Severe depression (Sertraline)	15 years	De facto	Postgraduate

					Degree
Mandy	38	Moderate depression (Escitalopram)	2 years	Married	Grade 12 completion
Nadia	42	Moderate depression, panic disorder (Paroxetine)	12 years	Married	Postgraduate Degree
Phoebe	40	Mild depression, panic disorder (Paroxetine)	13 years	Married	Grade 12 completion
Sonia	30	Moderate depression (Sertraline)	10 months	Married	Bachelor Degree
Tahlia	26	Severe depression (Sertraline)	10 months	De facto	Bachelor Degree

Ten women were included in this study; each woman had made a conscious decision to continue medication despite adverse sexual effects. This enabled us to focus on coping strategies and explore these strategies in detail. According to Smith et al. (2009, p. 51), given the complexity of most human phenomena, 'it is more problematic to meet IPA's commitments with a sample size which is too large than with one that is too small'. Whilst no definitive criteria exist for sample size in IPA, the authors felt a sample of ten women adequately captured patterns of similarity within the group whilst recognising the particularities of individual lives. Whilst it is acknowledged that the findings are not able to be generalised, the study provides important information about women's lived experiences. It also lays the groundwork for future research.

Data were collected through two semi-structured interviews comprising of open-ended questions. The interview schedule was informed by the literature review and the professional experience of the first author. The data were analysed following IPA guidelines put forward by Smith et al. (2009), namely, reading and re-reading the transcripts separately for each woman or case, initial noting, developing emergent themes, and searching for connection across emergent themes. The themes that emerged from the first interview were discussed during the second interview to check the interpretation. The next stage involved looking for recurrent themes across the data from the ten women and this resulted in four super-ordinate themes.

## Results

The four super-ordinate themes were: i) searching, ii) suffering in silence, iii) trying to resolve and iv) accepting what is. This paper expands on the first major theme, 'searching', as this theme was reported by all the women and has particular relevance for improving experiences in a primary care setting. The theme *searching*, included two sub-ordinate themes i) searching for answers and ii) searching for validation.

### *Searching for answers*

With the exception of one woman, women were not informed about the adverse sexual effects of SSRIs when the medication was prescribed, leaving them feeling confused and 'searching for answers' about the cause of their sexual problems. As such, this lack of information left some women feeling angry:

*At one stage, I went to the doctor and said, "You need to see my husband, he has bad anxiety and needs this medication". She said, "Oh the sexual side effects are really bad for men". Nothing about women though. I'd been on them for years and she had never spoken about those side effects. Looking back, I feel a bit ripped off, yeah, a bit peeved to be honest. (Mandy)*

Despite feelings of anger, a few women reflected on their situation and perceived withholding of information about adverse sexual effects to be deliberate, believing GPs actively did this to protect their mental health. Mandy added:

*I wonder if doctors look at women and think if I tell them they might not take them. I mean doctors have to consider the children and if a woman comes in and says, 'I'm depressed, it's just easier to hand over the medication, do you know what I mean?*

Interestingly, a few women said they were 'owed an explanation' (Helen) and emphasised how having information about untoward sexual effects would not have deterred them from taking medication. Helen continued:

*I really hate the fact that no one told me about this [the sexual side effects]. I reckon I would have still taken the medication even if I had known what it would do. At some stage, I would have then decided if it was still worth it.*



As the majority of women perceived they did not have a legitimate medical reason for their sexual problems, they spent time questioning whether the adverse effects were psychological or caused by factors such as weight gain or other aspects related to their current relationship. For some women, 'searching for answers' continued for several years as outlined by Nadia:

*Once I found out that the Aropax was causing the lack of libido, and all the other sexual problems, I started to look for remedies to try and resolve the problem. Until then, I was just, you know, hiding...I guess. For quite a few years I was secretly hoping it would go away.*

Women were often embarrassed about the sexual nature of their problem and felt uncomfortable communicating with others, which affected their ability to seek help. For Tahlia, the internet became a source of information:

*I found out about the sexual side effects through my group [mental health support group] This guy, in his 50s said something about "... the side effects they don't tell you about" and he mentioned sex problems and libido. That's when I jumped onto the net to find out more. All the information about Zoloft and the associated sex problems were on there - that was a turning point in my journey.*

In contrast with most of the women's experiences, Alison, who had received information from her GP, talked about feeling prepared. Her experiences highlighted the importance of knowing about the adverse sexual effects in advance:

*I remembered exactly what she had told me um, so (pause) I guess to an extent it did help because you know I sort of had that awareness up front that this could be an issue....when it actually came up as an issue I was kind of a bit more prepared for it. If she hadn't said those couple of sentences to me I would be thinking "What the hell is wrong? What's going on? I don't understand this at all?" I'd be pretty confronted and scared by that I guess.*

### *Searching for validation*

Despite being embarrassed about their sexual problems, women described how they sought to address their problem by raising issues directly with their GP; however, their experiences of not having their concerns validated affected how they coped with their difficulties:

*I went to the doctor in the end and said “My sexual desire is really low and they go “yeah, that happens” they kind of shrug their shoulders you know “You can have good mental health or good sex but you can’t have both” kind of attitude. What they don’t tell you is that this is one of the main things that can tear you apart. (Phoebe)*

Tahlia, who received a positive reaction, revealed how this helped:

*It really helped to have the doctor support the idea, that yes, this {sexual problem} could be a side effect. When I had raised it before, she was a bit non-committal about whether it was a side effect, I felt quite relieved to be honest when she agreed with me – I knew then that it wasn’t in my head!*

Some women commented that their concerns had not been validated because of their gender. These women found it hard to cope with the implication that sex was somehow less important for women. As Charlotte explained:

*I felt as though I was the only woman in the Universe who was concerned about the sex problems. I really got the impression that I should just put up with it, you know, go away and just deal with it. I often wonder if a doctor would treat a man the same way?*

Most women reported feeling concerned that GPs believed their problem was psychological; this lack of validation by GPs led these women to seek validation elsewhere. As Lisa highlighted, ‘it’s *the type of problem you keep to yourself*’, as such, women turned to online support groups, which helped reduce their sense of isolation:

*I couldn’t believe it when I found a support group on the net, there were literally hundreds of women on there talking about this stuff and feeling distressed about it- just reading their comments, I’m thumping the desk shouting “yes, this is me, this is my story”. It was such a good feeling to know I was not alone..... (Sonia)*

In contrast, Nadia experienced a positive outcome because her concerns were validated. She provided insight into a conversation that gave her perspective and helped her to cope with the long-term sexual problems she had been experiencing:

*After a while, I had a long conversation with my GP and he really listened to me and helped me to get my head around it all. He said to me “So, how many friends at your age with kids, mortgage and busy lives are having amazing sex all the time? Maybe you are missing something that’s not a reality anymore”. That was a bit of a wake -up call to be honest.*

## Discussion

Women found that interactions with GPs when they were initially prescribed the SSRIs, set the scene for how they coped with adverse sexual effects. Most women described their experiences as inadequate, and in an attempt to reduce feelings of isolation, confusion and distress, they actively tried to make sense of their situation and spent prolonged amounts of time searching for an explanation. This hindered their attempts to prepare for adverse side effects and adopt strategies that would help them to move forward. Our findings support previous research, which found withholding information about adverse sexual effects had the potential to increase isolation and distress amongst patients and inadvertently damage the therapeutic relationship between clinician and patient (Bahrack & Harris, 2009; Higgins, Barker & Begley, 2006). Whilst the specific reasons for withholding information were not included in the aim of our study, recent literature has identified a number of personal, structural and organisational factors that impede or facilitate a proactive discussion of sexual problems (Dyer & das Nair, 2013; Quinn et al., 2011).

According to Heider's (1958) attribution theory, people attempt to provide a causal explanation for unexpected events; hence, it is not surprising women sought a causal explanation for their side effects. Furthermore, Roesch and Weiner (2001) reported that having an explanation for an illness or health problem positively affects coping and psychological adjustment. Our study also supports this finding; women who had positive interactions with GPs, and who were informed about potential sexual problems, felt supported and better able to cope. Happell, Manias and Roper (2004) concurred and highlighted that patients with mental health problems want to know about the adverse drug effects from their medication in order to be better prepared. Indeed, several researchers have suggested that increased knowledge about the adverse effects of medication may improve patient outcomes in patients with mental health problems (Gray, White, Schuklz & Abderhladen, 2010; Quinn et al., 2011). Once the women in our study had an explanation for the adverse effects, they reported being relieved and able to move forward and adjust to these effects.

Women have reported that their experiences of not having concerns validated also impacted on how they understood and initially coped with their difficulties. In some cases, this lack of validation appeared to reinforce the 'double standard' sexual script that views females as sexually passive (McCormick, 2012, p.99). There

are similarities between this study and other studies that reported how mental health clinicians, in particular, perceive iatrogenic sexual difficulties as a male problem (Phillips, 2009; Quinn et al., 2011). Indeed, our findings seem to be consistent with one particular study by Higgins et al. (2006), which reported that mental health clinicians perceived women to be less concerned about iatrogenic sexual difficulties and more willing to tolerate the adverse sexual effects. Our findings suggest that the inadvertent reinforcement of traditional sexual scripts had a negative impact on women's coping experiences and acted as a barrier to the therapeutic relationship. These findings further support the need for GPs to take a proactive and empathic role in discussing sexual problems and to create a safe space for disclosure and validation of such problems.

## **Conclusion**

The adverse sexual effects resulting from SSRI use impact quality of life and are a common cause for non-adherence to medication. Current efforts by GPs to address this issue are most likely inadequate and have an impact on how women cope with their medication. In this context, there needs to be a continual shift towards a patient-centred approach, which emphasises women's active participation in decisions about their health, and seeks to strengthen the therapeutic alliance. Empathic discussions with women and collaborative decision-making can provide an opportunity to improve the management of sexual difficulties associated with SSRI use.

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