

Benefits and Limitations of Professional-Family Interactions: The Family Perspective

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Families of persons with severe mental illness often experience burden and stress related to the caregiving role. There is a paucity of research describing effective interventions for relieving this burden. This article reports the findings of a study that elicited families' perceptions of professional interventions. Two focus groups were conducted with relatives of persons with schizophrenia or bipolar disorder. Participants described their experiences of the illness, current concerns, and coping strategies. A major focus of the study was the families' evaluations of past and future interventions from health professionals. Content analysis of the data identified critical elements of supportive and nonsupportive behaviors from professionals. Recommendations for future interventions were identified.

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THE CURRENT CLIMATE of health care delivery is one of limited resources and shifting priorities. The mental health field has been radically altered by the emergence of managed health care by providers and the community as the preferred site for services delivered. These changes have significant impact on those persons who have severe and persistent mental illnesses. These persons require ongoing support to effectively manage their illnesses and achieve a satisfactory quality of life. For the families of these patients the impact is equally severe as they continue to be a primary source of help and support for patients. Shrinking financial resources of the formal health system means that responsibility for the ongoing support of patients is increasing for the family members (Reinhard, 1994). Thus, an investigation of the perceptions of these caregivers regarding appropriate interventions to help them manage their caregiving role is very timely and necessary. The purpose of this study was to elicit family caregivers'

evaluations of family-focused interventions as well as informal interactions with health professionals and the relevance of these contacts to families' needs. A second purpose was to identify from the families' perspectives, critical dimensions of future interventions by health professionals that they felt would meet their needs.

RELATED LITERATURE

There is ample evidence to support the idea that burden exists for families caring for mentally ill relatives (Biegel, Milligan, Putnam & Song, 1994; Loukissa, 1995; Maurin & Boyd, 1990; Reinhard & Horwitz, 1995; Rose, 1996). Most recently, the role of contextual factors in the caregiving role has been recognized as important influences in the experiences of that burden. Rather than affecting all families equally, burden is now viewed as having an impact on families differentially. Reinhard and Horwitz (1995) noted that all caregiving activities do not result in burden. Rather, it is the meaning that the caregiver assigns to the activity that results in a feeling of burden. As well, there may be gratification associated with caregiving that mediates the burden (Bulger, Wandersman & Goldman, 1993). Relationship to the patient has only recently been investigated and shown to be a factor in the

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0883-9417/98/1203-0002\$3.00/0*

amount of burden experienced (Greenberg, Kim & Greenley, 1997). Cook, Lefley, Pickett & Cohler (1994) found that the type of burden experienced is influenced by the age of the caregiver. Living with the ill relatives may be a factor that increases burden (Jones, Roth & Jones, 1995; Carpentier, Lesage, Goulet, Lalond & Renaud, 1992), although for some families it may be a way of coping (Winefield & Harvey, 1994). Other investigators suggest that the developmental stage of the family (Pickett, Cook & Cohler, 1994; Cook et al., 1994), the nature of the relationship between parent and ill child (Pickett, Cook, Bertram & Solomon, 1997), and the ethnicity of the caregivers (Horwitz & Reinhard, 1995) may have an effect on amount of burden experienced.

As these studies indicate, the experience of caregiving and associated burden is more complex than originally thought. Given this complexity, it is also becoming apparent that interventions aimed at reducing that burden must take into account the interplay of factors that make up the caregiving experience. Increasingly, an appreciation for the subjective experience of burden is being acknowledged. Strengths as well as problems exist for families who have a member with mental illness (Doornbos, 1996). The notion of a single primary caregiver who takes on the major responsibility of caregiving is being questioned also. Different family constellations may develop different organizational systems in which various members take on equal and complementary roles (Keith, 1995). Given these new insights into the caregiving experience and questions about the meaning of burden, it is critical that families be given an opportunity to identify what their needs are and what interventions might help.

Efforts to relieve family burden through education alone have had minimal impact (Lam, 1991). Psychoeducational interventions that combine information about the illness with education about coping are usually conducted in didactic sessions using a multiple family group format. The major studies to date that involve a long-term intensive family intervention are based primarily on the concept of expressed emotion (EE). What is known about working with families has largely been a result of these early intervention efforts. For example, the early psychoeducational interventions by Anderson, Hogarty and Reiss (1980) and Anderson, Griffin, Rossi, Pagonis, Holder (1986) were

designed to work with families to reduce EE and the recidivism of the patients. The clinical usefulness of interventions suggested by these studies has been questioned recently because EE focused on a singular aspect of family functioning and there is an emphasis on risk factors related to interpersonal conflict (Chesla, 1994). Further, Lam (1991) pointed out that these studies lacked a theoretical basis such as stress and coping that might elucidate more clearly the therapeutic elements.

Surprisingly, few recent studies have investigated family intervention programs. Muijen, Cooney, Strathdee, Bell and Hudson (1994) found no difference in satisfaction with care between families and patients who received intensive follow-up care by psychiatric nurse case managers (including family support) and those receiving the generic approach. Solomon, Draine, Mannion and Meisel (1997) found that families who participated in a three-month structured intervention program did not differ from families in a control group on measures of self-efficacy, burden, coping, or social support.

As these studies suggest, the effective elements of family interventions have yet to be identified. The purpose of this study was to identify from the families' perspective, what they saw as those effective elements.

METHOD

The study used a descriptive exploratory design with a focus group as the data collection method. Two focus groups were used to answer the research questions. Focus groups are useful in eliciting information about a particular topic from a homogeneous group of individuals (Krueger, 1994). In cases of families of persons with serious mental illnesses, the need for interventions has been well documented. The focus group format provided an opportunity for caregivers with similar experiences to share their common concerns and to offer suggestions for ways that health professionals can intervene to help them in their caregiving role. The focus group allowed for the mutual sharing of ideas that would stimulate discussion of the merits of the suggestions as well as evaluations of interventions the caregivers may have experienced in the past.

The use of focus groups as a research method differs from other types of groups in several important ways: the researcher is interested in a specific topic, the members of the group may or

may not know one another, and consensus is not the aim of the focus group sessions. The degree of structure of the questions posed by the group leader as well as the direction provided for the discussion can vary, although the method has generally been considered a qualitative. As a qualitative approach, no effort is made to enumerate responses or statistically analyze findings (Krueger, 1994). The overall goal is to elicit the members' perceptions and personal interpretations of past and potential future programs designed to meet their needs. The goal of the study was to derive suggestions for future interventions. The group sessions were semistructured, with general introductory questions leading to more specific ones regarding families' needs.

Two groups were conducted. The moderator was an experienced psychiatric nurse who had expertise in group therapy. She used an interview guide that focused on the following discussion points: introductions/general discussion of the group process; families' concerns about making difficult choices; ways that families gained knowledge about the illness; their emotional responses to caregiving, relationship issues, management strategies, and seeking/receiving social support. Examples of questions asked were: "In what ways have you gathered information about the illness?", "How many resources have you tried and which ones worked?", and "Let's talk about a family intervention that helped (did not help) you and why it helped (did not help)." Two open-ended questions were asked at several points during the group sessions in reference to problems identified: "In your opinion, should (problem) be a focus of an intervention for families?" and "In your opinion, what would you like to see as part of a family intervention program that has not already been discussed?" Elements of group process were attended to, such as noting who spoke and who did not, and seeking clarification and additional information using appropriate probes and therapeutic communication techniques.

Participants were members of two local support groups for families of mentally ill persons. The attendees in each group therefore knew each other from prior meetings. The ill relatives (not included in the study) had a diagnosis of schizophrenia or bipolar disorder. All participants had been members of the support group for a year or more. Six parents, two spouses, and one sibling were included. All participants were white, middle class, and ranged in age from 34 to 65 years. In the first group, a sister

of a bipolar patient, a spouse, and three parents (two were parents of the same patient) attended the group. In the second group, there was a mother and father of a male with schizophrenia, a mother of a son with schizophrenia, and a husband of a woman with bipolar disorder. The participants were relatively homogeneous in that they had been attending the support groups for an extended period of time and they had been in the caregiving role for at least 10 years. The number of hospitalizations of the ill relatives ranged from two to eight. Differences in caregiving role based on relationship to the patient were noted by the participants themselves ("I am not her mother" the sibling noted), although they also noted similarities in concern for the patient and commonalities in experiences with the health care system.

Informed consent was obtained and the sessions were audio tape recorded and transcribed verbatim. Analysis of the transcribed sessions consisted of a process of content analysis. The analysis process was guided by the interview questions and the overall research goal of describing the families' perceptions of needed interventions. Transcripts of the two sessions were read line by line to identify group members' perceptions in the first stage of coding the data. Subsequent readings of the data facilitated the grouping of similar data into broader categories.

RESULTS

The analysis of the transcribed data identified the following categories: a general description of the family experiences; perceptions of supportive and nonsupportive behaviors from professionals, families' coping strategies, perceptions of basic ingredients of interventions, families' perceptions of "what helps," and families' "wish list" items of components of the ideal helping relationship. It is important to note that the results as reported here do not reflect a consensus. Rather, they are meant to convey a broad spectrum of responses that taken together portray a picture of family caregiver needs and requests that for this group of respondents remained unanswered.

Family Experiences With the Ill Relative

Families described an environment of living with unanswered questions about the future and how to deal with the patient's unpredictable behavior. Whereas they were concerned about manage-

ment issues, as noted in other studies, these families were equally concerned about the relatives' changing appearance and what it meant. For example, they frequently talked about the relatives' weight gain and loss of attractive appearance. Others had more difficulty articulating the change other than speak of a certain "look" that the patient acquired over time. They were experienced enough to question the role of medications in this change. There were other key concerns for the families that reflected an awareness of their role: "What should I do if she doesn't come home?", "What should I do about her medications?", and "How involved should I get?"

The majority of families described feeling stuck, even though they had been dealing with the illness for many years. One mother's experience seemed to stand out in sharp contrast to the others. She described a process of "coming to terms" with her son's illness that she attributed to her own personal strength and not to the help received from others. Her son had been hospitalized so many times over a period of 19 years that she said she "had lost count." She described her current view this way: "I am real proud of the way things are now compared to what they used to be." Her son was living independently and she described him as "stable" with no hospitalizations in 7 years. In contrast, a couple whose son had been ill for a similar length of time were floundering, because their son had not been diagnosed until the previous year. They described their son as being unable to hold a job, and unable to relate to others because of ideas of persecution and his own aggressive behavior. Their needs for information were great: "Now (since taking medication) he looks like he doesn't know anything. I just can't understand it. Now with the pills, he doesn't know anything. I tell him he wasn't like that before. What's wrong?"

Perceptions of Supportive Behaviors

Meeting the primary nurse and being told that he or she was the contact person who could be called at any time about any concern was the major supportive behavior identified. Family members felt supported when they were given the opportunity to meet other patients who communicated to them what living with the illness was like. Finally, the families said that the opportunity to describe behaviors they observed and have a professional person interpret their meaning to the family made

them feel supported. Health professionals who gave concise explanations of what could be an expected response to medications were seen as supportive. Whereas messages about the patient "never getting better" were understood and in most cases was accepted in terms of not hoping for a cure, families still looked for some encouragement that all was not hopeless, but that there were problems that were "fixable." Finally, families wanted health professionals to let families express their own responses and make their own choices about responding to the patient without being judged.

Perceptions of Nonsupportive Behaviors

Those who did not have consistent contact with the same health care provider were confused about the roles of the various personnel they came into contact with in the hospital and/or community setting. Nurses were not identified as significant resources or persons who made a difference to the families' experiences. Participants described experiences of good initial contacts with health professionals, but not having the relationship sustained over time. The importance of finding someone who they felt they liked (and that was an elusive quality but seemed to be related to ease of communicating) was important but often lacking. Several families noted that health professionals made suggestions that they did not "buy into" and the alliance therefore was not made. Families were frustrated with what they saw as a reluctance on the part of professionals to "go out on a limb" and make some statement about prognosis. By the same token, families who received abrupt messages such as, "she will never get better" or "she's going to crack" were frustrated with the lack of follow-up explanation or elaboration.

Families responded intensely to incidents in which they felt judged or challenged by a psychiatrist. For example, one family member felt she had been criticized for not recognizing her relative's need for hospitalization sooner: "After several times that he was hospitalized, they would say, didn't you see how he was different?" Critical comments, particularly related to the nature of the relationship between family member and patient, were hard to accept. One participant said of her sister's therapist, "She thinks I am too much of a parent and that my sister is too dependent on me—But what do you do?"

When formal family sessions occurred, families frequently were frustrated by what they perceived as a message from health professionals on ways that families needed to change their behaviors. Instead, they wanted to see an emphasis on ways that patients and families could change together. Finally, they were angered by assumptions by professionals that because they had been caring for their ill relative for a long time that they understood the illness. They saw this as a major barrier to receiving help: "The doctor takes for granted that because you have been part of that process for a long time that you know why you are there and what's happening. And that's not true."

Family Coping Strategies

To further clarify where assistance was needed, families were asked to describe ways in which they had learned to cope with illness-related problems. However, most were adamant that even though they had been in the caregiving role for a long time, they did not always feel a sense of personal control over the stresses of living with the ill relative over time. They talked about ways that they tried to manage the stress or find an element of the situation that they could control. One mother identified a particularly useful book written in lay language that she called her bible. Others noted that reading was not how they coped, or they did not have the resources to seek out written material that they could use. Instead, they described patterns of learning by trial and error and coming to accept through experience how to respond in a way that helped the family to manage what one family called episodes: "It is a mental illness and they are living in their own world. They hear voices which I think is terribly sad. The main thing is whatever these voices [are saying], if they can just fight these voices. That's where medication comes in. So I began to understand that. When we understood this as a family, our lives were much better. It was like we got our son back. We called them [listening to voices] episodes."

She went on to describe situations of her son "screaming and hollering," an experience that resonated with other group members. "He got it out of his system by screaming and hollering and cursing and then he was okay. But when we [both parents] all jumped in and got irritated, it was like we were giants and then he got frightened. So we just stood our ground and let him do his thing. After

a while he was fine." Another family had difficulty coping with these episodes because they seemed to indicate that the patient was in another world: "he doesn't realize that people get up in the morning and take the bus to work, He's in another world. Yet he wants to join this world." Concern and frustration defined their experience as they considered the willfulness of the son's behavior that stopped as quickly as it started: "he wants to join this world. So I tell him we are going back to fantasy land. He says it is not a fantasy and I say it has to be a fantasy because you started it and when you get to a point you stop." This family struggled with disagreements between parents about how the patient should be handled. "He's easy to cope with as long as we let him have his own way, but he can't have his own way all the time because his way is wrong." This family has never had a session with the relative's psychiatrist or other health professional.

What seemed to help families make sense of the illness was identifying a pivotal event that resulted first in the emergence of the illness, and second in the display of symptoms. Making connections between cause and effect—when this happens, our relative acts this way—was an important element of what helped them to cope. Indeed, those who expressed frustration with ill relatives and with the responses from health professionals seemed to have the greatest difficulty in making these connections; for example, the father who said, "we don't know when he is going to go off." Finally the support group was seen as a major influence on their coping. For many, the group sessions helped to clear up misconceptions about the diagnosis and what it meant. They used it to share information about practical concerns and they challenged each other's thinking about the best way to respond to the patient.

Perceptions of Limitations

A critical finding of these focus groups was that families felt they had realistic expectations. They did not expect the health professionals to have all the answers as to why this illness happened or how the future might be. They recognized that there would be different treatment approaches from different professionals. They acknowledged that each patient is different and that professionals can only give general ideas about what treatment can be given their ill relative. One family described a

professional response to their son's adverse reaction to medication: "They had him on [Haloperidol] very heavy. One time he had a bad lapse and we had to take him to the hospital. They had to wean him off of it and start all over. They said this happened because they don't know themselves. They are dealing with the mind and they don't know either."

They were clear that you had to learn by "being around the patient." They described a wide range in quality of services from agency to agency, but the tone was less critical than it was "this is something you need to know." Some hospital emergency departments were seen as better equipped to deal with psychiatric patients than others. Some families felt they did not have to like the patient's therapist if he or she was working well with the ill relative.

The Basic Ingredients

Families were then asked for specific suggestions of what would help. As one family member stated: "You don't know me so don't make judgments about me or my family unless you take the time to get to know me. I think that is the basic ingredient." Another participant said that professionals should help families make sense of the times when family life resembles a "three ring circus." Other basic ingredients included finding ways to help families gain a sense of confidence in their efforts to deal with the ill relative and making sure that family and therapist are both giving the patient the same message. Some families were still struggling in their efforts to distinguish illness behaviors from personality behaviors and how to respond to each.

Whereas families derived a lot of support from seeing the common experiences among patients, they felt it was important to identify the uniqueness of their relative. They were adamant that a most basic ingredient was the simple fact of sitting down and talking, described in terms of communicating an attentive stance toward families and their needs in a way that was not rushed or pressured. Families wanted recognition that the needs of each family are different. They felt that generic approaches can be helpful if individualized interventions are also considered. For example, the participants in these groups saw the needs of spouses as different from those of a parent. "I think the key aspect of being married to a person who has an illness, it makes it completely different than having a child with it.

The key issue is relationships—not only with the spouse but with other people." Similarly, the sibling in the group felt she had special concerns related to the ways that her relationship was developing with her ill sister.

Making a Wish List

These families were able to identify other elements of helpful interventions, although they felt that some were items on a "wish list" and they did not expect them to happen. There was general agreement that a "quick admission" to the hospital during acute episodes would ease family stress significantly. They went on to describe incidents of lengthy waiting periods with highly distressed relatives. They said "wouldn't it be nice if" there was a special psychiatric emergency department where staff knew immediately what to do and the patient was speeded through the paper work and admitted.

The families identified the need for relevant community care with adequate housing for their relative. For patients who were receiving employment training, matching the patient to a skill the family knew he or she had was seen as important. They wanted to figure out what they called "the little things" about the patient such as "when should I panic if she doesn't come home on time?" They had varying opinions about the ability of professionals to help families distinguish illness behaviors from personality behaviors. As one family member stated: "You just don't know. I don't think anyone can help you with that. After years and years, we still don't know." Another family member said, "You tell yourself if this is part of the illness then you can work through it. But if you are unsure if this is the person, you say, Oh my God, this is hopeless." Families identified a need for help in understanding the patient's pain and its relationship to behavior. "When we understood this as a family, our lives were much better."

DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

There are limitations in this study. The small sample size limits generalizability beyond the persons studied. In addition, the diversity of relationship to the patient and the fact that only one sibling participated may have limited the degree to which participants felt a common link, thus affecting the credibility of the findings. However, the moderator

noted the spontaneity of responses, almost equal participation by all participants, and the more compelling common element of having a relative with a mental illness were factors that seemed to minimize this limitation. Finally, only two focus groups were conducted: the findings should therefore be considered preliminary. Nevertheless the findings of this study do highlight ongoing needs, concerns, and frustrations of persons who have been in a caregiving role for many years.

Many of the concerns expressed in these groups substantiate the findings of previous studies, such as the families' needs for help in managing disturbing behaviors and the desire for nonjudgmental communication with health professionals. Families can distinguish between "wish list items" and "basic elements" of what would help. However, at the same time, they felt it was important to develop interventions that addressed individual, unique experiences as well as shared concerns.

The families were diverse in terms of needs for help and support. Some of them felt they had learned to cope and found strength within themselves. Others described a personal expenditure of time, effort, and commitment that was significant, ongoing, and exhausting. They described the years involved in complex processes of figuring out the "right" approach. The stage at which families found themselves in terms of years of experience with the illness, the types and numbers of contacts with professionals in the past, and the degree of support from other family members clearly influenced their perceptions about how professionals can help in the future. A generic intervention that does not acknowledge this diversity may miss opportunities for effective assistance.

Previous studies of caregiver burden focused predominately on parents as primary caregivers, particularly mothers of adult children with schizophrenia. Whereas only two couples participated in these focus groups, mothers and fathers shared the different perspectives they held regarding the illness. Conflicts within these families were apparent, affecting their ability to cope with the stress. Other group members described their experiences that were influenced by the nature of their relationship to the patient. Spouses and siblings wanted to be treated in that context, because for them the nature and intent of the caregiving was often ambiguous. In a recent study by Jones (1997) the differential

burden of child and sibling caregivers was characterized by ambivalence.

Further research is needed that investigates the experiences of varied family constellations and how they influence needs for support. Such information will expand our knowledge of caregiving burden to include an understanding of how families as a unit are affected by the presence of the illness in their daily lives. Research is also needed regarding the distinct experiences of parents, spouses, adult children, and siblings. Interventions will then be based on an understanding of their impact on the family as a whole, rather than just the person denoted as the *primary caregiver*.

Families identified the importance of process as well as content of communication between themselves and health professionals. Their focus seemed to be on improving the quality of the informal interactions rather than formalized interventions. Families heard clear and unambiguous messages when they were given, but they continued to struggle with the significance of such statements as "he will never get better." Follow-up contacts with families are extremely important because the families deal with reactions of grief and frustration and a process of "coming to terms." Future studies should investigate the elements of informal professional/family communications that occur in treatment settings. Ways that families can be engaged in treatment plans that remain a viable entity in the ongoing management of the illness in the context of the family is needed. The role of the professional as collaborator with families while simultaneously acting as expert informant to families has not been studied. Understanding ways that such a role can be developed will enhance the development of family-professional relationships.

Whereas some of these families participated in group intervention programs, many had never been approached to participate in such a program and others felt they were more interested in individualized approaches that addressed their needs. Future interventions need to consider innovative approaches that maximize informal as well as formal encounters between families and health professionals. Families in this study were relieved when they finally learned the unique warning signs or triggers of crisis. An intervention that provided accessible and immediate contact and support for this process would help in minimizing disruption of family life and family relationships.

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