DATA TRENDS

SEEKING HELP FOR FAMILY MEMBERS EXPERIENCING THEIR FIRST EPISODE OF PSYCHOSIS

A recent qualitative study found that the very presence of family or support professionals determined a process of help-seeking.

Families often play a critical role in identifying and seeking help for psychosis. When a young person first experiences psychosis, family members are often confused and frustrated in attempting to make sense of the changes occurring in their loved one.[1] Resulting delays in accessing care are associated with negative outcomes such as worse psychiatric and social functioning.[2]

A recent qualitative study on the duration of untreated psychosis (DUP) period for young people served by the Early Assessment and Support Alliance (EASA) in Oregon found that the very presence of family or support professionals determined a process of help-seeking.[3] For all but one young adult (away at college with little family contact), a family member or professional counselor was available to assist the young person resulting in an eventual visit to a mental health professional. Conversely, being physically away from family led to the longest period of DUP.

A meta-synthesis[1] of articles on family members' experiences in seeking help when their loved ones experienced their first-episode of psychosis, and a qualitative study of young people served by the Early Assessment and Support Alliance (EASA) in Oregon emphasize the importance of families and the challenges they face in seeking care.[3] The meta-synthesis included studies from urban and rural communities in Australia, Canada, Brazil, Hong Kong, New Zealand, the United Kingdom, and the United States, and the qualitative study focused on the duration of untreated psychosis and causes among individuals receiving early psychosis services from EASA in the US. Considering the central importance of family members for seeking help with early psychosis, we will now summarize four themes from the meta-synthesis.

RESULTING THEMES

The first theme was, "*'Not Knowing' – trying to make sense and looking for answers*."[1] Family members may vary in their decision to seek treatment for their young person due to their level of understanding of psychosis – misinterpreting changes such as blank stares, reports of hearing voices, or odd mood shifts as normal teenage behavior or underestimating the seriousness of symptoms.[1,4] Cultural beliefs about mental illness and religion may also impact how families interpret behavior and the appropriate response.[5] Some family members may seek answers through discussions with extended family or engaging a religious leader. These help-seeking choices may be affected both by cultural norms and by distrust of mental health service providers stemming from historical systematic oppressions.[1,4,5]

Family members talked about experiencing feelings of desperation as they struggled to make sense of the behavioral changes. For some, these feelings were expressed through justifying, ignoring, or minimizing symptoms, while other family members distanced themselves from the young person as a coping strategy.

The second theme was the "*Crisis point – the cry for help*."[1] After a period of interpretation or informal help-seeking, there was often a "dramatic shift in help-seeking behavior" after reaching a personal limit of feeling overwhelmed and recognizing a need for professional help, or seeing behavior as dangerous. Two families in the EASA study[3] did not recognize the need for professional care until the young adults' mental health difficulties led to a medical emergency, resulting in a stronger sense that "something was wrong" than the appearance of hallucinations and delusions. Similarly, some families who experienced the impact of oppression were found to have "high coping strategies" which functioned until the young person's psychosis symptoms escalated into a dangerous situation and overwhelmed these families.[1,6,7] Finally, frustration around seeking help occurred when there was limited understanding of psychosis symptoms, and barriers to accessing mental health services from front-line service providers.

The third theme, "*Impact on the family member*,"[1] included emotional impact, family relationship impact, and stigmatization. Obtaining help brought relief, yet involuntary hospitalization resulted in traumatization and possible stigmatization. The help decreased the negative impact on the family members and increased their knowledge around psychosis. This resulted in increased hope within the family, which had a relationship-mending effect.

The final theme was "*The role of interactions in help-seeking*."[1] This theme addressed the interaction between families, informal sources of help, and helping professionals. Informal sources were sought to provide a reassuring explanation to diminish uneasy feelings. Parents also found support from school social workers who helped link them to mental health organizations. Trust in helping professions increased when issues of culture were addressed and parents were validated around their concerns. A key factor was clear communication between the family and helping professionals.

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PRACTICAL IMPLICATIONS

The presence of family members or other supporters can determine whether the person gets help and how long it takes. Family-level factors such as cultural beliefs, interpretation of behavior, and awareness of mental illness affect DUP length. The meta-synthesis concluded that all four themes influence family members seeking help. The interaction of service providers with families is paramount in all aspects of the process of seeking help. Reducing the length of DUP during the help-seeking period will depend heavily on recognizing emerging psychosis within the family. Efforts to reduce DUP must recognize that help-seeking for psychosis varies within communities that experience marginalization. Addressing factors that facilitate rapid help-seeking by significant others will ideally shorten delays in seeking care.

Addressing spiritual beliefs, cultural traditions, the historical impact of oppression, and stigma may decrease or eliminate delay in seeking help.[1,6,7] Education needs to be accessible, easy to understand, and non-threatening, and dispel cultural fears and stigma around first episodes of psychosis. Supportive interactions between service providers and family members are key in increasing early intervention and sustained help.

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