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A COMPARISON OF STRESS REDUCTION AND EDUCATIONAL/PROBLEM SOLVING GROUPS IN A PROGRAM FOR ADULT DAUGHTERS CARING FOR THEIR ELDERLY PARENTS

BY

MARY M. COPPOLA

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

1992

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

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CHAPTER ONE:

IDENTIFICATION OF THE PROBLEM

Health Services to the Elderly

The need for health care services for the elderly has grown dramatically in recent years. The provision of these services has occurred in two ways: through a political and legislative process involving the medical and social services; and through an informal network of patients, families and other community support systems. An exploration of these approaches is germane to the identification of the problem of how to support families who elect to provide caregiving services to their elderly relatives remaining at home.

The United States has experienced several important population shifts during this century. The primary change is the aging of our society and the unprecedented growth in the number and proportion of older Americans. There are approximately 30 million persons aged 65 and over in our country today, over 12 percent of the total population. This represents an increase of 60 percent from the number in 1960 (Soldo and Agree, 1988). By the year 2030 the elderly population will be twice that of today while the population as a whole will increase by only 35 percent. This will result in the elderly being a significantly larger portion of the overall population, rising from its current level of about 12 percent of the total to about 18 percent in the year 2030 (NYSOFA, 1983).

In addition, the older population itself is also aging at a staggering rate. In 1960 about one out of twenty people over 65 was over age 85. By 1980 one in eleven had reached age 85. It is projected that one in seven will have reached age 85 by the year 2000 (Crews and Cancellier, 1988; Rockefeller Institute of Government, 1986).

This extraordinary expansion of the older population can be explained by a number of factors, including progress in medicine and science. The principal factor accounting for the increase in the number of elderly stems from the high fertility rates in the last decade of the nineteenth century and the early decades of the twentieth century. Another factor in explaining this expansion is the decline in mortality. Improvements in sanitation, prenatal and postnatal care, control of infectious diseases, and the development of antibiotics have all contributed to sharp drops in the infant mortality rate since 1900. Finally, the size of the current older population reflects the imprint of the large pre-World War I immigration waves to America (Rich and Baum, 1984).

This "elder expansion" has been accompanied by increased concerns about health issues, which rank second only to economic concerns, for this cohort. As one ages, the risk of chronic, degenerative diseases increases markedly. Of the aged not placed in institutions, four our of every five have at least one chronic condition. The most common of these diseases are arthritis, hypertension, heart disease, and hearing impairments. Among those 65 and over the prevalence of these diseases is approximately five times that observed for younger persons (Soldo and Agree, 1988).

There tends to be some controversy surrounding estimates on future levels of impairments among the elderly. There are those who argue that future generations will experience lower rates of impairment than those found in today's elderly due to improved life styles and higher socio-economic standards. This argument would mean that recent changes would postpone the average age at which an individual experiences a chronic illness, thus implying additional years of a physically comfortable life. Others argue that while some improvements in health may occur, greater proportions of the elderly will be experiencing the chronic impairments associated with the later stages of life. This argument would suggest that we may be increasing life expectancy but with greater numbers of elderly disabled for an increasing number of years of illness (Rockefeller Institute of Government, 1986).

Not all of the major chronic illnesses pose a threat to the aged's quality of life or erode personal independence. Disability and frailty are not synonymous with old age. However, with an increasing older population having more than one chronic condition, it would be important to consider the functional capacity of the older person. For example, does someone need help to carry out basic activities of daily living (ADL) like bathing, dressing and eating? In 1984, of the 26.4 million persons aged 65 and over living in the community, about 6 million, or 22.7 percent, had some difficulty in performing at least one basic ADL. The risk for functional disability to occur increases rapidly after age 65. Where only about 15% of those aged 65 - 69 may need help with any ADLs, nearly 50% of those aged 85 and over have some difficulty performing at least one self-care activity (Soldo and Agree, 1988).

Perhaps the outcome of extending life expectancy will be to extend the period of functional dependence prior to death. The number of older, functionally-limited persons needing long term care is projected to increase to 9 million by the year 2000 and to 18 million by 2040. If this projection is accurate, the impact on this country's health care system will be enormous. Nursing home public expenditures alone could triple by the year 2000 to approximately $129 billion (Soldo and Agree, 1988).

Traditional Health Care Delivery System

In the United States, support services needed by older persons who have functional limitations resulting from, or in conjunction with, chronic illness or other conditions that make them frail and dependent, are provided through a pluralistic health care delivery system. Historical review reveals that the concept of government financed health care evolved not solely for the care of the aged, but for paupers who were unable to care for themselves. When a family could or would no longer care for a pauper, he or she became the government's responsibility by default. This responsibility ranged from providing financial assistance to families and individuals, to institutional programs like almshouses, hospitals, workhouses and prisons. This type of governmental support system was developed during the colonial period and did not distinguish between poverty due to physical disability and poverty due to economic distress.

In the 17th and 18th centuries, paupers were either auctioned to persons willing to support them at the lowest cost to the community, or they contracted to work in return for their care. It was not until after the American Revolution that the almshouse was considered to be the most suitable and least costly way to care for people in need. By 1867 several states had developed Boards of Charities which began to inspect state welfare institutions and ultimately assumed supervision of private institutions that received public funds. These State Boards of Charities later developed standards of care for hospitals of the aged, nursing homes and other welfare agencies.

Following the turn of the century there was much social reform which created public health dispensaries, hospitals for the rich and indigent, plus convalescent and rest homes. As a result of the Great Depression, social welfare policy changed drastically. Groups of Americans who once had frowned on public assistance now found themselves demanding it for the relief it provided. This shift in attitudes produced an important legislative action in the Social Security Act of 1935. Under this act two systems were created. One, a national retirement income system designed to provide income in the absence of wages to workers or their dependents when the worker retired or became disabled. The second, a system of federal grants to assist the states in providing financial support to the aged, to dependent children, to the blind, and to the disabled (Pegels, 1981).

Not until the mid-1960s did legislation appear which impacted directly on the provision of health services for the elderly. The two programs stemming from legislation enacted in 1965 constitute the most important elements of the federal effort to pursue health goals to aid the elderly, and at the same time, try to accommodate the desires of the medical and health service professions. The Medicare program was established especially for the elderly to provide universal health benefits. The

Medicaid program, applicable to all age groups, was to provide health benefits to several categories of the needy. These programs were a compromise measure to end the controversy over the establishment of some form of government sponsored health protection for all persons. Rather than comprehensive health insurance the concept was narrowed to one of a program for the aged; those with the largest medical expenses and who were least able to pay (Rich and Baum, 1984).

The private hospital insurance industry began in the Great Depression of the 1930s. Better known as Blue Cross, this hospital insurance was developed to help individuals cope with the costs of health care plus to bring relief to hospitals which had empty beds and declining revenues. Blue Shield, the medical insurance branch, was approved by the American Medical Association in 1938 to largely block the movement toward socialized medicine. The private health insurance industry grew steadily and by the end of the 1970s, 27% of personal health care was provided for through this option (Bates, 1983).

Although the above insurance programs provide a measure of relief, they have also produced problems which influence health care today. The health care delivery system in the United States is based on a market model. Essentially a number of physicians and hospitals operate in competition with one another. Underlying the model is a claim that competition will result in cheaper prices, the most efficient providers, the best quality of care, and the informed consumer will compare to find the best deal. This model has had many flaws in its years of operation. Health care providers are not dealing with informed consumers and consumers do not frequently compare services when they become ill. In addition, providers generate their own work by telling consumers they need particular services. Consumers are not technically able to judge the advice they receive, and tend to agree with providers and obtain the services. Obtaining health insurance removes the consumers incentive to economize plus weakens the market model.

Insured persons in the United States health care delivery system can not expect to receive comprehensive health care services. Individual consumers frequently encounter age-limit restrictions or the termination of insurance benefits after stated ceilings are reached. Consumers are often subject to waiting periods and sometimes are excluded from coverage due to pre-existing medical conditions. Hospital coverage under group plans can be of a limited duration and some types of illness are not covered for treatment and care.

Many people go unprotected for their health care coverage. These are individuals who are poor, who can not afford private insurance but are not poor enough to be eligible for Medicaid, some self-employed people who elect not to purchase policies or who are in small employee groups which do not provide it, and some who are not covered because they are between jobs (Bates, 1983). Other individuals are underinsured or simply can not get appropriate medical care. It is estimated that approximately 34 million Americans have no medical insurance (Carlson, 1990).

Likewise, those recipients of assistance from government programs can not expect to receive comprehensive health care services. Medicare has been criticized for its emphasis on hospital care, especially since a person contributing to Social Security has no choice but to buy into it. Elderly persons are thus pushed into hospitals when they have no real need to be there and longer hospital stays are promoted because home help for those recuperating is so difficult to obtain and insurance coverage is minimal or lacking. Medicaid also has been criticized for its emphasis on institutional care rather than on options permitting older persons to remain in their communities.

Since the inception of these programs the federal government and the states have given much latitude to the private sector. Providers like hospitals, nursing homes, and physicians plus insurance companies have been largely responsible for setting costs. These same players have determined aspects of service delivery like length of stay in a hospital. This collaboration of government and the private sector initially got Medicare and Medicaid approved, but has not served to design a quality health care system. Costs have continued to exceed all estimates of program operations. Inflation is a factor but partly the problem can be attributed to overcharging and to overtly fraudulent practices. With many scandals being exposed in the early seventies, the federal government has made moves to tighten its regulations and cut costs. The current focus on matching length of hospital stay to illnesses and surgical procedures is an effort to make the system responsive (Rich and Baum, 1984).

Presently older persons are bearing more of the burden of health costs. For example, the initial amount Medicare patients pay for hospital care and supplemental payments has increased sharply. Physicians often refuse to accept Medicare stipulated fees, increasing out of the pocket expenditures for older patients. Proposals to reduce the costs of Medicaid would reduce the proportion of older persons eligible to receive this benefit as well as decrease the services made available through Medicaid.

Long Term Care Continuum

While the United States has been somewhat successful in providing acute medical services to the general population, it has been much less successful in providing the necessary array of services to the mentally and physically chronically ill. The success earned in acute care services is due in large part to heavy federal intervention. This intervention has taken the form of Public Health Service grant-in-aid programs to Medicare and Medicaid, plus social service programs through Title XX. Despite this infusion of money and services over the past twenty years, long term care problems remain.

Long term care services are needed and used by persons of all ages to compensate for a diminished ability to care for themselves. These services can be provided in several settings such as the home, the community, or an institutional facility, like a nursing home. At the lowest end of the continuum are ordinary types of help which many persons need from time to time: reassurance, transportation and help with household tasks. Persons with functional incapacities need these types of assistance more frequently and over a longer period of time. Next come the types of assistance which help persons handle instrumental activities of daily living (IADLs): laundry, cooking, shopping and money management. Personal care services address the need for help with self-care tasks or ADLs, like bathing, dressing, toileting, eating and transferring. Also on this continuum are services like counseling, referral and respite care to aid families who care for impaired relatives. For persons with mental and emotional problems, supervision and protection are provided. Rehabilitative services (occupational, speech, and physical therapy) are part of the total array. Finally, medical services are usually provided by skilled professionals under the guidance of a physician. These services might range from skilled monitoring and observation to injections to tube feedings (Rockefeller Institute of Government, 1986; Monahan and Greene, 1981). Besides the direct services, the continuum also includes the professional and paraprofessional jobs, research, and capital generated through the provision of long term care. Financial support is obtained through both public and private sources.

Long term care has emerged as a prominent issue because there is a broad and growing population in need, a diversified but unbalanced financing system, and increasingly less ability to pay for long term care on an individual out of pocket basis because of rising costs. The burdens of long term care have touched the poor plus middle-income families and individuals for whom the high cost of caring for a chronically ill elderly adult can lead to poverty and the necessity of relying on public resources. Long term care did not evolve as a result of rational planning for the needs of America's elderly. Rather, it evolved piecemeal and as a byproduct of a health and social welfare system in crisis (Harrington, Newcomer, and Estes 1985). Today, the provision of long term care is a multibillion dollar service enterprise. It involves the public sector government agencies at the federal, state, and local levels, plus the private for-profit and nonprofit sectors.

Despite the many public dollars being spent and the number of organizations available, a host of long term care problems has been identified. Compounding the problem of public expenditures rising rapidly is the fragmented approach to the delivery of services. Older individuals needing services must struggle through the network of independent applications for Medicaid, SSI, Title XX and Title III programs. Even when communities make a full range of services available, there is seldom a single point of entry. Gaps in the continuum of services can create a "no-care zone" where existing services are not appropriate for an older person's needs (Wallace 1990, p. 254). As the system now operates, the older person is responsible to determine the type and frequency of services needed, where they are available, and how to design a comprehensive service package. Without the necessary case management services or knowledge, a person is pushed toward institutionalization.

A continued examination of the present health care delivery system is desirable to produce a better organized and integrated approach to meeting the needs of the elderly. It is likely the larger problem of operating the long term care continuum with a variety of service options to accommodate the changing health care needs of the elderly will only be exacerbated with the growing numbers of older adults unless refinements are made quickly. Clearly a full range of settings and services must exist so that older adults can maximize their choices without sacrificing quality in living arrangements and resources.

Policy Dilemmas

While there seems to be agreement that the elderly need something from the government, the particulars have not been highly specified. The elderly population as a whole has many needs which are experienced at different levels of intensity across a wide spectrum. Specification of what should be done in response to any identified problem meets with little agreement.

There are controversies about what policy aspect of the problem of old age should be addressed. Likewise, there are also differing perspectives on the goals to be achieved by any governmental intervention. Lampman has identified three general perspectives - a welfare, a social-insurance, and a public-finance perspective in viewing the goals of federal policy on aging (Achenbaum, 1978). The assumptions underlying the welfare perspective are that older persons are disadvantaged and should be guaranteed a minimum level of income and services. Programs are assessed by how well they provide this minimum, the standard poverty level. Adequacy is measured either individually, by benefit levels, or in the aggregate. Analysts who emphasize the social-insurance goals of programs for the elderly would assess: equitable rates of return on past contributions, a reasonable ratio between pre-retirement earnings and the retirement benefit, and a scaling of benefits relative to need. The public finance perspective is generally favored by economists who use the criteria of equity and efficiency to assess the success or failure of public programs.

Because the nature of the elderly as a group is changing, individual and family systems providing for old age problems are facing difficulties. Public intervention has become necessary in making aging policy more responsive to today's realities, and the government faces many dilemmas as it tackles these policy changes. Public support for the idea that long term care needs of the elderly should be met primarily by the government is not new. The view that old age with its problems is not just a private trouble to be dealt with individually can be traced back to the New Deal. Reluctance of policy makers to make long term care a public responsibility can be understood as resulting from political economic theory and misconceptions about older people and their family relationships.

To some extent, policy makers and the general public both subscribe to the notion that families are alienated from and abandon their elderly members to be cared for by the state. Despite the fact there is considerable evidence to the contrary, the belief persists that adult children do not care for elderly parents as they did in the past. The perception that family caregiving is on the decline in the U.S. worries policy makers who fear publicly sponsored programs will begin to supplant family care, adding to the exorbitant cost of long term care for the elderly. This myth of family neglect has been used against families in the interest of cost containment. As this and other myths persist, politicians express reservations about the extent of responsibility the government should assume in caring for the elderly. Policy makers believe the way to control large numbers of families demanding services if they were made available by the government is to limit these benefits and services.

According to political economic theory, there is always tension between democracy and capitalism, with attempts to curtail social spending to have resources to foster the growth of profit and concentration of wealth. This theory suggests that government responsibility appears to comply with public preference to fulfill its role of legitimization. Hence, it appears the best interests of elderly people are being protected while at the same time preventing a major challenge to the existing distribution of wealth and power. An example is that much of social spending has been financed by the working class through a regressive payroll tax (Biegel and Blum, 1990).

In examining the limitations as well as the scope of the formal support network and its role in the provision of long term care, a parallel situation is that of the deinstitutionalization of patients from state mental hospitals in the past twenty years. Many of the deficiencies in the formal support network that undermined community based care of the mentally ill also apply to the formal network of long term care supports for older adults. This example provides many of the key concerns about the role of the formal service network in providing or supplementing long term care of the elderly.

The impetus for the deinstitutionalization of the mentally ill arose from the concerns of many individuals who found the conditions of the mentally ill placed in institutions unacceptable and advocated a shift to community based options. However, a comprehensive network of community based alternatives did not exist, even though patients were being discharged. The results were patients who had no place to go and often times had no supportive network to ease the transition. Another problem of the deinstitutionalization movement was the difficulty in developing non-institutional structures which could be viewed as equally effective and efficient.

A third problem of this movement was the lack of financial commitment and political support necessary to provide the appropriate range of community based services to facilitate successful reintegration into the community. Within a brief time span, it became evident that alternatives to institutionalization did not come cheaply and the proposed savings of a community based treatment model were not compatible with the extensive range of services needed. In addition, without public education and a lobbying campaign to develop support for the needed expenditures, the network of community based services never developed as originally proposed (Rubin, 1986).

The situation of the mentally ill who were discharged from institutions parallels that of the elderly under the recent Medicare prospective payment plan for hospitalization. Since the inception of this plan in 1983, many have expressed concerns that older patients are being discharged from hospitals "quicker and sicker." The issues mentioned above - institutionalization versus community based services, the lack of a viable community based service network, the costs of providing a range of noninstitutional care, and the commitment necessary to undertake these costs - get to the root of the question of federal and state responsibility in the provision of long term care.

New York State's Efforts

New York State has a history of heavy investment in social welfare. These efforts have resulted in the eligibility of more people for more services, and continuing concern with cost containment problems. Significant activity towards the establishment of an effective, balanced service delivery structure has taken place in the last few years in the generic long term care, mental health and mental retardation areas. New services have been developed which broaden the continuum of supports available to the population requiring long term care services. Also, programs to improve the coordination and management of resources have been established.

One recent initiative undertaken by New York State made a heavy investment in home care in an effort to counterbalance the heavy emphasis on institutional care. By 1980 there were well over 100 home health agencies certified for medicare and medicaid plus a growing list of proprietary home health agencies. Between the years 1974 and 1977, per capita medicaid expenditures for home care increased by almost 800 percent in New York. In 1978 New York accounted for about 76 percent of the entire nation's medicaid expenditures for home health care (Morris, 1981).

A further commitment to the option of home care can be seen in the establishment of the Long Term Home Health Care Program. Better known as the "Nursing Home Without Walls," this program is designed to provide and coordinate a range of health, social and environmental services to persons who require a skilled nursing or intermediate level of care. The cost of care for an individual can not exceed seventy-five percent of the average annual cost of long term institutional care in the area of the patients' residence, fifty percent if the patient is a resident of an adult home (Lombardi, 1988).

Other interesting service packages that are being encouraged in New York include geriatric day care and congregate housing for the elderly. Geriatric day care is a service providing supervised activities and health related services to elderly who are ambulatory. The program provides primary care, home health care, respite care and drugs. Congregate housing for the elderly develops innovative housing which is specially designed and managed to meet the needs of the elderly. For example, NYC Housing Authority is using capable elderly residents as floor captains in its senior citizen housing. New York is also exploring new ways to establish a technical assistance program aimed at developers interested in using federal housing funds for construction focused on meeting the daily needs of older persons (Morris, 1981).

A variety of these non-institutional services for the elderly and disabled have met with increasing use and success. However, the promotion of long term alternatives has had its problems for New York State. Most of these services have been funded, (out of necessity) by Medicaid, and thus, are still medically oriented and frequently only available to the very poor. In addition, as more services have been developed, multiple and conflicting program criteria and regulatory standards have evolved. Efforts to effectively manage clients and insure that they obtain the most appropriate and economical forms of care have been hampered (Axelrod and Callender, 1984).

In New York, as in other states, long term care is shaped heavily by the requirements of federal policies and programs. One policy in particular, the Older Americans Act of 1965, created layers of administrative structure, with multiple ambiguities of how to regulate the dispensation of services to the elderly. The passage of the 1973 amendments created The Area Agencies on Aging in order to provide a mechanism for the actual delivery of services to older Americans. The New York State Office for the Aging provides for the planning, coordination and provision of services for the elderly, distributing both federal and state funds to 59 Area Agencies on Aging. Ideally, the concept of an area agency was striving for a comprehensive and coordinated service delivery system. In reality the area agencies made the aging network cumbersome, diffused control, created more fragmentation and divided responsibility across and between all levels of government. While New York has tried to initiate new policies and approaches, the state must still cope with a difficult period of cost control. Some fear the potential explosion of long term care expenditures will force the federal government to be more restrictive, perhaps even eliminating financial supports and subsidies for long term care (Morris, 1981; Rich and Baum, 1984; NYSOFA, 1987).

Special Interest Groups

The health services in our country could not escape from the trend for citizen participation in almost all federal legislative programs. As a result of the indignation and pain at their treatment, awareness grew in the 1960s towards more public participation in decision-making. Out of the discovery that health services were not available freely at the time of need, nor equally to all citizens, demands developed from citizens and organized groups for a role in the planning, management and delivery of their health care services. The Older Americans Act of 1965 directly and indirectly created a network of planning and provider agencies and professional organizations which acted as an influential catalyst to interest group politics in the field of aging (Estes, 1979).

Interest groups representing older adults play an important role in both the formulation of policies for the elderly plus the review and evaluation of the administration of these policies. One of the largest of these organizations is the American Association of Retired Persons. Organized in 1958, this group plays a key role in debating and proposing solutions to legislation affecting the elderly at both the state and federal levels. Another organization, The National Council of Senior Citizens, was established in 1961 to promote the issue of Medicare. Over the years it has helped to develop rental apartment buildings for the elderly and been a sponsor of a program offering part time employment to low income persons over the age of fifty-five. The Gray Panthers, another advocacy group, originated because of the determination of Maggie Kuhn. In the early 1970s the group was a movement to address the special problems of retired people and to oppose the Vietnam War. By the mid-1970s the group had gained recognition for bringing together young and old people to combat ageism and to oppose social injustice at all levels (Rich and Baum, 1984).

An example of an organization seeking support for families and alternatives to institutionalization is the Older Women's League. This group was formed following the White House Mini-Conference on Older Women in 1980. The organization has nearly 8,000 members and chartered chapters in 30 states. Through education, research, and advocacy, members work for changes in public policy to "eliminate the inequities older women face" (Older Women's League 1983, p. 1). Long term care has become a focus for this group because they perceive it as a women's issue. Recent efforts of the organization have been directed at advocating specific legislative proposals such as coordinated community based services, expanded home health care services covered by Medicare, and caregiver financial incentives.

The National Association of Social Workers (N.A.S.W.) is an example of a professional organization seeking to affect the support available in long term care. N.A.S.W. newly formed an Aging Subcommittee as part of their Commission on Family and Primary Associations to discuss topics like family caregiving and social workers in gerontology. This group recently met with the staff director of the U.S. House Select Committee on Aging to lobby for their concerns (N.A.S.W., 1988a). Efforts were made to urge the Democratic Party to commit itself to strengthen families and family caregivers by making existing legislation more responsive to current realities in American families (N.A.S.W., 1988b). Recently the president of N.A.S.W. urged members to support their proposed universal health plan; a response the organization believes is needed in restructuring the present health care system (N.A.S.W., 1990).

Self-help and responsibility is required of consumers in our pluralist health system and this is acceptable for the healthy, intelligent and employed, but becomes a great burden on those unfortunate enough to be handicapped, disabled, unemployed or old. In such a society which believes that success in the marketplace is the acid test for all services, consumers must have the power to obtain information, and consumer support systems are needed in order to constrain suppliers to give good service (Bates, 1983). In the past decade, the number of associations advocating for the aged has increased substantially. Since it is estimated 50 to 70 percent of those over 65 vote in elections, senior citizens already constitute a powerful voting block, and their political clout will undoubtedly grow as they increase in number (Hill and Kent, 1988).

Informal Network of Family Caregivers

In the past, people have equated nursing homes with long term care, although they are only one possibility in the range of long term care services. The range of long term care providers is as broad as the services they offer. These include both informal and formal providers of services and the settings in which services are performed. Together, these two providers create a system that has made it possible for the majority of all elderly to live in the community.

The formal network is typically defined as community services and agencies designed to assume some of the caregiving tasks for older adults. These services are intended to complement family care and strengthen the family's ability to respond to the needs of their older family member(s) (Report of the Task Force on Older Women, 1986; Springer and Brubaker, 1984). The formal component of the social support system of an older person is comprised of a collection of basic entitlements and services provided by large scale bureaucratic organizations. Political and economic entities which determine basic entitlements available to all older people impact on their well being in the areas of income maintenance, health, housing, safety, education, and transportation. Governmental and voluntary agencies that carry out economic and social policies provide the actual services as mandated under laws like Social Security and Medicare.

Lying somewhere between formal organizations and informal supports are nonservice formal or semi-formal organizations. These providers also perform a helping function with respect to the elderly. For example, postal workers, storekeepers, bartenders, building superintendents, friendship delegations from unions, or visitation groups from churches may all play a role in the elderly's support system. This network has been labeled tertiary in that it resembles the informal network but originates from and is related to formal organizations (Cantor, 1979).

Informal support systems are usually viewed as those individuals closest to the daily life of an older person. Family members, friends, and neighbors are seen as the significant others with whom older people have the most frequent interaction both instrumentally and affectively. This assistance can allow the caregiver to keep his/her older dependent family member at home longer than would otherwise be the case (Springer and Brubaker, 1984; Cantor, 1979).

The collaboration and interaction of the formal and informal support networks plays a critical role in providing the older person with assistance to deal with a variety of social, emotional and medical problems. The challenge in most cases is to attempt to achieve an appropriate balance of such forms of aid. The factors which must be considered are not simply preferences of the older person, but also such factors as the limits of energy of the informal providers, the level of skill and technology required to apply a treatment, and the duration of time for which assistance is likely to be needed (O'Brien and Wagner, 1980).

Policymakers and researchers are very interested in the role of the formal sector in supporting informal caregivers as well as the proper mix of informal and formal services required to meet the needs of noninstitutionalized elderly care recipients. Litwak and his associates (1969)suggested that the dependency needs of an older person could be met by a balance of the support networks, as defined by function. Thus, the informal system might be better suited for non uniform aspects of care: those which are simple, unpredictable and nontechnical. In contrast, the formal system might be better suited for care which requires expert knowledge and large scale resources (Stone, Cafferata, and Sangel, 1987). Bowers (1987) found defining tasks of caregiving was not consistent with the experiential world of the caregiver. Still other research suggested that the formal system supplements the efforts of the informal system. This viewpoint recognizes that much care needed by chronically impaired persons is routine but at the same time, consuming and taxing for caregivers. Service providers can supplement the efforts of primary caregivers by offering respite versus specialized help (Noelker and Bass, 1989). It would seem effective collaboration between formal and informal support networks depends on shared tasks and functions, the cultural meanings attached to caregiving and on shared perspectives (Risteen Hasselkus, 1988).

When services are available many of the elderly and informal caregivers report not utilizing the formal support network. In some cases neither the frail elderly nor their family and friends are connected to networks that can link them to formal services. Some caregivers feel they are not ready to utilize services but are able to draw upon others to fill in for them. Others believe that dependence on services is a sign of personal failure. Many Americans fear the intrusion of services into their homes because they are alien. Still other caregivers cling to duties as a source of self esteem (Caserta et al., 1987; Abel, 1987; Cicirelli, 1981).

The 1982 National Long Term Care Survey and Informal Caregivers Survey confirmed previous studies, pointing to the low use of formal care by caregivers. Data revealed that caregivers tended to provide care alone or with assistance from unpaid helpers. Less than 10% reported the use of paid services and this use of formal care was used to assist the most severely impaired elderly (Stone, Cafferata, and Sangel, 1987). In a smaller study, data showed that 42% of the households surveyed (N=519) did not use formal services to meet the care recipient's personal care and home health needs. Findings indicated that community services are triaged or supplied to elderly persons who are most disabled. Caregivers seemed to deplete their physical and emotional resources before the formal system was investigated (Noelker and Bass, 1989).

Low use of the formal network points to the existence of a solid core of informal social support, particularly in a time of crisis. Although family structure has changed and is continuing to change, there is strong evidence of an informal support network of kin and nonkin interaction with the elderly (Cantor, 1979; Bromberg, 1983). The social myth that in contemporary American society old people are alienated from their families has been refuted since Shanas (1979b) eloquently addressed it in her now familiar article. This article points out that the proportion of elderly with children who either live with one of their children or within ten minutes distance of a child has remained fairly constant over 20 years. Brody (1985) underlined this theme by noting that having a dependent elderly parent has become a normative experience for individuals and families. Rather than ignoring these elderly relatives, families have responded with the provision of difficult care over long periods of time.

What becomes quite evident in reviewing the existing kin networks is that the modified extended family is bound together by choice and through affection and patterns of mutual aid. Parents and adult children alike turn to each other in times of illness and crisis. These patterns are indicators of the mutual expectations of generations for each other (Troll, Miller, and Atchley, 1979; Bromberg, 1983; Shanas, 1979a). The family really seems to link the elderly to the formal support network. In a variety of ways like nurturance, provision of information, influence in decision making, and seeking service options, the family responds to buffer against bureaucracies (Hanson, Sauer, and Seelbach, 1983; Brody, 1985).

Caregiving activities vary widely across families and can range from linkage with the formal service sector to emotional support, direct service provision and financial assistance. For example, families may develop a schedule to share with transporting a parent to the doctor, or relatives may stay with an old person so other caregiving relatives can spend time with friends. Family members may provide direct support such as cleaning the house or offer emotional support by being empathic during difficult times, offering possible solutions to frustrating situations or simply listening to caregiving experiences (Springer and Brubaker, 1984; Ory, 1985).

In some instances family care can be a higher quality form of care than is available elsewhere. Because of the affection family members have for the elderly person plus the knowledge of habits, preferences, abilities and history of this relative, the care they provide can be individualized within a familiar setting which imposes the least amount of restrictions upon the elderly family member. The strength of filial responsibility norms support the importance of the affective and emotive functions of the family unit today. Families do not quickly institutionalize elderly persons. Even when care is hired or someone is placed in an institution, families spend a great deal of time in overseeing care, providing amenities and giving elderly relatives affection and support (Gilhooly, Zarit, and Birren, 1986; Hamon and Blieszner, 1990).

Family resources of older persons often depend on the availability and proximity of family. While both psychological support and financial assistance can be provided by relatives living at a distance, direct services like meal preparation, personal care, and home maintenance is possible when relatives can have daily or weekly contact. Co-resident care incorporates caregiving activities within the overall structure of ongoing household activities and can involve 24 hour supervision (Hays, 1984; Gilhooly, Zarit, and Birren, 1986).

Overall, it seems clear that the informal family network is an important resource. There is strong evidence that considerable intergenerational exchange takes place between families and their elderly members. Only when family are not available, and for certain defined tasks, do others in the informal support network and the formal support network become important in the provision of supports. When exchanges occur providing some autonomy, when emotional support is exchanged versus goods and services, and when a balance is achieved between giving and receiving, both parties appear the most comfortable in their value of supporting mutual aid in today's modified extended family. Caregiving can have some positive benefits for family members too. Families may draw closer together through their expression of love and fulfillment of obligations. Also, families can feel that their services make a difference in guaranteeing appropriate and high quality care (Cantor, 1979; Hanson, Sauer, and Seelbach 1983; Ory, 1985).

Dilemmas in Family Caregiving

Caregivers can pay a high price physically, emotionally and financially for the services they provide. The impact caregiving can have in changing a family member's life can be enormous. Changes like health, social activities, occupation and family relationships are some of the ways the caregiving role is felt by those who elect to take it on. Moritz, Kasl, and Berkman (1989) distinguish impact of caregiving as the objective changes, versus burden, or the subjective experiences that certain caregiving tasks are felt as stressful. Objectively it is simple to point to the reasons why caregiving can be an overwhelming experience.

Exhaustion of a caretaker has been the reason for many family members to seek institutionalization. When one is caring for another who is ill and restless at night, depletion of physical resources can occur quickly. Sometimes fatigue can be brought on by the nature of the caregiving demand. Depending on life stage demands, a caregiver can become exhausted in trying to juggle different pressures. Particularly pressured are adult children caught between a spouse, their own children and elderly parents. The tension generated by these multiple demands can leave one feeling drained and unsatisfied.

While caregiving by families is common, decision making about the arrangements does not always occur with agreement. If financial resources are scarce, the caregiver may be making a large commitment and substantial sacrifice to provide needed services for the ill relative. Decisions may be required by several parties necessitating family cooperation and the possible emergence of old conflictual dynamics. If a caregiver perceives they are providing the majority of care, conflict can often arise in families over the inequality of time or energy. Some family members may resent providing arrangements without being asked to contribute to the decision-making process. When disagreement occurs over how care should be provided conflict between family members can sever relationships, isolating the caregiver and causing feelings of powerlessness (Parsons and Cox, 1989; Gilhooly, Zarit, and Birren, 1986).

Often times caregivers are overworked and under stress, experiencing a complex mixture of emotions. On the one hand caregivers may feel love, pride and a sense of personal accomplishment for providing care to a relative. On the other hand grief, loneliness, frustration, anger, guilt, anxiety and depression may all be felt at various times during the course of caregiving.

Many caregivers experience grief over their lost relationship with a husband/parent, for their loss of identity as a dyad. This type of loss is not final as in death. This open-ended experience can go on and on as the caregiver watches their relative deteriorate, feeling helpless in not being able to stop the process. Grief can also be felt over lost lifestyles. As a caregiver spends day after day at home with an ill relative feelings of being trapped or cheated out of life can surface.

Loneliness is often a by-product of the caregiving role. It may be caused by being confined to the house 24 hours a day or by just being too busy and tired to keep up social contacts. Some times caregivers will organize their social life around activities the elder person enjoys but give up their own friends and interests in the process. It is also not unusual for a full time caregiver to feel isolated from a husband or children even though they all live in the same house (Sommers and Shields, 1987).

Anger is another common emotion among caregivers. Sometimes the anger is for family or friends who do not do enough. If an adult child has remained at home and forgoes marriage to care for a parent, there may be regret and anger over their chance for a separate life. If sibling rivalry has persisted over the years, anger may be felt toward a sibling who appears to be getting most of the credit for doing little. There is also a sense of betrayal at systems caregivers believed would support them. Perhaps lifetime savings will all have to be used for nursing care instead of insurance coverage paying for services. Or, anger is directed at the medical community which fails to provide adequate information and assistance. Finally, anger can be turned on the disabled relative for getting ill or for being the wrong parent to become ill (Schmidt, 1980; Sommers and Shields, 1987).

Family members can have high expectations of themselves in the caregiving role. They quickly note the disparity between what they are actually doing and what they feel they should do. Guilt, another emotion felt when caregiving, can cause a person to doubt their effectiveness, believe they are not nurturing enough, perceive that others handle their ill relative in a better way and that they are not doing more for their relative. Guilt can be the result of conflicting feelings. A caregiver may want their relative to live and improve but also hope the relative is released from misery by dying peacefully. This conflict can make the caregiver feel guilty for thinking of death as a viable option (Schoonover et al., 1988; Sommers and Shields, 1987).

A number of situations can complicate the task of caregiving. For example, many women who are caregivers also work outside the home. Caregivers who have children at home face two different generations who need nurturance. With adult children living at various distances from their aging parents, many children find themselves caregivers at a distance. Minority caregivers, in general, can expect to face extra strains. Since the majority of caregivers tend to be women caring for an elderly relative, this means not just redistributing existing tasks, but creates a larger package of responsibilities (Brody, 1981). Sharing caregiving within families becomes essential to the integrity of the whole family unit. If a husband and children can not adopt a supportive role where the older adult is made to feel part of the life of the family, than feelings of resentment over the time and energy spent elsewhere may lead to demands the caregiver can not meet. In the extreme case, limitations on the kinds and amounts of caregiving provided over time could result in marital disruption.

The caregiver's willingness to provide help over an extended period of time requires strong motivation and commitment to the welfare of a disabled relative. For many, the rigors of managing a household plus providing full time personal care can be physically and emotionally draining. The need for constant care without relief can cause some to develop health problems (Ory, 1985). While some caregivers may be available to help on an intermittent basis, it may be difficult for them to be with an older adult on an extended basis if the differences in values, interests, and general life style are too great. If there are great sacrifices involved some caregivers may have less of a commitment to provide help. The problems an older adult faces such as, preventing social isolation and finding ways to use their time, are difficult to satisfy through caregiving. If the bonds of attachment to the dependent person are weak there is likely to be little motivation to provide sustained and extensive care. Premature institutionalization, neglect or abuse may occur when the family caregiver is unable to deal with the frustrations of extended care (Cicirelli, 1981; Gilhooly, Zarit, and Birren, 1986).

The financial resources of a family are an important factor in determining the breadth and quality of caregiving as well as if using alternatives is a feasible option. If the dependent relative requires continuous care and supervision, while the family caregiver needs to work daily to pay bills, it can be a real dilemma unless some relative is free to provide care. Long term care services and supplies are expensive to many middle income people. Although some can purchase some assistance for limited periods of time, an extended illness may exhaust their resources. Low income people face special problems in delivering care. Those who work may have jobs with rigid schedules so that time away from the job to help a relative may mean some penalties or no pay. Poor people are unlikely to be able to purchase assistance outside of formal organizations and formal services provide limited access or coverage (Abel, 1987). Many women caring for disabled spouses have been homemakers, with no income or pensions in their own names. Even if wives do work they may be faced with pressures to quit their jobs and stay home to provide care. This decision will cost a wife her present income as well as pension or Social Security income in the future (Sommers and Shields, 1987; Older Women's League, 1989). In addition, given the advanced ages of family caregivers, many are assuming this financial commitment at the point when they are planning for their own retirement. Over the long term, assuming financial obligations can represent an immense strain.

Role Reversal

As an elderly relative's illness progresses many changes in family relationships and roles are likely to occur. The older person is experiencing the many losses involved in aging like independence, memory and friendships. There is a sense of "role shrinking" as past functions once performed by an older adult just dwindle (Bromberg 1983, p. 77). The caregiver generally takes on the many role behaviors and tasks formerly enacted by the now dependent adult. This can be difficult for a spouse who is assuming new gender specific roles or for an adult child who must assume a parent's roles.

Facing role reversal, where adult children care for their parents who had always cared for them, can bring unresolved tensions to the surface. Any ambivalence with relationships can be exacerbated by the many pressures faced in balancing multiple roles. Features like power and dominance in relationships will inevitably change. Where there were once rigid and long established behavior patterns in relationships, there may be little which now feels familiar. A caregiver can have difficult adjustment problems when coping with the loss of a former relationship. While the older adult is very much alive, transformation of the person may make a fulfilling relationship only be a memory (Gilhooly, Zarit, and Birren, 1986).

The Role of Women

The informal social networks of most older people are dominated by kin, with women assuming the central caregiving roles. Most likely, the caregiver of an elderly couple is the wife since women generally live longer than men and are younger than their husbands. If a spouse is unavailable or the level of support required can not be met by a spouse, adult daughters usually assume the role of primary caregiver. Childless adults appear to compensate for their lack of offspring by developing close relationships with other kin. The majority of these other helpers are also women (Stoller, 1990; Johnson and Catalano, 1981).

The average caregiver to the elderly is 45 years old, female, and married. Recent statistics indicate three out of every four caregivers to the elderly are women and two-thirds of these women are married. Among children who provide primary care to their parents, daughters outnumber sons three to one (Older Women's League, 1989; Stone, Cafferata, and Sangel, 1987). Such data do not imply lack of responsibility or family feeling on the part of males; rather, they reflect the cultural assignment of gender-appropriate roles (Brody, 1981).

A look at traditional Western sex role socialization can explain some of the gender differences in caregiving patterns. For instance, parents socialize girls to be more affiliative and nurturing while boys are expected to express initiative in mastering tasks and to be less focused on interpersonal closeness. Masculinity is associated with an emphasis on getting the task completed while femininity is associated with an expressive and affective concern with the well being of others (Kaye and Applegate, 1990). Given different life experiences and socialization patterns experienced by men and women, the demands of the caregiver role may elicit different responses. Women may expect that caregiving is a continuation of earlier family responsibilities while men may view caregiving as foreign. Women may be dependent on others for social support and focused on family relationships with an active involvement in daily tasks. In contrast, men may expect to receive more assistance from others in completing daily tasks (Pruchno and Resch, 1989a).

Gender appropriate roles played by caregivers can also extend to the particular tasks they perform. Studies demonstrate the sexes differ in the types of aid they provide. Male caregivers help with home repairs, household chores, driving, decision making and financial assistance. Females assist with cooking, shopping, laundry and personal care. Generally there is a smaller time and intimacy commitment to caregiving by men. The caregiving tasks linked to men can usually be performed at the times they choose. However, womens' tasks often demand that caregivers be on call 24 hours a day. Furthermore, the tasks associated with women are the ones researchers have correlated with high levels of stress (Young and Kahana, 1989; Pruchno and Resch, 1989a; Horowitz, 1985b; Abel, 1987).

In addition to women assuming the traditional nurturing tasks and their stronger emotional tie to their family of origin, the fact that they have more flexible free time in their role as homemakers makes them a logical choice for primary caregivers. This nurturing work is seen as a women's duty or function and is sharply differentiated from what is viewed as productive labor in the paid work force (Hartman, 1990; Rubin, 1986). Women caregivers who do seek employment generally end up over-represented in the secondary labor market with low wages and few benefits. For many women the cycle of caregiving begins with their children, is revisited when a parent becomes ill, and again, when their aging spouse needs care (Abel, 1987).

The women's movement and changes in attitudes about gender appropriate roles have been influential in the unprecedented increase in the number of women entering the work force. Scharlach (1987b) indicates a fourfold jump in the number of working women in the past 50 years. Forces operating to produce such numbers include: the rising divorce rate which sends many women to work; many women have fewer children to keep them home than did previous generations; labor saving devices for the home results in more free time; increasing educational levels stimulate career interests; and inflation coupled with the rising cost of living compel many women to seek work outside the home (Brody, 1981). For those women who hold full time or part time jobs in addition to their caregiving responsibilities, they can expect to experience the compounded demands of these multiple roles. The effects of women's participation in the labor force on their ability and willingness to continue being caregivers have yet to be seen.

As a result of the widespread changes in women's lifestyles there has been a corresponding increase in role obligations. Influenced by societal norms and personal values, a woman's obligations can include her family, job, parents, marriage and social contacts. Role overload refers to the perception that there is not sufficient time, energy or resources to fulfill the obligations of all the roles one must play (Scharlach, 1987b). Role overload is likely to occur among women who serve as caregivers for elderly adults in addition to their other responsibilities.

Particularly at risk for role overload are caregiving daughters and daughters-in-law. Brody (1981) has labelled these females, "women in the middle" (p. 471). Such women are in the middle age period of their life cycle as well as in the middle of two potentially competing values. They may be experiencing pressure from the traditional value that care of the elderly is a family responsibility versus the value that women should be free to work outside the home if this is their choice. The various roles women have assumed compete for their time and energy more than ever before.

Women in the middle may have feelings of resentment and guilt which get played out as the caregiving role progresses. For instance, women may dislike having to resume child rearing responsibilities in mid-life in the form of caring for their parents. There may be perceived adverse effects on physical and mental health as a result of how the caregiving responsibilities are handled. Also, there is likely to be an impact on the care recipient if the caregiver is strained and dissatisfied (Quayhagen and Quayhagen, 1988; Scharlach, 1987b).

A prime example of how a woman can be pulled between competing demands is the impact of caregiving on work. Caregivers report interference with their work activities due to the variety of ways they deal with parent care responsibilities. While on the job women may leave work early or extend lunch breaks, and make or receive caregiving related telephone calls. Women relate being so tired as a result of caregiving that it is difficult to perform well at their jobs. Due to the demands of caregiving, women report turning down training opportunities or the chance to advance because it means re-location (Scharlach and Boyd, 1989).

In coping with the demands for parent caregiving many women are reallocating their energies and making many personal sacrifices. For women caught in the middle the task load is great, with their family responsibilities involving competing demands from several generations. Middle aged women may themselves be slowing down and facing caregiving demands with depleting physical energies. The demand to face irreversible declines in their parents' health and functional status means these women must cope with anticipatory bereavement issues. In addition, parental caregiving may conflict with a woman's expectations of leisure time and independence from family responsibilities in her retirement years (Stoller, 1983; Lang and Brody, 1983; Scharlach, 1987b; Gilhooly, Zarit, and Birren, 1986; Neugarten, 1968).

Reactions to Caregiving

The life crises which we consider to be normal usually occur in a somewhat predictable fashion as individuals move through defined age categories. Those categories are associated with age specific mental, emotional and biological developments and capacities. In contrast, the demands of parent care are often incompatible with the caregiver's mental, emotional and biological capacities. Especially for adult children, the reality is that the increasing demands of caregiving are not in sync with their declining abilities to meet those demands. Parent care is not a single stage that fits neatly into the stages of the life cycle. Parent care can overlay many different ages and stages in different individuals and families. Also, parent care is often an extended process which can span several of the caregiver's stages. Reactions to the necessity to provide parent care range from healthy to pathological, as do responses to other life crises (Brody, 1985).

While a family caregiver may decide it would be appropriate and effective to care for an older adult, there are many practical factors that influence and often limit the capabilities of a family member to provide the needed care. As mentioned earlier, women are facing an immense number of life transitions and multiple roles in middle age. Age related changes such as widowhood, empty nest syndrome, adult children returning home, retirement and the onset of chronic ailments all complicate caregiving. Different factors are related to the stresses of caregiving and can cause the subjective perception of burden. Burden need not be correlated with the severity of the older persons' physical or mental health problems. Rather, perceived burden has been associated with factors like social supports available, the sociodemographic characteristics of the caregiver, past history of family dynamics, and the caregiver's preexisting coping abilities (Ory, 1985; Brody, 1981; Report of the Task Force on Older Women, 1986).

Caregiving contains a number of potentially stress producing features associated with the work, including isolation. There tend to be no boundaries in time, no sense of completion and no time off from the work. While there is freedom from the supervision via respite activities, there are few tangible rewards available as incentives for good performance. Friendship patterns and old activities are often disrupted quite suddenly. Unlike childrearing, care for the elderly is unpredictable, with little planning being completed for the future (Stoller and Pugliesi, 1989; Fengler and Goodrich, 1979; Abel, 1987).

Given the potential for a high stress situation, combined with the prolonged dependency of the patient, relatives respond with adaptive mechanisms to help them cope with caregiving. For example, as an older person deteriorates and becomes more irritable the pressures increase on families. A caregiver may react to the pressures by creating a distance between the older person and herself. The distance may be a physical one or, in some cases, an emotional one, where the caregiver continues to meet instrumental needs with minimal emotional commitment. Some caregivers establish distance through enlarging the family network. In this way there are more persons involved in the daily care activities.

Another coping strategy is a process where the caregiver accepts this role as permanent and full time, to the exclusion of others. The caregiver defines the role to be enhancing to her self esteem and it replaces the loss of other roles. A spouse can make a total commitment, thus, ignoring the role losses of the aging process (Johnson and Catalano, 1983; Brody, 1985).

Some caregivers are not equipped to develop coping mechanisms or the physical and emotional stress becomes too much with which to cope. Frequently the physical labor involved in caregiving puts strain on the body causing damage to discs in the lower spine, lower back pain or increased susceptibility to arthritis. Stress can lead to poor eating habits and may even lead some caregivers to drug or alcohol use. Finally, caregivers may feel such despair in being powerless to change their relatives' outcome that their hopelessness turns into depression (Sommers and Shields, 1987; Fitting et al., 1986).

Examination of an informal caregiver's role points to the high level of stress often faced by many family members who care for the elderly. For instance, the physical pressures and time commitment of caregiving are unrelenting. The 24-hour a day responsibility for providing care for a dependent relative can produce enormous strains on the entire family. Routines are often disrupted and questions of autonomy over lifestyle decisions arise. Privacy can suffer and unstructured time away from these responsibilities can become minimal or non-existent.

The demands and burdens of caregiving change over time. The progressive nature of some diseases results in shifting demands on the caregiver. Caregivers' resources and other responsibilities also change over time. At some points caregivers' support networks may mobilize and then may dissipate at other times. Caregivers may be faced with losing their social lives, feeling overwhelmed, or develop health problems of their own. Thus, caregivers require a mix of service options that can be activated as circumstances dictate (Gwyther and George, 1986).

There is evidence to support that families who care for impaired elderly relatives may become "burned out" and have to turn to institutional care out of sheer exhaustion of resources. Families tend to be guided by a sense of indebtedness and/or fear of nursing home placement. However, even with such motivation, the long hours, restricted freedom, regimentation, frustration as well as other factors, places a real burden on family caregivers (Frankfather, Smith, and Caro, 1981).

Current Responses to Family Caregiving

The United States is one of the few industrialized countries in the world without a comprehensive plan for the care of the elderly. Cultural values and the history of the United States are at odds with the widespread support for policies which embrace universal coverage for the care of the elderly. Such policies are contrary to the ideology supporting individualism and a limited Federal government role in the affairs of state government and the family. Several factors such as, the complex bureaucratic structure of the Federal government, the distrust of government power, a tradition of low taxes, a confidence in the private sector to meet social welfare needs, and a strong sense of individual responsibility all contribute to the slow evolution of a welfare state in the U.S. (Kosberg, 1985).

Paradoxically, it seems as though U.S. citizens believe that government should be doing more to assist families to care for their elderly relatives. In a 1981 Roper poll, 69% of respondents expressed the opinion that spending on social services for older people was too low, while only 5% thought it was too high. During the 1983 - 87 period, a majority (83 - 88%) in a Gallup Report disapproved of cuts in entitlement programs for the aged to reduce the Federal deficit. A 1981 Harris poll showed 54% favoring government responsibility (Biegel and Blum, 1990). All of these findings reflect a willingness to use tax funds to finance programs for the elderly and can be interpreted as support for government versus private responsibility.

A method for minimizing government expenses in the care of the aged is by encouraging or mandating family support of elderly relatives. This notion has been discussed as a way to cut federal costs and reaffirm filial responsibility. Aside from the implications such a mandate would have on our constitution, such a method could result in resentment by families, place more burden and stress on families while causing embarrassment and guilt for the elderly relative. In conjunction with this mandate, discussions have included financial incentives for caregiving by families like tax credits or other forms of allowances or tax benefits. Again, paradoxically, there can be policy disincentives for family care of the aged as can be seen in previous attempts of family aid like, financially reducing benefits to the elderly being cared for by their families, or governmental support soley for institutionalization (Kosberg, 1985).

Looking to the family as care providers for ill elderly presupposes the existence, availability and suitability of family members. A government policy which limits its focus only to family care also fails to address those elderly without families and fails to recognize changes in the family. Trends demonstrate that family households are a smaller portion of U.S. households, and that the composition of family households is different now than it was 25 years ago. For instance, in 1960 married couples with children accounted for 44% of U.S. households compared to 28% by 1985 (Crews and Cancellier, 1988). With a trend toward smaller families, parents with fewer children may have fewer support options in old age. As the divorce rates increase, more children may not acknowledge any obligation to their elderly parents as they are involved in problems surrounding a divorce, or adjusting to a remarriage. As more women become employed outside the home and families rely on double incomes to maintain a desired standard of living, the adult daughter may not be available to provide support to dependent parents (Frankfather, Smith, and Caro, 1981).

For those elderly where care within the family is the best choice, many types of assistance are being made available to the family caregivers. This assistance can take the form of support services like transportation, day care and respite, or financial assistance, or training and counseling. For example, educational strategies have been developed primarily to bolster and develop the caregiving capacity of informal supports to meet the needs of the frail elderly. These types of programs aim to support informal care providers by offering information, peer support and skills training. In New York, the State's Office for the Aging program, "Practical Help" designed a training curriculum and a Train-The-Trainers Coordinator Program. Both initiatives are aimed at establishing a statewide network of people skilled at coordinating quality training sessions for informal caregivers (NYSOFA, 1983).

Service programs usually relate to a perceived need to expand or enhance the accessibility of formal community supports such as case management. As a response to the need to link formal and informal support systems of the elderly, the Jewish Family and Children's Service of Greater Boston and the Boston University School of Social Work collaborated in a research and demonstration project designed to train family members of elderly persons as case managers. The family centered intervention focused on increasing the involvement of family members without increasing their responsibility for direct service provision (Seltzer, Ivry, and Litchfield, 1987).

Recently, attention is being directed by employers toward helping employees balance their work and caregiving responsibilities for elderly relatives and friends. Examination of a variety of options and benefits is underway by corporations who recognize the strains placed on employees involved in eldercare. Examples of some of these benefits include EAPs and support groups, flex time, flexplace, subsidies or vouchers, health insurance, day care centers, family illness days and seminars/fairs/printed materials (Ingersoll-Dayton, Chapman, and Neal, 1990; Denton, Love, and Slate, 1990; Scharlach and Boyd, 1989).

Future Policies for Family Caregiving

It appears that the U.S. is moving gradually toward the provision of publicly financed, comprehensive long term care within an entitlement framework. A two-tier approach may become a popular policy option. If seriously impaired persons are without family resources, the state would assume complete responsibility. If elderly have family resources, the state would offer modest benefits with the basic responsibility remaining explicitly with the family. The two-tier approach would acknowledge that caregiving responsibility is so great that the families deserve assistance. Hopefully a compensation to families might be an adequate incentive to continue their support. Ideally benefits could be structured to keep public costs modest but sufficiently attractive to prevent the dissolution of a family (Frankfather, Smith, and Caro, 1981).

Whatever form the comprehensive plan for the care of the elderly takes the Federal government clearly can not just focus on what it can get families to do for free. States are already experimenting with pro-active policies which attempt to fill gaps in the total range of services being provided to the elderly. A small amount of targeted assistance will not prevent institutionalization, nor will it substitute for the care provided by family members. Assistance can, however, encourage caregivers to remain motivated and enhance their abilities to keep an elderly relative in the community. A recent study revealed that 70% of the 50 states and territories responding to a survey have arrangements which allow paid family caregiving. These programs have developed from various sources and have used a broad range of resources to finance family care provisions. While it is too early to judge the results or the impacts of these programs, it is significant that at least 35 states permit payment of relatives to provide home care under some circumstances (Linsk, Keigher, and Osterbusch, 1988).

Given the potential for employment and caregiving to support as well as conflict with one another, it is critical that policy makers give attention to the workplace and its implications for long term care of frail elderly persons. For example, work can be a source of respite and social interaction. Also, work can be a context for competent feelings of self-esteem (Schlarch and Boyd, 1989). An emerging policy option that may be beneficial to informal caregivers is family leave. In the past, such a policy has been confined to single parents who work or dual income couples with children. With the exception of Connecticut, no state includes eldercare in its family leave policy and federal initiatives to include such a provision have been put on hold (Wisensale and Allison, 1988).

Not all families are successful caregivers and some may do more harm than good by keeping their loved ones out of more formal service arrangements. It is quite likely that most families could use formal help of one kind or another at some point during their caregiving period. Obviously the bridges between the formal and informal care systems are weak and need further examination since families are extremely diverse in their capacities and needs. It has been difficult to acknowledge the contribution of this informal support system. Partly the reluctance to expand Federal support of community based services is due to a fear such formal programs will substitute for informal programs and add immeasurably to the public burden. Perhaps the simple knowledge that subsidies or other formal help is available if needed might be a source of continued encouragement to families who might otherwise give up.

Public services alone can not meet the needs of the elderly to remain in their communities. However, a combination of public agencies, private and voluntary social service agencies plus private practice, can expand the diversity of service sources. Private practitioners can work with the frail elderly and families in a variety of ways, namely, clinical treatment approaches, resource facilitation, case management and the coordination of planning formal and informal caregiving. The private sector, then, can be a potential resource for policy makers in designing more alternatives for long term care. One example of practitioners in the private sector who help elderly remain in their homes is Aging Network Services in Washington, D.C. Two social workers assist long distance caretakers of frail elderly by locating appropriate case management services. This type of service attracts professionals who find it difficult and expensive to travel to meet recurring or emergency care needs of their parents in distant cities (Fauri and Bradford, 1986).

In order to deal with the many perplexities of the long term care delivery system better information is needed to support sound decision making. It is important to keep in mind that there are no immediate solutions to the policy dilemmas posed by the long term care continuum. The caregiving issue cuts across generational lines and raises fundamental questions of equity and balance in social policy. A progressive public policy agenda on the caregiving issue must involve efforts toward both short and long term goals rooted in a sense of interdependence and continuity across the life span.

CHAPTER TWO:

RATIONALE FOR PROGRAM

Stresses Associated with Caregiving

Our society believes that frail and disabled persons are best cared for by their families and expects the family to serve as the first line of defense against premature institutionalization of disabled people. Thus, it is vitally important to safeguard the well-being of the family as a caregiving unit. It has been well established that providing care to a disabled relative creates varying levels of emotional, physical, financial and familial strain for informal caregivers. Studies have been focused on identifying those stresses associated with caregiving that can have negative effects. At times, these negative effects have been found to be persistent and severe in come caregivers. Most recently attention has been paid to the prolonged or cumulative consequences of being exposed to the negative stresses of caregiving. In identifying these stresses it is hoped caregivers can be supported by more informed programming, practices and policies.

Caregiver resources, including both social and personal resources, can serve to reduce the stress of the caretaker role. Zarit (1980) found that caregivers reported feeling less burdened when they were visited on a regular basis by family members and friends. Fengler and Goodrich (1979) report that caregiving wives found children, relatives and friends who visited an important support which aided in promoting high morale. It would seem that the presence of a strong support network is a factor in mediating the effects of caregiving by providing a confiding relationship, feelings of personal affection, opportunities to relate in a meaningful way to others or tangible assistance in time of need (Clipp and George, 1990).

Friends and neighbors while not always directly involved can also be a source of help for the caregiver. By providing a secondary level of assistance in performing small, structured tasks like shopping, escorting and visiting, friends and neighbors can be part of the service plan for a homebound elderly adult. Since they are available within the neighborhood they can often alert family of a crisis (Cantor, 1983).

A factor in maintaining successful caregiving seems to be a balanced life perspective which includes thinking through potential problems and planning contingencies for the future with the elderly relative (Cantor, 1983; Rakowski and Clark, 1985). An overwhelming concern of adult children who are caregivers is their ability to obtain necessary help when the need arises. Separate from the financial ability to pay for services is the desire to learn about community resources and the availability of dependable professionals. Under conditions of stress or long term caregiving it may be more difficult for families to keep future options in mind. With a limited future outlook caregivers may have difficulty seeing how services would provide realistic opportunities and relieve stress.

Too often caregivers save up their respite time until they become ill and need help with their loved one. Or, caregivers assume the full responsibility for a relative, versus asking for help, due to cultural norms of independence and self-sufficiency (Gaynor, 1989; Berman et al., 1987). It has been demonstrated that use of the formal network provides caregivers with a period of time during which to regroup their inner resources. Day care, day hospital or respite programs can help caregivers cope and plan for the next stage in the process of caring. When and how the formal delivery system is utilized seems to impact on a caregivers' ability to withstand the stress associated with the role.

The conditions under which caregivers live and work can become increasingly stressful as the functional abilities of the disabled relative continue to decline. Many persons vary in their ability to accept the consequences of caregiving. Some experience fear, anger, disbelief, frustration and helplessness and it is not uncommon for caregivers to report experiencing chronic health care problems that require regular medical attention, such as high blood pressure, diabetes, and arthritis (Wilson, 1990). Physical health of the caregiver is critical to the person's ability to continue to provide care for the impaired older adult. Caregivers who are depressed may fail to eat properly or may lose sleep and this may increase their susceptibility to physical health problems through failure to care for oneself (Pruchno et al., 1990). The physical costs of caretaking seem to weigh most heavily on spouses, who because of their age, are perhaps more vulnerable in terms of effects on health (Fischer and Hoffman, 1984). At some point the caregiving burden becomes so great that outside assistance is required. The longer a person has been caregiving the greater the chances that family members or friends will also provide help. However, the longer persons have been caregiving the greater the chances that they are also suffering health problems. It could be that family intercede once there is evidence that the primary caregiver is deteriorating. Or, caregivers in their reluctance to ask for help may only seek assistance from family when health problems prohibit them from managing on their own (Snyder and Keefe, 1985).

Another set of variables affecting well-being consists of the caregivers' perceptions of the burden or stress associated with the caregiving situation. This subjective appraisal can include the quality of visits with a loved one, the extent to which the older adult is seen as overly demanding, perceptions of the adequacy of professionals providing assistance, and how the caregiver feels about his/her ability to meet the needs of a relative while dealing with other responsibilities. It is expected that the more burdened caregivers feel, the more likely they are to institutionalize an elderly relative (Brody, Dempsey and Pruchno, 1990; Pruchno, Michaels and Potashnik, 1990).

If the level of caregiver stress is partially the outcome of his/her interpretation of the care providing situation, than one must examine the elder's behavior and concomitant strain of the care responsibilities. For instance, patients who are assaultive, incontinent or confused can present special difficulties in management. An increase in an elder's anxiety or agitation that accompanies cognitive deterioration can have overt results in the form of behavioral outbursts. If the caregiver expects these symptoms as characteristic of the illness/aging process they may be accepted with no unique social meaning. However, despite the elder's health status, problems in social functioning and disruptive behavior may be seen as inappropriate and the elder could be held responsible or stigmatized. Caregivers may become angry, resentful, shocked and more stressed as they cope with this situation on a daily basis. Or, caregivers may view these symptoms as an indicator for more constant supervision to protect and maintain the elder. The symptoms could then cause a more intense pattern of care or a more isolated pattern of interaction, both resulting in greater strain on the caregiver (Deimling and Bass, 1986).

Stressors differ in their intensity and course over time and will have different effects on caregivers and their perceptions. For example, a behavior like forgetfulness can increase over the development of the disease but may not cause increased levels of caregiver stress. Once caregivers learn to accept changes and accommodate their expectations to these changes, stress levels off or even declines. On the other hand, behaviors that do not develop in a predictable way, such as verbal abuse or delusions, do not allow accommodation to occur. As the disoriented or asocial behavior continues, caregivers' lives can be stressed to the point that their own mental health suffers (Gilhooly, 1984; Pruchno and Resch, 1989b). As the elderly person progressively loses more control a caregiver may feel the need to gain more control over interactions with the elderly person. The perception of lack of control and unpreparedness in this context could explain feelings of depression (Coppel et al., 1985).

Some caregivers seem to manage well in their role, yet others experience a host of strains and mental health symptoms such as depression, nervousness, anxiety, sleeplessness, frustration, and lowered morale. Many spouses, for example, indicate they are burned out in their role and that being a caregiver has negatively affected their appetite and eating habits which in turn impacted on their physical health. Other caregivers describe the role effecting their social activities and relationships with other people. Time formerly spent on hobbies, volunteer work, church attendance and relaxation is now limited or relinquished to the caretaker role. Interference with time and freedom, income, plans for vacations and the future, as well as privacy are prevalent complaints of caregivers, all taking a toll on their mental health (Wilson, 1990). In households that are shared by the caregiver and elderly relative there seems to be consistently more caregiver strain than in situations where the older adult lives separately. For example, a study completed by Brody et al. (1988) demonstrated that daughters living in three generation households experienced more feelings of isolation and were likely to report feelings of depression and restlessness as compared with daughters whose parents lived separately. Depending on investment in the role, several studies have suggested that women who are caregivers are more depressed than caregiving husbands (Boyd and Weissman, 1982; Horowitz, 1985a; Pruchno and Resch, 1989b).

Much research has indicated that a pervasive consequence of caregiving is the emotional strain generated by the perceived burden of the overall caregiving situation (see for example, Cantor, 1983; Gallagher, 1985; Rabins et al., 1982; Zarit et al., 1980). Likewise, several researchers have found that strong negative feelings such as anger, anxiety, guilt and depression have been experienced as problems by family caregivers (see for example, Brody, 1985; George and Gwyther, 1986; Grad and Sainsbury, 1968; Poulshock and Deimling, 1984). Mental health problems are of particular concern because studies have shown a relationship between depression, family strain, and possible use of psychotropic drugs and permanent institutionalization of the care receiver (Colerick and George, 1986; Morycz, 1985).

Various Strategies for Caregiver Enhancement

Recognition of the stresses associated with caregiving as well as the special needs of caretaker family members has resulted in the development of a number of programs designed to assist them. The intervention strategies typically involve working with the family caregivers of the elderly to lessen family burden. Strategies may involve direct intervention so that the degree of family burden is prevented from becoming excessive, or may focus on secondary intervention that attempts to reduce the negative effects of burden that have reached excessive levels. In either approach, intervention with family caregivers has implications for the well being of older adults by raising the quality of care provided and improving the quality of the relationship between caregivers and older adults. Ultimately the hope is to increase the length of time older adults will continue to be cared for in the family setting. These programs vary in their extensiveness in addition to their use of modalities, from written materials that provide information, to peer support groups, coordination and formalization of services, and professionally led groups.

Peer led groups or mutual support groups have been known to have special advantages for persons facing a common problem in living. In the case of caregivers for the elderly these groups have emerged in many settings and have been directed toward family members as well as any interested individuals, like potential caregivers and friends. There are groups organized around a specific diagnosis, like senile dementia, and groups focused on specific caregiver populations, like wives or daughters. These groups stress information, emotional support, advocacy or any combination of these. Often times these groups are self directed with leadership coming from within the group, or occasionally a professional staff person may act as a group facilitator.

Agencies and persons working with caregivers of the elderly have cited several reasons why the strategy of a mutual support group is well suited to the needs of caregivers. Peer led groups can help caregivers successfully label their problem in less threatening and stigmatizing ways. Caregivers often have difficulty in understanding their emotions and explaining them to others. When they turn to others who have had similar experiences, they are likely to be understood. Traditionally these mutual aid groups offer invaluable consumer information and practical coping suggestions which are not easily found elsewhere. Caregivers can practice, repeat and validate each other's skills in coping. Professionals acknowledge that they often do not understand totally what is involved in managing a chronically ill person. In a mutual support group caregivers can turn to each other and be directed to other sources of help.

Mutual aid groups can also be an empowering strategy for mobilizing communities to deal with a significant public health problem. If a family is uncertain in its capacity to care for a relative, associating with other families helps to create a sense of community. For those caregivers who are isolated by the constant demands of a relative, mutual support groups can have the added benefit of offering a socially acceptable outlet. Social relationships can be formed at these meetings which might extend outside the group context. Families meeting in the group may call each other, write, or socialize with or without impaired relatives.

Caregivers tend to be enmeshed in chronic, long-term situations that may worsen over time. These caregivers have a need for continuing aid and support throughout this experience. Open-ended mutual support groups allow the continuation of a group for a long period of time. They can be available on an as needed and sustained basis thus having the advantage of assisting members through long term or progressively debilitating problems (Gwyther, 1987; Biegel, Shore and Gordon, 1984).

One example of a mutual support group for caregivers is the well known Alzheimer's Disease and Related Disorders Association (ADRDA). In the 1980s ADRDA developed in response to a national demand for leadership in assisting Alzheimer's patients and their family caregivers. Starting out as grassroot support groups these mutual aid groups developed into regional chapters and eventually received the backing of a national movement with encouragement from the federal Administration on Aging (Gwyther, 1987). Another example of a mutual support group is the Volunteer Information Provider Program (VIPP). This demonstration project operated in five rural Missouri counties to help families deal with the strain of caregiving. Two major community based organizations in rural areas, the Cooperative Extension Services and the Extension Homemaker Clubs, organized volunteers to share information with caregivers. This strategy utilized the personal networking of peers to disseminate information and support caregivers in need through modeling and offering creative ways to cope with stressful situations (Halpert, 1988). A third example of a mutual aid group is a telephone network program which matches family caregivers of Alzheimer's victims. Family caregivers gain support from others in similar circumstances as well as learn information provided via mini-lectures transmitted over the phone (Goodman and Pynoos, 1988).

Another strategy which provides support to caregivers of the elderly involves the recognition of the role of the family in caring for an older person and the coordination of that role into an overall service plan. This intervention determines the care which the family is providing and uses formal agency services to meet gaps in care. The family's caregiving services become part of a service package and all parties involved sign an agreement detailing the formal and informal services. This type of intervention may involve paying for care provided within the family. Provision of financial support in this manner is used to encourage and enable caregivers to provide care who would not otherwise be able to do so.

One example of this type of intervention is Home Based Care, a program of the Maine Department of Human Resources. In-home services are provided to elderly at risk for institutionalization. The program is structured to provide families with services and funding only when all other resources have been exhausted, to assure maintenance of effort. This intervention strategy emphasizes aid to family members as a means of extending and/or continuing their caregiving efforts; acknowledges caregivers and their reactions to the stresses brought on by their individual circumstances; and mediates troubled family relations originating from caregiving (Biegel, Shore and Gordon, 1984).

Most professionally led programs consist of two major components. The first is educational, including information about the nature of aging diseases, legal issues involved in caregiving, community resources available, and practical ways of dealing with common problems of caregiving for an elder relative. The rationale for caregiver programs that focus on educational and skill training modalities is based on the premise that basic knowledge will help increase the coping capacities of caregivers. In these programs the aim is to increase technical skills and competency, as well as to increase knowledge and understanding of issues associated with the aging process. The second aspect of professionally led groups involves peer support in dealing with feelings of isolation, grief, helplessness, and guilt in dealing with family members, plus the need for respite. The opportunity to discuss individual problems in a supportive environment is aimed at reducing the perception of burden and levels of frustration in caregivers (Biegel, Shore and Gordon, 1984; Kahan et al., 1985).

Professionally led training and support groups have been demonstrated to be effective in helping families cope with specific conditions, such as behavioral disturbances and serious mental confusion, that have frequently been found to precipitate families seeking nursing home placement. For example, programs focused on assisting relatives of the mentally impaired deal with stressful problems related to caregiving, such as the elderly person's denial of memory loss or the relative's paranoid ideation, have helped these families cope better. In other training and support groups families have been taught behavior modification techniques that have been used successfully in nursing homes to deal with behavior problems like screaming or incontinence (Doty, 1986).

The case could be made that both individual and group interventions are helpful for caregivers but that each modality possesses unique advantages. The value of a group process rather than individual counseling should not be minimized. Sharing feelings and reactions about caregiving with each other, recognizing the universal nature of the problem and hearing others' solutions to it, gaining greater knowledge of community resources, receiving feedback about what might occur in their future role as caregiver, and having many others to talk to during the group sessions all are features which can be very therapeutic to group participants (Toseland et al., 1990; Cohen, 1983). The small group format is a particularly good modality of treatment for caregivers because the small group brings together people with common experiences and needs in a supportive atmosphere. Through the group interaction members recognize their own humanness as well as their need for support and nurturing. Frequently self esteem is enhanced as group participants recognize each other for the special role they play in the lives of their aging relatives (Blick and Peck, 1984). The role of the leader in this modality becomes crucial so that members are encouraged to express themselves emotionally while also receiving the benefits of the supportive and educational components of group experience. Leaders must be able to sense group members' needs for expression, confront defenses, prevent personal attacks, and regulate the level of anxiety (Schmidt and Keyes, 1985).

Implications for Social Work Practice

The possible psychological and physical impact of long term care on the caregiver has been recognized by health and social service agencies and policy makers. Social workers are in a unique position to determine the availability of services needed by caregivers in their communities such as support groups, homemaker and home nursing care, emotional counseling, legal services, specialized transportation, and respite services. In addition, once the gaps in services are identified, social workers can advocate for the establishment of these programs. For example, social workers can help organize low cost transportation services through church groups and community volunteer organizations. In the case of caregivers, these family caretakers can be assisted in forming support groups. For instance, social workers can locate meeting sites, recruit group members, and provide consultation on emotional issues.

Social workers can also play an important part in organizing training programs which will assist caregivers both directly and indirectly. For example, social workers might work with a senior citizen center to provide classes for caregivers on financial planning for long term care or writing a will. Social workers might conduct workshops for lawyers to highlight the emotional issues involved in filing for conservatorship or arranging for nursing home placement. In some cases social workers might educate fellow health and mental health colleagues about the special needs of caregivers and the family dynamics of caregiving situations (Snyder and Keefe, 1985).

Intervention with family caregivers can involve a multiplicity of professional roles for the social worker. The worker serves as a consultant to the family caregiver, providing information about the aging process as well as information about services. In this role the consultant offers encouragement, support and help with problem solving. In the facilitator role the social worker supports the family caregiver by helping to make connections with resources; to provide emotional and physical supports directly to the caregiver; and to work with those involved in the informal network to play a more active part in relieving the caregiver. In the role as initiator-developer, the worker helps to create supports for the family caregiver such as classes or self-help groups and moves towards the development of needed services like respite care. Another role, that of internetwork linker, involves mobilizing agencies and organizations in the formal network to plan a coordinated service package. The social worker may also be a resource provider, either connecting the family to resources or through the worker's own efforts (Biegel, Shore and Gordon, 1984).

Caregiver Support Groups

Professionally led support groups are a modality for which social workers are especially suited. Social workers aim to support the adaptive coping responses of individuals and to clarify and explore the maladaptive responses so that stress and strain can be reduced. As leaders of support groups for family caregivers social workers can design an effective intervention to increase caregivers' confidence in problem solving, help caregivers redefine difficult situations and teach caregivers how to gather social support (Wilson, 1990; Pratt, Schmall and Wright, 1986).

The group programs providing education and support to family caregivers tend to be time limited interventions. They usually meet for six to eight weekly sessions for approximately 1 1/2 to 2 hours. While many groups have one leader, many groups are frequently co-led. Common arrangements have included a nurse and a social worker, a professional and a caregiver, and a licensed practitioner with a student intern. Recently the bulk of program efforts have focused on aspects of providing social support to caregivers and assisting caregivers to cope with feelings associated with the caregiving role (Toseland and Rossiter, 1989; Lidoff and Harris, 1985; Clark and Rakowski, 1983).

In a literature review of 29 evaluative studies of group intervention programs Toseland and Rossiter (1989) reported on seven major themes forming the basis for interaction in most support groups. Those themes were: information about the care receiver's situation, the group and its members as a mutual support system, the emotional impact of caregiving, self-care, problematic interpersonal relationships, the development and use of support systems outside of the group, and home care skills (pg. 439). Groups do not generally deal with all of these themes in great detail. Typically groups will spend half of their meeting time on presentation of information with a question and answer period. The second half of the group is devoted to more of an interactional format where participants share their problems and concerns with the group.

The majority of evaluative caregiver support group studies report positive outcomes for participants. For instance, practitioners will cite observations of group processes and note a supportive atmosphere, where members disclose personal details and are able to express their feelings regarding the caregiving experience. In other studies participants will be quoted as reporting positive group experiences which were meaningful and useful. Practitioners' assessments of outcomes also report active participation, good attendance and requests for group extensions (Toseland and Rossiter, 1989).

Unfortunately the above mentioned positive group outcomes are not generally substantiated with data collected through the use of standardized measures in case study or experimental evaluations. Clark and Rakowski (1983) speculated that the lack of empirical data regarding the value of support groups resulted from practitioners being focused on service versus research, practitioners not documenting their experiences for publication, and the additional costs of research activities (pg. 640). Zarit (1989) has suggested that in the past 15 years research on caregiving has exploded but remained focused on descriptive studies of the caregivers' experiences. Both he and Haley (1991) have pointed out that there needs to be a better understanding of the goals and processes of interventions in order to measure the probable effects of intervention.

Overall the aging field is at an early point of development in learning about the effectiveness of support groups for caregivers. Recently, several rigorous studies which used standardized measures have found that participation in a support group can be helpful for caregivers (Gallagher et al., 1989; Greene and Monahan, 1987; Montgomery, 1988; Toseland, Rossiter, and Labrecque, 1989a; Toseland, Rossiter, and Labrecque, 1989b). A review of past studies discussed in the literature indicates several areas related to caregiving evaluation which need attention. Samples, for instance, are usually drawn from only one or two sources like social agency files or a clinic. Samples drawn from these kinds of sources are biased and do not represent the caregiver population at large. Such recruitment strategies are generally focused on individuals who are distressed and judge themselves to be in need of help, and could underrepresent those individuals who do not have much felt difficulty with the caregiver role. Also, such limited samples tend to be fairly homogenous in social class and other characteristics. Another related issue concerns the diseases which have been studied. Most recent work has focused on those caring for a person with Alzheimer's disease or a related organic brain syndrome. Other caregiving situations have not been examined as closely, and it is not known to what extent the findings of cognitively impaired adult populations apply to other diseases (Biegel and Blum, 1990; Schultz, Visintainer and Williamson, 1990; and Toseland and Rossiter, 1989).

Caregiving research has not displayed a consistent method of establishing who qualifies as a caregiver. Sometimes the care receiver identifies the caregiver; in other studies the researcher develops particular criteria for identifying a person, and some caregivers have been identified by membership in a group or organization. These methods for respondent selection do not necessarily distinguish the primary caregiver from others assisting in the older person's care. Other factors such as age, sex, social support systems, time spent on caregiving, and where the caregiver resides all have impact on individual response to the caregiving role (Biegel and Blum, 1990; Toseland and Rossiter, 1989).

There is great variability across studies concerning how the consequences of caregiving have been conceptualized and empirically measured. Some investigations have focused on how much stress caregivers attribute to their caregiving experiences. In some studies the degree of satisfaction as a caregiver is examined. Existing studies fall short, however, when they do not indicate whether support groups can help caregivers cope; or alleviate stress; or increase access to and use of resources; or improve caregivers' ability to better care for themselves. Rather than trying to measure global psychological changes or global changes in stress and burden there is some evidence to suggest selecting outcome measures that are focused on behavioral changes (Haley et al., 1987; Zarit et al., 1987).

Finally, caregiving research has not paid enough attention to the format, content, and approach of intervention strategies used in support groups. Better intervention programs can not be developed without a responsiveness to existing data about the concerns of caregivers (Haley, 1991; Toseland and Rossiter, 1989). Likewise, complex interrelationships between variables need to be examined. It would be helpful to researchers and practitioners alike if the efficacy of different approaches with different types of caregivers was addressed.

Definition of Stress

Support groups are being used with increasing frequency to help caregivers cope with the stress of caregiving. Reflective of the general population, the typical participants are females who are related to the person needing care. A review of the literature done by Toseland and Rossiter (1989) point to the majority of these female participants being wives or daughters of the care receiver. The authors found that participants ranged in age from 16 to 80 years, with most falling between the ages of

40 and 65. In addition, participants were shown to be primarily from middle socioeconomic backgrounds.

Several factors contributing to the stress experienced by female caregivers of the elderly have been described above. The use of an intervention approach to help reduce this stress, and which can teach new coping skills to respond to the caregiver role, makes good practice sense. First, a stress reduction model can be incorporated into a group format successfully. Women have the benefit of working on assignments at home and are able to share results with group members for constructive feedback. Second, a stress reduction model can be an approach to teaching both physical and cognitive coping skills. Such skills acquired during the group intervention can perhaps remediate symptoms and be used in a preventive manner. Third, a stress reduction model can include major practice principles like : educating the client about the nature of stressful reactions, having the client rehearse various physical and cognitive coping skills, and helping the client apply these skills during exposure to stressful situations. This format can be tailored to make an individual contract with the client to address her particular stressors.

The concept of stress has a variety of meanings and is used in many different ways. It is helpful to examine its components. The tendency has been to distinguish three basic types of stress: physiological, psychological and social. Physiological stress is concerned with the disturbances of tissue systems, psychological stress focuses on cognitive factors leading to the evaluation of threat, and social stress concentrates on the disruption of a social unit or system. While many researchers believe these three types of stress are related, it is not clear what the nature of the relationship might look like (Monat and Lazarus, 1977).

The typical stress definition will usually consider basic components like critical life events, plus reactions and responses to challenging experiences. By defining stress as a function of environmental events and a person's response to these events, it becomes easier to understand factors influencing behavior, adjustment and well being. For the purposes of this study stress was defined as a dynamic process that involved environmental demands, cognitive appraisal and person-environment transactions. This stress relationship was viewed as bidirectional with the person and environment each acting on the other. In alignment with stress researchers, stress was viewed as a person's appraisal of an event, the appraisal of a person's capability to respond to the stressful event, the anticipated cost of the intended response, and the appraisal of the impact or consequences (Lazarus, 1966; Harel, 1988).

Stress is often viewed in connection with other concepts but they all have distinguishing traits. For instance, frustration refers to the blockage or delay in progress toward a goal. It refers to something ongoing or which has already happened. Like frustration, threat also involves some harm but it is one which has not happened yet. The harm is anticipated on the basis of cues. Conflict involves the presence of two incompatible goals at the same point in time. In this case conflict usually means frustration or threat of some sort is inevitable (Monat and Lazarus, 1977).

A distinction can also be made between injurious and non-injurious stress responses. Not all stress can or should be avoided. A normal adaptive stress response can occur when the source of stress is identifiable and clear. An individual can meet this challenge and return to a baseline level of typical functioning. However, when the source of stress is ambiguous, undefined, prolonged or when several sources exist simultaneously the person does not return to regular functioning as rapidly. It is this prolonged, unabated stress from which there is no or little relief that is primarily responsible for the development of stress related disorders (Pelletier, 1977).

Coping responses or processes have been examined by stress researchers to understand how individuals adapt to stress. On the one hand some have emphasized general coping traits, styles or dispositions, while others have preferred to study ongoing strategies in particular stress situations (Monat and Lazarus, 1977). Using the definition for stress which highlights the relationship between person and environment, coping has two major functions: 1. emotion-focused coping, designed to regulate emotions and 2. problem-focused coping, designed to manage the problem causing the distress. Folkman and Lazarus have demonstrated that both forms of coping are used in most stressful encounters and that the amounts of each form vary according to how the encounter is appraised (Folkman, 1984; Lazarus and Folkman, 1984).

Stress Inoculation Approach

In the present study stress inoculation training was the approach used to assist adult daughters in reducing the stress and strain experienced from their caregiving activities. No one stress management technique is likely to be effective with all individuals. Stress inoculation training was selected because of its flexibility which includes a variety of techniques, depending on the needs of the participants. As

Lazarus (1981) has pointed out, coping is a compilation of many acts which span over time and undergo change. Hence, one particular coping technique which was helpful at one time may not be as useful at another time. Likewise, what might be useful for one population or one type of stressor may not be relevant at other times. An ideal stress management program should contain a flexible repertoire of many coping strategies. The stress inoculation approach allowed training for skills in both functions of coping: emotion-focused and problem-focused coping. For instance, in caregiving situations that were seen as potentially changeable, women were taught problem-focused forms of coping like decision making, direct action and information collection. In caregiving situations which were seen as unchangeable, women were trained in compromise or acceptance techniques.

The approach of stress inoculation was developed by Meichenbaum and Cameron who used it to help clients with severe phobic reactions to manage anxiety in stressful situations. They found that stress inoculation was superior to systematic desensitization and two other anxiety treatments in reducing avoidance behavior and in promoting treatment generalization of multiphobic clients (Cormier and Cormier, 1985). One advantage of stress inoculation, as compared with either cognitive restructuring or relaxation, is that both behavioral and cognitive coping skills are learned and applied as part of the stress inoculation approach. Another advantage of stress inoculation which makes it a practical clinical tool is that it involves the client in the development and implementation of the procedure. Stress inoculation is designed to develop coping skills to resolve immediate problems as well as to apply to future difficulties. In some ways this approach is similar to medical inoculation in that coping skills are gained to provide resistance to exposure to stressful situations (Meichenbaum, 1985).

Stress inoculation as originally designed contains three phases: conceptualization, skills acquisition and rehearsal, and application and follow-through. In stage one clients are helped to better understand the nature of stress and its effect on behavior and emotion. The conceptualization phase assists clients to have a framework within which to view their responses to stress and to assess their relative effectiveness. The initial phase provides the clinician and participants with information necessary for judging how to structure phase two. In the second phase clients develop and rehearse a variety of coping techniques, including direct actions and cognitive coping modes. Clients learn these techniques experientially and rehearse them until they are utilized comfortably. In the last phase clients have the opportunity to practice skills under stress conditions which are simulated. Once the client copes well in simulation she is encouraged to try her coping skills in actual situations (Patterson, 1980; Wertkin, 1985; Jaremko, 1979).

The second phase seems to be the most important one for it is here where the client is taught coping skills to deal with her stress. The components of the rehearsal phase are physical means of coping, cognitive restructuring or self-instructions, and generalized cognitive strategies. Some form of physical coping is taught in phase two to teach the client to discriminate and control her physiological mechanisms. Exercises like deep breathing, progressive relaxation and stretching are used. Cognitive restructuring techniques are especially important for negative self statements replacing with positive coping statements. These self statements focus on the situational stressors troubling the client, allowing them to cope more effectively with these stressors. Cognitive coping strategies are specified ways of perceiving or dealing with a stressor. Multiple cognitive strategies are provided so that the client can use them as needed when one or more will be likely to be effective (Jaremko, 1979; Wertkin, 1985).

For this study the method used in the cognitive restructuring component was focused on identifying the absence of specific cognitive skills and responses and teaching the caregivers problem solving skills. In problem solving, caregivers were taught how to identify problems, generate possible solutions, tentatively select one solution and then test it out for its effectiveness. Coping skills were taught in the actual crisis or problem situations brought to the group by the caregivers. Use of this method allowed the focus to be placed on modifying the caregivers' thinking and reasoning.

The three phases of stress inoculation are not performed in a progression but, rather, they often overlap and are seen as interdependent. The clinician or trainer using stress inoculation is not hampered by the use of a few available techniques. Instead, the clinician can select from a range of techniques for the one that seems most appropriate at the time. Not only is stress inoculation feasible but it can be applied by various levels of professional and paraprofessionals with the appropriate training. In addition, stress inoculation can be combined with other interventions to supplement and enhance a clinician's tools (Meichenbaum, 1985).

The use of the stress inoculation approach is more complex and time consuming than the traditional approaches to stress management. The assessment of a person's coping behaviors and what should be suggested in a training program takes time. Yet the process is closely aligned to social work practice in that the focus remains on the individuality of each client and the right for self determination as it applies to each stressful situation.

Applications of Stress Inoculation Approach

The stress inoculation approach has been applied on a treatment and preventive basis to a wide variety of clinical and non-clinical populations. Recently, with a focus being placed on psychology-based interventions in medical settings, stress inoculation has been applied to the treatment of acute and chronic pain patients. For instance, Hackett and Horan (1980) reported on the use of coping skills training, such as imagery and self-statements, to deal with pain. Also, stress inoculation training has been applied to patients who suffer from a variety of medical problems like, headaches, cancer, backaches, and arthritis. Crowther (1983) described a study where stress management training plus relaxation imagery were demonstrated to be effective in controlling hypertension. Stress inoculation has also been used with patients preparing for surgery. Treatment which encourages cognitive reappraisal of anxiety-provoking events, soothing self talk and cognitive mastery seems to be an effective way of increasing both pre- and post- operative stress tolerance (Langer, Janis and Wolfer, 1982; Blythe and Erdahl, 1986).

In the medical arena recent efforts have focused on providing stress management training for hospital staff. Nurses in particular experience much stress as it relates to time management, patient complaints and competency concerns. Stress inoculation training regimens have been used with nurses to help alter environmental stressors and/or change perceptions, and regimens have been used to help them cope with critical care units, like the treatment of burn patients (Meichenbaum, 1985; Von Baeyer and Krause, 1983-84). Another group receiving attention for the dangers, challenges and strains related to high levels of arousal they encounter are police officers. Stress management programs have been designed to focus on self monitoring techniques in response to threatening or emotionally loaded situations (Meichenbaum, 1985; Sarason et al., 1979). Managers in the field of business have also been the target of stress training with the goals of reducing stress levels, increasing productivity and decreasing absenteeism. While such application to nonclinical populations in business and industry is still in the exploratory stages, findings do point to the potential for stress training programs to help workers cope with occupational stress (Allen and Blanchard, 1980; Higgins, 1986).

In other applications stress inoculation has been used in the treatment of clients' anxiety. For instance, speech anxious students have received cognitive restructuring and coping relaxation treatment to deal with their concerns in anxiety arousing situations (Altmaier, 1982). Elderly students have received stress inoculation training to deal with problems of test anxiety (Kooken and Hayslip, 1984). Schlichter and Horan (1981) report on the promising effects of stress inoculation on the anger and aggression management skills of institutionalized juvenile delinquents. Likewise, stress inoculation has been shown to be effective in treating inappropriate anger with adults reporting chronic anger problems (Bistline and Frieden, 1984; Novaco, 1977).

Applications of Stress Inoculation Approach with Caregiver Groups

A search of the literature for use of stress inoculation techniques with female caregivers of the elderly did not reveal many previous studies. There were a few studies which demonstrated the effectiveness of stress management training for females vulnerable to stress due to their life situation. For example, Tableman et al. (1982) described a coping skills training package for women supported by public assistance. In 10 weekly sessions low income women were assisted to improve their communication and problem solving skills. The participants reported an increase in self confidence and a decrease in anxiety and depression. Sessions explored stress awareness and stress resolution techniques like role playing, redefining the situation and positive self talk. Another study conducted by Rose (1989) described a structured, educational group used to teach single parents coping skills. Using interventions like relaxation, restructuring and assertiveness training mostly female participants learned more effective ways to cope with their stress in a single parent family.

Within the last five years a few studies have been completed which directly address the stress of caregivers. For instance, Scharlach (1987a) conducted a study with daughters which aimed to decrease unnecessary assistance to their mothers while decreasing feelings of strain, and hopefully improving the quality of the relationship. Two types of interventions were utilized. One, a supportive educational experience designed to help daughters be more sensitive to their mothers' needs, and the other, a cognitive-behavioral presentation designed to help daughters clarify and reevaluate their attitudes about appropriate parent care. Results indicated that the cognitive-behavioral intervention was significantly more effective than the second intervention or control condition in decreasing a daughter's burden. Techniques used in the cognitive-behavioral intervention were values clarification, priority setting, role playing and examining self-defeating thoughts. This study demonstrated that a daughter could modify unrealistic attitudes and learn to encourage less dependence of her mother; both results contributing to lessen feelings of burden. In another study a cognitive-behavioral intervention was also used to focus on the needs and limitations of caregivers. A program was designed to teach caregivers problem solving skills, increase their knowledge of ways to cope and modify the way they defined their role. Gendron et al. (1986) used behavioral techniques like, meditative relaxation and assertiveness training, and cognitive restructuring over an eight week period. A consistent pattern of positive changes across subjects was noted.

A demonstration project in the southwest conducted 34 professionally guided support groups for informal caregivers of the frail elderly. The aims of the project were to reduce stress as well as improve effectiveness and ultimately reduce the occurrence of decisions to institutionalize a relative. Greene and Monahan (1987) reported on groups of caregivers which met for over an 8 week period. The intervention components consisted of dealing with caregivers' feelings about the role, educating caregivers about information useful to their role and relaxation training.

Results were qualified due to the non-experimental nature of the study but suggested that this model had promise to affect the average risk of institutionalization.

Another approach to alleviating caregivers' stress has been to conduct training in behavioral management procedures. Zarit, Anthony and Boutselis (1987) used a supportive and educational model but also incorporated skills training for controlling the patients' behavior and for making better use of social support networks. Using both group and individual and family counseling formats, the authors introduced a problem solving approach for behavior management of demented patients. The two treatment approaches did result in lower reports of burden and psychiatric symptoms, but not a significant change over the control group.

A review of the literature suggests that caregivers benefit from the education, validation, and support found in groups. Research studies also suggest that stress inoculation is an appropriate intervention for the caregiver population who can experience both intense and long term chronic stress. However, no study has offered a formal stress inoculation approach to female caregivers of the frail elderly within the context of a group setting. The present study sought to operationalize these concepts and extend the previous research by Dr. Ronald Toseland.

CHAPTER THREE:

METHODOLOGY

The Setting

The study design built upon research which was being conducted in the School of Social Welfare at the University at Albany, State University of New York. A faculty member, Dr. Ronald Toseland, received a federal grant from the Prevention Branch of the National Institute of Mental Health (NIMH). His research examined education/support groups for informal caregivers emphasizing a comparison between professionally-led groups and self-help support groups. Dr. Toseland was the Principal Investigator (P.I.) for this grant and this author, its Project Director. By maximizing the accessibility of research activities underway, it was believed the doctoral project requirements could be fulfilled, while at the same time contributing to the grant research. Consultation with project staff, administrative staff from the University, and funding sources indicated agreement with, and support for the doctoral project.

The NIMH research grant was funded for a two year period; beginning in June of 1986 and ending in June of 1988. Research activities were completed in two stages to accommodate two waves of study participants. Time One included a recruitment period (July through August 1986), a screening and pre-test period (July through September 1986), a group intervention (September through December 1986), and a post-test period (December 1986 through January 1987). Similarly, Time Two included all the same periods, beginning in November 1986 and ending in June 1987.

The second year of the grant involved data collection for six months and one year follow up interviews. It was during Time Two of the NIMH research grant that the doctoral project was conducted. The addition of the doctoral project meant adding two groups and two leaders to the existing research design funded by NIMH.

Resources needed to implement the study design were considered. Arrangements made with the host agency (SUNYA) indicated a good deal of support for the program. Since the study design built upon the NIMH grant research many of the pieces necessary to implement the program were in place. The Project Director was hired with the understanding that doctoral work would be a byproduct of the day-to-day operations of the grant project. Hence, the Project Director had the freedom to establish information systems, negotiate working relationships and utilize available resources as part of the job. Reports were made on a regular basis to the faculty member who wrote the grant and who was supportive of expanding research activity on the grant. The possibility that NIMH would have completely stopped funding to this project after the first year of the grant was highly unlikely. In the event the budget was erased completely, the intervention would have been completed and data collected for the pre- and post-tests. Arrangements would have been needed to make computer runs of data and analyze the results. These arrangements could have been made fairly quickly and cheaply with the host agency.

Besides the political backing of the university-at-large to operate the NIMH grant and other related research activities, the research grant received the support of the School of Social Welfare where the NIMH grant offices were located. The academic environment was conducive to supporting research work as well as offering expertise in the various stages of the study design. In addition, direct resources such as xerox equipment, personal computers and private library collections were made available. SUNYA has established relationships with community agencies and interest groups over the years through field placements, alumni, previous research efforts and projects, which provided valuable resources to the study design.

Staffing Pattern

The Principal Investigator of the NIMH grant was also a full time faculty member in the School of Social Welfare at the University at Albany, State University of New York. His ongoing involvement with the grant project centered around projected program activity level and technical assistance for research methodology and computer technology. His background lent itself well to the project for he had co-authored a textbook on group work, had written several articles based on his research in the fields of adult development and aging plus maintained working relationships with the practice community as a part-time staff person in a local agency.

Acting on a consulting basis, there was a Research Associate who was also Director of the Ringel Institute of Gerontology at the University at Albany. He was trained as a clinical psychologist and had worked with families in the process of caregiving. At the time this research was conducted, he was the Editor-in-Chief of The Gerontologist. As an educator and researcher this consultant agreed to offer his expertise on the current literature plus critique the ongoing design and implementation of the research grant. His initial connection to the NIMH grant project originated from his review of the grant proposal and technical assistance in negotiating the University systems for the required paperwork.

Other staff of the research grant included a half-time secretary, a half-time Research Assistant and a full-time Project Director. The secretary, in addition to performing daily clerical duties, was helpful in maintaining subject files, preparing resource guides and updating respite care listings. She was also attending classes at the University as a part-time MSW student and remained very motivated to learn more about the research activities. The half-time Research Assistant was also a full-time doctoral student in the School of Social Welfare. She was selected to work on this grant project because of her interests in group work and research design. The Research Assistant had responsibility for coding data, rating audiotapes and interviewing subjects to collect data. The Project Director was responsible for developing and implementing a recruitment plan; supervising research staff to collect and code data; organizing support staff; training and directing group leaders; and monitoring the budget. In addition, the Project Director acted as a professional group leader in the study design.

Related staff persons who had other duties but who also completed tasks on the NIMH grant included a MSW student and a doctoral student in social welfare. Both students reported directly to the P.I. for work on his projects. During peak times for the NIMH grant (like pre-test interviews) these two students were asked to assist with the caregivers grant. The MSW student made telephone referrals, assisted in the development of resource guides and completed much of the coding for the pre-test assessment. The doctoral student mainly assisted in the interviews for the pre-test and well as follow up assessments.

Consulting staff for the grant project included three other professional group leaders who led groups using developed curricula. Their primary responsibilities included learning the curricula, encouraging and tracking group attendance, leading the groups and participating in any training necessary to prepare them for work in the groups. Since these three professionals worked full-time in community agencies, the demand on their time was kept minimal.

When the NIMH grant was conceived, part of the budget included a contractual arrangement with the Catholic Family Services agency in Albany (CFS) to assist in various activities of the project. Initially it was agreed that the Assistant Director of Community Outreach Services would be involved in recruitment plans. The agency's long established network in the Albany community was seen as being most helpful in accessing staff to refer potential subjects. Later it was agreed the agency would be responsive to those subjects who were ineligible for the study but who needed referral/counseling services. After three months of operation the grant staff lost the services of the CFS worker due to a job change. The agency's solution was to use the services of the Executive Director of CFS until another staff member was hired. The Executive Director was responsible for some involvement in the recruitment plan, assisting with obtaining space for the group sessions, following up with women who were ineligible for the research study but who wanted services, and providing assistance in obtaining community resource materials for group sessions.

The Program Population

As previously mentioned, primary informal caregivers may be spouses, adult children, other relatives, neighbors and friends. In this study "primary" referred to a caregiver who provided more care than anyone else, including both professionals and non-professionals who may have shared some caregiving responsibilities. Findings from the literature review converge to suggest that a large number of primary caregivers can experience severe psychiatric symptoms which include depression, psychosomatic illness, anxiety, irritability, and an additional significant number experience less severe symptoms of emotional stress. It is estimated that over fifty percent experience physical health changes and restrictions in social life and leisure activities. Since spouses and adult children experience the most stress, and therefore are at higher risk for mental impairment, only they were considered for inclusion in this study.

Clinical experience, as well as the literature on group intervention with family caregivers, indicates that adult children are much more likely to volunteer to participate in groups for caregivers than are older spouses. For example in a study of group intervention for caregivers, Silverman and Brahce (1979) indicated that the mean age of participants was 47.5 years. Research suggests spouses are less likely to attend group meetings because they often have chronic health problems of their own and may be experiencing a loss of energy due to their advancing age (Fengler and Goodrich, 1979; Crossman, London and Barry, 1981). The difference in age and life experiences between these two groups of caregivers is striking, and the group work literature indicates that group development is enhanced by including participants with similar concerns and demographic backgrounds (Toseland and Rivas, 1984). Therefore, on further reflection, it was decided to include only adult children in this study. Furthermore, to try to control for as many demographic variables as possible, which could have a potential "wash out effect" on the results, it was decided to use only female children between the ages of 40 and 60. Middle-aged women are "overburdened," that is, they often have work, family, and marital responsibilities in addition to caring for an aging parent (Brody, 1981; Fengler and Goodrich, 1979). The additional burden of conflicting roles produces stress beyond that caused solely by caregiving, making adult women a particularly vulnerable group. Most of these women should have been experiencing sufficient burden to meet the criteria for inclusion in this study.

To further restrict the sample to reduce the amount of potential variability in the subject pool, it was decided to select only women between the ages of 40 and 60 who have the competing demands of both being married and having children living at home. Although women between the ages of 40 and 60 are not likely to have young children at home, the additional burdens of caring for latency age and adolescent children are obvious. In contrast, one might question the choice of selecting only married women because it has been suggested that sources of social support can mitigate the effects of stress (Brown and Harris, 1978; Zarit, Reever, and Back-Peterson, 1980). However, other studies have not found an association between social support and caregiving burden (Newbrigging, 1981; Machin, 1980). For instance, in a recent study concerning factors associated with the psychological well-being of people supporting an older relative in the community, Gilhooly (1984) found that the presence of other family members, relatives or friends to provide support and supplemental care was not associated with the psychological well-being of the primary caregiver. The presence of spouses may make it more difficult for adult women providing care because of competing demands for time from their husbands and because of conflicting views about how to best provide care for dependent parents.

It was also decided to restrict the sample by characteristics to the care receiver. The research evidence indicates that the types of functional disabilities of the care receiver contribute to the burden, and hence the stress, experienced by caregivers (see, for example, Sanford, 1975). That is, older adults typically have a number of chronic illnesses that decompensate into acute flare-ups at various times. Also, they may have many different medical conditions, the comparative severity of which are often difficult to evaluate. Hence, it was decided to focus on specific functional disabilities manifested by care receivers at the time of initial caregiver screening, rather than focusing on the duration of severity of specific illnesses. The kinds of functional disabilities that make it particularly difficult to provide care include: inability to ambulate; especially the inability to lift oneself (on and off a bedpan, in and out of bed, etc.); confusion (including, but not limited to daytime or nighttime wandering; and incontinence (see, for example, Mace and Rabins, 1981). Sanford (1975) reported that only 13% of a sample of caregivers could tolerate care receivers' inability to walk unaided, that only 21% could tolerate inability to get on or off the commode unaided, 33% could tolerate daytime wandering, 35% could tolerate inability to get out of bed unaided, and 43% could tolerate incontinence of feces. In contrast, 93% could tolerate inability to wash or shave. Thus, when screening prospective subjects for this study, caregivers were asked about the functional disabilities experienced by the parent for whom they were providing care. Only those caregivers who were providing care for a parent who had at least one of the kinds of disabilities noted here, were included in the sample.

The sample was not restricted by the sex of the care receiver. There is some evidence, although it is relatively weak, to suggest that female caregivers have more difficulty caring for males than females (see, for example, Gilhooly, 1984). Even with the large pool of potential subjects available in the Capital District area, it was not feasible in terms of recruitment to consider only married women, between the ages of 40 and 60, with children living at home, caring for a frail father.

Screening Subjects

When subjects expressed interest in participating in the study they were screened by telephone, or, if no telephone was available, by appointment at the project offices. Subjects had to be a daughter of an older adult, age 60 or above, for whom they provided primary care. Potential subjects also had to be married and have at least one child. Next, potential subjects were asked to describe the specific functional disabilities the parent for whom they cared manifested. The screening process only continued if the potential subject was caring for a parent who had one or more of the kinds of functional disabilities noted earlier.

Potential subjects were asked if they were receiving treatment for any current mental health problems or if they were experiencing any symptoms for which they had not sought help. If the potential subject was being treated for a mental health problem, she was excluded from the study. If the subject indicated she was experiencing symptoms of mental distress for which she was not currently being treated, the interviewer elicited the nature and extent of these symptoms from the potential subject. By using criteria clearly specified in the DSM - III (American Psychiatric Association, 1980), the interviewer determined whether or not the subject had a diagnosable mental disorder. If the subject had a mental health disorder, she was excluded from the study and referred to appropriate treatment resources. In those cases where the interviewer found it difficult to accurately determine the potential subject's mental health status by telephone, an in-person screening interview was scheduled. After the screening interview was completed, the interviewer consulted with project staff. If there was any disagreement among project staff the potential subject was excluded from the study.

Once subjects were screened for mental health problems, they were asked about the degree of burden they experienced as a result of caregiving. The interviewer ranked the caregiving situation (kinds of activities provided), how the caregiving activities affected the caregiver, and the kinds of medical and/or emotional needs the care receiver was described to have by using three point likert scales (high, medium, low). The perceived burden of caregiving rather than the "actual" degree of impairment of the older person being cared for was used to determine eligibility for the study. This procedure was consistent with the methodology used in caregiving studies reviewed. That is, it is the perceived burden of caregiving rather than the actual degree of impairment of the older person being cared for that contributes to the psychiatric symptoms described in the majority of the studies that were reviewed.

Two issues that arose in screening potential subjects deserve further clarification. The literature suggests that only two-thirds of the caregivers report symptoms of emotional stress with one-third experiencing "severe" psychiatric symptoms (see, for example, Sainsbury and Grad de Alarcon, 1970). Thus, no intervention, even if it was 100% effective, would do anything to ameliorate mental distress in one-third of caregivers who do not report stress. To overcome this limitation, all caregivers who were asked to participate were experiencing a moderate to severe level of caregiving burden, thereby placing them at high risk.

A second issue that arose from the method of screening potential subjects was that by excluding those subjects who were experiencing mental health problems (because of the preventive nature of this study), subjects who were included might be those who have learned to cope with the stress of caregiving and, therefore, would not develop symptoms of mental impairment whether or not they participated in a support group. If so, neither intervention would be relevant for them. The literature suggests this would not be the case. Longitudinal studies (see, for example, Sainsbury and Grad de Alarcon, 1970; Johnson and Catalano, 1983) indicate that deterioration in caregivers' mental health, physical health, and social and leisure activities is likely to occur over time with the caregiver experiencing increasing emotional, physical and social stress. This is also observed clinically when caregivers seek advice and support from mental health practitioners about whether or not to institutionalize a parent who is becoming increasingly impaired. Thus, the incidence of mental disorders among caregivers is likely to increase over time, but with intervention, the rate of increase is likely to be slowed or reversed. The post-test in the study allowed for an assessment of group effectiveness in lowering the incidence of mental health symptoms (for a copy of the telephone screening protocol and intake form see Appendixes A1 and A2).

Before the final decision was reached about a potential subject the telephone interviewer described the research activities and commitment expected from study subjects. The project staff were of the belief that caregivers needed to be convinced about the worthiness of the research prior to actual involvement. For some, the notion of helping other caregivers by contributing information seemed foreign or the idea of a research project seemed too intrusive and sterile. In contrast, some caregivers were interested in the research but felt too overwhelmed with their caregiving activities to view their participation anything more than another thing to do. Other women did agree to participate yet experienced an unanticipated event, like the sudden death of a parent, a family emergency or an illness the caregiver developed which excluded them from the study. Anticipating for possible dropouts, several additional caregivers were screened to keep on a stand-by list.

After initial screening, potential subjects who continued to express an interest in participating were scheduled for a personal interview in which a project staff member read a consent form and asked if potential subjects had any questions. After all questions were answered to the subjects' satisfaction, they were asked to sign a typed copy of the consent form and this consent form was kept on file in the project offices. The consent form and study design received approval by the SUNYA Institutional Review Board prior to the start of the intervention. The consent form informed subjects about how their confidentiality would be safeguarded, the compensation they would receive for taking the research measures, and their freedom to terminate participation in the research at any time. The form also notified subjects that the data collected about their participation in the project would be reported in aggregate form (i.e., without identifying information, in published and unpublished reports) (see Appendix 3).

Randomization

Once decisions were made regarding potential subjects and the pre-test instruments completed, individuals were grouped according to their county of residence. To avoid any bias on the part of interviewers the principal investigator, who had no face to face contact, and minimal telephone contact with subjects, made the randomization assignments. Subjects were randomized by county to permit the group interventions to be located within an accessible distance to their residences. Wherever possible flexibility was allowed to accommodate schedules and travel plans.

Control Condition

Participants in the control condition had the option to continue to receive existing community services. Because these caregivers were not seeking a group experience, in this instance, neither a sought after nor a necessary intervention was being denied to them. Participants in the control condition responded to the same assessment measures as participants in the two experimental groups. After the group interventions were completed and the post-test administered to the control group, these participants received resource directories for their counties and a listing of education/support groups available for caregivers in the Capital District area (see Appendixes 4 and 5). In addition, special attention was made to needed referrals, either requested by the subject or recommended by the interviewer (i.e., individual or marital counseling, A.A., grief counseling, nursing home placement, etc.).

Participants in all conditions were paid $80.00 for responding to the assessments. This was particularly important as an incentive for the control group participants who were asked to take two assessment measures at different times but did not participate in either type of support group.

Equivalence of the Intervention Conditions

Subjects in the two intervention conditions participated in group meetings two hours a week for eight weeks. Including travel time, this allowed them to have approximately three hours a week away from care receivers. Comparable "time out" was provided for control group members. They were reimbursed a sum of money ($90.00) to allow them to have someone care for their parent for three hours each week for a period of eight consecutive weeks. During the pre-test assessment of subjects, everyone was encouraged to use time weekly in recreational or leisure activities, which removed them physically as well as psychologically from the responsibilities involved in caring for their parent. All participants were provided with a list of sample short and long-term respite care services available in the Capital District at the completion of the pre-test assessment (see Appendix 6).

It was recognized that it would not be ethically appropriate to attempt to prevent subjects in the intervention or the control conditions from seeking additional services. However, to reduce the chances that the data would be biased by subjects' exposure to interventions similar to the ones proposed in this study, all potential subjects were asked about their use of services during the telephone screening interview. Any potential subjects who have been involved, were involved, or planned to be involved, in a professional intervention program designed for caregivers were excluded from the study. Since there were only a few intervention programs for caregivers in the Capital District area, it was not anticipated that many potential subjects would be excluded because of their participation in other intervention programs. In the event that some subjects did participate in other professional intervention programs during the course of the study, data from these subjects would be analyzed separately so as not to bias the findings of the study.

Although attempts to control confounding effects by screening and separate data analysis were planned for, no attempts were made to control subjects' access to other needed community resources once the study had begun. Moreover, it was anticipated that the intervention program would increase subjects' awareness of available community services and this, in turn, might increase their usage of these resources (for example, available health, recreational, and social services). At pre-test and post-test assessments, subjects were asked about their use of community services and this information was used as outcome data in analyzing and discussing the results of the research grant.

Group Leaders

The four female group leaders were professional clinical social workers, with two or more years of experience in work with the chronically ill and the elderly. The leaders were required to: 1) attend four, two-hour weekly training sessions prior to leading a group, 2) demonstrate mastery of the material following the training sessions through role-playing and other exercises, and 3) complete required readings about normative aging and psychopathology in aging with particular reference to caregiving and care receiving.

Prior to the selection of the group leaders, candidates were asked to take part in an interview with the P.I. and the Project Director. During the interview potential group leaders were asked about their educational and clinical backgrounds. Criteria for selection of the leaders included their professional training and experience as well as their familiarity with the difficulties experienced by caregivers and care receivers. Potential leaders were also asked about the quantity and quality of their professional training and experience (especially in the area of group intervention). In addition, potential leaders were asked their opinions regarding the use of the two interventions (educational/problem solving and stress reduction) to determine if any strong biases about the effectiveness of either intervention, or any reluctance to receive training in either intervention existed.

For the research grant it was important to have consistency in presentation and to cover certain amounts of material. However, it seemed equally important to provide the group leaders with some flexibility so that their individual styles were not hampered. The training meetings with leaders allowed time for discussion of this issue. With all in agreement, it was decided the leaders would check in weekly with the P.I. to provide feedback and get guidance, if needed, for the next group session. The professionals participated in detailed weekly telephone consultation lasting up to 30 minutes after each group meeting, based on the P.I.'s review of audiotapes of the previous week's meeting.

Data Collection

All data collected from caregivers was obtained by in-person interviews. Despite the limitations of indirect assessments, it was decided to collect data about care receivers from caregivers rather than to collect data directly from care receivers. This decision was made for several reasons. Mentally and/or physically frail care receivers may not be able to provide accurate data or may not have the energy to respond to an in-person interview. Both caregivers and care receivers may object to behavioral observations (if accurate information could not be obtained from an in-person interview) and the observation of all the care receivers involved in the study would be extremely time-consuming and expensive.

Caregivers were given a choice of whether they wanted to be tested in their own home or in the project offices. Participants were given the choice of where they preferred to be tested to assure a high response rate and so as not to add to the burdens of caregiving these participants were experiencing. Pilot testing of the pre-test indicated that it would take subjects approximately 1 hour and 30 minutes to complete the assessment measures. Subjects were interviewed within the month preceding the start of all groups and within 2 weeks following the last group session.

In the personal interview, questions asked of caregivers were aimed at studying the effectiveness of the practice interventions as measured by changes in caregiving situation, burden level, psychological status, social supports, personal problems and satisfaction with participation in the caregiver support project.

Changes in the caregiving situation examined factors such as perceived health, hours spent caregiving daily and the tasks performed by caregivers. Changes in burden level were measured by the well known Zarit Burden Inventory (see Zarit and Zarit, 1982a; Zarit, 1982; Zarit and Zarit, 1982b; Zarit, Reever and Bach-Peterson, 1980; and Zarit, 1983) and a scale developed for this project, reviewing problems associated with caregiving (personal, familial and societal tasks). Changes in psychological status were measured by the Bradburn Affect Balance Scale (BABS) and the Brief Symptom Inventory (BSI). These measures examined emotional well-being and psychiatric symptomatology (Bradburn, 1969; Derogatis, et al., 1974; Waskow and Parloff, 1975). Social support measures included changes in network size, satisfaction with support received and familiarity with community resources. Changes in personal problems were measured by perceived changes in personally identified pressing problems as well as perceived changes in areas like knowledge, feelings, actions and thoughts. The remaining measures were given to participants in all treatment conditions at the last group meeting. Satisfaction was measured by five-point Likert-type scales for rating the group leader, group, overall satisfaction with project, and whether the project would be recommended to a friend in a similar situation (Zarit, 1983; Lieberman, Yalom and Miles, 1973; Lieberman and Borman, 1979; and Lieberman, 1981).

Design

Subjects were randomly assigned to intervention conditions as part of the NIMH grant. For purposes of the doctoral project 20 participants were assigned to the stress reduction condition, 10 to each leader. Subjects were not informed of the type of group in which they were participating nor the nature of the research hypotheses.

In the professionally-led stress reduction condition, the trained group leaders assumed responsibility for the planning and ongoing maintenance of their groups. A detailed curriculum was followed to guide the two leaders in conducting their groups for women caregivers. Material in the curriculum was compiled from reviewing existing curricula used with various populations, speaking with professionals who had used stress reduction approaches in groups and reviewing the audiotapes from groups led in time one of the NIMH grant.

The stress reduction approach involved exercises and role-playing activities during the weekly sessions in addition to homework practice assignments. Topics for the group sessions included: an introduction and rationale for using stress reduction as a coping skill; differentiation of proprioceptive cues associated with muscle tension from those associated with muscle relaxation; relaxation of muscle groups; relaxation through meditation; real life situations and the individualizing of stress reduction approaches; developing a stressful events hierarchy; and stress coping thoughts. Time in each group session was divided to allow delivery of content on stress reduction, review of group members' experiences with using the stress reduction approaches, and the sharing of experiences of individual caregiving situations.

This group intervention was based on a systems framework which maintains that human beings continue to learn skills that help them cope with the stresses of the psychological, social, and physical environment in which they live. Hence, the emphasis was on helping participants to cope more effectively with the caregiving situation by making it more manageable and by altering their outlook and responses to the situation so as to reduce stress. In addition to the stress reduction component of each session which lasted about one hour, the second hour focused on a problem solving protocol. The problem solving component used a six-step model with the following goals: 1) identify the problem, its antecedents, and its consequences; 2) generate alternate solutions; 3) examine pros and cons of each solution; 4) discuss and cognitively rehearse an action plan; 5) carry out the plan; and 6) evaluate the plan (Zarit, Orr, and Zarit, 1985). Each week one to three participants had the opportunity to work on particular problems they were having with caregiving using this model.

Evaluation of this intervention focused on the processes of change of the overall program development and implementation. Attention was given to change process research, versus focusing strictly on outcome measures, so that a clearer understanding of how and why changes occurred or did not occur for these female caregivers could be attained. Evaluation focused on process would emphasize the ongoing interactions between program staff and the target population as a result of program input. In this way effects of the various program components, as well as the characteristics of the women exposed to them, could be more meaningful in understanding why caregiver support groups are helpful or not.

The qualitative study of program process was selected because it permitted the examination of select issues in depth and detail. The aim was to view the unfolding of a caregiver support group from the point of recruiting participants to the completion of the group activity and the reactions of those subjected to its impact. This conceptual framework allowed the formulation of several questions important to social work practitioners who might want to duplicate such a program. For instance, the process oriented approach addressed issues like: Why the program reached some caregivers and not others? What professionals and agencies became involved in recruitment and with what effect? What roles were played by the group leaders? What limitations were there in conducting this kind of a group (Chommie and Hudson, 1974)?

In examining the process of change for these caregivers two types of group outcomes or changes over the course of the intervention were analyzed. Following the model described by Greenberg (1986), this research looked for immediate outcomes or impacts that indicated change in an individual session. These immediate or in-session changes were related to intermediate changes or those outcome measures evaluating changes in attitudes and behaviors. Audiotape recordings of the group sessions were analyzed to assess trends in the group discussions, common themes in caregiving activities, and concerns of the caregiver population. By analyzing the content of the sessions, variables related to behavioral and cognitive changes were identified for this client group.

CHAPTER FOUR:

CONDUCTING THE PROGRAM

Marketing Strategy

The adoption of a marketing approach to the planning and implementation of social services has been shown to be an effective practice that complements social planning (Stoner, 1986; Lauffer, 1986; Genkins, 1985; Winston, 1984; Fine and Fine, 1986). A carefully planned social marketing strategy can be a useful tool in attracting consumers and resources and informing providers about issues of practice. For the doctoral project a marketing orientation was adopted and seen as key to achieving the goals of the program.

In using the marketing approach the first and foremost concern was the consumers or caregivers who would receive some benefit from the services provided via the support groups. Their selection has been described earlier but thought was also given in regard to consumer satisfaction so that the needs and interests of the caregivers were well understood in shaping the services provided to them. A second concern was the product being offered and its responsiveness to the needs of caregivers. Much time was spent styling and packaging the curriculum to be a quality intervention program. Legitimacy was sought through the careful selection and training of leaders to facilitate these support groups. Thirdly, attention was directed to where and how services were to be distributed. The factors of place, price and promotion became as critical as the curriculum package itself. Finally, an assessment of performance would be measured; both of the group leaders as well as obtaining indicators of desired behavior changes in the caregivers. This chapter highlights the marketing approach utilized in conducting the caregivers' support program.

Attendance/Drop Out Factors

Because the focus of these groups was educational, with a prescribed format and curricula, it was desirable to have a group membership who provided continuity through regular attendance. In organizing the groups a number of potential obstacles to group attendance were identified. These obstacles were addressed with possible solutions so that group leaders would be prepared in advance to respond to caregivers' concerns. An obvious obstacle for this clientele would be respite care for the parent while the caregiver attended the group. To assist the caregivers the research grant provided a monetary allotment which could be used to hire a "sitter" and provide the needed respite. Several problems arose for caregivers who attempted to purchase such services. When the principal investigator prepared the grant he failed to obtain an accurate market value of home health aide services in the Capital District area. The allotment to caregivers was $90.00 for 8 sessions which calculated to be $3.75/hour to use in hiring assistance. Agencies charged more than twice that amount and generally required a 4 hour minimum stay. Even if the caregiver could put this allotment with her cash reserves, many times there were simply no services available to purchase or no one who would be willing to take a case which was beyond the city limits served.

A related issue to obtaining respite care to relieve the caregiver for group participation was the use of family members as "sitters". On one hand some families were quite supportive of the idea of a group for caregivers and willingly stayed with parents. Caregivers could leave home one night a week knowing that their relative would feel secure with another family member. In some cases the allotment was given to the family member as a payment and thank you; recognizing them for their time and effort. On the other hand some families already felt pressured to help with an aging relative. Unless group attendance was highlighted by the caregiver as a priority for her, it was viewed as another intrusion for family members to schedule around. Families might have been called on to assist earlier that week and both the caregiver and relative were reluctant to make special arrangements again.

Other kinds of family stressors also posed problems for caregivers in their ability to attend group sessions. Often both the caregiver and her husband had pressing work schedules, making demands on their time. If one had to be out of town for business or attend an evening function, group was not a priority that week. Since these women also had responsibilities to children, there were occasions where a family commitment took priority over group attendance. If budgets were stretched, the respite allotment was used for a family expense, prohibiting attendance at group.

In general, illness was the reason most caregivers gave for missing group sessions. The illness was more likely to be a problem the care receiver was experiencing but was frequently related to caregiver illness. Parents would experience a medical crisis that week, demanding special attention, and caregivers were hesitant to leave them with family who were less familiar with the care regimen. At times, parents strongly reacted to their caregivers being absent on a weekly basis and objected to these women leaving them even for a few hours when their illness was causing them to feel uncomfortable, uncertain, or scared. Caregivers reported parents being uncooperative with daily routines, having temper tantrums, or refusing to stay with sitters as ways to express their displeasure with the weekly absences. In a few cases the parents' illnesses became so complicated that hospitalization was required, making group attendance unlikely. The caregivers themselves had their share of illness related to a variety of causes. Caregivers were very depleted due to their multiple demands and were susceptible to colds/viruses or simply were exhausted and needed a rest. Some women were experiencing problems typical of their middle age status in life and needed medical attention. Other women had ignored medical conditions for too long due to their caregiving stresses and now required hospitalization.

Weather became an important factor in this caregiver population. If there was the slightest problem with driving, caregivers became very uncomfortable about venturing forth for an evening group session. Anticipating this obstacle, the groups were started in early April to avoid snow as well as to have the eight sessions completed prior to the vacation season. Unfortunately, in the northeast, weather can be unpredictable, which caused for a couple of uncertain evenings in April. The project offices acted as the coordinating center for cancellations and notified participants that groups were postponed rather than have these women risk an accident or face several no shows.

Realizing that caregivers and their families can have heavy financial burdens the research grant offered a travel allotment to cover additional expenses of transportation to groups. Similar to the respite allotment, the monies were not adequate to pay for some services, like a taxi, but could be combined with other resources. The difficulty that many caregivers faced was not having a vehicle to use. Once groups began some caregivers developed their own car pool to share rides. While all groups were accessible by public transportation it meant travelling in the evening and this was not an option some caregivers favored.

The purpose of the groups was explained to caregivers prior to their actual participation during the telephone screening, when they signed the consent form, and when they were notified of specific group logistics. Even so, when caregivers attended the first session and were confronted with the realities that the group would focus on them, not the care receiver, plus the fact that they had some responsibility as a group member, some caregivers' expectations of the groups were not immediately realized. A few expressed concerns that they might not be "stressed enough" to qualify to be in a group or had second thoughts once they heard about other caregiver situations. The skill of the group leaders was used to address these concerns as well as the others listed above. Whenever possible, accommodations were made to assist caregivers in continuing on as group participants and minimizing dropouts. Because caregivers were informed during the screening process that the success of these groups depended on their active involvement, participants were very conscientious in notifying their leaders of cancellations. If the number of cancellations became too many for an evening the leader had the option of postponing a session.

Training of Leaders

As mentioned previously leaders were selected for their education and training as MSWs plus their variety of experiences as independent practitioners. Because each of these women had backgrounds rich in groupwork experiences and practice with elderly clients, it made the training of the specific interventions go very smoothly. Prior to the first caregiver group sessions leaders met with the research staff to discuss materials they had received and reviewed. Training sessions focused on the information to be delivered each week, the format for delivering information and integrating it with the clinical needs of the caregivers, plus particular techniques for leading the groups. The training agenda also included a discussion of practical items like attendance rosters, duplication of materials, obtaining supplies, equipment usage, and logistics of groups.

The research project staff took the initiative in making all the group arrangements for the leaders. The planning details of setting up the groups were completed for leaders so that they could spend their time getting familiar with the educational materials. Those items which were directly connected to the research grant like consent forms for taping, financial payment information, and purpose of the research study were handled by staff for efficiency and continuity. Items such as scheduling caregivers, securing rooms, and preparing handouts were completed in advance. One week prior to starting the group sessions leaders received recording equipment, and handouts, as well as group rosters. Leaders made their first contact with group members by telephone at this time to introduce themselves and remind women of group logistics.

With the exception of the author, all the group leaders worked full time at a social service agency in the local community. Their work experiences and professional identities provided them a context within which to view the caregivers and the special needs of these women. As facilitators of these groups the leaders provided legitimacy and credibility to the concerns of the caregivers. They acted as important sources of information about the community service system. In addition, they displayed a particular sensitivity to the caregiving issues since all of the MSW leaders had personal caregiving situations they had experienced firsthand. Perhaps most important, the leaders were able to create a safe environment where the caregivers felt free to communicate openly and gained a sense of belonging to the group. Their competencies in organizing, being committed to helping people, using humor appropriately, respecting confidentiality and using effective interpersonal skills served them well in connecting with the caregivers.

For purposes of the research it was important to do integrity checks of the interventions being used. These checks proved to be critical in maintaining the consistency in presentation and process for all groups. The MSW group leaders continuously struggled with closely following the designated protocol. Despite the six hours of extensive training and their years of groupwork experience the professional leaders needed weekly reminders to stay with the protocol. Leaders explained that the groups had "minds of their own" which the MSWs paid attention to in addressing immediate concerns. Previous experiences had taught them to let the group define sessions instead of adhering to a structured format. While some flexibility was designed in the protocol, and the leaders' individual styles accounted for, the MSWs still strayed from the format. To compensate for this leaders were encouraged to telephone each other between sessions to compare notes; research staff picked up tapes weekly for review so immediate feedback was given; and specific suggestions were offered to leaders regarding their particular group.

Group Locations/Group Meeting Sites

Caregivers were randomly assigned to groups, within the constraints of their schedules and the county in which they lived. At the time of the pre-test interview caregivers indicated a few preferred times when their schedules would permit consistent group attendance. Review of these preferred times quickly pointed out that evening groups would be best to accommodate job constraints, family responsibilities and coverage for respite care. These preferred times were matched with the availability of rooms in the local community and leaders' schedules. On a rare occasion a caregiver was assigned to a group outside of her county of residence because of scheduling problems. The aim was to keep travelling distances reasonable for convenience and to minimize time away from caregiving responsibilities.

Group meetings were held at four different types of locations within the Capital District area. As is typical for caregiver support groups, meeting locations were at health and social service agencies (a geriatric center and a physical rehabilitation center) plus at civic and religious organizations (a family community center and a church). These locations for group meetings were selected for a variety of reasons. The project staff were seeking neutral and comfortable locations, hence, the university campus was eliminated as an option because many caregivers had been interviewed there in the research project offices. Less sterile environments were selected which could afford caregivers easy access to bathrooms and telephones, permit smoking, make a kitchen available for refreshments and be the right size for encouraging intimacy and privacy. In addition, meeting locations were selected for their centrality in a county, permitting a direct route with easy accessibility by public transportation. Realizing that caregivers might not be familiar with meeting places, attention was given to safe locations which had adequate parking lots that were well lighted.

Financial Payments to Subjects

To help assure continued participation in the research grant, for equitability across conditions, and to respond to the particular needs of caregivers of the elderly, financial payments were made to all women who were involved in the project. As previously mentioned all women were compensated $20.00 each time they completed a research interview (pre-test, post-test, 6 month and 1 year follow up). All women also received $90.00 for respite care services. For those women who attended support groups $40.00 was allocated to each to help cover travel costs. These financial payments were tracked by the Project Director and dispersed by an agent of The University at Albany Research Foundation.

One problem with these financial payments was the low estimation of amounts required to purchase community services. If a caregiver was on a fixed income or had many expenses to meet she did not find the allocated amounts alone sufficient to cover respite care or travel costs. The intent of the P.I. was to make planning for attendance at groups stress free, thus, not adding to the felt burden by caregivers. However, the reality of the academic setting produced a mindset for payments as though the caregivers were personnel requesting reimbursements. For example, the Research Foundation wanted to reimburse travel by the mile. Some caregivers did not own a personal vehicle or were travelling longer distances to attend a group. In the effort to make reasonable budget requests of the funding source and satisfy administrative costs of the university, reimbursements to subjects suffered.

The University Research Foundation complicated the financial payments to subjects in other ways. The typical reimbursement procedure was to make a payment after an event had occurred, as in attendance at a conference. It took much convincing of the Research Foundation agent to make a payment in advance of the group start date so that caregivers would have some cash to purchase services, which was the original intent. A compromise arrangement was agreed to which made partial payments to caregivers by week 2 of the groups. Detailed attendance records were kept by the Project Director in conjunction with the group leaders so that a second payment could be made to caregivers as soon after completion of the groups as possible. When caregivers missed a session a formula was used to calculate payments so the Research Foundation would not be "overpaying" subjects.

In the final analysis most caregivers reported the money not being significant when compared to the opportunity for a group experience. A few caregivers refused the financial payments or attempted to return them to The University; saying their participation helped them and others which was enough of a payment. Several caregivers used the financial payments for other needs related to their individual situations. For instance, payments were used to buy equipment or something special for the care receiver, the money was spent on entertainment for the caregiver and her spouse, or the money was being saved to combine with other resources for a much needed vacation. It would seem that these caregivers either used the payments for purposes associated with group attendance or found other uses related to the caregiving context.

Promoting the Program in the Local Community

This author was fortunate to have been involved with the NIMH research project since day one of the grant. Both positive experiences and errors in strategies were dealt with on a primary level by the Project Director and P.I. Thus, the doctoral project benefited from any problems encountered during Time One of the group interventions (July through December 1986). In this case, marketing statistics were reviewed to note where subjects were successfully acquired for fall groups in the NIMH grant.

A recruitment plan was devised for use in the NIMH research grant. It was proposed that the subjects required for the grant would be recruited by the following means: 1) utilizing the extensive community network of the School of Social Welfare at the University at Albany including close working arrangements with a large teaching hospital, several smaller hospitals, the Visiting Nurse Association, and so forth; 2) other agencies that agreed to cooperate in a needs assessment survey completed 3 to 4 months prior to actual receipt of the grant monies; 3) sending fliers to community agencies; 4) public service announcements in local papers as well as on radio and television; and 5) speaking at meetings of civic organizations. For Time One of subject recruitment in the NIMH grant this plan was executed by the Project Director and the assistant director of Community Outreach Services (from Catholic Family Services - Albany) over the summer months of 1986 (July through August). Recruitment was not extended over a longer period of time since it was seen as more prudent to start the group interventions in mid-September to avoid any travel later in inclement weather, plus to adhere to a structured timetable for follow-up interviews in Year 2 of the grant.

Review of the original recruitment plan revealed that several assumptions had been made of the service delivery network. First, the service delivery network did not view the NIMH grant as another resource for its clients, rather, referrals were seen as time consuming because agency personnel had to learn the subject criteria and then approach potential candidates. Agencies complained the criteria were too strict; limiting many of their known caregivers to be eligible for the program. Second, due to changes in the arrangements for home care of older persons necessitated by the implementation of DRGs, many hospitals were not getting familiar with the families as before, and professional home care agencies were finding families too stressed to participate in anything other than planning and coordinating direct services for the patient. To compound the problem of agency cooperation, a recruitment plan lasting only two months did not give many county bureaucracies and large organizations time to disseminate details about the program to all their staff.

In the revised recruitment plan, much time was reserved for follow up with agencies who had made a few referrals in the fall to update staff about the program, and to review with new staff the possibility of informing clients about this resource. Five months (November 1986 through March 1987) was designated to be used as public relations time with those agencies who had not made referrals and with agencies that were not contacted in the first recruitment effort. Initially the Project Director contacted agency representatives by telephone to describe the project. Next, a brief two page description of the project was mailed to agencies who expressed an interest, along with several fliers to be distributed to staff and/or potential subjects (see Appendix 7). Follow up calls were made to agencies to clarify project details, and where warranted, the Project Director made visits to agencies to speak at staff meetings to specify the project goals.

Also, over this five month public relations period efforts were concentrated on those areas in the original recruitment plan which proved to be successful sources for referrals. For example, the media seemed to be an excellent way to reach caregivers who were not currently connected to an agency or who were fairly isolated because of demands placed upon their time. Hence, newspapers, radio public service announcements and radio talk shows were used a second time (see Appendixes 8 and 9). Maximizing on the fact that groups had already run successfully, efforts were concentrated on obtaining interviews with group leaders and group participants for the local television stations and cable channels.

A review of the first wave of participants revealed the obvious lack of minority caregivers. Thus, in the revised recruitment plan efforts were made to reach out to minority populations through traditional and non-traditional methods. For instance, a brief article was prepared and circulated to local church newsletters and bulletins (see Appendix 10). Contacts were made to local prominent, minority, community leaders to obtain invitations to speak to organizations and church groups. Especially important was an opportunity to speak at a monthly breakfast meeting of Black Ministers. In addition, special efforts were made to reach women's associations and clubs.

Some agencies had expressed a concern for the protection of the confidentiality of their clients in the first wave of recruitment. The additional time allocated to the public relations campaign allowed the Project Director to make individual arrangements with agencies to satisfy legal council as well as professional staff. Sample materials were prepared for the approval of agency administration. Once found agreeable it was suggested the agency endorse this project with their letterhead. In this manner correspondence was mailed to clients for their review and permission firsthand. The agencies then provided the Project Director with lists of potential subjects or the subjects telephoned the project offices directly (for example, see Appendix 11).

The Project Director also utilized the services of the contractual agency, CFS-Albany, to reach other sources in the Albany area. A review of the recruitment plan pointed out that many service organizations, like the P.T.A.s, had not been approached and were contacts the Catholic Family and Community Services agency had previously established through its programming. It was decided a public informational meeting might be a good recruitment strategy to have organizational representatives learn about the proposed research and bring details firsthand to their peers (see Appendix 12).

Cooperation from the local Albany area was modest, but even so, the group interventions ran without many major problems during Time One of the NIMH research grant. The recruitment plan was revised for Time Two of the NIMH grant as well as the doctoral project and relationships with agencies attended to more carefully to aim for increased involvement. Time was taken to plan meetings with important referral sources as the Visiting Nurse Association, hospital discharge planners and home care agencies. Follow up meetings were planned with those agencies who were currently offering, or had offered, education/support groups for informal caregivers to review referral mechanisms and any new turf issues. A second meeting was held with NYSOFA to determine what stage their "train the coordinators" program had reached to avoid overlap in the Albany area. Since the four county area within which the research grant operated was manageable in size, it was not too burdensome to make face-to-face contacts with providers, attend planned programs to observe other caregiver groups, or be in contact frequently by telephone to use the informal networks.

An important element to completion of the doctoral project was the recruitment of subjects to receive the intervention. A revised recruitment plan to correct for errors made previously was essential. Even with some strategic errors in Time One of the NIMH grant the necessary number of subjects was obtained, with a large waiting list. It was reasonable to assume the caregivers population in the Capital District had not been exhausted and subjects would be recruited. If recruitment did become a problem a few contingency options were outlined. One possibility was to recruit more heavily from a county which had been responsive. While the groups would not be completely random in all counties used in the study, some conclusions could still be made about caregiving and the intervention. Lastly, a group could be brought to the caregivers; either in a rural part of a county where transportation was a difficulty or in a heavily minority populated area where skepticism may have prevented more interest in the research grant.

Equipment Failure

All group sessions were audiotape recorded. Project staff reviewed tapes as a check on treatment integrity, to make suggestions to group leaders for future sessions, and to examine the group processes that may have contributed to therapeutic outcomes. Caregivers were aware of this procedure which was explained in the context of research data when they signed consent forms. While a few comments and jokes were made initially, the caregivers quickly forgot about the recording equipment and went about the business of the group sessions. The leaders, however, felt differently about the equipment and expressed their thoughts several times throughout the duration of the groups.

The clinical concerns which leaders had about the use of recording equipment centered around confidentiality and group process. Leaders were not convinced that caregivers felt totally free to express themselves about sensitive topics knowing their words were being recorded. Many caregivers had difficulty in saying anything which implied negativity about their parent, spouse or family. While caregivers were assured complete privacy and anonymity as participants in this research project, the leaders believed these women did not say everything because of the equipment. Leaders felt the group process was interrupted by the activity associated with operating the recorders, which used 90 minute tapes. Tapes had to be turned over or changed in order to capture the entire session. While the tapes and equipment were sensitive to recording at low volume their use in a large room, with nothing to absorb extraneous sounds, and recording women who spoke softly could not guarantee complete success. Leaders felt they had important work to do regarding group format and meeting members' needs. To be concerned about reminding everyone to speak loudly for the recorder would be a distraction from the important work the group had to do.

In both the Fall and Spring groups experienced equipment failure. The sessions were not being recorded in their entirety or were lost completely. Leaders attributed the recording problems to faulty equipment, inexpensive microphones which did not capture voices clearly, and room and group set up not being ideal recording conditions. Equipment was replaced and review sessions held for leaders regarding operation/set up of these recorders. When sessions were not taped adequately in Time Two, leaders presented the idea of preparing written process recordings for the research staff so that there was some outcome data to examine. Recordings or notes were prepared on a couple of occasions but leaders continued to struggle with the equipment. It is the author's speculation that the equipment was not superior and/or the leaders felt uneasy with their groupwork skills being examined and critiqued so closely.

CHAPTER FIVE:

RESULTS OF IMPLEMENTING PROGRAM

Development of Consistent Themes Across Group Intervention

In designing any intervention for a client population it is important to recognize that particular population's priorities. Intervention strategies will only be useful if they can match the concerns of the clients at a given point in time. In this study major themes of concern about aging relatives, caregiving and intergenerational relationships emerged and continued to repeat themselves, both within one group and across groups. This finding in implementing the program replicates other studies found in the literature where psycho-educational programs were offered to support the caregiver population (see for example, Clark and Rakowski, 1983; Hartford and Parsons, 1982; Toseland, Rossiter and Labrecque, 1989a; Zarit, in press). These consistent themes help to provide direction as to the kinds of help needed by caregivers of the elderly.

Several common themes were identified from both of the stress inoculation groups. They tended to fall within four major categories or systems involved in the process of providing caregiving services. The client systems identified by participants were those having to do with self, family, elder, and environment.

The Self System

The client self system involved themes which focused on analysis of coping styles and acceptance of feelings as a caregiver for a frail parent. A key issue for these women was the struggle to help an older relative while maintaining balance in their lives. Traditional means of coping or techniques which had been successful in the past were not necessarily applicable in this situation. Participants had come to the conclusion that the role of caregiver did not have a job description. They realized that their generation was the first to encounter the dilemma of elder care and they would be moving in uncharted territory. This realization produced anxiety, confusion and an enormous amount of stress as the caregivers attempted to maintain their usual roles and cope with the new challenges their caregiving situations offered.

Participants in the groups attributed part of their imbalance to what they labeled the superwoman complex. They normally assumed multiple roles as wives, mothers, workers and friends which they juggled accordingly. Their own expectations, as well as what they perceived to be the expectations others placed on them, caused them to believe they could continue to do everything perfectly as this additional role of caregiver was assumed. They discovered that the caregiving role was very demanding on their emotional, physical, spiritual and mental reserves in ways they had not ever imagined. These women continued to lose control over their lives as those they interacted with placed more expectations on them. These women reported their typical response was to avoid reaching out for help and to internalize their feelings while marching forward. The results of these behaviors over time produced complex, overloaded lifestyles. No matter how efficient or organized these women were, the element of time was always a constraint. In addition, all of these women had developed some physical reaction to their stress such as headaches, backaches, muscle tension and insomnia. At the time participants came to the support groups they were ready and willing to examine their current coping styles and ways to improve them.

A related self-theme expressed by group participants was the wealth of feelings they experienced in their lives since taking on the caregiver role. For some this was the first time they had allowed themselves to verbalize how they felt about caregiving and those individuals significantly impacting on their lives. For others this was an opportunity to permit themselves to ventilate in a protected environment where a framework was provided for identifying and labeling feelings. Participants were encouraged to express their feelings so that they could begin to understand them within the context of the caregiving situation. The goal of learning how to manage problems was closely linked with acceptance of feelings about the difficulties of caregiving.

The range of feelings expressed in the support groups was extensive, which reflected the complicated actions caregivers had to take, the intrapersonal tasks with which caregivers struggled and the breadth of knowledge needed by caregivers to do their jobs. Even though there was diversity in the feelings expressed, each time a woman described her emotion, she received confirmation that the feeling had been experienced by another in the group. The caregiving role produced feelings of: powerlessness that a woman could not change the process of aging for her parent; resentment that she was the primary caregiver upon whom the major responsibility fell for her parent; anger that family members were not more helpful or the health care system was so difficult to negotiate; exhaustion which resulted from the commitment to be all things to all people without any relief; and fear of someday being old and a burden on her family. Perhaps the overriding feeling of all those discussed in group sessions was that of guilt. This generation of women seemed particularly susceptible to feelings of guilt aroused by their children who thought they should be available constantly to do activities with or for them, their spouses who wanted more attention or responsiveness to needs and their parents for whom they felt they could never do enough or be there often enough. Guilt, like many of these feelings, was related to this generation's lack of assertiveness and unfamiliarity with being their own person separate from the identity created for them by family and society.

In conjunction with these feelings which caused discomfort were those which promoted the entire caregiving function to occur. Positive feelings of love and affection, motivation and commitment plus pride and a sense of personal accomplishment were common among group participants. Also, throughout the group sessions there was the appropriate use of humor which allowed caregivers to laugh at themselves during trying times. Frequently the women reminded each other about the rewards of caregiving so that the positive feelings became a tool in helping them adjust.

The Family System

The recognition of themes involving interaction with relatives and the history of the relationships held with these relatives became the basis for the second client system. Group participants were very concerned how their caregiving responsibilities would impact on or interfere with their nuclear and extended families. The time constraint made caregivers feel as though they were not spreading themselves out equally and being fair to everyone involved. Time was also an issue when the caregivers felt they were doing their share with parents but other relatives were invisible or kept a low profile.

Interaction with family members took on a new meaning when examined within the context of caregiving. Behaviors which were formerly ignored or excused became a concern after years of caregiving rendered women unappreciated and frustrated. In their nuclear family women began to challenge siblings' behavior when they felt they were not receiving enough support. Women waited for siblings to volunteer but found they were not forthcoming, or completed tasks on their own schedules. In their extended families women expected members to change along with them to accommodate the elder care situation. Instead, children and spouses behaved as always, perhaps not recognizing the need to help with chores more often or to allow some personal distance to the caregivers. Interactions with family became increasingly strained, nonproductive, distant and unfilling.

Intertwined with family interaction were themes of the roles caregivers adopted with relatives based on years of history together. For instance, siblings who might have been seemingly favored by a parent at an earlier age continued to be singled out for favorable mention when they might reside out of town and visit once a month. Old jealousy resurfaced and caregivers reported anger at not being recognized for their current contributions as responsible adults. Disagreement over how to do some caregiver task or what decision to make was a common theme caregivers cited. Group participants felt the issue of what was best for a parent could not be separated from the status or power a role had always held within the family. In their extended families caregivers believed their spouses and children expected them to perform as before the added strain of parent care. These women were to be available to do activities and run the household smoothly. Likewise, women wanted to perform traditional activities and shelter their extended family from the painful realities of the current situation. History of a caregiver's nuclear and extended families was a predictable feature as well as a troublesome aspect to shake.

Acting as a backdrop for interactions with relatives and the history of relationships was the developmental cycle of the family. Themes emanating from this facet of human behavior focused on the caregivers' extended families and their course of passage through the stage of the middle years. Several caregivers mentioned looking forward to some free time with their spouses now that children were older and leaving the house. Instead, caregivers found themselves entrapped in a demanding situation where they were caring for their parents. At a time when these women wanted to stand back to view their accomplishments in raising children and sustaining a strong relationship with a spouse they were busier than before with little opportunity for reflection. Rather than receiving respect and approval from their parents for accomplishments, caregivers were providing the encouragement and reinforcement to parents with whom they had traded roles. In trying to prepare themselves for their own aging and mortality, caregivers did not concentrate on their strengths and life achievements but on not being a burden to others as they felt their parents had become to them.

The Elder System

The client elder system was related to themes of responding to parents' needs as well as the quality of the relationships caregivers held with their parents. Being responsive to meeting parents' needs was more than physical care and safety but also included legal and financial issues as well as their overall psycho-social lives. Group participants reported the struggles they faced in providing services with which they had little familiarity. They described the desires they had to see their parents less isolated or depressed but not knowing how to stimulate them with so many limitations. Caregivers related a theme of protection where they found themselves insulating their parents from problems or sad news for fear the elders would not respond well. A real dilemma for many caregivers was managing their parents' monies to pay for needed services. Often times money was available but parents refused to pay for care or were so demented choices needed to be made on their behalf. These women were uncomfortable with making decisions which involved the spending of life savings.

The most frequent theme mentioned in regard to quality of relationship with a parent was the change in elders, making current interactions very different and foreign. Caregivers were in the process of grieving for their parents, describing elders as "non-persons" with whom they interacted. The longing for a parent the way they used to be, caused a caregiver to doubt she understood her relative in the present. If a parent was still fairly intact mentally, a caregiver had difficulties promoting independence since the elder was relying on her for all decision making. A large part of relating to parents now seemed to be the theme of willingness of group participants to accept they could not make them young again. Caregivers described relationships with parents as one-sided, conflictual, one-dimensional and dysfunctional.

The Environment System

In the realm of the client environment system, a major theme was that of understanding how to deal with societal and health care networks. If caregivers recognized the need to plan and make future arrangements they did not always know where or how to begin. Gaining access to services they could trust and rely on when they needed them were issues caregivers reported. Typically a crisis prompted the use of services within the environment. In those instances services would be arranged for quickly and caregivers would question the qualifications of staff, be worried if they were doing the right thing or feel guilty about the fact there was a crisis. Lack of education about diseases and community resources hampered caregivers' confidence in their choices. A final theme closely related to the above was the release of some control as the primary caregiver. It was not unusual for caregivers to relate doing this job alone for five years or more. Some form of respite was not utilized because caregivers admitted they would not be comfortable being away from their parents coupled with the fact that they believed no one else could care for their parents as well as they. The comfort and fulfillment many caregivers found in their role inhibited them from exploring opportunities for assistance and considering what they could do in planning for future arrangements.

Progress Toward Problem Identification and Resolution

This study was aimed at combining cognitive and behavioral strategies in an effort to provide caregivers with a way to manage the stress of their parent care situations. The stress inoculation approach was utilized to assist in understanding feelings in the caregiving situation. In addition, this approach offered some coping skills to assist these women in relaxing physically and mentally while learning different ways to view and think about caregiving. Initially information was provided which explained the purpose of stress inoculation and the concept of stress in caregiving including identification of stressors and symptoms. Next, direct action coping skills were detailed which included a variety of strategies like collecting factual information, identifying short circuit routes, mental relaxation exercises (attention diversion, imagery manipulation), physical relaxation exercises (muscle relaxation and breathing techniques) and palliative measures (perspective taking, social support network, ventilation of feelings). A description of cognitive coping skills followed which provided a model for dealing with a stressful situation through the use of positive self statements. Finally, an application of all coping skills to real life problem related situations was practiced in a sequence of imagining, role playing and actually executing skills.

Reinforcement of these coping skills was attempted through various means during the eight week groups. Women received mini-lectures of about 10-15 minutes where concepts were presented and the importance of each topic to caregiving and coping was outlined. Tape recordings of physical and mental relaxation exercises were given to each participant to try at home after the exercises were explained and practiced in group. Homework assignments were made to help underscore a coping skill. For instance, participants were asked to complete a stress hierarchy, measure their levels of stress using meters provided, and keep a diary on their dysfunctional thoughts for a week. Readings were handed out after each session which addressed topics like dependent elderly, community solutions, losses of the elderly and family discord. It was hoped a caregiver could identify with at least one of these reinforcing methods to assist in making the stress inoculation approach meaningful.

The second approach utilized in this study was that of problem solving. Caregivers were provided the opportunity to consider a unique area of most concern to them. This problem area was identified from the stress hierarchy prepared by a caregiver after session #1. Each week 2 to 3 participants would try to describe their stressful caregiving situations, rank the level of stress in their situations and identify stress related thoughts and reactions while in the stressful experiences. The group then offered suggestions based on experiences in caregiving as well as from the coping skills just learned. It was left up to a participant to select the most useful strategy(ies) which had meaning for her or that she could accept and try. Emphasis was placed on describing, illustrating, roleplaying and/or rehearsing strategies so that participants were comfortable in trying them during the week without the group. In future sessions caregivers refined their skills or selected different strategies after reporting how their utilization of coping skills worked.

It is important to note that caregivers were given instructions to practice the strategies several times until they felt right or the results aimed for were achieved. Participants were told they needed to feel at ease with any strategy selected to make this intervention a collaborative effort. To assure some positive feedback, a paradoxical approach was employed giving permission to participants to simply think about using strategies or to only complete a portion of the strategies. This approach was used because the goal was to reinforce positive feelings about self and remind a woman she had some control in her situation. Above all, the intent was to decrease stress and not provide another thing to cause burden for the caregiver. If women did not use the strategies once they agreed to them, the efforts in group would be toward understanding what prevented or inhibited participants. Revisions in the recommendations were always made with the participants' cooperation and collaboration.

This problem solving period was to help reduce stress the caregiver was experiencing in the here and now. In addition, the caregiver was to see the cognitive and behavioral model of solving problems being presented, and doing conscious things to reduce her stress. It was hoped the caregiver would be inoculated for the future by having some useful techniques to use when her home situation became stressful again.

Case Examples

Caregivers brought a variety of problems to the group and achieved different levels of resolution via attitudinal and behavioral changes. Participants were rated in their movement toward resolution by group leaders who used a likert scale ranging from -2, or much worse, to +4, or completely improved. The following examples serve to illustrate the progress made toward problem identification and resolution by some of the group participants.

Helen's event which triggered stress was her mother demanding immediate attention for small requests, which if not tended to by Helen, would cause her mother to manipulate others by phoning neighbors, church members or the police for a response. This caregiver's reaction was to feel angry, frustrated and guilty. Her thoughts would focus on worrying about how she as a caregiver would look to others if she ignored her mother and if her small tailoring business would survive these constant interruptions. The recommendations Helen selected from the group were to 1) schedule only three visits to her mother's house per day instead of running next door each time her mother called and 2) note her mother's reaction(s) to less visits by checking with the neighborhood. Helen had particular difficulty in hearing the group's suggestions because of her resistance to change. This resistance was demonstrated in her "yes, but" responses and her missing sessions (3 out of 8). This caregiver was rated zero, or no change, because of her need to hold onto guilt and the needs which were met from being manipulated by her mother in this relationship. Her general attitude about caregiving had changed prior to the group intervention in that she had learned through her children to give herself permission not to be perfect and to have a right to her feelings. One success did occur for Helen during the group and that was to use airline tickets her children on the West coast sent her for a 3 week vacation. Group participants encouraged her to take this break and Helen was able to arrange for respite care to briefly deviate from her routine.

The problem causing Phyllis stress was similar in that her mother would call her continuously during the evening hours once Phyllis came home from work. These calls were draining Phyllis and disrupting her family because they were for minor issues such as what was on television that night or adding one item to a grocery list. This caregiver's reactions were to feel guilty, believing she should go over to her mother's apartment to be with her, and frustration, that she was not able to take more time out of her day to listen to her mother. Phyllis did well in reducing her stress because she was able to make the connection that one's attitude affects the approach to a situation. She learned to recognize her own problems to be important and to assign significance to them so change would occur. The group's recommendations were to 1) reduce the number of calls accepted by Phyllis in one evening and 2) call the apartment complex manager to receive feedback and explore ways her mother could be less isolated. She deviated from the first suggestion by initiating calls to her mother twice each night. After those calls Phyllis would not come to the phone anymore or take the receiver off the hook. Phyllis did not call the apartment manager but was giving thought to future arrangements for her mother, confronting her inevitable decline. This caregiver received a ranking of +2, or somewhat improved, because she had started to take more time for herself to relieve her burden and felt less guilty in doing so.

Ruth's stressful event was her mother's need for independence and control having lost so much functioning due to multiple medical problems. Ruth's mother would act on her need by being incontinent of urine throughout the house due to her refusal to be toileted frequently. The caregiver reacted with much anger and frustration thinking that her mother could have some bladder control if she tried, and feeling her mother was getting even with her for not being allowed some control over her life. A related issue which compounded those feelings was Ruth's poor communication with her sister whom Ruth felt did little to support her. Ruth admitted to taking out some of her anger on her mother because she was so tired and stressed. The group leader ranked Ruth as +1, or a little improved, because she was able to realize the emotions she felt toward her mother and sister. In addition, Ruth tried some direct action coping skills the group recommended to help the incontinence problem: administering the diuretic earlier in the day, using adult diapers and a special cover for the bed mattress. There was some recognition that her mother needed to maintain independence and Ruth was learning to provide her with choices as much as possible. However, attitudinally Ruth had not come to terms with her sensitivity and hurt feelings when others did not respond as she expected. The group helped her to cope with the anger toward her mother by suggesting Ruth leave the room for a few moments, to relax more using the guided imagery tape, and by supporting her plans to take a much needed vacation. Still, Ruth had much work to do in communicating her feelings.

In Mary's caregiving situation, she was stressed in dealing with her mother's indecisiveness plus avoidance/denial of her father's diagnosis of Alzheimer's Disease. She needed to relieve her stress in order to tolerate her mother's natural reactions more evenly since the disease was progressing. Mary admitted to feeling angry with her mother for not making simple decisions. She also felt torn between her parents and her family because she was not receiving assistance from anyone. In group she examined her attitude which equated caregiving to an obligation and responsibility to the exclusion of taking care of herself. The group focused on Mary's need to reduce stress quickly through actions like 1) looking for a neighbor to take daily walks and 2) signing up for a continuing education class one night a week. For the future they suggested Mary think about asking others for help and what it meant for her to keep control in all parts of her life. This caregiver made good progress during the group intervention, being ranked at +3, or much improved. Within one week she signed up for a night course, started walking with her daughter until a neighbor could be located and began using the physical relaxation tapes regularly. By the end of the group she had talked with her husband and children, explaining how caregiving affected her, resulting in more assistance at home. Mary had also started to be more vocal with her brothers but admitted that changing lifelong thought patterns and feelings was difficult.

Judith requested assistance in dealing with her mother who had been living with her and her husband a while ago for recovery after a fall. Her mother was consuming her time, making demands and questioning her whereabouts which changed Judith's lifestyle. Her thoughts were that her mother was bossing her around, and trying to control things, while she wanted to do as she pleased with her family. Since her mother had returned to her own apartment Judith's life was more manageable. However, Judith knew that taking her mother in again would become an issue soon because she had just turned 90 years old and was getting increasingly frail. Judith and her husband were in the midst of building a new home which was not likely to meet with her mother's approval. The group leader rated Judith as +2, or somewhat improved, for the work she completed during the eight weeks. This caregiver was able to share many feelings in group about her mother which she had not been able to express to anyone previously. Her attitude was refocused on realizing her life was important, too, and it would be fine to live it the way she chose as an adult. She agreed to the participants' recommendation of exploring alternative living arrangements for her mother in being planful for the future. By the time the group ended Judith had made phone calls to several area facilities.

Patricia came to group feeling depressed and frustrated over her mother's deterioration including loss of hearing, eyesight and mental acuity. This gradual decline was difficult for Patricia to accept because her reaction was that she had already lost the mother she enjoyed for years. Her mother wanted to take care of herself and be independent but could not do so safely. When Patricia intervened it caused a constant battle between mother and daughter. Initially the group suggested Patricia try to develop positive thoughts and view the good parts of her relationship with her mother. When her mother had a "good day" participants told Patricia to respond in a reinforcing fashion to communicate how she still enjoyed doing activities with her. For the caregiver, the group supported Patricia's part time job and recommended she continue with the physical relaxation tapes which proved helpful. While Patricia accepted these strategies she was not convinced and ended up saying her caregiving situation was not as bad as others in the group. The following week participants asked for more collaboration from Patricia. She had thought the situation over. In addition to those strategies she wanted to add one of her own which was to take a course in gerontology so that she could better understand her mother's aging process. Patricia was ranked a +1, or a little improved, because she had started to accept the fact her mother was aging and would never be her former self. Also, she seemed to realize she was not alone and to gain from sharing with others.

Barbara came to her group having just placed her mother in a nursing home two weeks prior to the first group session. She expressed enormous guilt over her decision for placement which was precipitated by an infection, mental deterioration and immobility. Her thoughts revolved around the notion that she did the wrong thing and this facility was a poor selection. Barbara complained to the group about the questionable care her mother was receiving because she could not notice any changes in her mother's physical status. The group attempted to support Barbara in gaining comfort with the difficult decision she made. They allowed her much time to ventilate her anger and guilt and to begin to talk about her depression. Barbara's homework was to 1) investigate the facility's patient bill of rights; 2) attend family night at the facility to learn about others' concerns and 3) ask questions of staff when she was uncertain of a procedure or unhappy with treatment. This caregiver was ranked as +3, or much improved, at group's end. Barbara had concluded in the eight weeks that she could not provide the needed care at home any longer. Her complaining about nursing home staff was a way to place blame since she had not accepted her mother's aging process. Barbara was able to benefit from talking about the placement process, had connected with staff to learn more about her mother's daily routine and served as an "expert" to group participants who were exploring nursing homes.

The problem providing stress for Lynn was her mother's inability to recognize her due to the advanced stages of Alzheimer's Disease. Lynn was a nurse and trained to understand the dynamics of this illness. She had provided many stimulants for reality orientation in her mother's environment. However, as a caregiver she was experiencing pain for not being seen as one of her mother's daughters. Before the group could get to discuss Lynn's problem she had gone back to work full time for a home care agency. Listening to these caregivers convinced Lynn she needed some balance and could not give up her entire life. In addition, Lynn was using the physical relaxation tapes daily and had quickly mastered their application to real life stressful experiences. The group participants urged Lynn to continue with her changed behaviors and to monitor her mother's status so that nursing home placement could be planned when appropriate. Lynn was ranked as a +2, or somewhat improved, for she had articulated her guilt and frustration with five years of caregiving well. After comparing notes with others in the group she was able to see how depressed she had become. Much of her accomplishment was due to work she had completed prior to entering group and acting on these decisions.

Edna asked for help in making her husband more aware of what she did in the role of caring for his mother. Edna described herself as a depressed woman who was constantly tired and cried easily. She felt she could not provide for her mother-in-law any longer because her husband offered her no relief and she was hurt by his lack of respect for her efforts. Edna's self esteem was so poor that she delayed in discussing her issues until week #7, placing importance on everyone else's problems. Group participants questioned Edna at length to understand the details of her caregiving situation. She was raising 12 children, had never used respite services and was caring for a frail mother-in-law in her 90's. Their recommendations were to 1) take time for herself; 2) talk to her husband more often versus shying away from the topic and 3) identify her feelings toward her husband in the current situation. Edna's movement on her problem was particularly noteworthy because the group delayed meeting for their final sessions for two weeks to be certain she would be able to attend and provide feedback on her attempt at using their suggestions. The group leader ranked Edna at a +3, or much improved, for she was able to express her negative feelings to her husband and devise a plan to share caregiving responsibilities with him. She was able to be assertive and let go of some old ways of responding to her spouse and in-law. Edna came to the last session looking physically changed, for she had taken time to dress more formally and had her hair cut and set professionally. She not only worked on all 3 recommendations but had decided with her husband to place his mother in a nursing home. Several facilities were called and applications were being mailed for completion. Respite care was also being explored as a way to assist Edna until placement could be finalized.

Caregivers' Qualitative Feedback

After conducting the groups it was the impression of the leaders that the caregivers derived as much from having the opportunity to share their feelings as they did from the cognitive-behavioral approaches. This was confirmed by these women who claimed they had found a place to express their true feelings without judgement.

They could talk to others who could relate to their situations and not be embarrassed. For some it was the first chance to take a load off of their shoulders by sharing their caregiving story. As one caregiver expressed it, "This is a place where we can say it all, we all relate. We wouldn't tell our neighbors that mom wets." For many participants the sharing process allowed them to compare notes with others to see how they were handling their caregiving situations. While validating feelings and thoughts it also permitted these women to get practical ideas to use in their daily routine of providing care. A woman noted, "Someone else can see through your problem and solutions better than you."

Sharing and comparing in group sessions also demonstrated to some caregivers that their personal situations were not nearly as bad as they had imagined. Once stories were told describing responsibilities and home lifestyles, it helped to offer perspective to the problems causing these women stress. In certain instances caregivers were no longer hopeless that their situations could not be changed. In other cases caregivers had their eyes opened to what it could be like for them in the future. One participant related, "We don't have any right to feel sorry for ourselves because there are thousands of us out there." A few caregivers were able to use examples of their peers at home to begin to approach their own situations in a non-threatening way. The informal exchange was extended to the pre-group period where caregivers would arrive for the session and begin to converse with each other about amusing stories which happened with their parents that week.

Another benefit from the support groups was an expansion in the womens' social network. Once the caregivers learned it was acceptable to talk about their situations and ask for assistance, they quickly adapted to using each other in group to help meet their needs. The participants wanted to exchange names and telephone numbers by session number two. The bonding which occurred rapidly was a result of the connection as women in similar situations. Aside from the similarity of being caregivers they were wives, mothers, sisters and daughters. These shared roles permitted them to identify immediately with the joys, difficulties, pleasure and pain they had experienced in their lives. It seemed as though the participants wanted to extend this connection outside of the group. Once the name list was handed out to the group participants some women called each other between sessions and others made car pooling arrangements. As the group progressed it was common to see women talking at their cars a half hour or more beyond the end of the session or stopping together on the way home for coffee.

Group participants gave the physical and mental relaxation exercises mixed reviews. This portion of the intervention was useful for some women who faithfully practiced the exercises at home. For these caregivers the tapes and accompanying directions "were easy to follow" and "clear in their focus." Women described using the physical relaxation exercises to help them get to sleep, to loosen up for the day or as a way to stretch in the shower. Several caregivers said they used the mental relaxation exercises to "sooth and calm" them while in pressured job situations or while in difficult situations with their parents. Those participants who did not benefit from the exercises outside of the group related being too stressed out, did not find the time, were not able to be consistent or found it difficult to spend even fifteen minutes concentrating.

The cognitive coping skills and their application to real life problems was the most highly received portion of the intervention. In addition to being able to expose themselves to women who knew what they were going through, the caregivers could trust the suggestions they received. They admitted it was easier to do step by step cognitive restructuring in the safety of the group. However, in dealing with real life problems, after an event occurred, they now felt able to examine their thoughts and plan for the future when faced with a similar situation. A few participants thought having the group's feedback in writing to review later on would have been useful. This part of the group seemed helpful to caregivers because as one woman phrased it, "We are providing role models for each other and our daughters."

Development of Project as a Resource in the Local Community

At the time the NIMH grant was implemented there were only a handful of caregiver education/support groups available in the Albany area to anyone involved in providing care for an older adult. Four counties in the Capital District region each had an Alzheimers Disease and Related Disorder self help group. Two Catholic Family and Community Service agencies held groups designed to educate caregivers about community resources and which allowed for discussion time of the concerns of taking care of an older family member. One senior citizen center had guest speakers on a quarterly basis and a Veterans medical center held an ongoing group to provide support. The initiation of the NIMH grant was not seen as a threat but, rather, as a resource on many levels in the Albany area.

Once the grant and subsequent doctoral project were in the operational phases several different sources contacted the University offices. Due to the extensive public relations efforts both agencies and caregivers telephoned to ask for assistance in locating specific resources within the community. Agencies recognizing a need of their clientele for education and support in the area of elder care used the project as a consultant source in designing their own groups. Agencies and organizations interested in gaining assistance to advertise services or products contacted the project offices. For instance, Money magazine offered a free financial management consultation to a caregiver consenting to be interviewed regarding her parent care and money matters. Television stations planning informational/educational spots, consulted the project staff to either be spokespersons on a topic or to assist in identifying a local expert. Finally, the project acted as a clearinghouse in gathering information, organizing the details and presenting it in an easy to use format for professionals and consumers. One example of this function was a directory, divided by counties, listing respite services.

CHAPTER SIX:

CONCLUSIONS

Limitations of Project and Methodology

In this study a brief eight week intervention focusing on the acquisition and application of behavioral and cognitive coping skills was offered to women who were caring for an elderly parent or parent-in-law. A short term intervention was purposely selected to encourage maximum participation from a population which was very stressed and who had multiple reasons for making group attendance difficult. In retrospect the design of eight consecutive sessions lasting two hours each was perhaps not the most useful for participants or group leaders. The time frame of sessions allowed for a natural bonding among participants. However, it was a short time frame within which to complete all the teaching, practicing and problem solving activities set in the protocol. As a result, sessions were highly structured which, at times, did not allow women to fully express their thoughts or feelings on a topic. Leaders felt forced into following the prescribed format which hampered their groupwork styles and may have directed the groups away from some spontaneity.

A related issue to group format was the expectations women brought with them to the first session. The vast majority of participants had never been group members in any kind of clinical/counseling situation. Several women expected a lecture and classroom setting, and brought paper and pencil to take notes. Other women were not anticipating a planned format for each session and were comfortable with free floating discussions where they could ventilate or exchange ideas. For some women this was the first time they verbalized their feelings about caregiving to anyone and they found comfort in the supportive nature of sessions. With such varying agendas it was a constant struggle for leaders to keep to the research protocol. Participants were often reluctant to stop talking and the momentum of the group as a whole directed participants versus the leaders' facilitation.

The decision to combine cognitive and behavioral strategies with problem solving in one format was not the best choice for the majority of participants. As previously mentioned, caregivers' expectations for the groups were not in alignment with what was actually delivered. Likewise, caregivers presented with various learning styles, personalities and stresses which made the achievement of a fit between program and participants quite difficult. Though in the weekly sessions attempts were made to tailor the intervention to each individual caregiver, there was still the sense of a forced process. Participants did report positive personal changes from their participation, but not related to improved psychological and/or physiological status. It would seem the supportive component of the groups was beneficial at least in the short term to caregivers. By the end of the eight weeks participants felt validated, had received information about resources, and discovered tangible ways to cope with personal problems related to caregiving from their peers. The nature of the stress inoculation approach suggests an application which allows time for conceptualization, rehearsals, applications and refinements. The methodology may have been best applied to this population if there had been more sessions or if sessions were spread out over a longer time frame. In this way time would have been allocated for the stress inoculation approach and ample time would have been available to address the caregivers' pressing need to gain support and share about their situations. Without a follow up it is only speculation as to whether exposure to stress inoculation for eight weeks had any lasting effects for caregivers, especially in regard to their management of stress levels.

It should be noted that the NIMH grant was conducted within a 50 mile radius of the city of Albany, New York. While attempts were made in both waves one and two of the recruitment phase to attract minority participants and persons from rural locations, few actually ended up in the research grant. The stress inoculation groups consisted of participants who were typically 50 years old, married, and white. Approximately 75% were employed, either full- or part-time. Given the homogenous nature of the subjects it is difficult to determine how other caregiver populations would respond to this type of intervention.

Recommendations for Future Studies

Elder care is definitely a growing practice area in today's aging society. It has been necessary for social workers to develop ways in which to respond to the needs of both the elderly and their caregivers. One type of intervention which has proven successful is the use of groupwork. Based on the experiences of group leaders in this project several recommendations are noted which future group leaders would do well to consider.

It seems prudent to consider offering a specific type of group for a particular kind of caregiver. The nature of the caregiving which is being provided for an elderly person can vary depending on who is providing the actual services. The caregiver will respond to this role much differently if he/she is a spouse versus an adult child versus a nephew versus a neighbor. Likewise, the kind of caregiving will be adapted to match the intensity of need presented by an illness or problem unique to the elderly. Isolating the impact groups can have on caregivers suggests addressing the characteristics of the caregivers such as age, gender, socioeconomic status, personality, family composition, and employment history. Characteristics of the caregiver and care receiver relationship such as duration of caregiving relationship, nature of relationship between caregiver and care receiver (i.e. spouse, child) plus the nature of the problem that necessitates caregiving occur (i.e. Alzheimer's Disease, stroke, general frailty) should also be considered. To achieve the greatest impact on caregivers while addressing their concerns, the composition of the group should be kept similar.

A related consideration is the point at which groups are likely to be helpful in the caregiving process. Clearly a caregiver who has recently started to have the primary responsibility for a relative will have different needs than a caregiver who has been involved in the process for over five years. Over time the nature of tasks change, the relationship of caregiver and care receiver changes and the perceptions of the role are reformulated. It makes good practice sense to offer caregiver groups when the recipients will be most ready to benefit from the intervention. In addition, the content or format of groups needs to be specific enough to meet the population's needs at a point in time. For instance, as a new caregiver it would be important to connect with peers and receive their validation and support for a role which is unfamiliar. As the caregiver moves through the cycle it would be useful to receive information regarding resources and assistance which is available in the local community. Later in the cycle it would be critical to get assistance with decision making and problem solving as the caregiver plans for an elder. Practitioners who can more accurately assess the problems that motivate caregivers to seek help will be more successful in offering groups to address their current concerns. A mixture of support services throughout the caregiving cycle would allow individuals the opportunity to utilize help as they required it; at their own pace.

The size of a caregiver group can influence what and how much will be accomplished. If there is an advertised speaker or presentation an open ended group permitting membership to fluctuate can attract 20 to 50 caregivers. In a group this large a presentation with a question and answer period is the most effective format. To address personal issues of caregivers and encourage sharing, a more intimate group is required. Leaders from this study believe 5 to 9 participants is an appropriate size for a group if there is to be problem solving and an in depth review of personal situations. With these numbers the group can track each member's concerns and not miss critical details. The tendency to form cliques can be monitored more closely as well.

Flexibility seems to be a crucial element in designing groups for caregivers. Because there are so many demands placed on caregivers, attendance at sessions can be a real problem. In this study participants were closely followed and gained monetary benefits from their attendance. Even so, the nature of their work caused unavoidable absences. Caregiver groups need to be offered at convenient times in easy to reach locations to encourage continued attendance. It would also be important to keep attendance in mind when designing formats which are closed ended and demand a certain amount of continuity from session to session.

A competent leader to direct the group intervention is another key factor. It can be argued that peer leaders do well in guiding groups if the agenda is support and offering practical suggestions to caregivers. However, it is the contention of the leaders in the NIMH research grant that a professional is required to facilitate caregiver groups which are therapeutically oriented. Professionals can maintain objectivity, which is difficult for peers who are immersed in their own caregiving situation or who are still resolving the loss of a relative. Professionals can regulate the group when it gets lost in a discussion, it is over powering a member or when some expertise is required to address an issue. This is not to imply that a peer leader would not be appropriate in caregiver groups which focus on the therapeutic resolution of problems. Several caregiver groups have been successful with a peer co-leader and a professional such as a social worker or nurse. However, a professional group leader with training and a sensitivity to family caregiving responsibilities can offer valuable assistance in confronting defenses, providing consistency, and attending to group dynamics.

Brief psychoeducational interventions such as the one described in this study can be useful to caregivers. Researchers need to consider the types of changes that can reasonably occur in a brief intervention, as well as the goals caregivers outline for themselves and the levels of distress they initially bring to the group. A review of the literature and practice experiences point to the chronicity of the stressors caregivers experience. A short term intervention may not yield successful outcomes if the research aim is to eliminate stress or reduce the stress to levels demonstrating significant statistical differences. Time would be well spent by researchers to develop dependable measures, to more clearly specify the outcomes of a study and to design participant eligibility criteria consistent with treatment objectives.

Implications for Social Work Practice

Several implications for practice can be drawn from this study. First, in examining the caregiving role and process more thoroughly, a greater understanding can be reached of the impacts on family systems and life cycles. Group interventions which help the primary caregiver to respond to the role must include guidance in identifying several ways in which families can give assistance. Help provided by the extended family is associated with lower levels of caregiver stress, thus, skills must be taught for organizing and utilizing family support. Similarly, to build up the social network of caregivers, programs need to consider reaching beyond the primary caregiver to other family members and educate them about the needs of both caregivers and patients.

While it seems natural for there to be an identified primary caregiver on whom the coordination for care falls, there does not have to be role exclusivity in providing support and services within the family system. More emphasis needs to be placed on the interactions and interchanges that occurred within the family before help became a reality. In this way factors and interpersonal dynamics which influence the composition and behaviors of the family network that provides care to an older person in the present could be described. Using therapeutic techniques such as family systems theory, brief therapy theory, and developmental stage theory social workers can identify and resolve conflicts while moving toward restructuring the family responsibilities and roles.

In conjunction with individual, family and group counseling activities there needs to be education about community resources and the availability of dependable, professionally supervised social services, such as assessment, case management and in-home services. Social workers can be very instrumental in educating consumers on how to deal with time consuming bureaucratic systems. Similarly, practitioners can arrange for instruction in caring for the sick, particularly in the area of personal care, so that caregivers can wisely use their limited resources.

The use of formal and informal support systems can protect caregivers from the damaging consequences of stress. Social workers can be instrumental in helping the public, private and voluntary sectors of U.S. society design resources to improve and enhance the quality of caregiving relationships. In the public sector stronger efforts should be directed by governmental bodies toward developing a system to minimize the financial burden associated with caring for a disabled family member. Families need to have assistance in advanced planning for financial and legal issues. Such planning would help to clarify responsibilities expected of relatives while protecting assets which might be needed to support others, like a spouse. Social workers need to collaborate with medical professionals to be proactive in designing programs for the frail elderly. In addition, social workers should combine forces with families to advocate for a national policy that provides direct financial assistance to family members.

In the private, for profit sector, organizations can respond to the eldercare concept by providing adult day care services in the workplace for those relatives who want to continue to work. Other options would be to implement a flex-time program or a job sharing program to support and encourage caring for a disabled relative. These program initiatives would help to minimize the conflict that relatives experience between work responsibility and caregiving tasks. By aiding in the design of these programs social workers will be responding to the changing roles and functions of families, especially women, in society today.

From the perspective of the voluntary sector, responses could include various services provided by churches and volunteer groups. Performing tasks such as grocery shopping, meal preparation, light housekeeping and transportation could make a significant difference in the lives of caregivers who need respite from the daily stress of the role. Social workers can be involved in training and supporting the efforts of friends, unions, and neighborhood groups. In turn, these informal supports would be well suited to act as organizers for volunteers in a community who desire to assist the frail elderly. Though a service plan for an older person can not revolve around volunteers, their proximity and availability make them ideal for performing time limited and neighbor-centered tasks.

Clearly there is no one solution to relieving the burden of caregiving. The issue of family support for the elderly is composed of multiple problems. Just as there need to be various kinds of group interventions at intervals within the caregiving cycle there also needs to be a combination of financial aid, counseling, in-home, respite services and other options on the long term care continuum. It will be through the use of differential diagnosis and planning that social workers will maximize the potential of informal and formal supports in caring for the frail elderly. It will be through the continued efforts of social workers and other professionals that advocacy for serving the best interests of people while doing the least harm will effect a change in public policies.

Appendix 1

Telephone Screening Protocol

How did potential volunteer learn about project?

What does potential volunteer know about project?

Does potential volunteer have any questions, which need to be answered or concerns which need to be addressed first?

Introduction

We are researchers doing a special project funded by the Federal Government. The major objective of this project is to investigate the effectiveness of ways to prevent stress and other symptoms from occurring among adult children who provide care for an aging parent. Your participation in our project would be helpful, to you personally, and you would be helping others in the same situation.

(pause for feedback)

If you agree to participate in this project, and you are found to be eligible, you will be asked to answer a series of questions about the care you provide. At four times during the year (March, late spring, 6 months, and 1 year time periods) a researcher will make a convenient appointment with you (in our offices, in your home or at mutually convenient location) to ask these questions. Each time you are asked the questions, you will be reimbursed at the rate of $20.00. In addition to answering these questions, you will be provided with $90.00 for respite care. This money can be used to hire someone to care for your parent while providing you with some free time.

(pause for feedback)

There is also the possibility you may be asked to participate in an education/support group. We are certain that the program will run for an 8 week period starting late March. If you agree to participate in the project, you will be expected to attend group sessions.

(pause for feedback)

We want to make sure our project will benefit you, so I need to ask you a few questions about your caregiving situation. Are you willing to answer these questions?

(FOLLOW QUESTIONNAIRE ON ATTACHED SHEETS)

If criteria are NOT satisfied.

Thank you for answering our questions.

I am sorry to disappoint you, but you are not eligible for our project. You do not meet all of our grant criteria (give example if appropriate).

However, we want to be helpful. What can we do for you? (PROBE: does caregiver need resources and/or referrals we can provide?)

If criteria ARE satisfied.

Thank you for answering our questions.

Your are eligible for our project. We will be in touch with you in the near future to set an appointment for the first series of questions. A researcher and you will spend a little over an hour together, where you will be asked questions about your caregiving situation. (NOTE: make certain address and phone number have been obtained.) At that time we can talk more about your participation in our project and how payments will be made.

Appendix 2

TELEPHONE SCREENING PROTOCOL

NAME:______________________________ CODE # ______________

ADDRESS:___________________________

___________________________ PHONE #____________Work

____________Home

1. How did potential volunteer learn about project?

1	2	3	4	5
newspaper	radio P.S.A.	radio talk-show	agency	other

If agency, name of agency and agency representative.

____

____

If other, describe.

____

2. Verify potential volunteer is caring for a parent.

1. Yes ______ 2. No______
3. Mother ______ 4. Father ______

If no, describe caregiving relationship.

____

____

3. How old is your parent? ________ years

4. How long has potential volunteer been caring for her parent?

months __________ years __________

5. Tell me about your caregiving situation. What are you doing for your parent? (PROBE: kinds of caregiving activities)

____

____

____

____

high	medium	low

Appendix 2 (continued)

6. How do your caregiver activities effect you? (PROBE: demanding, time consuming, stressful, a burden, etc.).

____

____

____

high medium low

7. What kinds of medical or emotional needs does your parent have? (PROBE: nature of disability).

____

____

____

high medium low

8. Are you between the ages of 40 and 60?

1. Yes ________ 2. No __________

If no, how old is potential volunteer? years __________

9. Does the potential volunteer have any children of her own?

1. Yes________ 2. No__________

If yes, how many children are in her family?___________

10. Does your parent live in his/her own home or an apartment? (PROBE: does parent live independently from daughter) __________________

Describe arrangements. ______________________________

____

11. Has the potential volunteer been involved (or does she plan to be involved) in a support group for caregivers of the elderly?

1. Yes _________ 2. No_________

If yes, describe group. ______________________________

____

____

Appendix 2 (continued)

12. In the last year or so have you seen a counselor about any personal problems you have been experiencing?

1. Yes ______ 2. No______

If yes, describe nature of counseling activity. ________________________________

____

____

high medium low

* (PROBE: The idea of this project is to prevent caregivers from having problems and to have an opportunity to share concerns. If you have seen a counselor recently it may have carry over effects in the project.)

** (PROBE: If you don't answer this question regarding counseling, it is O.K., but you can't participate in our project.)

If potential volunteer appears eligible at this point, ask her what time of day would be convenient should she be asked to participate in an education/support group.

Afternoons ______________ Evenings_________________

COMMENTS:

Appendix 2 (continued)

5. Caregiving Situation (frequency; whether burden is shared)

Low	Medium	High
telephone reassurance	housecleaning	total care
errands	admin/supervise drugs	24 hours
M.D. appts.	groceries/meal prep	administer drugs
	finances	med. treatments
		personal care
		cooking/feeding

6. Caregiver activities effect you

Low	Medium	High
ups & downs	time consuming skills	admit stressful
periodically requires attention	social time limited	burden
	time away from family	physical symptoms
	guilty	resentful/angry/bitter
		dysfunctional behaviour
		interpersonal problems with spouse, siblings, children

7. Medical/Emotional needs parent has

Low	Medium	High
reassurance	mobile w/ assistance	emotional problems diagnosed
friendly visiting	medical visits/check-ups & treatments	immobile most times or bedridden
transportation	meal preparation	
errands	assistance w/ bills, banking, financial decision making	needs help toileting bathing, feeding, dressing
M.D. visits		
		taking multiple meds
		diff. in communication
		recent hospitalizations

Appendix 3

CONSENT FORM

I am aware that my participation in this research project concerning caregiving is completely voluntary. I am free to terminate my participation at any time. I am aware that as a result of agreeing to participate in this project, I will be asked to complete research forms four times during the course of the next year. I will receive twenty dollars each time I am asked to participate in a group, I am aware these groups will be audio-taped for research purposes.

Data collected during this research project may be used in published and unpublished reports. I am aware that MY RESPONSES ARE CONFIDENTIAL and any data resulting from my responses will be reported in aggregate and will NOT BE IDENTIFIED WITH ME INDIVIDUALLY.

First Name Last Name Date

Appendix 4

RESOURCE GUIDE

ALBANY COUNTY

GROUP INTERVENTIONS WITH PRIMARY CAREGIVERS PROJECT

Appendix 4 (continued)

The staff of the "Group Interventions with Primary Caregivers" project have prepared this resource guide for your convenience. It contains information about agencies and organizations within your county of residence. A review of the guide will show you that information has been organized into categories of community services, like senior centers and meal programs. Since it would be impossible to include all current services under each category, the staff have selected a variety of services to provide a general overview of resources available to you. Hence, the inclusion of certain services is not meant to imply our special recommendation or endorsement. Rather, we offer this resource guide to you as a way to get started in the selection of services for your parent.

In addition, should you desire some information about counseling resources you will note an absence of any agencies or individuals listed in this guide. The decision to seek counseling services is a private matter based on individual concerns and circumstances. To obtain the best fit of needs and services, we would encourage you to call the project office so we may refer you to a local resource. The list we have compiled includes a variety of agencies which are non-sectarian with a sliding fee scale.

Keep in mind that contact persons and phone numbers can change frequently, so that the information included was accurate at the time this guide was produced. If this guide does not provide you with the kind of information you are seeking, please call Mary Coppola, Project Director, at 442-5374 for further assistance.

Project Staff

Ronald Toseland Principal Investigator
Mary Coppola Project Director
Cathie Doyle Research Assistant
Rosemary Gearwar Project Secretary

Appendix 4 (continued)

MEAL PROGRAMS

Congregate Meal Sites

Albany Jewish Community Center 438-6651
340 Whitehall Road, Albany, NY 12208
Contact Person: Joan Schenkel

Kosher Meals on Wheels; also dinner on Mon. at 4:45 and lunches on Tu-Fri at 12:30.

Albany Meals on Wheels, Inc. 465-6465
20 Rensselaer Street, Albany, NY 12202
Contact Person: Jim Kovarik (Hours: 9-4:30 p.m., daily)

B'nai B'rith Social Club 465-2293
400 Hudson Avenue, Albany, NY 12203
Contact Person: Larisa Karkov
Hours: Sunday 1 p.m., Mon-Sat 5:00 p.m.

Colonie Senior Lunch Program 783-2824
P.O. Box 21, Newtonville, NY 12128 783-2823
Contact Person: Ann Wilening

Two Mondays per month (lunch site) -
91 Fiddlers Lane, Latham

Helderberg Senior Services 797-3652
Hiawatha Grange Hall, Rt. 32, Westerlo, NY 12193
Contact Person: Delyghte Woodruff (Hours: 10-2 p.m., M-F)

Saint Peter's Mobile Meals Program 454-1536
315 South Manning Blvd., Albany, NY 12208
Contact Person: Katherine Corr
Available 5-7 days per week.

Food Pantries

Co Cap 237-9201
169 Mohawk St., Cohoes, NY 12047
Contact Person: Bill Horan (Hours: 9-5 p.m., M-F)

Appendix 4 (continued)

Focus Food Pantry (Trinity United Methodist Church) 436-8544
Lark & Lancaster Streets, Albany, NY 1210
Contact Person: Rev. Richard Guralnick
Hours: 10:30 - noon, M. Th, F (from 20th day of month on)

Guilderland Food Pantry 456-5410
2291 Western Ave, Guilderland, NY 12084
Contact Person: Bertie Chesebrough (by appointment only)

Hilltowns Community Center 872-2648
2669 Star Route, Altamont, NY 12009
Hours: 4th Tues. of month, 2-4 p.m. & 7-8 p.m. (upon request)

SENIOR CENTERS

Albany Jewish Community Center 438-6651
340 Whitehall Road, Albany, NY 12208

Altamont Senior Citizens Center 861-6030
P.O. Box 212, Altamont, NY 12009
Contact Person: Douglas Spoore

Bethlehem Senior Citizen 439-4955
Town Hall, Delmar, NY 12054
Contact Person: Karen Pelitier

Cohoes Multi-Service Senior Citizens 235-2420
10 Cayuga Plaza, Cohoes, NY 12047
Contact Person: Ann Yuzynko

Colonie Senior Services Center 783-2823
P.O. Box 21, Newtonville, NY 12128
Contact Person: Ann Wilening

Green Island Senior Citizens 273-1033
89 Hudson Avenue, Greed Island, NY 12183
Contact Person: Carolyn Miller, Executive Director
Joan Perry, Meal Program

Guilderland Office for Senior Center 356-1980
Guilderland Town Hall, Western Avenue, Albany, NY 12205
Contact Person: Mrs. Stewart

Appendix 4 (continued)

Hart Social Center 26 Wilson Avenue, Albany, NY 12204 Contact Person: Margaret Ditterich	459-1272
Helderberg Senior Citizens Box 18, Westerlo, NY 12193	797-3652
Herbert B. Kuhn Senior Citizens 2 Thunder Road, Albany, NY 12205 Contact Person: Ann Joachin	869-7172
Hilltown Senior Citizens RD1, Berne, NY 12023	872-1085
Lishakill Senior Citizens 1653 Central Avenue, Albany, NY 12205 Contact Person: Stephanie Orscian	869-7927
Menands Senior Citizens Club 21 1/2 Lyons Avenue, Menands, NY 12204 Contact Person: William Dennin	436-8858
Ohav Shalom Senior Association 115 New Krumkill Road, Albany, NY 12208	489-5531
New Scotland Senior Citizens Club Box 56, RD #1, Voorheesville, NY 12186	439-4039
Sacred Heart Senior Citizens Club 31 Walter Street, Albany, NY 12204 Contact Person: Sr. Joseph Mary	462-0506
Salvation Army Senior Citizens 22 Clinton Avenue, Albany, NY 12207	439-4272
St. Francis Desalles Senior Center 1 Maria Drive, Loudonville, NY 12211 Contact Person: Frank Messaha	489-8386
Towers of Colonie Senior Service 420 Sand Creek Road, Albany, NY 12205	459-7417

Appendix 4 (continued)

Watervliet Senior Service Center 1541 Broadway, Watervliet, NY 12189 Contact Person: Penny Norton	273-4422
Senior Service Centers of Albany Area 25 Delaware Avenue, Albany, NY 12210 Contact Person: June Bonneau	465-3322
Dewitt Clinton Apartments (subsidized) 142 State Street, Albany, NY 12202 Contact Person: Lori Goodman	449-3191
Goodrich School Fiddler's Lane, Colonie, NY 12210 Contact Person: Jane Medved	783-2824
Ida Yarbrough 260 North Pearl Street, Albany, NY 12207 Contact Person: Virginia Phoenix	465-3074
Louise Corning 25 Delaware Avenue, Albany, NY 12210 Contact Person: Liz Fredericks	465-3325
Newgate Social Adult Day Care Center 99 South Pearl Street, Albany, NY 12207 Contact Person: Nancy Hill	449-8035
Riverside 200 Green Street, Albany, NY 12202	462-4732
Second Avenue 6 Krank Street, Albany, NY 12202 Contact Person: Barbara Wazny	462-2460
South Mall Towers 101 South Pearl Street, Albany, NY 12207 Contact Person: Ada Kitchen	465-3766
Townsend 45 Central Avenue, Albany, NY 12206 Contact Person: Cindy Klug	434-1720

Appendix 4 (continued)

Westview 482-2120
680 Central Avenue, Albany, NY 12206
Contact Person: Vanessa Senglaub

RESPITE CARE

Albany Guardian Society Home 465-6395
553 Clinton Avenue, Albany, NY 12206
Contact Person: Floyd Milbank

The Albany Guardian Society, an adult home, is a residential facility which provides domiciliary care to generally well elderly, who because of age or infirmity cannot or choose not to live independently. The Home has a limited number of private rooms to accommodate elders staying for a short term and provides 24 hour professional services to respite residents.

The Foundation for Long-Term Care, Inc. 449-7873
194 Washington Avenue, Albany, NY 12210

Respite services provided through in-home care arrangements or by short-term nursing home placement.

Teresian House 456-2000
Washington Avenue Extension, Albany, NY 12203
Contact Person: Sue DelVecchio

Teresian House is a Roman Catholic facility in suburban Albany which provides respite services, on the basis of room availability, to elderly individuals who require health related level care. This modern health care facility offers 24 hour per day professional services and daily Catholic mass.

V.A. Medical Center 462-3311
113 Holland Avenue, Albany, NY 12208 Ext. 381
Contact Person: Sarah Goebel, CSW Ext. 453

The Veteran's Administration Medical Center provides respite care for chronically ill or disable veterans for a total of 30 days per calendar year, generally taken 1 or 2 weeks at a time. The levels of care provided through the V.A.'s Respite program include adult home, health related and skilled nursing. A team of respite care personnel see to the needs of the veteran. If the veteran has never utilized VAMC services, eligibility must first be established. This program is open only to veterans and there is no charge.

Appendix 4 (continued)

Visiting Nurse Association of Albany, Inc. 489-2681
35 Colvin Avenue, Albany, NY 12206

The VNA of Albany provides home-based respite care under their Long Term Home Health Care Program. The reimbursement is $7.40 per hour and $88.80 for a 24 hour period. Respite care at the skilled nursing level is also available at a rate of $75.94 per day.

INCOME SERVICES

Albany County Department of Social Services 447-7000
40 Howard Street, Albany, NY 12207

Food Stamps, 37 Howard Street 447-7580

Fuel Unit, 40 Howard Street 447-7690
H.E.A.P. Home Energy Assistance Program
(Assistance for fuel and energy bills.)

Colonie Residents contact Colonie Senior Service Center 783-2823

Medicaid, 112 State Street 447-7400

Title II, 112 State Street 447-7458
(Home Service for low-income persons.)

Albany County Opportunity 463-3175
35 Clinton Avenue, Albany, NY 12207
Weatherization assistance.

Cathedral Social Service 463-2279
125 Eagle Street, Albany, NY 12202
Contact Person: Sr. Pat Brennan

Provides assistance and information on housing, advocacy, for food stamps, SSI, social security, shopping and banking.

Cooperative Extension of Albany County 765-3530
Box 131, Martin Road, Voorheesville, NY 12186
Contact Person: Tom Rotello
Weatherization Assistance

Appendix 4 (continued)

HIECA Program - Public Service Commission 1-800-342-3237 (toll free)
Three Empire State Plaza, Albany, NY 12223

Utility company free surveys of heating and insulation systems and low-interest loans.

Human Resource Center 449-5300
558 Broadway, Menands, NY 12204

Food stamps may be applied for at this agency for residents living within the following zip code areas: 12204, 12210, 12111, 12189, 12183, 12047.

New York State Tax Department (Taxpayer Assistance Bureau) 1-800-342-3536

Social Security Administration 765-3530
Federal Building, 1 Clinton Avenue, Albany, NY 12207

Administers the Federal Social Security program. Provides assistance in applying for Social Security retirement, disability and survivors benefits; public assistance payments for the aged, disabled and blind; Social Security numbers; also with enrollment for Medicare and obtaining reimbursement for covered medical services. Hours: 9-5 p.m., M-F.

Residents of Latham - contact Troy Office-Social Security 271-6500
1801 6th Avenue, Troy, NY 12180

Town of Colonie Assessor's Office 783-2701
Memorial Town Hall, Newtonville, NY 12128

Property owners in the Town of Colonie who are 65 years of age or over may be eligible for a tax exemption on real property taxes if income does not exceed the current eligibility level.

Veterans Service Agency 445-7549
Leo W. O'Brien Federal Building
488 Broadway, Albany, NY 12207

For tax exemptions for veterans who reside in Colonie, please contact the Town Assessor's Office regarding eligibility and application forms.

Appendix 4 (continued)

West Hill Improvement Corp 462-6469
340 First Street, Albany, NY 12206
Contact Person: Gregory Bell, Executive Director

Assist low and middle income persons in applying for housing rehab. assistance, weatherization, SONYMA mortgages. Neighborhood improvement stabilization, also tool library available to residents of Albany. Hours: 9-5 p.m. Limitations: low to middle income, West Hill, Pine Hills, Old Campus Neighborhoods.

DAY CARE

Bright Horizons Day Service Program 785-7415
Colonie Sr. Service Cntr. Inc.
P.O. Box 21, Newtonville, NY 12128

Adult day services program held at St. Joseph's Provincial House, Watervliet-Shaker Road, Latham, for persons 60 years of age or older. Social, recreational and other life-enhancement activities, nutritious lunches and snacks provided.

Capital District Psychiatric Center 445-6960
75 New Scotland Avenue, Albany, NY 12208

Adult Day Hospital Program for people 65 or older with mental or emotional problems. (Ask for Geriatrics).

Cohoes Adult Day Care 235-2420
10 Cayuga Plaza, Cohoes, NY 12047

Cypress Manor, Inc. 465-8850
219 South Pearl Street, Albany, NY 12207

Newgate 449-8035
99 South Pearl Street, Albany, NY 12207

This is a program of the Senior Service Centers of the Albany Area.

HOME MAKERS/HOME HEALTH AIDES

Albany County Department of Health 445-7811
South Ferry and Green Streets, Albany, NY 12201

Public Health Nursing, physical therapy and health guidance in the home of needy residents in the rural and suburban sections of Albany.

Appendix 4 (continued)

Attentive Care Nursing Services 438-6271
855 Central Avenue, Albany, NY 12206

Colonie Memorial Town Hall 783-2719
Contact Person: Sue Kaiser

Has home health nurse who will come into your home to provide such services as bathing, injections, blood pressures, and other nursing duties. For Town of Colonie residents only.

Homeaide Service of Eastern New York 459-6853
10 Colvin Avenue, Albany, NY 12206

Trained Homemaker and Home Health Aides at a cost to assist individual with bathing, feeding, mobility, etc. Medicare and Medicaid accepted.

Medical Personnel Pool Capital District 463-2171
90 State Street, Albany, NY 12207

Quality Care 438-6601
Executive Park East, Stuyvesant Plaza, Albany, NY 12203

Tri-Cities & Helpmates 785-3997
1123 Troy-Schenectady Road, Latham, NY 12110

U.S. Ethicare Corporation 463-2433
74 State Street, Albany, NY 12207

TELEPHONE REASSURANCE & FRIENDLY VISITING

Albany County Department for Aging and Handicapped 447-7177
112 State Street, Albany, NY 12207

Telephone Assurance Program has volunteers who make regular phone calls to isolated, handicapped, and home bound individuals.

Retired Senior Volunteer Program (RSVP) 442-5586
Room 103, Draper Hall, Albany, NY 12222

RSVP (Sponsored by SUNY College of Continuing Studies) has a Home Visitor Program offering companionship and socialization to the homebound elderly.

Salvation Army 453-6678
20-22 Clinton Avenue, Albany, NY 12206

Friendly visiting to needy elderly in Albany County.

Appendix 4 (continued)

VISITING NURSES

St. Peter's Hospital Home Care 454-1377
315 South Manning Boulevard, Albany, NY 12208

Nursing, physical therapy, occupational therapy, speech therapy, social work, dietitian for homebound elderly with a physicians referral on a short-term basis.

Visiting Nurse Association of Albany 489-2681
35 Colvin Avenue, Albany, NY 12206
Contact Person: Mary C. Bromirski, MA, RN

Provides nursing, physical, occupational and speech therapies; medical, social, and home health aide services, nutrition counseling, psychiatric nurse counseling to sick at home (under medical direction); health teaching; alcohol abuse counseling for geriatric patients; hospice and respite services, certified as a home health agency and long term home health care program. Hours: 8-8 p.m., M-F; 8-4 p.m. includes weekends and holidays. 24 hour "on call" Fees: Based on actual cost and ability to pay. Accepts third party payments. Limitations: Albany and Southern Saratoga Counties.

SENIOR TRANSPORTATION SERVICES

Albany County Opportunity, Inc. 463-3175
35 Clinton Avenue, Albany, NY 12207

Operates Albany transportation project for low-income households. Transportation for the handicapped also available.

Capital District Transportation Authority 482-8822
110 Watervliet Avenue, Albany, NY 12206

Bus services in Capital District. Reduced cost for seniors with Bus Identification Card.

CDTA'S Star

Special bus service to transport mobility-disabled capital district residents. Fare is $2.00 one way. Reservations can be made from 6 a.m. to 9 p.m. (M-F) and should be made no later than 48 hours in advance of a desired trip. Passengers must present a valid CDTA Handicap half-fare card upon boarding, or use a wheelchair.

Appendix 4 (continued)

Center for Independence 459-6422
22 Colvin Avenue, Albany, NY 12206

The Center has only one equipped van which they limit to transporting clients to and form the Center for services or to other places as part of helping clients to more independent living. They may provide some emergency transportation, but only if they can fit it into their schedule.

Colonie Senior Service Centers, Inc. 782-2823
91 Fiddlers Lane, Newtonville, NY

Offers transportation for residents age 60+. Shopping, medical appointments and Handicapped Service.

Senior Action Council 436-4808
260 North Pearl Street, Albany, NY 12207

Wheelchair transportation is available as well as transportation for those who can get into a car. A donation is requested.

Senior Service Centers of the Albany Area, Inc. 434-4219

Transportation for seniors available within Albany city limits to and from senior centers.

LEGAL SERVICES

Albany County Bar Association 445-7691
Albany County Court House, Albany, NY 12207

Lawyer referral. Services and consultation with fee.

Albany County Department for Aging & Handicapped 447-7177
112 State Street, Albany, NY 12207

Has legal screening service for Seniors.

Attorney General's Office - Consumer Fraud Unit 474-5481
Justice Building, Room D10, Albany, NY

Handles any consumer fraud complaint in New York State.

Colonie Senior Citizen Services Department 783-2824
91 Fiddlers Lane, Latham, NY 12110

Free legal assistance is available, by appointment, to senior citizens as well as family members who are acting in their behalf. An attorney for the Albany County Department for Aging & Handicapped is available from 10:30 a.m. until 2:00 p.m. on the first Monday of each month.

Appendix 4 (continued)

Consumer Credit Counseling Services 11A Vatrano Road, Albany, NY 12205 Assists people with acute debt problems by teaching budget planning and debt management.	459-8883
Consumer Product Safety Commission Federal agency receives reports on injuries/deaths relating to hazardous manufactured products.	1-800-638-2772
Federal Tax Information Hotline Operated by Internal Revenue Service. Provides assistance on federal tax questions and Federal Tax forms.	1-800-424-1040
Insurance Hotline Information about insurance, insurance companies and their policies. Handles problems and complaints.	1-800-342-3736
Legal Aid Society 55 Columbia Street, Albany, NY 12207 Acts as advocates for low-income persons. Handles fair hearing, landlord-tenant relations, etc. Call at 9 a.m. First eight calls gets on a Telephone Assistance list. They'll return your call if you meet eligibility requirements.	462-6765
Legislative Hotline Information on the status of any pending bill for the current year, the Senators and Assemblyman serving on committees, and how votes were cast.	1-800-342-9860
NYS Consumer Protection Board 99 Washington Avenue, Albany, NY 12210 Will refer consumers to agencies which can assist in resolving complaint. Will represent consumer before Public Service Commission.	474-8583
Public Defender's Office 112 State Street, 7th Floor, Albany, NY 12207 Provides legal services to persons who have been arrested for a crime and are unable to afford a lawyer.	447-7150
Public Service Commission Hotline Receives complaints on utility billings, service disconnections, and home insulation. Provides information on hearings.	1-800-342-3377

Appendix 4 (continued)

Senior Citizens Hotline 1-800-342-9871

New York State Office for the Aging uses this hotline to offer help and information about programs and services for seniors.

Senior Service Centers of the Albany Area Inc. 465-3322

Legal screenings available at some centers to anyone 60+ years of age.

Small Claims Court 462-8550

City Hall, Albany, NY 12207

Hours: 9-7 p.m. third Monday of each month.

HEALTH SCREENING PROGRAM

Albany Medical Center Hospital 445-3125

43 New Scotland Avenue, Albany, NY 12208

The region's only academic health science's center providing full-service including acute and tertiary medical and surgical care, out-patient services, and clinics. Hours: 24 hours, 7 days a week. Fees: vary.

American Heart Association 869-1961

433 New Karner Road, Albany, NY 12205

Provides hypertension screening, information, referral, and follow-up.

Colonie Senior Citizen Services Office 783-2824

91 Fiddler's Lane, Latham, NY 12110

The Town Nurse and trained volunteers take blood pressure readings on the 4th Monday of each month from 2-3 p.m. No appointment is necessary.

Health Department - Albany County 445-7811

South Ferry & Green Streets, Albany, NY 12201

Contact Person: William A. Grattan, Commissioner

Nursing; Health Guidance, Maternal-Child, Communicable Disease, Home Care, Physical Therapy. Clinics: Dental, Eye Screening, TB, VD, X-ray. Satellites: Cohoes, Ravena, Hilltowns. Environmental Health. Hours: 8:30-4 p.m., M-F. Fees: Free. TB, VD, Public Health Nursing. $3, $5 - other clinics. Sliding Scale: Home Nursing. Variable: environmental. See Visiting Nurses.

Appendix 4 (continued)

Senior Service Centers of the Albany Area, Inc. 465-3322
25 Delaware Street, Albany, NY 12210

Provides health programs on variety of topics. Screenings offered: blood pressure, eye, foot, glaucoma, etc. Also provides health counseling and information on health.

VOLUNTEER PROGRAMS (RSVP AND OTHERS)

Retired Senior Volunteer Program (RSVP) 442-5587
Draper Hall, Room 103, 1400 Washington Avenue, Albany, NY 12222

Program sponsored by SUNYA for persons age 60+.

Town of Colonie Senior Citizen Services Department 783-2824

They maintain an active RSVP station.

Service Corps of Retired Executives (SCORE) 472-6300
445 Broadway, Room 242, Albany, NY 12207
Contact Person: Marvin Zepf

SCORE is an organization of volunteers who have combined their knowledge and expertise of the business field to give counseling and advice to persons starting and pursuing business careers. Tuesday appointments only.

Volunteer Center of Albany, Inc. 434-2061
196 Morton Avenue, Albany, NY 12202
Contact Person: Alta Schallehn

Develops, coordinates and publishes volunteer activities, including opportunities for physically disabled.

SPECIAL SERVICES

Aging, Albany County Department For 447-7177
112 State Street, 7th Floor, Albany, NY 12207
Contact Person: Brenda Jones, Communication Technician

Information and Referral, counseling and assistance in obtaining community service, income services and residential service. Hours: 9-4 p.m., M-F., Fees: $1 for CDTA Bus Pass (65 or over), $2 for Merchants Discount Card. Limitations: 60+ for supportive services; 55 for employment. Camera (Picture ID) - 9:30-3:30 p.m., bring I.D. with you.

Al-Anon Family Group 438-5551
P.O. Box 8706, Albany, NY 12209

Information for Albany, Saratoga, Schenectady and Troy.

Appendix 4 (continued)

Alcoholism Receiving Center 465-7388
75 New Scotland Avenue, Unit G., Albany, NY 12208
Contact Person: Chris Duel, Executive Director

Provides a safe environment for person to sober up; as well as counseling, referrals and outreach work through requests and through our van service. Hours: 24 hours every day. Limitations: Adolescents and adults. Pick-up is confined to Albany County.

Alcoholism Rehabilitation Center - St. Peter's Hospital 465-7388
315 South Manning Blvd., Albany, NY 12208 (24 hour detox) 454-1303
Contact Person: Karen Giles, Director

Inpatient Detoxification Program, Out-patient Clinic, Out-Patient Satellite Program (Cohoes), Day Rehabilitation Program, Community Residence Program, Short Term Out-Patient Program, Drinking Driver Program, Outreach Program, Prevention and Education Services, programs for families and significant others of an alcoholic. Hours Vary (Inpatient Detoxification 24 hours a day) Fees: Vary. Limitations: Persons with primary psychotic, and/or depressed conditions who require treatment in a more controlled environment. No age limitations.

Arthritis Foundation, Northeastern NY Chapter 459-5082
1237 Central Avenue, Albany, NY 12205
Contact Person: Ronald K. Loy, Executive Director
Hours: 9-5 p.m., M-F.

Blind and Visually Handicapped, NYS Commission for the 474-1701
74 State Street, Albany, NY 12207
Contact Person: Robert J. Ross, District Manager

Provides counseling and vocational rehabilitation services for those seeking employment. Special service programs for children and elderly (55 and over). Hours: 8:30 - 5 p.m., M-F. Limitations: Helps legally and totally blind of all ages. Services to Capital District and surrounding counties.

Blind, Northeastern Association at Albany 463-1211
301 Washington Avenue, Albany, NY 12206
Contact Person: Michael B. Freedman, Executive Director

Comprehensive vocational rehabilitation programs (diagnostic evaluation, pre-vocational training, placement into competitive employment and follow-up community programs (low vision clinic, elderly, visually impaired, rehabilitation programs, and sewing workshop). Hours 8:30-5 p.m.

Appendix 4 (continued)

Capital Area Speech Center 462-6222
525 Washington Avenue, Albany, NY 12206
Contact Person: Arlene Westbrook

Diagnostic and treatment services for adults with speech, language and hearing problems; speech and voice improvement. Hours: 9-5 p.m., other hours by appt. Fees: Medicaid, Medicare, health insurance, sliding scale. English for Foreigners Program

Center for the Disabled 489-8336
(United Cerebral Palsy of the Capital District)
314 South Manning Boulevard, Albany, NY 12208
Contact Person: Bonnie Meservey, Chief-Client & Family Services

Multi-disciplinary facility providing programs to physically handicapped children and adults. The programs include Vocational Programs for Adults; Community Residence for Children and Adults; Day Training for Adults. Support services include comprehensive screening and assessment, medical consultation, denial and family/individual counseling, psychological, outpatient therapies and respite. Specialty Medical Clinics. Hours: 8:30 - 4:30 p.m., M-F. Fees: Medicaid, Private Insurance. Private Pay: Sliding Scale.

Center for Independence - Capital District 459-6422
22 Colvin Avenue, Albany, NY 12206
Contact Person: John Farina, Counselor

Provide independent living services to people with disabilities of all ages who live in the Capital District area. Services include housing, assistance, counseling, wheelchair transportation, skills training in cooking and budgeting, advocacy and I & R. Hours: 9-5 p.m., M-F. Limitations: Capital District area.

Client Assistance Program (Special Program)
Contact Person: Clifton Perez

Advocacy/information referral for disabled people who are within the rehabilitation process, legal services are available.

Foster Grandparent Program 2331 Fifth Avenue, Troy, NY 12180 272-6052

Work program for the elderly, who receive a stipend, possibly a meal each day, and transportation allowance. Must be income eligible.

Appendix 4 (continued)

Health Equipment

American Red Cross Hackett Boulevard, Albany, NY 462-7461

Senior citizens may borrow hospital beds, crutches, walkers, canes, commodes and wheelchairs FREE from the Red Cross. A doctor must call or provide a prescription for the equipment. Individuals must make own arrangements to pick up and return equipment. Equipment is available Monday through Friday. Ask for the "Loan Closet."

Helpline Equinox, 214 Lark St., Albany, NY 12210 436-6000
A 24 hour professionally staff information referral service.

New York State Office for the Aging 474-5731
Empire State Plaza, Albany, NY 12223 Hotline (toll free) 1-800-342-9891

Rape Crisis Center 447-7100
112 State Street, Albany, NY 12207 (Hotline) 445-7547

Crisis intervention, counseling for sexual assault victims and family, short and long term counseling.

Saint Peter's Hospice 454-1686
315 South Manning Boulevard, Albany, NY 12208

Provides care to the terminally ill and their families. Components of Hospice care are: consultation, home care, in-patient care, day care, bereavement, and community education.

Substance Abuse Prevention, Education, Treatment Program - Albany County (PET) 445-7888
59 South Ferry, Albany, NY 12202
Contact Person: Kathy Provencher, Director

Consultation, training, presentations regarding substance abuse prevention/intervention for schools, parents, families, community action groups and civic groups.

Veterans Service Agency 447-7710
112 State Street, Albany, NY 12207
Contact Person: Edward J. Clark, Director

Appendix 4 (continued)

Vocational Rehabilitation Office of New York State	473-8097

55 Elk Street, Room 301, Albany, NY 12207
Contact Person: Thomas Paduano, District Office Manager

Individual counseling and guidance, medical examinations and other diagnostic services; physical restoration and training; placement and follow-up; all for physically and mentally handicapped. Hours: 8:30 - 5 p.m. M-F., Fees: None for counseling, diagnostic services or placement; other services have sliding scale.

Widowed Persons Services	482-0497

930 Madison Avenue, Albany, NY 12208

Volunteer widows and widowers help newly widowed through the emotional and practical problems of losing a spouse.

Appendix 4 (continued)

RELATED HEALTH AGENCIES
AND
SUPPORT GROUPS

Albany Relatives (Alliance for the Mentally Ill) 482-2048
c/o Mental Health Association
260 Washington Avenue, Albany, NY 12210
24 hours a day.

Alzheimer's Disease & Related Disorders Association Support Group
P.O. Box 8809, Albany, NY 12203 463-0887
Monday through Friday - 10 a.m. to 2 p.m.

American Cancer Society - Albany County Unit 438-7841
Executive Park Tower, Albany, NY 12203
Monday through Saturday - 9 a.m. to 5 p.m.

American Heart Association 869-1961
433 New Karner Road, Albany, NY 12205
Monday through Friday - 9 a.m. to 4:30 p.m.

American Lung Association of New York State, Inc. 459-4197
8 Mountain View Avenue, Albany, NY 12205
Monday through Friday - 8:30 a.m. to 4:30 p.m.

American Red Cross - Albany Area Chapter 462-7461
Hackett Blvd. at Clara Barton Drive, Albany, NY 12208
Monday through Friday - 8 a.m. to 5 p.m.; 24 hour emergency line.

American Red Cross - Rensselaer Area Chapter 235-4452
737 2nd Avenue, Troy, NY 12182
Monday through Friday - 9 a.m. to 5 p.m.; 24 hour emergency line.

American Red Cross - Saratoga Area Chapter 584-2510
368 Broadway, Saratoga Springs, NY 12866
Monday through Friday - 9 a.m. to 5 p.m.; 24 hour emergency line.

American Red Cross - Schenectady Area Chapter 393-3606
8 South Church Street, Schenectady, NY 12305
Monday through Friday - 8:30 a.m. to 5 p.m.; 24 hour emergency line.

Arthritis Foundation 459-5082
1237 Central Avenue, Albany, NY 12205
Monday through Friday - 9 a.m. to 5 p.m.

Appendix 4 (continued)

Cardiac Rehabilitation Program 454-1369
St. Peter's Hospital, 315 S. Manning Blvd., Albany, NY 12208

Diabetes, American Association - Capital District Chapter 489-1755
50 Colvin Avenue, Albany, NY 12205
Monday through Friday - 9 a.m. to 5 p.m.

Fresh Start Program for Smoking Cessation 438-7841
c/o American Cancer Society
Executive Park Tower Bldg., Albany, NY 12203
Monday through Friday - 9 a.m. to 4 p.m.

Appendix 5

Education/Support Groups in the Capital District

Alzheimers Disease and Related Disorder (p.m.) 438-4929
Association of the Capital District 438-3660
87 Brookline Avenue, Albany, NY 12203
Contact Person: Janet Wilson - 463-0887 (10-2 p.m., M-F)

Education/support group for anyone involved in providing care for an adult with Alzheimer's disease or a related disorder. Meets regularly on third Thursday of each month in St. Paul's Episcopal Church, 21 Hackett Blvd., Albany at 7:30 p.m.

Alzheimers Disease and Related Disorder Association of Saratoga
Contact Person: Evelyn Chowske Ext. 488 584-6000
Jackie Marcelle 587-3600

Meets on the 2nd Monday of each month in Conference Room D at Saratoga Hospital from 7:30 - 9:00 p.m.

Alzheimers Disease and Related Disorder Assoc. of Schenectady 346-7513
Contact Person: Joe Battaglino

Meets on the 2nd and 4th Thursday of every month in the Reynolds Conference Room, 4th Floor, at Ellis Hospital from 7:30 - 9:00 p.m.

Catholic Family and Community Service 372-5667
816 Union Street, Schenectady, NY 12308
Contact Person: Shirley Kotek

Support Group for adult children and spouses who are caring for an elderly relative. The group meets two hours a week for 12 consecutive weeks. Group typically meets in the afternoon at the CFS Agency Sessions are designed to educate adults about the availability of community services for the elderly as well as discuss the concerns of taking care of an older family member. The program is free, but donations are appreciated. New group expected to start in February.

Appendix 5 (continued)

Catholic Family and Community Services, Saratoga County 587-5000
142 Regent Street, Saratoga Springs, NY 12866
Contact Person: Sister Lauren

Support group for anyone involved in providing care for an older adult. The group is on-going, meeting the second Tuesday of each month. Group typically meets in the evening from 7:00 - 8:30 p.m. at the Saratoga Infirmary in Ballston Spa. The program is free.

Colonie Senior Citizen Services 783-2824
91 Fiddlers Lane, Latham, NY 12110
Contact Person: Joan Davenport

Program for caregivers offered every three months. Each meeting has a speaker present plus provides the opportunity for small discussion/sharing groups. Literature and educational materials available as well. Group typically meets in the evening from 7:00 - 9:00 p.m. at the Senior Citizen Center. The group is open to anyone providing care for an older adult. Next program is expected to occur in February.

James A. Eddy Memorial Geriatric Center 274-9890
2268 Burdett Avenue, Troy, NY 12180
Contact Person: Debbie Hanish-Shreyer

Alzheimer's support group meets on the first Thursday of each month in second floor boardroom at Eddy Memorial from 7:30 - 9:00 p.m.

Veterans Administration Medical Center 462-3311
113 Holland Avenue, Albany, NY 12208

Contact Person:	Jonathan Hurwit	Ext. 648
	Mike Hart	Ext. 548
	Betty Price	Ext. 208

Education/support group for anyone involved in providing care for an older adult. The group is on-going, meeting the second Wednesday of each month. Group meets from 9:45 - 12:00 noon at the V.A. Hospital. This group is open to the public; veterans status is not required.

Appendix 6

DIRECTORY

OF

RESPITE SERVICE AGENCIES

(Short-Term)

Alternative Care of Northeastern
New York
1346 Union Street
Schenectady, NY 12308
374-2117
Contact Person: J. Houppert

Services

R.N. supervisor does assessment during an initial home visit.

No medicare accepted. No waiting list maintained.

Counties served: Albany, Rensselaer, Saratoga and Schenectady.

Cost

$7.00 per hour (4 hour minimum)

Special Service

Nurse Visit (less than 4 hours if need be)

Staff

Home Health Aide (some certified) - R.N. and L.P.N.

Alzheimer's Disease and Related
Disorder Association (A.D.R.D.A.)
of the Capital District
P.O. Box 8809
Albany, NY 12208
463-0887, 438-4329, 438-3660
Contact Person: Janet Wilson

Services

New Program: Will provide home health care for Alzheimer's patients (up to 2 hours per week). Additional services available.

Counties served: Albany, Rensselaer, Saratoga and Schenectady.

Cost

$10.00 fee to join A.D.R.D.A. Must be a member to use services.

Attentive Care Nursing Service
855 Central Avenue
Albany, NY 12206
438-6271

Services

Home Health Aides; Nurse's aides; R.N.; L.P.N.

Counties served: Albany, Rensselaer, Saratoga and Schenectady. (Depends on distance and staff availability. Saratoga is more difficult.)

Require 24 hour advance notice.

Cost

$7.60 per hour is starting rate (4 hour minimum)

Staff

Some Home Health Aides are certified. Nurse's aides are required to have two years of experience.

Appendix 6 (continued)

Family and Child Service of
Schenectady
246 Union Street
Schenectady, NY 12305
333-1369
Contact Person: Ann Walraven

Services

Homemaker's Program - no personal care, but will provide housekeeping services and will accompany on short, outdoor trips.

Counties served: Schenectady only.

Cost

Sliding scale (3 hour minimum)

Staff

Trained Home Makers.

Grace Adult Home
122 North Main
Mechanicville, NY 12118
664-4112
Contact Person: Grace Lennon

Services

Two beds. Must be classified "adult care."
Maximum of six weeks per year.
Must be ambulatory without assistance. No waiting list.

Counties served: Albany, Schenectady, Rensselaer and Saratoga.

Cost

$40-80 per day depending on care required.

Private pay only.

Appendix 6 (continued)

Home Aides, Greater Adirondack
10 Glen Street
Glens Falls, NY 12801
793-4148
Contact Person: Nancy Pairbanks

Services

Certified Home Health Aides available (24 hour service).

Counties served: Saratoga, Warren, and Washington.

Cost

Sliding Scale

Staff

Home Health Aides

Medical Personnel Pool
90 State Street
Suite 522
Albany, NY 12207

Services

Nurse's Aides L.P.N.'s, and R.N.'s available. L.P.N. receives clients' requests and matches clients' needs to employees' skills. R.N. supervisor makes a health care assessment. R.N. supervisor also makes direct contact with the client's medical doctor.

Counties served: Albany, Rensselaer, Saratoga and Schenectady. (Depends on distance and staff availability.)

Cost

$7.95 per hour for nurse's aide. (4 hour minimum)

Appendix 6 (continued)

Special Service

A bed and a bath: two hour unit of service (bathe, dress, feed) = $20.00.

Staff

Nurse's Aides - perform custodial care only: they do not administer medication. L.P.N's and R.N.'s available. All nurses have at least one year's experience in a medical facility. Bonded.

Olsten Health Care Services
52 James Street
Albany, NY
462-3346

Services

Home Health Aides: Personal Care Aides: R.N. and L.P.N.'s. Initial assessment done in client's home by the Director of Nursing.

No waiting list. Advance notice for weekends strongly suggested.

Counties served: Albany, Rensselaer, Saratoga and Schenectady.

Cost

$7.50 $7.75 per hour (four hour minimum)

Staff

Personal Care Aides and Home Health Aides are NYS certified by the Department of Social Services. L.P.N.'s and R.N.s are available.

Public Health Nursing Services
584-7460

Services

Home nursing care, physical therapy, R.N., occupational therapy, speech therapy, home health aides, medical social worker, nutritionist, homemakers and housekeepers.

Special Service

Advisable to inquire about long term home health care program regarding eligibility and services available.

Counties served: Saratoga County only.

Cost

Accept medicaid and medicare. Sliding fee scale available.

Quality Care
Executive Park East
Stuyvesant Plaza
Albany, NY 12203

Services

Home Health Aides: Personal Care Aides; R.N.'s and L.P.N.'s. Initial assessment done by field staff supervisor.

Counties served: Albany, Rensselaer, Saratoga and Schenectady.

Staff

NYS certified Home Health Aides

Tri-Cities and Helpmates
123 Troy-Schenectady Road
Latham, NY 12110
785-3997

Services

Personal Care Aides and Home Health Aides available. R.N. makes an assessment and determines family's needs. No waiting list per se.

Counties served: Albany, Rensselaer, Saratoga and Schenectady.

Appendix 6 (continued)

Personal Care Aide: $7.50 per hour.
Home Health Aides: $8.50 per hour.
(two hour minimum)

Staff

Personal Care Aides complete a training course which includes field supervision by an R.N. Home Health Aides are N.Y.S. certified. R.N. and L.P.N. available.

Upjohn Health Care Services
Executive Park North
Stuyvesant Plaza
Albany, Ny 12203
482-4424

Services

Homemakers: Personal Care Aides: Home Health Aides available. Service Coordinator takes a service request and determines level of service. R.N. Nursing Supervisor makes a home visit and designs a treatment plan.

Counties served: Albany county only.

Cost

$7.95 per hour (4 hour minimum)

Staff

Personal Care Aides are required to have one year of experience in a nursing home or hospital and take an equivalency examination to determine readiness for the job. Home Health Aides are N.Y.S. certified/DSS approved.

Appendix 6 (continued)

ADDITIONAL INFORMATION/REFERRAL SERVICES

Department for the Aging - Albany County
112 State Street
Seventh Floor
Albany, NY 12207
447-7177
Contact Person: Brenda Jones

Office for the Aging - Columbia County
71 North Third Street
Hudson, NY 12534
828-4258
Contact Person: Kit Carter

Department for the Aging - Rensselaer County
County Office Building
Troy, NY 12180
270-2730
Contact Person: Joseph Agostine

Office for the Aging - Saratoga County
South Street School
South Street, Exit 270
Ballston Spa, NY 12020
885-5381
Contact Person: Franklin DeMarinis

Office for the Aging - Schenectady County
101 Nott Terrace
Schenectady, NY 12308
382-8481
Contact Person: Lyn Kucij

Appendix 6 (continued)

RESPITE SERVICE AGENCIES

(Long-Term)

Albany Guardian Society
553 Clinton Avenue
Albany, NY

Home	465-1321
Nurse	465-8545
Administrator	465-6395

Services

Potential client must be ambulatory and able to go downstairs in facility. Activities of daily living must be completed by client without assistance. Nursing round the clock - R.N.'s and L.P.N.'s. Fairly lengthy intake procedure: 2-3 days to 3-4 weeks. No waiting list. No county restrictions.

Costs

$225/week. Medicare not accepted.

Eddy Memorial Geriatric Center
2256 Burdett Avenue
Troy, NY 12180
274-9890
Contact Person: Charlotte St. Pierre

Services

One to six weeks care in house. L.P.N. 's; R.N.'s; Nurse Aides. Waiting list - depends on level of care needed and dates.

Counties served: Albany, Rensselaer, Saratoga and Schenectady.

Medicare coverage only with DSS approval in the county in which the person lives.

Costs

$85/day - health related
$95/day - skill (more assistance)

Appendix 6 (continued)

Grace Adult Home
122 North Main
Mechanicville, NY 12118
644-4112
Contact Person: Grace Lennon

Services

Has four beds. Accept clients who need supervision, but mobile. Can be wheelchair bound if client is able to transfer on his/her own.

Provides personal care: laundry, hygiene, 3 meals/day

Counties served: Albany, Schenectady, Rensselaer and Saratoga.

Cost

$1200/month

Wesley Health Care Center
Lawrence Street
Saratoga Springs, NY 12866
587-3600
Contact Person: Harriet Smith

Services

Must apply and submit to home visit assessment completed by Social Worker and R.N. Must be classified as "Skilled Nursing." Alzheimer's clients accepted.

Counties served: Albany, Rensselaer, Saratoga and Schenectady.

Cost

$107/day - skilled nursing
Minimum one week, maximum six weeks. Must have Medicaid coverage, otherwise private pay. Reservation only.

Appendix 6 (continued)

Teresian House
Washington Avenue Extension
Albany, NY
456-2000
Contact Person: Sue Delvecchio
(Director of Social Services)

Services

R.N., L.P.N. and four aides. 1-6 weeks care: client must be at health related level, requiring skilled nursing care. Lengthy intake procedure (minimum 2 weeks for paperwork and interviews). Waiting list can vary.

Early Alzheimer clients accepted.

Counties served: Albany, Rensselaer, Saratoga and Schenectady.

Costs

$94/day. Medicaid accepted.

V.A. Medical Center
113 Holland Avenue
Albany, NY 12208
462-3311 (Extension 381)
Contact Person: Sarah Gobel

Services

Social Worker, physician, R.N. and aide. Intermediate care ward. Prospective clients must be veterans or family members of veterans.

Counties served: Albany, Rensselaer, Saratoga and Schenectady.

Cost

$492 for four weeks.

5 days to 4 weeks maximum. Four weeks per year without cost for veterans. Cost only for non-service connected VA's or if income is above $25,000. Waiting list varies.

Appendix 7

Group Intervention With Caregivers of Older Persons

Project Description

The Ringel Institute of Gerontology, in conjunction with the School of Social Welfare, at the Sate University of New York at Albany have been awarded a grant from the National Institute of Mental Health. The grant is to sponsor a project entitled "Group Interventions with Primary Caregivers." Ron Toseland, Ph.D. is the Principal Investigator and Mary Coppola, ACSW is the Project Director.

In recent years, there has been an increasing awareness of the extent of informal caregiving and its importance in maintaining older persons abilities to cope with changes experienced during the aging process. A large body of research indicates that older persons are not abandoned by their families, rather family members, neighbors and friends provide a significant level of informal help to older persons. Research studies also indicate that there is stress associated with the demand of caregiving which can cause the helper to experience psychological, social and/or physical deterioration.

The major objective of this project is to investigate the effectiveness of education/support groups in preventing stress, depression or other symptoms from occurring among adult women who are the children of an infirm parent. The effectiveness of two types of groups will be contrasted: professionally-led support groups and self-help support groups. Short-term and long-term prevention will be assessed among caregivers. as well as among care receivers.

Participants will be randomly assigned to one of three conditions: a professionally-led group, a self-help group, and a respite care group. There will be 2 groups of 9 participants in each type of group intervention, and 18 participants in the respite care group. This process will tentatively start in October 1986 and will be repeated again in the spring with a new set of participants. Groups will be held at community agencies located within convenient traveling distances of the participants' county of residence. Each session will be a two hour group meeting covering 1) a topical area related to an aspect of the caregiving role, and 2)a time for discussion and information sharing about how to cope with particular stressors in providing care to a parent.

To evaluate the prevention of stress, depression, or other symptoms among caregivers, participants will be assessed prior to participating in the eight two hour weekly group meetings, within two weeks following the last meeting, and then again at 6 months, and 1 year.

Appendix 7 (continued)

Benefits To Participants

- Increase their understanding and knowledge of the aging process
- Better understand their emotional reactions and needs as well as those of their parent
- Learn to deal more effectively with their own needs as well as those of their parent
- Improve their personal care skills
- Acquire greater knowledge of community resources and their functions
- Develop and express ways to assist themselves and their parent in maintaining as active and productive a way of life as possible
- Monetary compensation for traveling to and from group meeting ($40)
- Monetary compensation for participating in pre, post, 6 month and 1 year assessment activities ($80)/total)
- Monetary compensation to provide for respite care during 8 week meeting period ($90)

CRITERIA FOR PARTICIPANTS' INVOLVEMENT

We are seeking volunteers for the project, "Group Interventions with Primary Caregivers" who meet the following criteria:

A daughter who is the primary informal caregiver for her parent(s). ("Primary" refers to a caregiver who provides more care than anyone else, including both professional and non-professionals who may share some caregiving responsibilities.)

Women volunteers must be between the ages of 40 and 60, married, and have at least one child of their own.

The parent who is being cared for must be age 60 or above, reside in the community (house, apartment, high-rise unit), and have at least one physical or emotional disability.

Women who have been involved, are involved, or plan to be involved in self-help groups or a professional intervention program designed for caregivers should not be recommended for this project.

Appendix 7 (continued)

At the time they volunteer, women must not be displaying any major mental health problems but should be experiencing stress or feel a burden in caring for their parents.

Contact person for this project is Mary Coppola at 442-5374.

Appendix 7 (continued)

Group Intervention With Caregivers of Older Persons

The Ringel Institute of Gerontology, in conjunction with the School of Social Welfare, at the University at Albany have been awarded a grant from the National Institute of Mental health. The grant is to sponsor a project entitled "Group Interventions With Primary Caregivers." The major objective of this project is to investigate the effectiveness of ways to prevent stress and other symptoms from occurring among adult women who provide care for an aging parent.

If you agree to participate in this program, and you are found to be eligible, you will be asked to answer a series of questions about the care you provide. At four times during the year a researcher will make a convenient appointment with you to ask these questions. Each time you are asked the questions you will be reimbursed at the rate of twenty dollars ($20.) In addition to answering these questions you will be provided with ninety dollars ($90.) for respite care. This money can be used to hire someone to care for you parent while providing you with some free time.

There is also the possibility you may be asked to participate in an education/support group. It is hoped this part of the program would: 1. increase your understanding of the aging process; 2. increase you understanding of your reactions as well as those of your parent; and 3. increase your knowledge of how to deal with your needs and your parent's needs.

In order to be considered for this program, you must be:

- A daughter who is the primary informal caregiver for her parent(s).
- Between the ages of 40 and 60, married, and have at least one child of your own.
- Caring for a parent who is age 60 or above who resides in the community.
- A daughter who has not been involved or does not plan to be involved, in self-help groups or a professional intervention program designed for caregivers.

FOR MORE DETAILS ABOUT THIS PROGRAM CONTACT
MARY COPPOLA AT 442-5374.

Appendix 8.1

Care of ill relatives focus of new study
Look at impact of support groups

Times Union
Page B8
January 25, 1987
By Grace O'Connor

More than a decade ago, Ester Rothchild of Slingerlands started taking care of her elderly mother, who was an invalid. "There were no such things as support groups" at that time, she said.

Since then she has come to realize the value of leaning on others, both personally and as a participant, in a project begun in the fall to study the effects of group interventions on primary care-givers.

In the early 1980s Rothchild's husband developed Alzheimer's disease. Now, she said, there are 150 Alzheimer's support groups around the country but then there were almost none.

As it happened, however, she and her late husband resided in Florida where "someone had just started a group." It helped her get through the ordeal.

The right support group can be a stress-saver, she said, a lifeline to people struggling to cope with the devastating effects of the disease.

Now, three years after her husband's death, Rothchild is involved in a research program to determine the value of various types of support groups to women caring for aged parents. In the fall she was one of four leaders of small circles of Capital District women aged 40 to 65 serving as the primary care providers to elderly parents.

The project of the Ringel Institute of Gerontology was run in conjunction with the School of Social Welfare of the State University at Albany.

A second portion of the project will begin in March or early April and Rothchild will again be one the group leaders.

She said caring for her dying husband was not like looking after her aged mother because, "you expect to get older with your spouse, to experience the golden years together." Instead, she found it necessary to be his nurse and care provider.

The moral support she received in the Florida support group, she said, helped her survive the emotional and physical trauma she felt because of her husband's disease.

Mary M. Coppola, project director of the care-provider study, said 80 women are being sought for the second program, about twice as many as were included in part one. Women interested in the study may call Coppola at 442-5374.

Volunteers should be between the ages of 40 and 60, and married with at least one child. Each should be the primary informal care giver for a parent age 60 or over still living in the community and having at least one physical or emotional disability.

The project is funded by a grant from the National Institute of Mental Health. The goal of the research, according to Ronald William Toseland, who wrote the grant and is serving as principal investigator, is to learn the effectiveness of education-support groups in preventing stress, depression or other symptoms in adult women caring for an ill or aged parent.

Coppola said the 3-year project will include a year of follow-up interviews with volunteers, to determine if support groups proved helpful and, if so, how. In the third year, researchers will study results and organize them into a report that will be shared with colleges and other institutions which deal with care providers for the elderly.

Results may also prove helpful in encouraging the government to do more to assist people charged with being primary care-givers to the aged members of their family.

Rothchild said in the first group there were people dealing with mothers who were stubborn, demanding, unreasonable, unable to understand or communicate and difficult about eating or doing other things good for them.

One woman, Rothchild said, whose mother is 92 and possesses all her faculties, told the leader, "I thought I had problems until I heard what other people said. My mother is well. I can speak to her."

What happens in support groups, Rothchild said, " is people find out they are not unique. They are not the only ones. Others share similar problems."

At the conclusion of the first project last fall, after eight weeks of give and take, the nine women in Rothchild's group decided they wanted to continue. Rothchild said this desire to meet once a month on their own gave her "personal satisfaction" and she volunteered to go on as group leader. "This is what I wanted to accomplish."

Participants gain in various ways, Coppola said. They improve personal care skills; learn more about community resources available to them; and develop ways to help themselves and their parent stay as active and productive as possible.

Caring for the elderly
Study begun on stress of a daughter's responsibility

The Times Record
Page 27
August 28, 1986
By Jill Bryce

ALBANY - Marilyn H. has been caring for her 80-year-old mother for 10 years. Sometimes, she says, she feels trapped by the responsibility of buying the groceries, taking her mother to doctor's appointments, getting prescriptions filled and listening to day-to-day problems.

"It's funny. It's a cycle and everything reverses," says Marilyn. "Our parents become our children and we become the parents. My mother turns to me with her troubles. I'm responsible for her and for her health because I'm the female".

It's a statement which could be echoed time and time again in our rapidly aging society. According to "The Gerontologist," a book on aging by Elaine Brody, the number of people 85 and over is expected to double by the 2000. Those aged 75 to 84 years will make up 57 percent of the population.

The responsibility for physical care and companionship has fallen to the children, primarily the daughters and daughters-in-law -- a group the Philadelphia Geriatric Center characterized as the "women in the middle."

The National Institute of Mental Health has awarded a grant to study how effective support groups are in preventing stress and anxiety among adult women who care for an elderly parent.

The study, by the Ringel Institute of Gerontology and the School of Social Welfare at State University at Albany, is being conducted to determine how a daughter is affected when caring for an aged parent.

"Care of an elderly parent can get to be such a burden, the caretaker can't continue. Anger, guilt and resentfulness occur. Stress develops," says Mary Coppola, director of the study.

Many women are "in the middle" because they feel pressure from two competing values, says author Brody: The traditional values that make care of the elderly a family responsibility and the more recent values that free women to work outside the home.

In recent years, more and more women are adding the roles of paid worker and caregiving-daughter of dependent older people to the traditional roles of wife, homemaker, mother and grandmother.

But as more and more women enter the work force, the future of care for the aged is a questionable one. If women become less available for taking care of their parents, will the elderly receive less family care?

And what of the effect on the female caretaker who wants to work but feels responsible for a parent and cannot hold down a job?

The researchers are looking for volunteers for October and again in the spring. To be considered for the program, you must be:

- a daughter who is the primary informal caregiver for her parent.
- between the ages of 40 and 60, married and have at least one child of your own.
- caring for a parent age 60 or older who resides in the community.
- a daughter who has not been involved or does not plan to be involved in a self-help group or a professional intervention designed for caregivers.
- Have no major mental health problem, but experiencing stress or feeling a burden in caring for the parent.

Participants will gain an increased knowledge of the aging process and a better understanding of their emotional reactions and needs as well as those of their parent, according to Coppola. All information will be kept confidential.

Results of the study will be given to the federal government in hopes of gaining money for the development of support groups for daughters caring for a parent.

Participants will be asked to answer a series of questions about the care provided. Four times during the year, a researcher will make an appointment to ask these questions and volunteers will receive a stipend each time. In addition, volunteers will receive funds for respite care.

Interested parties may contact Mary Coppola at State University at Albany.

Appendix 8.3

Care for your Aging Parent

YWCA of Albany
Winter 1987 Classes
28 Colvin Avenue, Albany, N.Y. 12206

Do you need some help and support in coping with the problems of caring for an aging parent? The Ringel Institute of Gerontology at SUNYA is currently sponsoring a care-giver support program. This program provides educational, emotional, and financial assistance to adult children who are caring for a parent at home. Eligible participants will be reimbursed for their activity in this project. The YWCA urges anyone who is interested in participating in this program to call Mary Coppola, Project Director, at 442-5374, for more information.

Appendix 9

January 7, 1987

Enclosed please find information describing a project for relatives who find themselves caring for an elderly parent in the home. The Ringel Institute of Gerontology, in conjunction with the School of Social Welfare, at the University at Albany are sponsoring this endeavor. The study, titled "Group Interventions with Primary Caregivers," began its first series of programming in October with 56 volunteers from the Capital District Area.

Recruitment efforts are currently underway to identify a new set of participants so the programming can be repeated in the Spring. I would appreciate it if you could please relate this information in a free Public Service Announcement on your station. I believe there are many families in our communities who might be interested in informal caregiving or know of someone else who is a caregiver and could benefit from assistance.

Enclosed is a suggested P.S.A. prepared for your convenience. Also, there is a two page description of the project providing more details. If you have any questions or need additional information, I can be reached daily at 442-5374.

Thank you very much for your cooperation.

Sincerely,

Mary M. Coppola, ACSW
Project Director

MMC/bm
Enclosure

Appendix 9 (continued)

GROUP INTERVENTIONS WITH PRIMARY CAREGIVERS

Suggested Public Service Announcement

THE RINGEL INSTITUTE OF GERONTOLOGY AT THE UNIVERSITY AT ALBANY IS SPONSORING A CAREGIVERS SUPPORT PROGRAM. THE PROGRAM IS INTENDED TO PROVIDE EDUCATIONAL, EMOTIONAL AND FINANCIAL ASSISTANCE TO ADULT CHILDREN WHO ARE PROVIDING CARE FOR A PARENT AT HOME. ELIGIBLE PARTICIPANTS WILL BE REIMBURSED FOR THEIR ACTIVITIES IN THIS PROJECT. IF YOU ARE INTERESTED IN PARTICIPATING, OR WISH FURTHER INFORMATION, PLEASE CONTACT MARY COPPOLA AT 442-5374.

Date PSA Prepared:	1/7/87
Dates during which PSA should be used:	Anytime between 1/10/87 - 2/15/87
Contact:	Mary Coppola Project Director 442-5374

Appendix 10

November 19, 1986

Dear Editor:

The enclosed two page description announces a project for relatives who find themselves caring for an elderly parent in the home. The Ringel Institute of Gerontology, in conjunction with the School of Social Welfare, at the University at Albany are sponsoring this endeavor. It is my belief there are many families in our community who would be interested in knowing about this project.

As you may be aware, spouses and adult daughters provide the bulk of care for the growing number of older persons in our community. They prevent many from being institutionalized prematurely. I believe that the Caregivers Support Program would be of interest to your readers because many have either directly experienced the stresses and strains of providing care of know of someone who has.

Currently we have been approaching local human service agencies, churches and programs serving elderly families for possible volunteers. Since we will need over 80 volunteers this Spring who meet the grant's eligibility criteria, there is a desire to be as thorough in our recruitment efforts as possible. I would greatly appreciate any coverage you could give to this important project in your publication. Should you need more information than is provided in the suggested article please call me. I can be reached daily at 442-5374.

Sincerely,

Mary M. Coppola, ACSW
Project Director

MMC/bm
Enc.

CAREGIVERS SUPPORT PROGRAM

In recent years there has been an increasing awareness of the extent of formal caregiving and its importance in maintaining older persons abilities to cope with changes experienced during the aging process. A large body of research indicates that older persons are not abandoned by their families; rather, family members, neighbors and friends provide a significant level of informal help to older persons. Research studies also indicate that there is stress associated with the demand of caregiving which can cause the helper to experience psychological, social and/or physical deterioration.

The Ringel Institute of Gerontology, in conjunction with the School of Social Welfare, Rockefeller College of Public Affairs and Policy, State University of New York at Albany, has been awarded a grant from the National Institute of Mental Health to study caregivers and their activities. The major objective of this project is to reduce or prevent stress and other symptoms from occurring among adult daughters who provide care for an aging parent and to prevent or delay the premature institutionalization of aging parents.

Daughters who care to participate will be asked to answer questions about their experiences in caring for their parents and they may be asked to join a support group that will meet for two hours once a week for eight weeks. All participants will be reimbursed for the time they spend answering questions about their caregiving situation. Participants will also receive money to hire someone to care for their parents so they can have a respite, and to cover expenses resulting from traveling to and from group meetings.

Benefits to participants include an increased understanding and knowledge of the aging process and the implications of their parent's disability. They will learn how to cope more effectively with their emotional reactions and those of their parents. Participants will be informed about how to access community resources to help their situation. In addition, they will be given a community resource directory to use as needs arise in the future. Most importantly, participants will have the opportunity to share some of their frustrations with women who are in similar situations.

With enthusiastic support from the community, the Caregivers Support Program offered its first program for 56 volunteers in the Fall, 1986. Recruitment efforts are currently underway to identify a second group of participants for the Spring program. Those interested in learning more details about the project may contact Mary Coppola, Project Director at 442-5374, or Dr. Ronald Toseland, School of Social Welfare, State University of New York at Albany, who designed the grant.

Appendix 11.1

October 22, 1986

Director of Social Services
Ohav Shalom Senior Citizens
Housing Project
115 New Krumkill Road
Albany, New York 12208

Dear Director:

As per our conversation this week, I have enclosed a copy of the letter I sent to Raymond Tolar on August 13, 1986. This is simply a sample letter which you can edit as you wish to meet your needs. We had agreed that this letter would be mailed, on your letterhead, to appropriate families associated with your organization. Also, it was suggested there be a follow-up phone call to determine the potential volunteer's interest. Your idea of my meeting with interested families is an excellent one since it does not make more work for you, or place you in "the middle," interpreting the project to others.

If you are not certain about the eligibility of potential volunteers, please include them on your mailing list. Once an interested woman telephones me I can explain the project in more detail and determine her eligibility. As I mentioned previously, we are trying to be flexible in screening the potential volunteers. At the very least, we would like to try to provide them with referrals to community resources if this is needed.

Please contact me once you have had the opportunity to think about the best way to recruit caregivers at your agency. I can be reached daily at 442-5374. Again, thank you for your interest and cooperation in this project.

Sincerely,

Mary M. Coppola, ACSW
Project Director

Enc.
MMC/bm

Appendix 11.2

SAMPLE LETTER

Dear ________________:

The enclosed program announcement describes a support program available to adult children who find themselves caring for an elderly
Ringel Institute of Gerontology and the University at Al
endeavor. We have reviewed the details of this program
eligible for participation.

The researchers at S.U.N.Y.A. are conducting this pr
received from the Federal Government. These researchers
with older persons and their children. They recognize t
experience in providing care for a parent and wish to de
those in the role of the caregiver. As advocates for th
to learn more about the problems of caregivers in order
of improved programs to serve families.

A review of the program announcement should indicate
participation in this program. Aside from receiving mon
activities in the program, you will have the knowledge t
other people in a similar situation.

We urge you to consider volunteering for this worthw
friend are interested in further information call the Di
Coppola, at 442-5374. You can ask questions as well as
program with no obligation at this time.

Meanwhile, if we can be of any assistance in clarify
us at 489-5531. Thank you for your consideration in thi

Sincerely,

Executive Director

Social Worker

Appendix 11.3

October 31, 1986

Ms. Mary Coppola
Project Director
School of Social Welfare
Richardson Hall
135 Western Ave.
Albany, N.Y. 12222

Dear Mary,

I have enclosed a sample letter on our letterhead which is to be mailed to potential volunteers.

The enclosed mailing list includes all daughters that may be potential volunteers. Many of the candidates work. Therefore, you may be more successful if you schedule evening meetings.

Please contact me if there is any way I can be of assistance to you in this project.

Sincerely,

Director of Social Services
Congregation Ohav Shalom

Appendix 11.4

Dear

The enclosed program announcement describes a support program available to adult daughters who find themselves caring for an elderly parent in the home. The Ringel Institute of Gerontology and the University at Albany are sponsoring this endeavor. We have reviewed the details of this program and believe you might be eligible for participation.

The researchers at S.U.N.Y.A. are conducting this program through a grant received from the Federal Government. These researchers are interested in working with older persons and their daughters. They recognized the problems that adults experience in providing care for a parent and wish to develop something helpful for those in the role of caregiver. As advocates for the elderly these researchers which to learn more about the problems of caregivers in order to encourage the development of improved programs to serve families.

A review of the program announcement should indicate the benefits of participation in this program. Aside from receiving monetary compensation for your activities in the program, you will have the knowledge that your participation will help other people in a similar situation.

We urge you to consider volunteering for this worthwhile program. If you or a friend are interested in further information call the Director of the program, Mary Coppola, at 442-5374. You can ask questions as well as obtain details about the program with no obligation at this time.

Meanwhile, if we can be of any assistance in clarifying this program please call us at 489-5702. Thank you for your consideration in this matter.

Sincerely,

Director of Social Services
Congregation Ohav Shalo

Appendix 11.5

November 14, 1986

Executive Director
Albany Catholic Family and
Community Services
150 Hamilton Street
Albany, New York 12207

Dear Mr. Grasso:

I have attached a list of primary caregivers who have volunteered to participate in the "Group Interventions with Primary Caregivers" program sponsored by the Ringel Institute of Gerontology in connection with the School of Social Welfare at the University of Albany.

Please feel free to call if you need anything further.

Sincerely yours,

Director of Social Services
County of Albany D.S.S.

enc.

JEM/td

Appendix 12

January 14, 1987

Dear Friend,

On Wednesday, January 28, 1987 from 7:00 p.m. to 9:00 p.m. Catholic Family and Community Services of Albany and Southern Rensselaer Counties will conduct a public informational meeting to introduce two very important new programs. The meeting will be held at the Brady Building on 40 North Main Avenue (next to St. Catherine's Home for Children) in Albany. We believe that these new services could be of vital interest and assistance to members of your parish. Many of the services provided through these programs are free or have a nominal cost.

One of our new Projects is the Family Life Education Program which helps both parents and children address some of the most pressing issues confronting families today. We will examine such areas as drug and alcohol abuse; adolescent sexuality; acting out behavior by children; school performance; and family conflict. The Program will provide preventive education, that is, it will assist family members to develop the skills needed to successfully resolve such problems before they become a crisis. In addition, we will also help families to learn behaviors that will greatly enhance their family relationships.

The Group Intervention With Caregivers of Older Persons Project is implemented by the Ringel Institute of Gerontology of the University at Albany with assistance from our office. It provides educational, emotional, and financial assistance to adult children who are caring for an elderly or infirmed parent.

We respectfully request your assistance in spreading the word about these two new available services. Please send one or more representatives of your Parish to this meeting to hear about these programs. We will have plenty of handouts to distribute within your Parish, and will answer questions about the Projects at this meeting. In order for us to have enough material on hand we ask for a R.S.V.P. by Monday January 26, 1987. You need only call me at 436-9745.

My sincerest appreciation for helping us to inform people about these critically needed new services.

Yours truly,

Executive Director
Catholic Family & Community Services

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