INFORMATION TO USERS

The most advanced technology has been used to photograph and reproduce this manuscript from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book. These are also available as one exposure on a standard 35mm slide or as a 17" x 23" black and white photographic print for an additional charge.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

U·M·I

University Microfilms International
A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
313/761-4700 800/521-0600

Order Number 9000052

An educational group program emphasizing community resources: A model for training caregivers of the chronically mentally ill

Moore, Penelope Johnson, D.S.W.

City University of New York, 1989

U·M·I
300 N. Zeeb Rd.
Ann Arbor, MI 48106

A

An Educational Group Program Emphasizing Community Resources A Model for Training Caregivers of the Chronically Mentally Ill

by

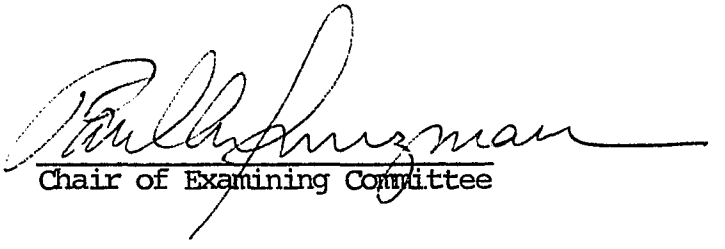
Penelope Johnson Moore

A dissertation submitted to the Graduate Faculty in Social Welfare in partial fulfillment of the requirements for the degree of Doctor of Social Welfare, the City University of New York.

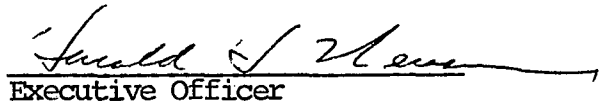
1989

This manuscript has been read and accepted for the Graduate Faculty in Social Welfare in satisfaction of the dissertation requirement for the degree of Doctor of Social Welfare.

2/17/89
date


Chair of Examining Committee

2/17/89
date


Executive Officer

Paul Kurzman

Mildred Mailick

Michael Smith
Supervisory Committee

The City University of New York

Abstract

AN EDUCATIONAL GROUP PROGRAM EMPHASIZING COMMUNITY RESOURCES
A MODEL FOR TRAINING CAREGIVERS OF THE
CHRONICALLY MENTALLY ILL

by

Penelope Johnson Moore

Advisor: Professor Paul Kurzman

This educational group program emphasizing community resources was designed to address the problem of poor coordination and fragmentation of services within the community mental health delivery system. The study first recognized various aspects of family burden that makes it difficult for family caregivers of the chronically mentally ill to reach out to one another, but especially to mental health professionals for needed support and services. Secondly, it makes the assumption that, given caregivers' experiences, there may be a reluctance on their part to become linked to formal service providers. However, if taught what the mental health system is and how it operates, it was believed that caregivers would be better equipped to make decisions about the usefulness of various programs and services in meeting their needs.

The broad goals of intervention were to provide caregivers with concrete information about resources, to link them with resources, and to increase their confidence as care providers. The study was conducted in a satellite

clinic of the outpatient department of psychiatry at a large metropolitan hospital. Participants were primarily the female parents of adult chronic patients who were living at home at the time of the study. Most parents worked, were over forty years of age, and could be considered of low middle income.

Four sets of questionnaires were developed to evaluate the experience of caregivers participating in a six weeks training program. The Needs Assessment Questionnaire was developed to determine what caregivers wanted from participation. A Participant Evaluation Questionnaire was developed and administered immediately after intervention, and a Program Evaluation Follow Up Questionnaire was administered after two years to determine caregivers' short-term and long-term satisfaction with the training protocol. An End of Meeting Feedback Sheet was developed to monitor on a weekly basis caregivers' satisfaction with the program.

The findings showed that caregivers were generally satisfied with the information obtained during training. Caregivers who had established links with resources prior to training felt more knowledgeable when dealing with mental health professionals or others in their support groups. Caregivers who were not linked to services began to utilize both professional and/or self-help resources following their involvement in the program. In addition, caregivers who were

committed to their role as primary caretakers before training remained committed to this role after training. However, they became more confident confronting and dealing with aspects of their relatives' illness.

Acknowledgements

I wish to thank Professors Paul Kurzman, Mildred Malick, and Michael Smith, members of my supervisory committee. Without their advice, guidance, and support this project would not have been completed.

Gratitude is also extended to those Administrators and staff at Hillside Hospital who guided me administratively and provided technical assistance in operationalizing this project. Of special significance were the contributions of Dr. Abraham Lurie, former Director of Social Work Services, Mrs. Anita Mehr, former Associate Director of Social Work in the Outpatient Department of Psychiatry, and Mr. Leonard Tuzman, Divisional Director, Department of Social Work Services, Hillside Hospital.

At the Hillside Eastern Queens Mental Health Center, a special thank you to Mr. Eugene Jefferson, Project Director, who has been a mentor and friend throughout my years with the Medical Center; Mrs. Phyllis Slaughter, who as a supervisor and a friend, provided moral support and participated in various phases of the dissertation project; and Dr. Vera Liang, Medical Director, who supported the project administratively and assisted in identifying families who might potentially benefit from the program. Mrs. Carol Montanaro has been a dear friend and I wish to thank her for emotionally supporting me over the years of work and study.

Execution of this project would have been more difficult without the volunteer support of the following people who served as guest speakers: Ms. Elaine Bernhard, Dr. Alan Jaffey, Mr. Eugene Jefferson, Dr. Jeffery Phillips, Mrs. Phyllis Slaughter, Ms. Nilsa Vergara, and Mrs. Gwendolyn Wellington.

I thank my family, my mother, sister, and brother for encouraging and inspiring me to pursue graduate studies.

To my Husband, Fred, thank you for your love and support, and especially for teaching me to use the word processor, and for the many editorial remarks that helped to move the writing of this paper along.

Finally, I wish to thank my research consultants, Deborah Pheasant and Daniel Remine, Drs. Samuel Miller and Milton Nobel, the family caregivers whose commitment to participation made for the success of the program, and my numerous friends whose prayer support helped me maintain the momentum and enthusiasum to finish the doctoral program.

Dedicated to my Mother and Husband

Table of Contents

Page

Page

List of Tables

Chapter IV Page

Table

Chapter One

Introduction

The care of the chronically mentally ill in community-based programs is a national problem as this population represents one of the largest underserved groups of mental patients in American society. While statistics on the total number of mentally ill are unreliable due to the varying definitions given for mental illness, as well as to the reluctance of those afflicted to acknowledge their illness, one estimate is that "over 2 million people in the United States have or will have schizophrenia. . . On any given day, there are 600,000 people with schizophrenia under active treatment and each year another 100,000 Americans are diagnosed with it for the first time. The care and treatment of the severely and chronically mentally ill has probably had the lowest priority in the entire area of human services" (Torrey, 1983, p. 1).

The conditions which presently confront the chronic mentally disabled emerged following passage of the Community Mental Health Act of 1963 which shifted the emphasis of care for chronic patients away from large institutions and onto the community. This process has come to be known as deinstitutionalization. In the early 1970s, the formulation of appropriate program strategies to meet the needs of chronic patients were in part mitigated by mental health professionals who were traditionally more comfortable working with higher functioning persons capable of

"insight through individual and group psychotherapy" (Lamb, 1970, p. 119), as well as by policies of deinstitutionalization. Deinstitutionalization provided the official mechanism by which states began systematically to empty out large state hospitals independent of localities' ability to absorb the large influx of patients in outpatient treatment facilities.

An immediate and unintended impact of this policy involves the problems of fragmentation of services among agency providers and poor coordination of local services. These problems have persisted within the mental health delivery system due to a variety of reasons, most notably, inadequate funding and preparation of staff to work with chronic patients. Systemic problems of this kind have also served to undermine those philosophical aspects of the Community Mental Health Act that assert the rights of chronic patients for comprehensive, accessible, and humane services (Bachrach, 1982; Dunham, 1969; Fairweather, et al., 1969).

Increasingly, the literature has pointed to the need to involve all persons in society, particularly patients' families, in the process of evolving more integrated treatment programs and improved quality of care in the community. Based on concerns about the inadequacy of community support programs for this population group and the lack of preparation of family members to execute caregiving responsibilities, this study is designed both to address and

alleviate the myriad problems that care providers are likely to face as a result of a mental health system marked by fragmentation and poor coordination of services.

Family caregivers were chosen for this study as "they tend to be on the frontline as far as their availability and willingness to provide the necessary help and support their mentally ill loved ones need" (Hatfield, 1978; Lamb & Oliphant, 1978; Goldman, 1982; Iodice & Wodorski, 1937). By developing a program aimed at teaching caregivers about the mental health delivery system and their unique role as care providers, it was hoped that professionals might learn more about families' specific needs for training in the area of community resources knowledge development and about the feasibility of refining this particular educational model of training for future use. The potential benefits of sponsoring an educational group of this kind is that (1) it provides a cost-effective intervention to clients who are reluctant to become involved with professional service providers, and (2) it provides focus and direction in support of the family caregivers' efforts to maximize all available resources on behalf of their mentally ill family members.

Chapter Two provides a comprehensive review of the literature and documents the rationale for the educational group program to strengthen the caregiving abilities of patients' families.

Chapter Three provides a brief overview of one psychiatric hospital's - the Long Island Jewish/Hillside Medical Center, Hillside Hospital Division - response to the challenge of providing enlarged services to chronic patients in the community. The program design and research methodology are also presented in this chapter.

Chapter Four presents the findings and results of the evaluation of the caregivers' training program and Chapter Five deals with the discussion, conclusions, and recommendations drawn from this project.

Chapter Two

Family Caregivers, Participants in Community Care: Literature Review and Background of Study

I. Policy Trends and Patients' Families: A Brief Historical Overview

Roles for families in the treatment of the mentally ill came about as a result of the mental health policy trends towards community care since the late 1950s. Before that time families often were subjected to the same kinds of stigmatization as their mentally ill relatives, and were more likely to hide the problem or separate themselves from the afflicted as did others in society. In addition, economic factors have tended to weigh heavily on families' abilities to provide for their mentally ill relatives, such that throughout history, families' responses to the mentally ill have tended to dovetail with those of the larger society both in terms of their beliefs about mental illness and their resources to respond to the mentally ill.

The general belief about the mentally ill in colonial times was that those afflicted were demon-possessed. Mentally ill individuals were beaten or banished from the colonies. With an increase in the number of mentally ill, jails and poorhouses offered localities relief from this group of societal "misfits." Treatment consisted of "bloodletting," chaining, or beating those afflicted. For families, the shame engendered by these harsh societal attitudes, coupled with the generally impoverished conditions in the colonies, made it impossible for poor

families to sustain a mentally disabled family member at home (Newman, 1983).

At the beginning of the nineteenth century, psychiatry began to place importance on the psychological needs of patients. Although there had never been agreement as to what caused mental illness, it had been observed that patients' conditions improved when patients were treated with kindness and sympathy. This form of "moral treatment" was introduced by a French psychiatrist, Phillippe Pinel. Moral treatment was significant because it represented the first attempt by psychiatry to provide systematic and responsible care for an appreciable number of mental patients. In the United States, the scope of moral treatment was limited to private hospitals primarily in the northeast. Affluent citizens reaped the benefits of private hospital care; families of modest means kept mentally ill relatives at home, but hidden and excluded from family life; and poor families were denied treatment (Bockoven, 1972).

The plight of the mentally ill poor was first addressed in the mid-nineteenth century through the crusading efforts of Dorothea Dix. Shocked by the deplorable conditions she observed in Massachusetts jails, Miss Dix challenged the State Legislature to erect a state hospital for the practice of moral treatment. In time, Miss Dix carried her cause to every state and succeeded in helping to develop state hospitals throughout the country. An unintended consequence of the state hospital system was that it eventually became a

place where patients were ignored, neglected, and soon forgotten by the average citizen and their families (Group For The Advancement of Psychiatry, 1978, p. 298).

By the end of the nineteenth century, state hospitals had become so overcrowded as a result of new immigrant groups that moral treatment had been replaced with custodial care. The fact that many hospitals had been built in remote places to provide a rural retreat and because the land was cheap made it impossible to attract qualified psychiatrists and various professional resources. The resulting isolation helped to create another condition known as institutionalization that would serve to undermine the abilities of both patients and staff to function in a changing society outside these institutions in years to come.

Two psychiatrists, whose influences are still evident in the field of mental health, emerged at the turn of the century. Sigmund Freud had the greatest influence on psychiatric thinking about patients' families, and Adolph Meyer had the greatest influence on the gradual change of mental health service delivery from a system that was institutionally based to one that incorporated various community components.

Given the impact of immigration and industrialization on America at the beginning of the twentieth century, psychiatry had broadened its conception of mental illness to include psychological and social factors. Freud's analytic focus began to link patients' manifest behaviors with their

inner life experiences. The impact of the family and early life experiences in shaping the personality of the individual helped to shape Freud's and his followers' belief that families were responsible for causing mental illness.

Unlike Freud, whose work was focused on disease entities and causation, Adolph Meyer's work emphasized prevention. He became recognized for his pioneering work in social psychiatry which created roles for social workers and other mental health practitioners. Dr. Meyer helped to develop the area of child guidance which emphasized work with children and their families before the onset of severe dysfunction. He also lent credibility to another pioneer in mental health reform by helping to publish the manuscript of Clifford Beers, a former mental patient. Clifford Beers' advocacy for improvements in the mental health delivery system led to the organization of the National Committee for Mental Health. This organization became the forerunner of the National Institute of Mental Health (N.I.M.H.). The N.I.M.H. rose to a position of national prominence by providing leadership in the field of mental health through research, demonstration projects, training programs, and grants-in-aid to states for mental health purposes. Philosophically, the first director of N.I.M.H. put forth the idea that the mentally ill can best be served by a community-based program of treatment providing continuity of care, available to everyone at the time of need (Deutsch, 1949; Connery, 1968, p. 21).

The belief that chronically mentally ill patients might participate in a system of community care gained credence following the discovery of psychotropic drugs in the mid-1950s. Drug therapy proved that chronic schizophrenic patients could be stabilized such that their behavior was more predictable and thus more manageable. This breakthrough in psychiatry coupled with the general reform spirit of the 1960s led President Kennedy to advocate for the Community Mental Health Act of 1963. This legislation not only focused on all categories of patients in need of outpatient mental health services, but also recognized the role of all citizens and patients' families as crucial if such a system of care were to succeed. In fact, many families already had begun to organize in the 1960s to advocate for their own rights and the rights of their mentally ill loved ones.

In order to start the process of dismantling large state institutions, policies of deinstitutionalization were implemented in most states by the early 1970s. Several assumptions were made about the benefits that would accrue to patients under this new system of community care. As previously mentioned, it was expected that patients would be maintained with medication; that patients would no longer need to remain for life in institutions; that the public would be more sensitive, sympathetic, and accepting of chronic patients; that community care would represent a more normal and, therefore, more therapeutic form of treatment;

and, that comprehensive treatment programs and community residential models of rehabilitation would be designed specifically for the after-care of chronic patients (Padavan, 1985, pp.4-5).

The shortcomings of deinstitutionalization have been well documented in the literature and in many newspaper publications over the past several years. These articles and other critics of the Mental Health Act, with respect to chronic patients in general and of deinstitutionalization in particular, comment on the gross inability of bureaucrats to anticipate the vast number of problems associated with a policy decision of this magnitude. Specifically, the architects of the Community Mental Health Act were unable to anticipate the extent of continuous, extensive, supportive treatment and social services that chronic patients would need. Equally unanticipated was the high level of community resistance, the excessive cost of community care, and the new era of conservatism of the 1980s, wherein the federal government's de-emphasized spending for human services would result in the dumping of patients in the streets and on families ill-prepared to meet their needs (Padavan, 1985; Nancy Scheper-Hughes, 1981).

II. Family Burden: An Impediment to Community Care

Preparation of families for participation in a system of community care for chronic patients involves paying attention to their needs and helping them to overcome aspects of family burden. Family burdens are those difficulties that serve to weaken families' efforts to serve as caretakers for their mentally ill relatives or friends. Several problem areas have been identified in the literature: intrafamilial stressors, emotional stressors, financial stressors, societal attitudes toward the mentally ill, the attitudes of mental health professionals toward the mentally ill, the negative impact of public policies, and the negative impact of agency practices on patients and their families.

Intrafamilial stressors were identified in a study by Agnes Hatfield (1978, p. 37) which revealed that parents, children, and marital relationships suffer when a family member has to deal with a crippling illness: spouses often blame one another; there is often resentment when caretaking responsibility falls overwhelmingly on one person; and family members become physically, emotionally and, more often than not, financially drained.

Emotional stressors for family caregivers were identified by Kreisman and Joy (1974, p. 39). Although there are families that possess the internal resources to provide increased support and tolerance for their mentally ill members, some families are not as well prepared emotionally

for the challenge of caretaking. Some families react with fear because of bizarre behavior, with anger because of the patient's disruptiveness, or with resentment because of increased generalized strain in the family environment. A sense of shame is often found when family members experience intense feelings of guilt about the illness. Rejection of the ill family member might be evident where relatives explain the illness in moral terms. In general, responses can and do change based on the mental status of the mentally ill individual and/or other family members at any given time.

The financial burden on family caregivers can be great in the light of inadequate funding of programs for chronic patients. Even though most chronic patients qualify for benefits under Supplemental Security Income (SSI), a federally funded program, and other special state funding plans, securing these resources usually involves a great deal of advocacy and technical know-how in order to get through bureaucratic red tape. In addition, some special funds, i.e., community supports systems funding, often are targeted for categories of patients based on period of hospitalization and involvement in a residential treatment program. Many patients new to the mental health system are not eligible for these benefits. Although several states are beginning to expand the eligibility criteria for community support systems funding, patients must be in the system in order to benefit. Patients outside the system are

generally totally dependent on the family whose private insurance tends not to cover the cost of extended care (Kahn, 1969; Connery, 1968; Mechanic, 1969).

Societal attitudes toward the mentally ill have been burdensome for family caretakers. Irrational fears and prejudices continue to characterize the way in which the general public responds to those who are mentally ill. These attitudes lead to stigmatization and rejection. According to Marcus (1977, p. 396), "for families dealing with the public's attitude means confronting ignorance or callousness, having to explain inexplicable behavior, suppressing anger or shame, and eventually developing a thick skin, a sense of humor or a casual indifference." Moreover, extended family members who may be long on advice but short on practical help and support are potentially more stressful for families than the general public, since there is often the added frustration associated with unfulfilled expectations of help and/or support (Sarbin & Mancuso, 1970; Morrison, 1980; Mancuso, 1977).

Mental health professionals also have added to family burden by promoting psychoanalytic theories that locate the source of most human problems within the psyche of the client (or the client's parents). Bateson's (1956) theory of faulty communication modes within the family that results in a double-bind for the child amplifies this observation with respect to blaming the family. According to Bateson (1956, p.256), the family situation that ultimately leads to

an individual suffering from schizophrenia is the following: (1) A child whose mother becomes anxious and withdraws if the child responds to her as a loving mother. The child's very existence has a special meaning to the mother which arouses her anxiety and hostility when she is in danger of intimate contact with the child. (2) A mother to whom feelings of anxiety and hostility toward the child are not acceptable and whose way of denying them is to express overt loving behavior to persuade the child to respond to her as a loving mother and to withdraw from him if he does not. (3) The absence of anyone in the family, such as a strong and insightful father, who can intervene in the relationship between the mother and child and support the child in the face of the contradictions involved.

Other theorists such as Lidz and Lidz (1956, p. 133) call attention to the frequency of broken homes, markedly unstable parents, and unusual patterns of childrearing in their study of the deficiences in the relationships between parents of schizophrenics. Their study of parents' relationships is the basis of their theory of marital schism and skew in families of schizophrenics.

Family therapist Murray Bowen (1960, p. 348) promoted the idea that schizophrenia is a process that takes three or more generations to develop. It is hypothesized that "the basic character problem in the patient, on which schizophrenic systems are later superimposed is an unresolved, symbiotic attachment to the mother."

In terms of treating the mentally ill, therapeutic interventions have tended to exclude parents from the treatment process. Darling (1983, p. 99) states that parents are excluded in part because professionals adhere to the medical model which locates the illness in the patient. By separating the patient from the family system it was felt that the patient would be more likely to improve. Although family theorists provided valuable insights regarding family functioning, their negative evaluations of the parent-child relationship added to the nature of resistances families subsequently brought to their interactions with professionals. These negative evaluations have also caused many family caregivers to step outside the formal mental health delivery system to seek the help and support they need in the form of self-help activities.

Still another aspect of family burden is the negative impact of public policies. As previously mentioned, deinstitutionalization led to the "dumping" of patients on families and local communities to the extent that now localities are beginning to challenge this law on the basis of limited resources and the overwhelming needs of chronic patients. This issue is most evident in the situation of the mentally ill homeless in large cities such as New York. For several years, critics have expressed concerns about the ability of localities to absorb the cost of community care in light of de-emphasized federal spending for human

service programs in general. Consequently, all informal caregiving structures have been burdened by increased demand (Scheper-Hughes, 1981; Padavan, 1985).

Finally, the complexity of the mental health system based on the variety of mandated service vendors creates additional burdens on families who are actively forced to engage in a system marked by redundancy and competition among various provider agencies. According to a special report by The Group for the Advancement of Psychiatry (1978, p. 366), "as long as there is budgetary competition within state mental health systems between institutional and community-based components, patient-based comprehensive planning and implementation of mental health services will be severely compromised if not impossible. Competing systems tend to entrench bureaucratic and protection-of-the-institution components, often at the expense of the community component." In addition, there is differential availability and accessibility of resources according to geographic areas; and there are a variety of state, city, and voluntary agency programs which have different philosophical and service agendas. The negative impact of this kind of delivery system is that many caregivers learn by trial and error which programs are best able to address their needs. Less persistent caregivers may become discouraged and wait for some form of crisis to erupt before going to a psychiatric emergency room (New York City Department of Mental Health, Mental Retardation and Alcoholism Services, 1977).

III. Interventions To Overcome Family Burden

Therapy approaches geared toward overcoming negative attitudes, practices, and policies impacting family caregivers can be divided into two categories: (1) client-centered interventions, i.e. self-help/mutual-help groups; and (2) a variety of supportive therapies emanating from mental health professionals, i.e., psychoeducational approaches, multiple family group approach, and parents' groups.

Examples of several treatment modalities designed to mitigate the negative impact of family burden are presented in outline form below so as to show how they differ from one another, as well as to highlight why these therapeutic interventions appear to be more reponsive to the needs of families with a mentally ill member. Six variables seem helpful in amplifying the basic similarities and differences between various new models of intervention: (1) vehicle for change, (2) theoretical underpinnings, (3) goals and objectives, (4) components of intervention, (5) role of the therapist, and (6) method of evaluation. Each model is followed by a list of its relative strengths and limitations.

MODEL OF INTERVENTION
Self-Help/Mutual-Help Groups
Alex Gitterman and Lawrence Shulman;
Frank Reissman; Phyllis Silverman; etc.

Vehicle for change
Small Group Format Usually Comprising Relatives Only

Theoretical Underpinnings

William Schwartz revitalized the concept of mutual aid in the group. Mutual aid is given primacy in the group because it shifts the source of helping from the group leader to the members themselves.

Schwartz defined a social work group as follows: the group is an enterprise of mutual aid, an alliance of individuals who need each other, in varying degrees, to work on certain common problems. The group is a helping system in which clients need each other, to create not one but many helping relationships. Group members' interdependence on one another is a vital ingredient of group process and constitutes a common need over and above the specific tasks for which the group was formed.

A related conceptualization to mutual aid is self help which implies the organization of individuals around a chronic condition that affects members' lives. According to Remine (1987), within the overall rubric of mutual aid and support, self-help groups can offer their members emotional support and guidance, social interaction, one-to-one networking, and advocacy. In addition, members should gain new factual knowledge of the problems for which they organized. With greater knowledge and emotional supports, group members should be able to advocate for change both with regard to their particular situation and to the problem in general.

Other concepts related to mutual aid and self help are reciprocity and the helper-therapy principle. Blackman and Goldstein (1968) discussed reciprocity in the context of group members providing help or support to others based on their own experiences of being given help or support. The idea of the helper-therapy principle developed out of the work of Frank Reissman who found that those who help are helped most. The helper by virtue of his role in the group must develop greater competence in a given area of learning and be able to think about problems in new and different ways to arrive at more favorable solutions. This process thus increases the ego strengths and self-respect of the helper.

To the extent that mutual-aid groups reduce emotional distress or enhance ego strengths and social competence for their members, they are powerful forces for primary prevention in mental health.

Goals and Objectives

1. To promote feeling among members that they are not alone.

2. To provide empathy , mutual affirmation, explanation, sharing, morale building, self disclosure, positive reinforcement, personal goal setting and catharsis.

3. To instill hope in one another as the group demonstrates its ability to successfully solve problems.

4. To help members feel better as they experience giving help, support, or guidance to others.

5. To restructure members' cognition or conceptualization of problems by examining existing belief systems and/or obtaining new knowledge concerning causes and effects of problems.

Components of Intervention

1. Promoting the helper-therapy principle also considered to be the most powerful mechanism in mutual aid.

2. Group reinforcement.

3. Continuous intervention.

4. An ideological perspective.

5. The implicit demand that the individual do something for himself.

Role of Therapist

1. A commitment to building on the inherent strengths of the group and providing nurturance so that members can strive toward realization of their own goals.

2. Respect for privacy of the group based on cooperation and collaboration.

3. Professionals might make referrals to such groups.

4. Providing consultation, serving as advisors, or initiating development of new mutual-help groups.

Method of Evaluation

There has been no way to systematically evaluate mutual-help groups, except to poll self-help groups to assess what members view to be their most helpful aspects, etc.

Strengths of Self-Help/Mutual-Help Groups

1. Mutual-aid processes in the context of self-help or mutual-help groups helps to combat the isolation experienced by many families of chronic mental patients. Members of such groups are challenged to deal with common issues, to model for one another useful coping strategies, and to engage in ongoing problem-solving activities for the common good.

2. The introduction of new information in the group is not only educative, but diminishes caregivers' sense of guilt about possibly causing their loved one's illness.

3. Self-help/mutual-help groups represent no extra cost to families who may have already experienced financial hardships associated with community care.

4. Self-help/Mutual-help groups offer a recognized service alternative to families who are not yet able to utilize professional treatment programs.

Limitations of Self-Help/Mutual-Help Groups

1. Self-help/mutual-help groups may foster isolation of its members from a range of resources, i.e., mental health professionals whose access to agency resources can be vital in establishing and maintaining a group, whose training and professional expertise can be drawn on in facilitating group process and prioritizing the work of the group, and whose access to a larger client base can lead to referral and revitalization of the group's membership (Remine, 1987).

2. Self-help/mutual-help groups that are not connected to larger organizations frequently lack knowledge regarding formal mental health and social services. They are not sophisticated as to how or where to refer members who need additional help. They may not know how to work with other service providers in cooperative ventures, and they are often unaware of how to advocate for changes in formal service systems (Remine, 1987).

PARENTS' GROUP
Supportive Group Counseling Approaches
Nancy Atwood

Vehicle for Change

Group Treatment For Family Members Which Does Not Include Patients

---

Theoretical Underpinnings

Model derives conceptual and methodological elements from the fields of social psychiatry, social group work, and group psychotherapy. Main tasks of building a model of group intervention is to facilitate the emergence of various self-help elements. The self-help model avoids a dignity-diminishing presumption of defect and presumes, instead, a normal motivation for problem solving.

Experience in social group work offers guidance about leadership in which the normative leadership style is enabling and compatible with emphasis on self help. Short term interventions have proven helpful in that they focus on problem-solving and drop-out rates are reduced.

Goals and Objectives

Promotion of the Mutual-Help/Self-Help process

Components of Intervention

1. Legitimation of relative's role as significant others.
2. Validation of the problem as defined by the family.
3. Satisfaction of the need to share problems with others.
4. Affirmation of the problem's manageability.
5. Consistency of support.
6. Clear statement of contract.
7. Establishing the group as time limited and closed.
8. Emphasis on promoting peer support.
9. Permitting the expression of affect.
10. Providing information.

Role of Therapist

Leadership style is enabling; focusing on whatever is meaningful for participants; exploring circumstances, perceptions, behaviors, and feelings that accompany particular interactions with ill family members. Helps group examine situations and to understand from them general principles that can be extracted and applied to many other circumstances occurring within the family setting.

Evaluation

No consistent methods have been developed.

Strengths of Group Counseling Approaches

1. Supportive counseling approaches systematically address a range of therapy functions with the help of professional staff committed to promoting mutual-aid group processes.

2. Integration of new information about managing schizophrenia and utilizing community resources enhanced through technical assistance provided by mental health professionals.

3. Time limitations placed on groups might help to minimize overdependence on professional facilitators and thereby support the problem-solving potential of caregivers.

4. Supportive counseling groups are a cost-effective means of reaching out to family caregivers without overtaxing meager resources in many treatment settings.

5. Supportive counseling groups can provide a linkage of caregivers to other programs and services.

Limitations of Supportive Group Counseling Approaches

1. Sponsorship of supportive groups may be problematic in many host settings where they are likely to compete with other services for meager resources, or where administrative priorities are not focused on development of such groups.

2. Since most supportive groups are time limited, such a constraint diminishes opportunities for successfully working through issues in the group.

MULTIPLE FAMILY GROUPS
William R. McFarlane

Vehicle for Change

Groups of two or three therapists meeting with four to eight families including parents, patients, and siblings.

Theoretical Underpinnings

Based on research of family factors that have been correlated with schizophrenia, multiple family therapy (MFT) focuses only on those who may be influenced by this mode of intervention. These factors are (1) expressed emotions (EE), (2) communication deviance, (3) social isolation, and (4) stigma/burden. Family factors are considered to be only some of the non-biological influences in schizophrenia which is considered a syndrome composed of several "diseases" with heterogeneous forms, courses, causes, and treatments.

Goals and Objectives

General goal is to improve the course of illness beyond that achievable with drug therapy. There are six specific objectives: Prevention of relapse - (1) reduction of isolation; (2) reduction of stigma and burden; (3) disenmeshment and reduction of EE; (4) reduction of communication dysfunction and communication deviance. Improved psychosocial functions - (5) correction of more covert, dependency-inducing interactive patterns when present, and social network expansion - (6) creation of a semi-permanent social network organized around the long-term needs of families with schizophrenic members.

Components of Intervention

Four phases of group development

Phase 1 Exploration of each family member's understanding of the illness and its causes, recent history, precipitating events, and goals for patients and themselves.

Phase 2 Building group cohesion: General assessment of family's strengths, and work of forming a group. Focus on subphase after three or four visits critical for fostering alliances among families; try to promote transition from leader-centered to group-centered work.

Phase 3 Disenmeshment and problem-solving - members begin to comment on the processes they observe in other families.

Phase 4 Building a social network - parents begin to socialize with one another; and bring problems to the group rather than to the therapist.

Role of Therapist

1. Type 1 Intervention - Self-Triangulation - includes questioning, eliciting responses or intrafamily interaction, supporting or directly confronting a family or one member, interpreting, clarifying, etc.

2. Type 2 Intervention - Group Interpretation - therapist takes on complementary position to entire group to lay ground rules, share personal reactions; point out commonalities in families or subgroups; set group themes and conventional group interpretations.

3. Type 3 Interventions - Cross Family Linkage - use of relationship to promote relationships across family boundaries.

Methods of Evaluation

No systematic evaluation yielding outcome data available. Several independent reports based on practice experiences in the literature.

Strengths of Multiple Family Groups

1. Multiple family groups capitalize on mutual-aid group processes.

2. That multiple family groups usually start with the family while the patient is in the hospital makes for a transition group and a continuum of care beyond the hospital for patients and their families.

3. Multiple family groups stem from the medical model and seek all family members' active participation in a treatment plan designed to prevent relapse of the identified patient.

4. Multiple family groups adopt a "non-blaming stance" toward patients' families while educating them about the illness, teaching families more effective ways to improve the overall psychosocial functioning of the family.

Limitations of Multiple Family Groups

1. The process of engaging families while the patient is in the hospital can break down if for some reason the patient leaves the hospital prematurely.

2. Multiple family groups appear to make the assumption that the institutional model for reducing patient relapse is correct and therefore may not present substantive information about alternative programs that may be more in keeping with families natural proclivities around seeking and utilizing help.

CRISIS-ORIENTED FAMILY THERAPY - A PSYCHOEDUCATIONAL APPROACH

Hal S. Kopeikin, Valarie Marshall, Michael J. Goldstein

Vehicle for Change

Patients and their families are seen for the 6 weeks immediately following discharge from a psychiatric hospital. Crisis oriented family therapy is combined with a moderate dose of injectable phenothiazine.

Theoretical Underpinnings

Patients are especially vulnerable to the tensions of returning to a family recently disrupted by a psychotic breakdown. Other family members are also under considerable stress and may have difficulty supporting the patient. The potential for conflict is high. Coping with difficulties is very important since family environment has been found to influence the course of schizophrenia. Crisis-oriented intervention is designed to help patients and families cope with stresses of the hospital to home transition.

Goals and Objectives

Helping patients and families use events of psychosis to deal with potentially disruptive future events and to resolve the current crisis.

1. To help patients and families agree on two or three current, potentially stressful issues that might instigate a break.

2. To develop strategies both to avoid stress and cope with it.

3. To get patients and families to implement these prevention-coping strategies.

4. To anticipate and plan for future stressful experiences.

Components of Intervention: Four sequential therapeutic objectives guide sessions

1. Identifying stressors.

2. Developing stress prevention and coping strategies. Each stressful event is identified and considered from a prevention perspective and then from a coping perspective. Alternative plans are developed by clarifying what each entails, and

exploring its strengths and weaknesses. Plans are improved as new insights are obtained, and understood and accepted by those carrying them out.

3. Anticipatory planning prepares the patient for taxing events likely to transpire in the months following therapy. This stage involves repeating the first two objectives, but with an emphasis on future stressors rather than current ones.

Role of the Therapist

1. Therapist must take a fairly active role in helping families reach consensus when identifying stressors.

2. Therapist active in second objective to provide a comprehensible explanation of prevention and coping strategies.

3. Therapist active where patients or family members lack skills to carry out objectives. Therapist may need to provide instruction, modeling, coaching, and practice within sessions.

4. Therapist active in helping patients identify potential stressors, and think through coping strategies as in first and second sequences.

Method of Evaluation

Patients were randomly assigned to one of four treatment conditions:

1. Moderate dose phenothiazine with family therapy.

2. Moderate dose phenothiazine without family therapy.

3. Low dose phenothiazine with family therapy.

4. Low dose phenothiazine without family therapy.

This factorial design (2x2) made it possible to measure separate effects of medication and crisis-oriented family therapy, in addition to their combined or interactive effects. Although family therapy and adequate medication level were somewhat effective independently; they were maximally so in combination. Over a six-month period, not one of the twenty-five patients on medication and family therapy relapsed.

Strengths of Crisis-Oriented Family Therapy

1. Crisis-oriented family therapy is a psycho-educational approach which attempts to maximize the most recent family crisis. In so doing, families can be enlisted to cooperate fully in the treatment plan.

2. Patients' participation in taking medication coupled with family involvement helps to hasten discharge from the hospital in keeping with the trend toward shorter hospital stays. While serving the purposes of the hospital to quickly discharge patients, families are given information on case management that helps them continue coping once the patient returns home.

Limitations of Crisis-Oriented Family Therapy

1. A psychoeducational approach that is crisis focused may leave family caregivers without the necessary institutional supports to continue managing their relatives' schizophrenic illness over the long run.

2. A crisis-oriented model appears restrictive in that it focuses on one patient and one family around a specific crisis, versus joining several families in order to promote broader learning opportunities associated with mutual-aid group processes. Consistent with the medical model, this approach seems to foster isolation among families.

PSYCHOEDUCATIONAL FAMILY THERAPY
Anderson, Hogarty and Reiss

Vehicle for Change

Chronic patients and their families participate in a highly structured family intervention program; used in conjunction with maintenance chemotherapy (family sessions may at times be conducted without the patient).

Theoretical Underpinnings

Program based on assumption that whatever the "cause" of schizophrenia, patients with schizophrenia appear to have a vulnerability to internal and external stimuli. This vulnerability to stimulation is probably exacerbated by stimulating environments in the home, workplace, or treatment setting, which have been shown to be correlated with high relapse rates. The family environment is particularly important because of the amount of time the patient spends in it; and also because the family is believed to provide individuals with the most intense emotional experiences they are likely to encounter.

Goals and Objectives

1. To decrease patient vulnerability to environmental stimulation through maintenance chemotherapy.

2. To increase predictability and stability of the family environment through decreasing anxiety about the patient and increasing their knowledge about the illness and their ability to react constructively to patients. (It is hoped that these goals will decrease the reciprocal pressures between the patient and family and diminish the possibility of overstimulation).

Components of Intervention: This model is supportive, concrete, and educational.

Phase I Connecting with family begins as soon as possible after patient is admitted to the hospital. Family's involvement at the beginning appears to be critical to the maintenance of an effective aftercare program.

Phase II Teaching survival skills for living with schizophrenia is primarily educative and accomplished in a day-long workshop format attended by all members of four or five families new to the program. A multiple-family enterprise is undertaken to diminish feelings of isolation and sensitivity, and to normalize the experience.

Phase III Reentry and application of survival skills themes to individual families - This stage involves sessions with the patients as soon as acute phase of illness is under control. Management themes are applied to individualized and specific situations and concerns in a structured and directive manner. This phase also teaches family about therapeutic resources.

Phase IV Continual treatment or disengagement - Once effective functioning achieved, patient and family given options of continuing in intensive weekly family therapy, gradually decreasing frequency through maintenance session of a year or more.

Role of Therapist

Phase I Therapist demonstrates respect for family boundaries. Therapist joins with family through social conversation and thoughtful sharing of information prior to introducing attempts to change family patterns.

Attempts to adapt to family's style of relating and strives to increase their level of comfort, acceptance, and feeling of being understood. Concrete information about the therapeutic process is given. Clinician stresses his availability, interest, and commitment. Family is kept informed of hospital decisions, etc. Concrete suggestions also are made about what the family can do to augment treatment process, and work is focused on developing a contract for treatment.

Phase II Therapist works to create a social network by interacting with families over coffee and lunch breaks. Therapist summarizes in clear understandable language all that is known about schizophrenia. Specific techniques for managing schizophrenia provided. Families are encouraged to normalize their own routines in the home. Modified expectations for the patient are presented.

Phase III Therapist primary focus is on a reinforcement of family boundaries and the gradual resumption of responsibility by the patient. Interpersonal and generational boundaries are clarified, and effort is devoted to diminishing the family's isolation for the larger community.

Phase IV Therapist continues work or disengages with family based on family's decision. Ongoing treatment follows along traditional family therapy lines. If family decides to disengage, therapist focus is on maintaining initial gains. Clinician conducts periodic reviews of accomplishment to reinforce morale and to keep new troubles in perspective.

Methods of Evaluation

Approximately 33 patients and their families have been or are involved in this research study. Population is chronic; average age 29; average length of illness 8 1/2 years. Most patients are males, living in parental homes. A few live with spouses and a few are themselves parents. Patients assigned to one of two treatment groups - family therapy alone or family therapy plus social-skills training. Families in both treatments do better than families in one or the other modality. Families in both family therapy and social-skills training along with patients on medication show no relapse in the first three years of the project.

Strengths of Anderson, et al.'s Psychoeducational Family Therapy

1. The Anderson et al. family therapy approach is highly supportive and provides family caregivers with continuous support through their relatives' hospitalization and re-entry into the community. Although the intensive educational training features of the program are time-limited, there is a process of disengagement that allows caregivers to terminate or connect with other treatment modalities.

2. This model taps into the mutual-aid processes inherent in a multiple family group and less formal group approaches, but also tailors the intervention to individual families' needs as they progress through various intervention phases.

3. The Anderson, et al. approach further maximizes the crisis situation by intervening with the family as soon as possible after patients are admitted to the hospital.

4. In addition, the phase-oriented aspects of this approach anticipate and build-in mechanisms to prevent premature discontinuation of treatment.

Limitations of Anderson, et al.'s Psychoeducational Family Therapy

1. Despite attempts to individualize and respond to families' needs, this approach is still illness-focused and serves the purpose of the hospital to reduce the length of stay. This might create additional pressures for both patients and families to respond to a treatment protocol which is highly intensive and demanding.

2. This model also taps into the family system as its primary resource for assisting the patient towards community functioning, despite the severity of emotional disturbance.

BEHAVIORAL FAMILY INTERVENTIONS IN THE MANAGEMENT OF CHRONIC SCHIZOPHRENIA
A Psychoeducational Approach

Ian R. Falloon & Robert Liberman

Vehicle for Change

Group meetings with patients and their families. Patients are maintained on neuroleptic medication.

Theoretical Underpinnings

The behavioral family therapy approach is based on the principles of learning theory. The uniqueness of every individual and his or her interpersonal environment is stressed. Any attempt to modify family interaction is considered carefully for the consequences (both positive and negative) of that change upon the functioning of all family members. Schizophrenia is viewed as a biological illness provoked by environment stressors. The psychosocial management program is based on the effective management of underlying biochemical dysfunction through the use of medication.

Goals and Objectives

Maximal improvements of the social functioning of all members of the family through learning more effective communication skills that would reduce the level of criticism and over involvement in family interactions.

Components of Intervention

1. A detailed systemic analysis of family behavior conducted prior to starting family therapy. There are three levels of assessment: (a) identifying the specific assets and deficits of individual family members; (b) identifying the assets and deficits of the family group as a whole; and (c) identifying the role that specified problem behaviors play in the functioning of the family group.

2. Educational workshop for patients and relatives two formats developed: (a) a four-month sequence that all new patients and their relatives were expected to attend; and (b) a six-session seminar that covered some of the same material but is aimed at relatives in the community at large, regardless of patient involvement. Information and skills were conveyed through lecture-discussion, films, case studies, and role playing.

3. Personal Effectiveness Training in a family group - patients known to be from high EE families receive five weeks of intensive social skills training,

while relatives are seen separately for education about schizophrenia and its management. At the end of five weeks, patients and relatives are seen together in a multiple family group focused on family communication deficits. After one hour of the multiple family group, there would be one hour of individual family therapy. Specific homework task assigned after each session. The next session begins with review of homework assignments.

4. Development of a problem-solving approach also utilized the multi-family approach in two hour weekly sessions over nine weeks. Each session used to educate families about schizophrenia, then providing training in communication skills.

5. Behavioral family therapy in the home: Rationale for home intervention is that skills learned in a clinic setting do not necessarily generalize to the home setting. Patients and families are more relaxed in their own homes and are more willing to assimilate new patterns of behavior. A further benefit is increased participation of members of the household who might resist attendance at a clinic. Families receive two educational sessions, communication training and problem-solving training.

Role of the Therapist

The role of the therapist is varied and involves: conducting an intensive initial behavioral assessment; teaching; offering direct opinions and advice when indicated; advocating for concrete services as needed; and acting as a family friend who supports and provokes a structure for the family's efforts. The therapist is available around the clock to make home visits and conduct sessions on the telephone in case of a crisis. All attempts are made to avoid hospitalization unless there is a serious threat of suicidal behavior. The format of most family therapy sessions is dominated by communication or problem-solving interventions. Other behavioral therapy techniques are utilized such as positive reinforcement, shaping, extinction, modeling, rehearsal, and homework as outlined above.

Evaluation

Evaluation protocols are designed for each behavioral therapy approach and are outlined as follows:

1. Evaluation of personal effective training - question to be answered was whether learning more effective communication skills would reduce levels of criticism and overinvolvement in family

interactions. A simple measure of frequency of completed family interactions that were assigned weekly showed some change had occurred. This further confirmed by the Camberwell Family Interviews conducted at end of treatment period.

2. Evaluation of problem-solving approach: All family members interviewed by an independent research worker before and after multiple family group sessions. The mean number of critical comments of high expressed emotions (EE) parents was reduced by 60 percent following treatment. A control group of matched high EE parents who were not involved in the treatment program showed a 16 percent decrease. A family conflict inventory also administered before and after family intervention. Frequency distribution showed a significant reduction in conflict after treatment.

3. Home-based Family Therapy - 40 families randomly assigned to receive family therapy or clinic-based individual supportive psychotherapy with an experienced staff therapist. All patients receive optimal medication administered by independent researcher. Researcher also evaluates mental status of patient with standardized rating scale on monthly basis. Rehabilitation counseling also provided to patients; study compares the outcome of two treatment approaches - nine months after discharge and over two years.

Strengths of Behavioral Family Therapy Interventions

1. Behavioral approach of psychoeducation is a more highly structured, yet supportive, therapy which focuses on the interactions between patients and families. With appropriate dosages of medication, there is a greater opportunity for patients and families to practice and test out, with the help of the therapist, more desirable ways of relating to one another in the home environment.

2. The added clarity provided by a behavioral approach has the benefit of helping to refine the caretaking responsibilities and role behaviors of the family.

3. The incorporation of home visits provides additional supports to the hard-to-reach family or to families with some hard-to-reach members. This feature helps to minimize the potential for less actively involved family members to sabotage treatment plans, and for families to prematurely terminate treatment.

Limitations of Behavioral Family Therapy Interventions

1. The behavioral approach is also focused on returning patients to the home community as soon as possible. This emphasis may create additional pressures on families who need the respite provided by hospitalization.

2. Families of patients who are quick to terminate their hospital stay would not benefit from this treatment.

3. Not all families would be suited to a treatment modality providing such a high degree of structure.

4. An intensive behavioral approach does not address those benefits afforded families in the context of small group interactions.

IV. Overall Strengths and Limitations of New Therapies

New therapies had to be developed in order to address systematically the negative attitudes, practices, and policies which undergirded therapeutic interventions with patients and families prior to the current move toward community care. Some ways in which new therapies differ from traditional therapy and service delivery follows:

One, patients and families are not as frequently blamed for causing mental illness; rather, emphasis is now placed on how familial attitudes influence the course of schizophrenia. Thus, evaluation of interpersonal relationships, instead of relatives' personalities, open up a range of options for professionals and families to engage in problem-solving activities on behalf of mental patients.

Two, new therapies and research are focusing on patients' and caregivers' needs. For example, Agnes Hatfield conducted a study in 1979 on the needs of family caregivers. It was found that families need information about schizophrenia and its management; advice about appropriate expectations; specific techniques for managing highly intrusive and difficult behavior; and information and skills about obtaining available community resources. In addition, families need to talk with people who have known similar experiences, and require periodic respite from caregiving responsibilities.

Three, unlike Freudian based theories that also helped to alienate patients' families, new therapies draw on multiple theories and disciplines to engage patients and families. As the models help to highlight, supportive psychotherapy and behavioral therapy techniques, as well as social supports systems theory, have been the foundation of the experimental and self help modalities. A distinction must be made, however, between supportive psychotherapy techniques and social supports. Although each plays a role in new therapies, each suggests somewhat different activities for professional and family caregivers.

Judith Nelsen (1980, pp. 338-392) defines four different types of support basic to all individuals at some time in their lives. The most basic to all individuals is protection, which means that one person takes over for another to ensure the other's survival or well-being in some area of functioning. The second type of support is acceptance, which reduces the feeling of being alone, confirms one's sense of self worth, and communicates understanding that one's behavior is not outside the range of human experience. The third type of support is validation or feedback regarding ways in which one is good, strong, or likely to be effective. The final type of support is providing education regarding circumstances, inner experiences, or aspects of one's environment over which one is better able to develop mastery by obtaining information.

Lola Selby (1956, p. 405-406) focuses on techniques of support which succinctly summarize and dovetail with techniques recommended by Nelsen. Selby cites the following as the most commonly used techniques in supportive treatment: (1) direct guidance and advice in practical matters; (2) environmental modification with the provision of specific and tangible services as needed; (3) provision of opportunity for the client or patient to discuss freely his troubling problems and his feelings about them; (4) expression of understanding by the helper, along with assurance of interest in and concern for the patient or client; (5) encouragement and praise implying confidence in the patient's worth and abilities; and (6) protective action and exercise of professional authority when needed.

The supportive role of the therapist is clearly spelled out in both Nelsen's and Selby's work. The therapist uses himself/herself flexibly in meeting patients' and families' needs. The formal design of therapeutic interventions, i.e., multiple family groups, psychoeducational approaches, and parents' support groups seem to require this more intensive, clinically supportive use of the therapist.

In contrast, self-help/mutual-help groups seem to draw on social support systems theory. Social support systems are defined by Caplan (1974, pp.4-7) as playing a critical role in the general health and well being of individuals. If an individual in distress does not receive feedback that his actions are leading to desirable and/or anticipated

consequences, then he cannot feel safe and valued. His autonomic nervous system and hormonal mechanisms are continually in a state of emergency arousal, so that the resulting physiological depletion and fatigue increases his susceptibility to a wide range of physical and mental disorders. A Social support group provides individuals with consistent communication of what is expected of them; supports and assists them with tasks; evaluates their performance; and bestows upon them appropriate rewards. More broadly speaking, support systems help to maintain the psychological and physical integrity of the individual over time.

Professional roles differ when working with social support systems or helping systems that exist outside the boundaries of professional services. First, individuals who belong to such groups need to gain a sense of confidence in their own ability to deal with issues apart from professionals so that they truly gain some control over their lives. Second, individuals tend to seek help first from their relatives, friends, or neighbors, as well as clergy, doctors, and other community gatekeepers. If an overall goal is to enable individuals to seek help more effectively, and, sooner, as a mode of prevention as well as treatment, then these linkages should be encouraged among group members. To the extent that professionals attempt to initiate development of informal support systems for families of chronically mentally ill individuals, who tend

to be isolated from one another as well as the larger society, such activities help to strengthen their relationship with professional care providers and support self-help/mutual-help activities on their own behalf (Montrel, et al., 1980).

Finally, unlike institutionally based care which was largely custodial in nature, new therapies focus on the specifics of community living. The emphasis on practical problem-solving activities with patients and families helps to establish mechanisms for continuity of care, and promotes an ongoing partnership between professional providers and family caregivers. Current research endeavors seem to suggest that professional and family caregivers are interdependent in the context of community treatment for the mentally ill, as families provide staff coverage in the "community's institution without walls."

A major limiting factor of new programs is their isolation from one another and from the larger mental health system of which they are a part. As previously discussed, new programs are forced to participate in a mental health delivery system marked by fragmented services.

Current funding practices also restrict new programs in that established services in most agency settings receive priority over new programs (Bachrach, 1982, p. 195). We might infer that newer therapies must, therefore, look outside current funding structures in order to finance innovative treatment programs. For example, parents' support groups and mutual-help groups promoting self-help

initiatives operate on minimal financial resources. In some instances, individual groups engage in modest fundraising or receive foundation grant support (Atwood, 1978; Hatfield, 1981). Multiple family groups appear to be generally viewed as a cost-effective way of providing services to caregivers, as they require a more flexible use of family therapists in the existing hospital or clinic setting (McFarlane, 1983). Only with the psychoeducational approaches are financial resources being generously allocated to pay for staff activities. It is necessary to point out, however, that psychoeducational programs have been widely supported by National Institute of Mental Health grant monies since research geared toward learning how best to maintain chronic patients in the community is considered a national mental health priority (Beels & McFarlane, 1983; M. Goldstein, et al., 1982).

Unsophisticated and relatively new methods of evaluation are yet another limiting factor for new therapies in the context of community care. (Please refer to models). In the absence of strong research findings which help to recommend these programs, new therapeutic interventions are likely to continue competing not only with traditional, institutionally based programs, but with one another as well. In recognition of a need to evolve a more coordinated and integrated approach in utilizing new treatments, Beels and McFarlane (1982, p. 549) proposed the following

hypothetical sequence, fully aware that this "prescriptive use of services is utopian." They note "this recommended plan of action would be contingent upon a comprehensive treatment system that would refer patients from one system to another based on clinical considerations, rather than administrative or fiscal reasons." These authors suggest the following:

> Patients recovering from first episodes (of schizophrenia) would be offered the Goldstein approach of short-term psychoeducation because it applies well to all forms of acute psychosis. Since the diagnosis may not be clear at that point, it is better not to introduce the family and patient to the long-term prognostic implications of the Anderson program.... If the course of the illness is long, the prognosis becomes worse, or the diagnosis of schizophrenia becomes clear, the Anderson or Falloon and Liberman programs are indicated. Resistance or crises during any of these might be met by strategic sessions with the family alone.
>
> After a psychoeducation introduction drawn from one of the programs, multiple family groups are clearly the most economical and supportive ways of providing maintenance and development of skills and morale over the long haul. A multiple family group can turn into an autonomous self-help group, or it can be the backbone of a service's continuity of care (Beels & McFarlane, 1982, p. 549).

V. Rationale for Proposed Program

The utilization of community mental health programs is impeded by the degree of fragmentation and competition evident within the delivery system. Except for the psycho-education models of Falloon and Liberman and Carol Anderson where a part of the training format includes teaching families about resources, little attention has been devoted specifically to linking patients and family caregivers to the delivery system as a whole. Although these authors consider information about resources an important aspect of working with families, this aspect was not the primary emphasis of their research and did not receive serious attention in the evaluation of these programs. (Please refer to models). Rather, the primary emphasis of various psychoeducational approaches seems to be that of providing a variety of supportive and educational techniques aimed at lowering the level of criticism in the families of schizo-phrenic patients, while increasing caregivers' abilities to react constructively to patients. Another crucial observation regarding the intervention programs presented as models thus far, is that their primary thrust appears to be on emotional factors affecting caregivers, and the burdens associated with caring for mentally ill relatives in the home or community. However, in this study, an attempt is being made to show that caregivers are also burdened by the mental health system itself, which is comprised of programs with different treatment orientations as well as different

political and service agendas. It is believed, based on the complexity and politics of the delivery system, that mental health professionals need to play a more active role in drawing caregivers - who may have been adversely affected by particular service entities - into the system to receive the support they need. This belief is accompanied by the perception that the community mental health delivery system is a battlefield of programs and services. Patients and family caregivers are typically lacking in the necessary skills to know what they need. Equally important is their lack of knowledge about how to negotiate the various entities that, at best, hold only partial answers to the problems they confront.

If caregivers are to utilize community care services optimally, then they must be taught how to become their own best client representatives. For this reason, an intensive, short-term educational group was developed to teach caregivers how the system can operate for instead of against them. The basic assumptions of this method of engaging caregivers are: (1) the structure of the community mental health system contributes to families' level of stress, burden, feelings of demoralization and isolation; and (2) by teaching caregivers to become resource experts in their own right, professionals would better support their individual efforts to seek services they need for themselves and their mentally ill family members.

As mentioned earlier, this intervention program differs from other short-term psychoeducational approaches primarily in that it targets work only with family members, and it emphasizes community resources. More specifically, in this program the role of the therapist is geared toward engaging caregivers in a mutual helping exchange so as to bring to the forefront their own knowledge and experiences about programs and services that have proven either helpful or perhaps not so helpful to them in the past. This feature of the program seeks to stimulate aspects of mutual-aid processes in the group. In this model, professionals further contribute to group process by providing information, guidance, and encouragement through a labyrinth of agencies, programs and other potential impediments to care. A potential benefit for caregivers participating in this educational group project is that it may also serve to diminish certain frustrations associated with a mental health system characterized by fragmentation of programs and services. The supportive aspects of an educational program of this kind are that caregivers are not only helped to feel that they are not alone in a hostile and chaotic service environment, but that they have a range of programs and resources available to them. While individual programs may not meet all their needs, they can identify an agency and professional staff committed to helping them to tap various resources as needed, regardless of the nature of the families' burden.

The following model provides a brief descriptive overview of the educational group to train caregivers in the area of community resources. As in other new therapy approaches, families' experiences of mental illness are validated and they are not blamed for its cause. However, the purpose of validating their experiences differs from other therapies in that caregivers are challenged to examine how the mental health delivery system further aggravates the difficulties they confront. With respect to the program's theoretical underpinnings, concepts are borrowed primarily from the literature on social supports systems theory. This theoretical base incorporates the ideas of self-help/mutual-help networks such that group members are seen as possessing those strengths needed in order to master adversity. Value is placed on families seeking solutions to problems on their own, thus diminishing a sense of total dependence on professional providers.

This group differs in its application of these concepts, however, in that it creates a mechanism for teaching caregivers how to interact with professional service providers and formally organized self-help groups as needed, in order to better manage their mentally ill relatives.

Emphasizing caregivers need for knowledge about mental health resources also integrates themes addressed in the psychoeducational models of Carol Anderson, et al. and Falloon and Liberman. These researchers recognized the need

for this kind of training in their respective programs; however, these models may not have gone far enough in developing this component. Therefore, families who may not yet be prepared to take advantage of the various therapy models discussed herein may need specific training about service alternatives that could lead to more sophisticated planning for themselves as they make decisions about utilizing the mental health delivery system.

The various aspects of this intervention program, along with its strengths and limitations, will be discussed in detail later in this text. The process through which its final goals and objectives were clarified will be discussed as we address the organizational context in which the program was implemented. The next chapter also helps to clarify ways in which the educational groups involved in this project differs from other group programs within the Long Island Jewish-Hillside Medical Center, Hillside Hospital Division.

VI. An Educational Group Emphasizing Community Resources

Penelope Johnson Moore

Vehicle for Change

A small group comprised of 10 to 12 family members offering direct or indirect care, or support, to a chronic mentally ill relative in the community. Group does not include the identified patient.

Theoretical Underpinnings

Research findings on family burden shows that families are easily overwhelmed by the demands of caring for a chronic schizophrenic family member and families need help from one another as well as from various human service and mental health agencies in the community to carry out their primary caregiving roles and responsibilities. The literature on social networks and social supports provides a conceptual framework in the area of primary prevention in community mental health which addresses the need to strengthen the innate caregiving potential of family caregivers. The work on social supports is based on the research of John Cassel and Gerald Caplan (1974) who define support systems as an enduring pattern of continuous or intermittent ties that play a significant part in maintaining the psychological and physical integrity of the individual over time. The support system serves as a buffer against disease by helping to sustain the person in need of help and thus minimizing the negative consequences of emotional and/or physical stress...

Malcolm Knowles (1980) promotes the idea of group process as a good format for learning, wherein members are able to acquire new knowledge and improved skills as a result of mutual exchange and problem-solving activities. The educational group provides friends and relatives of schizophrenic patients an opportunity to reassess positive strengths for coping with life-long adverse situations; it promotes the mutual-aid process of sharing experiences with others having similar problems; it promotes the helper-therapy principle wherein caregivers are taught and can experience how they ultimately help themselves as they become involved in helping others; and it facilitates a beginning process of forming a positive reference group and connecting with the larger society. Finally, the educational group enhances the opportunity to develop horizontal linkages with other caregivers and vertical linkages with professionals and the formal delivery system (Collins, 1976; Toseland, & Hacker, 1982).

Goals and Objectives

1. Increase caregivers' knowledge about mental illness and their ability to share with others information about the mental health delivery system, the differences between various treatment programs (state, city and voluntary agency programs), the formal versus informal systems of care; eligibility requirements for various programs based on legal auspices; and the advantages and disadvantages of engaging in either the formal or informal systems of treatment.

    a. To teach caregivers how to apply concepts and share with others information about the mental health delivery system, its political complexities, differences between state, city, and voluntary agency programs; the formal and informal systems of care; eligibility requirements for various programs based on legal auspices, and the advantages and disadvantages of engaging in either the formal or informal systems of treatment through a minimum of six 1 1/2 hour training sessions.

2. Increase caregivers' awareness and utilization of treatment programs (both formal and informal service systems).

    a. To increase the number of caregivers seeking supportive services through informal and formal treatment programs.

    b. To increase the number of caregivers applying for general social services, i.e., Medicaid, by assisting with applications and follow-through as needed.

3. Increase caregivers' self-confidence regarding the care they provide to a mentally ill family member.

    a. To facilitate the helper-therapy principle by encouraging caregivers to identify their own learning needs; to share with others mutual experiences; and to join together outside training sessions to engage in ongoing problem-solving activities.

Components of Intervention

1. Intensive initial interview and completion of Needs Assessment Questionnaire wherein the format of the six-week training program are spelled out. A contract is agreed to wherein a commitment to regular attendance and responsibility for individual learning is underscored. Caregivers identify the areas where they feel they need expert information and agency staff agree to secure expert speakers to address specific problem areas.

2. There are six weekly sessions of approximately 1 1/2 to 2 hours in duration. Topics include: The Role of Natural (Family) Caregivers Vis-a-Vis Professional Caregivers; What is Mental Illness; The Impact of Mental Illness on The Family; Psychopharmacology; The Role of Self-Help in Community Care; and Community Resources.

3. Additional time is provided for program evaluation and referral of participants to ongoing professional, self-help, or ancillary services based on their requests.

4. Members are encouraged to exchange personal telephone numbers and make plans to network when the training program ends.

5. Each meeting incorporates refreshments so as to encourage the establishment of informal interactions among participants.

Role of Therapist

1. Caregivers are approached on the basis of cooperation and collaboration around goal formulation; however, social work staff and guest speakers are active and directive in imparting information based on previously agreed upon topics of interest.

2. Professional staff facilitates group process by encouraging caregivers to share experiences and coping strategies that have worked for them over time.

3. Professional staff gives concrete advice about resources, advocates where families may not yet be able to do this for themselves, and provide ongoing consultation as needed when training terminates.

Method of Evaluation

Four research instruments were developed. A Needs Assessment Questionnaire was designed to determine caregivers' goals for program participation. End of Meeting Feedback Sheets were developed to monitor how well the program addressed the needs of caregivers on a weekly basis. A Participants Evaluation Questionnaire administered at the end of the sixth session was used to assess the impact of the training experience on caregivers' ability to use resources with increased confidence; and a Program Evaluation Follow Up Questionnaire sought to determine if caregivers were ultimately better able to reach outside the immediate family to secure needed support from other caregivers and professional providers of community services.

Chapter Three

Organizational Context, Program Design, Methods and Implementation

I. Organizational Structure and Environment of Long Island Jewish-Hillside Medical Center

The setting for this educational group project was the Hillside Eastern Queens Mental Health Center - a Satellite clinic of the Long Island Jewish Hillside Medical Center (LIJ-HMC), Hillside Hospital Division. Before discussing the satellite clinic, it is first necessary to provide a brief overview of the Medical Center. Consistent with changing trends in medical and psychiatric hospitals, the Long Island Jewish-Hillside Medical Center is a large, complex organization whose organizational structure takes on different forms in order to meet the general health and mental health needs of a variety of patient populations in Queens and Nassau Counties. In addition to the complexity of form is the complexity associated with diverse funding sources, multiple levels of accountability, and complicated inter-organizational relationships characterizing the Medical Center.

Specifically, the LIJ-HMC is a voluntary teaching hospital consisting of two medical centers covering the north shore of Long Island in Queens and Nassau Counties. The Hillside Hospital Division is a 203-bed psychiatric facility that has 1,400 admissions and 91,000 outpatients visits per year (Rock, 1983, p. 135).

Under a contractual affiliation at the request of the New York City Health and Hospitals Corporation in 1964, LIJ-HMC assumed additional responsibility for administration of the Queens' Hospital Center (QHC). Through the affiliation agreement, Hillside administers inpatient and outpatient psychiatry at QHC; and in addition has administrative responsibility for a federally funded Community Mental Health Center (CMHC). According to Dunham (1969), a CMHC is by definition a facility that provides a range of diagnostic and treatment services to all age groups in a particular geographic area, in this instance, Queens County. The Queens Hospital's CMHC also is attached to a day and night hospital program and various rehabilitation programs.

A major characteristic of the organizational and hierarchial structure within the Medical Center is that the hospital setting is the host for all non-medical disciplines such that psychiatry accommodates psychology, social work, psychiatric nursing, recreation therapy, etc. A chain of command exists within each respective profession. With respect to Social Work Services at LIJ-HMC, there is a Director of Social Work for the Medical Center which includes the Queens Hospital Affiliation. There are Associate Directors of each Division, Project Directors and Administrative Managers of various services, followed by Senior Social Workers and other line workers. In addition, there is a central staff with management support functions

including professional hospital administrators, and departments such as personnel, purchasing, and fiscal affairs.

Research and education are also priorities at LIJ-HMC. The Medical Center is affiliated with two medical schools in the area - the State University at Stony Brook, Long Island, and The Graduate School and University Center of the City University of New York. In 1985, Hillside Hospital was awarded a National Institute of Mental Health Research Grant to replicate the psychoeducation models of Carol Anderson, et al. and Ian Falloon and Robert Liberman. Research activities of this kind are consonant with the broad program goals outlined in the Community Mental Health Legislation of 1963.

The complexities associated with the large number of programs and services provided by the Medical Center (the Hillside Division, in particular, for purposes of our discussion), has made it imperative for LIJ-HMC to devise effective strategies for dealing with intra- and inter-organizational relationships. In terms of the larger community, Hillside Hospital has used collaboration as its chief strategy for dealing with external environmental relations, as evidenced in its ability to win support for several community residence and supportive living programs, day and continuing treatment programs, and several Satellite clinics in Queens and Nassau Counties for the treatment of psychiatric patients. These programs are funded through a variety of contractual arrangements with various city,

state, federal, and philanthropic organizations mandated to ensure the delivery of mental health services to local geographic regions.

Hillside Hospital has further extended the services it provides to discharged chronic patients through various collaborative relationships with other local community agencies. These relationships make it possible to offer patients foster home placements, job training, extended family counseling in the home, homemaker services, and socialization programs (Lurie & Karlinger, 1968, p. 403).

Another aspect of Hillside Hospital's collaborative efforts to reach the "silent partners" who treat chronic patients in the community has been to initiate development of a self-help group calling itself PATH (People Acting Together With Hope). According to Lurie and Shulman (1983, p. 13) "the purpose of the group was to organize an active group of relatives of psychiatric patients to develop a program and lobby effort to influence legislation on behalf of psychiatric patients. It was also expected that the group would work with professional staff of the Medical Center in the development of new and needed services."

PATH has subsequently become affiliated with the Alliance for the Mentally Ill of Long Island (AMI); which forms the Long Island Chapter of the National Alliance for the Mentally Ill (NAMI). "The goal of AMI of Long Island is to be an effective political and social action force acting on county and mental health policy (Rock, 1984, p. 10)."

II. Organizational Structure of the Hillside Eastern Queens Mental Health Center (HEQ)

The formal organizational structure in the satellite clinic is a microcosm of both the bureaucratic and matrix organizational forms evident at Hillside Hospital where diagnostic and treatment services are provided by an interdisciplinary team of psychiatrists, psychologists, and social workers. The chain of command exists within departments, with line staff reporting to respective supervisors by discipline. In addition, there is a Project Director (Social Worker) who has administrative authority over the total operations of the clinic and a Medical Director who supervises clinical practice in the clinic. These dual directors relate to department heads at the main hospital concerning professional issues and to professional administrators concerning administration of the clinic's contract with the New York City Department of Mental Health, Mental Retardation and Alcoholism Services. In keeping with this contractual agreement, HEQ maintains approximately 5,793 outpatient clinic visits annually.

III. Legitimization

The process of legitimizing the caregivers' group project in the Medical Center involved working through various constraints to innovation. Consideration of cost factors associated with financing and dealing with administrators who would be affected were the most important difficulties to be overcome in gaining acceptance of this program. Cost factors, as identified in the literature, pertain not only to financial considerations, but to the risks that decisionmakers incur when they are unable to predict and control employee behavior and the reactions of external support groups during the early iniation phase of a new program (Patti, 1974, pp.370-371).

Financially, the Medical Center was cutting back on outpatient services that were not self-supporting due to a retrenchment in various governmental streams of funding when this proposal was introduced. The basis for considering this educational program at the Social Work Department level was that financial costs would be minimal. This prerequisite was subsequently reinforced as the substance of the proposal was presented to the Medical Director of the Outpatient Department of Psychiatry (OPD) who demanded a fee for service for any groups that would operate on the main hospitals' campus. To avoid excessive financial costs, the program was structured to involve staff as guest speakers who would volunteer their time. This design did not fully anticipate the total financial burden associated with

running a group program, however, and the resulting failure to generate a fee for service altered the original program design.

Additional cost considerations for administrators who potentially would be effected by the program proposal are described below: The Director of Social Work Services was concerned about the substance of the proposal. Specifically, he was comfortable with the program's goals and objectives; however, he wanted to be equally comfortable that participants understood the nature of their involvement and what to expect from participation, that their rights as potential recipients of services would be protected, and that the role of staff involved in the project was clearly defined and consistent with professional practice within the Medical Center. Another consideration was the potential impact of this kind of group program on PATH. While it was anticipated that this program might be viewed as a competitor with PATH, it was felt that this problem could be overcome through outreach and education strategies. In fact, a positive feature of the proposal was that this short-term educational group might benefit PATH and other programs by increasing caregivers' utilization of various treatment and supportive services.

Comfortable that he could support the substance of the proposal, the Director of Social Work Services advocated for departmental sponsorship of this program. Without this support, the project would have never gotten off the ground, because legal authority is vested in the formal hierarchy of

the organization. For would-be innovators far removed from the centers of power in organizations, enlisting the support of influential others is critical in gaining recognition for a new program, since organizational leaders will respect those in similar positions of authority within the decision-making structure as opposed to those far removed from power centers. (Shephard, 1969, p. 519; Patti & Resnick, 1977, p. 51). Typically, those outside the power structure are skeptically regarded; "since any change is likely to run counter to certain vested interests, and to violate certain territorial rights. Sentiments of vested interest and territorial rights are sanctified as delegations of legitimate authority in traditional organizations, thus guaranteeing quick and effective counteraction against disturbances (Shephard, 1969, p. 519)."

In the role of "professional advocate" for this project, the Director of Social Work Services acted administratively to secure top level organizational clearances for the Social Work Department to sponsor the caregivers program. Appropriate explanatory materials were forwarded to the Human Subjects Review Committee of the Medical Center and to the Department of Community Psychiatry. No unusual problems were anticipated nor were any encountered in obtaining departmental approval to implement the project.

Within the Social Work Department, promoting the care-givers' program called for collaborative strategies based on the assumption that the best way to induce change is to work

with the target system. According to Patti and Resnick (1972, p. 55), collaborative strategies appear to work best in situations where there is issue consensus or issue difference whereby education and/or persuasion tend to mediate such differences. At this level, the key players were the Associate Director of Social Work in the Outpatient Department of Psychiatry (OPD), the Medical Director of OPD, Project Directors in two satellite clinics and PATH leadership.

Collaborative strategies, when operationalized, seem to be consistent with Brager's (1967, p.68) recommended strategies for change which include problem-solving, education, and persuasion. Although Brager includes bargaining and adversarial strategies as options to a change agent, these two options did not seem appropriate in attempting to legitimize this project. Problem-solving activities involved working closely with the Associate Director of Social Work in OPD who was charged with ongoing project supervision. Efforts to recruit caregivers included sending out flyers, meeting with staff on various services, and generally attempting to educate staff to the program's goals and objectives. Had there been enough caregivers willing to pay a fee for service, the Associate Director of Social Work was willing to be the instrumental group leader, since the Medical Director expressed anxiety about staff whose work was unfamiliar to him conducting research in OPD.

Problem-solving also included efforts to reach out to PATH leaders who might have been a potential resource for generating referrals for the project. However, these initiatives were blocked by PATH's leadership who questioned the hospital's motives for wanting to sponsor a project emphasizing the education of caregivers about mental health resources in the context of small groups. That a fee might be associated with such a program also suggested that the self-help group might be ineffective in educating caregivers concerning mental illness, and providing its members with the necessary supports to cope. The inability to work through this conflict seems related to the fact that PATH sees its role as educating families about resources, and it is dependent on the Medical Center for certain support services such as meeting space, referrals, and various reciprocal services. Any program such as that outlined in this proposal might have been viewed as a competitor for PATH's members and meager resources. The author's physical and professional distance from the self-help group further impeded satisfactorily working through this kind of resistance.

Still another aspect of problem-solving was identifying other out-patient clinics that would be willing to sponsor one of the group cycles. Ideally, two or three caregivers' groups would be conducted in different settings. It was thought that different settings might offer differing insights about caregivers' needs and some basis for

comparing their responses to the training format. However, resistances also were encountered when other clinic Directors were approached. For example, the Project Director at the Day Treatment Clinic was interested in developing a group for caregivers, but had already committed the work with such a group to student interns in that setting. Both the timing and the competing vested interests proved to be major constraining forces for this administrator.

Although HEQ did not have a large population of chronic patients, the Medical and Project Directors agreed to sponsor this project. Not only was there less organizational and psychological distance between the author and the clinic's Medical and Administrative Directors, but sponsoring the project would also bring some prestige to the satellite clinic. Logistically, referrals would be generated from current cases and new applicants to the clinic. Some referrals also would be obtained through general advertising of the program to staff at the main hospital and in other community agencies. Petty cash funds would be allocated for refreshments. The clinic would provide space, telephone, typing, and Xeroxing services.

A. Staffing

Another aspect of legitimation involved identifying suitable staff to participate as guest speakers at care-givers' group meetings. The rationale for using guest speakers was two-fold: (1) it would provide caregivers with

a practical linkage to other professional and support services; and (2) it was one way to work around cost constraints. Guest speakers were amenable to volunteer their time for one meeting, but were uneasy about making a longer-term commitment. Hillside Hospital Administration and the Department of Social Work Services raised no objections about staff volunteering to participate in the project as long as meetings were held in the evenings so as not to intefere with routine work responsibilities. It was possible to recruit staff from HEQ, Hillside Hospital, another community mental health clinic, and a member of the Family Alliance of The Mentally Ill (FAMI) to volunteer as guest speakers. All administrative tasks associated with planning and implementing the project were executed by the author.

B. Program Design

Short-Term Goals

1. To increase caregivers' knowledge about mental illness and their ability to share with others information about the mental health delivery system, the differences among various treatment programs (state, city, and voluntary agency programs); the formal versus informal systems of care; eligibility requirements for various programs based on legal auspices; and the advantages and disadvantages of engaging in either the formal or informal systems of treatment.

Long Term Goals

2. To increase caregivers' awareness and utilization of treatment programs (both formal and informal service systems).

3. To increase caregivers' self-confidence regarding the care they provide to a mentally ill family member.

These goals were to be achieved through the following objectives:

1. To teach caregivers how to apply concepts and share with others information about the mental health delivery system, its political complexities, differences among state, city, and voluntary agency programs; the formal and informal systems of care; eligibility requirements for various programs based on legal auspices; and the advantages and disadvantages of engaging in either the formal or informal systems of treatment through a minimum of six 1-1/2 hour training sessions.

2. To increase the number of caregivers seeking supportive services through informal and formal treatment programs.

3. To increase the number of caregivers applying for general social services, i.e., Medicaid, by assisting with applications and follow-through as needed.

4. To facilitate the helper-therapy principle by encouraging caregivers to identify their own learning needs; to share with others areas of "natural expertise"; and to join together outside training sessions to engage in ongoing problem-solving activities.

C. Practice Principles

Principle: Caregivers shall define their own learning needs in relation to the educational group program.

Rule: Caregivers participating in the project will be given an opportunity to discuss common experiences and have input in setting priorities and in determining the content of the training program.

Principle: Caregivers shall be given accurate information about mental illness and available community resources.

Rule:

(1) Caregivers will be exposed to a clear knowledge base concerning mental health issues of interest to them.

(2) Caregivers will be informed about how to obtain community resources as well as linked to agency resource personnel who can further the individual and collective interest of participants who wish to continue their involvement with outside organizations after the training sessions end.

Principle: Caregivers shall be given an opportunity to strengthen their help-giving skills by modeling for one another how they have dealt with long-term stress in the family unit.

Rule: Caregivers will be encouraged to share with one another various experiences they have had which enabled them to deal more effectively with a chronically ill family member.

D. Target Population

Problems of legitimization, lack of funding, staffing and time constraints limited the original scope of this project as far as settings in which it could be implemented, and the population of clients from which to draw a sample. Thus, the target population became restricted to a delimited number of referrals from staff at Hillside Hospital, and to those caregivers residing in the catchment area served by the Hillside Eastern Queens Mental Health Center.

Ideally, the research design would include participants whose mentally ill loved ones had a known diagnosis of schizophrenia, chronic type, based on the diagnostic criteria as outlined in the DSM-III Classification Manual used by the American Psychiatric Association. However, the pool from which caregivers were recruited was small at HEQ, and it was necessary to assess whether first time applicants for treatment would be appropriate for the caregivers' group program. It was decided that the following criteria would be used for the selection of participants:

-Friends and relatives must be involved either directly or indirectly with a family member or friend experiencing mental illness of an enduring or chronic nature.

-Friends and relatives must either receive services from a mental health agency or may be identified by a professional as a potential bridge person between an agency and a chronic patient.

-Friends and relatives must be willing to commit themselves to attending group meetings for the purpose of sharing experiences and exploring the usefulness of such an exchange in the future.

E. Description of Participants

Twenty-three caregivers participated in the program. The group was comprised of 18 parents (78%), four other relatives and one friend. Fourteen group members were Black, seven were white, and two were Hispanic. Of this group, 15 participants were married.

Caregivers' ages ranged from 20 to 59 years old: 14 were 50 to 59, seven were 40 to 49, and two were under 40.

Educationally, 13 caregivers (57%) had completed some college, nine Caregivers (39%) had only a high school education, and only one Caregiver had less than a high school education. Forty eight percent of these participants were employed full time, 26 percent were employed part-time, and 26 percent were unemployed. The personal incomes of caregivers were as follows: two had less than $5,000; two had incomes between $5000 - $9,999; six had between $10,000 - $14,999; three had between $15,000 - $19,999; five had between $20,000 - $24,999; one had between $25,000 - $29,999; and only four had incomes over $30,000. (Please see personal data in chapter III for additional information.)

IV. Methodology

The evaluation design consisted of a single-group study, using an after-only measure to obtain descriptive information about the effectiveness of the training intervention toward achieving the objectives outlined under the program's design. Caregivers' expressed satisfaction or dissatisfaction with training was the basis on which this assessment was made.

In addition, descriptive data was obtained on End of Meeting Feedback Sheets after each group session in order to get immediate feedback about how caregivers thought the program was meeting their needs. Although a follow-up study was not a feature of the original evaluation design, the Faculty Supervisory Committee suggested that one be done in order to strengthen the findings, especially since a comparison group was not available and much time had elapsed between the collection of data and analysis of results. The two-year follow-up evaluation helped to assess the extent to which caregivers remembered their training experience and its impact on their role as care providers. This information was considered of value in assessing the potential long-term effectiveness of a program of this kind.

The protocol used in this study falls under the general rubric of formative evaluation which applies well where the purpose of conducting a program evaluation is to produce information that is fed back during the development of a program to assist its performance (Weiss, p. 17). However,

there are limitations with the single-group, after-only measure used in this study which require attention.

The primary disadvantage with the single-group, after-only measure of the research design is that there is no way to control for variables which threaten internal validity. Although there are a number of factors which typically threaten internal validity such as the effects of testing, instrumentation, statistical regression, sample selection biases, experimental mortality, selection-maturation interaction to list a few, these factors are more prevalent in more sophisticated experimental research studies.

In this study, however, three primary factors stood out as compromising the program's findings, including care-givers' self-reports concerning the training experience, history, and maturation. According to Tripodi (1983, p. 71), self-reports of respondents are subject to response errors due to faulty memories, perceptual distortions, or halo effects, where responses to some questions are influenced by previous questions. History would refer to any change in caregivers' role performance that occurred subsequent to starting the program, but which did not occur as a result of program intervention. Maturation associated with physical and emotional changes in caregivers during the course of the program would also influence their self-report of the training experience.

In the absence of controls or even a comparison group which helps to improve the ability to make informed

inferences about the impact of program interventions, it is impossible to know with any relative certainty whether changes that occur in the target group resulted from the intervention strategy or from other causes. Moreover, generalizations of findings to other populations, settings, treatment variables and measurement variables cannot be made, because not only is this design weakened by being unable to deal with factors of internal validity, but it also is weakened by its inability to address issues of external validity which only can be controlled in an experimental design where random sampling techniques are involved.

Despite the shortcomings associated with the one-group, after-only measure of this study, it does provide both qualitative and quantitative-descriptive information about caregivers' perceptions of the program in meeting their needs. Although the findings are unique to this group's experience, inferences can be drawn which can guide practice interventions if the program is replicated with other groups who have similar characteristics and problems. The ability to make inferences about the stability of changes in caregivers over time has been enhanced with the two-year follow-up data.

A. Development of Research Instruments

Questionnaires were chosen as the primary evaluation tool for this study, because they are one of the least expensive and least time consuming ways of collecting data

in social research (Epstein & Tripodi, 1977; Tripodi & Epstein, 1980). Four instruments were developed for this project: Needs Assessment Questionnaire, End of Meeting Feedback Sheet, Participant Evaluation Questionnaire, and Program Evaluation Follow-up Questionnaire.

Since the emphasis of this study was that of developing a format for training caregivers about mental health resources, it was first necessary to develop a Needs Assessment Questionnaire that would provide useful information about caregivers and provide them an opportunity to state what kind of help or support they need. The focal question for this descriptive study became: What kind of support do family caregivers need in order to better utilize community resources for themselves and their mentally ill family members?

Support was operationally defined to include any activities on the part of caregivers and mental health professionals involved in the project which helped to enhance caregivers confidence about utilizing resources in their attempts to care for a mentally ill relative or friend.

Two procedures were used in developing the Needs Assessment Questionnaire. Based on the literature review, issues of family burden; as well as environmental factors that increased strain on families' coping abilities, became more evident. Discussions with professional staff at HEQ during the period of problem formulation also offered useful

insights about the unique struggles of some families known to the clinic. This information was helpful in developing the content and structure of the questionnaire. For example, we wished to learn about caregivers' role in and attitudes toward providing community assistance to a family member or friend who is undergoing emotional stress; their motivations for giving help; to whom they look for support either professionally or nonprofessionally; their feelings of comfort in their help-giving roles; and what kind of help they would like from the educational group program. In addition, the questionnaire elicited descriptive personal data about caregivers. It should be pointed out, however, that when asked to provide information concerning household income on the questionnaire, Caregivers tended to provide information about their personal incomes instead. This will be reflected later in this text. (Please see Appendix A for copy of Needs Assessment Questionnaire).

A draft questionnaire was pretested for clarity of content, logic, and format. It was administered to several staff members at HEQ, wherein questions were examined to determine if the wording might suggest one answer rather than another. Where questions were not clear, they were revised; and redundant questions were deleted. (This procedure was followed in developing all three questionnaires.) The questionnaire was further reviewed to avoid bias and refined through technical assistance provided by the faculty committee supervising this dissertation

project at the Hunter College School of Social Work. Prior to pretesting the questionnaire with a small group of caregivers who expressed an early interest in participating in the program, the questionnaire was subject to additional review by the Director of Social Work Services for the Medical Center, Associate Director of Social Work, OPD; Project Director, HEQ; and the Human Subjects Review Committee of the Medical Center. More extensive measures of reliability and validity did not seem appropriate for this study.

The End of Meeting Feedback Sheet was designed to secure participants' subjective feelings about the training experience. This questionnaire included closed-ended questions which asked participants to indicate how they felt about each meeting, open-ended questions where they might make suggestions for improving the program, and blank spaces provided for participants to make additional comments about the program. (Please see Appendix B for copy of End of Meeting Feedback Sheet).

The Participants Evaluation Questionnaire sought to gather information on whether the training program had a positive or negative impact on participants' attitudes, knowledge, and skills in dealing with their mentally ill family members; whether participants were able to share information with others; whether participants would recommend this training format to other caregivers; whether participants had more confidence in their ability to

continue in their role as caregivers; if participants were more informed about other community and professional resources as a result of training; if participants understand better how to go about obtaining needed resources; and whether participants were interested in continuing the exchange of mutual help introduced through training. (Please see copy of Participants Evaluation Questionnaire in Appendix C).

Due to the lag time between running the caregivers' groups and analyzing the data, it was deemed appropriate to initiate a Program Evaluation Follow Up Questionnaire to assess the long-term effects of group training. This questionnaire attempted to obtain descriptive data about caregivers' perceptions on the three broad goals of training by ascertaining whether they remembered topics covered, how they felt the training influenced their ability to utilize mental health and general social service programs, and the ways in which training impacted upon their ability to continue in their help-giving role. (Please see copy of Program Evaluation Follow Up Questionnaire in Appendix D).

B. Data Collection Procedures

In addition to cost-effectiveness, questionnaires offer the advantage of standardized wording, structured order of questions, instructions for recording responses which ensures some uniformity from one measurement situation to another; and in their anonymity, respondents may have greater confidence and, thus, feel freer to express their

views (Selltiz, Jahoda, Deutsch, & Cook, 1959, pp. 239-240). However, a major limitation of questionnaires is that respondents may readily answer fixed alternative questions, and fail to answer questions requiring more thought and concentration.

To safeguard against the bias caused by respondents' reluctance to answer open-ended questions, a structured interview was built into the data collection process. The purpose of the interview was to explain fully the goals and objectives of the group program, to respond to any questions or concerns caregivers may have about their participation, to point out that their responses would be confidential, and to administer the questionnaire. Individual appointments were made to administer the questionnaire. Each questionnaire was carefully reviewed after the caregiver first completed it independently. Questions which were not fully answered were rephrased by the interviewer; or caregivers were probed in order to obtain more complete answers.

Since the End of Meeting Feedback Sheet was designed to provide caregivers an opportunity to briefly state their reactions to the program at the end of each session, an interview was not used. However, an interview was part of the administration of the Participant Evaluation Questionnaire; and a telephone interview was part of the Program Evaluation Follow-up Questionnaire. The structured interviews proved to be helpful in getting more complete and detailed information from caregivers who were unable to

complete the questionnaire on their own. Verbatim notes were taken of caregivers' responses, as needed.

V. Implementation

According to Weissman (1981), "Problems of implementation are, at core, problems of constraints." Working through constraints of legitimization was the first step towards operationalizing the caregivers' group program. At this stage of program initiation, the primary emphasis of professional activity was on internal organizational development. This process involved integration of organizational mission into the framework of the project; establishing an organizational structure to facilitate achievement of objectives; obtaining sanctions and legitimacy for the project; specifying goals in particular first targets for intervention and interventive strategies; and beginning provision of services (Kamerman, 1975, pp. 416-417).

Since the implementation estimate would have to take into account the level of integration and acceptance of the program achieved during the initiation stage, the prognosis for success in achieving the program's goals and objectives was guarded. Both the external and internal constraints to operationalization were formidable. The general lack of resources (funding, support staff, and limited referral sources) altered the original scope of the program design. For example, the objective of improving caregivers' access to the mental health delivery system had to be reconsidered in that many caregivers who would be referred through HEQ were already involved in the mental health system. As a

result, this objective was refined somewhat to include an assessment of the extent to which participation in this program might lead caregivers to consider other service alternatives. Another constraint that complicated program implementation was overcoming problems in coordinating various activities so as to ensure appropriate and timely follow-up actions. The following sequence of behaviors describes the actual implementation process.

Implementation began during the process of legitimization wherein HEQ became the designated setting for the group program. In February, 1983, an official memorandum was sent to the Medical Director of HEQ explaining the program and apprising her of the plan to begin recruiting caregivers known to the clinic. (Prior verbal approval had been obtained during the early phases of legitimization). Simultaneously, a memorandum was distributed to staff requesting their assistance in referring clients whom they felt might benefit from the caregivers' group program. (Please see copies of memoranda in Appendix E).

Over the next several months, correspondence was sent to outside agencies including Creedmoor State Hospital and Transitional Services, Inc. in order to stimulate referrals. However, these overtures met with no success. In August 1983 a brief description of the project was advertised in the LIJ-HMC Newsletter so as to inform staff and possibly generate referrals from other divisions of the Medical Center.

As names were identified, letters were sent to family members and followed up with a telephone call. (Please see Appendix F for copy of outreach letter). At the stage where individual appointments were scheduled, issues of confidentiality were discussed in-depth, and a working contract was established wherein a commitment to regular attendance and responsibility for individual learning was underscored. Family members agreeing to participate filled out the Needs Assessment Questionnaire devised specifically for ascertaining the training needs of caregivers.

In addition to a review of the Needs Assessment Questionnaire to ensure that it was completed appropriately, the pre-screening interview was used to explain the End of Meeting Feedback Sheets and the Program Evaluation Questionnaire. Participants also were informed of the leader's desire to tape sessions in order to better evaluate the training experience. The taping of sessions seemed to be the most expedient way to overcome staffing shortages and maintain an accurate record of group interactions. Caregivers raised no objections to having sessions taped.

The recruiting of group participants commenced in the summer and fall of 1983, and the first caregivers' group consisted of 17 participants, 14 of whom completed at least three out of six sessions. (In order to be included in the study's findings, caregivers had to attend at least three out of six sessions; the low drop out rate for this group

cycle suggests that many caregivers were interested in what the program had to offer). This group began on October 11 and ended on November 15, 1983.

Participants of the first group cycle agreed to meet on six consecutive Tuesdays from 6:30 to 8:00 p.m. Training folders containing relevant reading materials were disseminated at the first meeting, along with the End of Meeting Feedback Sheets which were to be filled out and handed in at the end of each meeting. The importance of bringing the folder to each meeting was stressed as relevant pieces of literature would be distributed each week. As a result, each member compiled a training kit that could be used for future reference when the program terminated. Participants would be contacted by telephone prior to each session as a reminder and as a means of encouraging maximum participation. (Please see appendix G for content of training packet).

Recruitment of group participants for the second group cycle began during the fall of 1983 as caregivers were identified by staff at HEQ. Over a five-month period from approximately early November, 1983 to early March, 1984, 10 participants were identified. All 10 completed at least three out of six sessions. The second group cycle began on March 13 and ended April 24, 1984. This group also met on Tuesdays from 6:30 to 8:00 p.m., but participants unanimously agreed to cancel the session which fell during Easter week due to the holiday and competing personal commitments.

The administrative task of disseminating training folders, explaining the format of future meetings, and providing an overview of the program comprised much of the first session. In addition, members were encouraged to come prepared each week to raise appropriate questions of guest speakers and to add to their general information.

The main difference between the second group cycle and the first group cycle was the guest speaker from FAMI who addressed the group in the second cycle. Rather than present information on self-help under the general umbrella of community resources, as this topic was handled in the first group cycle, this area was broadened as outlined below. Therefore, the topic pertaining to general community resources became the entire focus of the sixth session, whereas the sixth session was entirely devoted to program evaluation in the first group cycle.

Below is a revision of the outline of topics and format for the educational group program:

Session I: Topic-The Role of Family Caregivers vis-a-vis Professional Care Providers.

Attention was focused on areas of exchange between the formal and informal mental health delivery system. The chart extracted from the Natural Supports Program's training manual, found in Appendix G was adapted to the content material developed for this session. The purpose of the session was to provide a conceptual framework in which friends and family members of the mentally ill might themselves be partners in a system of care, and without which the formal and semi-formal system could not function optimally.

Session II: Topic-What Is Mental Illness?

Discussion focused on the broad categories and manifestations of mental illness. There was also a close look at schizophrenia and problems associated with treatment and the management of symptomatic behavior. Didactic material was presented in the first forty-five minutes and another hour was devoted to verbal interactions among all participants.

Session III: Topic-The Impact of Mental Illness on the Family

An expert on family therapy spoke on psycho-education amplifying the Carol Anderson Model. Caregivers were encouraged to share with one another how they experience their mentally ill relatives and to explore with the guest speaker how various treatment approaches and systems of care provision can provide the assistance they need.

Session IV: Topic-The Use of Medication in the Treatment of Mental Illness.

An overview of the four basic classes of drugs was discussed including (1) anti-anxiety agents, (2) antipsychotics, (3) anti-depressants, and (4) mood-stabilizing drugs. The use of medication was presented as only one aspect of a treatment program. Group discussion elicited from caregivers a range of fears and concerns about medication and long-term side effects. Participants whose relatives have taken medication without major complications were able to provide a helpful perspective on this aspect of discussion.

Session V: Topic-Self-Help with Friends and Relatives of the Mentally Ill

The guest speaker was a member of FAMI, a local chapter of AMI-The Alliance for the Mentally Ill of New York. The importance of support for family members who feel burdened, isolated and alone in coping with problems of providing community care were discussed. The contributions of the local and national alliances in educating the public about mental illness, providing support to families, and advocating for improved services for patients

was explained. In addition, the speaker focused on her own experience with her mentally ill son which eventually led to an alternative living arrangement in the community following the last of several hospitalizations.

Session VI: Topic-Community Resources

Information about the various state, city, voluntary hospital and private agencies was provided. Caregivers were given a brief directory of various mental health and human service agencies serving the catchment area; and where possible, the names of professional staff to contact regarding eligibility requirements and how to apply for services. Staff at HEQ were also designated to assist caregivers needing additional support in getting linked with services.

VI. Sample Process of a Group Session

Group Cycle #2 - Session III

Guest Speaker: Gwendolyn Wellington, ACSW
Hillside Hospital

Topic: The Impact of Mental Illness on the Family

Date: March 27, 1984

Attending: Barbara J., Mildred C., Elizabeth S., Pamela W., Alice C., Leon C., Barbara S., Leonard S., and Susan C.

Staffed by: Penelope Johnson, ACSW
Hillside Eastern Queens Mental Health Center

Introductions:

Ms. Gwendolyn Wellington, Social Worker, Hillside Hospital was introduced and group members were asked to introduce themselves, stating briefly their reasons for participating in this program. Ms. Johnson then provided feedback to members and the guest speaker about questions members would like addressed in the session. This information had been obtained on the End of Meeting Feedback Sheets from the previous week. Questions included: (1) What can be expected when treating a patient who is mentally retarded and mentally ill?; (2) How can one cope with the patient's aggressive, hostile behaviors at home?; (3) How can one get the patient to seek help?; and (4) How can one help siblings and other family members deal with mental illness in ways that are helpful to the patient?

Guest Speaker:

> "I will start by providing a brief overview of family therapy and how my interest in this field of study developed. Family therapy has only been around as a formal discipline since the 1950s. It emerged in response to the needs of families who were experiencing a multiplicity of problems when men returned home from war. Initially, family therapy was not well thought of by classically trained mental health professionals who believed that families were the cause of the individual's problems. Family therapists, on the contrary, had begun to view the problems presented by men returning home from war not as problems of the individual, but as problems related to that individual's experiences of combat. The focus of family therapy was that of helping the individual and the family cope with changes brought on by external circumstances."

"It was primarily through trial and error that I learned how important the family is in the treatment process. When I first started practicing, my tendency was to engage the family in order to get a psycho-social history. After that, I worked with the patient and developed a treatment plan. However, the plan invariably fell through, because the family had not been involved. This usually occurred when the patient returned to the same home environment that he/she left. Oftentimes, I would not have spent enough time preparing the patient for the return home, and the family usually had no preparation. It was not long before I decided to go back to school where I received specific training in family therapy. Training helped me learn how to work with families; and as a result of my training I have seen the impact of having the family as an ally in treatment."

"As we talk tonight, I would like each of you to think about what you might do in order to be of help to mental health professionals working with the person you love and would like to see improve. However, it is first necessary for us to look at some of the feelings that typically interfere with your ability to help a mentally ill relative."

"Most families tend to feel guilty about having a mentally ill family member. This feeling causes people to wonder what they did wrong and it is often compounded when the patient is taken to a psychiatrist who then communicates that the patient is better off if the family does not interfere with the treatment process. Therefore, when I work with families, one of the first things I try to deal with is their guilt. Guilt feelings are natural feelings to have, but they must be alleviated before family members can become a helpful asset to the patient or to those involved in the patient's care."

"Furthermore, I let families know that guilt has many dimensions. For example, many people feel the need to adjust their entire life to the caretaking demands of the patient. Over time, however, this behavior can lead to resentment that perpetuates a cycle of first guilt, then anger. If these feelings are not verbalized or worked through, people become prone to various emotional or physical health complaints of their own. In addition, these feelings impede the family caregivers' effectiveness."

"I see a lot of smiling faces in the group, does that mean we have a lot of guilty people here?." (Laughter)

Barbara J.: "I would like to say that a lot of my guilt comes out when I do things and then feel I have no right to enjoy them."

Guest Speaker:

"That is right and when you feel like that you are not going to be able to do your best for the person you are helping. A major reason that your ability to help is impeded is that you are so angry about having to be in the position you are in. This problem becomes worse because the person you are trying to help perceives your anger. You both probably start to react to the anger, but never really talk about it."

"Usually, I tell families, if you did something, you did it for a reason. Since no one is perfect, if it does not work out right, you did not act maliciously, you were only trying to be helpful. Therefore, you should not dwell on it, because that also interferes with overall progress. It is very important that families do not get hung up on ideas such as `why me?', or `what did I do to deserve this?'"

"The way in which families cope with mental illness often has to do with what else is going on in the family at the same time. For example, if a family has high anxiety about a number of other problems involving other family members or situations, it is necessary for them to get help in partializing things. By breaking the problems down into manageable units, it is possible to decrease the level of anxiety in certain areas. Once the anxiety is lowered, it is possible to better deal with the person who is mentally ill."

"For many families, one of the most difficult periods is shortly after the hospitalization of their relative. In the Medical Center, we have learned how to maximize the help we provide to families during the discharge planning session. Families are given an opportunity to talk at length about some of the problems they can anticipate when the patient returns home."

"A major aspect of my work, in particular, is making sure the family knows as much as possible about their relative's illness. I encourage them to ask very specific questions about the illness such as: What are the symptoms of the patient's illness?; What does it mean to have this type of illness?; How long will the illness last?; Will the patient be able to work? I also suggest that families speak to the doctor, and, if necessary, to make a list of questions so they do not forget what they wanted to ask."

"Based on the answers they get, I encourage families to start making a realistic appraisal of the patient's functioning. This includes looking at the diagnosis, and examining whether their expectations of the patient are realistic. Developing a realistic appraisal also involves having a clear notion of your own dreams for the patient. For example, I once worked with a family whose son suffered an emotional break while in medical school. As soon as he was pulled together and discharged from the hospital, the family rushed him back to school. Soon afterwards, this young man suffered a relapse. The most difficult part of working with this family was getting the parents to see that their son might not ever become a doctor, and that that may not be such a terrible thing."

Leon C.: "Sometimes doctors don't know the prognosis. If we can't get clear guidelines from them, it's difficult to get a realistic appraisal of the patient. Sometimes we might tend to be overlenient. I really don't know what to expect from someone who is mentally ill."

Guest Speaker: "Well, you might start by trying to get an overview of what is a normal level of functioning for the patient. Generally, you can know this based on what the patient's lifestyle was like prior to the onset of illness. For instance, you might try to see how much the person deviates from their usual functioning. Now, if a person never had tremendous insight, you can not expect them to demonstrate extraordinary insights following a hospitalization. What you might hope for is a person who functions at least as well as they did prior to the onset of mental illness. I must point out, however, that the patient's overall functioning is subject to deterioration as the illness persists over time."

Barbara S.: "I have an interesting problem: my daughter is able to drive, but recently she states that she is afraid and refuses to drive."

Guest Speaker: "Who takes your daughter places?"

Barbara S.: "Me or my husband."

Guest Speaker: "Perhaps you could help your daughter by doing less for her. You really can't force her to do things, but you can control yourself in some situations."

Pamela W.: "What can I do, my son refuses to come out of his room."

Guest Speaker: "How old is he?"

Pamela W.: "Sixteen."

Guest Speaker: "At that age, you could have your son involuntarily hospitalized. If he were 18 years old, then he would be able to refuse. What you need to assess is whether he is a danger to himself by staying in his room."

Mildred C.: "I am beginning to think that my son is a danger to himself. He buys all kinds of oil, castor oil, cooking oil, and he is eating excessive amounts in his food. Sometimes, he drinks it straight."

Guest Speaker: "How old is your son?"

Mildred C.: "He is 20."

Guest Speaker: "Is he beginning to lose weight, because oil can act as a laxative."

Mildred C.: "Yes, he is losing weight."

Guest Speaker: "Where would he live if he weren't living with you?"

Mildred C.: "Probably on the street, or he might go to different family members who end up calling me to pick him up. Once he spent a couple of nights in his old car which is broken down and collecting tickets on the street."

Guest Speaker: "I can't tell you what to do, but it may be that your son is too comfortable living at home to change anything. Do you think he would fight if you tried to take him to an emergency room?"

Mildred C.: "Yes, I do."

Guest Speaker: "Well, you could with the help of other family members set up a situation so that the police can come and pick up your son. Another possibility is to stop by the local precinct and inform the police of the situation with the car. In that way, they could come to question your son about that and assess the situation for themselves. Still another way of getting help might be to have two Psychiatrists come to the home."

Mildred C.: "We tried that, but my son refused to come down stairs."

Guest Speaker: "It seems to me that your family needs to agree upon what they are going to tolerate and take action accordingly. But this gets us into the area of

threats, if you say you are going to do something, you have to be prepared to follow through. My general rule of thumb is, if it is your house, you can set the rules. You don't need to be held hostage in your own house; and with respect to household policies, you should expect the patient to adhere to basic rules."

"It is important for parents to remember that they have other children and they should give them attention as well. Otherwise, other siblings and other family members begin to feel neglected, because the patient becomes the total focus of the whole family."

Barbara J.: "Several people here have teenagers, and I have observed that a lot of things my son does, my teenage daughter does too. But I always attribute his behavior to his illness, and the whole family tends to blame him even when the other children use him to get away with things themselves. Recently, I mentioned to him that everyone needs a crazy to take the pressure off of them. I tried to get him to see that other people have problems and should be allowed to deal with their own problems. Why should he allow them to use him in that way?"

Guest Speaker: "That is exactly what you should have said. You were actually helping him choose the role he functions in. Each of us has some control over the role we play in the family."

Susan C.: "Suppose you try to set rules and the person gets out of following them. For instance, my son pays the other children to wash dishes when it's his turn."

Guest Speaker: "Is your son contributing to the household for other expenses?"

Susan C.: "Yes."

Guest Speaker: "If your son chooses to spend his pocket money to pay his siblings to do things for him, maybe it is best that you stay out of it. He has a right to develop his own relationship with his siblings. Family therapists call this issue generational boundaries. Certain boundaries exist that should never be fluid, so that parents should not complain to their children about one another, and children should have relationships that exist separate and apart from their parents."

Penelope Johnson: "We are getting pressed for time. I wonder if those who haven't asked questions wish to raise questions or comment at this time?"

Elizabeth S.: "What is a nervous breakdown and can just plain disobedience cause mental illness?"

Guest Speaker: "No one really knows what causes mental illness. Some people think it is genetic, others think it is caused by environmental factors, while others believe it to be a combination of factors. But with respect to a nervous breakdown, this term is usually used when a person is no longer able to function as they usually do. However, under this heading is a whole range of illnesses."

Elizabeth S.: "I brought my daughter to the clinic because the school kept complaining about her behavior. Sometimes she would disrupt the whole class. But I see her as being disobedient."

Guest Speaker: "Rebelliousness is somewhat different from what we are talking about. It sounds like your daughter needs a good evaluation, and if the problem is rebelliousness, perhaps some behavioral exercises which sets firm but kind limits would be helpful."

"There are ways to set limits on individuals suffering of mental illness without rejecting the patient. This brings me to a few last points I want to mention. Families need to learn how to act with a low emotional level. Research has shown that families who react with a high emotional level have a higher incidence of patients being rehospitalized than do families who exhibit a low emotional level. What do I mean by a high emotional level?"

Group: "Easily excitable?"

Guest Speaker: "That is right. In other words, families that are easily excitable tend to raise the patient's anxiety. Therefore, it is important for families to learn how to put things in perspective, and not react in an extreme fashion to everything the patient does. For example, the son who pays his siblings to wash dishes. As a parent, you might try to reframe this so that instead of saying that he is lazy, you might view your son as being pretty smart to figure out ways to get people to do things for him. In this situation, you would try to view things in such a way as to engender a new attitude within yourself about the behavior you see."

Elizabeth S.: "Have you worked with foster children?"

Guest Speaker: "Yes I have. Are you dealing with the problems of a mentally ill foster child?"

Elizabeth S.: "Yes."

Guest Speaker: "I can comment on this question in conjunction with the question asked earlier about dealing with children who are mentally ill and mentally retarded. Life tends to be twice as devastating for any person who has one handicap that is compounded by another handicapping condition. A major problem for the mentally retarded, however, is that so few facilities exist to deal with their dual diagnosis. This does not present quite the same problem for a foster child who happens to need psychiatric care."

Barbara S.: "There is a point where patients who have had an acute episode come back to a point of normalcy. Can the shame of having a breakdown ever be removed?"

Guest Speaker: "Sure, but it is removed with therapy and help. The person has to be helped to feel comfortable with themselves over time."

"A few final points to remember are: (1) it is important not to reject the patient when you set limits. For example, you might start out by praising the individual on their recent gains, before saying something to correct certain problematic behaviors.

(2) Do confront negative behaviors, unless you see that the person is paranoid, delusional, or psychotic. If that occurs the person is in need of professional help. If you challenge the behavior, you heighten the patient's anxiety and this can lead to a blow-up.

(3) Try to compare the patient to their own better period's functioning, rather than comparing him/her to someone else. Comparative statements are often heard as critical to the patient.

(4) Make sure you keep focus on other family members and their needs. Do not allow the patient to become the total focus of all family interactions.

(5) Try not to feel compelled to make communication. Converse as you would normally.

(6) Differentiate description from evaluation. In other words, say what happened as opposed to how you feel about what happened. For instance, the patient's dress is too tight. You might comment, "you seem to have gained a little weight," rather than, "you look like a slut in that dress."

(7) Accept responsibility for your statements and let others accept responsibility for theirs. An example of this might be, the patient says something in an angry manner, because he/she needs to get some distance. Sometimes a family member will comment, "Oh, you didn't mean that." That type of statement negates what the patient is trying to communicate.

(8) Finally, the ultimate goal for all families may be to help its members separate and feel free to come and go. However, in order to do this, all the issues we have touched on would have to be worked through. If family members get caught up and fearful about their ability to come and go freely, it can lead to a lot of problems and an inability to separate."

Chapter Four

Findings and Interpretations

I. The Needs Assessment Questionnaire

The Needs Assessment Questionnaire was designed to obtain a profile of family caregivers enrolled in this educational group program. A profile was necessary in order to tailor the training protocol to caregivers' specific requests for help. Questions were constructed so as to elicit both general and specific information about family providers.

One broad category of questions dealt with caregivers' roles and attitudes about providing community assistance to a mentally ill family member or friend. In terms of their role behavior, we wanted to know in what way they were related and the kind of help they provided to a mentally ill family member.

Attitude questions focused on caregivers' underlying motivations for helping, their level of comfort in the helping role, and whether other people in the larger community made helping a mentally ill relative more or less difficult.

A second broad category of questions sought to learn how training about mental health resources could support caregivers in their role as community care providers. In this part of the questionnaire, we simply asked caregivers to state what kind of help they would like. Finally, the Needs Assessment Questionnaire sought to obtain personal descriptive data about caregivers.

Demographic Profile of Family Caregivers

This group program enrolled 23 caregivers, 78 percent of whom were females, and 78 percent of whom were parents. Of the nonparents, there were two siblings, two other relatives (cousin, aunt, or uncle), and only one caregiver who was a friend. The racial mix in the group was 61 percent Black, 30 percent Caucasian, and nine percent Hispanic. Sixty-five percent (15) of these caregivers were married, 17 percent (4) were divorced, nine percent (2) were widowed, and nine percent (2) were separated or never married. Regarding their age, only one caregiver was in each of categories 20 - 29 and 30 - 39, seven caregivers were 40 - 49, 10 were in the category 50 - 59, and four caregivers were over 60.

Seventy-four percent of the group were employed. Thirteen percent (3) of these caregivers were unemployed: two were retired, and one was a student. Only one caregiver had less than a high school education. Thirty-five percent (9) of these caregivers were high school graduates and 57 percent (13) completed some college or were college graduates. The personal incomes of caregivers were as follows: two had less than $5,000; two had between $5,000 - $9,999; six had between $10,000 - $14,999; three had between $15,000 - $19,999; five had between $20,000 - $24,999; one had between $25,000 - $29,999; and only four had incomes over $30,000.

Profile of Caregivers' Role Behavior

Questions 1a and 2, from the Needs Assessment Questionnaire, were designed to show the role in which family members perform as caregivers. They were asked to state briefly what they do in order to be of help to a mentally ill family member.

Three categories resulted from caregivers' written responses to question 1a. Seventy percent (16) of caregivers seemed to provide therapeutic services in that their statements reflected attempts to talk with the patient in order to help the patient cope with his/her problems differently. Twenty-two percent indicated that they provide a combination of therapeutic and concrete services as evidenced in their attempts to talk or reason with their mentally ill relative, in addition to performing specific tasks, such as assisting with cooking, cleaning, food, housing, and budgeting. Only nine percent (2) of caregivers stressed provision of concrete help as the primary assistance they offer.

Typical statements that reflect therapeutic remarks are as follows:

> "I try to be kind and patient when dealing with my son, in order to avoid any type of stress."
>
> "I try to encourage my son, to show him nothing is easy and to try to look at the good side of any situation."
>
> "I listen, sometimes I offer advice."
>
> "Chris is very hostile, so I try to calm him down first. Then I let him approach the subject and listen to his viewpoints."

> "I realize Susan's problems and limitations. I try to conceal my disappointment, and call upon patience. I understand my daughter needs professional help."

Statements that reflected a combination of therapeutic and concrete services were:

> "I provide moral support and housing. I try to be a friend who is supportive of his needs."
>
> "I provide food, try to talk to him and on occasion I have read to him about things that might help him deal with his illness. This does not appear to be helpful as he has fixed opinions."
>
> "I try to explain to my daughter that voices are not real, and that she should not pay attention to them. Also, she doesn't know how to budget and I try to teach her to budget."
>
> "Wash clothes, cook food, try to talk to him, but he doesn't listen."
>
> "I give him food, shelter, and support him in his endeavors."

The following statements reflect more the provision of concrete help.

> "Provide a roof over his head, home-cooked meals and vitamins, clothing and laundering service; transport him by car for necessary doctors' and dental appointments."
>
> "Food shopping, cooking, cleaning house, chauffeuring."

In question 2, various tasks were listed and caregivers were asked to check either yes or no beside any item reflecting the type of assistance provided to a mentally ill relative. Additional space was provided for caregivers to expand this list as needed.

Table I shows, in descending order, the tasks and services that program participants most frequently indicated they provide. Both from a review of their responses in

Table I and from their written remarks, it was observed that caregivers perform some types of assistance more frequently than others. For example, almost all program participants say they provide emotional support (96%), give advice about seeking treatment (91%), or provide food (91%), while only about half take the person shopping (52%), give advice about planning a budget (52%), or provide transportation to recreational activities (43%). From the data, no pattern could be discerned about their helping behavior based on sex, race, age, marital status, and income.

Table I

Types of Assistance Provided by Caregivers

List of Services (23)	Number of Caregivers	
	N	%
Provide emotional support	22	96
Give advice about seeking treatment	21	91
Provide Food	21	91
Provide Clothing	19	83
Provide advice and counseling about work and other problems	19	83
Provide Money	16	70
Provide help with cleaning	15	65
Provide transportation to treatment facilities	13	57
Give advice and counseling about housing	13	57
Provide assistance with meal preparations	13	57
Take person shopping	12	52
Give advice and counseling about planning a budget	12	52
Provide transportation to recreational facilities	10	43

Caregivers' Motivation For Providing Community Care

The third question asked caregivers to state their reasons for becoming involved as care providers for an emotionally ill friend or relative. Their responses revealed that 18 Caregivers (78%) were involved because of a sense of parental or familial duty or responsibility. This number represents all the parents attending the training group. Statements such as, "She is my daughter and I want to help her," or "The young woman needs help, if not from her parents, then who?," represent statements made by parents who experience caregiving as a duty.

Only three caregivers (13%) stated that their involvement was for reasons other than a sense of duty or responsibility. They seemed to be involved for altruistic reasons. For example, one wrote "I feel that I can help, since I have been sick myself...I can use what I learned about myself to help someone else." The remaining two caregivers said their involvement was associated with a desire to lend support to a primary caregiver.

Caregivers' attitudes about their role was elicited from a question (3a) which asked, "How do you feel about giving the help you provide?" Based on the literature review, one might expect that caregivers would experience caregiving as burdensome. This expectation was most apparent in the answers provided by five caregivers who described feelings of helplessness, hurt, disappointment, or inadequacy about helping a mentally ill loved one. Ten caregivers described feeling good at times but uncertain in some situations, and seven caregivers described feeling good and reasonably confident about the help they provide.

These findings suggest that, despite frustrations, most caregivers (65%) felt good or reasonably sure of themselves in handling role responsibilities, regardless of their reasons for becoming involved. Only 22 percent of Caregivers readily acknowledged feeling less certain about their roles.

Caregivers' level of comfort dealing with the behavior of their mentally ill relative was further probed in questions 4, 4a, and b. The data shows greater variation in caregivers' reponses when they were asked to rate how comfortable they felt dealing with the behavior of their relatives or friends?

The sample was equally divided with respect to level of comfort. Eleven caregivers (50%) indicated that they were usually or somewhat comfortable, and 11 indicated that they were usually or somewhat uncomfortable.

There was a shift in the percentage of caregivers who acknowledged feelings of discomfort based on their reponses to the forced choices in question 4. We might speculate, based on their responses to questions 3 and 3a above, that caregivers were actually communicating their commitment to helping a mentally ill relative when it was indicated that they felt good about their role. They appeared to feel good about their commitment to help. However, half of these participants acknowledged uncomfortable feelings when dealing with specific aspects of their relative's illness.

The sample was divided by level of comfort into two subgroups, those caregivers who evidenced high comfort (i.e., usually or somewhat comfortable) and those who evidenced low comfort (i.e., usually or somewhat uncomfortable) in order to compare subgroups. Caregivers' level of comfort was compared against caregivers' education and personal income as the group was almost equally divided

on these variables as well. (As previously noted, caregivers had been asked to indicate their annual household incomes on the Needs Assessment Questionnaire, but they tended to reflect their personal incomes instead. These income levels were accepted for purposes of comparison).

Table II shows that 45 percent of low-income caregivers versus 55 percent of high-income caregivers rated themselves low on level of comfort, and 55 percent of low-income versus 45 percent of high-income caregivers rated themselves high on level of comfort. There is little difference between caregivers based on income.

Table II

Do you usually feel comfortable dealing with the behavior of your mentally ill relative or friend?

N=23	Low Income	High Income
Low Comfort	45% (5)	55% (6)
High Comfort	55 (6)	45 (5)
	100% (11)	100% (11)

No answer = 1

Table III, however, shows some differences between caregivers on the basis of education and level of comfort. Seventy percent of caregivers with low educational achievement versus 42 percent of caregivers with high educational achievement rated themselves low on level of comfort; and 30 percent of caregivers with low educational achievement versus 58 percent of caregivers with high educational achievement rated themselves high on level of comfort. These findings suggest that caregivers of low educational achievement tended to rate themselves low on level of comfort more frequently than did caregivers high on educational achievement who tended to rate themselves high on level of comfort.

Table III

Do you usually feel comfortable dealing with the behavior of your mentally ill relative?

N=23	Low Education	High Education
Low Comfort	70% (7)	42% (5)
High Comfort	30 (3)	58 (7)
	100% (10)	100% (12)

No answer = 1

Table IV, on the other hand, shows that when comparing education and income, caregivers in the low-income, high-education group tended to rate themselves low on level of comfort more frequently than did caregivers in the low-income, low-education group or caregivers in the high-income group. In both the low-income, low-education group and the high-income groups, caregivers were more evenly divided when rating themselves of low or high comfort in dealing with their relatives' illness. Among low-income caregivers, high educational achievement did not appear to be positively associated with a high level of comfort.

Table IV

Caregivers' Level Of Comfort by Income and Education

	Low Income (Under $15,000)		High Income ($15,000 and over)	
N=23	Low Ed	High Ed	Low Ed	High Ed
Low Comfort	2 (50%)	4 (67%)	5 (80%)	1 (20%)
High Comfort	2 (50)	2 (33)	1 (20)	5 (80)
	4 (100%)	6 (100%)	6 (100%)	6 (100%)

No answer = 1

Questions 4a and b asked for clarification of the nature of caregivers' comfort or discomfort. When questioned about specific aspects of care provision which are difficult to deal with, caregivers' open-ended responses fell into four main categories: (1) anxiety about patient's symptomatic behavior (43%), (2) inability to communicate with patient (30%), (3) patient's resistance to the help offered (26%), and (4) difficulty accepting patient's limitations (13%). Some caregivers cited more than one area of difficulty in their written remarks. Table V shows the frequency of caregivers' responses to questions 4a and b.

Table V

Problematic Aspects of Caregiving

N=23

Most Difficult Aspects of Helping	Number of Caregivers	
	N	%
Patients' symptomatic behavior	10	43
Inability to communicate with patient	7	30
Patients' resistance to help	6	26
Difficulty accepting patient's limitations	3	13

In question b, caregivers were asked to rate the effect on the help they provide of other people's attitudes about the mentally ill. Eighty-three percent of caregivers indicated that the reactions of others usually has no effect or never has an effect on their helping role. Caregivers' responses are presented in Table VI.

Table VI

Reactions Of Others On Helping Behavior

N=23

Level of Effect	Number of Caregivers N	%
Always has an effect	2	9
Usually has an effect	2	9
Usually has no effect	5	22
Never has an effect	14	61

There were two probe questions (6a and 6b) which asked caregivers to answer yes or no as to whether the reactions of others made them feel uncomfortable and, if yes, in what way did they feel uncomfortable. Only six caregivers checked yes, the reactions of others made them feel uncomfortable, which seems to support caregivers' responses to question 6. It also supports other findings (question 3a) that most caregivers feel somewhat confident about their commitment as care providers. Even though there may be problematic aspects of providing care, caregivers' role behavior did not seem to be influenced by people in the larger community.

Caregivers who said the reactions of others affected their role behavior focused on their feelings of embarrassment and/or insecurity when others both within and outside the family questioned what is wrong with the patient, or questioned the caregivers' methods of dealing with various problems. For example, caregivers stated: "I am uncomfortable when people ask me what is the matter with him," or, "Not knowing if my approach to the problem of my nephew is correct."

Another aspect of interest was to determine the nature and extent of caregivers' informal support networks. This information would be helpful towards improving linkages to other support systems. Responses to question 5 show, however, that most group participants (20) were already engaged in social networks that consisted of more than one other person. Nine caregivers reported that they turned to three other people; four caregivers turned to four other people; four caregivers turned to five other people; three caregivers turned to two other people; and only three caregivers indicated that they turn to only one other person for support. A crosscheck of these responses to those of question 7 revealed that the three individuals who turn to only one other person for support were not primary care providers, whereas most group participants were the primary helping person (Question 7 reads: Do you provide the primary help to your relative or friend who is having emotional difficulties?). Table VII below shows a frequency ranking of people caregivers look to for support.

Table VII

Caregivers' Informal Support System

N=23

Source of Support	Number of Caregivers	
	N	%
Another Family Member	19	83
Professional (Psychiatrist, Psychologist, Social Worker)	16	70
Spouse	15	65
A Friend	11	50
Clergy	11	50

The final area of exploration on the Needs Assessment Questionnaire focused on caregivers' reasons for participating in the group program. Caregivers' responses to the question, "What kind of assistance would you like to obtain from this group?" can be divided into four categories: 23 were seeking information; 20 wanted linkage with professional or self-help agents; 18 wanted the opportunity to share mutual problems and concerns with others; and 12 wanted reassurance or validation of their ability to help others with similar problems. We might speculate that caregivers' requests for help represented possible deficits in their informal support systems, despite the variety of supportive others available to them.

When asked to list some topics they would like to discuss, 19 participants stated that they wanted to talk about specific topics, i.e., treatment, financial assistance, socialization programs, housing, self-help, medication, and employment. Six caregivers wished to discuss ways of managing the patient's symptomatic behavior, five caregivers wished to discuss ways of

improving their relationship with the patient, and five caregivers wished to learn how to deal with their own anxiety about their role as care providers. The last question, which asked caregivers to state if there were any other reasons for attending the group program, did not reveal new material that had not already been covered by the two preceding questions.

Summary

The Needs Assessment Questionnaire provided a profile of family caregivers who had taken on the job of providing community care to their chronically mentally ill relatives. Despite the difficulties involved, they evidenced a sense of commitment to this task based on a sense of familial duty or responsibility. By participating in this educational group program, these caregivers acknowledged their need for help, and they came seeking very practical information, guidance, and enlarged social and professional networks in order to improve their role performance. Of critical importance to this group also was the expertise that professionals could offer both in terms of their knowledge base and practice experiences. That the program's broad goals were geared toward supporting the help-giving abilities of caregivers, this group represented a good sample for exploring the ways in which training about community resources might enhance the services caregivers are already providing.

Personal Data of Family Caregivers

Gender		Number
Male		5
Female		18
	Total	23

Age		Number
20-29		1
30-39		1
40-49		7
50-59		10
60 and over		4
	Total	23

Relationship to Patient		Number
Parent		18
Cousin, Aunt, Uncle		2
Friend		1
Other (Brother)		2
	Total	23

Race		Number
Black		14
Caucasian		7
Hispanic		2
Native American		0
Other (Asian)		0
	Total	23

Employment Status	Number
Full-time	11
Part-time	6
Unemployed	3
Never worked	0
Retired	2
Other (Student)	1
Total	23

Marital Status	
Married	15
Divorced	4
Separated	1
Widowed	2
Never Married	1
Total	23

Educational Background	Number
Some grade school	1
High school graduate	9
Some college	11
College graduate	2
Some graduate school	0
Graduate degree	0
Total	23

Family Income	Number
Less than $5,000	2
$5,000-$9,999	2
$10,000-$14,999	6
$15,000-$19,999	3
$20,000-$24,999	5
$25-000-$29,999	1
$30,000 and over	4
Total	23

II. Participants' Evaluation Questionnaire

Participants' Evaluation Questionnaires sought to elicit information consistent with the objectives of the program as outlined in Chapter II. Questions were constructed such that group participants would provide information relevant to their unique experiences during training, as well as information regarding the relative strengths and limitations of this educational program. Specifically, questions 1 through 6 related to various aspects of planning for meetings. Caregivers were asked to rate their experience of the training program, and to describe the impact of the group experience on their caregiving abilities in questions 7 and 8, respectively. These questions also sought feedback on practical information caregivers may have learned from training.

The program's influence on caregivers' attitudes about mental illness, about others in the larger environment, and about their mentally ill loved ones was the focus of questions 9 through 12.

Finally, questions 13 and 14 were included to determine if caregivers were able to begin thinking in terms of enlarged social and professional networks as a result of a six-week educational training program. (Please see copy of Participants' Evaluation Questionnaire in Appendix # B).

Overall Program Rating

In order to be included in the study, caregivers had to attend at least three out of six sessions. It was thought that those attending a minimum of one half the meetings would be better able to comment on the group experience than would those who attended only one or two sessions. Caregivers' responses to question 1, "How many sessions were you able to attend?," shows that they all maintained good attendance. Nine caregivers attended six sessions; eight caregivers attended five sessions; four caregivers attended four sessions; and only two caregivers attended the minimum of three sessions. In one instance, a caregiver joined the program during the fourth group meeting.

All caregivers gave the program an excellent or good rating when asked in question 2, "How would you rate this program?" They were asked to check excellent, good, fair, or poor.

High ratings also were evident in caregivers' reponses to the third question where they were provided a rating scale to mark E for excellent, G for good, F for fair, and P for poor. They were asked to rate specific aspects of planning that went into the program such as room facilities, guest speakers, discussion among participants, usefulness of information, material covered, and the way meetings were planned.

Fifteen caregivers rated the program excellent or good on all but one item in this list (Please see Table VIII). Discussion among participants proved to be the most sensitive item in that there was greater variation in caregivers' pattern of response. For example, five caregivers rated discussion among participants excellent; 17 caregivers rated this item good; and only one caregiver gave it a fair rating. We might infer that participants generally were less satisfied with this aspect of the program.

On the other hand, the program appeared to be strongest on its choice of guest speakers and the way meetings were planned, as 19 Caregivers rated each of these indicators excellent and four rated them good.

Material covered received the second highest rank with 17 caregivers rating it excellent and six caregivers giving this aspect of the program a good rating.

Room facilities were rated excellent by 16 caregivers, and good by seven group participants.

Fifteen caregivers indicated that the program was excellent and eight caregivers rated the program good with respect to the usefulness of information.

Table VIII below summarizes the findings on various aspects of planning: (E = Excellent, G = Good, F = Fair, and P = Poor).

Table VIII

Aspects of Planning Group Meetings

N=23	Number of Caregivers			
	E	G	F	P
Guest Speakers	19	4	O	O
Way Meetings were planned	19	4	O	O
Material Covered	17	6	O	O
Room Facilities	16	7	O	O
Usefulness of Information	15	8	O	O
Discussion Among Participants	5	17	1	O

When asked in question 4, "What part of the program did you find most helpful?," five response categories emerged from participants' written remarks to this open ended question. They were as follows: (1) presentations by guest speakers and printed materials; (2) listening to guest speakers and sharing experiences with others; (3) sharing experiences with others; (4) sharing experiences with others and printed materials; and (5) presentation by guest speakers and printed materials. For one woman, learning that there is help for her son was the most helpful part of the program. However, since she did not pinpoint what aspect of the program contributed to her increased awareness, her remarks are not included in the categories as outlined below.

Thirteen caregivers said that the guest speakers' presentations were the most helpful part of the program. The following statements are representative of this response category:

> "The most helpful part was the meeting in which the speaker who has a mentally ill son talked about her experience. I was able to see what I might have to do in order to force my son to get help. The fact that she went through it made her presentation more real."
>
> "Dr. Jaffey's and Mrs. Slaughter's explanations on the different types of illnesses and medications."
>
> "Mostly speakers, questions, and answers."

Listening to the presentations of guest speakers and sharing experiences with others was emphasized by four participants. Their comments were as follows:

> "Medication discussions, and encouragement from other participants."
>
> "Guest speakers and sharing experiences with others."
>
> "The group discussion and questions after each speaker."
>
> "Symptoms of schizophrenia and the informal group discussions."

Three caregivers indicated that sharing experiences with others was the most helpful part of the program. For example:

> "The part that allowed everyone to talk about how they dealt with their problems. I got a few ideas about how to deal with our problem at home."
>
> "Learning that other people have the same problems as you; and that you aren't the only one with family problems of this kind."

> "Being able to talk problems out. Finding the answer to so many problems. Some of the answers I learned not so much from speakers, but from hearing how other members deal with their problems. For example, our focus was often on the children, but I learned that parents feel rejected and have to overcome their problem in order to help their children."

Only one caregiver said that "discussion among parents and leaflets" (printed material) were the most helpful part of the group program, and another caregiver indicated that the presentation of guest speakers and printed material helped her understand the nature of mental illness.

As for question 5, "What part of the program did you find the least helpful to you?," only 11 participants expressed dissatisfaction with specific aspects of the program. Six caregivers identified at least one topic which did not apply to their particular situation, e.g., "the session on medication, because my interest is not in that." Three caregivers felt that time was misused during meetings, i.e., "too much time was devoted to individuals discussing their own specific problems" or "not enough time was provided for individual questions." Finally, two Caregivers (one couple) did not feel the program adequately met their needs. Exploration reveals that this couple's adult daughter resides in a community residential program, and visits the family on weekends and holidays. Although this couple was dissatisfied that after years of treatment and special services their daughter was still unable to function independently, they were still further along in securing the

necessary help to deal with this problem than were most group participants. Their answers to the question follows:

> "Mostly, the problems of other clients in no way related to mine, so I got little value from their trials and tribulations."
>
> "I felt that we were further along in dealing with our troubles than some of the members. Therefore, some of the sessions did not give us that much concrete information that we didn't have."

Consistent with caregivers' generally favorable reactions to training, they all checked "yes" when asked, "Would you recommend participation in this group program to others in your situation?" One person qualified this statement, however, by indicating that he would recommend the program to someone else, but not if they were in his situation. (This was the man whose daughter is in a residential treatment program, as previously discussed.)

Caregivers' Self Report of Knowledge Gained from Group Program

Question 7 presented caregivers with the opportunity to rate, on a Likert Scale (excellent, good, fair, or poor), the extent to which each of nine statements most clearly represented their experience in the training program. These nine indicators, identified in Table IX were: (1) sharing experiences with others; (2) obtaining answers to questions of interest; (3) understanding that emotional illness is related to problems in coping and handling stress; (4) understanding the behavior of someone suffering from

long-term emotional disturbance; (5) feeling more confident in your ability to provide care to a friend or relative who has long-term emotional disturbance; (6) feeling that your contribution to group discussions was beneficial to others; (7) learning about available community resources; (8) learning how to go about obtaining needed resources; and (9) learning the difference between how various state, city, and private agencies operate.

Since participants tended to rate the program favorably, data analysis focused on identifying response patterns that might point out areas for potentially strengthening the program design.

1. Only two caregivers rated the program fair or poor on providing opportunities to share experiences with others. By cross-referencing responses on this item to responses to items on question 3, it was revealed that one of these caregivers had identified discussion among participants as one of the program's main weaknesses. It was not possible to determine the other caregiver's dissatisfaction with this indicator from questionnaire data.

2. In terms of obtaining answers to questions of interest, only three caregivers gave the program a fair or poor rating. It would appear that these individuals felt consistently blocked in their ability to address issues of interest to themselves.

3. All caregivers rated the program excellent or good in teaching that emotional illness is related to problems in coping and handling stress. We might expect this result based on the educational emphasis of the program design.

4. Only one caregiver rated the program fair on understanding the behavior of someone suffering from long term emotional disturbance.

5. As for feeling more confident in their ability to provide care to a friend or relative who suffers from emotional disturbance, only three caregivers rated the program fair. It was difficult from cross-referencing of data to draw inferences about program weaknesses on this indicator.

6. Feeling that their contribution to group discussions was beneficial to others was the most sensitive of items on this aspect of evaluation. Here, nine participants rated this item fair or poor. This finding suggests that it was difficult for people to get feedback about their contribution to group discussion in the context of a short-term program that emphasized a highly didactic, versus an interactional, approach.

7. Learning about available community resources received a fair or poor rating by four caregivers. Of these four caregivers, one couple had given consistent feedback that the program was not meeting their unique needs. It was not possible to draw inferences about the other two caregivers, since no consistent response pattern emerged in their overall evaluation of the program.

8. Regarding how to go about obtaining needed resources, only two caregivers rated the program fair or poor. No inferences were drawn from one caregiver's rating, but the other reiterated that the program failed to meet his needs.

9. Three caregivers gave the program a fair or poor rating with respect to learning the difference between how various state, city, and private agencies operate. There were no clues that helped explain possible program weaknesses on this item.

Table IX

Caregivers' Rating of Knowledge Gained from Group Training

N=23	Number of Caregivers			
Learning Indicators	Excellent	Good	Fair	Poor
Sharing experiences with others	10	11	2	0
Obtaining answers to questions of interest	10	10	3	0
Understanding that emotional illness is related to problems in coping and handling stress	16	7	0	0
Understanding the behavior of someone suffering from long-term emotional disturbance	15	7	1	0
Feeling more confident in your ability to provide care to a friend or relative who has long-term emotional disturbance	13	7	3	0
Feeling that your contribution to group discussions was beneficial to others	5	9	6	3
Learning about available community resources	11	8	3	1
Learning how to go about obtaining needed resources	9	12	1	1
Learning the difference between how various state, city, and private agencies operate	7	13	3	0

Caregivers were probed regarding the impact of the group experience on supporting their mentally ill friend or relative. Thus, question 8 provided increased insights about what caregivers learned from training. An assessment was made of caregivers' verbal reports to determine if these would match what they said they would like to obtain from training on the Needs Assessment Questionnaire. Prior to training, caregivers requested: (1) information, (2) linkage with professional or self-help agents, (3) an opportunity to share mutual problems and concerns with others, and (4) reassurance or validation of their ability to help others with similar problems. (Please refer to p. 109).

Although caregivers tended to check off more than one area where help was desired prior to training, their written responses on the Participants' Evaluation Questionnaire tended to emphasize only one area where they felt particularly helped. Only two caregivers seemed to highlight two of these categories in their written statements. Further examination of questionnaire data shows that while caregivers' statements can be grouped under one of the above categories, each person left the group experience feeling helped in a different way. The variety of reponses to this question helps to amplify conclusions drawn from the Needs Assessment Questionnaire where it was determined that caregivers came to this program seeking very practical information, guidance, and enlarged social and professional networks in order to improve their role performance.

The following list of categories and caregivers' responses are provided so as to fully appreciate the variety of ways in which caregivers felt helped by the group experience.

Two participants were most responsive to information provided in the program. Their responses are as follows:

> "Informed of new ideas which were very interesting."
>
> "The group has provided information and material which I can share with my siblings and parents who have not been receptive to learning about mental illness despite the fact that I have two sisters who have a history of psychiatric illness."

Five participants felt the group helped them most by linking them with professional or self-help agents. Their remarks are stated below:

> "The group helped me think about how to get help from the crisis team. Another member provided the name of a psychiatrist who could come to the house. The program was good in that it linked me to resources."
>
> "I learned that you can't just pat the person on the head and let them misuse you. I have learned to recognize that someone who is emotionally sick needs professional treatment."
>
> "None, except in the last session when the material on other organizations was provided which suggested where one might go for other kinds of services."
>
> "A large impact in that it gave me confidence in therapy and medication."
>
> "I learned that I was not alone. The session devoted to community resources was helpful in explicating how I would have to go to particular agencies or programs to request specific answers to questions concerning the progress of my child who is in a community residence program."

Six participants focused their remarks on the opportunity to share mutual problems and concerns with others as indicated below:

> "Listening to how others handled a similar situation enabled me to cope with the person and associated problems easier."
>
> "A feeling of being part of a big family of all those who suffer from mental illness and the ones who every day care for them."
>
> "Because of group experience, I realize that my problems could be a lot worse and I am better able to cope."
>
> "Reinforced. The interchange of problems made our problems more understandable and more manageable."
>
> "Things don't look so bleak anymore."
>
> "Group therapy is important to me in coping with my ill son."

There were nine participants who said that they felt reassured about providing care. Although the Needs Assessment Questionnaire asked whether caregivers felt a need for reassurance or validation of their ability to help others (possibly other caregivers) with similar problems as their own, Caregivers responded on the basis of how they felt helped with respect to the relative for whom they provide primary care. Therefore, responses to this item suggest that many participants were still too overwhelmed by their own problems to feel that they could be of help to someone else.

The following comments by nine caregivers further amplifies how information was used to help caregivers improve their handling of immediate situations at home.

> "I was able to accept certain behavior patterns at home more easily and without hard feelings."
>
> "Made me more tolerant and understanding. Realize that they can't help themselves after a point."
>
> "I learned to talk to my friend's nephew differently; I helped to explain to him that he had a problem that could be helped if he cooperated. Before, I didn't have too much to say to him."
>
> "I felt more compassionate for my son."
>
> "The group helped me a lot in that it made me feel that I can give a little assistance to someone else (my cousin). I can explain to her what I learned. I think this would help her in dealing with a lot of emotional problems of her children."
>
> "The group experience gave me a lot of insights about emotional illness, how to get help, and in realizing that it will take a long time before any progress is made. Also helped me learn not to say certain things that did more harm than good in a situation."
>
> "I became more convinced that home care is preferable to hospitalization."
>
> "It helped reinforce my determination to be as supportive as possible and to help find the best treatment available."
>
> "It helped me in being able to understand the situation with my nephew and my son, and helped me understand my role in dealing with them. I felt that I always got overly involved with my nephew. I realized that I had to pull back without feeling guilty. I found out that this was the best way to help him. It also forced his mother to get involved."

The Impact of Training on Attitude Change

Question 9 through 12 asked caregivers to answer yes, no, or not sure as to whether the educational group program changed their attitude about mental illness, others in the larger environment, and towards their mentally ill relative. A probe follows each question to determine how training may have impacted on attitude change.

Regarding question 9, "Has this program changed the way you think and feel about emotional disturbance?," 15 caregivers answered yes, three said no, and five said they were not sure. Of the 15 participants who answered the second part of question 9, "If yes, in what way has your thinking changed?," their comments seemed to reinforce themes articulated in question 8. Ten caregivers reported an increased understanding of the patient and/or themselves; two caregivers felt they obtained increased confidence in therapy and medication for the treatment of mental illness; one person realized that she was not to blame; one person realized that he was not alone in his suffering, and one caregiver felt more determined to provide continued care.

In response to question 10, "Based on this experience, do you think this program has helped you better cope with community resistance to helping people who have emotional problems?," only one man who felt the program failed to meet his needs answered no.

Question 11 states, "Do you feel more comfortable talking with a neighbor or friend about mental illness?" Three caregivers answered no. Caregivers were probed in question 11a and asked, "Please check very comfortable, comfortable or uncomfortable to describe your feelings about talking to a neighbor or friend." Eight caregivers checked very comfortable; 13 Caregivers said they were comfortable, and only two checked uncomfortable. This questionnaire item shows that four more caregivers report feeling comfortable coping with community resistance following participation in this training program.

This finding was revealed by comparing caregivers' responses on question 11 with their reponses to question 6a on the Needs Assessment Questionnaire. Question 6a states, "Do the reaction of others make you feel uncomfortable?, yes or no." On the Needs Assessment Questionnaire, seven caregivers checked yes, the reactions of others made them feel uncomfortable, whereas after training, only two caregivers indicated that they are uncomfortable talking with a neighbor or friend about mental illness.

Of the 21 caregivers who described feeling either very comfortable or comfortable, four stated that they were never ashamed or uncomfortable, three stated that they are no longer ashamed but would be selective about who to tell, five indicated that they feel comfortable enough to recommend treatment to others, and nine said they generally

are more open to talking about mental illness. Of the two caregivers who report still feeling uncomfortable talking to a neighbor or friend, one was concerned because her son had been ridiculed by neighbors, and the other indicated that she would never discuss personal problems with a neighbor or friend.

Table X shows the increase in the number of Caregivers who said they felt more comfortable dealing with the reactions of others after training.

Table X

Caregivers' level of comfort dealing with others

N=23	Before training		After training	
	N	%	N	%
Low Comfort	6	26	2	9
High Comfort	17	74	21	91
Total	23	100%	23	100%

With respect to question 12, "Has the group program changed the way you feel about your family member who is undergoing emotional stress?, yes or no," only four caregivers checked no. Responses to question 12a, "If yes, how has it changed the way you feel and what you do?", were as follows: 12 caregivers indicated that increased understanding made them more tolerant, sympathetic, accepting, or patient in dealing with aspects of their relatives' illness; four caregivers commented about learning the importance of setting limits for the patient; and three reflected greater confidence about their handling of situations involving the patient.

The Impact of Training on Building Social and Professional Networks

To obtain information about how the program may have promoted linkage with informal networks of support, question 13 asked caregivers if they would share substantive material obtained from this program with others. To this question, only three caregivers answered not sure. This finding was questionable, however, in that findings on the Needs Assessment Questionnaire showed that many caregivers were talking with several people in their support system prior to this intervention. In addition, many program participants had previous relationships with the agency prior to group exposure.

When asked, "Would you like to continue meeting?" (question 14), only three caregivers answered no.

Two caregivers answered no and one caregiver failed to respond to question 14a, "Would you like to meet informally as a part of a mutual support group?"

"Question 14b ascertained if professional staff would be seen as having a role in an ongoing group, to which 21 caregivers checked yes, one caregiver checked not sure, and one caregiver failed to respond.

The final question 14c asked caregivers who responded yes to question 14b, "In what way do you think professional staff should be involved?" caregivers' responses evidenced understanding of the need to work with professionals in dealing with the problems of the mentally ill. Examples of caregivers' responses were as follows:

"I think people meeting together is all right, but having the professional there would make it more meaningful. For example, if questions come up, people answer based on their experience which might not answer the question."

"Professionals should be involved in helping parents understand what their appropriate role should be in supporting their relative and to what extent so as not to undermine their relative's treatment program."

Professionals should be there to stimulate conversation in the group and to focus members on group goals."

Summary

The Participants' Evaluation Questionnaire revealed that, in general, all but one couple who participated in this group program seemed to feel that participation improved their role performance as primary care providers. It appears that emphasizing mental health resources helped caregivers not only to broaden their basic understanding about mental illness and its treatment, but also seemed to answer practical questions which enabled them to feel more comfortable and/or confident in their role behavior. That many caregivers were not as confident about helping someone else manage a mentally ill relative suggests that most participants either did not have this as a goal for participating in the group, were too overwhelmed by their own situations to concern themselves with the practical problems of others, or did not have enough time given the short term of the group to feel secure in this aspect of learning.

III. Program Evaluation Follow up Questionnaire

Attempts to determine the long-term effects of this group program were undertaken in a Program Evaluation Follow Up Questionnaire. Unlike the Participants' Evaluation, which was designed to make judgments about the program in meeting its objectives, this instrument sought to obtain additional descriptive information about caregivers in relation to broad program goals. Findings on the two-year follow-up are particularly susceptible to problems of reliability, however, in that assessment of caregivers' perceptions over time was not part of the original research design, and, in the absence of a control group and previously established research measurements, it is impossible to accept as reliable caregivers' self-reports two years after training. Some additional threats to internal validity and reliability were history, maturation, and self-reports as discussed under research methodology in Chapter II. Even so, follow-up findings were deemed useful in improving our guesses about caregivers' perceptions of the training experience.

The focus of this three-part instrument was to assess caregivers' ability to retain information, to assess their maintenance of understanding about how to apply information in order to increase utilization of various resources, and to assess their ability to maintain and/or improve their caregiving relationship with a mentally ill relative.

Part I asked caregivers to rate broad topic areas emphasized during training on the basis of how much they remembered.

Part II sought information about the ways in which training may have influenced caregivers' utilization of formal and informal mental health services.

Part III sought information about caregivers' feelings regarding their ability to provide continued care for a mentally ill family member. These areas respectively are discussed below.

Part I

The first questionnaire item states, "Please rate the following topic areas based on the amount of information that you remember from participating in the caregivers' training program," (1 = a great deal of information, 2 = some information, 3 = a little information, and 4 = do not remember). Topic areas were (1) what is mental illness?; (2) the impact of mental illness on the family; (3) the role of professionals in the treatment of the mentally ill; (4) the role of Caregivers in the treatment of the mentally ill; (5) the use of medication in the treatment of the mentally ill; (6) the role of self-help in helping families of the mentally ill; (7) difference between state, city, and voluntary agency programs in treating the mentally ill; and (8) eligibility requirements for treatment in a state, city, or voluntary agency program. (Please see Program Evaluation Follow Up Questionnaire in Appendix # D).

Twenty (87%) of the original combined group total of 23 participants responded to the two-year follow-up study. Their responses to the first question on the questionnaire are reflected in Table XI entitled "Information Remembered After Two Years." Table XI ranks from highest to lowest caregivers' ratings of topic areas as outlined above. Due to the relatively small sample size, the four rating categories have been collapsed into two to distinguish between caregivers who report having remembered a great deal or some information, and those who report having remembered a little or no information.

All 20 caregivers stated that they remembered a great deal or some information about the topic pertaining to the impact of mental illness on the family.

Topics receiving the next highest recall ratings were: what is mental illness?, the role of family caregivers in the treatment of the mentally ill, and the role of self-help in helping families of the mentally ill. Seventeen caregivers indicated that they remembered either a great deal or some information on these topic areas.

Sixteen caregivers said they remembered either a great deal or some information about the topics: the role of professionals in the treatment of the mentally ill and the use of medication in the treatment of mental illness.

Topics concerning state, city and voluntary agency programs were remembered less well by program participants. Eleven caregivers indicated that they remembered either a

great deal or some information about the difference between state, city, and voluntary agency programs in treating the mentally ill, and only nine caregivers indicated that they remembered either a great deal or some information about the eligibility requirements for treatment in a state, city or voluntary agency program.

Caregivers' overall responses to information retained after two years resulted in a favorable rating of the program, which is consistent with their generally favorable rating of the learning experience immediately after training. It is worth pointing out, however, that the topics pertaining to state, city, and voluntary agency programs were rated less favorably both immediately after training and in the two-year follow-up study. This observation suggests that Caregivers appeared to show the highest level of memory recall for those topics which may have helped them in clarifying, if not in enhancing, their direct role relationship with a mentally ill relative, versus remembering information regarding external systems which would involve placing another agent or agency in charge of the patient's care.

In other words, this finding supports conclusions drawn from the Needs Assessment Questionnaire where it was determined that caregivers' motivation for program participation was to obtain practical help and support in order to improve their role behavior as primary caregivers.

Table XI

Information Remembered After Two Years

N=20	Number of Caregivers	
Topic Areas	A great deal or some information	A little or no information
The impact of mental illness on the family	20	0
What is mental illness?	17	3
The role of family caregivers in the treatment of the mentally ill	17	3
The role of self help in helping families of the mentally ill	17	3
The role of professionals in the treatment of the mentally ill	16	4
The use of medication in the treatment of mental illness	16	4
Difference between state, city, and voluntary agency programs in treating the mentally ill	11	9
Eligibility requirements for treatment in a state, city, or voluntary agency program	9	11

Part II

Did the training program influence your use of formal or informal services on behalf of your emotionally ill friend or relative?

Caregivers were asked to respond to the above question first in an open-ended fashion and then by stating more specifically how this program might have impacted on their use of mental health professionals, self-help or mutual-support groups, and general social services before and after training. Caregivers answered question II as outlined above by stating yes or no along with their explanatory comments. Fourteen caregivers responded yes the group program influenced their utilization of formal or informal mental health services. Of the 14 answering yes, 12 caregivers said that they learned how to use services, whereas two caregivers said they learned to talk more openly about mental illness. Of the remaining six caregivers who stated no the program did not influence their use of services, five caregivers' mentally ill relative was already in treatment and one caregiver stated that she is not the primary caregiver.

Question II (1) which states "Did you have a relationship with a mental health professional prior to attending the Caregivers' training program? yes or no," shows that a total of eight caregivers checked yes and 12 checked no.

The probe question [II (1a)] states, "If yes, in what way, if any, did the program influence your relationship with this person?" Six caregivers' remarks suggested that the group program provided increased insight about mental illness which enabled them to converse with professionals and thereby obtain more information than they would normally. One caregiver said there was no need to make changes in her relationship with a professional, and another caregiver felt the program had no impact on his use of a professional.

A second probe [question II (1b)] asked those caregivers who answered no to question II (1) if they had sought the services of a mental health professional within the past two years. Nine caregivers answered yes and only three answered no, which represents an increase in the total number of caregivers (17) linked to professional services two years after training.

Caregivers' utilization of nonprofessional resources were explored in Question II (2), "Were you involved with a self-help or mutual-support group prior to attending this training program? Only two caregivers checked yes. In a probe question [II (2a)], seven caregivers checked yes, they subsequently became involved in self-help or mutual-support groups. Thus five caregivers who were previously uninvolved, became involved with a self help group after attending this training program. The two caregivers who were previously involved with a self-help or mutual-support group said the

program improved their ability to speak more knowledgeably in the support group. Although these findings show that caregivers still feel positively about the program on this aspect of training, it is unclear to what extent other factors may have influenced their involvement with non-professional supports.

The 13 caregivers who did not join with others outside their immediate families for support offered the following explanatory remarks: six caregivers indicated that they already had help in managing their problem, suggesting that their informal support system was adequate; four caregivers stated that time constraints prevented involvement; one couple said the program generally failed to meet their needs; and one nonprimary caregiver felt that her need for information had been met in the short-term group program.

When questioned [II (3)], "Have you applied for Medicaid or general social services of any kind as a result of training?," only five caregivers checked yes and further indicated that they felt knowledgeable about the necessary steps required to file applications in response to question II (3a). [Question II (3a) states "If yes, did you feel knowledgeable about the appropriate steps you needed to take in filing your application? yes or no."]

However, cross-referencing data of the fifteen caregivers who checked no they had not applied for Medicaid or general social services with their responses to question II (3b), which states, "If no, please state your reasons for

not applying," reveals that caregivers' responses to question II (3) above may not accurately reflect activity in this area. For example, eight of the 15 caregivers who said they had not applied for Medicaid or general social services had relatives already in treatment and already receiving these benefits. Four caregivers became involved instrumentally in hospitalizing a mentally ill relative and the hospital staff facilitated the necessary paperwork in order to secure needed benefits. Finally, there were three participants who were not primary caregivers, but who supported a primary caregiver in his/her efforts to secure concrete services.

These findings point to an overall increase in some caregivers utilizing general social services and Medicaid two years after training. It must be reiterated that this result may or may not be related to the training program.

Part III

Did the training program affect the care you provide to a mentally ill family member?

Questionnaire data shows that over half (16) of these caregivers felt the training program positively affected their caregiving ability. Only three caregivers reported that the group had no effect, and one caregiver was not sure whether the program affected her caregiving role. For the most part, 16 caregivers' comments revealed increased confidence in dealing with their mentally ill relative in one of three different ways: (1) six caregivers were

mobilized to seek professional help with their problems; (2) three caregivers started setting limits on how they allowed themselves to be manipulated by a mentally ill relative; and (3) seven caregivers gained increased empathy for the patient as a result of increasing their understanding of mental illness.

Below are remarks by caregivers who were mobilized to seek professional help:

> "The program identified different places where I might go for help. I was directed from the training program to another group program that eventually led to hospitalization for my son."
>
> "The program forced me to not ignore his illness. I learned that I had to block out my guilt feelings enough to take more effective steps to get him help."
>
> "It made me think of myself more. It made me aware that I couldn't help my nephew if he wasn't willing to help himself. Also made me realize I had to make a decision to send my nephew back to his mother. She has been forced to take steps to help him. I advise her about getting help, and three weeks ago my nephew got SSI."
>
> "I learned to exercise more patience and not lose my temper. I knew it was necessary to get professional help in order to cope with problems."
>
> "The group helped me better understand that my son is mentally ill and that he needs special care. I developed a little more patience."
>
> "I learned to accept the problem. By listening to others I learned that the problem would be long-term, and that I would need help in dealing with it. I also got the strength to set limits on my son which eventually forced him into treatment."

The following statements reveal how caregivers began to set limits for relatives who are emotionally ill:

> "We began to exert greater discipline." (One couple gave the same essential answer to this question.)

"I learned that while my sons may have an illness, they are not completely helpless. I started forcing them to take more responsibility around the house. They are now cooking, cleaning their room, etc."

Attitude change was reflected in the statements below:

"I developed a more positive attitude towards my niece. The program let me know that some people need mental health care. We now view the problem as an illness. We recognize my niece's limitations and don't mind others knowing that she is hospitalized."

"I have better communication with my daughter. I understand that some of her behaviors that got on my nerves are normal for the patient and I can ignore many of these."

"It gave me insight and made me get more closely involved in dealing with the problem. I used to make snap judgements. I learned the importance of trying to understand the situation."

"I understand the illness more. However, my actions with my brother haven't changed very much."

"I was better able to cope."

"It helped me in that I understand I am not alone and I am not as angry as before."

"It helped me realize that I need to be more patient, and that others have similar problems."

Seventeen of 20 caregivers checked yes to question III (1). The question asked, "Have you talked informally with other relatives or friends about your problems?" Nine caregivers further indicated yes to question III (1a), "Were you able to discuss these concerns with others prior to attending the caregivers' training group?" In their comments to question (1a), caregivers who said they shared concerns with others prior to training pointed out how the group program gave them additional information about mental illness. Caregivers who had not shared their concerns previously talked about feeling ashamed or afraid of what others would

think. The group program is said to have provided support and/or permission to discuss their concerns with others.

Caregivers who reported some difficulties in being able to share concerns with others on the Program' Evaluation Follow Up Questionnaire revealed aspects of their anxiety which were not evident in their responses to questions on the Needs Assessment Questionnaire, exploring the ways in which the reactions of others affect their ability to provide care. For instance, most Caregivers (19) indicated that the reactions of others never or usually had no affect on their help-giving behavior and 16 caregivers said that the reactions of others did not make them feel uncomfortable (Please refer to p. 96 for information).

It would appear, however, that 11 caregivers participating in the follow-up study were affected by the reactions of others, as evidenced in their statements about feeling ashamed of what others would think of them for trying to express their concerns. We might infer from caregivers' remarks that many individuals had been highly defended which helped them to cope with embarrassment and fears associated with their provider role. Still others may not have known where to start as far as sharing their concerns with others.

The following quotes help to amplify some ways in which the program may have helped caregivers acknowledge areas of vulnerability and formulate more helpful strategies for dealing with others in their extended families or the community at large.

"I hardly mentioned concerns because of fears of what others would think, especially family members who tend to think mental illness is caused by the family or other traumatic situations. They never thought it could be related to a chemical imbalance."

"I got a lot out of the rap sessions. Prior to attending sessions, I did not know how to talk about my problems. I didn't feel comfortable talking to my friends, because I didn't know how they would react."

"Before the group, I kept a lot inside. I learned that you are not alone. The open manner in which others spoke along with the speakers helped build my confidence in dealing with the problems and in sharing my feelings."

"I was unable to talk with others who gave poor advice on handling problems. Now I know better how to explain what is going on."

"I still have trouble talking to family members; but I have been participating in PATH and another faith group in which I am able to share openly with others."

"I never really talked to anyone outside the family about problems. I didn't know how others might accept this."

"I didn't know to talk to someone before the group. People were so open in sessions. It showed me that you can be rational in discussing problems as opposed to being irrational."

"I just accepted things as they were. The group pointed out how I allowed myself to be dumped on. I got angry enough to take charge of myself in this situation with my nephew. I needed someone else to point it out."

"We were ashamed to let others know the problem. Now my being more open helps my sister open up more in dealing with my niece."

"I didn't know where to go to find a support system. If I went to the hospital, I would have had to be involved with a therapist for myself."

"Before attending the sessions, I had not accepted the illness myself. I hoped my son's problems were a passing thing. Now I realize his condition is a sickness."

Question III (2) asked if caregivers had referred a friend or relative to a mental health professional for consultation and/or treatment. This question was included to further assess caregivers' level of comfort in sharing what they learned from training. An underlying assumption of this question was that caregivers who felt secure sharing information about mental illness would be more likely to link others to formal services.

However, as the question reads, it was unclear whether caregivers were being asked if they referred previously unidentified patients for professional help or if their referrals were of known patients. Thirteen caregivers checked yes to question III (2). Questionnaire data shows that of the seven caregivers who checked no, five caregivers' mentally ill relative was already in treatment, and two were not primary caregivers.

Although there may be reliability problems associated with question III (2), it would appear that caregivers who said they made referrals had begun to link previously unidentified clients to professional mental health services. For example, some caregivers' remarks are as follows: "Whenever people tell me about their fears, I tell them to go for help;" "I have sisters and brothers who need help. I got my brother to go for help;" "I referred two cousins for marital counseling, but I am not sure if they followed through;" and "I referred a neighbor who followed through."

Finally, question III (3) assessed caregivers' ability to utilize resources two years following training. The question states, "If you needed help in solving a problem involving your emotionally ill family member, how might you go about solving such a problem?" Four response categories emerged: (1) 14 caregivers indicated that they would bring the situation to the attention of a mental health professional for advice; (2) two caregivers said they would first seek advice from their self-help group; (3) one nonprimary caregiver said that she would consult with another family member; and (4) two nonprimary caregivers said they would encourage the patient to seek professional help. One person failed to answer this question.

With respect to caregivers who would consult with a mental health professional, only six of these 14 had a relationship with a mental health professional prior to training. This shows an increase by eight caregivers who report that they would seek professional help in problem-solving two years after training.

In terms of the two caregivers who would seek self-help services, neither had been involved with a self-help group, and only one had a relationship with a mental health professional prior to training. Of the three nonprimary caregivers, only one had a relationship with a mental health professional before training.

Summary

Information obtained from the Program Evaluation Follow Up Questionnaire must be considered in the context of those variables which tend to contaminate feedback in non-experimental research designs. With respect to this study, factors affecting reliable findings, including self-reports, history, and maturation, are even more problematic, since a follow-up was not an original aspect of the research design. However, if the purpose of securing data is to assess caregivers' perceptions of the long-term benefits of training about mental health resources, and to assist in making decisions about replicating this study, then it can be concluded that many program participants remained generally positive about the training experience over time.

For example, many caregivers demonstrated a relatively high frequency of recall concerning most topics of discussion which they report helped them in utilizing needed services. Individuals already known to treatment facilities felt that information obtained helped to improve their communication with mental health professionals.

In terms of increased utilization of non professional resources, caregivers did not frequently report increased utilization of self-help groups or family and friendship networks of support. It would appear that many caregivers felt a greater need for partnership with a mental health professional(s), along with concrete services in order to

alleviate stress associated with caring for a mentally ill relative. With information and an increased ability to utilize services, caregivers appeared to be more confident in their caregiving abilities. This was made evident in their remarks about being better able to confront and deal with certain difficulties presented by their family member because of mental illness.

Caregivers also reported an increased level of comfort in dealing not only with a mentally ill relative, but with the reactions of others as well. In general, it would appear that caregivers were better able to openly discuss problems of concern both with the identified patient and with others.

IV. End Of Meeting Feedback Sheet

Questionnaires which asked for participants' reactions were distributed at the end of each of the six sessions. The End of Meeting Feedback Sheets were divided into three parts. Caregivers were requested to rate each session on the basis of overall degree of learning and their overall perceptions about the day's session with respect to guest speakers, topics covered, ease or difficulty of talking and sharing ideas, and feelings of encouragement or disappointment as they left the meeting.

Additional space was provided for participants to list positive and/or negative comments about the session.

Caregivers also were asked to suggest how the program might be improved with respect to the type of expert they would like to hear, specific experts they might like to hear, suggestions for future topics, and methods for presenting material to the group.

Finally, space was provided for caregivers to write additional comments concerning the meeting. (Please see End Of Meeting Feedback Sheet in Appendix # B).

As discussed under methodology, End Of Meeting Feedback Sheets were not completed with the assistance of an interviewer, and, as may be expected, open-ended questions on these questionnaires were not always answered. Caregivers most frequently responded to the closed-ended questions where they simply had to check off their answers. Spaces for

open ended responses were usually left blank or filled with sketchy information.

Problems of reliability were also evident. Since attendance varied from session to session in both group cycles, some caregivers failed to hand in Feedback Sheets; and not everyone who completed Feedback Sheets was included in the study's sample. (As previously noted, caregivers had to complete at least three of six sessions in order to be included in the sample evaluated in this study.)

Despite the obvious limitations of data obtained on End of Meeting Feedback Sheets, these findings were useful in helping to improve the program design. For the most part, this participant feedback provided additional descriptive data similar to that obtained on either the Needs Assessment or Participants Evaluation Questionnaires. With respect to Part I of the End Of Meeting Sheet, caregivers attending each session tended to give the program a positive rating on questionnaire items as listed above.

Question 8 of Part I asked caregivers to list any positive and/or negative comments about the session. Their answers indicated that sessions were generally good and/or informative. Some caregivers specified that particular sessions helped to increase their understanding of mental illness or mental health resources. A few caregivers expressed positive feelings about the way in which group members shared freely in sessions and the way in which professionals responded to questions.

Negative comments focused on the participants' feeling that there was not enough time to deal with individual situations involving a mentally ill relative at home. Because not all caregivers who responded to the End of Meeting Feedback sheets were included in the final research report, it was impossible to discern those who did or did not have other opportunities to interact with mental health professionals outside of this program.

Part II of the End of Meeting Feedback Sheet asked caregivers to indicate any suggestions they may have for improving the group program. The following suggestions were given for the type of expert and specific experts caregivers would like to hear in future meetings: psychiatrist, social worker, police officer dealing with psychiatric patients, pharmacist, neurologist, recovered mental patient, and relative of a mental patient. Feedback of this kind was used to alert guest speakers about the kind of information caregivers wanted.

For example, the psychiatrist was asked to address a range of issues in his presentation including psychopharmacology, neurology, and nutrition. The expert on community resources discussed at length the role of the police in handling psychiatric emergencies. In the second group cycle, we were able to invite a representative from FAMI (Family Alliance For The Mentally Ill) who not only shared her experiences with her son, but also talked at length about resources available through the self-help organization.

In terms of suggesting topics for future meetings, caregivers reiterated previous requests such as information on how to improve their relationship with a mentally ill relative, how to obtain community resources, and increased understanding about the long-term effects of medication.

As for other methods of presenting material to the group, caregivers felt the existing format was good. One or two suggested the use of films and more literature. Limitations of time and financial resources, however, made it difficult to respond to these requests during this program.

Part III of the End Of Meeting Feedback Sheets continued to reflect caregivers' favorable feelings about the program. These comments can also be used to summarize data obtained on this instrument as a whole. For the most part, caregivers expressed that they liked the information provided, the quality of guest speakers, the recognition that they are not alone, and the concrete help obtained from learning what resources are available and how to go about obtaining them. Their major area of dissatisfaction was that there was not more time in general to explore in-depth their many concerns.

Chapter Five

Discussion, Conclusions, and Recommendations

I. Introduction and Background

The thrust towards community care of the chronically mentally ill compounded previous insults both to patients and their families, since neither was prepared for the mass closing of state mental institutions. In the literature review, we learned that some major obstacles to effective community care have included: negative beliefs held by the public towards the mentally ill; pervasive fears associated with patients' bizarre behaviors; negative public policies that disenfranchised patients from their rights as citizens; a paucity of financial and therapeutic resources to adequately support the chronically mentally ill in the community; and a tendency to undermine the caregiving potential of families by attributing to them blame and excluding them from various treatment programs.

We also learned, that although family caregivers often lacked knowledge and skills for managing their relatives at home, they rose to the challenge of community care first by reaching out to one another for support and insights into coping with their responsibilities. Families began to turn to one another in order to avoid the negative labeling customarily experienced in their interactions with mental health professionals.

As a result of families banning together for mutual support, a national movement was developed which promoted mutual aid and self help among lay caregivers. Another aspect of the family movement, in addition to offering its members mutual support, was its emphasis on advocacy. Many local groups which became part of the national movement have begun successfully to lobby local, state, and the federal governments to develop favorable legislation and programs for chronic patients. In addition, families also have begun to challenge professional providers by resisting their negative labels and demanding that they search for more helpful ways of meeting caregivers' needs as partners in community care.

As professionals have begun to listen to families who seek their advice and help, there has been the emergence of several therapy interventions designed to give families what they say they need. Several examples of these new treatments have been outlined in this text and include various psychoeducational models, multiple family groups, and supportive group counseling approaches. These models essentially try to respond to families' requests for information about mental illness and treatment, especially information about medication and its side effects. In addition, each model has as a broad goal the hope of diminishing family members' guilt and sense of blame for possibly causing their relative's illness. Each also provides skills training on management techniques at home.

Despite the inroads reported as a result of professionals and family providers working together, the community mental health delivery system remains a potpourri of service entities. Many problems have been evident within the system including insufficient funding of old and now new programs, inadequate staffing of community services, and staff poorly trained in new technologies to respond effectively to a community based system of care. All of these issues are chronically exacerbated because of poor coordination and competition among existing services.

It was out of concern about how aspects of competition and fragmentation of services further impacts negatively on family caregivers' ability to realize the benefits of existing programs and services, that this study's educational model of intervention was developed. Although the psychoeducational models of Anderson, et al., and Falloon and Liberman each incorporates a piece on community resources, it was felt that they do not go far enough in diminishing the negative impact caused by fragmentation of services. These models seem to imply that caregivers already are in the system and simply need to be directed from one place to another. However, the educational model of this study assumes that caregivers first need to understand what the system is and how to gain access to various service entities before they can maximize what it has to offer.

Therefore, some additional skills were deemed necessary as part of the repertoire of professionals working with families in order to remove some of the impediments to care. As outlined in this study, a short-term training program provided one mechanism for exploring the usefulness of this kind of intervention. The program's educational emphasis was designed to enhance family caregivers' knowledge about planning the care of a mentally ill relative by teaching them how to deal with the larger service environment, and examining their feelings about their role behavior in that regard.

II. Methods

A. Site Selection

The Hillside Eastern Queens Mental Health Center, a Satellite clinic of the Hillside Hospital's Outpatient Department of Psychiatry, agreed to sponsor this group program. Key factors in this decision were as follows: (1) the Clinic's desire to reach out to an underserved segment of its target population, since the number of chronic patients known to the agency was small, but growing; (2) the Clinic Administrators' knowledge of the Author and comfort with the goals and objectives of the program, which they felt would not detract from broad agency goals and objectives; (3) the relatively low financial cost of running the program was an attractive feature for both the Hospital's and the Clinic's Administrators, and made recruitment of program participants easier as there was no out-of-pocket fee; and (4) finally, the fact that the Clinic's target population was not comprised largely of a chronic patient clientele seemed to eliminate the potential for competition that was acutely evident in other parts of the Medical Center, where resources were more heavily invested in the development and maintenance of programs for chronic patients and their families.

B. Sample Selection

Family caregivers were chosen who resided in the catchment area served by the Hillside Eastern Queens Mental Health Center. Some caregivers whose family members were known to the Clinic were referred by their therapists.

Other referrals were generated from new intakes, staff at Hillside Hospital, and other community programs familiar with this project.

The criteria for participation were that friends or relatives must be involved either directly or indirectly with their mentally ill relative's care; that they must be identified by a professional as being a potential bridge person between their relative and the mental health delivery system; and that they must commit themselves to participating in the six-week training program.

C. Study Sample

The sample of caregivers participating in this study was comprised primarily of parents of mentally ill adult children. Over half were black (61%), married (65%), and possessed at least a high school education (96%). At least 48 percent of caregivers also completed some college. Average personal income was in excess of $15,000 for over half (57%) of these participants.

D. Research Design

This study utilized a single group design, which yielded descriptive information about caregivers and their satisfaction and dissatisfaction with the training intervention. The single group design was chosen because of the difficulties involved in seeking organizational clearance to conduct group cycles in other settings, and because there were no other known models for evaluating group programs emphasizing mental health resources. The methodology was completed by incorporating information about caregivers from

the current literature, discussions with professional staff within the Medical Center, and with the technical assistance provided both by Hospital Staff and the faculty committee supervising the project at the Hunter College School of Social Work.

E. Development of Research Instruments

In total, four research questionnaires were developed to evaluate this study. Questionnaires were inexpensive to develop and relatively easy to administer. The four instruments were a Needs Assessment Questionnaire, End of Meeting Feedback Sheet, Participant Evaluation Questionnaire and Program Evaluation Follow Up Questionnaire.

The Needs Assessment Questionnaire was designed to provide information about caregivers, and provide them an opportunity to state what kind of help they needed in order to better utilize community resources for themselves and their mentally ill relatives.

End of Meeting Feedback Sheets were designed to obtain caregivers' subjective feelings about the training program. In addition to asking caregivers to respond to closed-ended questions as to how they felt immediately following each meeting, open-ended questions and space for additional comments were provided for participants to elaborate on their experience of the evening's meeting.

The Participant Evaluation Questionnaire was designed to assess whether training positively or negatively impacted on caregivers' abilities to deal with a mentally ill relative and the mental health delivery system.

Finally, caregivers' long-term perceptions regarding the value of the training experience were elicited on the Program Evaluation Follow Up Questionnaire administered after two years. This instrument sought information about caregivers' ability to remember topics covered, to describe how they felt the group experience enhanced their utilization of mental health and general social service programs, and to describe how they felt helped to continue providing care to their mentally ill relative.

The content and structure of each questionnaire was reviewed by the faculty committee charged with project supervision. A draft of each questionnaire subsequently was pretested for clarity of content, logic, and format, using several staff members at the Hillside Eastern Queens Clinic. Where questions were not clear, they were revised, and redundant questions were deleted. In addition, questionnaires were further refined following a pretest with a small group of caregivers who expressed an early interest in program participation.

Personal interviews with Caregivers also were built into the data collection process, except in completion of End of Meeting Feedback Sheets. The interviews made it possible to avoid bias by securing more complete answers to open-ended questions, and yield more detailed information about caregivers participating in the program.

III. Results

A. Needs Assessment Questionnaire

A Needs Assessment Instrument was developed based on a desire to respond to family caregivers' needs as defined by them. From this instrument, a profile of caregivers participating in this study emerged. In terms of their role behavior, the findings showed that most family caregivers provided a combination of emotional support and concrete help to their mentally ill relative. The chief means of providing emotional support was through talking with a mentally ill relative about aspects of the patient's problematic behavior and trying to give advice about making improvements. For example, caregivers might discuss the patient's illness with him/her and offer advice about socialization, work, or budgeting. Most often this kind of advice giving was coupled with the provision of concrete help such as providing food, clothing, shelter, money, and transportation. In other words, this group of caregivers provided a range of services that touched on practically all areas of daily living activities for their mentally ill relative.

Most caregivers' reasons for becoming involved in their relatives' care was based on a sense of familial duty or responsibility, and, despite their frustrations in carrying out this reponsibility, they seemed to feel positive about their commitment to helping. This attitude about the help caregivers offered seemed to be related to families' lack of

knowledge about alternative resources which might offer help or relief to them. For example, many caregivers expressed concern that there was no one else to handle problems if not an extended family member.

Caregivers' feelings of comfort about carrying out role responsibilities also were explored which provided some clues as to the emotional cost of providing care. Initially, caregivers tended to minimize the difficulties involved in caregiving. Aspects of their level of comfort were further explored by comparing level of comfort with personal income and educational achievement, since the group was almost equally divided on these variables.

A multivariate analysis showed a difference between caregivers based on personal income. Among low-income caregivers, there was a higher tendency for caregivers of high education to rate themselves low on level of comfort when dealing with a mentally ill relative; whereas among high-income caregivers, there was no discernible difference in the way caregivers rated themselves on the basis of education. Furthermore, a bivariate table of analysis revealed that caregivers of higher educational achievement tended to rate themselves more comfortable dealing with the behavior of a mentally ill relative, than did caregivers of low educational achievement.

That differences were evident among participants based on high versus low income and education, suggest that those caregivers who were more successful financially also were more knowledgeable in general. This relative success may have contributed to a heightened sense of inner confidence or security when it came to dealing with their relatives' illness. This finding supports the conclusions drawn from research in the psychoeducation field which shows that caregivers who are more knowledgeable feel more confident providing care. Although this group had yet to experience the training protocol of this program, we might expect to see similar results from this study.

The most difficult aspects of care provision cited by caregivers included: anxiety about their relatives' symptomatic behavior, their inability to communicate with the patient, the patient's resistance to help offered, and their difficulty accepting the patient's limitations. Each difficulty cited related to some area where, in order for the caregivers to feel successful, they needed the cooperation of the patient. Therefore, how to get the patient's cooperation, which might alleviate some of the stress of caregiving, appeared to be an area where caregivers hoped to get concrete suggestions from professional experts.

On the Needs Assessment Questionnaire, caregivers tended to deny that concerns about what others thought had an impact on their role behavior. However, findings on the

Participants' Evaluation showed them acknowledging feelings of shame and embarrassment associated with how others responded to their family's situation; and on the Program Evaluation Follow Up Questionnaire, they reported that they no longer were feeling ashamed of what others thought. Perhaps, initially, denial was the only adaptive tool available to caregivers who were as committed as these were to maintaining their relatives in the community. We might also speculate that many caregivers were able to insulate themselves somewhat from the negative feedback of others through the supportive networks they developed on their own prior to training.

For instance, caregivers (20%) had at least two to five other people they turned to for support before enrolling in this group program. Their ability to develop both professional and social networks on their own demonstrated that this group was fairly sophisticated about utilizing services, and had already recognized the need for help and/or support in coping with chronic mental illness in the family. This recognition of need for help no doubt made it easier to take advantage of the opportunity provided in this program to fill informational gaps which may have been missing in their existing networks.

Caregivers' expressed needs at the beginning of this program included: (1) a desire for information about mental illness, its treatment, how to manage a patient's symtomatic behaviors, and how to secure financial assistance for

treatment; (2) a desire for linkage with professional programs and self-help groups; (3) a desire to share with others mutual problems and concerns about planning for their mentally ill relative; and (4) validation of their ability to continue as primary care providers.

B. Program Evaluation Questionnaire

In general, caregivers expressed satisfaction with the program design, with respect to substantive material, and the program's impact on changing certain attitudes and perceptions about their role as caregivers. For example, caregivers' excellent and good ratings on six aspects of planning meetings suggest a high degree of satisfaction on structural aspects of the program design. Of the six features listed, the presentations of guest speakers seemed to be the most helpful aspect of the program since nineteen caregivers included this statement in their responses. The second most helpful aspect of the program design was providing caregivers with the oportunity to share experiences with others. These findings seem to suggest that caregivers were most receptive to engaging in an exchange first with mental health professionals who could provide expert knowledge and information about mental illness, and, second, with one another for discussion of practical problems and concerns associated with caring for a mentally ill relative.

As for the least helpful aspects of the program, only 11 caregivers voiced some dissatisfactions. Of this group, several caregivers tended to identify at least one topic that did not apply to their particular situation, whereas one or two felt there was not enough time devoted to their particular issues. Only one couple gave the program a consistently poor rating.

These findings were useful for improving the program design. For example, it could be anticipated that for caregivers who have differing needs for information, there may in fact be some topics which are more or less appealing to members of the group as a whole. Through the careful outlining of content material that would be presented at each meeting, caregivers could either better prepare themselves for the topic of discussion or make an informed decision about whether to attend a specific meeting.

For participants who would need more time, perhaps additional meetings could be scheduled, or more time allotted to a particular topic to allow for more complete coverage of substantive material. Clarifying caregivers' appropriateness for this kind of training group could be accomplished through a more careful screening protocol. In the case of the couple who felt that this group did not meet their needs, the pressure to recruit participants for the study may have interfered with directing them on to more specialized services in keeping with the reality of their unique needs.

Caregivers' reactions to substantive material was assessed in two ways. First, they were asked to rate (excellent, good, fair, or poor) statements that most clearly represented their experiences in the training program. Second, they were asked to describe how the group experience impacted on the care they provided to a mentally ill relative.

There were nine learning indicators listed on the Likert rating scale. For the most part, all learning indicators received a favorable rating by over half the Participants. Of importance, however, was the one item which received an excellent or good rating by all 23 caregivers, and the one item which showed greater variation in caregivers' responses. The most highly rated item was understanding that emotional illness is related to problems in coping and handling stress. This might suggest that caregivers were particularly open to information that helped to change their cognition about the meaning of mental illness, and, thus, relieve themselves of guilt feelings associated with having an ill family member.

The item that showed more variation in caregivers' ratings was feeling that your contribution to group discussions was beneficial to others. On this item, only 14 caregivers provided an excellent or good rating. Although there was no way to accurately assess the real meaning of this finding, we might speculate that many caregivers felt too insecure with their general knowledge base in order to feel comfortable imparting information about mental illness to others.

This finding also may offer some insights about caregivers' generalized anxieties about discussing the problems of their mentally ill relatives with others. Such feelings potentially could interfere with their ability to perceive accurately how others may have benefited from their contribution to group discussion. This interpretation seems particularly likely since many caregivers reported that the opportunity to share experiences with others was the second most helpful aspect of program participation.

In assessing caregivers' written statements of how substantive material may have impacted on the care they provide, these statements reflected that they received help in the four areas they had identified on the Needs Assessment Questionnaire. The areas previously identified were as follows: (1) information, (2) linkage with professional or self-help agents, (3) an opportunity to share mutual problems and concerns with others, and (4) reassurance or validation of their ability to help others with similar problems.

It must be pointed out, however, that these caregivers tended to emphasize one area in which they felt particularly helped as opposed to two or three. Furthermore, those who made reference to obtaining reassurance or validation of their ability to help usually referred to the helping of their mentally ill relative versus other caregivers. These findings show that the program was able to address some of the specific needs and requests for help expressed by

caregivers, and that caregivers primarily were motivated to participate to get practical help in managing the patient's illness at home.

Caregivers' generally positive feelings about the program became more evident when probed regarding the impact of training on attitude change. Regarding how the program changed the way caregivers think and feel about emotional disturbance, they expressed more hopeful feelings about dealing with emotional disturbance. It appeared that increased information about mental illness and its treatment, realizing that others have similar problems, and feeling less guilty about the illness may have increased caregivers' perceptions of being able to cope and deal with the burdens of caregiving.

This finding was supported somewhat when caregivers were questioned specifically about whether the program changed the way they feel about their mentally ill family member. Caregivers' remarks suggested that information about mental illness made them more understanding and tolerant of the patient's behavior, enabled them to set more appropriate limits on the patient's unacceptable behaviors, and increased their confidence about handling various situations involving the patient.

As for being able to talk about mental illness with a neighbor or friend, or deal with the negative attitudes of others, many caregivers who had reported feelings of embarrassment became less concerned about what others

thought about their situation after training. These findings further attest to how the program may have supported the caregiving potential of family providers by freeing them to channel their energies toward patient care.

Although it was too soon after training to assess the extent to which a short-term program of this kind may have promoted linkages with other formal and informal service providers, it was clear that caregivers saw the importance of such linkages from their responses. For example, 20 caregivers expressed a desire to continue meeting informally after training, and 21 caregivers felt that professional staff should be involved in such meetings. The need for the ongoing involvement with professionals was related to caregivers' desire for expert knowledge and information, and the structure professionals would bring to meetings.

C. Program Evaluation Follow Up Questionnaire

The findings of the Program Follow Up Questionnaire showed that caregivers still felt positive about their exposure to this training program. Despite obvious problems of reliability, they continued to rate the program high as far as having met its goals and objectives. As previously mentioned, the focus of the follow-up study was to assess caregivers' ability to retain information learned in the program, to assess their practical application of knowledge obtained in securing mental health resources, and to assess how they felt the program may have continued to influence their relationship with a mentally ill relative.

Caregivers showed the greatest recall for topics which helped them clarify or enhance their relationship with a mentally ill relative. For instance, all 20 caregivers, who responded to the Program Evaluation Follow Up Questionnaire, remembered the topic pertaining to the impact of mental illness on the family. The next highest recall ratings were for topics such as what is mental illness?; the role of family caregivers in the treatment of the mentally ill; and the role of self-help in helping families of the mentally ill. Topics concerning: differences between state, city, and voluntary agency programs and eligibility requirements for treatment in state, city, or voluntary agency programs were remembered less well by program participants.

Based on this pattern of informational recall, we might conclude that caregivers still were invested in maintaining their role as primary caregivers for their mentally ill relatives after two years. Topics which may have provided insights on how to explore service alternatives outside the family remained the least popular both immediately after training and after two years. This finding also may help to explain why the couple who consistently gave the program a poor rating felt least helped through training. Based on their feedback, we might infer that this kind of program, which emphasizes community resources, is least helpful to caregivers who already are far along in securing services and managing certain aspects of daily living for a mentally ill relative, especially if they already have achieved an

alternative living arrangement for the patient. In such instances, caregivers would have had to master the particulars of planning the care of their relative, despite the fact that they may not feel totally satisfied with the alternative care placement.

Did The Training Program Influence Utilization of Services?

Findings after two years revealed that training did influence many caregivers to use mental health resources, and to begin talking openly about mental illness. Caregivers who denied increased use of services were either already in treatment prior to training or were not the primary care provider for their mentally ill relative.

It appears that caregivers were particularly pleased with the way their ability to communicate with others improved after involvement in this program. Caregivers who had a relationship with a mental health professional before training reported that they were better able to communicate with professionals after obtaining increased information and awareness about mental illness. Caregivers who did not have a relationship with a professional reported that they were influenced to reach out for professional help.

Several caregivers were influenced to join self-help or mutual-support groups which they attributed to participation in this training program. Caregivers already attending such groups said they were better able to communicate in these groups.

These findings suggested that this educational program was successful either in mobilizing caregivers to seek services or in enhancing their self-confidence about how to use those services already in place. That 17 as compared to seven caregivers were linked to professional services versus self-help or mutual-help groups after two years seems to suggest that more participants felt in need of a relationship with professional service providers in their efforts to manage a mentally ill relative at home. Since many caregivers had rather extensive informal networks of support prior to training, it further suggests that participants felt in need of professional resources which many did not have upon starting the program.

When questioned about applying for Medicaid or general social services, it was unclear to what extent caregivers felt mastery in this area of learning as a result of training. The caregivers who said they did apply for Medicaid and general social services reported that they felt knowledgeable about the application process. It appears, however, that the remainder of caregivers (4) who obtained these resources after training were able to do so through the help of hospital staff after forcing the patient to seek professional help.

That some caregivers went through formal channels to get professional assistance with the application process for Medicaid and general social services again may point out an area where they felt mental health professionals should be helping them. For most people, including professionals,

bureaucratic red tape can be an effective deterrent to seeking needed resources. Perhaps family caregivers need professional advocates who are strategically situated in similar bureaucratic positions to help break down communication barriers or cut through the red tape around securing concrete services.

Did Training Affect the Care You Provide to a Mentally Ill Family Member?

Based on caregivers' self-reports, training positively affected the care they provided a mentally ill relative. From their remarks, it appeared that caregivers experienced increased confidence in their ability to deal with their relatives' problematic behaviors. Increased confidence was evidenced primarily in caregivers' willingness to seek professional help with their problems, their beginning to set limits on their relatives' potentially abusive behaviors in the home, and their increased empathy for the patient as a result of their own improved understanding of mental illness. These qualitative statements, as expressed in caregivers' written comments, seemed to show an integration of the three broad goals of this training program. By increasing their understanding of mental illness and the mental health delivery system, they became more adept in recognizing problematic behaviors and organizing resources to address these problems. The resources they identified included shoring up their own responses to problems, as well as reaching outside the family system for support as needed.

To further assess caregivers' level of confidence associated with providing care two years after training, they were asked whether they would share with others what they learned from training, if they would refer a friend or relative for formal mental health services, and how they might go about solving a problem with a mentally ill relative.

Seventeen caregivers indicated that they did share with others what they learned from training. Those nine caregivers who had talked with relatives before training were able to obtain additional information that they then shared. The eight caregivers who had not previously talked with another relative indicated that they obtained support and encouragement from the program to begin discussing their concerns with other relatives.

It appears that caregivers also became more comfortable talking to others in the larger community about mental illness. In fact, findings from the follow-up study revealed that caregivers had been helped to overcome some feelings of shame and embarrassment associated with having a mentally ill relative, even though they denied that these feelings affected the care they provided before and immediately after training.

In terms of linking others with mental health services, the findings showed that caregivers felt comfortable enough discussing the topic of mental illness that they had begun to refer people in their larger social networks for mental health care where necessary. Only those caregivers who were already known to treatment programs or who were nonprimary

caregivers denied referring others for services. This suggests that caregivers who may have been learning about mental illness and mental health resources for the first time were more enthusiastic and eager for others to benefit from the information they obtained. Caregivers who had an ongoing relationship with professional providers or who were acting as a supportive other to a primary caregiver seemed to be more concerned with improving the quality of these existing relationships.

With respect to how caregivers would go about solving a problem with a mentally ill relative two years after training, 16 caregivers saw bringing problems to the attention of mental health professionals for help as being the most effective way of solving problems involving an emotionally ill relative. This finding showed an increase in the number of caregivers who attributed their involvement with a professional to participation in this group program. Two caregivers said they would first seek the help of their self-help group, however, these caregivers had not belonged to a self-help group before training; and only one caregiver said that she would first consult with another family member. (One person failed to answer the question.). Thus, 18 of the 20 caregivers who responded to the follow-up study saw self-help or professional support as being an essential aspect of helping them to manage a mentally ill relative in the community.

D. Findings From End Of Meeting Feedback Sheets

The major feedback obtained immediately after each group session was generally positive with respect to the information provided, the quality of guest speakers, the recognition that caregivers were not alone in their individual struggles, and the concrete help provided in learning about community resources and how to go about obtaining the same. This kind of feedback was valuable in keeping the program relevant to caregivers expressed needs for help and support. Their chief criticism on the Feedback Sheets was that there was either too much time spent on some issues or not enough time devoted to others. However, members of the group differed on what was too much or too little time and on what issues. What was too much for one person concerning a given topic may have been too little for someone else on the same topic.

This finding suggested that a short-term group program is bound to be experienced as not providing enough support to members who present such overwhelming needs which are inherent in the role of primary caregiving. However, this reality forces professionals interested in developing such a program to pay careful attention to how such groups could be continued via members' own self-help iniatives, or how

mechanisms for linking members to relevant professional and existing self-help groups can be insured after training. In this program, caregivers were linked to agency staff in the host organization who would act as an ongoing consultant around specific problems or issues so that members would not retreat to their prior isolation. Through these primary linkages, many caregivers did go on to improve their utilization of both the formal and informal delivery systems.

IV. Conclusions

The underlying purpose of this project was to support the caregiving potential of family caregivers of the chronically mentally ill by educating them about mental illness and the mental health delivery system. With increased knowledge of mental illness and resources, caregivers possibly could improve their skills as resource brokers on behalf of their mentally ill relatives. Based on the program's findings, it appeared that caregivers felt helped by participating in this short-term educational group.

An area of strength worked with in this training program was caregivers' commitment to becoming better care providers. Therefore, they were very receptive to professional experts who answered many of their questions. In fact, those caregivers who did not have a relationship with a mental health professional pursued these relationships after training, and, in general, all caregivers improved their communication with others (family, friends, others in the larger community) following exposure to information provided by expert speakers.

Caregivers also modified their responses to their mentally ill relatives in that they began to reassess the patients' needs in light of new information. This aspect of caregivers' increased knowledge led to their forcing the patient to seek professional help where needed, improving their own relationship with the patient based on increased empathy and understanding, and feeling more confident about their overall role performance.

A long-term benefit of linking caregivers previously isolated from the formal delivery system was that a mechanism was established where they learned how to go about keeping current on mental illness, its treatment, changes in the delivery system; and, perhaps most importantly, how to gain access to the system in the first place. Although a key drawback of a short-term program emphazing resources was that it sacrificed the mutual-aid component known to be of benefit to families, the real trade-off was the teaching aspect of this group. One might argue that if families need long-term help managing chronic mental illness, then they need some form of intensive supportive program which can only be offered through formal services. Formal services as implied here refers to ongoing agency programs or the range of services provided by formal self-help organizations where financial resources are being specifically targeted to ensure the continuance of specialized services.

For professionals interested in replicating this program, overcoming structural impediments to implementation within formal organizational settings is of primary importance. With organizational support, caregivers could gain a rich exposure to the mental health delivery system and a broad appreciation for the role they play as primary care providers. A major benefit that accrues to the institution -- hospital, clinic, agency -- is that it

supports the development of a continuum of care in the community as it reaches out to potential users of services and links them to the mental health system.

In so doing, the organization also creates a cost effective means of supporting community outreach activities without having to forego its commitment to other therapeutic approaches. In fact, it is this program's emphasis on reaching out and linking caregivers to other services that makes it stand out from various client and professionally centered interventions, where the potential for competition is greater.

Another crucial aspect about securing solid organizational sanctions is that the formal delivery system can actively support and sustain caregivers' involvement in all areas of community care. As illustrated in the practice experiences of others, professionals can actively assist caregivers, who have experienced an orientation to mental health services, to move beyond the short-term benefits of this program to develop ongoing associations of mutual aid and/or self-help when such groups do not exist. These groups have been known to become very active in lobbying for expanded services for chronic patients in the community. This kind of self-help activity in turn is supportive of institutional goals which include the maintenance of patients in society.

Although cost factors are a consideration, a formal organization might be better able to absorb some of the out-of-pocket expenses associated with developing ongoing educational groups for family caregivers. Some cost would be defrayed in that there would be a larger pool from which to draw guest speakers who are specialists in various aspects of mental illness and new treatment technologies. Furthermore, a program could be enhanced with relevant films and literature. Site visits to other services or associations for caregivers of the mentally ill would provide additional exposure that could help ease a group's anxieties about their immediate situation and open them to exercising a range of options in dealing with their own needs and the needs of their mentally ill relatives.

V. Recommendations

1. A short-term educational program emphasizing community resources seemed to work well in the context of a general mental health clinic setting, where there is not a large array of services provided to chronic patients and their families. In this kind of setting, it may be possible to offer services to a segment of the clinic's population (family caregivers) who might not otherwise seek formal admission to the agency.

2. An educational program emphasizing resources could represent not only a cost-efficient means of reaching out to family caregivers, but it also can reduce the added burden that families experience as a result of wasting their energies searching for answers to their questions. By training caregivers to become resource experts, they become more efficient planners of their relatives' care by maximizing their energies in the pursuit of services.

3. If no fee restrictions are imposed on short-term informational groups, families might be more willing to attend meetings at an agency close to home, which is more likely to be stigma-avoidant, as opposed to feeling prematurely forced into participation in a formal agency program.

4. A potential benefit of this kind of program to a formal institution or parent organization such as the Hillside Division of the Long Island Jewish Hillside Medical Center is that it could facilitate case-finding by linking families to its various inpatient and outpatient clinics, the self-help organization affiliated with the Medical Center, as well as link the hospital with other community agencies as improved coordination of services for previously isolated families becomes a reality.

Appendix A

Needs Assessment Questionnaire

NEEDS ASSESSMENT QUESTIONNAIRE

We appreciate your willingness to participate in a group program, which seeks to help you in dealing with a relative or friend who has difficulty coping with emotional problems. Your response to this questionnaire will help us to understand what you need help with and to plan the content material of future meetings. Your answers will be handled confidentially and will be used solely for the purpose of planning and evaluating our work together. Thank you for your time and cooperation.

I. Please provide the following information concerning your role in and attitudes toward providing community assistance to a family member or friend who is undergoing emotional stress.

1. What is your relationship to the person who is having emotional difficulties? (Check all that apply.)

_____ Parent

_____ Spouse

_____ Child

_____ Grandparent

_____ Cousin, Aunt, Uncle

_____ Friend

_____ Other, (Please specify)_____

_____

_____

a. Briefly describe in a few sentences the kinds of things you do in order to be of help to this person?_____

_____

_____

2. From the list below, please specify what kind of assistance you provide: (Check yes or no beside each item)

Provide emotional support	_____Yes _____No
Give advice about seeking treatment	_____Yes _____No
Provide money	_____Yes _____No
Provide food	_____Yes _____No
Provide clothing	_____Yes _____No
Provide transportation to treatment facilities	_____Yes _____No
Provide transportation to recreational facilities	_____Yes _____No
Take person shopping	_____Yes _____No
Give advice and counseling about planning a budget	_____Yes _____No
Give advice and counseling about housing	_____Yes _____No
Give advice and counseling about work or other problems	_____Yes _____No
Provide assistance with meal preparations	_____Yes _____No
Provide help with cleaning	_____Yes _____No

Other (Please specify)_____

_____

_____

3. Please state in one or two sentences your reason for becoming involved in providing help to your relative or friend who is experiencing emotional difficulties.

_____

_____

_____

_____

3.

a. How do you feel about giving the help you provide?

_____

_____

_____

_____

4. Do you usually feel comfortable dealing with the behavior of your relative or friend? (Check one)

_____Usually comfortable

_____Somewhat comfortable

_____Usually uncomfortable

_____Somewhat uncomfortable

a. If you checked usually or somewhat uncomfortable, what specific things do you have the most difficulty in dealing with? (Please state)_____

_____

_____

_____

b. If you checked usually or somewhat comfortable, in what situations do you find it more difficult to be of help to your friend or relative? (Please state)_____

_____

_____

_____

_____

_____

4.

5. If you reach out for support, to whom do you turn to discuss problems you have in helping your family member: (Please check yes or no.)

Another family member _____Yes _____No

A friend _____Yes _____No

Spouse _____Yes _____No

Professional (Psychiatrist, psychologist, Social worker) _____Yes _____No

Clergy _____Yes _____No

Other (Please specify) _____

a. Of the persons you reach out to, which one is most helpful? (Please state) _____

b. If you are not receiving support, what kinds of things would be helpful to discuss with someone? (Please state)

_____

_____

_____

_____

6. Do the reactions of others in your community have an effect on the help you give to your relative or friend? (Check one)

_____Always has an effect

_____Usually has an effect

_____Usually has no effect

_____Never has an effect

5.

a. Does the reactions of others make you feel uncomfortable:

_____Yes _____No

b. If yes, in what way do you feel uncomfortable:

(Please state)_____

_____

_____

_____

7. Do you provide the primary help to your relative or friend who is having emotional difficulties?

_____Yes

_____No

_____Not sure

a. If no, who else is involved with this person's care and what do they do? (Please state)_____

_____

_____

_____

_____

II. Since this is a group program to determine the needs of family members, your response to this part of the questionnaire will help us in planning future meetings.

1. Please list some topics you would like to discuss in the six weeks of group meetings.

_____

_____

_____

6.

_____

_____

_____

_____

_____

2. What kind of assistance would you like to obtain from this group? (Please check all that apply)

_____Opportunity to share mutual problems and concerns with others

_____Information about emotional illness

_____Information about inpatient hospital programs

_____Information about outpatient hospital programs

_____Information about socialization programs

_____Information about community residences

_____Information about medication

_____Information about how to obtain better community services for friends and relatives who have difficulty coping with stress

_____Information about how to obtain benefits and entitlements such as SSI, Medicaid, Housing, etc.

_____Identifying professional resource people who can help in solving problems

_____Referral to other organizations or groups, such as Hillside Hospital's self help group (PATH) which is engaged in advocacy on behalf of patients.

_____Reassurance that you have the ability to help others with similar problems as your own

_____Other (Please specify)_____

_____

_____

3. Are there any other reasons for attending this program?

Please state_____

_____

_____

_____

_____

III. Please provide some descriptive personal data about yourself.

1. Marital status (Please check)

_____Married

_____Divorced

_____Separated

_____Widowed

_____Never married

2. Highest grade completed

_____Some grade school (but not high school graduate)

_____High school graduate

_____Some college (but not college graduate)

_____College graduate

_____Some graduate school

_____Graduate school degree

a. If college, what was your educational major:

3. Are you employed:

_____Yes

_____No

a. Employment (please check)

_____Full-time

_____Part-time

_____Unemployed

_____Never worked

_____Retired

_____Other (Please specify)_____

_____

b. If you work, what kind of work do you do? (Please specify)_____

c. If retired, what kind of work did you do prior to retirement: (Please state)_____

_____

d. If unemployed, what is your line of work when employed? (Please state)_____

_____

4. What is your age?

_____20 - 29

_____30 - 39

_____40 - 49

_____50 - 59

_____Over 60

9.

5. Annual household income:

_____less than $4,000

_____ $5,000 - $9,999

_____$10,000 - $14,000

_____$15,000 - $19,999

_____$20,000 - $24,999

_____$25,000 - $29,999

_____Over $30,000

6. How did you learn about this group program? (Please state)

_____

_____

_____

_____

Thank you.

Appendix B

End Of Meeting Feedback Sheet

END OF MEETING FEEDBACK SHEET

Session Number:_____ Date:_____

Meeting Place:_____ Time:_____

Would you give us just a few minutes to let us know how you feel about today's meeting? It will help us plan for future meetings.

I. Please check the statement that best describes how you feel; then add your comments, if any. If there is not enough space, please feel free to use the back of the sheet. Thank you.

1. I think that in this session I learned
   - _____a great deal
   - _____quite a lot
   - _____Some
   - _____a little
2. On the whole, today's session was
   - _____excellent
   - _____pretty good
   - _____average
   - _____poor
3. The guest speaker was
   - _____excellent
   - _____pretty good
   - _____average
   - _____Poor
4. The topic was covered
   - _____well
   - _____moderately well
   - _____fairly well
   - _____poorly

2.

5. Talking and sharing ideas with others in the group was:

_____very easy

_____somewhat easy

_____somewhat difficult

_____very difficult

6. I am leaving the meeting feeling

_____encouraged

_____all right

_____disappointed

_____frustrated

7. As of now, the topics of discussion interest me

_____intensely

_____quite a bit

_____somewhat

_____a little

8. Please list any positive comments and/or negative comments about the session.

Postive Comments	Negative Comments
a._____	a._____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

3.

II. Please indicate any suggestions you may have for improving this group program:

1. Type of expert you would like to hear in future sessions:

_____

_____

2. Specific experts you would like to hear in future meetings:

_____

_____

3. Suggestions for future topics:_____

_____

_____

4. Methods for presenting material to the group:_____

_____

_____

III. Please write any additional comments below:_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Appendix C

Participants Evaluation Questionnaire

1.

PARTICIPANTS EVALUATION QUESTIONNAIRE

Please complete this questionnaire for the purpose of helping us to evaluate and improve our group program. Your answers will be treated confidentially. Thank you.

1. How many sessions were you able to attend? Please circle

   1 2 3 4 5 6

2. Overall, how would you rate this program?

   _____excellent

   _____good

   _____fair

   _____poor

3. Please use E for excellent; G for good; F for fair; P for poor.

   _____room facilities

   _____guest speakers

   _____discussion among participants

   _____usefulness of information

   _____material covered

   _____way meetings were planned

4. What part of the program did you find most helpful to you?

   (Please state)_____

   _____

   _____

   _____

5. What part of the program did you find the least helpful to you?

   (Please state)_____

   _____

   _____

6. Would you recommend participation in this group program to others in your situation?

_____Yes

_____No

_____Not sure

If no or not sure, please explain your reasons.

_____

_____

_____

_____

7. Please check the number beside each statement that most clearly represents your experience in the training program.

	Excellent 1	Good 2	Fair 3	Poor 4
Sharing experiences with others				
Obtaining answers to questions of interest				
Understanding that emotional illness is related to problems in coping and handling stress				
Understanding the behavior of someone suffering from long term emotional disturbance				
Feeling more confident in your ability to provide care to a friend or relative who has long term emotional disturbance				
Feeling that your contribution to group discussions was beneficial to others				
Learning about available community resources				
Learning how to go about obtaining needed resources				
Learning the differences between how various state, city, and private agencies operate				

8. Briefly describe the impact of the group experience on your ability to continue to support your friend or relative with emotional problems._____

_____

_____

_____

9. Has this program changed the way you think and feel about emotional disturbance?

_____yes

_____no

_____not sure

If yes, in what way has your thinking changed?_____

_____

_____

_____

10. Based on this experience, do you think this program has helped you better cope with community resistance to helping people who have emotional problems? _____yes _____no

11. Do you now feel more comfortable talking with a neighbor or friend about mental illness? _____yes _____no

a. Please check the response which best describes your feelings about talking to a neighbor or friend.

_____very comfortable

_____comfortable

_____uncomfortable

b. If you checked very comfortable or comfortable, how comfortable would you say you feel? (Please state)_____

_____

_____

12. Has the group program changed the way you feel about your family member who is undergoing emotional stress? ____yes ____no

    a. If yes, how has it changed the way you feel and what you do? (Please state)_____

    _____

    _____

13. Will you share with others (family members, friends, etc.) what you have learned from the group program?

    _____yes

    _____no

    _____not sure

14. Would you like to continue meetings?

    _____yes

    _____no

    _____not sure

    a. Would you like to meet informally as part of a mutual support group? _____yes _____no

    b. If yes to 14-a, would professional staff be seen as having a role in the group (should participants decide to continue meeting) on an ongoing basis?

    _____yes

    _____no

    _____not sure

    c. If yes (to question 14-b), in what way do you think professional staff should be involved? (Please state)_____

    _____

    _____

    _____

Appendix D

Program Evaluation Follow Up Questionnaire

Program Evaluation Follow-up Questionnaire

Please complete this questionnaire for the purpose of helping us evaluate the long-term effects of our group program. Your answers will be treated confidentially. Thank you.

I. Please rate the following topic areas based on the amount of information that you remember from participating in the caregiver's training program.

(Note: 1=a great deal of information; 2=some information; 3=a little information; 4=do not remember)

_____What is mental illness?

_____The impact of mental illness on the family

_____The role of professionals in the treatment of the mentally ill

_____The role of family caregivers in the treatment of the mentally ill

_____The use of medication in the treatment of mental illness

_____The role of self-help in helping families of the mentally ill

_____Difference between state, city and voluntary agency programs in treating the mentally ill

_____Eligibility requirements for treatment in a state, city or voluntary agency program

II. Did the training program influence your use of formal or informal services on behalf of your emotionally ill friend or relative?_____

1. Did you have an ongoing relationship with a mental health professional prior to attending the caregiver's training program? _____Yes_____No.

   a. If yes, in what way, if any, did the program influence your relationship with this person?_____

      _____

      _____

b. If no, have you sought the services of a mental health professional within the past two years?_____yes_____no.

If your answer was no, please explain_____

_____

_____

2. Were you involved with a self-help or mutual support group prior to attending this training program?_____yes_____no.

a. If yes, what way, if any, did the program influence your involvement in such a group?_____

_____

_____

b. If no, did participation in the training group lead you to become involved in a self-help group or to join with others outside the immediate family for mutual support? _____Yes_____No.

If your answer was no, please explain_____

_____

_____

3. Have you applied for medicaid or general social services of any kind as a result of training?_____Yes_____No.

a. If yes, did you feel knowledgeable about the appropriate steps you needed to take in filing your application?

_____yes_____no.

b. If no, please state your reasons for not applying._____

_____

_____

III. Did the training program affect the care you provide to a mentally ill family member?_____

1. Have you talked informally with other relatives and friends about your problems?_____yes_____no.

a. Were you able to discuss these concerns with others prior to attending the caregivers training group?

_____yes_____no. Comment?_____

_____

_____

2. Have you referred a friend or relative to a mental health professional for consultation and/or treatment?_____Yes _____No.

3. If you needed help in solving a problem involving your emotionally ill family member, how might you go about solving such a problem? (Please state)_____

_____

_____

_____

_____

_____

Appendix E

Memoranda to Medical Director and HEQ Staff

LONG ISLAND JEWISH - HILLSIDE MEDICAL CENTER

MEMORANDUM

To Dr. Vera Liang
Medical Director - HEQ

Date February 17, 1983

From Penelope Johnson, CSW

Subject Dissertation Project
Plan for Implementation

As you know, I am a third year Doctoral Candidate at the Hunter College School of Social Work. I have satisfied all course requirements and passed the necessary written and oral examinations as partial requirements for the DSW degree. Most recently, I have obtained academic acceptance of my project proposal which is also being considered by the Human Subjects Review Committee of the Medical Center. Dr. Lurie, Director, Social Work Services for the Medical Center has informed me that special consent forms for program participants are not required. He did not anticipate any unusual problems in obtaining organizational approval for the project; and will inform me when the necessary forms have been signed by him and Dr. Rabiner.

This project will be a demonstration effort to study the caregiving role and potential of family members and friends of chronic mental patients; and to provide information and skills development to strengthen and supplement their caregiving at the neighborhood level. Services will be offered through a small group format; emphasizing education, skills training, and peer support. Research studies in recent years, especially in service delivery to the elderly, have found this to be a very effective means of strengthening the informal supports of the aged. This project will test the applicability of the small group as a format for training the informal caregivers of many chronically mentally ill patients.

Intervention will be targeted on the community mental health catchment area of Eastern Queens. Group members will be people who may or may not be in treatment at one of the outpatient psychiatric clinics at LIJ-HMC, or the State or City hospitals serving the area. Participants may also be community residents who are in need of the service; but have had no previous involvement with the formal mental health delivery system.

In order to satisfy the requirements of the doctoral program, the research must include a minimum of two training groups; but preferably three groups of 10-15 participants; as well as use of a control group in order to compare and contrast the impact of training interventions. From my discussions with Mr. Jefferson and Dr. Lurie, it is felt that at least one training group can be organized and held at HEQ; and that other groups may be conducted at Hillside Hospital; (including the PATH group) and/or the Queens Hospital affiliation.

Recruitment of participants will be based primarily on referrals made by professional staff at HEQ and the Medical Center; and from other community agencies that comprise the Queens Mental Health Council. A list will be compiled and letters will be mailed; to be followed up by a telephone call and "personal" interviews to develop potential members interest in participation.

It is hoped that training will begin with the first group of caregivers at HEQ in the summer of 1983. A second and third group will follow sequentially either at HEQ or at another Hillside Clinic. These groups are expected to run during the Fall of this year. A control group will be identified and measured concurrently with one of the above groups either at Hillside or at the Queens Hospital affiliation. It is hoped that the collection of data will be complete by December, 1983; but certainly no later than June 1984. Evaluation and reporting of findings will ensue after that time.

I will be happy to further discuss any questions, ideas, or suggestions that you may have concerning the project.

cc: Marvin Drucker, M.D.
Director of Community Psychiatry

LONG ISLAND JEWISH - HILLSIDE MEDICAL CENTER

MEMORANDUM

To Staff, HEQ **Date** February 17, 1983

From Penelope Johnson, CSW **Subject** Dissertation Project
Recruitment of Participants

As you may know; I am a third year doctoral candidate at the Hunter College School of Social Work. Having completed the necessary academic requirements, I am now in the process of satisfying the research demands of the program.

My project will test the effectiveness of the small group in strengthening the informal natural supports of many chronically mentally ill patients. It will be a demonstration effort to study the caregiving role and potential of family members and friends of chronic mental patients; and to provide information and skills development to strengthen and supplement this caregiving at the neighborhood level.

In order to develop a list of names for potential program participants, I need the help of staff in referring clients whom you think might benefit from a caregivers support group. Selection of participants for the program will be based on the following criteria:

Friends and relatives must be involved either directly or indirectly with a family member or friend experiencing mental illness of an enduring or chronic nature. (The length of the mentally handicapped persons illness will not be a factor in considering friends and relatives for the project).

Friends and relatives may either receive services from a mental health agency or may be identified by a professional as a potential bridge person between an agency and a chronic patient.

Friends and relatives must be willing to commit themselves to attending group meetings for the purpose of sharing experiences and exploring the usefulness of such an exchange in terms of future benefits to their informal helping networks.

The project will be comprised of six training sessions attended by 10-15 natural caregivers. The particulars concerning the content and time to allow for each meeting will evolve from the particpants expressed needs, interest, and goals for training. Sessions are expected to be both didactic and experiential so that members have a range of opportunities to acquire new knowledge and improved skills; and engage in a process of mutual exchange and problem solving activities. The group process will also emphasize the importance of developing both horizontal and vertical linkages between professionals and lay participants. If you have clients who might be appropriate for the caregivers group, please make their names known to me as soon as possible.

Thank you for your time and cooperation.

Appendix F

Out-Reach Letter

LONG ISLAND JEWISH—HILLSIDE MEDICAL CENTER
HILLSIDE EASTERN QUEENS MENTAL HEALTH CENTER • 96-09 Springfield Blvd., Queens Village, N.Y. 11429 • (718) 740-3310

Dear

As a therapist, I have often been called upon to treat patients with chronic mental illness. I have been most impressed with the efforts of close family members who have been supportive in providing consistent care; and in seeking the best possible treatment for their relatives. Over the years, my interest in understanding the struggle of family members and patients dealing with longterm psychiatric illness has led to a desire to do further research in this area. Therefore, I have chosen to deal with this as the subject of my doctoral program.

Exploration of the many problems facing the chronically ill and their families reveals that we often fail to give due credit to family members who have in fact been care providers long before, and after, patients become involved with formal service programs. It is for this reason that I would like to develop a program that would identify and deal with the special needs of those family members who are involved in a caretaking role.

Since your name was given to me by the staff at Hillside Eastern Queens, I would like to invite you to participate in a six session training program which will serve as an opportunity to share mutual experiences; as well as increase your current knowledge and understanding about mental illness and various support services. In addition, I would like to learn from you how this training experience may benefit you in maintaining your family members in the home or community.

I will be contacting you again within a few weeks to perhaps make an appointment in order to discuss the program. If you have questions prior to my call, please feel free to contact me at the above number.

Sincerely,

Penelope Johnson, CSW

Appendix G

Contents of Training Packet

TYPES OF ASSISTANCE

	INFORMAL	FORMAL	SEMIFORMAL
CONSISTS OF:	family, friends, neighbors, building supers, etc.	large bureaucratic organizations under government or private auspices such as hospital, Social Security, Medicaid	Local, neighborhood based organizations such as church groups, block associations, senior centers
STRUCTURE:	informal and flexible, no eligibility requirements, bound by affective (emotional) ties local, accessible	highly structured, inflexible rules and regulations re: provision and nature of services, instrumental (functional, depersonalized) often centralized and inaccessible for disabled	subject to guide lines and regulations but flexible in interpretations, more responsive to individual variations and situations, tend to be decentralized, neighborhood based
MAJOR TYPES OF ASSISTANCE:	social and emotional supervision, management help with activities of daily living, personal assistance during illness or crisis	financial, health care, institutionalized social services	social and emotional, nuturitional, access to formal system (I & R, transportation, linkage) limited home care, mental health

HILLSIDE EASTERN QUEENS MENTAL HEALTH CENTER

ANNOUNCEMENT

MEETING:	Caregivers Support Group
DATE:	Tuesday, March 20, 1984
TIME:	6:00 P.M.
PLACE:	Hillside Eastern Queens Mental Health Center 96-09 Springfield Blvd. Queens Village, NY 11429

AGENDA

I.	Guest Speaker - Nilsa Vergara
II.	Topic: What is Mental Illness?
III.	Discussion
Note:	Refreshments will be served
	Please complete the enclosed questionnaire regarding the meeting of 10/11/83 and bring it with you on Tuesday night.

HILLSIDE EASTERN QUEENS MENTAL HEALTH CENTER

CAREGIVERS SUPPORT GROUP

April 3, 1984

A G E N D A

I. GUEST SPEAKER----------Dr. Jeff Phillips

II. TOPIC----------The Treatment of Mental Illness With Medication

III. DISCUSSION

Note: Refreshments will be served

Please return Feedback Sheets from our last meeting.

Thank you.

HILLSIDE EASTERN QUEENS MENTAL HEALTH CENTER

CAREGIVERS SUPPORT GROUP

April 10, 1984

A G E N D A

I. GUEST SPEAKER----------Elaine Bernhard

II. TOPIC----------"The Function of Self-Help in Coping With Mental Illness in the Family"

III. DISCUSSION

Note: Refreshments will be served

Kindly return Feedback Sheets from our last meeting.

ALLIANCE FOR THE MENTALLY ILL OF NEW YORK STATE

Dedicated to improving the quality of life for those who suffer from chronic mental illness.

AMI of New York is affiliated with the National Alliance for the Mentally Ill. Members of AMI of New York are local organizations of families and friends of the mentally ill.

CHRONIC MENTAL ILLNESS:

Include the schizophrenias and other severe affective mental disorders such as depression, manic depression, and personality disorder.

Are serious diseases with biochemical and environmental components not yet understood.

Are characterized by disturbed thinking, feeling, and behaving, and strike young people in their most productive years.

Can devastate caring families emotionally, physically, and financially.

Occur in all classes, ethnic and national groups all over the world.

Afflict millions of people in the United States and cost billions of dollars in care and lost earnings, yet are scientifically under-researched and widely misunderstood.

Can improve with proper treatment, rehabilitation and support.

WORK WITH US AS WE SHARE TALENTS AND STRENGTHS TO:

Develop self help/advocacy groups through which we can share problems and knowledge and learn that we are not alone and not to blame.

Gain knowledge about the causes, symptoms and treatments of chronic mental illnesses and ways in which families can overcome despair, frustration and isolatio

Find information about professionals who will work with, not against, families; sources of help in crisis; community services; and available financial aids.

Change stereotypes and overcome stigmas associated with mental illnesses, so as to secure a fair place in our society for those suffering from chronic mental illnesses. Community involvement with the mentally ill is essential for their recovery.

Foster research into the biochemical aspects of chronic mental illnesses that could lead to breakthroughs in our understanding of causes, more effective treatments, and prevention, and eventually bring about the eradication of these diseases.

Encourage local, state and national legislation and funding to insure quality institutional and community services to the chronically mentally ill.

Promote changes in training for mental health professionals to foster a more enlightened awareness of the nature of chronic mental illnesses and how families can be involved in their treatment.

For MORE INFORMATION:

Write to: AMI of New York
P.O. Box 746
New Paltz, N.Y. 12561

or telephone: (914) 255-5134
(212) 475-1566
(516) 473-8442
(315) 446-2015

FAMILIES OF THE MENTALLY ILL

GETTING SATISFACTORY RESULTS:

SOME DO'S AND DON'TS

Families need to know how to be effective in getting help for a seriously ill mental patient. They need to know what questions to ask, what people to see and where to go. They need to understand the various parts of the system and how best to interact with each part.

Frequently, when a parent, relative or close friend becomes involved -- especially during the early phases of the illness, each person is so overwhelmed by the experience that vague information and "jargon" is accepted as substantive. Several studies have been made during the past ten years; each supports the fact that families are not getting what they want. They want honest, direct information about the illness and they want specific, practical suggestions about how to cope during acute or stable phases of the illness. To get this kind of information there are some actions which you must do. Following are some hints to obtain positive results from "the system":

THINGS TO DO

* Keep a record of everything. List names, addresses, phone numbers, etc. Nothing is unimportant. Every date, time, etc. may come in handy. Make notes of what went on during conferences, keep all notices, letters, etc. Make copies of everything you mail, keep a notebook or file of all contacts. Don't throw anything away.

* Be polite. Keep all conversations to the point. Ask for specific information.

* Request permission from your relative to review all documents. Only if permission is granted in writing will you be able to do so. This applies to persons 18 or older.

* If the patient is in a private hospital (rather than a state institution) you may have your own physician who is in charge. Get the name of the Primary Therapist on the ward. This is usually a psychiatric nurse. He/she will know most about the patient. Ask for an appointment to meet with this person; make it at their convenience. Come prepared with a list of specific questions. Some sample questionsa are:

> "What are the specific symptoms about which you are most concerned?"

"What do these indicate? How are you monitoring them? Who is documenting in the chart? How often is the medication being monitored? What, specifically, is he/she getting? How much? How often? Has the patient been informed on medication side-effects? When can I look at the record book or chart? When can we meet to plan the transition back home?"

* Keep the meeting short. If you come with a list of questions you will be able to get all the information you need in less than half an hour.

* Write letters of appreciation when warranted; write letters of criticism when necessary. Send these to the head of the hospital (or unit -- or both) and send copies to anyone else who may be involved, including the Governor.

* Keep the patient informed about everything you plan to do. He/she might disapprove of your action or may wish to modify your plan.

* Finally, BE ASSERTIVE! As a taxpayer, you are entitled to information, respect and courtesy. Your taxes go to public employees. <u>You are not asking for gratuities</u>. You are simply helping to get the job done.

EARLY SYMPTOMS

Reactions by Other Family Members:

When a family member unexpectedly becomes ill, shock is a typical reaction. This is true of families who are confronted with severe mental illness. In many ways the reaction is not unlike one to any other catastrophic illness. The initial response is to comfort and protect the afflicted person. As symptoms become more florid (and more frightening) extreme ambivalence is experienced. Responses reported by families were:

Denial of the illness entirely. (This can't happen in our family.)

Denial of the severity of the illness. (She's only going through a phase. She'll be OK.)

Fear of discussing one's fears.

Increased drinking.

Dependence upon tranquilizers.

Withdrawal from social activities.

Shame and guilt. (Where did we go wrong? What will people think?)

Feelings of isolation. (Nobody knows what I'm going through. No one can understand.)

Bitterness. (It isn't fair. Why us?)

Blaming each other. (If you had been a better father . . . If you had stayed home more . . .)

Depression.

Sleeplessness.

Weight loss.

Anxiety.

Inability to think or talk about anything but the illness.

Marital dissention.

Preoccupation with "moving away."

Repeated "separations."

Divorce.

Extreme ambivalence toward the afflicted member.

Excessive searching of the past for possible explanations.

Family divisiveness. (One member demands too much, others too little of patient.)

HILLSIDE EASTERN QUEENS MENTAL HEALTH CENTER

CAREGIVERS SUPPORT GROUP

April 24, 1984

A G E N D A

I. GUEST SPEAKER----------Mr. Eugene Jefferson, CSW
Program Director

II. The Mental Health Delivery System in Queens

III. DISCUSSION

Note: Refreshments will be served

HILLSIDE EASTERN QUEENS MENTAL HEALTH CENTER

LOCAL MENTAL HEALTH AND REHABILITATION SERVICES

AGENCY	TELEPHONE NUMBERS
Long Island Jewish-Hillside Medical Center	470-2000
Central Intake	470-4551
Emergency Room	470-2816
Walk-In Clinic	470-4314
Social Work Services	470-4256
Queens Hospital Center	990-2200
Mental Health Center	990-3551
City Hospital Center, Elmhurst	830-1551
Queens County Mental Health Society, Inc. (Referral and Information Services)	479-0030
Creedmoor Psychiatric Center	464-7500
Catholic Charities	596-5500
Advanced Center for Psychotherapy	658-1123
Bleuler Psychotherapy Center	275-6010
Transitional Services, Inc.	464-3772
Vocational Evaluation, Testing and Placement Center	526-8400
PATH (Self Help Group - Hillside Hospital)	470-4268
Office of Vocational Rehabilitation Services (Main Office)	359-5858

Selected Bibliography

Anderson, Carol, Hogarty, G. E., and Reiss, D. J." Family Treatment Adult Schizophrenic Patients: A Research Based Psycho-Educational Approach." A paper submitted for publication to the Schizophrenia Bulletin, 30 Nov. 1979.

_____. "Family Treatment of Adult Schizophrenic Patients: A Psychoeducational Approach." Schizophrenia Bulletin. 6 (1980): 490-505.

Anderson, Carol M. "A Psychoeducational Program for Families of Patients with Schizophrenia." Family Therapy In Schizophrenia, ed. William McFarlane. New York and London: The Guildford Press, 1983. 99-115.

_____. "Families Advocate for the Mentally Ill." Practice Digest. Vol. 6, No. 2 (Autumn, 1983): 14-16.

Appleton, William S. "Mistreatment of Patients' Families by Psychiatrists." American Journal of Psychiatry. 131; 6 (June, 1974): 655-657.

Atwood, Nancy. "Supportive Group Counseling for the Relatives of Schizophrenic Patients." In Family Therapy In Schizophrenia, ed. William McFarlane. New York and London: The Guilford Press, 1983: 189-203.

Atwood, Nancy and Williams, Martha. "Group Support For The Families of The Mentally Ill." Schizophrenia Bulletin. Vol. 1, No. 3 (1978): 415-422.

Bachrach, Leona L. "Young Adult Chronic Patients: An Analytical Review of the Literature." Hospital and Community Psychiatry. Vol. 33, No. 3 (March, 1982).

Baker, Frank. "The Interface Between Professional and Natural Support Systems." Clinical Social Work Journal. Vol. 5, No. 2 (1977): 139-147.

Bateson, G., Jackson, D.D., Haley, J., and Weakland, J. "Towards A Theory of Schizophrenia." Behavioral Science, 1 (1956): 251-264.

Beels, C. Christian. "Social Networks, The Family, and The Schizophrenic Patient." Schizophrenia Bulletin. Vol. 4 (1978): 512-520.

Beels, C. Christian and McFarlane, Wiilliam, R. "Family Treatments of Schizophrenia: Background and State of The Art." Hospital and Community Psychiatry. Vol. 33, No. 7 (July, 1982).

Beels, C. Christian. "Social Support and Schizophrenia." Schizophrenia Bulletin. Vol. 7, No. 1 (1981): 51-71.

Berkowitz, B., Kuipers, L., Eberlein-Frief, R., et al.: "Lowering Expressed Emotion in Relatives of Schizophrenics." In New Developments In Interventions With Families of Schizophrenics, ed. Michael Goldstein. Washington, D. C.: Jossey-Bass, Inc., 1981.

Blackman, Sheldon and Goldstein, Kenneth M. "Some Aspects of a Theory of Community Mental Health." Community Health Journal. Vol. 4, No. 1 (February, 1968).

Bockoven, J. Sanborne, M. D. Moral Treatment In Community Mental Health. New York, N. Y.: Springer Publishing Company, Inc., 1972.

Boffey, Phillip M. "Schizophrenia Puzzle: Toll Rises Amid Hope." The New York Times, 16 March 1986.

Bowen, Murray. "A Family Concept of Schizophrenia." The Etiology of Schizophrenia, ed. D. D. Jackson. New York: Basic Books, Inc., 1960.

Brager, George. "Institutional Change: Perimeters of the Possible." Social Work. (January, 1967): 59-69.

Brown, G. W., Birley, J. L. T., and Wing, J. K. "Influence of Family Life on the Course of Schizophrenic Disorders: A Replication." British Journal of Psychiatry 121 (1972): 241-258.

Callohan, James Jr. "Obstacles to Social Planning." Social Work (November, 1973): 70-79.

Caplan, Gerald. The Theory and Practice of Mental Health Consultation. Basic Books, New York, 1970.

_____. Support Systems and Community Mental Health. New York: Behavioral Publications, 1974.

Caplan, Gerald and Killilea, Marie. Support Systems and Mutual Help: Multidisciplinary Explorations. New York: Grune and Stratton, Inc., 1976.

Commission on Mental Health: Report to the President, Vol. 2 Washington, D. C.: U. S. Government Printing Office, 1978.

Collins, Alice H. "Natural Delivery Systems: Accessible Sources of Power for Mental Health." American Journal of Orthopsychiatry Vol. 43 (1973).

Collins, Alice and Pancoast, Diane L. Natural Helping Networks: A Strategy for Prevention. Washington, D. C.: National Association of Social Workers. 1976.

Connery, Robert. The Politics of Mental Health. New York and London: Columbia University Press, 1968.

Darling, Rosalyn B. "Parent - Professional Interaction: The Roots of Misunderstanding." In The Family with a Handicapped Child: Understanding and Treatment, ed. Milton Seligman. New York and London: Grune and Stratton, Inc., 1983.

Delgado, Melvin and Humm-Delgado, Denise. "Natural Support Systems: Source of Strength in Hispanic Communities." Social Work Vol. 27, No. 1 (January, 1982).

Deutsch, Albert. The Mentally Ill In America. New York and London: Columbia University Press, 1949.

Dincin, J., Selleck, V., Streicker, S. "Restructuring Parental Attitudes - Working with Parents of the Adult Mentally Ill." Schizophrenia Bulletin Vol. 4, No. 4 (1978).

Docherty, John P. "We Turned Mentally Ill into the Streets," Newsday, 2 December 1984.

Doll, William. "Family Coping With The Mentally Ill: An Unanticipated Problem of Deinstitutionalization." Hospital and Community Psychiatry Vol. 27, No. 3 (March, 1976).

Dunham, H. Warren. "Community Psychiatry: The Newest Therapeutic Bandwagon." Perspectives in Community Mental Health, ed. Arthur J. Bindman and Allen D. Speigel. Chicago: Aldine Publishing Company, 1969.

English, Bella. "State Mental Patient Dumping - It's Spilling Into Hospitals," Daily News, 12 December 1982.

Epstein, Irwin and Tripodi, Tony. Research Techniques for Planning, Monitoring, and Evaluation. New York: Columbia University Press, 1977.

Fairweather, G. W., Sanders, D. H., Maynard, H., Cressler, D. L., Black, D. S. Communtiy Life For The Mentally Ill: An Alternative To Institutional Care. Chicago: Aldine Publishing Co., 1969.

Falloon, Ian R. H., Boyd, J. L., McGill, C. W., et al. "Family Management Training in the Community Care of Schizophrenia." In New Developments in Interventions With Families of Schizophrenics, ed. Michael Goldstein. Washington, D. C.: Jossey - Bass, Inc., 1981.

_____. "Family Management in the Prevention of Exacerbations of Schizophrenia: A Controlled Study." New England Journal of Medicine 306 (1982): 1437-1440.

Falloon, Ian R. H. and Liberman, Robert P. "Behavioral Family Interventions in the Management of Chronic Schizophrenia." In Family Therapy In Schizophrenia, ed. William McFarlane. New York and London: The Guilford Press, 1983. 117-137.

Ferris, Patricia A. and Marshall, Catherine A. "A Model Project for Families of the Chronically Mentally Ill." Social Work, Vol. 32, No. 2 (1987).

Freeman, Howard E. and Simmons, Ozzie G. The Mental Patient Comes Home. New York: John Wiley and Sons, Inc., 1963.

Froland, Charles, Pancoast, Diane L., Chapman, Nancy J., and Kimboko, Priscilla J. Helping Networks and Human Services. Beverly Hill, Cal.: Sage Publications, 1981.

Gartner, Alan and Reissman, Frank. Self-Help in the Human Services. San Francisco, Ca.: Jossey-Bass, 1977.

Gartner, Audrey J., and Reissman, Frank. "Self-Help and Mental Health." Hospital and Community Psychiatry Vol. 33, No. 8 (August, 1982): 631-635.

Gitterman, Alex and Shulman, Lawrence. Mutual Aid Groups and The Life Cycle. Itasca, Illinois: F. E. Peacock Publishers, Inc., 1986.

Goldman, Howard H. "Mental Illness and Family Burden: A Public Health Perspective." Hospital and Community Psychiatry Vol. 33, No. 7 (July, 1982).

Goldstein, M. J. ed. New Developments in Interventions with Families of Schizophrenics. Washington, D. C.: Jossey-Bass, Inc., 1981.

Goldstein, M. J., Rodnick, E. H., Evans, J. R., et al. "Drug and Family Therapy in the Aftercare of Acute Schizophrenics." Archives of General Psychiatry 35 (1978): 1169-1177.

Goleman, Daniel. "Schizophrenia: Early Signs Found," The New York Times, 11 December 1984.

Gottlieb, Benjamin H. "Preventive Interventions Involving Social Networks and Social Support." In Social Networks and Social Support, ed. Benjamin Gottlieb. Beverly Hills: Sage Publication, 1981.

Hass, J. Eugene and Drabek, Thomas E. Complex Organizations: A Sociological Perspective. New York: Macmillan Publishing Co., 1973.

Hatfield, Agnes B. "Psychological Costs of Schizophrenia to the Family." Social Work September, 1978.

_____. "Help-Seeking Behavior in Families of Schizophrenics." American Journal of Community Psychology Vol. 7, No. 5 (1979).

_____. "Self-Help Groups for Families of the Mentally Ill." Social Work (September, 1981).

_____. "What Families Want of Family Therapists." In Family Therapy in Schizophrenia, ed. William McFarlane. New York and London: The Guilford Press, 1983: 41-63.

Hess, Robert. "Helping Thyself to Mental Health." Innovations Vol. 7, No. 1 (Spring, 1980): 18-22.

Hirsch, Barton J. "Natural Support Systems and Coping with Major Life Changes." American Journal of Community Psychology Vol. 8, No. 2 (1980).

Hirsch, Barton J. "Social Networks and the Coping Process: Creating Personal Communities." Social Networks and Social Support. Beverly Hills, Ca.: Sage Publications, 1981.

Hogarty, G. E., Goldberg, S. C., Schooler, N. R., et al. "Drug and Sociotherapy in the Aftercare of Schizophrenic Patients: Two Year Relapse Rates." Archives of General Psychiatry 31 (1979): 603-608.

Hogarty, G. E., Schooler, N. R., Ulrich, R. et al. "Fluephenazine and Social Therapy in the Aftercare of Schizophrenic Patients: Relapse Analysis of a Two Year Controlled Study of Fluphenazine Decanoate and Fluphenazine Hydrochloride." Archives of General Psychiatry 36 (1979): 1286-1294.

Implementing a City-State Plan for the Integration of Mental Health Services in New York City. An unpublished project proposal, 1977. New York City Department of Mental Health, Mental Retardation and Alcoholism Services.

Iodice, Jody D. and Wodaski, John S. "Aftercare Treatment for Schizophrenics." Social Work Vol. 32, No. 2, 1987.

Jenkins, Lowell and Cook, Alicia S. "The Rural Hospice: Integrating Formal and Informal Systems." Social Work (Sept., 1981): 414-416.

Kahn, Alfred J. Studies in Social Policy and Planning. New York: Russell Sage Foundations, 1969.

Kamerman, Sheila B. "A paradigm For Programming." Social Service Review (September, 1975).

Kandel, Denise B., and Williams, Richard H. Psychiatric Rehabilitation, Some Problems of Research. New York: The Atherton Press, 1964.

Katz, Alfred H. "Application of Self-Help Concepts in Current Social Welfare." Social Work. Vol. 20 (July, 1965): 68-74.

Killilea, Marie. "Mutual Help Organizations: Interpretations in the Literature." Support System and Mutual Help: Multidisciplinary Explorations. New York: Grune and Stratton, Inc. 1976.

Knowles, Malcom. Self-Directed Learning: A Guide for Learners and Teachers. Chicago: Association Press-Follett Publishing Company, 1980.

Kootnz, H., O'Donnell, C., and Weihrich, H. Management. New York: McGraw Hill Book Company, 1980.

Kopeikin, Hal S., Marshall, V., Goldstein, M. J. "Stages and Impact of Crisis-Oriented Family Therapy in the After-Care of Acute Schizophrenia." In Family Therapy in Schizophrenia, ed. William McFarlane. New York and London: The Guilford Press, 1983: 69-96.

Kreisman, Delores E., and Joy, Virginia D. "Family Response to the Mental Illness of a Relative: A Review of the Literature." Schizophrenia Bulletin. No. 10. (Fall, 1974).

Lamb, Richard A. Treating the Long Term Mentally Ill Beyond Deinstitutionalization. San Francisco Ca.: Jossey-Bass, Inc., 1982.

Lamb, Richard A. and Associates, Community Survival for Long-Term Patients. San Francisco, Ca.: Jossey-Bass Publications, 1976.

Lamb, Richard and Oliphant, Eve. "Schizophrenia Through the Eyes of Families." Hospital and Community Psychiatry. Vol. 29, No. 12 (December, 1978).

Laurino, Maria. "Circling the Cukoo's Nest: One Man's Life on the Streets." The Village Voice. 23 April 1985.

Leff, J., Kuipers, L., Berkowitz, R., et al.: "A Controlled Trial of Social Intervention in the Families of Schizophrenic Patients." British Journal of Psychiatry 141 (1982): 121-134.

Lehman, Stanley and Associates. "Environmental Adaptation of the Mental Patients." The Journal of Community Psychology Vol. 6, No. 2 (1978).

Levy, Leon H. "Self-Help Groups Viewed by Mental Health Professionals: A Survey and Comments." American Journal of Community Psychology Vol. 6, No. 4 (1978).

Lidz, Theodore, Fleck, S., Cornelison, A. "Marital Schism and Marital Skew. "Schizophrenia and the Family. New York: International Universities Press, Inc., 1965.

Lieberman, M. A. and Mullan, J. T. "Does Help Help? The Adaptive Consequences of Obtaining Help from Professionals and Social Networks." American Journal of Community Psychology Vol. 6, No. 5 (1978).

Linscott, Sigrid. "Are Friends Still Friends in Adversity?" The New York Times, 29 August 1984.

Lukoff, David, Snyder, K. Ventura, J. and Nuechterlein, K.H. "Life Events, Familial Stress, and Coping in the Developmental Course of Schizophrenia." Schizophrenia Bulletin Vol. 10, No. 2 (1984).

Lurie, Abraham and Karliner, William. "The Rehabilitation of Discharged Psychiatric Patients." Journal of the Hillside Hospital Vol. XVII, No. 4 (Oct. 1968).

Lurie, Abraham and Shulman, Lawrence. "Professional Self-Interest and Self-Help Groups." Social Work in Health Care Vol. 8, (1983).

Mandelbaum, Arthur and Wheeler, Mary E. "The Meaning of a Defective Child to Parents." Social Casework Vol. 41, (1960): 360-367.

Marcus, Lee M. "Patterns of Coping in Families of Psychotics." American Journal of Orthopsychiatry Vol. 47, No. 3 (July, 1977): 388-399.

McClean, Carol S., Greer, K., Scott, J., Beck, J. "Group Treatment for Parents of the Adult Mentally Ill." Hospital and Community Psychiatry Vol. 33, No. 7 (July, 1982): 564-568.

McFarlane, William. Family Therapy in Schizophrenia. New York and London: The Guilford Press, 1983.

_____. "Multiple Family Therapy in Schizophrenia." In Family Therapy in Schizophrenia. The Guilford Press, New York and London, 1983: 141-171.

Mellor, M. Joanna, Rzetelny, H., Hudis, I. E. "Self-Help Groups for Caregivers of the Aged." Strengthening Informal Supports for the Aging, Theory, Practice, and Policy Implications. New York: Community Service Society, 1986: 52-59.

Melvin, Tessa. "Seminar Bolsters Natural Helpers." The New York Times, 17 January 1982.

Mitchell, Roger E., and Hurley, Daniel J. "Collaboration with Natural Helping Networks: Lessons from Studying Paraprofessionals." Social Networks and Social Supports. Beverly Hills, Ca.: Sage Publications, 1981.

Mitchell, Roger E., Trickett, Edison, T. "Task Force Report: Social Networks as Mediators of Social Support." Community Mental Health Journal Vol.16, No.1 (Spring 1980).

Montrel, Emily, Robinson, J., Walters, J. "The Neighborhood Self-Help Project." Occasional Paper #9, January 1980. School of Social Service Administration, University of Chicago, Chicago.

Morrison, James K. "The Public's Current Beliefs About Mental Illness: Serious Obstacle to Effective Community Psychology." American Journal of Community Psychology Vol. 8, No. 6 (1980).

_____. "Changing Negative Attributions to Mental Patients by Means of Demythologizing Seminars." Journal of Clinical Psychology 33, (1977).

Morrison, James K. and Becker, R. E., and Bourgeois, C. A. "Decreasing Adolescents' Fear of Mental Patients by Means of Demythologizing." Psychological Reports 44 (1979).

Morrison, J. K., Cocozza, J. A., and Vanderwyst, D. "Changing Students Constructs of Mental Patients by Means of Educative Seminars." Journal of Clinical Psychology 34 (1978).

Morrison. J. K., and Teta, D. C. "Effect of Demythologizing Seminars on Attributions to Mental Health Professionals." Psychological Reports, 43 (1978).

_____. "Impact of a Humanistic Approach on Students' Attitudes, Attributions, and Ethical Conflicts, Psychological Reports 45 (1979).

_____. "Increase of Positive Self-Attributions by Means of Demythologizing Seminars." Journal of Clinical Psychology 33 (1977).

Neighborhood and Family Service Project: Two Year Report. Southeast Community Organization, Inc. Baltimore, South Community Organization, Inc. Milwaukee, Wisconsin: National Institute of Mental Health, 1 March 1976 - 15 May 1978.

Nelsen, Judith C. "Support: A Necessary Condition for Change." Social Work (September, 1980).

Newman, Joseph. "Handicapped Persons and Their Families: Philosophical, Historical, and Legislative Perspectives." The Family With a Handicapped Child Understanding and Treatment, ed. Milton Seligman. New York and London: Grune and Stratton, Inc., 1983.

Nobel, Milton, ed., Primary Prevention in Mental Health and Social Work: A Source Book of Curriculum and Teaching Materials. New York: Council on Social Work Education, 1981.

Olshansky, Simon. "Chronic Sorrow: A Response to Having a Mentally Defective Child." Social Casework 43 (1962): 190-193.

Patti, Rino J. "Organizational Resistance and Change: The View From Below." Social Service Review (September, 1974): 367-383.

Patti, Rino J. and Resnick, Herman. "Changing The Agency From Within." Social Work (July, 1972): 48-57.

Pavadan, Frank (Senator). "The Mentally Ill Homeless: Shelters Become Sanctuaries for the Victims of Neglect." New York: A Report of the New York State Senate Committee on Mental Hygiene and Addiction Control. January, 1985.

Passamanick, Benjamin, Scarpiti, F. Dintz, S. Schizophrenics in the Community. New York: Appleton, Century Crafts, 1967.

Perlmutter, Felice D. and Slavin, Simon. Leadership in Social Administration: Perspectives For The 1980s. Philadelphia: Temple University Press, 1980.

Perrow, Charles. Organizational Analysis: A Sociological View. Monterey, Ca.: Brooks Cole Publishing Company, 1970.

President's Commission on Mental Health. Report to the President, Vol. 1, 1970. U. S. Government Printing Office, Washington, D. C.

Raiff, Norma, and Shore, Barbara K. "Interfacing Mutual-Help and Mental Health Delivery Systems: Implications for Policy and Administration Curricula." Paper presented at Council of Social Work Education, annual program meeting. Boston, Mass.: 1979.

Remine, Daniel. Report to the Department of Health and Human Services on Caregivers and Support Groups for Caregivers. An unpublished paper, 1987.

Report of the National Task Force on Mental Health/Mental Retardation Administration. Administration in Mental Health Vol. 6, No. 4 (Summer, 1979).

Reissman, Frank. "The Helper Therapy Principle." Social Work 10, 2 (April, 1965): 27-32.

Rock, Barry D. "Goal and Outcome in Social Work Health Care Practice: The Use of Goal Attainment Scaling." DSW Dissertation, The City University of New York. New York: 1983.

Rock, Marjorie. "Empowering Relatives of the Mentally Ill: The Role of Support Groups." 1984. A paper presented at the American Public Health Association, Anaheim, Ca.

Rzetelny, Harriet, and Mellor, Joanna. Support Groups for Caregivers of the Aged: A Training Manual for Facilitators. New York: Community Service Society. 1981.

Sarbin, Theodore R. and Mancuso, James C. "Failure of a Moral Enterprise: Attitudes of the Public Toward Mental Illness." Journal of Consulting and Clinical Psychology Vol. 35, No. 2 (1970).

Scheper-Hughes, Nancy. "Dilemmas in Deinstitutionalization: A View From Inner City Boston." Journal of Operational Psychiatry Vol. 12, No. 2 (1970).

Selby, Lola G. "Supportive Treatment: The Development of a Concept and a Helping Method." Social Service Review 30 (1956): 400-414.

Selltiz, Claire, Jahoda, M., Deutsch, M., and Cook, S. W. Research Methods In Social Relations. New York: Holt, Rinehart, and Winston, 1959.

Shephard, Herbert. "Innovation Resisting and Innovation Producing Organizations." The Planning of Change, ed. Benne, Bennis, and Chin. New York: Holt, Rinehart, and Winston, Inc., 1969.

Silverman, Phyllis R. Mutual Help Groups: A Guide for Mental Health Workers, 1978. U. S. Government Printing Office, Washington, D. C.

The Committee on Psychiatry and the Community. "The Chronic Mental Patient in the Community." Group For The Advancement of Psychiatry Vol. X, No. 102 (May, 1978).

The New York State Congressional Record, 22 September 1980.

Torrey, E. Fuller. Surviving Schizophrenia - A Family Manual. New York: Harper and Row, 1983.

Toseland, Ronald W. and Hacker, Lynda. "Self-Help Groups and Professional Involvement." Social Work Vol. 27, No. 4 (July, 1982): 341-346.

Tripodi, Tony. Evaluative Research For Social Workers. Englewood Cliffs, N. J., 1983.

Tripodi, Tony, Fellin, P. and Epstein I. Differential Social Program Evaluation. Itasca, Ill.: F. E. Peacock Pub., Inc., 1978.

Vaughn, C. E. and Leff, J. P. "The Influence of Family and Social Factors on the Course of Psychiatric Illness." British Journal of Psychiatry 129 (L976): 125-137.

_____. "Patterns of Emotional Response in Relatives of Schizophrenic Patients." Schizophrenia Bulletin Vol. 7, No. 1 (1981).

Walizer, Michael H., and Wienir, Paul L. Research Methods and Analysis: Searching For Relationships. New York: Harper and Row Pub., 1978.

Wallace, Charles J. "Community and Interpersonal Functioning in the Course of Schizophrenic Disorders." Schizophrenia Bulletin Vol. 10, No. 2 (1984).

Wax, John. "Developing Social Work Power in a Medical Organization." Social Work (October, 1968): 62-71.

Weinmand, B., Sanders, R., Kleiner, R., and Wilson, S. "Community Based Treatment of the Chronic Psychotic." Community Mental Health Journal Vol. 6, No. 1 (1970).

Weiss, Carol H. Evaluation Research, Methods of Assessing Program Effectiveness. New Jersey: Prentice Hall, Inc., 1972.

Weissman, Harold. Class Lecture Notes. Course conducted in the Spring, 1981. Hunter College School of Social Work, New York.

White, Stephen L. "The Community Mental Health Center As A Matrix Organization." Administration in Mental Health Vol. 6, No. 2 (Winter 1978).

Williamson, John B., Karp, D. A., and Dalphin, J. R. The Research Craft: An Introduction to Social Science Methods. Boston and Toronto: Little, Brown and Company, 1977.

Wynne, Lyman. C., Ryckoff, I., Day, J., and Hirsch, S. I. "Pseudo-Mutuality in the Family Relations of Schizophrenics." Psychiatry 21 (1958): 205-220.