Families of People With a Severe Mental Illness: Role Conflict, Ambiguity and Family Burden

James G. Hanson
University of Northern Iowa

Recommended Citation

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James G. Hanson

University of Northern Iowa
Department of Social Work

The perspective of families of people with a severe mental illness has become a focus of interest for mental health professionals. This paper reports the results of an ethnographic study of families' perceptions of dealing with a severe mental illness in their midst. The findings suggest that the families face continual role conflict and ambiguity as the illness moves through characteristic stages. Attention is given to the families' experience and needs and to social workers' responsibilities for involving and communicating with such families in order to reduce a portion of their burden.

The perspective of the families of people with a severe mental illness has become the focus of much interest by mental health professionals (Francell, Conn, & Gray, 1988; Grella & Grusky, 1989; Solomon, Beck, & Gordon, 1988). Often, this interest falls under the rubric of family burden and relates to discrete effects of the mental illness on family life (Hatfield, 1979, 1981; Lamb & Oliphant, 1978). Less attention has been given to the continuous or chronic stressors experienced by such families (Kessler, Price & Wortman, 1985).

Stress can be defined as a dynamic state involving uncertainty about something important (Schuler, 1982). The potential to feel stress exists when a person perceives that environmental demands threaten the individual's capabilities and resources for meeting those demands (Stout & Porter, 1984). Although, stress may result from a variety of factors (Jamal, 1984), two important factors are social role ambiguity and conflict (Kahn, Wolfe, Quinn, Snock & Rosenthal, 1964). Role ambiguity exists when information about the role is vague or inadequate; role

conflict refers to the perception of incompatible demands being placed on a role occupant (Abdel-Halim, 1982).

For families of people with a severe mental illness, a close relative's severe mental illness is the central source of chronic stress and is critical in precipitating major role changes for family members (Angermeyer, 1985; Thurer, 1983). Recurring cycles of exacerbation and remission of symptoms and the character of the families' interaction with the system of mental health care also cause much stress. Recently, elements of this interaction have been termed iatrogenic (Lefley, 1989). That is, features endemic to the families' interaction with the service delivery system have damaging effects on the families of people with severe mental illnesses. While some work has been done with regard to families' perceptions of their interaction with mental health professionals in different stages of the service delivery system (Bernheim, 1990; Bernheim, & Switalski, 1988; Stewart, 1984), this paper is believed to be the first to describe the families' perspective of dealing with a mental illness across the stages.

Families deal with four distinct stages in a process of dealing with a severe mental illness: 1) prior to professional help; 2) hospitalization; 3) community care; and 4) a return to primary care by the family. From ethnographic data, this paper describes a process in which the families learn varied roles for each stage. It describes both the families' adaptation across these stages and the changing and ambiguous role demands that create an unnecessary burden.

Method

Procedure

The framework for viewing the families' varying positions emerged from a ethnographic study of the families of people with a mental illness (Hanson, 1989). Ethnographic methods (Spradley, 1979) were used to collect data from 34 separate informants, from 29 different families, in a mid-western state about their experiences in dealing with a severe mental illness.

The primary data for this method is the analysis of verbatim transcripts of informant interviews. The interviews were

recorded to ensure a verbatim record. The method assumes that analysis of the language used by the informants will reveal an organized picture of the phenomena important to the language users. The size of the sample in this type of research is related to the completeness of the understanding obtained at any given point. Interviews continue until no new information is forthcoming which adds to the cognitive picture.

Interviews started with a form of the question: "What has your experience of having a family member with a severe mental illness been like?" Family members needed only that question to facilitate a lengthy description of their experience. All the informants talked freely and no family member turned down a request for an interview, even on "cold" calls.

The external validity or trustworthiness of interview data depends on the internal variety of the informants. Thus, the sampling in qualitative research resembles purposive sampling in quantitative efforts. In this study, there was an attempt to vary the relationships of the informants to the person with the mental illness. Some variability exists. However, most informants had sons with a mental illness. An attempt was also made to include informants who either were or were not members of the Alliance for the Mentally Ill (AMI). The assumption that members of an active support group might differ from those receiving no formal support seemed plausible. However, these two groups did not differ on the dimensions which became the foci of the study.

The process resulted in a draft narrative which "translated" the families' experience with a family member with a severe mental illness. The draft was given to eight of the informants for a critique of the material. These eight informants indicated that the text accurately reflected significant parts of their experience. Finally, 98 members of AMI completed a survey developed from themes in the interview data, in an effort to cross-validate the findings from the ethnographic data (Hanson, 1989).

In spite of the various checks and balances used, some methodological caution must be made with the findings as reported here. The results focus on parents' views as the view of the family, for example, while the data provided a beginning suggestion that the views of siblings or children may be

different. The families in this study were also either working
or middle class. All informants were white. Generalizations to
larger populations must consider these sampling characteristics.

Sample Characteristics

The 34 informants for the study were from families of people
who have a severe mental illness who lived in eight of the 27
catchment areas of a mid-western's state's mental health system.
A total of 14 formal interviews were conducted with the 34
separate informants. Nine of the informants were interviewed
individually, while the other twenty-seven were interviewed in
small group settings. The settings varied from community sites
such as the family's home, restaurants, or the informants work
place to agency and off ice settings. The variation of both the
type of interview, individual or group, and of the settings can be
seen as a check on informant reactivity to either the interviewer
or the setting.

The relationship of the family members to the person with
the mental illness was: mothers - 20; fathers - 9; child - 1; wife
- 2; sister - 2; and inlaw - 1. The gender of the person with
the mental illness is weighted toward the males, n=26. Twenty-
four of the informants were affiliated with AMI, while twelve
were not.

The criterion for inclusion in the study was that a family
member had experienced one or more in-patient psychiatric
hospitalizations. The diagnosis of the person with the mental ill-
ness is not included, although all had at least one diagnosis of a
major mental illness such as schizophrenia or bi-polar disorder.
Early on in the process, it became clear that this information is
often not available to family members. In some cases, the family
has never been told. In others, the person with the mental illness
has received many different diagnoses either from a number of
several agencies or from a single agency. Typical of many family
members' knowledge of the diagnosis was:

> "He has several. Some say schizophrenia. Others say thought
> disorder. That kind of stuff or combinations. so, I don't know
> myself what I would say. To me all things say schizophrenia, but
> I don't know enough to say anything."

Findings

The Family Role During The Early Years of The Illness

Successful parenting involves reasonable assessments of the child's developmental level and a gradual fostering of self-sufficiency as the child ages. Most parents handle the process well, helping their children achieve a healthy entry into adulthood. Parents in such families are able to move from a complete "executive" role in infancy to an advisory or consulting role in young adulthood.

For families of people who develop a severe mental illness, this typical pattern progresses until a time between early adolescence and young adulthood. Then, the mental illness begins to assert itself and the normal developmental progression toward self-sufficiency gradually reverses itself. Family members were very aware of this insidious reversal and assigned meaning to changes based on the knowledge at their disposal. For example:

> "We can remember from back in high school. Weld sit around the table at meal time and be in a conversation. If he would say something, someone would invariably look at him and say, 'What?'. What he said was not entirely appropriate to the conversation or what he said was appropriate to him, but it didn't really come out so we could understand it. It was a little bit 'off track' ".
>
> "His actions became sort of strange, but we wrote a lot of it off to the fact that he was depressed, feeling bad and sorry for himself because he didn't get into the service, didn't have a job, didn't have a girlfriend."

The families said that they noticed problems earlier than others and that they actively sought help. The families felt that they handled the undiagnosed illness in this early stage as well as they could. They used several plausible explanations; i.e. the fits and starts of "normal" development, drug/alcohol abuse, peer problems, or "family" problems. Typical of early helping responses of both the professional and lay networks were:

> "The therapist we approached first said that he's just in his teenage years. Some is rebellion, some is experimentation, whatever, that it was a pretty natural thing."

> "We had a mental health center here, so we made a call. They immediately wanted to sign us up as clients to see one of their social workers to have sessions to talk. So we had our sessions and it didn't pertain to anything at all."
>
> "He started smoking pot and drinking. We were alarmed about it and didn't like it, but everyone said that a little pot smoking is not going to hurt you."

Left to their own resources, the families typically reverted to an active executive parenting role. While resuming this role would usually be considered age inappropriate, the 20/20 vision of hindsight suggests it was a normal and appropriate reaction to an abnormal situation.

Unfortunately, the families had no prescribed role to use as a model, i. e. no social guide on how to be a parent of a person with an undiagnosed severe mental illness. Although the families felt that they handled the situation as well as they could, they also experienced tremendous stress from much unsureness about how to be a parent. For example:

> "We were sure it was something it that we were doing." "I have this thought, I have this fantasy. I'm mad because I didn't invent those baby carriers or study the Indians, because if I could have just fastened him to me I think he. . . . See I fantasize about what I could have done to him to have him be different or feel different."

Families described much role conflict during this early period. They struggled to fulfill the role of "normal" parents, thus encouraging self-sufficiency and independence. They were also torn by, the need to respond to the deterioration they saw by increasing their caregiving. They often received feedback that they were not fulfilling their role properly, without receiving information on how to parent correctly. For example:

> "Almost everyone in our family thought that it was something that we were doing wrong. He'd stay with my mother sometimes and finally went to live with his aunt. That did no good at all and he finally left, took off. Even now some of them don't believe that there is anything wrong with him, that we should be doing something different. It's really a mess."

The families suggested that the stress of not knowing how to be a parent of a person with a severe mental illness, when combined with their inability to be both a caregiving parent and a launching parent simultaneously was tremendous.

> "We felt that they were saying that he was trying to avoid responsibility. That he had a good thing going and why work or do anything when he didn't have to. It made a lot of sense and we did everything we could, but we couldn't bring ourselves to say you're going to move out. Because in the back of our minds we had the feeling that we knew a lot better than they did that he had some limitations that were preventing him from doing what they thought he could do."
>
> "You get to the point where you're ready to reach for anything that's a straw that might help. Is there something that we could be doing?"

The Family Role in Hospitalization

For the families in this study, the early years of dealing with the undiagnosed illness lasted from three to fifteen years before formal entry into the mental health system. Entry can occur via acceptance at an out-patient facility. However, the initial entry for these families was through admission to an in-patient psychiatric hospital; most commonly a public state hospital.

The families had feelings of much hope and relief connected with the first hospitalization.

> "I thought held get better there. In fact, that's what I told him."
>
> "I thought he would come out of the hospital with an understanding of what his problem was, how to handle it and go on with his life in a much more normal fashion. That was a great expectation!'
>
> "It marks the first time that a loved one deserves and qualifies for care."

Early in the hospital stay, however, the families experienced two major demands by inpatient staff: 1) that the family remain uninvolved and uniformed and that 2) all decision making functions be the exclusive domain of the professional staff. Each of these demands contributed to a major change of role for the

families and quickly became sources of conflict between the
family and hospital staff.

The families' experience indicated that the demand for non-
involvement was not expressed directly, but rather communi-
cated through the staff's behavior and through messages about
what is good for the patient.

> "We would go for visits, which were regulated, and, on those
> days, we did not see any staff. I think we had one or two meetings
> with the doctor who was treating him and he was very guarded
> about what he would say or even what he thought was best!"
>
> "The first hospital he was in ended up telling me it was none
> of my business. The last one told me to just put up with the
> mistakes he is making."

Families were very aware that hospital treatment is now
short-term. They wanted all of the information that they could
get for use when their relative returned to them, as was almost
certain to happen.

> "(A private hospital) did the best job. The family must agree
> on admission to see a social worker weekly. This was most helpful
> to see as it was our first experience with hospital care. We dis-
> cussed progress, treatment plans, coping methods, blame, guilt,
> letting go, and taking care of yourself during a crisis. (A different
> private facility) offered no family support and the treatment plan
> was not shared. The family was treated like outsiders and we were
> often upset because of the lack of communication!"

Families also learned that executive decisions about caregiv-
ing were the domain of the professionals. They firmly believe
that their thoughts, experiences, opinions are not valued and
that they should not interfere.

> "One time I went to see him and he just fell on me and began
> to cry. . . . It was a tough visit. None were particularly joyful.
> The next day I called twice and probably the following morning.
> Lo and behold, the social worker called and said, 'You're calling
> too often. Quit being a smother mother. We can't allow you to
> do this.' "

The families experienced much doubt about whether or not they were reading the expectation right. They all decided that they were, in fact, expected to remain on the sidelines. All had much opposition to doing so.

> "I went to see the guy and he said, 'You love your son too much. Leave him alone. He's got to get to the bottom before he'll get better.' Well, I couldn't accept that philosophy!'

The Family Role in Community Programming

The transfer of treatment from the hospital to the community changed the role demands for families in three ways. First, families felt that they were expected to resume its role of seeking and obtaining resources.

> "Basically, families handle their own mentally ill person, so you'd better know the hospital system. You'd better know what's available in the community. You'd better know how to access treatment and vocational programs and the welfare system.... It's up to you to find out what's available, to know the benefits and to go out and seek them."
> "There all just all these things. If they didn't have the family to fall back on...

Second, the family felt obligated to resume a role of directly providing basic help. Food, shelter, safety are frequently not available through the community mental health system for the person with the mental illness (Hatfield, 1979; Johnson, 1990). The families indicated that neither is survival skill training.

> "I've intensely with him ever since he left the group home. To help him with his independent living skills, VocRehab and SRS. Trying to get him into some kind of program or something. it takes about 20 hours a week."

Third, the families believe that community professionals expected them to act as ward attendants insuring that their family member had transportation, supervision, complied with medication, adhered to schedules for time-structuring activities, attended programs, kept appointments, and much more. Typical of these kinds of expectations was:

"This young fellow, and this kind of ticked me of, said, 'Now, these people are going to have this meeting at a certain time and I want you to get your son down here. I want to make this clear. Will you see that he gets here?' I said, 'I'll do the best I can, but he's 25 years old. I can't take him like a little kid by the hand and lead him down there.

He wouldn't go. Anyway the doctor said, 'Just forget the whole thing. He'll never see a psychiatrist in this town again.' "

In one sense, families were back on more familiar ground when their loved one was in a community program. That is, some of their former caregiving role was returned to them. However, the data suggested that such ambiguity and conflict remained due to the fact that the executive role remained in the hands of the professionals, relegating the family to a sub-servient role.

The Family Role as Caregiver of Last Resort

Families could choose to adapt to their role of family members of a person with a severe mental illness, if the treatment process were reasonably static. That is, if typically a person with a severe mental illness were continuously served by either an in-patient or community program from the time of diagnosis of the illness until a return of an ability to exercise self care. The families' role varies somewhat between the hospital and community programs, but the families suggest that it is essentially to do as told by mental health professionals. Given an understanding of this meta-rule much of the role ambiguity and conflict could be avoided by compliance.

However, the families invariably described situations in which they were "back to square one". They described frequent and unpredictable situations in which their relative became a non-patient or non-client and was without formal help. When this occurred, the family felt forced to re-assume a total care-giving role.

Because of this reality, they felt that they could not ever give up the executive role they held before professional inter-vention. To do so would leave them unprepared to resume total responsibility, as they often must.

"They put my son, who was still very psychotic, into a satellite apartment, with no supervision.... He walked all the way home and stood in the bushes. My daughter looked out of the window as we were eating and said, 'Mom, he's standing out there in the bushes.' We had told him it wasn't appropriate for him to live at home, but he would rather stand in the bushes than live in an apartment where he was terrified."

"Well, the funny part of the story if you can still laugh, is that after we brought him in and fed him, intending to take him back after we ate, we got a call from the mental health center telling us that he was no longer eligible for the program because he had left without permission."

"You're suddenly back to square one. What are you going to do? You bring him in and start over. You flounder around, get out the phone book and say, 'Look, what can we do next?' What facility or program can we try?"

Discussion

This study is one of a very few efforts that have applied ethnography to phenomena of importance in caregiving for families of people with a severe mental illness. While validity and trustworthiness issues are addressed by the diversity manifested in the group/individual interviews, the variation of the settings, inclusion of both AMI and non-AMI informants and were extended by use of a survey, caution should be advised for generalizations from the findings. Although there is a high degree of correspondence with the findings of related studies (Francell, Conn & Gray, 1988; Grella & Grusky, 1989), further investigation into the family experience is needed. In spite of the methodological compromises, however, the findings do appear to paint a rather clear picture of a portion of the family experience.

The results suggest that families of people who have a severe mental illness; face continual role conflict and ambiguity as the illness revolves through its characteristic stages of treatment and no treatment. First, they are torn between an ideal of "normal" parenting and their logical adaptation to the parenting needs of a person with a severe mental illness, albeit undiagnosed. Second, their natural and necessary tendency to resume caregiving

is judged as wrong by hospital personnel and their role changes to that of bystander. Then, the families are conditionally expected to resume caregiving and are given a role resembling that of a ward attendant when their loved one returns to the community. Finally, they must, by default, often resume both exclusive and executive caregiving until their loved one is either rehospitalized or enters new program.

Obviously, there is nothing that social workers can do to relieve families' stress before they come into formal contact with the mental health system. However, once the contact is made, social workers can help families by recognizing both difficulty these families have faced and the tremendous effort they have put forth, to a greater degree than has existed in the past. Acknowledging these families' strengths can go far to normalizing their challenge and, thus, reducing stress once contact has occurred.

It is also true that macro-level phenomena dictate that families will continue to face numerous and often unpredictable system entries and exits by their loved one. Certainly, social workers need to advocate for change at this level. However, social workers can also ease families' burden by more actively involving families in helping efforts. Families are interested in involvement (Spaniol, 1990) and such involvement is rapidly becoming the standard for effective helping (Lefley, 1990; NIMH, 1988). Minimally, social workers can help the families anticipate and plan for the inevitable transitions.

Finally, communication with families is critical for helping the families reduce role ambiguity and conflict and for removing an unnecessary burden and stress. social workers are usually the professionals responsible for acting as a liaison between agencies and institutions and the family. They must bear much responsibility for changing the unproductive patterns of the past (Goffman, 1961; Rothman, 1971; Terkelsen, 1990).

The necessity of improving communication with families and of changing the traditional patterns of interaction is dramatically demonstrated by one daughter's plea:

"The latest thing is that my Mom wrote a letter to this therapist and it's the most heartfelt letter that I've ever read. This guy didn't

even respond to it. Not even an acknowledgment that he received it. There were specific things that she wanted help with. She did an excellent job of identifying manageable things that he could respond to and there was nothing. Mom's invisible. How can her thoughts and feelings be invisible to this man?"

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