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# Community Health Workers: a Resource to Support Antipsychotic Medication Adherence

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## Abstract

*Community health workers (CHWs) are frontline public health workers who are becoming increasingly integrated into medical settings for the prevention, treatment, and control of chronic disease. In particular, they have demonstrated the ability to improve medication adherence in underserved populations. One overlooked population that could benefit from CHW intervention is individuals with severe mental illnesses such as schizophrenia and bipolar disorder. These conditions are disproportionately weighted to economically disadvantaged communities and people of color, and are typically treated using antipsychotic medications. A number of factors, including social disadvantage, contribute to antipsychotic non-adherence, which is highly prevalent and drastically increases the burden of illness and economic impact of these conditions. This commentary examines the ways in which CHWs may be able to best serve individuals with severe mental illness, and proposes methods for facilitating this expanded scope of work.*

## The Burden of Medication Non-Adherence

Antipsychotic medications are used to treat serious psychiatric disorders such as schizophrenia, bipolar disorder, and severe depression, and are among the most commonly prescribed prescription drugs in the USA. They accounted for \$18.2 billion and 57 million prescriptions in 2011, and they are increasingly being prescribed.<sup>1</sup> However, non-adherence is highly prevalent and problematic for many individuals who are prescribed antipsychotic drugs. In a long-term study of treatment for schizophrenia, 74% of patients discontinued medication use within 18 months.<sup>2</sup> An analysis of claims from commercial health plans demonstrated that 79% of patients with bipolar disorder who were prescribed an antipsychotic took their medications less than 75% of the time.<sup>3</sup> Further, poorer

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adherence was associated with a higher risk of hospitalization and emergency room visits. Another study<sup>4</sup> found that non-adherence among patients with schizophrenia was strongly related to a return of psychotic symptoms, with about 80% of non-adherent patients experiencing an exacerbation of psychotic symptoms within the first year, compared with only 25% of adherent patients. Non-adherence is also associated with increased risk of hospitalization, longer hospital stays, and increased health care costs.<sup>5</sup> An estimated \$10.7 billion dollars are spent annually on inpatient hospitalizations and long-term care for schizophrenia,<sup>6</sup> and about 37% of the re-hospitalization costs may be attributable to medication non-adherence.<sup>7</sup>

The causes of non-adherence are multi-factorial.<sup>8</sup> Side effects including weight gain, sedation, and extrapyramidal symptoms such as muscle spasms and tremor may be the reason for discontinuation in roughly 20% of patients while another one third may be attributed to lack of efficacy. Severity of psychopathology and cognitive impairment are also associated with greater risk for discontinuation,<sup>8, 9</sup> perhaps because of difficulties with remembering to take the medication, misunderstanding treatment instructions, and/or poor insight about the importance of treatment. Mitchell and Selmes<sup>8</sup> also highlighted the importance of strong communication and a therapeutic alliance between patient and doctor in assisting with adherence to treatment.

People of color are also at higher risk for medication non-adherence. This population faces challenges in accessing specialty mental health services<sup>10, 11</sup> despite a higher diagnosed rate of severe mental illness. For example, African Americans and Latino Americans receive diagnoses of psychotic disorders including schizophrenia about three times as often as White patients,<sup>12, 13</sup> and individuals from disadvantaged socioeconomic backgrounds also have higher rates of schizophrenia.<sup>14</sup> Further, the experience of racial discrimination has been linked with longer delays in seeking medical treatment and higher rates of non-adherence.<sup>15</sup> Thus, understanding the mechanisms and barriers to achieving adherence allows for the optimal delivery of appropriate interventions to address these barriers and is critical for improving patient outcomes and reducing the burden to society.

## **How Community Health Workers can Support Adherence to Antipsychotic Medications**

There is growing evidence that community health workers (CHWs) can improve physical health outcomes; these frontline public health workers are trusted members of the communities they serve and they deliver culturally appropriate services and interventions, improve access to and use of clinical and social services, and foster healthy lifestyles. CHWs' ability to connect with members of underserved populations and experience working in the community make them highly effective, leading to improved health behaviors and health outcomes.<sup>16-18</sup> Because of their unique roles and skills, CHWs are increasingly becoming integrated into primary care settings particularly for the prevention, treatment, and control of chronic disease.<sup>19-22</sup> CHWs are an important workforce to engage as the US health care system is transforming to focus on community-clinical linkages and support for vulnerable populations.<sup>23</sup> Thus, CHWs may be an asset for supporting appropriate use of antipsychotic medication.<sup>16, 17</sup> CHWs are unique from peer support specialists because CHWs do not necessarily have a mental health diagnosis or share the same diagnosis as the patient, but due to other shared life experiences and trust, they are able to communicate effectively with patients. CHWs are adept not only at serving as liaisons between providers and patients for a wide range of diagnoses, they receive specialty training in understanding the complex social and behavioral reasons that serve as barriers to medication adherence. In this way, CHWs can complement peer support specialists in improving mental health treatment outcomes. Recent research has begun to explore CHWs' roles in supporting mental health services<sup>24, 25</sup> and medication adherence.<sup>26, 27</sup>

CHWs' well-recognized roles in providing health education, cultural mediation (i.e., respectfully communicating differences), social support, and capacity building may be directly related to supporting constructs outlined in the World Health Organization's Multidimensional Adherence Model.<sup>28</sup> These include socioeconomic factors (e.g., illiteracy, unemployment, high cost of medicines), health care team/health system-related factors (e.g., poor health education of the patient), condition-related factors (e.g., medical and psychiatric comorbidities), therapy-related factors (e.g., high frequency of doses, co-prescriptions), and patient-related factors (e.g., personality traits).<sup>28</sup> Potential CHW roles for each of these factors are outlined in Table 1: participating in multidisciplinary care teams and offering care coordination between office visits, bridging cultural gaps or building understanding between care providers and patients, ensuring that patients get the services they need, providing informal counseling and social support, and building individual and community capacity.<sup>29</sup>

Multifaceted interventions that include secondary care specialists such as CHWs have demonstrated improvements in adherence over a 90-day period,<sup>30, 31</sup> and continued monitoring through relapse prevention programs also improve long-term adherence outcomes.<sup>32</sup> For example, one randomized controlled trial ( $N=153$ ) increased the use of adaptive strategies and counseling. After 4 months, patients who received the intervention had significantly higher adherence to antidepressant medication compared to patients provided with usual care. Additionally, those who received the intervention rated the quality of care to be good to excellent. Similar studies have also

**Table 1**  
Potential CHW roles for medication adherence dimensions

<b>WHO medication adherence dimension</b>	<b>Factors affecting adherence</b>	<b>Potential CHW roles</b>
Socioeconomic-related factors	Illiteracy, unemployment, high cost of medications	<ul style="list-style-type: none"> <li>• Provide information for people with limited health literacy</li> <li>• Access social assistance and reduced cost medication programs</li> </ul>
Health care team/health system-related factors	Health education, multidisciplinary care, assessment and monitoring of patients	<ul style="list-style-type: none"> <li>• Serve as cultural mediators between communities and providers</li> <li>• Conduct care coordination and monitoring between office/clinic visits</li> </ul>
Condition-related factors	Comorbidities, instructions about managing disease, poor understanding of the disease and its symptoms	<ul style="list-style-type: none"> <li>• Administer mental health and substance abuse screenings</li> <li>• Provide culturally appropriate and health coaching and information on the use of medication</li> <li>• Offer social support</li> </ul>
Therapy-related factors	High frequency of doses, co-prescribing, adequate doses of medications	<ul style="list-style-type: none"> <li>• Develop systems to remind individuals/family members to take medication regularly</li> </ul>
Patient-related factors	Personality traits, perceived need for treatment, perceived effect of treatment	<ul style="list-style-type: none"> <li>• Counsel individuals/family members on value of treatment adherence</li> </ul>

shown an increase in adherence among patient with cardiovascular disease.<sup>33, 34</sup> Simple advice, health education, and an additional level of support are beneficial throughout treatment, and CHWs are well-equipped to assist in providing these services.<sup>31, 35</sup>

Although antipsychotics are among the most frequently prescribed medications in the country, non-adherence serves as a substantial barrier for optimal treatment outcomes in many cases. This issue is disproportionately weighted toward high-risk and high-needs populations, including individuals with disadvantaged socioeconomic status and people of color. Because of the trust and often long-term relationship with individuals and communities, CHWs are well situated between the clinic and community to take an active role in patients' treatment teams to improve adherence. They can serve as an additional layer of support and communication to help patients create plans for taking medication and addressing reasons why they might be non-adherent.

Importantly, many patients may make the informed choice that they would like to stop taking antipsychotic medications or reduce the dosage level if the medications are perceived as ineffective and/ or if the side effects appear to outweigh the benefits.<sup>36</sup> Many patients are able to recover from schizophrenia without the assistance of antipsychotic medications, and contrary to public belief, it appears that not all patients require continuous medication throughout their lives.<sup>37</sup> In fact, the best long-term functional outcomes appear to occur when patients engage in a gradual dose reduction following remission of symptoms.<sup>38</sup> In this situation, CHWs could assist with informing patients of their treatment options, advocating on behalf of the patient, and communicating patients' concerns and desires with the prescribing physician, ensuring a safe and gradual tapering of the medications rather than an abrupt withdrawal.

Additionally, the impact of CHWs could be optimal if targeted at patients with the highest likelihood of non-compliance. The most prominent risk factors for non-adherence include substance abuse,<sup>39</sup> depression,<sup>40</sup> poor social support,<sup>41</sup> and minority ethnicity status.<sup>14</sup> CHWs not only offer a bridge between the oftentimes disconnected community and clinic, but they also add an extra layer of support for high-needs patients through their roles in social support and cultural mediation. CHWs can engage in important conversations about patients' life goals and expectations of the positive impact of their medication on their overall well-being (e.g., provide the opportunity to go back to work or school, make additional friends). This additional care could potentially enhance the patients' perceived social support, which could in turn improve patients' prognosis for the course of schizophrenia.<sup>42</sup> In particular, African American patients may have difficulty forming trusting alliances with White physicians,<sup>43</sup> and the opportunity to have a community member on their treatment team could enhance their trust and adherence to treatment.

Finally, it should be noted that effective treatment of severe mental illness can and should include more than merely pharmacological intervention. Several additional interventions, including cognitive-behavioral therapy (CBT), assertive community treatment, skills training for employment and independent living, and family-based services have been proven to be effective.<sup>44</sup> In particular, CBT has been shown to reduce symptoms even in individuals who demonstrated limited benefits from antipsychotic intervention.<sup>45</sup> These treatment modalities should be used in the context of a comprehensive recovery-oriented model of mental health care.<sup>46</sup> Although CHWs are currently most frequently utilized in medical/primary care services, if their roles can expand within mental health treatment, they may be a valuable asset in facilitating access and adherence to these important treatment options.

## **Implications for Behavioral Health**

Integrating CHWs into adherence work offers the opportunity to not just facilitate community-clinical linkages but to truly impact the outcomes for some of the most difficult, expensive, and hard to reach individuals living with severe mental illness. In particular, adherence to antipsychotic medications presents a large challenge to underserved populations, and CHWs are appropriately

situated to assist with these communities. As health care works to better address the social determinants of health, it will be necessary to extend mental health services beyond the walls of the clinic and into the community. CHWs are the ideal workforce to move this agenda forward and make progress on improving medication adherence and patient outcomes.

To this end, this commentary serves as a recommendation for supporting efforts to integrate CHWs into behavioral health care teams in mental health facilities or primary care settings. Efforts to include CHWs in these new practices require substantial specialized training and workforce development that complements, not overshadows, CHWs' core roles. Progress toward CHWs specifically addressing adherence among individuals living with mental disorders is an investment requiring thoughtful and creative team-based approaches. Specific trainings regarding antipsychotic medications will be useful, including describing reasons for prescribing, common side effects and discontinuation effects, and barriers to adherence. Additionally, it will be crucial to provide CHWs with trainings to educate them about the unique characteristics and challenges faced by individuals with severe mental illness. These trainings may cover the typical symptoms, cognitive limitations, and lack of resources that can impact their ability to advocate for themselves and adhere to treatment recommendations. Finally, trainings should be aimed at correcting any potential misconceptions that CHWs may have regarding individuals with mental illness, perhaps fueled by inaccurate representations in the media.<sup>47, 48</sup> Including CHWs in addressing adherence issues provides additional opportunities to extend behavioral health care outside of clinic walls and encourages comprehensive community-based, patient-centered care.

## Compliance with Ethical Standards

*Conflict of Interest* The authors declare that they have no conflict of interest.

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