THE EFFECTS OF GROUP SUPPORT ON FAMILY MEMBERS OF SCHIZOPHRENIC OUTPATIENTS

by

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A Thesis

Presented To
The Oregon Health Sciences University
School of Nursing
in partial fulfillment
of the requirements for the degree of
Master of Nursing

June 8, 1984

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Acknowledgements

My appreciation to all those people who assisted me in the preparation of this thesis. My thanks to the readers. My deep gratitude to Shirley Murphy, my thesis advisor, whose competent guidance permitted me to complete this study. My sincere gratitude to Mary Furrow, whose continual interest and support permitted me to undertake and bring this project to realization. A special thanks to my husband, Ed Engel, for his endless patience and support, and to all my family for their years of continued faith in me.

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Introduction

Statement of the Problem

One outcome of the community mental health movement has been an increase in the number of patients with psychiatric disorders living with their families. It is now estimated that at least two-thirds of the mentally ill population of patients return to nuclear family homes following hospitalization (Thompson & Doll, 1982). Since most family members are unprepared to deal with the adjustments involved, the problems generated by having a schizophrenic first-order relative in the family home can be overwhelming. While reactions vary, many families feel trapped by the presence of these relatives. Jersild (1967) reports that feelings of anger, confusion, hurt, and frustration are experienced by families of schizophrenic persons.

Kreisman and Joy (1974) state that a family member with a psychiatric disorder can have a profound effect on other family members. The ambiguous nature of psychiatric illness, especially one with consequent episodic disruptions of unpredictable behavior, requires adjustment in the family. Family roles may have to shift to accommodate the behaviors or deficiencies of the ill member. Family members may "put up with" deviant behavior

at the cost of the emotional well-being of all (Doll, 1976). Doll adds that the failure to monitor family-patient conditions at home and to provide mechanisms for support and relief can cripple the community mental health movement.

Hatfield (1977) observed that families have a great need to know what they are up against. After polling members of a Schizophrenic Association Chapter in Washington, DC regarding their choices of help, their responses revealed the importance of both information and social support in dealing with stress. Lamb and Oliphant (1978) state that families of schizophrenics can be helped by providing practical, realistic advice on how to deal with the illness and by offering empathy and support. In a study reported by Zelitch (1980), 50% of the relatives interviewed stated that their own mental health ahd been adversely affected by the schizophrenic relative's illness and 25% reported that their family income or resources had decreased by 10%.

According to Hatfield (1978), families of the mentally ill risk the deterioration of their psychological and physical resources to the point that their personal efficiency may be reduced and the organization and stability of family life is threatened. Humane considerations require that society take notice and create services to minimize this distress.

The problem to be addressed in this study is: To what extent does information provided in a supportive environment reduce the objective burden of family members of schizophrenic patients?

Purpose of the Study

The purpose of this exploratory study is to observe and describe a short-term support group for family members of schizophrenic patients. The support group objectives, which were mutually identified by clinic staff and relatives, were: 1) to provide education to families about various aspects of schizophrenia (theories of etiology, the chronic course of the condition, psychotropic drugs and their desired actions and side-effects); 2) to provide a setting for mutual support and self-help among families with similar concerns; 3) to help families explore community and other resources; and 4) to instruct relatives in basic behavioral techniques they can apply in dealing with their family members.

Literature Review and Conceptual Framework

The review of the literature covers the following areas: 1) family burden as the result of the mental illness of an immediate relative; 2) issues in providing information for families; and 3) multiple family group interaction as a means of providing social support.

Family Response to Mental Illness of an Immediate Relative

Attitude related to outcome. Kreisman and Joy's review in 1974 was one of the first articles to report an extensive reivew of the literature of family response to mental illness of a relative. They reported conflicting results regarding the influence of positive family attitudes on patient outcomes. Differing attitudes toward mental illness and disclosure of feelings were two variables significantly related to relative/patient outcome. Tolerance of deviance whether defined as low expectations for work, social participation, or the extent to which families would allow a symptomatic patient at home, were only slightly related to patient relapse. Once the stress of living with a sick family member becomes too great, families tended to view hospitals as placements of choice for their relatives. However, with each additional hospitalization, deterioration of the relationship between patient and family ensued. Kreisman and Joy (1974) concluded that the relationship between family variables and successful prognosis of the patient could not be explained. The only consistent finding resulting from their extensive review of the literature was that the relationship between failure of the community to provide support and rehospitalization of the patient, is accompanied by symptom reappearance.

Issues in Providing Help for Families

Family viewed as part of the problem versus part of the solution. Dincin, Selleck, and Streicker (1978) described a relatives' group at Thresholds, a psychiatric rehabilitation agency serving a clientele whose average age is 25 years (range 16-40 years). Sixty-five percent of the patients lived with parents; others lived in hospitals, sheltered care facilities, group homes, or shared apartments. Dincin et al. (1978) reported that parents of patients were considered to be impediments rather than supports to rehabilitation efforts at Thresholds. Thus, the staff concluded that if parents' attitudes and behavior could be changed from "enemy to ally," patients' prognoses might improve. In contrast, Kint (1977) stated that the issue is not problem families, but problems for families. Dincin et al. (1978) argued that since many discharged patients return to family homes, there is an apparent need to involve the family in treatment regardless of whether they were perceived as helps or hindrances to patients. Relatives' group sessions of 1 1/2 hours duration for twelve weeks were instituted. Discussions included: promoting acceptance of schizophrenia in family members, dealing with parental guilt, behavioral management techniques, achievement expectations, problems regarding holidays, financial burdens, psychiatric medications, and

parents' rights to their own lives. Study conclusions were that the sickest member of a family generally controls family life, and a general feeling of tension and "stepping on eggshells" pervades the family atmosphere. In some cases, families fear physical attacks by the client. Parents' rights to their own lives was encouraged by assigning as "homework" to do something pleasurable for themselves. This "permission to live" spurred relatives to socialize more freely, take educational courses, and seek other outlets as diversion.

Costs to families. Thompson and Doll (1982) report that social/psychological costs to families of schizophrenic patients include: financial burden; role strains; disruption of everyday routines; requirement of supervision; and problems with neighbors. Families of schizophrenic persons, in citing emotional or subjective costs, listed feelings of embarrassment, resentment, and exclusion (Thompson & Doll, 1982). Overall, nearly 46% of the study families considered themselves as under moderate burden and 27% were under severe burden (Thompson & Doll, 1982). These findings are supported by previous stuides (Grad & Sainsbury, 1963; Hoenig & Hamilton, 1969). Thus it would appear that many families need assistance and support in coping and supportive group counseling (Atwood & Williams, 1978; Kint, 1977).

Services to families. According to Dincin et al. (1978), families need to stand firm regarding their schizophrenic relative's finances. Mentally ill family members may make financial demands and continually handing out money to them deters their financial independence (Dincin et al., 1978). In the Dincin study, medication was a topic of much discussion among families. Thresholds instructed the relatives that some patients have to continue medication indefinitely to control symptoms, as a diabetic may take insulin. Evaluation criteria for group sessions were: 1) statements by relatives, and 2) actions taken by relatives as observed by staff. At the termination of the 12 week sessions, the relatives are invited to an alumni group which meets every three weeks at Thresholds.

Therapies and educational approaches. The provision of information regarding theories of causation, outcome, symptomatology, and effective management of schizophrenia tends to decrease guilt, anger, and other emotional responses of the family and the resultant need to react by either over-protecting or attacking the patient (Anderson, Hogarty, & Reiss, 1980). Some protection of the schizophrenic may be necessary; however, excessive protection can cause additional stress for the family by increasing intensity of the home environment (Anderson et al., 1980).

An on-going therapy program conducted by Anderson

et al. (1980) was based on two goals: 1) decreased patient vulnerability to environmental stimulation through a program of maintenance chemotherapy and 2) increased stability of family environment. Stability of environment was accomplished by: decreasing anxiety of family members by increasing their knowledge about the patient's illness; and increasing their confidence in their ability to manage the illness. In turn, these goals are expected to decrease pressures between patient and family and overstimulation in family life. In Phase I, families are connected soon after hospital admission of their schizophrenic relative for purposes of establishing rapport and gaining confidence between families and mental health professionals. Phase II is the participation in a day-long, multiple-family survival skills workshop providing basic information about schizophrenia and its treatment. It is designed to decrease families' anxiety, sense of helplessness, and feelings of stigma and isolation. Phase III lasts six months to a year and involves family sessions with the patient. Sessions are held every two or three weeks and emphasize individualizing the information presented at the workshop. Once the goals for effective functioning have been attained, considering patient abilities and family structure, Phase IV presents families with two options for further treatment. Families become involved in more intensive weekly family therapy

or may elect to decrease frequency gradually to maintenance-type family sessions.

Behavioral training. Boyd, McGill, and Falloon (1981) in an ongoing program begun at the University of Southern California in 1978, emphasizes behavioral training in social and communication skills. They report that this training, combined with low maintenance doses of neuroleptics and family education regarding schizophrenia, best meets the needs of families caring for schizophrenic relatives. Behavioral assessments include the patient, individual members of the family, and the family as a group. In this two year program, educational workshops are conducted for each family. Training and problem-solving are provided in weekly sessions for three months, biweekly sessions for six months, and monthly follow-ups with the option of joining a multiple family group for up to 15 months. Goals of treatment are prevention of relapse and rehospitalization for the patient, and promotion of improved social functioning for all family members. Family sessions are carried out in the home, a strategy which is designed to convey concern and respect. Home sessions also eliminate missed appointments, which is a commonly identified problem. In addition, approaching the management of mental illness as a technical

problem reduces relatives' sense of guilt and helplessness. The skills training is accomplished by emphasizing positive feelings, reducing criticism, listening respectfully, discussing behavioral changes calmly and directly, modeling, and providing performance feedback.

Boyd et al. (1981) found that two educational sessions on the nature of schizophrenia and psychiatric medications provided a strong intervention and were cost-effective. Benefits for families were: 1) the understanding of the illness and the rationale for the use of neuroleptic medications, 2) optimism toward the treatment of schizophrenia as a chronic illness, and 3) promotion of therapeutic alliance with the entire family, and a greater possibility that the assigned therapist would be contacted more readily by the family if changes were noted in the patient's condition. Benefits for the patients were: 1) medication compliance and 2) hostility reduction toward the family member.

An on-going controlled treatment outcome study ($\bar{n}$ = 40), with a two year follow-up to assess the effectiveness of these techniques is now in progress. Subjects were randomly assigned to receive home-based family therapy or control treatment consisting of clinic-based, individual supportive psychotherapy. At the time of publication of their article in 1981, 30 families had

participated in the program for nine months. Preliminary findings suggest that family interventions were highly effective in preventing relapses and psychiatric hospitalizations. Boyd et al. (1981) posit that much is to be gained by expanding family involvement in management of schizophrenia, and that by teaching families specific skills, cost-effectiveness is increased in the community mental health system.

Lowering expressed emotion. After replicating a study by Brown, Birley, and Wing (1972), Vaughn and Leff (1976) expanded their study to describe family expressed emotion (EE) and its relationship to relapse in schizophrenic patients. Vaughn and Leff (1976) in London, designed a family intervention that would lower high expressed emotion (i.e., highly critical or emotionally involved attitudes) to low expressed emotion (i.e., effective coping methods including generally warm, supportive, and respectfully disengaged attitudes and behaviors). In a clinical trial using 12 families each in experimental and control groups, Vaughn and Leff (1976) began a series of four lectures given by therapists in homes of relatives with high expressed emotion. The lectures covered phenomena, etiology, course, and management of schizophrenia. A follow-up test was given to determine the relatives' understanding of the information provided.

They were then invited to join one of two mixed relative groups, equally divided between those with low EE, and high EE, meeting weekly for a nine month trial period. The therapist guided the discussion of practical management problems, socializing without the patient, reducing guilt and isolation, and reducing the fear of relinquishing control, with the goal of permitting a transfer of attitudes from relatives with low EE to those with high EE.

A control group of families with high EE recevied only routine medication and individual supportive sessions. After nine months the experimental group's high EE rating decreased. No relapses were noted among the patients of families involved in the experimental group. None of the patients whose relatives were in the experimental group versus five of the ten patients whose relatives were in the control group had relapsed after nine months. Vaughn and Leff (1976) summarized that although their sample was too small to generalize, this approach seemed promising.

In a follow-up study, Vaughn and Leff (1981) were able to further identify four characteristic response styles of high EE versus low EE relatives. These responses included: level of intrusiveness, emotional response, attitude toward the patient's illness, and level of

tolerance and expectations. The investigators postulated that mental health education is a basic need for all patients and families, and that the administering of solutions to problems associated with the management of schizophrenic pateints is likely to fail without the involvement of the patient and family in decisions regarding treatment process.

Multiple family groups. Dincin et al. (1978) concluded that group therapy gave relatives of patients an opportunity to discuss openly with their peers many issues that had not been expressed previously. Beels and McFarlane (1982) reviewed family treatment of schizophrenia and reported certain advantages to multiple family groups. Participants may feel more relaxed in that they can either observe or contribute as they are able. Opportunities to give advice and information are said to develop the family's sense of its own expertise. This expertise derives from an educational format and from the sense of having access to the experience of everyone in the group.

The idea of multiple family therapy groups had its beginning at Creedmoor Psychiatric Center in New York in the mid 1960s. Laquer (1964), a Creedmoor psychiatrist caring for a large number of patients, noticed that on visiting nights the families often became involved in

supportive conversations with one another. Upon inquiring, he learned that indeed, family members' sharing of concerns and information formed a supportive bond between them. Thus Laquer began having groups of family members meet with both the staff and patient/relatives to determine whether the entire network could fulfill a supportive function.

Therapists gathered patients and families involved in in-patient or out-patient care and combined multiple family groups with other treatment such as day care or crisis intervention. In the course of this group development, the therapists found themselves involved in a great deal of education, answering questions regarding diagnosis and medication, especially in the early stages of the group. Following this information-sharing phase, however, group process evolved naturally as the family members began to relate their experiences, offer each other advice, and reflect on other families' behaviors in relation to their own (Beels & McFarlane, 1982).

Social support. Hatfield (1979) has pointed out that a group structure may enhance families' sense of social support. She gathered data from 89 questionnaires and 30 follow-up interviews with family members of the Schizophrenic Association of Greater Washington, DC, a voluntary self-help organization. An assessment was

made in 1976 to determine the effect of mental illness on the family, and to examine the types of services and supports families need to deal with a mentally ill relative. Eighty-five percent of the respondents were parents. The remaining 15% were other close relatives such as spouses or siblings. Among the findings was family members' difficulties locating reliable and knowledgeable confidants.

According to Beels (1981), social support and the course of schizophrenia as an illness may positively influence each other. Bells (1981) reports that the best evidence of support affecting the course of schizophrenia comes from cross-cultural studies. Waxler (1979) reported that although the lifetime risk of schizophrenia is about the same world-wide, the course of the illness is more benign in non-industrial cultures with a village social structure. Additionally there was high social function and low rates of rehospitalization among schizophrenic patients whose families were involved in therapy in a traditional Lutheran farming community in Wisconsin. Beels postulated that family therapy may be especially effective combined with social support for the family incorporated into the local culture. The combination of a supportive family approach and a congruent religious ideology were important differences.

This supportive family approach was made available by social and occupational roles enhanced by farm life and family structure, stability in the community, and clinic staff providing exceptional continuity of patient care.

Summary

Kreisman and Joy (1974) viewed previous studies as impressionistic in nature, inconsistent, descriptive rather than explanatory, limited in scope and techniques, and did not use the types of controls that would permit clear conclusions to be drawn. Moreover, difficulties in interpretation resulted from small samples and the omission of rigorous sampling procedures. Little effort had been directed at the measurement and analysis of variables in conjunction with the relationship between patient and family. These authors posited that important information could be gained by studying both main and interacting effects. Thus, they recommended multivariate research to investigate these complex interacting variables.

Similarly, Dincin et al. (1978) reported few accounts in the literature of parents' and relatives' groups for families of clients whose diagnosis was schizophrenia. Beels and McFarlane (1982) concluded that aside from generally positive experiences and anecdotal accounts of success, multiple family group therapy for mental patients' relatives has not yet been the subject of a well designed clinical trial.

Conceptual Framework

The following propositions are deduced from the study concepts and conceptual relationships as related in the review of the literature:

1. Family members' levels of adaptation to schizophrenia in a relative varies directly with 1) opinions about mental illness; 2) perceived objective burdens associated with the condition; 3) methods of coping; and 4) perceived social support.

2. Three important sets of factors: 1) demographic data; 2) provision of information regarding the illness of schizophrenia; and 3) perceived social support provided by others experiencing similar stressors, will influence levels of adaptation.

3. Information on schizophrenia provided in a group setting, whereby social support may be provided by others experiencing similar stressors, may affect coping methods of family members.

Research Questions

Question one. Will the family members of schizophrenics who receive education regarding the illness of schizophrenia in a group setting report a greater decrease in objective burden than those who receive information via a booklet?

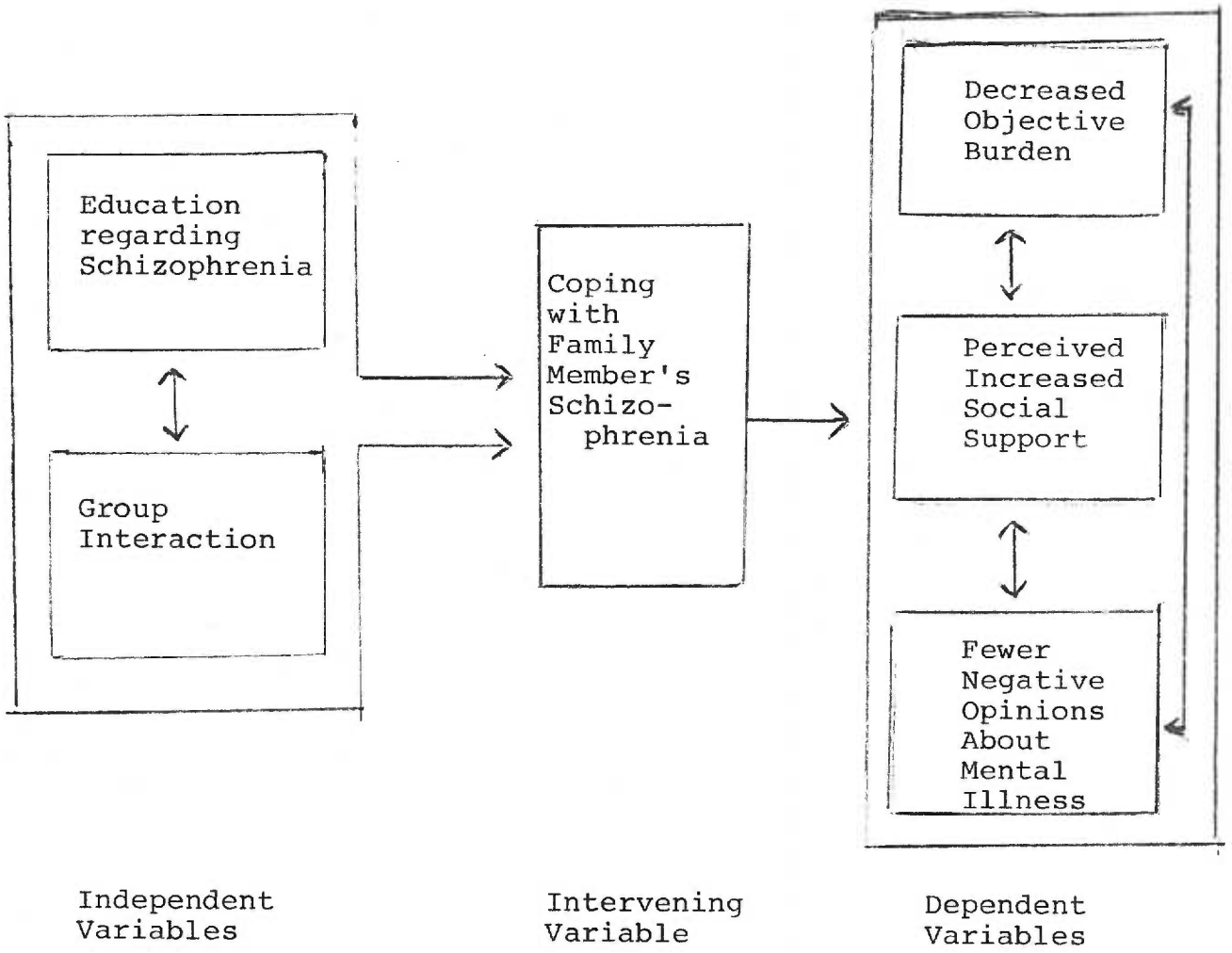
Question two. Will the family members of

schizophrenics who receive education regarding the illness of schizophrenia in a group setting report fewer negative opinions about mental illness than those who receive information via a booklet?

Question three. Will the family members of schizophrenics who receive education regarding the illness of schizophrenia in a group setting report a greater increase in perceived social support than those who receive information via a booklet?

The study framework is diagrammed in Figure 1.

Figure 1. Diagram of Study Framework



Chapter II

Methods

Design

A nonequivalent control group design was selected for this study because of the design's appropriateness for field settings.

Sample and Setting

A Veterans' Administration Mental Health Out-patient Clinic (VAMHOPC) located in a major northwestern city was the study setting. The VAMHOPC serves a catchment population of veterans of the United States military service within a fifty mile radius of the clinic. The experimental group subjects were obtained from clinic staff referral for the purpose of providing information about schizophrenia in a group setting. The group was co-led by a clinical nurse specialist or a clinic staff psychologist, and temporarily assigned student clinical nurse specialist in psychiatric/mental health nursing. The group sessions were held in the clinic for 1 1/2 hours one evening per week for five consecutive weeks. The experimental group was comprised of six subjects: parents, spouses, and an adult sibling of schizophrenic patients currently undergoing treatment at the clinic.

The control group was composed of eight subjects: parents and one adult sibling of patients diagnosed as having schizophrenia. Subjects were referred by two

community mental health out-patient agencies located in the same metropolitan area.

The patients consented to having the clinic staff contact their family members before the invitation to join the group was extended to relatives. The family members were mailed letters that explained the purpose of the study and were informed that they would be contacted by phone to invite their participation. The anticipated number of participants was between eight and fifteen persons in each group.

Although subjects were not randomly assigned to the experimental and control groups, the groups were similar on demographic variables (see Table 1 for a summary of the variables). The mean ages of both groups was 44 years. The mean length of time married was also comparable: 18.4 years for the experimental group and 17.3 years for the control group. The number of schizophrenic family members living with relatives was three out of six (50%) for the experimental group and one out of eight (12%) for the control group. Schizophrenic patients not living with relatives had the same mean scores on the contact variable: one time per week. Gender differences were as follows: The experimental group was comprised of six females (three mothers, two wives, and one sister) compared to five females (all mothers) and three males

Table 1

Demographic Data on the Two Study Groups

Variable	Experimental Group (n = 6)	Control Group (n = 8)
Age Range in Years	20-60+	30-60+
Mean Age	44.1	44.8
Gender		
Female	6 (100)	5 (62.5)
Male	---	3 (37.5)
Marital Status		
Married	5 (83.3)	7 (87.5)
Divorced	1 (16.7)	1 (12.5)
Range in Years Married	0-35	0-38
Mean Number of Years Married	18.5	17.3
Range in Years of Education	12-15	10-19
Mean Number of Years Education	13	15
Occupation		
Housewife	2 (33.3)	2 (25)
Self-employed	1 (16.7)	2 (25)
Skilled Labor	3 (50)	3 (37.5)
Professional	---	1 (12.5)
Relationship to Clinic Patient		
Mother	3 (50)	5 (62.5)
Father	---	2 (25)
Wife	2 (33.3)	---
Sibling	1 (16.7)	1 (12.5)
Living Arrangement of Schizophrenic Relative		
Lives with Family Member	3 (50)	1 (12.5)
Lives Elsewhere	3 (50)	7 (87.5)
Range of Average Contact	Every day - one time per month	Every day - one time per month
Mean Contact	One time per week	One time per week

Note. Numbers in parentheses indicate percentages.

(two fathers and one brother) in the control group. The mean years of education was 13 for the experimental group and 15 for the control group. The mean number of hospitalizations of the schizophrenic family member was four for the experimental group and six for the control group.

Dependent, Independent, and Intervening Variables

The dependent variables were objective burden; perceived social support, and opinions about mental illness among the family members of schizophrenics. Objective burden was measured by the Index of Objective Burden (Thompson & Doll, 1982). Perceived social support was measured using Coppel's (1980) Index of Social Support. Wilson and Kneisl's (1979) Beliefs about Mental Illness Scale was used to measure family members' opinions about mental illness. (See Appendixes A through C for these instruments.)

The intervening variable was coping with a family member's schizophrenia. Coping was measured by the Ways of Coping Scale (Jalowiec & Powers, 1981) (see Appendix D).

The independent variables were education about schizophrenia and group interaction.

Data Collection

Dependent Variables

Index of Social Support. Coppel's Index measures

both objective (size of and contact with network), and subjective quality of social supports. The size of network was measured by items asking how many confidants, friends, family members, and social groups respondents were involved with currently. The contact with persons in one's network was measured by asking how many times, in an average week, respondents have contact with persons in their networks. Coppel suggests one score is computed to determine size of network (number of friends, family, etc.) and another score to represent the average weekly contact with these four network components. Coefficient alpha was 0.54 for the size of network scale and 0.41 for the contact with network scale. (See Appendix A.)

Coppel's scale measuring perceived quality of social support was based on concepts of social support posited by Caplan (1974) and Cobb (1976); that is aid, affirmation, and affection. Participants rate each of 15 self-descriptive statements related to their social supports on a five-point scale ranging from "Not at all like me" to "Very much like me" (see Appendix A). A total score was obtained for analysis by adding the value circled adjacent to each item.

Based on normative data gathered on 170 undergraduate students, the 15 item scale evolved from factor analysis of an original pool of 40 statements. This

social support scale demonstrated high internal consistency (coefficient α = 0.89) and a test-retest reliability coefficient of r = 0.82 over a two week interval (n = 90).

Index of Objective Burden. Objective burden was defined in terms of disruptions schizophrenic clients have on family life. The five indicators of objective burden established by Thompson and Doll (1982) were: 1) financial burden; 2) role strains due to relatives having to neglect their responsibilities to other family members; 3) interruptions in the family's normal way of life (e.g., eating and sleeping time); 4) supervision that would otherwise be unnecessary; and 5) problems with neighbors. Objective burden was measured by both quantity and quality of the five consequences. Presence of burden was established by Cronbach's α = 0.67. Extent of burden is scored from zero to five, with zero indicating "no burden," one or two indicating "moderate burden," and three to five indicating "severe burden" (see Appendix B).

Beliefs About Mental Illness. This 25-item scale developed by Wilson and Kneisl (1979) is a modification of Cohen and Streuning's (1962) 70-item scale, measuring attitudes toward the causes and treatments of mental illness. Five attitude orientations are represented in the 25 items: authoritarianism; benevolence; mental

hygiene ideation; social restrictiveness; and interpersonal etiology. Authoritarianism items (Scale I, 1-5) reflect a view of the mentally ill as an inferior class requiring coercive handling. Benevolence (Scale II, 6-10) reveals a kindly paternalistic view of patients, with emphasis on religion and humanism rather than science. Mental hygiene ideation (Scale III, 11-15) reflects an orientation that embodies the tenets of modern mental health professionals and the mental hygiene movement. The key belief in social restrictiveness (Scale IV, 16-20) is that mentally ill people are a threat to society, particularly the family, therefore must be restricted in their functioning. Interpersonal etiology items (Scale V, 21-25) reflect the belief that mental illness arises from interpersonal experience, especially deprivation of parental love during childhood. Each scale is scored separately with each question rated on a scale of five (strongly agree) to zero (strongly disagree). Total scores for each scale can range from a high of 25 to a low of zero (see Appendix C). Validity and reliability were not reported by Wilson and Kneisl.

Independent Variables

Education regarding schizophrenia. Family members of schizophrenics were instructed in a variety of specific aspects of understanding the illness of schizophrenia.

These included a description of the course of the illness, symptoms, theories of etiology, medications, and side effects. Relatives of schizophrenics were also instructed in management of specific problematic behaviors exhibited by their schizophrenic family member, management of their daily activities and management of their environment. Family members of schizophrenics were encouraged to take recreation time for themselves (see Appendix E for Group Sessions Format). Both groups received the same information about schizophrenia.

Group interaction. The experimental group met in group meetings for the provision of information regarding schizophrenia. The control group received similar information in a booklet presented to them individually (see Appendix E for the educational booklet).

Intervening Variable

Ways of Coping Scale. Forty coping strategies were compiled following an exhaustive review of the literature by Jalowiec and Powers. It is an improvement over the Folkman and Lazarus Ways of Coping Scale because the Folkman and Lazarus checklist is binary. A Likert-type format with a five-point scale was developed so that subjects could rate each coping method according to degree of use. The end points of the scale are

represented by "never" and "always." Overall coping scores are obtained by summing ratings of all coping methods. Sub-scale scores can also be obtained. Fiteen items measure cognitive strategies while 25 items measure effective coping strategies (see Appendix D).

Face and construct validity of the Ways of Coping Scale were based on a review of articles in the field of coping and adaptation (Coelho, Hamburg, & Adams, 1974; Haan, 1977; Hamburg, 1974; Hamburg & Adams, 1967; Lazarus, 1976; Mechanic, 1978; Meninger, Maymon, & Pruyser, 1963; Moos, 1976; and White, 1974).

Test-retest method was used to establish reliability of the coping scale. A pilot study was conducted using 28 adult volunteers who were retested after approximately two weeks. Spearman's rank ordering of the test-retest data indicated that the instrument was reliable ($r_s = 0.79$, $p \leq .001$.

Procedure

The study procedure included four steps: 1) recruitment of subjects, 2) administration of pre-test to subjects, 3) administration of research treatment to experimental group, and 4) administration of post-tests to the experimental and control groups.

Step 1. After initial contact by letter, a phone call was made to elicit study participation and to

schedule appointments with family members for a personal pre-group interview. The interview did not include the relative diagnosed as schizophrenic. Optional interview sites were offered at the family member's home or the out-patient clinic. All but one pre-group interview was conducted in participants' homes and all post-group interviews were in their homes.

The control group was contacted in the same manner as the experimental group. To control for group participation, the same format providing the same educational information was presented to them at the conclusion of the interview. The control group participants were encouraged to read the booklet so questions could be answered following the conclusion of the post-test.

Step 2. The pre-intervention interview included the signing of consent forms (see Appendix G), collection of demographic data (see Appendix H), and the administration of study instruments.

Step 3. The information plus discussion group, which was the study "treatment" was convened for 1 1/2 hours on a weekly basis for a five week period.

Step 4. At the completion of the five weekly sessions, interviews with participating family members from both study groups were conducted. The post-test

interviews followed the same structured format as the pre-test interviews.

Analysis

The student's t-test was used to measure the differences between the scores of the group means of the experimental and control groups on the pre and post-test measures.

Chapter III

Results and Discussion

The t-tests conducted to test between group mean score differences on the Index of Objective Burden, Index of Social Support, and Beliefs about Mental Illness Scale were all non-significant. These outcomes may be due primarily to the small sample sizes of both study groups. Due to the small and non-randomized samples, any statements regarding the results must be conjectural.

Findings Regarding Research Question One

Research question one was: Will family members of schizophrenics who receive education about schizophrenia in a group setting report a decrease in objective burden when compared to family members who receive information via a booklet?

Objective Burden. The mean scores on the Objective Burden Scale decreased slightly between pretest and posttest measurement for the experimental group while scores remained the same at both testing periods for the control group. Both groups had the same pretest mean score of 1.7, but only the experimental group mean of 1.3 was lower after intervention, indicating less perceived objective burden. Fifty percent of the subjects in the experimental group reported moderate burden and 33% severe burden. The remaining subjects in both groups

reported no perceived burden.

T-tests were conducted to examine the group mean scores on the Index of Objective Burden (see Table 2 for a summary of this measure). An α of <.05 was set as the critical value for t. The difference between pretest and posttest mean scores for the experimental group was $t = 1.58$ and for controls, $t = 0.00$. The difference between groups on the pretest mean scores was $t = -0.09$ and on posttest mean scores was $t = -0.44$. All t-tests were non-significant.

Thompson and Doll (1982) reported that of those family care-givers interviewed ($n = 125$), 46% considered themselves to be under moderate burden and 27% were under severe burden. The level of objective burden among experimental group participants was found to be consistent with the studies of Thompson and Doll (1982); Grad and Sainsbury (1963); and Hoenig and Hamilton (1969). However, the perceived objective burden among control group subjects was higher than those reported in other studies. Greater objective burden may be due to the increased mean number of hospitalizations among schizophrenic relatives in the control group, even though fewer schizophrenic relatives in the control group lived with their family member. Thus living arrangements explain only part of the objective burden that family

Table 2

Means, Standard Deviations, and t Values on The Objective Burden Scale

	Experimental Group (n = 6)		t Value Within Group Differences	Control Group (n = 8)		t Value Within Group Differences	t Value Between Group Differences
	M	SD		M	SD		
pre	1.7	(1.5)		1.7	(1.7)		-0.09
			1.58			0.00	
post	1.3	(1.4)		1.7	(2.2)		-0.41

Note. Pre and post indicate pretest and posttest measurement times.

$p \leq 0.05$ two-tailed test

members experience.

As stated above, no conclusions can be drawn from the results of this study. The dangers of a small and non-randomized samples include the potential for sampling errors which cannot be controlled. Moreover, the scale contains only five items which may not be a sufficient number to discriminate between two groups of similar study subjects.

Findings Regarding Research Question Two

Research question two was: Will family members of schizophrenics who receive education about schizophrenia in a group setting report fewer negative opinions about mental illness compared to family members who receive information via a booklet?

Beliefs About Mental Illness (BMI). Mean scores varied among the study subjects on all five attitude orientations on the BMI scale. Total scores on each subscale can range between a high of 25 (strongly agree) to a low of 0 (strongly disagree). (See Table 3 for a summary of all BMI measures).

Authoritarianism Subscale. Authoritarianism ideally should have decreased but was found to increase for both groups between pretest and posttest. The experimental group mean scores were 10.3 on pretest and 11.0 on experimental group was $t = -0.58$ and within the control

Table 3

Means, Standard Deviations, and t Values on The Beliefs About Mental Illness Scale

	Experimental Group (n = 6)		t Value Within Group Differences	Control Group (n = 8)		t Value Within Group Differences	t Value Between Group Differences
	M	SD		M	SD		
Authoritarianism							
pre	10.3	(6.6)		5.0	(5.5)		1.64
			-0.58			-3.25	
post	11.0	(5.9)		7.7	(6.5)		1.07
Benevolence							
pre	15.5	(3.4)		16.4	(3.5)		-0.47
			0.66			-0.57	
post	14.5	(4.1)		16.7	(3.1)		-1.17
Mental Hygiene Ideation							
pre	14.5	(4.1)		18.4	(3.2)		-1.97
			0.65			-0.34	
post	17.3	(2.1)		18.6	(3.6)		-1.25
Social Restrictiveness							
pre	8.8	(4.3)		9.2	(4.2)		-0.18
			-1.54			0.40	
post	10.5	(3.9)		8.5	(3.2)		1.04
Interpersonal Etiology							
pre	6.7	(4.7)		7.2	(4.9)		-0.22
			0.15			-0.26	
post	6.5	(3.0)		7.5	(5.6)		-0.39

Note. Pre and post indicate pretest and posttest measurement times.

$p \leq .05$ two-tailed test

group, t = -3.25. The difference between groups on the pretest mean was t = 1.64 and t = 1.07 between group posttests. All t-tests were non-significant.

Benevolence Subscale. Benevolence mean scores decreased slightly for the experimental group from 15.5 on pretest to 14.5 on posttest. Control group mean scores were unchanged at 16.4 on pretest and 16.7 on posttest. Differences between group mean scores on pre and posttests for the experimental group was t = 0.66, and for controls t = -0.57. Between group differences on pretest mean scores was t = -0.47, and between group posttests t = -1.17. All t-tests were non-significant.

Mental Hygiene Ideation Subscale (MHI). MHI mean scores increased for the experimental group from 14.5 on pretest to 17.3 on posttest. Mean scores for the control group were unchanged at 18.4 on pretest and 18.6 on posttest. The difference between the pretest and posttest mean scores for the experimental group was t = 0.65 and for controls it was t = -0.34. Pretest mean score differences between groups was t = -1.97 and posttest mean differences between groups was t = -1.25. All t-tests were non-significant.

Social Restrictiveness Subscale. Mean scores on social restrictiveness increased from a pretest mean score of 8.8 to a posttest mean score of 10.5 for the

experimental group. Mean scores for the control group decreased slightly from 9.2 on pretest to 8.5 on posttest. The difference between the pre andposttest means within the experimental group was $t = -1.54$, and within the control group, $t = 0.40$. Differences between groups on pretests was $t = -0.18$ and on posttests was $t = 1.04$. All t-tests were non-significant.

Interpersonal Etiology Subscale. Mean scores on interpersonal etiology were unchanged on pretest and posttest for both groups. Pretest mean score for the experimental group was 6.7 and 6.5 on posttest. Control group mean scores were 7.2 on pretest, and 7.5 on posttest. The difference between the pretest and posttest mean scores for the experimental group was $t = 0.15$ and for the control group it was $t = -0.26$. The between group mean difference on the pretest was $t = -0.22$, and on the posttest $t = -0.39$. All t-tests were non-significant.

The desired goal in the last three attitude orientations of the BMI Scale, which was not achieved, was to report an increase in mean scores. This goal was not reached. Due to the short span of time between pretest and posttest, it might be that opinions regarding mental illness are difficult to change or to ascertain in the few weeks time period involved in this study, and coincidental environmental influences during this time

period are difficult to control. Kreisman and Joy (1974) reported that differing attitudes toward mental illness and disclosure of feelings were two variables significantly related to family relationship outcomes. Due to the varied results on the BMI subscales in this study, comparative results are unsupported. Moreover, if differences occurred, they may not be detected, since small samples reduce statistical power. Each subscale of the BMI consisted of only five items. The likelihood of detecting group differences is less likely when there are so few items.

Finding Regarding Research Question Three

Research question three was: Will family members of schizophrenics who receive education about schizophrenia in a group setting report a greater increase in perceived social support than family members who receive information from a booklet?

Social Support. Mean scores on the Social Support Scale were similar for both the experimental and control groups on the posttest. The possible range of scores was from 75 indicating high perceived social support, to 15 indicating low perceived social support. The experimental group reported an increase in perceived social support. The pretest mean score was 52.0 whereas the posttest mean score was 57.5. The control pretest mean was 58.9, whereas the posttest mean was 58.0. Both

experimental and control group posttest means were similar. The differences between the pretest and posttest mean scores for the experimental group was $t = -1.05$ and for the control group it was $t = 0.50$. The between group difference on the pretest mean score was $t = -1.26$ and $t = -0.08$ between posttests. All t-test were non-significant. (See Table 4 for a summary of this measure).

The results may indicate that the group interaction intervention increased perceived social support, the desired outcome. Such findings are consistent with reports by Vaughn and Leff (1976); Dincin et al. (1978); Beels and McFarlane (1982); Hatfield (1979); and Beels (1981) as to the benefits of group interaction in the provision of information as cited in the review of the literature. The measurement of social support may have been problematic even though instrument validity and reliability are high. Study subjects experienced more difficulty responding to the social support items than to the other study measures.

Also to be taken into consideration is the possibility that the personal contact of the investigator, especially in a home setting, vicariously provided some measure of social support. Perhaps a more pure research study could be obtained utilizing mailed questionnaires, minimizing the personal contact. However, risks are also inherent

Table 4

Means, Standard Deviations, and t Values on

The Perceived Social Support Scale

	Experimental Group (n = 6)		t Value Within Group Differences	Control Group (n = 8)		t Value Within Group Differences	t Value Between Group Differences
	M	SD		M	SD		
pre	52.0	(14.0)	-1.05	58.9	(5.9)	0.50	-1.26
post	57.5	(15.4)		58.0	(6.8)		-0.08

Note. Pre and post indicate pretest and posttest measurement times.

$p \leq 0.05$ two-tailed test

through mailing materials in that there may be a low rate of return on the questionnaires, or there may be possible contamination through communication with other family members in the household. Again, no conclusions can be drawn.

Other Measures

Ways of coping. No research question or hypothesis was developed to measure coping mechanisms. Rather, the use of a scale was for exploratory purposes. Coping was measured by the Ways of Coping Scale which can be divided into cognitive and affective subscales (see Table 5 for a summary of this measure).

Cognitive subscale. The range of possible scores is from a high of 75 to a low of 15 on the cognitive subscale. Mean scores for the experimental group were 52.3 on the pretest and 51.3 on posttest. For the control group, the pretest mean score was 53.4 and the posttest mean score was 55.2. The experimental group difference between the pretest and posttest mean scores was $t = 0.28$ and for the control group it was $t = -1.03$. Differences between groups on pretest means was $t = -0.29$ and between posttest means was $t = -0.99$. All t-tests were non-significant.

Affectable subscale. The range of possible scores on the affective subscale was from a high score of 125,

Table 5

Means, Standard Deviations, and t Values on The Ways of Coping Scale

	Experimental Group (n = 6)		t Value Within Group Differences	Control Group (n = 8)		t Value Within Group Differences	t Value Between Group Differences
	M	SD		M	SD		
Coping - Cognitive							
pre	52.3	(9.5)	0.28	53.4	(5.4)	-1.03	-0.29
post	51.3	(7.8)		55.2	(6.9)		-0.99
Affective							
pre	61.5	(13.5)	-0.75	62.2	(9.0)	0.32	-0.13
post	64.2	(8.6)		61.7	(9.4)		0.49

Note. Pre and post indicate pretest and posttest measurement times

p - 0.05 two-tailed

to a low of 25. Mean scores for the experimental group were 61.5 on the pretest and 64.2 on the posttest. For the control group, the pretest mean score was 62.2, and the posttest mean score was 61.7. Within group differences on pretest and posttest mean scores was $\underline{6} = -0.75$ for the experimental group and $\underline{t} = 0.32$ for the control group. The differences between groups on pretest mean was $\underline{t} = -0.13$ and between posttests, $\underline{t} = 0.49$. All $\underline{t}$-tests were non-significant.

Both experimental and control groups scored similarly on both subscales. The scoring indicated that both groups used more cognitive coping methods more frequently than affective methods. In summary, the results of these measures must be viewed with caution due to the small sample size. No published studies of schizophrenic families have reported the use of a standardized coping scale, thus no comparisons can be made. Additionally, the subjects of both the experimental and control groups were a convenience sample, rather than randomly assigned. The non-significance of the $\underline{t}$-test values in all the measures may be related to these factors.

Composite Case Studies

The statistical similarities of the two study groups may be due to sample size. Therefore composite case studies were written to describe the study groups.

Experimental group. Similarities were noted within the experimental group as all potential participants welcomed the investigator to the pre-study interview and stated their interest in attending the group sessions. All participants became somewhat flustered during the administration of the social support scale with one family member becoming increasingly frustrated. One mother, relating to the questionnaires, commented on completion that "They really make you think about yourself."

During the group sessions, all six participants asked questions with four participating more eagerly. All shared experiences with each other regarding their schizophrenic relatives. Several mothers whose sons resided with them commented that although they loved their sons and were constantly concerned regarding their welfare, the chronicity of schizophrenia with its "ups" and "downs" was physically and emotionally draining. One mother reported that life was much easier since her son had moved into a rooming house, but found that she still had to press him on matters of personal hygiene, laundering his clothes, and budgeting his funds. He very often requested extra money to tide him over till next "check" arrived. "I find it a never-ending struggle and it is discouraging," she told the group. Following the fourth group session, several members of the group

began to linger to talk outside the clinic, indicating bonding was taking place among the group members.

At the completion of the five group sessions, participants unanimously expressed comfort in knowing that they were not alone with their problems. The majority seemed grateful for additional information regarding community support programs and were eager for the additional reading list provided.

The wives in the group related that they felt they had similar problems as other group members, however, they experienced unique problems as wives and shared their perceptions. Wives expressed a wish to have a similar group exclusively for wives of schizophrenics. During the course of the group sessions, the wives had shared that living with a schizophrenic husband required the wife to be the principal decision-maker and bear the majority of responsibility in a marriage. Additionally, if there were children, the wives related how difficult it was to explain the father's illness. The children in turn were required to adjust to the chronicity of the course of schizophrenia and possible instability of the household. Wives shared that the schizophrenic father is unable to fulfill the necessary perceived role model of father for the children. This can lead to problems in the psychological development of the children. One of

the wives reported that she was experiencing behavior problems with her son.

Two experimental group members said they would not care to become involved in continued meetings with the sole purpose of socialization without an educational format. The remaining four members of the group requested additional intermittent meetings for the support they derived from the group. Several members of the experimental group expressed a wish to exchange phone numbers and to be able to contact one another as desired following the final group session. Only one member of the group was reluctant to share contact information and was not pressed to do so. Thus, group contact appeared to meet some of the family members' needs.

At the time of the post-group interviews, one wife related that she had been somewhat uncomfortable during the group sessions as she continued to find it difficult to accept the chronicity of her husband's diagnosis of schizophrenia, even after five hospitalizations. She reported, "I married my husband because I needed his strength and I wanted to be able to rely on him, and now I have to be the strength with no one to lean on." She further stated that she found herself becoming increasingly depressed with her feelings, which in turn affected her children. She related that she had sought counseling at a nearby mental health clinic and that

recently her son had required initiation of therapy for depression also, due to his father's illness.

During the post-group interviews, the experimental group participants again expressed appreciation for the opportunity to participate in the educational sessions. Five of the group members questioned whether there might be the possibility of follow-up sessions at some time in the future, as they believed the meetings were of such benefit to them.

Control group. As with the experimental group, the investigator was graciously invited into the homes of the potential control group for the pre- and post-test interviews. This group also experienced some difficulty answering items on the social support scale. Interest in having the opportunity to participate in a study for research purposes was also verbalized by the control group participants. The informational booklet was presented to each subject at the completion of the pre-group interview.

As with the experimental group, the control subjects were more relaxed in the presence of the investigator during the post-test interviews. After the administration of the instruments, the subjects all freely asked questions either prompted by the booklet or by some issue that was concerning them. They received the additional list of reading material as eagerly as the experimental

group. Two members of the control group were familiar with some of the suggested additional reading material, having searched out reading of their own prior to involvement in this study. All participants in the control group stated that they wished they had had some information as was in the booklet available when their schizophrenic relative was first diagnosed, as they would have been even more benefitted than now. Five participants in this group stated that they had shared the informational booklet with other members in their families.

One father of a schizophrenic son by his first marriage related that he had remarried a woman with two daughters. His son visited in his home on weekends. The schizophrenic son's reception usually was exceptionally cool with much tension in the household during these visits. After reading the informational booklet provided in this study, he stated that he had shared the booklet with his wife and step-daughters. He continued that he had, with much relief, noted a change in the home atmosphere during his son's visit the following weekend. The father reported that although the son's reception was not what could be called warm, he was tolerated better, and his wife and step-daughters had made increased attempts to communicate with his son.

The investigator had opportunity for only two contacts

with the control group participants; i.e., at the time of pre- and post-group interviews, as compared to seven contacts; i.e., pre- and post-inteviews plus five group sessions with the experimental group. Due to the more limited contact, there was less opportunity for observation to gather the depth of information as compared to that provided by the experimental group.

In conclusion, both information and group interaction were positive experiences for the experimental group. The opportunity for group interaction provided the experimental group with social support in addition to information. The booklet alone, providing information, afforded some perceived benefit for the control group participants, and permitted a sharing and increased understanding within families.

Chapter IV

Nursing Implications, Limitations, Recommendations

Summary

The literature reports it is now estimated that at least two-thirds of the mentally ill population of patients return to their family homes following hospitalization. Family members have a need to be prepared to deal with the adjustments involved, as the problems created in having a schizophrenic relative in the family can be overwhelming. The purpose of this study was to explore methods of assisting family members to better cope with the problem generated through involvement with their schizophrenic relative. Education regarding the illness of schizophrenia was provided to family members of schizophrenics in a group setting or individually via a booklet.

A convenience sample of six family members of schizophrenics referred by the staff of a VAMHOPC in the community comprised the experimental group. A control group was comprised of eight family members of schizophrenics referred by the staffs from two community mental health out-patient clinics. The experimental group received education regarding schizophrenia, including theories of etiology, course of the illness, behavioral management, medications and side effects,

management of the environment, and community resources in five 1 1/2 hour weekly sessions at the VAMHOPC. The control group was provided with the same information individually via a booklet. Data was collected from both groups before and after interventions utilizing pre and post-tests.

The dependent variables were: perceived social support; objective burden; and opinions about mental illness. The intervening variable was coping with a family member's schizophrenia. Independent variables were: education regarding schizophrenia and group interaction.

Perceived social support was measured by the Index of Social Support. Objective burden was tested by the Index of Objective Burden. Opinions about mental illness was measured by the Beliefs about Mental Illness Scale. Coping with a family member's schizophrenia was measured by the Ways of Coping Scale.

The data were analyzed using t-tests to measure differences between mean scores on each instrument and instrument sub-scales. All t-tests for both groups on pre tests and post tests were non-significant. If differences existed, they may not have been detected due to the small sample size. Any statements made regarding the results must be viewed as conjectural due to the small,

non-randomized sample. However, the study suggests that family members of schizophrenics who receive education regarding the illness of schizophrenia in a group setting report a greater increase in perceived social support and a greater decrease in perceived objective burden than those who receive information via a booklet. It cannot be speculated that there were fewer negative opinions about mental illness following interventions for either the experimental or control groups because the group mean scores were so varied.

Nursing Implications

In general, the family members in the experimental group seemed even more receptive to information and eager to learn than the control group subjects. This may have been due to the stimulation of group interaction, which this investigator was able to view during the period of the five group sessions. The advantage of receiving response to a question at the time of interest without having to wait, as during group sessions, may have been more conducive to information-seeking than having a question arise during the reading of a booklet in the home and having to wait several weeks till the time of the post-test interview to receive a response. For nurses then, it would be important to provide information to family members regarding involvement with a schizophrenic

relative at the time of perceived need for information. The group interaction can provide a source of initiation into continued bonding for an expanded support system for family members.

The advantage of an informational booklet would be the availability of an informational resource for continued reference and to provide a source of shared information to others within the family environment, thus possibly further enhancing the circle of support through better understanding of the illness of schizophrenia. There may be advantages to the provision of information in a group setting. However, it is also time-consuming and requires additional staff commitment in a community mental health setting; which may not be feasible. Booklets are low cost and could be readily available. Ideally, nurses could provide booklets initially for provision of information and follow up with group meetings to provide an environment for interaction and social support.

There were perceived benefits from the nursing aspect, in conducting the pretest and posttest interviews in the home. It was very helpful from the standpoint of evaluating the environment and observing the participant family member in relaxed surroundings, i.e., as compared to an office. A nurse's very presence in home visits can impart a sense of caring and provide a measure of social

support. This assessment information can be used to modify or individualize patient care plans. In attempting to reduce the stress of the patient and families, stress reduction interventions are based on assessments of home environment.

Provision of information is a role well-suited for nurses as they not only can project a caring attitude, but possess a clinical knowledge of psychiatric medications, their uses and side effects, and can frequently maintain a close association with schizophrenic patients and their family members to provide continued support.

Limitations

Although numerous articles have been written on the problems of families of schizophrenics, few actual research studies have been conducted. The small sample sizes of both study groups and the use of a convenience sample must be viewed as limitations in this study.

The difficulty in obtaining sufficient numbers of study subjects was not anticipated. Three community mental health out-patient agencies were contacted to obtain subjects for the control group. Several factors may account for this problem. The frequency of hospitalizations may result in changes in the relationship between the patient and family. Family members may perceive objective burden but not know how to seek help. Any results must be viewed

cautiously due to the small sample size. There may be some cause for speculation as to whether the control group's higher education level might have any influence on the continued contact between family members and schizophrenic relatives despite the fact that they reported more hospitalizations.

Participation in a group may be influenced by the season, day of the week or the time of the day the group meetings are scheduled. A day time meeting would exclude day workers. Evening hours would exclude those working into early evening and those taking evening classes. Transportation can be a problem in that bus riders may be apprehensive regarding riding the bus after dark. Holidays occurring within the period of a study may influence participants, as these special occasions can be times of increased family tensions. It may be advisable to plan a study so as to avoid holiday times and to permit consistent sampling.

Recommendations for Future Study

Families of schizophrenics appear to have been neglected by mental health caregivers. There is a need to provide information regarding the illness of schizophrenia, preferably during the time of the ill family member's first hospitalization or shortly thereafter (taking into consideration the DSM III criteria that history of

symptoms must be present for six months prior to diagnosis of schizophrenia). The development of educational interventions by nurses could be an important service addition for families and their schizophrenic relatives.

There is a need for repeated studies on this topic if indeed the problem of obtaining large sample sizes is consistent. The particular measurement tools used in this study: Index of Objective Burden; Index of Social Support; Beliefs About Mental Illness Scale; and Ways of Coping Scale, might be considered useful instruments for future studies judged by the test-retest scores for both groups. A study design utilizing three or four groups to measure: 1) provision of information in a group setting; 2) provision of information via a booklet; 3) group meetings without provision of information; and 4) a control group with no contact could result in a more powerful study.

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APPENDICES

APPENDIX A

INDEX OF SOCIAL SUPPORT

COPPEL INDEX OF SOCIAL SUPPORT

Directions: People can have many different kinds of feelings about themselves and their relationships with other people in their lives. Below are some sentences which describe certain feelings that many people have. Read each statement carefully and think about yourself and your life currently. Each statement will either be 1) NOT like you, 2) A LITTLE like you, 3) SOMEWHAT like you, 4) FAIRLY MUCH like you, 5) VERY MUCH like you. Circle the number that indicates how you feel. There are no right or wrong answers. Be as accurate and honest as you can about your feelings.

	Not at all like me	A little like me	Some-what like me	Fairly much like me	Very much like me
1. People have been there when I've needed them.	1	2	3	4	5
2. When I'm distressed, there are people who I can communicate with.	1	2	3	4	5
3. There are people in my life who let me know if I'm doing something right or not.	1	2	3	4	5
4. There are people who serve as good examples for me in dealing with problems.	1	2	3	4	5
5. There are people to whom I give and from whom I receive support during difficult periods.	1	2	3	4	5
6. I know what people expect of me.	1	2	3	4	5
7. When I'm distressed, there are people who treat me in a personal manner.	1	2	3	4	5

	Not at all like me	A little like me	Some-what like me	Fairly much like me	Very much like me
8. There are people to whom I can go who can provide me with some ideas or answers to dealing with my problems.	1	2	3	4	5
9. I depend on my family and friends to help me handle stressful situations.	1	2	3	4	5
10. Family and/or friends help me approach difficult situations in a thoughtful rather than impul-sive way.	1	2	3	4	5
11. There are people in my life who have the same or similar prob-lems as I do, and with whom I can discuss things.	1	2	3	4	5
12. There are people in my life who I feel safe with.	1	2	3	4	5
13. The people around me give me confidence in my ability to cope with stressful events in my life.	1	2	3	4	5
14. I have a group (or groups) in which I feel I belong.	1	2	3	4	5
15. The contact I have with my family and friends has a strong positive influence on my moods.	1	2	3	4	5

A total score was obtained for analysis by adding the value circled adjacent to each item.

PLEASE CIRCLE THE RESPONSE WHICH INDICATES YOUR CURRENT SITUATION. WHILE YOUR SOCIAL CONTACTS MAY VARY FROM WEEK TO WEEK, PLEASE TRY AND INDICATE THE AVERAGE NUMBER OF TOTAL CONTACTS PER WEEK.

*1. How many confidants, or people who you can talk to about very personal matters, do you presently have? 0 1 2 3 4 5 6+

In total, how often do you have contact with them in the average week?

0 1 2 3 4 5 6 7 8+ **

*2. How many friends, or people who you feel close to (other than confidants and acquaintances), do you presently have?

0 1 2 3 4 5 6 7 8 9 10+

In total, how many times a week do you see friends?

0 1 2 3 4 5 6 7 8+**

*3. How many relatives do you presently have that you feel close to?

0 1 2 3 4 5 6 7 8+

In total, how many times a week do you see, call, or correspond with relatives?

0 1 2 3 4 5 6 7 8+ **

4. How many times a week do you meet with a social group, club, or organization? (Circle one)

0 1 2 3 4 5 6 7 8+ **

* How many groups are you presently involved with?

0 1 2 3 4 5 6+

5. Are you presently seeing a helping professional? Yes No

If so, how many times a week? 0 1 2 3 4 5 6+

6. How much weekly involvement or contact do you have with religious organizations or religious leaders (clergy, rabbi, etc.)? (Circle one)

None 1 2 3 4 5 6 7 8+

Note. * indicates item was used to form 4-item scale, 'Size of Network'
** indicates item was used to form 4-item scale, 'Contact with Network'.

Below is a list of persons that generally make up one's social network.

	How many persons in each category have you lost support from during the past year?	How many persons in each category do you have on-going difficulty with in your relationship?	How many persons in each category expect compensation in return for support given to you?
Spouse or partner			
Family members			
Friends			
Work or school associates			
Neighbors			
Health care providers			
Counselor or therapist			
Minister/priest/rabbi			
Other (specify):			

APPENDIX B

INDEX OF OBJECTIVE BURDEN

Objective Burden Scale

Please mark (X) after the appropriate response.

Having a family member who has been in a mental hospital may raise problems for the family. Here are statements made by relatives because the former patient is living in the house, or near-by.

Would you tell us which ones have been a problem for you?

1. Because he/she lives here or nearby, I sometimes have to neglect my responsibilities to other family members.

   Is a problem _____ Is not a problem _____

2. It is a financial burden.

   Is a problem _____ Is not a problem _____

3. Once a person has been mentally ill he/she needs more supervision and advice from his/her family than would otherwise be necessary.

   Is a problem _____ Is not a problem _____

4. It affects the families' normal ways of life, like eating and sleeping times.

   Is a problem _____ Is not a problem _____

5. Having a mental patient at home causes some of the neighbors to make remarks or to complain.

   Is a problem _____ Is not a problem _____

Scoring of the Objective Burden Scale:

No Burden	Moderate Burden		Severe Burden		
0	1	2	3	4	5

Objective burden was thus measured by whether each of the five effects on the household was present or not, as well as by an additive summary score.

APPENDIX C

BELIEFS ABOUT MENTAL ILLNESS SCALE

Beliefs about "Mental Illness"

DIRECTIONS

The following statements reflect ideas and beliefs about conditions that are labeled "mental illness" and about people who become "mental patients." Rate each with a score ranging from 5 to 0, based on the following scale:

5 Strongly agree
4 Agree
3 Not sure but probably agree
2 Not sure but probably disagree
1 Disagree
0 Strongly disagree

There are no right or wrong answers, so be as honest as you can.

____ 1. When you have a problem or worry, it is better not to think about it but rather keep busy with more pleasant things.

____ 2. All clients in mental hospitals should be prevented by a painless operation from having children.

____ 3. One of the main causes of mental illness is a lack of moral strength or will power.

____ 4. Every person should have complete faith in some supernatural power whose decisions he or she obeys without question.

____ 5. Although some mental clients seem all right, it is dangerous to forget for a moment that they are mentally ill.

____ 6. Even though clients in mental hospitals behave in funny ways, it is wrong to laugh about them.

____ 7. Clients in mental hospitals are in many ways like children.

Source: Adapted from items in Jacob Cohen and E. L. Struening, "Opinions about Mental Illness Scale," *Journal of Abnormal and Social Psychology* 64 (1962): 349-60. Copyright 1962 by the American Psychological Association. Reprinted by permission.

____ 8. Our mental hospitals seem more like prisons than like places where mentally ill people can be cared for.

____ 9. Although they usually aren't aware of it, many people become mentally ill to avoid the difficult problems of everyday life.

____ 10. More tax money should be spent in the care and treatment of people with severe mental illness.

____ 11. Many mental clients are capable of skilled labor, even though in some ways they are very disturbed mentally.

____ 12. Many people who have never been clients in a mental hospital are more mentally ill than many hospitalized mental clients.

____ 13. Many mental clients would remain in the hospital until they were well even if the doors were unlocked.

____ 14. The clients of a mental hospital should have something to say about the way the hospital is run.

____ 15. More tax money should be spent in the care and treatment of people with severe mental illness.

____ 16. A woman would be foolish to marry a man who has had a severe mental illness, even though he seems fully recovered.

____ 17. People who have been clients in a mental hospital will never be their old selves again.

____ 18. Small children should not be allowed to visit their parents who are clients in menta hospitals.

____ 19. Most clients in mental hospitals don't care how they look.

____ 20. Anyone who is in a hospital for a mental illness should not be allowed to vote.

____ 21. Mental clients come from homes where the parents took little interest in their children.

____ 22. The mental illness of many people is caused by the separation or divorce of their parents during childhood.

____ 23. If parents loved their children more, there would be less mental illness.

____ 24. If the children of normal parents were raised by mentally ill parents, they would probably become mentally ill.

____ 25. People who are successful in their work seldom become mentally ill.

EXPLANATION OF SCORING

Five attitude orientations are represented in the above twenty-five items. Each scale is scored separately. Add your individual scores for attitude items 1-5, 6-10, 11-15, 16-20, and 21-25. Total scores for each scale can range from a high of 25 to a low of 0.

APPENDIX D

WAYS OF COPING SCALE

WAYS OF COPING

The two preceding questionnaires gave you the opportunity to indicate the stresses in your life. People cope with stress in different ways. The scale below lists 40 different ways of coping with stress. We are interested in finding out how you cope with stress. You may not use some of these at all.

Directions: Rate each method of coping according to the degree of use by circlir one of the numbers from one to five for each item.

COPING METHODS	NOT AT ALL	RARELY	SOMETIMES	OFTEN	VERY OFTEN
1. Hope that things will get better	1	2	3	4	5
2. Try to maintain some control over the situation	1	2	3	4	5
3. Find out more about the situation so you can handle it better	1	2	3	4	5
4. Think through different ways to handle the situation	1	2	3	4	5
5. Look at the problem objectively	1	2	3	4	5
6. Eat, smoke, chew gum	1	2	3	4	5
7. Try out different ways of solving the problem to see which works the best	1	2	3	4	5
8. Draw on past experience to help you handle the situation	1	2	3	4	5
9. Try to find meaning in the situation	1	2	3	4	5
10. Pray; trust in God	1	2	3	4	5

COPING METHODS	NOT AT ALL	RARELY	SOMETIMES	OFTEN	VERY OFTEN
11. Get nervous	1	2	3	4	5
12. Worry	1	2	3	4	5
13. Break the problem down into "smaller pieces"	1	2	3	4	5
14. Seek comfort or help from family or friends	1	2	3	4	5
15. Set specific goals to help solve the problem	1	2	3	4	5
16. Accept the situation as it is	1	2	3	4	5
17. Want to be alone	1	2	3	4	5
18. Laugh it off figuring that things could be worse	1	2	3	4	5
19. Try to put the problem out of your mind	1	2	3	4	5
20. Daydream, fantasize	1	2	3	4	5
21. Get prepared to expect the worst	1	2	3	4	5
22. Talk the problem over with someone who has been in the same type of situation	1	2	3	4	5
23. Actively try to change the situation	1	2	3	4	5
24. Get mad, curse, swear	1	2	3	4	5
25. Cry, get depressed	1	2	3	4	5

COPING METHODS	NOT AT ALL	RARELY	SOMETIMES	OFTEN	VERY OFTEN
26. Go to sleep figuring things will look better in the morning	1	2	3	4	5
27. Don't worry about it, everything will probably work out fine	1	2	3	4	5
28. Withdraw from the situation	1	2	3	4	5
29. Work off tension with physical activity	1	2	3	4	5
30. Settle for the next best thing	1	2	3	4	5
31. Take out your tensions on someone or something else	1	2	3	4	5
32. Drink alcoholic beverages	1	2	3	4	5
33. Resign yourself to the situation because things look hopeless	1	2	3	4	5
34. Do nothing in the hope that the problem will take care of itself	1	2	3	4	5
35. Resign yourself to the situation because it's your fate	1	2	3	4	5
36. Do anything just to do something	1	2	3	4	5
37. Blame someone else for your problems	1	2	3	4	5
38. Meditation, yoga, biofeedback	1	2	3	4	5
39. Let someone else solve the problem	1	2	3	4	5
40. Take drugs	1	2	3	4	5

Scoring on The Ways of Coping Subscales

Affective-oriented coping methods: (Total 25)

Sum responses to question numbers: 1, 6, 10, 11, 12, 14, 17, 18, 19, 20, 21, 24, 25, 26, 27, 28, 29, 31, 32, 33, 34, 35, 37, 38, 40.

Cognitive-oriented coping methods: (Total 15)

Sum responses to question numbers: 2, 3, 4, 5, 7, 8 9, 13, 15, 16, 22, 23, 30, 36, 39.

APPENDIX E

SUPPORT GROUP FORMAT

Appendix E

Support Group Format

Week 1:
- Name tags.
- Introductions.
- Announce tenative schedule of topics.
- Ask what concerns or questions they may have and would like discussed at the sessions.
- Remarks regarding importance of family.

Week 2:
- What is schizophrenia?
- Occurrence of schizophrenia in population.
- Symptoms of schizophrenia:
  - Changes in thought process.
  - Perception difficulties.
  - Delusions, hallucinations.
  - Impaired judgement and insight.
  - Thought broadcasting.
  - Ideas of reference.
- Treatment in general.

Week 3:
- Theories of etiology:
  - Stress
  - Genetic predisposition
  - Environmental
  - Biochemical -- emphasize
    - Limbic system/dopamine/neuroreceptors
- Specific medications used: how medications work.
- Interactions with street drugs:
  - Amphetamines, Hallucogens, Depressants
  - Alcohol
  - Cold medications (ephedrine)
- Side effects:
  - Drowsiness, akinesia, akathesia, dystonias, dyskinesias, dry mouth, constipation, increased appetite, weight gain, dermatitis, phototoxicity (especially with thorazine)

- Use of side effects medications:
  - Problems with: dry mouth, blurred vision, constipation.

Week 4:
- Management techniques
  - General ideas about acceptance -- one has to accept before taking action -- discuss.
  - Sharing of ideas.

Behavior modification techniques.
Compile voluntary list of members' names, addresses, phone numbers.

Week 5:
Financial planning for future of patient.
Employment resources for patient.
Support for housing.
Early signs of schizophrenia
Distribution of members' names, addresses, phone numbers lists.
Names and locations of ongoing family support groups in area, distributed.
List of suggested reading regarding schizophrenia, distributed.

APPENDIX F

EDUCATIONAL BOOKLET

SCHIZOPHRENIA

What is schizophrenia? Schizophrenia can be described as an illness in which there is primarily a disorder in thinking. Severe stress appears to trigger an episode of schizophrenia in susceptible individuals. Approximately 2,000,000 people in this country suffer from schizophrenia, accounting for about 69 percent of all major mental disorders. It afflicts approximately one percent of the world's people. According to the World Health Organization, under-developed nations show a lower rate of chronicity and dependence and a higher rate of return to productive activity than do technological societies. This may be due, in part, to the ease with which a mentally ill person can function in a rural culture: one can do simple farm chores or harvest crops while experiencing symptoms such as hearing voices, whereas performing secretarial tasks or operating complex machinery might be poorly accomplished if a person were distracted by voices. In addition, the more tranquil, pastoral life may be less stressful to certain fragile individuals.

Current research on schizophrenia indicates no one known cause. Rather it probably results from such diverse factors as genetic, neurological, bio-chemical, and environmental. Physical trauma, advanced age, or

drug abuse may also precipitate the illness.

Tragically, schizophrenia most often occurs at a crucial stage of development--in late adolescence or early adulthood. Consequently, many afflicted individuals are prevented from developing adequate vocational and social skills to cope with expectations of normal adulthood. Not all persons, however, become chronically disabled. Some recover from psychotic episodes.

As schizophrenia usually develops gradually, often afflicting quiet or introspective individuals, only in retrospect can most families recall early signs which went undetected, sometimes for years. It is not until the illness is fully manifested that the family will remember brief or transitory episodes during which a young person may have experienced visual or auditory hallucinations. Much of the unusual behavior is assigned to "adolescence" as an acceptable cause. For example, sudden outbursts of hostility are considered normal rebellion, reclusiveness is rationalized as "studiousness," and decline in academic performance may be excused as "preoccupation with more relevant issues." In short, the family wants desperately to believe that nothing serious is happening. Likewise, the affected person is also struggling to deny the illness. Losing control of one's thought or behavior--even for a brief period--is a

terrifying ordeal. Further, many competent and sensitive professionals wish to delay the ultimate pronouncement; they, too, want to believe that the illness may be transitory and not schizophrenia.

Family advocates advise families to remain involved, to trust one's instincts and to actively protect the patient during acute or early phases of the illness. Intuitively, most families act protectively after sensing the terror which the patient is experiencing due to his or her mounting fears of loss of control. The following examples are intended to clarify this point.

Example one:

Seven A.M. The alarm clock wakes Joe. It continues to ring and ring, louder and louder, and seems never to stop. Joe gets up. The ringing is now almost deafening. He covers his ears, but he still hears it. He does not know what to make of this. He goes to the window and opens it, and the loud noise of the alarm clock spreads through the air, presumably heard by everybody. At first it sounds like the siren of an ambulance, then like that of a police car, then of a fire engine; finally it seems so powerful as to transmit a warning signal to the whole city. The streets, too, are unusual this morning. The buildings have assumed funny shapes. Everything is brightly hued, like Technicolor. In the twenty-four years of his young life Joe has never experienced a similar

sense of foreboding and of ominous mystery.

Example two:

It is dusk, Ann is heading for home, just a few blocks away. But the dusk is darker than at the beginning of other evenings, and the lights that are coming on are dimmer than usual. The noises of the city are different--continuous, with an incessant sound of dismay, sometimes fading away and then coming back, like waves. There is a whispering in the air, diffused, unintelligible. Gradually, words become clearly distinguishable. They are about her. She looks backward, and there they are, peculiar men with grotesque faces who follow her. What do they want from a poor, innocent, twenty-two year old girl? They are spying on her. They may want to catch up with her and perhaps kidnap her. She runs home in a state of panic. Her trembling hands try to find the keyhole; she opens the door, bursts into tears, and screams, "Mother, Mother, they're following me, they're after me!"

Joe and Ann are having acute attacks of schizophrenia. If Joe or Ann is a member of your family his or her suffering immediately becomes your suffering, and his or her problem your most crucial problem (Arieti, 1979).

Typically, following an episode or during a crisis, the family will seek help from a psychiatrist or family physician. Quite often the young patient will refuse to

cooperate in the treatment plan, i.e., medications will be refused. Almost always the family will become angry at this apparent rejection. Hours will be spent in endless arguments over the patient's irrationality. It is important to remember that the patient may be petrified with fear knowing that the resistance is irrational but unable to quiet "the voices," or control the intrusive hallucinations. (Hallucinations are impressions of the senses--sight, touch, sound, smell, or taste--that have no basis in reality). Regardless of the steps which may or may not be taken, improvement may not occur. Nonetheless, every effort should be made to provide the patient with a non-threatening, non-judgemental environment. Professional help should be sought and advice followed. (Evaluate the advice you receive). Families can benefit from support and guidance.

Reports from helping persons say that families do undergo periods of confusion, conflict, denial, and fear. Initially, each family member may withdraw, preoccupied with a review of possible guilt. Feelings of rejection, anger, guilt, and fear are typical. Almost always families report periods of depression and sorrow.

After a period of time--generally several years--most families accept the full significance of the illness and begin the process of reassembling their lives

finally free from shame or guilt. In the process they become knowledgeable by reading "everything." Some are attracted to the non-traditional remedies. Ultimately, most place their hopes in scientific research, convinced that only when a cure is found, will the stigma of mental illness disappear.

Early Symptoms of Mental Illness

Below is a list of some early symptoms of mental illness. It was developed by families, each with a schizophrenic member. Many of the behaviors are within the range of normal responses to situations. However, it was the conclusion of the group that, even with the mildest of symptoms, there was a vague, yet distinct, awareness that the behavior was "unusual."

Social withdrawal was observed by all families. Several families felt that transitory lapses seemed like mild epileptic seizures. Others believed that drugs were a precipitating factor, but not the cause of the illness. Most commented that the afflicted offspring had been "a good child, never causing any trouble." Seldom had the patient been socially "outgoing" during the formative years.

Prior to full manifestation of the illness, families may notice a few of these symptoms:

° Depression--intense and unremitting

° Excessive fatigue and sleepiness or an inability to sleep

- Social withdrawal, isolation and reclusiveness
- Sudden shift in basic personality
- Deterioration of social relationships
- Hyperactivity or inactivity or alterations between the two
- Inability to concentrate or cope with minor problems
- Extreme religiosity or peroccupation with the occult
- Hostility from one formerly passive and compliant
- Indifference, even in highly important situations
- Dropping out of activities (and of life in general)
- Decline in academic or athletic performance
- Involvement in auto accidents
- Drug or alcohol abuse
- Forgetfulness and loss of valuable possessions
- Extreme devastation from peer or family disapproval
- Noticeable and rapid weight loss
- Attempts at escape through geographic change; frequent moves or hitch-hiking trips
- Excessive writing (or childlike printing) without apparent meaning
- Inability to cry or excessive crying
- Unusual sensitivity to stimuli (noise, light, clothing)
- Bizarre behavior (skipping, wearing torn clothing)
- Inappropriate laughter
- Irrational statements
- Strange posturing

° Refusal to touch persons or objects; insulation of hands with paper, gloves, etc.

° Shaving head or removal of body hair

° Cutting oneself; threats of self mutilation

° Staring, not blinking or blinking incessantly

° Expressionless gaze

° Rigid obstinacy

° Peculiar use of words or language structure

This is an example provided by a family. You may have noticed similar behaviors.

A man had been hired as a bus driver just two days prior to his having a minor accident when driving. The accident amounted to very little: the bus collided with a car, which sustained minimal damage. Nobody was hurt. The man had nevertheless become agitated and had to return home. Seven hours later, his wife took him to a physician's office, relating that since the accident her husband had talked nonsense.

According to her, he had shown no abnormality whatever prior to the accident. She was pregnant, and the night before they had talked about the expected baby, and they were very happy. When seen by the doctor, the patient was excited and could not stay still. The man recognized that something important was disturbing him, but was not able to say what it was. When the doctor's phone rang during the appointment, the man thought

that someone was calling the doctor concerning him. They must be after him. They must know where he is. Everything was moving, confusing, strange. When he heard the voice of a woman at the end of the line, he assumed that it was the voice of his aunt who was talking to the doctor about him. He did not know what was happening. (Arieti, 1979)

Many helping professionals report hearing patients relate confusing statements. The world seems to be going very fast to them and spinning. Their thoughts race as if the people of the world are going a little faster, they try to go with the world, and they shouldn't. They may relate that it is their opinion that the people are rushing slowly and slowly and when they reach a certain point, they start to realize that they are going fast or slow, and they cannot be judges of the world as it is spinning. The world has changed, is going fast, keeps going, going. They can't keep up with it.

In talking to the doctor, the man in the brief example above related that he had made an attempt to adjust to civilian life after returning from the army. But old personal difficulties returned, like his shyness, fearfulness, indecision, and lack of initiative--which were not obvious as long as he was in the army--surfaced again once he became a civilian, and they hindered his readjustment. He felt demands were made on him at the same

time he was having personal difficulties. He felt that as soon as possible he should marry the girl to whom he had been engaged for so long and who had waited for his return. He was insecure, especially because he had no special skills to offer any prospective employer.

Having finally secured a good job as a bus driver; two days later he had the accident. He believed he would lose the job, and this belief reinforced his deep feeling of worthlessness. The accident was, to him, proof of his inherent incompetence, especially since he attached so much importance to having a job. He felt no one would have confidence in him. His security was founded only on the evidence that he had a job.

These ideas seemed to be an injury to his self-esteem and self-identity that he could not endure. He started to think irrationally, and his thoughts became disorganized. He saw the world in an unusual way--as going too fast, so fast that he could not cope with its movement. The signs may have been visible, but the illness required a combination of perceived stressors to be frankly manifested as schizophrenia.

Reactions by Family Members

When a family member unexpectedly becomes ill, shock is a typical reaction. This is also 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 visible (and more frightening) conflicting feelings are experienced. Some responses that have been reported by families are:

° Denial of the illness entirely (This can't happen in our family

° 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--or mother--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

° Conflicting feelings towards the afflicted member

° Excessive searching of the past for possible explanations

° Family division (One member demands too much, others too little of the patient)

Recent studies seem to support the fact that supportive, non-judgmental and non-critical families aid, or facilitate the recovery process.

Compound or Multicausal Illness

Unfortunately, the specific cause of schizophrenia is not known. However, the following comments represent a general summary of important factors.

Life stresses. Schizophrenia usually begins between the ages of sixteen and thirty, the time when a person faces the difficult stress of gaining financial and emotional independence through leaving home to go to school, work, or start a family. Once schizophrenia starts, stresses in life such as family deaths, change of residence, financial problems and arguments within the family will temporarily make the illness worse.

Unknown factors. A proper chemical balance in the brain is important for normal functioning. Important brain chemicals called neurotransmitters are essential for the

transfer of "messages" between nerves which enable us to think and feel in a normal manner. In schizophrenia some of these chemicals, such as dopamine, are out of balance. There may be either too much dopamine, or the receptors on the nerves are overly sensitive to normal amounts of it. The result is that too many messages are experienced at the same time. This causes the person to hear mysterious "voices," to have false and absurd beliefs and to be unable to think logically. This explanation is also termed the biochemical theory of the cause of schizophrenia. Another brain change in some patients (occurring even before medicines are used) is an enlargement in the fluid-filled spaces (ventricles) in the center of the brain. Reports have been made that food allergies can cause schizophrenia; however, no well-controlled research has yet been done to validate the reports.

Environment. A disruptive environment may contribute to the development of schizophrenia. Individuals living in surroundings involving continued stresses in daily living, communication difficulties, and/or with little serenity in their lives may be prone to demonstrate symptoms of schizophrenia.

Hereditary factors. About one-third of persons who develop schizophrenia have a close blood-relative who also has it. Research has shown that such cases are mostly due

to a hereditary susceptibility rather than to child-rearing practices. Probably heredity affects the ability of a person's brain to maintain a normal chemical balance. Additionally, a combination of the suggested causes may trigger the development of schizophrenia.

Treatment

There are several approaches to the treatment of schizophrenia. The choice of treatment may depend on the beliefs and training of the mental health professional responsible for the treatment program. Two principle treatment methods are psychotherapy and drug therapy. There are some therapists who administer mainly one or only one method. However, often both psychotherapy and drug therapy are administered together. In this booklet, the use of medications in therapy will be discussed since medications are frequently ordered for patients with schizophrenia.

Medications: Restoring chemical balance. The unusual chemical sensitivity of the brain can be partially corrected by the use of a broad category of medicines called neuroleptics. These medications are also called major tranquilizers and anti-psychotic drugs. The amount of neuroleptic required at a give time will vary depending upon the intensity of the illness or the person's body chemistry. In general, a person needs up to three times

as much medicine during severe psychotic states, followed by a gradual reduction in dose over a period of two to six months. Over time, persons suffering from chronic mental illness will have their medication dosages reduced, due perhaps to the fact that neuroleptics may return the dopamine levels to a proper balance. Some of the medications used are: Haldol, Serentil, Thorazine, Mellaril, Stelazine, Trilafon, and Prolixin.

Schizophrenia, like diabetes, may not be curable, but it is an illness which can and must be controlled. Most people benefit a great deal from medications when dose adjustments and side effects are properly handled. Generally, major symptoms are diminished. The majority of patients with schizophrenia must continue on maintenance medications to keep their illness under control. These medications are to schizophrenia as insulin is to diabetes. Both schizophrenia and diabetes can usually be controlled.

Side effects. There is no perfect medicine, because each individual who takes a drug responds uniquely to the drug, the dose given, etc. Even aspirin can have serious side effects in some individuals. Medications are prescribed when known good effects outweigh bad effects. Most side effects are nuisance side effects which are bothersome or cause inconvenience but are not physically harmful. These include: drowsiness; akinesia (rigidity);

akathisia (restlessness); dystonias (spasms of the neck or back muscles); dyskinesias (uncontrolled movement); dry mouth; constipation; increased appetite; weight gain; dermatitis (rash, itching); photosensitivity to sunlight--wear dark glasses, use sunscreen lotion--(occurs most commonly with Thorazine). There are medications used to relieve these side effects, however, these medications may also cause annoying symptoms such as dry mouth; blurred vision; and constipation.

A patient with tardive dyskinesia has uncontrolled movements of the face, mouth, tongue, and sometimes of his body. This side effect usually occurs when a patient has been on medication for schizophrenia for a long period of time.

Interactions with other substances. Persons with the illness of schizophrenia should espeically avoid "street" drugs such as: amphetamines (diet pills, "uppers," "BAM," etc.); hallucinogens like LSD, PCP ("angel dust," "green," "killer weed," etc.); marijuana ("pot," "herbs," "grass," etc.); and depressants. If not with the initial use, with repeated use of the drugs, there is a very high likelihood of worsening of symptoms. The use of common stimulants, nasal decongestants, and cold medications by schizophrenics, can also trigger an increase in symptoms. Moderate to heavy use of alcohol can result in a crisis for patients with

schizophrenia. Some experts suggest that persons with schizophrenia should avoid heavy use of coffee and cigarettes.

Guidelines for Behavioral Management

Avoid:

- Critical comments (regarding shaving, bathing, etc.)
- Hovering

Do:

- Praise (remind if necessary)
- Lower expectations
- Be "neutral" but respectful to avoid pressuring the patient with your expectations
- Compare today's behavior to yesterday's behavior (not to the ideal)
- Set firm limits regarding: violence, illegal drugs, etc.
- Express feelings and frustrations to someone (but not to the patient)
- Support therapy and medications
- Care for yourself--have some time away from the patient--recreation
- Listen respectfully--don't make fun of the patient
- Request changes directly and calmly

Suggested Reading List

Arieti, Silvano, MD. (1979). Understanding and helping the schizophrenic: A guide for family and friends. New York: Touchstone Press. (Available in paperback, $6.95).

Bernheim, Kayla and Lewine, Richard. (1979). Schizophrenia, symptoms, causes, treatments. New York: Norton. (265 pages, paperbound)

Bernheim, Kayla, Lewine, Richard, and Beale, Caroline. (1982). The caring family: Living with chronic mental illness. New York: Random House. (226 pages, hardbound - $13.50).

Mendel, Werner M. (1976). Schizophrenia, the experience and its treatment. San Francisco: Jossey-Bass, Inc. Publishers. ($13.95).

Patterson, Daniel, MD. (1982). Living with schizophrenia. Princeton, NJ: E. R. Suibb Sons, Inc. Professional Service Dept., P.O. Box 400, Princeton, NJ 08540 (Free - booklet - single copy requests).

Vine, Phyllis. (1982). Families in pain: Children, siblings, spouses, and parents of the mentally ill speak out. New York: Pantheon Books. (273 pages, paperbound, $6.95)

Advocacy Groups

Suggestions for Parent Advocacy Organizations by Anthony Hoffman, California Asso. Families of the Mentally Disturbed, National Alliance for the Mentally Ill, 1234 Massachusetts Ave., N.W., Wash. DC 20005. (free)

Local Advocacy Groups

TMED, Rm. 301, 718 W. Burnside, Portland, Oregon, 228-5684, Jean Stanford.

Washington County -- FAMILIES, Ed Wood, 297-4350.

Clackamas County -- MIND, Fred Winter (Gladstone) 656-1329.

Save-A-Mind, Ginny Krumdiek, 427 Spyglass, Eugene, Oregon 97401, phone (503) 687-2185.

Published Articles Consulted for this Booklet

Arieti, Silvano MD. (1979). Understanding and helping the schizophrenic: A guide for families and friends. New York: Touchstone Press.

Bernheim, Kayla F. (1982) Supportive family counseling, Schizophrenia Bulletin, 8(4), 634-640.

Owen, Eleanor (ed) (1982). Connections: A self-help and resource guide for patients, professionals, families. Washington Advocates for the Mentally Ill, Seattle, Wash., phone (206) 623-9264.

Patterson, Daniel (1982) Living with Schizophrenia, New Jersey: E.R. Squibb Son, Inc., Professional Service Dept., P.O. Box, Princeton, NJ 08540.

APPENDIX G

CONSENTS

Informed Consent Form

A Support Group for Families of Schizophrenics: An Exploratory Study

Investigator: Virginia E. Engel, R.N., B.S.N.

I agree to participate in a research study to assess the benefits of providing information, in a group setting, to family members of schizophrenic patients regarding the illness of schizophrenia. I understand I will be personally interviewed, by appointment, for approximately one hour at some date before the beginning of the group meetings, and again, by appointment, for approximately one hour at some date after the conclusion of the group meetings. I understand I will be asked to respond to questionnaires during these interviews. I understand the group will meet in 1 1/2 hour sessions for five consecutive weeks, at the Portland Veterans' Administration Hospital- Mental Health Clinic. These sessions will include: provision of information regarding the disorder of schizophrenia; management procedures; and sharing of information regarding community resources.

It is hoped the benefits of participation in the group include increased information regarding schizophrenia, and the sharing of support from a group. The risks might be some personal discomfort in group participation.

The information obtained will be kept confidential. My name will not appear on the records and anonymity will be assured by the use of code numbers. Any questions you may have will be answered by Virginia Engel, R.N. I understand that I may refuse to participate or withdraw from this study at any time without affecting my relationship with the Oregon Health Sciences University or the Veterans' Administration Medical Center.

It is not the policy of the Department of Health and Human Services, or any other agency funding the research project in which you are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions please call Dr. Michael Baird, M.D., at (503) 225-8014.

I have read the foregoing and agree to participate in this study.

Signature _____

Date _____

Signature of Investigator/Witness _____

Date _____

Informed Consent Form

Oregon Health Sciences University

Investigator: Virginia Engel, R.N.,B.S.N.

Title of Study: A Support Group for Families of Schizophrenics: An Exploratory Study.

Procedure: Participants will receive a booklet containing information regarding: the disorder of schizophrenia; management procedures; and community resources. A one hour personal interview will be conducted at the time of receival of this booklet, and again approximately six weeks after receiving the booklet, allowing time for participants to complete reading of the booklet. These interviews would be arranged by appointment with each participant either in his/her home or in the clinic.

Confidentiality will be maintained as no names are used on the interview form. Pre and post interviews are related by participant's self-selected identification number.

It is not the policy of the Department of Health and Human Services, or any other agency funding the research project in which you are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions please call Dr. Michael Baird, M.D., at (503) 225-8014.

I understand I may refuse to participate, or withdraw from this study at any time without affecting my relationship with or treatment at, the Oregon Health Sciences University.

I have read the foregoing and agree to participate in this study.

Signature: _____

Date: _____

Standard Form 507 GPO 648—16—81472-2 502-689

CLINICAL RECORD

Report on _____
or
Continuation of S. F. _____
(Strike out one line) (Specify type of examination or data)

(Sign and date)

Informed Consent Form
A Support Group for Families of Schizophrenics:
An Exploratory Study.
Investigator: Virginia E. Engel, R.N., B.S.N.

I agree to participate in a research study to assess the benefits of providing information, in a group setting, to family members of schizophrenic patients regarding the illness of schizophrenia. I understand I will be personally interviewed, by appointment, for approximately one hour at some date before the beginning of the group meetings, and again, by appointment, for approximately one hour at some date after the conclusion of the group meetings. I understand I will be asked to respond to questionnaires during these interviews. I understand the group will meet in 1 1/2 hour sessions for five consecutive weeks, at the Portland Veterans' Administration Hospital-Mental Health Clinic. These sessions will include: provision of information regarding the disorder of schizophrenia; management procedures; and sharing of information regarding community resources.

It is hoped the benefits of participation in the group include: increased information regarding schizophrenia, and the sharing of support from a group. The risks might be some personal discomfort in group participation.

The information obtained will be kept confidential. My name will not appear on the records and anonymity will be assured by the use of code numbers. Any questions you may have will be answered by Virginia Engel, R.N. I understand that I may refuse to participate or withdraw from this study at any time without affecting my relationship with the Oregon Health Sciences University or the Veterans" Administration Medical Center.

I have read the foregoing and agree to participate in this study.

Signature: _____
Date: _____
Signature of Investigator/Witness _____
Date: _____

(Continue on reverse side)

PATIENT'S IDENTIFICATION (For typed or written entries give: Name—last, first, middle; grade; date; hospital or medical facility)

REGISTER NO.

WARD NO.

REPORT ON _____ or CONTINUATION OF _____

Standard Form 507
GENERAL SERVICES ADMINISTRATION AND
INTERAGENCY COMMITTEE ON MEDICAL RECORDS
FPMR 101-11.80 6-B
OCTOBER 1975 507-106

PART I-AGREEMENT TO PARTICIPATE IN RESEARCH BY OR UNDER THE DIRECTION OF THE VETERANS ADMINISTRATION

DATE

1. I, _____, voluntarily consent to participate as a subject
(Type or print subject's name)

in the investigation entitled _____
(Title of study)

2. I have signed one or more information sheets with this title to show that I have read the description including the purpose and nature of the investigation, the procedures to be used, the risks, inconveniences, side effects and benefits to be expected, as well as other courses of action open to me and my right to withdraw from the investigation at any time. Each of these items has been explained to me by the investigator in the presence of a witness. The investigator has answered my questions concerning the investigation and I believe I understand what is intended.

3. I understand that no guarantees or assurances have been given me since the results and risks of an investigation are not always known beforehand. I have been told that this investigation has been carefully planned, that the plan has been reviewed by knowledgeable people, and that every reasonable precaution will be taken to protect my well-being.

4. In the event I sustain physical injury as a result of participation in this investigation, if I am eligible for medical care as a veteran, all necessary and appropriate care will be provided. If I am not eligible for medical care as a veteran, humanitarian emergency care will nevertheless be provided.

5. I realize I have not released this institution from liability for negligence. Compensation may or may not be payable, in the event of physical injury arising from such research, under applicable federal laws.

6. I understand that all information obtained about me during the course of this study will be made available only to doctors who are taking care of me and to qualified investigators and their assistants where their access to this information is appropriate and authorized. They will be bound by the same requirements to maintain my privacy and anonymity as apply to all medical personnel within the Veterans Administration.

7. I further understand that, where required by law, the appropriate federal officer or agency will have free access to information obtained in this study should it become necessary. Generally, I may expect the same respect for my privacy and anonymity from these agencies as is afforded by the Veterans Administration and its employees. The provisions of the Privacy Act apply to all agencies.

8. In the event that research in which I participate involves certain new drugs, information concerning my response to the drug(s) will be supplied to the sponsoring pharmaceutical house(s) that made the drug(s) available. This information will be given to them in such a way that I cannot be identified.

I _____
NAME OF VOLUNTEER

HAVE READ THIS CONSENT FORM. ALL MY QUESTIONS HAVE BEEN ANSWERED, AND I FREELY AND VOLUNTARILY CHOOSE TO PARTICIPATE. I UNDERSTAND THAT MY RIGHTS AND PRIVACY WILL BE MAINTAINED. I AGREE TO PARTICIPATE AS A VOLUNTEER IN THIS PROGRAM.

9. Nevertheless, I wish to limit my participation in the investigation as follows:

VA FACILITY	SUBJECT'S SIGNATURE
WITNESS'S NAME AND ADDRESS *(Print or type)*	WITNESS'S SIGNATURE
INVESTIGATOR'S NAME *(Print or type)*	INVESTIGATOR'S SIGNATURE

☐ Signed information sheets attached. ☐ Signed information sheets available at:

SUBJECT'S IDENTIFICATION *(I.D. plate or give name - last, first, middle)*

SUBJECT'S I.D. NO. | WARD

AGREEMENT TO PARTICIPATE IN RESEARCH BY OR UNDER THE DIRECTION OF THE VETERANS ADMINISTRATION

VA FORM SEP 1979 10-1086 SUPERSEDES VA FORM 10-1086 JUN 1975, WHICH WILL NOT BE USED.

APPENDIX H

DEMOGRAPHIC DATA

Demographic Data

of Family Member

Number _____

Age range: (Circle) 18-25 26-30 31-40 51-60

41-50 60 and over

Sex _____

Marital status _____ Number of years married _____

Last level of school attendance _____

Schizophrenic relative/patient's number of hospitalizations

_____

Relationship to the patient _____

Occupation _____

Living arrangement of family member in relationship to the patient:

Lives with _____

Lives elsewhere:

where _____

An Abstract of the Thesis of

Virginia E. Engel

For the Master of Nursing

Title of Study: The Effects of Group Support on Family Members of Schizophrenic Outpatients

Approved: [redacted]

Shirley A. Murphy, RN, Ph.D., Professor, Thesis Advisor

The purpose of this study was to explore the effects of group support on family members while receiving information regarding schizophrenia. The experimental group consisted of six family members of patients referred by a Veterans' Administration mental health outpatient clinic staff in a major northwestern city. These family members were presented information over a five week period in 1 1/2 hour sessions in a group setting that encouraged interaction among attendees. A control group consisted of eight family members of patients referred by two community mental health agencies in the same metropolitan area. Information about schizophrenia was provided by giving them a booklet. A non-equivalent control group design was used. Data were gathered using the following instruments: Beliefs About Mental Illness Scale; Index of Objective Burden; Index of Social Support; and Ways of Coping Scale. The Student's *t*-test was used to measure within and between

group differences on pretest and posttest mean scores on experimental and control groups. The results must be viewed with caution due to the small sample size, and lack of statistical significance. However, the results suggest that education combined with group interaction might indeed provide a greater increase in perceived social support and decrease in perceived objective burden compared to subjects who receive the same information by booklet.