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Perceptions of elderly caregivers of Alzheimer's patients

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The University of Arizona, 1991
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SIGNED Sherly Harris-Ricketts

APPROVAL BY THE THESIS DIRECTOR

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DEDICATION

This thesis is dedicated to Tom and Marian Harris. Their help, love, guidance and encouragement has made this possible. Their "unconditional positive regard" has been my greatest strength and their greatest gift.
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ABSTRACT

Alzheimer's disease affects over three million Americans, most of whom are over age sixty-five. Using qualitative naturalistic inquiry to identify areas of concern for elderly spousal caregivers were identified, in order to; add to the knowledge base, aid in the improvement of existing services and in research and development of new ones.

Using an open-ended interview the perceptions of elderly spousal caregivers of patients with Alzheimer's disease were elicited. A constant comparative analysis of the data was made by the use of an ethnograph program to draw conclusions about caregiver needs and the ability of community resources to meet those needs. Barriers are identified and recommendations for future research and community resources are presented.
CHAPTER ONE
INTRODUCTION

Alzheimer's dementia has become the focused disease of today's elderly population. It has been recognized as one of the most critical medical-social-economic problems facing our country (Wright, Lund, Pett, & Caserta, 1987).

Alzheimer's disease affects over three million Americans, most of whom are over age sixty-five and constitute the fastest growing segment of our population. It is a chronic and irreversible form of dementia which claims the lives of over 100,000 adults annually and is the fourth leading cause of death, surpassed only by heart disease, cancer and stroke (Alzheimer's Association Newsletter, 1988). The number of people with severe dementia is expected to increase sixty percent by the year 2000 (U.S. Congress, 1987).

Alzheimer's disease is characterized by an insidious onset and is accompanied by a variety of cognitive and behavioral symptoms such as memory loss, confusion, and, in advanced stages, incoherent speech and incontinence. As Alzheimer's disease progresses, through its three recognized stages (see Table 1), the patient becomes increasingly dependent on family and friends as a natural support systems to provide care (Wright, Lund, Pett, & Caserta, 1987). The social isolation and perceived embarrassment of caring for an elderly parent or spouse who displays demented behavior causes
Table 1: Stages of Alzheimer’s Disease as reported by the American Alzheimer’s and Related Disorder Association (1988).

<table>
<thead>
<tr>
<th>STAGE</th>
<th>DURATION</th>
<th>SYMPTOMS</th>
</tr>
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| First Stage | 2 to 4 yrs | *Progressive forgetfulness; *
|             |          | *difficulty with routine chores.                                          |
|             |          | *Confusion about direction decisions and money management.                |
|             |          | *Loss of initiative; spontaneity.                                         |
|             |          | *Repetitive actions                                                      |
|             |          | *Mood and personality changes.                                            |
|             |          | *increasing memory loss, confusion and shorter attention span.           |
|             |          | *Difficulty organizing thoughts and recognizing friends and family members |
|             |          | *Sloppy and confused about dressing and self-care.                        |
|             |          | *Wandering and forgetting directions.                                     |
|             |          | *Hallucinations                                                          |
|             |          | *sleeps too often, or stays up at night.                                 |
|             |          | *Mood swings; anger, temper; crying                                       |
|             |          | *Cravings for junk food.                                                 |
| Second Stage| 2-10 yrs | *Doesn’t recognize self in mirror.                                       |
|             |          | *Completely dependent on someone else for care.                          |
| Third stage | 1-3 yrs  | *Oral communication disappears                                            |
|             |          | *Incontinence.                                                           |
|             |          | *Weight loss.                                                            |
|             |          | *Death. Occurs usually from infection.                                   |
many families not to seek formal diagnosis. It is therefore unknown how many cases actually exist (Whitney, 1985). It is known, however, that more than twenty percent of those over age eighty will be affected by dementia of the Alzheimer's type (Kvale, 1986). There is no clear cut predilection for one sex over the other. It can strike rich or poor, educated as well as uneducated, urban and rural populations (Lipkin, 1987).

As our mature population expands, more individuals and families are going to be affected by this disease which, at the present time, has no cure. The principal goal of treatment is to provide supportive care and control symptoms (Miller, 1989). This care falls primarily on the caregiver, who often needs to be considered a patient as much as the demented individual (Smith, 1988). In an evaluative report on twenty-nine caregiver support groups, Toseland and Rossiter (1989) reported that: the typical caregiver support group was made up of wives and daughters of the person needing care; the caregivers range in age from 16 to 80 years; their socio-economic range is that of the middle class; the majority, (72%) were providing care to someone with Alzheimer's disease or a related organic brain syndrome. The remaining groups pertained to caregivers of elderly persons with unspecified impairments.
STATEMENT OF THE PROBLEM

Even with growing public awareness regarding the impact of Alzheimer's disease on our society, relatively few studies have investigated the equally important impact on the primary caregiver (Wright, et al., 1987).

Because the victims of Alzheimer's disease come from a divergent population, i.e., gender, age, educational background, social and economic backgrounds, it is reasonable to assume that their caregivers will be just as divergent. Community support systems cannot come in a "one size fits all" format. Care giving can be a long term commitment often lasting for years. This Study focuses on the perceived needs of a specific group of caregivers. It is important to know what types of programs are being used by elderly spousal caregivers and their satisfaction with those programs. Because caregiver research is in its early stages (Haley, 1991), it is reasonable to look at individual sample populations. A focused view may then be extrapolated as a piece of the whole.

This study utilizes interviews with elderly spousal caregivers of Alzheimer's disease to investigate the following research questions.

1. How do elderly spouses adjust to their roles as Alzheimer's caregivers?
2. How do support systems aid or impede caregiver adjustment?

3. What kinds of support do elderly spousal caregivers need most?

4. What changes, if any, would the elderly spousal caregivers like to see occur in current and/or future support systems?

5. What are the implications for future researchers, counselors and clinicians, for meeting the needs of elderly spousal caregivers of Alzheimer's disease patients?

Existing studies have failed to establish a clear link between client satisfaction measures and other important outcome indices. For example, existing studies do not indicate whether support groups can help caregivers to cope with or alleviate stress from particular problems they experience in providing care; prevent, diminish or alleviate common psychological disturbances such as depression; increase access to and use of informal social support systems and community resources; or improve caregivers' ability to care for themselves (Toseland & Rossiter, 1989).

This research describes the perceptions of elderly spousal caregivers of Alzheimer's disease patients towards community support systems in which they have participated, (see Appendix D) and looks at the implications of their experiences, based
on identifiable themes, for future program design and implementation. The research questions for this naturalistic inquiry have come from an intensive review of the current literature.

Utilizing the method of naturalistic inquiry, the purpose of this research is to identify the qualitative issues which will provide insightful information about the perceptions of elderly spousal caregivers of Alzheimer's patients towards support systems. In addition to adding to the knowledge base, such information could aid in the improvement of existing services and in the research and development of future support. Using the responses from open-ended interviews of elderly spousal caregivers regarding their experiences using support services, the perceived benefits and limitations are examined.

SIGNIFICANCE OF THE PROBLEM

Caregiver intervention has been largely driven by the best guesses of practitioners about the needs of caregivers, rather than by any systematic analysis of the caregiver's own priorities. At a time when it is fashionable to be skeptical about the efficacy of interventions such as support groups, psychotherapy, and respite care for family caregivers, it will serve us to be reminded that interventions for caregivers, and evaluations of those efforts, are at a very early point of development and that further progress can reasonably be
expected (Haley, 1991). It's obvious that the viability and success of caregiving is based on the perceptions of the caregivers. It is therefore, reasonable to ascertain what those goals and perceptions might be.

Although there is considerable public interest in how to relieve some of the burden and stress caregivers face, development of clinical intervention and research on their effectiveness are both in their preliminary stages (Zarit, Boutselis, & Anthony, 1987).

Clinical impressions and participants' self reports of satisfaction have been confirmed by rigorous studies, but caregiver's feelings of burden, levels of stress, and sense of well-being are not, leaving a need to develop better intervention programs, responsive to the data about the concerns of caregivers (Haley, 1991). All services provided to individuals with Alzheimer's disease and their families should be provided in a context of continuity of care (Buchwalter, 1988). The literature indicates that many of the current programs are not effective. While they may provide some relief for caregivers, the major stressors and burdens that were initially cited by the caregivers prior to treatment, still exist after treatment (Buchwalter, 1988).

Development of more effective interventions will require more and better research on the processes occurring during interventions, on targeting appropriate populations, and means
of evaluating the interventions (Haley, 1991). This research targets an appropriate population and uses qualitative data to evaluate satisfaction of support interventions. As is indicated by the Literature review, (see Haley, 1991; Toseland & Rossiter, 1987; Whitlatch, et al., 1991; Zarit, et al., 1987), Alzheimer's research needs to lessen its global view and focus direct attention on specific populations in order to effect lasting and comprehensive support programs. This research identified one group of elderly spousal caregivers, of dementia patients, found common themes, and made recommendations for future research. Optimal intensity and duration of the intervention, and it's timing during the course of the caregiving career, are also critical issues. It is likely that we will develop effective interventions for caregivers. This, however, may take up to fifteen years of work (Haley, 1991). Researchers are urged to do their best to ignore demands for immediate, simple answers, and to persevere in work that will eventually lead to effective interventions that improve the lives of older persons and their caregivers (Haley, 1991).

SCOPE AND LIMITATIONS

The scope of this research is limited by the responses elicited through the open-ended interview and the observations of the researcher.

Limitations included a small sample, of eight individuals
and the inability to control responses, which is inherent in naturalistic inquiry. The open-ended interview will lend itself to a number of wandering, rather than specific responses.

**SUMMARY**

Until we have a cure for Alzheimer’s disease, treatment for those affected and for their caregivers remains the primary goal of research. While few studies have investigated the impact on the primary caregiver, it will serve us to be reminded that interventions for caregivers, and evaluations of those efforts, are at a very early point of development and that further progress can reasonably be expected.

Alzheimer’s research needs to lessen its global view. It must focus direct attention on specific populations in order to effect lasting and comprehensive support programs.

This research, using naturalistic inquiry to identify the qualitative issues, describes the perceptions of elderly spousal caregivers of Alzheimer’s disease patients towards community support systems in which they have participated, and looks at the implications of their experiences, based on identifiable themes, for future program design and implementation.
CHAPTER TWO
LITERATURE REVIEW

To provide credence for this work the literature review will look at the various types of support used by elderly spousal caregivers, including: caregiver perceptions of behavioral problems: caregiver groups, individual and family counseling; respite care; telephone networks; psycho-social supports; and memory training. The literature review will also include current information on depression in the elderly, regarding the subjective burden of caregivers.

CAREGIVER PERCEPTIONS OF BEHAVIORAL PROBLEMS

In a study done by Haley, Brown and Levine,(1987) of 44 primary caregivers of elderly patients with dementia, results indicated that although self-care deficits and disorientation are common, they are less concern to caregivers than a number of prevalent and highly stressful behavioral problems such as agitation, hallucinations and dangerous or embarrassing behaviors which the caregivers reported being ill equipped to handle. These were perceived as much more stressful for the caregiver than coping with the patients' loss of activities of daily living (ADL) skills. This is important information for clinicians planning behavioral or supportive interventions for community dwelling dementia patients, who are cared for by family members. The high prevalence of disability and
behavioral problems, gives a clear picture of the devastating nature of dementia and the daily stresses experienced by the family member who must manage these problems (Haley, Brown, & Levine 1987b).

Existing studies have failed to establish a clear link between client satisfaction measures and other important outcome indices. For example, existing studies do not indicate whether support groups can help caregivers to cope with or alleviate stress from particular problems they experience in providing care; prevent, diminish or alleviate common psychological disturbances such as depression; increase access to and use of informal social support systems and community resources; or improve caregivers' ability to care for themselves (Toseland & Rossiter, 1989).

GROUPS, INDIVIDUAL AND FAMILY SUPPORT

Support groups are being used with increasing frequency to help caregivers cope with the stress of caregiving. Nearly 5.1 million older persons need assistance with some aspect of personal care or home management activities to live independently (Klien, Dean, & Bogdenoff, 1967). The majority rely on family caregivers (Klien et al., 1967). Caregiver support group intervention has the potential to prevent stressors from overwhelming caregivers. By providing needed respite from caregiving, helping to reduce isolation and loneliness, and provide an opportunity to share experiences in
a supportive environment, with peers who share similar concerns. They must encourage a mutual sharing of information about effective coping and strategies.

By providing caregivers with support, understanding, affirmation and validation of thoughts and feelings, groups can help to universalizing and normalizing the caregivers experiences. Caregiver support groups must stand ready to instill hope by assuring the caregivers that they are playing a vital role in the life of the patient. It is the responsibility of support groups to educate caregivers about the effects of chronic disabilities and to inform them about community resources. Caregivers need help from support groups in identifying problems and concerns and how to effectively use systematic problem solving procedures to resolve specific concerns (Toseland, & Rossiter, 1989).

There has been little systematic research on the effectiveness of counseling intervention for caregivers. Most published reports have been clinical descriptions of group interventions, which reported clinicians' observations of positive effects of groups without controlled assessment of outcome (Haley, Brown, & Levine, 1987a).

In a study done by Haley, Brown, And Levine (1987) their aim was to systematically evaluate the effectiveness of group intervention for caregivers of elderly dementia patients. On measures of caregivers' satisfaction with the groups and
caregivers' rating of the important components of group membership, the groups were consistently rated as helpful and as addressing the concerns of the caregivers. On the more objective measures of caregiver psychological and social functioning, however, group participants did not show significant change after participation as compared to wait list controls (Haley et al., 1987a). In a recent study by Zarit, Anthony, & Boutsellis, (1987) similar results were shown. They studied two interventions, one group therapy and the other individual and family counseling with caregivers of Alzheimer's patients. Zarit et al., (1987) chronicled subjects' perceptions of treatment benefits. Through a battery of measures that were administered to caregivers prior to the interventions, following the interventions, and after one year. Outcomes were measured in four ways: Through changes in caregivers' report of stress; improvement in management of the patients' problem behaviors; increased use of social support; and caregivers perception of treatment benefits (Zarit et al., 1987). Caregivers receiving family counseling of support group intervention showed no greater improvement than the waiting list control group. One interpretation of these findings may be that caregivers are denying how stressful their situation is because they believe they ought to continue in their care-giving roles (Zarit, et al., 1987).
However, in a follow-up study two years later, Whitlatch, Zarit and Eye (1991) did a re-analysis of their previous reported study, using the method of predictive analysis. Compared with subjects on a waiting list of those enrolled in a support group, caregivers in individual and family counseling were more likely to have successful outcomes on all dependent measures (Whitlatch, et al., 1991). The findings differed from those previously reported (Zarit, et al., 1987). These findings, suggested that a program of individual and family counseling may have particular benefits in relieving distress, compared with a waitlist condition (Whitlatch, et al., 1991). In light of these findings previous reports on caregiver interventions must be re-evaluated. One implication of these findings is that brief counseling interventions, consisting of individual therapy, may in fact be more beneficial than previously thought (Whitlatch, et al., 1991). It is interesting to note that the research team of therapists who conducted the original research had the impression that support groups were more effective. They hypothesized that the opportunities the group provided, for exchanging information and emotional expression, created the expectation among leaders that participants were improving, when in fact, many subjects were experiencing little or no change. Because caregivers receive less immediate, one on one, attention, in a group atmosphere, groups may not be the best choice for
individuals who are experiencing high levels of stress (Zarit, et al., 1987).

Toseland and Rossiter, (1989) report that seven major themes formed the basis for interaction within groups: information, support, emotional impact, self-care, interpersonal relationships, use of support systems outside the group and home care skills. Of the twenty-nine support groups studied by Toseland and Rossiter, (1989) no single group dealt with all of the themes in detail. Evaluation of the groups came from three sources: practitioner's observations of the group processes, self reports elicited by questionnaires and standardized measures, and practitioners' observations of outcomes.

While research moves from it's exploratory to a more mature phase, a clearer understanding of the needs to be address in groups is imperative. Toseland and Rossiter's review of groups, clearly indicates three areas in particular, that need attention when evaluating groups: the measure of outcomes, the composition of caregiver support groups, and the types of intervention programs offered to participants (Toseland & Rossiter, 1989).

In a study by Cantor (1983) caregivers reported that the most detrimental impacts in their lives as caregivers, was in the loss free time for themselves. Citing a large degree of social isolation, not taking vacations, and the loss of time
for leisure activities. More attention to the ways in which caregiving has an impact on the lives of caregivers and assessing caregiver goals and objectives will help to facilitate how they can learn to cope and adapt to change (Zarit, et al., 1987).

The failure of the first few experimental investigations to extend findings of participant satisfaction with caregiver support groups may be the result of selecting outcome measures that are focused on the global psychological changes rather than on more specific measures. Much evidence suggests that relationship to care receiver, and to a lesser extent, gender, is an important variable on individual response to caregiving (Fitting & Rabins, 1985). Spouses experience caregiving differently than adult children, and women tend to experience the burden of caregiving differently than men (Toseland & Rossiter, 1989).

Overall, there is still much to be learned about the effectiveness of support groups for caregivers. Although the majority of researchers have reported on the favorable outcomes, results are based almost exclusively on clinical impressions, client testimonials, and brief evaluation questionnaires from small samples of participants who were not contrasted to untreated controls.

When different interventions all receive positive evaluations there is no way to determine if one is better than
another and to justify policy accordingly. Methods to improve validity of assessments of caregivers' satisfaction with support groups are needed. Caregivers are apt to respond more objectively if they can respond anonymously (Toseland & Rossiter, 1989). When support groups are developed, targeting groups for spouses, adult children, and by gender may be wise (Toseland & Rossiter, 1989).

Although local chapters of the Alzheimer's Disease and related disorders Association (ADRDA) sponsor long term support groups for persons caring for someone with Alzheimer's disease, Toseland & Rossiter (1989) found no studies of these groups in the databases. They also noted a lack of group programs in which specific stress reduction techniques had been utilized.

RESPITE CARE

Respite care has gained widespread attention as one of a number of strategies designed to prolong community residence for the disabled aged. It has also emerged as the top priority unmet need expressed by caregivers (Lawton, Brody, & Saperstein, 1989). Research reports about the effects of respite care are scarce, however and in the main are limited to brief, simple caregiver evaluations of the services received.

In a study by Burdz, Eaton and Bond (1988), it is reported that eighty-one percent of the caregivers perceived
the respite program to be very beneficial. However, sixty-eight percent also reported that their overall situation had remained unchanged. While the respite care program has a perceived positive influence on caregivers, many respite group caregivers reported a worsening in their situation, the patient's situation, or in their relationship with the patient following respite care. Caregivers in the dementia group were much more likely to report greater difficulties (Burdz, et al., 1988).

An intensive study by Lundervold and Lewin (1987), of three caregivers of family members with Alzheimer’s disease, using single case design, showed the effects of four to six hours of in-home respite care per week, indicated no significant improvement for the caregiver.

The Respite Demonstration Program.

After a baseline interview of 642 caregivers of aged Alzheimer’s victims, half were offered formal respite care. Respite care for the purpose of this study were defined as services provided by formal sources: government, social or health agencies, or independent paid workers, or the informal services of family or friends. Respite could take place in or out of the home. The services were either planned in advance for a specific purpose, used regularly for periodic relief, or for response to emergencies (Lawton, et al., 1989).

The magnitude of the intervention was limited by the fact
that caregivers needed considerable time, education and encouragement to begin to understand and use respite. They often waited until late in the caregiving process or when a crisis occurred to seek help. Over the longer range, it will be to the advantage of caregivers for respite services to become more familiar and accessible at much earlier stages in the caregiving cycle (Lawton, et al., 1989). Finally the indicator of impact most proximate to the actual intervention of all the outcomes measures asked the caregivers to evaluate the service directly. The conclusion that ordinary respite care is a mild intervention with modest effects seems inescapable. However, justification for it's continuation is easy: Caregivers show discriminating judgment in deciding whether to use such services and the usual principals of supply and demand on the part of the consumer [caregiver] can probably be counted on to regulate the extent to which it is used and paid for by those who need it (Lawton, et al., 1989).

Certain additional services were considered essential for effective respite: assessment, caregiver education, managing patient behavioral problems, case management information or referral, coordination and monitoring by project staff and counseling. Another core service was that of transportation (Lawton, et al., 1898).

The theory behind respite services suggests that unrelenting caregiver demands may have unfavorable outcomes
for the caregiver and the impaired person. Periodic relief of such external stress is therefore seen as directly therapeutic for the caregiver and indirectly therapeutic for the patient (Lawton, et al., 1989).

A level closer to the intervention is the subjective well-being of the caregiver. Enhancing the well-being of the caregiver was the central focus of the program. The two most relevant pieces of information in this regard are, first, that by no means does every caregiver need additional respite services, and, that the magnitude of the presumed intervention needs to be considered (Lawton, et al., 1989).

The results of the respite program give some support to the idea that such assistance for the caregiver had favorable outcomes for the impaired person. They remained for a longer period of time in the community before being placed in long-term care, (22 days as estimated by the data). However those 22 days represented a relatively short period of time (Lawton et al., 1989).

Although the focus of the respite was on giving the caregivers time off, the reasons for needing the time, were so diverse, that a focus on a specific problem can hardly be said to have existed. The service provided substitute helpers when the caregivers were: ill or hospitalized, allowed them to go shopping, or out to events with other family members, permitted them a few hours in which to rest or to catch up on household
chores, and even to simply get out of the house for a short time (Brody, Saperstein, & Lawton, "in press").

**TELEPHONE NETWORKS**

The need to reach out and touch someone, can now be seen in new uses of telecommunication technology. Tele-people-programs have emerged. Among them are social service programs using telecommunications, such as telephone reassurance to provide increased safety for the frail elderly, live training conferences beamed via satellite to far away communities, suicide prevention and hot lines, and conference call groups for the blind and disabled (Evans, Smith, Werkhoven, Fox, & Pritzl, 1986).

Caregivers of Alzheimer's victims need all the touch that high tech can bring. Caring for a relative with Alzheimer's disease is an emotionally wrenching crisis. Energy is diverted toward holding together the life of a person whose condition is irreversible and deteriorating. It is a chronic crisis, of a gradual increase in labor and loss (Evans, et al., 1986).

Rather than a disruption of roles, such as results from a divorce or death, caregiving results in a daily accumulation of roles. Because caregivers may be burden with the multiple responsibilities of middle age or the frailties of old age, they are often unable to participate in support groups or professional counseling (Goodman & Pynoos, 1988).
The phone network goals are similar to those of support groups, to provide support and information. However, some very important differences exist. In a group, disclosure is made one-to-all regardless of the variety of dyadic relationships that might exist among members of the group. The level of intimacy therefore, is likely to be compromised. The phone network on the other hand, is a series of one-to-one communications. The level of intimacy depended more on rapport and closeness within each relationship than on group evolution. Some relationships moved rapidly to a discussion of personal needs and some never arrived. Similarity of circumstances helps generate intimacy in both networks and support groups (Goodman & Pynoos, 1988).

In a study by Goodman and Pynoos, (1988) participants evaluated the program, informally, during their telephone conversations and in several group meetings with staff members. The benefits experienced were similar to those mentioned for support groups (as reported in Glosser & Wexler, 1985).

The evaluation included a sense of shared struggle, satisfaction at their openness and capacity to help each other, increased confidence from modeling each other, and from self-acceptance and greater self awareness. The network of spouses was rapidly cohesive and was evaluated by staff as a complete success. However, the network of adult children was
only moderately successful (Goodman & Pynoos, 1988).

SOCIAL NETWORKS

In a study of social networks done by Pagel, Erdly, and Becke (1987) of spouses caring for husband or wife with Alzheimer’s disease, measures of helpful as well as upsetting aspects of the caregivers’ networks, derived from interviews and daily interactions ratings, were studied.

Social exchange theorists have formalized that, at best relationships involve costs as well as benefits (Simpson, 1972; Rook, 1984; Thibaut & Kelly, 1959). Costs may include such things as broken promises, network members who, in the provision of support, are irritating, annoying, or over involved, and help that comes with strings attached (Pagel, et al., 1987).

Perhaps the most intriguing aspect of this study was the finding that helpful aspects of one’s social network, bore little or no relationship to depression and overall network satisfaction, whereas, upset with one’s network was consistently related to depression and to reduced satisfaction (Pagel, et al., 1987).

The finding that helpfulness is unrelated to depression is somewhat surprising. Even after controlling for initial depression and upset levels, changes in upset over time predicted changes in depression. These results rule out the likelihood that measures of upset are simply alternative
measures of depression and strongly support the likelihood that upsetting relationships in one's network play an important role in the etiology and maintenance of emotional problems (Pagel, et al., 1987). There was some evidence from a previous study that some caregivers were prone to self-blame for events over which they had no control. More generally, personality theorists emphasize that some people are more prone to this sort of reaction than others are. Or perhaps the anticipated loss of a spouse makes the caregiver acutely vulnerable to the integrity of other attachments and upsetting interactions are viewed as a threat to those attachments (Pagel, et al., 1987).

Social support has been typically measured and interpreted as a global uni-directional construct (e.g.; ranging from no support to more support). Pagel et al. proposed that when support quality is assessed by questioning about adequacy or satisfaction with support, individuals are actually responding with summary assessments composed of not only positive, but negative stressful perceptions of the network as well. Only the positive component has tended to an artificial conceptual separation of network support and stress in the literature (Fiore, Becker, & Coppel, 1983).

Spouse caregivers to Alzheimer's disease patients are identified as a high risk population for depression. Caring for an Alzheimer's disease spouse is considered to be a major
life stressor. It seems important to begin to assess major components of support and to ask which aspects affect health and under what circumstances. Five overlapping components appear repeatedly in both theoretical and experimental papers and are separately examined in a study by Fiore, becker & Coppel, 1983. They included: cognitive guidance, (information), emotional support (need for strong dependable relationships), socializing (a sense of belonging to a network; a sense of social integration), tangible assistance (a sense that network members will respond with physical help), and the availability of someone to self disclose to or to confide in (Fiore et al., 1983.

PSYCHOSOCIAL SUPPORT

Caregivers report psychosocial benefits tend to come in the form off feeling better prepared about the future because of increased knowledge about dementia and coping skills which might help them to face the progression of the dementia (Haley et al., 1987a). Clinically, many caregivers also seemed more concerned with the goal of improving their effectiveness as caregivers than with decreasing their current levels of distress. Objectively assessing changes in these kinds of long-term outcomes to more fully understand the benefits and limitations of psychosocial intervention, will be a major challenge for future clinical research, with caregiving families (Haley et al., 1987a).
SUBJECTIVE BURDEN OF CAREGIVERS

In a two year follow-up study of husbands and wives who were caregivers for a spouse with senile dementia, Zarit, Todd and Zarit (1986) showed that while the burdens of caregiving among men and women differed initially, it evolved into a less differentiated state after a two year period. The initial study was concerned with identifying differences between husbands and wives who were caregivers as well as looking at caregiver burden. In the follow-up study, they wanted to see if the differences found between husband and wives remain constant over time (Zarit et al., 1986) In the initial study, husbands who were caregivers reported less burden than wives. This difference appeared to be related to the husbands greater tolerance of memory and behavioral problems, although the possibility that men under reported, and women over reported their subjective burden could not be ruled out. For wives, both the quality of the past relationship and the memory and behavior problems were significantly associated with burden. At initial test time one burden was reported higher for wives than for husbands. However, average scores for burden were about the same for the men and women at test time two. Women’s burden scores showed a significant decrease from time one to time two. This study clarifies the relation of the caregivers subjective burden to the decision to institutionalize, and also provides information on the
differences between husbands and wives and other factors associated with burden (Zarit et al., 1986).

Caregivers feel burdened when the patient manifests deficits in behavior and caregivers have difficulty tolerating those behaviors. This finding underscores the point that caregivers react differently to problem behaviors and vary in their skills for managing these problems. The longitudinal analysis in the Zarit et al., (1986), study suggests that caregivers' ability to tolerate problem behaviors actually increases, even as the disease progresses. Further, all caregivers do not find the same problems to be troublesome. While some become upset with incontinence, others may have more difficulty with repetitive behaviors, and a few are able to remain calm in the face of extreme behavioral deficits. This Variability in caregivers' reactions is, in fact, of major importance for planning interventions to alleviate their stress (Zarit, Orr & Zarit, 1985).

A study of male support groups by Davies, Priddy, and Tinklenberg, (1986) showed that men may reveal more about what problems they face in the company of an all male group. Supporting the hypothesis of Zarit, et al., 1989) that men may be more reluctant to talk about their problems than women, thus reflecting lower scores on burden. In their follow-up study, (Davies, Priddy and Tinklenberg, 1988) found that the longer the group stayed together the more self-sufficient it
became. This raised the question of just how much time is actually needed in order for a meaningful therapeutic intervention to occur. A sense of bonding and safety among group members was a must. In the beginning of the therapy sessions, the men just carried on small talk rather than to risk exposure of true feelings and concerns. It served however, as a time of bonding for the participants (Moseley, Davies, Priddy, 1988). They reported that the original group, in it’s three years of existence has become a tightly knit band of individuals sharing in a common process. They identified several themes that were common to the men that were distinctly different from the women caregivers. These include: pride, which would prevent them from seeking available assistance, role change, to that of a caregiver, traditional roles such as housekeeping, cooking, cleaning, shopping, skills that had to be learned late in life and the "off limits" direct expression of emotions (Moseley, et al., 1988). An important issue in research on caregivers is their variability - how they differ from one another in their responses to caregiver demands. Whether the caregiver is a man or a woman may also make a major difference. Caregiving is usually defined as a woman’s role, an expansion of the traditional responsibilities of a wife or daughter. There has been some suggestion based on qualitative studies that the caregiver role conflicts with the decisions many women are
making to take more control of their lives and not be locked into traditional roles (Zarit, et al., 1986). Wives find their husbands dependency upsetting while husbands as caregivers are more likely to have problems assuming household responsibilities and to be distressed because their wife can no longer interact with them. Many interviewers, at time two, felt that wives had adopted a similar coping style to those of the men. Another factor that may account for wife's initial burden scores is that they experienced conflicting demands or resentment at having been placed again in a caregiving role. A major implication of these findings is that carefully planned interventions may effectively relieve some of the burden caregivers experience. Programs that focus on improving coping skills with everyday problems, that provide opportunities for respite, and that give attention to early interventions with wives, may have considerable impact on subjective burden (Zarit, et al., 1986).

MEMORY TRAINING AND OTHER SIGNIFICANT LITERATURE

Because memory training is not likely to offset entirely the impairment in cognitive abilities caused by the underlying brain disease, an assessment of the effect of interventions on caregivers is crucial (Zarit, Zarit, & Reever, 1982). Hence the value of interventions needs to be based on their effects on both caregivers and dementia patients (Zarit, et al., 1982).
In comparison to other studies, this research on memory training also focused on the practical implications. In particular, whether everyday problems are lessened and whether the stress on caregivers is reduced. At first glance, it would appear the memory training classes had a detrimental effect on caregivers because they seem to have become more depressed after attending the sessions. One explanation is that observing the dementia in the class serve to emphasize the extent of the impairment. The classes may also have been viewed by the caregiver as their last hope for treatment, since little else is available. The more promising results are the decreases in memory and behavior problems and in the distress associated with them seen in the problem solving group (Zarit, et al., 1982). The practical problem solving approach of the clinical classes, presented in this research have been used in a counseling program for caregivers (Zarit, et al., 1982). Many of the caregivers reported that the most beneficial part of the program was meeting other people coping with the same problems Zarit, et al., 1982).

Care of an Alzheimer's disease patient typically imposes a heavy chronic stress. In addition to memory deterioration the patients often show signs of sleep disturbances, agitation, intense dependency, paranoia and belligerence. The caregivers interaction with the spouse often yields to a cycle of anger, verbal, if not physical abuse, acute guilt,
leniency, firmness, etc. Depression was the principal outcome variable because care of an Alzheimer's patient entails most of the ingredients that psychosocial explanations of depression invoke (Brown, Harris, & Copeland, 1977; Fiore et al., 1983).

One of the major forces acting upon successful interventions with Alzheimer's patients, families and their caregivers is depression. This factor is prevalent throughout the literature and deserves to be assessed for purposes of clarification and interpretation of data. However, the researcher wants to make clear to the reader, that this is not a study on depression in the elderly. The focus on depression for purposes of this study, are simple to address it as an issue in the lives of the study sample. Along similar lines, keeping with the view that unmet support expectations are stressful, life events researchers, Muller, Edwards, & Yarves, 1977; and Sarason, Johnson, & Siegel, 1978, reported that depression correlates more highly with the perceived undesirability of events than with the balance between desirable and undesirable events, which in turn correlates more highly with status than do desirable events (Fiore et al., 1983).

The results of the Fiore et al., (1983) study, which included a social support interview, supported their hypothesis that Alzheimer's disease caregivers provided a
group at high risk for depression. Of the five support areas researched, only cognitive guidance, provided a correlation to depression. Upset in the cognitive guidance area would result from not being helped with problem-solving, when seeking it, or being given unasked for or bad advice. It may be that cognitive guidance, was especially related to depression as a result of the type of problems faced by this population. Caring for a spouse with Alzheimer’s disease requires skills, behaviors, and knowledge which most of the subjects had not acquired from prior life experiences (Fiore et al., 1983).

The person’s expectations of support, clearly related to the severity of depression. The study by Fiore et al, 1983, clearly points up the need to recognize the multifaceted nature of support and separately investigate it’s different components and the context in which they are being sought (Fiore et al., 1983).

SUMMARY

The "support" in social support systems may exist objectively, yet the individual may perceive the network to be hindering, instead of facilitating coping and adaptation (Jung, 1984, as cited in Wright, 1987).

Clearly, additional investigations of clinical intervention programs are needed to clarify this discrepancy (Toseland & Rossiter, 1989). We need to consider the types of change that can reasonably occur in a brief intervention, as
well as the goals caregivers have for themselves, and their initial levels of distress. Low reports of distress may indicate, in part, that these measures do not adequately assess problems and concerns caregivers have that motivate them to seek help (Whitlatch, Zarit, & von Eye, 1991). Conversely, interventions designed for highly distressed caregivers, need to be targeted to those individuals. For caregivers experiencing low levels of distress, a program of prevention, rather than remediation may be more appropriate (Whitlatch, et al., 1991).

The physical demands of caregiving, such as sleep loss, (Golodetz, Evans, Heinritz, & Gibson, 1969) and the curtailment of social lives, (Sainsbury & Alarcon, 1970 increase the stress levels and lower the coping abilities of caregivers (Farkas, 1980). Accumulated physical, social, and psychological stressors can impair caregiver’s ability to provide care and can jeopardize frail family member’s ability to live in the community.

The past and current exploratory research and program development characterizes new areas of inquiry (Toseland, 1989). The rigors of design used to evaluate the different types of support group programs for caregivers, indicates that research is moving from an exploratory phase to a more mature phase (Toseland, 1989). Unfortunately, the consistent tendency for clients to give highly positive, but undifferentiated
evaluations of services, is a persistent problem in clinical research (Lebow, 1987)

From the literature this researcher has identified these questions:

1. How do elderly spouses adjust to their roles as Alzheimer's caregivers? A question on role adjustment is appropriate because the literature (see Haley, Brown and Levine, 1987b; Cantor, 1983; Brown, Harris and Copeland, 1977; Fiore et al., 1983) points out that there are many adjustments that need to be made by the caregiver, these include: coping with the patient's loss of activities and daily living skills; behavioral problems ranging from emotional and physical abuse to sleep disturbances; disabilities, both the caregivers and the victims; social isolation from the Alzheimer's patient as well as friends and family; lack of free time for self, travel and leisure activities; memory loss and death of the Alzheimer's patient.

2. How do support systems aid or impede caregiver adjustment? The literature suggests that not all support systems are meeting the expectations of those utilizing the services (see Klien, Dean, & Bogenoff, 1967; Zarit et al., 1987; Toseland and Rossiter, 1989). The verdict is not yet in on the success of programs, the appropriate use of programs (see Zarit et al., 1987), or the types of programs necessary, i.e., educational, cognitive, group, individual (see Keien et al.,
3. What kinds of support do elderly spousal caregivers need most? There has been little systematic research on the effectiveness of intervention, with most published reports coming from clinicians' observations of positive effects (see Haley Brown, & Levine 1987a). There has been little study of existing long term groups and even less information on how their success in providing services is viewed by participants (see Toseland & Rossiter, 1989).

4. What changes, if any, would the elderly spousal caregivers like to see occur in current and/or future support systems? Enhancing caregiver well-being should be the central focus of caregiver intervention programs (see Lawton et al., 1989). The caregiver must perceive the intervention as helpful, therefore asking for input on how existing programs could be improved to meet more of the caregivers expectations is a logical progression.

5. What are the implications for future researchers, counselors and clinicians, for meeting the needs of elderly spousal caregivers of Alzheimer’s disease patients? It becomes exceedingly difficult to determine essential services when caregivers represent such a diverse population (Lawton et al., 1989). By looking at a specific population, and asking specific questions about that population, counselors and clinicians can better evaluate the types of support services
needed and utilized by that population as well as determining the course of future support (see Zarit et al., 1986; Toseland & Rossiter, 1989; Brody, Saperstein and Lawton, "in press").

The literature shows an expansive amount of research in the area of Alzheimer's disease. There is however, a dearth of conclusive information as to which types of caregiver programs are meeting the needs of the caregivers.

Most research regarding the application of a formal support system, has relied on a checklist or self report for caregiver input. These have proven to be less than satisfactory as a measure of caregiver satisfaction. The global nature of the research must be narrowed to meet the specific needs of identifiable populations. It remains, therefore, important to continue to look for new ways of assessing caregiver needs and program development. Simply asking the right questions and recording responses may be a step in the right direction.
CHAPTER THREE

METHODOLOGY

This research will report the perceived effectiveness of current community support systems and programs for Alzheimer's disease victim's and their elderly, spousal caregivers.

Community Support Systems

This refers to the private and public support that is solicited by the caregiver (see Appendix D). This support is available to anyone wishing and able to meet specific participation criteria. It does not include support by friends, family members or other non-professional interventions. Examples used in this research include: adult daycare; respite care; caregiver support groups; individual counseling; doctors; ministers; community meal programs.

DESIGN OF THE STUDY

This research design will be naturalistic inquiry to elicit descriptive cases. The case study approach was chosen because the researcher is interested in insight, discovery, and interpretation rather than hypothesis testing (Merriam, 1988). Traditional research is based on the assumption that there is a single, objective reality that we can observe, know, and measure (Merriam, 1988). In contrast, qualitative research assumes that there are multiple realities, that the world is not objective, but a function of personal interaction
and perception (Merriam, 1988).

This research will lend itself to the data sources used. The meaning of the experience to the caregivers is what is to be ascertained. This research will utilize data collected from informal observations, a standardized depression assessment instrument, and a semi-structured interview using open-ended questions stemming from pertinent themes defined in the literature review.

POPULATION AND SAMPLE

The purposive sample of eight were drawn from caregivers currently participating in local community resource programs (e.g. the local Alzheimer’s Disease and Related Disorders Association, local respite and day care centers, research projects and support groups; see appendix B). All participants are elderly, (over 60 years of age), and the primary caregiver of a spouse suffering from Alzheimer’s disease. Because they are being drawn from current community programs, they have experience, of varying degree, with support systems.

Participants were both male and female caregivers with spouses currently at home, institutionalized or deceased.

Participants were advised that this research is in partial fulfillment of the requirements for the researcher’s masters degree, and they will be asked to read and sign a participants agreement form (Appendix C).
INSTRUMENTATION

Observation:
What is known and observed can be expanded through the sensitivity of observing non-verbal aspects (Mirriam, 1988). The importance of the researcher as the primary instrument cannot be overemphasized. The researcher is "The Primary Instrument" for data collection and analysis (Merriam, pg.19, 1988) In this way the total context, both verbal and non-verbal, can be evaluated, considered and adaptation can be made. Non verbal communication (eg. Crying, smiling, gestures) as well as surroundings were observed by the researcher to provide additional insight into the world of the caregiver.

Semi-structured interview:
The semi-structured interviews are the cornerstone of this research. They consisted of a face-to-face, taped, interview, with the caregiver. The open-ended questions were designed to answer the research questions (appendix D) are focused on the perceptions of the caregivers. Questions will illicit perceived satisfaction/dissatisfaction of programs and services that the caregiver has participated in, and perceived needs for change in current programs or the need for new ones.

The interviews were administered in an informal style where no forced responses were necessary. All interview questions were asked and answered in the same informal style
with each research participant. The interviews took a minimum of forty minutes and lasted as long as two hours. The interview sites were in the homes of the participants, creating a familiar and comfortable atmosphere for the caregivers and patients as well.

Credibility will be accomplished through methodological triangulation. One method to determine credibility and dependability was to assess the quality of the informant's information by comparing it to the accounts given by other informants. Observations of verbal and non-verbal responses will be considered in evaluating dependability. Dependability will also be assessed on the ability of the researcher to leave a trail on this research study which can be easily followed or retraced.

QUALITATIVE DATA ANALYSIS

A brief overview of qualitative analysis is offered for purposes of clarification. Qualitative analysis consists of data that appears in the form of words and not numbers. In any qualitative study it the researcher who is the "primary instrument" used for data collection and analysis (Merriam, 1988). The data may be collected in a variety of ways including, interviews, observations, tape recording and documents and is generally put in the form of a transcription producing an extended text (Miles, and Huberman, 1984). For this study, observations, interviews and tape recordings were
used, however, data reduction was done only on the written transcriptions of the taped interviews.

For analysis of the data to occur three things must happen:

1. Data reduction, which will occur over the life of the research and consist of various methods such as establishing research questions, which data collection methods to use, coding and looking for themes. In short, data reduction is the researchers method of establishing analytic choices about what is to be in the final analysis of the data. This was accomplished in this study by using the ethnograph program to enter codes and look for themes as each new transcript was placed in the data base.

2. The next step in preparing for data analysis is the data display. This usually takes the form of a narrative text, but for simplification, may involve an array of matrices graphs, networks and charts. Because of the limited number of subjects in this study, this procedure involved only the cataloguing of each transcript into the data base so that codes and themes could be search between multiple transcriptions.

3. The third step in data analysis is conclusion drawing and verification. This is accomplished by the analyst looking at the data catalogues for clusters [themes] and deciding what it means (Mills and Huberman, 1984).
The competent researchers holds these conclusions lightly, maintaining openness and skepticism, the conclusions are still there, vague at first but becoming increasingly grounded (Glaser and Strauss, 1967).

Mills and Huberman (1984) make the claim that field research is far better than solely quantified approaches at developing explanations of local causality - the actual events that led to specific outcomes.

The specific methods used in this research, for data analysis are laid out in the flow chart (Illustration 1). Constant comparative analysis of the interviews after they were transcribed and coded. Patterns such as depression, stress, support, benefits, suggestions, adjustments and goals were explored and linked with the coded data being entered into the computer using the computer program "The Ethnograph", (Seidler, Kjolseth, & Seymour, 1988). In order to perform the constant comparative analysis and to track of the patterns and themes that emerge, the researcher did a line by line analysis of each transcription, using common words to identify the themes and patterns. The coded data for each transcript was accomplished by cataloguing multiple transcripts into the data base and searching for common themes. This allowed for easier management of the data. Interpretation and conclusions based on the identified themes and patterns is then established.
Flow Chart of Data Collection, Reduction and Interpretation

1. Transcript
   - Numbered
   - Coded
   - Priority codes
   - Catalogue
   - Multiple codes
   - Interpret codes
   - Match multiple codes
   - Establish themes/patterns
   - Formulate conclusions
PRESENTATION AND INTERPRETATION OF DATA

The following chapter presents the perceptions of each of the eight, elderly spousal caregivers as individual case studies in order to answer the research questions:

1) How do elderly spouses adjust to their roles as Alzheimer's caregivers?
2) How do support systems aid or impede caregiver adjustment?
3) What changes, if any, would the elderly spousal caregivers like to see in current and/or future support programs.
4) What kinds of support do elderly spousal caregivers need most?
5) What are the implications for future researchers, counselors and clinicians for meeting the needs of elderly spousal caregivers of Alzheimer's disease patients?

The case studies are presented in the order in which each of the in-depth, open-ended interviews were conducted. Each case study includes a background profile, depression information, (gathered from the interview, observations and the Hamilton Rating Scale for Depression) background information, and personal perceptions (data) of each individual that addresses the first two research questions.
The individual case studies are followed by a group analysis of the data as it relates to the third and fourth research questions. This chapter concludes with a summary of the findings. Chapter five, addresses the data as it relates to the fifth research question "What are the implications for future researchers, counselors and clinicians for meeting the needs of the elderly spousal caregivers of Alzheimer’s disease patients?"
CASE #1 "JIM"

**Background Information:** "Jim" is a sixty-seven year old retired appliance salesman with a high school education. He has been a caregiver to his wife Amy for nearly seven years. Jim is originally from Kansas but has lived in Tucson for most of his adult life. He and his wife have two sons and two daughters. They put both of their daughters through college and would have done the same for their sons had they been willing to go. He is self-described as a "fallen Catholic." Jim and his wife have lived in the same house since the day they were married, forty-five years ago. He describes their marriage as a good one, even though, as a salesman, he was on the road a lot. He credits Amy with raising the kids and keeping everyone happy.

To this day, they appear to be a loving and attentive couple. Their home is filled with pictures of family and friends and Amy likes to talk about all of them. During the course of the interview she sat quietly on the couch and listened with surprising attentiveness, to what Jim was telling me. Amy is a second-stage Alzheimer's patient, who requires 24 hour supervision. She has forgotten how to do most of the household chores that she once did routinely and

1. All names have been changed to protect the privacy rights of individuals and their families who have participated in this research.
refers to pictures of her grandchildren as her own children.

While Jim has many unresolved problems, he does not appear to be depressed. He reports sleeping well at night, keeping active and does not consider his wife’s care too burdensome for him at the current time. He talks frankly about her needs, his ability to meet them, and has explored the possibilities of his own mortality and reasons for living.

This may sound a little strange to some people but it doesn’t sound strange to me. In the support group that Jessie has I’ve listened to a lot of people there and they say, well I’ve talked about that program. The lady with the forty-year old husband with Alzheimer’s disease wrote down these letters "gog" which mean "go out gracefully." In other words, what I’m trying to say is when you feel that you’ve done all that you can do, that there’s nothing else in life that’s really any fun, why live? Why be here? I’m speaking of the Hemlock Society. It seems that the book somebody wrote here a while back is a best seller. I felt, long before I knew about the Hemlock Society, that when I felt that I’d gotten
to the point where I could not take care of myself; couldn’t bathe myself, couldn’t go to the bathroom and feed myself, that I couldn’t see any sense of being here on earth.

There are other doctors that are beginning to think that when a person says "I think I’ve been here as long as I need to be here, work is done and life is no longer enjoyable and I can’t see a person living beyond being needed." When your not needed anymore why put a burden on your children.

And as long as you’re needed, you’ve got to be there, just as long as you can. But when it gets to where you can’t wait on your personal self and you’re spending money for doctors and hospitals and your money is just going, I can’t see some doctor keeping you alive as long as he can. I just can’t see by no way, shape or form.

Jim is a pleasant, soft spoken man with a generous smile and a lighthearted gleam in his eye. He comments on a stress reducer:
If things get a little hectic, I go out and mow the lawn or trim the bushes. Things that need to be done. I like growing trees. I don’t know why. I feed the birds. I do things like that. If there’s nothing to do around my place, there is always something to do around the neighbors’.

QUESTION #1
How do Elderly Spouses Adjust to Their Role as a Caregiver?

Jim has had to make numerous adjustments in his role as a caregiver. Since he really had no previous domestic experience, he finds some difficulties in cooking, cleaning, and laundry.

Well I’m really not equipped to do the ironing. I used to sell appliances, and I used to sell those things, what you call em, "Mangles." We still have one, but we don’t use it. I use to demonstrate on them a lot. But it seems like I don’t have the knack any more. I’m O.K. on the laundry. I have no problems there. I’m really not.. I really wonder if I’m equipped to do the proper type of
cooking. The kinds of meals that people really need. I cook a meal that satisfies me but whether it's the nutritious type of meal that I need and I'm not sure about the meals I fix for Amy. I'm mainly concerned with her because I know what satisfies me. I use a lot of vegetables in stew that we eat about twice a week.

Jim also expresses concern over Amy's behavioral problems.

The hardest for me is she forgets where she puts things. She can't put things in the same place twice. I have to look in three or four drawers to find what she use to put in the same place all the time. That's one of the biggest things I find to cope.

Jim's biggest role adjustment, however, is that of family financier. Amy used to pay all the bills and keep the books (She was a bookkeeper before they were married). He explains that he it was his responsibility to make the money and hers to spend. It was an old fashioned marriage, he was the provider and she made do with the provisions! Jim has many serious concerns about financial matters these days:
We’ve had people come in two or three times to do the cleaning but they start out at seven dollars an hour and that’s more than I get for helping around the neighborhood doing yard work.

There is one thing that I think is a big problem that nobody hardly seem to talk about. That the finance end of things. Now I have an insurance man that we have a policy with that takes care of whatever medicare doesn’t take care of. Now when these guys come and tell you what there going to pay, you can’t really believe it. My problem is being able to keep all these insurance and medicare things in order so that I can get them out to the insurance companies. They always want to sell you another policy but they don’t make any offers to go through the bills. My father lost his farm and you know that’s hard when you’ve worked all your life. I had this house built and we moved in the day we got married. I hate to think of the time coming when I might
QUESTION #2

How do support systems Aide or Impede caregiver Adjustments?

Jim has used several local support systems for helping him meet his adjustment to his wife's Alzheimer's disease. He uses Adult daycare as a place where Amy can go and still feel safe, wanted and useful, and to provide him with some time to himself where he isn't constantly looking out for her health and welfare. Because he need not worry about her running off from the house when she is at the daycare center, he can slip back home and have a nice nap. A habit he finds very appealing!

Amy is used to being around a lot of people. She used to work. Then when we got married she took care of the children and still did volunteer work at church. She was always at her best when she was around a group of people. She worked here at a big department store from before she was out of high school until right before we got married. Then she didn't work until our oldest boy was out of high school. I think going to daycare and being around people is good for her. She always liked to help people. She
even told me on a couple of mornings that she wanted to go early so she could serve coffee and the like. The lady's tell me she is a lot of help. When she's there I can be outside more. When she is at Handmaker, [the adult day care center] I don't have to worry about dropping off to sleep. If I could afford it, she would go there five days a week or go three days a week full-time.

Jim is also a longtime member of an Alzheimer's support group. He feel the camaraderie of the group is good for his mental health as well as an outlet for sharing information. While he feels very good about the emotional support he gets from the group leader, he feels a close kinship to the other members of the group.

I think Jessie [the caregiver support group leader] keeps us updated. And some of the people who go there. There was one young lady who was, whose husband was diagnosed when he was in his early forties. She has been in some of these deals where they come into your home and videotape a typical day in the home. I think Jessie's program is real good.
That lady was good because she would talk about the things that she did as a caregiver. How to take care of hair and nails and things like that. A lot of caregivers are informative about the things they do.

Jim is delighted with the daycare program in helping him to adjust to his role of caregiver. By providing him with an environment where he can have some personal time and still feel Amy is being taken care of in the best possible manner, he is relieved of many guilt feelings. He thinks that the caregiver support group sometimes impedes his adjustment to his caregiver role, by focusing to much on the emotional rather than the practical side of care giving and by not always listening and responding to the suggestions of the group members.

I think sometimes these support groups, I made a suggestion sometime that we the support givers, share each other's names and addresses because some of those people like ironing, and I don't think I'm very good at it. There might be some of those people where the man may be going to the daycare and the lady would still like to do little things like
ironing. But they didn’t listen up there. They didn’t want us to share names and numbers. I brought it up again sometime later and they said well no that wouldn’t be a very good idea. I know that I’m about the only man that goes to Jessie’s [group] on a regular basis. They get their wives into a home of some sort and then they never come again. Sometimes I wonder if these groups would like to do more work. Either for themselves or for others.

In the support groups we need to look out for each other. The other day I did some plumbing work for a woman whose husband has Alzheimer’s and can’t do the work. Plumbing I can do. The support groups need to help people become more relying on themselves and each other.
CASE # 2

"MARY"

Background: "Mary" is a seventy-five year old retired secretary, with a high school education, from New York. She moved to Tucson, with her recently deceased husband, about twelve years ago to retire on the advice of her husband’s physician. He had what they thought was arthritis and felt Florida would be too humid. Bob prospered in New York as a Deli store owner. While they had no children, they "adopted" many stray animals into their lives. A habit that Mary continues with to this day, by volunteering with the community "Adopt a Pet" program. Mary describes their life together before his diagnosis:

We socialized a lot. Had friends over for cards and often went out to dinner. Nearly every night. Sometimes into Tucson, sometimes here. Usually with another couple. Well, we were just a quiet couple. Never much into sports or anything like that but we were happy, and together. We would take walks, read books, go out with

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2. All names have been changed to protect the privacy rights of individuals and their families who have participated in this research.
friends. Sometimes we would travel.

Mary has been a widow for the past five months and is still coping with her grief and loss. She describes their life after Bob's diagnosis:

Well, at first he had a different diagnosis. They said it was Parkinson's disease because he had a terrible shaking. So they put him on some medication for it and he only got worse. He became confused and sometimes paranoid. We went back to the neurologist and he took him off the Parkinson's medication and John got better for a time. But the memory problems just continued to worsen and we gradually started doing less and less, staying home more and more. We would still go for walks. Bob liked that right up to the end. We would go out to dinner but less often. I got so I couldn't tell when he was going to act up. I think he knew enough to keep quiet when people were around. But I couldn't hold a sensible conversation with him.

Mary is clinically depressed at this time, but does not
appear to be suicidal. Her acute depression will pass, in due course. Having just lost her husband, her feelings of anger, guilt, grief, sadness and regret, as indicated on the Hamilton Rating Scale for Depression, are acute symptoms of her grieving process:

You feel so terribly guilty that you think you have to do everything on your own. Sometimes it's such a stressful situation that you have to overcome the guilt or you can kill yourself. You have to take charge of yourself. Don't wear yourself out. Then your no good to yourself or the patient.

More concern and attention for her recovery may lie in focusing on her physical health which she describes:

I tell you I don’t think my resistance is as good as it should be. I ended up with walking pneumonia. I had to watch him fade away. So, I guess my resistance, on top of this last year, which was so bad, that must be it. (What is making her feel so badly)

Still, Mary is coping nicely and has made plans for her future.

Well, I still go to the caregivers
group. I went to visit a friend in New Mexico for a while and next month I'm going to visit my sister in California. And I'm getting back to my computer club. And working more with the animal league stuff. I'm keeping pretty busy.

**QUESTION #1**

**How do Elderly Spouses adjust to their role as a caregiver?**

Mary has lived through the spectrum of the entire caregiver process. She has made many adjustments and looks at the cycle with the perception of a veteran. One of her husband's most chronic behavioral problems was hostility and she describes the progression:

It starts where there really isn't very much of a problem. Just a little aggravation here and there. Then all of a sudden it can progress very rapidly to a different phase.

He forgot who I was. He would go off and say, "Oh you're the hotel keeper." and "I'm going to fire you." Then he would be combative. I had to call the Sheriff a couple of times. He just wasn't himself. It wasn't just memory. He couldn't think straight. I took him
into Tucson to the Handmaker day care. At one point they were afraid to take him. They were afraid that he might hurt one of the other patient’s there. He resented it. He didn’t want to go, but I think he got something out of it. Eventually this new day care opened here and he went there three times. Then it got so bad that I had to try and put him in a nursing home. They told me there also, that he was raising a big fuss. Helen [day care coordinator] had to tell me that she couldn’t keep him there anymore, because he was trying to get out. She played more BINGO than ever before with him. I think he still understood the numbers. He felt in control of it.

He was reading the paper one afternoon. Even though, he really couldn’t read, here was this thing about this guy who had strangled his wife. He tried to make it look like a fire. Well, John commented on it. That night he ran after me with a knife saying he was going
to murder me. I ran out to a neighbor that I had never met. That was the only light that was on.

While Mary sought places to help Bob, she used the time to educate herself about the disease and provide some tranquility to her life.

When I took him to Tucson it was really only for a half day so I couldn't come home and go back again. But I did various errands and there was the Arizona Inn. The day care was right near there and someone had told me about the nice garden in the back. So I went there and it was very relaxing. If I couldn't get away from him, I think I would have gone nuts. Which is a terrible thing to say.

Mary has made adjustments based on advice from her doctor as well. She says because her lifetime friends and relatives are so far away, she felt that sound medical advise was the best choice. As Bob's conditioned worsened, Mary became aware of several other, very important adjustments.

I go to the caregiver support group that is held at Friends In Deed. The most important thing is to get help. You can't do it alone. Some help. One
person in our group used to get a "cleaning woman" to come in and stay with her husband. He absolutely would not tolerate a baby sitter. He knew too much about what was going on for that, but a cleaning lady was alright. So she would go off while the cleaning lady was there. Of course the so-called cleaning lady knew what she was really there for. So there are ways of getting around it. But help is the most important thing.

So the doctor kept telling me to institutionalize him. I kept putting it off. I didn't want to do it until he didn't know what was happening. He was still too aware. Then I couldn't handle it anymore so I got him into Flower Square in the Alzheimer's unit. I wanted an Alzheimer's unit so he could be with people like himself and he wouldn't have to be sedated. I looked around and they were all walking except for one or two. He carried on so, that they did have to sedate him. He wasn't there more than five or six weeks when he got the
pneumonia. He had the swallowing problem at home too. I had a lot of trouble getting him to eat. Getting food down him.

When they put him in the nursing home I had to make a decision whether to allow feeding tubes or not. In retrospect I wish I hadn't done it. It just prolonged it. The doctor and I came to the same decision on the same day. That it wasn't working and I had to have him take the tubes out. Besides rushing back and forth to Tucson all the time, I had to watch him fade away.

Another important issue to adjust to was that of taking over responsibility for all legal and financial matters: Learning about trust and living wills and thinking through the possibilities. You have to know what to do to provide for the sick spouse in case you should die first. Just what would happen if either one of you died. Make preparations. I finally did. I had an irrevocable trust set up so Bob would be taken care of if I went first. People don't think about
QUESTION #2
How do Support Systems Aide or Impede Caregiver Adjustment?

Mary has been very satisfied with the support systems she has been involved with. She feels they provided a lifestyle for Bob that he was able to function in. She says, "He could get some enjoyment out of life and participate in some of the things." The group support allowed her access to group information and emotional support:

I think this (support groups) is an important aspect of the caregiver process. This isn’t going to get any better. It’s only going to get worse. Take care of it. Helen is a patient advocate. She sees people outside the group. Sometimes people don’t listen to her advice and they do just the opposite. Then they learn the hard way that they should have listened to the people who have had more experience dealing with the situation than they have.

Mary feels the only way the support systems have impeded her is their lack of accessibility, their lack of numbers and not
knowing they are there.

You feel in the early stages that you can handle it all yourself and you try to do that. Advertising may be one way the groups could try and get people involved sooner. Local newspaper editorials explaining the need to get help as soon as possible.
CASE #3
"ALICE"

**Background:** "Alice" is a seventy-six year old housewife who shared in and promoted her husband Ted's career and helped him maintain his engineering business for over twenty-five years. She is a college graduate and a native of the Southwest. She is very proud of the survival of her fifty-six year marriage and claims that, if not for the horrors of this terrible disease, that has "stolen our lives together, we would still be on our honeymoon."

She has been a caregiver for the past six years and has recently had to institutionalize her husband. She describes their life prior to the diagnosis:

> A typical day was a lot of fun. He was a very outgoing, very smart man. He was an aircraft engineer. We led a very social life. And when we had a business of our own, we lived in one another's pockets for twenty-five years. Until our fiftieth anniversary. On a typical day after we retired we would get up when we wanted to, get breakfast and just goof

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3. All names have been changed to protect the privacy rights of individuals and their families who have participated in this research.
around. It would be just a fun day. We would do whatever came along. There were no really set patterns. Neither one of us was too athletic. We didn’t play golf anymore. He because of his eyesight and me because of my arthritis. But we had a lot of friends and we visited. As far as our house was concerned, at that time, he would help. He’d always do the vacuuming or any outside work. Sort of a normal retirement I’d say. In the evenings we’d sit and have a drink and have our dinner, if we hadn’t planned to go out. And watch television and read, or we’d have friends in to play cards. Or I’d knit, things like that. It was just a pretty normal life.

After six years as a caregiver, a role she still assumes in many forms, in spite of Ted’s recent institutionalization, she describes a typical day in a much less romantic fashion:

Now a typical day is a lot different. Now he’s in an adult care home. I usually call to see how his night went. Or I may have to go by and take him to
the doctor. Which I do. Take him to theootnote{foot doctor; take him to the skin doctor;
take him to the dentist. Take him to get
his hair cut. That sort of thing. It's
sort of hard for me to get acclimated to
doing things by myself. Because we were
married fifty-six years last June. And
when you've had someone beside you for,
well really sixty years, cause I knew him
four years before we got married, it's
hard. But I usually get up and have my
coffee and sometimes just sit, I have
embroidery and crocheting over here, and
crossword puzzles. A typical day isn't
any thing like what we used to do. It's
just trying, for myself, to fill the
hours so I don't worry about what is
going on with him.

Alice, like Mary, is involved in a critical stage of the
care giving process, and suffers from mild depression. She is
not suicidal and has a solid support system to fall back on in
her support group, doctor, minister and friends. Her guilt
over the recent decision to institutionalize Ted has been
compounded by the discovery that he has prostate cancer and
she doesn't know whether to allow surgery or not.
I have more than the Alzheimer's to cope with now. My husband has prostate cancer. I have to decide whether to let them operate or not. I don't think we're going to. There is no way to get through to him what is going on.

I worked my way through it, I think. I have a very understanding doctor and through one of the ministers in my church, and my talk with her was a big help. I don't think anyone from outside can talk me out of the guilt feelings that you have. I have em but I don't let them pull me down anymore. I'm just living one day at a time.

I have my little house here and things that I like to do. And a few friends. I don't have as many friends as we used to have. That is the one thing that really does happen. You know, they can't handle it. But I manage quite well. I have two children here in town and they call often and keep track of me. I really don't feel put upon or neglected.
There were only eight people in our last support group. I feel sorry for those who will not learn. They're trying to do this on their own without learning anything about it. I know you can't push people into it.

QUESTION #1
How do Elderly Spouses adjust to their role as a caregiver?

Adjustment has been a long and thankless task for Alice. She has really had to work at it. Her husband's behavioral problems caused the first adjustments to her caregiver role.

The first two or three years I figured I could handle anything. Our ego sometimes gets in the way. But as he got a little worse, I could tell that eventually I wouldn't be able to handle it. Not physically anyway. He's a big man. I don't know. Not being able to get him to shower. And for a time he had an incontinence problem. And the fact that he would lose his temper. Not that he was ever violent. But he would seem to lose his temper more at me than at anything else.
Those were the things that were hardest for me to handle. The hardest thing for me was sitting here and watching that man do nothing. If I lifted something heavy he would always help, but it didn't mean anything to him. That and the fact that I really wasn't important to him except to take care of him. To this day I'm not. I think that was the hardest thing for me to handle.

I started about the second year that we had any inkling that this was going on. I started with a caregivers group in the county. I'm not in one right now, but I was gone when the last one started. But I will get into another one as soon as I get things organized again.

We both benefitted from the adult day care program. I know it was good for him and it gave me a whole day when I could just go out. He would not go out after so many years. He was just afraid. He was even afraid of the steps and the walkway where we lived before. It got to the point where he wouldn't even go out
to the mailbox by himself. But it eventually got to the point where I couldn’t even do that. I wasn’t comfortable with that, so the day care really did us both a lot of good.

Alice, in addition to relying on her family and friends, has used a wide variety of community resources, including several different support groups, adult day care, individual counseling, ministers, doctors, and the local chapter of the Alzheimer’s Association to adjust to her caregiving role.

I started right away. I started with Jessie [support group leader] and I went to a closed circuit Television about it, and it was a great beginning into the world of Alzheimer’s. I can’t think of anything I’ve tried that hasn’t helped.

In addition to this, she has not been beyond helping herself. She has formed a support group of her own and recommends it highly for others.

I think it’s important for the caregivers to keep in touch with each other. The groups come and go. They only last a short time. Several months at the most. I have several women, who are dealing with Alzheimer’s or who have dealt with
it, and we have quite a feeling for one another. This is something I think could be furthered.

A lot of people try to sweep this under the rug. But the majority of the women are dealing with it. I haven't met to many men who are dealing with it. The majority of the women that I've met really appreciate talking or just being called. Being included in something. I don’t know if a caregivers group could do this or not but it’s worth a try.

**QUESTION #2**

**How do Support Systems Aide or Impede Caregiver Adjustment?**

Alice has been pleased with the caliber of support she has received. She admits that it would have been impossible to cope with this disease without it.

I couldn’t say enough about support groups. Only thing was, several of them were not just for Alzheimer’s caregivers. Sometimes I was the only one in the group dealing with an Alzheimer’s victim.

The people that supervise the groups have been very good. Particularly in teaching you the need to realize and focus your mind on
something else, rather than on what you're doing. Their should be more of them, I would think. Sometimes I think we're not reaching everybody. A couple of the groups I was in, people would come for a time or two and didn't seem to cohere to the group and just leave. I always felt they should be dragged back by the hair.

I think the caregivers groups that I went to helped me the most. And I did go to one ten-week session of family counseling that I thought did a lot for me. It helped me put a lot of things into perspective that I just didn't know how to handle. It was individual counseling and I think it helped a lot.

Alice says that the one area that the community support fails to address in depth, and certainly needs to, is that of financial information. By ignoring the financial drain that Alzheimer's disease causes, community support impedes the development of security and emotional stability that are necessary to caregivers.

The one thing that is really lacking is more knowledge of what we can do financially. I know pretty soon that I'm
going to be at the end of my resources. Period. And most of us, when we talk, really don’t know what’s available and how to go about doing it. You don’t know what help you can get. I know one case, that was really almost tragic but, it wasn’t until something really bad happened that she knew where to go. I think something like that should be made available. Really hard facts. I guess that’s what I’m trying to say, really hard facts, as to the "How to’s".
CASE # 4

MARTY

Background: "Marty" is a seventy-eight year old retired experimental design aircraft supervisor from Ohio. He has a high school education and an extensive on-the-job training background in both the public and private sector. He has worked on top secret government projects more than once and still has a "keep your mouth shut" attitude. Self disclosure is not his strong point. He was willing to participate in this research based upon what he sees as a duty to his fellow man and to his wife, Emily. They have been married forty-four years and have a son who still lives in Ohio. Emily has been a housewife and church volunteer throughout their married life. She is a happy, smiling lady, who appears devoted to her husband and the home he built for her some ten years ago. Marty has been a full time caregiver to his wife for about six years now. He reports that her memory loss began approximately ten years ago. Marty first sought help for his wife at the University of Arizona’s Memory Disorders Clinic which he had read about in the local paper.

While Marty is equally devoted to his wife, his comments easily tell of a man who feels he should have enjoyed a

4. All names have been changed to protect the privacy rights of individuals and their families who have participated in this research.
different type of retirement than the one he has ended up with:

Well, we traveled more. We played a lot of golf and we walked and went swimming. She has always been very involved in the church so she went to church several times a week. Now I only take her when the priest is giving holy communion. She stays at home now while I go to church. She sits in the chair and prays with her rosary beads. I built this house for our retirement, but it hasn’t been much of a retirement.

Marty is self-absorbed in his reactions to his role as a caregiver. While he has basic concerns about his wife’s care and comfort, he feels sorry for himself as well. He exhibits some anger and resents not being able to do the things he wants to do when he wants to do them. He is not particularly depressed however, and is does not appear to be suicidal. He denies having any difficulty coping and states that his son, in Ohio, helps him with any major decisions he needs to make.

It’s difficult for me not to be able to go places anymore. But she is content to be at home. She has her sewing, her rosary and the television. She doesn’t
want to leave the house much. So far, I can handle everything.
My son, we keep in very close contact, even though he doesn’t live near. He calls often and I would rely on him to help me make any big decisions regarding Emily.

**QUESTION #1**

**How do Elderly Spouses adjust to their role as a caregiver?**

Marty has not had to make adjustments in handling financial or legal matters for the household. He has always taken care of those matters. He definitely feels lost, however when left to the cooking and housework:

Sometimes I get help with the housework but I try to take care of as much of that as I can. I’ve become good friends with another fellow who takes his wife to the day care and we see each other at Helen’s [support group leader] support group. We try to exchange information on care, and other things. Like things that are easy to cook, quick meals. I worry about the things she eats. I try to make nutritious meals. I fix a big vegetable stew at least twice a week and we will
have fresh fruit. I just don’t know if she is getting all the things she needs.

I think husbands and wives should be better prepared to take over. I was a mechanical engineer all my life. Worked on experimental designs in both the public and private sector. Now, I’m experimenting in the kitchen. This is not the way I imagined retirement would be.

Other adjustments Marty has made involve a sharp reduction in their social life, looking out for Emily’s personal and physical needs, and an increasing desire to reach out to others:

I diet and exercise. I keep myself in pretty good shape. I have to. I need to take care of her. She is pretty healthy too. She might live many more years.

I also go to the support group meetings. They are good because Helen [the group support leader] gets a lot of speakers with a lot of good information to come and talk to us. I’ve also been able to hear stories about other people who are much worse off than I am. She
doesn't act out. She hasn't forgotten who I am. Although she doesn't remember family and friends now when they call or come by for a visit. We used to belong to the country club and we would have dinner with friends and play cards there, but we don't go much anymore. There is a lot of social isolation with this illness. She is good though. I know things could be much worse.

I feel I can handle everything okay right now and she gets nervous and withdrawn around people she doesn't know. Especially when they are in the house. I have a lady come in sometimes to help with the housework. I've gotten so I just take my wife for a drive or something until she gets finished. She's is very upset watching a stranger clean in her house. She doesn't mind letting me do everything. Like it is a natural thing, even though I never did housework before we retired.

Marty feels he still needs help in adjusting to his feelings of anger and guilt.
I need to know how to better cope with this illness. How to stay calm and not get angry. She never gets angry with me, but I get angry with her. She forgets more and more and never improves. I get mad at her and then I’m feeling sorry and guilty for it. I don’t think she knows it most of the time. I wish we would have had more time to enjoy our retirement. A counselor who could help with this would be nice.

**QUESTION #2**

*How do Support Systems Aide or Impede Caregiver Adjustment?*

Marty has been satisfied with the adult day care center that he takes his wife to. He wishes it would be possible for her to attend more often but it only meets once a week. So far he has been lucky and able to leave Emily at home when he attends his weekly support group meeting.

The support group and Helen are very good about providing all kinds of information. She stays at home once a week while I go to the support group meeting. She does ok.

Well I have time to do a few things. I think it’s better for her. She thinks
she is doing something. It's the only place she will go besides church. She wants to be at home. I imagined retirement would be. I can't think of anything. You learn that it is so important to keep a good feeling between you. It is good if you can sit and talk. Find things to enjoy for as long as possible. I've learned to keep things simple, but it's hard to get Emily to respond to anything for more than a few minutes.

We've never really had a clear diagnosis. No one has ever said she has Alzheimer's disease. They say things like "Alzheimer's type dementia." But she has been getting steadily worse now for about six years. No improvement. No physical impairment and nothing else to explain the decline. Helen seems to keep us up on the newest information.

You have to have a sense of humor and take everything one day at a time.

While Marty may say that one must keep a sense of humor,
there was none in any of his remarks. He appears to be a man with a lot of anxiety about what did not happen in his retirement and in what lies ahead. His closing remark was "I get a lot of counselors at the support group."
CASE 5

ERIC

Background "Eric" is a seventy-nine year old retired barber, with an eighth grade education, who immigrated to the United States in 1934 to escape the Hitler's Germany. He still speaks with a strong German accent. He is definitely more comfortable listening than talking. Eric is a soft-spoken man who's humble beginnings are seen in his downward glances as he talks. It appears difficult for him to maintain eye contact during a conversation. He has been a caregiver to his wife, Gretel, for about ten years. She developed symptoms almost immediately after they retired. He reports that friends were first to notice the changes in his wife's personality and reports that the progress of the disease has been markedly slow. She is a calm lady who gives him little trouble, "She's always the same." He describes their past and current life:

We used to travel a lot. Do a lot of fun things together. Eat out, go for walks, entertain our friends, play cards, ya

5. All names have been changed to protect the privacy rights of individuals and their families who have participated in this research.
lots of things. Gretel took care of the house and I took care of her.

Eric describes their life now:

Now I have to do everything. I don’t mind though. Traveling is not so good anymore. We have some setbacks there. You can’t go out too much anymore. And you lose your friends. couples friends. We have friends here now, visiting us. Very old friends. There is a difference in their attitude. They don’t act out against us. I mean they don’t feel like they couldn’t associate with us anymore. They are very good friends. Otherwise, I don’t know. Socially I have to watch her more and more. Let’s put it this way, I’m not as free.

Eric uses far more community resources than any of the other caregivers. He has used, or is currently using, adult day care, caregiver support groups, senior meals, doctors, nursing homes and individual counseling, in addition to the non-community support of family, friends and neighbors.

Eric is a very optimistic man. His major symptom of depression, in fact, is his optimism. He simply refuses to believe he is under any undue pressure. He feels that if he
has all the facts that will be enough to see him through. While he patiently answered each question put to him, his answers were both deliberate and delivered without any passion for the underlying feelings. There is a sensitive man inside who is suffering from increasing bouts of high blood pressure, gradual weight loss, guilt, anger and frustration. He maintains that learning to cope with his wife’s Alzheimer’s disease is just part of life and that everything will work out in the end. In his interview, however, he repeats his need for some personal independence and seems to be seeking new avenues to achieve that end.

This attitude, in part, probably stems from his philosophy of life. He managed to escape the travesties of Hitler, and emigrate to a land of varied and great opportunities. He maintains that they have lived a comfortable and happy life. While he still has many concerns over Gretels’ future, he views his caregiver role as, “Just another job that must be done in order to get on with living.” He has relied heavily on the caregiver support group for encouragement and information on skills and coping.

Eric is not clinically depressed, and may not become so if he continues to seek and receive support. There is a potential danger for him, however, if he doesn’t continue to admit to his own inabilities as a caregiver and needs as an individual. His philosophy of being able to take everything
as it comes along may not hold up as his wife's illness continues to progress. He is a contradiction in styles stating in practically the same thought that he can handle everything and then explaining how he relies on others.

I can handle everything. It's hard. Frustrating but I still can handle it. Ya, ya, since I joined the support group these last two years. It helps a lot (support group) You get everyone's opinion and experience. Otherwise I wouldn't know anything.

This seemed to be a common theme throughout the interview process. He must learn to look at the situation with a little more reality and a little less optimism.

**QUESTION #1**

How do Elderly Spouses adjust to their role as a caregiver?

As was indicated in the section on depression, Eric has made one major adjustment, denial of the problem. The living that he refers to "getting on with" is his life not that of Gretel. He looks after her physical and comfort needs, but saves his emotional involvement for himself.

She does funny things in the house, you know. Oh ya. I can handle it. It's me who's getting excited and losing my temper. I don't think I'm the only one.
As it goes along I understand more and more. I try not to think about it. I try to calm myself. Take it in stride. Patience. I try to be patient. Socially I have to watch her more and more. Let’s put it this way, I’m not as free. Sometimes caregivers can’t get away from the patient. They don’t want them to leave. It’s no good. They want you to be there always. I would have trouble with that. As things come up I can handle them.

Ya, I have to do the cooking and the cleaning as much as I can do it. The cooking, well we go to the senior center four or five times a week for dinner, you know, lunch, that’s what we call our dinner, and then we just have sandwiches or something in the evening. I cook Saturdays and Sundays and she helps me peel potatoes and things like that.

When asked about in-home respite or nursing home care, it is clear that this option has already been thought through: I have to because she is not manageable in public any longer. I had some friends from Germany, a cousin of mine and we
took some trips, with the car and with the airplane but when we get there, there are some problems for her and for me.

For instance, going to the toilet. She has real trouble, taking care of herself properly. So the next time I went alone and put her in a boarding home. A center. She did fine there. She didn’t cry for me or anything. Once I’m out of sight she’s Ok.

Eric has adjusted to Gretel by finding some other outlet that allows him to continue on with his life as conveniently as possible. He remains dispassionate about Gretel’s actions or feelings. Alzheimer’s has become a constant inconvenience that must be continually worked around.

QUESTION #2

How do Support Systems Aide or Impede Caregiver Adjustment?

He truly is taking everything one day at a time, feeling that he can find the answer to each problem as it presents itself. So far, he has met with good success, in part because of his devotion and determination, and in part to the availability of community resources. Eric responds to the help of the adult day care:

Well I have time to do the shopping and a
few things. Not many but some. I don’t know that it has helped her in any way but it hasn’t hurt her. Life goes on for her. She’s always the same. She never gets cross with me. She is always the same.

Eric has viewed his individual counseling as a way to confer on decisions he must make and a means of acquiring information, rather than as an outlet for emotional needs.

She [Helen, the support group leader] visits certain homes and checks up on certain caregivers. I think this is a good thing. I do. She always takes it personal. She has some other ladies that work with her that are very knowledgeable too. But she’s the best. I would ask Helen, that is the person I would ask for advice. I know she will give me advice.

Eric sees no impediment being placed on him as a result of community support and would like to see more support available, including skills training:

I just got a cookbook and picked it up myself. It might be helpful if they had a clinic on these types of skills. Easy cooking for basic meals for example.
Background Information: "Gail" is a seventy year old retired educator with a Master's Degree in Education. She has been an elementary school teacher since 1952 and has enjoyed a rich and productive home life as well. She and her husband, Tom have lived in Tucson since moving to Arizona in 1950. She describes their marriage as solid and loving. There was always a lot of things going on in their lives and they shared a rich social life with many friends. They also raised three children, and have many grandchildren, most of whom have quit coming to visit. Gail has been a caregiver to Tom for nearly eight years, as he has rapidly progressed through the disease process. He is a stage three Alzheimer's patient, still living at home. Gail has been a caregiver for her own mother, also a victim of Alzheimer's disease, and her mother-in law, who, according to Gail, "Came for a visit fifteen years ago and never left." Gail is an emotionally strong, well spoken women who has managed to gain this strength in the face of adversity. Her interview was frank, realistic, and full of passion that she doesn't try to hide. She describes a typical

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6. All names have been changed to protect the privacy rights of individuals and their families who have participated in this research.
day prior to her husband's illness:

Well, we'd get up and have breakfast. And I might go and have a swim. We might play golf in the afternoons or visit with friends. And we might go out to lunch or go out to dinner or to a movie.

And a typical day now...

Well, it varies. I have help now five times a week. Tom is no longer functional as an individual. He is incontinent and mostly non-verbal. He manages a few phrases, but not much. I try to get out as much as possible. I'm not invited to any couples, I see no couples, but I'm not invited out as a single person, although, I'm single, in fact. I do have a lot of female friends and I belong to the University Women's Club. I meet for lunch once a month with friends. I use to go to their parties but I notice now that I don't.

You know you really do lose a lot of social contact. Mine hasn't been so devastating because I have so many friends. I have some friends that I
started teaching with in 1952. And we’re like a bunch of relatives we’re so close. And so I see them. And I play bridge with some other friends. I see less of my grandchildren. I used to have my grandchildren here all the time for dinner. And I don’t anymore because the older they get the more turned off they get by grandpa.

During the last ten years, Gail has had to deal with a lot of emotional and physical changes in the lives of those around her as well as herself. When her mother-in-law came to visit and her mother became ill, she still had Tom to help out and provide her with strength and moral support. When it became apparent that he too, would soon require her caregiving skills, Gail went through a bout of severe depression.

I really hit bottom. I didn’t think life was worth living. And I went to a counselor. My Mother had Alzheimer’s disease. My Mother-in-law came to visit fifteen years ago and never left. Now my husband has Alzheimer’s. But I went through actually hating him, and wanting to drive us both off a cliff. That’s hard for you to take. So when you get
over that, and you realize that others have that same kind of reaction, you know "misery loves company". It's like a healing process. Like I went to the mountains and he tried to jump out of the car, and I thought "Why not let him?" And this friend was driving up to the mountains and her husband tried to jump out of the car and she thought, "Why not let him?" Well, we both thought "They might get hurt." So we had a good laugh.

So I went to a group support meeting and I met a woman who's husband was in the last two years of his life. He died at fifty with Alzheimer's. His behavior and her thoughts parallel my own so closely that I was really dragging. All of a sudden, one day at the group meeting tears started running down my face. I never cried because I was always taught that you never cried in front of other people. And they all kept encouraging me to keep crying. And I did. I cried a barrel of tears. And just sort of healed then. And after that, I'm able to take
anything. I mean, three people you are taking care of. After you survive that, I mean, what is there?

Gail has learned to take care of her emotional needs. During the course of her husband's illness she has been careful to seek professional help on many levels. She is involved in group as well as individual therapy, and no longer has suicidal ideation. While her life is not without stressors, Gail has built a solid foundation for coping.

QUESTION #1

How do Elderly Spouses Adjust to Their Role as a Caregiver?

Seeking individual counseling and support groups has helped Gail to adjust not only to her role as a caregiver but to her retirement and her special status as a "single" person. After being a couple for so long it has been hard but she credits her close friends with seeing her through.

My social life hasn't been so devastating because I have so many friends. I have some friends that I started teaching with in 1952. And we're like a bunch of relatives we're so close. And so I see them. And I play bridge with some other friends.

I met one woman who hasn't been anywhere
for fifteen years. I met a woman from Green Valley who said people even avoid her in the grocery store. Because they haven’t invited her out, so it’s better to avoid her than to talk to her and be embarrassed. I don’t think there is enough education to show the horrors of this disease. A lot of people think Alzheimer’s is kind of like forgetting your car keys and leaving the fire on. And it’s much more devastating than that."

She left teaching when it became apparent that her services were required on a full time basis at home. She has adjusted by seeking out the help she needs and accepting the fact that she can no longer be the sole provider for her husband. She placed her mother in a care home facility two years ago and her mother-in-law died of a stroke complications a little more than a year ago. She was in her nineties, and even though her mental functions were sound, her physical needs were demanding on Gail.

Maybe if I didn’t already have my mom in an institution I could place Tom. My mother-in-law died two years ago, but I
kept her here for thirteen years. She had a stroke. No Alzheimer's but I had to bath and dress her for a couple of years. When I look at my mother and then I look at him, I think, You know if I'm reasonably able to take care of him at home, then this is where he belongs. Of course it's hard, but you know we do have some responsibilities towards one another. It's really easy to pack somebody off into a nursing home. And that's what our society is doing. Whenever it gets too hard. There is a lot of pressure on caregivers to put away them away. Even the good places are very, very depressing.

Gail considers herself to be an emotional widow but concedes that she will have to grieve again once Tom actually dies.

It's like being a widow and you're not. Being a widow is easier. It really is. Because you make a final adjustment. Even with this friend. A friend whose spouse died with Alzheimer's, I said to her, "Since you grieved his death before,
did you have to go through the process again?" She said, "Yes. I didn’t think I would, but yes you do." You lose them, yes. And also you don’t just lose them. I mean if he had died that would be the end of a nice relationship. Now it is impossible to get on with my life.

Gail has also had to adjust to the fact that Tom’s acting out and behavioral problems have limited her access to community resources. She has made this adjustment by keeping him at home and getting in-home care.

laugh. He tried to jump out of a hotel window in Boston and I was bothered and embarrassed. But after a while, well, if nobody likes his bizarre behavior then too bad. He doesn’t go out anymore.

His jealousy was so bad. I was the most important thing in his life. If he had nothing else, but just me, he would have been happy. The only quarrels we ever had in our life was did I love him enough? He didn’t manifest this jealousy during our life together, but it must have been there. Like on Sunday mornings I didn’t get up because he
wanted me by his side when he awakened. So I would just lie there quietly and read a book. After his illness he would be angry if people just spoke to me. He got mad at a box boy at a local supermarket. He’s even hit some of his own children. My mother had some acting out as well but never with my family.

I had an aide that would come and sit with them on Tuesday and Thursday afternoons. She suggested that I put my husband in a home. But there was no way they would take care of him. We visited one place. It had wall to wall carpeting. He use to void in corners of rooms with wall to wall carpeting. He’d stopped using the toilet. They said there was no way they could put up with that. And they didn’t keep their doors locked. One place said they only take people if they sleep at night. Well, Alzheimer’s are often night people. So then I gave up. I have an aide now on a full-time basis. Sometimes I’m able to leave town.
Gail is in fact, able to spend six to seven weeks a year, away from home because she is able to pay for the services of a full-time aide. She recognizes the expense of the illness, however, and has concerns for those who cannot afford respite care.

There is no diaper service. The diapers they have are very unsatisfactory and they’re seventy cents apiece, and he is changed at least nine to ten times a day. Of course I have gone to using the felt pads to use as liners because the ones you buy are plastic and he sweats so in them. I don’t know, I just try to solve my own problems as they come. I can’t take him to the doctor and it costs eighty-seven dollars to have a doctor come to the house. I do have medicare, but even so it’s very difficult. My doctor does come, I don’t know if all doctors do or not. There are places you can call to get sitters, but they are so expensive. Some are ten dollars an hour.

I met women that have not gone out. They can’t afford a sitter because they are living on their social security.
they’ve had to deal with the illness for so long, it’s completely taken over their lives.

QUESTION #2

How do Support Systems Aide or Impede Caregiver Adjustment?

Gail’s experience with support systems has met with mixed feelings. She credits the caregiver support groups with helping her through the emotional adjustments she had to make but admits that they fall short when it comes to providing hands on practical help.

I went to an Alzheimer’s Association meeting. They had a visiting nurse talking and I said I have a severe problem. My husband is falling down and I’m not strong enough to lift him to get him up? No Advice. No advice.

Gail talks about other community resources she has used and met with unsatisfactory results:

The things that I find lacking in the community services are things like routine services. I went to four dentists and shed a lot of tears. They were no help at the dentist. They referred us to go to the University! I
didn’t go there because I was going to a neurologist. Such a thing as a dentist! They must surely have problems. The last dentist I went to said "I’m sorry we can’t clean his teeth because he won’t open his mouth. Well Alzheimer’s can go on for years. Ten, fifteen years. My mom has had it for ten years now. She’s ninety. She doesn’t walk or get any exercise. So this is one problem that hasn’t been addressed. And you can’t go that long without dental treatment.

There is no diaper service.

Gail has met with problems at local hospitals as well. They were afraid of him when he was in the hospital for a broken hip. They wouldn’t give him the physical therapy that he was suppose to have to rehabilitate him. They said they were afraid to get him up because he might fall. He had a bad open sore on his hip on the day they sent him home. They said there was nothing they could do for him in the way of therapy. So they can’t keep him in the hospital like they do
most people with breaks. On top of that, they sent in a counselor. A young girl who did not have my family history, who suggested I put him in a nursing home... So I felt there was a lack of education in the hospital. That was the extent of the help I’ve had.

And Gail had these comments on in-home respite.

There are places you can call to get sitters, but they are so expensive. Some are ten dollars an hour. I’ve met women that have not gone out. They can’t afford a sitter because they are living on their social security. I hear that Pima County has a list of where to go to get aides. But I think the cost is what keeps people away.

Gail also has concerns over her financial future.

If he lives to be ninety, I’m going to run out of money. If I die, because he doesn’t have any retirement, I don’t know what will happen. If I had known we would be facing these economic realities several years ago, I would have postponed my own retirement. If I had stayed on
five more years, I would have retired with over four-hundred additional dollars a month. We’ve already had to sell our large foothills home in order to reinvest the money. And my citrus farm has been having problems the last few years, so I may be forced into selling it off as well. The land is worth a great deal of money, but I wanted to leave it to the children.
CASE #7

JILL

Background Information: "Jill" is an outspoken articulate woman who is a sixty-six year old retired university professor from Pennsylvania. She holds two master’s degrees and has been a forceful women, (by making her opinions known and acting on them), all her life. She has been the caregiver for her husband, Jeff since his diagnosis a little over two years ago. She took an early retirement to look after him. She is unlike the other case studies in many ways. First, as the fledgling of the group, she hasn’t had to make as many caregiver adjustments or deal with as many issues as the others. Second, Jeff is atypical as an Alzheimer’s patient. Most people with Alzheimer’s disease are relatively healthy, Jeff has several other serious, and chronic ailments. Another important difference that separates Jill from the other case studies, in this research, is that she is the only one who reports having a less than satisfactory marriage.

Well, we lived relatively separate lives.

He had his work and I had mine. We’ve never really been close as a couple.

More like roommates, even though we’ve

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7. All names have been changed to protect the privacy rights of individuals and their families who have participated in this research.
been married for nearly forty years.

Jill describes a typical day prior to Jeff's illness:

I wouldn’t have called us close. We have separate rooms. We even have spent up to three years living in different states. I’ve always had a career. About the only thing we ever did together was travel. We traveled as a family with our daughter. So a typical day was more or less, each of us going our own separate ways. My own professional background is going to be the best thing that ever happened to him.

And a typical day now:

Well, he’s been ill for some time. Not with the Alzheimer’s disease but with many other medical problems. That’s why he really decided to come to Arizona. I had been here for several years but he came out permanently when his health problems caused him to take an early retirement. So we never had what I would call a typical day. I still worked up until this year and he is very lucky to have me. He is constantly on medication
for one thing or another. He has heart problems, ulcers and other things they haven’t even diagnosed. I personally feel that some of his supposed Alzheimer’s disease is the result of lack of oxygen to the brain which he suffered during his last heart episode. Still, a typical day for him now would be an early breakfast, then he goes for a walk down the hill and out past the golf course. He likes to walk down that way. So far he’s always been able to find his way back, but I can see him from up here anyway and he never deviates from the path he started on.

Then he comes home and sits outside on the patio until it gets too hot. He just looks at the view or plays with the dog. Sometimes he’ll take out some of his rock collection and just look them over. We will have lunch then and in the afternoons, sometimes we go to the mall. We look around and walk inside where it is cool. Sometimes we eat dinner out and other times we come back home. He is
Jill is not clinically depressed, but as indicated by the Hamilton Scale for Depression, she has certain issues that she will have to come to terms with, including her overwhelming loss of personal freedom, and her idea that she will be able to handle everything alone.

I always wanted to travel when I retired. I wanted to spend several months just living in Spain. I'm taking care of him. And he's very lucky to have me considering the kind of marriage we've had. But I intend to take care of him until the day he dies. It's hard sometimes but I'm not going to leave him. I don't seem to have any life of my own anymore. You know I have a whole closet full of clothes that I used to wear to work just sitting there. I never wear them anymore. I feel like I've lost myself. My work was very important to me and now that I haven't got that, well I don't think I know who I am anymore. Just his provider. Sometimes I think I would like to go back to work but how could I? I intend to stay here with him.
He doesn’t like strangers in the house. I think he would go berserk if I left him in the house with strangers.

QUESTION #1
How do Elderly Spouses Adjust to Their Role as a Caregiver?
As was stated earlier, Jill has not been a caregiver for an extended period of time. She has made a number of adjustments, however, and decided on a course of action.

I’ve had to adjust to being alone with him all the time. He doesn’t like having other people in the house. Not even his own daughter. He doesn’t even remember his own daughter anymore. She doesn’t like to come down here and visit because he doesn’t recognize her. He is polite and everything and he knows he has a daughter, but he doesn’t know it’s her. Actually, our son-in-law gets on with him better. He copes with the illness better than our daughter. He doesn’t know his grandchildren either. In fact he is usually pretty mean to them. Not physically, but he yells at them not to touch or do anything when they’re here. But our son-in-law has been very good to
him. Sometimes he even comes down from Phoenix by himself.

Jill is concerned about her reactions to his peculiar behavior which she finds harder to cope with than his physical demands, which she feels qualified to handle.

I feel I can handle any of his physical needs but I have trouble with a lot of his behaviors. He is pretty good when I take him out most of the time, but occasionally his behavior becomes unpredictable.

For instance we were in Dillard’s at the mall and he went into the mens room. Well, he was in there a pretty long time and so I finally went in to get him. He was sitting in a stall with the door open and all of his clothes were covered in feces. He hadn’t pulled his pants down and even his socks and shoes were covered. Well I cleaned him up as best I could and told him to wait there for me. I hurried down to the mens department and bought him new underwear, pants, socks and shoes. Well I was only gone about ten minutes but I was worried that he may
have tried to leave. Fortunately, he was still there when I got back. While I was dressing him another man came in to use the rest room. I asked if he could wait just a minute and he left. When we were leaving the store later, I saw him again walking with his wife and I overheard him tell her, "That’s the man that was naked in the bathroom." So I just don’t know how much longer I’ll be able to take him out.

He doesn’t like to go anywhere overnight. He loves to ride in the car, but we have to be home at night. I’ve tried taking him on some short overnight trips but he acts out and we have to return home. We have no social life. He doesn’t want to have people in the house and he doesn’t want to be away from it.

He’s also very possessive of things. He thinks everything is his. He hides things in his room. He loves candy and he places it all over his room. One time, I found he had eaten an entire package of Hershey’s kisses that I had
just bought at the store. The wrappers were in all of his drawers.

He once hid the title to the car in the hubcap. I don't know to this day how he got it there. I knew it was missing because I'd wanted to sell the car. I think he decided that I would not be able to sell it if I didn't have the title. Well, I think it would have remained lost for a very long time, but I happened to have a flat tire. When the mechanic came over to change it, he popped off the hubcap and out dropped my husbands credit card wallet with his old expired driver's license and the title to the car.

I also have a problem with his temper. He gets very angry and argumentative with me sometimes.

Jill knows that Jeff is not going to get any better. As the result of needless legal costs, she is indignant towards the legal community by their unacceptance that Jeff is still entitled to his personal dignity and pride. She is unpiling to accept that kind of treatment towards him.
I wanted to set up a living trust so I went to an attorney. Well I ended up going to three attorneys and spending over fourteen hundred dollars before I found one who knew what to do. The first one said the only way I could act on behalf of my husband was to have him go before a judge and have him pronounced incompetent. Well, I know he’s bad off, but I would never put him through that sort of humiliation. He still is very much aware of things. He wants his own money.

So I think it is very important that caregivers have some place to go where they can work out these things without spending a lot of time and money.

**QUESTION #2**

**How do Support Systems Aide or Impede Caregiver Adjustment?**

Jill hasn’t joined a caregiver support group yet or sought other individual or family counseling. She has tried several adult day care programs and found that she is the main beneficiary of the adult day care programs.

I tried before to get him to go to Handmaker’s but he refused. We went
there one day and there were just too many people crowded into a small area. They didn’t seem to be doing much of anything but sitting and playing puzzles all day. He didn’t like it there at all.

Then I heard about Streams In the Deserts program and thought we might look into that. So far he hasn’t balked about going. I enjoy having most of the day off, even if I have to drive clear over there from the other side of town. I understand that Margaret [the day care coordinator] is supposed to start a center here on this side of town. I hope she gets it going soon so I can switch centers.

I don’t think it effects him one way or the other. I don’t think he remembers being there from one time to the next. The ladies say he is very cooperative and participates. They say he even visits with some of the other guests. I don’t see him exhibit that type of behavior at home.

Jill sees the role of caregiver support as an organization
that should be supplying the caregiver with more practical and financial information.

They need to focus on the practical concerns of dealing with this disease. He's fallen in the kitchen a couple of times and I can't lift him up by myself, even though I know all the techniques. I've got a bad back and I just can't lift him. You need to have contingency plans. You need to know the tricks.

For example, the doctor put Jeff on a stool softener because of constipation caused by medications he was taking the last time he was in the hospital. I have to be very careful with him. He won't tell me when he goes to the bathroom. The only way I know is to check his underwear because he doesn't wipe himself well, if he does at all. Anyway, he was so constipated that the doctor put him on a stool softener. I couldn't get him to swallow them. I dissolved his other medications in his juice, but I didn't know what to do with this gelatin capsule that the stool
softener was in. He would just hold it in his mouth and spit it out when I wasn’t looking. I found them in the bathroom sink. Well I noticed that he had spit one of them out in a glass of warm water and it had dissolved. So I just started putting it in his coffee. That’s the kind of thing caregivers need to know about. How to cope with behaviors and overcome the little things like giving medications.

Jill reiterated the point about the need for support and information on finances.

The big thing they need to know about though is finances. You have to get all your affairs in order before the disease progresses too rapidly. I’m comfortable. We have enough money, and if I should die first, Jeff will be well provided for. But others are not so fortunate. I am totally against people having to spend down their entire life’s income in order to be given the financial help they need. People’s homes and property need to be protected and support services need to
help them know and understand their options.
CASE #8

TERRY

Background Information: "Terry" is a seventy-seven year old from Pennsylvania who retired from a steel mill, after forty-two years as a melder. While his formal education ended in the eighth grade, he is a well read, and articulate man. This researcher would have believed him to be a retired judge if he had so claimed. His home is austere, with many volumes of books, a statement of education on his own terms. There is little else, besides the furniture and a few mementos, that footnote the past. Terry is as austere as his environment and concealed himself and his feelings very well during the course of the interviews. He even concealed his wife, Sue, insisting that we have our interview while she was in the adult day care center. His reasoning was that she would not like him talking about their life together with a stranger. She really had nothing to worry about.

Terry also has a divorced daughter, whose name was not mentioned, that lives with him and his wife. She works outside the home and, according to Terry, has little contact with him or with Sue.

Our daughter has lived here for the past

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8. All names have been changed to protect the privacy rights of individuals and their families who have participated in this research.
two years, since her divorce. She has a private entrance and comes and goes as she pleases. Sometimes she stays in Tucson with a friend and may be gone for several days at a time. She doesn’t seem to take much interest in Sue’s condition and never sits with her. Doesn’t even really talk to me, much.

Terry described a typical day prior to his wife’s illness:

We would take breakfast outside on the back porch during fair weather. Sit maybe over an hour after the meal and read the papers. Sue always read the local paper and I would read the Wall Street Journal. We often played a round of golf in the afternoon and had dinner with friends at the country club. Then we would play cards and come home. We went to bed early and got up early. That’s the way it has always been. There has never been any reason to change.

Terry has been a caregiver to Sue for about five years and refers to her condition as one might refer to the care of a child. He describes a typical day now:

I get up and stretch, make coffee and
return to the bedroom to get Sue up. I usually have to bribe her to get her to do anything. Offers of food are always good. Once we have breakfast, I clean up the kitchen and then start looking for things that will interest her. She can’t concentrate on anything more than about twenty minutes. Although while I’m cleaning the kitchen she will work a crossword puzzle from a magazine or the newspaper. She still pretends to read the paper sometimes, but I don’t think she understands it very well. But, it is amazing how well she can do a crossword puzzle. I guess it’s the one holdover she has from before. Then I try to get her interested in a puzzle or a TV game show. She still likes to go to the golf course, not to play of course, just to look or walk, so we get in the golf cart and ride over for a while. We eat lunch and then she takes a nap. Then I spend the rest of the day and evening getting her dinner and finding things that she likes to do, which isn’t easy.
There is certainly something to be read into what Terry
doesn’t say or reveal but it would be strictly without
foundation. For instance, one might infer that Terry treats
his wife’s condition like an everyday normal occurrence
because he lived his life in this manner, knowing each day
what to expect and how it was going to be. He knew when he
would go to work; when he would go on vacation; his exact bank
balance; what he would eat for dinner every Sunday. Terry is
unable to admit that things are not better or worse for him—they just are.

I guess I miss not traveling. We always
talked about traveling when we retired.
But then we never traveled before so
there really isn’t much to miss, I guess.
I also miss not playing golf. I
sometimes try to play while she is at the
day care. It’s a good pick me up.

QUESTION #1
How do Elderly Spouses Adjust to Their Role as a Caregiver?

Terry’s major adjustment to his role as a caregiver has
been simply to do what must be done. However, in Terry’s
case, this is not really an adjustment. He is reacting to the
world around him in the same manner that he has always
responded. He has chosen to organize his life around meeting
the needs of himself and his wife and that is just the way it is. He reflects on her illness:

   It's a good thing that this Alzheimer's happened to Sue rather than to me. I think she would have been an alcoholic and she would not have cared for me the way I care for her. She likes to drink. We have always had cocktails before dinner. So I still make her one cocktail. She drinks it right down and wants more. She wants to know why her glass is empty and I tell her because she drank it already. I know she would just continue to drink if I let her.

Terry has no unrealistic expectations for his wife's future. He is aware that the time is coming when he will have to place her in a nursing home. Being the predictable and responsible person that he is, Terry will make that decision when he thinks it is appropriate.

   Sue doesn't like to get her head wet so it is difficult for me to help her shampoo her hair. I usually offer her a sweet treat. She loves sweets. Sometimes I have to offer her a little candy bar, you know one of those Hershey bars, just
to get her into bed at night. Anyway, she doesn’t like to get her head wet, so I try to talk her into the shower and I go with her and wash her hair. I tell her we can’t get out and have ice cream until we are clean. Most of the time she is okay with that. I know that sometime she won’t be, and I will have to put her in a home. I’m just waiting until I cannot handle her anymore. My daughter acts as if it is no concern of hers, so I leave her out of it. The doctor says it is up to me to decide because Sue is not capable of speaking for herself anymore. She doesn’t even respond when I ask her what she would like for dinner. They told me in the support group that she won’t respond to any choice questions, that are about more than two things. So I ask her would you like chicken or beef? She always says chicken, even though I know she likes a good steak as well as anybody. Our support group leader says "that’s the one she remembers." I guess that’s true. She lived on a farm when
she was growing up and she often talks about how she and her mother would pluck chickens and cook them for Sunday dinner.

Terry talks about his major concern:

She talks a lot as if she were still living in the past. Sometimes she forgets who I am. That is very bothersome. I have to tell her that I am her husband. She has been afraid of me from time to time and run out of the house. Now I lock all the doors.

QUESTION #2

How do Support Systems Aid or Impede Caregiver Adjustment?

Terry has joined a caregiver support group and is doing a nice job providing support for the group. (This researcher knows this because of several confirmation talks with both group leaders and members, who are willing to concede that "Terry appears to have it all together.") Terry wanted information about the illness, what to expect in the future, and how to handle certain behaviors. Instead, what he has gotten out of the caregiver experience is an opportunity to provide others with needed support and information.

It seems to me that many caregivers, men in particular, don’t know how to take care of the simplest things. They are
too afraid that they will not be doing something right. Too much of this not enough of that. So what? The person with the Alzheimer's doesn't know if you put too much cinnamon on the toast. Just be there to see that she eats it.

The support groups are fine. I go to the meetings every week. I enjoy the talking to other people that have the same sorts of problems I have. We have a lot more in common. I wish they would include information on things like how to keep the patient entertained and out of trouble. They like to wander off. I would like some practical advice on how to answer the same questions over and over again.

Terry takes his wife to two different adult day care centers. He says it gives him a chance to allow someone else to find something for Sue to do and it gives him time to do the housework or play a round of golf. The drawbacks are minimal, and he feels there is no harm done to Sue.

The day care helps me get enough time to take care of errands like shopping and to clean house. I like to play golf a
couple of times a week. I still have a standing tee off with one of my friends on Thursday mornings. Sue does Okay. If there is someone to tell her what to do every twenty minutes or so she is going to be alright.

Terry is a man that has planned all his life for his future. Now that the future is here, and there is no one to share it with, he will simply go on planning

Sue will reach a point where I can no longer care for her and I will place her in a home. I am thankful that I can afford to do that. Others cannot. I will miss her company but, really she is already not the Sue that I was married to for forty-three years.
CASE STUDIES SUMMARY

While each of the case studies presented has a unique and undeniable personal focus to it, there are certain aspects that each shares. The most important is that each caregiver feels in their own way, that they are doing their best for their spouse.

The answers to research questions three and four lie in the responses of the group collectively because community resources are delivered on the assumption that there is a consumer need. A commodity, whether for private or public consumption is based on the needs of the population requesting that commodity.

QUESTION #3
WHAT KINDS OF SUPPORT DO ELDERLY SPOUSAL CAREGIVERS NEED MOST?

This research has shown that there are a number of support alternatives in the community, including adult day care, respite care, caregiver support groups, nursing homes, senior meal programs, and that these are funded and provided by public and private institutions. While most are available in some form on a sliding fee scale, for those unable to pay the full costs, financing Alzheimer’s disease remains a major concern for caregivers. Many of them feel they need to be better informed as to what types of financial help is available and how they go about accessing it. They want to know how to fill out insurance and Medicare forms, understand
legal wills and trusts, and know who to contact for advice.

Alice comments: "The one thing that is really lacking is more knowledge of what we can do financially. I know that I’m going to be at the end of my resources soon. And most of us, when we talk, really don’t know what’s available and how to go about doing it."

And Gail says: "I hear Pima County has a list of places to go to get aides but they are so expensive. Some are ten dollars an hour. I have met women that never get out. They cannot afford a sitter because they are living off their Social Security. The costs is what keeps people away. If he lives to be ninety, I’m going to run out of money. If I die, I don’t know what will happen to him, because he doesn’t have any retirement income."

Mary adds: "You need to prepare yourself for the day when the patient is not able to handle financial and legal things."
You must know how to do it yourself or how to get the right kinds of help. I think this is an important aspect of the caregiver process. Learning about living wills and trusts and thinking through the possibilities."

Jim has this to say about other financial implications: "One thing that I think is a big problem that nobody hardly seems to talk about is the finance end of things. My problem is keeping all these insurance and medicare forms in order. I hate to think of the time coming when I might loose this place because of this. You can never afford enough insurance. I don't think we should have to expect our children to come and look after us.

Jill discusses her experiences and costs of trying to get legal control over their joint financial arrangements: "I went to three attorneys and spent over fourteen hundred dollars before I found one who knew what to do. The big thing
caregivers need to know about is finances. You have to get all your affairs in order before the disease progresses too far."

The data has also shown a number of common supports that need to be met for the caregiver. Some are being met by the community and others are not. Issues surrounding moral support and information about disease effects are being met by caregiver support groups.

However, practical information on coping with particular behavioral problems are reported in the data to be lacking in most of the community support systems. Although, the caregivers do report on different behavioral problems, including, temper and anger, acting out physically, sleep disturbances, hiding things, fear of water, fear of strangers and strange environments, need to be at home, wandering off, incontinence, not recognizing the spousal caregiver, and close relatives and friends, these behaviors are recognized in the literature as common and recurring. Yet the caregivers still identify coping skills for these behaviors, as an unmet need in community support.

Jill comments: "Caregivers need to know how to cope with behaviors and overcome the little things."
Jim reports: "I need to be told more about how to cope with these things, rather than to get into a confrontation. It doesn’t do her any good and it doesn’t do me any good."

Amy adds: "I would like to be told how to talk to the patient. It starts with just a little aggravation here and there. Then all of a sudden it can progress very rapidly to a different phase."

The problem of social isolation creates another unmet need for caregivers. Many support groups do not provide long-term or ongoing support and in a way add to the problem of social isolation. For people who find themselves in a new group every six to eight weeks, there is a sense of loss and incongruity. The caregivers comment on their social isolation:

Gail: "I’m never invited to any couples things. You really suffer a lot of social isolation. I see less and less of my grandchildren. They have become increasingly turned off by grandpa. But I was used to having them at the house all the time and that is no more."
Eric: "You lose your friends, couples friends."

Several of the caregivers are concerned over losing contact with other group members, who have essentially become their social outlet and in many ways fill the gap left by family and friends who are no longer comfortable around the caregiver and the Alzheimer’s patient.

Alice: "I think it’s important for the caregivers to keep in touch with one another. The groups come and go. They only last a short time. I have several women, who are dealing with Alzheimer’s, and we have quite a feeling for one another."

Marty: "Several of us, we try to stay in touch. Go for exercise together and walks. Exchange ideas, recipes, plan nutritional meals. I’ve become good friends with another fellow who takes his wife to the same day care that my wife attends."

**QUESTION #4**

**WHAT CHANGES, IF ANY WOULD THE ELDERLY SPOUSAL CAREGIVERS LIKE TO SEE OCCUR IN CURRENT AND/OR FUTURE SUPPORT SYSTEMS?**

By now the data has revealed the answers to this
question. The elderly spousal caregivers were forthcoming with their needs during the interview process, and were eager to share what they felt were necessary components of good support systems. They unanimously stand behind the contention that effective caregiver support will include additional information on financial issues, including insurance, living wills, trusts, financial management and where to go to help finance the disease process without losing all of one’s worldly goods.

Jill: "I think it is very important that caregivers have a place to go where they can work out these things without spending a lot of time and money."

Jim: "I think the Alzheimer’s Association needs to give us more information on finances. We need to know more about programs where people can go for financial help."

Several were able to offer pertinent suggestions for meeting their needs:
Gail: "Caregivers need to be provided with lists of community resources such as dentists, doctors and nursing homes, which will help them work with Alzheimer's patients."

Eric: "It might be helpful if they had clinics on these types of [domestic] skills."

Mary: "Advertising maybe one way the groups could try and get people involved sooner. Local papers carry editorials explaining the need to get help as soon as possible. They already have various meetings with lectures on sleep disorders, nutrition, why not one on Alzheimer's disease? So people interested could just come by and participate. In-home respite needs to be both accessible and affordable to those who cannot get their spouses to leave home or those who are not physically capable of leaving home. You just can't keep on paying for in-home respite with Alzheimer's because
it is such an ongoing thing."
Jim: "I wonder if the groups would like to do more work. Either for themselves or for others. In the support groups we need to learn to look out for each other. Pool our resources. The support groups need to help the caregiver become more reliant on themselves and each other and not the government."

Marty: "Husbands and wives need to be better prepared to take over."

Alice: "The Alzheimer’s Association could serve the caregiver better by getting information out about seeking help early. Something could be made available. Really hard facts [on Alzheimer’s disease] as to the how to’s."

An additional theme prevalent among the caregivers was the constant reminder that those having to deal with Alzheimer’s disease seek help as early as possible and not wait until they are in a state of desperation. They suggested that caregivers consult their doctors, ministers and their local Alzheimer’s Association for pertinent reading material
on the course of the illness.

Alice: "Study and learn all you can about it [Alzheimer's disease]. I started right away. I feel sorry for those who will not learn. They are trying to do this on their own without learning anything about it."

Mary: "The important thing is to just get help. You can't do it alone."

ADDITIONAL CAREGIVER PERCEPTIONS OF COMMUNITY SUPPORT

There were a number of issues mentioned by a minority of the caregivers, in this research, that may be of concern to other caregivers. They include: skills for living alone; finding the right nursing homes and hospitals; training for day care center, hospital and nursing home staffs in meeting the special needs of Alzheimer's patients; caregiver self-care programs.

SUMMARY OF DATA INTERPRETATION

The data gathered through this naturalistic inquiry, has shown a number of common goals and problems experienced by caregivers. The major themes shared by the caregivers relate to needs for financial information, help with the day to day practical and behavioral problems and the need for early
support intervention and information.

The final research question "What are the implications for future researchers, counselors and clinicians for meeting the needs of elderly spousal caregivers of Alzheimer's disease patient?" is addressed in Chapter Five.
CHAPTER FIVE

IMPLICATIONS AND SUGGESTIONS FOR FUTURE RESEARCH.

QUESTION #5

WHAT ARE THE IMPLICATIONS FOR FUTURE RESEARCHERS, COUNSELORS AND CLINICIANS FOR MEETING THE NEEDS OF ELDERLY SPOUSAL CAREGIVERS OF ALZHEIMER’S DISEASE PATIENTS?

Counselors and clinical professionals will be better able to serve the elderly spousal caregiver by heeding the recommendations offered by the research participants. Mental health counselors must deal with the caregiver in a holistic manner, looking carefully at the world in which the client lives. It is a different world from any other as pointed out by the respondents:

Alice: "It’s sort of hard for me to get acclimated to doing things by myself. And I don’t think anyone from the outside can talk you out of the guilt feelings that you have. I have em, but I don’t let them bug me anymore. I started, when I went to counseling, learning how to deal with the guilt."

Marty: "How to better cope with this illness. How to stay calm and not get
angry. She forgets more and more and never improves. I get mad at her and then I feel sorry and guilty."

Jim: "One of the first things I need to know is how to cope with all of this. I need to know more. I’m not a person with a lot of patience. I need help to have more patience. Do counselors do that type of thing? Can they give you more patience? It is hard to realize that a child can learn, but my wife is not going to learn anymore. Instead of learning it’s going the other way. I think counselors could help us cope with this. She did it all, now I have to."

Jill: "I’ve lost myself. My work was very important to me and now that I haven’t got that, well, I don’t think I know who I am anymore. I need someone to help me define my new roles. To find myself. I feel that I was robbed of my identity. I led an interesting and vital life. I wanted my retirement to be a lot
different. I didn’t even want to retire."

Terry: "It would help if the doctors made a clearer and quicker diagnosis. It would also help if the insurance companies allowed people the flexibility of coordinating their own health care. I mean if your sent to a neurologist for a diagnosis, he doesn’t do anything, but that. Then you have to go someplace else to get a primary care physician to tell you about treatment. Well they see so many people, that they don’t even remember your name. You never get an opportunity to work with one person who you know and who knows you."

Mary: "I need someone to help convince me that I’m not guilty. Why did I lose my temper with him? It wasn’t his fault. I wish I hadn’t done that, or I wish I had done this differently. And intellectually, I know that I’ve done what I could, but emotionally I don’t."
People need both support groups and individual counseling to get through this. You need someone to back you up."

Eric: "Counseling would be a good thing. We have Helen [support group leader] and she is just marvelous. She comes to the house and checks up on certain caregivers. She has two or three ladies who work with her that are pretty good too, but Helen is the best. It is important for caregivers to have a helpful contact outside the support group."

Caregivers are the second victims of this devastating disease. At a time when couples should be enjoying their remaining years together, they are torn apart, emotionally and mentally but not physically. The caregiver is left to deal with the physical presence of a loved one without being able to let go emotionally. As was clearly stated in the data, it is like being a widow/widower without the benefits. They are not considered single by friends, family or society, nor afforded the opportunity to grieve for the person you’ve lost. They are living in an impossible situation with a person who probably doesn’t even know who they are. Counselors and
Clinicians working with this particular group of elderly individuals, must be willing to see into this world and help the caregiver make sound judgments for the care of the patient and in the interests of the caregiver.

Clinicians working in nursing homes and hospitals must learn to recognize the needs of the Alzheimer's patient and the important role that the caregiver plays in making those needs known. The professional staff must be willing to work closely with the caregiver to make the transition from home to nursing care as smooth as possible. And to Recognize that the caregiver not only speaks for the Alzheimer's patient, but is also expressing his/her own needs about the care home as well. Again, the duality of having two victims must be recognized by the professional community. Special care must be taken to guard against declining health in the caregiver.

Mental health care and support must not terminate once the Alzheimer's patient has died. For the caregiver, it must continue through the grieving process. This is the second time that the elderly caregiver spouse has lost the same individual; once to the disease and once to the death of the physical body.

Social isolation is a challenge for everyone providing services to Alzheimer's caregivers. Since their time and resources are taken up with the job of being a primary caregiver, counselors and clinicians must focus attention on
providing them with needed respite services, age appropriate activities and opportunities for social interaction, during, and especially after the caregiving process.

Depression, at least among the sample used in this research, was not a major issue or concern. While the elderly, as a group, are at high risk for depression, it may be that this sample was receiving enough outside support to help sustain their emotional well-being, even when faced with the demands of being a caregiver. They are probably, as a special group, receiving more mental health care than the average elderly individual, who is not a primary caregiver for a spouse with Alzheimer’s disease. Most were able to acknowledge, that they went through periods of anger, guilt, loss, and suicidal ideation, as well as some physical symptoms of depression. These episodes were regarded as having been acute and not a chronic state. However, it will serve the mental health counselor well to remember that depression can occur within this high risk population at anytime and special precautions, (i.e., watching for symptoms, keeping updated on changes in the Alzheimer’s spouse, monitoring medication and alcohol consumption) should be taken to guard against it.
SUGGESTIONS FOR FUTURE RESEARCH

Those wishing to continue on a course of naturalistic inquiry in order to duplicate or expand on this research should have no trouble finding respondents through the local chapter of the Alzheimer's Association. In the interest of time and efficacy of the data, the following adjustments to the research are recommended:

1. Use fewer case studies but do several interviews and observations rather than relying on a single period in the caregiving cycle.

2. Conduct interviews with a group of caregivers who are caring for spouses at approximately the same stage of the disease and who are using the same community supports. This approach will narrow the study to make the data more manageable, and lend itself to more focused information on specific support systems.

3. Reverse the study and conduct interviews with those providing care in one or more community support systems. This would allow a comparison of what caregivers needs are perceived to be and their perceived ability to meet those needs.

4. Do a similar study on a single stage of the disease to focus clearly on the needs of caregivers coping within that particular stage.
CONCLUSIONS

Alzheimer's is a growing and insidious disease that can attack the future of everyone. With an increasing life expectancy of our worldwide population, it is doubtful that anything but a cure will keep this disease from touching the lives of each and everyone of us. We must adapt support systems that lend themselves to the various populations seeking help and to the differing needs of the caregivers as the patient moves through the various stages of the disease. The professional community must also learn to work with, and help strengthen the social support systems within the caregivers world. The caregiver must be able relate and function among family and friends without feelings of guilt and isolation. As professionals, we have an obligation that is summarized nicely by one of the participants in this research:

I would tell people though, if you are dealing with someone with Alzheimer’s, to always approach them positively. Always smile, even if they are angry with you and put this sign over the bed. "Do not handle this person unless you have a smile on your face and a positive attitude. If you don’t have it, then
leave."

This extends to the care and treatment of the heroic caregiver as well.
Appendix A: Human Subjects Form

PROJECT APPROVAL FORM
REQUEST FOR ETHICAL REVIEW OF ACTIVITIES INVOLVING HUMAN SUBJECTS
IN QUESTIONNAIRES, INTERVIEWS, OBSERVATIONS, VIDEO/AUDIO TAPES, ETC.

1. **Sherlyn L. Harris-Ricketts**
   Department: Counseling and Guidance
   Elderly Caregiver Perceptions of Support Systems in Meeting Their Special Needs
   Title of Project

2. **SUPERVISING OFFICIAL**

   I certify that (1) facilities and personnel are available to the investigator for assuring the safety and well-being of human subjects involved; (2) I will be responsible for continuing surveillance of the proposed program with respect to the rights and welfare of human subjects; (3) no procedural changes relating to the human subjects involved will be allowed without prior review by the Human Subjects Committee; (4) I am satisfied that the procedures to be used for obtaining informed consent comply with the spirit and intent of DHHS regulations; (5) I certify that the investigator is fully competent to accomplish the goals and techniques stated in the attached proposal; (6) the signed consent forms will be filed in the Departmental file and retained for a period of six years.

   **[Signature]**
   Head of Department, Dean of the College of comparable authority (Signature)

3. **DEPARTMENTAL REVIEW COMMITTEE**

   We [ ] have examined the proposal cited above, and find that the information contained therein is complete; that the scientific aspects of the project include appropriate provision for protecting the rights and welfare of the human subjects involved; and that the required forms have been filled out properly in accordance with the Institutional Assurance filed by the University of Arizona with the U.S. Department of Health and Human Services.

   [ ] Exempt from Human Subjects Committee review.
   [ ] Minimal risk to human subjects: Human Subjects Committee expedited review requested.
   [ ] Possible risk to subjects: Human Subjects Committee review recommended.

   **[Signature]**
   Chairman of Departmental Review Committee (Signature)
   **6/6/91**
   Date

4. **HUMAN SUBJECTS COMMITTEE**

   The proposal above was approved on this date by the Human Subjects Committee.

   **[Signature]**
   Chairman
   **[Date]**
Appendix B: Participants Form

SUBJECT'S PARTICIPATION FORM

You are being asked to voluntarily participate in a research study on Alzheimer's caregivers. The study is being conducted by Sherlyn L. Harris-Ricketts in partial fulfillment of the requirements for a Master of Arts degree in counseling and guidance. The purpose of the study is to investigate the perceptions of Alzheimer's caregivers towards outside support. It is hoped that the information will help doctors, clinicians, social workers and counselors aide current support systems in meeting the needs of Alzheimer's caregivers and offer caregiver input in development of new programs.

As a participant you will be asked a series of open-ended questions in an informal interview that will be audio taped and later transcribed for data analysis. You will also be asked a series of questions regarding your current moods, feelings and physical state. It is anticipated that this interview will last approximately one hour. Risks are minimal but may include some emotional discomfort or stress due to the sensitive nature of the research. You may ask the investigator to stop at any time and your request will be honored immediately, without incurring any ill will. There is no cost to you. Your responses will be grouped with the responses of other individuals participating in the study. Your name will never be used in the published results of this research, nor will any record be kept of your participation. All raw data will be destroyed at the conclusion of this project and a copy of the written findings will be furnished to you upon request.

'I have read the above "Subject's Consent." The nature, demands, risks, and benefits of the research study have been explained to me. I understand that I may ask questions and that I am free to withdraw from the study at any time. I also understand that this consent form will be filed in an area designated by the Human Subjects committee with access restricted to the principal investigator or authorized representatives of the department of Counseling and Guidance. A copy of this consent form will be given to me.'

SUBJECTS

DATE________________ SIGNATURE_____________________

I have carefully explained to the subject the nature of the above project. I hereby certify that to the best of my knowledge the subject signing this consent form understands clearly the nature, demands, benefits and risks involved in participating in this study.

INVESTIGATORS

DATE________________ SIGNATURE_____________________

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Appendix C: Sample Interview Questions

SAMPLE QUESTIONS
(Questions that give information on research question #1)

1. Tell me what your life was like before your spouse was diagnosed with Alzheimer’s Disease? (prompt: Describe a typical day)
2. In what ways has your life changed? (What is a typical day like now?)
3. What has been the easiest adjustment for you?
4. What has been the hardest adjustment for you?

(Questions that give information on research question #2 and #3)

5. What types of support are you familiar with? What type(s) of support are you or have you used?
6. Do you feel you have (or have had) enough information on what support is available to you?
7. What support is helping you the most?
8. What support is helping you the least?

(Questions that give information on research question #4)

9. What changes would you make in support that would improve the quality of your life?
10. What changes would you like to see made in the current support system?

(Questions that give information for research Question #5)

11. What do you feel you need most from outside support?
12. Who takes care of your feelings? What would you like others to understand about your particular situation?
13. Who, in your support system, offers the most of what you need?
Appendix D: List of Community Support Used By Participants

Arizona Chapter of the Alzheimer's and Related Disorders Association
- Support Groups
Friends In Deed Caregiver Support Group
Handmaker Adult Day Care Center
Meals on Wheels community Food Program - Green Valley
Meals on Wheels Community Food Program - Tucson
Nurse Finders - In-Home Respite Services.
Our Lady of the Valley Catholic Church Senior Center Program
Our Savior Lutheran Adult Day Care Program
Pima County Caregiver Support Group
Streams in The Desert :Lutheran Adult Day Care Program

Also cited were
Group homes - for respite care
Nursing Homes
Private Doctors
Private Counselors
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