INFORMATION TO USERS

This reproduction was made from a copy of a document sent to us for microfilming. While the most advanced technology has been used to photograph and reproduce this document, the quality of the reproduction is heavily dependent upon the quality of the material submitted.

The following explanation of techniques is provided to help clarify markings or notations which may appear on this reproduction.

1. The sign or "target" for pages apparently lacking from the document photographed is "Missing Page(s)". If it was possible to obtain the missing page(s) or section, they are spliced into the film along with adjacent pages. This may have necessitated cutting through an image and duplicating adjacent pages to assure complete continuity.

2. When an image on the film is obliterated with a round black mark, it is an indication of either blurred copy because of movement during exposure, duplicate copy, or copyrighted materials that should not have been filmed. For blurred pages, a good image of the page can be found in the adjacent frame. If copyrighted materials were deleted, a target note will appear listing the pages in the adjacent frame.

3. When a map, drawing or chart, etc., is part of the material being photographed, a definite method of "sectioning" the material has been followed. It is customary to begin filming at the upper left hand corner of a large sheet and to continue from left to right in equal sections with small overlaps. If necessary, sectioning is continued again–beginning below the first row and continuing on until complete.

4. For illustrations that cannot be satisfactorily reproduced by xerographic means, photographic prints can be purchased at additional cost and inserted into your xerographic copy. These prints are available upon request from the Dissertations Customer Services Department.

5. Some pages in any document may have indistinct print. In all cases the best available copy has been filmed.

University Microfilms International
300 N. Zeeb Road
Ann Arbor, MI 48106

Sanchez, Carmen Delia

STRENGTHENING THE INFORMAL SUPPORT SYSTEM OF THE HISPANIC ELDERLY: GROUP PROGRAM FOR CAREGIVERS AND POTENTIAL CAREGIVERS

City University of New York

D.S.W. 1984

PLEASE NOTE:

In all cases this material has been filmed in the best possible way from the available copy. Problems encountered with this document have been identified here with a check mark __✓__.

1. Glossy photographs or pages _____
2. Colored illustrations, paper or print _____
3. Photographs with dark background _____
4. Illustrations are poor copy _____
5. Pages with black marks, not original copy _____
6. Print shows through as there is text on both sides of page _____
7. Indistinct, broken or small print on several pages ✓
8. Print exceeds margin requirements _____
9. Tightly bound copy with print lost in spine _____
10. Computer printout pages with indistinct print _____
11. Page(s) _____ lacking when material received, and not available from school or author.
12. Page(s) _____ seem to be missing in numbering only as text follows.
13. Two pages numbered _____. Text follows.
14. Curling and wrinkled pages ✓
15. Other _____

STRENGTHENING THE INFORMAL SUPPORT SYSTEM OF THE HISPANIC ELDERLY: GROUP PROGRAM FOR CAREGIVERS AND POTENTIAL CAREGIVERS

By

Carmen D. Sanchez

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

1984

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

4/24/84
date

Michael J Smith
Chairman of Examining Committee

26/4/84
date

Executive Officer

Rose Dobrof, DSW

George Getzel, DSW

Supervisory Committee

The City University of New York

Abstract

STRENGTHENING THE INFORMAL SUPPORT SYSTEM

OF THE HISPANIC ELDERLY:

GROUP PROGRAM FOR CAREGIVERS AND POTENTIAL CAREGIVERS

by

Carmen D. Sanchez

Advisor: Professor Michael Smith

The Strengthening the Informal Support System of the Hispanic Elderly, a project designed to supply the Hispanic adult caregiver, i.e., relatives, friends and neighbors, with information and social support through a group approach offered experiential learning and facilitated the formation of an informal support network in which the participants explored their personal feelings towards their caregiving role, shared problems and concerns and engaged in mutual problem-solving activities.

The primacy of the informal support system for the Hispanic elderly, the self-help group approach and the relationship between formal and informal systems, particularly the concept of maximizing the sharing functions between the two, were the cornerstones of the project.

The program was developed and implemented in four different settings: a home attendant program, a senior health program, a senior citizen center and a community church, located in areas of Hispanic concentration in New York City.

Fifty-eight persons participated in the project: children, spouses, grandchildren, siblings, in-laws, friends and neighbors of the elderly (58%) and elderly people (42%). All participants were Hispanics, the majority born in Puerto Rico (64%). Some participants were principal caregivers of an elderly person (58%) while others were either anticipating a caregiving role or elderly people who out of self-interest wanted to learn about the aging process. Over 50 percent of the participants were 51 years old with a concentration in the ages of 61 to 70. Close to three-fourths were females. Both educational and income levels of the participants was low.

The program was effective in meeting the needs of the participants in two basic areas: educational and emotional support. The educational component was met through education on the aging process, common and chronic illnesses in old age, sensory losses and communication problems, community resources, benefits, entitlements and skills in mediating with the formal system. The mutual aid and peer-support aspects were met through the sharing of problems, experiences and solutions, socialization and support from other group members.

Findings of the project indicate the existence and importance of an informal support system among the Hispanic elderly, composed of relatives, friends and neighbors, Recognition should be given to the inherent strengths that exist in this informal support system. Human service providers should not undermine a system of service delivery that has always existed and at the same time should not use its existence as a pretext not to provide services. The natural support system should be the focus of study and further research.

ACKNOWLEDGEMENTS

This doctoral project could have not been completed without the contribution of several significant persons. I am delighted to have the opportunity to acknowledge the support and encouragement many people gave me throughout the project.

First, I wish to thank Dr. Rose Dobrof, director of the Hunter Brookdale Center on Aging, whose influence has been present throughout the project. This magnificent person has directed and supported me with her intellect, skills and personal wisdom during the doctoral program at the Hunter College School of Social Work. Her friendship and support I shall always appreciate.

Second, I wish to thank the other members of my doctoral committee. Dr. Michael Smith for the invaluable direction he provided in all phases of the project and Dr. George Getzel for his generosity and encouragement.

At a more personal level, I am grateful to my friends - my informal support system - who have not only put up with me, but have encouraged me to persist in my efforts to complete my graduate studies. Chief among these has been Max, my "companero", whose love and stern editing proved invaluable.

To my sons Daniel and Jose, I am grateful for the many times they pulled me out of my books and shared with me their childhood world.

I want to dedicate this project to my parents, Nicolasa and Jose, who gave me life and whose moral and emotional support was essential in my completing the degree. Finally, I also dedicate this

project to the caregivers and elderly persons who participated and inspired me in the project.

TABLE OF CONTENTS

LIST OF TABLES

List of Tables (cont'd)

Chapter V (cont'd)

List of Tables (Cont'd)

Chapter V (Cont'd)

CHAPTER I

INTRODUCTION

As a result of immigration and birth-rate patterns, the minority elderly population is growing at a more rapid pace than non-minority elders. Minority elderly population has lower incomes, a higher probability of living in sub-standard conditions, and has higher rates of illness than the latter. As a consequence, non-minority elderly tend to have higher levels of need for services than non-minority elderly. In the past, service delivery systems have emphasized almost exclusively using formal networks (community agencies, centers and other formal services) to meet the needs of the elderly, but there is an increasing awareness that natural supports systems should be promoted, strengthened and supported (Safford:1980). Family, friends, neighbors, civic organizations, and religious groups constitute an important and hitherto little recognized source of social support for the elderly. It is to these informal supports that people in need of help first turn. Informal supports such as family, friends, and neighbors provide an estimated 80 percent of the support services needed by frail elderly (Brody:1977). This statistic speaks to not only the lack of availability of government formal services but also to the depth and scope of informal supports.

The primary component of the natural support system of the elderly--relatives, friends, and neighbors--provides an array of services that are ongoing, generally non-technical in nature (such as providing emotional support), and involve a long-term commitment. The

challenge to the providers of social services is to enhance and sustain this network. If supporting frail populations to remain independent in the community is a societal goal, then it is imperative that the families and friends, who sustain the frail elderly in their communities, be assisted.

The "Strengthening the Informal Support System of the Hispanic Elderly" project was aimed at enhancing and sustaining the caregiving capacity of the Hispanic population. The training program which will be described was conducted with fifty-eight persons who were the major caregivers or friends and neighbors of Hispanic elderly residing in four selected sites throughout New York City. The major objectives of the program were:

1. To supply the adult caregiver, i.e., relatives, friends, and neighbors of the Hispanic elderly with information and social support through a group program;

2. To test a group approach with Hispanic caregivers as a means for meeting some of their immediate needs for information and support; and

3. To offer experiential learning as well as to facilitate an informal support network in which the participants could explore their personal feelings towards their caregiving role, share problems and concerns and engage in mutual problem-solving activities.

In designing a program for caregivers, a review was made of the literature on the dimensions of the informal support system of the aged, especially the Hispanic aged, and on the family as a caregiving unit to the older person. This review was done in order to provide a contextual background from which the program could unfold. Chapter II presents this review of the literature as well as the rationale for establishing the program. The first section focuses on the current literature on family support systems in old age. It emphasizes the importance of

increasing our knowledge of family caregiving. Next is a review of programs which have been developed to strengthen and enhance the informal support system of the elderly. Finally, a discussion on the Puerto Rican aged and their relationship to the formal and informal support system is presented.

Chapter III provides the theoretical and conceptual framework of the program. This theoretical base rests on the concept of support systems, the self-help concept, Litwak's theory of shared functions, and andragogy as the teaching-learning strategy.

Chapter IV presents an overview of the program with a description of the program's content, instructional methods, recruitment of participants, selection of sites and evaluation plan for the project. The chapter ends with a description of the project sites and salient characteristics of project participants.

Chapter V deals with the initiation, implementation and completion of the project. The first section provides a description of the planning and initiation phases, focusing on implementation problems. Some of the problems mentioned are: participants' selection and recruitment, problems of attrition, space, and scheduling of sessions. A section describing each cycle is included, focusing on salient characteristics of participants, outcome of the program and evaluation by participants. Other sections presented are: overview of participants in the total program, common themes that evolved throughout the cycles and an overall evaluation of the project.

The final chapter presents a summary of the findings, recommendations and implications of the project, including suggestions for replication of the program.

The present project was undertaken for personal and professional motives. On the professional level, the project director believes that the topic of informal and formal help to the elderly has importance and relevance for social work practice as well as for social welfare policy and curriculum. On the personal level, the project director, being Hispanic, feels committed to servicing and studying this population. This personal motivation is reinforced by the fact that the project director is part of an extended Hispanic family in which the care of a 95-year-old frail grandmother has drained it physically, emotionally, and economically. But at the same time, this care has served to strengthen familial bonds and enhearten the family's collective spirit. The day-to-day care of the 95-year-old grandmother is provided by her only daughter, who is 60 years old and increasingly in need of medical services herself. She is supported by the project director's parents who are almost 70 years old and who visit the grandmother three to four times a week. This network is completed by the children, grandchildren (including the project director), and great-grandchildren who live in New York and take turns traveling to Puerto Rico to help in the care of the grandmother.

Developing and implementing the project was a learning and rewarding experience for the project director and it is her hope that it will in some way inspire the reader.

CHAPTER II

EXTENT OF THE NEED AND LITERATURE REVIEW

This chapter's purpose is to provide background information substantiating the need for the project. It presents a literature review of the major components on which the "Strengthening the Informal Support System of the Hispanic Elderly" program was developed. First, it focuses on current societal and professional concerns which emphasize the importance of increasing our knowledge of family caregiving. Then follows a presentation on programs which have been developed to strengthen the informal support system of the elderly. Lastly, there is a section on the Puerto Rican elderly in the United States focusing on its relationship to the formal and informal support systems.

FAMILY SUPPORTS IN OLD AGE

The physically and mentally impaired elderly are a subgroup in our society whose special needs are not being adequately or appropriately met. In spite of the extensive interest in alternatives to institutional care, there are relatively few community alternatives to institutionalization. Not only is there a lack of appropriate services in the community, but an underutilization of the existing services by the elderly and their families.

The present system of long-term care for the elderly in the United States provides large amounts of public funds for institutional care but minimal funding for community oriented supportive

services. As a consequence, older people are forced into institutions prematurely or, in some cases, unnecessarily (Brody:1977).

Having at least one elderly parent is increasingly probable for middle-aged adults in the United States in the 1980's. The elderly are now the fastest growing group in the United States. In 1900, persons 65 and older were only 4 percent of the population, and in 1970 they were 10 percent of the population. Today, those 65 and over number approximately 24.1 millions and constitute over 11 percent of the population. Projections for the year 2000 indicate that the elderly will constitute 15 to 20 percent of the United States population (Neugarten:1976).

The older population has experienced not only growth, but also changes in composition. Life expectancy has increased from age 40 in 1900 to 74.5 in 1982. The differential growth within the elderly cohort itself is a critical issue. As a result of fluctuations in birth rates and advances in medical technology, we are witnessing a growth in the older-old population. Between 1960 and 1970, the aged 75 and over increased at three times the rate of those 65 to 74 (Brody and Brody: 1974). Today, the 75-plus cohort represents 38 percent of the elderly population and is projected to increase to 45 percent in the year 2000. The 85 and older cohort has had the largest rate of increase: 4 percent in 1900, 8 percent in 1977, and is projected to increase to 11 percent in the year 2000. Generally, the "old-old" (80+), who need the most health and support services, will increase twice as fast as the younger elderly (Glick: 1979). It is the people in the 75+ cohort that are most likely to be widowed and living alone, to have chronic and severe health problems, and therefore to need long-term care, either in the

community or in an institutional setting.

Parallel to the growth in the aging population, major demographic changes affecting the family have also occurred. With more people surviving into old age, younger generations have more elderly relatives than in the past; more families today will have surviving elderly parents. Because life expectancy has increased, we are approaching the four- and even five-generation family (Townsend:1966). More families than ever before include four living generations. Shanas reported in 1980 that half of the parents over 65 are members of four generation families. In many families already there are two generations of older members, e.g., the grandparents in their mid-60's and the greatgrandparents in their 80's (Townsend:1966).

As the older population ages, so do the children and relatives. Since those in need of care are largely the 75+ (and to an even greater extent, the 85+ cohort) their children most often are in middle-age or early old age. Increasingly, middle-aged adults are expected to be responsible for their parents as well as for their own children; in the past, middle-agers were more likely to be the oldest generation and consequently did not have the responsibility of caring for their aged relatives. These structural changes make obsolete any expectations of roles based on the situations of previous generations. Present generations have not been adequately prepared for the possibility that they may need to assume more responsibilities for their aged family members as generations come together. They have no role models to follow. For today's middle-age population this is an added dimension to the exigencies of filial responsibility. Adherence to this value of filial responsibility remains strong in our society.

This is the primary motiviation for responding to a parent in need and one which is independent of anticipated rewards (Horowitz:1982).

Demographics also indicate that the middle-age generation of today will face novel difficulties when they reach old age. During the same period that the older segment of the population has significantly increased, the size of families has significantly decreased, due to declining birth rate. Many young couples are remaining childless or having only one child (U.S. Bureau of the Census:1982), or are simply living together without being married. Furthermore, those having children tend to bear them at a later age (at least among middle and upper classes). When these couples themselves age, their children may not be well enough established to be a viable source of help. Finally, there are increasingly fewer relatives available as caregivers to the aged, particularly as geographic dispersion of family members occurs in our highly mobile society.

These demographic developments have been paralleled by a tremendous influx of women into the labor force. The proportion of women who work outside their homes has increased to more than fifty percent (51%) of all working women, representing 41 percent of the total work force in the United States (Brody:1981). Working women, who also have responsibilities towards spouses, children and frequently grandchildren, can no longer provide the daily help and supervision needed by the elderly. Since women have traditionally provided care for the frail elderly in the family, and in view of the cited demographic changes, it is clear that the number of relatives now available for this role is reduced.

The demographic changes taking place emphasize the need to examine issues surrounding family caregiving. Research on families and the aged has consistently demonstrated that families are the predominant service and health care provider to the impaired elderly (Cantor:1975, Rosow:1967, Shanas, et. al.:1968, Shanas:1979, Sussman: 1965, Townsend:1965). The commitment of families to their elderly is amply documented (Benston & Cutler:1976, Tobin & Kulys:1980, Troll: 1971, Troll, Miller & Atchley:1979, Horowitz:1982). Troll, Miller and Atchley contend that emerging research on the families and the elderly indicate that both are deeply intertwined. They also point out that in cases when family contact is absent, the elderly creates a "pseudo-family" with friends and neighbors.

The accessibility of a family support system appears as the primary factor in reducing the probability of institutionalization for the chronically ill person (Townsend:1965, Brody:1967). Where intact families exist, institutional placement of older persons with chronic dysfunctions is not the general rule. Families of the impaired make considerable sacrifices in order to maintain their aged relatives in the community. As Elaine Brody (1977) pointed out:

> ...studies of the paths leading to institutional care have shown that placing an elderly relative is the last, rather than the first resort of families. In general, they have exhausted all other alternatives, endured severe personal, social, and economic stress in the process, and made the final decision with utmost reluctance.

Families for the most part, will go to extraordinary lengths before institutionalization is considered. In addition, a substantial amount of care is also provided by friends and neighbors, augmented by community supported long-term care services. This accounts for the large number of persons who need long-term care services, yet they

are able to remain in the community. One million elderly over 60 are now residents of long-term care facilities, but this figure still represents only 5 percent of the total elderly population. Ninety-five percent of those 65 years and over, live in the community.

Most older people are tied into a network of social support in which the children primarily, and friends and neighbors secondarily, provide important supportive services. Children occupy the key role in the natural support systems of the elderly, while other relatives serve "as a reservoir of kin from which replacements and substitutions for missing or lost relatives can be obtained" (Troll:1971). Brody (1977) estimated that 70 to 80 percent of the care provided to older people is being provided by adult children. Even among non-kin, research has documented the establishment of patterns of affection and reciprocity, and of assistance among friends and neighbors and the elderly (Cantor:1975, Rosow:1967, Lopata:1975). Research findings also confirm that the family bears the major burden of caregiving when older persons experience major functional disabilities (Shanas: 1977, Cantor:1979, Brody:1981, and Tobin and Kulys:1980). Friends, neighbors, and members of voluntary organizations become critically involved in the provision of informal supports only to the extent that family members are not available (Cantor:1979). Cicirelli's study (1981) demonstrated that childless elderly or elderly with only one child will not only substitute other kin as providers of needed services, but will also tend to substitute non-family providers, especially friends and hired providers. Steint's study (1981) looked at how members and clergy of local parish churches provide emergency care and ongoing social supports for older members who lack nearby

kin of their own.

The care provided to the elderly by the family has been the focus of various research works (Cantor:1975, Townsend:1966, Blenkner: 1965, Brody:1977, Horowitz:1982, Frankfather, et. al.:1981). Many researchers see mutual aid as the crucial dimension in the relationships between the aged and their children. Aid flows in both directions and may consist of help with shopping, housework, baby-sitting, information, advice, moral support, gifts, or money. Shanas reported that 70 percent of old people give aid to their children and receive some type of aid from their children. This results in mutual aid for many families.

Kin can function as important resources for their elderly, meeting health or financial needs in the form of services, gifts, and/or monetary contributions. The family can provide affection and companionship at a time when the older person's social network may be limited by ailments and lack of personal resources. Cantor (1975) noted the presence of exchange between the inner-city elderly and kin in the following activities: material and non-material aid, social activities such as visiting, recreation, telephoning, regular and occasional services, e.g., shopping, escort, physical care, household chores, meal preparation, and giving advice. For example, in Cantor's study, 75 percent of the respondents reported helping their children in some manner and 87 percent reported that their children helped them. Cantor (1976) also found that the aged received help from kin, particularly in crisis situations when it seemed required.

Financial contributions to aged relatives appears to be a relatively insignificant component of the help provided by the family when compared to the emotional and social support provided. Cantor(1975)

found that children responded with more services as their parents became more frail. Sussman in 1970 stated that services to the elderly such as physical care, shelter, escorting, shopping, performing household tasks, sharing leisure time, etc., were expected and practiced roles of children and other kin members.

In addition to providing direct services or financial aid, the family might serve as mediator or advocate with the formal organizations which provide services to the aged (Shanas & Sussman: 1977). The caring role may involve performing tasks which ensure that the older person receives services from the formal organizations.

There appears to be three major caregiving activities within the social support system of the elderly: emotional support, financial and linkage. Caregivers may provide many different types of services to varying degrees (Horowitz:1978).

Affection in the relationship of the elderly and the children has also been studied. Although it is difficult to measure love or affection, there is evidence of high affectional solidarity between aging parents and adult children (Troll:1979). It can not be assumed that affectional closeness determines interaction frequency or that interaction frequency is a good indicator of affection, since distance can influence the correlation. Relationships are rather higher when parents are in good health and financially independent (Troll:1979). While there is difficulty to generalize about the many complex relationships between the aged and their children, the research shows a generally positive picture regarding proximity, interaction frequency, aid or help, and affection of the relationships. As indicated by residential proximity, contact between the elderly and their family

members is high. Research findings point to the fact that there is a great deal of face-to-face visiting, telephoning, and close association between the elderly and their children (Shanas:1968,1979, Cantor:1975). Cantor's study found that 81 percent of the elderly reported seeing their children at least once a week. Shanas' nationwide study (1979) found that 53 percent of the elderly interviewed saw a child the day of or the day prior to the interview, while 77 percent had done so within the previous week. This means that older parents were seeing their children regularly.

In summary, there is a huge body of knowledge supporting the strength of the links between aging parents and their children. Most older people do have children and interact with them. Intergenerational help patterns tend to be reciprocal until changes in health and/or financial status of the elderly occur. Adult children respond to the needs of their elderly parents and emerge as the primary caregivers to them. As a result of the dramatic demographic shifts previously mentioned, the current pressures, on both the informal and formal providers of services to the impaired elderly, can only be expected to increase in the near future.

The capacity of the family to help its older members is crucial today and in the future. As individuals we are highly affected by our families and the roles we play within them. We have to respond to the aging of our parents or relatives with various degrees of understanding and coping skills at the same time that we are adjusting to our own aging process.

The current theory and practice, which promote the maintenance of the aged, even the frail aged, in the community and foster their

independence, have many implications for families and service agencies. Mainly this suggests that the family should develop and maintain an aggressive role in encouraging maximum independence for their aged members. And since the family will undoubtedly continue to be the primary source of care and assistance to the older population, it is essential that social service agencies augment their recognition and support of the family's efforts (Silverman:1977).

Although the family has been recognized as the primary support system for elderly persons residing in the community (Lebowitz:1978), there is evidence that adult children need assistance in their caregiving role (Silverman-Brahce:1979). Shanas and Sussman have written about the need to provide incentives to families to take major responsibilities for the care of the impaired elderly. They have emphasized that older parents now need adult children who can aid them in locating and utilizing the many varied services currently available; that is, who can act as mediators so that specialized services can be obtained (Shanas & Sussman:1977). A number of major policy papers have called for the provision of a variety of formal services to help families who care for their aged relatives. The effect of formal care intervention on family caregiving was the subject of the study conducted in 1979 by Cantor. She found that the initiation of formal care for her sample of older persons already receiving help from a spouse or child, resulted more often in a shifting or redirecting of family care than in the withdrawal of such care. At the present time, support for adult children with aged parents has just begun to develop (Brandein & Posthoff:1977, Powell:1976, Silverman, Kahn & Enderson:1977, Zimmer & Sainer:1978).

Any effort to develop programs of assistance for family caregivers should consider the preferences of the intended recipients. Various studies have focused on the attitudes of both current and potential caregivers for the elderly. Sussman (1979) was one of the first to examine this area in depth in his study "Social and Economic Supports and Family Environments for the Elderly". Sussman's findings were that medical care for the elderly was the preferred service support by the respondents, and a monthly compensation to the caregiver the preferred financial program. When both programs were considered together, the majority of the respondents chose the monthly compensation as the most desirable, thus indicating a clear preference for the flexibility of a financial incentive. Horowitz in 1981 replicated Sussman's option questions. The patterns that emerged in her study were generally consistent with Sussman's study. The monthly compensation was ranked first by the largest number of respondents. There was slightly less consistency between the two studies in service preferences, with the Horowitz sample choosing home-maker services almost as frequently as medical care.

CURRENT PROGRAM INITIATIVES ON INFORMAL SUPPORTS

At the present time there are a number of programs and demonstration projects operating throughout the country. This is in response to the growing recognition of the role played by the informal supports, including family members, in the care for the elderly.

Pilot projects to enhance the role of the informal caregivers through the provision of financial incentives have been undertaken. Direct grants to families who care for their elderly relatives at home

have been utilized by various states to help families in dealing with unnecessary and expensive institutionalization. The projects in Maryland, California and Florida are of particular interest.

Maryland's Family Support Demonstration Project has been in existence over the past few years. The project was undertaken by the Maryland State Office for the Aging in 1979 and according to the Project Coordinator, Shirley Whitfield, it has been successful in helping 101 families to keep elderly relatives who are in poor health at home (State of Maryland:1979). The two-year study involved making monthly payments based on income to families of the impaired elderly. The funds were provided by the State to conduct the project in order to test specific methods of supporting and strengthening informal supports. The project was carried out by three local host-agencies: John Hopkins Hospital Department of Social Work in Baltimore City, the Montgomery County Division of Elder Affairs, and the Commission on Aging in Worcester County, a rural area on Maryland's eastern shore.

Florida's Home Care for the Elderly Program started in 1977 to encourage care provision for the elderly residing within the family. The program provided a schedule of subsidy payments funded by the State. Payments were made to relatives caring for family members. In 1980 the program provided services to caregivers of 1,424 elderly.

California has been providing reimbursement for family-based care since 1958. The In-Home Service Program provides, among other benefits, payments to individuals, including informal care providers, for specified services rendered to eligible program recipients who live in their own homes.

One of the most remarkable developments in the field of health

care within the last few years has been the creation of self-help groups for persons dealing with common problems. The area of aging is no exception.

The growing body of knowledge on the informal support system and its role in providing long-term care to the elderly has encouraged a variety of efforts to support caregivers of the aged. Educational strategies have been developed to support and expand the caregiver's capacity to meet the needs of their aged relatives. A model project is the Natural Supports Program of the Community Service Society of New York.

The Natural Supports Program was initiated in 1976, as a three-year demonstration project, to explore the nature and extent of care provided to the elderly by their relatives, to determine what supportive services might be needed to enhance and prolong this care, and to make public policy recommendations that would enable the families to continue to provide care for the aged relatives as an alternative to unnecessary institutionalization. The program initially targetted its training program to family members who provide care to an elderly relative. As the program was implemented, it was determined that friends and neighbors who were often providing a great deal of care to elderly persons were suffering the same stresses as those experienced by family caregivers. Two completely different strategies were developed to address the needs and interests of the caregiving population: services to individual families which included respite care, counseling, escort services, and assistance in systems negotiation and advocacy, and services to community based groups, including caregivers.

The most frequently identified service need by individual families was home-care. This was defined as a combination of personal care and household chores help. The second most frequently identified

service need was counseling services. Counseling related mainly to the onset of increased dependency, and understanding of the aging process and interpersonal conflicts. Families also requested help with systems negotiations and advocacy around obtaining medicaid entitlements. Service requests by groups indicated interests in meetings which provided information about community resources including how to obtain entitlements for the elderly relatives, and sharing the caregiving experience with others (Gross-Andrews & Zimmer:1978).

Another model project was developed jointly by the Institute of Gerontology at the University of Michigan and the Children and Family Services of Michigan, Inc. The As Parents Grow Old (APGO) Program integrated a combination of educational and therapeutic approaches. The model entailed six group sessions for twelve to fourteen participants with a discrete curricula designed for each session. The groups were run by two co-facilitators who had been especially trained to run the APGO groups. In addition to conducting the educational component, the group facilitators functioned to promote communication and peer support within the group. The vast majority of 125 participants reported improvement in the ability to cope and deal with the caregiving situation and in knowledge of the aging process and utilization of community resources (Silverman & Brahce:1979).

Florence Safford (1977) developed a training program for families of the mentally impaired aged at the Isabella Geriatric Institution in New York City. The program's objectives were to help families with impaired kin in the community to function more effectively in planning, assessment, and decision-making by teaching them the essential knowledge, tasks, and attitudes associated with the role of caregiver. The

educational and support program for families of the mentally impaired aged in both community and institutions was offered over a three year period under the auspice of a geriatric center. The experience of the program demonstrated that most family members needed help in learning to assume a responsible role toward their impaired kin, inasmuch as our society does not prepare adults for the kind of problems which they confront as caregivers (Safford:1980). The program also indicated a need for similar interventions sponsored by a variety of agencies.

Another program which focused on the family as primary caregiver to the elderly was developed by Brandwein in 1977. The project designed a therapeutic-didactic model for intervention with adult children of aged parents. Therapeutically, the model provided an opportunity for the participants to ventilate feelings, explore alternatives, and assess existing attitudes. At the didactic level, information was offered to help the participants understand the aging process which facilitated effective use of community resources (Brandwein:1977).

Some community mental health centers have offered short-term counseling groups for persons with elderly persons. Weisshaus' report about counseling groups of daughters of elderly mothers is an example. Participants in the groups reported that counseling groups were helpful because they could share anxieties and common experiences with others who had similar concerns. Provision of information about community resources and the aging process was another useful feature of these groups (Weisshaus:1979).

The emerging conclusion from the programs just described is that families who care for aged relatives have a need for two kinds of

programs. First are the educational and preventive programs that could provide current knowledge about aging and community resources. And second, support from other caregivers which includes an opportunity to ventilate feelings and concerns about their caregiving situations. The children of the frail elderly do have definite ideas concerning their needs for support. They state a clear and urgent need for open communication with providers of health and social services. They express a desire for education about aging. They want to know about strokes, senile dementia, nutrition and other physical and mental problems, and most of all they want an opportunity to share their concerns.

In testimony to the Sub-Committee on the Special Problems of the Aging in 1979, the Community Service Society of New York identified some needs of the informal supports network and services that could strengthen them. Based on the experience with the Natural Supports Program, the critical areas identified were: (1) home care and respite care, (2) knowledge of and access to resources and entitlements, (3) information and training related to the aging process, and management of the chronically disabled, (4) emotional support to cope with the stress created by the caregiving situation, and (5) financial assistance to enable the support network to survive.

Caregivers of the elderly are often not equipped with the knowledge, resources, or skills necessary to provide them with continuing, optimum support. As a consequence family relationships suffer; and the ability of adults to assist their elderly parents, is undermined.

The general conclusion emerging from the preceding discussion is that great emphasis needs to be given to strengthening the natural support system of the elderly.

Although there have been a variety of efforts, as demonstrated by the previously described projects, no programs have yet been designed to reach minorities. For example, the Hispanic population, where a stronger family network is believed to exist, has not been targetted by these programs.

A general background information on the Hispanic elderly and his/her family is deemed necessary at this point in order to sustain the need to develop caregivers support programs for this population.

THE PUERTO RICAN ELDERLY

Attention to the problems encountered by older Puerto Ricans and their families in the metropolitan New York area (where 95% of the Puerto Rican elderly in the mainland were living in 1979) is, for a variety of reasons, of quite recent origin. Zambrana, Merino and Santana concluded in 1979 that "no truly reliable data exist on the Puerto Rican elderly population of the East Harlem area" (Zambrana, et.al.:1979). This conclusion could be extended to the United States as a whole. Although analysis of the 1980 Census data yields more information about this group's size and socioeconomic standing, serious questions have already been raised about some aspects of the reliability of the data.

A few factors account for the relative paucity of attention to the Puerto Rican aged--attention measured by the existence of both a reliable data bank about this cohort and of a network of services available and accessible to them.

First, relative to many other groups, notably the Italians, the Jewish, the Irish, and the Black population, the elderly are under-represented in the Puerto Rican community. As a necessary corollary, the Puerto Rican elderly are a small percentage of the elderly in New York

City, while Puerto Ricans as a whole form a large percentage of the city's population. In 1975, only 1.5 percent of the mainland Puerto Rican population was 65 years or older. In New York City, where the Puerto Rican population accounts for 860,552, only 4 percent were 65 years old and over (1980 Census). The Puerto Rican population in the mainland United Stated is a young population (median age is 19.9). The age composition of the Puerto Rican population is a function of the history of migration: the majority of the Puerto Rican population came in the 1950s and after. The typical Puerto Rican adult and elderly in the United States were born in Puerto Rico. In contrast, the Irish, Italians, and Jewish migrations date back as early as the 1890-1915 period particularly for the Italians and Irish, the decade of the 1920's.

A second factor which may contribute to the relatively smaller population of older people in the Puerto Rican community is the "return migration" of the old to Puerto Rico--particularly when the old person becomes chronically ill or infirm (Zambrana, et.al.:1979). The return migration trend of the older Puerto Rican has been recently confirmed by Elias Gutierrez, a Puerto Rican planner who stated that "the inflow migration graft onto the island a significant number of older people. As a result, by the end of the century we will no longer be a young country" (Gutierrez:1982). The desire to return home as life's journey nears its end is very much a part of the value system and cultural tradition of this generation.

But there are also negative reasons for this lack of attention. In the Report of the Mini-Conferences on Hispanic Aging issued by the White House Conference on Aging, there is this explicit conclusion:

> ...the sense of isolation...(of the Hispanic aged)... expresses itself in well-documented under-use of social services that, on the surface appear readily available to them. The 1980 national needs assessment of Hispanic elderly conducted by the Asociacion Pro Personas Mayores showed that 76% reported a need for social services, 25% use only one service. The fundamental cause of this less-than-full use is not elusive...*social services...based on cultural values different from those of potential users... and delivered by persons who seldom speak their language, are doomed to underutilization* (Emphasis mine).

In New York City, there are some exceptions to the gloomy conclusion reached by the White House Conference Report: the City's Department for the Aging, the Institute for the Puerto Rican/Hispanic Elderly, the Casita Maria Senior Center, the Casa Boricua Senior Center and the Consumers Action of Bedford Stuyvesant. Despite these not inconsequential exceptions, the picture of the situation of older Puerto Ricans and other Hispanics in New York City is one of a group in which the incidence of poverty, poor housing, and serious health problems is very high. The 1978 Department for the Aging report included the finding that 23.2% of the Hispanic aged had incomes below the poverty level, in comparison to 14% of the elderly population of the City, and the combination of discrimination and low income forces most of the Hispanic aged to live in neighborhoods characterized by sub-standard housing, poorly maintained public areas, and high crime rates. Several studies also point to the higher incidence, in comparison with non-minority aged, of severe mental and physical impairment among Hispanic elderly (Cantor: 1975, Johnson:1972, Zambrana, et.al.:1979).

We have then three interrelated problems: one the sparcity and unevenness of the data about the situation of Hispanic elderly in New York City, a deficit which adversely affects the efficiency of the planning for, location, and delivery of services to this population;

two, the high incidence of health, economic, and housing problems among older Hispanics; and three, the evidence that even when services do exist, they tend to be under-utilized by Hispanic elderly and their families.

Several factors have influenced the Puerto Rican elderly relationship to human services. These are summarized in the conclusion reached in the White House Conference that failure is built into service delivery systems by professionals who do not take into account the cultural values and norms of the community served, and when the services are delivered by people who do not speak the language of the group they hope to serve. Hispanics, like all other immigrant and minority groups of the present and in the past, are more likely to use and to benefit from social, health, and educational service programs if these programs are organized and delivered in a culturally sensitive fashion. This point has been amply documented. It is rather to the particular obstacles in the path of service delivery to older Hispanics that we must turn.

In the first place, there is a language barrier. The majority of older Puerto Ricans, were, as noted before, not mainland born, and their settlement here in ghettos often meant that Spanish continued to be their language of communication, not only at home, but in many of their daily activities. Moreover, in contrast to most other migrant groups who did not bring United States citizenship with them and whose visits to their homelands were precluded by distance and/or the circumstances of their migration (e.g., the Haitians, the Russian Jews, the Vietnamese, the Cubans), Puerto Ricans tend to maintain close ties with island and make many frequent visits to Puerto Rico. It is reasonable to assume, as many researchers, administrators, and practitioners do,

that the ties to the island serve to reduce the need to learn English. Also, the Puerto Rican elderly today are likely to have made their migration as adults with little education, and in general, adult in-migrants do not gain proficiency and fluency in their second language to the degree that those who migrate as children or teen-agers. A recent survey conducted by the Puerto Rican Congress of New Jersey found that 80 percent of the Hispanic elderly surveyed spoke no English. The survey covered 452 elderly Hispanics in five New Jersey cities and 89 percent of them were Puerto Ricans. The inability to speak and/or read English presents a unique problem which impedes the dissemination of information about social services, and severely hampers, if it does not preclude, the ability to negotiate service delivery systems. This mainly monolingual elderly is found concentrated in urban areas where service delivery systems are large and complex. Although all three major Hispanic populations (Chicanos, Puerto Ricans and Cubans) are clustered in urban or metropolitan areas, the Puerto Ricans have the highest percentage of inner-city residence.

Second, in common with other migrant groups, the elderly of the group having been born and socialized in the culture of their birth, are most likely to live according to these norms and are least likely to have accepted the different values and behavior of the culture in which they find themselves. Practitioners in agencies serving Puerto Rican families and children report, for example, intergenerational conflict about childrearing practices, with the grandparents holding to the cultural norms which require sheltering teenage girls and the parents and children favoring the permissiveness of the mainland society.

In the Puerto Rican community, the family is a source of strength for Puerto Ricans of all ages. The Puerto Rican cultural heritage is one that underlines family responsibility for care of those in need. This tradition means that the family is a significant primary provider of social services. In accordance with cultural norms and values, and as a practical necessity, Puerto Rican families are likely to adhere to traditional and extended family systems. For many Puerto Rican elderly, the extended family concept is still of great importance. Many Puerto Rican elderly share a household with a child or relative. However, the strong familial and informal support which has sustained and provided them with important roles, has begun to weaken. Various studies identify a slow but steady disintegration of their natural support system as a result of the impact of acculturation of younger members to the mores of the American society. In a 1970 study of the inner-city elderly, the Area Agency on Aging found that 27 percent of the Spanish-speaking elderly were living alone (Cantor:1975). This trend toward living alone on the part of the Puerto Rican elderly appears to be continuing as indicated by the Survey of Income and Education of 1976. Several factors may contribute to this, for example, the increasing number of childless widows, the mobility of the children, and the elderly attachment to the neighborhood they live in.

The Puerto Rican culture places a high value on the concept that life is a network of interpersonal relationships. Family consists not only of the nuclear family but extends to distant relatives and includes close friends. Father Fitzpatrick, in his study of the Puerto Rican family, writes of the centrality of the value of personalismo...

"a form of individualism that focuses in the inner importance of the person... Personalismo ... is rooted in the family... the Puerto Rican has a deep sense of that network of primary relationships that is his family, senses the family as an extension of the person, and the network of obligation follows" (Fitzpatrick:1981). Puerto Rican elderly are part of this network of primary relationships and there are benefits which are abscribed to them from their position in the network and the respect accorded to them. They have a more direct involvement in the family than most American elderly, i.e., helping in the child-rearing and giving advice. In the inner-city elderly study, Cantor found the Hispanic elderly (primarily Puerto Rican) "to be more involved in the lives of their children than were their non-Hispanic counterparts, and also older Hispanics were more likely to describe a sense of closeness to their children than were non-Hispanics" (Cantor:1975). The fact that Puerto Rican aged are more likely to live in households with other relatives is a function not only of the value system of this community, but is also a matter of economic necessity. The shared household is one way poorer families meet their housing needs, and in addition, the grandparents often take care of the children in the increasing number of single parent families, or in families where both parents work. Despite the impact of the majority culture on Puerto Rican family life and economic deprivation suffered by many, the family remains the major psychological support for its members, including the aged.

Cultural norms and values have served to isolate many older Puerto Ricans and other Hispanics from the service delivery system, language and cultural barriers have served to deny them access to programs and benefits. The structural and relational system of the Puerto Rican

families can ironically become an impediment to access and utilization of services and benefits to older Puerto Ricans. This is compounded by the dysfunctional consequences of certain governments' policies and the attitudes and behavior of some non-Hispanic service providers.

Referring first to the public policies, the Supplemental Security Income Program is an example of the adverse consequences of a governmental policy. Many older people who live in shared households, by virtue of this living arrangement, are not eligible for SSI benefits, or if eligible, receive a lower benefit level than they would if they lived alone (the shared household is deemed income for the older person). Thus the extended family unit, a function as we have seen of both cultural norms and economic necessity, penalizes many aged Puerto Ricans and limits their income support from public sources to the minimum or near minimum Social Security Retirement or Survivors benefit level.

The attitudes and behavior of non-Hispanic service providers operate in more subtle fashions than do public policies and regulations, yet their detrimental impact is clear and pervasive. In an unpublished study of the impact of ethnicity on family relationships and service utilization of the aged, Brookdale Center on Aging of Hunter College looked at the role of hospital social workers and others involved in discharge planning in work with aged Puerto Rican and their families (Horowitz:1983). The workers were asked how they accounted for the fact that Puerto Ricans have a low rate of utilization of long-term care facilities--despite the high incidence of chronic illness, mental impairment, and disability among them. Non-minority workers were likely to cite the strength of the Puerto Rican family group--"they take care of their own at home"--to account for this underutilization.

Puerto Rican and other Hispanic workers, in contrast typically cited many factors: no access to these services due to discriminatory practices or attitudes; lack of knowledge among Puerto Rican families about the availability of these services; the family's reluctance and/or inability to make demands on the system in order to gain access.

The difference between the perceptions of the Puerto Rican workers and their non-minority colleagues is remarkable and the consequences often costly to the Puerto Rican older person and the family. Discharge planners in hospital and other access workers, knowing that the Puerto Rican older person is likely to live in an extended family situation, and believing that this is entirely a matter of choice, often forget the economic and housing deficits that make it a matter of necessity. They rarely explore alternatives with the family or the older person. Too often there is simply the assumption on the part of the worker that the family is available and able to care for the older person and no consideration is given to the price the family and the older person might pay for this assumption. The reality that a daughter or daughter-in-law might have to quit a job or reduce her hours of employment, or that children may start missing school in order that they may "rotate the duty" rarely seems to enter into the calculus of some workers. School attendance for the children and the work incomes of adult members of the family are both essential to the family's current living and hopes for the future, yet dependency of the ill or impaired aged relative can place both present and future in jeopardy.

The language barrier is clearly a factor here: it is difficult to describe the complexity of family relationships and responsibilities across that barrier, and so the client-worker speech is frequently

limited to basic information, rather than a joint assessment of the total family situation and service needs.

Progress has been made in the last several years, yet the picture remains a grim one. Access to institutional care is still blocked for many older Puerto Ricans and other Hispanics: the CABS Nursing Home has a long waiting list; the number of Puerto Ricans in the superior voluntary remains small, and when impaired and disabled Puerto Rican older people are placed in long-term facilities, they tend still to "end up" in the least adequate facilities in the city.

CABS Home Attendant Program, a Human Resources Administration funded program, includes substantial numbers of Puerto Ricans and other minority clients, but there are important deficits in this program that particularly weigh heavily on minority aged and their families. The case management task remains with the Department of Social Services and the vendor agency carries responsibility for the delivery of the home health care services. This division of functions is problematic at best; when it is combined with the heavy Department of Social Services caseload and reimbursement rate to the vendor agency which only allows for minimal supervision of the direct service workers, help to these families and older people is likely to be limited to the provision of a home health care worker. These families are less likely than families from other ethnic groups to know about benefits and programs to which they are entitled, and therefore, less likely to complain to the agency about inadequate service delivery, and most likely to "make do".

The studies of the family relationships of older people have demonstrated that American families, regardless of class and ethnicity,

try to take care of their own aged members. Families are more likely to continue to provide care without outside help, even at considerable cost to the physical, mental, and economic resources of family members, than they are to seek unnecessary services or to place an old person in a long-term care facility prematurely. This tendency is particularly strong among Puerto Rican families. The strength of family solidarity, the fact that Puerto Ricans do not feel able to make demands or register complaints, and the lack of sufficient agency staff to do both aggressive outreach and individualized assessment operate in a synergistic fashion as obstacles to service delivery. Balanced against severe handicaps of language, economic deprivation and lack of adequate services from the formal system, is the fact that the Hispanic elderly still function within the protective environment of the extended family. The socio-economic barriers encountered by the Hispanic elderly, in addition to their traditional role within the extended family, make them more dependent on their natural support network than their non-Hispanic counterparts.

Finally, combinations of lack of information and/or misinformation or a fatalistic view of the infirmities and impairments of old age may become obstacles in the path of access to and utilization of needed services.

As seen from the foregoing discussion, the Hispanic impaired elderly are a sub-group in society whose special needs have been overlooked or inappropriately treated by many sectors of society. Hispanic families deal with older people who exhibit greater health needs and who have less of their own resources, than will families of white ethnics. In addition, the probability is that the caregivers will have

fewer economic and social resources of their own to meet the needs of their parents or relatives. If the factors of functional, social, and economic resources prove to be central in providing successful community and home care services, minority elderly (especially Puerto Ricans) and their families will clearly have the most stressful experience.

In sum, this chapter has presented the existing literature which establishes the need for the project. The first conclusion drawn from this review is that of the existence and strength of the links between aging parents and their children: adult children are the primary caregivers and help patterns tend to be reciprocal until changes occur in the health and financial status of the elderly. The second conclusion is that the increasing recognition of the role played by the informal support system, including family members, in the care of the elderly, has resulted in the development of a number of demonstration projects and programs to enhance and support the caregiving role of the support system: these programs have ranged from financial incentives to self-help group developments for caregivers. The final conclusion is that of the identification of forces which impede a satisfactory level of utilization of social services by the Hispanic elderly (in particular the Puerto Rican) and their families. The cultural norms and values of Puerto Ricnans and other Hispanics tend to isolate them from the service delivery systems. This is compounded by the dysfunctional consequences of certain governmental policies and the attitudes and behavior of some service providers.

The general conclusion emerging from this literature review is that great emphasis needs to be given to strengthening the natural support system of the elderly and particularly the Hispanic elderly.

Recognizing this, a group program was modeled and developed on the successful Community Service Society Natural Support Program. Here, care-giving relatives and friends of the Hispanic elderly were offered the opportunity to participate in caregivers groups. The project operated under the assumption that families have been providing care to the elderly and that there is a need to support and strengthen, not substitute, this system of support.

The next chapter will present the theoretical and empirical background which guided the formulation of the project. The focus will be on the areas of support systems, self-help approach, relationship between formal and informal organizations, and andragogy as a model for presenting affective content in group programs.

CHAPTER III

THEORETICAL AND CONCEPTUAL BACKGROUND

This chapter will present the theoretical and empirical background which guided the formulation of the project. The major theoretical constructs of the project rest on the areas of support systems, the self-help concept, Litwak's theory of Shared Functions, and andragogy as the teaching-learning strategy. The discussion of the areas will follow the order in which they are mentioned.

SUPPORT SYSTEMS

The informal support system is distinguishable from the formal or organizational support system by virtue of its individualistic and non-bureaucratic nature and by the fact that members of this informal network are selected by the elderly from among kin, friends and neighbors (Sussman & Shanas:1977).

If one can visualize an older person at the core of and interacting with a series of sub-systems (networks) which usually operate independently but at times intersect, the concept of a broad-based social support system becomes clearer.

At the outmost reaches of such schema are the political and economic entities which determine the basic entitlements available to all older people; these impact significantly on their well-being in

the areas of income maintenance, health, housing, safety, education and transportation. Somewhat closer to the older person in terms of social distance, though still far from playing a central role, are the governmental and voluntary agencies that carry out the economic and social policies by providing the services mandate under such laws as the Older Americans Act and the Social Security Act. These organizations in the two outermost rings are clearly the formal part of the support system. As Sussman noted, like all bureaucratic organizations, they attempt to function instrumentally and objectively according to an ideology of efficiency and rationality (Sussman and Shanas:1977).

Still closer and standing somewhere between formal organizations and primary group members, are non-service formal or quasi-formal organizations. They can serve a helping function with respect to the elderly in the role, for example, of mailmen, building superintendents, ministers or visitation groups from a church.

Finally, closest to the daily life of an older person are the individuals who comprise the informal support system--kin, friends and neighbors. It is precisely these "significant others" with whom older persons have the most frequent interaction both instrumentally and effectively. This system--the innermost ring--is the focus of the project. The extent and relative role of the various elements of this informal support system will be examined.

The concept of informal support systems was initially delineated in Bott's study (1957) of younger married couples and had spread ever since. Gerald Caplan (1974) has in recent years focused specifically on "social supports" as the protective elements that stand against the vulnerability of persons at risk of developing serious mental illness.

Caplan and Killilea's (1976) most recent publication in this area deals explicitly with the mental health implications of such groups. The concept of support system was defined by Caplan (1976) in the following manner:

> Support system implies an enduring pattern of continuous or intermittent ties that play a significant part in the maintaining of the psychological and physical integrity of the individual over time. (p.41)

Caplan also discusses the general effect of support systems as the "social aggregates that act as a buffer against disease" and "in such relationships (support system) the person is dealt with as a unique individual" (Caplan 1976:29).

The support system contributes to identifying the individual as someone unique. The person is helped to understand that s/he is a unique individual with certain needs that others within the support system can satisfy. However, his/her continued satisfaction is dependent upon reciprocity.

Interpersonal contact is important to most individuals. A primary function of interaction is to help or to be helped by others, i.e., to establish a mutual helping relationship. Assistance-oriented interaction is another way of describing relationships within a support system. Caplan used the term "support system" to describe this interaction.

While the support system helps the individual to recognize him/herself as an individual and has positive effects for the person's mental health, the length of the relationship does not appear to be a dominant factor in whether the individual benefits from interactions while a member of a support system. Caplan describes informal social supports as fulfilling specific functions:

> Such support may be of a continuing nature or intermittent and short-term, and may be utilized from time to time by the individual in event of an acute need or crisis. Both enduring and short-term supports are likely to consist of three elements: (a) the significant others help the individual mobilize his psychological resources and master his emotional burdens; (b) they share his tasks; and (c) they provide him with extra supplies of money, materials, tools, skills and cognitive guidance to improve this handling of his situation (p.20).

Therefore, support systems are relationships established by individuals at various points during their life (especially in time of crisis) that help them satisfy immediate needs. These relationships act to rally the individual's emotional and physical forces. The support can be received in a variety of settings and times. Caplan (1974) sees the support ranging from kin to kith, non-professional community persons, religious denominations, mutual assistance and self-help groups.

Informal or natural supports systems are defined by Arling (1978) in the following terms:

> Natural support systems develop as implicit or latent consequences of social relationships which serve a range of purposes. They are natural systems in the sense that no formal, technical procedures govern their operation, and they are not normally established for the explicit purpose of providing support. Group members have generalized roles, e.g., friend, relative, fellow-worker, neighbor, etc., and when support becomes the objective of the relationship, the system normally does not have a set of standardized responses for determining how care should be provided. Instead, the methods of caregiving arise spontaneously (p.2).

Baker's definition of natural support systems encompasses the following:

> In most communities there exists a network of individuals and groups who band together to help each other in dealing with a variety of problems in living. Such groupings which provide attachment among individuals or between individuals and groups such that adaptive competence is improved in dealing with short-term crisis and life transition are referred....to as natural support systems. The word "natural" is used to differentiate such systems from the professional caregiving systems of the

> community..... Natural support systems include family and friendship groups, local informal caregivers, voluntary service groups not directed by caregiving professionals and mutual help groups. (p.140)

Lopata (1975) provides another definition of 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 as helpful in maintaining a style of life.

Support systems have also been categorized in terms of who is giving the support. For example, a professional who is not kin or kith to the recipient of the support, the support is seen as emanating from the formal system. On the other hand, when kin or kith provides the support it is then seen as informal.

Informal support system has been defined as an amalgam of informal services provided by family, friends, neighbors, and intimates of the older person. The concept of informal support system has been a topic of intensive research. Thus, for example, Litwak and Szelenyi (1969) showed that people relied on family, friends, and neighbors for different services. Lopata (1975) did a study on the support system of elderly urbanites in Chicago. Cantor (1975) studied the inner-city elderly of New York City using disparate measures of the concept of informal support systems. All these studies indicated that elderly individuals relied on family, friends, and neighbors for various types of support.

Cantor, former director of Research for the Office for the Aging in New York City, has studied the difference between the formal and informal support systems of the aged (1975) and performed systematic

comparisons on social supports among the Blacks, Hispanic-Americans and Whites. Regarding formal support systems, she has asked, how important are formal support systems in the life of the elderly and why in this society is it important to have structured support mechanisms to meet the needs of the elderly? Cantor (1976) viewed the needs of the elderly, especially the frail elderly, as being so complex that the resources of both the formal and informal support systems would be required. She labeled this integration of the two systems the social support system. The social support system has been broadly defined to include formal and informal activities as well as the personal support services required by an older person so that s/he could maintain a relative degree of independence while still in the community. Such a system is seen as enabling the older person to meet three major needs: socialization, the carrying out of tasks of daily living and assistance during time of illness or crisis.

The family according to Caplan (1974), is a primary support system. He points out that the family is the principal source of the emotional and necessary guidance for the elderly individual when crises occur.

> ...during the frustration and confusion of struggling with an at-present insurmountable problem, most individuals feel weak and impotent and tend to forget their continuing strengths. At such times, their families remind them of their past achievements and validate their pre-crisis self-image of competence and ability to stand firm (p.43).

Most older people are tied into a network of social support within which kin (especially adult children) and friends and neighbors provide important supportive services (Cantor: 1975, Lopata: 1975, Brody: 1978). Similarly, the key role of family members has been shown to be significant in many international studies (Shanas and Townsend,

et.al.:1968). Townsend (1957) and Litwak (1960) provided evidence that the extended family often remained a significant source of social support in times of need despite the apparent isolation of the nuclear family unit from the extended familiar ties. Research findings also support the conclusion that the majority of older people are integral members within a modified extended family system (Cantor: 1975, Shanas et. al.: 1968, Sussman: 1955, Townsend: 1965). The findings of these studies indicate that the family remains the locus of social interaction and the major provider of needed emotional and social support. Patterns of mutual aid and frequent interaction between family members and the elderly appears to be indicative of family support and solidarity.

Brody (1966) states that:

> Evidence also has accumulated reinforcing clinical observations and experience: No matter what supports, services, programs are provided for the aging person by the community, they can supplement but not substitute for the emotional bonds with adult children (p.201).

The importance of the support system in the Hispanic community has also been a focus of research in recent years. The belief that natural support systems within the Hispanic community serve as a resource in meeting many personal needs continues to be supported in the literature. Contrary to various opinions about its demise, there is evidence to suggest that Hispanics utilize the system in a most significant manner (Padilla, Carlos, Keefe:1976). Particularly significant is the finding that the elderly remain actively involved as participants in these naturalistic support systems (Valle and Mendoza: 1978). Other researchers have found that Hispanic family members (irrespective of class) not only feel an obligation to help each other

but actually do so in practice (Gonzalez and Garcia:1974).

Delgado (1982) emphasized that in the Hispanic communities the natural support system serves to minimize the use of formal resources. The extended family and religious institutions are important parts of this support system in the Hispanic community.

The family is the primary support for individuals in crisis. It is important to mention, however, that the family in the Hispanic culture goes beyond the nuclear family to include extended members. As Mizio (1974) stated:

> .....the Puerto Rican definition of family goes beyond the family of origin so that it encompasses not only those related by blood and marriage, but includes those who are tied to it as well through customs. Reciprocal obligation and supports exist in these relationships (p.7).

Hispanic families consist of blood relatives and a wide ranging constellation of "adopted relatives" who fulfill either informal or formal functions within the extended family. These members consist of close friends and neighbors who have engaged in important family matters and events.

The ritual kinship process known as "compadrazgo" formally includes friends and key neighbors as well as distant relatives in the family. This ritual is widely used among the different Hispanic groups. Organized religion is a very important aspect of the Hispanic support system. Religion serves as a support system for individuals in crisis (Delgado: 1982).

In the Hispanic culture religion takes two forms: organized religion (Roman Catholicism) and alternative religions (Pentecostal, Baptist). Although the Roman Catholic Church has been traditionally regarded as the primary religion of Hispanics, and in some instances

continues to be so, its influence has varied with some groups, like the Peurto Ricans. Alternative religions had offered many social and psychological support services to members. As Garrison pointed out (1978):

> Each of these small churches has a missionary society that answers requests of members, visits homes, and cares for the ill and disturbed... most Pentecostals go to their minister or members of their church with any problem they might have... (p.578).

Garrison's description resembles that of a multiservice organization situated in the Hispanic community with a bilingual, bicultural staff.

Garrison's study (1978) focused on the supports available and habitually utilized by the first generation migrant Puerto Rican women. She found an active Puerto Rican community life evidenced by many Spanish-speaking churches, bodegas (grocery stores) botanicas (religious object stores), social clubs, and centros Espiritistas (spiritual centers). When describing the typical core support system of the subjects in her study, Garrison said:

> ...the women have a personal network of kin, friends, and neighbors in the immediate vicinity....whom they name individually as important people in their life. Three fourths (79%) of the sample population lived either in an extended family household or had kin living in the immediate vicinity, frequently in the same building with whom they interact at least once a week. (p.573)

Leutz (1976) also studied the informal community caregiver as the link between the health care system and local residents. He found that the churches were the most formal of the informal support systems that he studied. His findings confirmed the existence in the Hispanic church of informal community communication networks through which a variety of people obtain assistance with their problems. His findings also confirmed that informal caregivers function as important communication links between residents and the world outside the neighborhood.

Information from formal agencies can be spread through these channels.

Weeks and Cuellar (1981) also pointed out the importance of the informal support system among Hispanics. They stated that Hispanics show a great reluctance to turn to professionals for help. If a family member is not available, they turn to friends and neighbors or other community supports, for assistance.

This review of the natural support system points out the importance of the role of the family in the support system of the elderly, especially the Hispanic elderly. The notion of the informal support system developed by Caplan and others was very valuable in the development of the group program for caregivers of the Hispanic elderly. The discussion will now turn to the self-help concept.

SELF-HELP CONCEPT

Underlying the project goals and activities is the assumption that mutual-aid and self-help play a continuing and important role in contemporary urban society.

The concept of self-help is not a new one: such groups have been described by Kropotkin (1972) as occurring in primitive times but beginning with the commotion of the sixties, when dissatisfaction with traditional institutions was being voiced, the self-help group concept began to gain popularity as an alternative to seeking help from institutionalized service agencies.

In Peter Kropotkin's classic conception, social cooperation in the form of self-help is seen as fundamental to man's survival throughout the ages (Kropotkin:1972). In general, Kropotkin notes, intra-group cooperation is a factor in the survival of any animal species. Physically

weaker and more vulnerable than many other species, man's survival was especially dependent on the development of socially cooperative relationships in food gathering, childrearing, land use, and defense against enemies. Intra-group aid and cooperation was apparently a critical factor in man's fitness for survival. As Kropotkin pointed out, however, the social functions of self-help extend beyond defense against threats posed by the physical environment. Membership in a viable social group, based on commitment of mutual aid and support, appears to be a constant and basic human need.

The complex self-help groups of today have evolved because of basic needs for group living, sociability and mutual helpfulness. Self-help ordinarily refers to the provision of aid to oneself. By extension however, collectives of individuals formed into self-help groups, provide mutual aid to each other around common problems and operate under such concepts as "self-determinism" of the group and "joint responsibility" (Barish:1971).

The nature and structure of self-help groups in particular, comprises a wide area that is not easy to conceptualize. A definition of self-help groups which has been used by two authorities in the field, Alfred Katz and Eugene Bender (1976), is the following:

> ...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 situation 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 social institutions (p. 9).

Katz and Bender indicate that interpersonal contact in self-help groups is highly valued. Self-help groups may provide material as well

as emotional support. In the analysis that they make, the attraction of self-help groups is based on:

> ...the need to live and be valued and be accepted for what they are, transcending boundaries of their own egos...(p.11).

Alan Gartner and Frank Riessman (1977) see the self-help approach as:

> ...having great potential importance for a marked improvement in the quality of human service practice. We view the self-help approach as sometimes providing a challenge to the professional, sometimes a way of expanding and enriching professional practice and the total human service practice, but rarely as displacing the professional where the professional's expertise is appropriate (p. 3).

They see the potential expansion of the human services via the addition and integration of self-help approaches as redistributive, because at the present time the poor, minorities and the aged do not receive sufficient services. In essence, they see the self-help movement as arising out of the needs of modern society.

> Many of the services provided by self-help units were performed in the past by the family, the church, the neighborhood, and the community. But these institutions have lost much of their power; we need new alternatives, new forms. It is in this context that self-help approaches take on their full significance (p. 3).

Katz and Bender (1976) indicate that implicit in every self-help group, including those focused on individual adaptation, is a criticism of deficiencies or failures of the larger society.

Lieberman (1979) says that the motivation for seeking out for self-help groups rests upon the notion that self-help groups arise to fulfill services not being currently met in society by other systems.

Most self-help groups share common characteristics and use similar techniques. The use of members to help other members is an essential characteristic of self-help groups (Barish:1971). Riessman

(1965) has pointed out in his "helper theory" that when a person is placed in a helper role, he not only provides help to others but in turn, is helped by his own activities.

Katz and Bender (1976) suggest that self-help groups may have a variety of functions and characteristics. In their view, face-to-face interaction is the key defining characteristic of self-help groups; so is personal participation. In taking part, individuals are related, sympathetically or empathetically, to others, either peer in outlook or peers in the possession of a common problem or common need. The group supplies a point of connection and identification with others, a baseline for activities, a source of ego-reinforcement, a value-system by which the individual's tasks, joys, sorrows, accomplishments, and frustrations can be evaluated and dealt with.

Basic to the concept of the self-help group is the assumption that its members agree upon and engage in some actions. Such behavior may be directed at the community, at personal change, at learning something--a body of knowledge or a skill.

Self-help groups help members perceive and deal with their immediate social reality more satisfactorily and aid them in finding workable approaches to many personal dilemmas.

Typologies of self-help groups are varied, no single typology has been set up. Alfred Katz classified these groups into three major types: assimilative, separative, and mixed. Barish considered that a complete and definitive typology still needs to be devised. He states that the majority of, if not all, self-help groups fall into three broad categories--those organized around social, physical or emotional problem conditions--those organized around social, physical or emotional

problem conditions. Any one group may be active in any or all of these areas, but usually it has one primary focus (Barish: 1971).

The typology offered by Katz and Bender (1976) is the following:

1. groups that are primarily focused on self-fulfillment or personal growth (therapeutic)
2. groups that are primarily focused on social advocacy
3. groups whose primary focus is to create alternative patterns of living
4. "Outcast-haven"--groups that involve total commitment in a living arrangement
5. mixed forms of self-help groups.

In spite of the fact that self-help groups can arise spontaneously, it is not uncommon for them to be stimulated by professionals. Self-help groups are often erroneously believed to be antiprofessional. The findings reported by Lieberman (1979) indicate not only that professionals have been involved in the founding and support of most self-help groups but also that most participants utilize professional help to a greater extent than do nonmembers of self-help groups and in a number of cases, indicate fairly high satisfaction in their experience with professionals.

Since the emphasis on self-help groups is on personal participation there is always the distinct possibility of conflict between professional and organizational representatives that go against the self-help cultural value system (killilea: 1976). The balance between members of the self-help group and the professional activity is not entirely understood and is certainly an area for future investigation as Killilea (1976) points out. Katz and Bender (1976) mention that one of the dangers often perceived by self-help groups is cooptation by professionals who may be perceived as being foreign to the particular character of the group. Frequently professional attraction to these groups develops out of a desire to provide resources to members, who

are perceived as lacking skills. But this in turn may limit the group's autonomy or change group norms.

Barish (1971) has established the educational and informational aspect of self-help groups as a salient characteristic. He states that:

> The use of education in self-help groups is important. Here, education refers to the promotion of greater factual understanding of the problem condition. Education is generally directed at the general public, but is very often offered to the members of self-help groups as well. Some groups are formed purely for the purpose of educating the public and themselves about their problems (p. 1165).

Education in groups is directed at individual members but often extends to society. Killilea (1976) notes that self-help groups combine expressive and instrumental activities.

The previous discussion of the self-help concept focused primarily on the benefits of self-help groups. It is clear that while many benefits exist, there are some limitations in self-help approaches. Gartner and Riessman (1977) offer the following limitations of self-help, mutual aid approaches:

> Frequently they foster dependence, sometimes life-long dependence on the part of the participants; some of them are authoritarian and impose a new orthodoxy, frequently a very simplistic one; their lack of record-keeping and overall non-systematic approach leads to great difficulties in determining accountability and effectiveness; many of them have a strong antiprofessional bias that prevents a useful integration of the aprofessional and the professional approaches; they run the risk of blaming and stigmatizing the victim if the service fails in any way, because of their emphasis on individual responsibility rather than the social causation of problems; and finally, they have a tendency to fragment social change as each group "does its own thing" (p.125).

The limitations presented by Gartner and Riessman are of particular concern to this project and as such have been considered in its design.

The self-help group movement has many implications for social work. It is a natural and beneficial extension of the philosophy which

underpins the social work profession. Such groups have moved into the helping areas and have taken on the helping that social workers have traditionally considered their own. A self-help group embodies the principle of helping the client to determine his/her own goals and to implement a plan to attain these goals. Its members come together in the pursuit of agreed-upon goals and in response to their own recognized and mutual needs.

The self-help group approach, previously described, is seen as a vital and integral part of the project. A self-help group approach appeared particularly well-suited for use with groups of caregivers of the aged for various reasons. First, caregivers of the elderly are a recently identified population and the professional service network is only just beginning to recognize their needs. Second, caregivers themselves possess the necessary expertise and hold many of the solutions to their own problems. Group meetings can be a conduit for this knowledge between caregivers. The professional ethic which stresses the importance of clients formulating their own goals and directions is most evident here. This self-help approach also translates into greater investment on the part of the group members by virtue of their sense of ownership. Finally, caregivers of the aged are not members of a deviant group but entangled in chronic, long-lived situations which may get worse over time. The chronicity of the older person's situation creates a need for continuing aid and support by the caregiver. A self-help approach allows for the existence of a group over a long period of time. This in turn sets the stage for the development of a self-help network of caregivers to which people can turn in times of crisis or as needed.

The concept of self-help is not new to poor minorities. In fact, it is deeply imbedded in the tradition of poor people. Gartner and Riessman state that there are also deep self-help traditions among the poor (Gartner & Riessman: 1977). Mutual aid societies among blacks can be traced back to the eighteenth century in Afro-American history. Many of these traditions were expressed in relation to social action, welfare rights, tenants groups, neighborhood mutual aid and the like. Since the self-help concept is entrenched in the historical tradition of poor minorities, it was also utilized as a unifying concept in the project design.

KINSHIP AND FORMAL ORGANIZATIONS

The existence and persistence of the modern organization in the forseeable future suggest that individuals and primary groups such as families, kin networks, or peer groups will have to relate to bureaucracies in some fashion and will need to deal with them competently. Elderly persons must deal with complex bureaucracies. Since these individuals are members of primary groups and tend to look for relatives and kin for assistance, it is likely that family and kin networks will play facilitating and mediating roles for the elderly member in dealing with bureaucracies (Shanas: 1977).

The functions of relatives, friends and neighbors (informal support system) and the formal organizations have a great deal of relevance to provision of services to the aged. Derived from organizational theory and based upon empirical research on the linkages of primary groups, such as families, with bureaucratic organizations, there is a most important finding--human service bureaucracies and families need one another. The task is to develop a complementary relationship with

appropriate social distance, between these two structures so that each performs its functions effectively without interfering with the other group.

The relationship between the formal and the informal system will be the focus of the discussion of the theoretical model adopted as a rationale for the usefulness of the project: Litwak's theory of shared function.

The work of Eugene Litwak provides an important conceptual base for the concern with relationship of the informal networks of family and frineds to the formal system of community services for the elderly (Litwak & Dobrof: 1977). In its most basic formulation. Litwak developed the position that families and friends are best able to handle the unpredictable, non-technical, diffuse tasks of living whereas organizations are best to handle the predictable, technical and specific ones. There must be then, a sharing of functions and balance or congruence between the two of them. He argued that families and other primary groups are indeed different from formal organizations in important functional and structural ways.

In developing a concept of "fit" between family and institutional or organizational supports, Litwak draws on the idea of shared functions. "Fit" involves the identification of the kinds of support needed by the aged that are shared between the family and formal organizations. According to this scheme, the family performs two primary support functions: instrumental functions and emotional functions such as bonding and tension management. Litwak sees a potential conflict or tension in the sharing of functions between bureaucratic institutions and family systems, and a balance must therefore be struck between the

provision of bureaucratic support for the family and the maintenance of family support networks.

In his conceptualization, Litwak resolves this problem by delegating routine support tasks such as the provision of day care and help with household chores to service agencies while leaving the family to handle socialization functions and individual needs, such as the need for help in an emergency. In doing so, he arrives at a concept of "maximal fit" or optimal sharing of functions between the formal organizations and the informal system. Therefore, most goals require some combination of primary groups and bureaucracies to achieve maximum effectiveness. Primary groups and formal organizations must coordinate their activities to maximize goal achievements while keeping a distance to prevent from clashing. The middle point is considered to be the point of balance between the two contradictory demands.

The balance concept of linkage rests on the nature of the tasks of each bureaucratic and primary group and the presumed competence peculiar to each particular structure. The assumption is that primary groups are more competent because they are organized to perform non-uniform tasks while bureaucratic structures are designed to handle uniform tasks.

While this representation of function is conceptually and practically sound, it does not mean that families and kin network members do not get involved in the technical applications usually reserved to the bureaucratic organization and professionals of human service systems. This mutual involvement has some desirable outcomes. Each structure may be able to get respite from the other since it is usually emotionally draining to perform any particular activity such as

providing emotional components of these services. Ultimately the need for mediation to develop a complementary relationship is apparent... But more than this: both agency and family will perform their tasks better if they can find ways to work cooperatively together. There are many examples from the world of older people and their families which illustrate the unlucky consequences of lack of cooperative relationships between service organizations and older people and their families and friends. One example, from the vantage point of view of the service organization, is when the staff of the agency itself may not recognize the importance of family and friends, or the recognition might be there, but not articulated in organizational policies and staff behavior. Families and friends then are likely to be disregarded or they may experience a distance between the agency and themselves.

One of the implications that the concept of balance has in terms of practice is that there may be times that conflict may arise in family groups when they have to deal with such issues as protective care for their aged relatives. On the other hand, there may be times when the organizations have to be aggressive in their efforts or outreach program to bring significant primary groups into action. From this point of view, a program which will enable the family and the formal organizations to find a balance in their shared function of caring for an elderly person, will provide an important tie or connection in the system. This is a central concept in the "Strengthening the Informal Support System of the Hispanic Elderly" project. Awareness of the characteristic action potential of both the informal and formal systems is an essential component to develop satisfactory linkages where the strengths of each might be maximized toward the specific

purpose that joins them together: servicing the elderly person.

LEARNING PRINCIPLES

The written works on instructional methods that should be applied in teaching adults are not very specific on which strategies are most effective. We do know that learning means change; that learning is active, not passive. The learner opens himself up, he stretches himself, he reaches out, he incorporates new experiences, he expresses or unfolds what is latent within him. The critical part of the process is how the learner is aided to embark in this active, growing, changing, painful or exhilarating experience that can be called learning.

We know that learning is a profoundly human activity. The main task is to provide the climate, atmosphere, freedom, stimulus, self-confidence, and self-discipline in which learning is promoted. There are some insights about which there is agreement, that can be employed as a foundation for a training program.

Relevancy: No adult will deeply absorb himself in study unless he sees, and feels that the subject is part of his life. The study must be close enough to him to enter into his personal situation. Without relevance there will not be the engagement that constitutes real learning.

Relationship: No knowledge or skill or attitude is discrete: the adult wants to know how it relates to his experience, to what he is, to what he knows.

Responsibility: Once the person enters a learning experience, he must act about it, and acting is assuming already some

obligation at least to question, to try to understand, or to do something about the consequence of the study.

The learning-teaching principle utilized for the caregivers program was the theory of adult education articulated by Malcolm Knowles: Andragogy. Andragogy is the art and science of leading adult learning which incorporates principles of affective learning and experiential learning processes. It assumes the self-concept of an adult as a mature person capable of self-direction.

Knowles (1970) originally postulated the principles of adult learning, or andragogy, in contradiction to principles of child-learning or pedagogy. Knowles' model was deemed useful in formulating a framework for principles to be used in the design of the project. The assumptions of the andragogical model relevant for this project are the following:

1. Andragogy recognizes the self-concept of an adult learner as a mature person, whose self-concept becomes less that that of a dependent person and more of a self-directed individual.

2. It considers the adult learner's life experience as huge, varied and valuable to the learning process. As an individual acquires experience, it becomes an important resource for learning. This assumption has various implications for the design of the project. First, considering that the adult learner is bringing varied experience to the program, teaching strategies that draw upon this are useful. For example, case illustrations, role playing and simulation exercises are incorporated in the group discussions. Second, provisions for practical application and utilization of knowledge should be built into the program design acknowledging that based on the cumulative experience adult learners tend to be self-directed.

3. Andragogy views the adult learner as having a reciprocal relationship with the instructor and other learners. The quality and amount of learning is related to the quality and amount of these interactions. The instructor then

should involve the learner as fully as possible in this interactional process.

4. It lets the adult learner choose the content and process of the learning experience based on the individual interest and needs. It has great concern for how the learner feels about the content as well as the process of learning.

Andragogy, then embodies principles of experiential learning adding assumptions about the adult learner. Both of these components make it a useful and compatible teaching-learning strategy to use with the self-help model group program described in this project. Both the self-help and andragogy framework view the adult participants as individuals of worth with valuable information and experience to bring to the group program or to the learning situation.

SUMMARY

In summary, the theoretical framework for this project encompasses the following aspects:

--Among Hispanics, the informal support system (the family, friends and community) plays an even larger role in meeting the needs of the elderly than it does among the larger population. Key within the informal system of the Hispanic elderly are the extended family and religious institutions. The primacy of the informal system for the Hispanic elderly was one of the cornerstones of the project.

--Self-help groups have a deeply imbedded tradition among poor minorities. A self-help group approach was particularly well suited for use with groups of caregivers of the Hispanic aged. As a recently identified population in need of services, this group possesses the necessary expertise and holds many of the solutions to their own problems. Group approach was the channel for utilization of this knowledge between the caregivers. The program was organized to meet specific and

personalized sets of problems that the group members confronted.

--Litwak's work on the relationship between the formal and informal systems, and particularly his concept of maximizing the sharing of functions between the two, was another of the project's premises. As such the project sought to enable the family and formal organizations to find a balance in their shared function in caring for an elderly person.

--Andragogy, the theory of adult education developed by Knowles, was used as the teaching strategy in the project because of its compatibility with the self-help group approach. Both view the learner/participant as active sources of information in the learning process.

The above theoretical premises were interwoven and applied to the Hispanic population of New York City to develop the framework for the project. The following chapter will provide a baseline description of the program.

CHAPTER IV

A BASELINE DESCRIPTION

This chapter begins with an overall description of the project. An overview of the nature of the project is presented next, followed by sections that deal with programmatic details, project content, instructional methods, recruitment of participants, selection of sites and evaluation plan for the project. The chapter ends with a description of the project sites and project participants.

NATURE OF THE PROJECT

The "Strengthening the Informal Support System of the Hispanic Aged" project was designed to supply the adult caregiver, i.e., relatives, friends, and neighbors of the Hispanic aged, with information and social support through a group program. It was formulated to test a group approach as opposed to an individual approach with Hispanic caregivers as the means for meeting some of their immediate needs for information and support. It was expected to offer experiential learning as well as to facilitate an informal support group network in which the participants could explore their personal feelings towards their caregiving role, share problems and concerns and engage in mutual problem-solving activities. The project was also directed at encouraging the fuller utilization of social support systems by caregivers to enhance their efforts in maintaining the functionally disabled elderly in the community. The groups were developed in different settings and

located in areas of Hispanic concentration.

As the project evolved, the needs of the service population and the composition of the groups changed. Other participants, besides caregivers, became involved in the program. These new participants, elderly persons, represented potential caregivers and individuals who, out of self-interest, wanted to learn about their own aging process.

The project was funded as a one-year demonstration project by the Brookdale Center on Aging of Hunter College through a grant from the New York Community Trust.

Model and Format:

The model utilized the self-help concept with adaptations, to inform and support Hispanics on how to cope with their caregiving role. The concept of self-help was emphasized in the groups as means of providing future continuity to the program, through the development of an informal support network among participants. The group program for caregivers was also utilized by various agencies as a mechanism to offer supportive services which they were not offering their clientele and to obtain feedback on the concrete services they were providing.

As Litwak pointed out (Litwak: 1965), the functions of relatives, friends and neighbors (informal support system) and the formal organizations have a great deal of relevance to provisions of services to the aged. The formal and informal systems are generally defined descriptively. Thus, a system is considered informal if it is personal, individualized, idiosyncratic, and uses knowledge based on everyday experience. The formal system, on the other hand, is considered instrumental and objective, applying technical knowledge uniformly and imparitally to large aggregates of people. According to Litwak's

theory of shared-function, in a technological society, the family, friends and neighbors and the bureaucratic organizations share functions in all areas of life. Thus, the formal and informal systems are complementary to each other. People with everyday knowledge who have immediate access to each other and who are devoted to each other may be more effective in some situations than professionals in organizations with technical knowledge.

In order to understand the nature of help that the elderly need and receive, it is important to understand the nature of the informal and formal systems. This project attempted to address this issue by assisting the participants in acknowledging the existence of the informal support system. This included a description of the kinds of care provided by the informal system to the Hispanic elderly, in comparison to the services received by this group from the formal organizations. The initial aim of the project was the dissemination of information to relatives, friends and neighbors of the Hispanic aged concerning available services, and the discussion of mediating strategies for dealing with formal organizations in the development of linkages between the families and the service providers. Relatives, friends, and neighbors involved with elderly individuals, have limited or no access to information concerning the problems and needs of the aged or how to obtain needed services for elderly persons. This is aggravated by the fact that the caregivers are usually monolingual (Spanish) and there are cultural and communication barriers to their utilization of services.

A second objective of the project was to compile information about the nature of the informal support system of the Hispanic elderly. In reviewing the literature, it was found that little is known about

the Hispanic informal support system or the relationship of the Hispanic elderly to the formal support system.

In the planning phase, decisions were made to offer six one-and-a-half hour sessions to a closed membership group. Six sessions were chosen to allow an adequate amount of time for the group to go through the phases of group development (Hartford: 1971), and to complete the content that would be needed to be covered. It was anticipated that each group would have from ten to twelve members. It was determined that a Hispanic social worker with group skills and a thorough understanding of social gerontology would provide the most appropriate leadership.

The specific goals of the project were:

1. To test the use of a group approach in strengthening the capability of Hispanic individuals to care for an older person.

2. To promote and assist group development among individuals from a Hispanic background with emphasis on the mutual-aid/self-help concept.

3. To involve an underserved target population of low-socio-economic and Hispanic background.

4. To train non-agency caregivers to assume a significant role, along with the agencies, to improve the care provided to elderly relatives or friends, and to link the formal and informal systems.

These goals were expected to achieve the following programmatic processes, as participants in the group would:

a. Increase their understanding and knowledge of the aging process;

b. Understand the emotional reactions and needs of older people;

c. Develop a greater awareness and sensitivity in their response to the aging process of their elderly relatives or friends;

d. Expand their knowledge of benefits and entitlements for the aged and improve access to community supports;

e. Improve dialogue and analysis of alternatives available to themselves and their aged recipient of care in maintaining an active and productive life;

f. Increase their effectiveness in addressing the needs of the elderly by facilitating the development of support systems within the group.

The program was designed to have an educational-consultative thrust. The educational component was to be provided through didactic lectures and content material to be disseminated and discussed during the group sessions. At each session, a topic was presented by a masters-level social worker (who was also the project director). The discussion topics selected for the sessions focused on a combination of therapeutic and didactic methods. Each session would begin with the distribution of a packet containing articles and other printed material relevant to the discussion topics for that session. This material was to be used as reference or for additional information. Material included handouts on: You and Your Aging Relative; Physical and Emotional Aspects of Aging; You and Your Communication With the Doctor; Accidents and the Elderly; Communication Skills; and specific information on medical conditions, among others. (See Appendix C for list of materials)

The consultative component of the session was implemented by encouraging interaction between the participants and the facilitator. For each session the project director used case-illustrations or exercises related to the caregiving experience, aimed at eliciting discussions among participants. It was anticipated that throughout the sessions,

the participants would share their feelings about their caregiving role, offer emotional support to other members of the group and explore solutions to mutual problems.

A selective group approach was used, as it seemed more relevant to the needs of the participants. The group approach was not aimed at long term psychotherapy, but aimed at a supportive, current functioning, reality-oriented focus. Crises were dealt with as they occurred, using didactics to explain the physical and psychological aspects of aging, with an emphasis on helping the participants cope with their current situations.

From the participants' point of view, the consultative approach would be implemented by providing an environment that would permit and support expression of feelings about the caregiving experience and elicit empathetic responses from other members. The group would develop support, mutual-aid, and strength, which the participants could carry outside the group, plus practical help in carrying out the support role. To the extent possible, group discussion would include helping participants gain some insight into their own feelings and behaviors and those of the elderly person for whom they provide care.

The instructional method used in the sessions was a presentation by the group facilitator followed by discussion. The presentation was used as the primary instructional tool and set the parameters of the discussion for each session. Case-illustrations were primarily used to promote discussion among the participants. Participants also received handouts which served to augment the presentation and discussion. *The participants were a valuable resource in carrying out the educational and consultative component of the project. The experiences of these*

caregivers with the elderly enhanced and enriched the group sessions which in turn helped to achieve the goals of the project.

The project director was involved in planning and organizing the groups and developing the format of the project, as well as running the groups. The planning and organizing of the project involved the development of the training materials and the review, adaptation, and translation of relevant articles. This role also involved balancing the didactic and the experiential content of each session.

The project director was responsible for initiating and capitalizing on the group process, directing and presenting the educational material and creating a climate conducive to the exploration of feelings and personal situations.

All the group sessions were conducted in Spanish. All the printed material was also in Spanish so that it could be easily understood by the participants. The project was also designed to allow individuals to discuss, with the project director, specific topics or to answer individual's requests. The project director was available between meetings and after each session to supplement the group sessions with individual assistance.

Program Content:

The topics discussed at the six sessions were the following:

Session 1: Topic: Program Overview, Physical and Psychological Aspects of Aging:

An overview of the program was provided to the participants, giving them an opportunity to initiate discussion concerning program content.

The first topic discussed at this session was the role of the family in providing care for the elderly. The discussion focused on the physical and emotional aspects of aging providing the participants with basic information on

these aspects. Some of the discussions focused specifically upon the emotional reactions of older people to such psychological conditions as loss, grief, anger, resentment, dependence and the emotional reactions of caregivers.

Session 2: Topic: Understanding Illness and Confusion Experienced by the Elderly:

The session focused upon providing basic information on physical conditions that occur and intensify as part of the aging process. Conditions such as diabetes, arthritis, high blood pressure, organic brain syndrome, and heart related problems were discussed. The onset of specific behavioral changes and their implications were also explored.

Session 3: Topic: Understanding Sensory Deprivation and Improving Communication:

Information was provided on the sensory losses (vision, hearing, etc.) occuring during the aging process. Problems in communication by the caregivers and the elderly were examined during this session. The group focused on developing improved communication skills with an emphasis on non-verbal communication such as touching and listening.

Session 4: Topic: Special Reactions to Aging:

During this session participants addressed questions such as: Can you accept your relative's old age? Do you like your aging relatives? Can you accept your own aging? Are you overburdened? In examining these questions, the participants explored the emotional cost involved in caregiving roles. Some problem-solving and coping techniques were discussed.

Session 5: Topic: Helping Your Aging Relative Cope With His/Her Aging:

The session dealt with the availability and utilization of community resources for the elderly. The participants were provided with information concerning benefits and entitlements, i.e., Supplemental Security Income, Social Security, Medicare, Medicaid, Food Stamps, Housing, and Home Energy Assistance Program, among others. The discussion centered on how to make the most effective use of available resources. Some advocacy skills in dealing with the formal organizations were introduced.

Session 6: Topic: Evaluating the Program

This session included an informal evaluation and discussion of the program designed to provide the participants with an opportunity to review the topics and format of the sessions and to offer suggestions for future programs. Participants were requested to complete a written evaluation questionnaire. Encouragement to develop self-help groups was made as well as introducing members of the group to established caregiver groups in the community. All participants received a certificate of participation. (See appendix B)

EVALUATION PLAN

This was an exploratory pilot program that provided an opportunity to begin defining service needs of Hispanic caregivers. The evaluation design was a formative one, which led to a model of replication of the program. The evaluation design consisted primarily of an after only measure of one group receiving one program.

The effectiveness of the program was evaluated against predetermined goals by means of a post-intervention self-administered questionnaire. Due to practical constraints of time and money in running comparable groups, the evaluation design was non-experimental and exploratory.

Several strategies were used to assess the program. An initial interview questionnaire was administered to the participants in the program which served as a needs assessment instrument, as a way of collecting some baseline data on the characteristics of the caregiving population and the aged relative or friend, and as a profile of the interaction of the caregiver with the aged. These interviews were held with the participants prior to the group intervention.

Careful attention was given to the dynamics of the program while it was being implemented to assess all progress made during the

project. The purpose of this exploratory design was to study the processes of program implementation and find out the extent to which the program was producing the quantity, quality and coverage of service that was expected. Some measurements of group process were taken following the sessions in addition to annotating the project director's observation at the verbal and non-verbal level. Participants' observations was another evaluation strategy used to assess the project. The project director served as the observer and the focal point of the observation was group process and interaction among and between members of the group.

Program effectiveness was assessed in terms of the expressed satisfaction or dissatisfaction of the participants. The after only measure consisted of a self-administered evaluation questionnaire at the end of the cycle. The questionnaire was made up of open-ended and close-ended questions asking for the participants' evaluation of the program and opinion of whether they found the program helpful or not. The questionnaire covered areas such as: benefits derived from the group program, areas in which the program was helpful or not helpful, support from other members, would they recommend the program to other people and would they participate in similar programs in the future. This method of assessing the effectiveness of the group provided for obtaining feedback of the participants' perception of the program.

This aspect of evaluation of the program proved to be problematic and not completely successful. Some of the participants did not respond to all the questions and they needed individual help in following instructions to answer them. For example, when numerating in order of preference the aspects of the program which they found most helpful,

they tended to pub a check mark where they had to put numbers. Another problem was created by administering the instrument in the last session of the cycle, which left out those participants who did not attend that session but had attended previous ones.

Success criteria for the program were determined by positive outcomes based on the project's objectives. Failure criteria were determined by lack of success in meeting the objectives.

The data obtained in the project is treated descriptively because of the small number of participants. The final results of the project will be shared with the participating agencies and with other agencies in order to encourage them to set up similar programs with Hispanic caregivers.

PROJECT SITES

The program was designed to be implemented in the Bedford-Stuyvesant section of Brooklyn under the auspices of a Community Action Organization. This organization has had a working relationship with Brookdale Center on Aging and had been characterized for its services to minority populations. But it became necessary to move the program to other sites (the reasons for this are dealt with in Chapter V). Other sites for the program were chosen for their reputation for having contacts with the Hispanic aged in the community.

As a result of the program's focus on the Hispanic elderly, many agencies contacted the program for information about the Hispanic elderly and his/her family and needs. Other agencies were curious about the program but were not prepared to offer their resources for the implementation of the program. One of the agencies that initially did not express an interest in developing a group for caregivers, subsequently

started a group program after some initial exposure to the project.

Criteria for site selection:

The criteria for the selection of agencies to participate in the project included: 1) location in a predominantly Hispanic neighborhood; 2) serving Hispanic aged and/or his/her family; and 3) willingness to have the project implemented in Spanish and at the agency.

The final selection of agencies was made after review of the preceeding criteria and the agency's acceptability to the Hispanic elderly and those involved in their care (i.e., family, neighbors, friends).

The project was implemented in four communities in New York City, having a large concentration of Hispanic population. Two communities were located in Brooklyn, one in the Bedford-Stuyvesant sector and the other in Bushwick. The other two communities were the East Harlem section of Manhattan and the South Bronx. The particular agencies selected to participate in the project were: a Home Attendant Program, a Community Church, a Senior Health Program, and a Senior Citizen Center.

The original conception of the program projected developing four cycles in one setting. This became impossible because the pool of potential participants was not large enough to develop four cycles of the program. It was clear then, that there was a need to locate subsequent cycles in other agencies in other communities. This expansion of the program provided for the implementation of the program in agencies providing different services to the aged and allowed implementation of the program in different geographic and organizational settings.

Selection of Participants:

Group participants were selected and recruited from the caseload of the participating organizations.

Outreach efforts were limited to the catchment area of the sites in order to facilitate attendance. Recruitment was carried out by several different methods. First, identification of potential participants was made with the assistance of the organization's staff who were familiar with the population. In several cases the staff would give the project director names of persons who seemed interested or would benefit from the program. Other potential participants were through the clients records if they met the following criteria: (1) Hispanic; (2) receiving services from the agency; and (3) available address or telephone number. Second, once the caregivers were identified, a personal letter was sent to them with information about the program and an invitation asking them to contact the agency or the project director if interested in participating. Letters were sent to the care of the older person when the caregiver's address was not available. This selection process provided the opportunity for the older person to become interested in the program. Follow-up was done via telephone calls when the phone number was available. Third, signs advertising the program were placed around the facilities of the participating agencies. Two of the agencies advertised the program in local neighborhood papers. Word of mouth by those already interested in the program attracted other members to the groups.

An initial interview was set up with those individuals who expressed a desire to participate in the program. The initial interview as a mechanism for the selection of the participants and provided an

opportunity to explore their needs. At the time of the interview, a questionnaire was administered to the participants to obtain baseline information and qualitative data to be used in grouping the caregivers. There was no fee charged for the program and anyone involved in a caregiving network who expressed interest in participating was accepted. This selection process allowed for identical criteria to be used in every cycle of the project. Further description of selection of participants in each site will be given in the next chapter.

Level of Involvement of Agencies Staffs:

The project was designed to include the participation of the directors and staff of the different organizations involved in the program. In the initial phase, the directors were involved in the following ways: (1) granting permission for their respective organizations to participate in the project; (2) assigning a contact person in the organization to participate in the development of the project with the project director; (3) providing space for the group sessions; (4) orientating the group leader to the organization, population, and community; and, (5) advertising the project and helping in the identification of potential participants for the program. The staff person assigned to work with the project director helped in identification and recruitment of the participants, made recommendations on relevant content to include in the group sessions, served as a contact person for participants, and suggested ways to enhance the participants' involvement in the project.

Directors and staff were invited to attend group sessions and encouraged to use the project director for consultation. The project director also used them as consultants.

DESCRIPTION OF PROJECT SITES

Four organizations participated in the program. They were all located in areas with large concentrations of Hispanics and all providing services to the Hispanic elderly.

The various settings were different in terms of services provided to the elderly, size and type of organization. They varied from a more bureaucratic organization, to a community-based agency, to a church. The differences between the sites made the development of the project different in terms of access to each agency's staff and information, and final implementation of the project in each site. The four participating organizations are briefly described below. Names have been changed to protect confidentiality of both the sponsoring agencies and ultimately, the program participants.

Broadway Home Attendant Program:

Broadway Home Attendant Program is located in the Bedford-Stuyvesant sector of Brooklyn and serves the Bedford, Stuyvesant, and Williamsburg areas of Brooklyn. This is a vendor agency for home attendant services working under a contract with the Human Resources Administration, the public agency in New York City for income maintenance and social service programs. Broadway Home Attendant Program is part of a larger, private, non-profit organization which administers a Nursing Home, a Housekeeping Program and is in the process of developing a housing project for the elderly.

The agency's basic structure is dictated by the City, although it enjoys some freedom of action in organizing itself. A model budget and staff pattern is established by the City. Each vendor agency for

home attendant services has a maximum authorized caseload. The clients are assigned to the agency by the Human Resources Administration and this agency serves around 1,100 clients, the maximum allowed by the City. The population served is mixed with concentration of Blacks and Hispanics.

The Broadway Home Attendant Program is responsible for recruiting, screening, hiring, assigning, paying, supervising, and dismissing home attendants. In addition, as a vendor agency, it is expected to provide job orientation for home attendants, process time sheets, provide information to the General Social Services' case managers about the client's status, and resolve complaints by clients and home attendants. Most staff in the agency is bilingual. Staffing pattern is composed by personnel specialists who supervise up to 115 cases, registered nurses for every 230 cases, an administrator, bookkeeper and clerical staff to maintain personnel records and process time reports for the home attendants. The range of tasks the home attendant is to perform is defined for both the worker and the client before services are initiated. Clients are expected to be self-directing; they are to provide the worker with direction and supervision within the range of permitted tasks. The home attendants serve at the pleasure of the clients, when clients are dissatisfied with their job, the agency is expected to replace them.

The specific sphere of competence of this agency is to provide home attendant services to its clients through an exchange relationship with the Human Resources Administration. In the organization there is a systematic division of labor, rights and power, and a hierarchical structure with leadership and direction emanating from the top. That is, "each lower office is under control and supervision of a higher one" (Etzioni: 1964, p. 51). For example, home attendants respond to the

personnel specialist who in turn responds to the administrator. Although the traditional model of bureaucracy, which Weber envisioned in a form of a pyramid, turned out to be too rigid for the administration of human services when both formal and informal tasks have to be carried out, this agency has many of the aspects (mentioned above) of a highly bureaucraticized organization.

The contacts for the implementation of the program in this agency were very formal in nature, although a working relationship was maintained with the administration and supervisory staff.

When the various settings in which the program was implemented are examined, variability and scope of organizational structures are great. And of the four agencies, the greatest variability in levels of bureaucratization is found between the Home Attendant agency and the next site examined.

Brooklyn Baptist Church:

Brooklyn Baptist Church is a community church located in the Bushwick sector of Brooklyn, a predominantly Hispanic neighborhood. It is a non-profit organization founded in 1948, characterized by its involvement in community programs for the Hispanic community. It has sponsored workshops in housing, health and other social services of concern to the community. It has a membership of approximately 270, the majority being Hispanics and other adults.

This is a voluntary association, which blends together structural aspects of both formal organizations and of a small informal primary group as described by Litwak (Dobrof & Litwak: 1977). This organization contrasts with the site previously described (Home Attendant Program) in specificity of agency's service, level of

bureaucratization, level of inter-personal relationships, and level of participatory decision-making.

Churches are considered the most formal of the informal care-givers of the elderly (Leutz: 1976). They are active in community affairs, especially in housing and services to the youth and elderly. Organized religion is a very important aspect of the Hispanic support system, it serves as a support system for individuals in crisis (Delgado & Humm-Delgado: 1982).

As Garrison pointed out:

> Each of these small churches has a missionary society that answers requests of members, visits homes, and cares for the ill and disturbed...the church offers many social and psychological supports (Garrison: 1978, p. 561).

In developing the project site, the contacts with the minister and some church members were informal in nature. All the arrangements for selection and recruitment of the participants for the group were made by them, eliminating all the constraints found in a more bureaucraticized setting. For example, in the church, participants were recruited in a more one-to-one basis and through word-of-mouth, while in the Broadway agency, participants were recruited through the impersonal process of compiling a mailing list of Spanish surnamed clients from the caseloads and the mailing of a form letter to those on the lists.

Spanish Senior Health Program:

The Spanish Senior Health Program is located in the East Harlem sector of Manhattan. It is a service unit of the Spanish Council for Human Services. The Council was established in 1964 as the Harlem Tenants Association. Since that time it has been involved in community development. In 1970 the Council grew to be one of the major providers

of social services to the East Harlem (El Barrio) Hispanic neighborhood of Manhattan. The Council is a community controlled and ethnically based organization... "rooted in the firm commitment that those who will be the client population should also be providers of services" (Spanish Council for Human Services: 1982). Without sacrificing quality of staff or services, all attempts are made to assure that representatives from the client population are represented in the different service components of the organization. The Council, over the years, has offered varied services which have ranged from education of pre-school children to drug-free treatment for the substance abuser. It planned and built Taino Towers, a comprehensive residential community in East Harlem. The Boriken Comprehensive Health Center, a Home Attendant Program and the Senior Health Program are among the service units administered by the Council.

This organization originated as a typical community organization, one whose primary concern was the betterment or overall well-being of the community. Neighborhood organizations are often general-purpose organizations not devoted to any particular subjects other than those pertinent to the preservation and improvement of the neighborhood (Knittel: 1970). Housing and planning were two interests of the organization. Originally the group was consistent with a democratic non-partisan nature organization. It was not indebted to any individual or business for support. Individual contributions usually sustained and maintained the group. As the community organization evolved into the delivery of services, it needed to look into sources of funding for the services and administration, which led to a bureaucratization of its structure.

The delivery of health care services to seniors is the chief function of the Boriken Senior Health Program. Health services operate through third-party reimbursement that could include Medicare or Medicaid funds. The sources of funding impose on the agency contingencies which have ultimate control on how it is operated. Even though the agency has a Board of Directors which serves as its Executive Directive, the agency's activities are limited by constraints imposed by the funding sources, i.e., staffing, types of services, etc. For reimbursement from Medicaid or Medicare, for example, the agency must be certified and must assume responsibility for conducting patient assessment and development of a plan of treatment, supervision and monitoring of the actual provision of services.

In keeping with the commitment to the community, the staff in the agency is bilingual and most of them are from the neighborhood. This consciously close relationship to the community is the major difference between the Boriken program and the Broadway program. Other major differences stem from the fact that Boriken offers direct health services, which enable it to establish close contact between its clients and staff. For this reason, Boriken bureaucratic structure is not as rigid but is more complex than that of the Broadway program. This comparative complexity results from the fact that Boriken offers comprehensive health care services for which clients pay. The similarities that exist between the programs--hierarchical structures, compliance with overseeing agencies, norms and regulations--arise from the dependency of both agencies on outside funding sources.

Contacts for the implementation of the program in this agency were made with the director of the senior health program and a community

worker and were quite informal in nature. Meetings were held whenever they were needed and the project director was given unrestrained access to all levels of the bureaucracy for the collection of information and the implemention of the program.

Boricua Senior Citizen Center:

This agency is located in the Southeast sector of the Bronx and serves primarily Hispanic seniors. This senior center is funded by the Department of Human Resources Administration under the auspices of the Christian Benevolent Association. The Association has been in existence for over ten years and has been characterized by the development of services for the aged, primarily the Hispanic aged. Among the services provided under the Association's auspices are a Home Attendant Program, Transportation services and the Senior Citizen Center.

The multipurpose senior center is a place in the community where older people come together in order to socialize, to learn new roles, and to maintain or develop their involvement in the community. The center usually serves a bridge between the elderly and the community and as a focal point in the delivery of services to elderly people in the community.

Senior centers are funded through different sources. The Administration on Aging is the government agency at the Federal level specifically authorized to promote the development of senior centers. Title V of the Older American Act specifically addresses the development of center facilities. It authorizes grants up to 75% of the cost of acquiring, altering or renovating facilities including initial equipment and furnishing of the facilities. Title XX of the Social Security Act (Social Services) provides funds for the centers, which

is the case of this particular center. Centers usually look for local matching funds or private funds. As with the Home Attendant Program and the Boriken Senior Health Program, this organization depends on outside funding sources. It has an exchange relationship with the Human Resources Administration which defines guidelines for the provision of services and administration of funds.

The center is part of a unit of a non-profit organization which has a Board of Directors. The center itself has an advisory council and a participants' council. The Board of Directors is responsible for establishing major policies for the center and employing and discharging the center's director. It has a centralized system; the administration, staff and services are housed in the same central facility. The center is staffed with a director, program coordinator, accountant, and senior volunteers. This model provides a mechanism for maximizing the resources of the professional staff (program coordinator and director) by using them in supervisory rather than direct services. It maintains a staff that reflects the ethnic composition and language of the participants. The centralized administration provides for more coordinated activities within the center and gives the elderly and their opinions a powerful voice in program planning and activities. Working in close proximity with each other, staff members have opportunities to learn from seniors and provide them with the opportunity to meet and exchange ideas. The governance of the center is the responsibility of the advisory council and the participants' council.

The Board of Directors is legally and fiscally responsible for the center. Members of the Board are drawn from a base of community supporters including service consumers, public officials and local

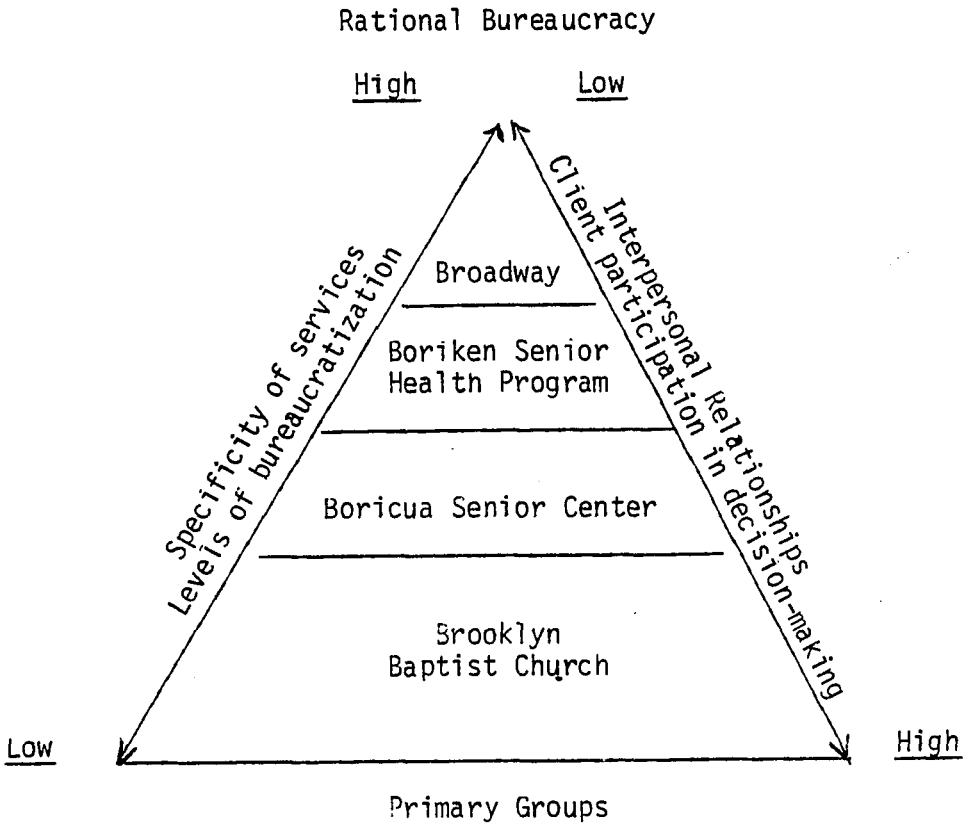
business leaders. The participants' council serves as a liaison between the board members and center participants.

The Boricua Senior Citizen Center has an active caseload of approximately 150 seniors. It provides recreational and social programs, nutritional programs (group meals), escort services, information and referral services, health and related assistance, and counseling.

In developing the program at this agency, close work was done with the center's director and senior participants. The contacts were very informal in nature. As in the Boriken Senior Health program, meetings were held as needed and the project director was given unrestrained access to the staff and records.

A comparison with the previous agencies shows that Boricua Senior Citizen Center is most similar to the Church. Clients are involved, through the participants' council in the agency's decision-making process. The services it provides are defined in general terms--socialization of senior citizens. The bureaucracy is small and staff functions are broadly defined with overlapping roles.

A summary of the differences and similarities among the four agencies is presented in the following illustration using rational bureaucracy and primary groups as parameters.



The agencies which had a more specific definition of their services also had a higher level of bureaucratization (Broadway and Boriken) and were thus closer to the rational bureaucracy model in the organizational spectrum. Those agencies with high levels of interpersonal relationships also had high levels of participatory decision-making (Boricua and Brooklyn Baptist Church) and were closer to the primary group model in the organizational spectrum.

The following chapter will show how these differences and similarities aided or hindered the implementation of the project in each of the agencies.

DESCRIPTION OF THE PARTICIPANTS

Fifty-eight persons participated in the program at the four different project sites. The participants consisted of children spouses, siblings, grandchildren, in-laws, friends and neighbors of the elderly and some elderly.

Analysis of major demographic characteristics of the participants is presented in Chapter V. It reveals that forty-two of the participants were female (72%) and sixteen were male (28%).

The ages of the participants ranged from seventeen to seventy-nine years old. Over fifty percent of them were fifty-one years old and over (57%) with a concentration in the ages 61 to 70. Nine percent of the participants were below age thirty; fifteen percent between the ages of thirty-one to forty; nineteen percent between the ages forty-one to fifty; twenty-three percent fifty-one to sixty; and thirty-one over sixty years old.

Fifty-eight percent of the participants were married, thirteen percent single, and twelve percent widowers.

Only two of the participants were born in the mainland United States. *Thirty-nine of them (64%) were born in Puerto Rico, nine in other Caribbean Islands (Cuba, Dominican Republic) and six in Central or South America.* All of them, except two, had lived in the United States for over ten years. A large number of them (55%) had lived in the United States for twenty years or more.

There were thirty-one persons with less than twelfth grade education, seventeen with high school diploma, and five with college or professional diploma. Twenty-one were working full-time and six were working part-time. Fifteen of them were retired, fourteen were

unemployed and two were students.

The family income of the participants was less than $5,000 per year in thirty-three percent of the cases. Sixty-six percent earned less than $10,000 a year. These percentages fall below the figures reported for the median income of the Hispanic population in 1979. The median income reported for Hispanics was: 12 percent had incomes under $5,000 and about 39 percent had incomes between $5,000 and $15,000.

Two characteristics stand out from this data. First, in spite of the high percentage of people with levels of education of high school or higher (40%) a disproportionate number of participants live at or near the poverty line. The second salient characteristic is the age variability of the group. As stated before, the ages ranged from seventeen to seventy-nine; 43% of the participants were fifty or younger and 57% were fifty-one or older.

SUMMARY

This chapter has presented an overview of the Group Program for Hispanic Caregivers. This program was designed to incorporate education and support elements. These elements were combined to: 1) provide the group participants with concrete, practical information about the aging process and how to deal with their aging relatives or friends; 2) provide a support group in which participants could share their problems, concerns and feelings.

The educational and supportive elements of the program were combined to provide the participants an opportunity to express feelings and concerns about their caregiving experience. Educational material was presented and organized by the project director by means of lectures supplemented by handouts. Topics for group discussion included:

psychological and physical aspects of the aging process, common and chronic illnesses in old age, communication with the elderly, understanding sensory losses in old age, special reactions to aging, and community resources, benefits and entitlements for the elderly.

A general evaluation instrument was distributed at the end of each cycle and completed by participants. Questions asked group members to identify how the program had been helpful to them and to define what they liked and disliked about it.

The project was implemented in four different agencies that ranged from a very bureaucratized structure to a primary voluntary association. Group participants included caregivers of the elderly (children, spouses, in-laws, siblings, grandchildren, and friends and neighbors) and elderly persons who were anticipating a caregiver role or wanted to learn about their own aging process.

The next chapter will describe the actual initiation, implementation, completion of the program and description of salient differences and common issues raised by participants in the group process. The chapter ends with the participants' evaluation of the project.

CHAPTER V

PROGRAM INITIATION, IMPLEMENTATION AND EVALUATION

This chapter provides a general overview of the program initiation, the implementation and completion of the program. It is divided into three major sections: the program planning and initiation phase, implementation problems and a description of the development and evaluation of the project in the four different cycles. The chapter begins with a focus on when and how the program was initiated, followed by a description of the implementation problems in developing the program. The discussion turns to description of program cycles. In this description each cycle is discussed focusing on four major aspects: how the program was initiated in each site, who the participants were and why they became interested in the program; how the group developed through the program; and, how the participants evaluated the experience. The final section of the chapter describes characteristics of the program's participants and common issues that evolved in the cycles. A brief summary closes out the chapter.

PROGRAM INITIATION

The project was initiated in January 1982. The months of January, February and March were utilized to design the curriculum to be included in the program, translation of the material into Spanish and contact of the site for implementation of the program.

The task of developing training material for caregivers was a challenging responsibility. It involved decisions as to what and how much to include, how to present it, while taking into consideration the needs and requests of the program's target population. The fact that the target population was Hispanic involved translating and adapting the material. One of the main and most time consuming problems was the compilation and translation of the training material. Translation included the adaptation of material to Spanish speakers and in particular to Puerto Ricans. This part took longer than expected.

During the initial stage, several planning meetings took place with the Administration and staff of the agency where the project was to be implemented. From these meetings several problems were identified related to the organization of the project cycles which influenced the change from the initial conception of the program. These problems will be described in the following section.

Problems Related to the Initiation and Implementation of the Program:

The original conception of the program projected developing four cycles in one setting. All the cycles would take place at the Broadway Home attendant Program. This agency has a working relationship with Brookdale Center on Aging, the agency sponsoring the project. In the initial contacts with Broadway Home Attendant Program, it had anticipated to have enough participants to run the four cycles of the program there. Several planning meetings were held at the agency for this purpose. The program was welcomed by the Administrator who gave his approval to set up cycles during the months of March and April 1982. The program was seen by the Administrator as a way of providing supportive services

to the clientele and the relatives, since the direct involvement of the agency was with the home attendants place at the older person's house. The "service" to families and the elderly was limited to provision, training and supervision of the home care workers.

During the initial planning meetings with the Administration and staff, the project director attempted to identify the potential participants for the program. This was done with the assistance of personnel specialists who were familiar with the clients and relatives served by the agency. These individuals were key figures in identifying the Hispanic aged population served by the agency because of their close work with the home attendants. As a preliminary step in obtaining their collaboration, the project director had two meetings with this staff to explain to them the nature of the program and the impact on their clientele and the clientele's relatives. The first and major problem encountered in the organization of the cycles at this agency had to do with the identification and recruitment of the participants.

Identification and Recruitment of Participants:

The method chosen by the project director and the staff for the identification of potential participants involved the personnel specialists going through the caseloads and classifying the Hispanics by Spanish surname to come up with a list of clients and emergency contact persons (assuming this person was the caregiver) along with addresses and telephone numbers.

The identification of potential participants was made by the staff as follows: from approximately 1,100 clients that the agency was serving, only 97 (9%) were identified as Hispanics, five of which were

minors (i.e., under 18). From the remaining ninety-three older clients, twenty-nine (31%) had no relative or emergency contact person, diminishing the number to 64 potential participants. With this number of potential participants, the possibility of implementing four cycles of the project was very minimal. So it became clear that additional sites had to be contacted.

This method demonstrated that the staff's only contact with the clientele was through the agency's records. While this is understandable since this staff is only responsible for the supervision of the home care workers, it reveals the distance that exists between the agency and its clientele, and the consequent ignorance by the agency of its target population. An agency that saw itself as serving a large Hispanic population, could only identify its Hispanic clients by a survey of surnames in its records, and thus revealed the tenuous link between itself and its population. This is in part justified by the division of labor which exists between agencies of this type and the Human Resources Administration--the latter is in charge of the case management while the former provides services.

Problems of Attrition:

Although the project director and the Broadway Home Attendant Program Administrator had anticipated that four cycles of the program could be implemented in this agency, this became impossible as mentioned above, because the pool of potential participants in the program was not as large as anticipated. The reasons for this difference between expectations and reality are analyzed below.

First, although the Broadway Home Attendant Program is an agency under Hispanic auspices, the clientele of the agency is a mixed one.

The total number of Hispanic aged served by the program turned out to be smaller than assumed. Out of 1,100 home attendant clients in early 1982, only approximately ten percent were Hispanic and elderly. The Department of Social Services identifies the agency's clientele and mandates the services it provides. Although the agency is located in a Hispanic community, its clients are selected by the Department of Social Services, following medical and economic criteria, from a catchment area much larger than the community involved.

Second, there is a history of underutilization of these services by Hispanics (Asociacion Pro-Personas Mayores: 1980). This study states that "... compared with the aged population in general, older Hispanics' access to social services is even more impeded to the degree that cultural differences, including language, inhibit their full use of anglo-provided services" (p. XI).

Third, and again contrary to the expectations, a number of the Hispanic aged served at Broadway Home Attendant Program did not have a relative nearby. Some appeared to be family-less in an absolute sense (31 percent) but more characteristically it seemed that their close relatives lived at some distance from them in the mainland or in Puerto Rico.

Fourth, and not unexpectedly, some relatives who were contacted, were not interested in the group, or whose heavy family and work responsibilities precluded their attendance.

It was clear, therefore, that there was a need to locate subsequent cycles in agencies and organizations in other communities. Thus opportunity was borne out of adversity; adversity because the outreach task became more complex and time consuming than anticipated; opportunity

because outreach efforts permitted the expansion of the programmatic aspects of the project and created new links to minority communities. In addition, the errors of the first experience served as a lesson to the approach and screening of the so-called minority agencies or organizations; to select agencies that were neighborhood and community based and thus had more knowledge of their clientele and were serving Hispanics. The experience proved that it was more feasible to develop and implement the project in less bureaucratic organizations--those who know their clientele and have more contact with them. The programmatic expansion of the program also provided for the implementation in agencies that were providing other services to the aged person; for example, senior citizen centers or health programs. Finally, it allowed for the implementation of the project in different geographic and organizational settings.

Other Problems of Implementation:

In addition to the factors already mentioned, other problems arose in the implementation stage. First, many Hispanic people are reluctant to join groups because group participation has not been part of their lifestyle. This is the case more often for the older adults that it is for the young. For the former, group participation has been more instrumentally oriented than affective, and almost exclusive to problem-solving groups. Once potential participants had been identified, this reluctance to participate demanded a great deal of outreach efforts by the project director. The announcement of the program through letters and flyers was not enough, necessitating phone canvassing of prospective members.

Second, there were factors of time scheduling, number of sessions and location of training.

Time Schedule: Factors such as: (1) how much time was available for the group program; (2) time when the agency was open; and (3) responsibilities and conflicting workload of the caregivers had all to be taken into consideration when scheduling the time for the meetings.

Number of Sessions: Although the original design of the project provided for eight sessions per cycle, the number of sessions had to be reduced because of the limited availability of the participants and of the meeting places. All the sessions were scheduled to take place on a weekly basis to provide for continuity, but not all of the participants could commit themselves to eight weekly sessions. And, some agencies could not provide the space on a weekly basis for eight consecutive weeks.

Training Location: The availability of space in the agencies varied from cycle to cycle. Accessibility and convenience of the location to the participants had to be taken into consideration. Other factors such as well-lit, clean, pleasant and quiet locations were required in creating a positive environment for the group sessions. In keeping with Knowles' principle of Andragogy, careful attention had to be paid to the learning environment in which the training would take place.

As a result of the combination of all the problems mentioned, scheduling the sessions in each site proved to be different.

PROGRAM IMPLEMENTATION AND EVALUATION

The actual implementation (beginning of the group cycles) started in the month of March 1982 and ended in March 1983. Four cycles were

organized and completed during this period. The first cycle was located at Broadway Home Attendant Program and met from March to May 1982. The second cycle was located at Brooklyn Baptist Church and met during the month of August 1982. The third group met from November 1982 to January 1983 at the Senior Health Program of the Spanish Council for Human Services in East Harlem. The fourth and last cycle was located at the Boricua Senior Citizen Center in the South Bronx and met from February to March 1983.

Table 5:1 provides a summary of the development of the program in the four different sites, by agency, number of participants, number of sessions and meeting time.

TABLE 5:1

Summary of Salient Aspects of Project Cycles

Cycle	Agency	Participants	Sessions	Day and Time
I	Home Attendant Program	12	6	Sundays - 3:00 P.M.
II	Community Church	22	4	Fridays - 7:00 P.M.
III	Senior Health Program	10	5	Mondays - 10:00 A.M.
IV	Senior Citizen Program	14	5	Fridays - 10:00 A.M.

The next section will include a description of each cycle including analysis of the participants' characteristics and common issues discussed in the group sessions. Process records of a selected meeting has been included in the Appendix A, so that the reader can get a broader picture of the meetings and the ways in which the participants used the group and group facilitator for support and information.

Description of the Cycles:

The following account is an overview of group development and participation in each cycle. In this description, cycles will be referred to as Cycle I, Cycle II, Cycle III, and Cycle IV. The description will include the site and how it was selected, who the participants were, why they participated, how the group developed throughout the sessions, and an evaluation of the cycle by participants.

Cycle I:

The first caregivers' group sponsored by the Broadway Home Attendant Program, took place at the Broadway Nursing Home on Atlantic Avenue, Brooklyn. The Nursing Home, which along with the Home Attendant Program is part of the Consumers Organization of Bedford-Stuyvesant and was chosen as the meeting site because it was accessible to all participants and because the Home Attendant Program site was closed on Sundays.

The sessions began on the last week of March and ended in the first week of May 1982. Six sessions were held on Sundays starting at 2:00 P.M., on a weekly basis with the exception of Mother's Day. The time and day was selected by the group participants.

The participants for this cycle were drawn from the caseload of the Broadway Home Attendant Program as described previously. Twelve participants registered for the sessions but only seven showed up in the first session. And of these, only five completed the program. Three other members joined the group beginning in the second session. Two of these were attracted to the group in response to outreach undertaken by the initial participants. The other one was originally registered to participate but could not attend the first session. Twelve persons in all attended the program in this cycle.

The sessions took place in a medium-size room in the second floor of the Broadway Nursing Home. The size and facilities of the room provided a comfortable setting for the sessions. The room is ordinarily used as an activity room for residents, therefore, it contained tables, chairs, and a blackboard. The location of the room provided for privacy, although the intercom of the Nursing Home interfered sometimes with the sessions.

The sessions were scheduled to begin at 2:00 P.M., but many times they did not begin until 2:30 P.M. because of late arrivals. This situation posed a problem because often the participants who came early wanted to leave early. Frequently the sessions would last more than one hour. Refreshments were served after each session.

In spite of the problems encountered in the recruitment of the participants for this cycle, those who participated were very enthusiastic and showed interest in the sessions. All of them attended at least four sessions. Those members who had to be absent would call ahead of time to inform the project director. All the material handed out at the sessions would be mailed out to those who were absent. Though receiving indirect services from the same agency and living in the same neighborhood, members did not know each other beforehand, except in the case of those who were related to each other.

The content per session of this cycle was the following:

Session I: The Aging Person and the Family: discussion of the types of help that the family provides to the elderly; Physical and Emotional Aspects of Aging, specifically the changes and coping mechanism of old age

Session II: Common Medical Problems of the Aged: chronic illnesses in old age and behavioral problems associated with some of them.

Session III: Understanding Sensory Losses in Old Age: vision, hearing and memory losses; Communication with the Elderly and Ways to Improve it.

Session IV: Special Reactions to Aging: Dealing with Our Feelings Toward the Aging Relative and our own Aging Process.

Session V: Helping the Elderly in the Community: services, community resources, and benefits and entitlements for the elderly.

Session VI: Evaluation and Closing of the Program: Alternatives to follow-up and development of caregivers groups.

Initial interviews were completed with twelve participants of this cycle. Analysis of the data in the questionnaires reveals the following profile of the participants in this cycle.

Women caring for parents, sisters or in-laws formed the core of this group. All of the participants were providing some type of care to an elderly relative or neighbor, although eight considered themselves to be the principal caregiver of the elderly person. The elderly person receiving the care was likely to be over 85 years old (67 percent of the cases), widow (67 percent) and living with a relative (60 percent).

The caregiver was generally a female (83 percent), middle-aged (average age--50), full-time employed (60 percent), and the daughter or daughter-in-law (76 percent) of the elderly person. Eight of the participants in this cycle were related in some way to another participant: two married couples, a mother and daughter, and two sisters. There was a seventeen year old caregiver who attended five of the sessions.

The following similarities were found among the participants. In the initial interview all said that they were in the program to obtain information and education about specific medical conditions of the elderly and the aging process, to locate resources in the community, to help the elderly person and to seek advice in planning and directing

future action with the elderly. Initially they did not perceive a need for peer support.

Following is descriptive analysis of the activities performed by the caregivers of this cycle on behalf of the elderly and the constraints faced by them while doing so. The information was obtained from the initial interview with the participants.

(TABLE 5:2)

TABLE 5:2

Activities Performed by Caregivers in Cycle I*
(N=12)

Items	At least once a day	Three to four times a week	At least once a month	Never
Shopping for personal things and food	16%	16%	16%	50%
Prepare meals	35	15	0	50
Light Housecleaning (Dust, dishes, etc.)	25	12.5	12.5	60
Heavy housecleaning (Floors, windows)	12.5	12.5	12.5	60
Administer and supervise medication	50	0	0	50
Laundry	15	25	10	50
Help or supervise personal hygiene (Bathing, clothing)	50	8	0	42
Contribute money for expenses	8	0	34	58
Help manage finances (Cash checks, pay bills)	8	0	58	34
Assist in transportation (Take to appointments or to church)	0	0	42	58
Emotional support (Visit, talk, phone)	92	8	0	0
Take home for weekends	0	0	25	15
Help mediate with agencies	0	0	42	15

* It should be noted that participants for this cycle were recruited from a Home Attendant Agency, as such, the elderly person was receiving these services from the agency. Differences in percentages reflect those who did not answer the question.

Table 5:2 illustrates the types of activities done by the caregivers in this group by frequency of each activity. Thirteen categories of activities are displayed in this table with a frequency distribution for each category. Emotional support emerges as the most frequent service provided (on a daily basis) to the elderly by the caregivers (92 percent of the cases). Emotional support involved visiting, talking and calling over the phone. Concrete services in the form of shopping, meals preparation, and housecleaning were provided in less than fifty percent of the cases on a daily basis. Although the older person was receiving the home attendant services ranging from four to twenty-four hours daily, the caregivers were also involved in providing supervision, or administering medication, or assisting and supervising grooming and personal hygiene in fifty percent of the cases. Linkage services, such as mediating with the formal organizations were performed on a monthly basis by 42 percent of the caregivers. Concrete services were provided in the majority of the cases by the home attendant as can be seen in Table 5:3.

The caregivers in this cycle were asked to select which of the activities done for the elderly was most difficult. Thirty-three percent of them stated that none was difficult. Twenty-five percent considered that providing personal care was the most difficult, while sixteen percent considered that dealing with other relatives was the most difficult. Emotional support, dealing with the agencies and meal preparation was considered the most difficult by twenty-five percent of the participants.

TABLE 5:3

Services that the Older Person Receives from Formal Organizations: Cycle I (N=12)

Items	Receiving from Agencies	Not Receiving	No Answer
Counseling	0	92%	8%
Escort services	0	92	8
Transportation	75%	17	8
House repairs	0	92	8
Friendly visitors	0	92	8
Telephone reassurance	0	92	8
Legal services	0	92	8
Personal care*	92	0	8
Shopping*	92	0	8
Light housecleaning*	100	0	0
Laundry*	92	0	8
Financial help**	75	25	0
Home health aid*	83	0	17
Home attendant	100	0	0
Visiting nurse	75	17	8
Meals on Wheels	0	92	8
Senior Citizen Center	0	92	8

* Services provided by the Home Attendant
** Caregivers referred to Supplemental Security Income for financial help

This table shows that most of the services that the older person receives from the formal organizations are provided by the home attendant.

In seventy-five of the cases the elderly person receives transportation services and a visiting nurse. The majority of the elderly persons did not receive counseling services, escort services, house repairs, friendly visitors, telephone reassurance, legal services, meals on wheels, nor did they attend a senior citizen center (92 percent). In the majority of the cases the caregiver provides those services that the elderly person does not receive from the formal organizations (See Table 5:2). In some cases the caregiver provides some of the services also provided by the home attendant.

Data on Table 5:2 and Table 5:3 reveal that families and friends remain involved even when the services from the formal are being utilized. Similar to the findings of Horowitz (1982) and Frankfather, et. al.,(1980), formal services did not displace the caregivers.

Data on Table 5:3 points to the underutilization of services by the elderly Hispanic (Asociacion Nacional Pro-Personas Mayores:1980). It is possible that elderly persons have little knowledge of existing services and resources (Kaplan, et. al:1979) or that services are not accessible to the Hispanic elderly, or that the elderly simply do not want to receive services from formal providers. As one participant said:

> My mother would never accept food delivered to her from a senior center.

The reasons for this are highly speculative because the literature on utilization of the formal system by the Hispanic elderly is very limited. The works of Cantor (1975) in New York City, Brody (1974) in Philadelphia, and the Asociacion Pro-Personas Mayores (1980), in Los Angeles provide some of the most improtant data on the Hispanic elderly in urban settings. Although there are more formal resources available

to the elderly person in urban areas, the extent of the utilization of these resources is still relatively low. Both Cantor and Brody emphasize that the informal system plays a major role in the lives of the urban elderly.

Even though participants in this cycle did not perceive a need for peer support and group interaction, over the six-week sessions they became very supportive of each other and comfortable in expressing their feelings about their caregiving situation. The sessions that dealt with medical problems in old age and special reactions to aging were key sessions in this cycle. The size of the group per session (generally six) helped to develop a sense of cohesion which enhanced the level of information and experience sharing. In the very first session, members brought up personal situations and related to other members things they were doing for their elderly relative or friend. They brought up problems related to the topics discussed in the session, for example, the involvement of the family in providing care to an elderly person and changes that their elderly members were going through as a result of aging. At the end of the first session one of the members commented the following:

> This session has been of great help to me because when you take care of your mother, you feel that you are not doing enough. Now I see that I am not alone, and talking to all of you made me feel better.

Having members of the same family in the group, e.g., sisters and married couples, gave them the opportunity to discuss problems that arose in their relationship. Two of the members were sons of an elderly mother and came with their wives to the group sessions. In one of the cases, the man was the most articulate in describing the things he would do for

his mother while the wife presented some of the conflicts that would arise as a result of his "dedication" to his mother:

> We never go out of the city. We never plan to go on vacation because he feels that if we go away, something might happen to mother, even though she has a twenty-four hour home attendant living with her.

While Mr. C. admitted being afraid of leaving his mother alone, he claimed that his wife never mentioned her mixed feelings about his inability to leave his mother. His wife admitted that the group experience made her realize that it was fair for her to bring up the issue because other participants were confronting similar situations. Issues regarding who should take care of the elderly relative all the time, and what things should be done for the elderly were brought up in the discussions. Members expressed different ways of sharing responsibilities and pointed to the importance of having relatives or friends take over their responsibilities while they went away on vacation. The members of the group reassured the two sons that "nothing would happen to mother" while they were away because their own experience had demonstrated this. The two sons admitted that often they would be so involved and close to mother that they would forget their partner's needs. Members also pointed to the fact that some offspring do not resent the time they spend with their parents, yet they are not aware that they impose a burden on their spouses for being so dedicated. Discussion of these issues was found beneficial by both couples in the group. Group members suggested different alternatives in dealing with the situations, such as alternating the responsibilities, spending time out for dinner or at the movies, and making mother aware that nothing happens while her sons are away.

The issue of dependence and independence of the elderly was brought up by some members in the group. Two of the daughters in the group preferred to have the elderly living with them so that they would not have to worry about leaving them alone. They did not understand "why mother prefers to live alone in such a bad neighborhood." Group discussion helped these women understand that some elderly persons like to live alone and be independent from their sons/daughters. Some will not leave their neighborhood because they are attached to it, their friends and activities, and are not willing to risk that. They also do not want to be a burden on their sons/daughters. These two daughters talked about their needs to have mother living with them so that they could spend more time with her. Members helped them to see the advantages of their mother's being independent and some of them expressed the wish that their elderly relative would not be so dependent upon them.

The discussion of communication problems and sensory losses gave the participants the opportunity to explore their feelings toward dealing with a deaf or blind elderly relative; which was the case of three of the members. Some members said that they can not be patient when they have to repeat things to the elderly. Participants frequently mentioned strong and conflicting feelings in responding to their parent's demands for attention and for help. Some members discovered that when they responded to their older relatives in a different manner, taking into consideration that there was some hearing or sight loss, they would receive better responses which would alleviate the communication problems.

As a result of the experience in the group program, one of the members in this group requested that the program be given in her

community church because she felt she had learned and benefitted from it and would like other people in her church to have the experience. Arrangements were made to follow up on this request.

An evaluation questionnaire was given to each participant at the last session. Eight members attended the last session and answered the questionnaire. The majority of the participants in this cycle (75%) attended more than four sessions. When asked if there had been any problems in attending, five answered that attending had not been a problem. The other three found it a moderate problem to attend because of other family responsibilities. One of them found it difficult to leave the older person with someone on a Sunday afternoon. This member attended only three of the sessions.

TABLE 5:4

Assessment of the Program: Cycle I

Was the program helpful in your daily life?	N	%
YES	8	100%
NO	0	0%
TOTAL	8	100%

All of the participants in this cycle found that the program was helpful to their daily living. The following table presents the participants' responses on how the program was helpful.

TABLE 5:5

The Most Important ways in Which the Program was Found Helpful: Cycle I

Aspect	Frequency	Percentage
Helped me improve my knowledge about aging and community resources	3	27%
Helped me understand my own feelings and the older person's feelings	3	27%
Helped me share the guilt feelings with other participants	2	18%
Helped me get ready for my own aging	2	18%
Helped me deal better with the older person	1	10%
Total responses	11	100%

The participants found the program helpful in various aspects. Three participants mentioned that the program had been helpful in improving their knowledge about aging and community resources. Three found the experience helpful because it helped them understand their own feelings and those of the older person. Two found that sharing their caregiving experience with others was helpful, especially sharing their guilt feelings. Some participants mentioned more than one area in which the program was helpful. Some comments that illustrate their responses follow:

> It helped me a lot in the sense that I feel relief of guilt feelings in many aspects. I feel better talking to my mother and I understand her better.
>
> I learned to be more patient with my parents, considering the changes they are going through.

I improved my feelings towards my mother. I learned to deal better with older people. I learned about Medicare, Medicaid, Home Energy Assistance Program and SSI.

The information obtained in the group helped me a lot, but most of all, it was helpful because I was able to share my problems and anxieties with a group of people who have common problems with me. It also helped me to get ready for my own aging.

It helped me understand my feelings towards my grandmother and to understand how she feels.

The group participants were asked to enumerate in order of preference the program aspects which they found most helpful. The following table reflects their responses to first and second choice.

TABLE 5:6

Most Helpful Aspects of the Program: Cycle I

Aspect	Mentioned First	Mentioned Second
Information about chronic illnesses and disabilities in old age	4	1
Information about benefits and entitlements	0	1
Information about community resources	1	1
Sharing and discussing problems with other caregivers	3	3
Material handed out at the sessions	2	0
Learn how to mediate and deal with the agencies	0	1

Information received about chronic illnesses and disabilities in old age emerges as the most helpful aspect of the program mentioned by

participants in this cycle. The second most helpful aspect was the interaction with other caregivers as a way to share and discuss their problems.

In addition to selecting which aspects of the program were found most helpful, the group participants were asked to assess how helpful the program was in more specific areas.

(TABLE 5:7)

TABLE 5:7

Areas in Which Group Experience was Found Helpful: Cycle I

	Helped a lot		Helped a little		No help	
	N	%	N	%	N	%
Learn how other people deal with their aged relatives	6	75%	1	13%	0	0%
Improve my communication with the elderly person	6	75	1	13	0	0
Understand the complaints of the older person	8	100	0	0	0	0
Establish contact with other people who are caring for an elderly person	6	75	2	25	0	0
Talk and share my feelings with other persons	6	75	1	13	0	0
Understand my own aging process	6	75	2	25	0	0
Know where to begin to look for help	6	75	1	13	1	13
Increase my knowledge about illnesses in old age and how to deal with some conditions	8	100	0	0	0	0
Understand the sensory losses in old age	8	100	0	0	0	0
Learn about confusion in old age	7	88	2	25	0	0
Talk about my experience as a caregiver	7	88	1	13	0	0
Learn about nursing homes	3	38	3	38	0	0
Learn to deal with family problems	4	50	1	13	0	0
Learn to give attention to my needs and my family needs	7	88	0	0	0	0
Talk about my frustrations	6	75	2	25	0	0

Differences in percentages reflect those who did not answer.

The majority of the participants reported improvement in all except one of the areas. Only three reported that learning about nursing homes helped them a lot and another three stated that it helped a little. Overall, this table shows improvement in all areas which demonstrates that the program did meet the needs of the participants in these areas.

All of the participants said that they had the opportunity to share problems and experiences with other members of the group.

TABLE 5:8

Support From Other Members of the Group: Cycle I

Were other members supportive?	N	%
YES	8	100%
NO	0	0%
Total	8	100%

Participants gave their opinions on how the support of other members was helpful:

> Sharing and talking with them made me feel comfortable, they were very understanding.
>
> They accepted me and my problems.
>
> While talking to others, I realized that I am not alone, other people have similar problems.

Two of the participants reported that they had been in contact with other members of the group at times other than the meeting time. These two participants were not related in any other way to other members

of the group. Only these two reported that they intended to continue their contacts with other members of the group.

Six of the participants were interested in other group programs and all of them stated they would recommend this program to other people.

Some of the recommendations made by the participants to improve the program were: (1) to develop the program not only with caregivers, but to include elderly people as well; (2) to include the elderly person in the same group to facilitate interaction between them; and (3) to make the sessions longer, allowing for more individual services.

Following some of the recommendations made by the participants, the next cycle of the program was developed in a community church, upon the request of one of the members in the group, and included not only caregivers but elderly persons as well.

Cycle II:

The second cycle of the program was developed as a result of a request made by a participant in the first cycle. The person who made the request is a member of the Brooklyn Baptist Church in Bushwick, Brooklyn. She served as the contact person to do the outreach with the Minister. A letter explaining the program was sent to the Minister and was followed by a planning meeting with him and the President of the Ladies Association of the Church. The program was welcomed by them and was placed in the Church's calendar of activities for the month of August 1982. They announced the program in the Church newsletter and agreed to recruit the participants for the program. Three weeks before the program was scheduled, they had a list of twenty-four persons with addresses and phone numbers. Letters and flyers about the program were

sent to them. Participants were recruited from the membership of the Church and non-members in the community. As opposed to the first cycle of the program, recruitment of participants was not a problem in this cycle. The minister explained that the Church frequently ran programs, workshops and brought in speakers and the response of the members was always positive. The fact that this was an established group--a congregation--facilitated bringing them together for the program. More persons than the expected number attended the program.

This cycle took place during the month of August in four sessions held on Friday nights at 7:00 P.M. Only four sessions could be scheduled because of other activities taking place at the Church. Night sessions were chosen because the majority of the participants work during the day and usually the Church's activities take place at nights.

Twenty-four persons registered to participate for the program originally and thirty-five attended the first session. Those who had registered invited other friends, relatives or neighbors after they received the information describing the program. The number of participants per session varied. The second session was attended by thirty-five persons, some new members as others that came to the first session were absent. The third session was attended by twenty-four persons and the last by thirty-six. In all, fifty-one persons attended the four sessions, and twenty-two completed the cycle, attending the whole program.

All sessions were scheduled and began at 7:00 and lasted approximately one-and-a-half hours each. The last ten minutes of each session were set aside for a "social time" which included refreshments and informal conversations with the group members.

All the meetings took place in a large room which is used for the Church services. Seating arrangements was not a problem since the room accommodated more than 150 persons. Seats were arranged in rows. Because of the fixed rows and the large number of participants, the group could not be arranged in a circle. The large number of participants per session also limited the intra-group interaction, although the fact that most of them knew each other beforehand facilitated some discussion. The after meeting get-togethers provided for small group interaction between the project director and the participants.

The material included in the previous cycle proved to be relevant in this cycle in which the majority of the participants were aged. The discussion of the physical and emotional aspects of aging, conditions in old age and community resources were key topics in this cycle. The topic of special reactions to aging was not included as a separate session but discussed throughout all sessions. In the first session, participants were given the topics covered in the first cycle so that they could select which they preferred to be included in the four sessions. Through consensus, the group chose the following topics:

Session I: The Aging Person and the Family, including discussion of the types of help that the family provides to the elderly. Physical and emotional aspects of aging as related to the changes and coping mechanisms in old age.

Session II: Common and chronic illnesses in old age, including medical and behavioral problems associated with some conditions.

Session III: Understanding Sensory Losses in Old Age. Vision and hearing impairments as well as memory losses with emphasis on their social aspects. Communication with the elderly and some skills to improve communication.

Session IV: Helping the elderly in the community. Description of community resources, including benefits and entitlements. Evaluation, closing of the program, and suggestions on how to develop caregiver groups.

All participants received a packet of information after each session and a certificate of participation in the last session.

While there were more participants, there were fewer caregivers in this cycle. Only four of the participants were principal caregivers of an elderly person. The core of the group was made up of potential caregivers--friends, neighbors (9), and elderly people (9); most of them members of the Church. They all considered themselves as "indirect or potential caregivers" because of the work they were doing through the Church: visiting and counseling elderly people in the community. The majority of the participants were over fifty years old and wanted to "get ready for their own aging". This was different from the original goals of the program but was expected as the program moved to different settings.

Twenty-two participants completed the initial questionnaire. The reasons why they participated in the program are summarized in the following table.

(TABLE 5:9)

TABLE 5:9

Motivation to Participate in the Program: Cycle II

Item	Mentioned		Not Mentioned	
	N	%	N	%
Learn about chronic illnesses and disabilities in old age	20	91%	2	9%
Learn about benefits and entitlements	18	82	4	18
Learn about emotional reactions and needs of older people	17	77	5	23
Share my experiences with other group members	19	86	3	14
Learn about programs and community resources for the aged	17	17	5	23
Listen to other people who are caring for an older person	12	54	10	46
Learn to get ready for my own aging	22	100	0	0

Table 5:9 demonstrates that although the group participants were not direct caregivers the reasons they participated in the program were similar to those of the participants in the previous cycle. The main reason mentioned by all participants was to learn to get ready for their own aging. When asked how they thought the program would help them, eighty-two percent responded that it would prepare them for future caregiving roles.

Analysis of sociodemographic characteristics of the participants shows that the majority of them were females (78 percent) with only 7

males in the group. Sixty-three percent were married, thirteen percent widowed, eleven percent single and thirteen percent divorced or separated. The ages of the participants ranged from 30 to 79 years, with a median age of 54 years old.

The educational level of the participants was beyond high school courses in the majority of the cases (65 percent). Forty-five percent had a High School Diploma, and twenty percent had either College courses or Professional Diplomas. Five percent had no formal schooling whatsoever.

Fifty-four percent of the participants were employed full-time and another fifteen percent were employed part-time. The rest (31%) were either retired, unemployed or students. The family annual income was less than $10,000 in thirty-seven percent of the cases. Eighteen percent earned over $20,000 a year.

Fifteen of the respondents were born in Puerto Rico (68%), and the rest were born in the other Caribbean Hispanic Islands (Cuba, Dominican Republic). Seventy-two percent had lived more than fifteen years in the mainland United States, the majority of them over twenty years.

Those who were principal caregivers of an elderly person were all females. Two were daughters, one a spouse, and one a sister of an elderly person. Two of them, the daughters, worked full-time, and the other two were retired. In three of the cases the older person was living with the caregiver and in the other case, with a niece. Caregivers played a crucial role in this cycle by providing the "raw material" for the group discussions. In turn, the other participants

aided the caregivers providing opinions, suggestions and moral support for the caregiving role. The following case illustrates the dynamics of this group: One participant, a 30 year old woman, exhibited considerable anxiety concerning the depression of her 59 year old mother. Mother is diabetic and blind. This participant related to the group the problems she is facing because she works full-time and is the only one providing care to her mother. Although she understands her mother's condition, she cannot deal with her mother's refusal to accept her blindness. Mother spends most of the day alone and crying. When the daughter gets home, besides doing all the house chores, which range from meal preparation to dealing with agencies, she has to convince her mother that her condition is not "the end of life". Others in the group pointed out that the mother's condition, especially the depression, could increase unless she started to go out of the house. They recommended that the mother be invited to the group sessions, where she could have an opportunity to express her feelings and the one that dealt with sensory losses helped the most. In the final session, both the mother and daughter said that the group experience, although limited in time, had helped them both, but particularly the mother. Mother was able to understand that the sight loss was mostly a result of her diabetes and that there were ways to deal with her problems, such as visiting the church more often and participating in activities. The daughter became aware of the different alternatives in the community that could help her mother during the day.

Another participant, a sister of a 56 year old woman, expressed great relief when she had an opportunity to tell the group how she felt about the demands her sister placed on her and she realized that there

are other ways to help her sister without being overwhelmed. She described her sister as a very demanding person who had been paralyzed by a stroke. Although the sister has children and relatives helping her, she only calls the participant when she needs help. The participant said that the most difficult thing for her is to talk to her sister because all her sister does is complain about her disabilities. This participant also complained about the frequent problems involving other relatives when they visit and try to help her sister. Through the discussion, this participant and others said that they had gained practical knowledge that helped them understand their elderly friends and relatives' changing needs as well as their own feelings and actions towards these needs.

Having elderly persons in the group helped other participants gain insight into the aging process. For example, a 73 year old male participant commented:

> I am 73 years old, but I feel like a twenty year old man. I do not feel that because I have high blood pressure I should stay home and cry all day. I come to Church, I visit other people in the community, and besides, my father died when he was 100 years old, so I still have many years to live.

Other participants commented:

> It is not how many years you have lived, but what your heart dictates you are. I feel very young and I wish the young people of today would feel as strong as I feel.
>
> Being part of this group helped me feel proud of what I have accomplished in life. I don't feel old, life is just beginning.

As caregivers in the group tried to make decisions about how to cope with their dependent elderly relatives, they found a few models in the group to turn to for guidance. When they shared their situations, they found the other members, especially the elderly, very supportive.

The information about specific conditions and community resources, and the sharing of experiences with others at different stages of the aging process allowed them to place their situations in perspective and reduce their anxieties.

The thirty-two participants who completed the evaluation questionnaire at the last meeting are used as the population in the analysis of the evaluation of this cycle.

Twenty-two (68%) attended four sessions of the cycle, while eleven (32%) attended three sessions. Ninety-one percent found no problem in attending the sessions. Two found it a moderate problem, and the reasons given were that it interfered with other family responsibilities.

TABLE 5:10

Assessment of the Program: Cycle II

Was the program helpful in your daily life?	N	%
YES	32	100%
NO	0	0
TOTAL	32	100%

All of the participants found that the program had been helpful in their daily living. The answers to the open-ended question on which ways the program had been helpful, fell roughly in the following categories:

TABLE 5:11

Most Important Way in Which the Program Was Found Helpful: Cycle II

Aspect	Frequency	Percentage
Helped me improve knowledge about aging and community resources	26	81%
Helped me understand my own feelings and the older person's feelings	4	13
Helped me get ready for my own aging	1	3
Helped me understand and deal better with the elderly	1	3
Total Responses	32	100%

Eighty-one percent found the program helpful in improving their knowledge about aging and community resources, while thirteen percent found it helpful in understanding their own feelings and that of the older person. The following comments add to their perception of how the program was found helpful:

> It helped me understand the aged person more, particularly my sister.
>
> I learned a lot of new things, particularly about some programs that you are entitled to and do not know how to apply.
>
> .....acquiring more knowledge in how to help my elderly friends.
>
> I learned a lot about specific conditions in old age that will help me because I am getting old.

The group participants enumerated in order of preference, the program aspects which they found most helpful. The following table shows their first and second choices:

TABLE 5:12

Most Helpful Aspects of the Program: Cycle II

Aspect	Mentioned First	Mentioned Second
Information about chronic illnesses and disabilities in old age	20	2
Information about benefits and entitlements	6	12
Information about community resources	1	8
Sharing and discussing problems with other members of the group	0	4
Material handed out in the sessions	2	3
Learn how to mediate and deal with the agencies	2	0

Participants mentioned the information about chronic illnesses and disabilities in old age as the most helpful aspect of the program. As a second choice, their response was the information received about benefits and entitlements. This table reflects that information about chronic illnesses and aging, as a single category, was the most helpful aspect and not its combination with information on community resources as reflected in the previous table. Sharing and discussing with other participants was mentioned second by four participants.

Group participants were asked to assess how helpful the program was in various areas. The following table presents their responses:

TABLE 5:13

Areas in Which Group Experience was Found Helpful: Cycle II

	Helped a lot		Helped a little		No Help	
	N	%	N	%	N	%
Learn how other people deal with their aged relatives	18	56%	8	25%		
Improve my communication with the elderly person	20	63	3	9		
Understand the complaints of the older person	24	75	3	9		
Establish contact with other people who are caring for an elderly person	18	56	6	18		
Talk and share my own aging with other persons	11	34	7	21		
Understand my own aging process	31	96				
Know where to begin to look for help	24	75	4	13		
Increase my knowledge about illnesses in old age and how to deal with them	29	90	1	3		
Understand the losses that occur in old age	28	87	2	6		
Learn about confusion in old age	24	75	3	9		
Talk about my experiences as a caregiver	22	68	2	6		
Learn about nursing homes	19	59	3	9		
Learn to deal with family problems	16	50	5	15		
Learn to give attention to my own needs and my family needs	22	68	3	9		
Talk about my frustrations	17	53	3	9		

Differences in percentages reflect those who did not answer

The participants in this cycle reported improvement in all areas mentioned. Only in one of the areas, sharing and talking about their feelings with other persons, was improvement reported for less than fifty percent of the participants. No one mentioned "no help", in any of the areas. There were a number of participants who did not respond to some areas of the questionnaire. Overall, this table shows that the participants found the program helpful in all areas which demonstrates that the program met some of their needs and expectations.

Over fifty percent of the group participants (53%) said that they had an opportunity to share problems and experiences with other group members. Twenty-one percent said that they did not and the rest did not answer the question.

TABLE 5:14

Support From Other Members of the Group: Cycle II

Were other members supportive?	N	%
YES	18	56%
NO	2	6
NO ANSWER	12	38
TOTAL	32	100%

Over fifty percent (56%) of the participants reported that other members of the group were supportive. Thirty-eight percent did not answer the questions and no reasons were given for this. Some of the ways in which other members were supportive are illustrated in the

following comments:

> They brought up examples of the ways they deal with their aged relatives or friends.
>
> By the way they shared and participated in the discussion.
>
> We shared common problems and situations.
>
> They helped me with their comments about how to deal with the elderly person.
>
> I learned from the experience of others and just talking to them helped me a lot.

Seventy-five percent of the participants stated that they kept in contact with other members of the group between meetings. This is understandable because most of them are members of the Church and participate in the same activities. Eighty-four percent of them reported that they plan to see other members in the future. Thirty-seven group members said they would like to participate in other group programs and those who did not wish to participate (16%) stated that other family responsibilities would interfere with participation in other programs. Some of the reasons mentioned by those who were interested in participating:

> .....because you always learn new things.
>
> I will continue to help the aged in the community.
>
> To increase my knowledge about the elderly and ways to help them.
>
> To learn from other persons and share with them.

The most significant aspects of this cycle were the education of the participants and the strengthening of links of an already existing natural helping network; i.e., a congregation of church members. Although the majority of the participants were not principal caregivers of an elderly person, they formed part of an existing informal network

and were providing assistance to the elderly members of the Church and the community, for example, visiting and assisting them with some service agencies. They saw the program as a way of strengthening the mutual aid of the members of the Church.

Developing the program in this site provided access to a larger client population but moved the project away from its central focus, the caregivers. This cycle had less caregivers than any of the others.

Cycle III:

The third cycle of the project took place at the Spanish Senior Health Program of the Spanish Council for Human Services, located in the East Harlem section of Manhattan. This agency requested in-service training for its community health workers from Brookdale Center on Aging. As a result, the project director offered a workshop on how to deal with the Hispanic elderly. Through this workshop the staff of the agency was exposed to the caregivers project and made a request to have the program developed there. The agency was serving mainly Hispanic elderly and their families and seemed appropriate as a site where the program could be developed. At the several planning meetings held with the director and staff of the Senior Health Program, the staff showed much enthusiasm about having the program at their agency.

Five sessions were held beginning on the last week of November 1982 and ending on the second week of January 1983. Although sessions were scheduled to take place on a weekly basis, two of the sessions were postponed because the agency closed on holidays. The group met on Mondays at 10:00 in the morning.

The participants for this cycle were drawn from the agency's

caseload, including active and inactive clients. Recruitment of participants proved problematic as in Cycle I of the project. Approximately three hundred letters were mailed to the identified potential participants. The agency's mailing list was reviewed in order to identify those clients who had a relative or contact person for emergencies. Clerical staff of the agency were helpful in this search. Less than 10 percent responded and only twenty-five persons were interested in participating. A large number of letters were returned "undeliverable" and many phones were disconnected. This showed that there was a failure on the part of the agency to keep accurate records of client's addresses and also indicated existence of a distance between agency and clients. Even though the program was advertised and discussed with staff members, there was little referral of clients for the program. However three staff members, who were also caregivers, participated in the program.

Letters with detailed information of the dates and program content were mailed to those who were interested in the program. Only ten out of twenty-five persons who expressed interest in participating, actually participated in the program. Follow up done with the other fifteen persons revealed that they had family problems which precluded their attendance.

The sessions were held in the staff lounge of the agency. The room provided adequate space and facilities for the meetings. It contained a large table, blackboard and was located far from the clinic and waiting room area, which allowed privacy. The sessions began at 10:00 and lasted one and a half hours. The last ten minutes of each session were used to serve coffee and refreshments and for informal conversations with group members.

The content per session in this cycle was similar to the content of Cycle I, with the exception of the last session which was integrated into session five to make it a five-session cycle at the request of the participants. The content per session was as follows:

Session I: The aging person and the family, including types of help that the family provides to its aging members and problems faced while doing so; the physical and emotional aspects of aging and understanding of the aging process.

Session II: Common medical problems in old age, including information on chronic illnesses in old age and behavioral problems with some of them as well as social aspects.

Session III: Understanding sensory losses in old age, hearing and vision impairments in old age and communication problems.

Session IV: Special reactions to aging, dealing with our feelings towards our aged relative or friend and our own aging.

Session V: Community resources and ways to help our elderly in the community information about benefits and entitlements for the elderly and dealing with the service agencies; evaluation and follow-up alternatives for the group.

All participants in this cycle received a packet with supplemental material after each session and a certificate of participation in the last session.

Initial interviews were completed with ten participants in the group. Analysis of the questionnaires revealed the following participant's profile:

In a duplicated count, the participants identified themselves as caregivers (8), elderly persons (6), and people anticipating a caregiving role in the future (2). The ages of the participants ranged from seventeen years old to seventy-three. Besides the seventeen year old, there were three other members below thirty years of age. The rest (6)

were over 64 years old. The presence of a teen-age member in this cycle, as well as in the first cycle of the program, illustrates the importance of the grandparent-grandchild relationship in the Hispanic culture and also points to the fact that all family members share in the caregiving tasks. This member was living with her grandparents during the week and spent time with her parents on weekends.

Seven members were female. Three were married, two divorced and three were widows. Six were retired, which was not surprising since six members were over 64 years old.

A large number of the participants (7) were born in Puerto Rico and had been in the United States over twenty years. Only two were born in the mainland United States, and one member was from Colombia.

The educational level of the group participants was low. Five of them had less than a high school diploma, and only two had gone beyond high school. As expected, the annual income was also low. Five earned less than $10,000 and only two were employed full-time.

The participants in this cycle were attracted to the program for various reasons. The following table summarizes their responses:

(Table 5:15)

TABLE 5:15

Motivation to Participate in the Program: Cycle III

Item	Mentioned		Not Mentioned	
	N	%	N	%
Learn about chronic illnesses and disabilities in old age	10	100%	0	0
Learn about benefits and entitlements	10	100	0	0
Learn about emotional reactions and needs of the older person	8	80	2	20
Share my experiences with other group members	8	80	2	20
Learn about programs and community resources	9	90	1	10
Listen to other people who are caring for an older person	8	80	2	20
Learn to get ready for my own aging	7	70	3	30

One member's husband had recently died and she was attracted to the program because she wanted to spend time out of her house. Her participation in the program was very helpful to other members, as death and dying came up in the group discussions.

Eight participants were caregivers, five of them primary caregivers. The caregiver was, in the majority of cases, a spouse (2) or an offspring (4). Three of the caregivers were daughters and one was a son. The rest were friends and neighbors of the elderly.

The elderly person receiving care was likely to be over 65 years

old (75%), married (50%), and living with the caregiver (62%).

The activities performed by the caregivers in the group were varied and numerous. They ranged from meal preparation to aid in dealing with the service agencies. Table 5:16 presents a description and frequency of the activities performed by them.

TABLE 5:16

Activities Performed by the Caregivers: Cycle III
(N=8)

Item	At least once a day	Three to four times a week	At least once a month	Never
Shopping for food or personal things	0%	62%	13%	25%
Meal preparation	13	25	25	37
Light housecleaning (dishes, dusting, etc.)	13	50	0	37
Heavy housecleaning (floors, windows, etc.)	0	13	50	37
Administer and supervise medication	50	13	0	37
Laundry	0	25	25	50
Help in personal hygiene	25	13	0	62
Contribute money for expenses	0	13	37	50
Help manage finances (cash check, pay bills)	0	0	62	37
Assist in transportation to appointments	0	0	50	50
Emotional support (visit, talk, phone)	87	13	0	0
Help mediate with agencies	0	0	75	25
Take home for weekends	13	0	13	74

Emotional support emerges as the most frequent activity performed by the caregivers in this cycle. Eighty-seven percent do it on a daily basis, and thirteen percent on a weekly basis. Instrumental assistance is the most frequent activity in which the caregivers are involved. The activities include, meal preparation, housecleaning chores, personal hygiene and assisting in transportation. Not all the activities performed by the caregivers required the same amount of time. For example, transportation and helping in managing finances are activities usually performed on a monthly basis. On the other hand, almost over fifty percent of the respondents who helped with household chores and meal preparation are involved on a daily and weekly basis. Financial assistance emerges as one of the less frequent typed of help provided to the elderly.

The participants were asked to select which of the activities was the most difficult and thirty-seven percent responded that none were difficult. However, fifty percent mentioned that providing emotional support and communicating with the elderly person was the most difficult activity in their caregiving role.

> The most difficult thing for me is to make my mother understand that I have my own problems and she is always complaining about her own things.
>
> It is hard to talk to my mother when she does not understand and sometimes does not recognize me.
>
> Providing personal care to my wife is the most difficult thing, she used to do everything for herself.

Light caregivers mentioned that the older person's major problem was physical and mental. One member described his wife's condition as follows:

> She is bedridden with a colostomy and paralyzed. Everything has to be done for her in the bed.
>
> My mother is mentally ill and sometimes she gets aggressive.

The next table shows the services that the older person receives from the formal organizations.

TABLE 5:17

Services That the Older Person Receives from Formal Organizations: Cycle III (N=8)

Services	Receiving		Not Receiving	
	N	%	N	%
Counseling	2	25%	6	75%
Escort services	0	0	8	100
Transportation	4	50	4	50
House repairs	0	0	8	100
Friendly visitors	0	0	8	100
Telephone reassurance	0	0	8	100
Legal services	0	0	8	100
Personal care*	4	50	4	50
Shopping*	4	50	4	50
Light housecleaning*	4	50	4	50
Laundry*	4	50	4	50
Financial help**	6	75	2	25
Home health aid	0	0	8	100
Home attendant	4	50	4	50
Visiting nurse	4	50	4	50
Meals on wheels	0	0	8	100
Senior Citizen Center	0	0	8	100

* These services were performed by the Home Attendant
** Supplemental Security Income (SSI)

The home attendant provides most of the services that the elderly person receives (50% had one). In addition to the home attendant, transportation and visiting nurse are the only services that the elderly person receives from the formal agencies.

Data in Table 5:16 and Table 5:17 demonstrate again that caregivers provide a wide range of activities for the elderly even when there is a home attendant involved.

The informational and supportive aspects of the program provided the opportunity for group members to interact and share concerns regarding the topics discussed. The sessions were initiated with exercises and role playing so as to facilitate group interaction. In the initial meeting, members introduced themselves in relationship to their interaction with an elderly person. Group members described their feelings and relations with the elderly, and group cohesiveness developed quickly as common problems were articulated and recognized. One of the members had recently lost her husband and was still coping with that loss. While describing her situation she cried very often and group members expressed support, encouraging her to explore ways in which she could become involved so as to cope with her loneliness. Quotes from several group members illustrate how they articulated their situations:

> I am very concerned about my mother because she is very frail and needs a lot of supervision. She lives with my brother but he is not capable of providing all the assistance she needs. I cannot bring her to live with me because I don't have enough room in my apartment. We have applied for a home attendant but her doctor won't sign the papers she needs.

> I live with my grandmother and my grandfather. They are both very old but still not very sick. My grandfather had high blood pressure but he helps my grandmother in the house. They need somebody to be with them because they don't speak English and need help in going shopping or moving around.

> I am married to a 70 year old man, who is not the father of my kids and I have a lot of problems with my children because they do not obey him and do not understand that he is a sick man.

The caregivers in this cycle were providing strong support for their elderly relatives, but obviously functioned with specific constraints. The group members were supportive of a twenty-three year old single mother of a five year old child who was taking care of her mentally-ill mother and attending school. This member was afraid of institutionalizing her mother who was aggressive. With the assistance of group members and her caseworker at the agency, this member was convinced that the best thing for her mother, herself and her child was for her mother to receive in-patient services for her mental condition.

The issue of communication with parents and other family members was raised frequently in group discussions. One member, who was attending the group while working at the agency, raised problems she was having in getting her sister to share some of the responsibilities of caring for the mother. She also raised the problem of communication with her mother. Some members concluded that sharing responsibilities with other family members helped them to feel less pressured and improved their communication with the elderly. They suggested ways in which this member could involve her sister in helping the mother, such as taking her for weekends or visiting more often. They discussed how to balance the time one spends with the elderly, and the time one devotes to oneself and other family members. Communication and listening skills were an important topic of discussion in this group. Members were given suggestions on listening while encouraged to practice these skills in the group.

The group facilitator encouraged group members to present suggestions to others and seek feedback on suggestions in all the sessions.

As the group sessions progressed, group members became increasingly self-directed, helping each other with suggestions and using their own experiences as examples.

One group member, a neighbor and friend of an elderly person, was actively involved in making other members aware of the role of friends and neighbors in times of crisis. She pointed out to the group that many times the relatives of the elderly do not turn to their neighbors for help, yet there are a lot of friends and neighbors who are willing to help, making suggestions, visiting the elderly, and even offering advice to the relative involved.

Members of the group made observations on how they were influenced by the situations of their aged relative or friend. This feeling is summarized by the comment of a group member:

> My mother is always very sad. Whenever I go visit her, I leave depressed. She feels that she is no longer independent and that mades her sad... and I feel sad too.

A young member of the group confided that she was frequently upset and depressed due to her elderly mother's illness.

In some instances, the available family members also suffered from debilitating conditions, as was the case of a 73 year old man was providing care to his 73 year old wife. Mr. F. did not trust the person who was helping his wife, in this a case a home attendant. He preferred to be in the house watching his wife even when he had medical appointments.

The feelings that surround the loss of a person were discussed as well as alternatives in dealing with a widow parent. Discussion moved into planning for their own death and ways in which they prefer to die. For example, some members mentioned that they preferred to die in their sleep and not of a long-term illness.

A general evaluation instrument was distributed at the end of the last session to be completed anonymously. Members were asked ways in which the group program was helpful. Eight members completed the evaluation forms and their responses are used for the evaluation of the cycle.

Six participants attended four of the five sessions, while two completed the cycle. Seven found no problem attending the meetings. One found it a little problematic because of job responsibilities.

TABLE 5:18

Assessment of the Program: Cycle III

Was the program helpful in your daily life?	N	%
YES	8	100%
NO	0	0%
Total	8	100%

All the participants considered the program helpful in their daily life. Their answers are summarized in the next Table.

(Table 5:19)

TABLE 5:19

Ways in Which the Program was Found Helpful: Cycle III

Aspect	Frequency	Percent
Helped me improve knowledge about aging and community resources	3	38%
Helped me understand my own feelings and the older person's feelings	3	38
Helped deal better with the elderly	1	12
Helped understand that we all share the same problems	1	12

Participants mentioned various ways in which the program was helpful. Three persons mentioned that the program had helped them improve their knowledge about aging and community resources while another three mentioned that it helped them understand their own and their older relative's feelings. Other ways in which the program was found helpful was in dealing better with the elderly and sharing with others the same problems. The following quotes add to the perception of how the program was helpful.

> It helped me to understand myself and control my emotions while dealing with my mother.
>
> The information I received on community resources and the physical and emotional aspects of aging was very helpful.
>
> I felt relief after I discovered that other people have similar problems.

Participants were asked to rate the program in various items: information, material handed out, group interaction and specific skills. Their answers are summarized in the following Table:

TABLE 5:20

Most Helpful Aspects of the Program: Cycle III

Aspect	Mentioned first	Mentioned second
Information about chronic illnesses and disabilities in old age	5	3
Information about benefits and entitlements	0	3
Information about community resources	0	0
Sharing and discussing problems with other members	3	2
Material handed out in the sessions	0	0
Learned how to mediate with the agencies	0	0

Five participants mentioned as the most helpful aspect the information received about chronic illnesses and disabilities in old age. Three mentioned sharing and discussing their problems with other members of the group as the most helpful aspect. Information about chronic illnesses and information about benefits and entitlements were both selected as the second most helpful aspect of the program.

The participants assesses the program in various areas presented in the next Table.

(Table 5:21)

TABLE 5:21

Areas in Which Group Experience was Found Helpful: Cycle III

	Helped a lot		Helped a little		No Help	
	N	%	N	%	N	%
Learn how other people deal with their aged relatives	6	75%	1	12.5%		
Improve my communication with the elderly person	6	75	1	12.5		
Understand the complaints of the older person	5	63	1	12.5	1	12.5%
Establish contact with other people who are caring for an older relative	3	38	3	38		
Talk and share my feelings with other persons	7	87.5	1	12.5		
Understand my own aging process	6	75	2	25		
Know where to begin to look for help	6	75	1	12.5		
Increase my knowledge about illnesses in old age and how to deal with them	7	87.5	1	12.5		
Understand the losses that occur in old age	7	87.5				
Learn about confusion in old age	6	75	1	12.5		
Talk about my experience as a caregiver	7	87.5	1	12.5		
Learn about nursing homes	3	38	2	25	1	12.5
Learn to deal with family problems	4	50	1	12.5	1	12.5
Learn to give attention to my own needs and my family needs	5	63	1	12.5		
Talk about my frustrations	5	63	2	25		

Differences in percentages and frequencies reflect those who did not answer

Overall, the participants expressed that the program has been helpful in most of the areas. Three areas in which the participants reported no help are: understanding the complaints of the older person, learning about nursing homes, and learning to deal with family problems.

The majority of the participants (87.5%) reported that they had an opportunity to share and discuss their problems with other members of the group. One of the participants reported that he did not have the opportunity to share with other members.

TABLE 5:22

Support From Other Members of the Group: Cycle III

Were other members supportive?	N	%
YES	8	100%
NO	0	0
TOTAL	8	100%

All of the participants found other members in the group supportive. The following comments illustrate some ways in which members found support in the group:

> I found answers to my problems.
>
> I realized that the majority of the persons in the group know how to handle their problems and that helped me.
>
> ...because they discussed problems that I am facing with my mother.
>
> They gave me a lot of support in dealing with my situation.
>
> Other persons in the group are going through the same problems that I am dealing with.

Six participants expressed that they have kept in contact with other members of the group. The staff members of the agency commented that now they could relate to each other in a different way because they share a common problem. They reported that the relationship improved after having been exposed to the group program. Other members became aware that they lived in the same housing project and that they could visit each other more often and help each other in dealing with their aged relatives. Two of the participants mentioned that they live far from other members and that would affect the contact between them. All members exchanged telephone numbers and addresses in order to maintain contact with each other.

All of the participants expressed interest in attending other group programs but stated that they preferred programs formed and led by professionals. They were all informed about other caregivers groups in the community and ways to develop their own group.

Members of the group commented on ways to improve the program. In many instances, comments were added to the questionnaire.

> The program was very good. Thank you very much. I wish we could do it again.
>
> Future programs should include a section on nutrition and exercises to help the elderly.
>
> Elderly persons should be included in the program so that they can understand the changes they are going through.
>
> The program should be given in all senior centers.

Cycle IV:

The development of three cycles of the program was announced in Brookdale Center on Aging Newsletter resulting in various requests by agencies serving the Hispanic elderly to develop the program at their

agencies. The Boricua Senior Citizen Center in the South Bronx was chosen to be the site for the last cycle of the program because of the area's large Hispanic population. The recommendations of previous participants in the program to include aged persons and to develop the program in senior centers also weighed in the selection of this site.

The center is one of the services offered under the auspices of the Christian Benevolent Association. Other services included a home attendant program and a transportation service for elderly people. The program intended to attract people served by all services. Outreach efforts included announcing the program in the various service units, posting flyers announcing the program in the Association's building, and work of mouth. A meeting to explain the nature of the program to the seniors at the center was held a month before the program started. The majority of the participants were drawn from the caseload of the senior center. Two hundred and seventy-three letters were mailed to the emergency contact persons identified in the clients' records. The response rate was close to ten percent. Twenty-eight persons contacted the project director to participate in the program, although twelve of them could not attend because of familial or work responsibilities. In summary, eighteen persons registered to participate and fourteen attended the program.

Five sessions were carried out from February 11th to March 11, 1983. The meetings were held on Fridays at 10:00 in the morning.

The meetings took place in a large room used for classes at the senior center. The space and facilities were adequate and provided privacy for the sessions. Each session lasted one-and-a-half hours. Refreshments were served after each session.

The content per session for this cycle was the same as the one used in Cycle III. All sessions were supplemented with a packet of information and certificates of participation were given at the last meeting.

Participants for this cycle were attracted to the program for a variety of reason. One of them expressed that she was a caregiver for her mother and also worked in a program serving elderly persons. She considered that the information received in the program would benefit her both in her personal life and in her job. All of the participants expressed interest in obtaining information about the aging process, benefits and entitlements for the aged, community resources for the aged as well as discussing some of their problems with other members of the group. Two of the participants were interested in learning how to cope with their own aging process.

Initial interviews were completed with the fourteen participants. The majority (10) were providing care to an elderly relative or friend. Two other participants were seniors attending the senior center, and two were friends of elderly persons.

The ages of the participants in this cycle ranged from 34 to 69 years old, with a median age of 51. Thirty-six percent were over 60 years old, and twenty-eight below forty.

Over seventy percent (71%) of the participants were female and twenty-nine were male. Fifty percent were married, forty-two divorced, and seven percent single.

None of the participants in this cycle were born in the continental United States. Seventy-eight percent were born in Puerto Rico, and the rest in Central America or in other Caribbean Islands. Fifty percent had

lived in the United States over thirty years, while seventy-eight percent had lived over twenty years.

None of the participants had gone beyond high school. Only fourteen percent had completed high school and sixty-four percent had high school courses. There was one member with no schooling. Only thirty percent were working. Thirty-five percent were unemployed. Income was less than $10,000 in ninety percent of the cases.

The group formed by children of the elderly (50%), friends or neighbors (14%), spouses of an elderly person (7%), and elderly persons (26%). Ten of the participants were principal caregivers although in four of the cases the caregiving activities were shared with other relatives.

The elderly care recipient was likely to be over seventy years old and a mother of a participant. In forty percent of the cases, the elderly was living alone, while in thirty percent of the cases the elderly was living with the caregiver.

The following table provides descriptive information of the activities performed by the caregivers in this cycle.

(Table 5:23)

TABLE 5:23

Activities Performed by Caregivers: Cycle IV
(N=10)

Items	At least once a day	Three to four times a week	At least once a month	Never
Shopping for personal things or food	20%	20%	30%	30%
Meal preparation	40	10	20	30
Light housecleaning (Dust, dishes, etc.)	20	30	20	30
Heavy housecleaning (Floors, windows)	10	30	20	40
Administer and supervise medication	40	20	20	20
Laundry	10	40	0	50
Help or supervise personal hygiene	10	10	0	60
Contribute money for expenses	0	0	20	80
Help manage finances (Cash checks, pay bills)	0	0	50	50
Assist in transportation (Take to appointments)	0	10	50	40
Emotional support (Visit, talk, phone)	90	10	0	0
Take home for weekends	0	0	30	70
Help mediate with agencies	0	0	70	30

When compared with previous cycles, the caregivers in this cycle were providing more care to the elderly person in terms of frequency. Emotional support emerges as the most frequent activity done by the

caregivers (90%). Because only thirty percent of the elderly persons were receiving home attendant services, the caregivers had to be more involved in the care of the elderly.

Other services that the older person was receiving from agencies were transportation (30%), financial assistance (50%), visiting nurse (40%), and senior citizen center (30%).

Participants in the group were asked to mention which of the things done for the elderly was the most difficult and only fifty percent reported having difficulties. Communication with elderly (30%) and providing personal care (20%) were reported as difficult. Fifty percent reported that having a home attendant would help them in dealing with the elderly.

In fifty percent of the cases, physical problems were reported as the older person's major problem.

> He has a stomach ulcer and diabetes and is always at the doctor's.
>
> She is blind and requires somebody to check her medication for the diabetes.
>
> The arthritis makes it hard for her to move around.

Other problems that the elderly faced were mentioned, i.e., memory problems, isolation and financial problems.

Members of the group were spontaneous in sharing and discussing their problems with one another. From the initial meeting they engaged in problem-solving situations and interacted in such ways as to influence one another. For example, the children of elderly parents in the group exchanged ideas on ways in which they were coping with their parents' demands. One of them was very helpful to others, offering suggestions as to how to divide the time between family responsibilities and attention

to the aged person. Free expression, mutual support, and high communication characterized the group process. Members tried to help each other while understanding their own problems and actions.

Attendance throughout the five sessions was consistent and this facilitated the discussion of problems. Ten of the participants attended five of the sessions while the other two attended four. All of the caregivers in the group acknowledged facing difficulties in their caregiving role and wanted to find ways in which their relationship with the elderly would be improved, especially their communication problems. Some felt frustrated by other personal problems that interfered with their relationship with the elderly. Statements included: daughters not getting support from their husbands in devoting time to their mothers; wives feeling trapped between their own children's demands and those of their sick husbands. Through the sharing of information and identification with one another, group cohesiveness developed. This was exemplified by the interaction after the meetings were over.

Members of the group also began to deal with some of their feelings toward the aged relative or friend. Some of them showed anger towards the elderly, while others expressed guilt. Some members related incidents where they had felt very angry with the elderly person for the amount of time their care demanded. Another member stated how guilty she felt about not being able to bring her mother to live with her. All the members admitted feeling similarly and began to look for solutions with the notion that it was within their power to effect changes in their situations.

The information provided to the group members regarding specific conditions in old age, the aging process, and community resources was an

important component of the group process. Through the information they received, the apprehension and concern about their aged relative or friends were overcome. Such information was necessary to facilitate decision-making regarding the availability and choices of service providers. Some participants acknowledged their lack of information about some services available for the elderly, while others were hesitant to apply for services for fear of not qualifying. One participant confided that she learned that agencies were not only for the homeless or familyless.

Elderly members of the group emphasized how important it was for them to talk and be listened to by their children. Communication again became an important topic of discussion. The topic of reminiscing as a form of communication used by the elderly was stressed by the group facilitator. Participants became aware of how some of their elderly relatives or friends talk about their past to show how things have changed or as a way of helping with child-rearing. Other members mentioned that when the elderly person lives alone, they need to have enough relatives visit or call them so as not to feel isolated. Communication skills were presented to the group participants.

When the sessions ended, the expectation was that the participants would exhibit mixed emotions including a feeling of abandonment by the other participants and the group facilitator. It was not surprising that anger was released, since members had made an emotional investment by their participation in the group. They had risked themselves in front of others. Members were helped to understand that these risks had been positive, because now they were better able to deal with their situations. Alternatives to follow-up were also discussed.

Twelve participants completed the evaluation instrument administered at the last session.

TABLE 5:24

Assessment of the Program: Cycle IV

Was the program helpful in your daily life?	N	%
YES	12	100%
NO	0	0
TOTAL	12	100%

The program was found helpful by all of the participants in this cycle. The open-ended question as to ways in which the program was helpful is categorized in the following table:

TABLE 5:25

The Most Important ways in Which the Program was Found Helpful: Cycle IV

Aspect	Frequency	Percent
Helped me improve knowledge about aging and community resources	7	54%
Helped me understand my own feelings and those of the older person	2	18
Helped me deal better with the elderly	2	18
Helped me understand my own aging	1	10

Fifty-four percent of the participants found the program helpful in improving their knowledge about aging and community resources. The other respondents found it helpful in helping them understand their own feelings and those of the elderly person (18%) and in dealing with their aged member (18%). The following comments add to the responses:

It was very educational.

It has helped me help others.

It helped me understand how I feel about my mother and how to help her more.

I learned a lot about my own aging process.

The participants were asked to enumerate the most helpful aspects of the program. First and second mentioned are presented in the next table.

TABLE 5:26

Most Helpful Aspects of the Program: Cycle IV

Aspect	Mentioned first	Mentioned second
Information about chronic illnesses and disabilities in old age	10	1
Information about benefits and entitlements	1	5
Information about community resources	0	3
Sharing and discussing problems with other members of the group	0	2
Material handed out in the sessions	0	0
Learn how to mediate with the agencies	1	0

Participants mentioned most frequently as first the information about chronic illnesses and disabilities in old age. The second most frequently mentioned were information about benefits and entitlements (6) and information about community resources (3). Sharing and discussing problems with others was mentioned second by two participants.

Assessment of the program by participants was more specifically done in various areas. Table 5:27 reflects their responses to this question.

(Table 5:27)

TABLE 5:27

Areas in Which Group Experience was Found Helpful: Cycle IV

	Helped a lot		Helped a little		No help	
	N	%	N	%	N	%
Learn how other people deal with their aged relatives	12	100%	0	0%	0	0%
Improve my communication with the elderly person	11	92	1	8	0	0
Understand the complaints of the older person	11	92	1	8	0	0
Establish contact with other caregivers	10	84	2	16	0	0
Talk and share my feelings with other persons	10	84	2	16	0	0
Understand my own aging process	12	100	0	0	0	0
Know where to begin to look for help	11	92	1	8	0	0
Increase my knowledge about illnesses in old age and how to deal with them	12	100	0	0	0	0
Understand the losses in old age	11	92	1	8	0	0
Learn about confusion in old age	11	92	1	8	0	0
Talk about my experience as a caregiver	9	75	3	25	0	0
Learn about nursing homes	8	66	4	34	0	0
Learn how to deal with family problems	10	84	2	16	0	0
Learn to give attention to my needs and my family needs	10	84	2	16	0	0
Talk about my frustrations	12	100	0	0	0	0

In general, the participants reported that the program was helpful in all areas mentioned. None of them cited any areas in which the program was not helpful. Their responses demonstrate that the program met some of their needs and expectations.

All of the participants mentioned that they had an opportunity to share their problems and experiences with other members.

TABLE 5:28

Support From Other Members: Cycle IV

Were other members supportive?	N	%
YES	12	100%
NO	0	0
TOTAL	12	100%

All of the participants reported that other members were supportive. Their responses are illustrated in the following comments:

> ...because they all discussed their problems and listened to mine.
>
> Everyone had the opportunity to talk about their problems while being attentive to ours.
>
> They gave me advice on how to deal with my mother.

Six out of the twelve participants reported having kept contact with other members. Eighty-three percent stated that they planned to see other members in the future. All of the participants were interested in being part of other group programs. Some reasons for these were mentioned as follows:

> These group programs are very useful because one will be part of the aged population soon.

I am interested in learning more.

...because it has been very helpful in my life.

You always learn from others.

Participants' reactions to the program were generally positive. All of the participants stated that they would recommend the program to other people. Several members made additional comments to improve the program. The following are some of them:

I would benefit if I continue seeing other members.

Follow-up should be done at least once a month.

The program has been very good and should be done with elderly people.

The program should be repeated at other senior centers

OVERVIEW OF ALL THE PARTICIPANTS IN THE PROGRAM

This section includes an assessment of the total number of participants and sessions attended. The results of the program are analyzed from the data collected at the beginning of the cycles in the initial questionnaire and the evaluation forms completed by the participants at the end of each cycle. Demographic characteristics of the participants as well as the aged receiving care are examined to describe the population served by the project and to compare it to the general population. Also included are common issues compiled throughout the sessions that describe family caregiving among Hispanics. The section concludes with an evaluation of the four cycles and a summary of key aspects of the program.

Program Registration and Participation:

There were 79 persons who registered to participate in the four cycles of the program, fifty-eight of whom actually participated.

TABLE 5:29

Enrollment in the Program by cycles

Cycle	Registered to participate	Actually participated
Cycle I	12	12
Cycle II	24	22
Cycle III	25	10
Cycle IV	18	14
Total	79	58

Cycle II had the largest number of participants in the program as well as the largest number of people who registered to participate. The actual number of participants are those who completed at least half of the sessions scheduled for each cycle. The following table illustrates the number of sessions attended by participants in each cycle.

TABLE 5:30

Number of Sessions Attended by Participants in Each Cycle

Number of sessions attended	All Cycles	Cycle I	Cycle II	Cycle III	Cycle IV
Six sessions	0	0			
Five sessions	12	3	0	2	7
Four sessions	22	3	13	6	3
Three sessions	14	1	11	0	2
Two sessions	9	1	8	0	0
One session	0	0	0	0	0
Total	58	8	32	8	12

The data presented in the previous table is obtained from those participants who completed the final evaluation and attended the last session per cycle. All the participants in the four cycles attended at least two sessions of the program. The majority attended four sessions. Differences in number of sessions reflect the number of sessions in each cycle. For example, Cycle I had six sessions, while Cycle II had four.

The analysis of the program participants' characteristics and types of involvement in the caregiving role, is based on the fifty-eight participants who completed the initial questionnaire at the beginning of each cycle.

Demographic Characteristics of Program Participants:

In planning a program for any target population, it is important to identify the ages, sex, educational level and other sociodemographic characteristics of the population. Table 5:31 presents a distribution of the major demographic characteristics of the participants in the program.

TABLE 5:31

TABLE 5:31

Distribution of Major Demographic Characteristics of Group Participants

	Frequency	Percent
Age		
Less than 30	5	9%
31 to 40	9	15
41 to 50	11	19
51 to 60	13	23
61 to 70	17	29
Over 71	3	5
Sex		
Female	42	72
Male	16	28
Marital Status		
Single (never married)	7	12
Married	33	57
Separated/Divorced	9	17
Widow	6	12
Place of Birth		
Mainland U.S.A.	3	6
Puerto Rico	39	64
Other Caribbean Islands	9	16
Central America	3	6
South America	3	6
Europe	1	2
Education		
No schooling	2	3
Elementary School	8	15
High School Courses	21	37
High School Graduate	17	30
College Courses	5	7
College Diploma, Professional Diploma	2	3
No answer	3	5
Working Status		
Full-time employed	21	36
Part-time employed	6	10
Not Working*	31	54
Income		
Less than $5,000	19	33
$5,000 to $10,000	15	22
$10,000 to $15,000	6	10
$15,000 to $20,000	4	7
Over $20,000	7	12

* Includes: retired, unemployed, housewife and students

Data on the previous table demonstrate that over fifty percent of the participants in the program were 51 years old and over (57%) and with the largest concentration in the ages of 61 to 70 (29%). It is interesting to note that two of the participants were seventeen years old and grandchildren of an elderly person.

As the data indicate, more than half of the participants revealed that fifty percent had less than a high school diploma. Only thirty percent had completed high school and ten percent had college courses or were college graduates. Three percent had no schooling.

The annual income of the participants was also low when compared to the general population. ($14,000 for Hispanics and $20,000 for non-Hispanics). The lower median income is reflected in the income distribution of the participants: thirty-three had incomes below $5,000, and about 55 percent below $10,000. In the upper end of the distribution, only 12 percent earned more than $20,000 a year.

Participants in the program were attracted to participate in it for different reasons. The following table presents the responses to this question.

(Table 5:32)

TABLE 5:32

Reasons to Participate in the Group Program
(N=58)

Aspects	Mentioned	Not Mentioned
To learn about chronic illnesses and disabilities in old age	91%	9%
Learn about benefits and entitlements for the aged	81	19
Learn about emotional reactions and needs of older people	81	19
Share experiences with other caregivers	76	24
Learn about programs and community resources for the aged	83	17
Listen to other people who are caring for elderly persons	71	29
Learn to get ready for own aging	81	19

One basic characteristic of the group participants was the involvement in the program for educational reasons. The most frequently mentioned reason to participate was to learn about chronic illnesses and disabilities in old age (91%). The second most frequently mentioned was to learn about community resources for the aged (83%). The motivation to listen to other people who are providing care to an older person was mentioned to a lesser extent (71%).

The participants were asked how they thought the program could be helpful to them. Their responses to this open-ended question are summarized in Table 5:33.

(Table 5:33)

TABLE 5:33

How can the program be helpful to you?

	Frequency	Percents
Learn to deal with the older person's disabilities	18	55%
Communicate better with the elderly	6	18
Share my problems with others	3	9
Prepare for caregiver's role	2	6
Learn about the aging process	2	6
Learn about programs in the community	2	6
Total responses	33	100%

A great number of the participants who answered the question were interested in getting information about specific conditions of old age and how to manage them. Only a small number of them stated that sharing their caregiving role in the group would be beneficial.

Thirty-four (58%) of the participants were caregivers of an elderly person. The following section will present demographic characteristics of this population, a description of the activities done for the elderly, and problems encountered while providing care to an elderly person.

Caregiving Population Characteristics:

Children represented over fifty percent of the caregiving population of the project. Daughters composed forty-six percent and sons represented fifteen percent. Distribution of the major sociodemographic characteristics for the caregiving population are presented in Table 5:34.

TABLE 5:34

Demographic Characteristics of the Caregivers

	Frequency	Percents
Age		
Less than 30	6	18%
31 to 40	6	18
41 to 50	5	15
51 to 60	9	23
6i to 70	5	15
Over 70	4	11
Sex		
Female	28	82
Male	6	18
Marital Status		
Single (never married)	5	15
Married	18	53
Divorced/Separated	8	23
Widow	3	9
Relationship to Older Person		
Spouse	4	12
Daughter	16	46
Son	5	15
Daugnter-in-law	2	5
Sister	2	5
Granddaughter	2	5
Friend/Neighbor	4	12
Education		
No school		
Elementary School	5	15
High School Courses	15	45
High School Graduate	7	21
College Courses	2	5
College or Professional Diploma	2	5
Working Status		
Full-time Employed	10	29
Part-time Employed	5	15
Not working (Retired, unemployed, housewife and students)	19	56
Income		
Less than $5,000	11	32
$5,000 to $10,000	12	35
$10,000 to $15,000	4	12
$15,000 to $20,000	3	9
No answer	2	6

As the data indicate, more than half of the caregivers (53%) are currently married and living with their spouses; fifteen percent have never been married, while the remaining respondents are widowers (9%), separated or divorced (23%).

The ages of the caregiving population ranged from seventeen to seventy years old, with a median age of forty-eight. Related to the general demographic trends, we see a middle-aged population facing the needs of an old, frail elderly relative or friend. Thirty-six percent of the caregivers were under the age of forty, with approximately one fourth below thirty years old, and eleven percent over seventy-one years old.

Family income of the caregivers ranged from under $5,000 annually, to over $20,000. Over fifty percent (67%) fall within the lower income group (under $10,000); twelve percent earned between $10,000 to $15,000 and only nine percent reported incomes of $20,000 or more.

It should be noted that education and income were strongly related in this sample; with the population emerging as a disadvantaged group. Only twenty-nine percent were not working.

The care recipient population in the project were predominantly living with the caregiver (47%).

The Older Person:

Table 5:35 describes the sociodemographic characteristics of the older person receiving care by a relative or friend.

(Table 5:35)

TABLE 5:35

Demographic Characteristics of the Care Recipient (older person)

	Frequency	Percents
Age		
Less than 60	3	9%
61 to 69	8	23
70 to 79	8	23
80 to 89	14	41
Over 90	1	4
Marital Status		
Single (never married)	4	12
Married	10	29
Separated/Divorced	7	21
Widowed	13	38
Living Arrangements		
With Participant Caregiver	16	47
With Spouse	3	9
Alone	9	26
With Other Relatives	6	18
Source of Income		
Social Security	13	39
Supplemental Security Income	13	39
Both Social Security and SSI	5	15
Pensions	1	3
Help from Relatives	2	4

The older person receiving care is most often over 70 years of age (68%), widowed (38%), and living with the caregiver (47%).

The major problems of the older person reported by the caregivers were physical (65% of the caregivers mentioned it). The most common physical problems mentioned by the caregivers were: arthritis, diabetes, heart conditions and paralysis (as a result of strokes). Other problems

that the elderly person was facing were: isolation, companionship, financial problems, and emotional problems.

What do Caregivers do for Their Elderly?

Detailed information was collected to describe the activities performed by the caregivers for the elderly person. In order to determine the frequency with which specified types of activities are provided to the elderly person, respondents were asked to check if and how often they provided help with the following services: household chores, shopping, meal preparation, personal assistance, and others. Their responses are presented in Table 5:36.

Caregiving activities were conceptualized as falling into four major categories of assistance: emotional support, financial aid, instrumental assistance, and linkage services.

(Table 5:36)

TABLE 5:36

Activities Done by the Caregivers: All Cycles

Items	At least once a day		Three to four times a week		At least monthly		Never	
	N	%	N	%	N	%	N	%
Shopping for personal things or food	4	12%	11	32%	7	21%	12	35%
Meal preparation	12	35	10	30	0	0	12	35
Light housecleaning (dishes, dusting, etc)	7	21	9	26	3	9	15	44
Heavy housecleaning (floors, windows)	4	12	4	12	8	23	18	53
Administer or supervise medication	15	44	3	9	2	6	14	41
Help with laundry	3	9	10	30	2	6	19	55
Personal hygiene (bathing, clothing)	10	29	4	12	2	6	18	53
Contribute money for expenses	1	3	3	9	12	35	18	53
Help manage finances (cash checks, pay bills)	0	0	2	6	20	59	12	35
Assist in transportation	0	0	3	9	14	41	17	50
Emotional support (visit, phone, talk)	31	91	3	9	0	0	0	0
Take home on weekends	0	0	0	0	7	21	11	32
Help mediate with agencies	0	0	0	0	18	53	16	47

It should be noted that in eighteen cases the elderly live with the caregivers.

The most prevalent type of assistance given to the elderly was in the area of emotional support, defined as visiting, talking over the phone, or in person and advice-giving. The overwhelming majority of the caregivers (91%) reported providing help in this way daily. It should be noted that even when the elderly person was not living with the caregiver, this was reported as the most frequent activity performed by the caregiver.

While emotional support was the most common caregiving activity performed by the caregivers, the majority of them were also involved in providing a range of instrumental activities for the elderly. These activities include: shopping (65%), meal preparation (65%), light housecleaning (56%), laundry (44%), and personal hygiene (47%). Fifty percent reported assisting in transportation and over fifty percent (59%) reported assisting in transportation and over fifty percent (59%) reported supervising or administering medication.

Financial assistance does not emerge as a frequent help provided to the elderly. But if one takes into consideration the income of the caregivers, then it emerges as a major contribution to the elderly.

From the data presented in Table 5:35, it appears that not all the activities require the same amount of time or regularity. For example, transportation services are provided by 44 percent of the participants on a monthly basis. On the other hand, almost fifty percent of the respondents who help with household activities and meal preparation are involved on a daily basis.

It is important to note the high number of caregivers who were involved in negotiating with the formal system on behalf of the elderly. Over fifty percent (53%) of the caregivers reported that they helped their relatives or friends by dealing with service agencies and/or getting

information about services. The responses of the children speak of the importance of this help in assuring that the elderly receive their entitlements:

> I represent my mother in all her appointments with the Supplemental Security Income, first because she is home-bound and second, because she does not speak English. Even with my lack of fluency in English, I do it so that she may receive what she is entitled to.

Perceived Problems of Participants in Relation to the Elderly:

The participant caregivers were asked to mention the most difficult thing or problems they were facing in relation to their aged member. The open-ended responses fell roughly in the categories listed in Table 5:37.

TABLE 5:37

Perceived Problems While Dealing with the Elderly

	Frequency	Percent
Which of the things you do for the elderly is more difficult?		
None	13	39%
Talking or listening to the elderly (communication)	8	25
Provide personal care	7	22
Prepare food	2	5
Deal with other relatives	2	5
Provide emotional support	1	2
Deal with the service agencies	1	2
Total responses	34	100%

It is interesting to note that thirteen caregivers did not mention any problem while dealing with the elderly. It should be noted

that these responses were given at the beginning of the cycles and the group process revealed different aspects to this question which will be mentioned in another section. Table 5:37 also provides further analysis of this question.

However, those caregivers who reported having difficulties, mentioned as the most frequent problem their communication with the elderly and providing personal care.

Impact of the Caregiving Situation:

Caregivers in the group program were asked to describe the impact of their caregiving situation in different areas. They were given a series of situations which generally are experienced by people in a caregiving situation and were asked to rate whether they were experiencing the situation a lot, a little, or not at all. Table 5:38 reflects their answers.

TABLE 5:38

Impact of the Caregiving Situation
(N=34)

Situation	Experienced a lot	Experienced a little	Not Experienced at all
Time spent with the older person keeps me from spending time with other family members	24%	14%	62%
I do not enjoy leisure activities in my free time because of the time spent with the older person	29	18	53
The time spent with the older person interferes with my job	9	29	62
The time spent with the older person keeps me from doing my own house chores	6	18	76
Worrying about the older person affects my health	24	41	35
The money spent on the older person keeps me from buying things that I want	6	15	79
I worry about my own aging	18	29	53

More caregivers expressed lack of conflict in their caregiving situations than those who reported having any conflict which is consistent with the answer to the previous question (Table 5:36). It is interesting, but not surprising among Hispanics, not to talk openly about their conflicts. A cultural issue among the Hispanics is to see their caregiving situations as a responsibility toward their aged relatives. Not to admit that there are problems while taking care of an elderly is a way of acknowledging their respect for them.

In all except the first and second situations, there are more respondents who answered that the situations were experienced a little. But in the first and second situation the trend is different, with more respondents answering that the situations were experienced a lot. It seems that there are other factors that make these respondents feel affected by the situations more. We can only speculate as to these factors: living with the elderly person in the same household, dealing with a very frail elderly, having other familial responsibilities and working outside. The only situation which was mentioned by a large number of participants as affecting them a little or a lot is the one that reads: "Worrying about the older person affects my health" (65% compared to 35%). The analysis of the data in terms of frequency and percentages does not provide for more comparisons of those caregivers who experienced the situations a lot or a little as to other characteristics. Cross tabulations of variables would be helpful but were not available.

Services Received from Formal Organizations:

The following table presents a distribution of the services that the older person was receiving from the formal organizations by frequency and distribution.

TABLE 5:39

Services Received from the Formal Organizations

Item	Receiving from agency		Not Receiving	
	N	%	N	%
Counseling	2	6%	32	94%
Escort services	0	0	34	100
Transportation	16	47	18	53
House repairs	2	6	32	94
Friendly visitors	3	9	31	91
Telephone reassurance	3	9	31	91
Legal services	2	6	32	94
Personal care*	15	44	19	56
Shopping*	15	44	19	56
Light housecleaning*	15	44	19	56
Laundry*	15	44	19	56
Financial help**	18	53	16	47
Home health aid	0	0	34	100
Home attendant	15	44	19	56
Visiting nurse	17	50	17	50
Meals on wheels	0	0	34	100
Senior Citizen Center	2	6	32	94

* Services rendered by the Home Attendant
** Referred to as Suplemental Security Income

Data in this table reveals that the elderly was receiving Home Attendant services in the majority of cases (44%), transportation services

(47%), and visiting nurse services (50%) from the formal organizations. No in-depth analysis was done to explore the reasons for not receiving other services. It should also be noted that the Home Attendant was providing most of the services that the elderly receives.

The following table compares the services that the elderly was receiving from both the caregivers and the formal organizations.

TABLE 5:40

Services Received by the Elderly from Formal and Informal Systems

Items	From Agencies		From Caregivers	
	Do	Do not receive	Do	Do not receive
Counseling	2 (6%)	32 (94%)	34 (100%)	0 (0%)
Escort services	0 (0%)	34 (100%)	0 (0%)	34 (100%)
Transportation	16 (47%)	18 (53%)	17 (50%)	17 (50%)
House Repairs	2 (6%)	32 (94%)	0 (0%)	34 (100%)
Friendly visitors	3 (9%)	31 (91%)	34 (100%)	0 (0%)
Telephone reassurance	3 (9%)	31 (91%)	34 (100%)	0 (0%)
Legal services	2 (6%)	32 (94%)	0 (100%)	34 (100%)
Meal Services	0 (0%)	34 (100%)	22 (65%)	12 (35%)
Shopping	15 (44%)	19 (56%)	22 (65%)	12 (35%)
Light housecleaning	15 (44%)	19 (56%)	19 (56%)	15 (44%)
Heavy housecleaning	0 (0%)	34 (100%)	16 (47%)	18 (53%)
Laundry	15 (44%)	19 (56%)	15 (44%)	19 (56%)
Personal hygiene	0 (0%)	34 (100%)	16 (47%)	18 (53%)
Financial help	18 (53%)	16 (47%)	15 (44%)	19 (56%)
Manage finances	0 (0%)	34 (100%)	22 (65%)	12 (35%)
Home attendant	15 (44%)	19 (56%)	0 (0%)	34 (100%)
Visiting nurse (supervise medication)	17 (50%)	17 (50%)	20 (59%)	14 (41%)
Mediate with agencies	0 (0%)	34 (100%)	18 (53%)	16 (47%)
Senior Citizen Center (take home for weekends)	2 (6%)	32 (94%)	7 (32%)	11 (32%)

The involvement of the informal system remains high even when the elderly was receiving services from the formal organizations. For example, the presence of a home attendant did not push aside the caregiver's involvement. The family was also providing those services that the elderly was not getting from the formal organizations, like heavy housecleaning and personal hygiene.

The following comments by caregivers in the program reflect some of the things done for the elderly that require more technical knowledge from the caregivers:

> My mother has a machine connected to her back that helps her to move around. This machine is battery operated and needs to be cleaned very often, especially in the part that is attached to the body to prevent infections. I am a registered nurse and I am trained to do it myself but when I am not around, my mother has to wait until I am available. She receives a visiting nurse once in a while but she needs more supervision in this area.

> I cut my mother's nails but sometimes I am afraid because she is diabetic and might get infections.

> I handle all my mother's finances. I cash her checks every month and pay her bills. She has a home attendant that could do those things but my mother refuses to ask anybody except me.

The last comment reflects that even when there is a home attendant to help the elderly, the caregiver is the one that the elderly tends to depend on.

The help provided to the elderly by the family and friends is generally recognized by the elderly as a vital resource. Such help is usually preferred by the elderly over the formal services provided under public auspices. The following illustrates this:

> When my mother goes to the hospital, I have to prepare her meals and bring them to the hospital. My mother prefers that over eating food prepared by the facility. When she is at home she does not let the home attendant cook, either she cooks or I bring her food from my house.

The latter more closely parallels the situation of the adult relative with an aging parent who is dependent and makes demands requiring a lot of assistance from the child. The adult child may experience exhaustion, guilt, and uncertainty as to what to do for the elderly. The following section will present common issues that arose from the group experience.

Common Themes and Discussion that Evolved Throughout the Project:

The information below presents issues in family caregiving by Hispanics. It was compiled from the progress notes taken at the end of the sessions and from observations by the project director at the verbal and non-verbal level during the group sessions.

The project director found the group members throughout the four cycles to be extremely expressive in their accounts of the caregiving experience, relationship with the elderly and personal problems. Although the initial interviews with the participants provided some information on their caregiving experience, the group process facilitated some common issues. Seven major issues will be presented as follows: relationship to the homeland, guilt, preventing institutionalization and family responsibilities, communication problems, coping with their own aging, self-help and group development, and need for individual services, i.e., entitlements, counseling, etc.

1. Relationship to the Homeland:

The homeland had a very significant role for both the elderly person and the caregivers in the project. In the case of the elderly person, geographic distance presented specific constraints based on the availability of family members. Many elderly have children in Puerto Rico, Cuba, Dominican Republic, and parts of Central and South America,

while they have remained living in New York for a variety of reasons. In these situations, neighbors and friends sometimes took over.

> ... and I have been neighbor for Mrs. T. for over ten years. She has two married sons living in Puerto Rico. They have their jobs and family there and decided to stay for good. Mrs. T. does not want to be a burden for them and prefers to remain in New York where she is receiving SSI and Medicaid, which she cannot get in Puerto Rico. Her children write to her frequently and if there is any emergency, they will fly to New York.

In other cases, many family members have moved to the suburban areas of the city while the elderly members have remained in the inner-city. This phenomenon is very common among Hispanic elderly that have decided to stay in their old neighborhoods instead of moving with or close to their children.

> My mother-in-law has another child besides my husband but he moved with his family to Long Island a few years ago. He visits on weekends but even that is hard for him and he can only stay a few hours.

In many instances, the children that live far away from their parents will make every possible effort to help in times of crisis. One of the participants in the program illustrates this situation.

> I have been living in Puerto Rico for the past five years. I am the only daughter and have two brothers in New York. When my mother had a stroke six months ago, I left everything behind me, my job, husband and friends, and came to take care of my mother. I don't know how long I will be with her, but for sure I will not leave until she is better. I might take her with me to Puerto Rico. Although my brothers live nearby they have their own family and job responsibilities and cannot be with mother when she needs them.

In other circumstances the situation is reversed. The elderly person has left for Puerto Rico while her children have remained in the United States. This trend is more common than the other because the elderly tend to go back to the island after they retire. Return migration of the elderly Puerto Rican in the past ten years has increased.

> My mother went back to the island ten years ago because she wanted to spend the rest of her life there after my father passed away.

> She lived by herself near some relatives. My sister and I grew up in New York and cannot get used to living in Puerto Rico but we would visit her. Five months ago she started showing signs of disorientation and it was clear to us that she could no longer live alone, so we brought her over for good.

Geographic distance between family members makes caregiving and support more difficult. In the case of the Puerto Rican, the fact that movement from and to the island is not so hard, does not create an extremely difficult situation, but still presents problems both for the elderly and the caregivers, especially when dealing with a poor population.

2. Guilt

Guilt sometimes amplifies the stress involved in a caregiving role. Middle-aged children are caught between the care and guidance of their own children, the vulnerability and dependence of their old parents, and the responsibility of earning a living for the family. Guilt feelings create an overwhelming sense of failure when the caregiver cannot handle family problems and caregiving tasks.

Expressions and manifestations of guilt were brought up by the participants in all four cycles, regardless of the amount of care they were providing to the elderly person. Members expressed their guilt feelings in a variety of ways:

> ....the problem is that you feel guilty if you cannot visit every day.

> ....when you offer constant love and attention, you must continue doing so, no matter how you feel at times. That will make them (the elderly) feel good.

> The situation can be compared to that of a politician. You are good if you offer something. When you stop, you are bad, and they make you feel bad.

> Not having enough money to take your father to a private doctor, and depending instead on public service, makes you feel terrible.

> I placed my mother in a nursing home because she was very sick and I was having problems with my husband and my daughter. I took her out of the home because I couldn't handle how guilty I was feeling. I felt I was not a good daughter. I brought her to the house and things went better with my family. With the assistance of a home attendant, I can work part-time and my daughter helps me with my mother.

Guilt feelings around visiting and spending more time with the elderly were expressed by those members who were not living with the elderly relative. For example, one common concern was not having enough space in the apartment to have a relative living with them or living too far away, which limited the visiting hours.

The reality is that sometimes the caregivers felt overwhelmed by all the responsibilities that they have and sometimes were not able to manage alone. They need other people with whom they can share information and from whom they can receive understanding. Members of the group were helped to view their situations and limitations in a realistic way by other group members. They were also helped to gain some insight into and relief from their guilt feelings by understanding their relationship with their aged relatives.

A sense of helplessness seemed to emerge from a number of caregivers in the program, mostly during the discussion of physical impairments of the elderly. As some members stated:

> Sometimes I don't know how to handle my mother's deterioration. I feel useless not having control of her health.
>
> ...I wish I could help my mother to recover her memory. She does not even recognize me sometimes.
>
> My mother is always depressed and most of the time she refuses to eat or get out of bed, no matter what I do to motivate her.

Group members shared common feelings of powerlessness when dealing with the deterioration of a relative or friend.

3. Family Responsibilities:

As caregivers try to make decisions on how to help their elderly members and how to cope with their elderly's dependence on them, they find themselves in a new situation. Most of them are women and have become part of the labor force. As a result, they are able to spend less time doing things for the elderly. The geographic distance among family members are wider, making the responsibilities, decision-making and support more difficult.

> I work full-time, have my husband and children to take care of at the same time that my mother, who lives alone, requests my assistance in different ways. For instance, if she needs to see a doctor, I have to be absent from work to take her. If she goes to a hospital I have to take her, intercede for her, and bring her back home. Meanwhile, I get home late to cook, to do the housework after I missed a day from work.

> I live with my grandparents but I also go to school. Before I leave in the morning I have to make sure that they both have taken their high blood pressure pills and that they do not need to go out shopping. They do not speak English, which means that whenever they have an appointment at any agency, I will be absent from school.

Financial management and financial help are other services provided by the caregivers that can be both time consuming and a financial burden.

> At the end of the month I have to cash my mother's SSI check and pay her bills. Sometimes the money is not enough and I have to put some of my money to cover the balance. Whenever there is a mistake in her bills I have to make a trip to the agency to deal with it.

Problems in allocating responsibilities for the aged among family members were described:

> Even though I have other brothers, they rely on me to watch over mother and if I request their help they claim they are too busy.

> My brother's wife is very demanding on my brother's time and she gets upset if I call him to take father to a doctor's appointment.

Some caregivers experience health ailments as a result of their responsibilities for their aged members. Worrying about the older

person's health affects some caregivers.

> My husband does not sleep at nights. He is always worried that his mother might fall or get sick. He visits her every day after work and sometimes is very depressed when he gets home.

4. Institutionalization:

Families of the elderly tend to maintain them in the house or in the community at considerable emotional and financial sacrifice. Sometimes they do not even consider that as an option.

It was revealed through group discussion that institutionalization of the elderly was not an option considered by participants. Even the presentation of information on nursing homes was not welcomed by the group members. Some comments that reflect this feeling among participants follow:

> ....but I will never think of a nursing home. If my husband or children are not supportive of my mother being with us, I rather move out with her, but only if I die will I stop taking care of her.

> That is what the family is for... we have a large family and none of us will ever think of an institution.

> Only those who have no feelings toward the aged will abandon them in a nursing home, especially in a country which is not your own and the aged does not speak their language.

There was a group member who had the experience of placing her mother in a nursing home because of the pressures she was having with her husband and daughter. Both of them refused to help or be supportive in her caregiving role and she became very depressed to the point that she could not manage the pressures. After having her mother in the nursing home for a month, she took her out.

> I was going crazy dealing with my mother at the nursing home and was ready to be institutionalized as a result of my guilt feelings. After me and my family sought help with a therapist, we were able to bring mother back to the house. Things are working better now with the help of a home attendant.

5. Communication Problems:

Another topic that evolved in the group cycles was the problem of communication and sharing between members of different generations in the same family. The following case exemplifies this issue:

> Lissette, 17 years old is providing some care to her grandmother, 89 years old, after she comes from school. The grandmother has always lived in the house and helped raise Lissette. After the grandmother became very sick and dependent, the communication between them has been affected. The grandmother is bedridden, blind and paralyzed. She likes to talk to Lissette about different things but Lissette finds her conversation dull and non-attractive. The grandmother talks about life in Puerto Rico and other things that Lissette does not relate to.

Some members complained that their elderly relatives are "stubborn" and wanted things "their own way" which interfered with their communication.

Some of the members were experiencing tension among the younger members of the family and the elderly person. Some of them suggested developing a group program for teen-agers, so that they could understand that the problems the elderly person had were real.

6. Coping With Their Own Aging:

The participants throughout the sessions brought concerns about their own aging process. They experienced mixed feelings about this issue. Some comments that reflect their feelings are:

> I do not mind taking care of my father, it helps me to get ready for my own aging.
>
> When I look at the deterioration of my mother, I cannot but fear my own aging... I am getting there too.
>
> My mother does not realize that I am 59 years old and sick, she is just concerned about herself.
>
> Getting old does not worry me, on the contrary, I look forward to it. I just hope that I could live long enough to help my children.

Some members reacted to their aged relatives or friends' dependence on them and projected themselves into the future as very independent and reluctant to request help from their children. Some manifested an intense desire not to become a burden on their children.

> I hope that I never have to depend on my children for help or support. They have their own life and I do not want to be a burden on anyone.

Other members had different conceptions of being old:

> Sometimes I see old age as a punishment, not only to the old person but to the person who has to take care of them.

Fear of aging and death was a recurrent theme in group discussions. Information about the aging process helped participants to gain a greater understanding of the emotional and physical aspects of aging. The presence of older individuals in the group also allowed the participants to examine their attitudes towards their own aging. One group participant had experienced the death of her husband and while group members engaged in supporting her, they had the opportunity to explore their feelings around death. Some of them engaged in planning and discussing how they would deal with their aged relatives' death.

7. Self-help and Group Development:

As previously noted, group participants became involved in the program mainly to obtain information and education. During the group process, participants shared information concerning their own caregiving roles, their problems and how they felt about their situations. Over the sessions they became very supportive of each other and formed a network of members ready to support each other even outside the group program. As they grew more supportive of each other they were able to express and share feelings.

All except two participants considered that other members were supportive. Over fifty percent of the participants (55%) considered that sharing problems and feelings with other caregivers was an important aspect of the program.

The following comments reflect some ways in which participants developed self-help and mutual-aid:

> Being with other people who are having similar problems has been helpful. I needed to know how they were feeling and dealing with some situations.
>
> The meetings showed me that I am not alone. Things could be worse for other people. There are others facing similar or more difficult problems with their aged relatives.
>
> I never thought that I could talk freely with other people who would be so understanding. Some of my friends cannot be helpful because they are not dealing with similar situations.
>
> It feels good when you find other people in the same boat.

8. Request for Individual Services:

Caregivers in all cycles expressed a need for individual services to supplement the group program. Although the scope of the program did not allow for continued individual services, this assistance was provided to several members in all group cycles. Assistance was provided in the areas of benefits and entitlements, counseling, transportation services and dealing with some service agencies. The project director was able to assess the individual request and offer some services or refer the person to the appropriate agency. For some caregivers, the necessity of dealing with the formal organizations in a language different from the one spoken by them proved to be a deterrent to service utilization or in mediating with agencies on behalf of the elderly. One of the participants in Cycle I illustrates this issue:

> My mother received a letter from the Social Security Administration regarding her SSI benefits. She gave me the letter since she does not understand English. I know just a little but I represent her with the agencies. I went to the SSI office and they told me that my mother owed them some money for which they will deduct a monthly amount from her check. I signed the papers because they might just make her ineligible, but I still do not understand why they do it.

It is obvious that information on benefits and entitlements is especially necessary for the caregivers. Mr. C. was not clear of his mother's rights to request a review of her case or of what he was signing on behalf of his mother. His lack of fluency in the English language was creating a problem in mediating with formal organizations. Some service providers do not offer information in Spanish about the services and the majority of the notifications of eligibility or ineligibility are in English. In the majority of the cases, the caregiver is also the mediator with the formal organizations and this could be a difficult task if the caregiver is not knowledgeable of the services and lacks fluency in the English language.

Mediating with the formal system was one of the major difficulties that some members brought up in the sessions. Sometimes they considered that it would take time from their jobs to deal with the issue. They also saw it as time consuming and difficult because of the language barrier. The following comment speaks to this issue:

> My mother received a letter from the Home Energy Assistance Program with an application. There was a number to call for information for Spanish speaking people, but when I called they answered in English and they could not find a person to help me in Spanish.

Even when the agency announces that it will provide help for people who do not speak the language, the experience demonstrates the opposite.

Although, as explained before, the project scope did not provide

for consultation or as a source of information. This points to the need for individual services even when this falls outside of the program's scope.

EVALUATION OF THE PROJECT

The evaluation presented in this section is based on data from the sixty group participants who attended the last meeting in each cycle and completed the evaluation questionnaire. This method of evaluating the program left out those participants who did not attend the last session of the cycles. To provide for the inclusion of all the participants in the assessment of the project, data was also collected from the minutes, process recording of each session and observations made by the project director throughout the groups. The analysis, which is largely descriptive, presents the assessment of the program by the participants, the aspects which they found most helpful and areas in which they considered the program benefited them. Although generalization of the findings is limited by the sample size, the findings may provide some clues in developing caregiver support groups for Hispanics.

The major purpose of the evaluation component is to evaluate the program in relation to its goals and objectives which can be summarized as follows:

Goals:

1. To test the use of a group approach in strengthening the capability of Hispanic individuals to care for an older person.
2. To promote and assist group development among Hispanics with emphasis on the mutual-aid/self-help concept.
3. To involve an underserved target population of low-socioeconomic Hispanic background.
4. To train non-agency caregivers to assume a significant role, along with agencies, to improve the care provided to elderly relatives or friends.

Objectives:

a. Increase the participants' understanding and knowledge of the aging process.

b. Increase their understanding of the emotional reactions and needs of older people.

c. Develop a greater awareness and sensitivity in their responses to the aging process of the elderly relatives or friends.

d. Improve dialogue and analysis of alternatives available to themselves and their aged members in maintaining an active and productive life.

f. Increase their effectiveness in addressing the needs of the elderly by facilitating the development of support system within the group.

Evaluation of Project by Project Participants:

The final evaluation by the group participants demonstrated that the program was valuable in helping them in their caregiving role. The concrete information about aging and community resources, the opportunity to meet with other caregivers in similar situations and the opportunity to share with others, were areas in which they found the program helpful.

In all, sixty participants completed the evaluation questionnaire. The evaluation of the project will be based on their responses.

TABLE 5:41

Assessment of the Program

	All Cycles		Cycle I		Cycle II		Cycle III		Cycle IV	
	N	%	N	%	N	%	N	%	N	%
Was the program helpful in your daily life?										
YES	60	100%	8	100%	32	100%	8	100%	12	100%
NO	0	0	0	0	0	0	0	0	0	0
Total	60	100%	8	100%	32	100%	8	100%	12	100%

All the participants in the program found that it had been helpful. The specific aspects are mentioned in the next table.

TABLE 5:42

Ways in Which the Program was Found Helpful

Aspects	Frequency	Percents
Helped me improve my knowledge about aging and community resources	39	63%
Helped me understand my own feelings and the older person's feelings	11	18
Helped me deal better with the older person	5	8
Helped me get ready for my own aging	4	6
Helped me share the guilt feelings with other participants	2	3
We all share the same problems	1	2

Evaluation results revealed that at the end of the group program the participants became aware of different community resources and furthermore, that the information about the aging process helped them a lot. Sixty-three percent of the participants considered that the program was helpful in these aspects.

Participants were also helped to understand their own feelings and those of the older person and found the program helpful in dealing better with their elderly relatives or friends (11% and 5% respectively).

The group participants were asked to evaluate in order of preference various aspects of the program. Their choices to first and second

aspects are presented in the following table.

TABLE 5:43

Most Helpful Aspects of the Program

Aspect	Mentioned First	Mentioned Second
Information about chronic illnesses and disabilities in old age	39	7
Information about benefits and entitlements	7	20
Information about community resources	2	12
Sharing and discussing problems with other caregivers	6	11
Learn how to mediate and deal with the agencies	3	1
Material handed out at the sessions	4	3

Consistent with the areas mentioned as most helpful in the previous table, respondents again mentioned as the most helpful aspects of the program the information about chronic illnesses and disabilities in old age, and as the second most frequently mentioned the information about benefits and entitlements. Sharing and discussing problems with other members was mentioned by eleven participants as the second most important aspect of the program. This finding indicates that the intervention helped the participants in the support gained from other members.

In addition to reporting which aspects of the program were found helpful, the participants mentioned specific areas in which the program helped them a lot, a little, or not at all. The next table presents their responses.

TABLE 5:44

Areas in Which Group Experience was Helpful

	Helped a lot		Helped a little		No help	
	N	%	N	%	N	%
Learned how other people deal with their aged relatives	42	70%	10	17%	0	0%
Improved my communication with the elderly person	43	72	6	10	0	0
Understood the complaints of the older person	48	80	5	8	1	2
Established contact with other caregivers	37	62	13	22	0	0
Talked and shared my feelings with other people	34	57	11	18	0	0
Understood my own aging process	55	92	4	7	0	0
Know where to begin for help	47	78	7	12	1	2
Increased my knowledge about illnesses in old age and how to deal with some conditions	56	93	2	3	0	0
Understood the losses in old age	54	90	3	5	0	0
Learned about confusion in old age	48	80	7	12	0	0
Talked about my experiences as a caregiver	45	75	7	12	0	0
Learned about nursing homes	33	55	12	20	1	2
Learned to deal with family problems	34	57	9	15	2	3
Learned to give attention to my needs and my family needs	44	73	6	10	0	0
Talked about my frustrations	40	67	7	12	0	0

Differences in percentages reflect those who did not answer

Consistently more participants reported that they were helped a lot in all areas mentioned than those who were helped a little. The areas that reported no help received were: understanding the complaints of the older person (2%); learning to deal with family problems (3%); learning about nursing homes (2%); and knowing where to begin for help (2%).

The program can be considered successful since it helped the majority of the participants in all areas mentioned. Basically these areas encompassed the objectives of the project.

Over seventy-five percent of the group participants (77%) mentioned that they had the opportunity to share and discuss their problems with other members of the group. Group interaction and sharing was an important aspect of the group program.

Members were asked if other members had been supportive and their responses are presented in the following table:

TABLE 5:45

Support From Other Members of the Group

	All Cycles		Cycle I		Cycle II		Cycle III		Cycle IV	
	N	%	N	%	N	%	N	%	N	%
Were other members supportive?										
YES	46	77%	8	100%	18	56%	8	100%	12	100%
NO	2	3	0	0	2	6	0	0	0	0
No answer	12	20	0	0	12	38	0	0	0	0
Total	60	100%	8	100%	32	100%	8	100%	12	100%

Data in this table reveals that over seventy-five percent of the participants received support from other members. In all except Cycle II

all the participants expressed having received support from other members. It should be noted that the size of Cycle II did not provide for much interaction among members which explains why some of the members did not find others supportive.

Evidently peer support was one of the most important aspects of the group development in all cycles.

Through the group experience the participants gained practical knowledge that helped them understand the aging process, understand their aged relatives' needs as well as their own feelings and actions toward these needs. In addition, the group program provided an opportunity for the participants to express their shared concerns, to look for alternatives in dealing with those concerns and to learn of community resources available to them.

As the group program ended, the participants were encouraged to continue meeting as a group and were introduced to existing caregiver groups in the community. All the participants expressed that they would recommend the program to other people.

SUMMARY

The focus of this chapter has been to discuss the initiation, implementation and evaluation of the program. Some implementation problems emerged as the program was initiated which influenced the development of the cycles at different sites. These problems had to do with not having enough participants to develop the program in one agency as originally conceived. The implementation of the program in different agencies presented problems in identification and recruitment of participants, identification and selection of sites as well as scheduling the sessions (place and time). As the program was organized in different

agencies, its implementation proved to be different in each cycle. The identification and recruitment of participants proved to be more difficult in a more bureaucratized organization (Home Attendant Program) as opposed to a community-based group (Church). The development of the program in a community-based group facilitated recruitment and participation but at the same time attracted more participants who were not caregivers which brought a different focus to the program.

Fifty-eight persons participated in the program at the four different cycles. The participants consisted of children, spouses, grandchildren, siblings, in-laws, friends and neighbors of the elderly (58%), and some elderly people (42%). Some of the participants were involved in providing care to an elderly person (58%) while others were either anticipating a caregiving role in the future or elderly people who out of self-interest wanted to learn about their aging process. Over fifty percent of the participants (57%) were 51 years old with a concentration in the ages 61 to 70 (29%). Close to three-fourths (72%) of the participants were females. Sixty-four percent of them were born in Puerto Rico. The educational level of the participants was in general low, (only 30% had completed high school) and their annual income was also low (about 55% had incomes below $10,000).

Group participants throughout the cycles were expressive in their accounts of the caregiving experience, relationship with the elderly and personal problems. Group interaction and cohesion facilitated expression of feelings and sharing of problems among group members. Major common issues evolved in all cycles: relationship to the homeland, guilt, institutionalization, family responsibilities, communication problems, coping with their aging process, self-help and mutual-aid development and need

for individual services.

Final evaluation of the group experience by the participants demonstrated that the program was valuable in various aspects: information obtained on specific topics, understanding their own feelings and those of the elderly person, getting ready for their own aging, sharing and discussing problems with other group members and learning how to mediate with service agencies on behalf of the elderly person.

The next chapter will present conclusions, implications and recommendations for the development of caregiver groups.

CHAPTER VI

SUMMARY, CONCLUSIONS, RECOMMENDATIONS AND IMPLICATIONS

The project reported here has focused on strengthening the informal support system of the Hispanic elderly through a group program for caregivers and potential caregivers. Development of four cycles of the program with the participation of fifty-eight relatives, friends, and neighbors of the Hispanic elderly has produced important data on what is becoming an area of interest in gerontology: the need to support and enhance the informal support system of the elderly. This project has represented an attempt to better understand the caregiving situation of the Hispanic population: what is involved, what are the common issues of these caregivers, and how to design and develop programs to serve them better. Although limited in scope, its goal has been to contribute to the knowledge base needed for service providers and policy makers if they are to intervene appropriately in their attempts to support Hispanic families caring for an elderly relative.

The "Strengthening the Informal Support System of the Hispanic Elderly" can be considered a successful program in many respects. Although there were some implementation problems which affected the project, its outcome, based on the participants' evaluation was positive. The project provided valuable information about the informal support system of the Hispanic elderly and about the elderly served by the project.

One simple objective has been, namely, a service of benefit to

Hispanic relatives, friends and neighbors caring for an elderly person proved operationally feasible. Through this project a model of service to support and enhance the informal support system has been produced which may be useful for expansion and replication of caregiver groups with the Hispanic population. While the ability to generalize from the data is limited, the exploratory nature of the project does, however, make it possible to generate some conclusions and recommendations useful for practitioners in the field of aging.

The premises documented by the project are:

1. That a group approach is useful in strengthening the capability of Hispanic individuals to care for an elderly person;

2. That group development among individuals of Hispanic background, with emphasis on the mutual-aid/self-help concept, can be promoted;

3. That such a project can involve an underserved target population of low-socioeconomic and Hispanic background;

4. That non-agency caregivers can be given training and they do assume a significant role, along with agencies, to improve the care provided to elderly Hispanic individuals.

From ratings of the program participants, it was determined that the following objectives were met:

A. To increase the caregivers' understanding and knowledge of the aging process;

B. To increase the caregivers' understanding of the emotional reactions and needs of the older person;

C. To develop a greater awareness and sensitivity in the caregivers' responses to the aging process of their elderly relatives or friends;

D. To expand their knowledge of benefits and entitlements and improve access to community supports;

E. To improve dialogue and discussion of alternatives available to themselves and the aged person;

F. To increase their effectiveness in addressing the needs of the elderly by facilitating the development of support systems within the group.

SUMMARY OF MAJOR FINDINGS

1. Data indicate rather clearly the existence of an informal support system among the Hispanic elderly. This system is composed of relatives, friends and neighbors. The project gives further support to the growing body of evidence regarding the salience of family support to the elderly. Daughters, in-laws, sisters, grandchildren, spouses, friends and neighbors of the Hispanic elderly take primary responsibility in the caregiving role. Children represented over fifty percent of the caregiving population that participated in the project. Daughters represented 46 percent and sons represented 15 percent. Most of the participants were female (72%), married (57%), fifty-one years old and over (57%).

2. The study population comes from a predominantly low-income, near-poverty level population. For the most part, caregivers earned less than $10,000 per year (65%), with thirty-two percent earning less than $5,000. Only forty-four percent of the caregivers were working (full or part-time). The rest (56%) were unemployed, retired or students.

3. The typical aged person receiving care is likely to be over 70 years old (64%), living with the caregiver (47%), widow (38%), and receiving income from Social Security (39%) or Supplemental Security Income (39%).

4. Caregiving activities involve a variety of services ranging from emotional support, instrumental activities and financial assistance to linkage services. Emotional support emerges as the most frequent activity performed by the caregivers (91%). Instrumental activities were performed by the majority of the caregivers: shopping (65%), meal preparation (65%), light housecleaning (56%), laundry (44%), and personal hygiene (47%). Financial assistance does not emerge as a frequent help provided to the elderly. Over fifty percent (53%) of the caregivers were involved in negotiating with the formal system on behalf of the elderly.

5. Providing emotional support (25%) and providing personal care (25%) emerged as the most frequent problems mentioned by the caregivers in their caregiving role. It is significant, however, to note that more caregivers expressed lack of conflict in their caregiving situation than those who reported having any conflict. It is interesting, but not surprising among Hispanics, not to talk openly about their conflicts unless an atmosphere of trust is developed. This was the case at the beginning of the program, where only a few caregivers admitted in the initial interview that there were problems while taking care of the elderly person. As the group developed a sense of cohesiveness, the caregivers were more open to talk about their conflicts.

6. It is noteworthy that the use of formal services by the elderly population of the project is low. The services that the elderly person is receiving are: home attendant (44%), transportation services (47%), and visiting nurse (50%). No in-depth analysis was done to explore this underutilization of services. However, it is important to mention that the involvement of the informal system remains high; even

when the elderly are receiving these services from the formal organizations. For example, the presence of a home attendant does not exclude the caregivers involvement. The service most frequently mentioned as needed by the caregivers were home attendant services. It is clear that these caregivers are important resources for the Hispanic elderly, especially when lack of services from the formal system predominates. Through the caregivers a considerable number of linking and mediating functions are carried out.

7. The project was found effective in meeting the needs of the caregivers in two basic areas: educational and emotional support. The educational aspect was met through education on community resources and benefits and entitlements, problems and conditions related to the aging process, common and chronic illnesses in old age, sensory losses and communication problems, ways to improve skills in providing care to an elderly person, and skills in mediating with the formal system. The information provided to the group members regarding these specific topics was an important component of the group process. Through the information received, the apprehension and concern about the aged person were overcome by the caregivers. Such information proved necessary to facilitate decision-making regarding the availability and choices of service providers. Participants acknowledged their lack of information about services available, while some were hesitant to apply for services for fear of not qualifying. The mutual-aid/peer-support aspect was met through the sharing of problems, experiences and solutions, socialization, problems ventilation and support from others.

8. The project demonstrated that caregivers are more likely to be attracted to the group sessions and remain in them if provided with

concrete information from the outset. One basic characteristic of the group participants was their involvement in the program for educational reasons. The most frequently mentioned reason for participating was to learn about chronic illnesses and disabilities in old age (53%), followed by learning about community resources and benefits and entitlements (48%). The motivation to listen to other people who are providing care to an elderly person was mentioned by 41% of the participants.

9. Analysis of expressed satisfaction by participants reveals that at the end of the program the participants became aware of different community resources and furthermore, that the information about the aging process helped them a lot. Sixty-three percent of the participants considered the program helpful in these areas. Over seventy-five percent of the group participants (77%) mentioned that they had the opportunity to share and discuss their problems with other group members and that group interaction and sharing was an important aspect of the group program. Seventy-five percent of the members stated that they received support from other members. Evidently peer support was an important aspect of the group program. Through the group experience, the participants gained practical knowledge that helped them understand the aging process, understand their aging relatives' needs as well as their own feelings and actions toward these needs. In addition, the group provided an opportunity for the participants to express their shared concerns, to look for alternatives in dealing with these concerns, and to learn of community resources available to them.

10. From the record of participation and enrollment of those involved in the program, it was demonstrated that the assumed need for developing a group program to strengthen the informal support system of

the Hispanic elderly was correct. The finding that seventy-three percent of those who registered to participate in the program attended at least four of the sessions, sustains this point.

POLICY, ORGANIZATIONAL AND DIRECT PRACTICE CONSIDERATIONS

The project's findings suggest considerations in the areas of public policy, organization and direct practice.

Policy Considerations:

1. Filial Responsibility: The continued adherence to the value of filial responsibility is documented by the project. This finding is consistent with those of Adams (1968), Brody (1979) and Horowitz (1982), where obligation, love and reciprocity represent major components of the relationship between children and their elderly parents. One serious result of this is that in the situation of the Hispanic caregiving population, an excess of filial responsibility can sometimes block the perceived need for services, as for example, the need for institutional care. The adherence to the value of filial responsibility remains strong even where there is a geographic distance between children and parents. The project documents the cases of several daughters who left homes, jobs and family to be next to their elderly parent. Moreover, these women expressed no negative feelings about what they were doing. This is perhaps the purest example of "familism", the belief that the interests of the individual are subordinate to those of the family, that children have an obligation to be with their ill parents and that this responsibility is equal to that of a parent toward his/her sick child. Finally, this notion of "familism" places a greater emphasis on the instrumental and emotional aspects of caregiving than on financial obligations.

2. Disincentive Issue: Project findings sustain the notion that families do not diminish or give up their responsibilities when formal services exist. This was shown most clearly by those cases where families had obtained a home attendant or visiting nurse for their elderly relative and still maintained their former level of caregiving. The disincentive issue may become more significant however, when and if the rate of utilization of services by the Hispanic elderly and their families increases.

3. Ethnicity and Social Services: Although, in comparison to the general population, the Hispanic elderly are more likely to have functional children with whom they interact and from whom they receive a great and varied amount of help, it is clear that this ethnical attribute is on the wane. The project findings document the impact of the dominant culture on the Hispanic elderly who are affected by the strains of bridging the two cultures. And given that physical condition of the parents, and socio-economic status are the basic and long range determinants of aid from children to their parents, ethnicity overall will diminish in importance as an independent significant predictor of informal supports.

Yet while it remains significant, ethnicity can be a double-edged sword. Superficial assumptions about Hispanic ethnicity have resulted in built-in failures in the system. For example, the notion that the Hispanic family takes care of its own has impeded service providers from disseminating information concerning institutionalization. As a result, the needs of the Hispanic elderly are not being met. On the other hand, ignorance and/or disregard for Hispanic ethnicity have also resulted in flawed policy development. For example, the exclusion of

Puerto Rico from SSI and Medicaid payments has forced many Puerto Rican elderly to migrate from the island in order to receive these benefits. Similarly, the policy of paying lower SSI benefits to those who live in shared households, penalizes Hispanics.

4. Prevention Issue: One of the most significant aspects of the project was its documentation of the strong communitarian primary group tradition among Hispanics, especially as it relates to the care of the elderly. Public policy developers focusing on preventive caregiving should make churches and similar community oriented and informal institutions the target of their programs.

Organizational Considerations:

1. The project findings demonstrate that intermediary structures are useful vehicles for developing mutual-aid/self-help groups. Such structures take advantage of the latent strengths of the Hispanic family. For example, the effectiveness of Hispanic community churches in reaching primary groups is due to the reliance of the elderly on friends and neighbors to provide care, which in turn is a result of the belief that such care is a community responsibility. The use of intermediary structures as vehicles for developing mutual-aid/self-help groups is an approach that varies considerably from those which limit the use of these structures to the recruitment of volunteers and/or the assistance of natural supports.

2. Balance of Shared Functions: The theory of Shared Functions (Litwak:1965) provides a useful theoretical approach for looking at the relationship between the family and the formal service network in the care of the Hispanic aged. Explicit in this conception is the proposition that both primary groups and formal organizations are partners in

the care of the elderly. The project documents families performing tasks which were indicative of shared functions. Structurally, these families represent the extended family type and research has shown that families of this type are more able to share in the care of their aged members.

The theory of shared functions does not obscure the fact that formal organizations differ from primary groups in important functions and structural attributes. Moreover, it is these attributes which make the formal organization more efficient in the performance of some tasks, and the primary groups a more congenial environment for others. The project findings provide strong evidence in support of the assignment to the primary group (family, church) of tasks which are personally valued and sanctioned and which are designed to provide for the old person at a level above that which meets the socially sanctioned minimal and uniform level.

The analysis of the attributes of primary groups and formal organizations yields an assessment of their comparative capacities to perform certain tasks in maximal fashion. Logically, allocation of tasks required for the provision of care to the dependent old person should be a reasonably straight forward exercise. The formal organization has no substantial advantage over the primary group when expertise and professional knowledge are not required or of limited value. In the case of Hispanic families, the project demonstrates that families do need bureaucracies for services, that they are not really isolated, but that they are not being approached by bureaucracies in the right way (for example, the proper language--Spanish). In addition, the fact that these families receive a lot of support from the churches, predisposes Hispanics to rely

more on these types of primary groups and to minimize their use of formal resources.

Acceptance of the assumption of shared functions required that ways be developed which facilitate the coordination of the efforts of the primary groups and formal organizations in the fulfillment of the functions for which they share responsibility. The findings of the project indicate that an increase in the sharing of functions can be achieved through the education of primary caregivers.

Direct Practice Considerations:

1. Programming Considerations: In addition to demonstrating the effectiveness of group service, the project points out the need for supportive individual services to supplement group programs. The specific areas to be addressed through the individual assistance are benefits, entitlements, counseling and mediation with the formal support system.

As a result of the diversity within caregiving situations, it is necessary to identify a specific target population for outreach purposes and program development. Factors to be taken into consideration for group composition are: factors related to the older person receiving care, e.g., physical and mental deterioration, residence in the home of the caregiver or alone; factors related to the caregiver, e.g., relationship to the older person, demographic characteristics and size of the caring network; inclusion of one or several members of the caring network; and inclusion of the older person(s) of concern to the group.

Personalized outreach and clarity of outreach materials are important as there is a tendency to misinterpret the program as being for the aged rather than for the relatives of the aged. An effective outreach technique is the use of the older person of concern as the recruiter.

And finally, because among Hispanics, care of the aged is perceived as a community concern, outreach needs to focus not only on relatives, but on friends, neighbors and others in the community.

2. Learning Principles: The educational-learning component of the project demonstrates that care should be taken to insure that the atmosphere of freedom, stimulus, self-confidence and self-discipline necessary for learning, is present throughout the program. In order to do this, the following proved essential foundations for the learning-teaching component of the project:

--Relevancy: The adult caregiver attends a group program because the subject is part of his/her life. Since there is relevance, there is engagement.

--Relationship: The adult caregiver relates the learning to his/her experience.

--Responsibility: Once the adult caregiver enters the learning situation, he/she assumes an obligation to the subject of study, either at an intellectual or practical level or both.

--Andragogy: The project's findings sustain the relevancy of this theory of adult education to caregiver programs. Its relevancy consists, first, in that it recognizes the self-concept of an adult learner as a mature person, whose self-concept becomes less that of a dependent person and more that of a self-directed individual. Second, it considers the adult learner's life experience as hugh, varied and valuable to the learning process (e.g., case illustrations, role-playing and simulation exercises are relied on

heavily). Third, it views the adult learner as having a reciprocal relationship with the instructor and other learners and thus, takes into consideration the learner's feelings regarding the content and process of learning.

3. Hispanic Issues: Several programmatic considerations regarding Hispanics are raised by the project.

a) Language use is critical to the design and implementation of caregiver programs for Hispanics. The use of Spanish as the main language is demonstrated by the finding that second and third generation Puerto Ricans who participated in the project, expressed a preference for Spanish in verbal and written communication. At the same time, the inability of many participants to read and/or speak English hampered the dissemination of information about social services.

b) The development of the program evidences the existence of certain common issues in family caregiving by Hispanics which have implications for the development and content of similar programs:

- The significant role that the relationship with the homeland plays for both the elderly and the family;
- Expressions and feelings of guilt and hopelessness amplified by the stress of the caregiving role;
- Communication problems between members of different generations in the caregiving unit;
- Increased fear of the individual aging process as a result of the caregiving experience;
- lack of trust for the formal service provider, particularly fear that the elderly relative will not be understood or that services will not be provided properly;

- Unfavorable attitudes toward institutionalization of elderly members of the family;
- Need for individual services to supplement the group program.

c) The incorporation of education and training materials for Hispanic caregiver groups should focus on helping the families in their roles as caregivers and mediators of services. Specific topics should include chronic illnesses, the aging process, community resources, benefits and entitlements, communication problems, and emotional reactions to the caregiving role.

CONCLUSIONS

As the project evolved and the need to develop the program in different settings was demonstrated, it broadened its emphasis beyond the natural supports approach to include much more intensive work on mutual-aid and self-help with the Hispanic elderly themselves. Some observations on the project's results are presented:

First, it is difficult to organize groups through formal agencies because of their bureaucratic bottlenecks. Working through formal agencies means working with staff members and through written records, as was done with two of the project sites. Churches and more community-oriented organizations have proved very effective as vehicles for reaching primary groups in the Hispanic community, since the elderly rely more on neighbors or friends and are accustomed to primary groups and community-based organizations. The Hispanic community tends to use the Church and to prefer one-to-one help, rooted in the family and in the importance of visiting. On the other hand, it has proved necessary to use certain formal agencies--for example, home attendant agencies--in

order to reach the most sick elderly. This does not necessarily mean that a large number of caregivers will be found through this means, since usually the elderly Hispanic uses a home attendant as a last resort, when there is lack of family support.

Second, the self-help model utilized in the project represents an important use of mediating structures as a matrix for the organization of self-help efforts--a different thrust from using such structures for recruiting volunteers or for assisting natural support groups. The self-help approach represents an attempt to take special advantage of the latent strengths of the Hispanic family. The project also proved the need to develop self-help groups with seniors since they can also benefit from the information provided to the caregivers.

Other conclusions derived from the project are:

1. The findings that a range of relatives, friends and neighbors of various age groups are involved in providing care to an elderly Hispanic suggest the need for the inclusion of younger kin and friends in caregiver programs to enable them to share the caregiving links with more understanding. The range of ages and diversity of relationships also suggests that such diversity should be anticipated in planning caregiver programs for Hispanics.

2. Future programs should also be planned taking into consideration the needs of a large female caregiver cohort. The findings that females are the predominant caregiver figure in the Hispanic community supports this.

3. Because the role of caregiving is stressful and emotionally demanding in many phases, this project demonstrated the need for educating and training this population to sustain and enhance their capabilities.

Training in this context refers to providing information and support to the caregiver, assisting them in their natural familiar environment and reducing anxieties through a peer-support approach.

4. The group experience with relatives, friends and neighbors of the Hispanic elderly supports the view that this population does share similar experiences in the caregiving role and that they need support in doing it. The group process acted as a means of supporting and strengthening their activities. Based on the experience, some major needs of informal support networks were identified and services that can strengthen them:

   a. knowledge and access to community resources, benefits and entitlements;

   b. information about specific conditions in old age and skills related to their management;

   c. emotional support to cope with the stress created by the caregiving situation; and,

   d. home care and respite care.

5. Another major conclusion derived from the findings is the natural progression of the caregiver from the initial engagement in the program to obtain concrete information about services and specific conditions, to the use of peer support and engagement in self-help activities. During the process of obtaining the information, participants shared information concerning their own caregiving experiences, their problems and feelings. This resulted in the development of peer support and mutual aid.

6. The group program also filled an important mental health preventive function. The information provided concerning the aging process led to greater understanding of the emotional and physical aspects of aging and allowed the participants to examine their own attitudes

towards aging, not only of their aging relatives or friends, but of themselves.

7. Probably one of the most important outcomes of the experience was that members appeared to function better and that they reported that they had a better understanding of their situation and had found some relief in sharing with others. The group approach provided an opportunity for the participants to share their concerns, their needs and come to terms with some of their unresolved conflicts. This process is enhanced through a mutual sharing and bond of trust between members who are "in the same boat". The peer support gained through group participation is of value and self-help groups of caregivers can be formed to allow this source of mutual-aid to continue as needed.

RECOMMENDATIONS

Through the project, some recommendations have been produced that can be useful for expansion and implementation of similar projects.

1. The group experience must be designed to accommodate the special needs of each different group. For example, scheduling should take into account the availability of the participants, i.e., those who work, those who cannot leave the elderly person alone, or those who live in a high crime area. For these particular situations, scheduling the sessions on weekends, at daytime and providing some respite care or transportation should all be considered.

2. Several options exist for leadership of such groups. They can be facilitated by a professional group leader, by a staff person of the agency, or by co-leaders including resource persons. A professional

from outside of the agency often has a fresh perspective when dealing with group members. Such person is generally trained in group process and offers participants an opportunity to interact with outsiders. Although time consuming, a team approach between a professional and a staff person can combine the benefits of both and is usually recommended. The program should be conducted in Spanish.

3. The project experience suggests that group programs should be initiated by local community agencies, voluntary associations like churches, in areas with large concentrations of Hispanics. The rationale behind this is that such organizations would be better able to know who would benefit from the program. They know the clientele and their input would be more likely to lead to success in implementation, particularly in attracting group participants.

4. A secondary problem in outreach occurs when it becomes evident that the wrong agency has been selected as the center to develop the program. It proves difficult to recruit and select the participants. This points to the issue that an assessment of the agency should be made before implementing the program. People are more likely to participate or attend group programs if they are located or sponsored by local community groups, which already enjoy a high degree of visibility and respect and are recognized as an agency serving the Hispanic.

5. Highly publicized meetings do not usually assure good attendance especially with Hispanic populations. A more personalistic and individualized approach seems to be needed to attract Hispanics. Outreach efforts should include phone calls as well as letters and personal contacts whenever possible.

6. In designing a program for caregivers, attracting high numbers of participants seems to be a problem. Various reasons can be mentioned, in addition to the one previously cited regarding Hispanics. First, caregivers of the elderly generally do not recognize themselves as a distinct constituency. In general, they do not see themselves as a group in need of services. This suggests that flyers or outreach material should concentrate not on the term "caregivers" but should point more to "helping the older person". In addition, individuals who happened to be caregivers but not the primary user of a service of the agency, may have attitudes and values against asking or accepting social service help. Another issue that became clear in this project is that those who were providing care were not interested initially in peer support but wanted concrete information and specific help. The focus on education tends to attract greater numbers of people at the outset.

7. There seem to be certain conditions which appear to be more conducive to effective learning and training of caregivers:

a. The number of sessions should be predetermined, allowing for one or two extra sessions if requested by participants. Six sessions seems an appropriate number for many participants who might otherwise have difficulties in committing themselves to a longer period of time.

b. Eight to twelve group members is an optimum size for providing mutual-aid and support for members.

c. Numerous topics can be incorporated into this type of program, and those included in the project provide a framework from which adaptations can be made. Some examples of topics that have proven of interest are:

- physical and emotional aspects of the aging process
- common and chronic illnesses in old age
- sensory losses and communication problems
- emotional reactions to the elderly's and caregivers' aging process
- community resources, benefits and entitlements for the aged

The project has potential for replication and expansion incorporating some of these recommendations. The support group which has proven valuable for the participants can be replicated in many settings. The need is there, the material is available and there are organizations that can be counted upon to be responsive.

IMPLICATIONS

When we look at the situation of ill and impaired older people in the community, and at what they need in order to remain in their familiar surroundings, it is clear that they need an array of supports and services--financial help, clothing, shelter, personal assistance, emotional support and activities that at least occupy their days and more ideally, make lives worth living. If we look at this list, it is obvious that families, friends and neighbors are best able to do certain things while the responsibility for other tasks is best assigned to the formal organizations. For example, most older people rely on Social Security or Supplemental Security Income for their basic income, but families often provide extra money. Both contribute to the older person's standard of living and at the same time serve to articulate family devotion and responsibility.

In general, there is a division of labor between family and organizations. A corollary to this is that in general, the ill and impaired elderly does better if she/he has available to him/her both family and formal organizations. Families, particularly children, as demonstrated in the project, are extensively involved in the care of their elderly relatives and are carrying a major burden of support. It is important, however, not to view the family support system as one best left alone by the formal system. Clearly, the caregiving population needs the collaboration of the formal system. Especially in the case of the Hispanic, where

a strong familiar system still exists, and in these times of fiscal constraints, there is the danger of viewing the family support as a "cost effective" approach to the care of the elderly.

It is imperative, therefore, to use knowledge gained from this project in order to identify the most appropriate means to address the needs of the Hispanic elderly and their families. Caregivers in the project stated the need for more services and more coordination with the formal organizations. The need for the partnership to guarantee coordination is clear.

Experience obtained in the project points to the interrelationship of the service needs of the older person and of their relatives or friends and neighbors who form the informal support network. This suggests the desirability of an integration and coordination of the informal system and the formal network. Senior centers, home-care agencies and other service organizations should broaden their client focus to offer services targetted at the older person and his/her caregiver.

If we accept that the elderly impaired do better if there is coordination of effort between the formal and informal systems, then priority must be given to training of professionals for this collaborative relationship.

While the concept of the informal caregiving network is not new, there is little general knowledge of the specific roles, stresses, needs, and problems that caregivers face. There is a need for educating and training of health and social professionals. Current social work practice among the elderly does not, in general, focus on the family but rather on the adult child seeking guidance or the older person with functional limitations. Work with kin and other people involved in the informal helping

network of the elderly should become a primary element of the framework of social work practice in the field of aging. Lack of knowledge about the valuable role performed by informal support networks often means that professionals do not use the family and friends as a resource. Caregiver groups have proven to be effective in developing this commitment. However, education and training for these practitioners is needed and should include the following areas:

- assessment of the level of support which family, friends and neighbors provide to the elderly individual;
- how to mobilize self-help groups for service delivery;
- how to identify supporting people in the neighborhood and how to expand their functions (i.e., community churches).

Closely related to the need for education and training is the need to broaden the understanding of the term "caregiver" to include not only the children of the frail elderly, but the friends, neighbors, spouses, siblings, and other kin. Any service program designed for caregivers should include the older person's caregiver and the non-relative caregiver and should seek to provide services that will accommodate the needs of these groups.

There are implications for service derived from this project. The first point to emphasize is that we are dealing with two distinct target populations: the elderly and the caregiver. The elderly, due to their vulnerability to disabilities, have a set of needs and their caregivers, in the process of assisting them, have needs specific to the supportive role they have undertaken. This is not to say that services to support the aged (i.e., home attendant) do not relieve the burden of care for the caregiver. On the contrary, they do. However, the primary target of these services is the elderly, and more important, the eligibility criteria is based on the elderly aside from the resources of the

family. To this extent, it is imperative to realize that the older person will be in need of a number of supportive services, regardless of the availability of family supports (Monk: 1979). If the elderly are to remain in the community, there are a range of supportive services necessary such as home attendants, senior centers, visiting nurse, etc. By the same token, these supportive services are of help to the family, which is the first source of help to the elderly. The two most frequently cited needed services for the elderly are homemakers and transportation services.

The second target population--the caregivers--have unique service needs derived from the caregiving responsibilities they have undertaken. Occasional periods of relaxation and time to attend to personal interests are crucial in alleviating the stress involved in caring for an elderly person. Although specific mention of this matter was not made at the initial interview with the project participants, the importance of some respite care was mentioned during the group meetings. Restrictions on time and freedom appears as one of the most common problems mentioned in providing care to an elderly person, and respite services, emerges as the most common service identified as needed to help the caregivers in their role. Respite services should be available to families at least on a monthly basis at minimal or no cost.

Caregivers also seek information, advocacy, peer support, and help in coping with their caregiving role. Even with the presence of supportive social services to the elderly, the physical and emotional burden remains with the caregiver. Emotional support emerges as the most frequent service provided by the caregiver to the elderly, but is also mentioned as the most difficult task. It is, in addition, an

assignment that cannot be easily undertaken by the formal service. Group programs are an effective means of helping the caregivers in fulfilling this task, via education and support to cope in general with the emotional strain of providing care to an elderly relative. Mutual support from other caregivers is of great value in this respect. Horowitz' findings (1982) suggest that development of self-help groups and training programs for caregivers should be encouraged and supported. Many of the respondents in her study felt isolated and believed that they were faced with problems unique to their particular situations, yet their efforts were going unrecognized. There was willingness on the part of the caregivers to spend time talking about their concerns and fears.

Consideration must be given to developing services to aid caregivers through the formal system in addition to using the resources of local communities through the mediating structures. Close work needs to be done with religious organizations to develop and assist projects to help caregivers. The church provides a base of support for individuals and an array of services to families and their communities. These organizations should be used as training or sponsor sites for caregiver programs. As policy-makers and agency workers devote increasing attention to informal and community supports for the elderly, the role of the local community church should not be forgotten. Built on a set of shared values, ongoing contacts between members, and an exchange of help among the congregation, churches fulfill important functions of service delivery, emotional support, and opportunity for individuals to gain a sense of belonging. This intra-community approach is viable in dealing with Hispanic populations based on cultural acceptability.

Finally, inherent strengths exist in the Hispanic informal support

system. For this reason, human service providers should not undermine a system of service delivery that has always existed. At the same time, however, human service providers should not use the existence of a natural support system as a pretext not to provide services. The natural support systems should be supported and should be the focus of study and research. There is a lot to learn about how Hispanic culture has managed to support its elderly and frail members amid all the constraints they encounter.

To summarize, the necessity for a group program to strengthen the informal support system of the Hispanic elderly has been made evident. The program content and design fit the needs of the participants and can be utilized for future programs.

The development of the program according to its goals resulted in a challenging and at the same time, rewarding task professionally as well as personally. Personally, it was a means to serve the Hispanic community, particularly Puerto Ricans, and offer it a service which indirectly benefits the elderly. Professionally, the knowledge gained regarding the needs of the Hispanic elderly and their relatives has served as a stimulus to continue working for the well-being of this community.

APPENDICES

Appendix A

SAMPLE OF A GROUP SESSION

Natural Supports Program for Hispanic Caregivers: Cycle I

Group Program at CABS Nursing Home
Fourth Session: May 2, 1982 3:00 P.M.

Topic: Special Reactions to Aging
Dealing With Our Feelings

Participants: Maria, Evelio, Luz, Ana, Georgina
(Ana is new, Luz was absent in the previous session
Irma and Lissette are absent today)

Evelio and Maria were the first ones to arrived at the meeting. They were followed by Luz. Georgina came with Ana and introduced her as a member of the church she goes to and a personal friend. Ana explains that she is not taking care of an elderly person but has many friends and relatives who are old and would like to know about aging. A brief summary of the previous sessions as well as material handed out were given to Ana. The topic of discussion for the session was introduced and in order to get a feeling of the member's opinions about being old, they were asked to describe what it meant to them to be old. Their answers were later given value in terms of positive and negative aspects. The first one to answer was Maria and she said that for her being old was a punishment. She said that: "You are punished because you have a lot of problems when you are old and you also give problems to the people near you". Evelio responded by saying: " That is not so, it varies from person to person, and life is not a punishment" Maria went on saying that her personal view of aging was that and that one should die before getting to be frail and not healthy. "One should only live to certain age, although if you have money things are different. If you can pay for services you do not become a burden on your family."

Evelio said that there are differences in how people aged as was mentioned in previous sessions. "There are some persons that the more they live the more attached they become to life." Ana mentioned that she is getting old and she does think of old age as a bad stage in life. She have many aged people around her whom she like to talk to and help. Evelio described the aging process as a natural thing, it happens to every one. He mentioned that his mother is not depressed because she is old. She enjoys watching T.V., listening to music, talking to people, and reading. "She is old because she reached certain age, but she does not feel she is finished." Evelio went on to describe that how we feel about being old depended on our experiences and many factors influence or perception.

Ana said that there were some old people that were always crying and had become very sentimental over time, "some act like children ."

Evelio mentioned that health is one of the most important factors in old age.."being healthy makes a difference."

Georgina replied that some people just did not accept getting old while there were others who felt proud of their age and accepted it as natural. "I know many persons in their 70s who are very active in the community, they get together with their friends to socialize and they do not sit around to wait for the end."

The discussion led to analize their description of old age in terms of positive and negative characteristics. It was mentioned that the aging process involved different aspects and how everyone viewed aging influenced their own aging process because of the individual differences.

Evelio mentioned that although his mother had some physical problems that limited her in many ways, she loved being alive. "She never misses a medical appointment, and she goes to the doctor because she wants to live longer."

Luz described the person she takes care of as very attached to life, ..."she likes to feel independent, likes to dress up, make up and go out if possible." But on the other hand she has a sister who is only 50 years old and is always home, and feels and act as if she were 90 years old.

Each member presented material which described their perception of old age and description of how they view other people reacting to being old. The discussion moved to the topic of feelings towards their caregiving role. The project director briefly mentioned some of the feelings that come into play when we are taking care of an elderly person and asked members to comment on their own experiences.

Maria touched immediately on one universal theme when she described the round-o-clock nature of the caregiving situation. She mentioned that " although she is not taking care of an elderly relative, she knows of personal friends and relatives who are involved in this role and this is one of the reasons why she condidered being old as a punishment not only to the old person but to the relatives who have to take care of them. Everyone experienced the time consuming or restricting demands of the frail elderly relative to a greater or lesser extent.

Evelio felt particularly burdened by his mother's constant demands for attention. He described that sometimes she would find everything he does for her wrong. He mentioned a situation that happened during the week in which his suggestion in dealing with a situation was not accepted and at the end his mother admitted she was wrong. His mother "would not agree with what I say, but whatever my brother does is right." Evelio explains that his brother who is younger than him, "has been my mother's favorite always." His brother is very sick at the present

time , but when he was younger they had problems because of the mother being more attached to Evelio's brother than to him. Evelio has always lived with his mother or close to her.

Maria mentioned that in her family she had the same situation where the mother always demonstrated more affection "to my siblings which pushed me out of my house at a young age" She left her country (Colombia) when she was 17 years old and came to the United States with some relatives. Maria blames her mother for that decision and she shows anger while talking. Some group members were very supportive of her while she was talking and commented" It must have been a hard decision to leave your country at such age and come to a different country!"

Evelio mentioned that he has lived with his mother or close to her in Cuba (25 years ago) and since they have been in the United States. He was married for a short time before marrying Maria five years ago.He moved : with Maria but has always managed to live close to his mother. He visits her everyday or calls her if unable to visit. He has not worked for the past seven years because of physical problems. But he receives Social Security. Evelio stated that he feels responsible for his mother because she does not have other relatives in the United States except him and his brother (who is in an institution). He commented that his mother is very demanding of his time and would call him over the phone for everything, eventhough she has a 24 hour home attendant. Sometimes Evelio feels annoyed when he has to leave whatever he is doing to attend the so called "emergencies" of his mother. He mentioned that he can never make plans to go outside of the city because he is afraid something might happen to his mother while he is away. This situation has created conflict in his relationship with Maria who wishes that they could go away on a trip.

Georgina identified with the situation described by Evelio. She described her mother-in-law as very demanding but at the same time refusing to be helped. She described her mother-in-law as a person who was very independent and active and had not been aboe to accept her present illness. Georgina's husband (only child) is very attached to his mother and worries a lot about her to the extent that he does not sleep well at nights. His father, who is much younger than his mother has a history of mental illness. Manuel is very concern that his father might neglect taking care of his mother.

This discusion brought into higher resolution the emotional conflicts which are part of the caregiving role. Sympathy for the person whom they were taking care of seemed to increased the guilt they felt when they become frustrated and angered by the demands of the elderly person.

Georgina also admitted to the anxieties that one's one aging process creates in connection with seeing other people grow old and frail.

One of the things shared by the group members was how hard the caregiving role was made by the fact that whole responsibility for the caring seemed to fall on one person's shoulders. Both Evelio and Georgina mentioned the fact that they were the main person providing care to their relatives,

in part because they were only child (as in the case of Georgina's husband) or had always been in that role (as in Evelio's case).

Georgina also mentioned the frustration she feels when she would like to do more for her mother-in-law and feels her hands tied.

Another source of anger and frustration mentioned by the group members was the fact thact decision-making as it related to the elderly rested mainly on the caregiver while other family members might critizise the decision. Evelio mentioned that when his mother began having physical problems, his brother suggested a nursing home and Evelio becam very upset refusing to consider that option. He said he would do whatever was necessary to keep his mother at home.

Luz mentioned that some children are very attached to their parents and get overwhelmed by the caregiving role but there were also many children who just forget that their parents exist. She used the case of the person she takes care of as an example. Evelio commented that no matter how upset he might become he would never neglect his mother.

Fear was mentioned as another common feeling among members. Georgina talked about her husband checking on his mother every day because of fear that something might go wrong. He does not trust his father as is afraid that when he goes out shopping his mother might fall. Georgina added that this is unfair to Manuel's father because he needs to go out and is also overwhelmed by the demands of his wife.

The members shared different concerns with the difficult feelings involved in the caregiving role. They also shared their different experiences and emotions involved toward their other family members.

Some members found extremely helpful to have shared the feelings with other members. Evelio commented that he had been helped while sharing his feelings and problems with the other members and felt he was not alone. He also mentioned that he rarely mentioned how he felt to others.

The project director emphazised that beyond sharing experiences and feelings which was itself important, the exploration and development of posibilities of constructive changes in the situations of them as caregivers was an essential capacity of the group. Evelio commented that he shares the information received in the meetings with other people.

The meeting ended with a reminder of the next meeting's topic: community resources, social services and alternatives in dealing with the formal system in behalf of the elderly.

Appendix B

CERTIFICATE OF PARTICIPATION

Brookdale Center on Aging
of
Hunter College

CERTIFICADO DE PARTICIPACION

es otorgado a

_____

en reconocimiento por haber completado satisfactoriamente el

TALLER PARA FAMILIARES, AMIGOS Y VECINOS

DEL ENVEJECIENTE HISPANO

auspiciado por Brookdale Center on Aging of Hunter College

Dado este dia _____ *del mes de* _____ *del* _____

Rose Dobrof, DSW
Executive Director
Brookdale Center on Aging

Carmen Sanchez
Project Director
Brookdale Center on Aging

Appendix C

HANDOUTS FOR GROUP SESSIONS

HANDOUT FOR GROUP MEETINGS

Item	Session
1. Program content (Spanish)	1
2. Role playing situations (Spanish)	1
3. Minorities and how they age (Spanish-English)	1
4. You and your aging parents (Spanish-English)	1
5. Physical and psychological changes in old age (Spanish -English)	1
6. Physical and emotional aspects of aging (Spanish)	1
7. Common and chronic illnesses in old age (Spanish-English)	2
8. What do we know about aging (Spanish-English)	2
9. Senility: Myth or Madness(Spanish-English)	2
10. Organic Brain Syndromes (Spanish-English)	2
11. Behavioral changes in O.B.S. (Spanish-English)	2
12. High Blood Pressure (Spanish-English)	2
13. Arthritis (Spanish-English)	2
14. Diabetes (Spanish-English)	2
15. Cold-Heat,and Aging (Spanish)	2
16. The accidents and the aged (Spanish-English)	2
17. Finding good medical care for the aged (Spanish-English)	2
18. Safe use of medications (Spanish-English)	2
19. On medications (Spanish-English)	2
20. How to help the elderly in communicating with the doctor (Spanish-English)	2
21. Vision (Spanish-English)	3
22. Hearing (Spanish-English)	3
23. Memory Aids (Spanish- English)	3
24. Communication: Have your tried listening? (Spanish-English)	3
25. Ways to improve our communication with the elderly (Spanish)	3
26. Therapeutic elements in listening (Spanish)	3
27. The value of reminiscence (Spanish-English)	3
28. Dealing with our feelings (Spanish)	4
29. Taking care of other people (Spanish)	4
30. Where should our elderly live (Spanish)	5
31. Tips in applying for help. (Spanish)	5
32. Whre to look for help (Spanish-English)	5
33. Food Stamps (Spanish)	5
34. Medicare (Spanish)	5
35. Medicaid (Spanish)	5
36. Supplemental Security Income (Spanish)	5
37. Con Edison Flyers (Spanish)	5
38. Department for the AGing services (English)	5
39. Home Energy Assistance Program (Spanish)	5
40. Puerto Rican Institute for Older People (Spanish)	5
41. Caregivers Network	6
41. Certificate of participation	6

Appendix D

QUESTIONNAIRE FOR PARTICIPANTS (SPANISH)

PROGRAMA DE GRUPO PARA PERSONAS HISPANAS CON ENVEJECIENTES

Explicación del cuestionario:

El propósito de este cuestionario es conocer sobre la experiencia suya bregando o cuidando de un anciano. Nos proveerá información que utilizaremos para evaluar el programa y para entender mejor cuales son sus necesidades y preocupaciones. Nos ayudará a desarrollar una imágen de como Usted brega con sus familiares y amigos ancianos, cómo se siente y qué cree de los problemas del envejeciente. También nos ayudará para adaptar el programa a sus necesidades.

Toda la información de este cuestionario será utilizada solamente para fines del programa y las contestaciones serán confidenciales, sin usar nombre. Consideramos sus respuestas muy valiosas y le agradecemos que conteste todas las preguntas que se apliquen a su caso. Si necesita ayuda, puede esperar hasta que comience el programa y tendré mucho gusto en ayudarle.

MUCHAS GRACIAS

Comenzaremos la entrevista con alguna información general sobre Usted y su familiar envejeciente.

1. ¿Cuida Usted de alguna persona anciana? _____Sí _____No
   (Si contesta no a esta pregunta favor pasar a la página 5)

2. ¿Qué parentezco tiene Usted con el anciano(a)?_____

3. ¿Qué edad tiene el anciano(a) _____

4. ¿Cuál es el status civil del anciano(a)?:

   _____ Casado(a) _____ Separado(a)

   _____ Viudo(a) _____ Divorciado(a)

   _____ Soltero(a)

5. ¿De dónde recibe ingresos el anciano(a)?:

   _____ Seguro Social

   _____ S.S.I. (SEguro de Ingreso Suplementario)

   _____ Pensión (Veteranos, Gobierno, Etc.)

   _____ Inversiones (Rentas)

   _____ Ayuda de familiares

   _____ Otro tipo de ayuda (Especifique)_____

6. ¿Con quién vive el anciano?:

   _____ Con el entrevistado

   _____ Con esposo(a) (Marque ambos si entrevistado es esposo a)

   _____ Sólo (a)

   _____Con otros familiares (Si es así, ¿Con quién? _____)

   _____ Otro tipo de arreglo

7. ¿Se considera Usted el principal proveedor de cuidados al anciano(a)?

   _____ SI _____ NO

   (Si no es así, ¿Quién es el que más cuidados provee? _____)

3. ¿Qué cosas hace Usted por su familiar o amigo anciano? (Favor de indicar con una marca el tipo y frecuencia de la actividad)

Actividad	Nunca	Diariamente	Una vez semanal	Una vez mensual
a. Ir de compras para artículos personales y comida	____	____	____	____
b. Preparar Comidas	____	____	____	____
c. Hacer limpieza liviana (Barrer, fregar, sacar basura, etc.)	____	____	____	____
d. Hacer limpieza pesada (Lavar pisos, ventanas)	____	____	____	____
e. Suministrar o supervisar medicinas	____	____	____	____
f. Ayudar en lavado y planchado de ropa	____	____	____	____
g. Ayudar o supervisar en el cuidado personal (vestirse, bañarse)	____	____	____	____
h. Contribuir dinero a los gastos del hogar	____	____	____	____
i. Ayudar en manejo de cuentas (Pagar cuentas, cambiar cheques)	____	____	____	____
j. Proveer ayuda en la transportación (Llevar a citas, agencias, etc.)	____	____	____	____
k. Visitar, hablar por teléfono, darle compañía (Apoyo emocional)	____	____	____	____
l. Mediar con las agencias	____	____	____	____
m. Traer a la casa por fines de semana	____	____	____	____
n. Otro tipo de ayuda (Describa: _____	____	____	____	____

8. ¿Cuál de las cosas que Usted hace encuentra más difícil?_____

_____

_____

_____

9. ¿Cuáles han sido algunos de los problemas más serios a que se ha enfrentado al ayudar a su familiar o amigo anciano?

_____

_____

_____

_____

10. Leeré ahora una lista de situaciones que mucha gente se enfrenta cuando cuidan de una persona de mayor edad. Para cada una de ellas, dígame por favor si Usted la ha experimentado MUCHO, POCO o NADA:

	MUCHO	POCO	NADA
a. El tiempo que le dedico a mi familiar o amigo me quita del tiempo que debo dedicar a otros miembros de mi familia.	____	____	____
b. No disfruto de actividades en mi tiempo libre por el tiempo que le dedico a mi familiar o amigo.	____	____	____
c. El tiempo que dedico a mi familiar o amigo interfiere con mi trabajo.	____	____	____
d. La preocupación por mi familiar o amigo me afecta la salud.	____	____	____
e. El tiempo que paso ayudando a mi familiar o amigo no me permite hacer las tareas de la casa.	____	____	____
f. No puedo comprar todas las cosas que quiero por el dinero que gasto en mi familiar o amigo.	____	____	____
g. Me preocupa envejecer.	____	____	____

11. ¿Cuál diría Usted que es el problema más serio a que se enfrenta su su familiar o amigo en este momento?

_____ - _____

_____

_____

_____

12. ¿Qué servicios de agencias recibe su familiar o amigo en la actualidad?

	SI	NO
a. Consejería	___	___
b. Servicios de escorta	___	___
c. Transportación	___	___
d. Reparaciones en el hogar	___	___
e. Visitas amistosas	___	___
f. Apoyo telefónico	___	___
g. Servicios legales	___	___
h. Servicios de Cuidado Personal	___	___
i. Ayuda para ir de compras	___	___
j. Limpieza en el hogar de tipo liviano	___	___
k. Ayuda en el lavado y planchado de ropa	___	___
l. Ayuda económica	___	___
m. Ayuda en el hogar con asuntos de salud	___	___
n. Ama de llaves	___	___
o. Enfermera Visitante	___	___
p. Comida sobre ruedas	___	___
q. Centro de Ancianos	___	___
r. Otro servicio (Describa)		
_____	___	___

13. ¿Qué otros servicios podría Usted utilizar para ayudar al anciano(a)?

_____

_____

_____

_____

14. ¿Hay otra persona ayudando al anciano(a) además de Usted? ¿Quién? ¿Qué cosas hace por el)la? (Refiérase a otros familiares)

_____

_____

_____

_____

_____

15. ¿Está algún vecino o amigo ayudando al anciano(a)? ¿De qué manera?

_____ _____

_____

_____

_____

Las contestaciones a las próximas preguntas nos ayudarán a describir las personas que se preocupan o están envueltas cuidando ancianos. Se refieren a personas como Usted.

16. ¿Qué edad tiene Usted?

17. SEXO _____F _____M

_____

18. ¿Cuál es su status civil?

_____ Casado(a)

_____ Soltero(a)

_____ Viudo(a)

_____ Divorciado(a) Separado(a)

19. ¿Dónde nació? _____

Si nació fuera de Estados Unidos, ¿Cuánto tiempo lleva aquí?

_____ _____

20. ¿Hasta qué grado fué a la escuela?

_____ Ninguno
_____ Escuela Elemental o Intermedia
_____ Cursos de Escuela Superior
_____ Graduado de Escuela Superior
_____ Cursos de Colegio
_____ Graduado de Colegio o Diploma Profesional

21. ¿Trabaja Usted?

_____ Tiempo completo
_____ Tiempo parcial
_____ Otro _____
_____ Retirado
_____ Desempleado

22. ¿Cuál es su ocupación? _____

23. ¿Cuál es el ingreso anual de su familia? (Opcional)

_____ Menos de $5,000
_____ $5,000 a $5,000
_____ $5,000 a $10,000
_____ $10,000 a $15,000
_____ $15,000 a $20,000
_____ Sobre $20,000

Ahora nos gustaría obtener alguna información sobre el programa que vamos a desarrollar:

24. ¿Cómo se enteró del programa?

_____ Recibí anuncio por correo
_____ Me refirió el personal de la agencia
_____ Me enteré por un familiar o amigo
_____ Otra forma _____

25. ¿Qué razones tiene para querer participar en el programa?

a. Aprender sobre las enfermedades crónicas y las incapacidades de la vejez. _____
b. Aprender sobre derechos y beneficios del anciano. _____
c. Aprender sobre las reacciones y necesidades emocionales de las personas ancianas. _____
d. Compartir mis experiencias con otras personas _____
e. Aprender sobre recursos y programas en la comunidad _____
f. Oir de otras personas que cuidan ancianos. _____

26. ¿Cómo cree Usted que este programa puede ayudarle a Usted o su familiar?

_____

_____

_____

_____

27. ¿Qué cosas le gustaría que se discutieran en las reuniones?

_____

_____

_____

Nos gustaría saber qué día y hora es más conveniente para Usted asistir a las reuniones. Favor de indicarlo en orden de preferencia.

Día	Hora
_____	_____
_____	_____
_____	_____

MUCHAS GRACIAS POR SU COOPERACION

Appendix E

QUESTIONNAIRE FOR PARTICIPANTS (ENGLISH)

GROUP PROGRAM FOR HISPANIC CAREGIVERS: QUESTIONNAIRE

STATEMENT OF EXPLANATION:

The purpose of this interview is to learn about your experience as a caregiver. It will provide us information which will be used to evaluate the program and to better understand your needs and concerns regarding it. It will help us to develop a picture of how you are dealing with your aged friend or relative, what some of your feelings and beliefs are about related issues and adapt the program to your needs.

All information given in this interview will be only utilized for the purpose of the program and all your responses will be treated confifentially, no names will be used at any time. We consider your responses to be of great value and are greatful for your cooperation.

Do you have any questions before we begin?

We will begin the interview with some general background questions about you and your older relative.

1. Are you taking care of an elderly relative or friend? ___Yes ___No
   (If the answer is NO, go on to page 5)
2. What is your relationship to the older person? _____
3. How old is your _____? _____years old.
4. What is the marital status of your _____?
   _____ Married _____ Separated
   _____ Widowed _____ Divorced
   _____ Single _____ Other (_____)
5. Does your _____ receive income from:
   _____ Social Security ?
   _____ SSI (Supplemental Security Income)?
   _____ Pension?
   _____ Investments?
   _____ Financial help from relatives?
   _____ Other? (_____)
6. Who does your _____ live with?
   _____ Lives with respondent
   _____ Lives with spouse (Check both if respondent is spouse)
   _____ Lives alone
   _____ Lives with other family members (If so: Who? _____)
   _____ Other arrangement _____
7. Do you consider yourself to be the principal caregiver for your _____?
   _____ Yes _____ No
   (If NO: Who is the principal caregiver? _____)

8. What type of things do you do for your _____? (Please check type and frequency)

Activity	At least daily	At least weekly	Less than weekly
a. Shopping for personal items and food	_____	_____	_____
b. Meal preparation	_____	_____	_____
c. Lignt housecleaning (dishes, dust, etc)	_____	_____	_____
d. Heavy housecleaning (windows, floors, etc)	_____	_____	_____
e. Administer or supervise medication	_____	_____	_____
f. Laundry	_____	_____	_____
g. Personal hygiene (bathing, clothing,etc)	_____	_____	_____
h. Financial assistance	_____	_____	_____
i. Help manage finances (cash checks, pay bills)	_____	_____	_____
j. Assist in tranportation	_____	_____	_____
k. Emotional support (visit, phone,etc.)	_____	_____	_____
l. Mediate with agencies	_____	_____	_____
m. Bring home for weekends	_____	_____	_____
n. Other (Describe)_____ _____	_____	_____	_____

9. Which of the things you do, do you find most difficult? _____

_____

_____

_____

_____

10. What have been some of the major problems you have faced in helping your _____?

_____

_____

_____

_____

11. I will read you now a list of situations which many people say they face while helping an older relative. For each of these statements please tell me whether you experience the situation A LOT, A LITTLE, or NOT AT ALL.

	A lot	A little	Not at all
a. The time I am devoting to my relative is depriving other family members of time which should be spend with them	____	_____	_____
b. I am unable to enjoy enough leisure time activities because of the time I devote to my older relative	____	_____	_____
c. The time I devote to my older relative is interfering with my job	____	_____	_____
d. Worry about my relative is interfering with my health	____	_____	_____
e. Time spend helping my older relative is keeping me from doing my own housework	____	_____	_____
f. I am unable to buy all I would want for myself or my family because of the expenses I incur in behalf of my relative	____	_____	_____
g. I worry about my own aging	____	_____	_____

12. Which is in your opinion your _____'s major problem at the present time?

_____

_____

_____

_____

13. What services from agencies is your relative or friend receiving at the present time? (Please check)

Services	YES	NO
a. Counseling	___	___
b. Escort services	___	___
c. Transportation	___	___
d. Home repairs	___	___
e. Friendly visiting	___	___
f. Telephone reassurance	___	___
g. Legal services	___	___
h. Personal care services	___	___
i. Shopping assistance	___	___
j. Light housecleaning	___	___
k. Laundry	___	___
l. Financial assistance	___	___
m. Home health aid	___	___
n. Home attendant	___	___
o. Visiting Nurse	___	___
p. Meals-on-wheels	___	___
q. Senior Center	___	___
r. Other (Specify) _____	___	___

_____

14. What other services could you use to help your _____?

_____

_____

_____

_____

_____

15. Does anyone else besides you, help your _____? What other relatives are involved in his/her care and what do they do?

_____

_____

_____

_____

16. Are there are any neighbors or friends involved in caring for your _____? How do they help?

_____

_____

_____

_____

Answers to the following questions will help us describe those who are concerned about or providing some care to an elderly person. They refer to persons like you.

17. How old were you in your last birthday? SEX: ___F ___M
_____ years old.

18. What is your marital status?

____ Married ____ Single

____ Widowed ____ Divorced/Separated

19. Where were you born? _____ _____

If born outside of the U.S., How long have you been in the U.S.?

_____years

20. What is the highest level of education completed?

_____ No school _____ High School Graduate

_____ Junior or Grade School _____ Some College

_____ Some High School _____ College Graduate or Professional Diploma

21. Are you employed?

_____ Full Time _____ Retired

_____ Part Time _____ Unemployed

_____ Other _____

22. What is your occupation? _____

23. What is your family annual income?

_____ Less than $3,000	_____ $10,000 to $15,000
_____ $3,000 to $5,000	_____ $15,000 to $20,000
_____ $5,000 to $10,000	_____ More than $20,000

Now we would like to know some information concerning the group program.

24. How did you learn about the program?

_____ Received announcement through the mail

_____ Referred by agency's staff

_____ Informed by a friend or relative

_____ Other _____

25. What are your reasons for attending the program?

	YES	NO
To learn about chronic illnesses and disabilities in old age	___	___
To learn about benefits and entitlements for older people	___	___
To learn about emotional reactions and needs of older people	___	___
To share my experiences with others	___	___
To learn about community resources and services for older people	___	___
To hear from other people who are caring for an older person	___	___

Other_____

_____

26. How do you think this program can help you or your older relative?

_____

_____

_____

_____

27. What things would you be interested in discussing in the group meetings?

_____

_____

_____

_____

We would like to know what is the most convenient time and day for you to attend the meetings. Please give three options in order of preference.

	DAY	TIME
1.	_____	_____
2.	_____	_____
3.	_____	_____

THANK YOU VERY MUCH FOR YOUR COOPERATION.

Appendix F

GROUP OBSERVATION

GROUP OBSERVATION

Date:_____ Place:_____

Session Number:_____ Hour:_____ Duration:_____

Participants: Indicate number in each category.

Total present:_____ Male:_____ Female:_____

Total Absent:_____

New Members (if any)_____

Topic of session:_____

_____

_____

_____

Was the topic covered?_____

Actual number of participants: _____

(Indicate Participation of members in discussion, contributions, Etc).

Process: Describe what happened, who participated, how, services request how handled, emotional responses, involvement, communication among members, attitude towards ending session or limitation of time. To what extent are they critical, to what extente they begin to network after intervention, individual requests after session,etc.

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Appendix G

PROGRAM EVALUATION BY PARTICIPANTS (SPANISH)

Evaluación del programa de grupo por participantes

Para poder planificar y mejorar programas futuros, nos gustaría conocer su reacción al programa en que participó. Favor de indicar de indicar el número de sesiones a que asistió y evaluar en base a eso. Sus respuestas se mantendrán confidenciales y anónimas. Muchas gracias por su cooperación.

---

1. ¿A cuántas sesiones asistió?

_____sesiones

2. ¿El asistir a las reuniones fue problemático o le causó inconveniencias?

_____ Ningún problema _____un problema moderado

_____ Un poco de problema _____Un gran problema

Si fue problemático, ¿Qué le causó problemas? _____

_____

_____

_____

3. ¿Considera Usted que el programa le ayudó de alguna forma en su vida personal, o sea en algunas areas de su vida?

_____Sí _____No

Si fue de ayuda, podría indicar en qué aspectos le ayudó?

_____

_____

_____

_____

Si no le ayudó, favor de indicar en qué forma no fue de su agrado el programa, o en qué forma se sintió defraudado, para mejorar el programa:

_____

_____

_____

_____

_____

_____

4. ¿Qué aspectos del programa encontró de más ayuda? Por favor enumérelos en orden de preferencia:

_____Información sobre enfermedades de la vejez, enfermedades crónicas e incapacidades.

_____Conocer sobre beneficios y derechos de los ancianos (SSI, Medicaid, etc).

_____Conocer sobre recursos disponibles en la comunidad

_____Compartir y discutir los problemas de cuidar de un anciano con otras personas que se encuentran en la misma situación.

_____El material que se repartió en las reuniones.

_____Aprender cómo obtener servicios de las agencias.

5. Ahora me gustaría que me dijera si la experiencia de grupo fue de mucha ayuda, alguna ayuda o ninguna ayuda en las siguientes áreas. Favor de indicar una en cada área:

	Mucha ayuda.	Poca ayuda	Ninguna ayuda
a. Aprender como otras personas bregan con sus familiares ancianos	____	____	____
b. Mejorar mi comunicación con mi familiar anciano.	____	____	____
c. Entender más las quejas de mi familiar anciano .	____	____	____
d. Establecer contacto con otras personas que cuidan ancianos.	____	____	____
e. Sacar cosas para afuera (Ventilar problemas o preocupaciones) .	____	____	____
f. Entender mi propio proceso de envejecer.	____	____	____
g. Conocer donde empezar a buscar ayuda para mi familiar anciano o para mí.	____	____	____
h. Conocer sobre enfermedades de la vejez y cómo bregar con ellas	____	____	____
i. Entender las pérdidas que ocurren en la vejez.	____	____	____
j. Expresar sentimientos y emociones en relación a mi experiencia de cuidar un anciano	____	____	____

	Mucha ayuda	Poca ayuda	Ninguna ayuda
k. Aprender sobre asilos de ancianos.	_____	_____	_____
l. Aprender a bregar con conflictos familiares.	_____	_____	_____
m. Aprender a dar atención a mis necesidades y las de mi familia.	_____	_____	_____
n. Aprender sobre la confusión en las personas de mayor edad.	_____	_____	_____
o. Oportunidad de hablar sobre mis frustraciones.	_____	_____	_____

6. ¿Cree Usted que tuvo la oportunidad de compartir sus experiencias y/o problemas como proveedor de ayuda al anciano, con otros miembros del grupo?

_____Sí _____No

7. ¿Encontró que los miembros del grupo fueron de apoyo en alguna forma?

_____Sí _____No

¿ Porqué ? _____

_____

_____

_____

8. ¿Ha mantenido contacto con otros miembros del grupo fuera de las reuniones?

_____Sí _____No

9. ¿Cree que seguirá viendo a otros miembros?

_____Sí _____No

10. ¿Le interesaría participar en otros grupos de familiares que proveen ayuda a ancianos?

_____Sí _____No

¿Porqué?_____

_____

11. ¿Recomendaría Usted este programa a otras personas?

_____Sí _____No

12. ¿Tiene Usted alguna recomendación de cómo mejorar este programa?

_____

_____

_____

_____

_____

Otros comentarios que quiera hacer en relación a la experiencia y el programa en general:

_____

_____

_____

_____

_____

_____

MUCHAS GRACIAS POR SU PARTICIPACION EN EL PROGRAMA. FUE UN PLACER CONTAR CON SU PARTICIPACION:

Appendix H

PROGRAM EVALUATION BY PARTICIPANTS (ENGLISH)

Program's evaluation by participants

In order to plan and improve future programs, we would like to know your reaction to the program in which you have participated. Please indicate the number of sessions you attended and evaluate based on them. Your responses will remain confidential and anonimous. Thank you for your cooperation.

---

1. How many sessions did you attend?

   _____ sessions

2. Was attending the meetings problematic or inconvenient?

   _____ No problem _____ A moderate problem

   _____ A little problem _____ A great problem

   If it was problematic, can you explain how? _____

   _____

   _____

3. Do you think that the program helped you in any way in your personal life?

   _____YES _____NO

   If it helped you, can you indicate how? _____

   _____

   _____

   _____

   If it did not help you, please indicate what aspects of the program were not helpful, or in which way you were not helped. _____

   _____

   _____

   _____

   _____

4. Which aspects of the program did you find most helpful? (Please enumerate them in order of preference):

_____ Information on illnesses and disabilities in old age

_____ Information on benefits and entitlemenst for the aged

_____ Information on community resources for the aged

_____ Sharing and discussing problems of the caregiving role with other people who are in the same situation

_____ Learn how to obtain and mediate for service with the formal organizations

_____ The material that was given at the sessions

5. Now we would like to know if the group experience Helped a lot, Helped a Little, or Did not Help in the following areas:

	Helped a lot	Helped a Little	No Help
a. Learn how other people deal with their aging relatives	_____	_____	_____
b. Improve my communication with the elderly	_____	_____	_____
c. Understand the complaints of my older relative	_____	_____	_____
d. Establish contact with other caregivers	_____	_____	_____
e. Ventilate problems and concerns regarding the care provided to the aged	_____	_____	_____
f. Understand my own aging process	_____	_____	_____
g. Know where to begin to look for help	_____	_____	_____
h. Know about illnesses and disabilities in old age	_____	_____	_____
i. Understand sensory losses in old age	_____	_____	_____

	Helped a lot	Helped a Little	No Help
j. Express my feelings and emotions in my caregiving role	_____	_____	_____
k. Learn about nursing homes	_____	_____	_____
l. Learn how to deal with family conflicts	_____	_____	_____
m. Learn to pay attention to my needs and my family needs	_____	_____	_____
n. Learn about confusion in old age	_____	_____	_____
o. Opportunity to talk about my frustrations	_____	_____	_____

6. Do you think that you had the opportunity to share your caregiving experience or problems with other group members?

_____ YES _____ NO

7. Were other members supportive?

_____ YES _____ NO

How? _____ – _____

_____

_____

_____

8. Have you kept contact with other members?

_____ YES _____ NO

9. Do you think you would continue seeing other members?

_____ YES _____ NO

10. Would you be interested in participating in other caregiver groups?

_____ YES _____ NO

Why? _____

_____

_____

_____

11. Would you recommend this program to other people?

_____ YES _____ NO

12. Do you have any recommendations to improve the program?

_____

_____

_____

_____

_____

Any other comments that you would like to make regarding the experience?

_____

_____

_____

_____

_____

THANK YOU VERY MUCH FOR YOUR PARTICIPATION IN THE PROGRAM.

SELECTED BIBLIOGRAPHY

Adams, Bert N. "Interaction Theory and the Social Network." Sociometry, 30 (1964), 64-78.

_____. Kinship in Urban Setting. Chicago: Markham Publishing Company, 1968.

_____. The American Family. Chicago: Markham Publishing Company, 1971.

Arling, G. "Race, Social Reciprocity and Natural Supports." Paper presented at the 31st Annual Scientific Meeting of the Gerontological Society, Dallas, Texas, 1978.

Asociacion Nacional Pro-Personas Mayores. A National Study to Assess Service Needs of the Hispanic Elderly. Los Angeles, California, 1980.

Atchley, Robert. The Social Forces in Later Life: An Introduction to Social Gerontology. Belmont, California: Wadsworth Publishing Company, 1980.

Badillo-Ghali, Sonia. "Culture Sensitivity and the Puerto Rican." Social Casework, Vol. 58 (October, 1977), 64-71.

_____. "Understanding Puerto Rican Traditions." Social Work, Vol. 17, (January, 1982), 98-103.

Baker, Frank. "The Interface Between Professional and Natural Support Systems." Clinical Social Work Journal, Vol. 5, (Summer 1971), 139-148.

Bales, Robert. Interaction Process Analysis: A Method for the Study of Small Groups. Cambridge, Massachusetts: Adison-Wesley, 1950.

Barish, Herbert. "Self-Help Groups." Encyclopedia of Social Work Sixteenth Issue. Vol. II, No. 16 (1971), 1163-1169.

Barnett, Ada. "The Responsibility of the Federal Government." Adeline Hoffman (ed.). The Daily Needs and Interests of Older People. Springfield, Illinois: 1970.

Bastida, Elena. Family Integration and Adjustment to Aging Among Hispanic-American Elderly. Doctoral Thesis. University Microfilms Ann Arbor: Michigan, 1979.

Bayer, S., and E. Bayer. "You and Your Aging Parent: A Laboratory Approach." Journal of Jewish Communal Services. 2 (1975), 174-181.

Bell, William, "Community Care for the Elderly: An Alternative to Institutionalization." Gerontologist, Vol. 13 (Autumn, 1973), 349-354.

_____. "The Family Cycle: Primary Relationships and Social Participation Problems." Gerontologist, Vol. 13 (Autumn, 1973), 78-81.

Benefert, E. "Planning, Facilities, Programs and Services: Government and Non-Government." Gerontologist, Vol. 12 (1972), 36-48.

Bengston, Vern. "Generation and Family Effects in Value Socialization." American Sociological Review, Vol. 40 (1975), 358-371.

Bengston, Vern and Cutler, N.F. "Generations and Intergenerations Relations: Perspectives on Age Groups and Social Change." Binstock and Shanas (eds) Handbook of Aging and the Social Sciences. New York: Van Nostrand Reinhold Company, 1976.

Beraldo, Felix. "Aging and the Family." Special Issue Family Coordinator, Vol. 21 (1972).

Berezin, M.A. "Partial Grief in Family Members and Others Who Care for the Elderly Patient." Journal of Geriatric Psychiatry, Vol. 4 (1970), 53-64.

Berghorn, Forrest J.; Donna Schafer; Geoffrey H. Steere; Robert Wiseman. The Urban Elderly: A Study of Life Satisfaction. New Jersey: Allanheld Osmun and Company, 1978.

Betances, Samuel. "The Prejudice of Having No Prejudice in Puerto Rico." The Rican, Number 2 (Winter 1972), 42-46.

Binstock, Robert and Ethel Shanas, eds. Handbook of Aging and the Social Sciences. New York: Van Nostrand Reinhold Company, 1976.

Blank, Marie. "Recent Research Findings in Practice With the Aging." Social Casework, Vol. 52, No. 6 (June, 1971), 382-389.

_____. "A Perspective on Deinstitutionalization of Older Patients and a Proposal for Cummunity-Based Services." Journal of Gerontological Social Work, Vol. 1, No. 2 (1978), 135-145.

Blau, Zena S. Old Age in a Changing Society. New York: New View Points, Franklin Watts, Inc., 1973.

_____. "Structural Constraints on Friendship in Old Age." American Sociological Review, Vol. 26 (1961), 429-439.

Blenkner, Margaret. "Social Work and Family Relations in Later Life With some Thoughts on Filial Maturity." Streib and Shanas (eds.). Social Structure and the Family. New Jersey: Englewood Cliffs, 1965.

Blenkner, Margaret; Martin Bloom; and Margaret Nielsen. "A Research and Demonstration Project of Protective Services." Social Casework, Vol. 52, No. 8 (October, 1971), 483-489.

Bonilla, Frank and Ricardo Campos. "A Wealth of Poor: Puerto Ricans in a New Economic Order." Daedalus: Journal of the American Academy of Arts and Sciences, Vol. 110, No. 2 (Spring, 1981), 133-176.

Bram, Joseph. "The Lower Status Puerto Rican Family." Francesco Cordasco and Eugene Bucchioni (eds.). Puerto Rican Children in Mainland Schools. New York: Scarecrow Press, 1968.

Brandwein, C. and R. Postoff. "A Therapeutic and Didactic Model of Intervention for Working With Adult Children of Aged Parents." Gerontologist, Vol. 17, No. 5 Part II, (1977).

Brody, Elaine. A Social Work Guide For Long-Term Care Facilities, National Institute of Mental Health, H.E.W. Washington, D.C., 1979.

_____, "Aging is a Family Affair." Public Welfare, Vol. 25, No. 2 (April, 1967), 129-140.

_____, Long Term Care of Older People. New York: Human Sciences Press, 1977.

_____, "The Aging Family." Gerontologist, Vol. 6 (1966), 201-206.

_____, "The Aging of the Family." Annals of the American Academy of Political and Social Sciences, Vol. 438 (July, 1978), 13-27.

_____, "Women in the Middle and Family Help to Older People." Gerontologist, Vol. 21, No. 5 (1981) 471-480.

Brody, E. and S. Brody. "Decade of Decision for the Elderly." Social Work, (September, 1974).

Brody, E. and G. Spark. "Institutionalization of the Aged: A Family Crisis." Family Process, Vol. 5, No. 1 (1966), 76-90.

Brody, Stanley; W. Poulshock; and C. Maschiochi. "The Family Caring Unit: A Major Consideration in the Long-Term Care Support System." Gerontologist, Vol. 18 (December, 1978), 556-561.

Bott, E. Family and Social Network. Tavistock: London, 1957.

Bromeld, Theodore. "Explicit and Implicit Culture in Puerto Rico: A Case Study in Educational Anthropology." Harvard Educational Review, Vol. 28 (1958), 197-213.

Brown, Robert J. "Family Structure and Social Isolation of Older People." Journal of Gerontology, Vol. 15, No. 2 (April, 1960), 170-173.

Butler, Robert. Why Survive? Being Old in America. New York: Harper and Row, 1975.

Campos, Angel. "Proposed Strategy for the 1970's." Social Casework, Vol. 55, No. 2 (February, 1974), 111-116.

Cantor, Marjorie. "Effects of Ethnicity on Life Styles of the Inner City Elderly." Community Planning for an Aging Society. Pennsylvania: Dowden, Hutchinson and Ross Press, 1976, 41-58.

_____. Facts and Figures About New York City and Its Elderly. New York City Department for the Aging, 1975.

_____. "Life Space and the Social Support System of the Inner City Elderly of New York." Gerontologist, Vol. 15 (1975), 23-27.

_____. "Neighbors and Friends: An Overlooked Resource in the Informal Support System." Paper presented at the Gerontological Society Meeting. San Francisco, November 1977.

_____. "The Informal Support System of New York's Inner City Elderly: Is Ethnicity a Factor?." in Gelfard, D.E. and A.J. Kutsik (eds.). Ethnicity and Aging. New York: Springer Publishing Company, 1979.

Cantor, M. and M. Meyer. "Factors in Differential Utilization of Services by Urban Elderly." Journal of Gerontological Social Work, Vol. 1, No. 1 (Fall, 1978), 47-62.

Caplan, Gerald. Support Systems and Community Mental Health. New York: Behavioral Publications, 1974.

Caplan, Gerald and Marie Killilea, (eds.). Support Systems and Mutual Help: Multidisciplinary Explorations. New York: Grune and Stratton, 1976.

Center for Community Research. A Study of Self-Help Activities Among the Aged in New York City. New York, (June 1972).

Cicirelli, Victor. "Kin Relationships of Childless and One-Child Elderly in Relation to Social Services." Journal of Gerontological Social Work, Vol. 4, No. 1 (Fall, 1981), 19-33.

Christensen, Edward. "Counseling Puerto Ricans: Some Cultural Considerations." Personnel and Guidance Journal, Vol. 5, No. 5 (January, 1975).

Clark, Margaret and B.G. Anderson. Culture and Aging. Springfield, Illinois: C.C. Thomas, 1967.

Cohen, Margery. "Alternative to Institutional Care of the Aged." Casework, Vol. 54, No. 8 (October, 1973), 447-452.

Cohen, Stephen and Bruce Michael Gans. The Other Generation Gap. Chicago: Follet, 1978.

Collins, Alice and Diane Pancoast. Natural Helping Networks: A Strategy for Intervention. National Association of Social Workers, Washington, D.C. 1975.

Community Service Society of New York. Familial Responsibility and Public Welfare, Report of the Joint Committee on Filial Responsibility. Department of Public Affairs, C.S.S., February 1964.

Crogg, S.H. "Help Patterns: The Roles of Kin Network, Non-Family Resources and Institutions." Journal of Marriage and the Family, Vol. 2 (1972), 32-41.

Davis, Benjamin G. "Stress in Individuals Caring for Older Convalescing Family Members." (Ph.D. Thesis). Dissertation Abstracts International. 39 (10), Ann-Arbor University Microfilms, 1979.

Delgado, Melvin and Debise-Humm, Delgado. "Natural Supports Systems: A Source of Strength in Hispanic Communities." Social Work, Vol. 27, No. 1 (January, 1982), 83-90.

Dobrof, Rose. The Care of the Aged: A Shared Function. Unpublished Dissertation, Columbia University School of Social Work, 1976.

Dobrof, Rose and Eugene Litwak. Maintenance of Family Ties of Long-Term Care Patients: Theory and Guide to Practice. National Institute of Mental Health: U.S. Department of Health Education and Welfare, Publication No. (ADM) 77-4000, 1977.

Dorucci, Fernanda. "Classes for Adult Children of the Aged." Social Work, (November, 1974), 732-733.

Ehrlich, Phyllis. "Service Delivery for the Community Elderly: The Mutual Help Model." Journal of Gerontological Social Work. Vol. 2, No. 2 (Winter, 1979), 125-135.

Epstein, Irwin and Tony Tripodi. Research Techniques for Program Planning, Monitoring and Evaluation. New York: Columbia University Press, 1977.

Erickson, G. "The Concept of Personal Network in Clinical Practice." Family Process, Vol. 14, (1974), 487-498.

Etzioni, Amitai. Modern Organizations. Foundations of Modern Sociology Series. New Jersey: Prentice Hall, 1964.

Fernandez-Marina, Eduardo and Maldonado Sierra. "Three Basic Themes in Mexican and Puerto Rican Family Values." Journal of Social Psychology, Vol. 58 (1958), 167-181.

Fitzpatrick, Joseph. Puerto Rican Americans: The Meaning of Migration to the Mainland. New Jersey: Prentice Hall, 1971.

_____. "The Puerto Rican Family." In Ethnic Families in America, pp. 189-215. Edited by Charles Wendel and Robert Habenstein. New York: Elsebier North Holland, Inc., 1981.

Forward Management Associates, Inc. "The Final Report on the Study of Special Needs of Racial Ethnic Minorities and Provider Attitudes in Long-Term Care Facilities: Educational Implications." Washington, D.C., H.E.W. Human Resources Administration, January 1977.

Frankfather, Dwight L.; Smith, Michael.; and Caro, Francis. Family Care of the Elderly. Lexington, Massachusetts: Lexington Books, 1981.

Freed, Anna. "The Family Agency and the Kinship System of the Elderly." Social Casework, Vol. 56, No. 10 (December, 1975), 579-586.

Garrison, Vivian. "Support Systems of Schizophrenic and Non-Schizophrenic Puerto Rican Migrant Women in New York City." Schizophrenia Bulletin, No. 4 (1978), 561-596.

Gartner, Alan, and Frank Riessman. Self-Help in the Human Services. San Francisco: Josey-Bass Publishers, 1977.

Gelfand, D., and A. Kutcik, eds. Ethnicity and Aging. New York: Springer Publishing Co., 1979.

Giordano, Joseph. "Ethnics and Minorities: A Review of the Literature." Clinical Social Work Journal, Vol. 2, No. 3 (Fall 1974).

Gittler, Joseph, ed. Understanding Minority Groups. New York: John Wiley, 1956.

Glick, P.C. "The Future Marital Status and Living Arrangements of the Elderly." Gerontologist, (June 1979), 301-309.

Gobierno del Estado Libre Asociado de Puerto Rico, Junta de Planificacion. Informe de Recursos Humanos. San Juan, Puerto Rico, 1979.

Gonzalez, Agustin. "The Struggle to Develop Self-Help Institutions." Social Casework, Vol 55, No. 2 (February, 1974), 90-93.

Gonzalez, Miguel, and L. Garcia. "A Study of Extended Family Interactions Among Chicanos." Master's Thesis, School of Social Welfare, University of California Los Angeles, 1974.

Gording, M. A Short History of Puerto Rico. New York: Mentor Books, 1973.

Gottesman, Leonard. "Extended Care of the Aged: Psychosocial Aspects." Journal of Geriatric Psychiatry, 2 (1979), 220-249.

Gross-Andrews, Susanah, and Zimmer, Anna. "Incentives to Families Caring for Disabled Elderly: Research and Demonstration Project to Strengthen the Natural Support System." Journal of Gerontological Social Work, Vol. 1, No. 2 (Winter 1978), 119-134.

Gutierrez, Elias. "Datos del Censo del 1980." San Juan Star, 8 de mayo de 1982, p. 10.

Hartford, Margaret. Groups in Social Work. New York: Columbia University Press, 1971.

Hartford, Margaret, and Parsons, Rebecca. "Groups With Relatives of Dependent Adults." Gerontologist, Vol. 22, No. 4 (August 1982).

Hausman, Carol P. "Short-Term Counseling Groups for People With Elderly Parents." Gerontologist, Vol. 19 (1979), 102-107

Heir, John, and Weakland, John. Counseling Elders and Their Families. New York: Springer, 1979.

Hidalgo, Hilda. Counseling Inner City Adults in How to Start Higher Education. New York: Scarecrow Press, 1971.

Hill, Reuben. "Courtship in Puerto Rico: An Institution in Transition." Marriage and Family Life, Vol. 17 (February 1955), 26-35.

_____. Family Development in Three Generations. Cambridge, Massachusetts: Schenkman Publishing, 1971.

Holmes, Douglas. et. al. A Study of Self-Help Activities Among the Aged in New York City. New York: Center of Community Research, 1972.

Holmes, Monica, and Holmes, Douglas. Handbook of Human Services for Older Persons. New York: Human Sciences Press, 1979.

Horowitz, Amy. "Adult Children as Caregivers to Elderly Parents: Correlates and Consequences." Doctoral Thesis, Columbia University, 1982.

Horowitz, Amy. "Families Who Care: A Study of Natural Support Systems of the Elderly." Paper presented at the 31st Annual Meeting of The Gerontological Society, Dallas, Texas, November 1978.

Ingersoll, Berit, and Hollenshead, Carol. "Group Work With the Institutionalized Elderly." Journal of Gerontological Social Work, Vol. 3, No. 4 (Summer 1981), 21-36.

Johnson, Elizabeth, and Spencer, Donald. "Adult Children and Their Aging Parents: An Intervention Program." Family Relations, Vol. 31 (January, 1982) 115-122.

Johnson, Elizabeth, and Bursk, B. "Relationships Between the Elderly and Their Adult Children." Gerontologist, Vol. 17 (1977), 90-96.

Johnson, L. The People of East Harlem. New York: The Mount Sinai School of Medicine, 1972.

Kahn, Alfred. Social Policy and Social Services. 2nd Ed. New York: Random House, 1979.

Kamerman, Sheila. "Public Policy for the Elderly: Dilemmas in a Family Policy Perspective." In Strengthening Informal Supports for the Aging: Theory and Practice and Policy Implications. New York: Community Service Society, 1981.

Kamerman, Sheila, and Kahn, Alfred. Social Services in the United States: Policies and Programs. Philadelphia: Temple University Press, 1976.

Kaplan, J. "Implications of Forecasting Public Policy Issues in Aging." Gerontologist, Vol. 15 (1975), 290.

Katz, Alfred. "Application of Self-Help Concept in Current Social Welfare." Social Work, Vol. 10, No. 3 (July 1965), 68-81.

Katz, Alfred, and Bender, Eugene. The Strength In Us: Self-Help Groups In Modern World, New York: View Points, 1976.

Kaufman, Alan. "Social Policy and Long-Term Care of the Aged." Social Work, Vol. 25, No. 2 (March 1980) 135-137.

Kent, Donald. Research, Planning and Action For the Elderly: The Power and Potential of Social Sciences. New York: Behavioral Publications, 1972.

Knittel, Robert E. Organization of Community Groups. U.S. Department of Health, Education and Welfare, Bureau of Community Environmental Management, Washington, D.C., 1970.

Knowles, Malcolm Sheppard. The Modern Practice of Adult Education: Andragogy vs. Pedagogy. New York: Association Press, 1970.

Kobrinsky, Boris. "Innovations in Programs of Care For the Aged." Gerontology, Vol. 13, No. 1 (1973), 50-53.

Kropotkin, Peter. Mutual Aid: A Factor in Evolution. New York: New York University Press, 1972.

Kulys, R., and Tobin, S.S. "Older People and Their Responsible Others." Social Work, Vol. 25, No. 2 (1980), 138-145.

Landy, David. Tropical Childhood: Cultural Transmission and Learning in a Rural Puerto Rican Village. Chapel Hill University: North Carolina Press, 1959.

Lauria, A. "Respeto, Relajo and Interpersonal Relationships." Anthropological Quarterly, (1964), 53-67.

Lebowitz, Barry D. "Old Age and Family Functioning." Journal of Gerontological Social Work, Vol. 1 No. 1 (Winter 1978), 111-118.

Leichter, Hope J., and Mitchell, William. Kinship and Casework. New York: Teachers College Press, 1978.

Leutz, Walter. "The Informal Community Caregiver: A Link Between the Health Care System and Local Residents." American Journal of Ortopsychiatry, Vol. 46, No. 4 (October 1976), 768-688.

Levey, Samuel, and Stotsky, B. "Issues in Planning for Geriatric Services." Journal of American Geriatric Society, Vol. 17, No. 5 (1969), 459-468.

Lewis, Oscar. La Vida. New York: Random House, 1966.

Liebowitz, Bernard, and E. Brody. "Integration of Research and Practice in Creating a Continuum of Care for the Elderly." Gerontologist, Vol. 10, No. 1 (1970), 11-17.

Lin, E. et. al. "Social Support, Stressful Life Events and Illness: A Model and an Empirical Test." Journal of Health and Social Behavior, Vol. 20 (1979).

Litwak, Eugene. "Extended Kin Relations in an Industrial Democratic Society." In Shanas E., and Streib, G. (eds) Social Structure and the Family. New Jersey: Prentice Hall, 1965.

_____. "Geographic Mobility and Extended Family Cohesion." American Sociological Review, (June 1960).

Litwak, E., and Meyer H. "A Balance Theory of Coordination Between Bureaucratic Organizations and Community Primary Groups." Administrative Sciences Quarterly. II, (June 1966), 355-358.

_____. School, Family and Neighborhood: The Theory and Practice of School Community Relations. New York: Columbia University Press, 1969.

Litwak, E., and Ivan Szelenyi. "Primary Groups and Their Functions: Kin, Neighbors, and Friends." American Sociological Review, Vol. 34 (August 1969), 465-481.

Longress, John. "Racism and Its Effects on Puerto Rican Continentals." Social Casework, Vol. 58, No. 4 (April, 1977).

Lopata, Helen, "Contributions of the Extended Families to the Social Support Systems of Metropolitan Area Widows: Limitations of the Modified Kin Network." Journal of Marriage and Family, Vol. 40 (1978) 358-364.

_____. "Support Systems of Elderly Urbanites: Chicago of the 1970's." Gerontologist, Vol. 15 (February 1975), 35-41.

Maldonado, David. "The Chicano Aged." Social Work, Vol. 20, No. 3 (1975, 213-216.

Maldonado-Denis, Manuel. Puerto Rico: A Socio-Historic Interpretation. New York: Vintage Books, 1972.

Mayer, Mary. "Kin and Neighbors: Differential Roles in Differing Cultures." Paper presented at the 29th Annual Meeting of the Gerontological Society, New York, October 1976.

Mellor, Joanna.; Rzetelny, Harriet; and Hudis, Iris. "Self-Help Groups for Caregivers of the Aged." Paper presented at the First Annual Symposium of Social Work Groups, Cleveland, December, 1979.

Miller, Irving, and Solomon Renee. "The Development of Group Services for the Elderly." Journal of Gerontological Social Work, Vol. 2, No. 3 (Spring 1980), 241-257.

Miller, D. "The Sandwich Generation: Adult Children of the Aged." Social Work, Vol. 25, No. 5 (September 1981), 419-423.

Mindel, Charles, and Wright, Roosevelt. "The Use of Social Services by Black and White Elderly: The Role of Social Systems." Journal of Gerontological Social Work, Vol. 4, No. 3/4 (Spring-Summer 1982), 107-123.

Mitchell, J.C. Social Networks and Urban Situations. Manchester: Manchester University Press, 1969.

Mitchell, Roger, and Trickett, Edison. "Task Force Report: Social Networks as Mediators of Social Support." Community Mental Health Journal, Vol. 16 (Spring 1980), 27-44.

Mizio, Emelicia. "Impact of External Systems on the Puerto Rican Family." Social Casework, Vol. 55, No. 2 (February 1974), 76-83.

_____. "White Worker-Minority Client." Social Casework, Vol. 17, No. 3 (May 1972).

Montgomery, James E. "The Economics of Supportive Services for Families With Disabled and Aging Members." Family Relations, Vol. 31, No.1 (January 1982), 19-23.

Moroney, Robert. The Family and The State: Considerations for Social Policy. London, England: Longmans Limited, 1976.

Nelson, Gary. "Support for the Aged: Public and Private Responsibility." Social Work, (March 1982), 137-143.

Neugarten, Bernice L. (ed.). Middle Age and Aging, A Reader in Social Psychology. Chicago: University of Chicago Press, 1968.

Neugarten, Bernice and Robert Havighurst. Social Policy and Social Ethics and the Aging Society. Pennsylvania: Dowden, Hutchinson and Ross, Inc., 1976.

New York State Health Advisory Council. Enhancing and Sustaining Informal Support Networks. Conference Proceedings, November, 1981.

New York State Committee on Aging and New York State Senate Committee. Perspectives on Respite Care for the Elderly. New York, July 1981.

Norton, Dolores,; Morales, Jose; and Andrews, Edwin. The Neighborhood Self-Help Project. Chicago: School of Social Service Administration, University of Chicago, Occasional Paper #9, January, 1980.

Oriol, William. "Social Policy Priorities: Age Versus Youth; The Federal Government." Gerontologist, Vol. 10, No. 3. (1970), 207-126.

Otten, Jane, and Shelley, Florence. When Your Parents Grow Old. New York: Signet Books, 1976.

Padilla, Amado,; Carlos M,; and Keefe, S. "Mental Health Service Utilization by Mexican Americans." In Psychotherapy with Spanish Speaking: Issues in Research and Service Delivery. Los Angeles, Spanish-Speaking Mental Health Research Center, 1976.

Padilla, Elena. Up From Puerto Rico. New York: Columbia University Press, 1958.

Pfeiffer, Eric (Ed.). Alternatives to Institutional Care for Older Americans. Practice and Planning Center for the Study of Aging and Human Development. North Carolina: Duke University Press, 1972.

Powell, Lawton D., Community Planning for an Aging Society. Pennsylvania: Dowden, Hutchinson and Ross, Inc., 1976.

Puerto Rican Congress of New Jersey. The Hidden Sub-Minority: The Hispanic Elderly. New Jersey, 1976.

Riessman, Frank. "The Helper Theory Principle." Social Work, Vol. 10, No. 2 (April 1965), 27-32.

_____. "The Self-Help Movement Has Arrived." Social Policy, Vol. 6, (1976), 63-64.

Roberts, Lydia, and Rosa, Stephanie. Patterns of Living in Puerto Rican Families. Rio Piedras, Puerto Rico: University of Puerto Rico Press, 1949.

Robinson, Betsy, and Thurnher, Majda. "Taking Care of Aged Parents: A Family Cycle Transition." Gerontologist, Vol. 21, No. 5 (1981), 586-593.

Rodriguez, Rafaela. "Social Aspects of Aging in Puerto Rico." (Doctoral Thesis) Columbia University, 1970.

Rogler, Lloyd. Migrant in the City: The Life of a Puerto Rican Action Group. New York: Basic Books, 1972.

Roozman-Weigenberg, Catherine, and Fox, Michelle. "Agroup Work Approach With Adult Children of Institutionalized Elderly: An Investment in the Future." Journal of Gerontological Social Work, Vol. 2, No. 4 (Summer 1980), 355-362.

Rosow, Irving. Social Integration of the Aged. New York: Free Press, 1967.

Safford, Florence. "A Training Program for Families of the Mentally Impaired Elderly." Gerontologist, Vol. 20, No. 6 (December 1980), 656-660.

_____. Developing a Training Program For Families of the Mentally Impaired." New York, Isabella Geriatric Center, 1977.

Sager, Alan. "Assessing the Home Care Service Needs of the Elderly: Professional Prescriptions and Patient/Family Requests." Paper presented at the 31st Annual Meeting of the Gerontological Society, Dallas, Texas, November 1978.

Schlesinger, Mary,; Tobin, Sheldon; and Kulys, Regina. "The Responsible Child and Parental Well-Being." Journal of Gerontological Social Work, Vol. 3, No. 2 (Winter 1980), 3-16.

Schmidt, Mary. "Failing Parents, Aging Children." Journal of Gerontological Social Work, Vol. 2, No. 3 (Spring 1980), 259-268.

Schneiderman, Leonard. "Against the Family." Social Casework, Vol. 24, No. 5 (September 1979), 386-389.

Schoor, Alvin. "Family Values and Real Life." Social Casework, Vol. 57, No. 6 (June 1976), 397-404.

_____. Filial Responsibility in the Modern American Family. Washington, D.C., U.S. Department of Health, Education, and Welfare, 1960.

_____. "The Family Values and Public Policy: A Venture in Prediction and Prescription." Journal of Social Policy, Vol. 1 (1972), 33-43.

_____. "Thy Father and Thy Mother: A Second Look at Filial Responsibility." U.S. Department of Health and Human Services, Social Security Administration Office of Policy, SSA Publication No. 13-11953, 1980.

Schwartz, Arthur. Handbook for Children of Aging Parents. Chicago, Follet, 1977.

Shanas, Ethel. "Family Relationships of Older People." Health Information Foundation Research Series, Number 20, October, 1961.

_____."Family Responsibility and the Health of Older People." Journal of Gerontology, Vol. 15 (October 1960), 408-411.

_____. "The Family as a Social Support System in Old Age." Gerontologist, Vol. 19, No. 2 (1979), 169-174.

_____. The Health of Older People. Cambridge, Massachusetts: Harvard University Press, 1962.

Shanas, E., and Streib, Gordon. Social Structure and The Family: Generational Relations. New Jersey: Prentice-Hall, Inc., 1965.

Shanas, E., and Sussman M., Family, Bureaucracy and the Elderly. North Carolina: Duke University Press, 1977.

Shanas, E.; Townsend, P.; Friis, H.; Milhorj, P.; and Stehouwer, J., Old People in Three Industrial Societies. New York: Atherton Press, 1968.

Silverman, Alida,; Kahn, B.; and Anderson, Gary. "A Model for Working With Multigenerational Families." Social Casework, Vol. 58, No. 3 (March 1977).

Silverman, Alida, and Brahce, Carl. "As Parents Grow Old: An Intervention Model." Journal of Gerontological Social Work, Vol. 2, No. 1 (Fall 1979), 77-85.

Silverstone, Barbara. "Family Relationships of the Elderly: Problems and Implications for Helping Professionals." Aged Care and Services Review, Vol. 1 (1978), 1-9.

Silverstone, Barbara, and Kandel, Helen. You and Your Aging Parents. New York: Pantheon Books, 1976.

Simos, B.G. "Adult Children and Their Aging Parents." Social Work, Vol. 18 (1973), 78-85.

Soyer, David. "Reverie on Working With the Aged." Casework, Vol. 50, No. 5 (May 1969), 291-294.

Spanish Council for Human Services. Special Bulletin, New York: 1982.

Special Committee on Aging, United States Senate. Post White House Conference on Aging Reports, U.S. Government Printing Office, 1973.

Spencer, Marian, and Dorr, Caroline. Understanding Aging: A Multi-Disciplinary Approach. New York: Appleton-Century Crafts, 1975.

Spohn, Roberta. "The Influence of Housing and Community on Informal Supports." Journal of Gerontological Social Work, Vol. 5, No. 3/4 (Spring-Summer 1982), 139-144.

State of California, Department of Social Services. In-Home Supportive Services, April 1980 Survey, Selected Characteristics. Program Information Series Report No. 1980-05, October, 1980.

State of Maryland, Office on Aging and Office of the Comptroller, Tax Credits to Families Who Care for Elderly Relatives: A Report to The Assembly, September, 1977.

Steintz, Lucy. "The Local Church as Support For The Elderly." Journal of Gerontological Social Work, Vol. 4, No. 2 (Winter 1981), 43-54.

Stephen, Richard,: Blau, Z.; Oser, G.; and Millar, M. "Aging, Social Support Systems and Social Policy." Journal of Gerontological Social Work, Vol. 1, No. 1 (Fall 1979), 33-35.

Sterne, Richard,; Richard, J.; and Rabushka, A. The Urban Elderly Poor. Massachusetts: Lexington Books, 1974.

Steward, J.H. The People of Puerto Rico. Illinois: University of Illinois Press, 1956.

Sussman, Marvin. "Family Life of Old People." In Binstock, Roberts and Shanas, Ethel (eds.) Handbook of Aging and the Social Sciences. New York: Van Nostrand Reinhold, 1976.

_____. "Family Systems in the 1970's: Analysis, Policies and Programs." The ANNALS, Vol. 396 (July 1971), 40-56.

_____. "Relationship of Adult Children With Their Parents in the United States." In Shanas E. and G. Streib, Social Structure and the Family: Generational Relations, New Jersey: Prentice-Hall, 1965.

_____. "Social and Economic Supports and Family Environments for the Elderly." Final Report to Administration on Aging. AoA Grant #90-A-316, January 1979.

Sussman, Marvin, and Burchinal, Lee. "Kin, Family Network: Unheralded Structure in Current Conceptualizations of Family Functioning." Marriage and Family Living, Vol. 24, No. 3 (August 1962), 231-240.

Tobin, Sheldon,; Davidson, Stephen,; and Sack, Ann. Effective Social Services for Older Americans. Institute of Gerontology, The University of Michigan, Wayne State University, 1977.

Thomas, Piri. Down These Mean Streets. New York: Alfred Knopf, 1967.

Thomas, T.H. Wan. Stressful Life Events, Social Supports Networks, and Gerontological Health. Massachusetts, Lexington Books, 1982.

Torres-Gil, Fernando, and Mona Negron. "Policy Issues Concerning the Hispanic Elderly." Aging, Nos. 305-306 (March-April, 1980), 2-5.

Toseland, Ronald, and Hacker, Linda. "Self-Help Groups and Professional Involvement." Social Work, Vol. 27, No. 4 (July 1982), 341-347.

Townsend, Peter. Family Life of Old People. Illinois: The Free Press, 1957.

_____. "The Effects of Family Structure on the Likelihood of Admission to an Institution in Old Age." In Shanas, E., and Streib, G. Social Structure and the Family: Generational Relations. New Jersey: Prentice-Hall, 1965.

_____. "The Emergence of the Four Generation Family in Industrial Society." New Society, Vol. 8 (July 1966), 12-13.

Treas, Judith. "Family Support Systems for the Aged." Gerontologist, Vol. 17, No. 6 (1977), 486-491.

Troll, Lillian. "The Family of Later Life: A Decade of Review." Journal of Marriage and Family, Vol. 33 (1971), 263-290.

Troll, Lilliam,; Miller, Sheila,; and Atchley, Robert. Families in Later Life. California: Wadsworth Publishing Co., 1979.

U.S. Bureau of the Census, 1976 Survey of Income and Education for New York City, D.H.E.W. The Elderly Population of New York City, 1976 Publication No. 78-20248.

U.S. Bureau of the Census, Housing and Vacancy Survey of New York City, 1978.

U.S. Bureau of the Census, 1980 Advanced Reports. Census Population and Housing, Washington, D.C., 1982.

U.S. Commission on Civil Rights, Puerto Ricans in the Continental United States: An Uncertain Future, Washington, D.C., October 1976.

U.S. Commission on Civil Rights, Minority Elderly Services, New Programs, Old Problems, Washington, D.C., 1982.

U.S. Department of Commerce, Population Characteristics: Selected Characteristics of Persons and Families of Mexican, Puerto Rican and Other Spanish Origin, March, 1972.

U.S. Department of Health and Human Services, Social Security Administration, Social Security Bulletin: Annual Statistical Supplement 1977-79, Washington, D.C., 1980.

U.S. Department of Health, Education and Welfare, Office of Human Development, Administration on Aging, Older Americans Act of 1965, As Amended, 1976.

Valle, Ramon, and L. Mendoza. The Elder Latino. San Diego: Companile Press, 1978.

Valle, Ramon, and Vega, William. Hispanic Natural Support Systems: Mental Health Promotion Perspectives. State of California: Department of Mental Health, 1980.

Walz, Thomas. "The Family, The Family Agency and Post-Industrial Society." Casework, Vol. 56, No. 1 (January 1975), 13-20.

Weeks, John, and Cuellar, Jose. "The Role of Family Members in the Helping Networks of Older People." Gerontologist. Vol. 21, No. 4 (1981), 388-394.

Weiss, Carol. Evaluation Research. New Jersey: Prentice-Hall, 1972.

Weissbaus, S. "Determinants of Affect of Middle-Aged Women Toward Their Mothers." Paper presented at the 33rd Annual Scientific Meeting of the Gerontological Society, California, 1980.

White House Conference on Aging. Towards a National Policy on Aging. Washington, D.C., 1971.

Yalom, Irvin. The Theory and Practice of Group Psychotherapy. New York: Basic Books, Inc., 1975.

Young, M., and Willmatt, P. Family and Kinship in East London. London: Routledge and Kegan, 1975.

Zambrana, Ruth,; Merino, Rolando; and Santana, Sarah. "Health Services and the Puerto Rican Elderly." In Gelfard, D. and Kutsek, A. (Eds.) Ethnicity and Aging. New York: Springer Publishing, 1979.

Zimmer, Anna. Testimony of the Community Service Society of New York to the Subcommittee on the Special Problems of the Aging, Albany, New York, June 4, 1979.

Zimmer, Anna, and Hudis, Iris. "Education for Caregivers of the Aged: A Developmental View." Paper presented at the 33rd Annual Scientific Meeting of the Gerontological Society, San Diego, California, 1980.

Zimmer, Anna, and Sainer, Janet. "Strengthening the Family as an Informal Support for Their Aged Members: Implications for Policy and Planning." Paper presented at the 31st Annual Scientific Meeting of the Gerontological Society, Dallas, Texas, 1978.