



'I think we're all guinea pigs really': a qualitative study of medication and borderline personality disorder

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Accessible summary

- Seven service users with Borderline Personality Disorder (BPD) were interviewed to explore their experience of being treated with medication.
- Service users identified there was a lack of knowledge and understanding around the BPD diagnosis, which made treating this group difficult for staff.
- Service users also reported there was also a lack of resources for this diagnostic group so staff relied on medication, although this had improved with the introduction of a specialist service for people with a personality disorder.
- Service users had different opinions on whether they thought medication was a part of their recovery pathway, but agreed they should be involved in deciding whether it would be used as a treatment.

Abstract

National Institute for Clinical Excellence recommended the use of medication only in times of crisis for individuals with borderline personality disorder (BPD). Despite this recommendation most service users referred to a specialist personality disorder service were found to be on numerous medications. Although a number of qualitative studies have explored the experience of individuals with a diagnosis of BPD they have failed to discuss their experience of being treated with medication, despite its high prescription with this group (e.g. Sansone *et al.*). The aim of this study was to explore the experience of service users being treated with medication for the BPD diagnosis. Semi-structured interviews were carried out with seven service users under a specialist service for personality disorder. Interviews were transcribed and analysed using thematic analysis. The main themes to emerge were: staff knowledge and attitudes, lack of resources for BPD and the recovery pathway for BPD. Overall, service users felt that receiving the BPD diagnosis had had a negative impact on the care they received, with staff either refusing treatment or focusing on medication as a treatment option. The introduction of specialist services for this group appears to improve service user satisfaction with their treatment and adherence to the National Institute for Clinical Excellence guidelines.

Borderline personality disorder (BPD) has generated the most interest out of all the subtypes of personality disorder, because of their frequent presentation to mental health services (Fallon 2003), and their reputation as 'difficult' Declaration of interest: None.

individuals to work with (Woollaston & Hixenbaugh 2008). Recently the interest in this client group has increased dramatically due to the publication of recent guidelines for the treatment for personality disorders. The National Institute for Clinical Excellence (NICE 2009)

recommended the most effective treatments for two subgroups of personality disorder, including BPD. It was advised drug treatment should not be used to treat BPD or its symptoms, except for short-term treatment during a crisis, or for co-morbid diagnoses. Despite the lack of evidence supporting long-term medication use with this client group, research into the prescription of psychotropic medication by Sansone *et al.* (2003) found those with a diagnosis of BPD were prescribed significantly more psychotropic medication than those with other types of personality disorder or no diagnosis of a personality disorder.

Reviews of treatment for BPD have generally indicated that no reliable conclusions could be drawn regarding the efficacy or effectiveness of psychotropic medication because of methodological problems in studies conducted so far (e.g. Bellino *et al.* 2008). Bateman & Tyrer (2002) conducted a systematic literature review on therapies available to those with a diagnosis of personality disorder and concluded there was unknown efficacy and limited generalizability for both antipsychotics and mood stabilizers, with antidepressants having limited efficacy due to small sample sizes in studies. Similar to NICE guidelines they concluded that drug treatment should be used in 'crises', with psychological therapies suggested as the core method of treatment for a personality disorder diagnosis.

While NICE (2009) have outlined the treatment recommendations for this client group it does not acknowledge the complex nature of this diagnosis, and the numerous difficulties faced by professionals when treating this client group. A common issue facing mental health professionals with this client group is the heightened chance of co-morbidity, with 50–60% of individuals with BPD receiving a co-morbid diagnosis of a mood disorder, an anxiety disorder or a substance use disorder (Grant *et al.* 2008). Furthermore, the increased level of risk of self-harm and/or suicide within this client group (Oumaya *et al.* 2008) is likely to increase the urgency for mental health professionals to provide treatment. The heterogeneous nature of the diagnosis also indicates a difficulty in identifying a uniform treatment for individuals diagnosed with BPD (Leichsenring *et al.* 2011). Finally, the recommendation that medication can be used during crises (NICE 2009) causes greater difficulties for professionals due to the frequency of crises in this client group.

From the research it is evident that there seems to be limited knowledge on whether medication is effective for the symptoms of BPD, and how to manage this complex disorder. Most importantly, it neglects to inform professionals of the individual experiences of those being prescribed the medication.

Qualitative studies investigating the experiences of individuals with BPD are limited, with only seven identified published studies on BPD using a qualitative method (based on a database search of 'borderline personality disorder' and 'qualitative'), four of which focused on service users' experiences of therapy. Surprisingly, no papers have explored this client groups' experience of medication as a treatment, despite its frequent prescription in this client group (Sansone *et al.* 2003).

Using grounded theory, Fallon (2003) investigated the experiences of being in mental health services for individuals with BPD, to conceptualize their contact with psychiatric services. Service users felt accident and emergency and inpatient nursing staff in particular focused on utilizing the medical model (namely dressing wounds and offering medication), directing service users towards psychological services if they wanted to 'talk'.

Using Interpretative Phenomenological Analysis, Nehls (1999) studied the experience of living with the diagnosis of BPD. Service users discussed the benefits of receiving the diagnosis, but the downfall of receiving the discriminatory attitudes due to the 'PD' label, also identified by Horn *et al.* (2007). Service users reported helplessness at being told that there was a lack of treatment available for personality disorder, with one service user reporting they were informed by staff that medication does not work for personality disorder.

It is evident from the literature that individuals with BPD have concerns about their treatment, particularly with the lack of knowledge around treating individuals with a diagnosis of BPD. Unfortunately, because of the broad questions asked in previous qualitative research of BPD, it seems the experience of medication treatment has not been explored in any depth. While no research has appeared to focus on medication in BPD, there has been some research on the experience of medication in mental health service users.

Gault (2009) explored the issue of compliance with medication among service users and carers, using an adapted version of grounded theory. Service users reporting they did not trust professionals and their knowledge of prescribing medication, particularly when it took staff so long to find the most effective medication for individuals. The second theme, 'playing the game', described service users' experience of feeling like they lost their sense of autonomy and were subject to coercive treatment.

Also using grounded theory, Carrick *et al.* (2004) explored the experiences of service users who were prescribed antipsychotic medication, specifically the consequences of side effects on adherence. Authors identified the core concept of maximizing well-being, used to define the service users' quest for 'normality' and to

essentially recover. This involved service users desire to be in control of their treatment and receive adequate information.

Clearly the concerns around medication are not restricted to individuals with BPD; however, the increased stigma attributed to this diagnosis (e.g. Nehls 2000, Markham 2003, Woollaston & Hixenbaugh 2008) indicates they may be subjected to more negative treatment than the typical service user. Furthermore, researching medication treatment using a range of psychiatric disorders reduces the quality of the individual experience, particularly differences between diagnoses.

The objective of the research is to explore the views, opinions and experiences of those diagnosed with BPD with regards to their experience of medication as a treatment for BPD.

Method

The study recruited service users from a specialist service in Hertfordshire for those with a diagnosis of a personality disorder. The prospective participants were identified and approached by their care coordinators, with the inclusion criteria stating they must have received a formal diagnosis of BPD, and received medication as part of their treatment for this diagnosis, currently or in the past 6 months. The only exclusion criteria were no current psychotic symptoms and/or cognitive impairments, which were confirmed by care coordinator. They were asked by their care coordinator whether they would like an opportunity to discuss their views and opinions in an interview format on the use of medication as part of their treatment for BPD. They were then given an information sheet which outlined the rationale for the treatment, its ethical approval (granted by Hertfordshire Research Ethics Committee), and information around the potentially distressing nature of the research. Participants were asked to consider whether the topic of the research would be distressing to discuss, and if so, they were advised not to take part. Following consent participants were contacted by the researcher and interviewed at their local Community Mental Health Team centre. The researcher was a staff member of the specialist service, but had no involvement in care coordination or the treatment management of the service users. Furthermore, as there was no psychiatrist in the specialist service it was assumed participants would feel comfortable disclosing their experience of medication treatment (confidentiality was also confirmed in the information sheet, unless an issue of risk arose during the interview). Service users were approached by their care coordinators rather than the researcher to ensure they did not feel pressurized to take part.

The participants included were six women and one man, with an age range of 21–43. Each participant reported a past or current prescription of antidepressants and antipsychotics. Four of the participants had also been prescribed mood stabilizers and anxiolytics as part of their treatment for BPD.

The interviews were semi-structured, with the opening question of ‘Tell me about your experience of being treated with medication for your diagnosis of Borderline personality disorder’. Each interview lasted between 30 and 50 min and was audio-recorded and transcribed to ensure accuracy.

Based on the previous literature previously discussed the topics covered were:

- how participants were informed of this treatment;
- if they had any input into the decided treatment;
- what the benefits of medication are;
- what the disadvantages of medication are;
- what side effects of medication they have experienced;
- what other treatment options they were offered (if any).

If an area remained uncovered the participant was prompted; ‘you haven’t spoken about [insert topic here]. Is there anything you would like to mention on that topic?’ Participants were also asked if there was anything else they would like to raise in relation to their medication treatment before the interview ended.

Data were analysed using thematic analysis (following the procedure outlined in Braun & Clarke’s 2006 paper), in order to identify the key themes in the views and opinions of service users in relation to their medication treatment. This involved sentence-by-sentence coding which was then categorized into similar topics and eventually built up into themes.

Each interview was transcribed and analysed before the following interview took place to look for evidence of theoretical saturation. This occurred after five interviews, whereby no new themes were emerging from the data, to ensure all relevant themes had been identified. The researcher continued to recruit two more participants to ensure triangulation of sources, guaranteeing each of the four areas in Hertfordshire are represented. By recruiting from the four areas of Hertfordshire, it increased the likelihood that medication treatment from a variety of psychiatrist’s/Community Mental Health Team’s in the region of Hertfordshire was incorporated in the study.

To gain an additional perspective on the research and ensure the themes reflected the content of the interviews, themes were discussed regularly during supervision. Evidence for each of the themes was explored, as well as possible ways to further group the themes. This allowed

for the merging of several themes, and elimination of similar themes, reducing the themes from thirteen to three.

Results

There were three main themes identified from the thematic analysis; the most commonly reported issue was staff knowledge of and attitude towards the BPD diagnosis. Participants also identified a lack of resources available to individuals with BPD. Finally they identified important issues in the recovery pathway for BPD.

Staff knowledge and attitudes

The first theme identified was negative staff attitudes and the lack of understanding of the BPD diagnosis among staff:

They basically said to me 'they give you that title because there's nothing else that covers you'

He admitted that he didn't understand border[line] personality disorder, he didn't know anything about it.

You get the usual talk that medication don't work for BPD.

The poor knowledge exhibited by staff resulted in negative attitudes:

They just made me feel like I was a bit of a pain to be honest – they made me feel like they didn't know what to do with me, wasn't I useless 'cause the medication didn't work very well.

Some other attitudes experienced by service users were dismissive, unsympathetic and insensitive:

I said to him that I jumped out of quite a high tree to try and kill myself, he sort of laughed at me and sort of said 'well that was a bit stupid wasn't it?'

Service users also felt like they were 'guinea pigs' who were trialled on numerous medications because staff did not know how to treat them:

I just think when you first come into service that they experiment on you . . . over the course of years they've experimented with lots of different drugs.

I've felt like they didn't understand, and they just like piled me with any sort of medication.

Furthermore there appeared to be confusion among mental health professionals about what treatment 'worked' for individuals with a diagnosis of BPD, which led to service users feeling let down by services and unsure about their options for recovery:

What was it they said? 'Nothing really works for BPD, you're gonna be in and out of hospital, in repeated crisis.'

[They said] there was nothing they could do, and basically I just had to get on with it.

Lack of resources for BPD

The lack of knowledgeable staff resulted in service users feeling let down and rejected by services as they did not respond to typical treatment strategies:

They just made me feel like I was a bit of a pain to be honest . . . Wasn't I useless 'cause the medication didn't work very well.

Service users often experienced being told to take new medications without any information of their function:

They don't say why that particular [drug] or anything – they just give them to you.

No, they're pretty useless really . . . They don't really go through things with you in much detail.

The lack of information from staff led to service users seeking other resources, e.g. the internet; however, this came with some risks:

I do look things up myself, but sometimes it can be a bit scary.

Sometimes I take the name of the medication and just Google it, but . . . some medications have very similar names.

They also felt there was an overemphasis on the use of medication for treating BPD, rather than offering other types of treatment, despite the lack of evidence supporting its efficacy:

Sometimes I just wish the psychiatrist could understand that sometimes there's more to an illness than just throwing medication at it.

Evidently, for borderline personality disorder, so I'm told, medication doesn't help.

Service users reported that transferring to the specialist service had led to a positive change in their treatment:

I think that coming here is the first step I've known in the last eight-ten years erm – the first positive thing.

Service users generally felt they received better help and support from a specialist service for personality disorder than from community mental health teams:

It wasn't until [the CPDS] was set up I was ever offered any kind of actual help for the personality disorder.

The specialist service was also beneficial for promoting the use of alternative forms of treatment, i.e. talking therapies:

If I was to have a problem I could speak to someone rather than – without knowing that the first thing they're going to suggest is giving me meds.

The specialist service also placed an emphasis on evidence-based practice, offering a treatment that is widely acknowledged to be helpful for those with the BPD diagnosis:

My DBT [Dialectical Behaviour Therapy] that I'm doing now – I've done DBT a bit on the past – but I find it more beneficial than medication for instance.

The recovery pathway for BPD

The second superordinate theme identified from the data was the recovery pathway for individuals with BPD, which highlighted the need for service users to be involved in decisions around their treatment, and whether they wanted medication to be a part of their recovery plan. Participants repeatedly identified that they were poorly informed of the rationale for their treatment, particularly when they were being treated in an inpatient setting:

They don't say why that particular [drug] or anything – they just give them to you.

She said 'you either swallow it, or we'll give you an injection' so no choice.

Moreover, when treatment plans were decided they felt like they were not involved in the decision process, but merely informed of the outcome:

They'd never ever brought medication up unless they're changing them, and I never got a say in it.

This experience changed when moved to the specialist service, where they were given the choice of including medication as part of their treatment.

Involvement in decisions around their treatment allowed service users the power to decide on their own recovery pathway, which varied between individuals. Some felt that medication was not necessary for their recovery:

Now [I'm not on medication] I'm up at seven, go a college, work, I have a social life, I see my mates.

Whereas others saw medication as an important part of their recovery, and appreciated its benefits:

I don't know if I'm ready to come off what I'm on at the moment – I feel it's just right, I don't want to – what's the saying – upset the apple cart.

However, choosing to include medication as part of their recovery meant service users had to learn to manage the side effects associated with the medication:

What does concern me is weight gain; I've put on four stone since being on this medication.

Discussion

Despite the recommendations made by NICE (2009) and Bateman & Tyrer (2002) based on research evidence, studies (e.g. Sansone *et al.* 2003) suggest medication is still a primary intervention used with individuals with the BPD diagnosis. Unfortunately, this suggests that evidence-based practice is not being put into place by clinicians working with this client group. Additionally, as mentioned by one

service user, clinicians are using the loophole of treating individual symptoms of BPD with medication leading to a cocktail of psychotropic medications for individuals with a diagnosis of BPD. Generally the experience of being treated with medication for BPD has been largely negative, with individuals with BPD feeling like 'guinea pigs', although some positive changes are beginning to occur. This was particularly in relation to the set-up of a specialist service for those with a diagnosis of personality disorder, where the emphasis was on psychological treatment rather than medication.

Another frequently reported issue was staff knowledge and attitudes; service users generally felt that staff attitudes were negative and dismissive. Similarly to the Nehls (1999) study, the service users in the current study spoke about neglect from services over the years, and struggling to find a solution to the difficulties they were facing. Nehls (1999) also describes the feeling of helplessness felt by service users with the BPD diagnosis at being told there was no treatment available, which was expressed in the current study under the theme: 'staff knowledge and attitudes'. Several research papers (e.g. Nehls 2000, Markham 2003, Woolaston & Hixenbaugh 2008) have investigated the issue of staff attitudes towards the BPD diagnosis, and it seems that staff do tend to experience more negative attitudes towards this client group compared with other psychiatric populations. Contrary to recent reports (e.g. NIMHE 2003, NICE 2009) service users were often told that there was nothing to help individuals with the BPD diagnosis, which is likely to have instilled a sense of hopelessness within these individuals. This would indicate that recent reports indicating individuals with this diagnosis are treatable (NIMHE 2003) are not being accepted among mental health professionals, and the previous idea of this diagnosis being untreatable is still present within staff and services. Only four studies (Krawitz 2001, 2004, Commons Treloar & Lewis 2008, Commons Treloar 2009) have assessed the use of education programmes to improve staff attitudes to BPD, or to the personality disorder diagnosis, and have found promising, although generally short-term, improvements in staff attitudes. Encouragingly, some service users reported some improvements in services, such as having feedback taken on board, and improved understanding of BPD among some clinicians. Again, the most positive feedback was linked to the new specialist service the participants were under the care of; enabling service users to feel more positive about their prognosis, and being able to access a service that encouraged talking over medicating. Based on this feedback, an alternative method for addressing staff attitudes is developing more specialist services for individuals with this diagnosis. The sample interviewed was very pleased with the new specialist service they were

under the care of; particularly being offered a choice and alternatives to medication. One of the alternative treatment methods mentioned was Dialectical Behaviour Therapy, which is offered by the specialist service. Service users were aware of the enthusiasm among clinicians around this approach and its efficacy in treating individuals with BPD, and appreciated that they were able to access this treatment.

Service users also discussed the 'trial and error' culture of treatment, which seemed to be linked to poor staff knowledge of how to treat this disorder. This idea was also expressed in the Gault (2009) study, with both samples reporting it took a number of medications before, if ever, finding one which helped. Also similar to Gault (2009), service users also spoke of coercive treatment, both in the community, but more commonly, hospital. This was in stark contrast with service users' hopes for involvement in their treatment plan, and deciding their own recovery pathway.

An idea that was evident throughout the interviews was that service users were desperate to find their own recovery pathway; service users reported willingness to try whatever they felt might help them to recover, which overlapped with the Carrick *et al.* (2004) theme of maximizing well-being, whereby participants spoke about their quest for 'normality'. Service users across both samples discussed the use of medication in their quest for recovery and functioning, although this varied largely between individuals. This links in to the subtheme of tailoring treatment to the individual; it seems that the journey of recovery is an individual experience, which means different pathways for different people. For some, it seems medication has been a vital part of their recovery, whereas for others it was actually a hindrance, and prevented any chance of normality.

Another theme mentioned in the Carrick *et al.* (2004) study which coincided with the current study's findings was the idea of managing treatment, with both samples discussing the importance of being involved in treatment planning. Unfortunately, from the service users interviewed, this was not the norm in treatment planning, with most feeling like decisions were made without their involvement. Optimistically, with the introduction of the specialist service, service user involvement in care planning and choices around medication use was becoming more common.

Reflections

As with all qualitative studies there was an element of subjectivity in the analysis, particularly with the involvement of the author in the specialist service. It is possible

service users may have been less critical of the specialist service as they were aware of the authors' position in the team.

Involvement in the study was particularly meaningful to the author as it was a study carried out following service users' requests to have their voice heard around being treated with medication. Because of this purpose the author felt it was important to capture the issues presented by the service users in a quest to have their voices heard by professionals in mental health services, and hopefully to use the thoughts of service users to improve the services for individuals with the BPD diagnosis, primarily in medication use.

Implications

While the experiences of service users with a diagnosis of BPD have been researched, to date there has been no study to explore their experience of being treated with medication, despite its high prescription in this client group. By completing this study it allows clinicians to understand the treatment service users receive from their perspective and, in this case, the impact it has on their recovery.

The focus on medication has important implications for psychiatrists and nurses, who play a crucial role in medication treatment. The research illustrates individuals with this diagnosis feel let down by staff knowledge and attitudes towards BPD, indicating clinicians working with this client group need to ensure they are knowledgeable about this diagnosis, and are able to provide service users with relevant information on the diagnosis and its recommended treatment.

As part of service user involvement in treatment, staff should also consult with service users regarding their treatment plan, and take into account the service users' experience of treatment. This is particularly important when considering the side effects of medication; alternative medication should be offered if the service user reports the side effects are intolerable. Additionally, in line with NICE guidelines (2009) and NIMHE recommendations (2003) they should be offered psychological treatment. From the participants' interviews it was apparent they also felt psychological treatment also played an important role in their recovery.

Conclusion

The service users who were interviewed presented a long period of poor, neglectful treatment from services, a lack of involvement in their treatment plans, and poor knowledge and understanding among staff of the BPD diagnosis and how medication should be managed within this client

group. Service users had mixed views on the use of medication in their recovery pathway, but agreed they wanted the opportunity to decide for themselves. Services need to recognize that the use of medication is significant to individuals, and something to be done collaboratively, with adequate involvement, information, and support.

Nurses working in psychiatric settings have a pivotal role to play in ensuring the needs of service users with a diagnosis of BPD are met. The hands-on role of the psychiatric nurses allows them to explore the service users' opinion of their treatment and liaise with the team to ensure their opinions are heard.

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