Barriers to Family Care in Psychiatric Settings
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Purpose: To identify barriers to family care in psychiatric settings and to describe family and provider perspectives about what constitutes effective family care.

Design and Methods: A qualitative exploratory approach with focus groups. Seventy-eight people participated in 11 focus groups conducted with families, patients, and health professionals.

Findings: Families identified poor quality care, conflict with health professionals about treatment, and lack of a role for families in the treatment. African American families also identified isolation of their communities from the mental health care system. Adolescents emphasized their role as caregivers and their needs for support. Health professionals conveyed concerns about system-based barriers, professional practice-based barriers, and family-based barriers to care. Patients stated the need for their families to be better educated about mental illness.

Conclusions: The lack of family care in psychiatric settings is a multifaceted problem. Current health policies do not show endorsement of a family care approach. Responses from families and health professionals indicated conflicting opinions about content of family care. Health professionals reported they often lacked training and resources to deal with complex family issues. Families believed that lengthy and intensive interventions were neither necessary nor desired to address their concerns. Family care can be improved by focusing on building rapport and communicating problems and concerns between families and health professionals.

Families of people with serious mental illnesses have major responsibility for providing care and support to their ill relatives over extended time periods, in many cases years and decades. Many of these families experience substantial levels of stress and burden that adversely affect the health of individual members, as well as the health of the family unit (Doornbos, 2002). Family stress and burden related to mental illness are widespread. An estimated one-third to two-thirds of all mentally ill patients live with family members (Goldman, 1980; Intagliata, Willer, & Egri, 1986). Many of the remainder receive regular and active assistance from their families. Many families have repeatedly stated that they need, but do not get, information about the relative’s illness and treatment, support for their own anxieties and depressed mood, and assistance with managing illness symptoms (Rose, 1997; 1998). These problems are widespread, with reports of family stress and burden receiving international attention (Magliano et al., 2000; Ostman, Hansson, & Andersson, 2000).

Investigators of a patient outcomes research team (PORT) study (Lehman et al., 1998) recommended that families of psychiatric patients receive psychosocial interventions to help them deal with the stress. Further, these investigators strongly recommended that such intervention be offered to all families, not just to those identified as having “expressed emotion” or otherwise designated as being dysfunctional. Established and funded by the Agency for Health Care Policy and Research and the National Institute of Mental Health in the United States, the PORT team made recommendations for treatment approaches of people with schizophrenia based on sound scientific evidence. Subsequent follow-up analyses, however, indicated that fewer than half of affected families received such interventions (Lehman et al., 1998;
Dixon et al., 1999). The reasons for this lack of family intervention in psychiatric settings are unclear. Few investigators have studied actual or potential barriers to providing family care, although one study indicated that values, beliefs, and experiences of health care providers might be important (Lenert, Ziegler, Lee, Sommi, & Mahmoud, 2000). Professional practice constraints might also be factors, but little attention has been focused on these issues. Development of cost-effective and clinically efficacious family interventions is hampered by this lack of understanding of perceived care constraints (Budd & Hughes, 1997).

The current state of the art in family care consists of a predominant focus on family as context for treating patients’ illnesses, and families are contacted to provide information about patients. Where family care programs exist, they are seriously hampered by a lack of attention to family outcomes. For example, few programs exist to address the need for family roles in care continuity. Moreover, families’ needs related to stress management and quality of life have not been systematically addressed in these programs. Lack of understanding of ethnic minority and low-income families’ needs is a particular concern and lack of attention to personal and historical relationships within families is a serious gap in family-centered care.

The study reported here was designed to increase understanding of ways to foster family care in inpatient and outpatient psychiatric settings. The purpose of the study was to identify barriers to implementing family care as perceived by staff, families, and patients, as well as to identify family and provider perspectives about what constituted effective family care.

**Background**

The PORT investigators were concerned with intensive family psychoeducational interventions of 9 months or more, consisting of education, support, problem-solving training, and crisis intervention, but the broader term “family care” has been generally used in the literature to refer to any one or a combination of these factors. Most commonly, authors have referred to family care as a response to the general need for basic illness education or support for illness-related stress. The latter definition of family care was used in this study.

Ample evidence indicates that families’ needs for professional support are intensified because of their experiences of stigma associated with mental illness. Stigma undermines support that families might otherwise expect from their social and familial networks (Veltman, Cameron, & Stewart, 2002). Families avoid sharing concerns with friends and coworkers because they fear they will be misunderstood and their privacy will be violated (Chaftz & Barnes, 1989; Rose, 1997). Many families do not have family-based support because of conflicting beliefs about how to deal with the patient (Rose, 1997). Professional support has not filled the gap. Many community mental health programs and inpatient facilities include families during initial patient contact only, and follow-up care for families is usually for those with greatest need. In spite of acknowledgment of the importance of social support to this population, and awareness that usual sources of support are unavailable, investigators have documented that families do not receive adequate support from professionals (Biegal, Song, & Milligan, 1995; Rose, 1998a).

Surveys and descriptive studies of families’ needs have had fairly uniform results. Investigators have identified the following issues: including the family but not the patient or vice versa; inadequate understanding of ethnic minority and low-income families; lack of attention to historical context of family relationships as well as to the age and gender of all family members (Veltman et al., 2002); poor quality of interactions with health professionals (Muhlbaier, 2002); and poor access to care (Rose, 1998b). No studies were found that elicited perspectives of health care providers or patients on these issues.

Psychoeducational intervention programs, such as the types identified by the PORT investigators, have been studied extensively. Typically they are based on the concept of the family’s level of “Expressed Emotion” (EE) (Abramowitz & Coursey, 1989; Solomon, Draine, Mannion, & Meisel, 1996; Szmukler, Herrman, Colusa, Benson, & Bloch, 1996), and results have indicated that reducing EE in families can positively affect patients’ outcomes. Although dates are convincing that these psychoeducational family interventions are effective in reducing patients’ relapse, currently no such intervention has been adopted to directly address needs of the families themselves. Data on the barriers to any type of family care are limited, particularly from the perspectives of the health professionals who deliver care, families who are supposed to receive it, or the patients who should ultimately benefit from it.

**Methods**

The study was based on exploratory qualitative design, with focus-group methods (Morgan, 1998) used to collect the data. The group discussions were semi-structured, with questions derived from previous studies by the investigators and from the work of others in the field of family caregiving and mental illness.

**Procedure**

Notices about the study were posted in psychiatric treatment facilities and were mailed to leaders of community-based family support groups and to a local urban church in a major metropolitan area in the mid-Atlantic United States. Separate groups were conducted for health professionals, families, patients, and adolescents to encourage free expression of opinions (Morgan, 1998). A total of 78 persons participated in 11 groups. Eight groups were led by a moderator and a comoderator. Three groups with 3 participants each were led by one moderator.
The following focus groups were conducted: two general family groups by setting (one urban, one suburban), two groups of patients in community treatment programs, three groups of health professionals by setting (two inpatient, one outpatient), two groups of African American families, one group of adolescents, and one group of family members who attend support groups. Informed consent was obtained from all participants. Support-group families primarily attended programs offered by the National Alliance for the Mentally Ill (NAMI). Most of the African American families were recruited from a local church.

Data Collection

Group sessions were audiotape-recorded. Tabletop microphones were placed to ensure that all comments were recorded clearly and accurately. Tapes were immediately labeled and stored for subsequent verbatim transcription. The group discussions were focused on the following topics: the need for family care, including helping families deal with feelings of helplessness, anger, guilt, and loss; barriers to provision of family care; issues related to access and options for family care; and possible targets for improving family care, including communication and collaboration between families and professionals.

Demographic data were collected. Health professionals (HPs) were asked years of experience, educational level, patients’ usual diagnoses, and practice setting. Families and patients were asked number of years patient had been ill and diagnosis. All participants were asked about age, gender, occupation, and annual income.

The primary moderator led the discussion, introduced new topics, asked for clarification, and so on. The comoderator took notes of group process and major topics discussed. The moderator emphasized that all responses were welcomed and none was considered right or wrong. All topics were introduced to all groups, but the order and amount of time spent on each topic varied by group. Dialogue among group members was encouraged and relatively quiet members were periodically asked if they had anything to share.

Questions initially were broad and open-ended (“Tell me about an experience you have had”) and became more focused (“What kinds of questions did you have?”). A flip chart was used at times in the session to make lists of responses and to validate for participants that their opinions mattered. The moderator and comoderator met following each group session to discuss content and process and to make notes of initial impressions of themes discussed in the group. The groups lasted from 60 to 90 minutes.

Data Analysis

A sequential approach to the qualitative data analysis was used. First, transcripts were read with a focus on answering the research questions of the study and specific interview questions among all groups. Transcripts were analyzed for participant responses to questions about when and for whom family intervention should be used, questions about barriers to family care, and discussions of what types of families needed what types of care. The group observer’s process notes were also reviewed in the initial analysis.

Second, a more in-depth analysis procedure was conducted to identify critical issues for participants not identified in the first reading of the transcripts. This second iteration of the analysis consisted of multiple rereadings of the transcripts to identify and code key phrases, sentences, or paragraphs, using the participants’ own words as code labels. Passages coded similarly among transcripts were then grouped into larger, more interpretive categories. Comparisons were also made among family groups and between families and HPs.

Results of the two stages of the analysis were integrated, thus adding the depth of understanding to proceed beyond a description of the barriers to interpretations of the experiences of the barriers. For example, in the African American groups, content analysis indicated that they lacked basic information about mental illness. The thematic analysis helped us to see the importance of the relationship of the health care system to the African American community and the neglect that many African Americans felt concerning the system. Similarly, the issue of patient violence was not mentioned as a barrier per se, but it was identified in the thematic analysis as an important aspect of the family experience that indicated the need for intervention.

Trustworthiness of the findings was addressed in the following ways. First, the three members of the research team engaged in multiple readings of the transcripts to become familiar with the overall content and themes of the groups. The notes of the comoderator were considered here, particularly as they related to group process and intensity of the statements made. Second, coding of passages within a group was discussed among the coders until consensus was reached. Salient codes were chosen through a similar consensus procedure. Finally, these codes were linked to specific passages by using the computer program NUDIST that allowed for further scrutiny and availability of an audit trail (Morrison-Beedy, Cote-Arsenault, & Feinstein, 2001). Following the tenets of focus-group methods and the qualitative paradigm on which it is based (Morgan, 1998; Sim, 1998), no attempt was made to calculate frequencies of responses. Rather, the analysis was guided by the principle that salient themes were identified in the data and that all comments were of equal interest depending upon their context and place in the broader discussion (Knodel, 1993).

Findings

The focus groups ranged from 3 to 13 persons (mean = 7). Table 1 shows selected characteristics of the 78 participants by group. Health professionals had from 1 to more than 30 years of experience. Most HPs were nurses. One physician and one psychologist participated in the outpatient HP group. Although parents were the most frequent participants
Table 1. Description of Groups

<table>
<thead>
<tr>
<th>Group</th>
<th>Type</th>
<th>Participants</th>
<th>Age; ethnicity; sex</th>
<th>Recruitment site</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Health professionals</td>
<td>n = 7</td>
<td>Age range: 24-42, 2 RNs, 3 OTs, 1 SWs, 1 secretary</td>
<td>Black = 1; White = 6, male = 1; female = 6</td>
<td>General psychiatric inpatient treatment unit</td>
</tr>
<tr>
<td>2 Patients</td>
<td>n = 8</td>
<td>Age range: 31-55, schizophrenia; bipolar, male = 1; female = 5</td>
<td>Black = 4; White = 4, male = 5; female = 3</td>
<td>Community rehab program</td>
</tr>
<tr>
<td>3 Patients</td>
<td>n = 11</td>
<td>Age range: 27-56, schizophrenia; bipolar, male = 4; female = 7</td>
<td>Black = 5; White = 6, male = 4; female = 7</td>
<td>Community rehab program</td>
</tr>
<tr>
<td>4 Health professionals</td>
<td>n = 5</td>
<td>Age range: 28-41, 4 RNs, 1 counselor</td>
<td>Black = 1; White = 4, male = 2; female = 3</td>
<td>General psychiatric inpatient treatment unit</td>
</tr>
<tr>
<td>5 Black families</td>
<td>n = 3</td>
<td>Ages: 34, 48, 59, 1 parent, 1 sibling, 1 adult child</td>
<td>Black = 3; White = 0, male = 0; female = 3</td>
<td>Community</td>
</tr>
<tr>
<td>6 Suburban families</td>
<td>n = 3</td>
<td>Ages: 34, 35, 49, 1 sibling, 1 adult child</td>
<td>Black = 0; White = 3, male = 0; female = 3</td>
<td>Suburban psychiatric inpatient treatment unit</td>
</tr>
<tr>
<td>7 Health professionals</td>
<td>n = 13</td>
<td>Ages: 31-61, 4 RNs, 4 SWs, 3 counselors, 1 psychologist, 1 MD</td>
<td>Black = 6; White = 7, male = 2; female = 11</td>
<td>Outpatient hosp. (day) treatment</td>
</tr>
<tr>
<td>8 Black families</td>
<td>n = 12</td>
<td>Age range: 32-67, 3 parents, 4 spouses, 1 grandmother, 2 siblings, 1 cousin, 1 adult child</td>
<td>Black = 12; White = 0, male = 6; female = 6</td>
<td>Community (recruited from a local church)</td>
</tr>
<tr>
<td>9 Families, general</td>
<td>n = 5</td>
<td>Age range: 45-70, 2 parents, 1 spouse, 1 sibling, 1 adult child</td>
<td>Black = 2; White = 3, male = 0; female = 5</td>
<td>Community</td>
</tr>
<tr>
<td>10 Support group families</td>
<td>n = 8</td>
<td>Age range: 43-78, all parents</td>
<td>Black = 4; White = 2, male = 3; female = 5</td>
<td>NAMI group members</td>
</tr>
<tr>
<td>11 Adolescents</td>
<td>n = 3</td>
<td>Ages: 13, 14, 15, 1 sister, 1 daughter, 1 granddaughter</td>
<td>White = 2; Black = 1, male = 0; female = 3</td>
<td>Community</td>
</tr>
</tbody>
</table>

in the family groups—spouses, siblings, adult children, one cousin, and one grandmother also participated. Participants in the two patients’ focus groups (n = 19) were receiving outpatient care in community settings. More than half of the family participants were African American (n = 40); 34 participants were identified as Caucasian, and 2 as other. More women (n = 55) than men (n = 24) participated.

**HP Perspective of Barriers to Family Intervention**

HPs identified aspects of the health care system and professional practice models as major barriers to providing family care. These providers intensely discussed how the health care system hampered effective care through lack of support and poor coordination of services (Table 2). In addition, HPs acknowledged that lack of skill and experience were constraints to family care. HPs identified family-based constraints, but to a lesser extent than did other groups. They also identified the effects of inadequate staffing on providing family care.

The system does not support it. HPs working in inpatient settings identified the system-based barriers as a lack of resources (inadequate staffing, outdated educational materials), shorter lengths of stay, and a focus on crisis care. Many of the inpatient HPs admitted that all they could do was “deal with the crisis, stabilize the patient, and send him home.” Rather than merely being a constraint to family care, many HPs reported that the organizational structure impeded or obstructed delivery of such care. Examples of these impediments were lack of reward or recognition for family work, few opportunities for skill development, issues of patient confidentiality, and lack of a physical space in which to
Table 2. Mental Health System Barriers to Providing Family Interventions

<table>
<thead>
<tr>
<th>Health care providers</th>
<th>Family and patient participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of system support</td>
<td>HPs fail to acknowledge family caregiver experiences</td>
</tr>
<tr>
<td>• focus on crisis stabilization; shorter LOS</td>
<td>• families ignored in hallways; phone calls not returned</td>
</tr>
<tr>
<td>• inadequate staffing</td>
<td>• HPs fail to validate family perspectives on escalating behaviors and symptoms leading to re-hospitalization</td>
</tr>
<tr>
<td>• patient confidentiality constraints</td>
<td>• HPs believe patient's story; discredit family input</td>
</tr>
<tr>
<td>• outdated printed materials</td>
<td>• caregivers denied valuable information because of patient confidentiality rules; trust of HPs undermined</td>
</tr>
<tr>
<td>Services are uncoordinated</td>
<td>Services lack continuity and integration across settings</td>
</tr>
<tr>
<td>• lack of continuity from inpatient to outpatient care</td>
<td>• frequent turnover of therapists</td>
</tr>
<tr>
<td>• poor communication between care settings</td>
<td>• lack of 24 hr coverage for emergencies</td>
</tr>
<tr>
<td>Professional practice does not require family supports</td>
<td>• inadequate funding for community services</td>
</tr>
<tr>
<td>• no accountability for providing family intervention</td>
<td>Overemphasis on medical—rather than psychiatric—conditions in hospitals</td>
</tr>
<tr>
<td>• not within scope of practice for inpatient HPs</td>
<td>• shorter length of stay for inpatient care; premature discharges</td>
</tr>
<tr>
<td>HPs lack materials, skills, and experience</td>
<td>• HPs lack skills and experience. Clinicians who had interest in working with families, despite the lack of a mandate to do so, felt frustrated. They described not knowing how to help, or feeling that their efforts to help families were ineffective. A nurse explained, “You’re trying to find out what their experience is and they’ll . . . say, ‘Yeah, I’ve heard that before; I’ve heard that before’; and you feel as though you really are not helping.”</td>
</tr>
<tr>
<td>• unaware of effective intervention techniques</td>
<td>Less experienced HPs acknowledged that their frustration was fueled in part by the overwhelming effect of what one HP called the “enormity of what people need.” One nurse was frustrated that all she could do was make a referral. She said:</td>
</tr>
<tr>
<td>• families’ complex needs are overwhelming</td>
<td>We recently had a young kid who came in whose mother was so overwhelmed by his behavior. . . . We have a family meeting. . . . All we have to offer them is outpatient care. . . . we want to be able to offer a lot more and it’s frustrating . . . to see what the enormity of what people need.</td>
</tr>
</tbody>
</table>

meet families. HPs had to work around these impediments if they wanted to intervene with families.

“The bottom line: No time.” Many of the HPs underscored the effect of constrained time and resources on their ability to provide the necessary care. They talked about the “bottom line” that in a climate of limited resources and inadequate staffing, addressing patients’ needs, symptoms, and wishes took precedence over family intervention. One nurse explained:

I think that time is always an issue but overall we are aware that the initial practice is one on one; we are working with the patient. Unless the family becomes involved or is involved initially we don’t make that initiative because of time constraints. . . . We don’t always have the time to develop that or to seek that out.

Unless families made a concerted effort to contact staff, the interaction tended to be limited.

Services are not coordinated. Disruption of care between inpatient and outpatient settings was frequently mentioned as a barrier to family care. HPs did not agree about the reason for the lack of continuity of care. Although HPs said they wanted to know what occurred after discharge, some thought financial incentives to follow up were lacking, or that accountability was lacking. HPs in both outpatient sites and inpatient sites acknowledged poor integration and poor communication between the two sites. As a result, family concerns were not always adequately addressed. Inpatient HPs described situations in which they often wondered what happened to patients and families after referrals were made to outpatient clinics or therapists.

Professional practice does not mandate it. Many inpatient-based HPs said that formal family intervention was outside the accepted scope of their practice. They perceived it as the responsibility of the outpatient or community-based HPs. Family work was viewed as labor intensive, and “not practical.” One HP described it as a “luxury” that many facilities could not afford. Individual HPs had to decide how and when to intervene. One HP noted that professionals were not held accountable for family intervention and suggested that HPs who worked with families did so because they enjoyed it and believed it was important, not because they were expected to do so. Others agreed with her that, “Some people teach more than others. That’s just the way it is.”

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We recently had a young kid who came in whose mother was so overwhelmed by his behavior. . . . We have a family meeting. . . . All we have to offer them is outpatient care. . . . we want to be able to offer a lot more and it’s frustrating . . . to see what the enormity of what people need.

Families resist involvement. HPs said that some family members could not be drawn into an intervention because of the family’s own issues. They described these families as actively resisting efforts to intervene with them. These participants expressed frustration and puzzlement. One nurse said, “You tell them you would like to educate them and let them know. But they still resist coming in.” Other HPs suggested that family resistance might be because they were resigned to the situation and had little hope for change, or that families had their own problems such as poverty that forced families to have different priorities. Poorer families
were described as lacking “the basics” to cope and as a result, they were difficult to reach. Finally, for many of the HPs serving impoverished inner-city populations, the greatest obstacle to family involvement they described was alcohol or substance abuse. One HP said:

I think one difference is substance abuse and dependency. The parents who don’t want to be found out. Or they don’t want to be confronted on the effects of their drinking or drug on the identified patient. Those folks aren’t going to come to treatment. And unfortunately, that’s not a small group of people.

Despite these constraints, many HPs had empathy toward family experiences, particularly in getting patients hospitalized. HPs acknowledged families’ intense emotions when seeking care, and the need for HPs to be more supportive. One of the HPs described a “typical” situation:

They [families] have been up all night for the last couple of weeks. We see the end results. You have no idea what it took to get that patient in the hospital. Incredible amount of energy, to get them to the emergency room. And then sitting there for over 24 hours.

**Family, Patient, and Adolescent Perspectives of Barriers to Family Care**

**Families:** “HPs do not care enough to try.” The description and illustrative experiences offered by all the families groups, but most intensely by families in the African American and NAMI groups, was that many HPs did not engage in the most basic courtesies such as returning phone calls or acknowledging the presence of families in hospital corridors. Other families also said that therapists “believed the patient when they should not have,” that the patient acted differently around the family, but that families were not asked for their perspectives.

Families stated they often felt “caught in the middle” between the patient and the system. “Game playing” by patients—the ability of some patients to “fool” the therapists—was a major concern. “They [patients] have a way of hiding things from the therapist” was a frequently repeated sentiment. Families described emotional crises they faced without professional support, such as being forced to call the police, getting the patient committed to the hospital, and enduring patients’ verbal and physical abuses. This perceived lack of support undermined subsequent encounters between families and therapists. The refusal of therapists to share information because of patient confidentiality issues was also an alienating factor.

**African American families:** “Our communities lack knowledge, understanding of mental illness.” Two African American focus groups were conducted. Participants in one of these groups talked about the stigma of mental illness and a cultural taboo against discussing mental illness in the Black community. These problems were major impediments to seeking care and therefore to involving families in care. Participants in the group also believed that in some settings, African Americans were treated differently than were Caucasians. They described how young people in their communities were misdiagnosed with “behavior problems” rather than with mental illness. They believed that HPs had a responsibility to educate this community about mental illness and to provide fair access to care, regardless of income or race.

The second African American focus group members were less vocal about issues of race and unequal treatment. However, their knowledge and understanding of even the most basic facts about mental illness, such as relatives’ diagnoses or medications, was starkly deficient. In both of these groups, however, the participants described calling the police on more than one occasion to get their ill relative into the hospital. They believed they had no other options.

**Patients:** “Our families don’t understand the illness.” Patients talked primarily about family-based barriers to family care. They reinforced the need for family education to prevent hospitalization, and to help families understand behaviors as symptoms. Patients said families “don’t understand the process” of getting treatment. One patient said that families “need to stop thinking the medicine is so great, because it is not.” Another patient said that families had difficulty accepting the mental illness, that they did not know where to turn, and they often involved the police when it was not necessary. A third patient acknowledged that families “get caught up in their own issues,” while another said frankly that “Some families are crazier than the patient.” Patients identified the system-based barriers to family care as: families being treated “differently” in psychiatric units than in medical units; families being approached by staff only “to see what they have in their bags”; and patients not being given permission to discuss “what was going on” with families.

**Adolescents: Dealing with stigma.** Adolescents reported that stigma was an important factor in their responses to their relatives’ mental illness. They said they did not share illness experiences with friends, and worried that others would see their relatives as “crazy” or “slow.” They described their efforts to help their relatives (sister, mother, grandmother), without any support from health professionals. From their perspective, HPs did not seem to understand the effects of the illness on teenagers or the extent of the teenagers’ involvement in their relatives’ care.

**Families and HPs in Conflict**

In comparing the responses of the HP and family groups, tension was evident as a consequence of conflicting needs, perceptions, and resources. For example, HPs described some families they encountered as resistive to intervention, in denial about the illness, disagreeing about the patient’s treatment, or simply being exhausted. Family participants, on the other hand, described unhelpful HPs as those who refused to listen to family members, discredited family experiences with the patient, responded defensively when families asked questions, and inadequately prepared families for a patient’s discharge. One mother described her situation:

They [patient] have ways of hiding things from the therapist. She acts one way when she is in the hospital . . . I know that they sit just
As nice and straight and tall as if nothing is going on. And so they can be discharged. They discharged her the first time I took her to the hospital. 'Cause they told me to give her some [medication] and that was it. Couple of hours later we were right back in there. I don’t know if it’s because it’s just another patient having a crazy episode or whatever . . . she could have done anything she wanted to at that time. Because they discharged her and called me to come and get her. I had to come and take her home.

Although most families acknowledged this tension between families and HPs, they attributed it in part to problems in the health care system. System-based problems that families identified included the lack of 24-hour coverage for mental illness in emergency centers, frequent turnover of therapists, inadequate funding for community services, an overemphasis on medical—rather than psychiatric—conditions in hospitals, and shorter lengths of stay for psychiatric inpatients.

Addressing Barriers to Family Care: What Is Most Important?

All participants strongly rejected the notion that an intervention had to be intense and long term. Three major themes were identified from the discussions of removing barriers to family care: deciding who needs care the most, building rapport, and connecting with communities (Table 3).

Who needs care the most? Families and HPs agreed that families in the initial stages of mental illness needed the most help, but they were also the families most likely to be in denial about the illness. HPs described families who were dealing with shock and acute grief:

The grief process had to be addressed before she [family] could even absorb the information that was being offered to her. I could give her literature and answer her questions . . . [but] she’d ask the same questions again the next session. Because she was still processing her grief. This is a young man she had had hopes for . . . dreams for.

Although HPs said that some families needed support to deal with the grief associated with the diagnosis, their priority in working with all families was providing education. Families agreed with the importance of education, but they expressed strong feelings that they also needed help with practical concerns such as finances, getting posthospital treatment, and individualized advice on how to control the patient when in crisis.

Fear of aggression. Families who felt threatened, or had experienced episodes of violence, were seen as needing focused attention. Families discussed their concerns about patient aggression, describing patients as having a lot of strength, and acting in a threatening manner when acutely ill. An African American participant described an interaction with her son: “If I let him know that I’m scared of him, he would run over me any time he gets ready. But I won’t let him know it. Even though sometimes he strikes a little fear.” Families frequently said, “I’m not scared of him,” but they also needed help in getting the patient into hospital, because as one mother asserted, “You don’t know what the voices are telling him to do.” Some families said they needed help to avoid responding too intensely to patient aggression, such as calling the police and having the patient arrested.

The importance of building rapport. HPs in both outpatient and inpatient sites agreed that building rapport with families was an essential element of any family intervention. A participant from the outpatient HP group suggested that the approach should be to:

Hear their problems, and how this illness is impacting them. . . . They’re coming in and saying, you know, ‘This is hard on me.’ I can’t manage this, I have my own life and family. And to be able to know you hear them and recognize their concerns and validate their concerns.

The most intense opinions about rapport building centered on recognizing the uniqueness of individual situations and that families must be allowed time to process information without feeling rushed.

Connecting with communities. Families, most notably African American families, said they believed HPs should target broad interventions to the community. Parents talked about the need to involve schools and churches in recognizing mental illness and getting treatment for young people. They had the opinion that HPs have a responsibility to educate this community about mental illness and to provide fair access to care, regardless of income. Many families described a sense of isolation when dealing with an acutely ill relative in a nonsupportive community environment. One

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### Table 3. Recommendations for the Delivery of Family Interventions

<table>
<thead>
<tr>
<th>General recommendations (all groups)</th>
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<tbody>
<tr>
<td>Address the grief and shock associated with mental illness and perceived losses.</td>
</tr>
<tr>
<td>Offer education to all families, as needed.</td>
</tr>
<tr>
<td>Provide families with skills and resources to manage crises and potential violence.</td>
</tr>
<tr>
<td>Build rapport with families to optimize collaboration.</td>
</tr>
<tr>
<td>Reach out with education to community venues (e.g., schools and churches).</td>
</tr>
</tbody>
</table>

### Group-specific recommendations

**African American families:**
- Bolster community’s knowledge and understanding of mental illness.
- Reduce myths and stigma about mental illness through community-based interventions.
- Reduce police interventions by making emergency support services accessible.

**Adolescents:**
- Develop skills for children to manage the stigma associated with mental illness.
- Recognize the adolescent’s role in the family, the disruption of their normal activities, and their lack of preparation to manage the burden of caregiving.

**Patients:**
- Educate families about psychiatric illness to reduce their fears and misconceptions.
- Promote family skills in recognizing patients’ needs for support.
- Include families in treatment.

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Families and HPs agreed that patients who needed care the most were those in the initial stages of mental illness. They identified from the discussions of removing barriers to family care: deciding who needs care the most, building rapport, and connecting with communities. Three major themes were addressed:

- **Fear of aggression.**
  - Families who felt threatened or had experienced episodes of violence were seen as needing focused attention. They discussed their concerns about patient aggression, describing patients as having a lot of strength and acting in a threatening manner when acutely ill.
  - An African American participant described an interaction with her son: “If I let him know that I’m scared of him, he would run over me any time he gets ready. But I won’t let him know it. Even though sometimes he strikes a little fear.”
  - Families frequently said, “I’m not scared of him,” but they also needed help in getting the patient into hospital, because as one mother asserted, “You don’t know what the voices are telling him to do.”
  - Some families said they needed help to avoid responding too intensely to patient aggression, such as calling the police and having the patient arrested.

- **The importance of building rapport.**
  - HPs in both outpatient and inpatient sites agreed that building rapport with families was an essential element of any family intervention. A participant from the outpatient HP group suggested the approach should be to:
    - Hear their problems, and how this illness is impacting them.
    - They’re coming in and saying, you know, ‘This is hard on me.’
    - I can’t manage this, I have my own life and family. And to be able to know you hear them and recognize their concerns and validate their concerns.

- **Connecting with communities.**
  - Families, most notably African American families, said they believed HPs should target broad interventions to the community. Parents talked about the need to involve schools and churches in recognizing mental illness and getting treatment for young people. They had the opinion that HPs have a responsibility to educate this community about mental illness and to provide fair access to care, regardless of income. Many families described a sense of isolation when dealing with an acutely ill relative in a nonsupportive community environment.
Barriers to Family Care in Psychiatric Settings

Discussion

The findings of this study are important for several reasons. First, the inclusion of key groups of stakeholders—HPs, two groups of African American families, two groups of patients, and one group of adolescents—adds new perspectives to the understanding of experiences of mental illness that have been largely underreported. Second, the findings clarify the extent and nature of the great disparity between what families feel they need from health professionals and what they receive. A major difference was found between what HPs believe they should provide, but cannot provide because of system-based constraints.

The experiences of some of the African American families were of concern and warrant further study. The perception that racism influenced the quality of mental health care was expressed more strongly in one of the two groups. The second group had only three participants and they may not have had the experience necessary to voice an opinion on this issue. Nevertheless, it was a strong assertion by those who said it. Other studies have indicated that racism is an ongoing concern in health care, resulting in disparities in access to and quality of health care for minorities. For example, McLean, Campbell, and Cornish (2003) identified three categories of exclusion of African Caribbeans from mental health services in Britain: cultural, institutional, and socioeconomic. In the United States, the barriers to mental health care for African Americans continue, and they are disproportionately diagnosed as schizophrenic (Snowdon, 2001). A nationally sponsored workgroup on affective disorders indicated that a legacy of discrimination and racism remains a barrier to care for African Americans (Miranda, Lawson, & Escobar, 2002).

Of equal concern regarding the second African American group, however, was the severe and extensive lack of knowledge about mental illness in general. For both groups the African American families resorted to calling the police as a way of getting a relative into treatment. These findings are consistent with those of Hines-Martin and colleagues (1998) who reported that African American families had significant knowledge deficits related to mental illnesses and they frequently used law enforcement to initiate care because they were poorly connected to other health care resources.

The African American groups were also the most vocal about the sense of isolation and uncertainty they felt when dealing with ill relatives who were noncompliant with treatment and therefore became threatening and “scary.” They were cut off from family support because of the lack of acceptance within the African American community of mental illness and emotional problems. This finding is consistent with previous research indicating that African Americans were less likely than were Whites to seek help from family, friends, or religious helpers (Hines-Martin, 1998; Snowden, 2001). Lack of support is a major barrier that health professionals must address if care to these families is to improve.

The finding of disparate views of families and HPs was a concern. Families were asking for supportive interactions; HPs were concerned about providing education and meeting the needs of complex family situations. They had different notions of what constitutes quality care, a finding noted by others (Fischer, Shumway, & Owen, 2002). Families in this study wanted support to manage their caregiving burden and to support their ill relatives. Health providers indicated an array of system-based and practice-based barriers that impaired their ability to provide that support. Future research should address these concerns to enhance the delivery of family centered care in psychiatric settings.

Conclusions

The lack of family care in psychiatric settings is a multifaceted problem. Current health policies do not show endorsement of a family care approach. Responses from families and health professionals indicated conflicting opinions about content of family care. Health professionals reported they often lacked training and resources to deal with complex family issues. Families believed that lengthy and intensive interventions were neither necessary nor desired to address their concerns. Family care can be improved by focusing on building rapport and communicating problems and concerns between families and health professionals.

References


Lenert, L.A., Ziegler, J., Lee, T., Sommi, R., & Mahmoud, R. (2000). Differences in health values among patients, family members, and providers for outcomes in schizophrenia. Medical Care, 38, 1011-1021.


