



**All-Party Parliamentary Group
for Prescribed Drug Dependence**

**Antidepressant Withdrawal:
a Survey of Patients' Experience by the All-Party
Parliamentary Group for Prescribed Drug
Dependence**

September 2018

The All Party Parliamentary Group for Prescribed Drug Dependence

The following MPs and Peers are officers of the APPG for PDD:

- Chairman: Sir Oliver Letwin MP (Con)
- Co-chair: Norman Lamb (Lib Dem)
- Co-chair: Luciana Berger MP (Lab)
- Co-chair: Paul Flynn MP (Lab)
- Co-chair: Baroness Masham of Ilton
- Co-chair: Earl of Sandwich

This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the group. On behalf of the APPG-PDD, the report was researched and written by Dr James Davies, Dr Regina Pauli and Luke Montagu, with additional research support from Ria Paige Lindsay and Brett Raymond-Barker.

Contents

Introduction	4
Section One: Quantitative Data	5
1. Sample.....	6
2. Methods.....	6
3. Results.....	7
3.1. Information on Withdrawal Pre-treatment.....	7
3.2. Explanations for Antidepressant Treatment Given by Doctors.....	7
3.3. Advice about Withdrawal Provided to Patients by Doctors.....	8
3.4. Withdrawal Experience.....	9
3.5. Symptoms of Withdrawal.....	9
3.6 Sources of Support for those Experiencing Withdrawal.....	9
4. Discussion.....	11
Section Two: Qualitative Data	12
5. Question One: ‘Please describe the impact withdrawal has had on your life in your own words’	13
5.1. Theme 1: Withdrawal as Incapacitating.....	13
5.2. Theme 2: Disillusionment with medical professionals due to the mismanagement, misdiagnosis and denial of withdrawal.....	14
5.3. Theme 3: The impact of withdrawal on relationships.....	18
5.4. Theme 4: The impact of withdrawal on work and finances.....	21
5.5. Theme 5: The difficulties and implications of withdrawing.....	23
5.6. Theme 6: Negative outlook on life/feelings of hopelessness.....	25
6. Question Two: ‘Have you received any support from NHS health services other than your doctor/psychiatrist? Please describe the nature of any support you received’	28
7. Discussion.....	32
8. Conclusion.....	35

Introduction

In Sep 2017 the All-Party Parliamentary Group for Prescribed Drug Dependence, in conjunction with researchers at the University of Roehampton, undertook one of the largest direct-to-consumer international surveys of its kind into withdrawal from psychiatric drugs (antidepressants, antipsychotics and benzodiazepines). There were approximately 1700 respondents, 319 of whom were antidepressant users living in the U.K. This report will summarise both the quantitative and qualitative data on the U.K. antidepressant users (319) who reported their withdrawal experience.

Section One of this report will focus on the quantitative data and Section Two on the qualitative. While the quantitative data will report the usefulness of patient/doctor interactions, levels of withdrawal severity, duration etc., the qualitative data will give a more human perspective on the experiences most commonly reported by those with lived-experience of antidepressant withdrawal, from how their withdrawal was experienced, to how it was managed clinically and how it could be better managed in the future.

Section One

Quantitative Data

Key Points:

- 64% of patients claimed not to have received any information from their doctors on the potential risks/side effects of the antidepressants they were prescribed (66.5% in Dataset 1 and 59% in Dataset 2)
- 25% were given no advice at all about how to withdraw from their antidepressants (19% Dataset 1 and 31% Dataset 2)
- Only 3% felt the amount of information given to them about withdrawal was 'moderate' to 'a lot' (3.8% in Dataset 1 and 1.5% in Dataset 2)
- 34% were given predominantly biological explanations for why they were prescribed antidepressants (32.4% in Dataset 1 and 36.5% in Dataset 2), with 40% being told they had a chemical imbalance (39% in Dataset 1 and 40.8% in Dataset 2)
- 36% reported they were advised to reduce the dose over a few weeks or less (44% in Dataset 1 and 27.5 in Dataset 2), while 7% were told to withdraw cold-turkey (8.6 Dataset 1 and 6% Dataset 2)
- 47% experienced withdrawal symptoms for more than one year (38% in Dataset 1 and 56% in Dataset 2)
- On a scale of severity from 0-10 (10 being the most severe withdrawal), the mean average was 9 points (8.61 for Dataset 1 and 8.83 for Dataset 2)
- 30% reported being off work indefinitely as a result of antidepressant withdrawal (25% in Dataset 1 and 35.8% in Dataset 2). An average of 6 additional appointments being made as a result of withdrawal.
- 76.2% of participants considered a National Drug Telephone would be helpful, including 31.9% who thought it would be extremely helpful
- Nearly all who had accessed NHS Choice or NHS 111 for withdrawal support found the service unhelpful or extremely unhelpful

1. Sample

The quantitative data set down here pertains to U.K. antidepressant users only. There are two key datasets in this section, which we label Dataset 1 and Dataset 2.

Dataset 1 was derived from people who only took antidepressants, while Dataset 2 was derived from people who have taken antidepressants in combination with other prescribed psychoactive drugs, such as benzodiazepines and antipsychotics. We have separated the two datasets, since Dataset 2 comprises experiences resulting from poly-pharmacy, which makes it harder to determine the extent to which antidepressants were solely responsible for the withdrawal experiences reported. No such complications exist with respect to Dataset 1, as the people from whom these data were derived reported solely taking antidepressants.

2. Methods

The quantitative data were obtained from a large online survey of people self-identifying as experiencing withdrawal from psychoactive drugs, in particular antidepressants and benzodiazepines. It was an open access survey, undertaken by nearly 1700 service users (n= 1669) and was initially distributed via three well-known withdrawal support/advice internet sites. In this section we report the data pertaining to UK residents who had been prescribed antidepressants (n=319). 227 (71.2%) were female (age range 21- 80, mean 45.52, s.d. = 12.63), 87 (27.3%) male (age range 21-86, mean 44.44, s.d. 12.61) and 5 (1.4%) others or preferred not to say. 41.7% had taken prescription drugs for more than 10 years, 32.9% for between 3 and 9 years and 25.4% for two years or less.

185 (58%) had been prescribed only antidepressants, whereas 42% (n= 134) had been prescribed other drugs in addition to antidepressants (Benzodiazepine 73.1%, Z-drug 29.1%, Opioids 17.2%, Antipsychotics 45.5%, Stimulants 3% and Other 21.6%). Of these 134 participants 42.5% (n=57) had been prescribed at least one other category of drug in addition to antidepressants, 32.8% (n= 44) at least two other types of drugs and 18.7% (n=25) had experience of at least three additional types of prescription drugs. From now on, the single drug type (antidepressants only) is denoted as Dataset 1, and the multiple drug type group as Dataset 2.

Participants in Dataset 1 are clinically less complex than those in Dataset 2, with 51.9% (n=96) of participants having been diagnosed with a single disorder, compared with only 22.4% (n=30) in Dataset 2. In Dataset 1, 28.1% (n=52) of participants were diagnosed with depression only, 15.7% (n= 29) with anxiety only and 26.5% (n=49) had received a dual diagnosis of anxiety and depression. In Dataset 2 single diagnoses of depression or anxiety amounted to 4.5% (n=6) and 7.5% (n=10) respectively, and dual depression and anxiety diagnoses had been received by 14.9% (n= 20) of the multiple drug sample. 29.7% of Dataset 1 and 73.1% of Dataset 2 had been prescribed medication for multiple reasons including panic disorder, insomnia, pain, bipolar disorder, stress disorder and/or unspecified reasons. However, there were no differences between the datasets in terms of how long they have been taking their prescription drugs (modal value 'between 10 and 20 years' for both Datasets).

At the time of completing the survey, 80 participants (43.2%) reported to have withdrawn from all drugs in Dataset 1 and 56 (41.8%) in Dataset 2. In addition, 10.8% (n=20) in Dataset 1 had withdrawn from some antidepressants they had previously been prescribed and 34.1% (n=63) were considering withdrawal. In Dataset 2, 29.9% (n=40) had experience of withdrawal from some drugs and 16.4%

(n=22) were considering withdrawal. In both 11.9% (22 and 16 participants, respectively) were still taking the prescribed drug(s) and not considering withdrawal. Amongst long-term users (> 2 years, n= 153 in Dataset 1 and n= 117 in Dataset 2), 49.7% (n=77) had fully or partially withdrawn from antidepressants (Dataset 1) and 70.1% (n=81) from multiple drugs.

3. Results

In this section we will consider the communications participants had with their doctors about the causes of the issues for which they were prescribed the drugs and information received on possible risks and side/withdrawal effects.

3.1. Information on Withdrawal Pre-treatment

Our data indicate that initial prescribing and withdrawal management was predominately undertaken in primary care. Of the UK respondents who answered the question, 'Who initially diagnosed you and prescribed your medication', 76.4% indicated it was their G.P. and 23.6% their psychiatrist. Of the UK respondents who answered the question: 'Which kind of doctor did you primarily consult with during withdrawal', 87% indicated their G.P., 5.6% their psychiatrist, and 7.4% indicated both their G.P. and psychiatrist in equal measure.

With respect to the information on antidepressant withdrawal dispensed by doctors, respondents indicated that information was minimal at best.

A full 66.5% (n= 123) of participants in Dataset 1 and 59% (n=79) in Dataset 2 claimed not to have received any information about potential risks or side effects of the drug(s) they were prescribed, whereas 29.7% (n=55) and 39.6% (n=53) felt they had been given 'a little bit' of information.

Only 7 (3.8%) participants in Datasets 1 and 2 (1.5%) felt the amount of information given to them was 'moderate' to 'a lot'. Furthermore, 33% (n=61) of participants in Dataset 1 and 28.4% (n=38) in Dataset 2 felt they had not been given any explanation of the causes of the problems for which they were being prescribed drug(s).

3.2. Explanations for Antidepressant Treatment Given by Doctors

A large proportion of participants were given predominantly biological explanations (32.4% in Dataset 1 and 36.5% in Dataset 2). Table 1 shows the breakdown of specific causes which participants reported having been told (they could report multiple causes). In the table those participants who have been on prescription drugs for 10 years or more are reported separately from those who started a drug regime within the last 9 years, because we wanted to examine the effect of changes in clinical guidance in more recent years. It can be seen that chemical imbalance and genetic/inherited problem explanations have reduced significantly, whereas explanations relating the illness to specific events have increased significantly across the two time periods.

Table 1: Medical professionals' accounts of causes of illness for which drugs were prescribed split by whether initial diagnosis was made within the last nine years or ten or more years ago (Dataset 1 = Antidepressants only, Dataset 2 = multiple drugs)

Explanation of cause of illness	Dataset 1 (n= 185)		Dataset 2 (n=134)		Total (n=319)	
	9 yrs or less (n = 115)	10 yrs or more (n = 70)	9 yrs or less (n = 71)	10 yrs or more (n= 63)	9 yrs or less (n= 185)	10 yrs or more (n= 134)
Chemical imbalance	39.1%	51.4%	40.8%	57.1%	39.8%	54.1%*
Genetic/ inherited problem	8.7%	10%	12.4%	27%	10.2%	18%*
Something wrong with the brain	8.7%	7.1%	19.7%	30.2%	12.9%	18%
The way you think	11.3%	5.7%	21.1%	17.5%	15.1%	11.3%
Anxious disposition	12.2%	12.9%	25.4%	11.1%	17.2%	12%
Reaction to specific events	29.6%	15.7*	40.8%	28.5%	33.9%	21.8%*
No explanation	33.9%	31.4%	32.4%	23.8%	33.3%	27.8%

* Denotes statistically significant differences ($p < .05$) in proportion across the highlighted cells with Fisher's exact test

3.3. Advice about Withdrawal Provided to Patients by Doctors

Participants were asked what advice they were given by their doctor or psychiatrist about the best way to withdraw from the drug(s). Only 12.9% (n=36) of the participants who gave a response (n=280) were advised to reduce the dose slowly over several months or more, compared with 35.7% (n= 100) who reported they were advised to reduce the dose over a few weeks or less. Percentages for all response options are shown in Table 2.

Table 2: Advice received on how to best manage withdrawal from prescription drug.

	Dataset 1 (n= 163)	Dataset 2 (n=117)
No advice was given	19 %	30.8%
I was told not to stop	7.4%	12.7%
I was told to reduce the dose over a few weeks or less	40.5%	29.1%
I was told to reduce the dose slowly over several months or more	15.3%	9.4%
I was told to go 'cold turkey'	8.6%	6%
I was told something else	9.2%	10.3%

Table 3: Advice received by Long-term users (>2 years) on how to best manage withdrawal from prescription drug:

	Dataset 1 (n= 134)	Dataset 2 (n=102)
No advice was given	15.7%	31.4%

I was told not to stop	7.5%	15.7%
I was told to reduce the dose over a few weeks or less	44%	27.5%
I was told to reduce the dose slowly over several months or more	17.2%	9.8%
I was told to go 'cold turkey'	6%	4.9%
I was told something else	9.7%	10.8%

3.4. Withdrawal Experience

The large majority of participants reported having experienced withdrawal symptoms (Dataset 1: 84.9%, Dataset 2: 84.3%). In the antidepressants-only dataset 38.6% experienced withdrawal symptoms for more than one year, whilst 32.4% felt they lasted for up to three months, compared with 56.6% of the multiple drug dataset undergoing withdrawal in excess of one year. ⁱ

Participants were asked to rate the severity of impact of their withdrawal symptoms on their lives on a 11 point scale (0 = not at all, 10 = very severe impact). The mean severity for the antidepressants dataset was 8.61 (S.D. = 1.9) and 8.83 (S.D. = 1.75) for the multiple drugs dataset. The modal value for both datasets was 10. ⁱⁱ

3.5. Symptoms of Withdrawal

The most commonly reported symptoms of withdrawal (>70% of both datasets) were agitation, severe nervousness/anxiety, confusion/trouble concentrating, memory problems/brain fog and tiredness/fatigue and light headedness/dizziness. In addition, more than 65% in both samples reported experiencing intrusive thoughts, a sense of detachment/unreality or depersonalisation, insomnia, bouts of crying or tearfulness, racing thoughts and feelings of vertigo. The large majority of participants (>90%) attributed these symptoms to being caused by withdrawal.

Participants were asked how many additional appointments with their doctor they attended as a consequence of their withdrawal. Although the number of additional appointments varied widely, there is evidence that withdrawal may result in numerous additional appointments (median = 4.5 additional appointments in the antidepressant dataset (mean = 8.24 (s.d. = 10.12) and 7 in the multiple drugs dataset (mean = 12.52, S.D. = 13.33)).

Similarly time taken off work varied considerably with 25.9% and 14.7% respectively in Dataset 1 and Dataset 2 reporting taking no time off work due to withdrawal symptoms. However, 25% and 35.8% (Dataset 1 and 2 respectively) reported being off work indefinitely. The median time taken off work was one month in the antidepressant-only dataset but considerably higher in the multiple drug dataset.

3.6. Sources of Support for those Experiencing Withdrawal

Respondents found informal sources of support most helpful in coping with their withdrawal symptoms. This included freely available information on the internet, online peer support and support from family and friends. Whilst participants considered almost all sources of support listed in the survey as helpful (with the possible exception of doctor's leaflets), there were issues with access. Low access was reported with respect to trained counsellors, in person support groups, telephone support and NHS 111. Leaflets from doctors, support from doctor or psychiatrist,

signposting to local services NHS Choices and NHS 111 were generally considered not helpful. Participants were divided on the helpfulness of recommended websites, tapering protocols, in person support groups and telephone support, with approximately half considering these helpful and half not. However, given that all listed sources were considered potentially helpful, this is more likely to be reflective of issues with access and/or experience of the quality of the provision.

76.2% of participants in the antidepressant-only dataset considered a National Drug Telephone helpline as helpful including 31.9% who thought it would be extremely helpful. 23.8% considered such a provision not be helpful. However, 90% felt that an accompanying website would be helpful including 32.4% who thought it would be extremely helpful. The multiple drug dataset was more positive about both, 50% considered a national helpline extremely helpful and overall 90% felt it would be helpful. An accompanying website was considered helpful by 93% in this dataset including 45.5% who thought it would be extremely helpful.

Table 4. What was considered helpful or unhelpful (for self and others)

	Considered Helpful for Self			Considered Helpful for Others	
	Not Accessed	Helpful	Not Helpful	Helpful	Not Helpful
Information Leaflets provided by my doctor/psychiatrist	51.8	1.1	47.1	61.8	38.2
Information freely available on the internet	3.9	84.2	11.8	91.6	8.4
Information on recommended websites	19.8	55.4	24.8	90.9	9.1
Support from my doctor/ psychiatrist	7.6	15.8	76.6	68.6	31.4
Support from other health services	43.2	11.4	45.4	76.5	23.5
Online peer support	22.1	74.5	5.4	94.2	5.8
Support from a counsellor trained in prescribed drug withdrawal	71.8	10.1	18.1	88.3	11.7
Support from family members and/or friends	8.7	63.0	28.3	85.5	14.5
Tapering protocols and advice	31.4	33.9	34.7	86.	14
In-person support groups	70.9	15.1	14.0	83.1	16.9
Telephone support	61.5	14.7	23.7	77.5	22.5
Signposting to local services	57.0	6.1	36.8	69.5	30.5
NHS Choices	42.9	5.1	52.0	--	--
NHS 111	67.8	2.5	29.7	--	--

4. Discussion

These datasets reveal a deep deficit in the current understanding of the potential harms of antidepressants by doctors and psychiatrists. Most patients (64%) claim that they did not receive any information on risks or side effects from their doctors, which suggests that many patients may not be fully informed when selecting antidepressant treatment.

In addition, it appears that doctors are continuing to promote the belief that mental health problems are biological illnesses, despite the lack of evidence in support of this position.ⁱⁱⁱ Around half of the survey participants were told that their original symptoms were caused by a chemical imbalance, a genetic problem or something wrong with the brain. This position appears to be changing, however, with diagnoses in the last ten years less likely to be coupled with a biological explanation.

Furthermore, the data suggest that many doctors provided no advice regarding withdrawal from antidepressants (19% Dataset 1, 30.8% Dataset 2), while a significant proportion were told to taper over a few weeks or less (15.3% Dataset 1, 29.1% Dataset 2).

It is also worth noting that a higher proportion of Dataset 2 participants were given no advice on withdrawal, which perhaps reflects the greater complexity of withdrawal when considering more than one psychiatric drug, and the increased reluctance of doctors to give advice in these circumstances.

Turning to the patient experience, it is clear from this survey that some patients experience very severe, long lasting withdrawal symptoms that can lead to indefinite disability (a fact that will be explored further in Section Two). While the responses to this survey may well be affected by selection bias (since the respondents have already identified themselves as individuals suffering from withdrawal to the extent they have sought online support) it is striking that 38.6% of the antidepressant-only dataset reported symptoms lasting more than one year, while 56.6% of the multiple drug dataset reported the same outcome.

Furthermore, respondents rated the severity of their symptoms as almost 9 out of 10, suggesting that for some people who take antidepressants, withdrawal can lead to very extreme levels of suffering and distress. In our sample, this led to 25% of the antidepressant-only dataset and 35.8% of the multiple drug dataset reporting being off work indefinitely as a result of their withdrawal, with significant costs to their financial and social wellbeing (as Section Two will illustrate).

It is important to note that 76.6% of respondents to the survey considered support during withdrawal from their doctor or psychiatrist not to be helpful, while in contrast 74.5% said that online peer support was helpful. This ties in with earlier survey responses suggesting that doctors and psychiatrists do not understand the potential harms of antidepressant withdrawal sufficiently, and a majority are not informing patients about side effects.

It is also clear that participants are not satisfied with the information on antidepressant withdrawal on NHS Choices and NHS 111 (only 5.1% and 2.5% found them helpful respectively), while 76.2% would find a national telephone helpline helpful, and 93% would consider an accompanying website helpful. This indicates that current service provision in this area is insufficient, while providing additional evidence in support of the call by the BMA and other medical bodies for a national 24-hour helpline^{iv}.

Section Two

Qualitative Data

The qualitative data from the entire survey generated around 700 (A4 word) pages of qualitative data, 80 pages of which were generated by antidepressant-only users in the UK (186 respondents). In this section we set out the data that resulted from this cohort of 186 respondents, all of whom were asked the two following questions:

Question One: Please describe the impact withdrawal has had on your life in your own words.

&

Question Two: Have you received any support from NHS health services other than your doctor/psychiatrist? Please describe the nature of any support you received.

Of the 186 UK, antidepressant-only respondents, 156 answered Question 1 and 134 Question 2. The open-ended responses were analysed using Thematic Analysis (Braun & Clarke, 2006)^y, a method for identifying and analysing themes in qualitative data. All responses were read and annotated with respect to possible emergent themes. The qualitative responses were then systematically coded and collated according to themes using NVivo, a tool for managing qualitative data. Codes were collated into emergent themes, and these were checked in terms of appropriateness for capturing the coded extracts. In the report below emergent themes are illustrated with representative extracts from the qualitative data.

5. Question One: 'Please describe the impact withdrawal has had on your life in your own words.'

The analysis of the data on withdrawal experience resulted in six interconnected themes, (1) vivid descriptions of the incapacitating nature of withdrawal, (2) distrust of the medical profession, (3) the impact of withdrawal on relationships, (4) the impact of withdrawal on job and financial security, (5) the difficulty of the process of withdrawal (frequently resulting in failure) and (6) the impact of experience of withdrawal in relation to the first five themes on the person themselves. Each of these is further outlined and illustrated with extracts from the data below.

5.1. Theme 1: Withdrawal as Incapacitating

From the 156 respondents who answered this question, the most frequent theme that emerged was the incapacitating and disabling nature of withdrawal, which severely impacted the ability of those affected to function even in the most basic ways. This theme was expressed in a total of 78 out of 156 responses.

"I am unable to work, communicate or basically function on any level that makes life worth living."

"Some days are harder than others as I've learnt that there are definitely windows and waves in this process. But when those waves hit they hit hard I wonder how I will ever make it through this. Every day is a rollercoaster of different physical, intellectual, emotional and social whirlwinds wondering if there is something more to this and my organs are failing me slowly."

"I have lost my capacity to function on a daily basis and I exist as a shadow of the person I once was."

"The withdrawals are so severe I cannot function to do simple tasks like make a cup of tea let alone leave the house to go to work."

"This has destroyed my life as I knew it and made me incapable of functioning normally or healthily."

Furthermore, 27 respondents describe 'losing everything' or their 'lives being ruin' as a result of debilitating withdrawal:

"The withdrawal was so severe I'm lucky I did not end my life."

"These pills have ruined my life."

“My life has been put on hold because of withdrawal symptoms.”

“My life has been completely ruined.”

“My withdrawal from antidepressants has devastated my life.”

“My life has been devastated from the long term use, dependence and withdrawal of Venlafaxine.”

“Pure hell. Thought I was going mad.”

“It has completely ruined my life – I have lost everything I ever had”.

“Everyday is just a variation of hell; some days are more horrific, other days less so.”

“I struggle to live daily life and have at times considered committing suicide to end the daily effects.”

“Death sometimes seems like a welcome escape.”

Antidepressants have been described as “poison” and the experience of severe withdrawal as an “unmitigated hell”. The majority of the respondents also listed many diverse physical and mental/emotional symptoms, often describing how these impaired their ability to function normally, thus compounding existing and/or generating new feelings of depression and despair.

5.2. Theme 2: Disillusionment with medical professionals due to the mismanagement, misdiagnosis and denial of withdrawal.

The impact of withdrawal on the patient/professional relationship was widely indicated in the data. A total of 89 responses out of the 156 expressed their disillusionment with, and/or lack of trust in both medicine and medical professionals due to not being adequately informed, before treatment, of the potential severity of withdrawal and, once withdrawal commenced, being offered no adequate withdrawal support from their doctors or the wider NHS.

“I believe I attempted to withdraw from the drug too rapidly after receiving very little and dangerous advice from doctors who have very little comprehension on withdrawal issues”.

"I was told by one GP to just stop and take a piece of chocolate instead, and by another GP (in the same practice) to withdraw slowly."

"[I was told] To reduce my dose from 75mg a day to 37.5mg after two weeks. To then continue on 37.5mg for 1 week. To then reduce by taking every other day.... Even I know that's a pretty stupid way of tapering from Effexor."

"Their only response is to add more drugs which exacerbates the problems."

"I couldn't do anything for an entire month after my Doctor told me to suddenly stop taking it (Cymbalta). I felt so sick and giddy, it was like the room was spinning around me and I felt like I'd been poisoned."

"After one year on citalopram, I was advised to quit cold turkey after an increase from 20mg to 30mg made me manic. During withdrawals I didn't realise what was happening to me and thought I was dying. It was extremely scary. I have lost a lot of friends as a result of being housebound. I am extremely angry that I was misled by my doctor."

"I was told that 'discontinuation syndrome' could only have lasted a few weeks so I didn't know what I was talking about."

"I have to be my own doctor and educate myself as to self-care and how to taper off these dangerous and poisonous drugs as safely as possible."

Poorly managed and understood withdrawal also generated widespread lack of trust in doctors:

"I lost all confidence in doctors over the years."

"I felt so angry after that with the GP and it has since made it very hard for me to trust that particular doctor again so I have seen other doctors instead."

Much lack of trust can be attributed to withdrawal experiences being dismissed, denied or not taken seriously. It was widely reported that there was little understanding that the problems patients experienced were a result of withdrawal itself, with withdrawal being denied as a consequence:

"The debilitating protracted withdrawal condition is ignored by doctors and psychiatrists alike."

“They dismissed any notion of withdrawal and prescribed a number of different medication.”

“Doctors would not believe how severe my withdrawal side effects were.”

“My GP refused to acknowledge that drug had turned nasty on myself.”

“They [doctors] are in such complete denial of the harm they have been doing.”

“The indifference and lack of education from GPs and psychiatrists on the subject is shocking and disheartening - leading to feelings of isolation and helplessness.”

“She [the health psychologist] was just as clueless as every other health professional to the hell that I'm going through, repeating the mantra of... 'these medicines help lots of people', 'I've known lots of people come off with no problem', etc, etc. I always feel that this approach is just polite code for 'I don't believe you'. There were no pleasantries with the Psychiatrist, I just didn't know what I was talking about, apparently, when the reverse couldn't have been more true.”

This lack of understanding and/or denial was consistent with the lack of support and/or useful advice respondents received, which in turn exacerbated symptoms. For example, many of the respondents – 13 out of 156 responses - describe being told by their doctors that their problems upon withdrawal were actually due to relapse. As a result, the medication was either reinstated or they were told to withdraw cold turkey.

“There was no understanding of withdrawal. They all told me this was my problem returning. No one was supportive of the evidence I found or the fact that I felt completely different this time with extreme low mood and eating issues.”

“A psychiatrist I was talking to about my experience would not believe me...no one believed me... Everyone just wanted to put me on more medication and a stronger one at that.”

“The psychiatrists simply waived my story out of hand as impossible saying that 'it was just the old illness coming back', even though I've NEVER experienced ANYTHING even remotely approaching this.”

“I went cold turkey and the[n] reinstated because of my doctor's dumb advice that there's no such thing as Prozac withdrawal.”

"I experienced the worst anxiety and depression ever imaginable after coming off the drug. I was told it was just the anxiety and depression coming back but I have never experienced anything even close."

"[it was] written off as my 'original condition' returning, and proof that I needed the medication 'like a diabetic needs insulin."

"[I] turned to doctors for help and was told to start the drug again. I went to psychiatrists for help and was told I needed a stronger drug and higher dose."

Despite withdrawal being regularly misdiagnosed as relapse according to the respondents, many of these respondents reported - 36 out of 156 responses - that their withdrawal symptoms differed from their original problems:

"The withdrawal has been far worse than the initial depression ever was..."

"The symptoms of anxiety and depression were more severe than ever experienced before."

"Depression and despair ten times worse than I ever experienced before commencing the drug."

"I would give anything to just have my plain old anxiety back."

"This is far worse than anything I experienced before I went on the drug."

"I developed severe anxiety which I'd never had before and such extreme brain fog/memory problems that I had to give up my job."

"The anxiety is more severe than when I was on medication."

"I started getting odd symptoms around my body and my head, things I'd never experienced before yet no doctors could give me an explanation."

"I feel very emotionally unstable. A lot of bad feelings have developed that I never had; e.g I feel agitated and irritated for no apparent reason, I become stressed much more easily and less able to cope with minor stressors. I was never like this before I started SSRI's."

“Stopped my Sertraline in Jan 2014 and by March I was suffering multiple symptoms never experienced before taking SSRI’s.”

“I felt extremely anxious and depressed, worse than the original condition which had led me to be prescribed the drugs.”

Overall, the responses express shock, anger and/or the feeling of being let down by a health system ill-prepared to acknowledge and manage withdrawal in a satisfactory way, which left many respondents feeling very distressed, helpless and alone.

5.3. Theme 3: The Impact of Withdrawal on Relationships

52 out of the 156 responses indicate that withdrawal placed great strain on essential relationships with close friends, children and (or) spouses/partners. Many indicate the negative impact it exerted on others:

“My family are suffering as much as I am.”

“My three children and husband have suffered immeasurably.”

“My withdrawal symptoms include... aggressive behaviour towards family.”

“Find myself getting angry with partner and kids.”

“No sex drive (affects marriage).”

“It has affected my relationships with my partner and children.”

“Withdrawal was THE hardest thing I have ever done. It nearly destroyed me and my family.”

Responses also reveal some ways in which relationships were adversely impacted. There were references to how withdrawal resulted in the inability to take care of children, providing the support and nurturance children needed:

“Unable to even help my wife and our newborn baby.”

"[I have experienced] loss of caring for my family or myself."

"[Withdrawal] impaired relationships with my husband and children."

"The worst is losing years off your children's lives [not being available for them]."

"I stopped 6 months ago to start trying for a baby but am now pregnant. That has given me determination, but I am struggling with depression again now. This has impacted every aspect of my life."

"I was unable to look after my daughter myself for a long time."

Many indicated that their withdrawal introduced growing distance from their family and friends, with growing social isolation being experienced by most respondents. Withdrawal appeared to undermine the will to "to mix socially", to make social contact or to form and/or maintain relationships.

"I used to be out going and had a very good social life. I always had plans with my friends. I now rarely leave the house except to go to appointments."

"I have isolated myself from family and friends and just exist."

"Because of this symptom I have been cut off from the world. I have no friends or relationships of any sort beyond my immediate family."

"I have no life - isolated at 34 because I went on a drug for 'stress'."

"Cognitive dysfunction has made me lose confidence in decision making and socializing."

"[I] have become an emotional wreck and am unable to mix socially...whereas I used to be a good mixer."

"I could hardly leave my room to associate with family members and other people."

Relationships were placed under further strain by the stress withdrawal evoked in loved-ones, often owing to family members simply not being helped to understand withdrawal. This often led to family and relational disputes, a breakdown of mutual trust and understanding, the limits of key relationships being tested and relationship breakdown:

"I lost my relationship of 6 years and many friends."

"Withdrawal has cost be close relationships as partners and friends have been unable to cope/deal with the demands and support I have needed whilst trying to withdraw."

"loss of my girlfriend."

"I broke up with my girlfriend of 2 years because there was just no emotion in the relationship."

"I have paranoid thoughts and it's affected my ability to trust others and led me to distance from friends and family."

"My relationship was put under strain."

"This period put a strain on my relationship, on my family."

Other respondents indicated that they became increasingly dependent on others to provide care. If they were bedbound/housebound, which many reported, they were unable to care for themselves and others. Many respondents reported being unable to carry out their customary activities such as working, driving, washing and completing everyday tasks, needing to rely on others for support:

"I can no longer work and am completely dependent on care."

"I've become dependent on my husband and parents to care for me and at times keep me alive and safe!"

"I had to give up work in 2015, and I had to move back home with my parents."

"I made my husband leave his job to be with me as I didn't trust myself."

A further 17 responses explicitly report that the lack of understanding and acknowledgement for withdrawal heavily impacted their relationships:

"I got divorced because my then wife didn't really understand the withdrawal problems."

"I'm still in fairly early stages of withdrawal but find it is much harder for friends/relatives/medics to understand than when I had depression. I'm feel like I'm not being believed."

"I lost friends due to my bizarre behaviour."

"Nobody would take me seriously or help me, my family assumed I was mentally ill."

"Withdrawal has cost me close relationships as partners and friends have been unable to cope/deal with the demands and support I have needed whilst trying to withdraw."

There were also references about relatives and friends not believing that the drugs were the cause. Instead disclosures of withdrawal experiences were often branded as "overreactions", compounding tensions and mitigating support:

"...accusations from family of being crazy."

"It affected my relationships with family members, as my thoughts/feelings seemed irrational and my behaviour uncharacteristic and unpredictable."

5.4. Theme 4: The Impact of Withdrawal on Work and Finances

Many respondent accounts described working as too "challenging" given their symptoms, which often restricted the number of hours they could work, and/or the ability to function productively when at work:

"I had to take six months out of my PhD because I couldn't make decisions and was too exhausted to do much more than walk slowly to the park with my dog and sit still."

"I struggled with simple tasks at work like writing emails."

"I am unable to work, communicate or basically function on any level that makes life worth living."

"I've had to take months off work to try and withdraw but with no success."

"...find concentrating on things difficult, sometimes zone out during meetings and conversations (affects work)."

"The first few months off I could only work about an hour in the morning, after that the visual symptoms were just too much."

"Such extreme brain fog/memory problems that I had meant that I had to give up my job."

"...find concentrating on things difficult, sometimes zone out during meetings and conversations (affects work)."

"Affected work and only doing 3 hours a day. Very anxious and feel I have no meaning or purpose in life."

"The withdrawals are so severe I cannot function to do simple tasks like make a cup of tea let alone leave the house to go to work."

"Lost job due to being turned into zombie who cared about nothing other than lying in bed and doing nothing."

"I was completely incapacitated for the 1st year could not work for 2."

"Brain fog and severe trouble concentrating (am an IT Manager so imagine how bad that is for my job)."

Given withdrawal often resulted in a deep struggle to work or simply being unable to work, another impact incurred by respondents was the financial loss. 36 out of 156 respondents indicated financial loss, including loss of homes and dependence on benefits.

"I had to be off work which impacted us financially and we had just bought a house."

"The first months I managed to get by with a little casual work but around the four month mark things started to deteriorate....I am now more or less housebound."

"Paid privately for a psychiatrist who specialised in this area (thankfully I could borrow the money)."

"My withdrawals...[are] impacting majorly on family life and finance if I cannot work."

"I lost my apartment."

"I have lost my job and home."

The inability to work also adversely affected self-esteem, generating common psychological and emotional harms that accompany unemployment:

"I'm self-employed and constantly feel less intelligent than I once was... memory problems have hampered my ability to be as successful as I could have been."

"I've lost all my confidence and also had to give up my job that I loved so much."

"I reached the point where just getting out of bed and facing the world at all became a mammoth task. I also lost all my confidence and most of my self-esteem."

"I have lost my job, my family, my confidence, my soul and my future."

5.5. Theme 5: The Difficulties and Implications of Withdrawing

From the responses (34 out of 136) it is clear that withdrawal is an often protracted and sometimes unbearable process, generating consequences beyond the period of withdrawal itself:

"It has gotten a little easier with time but even after 5 years of being off venafloxine I am still not right."

"It is now just over 3 years since I stopped and I don't think I am really over it now, though things have improved. I still find it hard to concentrate on things and sleep is still a problem. I think my brain and body have been permanently damaged in many ways and fear for the future because of this."

"Cutting a long story short... after many, many years (2005-2017) of slowly rebuilding my life (literally) I have gradually weaned myself down (with symptoms all the way) to 20mg (where I started). I would love to be off completely."

"I have been waiting years for my system to reach homeostasis but I continue to suffer."

"Seven years on from last dose of the drug, I am not the same person I was before starting to take Seroxat."

"Over the past few years the symptoms have lessened - I will still occasionally get the muscles twitching."

While 30 respondents explicitly mention that it has taken several attempts to withdraw, others have been unsuccessful and so have had to reinstate the drug:

"After six months I reinstated the drug after suffering extensive and recurring withdrawals."

"I realised I couldn't stop, reinstated and tapered down over three months."

"I've had to take months off work to try and withdraw but with no success."

"It has been a merry-go-round of trying to come off them and failing since then."

15 respondents also expressed that they had no idea how to taper off the drugs (including how gradually), due to lack of information or support from their doctors:

"After my 1st cold turkey with awful withdrawal symptoms, I returned to my GP & she told me it was depression & I would need to stay on them all my life."

"I have been unable to successfully withdraw from the drug, as each time I have tried the withdrawal has been so bad. When I have sought advice from my GP I have been told that my depression had come back, and I would need to resume to a higher dose of the drug for at least 12 months."

"I feel like my recovery has been really stunted and that with the right sort of help, I probably would have been much better by now."

The pain of withdrawal has led to some individuals to simply give up in the attempt:

"I don't want to be on these drugs anymore as they have too many side effects and I don't believe they better my quality of life, but I can't stop."

"I made the decision not to reinstate and to continue pushing through the withdrawal. In hindsight this was possibly the wrong decision. I've never been so physically, mentally and emotionally broken."

"I can only withdraw for a limited time because the symptoms are too severe to tolerate. I have tried several times to come off unsuccessfully."

5.6. Theme 6: Negative Outlook on Life/Feelings of Hopelessness

Many respondents still suffering the adverse affects of withdrawal reported a growing sense of hopelessness and pessimism about the future. 22 respondents widely feared that the suffering "would never end" that "there is no way out" and that they would never again be able to "function on any level that makes life worth living":

"...feel I have no meaning or purpose in life"

"I know myself there have been times when I thought of ending it all. Lost all hope."

"...I don't know whether I will get my life back and what kind of life that will be or whether I will live long enough to find out..."

"have experienced and still having days of acute anxiety, depression, crying spells, and feeling of complete hopelessness."

"My whole life is over."

"I'm not scared of dying and going to hell because I've already been living a long, long time."

"Feelings of despair and uselessness, but I believe this may be because of all the horrible effects I am having after 9 months not taking this medicine from HELL and that I am still suffering, I look like a skeleton with just skin and bones."

13 out of 156 respondents explicitly stated that withdrawal adversely affected their self-esteem, self-worth and self-confidence: *"I've lost all my confidence"*, *"I have developed a slight stutter, (causes embarrassment)"*. Self-esteem was affected by simply not understanding what withdrawal was. Self-blame often ensued, leading to feelings of *"failure"*.

"FEELING A COMPLETE FAILURE."

"Experienced a gradual decrease in confidence."

"I also lost all my confidence and most of my self-esteem."

Many described experiencing diminished abilities, making them further doubt their self-worth and competence. One individual they felt *"less intelligent"* due to the memory problems, while issues like cognitive impairment made others feel inadequate and *"ashamed"*.

20 respondents also described losing any interest, joy and meaning in life, including in those activities and hobbies they previously enjoyed before the medication.

"Loss of interest in anything which I previously enjoyed before taking medication or during, such as listening to playing music."

"I lost the ability to concentrate or to find distraction or pleasure in things that I had previously enjoyed."

"No interest in previous hobbies, no energy, a sense of doom and gloom."

"I no longer enjoy spending time with friends and family, on my own hobbies, on my work."

"...disconnection from others and indifference, apathy and lack of joy in anything..."

12 respondents expressed that antidepressants had adversely altered the person they were prior to taking the medication; *"I feel apart and different from normal people", "I am not the same person I was before starting to take Seroxat"*. Other references (12 respondents) included feeling out of control in several areas of life. This was also evident in 16 references describing growing self-distrust:

"At this point I was frightened of being left on my own that I was having 24-hour care shared between my mum, dad and partner."

"I've felt detached and dissociated from people I care about and it's been very scary as I often don't know what to expect next."

"I had a growing sense that I would not be able to cope with more and more aspects of my life..."

"The best I can describe it was as if I lived in a war-torn world in my head, and experienced the kind of fear one would feel if one's life was constantly in danger, with waves of fear flooding my body without any reasonable cause."

Based on 10 of the responses given, a deeper sense of one's vulnerability also resulted from withdrawal. This was mainly attributed to being ill prepared for the effects of tapering and withdrawal, and the lack of understanding and affirmation from important others.

"During withdrawals, I did not realise what was happening to me and thought I was dying. It was extremely scary."

"I now have anxiety attacks in my home... my safe space has been destroyed and I don't know what it feels like to have a safe place anymore."

"I experienced a frightening incident in the middle of the night which left me feeling vulnerable and a danger to myself."

6. Question Two: 'Have you received any support from NHS health services other than your doctor/psychiatrist? Please describe the nature of any support you received.'

Of the 186 participants within the sample, 134 responded to the above. An overwhelming 87 responses indicated that no support was received from NHS health services:

"I regularly saw my GP but they offered no guidance or support."

"No, no one seems to have heard of it... My GP hadn't. It's very isolating."

"I did not receive any support from NHS health services."

"I have not had any support from NHS health services or been referred to a psychiatrist and my doctor did not help."

"I've looked for support and still looking"

13 responses indicated that their doctors and the NHS would not acknowledge withdrawal or significantly underestimated the length withdrawal symptoms can last:

"I was told it was not possible to be in withdrawal as it would only last a couple of weeks and then be out of my system."

"Too often I felt shrugged off as though coming off this medication is no big deal and maybe I was exaggerating how I felt or that it was the original condition of depression that was causing the symptoms."

"I was repeatedly told that if withdrawal only lasts 6 weeks and if it went beyond that then I would need to go back on the drugs because it was the original problem returning."

"There was no understanding of withdrawal. They all told me this was my problem returning."

As with data obtained from question one, 7 respondents to question 2 also emphasised that they were either advised to continue with the antidepressant, had their withdrawal misdiagnosed as

relapse or were recommended inappropriate support (for example illegal drug use services) not specific to prescribed drug withdrawal.

“My GP did not understand what I was going through. Subsequent problems were treated as anxiety returning.”

“Doctors are at a loss and do not know what to do apart from adopting the medical model and offering more medication.”

“If I went to the Dr it would just be written off as my 'original condition' returning, and proof that I needed the medication 'like a diabetic needs insulin’.”

“The only support I was offered was a charity that provide group support for adults that are recovering from illegal drug addiction.”

“I have had to attend a drug and alcohol recovery centre as there is no support for withdrawal from antidepressants.”

“The doctors have suggested restarting antidepressants, but this isn't a solution to how I'm feeling as the meds make me tired, foggy and lower my sex drive, dull emotions.”

Because of the lack of or total absence of support, 8 reported having to find support elsewhere;

“The only support has been through survivingantidepressants.org which is how I found out what has been happening to me.”

“I found the survivingantidepressants.org website which helped me so much about how to cope.”

“I subsequently joined a Venlafaxine withdrawal Facebook group and learnt how to taper gradually using liquid or opening the capsule and counting beads. When I told GP and psychiatrist about this they had not heard of either method of tapering.”

“It took my family finding professionals privately to help me. My life line was the support groups online where other fellow sufferers guided me through the darkness. The various resources I've used online have been and still are my lifeline.”

"I attend psychotherapy privately at my own expense. This is helpful, but he is not an expert on withdrawal."

"...survivingantidepressants.org site offered explanation that clicked with what I was experiencing."

"I have been on a waiting list to speak to someone at my local doctors for nearly a yr. I have sought a private councillor but high prices at over £50 have meant I could only attend a few sessions. My only support has been my family which don't know how to help but a hug is always welcome!"

24 out of 134 respondents received some form of counselling; CBT, 'Talking Therapies', iTalk or telephone counselling. However, 9 respondents described counselling or CBT to be largely unhelpful.

"I have numerous sessions of CBT therapy all which have been unhelpful."

"Weekly CBT therapy. Not particularly helpful."

"CBT with Newham Talking Therapies which are, excuse my honesty, A COMPLETE WASTE OF TIME!! They do NOT care about the patient, work strictly within the normal working week (I already have HUGE issues being able to keep going to work, you seriously want me to take even MORE time off of work???), no weekend services."

5 of the 24 who received therapy highlighted that therapists had limited understanding of withdrawal, often wanted to address unrelated issues. 2 of the 24 respondents indicated that their withdrawal symptoms made it challenging to engage in or attend therapeutic sessions.

"Referred to counselling however I find there is little understanding of the full nature of withdrawal here as well."

"Have attended numerous counselling seminars for stress reduction etc but none for actual withdrawal symptoms and what to expect and ways to cope."

"Yes, I did "Talking Therapies" for a few months but stopped this as I was experiencing severe eczema and gut problems. I don't plan on accessing this service again as it seemed to be geared towards suicidal people and was heavily risk assessed."

7 respondents indicated they referred to psychiatry for help. The general theme from these responses, however, was that psychiatric support was no more useful than that received by G.P.s.

“Nhs psychiatrist have been no help whatsoever, and completely dismissed my withdrawals.”

“I have been referred to psychiatrists 2 or three times. They have done nothing more than the GP was able to do. That is, they believed my withdrawal symptoms were just a return of my depressive symptoms (symptoms which I never had before being prescribed medication) and prescribed me more of the same medication.”

“Was referred to a mental health assessment which led to nothing. I requested to see a psych who knows about medications to help me deal with this. Nothing has happened. I am considering going to A&E.”

“The psychiatrist I had to see was horrific. She said to go back on them. I was so angry and disgusted. She then told me another lady was having the same problem with withdrawal. She then said she was staying on them because they didn't know what to do.”

“Doctors and Psychiatrists don't really seem to acknowledge how serious these withdrawals are and how they affect people.”

Support provided by mental health crisis teams was similarly experienced as dismissive towards “any notion of withdrawal”. One individual referred to their local Youth Crisis Team as “frustrating & overwhelming” as withdrawal was not taken seriously. Wellbeing Teams were also referred to as “not at all helpful”, and of a social worker one respondent said, “...this person who came over every week...could only offer sympathy and had no idea about this”. NHS 111 was similarly experienced as unhelpful.

“NHS 111. I asked them if it was OK to take vigorous exercise, spoke to an assessor and then a clinician for a total of 30 minutes and the clinician told me to talk to my doctor. I rang my surgery and they said if it's not urgent please ring NHS 111.”

Although many of the responses indicate lack of or poor support, there are 6 responses from the 134 responses that relay more positive experiences of the support received: two responses speak positively of occupational therapy; one response indicated their psychiatrist was helpful, one stated they received useful help from their endocrinologist; one found help in their ME clinic, and another found telephone counselling ‘a little helpful’.

7. Discussion

Two questions were posed to the 186 UK respondents of the survey who had only taken antidepressants. The first question was: "Please describe the impact withdrawal has had on your life in your own words". The key themes that emerged in response to this question were as follows:

- Theme 1: Withdrawal as Incapacitating
- Theme 2: Distrust of medical professionals due to the mismanagement, misdiagnosis and denial of withdrawal
- Theme 3: The impact of withdrawal on relationships
- Theme 4: The impact of withdrawal on work and finances
- Theme 5: The difficulties and implications of withdrawing
- Theme 6: Negative outlook on life/feelings of hopelessness

For around half of the respondents, withdrawal was described as incapacitating and disabling, with some respondents using similar language such as "unable to function", "incapable of functioning", "lost my capacity to function". This ties in with the quantitative data where 25% of respondents in the antidepressant-only dataset reported being off work indefinitely.

27 (15%) of the respondents go further, and use language suggesting that antidepressant withdrawal had a severe negative impact on their lives, using descriptors such as "pills have ruined my life", "withdrawal...has devastated my life", "completely ruined my life". The strength of the language used is consistent with the quantitative data, where respondents on average rated the severity of their symptoms as 9 out of 10.

The extreme nature of withdrawal, and the response to the situation by their doctors, has led over half of respondents to express a lack of trust in both medicine and medical professionals. There was inconsistency regarding the withdrawal and tapering advice given, with several respondents describing being told to taper rapidly or even cold turkey. The following statement seems to capture the sentiment of many respondents: "I believe I attempted to withdraw from the drug too rapidly after receiving very little and dangerous advice from doctors who have very little comprehension on withdrawal issues". One respondent was even told just to stop, and "take a piece of chocolate instead".

This lack of understanding is compounded by subsequent denial by doctors that withdrawal can cause such severe symptoms. Statements such as "doctors would not believe how severe my withdrawal side effects were" and "they are in complete denial of the harm they have been doing" are typical of the experience of many respondents. This corresponds with the quantitative data, where 77% of respondents did not consider support from their doctor or psychiatrist to be helpful.

Some doctors and psychiatrists refused to believe that the symptoms were withdrawal, and instead attributed them to relapse, requiring reinstatement or new medication. One typical response was: "a psychiatrist I was talking to about my experience would not believe me... no one believed me... everyone just wanted to put me on more medication and a stronger one at that". For respondents, despite being told otherwise, it was clear that their withdrawal symptoms differed substantively from their original issue: "I experienced the worst anxiety and depression ever imaginable after coming off the drug. I was told it was just the anxiety and depression coming back but I have never experienced anything even close".

Withdrawal placed great strain on relationships with family members and friends, and some respondents described how they became unable to look after their children. For example, one respondent said he was "unable to even help my wife and our newborn baby", while another

declared that “the worst is losing years off your children’s lives [not being there for them]”. Others described how withdrawal affected their ability to socialise: “[I] have become an emotional wreck and am unable to mix socially... whereas I used to be a good mixer.” Withdrawal also led to the breakdown of many key relationships, while some became dependent on their spouses or parents, who in some cases expressed a lack of understanding of withdrawal. For example, one respondent stated: “withdrawal has cost me close relationships as partners and friends have been unable to cope/deal with the demands and support I have needed whilst trying to withdraw”, while another said: “nobody would take me seriously or help me, my family assumed I was mentally ill”.

Respondents also describe the cognitive impact of withdrawal, pointing to the difficulty of concentrating and completing simple tasks, which often led to extended - and sometimes indefinite - leave from work. One respondent described “such extreme brain fog/memory problems that I had meant that I had to give up my job”. Another said: “the withdrawals are so severe I cannot function to do simple tasks like make a cup of tea let alone leave the house to go to work”, while another pronounced: “I was completely incapacitated for the 1st year could not work for 2”.

36 out of 156 respondents indicated financial loss, including the loss of their jobs and in some cases their home. This makes sense in the context of the quantitative data, where 37% reported symptoms lasting more than one year. The combination of debilitating cognitive symptoms and the loss of work had an adverse effect on the self esteem of some respondents: “I’ve lost all my confidence and also had to give up my job that I loved so much”, and “I have lost my job, my family, my confidence, my soul and my future”.

34 out of 136 respondents describe how the experience of withdrawal itself is often protracted and accompanied by unbearable suffering, for example “It has gotten a little easier with time but even after 5 years of being off venlafaxine I am still not right”. 30 respondents describe multiple attempts to taper, while some are unable to cope and reinstate the drug, and others have failed to withdraw: “I can only withdraw for a limited time because the symptoms are too severe to tolerate. I have tried several times to come off unsuccessfully.”

The extreme suffering combined with the duration and the uncertainty of recovery led some respondents to lose hope and enter a state of despair. 22 respondents described their fear that the suffering “would never end” and that “there is no way out”. For example, one respondent said “I don’t know whether I will get my life back and what kind of life that will be or whether I will live long enough to find out.” For some, this is accompanied by loss of any joy or interest in life, including previous hobbies and activities: “No interest in previous hobbies, no energy, a sense of doom and gloom”. 12 respondents describe how they feel that antidepressants have changed the person they were before medication, for example “I feel apart and different from normal people”, and “I am not the same person I was before starting to take Seroxat”.

Considering all of the themes together, a common narrative emerges from our sample. A typical respondent comes off his or her medication, and experiences withdrawal symptoms, sometimes following a rapid taper or cold turkey. He/she returns to the doctor who often denies that the medication caused the withdrawal, stating that the symptoms are a return of the previous disorder, therefore the medication is reinstated and/or new medication is dispensed. The respondent then often suffers symptoms much worse than anything previously experienced, and loses trust in the doctor or psychiatrist.

When the respondent suffers severe withdrawal symptoms, which can last for months (and in some cases, years) this can invariably result in significant loss (often for some of job, money and sometimes home). Withdrawal, especially when severe, also regularly has a profound negative impact on his/her relationships; it affects the ability to socialise, interest in hobbies and activities, the sense of self, and often leads to a state of hopelessness and despair.

The second question posed to respondents was: "Have you received any support from NHS health services other than your doctor/psychiatrist? Please describe the nature of any support you received".

134 out of 186 participants in the survey responded to this question. Of these, 87 responded that no support was received from NHS health services. Examples of responses include: "I've looked for support and [am] still looking", and "No, no one seems to have heard of it. My GP hadn't. It's very isolating".

The descriptions of the lack of support available via NHS services corresponds with the quantitative data, where only 5% found NHS choices helpful, while only 2.5% found NHS 111 helpful.

When support was obtained, respondents stated that they were told either to continue with their antidepressant, or that their withdrawal was misdiagnosed as relapse, or they were directed to drug & alcohol drug treatment services. Responses included "the only support I was offered was a charity that provide group support for adults that are recovering from illegal drug addiction", and "I have had to attend a drug and alcohol recovery centre as there is no support for withdrawal from antidepressants".

Because of the lack of appropriate NHS services, several respondents report turning to online peer support groups: "the only support has been through survivingantidepressants.org which is how I found out what has been happening to me", "my lifeline was the support groups online where other fellow sufferers guided me through the darkness. The various resources I've used online have been and still are my lifeline", "I subsequently joined a venlafaxine withdrawal Facebook group and learnt how to taper gradually using liquid or opening the capsule and counting beads. When I told GP and psychiatrist about this they had not heard of either method of tapering".

24 respondents tried CBT and other talking therapies. However most believed they were of little help. Responses included: "I have numerous sessions of CBT therapy all which have been unhelpful", "referred to counselling however I find there is little understanding of the full nature of withdrawal here as well".

Other respondents tried to access a psychiatrist for support, but found that this was also unhelpful. For example: "I have been referred to psychiatrists 2 or three times. They have done nothing more than the GP was able to do. That is, they believed my withdrawal symptoms were just a return of my depressive symptoms (symptoms which I never had before being prescribed medication) and prescribed me more of the same medication."

Respondents described the response of mental health crisis teams as similarly uninformed and sometimes dismissive. However a few responses relay positive experiences with their medical professionals, including occupational therapists, medical specialists and one psychiatrist.

Overall, the responses to these questions clearly indicate that, for these respondents, traditional sources of support (such as GPs, psychiatrists, NHS 111 and NHS Choices, mental health crisis teams) were entirely inadequate, with staff unaware and untrained in this area. This lack of awareness led some professionals to express disbelief in the patients' stories and to misdiagnose their symptoms, which compounded their feelings of hopelessness and frustration. As a result, many respondents turned away from the medical profession and accessed peer support through online groups such as survivingantidepressants.org, which were described as a lifeline.

8. Conclusion

The responses to this survey make clear the ruinous impact of antidepressant withdrawal on some individuals, as well as the failure of those responsible for their care to understand and to treat the problem. It also reveals that other government-funded sources of support are entirely inadequate, with individuals left to fend for themselves or rely on internet-based support groups.

Survey respondents describe the suffering caused by withdrawal in the most severe terms, with some claiming that the process had devastated or ruined their lives. For many the experience lasts more than one year, with some respondents describing incapacitating symptoms for longer than five years, which can lead to the breakdown of marriages, careers and - for over 25% of respondents - indefinite disability.

Respondents to this survey say that their doctors or psychiatrists mostly did not inform them about the risks of withdrawal, which could be considered a failure of informed consent. Many believe they were told to withdraw or taper too quickly, which they reported aggravated their symptoms. Furthermore, some say that doctors and psychiatrists subsequently denied that these symptoms were caused by withdrawal, and misdiagnosed withdrawal as relapse or as a new disorder, sometimes proposing new medication. It is not surprising that for some patients this leads to a profound distrust of the medical profession.

Respondents also make clear that other sources of support, such as NHS Choices, NHS 111 and traditional drug & alcohol treatment services, are similarly uninformative and unhelpful. This leads many to rely entirely on online peer support services, such as <http://survivingantidepressants.org/>.

This survey provides compelling evidence that antidepressant withdrawal can have devastating, life-changing consequences for some individuals. Doctors, psychiatrists and other medical professionals must urgently be provided with appropriate training in this area, both at medical school and as part of their continuing professional development. Clinical guidelines must also be updated to reflect the actual incidence, severity and duration of antidepressant withdrawal, and to enable doctors, psychiatrists and other practitioners to provide appropriate care, including slow tapering protocols. Lastly, government must ensure that individuals affected by withdrawal have access to proper support services, which we recommend should include local support groups as well as a national 24 hour helpline and accompanying website.

References and Notes

ⁱ When the same question was ask of the total international sample of AD users alone (580 people), the mean response was similar: 86.7% responded at least two months, 58.6% at least one year, and 16.2% more than three years.

ⁱⁱ Again, when the same question was ask of the total international sample of AD users alone (580 people), the mean response was similar: 8.35 (SD = 2.05) denoting that the majority experienced severe reactions (median = 9, mode = 10), with 249 (43%) indicating the highest level of severity on the scale (10).

ⁱⁱⁱ See: Moncrieff, J (2007) *Myth of the Chemical Cure*. London: Plagrave Macmillian.

^{iv} See: <https://www.bma.org.uk/news/media-centre/press-releases/2016/october/bma-calls-for-national-prescription-drug-helpline> and <http://prescribeddrug.org/appg-for-prescribed-drug-dependence-publishes-declaration-of-support-for-helpline/>

^v Braun, V & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101