

CONTROL, INTROVERSION, AND SOCIAL SUPPORT:  
A MODEL OF LONELINESS IN ALZHEIMER'S CAREGIVERS

by

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(ABSTRACT)

Loneliness in caregivers of Alzheimer's family members was examined through the use of an explanatory model. Stepwise multiple regression was used to test the association between characterological variables (introversion and control), situational variables (social support), demographics (income), and self-reported loneliness in a statewide mail survey of 190 caregivers. Results indicated that introversion, control, social support, and income account for almost two-thirds of the variance in loneliness. An interesting finding was that higher income was associated with higher levels of loneliness in the caregivers. Implications for practice are discussed and recommendations for future research are suggested.

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## Introduction

Caring for a person with Alzheimer's Disease is a particularly stressful life event that is frequently associated with negative outcomes such as emotional strain (Poulshock & Deimling, 1984; Robinson, 1983; Zarit, Reeve, & Bach-Peterson, 1980). Caregiving also affects relationships with other people (George & Gwyther, 1986). Isolation, reduced social contacts, and fewer visits from friends are among the changes caregivers experience (Cantor, 1983; Chenoweth & Spencer, 1986). Social deficits have also been associated with loneliness in both noncaregiver (Russell, Cutrona, Rose, & Yurko, 1984) and caregiver samples (Qualls, Norfleet, & Harder, 1986).

In spite of the proliferation of research into loneliness in adulthood, only a few studies have examined loneliness in caregivers. This investigation generates and tests an explanatory model of loneliness among caregivers of family members with Alzheimer's Disease. The model is used to identify and assess the: (a) amount of loneliness in the caregiver situation that can be accounted for within the parameters of the model; (b) amount of separate influence characterological, situational, and demographic factors have on loneliness while controlling for joint effects; and (c) relative

importance of characterological, situational, and demographic variables in jointly explaining self-perception of loneliness in caregivers.

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The explanatory model allows for the interplay of variables as proposed by Weiss (1974). It is assumed that each of the three types of variables has an important influence on the level of loneliness experienced. Characterological variables are personality traits or characteristics that may predispose individuals to loneliness. In the model, characterological variables are introversion and control. In contrast, situational factors are events or circumstances that precipitate loneliness. They impact on social relations and effect changes in the desired or expected social supports. In the Alzheimer's caregiver model, situational factors are expressed as the social support variable. The situational and characterological factors are not contradictory; rather, both contribute interactively to loneliness. Demographic factors within the model are presumed to have a direct effect on loneliness. These factors include: age, gender, income, education, and health status.



## Review of Literature

### Characterological Factors

Control. The perception that an individual is self-directed or in control, is considered a personal resource during stressful periods (Holahan & Holahan, 1987). Consequently, decreased physical and mental health, increased mortality, and reduced well-being are associated with loss of control (Langer & Rodin, 1976; Schulz & Aderman, 1973; Schulz & Brenner, 1977).

A number of researchers have found that caregivers experience loss of control in the caregiving situation. For example, Coppel, Burton, Becker, and Fiore (1985) observed that spousal caregivers often lose control over major portions of their lives because of the strenuous demands of caregiving. Similarly, Fitting, Rabins, Lucas, and Eastham (1986) noted that caregivers of dementia patients may feel powerless to change the outcome of their situation which can then lead to feelings of despair and depression.

In turn, loss of control experienced by caregivers may be related to loneliness. In a study of noncaregiver adults, Schultz and Moore (1984) found that control was significantly correlated with loneliness. Therefore, because caregivers are likely to experience more loss of control than noncaregivers, they may also be expected to

report higher levels of loneliness than noncaregivers.

Extraversion-introversion. This dimension of personality emerges early in life and remains stable over time (Schaie & Parham, 1976). Extraverted people are oriented toward the outer world of people, objects, and their environment (Jung, 1971). On the other hand, introverted types are more oriented inwards with less of an attachment to the environment (Jung, 1971). Although the trait of introversion remains stable, the level of expressed introversion has been observed to increase with age (Swenson, Pearson, & Osborne, 1973). Moreover, introversion has been related to loneliness in younger samples (Jones, 1982; Russell, Peplau, & Cutrona, 1980). Even though loneliness has been observed in caregivers (Qualls et al., 1986), research on related personality traits is not available. Furthermore, because the expression of introversion has been observed to increase with age and because introversion is associated with loneliness in younger samples of noncaregivers, it was included in the current investigation.

#### Situational Factors

Social Support. As previously mentioned, social contacts and social activities of family caregivers of Alzheimer's patients are restricted as a result of the caregiving experience (Burnley, 1985; Poulshock & Deimling,

1984; Zarit, Todd, & Zarit, 1986). Generally, support is thought to play an important role in maintaining well-being and decreasing susceptibility to negative outcomes (Arling, 1987; Holahan & Holahan, 1987). In a study of caregiver loneliness, Qualls and associates (1986) found that opportunities for social interaction decreased as caregiving demands increased. Furthermore, they found that caregivers experienced more loneliness than the noncaregiver group. Support was included because it has been associated with loneliness in previous studies.

#### Demographic Factors

Controversy exists over which demographic variables are important in understanding loneliness in various adult samples. For example, contrary to popular belief, older people are not necessarily lonelier than younger people (Creecy, Wright, & Berg, 1985).

In general, loneliness has been found to be related to lower levels of health and income (Creecy et al., 1985; Perlman, Gerson, & Spinner, 1978). Moreover, no difference in loneliness between elderly males and females has usually been found (Creecy et al., 1985; Schultz & Moore; 1984). In sum, gender, age, marital status, and household composition tend not to be related to loneliness, whereas poorer health and lower income have frequently been correlated with loneliness.

## Methods

### Sample

After pretesting, questionnaires were distributed to members of the fifteen active Alzheimer's Caregiver Support Groups in South Carolina. Ten support groups provided membership mailing lists while the remainder retained control of their membership lists. If a support group would not release a mailing list for reasons of confidentiality or because they did not maintain a mailing list, arrangements were made to either have the support group mail the questionnaires and subsequent follow-up letters, or to have the support group distribute the questionnaires at a group meeting (Caserta, Lund, Wright, & Redburn, 1987). After the initial mailing, three follow-up letters were sent to nonrespondents; the final letter included a replacement questionnaire (Dillman, 1978). A response rate of 79% was achieved,  $N = 190$ .

Respondents in this study were 44 male and 146 female caregivers of Alzheimer's patients. Almost half of the respondents cared for spouses (32% husbands and 17% wives) and 38% were caring for parents. The sample was 94% white and the average age for caregivers was 57 years. The mean educational level was 14 years. Table 1 provides descriptive information on the sample.

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### Measures

Loneliness. The dependent variable is conceptualized as a unidimensional or global phenomenon that varies in intensity. The UCLA Survey Loneliness Scale was used because it is recommended for survey investigations of loneliness (Russell et al., 1980). This Scale consists of four items derived from the twenty-item revised UCLA Loneliness Scale. The Survey Scale contains two positively and two negatively worded statements. A sample item is: "No one really knows me well". The subject responds with "never", "rarely", "sometimes", and "often". Values range from 1 to 4 so that low scores indicate less loneliness and high scores indicate greater loneliness. Items that are worded positively have reversed scoring.

The Survey Scale has a coefficient alpha of .75 and it is described as an appropriate scale to use with community-dwelling adults, ages 18 years to over 60 years (Gutek, Nakamura, Gahart, Handschumacker & Russell, 1980; Russell, 1982). It has also been used with samples of older adults (Moore & Schultz, 1982; Mullins, Johnson, & Andersson, 1987; Perlman et al., 1978).

Control. This construct was measured by a 7-item, mastery index constructed by Pearlin and Schooler (1978). The index consists of seven Likert-type items that assess perceived control or mastery over various life circumstances. A sample item is: "I have little control over the things that happen to me". The respondent indicates the level of agreement or disagreement on a scale ranging from 1 (strongly disagree) to 5 (strongly agree). A higher number indicates a greater level of perceived control. Reliability was established via factor analysis (Pearlin & Schooler, 1978).

Extraversion-introversion. This personality dimension was assessed by the Extraversion-Introversion (E-I) subscale of the Myers-Briggs Type Indicator Form F (Myers & McCaulley, 1985). The E-I index consists of 22 forced-choice items. A sample item is, "Do you tend to have (a) deep friendships with very few people, or (b) broad friendships with many different people?" Each item has one response weighted in favor of one of the two dimensions. Different weights are assigned to certain answers to control for social desirability bias (Myers & McCaulley, 1985). Scoring of the index results in numbers that range from 47-100 for extraversion and 101-159 for introversion. Various methods have been used to estimate the reliability of

continuous scores for the E-I index. The split-half procedure was found to be .76 (Webb, 1964); whereas, the Cronbach's Coefficient Alpha was found to be .86 (Stricker & Ross, 1963).

Social Support. Support was examined by the Social Provisions Scale developed by Russell and Cutrona (1984). A sample item is: "Other people do not view me as competent." Respondents answer each item according to a four-point Likert scale ranging from "strongly agree" (4) to "strongly disagree" (1). Negatively worded items are reverse scored. A higher score indicates greater perceived social support.

The Social Provisions Scale has been recommended for use with adult samples. Alphas ranging from .71 to .86 have been reported along with appropriate construct validity for this age-group (Blieszner & Mancini, 1985; Holahan & Holahan, 1987; Russell, 1986). Reliability and validity of the scale have also been determined with elderly samples (Cutrona, 1986; Russell, 1986; Russell & Cutrona, 1984).

Demographics. Background factors were assessed by asking each respondent to provide the following information: gender, age, education, employment status, health, income level, and family composition. In addition, each participant was requested to provide

the relationship to the patient and the patient's place of residence. Demographic variables were assessed by either forced-choice or open-ended items.

### Analysis

The data analysis proceeded in four steps. First, means and standard deviations were computed for loneliness, control, extraversion-introversion, social support, and all demographic variables relevant to the explanatory model. Second, Pearson correlation coefficients were calculated to identify the strength of association among all variables.

Third, though past research noted no differences in level of caregiver loneliness by gender of the caregiver, patient relationship, and residence of patient (Qualls et al., 1986); the effects of these variables were examined because past research about their importance to caregiver loneliness is not extensive. Moreover, although these demographic variables are not prominent in the explanatory model, it seemed important to consider their possible influence on loneliness, given the scarcity of previous research. A *t*-test procedure was used to assess differences in loneliness by gender. In addition, one-way analysis of variance procedures were independently performed on patient relationship and patient residence with



loneliness.

Fourth, a stepwise multiple regression was used to test the proposed explanatory model of loneliness and to identify the model variables having the most influence on loneliness. The model included introversion, control, social support, income, education, and health status as the explanatory variables, with loneliness, the criterion variable.

## Results

Overall, respondents reported a moderate degree of loneliness (See Table 2). As expected, loneliness was significantly correlated with social support, control, and introversion. Income was the only demographic variable significantly related to amount of caregiver loneliness (See Table 3). The correlations between the independent variables in the model were all in the moderate range, between .12 and .46.

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Insert Table 2 About Here

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Results of the  $t$ -test revealed no significant differences between male and female caregivers in the level of loneliness perceived ( $t = .93$ ,  $df = 43, 145$ ,  $p < .35$ ). The assumption of equal variance was tested because group sizes were not equal. Results indicated no significant differences in variability of scores on loneliness by gender ( $F = 1.07$ ,  $df = 43, 145$ ,  $p < .75$ ).

Independent one-way analysis of variance revealed no significant differences in loneliness by relationship to Alzheimer's patient ( $F = .83$ ,  $df = 5$ ,  $p < .05$ ).

Moreover, the ANOVA procedure indicated no significant difference between loneliness and whether the patient lived with the respondent, with another relative, or in an institution ( $F = 2.84$ ,  $df = 3$ ,  $p < .05$ ).

Multiple regression found four of the variables used in the study explained a statistically significant amount of the variance in loneliness. The strongest explainer of loneliness among caregivers was the situational variable of social support ( $B = -.64$ ). The next strongest contributors to loneliness were the characterological variables of introversion ( $B = .21$ ) and control ( $B = -.15$ ), followed by the demographic variable, income ( $B = .10$ ). These four variables account for 63% of the variance in loneliness. The model is significant at the .01 level.

## Discussion

The results of the current study reveal that lonelier caregivers are more likely to perceive themselves as having less social support and less personal control over life events. In addition, they are more likely to be introverted and to have higher incomes than less lonely caregivers. These findings support interactionist theory which states that loneliness stems from characterological vulnerabilities and situational constraints (Weiss, 1974).

Consistent with the work of Qualls and associates (1986), social support is by far the most important explainer of loneliness included in the model. Since previous studies have observed that caregivers of Alzheimer's patients experience restricted social contacts and social activities (Burnley, 1985; Chenoweth & Spencer, 1986; Poulshock & Deimling, 1984), this finding was expected. The data suggest that the perception of social support alleviates feelings of loneliness among caregivers and the level of support appears to determine the degree of loneliness.

Personal evaluation of social support is a subjective assessment of quality and quantity (Peplau, Miceli, & Morasch, 1982). It involves judging oneself against a number of standards such as comparison with

peers (Perlman & Goldenberg, 1981) or with one's previous relationships (Cutrona, 1982).

Recently, Johnson and Mullins (1987) introduced the concept of loneliness threshold to identify the level of social support that an individual wants in order to avoid loneliness. According to Johnson and Mullins (1987), loneliness threshold is influenced by cultural or subcultural values as well as by social support from earlier stages of life. Although loneliness threshold was conceptualized in an effort to understand loneliness across cultures, it also has implications for understanding loneliness in Alzheimer's caregivers. Because of the unique situation created by Alzheimer's Disease, how caregivers assess their feelings of loneliness is particularly noteworthy.

As an indiscriminate leveler, the progression of Alzheimer's Disease produces a series of losses in the lives of caregivers. Loneliness among caregivers may be, in part, a reflection of caregiver perception of these losses according to their own personal standards. The extent of losses in social support may be evident when caregivers make comparisons with previous stages in their lives, with their peers, and with the idealized version of how their lives might have been without Alzheimer's Disease.

Another influential explainer of loneliness is the personality construct of introversion. It was the strongest characterological contributor to loneliness among caregivers. With regard to the association between introversion and loneliness, a number of interesting findings were noted.

For one thing, introverts are believed to be more in tune with internal experiences (Collins, Martin, Ashmore, & Ross, 1973), whereas, extraverts react more directly to changing environmental circumstances. Because introverts are internally oriented, they may assess the caregiving experience in terms of how it affects their own internal processes. They may be more inclined to evaluate the circumstances according to abstract criteria. Even though there are many definitions of loneliness, it is generally agreed that it is an internal psychological construct.

For another thing, introverts value privacy (Morris, 1979). This predisposition may contribute to a reluctance to seek outside social support, whether it be emotional or instrumental. This reluctance may contribute to loneliness because introverted caregivers may naturally find it difficult to express social support needs to others.

In addition, introverts are controlled by long-

range plans and intentions (Collins et al., 1973). Special difficulties may arise for introverted caregivers due to the long duration and erosive nature of Alzheimer's Disease. Introverted caregivers may find that the inability to plan for the future is chronically problematic.

Control also emerged as a personal resource that reduces caregiver loneliness, supporting the observation of other researchers (Coppel et al., 1985; Fitting et al., 1986; Holahan & Holahan, 1987). It becomes evident that the loss of control, when coupled with the losses surrounding social activities and relationships, support the Creedy and associates (1985) observation that loneliness in the elderly results from an accumulation of losses and deficits.

Income was the only background variable that was associated with caregiver loneliness. Higher income caregivers identified themselves as lonelier than their lower income counterparts. This is contrary to most research findings. The apparent inconsistency between this study and other studies regarding the influence of income on loneliness, may be due to several factors.

First, the source of discrepancy may be due to how income was measured. In the current study, categories were used; the highest being "\$40,000 and above".

Clearly, actual income figures may have provided a more accurate assessment of the influence of income.

Secondly, Creecy and associates (1985) observed that a loss of income tends to isolate people from the level of contacts necessary to prevent loneliness. Even though the higher income caregivers in this study identified themselves as having more money in the household than lower income caregivers, they may also be experiencing a greater relative loss of income due to caregiving. Lower income caregivers may be eligible for social service assistance and take part in more community services. Higher income caregivers may not qualify for certain assistance programs and, therefore, devote a larger portion of their income to caregiving than caregivers with less income. Thus, it is possible that higher income caregivers experience the kind of loss that Creecy and colleagues (1985) identified as contributing to isolation and loneliness in elderly people.

Lastly, the mere purchasing or availability of physical assistance and services may not necessarily diminish loneliness. Feelings of isolation and loneliness may result from the disparity between previous life style and present circumstances. In some instances higher income caregivers may be more isolated



than lower income caregivers from certain kinds of support. For example, a higher income caregiver, who employs round-the-clock nurses or hires a full-time companion, may actually be limiting assistance from relatives and friends that, if given, may have lessened feelings of loneliness. Moreover, by not participating in community programs, they may increase their sense of isolation and loss.

## Conclusions

The current study contributes to a growing literature that indicates that caregivers of dementia patients experience negative well-being. The results also add to the understanding of loneliness among caregivers. Moreover, the data provide insight into the effects of reduced social support and diminished activities that are frequently a part of the caregiver process.

The results of this investigation have a number of implications for both research and service practitioners. From the practice perspective, these findings reiterate the suggestion of previous researchers that caregivers are a population in need of support and respite services. The loneliness reported by this sample underscores the need for supportive services regardless of income.

Revenson (1986) has suggested two approaches to alleviating loneliness in the elderly through social intervention that may also be applicable to loneliness in Alzheimer's caregivers. Revenson's first approach is the development or continuation of individually oriented programs of assistance. These programs may range from self-help groups to professional counseling.

In the case of Alzheimer's caregivers, special

considerations in program development must be made. Community programs aimed at direct assistance to caregivers must continue to be created and expanded. Presently, programs available to caregivers vary widely from community to community. Daycare and other respite services are often sporadic or nonexistent. Secondly, programs must ensure that the costs, in terms of effort and money, do not outweigh the benefits for the caregiver. Such services as professional counselors are often a luxury beyond the reach of many caregivers who first must find knowledgeable and sympathetic medical assistance for their Alzheimer's patient before considering their own needs. In itself, the challenge of finding medical care is still a difficult one in many communities.

According to Revenson (1986), a second approach to alleviating loneliness is the use of socio-political efforts. Legislative support for future research and the expansion of caregiver assistance programs is a step in the right direction. However, in the case of Alzheimer's caregivers, direct payments and assistance may not be the total answer.

The observation that caregivers experience loneliness, even when they have higher incomes and are members of support groups, indicates the necessity for

developing creative, innovative supports. Formal support services as well as strategies for enhancing the natural support networks of caregivers through education are apparent areas for future consideration. Informal social supports such as family members, friends, and neighbors can be educated to recognize signs of loneliness, withdrawal, and depression (Mullins, Longino, Marshall, & Tucker, 1987). Given the correlation between loneliness and depression, suicide, and alcoholism (Rook & Peplau, 1982; Week, Michela, Peplau, & Bragg, 1980; Wenz, 1977), the alternative of ignoring the importance of support may have dire consequences for caregivers.

Reaching out to caregivers with social supports is particularly challenging because introversion is also associated with loneliness. Simply increasing the amount or kinds of social support for caregivers may be inappropriate. Evaluator and funding agencies need to recognize that the meaning of supportive services may differ according to varying individual circumstances. For example, introverts may prefer to be alone and reluctant to seek outside emotional support. Yet, research continues to suggest that support remains a crucial variable in the development of loneliness. The dilemma becomes how to provide or encourage support

when the caregiver does not take the initiative or even under what circumstances is intervention appropriate.

Perhaps, an effort could be made to identify and assist caregivers through an outreach program sponsored through the Alzheimer's Support Groups, similar to the programs used in support groups like Alcoholics Anonymous. Moreover, such efforts need not be limited to the support groups themselves but may be expanded into other community organizations such as churches, the academic community, and service organizations. Expanded media services may also provide support. Introverts may prefer to receive information and support through reading or viewing.

In addition, more empirical research is clearly needed because a number of questions remain unanswered. The current results suggest several directions for future investigation. First, questions remain about the specific social support that impacts on loneliness. This could require the development of instruments that assess distinct social support processes. Qualitative approaches may also be necessary to uncover the mechanisms that trigger feelings of loneliness in caregivers. It is apparent that more diverse methods are needed to get at underlying themes in caregiver loneliness.

Next, the data reveal that personality constructs are a vital component in caregiver loneliness. Therefore, it is recommended that examination of personality variables be used in future investigations of well-being. Longitudinal studies are needed to determine if introversion and control operate in a consistent manner throughout the duration of caregiving. Moreover, efforts should be made to delineate whether the loneliness experienced by caregivers is transient, situational, or chronic. Data are also needed about which social supports best mediate loneliness over the course of caregiving. Above all, comprehensive, comparative studies are needed with noncaregivers to enable a more accurate description of the influence of characterological, situational, and demographic variables on loneliness and other measures of well-being during caregiving.

In summary, the current study supports the presence of loneliness in Alzheimer's caregivers. Furthermore, it adds to the understanding of major explainers of loneliness in adults. The need to include both characterological and situational variables, in addition to cogent demographic factors, underscores the importance of utilizing a comprehensive approach to investigating various dimensions of well-being, including loneliness.

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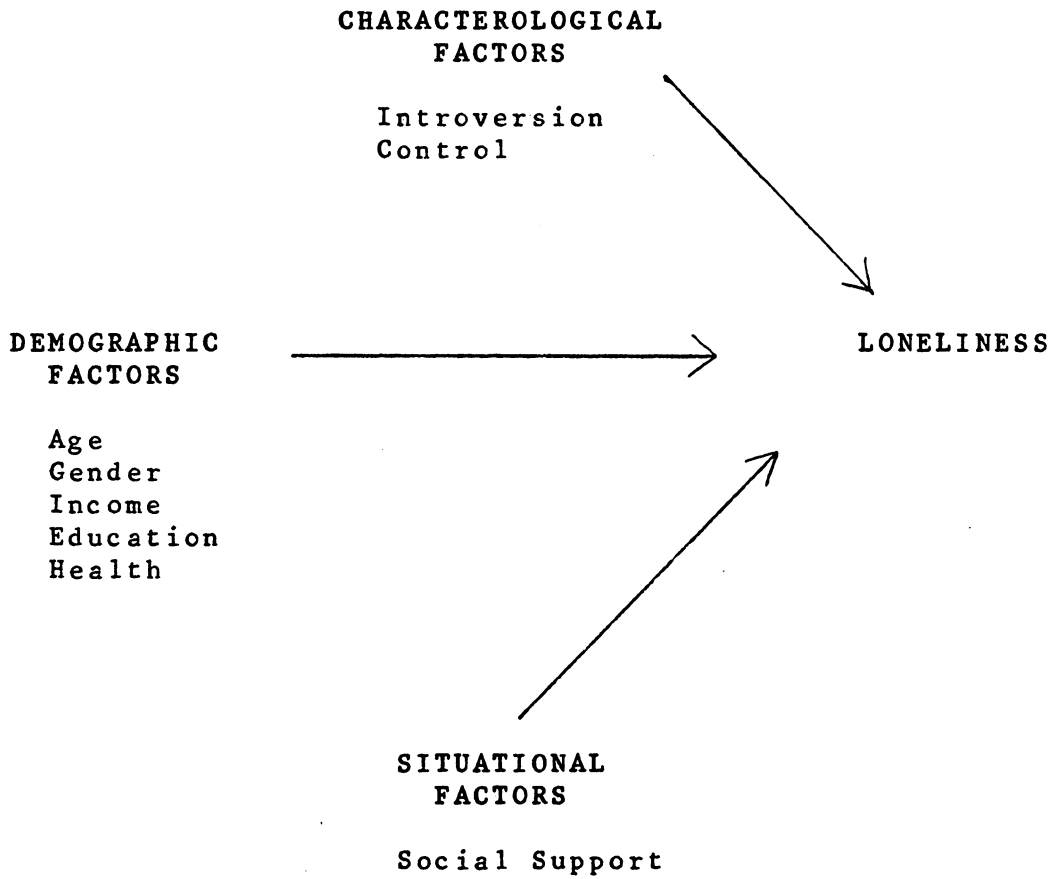


Figure 1

Model of Loneliness in Alzheimer's Caregivers

**Table 1**  
**Caregiver Characteristics**

Variable	number	percentage <sup>a</sup>
<b>Sex</b>		
Female	146	77
Male	44	23
<b>Age</b>		
22 - 40 years	33	17
41 - 60 years	64	34
61 - 84 years	93	49
<b>Annual Household Income</b>		
Less than \$10,000	19	10
\$10,000 - \$19,999	52	27
\$20,000 - \$29,999	44	23
\$30,000 - \$39,999	27	14
\$40,000 and above	48	25
<b>Education</b>		
Less than 12 years	25	13
High School diploma	54	28
Some College	42	22
College Graduate	50	26
Graduate School	19	10
<b>Relationship of Patient</b>		
Spouse	93	49
Parent	70	37
Other	27	14
<b>Residence of Patient</b>		
Caregiver's home	83	44
Other relative	29	15
Institution	61	32
Other	17	9

<sup>a</sup> Totals do not always add to 100% due to rounding errors.

Table 2

Mean Scores and Standard Deviations of Model Variables

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Variable	M	SD
Loneliness	2.15	.69
Control	3.23	.80
Introversion	108.38	29.56
Social Support	3.38	.54
Income	\$15,000-\$19,999	
	N = 190	

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Table 3

## Summary of Stepwise Regression on Loneliness

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Independent Variable	<u>Loneliness</u>	
	a r	Standardized Coefficient (Beta)
Social Support	-.75**	-.64**
Introversion	.43**	.21**
Control	-.47**	-.15**
Income	-.18**	.10*
R <sup>2</sup>		.63
Overall F		76.10**
N = 184		

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a  
Pearson Correlation Coefficient

\* p < .05  
\*\* p < .01



APPENDIX A

REVIEW OF LITERATURE

### Review of Literature

The purpose of this literature review is to describe in greater detail the studies that are most relevant to the current investigation. After a brief introduction on the importance of the current investigation, the remainder of this appendix is organized into five major sections. The first addresses the combined influences of situational and characterological determinants of loneliness across age-groups. In addition, studies of loneliness in caregivers are reviewed in-depth. The second section examines the pertinent research on control as it relates to dimensions of well-being, particularly loneliness. Attention is then focused on studies of control in the caregiver situation. The third section reviews the extraversion-introversion literature with special emphasis on studies of mature adults and those that have a Jungian theoretical rationale. The fourth section discusses the studies that examine social supports as they relate to dimensions of well-being, specifically in caregivers. The emphasis is on research that suggests the use of subjective assessments of social support. The final section briefly reviews studies that involve salient demographic and background variables that have been shown to impact on caregiver well-being and loneliness.

## Introduction

Senile dementia of the Alzheimer's Type affects five to ten percent of the population over the age of sixty-five (Zarit, Reever, & Bach-Peterson, 1980). The majority of those afflicted continues to live in the community with assistance from family members (Bergmann, 1975; Zarit et al., 1980). Care provided by family members is a strong determinant of whether the impaired person will remain in the community or be institutionalized (Fengler & Goodrich, 1979; George & Gwyther, 1986; Sanford, 1975; Shanas, 1979; Smyer, 1980; Zarit, Todd, & Zarit, 1986).

Caregiver functioning is determined by the context of caregiving and by characteristics of the caregiver more than by the extent of the patient's disability (Gwyther & George, 1986). However, caring for an impaired family member can produce various difficulties for the caregiver (Poulshock & Diemling, 1984). Moreover, caring for an Alzheimer's family member is a particularly stressful life event (Poulshock & Deimling, 1984; Robinson, 1983; Zarit et al., 1980). The mental and physical well-being of caregivers affects their ability to carry out their role. Since caregivers with lower levels of well-being may become limited in their capacity to respond to the demands of caregiving,

institutionalization of the impaired person may result (Poulshock & Deimling, 1984). Therefore, it becomes important to understand the dynamics involved in caregiver well-being. Unfortunately, much of the research on the impact of caregiving has been fragmented and methodologically flawed (Morycz, 1985).

Loneliness is one dimension of caregiver well-being that is in particular need of further investigation. Past research indicates that caregivers are at greater risk of loneliness because of reduced social supports and activities (George, 1983). Next to physical dependency, loneliness has been identified as the greatest fear associated with aging (Harris & Associates, 1975). Although loneliness is distressing in itself, it can also have serious repercussions. Loneliness has been related to suicide (Wenz, 1977), alcoholism and drug abuse (Rook and Peplau, 1982), various physical illnesses (Lynch, 1976; Paloutzian & Ellison, 1982; Rubenstein & Shaver, 1982), and depression (Weeks, Michela, Peplau, & Bragg, 1980; Wenz, 1977) in adult samples. Consequently, caregivers who are lonely may have an increased risk of developing other stress reactions.

The purpose of the present study is to examine the relationships between loneliness, the dependent

variable, and the independent variables: control, extraversion-introversion, and social support. The study specifies a conceptual framework for understanding loneliness in Alzheimer's caregivers and an explanatory model is generated and empirically tested. The model allows for the interplay of situational, characterological and certain demographic variables. Although Weiss (1973) suggests that situational and characterological variables are both contributors to loneliness, few previous studies have attempted to study both sets of variables in the same investigation (Weiss, 1982).

The following definitions were used throughout the current study:

1. Loneliness is a subjective, psychological construct that results from a deficit in social relationships (Weiss, 1973).

2. Control/Mastery is a multidimensional, psychological construct that indicates the belief an individual holds about the contingency relationship between the behavior of the individual and events which follow the behavior (Pearlin & Schooler, 1978).

3. Extraversion-introversion is defined according to Jung (1921) as a general attitude toward the world. Extraversion denotes the personal direction outward toward other people and objects; whereas, introversion

denotes attention and energy inward toward ideas (Jung 1921).

4. Social Support represents an inherent set of social needs. Six social needs have been identified by Weiss (1974): (a) guidance, provided by relationships with authoritative and trustworthy individuals who can give advice; (b) social integration, provided by a network of social relationships in which the individual shares interests and concerns; (c) attachment, provided by intimate relationships where the person receives a sense of safety and security; (d) opportunity for nurturance, provided through relationships in which the person is responsible for the well-being of another person; (e) reassurance of worth, provided by relationships where the person's skills, abilities, and talents are acknowledged; and, (f) reliable alliance, derived from relationships where the person can count on others for assistance under any circumstances (Russell, 1986; Weiss, 1974).

5. Alzheimer's caregivers are adult (over 21 years of age) family members or friends of individuals with Alzheimer's Disease who considers themselves to have primary responsibility for the patient. Membership in an active Alzheimer's Support Group in South Carolina denotes caregiver status in the current study even

though the term, caregiver, is recognized as having various interpretations (Cantor, 1983).

### Loneliness

There are many definitions of the psychological concept of loneliness (Andersson, 1985; de Jong-Gierveld 1978; Derlega & Margulis, 1982; Fromm-Reichman, 1959; Liederman, 1980; Lopata, 1969; Moustakas, 1961; Sadler & Johnson, 1980; Sermat, 1978; Sullivan, 1953; Weiss, 1973). These definitions generally share three characteristics: (a) Loneliness results in deficiencies in social relationships. (b) Loneliness, a subjective experience, is not related to objective social isolation. (c) Loneliness is experienced as distressing and unpleasant (Peplau & Perlman, 1982).

Two determinants of loneliness are situational factors and characterological variables (Peplau & Perlman, 1982; Weiss, 1973). Situational factors are events or circumstances that precipitate loneliness. They may change social relations or effect changes in the desired or expected social supports. Situational variables that may result in loneliness include: life cycle changes, relationship loss, and periods of stress. Examples of events associated with increased loneliness are relocation, hospitalization, divorce (Weiss, 1982), and widowhood (Lopata, 1979).

On the other hand, characterological variables are personality traits or characteristics that may predispose individuals to loneliness. These include anxiety (Ellison, 1978), neuroticism (Hojat, 1982), shyness, less willingness to take social risks, introversion, and low self-esteem (Weiss, 1982).

The use of both situational and characterological variables provides a comprehensive framework for investigating loneliness (Weiss, 1982). However, relatively few studies have examined the joint influence of situational and characterological variables on loneliness. Weiss (1982) noted two trends in loneliness research that have fostered limitations in researching loneliness. First, many studies have used a relatively constant interpersonal situation such as divorce or hospitalization. This research approach emphasizes characteristics as determinants of loneliness while ignoring the impact of the situation (Weiss, 1982). In contrast, most large surveys have failed to obtain personality data and rely solely on situational explainers of loneliness (Weiss, 1982).

Recently, situational and characterological variables have both been recognized as important to the examination of loneliness. To illustrate, Stokes (1985) used objective measures of social network variables as



well as measures of extraversion, neuroticism, and self-disclosure to examine loneliness in a sample of undergraduate college students. He found network density to be the only significant situational variable related to loneliness. Although he used both situational and characterological variables in the investigation, the use of a college student sample does not permit the generalization of findings to other age-groups. The sample consisted largely of young individuals who lived with their families of origin, were never-married, and did not live in geographically heterogeneous areas. In addition, Stokes (1985) focused on objective measures of social support. Generally, objective measures of support have not been shown to significantly correlate with measures of well-being (Antonucci, 1985; Krause, 1987; Mullins & Johnson, 1986)

There has been no lack of research into loneliness and the older adult (Andersson, 1984; Baum, 1982; Berg, Mellstrom, Persson, & Svanborg, 1981; Creecy, Berg, & Wright, 1985; Kivett, 1979; Lopata, 1969; Mullins & Johnson, 1986; Peplau, Bikson, Rook, & Goodchild, 1982; Peplau & Perlman, 1982; Perlman, Gerson, & Spinner, 1978; Revenson & Johnson, 1984; Schultz & Moore, 1984; Townsend, 1973). Despite the results of previous investigations, the myth that older people are at

greater risk of experiencing loneliness still exists (Revenson, 1986). For the most part, researchers have found that age, per se, is not predictive of loneliness (Rubenstein & Shaver, 1982). As a result of this insight, studies of loneliness in later life are beginning to examine specific situational and characterological determinants. There are several studies that have a bearing on the current investigation.

In examining loneliness in 131 elderly residents of a high-rise apartment unit, Mullins and Johnson (1986) found that respondents with no children or grandchildren were lonelier. However, overall, the amount of contact with family had no impact on loneliness; whereas, greater contact with neighbors and friends related to less loneliness. Mullins and Johnson (1986) further noted that individuals, who identified themselves as having no neighbors or friends also, reported less loneliness. It seems apparent from this study that neither actual contact nor specifically identified relationships successfully account for loneliness.

In a study of 57 older community-dwelling adults, Schultz and Moore (1984) investigated the personal characteristics that are related to loneliness. They concluded that loneliness was associated with anxiety, depression, and low levels of life satisfaction. These

results support earlier studies which used samples of college students (Goswick & Jones, 1981; Hojat, 1982; Weeks et al., 1980). Using the same sample in an earlier analysis, Moore and Schultz (1982) reported that the two unrelated measures of responsibility and control were both associated with self-reported loneliness. These two studies are noteworthy because they examine characterological variables, even though specific situational influences were not addressed.

Within the literature on loneliness in older adults, one investigation has particular importance for the current study. Creecy et al., (1985) formulated and empirically tested a causal model of loneliness in older adults. Drawing their sample of 2,797 from a larger survey of noninstitutionalized adults, they examined the causal relationship between five background variables (marital status, health, age, income, and sex) on social activities, social fulfillment, and loneliness. Path analysis found that social fulfillment was the most important predictor of loneliness in the causal model. The specified variables accounted for 36% of the variance in loneliness. The results of the Creecy et al. (1985) investigation indicate that loneliness in older adults is a combination of direct and indirect influences of the specified variables. It

should be noted, however, that this research did not examine the issue of characterological differences in loneliness. As mentioned earlier, this is a common flaw in the research of loneliness (Weiss, 1982).

Three observations emerge from the literature reviewed above. First, research using characterological variables in a study of loneliness in older adults found support for earlier findings that used college-aged samples (Schultz & Moore, 1984). This indicates that characterological variables are important in the study of loneliness in various age-groups. Second, the results of other recent investigations (Creedy et al., 1985; Mullins & Johnson, 1986) suggest that subjective assessments of social support might be a more valid approach to examining loneliness in community-dwelling adults than purely objective assessments of social interaction. Finally, the use of a causal model of loneliness (Creedy et al., 1985) supports the definition of loneliness as a psychological concept that can be explained, in part, by a combination of background and situational variables.

Recently, there has been a phenomenal growth in the number of studies that have investigated negative dimensions of well-being in Alzheimer's caregivers (Chenoweth & Spencer, 1986; Fitting, Rabins, Lucas, &

Eastham, 1986; George, 1983; George & Gwyther, 1986; Gwyther & George, 1986; Jenkins, Parham, & Jenkins, 1985; Montgomery, Stull, & Borgotta, 1985; Morycz, 1985; Poulshock & Deimling, 1984; Robinson, 1983; Thompson & Doll, 1982; Zarit et al., 1980; Zarit et al., 1986). In spite of the evidence that caregivers experience reduced social activities and social supports, scant research exists on loneliness in caregivers. For the most part, research into Alzheimer's caregiver loneliness has been sparse, descriptive, post hoc analysis.

For instance, in a statewide study of Alzheimer's caregivers (George, 1983), a post hoc analysis indicated that caregivers had a higher lonely dimension factor on the Affect-Balance Scale. This was related to moderate levels in social activity and low levels of social support. Another recent study by Fitting and associates (1986) also used a post hoc analysis to examine the age of caregivers in relation to loneliness. Younger caregivers were found to be more lonely based on higher scores on two subscales (psychopathic and paranoia) of the Minnesota Multiphasic Personality Inventory (MMPI).

Similarly, George and Gwyther (1986) compared a sample of 510 caregivers of impaired older adults to a random community sample. They found caregiver burden

was primarily experienced in the areas of social participation and mental health. In a survey of 289 caregivers, Chenoweth and Spencer (1986) observed that caregiving affected the caregiver's relationship with other people. Isolation, reduced social contacts, and fewer visits from friends were among the changes caregivers experienced due to caring for a dependent elder. Previously, Cantor (1983) had interviewed 111 caregivers and found that caregivers were often forced to adjust their lives to the increasing demands of caring for a dependent older person. This adjustment included a reduction in time to socialize with friends which contributed to the emotional strain of the caregivers. These three studies support the conclusions of an earlier investigation by Rabins, Mace, and Lucas (1982). They observed that half of a sample of 55 caregiver families experienced a significant loss of friends and increased family conflicts due to the demands of caregiving.

Although the studies above identified difficulties in the social activities and relationships of caregivers, they did not examine the consequences of the reduced activity. In a study of the Swedish aged, Berg and associates (1981) concluded that isolation from friends and family in addition to low levels of social activity

are associated with loneliness. However, one study was found to directly address the issue of loneliness in caregivers. In an exploratory study, Qualls, Norfleet, and Harder (1986) examined the nature and intensity of loneliness in four groups: (a) spouses of the demented, (b) spouses of the physically handicapped, (c) spouses of the normally aging, and (d) spouses of the demented and physically handicapped. It was found that the three groups containing caregivers of impaired spouses experienced significantly more loneliness than the normal group. Qualls et al. (1986) concluded that the type of impairment is not an important factor in determining the level of loneliness in caregivers but that all three caregiver groups experienced greater loneliness than the spouses in the normally aging group. Furthermore, the friendship subscale score of the Differential Loneliness Scale was found to be the only statistically significant predictor of loneliness. The friendship subscale accounted for approximately 20% of the variance in loneliness. Qualls and associates observed that loneliness in spousal caregivers is significantly related to perceived support, especially support from friends.

The Qualls and colleagues (1986) investigation has several important implications for the current study.

First, the finding that caregivers of spouses with various disabilities are lonelier than spouses of normally aging persons supports the premise of the current study that caregivers are lonelier than adults who do not experience caregiving. Second, the significance of the friendship subscale in predicting loneliness (Qualls et al., 1986) indicates a need for further examination of social support provided by friendship. Finally, this study, like the previously reviewed Creecy et al. (1985) research, did not consider specific background or situational variables, an approach recommended by Weiss (1982) for investigating loneliness.

To summarize, apart from the exploratory investigation by Qualls and her associates (1986), the majority of what is known about loneliness in Alzheimer's caregivers is based on descriptive, post hoc observations that are related to caregiver burden or stress. Even though these studies provide useful and interesting insights into caregiver loneliness, the focus necessary for understanding precisely which caregivers experience loneliness and why certain caregivers experience greater loneliness than others, is not provided. As mentioned earlier, none of the reviewed investigations attempted to study personality



variables as they relate to well-being in Alzheimer's caregivers. Missing from the literature are studies on the determinants of loneliness in Alzheimer's caregivers and studies of loneliness in mature adults using both situational and individual characterological variables in the same investigation. The results of existing research offer logical support for an investigation of loneliness in Alzheimer's caregivers using situational, characterological and background variables.

### Control

Pearlin and Schooler (1978) defined mastery or control as the extent to which individuals believe they control their own lives. According to Rotter (1966), locus of control orientation represents generalized views of personal control. Internal control denotes a belief in the individual's ability to achieve a direct impact on the external environment. External locus of control denotes a belief that results or rewards are dependent on forces outside of the individual.

Certain personality variables may be considered as personal resources during stressful periods (Johnson & Sarason, 1978). Control is an example of such a variable (Holahan & Holahan, 1987). An examination of the early literature shows a positive relationship between internal locus of control and mental adjustment,

coping with stress, and life satisfaction (Eaton, 1978; Hanes & Wild, 1977; Johnson & Sarason, 1978; Kivett, Watson & Bush, 1977; Kuypers, 1972; Lin, Simeone, Ensel, & Kuo, 1979; Palmore & Luikart, 1972; Pearlin & Schooler, 1978; Schulz & Decker, 1985; Vinokur & Selzer, 1975; Wheaton, 1983; Wolk, 1976). Consequently, loss of control has been found to be associated with decreased physical and mental health, increased mortality, and reduced well-being (Langer & Rodin, 1976; Schulz, 1976; Schulz & Aderman, 1973; Schulz & Brenner, 1977). However, the relationship between control and dimensions of well-being remains a complex one.

To illustrate, in a laboratory experiment, Houston (1972) found that subjects performed better under stressful conditions when there was agreement between their beliefs about control and their beliefs about the specific stressful situation. Subjects with greater control became more physiologically aroused when they believed they could influence the outcome of the experiment. In contrast, subjects who had less control and did not think they were responsible for the outcome experienced less stress. Believing an event is uncontrollable does not necessarily lead to a negative outcome. This has implications for the Alzheimer's caregiver situation because the progression of that

disease and its eventual outcome are not controllable. The results of studies of the relationship between control and well-being are inconsistent.

However, in one field study of institutionalized elders by Felton and Kahana (1974), it was concluded that external locus of control related positively to well-being. It was suggested that this finding resulted from congruence between externality in the individual and the fact that many aspects of institutional life are externally controlled. The results indicate that situational factors can impact on the association between control and well-being.

In addition to the studies that have related control to general well-being, a number of researchers have also determined that locus of control and loneliness are related. External locus of control has been correlated to the experience of loneliness in adolescents (Brennan, 1982; Brennan & Auslander, 1979) and in older adults (Schulz & Hanusa, 1980).

In a field experiment, Schulz (1976) demonstrated the importance of feelings of personal control in lessening loneliness even when the actual amount of social contact was the same. Results indicate residents in a retirement home, who could predict the frequency and duration of visits from college students, reported lower levels of loneliness than residents, who had the

same amount of visitation time, but could not predict or control visits.

Schulz and Hanusa (1980) later studied the long-term impact of control in a similar study. They found the positive effects to be temporary. It was concluded that once the ability to control and predict outcome had ended, there were no permanent changes in the self-perception of control. In contrast to these findings, Rodin and Langer (1977) found positive long-term effects on social participation and general well-being when an emphasis on taking responsibility for the outcome in addition to controlling it was added as a variable in the investigation.

In a study of 57 older community-dwelling adults, a statistically significant correlation was found between scores on the UCLA Loneliness Scale and a measure of control (Schultz & Moore, 1984). Lonelier individuals showed an external locus of control; whereas, less lonely individuals had an internal locus of control. Thus, there is a general trend in the literature that indicates increased personal control is associated with lower levels of loneliness.

Although a number of recent investigations have focused on control experienced by caregivers, to date none have related control to loneliness. Rather, the

majority of studies have made post hoc observations about broad aspects of caregiver control. For instance, Coppel, Burton, Becker, and Fiore (1985) noted that because of the strenuous demands of caregiving, spousal caregivers often lose control over major portions of their lives. This observation was supported in a later study that found caregivers experience a loss of social activities and social supports (George & Gwyther, 1986). Fitting and her associates (1986) observed that caregivers of dementia patients may feel powerless to change the outcome of their situation. The perception of lack of control may account for feelings of despair and depression. Furthermore, Lowenthal & Robinson (1976) emphasized the importance of maintaining control over social interaction for positive well-being. They suggest that loss of control over social activities may have an impact on well-being and recommend additional research in this area. It should be noted that these four studies did not use specific measures of control. Rather, they inferred control after they analyzed their data to address other research questions.

However, one recent exploratory study did use a specific measure of control to investigate the caregiver situation. Scott and Roberts (1986) administered Rotters Internal-External Locus of Control measure to a

small sample of Alzheimer's caregivers in order to examine caregiver coping. Locus of control was not statistically significantly correlated with perception of support from family or with the amount of conflict in caregivers (Scott & Roberts, 1986). It was concluded that control did not differ according to the stress the caregiver experienced. Consequently, the hypothesis that there will be a positive association between control, coping, and self-perception was not supported (Scott & Roberts, 1986). Therefore, the results support the premise that control is an independent personality variable since it was not related to either the level of strain, the amount or kind of support, or caregiver self-perception.

Although control is an important variable in the study of loneliness and other dimensions of well-being, there is evidence that suggests control should not be examined according to internal-external directionality when used in a study with extraversion-introversion (Morris, 1979). This argument will be presented in the next section.

#### Extraversion-introversion

Extraversion-introversion is a personality trait that emerges early in life and remains stable over time (Bronson, 1966; Costa & McCrea, 1978; Schaie & Parham,

1976; Wilson, Brown, & Matheny, 1971). The dimension reflects an actual, rather than a perceived, orientation and is independent of locus of control (Collins, Martin, Ashmore, & Ross, 1973).

The concept of extraversion-introversion in the current study is defined according to Carl Jung's theory of personality. Jung's (1921) theory is based on the assumption that human behavior, often considered as diverse and random, is actually orderly and consistent. He suggested that the ego has two orientations: extraversion, a turning toward the world of people and things; and introversion, a turning toward subjective, internal experiences.

The extraversion-introversion dimension does not purport to measure shyness versus gregariousness (Stricker & Ross, 1964). Rather, it is an individual's orientation to experiencing the world. In reviewing the literature, Morris (1979) concluded that extraversion-introversion differentiates among individuals in one or more of the following ways: (a) social activity, (b) social facility, (c) risk taking, and (d) preference for objectivity or abstraction.

Moreover, Jung (1921) hypothesized that although a person's basic orientation does not change with age, after midlife there is a preoccupation with self and a

turning inward. Thus, there is an increase in interiority or introversion. This turning inward is a process as opposed to a state (Bozarth, Barry, Myers, & Heyn, 1985). The age-trend of increased interiority or introversion has been observed in a number of studies (Weiss, 1982).

For example, the Kansas City Studies (Neugarten, 1977) demonstrated a definite increase in introversion with age. This increase was supported by the Swenson, Pearson, and Osborne (1973) observation that introversion increased with age on the MMPI introversion subscale. In studying the stability of personality traits, Costa and McCrea (1978) noted that although extraversion remains stable over time, a shift from the dominance to the affiliative side of extraversion with age may indicate an age-change in trait expression within a stable domain. The Costa & McCrea (1978) finding is in agreement with Jung's (1921) theory that inherent orientation does not change with time but more introversion is expressed.

Attention will now be focused on the relationship between introversion and locus of control because confusion may exist over the association between the two variables (Morris, 1979). As mentioned in the previous section, locus of control has been found to be



statistically significantly correlated to loneliness in different age-groups (Brennan, 1982; Brennan & Auslander, 1979; Schultz & Moore, 1984). In addition, introversion has also been statistically correlated with loneliness (Jones, 1982; Russell, Peplau, & Cutrona, 1980). However, studies that have examined the association between locus of control and introversion have concluded that they are independent personality variables and are not related (Collins et al., 1973; Eliot & Hardy, 1977).

As stated earlier, it is important that the issue of externality and internality of control be considered when used in studies with extraversion-introversion. According to Collins et al. (1973), the extravert is probably more attuned to external or social influences; whereas, the introvert is more attuned to internal forces. Further, it is probably more accurate to conceptualize extraverts and introverts as being affected differently by different environmental and internal conditions. Thus, Collins and associates (1973) concluded that the level of control is more important than the directionality when studying the personality variables of extraversion-introversion and control.

No investigation combining loneliness and

introversion in older samples was found. This is noteworthy because of the number of large-scale studies that have demonstrated that loneliness declines with age (Blau, 1973; Fidler, 1976; Lowenthal, Thurner, & Chiriboga, 1976; Rubenstein & Shaver, 1980; Shanas, 1968); whereas, introversion increases with age (Jung, 1921; Neugarten, 1977; Swenson et al., 1973). Clearly, a need existed to examine both introversion and loneliness in a mature adult sample. Furthermore, Morris (1979) recommends that extraversion-introversion in combination with situational variables should be considered when studying social and interpersonal processes.

### Social Support

Social support plays an important role in maintaining well-being and decreasing susceptibility to distressing outcomes (Arling, 1987; Hirsch, 1980; Holahan & Holahan, 1987; Kulus & Tobin, 1980; Liang, Dvorkin, Kahana, & Mazian, 1980; Lin et al., 1979; Luke, Norton, & Denbigh, 1981; Schulz & Decker, 1985; Stephens & Bernstein, 1984; Strain & Chappell, 1982; Theorell, 1976; Treas, 1977; Ward, Sherman, & La Gorg, 1984; Wilcox, 1981; Williams, Ware, & Donald, 1981). Social support can buffer stressful life events (Antonovsky, 1979; Caplan, 1974). According to van Tilburg and de Jong-Gierveld (1984), relationships are supportive if

the individual believes they provide intimacy, caring, emotional support, practical help, and information. A large social network and sufficient contact with family and friends are not necessarily considered social support (McFarlane, Norman, Streiner, & Roy, 1983). Social support of caregivers have been considered, directly or indirectly, in a number of studies without conclusive results.

As discussed earlier, it has been observed that social contacts and social activities of family caregivers of Alzheimer's patients are restricted as a result of the caregiving experience (Burnley, 1985; Chenoweth & Spencer 1986; George & Gwyther, 1986; Lezak, 1978; Mace & Rabins, 1981; Zarit et al., 1980; Zarit et al., 1986). However, it is not known what this observation means in terms of loneliness in Alzheimer's caregivers. With the exception of just one exploratory study that used a small sample, social support and loneliness have not previously been examined together in caregivers.

In the past, the majority of research on social support of caregivers has concentrated on dimensions of burden or strain. Loneliness was only considered as a portion of caregiver burden and not as a distinct and separate psychological dimension. Moreover, this

limitation has been compounded by examining social support according to instrumental assistance and frequency of contact measurements and not according to the needs met. Consequently, as previously noted, these two approaches have produced inconclusive results.

Repeatedly, research has found that objective measures of caregiver support are not predictive of burden or strain (Qualls et al., 1986). For instance, Zarit and colleagues (1986) totaled weekly frequency assistance from formal and informal sources of social support for a sample of Alzheimer's caregivers. Neither the type of support nor the frequency was statistically correlated with either caregiver well-being or the institutionalization of the patient. In addition, emotional support and instrumental aid were not related to caregiver morale. However, it should be noted that in an earlier, exploratory investigation of 29 Alzheimer's caregivers conflicting results were found (Zarit et al., 1980). Zarit and associates observed that frequency of family visits was the only variable under investigation that significantly related to the level of burden experienced by the caregivers in their earlier investigation. It was concluded that the small sample size in the first study may have biased the results.

Other researchers have found only weak statistical correlations between objective measures of social support and well-being. Jenkins et al. (1986) observed that measures of social support as assessed by the amount of assistance received from formal and informal sources were only weakly related to level of burden in Alzheimer's caregivers. The amount of help received was objectively assessed and not the qualities of relationships. Jenkins and associates (1986) hypothesized that the caregiver experience may be so demanding that despite the amount or kinds of actual support provided, the degree of caregiver burden is not lessened. Furthermore, Jenkins et al. recommended that future research include a more comprehensive analysis of the role of social support for caregivers since counting instrumental behaviors was not significantly related to dimensions of well-being.

Similar findings were observed in a study of 501 caregivers by George (1983). It was concluded that subjective social support had greater statistical significance than measures of objective support when it comes to assessing caregiver well-being. In comparing a sample of caregivers with the general population, George observed that the caregivers experienced deficits in social activities and supports. However, these

deficits were not significantly related to measures of well-being.

In a purposive sampling of 614 families, Poulshock and Deimling (1984) concluded through measures of impact on caregivers, that social relationships are affected by caregiving. Although they did not investigate specific relationship functions, they found that social and group activities were generally reduced by the demands of caregiving. Poulshock and Deimling (1984) recognized the importance of subjective perceptions of caregivers in analyzing the impact of caregiving.

Chenoweth and Spencer (1986) examined how caregiving affected the relationships of caregivers. In a survey of 289 caregivers, Chenoweth and Spencer found that caregiving resulted in isolation, reduced social contacts, and fewer visits from friends as the responsibilities of caring for a dependent older person increased. In a smaller sample of 55 caregivers, Rabins and associates (1982) found that caregivers reported loss of friends and increased family conflict due to caregiving responsibilities.

Available studies of caregivers suggest that reduced social activity and relationships result from increased caregiving involvement. This finding was confirmed in a comparative study of spousal caregivers

of patients with various impairments and a normal group of spouses (Qualls et al., 1986). It was found that when the time and energy demands of caregiving increase, opportunities for social interaction are decreased.

The loss of social support can be a serious one for never-married caregivers. In a study of single women caregivers, Burnley (1985) concluded that the relationships that single caregivers surrender to the demands of caregiving are more important than comparative social relationships of their married counterparts. The needs met by social relationships and activities in single caregivers may differ from those met by the social relationships of married caregivers. The spouse and other family members can provide social support to married caregivers that is normally provided in the social relationships and activities of the single caregiver. Additional research is needed to determine specific relational differences between single and married caregivers (Burnley, 1985).

Evidence suggests that loneliness is related more to the subjective aspect of dissatisfaction with relationships than with objective measures of interaction. In studies of older adults, objective measures of social support such as frequency of visits, number of friendships, and living arrangements have not

been significant predictors of dimensions of well-being (Harel & Deimling, 1984; Liang et al., 1980; Ward et al., 1984). It has been argued that perceived adequacy of support may be the best predictor of well-being (Antonucci, 1985; Russell, 1986).

In an investigation of rural elders, Kivett (1979) observed that loneliness resulted from the need for a specific type of relationship and not from the desire for company or the number of social exchanges. In reviewing the literature on social support, Lieberman (1982) concluded that the most salient variable related to social support and stress reduction is the individual's perception of reliable social supports, not whether, or how frequently, the supports are used. As a result of their research, Peplau and Perlman (1979) observed that subjective measures of satisfaction with social relationships are a more appropriate predictor of loneliness than objective measures.

This trend in the social support literature led Lieberman (1982) to observe that a definite need exists to discover strategies for combining the best of survey research techniques with the collection methods that are most often used in obtaining data from small, clinical samples. Moreover, Conner, Powers, and Bultena (p. 120; 1979) cautioned that researchers must stop asking such



questions as "how many" or "how often" social interaction occurs. Instead, attention should be directed towards understanding the broader meanings behind social relationships and the interaction process.

Russell, Cutrona, Rose, and Yurko (1984) used a subjective assessment of social support to examine loneliness in a sample of college students. Their approach was based on Weiss' (1974) conceptualization of social support and loneliness. According to Weiss, different types of relationships meet different needs or satisfy different "social provisions". Weiss suggested that there are two kinds of loneliness, social and emotional. Russell and associates (1984) found that emotional loneliness was related to the social provision of attachment in a study of college students. Usually, attachment is provided by a marital or romantic relationship. In addition, Russell and colleagues found that social loneliness was related to several social provisions that resulted from deficiencies in the social network. In conclusion, social and emotional loneliness appear to be related to different relational deficits. Social loneliness results from lack of friendship support; whereas, emotional loneliness results from a deficit in a romantic relationship. Although the two kinds of loneliness have different

deficits, they also can overlap (Russell et al., 1984).

Although Russell and colleagues (1984) investigated the relationship between subjective social provisions and loneliness, there were two limitations to the study. First, by using college students, the sample was homogeneous. This led to an emphasis on situational similarity that Weiss (1974) identified as one of the limitations that has produced flawed research on loneliness. Second, although the Weiss topology of loneliness and social provisions was used, the investigation ignored characterological influences as contributors to loneliness. This resulted in a situationally biased study that neglects the characterological determinants of loneliness (Weiss, 1974). It becomes apparent, after reviewing the literature on loneliness, that both situational and characterological variables should be used together in examining loneliness.

#### Background Variables

A number of background variables have been identified as important to understanding loneliness in adults. However, it should be noted that considerable controversy exists over which demographic variables are associated with loneliness in different samples. The

most salient of these variables are discussed next.

Age. Contrary to popular belief, the literature indicates that older people are not lonelier than younger people (Blau, 1973; Creecy et al., 1985; de Jong-Gierveld, 1984; Fidler, 1976; Harris & Associates, 1975; Lowenthal & Robinson, 1976; Rubenstein & Shaver, 1982; Weiss, 1982). For the most part, less loneliness has been reported as individuals age (Rubenstein & Shaver, 1982; Weiss, 1982). However, this is not conclusive.

In a comparative study of loneliness in different age-groups, Andersson (1984) found that the adolescent and old-age groups were higher in loneliness than the intervening age-groups. In examining loneliness in caregivers, Fitting and her colleagues (1986) observed that younger caregivers reported more loneliness than older caregivers. Whereas, in a study of older adults, Schultz and Moore (1984) concluded that age was not significantly correlated with performance on the UCLA Loneliness Scale. In sum, the effect of age on loneliness remains a controversial issue.

Gender. There is also confusion over the influence of gender on loneliness (de Jong-Gierveld, 1984; Gove, 1972; Wheeler, Reis, & Nezlek, 1983). In an investigation of loneliness in the elderly, Creecy and

associates (1985) found that gender did not statistically account for variance in loneliness. However, in a longitudinal study of caregiver burden (Zarit et al., 1986), women initially reported greater subjective burden than men. Two years later in a follow-up study, Zarit and his colleagues found that there was no difference in loneliness between the men and women.

In research using the UCLA Loneliness Scale, Schultz and Moore (1984) found that in a sample of elderly people, gender was not significantly related to loneliness. In summary, the literature indicates that gender is not consistently statistically associated with loneliness.

Health. Generally, loneliness has been found to be significantly related to lower levels of health (Perlman et al., 1978). Creecy and associates (1985) found that health was the second most important background variable in their causal model of loneliness in older adults. Creecy et al. (1985) concluded that health played a particularly important role in determining social activity and social fulfillment, both of which then impacted on loneliness.

Marital status/household composition. For the most part, the literature on marital status and loneliness indicates that marriage lessens the likelihood of

loneliness (Peplau et al., 1982). Creecy et al. (1985) reported that marital status accounted for the greatest variance in assessing loneliness in older adults.

However, as Lowenthal and Robinson (1976) pointed out, aloneness is not the same as loneliness. People who live alone are not more lonely when such factors as divorce, separation, and widowhood are taken into account (Lopata, 1979). In addition, Gubrium (1974) observed that divorced and widowed older adults had lower life satisfaction than marrieds and ever-single people. However, Gubrium (1974) made the distinction between isolation, or the lack of social involvement, and desolation, the unpleasant experience of being left alone due to loss.

In addition to marital status, household composition has been shown to influence well-being. Perlman et al. (1978) found greater loneliness among single older adults who lived with relatives than among those who either lived alone or lived with friends.

Socioeconomic status. The combination of income and education has been used to determine socioeconomic status (SES) in a study of caregivers by Brody, Kleban, Johnsen, Hoffman, and Schoonover (1987). They found that lower SES resulted in caregiver stress and difficulty in coping. This, in turn, suggests a

relationship to the previously discussed studies on caregiver burden and strain. Investigations of loneliness generally support the finding that loneliness is higher when income is lower (Creecy et al., 1985; Weiss, 1973). However, Thompson and Doll (1982) concluded in an examination of burden that social costs of caregiving are not related to sociodemographic characteristics. Therefore, the influence of income and education on loneliness in caregivers is unknown.

In sum, a review of the literature reveals that the demographic variables of: age, gender, marital status, and, household composition are not usually statistically significantly related to loneliness. On the other hand, health and socioeconomic status has been shown to correlate with loneliness. However, because so little is known about loneliness in Alzheimer's caregivers, the influence of specific demographic variables is in need of further study.

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**APPENDIX B**

**METHODS**

## Methodology

This appendix describes in greater detail the pilot study and sample used in the current investigation. In addition, it more fully explains the procedures used in data collection and data analysis

### Pilot Study

In May, 1986, the first pilot survey was sent to a sample of eight caregivers in Southwestern Virginia. This phase had three primary purposes: (a) to identify confusing or ambiguous items, (b) to determine if response choices provided adequate item variance, and (c) to obtain overall reaction to the questionnaire content.

As a result of feedback from the participants of the first phase of the pilot, the questionnaire was refined. Then the modified instrument was administered to six Alzheimer's caregivers on the West Coast of Florida in March, 1987. The second phase of the pilot fulfilled the same three purposes as the initial phase with the additional objective to evaluate graphics and print quality.

### Sample

Names and addresses of caregivers were solicited from the fifteen active Alzheimer's Support Groups in South Carolina. Even though the sampling frame did not

generate a random sample of caregivers of Alzheimer's patients, it did yield a heterogeneous sample from urban and rural areas throughout the state.

Attempts to obtain sample representativeness present a difficult problem in chronic illness research (Watson & Kendall, 1983). Nonprobability sampling has been widely used in studies of caregivers (Cantor, 1983; Coppel, Burton, Becker, & Fiore, 1985; Fitting, Rabins, Lucas, & Eastham, 1986; George & Gwyther, 1986; Jenkins, Parham, & Jenkins, 1985; Poulshock & Deimling, 1984; Zarit, Reeve, & Bach-Peterson, 1980; Zarit, Todd, & Zarit, 1986). Therefore, purposive sampling was deemed an acceptable method for the present investigation of loneliness in Alzheimer's caregivers.

All of the fifteen active Alzheimer's Support Groups in South Carolina agreed to participate in the study. Support groups that participated were: Abbeville, Aiken, Anderson, Beaufort, Charleston, Clemson, Columbia, Florence, Greenville, Manning, Moncks Corner, Orangeburg, Rock Hill, and Spartanburg (2). The local support groups either provided the investigator with a membership list, or agreed to address and mail the survey packets, or distribute the questionnaires themselves.

Five support groups expressed a strong desire to

protect their membership mailing lists and only agreed to participate in the study if they retained control of their membership lists. The five support groups that retained control of their membership lists during the study were: Aiken, Beaufort, Charleston, Columbia, and Spartanburg (1).

In a recent study, Caserta, Lund, Wright, and Redburn (1987) addressed the issue of confidentiality of support group mailing lists. They found that only 43.3% of caregiver support groups agreed to release membership lists to researchers. Consequently, Caserta and associates concluded that questionnaires that could not be directly mailed to subjects should be either passed out at group meetings or mailed by the support groups in order to increase participation.

Previously, Zweibel (1986) made a similar observation after reviewing the literature on sample recruitment in caregivers. She noted that as much as 60% of potential caregivers are lost before data collection begins and suggested that investigators adopt procedures that create favorable circumstances for caregivers and their support groups in order to increase response rates. For this reason, a procedure that allowed support groups to maintain control of their mailing lists was used in the current study. The total

number of members for the fifteen support groups was 357.

All correspondence with support group contact persons and prospective subjects contained a statement assuring participants of confidentiality and requesting their voluntary participation in the project (See Appendix C). Neither names nor any identifying location information appeared in the survey packets. Instead, each questionnaire had a participant number which was used for tracking purposes only. The list of corresponding names and identification numbers was kept separate from data sheets.

#### Procedure

The Total Design Method (TDM) was used in this study in order to heighten response rates (Dillman, 1978). The research instrument consisted of a mailed questionnaire formatted according to Dillman's (1978) guidelines.

The names and addresses of contact persons for each of the Alzheimer's Disease Support Groups were requested from the South Carolina Commission on Aging. A letter was sent to each contact person explaining the research project and asking for a copy of the Support Group mailing list (See Appendix C). A self-addressed stamped envelope was included with each letter.



The letter was printed on St. Francis Xavier Hospital letterhead stationery. It was cosigned by the Educational Coordinator of St. Francis Xavier Hospital, Charleston, South Carolina. The cosigner was used to foster credibility and provide community and state identification. In addition to requesting their voluntary cooperation in the study, the letter described the purpose of the survey, the potential usefulness of the information, and the confidential nature of the data (See Appendix C).

Telephone calls and personal meetings with representatives of the support groups were used as necessary to encourage participation. Thirteen support groups required telephone calls and/or personal meetings to secure their cooperation in the survey.

Next, survey packets were mailed on March 27, 1987 to individuals, when mailing lists had been made available, or to the five support groups which had agreed to distribute the surveys themselves. Each survey packet contained: (a) A letter, on St. Francis Xavier Hospital letterhead stationery, explaining the nature of the survey and requesting their help. (b) A printed questionnaire. The questionnaire consisted of three 22 cm by 28 cm sheets of paper, folded and stapled in the middle. The pages of the questionnaire were

typed then photographically reduced before reproduction on white paper. The cover included the project title, Alzheimer Caregiver Support Project, and the study sponsors names and addresses: St. Francis Xavier Hospital, Charleston, South Carolina and Department of Family and Child Development, Virginia Polytechnic Institute and State University. In addition, a graphic illustration symbolizing the caregiver-patient bond was used on the cover which was made of light aqua colored cover-stock paper (Appendix D). (c) A form designed to ensure that respondents were qualified caregivers of an Alzheimer's patient before completing the survey. The respondent was asked to return the uncompleted questionnaire if not presently a caregiver of an Alzheimer's patient. The form was printed on bright blue paper and inserted in the front of the questionnaire to increase the likelihood of it being read before the questionnaire. And, (d) a self-addressed, stamped envelope. (See Appendix C for all correspondence and form.)

One week after the initial mailing a follow-up postcard was sent. The postcard thanked those who had responded and served as a reminder to those who had not. A week later, a follow-up letter was mailed to individuals who had not yet responded. A final letter was sent to those who had still not returned a completed

questionnaire or disqualifying form three weeks after the original mailing. The final mailing also included another copy of the questionnaire and a return envelope (See Appendix C for all correspondence).

These follow-up procedures are designed to encourage maximum respondent participation in mail surveys (Dillman, 1978; Heberlein & Baumgartner, 1981; Yu & Cooper, 1983). The follow-up correspondence was printed on St. Francis Xavier letterhead stationery and all return envelopes were addressed to St. Francis Xavier Hospital in order to strengthen community awareness and state identification.

#### Instrumentation

The questionnaire included scales and questions that assessed: loneliness, control/ mastery, extraversion-introversion, and social support. In addition, demographic and background variables including age, income, perceived adequacy of income, marital status, health, education, household composition and information about the impaired family member were also assessed.

Scales appropriate for the general population were specifically selected to measure the variables instead of instruments constructed for caregivers. George and Gwyther (1986) pointed out three major difficulties in

the development and use of instruments that measure caregiver stress, strain, and well-being. First, if caregivers are studied with instruments designed particularly for them, the relative stress or well-being that caregiving imposes cannot be determined since the instruments cannot be administered to noncaregivers. Second, respondents are usually required to relate caregiving to its impact without considering other influences, thus, confounding the issue. Third, extant measures of caregiver well-being results in total scale scores. These summary scores fail to identify specific antecedents or correlates as well as dimensions of caregiver burden (George & Gwyther, 1986). The current study utilized instruments that were designed for the general population in order to avoid the limitations set forth by George and Gwyther (1986).

#### Social Support

In order to examine social support in Alzheimer's caregivers, it was decided to use five of the subscale scores of the Social Provisions Scale (See Appendix D) as one total support score. The Opportunity for Nurturance subscale was not used because it assessed outgoing support and not support received. Since caregivers, by the very nature of this distinction, take care of or nurture their Alzheimer's patient, measuring

this dimension would not contribute to understanding social support provided to caregivers. The five subscale scores were summed to arrive at a support score with a potential range of 20-80. (See Appendix E for a discussion of the factor analysis of the Social Provisions Scale.)

### Data Analysis

All responses to questionnaire items were coded directly on opscan forms that were read onto a computer disc. Then data were processed using the Statistical Analysis System (Helwig & Council, 1986) on the mainframe computer of Virginia Polytechnic Institute and State University. Data cleaning was done by identifying outliers, inconsistent codes, and the like. Data analysis was divided into two parts: descriptive procedures and inferential ones.

First, the analysis began with descriptive statistics to identify the characteristics of the sample as well as for the independent and dependent variables. Frequency checks were done for categorical variables; means and standard deviations were computed for continuous variables (See Appendix E for Tables).

Second, multiple regression analysis was employed in analyzing the data from this study because the research focused on investigating the relationships

between the dependent variable, loneliness, and the independent variables: control, introversion, and social support under conditions specified by demographic variables. A stepwise multiple regression was used to identify the order of importance that the independent variables had in explaining the variance in loneliness. Then a standard regression procedure was performed to determine the betas for each of the variables. Type one error rate was set at  $\alpha = .05$  (See Appendix E for a discussion of results).

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**APPENDIX C**

**CORRESPONDENCE**

## LETTER TO SUPPORT GROUPS

St. Francis Xavier  
H·O·S·P·I·T·A·L

CHARLESTON, SOUTH CAROLINA 29401

Your name was given to us by \_\_\_\_\_, Training Coordinator of the South Carolina Commission on Aging as the contact-person for your local Alzheimer's Support Group. We are writing to ask your help in a research study being conducted through Virginia Polytechnic Institute and State University and St. Francis Xavier Hospital in Charleston, South Carolina.

The study, Alzheimer Caregiver Support Project, is a state-wide mail survey that will be conducted in March 1987. The responsibilities of caring for an Alzheimer's family member can create changes in the lives of the people involved. At present, there is little information on how having a family member with Alzheimer's influences the relationships of the other family members.

The purpose of our study is to examine sources of stress, coping methods and relationships of Alzheimer caregivers. Because of the nature of this study, only individuals who actually have family members with Alzheimer's Disease can provide us with the necessary information. That is why we are requesting your help.

We are asking all of the local chapters of Alzheimer's Support Groups throughout South Carolina to provide us with a mailing list of their members for this state-wide survey.

You and your membership may be assured of absolute confidentiality. In addition, the privacy of your membership will be further protected because they will return their completed questionnaires directly without their names appearing any where on the questionnaire.

It is our hope that your local chapter will agree to take part in this project. We will be glad to make the results of the survey available to your membership upon the completion of the project. It is only by studying the thoughts and feelings of members of families with Alzheimer's Disease that knowledge can be gained that can help others in the future.

We will be happy to answer any questions you may have. Please feel free to write or call. Thank you for your assistance.

Sincerely,

and Monica Janas

A Tradition Of... Caring

## FIRST LETTER TO CAREGIVERS

St. Francis Xavier  
H·O·S·P·I·T·A·L

CHARLESTON, SOUTH CAROLINA 29401

March 24, 1987

Dear Caregiver:

Traditionally, family members provide most of the care required by persons who have Alzheimer's Disease and related disorders. The responsibilities of caregiving can create many changes in the lives of the people involved. At the present, there is little researched-based information on how caregivers are affected by the various demands of caring for someone with Alzheimer's Disease.

The purpose of our study, THE ALZHEIMER CAREGIVER SUPPORT PROJECT, is to examine specific sources of caregiver stress, coping methods, and how the relationships of caregivers are changed by the various responsibilities of providing care. We are especially interested in how these things affect the feelings and lives of you, the caregiver.

In an effort to increase our knowledge of this subject, we are conducting a state-wide survey of individuals who belong to local Support Groups for Alzheimer's Caregivers in South Carolina. You are among a sample of caregivers being asked to assist with this important research. In order for the results to be truly representative, it is essential that each questionnaire be completed and returned promptly. The time that you will take to complete the survey will be greatly appreciated and you will be making a real contribution to understanding the ways in which Alzheimer's Disease affects families.

You may be assured of absolute confidentiality. The questionnaires have a code number for mail identification. Your name will be checked off the mailing list when your questionnaire is returned and will never be associated with your responses in any way.

We will be most happy to answer any questions you may have. Please feel free to write or telephone .

Thank you for your assistance.

Sincerely,

St. Francis Xavier Hospital  
Charleston, South Carolina

Monica Janas  
Department of Family & Child  
Development  
Virginia Tech  
Blacksburg, Virginia

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## DISQUALIFYING FORM

This questionnaire is designed to obtain information from persons who are currently involved in caregiving for someone who has Alzheimer's Disease or a related disorder (including memory, intellectual or behavioral problems). You have received this questionnaire because your name was on the mailing list for your local Alzheimer's Support Group.

However, we want to be sure that you should fill out the questionnaire. Circle the number in front of the statement that best describes you.

1. I am currently caring for or helping to care for a relative or friend with Alzheimer's Disease or a related disorder. This can include care given outside of your home or for residents of nursing homes and hospitals.
2. I used to care for or help with the care of a relative or friend with Alzheimer's Disease or a related disorder, but I no longer provide care.
3. I do not have a relative or friend with Alzheimer's Disease or a related disorder.

**IF YOU CIRCLED NUMBER 1, PLEASE FILL OUT THE QUESTIONNAIRE AND RETURN IT IN THE SELF-ADDRESSED, STAMPED ENVELOPE.**

**IF YOU CIRCLED NUMBERS 2 OR 3, PLEASE FOLD THE QUESTIONNAIRE (WITHOUT ANSWERING ANY OF THE QUESTIONS) AND RETURN IT TO US IN THE SELF-ADDRESSED, STAMPED ENVELOPE.**

## FOLLOW-UP POSTCARD

Last week, a questionnaire was mailed to you. If you have already completed and returned it to us, please accept our sincere thanks. If not, your prompt response will be very much appreciated. It is important that your questionnaire be included in the study if the results are to be truly representative.

If by some chance you do not have the questionnaire, please call me immediately, ( , Collect) or send me a note. I will mail another one to you.

Sincerely,

St. Francis Xavier Hospital

Charleston, SC 29401

## SECOND LETTER TO CAREGIVERS

St. Francis Xavier  
H·O·S·P·I·T·A·L

CHARLESTON, SOUTH CAROLINA 29401

April 7, 1987

Dear Caregiver:

About two weeks ago, we wrote to you requesting your participation in a state-wide survey of Alzheimer's Caregivers in South Carolina. As of today, we have not received a completed questionnaire from you.

The purpose of our study, THE ALZHEIMER CAREGIVER SUPPORT PROJECT, is to examine specific sources of caregiver stress, methods of coping, and how the relationships of caregivers are changed by the various responsibilities of providing care. We are particularly interested in how these things affect the feelings and lives of you, the caregiver. Your response will help us to understand the ways in which Alzheimer's Disease affect families.

I am writing to you because of the importance that each questionnaire has to the usefulness of this study. In order for the results of this project to be truly representative, it is essential that each person return their completed questionnaire.

Your name was provided by your local Alzheimer's Support Group. Please know that we understand your desire for privacy. You may be assured of complete confidentiality. In no way will your responses be associated with your name or location.

In the event that your questionnaire has been misplaced, please call St. Francis Xavier Hospital immediately (collect), or send a note. We will be glad to mail you another one.

Your cooperation is greatly appreciated.

Sincerely,

St. Francis Xavier Hospital  
Charleston, South Carolina

Monica Janas  
Virginia Tech  
Blacksburg, Virginia

A Tradition Of... Caring

THIRD LETTER TO CAREGIVERS

St. Francis Xavier  
H·O·S·P·I·T·A·L

CHARLESTON, SOUTH CAROLINA 29401

April 17, 1987

Dear Caregiver:

Your assistance is important to the success of our state-wide study, Alzheimer Caregiver Support Project. If you have already completed and returned your questionnaire, please accept our sincere thanks and our apology for contacting you again.

The number of returned questionnaires is very encouraging. But, whether we will be able to accurately describe the stress, coping methods, feelings and relationships of people who care for someone with Alzheimer's Disease depends on you and others like you who have not yet responded. Past experiences suggest that those of you who have not returned questionnaires may have different insights than those who have already responded.

As we began this study, we were convinced that caregivers in South Carolina would understand the importance of providing us with information that can be useful to other families throughout the nation who may experience caregiving in the future. Your help is vital.

In case our other correspondence did not reach you, a replacement questionnaire is enclosed. May we urge you to complete and return it immediately. We will be happy to send you a copy of the results. Simply put your name, address and "copy of results requested" on the return envelope.

Thank you for your contribution to the success of this study.

Sincerely,

St. Francis Xavier Hospital  
Charleston, South Carolina

Monica Janas  
Virginia Tech  
Blacksburg, Virginia

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APPENDIX D

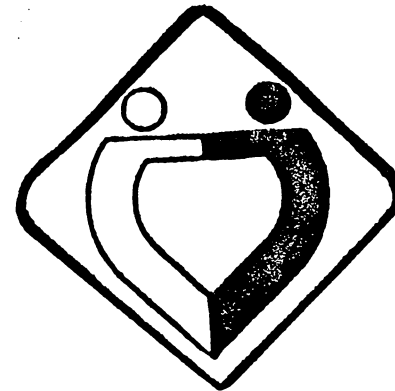
INSTRUMENTS



Is there anything else you would like to tell us about the social supports of being a caregiver for an elderly family member? If so, please use this space for that purpose.

Also, any comments you wish to make that you think may help us in future efforts to understand the social relationships of caregivers will be appreciated, either here or in a separate letter.

## CAREGIVER SOCIAL SUPPORT PROJECT



SUPPORT PROJECT COVER

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*Your contribution to this project is very greatly appreciated.  
If you would like a summary of results, please print your name and  
address on the back of the return envelop (NOT on the questionnaire).  
We will see that a summary is sent to you.*

DEPARTMENT OF FAMILY & CHILD DEVELOPMENT  
VIRGINIA POLYTECHNIC INSTITUTE  
AND STATE UNIVERSITY  
BLACKSBURG, VIRGINIA 24061

REVISED UCLA LONELINESS SCALE  
SURVEY VERSION

Please indicate how often you experience the following feelings:

- |  | NEVER |   | OFTEN |
|--|-------|---|-------|
| 1. I feel in tune with the people<br>around me . . . . . | 1     | 2 | 3 4   |
| 2. No one really knows me well . . .                     | 1     | 2 | 3 4   |
| 3. I can find companionship when<br>I want it . . . . .  | 1     | 2 | 3 4   |
| 4. People are around me but<br>not with me . . . . .     | 1     | 2 | 3 4   |

## CONTROL/MASTERY SCALE

How strongly do you agree or disagree that:

- |   | STRONGLY<br>DISAGREE | STRONGLY<br>AGREE |
|---|----------------------|-------------------|
| 1. I can do just about anything<br>I really set my mind to . . . . .                          | 1                    | 2 3 4 5           |
| 2. Sometimes I feel that I'm<br>being pushed around in life . . . . .                         | 1                    | 2 3 4 5           |
| 3. There is really no way I<br>can solve some of the<br>problems I have . . . . .             | 1                    | 2 3 4 5           |
| 4. What happens to me in the<br>future mostly depends on me . . . . .                         | 1                    | 2 3 4 5           |
| 5. There is little I can do<br>to change many of the important<br>things in my life . . . . . | 1                    | 2 3 4 5           |
| 6. I have little control<br>over the things that happen<br>to me . . . . .                    | 1                    | 2 3 4 5           |
| 7. I often feel helpless in<br>dealing with the problems<br>of life . . . . .                 | 1                    | 2 3 4 5           |

MYERS-BRIGGS TYPE INDICATOR  
EXTRAVERSION-INTROVERSION SUBSCALE

The items in this section will tell us how you prefer to do things. Circle the number in each statement that comes closest to how you usually feel or act.

1. When you are with a group of people, would you usually rather
  1. join in the talk of the group, or
  2. talk individually with people you know well?
2. Do you usually
  1. show your feelings freely, or
  2. keep your feelings to yourself?
3. At parties, do you
  1. sometimes get bored, or
  2. always have fun?
4. When you have to meet strangers, do you find it
  1. pleasant, or at least easy, or
  2. something that takes a good deal of effort?
5. Are you
  1. easy to get to know, or
  2. hard to get to know?

(MBTI continued)

## MYERS-BRIGGS TYPE INDICATOR (continued)

6. Among your friends, are you
  1. one of the last to hear what is going on, or
  2. full of news about everybody?
7. When you are in an embarrassing spot, do you
  1. change the subject, or
  2. turn it into a joke, or
  3. days later, think of what you should have said?
8. Are you usually
  1. a "good mixer," or
  2. rather quiet and reserved?
9. Do you tend to have
  1. deep friendships with a very few people, or
  2. broad friendships with many different people?
10. Do you think you get
  1. more enthusiastic about things than the average person, or
  2. less enthusiastic about things than the average person?
11. Can you
  1. talk easily to almost anyone for as long as you have to, or
  2. find a lot to say only to certain people or under certain conditions?

(MBTI continued)

## MYERS-BRIGGS TYPE INDICATOR (continued)

12. When something starts to be the fashion, are you usually
1. one of the first to try it, or
  2. not much interested?
13. When you are at a party, do you like to
1. help get things going, or
  2. let the others have fun in their own way?
14. Can the new people you meet tell what you are interested in
1. right away, or
  2. only after they really get to know you?
15. In a large group, do you more often
1. introduce others, or
  2. get introduced?
16. Do you think people close to you know how you feel
1. about most things, or
  2. only when you have some special reason to tell them?

## WHICH WORD IN EACH PAIR APPEALS TO YOU MORE?

17. 1. party  
2. theater

(MBTI continued)

## MYERS-BRIGGS TYPE INDICATOR (continued)

WHICH WORD IN EACH PAIR APPEALS TO YOU MORE?

18.     1. reserved  
          2. talkative

19.     1. hearty  
          2. quiet

20.     1. speak  
          2. write

21.     1. calm  
          2. lively

22.     1. sociable  
          2. detached

## SOCIAL PROVISIONS SCALE

Next, we would like you to describe your relationships with other people by responding to the following statements. Please circle the number which indicates your personal view of each statement.

- |   | STRONGLY<br>DISAGREE | STRONGLY<br>AGREE |
|---|----------------------|-------------------|
| 1. There are people I can<br>depend on to help me if<br>I really need it . . . . .  | 1                    | 2 3 4             |
| 2. There is no one I can<br>turn to for advice in<br>times of stress . . . . .      | 1                    | 2 3 4             |
| 3. There are people who depend<br>on me for help . . . . .                          | 1                    | 2 3 4             |
| 4. There are people who enjoy<br>the same social activities<br>as I do . . . . .    | 1                    | 2 3 4             |
| 5. Other people do not view<br>me as competent . . . . .                            | 1                    | 2 3 4             |
| 6. I feel responsible for<br>the personal well-being<br>of another person . . . . . | 1                    | 2 3 4             |

(Scale continued)



SOCIAL PROVISIONS SCALE (continued)

	STRONGLY DISAGREE		STRONGLY AGREE
7. There are people around me who think and feel like I do about most things . . . . .	1	2	3 4
8. I do not think other people respect my skills and abilities . . .	1	2	3 4
9. If something went wrong, there's no one who would help me . . . . .	1	2	3 4
10. My closeness to other people gives me a safe and secure feeling. . . . .	1	2	3 4
11. There is someone I could talk to about important decision in my life . . . . .	1	2	3 4
12. There are people who see me as competent and skilled . . . . .	1	2	3 4
13. There is no one who shares my interests . . . . .	1	2	3 4
14. There is no one who really relies on me . . . . .	1	2	3 4
15. There is someone I trust who I can turn to if I have a problem . .	1	2	3 4

(Scale continued)

## SOCIAL PROVISIONS SCALE (continued)

- |  | STRONGLY<br>DISAGREE |   | STRONGLY<br>AGREE |
|--|----------------------|---|-------------------|
| 16. I feel very close to at least<br>one other person . . . . .                              | 1                    | 2 | 3 4               |
| 17. There is no one I feel<br>comfortable talking to<br>about problems . . . . .             | 1                    | 2 | 3 4               |
| 18. There is no one I can<br>depend on for help . . . . .                                    | 1                    | 2 | 3 4               |
| 19. There are people who admire<br>my abilities. . . . .                                     | 1                    | 2 | 3 4               |
| 20. I feel a lack of closeness<br>with another person . . . . .                              | 1                    | 2 | 3 4               |
| 21. There is no one who likes<br>to do the things I do . . . . .                             | 1                    | 2 | 3 4               |
| 22. There are people I can<br>count on in an emergency. . . . .                              | 1                    | 2 | 3 4               |
| 23. No one needs me to care for them . . . . .   | 1                    | 2 | 3 4               |
| 24. I feel that I do not have<br>close personal relationships<br>with other people . . . . . | 1                    | 2 | 3 4               |

## DEMOGRAPHICS

Finally, we would like to request some general information needed to help us better understand the results of the study.

1. Who is the Alzheimer's person you care for?

1. HUSBAND

2. WIFE

3. FATHER

4. MOTHER

5. FRIEND

6. OTHER (please specify) \_\_\_\_\_

2. Where does your Alzheimer's patient live?

1. WITH YOU

2. WITH ANOTHER RELATIVE

3. IN A NURSING HOME

4. OTHER (please specify) \_\_\_\_\_

3. How long ago did you find out that the person you care for has Alzheimer's Disease? \_\_\_\_\_

(years or months)

4. Which ONE of these words best describes how you feel about having a member of your family with Alzheimer's Disease?

1. THREAT

2. LOSS

3. CHALLENGE

4. DUTY

(Demographics continued)

## DEMOGRAPHICS (continued)

5. What is your age? \_\_\_\_\_  
(years)
6. What is the age of your Alzheimer's patient? \_\_\_\_\_  
(years)
7. What is your sex?
1. MALE
  2. FEMALE
8. What is the sex of your Alzheimer's patient?
1. MALE
  2. FEMALE
9. At the present time, what is your marital status?
1. MARRIED
  2. SEPARATED
  3. DIVORCED
  4. WIDOWED
  5. NEVER MARRIED
10. What is the highest level of education that you have completed?
- \_\_\_\_\_
- (years completed or degree)
11. What is the highest level of education that your Alzheimer's patient has completed?
- \_\_\_\_\_
- (years completed or degree)

(Demographics continued)

## DEMOGRAPHICS (continued)

12. Which of the following best describes you?

1. EMPLOYED FULL-TIME
2. EMPLOYED PART-TIME
3. RETIRED
4. HOUSEWIFE
5. NONEMPLOYED
6. OTHER (please specify) \_\_\_\_\_

13. Which of the following best describes your racial or ethnic identification?

1. BLACK
2. WHITE (CAUCASIAN)
3. SPANISH OR MEXICAN HERITAGE
4. ORIENTAL
5. OTHER (please specify) \_\_\_\_\_

14. What is the approximate yearly income in your household?

1. Less than \$ 5,000
2. \$ 5,000 - \$ 6,999
3. \$ 7,000 - \$ 9,999
4. \$10,000 - \$14,999
5. \$15,000 - \$19,999
6. \$20,000 - \$29,999
7. \$30,000 - \$39,999
8. \$40,000 and above

(Demographics continued)

## DEMOGRAPHICS (continued)

15. Do you think your present income is adequate?

1. YES

2. NO

16. How would you rate your overall health at the present time?

1. EXCELLENT

2. GOOD

3. FAIR

4. POOR

17. How is your health now compared to how it was before your family member got Alzheimer's Disease?

1. BETTER

2. ABOUT THE SAME

3. WORSE

18. Including yourself, how many people live in your household?

\_\_\_\_\_ people

19. Are there children under age 18 in your household?

1. NO

2. YES.

If yes, please give their ages: \_\_\_\_\_, \_\_\_\_\_, \_\_\_\_\_

(Demographics continued)

DEMOGRAPHICS (continued)

20. How often have you attended Alzheimer's Support Group meetings?

1. REGULARLY
2. OCCASIONALLY
3. RARELY
3. NEVER

21. How helpful have you found the Alzheimer's Support Group?

1. VERY HELPFUL
2. SOMEWHAT HELPFUL
3. NOT PARTICULARLY HELPFUL

**APPENDIX E**

**RESULTS**



## Results

### Response Rate

A total of 357 questionnaires was distributed to individuals on the membership lists of the fifteen active Alzheimer's Support Groups in South Carolina. Responses were received from 281 individuals which resulted in a response rate of 78.7%.

The response rate was calculated as the number of questionnaires accounted for, divided by the number of survey packets that were distributed. Questionnaires were accounted for as follows: (a) 11 survey packets were returned because of incorrect addresses or because the household moved out of South Carolina. (b) 74 disqualifying forms with uncompleted questionnaires were returned. Former caregivers whose Alzheimer's patient had died accounted for 58 forms. The remainder were from professionals and other interested individuals whose names appeared on the membership lists. (c) 6 returned questionnaires were not included in the statistical analysis based on investigator judgement. Two completed questionnaires were eliminated because the respondents were under the age of 21 years and failed to meet the criteria for sample selection (See Appendix B). Another four questionnaires were eliminated because they were incomplete.

To summarize, the number of returned survey packets (11), disqualification forms (74), disqualified questionnaires (6), and completed questionnaires (190) were added together. This total (291) was then divided by the number of distributed surveys (357) to arrive at the response rate of 78.7%.

Two limitations of the present study are recognized due to using a purposive sampling frame. First, because caregiver selection is not a random process, it was expected that a sample of caregivers would be older and more female than the general population (Cantor, 1983; George & Gwyther, 1986). Second, the middle class may be over-represented. Because support groups are not usually composed of individuals who have the greatest and least resources, racial and ethnic minorities were expected to be underrepresented. Researchers using mailing lists for organizations or support groups for caregivers have consistently had samples that were more than 70% female, educated, and more affluent than the general population (Cantor, 1983; Chenoweth & Spencer, 1986; George, 1983; Jenkins, Parham, & Jenkins, 1985; Zarit, Todd, & Zarit, 1986).

The predominance of female caregivers, white respondents, and the over-representation of the middle class were observed in the present study (See Tables 1).

The sample is 77% female and 94% white. Education and income are both indicators of socioeconomic status. In the present study, 58% of the sample has at least some college and 39% of the household has annual incomes of \$30,000 or more. See Table 2 for a demographic profile of the Alzheimer's patients.

#### Factor Analysis of Social Provisions Scale

A factor analysis of item-scores of the Social Provisions Scale was undertaken to better explain the constructs that were being measured. The correlation matrix was factor-analyzed using principle components analysis. This procedure produces factors by extracting the number of factors with eigenvalues greater than or equal to 1.0. The Varimax technique was used to rotate the axis orthogonally.

Six factors emerged from the data. For the most part, the six factors found in this factor analysis are not the same as the six original subscales found by Russell and Cutrona (1984). (See Tables 3 and 4).

However, two major similarities were observed between the results of the current analysis and the original subscales. First, only Worth in the current factor analysis corresponded exactly with the Reassurance of Worth subscale (items 5, 8, 12, and 19). Second, taken together Factors 5 and 6 in the current

analysis correspond exactly with the original Opportunity for Nurturance subscale (items 3, 6, 14, and 23). It appears that Factors 5 and 6 do not measure the same things as the other social provision items. Conceptually, these items involve giving support to others while all the other items on the Social Provisions Scale involve receiving support.

In a recent study of depression in the elderly, the Social Provisions Scale was used without the Opportunity for Nurturance subscale (Holahan and Holahan, 1987). The investigators concluded that the subscale was conceptually different from the other five Social Provisions Scale subscales. Holahan and Holahan (1987) observed that Opportunity for Nurturance measured the giving of support and not the receiving of it. This observation was supported by the factor analysis of the current study.

Moreover, at least one other researcher has also found differences in the factors on the Social Provisions Scale. Using a sample of 494 older adults, Blieszner and Mancini (1985) performed a factor analysis with Varimax rotation on the Social Provisions Scale. Three factors were found in the Blieszner and Mancini study. Factor 1 included Reliable Alliance, Guidance, and Social Integration items; Factor 2 corresponded with

the original dimension of Worth; and, Factor 3 corresponded with Opportunity for Nurturance.

These findings are similar to the results in the current investigation. In both studies Worth and Opportunity for Nurturance emerged as distinct factors. However, in the Blieszner and Mancini (1985) study all other subscales factored into one construct; whereas, in the current investigation three different factors emerged from the same Social Provisions Scale items. Taken together, the results of the factor analysis in the current study and the Blieszner and Mancini (1985) investigation indicate a conflict among the constructs measured by the various items when a comparison is made with the original subscales of the Social Provisions Scale.

Although there is a conflict in the factors, the Scale, as a whole, still remains a valid instrument for assessing social support. The sum of the Social Provisions Scale items, omitting the four Nurturance items, was used to assess social support in the multiple regression analysis in the current study (See Figure 1).

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Table 1

## Demographic Profile of Caregivers

Demographic Category	Frequency	Percent <sup>a</sup>
<b>Gender:</b>		
Female	146	77
Male	44	23
<b>Race:</b>		
Black	10	5
White (Caucasian)	179	94
Spanish or Mexican	1	1
<b>Age Ranges:</b>		
22-34 years	15	7
35-44 years	32	17
45-54 years	33	17
55-64 years	33	17
65-74 years	46	24
75-84 years	31	16
<b>Education:</b>		
Less than 12 years	25	13
High School diploma	54	28
Some college	42	22
Bachelors degree	50	26
Masters degree	13	7
Doctorate degree	6	3
<b>Marital Status</b>		
Married	159	84
Divorced	10	5
Widowed	8	4
Never Married	13	7

(Table 1. continues)

<sup>a</sup>

Totals do not always add to 100% due to rounding errors.

Table 1 (Continued)

## Demographic Profile of Caregivers

Demographic Category	Frequency	Percent <sup>a</sup>
<b>Employment:</b>		
Employed Full-Time	52	27
Employed Part-Time	19	10
Retired	73	38
Housewife	42	22
Non-Employed	4	3
<b>Income:</b>		
Less than \$ 5,000	7	4
\$ 5,000 - \$ 9,999	12	6
\$10,000 - \$14,999	27	14
\$15,000 - \$19,999	25	13
\$20,000 - \$29,999	44	23
\$30,000 - \$39,999	27	14
\$40,000 and above	48	25
<b>Income Adequate:</b>		
Yes	101	53
No	89	47
<b>Health:</b>		
Excellent	39	21
Good	73	38
Fair	67	35
Poor	11	6
<b>Comparative Health:</b>		
Better	5	3
The same	123	66
Worse	59	3

<sup>a</sup>

Totals do not always add to 100% due to rounding errors.



Table 2

## Demographic Profile of Alzheimer's Patient

Demographic Category	Frequency	Percent <sup>a</sup>
<b>Gender:</b>		
Female	110	58
Male	80	42
<b>Age:</b>		
54-59 years	4	2
60-64 years	16	8
65-69 years	35	19
70-74 years	39	21
75-79 years	43	23
80-84 years	33	18
85-92 years	20	10
<b>Education:</b>		
Less than 8th grade	26	14
Completed 8th grade	15	8
Some High School	31	17
High School diploma	45	25
Some college	21	11
Bachelors degree	24	13
Graduate degree	21	12
<b>Relationship to caregiver:</b>		
Husband	61	32
Wife	32	17
Father	15	8
Mother	55	30
Friend	9	5
Other	18	10

(Table 2. continues)

<sup>a</sup>

Totals do not always add to 100% due to rounding errors.

Table 2. (continued)

## Demographic Profile of Alzheimer Patient

Demographic Category	Frequency	Percent <sup>a</sup>
<b>Residence:</b>		
With Caregiver	83	44
With Another Relative	29	15
In a Nursing Home	61	32
Other	17	9
<b>Time since Diagnosis</b>		
Less than 1 year	3	2
1 year	13	7
2 years	30	16
3 years	29	15
4 years	27	14
5 years	21	11
6 years	22	12
7 years	15	8
8 years or more	30	16

<sup>a</sup> Totals do not always add to 100% due to rounding errors.

Table 3

## Original Dimensions of the Social Provisions Scale

Subscale	Item
<u>Social Integration</u>	4. There are people who enjoy the same activities as I do.
	7. There are people around me who think and feel like I do about most things.
	13. There is no one who shares my interests.
	21. There is no one who likes to do the things I do.
<u>Alliance</u>	1. There are people I can depend on to help me if I really need it.
	9. If something went wrong, there's no one who would help me.
	18. There is no one I can depend on for help.
	22. There are people I can count on in an emergency.
<u>Nurturance</u>	3. There are people who depend on me for help.
	6. I feel responsible for the personal well-being of another person.
	14. There is no one who really relies on me.
	23. No one needs me to care for them.
<u>Attachment</u>	10. My closeness to other people gives me a safe and secure feeling.
	16. I feel very close to at least one other person.
	20. I feel a lack of closeness with another person.
	24. I feel that I do not have close personal relationships with other people.
<u>Worth</u>	5. Other people do not view me as competent.
	8. I do not think other people respect my skills and abilities.
	12. There are people who see me as competent and skilled.
	19. There are people who admire my abilities.
<u>Guidance</u>	2. There is no one I can turn to for advice in times of stress.
	11. There is someone I could talk to about important decisions in my life.
	15. There is someone I trust who I can turn to if I have problems.
	17. There is no one I feel comfortable talking to about problems.

Table 4

## Factor Analysis: Varimax Rotation of Social Provisions Scale

Factor	Item	Factor Loading
<u>Factor 1</u>	15. There is someone who I trust who I can turn to if I have problems.	.84
	11. There is someone I could talk to about important decisions in my life.	.72
	16. I feel very close to at least one other person.	.71
	2. There is no one I can turn to for advice in times of stress	.60
	18. There is no one I can depend on for help.	.58
	9. If something went wrong, there's no one who would help me.	.54
	10. My closeness to other people gives me a safe and secure feeling.	.52
	24. I feel that I do not have close personal relationships with other people.	.52
<u>Factor 2</u>	7. There are people around me who think and feel like I do about most things.	.71
	4. There are people who enjoy the same social activities as I do.	.60
	1. There are people I can depend on to help me if I really need it.	.55
	22. There are people I can count on in an emergency.	.53
	20. I feel a lack of closeness with another person.	.52
<u>Worth</u>	5. Other people do not view me as competent	.86
	8. I do not think other people respect my skills and abilities.	.63
	12. There are people who see me as competent and skilled.	.59
	19. There are people who admire my abilities.	.57
<u>Factor 4</u>	13. There is no one who shares my interests.	.77
	21. There is no one who likes to do the things I do.	.70
	17. There is no one I feel comfortable talking to about problems.	.56
<u>Factor 5</u>	23. No one needs me to care for them.	.70
	14. There is no one who really relies on me.	.70
	3. There are people who depend on me for help.	.60
<u>Factor 6</u>	6. I feel responsible for the personal well-being on another person.	.71

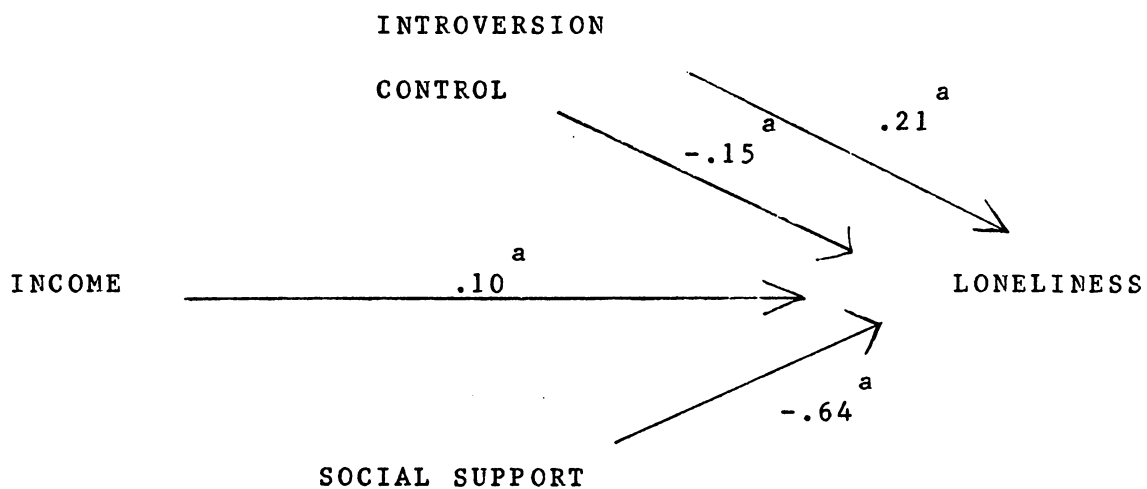


Figure 1

Explanatory Model of Loneliness in Alzheimer's Caregivers

<sup>a</sup>  
Betas

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