Stigma in the Field of Mental Health: The Attitudes, Experiences, and Coping Mechanisms of Parents of People Who Cope with a Psychiatric Illness

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Executive Summary

Background and Introduction
The implications of a prolonged psychiatric or mental illness\(^1\) – not only for those who cope with it, but for their families – are substantial. These include physical and mental difficulties, emotional problems, financial hardship, and a loss of social support. Stigma toward the illness, toward those who cope with it, and toward their families is an additional burden.

Stigma toward families has two main sources. The first, which is not unique to psychiatric illnesses, arises from the perception of the family as an "extension" of the person with the illness. This leads to generalization of the stigma: associating the entire family with negative attitudes toward the person with the illness. The second source is typical of psychiatric illnesses and stems from the fact that, unlike the case of other illnesses, when it comes to psychiatric illnesses, families, and particularly parents, are perceived as sharing responsibility for the development of the patient's condition.

Stigma toward the families of persons who cope with a psychiatric illness amplifies the already heavy burden they face, objectively, and the emotional stress they feel from caring for their ill relative. For example, stigma may cause people who had been close to distance themselves, thereby denying the family the support they need, or even forcing them to confront blame, lack of understanding, and lack of empathy. Furthermore, social stigma may be internalized, manifesting itself among family members as self-stigmatization. Parents of persons who cope with a psychiatric illness are liable to internalize society's negative perception of them, harboring feelings of guilt and shame that may tarnish their self-image and lessen their self-esteem.

Despite evidence that stigma endangers the individual who copes with a psychiatric illness and his family, the subject has not been studied widely. Only a few studies have been conducted in the field; this is the first of its kind to have been conducted in Israel. It focuses on stigma toward a psychiatric illness from the perspective of parents of people who cope with such an illness; it is one of three studies examining stigma in mental health in Israel in an attempt to identify possible directions for intervention. The second study in the series focuses on the general population and its attitudes toward mental health care and people with a psychiatric illness, and the third study focuses on the perceptions and experiences of people being treated at public mental health care clinics. All three studies are being conducted jointly by the Ministry of Health and the Myers-JDC-Brookdale Institute, and were funded with the help of the National Institute for Health Policy and Health Services Research. The interviews for this study were conducted between June and August 2003.

\(^1\) The pre-test revealed that the use in the questionnaire of politically correct terms would likely distort the study and its findings. We therefore often used the terms "mental illness" and "mentally ill" in the questionnaire, as these terms are familiar to the public. We use the terms "psychiatric illness" and "a person with a psychiatric illness" throughout this report, except when referring to the terms used by respondents, in which case we quote their use of "mental illness" and "mentally ill."
The Study Goals
The following were this study's goals:
• To examine the experiences of parents of people with a psychiatric illness.
• To illumine the phenomenon of stigma toward the families of people who cope with a psychiatric illness, the domains in which it is expressed, and how members of the family cope with it.
• To preliminarily identify areas that are particularly troublesome for families, in order to plan interventions that may help reduce stigma, as well as to provide a basis for further study in this area.

The Study Population
Fifty-two parents participated in the study, the majority of them mothers of a son or daughter who was coping with a psychiatric illness. Most of them had been coping with the illness for a long time (12 years, on average, had elapsed since they first felt that their son or daughter had a mental problem). Almost all of the respondents were located through organizations for people who cope with a psychiatric illness and their families. It is therefore important to note that the respondents do not constitute a representative sample of all parents of people who cope with a psychiatric illness.

The Study Method
The parents were interviewed by telephone using a questionnaire that included demographic questions as well as questions about stigma, about the effect of the illness on the family's relationships (both within the family and outside it), ways of coping with stigma, feelings related to stigma, the parents' perception of discrimination against people who cope with a psychiatric illness, and their perceptions of the etiology of psychiatric illness. The questionnaire was semi-structured: It included both "closed" statements which the parents were asked to rate, according to their degree of agreement with them; and open-ended questions, in which the parents were asked to describe in greater detail the experiences and feelings they had cited in the closed questions.

Findings
Stigma toward Family Members
About two-thirds of the parents reported that they were treated normally, even when others knew that they had a son or daughter with a psychiatric illness. About two-thirds of them had not felt that neighbors or friends had distanced themselves because of the illness. These results may be seen as constituting a relatively mild display of stigma, which may indicate a certain level of acceptance by the families' social environment. These findings are in line with the finding that only a small percentage of the parents reported feeling ashamed or embarrassed when attending a social event with their ill son or daughter. Nevertheless, it is important to note that a considerable number of the respondents did experience stigma and rejection: One-third reported that the people around them (their extended family, friends, neighbors, professional staff) treated them differently, as reflected inter alia in pity, blame, fear, and embarrassment. About one-fifth of the
respondents reported that their neighbors had distanced themselves once they had learned of the illness; one-quarter reported this of people to whom they had been close in the past.

While these findings may be seen to reveal relatively mild expressions of stigma toward families, it is nevertheless possible to conceive that the prevalence of stigma is greater, but was not brought to light by this study. There are two indications of this: the parents' responses to questions about the emotional implications of stigma, and their reports of what happens to their relatives or to other families.

The parents' reports of the emotional implications of stigma raise the conjecture that displays of stigma that appeared mild in their reports of their own experiences were in fact more numerous and less mild. Thus, although one-fifth of the respondents reported that neighbors had distanced themselves and one-quarter reported that people close to them had distanced themselves, many more – about two-thirds – of the respondents reported feeling lonely and lacking someone with whom to share their distress. Similarly, while one-third of the respondents reported that people who had heard about their son's/daughter's illness treated them discriminatorily, about half of them reported feeling "different," and more than half of them reported that no one understood their problems. These reports of loneliness, alienation, and feelings of "being different" may arise not only in response to the behavior of others in society, but also may result from the families' own tendency to distance themselves from others. However, it appears that this tendency, too, is related to a large extent to sensitivity to stigma and rejection from others.

In addition, when the parents reported what happens in other families or to others in their own family, their reports of stigma and its emotional implications were more numerous. Half of the respondents had heard of hurtful treatment of other families (from a few to very many times). They also reported more expansively on the difficulties faced by other members of their family, describing their own experiences and feelings, in contrast, to a more limited extent. There may be several reasons for this: First, the respondents tended at times to make light of the discrimination and rejection they experienced, perhaps in order to dull their feelings of hurt and insult. Second, this may reflect the difficulty people have reporting their negative experiences, compared to the greater ease with which they can speak about others in a similar situation. Third, it is possible that the gap between the respondents' self-reports and their reports about others in their environment reflects real differences arising from the unique characteristics of the parents who participated in the study.

As noted, most of these parents have been coping with their son's or daughter's illness for quite some time. We may assume that prolonged coping has influenced their adaptation to life with the illness, including the stigma that entails. The parents' description of the changes in and outside their family following the onset of the illness may reflect a process, which progresses from denial and frustration to acceptance, coping, and balance. In addition, it is possible that, over the years, these parents have succeeded, through their involvement in groups for the families of people who cope with psychiatric illness, in creating an accepting, supportive environment for themselves,
one in which stigma would also be less pronounced. Indeed, a large percentage of the respondents reported distancing themselves from people who had rejected or been intolerant of them.

The unique characteristics of the respondents in this study undoubtedly affected not only their experiences, but also the feelings aroused by the illness. In particular, they noted feelings of loss, sadness, and acceptance of the illness. In contrast, they cited confusion, embarrassment, shame, and difficulty accepting the illness as feelings of the past, or of other members of the family.

Additional evidence of stigma may be registered in the parents' feelings of guilt. Many of them noted that it was not only others who made them feel responsible for their son's or daughter's illness, but also that they themselves felt responsible for it. We may surmise that internalization of stigma in this way adds to the parents' emotional burden, and diminishes their sense of self-worth.

Stigma also affects the relationships of family members – both with each other, and with others outside the family. This influence may be direct – as reflected in the distancing of relatives and close friends – or indirect – for example as manifest in feelings of guilt, which may lead parents to devote their time to the care of their ill son or daughter at the expense of other members of the family. When we examined the effect of the illness on family relationships, we found that in many instances the family dynamic had been upset and undergone dramatic changes. At the same time, the nature of these changes was individual, and ranged from a strengthening of existing bonds and the formation of new ones, through concealment of the illness or no change in the relationship, to detachment and the end of others. This range of responses characterized both relationships within the family and with the broader social environment.

In examining relationships outside the family, it is interesting to note that alongside the fact that friends dissociated themselves, in many cases it was the respondents who chose to distance themselves, for a variety of reasons: the situation of their ill son or daughter left them with little free time; they wished to avoid dealing with the reactions of others and with the shame; they sensed that it would be too difficult to explain what they were going through and that others would not understand; or they thought others would not want to hear about the issue or would not be able to cope with it. At the same time, however, respondents often cited having formed new, stronger relationships with others who, like them, had a relative who was coping with a psychiatric illness. Respondents also reported that their sons and daughters sometimes formed relationships with others in their treatment framework, though these were often accompanied by ambivalence. At times, the parents reported taking it upon themselves to maintain and strengthen relationships on behalf of their son or daughter who was struggling with illness. In discussing the feelings of other family members, particularly the siblings of the ill son or daughter, the respondents often brought up the fear that the illness would ruin their social life; in many cases, they reported that siblings preferred to conceal it, for example by not inviting friends to their home.
Changes also took place in relationships within the family; this was described as an ongoing, dynamic and multi-dimensional process. For example, the parents' relationship with their ill son or daughter was marked by a transition to greater dependence, which required the parents' daily care and concern. The respondents expressed the feelings aroused by this process: anger, guilt, a desire for distance, frustration, loss and bereavement, and acceptance. The parents frequently described changes that had occurred among members of the entire family. In some cases, respondents noted that coping with the illness strengthened their family relationships, while in other cases it increased existing tensions, gave rise to anger and friction, and led family members to grow distant from one another – sometimes to the point of the disintegration of the relationship. Parents also cited a tendency to invest extensive resources in the care of their ill child – a tendency that came at the expense of their relationship with their spouse and their other children.

**Ways of Coping with Stigma**

The professional literature describes various mechanisms of coping with stigma, which are meant to mitigate its deleterious effects. The families interviewed were asked about three such mechanisms: concealment, education, and avoidance.

**Concealment** is characterized by an effort to hide the illness or information about it. The findings of this study indicated that, among the respondents, the extent of concealment was relatively modest. However, the respondents reported a higher rate of concealment by other members of the family, most of whom were not members of support organizations. In addition, while the closed questions addressed concealment in a broad context, the open-ended questions yielded responses that referred to more focused concealment (e.g., in certain places or with certain people, of whom the fear of rejection was particularly great). We may assume that these respondents – most of whom, as noted, were active in support groups for families of people coping with a psychiatric illness, and who had been dealing with a son or daughter with such an illness for some time – took fewer pains to conceal the illness. It is possible that efforts to conceal the psychiatric illness would be more prevalent in families that had only recently begun coping with it, or whose members were not active in support groups.

The second coping mechanism we examined – **education** – typically involves an attempt to teach others about mental health care and emotional problems, or to protest stigmatization. Many of the respondents in the current study used this mechanism. This reflects the important role they ascribed education in changing people's attitudes toward mental illness and toward their relative who was coping with a mental illness; it also thereby suggests indirectly that they perceive the public as having negative, discriminatory attitudes. However, it should be noted that the broad use of this method by the respondents apparently does not reflect its use among all families of persons with a psychiatric illness, as this is an active and sometimes even militant approach, which may require relinquishing privacy and discretion.
The third coping mechanism we examined – avoidance – has two facets. On one hand, it involves avoiding situations or people who are perceived as tending toward stigmatization; on the other hand, it is characterized by a preference for the company of those who are less likely to stigmatize. Responses to the direct questions about this indicated a moderate level of avoidance of people or situations in which there was a fear of stigma. At the same time, when asked about this indirectly, many parents indicated that they had distanced themselves from situations or people whom they feared would insult them; many of them also reported feelings of loneliness. In addition, many of the respondents who, as noted, participated or were activists in various organizations, reported preferring the company of people in a similar situation, from whom they had little fear of rejection. It appears that the preference for such relationships, which might compensate for the loss of others, was possible because the respondents were around other people in the same situation. Other family members who are not active in such organizations and who consequently may not be exposed to as many people in a similar situation might find it difficult to compensate for the loss of some social relationships by forming others. This in turn might diminish their social network, leading to even greater loneliness than that found in this study.

In addition to the mechanisms described in the literature, we examined a mechanism likely to facilitate coping with stigma, which involves expressing positive attitudes and empathy ("positive distinctiveness") toward people who cope with a mental illness and their families. Emphasis on the unique and positive characteristics of these people and their families can counteract negative stigma and block some of its destructive effects, especially those related to sense of self-esteem. This coping mechanism is related to social identity theory (Tajfel, 1982; Turner, 1987), according to which an individual's self-esteem is based in part on his belonging to various social groups and categories. The tendency to positively evaluate the group to which one belongs (known as ingroup bias or ingroup favoritism) contributes to a more positive sense of self-esteem. Although this mechanism may limit the harm to self-esteem, it is in itself limited (Ellemers, Van-Rijswijk, Roefs and Simons, 1997). In this study, we found that respondents emphasized the emotional, empathetic aspect of those coping with mental illness and their family members.

Directions for Action
The material gathered in this study may serve as the basis for a number of directions for action regarding the families' coping with the illness of one of their members, in general, and with the stigma this arouses, in particular.

1. The system of care could provide families with information – including information about the etiology of the illness, its course, and other relevant issues – beginning at the earliest stages of coping with the psychiatric illness. Respondents reported a lack of information for families, which was particularly acute during their initial attempts to cope with the illness, before they had joined various organizations – which also provide information. This is doubly important, because information can help a family adapt to its new situation while preventing some of the negative implications of stigmatization and self-stigmatization (e.g., by reducing feelings of guilt and responsibility).
2. **Encouraging family members to seek organizations and groups** which, in addition to providing relevant information, offer an extremely important opportunity to meet with other parents in a similar situation. These groups give families mutual support, help them develop skills and strengths, reduce their feelings of shame and of being misunderstood, and foster an accepting and understanding social environment. These frameworks are important especially when parents find themselves without sufficient social and emotional support – a situation that can reduce their mental well-being and impair their ability to cope with their son's or daughter's illness. The respondents' positive experiences in these groups indicate the importance of referring parents to them, already in the early stages of coping with their child's illness, so that they may benefit from them in progressing through the different stages of coping.

3. **In addition to encouraging parents to meet in groups, it may be helpful to develop and enhance a network of individual support and guidance to be provided by other parents.** In the earliest stages, the confusion of coping with a psychiatric illness is accompanied by embarrassment, shame, and a desire to conceal the illness, all of which can severely limit a parent's ability to benefit from support groups and organizations of the type described above. It is therefore important to try and formulate interim solutions, which will facilitate a gradual transition to coping and be suited to different coping styles and different levels of disorientation and willingness for exposure. For example, it might be possible to develop a series of meetings that are more personal in nature, at which parents who are new to coping with a psychiatric illness are helped by parents who are at a more advanced stage of coping with the illness. Later, they, too, may consider joining a group like those currently in existence.

4. **Treatment of and attention to parents' sense of responsibility for the illness, and their feelings of guilt.** One of the issues that must be dealt with in group or individual meetings is the blame that others place on parents for their son's or daughter's illness. The parents in this study reported encountering blame from various sources, among them neighbors, friends and relatives, and even professionals or the son or daughter who was coping with the illness. The immense potential for harm embedded in these accusations makes it essential to work through them in conversations with other parents, in an effort to share and thereby lessen the hurt. At the same time, the results of this study highlight the importance of assessing the attitudes of mental health professionals toward people who cope with a mental illness and their families – especially the degree to which they, too, tend to ascribe parents responsibility for their son's or daughter's illness. This may contribute to developing interventions to change attitudes and improve the communication between professionals and parents, thereby ameliorating their situation.

Blame and other negative attitudes toward parents are liable to filter down to them, and manifest themselves in feelings of culpability for their son's or daughter's illness. Such feelings were reported by half of the parents interviewed; it may be assumed that they add to
their emotional burden and continue to harm them in myriad ways, for example by increasing tension within the family and upsetting the family dynamic. Serious treatment of these feelings, alongside the provision of relevant information, can improve parents' feelings and make it easier for them to cope with their complex situation.

5. **Family counseling and support groups for children, siblings, and spouses** are also called for. Parents' groups can help address the difficulties within families that accompany the illness of a son or daughter. Changes in relationships within the family that result from the illness may dismantle family unity and harmony, further complicating coping. There is thus a need for information and family consultation, as well as for support groups for other members of the family, including children, siblings and spouses – frameworks whose absence is notable at present.

6. **It may be helpful to emphasize the positive characteristics of people who cope with a psychiatric illness and their families.** Support groups may do this. As can be seen in the study, many parents believe that empathy and sensitivity are characteristic of those who cope with a psychiatric illness and of their families; emphasizing these traits may help deflect some of the negative effects of stigma while reinforcing feelings of self-worth. In this context, we would note that some of the respondents reported that their coping with and acceptance of their ill son or daughter, and of themselves, has had a positive effect on them, as well as on their social environment.
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