

Families of Persons with Severe and Persistent  
Mental Illness: Caregiving and Support Needs

Judy Solmonson

Oregon Health Sciences University  
Department of Mental Health Nursing

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Approved:

[REDACTED]

Barbara S. Limandri, RN, DNSC, Associate Professor, Master's Research  
Project Advisor

[REDACTED]

Douglas A. Bigelow, Ph.D., Assistant Professor, First Reader

[REDACTED]

James Andrews, M.D., FRCPC, Assistant Professor, Second Reader

[REDACTED]

Carol A. Lindeman, Ph.D., Dean, School of Nursing

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When a member of the family has a long term chronic mental illness, the effects on the family are profound. The composite physical, psychological, and emotional burden wears down the family's ability to maintain a healthy environment for its ill family member and themselves. The reality of long term care for those who have one of the bewildering and poorly understood mental illnesses commonly drains the energy and resources of the family, strains family relationships, and creates a severely stressful environment (Grad & Sainsbury, 1963; Hatfield, 1978).

Deinstitutionalization has increased the burden (Goldman, 1982) and placed the family in the position, often, as primary care-giver for the person with a severe mental illness and, even more frequently, as the one on-going lifetime resource between hospitalizations and various mental health professionals (Evans, Bullard, & Solomon, 1961). In their extensive review of the literature, Kreisman and Joy (1974) found that the burden placed on these families had been poorly assessed and was not incorporated into mental health treatment planning. A growing body of literature (Chafetz & Barnes, 1989; Doll, 1976; and Hatfield, 1978) points to greater awareness of the burden of the family and their potential as collaborators in treatment, yet the difficult and frustrating position of the family remains poorly understood.

The purpose of this study was to describe what families of persons with a severe mental illness want and need to maintain good health for themselves and their ill family members.

## Introduction

### Family Burden

Keith and Matthews (1984) provided statistics indicating two million Americans were afflicted by severe and persistent mental disorders. If each of these affected only two other family members, a minimum of six million Americans are affected by mental illness.

Debuskey (1970) in his study on family reactions to long term physical diseases such as cystic fibrosis, leukemia, and heart disease noted that shock, fear, guilt, and confusion were common to all these diseases. Despite the awareness of the toll chronic physical illness takes on the family, a similar understanding on the impact of mental illness on family members is slow to develop.

The burden of mental illness imposes severe alterations in life style on the family as well as the ill member and is compounded by feelings of guilt, shame and stigma that create an atmosphere of mistrust and animosity between family and others. The presentation of unpredictable behaviors by the ill relative such as aggression, irrational beliefs, or withdrawal promotes confusion and chaos for the entire family. In addition, the mental and physical health of family members, the social and leisure activities of the family, and the domestic routine are usually adversely affected (Grad & Sainsbury, 1963).

### Exclusion of Families

Following World War II, psychiatry took on a radical environmental approach. Every psychiatric problem was given a social explanation linked to childhood experience to be treated by psychoanalysis and

child guidance: the oppression of caste and class to be treated by social psychiatry and economic reform; or current family dynamics to be treated by family therapy (Beels & McFarlane, 1982).

Laing (1967), a leading psychiatrist of the sixties, ridiculed Krepelin's idea which marked schizophrenia as a constitutional and organic condition. Instead, he thought it to be a creative response on the part of a patient to a mystifying family environment and an oppressive society. Lidz, Fleck, and Cornelison (1965) followed by Arieti (1974) viewed the family as emotionally disturbed. Arieti (1979) altered his view as he recognized a combination of causal factors (biologic, psychologic and sociologic) and saw the family less as a source of pathology and more as a major instrument of restoration.

The family is seldom identified as an important part of the treatment and rehabilitation team. This seems strange since many persons with severe mental illness rely heavily upon their relatives. Research done by Francell, Conn, and Gray (1988) found that families experienced profound stress as a result of their interactions with the mental health care system, particularly in negotiating crisis situations; acting as patient advocates and case managers; obtaining adequate community resources, continuity of care, and information; dealing with legal barriers; and communicating with mental health professionals.

Historically, family therapy has conveyed that the hospital or community mental health team provide a healthier atmosphere than the family provides, setting up a subtle competition between staff and family (Beels & McFarlane, 1982). The design of family therapy also

conveyed the accusation of guilt. Weekly meetings had the immediate purpose of improving communication and the longer term purpose of assisting the family to live apart or together with less stress. Each week the family was expected to bring problems which staff often approached by tracing their origin to parents' failure to be clear or empathic or to promote autonomy among their children. Despite the failure of some professionals to meet their needs and to understand them, the families still wanted assistance from professionals on management and coping strategies (Hatfield, 1979, 1981).

#### Development of Services to the Family

Multiple family groups emerged as awareness grew that families often had very supportive conversations with one another on visiting nights in the hospital. Education was the initial focus, but as group process took place, families began sharing their stories and offering support to one another. Several advantages were notable in the multiple family groups (Beels & McFarlane, 1982). The family developed a sense of its own expertise and set up the positive atmosphere of a self-help group with therapists as resource persons. Therapists easily shifted to behaviorally oriented family therapy as opportunities arose. In addition, the family gained a sense of social support through the group structure.

Parents' groups were a variant form of multiple family groups. They did not include the patient and usually focused on helping the parents to move the patient out of the home to more independent living (Dincin, Selleck, & Streiker, 1978). Working through guilt and disappointment and learning to become more independent of the patient



were some of the issues explored by these groups.

The integration of the family into the treatment of mentally ill persons continued to evolve in different forms that include individual families, multiple family groups, and parents' groups. In a study to ascertain the effectiveness of family educational intervention, McGill, Falloon, Boyd, and Wood-Siverio (1983) found that patients and their families in family treatment programs acquired and retained information about schizophrenia more readily than patients and families involved in individual treatment.

#### Families Priorities and Needs for Service

The desire to be helpful to families appears to have grown rapidly in the last few years. However, it remains important to understand the needs of the family as they perceive them in order for professionals to develop effective intervention strategies. Families are often very disturbed by patients' behaviors. The effects on family life and the emotional burden often cause deterioration of their psychological and physical resources to the point that their personal efficiency may be reduced and the organization and stability of their family life threatened (Hatfield, 1978).

Hatfield (1979) identified knowledge as the first priority, an important base for the caregiver role. Families living 24 hours a day with an ill relative wanted knowledge about the disease and practical techniques for coping with it. They wanted clear nontechnical explanations and the most accurate prognosis possible. Families needed advice concerning appropriate expectations for their ill relative, specific techniques for managing disturbed behavior, and information

about the common forms of treatment and practical management techniques for the major mental illnesses.

Another priority of families was knowledge of the treatment system, how to deal with it, and help in making treatment services work for them. Professional mental health services were often frustrating for the family in negotiating crises, acting as patient advocate, obtaining adequate community resources, dealing with legal barriers and communicating with mental health professionals (Francell, Conn, & Gray, 1988). McElroy (1987) concluded that the incongruity between the families' and the professionals' perceptions of priorities suggested that some professionals may need to modify their approaches with families to more specifically meet family needs.

Families also wanted support, someone to talk to who will be able to listen and understand their feelings and problems. Helping to release families from their guilt, being able to share their problems, and being empowered to lead their own lives were positive outcomes expressed by families involved in a community program (Dincin, Selleck, & Streicker, 1978). A later study by Hatfield (1979) revealed that families reported needing respite and "real" community support programs to relieve some of the burden placed on them.

The consumer advocacy movement has raised professional awareness of these needs and forced an examination of service development and delivery (Hornstra, Lubin, & Lewis, 1972). Self-help groups formed by relatives have emerged more and more frequently to fill the gap in support and education services not readily available from health professionals, as well as to advocate more directly for family members.

### Professionals' Response to the Family

Mental health professionals are developing a variety of service models, both educational and supportive, to respond to the needs of the family. Educational and supportive models of family intervention were preferred by the family over traditional family therapy (Anderson, Fogarty, and Reiss, 1980; Hatfield, 1979, 1981). There were significantly improved outcomes for the disabled family member (Falloon, et al., 1982) when family was involved in the treatment process. A supportive group approach helped families to deal with both management and emotional issues related to the mental illness of a relative (Rose, Finestone, & Bass, 1985).

Zipple and Spaniol (1987) divided current educational and supportive models into four general categories: (a) informational approaches that are designed primarily to provide information, (b) training approaches that are designed primarily to develop skills, (c) supportive approaches that are designed primarily to enhance the family's emotional capacity to cope with stress, and (d) comprehensive approaches that incorporate information, skill training, and support in a single intervention. Most models contained more than one of these approaches, but these divisions help conceptualize the goal of the intervention.

Marilyn Meisel, mother of a son with schizophrenia, teamed with Edie Mannion, a family therapist subspecializing in collaborative work with families of adults with mental illness, to found the Training and Education Center (T.E.C.) Network (Mannion and Meisel, 1989). Before implementing psychoeducational programs for families of adults with

mental illness they identified four basic tenets necessary for successful programs: collaboration, comprehensiveness, pragmatism, and flexibility. As a result of their collaborative work, they have noted four developmental stages in family work: a) catharsis, b) learning information and coping skills, c) applying information and coping skills, and d) learning advocacy skills.

Education and training, under the heading of "psychoeducation" has been receiving attention in the literature recently. Ryglewicz (1988) described the theme of psychoeducational work with families of persons with serious, ongoing mental disorders as education that provides information about the disorder and guidance about management in an atmosphere of mutual respect, collaboration and support. Increasingly, this education is presented on video tape. Neill (1989) has demonstrated the efficacy of education in a supportive group environment using "home grown" videotapes.

#### Literature Review of Family Service Needs

Two concepts about the nature of family service needs have emerged in the literature that frame this study: 1) family loss and the need for family support, and 2) family caregiving and the need for knowledge and skill. An understanding of these two concepts is necessary if psychoeducation is to be effectively designed and provided to the right people at the right time.

#### Family Loss and the Need for Family Support

One usually associates grief with loss through death, but families also grieve over the loss of their once-promising relative, now a different person, a stranger in the family (Hatfield, 1979). The

extensive needs of the ill family member and the unpredictable nature of mental illness often leave the family feeling hopeless and powerless (Francell, Conn, & Gray, 1988). A number of investigators reported that families suffered hardships that included physical symptoms of stress, marital discord, financial strain, and collapse of the indigenous social support system (Grad & Sainsbury, 1963; Lamb & Oliphant, 1978). Anger and fear were expressed by one husband who said, "A mentally sick person is the worst person in the world to live with" and that his greatest fear "is that my wife might kill me" (Doll, 1976). The emotional and physical toll on the family has brought cause to recognize the family as a client in need of supportive treatment.

#### Family Caregiving and the Need for Knowledge and Skill

The contemporary widespread policy of multiple, short-term hospitalizations, which accompanied deinstitutionalization, has increased the involvement of the family with their mentally ill member. It has been estimated that as many as two-thirds of released patients return to their families (Goldman, 1982). Evans, Bullard, and Solomon (1961) found that the family was the primary resource for the patient. Even after prolonged separation due to hospitalization, families often remained willing to help. Lamb and Oliphant (1978) concur that in this era of deinstitutionalization, families have become the primary care agents of a large proportion of persons with schizophrenia released from hospital.

Because of deinstitutionalization and the lack of community programs, many families turned their homes into psychiatric hospitals without the benefit of adequate numbers of trained staff to manage the

troubled relative. The families were fatigued and not prepared to handle that constant form of home-based psychiatric treatment.

Brown, Birley, and Wing (1972) contended that the expressed emotion (EE), a measure of relatives' expressed attitudes, exacerbates the course of mental illness with significant implications for relapse and rehospitalization rates. Rated at the time of the patient's hospitalization, families with high EE had a relapse rate of 56 percent, while families with low EE had only 21 percent. The EE behavior's of relatives were not generally abnormal or excessive, nor were they causative of mental illness, but the EE research did indicate that there were some things which can be done to make the course of mental illness better or worse. Mintz, Liberman, Miklowitz, & Mintz (1987) pointed out that EE research has stimulated the development of effective treatment programs that help to reduce the stress experienced by families and to improve the quality of life for all family members.

The emotional involvement of families often hinders their comprehension and retention of information and skills. The safe emotional distance provided by a locally produced teaching videotape improved families' abilities to cope and accept mental illness (Neill, 1989). Families reported they also learned to be more kind and gentle and not to allow their ill family member to withdraw from social contact.

#### Conceptual Framework

Mental illness is a complex brain disease involving a combination of biological, psychological, and environmental factors which are difficult to manage because of the unpredictable course of

exacerbations and remissions. The resulting stress severely alters the lives of family members as well as the ill person. How the family fits into the life of a person who is an adult in a chronological sense, yet seriously impaired in his or her ability to function, psychologically, interpersonally, and socially, creates an inherently ambiguous and conflicted role for the family (Pepper & Ryglewicz, 1984).

From the existing body of literature emerges a picture of the burden of the family divided into two quite different components: the burden of loss and the burden of caregiving. The burden of loss incorporates the grief and suffering experienced by the family as a result of the mental illness of a family member. A reduction in the quality of homelife, interference with family member's employment, disturbances in relationships with other family members, fear, and financial distress were also parts of the loss. The second role is that of caregiver wherein the family takes responsibility for the ill member's care. The family role has been inadequately assessed so families frequently have not been integrated into mental health treatment planning. When they have, the purpose was more often short term, to resolve the ill relative's problems without recognizing the family as either victims of grief in the short term or as long term collaborators in treatment. Alienation, treatment resistance and a restless search for something more are common responses among families when resolution of the symptoms does not occur despite their attempts to follow the prescribed treatment.

There appears to be a prioritization of needs between the support and caregiving roles. First come the support needs resulting from the

burden of loss. Like all people experiencing acute and/or chronic stress and pain, family members may be depressed, angry, anxious, demanding, and sometimes unreasonable in their demand for answers and solutions. Healing of these wounds must be addressed before the family is prepared for the second role, that of the caregiving burden. Similar to the general population, families of those with mental illness do not acknowledge their needs for emotional support. One major obstacle is the American image of independence and self-sufficiency which clouds the importance of meeting personal and emotional needs that result from a severe loss. These families, having borne the burden of (falsely) presumed guilt, may be less inclined to care for themselves. The limited attention in the literature given to addressing the families' emotional needs supports this assumption.

Clinicians and mental health administrators have the responsibility to provide the consultation, education, and support to families that will substantially improve the coping efforts and outcomes of all family members (Mintz, Liberman, Miklowitz, & Mintz, 1987). As the emotional pain eases, families can determine their needs and begin to equip themselves with the knowledge and skills necessary to fulfill their caregiving role. The empowerment which results from this greater understanding of the problems of mental illness and how to meet those problems may then lead to an understanding of the emotional entanglement which often confounds positive outcomes.

#### Research Questions

1. What are the specific caregiving and support needs of the family in relationship to their mentally ill relative?



## 2. How do specific caregiving and support needs differ among families?

### Method

#### Sample

All (63) family members who participated in the joint Oregon Mental Health Services Division (MHDDSD) and Oregon Alliance of Advocates for the Mentally Ill (OAAMI) educational workshops held at different locations (Corvallis and Pendleton) at two different times (October and March) were invited to participate in this research. Four workshop participants were consumers of mental health services, not family members, and were excluded. Of the remaining 59 participants, two participants with unlisted phones were unavailable for interview and one family member refused, saying she was too old to get involved and that her son was doing well now and had a good job. Four subjects were unavailable to respond. A total of 52 family members were included. The number of ill relatives among these 52 families was 58 (3 families who had 2, 3, and 4 ill members).

Table 1 shows the demographic distribution of the sample of family subjects. Ages ranged from 36 to 73 with 61.5% of the subjects between 47 and 64 years of age. Seven of the subjects were male and the remaining 45 were female. Only 4 of the subjects were outside the range of 12 to 18 years of formal education. The majority (80.8%) of family members were married. There was a fairly equal distribution of families residing in rural (16), town (12), suburban (12), and city (12) locations. Mental health consultations were enlisted by 43 (82.7%) of the family members to assist them in caring for their ill relative. There were 45 (86.5%) family members who were members of

OAAMI, 35 of whom participated regularly.

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Insert Table 1 about here

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A majority (77.6%) of the subjects were a parent of a person with mental illness with the remainder as spouse, sibling, or a more distant relationship (Table 2). Most (80.6%) families reported regular contact with their ill relative that was continuous, daily, or weekly with the remaining 19% on a monthly or quarterly basis.

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Insert Table 2 about here

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Table 3 shows the demographic distribution of the ill relatives. Eighty percent were between 20 and 44 years of age with the full range from age 18 to 75. Forty-one (70.7%) of the ill relatives were male and 17 (29%) were female. The number of years of formal education for this group ranged from 10 to 18 years with 85.9% receiving 12 to 14 years. The number of years of illness ranged from 6 months to 30 years with a mean of 10.8 years. Most of the ill relatives (94%) had a severe and persistent mental illness. The majority of ill relatives lived either in the family home (15, 25.9%) or independently (28, 48%).

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Insert Table 3 about here

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**Table 1**  
Characteristics of Family Participants (N=52)

		N
Age		
Mean	56.5 years	
Range	36-73 years	
Gender		
Female	88.5%	46
Male	11.5%	6
Education		
Mean years of school	15 years	
Range	9-23 years	
Relationship status		
Married	81.0%	43
Divorced	11.5%	6
Widowed	5.8%	3
Single	1.9%	1
Residential area		
Rural	30.8%	16
Town	23.0%	12
Suburban	23.0%	12
City	23.0%	12
Mental health consult	82.7%	43
AMI membership	87.0%	45
AMI attendance		
Regularly	67.3%	35
Frequently	17.0%	7
Rarely	9.6%	5
None	9.6%	5

Table 2  
Relationship and contact of family participants  
with ill relative

Relationship to relative	N	%
Parent	45	77.6
Spouse	5	8.6
Sibling	3	5.2
Other	5	8.6
Contact with relative		
Constant	16	27.6
Daily	14	24.0
Weekly	17	29.0
Monthly	7	12.0
Quarterly	4	7.0

**Table 3**  
Ill relative description (N=58)

Age		
Mean	35 years	
Range	18-75 years	
Gender		
Female	29%	17
Male	70.7%	41
Education		
Mean	13 years	
Range	10-18 years	
Years of illness		
Mean	10.7 years	
Range	.5-30 years	
Diagnosis		
Schizophrenia	26	45
Bipolar	13	22
Unipolar, depression	6	10
Schizoaffective	10	17
Other	3	5
Type of residence		
Family home	15	26
Supervised living	9	16
Independent housing	28	48
Hospital	6	10

Occupational categories and employment status are listed in Table 4. Most of the family members (75%) considered their occupation domestic (21), or professional (18). The 20 homemakers were considered in a full time occupation, acknowledging the service given without salary but with a trade in services with spouse. Each of the homemakers named community service as an additional piece of their work. Several noted their choice to be at home during early acute stages of their family member's illness. Employment status was full time for 30 (57.7%), part time for 11 (21%), and retired for 11 (21%). In contrast to the family members, ill relatives represented the same employment categories except the ill relatives predominated in skilled labor (8) and unskilled labor (37). Employment status for most of this group (92.7%) part time (13) and unemployed (41).

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Insert Table 4 about here

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The sample of ill relatives used mental health services (Table 5) ranging from medication management (47,81%), case management (34,59%), socialization (22,39%), to training, supervised work, and counseling, each of which were used by 11 (19%). Ten percent were hospitalized at the time of the survey.

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Insert Table 5 about here

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Table 4  
Employment status and categories for family and ill relative

Status	Family (N=52)	Ill Relative (N=58)
Full time	30 (57.7%)	2 ( 3.4%)
Part time	11 (21.0%)	13 (22.0%)
Retired	11 (21.0%)	2 ( 3.4%)
Unemployed	0	41 (70.7%)
Categories		
Domestic	21 (40.0%)	2 ( 3.4%)
Managerial	8 (15.0%)	1 ( 1.7%)
Professional	19 (36.5%)	4 ( 6.9%)
Sales and clerical	2 ( 3.8%)	2 ( 3.4%)
Skilled labor	2 ( 3.8%)	8 (13.8%)
Unskilled	0	37 (63.8%)
Student	0	4 ( 6.9%)

**Table 5**  
Mental health services used

	Yes	%
Medication	47	81
Case management	34	59
Training	11	19
Supervised work	11	19
Socialization	22	39
Counseling	11	19
Hospitalization	6	10



### Instrument

Data collection took the form of a thirty minute telephone survey. The researcher developed a questionnaire (Appendix A), requesting demographic information about the client (14 items) and the ill relative (14 items) and containing two scales to provide a description of the needs and wants of families. Based upon other research (McElroy, 1983; Hatfield, 1987; Krauss & Slavinsky, 1982), the research committee, and the researcher's experience, the researcher developed scales on loss and caregiving. The loss scale (15 items) and the caregiving scale (14 items) were tested for content validity by a committee of experts. Within the loss scale were three items (5, 9, 10) that relate to family members' needs regarding loss.

The researcher pilot tested the completed questionnaire with four family members. In addition two mental health experts reviewed and critiqued the questionnaire. The researcher revised the questionnaire based upon the critique and pilot results prior to using the tool with the study sample. All items were forced choice with a four point Likert scale, eliminating any uncertain categories.

### Procedure

One week prior to the telephone survey, the researcher mailed a letter of introduction to the sample. The letter (Appendix B) described the study, how the sample was selected, and the role of the study participant. Participation was completely voluntary and the letter explained that the participant may refuse to participate and may withdraw at any time during the study. Another cover letter (Appendix C) written by an OAAMI officer was included to introduce the researcher

and encourage participation. Since the sample was drawn from a short list of known participants in the OMHDSDD/OAAMI workshop, the sample was not anonymous. However, the data was treated confidentially with only random codes used to identify the survey results and names and phone numbers of participants were kept separate from the survey results. The questionnaire accompanied the letter with a request to complete the questionnaire before the phone call in order to allow time for thoughtful consideration of each item. The questionnaire with cover letters was sent out one week prior to the phone call with a request to prepare the answers. The researcher conducted phone interviews at an appointed time to collect the data. A telephone script (Appendix D) was used with each call.

## Results

### Question 1: What are the Specific Caregiving and Loss Needs?

Family members reported a range of caregiving needs limited to the choices of *sometimes* or *very often*. Informational needs included information about mental illness (92%), medication (92%), treatment (90%), work (71%), and housing (69%). Learning needs included learning how to obtain mental health services (79%), to handle a relative's apathy (76%), to talk with an ill relative (75%), to handle a relative's unpredictable schedule (63%), and to handle their ill relative's aggression (58%). Advocacy needs included general advocacy skills (90%), more involvement in mental health treatment planning for their ill relative (80%), and more contact with relative's case manager (78%). Support needs were a peer group (96%) and a listener (88%) who understands mental illness (96%), counseling to help deal with feelings brought about by relative's illness (65%) and someone to talk to the ill relative for the family (49%).

The emotional and physical losses accompanying the mental illness of a relative designated by the family member as *some* or *a great deal* were greatest in the amount of stress and sadness (94% each). Other losses included a reduction in the quality of homelife (79%), a sense of hopelessness (67%), problems affecting family members' employment (67%), financial distress (65%), anger (58%), problems with relationships to other family members (54%), fear (52%), embarrassment (50%), and guilt (19%). Twenty-nine percent indicated they had very little energy or time left for themselves as a result of their relative's illness.

Question 2: What are the Specific Caregiving and Support Need Differences Among Families?

To explore differences among families, demographic variables were correlated with caregiving needs and support needs and losses. The researcher computed Pearson's correlation coefficients for 7 variables: population density around family home, years of education of family member, years of ill relative's illness, ages of family member and ill relative, frequency of contact with the ill relative and attendance at AMI. Prior to analysis an alpha level of 0.05 was set as a cut off for statistical significance.

Density of population. The density of population did not correlate significantly with emotional loss. However, the more urban the population, the greater was the family's fear of the relative ( $r=.349, p=.01$ ). Those in more rural areas expressed a trend of greater need for information on medication.

Education of the family. The more educated the family member, the more they wanted information about treatment ( $r=.270, p=.05$ ). However, those with less years of education reported more anger about having a relative acquire a mental illness ( $r=-.269, p=.05$ ). A moderate trend toward people with more education experiencing greater financial stress and those with less education having greater fear of their ill relative was also indicated.

Loss Intensity Increases Need for Support

Years of illness. The more recent the illness the greater the sadness ( $r=-.323, p=.02$ ) the family experienced. Family also indicated

a greater need for a counselor for the ill relative ( $r = -.260, p = .05$ ) in the early years of illness. A need for advocacy skills increased with the length of illness ( $r = .362, p = .009$ ). Notable trends without statistical significance at the alpha level were a greater need for a listener and a peer group and problems in the work place for other family members as a result of the illness of their relative. Families whose relative had more years of mental illness had a greater need for supervised work for their relative and less anger.

Age of family member and ill relative. The younger the family member, the greater the embarrassment ( $r = -.333, p = .02$ ), the more need to learn how to talk to the ill relative ( $r = -.348, p = .01$ ), and a greater need for a listener.

Similarly, family life was affected by the age of the ill relative. The younger the relative, the more information about housing ( $r = -.423, p = .002$ ), and work ( $r = -.353, p = .01$ ) were in demand. Families needed more assistance in handling aggression ( $r = -.271, p = .05$ ) and the unpredictable schedule of their relative ( $r = -.304, p = .03$ ) and found they had less time and energy left for themselves ( $r = -.279, p = .05$ ).

Families with younger ill relatives needed more counseling services and experienced a higher level of stress, sadness, and fear of their relative. A desire for more information about treatment and an intermediary to talk with the ill relative for them was expressed.

Family contact. The more frequent the family had contact with their ill relative, the greater the reduction in the quality of homelife ( $r = -.363, p = .008$ ) and the greater the anger ( $r = -.297, p = .03$ ). Frequent contact also increased the amount of supervised work

( $r=.360, p=.006$ ) used by the ill relative. The frequency of contact decreased the longer the illness ( $r=.280, p=.035$ ). Sadness was also a part of the emotional response of the family who had more frequent contact.

These data are consistent with the concept that families experiencing intense loss need more support than knowledge and skill until the loss needs moderate.

Acute Needs for Support and Education Met by Alliance for the Mentally Ill (AMI)

Frequency of AMI participation. As might be anticipated, certain losses of the family were accompanied by more frequent AMI attendance. The emotional sadness of having a mentally ill relative ( $r=.274, p=.05$ ), and physical losses that include a reduction in the quality of homelife ( $r=.277, p=.05$ ), and fear of the ill relative ( $r=.301, p=.03$ ) were positively related to frequency of AMI attendance. Frequent participants also expressed a greater need for a listener ( $r=.302, p=.03$ ). Caregiving needs expressed by those attending AMI frequently were information on housing ( $r=.332, p=.02$ ) and work ( $r=.323, p=.02$ ). These regular participants found they had little time and energy left for themselves after caring for their ill relative ( $r=.363, p=.008$ ). These data are consistent with the concept that AMI affiliates meet the acute needs of the family for support, information, and skill.

Discussion

The results of these analyses clarify caregiving and support needs and how they differ among families, extend the findings of other

investigations by suggesting a priority of needs for families with relatives who have a severe and persistent mental illness, and substantiate the positive impact of AMI in meeting the acute needs of the family.

The high rate of response (only one refusal) may be attributed to a difficulty in saying no. Subjects may have been convinced by the cover letters that it was meaningful to participate in this study. The gratitude expressed by a majority of the subjects to the researcher indicated that the experience had been more helpful than anxiety producing and that they valued research about the needs of the families of persons with a mental illness.

The onset of mental illness in the late teens and early twenties and the mean years ill (10.5) of the relatives is consistent with the mean age of the subjects (56.5) who were primarily parents. The predominance of women (88.5%) as respondents on this survey about the needs of families with a mentally ill relative is consistent with other such surveys where women usually reply, up to 86% (Hatfield, Fierstein, & Johnson, 1982; Hatfield, 1978). The high involvement in the AMI organization by the majority (84.3%) of the subjects and the mean years ill(10.5) of the relative indicate the family is familiar with the mental health system and knows how to get services. The high rate of unemployment and part time work among ill relatives places them in the lower socioeconomic strata. The predominance of male ill relatives may indicate a higher degree of difficulty in managing the illness of a male.

The family burden was greater when there was more contact with the ill relative. The reduction in the quality of the family's homelife and anger and sadness were greater when the ill family member lives in the family home or otherwise has frequent contact. The family of a son recently diagnosed with schizophrenia repeatedly demanded of this researcher during the telephone interview, "What are you going to do about this?" The obvious anger and frustration in dealing with their son's illness without sufficient assistance and support was painfully evident. Another parent stated, "Its worse than having your child be dead. At least then, there's an end." Sadness was expressed by another saying, "I had great dreams for our son at one time." The loss was profound and caused long lasting trauma to the family.

The greater need for supervised work when families had frequent contact describe the need for meaningful daily activity not easily developed by the family unit. One subject proudly stated her son worked for his father as a draftsman on a part time basis. The family business allowed the latitude necessary to employ the ill son. This kind of latitude was not readily available in the job market. Supervised work settings require continuing education and support to employers in gaining their cooperation in employing persons with a mental illness. The less frequent contact as the years of illness increased may reflect more independence and self-sufficiency for the ill relative or it may be greater alienation and separation to ease the pain of both parties.

The higher degree of fear of the ill relative reported by the more urban population may be a result of the lack of community more



common in urban areas compounded by the self-imposed isolation of families in response to their relative's unpredictable and unexplainable behavior. It may also address the independent, self-sufficient nature of more rural people who regularly must solve problems alone.

The greater need for information about psychiatric medications in less densely populated areas may be explained by the smaller number of mental health care professionals including pharmacists who are familiar with specific information about the actions and side effects of this group of medications.

When symptoms of mental illness first appear and before some stability can be attained, the confusion and pain experienced by the family is very trying. Anger and sadness combine in the anguish of the family. They seek out an understanding listener and a peer group to gain support in treating this difficult illness that has so drastically changed their ill relative. The emotional and physical drain created problems for family members in their workplaces. Repeatedly subjects related the higher intensity of loss with early stages of the illness.

As the illness becomes more manageable with time and treatment, the more the family wanted supervised work. Meaningful activity gives dignity and satisfaction to the ill relative as well as to the family. A need for more advocacy skills that will assist in improving treatment, housing or work opportunities for all people with mental illnesses rises as the relative becomes more stable. One parent who was a strong advocate stated, "I don't like to talk about my own situation any more, but I like to listen."

The acuity of losses and needs is greater for younger families and their younger ill relative. Younger family members experienced greater embarrassment probably due to their limited understanding of the illness. Their inexperience in dealing with unusual behaviors created the need to learn how to talk to their ill relative. Under these circumstances their high need for a listener is expected.

A greater degree of stress, sadness, and fear was sustained by those with younger ill relatives. These reactions are consistent with family responses to long term physical illnesses (Debuskey, 1970). It is not surprising that these family members were asking for information about treatment, housing, and work as well as how to handle aggression and the unpredictable schedule of their relative. Getting assistance and information on how to manage the erratic course of mental illness is a natural choice for families as they deal with the first signs of illness in their young relative. The call for an intermediary would give them relief and a model to help them learn to communicate better.

Several comments described family feelings about professional services. "It seems family members are often very well informed and mental health professionals are undertrained." "I want the mental health team to know I am a resource rather than a part of the problem." "I'm concerned that the results of this study will not reflect the lack of service available to people just beginning to deal with mental illness." "Professionals still reflect the schizophrenogenic family concept. They are often not open to collaborating with the family." "Mental health doesn't come across as very compassionate." The concerns of these family members challenge the mental health treatment

team.

Family members with less formal education showed more fear and anger. Lack of information about the illness and skills to deal with it naturally draw upon this emotional response. People with more education revealed their propensity for more education by indicating a high need for more information about treatment for mental illness. The greater financial distress experienced by the more schooled family members may be a result of investing more in education and training and other kinds of treatment for the ill members in hope of preparing them to be self-sufficient. One woman explained she and her husband had divorced to maintain financial solvency while procuring mental health services for their ill son and had later remarried.

Since the stated goals of AMI groups are support, knowledge, advocacy, and research, it is reasonable to expect that the frequency of AMI attendance is significantly correlated to the intensity of loss and need for support and caregiving information and skills. The sadness about the affliction of mental illness upon their relative was understandably high. Those family members who found a considerable reduction in the quality of their homelife, and felt afraid or endangered by their relative sought the support of AMI. Family members constantly surrounded by the effects of this disease searched for effective ways to fulfill their needs. A portion of the considerable need for the support of a listener who understands was met by AMI's numerous affiliates and their regularly scheduled meetings. "She saved my life," reported one family member in describing an AMI member who willingly listened and understood her problems concerning her ill

relative. The lack of time and energy left for the family member who attends AMI frequently tells of a devaluing of self and limited attention to personal needs by family members overwhelmed with the care of their ill relative. The shared need for resources relieves and empowers the family member seeking it. Information about housing and work are more particularly sought at AMI due to its scarcity and the shared interest and concern about developing these resources among group members. The educational program of this group includes mental health professionals and skilled, seasoned family members whose expertise assists others.

The source of strength for AMI members is unclear. Several long term members indicated they no longer needed to talk about their ill relative but wanted to be more effective in advocating for the common needs of persons with a mental illness. This indicates a maturity factor in coping with a stigmatized identity. The admitted burn-out of several long time members and their requests for multi-faceted programs that would address both support and caregiving needs and advocacy skills revealed a void for some members in finding adequate reinforcement to sustain and nourish their continued giving to those new families who enter AMI in such desperation to understand and manage the mental illness of their loved one.

Limitations. Several limitations of this study should be noted here. First, the subjects studied were all connected with an AMI affiliate by virtue of their attendance at the family workshop co-sponsored by that organization. Membership indicates a familiarity with the mental health system, assertiveness, and personal advocacy

skills that do not generalize to all families who have a relative with a severe and persistent mental illness. Secondly, the acuity of needs may be greater for those people who are seeking help at a workshop intended to meet the needs of families, and therefore, not a representative sample of all families with a relative with a mental illness.

Despite these limitations, a number of the findings are noteworthy. A priority of needs was demonstrated among family members. In the early stages of a relative's illness, the family experienced loss and greater needs for support and specific information and skills. Stress, anger, and sadness reflected the emotional loss while families desperately sought information about treatment, housing, and work for their ill relative as well as skill in handling aggression and the unpredictable schedule of their relative. Alliance for the Mentally Ill (AMI), a self-help organization that meets regularly in small local groups had become a vital source of support and information for family members. Longer term members concentrated on more general advocacy skills as the illness of their relative became more manageable with time and treatment. The ready availability of AMI affiliates had restored hope and the promise of better days ahead for many families as they groped for resources in the early stages of their family members illness. Mental health care services can incorporate findings about the differences among families correlated with density of population around the family home, education of the family member, years of illness, the ages of the family member and the ill relative, family contact and frequency of AMI attendance.

### Recommendations

These findings suggest a priority of needs for families with relatives who have a severe and persistent mental illness and substantiate the positive impact of AMI in meeting those needs. Mental health professionals have a particular responsibility to the families of younger mentally ill relatives. It is important that mental health services be more accessible to families as they first recognize their relative's illness. Efforts to simplify and centralize professional services including the development of smaller satellite treatment centers in metropolitan areas would enhance accessibility.

The state mental health organization might also employ a family liaison who would provide expertise to AMI affiliates and other self-help support groups as well as community mental health centers. The development of support groups throughout the state would be greatly assisted by a knowledgeable professional who would teach and give support to the local leadership.

Another possibility would be for community mental health centers to prioritize services to the family with a specific professional who works exclusively with families. This family liaison's responsibility would be to provide support, knowledge, and skill training for family members. This alternative would allow opportunity for family to meet their support and caregiving needs from a professional who would develop a relationship with the family so that difficulties could be resolved before problems become too large. A multimedia orientation would be prepared and offered to each family as they enter the system. More in-depth material would be made available as the family shows

interest or readiness to this easily accessible professional. This liaison would develop family workshops offered regularly by the mental health center and serve as liaison to the local AMI group. Referring family members to AMI by word-of-mouth and through written brochures would be another responsibility. Case managers would use this person to provide in-depth family assistance and share in treatment planning that included the family and the entire treatment team. The liaison would arrange and prepare both family and staff in order to better utilize the time. Teaching staff about this priority and ways to integrate the family into treatment planning would improve staff response to the family. It would be the goal of this family liaison to develop a partnership relationship with the family to strengthen their caregiving skills and give sufficient support to maximize the health maintenance of both the family and their relative.

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Family Questionnaire

Information about yourself

1. Sex: Male\_\_\_ Female\_\_\_
2. Marital status  
Single\_\_\_ Married\_\_\_ Cohab\_\_\_ Separated\_\_\_ Divorced\_\_\_ Widowed
3. Relationship to ill family member:  
Parent\_\_\_ Sibling\_\_\_ Spouse\_\_\_ Other\_\_\_
4. Highest level of education: Grade \_\_\_\_\_
5. Age \_\_\_\_\_
6. Usual occupation of self \_\_\_\_\_
7. Your employment: Part-time\_\_\_ Full time\_\_\_ Retired\_\_\_ Unemployed\_\_\_
8. Usual occupation of spouse \_\_\_\_\_
9. Spouse's employment: Part-time\_\_\_ Full time\_\_\_ Retired\_\_\_
10. Residence: Rural\_\_\_ Town\_\_\_ Suburban\_\_\_ City\_\_\_
11. Member of AMI or other support group  
Yes \_\_\_ No \_\_\_
12. Frequency of participation  
None \_\_\_ Rarely \_\_\_ Frequently \_\_\_ Regularly \_\_\_
13. Frequency of contact with mentally ill family member  
Constant \_\_\_ Daily \_\_\_ Weekly \_\_\_ Monthly \_\_\_  
Quarterly \_\_\_ Yearly \_\_\_ Other \_\_\_
14. Have you ever engaged the services of a mental health professional (psychiatrist, social worker, psychologist, or nurse) to help you take care of your mentally ill relative?  
Yes \_\_\_ No \_\_\_

*Information about your mentally ill family member:*

15. Age \_\_\_\_
16. Sex: Male \_\_\_\_ Female \_\_\_\_
17. Diagnosis \_\_\_\_\_
18. Date of first major crisis \_\_\_\_\_
19. Highest level of education: Grade \_\_\_\_\_
20. Usual occupation \_\_\_\_\_
21. Amount of employment: Part time \_\_\_\_ Full time \_\_\_\_ Retired \_\_\_\_ Unemployed \_\_\_\_

Type(s) of mental health contacts:

22. Medication monitoring: Yes \_\_\_\_ No \_\_\_\_
23. Case management: Yes \_\_\_\_ No \_\_\_\_
24. Training: Yes \_\_\_\_ No \_\_\_\_
25. Work: Yes \_\_\_\_ No \_\_\_\_
26. Socialization Program: Yes \_\_\_\_ No \_\_\_\_
27. Other \_\_\_\_\_
28. Lives in:

Family home \_\_\_\_ Structured living facility \_\_\_\_  
Own home or apartment \_\_\_\_  
Hospital \_\_\_\_ No fixed address \_\_\_\_

*These questions have to do with the family education training workshop you attended in either Corvallis or Pendleton.*

29. You attended the workshop at which location?  
Corvallis \_\_\_\_ Pendleton \_\_\_\_
30. To what extent was your role in the family education training workshop defined?  
None            A little            Some            A lot
31. As a result of your participation in this conference has your sense of satisfaction in caring for you mentally ill relative changed?  
None            A little            Some            A lot

32. Did you gain a better sense of control over your life as a result of your workshop participation?  
No            A little            Some            A lot
33. Do you feel more comfortable about working with the mental health team since the workshop?  
Worse            The same            Better            Much better
34. Did you increase your sense of hope?  
No            A little            Some            A lot
35. Did you the workshop give you a better sense of direction?  
No            A little            Some            A lot
36. To what extent have you used the Bridges manual since the workshop?  
None            A little            Some            A lot
37. What topics of the manual were most helpful?
38. What changes would you suggest for the Bridges manual?
39. Did the Bridges workshop increase your awareness of supplemental materials available to help families?  
No            A little            Some            A lot
40. Was the information presented clearly?  
No            Fairly clear            Clear            Very clear
41. To what extent was the workshop too long or too short?  
Much too long    Too long    OK    Too short    Much too short
42. Was the facility adequate?  
No            Fairly adequate            Adequate            Very adequate
43. Was the timing (season, week, day) of this workshop appropriate?  
No            OK            Good            Very good
44. Did the workshop prepare you to take responsibility for the provision of education and/or support activities in your area?  
No            A little            Some            A lot
45. To what extent have you collaborated with AMI and/or the community mental health center to provide family education and support since the workshop?  
Less            The same            A little more            A lot more

46. What were the strengths of the workshop?

47. What additions or deletions would you suggest for the next workshop?

*Please tell me how much you need (or have needed) each of the following.*

48. I need information about mental illness.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_
49. I need information about what treatment is available for mental illness.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_
50. I need information about psychiatric medications.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_
51. I need information about housing for my ill relative.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_
52. I need information about work for my ill relative.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_
53. I need help in learning how to talk to my mentally ill relative.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_
54. I need help in getting mental health services for my ill relative?  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_
55. I need advocacy skills to improve housing, work and/or treatment options for mentally ill people.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_
56. I need someone to talk to my mentally ill relative for me.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_
57. I need help in learning how to deal with the withdrawal and/or apathy of my family member.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_
58. I need help to learn how to deal with my family member's aggressiveness.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_
59. I need help in learning how to manage the unpredictable schedule of my family member.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_

60. I need more contact with my ill relative's case manager.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_
61. I need more involvement in the mental health treatment plan for my ill relative.  
Never\_\_\_ Seldom \_\_\_ Sometimes \_\_\_ Very often \_\_\_

*Please answer these questions on the basis of your personal experience as it applies to now and in the past.*

62. How much do you feel embarrassed or stigmatized by having a mentally ill family member?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
63. To what extent does mental illness affect your work and/or the work of other family members?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
64. To what extent does mental illness reduce the quality of your homelife?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
- To what extent does your mentally ill family member cause you:
65. ....stress/anxiety?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
66. ....anger?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
67. ....sadness?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
68. ...problems in your relationships with other family members?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
69. ...a sense of hopelessness?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
70. To what extent do you want counseling to help you deal with these feelings?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
71. Do you feel guilty or to blame for the illness of your family member?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
72. To what extent do you feel endangered or afraid of your ill family member?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
73. To what extent does your family member cause you financial distress?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_

74. How much do you want a listener who understands mental illness?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
75. To what extent would you want a peer group who understands mental illness?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_
76. How much time and energy do you have left for yourself after taking care of your mentally ill family member?  
A great deal \_\_\_ Somewhat \_\_\_ Very little \_\_\_ None \_\_\_



Dear Bridges Conference Participant,

In recent years there has been a growing recognition of the burden of the family in caring for a mentally ill relative. This stress on the family makes it difficult to maintain a healthy environment for both themselves and their ill relative. Self-help groups such as AMI are a rich source of information because of their keen knowledge of the subject and their willingness to advocate for the needs of mentally ill persons.

I am a mental health nurse completing my master's degree at OHSU. I am surveying families who attended the Bridges conferences in Pendleton and Corvallis about their needs and about that meeting. I have contracted with Sydney Hatch of the Mental Health Services Division who was the training coordinator for that conference, to conduct a study to gain a better understanding of the needs of families.

I will be calling to interview you by phone. I have enclosed the questions I will ask. If you are willing to assist me, please consider your answers before my phone call one week from now. You may want to write them down on the questionnaire before we talk.

If you do not wish to be called, you may call me at 629-0388 to let me know. Refusal will not affect your relationship with the Mental Health Services Division or Oregon Health Sciences University. My research is sponsored by Dr. Barbara Limandri, faculty member of Oregon Health Sciences University Department of Mental Health Nursing. If you have any questions, you may call her at 279-7827.


The results of this study will be used to plan the spring and fall family training workshops in Oregon, in addition to gaining more information about the needs of families with mentally ill members. It will also be used for my research thesis on family needs. The information will be presented only in aggregate form and your responses will remain confidential.

Thank you for your time and consideration. I will be calling you the week of February 17.

Sincerely,

Judy Solmonson, RN

cc: Sydney Hatch  
Barbara Limandri, RN, DNSc



Oregon Alliance Of Advocates For The Mentally Ill

January 25, 1990

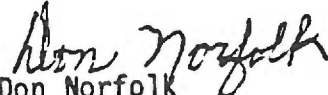
Dear "Bridges" Participant:

It has been some time now since you were first introduced to the training manual "Bridges". As you know, the publication of the manual was a joint effort of the Mental Health and Development Disabilities Division and the Oregon Alliance of Advocates for the Mentally Ill. We hoped "Bridges" would provide professionals, and family members alike, a better understanding of mental illness and provide coping skills so necessary for the handling of everyday problems of the disease a little easier.

Now it is time for us to evaluate how much "Bridges" and the conferences have helped. We also need to know what needs to be added to the manual and to future conferences that would make it more valuable to you. With these thoughts in mind, the Mental Health Division has commissioned the services of Judy Solmonson, a graduate student of the Oregon Health Sciences University, to conduct an evaluation study for us.

All of us at OAAMI would appreciate your taking the time to work with Judy in the completion of the questionnaire. Thanks for your cooperation and help. With your input, we will be able to continue to provide updates and the additional sections to "Bridges" and for future conferences, that tell us what you want and need.

Yours truly,

  
Don Norfolk  
OAAMI  
Director of Education



Affiliate of the National Alliance for the Mentally Ill

Telephone script

A. Introduction

Hello. This is Judy Solmonson, a graduate mental health nursing student from OHSU. You received a letter from me last week telling you about my research project in which I wish to gain a better understanding of the needs of families of persons with a mental illness and to evaluate the family education workshop you attended. Do you have time to talk now?

NO When would be a good time for me to call back?

-----

YES

Do I have your permission to ask the questions you received in the mail from me?

Please understand if you desire at any time to stop, you may, and it won't affect your relationship with the Mental Health Division or OHSU.

Do you have your questionnaire available?

First I will gather some basic information about you and your family member as you see on the questionnaire. Then I will follow with the rest of the questions listed.

Do you have any questions or comments before I start?

Let's begin with information about yourself.

- B. Demographics
- C. Workshop Evaluation Scale
- D. Caregiving Scale
- E. Loss Scale
- F. Closing

I appreciate the time you have taken to answer these questions. Do you have any questions about this study that you would like to ask me? Your information will be useful in planning future workshops and mental health services. Thank you.  
Good-by.

## Abstract

Title: Families of Persons with Severe and Persistent Mental  
Illness: Caregiving and Support Needs

Author: Judy Solmonson, RN, BA

Approved: \_\_\_\_\_  
Barbara J. Limandri, R.N., D.N.Sc.,  
Associate Professor, Master's Research Project Advisor

The purpose of this study was to gain a better understanding of what families of persons with a severe and persistent mental illness want and need to maintain good health for themselves and their ill family member. This descriptive correlational research used the entire population (63) of family participants in a workshop intended to meet the needs of families with mentally ill family members. A researcher developed instrument containing demographics and scales on a workshop evaluation, family needs, and family loss, was mailed one week prior to a 30 minute telephone interview. Correlations were used to determine specific support and caregiving needs, and how they differ among families.

Noteworthy findings indicated a priority of needs among family members and substantiated the positive impact of AMI in meeting needs of the family. In the early stages of a relative's illness, the family experienced more loss and greater needs for support and specific information and skills. After those needs were met, a broader base of information and skills were sought. Families of younger relatives with less years illness experienced stress, anger, and sadness ( $r=-.323$ ,  $p=.02$ ) while at the same time they desperately sought information about treatment, housing ( $r=-.423$ ,  $p=.002$ ), and work ( $r=-.353$ ,  $p=.01$ ) for their

ill relative as well as skill in handling aggression ( $r=-.271, p=.05$ ) and the unpredictable schedule of their relative ( $r=-.304, p=.03$ ). Advocates for the Mentally Ill (AMI), a self-help organization that meets regularly in small local groups, became a vital source of support and information for family members. Family members whose relative had been ill longer reported a greater focus on advocacy ( $r=.361, p=.009$ ).

Differences among families were correlated with density of population around the family home, education of the family member, years of illness, the ages of the family member and the ill relative, family contact and frequency of AMI attendance. More urban families reported more fear of their relative ( $r=.349, p=.01$ ). The younger the family member the greater their embarrassment ( $r=-.333, p=.02$ ) and the more need to learn how to talk to the ill relative ( $r=-.348, p=.01$ ). The less time and energy family members had for themselves, the more often they attended AMI meetings ( $r=.363, p=.008$ ). Frequent attenders also had a greater need for supervised work for their relative ( $r=.361, p=.006$ ) and found a greater reduction in the quality of their home life ( $r=-.363, p=.008$ ).

These findings suggest that mental health professionals have a particular responsibility to the families of younger mentally ill relatives. It is important that mental health services be more accessible to families as they first recognize their relative's illness. In addition, professional expertise that offers organizational skills, support, and education to self-help groups is also indicated.