

“All Roads Lead to Medication?” Qualitative Responses From an Australian First-Person Survey of Antipsychotic Discontinuation

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Objective: The purpose of the survey was to better understand the experiences of people who attempt antipsychotic discontinuation. **Method:** A multiple-choice and short-answer survey was distributed in 2011–2012 to potential participants involved in participating organizations. Respondents were asked about past discontinuation events, including decision negotiation and withdrawal experience. This article thematically analyses their free-text responses. **Results:** There were 98 valid surveys returned. Respondents highlighted the roles of the therapeutic alliance and health and illness explanatory models in understanding the context of discontinuation. Reported impacts of discontinuation were mixed and complex. Withdrawal syndromes were described by over half of the participants. Of the 98 respondents, 21 reported remaining antipsychotic-free at the time of survey completion. **Conclusions and Implications for Practice:** Participant accounts highlight the importance of context and relationships in their thinking about antipsychotic discontinuation. Although results cannot necessarily be generalized, participant descriptions of withdrawal syndromes suggest there may be a need to improve education, monitoring, and support strategies for some people during discontinuation. Shifting toward a more collaborative, transparent, and service-user-driven approach to discontinuation may help to mitigate some of the negative discontinuation impacts identified. The polarized discontinuation outcomes described highlight the individuality of every participant’s recovery journey and the need to avoid generalizing about the role of antipsychotics in care.

Keywords: substance withdrawal syndrome, health communication, antipsychotic agents, medication noncompliance

High antipsychotic discontinuation rates have been well documented in the literature (Barnes, 2011). A Cochrane Collaboration analysis, for example, estimates that over 50% of people prescribed antipsychotics will attempt discontinuation at some point (McIntosh, Conlon, Lawrie, & Stanfield, 2010). Historical framing of antipsychotic discontinuation as “noncompliance” has produced research focused on increasing adherence through monitoring, therapy, and support (e.g., Gray et al., 2006). Strong evidence of high postdiscontinuation relapse rates (Novick et al., 2010), at least in the short term (Viguera, Baldessarini, Hegarty, Van Krammen, & Tohen, 1997), has further increased research focus on adherence support.

Constructing antipsychotic discontinuation through a lens of “noncompliance” has attracted criticism recently, however, for failing to take into account the autonomy of people in recovery and the complex interplay of factors influencing discontinuation decisions (Deegan & Drake, 2006; Morrison, Hutton, Shiers, & Turkington, 2012). The historical focus on adherence/behavior change has also meant that less research has been undertaken into people’s first-hand experiences of antipsy-

chotic discontinuation. Given the increasing recognition of the centrality of lived experience in mental health care, and the high number of people who continue to stop antipsychotics despite adherence support (Barnes, 2011), it is imperative that we gain a more robust understanding of people’s perspectives and priorities during antipsychotic discontinuation.

A small number of investigations conducted in the United Kingdom, Scotland, and Israel have made important contributions to this topic (Read, 2009; Roe, Goldblatt, Baloush-Klienman, Swarbrick, & Davidson, 2009; Scottish Association for Mental Health, 2004). Findings from the Scottish Association for Mental Health (2004) and U.K. MIND studies (Read, 2009) suggest that people may not be well informed about the best way to stop psychiatric medications or what to do if unwanted effects occur while stopping. Findings also indicate that clinicians may not be sufficiently aware of people’s experiences and support needs during this time. These studies did not focus exclusively on antipsychotics, however, and there are many aspects of the lived experience of antipsychotic discontinuation that still require further characterization. Given documented differences in antipsychotic prescription (Conley, Kelly, Lambert, & Love, 2005) and psychiatric prognosis (Jablensky, 2000; Kulhara & Chakrabarti, 2001) across countries and cultures, it is unknown if people in recovery in Australia have similar or different experiences from their overseas counterparts. The survey reported here aimed to address some of these gaps in knowledge, by focusing specifically on first-hand experiences of antipsychotic discontinuation in an Australian context.

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Method

Study participants met the following criteria: over 18 years of age, English speaking, and currently or previously prescribed antipsychotics. Exclusion criteria were currently admitted to an acute psychiatric ward, unable to give informed consent, or communicate in English. Recruitment sites, selected as a convenience sample, were a large metropolitan public mental health service and a private mental health service in Victoria, Australia, and a number of state and national consumer peak bodies and advocacy groups. Although problematic in terms of representativeness, convenience sampling is a feasible technique for recruiting difficult-to-access populations (Malekinejad et al., 2008) around taboo topics such as nonadherence to antipsychotics. Respondents were able to complete the survey independently and return it via post or e-mail. Recruitment took place between April 2011 and March 2012. The study gained ethics approval from the Melbourne Health Mental Health Human Research Ethics Committee and was registered with two other institutional committees. To maintain participant confidentiality, pseudonyms have been used in the reporting of all findings.

The survey tool was adapted with permission from two surveys previously tested overseas (Read, 2009; Scottish Association for Mental Health, 2004) and contains 25 multiple-choice and short-answer questions. Short-answer questions included, “What was the experience of stopping antipsychotics like for you?” and “Do you have any other comments about your experience that you would like to share?” Participants were also able to add free text, to elaborate on multiple-choice answers relating to decision making and negotiation, withdrawal symptoms, and support strategies during discontinuation. Multiple-choice responses have already been quantitatively analyzed and reported elsewhere (Salomon, Hamilton, & Elsom, 2012). The purpose of this article is to qualitatively analyze participants’ extensive free-text survey responses and their implications for practice and recovery. Themes were identified and coded across surveys by the primary researcher, and then reviewed by the secondary researcher for consistency with the underlying original citations. Only themes that were identified as central by both researchers were included in the subsequent analysis. The software package Dedoose was used to support thematic coding.

Results

Participant Characteristics

The 98 respondents had the following characteristics: mean age of 42 (\pm 11) years; 50 men, 46 women, 1 transgender, 1 undisclosed gender; 10 reported never stopping or swapping an antipsychotic and, of the remaining respondents, 22 (25%) reported one attempt to stop and 65 (74%) reported multiple attempts; length of time on antipsychotics prior to discontinuation attempt—less than 1 year, 18 (21%), and more than 1 year, 67 (79%); current medication status—on antipsychotic, 57 (58%), off all antipsychotics, 21 (21%), and undisclosed medication status, 20 (20%). Of the 98 respondents, 89 provided at least some free-text responses; six of the nine non-free-text respondents were male.

Context of Stopping

Participants identified a variety of contextual factors as influential in discontinuation decision making. These included explanatory models of health and illness, medication side effects, and, in particular, how these factors were addressed in the therapeutic alliance.

Explanatory models of health and illness. A quarter of participants wrote about how distrust in the biomedical model of mental illness or a preference for pursuing alternative models of wellness influenced discontinuation decision making. Joanna, for example, describes, “I take a holistic approach to my health and wellbeing and believe that if I look after my emotional, mental, spiritual and physical health then I am able to remain stable without medication.” Valerie similarly describes the disjunction between her holistic expectations of treatment and her perception of antipsychotics: “Rather than addressing the behavioral, emotional and psychological issues that were affecting me, I was just drugged up. The medications took away my ability to function, without actually helping my symptoms.”

The Therapeutic Alliance

More than the impact of antipsychotic side effects on their own, participants wrote about negative communication events, with clinicians, as being influential in the decision to discontinue. Overall, 34% of participants wrote about this theme.

Feeling unheard. Feeling unheard or invalidated in discussions around discontinuation was one such concern. For example, Richard writes,

It is pointless having a discussion with a psychiatrist about stopping medication. If you are sick—you need medication. If you are well—See the medication is working! If you get sick again—You need more medication. It’s like a seamless Escher drawing, as the situation changes so do the reasons why you should be taking medication. All roads lead to Rx!

Ethan reports,

My first admission to a mental hospital set me up to hate the system. I was very poorly treated. . . . I felt not understood and commodified. I am a person. I was not treated as such . . . [My discontinuation] episode can be traced to my first admission and how I was dealt with.

Early experiences of being unheard could set the scene for a long process of people making decisions without seeking or trusting clinical support.

Inadequate information provision. For other people, lack of transparent communication about side effects triggered a movement toward discontinuation. Lara reports,

Lack of communication about antipsychotics was the contributing factor to my stopping attempt. I recall vividly when I was sitting on the couch, watching TV, and I looked down and I noticed my chest was wet, upon further inspection I realized that I was lactating. I was shocked, scared, and terrified. It was at that moment that I decided to quit.

Jacqueline also describes,

He did not explain anything about the “side effects,” just said take this and come back in a month. . . . Within three months I had gained 2

stone and gone from size 8 to size 16. I went back to the GP who just shrugged his shoulders as if it wasn't a problem. I weaned myself off them over a few weeks.

These examples highlight the great discrepancy that can exist between the lived experience of people in recovery and that of their clinicians. This discrepancy can lead to a breakdown in communication and decision collaboration.

Coercion in relationships. For other participants, coercive treatment negatively influenced the therapeutic alliance and informed the context of discontinuation. Valerie describes, "Despite the fact that they were more harmful than helpful, no doctor would support me to reduce my dose and come off the medications, they would just call me 'non compliant' and threaten me with a CTO." Taylor describes, "My 'relationship' with these people was poisoned and forever destroyed, the moment they aggressed against me on day one." In this case, an experience of coercion shut down the possibility of an alliance in decision making, even before it could be commenced.

Collaborative relationships. In contrast, the narratives of the 14% of participants describing positive clinical relationships highlight the valuable role clinicians played in a subset of peoples' discontinuation experiences. For example, Vivien reports,

I believed I had been incorrectly diagnosed, so the process of coming off them with a psychiatrist who listened to me and believed what I had to say about my symptoms and experiences was very validating and important to me.

Eamon describes feeling "lucky to have a supportive psychiatrist who follows my lead in treatment of illness." Overall, however, the majority of participants reported disappointments and transgressions in the therapeutic alliance that contributed to discontinuation attempts.

The Experience of Discontinuation

Discontinuation accounts were often polarized and complex. Some respondents, such as Rebecca, described extremely positive experiences from stopping, "I reduced my dose under supervision by mental health team . . . Great joy! Great goal achievement! No side effects other than weight loss positive (10 kilos) stopping zyprexa." Other respondents described wholly negative experiences, such as Daniel, who writes that the process was "bad, went through hell till I gave in [recommended medication] to stop it all." The majority of respondents, however, described both positive and challenging aspects to the process. Steve, for example, describes the discontinuation experience as "exciting, a little frightening, frustrating, intriguing." Key short-term features of the discontinuation experience included stopping in isolation and experiencing withdrawal effects.

Stopping in isolation. In total, 22% of respondents wrote about stopping in isolation. Some respondents described this as a result of a broader pattern of social isolation. For example, Caleb writes, "I internalized my emotions—therefore I spoke/communicated with nobody." Others, like Amy, write about unsuccessful attempts to recruit support that also eventually resulted in isolation:

Everyone was against it and I didn't know other "consumers" at that period in my life. Was not supported. Was then "dropped" by psy-

chiatrist once he knew I wasn't on medication and felt he couldn't offer anything if I didn't want medication.

For other people, the decision to attempt secret discontinuation was a strategic one, aimed at avoiding censure. Taylor describes, "Hiding my decision from psychiatrists who had the power to coerce me for enough time until I was certain the coast was clear." These examples highlight that, in some cases, clinical emphasis on supporting adherence may lead people who have decided to discontinue to disconnect from services.

Experiencing withdrawal symptoms. Over half (57%) of all free-text responses mentioned withdrawal symptoms. These spanned sleep-related, emotional, physical, psychotic, and cognitive domains. Symptoms included severe disturbances, such as those described by Audrey:

I couldn't stand or sit for more than 10 minutes—I would become breathless, dizzy, shake uncontrollably and then pass out, I would feel sick and have cold sweats, I had constant headaches (behind my eyes) and muscle spasms in my back and legs. . . . It stopped as soon as I started taking the medication again.

Morris also describes, "Nausea a lot, shaky on my feet/dizziness, feeling like I was going to fall over a lot of the time . . . Almost permanent insomnia, went often days and sometimes weeks without either sleeping at all, or getting very little sleep."

Other respondents described more mild or transitory withdrawal symptoms. For example, Valerie writes that her only symptom was "difficulty falling asleep for a short time."

Outcomes of Discontinuation

Reported discontinuation outcomes were polarized between people who remained successfully medication free and those who eventually recommenced antipsychotics.

Remaining antipsychotic free. There were 21 participants who reported remaining antipsychotic free at the time of survey completion. Major themes expressed by this cohort included finding a renewed sense of life and increasing role engagement. For example Valerie writes, "I am currently working and studying, two things I could not have done on the medications" Taylor describes, "I slowly regained my cognitive function as the chemical lobotomy wore off. It was the single most lifesaving decision of my life." Similarly, Katherine writes, "It was like waking up. It was like regaining self. It was like finding my sexuality again. It was like a fog lifting."

Some of these participants also described a process of grieving for "lost life" while medicated. For example, Vivien reflects, "It was a huge relief to stop taking them however I realized how much my thought processes and alertness had been affected by taking antipsychotics so I felt a lot of anger and grief at this loss." Among this group, there was an overriding sense of optimism and pride in the success of living medication free.

Recommencing medication. The majority of respondents in this study reported eventually recommencing antipsychotics.

A key theme highlighted by 31% of this group was the negative impact of stopping. In addition to withdrawal symptoms that have already been described, other impacts included relapse, rehospitalization, involuntary treatment, breakdown in relationships, and loss of employment.

One participant described an attempted suicide that resulted in limb amputation. Another respondent reported committing a violent crime and resultant incarceration. Eamon writes how he

became extremely depressed and unable to function. Unable to work or maintain simple life tasks. Avoided being hospitalized but only just. . . . My memories of this period are very sketchy. . . . I had to leave my job as I struggled in completing simple tasks such as organizing myself for attending work. Could not put 2 and 2 together, confused, disorientated and overwhelmed by depression, loss of problem solving and decision making skills.

There were 17% of respondents who reported an initial period of feeling the same or better, followed by a serious decline in functioning sometime after discontinuation, which led in turn to a need to recommence medication. Audrey illustrates this experience:

At first, I was ok—didn't really feel any different but then, when I had stopped completely, I started having suicide and self-harm urges, I had images of harming myself and others that wouldn't go away. I was depressed, I had auditory hallucination, couldn't sleep, couldn't eat, spent the majority of my time laying on the lounge staring at the TV.

For participants who recommenced antipsychotics, their accounts also often involved some form of sense making from what they had experienced. Accounts of 36% of respondents reflected on experiential knowledge gained through discontinuation and factors influencing their decision to go back on medication. Alison writes,

I have come to the realization that I need an antipsychotic drug; however the choice is mine as to which one I am going to use. Being on the wrong drug has left me with years of being lost and not wholly committed to society.

Carmia learns “there is no way in my 20 years of having schizophrenia can I stop my antipsychotic medication. I have tried and tried many times but I always end up sick again.”

Questions were also asked by some of this cohort about reasons for failure to remain medication free. Gavin, for example, ponders, “Whether the problem is a result of not having medication or side effects of going off of it, I do not know.” Eamon writes,

I'm concerned that I have a dependency on the medication, that the symptoms I experienced when I stopped the medication were withdrawal symptoms due to my metabolism going into chaos not a return of my mental illness symptoms. I wonder if I had stuck with it longer, instead of restarting the drug after 4 weeks if I would have balanced out again naturally.

Despite often-traumatic discontinuation experiences, 19% of respondents described ongoing disquiet with being back on medication. Steve writes,

A responsible position could not reject the benefits of antipsychotic meds, but the dynamic interactions between them and the illness is a catch 22. It feels like slavery, an “electronic collar” by other means. I hope to grow toward wellness and the reduction or abatement of their use.

Mathew reflects, “I still would like to stop meds completely. I think about it every day . . . On a personal note ‘I hate my meds.’ It makes me fat, depressed, lethargic. It strips my life and soul

away.” Overall, the experiences of discontinuation included negative impacts for most people. Nevertheless, the idea and the possibility of discontinuation held a strong appeal. It is reasonable to assume that many of the participants in this study will attempt discontinuation again.

Conclusions and Implications for Practice

The experience of many participants was discontinuation in isolation and specifically without collaboration with clinicians. The impacts of coercion, devaluing of participant priorities, and nontransparent information provision were influential in some attempts to discontinue in isolation. This is clearly problematic, given the range of withdrawal experiences people then dealt with unsupported. Some of the more serious risks described by respondents, such as rehospitalization, attempted suicide, and incarceration, may have been mitigated if communication channels between people in recovery and clinicians were more open during this time period.

The identified links between poor therapeutic alliance and eventual or repeated discontinuation underscores the importance of clinicians developing collaborative and transparent relationships with people in recovery. The impact of the therapeutic alliance on medication decision making and attitudes to discontinuation has been highlighted in previous research (Chue, 2006; Roe et al., 2009). The potential for unilateral clinician decision making to negatively impact on the therapeutic alliance has been noted in a variety of nonmental health contexts as well (Karnieli-Miller & Eisikovits, 2009).

Respondents highlighted how attitude toward mental distress and personal cost–benefit analyses of psychopharmacological treatment also impacts discontinuation decisions. Subjective attitude toward antipsychotics has consistently been shown to influence peoples' decisions around medications (Chue, 2006). Given that most episodes of discontinuation are deliberate (Barnes, 2011), nonjudgementally engaging with people's health beliefs and treatment priorities is vital in any clinical discussion of antipsychotic commencement or discontinuation. Many discontinuation attempts, historically interpreted by clinicians as reflecting a lack in insight, may be understood and anticipated if the person in recovery is asked about their perspective on psychotropic treatment (Morrison et al., 2012).

The many reported accounts of discontinuation syndromes highlight the importance of informing people in recovery about the possibility of such syndromes and supporting them should they occur. This need has been identified in other recent studies, which found that people were often poorly informed about what discontinuation syndromes to anticipate or how to access support if they occur (Read, 2009; Scottish Association for Mental Health, 2004). Although some evidence exists around antipsychotic discontinuation syndromes, they have not been comprehensively characterized as yet, or, in many cases, routinely communicated to people accessing services (Moncrieff, 2006; Salomon & Hamilton, 2012). Clearly, given the prevalence of such syndromes and frequency of attempted discontinuation, this topic warrants greater attention in future research.

Decreasing isolation may be a first important step to improving our ability to support people experiencing discontinuation syndromes. This may involve a move from an implicit zero-tolerance

policy regarding discontinuation, toward a harm-reductionist approach. A clinical relationship with service users based on the conceptual goals of harm minimization includes a value-neutral view of the user, a focus on problem solving, active participation of user, and a lack of clinician insistence on compliance (Cheung, 2000). Such an approach may positively impact the therapeutic alliance and promote safer and supported discontinuation.

There may also be potential for greater growth and learning in taking a harm-minimization approach to discontinuation. A significant number of study participants reported learning more about themselves and effective treatment options as a result of attempted discontinuation. This approach is gathering increasing support from a number of sources, including people in recovery and clinicians. For example, despite reporting high relapse rates in their randomized controlled trial of antipsychotic discontinuation, Gitlin et al. (2001) note that supporting controlled discontinuation may prevent covert discontinuation and allow for closer monitoring of emerging problems. A harm-minimization approach to discontinuation may also help promote service-user control over treatment decisions, a goal that has been identified by people in recovery as pivotal in the shared decision-making process (Woltmann & Whitley, 2010).

The case for a move toward a more collaborative, harm-minimization-based approach to discontinuation is strengthened by the reality that many people continue to stop their antipsychotics at present, even if they are warned to remain adherent or risk involuntary treatment (Barnes, 2011). In our study, a significant minority of participants expressed an ongoing disquiet with medications, suggestive of future attempts to stop. Furthermore, "compliance therapy" has not been found to significantly increase long-term adherence or treatment outcomes (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008). Accepting the reality of ongoing discontinuation attempts can thus be viewed as a practical measure, aimed at decreasing the time and effort clinicians expend on surveillance and increasing the time they might spend searching collaboratively with people in recovery for acceptable treatment options.

Although most people recommenced their antipsychotics by the time of survey completion, some respondents remained antipsychotic-free, to their own satisfaction and for a prolonged time. This is a pertinent reminder that, for a minority of people, discontinuation itself may be a therapeutic step rather than a cause of potential harm. Indeed, reports of discontinuation by this group highlight that, for some, discontinuation can be as lifesaving as it is disruptive and dangerous for others. Given the increasing evidence for potentially serious harms from antipsychotics, including neurological damage (Moncrieff & Leo, 2010), and metabolic and other side effects (Weinmann, Read, & Aderhold, 2009), the ethos of long-term antipsychotic treatment for all may be questioned (Morrison et al., 2012).

The potential for antipsychotic-free recovery for some people has been identified in a number of longitudinal studies (e.g., Bola, 2006; Calton, Ferriter, Huband, & Spandler, 2008). Although factors such as better early-life developmental achievements, lower vulnerability levels, increased resilience, and favorable prognostic characteristics have been associated with an increased probability of successful medication-free management (Harrow & Jobe, 2007), no clear criteria of identifying exactly who will do well off antipsychotics is currently agreed upon.

Given the difficulties in accurately identifying who will successfully discontinue antipsychotics, it is important that clinicians support people in trying different pharmacological and nonpharmacological strategies, and maintain open channels of communication while they figure out what works for them. This includes providing accurate information about side effects and potential long-term harms of continuing antipsychotics, as well as information about the potential harms of stopping (Morrison et al., 2012). Given the complexities of these decisions and the lack of any homogeneous recovery trajectory, the authors suggest that a shift toward a more person-centered, flexible, and transparent approach to discontinuation is warranted.

The weaknesses of this study include the small sample size and nonrandomized sampling technique. The researchers have attempted to access a diverse cross-section of people, however, by recruiting through both public and private services as well as service-user bodies and advocacy groups. Not all participants chose to provide free-text responses to all questions; thus, it is also possible that their particular experiences may have been overlooked. These methodological weaknesses mean that results may not be generalizable to a broader population. More rigorous, quantitative studies should be conducted to investigate the generalizability of these findings. The strength of the study is that it has sought to elicit first-person perspectives on an extremely important but underresearched topic. The large number of participants describing possible discontinuation syndromes underscores the need for future research in this area.

References

- Barnes, T. R. (2011). Evidence-based guidelines for the pharmacological treatment of schizophrenia: Recommendations from the British Association for Psychopharmacology. *Journal of Psychopharmacology*, *25*, 567–620. doi:10.1177/0269881110391123
- Bola, J. R. (2006). Medication-free research in early episode schizophrenia: Evidence of long-term harm? *Schizophrenia Bulletin*, *32*, 288–296. doi:10.1093/schbul/sbj019
- Calton, T., Ferriter, M., Huband, N., & Spandler, H. (2008). A systematic review of the Soteria paradigm for the treatment of people diagnosed with schizophrenia. *Schizophrenia Bulletin*, *34*, 181–192. doi:10.1093/schbul/sbm047
- Cheung, Y. W. (2000). Substance abuse and developments in harm reduction. *Canadian Medical Association Journal*, *162*, 1697–1700.
- Chue, P. (2006). The relationship between patient satisfaction and treatment outcomes in schizophrenia. *Journal of Psychopharmacology*, *20*, 38–56. doi:10.1177/1359786806071246
- Conley, R. R., Kelly, D. L., Lambert, T. J., & Love, R. C. (2005). Comparison of clozapine use in Maryland and in Victoria, Australia. *Psychiatric Services*, *56*, 320–323. doi:10.1176/appi.ps.56.3.320
- Deegan, P. E., & Drake, R. E. (2006). Shared decision making and medication management in the recovery process. *Psychiatric Services*, *57*, 1636–1639. doi:10.1176/appi.ps.57.11.1636
- Gitlin, M., Nuechterlein, K., Subotnik, K. L., Ventura, J., Mintz, J., Fogelson, G., . . . Aravagiri, M. (2001). Clinical outcome following neuroleptic discontinuation in patients with remitted recent-onset schizophrenia. *The American Journal of Psychiatry*, *158*, 1835–1842. doi:10.1176/appi.ajp.158.11.1835
- Gray, R., Leese, M., Bindman, J., Becker, T., Burti, L., David, A., . . . Tansella, M. (2006). Adherence therapy for people with schizophrenia: European multicentre randomised controlled trial. *The British Journal of Psychiatry*, *189*, 508–514. doi:10.1192/bjp.bp.105.019489

- Harrow, M., & Jobe, T. H. (2007). Factors involved in outcome and recovery in schizophrenia patients not on antipsychotic medications: A 15-year multifollow-up study. *Journal of Nervous and Mental Disease, 195*, 406–414.
- Haynes, R. B., Ackloo, E. S., Sahota, N., McDonald, H. P., & Yao, X. (2008). Interventions for enhancing medication adherence. *Cochrane Database of Systematic Reviews (Online)*, 2, CD000011.
- Jablensky, A. (2000). Epidemiology of schizophrenia: The global burden of disease and disability. *European Archives of Psychiatry and Clinical Neuroscience, 250*, 274–285. doi:10.1007/s004060070002
- Karnieli-Miller, O., & Eisikovits, Z. (2009). Physician as partner or salesman? Shared decision-making in real-time encounters. *Social Science & Medicine, 69*, 1–8. doi:10.1016/j.socscimed.2009.04.030
- Kulhara, P., & Chakrabarti, S. (2001). Culture and schizophrenia and other psychotic disorders. *Psychiatric Clinics of North America, 24*, 449–464. doi:10.1016/S0193-953X(05)70240-9
- Malekinejad, M., Johnston, L. G., Kendall, C., Kerr, L. R. F. S., Rifkin, M. R., & Rutherford, G. W. (2008). Using respondent-driven sampling methodology for HIV biological and behavioral surveillance in international settings: A systematic review. *AIDS and Behavior, 12*, S105–S130. doi:10.1007/s10461-008-9421-1
- McIntosh, A. M., Conlon, L., Lawrie, S. M., & Stanfield, A. C. (2010). Compliance therapy for schizophrenia. *Cochrane Database of Systematic Reviews (Online)*, 3, CD003442.
- Moncrieff, J. (2006). Why is it so difficult to stop psychiatric drug treatment? It may be nothing to do with the original problem. *Medical Hypotheses, 67*, 517–523. doi:10.1016/j.mehy.2006.03.009
- Moncrieff, J., & Leo, J. (2010). A systematic review of the effects of antipsychotic drugs on brain volume. *Psychological Medicine, 40*, 1409–1422. doi:10.1017/S0033291709992297
- Morrison, A. P., Hutton, P., Shiers, D., & Turkington, D. (2012). Antipsychotics: Is it time to introduce patient choice? *The British Journal of Psychiatry, 201*, 83–84. doi:10.1192/bjp.bp.112.112110
- Novick, D., Haro, J. M., Suarez, D., Perez, V., Dittmann, R. W., & Haddad, P. M. (2010). Predictors and clinical consequences of non-adherence with antipsychotic medication in the outpatient treatment of schizophrenia. *Psychiatry Research, 176*, 109–113. doi:10.1016/j.psychres.2009.05.004
- Read, J. (2009). *Psychiatric drugs: Key issues and service user perspectives*. New York, NY: Palgrave Macmillan.
- Roe, D., Goldblatt, H., Baloush-Klienman, V., Swarbrick, M., & Davidson, L. (2009). Why and how people decide to stop taking prescribed psychiatric medication: Exploring the subjective process of choice. *Psychiatric Rehabilitation Journal, 33*, 38–46. doi:10.2975/33.1.2009.38.46
- Salomon, C., & Hamilton, B. (2012). Antipsychotic discontinuation syndromes: A narrative review of the evidence and its integration into Australian mental health nursing textbooks. *International Journal of Mental Health Nursing*. Advance online publication. Retrieved from doi:10.1111/j.1447-0349.2012.00889.x
- Salomon, C., Hamilton, B., & Elsom, S. (2012). Experiences of antipsychotic discontinuation: Results from a survey of Australian consumers. Manuscript under review.
- Scottish Association for Mental Health. (2004). *All you need to know? Scottish survey of peoples experiences of psychiatric drugs*. Glasgow, Scotland: Scottish Association for Mental Health. Retrieved from <http://www.psychmind.co.uk/news/news2004/april04/allyouneedtoknow.pdf>
- Viguera, A. C., Baldessarini, R. J., Hegarty, J., Van Krammen, D. P., & Tohen, M. (1997). Clinical risk following abrupt and gradual withdrawal of maintenance neuroleptic treatment. *Archives of General Psychiatry, 54*, 49–55. doi:10.1001/archpsyc.1997.01830130055011
- Weinmann, S., Read, J., & Aderhold, V. (2009). Influence of antipsychotics on mortality in schizophrenia: Systematic review. *Schizophrenia Research, 113*, 1–11. doi:10.1016/j.schres.2009.05.018
- Woltmann, E. M., & Whitley, R. (2010). Shared decision making in public mental health care: Perspectives from consumers living with severe mental illness. *Psychiatric Rehabilitation Journal, 34*, 29–36. doi:10.2975/34.1.2010.29.36

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