Caregivers experienced 6 phases in coping over time with severe and persistent mental illness in a family member


QUESTION: What processes or phases do caregivers experience in caring for a family member with severe and persistent mental illness?

Design
Qualitative study done within a theoretical framework of symbolic interaction and dramaturgical interviewing.

Setting
Central midwestern USA.

Participants
26 people (69% women, 100% white) aged 40 – 76 years (mean age 56 y) who had participated in a 36 hour psychoeducational course, had a family member with a severe and persistent mental illness, and had been assisting their family member with the management of the mental illness for several years. Mentally ill family members ranged in age from 18 to 73 years (mean age 33 y) and were usually offspring.

Methods
26 semistructured interviews, each lasting 1.5 – 2 hours, were done using a flexible and indepth questioning method. Participants were interviewed until no new themes or phases emerged. Phases in the development of illness were evident after 18 interviews, and 8 additional interviews provided indepth understanding of themes specific to particular phases. Interviews were audiorecorded. Other verbal, contextual, and affective material was used to create an integrated record of each interview. A content analysis process including both qualitative and quantitative components was used. Both deductive (using a theoretical perspective) and inductive (generated directly from the data) coding were used.

Main findings
Participants described their family members as having substantial difficulty with memory and concentration, and problems including hallucinations, delusions, and violent behaviours. Participants experienced 6 phases in the journey through mental illness development. Phase 1, development of awareness, described the pattern of initial recognition of a problem, feelings of concern, and unsuccessful efforts to seek assistance. Phase 2, crisis, featured a worsening of the problem beyond the family’s ability to cope, an abrupt confrontation with the mental healthcare system, enormous emotional distress, difficulties communicating with healthcare providers, and financial concerns. Phase 3, cycle of instability and recurrent crises, often lasted many years and represented instability and recurrent crises; anger, grief, and loss; searching for explanations, treatment, and more knowledge; intensified financial concerns; some benefit from newer treatments; dissatisfaction with the healthcare system; and feelings of stigma. Phase 4, movement toward stability, described major changes in participants’ thoughts, values, and behaviours, including finding ways to regain control, managing guilt and helplessness, changing perceptions, dealing with ethical dilemmas related to control, and developing symptom management techniques. In phase 5, continuum of stability, participants felt they had improved symptom management and decision making skills, developed through the support of professionals, friends, and support groups. Phase 6, growth and advocacy, described participants’ awareness of their personal growth, and concern for their relative’s future.

Conclusion
Family members experienced a sequential progression of 6 phases as they cared for persons with severe and persistent mental illness.

COMMENTARY
The study by Muhlbauer identifies 6 phases of how families cope over time with the severe and persistent mental illness of a family member. The process of family coping is similar to navigating a storm on the water, including heeding storm warnings, confronting the storm, being adrift, realigning a compass, mastering navigational skills, and sailing after the height of the storm. Findings of this study are generally consistent with other recent research identifying similar stages of coping.1–3

The sample was drawn from a list of family members who had participated in psychoeducational groups provided in an academic setting in central midwestern USA. Participants were Caucasian, middle aged to elderly, well educated, and motivated to participate in the study. The select nature of the sample rules out concluding that the study findings apply to other populations, such as low income minority family members who may disproportionately experience health disparities. Further research is needed to know if similar phases of coping occur in samples with diverse racial, cultural, and sociodemographic characteristics. In addition, family members in various population groups and at different phases of coping could be assessed for their specific needs and preferences regarding nurse facilitated psychoeducation and other support services.

The phases of navigating the storm of mental illness have implications for clinical practice with families of individuals with persistent and severe mental illness. Families in the first 3 of the 6 identified phases of coping may be most in need of psychoeducation and other support. Nurses could evaluate the needs of families for counselling support in context of the phase of coping, and then tailor psychoeducational interventions to the family phase of coping.

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