

THE VALUE OF SUPPORT GROUPS FOR CAREGIVERS
OF A PATIENT WITH ALZHEIMER'S DISEASE:
A FAMILY SYSTEM'S PERSPECTIVE

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BY
RENEE STANLEY, M.S.

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TEXAS WOMAN'S UNIVERSITY
DENTON, TEXAS

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Date

To the Provost of the Graduate School:

I am submitting herewith a dissertation written by Renee Stanley entitled "The Value of Support Groups for Caregivers of a Patient with Alzheimer's Disease: A Family System's Perspective." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Marriage and Family Counseling.

Glen Jennings
Major Professor

We have read this dissertation
and recommend its acceptance

Delaine Haskins-Linton
Ronald A. Fanning
William T. Anderson
Carol Kershaw

Accepted

Leslie M. Thompson
Provost of the Graduate School

DEDICATED TO MY FAMILY

My husband, Paul, without whose love, encouragement, and understanding this would not have been possible.

Grow old along with me!

The best is yet to be,

The last of life for which the first was made.

Robert Browning

My children, Rick, David, Cindy, Marc, Wendy, and Roger,
and my grandchildren, Brett Alana, and Megan Beth, for your
encouragement, love, and forbearance.

I love you all very much.

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The Value of Support Groups for Caregivers
of Patients with Alzheimer's Disease:
A Family System's Perspective

Renee Stanley

May 16, 1987

The purpose of this study was two-fold. First, to examine, within a framework of family systems theory, whether or not primary caregivers of a patient with Alzheimer's disease perceive support groups to be a valuable means for assisting them in dealing with their feelings of stress and burden; stress related symptoms; family relationships; and coping and adapting strategies. Second, to evaluate how this decision has been influenced by their particular family system, such as, type of boundaries: permeable, moderate, or rigid; and family rules and regulations, including those for role expectations.

A qualitative study was conducted with 20 primary caregivers of patients with Alzheimer's disease, who are currently attending various support groups in Dallas, Texas, and the greater Dallas area. The caregivers were siblings, daughters, and spouses of the patients. They were all from a similar socio-economic background.

Data were analyzed according to qualitative methods (Bogden & Taylor, 1984), in order to develop concepts, insights, and understandings from patterns which emerged. The information gained, substantiated by the responses of the participants in in-depth interviews, revealed various patterns and themes. When re-analyzed within a framework of family systems theory, it was found that the family system played a major role in influencing the caregivers as follows.

Those participants who had described moderate boundaries perceived the support group as a valuable place for expressing feelings; sharing common experiences; receiving emotional support; and obtaining information on any topic pertaining to the patient. Caregivers who had reported rigid boundaries, related a tendency to resist outside assistance in any way, at times even from members of their own family. They stated a preference to keep the patient at home, often under extremely difficult circumstances, and at tremendous costs to themselves. They consistently denied any personal needs, or the need for emotional support. This carried through to, and influenced, their perception of the value derived from attending a support group.

Caregivers, who had reported extremely permeable boundaries, related that other family members tended to drift away, leaving the caregiver to feel "dumped on," and unsupported. Family relationships among this group of caregivers were often reported as conflictual, and they typically related their desire to seek the assistance of outside resources as much as possible. They were more open in expressing their feelings, and voiced their anger and resentment at other family members, as well as anger and impatience with the patient.

Family rules and regulations, including those with regard to role expectations, were also found to influence the way in which the caregivers responded.

It was concluded that: (a) support groups are not necessarily perceived as valuable by all caregivers, (b) some aspects are perceived as being more beneficial than others, (c) whether or not a person perceives a support group, or certain aspects of the group to be valuable, is influenced by their particular family background.

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CHAPTER I

INTRODUCTION

Rationale

According to Wiley (1983), by viewing the family as a "static entity in which tasks are assigned to its members" (p. 271), the integrity and functioning of the family would depend upon the fulfillment of these tasks. Any disability would result in disruption of task assignment and performance, and further result in disintegration of the family system. Based upon this framework, it is assumed that any catastrophic event, including an illness such as Alzheimer's disease, which affects a particular family member, would also affect the entire family, disrupt its equilibrium, and result in the type of disintegration described above.

Alzheimer's disease is the most common of a number of diseases known as dementia. A German Neurologist named Alois Alzheimer was the first to describe the disease in 1907. However, very little research was done in this area for the following 50 years, until research was again pursued by three British scientists in the 1960s. (Roach, 1985). Today, more than 3 million Americans are known to

be affected by this disease to some degree, and among them, five percent of those over the age of 64 are severely affected (Teusink & Mahler, 1984).

Theoretical Orientation

Systems in general, according to Bertalanffy (1968) are organizational structures composed of a set of interdependent parts. Any change in the system, therefore, would also affect change in other parts. A system has basic needs to adapt, survive and maintain itself, and it therefore takes action and behaves. If conflict should arise between the needs of the component parts and the goals of the system, system behavior attempts to regulate and control the behavior of these parts.

The family system is a "dynamic order of people (along with their intellectual, emotional, and behavioral processes) standing in mutual interaction" (Bertalanffy, 1968, p. 33). A human system possesses a multitude of ways and styles for exchanging matter and energy with the environment, including the distinctive human capacity of imagining that an exchange had taken place even if it had not. Moral, political, social, religious, economic and idiosyncratic values and constraints serve as its self-regulating capacity; sudden shifts in family dynamics show the system to be intrinsically active.

Thus, a catastrophic illness of a family member, such as Alzheimer's disease, can have a devastating impact on an entire family. As a result disequilibrium of the family system with regard to family relationships often occurs. Further, the caregiver may experience feelings of stress and burden; stress related symptoms, such as, depression, anxiety, or feelings of fatigue; and an inability to cope and adapt.

The patient's symptoms may place stress on families in a multitude of ways. To begin with, because the onset is insidious, there is often a prolonged period of uncertainty before the problem is diagnosed. In addition, since symptoms, as well as the course of the disease, vary according to the patient, it is not possible to determine from the diagnosis when problems will arise. Also, what one caregiver may find to be stressful, another may not.

Stress may be further compounded by the fact that the disease typically affects patients who are 65 years old, or over, thus placing extra demands on families at a time of life when members are facing their own transitional adjustments, are least able to cope with stress, and are in need of a great deal of support.

In cases where an adult child is the caregiver, he or she is likely to experience problems in their marriage, and/or with their own children because of the tremendous

amount of time and energy required for the care of the patient. In addition, just as the illness can impact the family system, the family system itself can also impact the family members' level of coping or adapting to the disease. Because the family system, made up of its history, boundaries, and rules and regulations, influences the way a family copes with, and adapts to a catastrophic event, this may ultimately influence the way that they perceive the value of a support group.

According to family systems theory, the organization of a family system can be seen as being composed of several individuals, or subsystems, one level below the family system itself (Beavers, 1977). Each system has a boundary surrounding it, as well as around and between each sub-system, or family member. For the system to remain alive the boundary must be both permeable and limiting at the same time. If the boundary is too permeable, however, the system will lose its integrity and identity. On the other hand, if the boundary is too limiting, necessary interaction with the world at large is cut off, and the life of the system is threatened.

Therefore, faced with a catastrophic illness, it is conceivable that a family with rigid boundaries may well refuse to seek outside help, and attempt to take care of the patient themselves, at no matter what cost. If the

boundary is too permeable, or open, family members may disperse, perhaps leaving one unsupported person to carry the entire brunt of the problem, or, their leaving, or lack of interest could force the patient prematurely into an institution. Further, family systems are governed by a set of rules and regulations, including role expectations, generally handed down through generations. These rules and regulations may dictate how one cares for a parent or spouse, and may also determine the family's level of coping or adapting to adverse situations. For instance, if there is a family rule, and role expectation, that says "men have to be the strong ones, and head of the household," the implication inferred in this could be that "women are fragile." Thus, should the patient be a male spouse, the female caregiver could, conceivably, have a great deal of difficulty in coping, and adjusting to an inexperienced and unfamiliar level of responsibility.

In addition, perceived feelings of burden may be determined by such factors as the caregiver's skills in coping with the patient, and by the support provided by others in the family (Zarit, Orr, & Zarit 1985). Since families with extremely loose boundaries may well disperse at the time of distress, leaving the caregiver without assistance or support, it is not unreasonable to assume

that a caregiver in such a case would certainly feel burdened, and have great difficulty with coping. Families, with rigid, or closed boundaries, on the other hand, might resist outside support of any kind. Pre-existing relationships among family members can also impact the level of coping and adaptation. Unresolved conflict that existed before the illness is likely to remain, and even to escalate given stressful circumstances.

In order to restore some functional stability, and to improve family satisfaction after a catastrophic event, it is important for families to arrive at the realization of the need to restructure. This may involve changes in established rules, roles, goals and/or patterns of interaction. Further, after these initial changes are made, subsequent changes are called for so as to bring the entire family into a coherent unit working in support of the newly instituted changes. These restructuring and consolidating processes continue to evolve over time as families strive toward adaptation. Families achieve this end by employing the type of strategy customarily used in their family system. Some, for instance, call upon social support in one form or another, to ease the strains of restructuring, while others do not, and continue to struggle alone.

Various authors have described adjustment coping strategies and adaptive coping strategies. McCubbin and Figley (1983) suggest families may use at least three basic adjustment coping strategies. These are: avoidance, elimination and assimilation. They are often used alone, or in combination with each other, generally depending upon the way a family has been accustomed to dealing with difficult situations in the past. Avoidance, is described as efforts to deny or ignore a stressor, and other demands, in the hope and belief that they will go away or resolve themselves. Elimination, is seen as an active effort on behalf of the family to rid itself of demands by removing or changing a stressor, or by changing its definition. Avoidance and elimination responses both serve to minimize or protect the family's need to make modifications in the structure of the family. Assimilation, involves efforts by the family to accept into its existing structure and patterns of interaction the demands created by a stressor. Thus the family absorbs the demands by making only minor changes within the family unit.

Another common series of basic coping strategies are described by Teusink and Mahler (1984). These are (a) initial denial that anything is wrong; (b) overinvolvement with the patient, in an attempt to compensate for the

illness; (c) anger when compensation fails; (d) guilt as an outcome of the anger, and (e) acceptance of the problem.

Statement of the Problem

During the last decade much attention has been focused on the Alzheimer's disease patient, and the nature of the disease itself. More recently the general impact of the disease on the families, and their manner of coping with the hardships it brings, is beginning to receive some added attention. As a result of this, various types of support groups have come into existence. However, little has been done in terms of reporting, through the framework of family systems theory, how primary caregivers themselves perceive that they, and other family members, have been affected by having a patient with Alzheimer's disease; and whether or not they have found support groups to be a valuable means for assisting them in coping with, and adapting to, the disease and its ramifications.

Purpose

The purpose of this study was two-fold. First, to examine, within a framework of family systems theory, whether or not primary caregivers of patients with Alzheimer's disease perceive support groups to be a

valuable means for assisting them in dealing with their feelings of stress and burden; stress related symptoms; family relationships; and coping and adapting strategies. Second, to evaluate how this decision has been influenced by their family system, such as type of boundaries: permeable, moderate, or rigid; and family rules and regulations, including those for role expectations.

Sample

The sample consisted of 20 primary caregivers of patient's diagnosed with Alzheimer's disease in Dallas, Texas, and the greater Dallas area. Their relationship to the patient is as follows: two sisters of female patients, three daughters of female patients, one daughter of a male patient, three male spouses, and eleven female spouses. The ages of the caregivers ranged from 45 to 70 years, and the patients from 60 to 75 years.

At the time of the study eleven of the patients were living at home. Two families were in the process of deliberating about the possibility of an outside placement for their patient. Six of the patients had been placed in a nursing home, and one had died, during 1986. Each caregiver had attended a support group while caring for the patient in their home, and were continuing to attend one at the present time. The patients had all been diagnosed by

a qualified physician as having Alzheimer's disease, and were considered to be in an early stage of the disease (Pajk 1984) at the time the interviews were conducted. All of the families were of a similar socio-economic level, with incomes ranging from \$15,000 to \$25,000.

Design

This study was qualitative in nature, as described by Taylor & Bogdan (1984). In-depth interviews were conducted with 20 primary caregivers of patients with Alzheimer's disease in order to develop concepts, insights, and understandings from patterns in the data.

Research Questions

1. How has the family system influenced the way that a caregiver of a patient with Alzheimer's disease, perceives that they and other family members have been affected by the illness?
2. How has the family system influenced the caregiver's perceived feelings of stress and burden, and stress related symptoms?
3. How has the family system influenced the caregiver's perception of family relationships?
4. How has the family system influenced the caregiver's coping and adapting strategies?

5. How has the family system influenced the caregiver's perception of the effectiveness of support groups?

Delimitations

This study was limited to the primary caregiver of an Alzheimer's patient, since other family members may not have been feeling quite as burdened, and therefore might react differently. The patients were each diagnosed by a qualified physician as having Alzheimer's disease. They were considered to be in an earlier stage of the disease, as described by Pajk (1984), during the time the interviews were being conducted. Another limitation was of socio-economic level. The families were all from a similar, middle-class, background in order to rule out possible pre-existing financial differences.

Definition of Terms

Dementia The preferred term currently being used to describe a syndrome where there is "intellectual deterioration, disorganization of the personality, and inability to carry out the normal tasks of daily living" (Pajk, 1984, p.217). It is described in "primary," and "secondary" categories.

Primary dementias Dementia's that are irreversible, arise spontaneously without a known cause, and have no known effective treatment.

Secondary dementias Dementias which are reversible and treatable, and may be caused by nutritional deficiency, metabolic disturbances, or other acute conditions.

Alzheimer's disease The most common irreversible dementia. Named after Alois Alzheimer, a German physician, who first described it in 1907. (Pajk, 1984).

Primary Caregiver A person who has assumed the greatest caregiving responsibility. This can be any family member, such as, a spouse, sibling, adult child, other relative, or a friend.

Coping A constantly changing cognitive and behavioral effort on the part of a person, to manage specific external and/or internal demands that are appraised as taxing, or as exceeding resources (Lazarus & Folkman, 1984).

Adaptation The ability of a system to respond to change, while at the same time preserving a minimum of intact identity (Beavers, 1977).

Burden The extent to which caregivers perceive their physical or emotional health, social status, and financial situation, as suffering as a result of caring for another family member (Zarit, Orr & Zarit, 1985).

Family system A family system is described as a "dynamic order of people (along with their intellectual, emotional, and behavioral processes) standing in mutual interaction" (Bertalanffy, 1968, p. 33).

Family Rules These are operating rules which govern family organization. They may be conscious or unconscious, vague and implicit, or clear and explicit. These rules also govern family relationships, and role expectations (Okun & Rappaport, 1980).

Boundaries A boundary is a limiting membrane surrounding a system. Boundaries in a living system must be both permeable and limiting for the system to remain alive. "If the boundary is too permeable, the system loses integrity and identity; if the boundary is impermeable, necessary interaction with the larger world is shut off, the system becomes increasingly entropic, and its life is threatened" (Beavers, 1977, p.23).

Support groups Support groups for caregivers of patient's with Alzheimer's disease are organized groups for the purpose of assisting people to deal with the disease and its ramifications. In general, they afford people the opportunity to share experiences and feelings, as well as offering information regarding the disease, current research findings, legal and financial implications, community resources, and patient management.

Summary

Alzheimer's disease effects more than 3 million Americans. Coping with the disease and its consequences generally requires of caregivers a completely new way of dealing with life situations, such as changing family relationships, and coping with perceived feelings of stress and burden. This study was undertaken in order to gain information that will assist caregivers of an Alzheimer's disease patient in these tasks. A framework of family systems theory was utilized to explore: (a) whether or not primary caregivers perceive that attendance of a support group is a valuable means for assisting them in dealing with their feelings of stress and burden; stress related symptoms; family relationships; and coping and adapting strategies; and (b) the extent to which this decision has been influenced by their family system.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

Evidence that Alzheimer's disease effecting a particular family member does indeed disrupt a family's equilibrium, and results in disintegration of the family system, can be found in the literature. The need for assisting families to adapt and cope with the disease and its consequences is also clearly shown, thus adding strength to the purpose of this study.

The following review of the literature reveals that a good deal has been written regarding the nature of Alzheimer's disease, its general impact on families, and their adjustment to the hardships of the disease. However, little has been done in terms of reporting, through the framework of family systems theory, how primary caregivers themselves perceive that they, and other family members, have been impacted by a patient with Alzheimer's disease; and whether or not they have found support groups to be a valuable means for assisting them in coping with, and adapting to, the disease and its ramifications.

The Nature of Alzheimer's Disease

Researchers, such as, Aronson & Lipkowitz (1981), have found that "Alzheimer's disease has a progressive deteriorative course, which may extend over seven to ten years, and has a profound impact on families" (p. 568). The course of the disease is devastating to the memory, judgment, intellectual function, and eventually to the day-to-day functioning of the afflicted person. Their behaviors change, for instance, they may begin to wander, become agitated, and sometimes assault others. Delusional and paranoid symptoms may also appear as functional capacities diminish.

The wife of an Alzheimer's disease patient writes, that among other problems, her husband's sleep patterns are irregular (Hemshorn, 1984). Sometimes he rests well for several nights, while other nights he remains awake. She also describes other behaviours such as, problems in getting dressed. If he is not helped, he might put on one sock, and a cap, or several layers of trousers, totally unaware of his appearance. He also manifests increasing incontinence; and forgetfulness: "he must be shown to the bathroom and even then, he forgets why he is there" (p.38).

Pajk (1984) describes various stages in the progression of the disease. At the beginning almost

imperceptible changes occur. Forgetfulness is common, especially for recent events. There is often difficulty in learning and remembering new information. Deterioration in appearance and personal hygiene may also be noted, as well as an inability to concentrate on such things as reading or watching television. Depression is not uncommon, because the patient is often aware that things "are not quite right". Gradually, tasks that require abstract thinking, such as balancing a checkbook, become more difficult. Activities requiring judgment, for instance, driving a car, or following instructions, are also impaired. In the later stages, there is a progressive difficulty in communication, due to deterioration of the areas of the brain involved in language and memory. Lack of motor function results in a loss of coordination. Patients at a stage of late dementia generally first lose the ability to speak, and then to walk. In the final stages of the disease, stupor and coma typically occur.

Impact on Families

Other family members, and in particular the primary caregiver, of a patient with Alzheimer's disease, face tremendous emotional, social, and financial impact. A quote in a report of the Secretary's Task Force on

Alzheimer's disease (U.S. Dept. of Health & Human Services, 1984) underscores this statement: "Dr. Lewis Thomas of Sloan-Kettering recently observed 'Alzheimer's disease causes more damage to the family than any other disease I can think of' "(p. 48).

Emotional Impact

A great deal of the emotional impact reported by the family is due to fear and uncertainty of what is happening. An intrinsic characteristic of the illness is that symptoms not only vary from patient to patient, but also from day to day in the same patient, greatly confounding diagnosis (Powell & Courtice, 1985). A further deterrant to the diagnosis, and to the added frustration of the families, is the fact that very often the patient may suddenly have a lucid interval and carry on a conversation that appears to be normal, after periods of having misarticulated words, or used sentences that did not make sense. Because physicians may not always be able to give concrete information regarding the course of the illness, families frequently become irritated with them, and feel abandoned or even cheated.

It is not uncommon for family relationships to become strained before the illness is fully recognized. Family members may respond by avoiding, isolating, or actually

becoming antagonistic toward the patient (Aronson and Lipkowitz 1984). For instance, poor information regarding the possible bizarreness of the patient's behavior may reawaken old conflicts in the relationship. Following reactions of this type by the family, they often experience feelings of guilt, anxiety, anger, and ambivalence. Because the patient's memory, and his or her ability to recognize loved-ones is impaired, loving relationships suffer. The family is subjected to witnessing a slow deterioration of the personality, typically within a physically healthy appearing person. Some families describe the progression of the disease as "a funeral that never ends" (Aonson & Lipkowitz, 1984, p. 569), and others talk about a "36 hour day" (Mace & Rabins, 1981, p. 3).

As the caregiver gradually becomes aware that they are alone with the problem, and that the partner, or parent, with whom they had shared things no longer exists, they experience a deep sense of loss (Mace & Rabins, 1981). Along with the deterioration of personality, role shifts often occur, resulting in ambiguity or complete role reversals. This may lead to confusion and/or conflict for both the patient and the caregiver. Mace & Rabins (1981) suggest four ways in which role changes may occur, as follows.

First, the husband and wife relationship often changes when one of them become ill. Dealing with this may be sad and painful. For instance, if the spouse is a wife who always depended upon her husband, she might not know the nature of their finances, what their insurance consists of, or even how to balance a checkbook. Simple tasks, like carving a turkey, may also become a difficult chore for someone who is not accustomed to doing this. Most difficult, however, is the fact that the spouse may not only have to take over these functions, but in so doing, must take them away from the other partner. Facing the realization of this may sadly symbolize all of the changes that have taken place. For the male spouse of an Alzheimer's patient, there is not only the loss of emotional support, but they too are often faced with previously unexperienced activities, such as the immediate problems of housekeeping, cooking, or washing clothes. Having to learn new skills when one is upset and tired makes matters even more difficult.

Second, the relationship of a parent with his or her adult "children" often has to change. Sometimes called "role reversals," the adult son or daughter gradually assumes increasing responsibility for the parent, while the parents' roles change accordingly. The son or daughter may feel sadness and grief at the loss of someone they love

and look up to. They may also feel guilty about having to take over. As the patient becomes more demanding and manipulative, it is not uncommon for the adult child to feel trapped, angry, used, and guilty at the same time.

Third, the patient also has to adjust to his or her changing roles in the family. Since this often means giving up independence, leadership, or responsibility, matters can become even more difficult for everyone involved. Finally, as the patient's role changes, the expectations of each family member for other members, change. Because relationships and expectations are generally based on family roles which have been established for a long period of time, changes often lead to conflicts and misunderstandings.

The family's lack of preparedness for these changes, and an altered need for caregiving, is a major issue. This is particularly the case when the caregiver has reached a time of life when he or she is faced with personal transitional adjustments. Hausman (1979) found that many families had looked forward to the time when they would be free to be able to do whatever they wished without having to consider the needs of others, such as caring for children, and financial concerns. In the case of an adult child being the caregiver, it is possible that he or she could experience problems in their marriage, and/or with

their own children, because of the tremendous amount of time and energy required by the patient.

As an outcome of all of this, families, and especially the primary caregiver, typically report feeling tremendously burdened, or stressed. Zarit, Orr, and Zarit (1983) state that burden is only minimally related to the severity of the disease. They found the most important predictors of burden to be, "how the family manages memory and behavior problems, the social support available to the caregiver, and the quality of the relationship between the patient and caregiver before the onset of the disease" (p.63).

Factors that influence feelings of burden were found to be: (a) burden tends to be less where the caregiver is more flexible, and tries out new approaches to management problems; (b) more feelings of frustration and stress are often reported by caregivers who fail to recognize that the patient is unable to respond as before, and who continue to relate to the patient as if he or she was not brain damaged; (c) the feelings of burden reported by the caregiver are less when the primary caregiver perceives other family members to be helpful and supportive, and when more family members are involved in the patient's care; and (d) current problems are endured with less burden when the caregiver reports a better relationship with the patient

prior to the disease. A further factor found to significantly influence the degree of feelings of burden was related to the frequency of family visits (Zarit, Reever, & Bach-Peterson, 1980). Caregivers reported less feelings of burden where more visits were made to the patient by other family members.

The families' feelings of burden and stress are also described by Glosser and Wexler (1985), along with feelings of depression, sadness, fearfulness, isolation, frustration and anger. They discuss how families continue to "struggle to understand the illness and its ramifications, and grieve for the loss of the afflicted individual who is no longer the person he or she once was, while altering their roles, schedules, responsibilities, and lifestyles and often suffering financial hardships" (p. 232).

Feelings of self-blame, loss of control, and depression are other commonalities among families with an Alzheimer's disease patient. A longitudinal study of spouses caring for a husband or wife with Alzheimer's disease (Pagel, Becker & Coppel, 1985, p. 169) which tested several predictions derived from the reformulated learned helplessness (RLH) depression model, found that indices of loss of control and causal attribution (CA) were more consistently related to depression, than to anxiety or hostility. These findings remained significant even after

controlling for a measure of the spouse's objective disability. However, hostility was related to CA attributions. After controlling for initial depression, analysis showed that perceived loss of control and its interaction with CA, significantly predicted follow-up depression. Further, the interaction of loss of control with an internal attribution predicted a higher level of depression than either one alone.

In addition to depression, other severe psychological problems may be found to develop in another family member. These include anxiety, stress response syndrome, or stress induced physical symptoms, such as high blood pressure or peptic ulcers. (U.S. Dept. of Health & Human Services, 1984.)

Many researchers report a series of typical responses observed in the family, similar to the mourning process described by Kubler-Ross (1969). For instance, Teusink and Mahler (1984) describe five stages: (a) Initial denial that anything is wrong; (b) overinvolvement with the patient, in an attempt to compensate for the illness; (c) anger when compensation fails; (d) guilt as an outcome of the anger; (e) Acceptance of the problem.

Denial may be instant, short-term, or persistent. Instant denial is a way that people adapt themselves to ideas and events too horrible to comprehend at once,

according to Powell and Courtice (1985). Their definition of denial is "a defense mechanism in which the person does not admit to himself consciously that painful facts exist" (p.33). Therefore, people continue to behave as if they had no problems, and stick to ways that appear comfortable and reassuring. Short-term denial, such as responding in disbelief to a sudden shock or catastrophe, according to the authors, "may be a way station in the process of accepting and dealing with the crisis"(p. 32). Persistent denial makes useful action more difficult, if not impossible. Further, as family members continue to encounter memory failures on the part of the patient, the initial denial of the illness, is replaced by many feelings, such as, upset, sorrow, grief, and anger.

Authors have found that almost everyone who lives with a person with impaired memory experiences anger, mixed with feelings of shame, embarrassment and fear; and depression. Anger is seen as a typical way humans react to frustration, disappointment and grief. The depression reported by caregivers, is frequently both an emotional and physical experience, indicating that the person has not been able to adapt to the stresses of life (Powell & Courtice 1985). The body generally shows the first signs of strain, with the caregiver developing any number of complaints, as depression reduces their efficiency, and disturbs

appetites, and sleep. Intellectual and emotional systems subsequently weaken, affecting a person's ability to think, work and remember.

Although families find it extremely difficult to acknowledge the problem, or that the behavior of a person they love has drastically changed, once the diagnosis is made, they are forced to consider the possibility that the patient may not recover. Also, as they face the probability that the patient may no longer be able to do things for themselves, the realization sets in that the major burden of caregiving must be taken over by a family member. This realization often leads to disbelief, and to feeling afraid, immobilized, and dazed.

Social Impact

Social isolation frequently occurs for many reasons. For instance, it may be due to the family's lack of understanding, or embarrassment, when a family member has Alzheimer's disease. A typical impulse is to try to hide it. Former friends may also become too uncomfortable, embarrassed, and ashamed of the patient, and they may stay away from the situation (Middleton, 1984).

In addition, the patients' odd behavior may largely contribute to social isolation. Some of these behaviors, described by Beam (1984), include clinging, hoarding,

repetitive motions and words, excessive fidgeting, and rearranging or fondling of objects. The fondling and hoarding of objects may result in unintentional shop-lifting, or in taking things from others, and, ultimately, additional embarrassment for the family.

An example of this was illustrated by an author writing about her own mother (Roach 1985). She described embarrassment when her mother, whom she had taken shopping, dragged her feet, pointed at things, and picked things off the shelf. Another embarrassing incident occurred at a visit to the home of an old friend, where, according to the author, her mother spent the weekend in a state of high agitation. She did not sit still, but followed her daughter from room to room, asking again and again when they were leaving, and whether they had tickets to go home. The author stated, "She ate like an animal. She reached for things that were not offered to her. She tapped her feet incessantly. I would grab her knee, under the table, holding her leg down, and softly but firmly ask her not to do it" (p. 101). After a few days of this type of interaction, her mother looked up, and loudly said, "You're hurting me" (p.101).

Still another source of social isolation is due to the fact that conflict is often reported among the other family members, when a relative is afflicted by Alzheimer's

disease (Glosser & Wexler, 1985). For instance, families report differences among members regarding assessment of the patient's degree of impairment, understanding of the illness, and plans for short and long-term care. Considerable dissention also revolves around the allocation of caregiving responsibilities, as well as old family conflicts, which often resurface around these issues. Thus, caregivers can become "double victims" (Glosser & Wexler, 1986, p.232), since they may not only lose the fellowship of the patient, but that of other relatives and friends, as well.

Finanancial Impact

Funds, and savings, if any, may easily be depleted by large medical costs, which generally do not result in any improvement of the patient's condition. Families frequently engage in frantic searches for answers or cures, particularly during the early stages of the disease, leading to tremendous outlays of time and money. Farkas, (1980) points out that families with little or no money are able to receive help from Medicaid, Supplemental Security Income, or other public assistance programs. When a family is in a middle, or upper middle class income bracket, however, they are generally not eligible for these programs.

Zarit, Orr and Zarit (1983) point out flaws in Medicare and Medicaid services. Medicare, while promising the elderly comprehensive health coverage, has many severe flaws with regard to the care of patients with long term illnesses. For instance, after the initial diagnosis, further medical evaluations and treatments are not covered. Neither are other services covered, such as, homemakers, in-home nursing, day care, or nursing home care, although these are generally available to older persons with other medical diagnoses. In addition, there is no reimbursement for any type of supportive services which might benefit the patient or family. Still other financial problems occur where their income level may prevent the family from hiring any of the above services, or from being able to place the patient in a nursing home, thus leaving the caregiver with little or no respite.

Middleton (1984), states that "the financial costs to the family are direct and indirect" (p. 9). Direct costs can be loss of income, either by the patient, or by the caregiver, who has had to give up working to assume responsibility for the patient. Indirect costs may be increased medical expenses, not only for the patient, but for the caregiver as well, who may well begin developing physical, and/or emotional problems, due to the stresses of the caregiver role.

Legal matters may impose even further costs, according to Mace & Rabins (1981). For instance, it is important for a will to be drawn up while a person is still considered legally competent. This is known as testamentary capacity, where the person knows that they are making a will, the nature and extent of their property, and the names and relationship of those who will benefit. In addition, while the patient is still able to manage their own affairs, it is advisable for them to sign a power of attorney, which can give broad or limited authority to a specified person. However, some patients may be unwilling to sign a power of attorney, and once the patient is unable to manage their property and affairs effectively, the family may have to file for a guardianship of property. Power of attorney, or guardianship of the property, is essential for many important transactions, including the sale of a home by one spouse, if it is owned jointly by husband and wife.

Common Problems for Families

In addition to the emotional, social, and financial problems previously discussed, caring for an Alzheimer's patient imposes other extensive problems on the family. The family organization substantially declines, partially due to impairment of the patient's functional ability and

communication skills, thus affecting areas such as planning, decision-making, and role accomplishment (Aronson, Levin & Lipkowitz, 1984).

Other frequently mentioned problems by caregivers include, "lack of support and information from physicians, poor understanding of the disease, depression, a trapped feeling, anger and fear about the patient's behavioral problems, isolation, and the caregiver's loss of self identity" (Barnes, Raskind, Scott & Murphy, 1981 p. 81). Many of the problems, such as "a deep sense of loss and sadness, the difficult task of assuming new and often confusing roles, the tremendous amount of time and energy devoted to direct care of the patient, and the various degrees of social isolation" (Barnes et al, 1981, p. 80), are also experienced by families with patients who have other types of catastrophic illnesses. These include strokes, post-traumatic dementia, multiple sclerosis, and cancer.

Unique to Alzheimer families, however, is the mysterious and insidious onset of the disease which often "produces an extended period of nightmarish uncertainty for both patient and family" (Barnes et al, 1981, p. 81). Since there is retention of normal physical appearance and vigor by most Alzheimer patients, it is more difficult for the family, or the community to accept the patient's severe

disability. This leads to a good deal of emotional stress and confusion, and the family is left feeling confused and alone. Further, the "persistent deterioration of the patient forces the family to keep adjusting to new problems and greater levels of impairment" (p. 84). Many caregivers experience "a cycle of isolation, self-neglect, sadness, frustration and guilt which grows worse as the patient deteriorates" (p. 82).

The equilibrium of families with an Alzheimer's disease patient may not only be threatened by the increased needs of the patient, but could be compounded by the fact that the primary caregiver is generally middle-aged, or older, may be a "child," sibling or spouse, and may be experiencing the demands of their own developmental stages. As noted earlier, when the caregiver is a spouse, ambiguity of roles, or total role reversal in a dependence/independence relationship, can cause confusion or conflict for each of the partners. In addition to the caregiver, who carries the brunt of the problem, the entire family unit generally pays a heavy toll.

Respite for the caregiver is almost nonexistent. Many express an inability to attend support group meetings, shop, accomplish personal errands, or enjoy a few minutes for themselves, because they do not have a responsible person with whom to leave their patient (Middleton, 1984).

Support Groups

The literature reveals the existence of many support groups, consisting of a variety of formats. For instance, Aronson, Levin, and Lipkowitz (1984) believe that coping with Alzheimer's disease and its consequences may require "a new reportory of defense mechanisms for family members and confrontation of issues ranging from anger to agitation to adaptation"

(p. 339). To assist families of Alzheimer patients in accomplishing this the authors developed a family/patient group program for moderately to severly demented, ambulatory, patients and their families. The program consists of simultaneous weekly patient/family group meetings. It was designed to help families to cope with declining family organization, rebuild a social support network, address anger and negative feelings, and learn new strategies for coping with the patient's behavior.

Further, it attempts to educate the family regarding a realistic level of the patient's abilities, and hopes to aid in lessening their denial of the patient's incapacity. At the same time the patient groups provide socialization activities at an appropriate functional level. For instance, positive reinforcement is used in an attempt to maintain self-esteem, as well as to encourage grooming, dressing, and maintenance of social skills.

The clinical impressions of the authors were that the program met the needs of the families involved. Many of them were arranging informal group activities, and were also meeting with each other between meetings. In addition, they had resumed a number of personal activities which they had given up as more of their attention was focused on providing care for the patient. Some were helped to make decisions regarding institutional placement for the patient.

Enthusiasm regarding attendance on the part of the patients was also observed. Additionally, positive carryover by the patient from the group sessions related to daily living skills, and social activities, was reported by the families. Other investigators, such as Barnes, Raskind, Scott, and Murphy (1981), reported that they found group participation for families to be especially beneficial for the primary care providers. Further, that support groups help to increase a family's understanding of the disease; to feel more supported and less isolated; and to resolve some of the feelings created by the illness. In addition, caregivers were helped to become more aware of their own needs, and to regain some self-identity in relation to the patient. According to the authors this type of support of the family system offers a way to strengthen its emotional well-being.

Similar findings were seen at the termination of a 10-week discussion group for relatives of patients with Alzheimer's disease (Lazarus, Stafford, Cooper, Cohler, & Dysken, 1981). It was found that when group participants, as opposed to nonparticipants, became more knowledgeable about the disease, they became more accepting of their ambivalence toward their afflicted family member. Relatives reported that they felt more in control of their lives, and less at the mercy of fate. They also learned new ways of coping while attempting to begin the painful process of disengagement. The authors concluded that the discussion group played a valuable supportive, and educational role for the family. They emphasized the necessity to regard the patient as "a member of a complex family network that is struggling to achieve mastery of a devastating life stress" (p. 357), and not as a separate entity. In addition, they noted families were attempting to maintain homeostasis and cohesiveness, while simultaneously beginning the "painful process of preparatory mourning and disengagement" (p. 357).

LaVorgna (1979) described observations of an initial six week group program for wives of male patients hospitalized in a Veterans Administration Health Care Facility. During the first session, many unresolved emotions, and evidence of continual struggle, began to

emerge. Helped by the presence of other women in the group who admitted openly that they were suffering, previously silent wives were able to say "I have been hurting too, for a long time and no one has known it" (p. 220). In subsequent meetings, many wives expressed guilt feelings over their husbands' hospitalization, and stated that they felt if they had been stronger this would not have occurred. Several asked questions suggesting that if they had better understood what was happening to their husbands, they could have coped more effectively. Areas of major concern, such as, the future for themselves and their families, were discussed, and the growing experience of sharing these concerns with others fostered the security needed to enable them to talk about personal needs and emotions.

Another area of concern was anxiety about money management, particularly for those women whose husbands had previously managed money matters. They were in agreement with each others' feelings that "a woman living alone can easily be taken advantage of by the business world" (p. 221). After a while, the discussions began to focus on topics of self preservation and self-survival. Participants related profound feelings of isolation and loneliness. By the sixth meeting they discussed the common search each member had made, hoping to find a cure,

a change of fate, or a return to the days before their husbands were ill. Some even admitted seeking cures for their husbands by quack doctors or faith healers. As a spirit of fellowship and acceptance of each other developed, each of the women felt more secure about expressing her feelings with regard to the guilt of placing her husband in a hospital, grief of the "loss" of her husband, and her fears of facing the future as a woman alone. At the end of the six sessions the author concluded that "the group served a significant purpose for its members" (p.221). They were now able to give thoughtful consideration to personal hopes for the future, instead of dwelling on only the anguishes of the past. Although the women continued to express feelings of sadness and grief, they were more able to feel sorry for themselves, and also began to take positive steps toward finding some personal happiness.

As another means of offering support to families of an Alzheimer's disease patient, an adult day care center was established with the primary goal of providing respite for the caregivers, and creating a meaningful situation outside of the home for the impaired person (Sands & Suzuki, 1983). The program was designed to meet the special needs of the Alzheimer patient, by maintaining stability, and offering structure to them. The authors reported that the

caregivers gained relief, as well as insight and emotional support from each other, and from the staff. In addition, they felt that the patients also showed improvement in emotional problems, as well as occasional gains in cognitive functioning. However, the latter conclusions were much more difficult to substantiate. The clinical impression of the authors was that "day care provides an alternative to nursing homes as relief to families caring for a person suffering from Alzheimer's disease." (p.23). Further, that it provides the patient with an opportunity to participate in what appears to be an emotionally therapeutic psychosocial atmosphere. They concluded that "day care may well have the potential for providing a better alternative than institutionalization for a large percentage of families caring for persons suffering from Alzheimer's disease" (p.23). Ultimately, the authors believe, this type of program may even help to improve nursing home care by removing patients who do not need to be in that setting.

Summary

The literature clearly reveals evidence that Alzheimer's disease affecting a particular family member indeed disrupts a family's equilibrium, and results in disintegration of the family system. Further, that there

is a dire necessity to assist families, and especially caregivers, to adapt and cope with the disease and its consequences.

Authors have suggested a variety of ways for accomplishing support and respite for caregivers, such as family/patient group programs, adult day-care programs for the patient, and several other types of group participation programs. However, not many have cited research studies, within a framework of family systems theory, to examine the value of such programs.

This dissertation, therefore, has consisted of a qualitative study, based upon a framework of family systems theory, to examine the following. First, whether or not primary caregivers of patients with Alzheimer's disease perceive support groups to be a valuable means for assisting them in dealing with their feelings of stress and burden; stress related symptoms; family relationships; and coping and adapting strategies. Second, to evaluate how this decision has been influenced by their family system, for instance, boundaries: whether permeable, moderate, or rigid; and family rules and regulations, including those for role expectations.

CHAPTER III

METHODOLOGY

Introduction

The foregoing review of the literature has revealed that a catastrophic illness, such as Alzheimer's disease, affecting three million Americans, is not only devastating to the patient, but also upsets the equilibrium of the entire family. Since the patient is typically 65 years or older, the disease brings extra demands to families at a time of life when members are frequently facing their own transitional adjustments, are least able to cope with stress, and are in need of a great deal of support.

In most cases, because of the severity of the disease, the tendency is to focus on the needs of the afflicted member, while the needs of other family members go unnoticed or unmet. While various types of support groups have been established, little has been done to evaluate the effectiveness of such groups, particularly from the caregiver's viewpoint, and the perspective of family system's theory. Therefore, this qualitative study was conducted, for the purpose of gaining information

regarding whether or not a caregiver's family system influences: their perceived feelings of stress and burden; stress related symptoms; family relationships; coping and adapting strategies; and the value of attending a support group. To accomplish this, in-depth interviews were held with 20 primary caregivers. Recurring common responses, significant statements, and expressed feelings, were analyzed and then organized according to various themes under three general categories covered by the semi-structured interview guide (appendix A.).

Following a preliminary analysis of the data, the surface level information gained was re-sorted, and then re-analyzed under a framework of family system's theory, made up of significant categories generated by the family history, and the demographic information form.

Sample

The sample consisted of twenty primary caregivers of patient's diagnosed with Alzheimer disease, who are currently attending an ongoing support group in Dallas, Texas, and the greater Dallas area.

Characteristics of the sample

The caregivers were related to the patient as follows: Two female sisters of female patients, three daughters of female patients, one daughter of a male patient, three male

spouses, and eleven female spouses. The ages of the caregivers ranged from 45 to 70 years, and the patients from 60 to 75 years.

At the time of the study eleven of the patients were living at home. Two families were in the process of deliberating over the possibility of an outside placement for their patient. Six of the patients had been placed in a nursing home; and one had died, during 1986. Each caregiver had attended a support group while caring for the patient in their home, and were continuing to attend one at the present time.

All of the patients had been diagnosed by a qualified physician as having Alzheimer's disease, and at the time of the study were considered to be in one of the earlier stages of the disease (Pajk, 1984). These stages consist of: forgetfulness, especially for recent events; difficulty in learning and remembering new information; deterioration in appearance and personal hygiene, and the ability to concentrate on such things as reading or watching television; a lessening of ability to accomplish tasks that require abstract thinking, such as balancing a checkbook, and for activities requiring judgement, such as driving a car or following instructions. In many cases depression may also be found because of the patient's awareness that something is wrong.

The families were all from a similar, middle-class background, with yearly incomes ranging from \$15,000 to \$25,000, in order to rule out possible pre-existing financial differences.

The director of the resource office for Alzheimer's Disease and Related Disorders Association (ADRDA) in Dallas was apprised of the study, as were the directors of existing support groups for families of Alzheimer's disease patients, in Dallas Texas, and the greater Dallas area, such as, Carrollton, Garland, Irving and Richardson, and Plano, Texas. They were requested to refer possible volunteers to participate in the study.

Although each support group is conducted a little differently, the program content is similar in most respects. The differences, in general, are that the smaller neighborhood groups tend to place more emphasis on shared experiences and feelings, and devote less time to information regarding the disease, community resources and patient management. The larger Dallas group, on the other hand, devotes more time to supplying information regarding the disease itself, research findings, community resources, and patient management, and less time to sharing experiences and feelings. Some of the caregivers attend both the larger Dallas group, and a smaller neighborhood group.

Procedure

Pilot Interviews

Prior to the study pilot interviews were conducted with two primary caregivers currently attending a support group. Through the process of conducting these interviews, and based upon relevant research literature, as well as the theoretical perspective of family systems theory, three broad areas were incorporated into a semi-structured interview guide. These areas reflected the research questions of the study.

The Interview Guide

To ensure that the same general areas were being explored with each of the respondents, a list of open-ended questions addressing three general areas was developed (Appendix A.). These areas were: How has the patient's illness impacted you personally? How has the patient's illness impacted your entire family system, and family relationships? How has the attendance of a support group made a difference to you, to your family, or to family relationships? If it has not please explain. The last area was explored for both a subjective and objective answer. For instance, in addition to the previous question, the respondent was asked, "how can a support group be more beneficial in meeting the needs of people in general?" In

order to reach below the surface meanings of the responses, each area was systematically explored further by the use of related questions and probes (Appendix B.).

In-depth interviews

After assessing the volunteers, to determine that they fit within the parameters of the specifications of the sample, appointments for interviews were made by telephone with each caregiver, at a time and place convenient for them. Nineteen of the caregivers chose their own homes, while one a female spouse, preferred the ADRDA office, since she was concerned about the possibility of being distracted by the patient who was in a very early stage of the disease, and "well aware of what was going on."

All of the interviews were audio-tape recorded. The length of each interview varied between one and a half, and two hours. At the beginning of each interview the purpose of the study was explained, and the caregivers were asked to sign a form giving permission to interview and audio-tape (Appendix C.), and complete a demographic information sheet (Appendix D.). A short family history was taken verbally in response to such questions as: "How would you describe your family relationships in general?" "Can you describe any rules that you have noticed in your family?" "How did you come to be caregiver of your patient?"

The concept of boundaries was explained, and a continuum from rigid through permeable was shown to the caregivers. They were asked "in times of difficulty does your family tend to band more together, move further apart, or fit into a more moderate level? They were then asked to indicate a position on the continuum where they thought their family belonged. The results were:

Boundaries	<u>Rigid</u>		<u>Moderate</u>			<u>Permeable</u>	
Caregivers	5	1	3	4	2	1	4

As seen above, boundaries were described, on a continuum, as being extremely closed by five caregivers, as open by four, as fairly moderate by nine, as moderate toward being closed by one, and as moderate toward being open by one.

The pre-constructed interview guide (Appendix A.) was used to elicit information, and to save the questions and answers from straying from the topic. Collected interview data was transcribed from the audio tapes into a typed form, and then analyzed according to suggestions by Taylor & Bogdan (1984). Confidentiality was preserved by assigning fictitious initials to the audio tapes of each participant.

Data Analysis

Three copies of the transcripts were made. The data was read, and then re-read for surface meanings. In one

copy of the transcripts notes or symbols were made in the margins, as a reminder for where themes began to occur, or to mark concepts that might apply to the analysis. Recurring common responses, significant statements, and expressed feelings were then coded accordingly by circling like statements with a particular colored pen. This was done for each transcript, and then the coded material was organized within the framework of the three general areas covered in the interview guide. In order to keep track of who said what, and in what context, a matrix type chart was made up, with a vertical column on the left hand side, for each response as it occurred. On the right hand side, there was a series of 20 boxes representing each respondent, arranged horizontally, allowing for check marks to be placed at each coinciding response. A preliminary analysis of the data, was then conducted. There were indications in the themes and patterns that emerged from these data, that a caregiver's particular family system greatly influences: their perception of the impact of the disease upon themselves; on family relationships; on their coping and adapting strategies; as well as their opinion of the value of attending a support group.

The first level of information yielded by the preliminary analysis was, therefore, re-sorted, and then re-analyzed under a family systems framework, made up of

significant categories generated by the family history, and the demographic information form (Appendix D). These general categories were, the influence of the family system: on the impact of the disease on the caregiver; on the impact of the disease on family relationships; on coping and adapting strategies; and on the value of attending a support group. The information obtained by the second analysis was also posted to the matrix type chart.

The coded sections of all of the transcripts in both of the copies were cut into individual segments. These segments were then cross referenced and filed, thus placing the information gained by the preliminary analysis under the categories developed in the family systems framework. Finally, findings were reported from this second level of analysis.

Summary

Catastrophic illnesses, and particularly Alzheimer's disease, create havoc, and impose excessive demands on families. Various types of support groups have been developed as a means of assisting families to cope and adapt to the extreme hardships the disease has imposed. However, the question of whether or not the attendance of these groups are perceived as valuable, appears to be

influenced by the variability of each caregiver's family system, for instance, boundaries: whether permeable, moderate, or rigid; and family rules and regulations, including those for role expectations.

A qualitative study was therefore conducted, within a framework of family systems theory, to examine the following. First, whether or not primary caregivers of patients with Alzheimer's disease perceive support groups to be a valuable means for assisting them in dealing with their feelings of stress and burden; stress related symptoms; family relationships; and coping and adapting strategies. Second, to evaluate how this decision has been influenced by their family system.

CHAPTER IV

FINDINGS OF THE STUDY

Introduction

A qualitative study was conducted, by the means of in-depth interviews, with 20 primary caregivers of patients with Alzheimer's disease. The purpose of the study was to determine, through the framework of family systems theory, whether or not a primary caregiver's family system is an influencing factor in how they perceive that they, and other family members, have been impacted by a patient with Alzheimer's disease; their feelings of stress and burden; stress related symptoms; family relationships; coping and adapting strategies; and, ultimately, the value of support groups.

A preliminary analysis was made by coding recurring common responses, significant statements, and expressed feelings, and organizing them accordingly into categories gained from the three general areas of questioning in the semi structured interview guide (Appendix A). The information gained by the preliminary analysis revealed patterns and themes, showing certain similarities and

differences in the caregiver's responses. These varying responses appeared to be largely dependent upon each person's particular family system, such as, their type of boundaries: permeable, moderate, or rigid; family rules and regulations; and role expectations. Therefore, the data gathered by the demographic information form, and the verbal family history, were also analyzed, and organized into the following four categories, the influence of the family system upon the impact of the disease on the caregiver; the influence of the family system on the impact of the disease on family relationships; the influence of the family system on coping and adapting strategies; and, the influence of the family system upon the perception of the value of support group attendance for each of the caregivers. The information, gained by the preliminary analysis, was then re-sorted, and finally filed, and re-analyzed under the broader framework relating to the family system.

Findings

Neither the stage of the patient's illness, nor the age or sex of the caregiver, or of the patient, was found to have a bearing on the perceived impact of the disease on the caregiver, or on family relationships; on coping and adapting strategies; or upon the value of support group attendance. However, the differences that were reported

appeared to be influenced by their particular family system, for instance, their type of boundaries: permeable, moderate or rigid boundaries; and family rules and regulations, including those for role expectations. Boundaries were described, on a continuum, as being extremely closed by five caregivers, as open by four, as fairly moderate by nine, as moderate toward being closed by one, and as moderate toward being open by one (p.47).

The Impact of the Disease on the Caregiver

Emotional Impact. The type of family boundaries, e.g., rigid, moderate, and permeable; and family rules and regulations, particularly those relating to role expectations, were found to be influencing factors in this category.

Only one caregiver, a daughter of a female patient, Mrs. I. J., related her increased feelings of stress and involvement with her mother to the progression of the disease:

As the symptoms became more severe, it became more difficult. Mother did not sleep well at night, she would be up and wandering around. So a lot of the time I would stay up at night too, and in the morning I'd be so tired and worried.....concerned about what was going on, and what was going to happen.

Regardless of family background, the caregivers all reported some distress with regard to the complete loss of freedom they were experiencing, although those who had reported closed boundaries, tended to minimize their feelings with regard to this.

The three male, and eight female spouses, expressed disappointment over shattered dreams for spending their later years together, having looked forward to a time when there would be no more, or fewer, child rearing responsibilities, and more time for recreation and relaxation, perhaps consisting of a chance for traveling, visiting married children, and so on. This was exemplified by Mr. K.L., husband of a patient, who stated:

we have always loved to travel, we have traveled a lot. I have seen it all, but we had planned to travel more. I would love to go again, but at this point I feel it would be selfish.

Other common feelings reported were, sadness; both for their loved ones, and for themselves, loneliness: for the loss of this other person, their former companion, spouse, or parent; and resulting depression. Sixteen of the caregivers, including the eleven spouses, related that the most devastating aspect of all was the loss of companionship, and the lack of communication between them.

A spouse, Mrs. Q.R. sadly said:

When someone dies you can go on with your own life. I am married, but don't have a husband.

I feel a loss of someone to share with...companionship. I am grieving now.

In a similar vein, another four of the spouses commented that it felt as if they were a widow, or widower.

Mr. M.N. related:

It is like being a widower, I guess you would say. There is no one to carry on a conversation with. I am on my own, so to speak.

Role changes were described as having had an extremely stressful effect on the caregivers, especially for those whose family rules adhered to certain role expectations. The response of Mr M. N., a spouse, was a good example of this. His statement also reflected disappointment in an earlier anticipated life-course event:

I have learned to do a lot of things I have never done before. I give her a bath, and do things like a practical nurse, as well as some housekeeping. Instead of me, at retirement age, being relaxed...I'm kind of hurting.

Role changes between generations were also found to be painful. Mrs. L. M., daughter of a patient, described her feelings from an adult child's point of view:

He was always the head of the household...such an independent man that I had never been put in the position before where I had to make decisions for him. Now I have kind of taken over his duties, and make his decisions, which I have never done.

All of the caregivers typically reported feelings of strain, stress, burden, or fatigue, at one time or another. However, six of them who had reported closed or moderate to closed boundaries, denied many of these feelings, quickly placing the focus on the needs of the patient, as well as on their own need to fulfill what they considered to be their duty as a caregiver.

The statement of Mrs. G.H., daughter of a female patient was typical of this:

It had a tremendous impact, they say a 36 hour day - there is no question about it. I knew she could not be left alone. She wouldn't, - couldn't eat by herself. She wouldn't get up to go to the bathroom, or take her medicine, and so on.

Fourteen of the caregivers expressed feelings of anger, resentment, and impatience, which often resulted in feelings of guilt generally stemming from any, or all of the former feelings, as well as from existing family rules which prohibited these feelings.

Mrs. I.J., daughter of a female patient, described how she felt:

Lots of times I would question religious philosophies, like, why me? I really don't deserve this. Then I would feel selfish and guilty for feeling that way. Sometimes, I did think, though, mother was a devout Christian, and taught a Sunday school class, and I thought, why is this thing happening to her? Why do bad things happen to good people? It's unfair.

Another typical response was by Mrs. O.P., spouse of a patient. She expressed the guilt she felt over the ambivalence she had been experiencing, due to her reaction to the disruption in their lives, and the feeling that she had become "stuck" at home as a result of the illness:

I have many mixed feelings. I have a lot of anger, lot of sadness, lot of impatience, lot of resentment, and self pity (I am ashamed to say...I feel guilty). It is a great burden, and of course has completely disrupted our lives. We can do nothing together now. So, I feel deprived in a way. I am stuck at home.

Physical Impact. Self neglect, and various kinds of stress related symptoms, such as, heart disease, high blood pressure, stroke, and a nervous stomach, were attributed to the impact of the disease by eight of the caregivers. Five of these people had similarly stated a rule: "we always handle situations like these on our own, regardless of costs to ourselves." For instance, Mrs. G.H. daughter of a patient, stated:

I have health problems of my own, and need to take care of myself. I have had an ongoing ear problem for the past three years, and also a cholesterol problem, and an extra crick in my heart. I don't know, but things seem to have gotten worse since mother is ill. I just barely hang in, one day at a time.

Other themes expressed by all, were worry about what was going to happen to the patient next; what the subsequent levels of the disease might bring; anxiety and apprehension for themselves, and their own health, as well as for that of the patient; and concern over what would happen if the patient were to outlive them. Mrs. K.L., wife of a patient, typically related:

I was emotionally affected, it depressed me. We can manage disease when it affects the body. This disease of the mind is not very easy to take.

I am also affected by the materials I have read about the disease, and from what I have heard from others. When something happens, I think, "oh my G. what is happening now, is he reaching the next level"?

Financial Impact. Because the caregivers were of a similar socio-economic level, there were many commonalities among their description of the financial impact of the illness. Most of them described the "crunch" of being in a middle income bracket. While being above a level to be eligible for various types of social assistance on the one hand, on the other hand they were forced to face the reality of being unable to afford the tremendous drain in finances the illness had brought, or was about to bring. Another great common concern among them was the inadequacy of private health insurance programs, as well as Medicare, for a long-term, or catastrophic illness. In addition, because of the income level of the caregivers, their patients are considered ineligible for Medicaid, which might otherwise have paid for nursing home costs.

The described situation by Mrs U.V., a spouse, was typical of this:

We withdrew our social security early, so we don't get as much as others. I don't have enough

income to keep him in a nursing home and keep myself. Medicare won't take care of Alzheimer's if we need it, and so I will have to apply for Medicaid for him. This will also take all of his social security and pension. This will mean that I will have only my small social security to live on. I don't know what that will mean.

Aside from the eligibility factor, for caregivers who had reported closed to moderately closed boundaries, a typical family rule: "in our family, we always take care of our own," also inhibited their willingness to accept financial aid from others.

While eight of the caregivers, whose patients were still at home reported that financial problems had not hit them yet, twelve others reported severe financial burden as a result of the illness. Most of these expenses were related to increased medical, and nursing home costs. In some cases, however, the expenses had to do with moving and resettling in a more affordable dwelling, or moving geographically closer to another family member.

Six of the female spouses described severe financial problems due to losses in their husband's income. Three of them also described their fears, and feelings of inadequacy for becoming the sole support of the family. This was especially true of those people whose families had

held to traditional male and female roles.

The following is a typical response by a spouse in this group, Mrs. W. X.:

It was a huge financial loss. On the last job he had he wasn't working right. It came off that he was disgruntled rather than ill. They suggested he resign from there. He then went to another place, but it did not work out for him. He couldn't manage what he had been trained for anymore, and so he got an easier job, and when he could not manage that, he had to leave there. He just went from job to job, had about 40 in all, and of course each one was a little lower class. Because of all those years of little bitty jobs, his social security was small when he finally quit. This has robbed him of a lot of income. It was totally frustrating to realize that I had to become the sole support of the family, and women's salaries are not adequate.

Social Impact. Many of the caregivers described feelings of social isolation, due to the withdrawal of former friends; as well as, in some cases, family members. However, the family background was found to be influential in this area also. For instance, social isolation appeared to be self-imposed in several instances, by the

caregiver's withdrawal from outside contact, rather than by the withdrawal of others. This was particularly true of caregivers who had reported a family system with closed boundaries. On the other hand, some who had reported moderate to moderately open boundaries, had managed to maintain a level of open communication, as well as a more satisfactory relationship, with other family members and friends. An example of this can be seen in a statement by a spouse, Mrs. Q. R:

Many people also feel that their friends have withdrawn from them. I think that by explaining to their friends, what is happening, and allowing them to participate in helping in some way, they can keep friendships.

The Impact of the Disease on Family Relationships

For the most part the caregivers reported that they had noticed very little change in their pre-existing family relationships. The manner in which the families reacted to the impact of the disease, appeared to be influenced by their particular family system: the degree of rigidity or permeability of the boundaries; and family rules and regulations, including role expectations.

Seven of the caregivers reporting moderate boundaries stated that the illness had seemed to draw the family

closer together. An example of this was evidenced in a statement by Mrs. O.P., wife of a patient:

It has brought us together for the one thing, and that's the main thing. We had already been a fairly close family, but this has made us closer.

On the other hand, four of the caregivers who had reported more open family systems described feelings of having been "dumped on," and abandoned by other family members. Mrs. J. K., a spouse, gave a typical description of the dynamics existing in these families:

He has two daughters from a previous marriage. Something that has gotten me down is that his daughter who lives here just doesn't understand. She wouldn't take care of him. She calls him now and then, but never comes to see him. This problem existed before he got sick. His other daughter has moved to Florida. I can't depend on either of them.

Another spouse in this group, Mrs. G. J., related that she felt as though she was being deserted by other members of her family, who were dealing with the illness by running away emotionally, as well as physically. She said:

Some of the kids try to run away from it. One of my daughters' suffers from depression, and says her father's illness makes her more depressed,

and prefers not to see him like this. Another daughter also tends to be depressed. Much of their problems existed before he got sick, but they are using depression as an excuse to run away. My son also runs away. My husband also has three sisters, but they never come to see him.

The married daughters of the three female, and one male patient, reported conflicts over priorities between the role as a caregiver for their parent, and that as a spouse and mother. They also found the illness of their parent to be wearing, and a strain on their relationships with their husbands, as well as with their children. In a typical response, Mrs. G.H., daughter of a female patient, now in the nursing home, said:

It's been difficult. My husband is not supportive. There were times before my mother came to live with me, when I would go to Fort Worth to take care of her, and often stayed there for a week at a time. That was a lot, and I was giving up a lot of time here to go over there. It made things even harder with my husband, and it was also hard on my son, who was still in high school at that time. For instance, when I was gone they had to eat out.

In a similar vein, Mrs. I. J. stated:

It is really wearing on a family. Our kids were approximately eight and ten years old at that time, and it was very difficult for them. It was also very hard on my marriage, having to spend so much time with the patient. Mother was very demanding, I did not have enough hours in the day to go around. I did not have the time for anything, because it is tiring both physically and emotionally. By the end of the day you do not have much time, or energy, or inclination, for communication. Also, my kids had been very close to mother, and so there was a lot of depression, and probably a lot of guilt on their parts for being angry with her a lot of the time.

In addition, three of the four adult children of patients, described conflicts among their siblings, with regard to the stipulations of family rules, and role expectations. Two of them related that they felt they had all of the responsibility, but no authority. This was particularly related by of Mrs. G.H., a daughter of a female patient. She described feelings of being out of control of her life, and frustration because her older brother had all of the authority in the family, and had had this even before her mother had become ill. She explained

that her brother had automatically taken over the role of their father, after he had died, and that the men in her family always held the position of authority. She stated that the situation had become increasingly conflictual because she had become the primary caregiver for her mother, but felt completely powerless when it came to making decisions. This was not only in regard to the major issue among them of deciding about a nursing home placement, and important financial matters, but also pertained to small matters, such as, how much money should be spent on groceries. Mrs. G.H. stated:

My brother really is and was over me when it comes to the money. I had a lot of responsibility, it was dumped on me without authority. I don't have any control of my life or what is going on.

Coping and Adapting Strategies

The stage of the patient's illness, and the age or sex of the caregiver, or of the patient, had little bearing on coping and adapting strategies. The caregivers described the various types of coping and adapting strategies employed by them. Some of them described their method of coping as keeping the patient at home, and "handling" the situation alone. Others reported involving the assistance of other family members, or of outside sources. Still

others stated they coped by searching out an outside placement for their patients. The strategies used by each caregiver, appeared to be greatly influenced by the particular family system, for instance type of boundaries: permeable, moderate, or rigid boundaries; and rules and regulations, especially those pertaining to: expectations in general; role expectations, for themselves and others; and family loyalties.

Some of the difficulties in coping were attributed in particular to those family rules which prohibited feelings of ambivalence, anger, and impatience with the patient, and to other principles and loyalties of their family system which strongly condemned seeking outside assistance, or placing a sick family member in an outside facility. Disregard or violation of these rules generally resulted in feelings of guilt, which further compounded the coping difficulties. Role expectations, and role changes were also contributing factors.

Other coping strategies seen among the caregivers were similar to those described by Tuesink & Mahler (1984). These are: Initial denial that anything is wrong, as well as denial of their own needs; overinvolvement with the patient in an attempt to compensate for the illness; anger when compensation fails; guilt as an outcome of the anger; and acceptance of the problem. These levels were not

necessarily found to be sequential in nature, or to coincide with the stage or seriousness of the patient's illness. Rather, several of the caregivers, while presenting with denial, at the same time, often expressed feelings of anger and guilt. Also, as the patient's illness progressed, the pattern seemed to repeat itself. In other words caregivers who may have reached an acceptance level for a particular stage of the illness, could present with denial all over again, and so on, as the patient's health reached a further stage of deterioration.

The family system was again seen as an influential factor in these cases. For instance, the caregivers who had reported a closed family system were more prone to denial, both in regard to the seriousness of the illness, and of their own needs. Feelings of guilt for this group generally centered around such themes as "why am I well, when he or she is sick," or "I would feel guilty if I were to go out and enjoy myself, while he, or she, is suffering." On the other hand, the caregivers who had reported a more open system, were more prone to expressing their feelings of anger, and impatience with the patient.

Those caregivers who regarded their family system to be rigid, and tightly knit, tended to keep their patients at home, regardless of the consequences to themselves. They reported being hesitant about seeking outside help,

and reluctant about receiving it, sometimes even from their own children. They stated that they preferred to "handle things" themselves, because "that is the way it should be," and that they planned to continue to do this as long as was humanly possible. This was how their family's had "always done things." Typical of this group, a spouse, Mr. K.L., who has a serious heart condition, said:

I will continue to do everything I can for her.
I only hope that I can stay around long enough to take care of her. ... Maybe I'm different, maybe I'm strong, but we've always been that way, my father, my mother, we're family oriented, that has always been number one. ... It is part of my life now, I just have to do my best. When problems happen in the family we just handle them and go on. I hate to bother other people, although people keep calling to see if they can help. ... I have other things I would like to be doing, but we all have certain priorities.

The other caregivers who had indicated boundaries toward the rigid end of the continuum, such as Mr. M.N., expressed a lack of desire for involving other family members in caregiving, seeing coping in this matter as their sole responsibility, he stated:

My daughter lived at home with us until about a

month ago, but has moved out to live with a friend. I want her to feel free to do things like other young people. This is my responsibility.

Representative of the six caregivers who had reported difficulties in coping with role changes, Mr. M.N. stated:

I have taken over her roles in addition to mine. ... I think for the most part, the things she used to do for herself are the most difficult. Like buying her clothes, and making sure that she has lipstick on - even buying this for her. She also used to take care of all of our correspondence, and now with Christmas coming up, I will have to take over sending out all of those cards. It is difficult.

In contrast, the responses by Mr. D.E., spouse of a patient now in a nursing home, reflected an attitude of a more moderate family system, more willing to accept outside assistance, and support. He related:

I have now placed her in a nursing home. I kept her home as long as it was reasonable. When she was home I was able to find nurses to help us. My daughter has also been a great help.

Four of the caregivers who had reported that they were from a family system with open boundaries, related that they had "poor coping skills." These were described as: difficulty in coping due to an inability to handle things in general, not knowing where to turn, and not seeing any available options. They related a desire, at times, to send the patient away, or to run away themselves, and escape. However, concern about possible repercussions, and feelings of guilt prevented them from doing this. Three of these caregivers felt as if they had been "dumped on," and abandoned by other family members, and friends. The statement of a spouse, Mrs. F. G., most exemplified this group:

I didn't cope too well. I don't cope well with things. When he first began getting bad, I cursed him and yelled and then I'd feel, I have to get away from him. Now at night, after I get him to bed, even though I'm tired, I go somewhere. I go to the shopping mall...anywhere just to get out. I always hate to come back...I don't see any options open for me, and escape would be so good, but I don't know if I could live with that either. I tend to cut off my nose to spite my face. I lost my friends for that reason, and don't want to do that with him.

The caregivers in this group, such as Mrs. J.K., a spouse, also indicated a stronger desire for the assistance of outside resources as a means for coping. She said:

What I need is somebody to sit with him for a few hours every now and then. I don't know if they can do that, like volunteers.

The Value of Support Groups

The stage of the patient's illness, and the age or sex of the caregiver, or of the patient, had no apparent bearing on the perceived value of support groups by the caregivers. There was considerable variability with regard to the aspects of the support group perceived as the most valuable. As was found in the former categories, these preferences appeared to be influenced by the family background. For instance, those caregivers who had reported a family system of closed boundaries, preferred receiving information and education about the disease itself, and about current research findings. They stated that they had no need of emotional support, and were not interested in sharing their feelings. These people also showed less inclination to attend support groups, and if they did identify themselves with one, attended less frequently.

On the other hand, the caregivers who had reported open boundaries, attended support groups more regularly, were more eager to hear about any outside resources, including possible placement facilities, which might be of assistance; were interested in sharing their feelings and experiences with the group; and looked forward to the social aspect. Caregivers who had reported moderate boundaries expressed interest in a more balanced type of program, including some of each of the aspects preferred by the others.

Fourteen of the caregivers, consisting of: nine who had reported fairly moderate boundaries, one who had reported moderate to open boundaries, and four who had reported open boundaries, stated that attending a support group had made a positive difference to them. They felt that it provided an opportunity for sharing common experiences, and feelings; and helped them to realize that they were not the only ones going through this experience. In addition, they regarded the support group as a place where they could have a social break, or "caregiver's night out," and make some new friends. For instance, Mrs. I. J., daughter of a female patient stated:

I think just the sharing helped, the realizing that you were not the only one going through that. I think psychologically there is some

comfort in knowing that you are not the only person going through it, - absolutely, the sharing is the most helpful. The biggies that I see are getting some information, and having the feeling that there is somebody that understands.

Some of the caregivers in this group, such as Mrs. G. H., daughter of a female patient, voiced a preference for a smaller sized group. She said:

Attending a smaller group is better than a larger one, simply because you can go into the group and vocalize your feelings, frustrations and anger.

... Being able to express feelings and sharing feelings with others, has more of a support feeling.

The influence of the family background was again reflected by another five caregivers who had reported that their particular family system had closed boundaries, and rules that typically specify, "I must be strong, and not feel sorry for myself," and "I must handle things on my own, without involving anyone else." In response to the question of the value of support groups, Mr. A. B., a spouse, replied:

I think certain things have helped, such as finding out where research groups are, but I don't get too excited about going there, because

I don't want to listen to all of those stories and problems. I don't want to cry about it. I don't want to feel sorry for myself about it. I don't want any pity about it. I guess I am strong in that respect. ... The way support groups could be more helpful would be if there was more education or information about legal matters. Also if recent reports could be reviewed regarding research that's being done. I would like to see the support group as a place where people can get this information, about the disease and other things related to it.

Another spouse, Mr. C.D. responded in a similar manner:

The main way the support group has helped me is by listening to the experts they bring in, in their particular fields, e.g., the neurologists, psychologists, etc. Some people do bring up their problems there, but I only listen. Suggestions on how to manage the patient are good, and also suggestions for a good doctor to see in this particular situation, and a good lawyer, and any other specialists or professionals we might like to know about.

Receiving information with regard to patient management in the home was also found to be extremely useful by this group of caregivers. A spouse, Mr. M. N., related:

I have learned some things about coping with different problems. For instance, as someone suggested, I got her an identity chain with her name on it. That helped when she was lost one time, and the police found her.

Mrs. I.J., daughter of a patient stated:

it helped when someone suggested that there were some knob covers that you could put on a door, which would just slip around but not open the door. This was a good way to keep mother in her room at night.

While many of the caregiver's reported that attending a support group had made a difference to them in a positive manner, several of them reported various negative feelings. In particular, people who were in denial of the patients illness, and their own need for emotional support, stated that they were uncomfortable when others discussed their feelings, or became emotional. Further, while intellectually looking for, and understanding the factual information regarding the disease and its progress, they stated that they really did not want

to hear from some of the other caregiver's about the more advanced stages that their patients were experiencing. It was as if this brought it too close to home, and to the reality that if they accepted that this could be happening to others, they would have to admit it could also happen, or, might even currently be happening, to their patient. Some of these feelings were expressed by Mrs. K.L., spouse of a patient:

My having learned so much about it, from the reading I have done, and hearing it from other member's of the group has depressed me, in a way. ... If you are not at a later stage, and you hear someone whose patient is at that stage, this can be a bad moment for you, and you may not be able to emotionally handle it.

In much the same fashion, Mrs. M.N. stated:

Yes, it helps to hear what other people have gone through. However, I had known pretty well what to expect from the beginning, and it was telling me something that I already knew. I knew what the disease is like. I try not to think about it. While the group is very informative, sometimes I wonder if we get information too soon. That can be to the detriment of the patient and the caregiver sometimes.

Neither the stage of the patient's disease, nor the place where the patient was residing made a difference to the caregiver's perception of their need for support. In fact, some caregivers with a patient in a more advanced stage of the illness, living in an outside care facility, expressed as much need for support as did some of the others. This was influenced by the family system, and whatever the boundaries, and family rules would allow. For instance, because caregivers who had reported a closed family system are more prone to denial, regardless of the stage of their patient's illness, it was found to be more difficult for them to admit to the need for, or acceptance of, support from someone outside of the system.

Further, the fact that a patient had reached a more advanced stage of the illness, and had been institutionalized, did not necessarily mean that the caregiver had reached an acceptance level in coping and adapting to the situation. Patterns of coping strategies, such as, denial of the seriousness of the patient's illness, or of their own needs; overinvolvement with the patient in an attempt to compensate for the illness; anger when compensation fails, guilt as an outcome of the anger; and acceptance of the problem; were seen to repeat over and over again as the patient's health further deteriorated. The family system was seen to influence these patterns.

Only two of the participants in this study indicated their acceptance of the problem. Each of these people had reported moderate boundaries, and although in both cases the patient was in a nursing home, they still attended the support group, and indicated their need and desire for continued support.

Summary

Reports by the caregivers interviewed for this study revealed that while each person perceived the value of support groups in a unique way, there were many similarities and differences among them. These similarities and differences appeared to be linked to their particular family system, such as their indicated type of boundaries: permeable, moderate, or rigid; and family rules and regulations, including role expectations. Therefore, an effort was made to examine the extent to which a caregiver's family background influences: their perceived feelings of stress and burden; stress related symptoms, family relationships; and, ultimately, their perception of the value of a support group.

Five of the twenty caregivers reported that at a time of difficulty their families tended to band together, and become more closely knit, while four others described themselves as drifting further apart. The remaining eleven fell into a more moderate level.

Those caregivers who had described rigid boundaries, professed more loyalty toward family rules. They were greatly into denial of the illness, stating that perhaps their patient had a "milder form" of the disease, or had been misdiagnosed. They also denied, or made light of the impact the illness had had upon them, and their own needs. They shifted the focus, instead, to the needs of the patient, and to their desire to fulfill what they considered to be their duty as a caregiver. They generally refused outside assistance, often even from other family members. Furthermore, they tended to keep their patients at home longer, if not permanently, and typically stated family rules like: "we take care of our own, no matter what;" "we must be strong and handle everything ourselves," and "we must never, never place a family member in a nursing home, because this is just not done in our family."

The coping and adapting strategies of these caregivers appeared to be greatly influenced by the above family rules, principles, and loyalties which prohibited feelings of ambivalence, anger, and impatience with a sick family member, as well as strongly condemning the acceptance of outside assistance, or the placement of their patient in an outside facility. Disregard or violation of

any of these rules generally resulted in feelings of guilt. While asserting that they were not experiencing difficulties in coping, several of these caregivers reported serious stress related symptoms. Role expectations and role changes were also contributing factors.

With regard to their perception of the value of attending a support group, the caregivers in this group reported the greatest benefit to be the receipt of information with regard to the patient, and the patient's well-being, such as, the progression of the disease, current research findings about the disease, and so on. They also found hints regarding patient management at home to be helpful. However, they saw no need for a support group as place for themselves: where they could receive emotional support, express their feelings, or share common experiences. A caregiver in this group typically reported, "we do what we have to, and that is all there is to it."

The four caregivers who had indicated boundaries at the open end of the continuum were much more open in expressing their feelings, regardless of whether they were positive or negative. They voiced their anger and resentment at other family members, as well as anger and impatience with the patient, although, at times followed by

feelings of guilt. They felt that they had been "dumped on," and generally sought ways to escape. They also reported conflictual relationships with other family members, as well as frustration with role changes, and various kinds of stress related symptoms. They admitted to "poor coping skills," describing them as difficulty in coping due to an inability to handle things well in general, not knowing where to turn, and not seeing any available options. They indicated a strong desire for the assistance of outside resources as a means of coping.

Those caregivers who had reported moderate boundaries also admitted feelings of anger, resentment, impatience, guilt, strain, stress, burden, and fatigue. However, they appeared better equipped for dealing with these feelings. For instance, in general, they showed more willingness to seek outside assistance, and were more comfortable with the idea of an outside placement for their patient. In addition, they considered other family members to be helpful and supportive.

Regarding their perception of the value of attending a support group, caregivers who had reported moderate to open boundaries, expressed a gain in having a place where they could, "unload" their feelings; share common experiences; hear how others had dealt with similar circumstances; and enjoy a period of respite, and companionship, with others.

In addition, these caregivers saw support groups as a useful source for obtaining information about the disease itself, patient management, and financial and legal implications. However, they regarded information about community resources, for example, available services such as, sitters, day-care facilities, and nursing homes, to be of greater value. Information regarding the pros and cons of an outside placement, including the type of care facility to look for, and the facilities which are available and equipped to handle patients with Alzheimer's disease, was also considered to be of value. Further, they perceived the support group as a valuable means for enhancing relationships with other family members, especially if the others attended the meetings along with the caregiver. However, they stated that even if the others did not attend, the information supplied could be shared, thus contributing to a greater level of understanding among them all.

Those caregivers whose patients were already in a care facility, stated that their idea of a valuable support group was a place where they could hear from other participants how they had adapted to this situation; to have the opportunity of sharing with others some of the feelings and frustrations they were experiencing as a result of the placement; and to receive emotional support.

Some of the issues they were attempting to contend with were, loneliness after their patient had departed; the fear that the patient would not eat, or survive, if they did not visit them at the care-facility on a daily basis; the hardship of traveling considerable distances to accomplish this; the upset and confusion around the manner in which various matters were handled at the facility; and their poor communication with staff members.

CHAPTER V

DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

Summary

A qualitative study was conducted with twenty primary caregivers of patients with Alzheimer's disease. The purpose of the study was to determine, through the framework of family systems theory, whether or not a primary caregiver's family system is an influencing factor in how they perceive: that they, and other family members, have been impacted by a patient with Alzheimer's disease; their feelings of stress and burden; stress related symptoms; family relationships; coping and adapting strategies; and, ultimately, the value of attending a support group.

Reports by the caregivers revealed that while each person perceived the value of support groups in a unique way, there were many similarities and differences among them. These similarities and differences appeared to be linked to their particular family system, such as their type of boundaries: permeable, moderate, or rigid; family rules and regulations; and role expectations. Therefore, an effort was made to determine the extent to which a

caregiver's family background influences: their perceived feelings of stress and burden; stress related symptoms, family relationships; and, ultimately, the effectiveness of a support group.

In order to accomplish this, in-depth interviews were held. The data gained were analyzed and then organized according to various themes under three general categories covered by a semi-structured interview guide (appendix A.). The first level of information gained by the preliminary analysis was re-sorted, and then re-analyzed under a framework of family systems theory, made up of significant categories generated by the family history, and the demographic information form.

The results of the analysis suggested that a caregiver's family background played a major role in influencing all of the areas investigated in the study. The findings of the analysis are as follows.

Findings

Analysis of the data revealed that while each caregiver responded in a unique way, there were many similarities and differences reported among them. These similarities and differences appeared to be linked to their particular family system, such as, their type of boundaries: permeable, moderate, or rigid, and family rules and regulations, including role expectations. Further,

that the caregiver's particular family system played a large role in influencing their perception of how they, and other family members have been impacted by the disease; their coping and adjusting strategies, and of the value of attending a support group.

Discussion and Conclusions

Following a catastrophic event, there is a need for families to restructure, in order to restore some functional stability in their lives, and to improve their own, as well as their family's, satisfaction. There is a tendency on the part of many professionals today to refer people to support groups in order to assist them with achieving this end. However, people typically cope with, and adapt to, difficult situations, and respond to support, by employing the various type of strategies customarily used in their particular family system. Thus, support groups may be perceived as valuable by some, while not so by others. In addition, certain aspects of support groups may or may not be perceived as beneficial, again depending upon a person's particular family system.

This was highly substantiated by the responses of the twenty caregiver's of an Alzheimer's disease patient, who participated in the study, It became evident from their

replies that their family backgrounds played a vital role in how they perceived that they, and other family members had been impacted by having a patient with Alzheimer's disease; how they attempted to cope with, and adapt to the illness; and thus, ultimately, to how they perceived the effectiveness of support groups. More specifically, each caregiver's response was found to be greatly influenced by their particular family background in the following ways.

The Family System

The family system, including type of boundaries: permeable, moderate, or rigid; and rules and regulations, including role expectations, was seen to influence caregivers as follows. Those participants who had reported rigid, or closed, boundaries, related a tendency to resist outside assistance in any way, sometimes even from members of their own family. They stated a preference to keep the patient at home, often under extremely difficult circumstances, and at tremendous costs to themselves. They consistently denied any personal needs, or the need for emotional support. This carried through to, and influenced, their perception of the value derived from attending a support group.

Caregivers who, on the other hand, had reported extremely permeable, or open boundaries, related that other family members tended to drift away, leaving the caregiver

to feel "dumped on," and unsupported. Family relationships among this group were often reported as conflictual, and the caregivers typically related their desire to seek the assistance of outside resources as much as possible. These caregivers were much more open in expressing their feelings, and voiced their anger and resentment at other family members, as well as anger and impatience with the patient.

Family rules and regulations, including those with regard to role expectations, were also found to influence the way in which the caregivers responded. For instance, several caregivers reported family rules which prohibited feelings of ambivalence, anger, and impatience with a sick family member. As a result these people generally described tremendous feelings of guilt, which further influenced their ability to act in any way.

Role expectations became problematic either when the patient could no longer assume their expected role, thus, generally leading to painful role changes, or when the caregiver insisted upon continuing their own roles under the most adverse conditions. One example of this was when the daughter of a male patient stated, "he was always the head of the household....such an independent man, that I had never been put in the position before where I had to make decisions for him." Another was when a male spouse,

who, although suffering with a serious heart condition himself, stated "I have to be strong, and handle things on my own. When things happen in the family we just handle them and go on." The family system also greatly influenced the caregiver's coping and adapting strategies, and in particular their decision regarding the placement of their patient in an outside care-facility. Caregiver's reporting a closed family system, generally expressed the rule "I must handle things on my own, without involving anyone else." Thus, they tended to care for the patient at home, and often refused outside assistance, sometimes even from other members of their own family.

The caregiver's particular family system was also seen to influence the way in which they perceived the value derived from attending a support group. For instance, the preferred order of priorities for caregivers reporting closed boundaries was to receive information about the disease: its progression, and research findings; hints regarding patient management at home; and legal and financial implications. They saw no need for emotional support for themselves.

On the other hand, the preferred order of priorities expressed by caregivers reporting open boundaries, was to be able to "unload" their feelings; share common experiences; receive information about community resources

that could be of help to them; and to discuss the pros and cons of placement of the patient in an outside care facility.

Those caregivers who had described moderate boundaries perceived the support group as a valuable place for expressing feelings; sharing common experiences; receiving emotional support; and obtaining information on any topic pertaining to the patient. In addition, dependant upon whether or not their patient was still residing at home, or was in an outside care facility, they welcomed appropriate information, such as, patient management at home, or the pros and cons of placing a patient in an outside care facility.

Implications and Recommendations

Implications

The main implications brought out by the conclusions of this study are: (a) that support groups are not necessarily perceived as valuable by all caregivers, (b) that some aspects are perceived as being more beneficial than others, (c) whether or not a person perceives a support group, or certain aspects of the group to be valuable, is influenced by their particular family background.

Recommendations

In light of the findings of this study, and in order to assist caregivers of patients with a catastrophic illness to restore some functional stability; to ease the strains of restructuring; and to improve their individual and family satisfaction; it is highly recommended that health-care professionals, and others, who work with caregivers of a patient with a catastrophic illness, be cognizant of the influence the dynamics of the particular family system has on their clients.

In planning and programming for support groups for caregivers of a patient with a catastrophic illness, the influence of the family background upon their perception of how they, and other family members have been impacted by the illness; their coping and adapting strategies; and the effectiveness of support groups; should be carefully considered. Further, consideration should be given to the reasons that some people are willing, and often eager to reach out for assistance, and emotional support, while others are not.

Recommendations for organizing the format of support groups are as follows. Based upon the findings and implications of this study, it might seem that a desirable solution, to satisfy the varied desires and needs of the participants of a support group, would be to divide them

into sub-groups, organized according to their particular family system. However, the feasibility of this is questionable for many reasons, for instance, the geographic location of the caregivers, and pre-assessment of their particular family background, may present with difficulties. Therefore, to better serve caregivers, and to accomodate their varied interests, a more viable solution might be for support groups to continue to offer programs consisting of general information and education for part of the time; and devote the remainder of the time to focusing more on the immediate status each family is experiencing. This might be accomplished by dividing the caregivers into three self-motivated sub-groups consisting of: caregivers with a patient at home; caregivers deliberating the decision regarding placement of their patient in an outside care-facility; and caregivers with a patient in an outside care-facility.

This type of arrangement would afford the participants a chance to hear some general information, as well as the opportunity to interact with others in similar circumstances, in a smaller sub-group. Because the findings of the study has suggested that the family system is an influential factor in determining whether the patient is cared for at home or in an outside care-facility, by grouping them in this manner, it is conceivable that the

caregivers would end up in groups of similar family backgrounds, as well as of similar interests.

Suggestions For Further Research

The trends found in this study suggest the appropriateness of additional research with a larger and more varied population, through a framework of family systems' theory, to substantiate further the extent to which a person's family background influences the way they perceive, cope with, and adapt to, catastrophic events. To further improve this type of study, it would be advantageous if future researchers were to obtain more information with regard to the family background, by taking a more extensive family history. Perhaps this could be accomplished by arranging an advance meeting for this purpose. It would also be interesting to see some research conducted to examine the influence of the family system on the various basic coping strategies discussed in this study, such as those described by Tuesink and Mahler (1984), and McCubbin and Figley (1983). This type of research would not only be of great value in assisting caregivers of patients with a catastrophic illness, but would also add to the literature of family systems theory, as well as to the literature on stress, and coping and adapting.

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APPENDIX A

Interview Guide

What impact has the patient's illness had upon you?.....

What impact has the patient's illness had on your family?...

Describe any changes in your family's financial situation as a result of the illness.

Describe any differences you perceive in family relationships since your patient has become ill.....

How did you come to be the caregiver?.....

How does this feel to you?.....

How do you cope (with any of the above issues)?.....

Please describe if going to the support group has, or has not, made a difference to you...your feelings....your family relationships...the way you cope.....

What aspects of the support groups have been the most valuable for you?...Please explain why.....

What aspects of the support groups have been the least valuable for you?...Please explain why.....

In your opinion how can a support group be more beneficial
in meeting the needs of caregivers in general?.....

Can you suggest possible ways that caregiver's can be
assisted, besides attending a support group.

APPENDIX B

List of probes

Can you tell me more?.....

Please continue.....

Was this happening before your patient became ill?.....

How does this feel?.....

Has this...happened in your family at another time?....

Can you describe how that... happened at another time?.

Could you explain this...a little more fully?.....

Do you have any examples?.....

In what ways are...effective?.....

In what ways are...not effective?.....

APPENDIX C

CONSENT TO INTERVIEW

I consent to participate in this interview, and to be audio-taped. I understand that this interview is strictly confidential, and will only be used for research purposes. This agreement can be terminated at any time during the interview.

(Date)

(Participant)

(Researcher)

APPENDIX D

Demographic Information

Name-----Address-----

-----Phone#-----

Age: 45 to 50--- 50 to 60--- 60 to 70--- 70 and over---

Approx yearly income: Under \$15,000---\$15,000 to \$25,000--

\$25,000 to \$50,000---Over \$50,000---

Relationship to patient-----

What was the diagnosis of your patient's illness?-----

Who made the diagnosis?-----

When was the diagnosis made?-----

Can you describe the stage of the disease currently being
experienced by the patient?-----

How long have you been attending a family support group?---
