CALIFORNIA STATE UNIVERSITY, NORTHRIDGE

SUPPORT GROUP FOR CAREGIVERS
OF CHRONICALLY ILL PERSONS

A project submitted in partial satisfaction
of the requirements for the degree of

Master of Public Health

by

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ABSTRACT

SUPPORT GROUP FOR CAREGIVERS
OF CHRONICALLY ILL PERSONS

by
Sharron Zollotuchen Levey
Master of Public Health

This exploratory study involved the design, implementation and evaluation of a support group for caregivers of chronically ill persons. A primary aim of this research was to establish the utility of the support group setting as a health education vehicle.

The bulk of this study was devoted to an extensive literature review in order to provide a current compilation of what support groups are, the stimulus for their occurrence, their history, current scientific research, taxonomies in use, how support groups work, their effectiveness, and their use as a vehicle for health education. The bibliography is coded to provide future reference in the above stated areas.
Using the literature review as a background, and on the basis of a needs assessment conducted at a community-based home health agency, a support group for caregivers of chronically ill persons was developed at the Van Nuys Senior Multipurpose Center in co-sponsorship with that Center. The feasibility of using these groups as a vehicle for health education programs was examined. A protocol for possible future support group sessions was developed.

Study conclusions validated the utility of these popular types of self-help groups. Furthermore, the study demonstrated the continued necessity for in-depth research concerning the functioning and effectiveness of these groups as a viable vehicle for formal versus informal health education.
CHAPTER I

INTRODUCTION

In the practice of mutual aid, which we can retrace to the earliest beginnings of evolution, we thus find the positive and undoubted origin of our ethical conceptions; and we can affirm that in the ethical progress of man, mutual support - not mutual struggle - has had the leading part. In its wide extension, even at the present time, we also see the best guarantee of a still loftier evolution of our race (Kropotkin 40:430).

When Petr Kropotkin wrote to the Social Darwinists of his time, 1914, about the evolution of man and the necessity for mutual aid/support, little did he know that by the 1980's there would be nearly one-half million self-help/support groups across our nation (1). Owing to the complexities and pressures (economic and social) in our society, resulting in fragmentation and isolation of individuals, the drive for "connection" and "support" from others has been magnified.

Included in the numbers of support groups are those for persons with specific disease entities. Many of these focus on chronic illnesses.

The growth and proliferation of the current self-help movement coincide with the period since the 1920's of the shift in major health problems from acute to chronic illness and toward conditions requiring extended attention. Today there is the very high probability that any one individual will be affected by some chronic condition
at least once, if not more often, in the course of a lifetime (22:412).

There is then a rise in the numbers of persons with chronic diseases. Fifty years ago 30 percent of all illnesses were chronic; today chronic diseases account for more than 80 percent. Figures from the United States Public Health Service (USPHS) indicate that chronic diseases now afflict approximately half of the population and account for 70 percent of all doctor visits (9:103). One reason given for the establishment and proliferation of self-help groups is that they represent a response to "fill the gap" in existing medical services with regard to care of persons with chronic diseases and all the associated coping mechanisms which are not being met (9, 19).

Self-help groups provide assistance, encouragement and needed services for those with chronic, disabling conditions involving a number of emotional and social adaptive problems... In view of the functions they perform, they seem to fill an important gap in the network of agencies and professional practitioners making up the health delivery system (22:407).

The health provider community can no longer doubt that the self-care/self-help movement with its associated mutual aid/support groups exist and seem to satisfy its participants. Governments and professional organizations are beginning to focus on this movement. The World Health Organization (WHO) sees as its goal "Health for all by the year 2000" and the vehicle for this goal to be an
adequate system of primary care. One essential component of primary care is community participation, sharing and support which includes recognition of the self-help movement (63:415). "There now exists self-help groups under almost every one of the 17 WHO disease categories" (6:16). In order to reach the WHO goal, planned and systematic steps must be taken to disseminate health information. The support group setting is an ideal place for this to occur and the health educator may be an ideal facilitator.

The use of health education with self-help groups has already occurred on two levels: 1) as a result of the group initially being set up and/or promoted by health professionals, the purpose of which to be patient education regarding care and coping with a specific disease entity or condition (i.e., burn centers, Multiple Sclerosis groups); and 2) as a result of a request for information, or expertise of a health professional, by an existing non-professionally connected support group. However, the feasibility of formally or informally incorporating a program of health education into the support group setting has only just begun to be scientifically explored. This is the task required of the health provider community if the goal of "Health for all by the year 2000" is to be reached.
Statement of the Problem

The effectiveness of bringing together individuals who share common health problems appears to be based not only in the tendency to trust and conform to the judgement of others who have the same problem . . . , but also in the quality of pertinent and understandable discussion and mutual reinforcement that occurs among participants in such groups (19:166).

An intervention program such as a self-help or support group "... has (been) found (to) give members an opportunity to share concerns, clarify problems and roles and develop skills for problem solving and coping" (26, 81:654). Individuals with a disease or problem and the persons who care for them need support. Caregivers (non-professional such as family or friends) of persons with chronic illnesses would benefit from a support group because of their isolated status and specific problems and feelings associated with the care of this person. According to Zarit, et al., findings demonstrate that "... an intervention program that increases social supports may be effective with a caregiver who reports excessive feelings of burden . . . The ability of caregivers to cope . . . may depend on the other supports available to them" (81: 653).

During the Investigator's internship with a community based home health agency, a well thought out and administered consumer survey (needs assessment) identified the need for a support group for caregivers of patients with chronic diseases (41). In addition, there is a need
to explore the actual capability of such a support group with regard to its serving as a vehicle for providing health education.

**Purpose of the Project**

The purpose of this exploratory study was: 1) to conduct an extensive search of the literature regarding support groups, 2) to design, implement and evaluate a support group for caregivers of chronically ill persons, and 3) to establish the utility of the support group as a health education vehicle.

**Major Study Assumptions**

1. The support group setting is a feasible mechanism for providing health education, for caregivers of persons with chronic illnesses, and includes the following dimensions:

   - **Knowledge** - source of information regarding care chronically ill persons
   - **Attitude** - help caregivers deal with their feelings, concerns and roles
   - **Behavior** - help caregivers develop skills for problem solving and coping

2. The support group can provide a setting whereby caregivers could:

   a. share their feelings, concerns and problems regarding the care of a chronically ill person;
   b. receive emotional support regarding these feelings, concerns and problems;
c. receive and share suggestions for solutions to problems;

d. receive health education information in general and specifically related to the caregiver's particular situation.

If the above conditions are met, it is anticipated that the caregiver will be able to:

a. better cope with the caregiving process;

b. anticipate and/or prevent problems before they occur or handle problems more efficiently when/if they occur.

These major assumptions, then, will function as the explicit dimensions to be explored in this study.

Limitations of the Study

Referrals for the support group would be obtained from administrative and staff nurses at National In-Home Health Services (NIHS), a community-based home health agency within the purview of this study. Group members will represent caregivers of patients with chronic illnesses currently or formerly receiving services from this agency. Persons receiving services through the agency's Continuity of Life Program (hospice program for terminal patients) are to be excluded per administration request since other forms of support are inherent to that program. Referrals to be obtained also from the Van Nuys Senior Multipurpose Center (VNSMC) from an on-going "Caring" support group and via advertisement of the group in their newsletter and in local newspapers.
Because of geographical limits, members of the group will come primarily from the central San Fernando Valley (Los Angeles, California). Also, because of the nature of the referral sources and the mode of advertising, members will be representative of the senior population (over age 60). Owing to the self selection nature of the population, results of this study cannot be generalized to the population as a whole.

This is a one time study for which the sponsoring agencies provided financial support with budget restrictions.

Definitions

Support Group: (Self-help Group, Mutual-aid Group) small group meetings where members, through mutual support, can share concerns, clarify problems and roles, and develop skills for problem solving and coping (see Figure 1).

Caregiver: person who gives care or assistance (physical or emotional). Caregivers can be professionals (formal), such as doctors, nurses, social workers, psychiatrists, psychologists, counselors, etc., or they can be non-professional (informal), such as family or friends. This study focuses on the latter, non-professional (informal) caregiver. Professional caregivers will be identified as such when applicable.
**Chronic disease:** impairments or deviations from normal which have one or more of the following characteristics: are permanent; leave residual disability; are caused by non-reversible pathological alterations; require special training of the patient for rehabilitation; may be expected to require a long period of supervision, observation or care (42:6, 73:1). Some chronic diseases are diabetes, heart disease, neuro-muscular ailments (Parkinson's Disease), orthopedic problems (arthritis), or mental/psychiatric conditions/degenerations (Alzheimer's Disease, senility).

**Home Health Agency:** agency which provides multidisciplinary health care on a family-centered basis to the sick, disabled, and injured in their places of residence (41:5, 77:18).
Sharing - our feelings, not only for our loved ones . . ., but how we were able to cope with the feelings inside of ourselves as the caregivers.

Understanding - being in a group with others with the same problems and what's more, being with people that are willing to listen.

Patience - trying to give 24 hours a day care 7 days a week and yet knowing in your heart that you are physically and mentally exhausted, yet not willing to admit this even to yourself, but in that group everyone understands - they've been there or are there.

Purpose - as caregivers to reach out to each other for understanding, comfort and information.

Openness - with each other to afford addistance in caregiving in ways we may not have considered previously.

Rapport - the knowledge that we are not alone in our problems and the reaching out to others in the same "boat" as we are.

Truth - to finally realize that some alternatives may not be appealing, but the only possible solution or just being able to face . . . the disease . . . and what that means to us personally.

Gathering - just the feeling within the group to be able to react and interact with people who know what (the disease) is and are trying to deal with it too.

Reporting - finding out what progress is being made within individual groups to advance education among all people.

One - As one person touches another and another and another so does understanding from one caregiver to another caregiver grow.

Unity - the closeness in sharing a common problem with total understanding of each one's individual problems and knowing that although some may be at different stages and not all will reach every stage - the possibility exists and therefore we are together.

Professionals - the final realization that all the professionals were in attendance at the meetings . . . YOU AND ME.

To coin a phrase --- put them all together and they spell SUPPORT GROUP

(Terry Cummings 3:1-2)

Figure 1 - Definition of a Support Group
CHAPTER II

LITERATURE REVIEW

The formation of a biological community without a functioning supportive social community leads to havoc (24:195).

An extensive search of the literature in the fields of sociology, psychology, and specifically support groups was conducted by the Investigator to assist in the planning, implementation and evaluation of this project. The bibliography was coded to provide the reader with convenient reference points to areas in the readings specifically regarding support groups.

Several questions were asked by the Investigator regarding support groups as they related to this project. The questions which form the subtopics for this Chapter (and which form the codes for the bibliography) were as follows:

1. General - What is a support group? Besides a definition, what are its characteristics?
2. History - What is the history of support groups? What is the stimulus for their occurrence? Why do people choose to go to
support groups as opposed to or in conjunction with other forms of therapy?

3. Case Studies/Research - What kinds and types of research has been conducted regarding support groups?

4. Taxonomies/Typologies - What taxonomies, typologies, or classifications regarding support groups have been developed?

5. How Groups Work/Effectiveness - How and why do support groups work or function? What is their effectiveness? What processes are observed?

6. Health Education - How is health education being incorporated into the support group setting?
(Questions: What is a support group? What are its characteristics?)

Support Systems

Support groups are part of the support systems found in our society. To many, support systems and self-help "... are the defining characteristics of human social life: the quest for community and the ability of human groups to adapt through the creation of social role structures" (25:55). It seems to be one of man's ways to create order and meaning to his life.

In a global sense, support systems have been defined as:

... continuing social aggregates ... that provide individuals with opportunities for feedback about themselves and for validation of their experiences about others, which may offset deficiencies in those communications within the larger community context (12:19).

Simply stated, support systems provide continuing guidance and direction as well as self-validation.

Some authors include the giving and receiving of tangible objects or services in their definition. Lopata defines a support system as "... a set of relations involving the giving and receiving of objects, services, social and emotional supports defined by the giver and the receiver as necessary or at least helpful in maintaining a
style of life" (25:55). Obviously, good communication between the giver and the receiver is necessary in this definition. An effective communication system as well as attitudes of sensitivity and respect for the needs of all its members are essential elements for a support system to be effective (33:126).

Two types of support systems have been identified:
1) natural - such as family or marital supports, and
2) spontaneous - those organized by informal caregivers such as those found in a special network of helping people in the community, voluntary service groups, or mutual-help groups (33:125-131). It is with the latter type that this project is focused.

Definitions

Support groups, mutual-help groups, and self-help groups are terms used synonymously in the literature.* They are small groups and as such have been defined as ". . . a plurality of individuals having something in common that makes a difference to them" (33:113). Definitions of self-help groups ranged from the simple to the complex. Simple definitions found in the literature were as follows:

. . . small groups engaged in perpetuating 'a network of affective relations' (33:114).

* The term 'self-help group' was used most often, especially with medically oriented groups, and as such will be used throughout the remainder of this paper.
clusters of like minded or like afflicted individuals who share experiences and offer one another mutual support and aid (9:96).

voluntary network of information sharing and mutual aid (59:269).

voluntary small group structures for mutual aid and the accomplishment of a special purpose (25:57).

Like most simple definitions, the highlights are mentioned, but their application is too general. They lacked specificity. A more comprehensive definition, for working and identification purposes was sought by the Investigator. The working definitions of three separate references were used and/or referred to throughout the literature and are reprinted here as follows (common and/or distinguishing elements and/or characteristics are underlined):

Their membership consists of those who share a common condition, situation, heritage, symptom, or experience. They are largely self-governing and self-regulating, emphasizing peer solidarity rather than hierarchical governance. As such they prefer control emanating from consensus rather than coercion — including majority rule. They tend to disregard in their own organization the usual institutional distinctions between consumer, professionals, and boards of directors, combining and exchanging such functions among each other. They advocate self-reliance and require equally intense commitment and responsibility to other members, actual or potential. They often provide an identifiable code of precepts, beliefs, and practices that include rules for conducting group meetings, entrance requirements for new members, and techniques for dealing with "backsliders." They minimize referrals to professionals or agencies since, in most cases, no appropriate help exists. Where it does, they tend to cooperate with professionals. They generally offer a face-to-
face, or phone-to-phone fellowship network that is usually available and accessible without charge. Groups tend to be self-supporting, occur mostly outside the aegis of institutions or agencies, and thrive largely on donations from members and friends rather than government or foundation grants, or fees from the public (Leonard D. Borman, 6:17).

Because of its length and wordiness, the Investigator found this definition too cumbersome for practical use. However it does point out some of the unique characteristics of self-help groups.

The next definition, formulated by Katz and Bender, was most often quoted in full, or in part, in the literature.

Self-help groups are voluntary small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change.* The initiators and members of such groups perceive that their needs are not, or cannot be met by or through existing social institutions. Self-help groups emphasize face-to-face social interactions and the assumption of personal responsibility by members. They often provide material assistance, as well as emotional support. They are frequently 'cause'-oriented, and promulgate an ideology or values through which members may attain an enhanced sense of personal identity (33:9).

The Investigator found Katz and Bender's definition limiting because of the last sentence which could be

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* Some authors used a shortened version of this definition by stopping at this point.
misconstrued to mean only "global" causes and not "personal" causes. Levy writes:

Its (the support group) primary purpose is to provide help and support for its members in dealing with their problems and improving their psychological function and effectiveness; its origins and sanctions for existence rest with the members of the group themselves rather than with some external agency or authority; it relies upon its own members' efforts, skill, knowledge, and concern as its primary source of help, with the structure of the relationship between members being one of peers, so far as helping and support are concerned; it is generally composed of members who share a common core of life experience and problems; and finally, its structure and mode of operation are under the control of members although they may in turn draw upon professional guidance and various theoretical and philosophical works (48:221-222, 46:311-312).

Levy's definition was of the greatest utility to the Investigator (not because of similarity in surnames) because it could easily be broken down into component parts or conditions which were understandable. It was general enough to readily encompass the identifiable characteristics of all types of self-help groups and yet it was specific enough to be workable. As underlined in the preceding text, Levy's definition of self-help groups must satisfy five conditions:

1) Purpose - help and support
2) Origin and sanction - with members themselves
3) Source of help - members themselves
4) Composition - common experience and problems
5) Control - members themselves
Note how the "members themselves" represented the key identifying ingredient in all of the definitions of self-help groups. Drawing from these given definitions, the Investigator presents the following as a proposed definition of self-help groups:

Self-help groups are small, voluntary groups of the members formed by the members and for the members to provide help and mutual support for common problems or experiences.

All of the above definitions of self-help groups were formulated by professionals. It is interesting to note how the participants in self-help groups describe themselves. According to Robinson, based on literature produced by self-help groups themselves, they described and defined their groups as "fellowships" with great stress put on their "common" positions and/or circumstances. It is this understanding based on common experience which produces the necessary common bond of mutual interest and desire to do something about their problem or situation. They also placed great emphasis on the "power of example" and the resumption of "normal activities" in their definition (65:265-6).

It is important, however, not to define self-help groups as refuges for their members. Again, according to Robinson, "... self-help groups are not just refuges. They are much more positive. As well as providing mutual support for those who share a particular problem,
self-help groups find practical solutions to specific difficulties and provide an opportunity for members to build, on the basis of mutual trust and understanding, a new set of relationships and even, for some, a new way of life" (63:416).

**Characteristics**

All of these definitions pointed to the unique characteristics of self-help groups despite their variety of foci. These characteristics were purposely underlined in the definitions presented by the Investigator above and have been itemized extensively in the literature (8:1588, 9:100, 33:9-11, 36:34, 50:67, 63:416, 79:61). Following is a list of identifiable characteristics drawn from the definitions presented by the Investigator and from the above cited literature references.

1. **Commonality** - members share a common condition, problem, situation, heritage, symptom, experience or need.

2. **Mutual help and support** - primary purpose for being.

3. **Peer oriented, sanctioned, and controlled** - groups are formed of members, by members, and for members whether or not a professional has been involved in initiating or referring to such a group. Groups are self-governing and self-regulating. Groups often start from positions of powerlessness.

4. **Helper-theory principle** - "One who gives help, receives help" - the primary source of help within these groups is the members themselves - their efforts, skill, knowledge, and concern - and by giving help,
members receive help. Face-to-face interaction and assumption of personal responsibility is emphasized. Members function as both providers and consumers of care.

5. **Non-professional** - many of these groups form because members perceive that their needs are not, or cannot be met by existing professional or social institutions. Even when their existence has been stimulated by a professional, it has been done to "fill a gap" in existing services. Referrals to and from professionals can and do occur.

6. **Cheap** - costs are minimal, if any, usually coming from voluntary donations.

Killilea added several more core characteristics of self-help groups to the list above (63:416).

7. **Differential Association** - refers to the reinforcement of self-concepts of normality, which hastens the individual's separation from their previous identities.

8. **Collective will-power and belief** - represents strong validation for the member when several people think the same as he/she.

9. **Importance of information** - the giving and receiving of information is very important for the members. From knowledge can come attitude and behavior if the member so chooses.

10. **Constructive action toward shared goals** - behavior change is a major goal of many of these groups and because it is a shared goal, constructive action seems to occur (63:416).

In addition to the above characteristics, Reissman felt "... one of the most significant characteristics of mutual aid groups is the fact that they are empowering and thus dealienating. They enable their members to feel and
use their own strength, their own power, to have control over their own lives" (61:41). Members attain a sense of self-esteem. Feelings of alienation from society is mentioned over and over again by members of self-help groups. In fact, it has been noted as one of the major motivating factors for creating or joining such groups. Our society emphasizes self-reliance and "normal" behavior (as defined by society). Anything that causes one to be dependent or display "abnormal" behavior, is considered to be "deviant." To have a disability, be it physical or mental, results in isolation from the social community.

Feelings of isolation and alienation are especially true for the increasing numbers of persons who have chronic diseases. Coping and/or adapting to a chronic disease, illness or health related disorder has been one of the major motivating forces for development of medical self-help groups.

As acute illness has been treated more successfully and the complications of chronic illness is reduced, patients have taken more notice of the problems that arise from trying to lead normal lives. Fellow sufferers may often understand these problems better than a doctor (43:1494).

Lieberman and Borman describe medical self-help groups as "... a network of persons suffering from the same affliction or condition, who meet together or otherwise contact each other regularly to exchange information and share common experiences" (50:44).
According to Gussow and Tracy, our present health delivery system is based on an acute illness relational model (22:413). This means that physicians' training and focus is different from their patients. They are trained in acute hospitals which deal with only ten percent of all medical problems. Also, the vast bulk of medical care in the United States is provided in ambulatory settings where fifty percent of the cases are for one or more chronic conditions. And finally, there are adaptive problems for the patient once the acute phase is over and he/she is faced with a "no cure" chronic condition, which professionals seem unable (or unwilling) to deal with.

"Whenever a hiatus exists between felt need and the existence of available services and programs adequate to meet such needs, the ground is prepared for the development of a social movement to fill that vacuum. The emergence of consumer-initiated services - in this case, self-help health organizations - constitutes such a movement" (22:413). Gussow and Tracy further report "Self-help groups provide assistance, encouragement and needed services for those with chronic, disabling conditions involving a number of emotional and social adaptive problems. . . . In view of the functions they perform, they seem to fill an important gap in the network of agencies and professional practitioners making up the health service delivery system" (22:407).
Because the chronically ill or disabled person most often requires the assistance of a caregiver and because this caregiver is usually non-professional (family member or friend), this person too has adaptive and coping problems unique to their situation. It is for this reason that many self-help groups are organized by and for family members or friends. The Investigator's project was developed for just such a population, that is, to provide a support group (or self-help group) for caregivers of chronically ill persons.

Self-Care Groups

It is important to note that self-help can go one step further toward assisting a person in independent behavior. This step is the self-care group. Self-help and self-care have often been used synonymously in the literature, but there are differences. Self-care has been described in the following ways:

... individual deliberate action on behalf of his own, his family's or his neighbor's well-being (9:96).

... activities a person initiates and performs in his own behalf in order to maintain life, health and well-being (36:35).

... those processes that permit people and families to take initiative, to take responsibility, and to function effectively in developing their own potential for health (57:487, 80:58).

... a process whereby a lay person can function effectively on his/her own behalf in health promotion and prevention and in
disease detection and treatment . . . (as) the primary health resource in the health care system (19:108).

Like self-help groups, self-care groups have sprung up from common health care problems such as inadequate service, complex bureaucracies, elevated health care costs, and depersonalization. Both self-help and self-care groups attempt to regain a sense of control for its participants and each involves the use of self as the major factor in providing health care (36:34). However, self-care groups go further by educating their participants to be more involved, if not to assume full responsibility, for their health care.

Seven areas of self-care activity have been identified by Norris:

1. Monitoring, assessing, diagnosing
2. Supporting life processes
3. Therapeutic and corrective self-care
4. Prevention of disease and maladjustments states
5. Specifying health needs and care requirements
6. Auditing and controlling the treatment program
7. Grassroots or self-initiated health care (57:487).

Butler, et al., prefers to refer to "self-care" as activities occurring in concentric circles (9:95). The Investigator found this description most helpful in planning this project as it clearly illustrated where health educational efforts could be most effective. The
following figure is the Investigator's own diagrammatic rendition of Butler's description.

Figure 2 - Self-care

It is interesting to note from studies done in Great Britain and Denmark that 90 percent of those who seek professional help have practiced relevant self-care before seeing the professional practitioner (9:97). Also,
"self-care practices account for 85 percent of all health care in the world" (9:96). Despite criticisms by the health provider community, self-care groups do not see themselves as competitors, as they did not perceive their needs to be met adequately in the first place. Secondly, the essence of self-care is control, responsibility, freedom, expanded options and an improved quality of life, all of which have been professed as goals of the medical community for their patients. Self-care should be viewed as a partnership with professionals (57:486).

Whether one refers to support groups, mutual aid groups, self-care groups or self-help groups, they all can be viewed in the poetic description offered by Gerald Caplan, that is, they represent "... a kind of island of stability and comfort in the turbulent sea of daily life" (11:6).
2. HISTORICAL DEVELOPMENT OF SUPPORT GROUPS

(Questions: What is the history of support groups? What is the stimulus for their occurrence? Why do people choose to go to support groups as opposed to or in conjunction with other forms of therapy?)

Early History

Mutual aid is not a new concept. "Throughout history, people have used connections with small groups, with family and kinfolk, with peers and the like minded, to give themselves anchorage in stormy, shifting seas . . ." (33:3). (However) "... there are underlying differences between primitive mutual aid, which were devoted to helping members survive in a hostile or impoverished environment, and the contemporary self-help groups of post-industrial society" (33:8). Anthropological and archeological research has shown that early, preliterate societies grouped together in tribes or clans for mutual aid. This was described as a "survival-type" of aid. Petr Kropotkin referred to this early form of mutual aid as being essential to the evolution of man when speaking to the Social Darwinists of his time (1918) (40).

Early forms of mutual aid became threatened with the creation of families. This was due to its associated individual accumulation of goods and hereditary
transmission of wealth and power. During the Dark Ages, state powers felt threatened by fraternal or communal activities based on early mutual aid principles and did everything in their power to eradicate such groups. This effort was unsuccessful. By the time the Middle Ages were reached, cooperation and mutual aid again became distinguishable in the form of communities joining together. This was especially evident in response to the effects of the Black Death which was so devastating at that time. However, this aid was exclusive, that is, only in-group members were afforded assistance due to strong prejudices regarding race, religion and territory. This tendency for "exclusive" mutual aid continued into present modern times (33:15-16).

The earliest historical reference found by the Investigator referred to Christine DePisan (1363-1431), a Venetian. She advocated the formation of women's clubs for the collective protection of women and where they could be educated and gain health knowledge (55:63). Generally, however, it wasn't until after the French Revolution and the post-Napoleonic reaction that writings regarding mutual aid could be found in the literature (22).

History in Modern Europe

Mutual aid in modern Europe was stimulated by several political and social factors. Beginning in the
16th Century, there was the Protestant challenge to Catholic dominance compounded by resultant inadequacies in church and state to meet needs of the uncomfortable and rebellious poor. Proceeding into the 19th Century, industrialization and the chaos (social, economic and health) of an evergrowing population stimulated the development of cooperative groups (i.e., "Friendly Societies," "Mutual Benefit Societies," etc.). It may be generally stated that "... the major impetus for mutual aid and self-help has come from the poor, the underprivileged, the powerless ... generated by the human need for emotional sustenance through day-to-day interaction with the like-minded" (33:14).

History in the United States

Mutual aid in the United States followed its own unique course. Early colonists followed the pattern of mutual aid through small community neighborliness. This was rather "survival-type" oriented in response to protection from enemies and nature. This was short-lived, however, due to: 1) marked individualism in production, ownership and consumership, 2) fertile land and 3) freedom from oppressive state control (32:272, 33:18). These are unique characteristics of American society that exist even today. As town and rural living became more complex in the 1800's, mutual assistance organizations were formed for collective purchasing power. By 1900, a directory
listed over 250 independent national voluntary lay organizations (82:452). It wasn't until the mid-19th century and the effects of the Industrial Revolution were felt that a wave of cooperative activity became evident. Trade unions were instrumental in this respect, however, exclusivity still prevailed. Immigrant groups turned to each other for help and large networks for self-help and mutual aid were organized. These were materialistic in nature.

The shift to mutual aid as we see it today was not easy owing to some definite social and psychological barriers in American culture.

1. Nature of the problems to which such groups were devoted. (These were usually disease oriented and the having of a disease was considered socially unacceptable and represented a "failure" in the idealized "strong, independent personality.")

2. Nature of the help required in dealing with the problems. ("Needing help" was not recognized as an acceptable trait in our society.)

3. Nature of the personnel best suited to give that help. (Physicians have been given a worshipped status in our society and the assistance of any other personnel was to be mistrusted.) (82:452-453)

World War II earmarked the greatest impact to the above barriers. Our insulation and isolation was broken. Viable alternatives became evident as other cultures were observed. An unprecedented growth in the numbers of self-help groups occurred in response to felt needs.
Influences for Joining Self-Help Group

Several other influences were documented in the literature as being stimulants for their occurrence in today's society. Fundamentalists view the expansion of the self-help movement in the following way,

... new institutions are thought to arise in society when there are meaningful and recognized needs among members of that society that are not being met by existing institutions (49:455).

Another fundamentalist view given was that self-help groups developed to provide alternative pathways to obtain services already acknowledged in the programs of other institutions in society, but inadequately or incorrectly meeting those needs (49:456).

Besides the two fundamentalist views given above, the literature points to another basic influence in our country, that being, the "American joiner instinct." Americans seem prone to seek a social identity and pride through joining clearly defined groups (16:120). This coincides with psychologists noting individual needs for affiliation and community with others in similar conditions (49:456).

Another major influence to the growth and proliferation of current self-help groups is a shift in disease patterns from acute to chronic illnesses and conditions requiring extended attention (22:415). Fifty years ago, 30 percent of all disease was classified as chronic. Today, 80 percent of all disease is chronic and
accounts for 70 percent of all doctor visits (9:103).

Chronic disease conditions require increased patient participation in management and rehabilitation. This has resulted in a fundamental change in the traditional doctor-patient relationship. Unfortunately (or fortunately, because who is to say doctors are the most qualified to give the needed assistance) there are not enough doctors or professionals available to meet all of the patient needs inherent to chronic disease and non-professionals began to take over therapeutic tasks. This especially holds true for "support" and "relationship" processes which became important with the coming of age of psychology and psychiatry (82:454). The convergence of theory, research and practice in the fields of education, psychiatry, applied sociology, and medicine all helped to influence the growth of self-help groups.

There is no doubt but that economics and rising, almost to a prohibitive point, health care costs have stimulated the occurrence of self-help groups. Self-help and self-care offer potential solutions to this problem. As was stated earlier in this Chapter, one of the characteristics of self-help groups is the fact that costs, if any, are minimal.

Along with the economic influence has been the consumer movement, so evident since the 1960's, and its demand for improved and accountable health care in
particular. Consumers have shown dissatisfaction with the existing health care system for several reasons: 1) medical care is too costly and too scarce; 2) doctors are greedy and callous; 3) doctors overprescribe tests and drugs and do unnecessary surgery (9:103). In a way, the self-help movement of the 1960's represented a consumer revolution due to the above plus a renewed wish by people for freedom to control their own health care.

Why People Choose Self-Help Groups

At this point, there are over one-half million self-help groups in the United States (6:16). "Self-help groups are providing for diverse populations in our society which are untouched, rebuffed or little affected by current delivery systems" (7:46). This is occurring at a time when more funds and services have been provided for professional rehabilitation activities than any time in our history. Why then are people choosing to go to self-help groups as opposed to or in conjunction with traditional forms of therapy? Several hypotheses have been proposed by Lieberman and Borman:

1. Self-help groups arise to fulfill services not currently met in society by other systems.

2. Individuals try a variety of helping resources and ultimately find self-help groups because they didn't receive the kinds of help they wanted from other sources. ("Disappointment Hypothesis")

3. Self-help groups require the least expenditure of effort in order to locate
a needed resource for themselves through exchange of tangible and intangible resources presented at self-help group meetings. ("Exchange Theory Hypothesis")

4. Individual perceives self-help groups as being the best fit between their needs and its particular characteristics of service delivery. ("Specification of Service Hypothesis")

5. Individuals immediate social network (primary source of help) is inadequate and self-help groups represent an alternative social support and social linkage system (50:116-123).

Whether one chooses one, all five, or any combination of the above five hypotheses as reasons for choosing a self-help group, there are several goals which have been documented in the literature as being the reason why one in fact joins a self-help group.

1. Endstate goals (extrinsic) such as mental health, awareness, existential issues, interpersonal relationships, political-social goals, change of life style.

2. Process goals (intrinsic) such as similarity-communion goals, cognitive-information processes, modeling, emotional support, linkage with others, altruism.


In summary, people have created and joined self-help groups for a variety of reasons. Initially group and individual survival in the face of environmental threats and deprivations was the motivating force. More recently individual needs carry equal strength and significance. In either case, ". . . men with like needs and goals
persistently seek each other out, no matter what the historical circumstances. The problem of the time and the focus of mutual aid differ widely, but the constant element is men's need to give and take help from one another" (33:23).
3. CASE STUDIES AND SUPPORT GROUP RESEARCH

(Question: What kinds and types of research have been conducted regarding support groups?)

The fact that support groups exist in increasing numbers and seem to be satisfying the needs of its members cannot be denied. Research into why and how these groups function or exist is minimal, but because of increased interest on the part of the health delivery system, more studies of a pure scientific nature should become evident in the literature in the future.

Consideration for Research

There are several problems or considerations which need to be approached when evaluating or assessing self-help groups. Lieberman discussed these problems of assessing the effectiveness or outcomes of self-help groups. (48:223,238). First he stated it is important to know what to measure. Like any scientific study, factors such as reliability, validity, comparability and relevance need to be considered when choosing a measurable instrument. Because of the differences in problems self-help participants present and differences in system level goals, many instruments presently used to assess psychotherapeutic outcomes are inadequate for self-help groups. Lieberman
felt that it was very important that outcome measures reflect system level criteria when assessing the impact of self-help groups. He presented a model proposed by Strupp and Hadley who assessed their groups from three different perspectives: the viewpoint of the client, the viewpoint of the mental health professional, and the viewpoint of society. Using this model, Lieberman suggested self-help groups be assessed from: the clients own perspectives, the perspective of the group, and the external point of view represented by the researcher.

Lieberman also stated that it was important to consider when to measure. Problems inherent with self-help groups which complicate this issue included the long term versus intermittent nature of help giving, the "after-only" requirement in the case of unexpected events (therefore the usual pre-post design cannot be used), the importance of the non-occurrence of events in the case of addictions, and finally, the problems of when to measure "spontaneous" recovery. When you measure must be carefully documented if the study is to be considered reliable, valid, comparable and relevant.

Finally, Lieberman stressed the problem of how to measure. Control groups are exceedingly difficult to design. Because of the nature of self-help groups, there is no way to control self-selection. Subjects cannot be randomly assigned. Another complication is that
frequently self-help group participants use multiple forms of help. About the only thing you can examine is how members and non-members differ and perhaps the kinds of involvement that occurs between members.

Generally, the studies found in the literature and reviewed by the Investigator were exploratory in nature or were just "reports of findings" on a particular self-help organization. Observation is a critical tool for the researcher and should not be discounted in any way. From observation can come further questions and inquiry and ultimately pure scientific research. As stated by Selltiz,

The significant chance observation . . . is largely a gift of the gods . . . We must distinguish between the chance observation that points to a hitherto unsuspected phenomenon or suggests some important hypothesis and the systematic followup observation that makes something of this gift (70:200).

Benefits of Self-Help Groups

Benefits of self-help groups as reported in bibliographic references numbers 5, 10, 13, 18, 19, 20*, 21, 28, 29, 42, 43, 52, 53, 54, 56, 62, 67, 68, 72, 74, 76, and 78 included:

1. help and understanding

2. renewed strength for coping

* Note: Bibliographic reference number 20 represented a group similar to the group developed by the Investigator. Needs to ventilate, express anger and resentment, besides opportunities for discussion and mutual support were stressed.
3. decreased isolation
4. decreased depression
5. increased sensitivity of health professionals
6. increased self reliance
7. increased independence
8. increased communication
9. attitude change
10. increased knowledge
11. increased decision making skills
12. decreased rehospitalization rate
13. a chance for normal people to experience normal grief

In general, the reports were positive in nature. At this point in the history of documentation regarding self-help groups, the Investigator was unable to find any reference pointing to a failure in the self-help group modality.

Besides benefiting the participants, professionals, if involved in any way, also reaped benefits. They became more sensitive to the needs of the members which were not being met by the existing medical or social provider communities. Professionals became more appreciative of the benefits of the support group setting. Levy reported on a national survey of the utilization and evaluation of self-help groups by out-patient mental health facilities making and receiving referrals to and from self-help groups (attitude survey of professionals) (47). It was
generally felt by the respondents that the self-help group's effectiveness was positive and that self-help groups could play an important role in a mental health delivery system. However, and unfortunately, only 30.7 percent of the respondents believed that the probability was high that their agencies would be interested in exploring how their activities might be integrated with those of self-help groups. This latter statement points to the continued reluctance on the part of professionals to recognize and utilize the worth of self-help groups.

**Case Studies**

Two studies surveyed members of self-help groups themselves. The first one by Hatfield involved sending a questionnaire to 250 members of a caregiver self-help group (families of schizophrenics) to determine their feelings regarding the merits of professional versus non-professional supports (23). One hundred seven questionnaires were returned of which 89 were usable. Results showed that friends (84%) and family (73%) significantly outweighed professional therapy (55%) in terms of perceived value to the caregiver. This affirmed the value of the self-help group as a support system. It was felt by Hatfield that the professional service community is markedly unsuccessful as supporters and even "... implicates the family as aggravating or even generating the
illness (dysfunctional guilt in traditional therapy)"
(23:568).

Another study by Knight, et al., surveyed eighty members of nine self-help groups in one of the first systematic attempts to ascertain the source of help giving for persons with psychological problems (37). The results of this survey suggested that: 1) self-help groups serve a different population than do professional therapists (the researcher finds this very interesting!), 2) help giving processes are mostly supportive in nature (this reaffirms the "helper theory principle"), and 3) optimistic attitudes toward increased collaboration with professionals and self-help groups is justified (Hooray! but there is a big step between optimistic attitude and action).

Of all the references cited by the Investigator, only two could be classified as "controlled" studies. The first was by Butler, et al., who reported on a self-care program called the "Activated Patient" in Reston, Virginia (1975) under the direction of Georgetown University (9). This program was based on Sehnert's book, How to be Your Own Doctor (Sometimes). It is interesting to note that this program was developed quite by accident as a result of a survey (needs assessment) of 145 persons (elderly) living in the area (39). The survey indicated the need for patient education regarding self-reliance and coping
with chronic medical problems. [The project developed by this Investigator was also as a result of a consumer survey/needs assessment which indicated the need for a support group for caregivers (41)]. The results of Butler's study of the experimental group showed: 1) participants health habits were usually affected in a positive manner. Test results on health knowledge, attitude, clinical skills, life styles, and treatment behavior were consistently higher for the experimental group. They consistently displayed more appropriate self-care activities; 2) the experimental group displayed greater readiness to use allied health professionals plus expressed more satisfaction with their doctors; and finally 3) the numbers of emergency medical calls decreased.

A second "controlled" study involved self-help intervention with widows (78). After two years it was determined that those receiving intervention followed the same general course of adaptation as the control group, but the rate for achieving landmark stages was increased for the intervention group.

One report, worth mentioning at this point, involved a review of the literature by its author, Levy, as well as his personal observations of self-help groups (46). Generally he found: 1) self-help groups to be variable and diverse in their approach (obviously one of the reasons scientific research is so difficult); 2) their
membership cut across various demographic dimensions along which social groups are usually divided, however, common purpose or problems overrode differences in socioeconomic, educational and occupational differences; and 3) membership, except for Alcoholics Anonymous, was predominantly female, a fact which is also true of other forms of psychotherapy. (Apparently cultural factors have conspired against men affiliating with self-help groups.) Katz and Bender (33) further observed that self-help groups average no more than 15-20 persons as that number has been established in the literature as constituting the upper limit for optimal communication.

Research on Help-Seeking Behavior

Because of the paucity of research available on self-help groups per se, the Investigator consulted the literature of psychology and sociology. Two studies were noteworthy regarding help-seeking behavior. According to empirical studies quoted by Lieberman and Borman (50), the majority of people experiencing troublesome life events do seek help. Age and race seems to be major factors which differentiate those who do or do not seek this help. As a person becomes aged, help-seeking declines. White persons, more than Blacks, seek help. In general, someone who is young, White, educated, middle class and female seeks help more readily than one who is older, Black, non-educated,
lower class and male. The help they seek is comfort, reassurance and advice.

Rosenblatt and Mayer described a study/survey comparing help-seeking experiences of women of different races and educational backgrounds (66). Their findings regarding utilization of professional help were that: 1) as women became more educated, they were more apt to seek professional help; 2) White women were more likely than Black women to seek and use professional helpers except at the very lowest economic levels; and 3) education has a greater effect on professional help seeking patterns of Whites. All of these findings were expected and in accord with previously published works. In regard to utilization of non-professional help, however, some interesting findings were noted. First of all the effect of education was not direct, rather it was curvilinear. That is, more educated women were more apt to use informal helpers up to a certain point and then use decreased. Second, both Black and White women made equal use of informal helpers, and lastly, the effect of education was approximately the same for both races.

Research on Caregivers
Feelings of Burden

The most influential study regarding development of the researcher's project was a study by Steven Zarit, et al. It referred specifically to feelings of burden felt by caregivers of impaired elderly (81).
The surprising aspect of this study is the extent of burden reported by primary caregivers of persons with senile dementia was not related to the behavior problems caused by the illness, but was associated with the social supports available. The ability of caregivers to cope may depend on the other supports available to them. One implication of these findings is that an intervention program that increases informal social supports may be effective with a caregiver who reports excessive feelings of burden.

It is the Investigator's opinion that Zarit's findings are applicable to diseases or conditions other than Alzheimer's Disease. Chronic diseases in general may cause excessive feelings of burden for the caregiver as well as the patient. Zarit and the researcher's opinion is supported by Garrison and Howes research into network therapy. "The goal (of network therapy) is to use effective and instrumental resources present to promote coping with problem behaviors. By helping the entire natural support network to share in the supportive care, the responsibilities of the primary caregiver are reduced and hence burden may be lessened". A support group, such as that developed by the Investigator, can meet such a goal.

Suggestions for Further Research

It is obvious to the Investigator, after surveying the above cited literature, that further research is necessary for the health provider community to efficiently tap this resource. Levin, in his report
on a Symposium of self-help and self-care conducted in Copenhagen in 1975 (44), states that research and the building of self-help and self-care theory should rely on culturally determined behavioral categories, with professionally derived categories being viewed as supplementary, not subordinate. It should be a synthesis of lay, professional and institutional attributes (44:51). This symposium proposed researchable issues under five main headings.

1. Social studies - social phenomena; historical, cultural and psychological forces; factors influencing lay interest in self-help and self-care.

2. Clinical and educational studies - criteria for self-help/self-care skills; developing educational strategies; clinical and descriptive studies of groups in the community setting; evaluation of programs and their available educational materials.


4. Policy studies - economic and organizational.

5. Quality control studies (44:53-73).

The above is a formidable list and it is the opinion of this Investigator that the task of attacking this list has just begun. Professional, lay, governmental, and international organization (as per WHO Declaration of Alma Ata [63:415]) interest is present and just may be the catalyst for action.
4. SUPPORT GROUP TAXONOMIES AND TYPOLORIES

(Question: What taxonomies, typologies, or classifications regarding support groups have been developed?)

Part of the research, found in the search of the literature, pertained to the breaking down of support groups into classifications, typologies, or taxonomies. Because of its importance in defining a group to be studied or compared, this concept is discussed separately in this section. The variety of origin and purpose, numbers, and extraordinary diversity inherent to support or self-help groups makes it almost impossible to study support groups as a whole except in very general terms. Thus attempts have been made by several authors to distinguish between the different types of groups. This section represents an attempt on the part of the Investigator to present these typologies, taxonomies, or classifications.

Classifications Based on Review of Available Literature

Killilea (12:37-93) did the most extensive search of the literature, found by the Investigator, and was most often quoted by other references. Her breakdown of how self-help groups are viewed represents not so much a
classification of self-help groups per se, but rather a classification of how groups are viewed by various authors in the literature. Her classification was separated into four general sections. First she referred to characteristics of a global nature. Next she referred to categories which focused on the relationship of these groups to the formal caregiving systems. Third she referred to the kinds of communal solidarity offered. Last she referred to writings regarding the functions of various groups. A summarization of Killilea's classifications follows. For the Investigator, it represented a vocabulary and major breakdown of the various ways in which self-help groups are viewed. This could subsequently be used and referred to when separating groups into workable (studyable) characteristics.

A. Characteristics of a global explanatory nature

1. Social assistance - Petr Kropotkin's evolutionary nature of man requiring group life and mutual aid confirms this characteristic.

2. Support system - "A support system implies an enduring pattern of continuous or intermittent ties that play a significant part in maintaining the psychological and physical integrity of the individual over time" (12:41).

3. Social movement - this represents a search for order and meaning to reality, not only to the larger external environment, but also to the immediate psycho-social situation.
4. A spiritual movement and a secular religion - this involves faith and acceptance of regulations handed down by a higher authority. This is particularly evident in groups such as A.A. where a "creed" is followed.

5. A product of social and political forces which shape the helping services - these forces are historical, social, intellectual, political and economic in nature.

6. A phenomenon of the service society - economics is the major basis for this viewpoint and refers to the "service revolution" following on the heels of the industrial revolution.

7. An expression of the Democratic ideal, that is consumer participation - "... people determine how they view themselves and through which they demand the kinds of services they feel are appropriate to meet their needs" (12:46).

B. Categories which focus on the relationship of these groups to the formal caregiving systems

1. Alternative caregiving systems - this is a consumer response to inadequacies in the classical medical care system responding to human needs for support in areas between treatment, adaptation, and rehabilitation.

2. An adjunct to the professions - self-help groups are here seen as a solution to the manpower problem.

3. An element in a planned system of care - this may represent the future place of self-help groups in the caregiving system as it only occurs in very few instances at present.

C. Kinds of communal solidarity offered

1. An intentional community - such as utopian communes or concept-type drug programs (i.e., Synanon).

2. A subculture or way of life - such as A.A.
3. **A supplementary community** - Parents without Partners and Little People of America represent this type of group.

4. **A temporary/transitional community** - such as ex-patient groups.

**D. Nature of the functions of various groups**

1. **Agencies of social control and a resocialization process** - such as Weight Watchers, Synanon, A.A.

2. **Expressive/social influence (instrumental) groups** - expressive groups are concerned principally with self-interest and satisfaction of their members. Social influence groups seek to impact the larger society and bring change on behalf of their members.

3. **Organizations of the deviant and stigmatized** - in order to counteract isolation and alienation. Actually most self-help groups in the United States are established by groups of individuals who share a condition stigmatized by the larger community (12:61).

4. **A vehicle to aid coping with long term deficits and deprivations** - such as ostomy groups.

5. **A vehicle to aid coping with life cycle transitions** - these groups provide access to new social roles (i.e., La Leche League, Parents Without Partners).

6. **A therapeutic method** - in and of itself as opposed to orthodox psychotherapy.

As the reader can see, Killilea's classification is quite extensive. Also groups transcend various classifications which is typical of all typologies. Killilea's classification is too great in number and diversity to be workable variables for practical research. Several authors have approached this problem and following is a presentation of their various attempts.
Classifications Based on Psychotherapeutic Method

The literature points to classifications as to type of psychotherapeutic methods used in general. One of the earliest attempts was by Thomas in 1943 (12:75). He broadly divided therapeutic methods into two types, analytic or repressive/inspirational, which overlapped depending on the type of therapy used. Following is the Investigator's diagrammatic representation of Thomas's classification which combines two figures representing his work.

<table>
<thead>
<tr>
<th>Group workers</th>
<th>Individual workers</th>
</tr>
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<tbody>
<tr>
<td>Schilder</td>
<td>Freud</td>
</tr>
<tr>
<td>Wender</td>
<td>Adler</td>
</tr>
<tr>
<td>Lazell</td>
<td>Jung</td>
</tr>
<tr>
<td>Chappell</td>
<td>Hypnosis - analytic</td>
</tr>
<tr>
<td>Marsh</td>
<td>Riggs</td>
</tr>
<tr>
<td>Pratt, etc.</td>
<td>Dyerine-Dubois</td>
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<tr>
<td></td>
<td>Mesmer</td>
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<tr>
<td></td>
<td>Hypnosis - suggestive</td>
</tr>
<tr>
<td>Schroeder</td>
<td>Suggestion</td>
</tr>
<tr>
<td>Altzhuler</td>
<td>Coue</td>
</tr>
<tr>
<td>Alcoholics</td>
<td>Christian Science</td>
</tr>
<tr>
<td>Anonymous</td>
<td></td>
</tr>
</tbody>
</table>

Analytic

Repressive, Inspirational

Figure 3 - Therapeutic Method Comparison
This classification, of course, refers to professional group and individual therapy, but it was a start.

More recently, Lieberman presented a continuum typology describing self-help groups depending on the amount of professional involvement (12:76). On one end of the continuum was socially sanctioned, professionally led groups (Type I). On the other end was the Self-Help Movement (Type IV). In between was the Human Potential Movement such as sensitivity training and encounter groups (Type II) and then Consciousness Raising Groups (Type III).

Classification Based on Structure and Function

Another general classification of self-help groups was presented by Hess (25:58). She divided structure into emergent or crystalized and divided function into expressive or instrumental. From this division a matrix was created into which various types of self-help groups could be placed according to structure and function.

As stated previously, support systems in general are of two types: spontaneous or natural support systems such as marital or family ties; and organized supports not directed by professionals such as voluntary service groups, religious supports, and mutual help supports (11). This latter type, mutual help or self-help groups, have been divided and classified in several ways by various authors. The simplistic division, found by the
Investigator, was by Tracy and Gussow. They divided self-help groups into two types:

**Type I - truly mutual help associations.** Provides direct services to patients and relatives in the form of education, coping skills, peer encouragement and other supporting activities in helping the afflicted deal adaptively with a problem. (Inner focused)

**Type II - foundation oriented associations.** Emphasis is on promoting research, fund-raising, public education, and legislation and lobbying activities. (Outer focused)

(9:100, 76:381)

These two types are not mutually exclusive, however Type I tends to be more loosely organized and operated with small or non-existent budgets. Lieberman (48:222) also used a similar two-type classification.

Gartner and Reissman further broke down Tracy and Gussow's Type I classification into four sub-categories:

1. Rehabilitative work (i.e., Mastectomy and stroke groups)
2. Behavior modification (i.e., drug, obesity, smoking groups)
3. Adjustment to lifestyle (i.e., widow's, women's groups)
4. Prevention and casefinding (i.e., high blood pressure groups) (9:100)

Bean and Levy preferred to divide self-help groups into three categories according to how their members are helped:

1. Groups that help with a crisis
2. Groups that help people with a permanent and/or stigmatized condition
3. Groups that help people trapped in a habit, addiction, or self destructive way of life (12:77).

Classification Based on Purpose and Composition

The most often quoted (and thus the researcher assumes preferred) classification of self-help groups was that developed by Levy which was based on the self-help groups purposes (objectives) and composition:

Type I - Behavioral control - The objective of these groups is some form of conduct reorganization or behavioral control. (i.e., A.A., Gamblers Anonymous, overweight groups)

Type II - Shared predicament - The objective of these groups is amelioration of stress, strain, or burden, through mutual support, caused by the shared, similar or common status or predicament of its members. (i.e., Parents Without Partners, ostomy associations, associations for parents of handicapped children) Noteworthy of these groups is that no change of status is required.

Type III - Survival oriented - The objective of these groups is to maintain or enhance self-esteem, through mutual support of consciousness raising, as its members, because of their lifestyle or sexual preferences, have been labeled as deviant by society and they are discriminated against. (i.e., gay groups, minority groups)

Type IV - Personal growth - These groups focus on, have as their objective, personal growth, self improvement, character development, and greater joy and effectiveness in living. (i.e., integrity groups, communes) (12:78, 17:39, 36:34, 46:312-313)
Classifications Based on Primary Focus

Another classification to be presented was that preferred and developed by Katz and Bender. The breakdown found most useful to them was one that divided groups according to what they (Katz and Bender) perceived to be the groups primary focus.

Type 1 - Groups that are primarily focused on self-fulfillment or personal growth. These are often referred to as "therapeutic groups." (i.e., Recovery, Inc.)

Type 2 - Groups that are primarily focused on social advocacy. (i.e., welfare rights organizations)

Type 3 - Groups whose primary focus is to create alternative patterns for living. (i.e., gay groups)

Type 4 - Groups whose focus is refuge for the desperate. Katz and Bender refer to these as "Rock Bottom" or "Outcast Haven" groups. (i.e., Synanon)

Type 5 - Groups of a mixed type. (i.e., Parents Without Partners) (32:278-280, 33:37)

Classifications Based on a Structural Continuum

Preferred by the researcher, over the division just presented, was a division developed by Katz based on the differentia that affect or determine a self-help groups structural properties. Each division represents a continuum. Katz refers to this continuum as being representative of the natural evolution of self-help groups. He further uses this continuum to measure the point in the
natural evolution a particular group happens to be. Refer to Figure 4 for the Investigator's diagrammatic representation of Katz's continuums. Although far from complete possibilities, these proposed continuums offer the Investigator measurable variables or divisions on which to base substantive study.

Whether one divided self-help groups according to division of literature, purpose, function, focus, objective or structural properties, some division is necessary to understand their differences and similarities. As stated before, the sheer numbers and their extraordinary diversity makes it impossible to study self-help groups as a single entity.
1. Nature and intensity of the groups ideology

- Detailed, rigidly enforced belief system (i.e., A.A.)
- Variety of ideologies (i.e., CR groups)
- No ideology (i.e., single parent groups)

2. Attitudes toward professional helpgivers and agencies

- Outright rejection (i.e., Synanon)
- Limited acceptance (i.e., Recovery, Inc.)
- Complete acceptance and cooperation (i.e., Parents Anonymous)

3. The degree of identification with or rejection of the dominant society and its values

- Rejects (i.e., feminist groups)
- Accepts (i.e., A.A.)

4. The degree to which it employs such democratic practices as the rotation of leadership and division of labor, as contrasted to centralization of power.

- Origin of informal organization phase
- Emergence of leadership organization
- Beginnings of formal organization phase
- Paid staff professional

Figure 4 - Structural Continuum Classification of Self-Help Groups (31:493-4)
5. THE EFFECTIVENESS OF SUPPORT GROUPS

(Questions: How and why do support groups work or function? What is their effectiveness? What processes are observed?)

Exploration into the literature of social research in general (i.e., group dynamics, behavior modification, etc.) as well as exploring the functioning and effectiveness of self-help groups in particular was involved in answering these questions. The groups' effectiveness was considered as a whole as well as specifically to changes in individual members' behavior.

Global Aspects of Social Research

Starting with the global aspects of social research in general, "... the overwhelming weight of evidence is that durability of cognitive and behavioral changes are proportional to the degree of active rather than passive participation of the learner. ... When the goal is to create a long term health habit, the most effective methods incorporate social support" (9:104). In conjunction with this, research supports the hypothesis that, "... the circumstances in which increased susceptibility to disease would occur would be those in which, for a variety of reasons, individuals are not receiving any evidence (feedback) that their actions are
leading to desirable and/or anticipated consequences" (11:1). Self-help groups appear to be effective for their participants in that they provide a social support system and that they exist for persons dissatisfied or resistant to the usual professional interventions or to society in general.

Self-help groups are also time-saving devices as far as individual counseling is concerned. Referring to group dynamics, "... a group of people who are dependent on each other develop a working capacity that is greater than that of individual group members" (21:934). This working capacity is enhanced in self-help groups, as opposed to other groups, because by definition there is a basis of similarity between its members. This latter fact is supported by psychological theory and research into peer influence (16:121) which includes studies regarding therapeutic mechanisms of change (i.e., identification, group cohesiveness, expectations, insight, hope, guidance, catharsis, etc.) and studies regarding group development of counternorms (norms groups develop pertaining to behavior, expressions of affect and cognitive processes among its members which may be counter to that of society). Emrick, et al., presented a model of mechanisms of impact in a consciousness-raising group (16:150) which helped the researcher visualize the processes which occur within a self-help group. This model was
modified by the Investigator (see items in parenthesis) and is presented as Figure 5 to represent self-help groups in general.

Expectations about the helping process

(Self-help group) ← Therapy

Group norms (or counternorms)

Self expression and revealing

Universality and cohesiveness

Increased peer influence

Identification

Feedback

Behavioral rehearsal

Self-concept change

Changes in concepts about (problem)

Behavioral change in society

Figure 5 - A model of the mechanisms of impact in (self-help) groups
Lieberman validated this modified model when he stated that "... the process of change induction in self-help systems involves a basic reorganization of beliefs and attitudes toward a particular problem or affliction in a predetermined direction. The values which usually underlie self-help organizations do not always fit comfortably or easily within more traditional views (i.e., those of mental health professionals) of change processes" (48:229).

Differences Between Professional Psychotherapy and Self-Help Group Therapy

The preceeding model (Figure 5) identifies branches for (traditional orthodox) psychotherapy and self-help group therapy. Before continuing, it is worthwhile to note the differences which occur between these two forms of therapy and may account for persons choosing the self-help method of therapy. There certainly are instances when one or the other (or a combination of the two) forms of therapy are preferred. See Figure 6 which lists some of the differences between Professional Psychotherapy and Self-help group therapy as described by Riessman.
<table>
<thead>
<tr>
<th>Professional Psychotherapy</th>
<th>Self-help group therapy (non-professional)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective, systematic</td>
<td>Subjective, informal</td>
</tr>
<tr>
<td>Elite</td>
<td>Non-elite</td>
</tr>
<tr>
<td>Mystifying</td>
<td>Demystifying</td>
</tr>
<tr>
<td>Expensive</td>
<td>Less expensive (or no cost at all)</td>
</tr>
<tr>
<td>Not sufficiently accountable</td>
<td>More accountable</td>
</tr>
<tr>
<td>Not sufficiently relevant</td>
<td>Immediately relevant</td>
</tr>
<tr>
<td>Condescending</td>
<td>Not condescending</td>
</tr>
<tr>
<td>Knowledge-based approach</td>
<td>Gut level approach</td>
</tr>
<tr>
<td>Need for distance and perspective</td>
<td>Shared disclosures, participants judge each other</td>
</tr>
<tr>
<td>Empathy, but not identification</td>
<td>Empathy and identification</td>
</tr>
<tr>
<td>Practice based on scientific analysis</td>
<td>Practice based on experience and intuition</td>
</tr>
<tr>
<td></td>
<td>Peer initiated</td>
</tr>
<tr>
<td></td>
<td>Consumer centered</td>
</tr>
</tbody>
</table>

Figure 6 - Professional vs Self-help Therapy (61:44-45)
Caplan and Killilea further compared professional and non-professional forms of mutual support as a continuum between a professional/client type of relationship to a friendship type of relationship (12:247-9). Combining two figures given by these authors, the Investigator presents Figure 7.

Figure 7 - Continuum of professional/client to friendship type of relationships
Again, depending upon one's specific circumstances, one or the other type of relationship may be more effective.

**Social Networks and Self-Help Groups**

Self-help groups, as has been stated previously, are part of society's social support system or network and as such can affect the help seeking process and influence an individual choice regarding seeking professional assistance. Lieberman and Borman have identified four ways in which social networks affect help seeking:

1. **By buffering the experience of stress** - serves as a natural support system that counteracts the effects of stressful life events.

2. **By precluding the necessity for professional assistance** - as people perceive their social network as their major source of help.

3. **By acting as screening and referral agents to professional services** - affects/influences decision making.

4. **By transmitting attitudes, values and norms about help-seeking** - may facilitate or discourage use of professional services (50:121).

Studying social networks is a good model for determining the effectiveness and functioning of complex social systems and interactions such as those evident in self-help groups. Findings have shown that how an individual views his social network (positive or negative) will determine how positive or negative the network is and visa versa (75).
Effective Characteristics of Self-Help Groups

From references to social research in general and differences between professional and non-professional types of therapy, we are faced with those references to specific characteristics inherent in self-help groups which make them effective for their participants as opposed to other forms of therapy. Many of these characteristics were mentioned in the discussion of the first section of this Chapter. They were also listed by Killilea in her extensive search of the literature (12).

First, an essential element of self-help groups is the common experience of its members. The fact that individuals share a central problem defines membership status in the group and overcomes individual differences which would otherwise interfere with communication (12:67).

A second characteristic of self-help groups which makes them effective is the element of mutual help and support. Lennenberg and Rowbotham have described a progression of helping with mutual exchange at the crux of each stage:

Stage I - contact between two individuals. The crux of this stage is identification.

Stage II - expansion of identification with another individual to identification with a group. The crux of this stage is passive acceptance of the program.

Stage III - expansion of group identification to identification with its program. The
The crux of this stage is active participation in the program (12:68).

The third and possibly the most powerful mechanism operative in self-help groups, accounting for its effectiveness, is the application of the "helper-therapy principle" (8:1588, 12:69, 60, 61:41-42). This principle is, "...a derivation of role theory, whereby a person playing a role tends to carry out the expectations and requirements of that role" (61:41). Simply stated, those who help are helped themselves. There is much research to support this theory (60). Research by Brager noted improved self image. Research by King and Janis indicates a helper becomes committed to a position by advocating that position ("self-persuasion"). Pearl has shown that being given a stake in the system contributes to commitment which leads to meaningful and self-development. Additional reasons why the person playing the helper role achieves special benefits were listed by Riessman:

1. The helper becomes less dependent.

2. In struggling with another person's problems which is like his/her own, the helper has a chance to observe his/her problems at a distance.

3. The helper obtains a feeling of social usefulness by playing the helping role (ego-enhancement, status, satisfaction, competence).

4. The helper role may serve as a distracting source of involvement and thus divert a person from their own problems and a general overconcern with self (61:42).
Along with the helper theory principle goes role-modeling, mentioned by Gussow and Tracy as a functioning element of self-help groups. "Continued interaction with club members experiencing a positive outcome often reinforces the meaning of such a model" (22:410).

There are cautions to be observed with the helper theory principle and its associated role-modeling. There is a danger of projection and/or manipulation, therefore the helper should not be involved with extensive therapy beyond his knowledge and awareness. Having professional supervision or consultants available would serve as a control for this problem and offer an excellent vehicle for professional involvement in self-help groups.

Killilea goes on to mention a fourth element adding to the effectiveness and functioning of self-help groups. This is called differential association (12:70). It refers to group pressure for change. In criminal groups, this principle has been used to change behavior by actually changing the group identity.

Collective will power and beliefs have been listed as a fifth effective element of self-help groups (12:71). The validation by a group assists a person in his/her individual feelings and attitudes. From this validation can come a sixth element, that being, constructive action toward shared goals (12:73). Passivity is overcome and self esteem is enhanced. From this can come a greater sense of personal responsibility and constructive action.
Reissman has added several more essential properties of self-help groups which lend to their functioning and effectiveness (61). First of all, he refers to consumer intensivity (61:42-43). He feels that self-help groups represent the essence of consumer involvement and thus can affect the quality and quantity of all human services. He quotes Fuller Torrey (who wrote The Mind Game) as saying:

... there are three universal components which are crucial for a successful psychotherapeutic intervention; these are 1) that the client and therapist share a similar world view, 2) that the client has certain expectations of the therapist's intervention, and 3) the personal characteristics of the therapist . . . Indeed a consumer-based approach such as the self-help mode with almost as many intervention formats as there are groups affords much greater opportunity to connect with clients' worldviews, expectations and systems of belief (61:44).

Along with consumer intensivity, Reissman mentions the aprofessional dimension as being another element of self-help groups (61:45). He stated one of the main reasons self-help groups can be effective is because such human service work can be performed by persons with no systematic knowledge of training; rather their ability or skill rests upon their humanness (feelings for people, caring, experience, spontaneity, availability, and time). He cautioned, however, that uncontrolled subjectivity and inadequate knowledge can seriously limit the value of a service and thus feels that there is a
need for training, supervision and knowledge from professionals to provide a balanced, well developed human service practice.

Another element mentioned by Reissman and other authors as accounting for a self-help groups effectiveness is the fact that they are empowering and thus de-alienating (61, 17:39). The isolation, stigma and "alien" aspects of their disease or condition can make coping with it most difficult in our society. This stigma is softened immediately after joining a self-help group. Staying with the group restores self respect, helps adjustment, and places the stigmatic elements in a minor context. From this can come normalization, a process which also occurs in self-help groups. Self-help groups function in a variety of unobtrusive ways to encourage members to behavior more like "normals" (22:410).

Observed Processes in Self-Help Groups

Besides those characteristics, elements and/or processes described above, Levy has listed eleven observed process operable in self-help groups which account for their functioning and effectiveness. He has divided them into two groups: 1) processes with a behavioral focus, and 2) processes with a cognitive focus. Included in the following list are the help giving activities observed in self-help groups as researched by Levy:
A. Processes with a behavioral focus - deals directly with members behavior

1. Direct and vicarious social reinforcement for the development of ego-syntronic behaviors and the elimination of problematic behaviors. (i.e., praise, applause, tangible token rewards, punishment, extinction)

2. Training, indoctrination and support in the use of various kinds of self-control behaviors. This includes monitoring ones' own behavior and advice on how to control and/or avoid situations likely to cue behavior. (i.e., behavioral prescription, behavioral proscription, rehearsal, confrontation, challenge)

3. Modeling of methods of coping with stresses and changing behavior. (i.e., testimonials)

4. Providing members with an agenda of or rationale for actions they can engage in to change their social environment. This process deals with an individual's feelings of powerlessness, helps them to direct attention outward from themself (externalizes the source of the distress) and helps them to view their problems in a broader context. It should result in an actual modification of their social environment so it is more supporting and less stressful. (i.e., personal goal setting, group goal setting)

B. Processes with a cognitive focus - deal with how members think, believe, and interpret

5. By providing members with a rationale for their problem or distress, and for the group's way of dealing with it, mystification over their experiences is removed and expectations for change and help is increased. (i.e., reassurance of competence, empathy, catharsis)

6. Provision of normative and instrumental information and advise. (i.e., explanations, justifications, giving and receiving feedback)
7. Expansion of the range of alternative perceptions of members' problems and circumstances and thus of actions they might take to cope. (i.e., reflection and paraphrase)

8. Enhancement of member's discriminative abilities regarding the stimulus and event contingencies in their lives. Members develop better analytic and discriminative abilities. (i.e., functional analysis)

9. Support for changes in attitudes toward one's self, one's own behavior, and society. (i.e., mutual affirmation, morale building)

10. Reduction or elimination of a sense of isolation or uniqueness regarding a member's problems or experiences through the operation of social comparison and consensual validation. (i.e., self-disclosure, ritualization, sharing)

11. The development of an alternative or substitute culture and social structure within which members can develop new definitions of their personal identities and new norms upon which they can base their self-esteem (46:315-320, 50: Chapter 11).

None of the characteristics, elements or processes discussed so far are unique. That they have all evolved to occur in the self-help group setting at the same time may collectively account for their effectiveness.

Motivation for Joining a Self-Help Group - Effectiveness

Success and effectiveness of self-help groups also seems to be enhanced by the reasons one joins a group in the first place. First of all, members are frustrated or rejected by the larger society and its institutions.
They feel bent, mutilated, and stapled by the bureaucratic system. They personally view their problem as having a high priority in their life situation and thus are motivated to resolving their personal dilemma when they go to a group meeting. This motivation makes self-selection a powerful ingredient in joining self-help groups which adds to its effectiveness.

Whether one joins a group because of self-selection, selective referral (professional or informal social network influences), or by selective recruitment efforts by established organizations to attract people, a group's ability to meet an individual's needs depends on several factors.

1. The group's function and goals
2. The degree of control exercised by the group's structure
3. The recognition of the group by the larger community
4. The severity of the member's stigma or handicap (33:109-119).

Groups vary from highly structured with well developed ideologies (i.e., A.A.) to loosely structured with diffuse ideologies (i.e., Parents Without Partners). For the most part, control and leadership with the group is achieved or earned rather than ascribed. Local autonomy and decentralization is an emphasized value and promotes group cohesion. Recognition by society or the community as well as the severity of the stigma or handicap can
make or break a self-help group. In many cases it is just this stigma which accounts for the group's solidarity.

Growth and Development of Self-Help Groups

Self-help groups are not static elements. They are subject to growth and development just as is any group. Drawing from classic social theory regarding the growth of an organization, Katz and Bender have described five possible stages of growth and development in self-help groups.

1. Origin
2. Informal organization stage
3. Emergence of leadership
4. Beginnings of formal organization
5. Beginnings of professionalism (33:122).

Stage 1 and 2 occur in all self-help groups. Evolution to stage 3 depends on group consensus. Proceeding to stage 4 and 5 also depend on group consensus, but can also alter the group such that it no longer can be considered a self-help group in the classic definition sense. Certainly, stage 5, with its professionalism, alters a group's makeup. There is a tendency, often times, after stage 5 is reached and recognized, for a larger organization to foster and encourage the development of newer and smaller classic self-help groups.
Obviously further research is warranted regarding the group and/or individual processes which occur within self-help groups. Research regarding constraint vs freedom within a group, goal displacement within self-help groups (which may or may not account for the frequent program goal alterations) and further research into growth and development of self-help groups has been suggested by the literature.

But no matter what functions, elements or processes are accountable for the self-help group modality being effective and despite the paucity of research in this area, it is evident that,

... even the least successful or effective self-help groups help give their members an anchorage, a reference point; many additionally give social support and companionship; some make possible real personal fulfillment and aid participants in establishing a changed and acceptable identity (33:231).
6. **HEALTH EDUCATION AND THE SUPPORT GROUP SETTING**

(Questions: How has health education been incorporated into the support group setting? How feasible is it to set up a formal or informal health education program within the support group setting?)

Information, including both technical and anticipatory guidance on expectable problems and phases or transitions, is an important element in almost all mutual help organizations (12:71).

The above quote stated the need for obtaining information as an important element in self-help groups. Also two studies found in the literature (39, 41), via consumer surveys/needs assessments, confirmed not only the need for health information, but the desire for a support group setting. However, despite the important nature of "information" and "support" to self-help groups, the literature was striking in its near absence of printed references regarding health education within the support group setting. The literature did point to this "near absence" being a problem and there were many "suggestions for further research" recommended. Unfortunately, this Investigator can only add to these "suggestions" and present, as able, that which was evident in the printed material.
Governmental, professional and consumer interest in health education has been particularly remarkable over the last twenty years in response to several swiftly moving social currents. One key factor is the consumer movement in general and its demand for improved health care in particular. The shift in disease patterns from acute to chronic, with the associated desire for preventive care, has contributed to increased interest in health education. Finally, economics has provided the final force contributing to self-help and self-care, which of necessity includes health education, in that they offer a potential solution to the increasing and enormous costs of health care delivery (9:101-105).

Governmental interest in this country is earmarked by the formation of the President's Committee on Health Education being appointed in 1971. By 1974, the Bureau of Health Education was formed within the Center for Disease Control. In 1973, the John E. Fogarty Center for Advanced Study in the Health Sciences of the National Institutes of Health, in collaboration with the American College of Preventive Medicine, established eight task forces to analyze preventive medicine. One of these task forces, consumer health education, noted that, "... consumerism, for all its shortcomings, can be a positive force for good health and health related behaviors"
and thus recommended (in 1975 when task force results were published) federal support for research and development in consumer health education, evaluation of resulting techniques and programs, and establishment of a high-level office of consumer health education within the Department of Health, Education and Welfare. These recommendations were honored with the passage of the National Consumer Health Information and Health Promotion Act of 1976 (PL94-317) and the resulting Office of Health Information and Health Promotion within the office of the Assistant Secretary of Health (9:103-105).

Interest has also been seen on an international level per the Declaration of Alma Ata (Section VII) coming from the International Conference on Primary Health Care (organized by WHO and UNICEF, 1978). Included in this declaration is, "... education concerning prevailing health problems and the methods of preventing and controlling them ..." (63:415). This conference also felt that any discussion of primary health care should take into account the "self-help" component. In 1979, an International Conference on the Role of Self-help and Mutual Aid was held in Yugoslavia. A major issue in this conference was the imbalance in resources available to the lay and professional health care systems and thus issues for research were identified in hopes of solving this imbalance (14:62).
Research Regarding Effectiveness of Health Education

With regard to specific studies on the effectiveness of impact of health education programs, the most comprehensive study, referred to in the literature, was that conducted by Little. Their survey concluded that, "... there is evidence that consumer health education programs are able to foster beneficial short-term impact on patient knowledge, attitudes, behavior, and health status" (9:105). (Long-term impact measurement had not been attempted due to expense and the fact that self-help programs measured had not been in existence long enough.) These findings were confirmed by results published on Georgetown University's "Activated Patient Program": 1) patients (and their families) deliberately became involved in their own health care, 2) patients entered in partnership with health professionals, and 3) patients accepted greater responsibility for their own well-being (9:98). The aim of this program was not to replace the physician, but to use professional care more appropriately.

Challenges to Health Education in Self-Help Group Settings

The question now is, who should disseminate health education? According to Fonoroff and Levin (19), everyone performs a health education function whenever one's role includes giving information on what somebody
needs to know in carrying out specific activities which prevent disease occurrence or disability. They further state that,

Health education specialists, however, have an even broader charge. This includes diagnostic and program development skills to determine strategies appropriate for presenting facts on risks associated with personal choice behaviors and evaluation skills to assess the extent to which such strategies impact on personal health behavior and ultimately on a community's epidemiologic profile (19:100).

This includes a special challenge with regard to self-help programs, which by definition are characterized by independence, aversion to formal structure, and tend to operate outside of the health care system. The challenge is whether planned educational strategies need to be bound by values and goals of the classic health care system or whether planning and conducting health education programs includes the flexibility for self-determination of health behavior inherent in the self-help group target population. The danger is there that intervention by professional health education specialists may undermine the very essence or "revolutionary" character of self-help resulting in negative evaluations of their worth and potential premature "writing off" of the self-help groups potential (19:112). Therefore, it is important for professionals to remember, when measuring the effectiveness of health education programs in the self-help setting, that,
Much that makes health education work is process, events occurring through natural interaction of people. Such events cannot easily be structured to represent independent variables (19:112).

Differences Between Patient Education and Self-Help Education

The majority of health education, especially regarding chronic diseases or conditions, conducted so far in this country has been included under the realm of patient education. The literature pointed to some very basic differences between this classic health care system method of delivering health education and self-help or self-care health education. The biggest difference is that patient education is determined by what the professional thinks is good for the patient, whereas self-help or self-care health education is determined by what the learner perceives as his needs or goals (45:70). Self-help or self-care education is much broader in scope, extends to the total environment, and is consumer controlled. Patient education is narrower, individual oriented, illness oriented and professionally controlled (57:487). Figure 8 shows how Levin has beautifully compared patient and self-care education.

It is obvious to this Investigator that patient education would be more effective if it incorporated the characteristics of self-care education. This is confirmed by Yearwood who states that in order for health education
to be effective, the professional should not only know something about the patient, his disease, and know something about other members of the patient's health team, but the professional should be aware of and incorporate into the health education program the patient's supportive network and available community resources (such as self-help groups) (80).

<table>
<thead>
<tr>
<th>Patient Education</th>
<th>Self-care Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Assigns a unique social role to the learner - that of a sick person under the care of another</td>
<td>Does not assume sickness, thereby assigning a generic meaning to care - that is, to look after</td>
</tr>
<tr>
<td>2. Goals are initiated in response to a state of disease</td>
<td>Goals are generally anticipatory of risk - derived from learners perceived needs and preferences</td>
</tr>
<tr>
<td>3. Control designed to impart new knowledge and skills in situations where it is assumed that the patient has little or no experience</td>
<td>Content emphasizes the individual as a decision maker and relies heavily on knowledge and skills he already has</td>
</tr>
<tr>
<td>4. Focuses on individual personal health behavior and activities</td>
<td>Relates personal health status to forces in the environment</td>
</tr>
</tbody>
</table>

Figure 8 - Patient Education versus Self-care Education (45:171)

Health Education Partnership

Health education within the self-help setting should operate on a partnership level between
professionals and members of the self-help group. It has been stated that desire of information is an important element in self-help groups. Obviously the members had not received their needed information from other traditional health care providers. Certainly physicians are too busy to impart all of the needed information to a patient in his office nor may he be the best person or modality to impart this information. Self-help groups do request consultation and input from professionals and health education specialist should see this as an excellent vehicle for providing health education on a formal or informal basis. Commercialized packages could be developed for use by self-help groups being careful not to use these packages as means of bending patient behavior to accommodate the needs of the system (9:105).

In summation, the literature has pointed to a desire and need for health education in the population and studies, be they few so far, have shown the effectiveness of health education in general and within a self-care setting, thus the Investigator concludes that it is, in fact, feasible to incorporate a formal (with caution) or informal health education program within the self-help/support group setting!!

... People want to be able to become more knowledgeable, to understand what is happening to them, and to be able to communicate to professionals. Today, more than ever, what people do for themselves will contribute to the improvement in their health status (39:666).
If you want to help pull a friend out of the mire, don't hesitate to get a little dirty. (Russian Saying, 17:38)

The purpose of this project was to: 1) conduct an extensive search of the literature regarding support groups; 2) design, implement, and evaluate a support group for caregivers of chronically ill persons; and 3) establish the utility of the support group as a health education vehicle. This Chapter will describe the methods used to achieve this outcome. The methodology was divided into four phases:

Phase I - Establishment of the Need
Phase II - Design of Support Group
Phase III - Implementation
Phase IV - Evaluation and Analysis

Phase I - Establishment of the Need

A. Review of the Literature

The bulk of this study was an extensive review of the literature performed by the Investigator. A major purpose of the review was to assist in the planning, implementation, and evaluation of this project. The
literature review was conducted to: provide a current compilation of what support groups are, the stimulus for their occurrence, their history, current scientific research, classifications in use, the dynamics of how support groups work, their effectiveness, and their use as a vehicle for health education. The bibliography was coded to provide future reference to the above stated areas so that it could be used as a tool for research. It is significant to note that the literature supported the feasibility of using the support group setting as a health education vehicle (see Chapter II).

B. Needs Assessment

In 1980, a consumer survey (needs assessment) was conducted for the National In-Home Health Services Agency, a private certified home health agency located in the San Fernando Valley, California (41). This survey consisted of a multipage questionnaire which was mailed to recipients of services from this agency. Survey results indicated the need for supportive services by patients and their families or designated caregivers. One of the questions dealt with the need for family (or caretaker) supportive group meetings. The question asked, "As a family member, if you had the opportunity to meet with other patients' families, to share problems and experiences, would you come?" A highly positive response (42 percent) supporting this need was obtained. Motivation (underlying
need) was not clearly identified, but was felt by the
surveyor to be: 1) psychosocial needs (group support),
2) educational needs (to learn more about the care of the
patient), and 3) informational needs (to exchange ideas
about common problems) (41:52).

Using the 1980 consumer survey (needs assessment)
as a baseline, a follow-up needs assessment was conducted
by the Investigator at the National In-Home Health Ser-
vices Agency in January, 1981. This needs assessment in-
cluded individual interviews with eleven members of the
agency's professional staff (administrators, nurses,
therapists). An introductory statement was made by the
Investigator referring to the 1980 consumer survey and
the specific question relating to the consumer need for
supportive group meetings. The professional staff member
was then asked for his/her opinion regarding the 1980 sur-
vey and the specific question pertaining to support group
meetings. They were further questioned as to whether they
felt the need identified earlier continued to exist, and
would they be in favor of a support group being imple-
mented for families or caregivers of their patients.
Responses were 100 percent favorable.

The positive nature of the above two needs
assessments was presented to the administration of the
National In-Home Health Services Agency as validation of
the need, and interest for a support group for caregivers
of chronically ill persons. Permission was obtained to proceed with Phase II.

**Phase II - Design Support Group**

A. **Program Plan** (see Appendix I)

A program plan (flow sheet) was developed by the Investigator to: 1) aid in the planning and implementation of this project, and 2) provide a guide for future similar projects held by this sponsoring agency or interested persons. A suggested format/content outline was included (see Appendix 2) with alternatives for group meeting sessions to be either structured (definite lesson plan) or unstructured (open, free-sharing discussion).

B. **Setting**

After the need for the project was determined, tentative dates for conducting two support group meetings were selected. Inquiries were made by the Investigator within the community to: 1) ascertain if similar groups were currently and/or had been in existence, and 2) arrange for a setting for this project's support group meetings. Telephone calls were made and personal interviews were held with administrators of organizations designed to give supportive assistance to members of the community. Specifically, the Investigator concentrated on identifying and meeting with administrators of senior citizen centers in the San Fernando Valley.
It was found that a similar support group was presently in existence at the Van Nuys Senior Multipurpose Center. This group was considering dissolution owing to lack of membership. The administration of this Center was favorably disposed to continuing sessions of this group under co-sponsorship with National In-Home Health Services as a means to increase membership within the group and to continue to provide a needed service for the community.

An attendance of ten to twenty persons was anticipated. A small room in the Van Nuys Senior Multipurpose Center was provided for the meeting, and movable chairs, tables and a blackboard were made available. The meetings were scheduled for Thursday, April 23, 1981 at 1 P.M. and Thursday, April 30, 1981 at 1 P.M. A verbal agreement between the co-sponsoring agencies was made on February 19, 1981 followed by a written agreement which was signed on April 9, 1981.

C. Population

1. Selection - Participants for the support group were limited to those persons presently attending, or solicited to attend, the on-going support group at the Van Nuys Senior Multipurpose Center. Participants also included those persons invited to attend who had received invitations and referrals from the National In-Home
Health Services. These were limited to families and caregivers of patients with chronic illness. Persons receiving services through the agency's Continuity of Life Program (hospice program for persons with terminal illnesses) were excluded, by administration request, since other forms of support were inherent to that program. Selection was further geographically limited to persons residing in the San Fernando Valley to insure accessibility to the meeting site.

The population, then, was self-selected (voluntary) and represented members of the senior citizen (over age sixty) population. Considering all of the above, the results of this study cannot be generalized to the population as a whole.

2. Solicitation - Forty-eight invitations were mailed on April 14, 1981 to families and caregivers of patients presently and formerly receiving services from National In-Home Health Services. Included were invitations to respondents of the 1980 Consumer Survey (needs assessment). Invitations were also given to four other home health agencies operating in the San Fernando Valley to distribute to qualifying interested caregivers.

Current members of the on-going support group were verbally invited to attend the co-sponsored sessions. The Van Nuys Senior Multipurpose Center also
advertised the group's meetings in their newsletter and in the local San Fernando Valley newspaper.

Professional staff members from the co-sponsoring agencies were invited to attend, but were cautioned to limit their interaction so as not to alter the basic form of the support group (refer to Chapter II).

Arrangements were made with the volunteer networks at National In-Home Health Services and at the Van Nuys Senior Multipurpose Center to provide assistance with transportation or to provide sitters for the chronically ill person should it be necessary.

Phase III - Implementation

A. Conduct Group Sessions

The first meeting was held April 23, 1981 with seven participants and five professional staff members in attendance. One participant attended as a result of a referral from National In-Home Health Services. Three participants were members of the on-going support group at the Van Nuys Senior Multipurpose Center. The remaining three participants attended as a result of advertising conducted by the Van Nuys Senior Multipurpose Center. The professional staff was represented by three members from Van Nuys Senior Multipurpose Center and two members from National In-Home Health Services (including the investigator). Professional involvement was limited to
facilitation roles for discussion or responding to questions specifically asked by participants.

By prearrangement with the co-sponsoring agencies, the first session was informal and unstructured with emphasis on open, supportive discussion. The first five minutes was devoted to introductions and definition of the support group format. Fifty minutes of open discussion and supportive sharing by the participants followed. Five minutes were reserved at the end of the meeting for verbal feedback and evaluation of the meeting by the participants.

The second meeting was held April 30, 1981. Eight participants, four of whom attended the first session, and six professional staff (three from Van Nuys Senior Multipurpose Center, three from National In-Home Health Services) were present. The format for this session was more structured. Following a five minute didactic presentation by the Investigator, the group focussed on discussing the topic, "How to Talk with your Doctor." Again the first five minutes was devoted to introductions and introductory remarks and the last five minutes was devoted to participant feedback and evaluation of the session.

B. Data Collection

Data collection, for the purpose of evaluation and analysis, was limited to individual and small group
observation by the Investigator and other professional staff present at the group meetings. After each meeting, the Investigator met with one or more of the professional staff present to discuss the functioning of the group as a whole and the interactions of the participants individually.

Verbal feedback responses of the participants regarding the support group meeting was also collected. Of particular interest was their opinions regarding the format of each meeting (structured versus unstructured) and whether they found the meetings useful and/or supportive.

1. **Individual and small group observation.**

Individual and small group observation was conducted by the Investigator and professional participants at the group meetings to determine, from the professional's viewpoint, whether the group qualified as a support group setting and, if so, to identify its type and stage of evolution. This was accomplished by comparing the group to definitions analyzed in the literature review.

Using Levy's definition of self-help groups as a guide (see Chapter II of this study; pg. 16), the group was observed as a whole to determine if it qualified as a self-help or support group. Items used as variables for measurement in the Levy definition were:
1. Purpose - Did the group provide help and support?

2. Origin and sanction - Did the origin and sanction of the group rest with the members themselves?

3. Source of help - Did the source of help or support come from the members themselves?

4. Composition - Did the composed members share a common core of life experience and problems?

5. Control - Did the members control the structure and mode of operation of the group?

A "yes" or "no" answer was recorded by the Investigator for each of the above questions. Explanatory comments were accepted if necessary or applicable. For the purpose of this study, the Investigator accepted three out of five "yes" answers as a positive indication that the group qualified as a support group.

To identify the type of support group the study group represented, Levy's four-type classification based on purpose and composition (see Chapter II of this study; pg. 53) was used for comparison. Comparison against Katz's continuum of growth and development (see Chapter II of this study; pg. 56) was used to determine in which phase the study support group happened to be.

Individual and small group observation was also used to determine the utility of the support group setting as a health education vehicle. The group was compared to characteristics of a support group as listed in the
These characteristics were further identified by the Investigator as being those essential traits of health education: knowledge, attitude, and behavior. Characteristics used for comparison included:

1. Commonality - Did the members share a common condition, problem, situation, heritage, symptom, experience, or need? (Attitude)

2. Mutual help and support - Was mutual help and support given? Was mutual help and support the primary purpose for this group being in existence? (Behavior)

3. Peer oriented, sanctioned and controlled - Despite the fact that professionals were involved with the formulation of this group and acted as facilitators for discussion, was the group peer oriented? Was the group sanctioned and controlled by the group members themselves? (Behavior)

4. Helper-theory principle - Did persons giving help or support appear to get help and support for themselves? (Behavior)

5. Non-professional - Was this group non-professional in focus and nature? That is, were the members' needs being met by other existing professional providers or social institutions? (Attitude)

6. Cheap - Was the cost for attending these group meetings minimal, if any? (Behavior)

7. Differential association - Did the members have reinforced their self-concept or normality? (Attitude)

8. Collective willpower and belief - Were members validated in their beliefs when
they realized other members felt or thought the same as they? Did they feel less alienated? (Attitude)

9. Importance of information - Was the giving and receiving of information important to members? (Knowledge)

10. Constructive action toward a shared goal - Was there any evidence of behavior change or action as a function of attending these group meetings? (Behavior)

A "yes" or "no" answer was recorded by the Investigator for each of the above characteristics' questions. Appropriate comments were also accepted. Also recorded was any observed changes (positive or negative) in knowledge, attitude, or behavior. A change was defined as any observed differences in knowledge, attitude, or behavior within or in between the meeting sessions. Since this project was an exploratory study in nature, any positive changes were deemed by the Investigator as having supported the feasibility of this support group setting as being an effective health education vehicle.

2. Verbal feedback by participants. Verbal feedback from the participants was solicited to determine the effectiveness of the group meeting from the participant's point of view. Positive or negative responses were recorded by the Investigator regarding participant satisfaction with the meeting formats (structured versus unstructured). Participant feelings regarding supportive or helpful aspects of the meetings was also solicited.
Phase IV - Evaluation and Analysis

The data was collected, evaluated, and analyzed to answer three areas of concern (in the form of questions):

1. From the viewpoint of the professional, did the group meetings qualify as support group meetings as compared to definitions presented in the literature? If so, what type of support group did it represent and at what stage is it in its growth and development?

2. From the viewpoint of the participants, did the group seem supportive or helpful? Did the participants prefer structured or unstructured formats? Did they notice any changes in their knowledge, attitudes, or behavior as a result of attending such a meeting?

3. As indicated in Chapter I of this study, health education incorporates the dimensions of knowledge, attitude, and behavior. Using the characteristics of a self-help group, as found in the literature, as indicators of knowledge, attitude and behavior, did the group demonstrate these characteristics? Did any change in knowledge, attitude, or behavior occur? Was the group a feasible vehicle for health education?

The results of this evaluation and analysis are discussed in Chapters IV and V of this study.
CHAPTER IV

RESULTS AND DISCUSSION OF FINDINGS

Self-care (including self-help) is . . . a universal activity. Everybody is doing it. Everybody always has done it . . . in different ways, and we're not even sure just how they've done it . . . (19:109).

Results

This section will describe the findings and results of efforts made toward achieving the purposes of the study.

A. Establishment of the Support Group Model

The components of Levy's definition of a support group (see Chapter II of this study, pg. 16) were used as the model for designing and implementing this project's support group. These components were used as variables against which the Investigator measured, by means of small group observation, whether this project's group did, in fact, qualify as a support or self-help group. The findings of those observations are presented below.

Purpose

The purpose for which a support group is in existence is to give help and support to its members. One hundred percent of the professional staff
observations (validated by verbal feedback from the participants) substantiated that the project's group did in fact provide help and support to its participants. Thus, the purpose of a support group was fulfilled from the professionals' and participants' viewpoints.

**Origin and Sanction**

The origin and sanction for a support group to be in existence rests with the members themselves. Professional involvement was instrumental in the initial creation of this project's support group, but it was based on the positive responses to two needs assessments which were reflective of the perceived needs and interest of potential participants. Therefore, this group originated from the needs of its members. It could not exist without member attendance and participation. It could not continue to exist without sanction from its members. The Investigator and other professional staff observed that this group relied heavily on professional involvement to schedule dates and provide the setting. The group also welcomed the professional as the facilitator for discussion. It was not determined whether the group would continue to exist without professional involvement. Therefore, regarding origin and sanction, this project's group qualifies conditionally.
Source of Help

To qualify as a support group, help or support must come from the members themselves. In a classical sense, this means professional staff should not be the providers of this help and support. Observations by the Investigator and professionals present at the meetings (substantiated by verbal feedback from participants) indicated that the participants did, in fact, receive and give help and support to and from each other. It was impossible, however, for professional presence to be ignored due to the disproportionate numbers of professionals present (seven participants to five professionals at the first meeting, eight participants to six professionals at the second meeting). It was observed by the Investigator that help and support was given by the professional staff present. Thus, regarding source of help, this project's support group qualifies conditionally.

Composition

The members of a support group share a common core of life experience and problems. Common experience and problems, that is, caregiver of a chronically ill person, was the basis for selection of population and solicitation of membership of this project's support group. In addition, the population of this group was further qualified by common geographical proximity to the meeting site and by common age group (over age 60, senior citizen
population). There was no doubt by all of the observers that the composition of this project's group qualified as a support group.

Control

As a support group, the members control the structure and mode of operation of the group. As this project's group was professionally instigated, the structure and mode of operation of the two group meetings were prearranged by the co-sponsoring agencies. The open-discussion, unstructured format of the first meeting was observed to be well received by the participants. The second meeting had a structured format with a planned curriculum. However, in response to the preferences of the group in attendance, the planned activities for that session were modified. That is, instead of role-playing activities, the group preferred open-discussion. Therefore, regarding control, although the structure and mode of operation were initially planned by professionals, the group dictated the course the meeting would take and thus qualifies as a support group with minimal qualification.

The following figure summarizes the above findings. Thus, with qualification, when compared to a model support group, this project's designed and implemented group qualifies as a support or self-help group.
### Component Elements of a model support group

<table>
<thead>
<tr>
<th></th>
<th>Observations of project's support group compared to model</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Purpose</strong></td>
<td>Yes, definitely</td>
</tr>
<tr>
<td><strong>Origin and Sanction</strong></td>
<td>Yes, conditionally</td>
</tr>
<tr>
<td><strong>Source of Help</strong></td>
<td>Yes, conditionally</td>
</tr>
<tr>
<td><strong>Composition</strong></td>
<td>Yes, definitely</td>
</tr>
<tr>
<td><strong>Control</strong></td>
<td>Yes, conditionally</td>
</tr>
</tbody>
</table>

*Figure 9 - Comparison of project's group to components of model support group*

#### B. Type of Support Group

Using Levy's four-type classification based on purpose and composition (see Chapter II of this study; pg. 53), this project's support group was identified as being Type II - Shared predicament. The objective of these groups is amelioration of stress, strain, or burden, through mutual support, caused by the shared, similar or common status or predicament of its members.

#### C. Stage of Growth and Development

Using Katz's continuum of growth and development (see Chapter II of this study; pg. 56), this project's group was identified as being in between the origin phase and the informal organizational phase.
D. Establishment of the Utility of the Support Group as a Health Education Vehicle

Figure 10 indicates the summary of responses to questions asked of the professional observers regarding characteristics of this project's support group (see Chapter II of this study; pg. 18-19). These characteristics were further identified by the Investigator as knowledge, attitude, and behavior traits (essential ingredients of health education). Also summarized are the professionals' observations regarding any changes, positive or negative, in knowledge, attitude and behavior noted within the meetings or between the meetings.

As changes in knowledge, attitudes, and/or behavior are professed as being the goal of health education, the fact that any changes occurred validated the utility of the support group as a health education vehicle for exploratory purposes.

Discussion of Findings

Considering the above results, the Investigator concluded that the purposes of this exploratory study/project were achieved. A useable literature review with resultant coded bibliography was developed. A support group was designed, implemented and evaluated that followed closely the model choosen from the literature. And, finally, the utility of the support group setting as a health education vehicle was validated by noting
changes in knowledge, attitudes, and behavior when compared to characteristics cited in the literature.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Did it occur</th>
<th>Observed changes in knowledge, attitude, or behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Commonality (Attitude)</td>
<td>yes</td>
<td>0</td>
</tr>
<tr>
<td>Mutual help and support (Behavior)</td>
<td>yes</td>
<td>+</td>
</tr>
<tr>
<td>Peer oriented, sanctioned, and controlled (Behavior)</td>
<td>yes*</td>
<td>0</td>
</tr>
<tr>
<td>Helper-theory principle (Behavior)</td>
<td>yes</td>
<td>0</td>
</tr>
<tr>
<td>Non-professional (Attitude)</td>
<td>yes*</td>
<td>0</td>
</tr>
<tr>
<td>Cheap (Behavior)</td>
<td>yes</td>
<td>0</td>
</tr>
<tr>
<td>Differential Association (Attitude)</td>
<td>yes</td>
<td>+</td>
</tr>
<tr>
<td>Collective willpower and belief (Attitude)</td>
<td>yes</td>
<td>+</td>
</tr>
<tr>
<td>Importance of information (Knowledge)</td>
<td>yes</td>
<td>+</td>
</tr>
<tr>
<td>Constructive action toward shared goal (Behavior)</td>
<td>yes</td>
<td>+</td>
</tr>
</tbody>
</table>

(* with qualification - professionals were involved in originating this group and acting as facilitators for discussion.)

Figure 10 - Characteristics and Changes in Knowledge, Attitudes, and Behavior
Although interest was professed by professional staff at National In-Home Health Services Agency via the needs assessments, interest and enthusiasm seemed to lag as the meeting dates approached. It was felt, by the Investigator, that this occurred due to multiple work pressures and priorities inherent to the professional's job description. Despite multiple written and personal reminders, staff referrals remained minimal. As a result, only one participant was present as a result of a National In-Home Health Services agency referral. This added to the disproportionate number of professional staff present at the meetings. Even though professional staff involvement was restricted to facilitating roles, their presence had to have had an effect, if from nothing else than from sheer strength in numbers alone. As indicated in the findings, the resultant professional presence conditionally qualified this group as a support group.

The support group continued to hold weekly meetings at the Van Nuys Senior Multipurpose Center for several months following the project's meeting dates.
CHAPTER V

SUMMARY, RECOMMENDATIONS AND CONCLUSIONS

Summary

The literature confirmed the explosive growth of different types of self-help/mutual support groups. Their effectiveness seemed to at least be supported by the increasing numbers of members participating in such groups. Unfortunately, scientific research is lagging as to why and how self-help groups work so as to better tap their potential within the health care delivery system.

Butler has noted:

Self-care and self-help, propelled by a variety of social forces, are moving to prominence on the health care scene. While their roles are not yet clearly defined, they show great promise. It seems only reasonable that this potential be tapped to benefit . . . .: the ailing who must cope with disability and chronic disease; the isolated, who can join shared experience; the stultified, who can discover new ideas and pleasures; the impoverished, who can participate without paying; the bewildered, who can be guided by their peers; the grieving, who can better adjust to their losses; the retired, who can have new leisure to learn about and take better care of their bodies (9:114).

Certainly caregivers of persons with chronic illnesses, the participants in this study, qualify as persons who would benefit from the self-help/support group modality. Also, since chronic disease afflicts a
disproportionate number of the elderly, the many self-help groups that deal with chronic disease would seem particularly appropriate for the older age group represented in this project.

Value of Information

The literature also indicated the value of information for the self-help group member. The results of this project, changes in knowledge, attitude and behavior as a result of attending support group meetings, validated this finding. As an exploratory study, the measurements of responses were superficial and lacked granularity. However, it was felt by the Investigator that the utility of support groups as health education vehicles was established. Incorporating health education into this setting is a resource that ought to be tapped by health educators and health providers. Besides acting as stimulus for the formation of support groups, health educators could consider offering their services as guests or consultants to existing support groups. Caution needs to be taken to fit the health education program to the support group and not the group to the program. Thus prepackaged health education programs may not be appropriate to the support group setting.
Provider/Consumer Discrepancies

The literature strongly disclosed a discrepancy in the relationship between the providers of health care and the consumers of health care. Providers are wary about economics and professional competition. They have reservations about the efficacy and value of self-help and especially of self-care. Self-help groups, on the other hand, feel threatened by professional domination (9:106). They have been motivated to join self-help groups because some needs have not been adequately met by the existing health provider establishment. The potential benefits of self-help groups to the health delivery system will only be achieved when this gap between providers and consumers is closed. By professionals gaining greater understanding, through observation and research, of the effectiveness of self-help groups, and visa versa, cooperation, rather than competition, can occur.

Self-Help Group Criticisms

Self-help groups have been criticized in many ways. It has been stated that self-help groups, "... may help perpetuate the inequities which characterize United States society in its health care and medical care system. By relieving some of the pressure on society to provide preventative services, self-help groups help to perpetuate the disparity between the resources the United States devotes to medical care and those it devotes to
prevention" (31:491). The Investigator qualifies this criticism as "brilliant hindsight" and agrees with Katz in disagreeing with this criticism. There are many examples (i.e., National Hemophilia Foundation) of the ways in which self-help groups have affected public policy toward prevention. Self-help groups, in a particular affected field, enthusiastically press for and support public programs designed to guarantee the widest utilization of practices conducive to prevention (31:491).

Self-help groups have also been criticized for serving only those persons who are interested, rather than those hardest to reach, thus they help to expand areas of inequality of access to care. Again this criticism can be refuted by looking at the facts. Self-help groups are characterized by welcoming persons of all classes and have even assisted public officials, or taken the initiative themselves, to survey populations for more effective demographic information (31:492). This study's support group went so far as to offer volunteer support to provide sitters for the chronically ill person while the caregiver went to the meeting and to provide volunteer transportation to the meeting if needed. That this service was not utilized may be due to a multitude of reasons, including the fact that use of this service was not advertised enough or encouraged enough by the referring sources.
A third criticism, found in the literature, is that self-help groups help perpetuate segregation, fragmentation, and isolation of individuals by focusing specifically on their symptoms and problems. In the Investigator's opinion, nothing could be further from the truth. It has been society, not self-help groups, which has caused this isolation to occur. A characteristic of self-help groups is that they stress normalization. Results from this study validate this finding. Members of this study's support group commented that they felt less segregated, fragmented or isolated from society as a result of attending support group meetings.

Despite these criticisms, self-help groups continue to be founded and grow. According to Katz and Bender, they will continue to do so, "... to the extent that the rate of change in peoples' values and beliefs outruns that of societies' institutions and as the latter are increasingly perceived as inflexible and unnurturant ..." (33:231).

**Recommendations**

The number one recommendation is the need for more research into the nature of support groups in general. More research into the use of the support groups setting as a health education vehicle is needed. The literature and this exploratory study validated the
utility of the support group setting as a health education vehicle. What was not investigated, however, is why and how the support group works as a health education vehicle. This information is essential for efficient utilization of this resource.

The literature also suggested that further research was needed. Emrick listed four pertinent areas to be investigated:

1. Descriptive evaluations of individuals who select one modality versus another or who respond to one type of therapist versus another in order to best match therapeutic agents and modalities with people in need of help.

2. More thorough empirical analysis of the relative importance of therapeutic mechanisms among self-help groups.

3. The choice and selection of outcome criteria for evaluating peer therapy needs to be clarified between peers and professionals as they don't always share the same goals.


To these suggested areas of research, the Investigator refers the reader to suggestions for further research itemized in Chapter II of this study as well as to the following:

1. Controlled studies regarding the use of formal versus informal health education techniques used in self-help group settings.

2. Attitudinal studies on professional views of the self-help modality. It is the view of the Investigator that attendance at this study's support group meetings would have
been enhanced with more sustained enthusiasm and understanding on the part of the referring professional staff.

3. Attitudinal studies of participants of self-help groups regarding professionals.

4. Research into specific needs of elderly persons within society in general and specifically within the support group setting.

Conclusions

The basic component of self-help groups is change: change in attitudes, change in levels of stress, change in behavior, change in knowledge. This, too, is the goal of health education. As stated by Katz and Bender, "It is not too visionary . . . to see the groups as a vehicle for social change, of an untapped and even unimagined potency. If the phrase people in action on their own behalf sums up the guiding motif of politics in the second half of the twentieth century, then the very form and thrust of the self-help movement is syn- tone to political and social change" (33:241).

As stated in the introduction to this project, the self-help group modality can be seen as instrumental in the creation of "Health for all by the year 2000"!
BIBLIOGRAPHY

Note: Numbers in parenthesis at the end of each reference refer to following subject areas (as discussed in Chapter III, Literature Review).

1 - General (includes definition)
2 - History
3 - Case Studies/Research
4 - Taxonomies/Typologies
5 - How Groups Work/Effectiveness
6 - Health Education


19. Fonaroff, Arlene and Lowell S. Levin, editors. "Issues in Self Care." Health Education Monographs. SOPHE. 5(2), Summer, 1977 (1, 2, 3, 5, 6)


44. Levin, Lowell S. Self-Care: Lay Initiatives in Health. (Based on proceedings of the International Symposium on the Role of the Individual in Primary Care, Copenhagen, 1975) New York: Prodist, 1976. (1, 3)


57. Norris, Catherine M. "Self-Care." American Journal of Nursing. March, 1979, p. 487. (1, 2, 6)


71. Social Policy (A special double issue on Self-Help). 7(2), Sept/Oct, 1976. (see references #6, 52 and 57) (1, 2, 5)


APPENDIX

1. Program Plan
2. Course Outline/Suggested Content
3. Project report to National In-Home Health Service
### APPENDIX 1

**PROGRAM PLAN**

**SUPPORT GROUP FOR CAREGIVERS**

#### 2-3 Months before:

<table>
<thead>
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<th>Step</th>
<th>Description</th>
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| 1.   | Determine need for support group  
      | a. Check with Administration  
      | b. Check with staff  
      | 1. Nurses  
      | 2. Social Service  
      | 3. Other services |
| 2.   | Select dates for program |
| 3.   | Select location  
      | a. Contact prospective locations  
      | 1. Schools  
      | 2. Senior Multi-purpose Centers  
      | 3. Churches/synagogues  
      | 4. Community buildings  
      | 5. Recreation rooms in apartment complexes  
      | b. Determine if joining an existing group or setting up a new group is preferred  
      | c. Establish agreement (verbal and written) for dates and location (Must be approved by both agencies) |
| 4.   | Develop course outline/content |
| 5.   | Develop invitation for participants |
| 6.   | Advertise program in newsletters and newspapers |

#### 1-2 Months Before

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| 1.   | Select/solicit participants  
      | a. Discuss with individual nurses |

**Date Completed**
PROGRAM PLAN continued

b. Review patient map

c. Develop invitation list

2. Confirm dates/location

   a. Walk through facility

3. Arrange for possible volunteer assistance and/or transportation assistance

1 month before:

1. Send invitations to prospective participants

2. Send invitation to other Home Health agencies

3. Announce program verbally at nurses staff meeting (give invitations for them to hand out to possible participants)

4. Followup with written reminder to nurses

5. Review course plan and content

2 weeks before:

1. Collect RSVP's

2. Arrange transportation/volunteers as able or needed

3. Finalize course plan and content

4. Remind facility of date/location of specific meeting room

5. Arrange audio/visual equipment if needed

Date completed
PROGRAM PLAN continued

At each session:

1. Bring:
   a. Sign-in sheet for enrollment
   b. Name cards and felt pen
   c. Audio/visual equipment if needed
   d. Handouts, if any
2. Give introductory remarks
3. Save 5 minutes at end for verbal evaluation feedback from participants and support staff

Following session(s):

1. Prepare evaluation/summary for agency (written and verbal, if requested)
   a. Include feedback from participants and support/consultant staff
   b. Include recommendations for future sessions

Date completed
APPENDIX 2

COURSE OUTLINE/CONTENT

SUPPORT GROUP FOR CAREGIVERS

I. Concept

Caregiver's of persons with chronic illnesses may have similar feelings, problems, and solutions for problems with regard to themselves and/or the person for whom care is given and this caregiver may be willing to share these feelings and/or solutions if given the proper setting (group).

II. Objectives

Given a support group setting, the caregiver of a person with a chronic illness will be able to:

A. share prior unexpressed feelings in a "safe" (supportive) environment.

B. describe some of the problems he/she has experienced in the care of a chronically ill person.

C. share suggested solutions (ones that have worked for him/herself) to problems in the care of chronically ill persons.

D. test (or act out) possible solutions to his/her own problem situation(s).

E. receive information in all aspects of health care, giving and receiving.

III. Suggested Format

A. Open format, unstructured
   1. Free discussion
   2. Share of feelings and ideas
   3. Supportive - must have positive statements, praiseworthy. No "teardown" or negative judgements.
   4. Information gathering
COURSE OUTLINE/CONTENT continued

B. Structured format, focused topic (i.e., "How to Talk with your Doctor")
   1. Presentation of topic by group leader (or guest speaker)
   2. Follow-up discussion
   3. Possible role-playing
APPENDIX 3

June 1, 1981

To: National In-Home Health Service Administration

From: Sharron Levey, PHN, CSUN MPH Student

Re: Project Report - "Caregiver Support Group"

On April 23, 1981 and April 30, 1981, a Caregiver Support Group was co-sponsored by this agency and the Multi-Purpose Center for Senior Citizens in Van Nuys. It was very well received by the participants who attended one or both sessions. This project was planned, implemented and evaluated by Sharron Levey, PHN, CSUN MPH student as part of her field placement experience in Health Education at this agency. This project was suggested by Ruth Geagea, PHN, MPH, Field Placement Advisor, as a result of a favorable response to a 1980 Consumer Survey of this agency where the concept of a support group was posed. (See Consumer Survey performed by Charlotte Laubach, RN, MPH student in Administrative files.)

The purpose of this project was to provide a supportive setting (group) for families (caregivers) of persons with chronic illnesses. This was based on the concept that persons in similar situations may have similar feelings, problems and solutions for problems which they would share if given the proper setting and to do so would help them in the care of their loved ones as well as help them to deal with their own feelings. Participants ideally would be families of persons who are presently, or have in the past, received services from NIHS as well as persons with similar family situations in the community at large. For the present project, caregivers of families participating in NIHS Continuity of Life Program were not to be solicited.

To prevent redundancy within the community and because of its ideal location for many of NIHS families, it was decided to join forces with the Multi-Purpose Center for Senior Citizens in Van Nuys and co-sponsor two sessions of their existing, but faltering, Caring
Support Group. The benefits were two-fold. NIHS families would have an on-going support group to attend as well as be introduced to the multiple services and activities afforded to them by the Multi-Purpose Center and the Multi-Purpose Center would have their group and agency attendance boosted by our participation and referrals. A letter of agreement was signed.

Arrangements were made for volunteer assistance and/or transportation assistance with NIHS volunteers and with the Multi-Purpose Center transportation department. No requests for this assistance were received.

Forty-eight invitations were mailed to families of patients presently and formerly receiving services from NIHS on the basis of geographical proximity to the Support Group site, response to the 1980 Consumer Survey, and personal referrals by staff nurses. Invitations were also sent to four local home health agencies. The Multi-Purpose Center advertised the two co-sponsored group sessions in their newsletter and in the local newspaper.

The sessions were held as planned on April 23 and April 30 respectively. There were 7 participants (one as result of a NIHS nursing referral) at the first session and 8 participants (4 of whom attended the first session) at the second session. Although attendance was minimal, participation and enthusiasm by those who did attend was high. The first session was an open discussion format. The second session focused on "How to talk with your doctor." All objectives of the program were apparently met by those who attended one or both sessions as per verbal feedback from both participants and support staff who also attended the sessions.

One of the most positive aspects of this project has been the valuable public relations this agency received by co-sponsoring such a group with another community agency. Both agencies were able to better acquaint the other of services rendered and available and thus an avenue for future patient referrals was established and/or reinforced.

Continued active staff participation with this specific support group is not necessary or required as the Multi-Purpose Center provides time and staff for this purpose as needed. I suggest that NIHS nursing and skilled staff continue to make referrals to this or any other on-going support group (or individual counseling) for any caregivers of persons with chronic illnesses whom it is felt would benefit from such a mode of assistance.
Should an individual staff member find that a support group would be helpful at some future date in an area not affording such a group, and this staff member would like to start such a group, I refer them to the Program Plan attached to this report.

It has been my pleasure to work with NIHS as a student and I thank you for the opportunity to present the results of this rewarding project.

/s/ Sharron Levey PHN
June 1, 1981