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Caregiver Support Groups: Benefits of Participation

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MASTERS IN SOCIAL WORK THESIS

Charlotte Jean McIntosh

Caregiver Support Groups: Benefits of Participation

1997

CAREGIVER SUPPORT GROUPS: BENEFITS OF PARTICIPATION

MASTER OF SOCIAL WORK
AUGSBURG COLLEGE
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CERTIFICATE OF APPROVAL

This is to certify that the Master's Thesis of:

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has been approved by the Examing Committee for the thesis requirements for the Master of Social Work Degree.

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ABSTRACT

CAREGIVER SUPPORT GROUPS: BENEFITS OF PARTICIPATION

As the population ages, many adults will find themselves dependent on others for care due to chronic illness or disability. Often a family member will assist an individual by becoming the caregiver. A caregiver experiences a unique set of stressors and challenges that come with this responsibility. In the community, there are caregiver support groups that are designed to assist a caregiver. This study explored three aspects of participation in a caregiver support group. The findings of this study reveal that participation in a caregiver support group has benefits for the caregivers. The caregivers reported that they learned about resources in the community, gained the ability to understand and communicate feelings about caregivers, received encouragement and understanding from other caregivers, and obtained educational information about chronic illness.

CHAROLETTE JEAN MCINTOSH

JUNE 2, 1997

TABLE OF CONTENTS

CHAPTER ONE Page

CHAPTER TWO

CHAPTER THREE

Page

CHAPTER FOUR

CHAPTER FIVE

Page

LISTS OF FIGURES AND TABLES

Page

CHAPTER 4

CHAPTER 4

Tables:

Chapter 5

CHAPTER ONE: INTRODUCTION

Overview

The first chapter has three sections. The Introduction describes both the physical and emotional challenges that are associated with caregiving. The Incidence of Caregiving section relates statistics on the aging population in the United States, and discusses the increased life expectancy. The Purpose of Research section outlines the intent of the study.

INTRODUCTION

As the population ages, many adults will find themselves dependent on others for care due to a chronic illness or disability. Family members often fill the role of coordinator and sometimes care providers. These caregivers find a unique set of stressors and challenges that come with this responsibility. Caregivers often assist care receivers with basic living skills such as grooming, bathing, toileting and feeding. They also assist care receivers in the coordination of their medical care, personal business, and household tasks. Caregivers find it difficult to reach out to others for assistance. Often caregivers are financially compromised, and cannot afford expensive in-home services. If a respite volunteer is available in the community, the caregiver must become involved in building a trusting relationship with the volunteer in order to comfortably leave their care receiver in the hands of another person. This is a very time consuming, and emotionally draining task. The obstacles presented are a sampling of caregiver challenges and tasks. Caregivers are encouraged to turn to caregiver support groups for assistance through this difficult period and can potentially benefit in a number of ways from their participation. Studies in the literature conclude that caregivers benefit from participation by learning about resources in the community, gain the ability to understand and communicate feelings about caregiving, receive encouragement and understanding, and obtain educational information about chronic illness.

INCIDENCE OF CAREGIVING

Due to the growth of the aging population (Brody, 1990), since the 1960s, care for the elderly has become a major focus of interest and study for researchers and professionals. Since 1900, the overall number of elders (persons 60 years of age and older) has increased nine fold. In actual numbers the population has gone from 3.1 million to 29.2 million and the number of Americans age sixty-five and older has tripled. By the year 2030, 65 million United States citizens will be sixty-five or older, fully 21.2 % of the population (Schneider & Kropf, 1992).

Given that attitudes about aging are generally negative, the “graying” of America’s population presents challenges to the community and families. Rubenstein, Kilbride, and Nagy (1992) state that although American cultural individualism views old age as a time to benefit from years of hard work. After years of independence, the frail elderly often are dependent on others for their basic care.

The demographic shift is due to two main factors. First, the average life expectancy has increased dramatically. A child born in 1986 can expect to live 28 years longer than a child born in 1900. Secondly, infants born during the postwar baby boom are growing older (Schneider & Kropf, 1992).

In the past 20 years the population of adults age 75 and older has significantly increased. By 2010, individuals 80 years of age and older will increase by 5.9 million. Because the very old (80 and over) are particularly vulnerable to chronic illness, they frequently become dependent on others for care (Brody, 1990).

PURPOSE OF RESEARCH

The benefits of caregiver support groups that have been identified in previous studies are presented in the following review of the literature. This study intends to explore participants perceived benefits resulting from their participation in caregiver support groups, confirm findings from previous studies, and possibly identify benefits not yet discovered.

The research questions to be studied are:

What types of support do participants receive from caregiver support groups?

What are the benefits of participation in a caregiver support group?

To what extent do caregiver support groups alter the stress of caregiving?

Summary

This chapter has generally described the emotional challenges and tasks associated with caregiving. As the population ages and life expectancy increases, chronic illnesses are also on the rise. Increasingly, family members are filling the role of caregiver. Studies indicate that individuals in a caregiver support group benefit from participation. The purpose of this study is to confirm extent that findings from previous studies in the literature were applicable to caregiver support groups in these agencies in Minnesota.

CHAPTER TWO: LITERATURE REVIEW

Overview

The second chapter has two sections. The Literature Review provides an outline of studies that describe and review caregiver support groups. This section also provides a general overview of the responsibilities and tasks associated with caregiving. The Theoretical Framework provides an definition of the Social Group Work Theory.

LITERATURE REVIEW

In a review of the literature, there were numerous studies that discussed the support individuals receive in the group work setting, the benefits of participation in a group, and stress alleviation through the group work process. The literature did not reveal any particular gaps in research. This research was designed to confirm findings of past research, and possibly define benefits not yet discovered. The following studies give a view of the group work process as it relates to caregiver support groups.

Caregiver support groups have existed for only the past 13 years (Fradkin & Heath, l992). In a study by Biegel, Sales and Schulz (l991), the overall findings indicated that participants in a caregiver support group were satisfied with their group experience and report a number of benefits from their group participation. Generally, this study concluded that most caregivers benefit from support groups, either formal groups lead by a professional or informal groups lead by a volunteer or peer (Bass, 1990). Toseland, Rossiter and Labrecque (1989) indicated in their study that both structures serve an important purpose and role. It has been said that the peer leaders are as effective as professionals. However, when a caregiver wants to explore more personal issues, a psychotherapy group led by a professional is recommended.

McCallion, Toseland and Diehl (1994) discovered that caregiver support groups lead by professional social workers tend to be structured, short term psycho-educational group programs. The goals of the group include: 1) reduction of isolation and loneliness; 2) encouraging the sharing of feelings, emotions and experiences; 3)sharing of problem-solving and coping strategies; 4) assisting caregivers in development and implementation of action plans; 5) educating caregivers about the aging process, community resources, and chronic disabilities; 6) providing encouragement and affirmation; and 7) validating the caregiver experience.

Toseland et al. (1989) indicate that once a caregiver support group is formed, there are two primary objectives for the group: problem solving and/or emotional support. In the problem-focused area, caregivers are given resources, tips on improving caregiver tasks, and ideas on how to solve problems associated with caregiving. In the emotion-focused area, members are encouraged to share emotions and self perceptions. Sharing information about caregiving and personal reactions to specific problems can lower stress. Learning that others have negative feelings at times towards their care receiver can help reduce guilt about the caregiver's own anger.

Getzel (1983) has concluded in his study on group work and caregivers that in order to structure an effective self-help group for caregivers, discussion and assistance with the following issues are critical. First, information pertaining to all aspects of the aging process (biological, social and psychological) should be thoroughly addressed. Direction about receiving assistance with obtaining resources and benefits is very important. A safe environment should be provided in which a caregiver can openly discuss interpersonal problems and general pressures of caregiving. The most important aspect of support groups is that they encourage and develop the concept of empowerment for the caregiver -- giving them a sense of gaining control (Bass, 1990).

Caregivers Defined

A person who provides primary assistance to another person in need -- elderly people, children, disabled individuals -- is considered a caregiver. There are two types of cargivers, formal and informal. The formal caregivers are volunteers or paid care providers, while informal caregivers are often untrained, unpaid family members or friends (Fradkin & Heath, l992). Assistance from a caregiver can enable an elder to remain at home despite a serious illness or disability (Rubenstein et al. l992).

Informal caregivers tend to be adult children, daughters-in-law, siblings and spouses. The majority of caregivers are female (70-87%) and one-third of them are married, employed and/or have childcare responsibilities. Wives and adult female children are the most likely to become caregivers (Tully & Sehm, 1994). Middle aged women are more often the primary caregivers of elderly parents and other relatives (Getzel, 1983).

Spouses also play an important role as caregivers, often caring for their partner through chronic disability and illness. Elderly spouses tend to display extreme loyalty to each other (Chappell, 1991). Most caregiving spouses are women, due to the fact that men tend to marry younger women, and men have a shorter life expectancy (Brody, 1990). Often spousal caregivers do not seek services because they feel they are only doing their duty, as promised in their marriage vows. They do not think of themselves as caregivers (Fradkin & Heath, 1992).

In a study concerning support strategies for caregiving, Montgomery and Borgatta (1989) discovered that it is difficult to obtain a sample of caregivers in the early stages of caregiving. Often caregivers seek assistance only when they reach a crisis point. They also concluded that policy makers fear that the system will be overloaded if more programs were widely available to caregivers. Through their study, though, they had difficulty locating a sample population of caregivers.

Factors that contribute to the caregivers' ability to provide care include the care receivers' attitude, physical and mental health, and their financial resources when making a decision about how much responsibility to assume. The caregivers must consider their own health concerns and needs, financial stability, emotional support, conflicting demands on time and their coping skills (Fradkin & Heath, 1992).

Even though more women are working outside the home, women are still more likely to become caregivers than men. Conflicts can occur between caregiving and paid employment (McCallion et al. 1994). Brody (1990) suggests that women who caregive are often bewildered and conflicted about their numerous roles. However, this issue does not belong only to the female caregiver, it is indeed an issue for the entire family and society as a whole.

Despite the popular myth of adult children abandoning their elderly parents, children now are actually more responsible for daily care than they were in the past (Brody, l990). In fact, the majority of families do not institutionalize their elders and indeed continue their caregiving duties after their elders are institutionalized. Only approximately 5 % of persons 65 years and older live in nursing homes, a statistic that has not changed in the past 15 years (Fradkin & Heath, 1992).

Montgomery and Borgetta (1989) compiled a caregiver task list in their study. The following calculates the number of hours spent on particular tasks. An average of 8 hours per week is devoted to personal care tasks, including bathing, dressing and toileting. Shopping for groceries or clothes, meal preparation and clean up entailed an average of 15 hours per week. Attending to legal matters, banking, and writing checks takes approximately 3 hours per week. Almost 7 hours per week were spent on transportation tasks, which include accompanying the care receiver or running errands for him or her. The amount of time spent assisting the elderly person differed significantly between caregivers who were spouses and those who were adult children. On the average, spouses devoted almost 7 hours more per week to personal care tasks than did adult children. Spouses spent about 14 hours more doing household tasks.

Affects of Caregiving

Caregiving has been referred to as the ultimate juggling act. The caregiver has multiple duties and responsibilities that change frequently (Fradkin & Heath, l992). Initially, caregivers experience a feeling of inadequacy or lack of control until skills and knowledge about caregiving are learned. Yet immediate solutions are often required in the care of a family member (Zimmer & Mellor, 1988)

Researchers have discovered a high incidence of depression among caregivers. Family caregivers often experience problems with low morale, isolation, loneliness, economic hardship and role overload (Spaid & Barusch, l992). In a study conducted to determine the problems and coping strategies of elderly spouse caregivers, it was determined that caregivers worry about their own health and future (Barusch, l988).

Caregivers also lose control over their personal time. The demands of meeting another person's daily needs is time consuming. Caregivers not only attend to the daily needs within the home, they are also responsible for arranging and transporting their care receiver to medical and therapeutic appointments. While trying to manage and coordinate the care receivers life, the caregiver is also often employed outside the home (Bass, 1990).

Physical, emotional and financial stress frequently accompany caregiving. Many times a caregiver is responsible for physically lifting an individual. This causes muscle strain and back problems if the caregiver has not received proper training in lifting techniques. Sleep deprivation sometimes accompanies caregiving duties as well. Disruptive sleep patterns are common while tending to a person who wakes several times a night or has a tendency to wander around the house specifically during the night, and leads to sleep deprivation for the caregiver (Fradkin & Heath, 1992).

Fradkin and Heath (1992) have described a variety of emotions experienced by a caregiver. Their feelings change day to day, hour to hour. The caregiver often experiences more than one emotion at a time. Caregivers often feel <u>guilty</u> for their desire to discontinue caregiving and yet, feel guilty for allowing others to help. Caregivers <u>grieve the loss</u> of their independence and the life they once shared with their care receiver. Caregivers experience a deep sense of loss watching their loved ones slowly lose their capabilities. Self-identity is often lost while caregiving. Often social activities are restricted leading to a sense of <u>isolation</u>. Caregivers often experience an emotional distance from others who do not caregive. Frequently caregivers feel they are the only qualified person for the task of caregiving. This leaves the caregiver physically and emotionally <u>exhausted</u>. The caregiver often resents the care receiver for being a burden. They are often <u>angry</u> at themselves for not being able to say no to some of the demands. At times, a caregiver will attempt to isolate the care receiver who displays embarrassing behavior. Many caregivers feel the care they are providing is an opportunity to assist elders that helped them at one time. They feel a real sense of duty. A care receiver that is pleasant and grateful contributes to a sense of joy in the caregiver. Endearing memories of a loved one often give them strength to continue. A time of sharing occurs in certain caregiving situations. This often leads to closeness. The caregiver and the care receiver actually spend time together having meaningful exchanges. Caregivers are often thankful their loved one is still alive and takes pride in their capabilities as a caregivers.

The economic hardships of caregivers vary case by case. Overall, though, about 60% of caregivers are responsible for out-of-pocket expenses. On the average, the total monthly expense of caregiving is approximately 7% of the caregiver's monthly income. The additional expenditure is due to special diets, telephone bills, medicines, and travel expenses (Fradkin & Heath, 1992).

THEORETICAL FRAMEWORK

Social Group Work Theory

The Social Group Work Theory is being used to gain an understanding of the dynamics and structure of group work. This theory gives specific information describing how the group work process can actually help participants.

Social group work is defined as a method of working with individuals in a group setting. The acquisition of socially desirable goals and the enhancement of social functioning are the primary goals (Skidmore & Thackery, 1976). Konopka (1983) stresses that the individual is the focus in a group. The group setting is the vehicle in which individual enrichment occurs.

The development of a group is complicated and challenging. It is the responsibility of the social worker to guide group members in the group work process. Schopler and Galinsky (1995) describe the intervention processes of a group. The intervention processes include composition, assessment, goal setting and contracting, programming, and evaluation and termination.

In the composition realm, a social worker examines the size of the group and the characteristics of the members (gender, race, etc.). The purpose and needs of the group must be defined. The members should have a common reason for attending. This provides an atmosphere of shared interests and concerns. The membership should vary in communication styles and behaviors.

The assessment portion is an ongoing process. The social worker must pay close attention to how the group is evolving. Progress toward individual and group goals must continually be monitored.

In the goal setting and contracting phase, a consensus of goals for the group is pursued. This provides a baseline in which the progress of the group is measured. With the participation of group members in this process, a sense of ownership and self determination is established.

The actual programming of the group is determined by both group members and social worker. Often the use of discussion, role playing, and structured exercises help build a bond among the members.

In the evaluation and termination phase, the group members with the assistance of the social worker review past accomplishments and experiences. Goals of the group are reviewed to determine whether progress has been made. Affirmation for participation is given by the social worker. At this time, it is important to decide whether the group should continue. If the group does not continue, the social worker helps each member determine the kinds of support or caregiver activities that would be helpful to them in the future (Schopler & Galinsky, 1995).

Glassman and Kates (1990) explain that the differentiation between group process and group purpose must be identified in order to understand group work. Group process refers to the relationship between members as they relate to each other and the group facilitator. The purpose of the group is the common topic that brings group members together. The process and purpose must come together in order to form a group. In the beginning phase of the group, the process is emphasized. During the middle phase the purpose is the focus in a context of process. In this phase, common objectives for the group are defined.

Summary

The literature suggests that there are core benefits to participation in caregiver support groups. These factors are learning about resources in the community, gaining the ability to understand and communicate feelings about caregiving, receiving encouragement and understanding from other caregivers, obtaining educational information about chronic illness.

CHAPTER THREE: METHODOLOGY

Overview

The third chapter has eight sections that explain the overall structure of the study. The eight sections include research design, study questions, operational definitions, study population/sample, measurement issues, data collection, data analysis, and human subjects. Findings from this study suggest that caregivers benefit from participation in a caregiver support group.

Research Design

The purpose of this study is descriptive in nature. This survey research was completed by identified participants using a standardized, self-administered questionnaire. The questionnaire has both open-ended and closed questions. This research represents a qualitative method of research. The study population consists of family members that are caregivers to frail elderly adults. Typically the family members that need care are spouses, siblings, and parents.

Study Questions

What types of support do participants receive from caregiver support groups?

What are the benefits of participation in a caregiver support group?

To what extent do caregiver support groups alter the stress of caregiving?

Operational Definitions

The following are operational definitions for the variables in this study.

support: to corroborate or substantiate as it relates to an individuals pressures and concerns as a caregiver.

caregiver support group: professionally led/facilitated groups with caregivers as participants.

benefits: 1) realizing they were not alone with their concerns, problems, and pressure; 2) receiving encouragement and understanding; 3) gaining the ability to understand and communicate feelings about caregiving; and 4) sharing resources.

participation: 1) interaction with others in the group; 2) attendance at the group on a regular basis.

caregiver: a person that provides day to day care for another individual that is incapable of independent self care.

stress: emotional or physical pressure or strain.

frail elderly adults: a person with chronic health issues who is 55 years or older.

family members: sibling, spouse, or parents of the caregiver.

Study Population/Sample

The study population consists of family members that are caregivers to frail elderly adults. Typically the family members that need care are spouses, siblings, and parents. The unit of analysis in this study is individual people.

A total of 32 caregiver support group participants from three agencies completed a self-administered questionnaire distributed to each group by the researcher. This sample was considered convenient in that those that participated were limited to those that attended the caregiver support group the day the questionnaire was distributed. The agencies participating all provided professionally-led caregiver support groups to caregivers who provide care to a frail elderly adult family member. Typically the family members that need care are spouses, siblings, and parents. Caregivers will benefit from the knowledge obtained in this study. This study affirms and encourages caregivers to continue to participate in caregiver support groups by identifying the benefits.

The three agencies that participated in the study conduct professionally led/facilitated caregiver support groups for individuals who provide care to frail elderly adult family members. Those agencies were Dakota Area Resources & Transportation for Seniors (DARTS) in West St. Paul, Volunteer Respite Program of Anoka County in Anoka, and Family Service St. Croix in Stillwater. DARTS is a program in West St. Paul that provides a variety of services to senior citizens. The Volunteer Respite Program of Anoka County is a county program that provides services such as economic assistance, job training, adult protective services, child protective services, developmental disabilities unit, and family resource unit. Most volunteer respite programs in the metropolitan area are located in non-profit agencies. Family Service St. Croix provides mental health counseling. It has a small division, Services to

Seniors that provides outreach services and respite services to individuals in the St. Croix Valley. It also has a very large Consumer Credit Counseling program.

Two other agencies were invited to participate, but declined the invitation. Those agencies were Fairview Community Center in Roseville and Family Service St. Paul in St. Paul. Both agencies had difficulty complying with the scheduling of the study. Family Service St. Paul conducts caregiver support groups during summer months. Fairview Community Center had scheduling difficulties as well plus the process of deciding whether or not to would participate would have taken approximately two months to determine due to the Board of Directors meeting schedule. The Alzheimer Association also conducts caregiver support groups, but this organization was not invited to participate in the study.

Measurement Issues

The instrument was designed using variables identified in the literature. A possible issue of a systematic error (validity) that could interfere with the reliability of the instrument is social desirability bias and cultural bias. The subjects in the study were primarily Caucasian females. It is possible the subjects attempted to portray themselves and their caregiving habits in a way that would not accurately reflect their actual behavior. An example of random error (reliability) that occurred is that of the subject simply not knowing the meaning of social work jargon used in the instrument. The use of such jargon was minimized.

The instrument for this study was constructed based on identified variables.

Data Collection

The self administered questionnaire consists of both open-ended and closed-ended questions. The open-ended style is typically used in a face-to-face interview, but is also used in the self-administered questionnaire. The closed-ended questions are both exhaustive and mutually exclusive. By exhaustive, it is meant that the answer category had all possible responses. Mutually exclusive option, means that the respondent do not feel compelled to select more than one answer.

The consent form, questionnaire, and writing utensil were distributed by the researcher at the beginning of the group session to all individuals that were willing to participate in the study. Once completed, the consent forms and questionnaires were collected by the researcher. Consent forms and questionnaires were separated in order to insure anonymity.

Data Analysis

The study questionnaire was organized to yield qualitative data. All responses to open-ended questions (qualitative) used content analysis techniques. All responses to closed-ended questions were sorted and coded using descriptive statistical analyses. The statistical program used was the Statistical Package for the Social Sciences (SPSS.).

Human Subjects

An application for approval of research was submitted to the Augsburg College Institutional Review Board (IRB) prior to any contact with human subjects. With minor revisions, the IRB approved the study (#96-43-3).

All subjects in the study participated strictly on a voluntary basis. Both the researcher and the facilitator of the group mentioned this to all participants prior to the study. A script has been constructed (Appendix B) that was read to the participants by the group facilitator one session before the study was conducted. The researcher also read the script again prior to the distribution of the consent form and questionnaire. The researcher required all participants to sign a consent form to participate (Appendix C) prior to completing the questionnaire. The questionnaire and consent form were separated. The consent forms were sealed in a envelope and placed in a locked file cabinet at the home of the researcher. Once the study was completed, the consent forms were shredded. The questionnaire did not require a name or any other identifying information.

Summary

This chapter outlined the study questions and explained the study design. Operational definitions for support, caregiver support groups, benefits, participation, caregiver, stress, frail elderly adults, and family members were defined. The individuals being targeted in the study are individuals that are caregivers to frail elderly family members. These individuals attend caregiver support groups from three agencies in the Twin Cities Metropolitan Area. The study questionnaire was designed to yield qualitative data. The data was analyzed using content analysis techniques and the SPSS program. The human subjects in this study were asked to voluntarily participate and sign a consent form. The study was conducted with the approval of the Augsburg College Institutional Review Board. The purpose of the study was to explore participants perceived benefits resulting from their participating in a caregiver support group, confirm findings from previous studies, and possibly identify benefits not yet discovered.

CHAPTER FOUR: RESULTS OF STUDY

Overview

The fourth chapter describes the results from the caregiver support group study. There are two sections that describe the results of this study in the form of demographic information and research question responses (qualitative).

Study Overview

Over a period of four weeks, the researcher attended six caregiver support groups in the Twin Cities metropolitan area. Five of the groups met at community senior citizen centers, and one group met at a long term care facility. The attendance of the groups ranged from one to thirteen participants. All groups were facilitated by professional staff from Family Service St. Croix, Dakota Area Resources and Transportation (DARTS), or the Anoka County Volunteer Respite Program.

Participants of the caregiver support groups were asked to complete a self-administered questionnaire, consent forms were completed prior to the beginning of each group. Thirty-two participants agreed to complete the questionnaire with three participants declining.

Profile of Caregivers

The age of the caregivers ranged from 46 to 90 years old (53% of the group ranged in age between 61-75 years old) (Table 4.1). The age of the care receiver

Table 4.1

CAREGIVER AGE

YEARS	FREQUENCY
46-50 years of age	1
51-55 years of age	2
56-60 years of age	2
61-65 years of age	6
66-70 years of age	5
71-75 years of age	6
76-80 years of age	2
81-85 years of age	2
86-90 years of age	2
no response	4
TOTAL	32

ranged from 40 to 95 years old (Table 4.2). Seventy-one per cent of the caregivers were retired, and the participants were overwhelmingly female (94%). The majority of the participants had annual household incomes between $10,000 and $30,000 (25% of the respondents declined to answer this question). Fifty-six per cent of the respondents were married with 31% widowed. The race of the study participants were Caucasian (87%), Native American accounted for 6%, and the remaining 7% did not respond to this question. As illustrated in Figure 1, 50% of the group participants provided care to their husbands. Thirty-two per cent were providing care to their mothers. Results showed that 50% of the caregivers lived in the same household as the care receiver, with 50% stating that the care receiver lived elsewhere, or had died . The average length of time in the role of a caregiver ranged from one years to 25 years (Table 4.3).

The group meeting schedules varied from twice per month to once per week with most caregivers attending twice per month. Sixty-nine per cent of the participants indicated that they had not attended any other caregiver support groups except for the current group. Over half of the caregivers reported that they had attended the current caregiver support group for between one to two years (Figure 2). One participant indicated she had attended the group for eleven years.

While discussing the purpose of the study with participants, it was discovered that some caregivers were attending the group after their caregiving was no longer needed due to the death of the care receiver. Some participants were confused by the

TABLE 4.2

CARE RECEIVER AGE

YEARS	FREQUENCY
41-60 years of age	2
61-80 years of age	15
81-95 years of age	12
no response	3
TOTAL	32

Figure 1

Relationship of Caregiver to Receiver

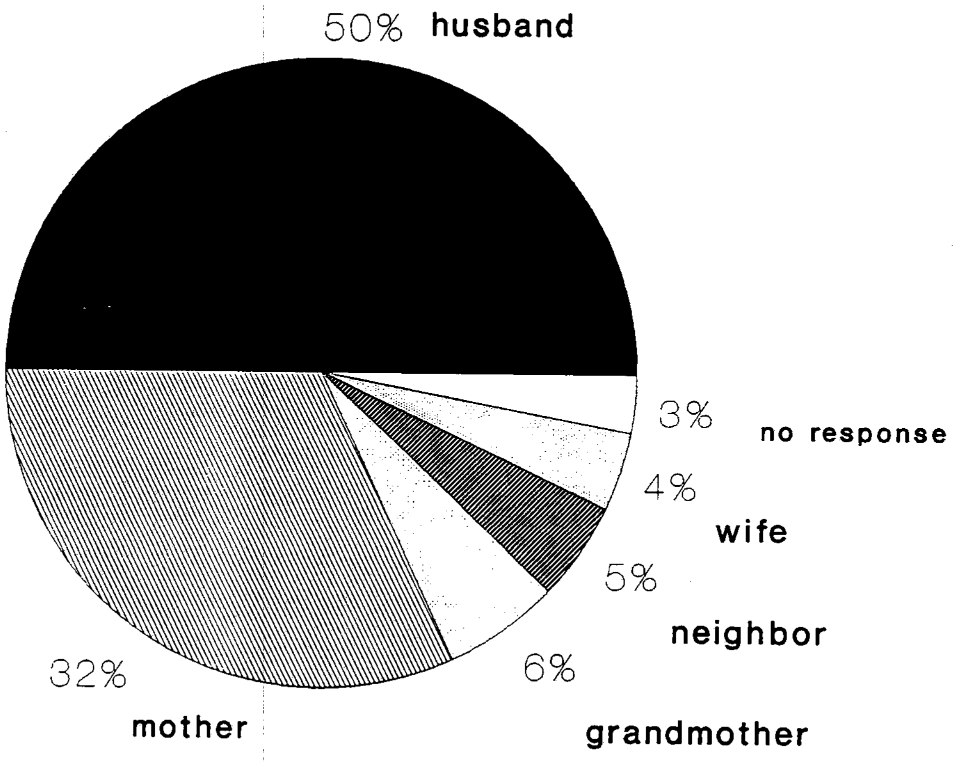


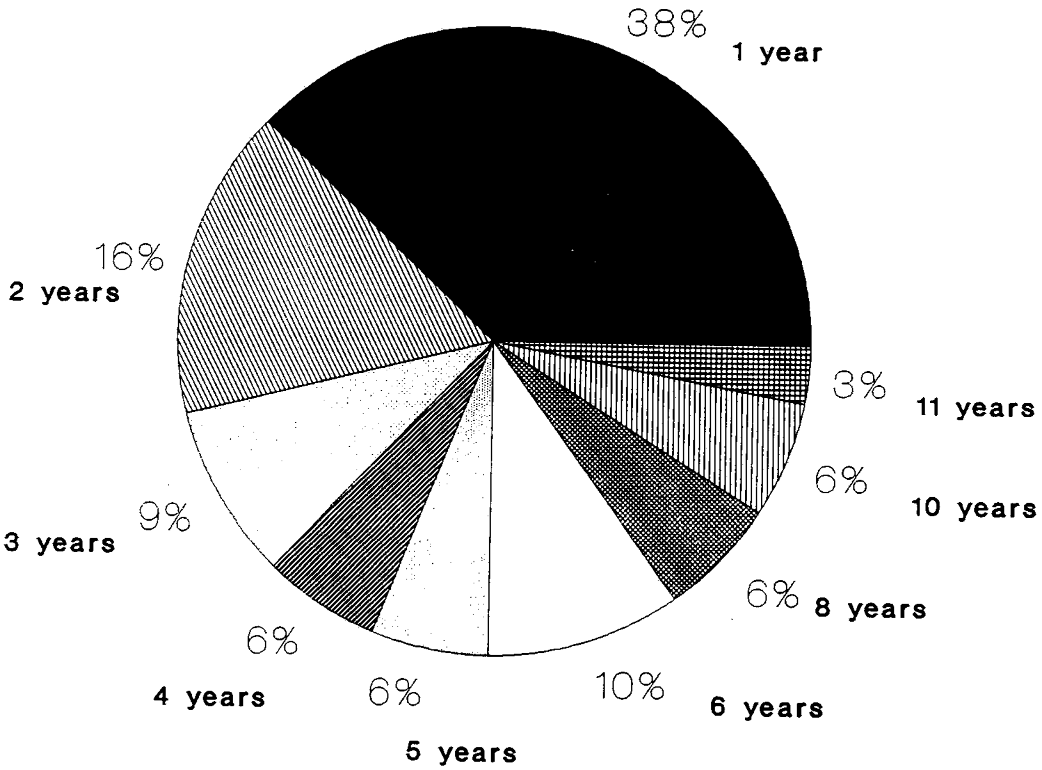
TABLE 4.3

LENGTH OF TIME AS CAREGIVER

YEARS	FREQUENCY
1-5 years	12
7-12 years	13
20 years	2
25 years	3
no response	2
TOTAL	32

Figure 2

Length of Time Attending
Caregiver Support Group



questionnaire because they had been a caregiver for multiple individuals at varied times over a number of years. They were not sure which caregiving situation they should address in the questionnaire. The caregivers also related that some care receivers no longer lived in the same housing unit, but lived in a long term care facility. Even though the care receiver lived off site, the caregiver still felt their level of responsibility as a caregiver was very high.

Research Question Responses

When the caregivers were asked to describe the types of support they receive by attending a caregiver support group, they responded by stating that receiving encouragement and understanding from other caregivers was the most important support they received. Next they stated that increased knowledge of resources, and a sense of not feeling alone were the second and third most common responses. The fourth most common response was that the group provided a place to vent frustrations. Lastly, the caregivers stated that they developed friendships and socialized during the group session. One person stated that the group helped her/him survive the death of her/his care receiver (Table 4.4).

When the caregivers were asked to state the actual benefits of participation in a caregiver support group, they responded by stating that the group provided them with the opportunity to leave the care receiver, and take a break from caregiving responsibilities and tasks. Secondly, the group members stated that the caregiver

Table 4.4

TYPES OF SUPPORT

RESPONSES
received encouragement and understanding from others that have actually been a caregiver
increased knowledge of resources
a sense of not feeling alone - that others face similar challenges
a place to vent frustrations
a place to socialize and develop friendships
surviving after the death of care receiver

support group was a place to express true feelings in an atmosphere of support, understanding, and confidentiality. Next, the caregivers stated that they learned about availability of resources and information pertaining to legal, medical and emotional concerns. Lastly, they stated that they had learned that feelings of frustration and anger are "normal" (Table 4.5).

When the caregivers were asked to what extent did participation in the group alter the stress of caregiving, they stated that they were more patient with the care receiver. They also stated that they had developed a sense of calm in a general state of uncertainty. Next, they stated that the expression of both the negative and positive feelings associated with caregiving and the care receiver helped alleviate stress they felt as a caregiver. Another stress reliever was socializing with other caregivers that understand the situation and feelings they experience day to day. The next most common response was that stress was relieved by having a respite volunteer come into the home to relieve the caregiver of day to day responsibilities and tasks. Lastly, one respondent simply stated that her/his ability to laugh had returned (Table 4.6).

Summary

The fourth chapter explained demographic information pertaining to the caregiver and care receivers in this study. The research question responses by caregivers demonstrated that the caregivers interviewed felt there were benefits to participation. The caregivers indicated that they received encouragement and understanding from

TABLE 4.5

BENEFITS OF PARTICIPATION

RESPONSES
a chance to leave the care receiver - have a break from caregiving duties and responsibilities
a place to express true feelings in an atmosphere of support, understanding, and confidentiality
availability of resources and information pertaining to legal, medical, and emotional concerns
to learn that feelings of frustration and anger are "normal"

TABLE 4.6

EXTENT THAT CAREGIVER SUPPORT GROUPS ALTER STRESS

RESPONSES
able to be more patient with care receiver
have developed a sense of calm in a general state of uncertainty
expression of negative and positive feelings
socializing with other caregivers that understand the situation and feelings
having a respite volunteer allows the caregiver to leave caregiving duties and care receivers
ability to laugh returned

others that have actually been a caregiver, and they increased knowledge of resources. The caregivers went on to say that the caregiver support group gave them an opportunity to take a break from caregiving duties, and the group was a place to express true feelings in an atmosphere of support, understanding, and confidentiality. The stress that comes with caregiving was minimized and demonstrated by the caregivers in that they felt they were more patient with the care receiver, and had developed a sense of calm in a general state of uncertainty.

CHAPTER FIVE: DISCUSSION

Overview

The fifth chapter provides a general discussion about the findings of the study, describes the strengths and limitations of the study, implications for social work practice, and implication for future social work research.

Caregiver Support Groups

All participants in the caregiver support groups in this study were invited to the group either by another member or the facilitator of the group. Caregivers are referred to the facilitator by many sources such as physicians, social workers or family members. A caregiver is allowed to participate whether or not the care receiver resides in the same home as the caregiver. Caregiving duties and responsibilities occur even though the family member is housed in a long term care facility.

All caregiver groups were structured similarly. Typically, the group began with the "check in" phase. All members that are willing to share are asked to give a brief comment about their status as a caregiver. Next, the facilitator comes equipped to discuss a predetermined topic. Occasionally, an outside speaker is invited to give a presentation. If a group member is in crisis, though, the group members with the facilitator's guidance will delay the predetermined topic for that day to assist the caregiver in either problem solving or simply providing emotional support through words of encouragement. The outside speaker for that session would not be allowed to participate in that portion of the group. In the closing portion of the group, the facilitator encourages the participants to reflect on the events of the group that day.

The group time is closely guarded by the participants. Some participants have a time limit due to the length of time a respite volunteer, family member, or friend is available to assist with the care receiver. Participants agreed to complete the questionnaire associated with the study, but made it clear that the researcher was not invited to stay beyond that time. It was also made clear by the facilitators that the researcher could come to the group one time only. The group time was too precious to have those that participated the first time be subjected to a second round of other participants completing the questionnaire.

As previously stated in Chapter 2, Theoretical Framework, the Social Group Work Theory supports the findings in this study. The group setting proves to be a positive environment for caregivers. The theory states that the acquisition of socially desirable goals and the enhancement of social functioning are the primary goals. The individual is the focus in a group and the group setting is the vehicle in which individual enrichment occurs.

The primary purpose of this study was to explore participants perceived benefits resulting from their participation in a caregiver support group, confirm findings from previous studies, and possibly identify benefits not yet discovered. The literature has revealed that the caregivers benefit from participation by learning about resources in the community, gaining the ability to understand and communicate feelings about caregiving, receiving encouragement and understanding from other caregivers, and obtaining educational information about chronic illness.

The original purpose and goal of this study has been achieved. The study has explored and described benefits resulting from participation in a caregiver support group. This study also confirms findings from previous studies described in Chapter 2, Literature Review. The discovery of benefits not revealed in the literature include the opportunity for caregivers to take a break from caregiving duties by attending the caregiver support group. Often this occurs with the assistance of a respite volunteer provided by the program that sponsors the caregiver support group. Next, caregivers described the development of friendships with other caregivers as a benefit. They also mentioned that the caregiver support group provides an opportunity to socialize with other participants. Occasionally the facilitator and participants use the regularly scheduled group time for holiday parties, and shared meals at restaurants. Another benefit to participation is the support a caregiver receives after the death of a care receiver. The facilitators report that approximately six months following the death of a care receiver, the caregiver stops attending the group. But immediately following the death of the care receiver, the group member rely on the group to provide support and general encouragement during the bereavement period (Table 5.1).

STRENGTHS AND LIMITATIONS

The sample was limited in that it was taken exclusively from caregiver support

TABLE 5.1

BENEFITS NOT REVEALED IN LITERATURE

--opportunity for caregivers to take a break from caregiving duties

--development of friendships

--socialization with other caregivers

--emotional support after the death of a care receiver groups in the Twin Cities metropolitan area, and was limited to 32 individuals. With such a small sample size, the findings were difficult to generalize. Plus due to poor weather conditions in March, fewer individuals attended the groups. Another limitation related to this study was that members of caregiver support groups might have had a concern that their non-participation in the study would affect their treatment in the group even though their participation was voluntary. Next, there was not much ethnic diversity in the groups. The researcher was not able to obtain a sample that gave a view of the minority population because the caregiver support group participants were predominantly Caucasion. Another limitation to this study includes using open-ended questions in a self-administered questionnaire. In this situation, the researcher did not have the time nor the opportunity to explain further or probe for more information. The caregiver support group participants were willing to complete the questionnaire as long as it could be completed in a brief amount of time (10-15 minutes). The group time was considered a precious commodity. Once the caregivers completed the questionnaire, they began conversing with other members. In one particular group, the facilitator encouraged the group members to begin the group with a "check in" while others were still completing the questionnaire. In one particular group, a participant was unable to read the questionnaire. The facilitator of the group read the questionnaire aloud which distracted other group members. At 5 out of 6 groups, at least one participant stated aloud that the questionnaire repeated the same question. Another participant stated that it made her anxious to be asked the same question repeatedly. All participants were encouraged to answer only the questions they were comfortable with answering. All facilitators reported that after the questionnaire were completed, participants wanted to talk about the experience. Participants that were late for the group were not given an opportunity to complete the questionnaire because it would have delayed the beginning of the group.

IMPLICATIONS FOR SOCIAL WORK PRACTICE

The social work profession should encourage the continuation and expansion of caregiver support groups. The funding for the existing programs is provided primarily through the State of Minnesota.

A companion piece to the caregiver support groups is the volunteer respite programs. Another area in which the social work profession should provide support and leadership is the volunteer respite program. The availability of respite volunteers is limited. The demand for volunteers exceeds the availability. If the general public had a better understanding of the role of a respite volunteer, possibly more individuals would participate. Even though the respite volunteer tasks are not complicated, the sense of responsibility can be overwhelming. Often prospective volunteers feel they possess inadequate nursing skills when in fact, the respite programs prohibit volunteers from assisting with skilled medical procedures. The volunteer also has a choice of how often they are available, and what level of care they feel comfortable providing.

The caregivers in this study seemed motivated to provide care as long as possible to their care receivers. They fear that the stress of caregiving compromises their own health leaving the care receiver vulnerable to institutionalization. The quality of life of the caregiver must be taken into consideration as well as the care receiver.

For individuals that are committed to preventing the institutionalization of a family member, services in the community must increase. There is a current trend in the United States to keep individuals living in the community. Maintaining family members in the community is considered more humane by providing quality care in the least restrictive environment. The cost of care is also significantly less. This approach requires more support from home-care services provided by skilled nurses and social workers. The social work profession must become actively involved in these services.

This study reveals that caregivers that have family members that are institutionalized participate in caregiver support groups. The level of care provided by the caregiver varies depending on the caregiver, the institution, and the level of care being provided to the care receiver. One caregiver support group in the study was housed in a long term care facility, but none of the members of the group had a care receiver that lived in that particular institution. Caregiver support groups should be provided on site to caregivers at the long term care facility in which the care receiver resides. The social worker in the institution could play a vital role in organizing and facilitating these groups.

IMPLICATIONS FOR FUTURE SOCIAL WORK RESEARCH

This study reached individuals that felt they benefited by attending caregiver support groups. The facilitators of the groups stated that there are caregivers that 1) attend one group and do not return, and 2) are never reached. Further research should be conducted that reach those that felt they did not benefit from a caregiver support group to determine what method of intervention would be helpful. What about individuals that are simply not comfortable in the group setting?

Further research should be done to determine the quality of care and longevity in the community of a care receiver when their caregiver does not attend a caregiver support group. Caregivers with a strong sense of responsibility, but no resources would most likely institutionalize the care receiver. What about the caregiver that continues to provide care without an outlet for support? Is there a higher incidence of elder abuse and neglect? For those that are not comfortable in a group setting, would a one-on-one mentoring program with a caregiver be more helpful?

Research should be done to discover why a person becomes a respite volunteer. Hopefully this could assist social workers in recruiting more volunteers, and increase the longevity of those that do step forward. Social work research could help determine what motivates an individual to become a respite volunteer.

Lastly, for caregivers that institutionalize a care receiver, a study could be conducted to determine what factors were involved that led the caregiver to decide that they could no longer be a caregiver. What are the actual responsibilities of a caregiver once the care receiver is institutionalized? Does the institution encourage or discourage the caregiver from participating in the care of the care receiver? As the study indicates, caregiving does not necessarily cease after the care receiver is institutionalized.

Summary

The fifth chapter's Discussion section described how the researcher interpreted the qualitative information obtained from the caregiver support group participants. The strengths and limitations of the study were identified. The Implications for Social Work Practice section outlined the importance of the social work profession assisting in the continuation and expansion of the availability of caregiver support groups. The Implications for Social Work Research section outlined the importance of continued research in the area of caregiving.

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APPENDICES

Appendix A

Caregiver Support Group: Benefits of Participation
QUESTIONNAIRE

Please answer the following questions as simply and honestly as possible. Respond only to the questions you are comfortable with answering. Thank you for your participation in this study.

I. CAREGIVER INFORMATION

1. How long have you been a caregiver?

2. Do you live in the same housing unit as the person needing care? Check one.

_____Yes _____No

3. What is your relationship to the person needing care?

4. Are you the primary person responsible for providing care to the individual needing care? Check one.

______Yes ______No

II. CAREGIVER SUPPORT GROUPS

5. How long have you attended this caregiver support group?

6. How often would you say that you attend groups?

7. In addition to this group, were you also involved in a caregiver support group in the past? Check one.

______Yes ______No (please go to question #9)

8. Please explain why you stopped going to that group.

9. Do you feel that your participation in the caregiver support groups helps you with caregiving? Check one.

______Yes ______No (go to question #11)

10. In what way do you feel the group(s) that you attend helps keeps you in your role as a caregiver?

11. Was there a particular event related to your role as a caregiver that prompted you to begin attending a caregiver support group?

12. Please identify the benefit(s) of participation in this caregiver support group.

13. Do you feel you have reduced the stress in your day to day life as a caregiver by attending this caregiver support group?

______Yes ______No (go to question #15)

14. Please explain how stress has been reduced in your day to day life.

15. What type of support do you feel you receive by attending this caregiver support group? Please explain.

16. Are there any other comments you would like to make about your role as a caregiver? If so, please explain.

III. DEMOGRAPHIC INFORMATION

17. What is your gender? (Check one)

_____Female _____Male

18. What is your race? Please check one.
_______a. African American
_______b. Asian American
_______c. Caucasian
_______d. Hispanic/Latin
_______e. Native American
_______ f. Other (please specify)____

19. What is the age of your care receiver (the person you are assisting)?

20. What is your current marital status? Please check one.
_______a. Divorced
_______b. Married/Domestic Partnership
_______c. Separated
_______d. Single (never married)
_______e. Widowed

21. What is your employment status? Please check one.
_______a. Not employed at this time
_______b. Employed part-time
_______c. Employed full-time
_______d. Retired
_______e. Other (please specify)_____________________________________

22. What is your age?

23. What is your household's total income for 1996, before taxes? Please check one.
_______a. Less than $10,000
_______b. $10,001 - $20,000
_______c. $20,001 - $30,000
_______d. $30,001 - $40,000
______ e. $40,001 - $50,000
_______f. $50,001 - $60,000
_______g. $60,001 - $70,000
_______h. more than $70,000

Thank you for your participation.

Appendix B

SCRIPT FOR CAREGIVER SUPPORT GROUP PRIOR TO STUDY

At the session prior to the distribution of the questionnaire, the principal investigator is requesting that the facilitator of the caregiver support group read the following statement:

NEXT SESSION YOU WILL BE ASKED TO PARTICIPATE IN A RESEARCH STUDY. PARTICIPATION IN THE STUDY REQUIRES THAT YOU COMPLETE A QUESTIONNAIRE AND CONSENT FORM. COMPLETING THE QUESTIONNAIRE SHOULD TAKE APPROXIMATELY 1/2 HOUR. THE STUDY IS BEING CONDUCTED BY CHAROLETTE MCINTOSH, A GRADUATE SOCIAL WORK STUDENT AT AUGSBURG COLLEGE. THE PURPOSE OF THE STUDY IS TO EXAMINE THE BENEFITS OF PARTICIPATION IN CAREGIVER SUPPORT GROUPS. THIS AGENCY IS NOT REQUIRING OR REQUESTING YOU PARTICIPATE IN THIS STUDY. YOUR PARTICIPATION IS YOUR DECISION AND IS STRICTLY VOLUNTARY. ALL DATA COLLECTED WILL BE KEPT CONFIDENTIAL. EACH PARTICIPANT IS BEING INSTRUCTED NOT TO DISCLOSE HIS/HER IDENTITY. ARE THERE ANY QUESTIONS? THANK YOU.

At the session in which the data is collected, the consent form and the questionnaire will be distributed. The script that was read to participants at the previous session by the group facilitator will be read again.

Appendix C

CONSENT FORM

CAREGIVER SUPPORT GROUP: BENEFITS OF PARTICIPATION

You are invited to be in a research study which is designed to determine whether there are benefits to participation in a caregiver support group. You were selected as a possible participant because you are a current caregiver support group participant. Please read this form and ask any questions you may have before agreeing to be in the study.

BACKGROUND INFORMATION:

The purpose of this study is to examine the benefits of participation in a caregiver support group. The particular caregiver that is being targeted are those who provide care for frail or elderly family members.

PROCEDURES:

Involvement in this study requires that you complete a questionnaire that the principal investigator of will be distributed during a caregiver support group. Once completed, return to the principal investigator.

RISKS AND BENEFITS OF BEING IN THE STUDY:

Participation does not involve psychological or physical risks. There is no direct financial benefit to you for participation.

CONFIDENTIALITY:

The results will be used to complete my thesis. Information will be reported in the aggregate which means that individual responses will not be identified. Neither the facilitator of the group or the any agency staff will have access to the completed questionnaires. Research records will be kept in a locked file; only the researchers (principal investigator and thesis advisor) will have access to the records. All raw data will be destroyed by December, 1997.

VOLUNTARY NATURE OF THE STUDY:

Your decision to participate or not participate will not affect your current or future relations with Augsburg College or the agency which sponsors the caregiver support group. If you decide to participate, you are free to withdraw at any time without affecting those relationships. Feel free to skip any questions on the questionnaire that you do not wish to answer.

CONTACTS AND QUESTIONS:

The researcher conducting this study is a Masters Degree student, Charolette McIntosh, Department of Social Work, Augsburg College. You may ask any questions you have now. If you have questions later, you may contact Charolette McIntosh at (612)430-3570 or Dr. Glenda Dewberry Rooney, thesis advisor, Augsburg College, (612)330-1338.

You will be given a copy of the consent form to keep for your record.

STATEMENT OF CONSENT:

I have read the above information. I have asked questions and received answers. I understand that my participation is voluntary. I consent to participate in this study.

SIGNATURE______________________________________ DATE____________

SIGNATURE OF RESEARCHER________________________ DATE____________