The Stigma of Families with Mental Illness

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Objective: This article describes family stigma, which is defined as the prejudice and discrimination experienced by individuals through associations with their relatives.

Methods: The authors describe family stigma and present current research related to mental illness stigma experienced by family members. Research indicates this type of stigma negatively impacts family members and relatives with mental illness.

Results: The authors also present strategies to eliminate stigma and discuss implications for the training goals of psychiatrists throughout the text.

Conclusion: The authors end this article with recommendations for psychiatry training goals.

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A common theme throughout this special series is that many families assume major roles in the lives of their relative's mental illness. Hence, service plans should prominently feature family members when so indicated by the relative with mental illness. Unfortunately, the family's role is frequently undermined by stigma—not solely prejudice and discrimination experienced by the person with mental illness. Family members experience stigma through their association with the person with mental illness. Erving Goffman (1) called this courtesy stigma, namely, the stigma experienced by parents, siblings, spouses, and children of people with mental illness. This article examines family stigma in detail and we begin with a general review of stigma paradigms as applied to families. The article then examines strategies that lead to the elimination of mental illness stigma. Throughout, we highlight implications of family stigma and stigma change for the training goals of psychiatry.

Structural Models of Stigma

Goffman (1) originally defined stigma as the mark that distinguishes someone as discredited; for example, people marked by skin color (ethnicity), physiology (gender), body size (obesity), and clothes (poverty) are stigmatized by the general public. Since then, models of stigma have become more complex so that now it means not only the public cues that signal membership in a stigmatized group, but also the cognitive (stereotypes), emotional (prejudice), and behavioral (discrimination) consequences of the cue. As stated above, the stigmatizing mark has meaning in terms of stereotypes; they are categorical statements about groups of people (2). They represent social efficiencies, in that individual stereotypes gain meaning only in the comparison of interpersonal groups. Public members may be aware of mental illness stereotypes but they may not endorse them. In turn, endorsing and agreeing with stereotypes is referred to as prejudice (2). People who agree that a particular ethnic group is framed in negative statements are prejudicial toward that group. As a stigma process, prejudice yields negative emotional evaluations. Prejudice leads to discrimination, the behavioral outcome of stigma.

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(3). Discrimination exists as lost opportunity; people with mental illness lose the chance to get regular work from a discriminating employer or live independently from a biased landlord.

In order to understand and describe mental illness stigma we distinguished public stigma from self-stigma. Public stigma occurs when members of the general public endorse stereotypes and act on discriminatory behaviors such as refusing to hire someone because of mental illness. The self-stigma process initially includes self-stereotype in which individuals become aware of the socially endorsed stereotype, e.g., individuals with mental illness are too incompetent or unpredictable to hold responsible jobs. The second step is comprised of self-prejudice in which individuals agree with the stereotype. The third stage is self-discrimination in which individuals apply the stereotype to themselves, e.g., “I must be too incompetent, I’m not going to look for work.” The self-stigma process leads to negative emotional reactions of low self-esteem and self-efficacy and behavioral responses such as avoiding the pursuit of employment (4, 5). Self-stereotype, self-prejudice, and self-discrimination significantly interfere with individuals improving their quality of life. Persons with mental illness experience public and self-stigma while family members and other associates experience family stigma as described in the next section.

Family Stigma

The following model provides a starting point; however, further research needs to either test this model or develop new models for understanding family stigma. Family stigma contains the stereotypes of blame, shame, and contamination; public attitudes which blame family members for incompetence may conjure the onset or relapse of a family member’s mental illness. Typically, blame is attributed to poor parenting skills which led to the child’s mental illness. Within the medical field, biological and genetic models have replaced the notion that bad parenting causes mental illness; however, the general public still attributes poor parenting as a cause of mental illness. In turn, family members may experience shame for being blamed for the mental illness. This shame may lead to family members avoiding contact with neighbors and friends. Contamination describes how close association with the stigmatized person might lead to diminished worth. For example, children may be perceived as being contaminated by their parent’s mental illness. The family stigma process negatively impacts individuals in numerous ways. Family members may avoid social situations, spend energy and resources on hiding the secret, and experience discrimination within employment and/or housing situations. Providing psychiatrists with skills to identify and address the impact of blame, shame, and contamination on family members and individuals with mental illness should be included as a training objective.

There has been limited exploration into family stigma. Future research may explore the breadth and depth of the problem and identify interventions that effectively reduce family stigma. The following family stigma research lacks a cohesive and comprehensive model and the studies typically explore perceptions of family members. Researchers explored whether family members experienced discrimination similar to people with mental illness. Studies demonstrated that between a quarter and a half of family members believe they should hide their relationship with a family member with mental illness in order to avoid bringing shame to the family (6–12). Three large studies reported about a fifth to a third of family members reported that their relative with mental illness caused strained and distant relationships with extended family members and friends (11–14). Additional research found 10% of a sample reported occasional avoidance by a few people (7). Findings demonstrated that between 20% and 30% of family members reported lower self-esteem because they have a relative with mental illness (11, 12, 15). Two studies explored variance between the family role and perceived avoidance; when compared to parents, spouses reported twice as much perceived avoidance (7, 13). Research also indicated that parents living with family members with mental illness reported more perceived avoidance than parents not living with family members with mental illness (7, 13). One study with 178 family members found that 25% worried other people might blame them for the relative’s mental illness (11). Additional research showed that family members with higher education were more likely to report perceived avoidance (7, 13).

Perspectives of the Public

Findings from a nationally representative study on public perceptions of family stigma indicated that family roles predicted stigma (16, 17). Parents were blamed for attributing the start of mental illness; they were also blamed for not helping the relative with mental illness adhere to recommended interventions. Furthermore, this nationally representative study found that when the general public blames family members for the relative’s mental illness, the public decreases its pity and in turn withholds help for family members (16, 17). Current research indicates that pub-
lic perceptions of family stigma negatively impacts family members, which in turn, negatively impacts their relatives with mental illness.

**Eliminating Family Stigma**

Researchers and advocates have jointly developed interventions that are effective in diminishing the stigma experienced by people with mental illness or by family members. These strategies may also be useful for guiding psychiatric trainees away from stigmatizing attitudes toward more empowering expectations. Psychiatrists may teach trainees some of the ways to incorporate addressing stigma into treatment plans. Psychiatrists may also incorporate strategies into treatment plans for family members to deal with stigma. Strategies may include family members developing an awareness of stigma, identifying coping techniques, finding safe and supportive environments to explore experiences with stigma, participating in antistigma programs, developing an awareness of the impact of stigma, and providing opportunities to practice coping skills. Moreover, psychiatrists may take an active role in setting up and providing antistigma interventions. These interventions are reviewed in terms of public versus self-stigma.

**Changing Public Stigma**

Research has identified three approaches to erasing public stigma: protest, education, and contact (3). Protest is a moral appeal for people to stop stigma; people should suppress stereotypes about mental illness. Protest research has shown, however, that thought suppression can actually lead to a rebound effect (18–20). Specifically, thought suppression includes telling people to avoid thinking negative thoughts about individuals with mental illness. However, the public may respond with anger by being told what to think. In turn, they endorse the opposite of the protest message. Overall, research indicates that people receiving a protest message are more likely to endorse a stereotype about a stigmatized group.

Education entails challenging myths about mental illness with facts. Education is especially appealing because a standardized curriculum can be designed and exported to schools and other educational venues across the country relatively quickly. Research on education is not always positive, however. Research suggests that education can lead to short term improvements in prejudice but that these improvements return to baseline soon after the education program ends (21). Moreover, participation in education programs has not been shown to influence discriminatory behaviors.

Contact involves fostering interactions between a person with mental illness and the public. Contact is most successful when the person with mental illness and the public are operating on similar planes (21). Neither group is dominant over the other. Research has shown that single sessions of contact change prejudice and diminish discrimination. These positive effects maintain over time—one study showed improved attitudes 1 week later (22).

**Targeting Stigma Change**

Stigma change is most effective when stigma change programs target specific power groups—people whose acknowledged authority yields some control over individuals with mental illness. These targets include landlords and employers who can prevent people from obtaining fundamental life goals (23). Police officers are often called into situations where they must make decisions about people with mental illness in multiple venues: as victim, perpetrator, or witness (24). The officer needs to judge whether the person with mental illness is credible. Health care providers are also important targets. People with mental illness are frequently redirected from state-of-the-art health care to less quality services (25).

**Changing Self-Stigma**

Several approaches may raise the diminished self-esteem and self-efficacy that result from self-stigma. Some researchers have framed self-stigma as self-statements that lead to depression, anxiety, or anger (26). As a result, they have proposed cognitive restructuring as a way to control the cognitive aspect of self-stigma. Self-esteem can replace self-stigma through the judicious use of self-talk.

Central to controlling self-stigma is promoting personal empowerment (27), participating in activities that promote a person’s sense of agency, and goal directedness. Often, this kind of effort requires disclosure of one’s mental illness (28). Disclosure is not limited to a categorical yes-no decision; people can decide to come out “strategically.” They might identify individual coworkers, neighbors, or churchgoers who seem especially open-minded on general issues related to health or specific issues regarding mental health. A complex decision like this is clearly at the discretion of the individual facing the results of this decision. An alternative approach is participating in consumer advocacy and mutual help groups. The support and positive identity provided by these groups counters the negative self-statements that fundamentally form self-stigma.
Family Stigma within Psychiatry Training

Psychiatry training programs may find it useful to incorporate family stigma and stigma interventions into the curriculum. Training programs may include advocacy for family members and provide opportunities for trainees to interact with family members. This contact may lead to a deeper understanding of the problems faced by families. When trainees provide stigma interventions, they need to teach skills on accessing resources (support groups, family therapy) for families to deal with stigma.

Research on family stigma interventions has lagged behind the development of other mental health interventions. This article presents the following strategies as a starting point for dealing with family stigma. Even though they deal with general aspects of stigma, the following material can be tailored to meet the needs of family members dealing with stigma. In order to address the impact of mental illness, The National Alliance on Mental Illness (NAMI) developed 3 programs: the Family to Family Education Program, the Provider Education Program, and the In Our Own Voice Program. Psychiatrists may find these useful when dealing with the impact of family stigma. Access to information about these programs can be found at www.nami.org.

The Family to Family Education Program is a standardized curriculum for family members who provide care for relatives with mental illness. The 12-week course is taught by family members who have received training. The course focuses on presenting knowledge about mental illness and treatments, teaching problem solving and communication skills, and providing coping skills. Over 100,000 family members from 44 states in the United States have graduated from this program. Within a study on this program, Dixon (29) demonstrated that participants reported increased empowerment and reduced displeasure and worry about relatives with mental illness.

The Provider Education Program is a 10-week course for mental health professionals. It is presented by two consumers, two Family to Family Education trainers, and one mental health professional who is either a family member or a consumer. This program utilizes five presenters to provide viewpoints from various key stake holders. Through personal stories, the course focuses on the courage needed to overcome hardships faced by consumers and family members. The course also reviews various types of mental health services. Numerous program participants reported that the course positively changed their approach toward consumers and family members.

In Our Own Voice was developed by consumers of men-
tal health services. It is a standardized 90-minute presentation for public audiences. Through the contact method, consumers utilize personal stories and interact with audiences to reduce stigma and to dispel myths about mental illness. Contact involves fostering interactions between individuals with mental illness and the public. These interactions include equal status, common goals, and no competition. Consumers complete an extensive training program and use fidelity checklists during the presentation to ensure that the standardized format is followed. The program includes five components. During the dark-days section, consumers explore the difficult moments of living with mental illness. Within the acceptance component, consumers acknowledge and share experiences of having and living with mental illness. During the treatment section, consumers explore the interventions utilized to address their mental illness. Within coping strategies, consumers present the emotional and behavioral techniques they use to deal with their mental illness. Finally, consumers discuss their successes, hopes, and dreams. Wood (30) demonstrated that program participants reported a significant decrease in stigma toward individuals with mental illness.

Conclusion

We conclude this article by highlighting three points relevant to the training goals of psychiatry. First, family stigma includes the prejudice and discrimination experienced by individuals with relatives with mental illness. They experience stigma through their association with their relatives. Research indicates this type of stigma negatively impacts family members and relatives with mental illness. Second, families assume major roles in supporting relatives with mental illness; service plans should prominently feature family members when so indicated by relatives with mental illness. Furthermore, collaborative plans should include strategies to assist family members and consumers in dealing with stigma. Third, service plans that address stigma may utilize the following programs: the Family to Family Education Program focuses on supporting family members who face family stigma; the Provider Education Program attempts to reduce stigma in mental health professionals; the program In Our Own Voice attempts to reduce public stigma through an interactive format with personal stories. Overall, psychiatrists play a crucial role in addressing the negative impact of family stigma. An interesting follow up paper might explore if current psychiatry training programs involve models or NAMI interventions to address stigma.
References