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Concerns over the prescription of clozapine for people diagnosed with 'borderline personality disorder' in private locked psychiatric units.

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Title: Concerns over the prescription of clozapine for people diagnosed with “borderline personality disorder” in private locked psychiatric units

Short Title: Clozapine Concerns

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Type: Editorial/Commentary

Purpose

The use of long-term antipsychotic medication for borderline personality disorder contravenes prescribing guidelines in the UK. There is evidence to suggest Clozapine can be beneficial yet anecdotally it is prescribed almost exclusively in locked settings. A single study suggests a substantial proportion of psychiatrists disapprove of this practice. This piece articulates concerns about the use of clozapine for 'BPD' that are absent from current literature.

Methodology

The article summarises the reflections and experiences of the authors lived experience, academic and clinical backgrounds.

Findings

The published literature is uniformly positive when describing the prescription of clozapine for those diagnosed with BPD however this in no way reflects the experience of the authors. There is no body of material reflecting a study showing that a substantial number of psychiatrists have issues with this practice.

Limitations

While it is a fact that there is a discrepancy between psychiatrists attitudes towards clozapine prescription for 'bpd' and the published literature, the described concerns in this article are based solely on the authors experiences and observations.

Practical Implications

Those seeking literature to articulate concerns about the use of clozapine with this population will likely be disheartened by the paucity of published literature.

Originality

This article is the first to raise substantial concerns about the use of clozapine for those diagnosed with 'bpd' and the circumstances in which it is prescribed.

January 18th 2022 was a big day for those interested in the topic of “personality disorder” and specialist out of area placements (we use inverted commas to recognise the contested nature of this construct and the view that for many it is insulting (Lamb et al 2018). A report was published by the British and Irish Group for the Study of Personality Disorder (Zimbron et al 2022) highlighting the lack of data held about people with a personality disorder diagnosis in locked rehabilitation settings, that 2 companies provide 70% of all placements, that 99% of placements are in the private sector and that placement length isn't agreed in advance. This raised concerns around whether market forces could drive quality provision and whether there should be quality standards to achieve to be a “specialist” unit, rather than it being a self-appointed title.

On the same day BBC File on Four aired the documentary “Mental Health Rehab – The Forgotten Patients” (BBC 2022). While it looked at mental health rehab in general, each patient and each unit featured was linked with “personality disorder”. The patients gave examples of poor care while a staff member described being involved in the opening of a centre of excellence for personality disorder where no one had any experience or preparation for working with the issues they claimed to specialise in.

Concerns about mental health rehabilitation placements have previously been expressed by (Rethink & RCP 2019, NDTI 2019, Harding et al 2020). One aspect of these concerns was the overuse of clozapine for 'BPD' in these "specialist" units.

The Journal of Personality Disorder published a study of Italian psychiatrists perspectives on the use of antipsychotics for the treatment of 'BPD' (Aguglia et al 2018). 72.7% thought that the prescription of Clozapine for those with this diagnosis was highly inappropriate or inappropriate. This reflects current policy in the UK and our experience where prescribing clozapine for someone with a 'BPD' diagnosis would be almost unheard of in the community and relatively rare in an acute inpatient setting.

The National Institute of Health and Clinical Excellence (NICE) produces evidence-based recommendations for health and care in England. There is "an obligation in public law to have regard for the NICE guidance and to provide clear reasons for any general policy that does not" (NICE 2014)

The NICE guidelines for 'BPD' state "antipsychotic drugs should not be used for the medium- and long-term treatment of borderline personality disorder." (NICE 2009)

One of their quality standards states "people with borderline or antisocial personality disorders are prescribed antipsychotic or sedative medication only for short-term crisis management or treatment of comorbid conditions" (NICE 2015).

Clozapine is a medication often used after non-responses to other antipsychotics in the treatment of schizophrenia (NICE 2020). Like other antipsychotic medication prescribed against NICE guidelines for those diagnosed with 'BPD' (Crawford et al

2011) clozapine is prescribed off licence. It's side effects include intestinal obstruction and agranulocytosis, seen as so potentially harmful that they require an intensive system of blood monitoring which is not required for other psychotropic interventions (NICE 2020)

The intimate and invasive nature of blood monitoring can clearly impact on people who have had very difficult experiences of physical touch with "BPD" being the psychiatric diagnosis most associated with childhood trauma (Porter et al 2020).

While some find the close nature of receiving medical care nurturing, others find it retraumatizing and that control over their body is again surrendered to another.

While it's imperative that blood monitoring takes place, it is arguable that people who often have histories of being subjected to physical and sexual violence should not be put in this position if care is to be truly trauma informed. (Sweeny et al 2018) Unlike restraint to preserve life, prescribing clozapine is not a necessity.

There are calls for the NICE guidelines to be revised to include the use of clozapine for people diagnosed with 'BPD'. Some have "found significant improvements in symptoms, and ...improved sense of wellbeing" (Mental Health Today 2018). Further studies are planned that will allow the clinical benefits to be demonstrated.

Enthusiasm for clozapine prescription may be based on uniformly positive literature that has been produced regarding its effectiveness. Results reported include reduction in: aggression, violence to self and others (Frogley et al 2012), enhanced observations, additional medications (Frogley et al 2013) and increased positive cognitive and affective changes (Dickens et al 2016). The only qualitative paper

describes interviews administered by people providing treatment to those they are interviewing. They reported very positive experiences (Dickens et al 2016).

The enthusiasm of individual services mirrors our experience. We regularly see clozapine being prescribed to young women in the course of our work scrutinising private locked rehabilitation settings. It may be that those in locked rehabilitation have problems so severe, the NHS has exhausted 'what normally works'. These unusual presentations may require unusual responses, so use of an off licence anti-psychotic with potentially lethal side effects requiring a regime of extensive blood monitoring becomes understandable.

The extensive use of medication for 'personality disorders' has been linked to the emotions of clinicians. Feelings of hopelessness and powerlessness when working with people in significant distress can drive prescribing (RCP 2020, Martean & Evans 2014, Gunderson & Choi-Kain 2018). This can be a teleological gesture, where 'doing' and modifications to the physical world are felt necessary to communicate (Bateman & Fonagy 2016). A prescription of clozapine could thus be viewed as a relational tool. As a drug has been prescribed it at least looks like someone cares enough to do something. Psychiatrists have acknowledged feeling a pressure to prescribe to facilitate doctor-patient relationships (Martean & Evans 2014).

Gunderson echoed this, commenting that "clinical experience has shown that medications can help build an alliance" (Gunderson & Choi-Kain 2018). Martean and Evans (2014) go further, recognising that the NICE guidelines do not take into account the clinical and relational pressures inherent in the prescribing of

medication. While they call for the NICE guidelines to be reviewed to take these into account, we would suggest that if an aim is to reduce inappropriate prescriptions, patients are better served by helping prescribers hold to the existing guidelines. The solution to the pressure to prescribe cannot be redefining appropriateness to include appeasement and relationship building, especially when the side effects are potentially lethal.

Prescribing may at times reassure clinicians more than it helps patients. This pressure can result in defensive psychiatry where a fear of getting it wrong “can prompt decision making which goes beyond patient-centred morality, moving from doing the right thing, and into the territory of being seen to do the right thing” (Warrender 2018). While understandable, it is not clear whether this intervention is based on a scientific rationale or is teleological - a “heroic surgical attack’...a frenzy of treatments each carrying more danger for the patient than the last, often involving him in varying degrees of unconsciousness, near death, pain, anxiety, mutilation, or poisoning” (Maine 1957).

The absence of concerns in published literature prompts us to share our concerns for the young women we see compelled to take this medication in locked rehabilitation settings. There are concerns around the over prescription of psychotropic medication for this population in general, (Paton et al 2015, Crawford et al 2011). The women we meet are rarely aware that their medication is not licensed for their diagnosis. They often have little knowledge of the side effects of their medications or their severity. They’re unaware of the sedative qualities and the staff seem also unaware, filling the patient’s notes with comments such as “wouldn’t get

out of bed” or “unmotivated”. The patients do not know that taking their medication goes against NICE or RCP recommendations (NICE 2009, RCP 2020). Given this we argue that the patients are not giving informed consent. It is possible that all of this information has been given but if this is the case, we have never seen it documented.

Perhaps the ethical implications are viewed as less important than the clinical ones. Those prescribing clozapine believe it works. Maisel argues that we should distinguish between “chemicals with effects and medications that treat illnesses” (Maisel 2016). It may be that clozapine for ‘BPD’ doesn’t correct a chemical imbalance but creates an altered state. This may include the pronounced side effect of fatigue although this effect is not experienced as secondary or marginal (Pilgrim 2020). A systematic review argued that existing studies on clozapine for ‘BPD’ were seriously limited in not investigating adverse effects, given it is “clozapine’s side effect profile that may in part contribute to its advantage over other antipsychotics” (Frogley et al 2012). It’s possible the effects considered adverse for one diagnosis being desirable in another reflects some of the stigma of ‘BPD’ (Lamb et al 2018, NIMHE 2003, Appleby 1988).

The women we meet sleep 12 hours at a stretch and are lethargic when awake. This results in a cycle of weight gain, increased clozapine doses and more weight gain. There may well be reduced: self-harm, suicidality, aggression, less need for enhanced observations and less use of additional medication (Frogley et al 2012) but we might argue this is because they’re asleep. They have high levels of trauma in their lives (Porter et al 2020). While sedated they do not have the traumatic re-

enactments of past events that restraint brings, yet being unwillingly drugged into compliance has been a common past experience for many of them. Unbalanced power dynamics are common in the treatment of 'BPD', with terms such as 'uncooperative' and 'non-compliant' viewed as pathology (Warrender et al 2020). Refusing the wisdom of professionals is often seen as a confirmation of an 'illness' (Watts 2018). Sedated people may be less of a problem for professionals. Whilst we acknowledge the positive experiences of many patients, one remarked that clozapine "closed my emotions off.... I can't feel anything." (Dickens et al 2016). This is not synonymous with being well and mirrors the authors experience of taking clozapine. While people celebrate the positives, they forget the impact of no longer being able to feel anything. Recovery cannot include denying someone the experience of feeling love, joy and connection to others. We cannot expect people to live a life of emotional deprivation to appease the staff around them. We again think back to Tom Maine warning us that sedation was always prescribed only when the health care professional had reached the limit of their tolerance for the patients distress - "It was always the patient and never the nurse who took the sedative." (Maine 1957) We wonder if we are utilising chemical restraint instead of the recommended intensive psychological intervention, especially given our repeated experience of "specialist" units where no genuine specialist input is not available (Harding et al 2020, BBC 2022).

In Sight In Mind highlights "Reports(that) have laid bare how woefully inadequate the care of people with longer-term severe mental health illness has become in some parts of the system." (Rethink & RCP 2018) with BMA lead for mental health, Dr Andrew Molodynski saying "the 'cut-off' nature of these institutions can be a breeding ground for the development of harsh and abusive cultures." (Rethink & RCP 2018)

A safeguard against abusive practices taking place is external oversight. There are concerns that “there is a lack of timely or regular review when people are placed out of area... the distance from home services means that ... there is a real likelihood of discontinuity of care. It can be more difficult...to assure the quality and robustness of placements” (NDTI 2019).

It is indisputable that prescription of clozapine for ‘BPD’ breaches current NICE guidelines (NICE 2009, NICE 2015). While this occurs with most prescribing for those diagnosed with ‘BPD’ (Paton et al 2015, Crawford et al 2011), in our experience, those in the NHS who are tasked with monitoring “specialist” personality disorder placements have as little specialist training as the placements themselves.

While there are repeated documented concerns that poor practice occurs in these units, it is our contention that the prescription of clozapine for people diagnosed with ‘BPD’ is one of those areas of questionable practice that blooms in isolated, cut off environments. While it could be that clozapine is prescribed more often in these units because they are specialist, when compared to the only guidelines we have to indicate quality these unique practices could also be considered maverick and reckless.

We do not know the proportion of those with a ‘BPD’ diagnosis who are prescribed clozapine that receive it in a locked setting. Equally, we do not know how many people with this diagnosis are in locked rehab settings (Zimbron et al 2022). We could argue that this is an anomaly of our data capturing system or we could argue

that 'BPD' is still a diagnosis of exclusion (NIMHE 2003) where this group is actively not thought about.

Looming on the horizon is a study that could ease some of our worries. The CALMED trial (Imperial College 2020) aims to investigate the clinical and cost effectiveness of clozapine for inpatients diagnosed with 'BPD'. This is the first RCT looking at clozapine for 'BPD' and has the potential to show whether clozapine is indeed an effective treatment. There have been a criticisms of this study (RITB 2019). While the women in the locked rehab might possibly be described as severe in their presentation, this study will recruit people with the relatively common presentation of being "an inpatient on a mental health ward for more than 28 days in the last 12 months, OR have had two or more admissions to hospital/ periods of care provided by Home Treatment over the last 12 months, AND a lifetime history of two or more incidents of harm to self or others which resulted in permanent damage/ disability, or would have done so had services not intervened". Sadly, for us this would be a typical presentation for many of those with this diagnosis, certainly different to someone who has resided in a locked rehab facility for 2 years.

Despite NICE recommending psychological treatment as the primary intervention for those with this diagnosis, study participants must show "failure to make an adequate clinical response to taking antipsychotic medication other than clozapine for at least three months". This is comparing one intervention specifically not recommended by NICE, with another. This may be more of a criticism of typical practice when supporting people diagnosed with 'BPD', than of this specific study.

Because in our experience few with a diagnosis of 'BPD' have access to specialist therapy, what this study is likely to reveal is whether the average person with the diagnosis benefits from clozapine as opposed to what they are likely to get otherwise. We still worry that any benefit shown will be linked to fewer hours of being awake and active, but we await the results that come in.

This article is an opinion piece and as such contains bias. It may be argued that it is polemic, and unfairly so given the consistency of the literature available. The Aguglia study (Aguglia 2018) has helped us wonder if we and others are all staring at a naked emperor, aware that that something grotesque is occurring but unable to articulate our concerns. We feel this article is a proportionate response to the paucity of literature reflecting the concerns of the 70%+ of psychiatrists mentioned who believe prescription of clozapine for 'BPD' is inappropriate or worse (Aguglia 2018).

There are a number of things that could reduce our concerns. We could see clear documentation of the acknowledged dissonance between recommended practice and current treatment plans, with evidence that the patient was if not consenting, then aware that something unusual was taking place in their care. We could see research measuring the quality of life and ability to function of the people taking this medication in locked settings. We could see clear acknowledgement and investigation into where people benefit from the intended effects, or 'side' effects. Most importantly we would like to see research detailing the lived experience of those prescribed clozapine in these settings that is not conducted by the treating institution.

We suspect our concerns can be undermined by issues of bias and anecdote. Our intention is not to convince people of their truth, but to acknowledge they exist. It is a relief to see the concern around what happens out of sight and out of mind is by no means unique to us. Research will continue in this area and we ask the researchers of tomorrow to hold our concerns in mind when planning their studies. We ask the prescribers of tomorrow to hold these concerns in mind in their consulting rooms. We ask the patients who will be given clozapine tomorrow be made fully aware of the risks that are known as well as the benefits that can be hoped for. The BIGSPD (Zimbron et al 2022) report and the Radio 4 documentary (BBC 2022) suggests there are issues to be concerned about in the area of “specialist” personality disorder units. We welcome new research in this area and it would be the greatest relief to us, the patients we meet and the families we hear from, if our concerns around clozapine were utterly unfounded.

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