Research finds peer support vital for those taking medication for severe mental illness

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Researchers at Aston Pharmacy School have found that people with severe mental illness could benefit from peer support to help them manage their medication and improve their health and quality of life.
The study, which was set up to review the complexities of medication in severe mental illness and identify possible solutions, found that without additional support, the risk is that they won't take their medication.

The term 'severe mental illness' incorporates a range of conditions, including schizophrenia and bipolar disorder. Most of the conditions are treated with medication such as antipsychotics and mood stabilizers, but side effects, particularly early in treatment, can be extreme. As a result, patient adherence to medication regimes can be very low.

The researchers, led by Dr. Jo Howe and Professor Ian Maidment, sought to understand how shared decision-making between patients and clinicians might improve this. The work has been carried out as part of the MEDIcation optimisATion in severE mental illness (MEDIATE) project, which ran from November 2021 to March 2023.

Part of the research involved an extensive review of the existing literature on the subject, but Dr. Howe says that what sets this study apart is that it also brought clinicians and people living with severe mental illness from Birmingham and Solihull Mental Health NHS Foundation Trust to discuss the issue and the direction of the study.

The researchers found that a person-centered approach, alongside a trusting relationship between the patient and the clinician, where people living with serious mental illness are supported to make medication-related decisions, helps ensure that they receive the right medication at the right dose and the right time.

However, a person diagnosed with a severe mental illness might only see their psychiatrist very infrequently, with gaps of many months. In the meantime, a bad reaction to medication might mean that the patient seeks out information, potentially from unreliable sources, and may stop taking medication altogether or self-medicate.
One of those involved in the study was lead patient researcher Max Carlish, who has lived with bipolar disorder for 19 years. He said, "At least as important as the pills you're taking is your relationship with your prescriber. That relationship is such a huge part of every service user's life and yet it's barely talked about and hardly researched. In the study, we found that many patients spent very little time having any kind of dialogue with their prescribers."

Trained, effective peer support could help to plug the gaps in medication advice. While peer support is common in mental health, there has traditionally been a reluctance to include support for medication as part of their role. However, the study found that more research is needed on the training and support required for peer support to work safely in this area.

These are serious conditions requiring strong medication, and the consequences if something goes wrong can be severe.

Dr. Howe said, "People with severe mental illness often feel they don't have enough information about their diagnosis or their medication and will instead turn to social media platforms such as Reddit, where there are lots of threads on things like schizophrenia and antipsychotics."

"This information can be right, but it might not be, and it can be hard to tell the difference without specialist knowledge. People living with serious mental illness can benefit from peer support, so it would be better to have a proper system in place and help them tell them identify good pieces of advice."

Crucially, patient groups and clinicians in the study agreed that there is a role for properly trained peer support. People with lived experience can offer advice that may not be in information leaflets or occur to people who have never taken the medication.
For example, this can be as simple as advising someone to take their medication before they go to bed if it makes them drowsy instead of first thing in the morning or reassuring them that highly unpleasant side effects at the start might fade in time.

Empathy and shared experience can make talking to someone with the same condition and taking advice from them much easier than with a professional without that lived experience. It can also help someone to feel more empowered in their decisions about their medication.

Carlish added, "In the future, peer support could play a really important role in that relationship between the prescriber and the prescribed-to, but at the moment, we just don't know how much of a difference peer support can make to getting people on the right medications because there's hardly any research on it."

Dr. Howe and the team also found very little research in minority ethnic communities. There is some evidence that members of minority communities are more likely to receive coercive medication, highlighting the importance of this area. More generally, there is very little research written from a patient perspective.

Professor Maidment, who conceived MEDIATE, was the chief investigator and who has worked in mental health for more than 25 years, said, "Untreated mental illness can have devastating consequences. Getting patients on the right medication that they are happy to take has been a key challenge for many years. We need to develop effective novel approaches. Our future research will focus on exploring how peer support workers can help people living with serious mental illness more effectively manage their medications and improve their quality of life."

The research is published in *BMJ Quality & Safety*. 

Provided by Aston University

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