

Responding to Stigma: First-Time Caregivers of Young People With First-Episode Psychosis

Terence V. McCann, R.N., Ph.D.

Dan I. Lubman, M.B. Ch.B., Ph.D.

Eileen Clark, M.Litt., M.Soc.Sci.

Objective: This study explored how caregivers of young adults who had experienced a first episode of psychosis coped with stigma while maintaining their caregiving role. **Methods:** Qualitative interviews were undertaken with 20 caregivers in Melbourne, Australia. **Results:** Some caregivers adopted an open approach about disclosing their young person's illness. Alternatively, some were secretive about the illness, because of fears of and experiences with stigmatization if others found out. Caregivers also suggested ways to minimize the stigma that intensified their burden of care. **Conclusions:** The findings showed the kinds of roles that family members and others have in supporting caregivers. Caregivers who were secretive about their situation were particularly vulnerable to feeling burdened and needed additional support from clinicians. Caregivers need increased support to enable them to better cope with and respond to stigma. (*Psychiatric Services* 62:548–550, 2011)

Prof. McCann is with the School of Nursing and Midwifery, Victoria University, P.O. Box 14428, Melbourne, Victoria 8001, Australia (e-mail: terence.mccann@vu.edu.au). Prof. Lubman is with Turning Point Alcohol and Drug Centre, Eastern Health Clinical School, and with Monash University, Melbourne, Australia. Ms. Clark is with Clarks Clerks, Albury, New South Wales, Australia.

For relatives and caregivers of people with mental illness, stigma affects many aspects of their already burdened lives, with friends avoiding not only the person who is ill but also the person's caregivers (1). Parents also have to contend with assignment of blame from lay people and professionals seeking causes of the illness (2,3). As a consequence, relatives and caregivers internalize the stigma of mental illness, resulting in a loss of self-esteem and in attempts to conceal the illness from others (3).

Stigmatization of people with mental illness has been examined in numerous studies, but few have explored the stigmatizing experiences of caregivers of people with schizophrenia (2), and even fewer have focused on caregivers of young people with a first episode of psychosis. The aim of this qualitative study was to explore how this population of caregivers copes with stigma while maintaining their caregiving role.

Methods

Interpretative phenomenological analysis was used to inform data collection and analysis (4). The approach entailed a rigorous assessment of participants' lived experience and how they make sense of their personal and social world. It is an especially useful method if the problem is novel or underresearched, if issues are complex or indistinguishable, and if the researcher is attempting to comprehend process and change.

Ethics approval was obtained from two institutional ethics committees. A

purposive sample of 20 caregivers was recruited via case managers at Orygen Youth Health, a first-episode psychosis center in Melbourne, Australia. Inclusion criteria were being a first-time caregiver, being in the role for less than three years, and being able to communicate in conversational English. Exclusion criteria were having received specialist family interventions and having a current serious and persistent mental illness.

Semistructured, in-depth, audio-recorded interviews were conducted, each lasting approximately one hour. The types of questions asked included, for example, "What do others do, if anything, to make it difficult for you in your support-giving role?" The interviews were conducted in 2008.

Smith and Osborn's (4) method was used for the data analysis. We read and coded transcribed data, then conducted an interim transformation of codes into conceptual themes and subthemes. When preliminary themes were insufficiently grounded, an iterative process resulted in a more focused analytical ordering of themes and subthemes.

Methodological rigor was addressed in three ways: dependability, credibility, and transferability (5). Dependability was maintained by creating an audit trail to link raw data and codes with themes and subthemes. Credibility was enhanced by using a semistructured interview guide to ensure a consistent approach to interviewing and through participant verification of the content of the interviews. We present adequate raw data for the reader's appraisal of our

process and findings to determine their transferability to other caregiver contexts that concern first-episode psychosis.

Results

Most participants were female (85%, $N=17$) and parents (85%, $N=17$). Their mean \pm SD duration of involvement with Orygen was 14.5 \pm 8.9 months (range two to 35 months). The main language spoken at home was English (80%, $N=16$), then Vietnamese (5%, $N=1$), English and Tagalog (5%, $N=1$), English and Spanish (5%, $N=1$), and English and Romanian (5%, $N=1$).

Two themes in the data reflected contrasting ways that caregivers coped with stigma: being open or being secretive. A third theme, reducing stigma-related burden, encompassed caregivers' suggestions about how to minimize stigma.

In being open, some caregivers responded to the young person's illness by disclosing their situation and having contact with others. There were two subthemes to being open. The first was being open with family about the young person's illness. Although respondents reported that most family members were supportive of their role as caregivers, it did not necessarily follow that support was guaranteed or consistent. The type of support given ranged from open discussion about how to support the young person to providing emotional support and sharing responsibility for care.

The second subtheme to an open style of coping, that of being open with friends, indicated that although some caregivers were cautious initially about sharing their experience with friends, eventually they adopted an open approach about disclosing the young person's illness. Open dialogue created a situation where they felt they were being listened to, which may have enabled them to receive emotional, instrumental, and practical support. For example, one interviewee responded, "I have friends that ring me often to see how we're going and see how she's going. I haven't hidden it. I may have at first but I certainly don't now. . . . I do get a lot of phone support."

In contrast to being open, being se-

cretive and minimizing contact with others was one way that some caregivers, particularly those from culturally diverse backgrounds, coped with their situation. There were four inter-related subthemes to adopting a secretive approach. The first concerned fears of and experiences with stigma from others, including friends and neighbors, which deterred caregivers from being open about their situation and the young person's illness and from having contact with others. The second was denial and blame from others. For example, respondents' accounts indicated that stigma was evident in family members' lack of understanding and lack of support of the caregiver's situation, denial that a family member had psychosis, and blame of the caregiver for something going "wrong" with the young person.

Loss of status was a third subtheme expressed by some caregivers who had adopted a secretive style of coping with stigma. Loss of status was sometimes accompanied by feelings of embarrassment, particularly when visible and dramatic methods were used to restrain and transport the young person to a hospital. Interviewee 14 described it this way: "The hardest thing I lost was my status because of my son. . . . The next thing was really shocking for everybody to go through . . . He had to be arrested by police to go to the hospital. . . . He [our son] was terribly embarrassed by all that with all the police around the home."

Fourth was the isolation associated with stigma. Some caregivers shut themselves off from others, citing others' fears of mental illness. Isolation ultimately also heightened the caregiver's concerns about the young person.

The theme of reducing stigma-related burden captured caregivers' views about what helped to minimize the stigma that exacerbated their burden of caregiving. Respondents articulated five overlapping ways to reduce stigma-related burden of care. One way was to talk openly and listen; respondents valued supportive discourse with their families and others, such as friends and colleagues. A second way was to be accessible and provide emotional, instrumental, and

practical support. A third way to reduce the caregiver's burden was for others to increase their understanding and acceptance of the caregiver's and the young person's situation and to refrain from treating them differently. Fourth was a desire for others to be nonjudgmental and a hope that public conceptualizations of first-episode psychosis would change so that the community as a whole would also become nonjudgmental. This desire for nonjudgment was strongest in regard to those closer to the caregivers, such as friends. The fifth way to reduce stigma-related burden was to actively engage the young person at different levels, from simple casual interactions to helping him or her take steps to get back to a relatively normal life.

Discussion

Some caregivers responded to stigma and sustained their caregiving role by being open about their situation, a finding consistent with a previous study of family caregivers of adults with schizophrenia and bipolar disorder (6). This coping mechanism has benefits and drawbacks. This approach enables caregivers to build a social buffer against stigma, harness support from family, and reduce isolation, and as such, it lessens the stigma-related burden of care (6). However, in this study, openness did not always result in support from family members and friends, a finding that has also been affirmed in a study of caregivers from different cultures (7). Indeed, in some circumstances stigmatizing attitudes from others can lead to social exclusion and withdrawal, because the caregiver and the young person with first-episode psychosis are treated as one and are stigmatized (2). For young people, openness and contact with others enable them to obtain greater support and acceptance from a wider range of people (2). From a community perspective, openness and contact with young people with a first episode of psychosis can help destigmatize the illness (8).

In contrast, some caregivers responded to stigma by being secretive. It is noteworthy in this study that even though only a small proportion

of caregivers were from culturally diverse backgrounds, overall they tended to be more secretive about their circumstances than European-Australian caregivers. This is consonant with Ryder and colleagues' (9) study, in which Chinese-Canadian caregivers were more secretive about psychosis than European-Canadian caregivers. Elsewhere, the limited literature on the experiences of stigma among caregivers of people with mental illness suggests that stigma is more commonly encountered by those who are disempowered and have multiple disadvantages (10). This form of "double stigma" (11) and self-stigma (12) can result in caregivers' being secretive and concealing themselves and the young person from outsiders (3) for fear of ridicule (13), rejection, exclusion (10), loss of self-esteem, and alienation (3) and because stigma is associated with assignment of blame, feelings of shame, and stereotypical fears about mental illness and contamination (8).

There are two contrasting consequences of being secretive. On the one hand, in the short term, secrecy helps shield the caregiver and the young person from stigma and minimizes the likelihood that differences will be detected and that devaluation and exclusion will occur (10). Secrecy is somewhat understandable because of the unequal status of somatic and mental illness in the public discourse (2) and between psychotic illness and other mental illnesses, such as depression (14). On the other hand, secrecy precludes the caregiver and the young person from having contact with and receiving support from others, it reinforces their social isolation and alienation from friends and neighbors, and for caregivers in particular, it heightens their overall burden of care (1,3). Secrecy may also mean that the caregiver is more reluctant to access timely care for the young person (15).

There are three limitations to this study. Recruitment through case managers may have produced an atypical sample of engaged caregivers

with less extreme views. Most caregivers in the study were women, and this restricted the findings to this gender because women may have different experiences and respond in dissimilar ways compared with men. Finally, only four caregivers from culturally diverse backgrounds took part, which restricted the generalizability of the findings.

Conclusions

Overall, a range of competing factors influenced the way caregivers responded to perceived or experienced stigma. The respondents, especially those from culturally diverse backgrounds, were vulnerable to stigma-related burden. Funding is needed to address stigma and improve community understanding of psychosis and the crucial role that caregivers take on to support their families (8). From a mental health professional perspective, it is important to incorporate stigma awareness and reduction strategies, including advocacy, in clinicians' training as well as in caregivers' education and support programs (8). The key to enhancing caregivers' self-esteem and counteracting self-stigma is the promotion of self-empowerment (12).

Further research should include more rigorous assessments of the impact of stigma among caregivers within culturally diverse communities and intervention trials targeted at reducing stigma and its negative sequelae among caregivers of young people with a first episode of psychosis. Interventions may need to be tailored specifically to address cultural beliefs and practices.

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