"I Didn't Just Cross a Line I Tripped Over an Edge": Experiences of Serious Adverse Effects with Selective Serotonin Reuptake Inhibitor Use

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Evidence that selective serotonin reuptake inhibitors (SSRIs) may elicit suicidal and/or aggressive thoughts and behaviours has been circulating for nearly thirty years. Despite a growing body of knowledge around these serious adverse effects, however, they continue to be surrounded by controversy. In particular they are subject to (arguable) counter-arguments that any risks from using the drugs are outweighed by benefits and/or more attributable to a person's 'underlying disease'. Moreover assessments of risks often use rates of completed suicides as the ultimate measure. In this paper we draw on people's own accounts of their experiences of serious adverse effects associated with SSRI use. In depth semi-structured interviews were undertaken with nine people who had either used SSRIs themselves or had witnessed the use of SSRIs by a close family member. We present four themes identified across the interviews relating to adverse effects from SSRIs: experiences of akathisia, aggression and suicidality; 'out of character' behaviour; harm to relationships; and accounts of responses from the medical profession. Participants reported that the experience of adverse effects had marked impacts on general wellbeing, identities and relationships. These accounts cast doubt on notions that serious adverse effects associated with SSRI use may stem from an underlying condition and/or be outweighed by benefits from SSRI use. In addition they offer a persuasive and poignant plea to further consider non-fatal adverse effects and their consequences in assessing the risks of these drugs.

Selective serotonin reuptake inhibitor (SSRI) antidepressants have become the subject of considerable controversy in recent years. Not only have serious questions been raised about the efficacy of these drugs (e.g., Moncrieff & Kirsch, 2005) but evidence has long been mounting of an association between SSRIs and suicide. This evidence - which has arisen from a range of sources including case reports (e.g., Teicher, Glod, & Cole, 1990), meta- and re-analyses of clinical trials (e.g., Kraus, 2006), legal cases (e.g., Healy, 2004a), epidemiological studies (e.g., Donovan et al., 2000) and primary care databases (e.g., Martinez et al., 2005) - has lead critics to urge far greater caution around the use of these drugs, particularly at the point of starting, stopping or changing dose (Healy, 2004a). According to Healy (2006) the current "best estimate for the likely risk of suicide on SSRIs over placebo is 2.6" (p. 93). Links between SSRIs and a number of other serious adverse (and withdrawal) effects – such as aggression, akathisia, mania and the wider realm of suicidality – have also been postulated (e.g., Breggin, 2003; Glenmullen, 2000; Healy, 2004a; Medawar, Herxheimer, Bell & Jofre, 2002; Whitaker, 2005), although the research evidence is less well established (see for instance Healy, Herxheimer, & Menkes, 2006, regarding the links between SSRIs and violence).

Although pharmaceutical regulatory bodies in the United States, the United Kingdom, Europe, Canada, Australia and New Zealand have responded to this evidence of serious potential adverse effects by issuing warnings about the risks associated with SSRIs (e.g., ADRAC, 2004; EMEA, 2005; FDA, 2005; Health Canada, 2004; Medsafe, 2004; MHRA, 2003), proponents of the drugs nevertheless continue to argue that their benefits outweigh the risks. For instance, it has been claimed that SSRIs are associated with a decrease in the rate of suicide at the population level (e.g., Khan, Khan, Leventhal, & Brown, 2001), although more recently others have countered that there is no evidence for any causal relationship between increasing use of SSRIs and declining rates of suicide (e.g., Safer & Zito, 2007). As well as this debate about whether SSRIs 'on balance' may help more people than they hurt, the currency in which such cost-benefit analyses are calculated is often restricted to measures of completed suicide. This can give a distorted view of the suicidal effects of these drugs because non-fatal experiences (including suicidal ideation, suicide attempts, akathisia and aggression) tend to be overlooked, or their seriousness minimised, by proponents (Liebert & Gavey, submitted for publication). For example, although one study reported a decreased risk of completed suicide with antidepressant

use, it also reported a marked increase in the risk of attempted suicide (Tiihonen, Lonnqvist, & Wahlbeck, 2006), yet such findings are rarely emphasised. In addition proponents have been found to employ constructions of depression that allow SSRI adverse effects to be attributed to an 'underlying disease', thereby further minimising the drugs' significance in causing harm and instead suggesting people's experiences derive from pre-existing suicidal tendencies (Liebert & Gavey, submitted for publication)[1].

Given these complexities, the debate on SSRIs is threatening paralysis, with many agreeing that we cannot 'really' know, in a traditional scientific sense, whether or not SSRIs *cause* suicidality (e.g., Simon, 2006). Nonetheless, as Simon (2006) has pointed out, "even if randomised trials and large observational studies find no effect [of SSRIs] on average rates of suicide attempt or suicide death, average effects may not apply to all individuals" (p. 1861). In light of this obvious point, it is arguably important to move beyond the broader debate about population level risks and benefits to explore more fully what these adverse drug effects are like for those people who do experience them. Beyond reports of clinical observations (e.g., Healy, 2004a) and an analysis of people's web-based reporting of SSRI problems (Medawar, Herxheimer, Bell, & Jofre, 2002), there is little detailed documentation in the literature of the nature and impact of such effects, particularly from those who have experienced them personally. In this article, we enter the debate about the risks of SSRIs through suggesting the need to look beyond medicalised assumptions that arguably limit the scope of concern to the relative risk of completed suicide. Instead, through engaging with people's own descriptions of their experiences with these drugs, we aim to provide more in depth understandings of the phenomenology and consequences of a wider range of serious adverse effects from SSRIs, including those that fall short of death. In doing so, we hope to highlight and illuminate the potential human cost of SSRI use for some people (see also Liebert & Gavey, 2006).

Research process

The analyses reported in this article arise within the context of a broader study that sought to explore knowledges of SSRI-induced suicidality and aggression in the New Zealand context through interviews with 24 people who had either professional or personal experiences relating to SSRIs, depression and/or suicidality (Liebert, 2006). Here, we draw on in depth interviews with nine people (six women, three men) about their experiences in relation to SSRIs. Given the broader aims of this study, we have ended up drawing on both interviews with people who have used the drugs themselves, and those who have had intimate contact with another person who was using the drugs. Six participants spoke about their own personal experience of using SSRIs and three spoke about their experiences with a close family member using SSRIs. For those who spoke about experiences in relation to a family member, the drugs had been implicated in the suicide of that person for two participants, and in a suicide attempt for the other. In this latter case, the interview was conducted jointly with the couple – to include both the man who was using SSRIs and his partner, a woman, who talked about her observations and experiences in relation to his SSRI use. By being in a position to include material from these converging sources, we have not only been able to generally enrich our analyses; but also, importantly, we have been able to include accounts relating to people who had died. See Table 1 for summaries of the nature of each participant's experiences, which are necessarily brief to protect participants' anonymity.

Participants were recruited via the dissemination of a general invitation through the networks of three mental health advocacy organisations. They were informed that the study was being undertaken in response to recent evidence and regulatory responses regarding SSRIs and risks of suicidality and aggression. Subsequently four people offered to be interviewed in Auckland, three in Wellington, and two in central North Island cities. All interviews were face to face, and lasted between one and four hours. The main focus of the interviews was on participants' personal experiences with SSRIS, which they were invited to start speaking about chronologically. We then asked further questions as relevant to invite further elaboration and reflection on their experiences. Where timely, participants were also asked about their views on issues such as current trends and understandings of depression, current trends in the use of antidepressants, and claims linking SSRIs to adverse effects, although these responses have not been integrated explicitly into the present analysis. One to two weeks after the interview participants were contacted and offered the opportunity to add further thoughts or to talk through anything that may have arisen for them from speaking about their experiences. All interviews were audio-taped and transcribed.

Our analysis was guided by two sets of principles that informed how we approached the interview material and how we present it here. Firstly, working within a critical realist epistemology, we were aiming to offer a *descriptive* analysis of people's experiences that was patterned by a critical conceptual analysis of the wider debate over adverse effects of SSRIs. We read the transcripts to identify common themes, across the interviews, in terms of salient kinds of experiences and issues discussed by the participants. To this end we arrived at four key themes, which we use below as a framework to organise our analysis. Our choice of themes as 'key' was determined in relation to our specific aim of illuminating the phenomenology of adverse SSRI effects. In particular, we wanted to focus on those issues that were brought up in the interviews that have arguably been 'side-lined' in previous debate around SSRI use. This led us to highlight those kinds of experiences reported by the participants that directly challenge some of the rhetoric used to minimise and/or discount the nature of adverse drug effects. In this sense, we do not suggest that our analysis necessarily represents the *full* range of potentially important issues discussed by all participants.

Secondly, the way in which we present the 'data' within the thematic frames we have chosen is guided by a social justice orientation and a commitment to making space for the

voices of people who are most directly affected by adverse drug effects. We have woven a context in which parts of their stories can be told, rather than attempting to re-tell their stories on their behalf (through more intensive 'top-down' interpretation of their accounts). We thus made a deliberate effort to use as many of their words as possible, with extracts only edited where necessary to enhance readability, protect anonymity and/or add context. In this sense, a major part of our analytic contribution is in the formation of a framework that allows relevant dimensions of participants' experiences to be voiced in a way that speaks directly to crucial questions in the wider debate about the human cost of SSRI adverse effects. We have also interspersed psychopharmacologist David Healy's (2004a) observations of SSRI-linked akathisia, suicidality and/or aggression experienced by patients and by 'healthy volunteer' research participants alongside our own material. In doing so we hope to highlight wider resonances between the phenomena described by participants in this study and those reported elsewhere by others.

Themes

In listening to and reading people's accounts, four recurring themes were considered particularly relevant to the objectives of this research: (1) experiences of akathisia, aggression and suicidality, (2) 'out of character' behaviour, (3) harm to relationships, and (4) responses from the medical profession.

"He's irrational angry volatile and definitely suicidal": Experiences of akathisia, aggression and suicidality

Akathisia

One well-known experience linked to SSRI related suicidality and/or aggression is a drug-induced agitation known as 'akathisia' (Breggin, 2003; Glenmullen, 2000; Healy, 2004a). Akathisia has been associated with a range of feelings and behaviours including 'dancing', pacing, nervousness, emotional lability, insomnia and anxiety, as well as euphoria, paranoia, mania and psychosis (Breggin, 2003; Putten, 1975). At its most extreme, it fosters lucid, intolerable and preoccupying suicidal and aggressive thoughts that can lead to violent and/or suicidal behaviours of the kind that has been associated with SSRI use (Breggin, 2003; Healy, 2004a).

Akathisia was described by Heather when interviewed about the seemingly SSRI-induced suicide of her daughter, Sophie. Soon after she started taking Prozac, Sophie told Heather she felt like she was "cracking up" and "was just feeling very strange". She was "hyped up", uncharacteristically "dancing around" and her "face [had] got so little". Similarly Healy noticed that people looked "pallid and somehow shrunken" when experiencing drug-induced akathisia (Healy, 2004a, p. 82). Elements of akathisia were also evident in Trish's description of her partner, Simon, during their joint interview about Simon's current use of Aropax: "It's not like a depression because ... it's angry it's volatile it's suicidal it's agitated. It's not ... wound down, it's wound up, but wound up in a negative way". Another informant, Linda, felt "not settled", "anxious", and "really odd" on Prozac. She "never slept for six months" while she was on the drug and felt that it "revved up my system ... it's like pushing my brains through my head or something ... I was going about rushing all over the place I couldn't keep still".

Akathisia in particular was a main theme in Debra's account of her husband, Richard, suiciding twenty months after he was put on a large number of psychopharmaceuticals. Richard became "agitated and anxious" after taking SSRIs. He was "rushing around all the time", "just *could not* sit still", "prancing up and down all night" and

> *wouldn't sleep in the house he'd go and sleep in the motor home at*

Table 1
Research participants

Participant (age)	Key experiences relating to SSRI use and suicidality and/or aggression
Daisy (mid 30's)	Past and current positive experiences using a range of psychopharmaceuticals including Aropax and Efexor. Made one suicide attempt while on Aropax.
Debra (mid 50's)	Husband, Richard (50's), developed akathisia, aggression and suicidality leading to suicide when taking psychopharmaceuticals, including a range of SSRIs.
Gail (mid 40's)[1]	Developed suicidality and made several suicide attempts when taking Aropax in the past.
Heather (mid 50's)[1]	Daughter, Sophie (20's), developed akathisia and suicidality leading to suicide when taking Prozac.
Jon (early 30's)	Developed anger and aggression and made one suicide attempt when taking Prozac in the past.
Linda (late 50's)	Developed aggression when taking Prozac in the past.
Simon (late 40's)	Current positive experiences on Aropax, and made suicide attempts when using Cipramil and Aropax in the past. Was interviewed with his partner, Trish, who believed he also developed suicidality and aggression from his current use of Aropax.
Stuart (late 50's)	Developed suicidality and aggression when taking Prozac in the past.
Trish (early 40's)	Believed her partner, Simon, developed suicidality and aggression from taking Aropax. Was interviewed with Simon, who had made several suicide attempts and believed he had positive experiences when on Aropax.

Note: All names are pseudonyms to protect the anonymity of participants.
[1] See Liebert and Gavey (2006) for more in depth narratives of Heather's and Gail's experiences.

night ... he wouldn't tell me [why] he said it would be better that way he said. "Be better that way". His head – must have been feeling so bad that he just wanted to get away [to] quiet, he couldn't stand the TV, couldn't hardly stand the lights on.

Akathisia also seemed referenced in people's descriptions of their labile moods. Debra further explained how Richard's mood was "like these waves going through him": "One minute he'd be OK, and happy, and he'd be walking along and he'd hold your hand or something" and then "next minute he'd be walking on that side of the road and you wouldn't think you were even with him". Trish similarly described how on Aropax Simon would sometimes "just, [snaps fingers] bingo! and gets angry or gets ... suicidal ... [and] there's no discernable cause for it, it just happens." These descriptions parallel those of Healy who found people's moods while on Zoloft were "swinging from gloom to doom in a matter of minutes" and "from tears to mania within an hour" (Healy, 2004a, p. 184).

When taking Prozac and then Luvox, one of Healy's patients described his mind "like a video on fast forward", saying that he felt "dangerous" and wanted to "get into my car and drive a long distance at high speed whilst sorting out the problems of Western civilisation as I went" (Healy, 2004a, p. 42). A similar experience was described in the present research by Stuart who, after taking Prozac, said he developed an anger that translated into a "drug-related" 'hypersensitivity' to perceived injustice and consequently a degree of aggressive social activism:

I was very aggressive, but I had the whole of [an area] reserved. I had parks created, I had trees planted, I had beaches fixed up ... And I had a ... church and house completely repainted, refurbished, new kindergarten started, ... All was done was done through anger, anger at people's failure to understand my vision. And they'd lie they'd cheat I'd catch them out ... It's all drug related because before those drugs I was just a peaceful relaxed person.

Similarly another informant, Jon, described how two weeks after taking Prozac, "I would just not, you know like if I was going to have argument I would not be prepared to lose the battle. I would, for some reason I would try anything to win it." Jon also explained how on the drugs he felt "out of control" and had his "thoughts running wild", and how these feelings manifested into anger and aggression:

I felt so angry that I really needed to do something just to be able to let it out, either to start yelling at my partner, or pick a fight with somebody else, or really have to do something because the feelings were so overwhelming I couldn't sit still with that feeling ... because I would start, you know how we have the fight or flight feeling, and if I just sat down and let it be, I started feeling out of control. You know my thoughts running wild, and I started getting to an anxious mood, panicking.

Indeed, many informants spoke of how they experienced an increase in anger and aggression when taking SSRIs.

Aggression

Aside from the documentation of legal cases (e.g., Healy, 2004a), there has been little research published on the potential for SSRIs to elicit aggression. The majority of participants in the present research, however, discussed increases in anger and aggression when taking these drugs. Trish explained how she was supporting Simon to come off his Aropax. Every time they shaved a bit off the dose he would get a number of withdrawal effects including becoming "very grumpy, snappy, cross with things, irritable". Linda noticed that she developed uncharacteristic road rage when taking Prozac to such an extent that she didn't think she was "very safe":

[I] had road rage from the Prozac. ... If somebody ... overtook me I'd be driving after them and following after them and that, and I mean I'm really [usually] the most conservative person that ever was. It was scary. ..... I couldn't help it I just went in there and that was it and then I just went away again ... it was just me at the time and I was just annoyed ... but I mean I'm not even like that ... because normally I let somebody pass.

Jon also found that, "because of Prozac", his feelings would become more "intense". He "started getting angry all the time" and this would manifest into aggression, "something shifted [in] which I had become very aggressive. I had become very angry and also I had become easily irritated". He would "throw things, I would take the remote control and just, throw it, bash things" and also was aggressive towards his partner:

Mostly to be honest [what I would do] is to pick a fight with my ex partner. Start yelling at him, and I'm quite embarrassed to say it but it's true, a lot of people say after you take Prozac, then your sex drive goes down, actually it's completely opposite. I ... [would either] pick a fight or have sex with him [my] ex partner, so, I remember because my ex partner told me that you know that what we have is either sex or fight, and at the time I sort of I couldn't understand but now I can [see] it's true.

Debra remembered Richard "crying, thinking he's going to hurt me" and how he was concerned that he might "kill someone":

Yeah it would agitate him the fact he'd said he'd kill someone but he was never- like he was angry, agitated and panicky but not like furious and wild. Like his ... Mum and his brother and I were in the lounge, and he decided to get off to bed, didn't want to be around anyone, and he went to bed and I went up and I sat on the side of the bed and I said "Oh you're not good are you?" "No" and started to talk to him. He said "I'm telling you something" he said just like that, "Telling you something" he said, "You'd better watch them tonight because I could kill the both of them".

Stuart also spoke of how he became homicidal and suicidal, both of which "stopped when I got off the drugs":

I'd go down to the wharf and try and jump into the harbour to commit suicide, always. So all this time ... every day I wanted to commit [suicide] right? While I was on the drugs, often I'd want to kill my entire family ... because, I was so angry about my situation that I blamed my family for it, so if I was going to go they were all going to go.

Indeed, experiencing suicidal thoughts and behaviours was the most common thread in people's interviews.

Suicidality

All but one of the interviewees (Linda) spoke of suicide attempts while taking an SSRI: whilst two participants spoke of completed suicides by their close family members, six spoke of intense suicidal thoughts and actions that did not result in death, as either experienced by themselves, or their partner (as in the case of Trish). Participants described suicide attempts that were temporally linked to either an increase or decrease in dose of the drug (including starting the drug and/or coming off it completely), and of experiencing a degree of uncertainty as to whether or not they actually wanted to die. Daisy, for example, described how, after her psychiatrist "increased the dose of Aropax that I was on", she then had the "lowest point of my illness, and my life really, and at that stage I guess you would say it was a suicide attempt I made". Heather explained that Sophie had her dose of Prozac upped to 30mg and started "self mutilation behaviour" one month later; she "slashed her wrist" and "in Sophie's mind she was attempting suicide". Over the next four months Sophie made five further suicide attempts, the final one being fatal: Heather and her husband were driving past Sophie's flat when they "saw these police cars there, so that told me straight away Sophie's dead, and I was just so, I didn't cry, my husband did, but it was like I just felt dead myself. She hung herself."

Trish spoke of how before starting Aropax, Simon was taking another SSRI, Cipramil. At one stage his dose of this drug was doubled, and three weeks later he took an "overdose of nortriptyline [a tricyclic antidepressant]". Consequently Simon was put on "Aropax 40 milligrams" and two weeks later made another suicide attempt. Simon described this attempt as having had an underlying feeling of "anger". In a diary entry Trish described how this anger contributed to Simon's suicidality: he was "so angry he swings seriously suicidal just like that." She went on to explain that Simon's behaviour "is unlike any previous episode of depression we've ever dealt with. The onset was sudden, he is not tired he is not lethargic he is quite vocal he's irrational angry volatile and definitely suicidal. ... It's a very frightening combination." Similarly, around the time that his Prozac dose was doubled, Jon spontaneously tried to overdose and believed that "the attempted suicide had a lot to do with my medications" as he was "quite upset and my feeling got more intense than it used to be because when I got angry it was so overwhelming ... it's really scary because I felt you know like either I would have to kill myself or kill somebody [else]."

Another informant, Gail, described how after being prescribed Aropax "sometime over the next four weeks", she "got suicidal ... in the sense that I was actually ... moving towards acting on it" and had "a number of suicide attempts over the next number of months. I had repeat admissions to an acute ward" before she "ended up in the public system, and was put on really really high doses of paroxetine [Aropax]". From then on,

life just got completely chaotic [with] repeat admissions. I was mostly attempting suicide with drug overdoses, took massive doses ... and actually I was taking so much that I would just start throwing up, which actually kind of saved me. But it would piss me off 'cause [it was] like "Fuck me I'm not going to die", ... It was like "Fuck so now I have to go to hospital, fuck" you know I was so angry about that ..... I kept being really suicidal and I couldn't work out how I had turned.

After nine months Gail took herself "off to rehab, to get clean [from the Aropax], get some clarity". She then had her one and only suicide attempt not on the drug and felt that "basically it had just become this kind of almost reflex thing: ... feel like shit? Get your hands on whatever pills you can, take far too many of them, pray that this one works".

Indeed of particular interest in speaking with people, was that all of those who had stopped taking the SSRIs at the time of the interview (and were still alive) spoke of changes that they felt were lingering from the initial effects of the drugs. Linda's aforementioned road rage was "all the time I was on Prozac, and ... for ages afterwards." Stuart too found that the anger and aggressive intolerance to injustice he developed when on Prozac continued to influence his behaviour even when he was off it, "I kind of got cured of it but it was still in the bloody head. There's still anger." He suggested that "it's rather like alcoholism. I don't think it'll ever go for me. ... I think that I'll always suffer from the drugs, that unless I have strategies all the time ... you see I can only take so much and then I explode. And that is I think a manifestation of the antidepressants". Jon explained how even after a year of being off the drug he remains "scared" of becoming angry:

But I'm really scared when I actually start getting angry. Even now ... I have to find some way not to get aggressive, because that was the behaviour I learned when I was actually taking the medication, so, and I also, I tell a lot of people that is how I feel I've changed. I know I'm different ... [from before] I was on the medication.

Indeed people's experiences of akathisia, suicidality and/or aggression during and after taking an SSRI were often noted as being a change from their usual self.

"The different person he became": Out of character behaviour

Repeatedly participants expressed confusion, and at times embarrassment, as to why their behaviour had switched to what it did while taking an SSRI; how the drugs seemed to have, as Stuart described it, "changed my personality". Heather spoke of how such a shift

caused Sophie considerable distress:

> *None of the behaviour, particularly from May [when Sophie started Prozac] was like her [and] I couldn't understand it. [She] couldn't understand it herself. One time when [Sophie] had her wrists bandaged up, [she] said, "I must be going crazy", she said, "Who would do this? Only if they're crazy". [She] just cried and cried because she couldn't understand what was happening to her.*

Jon felt like "the medication had changed me as a person" as his aggression when he was on Prozac was completely out of character. Before taking Prozac he would "withdraw myself" when angry, but while taking the drug and afterwards became "different", another "kind of person":

> *Before I was taking the medications [I was] more softer, and saying that you know [I didn't] like to make other people upset, because I am ...[usually] a people pleaser ... And then I'd become totally the other person I was "OK if you're going to have fight with me I'm ready for it. I will go for it".*

Gail was especially perplexed by her changed behaviour when on Aropax. She described how "life got kind of messier" as she "ended up moving house and oh a whole lot of shit happened, weird stuff that just normally would never happen. You know I took up with a new girl which I just would not do in the middle of this, so weird, and a girl I would never ever take up with normally". Gail found this dissonance between who she had been and become hugely disconcerting. She could "never figure out why did I go from being this, slightly eccentric but you know, largely competent, reasonably functional person, [and] become this other kind of thing". She explained how she became homeless and "there was huge chunks that we couldn't reconcile because ... before that [taking Aropax] ... [I was] managing big complex projects [in my job]. It's like, how ... the fuck did I end up being this kind of moron? I couldn't work it out. I couldn't work it out you know".

Debra too described the "different person" that Richard became as he was prescribed increasingly more psychopharmaceuticals:

> *And the neighbours say ... the difference ... in Richard that they'd never seen in him before, because he was quiet until he got around the table or around the BBQ and he'd start telling the jokes and laughing but, like normally Richard was a quiet person and if anyone came to his house he'd be the last one to tell them to go, and he wasn't moody, he was never a moody guy and yet these moods were coming through and but, you know, all the more of this [psychopharmaceuticals] he was on, the different person he became.*

Heather stressed how Sophie's "whole behaviour was just so unusual" and "her whole way of functioning was gone". She described a discussion with a psychiatrist about these changes:

> *[I said] "Sophie is different to what she used to be". Sophie is sitting right here beside me. The psychiatrist said, "Well what do you mean she's different?" and I [said], "Well, in the beginning, [when] she'd rung and she was in that acute state ... she said to me then, "Mum" she said, "I will never commit suicide because I know it would break your heart". I know it was the Prozac because that's when the suicidal behaviour started, after it was prescribed. I said to the psychiatrist, "She was not suicidal at the beginning". I said, "She told me it would break my heart" and I cried in front of Sophie, I said, "You know it's like she doesn't even care". And it was.*

Indeed, for some people a key part of feeling out of character was being unaware of, or somewhat disconnected from, the existence or impact of their aggressive or suicidal behaviour while on the drug. This seeming compulsion for people to act on aggressive or suicidal impulses while on SSRIs has been described as 'disinhibition' by Healy (2004a) and was one of the common themes in his own observations. One participant in his healthy volunteer study, for example, became "impulsive and disinhibited" and "without regard for consequences" while taking Zoloft (Healy, 2004a, p. 184). Similar experiences were depicted by Heather, who described how Sophie had developed a "suicidal obsession"; how her behaviour was "not a choice. It's like a real, compulsion". In particular Sophie "wasn't aware of what her actions were like". After she made a suicide attempt she would just "bounce back" as though, said Heather, she thought, "I hadn't done [anything] out of the ordinary. I've just been down to the shops to get groceries or something". Sophie "couldn't see the impact of it [her behaviour]" and yet "she was [usually] a very insightful person".

This lack of awareness was fundamental to Gail's experiences. She became suicidal on Aropax but "I didn't know that, which is kind of the place where it's a bit mad, but you can be in one half of your brain making plans, [and] in another part of your brain not recognise it. It's just, you know, [like you're a] wonderfully shut down person":

> *One three week period I had three admissions for suicide attempts. You know, how did I turn into somebody who kept doing that in such a, incompetent way but so driven, and, and also ... was so oblivious to what I was doing at the same time, you know, and I could never understand that. That was the bit that kind of confounded me about it all ..... 'Cause I didn't just cross a line I tripped over an edge I went into an abyss that I'd never gone into before I'd ... had periods of being very bleak in my past as a consequence of addiction and depression and the way they feed each other. I [had] had periods of being really bleak and wishing I was dead, but wishing I was dead is very very different from this kind of chronic obsessive or just that hugely impulsive acting on it. Really really different. ... Lots of people get to the bleak and wish I was dead, but relatively fewer of us go into that kind of lunacy.*

Similarly many of the participants described being seemingly unable to

comprehend why, or at times even *that*, they were acting in an aggressive and/or suicidal way, or what the impacts might be. After a day of Simon being "so angry he swings seriously suicidal just like that", Trish wrote in her diary:

> *At bedtime he [Simon] muses, and he told me to write this down word for word: "Why should I be so angry about you using the computer? Shouldn't you be able to use the computer if you want to? Why should I be so angry that she wants to spend some ridiculous amount of money on your daughter? It's a stupid thing to want to do but why should that make me want to kill myself?" And then he adds: "Write this down in your notes and maybe we can come back to it when I can think straighter". And then he adds: "Isn't it funny that I can think so rationally about this and yet I want to kill myself? This is bizarre".*

Debra explained how, just prior to his suicide, Richard was "in a trance"; that "he didn't want to die" but at the same time knew "exactly what he was going to do". Healy (2004a) too depicted one woman's SSRI-induced suicidality as akin to being in a "hypnotic trance" (p. 185); "It was as if there was nothing out there apart from the vehicle she was going to throw herself under" (p. 183). In addition another woman took Zoloft and then "found herself thinking of the beam in the ceiling of her bedroom, planning to hang herself from it. She was drawn to it, controlled by it, and knew she didn't care that finding her body the next day would disturb the rest of the family" (p. 184).

Indeed Healy found that another common theme in SSRI-induced suicidality seemed to be this "lack of concern for those left behind" (Healy, 2004a, p. 186). He comments regarding one woman's response to her suicidality, "she didn't think of her partner or child. This lack of feeling for them ate away at her later. When our biology changes, we change, but even in the midst of a high fever, when everything was unreal, she still knew she loved her daughter. Now she felt nothing" (Healy, 2004a, p. 183). Similar depictions of an apparent lack of consideration for others also came across in the interviews. In particular this disregard appeared to have a lingering effect on Jon who explained how when he was aggressive while taking Prozac he simply "didn't see" how he may have been affecting others:

> *[E]verybody said [they were] sort of afraid of me, and I couldn't even see that myself ... see that I was getting angry all the time. I thought I was just responding to, things that I felt weren't right, but I didn't see the way my reaction had been had on other people, and that really scared me because I didn't understand because like I needed help but yet at the same time I had driven people away from me, and I became very isolated and then I would get even more angry, and then I would push people away even more so.*

Being subjectively unaware of the impact of their behaviours on others also seemed possibly associated with a lack of empathy while taking SSRIs or, in some cases, a lack of emotions in general. Such 'depersonalization'(Breggin, 2003) or 'emotional blunting' (Healy, Herxheimer, & Menkes, 2006) has been recognised as a side effect of SSRIs. Stuart described how when on Prozac "it seems you're in a vacuum". Trish said of Simon when on Aropax, "I wouldn't say that [he's] an empathetic person at all at the moment, and hasn't been since he's been on the pills":

> *[Before Simon went on Aropax] I would have considered [him] a very sensitive and emotional person, you know, ... someone who found genuine pleasure and enjoyment in simple things, who, when upset would cry. And I thought that was magic. I thought that was really nice not many men will do that. And, you [directed to Simon] haven't shed a tear over anything, since you've been on the pills.*

Perhaps not surprisingly, these changes in people's subjective awareness and empathy had marked impacts on their relationships.

"I could feel this Sophie separating from us": Harm to relationships

Many participants spoke of how experiences of adverse effects from SSRIs affected relationships. After Sophie's first suicide attempt, Heather was "scared to let her out of my sight":

> *[I would] get up early in the morning, have my shower with the door open so that I could hear what Sophie was doing. [If] I had washing to hang out I would rush down early before she got up, hang it out and rush back up. [Sophie would get] irritated and she said to me, "You don't have to do that, follow me around and be scared".*

However it wasn't just suicide attempts that affected their relationship. After Sophie started taking Prozac Heather had "no idea" what was going on, "I couldn't understand why I couldn't get through to her anymore, when we talked about things it was like going round in circles":

> *I could feel this Sophie separating from us particularly from me because, she always called me her best friend and we [used to] talk for ages. We just had a wonderful mother and daughter relationship as well as a friendship and I couldn't understand why [it had changed].*

The interview with Trish and Simon also illustrated how the changes in Simon while on Aropax had influenced their relationship. Trish read again from her diary:

> *Last night it was too much wine again [referring to Simon] and talk of cutting things off [suiciding] or going to [Simon's empty house to suicide]. I find this just winds up my stress level and it isn't helpful at all for me but I'm getting better at coping with it and was pleased to realise it didn't stress me to tears that leave me lying awake for hours last night worrying. That's not to trivialise the danger of him hurting himself or killing himself is very real I know, but I'm learning how to cope with it better. I am a victim of emotional abuse over it ... I hate his abuse ... and his threats, and just mourn for Sally [Trish's daughter] who feels trapped and rejected. Over*

this I feel like a hostage.

Linda found that being on Prozac affected her friendships with others as "you can't communicate with people the same ..... because I suppose I'm too, confrontational I don't know." Gail too described how when she was on Aropax her "bad behaviour" impacted on her relationships and thus her living situation:

> *There was a lot of kind of bad behaviour stuff, you know, really stupid squabbles with family members. One family member in particular was being really supportive and you know I made his life fairly difficult you know. That complete self obsession where you expect everybody to dance on the end of a very short string that you're tugging on, and you're completely oblivious to how you're perceived in the world or what you're coming across like ... I ended up homeless, I was living out of my car, I was kind of roaming round the countryside a bit ... it was chaotic.*

Experiencing akathisia and suicidality when on Prozac also caused the family and professional life of one person Healy worked with to be "torn apart irrevocably" (Healy, 2004a, p. 41). Several interviewees spoke about how these effects on relationships carried on beyond the prescription period of the drug. Stuart for example became (and remains) highly distant from his two sons. Jon's confrontational anger and aggression affected people he met while on Prozac to such an extent that even now when he is off the drug he is "very afraid of even facing them because I feel so embarrassed". Moreover, Jon's behaviour had massive impacts on his relationship with his ex-partner:

> *I did a lot of stupid things when I was actually taking medication, I was even purposely having sex with someone to piss off my partner, and actually that goes against my principles. I did feel bad ... I felt that was the worst thing you could do to someone else but I was prepared to do things like that to destroy my ex ... so I was really scared, like that sort of really made me feel scared of trying new medications.*

After three months of being on Prozac, Jon realized that he would "get angry with my partner after I take the medication". His doctor advised him "that it's quite a normal reaction for people who are taking Prozac" however she "never [told] me that the consequences and the result [of the anger] can be so scary." Several participants also conveyed disappointment with the responses they received from medical professionals when experiencing suicidality and/or aggression from SSRI use.

"What she did was up the dose": Responses from the medical profession

People spoke of how their perspectives seemed often discredited relative to those of doctors'. Said Heather, "They don't want to know what my knowledge of [my daughter] was, what her history was, even if I tell them it, they then put their own viewpoint on it ... like in [using] medical or mental health [models]". Indeed overall Heather felt that mental health professionals had not listened to her or Sophie. She spoke of how Sophie herself said many times to her doctors that "I don't think this medication is helping me" and that "I think the problem is just stress, [it's] stress management that I need". However, "No-one listened to her. No-one had involved us in anything. No-one informed us or Sophie about the drugs, so we didn't know what we were facing. We don't even have an exact date of death." Heather's only acknowledgement that Sophie's behaviour might be drug-induced was after her first suicide attempt:

> *[Sophie's psychiatrist] actually said Prozac can cause a person to be aggressive to themselves. So that kind of gave me a shock, but, what she did was up the dose. She put it [Prozac] up to 40mgs which is what Sophie remained on for the rest of the treatment.*

Several other interviewees also received a degree of acknowledgement from doctors that their aggression and/or suicidality might be related to the SSRI they were taking. Gail remembered her psychiatrist deciding she was on "way too much" Aropax. However, this was the closest thing to a "clue" that the drugs may have been implicated in her suicidality, "nobody ever said it was the meds. There was that clue the psychiatrist gave me about 'No that was too much', but no it was, you know, 'You were depressed', you know and the substance abuse". Gail also had her behaviour attributed to other diagnoses, including "bipolar disorder" and "single episode psychosis".

Like Gail, all interviewees described how any increased akathisia, aggression and/or suicidality experienced with SSRI use was medicalised: diagnosed as being attributable to an "illness" and/or alcohol abuse and/or medicated. Heather spoke of how Sophie's behaviours received diagnoses of "anxiety disorder, depression, PMDD [premenstrual dysphoric disorder], anorexia, personality disorder, alcohol abuse ... social phobia". At one stage Heather was also told that she was responsible:

> *[It was] just a terrible terrible time where you have got professionals thinking that you have done these things to your child. [It] was terrible because, we had nurtured Sophie, protected her, taught her right from wrong. [She] couldn't understand the effects of her behaviour, and professionals thought we had actually done it to her.*

Trish asked Simon's psychiatrist to take him off Aropax and was told "they have been prescribing them [SSRIs] for years and they're perfectly safe to use". The psychiatrist then wrote a letter to Simon stating that "during our initial meeting I said that in my professional opinion your primary illness has caused your previous very serious multiple suicide attempts, rather than the medication your illness is treated with". Daisy also had her experiences medicalised after she attempted suicide following an increase in her Aropax dose. After her attempt she told "my husband and told my counsellor, and they sort of recognised that [the suicide attempt] as the illness, and at that stage ... [my psychiatrist] I think prescribed Lithium as well." Subsequently over the next three months, in "trying to get the right mix of medication to increase the effectiveness of the antidepressant",

Daisy was put on two anti-psychotic agents, developed anxiety attacks, and was then prescribed an anti-anxiety agent on an as-needed basis. Likewise Linda was prescribed an anti-anxiety agent "because I was having trouble with the Prozac".

Debra described the medicating of Richard's experiences of adverse drug effects as his "slow spiral down to committing suicide." During the interview she read from a letter written by the lawyers defending the psychiatrists involved in Richard's case, which conceded that, "Inadequate consideration was given to the possibility that Richard's restlessness and agitation may have been due to extrapyramidial side effects." However Richard was told by doctors, and believed, "he was going crazy, that this imbalance of chemicals in his head was the cause". Two weeks before his suicide, Richard saw a locum psychiatrist who "had a look at the medication he was on, and said 'Richard, your head's like a bowl of scrambled eggs, you've got to come off this.'" Consequently he was taken off all the psychopharmaceuticals "cold turkey". Richard's medical records described him as then experiencing "extremely anxious agitation and restless. He has thoughts of doing harm to his wife, mother and business contacts. He has had suicidal thoughts." Debra described the day that Richard suicided, and how an offer of support from mental health services had come, literally, a minute too late:

> *He came home he was out in the shed and he was cleaning up the shed ... [he] couldn't eat, felt so sick, just [imagine] what sort of a state are you in to be able to commit suicide. It doesn't bear thinking about you know, it's terrible, and looking at me there and being very quiet and not saying anything to me I peeped out and he was sweeping all the garage out and that you know, and he came in and we went to bed, and you wouldn't believe it. I woke up early hours of the morning, Richard standing alongside of me stark naked, and he'd been out of bed while I was sleeping and had been down to the lake again and tried to commit suicide again, and he said "All my clothes are out in the carport", and he was shivering, and I said "Come on you have to get in the shower and have a shower", and I helped him and I said "I'll ring ... [the] hospital", and the poor beggar in the state he was in he said "Don't ring them there's no use ringing them they wouldn't come last time" ..... [The next morning] the phone went and as it would be it was [someone from the hospital] saying that she had found a bed she'd worried all night and thought well he needs to be hospitalised. First person that thought he should be, and, when the phone went he must have thought "Aah what's this going to be now, something about me I guess", and so he went and I thought he was in the loo and I looked in the loo and he wasn't. When I hung- I was only on the phone a matter of a few- like a minute or more just to be told that to get him in [to hospital] you know, and of course I went rushing out I thought the only other place is the shed and as I rounded the corner of the carport to go out to the shed, I called out "We've got you some help at la-" I went to say "at last Richard" and here he is hanging in the shed, and I rushed to him and he was still as warm as warm, and his tongue was hanging way out here you know, and oh honestly Rachel it was just- and of course I thought I had the strength to lift him, but course the rope was that tight under his throat, and he'd gone.*

Discussion

In this paper we have presented accounts of the personal and relational nature of serious adverse effects associated with SSRI use. These have been placed within an analytical framework in such a way as to offer a counterpoise perspective in relation to rhetoric that might otherwise question the existence and/or significance of these effects.

First, participants' accounts may cast doubt on notions that people's experiences of suicidality and aggression are more plausibly located in 'the disease not the drug'. The existence of elements of akathisia and/or compulsion such as that described by Jon, "I start feeling out of control. You know my thoughts running wild", and Heather about Sophie, "It's like a real, compulsion", were found throughout people's accounts of experiences of suicidality and aggression. These features have been noted by others as distinguishing SSRI-related experiences of suicidality from those which might usually be linked to depression (see Breggin & Cohen, 1999; Glenmullen, 2000; Healy, 2004a). As Trish explained about Simon, "he is not tired he is not lethargic he is quite vocal he's irrational angry volatile and definitely suicidal", and as Gail said, they're "very really different places and lots of people get to the bleak and wish I was dead, but relatively fewer of us go into that kind of lunacy". Healy and Whitaker (2003) suggest that such a (dis)connection between the phenomenology of suicidality 'normally' associated with depression and that associated with SSRIs may be overlooked in clinical practice and research. Similarly, Putten (1975) warned clinicians over thirty years ago that akathisia may be misinterpreted as an 'agitated depression'.

The consistent impression in all but one of the participants' accounts that a person's behaviour on SSRIs was profoundly 'out of character' also challenges the assumption that a person may have had some sort of pre-existing 'condition' conducive to these experiences. Said Heather, "Sophie is *different* to what she used to be", Stuart, "before those drugs I was just a peaceful relaxed person", Jon, "the medication had changed me as a person", and Debra about Richard, "the different person he became".

In particular however, participants' accounts challenge the notion that serious adverse effects other than suicide might be outweighed by longer-term benefits from using SSRIs (see also Liebert & Gavey, submitted for publication). People's lived experiences of akathisia, aggression and suicidality had significant short and long term negative effects on both themselves and

those around them. First, they intensely affected people's own wellbeing, often troubling their identity. They led Sophie to ask Heather "Who would do this? Only if they're crazy" and Gail to ask herself "How ... the fuck did I end up being this kind of moron?" Simon reflected on his behaviour as "bizarre", Jon remains "embarrassed" of his past behaviour and "scared" of his own potential anger, while Stuart felt that antidepressants "changed me as a person". Similarly Grime and Pollock (2004) found that people they interviewed who had taken the drugs said it was the psychological side effects that altered a sense of self or identity, or caused a feeling of emotional flatness or estrangement, that they found most difficult to accept.

The subjective intensity of, and distress associated with, akathisia in particular seems often under-rated in research on SSRI adverse effects, as Gail described; "they took my depression and then medicated me into madness". Although described by some scholars as "a unique form of inner torture" (DeGrandpre, 2002), it seems often to be accepted by clinicians as a 'worthwhile' and/or 'necessary' SSRI effect along the treatment path (Liebert & Gavey, submitted for publication). In this way researchers, practitioners and regulatory bodies may overlook the ways in which this sort of iatrogenic "madness" can leave a highly problematic and disturbing legacy on people's identities and relationships beyond any immediate agitation. The same can be said for experiences of aggression and suicidality. As Healy has noted, the potential to (mis)attribute such adverse drug effects to "personal failings" or "a worsening of the illness", can "lead someone to spiral down", to the point that it can for some increase the risk of future suicide attempts (Healy, 2004a, p. 49).

Through the participants' accounts, it was clear that these sorts of distressing experiences were certainly noticed by clinicians; but most likely diagnosed as an(other) dimension of mental 'illness', rather than as an adverse effect of the SSRIs they had been prescribed. A letter from Simon's psychiatrist read, "your primary illness has caused your previous very serious multiple suicide attempts, rather than the medication your illness is treated with" and Sophie received diagnoses of "anxiety disorder, depression, PMDD, anorexia, personality disorder, alcohol abuse ... sociophobia". Healy (2004a) also noted several women whose drug-induced akathisia, aggression and/or suicidality was diagnosed as a 'personality disorder' and commented for one woman that "There were no more suicide attempts once the Prozac was stopped. But how long would the label "personality disorder" remain in her medical notes?" (p. 187). When people experienced adverse effects from SSRIs, it seems they were effectively "seduced and abandoned" by medical expert opinion (Chesler, 1972).

This 'abandonment' seems all the more concerning given the marked effects that SSRI adversity secondly had on people's relationships. Several participants described the pain and suffering associated with disrupted relationships with friends, family and partners when taking SSRIs. Heather, for example, felt that her and Sophie "just had a wonderful mother and daughter relationship as well as a friendship and I couldn't understand why [it had changed]" whilst Debra would experience having her husband Richard "one minute ... OK, and happy, and he'd be walking along and he'd hold your hand or something, and next minute he'd be walking on that side of the road and you wouldn't think you were even with him". Jon's aggression while on Prozac had "driven people away from me, and I became very isolated" and Trish at times had "tears [about Simon] that leave me lying awake for hours".

In highlighting the potentially devastating impacts of these experiences, we are calling for a sideways move in the current discourse on SSRI use. The accounts we report cast a shadow of doubt on the rhetorically powerful, but ultimately un-testable, 'disease not the drug' claim. Moreover the negative impacts of SSRIs on some people's wellbeing, identities and relationships offer a persuasive and poignant plea to further consider non-fatal adverse effects and their lasting consequences when assessing the risks of these drugs. The scientific evidence, as it currently stands, does not provide any definitive and unequivocal support for either side of the debate about whether SSRIs take or save, harm or heal, more lives. Nor, we acknowledge, does the present paper (intend to): participants' accounts told of experiences embedded within complex lives (and deaths). Nonetheless, it is important to recognise the considerable, apparently drug-related, distress experienced by some people who use SSRIs. Greater understanding around the *lived reality* of these people's experiences of serious adverse effects can only be of benefit to inform the broader debate around SSRI use.

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Notes

1 This argument, however, is embedded within controversy over depression diagnostics, including the inappropriate medicalisation of unhappiness (e.g., Gardner, 2003), 'disease mongering' through pharmaceutical industry marketing techniques (e.g., Healy, 2004b; Moynihan & Cassels, 2005) and the fragility of the serotonergic theory of depression (e.g., Lacasse & Leo, 2005).