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Antipsychotics and Identity: The Adverse Effect No One is Talking About

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Abstract

People who take antipsychotics, and people who are prescribed antipsychotics without taking them, experience effects which are not frequently discussed: effects on their identity and sense of self. Qualitative research indicates the relationship between taking APs and identity is multilayered, and changeable. Taking APs can restore people to their earlier, pre-symptom sense of self. Being prescribed and taking APs can also, on the other hand, be experienced as damaging, erasing and dulling people's sense of who they are. This complexity deserves exploration in clinical practice, which we believe is currently not done routinely. More work is needed to understand whether, and how, the relationship between identity and APs is being addressed. We outline the importance of having discussions in a clinical space around identity, and a sense of agency, on the grounds that true recovery-oriented care, which enacts shared decision-making principles, demands it. Further, we argue that it will allow for better therapeutic alliance and trust to be forged between clinician and client, ultimately leading to better care.

Keywords Antipsychotics · Medication · Neuroleptic Medication · Identity · Self-stigma · Psychosis · Schizophrenia

*“In the social jungle of human existence, there is no feeling of being alive without a sense of identity”
– Erik Erikson.*

Over the past 30 years, the principles advocated for by the recovery movement have been integrated into psychiatric practice (Anthony, 1993; Khanthavudh et al., 2023; Leamy et al., 2011). A key principle of recovery-oriented mental health care is being person-centered, with the aim

of supporting people to live a “satisfying, hopeful and contributing life” even with persisting limitations caused by illness (Anthony, 1993).¹ In a recovery-oriented model of care, people who are experiencing psychosis are recognized as experts in their own lives and experiences, whereas professionals are seen as experts in the treatment options available, the potential benefits of each course of treatment and the adverse effects associated with these treatments. The goals of treatment are decided collaboratively by the client and treatment team working together, rather than imposed in a “top-down” way by the treatment team (Anthony, 1993; Leamy et al., 2011). To achieve this, shared decision making (SDM) practices, which foster partnership and mutual respect, must be at the core of clinical encounters (Morant et al., 2016; Zisman-Ilani et al., 2017). Recovery-oriented care calls to move beyond the problematic mono-directional, paternalistic and power-imbalanced models that characterized the psychiatric care of the past. Instead, the aim is for

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¹ Recovery was described in the seminal article by William Anthony as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.

clinical practice to actively involve people while placing their values and preferences centre-stage throughout the recovery journey. In an attempt to understand what processes are involved in recovery, Leamy and colleagues created a conceptual framework of literature which resulted in five processes: Connectedness, Hope and Optimism, *Identity*, Meaning, Empowerment (Leamy et al., 2011). This piece, which was written by people with first-hand experience of mental health problems and taking anti-psychotic medication, as well as professional and research experience in this area of research, argues that discussions around identity need to be facilitated for people taking APs. Without this, true person-centred care, and principles of SDM cannot be enacted.

What is Identity?

Identity – our sense of who we are and how we see ourselves – is an essential part of living a meaningful life. This is reflected in the recurrence of the concept in philosophical, theoretical and empirical explorations across disciplines from psychology, psychiatry and sociology. The recovery approach has the notion of identity at its core, as is reflected in the CHIME framework (Leamy et al., 2011) and in notions of person-centred care, and as mentioned in first-person accounts (e.g. Holt & Tickle, 2014). Across the different theories of self and identity (Ben-David & Kealy, 2020; Levita, 1967; Erikson, 1959; Tajfel et al., 1979) there are commonalities: identity is considered flexible, it involves re-negotiation throughout the life course and it incorporates a social dimension: who I am exists in relation to a particular context; who is around me. For the purposes of this paper we use the term “identity” in this broad sense, combining a definition from personal and social identity, which goes beyond considering identity or the self as personality but rather includes a relationship to context: “identity is the social positioning of the self” (p.586, Bucholtz & Hall, 2005; McAdams et al., 2021). As context changes, the way people see themselves and others also shifts.

Identity as a Factor Impacting Antipsychotic Use

Antipsychotic (AP) medication is considered one of the first-line treatments for people with psychotic disorders in the acute phase of illness, as well as a way of preventing relapse (Leff & Wing, 1971; Leucht et al., 2012). However, less than 10% of people take their APs as prescribed. Many people skip or alter doses, take breaks, or stop taking their medication (Crellin et al., 2022). Stopping medication

without discussing it with a clinician cuts off an important source of support, and prevents the provision of optimal care. Therefore, a better understanding of the complex interplay of factors that affect a client’s decision to stop taking medication is crucial. Typically, the decision to either continue or discontinue medication is the outcome of weighing perceived advantages, such as symptom reduction, against perceived disadvantages, such as numbness/lack of feeling (Doane et al., 2020; Swarbrick & Roe, 2011). An important adverse effect of APs that is often not taken into account is the effect that taking antipsychotics can have on people’s sense of self and identity. Across different ways of conceptualizing identity change, people taking APs describe how taking antipsychotics impacted their sense of self (Barlatti et al., 2022; Ben-David & Kealy, 2020; Conneely et al., 2021; Cowan et al., 2021; Katz et al., 2019; Zangrilli et al., 2022). The effects that APs can have on identity can be categorized into at least two types: direct effects that are a consequence of the physical effects of the drugs, and indirect effects through the personal and societal meanings associated with APs.

Using APs is widely stigmatized, and unlike depression and anxiety, schizophrenia-spectrum disorders have been becoming more stigmatized by the public in recent years (Pescosolido et al., 2019; Schomerus et al., 2022). This significant public stigma means the effects on identity will often include self-stigma (Dubreucq et al., 2021). Having a complex emotional reaction to taking APs is thus understandable, given the stigma associated with taking antipsychotics and the even greater stigma associated with not taking antipsychotics when they have been prescribed (Keogh et al., 2022; Xu et al., 2016), and the wide variety of personal meanings people might have attached to taking medication for long-term or chronic conditions, in particular APs (Barlatti et al., 2022).

Importantly, both effects may be related to clients’ sense of agency being challenged. The act of taking medication may activate an “illness identity” or “patient identity” (Lally, 1989). Moreover, taking medication that impacts the very perception of self and reality and affective processes, may make individuals wonder who they really are: how can the line be drawn between what is the person and what is the person with the effects of the medication?

Dilemmas and Diverging Experiences

An example of a direct identity-related adverse effect can be found in a quote by a participant in a Danish tapering study after medication was discontinued: *“I feel like I’m coming home to myself. It’s impossible to navigate life when you can’t feel the small signals in the body. That’s what I feel*

the medicine took away from me. Waking up to a life that doesn't fit me at all or that I like. But grateful and happy that I have come back" (Mette Karlsen, personal communication). Diminished ability to feel signals due to AP-induced numbness will affect people in a more widespread way: their sense of connection to themselves may be impacted. An example of an indirect medication-related adverse effect can be found in what the medication symbolizes: *"I felt it was eroding of my self-image and when I took the medication it was more or less saying that I wasn't whole"* (Usher, 2001). Many studies describe how people see APs as an indicator of an "unwanted and stigmatized identity as a chronic psychiatric patient" (Thompson et al., 2020). Taking APs come to signify being "lesser", "weird" and somehow un-whole (Dumas, 1999; Murphy et al., 2015; Vedana & Miasso, 2014).

Qualitative studies of the experience of taking APs conducted across different contexts and countries, describe adverse effects related to identity and agency (Crellin et al., 2022; Morant et al., 2023; Roe et al., 2009; Thompson et al., 2020). This suggests it is an important topic for clinicians to take into account when considering treatment options and making decisions with clients. There should be a full open discussion before medication is initiated, and continuously throughout any AP treatment, to make sure the benefits of treatment exceed the harmful effects. Indeed, transparency about the risk of losing aspects of oneself and a sense of agency is needed. It may, for some people, be an unacceptable price to pay.

While there are many scales that measure the adverse effects of APs, or the benefits of using them, changes in one's sense of self and identity are not acknowledged nor are they commonly discussed as a reason for discontinuation. In contrast, some people describe APs as a way of unlocking their true identity. Some people report finally feeling like themselves again after taking APs, while others accept taking APs as a fact of life: necessary to prevent relapse (Bentley, 2010). Others report that it "erases" their sense of self and strips them of their "life and soul" (Thompson et al., 2020). Medication is described as eroding sense of self, and reducing or stopping the taking of APs is described as helping to restore identity (Bentley, 2010; Keogh et al., 2022; Morant et al., 2016; Usher, 2001). Describing their experiences on a lower dose of their antipsychotic, someone described themselves as feeling less like themselves: *"I wasn't feeling so good on those [lower] doses... It's hard to explain how I felt, just uncomfortable in myself, lack of self-satisfaction"* (Morant et al., 2023). A review of qualitative studies of experiences of APs summarizes the complex and highly individual ways people can experience the relationship between taking APs and identity in two juxtaposed theme names: medication is described as "depleting the

self" and "restoring the self" (Thompson et al., 2020). Some individuals have expressed that the act of taking medication is intertwined with creating their life story. For them, the quest for (re-)discovering a sense of identity is partly shaped by the trial-and-error journey of finding the right medication and dosage. Yet others describe that the act of taking medication, that they feel is necessary to prevent relapse, defines them as different from others and as dependent upon medication (Bentley, 2010).

Is Identity Falling Through the Cracks?

Who can clients turn to, to discuss this profound dilemma? Sadly, clients too often fall between the cracks of different professionals' perspectives. The prescribing doctors might not see the clients often enough to thoroughly get to know them or have the time needed to discuss issues related to identity. The psychologist, on the other hand, who might know the person well, and have a greater appreciation of the impact of medication on each client and their dilemmas about its use, might not feel qualified, or equipped to discuss medication which is not their "domain" or area of expertise (Ben-David & Kealy, 2020).

APs fall in the category of pharmacological treatment. The notion of selfhood, identity and belonging, however, might seem far-removed from, and of little relevance to, pharmacological treatment. The below anecdote, however, shows the opposite: how closely they are connected. MC conducted an interview study on how people who had been diagnosed with a psychotic disorder saw themselves in terms of their social identity and sense of self, which was nested in a larger quantitative study (Conneely et al., [under review](#)). The interviews did not include questions about medication, yet remarkably, almost every interviewee raised the topic of antipsychotic medication. Medication was described as key in people's identity shifts throughout their lives, with one participant saying: *"medication is a kind of balance between being there and being here. Being in the dark place and in the beautiful place"*. This suggests that talking about identity for people with psychosis is inextricably entwined with talking about medication.

Although SDM cannot be reduced to information sharing, at its most basic level SDM requires a flow of information in both directions between the treatment team and the client (Zisman-Ilani et al., 2017). Clients need to be informed about potential adverse effects and alternative treatment options; and the treatment team need to ask questions to understand the effects of treatments so that tweaks and changes can be agreed together. Encouraging a dialogue about the emotional and psychological effects of taking APs is essential. Without information about how APs influence

individuals' emotions, sense of self, identity and social belonging, the practice of genuine SDM is incomplete.

Clinicians might be reluctant to ask questions that may lead to conversations about medication, reducing it, and potentially increasing risk of relapse. Consequently, many people find disclosing dissatisfaction with medication difficult, which leads to the unilateral, and often hidden, decision to stop taking medication without support, and withholding information from psychiatrists and care teams. This often leads to people stopping medication on their own, which is far riskier than getting support from a qualified professional. Having and protecting a space to discuss clients' experiences, anticipations and expectations related to identity when faced with taking APs might lead to better therapeutic alliance and trust. This will allow making informed choices about medication-use which reflect one's preference and values and will lead to greater treatment satisfaction and better outcomes (Chang et al., 2019; Dixon et al., 2016).

Due to the possibility that many clinicians may not consider it within their professional scope, we fear that the dialogue about identity and APs might be overlooked. It could be deemed "too psychological and time-intensive" for appointments with psychiatrists, yet also regarded as too closely linked to the "pharmacological/biological" realm for psychologists, support workers or occupational therapists.

Although many conversations regarding APs revolve around reducing or discontinuing medication, people may feel a deeper concern and desire to delve into and explore feelings, tensions and dissonances about what taking anti-psychotic drugs means to them. Rather than simply focusing on a change in their dose, many seek to explore what these medications symbolize and represent in their lives (Asher et al., 2023). One might expect that clinicians/therapists are well-placed to explore the emotional and psychological meanings attached to APs. However, there is some evidence indicating that when asked about medication, team members who do not have the authority to prescribe push the question back to the psychiatrist. The lack of authority to change the dose may, consciously or unconsciously, lead the clinician to avoid the topic. It is understandable that clinicians without the authority to alter prescriptions might find it difficult to discuss medication. Moreover, clinicians may fear that discussing medication will lead to discontinuation and are reluctant to take the responsibility for this risk (Cooper et al., 2019). A survey of clinicians in Canada indicated that most clinicians believed the topic of identity was important to their patients, and yet few felt confident in addressing identity (Ben-David et al., 2021). Together, this might lead to a reluctance to inquire about the emotional impact of medication, prompting a desire to avoid the conversation entirely, or revert questions to psychiatrists.

How can we Move Forward?

We would like to acknowledge two important limitations that psychiatric practice and research face when it comes to considering the effects taking APs might have on identity. First, in psychiatry we are used to making decisions based on high quality evidence from randomized controlled trials and meta-analyses comparing different forms of treatments. Existing studies focus on APs' effects on symptom reduction and side effects, while neglecting possible implications on identity. When it comes to having a clear understanding of how best to assess the impact of APs on identity, and, once assessed, how best to support identity negotiation, we have little evidence (Ben-David & Kealy, 2020). Researchers should initially scope and collate existing ways of assessing and inquiring about identity-related adverse effects, so that measures can be used when assessing people's experiences of taking APs (Ben-David et al., 2021). Further, there is a need to assess how we can support people to explore the relationship between how they use APs and how they see themselves, which would be helped by moving away from dichotomous "adherent/non-adherent" ways of conceptualizing AP-use (Roe et al., 2021). A second limitation that must be contended with is that the models of identity that we do have at our disposal are predominantly stemming from white, western European philosophers and psychiatrists, and the way the self is understood is thus often considered exclusively in those terms. There is little consideration or awareness of other ways of understanding the self. Steps to rectify this are underway, with works such as Bhatia's exploring and proposing inclusive and decolonized models of identity (Bhatia, 2020; Bhatia & Priya, 2018). The nature of self, healing and other is so entrenched in the way we practice psychiatry and psychology that considering experiences without these lenses is hard to conceptualize. Building on existing movements, we believe there is a need for ethnographic, "ground up" research to understand how the self is felt, seen and understood, and impacted by APs in ways that are not adopting the lenses of self and identity we have grown accustomed to employing, so that we can create space to build and learn about views of the self that are not based on assumptions of the self from a narrow understanding.

At the start of this piece we put forward an understanding of identity that is dynamic in nature. We believe that particular events are likely to have greater impacts than others on people's sense of self. Given the widespread public stigma and physical effects of medications, there is a need for active input and negotiation of identity. We envisage and hope for a future where the non-psychiatrist clinicians, therapists and psychiatrists are empowered and encouraged to discuss identity negotiation with their clients and with each

other. Members of multidisciplinary teams meet clients in different settings, stages of illness and each profession has a different focus. Fostering inter- and intra-disciplinary discussion, and cross-disciplinary buy-in to aggregate knowledge from across the spectrum of care, about how taking APs impacts identity, will widen the scope of what can be achieved in clinical practice. We believe this will result in better alignment with the ideals of the recovery approach to care which aims to support clients to learn to live well, where what constitutes *living well* is defined by the individual rather than decided for them by their clinical team (Leamy et al., 2011; Leamy et al., 2023; Macpherson et al., 2016). Currently, an important part of using APs is overlooked, or avoided: discussions about identity seem to fall between the cracks of the multidisciplinary team. The different ways that people experience and react to APs and the wide range of individual ways it influences one's life, including sense of self and identity, deserve a safe space in which a discussion is not only tolerated but invited.

Declarations

Competing Interests The authors have no conflicts of interest to declare.

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