Helping Clozapine Help: A Role for Support Groups

by David F. Zita and John Goethe

Abstract

A successful clozapine support group operates from the principle that the drug is most successful when the person takes it as prescribed. The likelihood of initial and ongoing collaboration with treatment is increased when the tangible gains of the treatment can be experienced in the self and demonstrated in others. Clozapine support groups can advance the goals of collaboration and recovery.

Keywords: Clozapine, support groups, schizophrenia, psychotherapy.


The clinical effectiveness of clozapine in the treatment of severe and persisting mental illness is challenged by many factors, not the least of which is a set of side effects that many people find especially troublesome (Lieberman 1998; Young et al. 1998; Miller 2000). One way to help overcome one of the barriers to recovery is increased collaboration between consumers and providers of the medication. Toward this end, support groups can play a central role in recovery.

Clozapine side effects are troublesome. Side effects can be more tolerable when patients know what to expect, receive group support, and have hope that the medication will lead to improvements in life. A credible support group supplies consumers with accurate, easy-to-understand information about side effects.

Early clinical reports during a systemwide initiation of clozapine treatment found that high initial doses led to a very high frequency of side effects and made establishing effective collaboration difficult. As a result, a weekly clozapine support group was started in a State psychiatric hospital. Information sheets were developed for patients (table 1) and physicians (table 2) for dissemination and discussion of possible side effects. The group, which had a very fluid membership, was designed to support people beginning a treatment trial as well as those considering taking the medication.

The group focused on people's probable responses to the medication and how those responses were aiding them, or at least could aid them at some time in the future, to solve life problems. A major methodology was to trace newfound successes in psychosocial functioning to the opportunities created by the medication. Yet another method was to provide and promote support for people having the courage to try another treatment for psychosis. Yalom's curative factors for group therapy are as essential for a clozapine support group as for any other type of enduring therapy group (1983, 1995).

Support group leaders also benefit from learning as much as possible about the phenomenology of the response to antipsychotic medications and how people's experience is transformed by medication. For many people, the phenomenology of clozapine recovery from psychosis shares more with improvements in attention, memory, and planning than with more conventional psychological models of mental health treatment.

As a result, support group therapists will find it useful to help people monitor their information-processing efficiency. For example, do the people seem to listen to what is transpiring in the room? Can they understand and remember any of it? How long can they pay attention? When they speak, do they make sense? If they respond to others, to what degree is the response based on a shared interpersonal interaction rather than dominated by psychotic thinking? And so on. The essence of such a group is sharing the people's behavioral history of drug response as it unfolds. This learning continues, and is promoted through group col-

Send reprint requests to Dr. D.F. Zita, River Valley Services, P.O. Box 351, Middletown, CT 06457; e-mail: david.zita@po.state.ct.us.
Table 1. Connecticut Department of Mental Health clozapine project: A consumer’s guide to common side effects

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<th>Side effects</th>
<th>What you can do</th>
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| Drooling or too much spit (doctors call this hypersalivation) | • Chewing gum helps some people.  
• At night, you can put a towel or extra pillowcases on your pillow.  
• Some people also find it helpful to sleep with their heads propped up.  
• Ask your doctor about medications that might help you drool less if none of the suggestions listed above help. |
| Dizziness when you stand up (doctors call this hypotension) | • Try getting up from your chair and bed more slowly.  
• Ask your doctor whether you can take more frequent doses and/or have most of the medication at bedtime. |
| Sleepiness (doctors call this sedation)           | • Sleepiness usually goes away after you have been on the same dose for a while.  
• Ask your doctor whether you can have most of the medication just before bedtime.  
• Some people find it helpful to drink moderate amounts of caffeinated beverages. Ask your doctor whether this would be okay for you. |
| Feeling sick to your stomach (doctors call this nausea) | • Try to take your medication with food.  
• Ask your doctor whether you can take your medication in smaller, more frequent doses.  
• If your stomach really hurts, ask your doctor about getting an antacid. |
| Fast heartbeat (doctors call this tachycardia)     | • This is common and usually is not a problem.  
• Ask your doctor if you need medication to lower your heart rate. |
| Weight gain                                      | • Some people taking clozapine put on unwanted weight.  
• You may have to change your diet or get more regular exercise to keep off unwanted weight.  
• Some people recommend starting a regular exercise program when taking clozapine. |
| Not wanting to have blood drawn (doctors call this needle phobia) | • Drawing blood is a necessary part of treatment with clozapine, and most people get used to it after a while.  
• Ask for a referral for psychological services to help overcome a specific fear. |
| Better thinking but unhappiness                   | • Talk to people about what you are feeling; talking helps.  
• Come to the clozapine support group, lots of people do. |

Note.—Clozapine (Clozaril) can treat certain mental problems that other medications have not helped. Clozapine can be very helpful but sometimes has some side effects that can cause problems. Always let your doctor know what side effects you are having.

Source.—Connecticut Department of Mental Health 1993.

Laboration and the gains of others, until the people can map and consolidate gains on their own.

People seem to have the highest level of collaboration with the drug when they can see their response through the group leader’s eyes. Ultimately, it is the beneficial response to the drug that people learn from their providers that keeps them tolerating the side effects and continuing their recovery.
Table 2. Connecticut Department of Mental Health clozapine project: Suggestions for the management of common side effects

<table>
<thead>
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<th>Side effects</th>
<th>Management considerations</th>
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| Hypersalivation    | • Have patient use towel on pillow or multiple pillowcases and sleep with head elevated.  
|                    | • Have patients try chewing gum (preferably sugarless) to decrease drooling.  
|                    | • Give clonidine 0.1 mg hs—an alpha 2 adrenergic agonist.  
|                    | • Give atenolol 50 mg qd—a beta-blocker.  
|                    | • Give propantheline (Pro-Banthine) 7.5 mg hs—a peripherally acting anticholinergic.  
|                    | • Give glycopyrrolate (Robinul) 1 mg bid—a peripherally acting anticholinergic.  
|                    | • See Davydov and Botts 2000 and Rogers and Shramko 2000.  |
| Hypotension        | • Tell patients to rise from bed or chair slowly.  
|                    | • Offer more frequent dosing (e.g., qid) to minimize size of any one dose.  
|                    | • Give majority of daily dose at bedtime.  
|                    | • Reduce dosage, with subsequent slow increase if necessary.  |
| Sedation           | • Reassure patients that sedation is often transient.  
|                    | • As with hypotension, use tid or qid dosing and give majority of daily dose at bedtime.  
|                    | • Reduce dosage, with subsequent slow increase if necessary.  |
| Tachycardia        | • Know that the side effect is common and usually mild.  
|                    | • If tachycardia is severe and persistent, prescribe a beta-blocker (e.g., atenolol).  
|                    | • Hold clozapine dose if pulse is greater than 140 beats per minute.  |
| Nausea             | • Administer clozapine with food.  
|                    | • Use tid or qid dosing.  
|                    | • Suggest an antacid.  |
| Weight gain        | • Weigh patients prior to starting clozapine and weekly thereafter.  
|                    | • Recommend that patients follow a healthy diet and do regular exercise.  |
| Patient noncompliance | • Recommend individual and/or group sessions to provide support and education.  
|                    | • Base intervention on patient’s specific reason for refusal of medication (e.g., delusions, weekly blood draw, side effects).  |
| “Awakening” phenomena | • As patients improve they may become dysphoric or even depressed about their life situation; individual supportive psychotherapy or clozapine groups geared to patient’s level of functioning may be useful.  
|                    | • Psychosocial rehabilitation may help patients build new coping skills to manage old problems.  |

Source.—Connecticut Department of Mental Health 1993 and 2001.

References


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The Authors

David F. Zita, Ph.D., is Director of Clinical Internship Training, River Valley Services, Middletown, CT. John Goethe, M.D., is Chief of Professional Services, Capitol Region Mental Health Center, Hartford, CT; and Director, Burlingame Center for Psychiatric Research and Education, Institute of Living, Hartford, CT.