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Elder care: An evaluation of communication resources for lay caregivers in southern Nevada

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**ELDER CARE: AN EVALUATION OF COMMUNICATION RESOURCES
FOR LAY CAREGIVERS IN SOUTHERN NEVADA**

by

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**A thesis submitted in partial fulfillment
of the requirements for the**

**Master of Arts Degree
Hank Greenspun Department of Communication Studies
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ABSTRACT

Elder Care: An Evaluation of Communication Resources For Lay Caregivers in Southern Nevada

by

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**Dr. Anthony Ferri, Examination Committee Chair
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Hidden behind closed doors of nursing homes, hospitals and neighborhood residences, was a segment of the population suffering from dementing illnesses. Although seldom seen, these older Americans presented significant challenges for the family members caring for them. This study focused attention on these lay caregivers and the effectiveness of community resources, from their perspective. With assistance from Southern Nevada Alzheimer's Association staff, a survey was conducted. The results showed agencies rated as "satisfactory" in their efforts to provide information, with the Alzheimer's Association newsletter ranked as the primary source of information for caregivers. While the survey provided insights regarding caregivers who had contacted the Alzheimer's Association, it revealed little about those who had not. Increased communication could open the door to providing information and, according to this evaluation, the local Alzheimer's Association held this critical key.

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CHAPTER I

INTRODUCTION

**I want to share all the information I can find about this disease because I know that knowledge is essential to being a good caregiver.
-- Brenda Parris Sibley, A Year to Remember With My Mother and Alzheimer's Disease**

On whom did one rely for help with a 75-year-old mother who was no longer able to care for herself? The scenario required a series of choices to be made by family members and even making no decision could result in unfavorable consequences. Despite the fact that there are hundreds of agencies that focus on elder care issues, many people who found themselves in the position of lay caregiver were not readily aware of how to access these resources to find out what the agencies were, what they did, and, most importantly, how they could help. This thesis focused attention on dementing illnesses of the aging that required the help of a caregiver and, from a communication standpoint, identified and measured the effectiveness of resources available and accessible to lay caregivers in Southern Nevada.

Purpose

The purpose of this study was two-fold: (1) to examine the public's perception as to whether adequate health communication resources exist and are made available within the community to meet the needs of individuals finding themselves in the role of lay caregiver as they deal with elder care issues, and (2) to add to the body of current knowledge by demographically identifying Southern Nevada's lay caregivers and the challenges they face.

Justification

This empirical study was a worthwhile communication project to help a community with a fast growing senior population by filling a gap in current research concerning elder care health issues. This study attempted to:

- Increase awareness of some health communication issues affecting America's aging population.
- Identify today's lay caregivers and increase awareness of the challenges facing these family members who were trying, at best, to make informed decisions as to health, safety, quality of life and financial decisions for their loved ones and, at the least, to eliminate some of the uncertainty associated with those decisions.
- Examine the communication resources available and accessible to lay caregivers in the community.
- Measure, from the lay caregiver's perspective, how effectively these sources of information were disseminated to those in need.

Background

Recognizing the need to provide useful information to the many who may find themselves caring for an elderly family member with a dementing illness, Nancy L. Mace and Peter V. Rabins wrote, in the book The 36-Hour Day, that caregivers world-wide faced the same problems, the same need for assistance, and the same desire to care for their family member as long as possible (1991, p. xix). These authors described the symptoms of dementia as mental confusion, memory loss, disorientation, intellectual impairment, or similar problems, and cited Alzheimer's disease as the most frequent cause of irreversible dementia in adults (pp. 8 and 9).

Dennis Selkoe (1992) studied chemical changes the brain undergoes during the aging process which shed light on the mysteries of dementia. Consistent with Mace and Rabins' findings, Selkoe (1992) identified Alzheimer's disease as the leading probable cause of Americans suffering from dementing illnesses, at 55.6 percent, which was well ahead of stroke at 14.5 percent, Parkinson's Disease at 7.7 percent and brain injury at 4.4 percent. Dementia attributed to multiple causes made up 12.2 percent of the distribution, with other causes at 5.5 percent (p. 6).

Frena Gray Davidson (1994) investigated America's recent societal changes and brought into focus the shifting away from traditionally caring for elderly family members at home, and the movement that started in the 1940s, towards hospital and nursing home care settings to accommodate the sick and dying. Davidson also acknowledged caregiver challenges and fears of the horrible experiences associated with Alzheimer's disease, the uncertainty, and even the anger as to what the future held, how to cope, and how to get answers without being sure what the questions were (p. 1).

Echoing Davidson's concerns, former First Lady and author Rosalynn Carter explained the stigma and myths associated with mental illness, the trials and tribulations of family members as lay caregivers, and the need for increased efforts as far as public education and outreach (1998). Carter's book, Helping Someone With Mental Illness, included a resource directory of helpful publications along with names, telephone numbers, street and electronic mail addresses for many national organizations that could provide assistance.

An internet search revealed many websites describing caregiver experiences. In addition to these personal diaries, discussion groups were equally abundant as family members poured out their emotionally-charged struggles to find the ways and means to cope with their own unique challenges. One Caregiver Network Bulletin Board entry cited the sense of isolation that caregivers felt and the importance of interaction with other caregivers, as a support system (internet communication, October 29, 1996).

According to the National Alzheimer's Association, an estimated four million Americans were afflicted with Alzheimer's disease. This condition was identified as the fourth leading cause of death among American adults, after heart disease, cancer and stroke. In literature provided by the voluntary health organization, Alzheimer's disease was described as a progressive, degenerative disease of the brain with unknown causes and no cure at the present time. An Alzheimer's patient experienced confusion, personality and behavior changes, impaired judgment, and difficulty finding words, finishing thoughts or following directions. Over time, the disease left the person unable to perform even the simplest tasks of daily living, rendering them totally dependent on others for constant care and supervision.

The national association website provided a plethora of information, ranging from the latest medical breakthroughs to locating the closest community chapter. A visit to that local office, the Southern Nevada Chapter of the Alzheimer's Association, revealed a variety of communication resources available free to the public. Most materials were produced by the national organization's headquarters, and included educational brochures and a videotape lending library targeting specific audiences and age groups. Also available were listings for caregiver support groups in the area.

In an interview with Phyllis Montavon, Executive Director of the local chapter, it was evident that her primary concern was to guide caregivers to the resources they need to cope with a loved one suffering with Alzheimer's disease. Montavon identified distribution of a quarterly newsletter, caregiver workshops, annual fundraising events including a fashion show and a memory walk, along with dissemination of news releases to local media outlets, as elements of her public outreach program.

Although the resources of the local Alzheimer's chapter and other community agencies focused on issues of the aging are accessible to the public, it took time for lay caregivers to learn about these organizations. As a writer and licensed administrator for an assisted-living community in Southern Nevada, Linn Thomé (1999) explained that the constant theme she heard was frustration, guilt and often, a lack of knowledge as to available community resources (p. 26).

Caregiver Profile

In the fall of 1996, a random telephone poll was conducted as a joint effort of the National Alliance for Caregiving, the American Association of Retired Persons and

Glaxo Wellcome, the world's largest prescription drug company. The national survey focused on anyone caring for a relative or friend who was age 50 and older.

Survey results appeared in a 1997 article by Susan Levine and showed that:

- 22.4 million households were giving support to older relatives and friends.
- Nearly one in four households was involved in the often stressful and time-consuming task of caring for an aging relative - - a three-fold increase over the number of caregivers 10 years ago.
- The average caregiver spent 18 hours a week and some 4.1 million caregivers devoted a minimum of 40 hours a week to this function.
- Caregiving continued for an average of four years.
- 64 percent of caregivers worked either full or part-time and often jeopardized their jobs because of their responsibilities to relatives. Some quit or took early retirement to meet caregiving demands.
- Women were the caregivers nearly three-fourths of the time and the vast majority of them worked.
- Because many women had children later in life, they were caring simultaneously for both ends of the age spectrum, as 41 percent of caregivers for the elderly also had children under age 18.
- Nearly half of the caregivers said they had given up personal activities, hobbies and vacations; 15 percent admitted to physical or mental health problems.
- The typical situation was to care for a 77-year-old woman who lived alone and had a chronic health condition. A reported 22 percent had dementia.

Kate Warrick (1996) recapped findings from a survey conducted by Yankelovich Partners, Inc., for the National Alzheimer's Association during the summer of 1996. The survey consisted of 500 telephone interviews conducted among primary Alzheimer's disease caregivers who had, at some point, contacted the association. The results added more quantitative research in regard to today's caregiver and supported the previously referenced survey with these findings:

- Most caregivers were caring for their parent or spouse. 81 percent of caregivers were women and 30 percent were the sole caregiver for a person with Alzheimer's disease.
- On average, caregivers were in their mid-fifties with a median annual household income of \$35,000.
- Physicians and Alzheimer's Association newsletters were the primary sources of information for caregivers.
- Half of all caregivers lived in the same residence as their loved ones, making theirs a 24-hour a day job.
- Caregivers spent an average of 69 to 100 hours each week caring for loved ones, depending upon where the person with Alzheimer's resided.
- Respondents described providing care as "frustrating" (90 percent), "draining" (87 percent) and "painful" (87 percent).
- 49 percent strongly agreed that their caregiving duties caused stress within their families. An equal percentage felt they did not have enough time for themselves and 34 percent feared they might not be able to provide care much longer.
- 75 percent of caregivers were depressed at least occasionally, and 34 percent were depressed frequently or almost always. Those with loved ones in a nursing home or

other assisted living facility were more likely to be depressed than caregivers whose loved ones resided on their own, with the caregiver, or with other friends or family members. Almost half, 45 percent, felt they did not get enough sleep.

- One in five caregivers stopped working primarily to care for a loved one.
- 36 percent reported reducing their work hours and again, 36 percent reported a loss of income and 13 percent reported being turned down for promotions because of their caregiving responsibilities.

Beyond identifying today's caregiver, an investigation was made as to the changing roles of the caregiver. Mace and Rabins (1992) explained that the relationship of a parent with a dementing illness and an adult child often had to change with the adult child assuming responsibility to care for a parent. This shift in roles and responsibilities was referred to as role reversal, as the adult son or daughter gradually assumed increasing responsibility for a parent while the role of the parent changed accordingly (p. 238).

Eric Berne's Transactional Communications model demonstrated the role reversal concept (1976, p. 46). Although the transactional analysis theory of personality was borrowed from psychology it has application to the lay caregiver's role reversal.

In Berne's (1976) model, the "Parent" was an ego state that exhibited parental behavior, such as the stern or critical father (p. 46). The "Adult" was oriented toward objective autonomous data-processing and probability-estimating, for example, the exhibition of a "mature, reasonable interest" in another person (p. 48). Berne's "Child" was "an archaic relic from an early significant period of life that was influenced by parental parameters and examples included expressive behaviors such as tittering coyness and agitated schoolgirl" (p. 38).

By replacing “Sender” with “Caregiver” and “Receiver” with “Impaired Individual,” the caregiver operated more and more frequently in the parental mode and the impaired individual increasingly functioned in a child-like fashion, which typically does occur with dementing illnesses as shown in Figure 1.

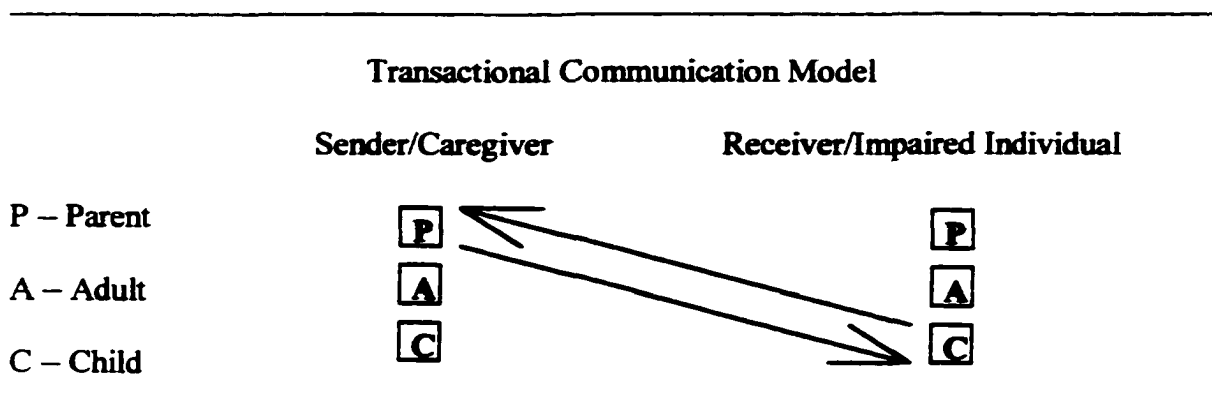


Figure 1. Eric Berne’s Transactional Communication Model demonstrated the role reversal concept.

Community Resources

To identify health communication resources available within the Southern Nevada community to assist the elderly and those caring for them, a search of printed materials was conducted and several social service agencies were contacted.

The area telephone book contained a guide to community services that listed many local agencies. A pamphlet created by Clark County identified and described services available through that governmental entity. The Howard W. Cannon Center, located at 340 North 11th Street in Las Vegas, was a one-stop shop for senior citizen information with an array of literature explaining federal, state and local agency

programs. The Southern Nevada Chapter of the Alzheimer's Association provided information targeting a variety of audience needs ranging from help locating medical and legal professionals who specialized in elder care issues to a lending library of videotapes such as Just For The Summer (Churchill Films) that demonstrated the burden dementing illness placed on all members of a household, including young people.

An interview was conducted with Lucille Clavier, a volunteer who worked at the Traveler's Aid Information Station at McCarran International Airport in Las Vegas. Clavier shared an unpublished listing of community agencies and telephone numbers that she compiled during her years as the airport's Retired Senior Volunteer Program (RSVP) coordinator.

CHAPTER II

REVIEW OF LITERATURE

A review of literature addressing elderly health care issues and communications was conducted. A collection of information was obtained from scholarly academic and medical journals, books and newspaper articles concerning mental illness and caregiving for loved ones with Alzheimer's disease and other forms of dementia. An internet search was done, as was a review of communications materials produced by the National Alzheimer's Association. To gain local perspective, an analysis of community communication resources was performed and interviews were conducted with the executive director of the Southern Nevada Chapter of the Alzheimer's Association and the coordinator of the Retired Senior Volunteer Program at McCarran Airport.

Quality of Life: Medical Perspective Versus Patient Perspective

In the mid 1980s, a change in thinking started to evolve in the world of medicine and geriatric care, according to Phillip Clark (1995, p. 402). There was a shift away from physicians striving to extend life expectancy and a movement towards emphasis on an individual's quality of life. This shift created confusion as to a clear "quality of life" definition. The medical profession's clinical, objective view was not the same as other health care providers and aides, patients and their families, who may all have more

subjective definitions. These varying perspectives created misunderstandings and problems, and Clark (1995) concluded that the only way an emergence could take place between geriatric practice and the recipients of these services, was through communications and understanding.

In a more recent article, Clark (1996) said that a culture clash was underway; pitting the scientific culture of chronic geriatric health problems against its impact on essential and personal quality of life values. Clark (1996) said improved dialogue between elderly people and their health care providers was the solution. Clark (1996) again identified a fundamental difference in communication from a health care provider's perspective and that of the patient, and offered new approaches for medical professionals to use as they worked towards narrowing this communications gap (p. 747).

Soundappan, et. al. (1997) stressed the importance of collaboration between physicians and home care nurses in order to effectively meet the needs of elderly patients. This team of medical professionals suggested that reduced hospitalizations and improved patient quality of life could be realized, however, the group's research indicated that most physicians did not consider themselves knowledgeable in regard to home care services. These authors suggested home care agencies should devote more time to enhancing communication programs for physicians (p. 84) and cautioned that because of a changing Medicare system, physicians had to become more familiar with home care services, as they eventually would be held accountable for the patients they referred and the services they ordered (p. 85).

Saldov and Chow (1994) conducted a study of the elderly living in Toronto, Canada, that could have implications for an increased multi-cultural elderly population in

the United States. They suggested that communication was critical in order to provide effective, efficient, and equitable health care service delivery for ethnic elderly individuals (p. 117). These authors developed a database of senior citizens living in Toronto's health care facilities that spoke neither of Canada's official languages of English or French, and then examined the extent of communication difficulties that arose. Although interpreter services appeared to be a logical solution to break through the language barrier, Saldov and Chow (1994) discovered that communication problems still arose and that some interpreter services provided were ineffective. They also pointed out that many statements of quality care and concerns for quality assurance in nursing homes in the United States and Canada completely overlooked the importance of language and culture in the delivery of health and social services (p. 125).

Focused specifically on Alzheimer's disease, Query and Kreps (1996, p. 338) realized that because of the catastrophic nature of this illness, some patients and their caregivers did not participate in appropriate health care regimens. The severe conditions that accompany Alzheimer's disease often triggered emotions in caregivers, so much so, that their interpretation of health care information was distorted and feelings of uncertainty were heightened. These emotions had the potential to serve as a deterrent to caregivers making appropriate health care and quality of life decisions that affected their loved ones.

These researchers conducted a study of lay caregivers and suggested a caregiver's level of communication competence was positively related to their achieving desired physiological and psychological health outcomes.

Query and Kreps (1996) developed a model of relational health communication competence (p. 336). Their hub and spoke model identified many health care variables that revolve around the patient. The figure illustrated today's health care trend for services to evolve around the consumer and portrayed the inter-dependent relationships between health care providers and patient. Surrounding the wheel, was the universe of communication competence that must flow through each area, or spoke of the wheel, in order for effective health care to be delivered. Extending beyond communication competence in the model, were positive factors such as social support and satisfaction realized by caregivers who saw themselves as competent communicators, in contrast to negative factors such as lack of social support and dissatisfaction that occurred among caregivers who did not perceive themselves as competent communicators (see Figure 2).

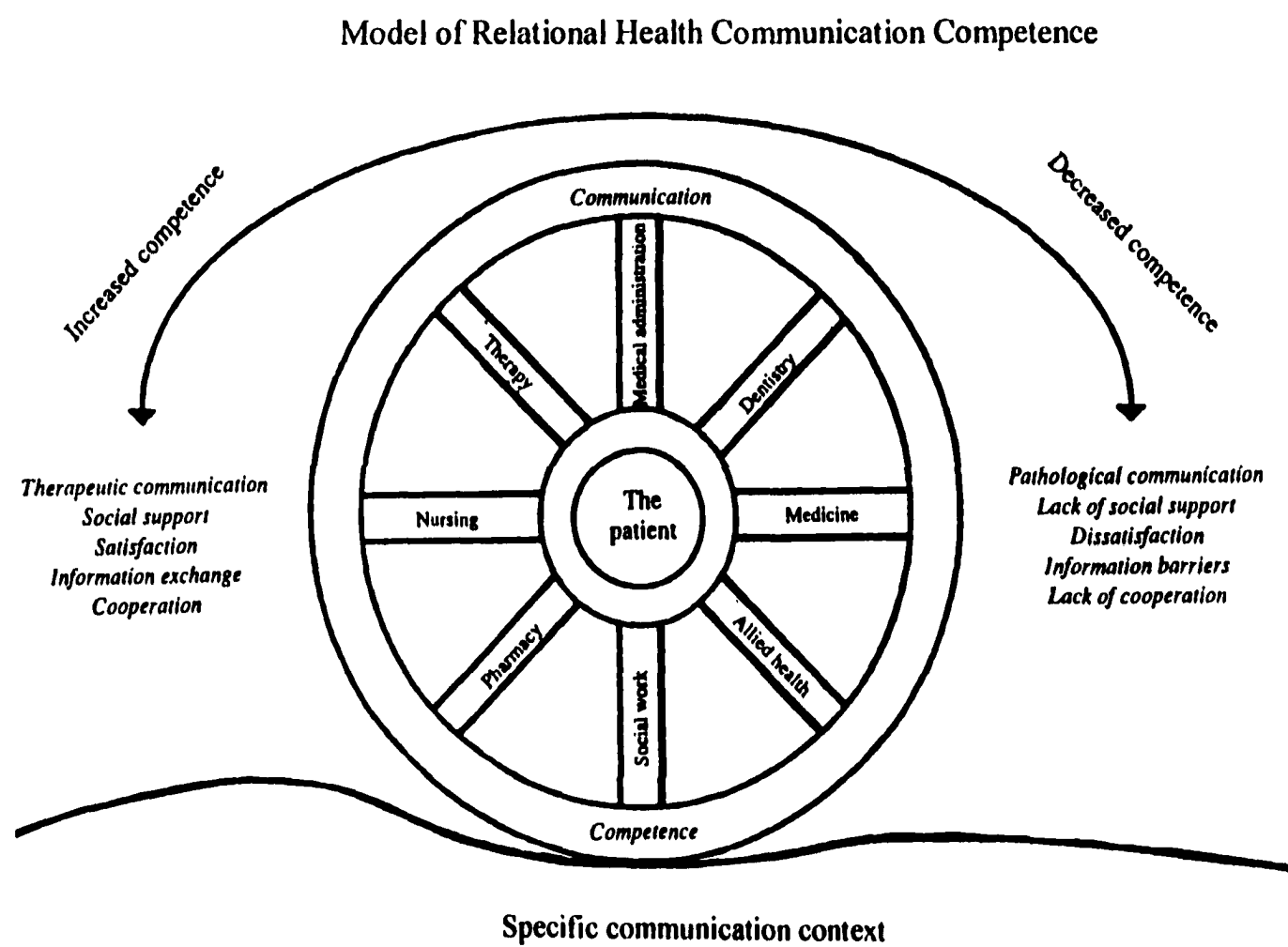


Figure 2. Query and Kreps model of relational health communication competence.

Query and Kreps' (1996) test of the model indicated that a caregiver's competence in communication was positively related to psychological health outcomes such as high levels of social support and low levels of cognitive depression (p. 335).

From a communication standpoint, research studies infused with phraseology such as varying viewpoints, perception differences, needs for increased dialogue, differing value systems, language barriers and cultural clashes, indicated a subject area fraught with challenges. On an intrapersonal level, for example, a lay caregiver's own perceived communication competence affected a patient's health outcome. Challenges abounded on an interpersonal level within the medical profession and among health care providers, patients themselves, and their families. In terms of mass communications, the stigma associated with mental illness combined with a lack of understanding of Alzheimer's disease and other dementias, presented major challenges for lay caregivers dealing with health care issues of the aging. It was for these reasons and more that further evaluation was important and necessary.

CHAPTER III

METHODOLOGY

With the assistance of Southern Nevada Alzheimer's Association staff members, an empirical study of lay caregivers was conducted that involved administering a series of survey questions. Surveys and other mailing materials were provided to chapter staff who, in turn, were responsible for survey distribution and their Las Vegas office served as the collection point for completed surveys.

Participants

The participants in this study were lay caregivers of loved ones with Alzheimer's disease. Names and addresses of these individuals were selected at random by the Southern Nevada Chapter of the Alzheimer's Association from their mailing list. Participation was voluntary and survey respondents were provided with written assurance that their identities and individual responses would remain confidential.

A total of 42 subjects participated in the study. The distribution of 200 surveys resulted in a response rate of 21 percent.

In an attempt to effectively gauge the attitudes and behaviors of family members and other lay caregivers who would typically need to seek out health communication information, assisted living facility operators and health care providers were excluded

from this analysis. Alzheimer's Association staff were relied upon to make this determination.

In late 1998, this researcher met with the local chapter's executive director, Phyllis Montavon, regarding the survey of lay caregivers in the community. Several meetings took place in order to develop relevant research questions and to determine the most effective and economical means for distributing the surveys to the appropriate target audience.

In Spring 1999, the proposed survey was presented to the chapter's Executive Board of Directors. A plan was approved that involved commitments on the part of the researcher and chapter staff. This researcher provided surveys and associated mailing materials to the chapter, compiled statistical data, and prepared a summary of survey findings for the chapter's use. The chapter absorbed costs associated with mailing the surveys and handled survey distribution and collection.

Apparatus

An anonymous mail out survey was used to collect data (see Appendix B). The four page survey posed a total of 27 questions with respondents asked to mark the most appropriate response in the majority of instances.

The survey consisted of two parts. The first part asked 24 questions regarding the caregiver's relationship to the Alzheimer's patient, his or her role as caregiver, and a series of questions regarding the caregiver's attitude towards available communication resources. Some questions provided space for additional caregiver comments. A few questions asked respondents to rank items on a Likert scale. For example, in questions

18 through 20. respondents rated statements on a four-point scale ranging from 1 as “Very Satisfied” to 4 as “Very Dissatisfied.”

The second part of the survey, questions 24 through 27, assessed the respondents’ demographic make up as far as gender, age range, marital status and education.

Although subjects were asked to respond to 27 questions, the survey in actuality expanded to include 50 response fields for scoring purposes. Ordinal questions, such as question 1, were assigned a value of 1 for a “Yes” response and a value of 2 for a “No” response.

The structure of some questions, question 2 for example, required adding variable strings to accommodate multiple responses. A total of 11 different familial relationships were listed and these were assigned values that ranged from 1 for “Spouse or significant other” through 11 for “Grandfather.” Separate fields were added for “Other family member” and “None of these” options to accommodate a respondent’s written comments.

Single questions requesting multiple responses were handled as a series of ordinal questions. For example, question 10 offered five choices the respondent could mark concerning who regularly helped with care. For scoring purposes, these five choice options were treated as five separate questions. If the subject marked “You alone,” a value of 1 was assigned and if this was not marked, a 2 was assigned. Again, to accommodate the “Other family member” and “None of these” options, separate fields were created.

For the most part, if subjects did not answer a question, a value of 9 was entered. Missing answers were assigned a value of 999 in questions that a “9” designation was also a response option. In question 3, so as not to confuse the response year of 1909 with

a 9 associated with the “no response” value, a 999 value was used. When survey respondents marked multiple answers to questions that sought only one answer, a value of 99 was assigned.

Survey Design

The collection of questions used in the survey was selected from three sources. These sources were a study conducted by Yankelovich Partners, Inc. for the Alzheimer’s Association (Warrick, 1996), a study of Toronto, Canada’s elderly population by Saldov and Chow (1994), and a communication competence study by Query and Kreps (1996). To conduct this communications assessment and to develop a profile of lay caregivers dealing with health care issues of the aging, these particular questions were chosen because of their timeliness and relevance towards meeting the thesis objective.

The original survey that was prepared for this assessment underwent a series of modifications and adaptations and ultimately resulted in a 27-item version. Creation of a shorter, more focused survey meant excluding items not specifically related to the objective. Therefore, questions in the aforementioned studies that were geared towards dietary, psychological, social, recreational and physical factors were not incorporated into the survey.

Survey length and appearance were critical factors. To avoid the perception of too much information being asked, which might result in a caregiver opting not to respond, the number of survey questions was pared down. To ensure that lettering was large enough to be easily read by elder respondents, the survey was prepared in 12 point

Arial font. Effort was also made to format questions with effective use of blank (or white) space so that there were not so many words as to be intimidating on the pages.

Surveys were printed on lilac colored paper stock to tie in with the purple theme color typically associated with and imprinted on all national and local Alzheimer's Association materials. This was done to draw attention to the survey when the envelope was opened and was also a subtle way to lend credibility and legitimacy to this request to divulge personal information.

Procedure

Permission was granted by Dr. William E. Schulze, Director of the Office of Sponsored Programs at the University of Nevada, Las Vegas, to conduct this human subjects research (see Appendix C).

Permission was also received from Phyllis Montavon of the Southern Nevada Chapter of the Alzheimer's Association, to assist with survey distribution.

The survey population was defined as individuals who had contacted the local Alzheimer's Association at some time and were included on their current mailing list. Using the chapter's newsletter mailing list of approximately 2,600 entries, a systematic sampling of 200 addresses was extracted in order to target appropriate survey recipients. To ensure confidentiality, Alzheimer's Association staff handled the random selection process and mailed surveys to lay caregivers throughout Las Vegas, North Las Vegas, Henderson, Boulder City, Pahrump and Caliente, Nevada.

Each mail piece contained a questionnaire, a letter of support from the local Alzheimer's Association chapter, a letter of informed consent from the University of

Nevada, Las Vegas, and a stamped self-addressed envelope. Again, to lend credibility to this request for survey participation, the return envelopes were addressed to the chapter office. Upon completion of the study, survey data entry and statistical analysis was performed via the Statistical Package for the Social Sciences (SPSS) 9.0 program on the University of Nevada at Las Vegas mainframe computer.

CHAPTER IV

RESULTS

Surveys were collected for the period of mid-June to mid-August 1999 and yielded 42 usable questionnaires. A total of three returned, unopened survey envelopes were also received.

The researcher will first report the demographics of the sample of Southern Nevada's lay caregivers that responded to the survey (see Table 1).

Of the 42 survey respondents, 76.2% (32) were female, 21.4% (9) were male and 2.4% (1) person did not answer the question.

Most respondents, 35.7% (15), were between the ages of 52 and 60; 21.4% (9) were between the ages of 70 and 78; 19.0% (8) were between the ages of 61 and 69; 9.5% (4) were 79 years and older; 7.1% (3) were between the ages of 34 and 42; and another 7.1% (3) were between the ages of 43 and 51. No respondents under the age of 34.

The results for marital status indicated that most respondents were married 52.4% (22); 19.0% (8) were divorced; 11.9% (5) were widowed; 7.1% (3) were single; another 7.1% (3) did not answer the question and 2.4% (1) responded with more than one answer.

In regard to education, most respondents, 40.5% (17), had done some college coursework; 31.0% (13) graduated high school; 11.9% (5) were college graduates; 4.8%

(2) had done some graduate coursework; another 4.8% (2) held graduate degrees; and 2.4% (1) had some high school. 4.8% (2) responded with more than one answer.

Comparative Analysis

Comparative analyses were performed in three areas. The first analysis sought to determine if there were differences between the perceived intensity level of Alzheimer's patient symptoms (dependent variable "symptoms") and patient caregiver groups ($F=1.18$, $df=7,29$, $p>.05$). No significant statistical differences were found (see Table 2).

The second analysis sought to determine if there were differences between perceived intensity level of Alzheimer's patient symptoms (dependent variable "symptoms") and caregiver age groups ($F=1.25$, $df=5, 31$, $p>.05$). No significant statistical differences were found (see Table 3).

In the third analysis, the Pearson correlation coefficient was used to determine if there was a relationship between caregiver perceptions of their own communication competence and their rating of the overall effectiveness of community agencies in providing information to caregivers (see Table 4 and Table 5). The result of this analysis indicated a moderate strength relationship between caregiver communication competence and agency effectiveness in providing information ($r=0.598$, $p<.001$).

In addition to these correlational analyses, survey respondents provided insights, in a very practical sense, as far as the challenges faced by today's lay caregivers.

Of those answering this survey, most, 71.4% (30), were primary caregivers to someone who suffered from Alzheimer's disease whereas 28.6% (12) were not.

The majority of respondents, 33.3% (14), were caring for their mother. The second most frequent relationship indicated was the 23.8% (10) who were providing care for a spouse or significant other. Caring for their father was third at 9.5% (4) and another 9.5% (4) listed "other family member" that included uncle and mother-in-law. Care for a brother was 4.8% (2), sister was 2.4% (1), daughter was also 2.4% (1) and another 2.4% (1) respondent did not answer the question. 11.9% (5) marked "none" and indicated responses including godmother and long time friend.

Alzheimer patient birth dates were from 1906 to 1942, indicating that patients ranged in age from 57 to 93. The years 1912, 1915 and 1920 were indicated most frequently with 9.5% (4) responses each. Next was 1923 and 1927, and each year received 7.1% (3) responses. The years 1909, 1916, 1918 and 1919 each received 4.8% (2) responses. Other patient birth years included 1906, 1907, 1910, 1911, 1913, 1917, 1924, 1925, 1926, 1930, 1935, and 1942, at 2.4% (1) response each.

Most lay caregivers 19.0% (8) started caring for a loved one with Alzheimer's disease in 1996. The second most frequent response was the year 1998 at 14.3% (6). The years 1994 and 1995 each were indicated by 9.5% (4) of respondents. Four years, 1990, 1991, 1992 and 1997, each received 4.8% (2) responses, and 2.4% (1) of caregivers started looking after someone in 1984, 1986, 1988 and 1993. A total of 16.7% (7) survey respondents did not answer the question and 2.4% (1) did not know the year. Based on these responses, a caregiver's regimen started as long ago as 1984, to as recently as 1998.

Most Alzheimer's patients, 47.6% (20), lived in the same home as their caregiver. The next most frequent location, 16.7% (7), was a nursing home. Assisted living facilities were the third most frequent residence with 11.9% (5) of the responses. Some

9.5% (4) of Alzheimer's patients lived with a spouse or other family member. 4.8% (2) of the respondents marked "other" as a response and another 4.8% (2) did not answer the question; 2.4% (1) indicated the patient lived by him or herself and another 2.4% (1) marked multiple answers. Those who marked "other" indicated their loved ones lived either in an Alzheimer care facility or in a group home with other Alzheimer patients.

Most respondents, 37.5% (15), spent more than 35 hours a week as a caregiver. The second most frequent response, 21.4% (9), indicated their loved one was in a nursing home. 9.5% (4) of caregivers spent four hours or less providing care and another 9.5% (4) did not answer the question. 7.1% (3) of respondents spent 31 to 35 hours, and another 7.1% (3) indicated their loved one had passed away. 4.8% (2) of respondents spent 5 to 9 hours a week providing care, 2.4% (1) spent 10 to 15 hours and another 2.4% (1) respondent spent 21 to 25 hours providing care.

Most caregivers, 57.2% (24), indicated that the Alzheimer's patient did not live with them prior to the diagnosis, whereas 38.1% (16) said the patient did, and 4.8% (2) did not answer this question.

Most caregivers, 37.5% (15), first observed Alzheimer's or dementia symptoms in their loved one 5 to 7 years earlier. A total of 23.8% (10) of respondents first observed symptoms 8 to 10 years prior. 16.5% (7) first observed symptoms 2 to 4 years ago, and 9.5% (4) made these first observations a year ago or less. 7.1% (3) of caregivers observed symptoms 11 or more years earlier and another 7.1% (3) did not answer the question.

Most caregivers, 38.1% (16), considered symptoms presently displayed by the person receiving their care or care in a nursing home, as "somewhat difficult." The

second most frequent response was “severe,” as indicated by 26.2% (11) of respondents. Another 11.9% (5) rated current symptoms as “mild,” 9.5% (4) indicated “very severe.” and 2.4% (1) rated symptoms “very mild.” 7.1% (3) did not answer the question and 4.8% (2) marked multiple answers.

Survey respondents were asked to identify who regularly helped care for the loved one. To “you alone,” most respondents, 52.4% (22), left this option blank which indicated they were not the sole caregiver, whereas 33.3% (14) indicated that they were. To “friend or neighbor,” most respondents 83.3% (35) left this option blank indicating that a friend or neighbor did not help care for the Alzheimer’s patient, whereas 2.4% (1) indicated they did. To “volunteer,” most respondents, 83.3% (35), left this blank indicating that a volunteer did not help with care, whereas 2.4% (1) indicated they did. To “paid individual,” most respondents, 73.8% (31), left this choice blank which indicated that a paid person did not help with care, although 11.9% (5) indicated they did. To “professional home health care,” most respondents, 71.4% (30), left this option blank which indicated that a professional home health care worker did not help with care, although 14.3% (6) indicated they did. A total of 14.3% (6) of survey respondents selected none of these options.

In response to “other family member” helping with care, most respondents, 52.4% (22), did not choose this as an option, although 47.6% (20) did. The most frequent responses at 7.1% (3) each were “wife” and “son and daughter.” The second most frequent responses were “daughter” and “husband” each with 4.8% (2) of responses. Other relationships receiving 2.4% (1) responses each were “brother and sister,” “daughter, husband and grandchildren,” “granddaughter,” “grandson and great

grandson," "mother-in-law," "caregiver's mother," "niece," "sister," "son-in-law" and "son, granddaughter and grandson."

Some caregivers, 23.8% (10), indicated that "someone else," helped with care. These caregivers identified adult day care, day care at assisted living facilities, husbands, sons-in-law, significant others and nursing homes, as resources they called on for help with patient care.

When asked about work schedule changes, most survey respondents 42.9% (18) indicated the question was not applicable. A total of 33.3% (14) of caregivers did have to change their work schedule, whereas 19.0% (8) did not, and 4.8% (2) did not answer the question.

Of caregivers who made work schedule changes, most indicated they quit working. Others cut back on the number of hours they worked or took early retirement. One caregiver took an extended leave from work, another stopped taking out of town assignments, and yet another long distance caregiver made many trips between their home and their loved one's residence.

When caregivers were asked how they first learned of the Alzheimer's Association, most respondents, 21.4% (9), marked the "other" category and 19.0% (8) marked multiple answers. The telephone book and professional health care workers were the sources most caregivers, 9.5% (4), consulted to first learn of the Alzheimer's Association. Other initial information sources were physicians, the American Association of Retired Persons (AARP), and national or local newspapers, with each of these responses indicated by 7.1% (3) of caregivers. Some 4.8% (2) of respondents each indicated that a friend or neighbor and a neighborhood newsletter, were the sources they

used to first learn about the Alzheimer's Association. Radio, magazines and the internet were used by 2.4% (1) of respondents. Another 2.4% (1) did not answer the question. None of the respondents marked the response options of clergy, co-worker, television, or law enforcement, as a first source of information. Some who marked "other" in response to this question indicated they first learned of the Alzheimer's Association via a family member who had Alzheimer's disease. Other responses were family, friends, research, senior citizen fairs, support groups, undergraduate studies in gerontology, and owner of an Alzheimer's home.

Most respondents, 73.8% (31), contacted the Alzheimer's Association after their loved one was diagnosed with Alzheimer's disease, whereas 19.0% (8) contacted the association prior to being diagnosed and a total of 7.1% (3) of respondents did not answer the question.

Most respondents, 64.3% (27), did not attend support group meetings although 33.3% (14) did, and 2.4% (1) did not answer the question.

Survey respondents were asked to identify the communications sources they rely on to keep informed regarding Alzheimer's disease. Most respondents, 92.9% (39), relied on the "Alzheimer's Association newsletter" to stay informed while the remaining 7.1% (3) did not. Most respondents, 59.5% (25), did not rely on "physicians" for information although 40.5% (17) of respondents did. Most respondents, 73.8% (31), did not rely on support groups for information, however 26.2% (11) did. Most respondents, 57.1% (24), did not rely on medical journals or health magazine, although 42.9% (18) did. Most respondents, 76.2% (32), did not rely on general interest magazines, however 23.8% (10) did. Most respondents, 78.6% (33), did not rely on national newspapers,

although 21.4% (9) did. Most respondents, 61.9% (26), did not rely on local newspapers, however 38.1% (16) did. Most respondents, 54.8% (23), did not rely on television for information, however 45.2% (19) did. Most respondents, 90.5% (38), did not rely on radio as a source for Alzheimer's information although 9.5% (4) did. Most respondents, 90.5% (38), did not rely on their pharmacist or pharmaceutical company literature for information, however 9.5% (4) did. Most respondents, 76.2% (32), relied neither on the internet or the American Association of Retired Persons (AARP) for information, although 23.8% (10) relied on both these sources. Most respondents, 57.1% (24), did not rely on the local Alzheimer's Association chapter for information, however 42.9% (18) did. One respondent identified the Veterans Administration as an information source.

Based on these responses, the Alzheimer's Association newsletter was the most relied upon source for information, which was followed by television. Tying for third source were medical journals and health magazines, and the local Alzheimer's Association chapter. Physicians ranked fourth, with local newspapers at fifth and support groups sixth. At seventh in the rankings were the internet, AARP and general interest magazines; with national newspapers at eighth. Caregivers indicated radio, pharmacists and materials provided by pharmaceutical companies as least relied on for information.

When caregivers were asked what one source they relied on most often for information, most respondents, 40.5% (17), indicated the Alzheimer's Association newsletter. Then, in descending order, the most relied on information sources were support groups at 16.7% (7), physicians with 9.5% (4), and the Alzheimer's Association and local Alzheimer's chapter at 7.2% (3) responses each. The internet, medical journals

and television were indicated by 4.8% (2) of responses. Least relied on was the AARP at 2.4% (1) of responses and another 2.4% (1) did not answer the question.

From 36 responses most caregivers, 55.6% (20), indicated they were somewhat satisfied with the kinds of information available within the community to help them make caregiving decisions and 25.0% (9) were very satisfied. In contrast, 13.9% (5), were somewhat dissatisfied and 5.6% (2) were very dissatisfied.

From 35 caregivers responding most, 57.1% (20), indicated they were somewhat satisfied with the accuracy of information available within the community and 20.0% (7) were very satisfied. Another 20.0% (7) were somewhat dissatisfied and 2.9% (1) were very dissatisfied.

From 36 responses most caregivers, 61.1% (22), were somewhat satisfied with the availability of information within the community to locate needed services and 11.1% (4) were very satisfied. Some 19.4% (7) respondents were somewhat dissatisfied and 8.3% (3) were very dissatisfied.

When evaluating a caregiver's own communication skills, most respondents, 54.5% (18) considered themselves somewhat effective in communicating, whereas 21.2% (7) rated themselves as very effective communicators, 15.2% (5) felt they were somewhat ineffective and 9.1% (3) were of the opinion that they were very ineffective. A total of 33 individuals responded to this question.

A total of 39 caregivers indicated the single service that they felt would help them the most in taking care of their loved one. Adult day care was identified by most respondents, at 15.4% (6). Other responses, in descending order, were financial assistance at 10.3% (4) and a day off at 10.3% (4), temporary nursing home/respice care

at 7.7% (3) and housekeeping assistance/help with chores at 7.7% (3). home health care at 5.1% (2), Alzheimer's disease information at 5.1% (2), and latest developments and treatments at 5.1% (2), legal assistance at 2.6% (1), financial advice at 2.6% (1), support groups at 2.6% (1), information on how to provide better care at 2.6% (1), an information hotline/800 number at 2.6% (1) , and someone to talk to at 2.6% (1). Some 10.3% (4) of respondents indicated other services including doctors who can detect and test the caregiver, more caregiver assistance, physicians specializing in Alzheimer's, and social services to plan for future. Some 7.7% (3) did not answer the question.

When rating the overall effectiveness of community agencies in providing information to caregivers, most respondents, 47.2% (17), rated them as "fair," 44.4% (16) rated the agencies as "good," 5.6% (2) rated them "excellent" and 2.8% (1) rated them as "poor."

A total of three comparative analyses were performed. The first analysis found no significant difference in caregiver perception of a patient's symptoms based on the caregiver's relationship to the patient. The second analysis found no significant difference in caregiver perception of a patient's symptoms based on the age range of the caregiver. The third analysis focused on caregivers' ratings of their own communication competence in relation to their ratings of the effectiveness of agencies in providing information for caregivers, and this test indicated a moderate strength relationship (see Table 4).

CHAPTER V

DISCUSSION

This final chapter should further explain the results found in this current study, the limitations, and the need for future research.

This recent survey of Southern Nevada's lay caregivers was consistent, in many ways, with the findings of the previously cited studies of Susan Levine and Kate Warrick.

Of the survey's 42 respondents, 76.2 percent were female and 21.4 percent were male. This information corresponded with Levine's study which indicated that women were the caregivers nearly three-quarters of the time and Warrick's study that stated 81% of caregivers were women.

This study indicated that most caregivers were between the ages of 52 and 60. Warrick's study indicated that, on average, caregivers were in their mid-fifties.

Some 33.3 percent of caregivers in Southern Nevada were caring for a parent, in this case, their mother, or for a spouse (23.8%). Likewise, the Warrick study indicated that most caregivers were caring for a parent or spouse.

Nearly half of all local caregivers, 47.6 percent, lived in the same residence as their loved ones, making theirs a 24-hour a day job. Warrick's study also stated that half of all caregivers lived in the same residence.

With regard to work schedules, 33.3 percent of respondents to this survey indicated they had to make changes and many quit working or took an early retirement. Warrick reported some 36 percent of caregivers reduced their work hours and again, 36 percent reported a loss of income. The Levine study also indicated that some caregivers quit or took early retirement to meet caregiving demands.

Warrick's study cited Alzheimer's Association newsletters and physicians as the primary sources of information for caregivers. Southern Nevada's caregivers identified Alzheimer's Association newsletters as the source they relied on most often for information as well, however, their second most frequent source was support groups, with physicians ranked third.

Comparative analysis determined no statistical difference as far as the caregiver's relationship to the Alzheimer's patient and the caregiver's perception of symptom severity if, for example, a son or daughter rated symptoms differently than a spouse or significant other. The n size for all groups was small, yet the analysis revealed that "daughters" evaluated their Alzheimer's patient's symptoms as "most severe" ($\bar{x} = 4.00, 1$).

A comparative analysis was also performed to determine if a caregiver's age range impacted the caregiver's perception of symptom severity if, for example, "younger" caregivers rated symptoms differently than their more senior counterparts. No statistical difference was indicated. Again, the n size for all groups was small, yet the analysis indicated caregivers between the ages of 61 and 69 evaluated Alzheimer's patient's symptoms as "most severe" ($\bar{x} = 4.20, 5$).

Parallels were also drawn in regard to the Query and Kreps Relational Health Communication Competence Model that suggested a caregiver's level of communication competence was positively related to their achieving desired physiological and psychological health outcomes (1996). This survey found evidence in support of Query and Kreps findings. A moderate strength relationship existed between caregiver responses in regard to perception of their own communication competence and their rating of the overall effectiveness of Southern Nevada's community agencies in providing information to caregivers.

It became apparent that lay caregivers could be more effective advocates for their loved ones if they had an increased level of understanding. It appeared that caregivers could resolve this communication problem by learning the language of healthcare professionals. By knowing the proper terminology, caregivers could pose the right questions to the appropriate agencies.

Implications

Research indicated that people are living longer, according to The World Almanac and Book of Facts (1992, p. 956). A person born in 1940 was expected to live, on average, to the age of 62.9 and, decade by decade, the trend was for life expectancy to continue to get longer. People born in 1970 were expected to live to age 70.8 and those born in 1980 were expected to live 73.7 years.

Longer life expectancy was typical of countries around the world. The Las Vegas Review Journal compared population percentages of people aged 65 and older in the year 1975, with estimates for the year 2025. Australia's graying population made up nine

percent in 1975 and was predicted to increase to 17 percent in 2025. Japan, with an eight percent elder population in 1975, was expected to jump to 24 percent in 2025, and the United States was anticipated to rise from 11 percent to 19 percent (1999, p. 1D).

With people living longer, there was a strong likelihood that more and more of them would suffer from dementing illnesses. The Alzheimer's Association estimated that some 14 million adults will have Alzheimer's disease by the year 2050.

In addition to increased longevity, the make up of America's family unit has changed. Couples who have had fewer children meant smaller families and fewer family members to shoulder the caregiving burden. Childless couples brought about concerns as far as who would care for this growing sector of the aging population. With couples opting to start families later in life, the caregiving role would, most likely, be placed on younger caregivers.

While studies indicated that today's average caregiver is in her mid-fifties, perhaps tomorrow's caregiver will be younger. As one of the youngest members of a support group at age 44, this researcher was at mid-career and unwilling to alter that position. If faced with these same choices a decade from now, the caregiving decisions might have been different.

Conclusions

This survey served as a first step in measuring the effectiveness of health communication resources available in Southern Nevada. For the most part, survey respondents gave community agencies satisfactory ratings as far as their effectiveness in

providing information to caregivers of individuals with Alzheimer's disease. There was, however, room for improvement.

Survey respondents indicated a wide and diverse range of information sources that they used. Caregivers sought out physicians, professional health care workers and pharmacists when they needed information. They looked through telephone books, newspapers, and neighborhood newsletters. They conducted internet searches. They contacted the American Association of Retired Persons and the Veterans Administration. They relied on undergraduate studies in gerontology. They also learned about Alzheimer's disease through friends and through senior citizen fairs. They did not learn about caregiving from law enforcement, co-workers, or the clergy. From a communications standpoint, these sources provided a host of opportunities for local agencies to expand their outreach efforts.

This author concluded that no real "How To" guide existed for a family member who started noticing, with more and more frequency, that a loved one was engaged in atypical behavior to the point that family member intervention became necessary. Seeking to answer the question of "What's wrong with Mom?" this author found little information to guide lay caregivers in their quest to identify the problem or problems in order to determine appropriate solutions or choices affecting the safety, finances, and possibly the health outcome of the person in need.

"No one comes knocking on your door to tell you what to do," said one support group participant who worked full time and shared responsibility with her sister in making decisions for their mother.

“It’s hard any time, but it’s really hard at first. You don’t know what to do.” said another in the group, who just placed her husband in a nearby nursing home.

Many respondents to this survey indicated that they were glad to be asked these questions and to share their experiences as a way to help others. One gentleman expressed fears that he, too, might suffer the Alzheimer’s fate, as did his brother.

It was concluded that health care issues of the elderly are not going away and, if anything, they will increase in importance in the years to come. In an attempt to eliminate some of the uncertainty associated with dementing illness, with family member caregiving, and with local resources, this researcher created a directory of information called Elder Care Guide to Southern Nevada’s Community Resources (see Appendix D). The intent was to provide a useful booklet that has practical application for the lay caregiver. This resulting guide represented a first edition of what could become a living document, expanding and evolving over time. A glossary of terms common to the medical and legal professions, and to government bureaucracy, was also compiled by the author, to further assist lay caregivers (see Appendix E).

It was hoped that this research would serve as an effective, relevant communication tool to help lay caregivers move away from that vast gray area of uncertainty, so that they could work towards a beginning plan for their future and the futures of their loved ones.

Limitations

Survey results collected from a segment of the public who had, at some point, contacted the Southern Nevada Chapter of the Alzheimer’s Association did not

necessarily speak for the community as a whole. The mere fact that someone was able to locate this resource while moving through the decision making process indicated that caregivers were able to seek out information they needed.

A survey response rate of 42 out of 200 surveys distributed, or 21 percent, is limiting and did not represent the entire caregiver population in Southern Nevada.

The focus of this survey was to evaluate caregivers of elderly individuals suffering from dementing illness and did not make reference to the myriad of other illnesses, mental or physical, that someone might experience.

This survey told little about others in the community whose aging loved ones may be living alone, and may be engaged in self neglect or acting out in behaviors that may have the potential to cause harm to themselves or to others.

This communication assessment was conducted to get a practical sense of what was happening now and as this study is being conducted at one point in time, the conclusions could be challenged in such a dynamic environment.

Nonetheless the evaluation served as a first step towards understanding and helping family members to make informed choices for their loved ones through accurate, effective, and accessible communication resources.

Future Research

This study showed that caregivers who have contacted the Southern Nevada Chapter of the Alzheimer's Association were satisfied with the information they received concerning community resources, yet there remains the challenge of providing information to those caregivers who are still seeking out these resources. Evidence based

on this evaluation indicated that the key to disseminating information was the Southern Nevada Chapter of the Alzheimer's Association. As a community resource, the chapter had the capability to expand this survey to include their entire membership and had the potential to serve as a clearing house to disseminate pertinent information to its members and to the public at large. While the group is still in the early stages of developing its communication strategies, staff have embarked on developing a public outreach program (see Appendix F).

Other issues for future analysis as a result of this study included the following:

- Research breakthroughs could bring about changes or delays in the onset of dementing illnesses.
- Changes in legislation may help or hinder caregiving in years to come.
- Technological changes may result in increased awareness of elder care issues which could, for example, take the form of national and local campaigns to publicize seminars on dementia via the internet and via teleconferences.
- The makeup of tomorrow's caregiver differ considerably from that of today's.
- Southern Nevada is one of the fastest growing areas in the United States. Out of necessity, more social service resources may become available to increase outreach efforts regarding elder care health issues.
- A Kaiser Foundation study shows that, by the year 2025, the number of Nevadans, age 65 and older, will increase by nearly 21 percent and that the Silver State will move from 39th to 15th highest in the nation for the percentage of seniors in its population (1999, p. 4B).

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APPENDIX A

TABLES

Table 1 Demographics of lay caregiver survey respondents in Southern Nevada

What is your gender?

Male	21.4 percent (9)
Female	76.2 percent (32)
No Answer	2.4 percent (1)

What is your age?

16 – 24	0
25 – 33	0
34 – 42	7.1 percent (3)
43 – 51	7.1 percent (3)
52 – 60	35.7 percent (15)
61 – 69	19.0 percent (8)
70 – 78	21.4 percent (9)
79 and over	9.5 percent (4)

Are you?

Married	52.4 percent (22)
Divorced	19.0 percent (8)
Widowed	11.9 percent (5)
Single	7.1 percent (3)
No answer	7.1 percent (3)
More than 1 answer	2.4 percent (1)

Which statement best describes your educational training?

Some Elementary School	0
8th Grade Graduate	0
Some High School	2.4 percent (1)
High School Graduate	31.0 percent (13)
Some College	40.5 percent (17)
College Graduate	11.9 percent (5)
Some Graduate College	4.8 percent (2)
Graduate Degree Holder	4.8 percent (2)
More than 1 answer	4.8 percent (2)

Table 2 Perception of patient symptoms by patient caregiver group

Symptoms displayed by the person receiving your care or the care of a nursing home are:

Very Mild	2.4 percent (1)
Mild	11.9 percent (5)
Somewhat Difficult	38.1 percent (16)
Severe	26.2 percent (11)
Very Severe	9.5 percent (4)
No Answer	7.1 percent (3)
Multiple Answers	4.8 percent (2)

What is your Alzheimer's patient's relationship to you?

Spouse or Significant Other	23.8 percent (10)
Father	9.5 percent (4)
Mother	33.3 percent (14)
Brother	4.8 percent (2)
Sister	2.4 percent (1)
Daughter	2.4 percent (1)
Other family member	9.5 percent (4)
None of these	11.9 percent (5)
No answer	2.4 percent (1)

Table 3 Perception of patient symptoms by caregiver age group

Symptoms displayed by the person receiving your care or the care of a nursing home are:

Very Mild	2.4 percent (1)
Mild	11.9 percent (5)
Somewhat Difficult	38.1 percent (16)
Severe	26.2 percent (11)
Very Severe	9.5 percent (4)
No Answer	7.1 percent (3)
Multiple Answers	4.8 percent (2)

What is your age?

16 – 24	0
25 – 33	0
34 – 42	7.1 percent (3)
43 – 51	7.1 percent (3)
52 – 60	35.7 percent (15)
61 – 69	19.0 percent (8)
70 – 78	21.4 percent (9)
79 and over	9.5 percent (4)

Table 4 **Pearson Correlations Between Caregiver Communication Competence and their Rating of Community Agencies**

		Communicate Effectively	Overall Rating of Community Agencies
Communicate Effectively	Pearson Correlation	1.000	.598*
	Sig. (2-tailed)	.	.000
	N	33	33
Overall Rating of Community Agencies	Pearson Correlation	.598*	1.000
	Sig. (2-tailed)	.000	.
	N	33	36

* Correlation is significant at the .001 level

Table 5 Pearson Correlations Between Caregiver Communication Competence and their Rating of Community Agencies

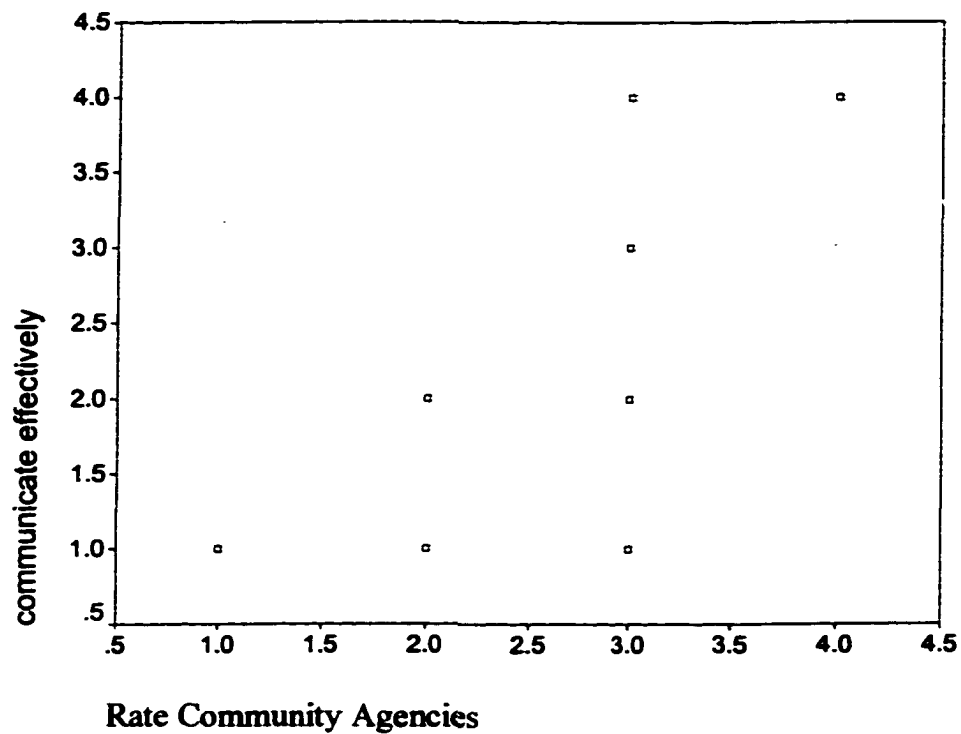


Table 6 Question Number and Variable Levels

Question 1 – “care”	Question 20 – “change work”
Question 2 – “relationship”	Question 21 – “how changed”
Question 3 – “other relation family”	Question 22 – “learn”
Question 4 – “other relation none”	Question 23 – “learn other”
Question 5 – “birth”	Question 24 – “contact”
Question 6 – “start”	Question 25 – “attend”
Question 7 – “reside”	Question 26 – “info. Alzheimers newsletter”
Question 8 – “other reside”	Question 27 – “information physician”
Question 9 – “hours”	Question 28 – “information support grps”
Question 10 – “diagnosis”	Question 29 – “info. medical journals”
Question 11 – “observe”	Question 30 – “info. general interest mag.”
Question 12 – “symptoms”	Question 31 – “info. national newspaper”
Question 13 – “care you”	Question 32 – “info. local newspapers”
Question 14 – “care friend”	Question 33 – “information television”
Question 15 – “care volunteer”	Question 34 – “information radio”
Question 16 – “care paid”	Question 35 – “information pharmacist”
Question 17 – “care professional”	Question 36 – “information internet”
Question 18 – “care other”	Question 37 – “information AARP”
Question 19 – “care someone else”	Question 38 – “info. local Alzheimer’s”

Question 39 – “information other”

Question 40 – “most rely”

Question 41 – “satisfy”

Question 42 – “accuracy”

Question 43 – “locate”

Question 44 – “effective”

Question 45 – “single service”

Question 46 – “service other”

Question 47 – “overall”

Question 48 – “gender”

Question 49 – “age”

Question 50 – “marital”

Question 51 – “educate”

APPENDIX B

INFORMED CONSENT, SURVEY AND LETTER TO PARTICIPANTS



**University of Nevada, Las Vegas
Hank Greenspun School of Communication**

Informed Consent

I am Debby Hauth, a graduate student in the Hank Greenspun School of Communication at the University of Nevada, Las Vegas.

I would like you to participate in a research project to learn more about people in the community who provide care for family members with Alzheimer's disease. The accompanying survey will take approximately ten minutes of time to complete.

There are no foreseen risks involved in this research. By participating, you will be adding to the general body of knowledge on this subject.

This questionnaire is anonymous. Your answers will be kept completely confidential. Results will be compiled in a statistical report format. You will not be compensated in any way for your participation.

If you have any questions regarding this research, please contact Debby Hauth or Dr. Anthony Ferri at the UNLV Hank Greenspun School of Communication at (702) 895-1371. For questions involving the rights of research subjects, please contact the UNLV Office of Sponsored Programs at (702) 895-1357.

Your participation is strictly voluntary and you may withdraw from participation at any time.

Thank you for your participation.

**Greenspun College of Urban Affairs
Hank Greenspun School of Communication
4505 Maryland Parkway • Box 455007 • Las Vegas, Nevada 89154-5007
(702) 895-3325 • FAX (702) 895-4805**

CAREGIVER QUESTIONNAIRE

I am a graduate student at the University of Nevada, Las Vegas and I am conducting a survey among people who provide care for family members with Alzheimer's disease. Please be assured that I am not selling anything, nor will you be asked to make a donation. Your opinions are extremely important and I would like to include them in my study. Please fill out and return your survey in the postage paid envelope. Please do not place your name on this survey. Your responses will remain confidential.

Instructions: Mark the appropriate choice or write in your responses as needed.

1. Are you the primary caregiver to a person who suffers from Alzheimer's disease? That is, do you regularly provide care or make decisions about the care of a patient with Alzheimer's disease?

Yes No

2. What is your Alzheimer's patient's relationship to you? (mark one answer).

<input type="checkbox"/> Spouse or Significant Other	<input type="checkbox"/> Son-in-law
<input type="checkbox"/> Father	<input type="checkbox"/> Daughter-in-law
<input type="checkbox"/> Mother	<input type="checkbox"/> Grandmother
<input type="checkbox"/> Brother	<input type="checkbox"/> Grandfather
<input type="checkbox"/> Sister	<input type="checkbox"/> Other family member (specify)
<input type="checkbox"/> Son	
<input type="checkbox"/> Daughter	<input type="checkbox"/> None of these (specify)

3. In what year was your Alzheimer's patient born? Please record exact year or your best estimate. 19 ____

4. In what year did you personally start caring for your Alzheimer's patient? Please enter a year. Do not enter a range.

19 ____ Don't know

5. Does your loved one reside . . . (Please mark one answer).

<input type="checkbox"/> By him or herself	<input type="checkbox"/> In an assisted living facility
<input type="checkbox"/> In the same home as you	<input type="checkbox"/> In a nursing home
<input type="checkbox"/> With his spouse or other family member	<input type="checkbox"/> Other (specify)
<input type="checkbox"/> With friend or neighbor	

6. About how many hours a week do you provide care?

<input type="checkbox"/> 4 hours or less	<input type="checkbox"/> 26 to 30 hours
<input type="checkbox"/> 5 to 9 hours	<input type="checkbox"/> 31 to 35 hours
<input type="checkbox"/> 10 to 15 hours	<input type="checkbox"/> More than 35 hours
<input type="checkbox"/> 16 to 20 hours	<input type="checkbox"/> My loved one is in a nursing home.
<input type="checkbox"/> 21 to 25 hours	<input type="checkbox"/> My loved one has passed away.

7. Before the diagnosis, did your loved one with Alzheimer's disease live with you? Yes No

8. About when did you first observe the symptoms of Alzheimer's or dementia in your loved one?

- a year ago or less 8 to 10 years ago
 2 to 4 years ago 11 or more years ago
 5 to 7 years ago

9. The symptoms presently displayed by the person receiving your care or the care of a nursing home are:

- very mild severe
 mild very severe
 somewhat difficult

10. Who helps care for your loved one on a regular basis? (Mark as many as apply).

- You alone Other family member (specify relation to loved one)
 Friend or neighbor
 Volunteer
 Paid individual Someone else (specify)
 Professional home health care worker

11. Since the symptoms appeared have you had to change your work schedule?

- Yes No Non-applicable

12. If you answered "Yes" to Question 11, please indicate exactly how your schedule has changed. If you answered "No" please go onto Question 13.

13. How did you first learn of the Alzheimer's Association?

- Physician Magazine
 Professional health care worker Newspaper (national or local)
 Pharmacist Telephone Book
 Friend or neighbor Internet or on-line service
 Clergy Neighborhood Newsletter
 Co-Worker Law Enforcement
 Television Other (specify)
 Radio
 American Assoc. Retired Persons (AARP)

14. Did you contact the Alzheimer's Association before or after your loved one was diagnosed? (Please mark only one answer).

- Before After

15. Do you attend Alzheimer's Association support group meetings?

- Yes No

16. On what sources do you rely to keep informed regarding Alzheimer's disease? (Please mark as many as apply).

- Alzheimer's Association Newsletter
 Physician
 Support Groups
 Medical Journals, Health Magazines
 General Interest Magazines such as Time or Newsweek
 National Newspaper
 Local Newspapers
 Television
 Radio
 Pharmacist and materials from pharmaceutical companies
 Internet or an on-line service
 American Association of Retired Persons (AARP)
 Local Alzheimer's Association Chapter
 Other (specify) _____

17. On which one source listed in Question 16, do you rely most often for information? Please specify one item only: _____

18. How satisfied are you with the kinds of information available within the community to help you make decisions as a caregiver?

- very satisfied somewhat dissatisfied
 somewhat satisfied very dissatisfied

19. How satisfied are you with the accuracy of information available within the community to help you make decisions as a caregiver?

- very satisfied somewhat dissatisfied
 somewhat satisfied very dissatisfied

20. How satisfied are you with the information available within the community to help you locate services needed as a caregiver?

- very satisfied somewhat dissatisfied
 somewhat satisfied very dissatisfied

21. How effective do you feel you are in communicating your concerns to representatives of agencies and businesses that work with patients with Alzheimer's disease?

- very effective somewhat ineffective
 somewhat effective very ineffective

22. What is the single service that would help you the most in taking care of your Alzheimer's patient? Please mark **one** answer only.

- Adult day care
- Home health care/visiting nurse
- Temporary nursing home/respice care
- Legal advice
- Legal assistance
- Financial advice
- Financial assistance
- Support groups
- Information on Alzheimer's disease
- Information on how to better care for my loved one
- Information on the latest medical developments/treatments
- Information hotline/800 number
- Housekeeping assistance, help with chores, housework
- Someone to talk to
- A day off
- Other (specify) _____

23. Overall, how would you rate the effectiveness of community agencies in providing information to caregivers of individuals with Alzheimer's disease?

- Excellent
- Good
- Fair
- Poor

24. What is your gender? Male Female

25. What is your age?

<input type="checkbox"/> 16-24	<input type="checkbox"/> 52-60
<input type="checkbox"/> 25-33	<input type="checkbox"/> 61-69
<input type="checkbox"/> 34-42	<input type="checkbox"/> 70-78
<input type="checkbox"/> 43-51	<input type="checkbox"/> 79 and over

26. Are you?

<input type="checkbox"/> Married	<input type="checkbox"/> Widowed
<input type="checkbox"/> Divorced	<input type="checkbox"/> Single

27. Which statement best describes your educational training?

- | | |
|---|---|
| <input type="checkbox"/> Some elementary school | <input type="checkbox"/> Some college |
| <input type="checkbox"/> 8 th grade graduate | <input type="checkbox"/> College graduate |
| <input type="checkbox"/> Some high school | <input type="checkbox"/> Some graduate college |
| <input type="checkbox"/> High school graduate | <input type="checkbox"/> Graduate degree holder |

Comments: _____

THANK YOU VERY MUCH FOR YOUR TIME.



Dear Friends,

A member of our Board of Directors is also a graduate student at the University of Nevada at Las Vegas.

Accompanying this letter is a questionnaire that will help this student with her research project and will also help us learn more about people in the community who provide care for loved ones with Alzheimer's disease.

I encourage you to take a few minutes to complete the survey. For your convenience, a postage-paid return envelope is also enclosed. Please send the survey to: Alzheimer's Association Southern Nevada Chapter, 5190 South Valley View Boulevard, Suite #101, Las Vegas, Nevada 89118.

Surveys will be accepted now through August 15, 1999 and your responses will remain confidential.

Thank you for taking time to fill out the questionnaire. The data collected will help our chapter to better serve your needs.

Sincerely,



Phyllis Montavon
Executive Director

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.

Southern Nevada Chapter • 5190 West Sahara Avenue, Suite A-5, Las Vegas, NV 89102 • Phone (702) 248-2770 • Fax (702) 248-2771

APPENDIX C

CORRESPONDENCE

UNLV

DATE: May 5, 1999

TO: Deborah L. Hauth
School of Communications
M/S 5007

FROM: *W. Green*
Dr. William E. Schulze, Director
Office of Sponsored Programs (X1357)

RE: Status of Human Subject Protocol Entitled:
"Elder Care: an Evaluation of Health Communication
Resources Available to Lay Caregivers in Southern
Nevada"

OSP #381s0599-036e

The protocol for the project referenced above has been reviewed by the Office of Sponsored Programs and it has been determined that it meets the criteria for exemption from full review by the UNLV human subjects Institutional Review Board. This protocol is approved for a period of one year from the date of this notification and work on the project may proceed.

Should the use of human subjects described in this protocol continue beyond a year from the date of this notification, it will be necessary to request an extension.

If you have any questions regarding this information, please contact Marsha Green in the Office of Sponsored Programs at 895-1357.

cc: A. Ferri (CS-5007)
OSP File

Office of Sponsored Programs
4505 Maryland Parkway • Box 451037 • Las Vegas, Nevada 89154-1037
(702) 895-1357 • FAX (702) 895-4242



Eisai Inc.
Glenpointe Centre West
500 Frank W. Burr Blvd.
Teaneck, New Jersey 07666
Telephone: 201 692-9160
Fax: 201 692-9183

March 19, 1998

Debby Hauth
1992 Freeman Court
Henderson, NV 89014

Dear Debby:

I am writing in regards to your request to replicate a survey that was conducted for Eisai & Pfizer and the National Alzheimer's Association in 1996.

It is my understanding that your intent is to administer this same survey to caregivers in Southern Nevada and that your purpose is of an academic nature, as part of the work you are doing in the masters degree program at the University of Nevada, Las Vegas. I also understand that your professors will oversee your efforts to ensure that a high degree of sensitivity, professionalism and confidentiality will be maintained when dealing with human subjects.

I also understand that you are working with the local Alzheimer's Association to seek survey participants and that you plan to share your results with the local chapter director.

I have given you permission verbally and now am giving you written permission to do this same survey in your community.

Sincerely,

A handwritten signature in black ink, appearing to read "Nila Sciretta", written in a cursive style.

Nila Sciretta
Manager
Public and Professional Relations

NS/ym

APPENDIX E
GLOSSARY OF TERMS

**ELDER CARE GUIDE TO SOUTHERN NEVADA'S
COMMUNITY RESOURCES**

(All phone numbers are for area code 702 unless otherwise indicated)

Assistance For Independent Living

Clark County Social Services

Main Office: 1600 Pinto Lane 455-3108
Las Vegas, Nevada 89106

Satellite Offices: Nucleus Plaza, 926 West Owens Avenue 455-7208
Las Vegas, Nevada 89106

Cannon Senior Center, 340 No. 11th St. 455-4342
Las Vegas, Nevada 89101

University Medical Center 383-2621
1300 West Charleston Blvd.
Las Vegas, Nevada 89101

Services include:

- Assistance in obtaining or paying for medical services.**
- Assistance in providing food, shelter and clothing.**
- Transportation requests to doctor's offices or other medical services.**
- Requests for financial assistance until lost Social Security, SSI checks or other ongoing sources are reinstated.**
- Requests for homemaker services for elderly or disabled individuals.**
- Requests to investigate possible abuse, neglect or exploitation of senior citizens.**
- Requests for assisting homebound residents with shopping.**
- Social and medical care for persons with HIV disease.**

Clark County Social Services Alternative Health Program

1600 Pinto Lane 455-3651
 Las Vegas, Nevada 89106

Services include: Providing continuity of health care for at-risk persons through home care and follow-up evaluations.
 Checking client progress and compliance to medical programs.
 Maximizing use of all client eligible community programs.
 Evaluating the ability of long term care clients to resume Independent living outside an institution.
 Providing emergency homemaker services for clients Discharged from the hospital until eligibility for other community services is determined.

Clark County Social Services Homemaker Home Health Aid Service

1600 Pinto Lane 455-4430
 Las Vegas, Nevada 89106

Services include: Providing homemaking and personal care for individuals, with special attention given to the needs of low income, minority, and physically and mentally disabled older persons.
 Meeting immediate and long-term needs to maintain individuals in their own home, are adjunct to other preventive and treatment services, and prevent or reduce institutional care.
 Marketing, laundry, light housekeeping, food preparation and personal care (baths, shampoos, etc.) for at-risk Clark County residents who show a demonstrated need for service, subject to eligibility requirements.

Clark County Social Services Senior Protective Services

Cannon Senior Center, 340 No. 11th Street 455-4291
 Las Vegas, Nevada 89101

Services include: Crisis and emergency social work services to senior citizens, age 60 and older, who are reported to be victims of abuse, neglect or exploitation.
 Investigations of reports or referrals containing allegations of abuse, neglect or exploitation.
 Courses of action to alleviate abuse, neglect or exploitation.
 Counseling to reduce anxiety and lessen depression.
 Referrals to other agencies when necessary.
 Temporary assistance to displaced or homeless seniors.

Community Home-Based Initiative Program (CHIP)

**Cannon Senior Center, 340 No. 11th Street 486-3545
Las Vegas, Nevada 89101**

Provides non-medical services to persons age 65 and older, to help them maintain independence in their own homes as an alternative to nursing home placement subject to program eligibility requirements.

Lend A Hand – Respite and Geriatric Case Management

Boulder City, Nevada 294-2363

Lifeline – Personal Medical Emergency Support

**102 East Lake Mead Drive 564-4516
Henderson, Nevada 89015**

Medical Equipment Loan Program

**Cannon Senior Center, 340 No. 11th Street 486-1522
Las Vegas, Nevada 89101**

Nevada State Welfare

**Cannon Senior Center, 340 No. 11th Street 486-3600
Las Vegas, Nevada 89101**

Community Assistance**Aging Services Division, State of Nevada**

**Cannon Senior Center, 340 No. 11th Street 486-3545
Las Vegas, Nevada 89101
Eldercare Help Line – Statewide 800 243-3638**

American Association of Retired Persons (AARP)

**Cannon Senior Center, 340 No. 11th Street 386-8661
Las Vegas, Nevada 89101**

Cannon Senior Services Center

**340 North 11th Street 366-1522
Las Vegas, Nevada**

Catholic Community Services of Nevada

**1501 Las Vegas Boulevard North 385-2550
Las Vegas, Nevada 89101**

Clark County Social Services

Main Office: 1600 Pinto Lane 455-4270
Las Vegas, Nevada 89101

Satellite Offices: Nucleus Plaza, 926 West Owens Avenue 455-7208
Las Vegas, Nevada 89106

Cannon Senior Center, 340 No. 11th St. 455-4342
Las Vegas, Nevada 89101

University Medical Center 383-2621
1300 West Charleston Blvd., Las Vegas, Nevada 89101

Services include: Assistance in obtaining or paying for medical services.
Assistance in providing food, shelter and clothing.
Requests for transportation to doctor's offices or other medical services.
Requests for financial assistance until lost Social Security SSI checks or other ongoing sources are reinstated.
Requests for homemaker services for elderly or disabled individuals.
Requests to investigate possible abuse, neglect or exploitation of senior citizens.
Requests for assisting homebound residents with shopping.
Social and medical care for persons with HIV disease.

Community Ombudsman – Nevada Division for Aging Services

Cannon Senior Center 455-4342
340 North 11th Street, Suite 203 fax: 486-3572
Las Vegas, Nevada 89101

Services include: Provide assistance to home-bound seniors and their family and friends. Services are free and confidential.

Consumer Credit Counseling Services at Southern Nevada

3650 South Decatur Boulevard 364-0344
Las Vegas, Nevada 89103
Open: Monday through Friday.

HELP of Southern Nevada

953 East Sahara Avenue 369-4357
Las Vegas, Nevada 89104

1020 South Main Street 382-HELP
Las Vegas, Nevada 89101

Lifeline Assistance Program by Sprint	244-7400
Makes telephone service accessible to low income households by providing subscriber and local service at reduced rates, based on program eligibility requirements.	
Low Income Home Energy Assistance Program	486-3000
Based on eligibility, benefits may be available to households to help with home heating and cooling costs.	
Nevada State Welfare Food Stamp Program	
Cannon Senior Center, 340 No. 11th St. Las Vegas, Nevada 89101	486-3600
1040 West Owens Avenue Las Vegas, Nevada 89106	486-5040
3700 East Charleston Boulevard Las Vegas, Nevada 89104	486-4520
145 Panama Street Henderson, Nevada 89015	486-6748
Salvation Army Family Welfare Services	
35 West Owens Avenue Las Vegas, Nevada 89106	649-8240
Senior Nutrition Program	
1001 Arizona Street Boulder City, Nevada 89005	293-5510
27 East Texas Avenue Henderson, Nevada 89015	565-6990
531 30th Street Las Vegas, Nevada 89101	385-5284
Social Security Administration	
General Information, Claims and Appointments	
Call toll free 7 a.m. to 7 p.m.	800 772-1213
Main Office:	248-8717
5460 West Sahara Avenue Las Vegas, Nevada 89102	TDD 248-8732
Open: Monday through Friday, 9 a.m. to 4 p.m.	

1820 East Lake Mead Boulevard North Las Vegas, Nevada 89030 Open: 9 a.m. to 4 p.m.	649-1982
Southwest Gas Senior Weatherization Program 5241 Spring Mountain Road Las Vegas, Nevada 89102	382-4412
USDA Commodities Food Bank	382-1765
Veterans Administration Information and Assistance 3233 West Charleston Boulevard Las Vegas, Nevada 89102	800 827-1000 TDD 800 829-4833
We Care Foundation 2216 South 6 th Street Las Vegas, Nevada 89104	369-4357
Day Care For Adults	
Friendship Circle 830 East Lake Mead Drive Henderson, Nevada 89009 Open: Monday through Friday, 7 a.m. to 5 p.m.	565-8836
Services include:	Daytime care for the frail elderly and handicapped adults with a wide array of recreational and educational activities designed to reinforce awareness and orientation and to promote social interaction. Meals and transportation can also be provided. Daily or hourly rates available. Private pay, Veterans Administration and Medicaid accepted. Nevada Division for Aging Services assists with low income clients. Fee structure is dependent on client need.
Hollyhock Adult Day Care Center 380 North Maryland Parkway Las Vegas, Nevada 89101	382-0093
Salvation Army Adult Health Day Care 830 East Lake Mead Drive Henderson, Nevada 89015	565-8836
2035 Yale Street North Las Vegas, Nevada 89030	649-2374

Legal Assistance

City of Las Vegas Senior Citizens Law Project

Cannon Senior Center, 340 No. 11th St. 229-6596
 Las Vegas, Nevada 89101 fax: 384-0314
 Open: Monday through Friday, 9 a.m. to 4 p.m.
 (by appointment only).
 Legal services to senior citizens over the age of 60.

Clark County Pro Bono Project

701 East Bridger, Suite 101 386-1070
 ext. 136
 Free legal assistance by private attorneys in civil
 matters to low income citizens.

Clark County Public Administrator – Guardian

1700 Pinto Lane 455-4332
 Las Vegas, Nevada 89106
 Open: Monday through Friday, 8 a.m. to 4:30 p.m.

Public Administrator oversees administration of the estates of deceased persons who have no qualified person willing and able to do so. The administrator is required by law to ensure that property of the deceased is secured until a relative or other designated person can claim the property.

The Public Guardian is lawfully invested with the power and is charged with the duty of taking care of an individual and/or the individual's property. This occurs after a request for guardianship is made and it is determined that a person is not capable of administering his/her own affairs.

Services used when:

There is no family.

Family members are ill, elderly or other circumstances prevent their effective performance as guardian.

Friends of family have exploited or neglected the person and would not be suitable to serve.

Family members live in other areas or states.

Lawyer Referral Service

382-0504

Nevada Legal Services

701 Bridger Avenue 386-1070
 Las Vegas, Nevada 89101 800 522-1070

Attorneys Practicing Elder Law

Jeffrey L. Burr and Associates 4455 South Pecos Road Las Vegas, Nevada 89107	433-4455
John P. Foley 601 South Rancho Drive Las Vegas, Nevada 89106	386-5900
Paula C. Gentile 626 South Third Street Las Vegas, Nevada 89101	384-0111
Bryan A. Lowe and Associates 4011 Meadows Lane, Suite 102 Las Vegas, Nevada 89107	259-0002
John O'Brien 300 South Fourth Street, Suite 1409 Las Vegas, Nevada 89101	382-5222
James O'Reilly 3321 N. Buffalo Street Las Vegas, Nevada 89129	477-7517
Jack Pursel 1312 South Sixth Street Las Vegas, Nevada 89101	382-6321

Note: This attorney's list was obtained from the Alzheimer's Association Southern Nevada Chapter. The Alzheimer's Association does not specifically recommend any attorney.

Medical

AID for AIDS of Nevada Central Community Service Center West Community Service Center Hotline	382-2326 648-0177 474-2437
American Heart Association	800 242-8721
Arthritis Foundation	800 283-7800

Cancer Information Service	
American Cancer Society	800 227-2345
National Cancer Institute	800 422-6237
Clark County Social Services Nursing Home Unit	
1600 Pinto Lane	455-3565
Las Vegas, Nevada 89106	
Arranges convalescent care for persons unable to function in independent living situations due to medical problems and determines eligibility for financial government assistance.	
National Center for Vision and Aging	800 331-2020
University Medical Center	
1300 W. Charleston Boulevard	383-2000
Medical – Alzheimer’s Disease Physicians Accepting AD Patients	
Medical Doctors	
Khaliq Baig, M.D.	254-4295
8440 W. Lake Mead Blvd.	
Las Vegas, Nevada 89128	
Charles Bernick, M.D.	474-0532
901 So. Rancho Lane, Suite 105	
Las Vegas, Nevada 89106	
Mark Burroff, D.O.	477-7540
2010 Goldring, Suite 302	
Las Vegas, Nevada 89106	
Leslie Gaelen, M.D.	731-9600
3121 So. Maryland Parkway, Suite 412	
Las Vegas, Nevada 89109	
Steven Glyman, M.D.	731-9110
1618 East Flamingo Road, Suite 2	
Las Vegas, Nevada 89119	
Donald Hartley, M.D.	733-8871
3201 So. Maryland Parkway, Suite 506	
Las Vegas, Nevada 89109	

- Thomas McCormick, M.D. 456-8866
 4660 So. Eastern Avenue, Suite 206
 Las Vegas, Nevada 89119
 Makes house calls. Call office for availability.
- Karl Meisenheimer, M.D. 732-0600
 3121 So. Maryland Parkway, Suite 400
 Las Vegas, Nevada 89109
- A. Randall Moody, M.D. 733-8018
 2080 East Flamingo Road, Suite 202
 Las Vegas, Nevada 89110
- Neila Shumaker, M.D. 877-3999
 6375 W. Charleston Boulevard, Suite A
 Las Vegas, Nevada 89102

Dentistry

- Dr. Dwight Meierhenry 735-1115
 738 East Sahara Avenue, Suite A
 Las Vegas, Nevada 89104

Note: This physician's list was obtained from the Alzheimer's Association Southern Nevada Chapter. The Alzheimer's Association does not specifically recommend any physician.

Medical – Low Income

- Cannon Senior Center 384-2273
 340 No. 11th Street
 Las Vegas, Nevada 89101
- Community Health Centers of Nevada 631-8800
 916 West Owens Avenue
 Las Vegas, Nevada 89106
- Medical Equipment Loan Program 366-1522
 Cannon Senior Center, 340 No. 11th St.
 Las Vegas, Nevada 89101
- Opticare 2000 369-1555

Senior Citizens Health Program 385-1291
 Clark County Health District
 625 Shadow Lane, Las Vegas, Nevada 89106
 Open: Monday through Friday, 8 a.m. to 4:30 p.m.
 Answering Service evenings and weekends.
Services: Health District provides physical examinations for seniors,
 home health and hospice care.

Mental Health

Alzheimer's Disease and Related Disorders Association
 Southern Nevada Chapter 248-2770
 5190 So. Valley View Blvd., Suite 101 Fax 248-2771
 Las Vegas, Nevada 89118

Services: Organizes family support groups, promotes community
 research into the cause, treatment and possible prevention
 of the disease. Provides support and assistance to families
 through respite services, information and referral, help lines,
 support groups and caregiver training.

Charter Behavioral Health System of Nevada 876-4357
 7000 Spring Mountain Road
 Las Vegas, Nevada 89117

Community Counseling Center 369-8700
 1120 Almond Tree Lane
 Las Vegas, Nevada 89104

Lake Mead Hospital Medical Center North Star Program 649-7711
 1409 East Lake Mead Boulevard
 North Las Vegas, Nevada 89030

Las Vegas Mental Health Center and Southern Nevada Adult Mental Health
 6161 West Charleston Boulevard 486-6000
 Las Vegas, Nevada 89102
 Hospital and Mental Health Unit 486-8020
 SNAHM Crisis Unit 486-8020

Mojave Mental Health 253-0818
 3171 South Jones Boulevard
 Las Vegas, Nevada 89102

Montevista Hospital	364-1111
5900 West Rochelle Avenue Las Vegas, Nevada 89103	
Services:	Inpatient and outpatient programs for senior adults, Information services and 24-Hour Crisis Response.
Support Groups	
Children of Older Persons Support Group	486-6263
Support Groups – Alzheimer’s Disease	
Delmar Gardens of Green Valley	361-6111
100 Delmar Gardens Drive Henderson, Nevada 89014 Meet 2 nd Wednesday, 2 p.m. to 3 p.m.	
Griffith United Methodist Church	384-5255
1701 East Oakey Blvd. Las Vegas, Nevada 89104 Meet 4 th Wednesday, 1:30 p.m.	
Hollyhock Adult Day Center	382-0093
380 No. Maryland Parkway Las Vegas, Nevada 89101 Meet 4 th Tuesday, 6:30 p.m.	
Kid Gloves Support Group	657-6509
2411 Bassler Street North Las Vegas, Nevada 89030 Meet 2 nd Saturday, 1 p.m. to 2:30 p.m.	
Lied Senior Center	648-3425
901 North Jones Las Vegas, Nevada 89108 Meet Wednesdays, 10 a.m.	
M. Marian Miller Center	736-9449
2550 East Hacienda Avenue Las Vegas, Nevada 89120 Meet 1 st and 3 rd Tuesdays, 7 p.m. to 9 p.m.	
North Las Vegas Care Center	649-7800
3215 East Cheyenne Avenue North Las Vegas, Nevada 89030 (Temporarily not meeting)	

St. Rose Dominican Hospital 369-9372
 98 East Lake Mead Drive
 Henderson, Nevada 89015
 Meet 1st and 3rd Thursdays, 2 p.m. to 3 p.m.

Summerlin – Desert Vista Community Center
 Las Vegas, Nevada 736-9449 or 363-7249
 Meet 1st Wednesday, 10 a.m. to noon

Transportation

Carevan Services Incorporated
 2029 North H Street 646-2273
 Las Vegas, Nevada 646-CARE

Medic Coach Service 454-6176

Nevada Medi-Car 382-5820

Senior and Handicapped Transportation
 Citizens Area Transit 228-7433
 301 East Clark Avenue, Suite 300 CAT-RIDE
 Las Vegas, Nevada 89101

Senior Center of Boulder City Transportation 293-3320

Southern Nevada Sightless 642-6000
 Services: For blind and visually impaired riders serving a
 five-mile radius of 100 No. Bruce St., Las Vegas, Nevada

State of Nevada Taxicab Authority Senior Ride Program 486-6535
 340 North 11th Street
 Las Vegas, Nevada 89101
 Open: Monday through Friday, 8 a.m. to 4 p.m.
 Services: Offers reduced fares for senior citizens.

Volunteer Programs

Alzheimer's Research Study 220-6224
 Charles Bernick, M.D.
 Clinical Studies Las Vegas
 2625 So. Rainbow Blvd. Suite D-102
 Las Vegas, Nevada 89102
 Services: Free screenings and memory testing available to people
 experiencing symptoms of memory loss.

Senior Companion Program 382-0721
 340 North 11th Street
 Las Vegas, Nevada 89101

Telephone Reassurance Program 383-1163
Services: This free program by Catholic Community Services has
 "Phone Pal" volunteers call enrolled senior citizens, the
 same everyday as a way to ease loneliness and paranoia
 by providing companionship and reassurance. Program
 also serves as a way to check on the well being of senior
 citizens living alone.

Volunteers of America 800 899-0089

Sources of Additional Information

American Pharmaceutical Association 800 237-2742
 Get answers to prescription drug questions regarding new
 prescriptions, changing prescriptions, drug interactions,
 risks and possible side effects.

Catholic Community Services of Nevada 385-2550
 1501 Las Vegas Blvd. North
 Las Vegas, Nevada 89101

Elder Abuse and Domestic Violence
Statewide Hotline: 800 500-1556
National Hotlines: 800 799-7233
 800 799-SAFE

Elder Care Help Line 800 243-3638
Services: Open: Monday through Friday, 9 a.m. to 4 p.m.
 Operated by Nevada Division for Aging Services, the
 help line provides a range of services, from information
 and referral, to in-home housekeeping assistance.

Medicare Medical Assistance 800 638-6833
 Qualified Medicare Beneficiary "QMB" and Specified
 Low Income Medicare Beneficiary "SLMB" program
 information, subject to eligibility requirements.

Medicare Part A Qualification Info. 800 772-1213
 or contact the nearest Social Security Office.

- Medicare Hospice Benefits** 800 658-8898
 National Hospice Organization
 1901 No. Moore Street, Suite 901
 Arlington, Virginia 22209
- Social Security Administration** 800 638-6833
 TDD 800 820-1201
- Services:** General information on hospice care programs and eligibility requirements.
- Mobile Home Owners League of the Silver State** 384-8428
- National Institute on Deafness and Other Communication Disorders**
Information Clearinghouse 800 241-1044
- Social Security Administration**
General Information, Claims and Appointments
 Call Toll Free 7 a.m. to 7 p.m. 800 772-1213
- Main Office:** 248-8717
 5460 West Sahara Avenue TDD 248-8732
 Las Vegas, Nevada 89102
 Open: Monday through Friday, 9 a.m. to 4 p.m.
- 1820 East Lake Mead Boulevard 649-1982
 North Las Vegas, Nevada 89030
 Open: 9 a.m. to 4 p.m.
- UNLV Medicaid Enrolled Health Plan** 877-3999
 Family Practice Center
 6375 West Charleston Boulevard
 Las Vegas, Nevada 89102
 Open: Monday & Wednesday to Friday, 9 a.m. to 5 p.m.
 Tuesday, 9 a.m. to 9 p.m.
- Services:** A Medicaid health plan program managed by the University of Nevada School of Medicine, subject to eligibility requirements.
- Widowed Persons Services** 385-6922

APPENDIX E
GLOSSARY OF TERMS

GLOSSARY OF TERMS

Assisted Living: Housing and 24-hour personal care services; for those who may need assistance in performing activities of daily living such as dressing, grooming, bathing, etc., or may be in the early states of dementia (Alzheimer's disease).

Audiologist: Tests hearing and helps fit devices to improve hearing.

Community Home-Based Initiatives Program (CHIP): provides non-medical services to older persons to help them maintain independence in their own homes as an alternative to nursing home placement.

Congregate Housing: Small, independent apartments with group settings for meals and other group activities along with personal care and chore services.

Geriatric Nursing Assistant: Gives direct personal care under supervision.

Homemaker: Performs homemaking chores than enable people to remain in their own homes.

Independent Living: Living on own in affordable housing.

Nursing Home: Shelter and 24-hour health care services.

Nutritionist: Supervises meal planning.

Occupational Therapist: Assists patients in activities that increase productive use of their time.

Ophthalmologist: Cares for conditions of the eye.

Physical Therapist: Teaches and supervises activities that maintain optimum body functioning and mobility.

Physician: Admits the patient, establishes the diagnosis, writes orders for medical care.

Podiatrist: Examines and corrects foot problems to increase comfort and mobility.

Professional Nurse (R.N.): Evaluates patient's needs, writes orders for nursing care, directs and supervises care, coordinates activities of other health team members.

Psychologist: Assists the patient and family in making emotional adjustments.

Public Administrator: Oversees the administration of the estates of deceased persons who have no qualified person willing and able to do so. The administrator is required by state law to ensure that the property of the deceased is secured until a relative or other designated person can claim the property.

Public Guardian: Is lawfully invested with the power and charged with the duty of taking care of an individual and/or the individual's property. This occurs after a request for guardianship is made and it is determined that a person is not capable of administering his/her own affairs.

Representative Payee: The Public Guardian oversees the Representative Payee Program for Clark County, Nevada. The Representative Payee or Rep Payee is a qualified individual who provides financial management for social security beneficiaries and private pensioners who are unable to manage their own financial affairs.

Social Worker: Assists patients and families in making social and economic adjustments to changes in their lives.

Speech Therapist: Tests speech communication skills and treats speech disorders.

Technician and Practical or Vocational Nurse: Helps the R.N. evaluate the patient's resident's needs and carry out the nursing care plan, supervises assistants.

Note: Sources used to compile this glossary of terms included The Geriatric Health Care Provider, a publication from the Alzheimer's Association, a United States Postal Service brochure entitled "Healthy Aging," a "Public Administrator" brochure produced by the Clark County Public Administrator's office, and a brochure entitled "Community Home-Based Initiatives Program: for Senior Citizens" produced by the Nevada Division for Aging Services.

APPENDIX F

PUBLIC OUTREACH PROGRAM

APPENDIX F

ALZHEIMER'S ASSOCIATION SOUTHERN NEVADA CHAPTER PUBLIC OUTREACH PROGRAM

Situation Analysis

The Southern Nevada Chapter of the Alzheimer's Association has a variety of effective communications tools in place to reach the public and increase awareness of the resources and services provided by the chapter.

These tools include regular distribution of a quarterly newsletter to a mailing list of approximately 2,600 addresses, and the drafting and distribution of news releases to media outlets on an "as needed" basis.

To further promote the efforts of the organization, to increase chapter membership, and to generate funds for this non-profit agency, "The Luncheon" event is a successful fashion show and luncheon hosted by the chapter in September and this is followed by a Memory Walk fundraiser in October. In addition, a series of educational workshops are offered throughout the year and staff participate in community health fairs, when possible.

During the 1998 Board of Directors Retreat, the need to increase public relations was identified as a top priority and it is the goal of this communications plan to help in these efforts.

Recommendations

Taken from the Operational Plan for fiscal year 1998, many facets of the organization's services are already identified as ways to increase awareness of chapter services. These include:

Publicize "Help Line" program and brochure. This can be done via a news release to media outlets. Taking this a step further, having the brochure translated into Spanish would reach an even broader audience - - especially Hispanic newspapers and radio stations. If this is a publication prepared by the national organization they, most likely, already have these materials in Spanish. The news release should include when the Help

Line program started, why it was started, its effectiveness in the community thus far, how people can call it, how people can volunteer for the help line, etc.

Publicize chapter training programs by way of a "Train the Trainer" program. This can be done via news release with two purposes: to recruit volunteers and to train bi-lingual volunteers. To make this less labor intense for staff, perhaps money could be allocated in the budget to produce a video of the program.

Publicize monthly educational programs. This can be done via news releases to media outlets for the community bulletin board sections of the paper and the bulletin boards run on television. Fliers with this same information can be created and distributed to various health care centers, senior centers, churches, etc. To reach the Hispanic community, fliers should be printed in Spanish also or in English on one side and Spanish on the opposite side. Important: indicate whether these are free to the public or if there is a fee to participate. Once the format is established, this could be routinely updated and distributed to media once a week or once a month, depending on media deadlines. Typically media outlets like to receive community billboard information four to six weeks in advance.

Publicize Speakers Bureau. This can be done by preparing a promotional piece announcing that speakers may be scheduled to do presentations at various civic functions. Suggested groups include the Breakfast Exchange Club, Rotary Club, Women In Communications, Public Relations Society of America, etc.

Publicize Multi-Cultural Outreach. Attention can be focused here when plans are formulated to target diverse cultures within the community. There are several local publications that reach the Hispanic community and can be targeted with materials printed in Spanish or Spanish-English versions.

Publicize ways the chapter helps by underwriting temporary respite services to families financially strapped for help.

Publicize the lending library of resources, books, videotapes, available free for the use of families and friends of Alzheimer's patients or to teachers who are working with their students to understand the aging processes.

Publicize the Safe Return program to help law enforcement, hotel and casino security, and family members. Identify how long the program has been in effect in Southern Nevada, why it is important, how the program has helped (some of the successes), how people can learn more.

Publicize support group days, times and locations of meetings by way of a public service announcement to media for community bulletin boards. Publicize new support groups as they come into service, especially in under served rural areas and for groups with "special needs." Make these known throughout Southern Nevada via media outlets.

Publicize “family needs assessments.” Explain what this is, what community social service agencies help in this regard and the chapter’s role.

Publicize fund raisers and upcoming special events.

Publicize planned giving program, when this becomes a reality.

For the most part, these initiatives are from the existing plan. With the exception of the special events, none of the topics are time critical. News releases focused in these areas can be timed for release to best serve the chapter.

A goal of drafting and distributing one news release a month seems realistic. In order to be an appealing story for television coverage, there must be something visual taking place i.e. Interviewing a family coping with Alzheimer’s, a daughter whose mother was located via her Safe Return bracelet, a class of high school students learning about the aging process – impaired hearing, impaired vision, difficulty in walking, eating, breathing, mixed up sleep patterns, etc. These kinds of scenarios show viewers why it is important to know this.

Opportunities

Keep a log of media inquiries and names of the reporters.

Expand media list.

Develop relationships with reporters. Place reminder calls to those who have called in the past and a “hello” call to those who cover lifestyle and health issues.

Contact Review Journal/Las Vegas Sun so that the chapter participates in the Senior Lifestyles supplement of the paper.

Approach television stations for appearances on public affairs programs i.e. AM Southern Nevada, some media outlets may go so far as to produce a public service spot to air on their station.

Approach the cable company in regard to airing public service announcements and/or community service video.

As some local government entities have programming on the local cable channel, it may be possible to schedule an appearance during a segment on seniors, aging, dementing illness, caregiving, etc. Perhaps the chapter could team up with social services agencies or governmental senior citizen programming to do a television segment. Make inquiries as far as the criteria that sets non-profits apart from paid advertisers.

When national organization distributes news releases, give it a local angle. Draft and distribute news releases to local media identifying how it is important to our community.

Escort media on a tour of a nursing home, group home, or to meet with a family agreeing to share their compelling story. Make stories easy for media to cover.

Take nominations for a "Caregiver of the Year Award," as is done by the Parkinson's Disease Foundation. This could be a lay caregiver, a medical professional, a support group facilitator or all three categories. The award presentation could be tied to The Luncheon, Memory Walk, or some other special event.

Publicize local chapter's web site when it comes on line and is staffed to respond to inquiries in a timely manner. When staffing permits, offer chat room times for discussion groups on the internet.

Approach United Way to help publicize chapter programs via space on billboards as a public service. Sometimes billboard companies have empty space that can be used, providing the chapter pays for production of the visual piece.

Team up with Northern Chapter for events.

Look for ways to team up with other entities i.e. nursing home residents become foster parents for kittens and puppies to help the Animal Foundation, or Girl Scouts visiting senior citizens in a nursing home.

Publicize lay caregiver research in Southern Nevada.

Publicize the chapter's participation in health fairs and other civic events.

Recruit elected officials to participate in Memory Walk, continue efforts for "Faces of Alzheimer's" wall of photographs to grow, maybe some high profile members of the community have pictures to add.

Request proclamations for Alzheimer's Awareness month.

Tap into the University of Nevada at Las Vegas, Community College, School of Medicine regarding course work focused on health and aging. Instructors and students may be interested in learning more about the organization through presentations and this may be a way to recruit new members or program volunteers.

Action Items

Draft and distribute at least one news release each month.

Formalize and expand contact lists with sections for media: television, radio, print, magazines, health care newsletters; urban area: health centers, senior centers, senior citizen organizations, support group facilitators, churches, law enforcement; rural area

schools, churches, law enforcement, libraries, etc. Try to have these materials in Spanish as well.

To increase communications with support group facilitators, news releases and announcements distributed to media outlets should also be forwarded to them. Ideas for consideration include scheduling periodic luncheons or gatherings to increase two-way communication between chapter and facilitators. Another idea is for board members to visit support groups providing the visit is planned in advance and with the support group facilitator's approval.

Progress Report

An all out chapter survey was conducted via e-mail in December which netted a surprising number of responses.

Additions have been made to the chapter's media list.

The first news release this year was drafted and distributed January 12, 1999.

The first draft of the communications plan was submitted to the Board for review and approval.

Other

To Increase Membership: Letter writing campaign to everyone who has ever contacted the local chapter requesting they become a member.

Letter writing campaign to Top Employers in Southern Nevada explaining the costs – benefits ratio of providing custom tailored brown bag lunch discussion groups/educational sessions for “sandwich generation” employees for a corporate membership of \$300 versus the cost of time these employees are going to take off from work to seek out this same information on their own.

**Prepared by Debby Hauth
As of January 12, 1999**

VITA

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