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Caregivers: Reasons for Support Group Attendance

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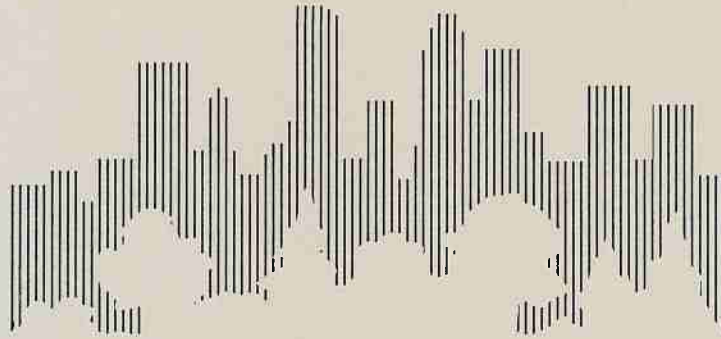
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MASTERS IN SOCIAL WORK THESIS

Nancy Jean Coryell

**Caregivers: Reasons for Support
Group Attendance**

1993

**MSW
Thesis**

Thesis
Coryell

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Nancy Jean Coryell

Master of Social Work Thesis

April 15, 1993

MASTER OF SOCIAL WORK
AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA

CERTIFICATE OF APPROVAL

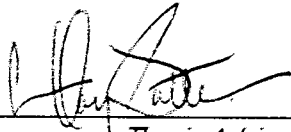
This is to certify that the Master's thesis of:

Nancy J. Coryell

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

Date of Oral Presentation: April 15, 1993

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Thesis Advisor



Thesis Reader



Thesis Reader

To my husband Cory
for the numerous times he lifted my spirits
and gave me the courage to pursue a dream

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ABSTRACT OF THESIS

This study examined the self-reported reasons informal caregivers of frail persons 65+ attend time-limited psychoeducational support groups. Results indicated that caregivers in this study attended support groups for practical information (community resources), relief of emotional stress, and skill development. Results also indicated that caregivers of spouses attended the support groups for different reasons than did caregivers of non-spouses. Caregivers of non-spouses tended to be experiencing more emotional strain and anger, and were receiving less emotional support from friends and relatives. Limitations of this study included small sample size, lack of variance in geographic location of the support groups, and lack of representation of diverse ethnic cultures. Additional study is required to further explore this area of research.

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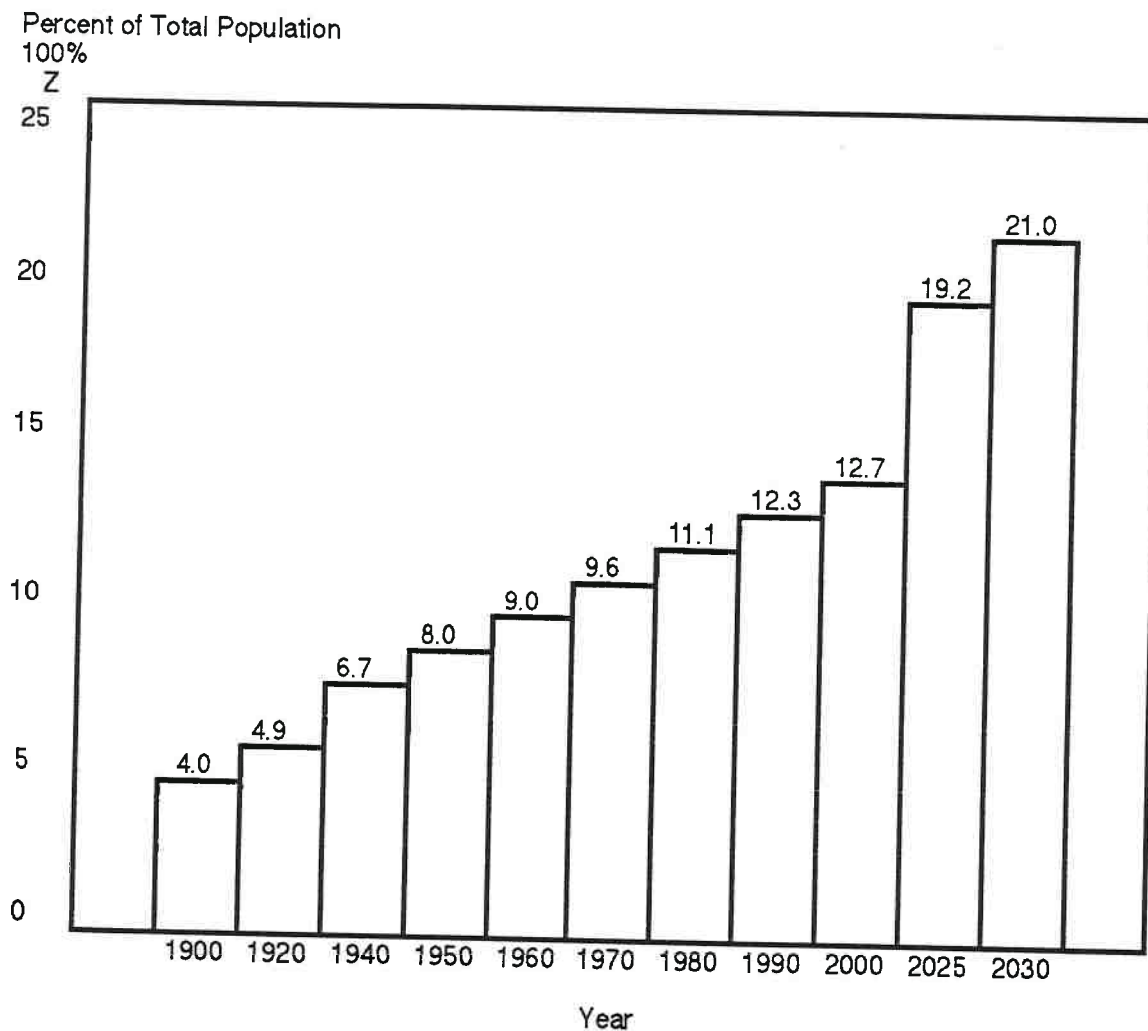
XII. Bibliography

Caregivers: Reasons For Support Group Attendance

I. Introduction

The 20th century has seen a rapid increase in the population of adults sixty-five years of age and older. Not only has this population segment increased in number it has also increased in proportion to the total population.

Figure 1: Annual Estimates of the Population: 65 Years and Older



Source: Historical Statistics of the United States: Colonial Times to 1970. United States Department of Commerce Bureau of Census. Washington, DC., 1975. Statistical Abstract of the United States. United States Department of Commerce, Washington, DC., 1992. Projections of the Population of the United States, By Age, Sex, and Race: 1988-2080. Current Population Reports. Series P-25. 1018 Washington, DC., January, 1989.

In 1900, the population of adults 65+ was estimated to be 3 million or 4% of the total population. This rose to 25 1/2 million (11.1 % of the total population) in 1980 and is expected to rise to an all time high of 64 million by 2030 (21% of the total population) (Stevens, 1990; American Association of Retired Persons, 1986). This means by the year 2030 one out of five persons in the United States will be 65 years of age or older (United States House of Representatives, 1987).

Table 1
Actual and Projected Life Expectancies at Birth and at Age 65 for
Men and Women: 1900-2080

Year	Life Expectancy at Birth		Life Expectancy at Age 65	
	Male	Female	Male	Female
Actual:				
1900	46.3	48.3	11.3	12.0
1910	48.4	51.8	11.4	12.1
1920	53.6	54.6	11.8	12.3
1930	58.1	61.6	11.8	12.9
1940	60.8	65.2	11.9	13.4
1950	65.5	71.0	12.7	15.0
1960	66.8	73.2	13.0	15.8
1970	67.0	74.6	13.0	16.8
1980	70.1	77.6	14.2	18.4
Projected:				
1990	72.1	79.0	15.0	19.4
2000	73.5	80.4	15.7	20.3
2010	74.4	81.3	16.2	21.0
2020	74.9	81.8	16.6	21.4
2030	75.4	82.3	17.0	21.8
2040	75.9	82.8	17.3	22.3
2050	76.4	83.3	17.7	22.7
2060	76.8	83.8	18.1	23.1
2080	77.8	84.7	18.8	23.9

Source: 1900 to 1940: At Birth: National Center for Health Statistics. Vital Statistics of the United States, 1980. Vol. II- Mortality. Hyattsville, MD. 1985. At Age 65: Social Security Administration. Social Security Area Population Projections. 1985. Actuarial Study No. 95. SSA Pub. No. 11-11542. October 1985. 1950 to 2080: U.S. Bureau of Census. Projections of the Population of the United States, By Age, Sex, and Race: 1988 to 2080. Current Population Reports. Series P-25. No. 1018 Washington, DC. January, 1989. Table B-5. (Ways and Means Committee, 1991, p.1098).

Table 1, created by the Ways and Means Committee of the United States House of Representatives in 1991, shows that in 1900, the life expectancy at birth for females was 48.3 years and 46.3 years for males. In 1980, life expectancy at birth rose to 77.6 years for females and 70.1 years for males. This represented an increase of 29.3 years for females and 23.8 years for males over the course of eighty years. By the year 2080 life expectancy at birth is expected to reach 84.7 years for females and 77.8 years for males.

This increase in life expectancy is a result of a decrease in infant and child mortality. It is also the result of persons who reach adulthood living longer (Committee on Ways and Means, 1991). A female reaching the age of 65 in 1980 can expect to live an additional 18.4 years; a male reaching the age of 65 in 1980 can expect to live an additional 14.2 years. By the year 2000 a female reaching the age of 65 is expected to live 20.3 years longer; a male reaching the age of 65 can expect to live an additional 15.7 years. This means persons reaching the age of 65 in the year 2000 can expect to live to the age of 85 if they are a female and to almost 80 if they are a male (Committee on Ways and Means, 1991).

In addition to an increase in population and age expectancy is the increased occurrence of age-associated health and physical ailments (Ward & Tobin, 1987). The older a person becomes the greater the likelihood of chronic illness (Rivlin & Wiener, 1988). It is estimated that 58% of the persons 85 years of age and older, the fastest growing segment of the senior population, are in some way disabled (Rivlin & Wiener, 1988). It is persons 85+ who have the greatest need for health and social services, who are at the greatest risk of chronic illnesses (osteoporosis, heart disease, strokes, Alzheimer's disease, etc.,) and who have the greatest dependence on the assistance of others. (Rivlin & Wiener, 1988). By 2050, this subgroup of persons 85+ is expected to

represent 16.1 million persons or 5.2 % of the total United States population (Taeuber, 1983).

The increased occurrence of age-associated health and physical ailments linked with an increase in medical technology and life expectancy will result in an expansion of persons who are very old and chronically ill (Monahan, Greene, & Coleman, 1992). This creates new roles and extended responsibilities for family members (Monahan, et al., 1992). These responsibilities can create an additional concern for their loved one's safety and health. They can cause an increased demand on family members' personal freedom and time, and result in a disruption of daily schedules, vacation plans, and social and leisure activities. (Horowitz, 1985).

In response to these extended roles and responsibilities caregiver support groups have been formed throughout communities. However, each caregiver who participates in a support group enters with different needs and expectations (Zarit, 1990). This study explores the needs of caregivers who attend time-limited psychoeducational support groups. This study asks:

1. What are the self-reported structural characteristics (length of time caregiving, relationship to person they are caring for, living arrangements, etc.) of caregivers who attend time-limited psychoeducational support groups?
2. What are the self-reported reasons informal caregivers attend time-limited psychoeducational caregiver support groups?
3. What are the self-reported needs for different types of information and assistance of caregivers who attend time-limited psychoeducational caregiver support groups?
4. What are the self-reported strains, feelings, and social supports of caregivers who attend time-limited psychoeducational support groups?

Answers to these questions will better equip social service agencies in developing and implementing support group interventions which focus on the immediate self-reported concerns, situations, and needs of caregivers. This is significant because it addresses information needed to guide policy, planning, and practice decisions in agencies implementing informal caregiver assistance.

II. A Review Of The Literature

Changes In Societal Trends

Throughout the ages families in the United States and across the world have provided care for family members who became dependent due to the mental and/or physical effects of chronic illness. This is not a new occurrence. Yet, today there exists a new awareness among service providers and researchers of recent social, economic, and demographic changes in our society which affect caregiving (Biegel, Sales & Schulz, 1991). Biegel et al. (1991) identify eight of these key changes in societal trends and issues:

1. Life expectancy and the aging of the population have increased dramatically during this century.
2. There has been a shift in the epidemiology of disease from acute to chronic diseases as well as a decrease in accidental deaths, resulting in an increase in the number of persons with limitations on functional activity and mobility.
3. There have been decreased death rates for heart disease and stroke, and five year cancer survival rates have increased.
4. There have been an increase in multigenerational families resulting in a growing number of elderly caregivers.
5. Family structures are changing due to declining fertility rates and the increasing divorce rate.
6. Greater numbers of women, the traditional caregivers, are in the labor force.
7. Concern about the increasing costs of institutional care for the elderly has led to the development of a number of state level initiatives to support caregivers that are aimed at delaying or preventing institutionalization.

8. Changes in health care reimbursement and medical technology have increased responsibilities of family caregivers (pp. 9-16).

Horowitz (1985) reported it was during the 1970's that social and health care professionals began to recognize and examine the family's role of caregiver. Professionals realized families were providing a critical supportive service and that these supportive services were a major factor in delaying nursing home placement (General Accounting Office, 1971). Research studies found that persons 65+ with family caregivers entered nursing homes at higher levels of disability than did those entering with no family support (Barney, 1977; Dunlop, 1980; Townsend, 1965).

Another study comparing costs between home care and public expenditures found that family and friends of the frail person 65+ were absorbing the largest portion of costs. Families provided for 80% of all home health care costs (National Center for Health Statistics, 1979). And 80% of frail persons 65+ depended on their family for home health care needs (Garland, Dean, Gurland, & Cook, 1978). It was estimated that for every one nursing home resident there were two persons 65+ with like disabilities being cared for by family members in the community (Shanas, 1979). It was during the 1970's that the academic community and the professional community began to realize not only the strengths of the family as a caregiver, but also the family's limitations (Horowitz, 1985).

This realization by professionals was coupled with social and demographic needs (Horowitz, 1985). The decade of 1970's saw not only an increase in the growth of persons 65+, but it also realized a decrease in family size, an increase of women in the paid labor force, and an increase in divorce rates (Horowitz, 1985). There were the sociological changes of urbanization and industrialization, along with rapid social change, and increased social mobility

and technology (Rando, 1984). The family as an institution changed with the extended family of the past replaced with the isolated nuclear family (Rando, 1984). Families also faced new limitations of fewer resources and support systems due to increased geographic and social distance. These changes in societal trends had a direct influence on the ability of families to care for a frail family member (Horowitz, 1985). Families were no longer able to bear the burden of support alone.

Gallagher's (1985) research found that in 1978 there was increased public awareness about Alzheimer's disease and the development of self-help organizations to aid families with family members suffering from degenerative brain disorders. She found that with this awareness came a sudden "press for services" from family members caring for a disabled family member. Because of the urgent need of services social service agencies were unable to research possible interventions and instead developed and implemented intervention programs designed to meet public demands. She reported it has only been in recent years that major research has begun on caregiver intervention.

Caregivers

Hamlet and Read (1990, p.75) define primary caregivers as "those persons who have the greatest direct involvement in the provision of informal supports to the frail elderly." National caregiver studies by the American Association of Retired Persons (1988) found that most caregivers are female family members, 57.3 years of age, daughters assisting their parents, and married. They also found younger caregivers were most likely to be married, female, and mothers. Better known as the "sandwiched generation " or the "women in the middle" (Brody, 1981) due to their being in-between caregiving responsibilities of their parents and family responsibilities.

Caregiving is defined by Horowitz (1985, p.195) as "an older person's need for assistance rather than any predefined behavior on the part of the caregiver." Therefore, caregiving experiences and activities can vary vastly among caregivers and range from an occasional errand to 24 hour a day care for a person who is bedridden. She says this is why it is difficult to define the critical elements or concepts of caregiving. For the purposes of this research Horowitz's (1985) conceptualization of caregiving behavior will be used. These concepts of the caregiving relationship include emotional support, direct service provision (errands, housekeeping, meals, health care, etc.), mediation with organizations, and financial assistance.

Caregiving Impact

Caregiving impact also varies among caregivers. Studies by Montgomery, Gonyea and Hooyman (1985) found that some family members find the caregiving role to be satisfying and others find the role to be stressful and burdensome. As a result they conceptualized caregiver burden in the dyad of subjective burden (feelings, emotions, and attitudes) and objective burden (events, activities, and happenings). Montgomery et al. contend that distinguishing between objective and subjective burden is important in that neither understand the causes and the consequences of each other. Therefore, an intervention intended to reduce the burden of one would not necessarily reduce or alter the burden of the other. For example, a caregiver may simultaneously experience low levels of objective burden and high levels of subjective burden at the same time.

Although very few studies have been conducted on the satisfactions related to caregiving, Horowitz's (1985) research indicates that most caregivers can identify at least one positive aspect of the role of caregiving. She found many caregivers find the caregiving role gives them a feeling of self-respect and

self-satisfaction due to their ability to cope with the situation and successfully fulfill the responsibility. She reported that the caregiving role can strengthen family relationships, relieve worry over proper care of the family member, serve as a role model for younger children, and put other stresses in proper perspectives. However, she cautioned, the caregiving experience does vary considerably between families and the professional must remember what is a positive aspect for one family may be a negative aspect for another family.

Theoretical Framework

Gallagher (1985), and Stevens and Hobfoll (1990) found that even though professionals continue to try to understand the stress and strain experienced by caregivers of frail adults 65+ very little has been done to test models of caregiver coping that can be used as a basis for intervention research. However, Gallagher reported that there have been studies of caregiver interventions of children with chronic diseases which have been applied by professionals to design and implement interventions for caregivers of frail adults 65+. She refers to three such models: the anticipatory grief model, the stage model, and the naturalistic coping strategy model. Horowitz (1985) refers to the theory of shared functions.

The Anticipatory Grief Model:

The anticipatory grief model suggests that the caregiving process be looked upon as an anticipatory mourning process that needs recognition through a caregiver intervention program (Rando, 1986). The model looks at the value of mourning by the caregiver prior to the actual death of the care receiver and contends that persons adapt better if anticipatory grief can be acknowledged and begin to be dealt with when the diagnosis is made (Gallagher, 1985). There are three aspects of anticipatory grief: psychological aspects, sociocultural aspects, and interpersonal aspects (Rando, 1984).

The psychological aspects of anticipatory grief include the emotional responses of anger, guilt, sorrow, and anxiety. These emotions are a result of the day-to-day physical separations, losses, and changes occurring in the relationship between the caregiver and the care receiver (Rando, 1984).

Anger comes from feelings of frustration, helplessness, and lack of control over a situation which is generated by a continuing process of loss (Rando, 1984). As time goes on financial resources may be drained and, despite the sacrifices, the loved one's health and abilities may continue to decline. The care receiver may no longer be able to fulfill the dependency needs of the family. This involves a shifting of roles and responsibilities to other family members and can result in anger within both the caregiver and the care receiver.

Anger can also be a result of personality changes due to the illness of the care receiver. It can result from disappointment over unfulfilled ambitions, expectations that will never be realized, and unfinished business between the caregiver and the care receiver. Caregivers need permission to appropriately express anger and know that it is a normal emotional reaction to loss (Rando, 1984).

Caregivers may experience feelings of guilt. Rando (1984) explains that caregivers often experience guilt when :

- a. they feel they have fallen short of their self-image.
- b. they recognize their anger and hostility towards the person.
- c. they have interpersonal conflicts during the illness.
- d. they feel responsible for the illness.
- e. they wish the end would come.
- f. they enjoy other aspects of life.

- g. they have unrealistic self-expectations that if s/he really loved the person s/he would only focus on the frail person (p. 345).

Sorrow is the sadness, pain, and anguish family members feel during anticipatory grief (Rando, 1984, p.342). Many times family members are afraid they will be overwhelmed with sorrow and distance themselves emotionally and/or physically from the disabled or dying person (Rando, 1984).

Caregiver anxiety associated with anticipatory grief is a result of continual and unpredictable losses and changes that occur as the care receiver's illness progresses. This, along with the inability to control what is happening, can cause intense frustration and anxiety for a caregiver (Rando, 1984). Rando (1984) states some common causes of caregiver anxiety are:

- a. The frightening sense of helplessness a caregiver can feel when a loved one is endangered and the outcome cannot be altered.
- b. The flood of intense emotion a caregiver can experience as the loved one's illness progresses.
- c. The caregiver's gradual loss of their loved one.
- d. The intense separation anxiety caregivers experience over the anticipation of parting from their loved one.
- e. The caregiver's contemplation of their own death (p. 344).

The interpersonal aspects of anticipatory grief are the rippling effects grief has on a person's family system. Systems theory views the family as a unit in which the sum of the individuals within the family is greater than the total of its individual members (Rando, 1984). Any stress or strain affecting one member of the family affects the whole family, and any stress or strain that affects the family unit as a whole affects each individual family member. As a result, the family as a unit is continually adjusting to change and struggles to maintain a balance. This

assures a reasonable amount of comfort and function for all family members and allows the family to function as a unit as well as individuals (Rosen, 1990). In order to do this the family unit develops rules, roles, communication patterns, and expectations of behavior, that reflect their coping strategies, system alliances, and coalitions. This keeps the family system in balance (Rando, 1984).

When an internal force such as illness or death occurs it challenges the family to adjust and regain equilibrium (Rosen, 1990). At the time, or close to the diagnosis, a disruption occurs within the homeostatic balance of the family system. Communication becomes more difficult as family members individually adjust to the diagnosis each at a different rate and degree of acceptance. Expectations are altered in anticipation and recognition that a family member will no longer function in the same capacity and will eventually not be a part of it. This creates a demand for change and adaptation for individual family members and the family unit as a whole (Rando, 1984).

Illness and death also cause considerable stress reactions within the family. Each family unit has a different ability to adapt in times of severe stress and many are closed systems with non permeable boundaries making it impossible for the dying or debilitated person to talk about her/his illness and eventual death (Kalish, 1985). Family units which remain open and have permeable boundaries share the pain and allow themselves to let go emotionally. These families are able to envision themselves continuing on without the presence of the ill person. They establish a balance of simultaneously letting go and holding on to the family member. Only in an open family system can such a process take place (Rosen, 1990). Anticipatory grief allows for purposeful planning and interaction between family members to assure the future well-being of the family (Rosen, 1990).

The sociocultural aspect of anticipatory grief is the lack of balance a family experiences as it shifts individual role assignments and begins to adapt to necessary realignments in the family structure. Individual family members begin to envision a future time in which their loved one no longer exists (Rando, 1986).

This experience takes on different dimensions for caregivers caring for a parent and caregivers caring for a spouse. When a parent becomes increasingly dependent it creates the stress of role adjustment for both the parent and the child. It is a dependency shift within a parental/child relationship that has evolved after years of shared experiences and interaction (Rando, 1986). Parental death means becoming the oldest generation, changing roles, being orphaned, and ending the opportunities to complete unfinished business (Rando, 1986). It can also mean the relief of caregiving responsibilities (Rando, 1986).

When a spouse of a person becomes increasingly dependent s/he experiences the stress of role adjustment and the loss of someone close to her/him. Over a period of years they developed together a network of close relations and shared experiences. There are memories of their courtship when their relationship began and memories of love and sharing together their hopes, secrets, tears and joys (Kalish, 1985). Suddenly, and unexpectedly, the dreams of the future are shattered and are gone forever.

The Stage or Phase Model:

Fortier and Wanlass (1984) proposed a stage or phase model which consists of five steps a person processes through in adapting to the crises: impact, denial, grief, focusing outward, and resource mobilization. Gallagher (1985) contended that caregivers go through these stages when adjusting to a family member's increased need and dependency. She found that after the impact of the diagnosis or crises, recognition and concern were followed by

denial, anger, guilt, and sadness as both the caregiver and care receiver attempt to cope with the situation.

The Naturalistic Coping Strategy:

The naturalistic coping strategy contends that specific mechanisms are related to caregiver well being and adjustment: the caregiver's ability to maintain family integration, the caregiver's understanding of the care receiver's diagnosis, and the caregiver's ability to establish and maintain a social support network (Gallagher, 1985).

Stroller and Puglieski (1989) look at the multiple demands on the caregiver's time and the competing commitment of multiple personal roles as potential "role overload" on the part of the caregiver. Many caregivers find that the caregiving role increasingly consumes all of their available time making it difficult to maintain friendships, fulfill employment responsibilities, and take care of other family obligations. Often what happens is that the caregiver does not realize until it is too late and her/his own health fails that s/he is taking on too much (Jacob, 1989). Caregivers need to know the danger signals of when they are approaching role overload so they can seek outside help (Jacobs, 1989).

Jacob's (1989) lists the following danger signals of caregiver overload:

1. Your relative's condition is worsening despite your best efforts.
2. No matter what you do, it isn't enough.
3. You feel you're the only person in the world enduring this.
4. You no longer have any time or place to be alone for even a brief respite.
5. Things you used to do occasionally to help out are now part of your daily routine.
6. Family relationships are breaking down because of the caregiving pressures.

7. Your caregiving duties are interfering with your work and social life to an unacceptable degree.
8. You're in a no-win situation just to avoid admitting failure.
9. You realize you're all alone-and doing it all - because you've shut out everyone who's offered help.
10. You refuse to think of yourself because "that would be selfish" (even though you're unselfish 99 percent of the time).
11. Your coping methods have become destructive: you're overeating or undereating, abusing drugs or alcohol, or taking it out on your relative.
12. There are no more happy times: loving and caring have given way to exhaustion and resentment, and you no longer feel good about yourself or take pride in what you're doing (p. 6).

The Theory of Shared Functions:

The theory of shared functions contends that in order to achieve a goal in caring for frail persons 65+ there needs to be a coordination of efforts and involvement by both the primary caregiver and the formal organization. Both have roles to play in the caregiving relationship (Dobrof & Litwak, 1977; Dono, et al., 1979; Litwak, 1965; Litwak & Figueira, 1968; Litwak & Meyer, 1974). Some tasks are performed better by the primary caregiver (non-uniform tasks which are simple and unpredictable) and some by the formal organization (uniform tasks of knowledge and resources). This model calls for a working together of these two sectors in order for caregiver needs be met. If a person 65+ can only rely on her/his family for her/his needs, or only on the formal organization, or if the two sectors work at cross purposes, service to the older person will be unbalanced and some needs will remain unmet (Lebowitz, 1978).

Support Groups

In response to the potential and actual burdensome effects of caregiving on the family caregiver, support groups have been formed throughout communities. Usually these programs are conducted on a time-limited basis meeting from every week to once or twice per month for six to ten weeks (Gallagher, 1985). Groups are generally facilitated by self-help organizations or by professionals in agency/service settings and consist of six to twenty participants per group (Gallagher, 1985). Program content varies from group to group with most programs focusing on dual themes of practical concerns (legal questions, funeral arrangements, etc.) and feelings (depression, grief, or anger). The format of the session usually begins with a specific topic of interest and is followed with a time of group interaction and discussion (Gallagher, 1985). Jacobs (1989, p.11) identifies the following six activities as the foundation of most caregiver support group formats: information sharing, personal sharing, mutual support time, problem solving, guest speakers, and socializing.

Caregivers who self-initiate participation in a support group are heterogeneous in that they have different goals or reasons for attendance (Zarit, 1990). Some persons enter the group because they want to prevent the caregiving experience from becoming stressful, others enter the group because they are distressed and in a current crisis (Zarit, 1990). And even if a caregiver is distressed s/he may have as a primary goal for participation not help for personal distress such as depression, but rather the need for information on how to assist, cure, or control the care receiver (Zarit, 1990).

There are clear factors which influence the primary reasons caregivers participate in a caregiver support group. These factors include a seeking by the caregiver of a wide variety of information and assistance involving the emotional/social aspects of caregiving, the need for practical information

regarding caregiving, and the need for information dealing with the skills involved in caregiving (Jacobs, 1989). Jacobs (1989) breaks down these factors as follows:

Emotional/Social Issues of:

Coping with death and dying
Preparing for widowhood
Dealing with personality conflicts
Family relations
Taking care of self
Leisure time
Dealing with social/sexual deprivation
Understanding/accepting role reversal
Maintaining self-esteem
Appropriate expressions of anger

Practical Information of:

Legal issues
Accessing community resources
Combining formal and informal services
Stages of Alzheimer's Disease
"Normal" and "abnormal" aging
Respite care
Entitlements
Relinquishing home care for institutional care
Housing options
Home safety

Skill Development of:

Household tasks

Balancing responsibilities
Provision of personal care
How to ask for and accept help
Techniques for handling problematic situations
Time management
Long distance caregiving
Decision-making
Case management
Administration of medications and health care (p. 14)

It has generally been assumed that caregiver goals and group intervention goals are synonymous (Zarit, 1990). However, this is not necessarily the case. For example, the goal of the group intervention may be to reduce depression or burden when, in fact, many caregivers report having no feelings of depression or burden (Zarit, 1990). Other goals of the intervention may be to reduce anger or anxiety when, in fact, many caregivers report having no feelings of anger or anxiety (Zarit, 1990).

Zarit (1990) contends that it is unrealistic for a support group intervention of eight to ten weeks to cover all of the aspects and possible negative consequences of caregiving. He states as an example that perceived burden on the part of the caregiver may involve financial burden, role conflict, role overload, role loss, emotional strain, and physical strain. An eight to ten week intervention may cover some of these issues, but it is unlikely to cover adequately and thoroughly any one area.

What needs to be addressed is what support group participants want to get from the program. What are their immediate concerns? Perlman's (1957) problem solving theory emphasizes the importance of looking at a person's immediate concern and the presenting difficulties in the person's environment.

Effective intervention begins where the client is and her/his perception of the problem. Not until this problem is dealt with can a person move on.

III. Methodology

Research Questions:

This study addresses the following questions:

1. What are the self-reported structural characteristics (length of time caregiving, relationship to person they are caring for, living arrangements, etc.) of caregivers who attend time-limited psychoeducational support groups?
2. What are the self-reported reasons informal caregivers attend time-limited psychoeducational caregiver support groups?
3. What are the self-reported needs for different types of information and assistance of caregivers who attend time-limited psychoeducational caregiver support groups?
4. What are the self-reported strains, feelings, and social supports of caregivers who attend time-limited psychoeducational support groups?

Definition of Terms:

Primary caregiver: The person most frequently involved and responsible for coordinating and providing care required by the care receiver (Pierce, Ader, & Peter, 1989; Hamlet & Read, 1990).

Informal caregiver: The relative or friend giving care on a day to day basis outside of a professional setting.

Frail elderly: Existence of some disability which limits an individual 65 years of age and older from participating in major social and recreational activities (Horowitz, 1985). Some studies narrowly define frail elderly as persons who are bed and/or housebound with similar characteristics of those persons who are in nursing homes (Horowitz, 1985). For the purposes of this study the first definition will be used.

Psychoeducational caregiver support groups: Professional led groups for informal caregivers of frail persons 65+ and younger adult persons needing continual care.

Time-limited: Seven to eight week duration.

Administrative Design:

Prior to the initiation of this study, approval was given by the Institutional Review Board of Augsburg College. Approval was granted from Dakota Area Resources and Transportation for Seniors (DARTS), West Saint Paul, Minnesota (Dakota County) and Ebenezer Community Services, Minneapolis, Minnesota (Hennepin County) prior to data collection. The principal investigator also met with the staff of both agencies to further explain the research and answer questions.

Sample:

The sample for this study was originally to be comprised of caregivers attending the first session of the January/February caregiver support groups offered by DARTS and Ebenezer Community Services. These two agencies were selected because they offered time-limited psychoeducational support groups for caregivers of persons who are elderly. Another reason for the selection of these agencies was the geographic difference of support group location. DARTS conducts support groups in a variety of locations in Dakota County and Ebenezer Community Services in various locations of Hennepin County. The diversity in location was important in that the data collected would be from a large cross-section of people representing different cultures, economic resources, and geographic locations in the Minneapolis/St. Paul metropolitan area.

Just prior to the distribution of the study questionnaire Ebenezer Community Services denied the principal investigator access to its support

groups. It was felt by Ebenezer Community Services that participation would involve too much group time and might be harmful to study participants. Ebenezer Community Services did allow the principal investigator to pretest the study questionnaire at its Edina caregiver support.

The final sample was comprised of fifteen informal caregivers of elderly persons attending the DARTS winter caregiver support groups which began in January/February, 1993. Two groups were offered one in Burnsville, Minnesota at the Burnsville Senior Center and the other in Mendota Heights, Minnesota at the St. Peter's Church. Due to the time constraints involved in obtaining agency and Institutional Review Board approval, no attempt was made to locate alternate caregiver support groups.

Sample Selection:

The sample consisted of self-identified informal caregivers who:

1. were willing to be surveyed and had signed a consent form.
2. consider themselves to be the primary persons providing assistance to a frail person 65+.
3. voluntarily attended a DARTS January/February caregiver support group.

Sampling Method:

The study sample was comprised of the caregivers who attended the first meeting of the two caregiver support groups offered by DARTS in January/February, 1993. Support group participants were recruited through DARTS by means of referral from other agencies, attendance at previous caregiver support groups offered through DARTS, referral from other programs offered through DARTS, and advertisements in local newspapers, doctors offices, churches and personal contacts.

Pre-test of Data Collection:

A pretest of the study questionnaire was administered by the principal investigator to caregivers participating in the Edina caregiver support group sponsored by Ebenezer Community Services in January, 1993. At the conclusion of the first group meeting, caregivers who had participated in the group were told about the study by the principal investigator and invited to remain an extra fifteen minutes to complete the pretest questionnaire. Results from the pre-test indicated a need for further break down of specific community resources (housing alternatives). These changes were implemented in the questionnaire before it was distributed at the DARTS caregiver support groups.

Procedure for Data Collection and Protection of Human Rights:

A survey questionnaire was administered by the principal investigator to caregivers at the beginning of the first session of two time-limited psychoeducational support groups facilitated by a DARTS professional in January/February, 1993. Prior to administering the questionnaire the principal investigator explained the study and assured the study subjects that their participation was voluntary. It was made clear that the refusal to participate would in no way affect their current or future services with DARTS or Augsburg College. The principal investigator also assured study subjects that individual responses would remain anonymous and any information collected would be presented in aggregate form. Participants were asked to sign consent forms before participation in the study. No follow-up was done on caregivers who were not able to attend the first support group meeting. No questionnaires were given out with the expectation of being mailed back to the principal investigator.

Measures:

The measures used in this study include several closed-ended single-item questions assessing self-reported caregiver strains, feelings, social supports,

structural characteristics and needs for information and assistance. Five open-ended questions were asked to assess the reasons caregivers attended the support group, what specific information or assistance would be useful, and caregiver difficulties and satisfactions.

Data Analysis:

Results presented in this study were based upon responses to qualitative and quantitative questions asked in the study questionnaire. Responses to qualitative data are categorized into coding categories as well as presented in narrative form. The unstructured responses of caregivers were listed individually in narrative form in order to fully capture each individual caregiver's thoughts and feelings. It was felt by the principal investigator do otherwise would destroy the diversity of caregiver needs and expectations. Descriptive data was analyzed and presented in narrative form.

IV. Study Results

Questionnaires were distributed to group members attending the first meeting of the winter caregiver support groups in Burnsville and Mendota Heights, Minnesota. The Burnsville group met initially on January 25, 1993. Six caregivers attended the meeting and six consented to taking part in the study. The Mendota Heights group met initially on February, 2, 1993. Nine caregivers attended the meeting and seven consented to taking part in the study. A combination of these two groups represents a sample size of 15 and produces a response rate of 87% (13).

Socio-Demographic Characteristics of Caregivers

Table 2 depicts the socio-demographic characteristics of caregivers at the time the questionnaires were distributed. The final sample was comprised of 3 males and 10 females who ranged in age from 40 to 81 years old. The largest age group represented was 60 to 69 year olds with 53.8% of the respondents falling within this age category. 30.8% of the respondents were between the ages of 40 and 59 years, and 15.4% were between the ages of 70 and 80 + years. The majority (92%) of the caregivers participating in the study were married and not employed (62%) at the time the questionnaire was distributed.

Total household incomes before 1992 taxes were evenly distributed with 30 % of the respondents reporting having earned between \$7,500 and \$14,999, 30% between \$15,000 and \$34,999, and 40% between \$35,000 and \$49,999.

A general profile of caregivers in this study indicates respondents to be white, female, over the age of 60, married, and having incomes ranging from \$7,500 to \$49,999.

Table 2

Socio-Demographic Characteristics of Caregivers

(N = 13)*

	Number	Percent
Gender		
Female	10	85.0
Male	<u>3</u>	<u>15.0</u>
TOTAL	13	100.0 %
Marital Status		
Divorced	0	0.0
Married/Domestic Partnership	12	92.0
Separated	0	0.0
Single (never married)	1	8.0
Widowed	<u>0</u>	<u>0.0</u>
TOTAL	13	100.0 %
Employment Status		
Employed part - time	3	23.0
Employed full - time	2	15.0
Not employed at this time	<u>8</u>	<u>62.0</u>
TOTAL	13	100.0 %
Age		
40 - 49 years	2	15.4
50 - 59 years	2	15.4
60 - 69 years	7	53.8
70 - 79 years	1	7.7
80+ years	<u>1</u>	<u>7.7</u>
TOTAL	13	100.0 %
Income		
\$ 7,500 - \$14,999	3	30.0
\$ 15,000 - \$24,999	1	10.0
\$ 25,000 - \$34,999	2	20.0
\$ 35,000 - \$49,999	<u>4</u>	<u>40.0</u>
TOTAL	10	100.0 %
Missing data	3	
Adjusted frequency		
* For some items		

Structural Characteristics of Caregivers

The structural characteristics of caregivers attending the Burnsville and Mendota Heights support groups are shown on Table 3.

Table 3
Structural Characteristics of Caregivers

(N=13)

	Number	Percent
<u>Lives In Same Housing Unit as Care Receiver</u>		
Yes	11	85%
No	<u>2</u>	<u>15</u>
TOTAL	13	100%
<u>Length of Time Caregiving</u>		
Less than 2 Years	6	46%
2 Years to Less Than 5 Years	7	54
5 Years to Less Than 10 Years	0	0
10 Years or More	<u>0</u>	<u>0</u>
TOTAL	13	100%
<u>Time Spent Caregiving</u>		
Less Than One Hour	1	8%
1 Hour to Less Than 4 Hours	2	15
4 Hours to Less Than 8 Hours	3	23
8 Hours or More	6	46
Don't Know	<u>1</u>	<u>8</u>
TOTAL	13	100%
<u>Age of Person Needing Care</u>		
59 Years or Younger	0	0%
60 - 65 Years	2	15
66 - 70 Years	3	23
71 - 75 Years	1	8
76 - 80 Years	2	15
81 + Years	<u>5</u>	<u>38</u>
TOTAL	13	99%*
* Not 100% due to rounding		

All respondents at the time of this study had been a caregiver less than five years and reported caring for a sister-in-law (8%), a son (8%), a parent (33%), or a spouse (50%) between 60 and 81+ years of age. Six persons were caregivers of a spouse and seven were caregivers of someone other than a spouse. 100% indicated themselves as the person most responsible for the person needing care. When asked how much time they spent caregiving in an average day 46% indicated they spent more than eight hours per day fulfilling caregiving duties. Health problems or disabilities of the person needing care included: stroke (paralysis), heart and lung diseases, dementia including Alzheimer's disease, Parkinson's disease, arthritis, osteoporosis, aphasia, diabetes, severe depression, congestive heart failure, and urinary disease.

Reasons for Attendance

Caregivers were asked to indicate the main reason(s) they decided to participate in a caregiver support group. Responses to this question have been analyzed in both narrative and categorized form. It was felt by the principal investigator that to categorize individual responses only would neutralize the impact of caregiver reasons for attendance. 92% of the respondents answered the question and several gave more than one reason. In the event that more than one reason was given all reasons were listed and analyzed.

Analysis of narrative responses:

"Emotional support." (2 responses)

"Be in touch with ongoing resources for physical therapy - speech therapy."

"Information and education."

"Resources."

"To be able to talk to others."

"To be informed about things."

"I wonder if some of the changes in my husband is to be expected and excused."

"To find guidance in handling a difficult patient when they have mood swings."

"Have two people to care for now - husband with stroke and mother with Alzheimer's and stroke."

"As a professional nurse I am seeking information on resources, trends, and networking with others about caregiving in our community, both for my personal situation and for my professional knowledge."

"To learn as much as possible about the matter of aging and caregiving as it affects me now as well as in the future."

"Learn how to handle my task better."

"They are my parents and not able to take care of themselves. Did not want to send them to a nursing home."

"My mother had a stroke in Nov. '91 but is able to remain in her own home with assistance - several of my siblings do not think they should have to help in that care."

"To get any help or advice to help me better care for my husband and myself."

"To learn to better serve my loved one."

Analysis by categories:

Table 4 shows self-reported reasons for attendance at caregiver support groups combined together into three categories (Jacobs, 1989): information and assistance involving the emotional /social aspects of caregiving, the need for practical information regarding caregiving, and the need for information dealing with the skills of caregiving.

This analysis indicates that a majority (76%) of the self-reported reasons caregivers participated in these caregiver support groups were for practical information of community resources (41%) and emotional assistance (35%). 23% of the caregivers indicated they participated for reasons of skill development.

Table 4

Reasons for Attendance at Support Group

Need For	Number of Responses	Percent of Responses
Practical Information	7	41%
Emotional Assistance	6	35
Skill Development	4	23
TOTAL	17	99%*
* not 100% due to rounding		

Information and Assistance Needed

Study participants were asked two questions regarding information and assistance they desired from the support group. First, participants were asked to indicate what specific information or assistance would be helpful to them. Seven respondents (54%) completed this question. Two of the seven respondents were caring for a spouse and five were caring for a person other than a spouse.

Narrative responses to this question are given below and in the event that more than one item was listed by a respondent all items were listed.

"How to get family members to help with caregiving without a hassle."

"Helping me to know an easier way to handle an adult when changing diapers-lifting and transporting from wheel chair to bed and visa versa."

"The needs of the caregiver, limitations, etc."

"How to handle frustration and anger."

"How to deal with mood changes of the person I am caring for."

"A comprehensive view of what is happening and what funding is awaiting for the senior population that are in need of care."

"The group and help that I need." *

"Resources for on going speech therapy." *

* indicates responses from a respondent caring for a spouse.

Table 5 shows caregiver responses above broken down into Jacobs (1989) three categories: information and assistance involving the emotional/social aspects of caregiving, the need for practical information regarding caregiving, and the need for information dealing with the skills of caregiving.

Table 5
Self-Reported Information and Assistance That Would Be Helpful

Need For	Number of Responses	Percent of Responses
Emotional Assistance	4	50%
Practical Information	2	25
Skill Development	<u>2</u>	<u>25</u>
TOTAL	8	100%

50% of the items listed by respondents as specific information or assistance that would be helpful to them from the support group were related to the emotional aspects of caregiving. The need for practical information and skill development were divided evenly with 25% of the items listed by the respondent in both categories. This indicates that in this study caregivers of persons other than a spouse may be overwhelmed and/or looking for, information and assistance with the emotional aspects of caregiving.

Reasons for the large no response rate for persons caring for a spouse (two out of six responded) are not known. However, it may indicate the caregiver of a spouse is enmeshed or fused tightly with the care receiver to the extent s/he

is not able to differentiate enough from his/her caregiving role to know what information or assistance is needed or desired (Nichols & Schwartz, 1991; Bowen, M., 1976). Evidence to support this analysis can be seen in the individual responses of caregivers of persons other than spouses. Their responses were very concrete and straight forward indicating they knew precisely the information they needed.

Using a five point Likert type scale study participants were also asked the amount of need or assistance they had for specific items listed by the principal investigator. Table 6 shows a majority of study participants listed care of self, time away, relief of emotional stress, and community services as the information and assistance most needed from the support group. One half (50%) of the group desired information on the emotional aspects of anger and grief associated with caregiving. Information and assistance least desired by study respondents were caregiving information for another state, medical or health information, information about ethical issues, and developing friendships with other caregivers.

Table 6

Caregiver Information or Assistance Needed

(N=13)*

	No Need		1		2		3		4		Great Need		5		TOTAL	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Care of Self	0	0%	0	0%	2	17%	7	58%	3	25%	12 **	100%				
Time Away	1	8	1	8	1	8	6	46	4	31	13	101 ***				
Emotional Stresses	0	0	0	0	5	38	3	23	5	38	13	99 ***				
Community Services	1	8	0	0	4	33	4	33	3	25	12 **	99 ***				
Anger	0	0	1	8	5	42	3	25	3	25	12 **	100				
Emotional Grief or Mourning	1	8	1	8	4	33	3	25	3	25	12 **	99 ***				
Alternative Housing	3	27	1	9	2	18	4	36	1	9	11 **	99 ***				
Financial	5	38	1	8	2	15	5	38	0	0	13	99 ***				
Legal	2	17	2	17	4	33	4	33	0	0	12 **	100				
Friendships	0	0	3	23	6	46	0	0	4	31	13	100				
Ethical Issues	1	9	1	9	7	64	1	9	1	9	11 **	100				
Medical/Health	3	25	2	17	5	42	2	17	0	0	12 **	101 ***				
Another City or State	10	91	1	9	0	0	0	0	0	0	11 **	100				

* For some items

** N does not equal 13 due to no response

*** not equal to 100% due to rounding

Table 7

Information and Assistance Needed in Order of Need

Order of Need	Caregiver of Spouse	Caregiver of Non-Spouse
1	Care of Self	Emotional Stress
2	Time Away	Time Away
3	Community Services	Alternative Housing
4	Grief or Mourning	Care of Self
5	Anger	Community Services
6	Emotional Stresses	Grief or Mourning
7	Financial	Anger
8	Friendships	Financial
9	Legal Issues	Legal
10	Medical/Health	Ethical Issues
11	Alternative Housing	Friendships
12	Ethical Issues	Medical/Health
13	Another City or State	Another City of State

Study data was also broken down into two categories: information and assistance desired of caregivers caring for a spouse, and information and assistance desired of caregivers caring for someone other than a spouse (Table 7). Caregivers caring for a spouse indicated learning ways to take care of themselves as caregivers to be their greatest need. This most likely is due to the difficulty caregivers of spouses can have in being relieved from their caregiving activities. This was followed by the need for learning ways to find time away from caregiving responsibilities (83%) and the need for information and assistance with community services (80%).

Caregivers caring for someone other than a spouse listed information and assistance with emotional stresses to be their greatest need (83%). Caregivers

of non-spouses generally are not as isolated as caregivers of spouses, yet are dealing with the emotional and social issues of role changes and other family obligations. This was followed by the need for information about housing alternatives (67%) and learning ways to take care of themselves as caregivers (67%).

The Most Difficult Task of Caregiving

Participants were asked what one thing was the most difficult for them as a caregiver. Individual responses were broken down into two categories: caregivers caring for a spouse and caregivers caring for someone other than a spouse. Narrative responses to this question are given below.

Responses of caregivers caring for a spouse:

"Never getting away from it."

"Having time for myself."

"Alone - restricted activities."

"To be patient with the person."

"Never being able to ever have a minute just for myself and be able to have peace of mind."

"Learning to be objective."

Responses of caregivers caring for someone other than a spouse:

"Communication and lifting since my mother can not walk anymore."

"The amount of time required."

"The isolation from other people when caregiving is on a 24 hour daily basis. The need to be given relief."

"Anger and mood changes of person caring for."

"The constant need to be needed - 24 hour care responsibility."

"Dealing with a demanding patient during mood swings."

Not being able to get away from caregiving activities was listed by two-thirds (67%) of the caregivers caring for a spouse as the most difficult aspect of caregiving. Caregivers caring for someone other than a spouse were more divided in their responses. They listed time away from caregiving responsibilities (50%), emotions (33%), and skills (17%) as the most difficult thing for them as a caregiver.

Help or Support Received by Caregiver

When asked about the amount of help or support they received from other people in relation to their caregiving activities all caregivers reported they had experienced being "down in the dumps" or "blue." However, respondents were evenly divided over the amount of emotional support they received from other people when experiencing these feelings. 50% of the caregivers indicated they had some or a lot of emotional support and 50% indicated they had little or no emotional support (Table 8).

Table 8
Help or Support Received by Caregiver

(N=13)*

Question: Please circle the answer that best describes the amount of help or support you are currently receiving from other people.

	A Lot		Some		A Little		None		No Need		TOTAL		NR
	#	%	#	%	#	%	#	%	#	%	#	%	
Emotional Support	2	17	4	33	4	33	2	17	0	0	12	100	1
Financial Support	0	0	2	15	2	15	6	46	3	23	13	99	0
Physical Help	0	0	5	38	3	23	3	23	2	15	13	0	0
Social Support	1	8	7	54	4	31	1	8	-	-	13	101	0

NR = No response

Total not equal to 100% due to rounding

Adjusted frequency

* For some items

61% of all caregivers (8) reported receiving little or no financial support from other people when needed and 46% (6) indicated receiving little or no physical help from others when needed. When asked how often they received help or support by talking on the telephone or getting together, 62% indicated they received social support some or a lot of the time.

When divided into the categories of caregivers of spouses and caregivers of persons other than a spouse (Tables 9 and 10) 100% (6) of the caregivers of spouses indicated they received a little or some emotional support. In comparison, a little over one-half (58%) of the caregivers of persons other than a spouse reported receiving a little or no support when feeling "down in the dumps" or "blue." This may be the reason caregivers of non-spouses indicated they needed help with the emotional stress and strain of caregiving.

83% (5) of those persons caring for a spouse were receiving no financial support when needed and 50% (3) were receiving a little or no physical help when needed. 83% (5) indicated they received some social support by talking on the telephone or getting together with friends and relatives.

Table 9
Help or Support Received by Caregivers of Spouse
 (N=6)*

	A Lot		Some		A Little		None		No Need		TOTAL		NR
	#	%	#	%	#	%	#	%	#	%	#	%	
Emotional Support	0	0	3	60	2	40	0	0	0	0	5	100	1
Financial Support	0	0	1	17	0	0	5	83	0	0	6	100	0
Physical Help	0	0	2	33	1	17	2	33	1	17	6	100	0
Social Support	0	0	5	83	1	17	0	0	-	-	6	100	0

NR = No response
 Adjusted frequency
 * For some items

Table 10

Help or Support Received by Caregivers of Persons Other Than Spouse

(N=7)

	A Lot		Some		A Little		None		No Need		TOTAL		NR
	#	%	#	%	#	%	#	%	#	%	#	%	
Emotional Support	2	29	1	14	2	29	2	29	0	0	7	101	0
Financial Support	0	0	1	14	2	29	1	14	3	43	7	100	0
Physical Help	0	0	3	43	2	29	1	14	1	14	7	100	0
Social Support	1	14	2	29	3	43	1	14	-	-	7	100	0

NR = No response

Total not equal to 100% due to rounding

In contrast, 43% (3) of the caregivers of persons other than a spouse reported having no need for financial assistance (Table 10). Of those persons needing financial assistance 43% (3) reported little or no financial support or help from other people when they needed it. 72% (5) indicated they received a little or some physical help and a little or some social support when necessary.

Caregiver Stress or Strain

Table 11

Strain or Stress Perceived by Caregiver

(N=13)

Question: Please circle the answer that best describes the amount of strain or stress you are experiencing at this time.

	No Strain		1		2		3		4		A Lot of Strain		5		TOTAL		NR
	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	
Emotional Strain	0	0	0	0	9	69	3	23	1	8	13	100	0				0
Physical Strain	2	15	3	23	7	54	1	8	0	0	13	100	0				0
Financial Strain	6	46	1	8	3	23	3	23	0	0	13	100	0				0

NR = No response

When asked about the amount of emotional stress and strain they were experiencing as caregivers (Table 11) over one-half (69%) of the respondents indicated a neutral response and just under one-third (31%) indicated they were experiencing some or a lot of emotional stress. A majority (54%) of the caregivers also indicated a neutral response when asked the amount of physical strain they were experiencing at that time. Caregivers in this study indicated having little or no financial strain.

Tables 12 and 13 show perceived caregiver strain and stress study results broken down into two groups: caregivers of a spouse and caregivers of persons other than a spouse. Study results indicate caregivers of spouses tended to experience less emotional and physical strain than did caregivers of persons other than a spouse.

Table 12
Strain or Stress Perceived by Caregivers of Spouse
 (N=6)

	No Strain				A Lot of Strain				TOTAL				
	1		2		3		4		5		#	%	NR
Emotional Strain	0	0	0	0	5	83	1	17	0	0	6	100	0
Physical Strain	2	33	2	33	2	33	0	0	0	0	6	99	0
Financial Strain	3	50	0	0	1	17	2	33	0	0	6	100	0

NR= No response

Total not equal to 100% due to rounding

Table 13

Strain or Stress Perceived by Caregivers of Persons Other Than a Spouse

(N=7)

	No Strain				A Lot of Strain				TOTAL				
	1		2		3		4		5		#	%	NR
Emotional Strain	0	0	0	0	4	57	2	29	1	14	7	100	0
Physical Strain	0	0	1	14	5	71	1	14	0	0	7	99	0
Financial Strain	3	43	1	14	2	29	1	14	0	0	7	100	0

NR= No Response

Total not equal to 100% due to rounding

Feelings Experienced by Caregiver

Table 14

Feelings Experienced by Caregiver

(N=13)*

Question: Please circle the answer that best fits the feelings you are currently experiencing as a caregiver.

	Never				A Great Deal				TOTAL				
	1		2		3		4		5		#	%	NR
Grieve or Mourn	1	8	1	8	9	69	2	15	0	0	13	100	0
Loneliness	3	25	1	8	4	33	2	17	2	17	12	100	1
Anger	2	15	4	31	4	31	2	15	1	8	13	100	0

NR = No response

Adjusted frequency

* For some items

On a Likert type five point scale caregivers were asked to circle the answer best describing the feelings they were currently experiencing as a

caregiver (Table 14). Respondents were evenly divided in their perceived feelings of loneliness and grief. A little less than one-half (46%) indicated they were experiencing little or no anger.

Tables 15 and 16 show feelings experienced by caregivers broken down into two categories: caregivers of a spouse and caregivers of a person other than a spouse. Study results indicate caregivers of spouses in this study tended to experience less grief, loneliness, and anger than did caregivers of persons other than a spouse.

Table 15
Feelings Experienced by Persons Caring For A Spouse
 (N=6)

	Never		1		2		3		4		A Great Deal		TOTAL		NR
	#	%	#	%	#	%	#	%	#	%	#	%	#	%	
Grieve or Mourn	1	17	1	17	3	50	1	17	0	0	6	101	0		
Loneliness	2	33	1	17	1	17	1	17	1	17	6	101	0		
Anger	2	33	1	17	3	50	0	0	0	0	6	100	0		

NR = No response
 Total not equal to 100% due to rounding

Table 16

Feelings Experienced by Persons Caring For Someone Other Than A Spouse

(N=7)*

	Never		1		2		3		4		A Great Deal		5		TOTAL		NR
	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	
Grieve or Mourn	0	0	0	0	6	85	1	14	0	0	7	99	0				
Loneliness	1	17	0	0	3	50	1	17	1	17	6	101	1				
Anger	0	0	3	43	1	14	2	29	1	14	7	100	0				

NR = No response

Total not equal to 100% due to rounding

Adjusted frequency

* For some items

These study findings agree with previous data indicating caregivers of persons other than a spouse tend to desire emotional help and assistance. However, it is not known if help with grief, loneliness, and anger is the emotional assistance caregivers desire from the support group.

V. Discussion

This study indicates there are factors influencing the primary reasons caregivers attend time limited psychoeducational support groups. These factors include a need by the caregiver for a wide variety of information and assistance involving the emotional/social aspects of caregiving, the need for practical information regarding caregiving, and the need for information on the skills involved in caregiving (Jacobs, 1989). These factors can be broken down further into a dyad of practical/skill information and emotional/ social needs (Gallagher, 1985).

Practical Information / Skills:

Results of this study indicate that caregivers seek a wide variety of information ranging from care of self to information on ethical issues. Caution must be taken not to assume the need for information is synonymous with the emotional/social issues of caregiving. A person indicating a need for resource information or assistance does not necessarily need this information because of an emotional issue. And a person's need for emotional assistance does not necessarily stem from a lack of resource information. Data results reflect a need for information, but a causal relationship between objective and subjective needs can not be made. Objective needs of practical resources may or may not be related to the emotional or subjective needs of the caregivers.

Care of self, time away, and community services were an immediate concern of caregivers. This could indicate a perceived need for information on services which enable the caregiver to obtain relief from caregiving responsibilities. Therefore, support groups should be psychoeducational with group formats providing information on home health care services, meals on wheels, shopper assistance, friendly visiting, respite care, hospice care, adult day

care, companion aides, homemaker/chore services, and transportation (Jacobs, 1989).

Emotional/Social Aspects:

Data results from this study on the reasons caregivers attend caregiver support groups coincide with the self-reported need for information and assistance caregivers listed would be helpful to them through the caregiver support groups. These two categories coincide, but cannot be ranked in order of priority. This is due to the unlimited number of needs given by respondents and the low response rate of caregivers of a spouse when asked for self-reported information and assistance needed.

However, study findings do tend to indicate a possible relationship between the primary needs of respondents caring for a spouse and those who are caring for someone other than a spouse. Caregivers of spouses expressed a need for information and assistance with the practical aspects of caregiving. The need for information on how to better take care of themselves as caregivers. Caregivers of persons other than a spouse tended to be concerned with the emotional stresses associated with their role as a caregiver.

The diversity found in this study of socio-demographics, structural characteristics, and information and assistance needed supports Zarit's (1990) research indicating it is unrealistic for a time-limited support group of eight to ten weeks to cover all of the possible aspects and negative consequences of caregiving. It also supports Jacob's (1989) and Gallagher's (1985) research that caregiver reasons for attendance at support groups fall into the categories of need for practical information and emotional assistance.

This study indicates a possible relationship between caregiver reasons for attendance and the relationship of the caregiver to the person s/he is caring for: caregiver of a spouse or caregiver of a person other than a spouse. This

supports Rando's (1986) research on the different dimensions experienced by a caregiver of spouse and a caregiver of a person other than spouse. He found that parental dependence creates a shift and changing of roles within the parental/child relationship and that spousal dependence requires a role adjustment involving a loss of a mate and shared dreams.

In response to the above study results, the principal investigator recommends the use of a break-out model for time limited psychoeducational caregiver support groups. A break-out model provides for caregivers to meet as a whole group and then breakout into subgroups based on the number of group participants. The use of this model allows support groups to be limited to eight weekly sessions and also provide specific information and assistance to a wide range of caregivers. Each group session is two and one-half hours long with caregivers meeting together for the first hour and then breaking off into subgroups of persons caring for a spouse and persons caring for someone other than a spouse the second hour.

The first hour session all caregivers meet together for information and assistance on the practical aspects of caregiving (community resources). This is information that may be needed by caregivers such as assistance on home health care services, meals on wheels, shopper assistance, friendly visiting, respite care, hospice care, adult day care, companion aides, homemaker/chore services, and transportation (Jacobs, 1989). This information is pertinent to all caregivers regardless of socio-demographics, structural characteristics, or their relationship to the care receiver.

The second hour caregivers are divided into subgroups of eight according to their relationship to the person they are caring for: persons giving care to a spouse and persons giving care to someone other than a spouse. The literature review for this research indicates that emotional/social needs are different for

persons caring for a spouse and persons caring for someone other than a spouse. Breaking out into small subgroups allows group discussions concerning the emotional/social aspects of caregiving. Emotional/social needs of caregivers include: psychological (emotions, loss, grief, feelings, etc.) needs, interpersonal (family system, communication, relationships, conflicts, etc.) needs, and sociocultural (role adjustment, family structure realignment, etc.) needs.

The thirty minute break between sessions allows caregivers time to establish friendships with other caregivers. This provides a future network of social support for caregivers who feel isolated and lonely in their caregiving roles. It also allows time for caregivers to seek personal assistance from the professional(s) facilitating the group.

Study Limitations

Limitations in this study include sample size, geographic location of caregiver support groups, and representation of diverse ethnic cultures.

A sample size of thirteen is not large enough to provide a strong relationship between variables in this study. What can be said is study results tend to indicate there is a possible relationship between the reasons caregivers attend caregiver support groups and their relationship to the caregiver (spouse or non-spouse). A larger sample size is necessary to confirm this relationship.

The lack of variance in geographic locations of the support groups in this study must be taken into consideration when applying study results. Data was not collected from a large cross-section of people representing different cultures, economic resources, and geographic locations. The questionnaire was distributed to caregiver groups in Dakota County, an outlying area (suburb) of urban Minneapolis and St. Paul, Minnesota which has a very low percentage of minority elders (14%) (Metropolitan Council, 1991). Dakota County differs from other counties in the Minneapolis/St. Paul metropolitan area in that:

1. Older people in Dakota County tend to have more education.
2. Older people in Dakota County are more likely to have living children.
3. For those with living children, older people in Dakota County are more likely to have children living nearby (within 30 minute drive).
4. Older people in Dakota County provide less transportation services and less visiting services to neighbors and friends (p.3).

Caregiver reasons for attendance at support groups could be quite different in an urban setting representing more diversity.

~ Another study limitation is the lack of racial diversity among study respondents. There are no minority cultures represented in this study. This lack of diversity in the study sample does not allow study results to reflect differences in socio-cultural heritage and perception of eldercare. If the study sample had included minority elders results may have been quite different.

The death and illness of a family member can cause different reactions within different ethnic cultures. Death in some cultures creates a greater psychological impact among family members than in other cultures. This is because of the intense (or lack of intense) emotional bonds within the nuclear family unit (Rando, 1986). Some cultures spread their psychological involvement over more individuals within their extended family and community. This disperses emotional involvement and reactions to illness and death are not as intense.

Many ethnic groups have rigid boundaries and are resistant to receiving outside help from professionals (Rosen, 1990). For example, in Asian families asking outsiders for help is a sign of humiliation and a disgrace to a family's honor. Asians move into the home of the family member who is ill. They become

a part of the household and provide the round-the-clock care and continual attention that is needed (Rosen, 1990).

Ethnic groups believe and behave in different ways creating boundaries from the family unit and the outside world. Professionals working with families facing loss and death need to be continually aware of differences in attitudes towards life, death, pain, suffering, grief, gender, expectations of family authority, and acceptance of professional help. Lack of diversity in the study sample do not allow for these differences in cultural attitudes.

Although this study provides useful information on the self-perceived reasons caregivers attend psychoeducational support groups study results do not warrant generalization into the general population of caregivers as a whole. Results suggest approaches to be used as a basis for developing support group models for caregivers. However, the professional must remember and be aware of study limitations.

Implications for Future Research

Future research needs to include a breakdown of what the emotional needs of caregivers are for persons caring for a spouse and persons caring for someone other than a spouse. What do caregivers mean when they say they need emotional information and assistance? Are they referring to their own emotional needs or to the needs of the person they are caring for? What do they mean by feelings of anger and grief? What affect does the length of caregiving have on caregiver need?

→ Gender and cultural issues also need to be addressed in future research. Why do more women participate in support groups than men? How do reasons for support group attendance differ between men and women? Racial and ethnic groups are similar in that in virtually every group women are expected to be the primary caregiver (Rosen, 1990). Some cultures are more flexible than others

and this role is not absolute, however, regardless of ethnic background women have been socialized to assume second-order caregiver roles. Regardless of ethnic identity the wife, daughter, daughter-in-law, mother, sister, or granddaughter nearly always assumes the role of primary caregiver. Professionals must respect this role of women, yet also be aware that women must be protected from the total burden and responsibility of care. Professionals must be aware of the potential exploitation of women in families in which a crisis is taking place. The possibilities for change need to be explored when roles have become so rigid they create obstacles to the functioning of a healthy family (Rosen, 1990).

The above caregiver issues need to be addressed by professionals in future research. This is necessary in order to design and implement support group strategies targeted for specific caregiver populations and further reduce caregiving stress and possible nursing home placement.

Summary

As medical technology increases more and more people today are living past the age of 65 and into their 90's (Rivlin & Wiener, 1988). Many of these persons are affected with acute diseases and chronic illnesses and are cared for at home by a spouse or other family member. This can create a tremendous strain on the family caregiver as s/he learns to cope with the day to day physical and emotional stresses of caregiving. Caregiver support groups have been formed throughout communities as an intervention to help alleviate caregiver stress and strain.

This paper examined the self-reported reasons caregivers attend caregiver support groups. Reasons for attendance included a need for information and assistance with the practical (community resources) and

emotional aspects of caregiving. A possible relationship was also found between caregiver need for information and caregiver relationship to care receiver (spouse or non-spouse). Findings from this study can be used to address information needed to guide policy, planning, and practice decisions in agencies implementing caregiver assistance.

XI. Appendices

Caregiver Support Groups: Reasons for Attendance

Consent Form

I am currently a graduate student at Augsburg College, in Minneapolis, and am conducting a study on caregivers. Attached is a questionnaire that identifies reasons caregivers attend caregiver support groups.

Caregivers attending support groups affiliated with Dakota Area Resources and Transportation for Seniors (DARTS) and Ebenezer Community Services have been invited to participate in this study. The purpose of this study is to identify reasons caregivers decide to participate in caregiver support groups. This study also identifies the similarities and differences between caregivers who attend caregiver support groups. It is my hope that results from this study will enhance community caregiver support services in the future.

If you should agree to be in this study, I would ask you to do the following things. Please sign the statement of consent to participate at the bottom of this page and then place this consent form in the manila envelope provided. This envelope will be sealed and secured in a locked file cabinet. Then answer the questions on the following pages and place the completed questionnaire in the envelope provided. The questionnaire should take approximately fifteen minutes to complete.

The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify an individual. Research records will be kept in a locked file; only Dr. Sharon Patten, an Associate Professor at Augsburg College, and I will have access to the records.

This survey is administered with the approval of Augsburg College, DARTS and Ebenezer Community Services. Your decision whether or not to participate will not affect your current or future relations with Augsburg College, DARTS, or Ebenezer Community Services. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

The researcher conducting this study is Nancy Coryell. You may ask questions you have now. If you have questions later, you may contact me at 892-7073 or Dr. Sharon Patten, my research advisor, at 330-1723.

You will be given a copy of this form to keep for your records.

I have read the above information. I have asked any questions I have and have received answers. I consent to participate in the study.

Signature _____

Date _____

Signature of Investigator _____

Date _____

CAREGIVER QUESTIONNAIRE

Thank you for your willingness to participate in this study. The questionnaire should take about fifteen minutes to complete. Please answer the questions below.

1. What is the main reason(s) you decided to participate in a caregiver support group?
Please be as specific as possible.

2. What specific information or assistance would be helpful to you from this support group?

3. Have you attended a caregiver support group in the past? Please circle one.
1. Yes 2. No

4. How long have you been a caregiver? Please check one.
 a. less than two years
 b. 2 years to less than 5 years
 c. 5 years to less than 10 years
 d. 10 years or more

5. Do you live in the same housing unit as the person needing care? Please circle one.
1. Yes 2. No

6. What one thing would you say is the most difficult for you as a caregiver? Please be as specific as possible.

7. What one thing would you say is the most satisfying for you as a caregiver?
Please be as specific as possible.

8. What information or assistance would you like to receive from this caregiver support group? Please circle the answer that fits the need you have for the following assistance or information.

As a caregiver how much do you have a need for:	No need for information				A great deal of need for information
a. medical / health information or assistance relating to the health needs of the person you are caring for?	1	2	3	4	5
b. financial information or assistance relating to caregiving?	1	2	3	4	5
c. information or assistance with community services available to caregivers?	1	2	3	4	5
d. information or assistance with housing alternatives for the person receiving care?	1	2	3	4	5
e. legal information regarding your role as a caregiver?	1	2	3	4	5
f. caregiving information or assistance for someone you are caring for in another city or state?	1	2	3	4	5
g. information or assistance on the emotional stresses of caregiving?	1	2	3	4	5
h. information or assistance with the ethical issues relating to caregiving?	1	2	3	4	5
i. information or assistance with the emotional grief or mourning which can accompany caregiving?	1	2	3	4	5
j. information or assistance with the anger which can accompany caregiving?	1	2	3	4	5
k. information on learning ways to take care of yourself as a caregiver?	1	2	3	4	5
l. information or assistance with learning ways to find time away from caregiving responsibilities?	1	2	3	4	5
m. friendships with other caregivers?	1	2	3	4	5
n. other please specify: _____	1	2	3	4	5

9. The next set of questions asks about the amount of help or support you receive from other people in relation to your caregiving activities. Please circle the answer that best describes the amount of help or support you are currently receiving from other people.

a. As a caregiver, how much emotional support do you receive from other people if you are "down in the dumps" or "blue?"

1. A Lot 2. Some 3. A Little 4. None 5. Never blue

b. As a caregiver, how much financial support or help do you receive from other people if you need it?

1. A Lot 2. Some 3. A Little 4. None 5. No need for financial help

c. As a caregiver, how much physical help do you receive from other people if you need it?

1. A Lot 2. Some 3. A Little 4. None 5. No need for physical help

d. How often do you receive help or support by talking on the phone or getting together with relatives or friends who do not live with you?

1. A Lot 2. Some 3. A Little 4. Never

10. Caregivers can experience strain. Please read the next three questions, and for each circle the answer that best fits the amount of strain or stress you are currently experiencing as a caregiver.

	No Strain		A Lot of Strain		
a. How much <u>emotional</u> strain are you experiencing as a caregiver?	1	2	3	4	5
b. How much <u>physical</u> strain are you experiencing as a caregiver?	1	2	3	4	5
c. How much <u>financial</u> strain are you experiencing as a caregiver?	1	2	3	4	5

11. Caregivers can experience a mixture of feelings. Please read the next set of questions, and for each circle the answer that best fits the feelings you are currently experiencing as a caregiver.

a. As a caregiver, do you ever grieve or mourn over the increased need and dependency of the person needing care?

Never grieve 1 2 3 4 5 Continually grieve

b. How much loneliness do you experience as a caregiver?

No loneliness 1 2 3 4 5 A great deal of loneliness

c. How much anger do you experience over the increased need and dependency of the person needing care?

No anger 1 2 3 4 5 A great deal of anger

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

13. Which age group represents the person needing care? Please check one.

- a. 19 years or under
- b. 20 - 29 years
- c. 30 - 39 years
- d. 40 - 49 years
- e. 50 - 59 years
- f. 60 - 65 years
- g. 66 - 70 years
- h. 71 - 75 years
- i. 76 - 80 years
- j. 81 + years

14. What is the main health problem or disability of the person needing care? Please be as specific as possible.

15. Are you the person most responsible for the person needing care? Please circle one.

- 1. Yes
- 2. No

16. In an average day, how much time do you estimate you spend caregiving? Please check one.
- | | |
|--|---|
| <input type="checkbox"/> a. Less than 1 hour | <input type="checkbox"/> d. 8 hours or more |
| <input type="checkbox"/> b. 1 hour to less than 4 hours | <input type="checkbox"/> e. Don't know |
| <input type="checkbox"/> c. 4 hours to less than 8 hours | |
17. If you were unable to provide care for a period of time would there be someone else you could call upon for help? Please circle one.
1. Yes Who? _____ 2. No
18. What is your gender? 1. Female 2. Male
19. What is your current marital status? Please check one.
- | |
|--|
| <input type="checkbox"/> a. Divorced |
| <input type="checkbox"/> b. Married / Domestic Partnership |
| <input type="checkbox"/> c. Separated |
| <input type="checkbox"/> d. Single (never married) |
| <input type="checkbox"/> e. Widowed |
20. What is your employment status? Please check one.
- | |
|---|
| <input type="checkbox"/> a. Not employed at this time |
| <input type="checkbox"/> b. Employed part - time |
| <input type="checkbox"/> c. Employed full - time |
21. Which of the following categories represents your age group? Please circle one.
- | | |
|---|---|
| <input type="checkbox"/> a. 19 years or under | <input type="checkbox"/> f. 60 - 65 years |
| <input type="checkbox"/> b. 20 - 29 years | <input type="checkbox"/> g. 66 - 70 years |
| <input type="checkbox"/> c. 30 - 39 years | <input type="checkbox"/> h. 71 - 75 years |
| <input type="checkbox"/> d. 40 - 49 years | <input type="checkbox"/> i. 76 - 80 years |
| <input type="checkbox"/> e. 50 - 59 years | <input type="checkbox"/> j. 81 + years |
22. What is your household's total income for 1992, before taxes? Please check one.
- | | |
|---|---|
| <input type="checkbox"/> a. Less than \$7,500 | <input type="checkbox"/> e. \$35,000 - \$49,999 |
| <input type="checkbox"/> b. \$ 7,500 - \$14,999 | <input type="checkbox"/> f. \$50,000 - \$74,999 |
| <input type="checkbox"/> c. \$15,000 - \$24,999 | <input type="checkbox"/> g. \$75,000 + |
| <input type="checkbox"/> d. \$25,000 - \$34,999 | |

Thank you for your participation!

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N. Coryell

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