

Developing Family Resilience in Chronic Psychiatric Illnesses

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Caregiving for an ill family member can be both stressful and rewarding. Caring for a relative with a psychiatric illness adds the burden of social stigma, both for the patient and the family caregivers, especially in minority cultures. Families from minority cultures may have a different understanding of mental illness and have difficulties with language, discrimination, and accessing services.

The appraisal of caregiving must be assessed separately from a caregiver's coping style. For example, caregiving may be perceived as low stress but the caregiver's coping skills may be poor, resulting in high caregiver burden. Low perceived stress with strong coping skills results in the most reward and the least burden.

High levels of caregiver burden occur in caregivers of relatives with schizophrenia,¹ bipolar disorder,² and chronic or recurrent mood disorders.³ Caregiver burden tends to be worse and more persistent with relatives who suffer from depressive disorders compared to bipolar disorder.⁴ Children of caregivers may have difficult behavior, loss of appetite, sleeplessness, with less playing and less attention at school.⁵

Caregiver burden can be reduced and caregiver reward can be maximized by improving family resilience. The concept of family resilience explains why some families experience lower burden and greater reward. Family resilience includes the ability to develop adaptive interpersonal skills, such as differentiating the person from the illness, and positive family qualities, such as mutual acceptance and empathic involvement. These family strengths contribute to a sense of family wellbeing and offset difficulties in other areas of family functioning. The wellbeing of the family unit ensures the best outcome for both patient and caregiver.

A SYSTEMIC VIEW OF ILLNESS

If a relative is ill, all family members are affected. If the strain of caregiving is great, then caregivers themselves become ill. If the caregiver is ill, then the ill patient has more difficulty with recovery. A systemic view of illness means understanding the

effect of illness on the family system and understanding the effects of the family system on illness presentation and outcome.

Family interventions to reduce caregiver burden, improve family resilience and optimize patient outcome

Family psychoeducation (FPE) reduces caregiver burden by improving understanding and coping skills.⁶ FPE is an evidence-based practice for individuals suffering from chronic psychiatric illnesses. Multiple family group psychoeducation is one form of FPE that has been shown to reduce symptom relapses and rehospitalizations for individuals with schizophrenia. In a 2.5 year study of family cognitive behavioral therapy relapse prevention in first episode psychosis, caregivers who completed the FPE program perceived less stress and an increase in perceived opportunities to make a positive contribution to the care of their relative compared to carers who received treatment as usual.⁷ Multi-family groups and family therapy are also effective for caregivers of family members with depression.⁸

The psychoeducation in FPE typically consists of education about the illness, support for families, problem-solving strategies, and illness-management techniques. In addition to understanding patients' likely physiologic arousal to environmental stressors, learning to defuse crises, and recognizing prodromal cues of decompensation, families are taught to reduce their own feelings of guilt, confusion, helplessness, and over-responsibility. By participating in FPE for at least 9 months, family caregivers become less judgmental and learn appropriate limits and expectations. It is especially effective when family members participate on a consistent basis. Despite being an evidence-based practice, family psychoeducation is not widely applied so more compact, shorter models have developed, such as the 12-week Family-to-Family program of the National Alliance on Mental Illness, which is supported by many public mental health authorities.

THE INDIVIDUAL FAMILY MEETING

Before referring a family member to FPE, simply meeting together with a patient and family member for a one-time meeting or over a short series of visits can be of benefit. Opportunities exist for improving communication. Families can be supportive and caring but may also be burdened by guilt for having feelings of frustration, helplessness and anger toward the ill family member. The patient may perceive the family's concern as interfering and feel resentful. Often the patients do not appreciate how their illness affects their family. An empathetic professional can acknowledge that such feelings are a normal part of the caregiving experience. The following exchange outlines a typical scenario and helpful strategies for the clinician.

John (the patient): I appreciate that my Mom worries about me but really, if I'm quiet, in a bad mood or just want to stay in my room, my mother freaks out. She starts hammering me with questions. I don't need her trying to micromanage my life.

Dr. K: Mrs. Jones, what do you think about what John is saying?

Mrs. Jones: I get so worried because John freezes me out when he begins to get sick, he'll go days hold up in his room, won't eat and becomes very nasty. His father and I are so scared that he'll take another overdose.

Dr. K: John, I know you've suffered terribly and of course you need to manage your own life, but what do you think it was like for your parents to find you in your bedroom following your overdose?

(Dr. K is aware that supporting the parents' position may result in the patient believing his concerns are being minimized.)

Dr. K: John, of course your parents and I are not aware of the extent of your suffering. What we are trying to do here today is to have your parents and you establish a way of helping each other deal with your illness. Let's work on a safety plan. John, if you will let your parents know when you are

beginning to have difficulty, Mrs. Jones will you agree to give John some space and not, in his words “micromanage”? And John, you need to understand how horrible it was for your parents, to have found you unconscious in your bed. Mom, can you work on relaxing and John, can you promise to let her know how you are doing?”

(An open discussion of the pitfalls and positive aspects of their safety plan can follow.)

Another aspect of the safety plan is to inquire of both the patient and caregiver what they first notice when the patient is beginning to have difficulty.)

Dr. K: Mrs. Jones and John, what warning signs do you notice when things are beginning to unravel for John? John, you shared that when you are beginning to decompensate, your thoughts become dark, and you stop eating. Mrs. Jones, you also notice that John starts skipping meals and withdraws. Would it be helpful for you to allow John a day or two when this might happen, but if it continues on the third day, you can inquire and ask John to call me? How does that sound John?

John: I can agree to that, I'll call you.

Mrs. Jones: John is agreeing now, but what if he refuses to contact you?

Dr. K: Mom can always call my office; you don't need a release of information, to inform me or my staff of your concerns. I'll return the call to John. If necessary I'll schedule a session. We can work together; hopefully we can intervene early enough to stop the progression that resulted in taking an overdose and requiring hospitalization.

In this way, the physician brings the patient and family together to develop a safety plan which underscores the reality that the impact and management of the illness is both the patient and family's responsibility. The physician should incorporate the warning signs John and his mother have identified into the plan. The physician stresses the importance of developing and using a strong alliance in combatting the ravages of mental illness. The single family meeting does not resolve all issues, but raising the consciousness of the patient and family can be the first step towards behavioral change. The family meeting is perhaps the first time the patient and family have had this discussion with a neutral third person. This interchange is

a powerful opportunity for honest communication and furthers understanding of each position. The family caregiver, Mrs. Jones, develops some mastery over the management of the illness and how to interact with the mental health system while maintaining a positive, collaborative relationship with her son. There is no better way to help a caregiver.

Children can be caregivers for a parent with a psychiatric illness. Children may be excluded from the family meeting as the parent may want to “protect” the child or may be fearful of being perceived an unfit parent. Physicians can explain that children often have questions about the illness, that they may have unfounded fears that are distressing them and distorting their understanding of the situation, and that they can benefit from support and education. When a person with a mental illness is a parent, activities supporting their parenting role should be discussed as part of their recovery, and specific tools provided. Children and teenagers can access books and online support.^{9, 10} Massachusetts offers a wraparound program for the entire family to help parents with mental illness raise their children.¹¹

Individual caregivers can benefit from psychoeducational material.¹² However, caregivers are reluctant to seek help and involving caregivers in a family meeting is a good first step in reducing burden. Helping caregivers use active coping skills rather than avoidant coping strategies is important. Caregivers can be encouraged to develop positive cognitions which helps develop resourcefulness and sense of coherence.¹³

CONCLUSIONS

This brief review provides the rationale for including families in the assessment and treatment of patients and provides guidelines for physicians and other clinicians when working with family members of patients with chronic mental illness. For the caregiver, low perceived stress and good coping skills result in the most reward and least burden. The caregivers benefit when the physician acknowledges their burden, supports their need for self care and helps set appropriate limits with the patient.

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