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Post-SSRI sexual dysfunction: Patient experiences of engagement with healthcare professionals

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Abstract.
OBJECTIVE: A petition to the European Medicines Agency provided an opportunity to collect reports of a specific adverse event from patients and healthcare professionals, along with details of clinicians' attitudes when asked to endorse patient reports.
METHODS: We approached a cohort of patients reporting post-SSRI sexual dysfunction (PSSD) to an adverse event reporting website, RxISK.org. The responses of patients on their interactions with healthcare professionals were subject to a qualitative analysis.
RESULTS: A total of 62 participants from 23 countries provided details of their experiences. While some had received support and validation of their condition, many described a number of difficulties including a lack of awareness or knowledge about PSSD, not being listened to, receiving unsympathetic or inappropriate responses, and a refusal to engage with the published medical literature.
CONCLUSIONS: Healthcare professionals are nervous about or reluctant to engage with novel problems on a treatment. This is not widely appreciated and the reasons for this concern are not understood.

Keywords: Post-SSRI sexual dysfunction (PSSD), antidepressants, selective serotonin reuptake inhibitors (SSRIs), erectile dysfunction, genital anaesthesia

1. Introduction

Selective serotonin reuptake inhibiting (SSRI) antidepressants produce an almost immediate genital numbing on taking and some degree of altered sexual function. This is ordinarily thought to clear once treatment stops. However, in 2006, reports appeared of cases in which sexual dysfunction remained after treatment stopped and endured for months or years afterwards [1, 2], quickly attracting the name post-SSRI sexual dysfunction (PSSD) [3]. It later became clear that there had been cases of PSSD reported to regulators as early as 1991.

RxISK.org launched in 2012 as a website for patients and doctors to report treatment related adverse events. It was expected that sexual effects on antidepressants would be commonly reported, but unexpected that there would be regular reports of PSSD and comparable problems on retinoids and finasteride. This led to a RxISK publication in 2014 on 120 cases [4] and a follow up article on 300

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cases in 2018 [5]. In 2012, Lareb, the Netherlands Pharmacovigilance Centre, warned about enduring sexual dysfunction [6]. In 2013, the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) mentioned that sexual dysfunction could endure after serotonin reuptake inhibiting antidepressants were discontinued [7]. The US label for fluoxetine also now includes enduring dysfunction [8].

While there is some continuity between the original effects of SSRIs and PSSD, this condition poses a challenge for doctors in that the problem may only appear after the triggering drug has been discontinued and can persist for years after the drug has been stopped. Despite the long-standing example of tardive dyskinesia, it is not unreasonable to think that doctors might be slow to link a medicine to effects happening after its discontinuation.

Because of this, RxISK submitted a petition to the Food and Drug Administration (FDA) and the European Medicines Agency (EMA) in May 2018 aimed at changing antidepressant product labels to warn of enduring sexual effects after discontinuing treatment [9].

Prompted by EMA advice in September 2018 that they had initiated a review of sexual dysfunctions after discontinuation of SSRIs and SNRIs, the authors informed EMA that several subjects who had reported this issue to RxISK were willing to share their name, email address, and details of their case with the agency, and several indicated they believed they could get supporting documentation from a healthcare professional. EMA accepted this offer, gave us questions they would like answers to, and set a deadline of five weeks for submission of materials.

Many reporters to RxISK had previously indicated they had met with disbelief or stronger from clinicians. To ensure the best chance of success when requesting a letter, we suggested making it clear that the healthcare professional did not have to agree that the antidepressant was responsible for the condition. The request was for a letter confirming the person existed, that they had been on a serotonin reuptake inhibitor and that there was no obvious competing explanation for their claimed difficulties.

After subjects submitted named reports to us, along with a letter from a healthcare professional or an indication that they did not believe it worth trying to get a letter, we submitted a total of 82 reports to EMA, of which 32 included supporting documentation from a healthcare professional. These included a mixture of new letters written specifically for the review and existing clinic letters that supported the individual's case.

Subsequently, we sent those who participated a set of questions designed to explore their interaction with clinicians and their efforts to establish the clinical reality of their condition e.g. laboratory tests requested and undertaken. Their responses provide the data for this article.

2. Methods

From the 82 individuals who reported cases to EMA, 77 were invited to take part in a study of their experiences when engaging with healthcare professionals. We restricted input to those subjects with PSSD ($n = 77$) and not persistent genital arousal disorder ($n = 5$).

An online questionnaire was built into the RxISK.org website, but not made publicly visible. A link to the questionnaire and a unique ID code were emailed to all prospective participants. This enquired about the participant's experience of requesting a supporting letter for the EMA review, and details of prior experiences of engagement with healthcare professionals about PSSD (Appendix 1).

Participants were asked whether they had seen a urologist or gynaecologist, whether they had undergone blood tests for hormone evaluation, whether they were continuing to consult with the original prescriber, and whether they had taken any published medical literature to a consultation.

Finally, participants were asked their opinion about their experiences, and whether they felt listened to and satisfied with the care received. There was space to add further comments.

Table 1

Treatments linked to enduring sexual dysfunction

Drug	Male	Female	Total (%)
Citalopram	14	2	16 (25.8)
Escitalopram	11	3	14 (22.6)
Paroxetine	9	0	9 (14.5)
Sertraline	6	2	8 (12.9)
Fluoxetine	4	2	6 (9.7)
Venlafaxine	4	0	4 (6.5)
Duloxetine	1	2	3 (4.8)
Amitriptyline/chlordiazepoxide*	1	0	1 (1.6)
Clomipramine	1	0	1 (1.6)

*Combined in the same drug product.

3. Results

Completed questionnaires were received from 62 subjects (51 male and 11 female). Ages ranged from 19 to 48 years (median 31 years) for females and 20 to 68 years (median age 35) for males.

Individuals from 23 countries responded: Europe ($n = 42$), North America ($n = 10$), Oceania ($n = 4$), Asia ($n = 3$), and South America ($n = 3$).

A breakdown of the reported drugs is shown in Table 1.

Twenty-six participants (19 male and 7 female) approached a healthcare professional to request a letter. Sixteen (12 male and 4 female) were successful. A supporting letter for one of the participants (P48) was written by one of the authors (DH).

Reasons for not approaching included: the participant did not think their doctor would help ($n = 22$), they already had existing documentation ($n = 5$), issues with timescale or availability of a healthcare professional ($n = 5$), the participant did not want to jeopardise their relationship with their doctor ($n = 1$), the doctor charges for letters ($n = 1$), and other reasons ($n = 2$).

Some indicated they have had several different clinicians over the decade or more that they have had PSSD. Nine participants were still seeing the doctor who originally prescribed their antidepressant.

Fifty-three participants (85%) had undergone a blood test for hormone evaluation. One participant had requested a blood test but had been refused.

Forty-four participants (71%) had seen a urologist or gynaecologist. Two had been refused, with one reportedly being asked "what are they going to do about it?" (P60)

Nine themes emerged: requesting a letter, awareness/knowledge of the condition, not being listened to, insensitive responses, suggested return to medication, response to published medical literature, lack of treatment, no longer mention it, and impact of invalidating responses.

All quotes are presented without correction to spelling or grammar. Words that have been removed for brevity or anonymity are marked with square brackets.

3.1. Requesting a letter

Several participants were seeing healthcare professionals already aware of their condition:

> "I asked my GP and psychologist. They already knew that i had PSSD and wrote a supporting letter." (P32)

One participant noted that his doctor seemed concerned about attributing the problem to the antidepressant:

> "I asked my new psychiatrist if he is able to provide me kindly with the letter. He agreed but seemed to feel relief at the same time that he is not pushed to directly say that SSRI caused my condition." (P45)

Some were unsuccessful in getting a supporting letter for various reasons:

> "The GP said she did not want to because she was not the person who prescribed me the psychiatric drugs." (P8)

> "My GP told me to wait till I get my evaluation from an urologist." (P40)

Two participants wrote to their GP rather than visiting in person, with one elaborating on the reason for taking this approach:

> "The reason I wrote to them and sent it, rather than doing it face-to-face, was I felt that they would not feel so pressured, or have reason to be defensive, and that it would give them more time to digest the information and end up writing a letter." (P6)

However, he reported: "I never heard back from the GP."

3.2. *Awareness/knowledge of the condition*

Many participants found that a lack of awareness and knowledge about PSSD among healthcare professionals was a significant barrier. They reported being told that such a complication from antidepressants was "impossible" and that healthcare professionals had never heard of such a problem.

One said their GP stated that SSRIs were "harm free" and "laughed at the idea they could make long term changes to a patient." (P19)

Some had difficulty convincing their original prescriber that the treatment had caused the problem:

> "I talked to my primary care doctor and she doesn't believe that my symptoms could be related to the medication that was discontinued years ago. She was the doctor who prescribed the medication." (P44)

Participants were often told that the problem was all in their mind:

> "he glibly stated it was all in my head, if i just press on all will be ok.. on saying the latter, he did so with the door opened to usher me out and away faster" (P20)

A finding of normal blood work only served to reinforce the notion that the sexual dysfunction must be psychological rather than physical:

> "Every time i have mentioned it to a GP they have referred me to a psychiatrist, after doing some bloodwork which always came back normal." (P4)

On some occasions, other physical conditions were suggested:

> "he smiled and suggested maybe i have a sexual disease." (P21)

Although some healthcare professionals were unwilling to accept the protracted nature of the participant's condition, they nevertheless seemed to recognise that sexual function could "take a while to return to normal" and that sexual side effects "might cause problems for a few months after ending SSRI drugs":

> "The GP told me that actually it is not uncommon for it to take a year for people to get back to normal." (P6)

Some participants had seen psychosexual therapists with mixed results. Four had been helpful in recognising that the problem was pharmacological in origin and not psychological. Other encounters were less successful:

> "The psychosexual counsellor wrote to my doctor saying that the approaches weren't working because I was putting the blame on SSRIs." (P43)

In some cases, participants found that even though their doctor had not seen or heard of the condition before, they were still able to recognise the problem as a drug effect:

> "I spoke to my GP and she agreed to read studies about PSSD and confirmed its existence, but she never had a patient with this condition. She was very supportive and referred me to an urologist." (P40)

After being laughed at by a previous doctor while describing the sexual dysfunction, one participant eventually found a helpful GP:

> "she was a lot more sympathetic and gave me the first honest response - 'It may never be the same again'." (P60)

A participant described visiting a medical centre for another issue, but was scheduled to see an OBGYN after mentioning PSSD when setting up the appointment:

> "There I was told that sometimes sexual function does not return to normal after SSRI withdrawal, that they know this happens but they do not know why." (P47)

One participant described being referred to healthcare professionals who were initially skeptical, "but now admit they are seeing more patients with the same condition as me and have cut back on prescribing this type of medication." (P51)

3.3. Not being listened to

Participants said that healthcare professionals "ignored what I said", "avoided my questioning" and were "not listening".

One participant reported that a doctor had failed to properly understand his symptoms and incorrectly recorded details of his condition in the medical notes:

> "he didn't even note on my records that I told him it had been caused following my commencing [the antidepressant]. Instead he inaccurately noted that I was "worried about lack of sex drive and erections" I had not told him that my libido had suffered as this was not the case but he immediately assumed that it was psychologically caused and noticed he "advised it was part of mental illness"" (P9)

There was concern that the dysfunction was being dismissed as a psychological issue without a proper understanding of the sexual symptoms or the specifics of the original issue:

> "I have fairly mild OCD, but OCD never made my genitals go numb, or orgasms pleasureless, or to have zero sex drive" (P25)

There was also concern that the timeline of events was being ignored, and in particular, the fact that participants had completely normal sexual functioning prior to treatment:

> "many times i told them that during depression i never feel any issue regarding of my sexual activity" (P12)

Another participant echoed this point by noting that throughout "life's ups and downs", they had never experienced any sexual issues "until that day of taking the first pill". (P31)

One participant felt that the doctor had failed to understand the impact of the condition:

> "I don't think she appreciated the seriousness of the situation. Almost like it is just a minor inconvenience to me." (P6)

Some found that healthcare professionals were completely unwilling to engage with the issue, with one recalling an uncomfortable experience with a urologist:

> "Whenever I brought up my sexual loss and the timeline of events with regards to antidepressants, he blanked me. Not once did he even say I wrong in blaming the meds, he didn't even acknowledge what I was saying. He seemed to have no interest in my sexual dysfunction at all. His complete disregard made me feel not only was I up against my sexual loss, but also up against a system that wasn't listening." (P43)

Another described unhelpful experiences with psychiatrists:

> "I visited several psychiatrists to discuss PSSD. One [. . .] dismissed PSSD as impossible and suggested that I was asexual and traumatised. Another could not engage with the notion of SSRI's having a long-term impact, instead pretending not to hear me or move onto another topic of conversation. This was a surreal experience." (P53)

Some participants were given the impression that doctors did not want to hear about the condition or "wanted to keep this topic away from them". A participant reported that a GP said:

> "I have noticed from your records that you have spoken to some other doctors from here about this. I think you shouldn't keep bringing it up." (P25)

Another noted a reluctance to implicate antidepressants:

> "There is a lot of silence. Almost as if they were afraid to admit that the antidepressants caused all of this." (P14)

3.4. Insensitive responses

Despite the sensitive nature of the condition and the serious impact that it can have, there were descriptions of unsympathetic or inappropriate responses from clinicians.

A participant described experiencing "erectile dysfunction and numbness in my penis" while taking an antidepressant. He said that none of the symptoms existed before being prescribed the drug, but they had remained despite tapering several months earlier:

> "I visited my psychiatrist [. . .] under whose supervision I took the drug for 8 years, and when I informed him about my persistent sexual dysfunctions, he said I was talking absolute rubbish and they were my psychological constructs." (P42)

Another reported that his GP "chuckled about the sexual dysfunction". He subsequently discussed his problem with a psychiatrist:

> "he said that he had never heard of this problem before. When I described exactly how [the antidepressant] had affected me sexually, i.e. lack of libido and no reaction to sexual stimulation...he laughed at me and said I was very lucky if experienced that level of libido before." (P36)

There were reports of doctors becoming defensive or angry. One participant spoke to her prescribing psychiatrist about the problem in the months after stopping the antidepressant:

> "He treated me like I was making it up or out to get him. He seemed more invested in avoiding being blamed than about my welfare." (P47)

Participants from two different countries described receiving comments from gynaecologists suggesting a change of partner:

> "I asked my gynaecologist to prescribe blood exams for me although he also said it is all in my head and that i should change boyfriend." (P39)

> "I mentioned my gynaecologist that I have problems with my libido and sexual functioning. He answered that "your earlier symptoms of depression are coming back (I was not diagnosed with depression) or maybe you should change a partner"." (P7)

Two participants reported asking for a change in medication while originally on the antidepressant due to sexual side effects, but were refused:

> "She said she is not interested in my sexual problems and doesn't consider it an important issue. I asked her to change medication she rejected it in the strongest terms." (P45)

3.5. Suggested return to medication

Several participants reported being advised to reinstate antidepressants:

> "I've told my psychiatrist when i left the pills and noticed like 2 months after that my sexuality hadn't returned, she said it was impossible and then started saying i should come back to medication as i was getting paranoid about the subject." (P3)

Two participants described being given antipsychotics having been told their problem was psychosomatic:

> "Two of the psychiatrists who thought that my problem was psychosomatic gave me antipsychotics [. . .] Also a third psychiatrist who was the one who gave me [the antidepressant] not only thought that my problem was psychosomatic but after 2 visits had the idea that i must doing electroconvulsive therapy for fixing the problem." (P33)

> "they done blood tests, checked hormones and sent me to an urologist [. . .] but everything was "fine" so they explained my symptoms as psycosomatic, so they prescribed me trazodone+bupropion firstly, then aripiprazole, without any improvements." (P24)

3.6. Response to published medical literature

Thirty-eight participants (61%) took medical literature about PSSD to consultations, reporting in some instances that it was helpful in raising awareness of the condition:

> "My GP believed in what i show her" (P11)

> "She started to believe me." (P17)

> "My Doctor acknowledged that it was the second time now he'd heard something" (P37)

Others had partial success after providing literature but noted that their healthcare professional remained skeptical:

> "He finally believed me. But said he couldn't help me and he was still not 100% sure about it." (P32)

Many participants had negative responses:

> "They refused to read it" (P10)

> "Most of the doctors I took it to didn't even look at it." (P23)

> "The GP said antidepressants do not cause persistant or permanent sexual dysfunction. Also said that antidepressants don't cause any effect for four to six weeks despite my sexual side effects taking effect on the same day as the first pill. After hearing this I researched these things he claimed could not happen and when I took in literature on the topics he was not interested in seeing it and used the term quacks from the internet" (P31)

A participant described sending an email to his psychiatrist with "a couple of links to the medical studies and reviews about PSSD", but decided not to see her anymore after receiving what he described as an "unbelievable harsh answer":

> "If you wish to have such "syndrome" continue what you are doing... read obscure studies and reviews in obscure databases and I can guarantee to you that you will have it till the end of your life!" (P45)

One participant from a non-English speaking country did not take published literature to a consultation because "it's difficult to find an English-speaking doctor".

3.7. Lack of treatment

Some felt they had been listened to but were disappointed with the lack of treatment options:

> "They accept it, but they cannot help." (P17)

> "My doctor listened to me but failed to treat PSSD even in three years." (P16)

> "I have spoken to two GP's and have also had a referral to the local urologist. Whilst sympathetic, none of those visited were able to assist." (P58)

Despite a failure to remedy the problem, one participant recognised that their experience with healthcare professionals had been positive in comparison to others they were aware of:

> "They could not help me because today there is no cure. I think I was "lucky" with them if I compare with many professionals who simply deny or tease." (P1)

3.8. No longer mention it

Some participants reported that they no longer mention PSSD to healthcare professionals due to repeated denials of their condition:

> "I have spoken to 3-4 different psychiatrists, and a few psychologists, as well as some GP's. I have had PSSD for over ten years so i don't remember the exact numbers. [. . .] Nowadays i don't bother bringing this problem up with my doctors as it has always been in vain." (P4)

> "I dropped the issue since every healthcare professional seems unhelpful and ignorant about the subject." (P39)

Due to a lack of treatment, there was a feeling that there was nothing to be gained by continuing to seek medical assistance:

> "She said to me to go back if things did not get better. But I have not gone back, because I know she has no cure for me." (P6)

3.9. Impact of invalidating responses

Encounters with healthcare professionals were described as a "huge battle" and "humiliating". Participants described feeling "frustrated" and "helpless".

> "I am very dissatisfied and feel that most healthcare professionals are absolutely not willing to even listen to my story. It is very difficult to talk to them." (P52)

The denials and lack of support added to the distress of having the condition:

> "I feel that repeatedly not being believed has significantly increased the distress that living with PSSD has had on me, and has almost been as distressing as living with the condition itself." (P25)

One participant said they were "disgusted" with the interactions they have had with doctors in regard to PSSD, and felt "insulted" and "made fun of".

There was also anger at not having been informed of the risk when the antidepressant was first prescribed:

> "I'm quite angry with the doctors I have visited so far, but especially my psychiatrist who didn't inform me about the possible long term side effects the pill can cause. I never had any problems with my sexual functioning before taking the medication and I don't think that genital anesthesia can be considered a symptom of depression." (P7)

4. Discussion

Time constraints, confidentiality issues, and the sensitive nature of the condition mean that the sample of individuals here is a subset of those affected and in contact with RxISK, which in turn is a subset of those affected by the condition. We have no reason to believe however that those responding here are atypical of the larger universe of PSSD patients. The reason to undertake this survey stemmed from an awareness that clinical responses like this were not atypical for patients with PSSD and indeed not atypical for patients with adverse effects in general.

There are two ways to view some of the responses. One is that they are understandable reactions from clinicians, given that the drug claimed to be triggering the problem may have been out of the patient's body for months or years, given also that there is no ready way for most doctors to examine the claimed problem, and finally given that the patients come with the stigma of a nervous problem.

An alternate view is that the apparent improbability of a link between the treatment and condition, or of being able to establish the link, elicits a latent clinical bias toward patients that might not surface in other clinical encounters.

In 1991, defending Prozac in the wake of compelling case reports that it caused suicidality, Eli Lilly pitched company trials against case reports, inviting doctors and the public to decide whether they were going to believe the anecdotes or the science. Since then, it has been more difficult for doctors to engage with patients reporting events not found in the drug's label. As a result, a range of problems from impulse control disorders on dopamine agonists, to suicidality on antidepressants now take decades to be accepted clinically, where, before 1991, significant novel adverse effects were accepted with a year or two of first reporting.

Although convincing case reports remain central to legal criteria for establishing cause and effect, medical journals stopped taking case reports, and turned to controlled trials and meta-analyses of trials. Drugs bulletins, a source of information on adverse events dried up while doctors increasingly were supplied with guidelines which primarily cover the benefits of treatments and not their adverse effects.

These data suggest that further study of doctors' views on adverse events, the merits of endorsing them, and how to establish them, is warranted. Generalists are likely best placed to intervene at the earliest opportunity in the event of hints of a problem, and also best placed in terms of access to databases and clinical experience to pinpoint treatments that prevent conditions like PSSD developing or that ameliorate the difficulties once they develop.

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Conflict of interest

All three authors are linked to RxISK.org. None have any consultancy or other links to groups with an interest in these results.

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Appendix 1

The Questionnaire

1. **As part of your Report for EMA/FDA, did you visit a healthcare professional to get a supporting letter?**
If you provided some existing documentation instead, select No.
[yes/no]
If yes, go to question 1.a.
If no, go to question 1.b.

1.a. **Tell us what happened.**
What type of healthcare professional? (GP, psychiatrist, psychologist, neurologist, etc.) How did they react? What did they say? Please tell us the story.
[free text]

1.b. **What was the main reason you didn't?**
A visit to my doctor costs too much
I didn't think my doctor would help
I was too embarrassed to discuss it
I didn't want to jeopardise my relationship with my doctor
I supplied some existing documentation instead
Other:

2. **If you have previously spoken to healthcare professionals about your PSSD, tell us about those experiences.**
What type of healthcare professionals? (GP, psychiatrist, psychologist, neurologist, etc.) How did they react? What did they say? Please tell us the story.
[free text]

3. **Are you still seeing the doctor who originally prescribed your antidepressant?**
[yes/no]
If yes, go to question 3.a.
If no, go to question 4.

3a. **Does your original prescriber agree that you have PSSD?**
Yes [go to question 4.]
Not completely, but he/she thinks it's possible [go to question 4.]
No [go to question 3.b.]

3b. **If your original prescriber doesn't believe that you have PSSD, is there a reason you haven't changed to a different doctor?**
[free text]

4. **Have you ever seen a urologist/gynaecologist about your PSSD?**
[yes/no]
If yes, go to question 5.
If no, go to question 4.a.

4a. Why not?
Too expensive
My doctor didn't suggest it and I didn't ask
I asked for a referral but my doctor refused
Another doctor already diagnosed me with PSSD so there was no need
Other:

5. Has a doctor sent you for blood tests to check your hormones?
[yes/no]
If yes, go to question 6.
If no, go to question 5.a.

5a. Why not?
Too expensive
My doctor didn't suggest blood tests and I didn't ask
I asked for blood tests but my doctor refused
My doctor diagnosed me with PSSD without needing blood tests
Other:

6. Have you ever taken any published medical literature about PSSD to show your doctor?
[yes/no]
If yes, go to question 6.a.
If no, go to question 7.

6a. What happened when you took published medical literature to show your doctor?
How did they react? Did they look at it? What did they say?
[free text]

7. Overall, how to do feel about the experiences you've had with healthcare professionals in relation to your PSSD?
Did they listen to you? Are you satisfied with the care you received?
[free text]

8. If there is anything else you want to say that we haven't asked about, please write it here:
[free text]