Treatment Advocacy Center

Engagement Stratagies for Treatment Non-Adherence

Reasons for Treatment Non-Adherence

Most people with severe mental illness (SMI) require lifelong medication and psychosocial intervention to live healthy and safe lives. People with SMI may not engage with treatment for a variety of reasons. Understanding the causes of treatment-nonadherence is a critical first step for promoting empathy among providers and helping people with SMI to understand their options for treatment.

The most common reason why people with schizophrenia spectrum disorders do not seek or maintain treatment is lack of insight, also called **anosognosia.**[1] Anosognosia is a symptom of SMI that prevents people from knowing that they are experiencing symptoms such as delusions or hallucinations. Anosognosia is estimated to impact approximately 60% of people with schizophrenia spectrum disorders and 50% of people with bipolar disorder.[2]

When someone has anosognosia, they typically have no awareness that there has been any change or decline in their mental state, behavior or functioning. If someone is not aware of a change in their mental state, it would naturally seem illogical for them to seek or maintain treatment, which can lead to prolonged periods of psychosis due to treatment non-adherence. AOT is intended to serve people with anosognosia through providing compassionate, person-centered care to individuals who may not believe that they are experiencing delusions, hallucinations, or other symptoms.

That being said, anosognosia is not the only cause of treatment non-adherence. Other important reasons for non-adherence include differences in cognitive functioning, financial and transportation barriers, lack of community support, and negative experiences with medications. Mistrust of doctors and poor therapeutic alliance can also contribute to non-adherence.[3] In order to provide person-centered care to individuals in AOT, it is important for AOT team members to be compassionate and curious about what may be causing or contributing to a participant's non-adherence.

Early Signs of Treatment Non-Adherence

Treatment non-adherence exists on a spectrum. When people think about treatment non-adherence, the first thing that comes to mind is often the cessation of prescribed medication, but this often occurs after other warning signs have been missed. Quality treatment engagement necessitates intervening at the first sign

of a participant's lack of engagement in treatment. Early warning signs of treatment non-adherence may include:

- Arriving late for scheduled appointments
- Canceling or rescheduling appointments
- Not communicating changes in contact information
- Not communicating concerns about medication or side-effects
- Decline in self-care such as neglecting personal hygiene
- Cognitive changes such as rambling, irrelevant conversation responses, or changing topics repeatedly in conversation

Discovering Participants' Goals

Because participants may have a hard time discerning their goals and values, you can partner with them to identify what may serve as a source of motivation. You can do this by:

- **Being curious and showing genuine interest in who they are.**
- **Normalizing not knowing and offering reassurance that you'll figure it out together.**
- **Paying attention to how they spend their time or how they want to spend their time.**
- **Affirming their unique skills, strengths, and interests, and reflecting those back to them.**
- **Gently exploring the circumstances that brought them to treatment, hospitalization, arrests, etc.**
- **Inquiring about what they perceive as the main challenges and frustrations they face.**
- **Asking questions like, "What gets you out of bed? What would make this process worthwhile? When do you feel most at ease or content? What's something that makes your day even a little better?"**

For participants who are further along the non-adherence spectrum, treatment team members may look for changes in behavior consistent with previous signs of decompensation and re-emergence of symptoms. However, it is important to note that these illnesses are relapsing, meaning decompensation can occur despite full treatment adherence.

Strategies for Improving Treatment Non-Adherence

Recognizing that resources vary significantly across AOT programs, the following engagement techniques can be implemented selectively based on your program's capacity and funding priorities.

- **Ensure AOT case managers carry caseloads small enough to allow significant, frequent contact with each participant.** The case manager, working with the treating psychiatrist and other appropriate team members, must monitor the participant's adherence to treatment and observe for behavior changes that may indicate decompensation. An AOT program must maintain a clear understanding of who is responsible for monitoring each AOT participant, and when and how to take action if warranted.
- **Use participant-driven treatment planning.** The best reasons for treatment adherence come from the participant. Treatment plans should be developed with the participant and should focus on helping them achieve personal life goals rather than being self-referential, where treatment adherence becomes the goal itself. Treatment plans with objectives like "take medication daily" or "attend all appointments" fail to reflect participants' values and goals. Instead, help participants connect treatment adherence to what they personally

value—pursuing hobbies, caring for pets, or building relationships.

- **Use Motivational Interviewing (MI),** an evidence-based collaborative, person-centered counseling approach designed to strengthen an individual's motivation and commitment to change. MI is a complex intervention that takes practice and appropriate supervision, however, basic MI—"MI spirit"—can be used by anyone to build an alliance with an AOT participant. MI utilizes reflective listening, open-ended questions, and affirmations of individual strengths to build intrinsic motivation and honor autonomy.
- **Utilize peer support specialists** in developing a program that is responsive to the needs of those it serves. Peer mentors can bridge trust gaps by sharing their own recovery journey, creating a safe space for participants to express concerns, translating clinical language and concepts into more relatable terms, and introducing participants to peer-led support groups and recovery communities, among many other benefits.
- **Apply therapeutic jurisprudence,** a legal movement that views the law as a potential therapeutic agent in promoting mental and physical well-being. Research on AOT has found a strong connection between the practice of therapeutic jurisprudence and participant satisfaction.[4] A judicial officer who takes interest in participants' progress, celebrates their successes, creates a welcoming and collaborative environment, and encourages participants' voice in treatment may contribute to more positive feelings toward treatment.
- **Apply Cognitive Behavioral Therapy for Psychosis (CBT-P),** a specialized form of cognitive behavioral therapy tailored for individuals experiencing psychosis. In this approach, the therapist works collaboratively with the individual to understand their experiences, thoughts, feelings, and goals from their perspective. CBT-P can help explore concerns, validate experiences, and reshape negative beliefs about treatment, making engagement more voluntary and meaningful.

The Importance of Therapeutic Alliance

Strategies for promoting treatment adherence will be most effective if the treatment team has a strong relationship with participants. This relationship, also called the therapeutic alliance, is especially important for participants who have anosognosia. Strategies to improve the therapeutic alliance should emphasize person-centeredness and a relational approach. For example:.

- Focusing on the participant's values and priorities rather than treatment for its own sake.
- Providing practical support that addresses immediate needs such as assisting with transportation or financial concerns.
- Celebrating successes, no matter how small.
- Recognizing the participant as an equal partner in treatment decisions and the leader in their recovery.
- Conducting outreach in person by making home visits or meeting participants in a setting where they feel comfortable.

- Moving away from the "expert" role toward joint decision-making.
- Encouraging participants to share concerns about medication side effects and be open to addressing them.
- Honoring participant autonomy by respecting their right to make choices.
- Processing relapses together without judgment and develop relapse prevention plans collaboratively.
- Identifying and strengthening social support networks.

Emergency Intervention

When consistent outreach and engagement strategies prove unsuccessful and the participant shows clear signs of psychiatric deterioration, prompt action becomes necessary. Ensure protocols are in place for immediate psychiatric evaluation, as research indicates the duration and number of untreated psychotic episodes can contribute to neurological damage over time.[5] Establish clear procedures for collaboration with law enforcement when needed for emergency pick-ups, including documented processes that respect participant dignity while ensuring safety. While these emergency measures may temporarily impact the therapeutic relationship, they are sometimes necessary to prevent further deterioration and should be followed by renewed engagement efforts and processing the relapse together to rebuild trust and support continued treatment.

Conclusion

Successful AOT engagement is about building trust, understanding each individual's unique needs, and creating a supportive, collaborative environment that empowers participants in their treatment journey. Understanding why treatment non-adherence occurs and empowering your AOT team to perform active outreach with participants is essential to building an effective AOT program.

Have questions about AOT implementation? Reach out to our AOT implementation team at aot@tac.org.

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