Along with Their Care Teams, People with Psychiatric Conditions Can Make Their Treatment Needs Known Before a Crisis Hits

People with serious mental illnesses (SMI) such as schizophrenia, bipolar disorder, or other psychotic disorders may periodically experience mental health crises or emergencies. During these crises, they may be unable to make treatment decisions or express their treatment wishes. A psychiatric advance directive (PAD) is a legal document that details a person’s preferences for medical treatment during a mental health crisis. Similar to a medical advance directive or living will, a PAD may include specific treatment preferences and may also name a trusted individual, such as a family member, who can make treatment decisions on behalf of the person with SMI during a crisis when they may not be able to speak for themselves. Past research has found that people who complete PADs feel more connected to their treatment providers, which can help with their recovery. However, people may need help identifying their treatment preferences, writing a clear PAD, and getting it officially notarized as may be required by some states.

In a recent NIDILRR-funded study, researchers tried incorporating PAD development into a team-based psychiatric treatment program called Assertive Community Treatment, or ACT. ACT includes comprehensive community-based services for individuals with SMI who typically are at risk for homelessness or hospitalization. An ACT team consists of a diverse group of medical and rehabilitation professionals, including clinicians or therapists, as well as trained, certified peer support specialists. The researchers wanted to find out whether ACT teams could help people with SMI to complete PADs, and whether there would be a difference in completion rate with assistance from a clinician compared to assistance from a peer support specialist. The researchers also wanted to find out which people with SMI were most likely to complete PADs when they had the opportunity.

Researchers at the field initiated project on Implementing Psychiatric Advance Directives with Peer Specialist Facilitators enrolled 145 people with SMI in a study between 2013 and 2015. All participants were receiving ACT services in North Carolina, and had a diagnosis of schizophrenia, bipolar disorder, schizoaffective disorder, psychosis, or a mood disorder with psychotic features. Each participant completed a background interview, where they answered questions about their diagnosis and health history (such as whether they had problems with substance abuse, and their history of hospitalizations); their living situation; and how long they had worked with an ACT team for mental health services. Each participant was then given the opportunity to work on a PAD over a period of 4-5 months, with about half of the participants assigned to work with a clinician and the other half with a peer support specialist. The clinicians and peer support specialists were given a manual to follow when helping the participants develop
PADs. These facilitators were trained to listen carefully to the participant and ask questions to identify the participant’s wishes and preferences about future treatment.

The researchers recorded the percentage of the participants who chose to complete a PAD and compared these PAD completion rates between the participants who worked with a clinician and the participants who worked with a peer support specialist. The researchers also had a psychiatrist review the completed PADs and rate their overall quality, including the level of detail provided and how consistent they were with local treatment standards. Finally, the researchers looked at factors from the participants’ background interviews to see which factors were related to PAD completion rates.

The researchers found that out of the 145 participants, 116 stayed in the study over the 4 or more months needed to work on PADs and participate in follow-up interviews. Out of the participants who stayed in the study, 58% completed a PAD. The completion rates were similar between the participants who worked with a clinician and those who worked with a peer support specialist. Nearly all of the PADs from both groups were rated as high-quality. All of the completed PADs included written instructions on the participant’s treatment preferences, and about 37% of the participants who completed the PAD also designated a person who could make decisions on their behalf.

When the researchers looked at the factors associated with PAD completion, they found that participants who were living in their own home or apartment were more than twice as likely to complete a PAD as those who were living with others (such as in a parent’s home) or in a shelter. The participants with substance use issues were more likely than those without substance use issues to complete a PAD. The participants who had been receiving ACT services for a longer period of time were more likely to complete a PAD. Finally, those participants who said they had needed to be hospitalized for their psychiatric condition in the past but were denied admission were less likely to complete a PAD than those who had not had this experience.

The authors also compared the PAD completion rate from this study to a previous study, where people with SMI were invited to complete PADs with assistance in a controlled research setting rather than a community setting. In both the previous study and this study, a majority of people with SMI were able to complete PADs and make plans for future treatment. In this study, both clinicians and peer support specialists were effective in helping people complete high-quality PADs. The authors noted that peer support specialists may have more time than clinicians to dedicate to helping consumers develop PADs, hence may be more readily available to provide assistance. Peers may also offer a unique perspective and may act as role models for consumers. ACT teams and other community mental health agencies may wish to incorporate peer-facilitated PAD development as a service that can empower consumers to take charge of their treatment decisions.
To Learn More
The National Resource Center for Psychiatric Advanced Directives offers information, articles, and webcasts on PADs, including a webcast on How to Write a Psychiatric Advanced Directive. http://www.nrc-pad.org/getting-started

The Center on Integrated Health Care and Self-Directed Recovery is dedicated to advancing knowledge and utilization of innovative models to promote health, recovery, and employment for people with mental health conditions. http://www.center4healthandsdc.org/

To Learn More About this Study

Research In Focus is a publication of the National Rehabilitation Information Center (NARIC), a library and information center focusing on disability and rehabilitation research, with a special focus on the research funded by NIDILRR. NARIC provides information, referral, and document delivery on a wide range of disability and rehabilitation topics. To learn more about this study and the work of the greater NIDILRR grantee community, visit NARIC at www.naric.com or call 800/346-2742 to speak to an information specialist.

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