

Guidelines for the Treatment of Schizophrenia: Summary

Our group was initially comprised of six psychiatrists, a professor of social work, a therapist, an epidemiologist, and a journalist. In our second day of work, we were joined by another psychiatrist and two people with lived experience in the mental health system, both of whom had at one time received a diagnosis of schizophrenia, and both of whom have achieved very substantial and long-term recovery.

Our group was not initially in agreement with some of what might be considered fundamental tenets of medication optimization: that for people with schizophrenia, there may be an over-reliance on medications; that medications may be currently overprescribed; that some people might reasonably wish to manage their experiences, diagnosed as schizophrenia, without medications, given the acknowledged risks and toxicities associated with these agents. So we had to begin our work by getting to know one another and appreciating each other's experience, concerns and perspectives.

Moreover, we realized early on that there were concerns on the part of some of our Oregon-based psychiatric colleagues that our work could have untoward and/or unintended negative consequences for patients and practitioners in Oregon. Specifically, there seemed to be concern that our work could be used to limit formulary options, or to otherwise restrict services, perhaps in the unstated service of cost containment. So these issues, too, needed to be addressed.

By the end of our first session, however, we had arrived at consensus on the following key points:

1. Based on our knowledge of people who have achieved recovery from schizophrenia, and based on our knowledge of the literature, there is a subset of people who can successfully discontinue medications and fare well. We acknowledged that identifying these people prospectively is at this point not possible.
2. Neuroleptic medications can be physically toxic, exemplified by risks of tardive dyskinesia, metabolic syndrome, and other physical consequences of use. There was not consensus on whether neuroleptics were harmful to the brain, though substantial evidence was presented.
3. Some symptoms, such as hearing voices for example, do not necessarily require treatment with neuroleptic medications. Some symptoms, such as command hallucinations to suicide, much more urgently require treatment under most circumstances.
4. Prescribing a neuroleptic medication always involves a risk-benefit analysis. In some cases with a higher risk of violence, neuroleptics may be especially indicated. It is

very likely that there is a subset of people who are experiencing their first episode of psychosis who would do better without exposure to neuroleptics. Again, this group is difficult if not impossible to positively identify prospectively. There is some evidence suggesting that neuroleptic exposure may worsen recovery outcomes for some people.

In our first day of work, the group turned its attention to the optimal management of first episode psychosis. It was the sense of the group that addressing the issues around treatment in first episode psychosis would be a good way of addressing more general issues of informed choice, when to use neuroleptics and for how long, and under what circumstances to withdraw them. The group wound up discussing first episode psychosis and its treatment in rather ideal terms: what we felt would be optimal, without regard to limitations of resources or other barriers to care.

One overarching principle of this discussion centered on the importance of providing a collaborative, supportive experience to the person going through a psychotic episode, by providing an easily accessible, welcoming, friendly, gentle and optimistic team of support – both for the person at the center of concern and for his or her family or other support system. There was strong general agreement that many people have terrible first experiences with the mental health system that leave them feeling misunderstood, not heard, not respected and often receiving treatment that feels coercive and noncollaborative. Moreover, if people and their families are told that the episode signals an irreversible brain disease that will require lifelong treatment, people may feel doomed. These initial experiences then can color the person's sense of trust and collaboration moving forward or be frankly traumatizing.

Another important principle is for the team to have accessible a wide range of supports and services, including the ability to conduct the initial evaluation in a comfortable, non-pathologizing, low-stress environment whenever possible, perhaps ideally in the person's home and not an emergency room. In addition, having options such as respite services specifically designed for people experiencing first episode psychosis may avert unnecessary hospitalizations, and the discouragement that may attend receiving services with people who are more chronically ill.

Engagement of the person at the center of concern is paramount. Again, this means engaging the person in a calm, welcoming manner that sees the experience of psychosis as important and potentially meaningful, and the engagement with the team as a positive step toward growth for the person at the center of concern. Probably the most critical element in this engagement is having plenty of time – not rushing to closure about what is happening and what should be done; making sure that all stakeholders are heard on their own terms; and that everyone has an opportunity to generate ideas about the best path forward. This means, too, not rushing to medicate symptoms until it is clear what the preferences, hopes, and ideas are of the person at the center of concern.

Of course, at the same time, our group acknowledged that some processes must run parallel to this engagement. One is to ensure that no urgent, unaddressed medical problems could be driving the psychotic experience (e.g., in the worst case scenario, acute poisoning presenting as psychosis). Another is to conduct a thorough and thoughtful risk analysis to ensure the safety of the person at the center of concern, as well as others.

Our group addressed who should participate on this sort of team. There was general consensus that the inclusion of peers or people with lived experience may be very helpful. This is not only because peers are sometimes able to empathize with the extreme states but also present, from the outset, a hopeful outcome and a possibility of a recovery. There was also general agreement that ideally the team should remain connected with the person over time, and regardless of the location of treatment – again, very challenging in practical terms given the current American medical system.

Other aspects of engagement include paying particular attention to the person's strengths, capacities, achievements, interests, hopes and dreams, rather than focusing exclusively on the person's incapacities and symptoms. The person's experience, perspective, explanatory model, and preferences for treatment, if any, should always be taken very seriously, and honored if possible.

The best explanatory model to offer the person and his or her family in the early going may be to say that the person is going through an extreme state, the exact nature and cause of which is not clear; that for many people, these extreme states do resolve with time and support, with or without medications; that for some people, these extreme states do turn out to be important learning opportunities or turning points in the person's life; that our paramount concern is to ensure the person's safety (and the safety of everyone else) and to come to a good, collaborative treatment path. It can further be explained that there are medications that may be quite helpful in addressing some of the symptoms or experiences that the person is having, but, like all medications and all treatments, there are risks as well as benefits to these medications. We make clear what those risks and benefits are for various options. In this regard, it would be very good to have prepared materials for the person at the center of concern and his or her family to review.

With regard to medication choice and recommendations, there was not unanimity in our group, but there did appear to be consensus that since a subgroup of people will do well without neuroleptics, and because it is currently impossible to prospectively identify these people, a conservative approach may be to use sedatives or benzodiazepines if possible early in the course of treatment, to see if neuroleptics can be avoided or minimized, and to buy time to make a more collaborative decision about their use.

A minority view in our group was that in such circumstances it may be more prudent to start a neuroleptic to address psychotic symptoms and then keep an open mind about reducing or eliminating them after the situation further resolves.

Other important ideas considered by the group:

1. For people started on neuroleptics in a first episode of psychosis, there should be clear understanding that the informed choice is an ongoing process, not a one-time event, and that people should be free to change their minds about the use of these agents.
2. Informed choice means informing people about the full range of risks associated with neuroleptics. It also means fully informing people about the risks of **not** choosing to take neuroleptics.
3. Informed choice, as important as it is, may be practically impossible for people and families in the throes of a first episode of psychosis. The psychiatric field may owe people stronger recommendations about the use of neuroleptics, with transparent options for other services: for example, a center might adopt as a policy that neuroleptics are not used, except in the most unusual circumstances, in the first two weeks of treatment; another center might adopt a policy that neuroleptics are to be used as standard treatment for psychotic symptoms, except under the most unusual circumstances. Patients and their families could then be offered an opportunity to seek treatment in a system consistent with their own choices.

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