

FOSTER CAREGIVING TO IMPAIRED ELDERLY:

A QUALITATIVE ANALYSIS

by

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TABLE OF CONTENTS

	<u>Page</u>
<u>LIST OF TABLES</u>	ix
<u>LIST OF FIGURES</u>	x
 <u>CHAPTER</u>	
I INTRODUCTION	1
Significance of the Study	3
Review of the Literature	4
Concept of Adult Foster Care	4
Definition and Terms	4
History of Adult Foster Care	5
Theoretical Issues	10
Policy Issues	16
Clinical Issues	20
Characteristics of Foster Care for Elderly	22
Foster Caregiving	26
Characteristics of Foster Caregivers	26
Motivations for Caregiving	28
Functions of the Caregiving Role	28
Problems Encountered by Foster Caregivers	29
Summary	30

<u>CHAPTER</u>	<u>Page</u>
I INTRODUCTION (Continued)	
Purpose	31
Research Questions	31
II METHODOLOGY	32
Sample and Setting	32
Sample Selection	33
Overall Study	33
Subsample	34
Sample Description	35
Foster Caregivers	35
Elderly Residents	38
Design	40
Methods of Data Collection	41
Focused, In-Depth Interviews	41
Participant Observation	44
Procedures	44
Data Analysis	46
III FINDINGS	48
Strategies	48
Caregiving Strategies to Manage the Needs and Problems of Residents	48

<u>CHAPTER</u>	<u>Page</u>
III FINDINGS (Continued)	
Social Support	50
Facilitating contact with relatives and the larger community	50
Providing activities	52
Giving tangible aid	52
Psychological Support	53
Physical Support and Well-Being	55
Providing direct care	56
Providing indirect care	57
Managing Problematic Behaviors	60
Limit setting	61
Harmonizing	61
Strategies Used by Caregivers to Cope With the Effects of Caregiving on Their Own Lives	62
Control Over Resident Selection	62
Attribution of Meaning to the Caregiving Experience	65
Insulation	65
Use of Outside Assistance	66
Summary	68
Consequences of Foster Caregiving	68
Benefits of Caregiving	70
Costs of Caregiving	72

	<u>Page</u>
<u>CHAPTER</u>	
III FINDINGS (Continued)	
Summary	77
Cost/Benefit Ratio	77
IV DISCUSSION & RECOMMENDATIONS	79
Discussion of Findings	79
Recommendations	81
Social Policy Issues	81
Implications for Nursing Practice	81
Implications for Further Research	83
<u>REFERENCES</u>	84
<u>APPENDICES</u>	
A Focused, In-Depth Interview With Family Member	
B Focused, In-Depth Interview With Elderly Individual	
C Consent Form	
<u>ABSTRACT</u>	

LIST OF TABLES

<u>TABLE</u>		<u>Page</u>
1	Caregiver Age	35
2	Caregiver Marital Status	36
3	Caregiver Educational Level	36
4	Caregiver Chronic Health Problems	37
5	Age of Residents	38
6	Chronic Health Problems of Residents	39
7	Frequencies of Costs and Benefits of Caregiving as Cited by Foster Caregivers	69

LIST OF FIGURES

<u>FIGURE</u>		<u>Page</u>
1	Conceptual Model	49

CHAPTER I
INTRODUCTION

The care of the dependent aged is one of the most provoking social problems of our time. At present, 11.3% of the population of the United States is 65 years and older, and it has been projected that this will increase to 21% by the year 2030 (United States Senate Special Committee on Aging [USSSCA], 1984). Of prime concern is the already significant increase in the percentage of those elderly 85 years and older. It is this age group that is substantially more vulnerable to the problems of chronic illness and dependency associated with old age (Brody, 1973). For example, of those individuals 65 years and older, 22% are limited in amount and kind of major activity, and 17% are unable to carry on major activity due to a chronic condition (USSSCA, 1984). However, at age 75, nearly half report such limitations. Twenty-four percent are limited in amount and kind of major activity and 22% are unable to carry on major activity (USSSCA, 1984). Because of their limitations, these individuals are often in need of protective living arrangements.

As the percentage of frail elderly in the population increases, the development of living and housing arrangements for elderly is becoming a major national priority (Steinhauer, 1982). The

diversity of this population requires an array of services and living arrangements that spans independent living in one's own home to institutionalization with skilled medical and nursing services. Additionally, current government policy is intended to decrease the "unnecessary" institutionalization of elderly men and women. Reports from the United States General Accounting Office state that 25% of institutionalized elderly are being cared for in an environment that exceeds their need (cited in Sherman & Newman, 1979). Pepper stated that these individuals could have remained in the community had appropriate services and living arrangements been available (cited in Steinhauer, 1982). Institutionalization often results in care that is more costly, more medically focused, and more socially restrictive than is necessary.

A current trend in service and living arrangement for frail elderly is the use of foster care (Steinhauer, 1982). Foster care enables an elderly individual to reside in the private home of a nonrelated person, where he/she can receive needed assistance and support in activities of daily life. The literature suggests that this option has the added benefit of allowing elderly to remain part of community and family life (Mor, Gutkin & Selzer, 1980; Newman & Sherman, 1979a, 1979b; Sherman & Newman, 1977; Sherman & Snider, 1981). Although the provision of adult foster care dates back to 600-700 A.D., it has developed slowly. Only in recent

years has it gained visibility as a living option for frail elderly. Most states now have formal or informal arrangements for the placement of elderly into foster care homes (McCain, 1983).

As a consequence of the aforementioned developments, more individuals will be involved in foster caregiving to frail elderly. However, relatively little research exists about this phenomenon. Those studies currently available on foster caregiving to frail elderly are descriptive in nature. They provide baseline data on the demographic characteristics of foster caregivers, identify problems encountered while caregiving, and motivations for caregiving (Bradshaw, Vonderhaar, Keeney, Tyler & Harris, 1976; Handy, 1968; Miller, 1977; Newman & Sherman, 1977; Oktay & Volland, 1981). This study will fill a gap in the literature by exploring in-depth the lives of foster caregivers. Specifically, it will address the strategies used by foster caregivers during the caregiving process and the consequences to foster caregivers of caring for frail elderly.

Significance of the Study

Nurses have long been in a position to support, educate, and guide those individuals caring for frail elderly. The gerontological nurse, with special knowledge in the social, biological, and psychological aspects of aging, is in a unique position to enhance care for elderly in a variety of living environments. An in-depth analysis of foster caregiving will help nurses provide

services that will enhance quality of life for elderly and their caregivers. As Brody (1973) noted, options must be created that are better than those currently available, not only on the basis of economic cost but on the basis of improved well-being.

Review of the Literature

The scope of the problem under study requires an understanding of the literature in three areas: (a) the concept of adult foster care, (b) the characteristics of adult foster care for elderly, and (c) foster caregiving. The literature encompassing the concept of foster care will be further subdivided into (a) definition and terms, (b) a history of adult foster care, (c) theoretical issues, (d) policy issues, and (e) clinical issues.

Concept of Adult Foster Care

Definition and Terms

Close examination of the literature reveals general agreement on several characteristics which serve to define the concept of adult foster care. These characteristics define foster care as a service which (a) is a living arrangement, (b) allows an individual to receive needed supervision and assistance in activities of daily living, (c) occurs in the home of a nonrelated person, (d) occurs in a home that is privately owned and managed, (e) provides opportunities for family and community living, and (f) is

small in size in relationship to other community living options such as board and care homes.

The literature reveals a lack of agreement on three other criteria that are relevant to the concept of foster care. These are: (a) the maximum number of residents allowed per foster home, (b) the type of resident acceptable for foster care placement, and (c) the specific services to be provided by the caregiver. To date, no standard criteria exists to define the concept of foster care in the United States.

The literature abounds with a wide array of terms to describe the people who manage foster homes, people who live in foster homes, and adult foster homes. People who manage foster homes have been referred to as sponsors, managers, caregivers, operators, and caretakers. People who live in foster homes have been referred to as residents, boarders, and patients. Terms commonly seen in the literature that seem analogous to foster homes are personal care homes, community care homes, and family care homes. For the purposes of this paper, caregiver will refer to the individual who manages the home, resident will refer to the person who lives in the home, and foster home will refer to the residence.

History of Adult Foster Care

The history of adult foster care will be reviewed to give the reader an understanding of the economic, political, and social factors that have helped to shape this interesting and important

social movement. The review will also illustrate the increased interest in adult foster care in recent years.

The placing of individuals in the private homes of nonrelated persons has been in practice in Europe for hundreds of years, with earliest accounts dating from the 14th century in Gheel, Belgium. According to legend, many mentally ill people migrated to Gheel to be cured by the magical and saintly remains of the Irish Princess Dymphna. The continued migration of the mentally ill to Gheel led to the establishment of permanent living arrangements for them in private homes. The movement continued to grow; in 1852 it was organized under medical supervision and became an integral part of that country's mental health planning (Steinhauer, 1982). This program served as a prototype which was later adopted by other European countries.

Meanwhile, in the United States the chronically mentally ill were grouped together with indigent children and adults in almshouses. In the 1850s, under the pioneering direction of Dorothea Dix, the mentally ill were differentiated from other groups of vulnerable people (McCoin, 1983). They were housed in state mental hospitals which proliferated during the next century. At the same time, leaders in the United States who had become familiar with foster care programs in Europe, tried to stimulate interest in this care alternative for the mentally ill. These attempts,

however, were relatively unsuccessful. From 1855 to 1930 only one state (Massachusetts) officially adopted a foster care program.

The concept of foster care was revitalized during the era of the Great Depression. The period between 1930 and 1960 spawned economic interest in care alternatives that could substitute for the more costly state mental hospitals. Consequently, the number of states officially adopting foster care programs increased to 17 by 1959 (Morrissey, 1967). In addition, a federal program of foster care was officially established by the Veterans Administration in 1951. Interest in the movement during these years was focused primarily on the mentally ill. However, references to foster care for the mentally retarded also began to appear in the literature by 1959.

The foster care movement continued to grow during the 1960s. The widespread use of psychotropic drugs during this period facilitated the use of community alternatives for the mentally ill. With the ability of these drugs to ameliorate symptoms, many mentally ill became better suited for community living. In addition, deinstitutionalization of the mentally ill, mentally retarded, and elderly became fashionable during this decade. This trend was spurred by the human rights movement and concomitant federal legislative acts of the Kennedy Administration. By 1964, the number of adult foster care programs for primarily the men-

tally ill and mentally retarded had grown to 26 (Sherman & Newman, 1977).

The most rapid growth in adult foster care has occurred since the late 1960s; the number of people living in foster homes has doubled or possibly even tripled since that time (McCoin, 1983). In large part this rapid growth can be attributed to the federal deficit and the concomitant need to contain federal spending. Thus, federal legislative acts of the 1970s prompted the use of less costly forms of community care for Supplemental Security Income (SSI) recipients. This further accelerated the deinstitutionalization of the mentally ill, mentally retarded and dependent elderly into the community (Steinhauer, 1982). A large proportion of those deinstitutionalized went into foster homes (McCoin, 1983). Bradshaw et al. (1976) in a national survey, determined that caseworkers were extensively using foster home placements because of pressures to free beds in mental hospitals and nursing homes. By 1975, all states had either formal or informal arrangements for the administration of foster care programs (McCoin, 1983). Additionally, the federal government funded two innovative demonstration projects that were designed to place elderly into foster homes (Fenske & Roecker, 1971; Wohlford, 1968). These projects were developed to prevent or delay nursing home care.

In addition to economic motivations for increasing the use of foster care, the 1970s saw a heightened interest in the special

needs of an increasing elderly population. Of prime concern, was the development of supportive living arrangements to replace the ill-reputed nursing home. As a result, the Health Care Financing Administration Waiver projects were developed. These projects prompted individual states to divert federal Medicaid funds, usually earmarked for institutional care of the elderly, into supports to maintain community residence. These projects were for those at "immediate risk" of institutionalization.

The advent of the 1980s brought increased national concern over the growing federal deficit and skyrocketing health care costs. A major regulatory measure, Diagnosis Related Groupings (DRGs), emerged in response to these concerns. Under this prospective payment plan, the federal contribution to hospital costs for the Medicare recipient is curbed. Hospitals have an economic incentive to reduce the cost of treating each patient. Therefore, pressures exist to discharge patients as early as possible into alternate care settings (Reamer, 1985). A foreseeable trend then, is an increase in the use of foster homes as a replacement for time usually spent in the acute hospital. Some hospitals have found it economically advantageous to develop and implement their own foster care programs (Oktay & Volland, 1981; Vandivort, Kurren, & Braun, 1984).

To date there are only rough estimates on the number of people living in adult foster homes in the United States. A

national survey in 1979, with responses from 30 states and the Veterans Administration, yielded population estimates of foster care residents between 61,000 and 64,000 (McCoin, 1983). Data on the number of elderly living in foster homes in the United States are not available. Lack of standard nomenclature and definitions among programs has made statistical reporting and analysis difficult.

In summary, interest and growth in foster care can be attributed to a variety of factors. The current emphasis on cost containment in federal spending has provided the primary impetus for the use of this living option. In addition, the preference for living options other than institutions, and the increasing proportion of older people in the population, promises increased visibility of foster care as a living option for the elderly.

Theoretical Issues

The literature on foster care contains numerous references to the positive benefits of living and participating in family and community life. McCoin (1983) aptly summarizes the literature by stating that adult foster care is based on the assumption that the "substitute family is the treatment of choice for many dependent and disabled groups" (p. 77).

Two descriptive studies specifically examine the integration of elderly residents into the foster family. Newman and Sherman (1979a) conducted interviews with 100 foster caregivers housing

from one to four elderly residents to measure familism. Subjects had physical or mental impairments or both. Familism as defined in this study was based on four measures: affection, social interaction, ritual, and minimization of social distance. High scores on measures of familism indicated family integration and participation. The researchers concluded that in two thirds to three fourths of the cases, integration occurred and was characterized by residents (a) participating with the family in outside activities, (b) conversing with and saying goodnight to each other, (c) exchanging cards and gifts with the caregiver and other residents, and (d) eating with the foster family. However, the researchers did find some maintenance of social distance between the residents and foster family. This was evidenced by about 50% of foster homes maintaining some segregated living space for "family" and residents. The results of this study must be viewed with caution. The instrument used to measure familism does not have proven reliability and validity. Additionally, some of the items used to measure familism may not be appropriate for frail elderly.

Mor et al. (1980) conducted 45 in-depth case studies involving interviews with dependent elderly residents in small foster care homes and other informants. Both urban and rural settings were used. Findings suggest that the majority of elderly residents become integrated into the foster family. Integration was

characterized by residents eating with the family, watching television with the family, and accompanying the family on outings outside the home.

In contrast, Murphy, Penne, and Luchins (1972) conducted a qualitative analysis of 50 adult foster homes in Canada to describe the extent that homes provided a family setting. The homes housed from 2-22 residents, most of whom were mentally impaired, but not primarily elderly. Findings suggest that residents were generally not integrated into family or community affairs. For example, in two thirds to three fourths of the homes, residents (a) ate separately from the foster family, (b) had segregated sitting rooms, and (c) were not involved in any type of household task. Although this study may seem similar to the previously mentioned studies, results are not comparable due to differences in sampling criteria. Information on variables that specifically affect integration of a resident into a foster home is missing.

Sherman and Newman (1977), based on interviews with administrative personnel and analysis of documents relevant to foster care for elderly in New York State, recommend no more than four residents per foster home in order to ensure a family setting. The researchers do not indicate how this number was obtained. Brody (1977) in an opinion article, questions whether 6, 10, or 15 residents per foster home can be considered "family" in nature. However, the relationship between the number of residents per

foster home and the maintenance of a family atmosphere remains unexplored. Further, other variables that could impact on the maintenance of a family atmosphere have not been identified and explored.

A small body of literature suggests the development of a family-type relationship between caregiver and resident. According to Oktay and Volland (1981), this relationship often becomes personal and built around the likes and dislikes of the resident. Strong ties of affection may develop (Bradshaw et al., 1976). Newman and Sherman (1979a) found that in 75% of foster homes, the caregiver perceived his/her relationship with the elderly resident as familial. However, in only 50% of homes did caregivers perceive the relationship between residents as familial. Qualitative research is needed to explore the relationships between and among those living in foster homes.

Although the literature indicates that foster care provides an opportunity for family living, Newman and Sherman (1979a) found that in only 29% of 100 homes studied were residents provided with the opportunity to live in a structurally traditional family of husband, wife, and at least one child. Approximately 50% of these homes had caregivers who were living alone or with one or more children. These findings have been substantiated by other investigators (Bradshaw et al., 1976; Miller, 1977). Additionally,

McCain (1983) questions the appropriateness of using the family as a model for foster care.

One descriptive study examines the extent that elderly residents participate in community activities. Newman and Sherman (1979b) conducted interviews with 100 caregivers of foster homes, housing a total of 234 elderly residents. The sample was divided into two groups: (a) Those placed into foster homes from state mental hospitals, and (b) those from their own homes or other sheltered living arrangements such as board and care homes. The latter group was older, with 50% of the residents over 81 years of age. Findings indicate that 68% of all elderly residents did not participate in regularly scheduled community activities such as crafts groups or church activities. The difference between the two groups was highly significant ($p < .01$) with 44% of those from state mental hospitals never participating, and 86% of those from their own homes or other sheltered living arrangements never participating. In addition, 68% of all elderly residents did not take walks in the neighborhood, and 60% did not visit with neighbors. Information on mental and functional impairments of the sample was not given. Although this study provides information on the extent of community participation, it does not analyze the important qualitative aspects of participation and nonparticipation in community activities.

Researchers have suggested several factors that may affect the amount of community participation by foster home residents. Miller (1977) and McCoin (1983) think that lack of community resources may serve as deterrents to participation. Miller (1977) elaborates by stating that foster homes, in contrast to hospitals, are "clearly second best in regard to availability of physical and recreational facilities" (p. 278). Newman and Sherman (1979b) suggest that age affects activity patterns among the elderly, with "older" elderly participating less often than "younger" elderly. They also state that supplied transportation by a relative or caregiver will significantly increase the likelihood of resident participation in community activities. Finally, Miller (1977) perceives difficulty in motivating residents as a factor in non-participation.

The reaction of the community to foster homes has been examined by researchers. Findings indicate that these homes are accepted by the community (Miller, 1977; Newman & Sherman, 1979b). In contrast to other community living arrangements, Newman and Sherman (1977) attribute the acceptance of foster homes to their small size, lack of publicity, and the fact that residents may be considered part of the caregiver's family.

In summary, research on family and community participation and integration is sparse and inconclusive. The majority of

literature is descriptive in nature. More research is needed on the important qualitative aspects of living in a foster family.

Policy Issues

The terms and operating criteria central to foster care are selected by individual state and federal programs. According to researchers, variations in terminology and operating criteria have resulted in difficulty differentiating foster homes from other community placements such as board and care homes, and difficulty in reporting and analyzing statistical data and in critically reviewing the literature (McCoin, 1983; Steinhauer, 1982). The need for uniform standards to ensure quality foster care has been expressed by researchers (Brody, 1977; McCoin, 1983; Miller, 1977; Steinhauer, 1982). In addition, McCoin (1983) advocates a uniform national policy to standardize terminology and to serve as a basis for a national policy on foster care.

Regulations governing the operation of foster homes in the United States vary among state and federal programs. In a 1979 national survey of adult foster care programs at the state level, the Veterans Administration, and the District of Columbia, McCoin (1983) found that (a) 13 states licensed programs, (b) 6 states certified programs, (c) 17 states and the Veterans Administration had a mix of licensed and certified programs, (d) 9 states had no official program, and (e) 7 states and the District of Columbia represented those in which the status of the program could not be

determined from the data. Regulations for private foster homes not under state or federal sponsorship are not discussed in the literature.

In a hierarchy of regulation, licensure would be at the apex (McCain, 1983). Bradshaw, Deines, and Tyler's national survey of foster care programs found that programs regulate items such as basic safety, residents' rights, and food sanitation (cited in Steinhauer, 1982). However, licensed programs had additional standards for such items as medication control, emergency procedures, and provider training. Overall, the number and type of items subject to control varies among states. Although licensing may exist as a requirement for some foster homes, the methods of enforcing regulation are often ill-defined (Steinhauer, 1982).

Researchers have not adequately addressed the kinds and amounts of regulation most appropriate to foster homes. Newman and Sherman (1977) fear that stringent regulations for small foster homes will provide little incentive for operation. Further, they fear that the "family atmosphere" could be regulated out of existence. In contrast, lax regulations could result in abuse of residents, formation of new "institutions," or a living alternative that does little to enhance the life of residents (Brody, 1977).

Individual state programs represent highly complicated and fragmented designs for the administration and utilization of

foster care. Steinhauer (1982), in an opinion article, states that a common picture of foster care reveals "enforcement of safety codes being delegated to a health agency, placement to a social service unit, and client supervision [is] usually undelegated. . . . [This is] superimposed on a complex mosaic of local regulation and safety ordinances" (p. 294). These complicated designs lower visibility and accountability for foster care in the United States. To ensure quality care, Steinhauer (1982) recommends a sophisticated prototype for the design and implementation of a program of foster care for the elderly. In this prototype, she delineates functions that should be performed at the state and local level. To date, it is the only article available on this subject. Further exploratory research is needed on various state models of foster care and their impact on quality care.

An examination of the literature reveals that federal involvement in foster care is minimal. In 1979 federal legislation did mandate state and local authorities to establish standards over foster homes in which a significant number of SSI recipients were living (Steinhauer, 1982). However, no federal role was stipulated in examining these standards (Steinhauer, 1982). Further, no federal agency will claim responsibility for enforcing this legislation (Steinhauer, 1982). McCain (1983) recommends a unified national policy on foster care with more accountability and leadership on the national level.

The literature addressing reimbursement for foster caregiving indicates that the amount of payment is variable and based on disability and need for care. Compiled financial information from state programs indicates that payments range from \$88 to \$350 per month per resident. This amount is slightly higher in states that supplement the SSI benefit (Mor, Gutkin, & Sherwood, 1985). McCain (1983) found that the average reimbursement rate was 50¢ per hour. One foster care program calculates the monthly reimbursement amount by converting the total score on an activity of daily living scale into a dollar amount (Vandivort et al., 1984). Other literature does not specifically address the method for calculating the amount of reimbursement.

Researchers frequently refer to the low reimbursement for foster caregiving. McCain (1983) states that the income derived from foster caregiving is extremely inadequate. At the same time, this living alternative represents considerable cost savings to the federal government (Miller, 1977; Vandivort et al., 1984). The complex ethical and social issues encompassing the amount of reimbursement for foster caregiving have yet to be explored. Additionally, specific methods for determining the amount of reimbursement need to be clearly identified and qualitatively analyzed.

Current sources of payment for foster caregiving include private and public funds. Accurate data on the number of privately

or publicly supported elderly living in foster homes does not exist. Mor et al., (1975) indicate that of all individuals living in community care facilities in the United States, 43% are publicly supported.

In summary, there is a plethora of terms, operating standards, reimbursement patterns and regulations that serve to identify the universe of foster care programs. In addition, state program designs for foster care are complicated and fragmented. The federal government has shown little interest or concern in this living option. Although researchers have identified the need for uniform policies and standards on the state and national levels, there is a scarcity of research that identifies and analyzes these complex issues.

Clinical Issues

Placement of an elderly individual into a foster home is based on "intuition" and "judgment" rather than on carefully identified and tested criteria. Further, the impacts of placement on the health, morale, and social well-being of the elderly resident are basically unexplored. Thus, the appropriateness and consequences of placement decisions remain largely unknown to the practitioner.

The literature reveals that in most cases there are no well-delineated plans for monitoring and supervising residents in foster homes. Visits by social workers are often infrequent and

sporadic (Sherman & Newman, 1979). In addition, the literature does not address standards for care. These factors constitute a potentially dangerous situation for frail elderly who can experience rapid and unpredictable changes in condition and who are particularly susceptible to environmental conditions. As noted in the literature, sometimes caregivers keep residents despite the need for higher levels of care (Bradshaw et al., 1976).

In most cases, when follow-up supervision and monitoring is done, it is done largely by social workers. Sometimes the services of a visiting nurse are used for individual, short-term skilled care (Bradshaw et al., 1976). Following a survey of foster caregivers, Bradshaw et al. (1976) recommend on-going social and nursing support to maintain adequate levels of care. The literature documents that both caregiver and resident need extensive support services (Handy, 1968; Oktay & Volland, 1981). Handy (1968) further elaborates by stating that caregivers cannot be expected to perform well with minimal outside assistance.

In general, provisions for caregiver training are lacking. Although some caregivers indicate previous experience in the health care field, their ability to adapt care to the home environment is not known. More importantly, the services that can be reasonably and safely expected from foster caregivers have not been addressed in the literature. For example, whether or under

what conditions caregivers should perform such skills as injections or oxygen administration are unknown.

The selection of a foster caregiver is largely intuitive (Miller, 1977; Vandivort et al., 1984). Caregivers represent a mix of demographic and personal characteristics. However, those characteristics associated with the affective dimensions of caregiving have not been identified.

In summary, criteria for placement, monitoring and supervision, caregiver training, and caregiver selection are largely unexplored. Research is needed on those criteria which enhance or diminish the effectiveness of this living option for frail elderly.

Characteristics of Foster Care for Elderly

The literature does not clearly indicate how foster care is chosen as a living option for elderly. Close examination of several descriptive studies suggests that the functional ability of the elderly individual is a factor in selection. For example, some programs use this option for elderly in need of minimal assistance in activities of daily living (Bradshaw et al., 1976; Miller, 1977). Wohlford (1968) elaborates by stating that foster care is for those who do not need nursing care. In contrast, other foster care programs are designed to serve only those elderly who have severe functional limitations and are in need of care

at an intermediate nursing level (Oktaay & Volland, 1981; Vandivort et al., 1984).

Prior to foster care placement, elderly come from a myriad of other living arrangements. These include (a) mental institutions, (b) nursing homes, (c) acute care hospitals, (d) other residential care facilities, and (e) their own homes.

Selection of a foster home for a given elderly individual is usually based on the judgment of the caseworker (Sherman & Newman, 1979). In a study of foster caregivers ($n = 100$), Sherman and Newman (1979) found that only 25% of caregivers participated in the selection of their resident. Additionally, only 29% had a clear picture of resident characteristics upon placement. In some instances, the potential resident and foster family meet together before a decision regarding placement is made (Vandivort et al., 1984). Many foster homes contain a "mix" of residents. For example, there is often a range of age groups and mental and physical disabilities among those living in a particular foster home (Bradshaw et al., 1976; Newman & Sherman, 1979a, 1979b).

Several researchers have indicated that individuals with certain behavioral disorders are not appropriate for foster care placement. These disorders include (a) hostility, (b) extreme aggressiveness, (c) a tendency toward violence, (d) excessively demanding behavior, (e) chronic wandering, and (f) addiction to

drugs and alcohol (Bradshaw et al., 1976; Miller, 1977; Oktay & Volland, 1981; Vandivort et al., 1984).

The services provided to elderly living in foster homes are not well-delineated in the literature. According to Sherman and Newman (1979), elderly living in foster homes receive social, psychological, and physical support services. However, they do not discuss the specific nature of these services. According to other literature, physical services range from minor assistance in activities of daily living to "skilled" nursing care such as bowel and bladder training (Bradshaw et al., 1976; Vandivort et al., 1984; Wohlford, 1968). Miller (1977) has indicated that these residents also receive 24-hour surveillance. The specific type of psychological and social support services received by elderly in foster care homes have not been discussed by researchers.

There is a dearth of information about the demographic and health characteristics of elderly living in foster homes in the United States. Bradshaw et al., (1976) conducted a descriptive survey of all licensed foster homes in Louisville, Kentucky, to obtain baseline data on the characteristics of foster home residents. The sample was age-integrated with 70% of the 422 residents over 65 years of age. The total sample represented a majority of women (68.2%) with a median age of 73. The median age for men was 67. The residents were primarily Caucasian (64%). Most were supported by social security and SSI or some other type

of public assistance (75%). The researchers described the sample as largely "self-sufficient" (p. 426). However, 11% were bedbound and 7% incontinent. All residents had some degree of mental and physical impairment. Those residents under 65 years of age were for the most part either mentally retarded or formerly hospitalized mental patients. Specific data on subjects' health characteristics and mental or functional impairments was not given.

Vandivort et al. (1984) described the demographic and functional characteristics of 93 elderly residents placed in foster homes under the auspices of a hospital social work department in Hawaii. The program was designed to serve elderly who would have otherwise been placed in a nursing home at the intermediate nursing level of care. Residents ranged in age from 50 to 95 with an average age of 76. Sixty percent were female. Forty percent of the residents were Caucasian (40%) with the remainder primarily Filipino, Japanese, and Chinese. At the time of placement into foster homes, 40% were incontinent of bowel and bladder, 62% required a device and assistance to ambulate, 83% needed supervision of medication, and 38% were disoriented to person, place, and time. In addition, residents had multiple medical conditions. The nature of these conditions was not specified.

As part of a larger study, Newman and Sherman (1979a) assessed demographic but not health characteristics of 232 elderly residents living in 100 foster homes in New York State. The

majority of residents were older (average age 75), female (75%) and either single or widowed (83%). The majority had held unskilled or semiskilled jobs.

Although these three studies provide some data regarding the characteristics of elderly in a few select programs of foster care, one cannot conclude with any confidence that they represent the total population of elderly living in foster homes. Further research is needed to adequately describe this population.

Foster Caregiving

Relatively little research exists about the phenomena of foster caregiving. There is a small body of descriptive and survey literature which is most easily divided into four categories: (a) characteristics of foster caregivers, (b) motivations for caregiving, (c) functions of the caregiving role, and (d) problems encountered by foster caregivers. These will be discussed individually.

Characteristics of Foster Caregivers

Studies indicate that foster caregiving is done primarily by women (Bradshaw et al., 1976; Miller, 1977; Newman & Sherman, 1979a). Bradshaw et al. (1976) found that 61% of foster caregivers were over 50 years old. Newman and Sherman (1979a) found the median age to be 56. In regards to marital status, approximately 50% were married, and 50% were either widowed, divorced, or single (Bradshaw et al., 1976; Newman & Sherman, 1979a). Bradshaw

et al. (1976) found that only 21% of caregivers had completed high school, and 5.6% had post high school education. In contrast, Newman and Sherman (1979a) found that 22% of those sampled were college graduates with 63% having between 7 and 12 years of schooling. Miller (1977) indicates that the majority of caregivers in his sample had completed high school. One finding of interest is that many caregivers have experience in the health care field (Bradshaw et al., 1976; Newman & Sherman, 1979a; Wohlford, 1968). However, Bradshaw et al. (1976) found that foster caregiving was the only employment for 85% of those surveyed. These results are similar to those of Newman and Sherman (1979a) who found that only 11% of caregivers were employed outside the home.

Several researchers have described personality characteristics that are amenable to foster caregiving. These include (a) flexibility, (b) adaptability, (c) kindness, (d) warmth, and (e) an ability to understand and cope with behavioral problems (Fenske & Roecker, 1971; Handy, 1968; Miller, 1977).

In summary, although a few descriptive studies have identified some characteristics of foster caregivers, the representativeness of these characteristics to all foster caregivers is not known. In addition, important information about health status, economic status, and the sheer number of people involved in foster caregiving is missing.

Motivations for Caregiving

Three investigators have focused on the motivations of foster caregivers. Fenske and Roecker (1971) found that the majority of caregivers were motivated by the need to earn money. Other motivations, in rank order, were: (a) the desire to help others, (b) the need for companionship, and (c) the desire to keep busy (Fenske & Roecker, 1971). Bradshaw et al. (1976), in rank order, identified: (a) financial stress, (b) already caring for incapacitated relatives at home, (c) knowing elderly who needed care, (d) interest in elderly, and (e) companionship. Oktay and Volland (1981) found caregivers motivated by their own sense of loneliness, strong religious convictions, a desire to help others, a desire to keep elderly out of nursing homes, and a need to earn money. Specific data on the frequency that these factors occurred in the population of foster caregivers was not given.

Functions of the Caregiving Role

There is no literature which specifically analyzes the functions of the caregiving role. Close inspection of the literature reveals that caregivers provide (a) shelter, (b) nutrition, (c) assistance in activities of daily living, and (d) supervision. Behavioral problems are often managed (Hardy, 1968; McCoin, 1983; Miller, 1977). In some instances, caregivers may provide a family atmosphere and social and recreational activities (McCoin, 1983; Newman & Sherman, 1977; Sherman & Snider, 1983). Exploratory

research is needed to analyze qualitatively the functions of the caregiving role and the impact of these functions on the lives of foster caregivers.

Problems Encountered by Foster Caregivers

Newman and Sherman (1977) conducted a survey of 100 caregivers in New York State to determine their perceptions of the foster care program. The lack of a formal selection process for placing elderly into foster care homes was problematic for caregivers and frequently resulted in mismatches between resident and caregiver. Additionally, a majority of caregivers felt that they did not receive the training needed to care for frail elderly before and during the client's stay. Lack of needed caregiver training in areas such as nursing care, medication management, nutrition, and home management has been cited by other researchers (Bradshaw, 1976; Handy, 1968; Sherman & Newman, 1979).

Bradshaw et al. (1976) in a survey of 183 foster caregivers, identified common problems faced by caregivers. These were: (a) managing problematic behaviors such as confusion, wandering, quarreling, and refusal to help; (b) meeting financial obligations given the low reimbursement for foster caregiving; (c) negotiating with the relatives of residents; (d) dealing with licensure and regulatory issues; and (e) obtaining services such as transportation, sitters, physician services, clinic appointments, getting residents admitted to the hospital, or reaching the social worker.

Other researchers have identified resident behaviors such as confusion, interpersonal difficulties, withdrawal, and refusal to eat, take baths, or drink as problematic for caregivers (Miller, 1977; Oktay & Volland, 1981; Sherman & Newman, 1977).

Miller (1977), in a descriptive analysis of foster care programs in Illinois, identified the confinement felt by those caring for residents with psychiatric problems. Confinement resulted from 24-hour surveillance of the resident's activities. Caregivers were not able to leave their homes without hiring and paying for a replacement. These replacements were often difficult to find.

In conclusion, foster caregivers are confronted with a variety of problems during the caregiving process. To date the impact of caregiving on the psychological, sociological, and physiological well-being of the caregiver has not been explored. More research is needed to explore these relationships and to plan interventions to reduce or relieve these problems.

Summary

The literature related to foster caregiving for frail elderly has been reviewed under the following headings: (a) concept of foster care (relevant historical, theoretical, political, and clinical issues); (b) characteristics of elderly living in foster homes; and (c) foster caregiving. A majority of the studies

reviewed used descriptive or survey designs. Many of these studies have been done by the same researchers in a limited geographical area of the United States. Thus, the amount and depth of knowledge related to foster caregiving is limited. This study will seek to fill one of the gaps in the literature by analyzing in-depth the phenomenon of foster caregiving.

Purpose

The purpose of this study will be to explore the phenomenon of foster caregiving to frail elderly. Specifically, the data will be analyzed to develop a conceptual framework addressing the following:

1. The strategies used by caregivers to handle the problems encountered in foster caregiving..
2. The consequences to foster caregivers of caring for frail elderly.

Research Questions

Two questions evolved from the analysis of the data:

1. What strategies are used by foster caregivers during the caregiving process?
2. What are the consequences to foster caregivers of caring for frail elderly?

CHAPTER II

METHODOLOGY

This exploratory study of foster caregiving used in-depth interviews and participant observation with a sample of nine foster caregivers and nine older persons who resided in foster homes. The following section describes the sample for the larger project and the sample, design, methods, and analysis for this study.

Sample and Setting

Subjects for this study represent a subsample of those subjects participating in a larger study by Archbold and Hoeffler (1981) on the use of institutional and community-based services by frail elderly in four rural counties in a Northwest state. The subjects in the study by Archbold and Hoeffler included both impaired older persons and their primary support person or family member. The sample was accessed through the impaired older person meeting the following sample criteria:

1. Elderly participants were 65 years or older.
2. Elderly participants were receiving Medicaid benefits.
3. Elderly participants lived in one of four placement areas: homes for the aged, nursing homes, in-own home community, or foster care.

4. Elderly participants lived in one of four rural counties in a Northwest state.

5. Elderly participants had a family member or primary support person whom the investigators could ask to participate in the study.

6. Elderly participants scored 15-31 on the Placement Information Base (PIB).

7. Both the elderly individual and family member or primary support person gave written permission for participation in the study.

Sample Selection

Overall Study

The sampling frame constituted those persons 65 years and older receiving Medicaid benefits in four rural counties in one state. A state service agency provided Archbold and Hoeffler (1981) with the names, placements, and PIB scores of eligible persons. The PIB score comprised a portion of the database used by the state agency to determine institutional or community placement for frail elderly. After receiving the names of subjects, the following procedure was followed:

1. The investigators selected the most functionally impaired group living in their own homes. These subjects had PIB scores in the 15-31 range.

2. From the groups of older persons in nursing homes, homes for the aged, and foster care, the investigators selected those whose scores on the PIB fell in the 15-31 range.

3. The investigators contacted all elderly subjects selected and ascertained their willingness to participate in the study.

4. If the elderly individual agreed to participate in the study, he/she was asked to identify a primary support person or family member who helped him/her the most.

5. The primary support person or family member was also asked to participate.

Subsample

This substudy used data from the subsample of primary support persons in the main study who are foster caregivers. In addition, some data were also used from the elderly subjects in foster homes.

Six potential foster caregivers and the elderly subjects they cared for were excluded from this study: One older person identified a friend as her primary caregiver; two had been transferred to nursing homes; one had died; and one cognitively intact elderly female refused to participate. Additionally, one foster caregiver refused to allow the investigator to interview a potential elderly subject living in her foster home stating that he was an unstable schizophrenic who might not tolerate the stress of an interview.

Sample Description

Foster Caregivers

All foster caregivers were women. The mean age for the sample was 62 years, with a range of 42-80 years (see Table 1). The majority of caregivers were either widowed, divorced, or separated (see Table 2).

Two-thirds of the caregivers had completed high school. Of these six, five had some post-high school education. However, none of the caregivers had completed college, and only two had completed a post-high school training program. One caregiver had completed training in cosmetology. Another caregiver had completed nurses aide training. One other caregiver had some training in the health care field. She had received 2 years of nurses training approximately 40 years prior to assumption of caregiving duties (see Table 3).

Table 1

Caregiver Age

Age class	Number of caregivers
40-50 years	4
51-60 years	4
61-70 years	0
71-80 years	1

Table 2

Caregiver Marital Status

Marital status	Number of caregivers
Married	2
Widowed	2
Divorced	4
Separated	1

Table 3

Caregiver Educational Level

Highest educational level attained	Number of caregivers
Grades 5-8	1
Grades 9-11	2
Completed high school	1
1-3 years college	1
Post high school business or trade school	4

Seven caregivers had chronic health and/or, weight problems. Of these seven, three reported that they had only one chronic health problem. Three other caregivers reported that they each had two chronic health problems. One caregiver reported several

chronic health problems. Only two caregivers reported that they did not have health or weight problems (see Table 4).

Data on the average yearly income of foster caregivers was not obtained. Eight of the nine caregivers were not employed outside their home. One caregiver had a part-time evening job. She was caring for one elderly resident who was cognitively impaired but who was able to manage while the caregiver was away. Both married caregivers had spouses who were not employed outside

Table 4

Caregiver Chronic Health Problems

Chronic health problem	Number of caregivers
Colitis	1
Back problems	1
Diabetes mellitus	1
Hypertension	1
Arthritis	1
Hyperthyroid	1
Asthma	1
Overweight	4
No health or weight problems	2

^aNot mutually exclusive.

the home. One of the husbands was retired; the other was a paraplegic who stated that he could only work one hour per day.

Elderly Residents

The nine elderly residents in this subsample ranged in age from 66 to 94 years with a mean age of 79 years (see Table 5). Seven were women, and two were men. Four were single, and five were widowed. All were Caucasian.

Seven of the nine elderly residents had chronic health problems (see Table 6). One elderly resident had multiple health problems. The remaining six residents had either one or two chronic health problems.

Five elderly residents had visual and/or hearing impairments. Of these five, three residents had hearing and visual impairments. Two other residents had visual impairments but no hearing impairment.

Table 5

Age of Residents

Age	Number of Residents
60-70	2
71-80	3
81-90	3
91-100	1

Five residents required assistance with ambulation. Three residents required special devices such as canes or walkers for ambulation inside and outside the house. Two other residents required one-person assistance when ambulating outside the house.

In regards to the mental status of residents, there were two categories of elderly. The first included persons with longstanding mental illness or mental retardation ($n = 4$). One elderly resident had a history of mental retardation. One was borderline mentally retarded and mentally ill. Two elderly residents had mental illness. In the second category ($n = 5$), two elderly residents were alert and oriented and able to complete the interview without difficulty. Two other residents had some mild cognitive

Table 6

Chronic Health Problems of Residents

Chronic Health Problem ^a	Number of Residents
Hypertension	1
Heart disease	5
Stroke	1
Arthritis	1
Chronic obstructive pulmonary disease	1
Back problem	1

^aNot mutually exclusive.

impairment. They were alert and able to complete the interview but were unable to remember their address, and had difficulty remembering details of some past events. One elderly resident had significantly more cognitive impairment. She had great difficulty remembering events, did not know her age, or address, and was disoriented to place and time.

Design

This study is part of a longitudinal, exploratory study by Archbold and Hoeffler (1981). Both this study and the larger study used qualitative research methods.

One goal of qualitative research is to understand how the participants in the study experience, create, and interpret their own social reality (Glaser & Strauss, 1967). To this end, Glaser (1967) suggests that the investigator enter the research field "fresh," or without specifically defined hypotheses and/or pre-conceived concepts about the study in question.

Two methods commonly used in qualitative research are unstructured interviews and participant observation. An unstructured interview allows for open-ended discussion to determine the subject's perspective on important aspects of his/her situation. Participant observation enables the researcher to enter and experience the subject's world so that it is understood from the subject's own definitional perspective. While in the field, the researcher records observations about: (a) the social setting and

what is happening in the setting, (b) strategies used by participants and the outcome of these strategies, and (c) consequences experienced by the participants (Glaser & Strauss, 1967).

The strength of qualitative research is that it permits exploration of areas not previously addressed or provides a fresh perspective in a familiar situation. Eventually, one is able to generate theory that is grounded in observable reality of the participants in the field (Glaser & Strauss, 1967).

Methods of Data Collection

This study utilized data obtained from focused, in-depth interviews with elderly residents living in foster homes and their foster caregivers (see Appendices A and B), and from participant observation. The interviews with caregivers were qualitatively analyzed for this study. The interviews with elderly residents were used for two specific purposes. First, portions of the interview with the elderly resident were used to help elaborate on the phenomenon of foster caregiving. Second, data on the elderly resident's social support system were used in the findings section as it related to the psychological support strategies used by caregivers.

Focused, In-Depth Interviews

The investigator analyzed the phenomenon of foster caregiving using data obtained from focused, in-depth interviews with foster

caregivers. The interviews provided data related to consequences of caregiving and successful strategies used by caregivers.

A description of individual sections of the caregiver interview guide follows (see Appendix A):

1. Questions 1-18 provide demographic data on the caregiver and describes the caregiver and interview setting.

2. Questions 19-20 probe the caregiver's perception of the elderly participant and activities performed by the caregiver.

3. Questions 21-24 describe the consequences (costs and benefits) of caregiving and strategies used by the caregiver.

4. Questions 25 and 41-42 identify any specific caregiver health problems and explore the subject's perception of her health.

5. Questions 26-32 assess knowledge of utilization of and attitude toward present and potential community services.

6. Questions 33-36 examine the decision-making process and feelings regarding alternative living arrangements for the caregiver's elderly resident.

7. Questions 37-39 tap the caregiver's perception of his/her financial status.

8. Questions 43-45 appraise life satisfaction and concerns.

9. Questions 46-50 assess personal and family emotional patterns during stress.

10. Questions 51-54 assess perceived social support and coping ability.

Sections of the interview guide with the elderly individual were also used in this study (see Appendix B). A description of the sections of this guide follows:

1. Questions 1-18 describe the setting and resident.
2. Questions 19-21 explore financial status.
3. Questions 22-25 and 46-47 explore physical and mental health status and the resident's perception of his/her current living situation.
4. Questions 26-28 assess activity and assistance patterns.
5. Questions 29-38 assess social supports and life satisfaction.
6. Questions 39-45 assess personal and family reactions to stress.
7. Questions 48-55 examine utilization of community resources.

The starred items on the interview guide were taken from the Older American Research and Service Center (OARS) multidimensional functional assessment and questionnaire. Items from the OARS provided a means for collecting and recording descriptive data and served as qualitative probes. The measure derived from Sanford's tolerance of disability description was also included in the interview guide. This measure served as a qualitative probe.

Participant Observation

Participant observation was used throughout the data collection process (Lofland, 1971). The investigator observed: (a) the physical environment of the homes and their immediate neighborhoods, (b) the verbal and nonverbal interactions of those people present in the homes, and (c) the functional and emotional status of elderly and their caregivers. Notes were recorded by the investigator regarding her observations and impressions during the data collection process.

Procedures

Data collection occurred between August 1981 and October 1982. The data collection procedure is described below.

The researchers sent a letter to each elderly individual identified as a potential participant. The letter described the study, advised the elderly individual that he/she had been selected as a potential candidate, and stated that he/she would be contacted by a researcher in approximately 2 weeks regarding participation in the study.

When the investigators arrived in the area, a phone call was made to the foster home to explain the study and to provide the name of the elderly individual who was a potential participant. Arrangements were made to visit the home, meet with the elderly individual, and discuss the possibility of participation in the study.

Each elderly individual agreeing to participate in the study was asked to identify a primary support person. Immediately upon completion of the interview with the elderly subject, the interviewer approached the foster caregiver identified as the primary support person and requested her participation in the study. All foster caregivers approached by the investigators agreed to participate in the study, and arrangements were made to conduct the interviews.

The interviewers met individually with each elderly person and individually with each foster caregiver to explain the study in detail, to discuss what it would involve for them, and to inform them of the potential risks and benefits of participation. The investigator answered any questions posed by the potential subjects and allowed them to read or have read to them the large-print consent form (see Appendix C). Each participant was given a copy of the consent form to keep.

The interview process involved one in-depth interview per participant and took 1 to 1 1/2 hours depending on the responses. Written notes were taken during the interview. Interviews occurred in the subjects' respective homes, and the investigator requested locations within the homes which would ensure privacy.

Immediately following each in-depth interview, the interviewer found a private place to document her observations and impressions of the interview experience and setting.

Data Analysis

Three types of data were collected: (a) unstructured interview data, (b) structured interview data, and (c) observations of the social setting and behavior.

The data collected in unstructured interviews and the observations of social setting and behavior were qualitatively analyzed using the process of constant comparative analysis (Glaser & Strauss, 1967). After recording and transcribing the data, a sentence-by-sentence analysis of the raw data was performed. From this analysis, data were categorized by an inductive process into higher levels of abstraction called concepts. For example, in this study caregivers made comments such as "I'm stuck at home" and "I'm always on call." These bits of raw data were categorized, and the concept of confinement emerged. Confinement then became part of a broader category referred to as "costs." Concepts were then linked to other variables and concepts to explain the social events and actions under investigation.

When doing qualitative research, it is necessary to ensure that concepts are accurate representations of the subject's perspective. This was done in three ways. First, samples of raw data were reviewed by experts, who consisted of members of the thesis committee, to verify the accuracy of the formed concepts. Second, raw data were tabulated by frequency to ensure that the formed concepts were representative of a majority of subjects.

Finally, this frequency information was again compared to the descriptive data. The structured interview data obtained from the OARS was used to describe the sample.

CHAPTER III

FINDINGS

This chapter focuses on the results of the analysis of the interview and observational data. Specifically, it includes an analysis of the strategies used by foster caregivers and the consequences of foster caregiving. The conceptual model is presented in Figure 1.

Strategies

Strategies to manage the complex problems, demands, and concerns associated with caregiving were described by caregivers. Strategies fell into two major categories: (a) caregiving strategies to manage the needs and problems of residents, and (b) strategies used by caregivers to cope with the effects of caregiving on their own lives.

Caregiving Strategies to Manage the Needs and Problems of Residents

Caregiving strategies aimed at managing the needs and problems of residents fell into four categories. These included strategies for meeting the resident's need for social support, psychological support, and physical support and well-being. In addition, strategies were devised for managing the problematic behaviors of residents.

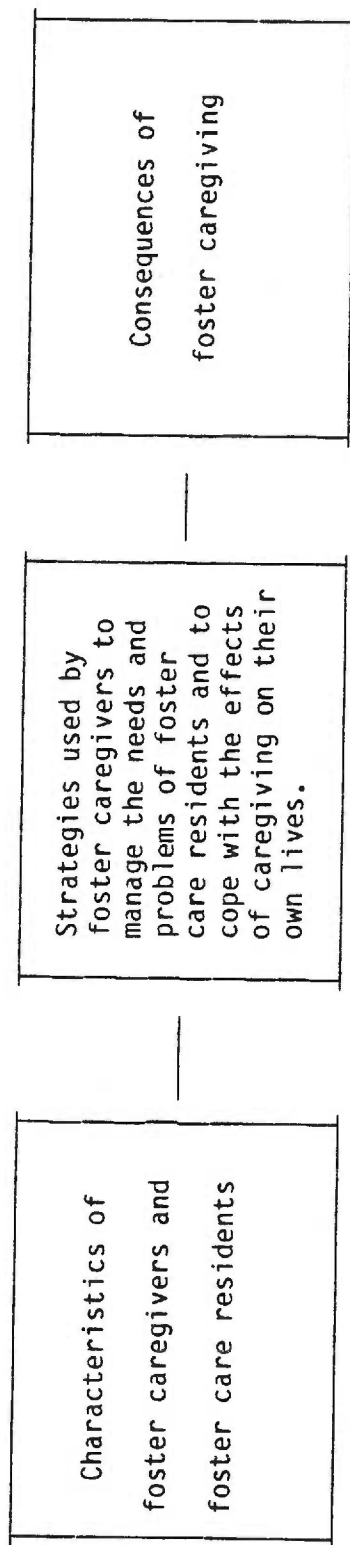


Figure 1. Conceptual model.

Social Support

Caregivers expressed awareness and concern regarding the social needs of their impaired elderly residents. Facilitating contact with relatives and the larger community and providing activities for the resident's enjoyment were two methods by which caregivers tried to meet these needs. In addition, caregivers gave tangible aid as a means of providing social support to their impaired elderly residents.

Facilitating contact with relatives and the larger community.

Caregivers facilitated contact with relatives and the larger community in a variety of ways. One caregiver said of her elderly resident's grandson and family: "I prod him to call . . . [they] have a boat and go on weekends. Both work all week." Another caregiver shared her efforts to reunite her elderly resident with her sister. The resident had been disowned because of her alcoholism. After the resident became settled in the foster home and no longer drank, the caregiver phoned the sister long distance to tell her how well the resident was doing. Caregivers also facilitated contact with relatives by assisting residents with letter writing. A major barrier to the use of this strategy was that the majority of elderly either did not have close living relatives or had relatives who had limited interest in them because of their past behavioral problems.

Four caregivers were instrumental in arranging contacts with the larger community. One caregiver arranged for an in-home movie presentation by members of the local fire department. Two caregivers arranged for their resident's participation in the Senior Citizens Club. Finally, one caregiver was in the process of arranging for a church volunteer to take her resident shopping. Caregivers indicated that attempts to facilitate contact between elderly residents and the larger community were limited by (a) mobility and health problems of residents, (b) lack of available transportation to community affairs, (c) inadequate community resources for dependent elderly with functional and sometimes cognitive impairments, (d) disinterest on the part of elderly in attending outside community activities, and (e) state policies which do not allow the caregiver to leave other residents without adult supervision. A woman who had been foster caregiving for elderly persons for 8 years stated, "Most elderly don't want to leave home . . . have to fight tooth and nail to get them to go to community activities so need more volunteers to go into people's homes." Another caregiver commented that her elderly resident had been "turned down" at Senior Citizens because of her cognitive impairments. Interestingly, the only caregiver who indicated that there were "lots of services" was caring for mentally retarded residents, one of whom was elderly. These residents had transportation provided to a daily activities center and had the option of

participating in other planned activities such as camping. They also did not have functional limitations precluding participation in outside activities.

Providing activities. The majority of caregivers provided outside activities for their resident's enjoyment. For the most part, however, these were infrequent and usually involved going for rides in the car or out to dinner. One caregiver took her elderly resident to church weekly, to visit friends weekly, and out to dinner occasionally. This caregiver enabled her resident to participate most frequently in outside activities. Interestingly, she was caring for only two residents, one of whom was her sister. Her residents' physical impairments were minimal. Another caregiver took her mentally retarded residents swimming (during summer months) and shopping. Data analysis revealed that caregivers who were caring for four or five residents with primarily functional impairments, did not use this strategy.

Giving tangible aid. Several caregivers used their own personal funds to purchase needed items for their impaired elderly residents. One caregiver purchased respiratory inhalers to manage her resident's chronic lung disease. The resident, who received only \$25 per month from welfare, did not have enough money to purchase the needed number of inhalers. Without the use of these inhalers, hospitalizations were more frequent. Another caregiver paid to have her elderly resident's teeth relined because he was

unable to chew food. Finally, one caregiver purchased clothes for her residents, stating that the \$25 per month received by her residents from welfare did not "go very far."

Psychological Support

All caregivers engaged in strategies to promote the psychological well-being of their residents. These strategies involved activities directed toward validating the resident's sense of self.

Older residents were encouraged to participate in household activities in order to promote a sense of usefulness and helpfulness. One caregiver stated that her resident, who was unhappy when initially placed into her foster home, just "wanted to help." "I let her do dishes. Then she was happy." In some cases, these activities occurred despite inconvenience to the caregiver. "I let them make their own sandwiches. It makes a mess, but pleases them."

Another strategy for validating the elderly resident's sense of self was promoting independence within their physical and mental capabilities. "I give them the wash rag. [This] gives them greater independence." "I let her pick out her own clothes . . . that's the only decision she can make." Methods by the caregiver to promote independence were preceded by an assessment of the elderly resident's capabilities and needs. This allowed for optimum independence.

There were other caregiving behaviors that facilitated psychological support of elderly residents. One caregiver indicated her strategy for helping her incontinent resident. "She tries to clean and I go in after her because I don't want to embarrass her." She offers the following advice to others caring for elderly: "Don't embarrass, do not make a big point of something they cannot help." Praising the efforts of elderly in activities of daily living was another strategy frequently used by caregivers.

Caregivers served as the "primary interactant" for their elderly residents. This role included participation in "everyday" conversation and listening to the resident's concerns, feelings, and problems. One caregiver states of her recent divorce, "I just couldn't handle our emotional problem and theirs [residents] too."

As a consequence of these behaviors, the caregiver emerged as the "significant other" to the elderly individual. One elderly resident referred to the caregiver as "my girl" and stated he loved her. In the majority of cases, the caregiver was the person that the elderly individual trusted and confided in. For example, another elderly resident stated that she felt "open" and able to "share her feelings" with the caregiver. The majority of these elderly residents did not have consistent contact with either friends or family. "There's no one else," stated one elderly resident. Thus, the caregiver became important in "validating the sense of self" for her elderly resident.

Physical Support and Well-Being

Caregivers managed their elderly residents' need for physical support and well-being with strategies that fell into two categories: direct care and indirect care. Direct care provision involved those activities that required "hands-on" or physical care. Indirect care involved caregiving behaviors that were more abstract and intangible. Although qualitatively different, both caregiving modes involved great time and energy.

Data analysis revealed that in some cases, the impairment of the elderly individual affected which physical support activities were used. Therefore, findings, when applicable, will be discussed in relationship to the resident's impairment. Elderly will be referred to as either (a) physically impaired, or (b) mentally impaired. Those with mental impairments ($n = 4$) had been diagnosed as either mentally ill or mentally retarded. Those who were mentally ill exhibited problems such as aggressiveness, wandering, and paranoid behavior. These residents did not have physical impairments. Those in the physically impaired group ($n = 5$) had mobility, visual, and hearing deficits. They also had more chronic health problems than the mentally impaired group. In addition, there was evidence of mild cognitive impairment in two residents and moderate cognitive impairment in one resident. Two residents were alert and oriented.

Providing direct care. Foster caregivers were regularly involved in assisting physically impaired elderly with such activities as bathing, dressing, shaving, and hair and nail care. Mentally impaired residents were physically able to perform these activities. Specifically, assistance was provided by: (a) helping into and out of the tub; (b) washing certain body parts; (c) turning on and off the water; (d) drying and styling hair; (e) cutting and filing nails; and (f) helping to pick out, put on, and take off clothes. Mobility assistance was also provided by caregivers. This most typically included help with (a) ambulating outside the house, (b) getting into and out of cars, and (c) getting on and off the toilet or into and out of bed.

Regardless of the physical or mental impairments of their elderly residents, all caregivers regularly performed the instrumental activities of daily living. This included personal shopping for self and residents, grocery shopping, housekeeping, home maintenance, and meal preparation. Meals were prepared and served three times per day. Usually a snack was offered. Consideration was given in meal preparation to resident (a) likes and dislikes, (b) food tolerances, and (c) dentition problems.

The majority of elderly took medications, and in all but one instance these were administered by the caregiver. The exception was an elderly resident who took her own medications after they were counted out by her daughter on monthly visits to the foster

home. Medications were typically given to control chronic health problems such as congestive heart failure, and high blood pressure. One cognitively impaired resident received a "psychiatric pill." In addition to administering medications, all caregivers provided transportation to medical care as needed.

Providing indirect care. Indirect care provision involved decision-making and supervision and monitoring. In addition, the assessment and use of community resources will be discussed.

The caregiver's assistance with decision-making was an important method of managing the physical health and well-being of impaired elderly. All but one elderly resident needed help with "everyday" decisions. The resident who did not need help from her caregiver was physically impaired with no signs of cognitive impairment. Help with "everyday" decisions encompassed the frequency and timing of activities of daily living. For those residents with mental impairments, total assistance was needed. "I tell her when to bathe, what to wear, when to change her underwear, everything." Another caregiver relates how her resident needs help with very simple decisions such as, "Should I turn out the lights?" Physically impaired residents were often independent in some simple decisions. For example, they could often decide what clothes to wear.

In a broader sense, caregivers were responsible for making important decisions regarding health condition and whether or not

to seek medical care. The majority of all residents had chronic diseases. In one case in particular, the resident's health status was very precarious, and she had been hospitalized many times in the past. The complex decision-making process encompassing health condition involved making an assessment of the elderly resident's condition and planning a method for assistance. Two caregivers had limited professional support for their decisions. The remainder had none. Usually there was little or no support from the resident's family. Thus, caregivers were forced into a position of decision-making with little or no support. In addition, they had few skills and limited educational background for making decisions regarding health status.

All residents needed supervision and monitoring to ensure physical support and well-being. Cognitively impaired residents were physically able to perform activities of daily living. However, they needed supervision and monitoring to complete activities in a safe and timely manner. Foster caregivers stressed the necessity of following through with activities such as bathing, dressing, and eating. "I tell her what to do and then follow through to see if she did it." One caregiver commented that instead of bathing, her resident "would stir the toilet water with her hand." Some of these residents needed constant monitoring and supervision to prevent injury. One was not safe around stoves.

Another was not "street-wise." She could not read signs and was not aware of traffic. Another resident wandered.

Physically impaired elderly needed supervision and monitoring to prevent physical injury. Due to their mobility and visual deficits, they needed a caregiver to be available to assist with activities of daily living. Caregivers also indicated that they made a special effort to monitor the health status of this group. "I make him go outside once and awhile for his vitamin D." Two caregivers made special efforts to prevent fatigue in their elderly residents. One caregiver monitored her resident's personal spending money to be certain she had enough to buy needed medications. Finally, one caregiver indicated that she made sure her resident drank his liquid nutritional supplement.

Caregivers assessed and used community resources to meet the physical needs of their elderly residents. All caregivers were knowledgeable regarding available community resources. "I've learned a lot about community services and who to call and that it takes a long time." In several instances, caregivers had negotiated with community agencies in an attempt to access needed services for their residents. One caregiver described the long, complicated process of trying to get Welfare to "approve" payment for the brand of respiratory inhaler that her elderly resident needed. The resident did not have sufficient personal funds to pay for the needed number of inhalers. Consequently, hospital

admissions were more frequent. Another caregiver was instrumental in getting her resident approved for a hearing aid.

Caregivers used community assistance provided by physicians and home health agencies. The nursing service provided by home health agencies was described by caregivers as "limited." Although none of the elderly in this sample currently had nursing services, a few caregivers had used these in the past for "skilled" procedures such as foley catheter insertions. In addition, two caregivers mentioned informal support services that were available to them. One caregiver knew a doctor whom she could call to her home in an emergency. Another caregiver mentioned that she had a "friend" who could do a foley catheter change if nurses from the home health agency didn't come.

Another caregiver made the following comment regarding Medicare. This occurred after attempting to get her resident's teeth relined. His dental problems resulted in an inability to chew and required that the caregiver puree his foods. "[We] need better medical--not enough is covered and what is [covered] is geared toward acute care."

Managing Problematic Behaviors

Strategies were devised by caregivers to manage the problematic behaviors of elderly. These strategies involved limit setting and harmonizing.

Limit setting. Two caregivers used limit setting as a method to control alcohol intake in their cognitively impaired residents. One caregiver limited her resident to four beers per night. "I do not allow her to get drunk . . . If she gets drunk, then she must go . . . She knows I mean what I say." This resident "becomes aggressive and strips" when drunk. An episode of drunken behavior would necessitate new living arrangements for the resident. Another caregiver limited her "new" alcoholic residents to one drink per night for 3 weeks and then withdrew alcohol completely. She also recruited the owner of the liquor store to stop selling alcohol to her residents. Several caregivers used limit setting to deal with uncooperative resident's behaviors such as refusals to change clothes and bathe. "If she won't do it, I say 'tomorrow you must do this' and then I tell her (the next day), 'It's time to change your underwear.' I give her leeway but she knows I'll only tolerate so much."

Harmonizing. The caregiver was a vital link in maintaining harmony within the home. This strategy encompassed two caregiving behaviors: peacemaking and conflict avoidance. One caregiver defined her role as that of "peacemaker." Conflicts erupted frequently among her residents, and she found it necessary to settle these disputes by acting as the "peacemaker."

Many caregivers sought to avoid conflicts between themselves and the residents. This required that caregivers be flexible and

adaptable. The following caregiver comments illustrate this point: "Let them basically do their own thing because there's no use matching will against will." "One must never force . . . can't make inferences . . . or she'll get angry." "Ask rather than tell, indicating it would be of help to you." One caregiver comments that she had to "accept her the way she [resident] is."

One caregiver was unable to develop successful strategies to manage the problematic drinking, smoking, and sexual behaviors of her impaired resident. She identified this overtaxing of her personal resources as a cost of foster caregiving.

Strategies Used by Caregivers to Cope

With the Effects of Caregiving on Their Own Lives

The day-to-day process of caregiving to impaired elderly had significant effects on the lives of caregivers. Strategies were devised by foster caregivers to help themselves cope with a multitude of demands, problems, and concerns. The strategies described by caregivers involved: control over resident selection, attribution of meaning to the caregiving experience, insulation, and use of outside assistance.

Control Over Resident Selection

Data analysis revealed that in the majority of cases, a particular resident was placed into a foster home based on the judgment of the caseworker. If family were available, they participated in the decision with the caseworker. Although caregivers

usually did not have control over the selection of a particular elderly person into their home, they were able to request certain "types" of residents. This option was an important strategy to cope with reactions to caregiving.

Two caregivers found caring for dependent elderly too confining. One caregiver had dependent elderly residents for 8 years and then switched to mentally ill/mentally retarded after her children left home. "You have to be home with the elderly a lot . . . okay while I had to be home with my kids. But it's too confining . . . they [mentally ill/mentally retarded] go to a program during the day so you have more time, can be home less with them." The other caregiver began initial caregiving duties with dependent elderly. After a short time she switched to mentally retarded. "[I] tried handicapped and loved it."

Two other caregivers found certain resident behaviors too problematic to live with. "in the beginning I did not think I could do it. In [the] beginning I started with men. [I] just didn't get along with them. . . . [I] decided they were too dirty (smoking and drinking). . . . [I] switched to female. [I] get along great." This caregiver stressed how important physical cleanliness was to her. The other caregiver "went to the state" and requested residents that would "otherwise be in a state hospital." However, many of these residents were rejected after they came to live with her. Although criteria for rejection was not

clear, it seemed to the researcher that smokers, wanderers, those who were difficult to get along with or those who engaged in sexual behaviors would not last in her home. The caregiver did state that "I couldn't keep any of them I didn't love."

One caregiver felt distressed over the low reimbursement for foster caregiving and her subsequent financial problems. She states her strategy to cope with this problem will be to select only "private" residents in the future. In this situation, the caregiver has leeway to establish her own reimbursement rate, which would be greater than that provided for state-supported residents.

In contrast, one caregiver's inability to control resident selection was very problematic to her. She received the "worst" cases from Welfare. The following example illustrates this situation.

The resident was staying at a "dumpy" motel where he was a "wino" and three pack per day smoker. Welfare notified the caregiver to go to the motel and pick him up. When the caregiver arrived, there were other sick gentlemen in the room. The resident was described by the caregiver as "real skinny" and "undernourished." This situation was exacerbated by the fact that Welfare did not provide the caregiver with "enough" information about the resident.

Further, this caregiver indicated her ambivalence about continuing in the caregiving role.

Attribution of Meaning to the Caregiving Experience

A sense of meaning in the caregiving experience provided caregivers with a method to cope with the demands of their role. Comments such as "[I] feel like I'm doing something [valuable]" were expressed by several caregivers. It was obvious that the caregiving role made them feel worthwhile. One of these caregivers expressed the meaning that the caregiving experience had on the lives of her children. "My kids have learned a lot from it too . . . to give a bit, not be so selfish. To look at how fortunate we are." Two other caregivers found religious meaning in the experience. Their faith and trust in God helped them cope with the caregiving experience.

Insulation

Strategies to provide the foster caregivers with insulation are designed to protect him/her from a variety of negative stimuli. Specific resident behaviors such as incessant chattering and repetitive story-telling resulted in the caregiver "insulating" herself from the resident. One particularly articulate caregiver elaborated on this phenomena by stating that if she were "sick or tired" it became more difficult to "insulate" herself. Consequently, the resident's behavior became more irritating. Several caregivers coped with the daily demands of caregiving by "tuning

out" for a prescribed portion of time each day. Taking naps and watching favorite television programs were favorite methods to accomplish this. Segregated living space for elderly residents and their caregiver provided another means of detachment from the demands of caregiving.

Use of Outside Assistance

Caregivers used outside assistance to ease the effects of caregiving on their own lives. In the majority of cases, respite from caregiving duties was provided by friends and relatives. Typically, this relief was for short periods of time while the caregiver did errands or shopping. One caregiver exchanged informal respite services with another caregiver. In this case, the residents were mentally retarded and without functional disabilities. Thus, they could be easily transferred from one location to another. The caregiver did point out, however, that she would be caring for her four residents in addition to another four or five residents.

In order to cope with the demands of caregiving, three caregivers paid for services from personal funds. One caregiver occasionally hired a "sitter" so that she could "get away" for an evening. This was an affordable option because her house and property were paid for--a gift from her deceased father. Another caregiver hired a sitter "periodically" for vacations. Her children paid for the vacations. This situation was unique among

those sampled because the majority of caregivers did not have children to assist them financially. Finally, a caregiver who was very stressed with the demands of caregiving, paid a small monthly sum for help with housekeeping. She had received housekeeping help from her daughter until the daughter became ill. However, the majority of caregivers were not in a financial position to pay for additional services from personal funds.

A few caregivers were able to use outside community programs to help them cope with the demands of caregiving. Two caregivers had mentally ill or mentally retarded residents who were physically able to attend daily activity centers. This helped relieve the caregiver's feelings of confinement. In addition, one of these residents exhibited less paranoid behavior and fewer hallucinations with regular attendance at the activity center. A third caregiver, whose very cognitively impaired resident attended Senior Citizens for a short time daily, described it as her "saving grace." Further, she did not feel she could continue in the caregiving role without this resource. The use of community assistance for relief of problems associated with caregiving was not available to all caregivers. Limitations to the use of community resources for impaired elderly have been discussed previously.

Summary

Caregivers described specific strategies for managing the social, psychological, and physical needs of their impaired elderly residents. These were strategies for (a) facilitating contact with relatives and the larger community, (b) providing activities for the resident's enjoyment, (c) giving tangible aid, (d) validating the resident's sense of self, and (e) providing direct and indirect care activities. In addition, caregivers described strategies aimed at limit setting and harmonizing to manage the problematic behaviors of residents.

Caregivers described a range of strategies to cope with the demands and problems of caregiving on their own lives. Of prime importance was the caregiver's ability to control resident selection. Other strategies used by caregivers involved (a) attribution of a positive meaning to the caregiving experience, (b) insulation, and (c) use of outside assistance.

Consequences of Foster Caregiving

This section will address the consequences of foster caregiving. The data analyzed include: (a) identification of costs and benefits as cited by caregivers (see Table 7), and (b) consequences of caregiving as perceived by caregivers and observed by the researchers. A natural consequence of any social interaction is an attempt by participations to maximize benefits and minimize

Table 7

Frequencies of Costs and Benefits of Caregiving as Cited by Foster Caregivers

Cost ^a	Frequency	Benefit ^a	Frequency
Confinement	6	Satisfaction with caregiving	6
Lack of privacy	3	Reimbursement for caregiving	5
Inadequate reimbursement	2	Enjoyment of people in general	2
Overtaxing of caregiver's personal resources because of problematic resident behaviors and difficult cases	2	Ability to stay home	2
		"Added strength" to the caregiver's life	1
Diminishing interpersonal relationships with friends, relatives	1	"Built-in" family	1
No costs identified	2	Keeping busy	1

^aNot mutually exclusive.

costs. A discussion of the cost/benefit ratio as perceived by caregivers will conclude this section.

Benefits of Caregiving

All caregivers were able to identify benefits of caregiving. The predominantly mentioned benefit was a sense of satisfaction with the caregiving role. Comments such as "I just enjoy it," "I feel like I'm doing a good service," and "[I] have satisfaction that she is well groomed" were common among caregivers. One caregiver found satisfaction in providing a secure and trusting relationship to a "pathetic thing who nobody else wants." Several caregivers mentioned the satisfaction of being able to keep elderly residents out of nursing homes and state hospitals, which one caregiver described as "bedlam" and not fit for "humans." When asked about the benefits of caregiving, a minority did not specifically identify a sense of satisfaction with the caregiving role. However, response to other questions clearly indicated that all caregivers found satisfaction in this role. For example, one caregiver, when describing her history as a caregiver, commented, "I just enjoy it."

The majority of caregivers identified the money received from caregiving as a benefit to them. Comments such as, "[Foster care was] so helpful to me financially . . . got us [family] off welfare" or "I needed to make a living after my husband died" were typical of caregivers. One caregiver became separated from her

husband after 20 years of marriage and needed to "earn a living." Questioning regarding the impact of caregiving on financial status revealed that, with the exception of one caregiver, all were dependent on caregiving to meet living expenses. The majority of these caregivers were middle-aged women who were either divorced, separated, or widowed. Only one had a specifically marketable job skill other than caregiving. One married caregiver had a handicapped husband who could work only "one hour a day." The only other married caregiver was not solely dependent on caregiving to meet everyday expenses. However, the money derived from caregiving helped to eliminate the financial "squeeze" that she and her husband felt as a retired couple living on a fixed income. Interestingly, this woman's entry into caregiving was exceptional. She did not actively seek caregiving duties but rather "discovered" an elderly gentleman in need of a home. She cared for him for 3 years without any financial compensation. Contact with a social worker "clued" her in to her eligibility for compensation as a foster caregiver. Several caregivers, when asked how well the money derived from caregiving took care of their needs, responded to the effect that "my needs are simple." One caregiver indicated that in 8 years of caregiving her only large purchase had been a bedroom set.

One third of the caregivers expressed their enjoyment of people as a benefit of caregiving. Two caregivers told the re-

searcher about past work experiences in factories and canneries. These experiences were not as gratifying because they did not involve working directly with people. Another caregiver found working with older people particularly enjoyable. "I've always been . . . fascinated by them; their past experience." Two caregivers identified being able to stay at home as a benefit of caregiving. One caregiver stated that there was no "clock punching" and "greater relaxation" at home. Caregiving was quite a change for this woman who had been a professional cosmetologist who became ill; she related her illness to stress. Finally, other benefits mentioned by a small minority of caregivers were: (a) having someone in the house, (b) providing the caregiver with a "family", (c) keeping the caregiver busy, and (d) adding strength to the caregiver's life. One caregiver indicated that the "added strength" she received from caregiving improved her mental health.

Costs of Caregiving

Seven of the nine caregivers identified costs of foster caregiving. The most salient and severe cost identified by caregivers was confinement. Comments reflecting feelings of being "tied down," "always on call," "stuck at home," and saddled with "around the clock work" were common among caregivers. Although three caregivers did not specifically identify confinement as a cost of caregiving, it could be inferred from analysis of the data in two

of three cases. The exception was a caregiver who, in response to questioning on the costs of caregiving, spontaneously replied that when she felt "tied down" she would take a vacation. Two factors made this possible. She had children who were willing to pay for these vacations and neighbors who were willing to provide respite. Thus, the freedom to "get away" from caregiving as desired relieved feelings of confinement and resulted in a "personally satisfying" caregiving experience. Further, this caregiver was one who did not identify any costs to caregiving.

Specific questions about the impacts of caregiving on leisure and social activities yielded interesting information. In all but one situation, these activities had either been greatly limited or dropped completely. Vacations, getaways to the coast and mountains, hobbies, and organized social activities were among those affected. "I dropped all my lodges (Rebecca, Female Relief Corp., and Daughters of Union Veterans). . . . [I] gave up oil painting." Another caregiver stated that she "used to get to church, but don't anymore." She also gave up involvement in church activities. Visits with family and friends were less frequent. In addition, caregiving activities left little time for oneself on a daily basis. One caregiver stated that she had 1 hour for herself during the day and then a little time after 9:00 in the evening. Another caregiver commented that in the past 5 years of caregiving

she had taken two 3-day vacations and one 2-week vacation. Several caregivers spontaneously mentioned the need for a vacation. One caregiver indicated to the researcher her need for more relaxation and specifically for a vacation. Another caregiver indicated her ambivalence about continuing in the caregiving role. "[I need] to do something where [I am] not stuck at home. [I] need to meet more people, be out more."

Data analysis revealed that the need to make arrangements for care of their elderly residents was problematic for several caregivers. "You can't go away for even a night without notifying welfare." "If you leave you must have someone over 18 years old in the house." One caregiver indicated that she could leave for 2 hours, but then she was "leery" of what would happen in her absence. She was caring for other dependent elderly. The need to make arrangements in advance eliminated the chance for spontaneity in outside activities. In most cases, occasional respite was provided by friends, neighbors, or the church. However, one caregiver admitted giving up all outside activities because she did not have friends or family to provide respite. "I cannot afford to hire someone to come in at \$3.65 per hour." Another caregiver indicated how hard it was to find people to come into her home.

Several caregivers identified lack of privacy as a cost of foster caregiving. The continual presence of other people in the

home limited opportunities for private interactions between spouses, members of the caregiver's family, and friends. One caregiver told the researcher that out-of-town friends had left prematurely due to the presence of her cognitively impaired resident. Another caregiver states "I don't have the privacy I would like to have. If I have company, it's a problem." One caregiver, who had relocated to a new area in the last 6 months, comments "[I'm] lucky I don't have friends here." In one instance, intrusion on personal space was severe. "She [cognitively impaired elderly resident] rummages through everything I own." Resident behaviors such as kissing the caregiver or constant chattering also imposed on the personal privacy of the caregiver.

Caregiving provided a much needed income for the majority of caregivers. However, two caregivers indicated that the reimbursement received for caregiving was a cost to them. A sense of exploitation was evident among these caregivers. One caregiver pointed out that institutionalization costs between \$1,000-\$1,500 per month, and she provides a "home-like atmosphere for around \$300-\$400 per month." Further, it was "impossible to make ends meet with just welfare patients." Another caregiver indicated that she made only "\$12 per day" for around-the-clock work and difficult caregiving situations.

Inadequate reimbursement as a cost of caregiving can be associated with state policies that establish reimbursement rates

for foster caregiving. In response to specific questioning regarding the impact of caregiving on financial status, it became evident that the majority of caregivers could only meet monthly expenses given the reimbursement for caregiving. Comments such as "[I] can pay the bills but see no profit" were typical among caregivers. In addition, further questioning revealed that the vast majority: (a) felt insecure regarding their financial futures, and (b) did not feel that they could count on family members to help in the event of financial difficulties. Overall, caregivers remained a financially vulnerable group.

A minority of caregivers identified other costs of foster caregiving. Two caregivers experienced an overtaxing of their personal resources while caring for impaired elderly. In one situation the caregiver was unable to manage the resident's behavior problems. The other caregiver received the most difficult cases from Welfare. One caregiver identified profound changes in her interpersonal relationships as a cost of caregiving to a cognitively impaired resident with unsociable behavior. "No one wants to see me anymore." "They [friends] honk for me instead of coming in the house." Data analysis revealed that several other caregivers experienced a lack of understanding from friends and relatives regarding their desire to be caregivers. My friends say, "How can you do this?" "They don't understand that I want to do this."

Summary

In summary, caregivers identified many diverse costs and benefits of foster caregiving. All caregivers identified benefits of caregiving. Those of most salience were money and a sense of satisfaction with caregiving. Other identified benefits were: enjoyment of people, being able to stay at home, having someone else in the house, providing a family for the caregiver, and adding of strength to the caregiver's life.

The majority of caregivers identified costs associated with caregiving. The most severe of these was confinement. Other identified costs were: lack of privacy, inadequate reimbursement, overtaxing of the caregiver's personal resources, and diminishing interpersonal relationships.

Cost/Benefit Ratio

Caregivers were asked to assess the cost/benefit ratio, that is, did the perceived costs outweigh the perceived benefits or vice versa. Seven of the nine caregivers responded that the benefits of caregiving outweighed the costs. One caregiver could not answer the question, despite rewording by the researcher. Another particularly reflective caregiver responded that some days the cost outweighed the benefits and other days the benefits outweighed the costs. Analysis of the observational and interview data revealed that there is frequent reassessment of this ratio by

caregivers. In fact, several caregivers indicated their ambivalence about continuing in the caregiving role. Variables that impacted heavily on the cost/benefit ratio for this sample of caregivers were: (a) the characteristics of elderly residents, (b) significant changes in the life of the caregiver such as divorce or illness, (c) the amount of money received for caregiving, and (d) significant changes in the physical or mental condition of residents. Whenever possible, caregivers used strategies to maximize the benefits and minimize the costs of the caregiving experience.

CHAPTER IV

DISCUSSION & RECOMMENDATIONS

This chapter will discuss the study results. In addition, recommendations for nursing practice, social policy, and further research will be made.

Discussion of Findings

Foster caregivers described strategies to manage the complex social, psychological, and physical needs of their impaired elderly residents. This involved the caregiver's recognition of a need or problem and the planning of a method to assist the impaired person. Although the findings of this study revealed that strategies were used to manage a variety of needs and problems, the success of these strategies is not known. For example, caregivers used strategies to avoid conflicts among residents and between themselves and residents. This generates further questions. How do the use of specific strategies impact the lives of caregivers and their elderly residents? What strategies are most effective for dealing with residents who have different types of impairments? To date, the literature indicates that caregivers provide social, psychological, and physical care activities to meet the needs of impaired elderly (Bradshaw et al., 1976; Miller,

1977; Newman & Sherman, 1977). However, the specific nature and impact of these activities has not been addressed.

Foster caregivers also described strategies to cope with the effects of caregiving on their own lives. In some cases, the use of a particular strategy facilitated the caregiver's desire to remain in the caregiving role. For the most part, however, the specific impact of these strategies on the well-being of elderly residents and their caregivers is not known. For example, one caregiver had segregated living space in her home for "elderly" and "family." Although she used this strategy to provide some "insulation" from her impaired residents, the effects on the caregiver and elderly residents are not known. The currently available literature on foster caregiving does not address strategies used by caregivers to help them cope with the effects of caregiving on their own lives.

Foster caregivers identified costs and benefits of the caregiving experience. However, weighting and cumulative effects of these costs and benefits on the lives of caregivers are not known. Also, the consequences of specific strategies on caregiving are not known. These issues have also not been addressed in the literature.

Foster caregiving is an extremely complex human phenomenon for which our knowledge based is limited. The process of foster

caregiving to impaired elderly is physically and mentally demanding. Nevertheless, foster caregivers are expected to function in this role with minimal support and assistance.

Recommendations

Social Policy Issues

In the past two decades foster care has grown rapidly, spurred primarily by government incentive to contain and reduce service costs. However, the success of this option cannot be measured solely on its ability to reduce costs. Living options must be created to meet the complex psychosocial and physical needs of impaired elderly and to serve to improve their overall well-being. To this end, health professionals and others involved in social policy-making must adamantly pursue legislation that will positively affect outcomes for this vulnerable population and their caregivers.

Implications for Nursing Practice

Nurses working in community settings are in a strategic position to provide needed support and services to foster caregivers. Of prime importance would be assistance in strategy development to manage caregiving problems. Foster caregiving involves care to a broad range of mentally and physically impaired elderly for which caregivers have little educational background or training. Nurses would be instrumental in assisting with strategies to manage these diverse physical and behavioral problems.

Suggestions include strategies to assist with activities of daily living, bowel management, dietary management, and behavioral problems such as wandering or aggressiveness. Nursing assistance in this area would also help relieve the physical and psychological stresses experienced by the caregiver.

The nurse's contact with the foster caregiver would make her a valuable resource in assessing and treating the health problems of the caregiver. The physical and psychological stresses of caregiving occur in middle age to a socially, physically, and economically vulnerable group. Many of the chronic health problems experienced by this group such as obesity, hypertension, and diabetes mellitus would be amenable to preventive and secondary teaching. In addition, nurses could appropriately link the caregiver to community resources to help manage their own needs and problems and those of the elderly person.

Theoretically, nurses would be ideal candidates to serve as primary resources to all foster caregivers. This role would encompass those supports and services previously mentioned, as well as being an "on-call" resource person for any caregiving concerns or problems related to elderly health status. As needed, the nurse could appropriately negotiate for further health and/or social services. The nurse as an involved professional in foster care would improve the quality of life for both elderly and caregivers.

Finally, nurses as champions of vulnerable groups have an ethical and professional responsibility to become familiar and involved with this living option. In a myriad of ways, nurses can work to ensure that this living option satisfactorily improves the well-being of impaired elderly and their caregivers.

Implications for Further Research

This qualitative study provided an in-depth analysis of foster caregiving to Medicaid-eligible impaired elderly in a rural area. Implications for further research derived from this study are to:

1. Test the validity of the identified strategies and consequences of foster caregiving using larger and more diverse samples. This would include varied geographical locations, income levels, and connections to governmental agencies.
2. Use longitudinal data to determine the changes and trends that occur in the use of strategies and in the consequences of caregiving over time.
3. Use probability sampling to provide further insight into the strategies used by foster caregivers and the consequences of caregiving.
4. Further analyze the impacts of caregiving to caregivers and their families as they relate to the health status and mental and physical impairments of elderly.

REFERENCES

- Archbold, P. & Hoeffler, B. (1981). Utilization of institutional or community based services by frail elderly in rural areas. In M. B. Neal, Long term care-related research in Oregon. Portland: Oregon Health Sciences University & Institute on Aging, Portland State University.
- Bradshaw, B. R., Vonderhaar, W., Keeney, V., Tyler, L. S., & Harris, S. (1976). Community based residential care for minimally impaired elderly: A survey analysis. Journal of the American Geriatrics Society, 24, 423-429.
- Brody, E. M. (1977). Comments on the Sherman/Newman paper. The Gerontologist, 17, 620-622.
- Brody, S. J. (1973). Comprehensive health care for the elderly: An analysis. The continuum of medical health and social services for the aged. The Gerontologist, 13, 412-417.
- Fenske, V. & Roecher, M. (1971). Finding homes for adults. Public Welfare, 29, 404-410.
- Glaser, B. G. & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine.
- Handy, I. (1968). Foster care as a therapeutic program for geriatric psychiatric patients. Journal of the American Geriatrics Society, 16, 350-358.

- Lofland, J. & Lofland, L. (1984). Analyzing social settings: A guide to qualitative observation and analysis (2nd ed.). Belmont, CA: Wadsworth.
- McCain, J. (1983). Adult foster homes: Their managers and residents. New York: Human Services Press.
- Miller, C. (1977). A program for adult foster care. Social Work, 22, 275-279.
- Mor, V., Gutkin, C. & Seltzer, M. (1980, November). Integration of the dependent aged into the family life of personal care homes. Paper presented at the 33rd annual meeting of the Gerontology Society, San Diego, CA. (Abstract from The Gerontologist, 1980, 20.)
- Mor, V., Gutkin, C. & Sherwood, S. (1985). The cost of residential care homes serving elderly adults. Journal of Gerontology, 40, 164-171.
- Morrissey, J. R. (1967). The case of family care for the mentally ill. New York: Behavioral.
- Murphy, H. B., Pennee, B., & Luchens, D. (1972, Sept.-Oct.). Foster homes: The new backwards? Canada's Mental Health Supplement, No. 71, 1-17.
- Newman, E. S. & Sherman, S. R. (1977). A survey of caretakers in adult foster homes. The Gerontologist, 17, 436-439.

- Newman, E. S. & Sherman, S. R. (1979a). Foster family care for the elderly: Surrogate family or mini institution. Aging and Human Development, 10, 165-176.
- Newman, E. S. & Sherman, S. R. (1979b). Community integration of the elderly in foster family care. Journal of Gerontological Social Work, 24(1), 324-388.
- Oktaý, J. S. & Volland, P. J. (1981). Community care program for the elderly. Health & Social Work, 6, 41-47.
- Reamer, F. G. (1985). Facing up to the challenge of DRGs. Health and Social Work, 10(2), 85-94.
- Sherman, S. & Newman, E. (1977). Foster family care for the elderly in New York State. The Gerontologist, 17(6), 513-522.
- Sherman, S. & Newman, E. (1979). Role of the caseworker in adult foster care. Social Work, 24, 324-328.
- Sherman, S. & Snider, D. (1981). Social participation in adult homes: Deinstitutionalized mental patients and the frail elderly. The Gerontologist, 21(5), 545-550.
- Steinhauer, M. (1982). Geriatric foster care: A prototype design and implementation issues. The Gerontologist, 22, 293-300.
- United States Senate Special Committee on Aging. (1984). Aging America: Trends and projections.

- Vandivort, R., Kurren, G., & Braun, K. (1984). Foster family care for frail elderly: A cost effective quality care alternative. Gerontological Social Work in Home Health Care, 4, 101-114.
- Wohlford, M. (1968). Adult foster care - A unique answer. Public Welfare, 26, 224-226.

APPENDIX A

FOCUSED, IN-DEPTH INTERVIEW WITH
FAMILY MEMBER

OREGON HEALTH SCIENCES UNIVERSITY
SCHOOL OF NURSING

INTERVIEW WITH FAMILY MEMBER

1. Subject number _____
2. Subject's address _____
 Street and Number City State
3. Subject's phone () _____
4. Date of interview _____
5. Time interview began _____
6. Interviewer's name _____
7. Relationship to elderly family member _____
8. Place of interview

9. Subject's residence if not the place of interview

10. Subgroup A - Home
 - B - Foster-care family
 - C - Foster care - non family
 - D - Home for aged
 - E - Nursing Home

11. Description of interview setting (include observations of physical environment: water, heat, etc.)

12. Description of interviewee

*13. Sex of Subject

- 1 Male
- 2 Female

*14. Race of Subject

- 1 White (Caucasian)
- 2 Black (Negro)
- 3 Oriental
- 4 Spanish American (Spanish surname)
- 5 American Indian
- 6 Other
- Not answered

*15. Age of subject

a. When were you born? _____
(Month) (Day) (Year)

b. How old are you? _____

- 1 65-69
- 2 70-74
- 3 75-79
- 4 80-84
- 5 85-89
- 6 90-94
- 7 95-99
- 8 100+

*16. How far did you go (have you gone) in school?

- 1 0-4 years
- 2 5-8 years
- 3 High school incomplete
- 4 High school completed
- 5 Post high school, business or trade school
- 6 1-3 years' college
- 7 4 years' college completed
- 8 Post graduate college
- Not answered

*17. Are you single(never married), widowed, divorced, or separated

- 1 Single (never married)
- 2 Married
- 3 Widowed
- 4 Divorced
- 5 Separated
- Not answered

13. Who lives with you? (include relationship to person)

Who is in your family?

19. Tell me about your older family member. (Include nature of relationship (historical and current) and description of physical and mental health).

PROBE: a. How much guidance does X need to make decisions?

b. How adaptable is X to change?

c. How involved are you in assisting X in making decisions?

d. How has that changed during your relationship with X?

PROBE: Overall, how would you rate your relationship with X?

Five years ago: ___ excellent ___ good ___ fair ___ poor

Currently: ___ excellent ___ good ___ fair ___ poor

20. Assistance patterns:

A. What kinds of help does X need?

B. What kinds of help does X expect from you?

C. What kinds of help do you provide and how much time is involved?

D. How was the initial agreement for assistance worked out?

Who was involved?

What part did you play in the decision-making?

E. How has the agreement changed over time?

When?

Why?

PROBE WITH:

(1) Personal care (bathing, dressing, mobility toilet, eating)

(2) managing medical regimes (taking meds, dressings, etc)

(3) home keeping

(4) home maintenance

(5) meal preparation

(6) shopping

(7) transportation

(8) money management

(9) contact with outside world

(10) negotiation of health and social service systems

a. To what extent are you involved?

b. What official assistance do you receive (e.g. caseworker)?

(11) other

21. SANFORD'S TOLERANCE OF DISABILITY

Does your older family member have any of the following problems?
If so, how difficult is it for you to live with?

Problem Occur. No Problem Management Difficult Intol.

Sleep disturbance _____
Incontinence - F _____
Incontinence - U _____
Inability to get
 out of bed _____
Inability to get
 off commode _____
Dangerous behavior _____
Inability to walk _____
Personality
 conflict _____
Physically
 aggressive _____
Inability to dress _____
Inability to wash _____
Inability to commu. _____
Daytime wandering _____
Inability to climb
 stairs _____
Inability to feed
 self _____

22. How do you manage these problems? What advice would you give others experiencing the same problem?

23. What does it mean to you to care for your older family member?

Probe: What are the benefits to you?

Probe: What are the costs to you?

24. What changes have you made in your life since the assumption of caregiving activities? What do you feel about these changes?

a. Leisure activities

b. Income and expenditures

c. Community activities

d. Employment status

e. Social/family relationships

f. Other

g. Overall, do the costs of caregiving outweigh the benefits, or the benefits outweigh the costs?

costs outweigh benefits _____

benefits outweigh costs _____

25. Have you any health problems limiting your own ability to provide care for your older family member?

26. What services do you think the government should provide for older persons?

What services do you know of in the community?

27. What role do you think family and friends should play in providing assistance to older people?

28. What help do you receive in providing care for your older family member?

a. From family and friends?

b. From community providers?

Probe: Here is a list of services that may be offered in the community.
Have you or your older family member received any of these?

29. How did you find out about x community services? (Describe the process of obtaining services)

Probe: What was the experience of getting and maintaining the service like for you?

30. What would it mean to you to no longer have x service?

31. What help, if any, do you think your older family member needs, but is not receiving?

Who should provide the help?

Why do you think it is not available?

32. (IF family member holds an AFS contract)
What are the pros and cons of the official contract?

33. How do (did) you feel about your older family member living in his/her own home?

34. What alternative living arrangements would you/did you consider for your older family member?

- 1. Long term care facilities
- 2. Board and Care homes
- 3. Senior citizens housing
- 4. Present residence with supportive community services and family
- 5. New, more efficient residence
- 6. Residence with family member
- 7. Other, explain

(Describe in detail the informant's evaluation of these alternatives and what role the respondent and other family members will play.)

35. Who participated (would participate) in decision making about an appropriate residence for 'X' your older family member?

To what extent was X involved in that decision?

36. How would you/did you feel about your older family member going into the alternative living situation?

37. Please tell me how well you think you (and your family) are doing financially as compared to other people your own age?

- 2 Better
- 1 Same
- 0 Worse
- No answer

Explain:

38. How well does the amount of money you have take care of your needs?

- 2 Very well
- 1 Fairly well
- 0 Poorly
- No answer

Explain:

Probe: Would you say you:

- 3 do without many needed things
- 2 have the things you need but none of the extras
- 1 have the things you need and a few of the extras

39. Do you feel that you will have enough for your need in the future?

- 2 Yes
- 1 No
- 0 No answer

Explain:

40. How would you rate your overall health at the present time?

- 3 Excellent
- 2 Good
- 1 Fair
- 0 Poor
- No answer

Explain:

41. Is your health now better, about the same, or worse than it was five years ago?

- 3 Better
- 2 About the same
- 0 Worse
- No answer

Explain:

42. How much do your health problems stand in the way of your doing the things you want to do?

- 3 Not at all
- 2 A little
- 0 A great deal
- No answer

Explain:

43. Taking everything into consideration, how would you describe your satisfaction with life at the present time?

- 2 Good
- 1 Fair
- 0 Poor
- No answer

Probe: What would make life more satisfying?

44. How often do you worry about things?

- 0 Very often
- 1 Fairly often
- 2 Hardly ever
- No answer

45. What kind of things do you worry about most?

46. Has there been a time in the past when the family needed to rally around a member? Explain.

47. In general, how do your family members react in times of trouble?

48. If you are having trouble making ends meet (financial problems), could you call on your family or relations? If so, what can you expect?

51. If something happened to you that you had trouble handling yourself, who is your family likely to turn to?

- _____ The family
- _____ Relatives
- _____ Friends
- _____ Professionals
- _____ Others (identify)

52. Do you have someone you can trust and confide in?

- 2 Yes
- 0 No
- Not answered

Probe: Who is it? How often do you see them/talk with them?

53. How would you rate your mental health at the present time?

- 3 Excellent
- 2 Good
- 1 Fair
- 0 Poor
- No answer

Explain:

54. Is your mental health better, about the same, or worse than it was five years ago?

- 3 Better
- 2 About the same
- 1 Worse
- No answer

Explain:

APPENDIX B

FOCUSED, IN-DEPTH INTERVIEW WITH
ELDERLY INDIVIDUAL

OREGON HEALTH SCIENCES UNIVERSITY
SCHOOL OF NURSING

INTERVIEW WITH ELDERLY INDIVIDUAL

1. Subject Number _____
2. Subject's Address _____
 Street and Number City State
3. Subject's Phone () _____
4. Date of Interview _____
5. Time Interview Began _____
6. Interviewer's Name _____
7. Name of family member or friend _____
8. Place of Interview (specify home or type of institution)

9. Subject' Residence if not the place of interview

10. Subgroup A - Home
 B - Foster care-family
 C - Foster care-non family
 D - Home for aged
 E - Nursing home

11. Description of Interview Setting (include observations of physical environment, water, heat, etc.)

12. Description of Interviewee

*13. Sex of Subject

- 1 Male
- 2 Female

*14. Race of Subject

- 1 White (Caucasian)
- 2 Black (Negro)
- 3 Oriental
- 4 Spanish American (Spanish surname)
- 5 American Indian
- 6 Other
- Not answered

*15. Age of subject

a. When were you born? _____
(Month) (Day) (Year)

b. How old are you? _____

- 1 65-69
- 2 70-74
- 3 75-79
- 4 80-84
- 5 85-89
- 6 90-94
- 7 95-99
- 8 100+

*16. How far did you go (have you gone) in school?

- 1 0-4 years
- 2 5-8 years
- 3 High school incomplete
- 4 High school completed
- 5 Post high school, business or trade school
- 6 1-3 years' college
- 7 4 years' college completed
- 8 Post graduate college
- Not answered

*17. Are you single(never married), widowed, divorced, or separated

- 1 Single (never married)
- 2 Married
- 3 Widowed
- 4 Divorced
- 5 Separated
- Not answered

*18. Who lives with you? (include relationship to person)

<u>Family History</u>				
Members	Age	Distance	Quality of Relationship	Contribution to caregiving

*19. Please tell me how well you think you (and your family) are doing financially as compared to other people your own age?

- 2 Better
- 1 Same
- 0 Worse
- Not answered

Explain:

*20. How well does the amount of money you have take care of your needs?

- 2 Very well
- 1 Fairly well
- 0 Poorly
- Not answered

Probe: Would you say you:

- 3 ___ do without many needed things
- 2 ___ have the things I need but none of the extras
- 1 ___ have the things I need and a few of the extras

*21. Do you feel that you will have enough for your needs in the future?

- 2 Yes
- 0 No
- Not answered

Explain:

*22. What is it like for you being an older person?

a. What is it like for you in this area?

b. How was it decided that you would live here?

Probe: What does it mean to you to be living in your (own home? a foster home? home for aged? nursing home?)

*23. a. How would you rate your overall health at the present time?

- 3 Excellent
- 2 Good
- 1 Fair
- 0 Poor
- Not answered

Explain:

b. What health or medical problems do you have?

- c. How do you manage these problems? What do you do for them?
(Meds, hearing aides, canes etc.)

*24. Is your health now better, about the same, or worse than it was five years ago?

- 3 Better
- 2 About the same
- 0 Worse
- Not answered

Explain:

*25. How much do your health problems stand in the way of your doing the things you want to do?

- 3 Not at all
- 2 A little
- 0 A great deal
- Not answered

Explain:

26. What kinds of activities do you usually do during a day?

27. Tell me about a recent typical day.

28. Tell me what you usually eat during the day.

a. How many meals do you eat each day?

29. 1) Assistance patterns.
(Ask general questions first and record response and perceptions. Then probe for each of the follow II areas if not covered.)

a. What kinds of activities do you need help with?

b. Who helps you, and how much time is involved?

c. How was the initial agreement for assistance worked out with caregiver?

d. Who was involved? (note AFS)

e. What part did you play in making the decision?

f. How has the agreement to provide service for what you need changed over time?

g. When?

Why?

h. What is it like for you (does it feel like) to receive this help?

i. How important was the activity (role) for you in the past?

2) Managing medical regimes (taking meds, dressings, etc.)

PROBES: Do you need assistance?
Has someone else always managed?
Was it an important part of your role?

3) Home keeping:
(repeat probes under #2)

4) Home maintenance:
(repeat probes under #2)

5) Meal preparation:
(repeat probes under #2)

6) Shopping:
(repeat probes under #2)

10) Negotiation of health and social service systems:

a. relative

b. nature of help
forms
phone
assessment of service

c. caseworker
extent of assistance

30. In what way has the kind of assistance you receive changed over the last year?

How did you feel about the change?

If you needed more assistance, would "X" be able to provide it?

How would you work that out with him/her?

*31. How many people do you know well enough to visit within their homes?

- 3 - Five or more
- 2 - Three to four
- 1 - One to two
- 0 - none
- - Not answered

*32. a. About how many times did you talk to someone--friends, relatives, or others on the telephone in the past week (either you called them or they called you)?

(IF SUBJECT HAS NO PHONE, QUESTION STILL APPLIES)

- 3 - Once a day or more
- 2 - 2-6 times
- 1 - Once
- 0 - not at all
- - not answered

b. PROBE: Who were the people you talked with and how satisfied were you with the contact?

- *33. a. How many times during the past week did you spend some time with someone who does not live with you, i.e., went to see them, or they came to visit you, or you went out to do things together?
- 3 Once a day or more
 - 2 2-6 times
 - 1 Once
 - 0 Not at all
 - Not answered
- b. Who were the people? What did you do together? How satisfactory was the contact?

34. How happy are you with the amount of contact you have with your friends and relatives?

- 1 happy
- 2 somewhat happy/unhappy
- 3 unhappy
- not answered

Explain:

*35. Do you have someone you can trust and confide in?

- 2 Yes
- 0 No
- Not answered

Probe: Who is it? How often do you see them, etc.

*36. Do you find yourself feeling lonely quite often, sometimes, or almost never?

- 0 Quite often
- 1 Sometimes
- 2 Almost never
- Not answered

Probe: What do you do if you feel lonely?

*37. Is there someone who could give you any help at all if you were sick or disabled, for example, your husband/wife, a member of your family or a friend? (PIB 17 - natural support)?

- 1 Yes
- 0 No one able to help
- Not answered

(IF "YES", ASK a. through c.)

- a. Is there someone who could take care of you indefinitely (as long as needed)? who?
- b. Is there someone who could take care of you for a short time (a few weeks to six months)? who?
- c. Is there someone who could help you now and then (taking him to the doctor or fixing lunch, etc.)? who?
- Not answered

Probe: Is this person willing to help you?

*38. Taking everything into consideration, how would you describe your satisfaction with life at the present time?

- 2 Good
- 1 Fair
- 0 Poor
- Not answered

Probe: What would make life more satisfying?

39. Has there been a time in the past when the family needed to rally around a member? Explain

PROBE: In general, how do your family members react in time of trouble?

40. Have you (or your spouse) ever been ill? If so, what arrangements were made? Who helped you?

41. If you are having trouble making ends meet (financial problems), could you call on your family or relations? If so, what can you expect?

42. Some people feel that in time of trouble, it is better to let off steam and show their emotions. Others prefer to keep their feelings to themselves. Which describes you?

44. If something happened to you that you had trouble handling yourself, who is your family likely to turn to?

- the family
- relatives
- friends
- professionals
- others (identify)

45. How often do you worry about things?

- 0 Very often
- 1 Fairly often
- 2 Hardly ever
- Not answered

Probe: What kinds of things do you worry about most?

46. How would you rate your overall mental health at the present time-- excellent, good, fair or poor

- 3 Excellent
- 2 Good
- 1 Fair
- 0 Poor
- Not answered

Explain:

47. Is your mental health better, about the same, or worse than it was five years ago?

- 3 Better
- 2 About the same
- 1 Worse
- Not answered

Expalin:

48. What services do you think the government (local, state, or federal) should provide for older persons?

What role do you think family and friends should play in providing services to older people?

49. What services do you know of in the community?

PROBE: How did you find out about them?

50. Which do you receive? Did you receive?

51. Here is a list of services that may be offered in the community.
Have you received any of these services (hand card to subject)?
52. Which would you like to recieve? (Would have been useful to you when
you were in your home? For example, visiting nurse, house-keeping, meals
on wheels, etc.)
53. What benefits have you gotten from having X service? What
problems have X service caused for you?

54. What would it mean to you to no longer receive X service?

55. How do you feel about relying on services (e.g. homemaker) provided by your community? County? State?

56. If (when) you could no longer stay in your home, what alternatives would (did) you consider? Describe them.

Probe: Here is a list of supervised residential settings that may be found in some communities. Did you consider any of these?

Who would be involved in the decision about your moving from X to Y?

57. Evaluate respondent's behavior during the interview on a 3-point scale, ranging from low, medium, to high.

<u>ITEM</u>	<u>LOW</u>				<u>HIGH</u>
Attention & concentration	Mind wanders frequently	3	2	1	Attended entire interview
Interaction with interviewer	No contact	3	2	1	Very responsive
Interest	Very casual	3	2	1	Intense interest
Cooperativeness	Barely civil	3	2	1	Went out of way to be helpful
Comfort	Tense	3	2	1	Relaxed
Openness	Guarded	3	2	1	Frank
Understanding	Confused	3	2	1	Comprehending
Mood	Sad	3	2	1	Happy

APPENDIX C

CONSENT FORM

UNIVERSITY OF OREGON HEALTH SCIENCES CENTER
SCHOOL OF NURSING

STUDY:* USE OF NURSING HOMES AND COMMUNITY-BASED SERVICES BY
OLDER PERSONS IN A RURAL AREA

INTERVIEWERS:** PATRICIA ARCHBOLD, RN., DNSc
BEVERLY HOFFER, RN., DNSc

PATRICIA ARCHBOLD AND BEVERLY HOFFER, NURSES AND FACULTY MEMBERS AT THE SCHOOL OF NURSING, UNIVERSITY OF OREGON HEALTH SCIENCES CENTER, ARE DOING A STUDY OF THE USE OF NURSING HOMES OR COMMUNITY-BASED SERVICES BY OLDER PERSONS IN A RURAL AREA IN COLLABORATION WITH THE DEPARTMENT OF HUMAN RESOURCES.

IF I AGREE TO BE IN THIS STUDY, THE FOLLOWING WILL HAPPEN: I WILL ANSWER QUESTIONS IN ONE INTERVIEW SESSION REQUIRING APPROXIMATELY TWO HOURS. I ALSO UNDERSTAND THAT A MEMBER OF MY FAMILY, OR A FRIEND, _____, WILL BE INTERVIEWED IN ONE SESSION REQUIRING APPROXIMATELY TWO HOURS. I UNDERSTAND THAT WHAT I SAY WILL BE WRITTEN DOWN, BUT THAT THE INFORMATION WILL BE KEPT CONFIDENTIAL.

SHARING MY THOUGHTS AND EXPERIENCES WITH DR. ARCHBOLD OR DR. HOFFER MAY NOT HELP ME PERSONALLY, BUT MAY HELP OTHERS IN THE FUTURE.

IF I HAVE COMMENTS OR QUESTIONS ABOUT THE STUDY, I SHOULD TALK WITH DR. ARCHBOLD OR DR. HOFFER. THEY WILL ANSWER MY QUESTIONS. I MAY DECIDE NOT TO ANSWER CERTAIN QUESTIONS, OR MAY STOP THE DISCUSSION AT ANY TIME. DOING SO WILL NOT AFFECT MY RELATIONSHIP WITH, OR TREATMENT AT, THE UNIVERSITY OF OREGON HEALTH SCIENCES CENTER, OR THE DEPARTMENT OF HUMAN RESOURCES.

WHEN THE STUDY IS FINISHED, DR. ARCHBOLD AND DR. HOFFER WILL
SEND ME A SUMMARY OF THE FINDINGS.

I HAVE READ WHAT IS WRITTEN ABOVE AND AGREE TO BE IN THE STUDY.

I HAVE HAD READ TO ME WHAT IS WRITTEN ABOVE AND AGREE TO BE IN
THE STUDY.

DATE

SIGNATURE OF OLDER PERSON

DATE

SIGNATURE OF FAMILY MEMBER OR FRIEND

* UTILIZATION OF INSTITUTIONAL OR COMMUNITY-BASED SERVICES BY FRAIL
ELDERLY IN RURAL AREAS.

** PATRICIA ARCHBOLD, RN., DNSc
ASSOCIATE PROFESSOR
PROJECT DIRECTOR, GERONTOLOGY PROJECT
SCHOOL OF NURSING, 225-8297

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ASSOCIATE PROFESSOR
DEPARTMENT OF PSYCHIATRIC/MENTAL HEALTH NURSING, 225-7827

AN ABSTRACT OF THE THESIS OF
MARTY MILES

FOR THE MASTER OF NURSING

DATE OF RECEIVING THIS DEGREE: JUNE 19, 1986

TITLE: FOSTER CAREGIVING TO IMPAIRED ELDERLY: A QUALITATIVE
ANALYSIS

APPROVED:

Patricia Archbold, R.N., D.N.Sc., Thesis Advisor

This exploratory study of foster caregiving is based on in-depth interviews and participant observation with a sample of nine foster caregivers and nine older persons who resided in foster homes. Subjects for this study were drawn from clients participating in a larger study on the use of institutional and community-based services by frail elderly in rural areas (Archbold & Hoeffler, 1981). A state service agency provided Archbold and Hoeffler (1981) with the names, placements, and functional assessment scores of Medicaid-eligible elderly 65 years and over in four rural counties in one state.

Analysis of the qualitative data identified strategies used by foster caregivers during the caregiving process. These strategies fell into two major categories: (a) caregiving strategies to manage the needs and problems of elderly residents, and (b) strategies used by caregivers to cope with the effects of caregiving on their own lives. Caregiving strategies involved: (a) facilitating contact with relatives and the larger community, (b) providing activities for the resident's enjoyment, (c) giving tangible

aid, (d) validating the resident's sense of self, and (e) providing direct and indirect care activities. Caregivers also described strategies directed toward limit-setting and harmonizing to manage the problematic behaviors of residents. The strategies described by caregivers to cope with the effects of caregiving on their own lives involved control over resident selection, attribution of a positive meaning to the caregiving experience, insulation, and use of outside assistance.

Data analysis revealed consequences to foster caregivers of caring for impaired elderly. The predominantly mentioned benefits were a sense of satisfaction with the caregiving role and the money received for caregiving. Other identified benefits were: enjoyment of people, being able to stay at home, having someone else in the house, providing a family for the caregiver, and the adding of strength to the caregiver's life. The most severe cost identified by caregivers was confinement. Other identified costs were: lack of privacy, inadequate reimbursement for caregiving, overtaxing of the caregiver's personal resources, and diminishing interpersonal relationships.