

1996

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<https://doi.org/10.7275/7676021>

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RISK FACTORS FOR DEPRESSION IN
PUERTO RICAN CAREGIVERS

A Thesis Presented

by

MARIA T. MUNOZ-RUIZ

Submitted to the Graduate School of the
University of Massachusetts Amherst
in partial fulfillment of the requirements
for the degree of

MASTER OF SCIENCE

September 1996

Department of Psychology

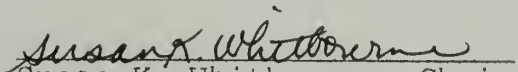
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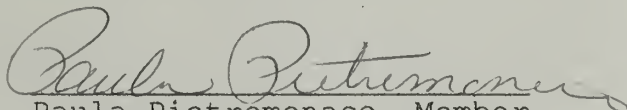
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ACKNOWLEDGMENTS

I would like to thank my advisor and chair of my committee Susan K. Whitbourne for her support, time, and dedication to this study. I am also grateful to the remaining members of my committee, Richard Halgin and Paula Pietromonaco for their helpful suggestions during the beginning stages of the present study. Finally, I would like to thank those fellow students who helped me during this process. Nancy, Kathy, Loren, Erin, and Michelle, thanks for your patience, encouragement and support.

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CHAPTER 1

INTRODUCTION

It is commonly known that the population of older adults is rapidly increasing and is projected to constitute 17-20% of the general population by the year 2030 (U.S. Bureau of the Census, 1992). In addition, the older population itself is aging. From the year 1930 to 1990 the percentage of older adults who are over age 85 (the "old-old"), has increased from 29% to 50%. This statistic suggests that the life-span of people is increasing; however, as will become evident, "longer lives" is not always synonymous with "healthy lives." Indeed, it is estimated that roughly 85% of older adults have a chronic illness (Minkler & Pasick, 1986) and approximately 25% have mental health problems (Benedict & Nacoste, 1990). It is evident that as the older population increases, so do the prevalence of their disorders.

Clearly, the dramatic shifts that have been predicted in the number of people entering old age will have effects on the younger population. As older adults live longer, they will need more care from their relatives. Consequently, many adults will have to take on the role of caregivers. In addition, due to lower mortality rates, caregivers will be likely to be older adults themselves.

Caregivers' responsibilities include providing informal care to the sick, the "old-old," and to the impaired elderly who are highly dependent on others. Family members are the most likely to be caregivers (Seltzer, 1988; Stone, Caferatta, & Sangl, 1987), and of them 72% are women (Stone et al. 1987; Zarit, Todd, & Zarit, 1986). Over half of the women between ages 45 to 49, and one third of women between ages 60 and 75 who have a living parent are likely to become a caregiver at any point in time (Himes, 1994). The mean age of caregivers is estimated to be 57.3 years.

The role of caregivers also involves providing assistance to infirmed elders who need constant supervision. Typically, elders who need supervision are those who have a progressive illnesses and whose prognosis often includes severe deterioration of intellect and basic functions. As elders' increasing incapacities place strenuous demands on caregivers, it is not surprising that caregivers' physical health and psychological well-being is affected. As a result of the caregiving situation, care providers are likely to experience negative feelings such as frustration, burden, and loss of self. These feelings have been known to result in depressive symptomatology and ultimately in clinical depression (Dura, Haywood-Niler, & Kiecolt-Glaser, 1990;

Rosenthal, Sulman, & Marshall, 1993). In light of the demands and burdens placed on caregivers, they are at times considered as the "other victims of the disease" (Seltzer, 1988).

Caregivers of chronically ill (Rosenthal et al., 1993) and demented patients (Pruchno et al., 1989) present more depressive symptoms than members of the general population. A review of research studies and literature suggests that risk factors such as poor health of the caregiver (Dura et al., 1990; Pruchno, Kleban, Michael, & Dempsey, 1990; Rosenthal, Sulman, & Marshall, 1990), feelings of burden (Pruchno et al., 1990), time pressure (Brody et al., 1990), and family conflicts (Skaff & Pearlin, 1992) relate to an increased prevalence of depression in caregivers. The caregiving experience becomes harder as the disease of the older patient progresses, level of dependency increases, and more attention is required. Consequently, caregivers often report feeling torn between their own needs and those of the patients, as well as overwhelmed with too many demands. Furthermore, they assert that they do not get enough rest. Thus, the best predictors of depression for those who provide care for older adults are competing commitments and the extensiveness of care involvement (Rosenthal et al., 1993).

Additional factors believed to be stressors affecting caregivers' well-being are family members' criticism of the care provided and loss of a sense of self. Semple (1992) proposed that disagreements and family criticisms of the caregiver, which threaten the caregiver's sense of value and competence, are likely to result in negative self-evaluations and feelings of failure. These feelings, in turn increase the likelihood of depression. However, it is also possible that these findings are true about caregivers who are oversensitive to family criticisms as a result of feeling depressed and overwhelmed. These findings warrant further study.

Skaiff and Pearlin (1992) argue that loss of self-esteem is an additional factor that further exacerbates feelings of depression among caregivers. They suggest that the caregiver's role is time consuming and results in limited social contact and decreased self worth. As the role of caregiver engulfs the individual, he/she is left without outside sources of self-evaluation, a process that intensifies the impact of experiences within the caregiver role. Furthermore, lack of social roles besides that of caregiver contribute to these feelings of low self-esteem and depressive symptomatology.

It is clear therefore, that research and literature reviews suggest that the role of caregivers has many repercussions regarding care providers' health with depression as the most common ramification. However, most of the research and empirical studies regarding caregivers' experiences have been based on nonminority populations failing to acknowledge the existence and need of multicultural groups (Wray, 1991). For instance, research on the use of long-term care facilities and formal help for psychological needs of minority elders had been limited until recent years (Starrett, Todd, Decker, & Walters, 1989; Torres-Gil & Nesm, 1980). This is true despite the fact that the older population has a high percentage of minority groups. Latinos alone constitute 5% of the elderly population, and represent the fastest growing subgroup of the aged (American Association of Retired Persons [AARP], 1988; Lopez-Aqueres, Kemp, Plopper, Staples, & Brummel-Smith, 1984). By the year 2030 the proportion of Latinos in the elderly population is estimated to be 30%, thus showing a 500% increase in 25 years (U.S. Bureau of the Census, 1992).

In general, more research on minority elders' health problems and their caregivers is needed because this population is likely to have poorer health than their

nonminority counterparts, and suffer from chronic conditions at younger ages (Crimmins, Saitre, & Ingegneri, 1987; Espino, Neufeld, Mulvihill, & Libow, 1988; Jackson, Antonucci, & Gibson, 1991). As a result, minority elders need care for a longer period of time. It has been suggested that among minorities, impoverished Latinos and African-Americans suffer more illness at every age than do either whites or other minority groups with higher incomes (Angel, Angel, & Himes, 1992). Among Latinos, Puerto Rican elders have consistently been found to have the poorest health (Wallace, Campbell, & Lew-Ting, 1994).

Espino and colleagues (1988) report data about the higher prevalence of chronic disorders among minorities, particularly Latinos. In a comparative study conducted in New York City, they found that Puerto Rican-Latino populations become functionally more impaired, physically and mentally, at a younger age than do their non-Latino counterparts. This result has implications for the role of Latino caregivers because to the extent that their older relatives need prolonged care, they may experience more burden. This situation is aggravated by the fact that Latinos traditionally care for their relatives at home and are less likely to use formal care such as long-term care

institutions, hospitals, home services, and day health care centers for older adults (Bean & Tienda, 1987; Bengtson, Rosenthal, & Burton, 1990; Greene & Oldrich, 1990; Sirroco, 1989; Wallace, Campbell, & Lew-Ting, 1994; Worobey & Angel, 1990a). These circumstances are plausible explanations for the higher prevalence of depression among Latino caregivers when compared to nonminorities (Mintzer et al., 1992).

Research studies show that older minorities are less likely to use long-term care institutions when compared to nonminority elders (Green & Oldrich, 1990; Sirroco, 1989; Worobey & Angel, 1990a). Green and Oldrich (1989) conducted a study to determine risk factors for nursing home admissions and discharge to the community, and found that ethnicity was a major factor in predicting admissions. Older Latinos and African American elders were at a much lower risk of admission than other elders, even after controlling for income, education, level of informal help, and some aspects of health such as cognitive impairment and functional disability. In fact, based on their findings it appears that Latinos and African-American elders have less than half (45%) the chance of admissions of other groups. These findings have also been more recently supported by others (Mui & Burnette, 1994). Thus, it seems that controlling for

other factors, the cultural belief system about institutionalization of elders has a strong effect on the use of long-term institutions among minority populations.

There are many possible explanations for the underutilization by aging minorities of formal help. First, cultural aversion, societal discrimination (Mui, 1993; Wallace, 1990b), and conflict over communication styles or inattention to acceptable types of interaction (Damron-Rodriguez, Wallace, & Kington, 1994) have been identified as factors contributing to this pattern. Second, minority elders are faced with structural barriers to obtaining adequate health care. One of the major structural barriers facing Latino elders is that they are disproportionately poor compared to other group of elders and consequently, are unable to pay for health care. Latino elders are estimated to be twice as poor as non-Latino whites (U.S. Bureau of the Census, 1992). In addition, this group is less likely to have health insurance and a routine place for health care compared to their nonminority counterparts (Solis, 1990; Wray, 1991). It is estimated that about 38% of African American elders and 36% of older Latinos have no insurance other than Medicare compared to 15% of nonminority elders (National Center for Health Statistics, 1990). Even those who have Medicare are

unable to afford insurance copayments because Medicare pays under 6% of all long-term care costs.

In studies that have controlled for economic and other differences between minorities and nonminorities, it has been found that elder minorities continue to face barriers to obtaining adequate health care (Wallace, 1990a). For example, in addition to low incomes and education, older Latinos have limited English proficiency and high levels of functional disabilities (Wallace et al., 1994).

Furthermore, strong family and community networks have been identified as additional factors contributing to the lower tendency of minorities to utilize formal help (Mui, 1993; Wallace, 1990b). It has been proposed that minorities usually care for their relatives at home because they feel more at ease with their extended caregiver network and feel alienated from institutional norms of a predominantly non-Latino white population (Greene & Monahan, 1984). Latinos and African-Americans have been found to rely on family-based support systems to a greater degree than non-Latino whites at all points in their lives (Bengston, Rosenthal, & Burton, 1990). In terms of their elders, older Latinos and African-Americans are also more likely to live with their relatives regardless of health levels (Burr & Mutchler, 1992). In

fact, it has been estimated that Latino elders are 3 times as likely to live with family as whites, even after controlling for income and health status (Woroby & Angel, 1990). Latino elders are more likely to live with family members because of factors such as familistic orientation and norms defining obligations toward parents (Worobey & Angel, 1990a). In addition, increased fertility among Latinos results in larger families which provide more opportunities for elders to live with their children (Bean & Tienda, 1987),

Although it seems like living arrangements observed in Latino populations are related to their cultural beliefs, it is unclear whether the tendency to care for elders at home is preserved because of culturally based norms, racial discrimination, or economic necessities (Smith, 1990; Worobey & Angel, 1990a). Regardless of the reason, underutilization of formal services by older minority groups has dysfunctional side effects. Aged Latinos rely completely on their relatives and as consequence place more overwhelming demands and financial burden on them. Such increased dependency appears, in turn, to lead to caregivers' higher risk of depression (Prudy & Arguello, 1992).

Despite the fact that traditionally minority elders, particularly Latinos and African Americans, have been taken

care of at home, there is some evidence suggesting a change in this pattern. Jackson, Burns, and Gibson (1992) propose that there is an increasing trend in nursing home utilization among these minority groups. They suggest that factors such as weakening cultural norms, long-term effects of financial burden on the family, and perhaps changes in the availability of community support may be triggering the emergence of this trend.

Markides (1989) also proposes that higher rates of institutionalization among minority populations will be observed in the future. He suggests that increasing rates of widowhood among older minority women will lead to higher dependency on their children, which in turn may worsen intergenerational relations within the family. This situation coupled with the fact that younger members of these minority groups have begun to acculturate and adopt values of the American society, suggest that increasing rates of institutionalization among aged Latinos and African Americans will be observed in the future. However, there is limited research on this area in particular.

Purpose of the Present Study and Hypothesis

The purpose of this study is to extend the research on Puerto Rican caregivers in an effort to identify factors

that may lead to increased levels of depression among this population. Two hypotheses were proposed. First, it was hypothesized that among Puerto Rican caregivers, those who live in the United States would be more depressed than those still living in their home country. The assumptions behind this hypothesis were that Puerto Rican elders in the United States are less likely to use community health services and have a larger caregiving network than their counterparts living in Puerto Rico.

Second, it was hypothesized that depression among Puerto Rican caregivers would be related to four factors:

- (1) elders' tendency to underutilize formal care,
- (2) elders' poor health, (3) caregivers' feelings of burden,
- (4) and culture's negative perception of elders' institutionalization.

CHAPTER II

METHOD

Sample

The sample consisted of twenty-eight Puerto Rican adults identified as primary care providers of an older relative, either physically or mentally impaired. Half of the participants currently live in the United States (US group) and the other half live in Puerto Rico (PR group). Eligibility for the study was limited to Puerto Rican caregivers who provide care to their relatives at home or in a family setting. Participants were identified through community sources such as ethnic minority organizations, support groups, churches, and community service organizations.

As shown in Table 1, the sample was primarily female (89.29%) whose ages ranged from 29 to 69 years old with a mean age of 45, most likely taking care of their mother (75%). The rest of the respondents were caring for their father (14.28%), mother or father-in-law (7.14%), grandmother (3.57%), or spouse (3.57%). About 71% of the caregivers were married, 14.29% divorced, 7.14% never married, and 3.57% were living with a significant other. A total of 46.43% of the caregivers had a job; however, 51.85%

of the participants had a family income of \$15,000 or less, placing them below the poverty line. The majority of the participants identified themselves as Catholic (82.14%). (See Table 1 for distribution of demographic characteristics).

Table 1

Demographic Characteristics of Participants

	Total (%)
<i>Relationship with elder</i>	
Mother	75
Father	14.28
Mother/Father in law	7.14
Spouse	3.57
Other	3.57
<i>Elder's marital status</i>	
Widowed	71.43
Separated	0
Divorced	3.57
Never married	0
Other	25
<i>Caregiver</i>	
<i>Gender</i>	
Male	10.71
Female	89.29
<i>Religion</i>	
None	3.57
Protestant	3.57
Catholic	82.14
Jewish	0
Other	10.71
<i>Income</i>	
\$15,000 or less	51.85
\$16,000 to \$35,000	40.74
\$36,000 to \$55,000	0
\$56,000 to \$75,000	0
\$76,000 to \$95,000	7.14
\$100,000 or more	0

Continued, next page

Table 1 continued

<i>Marital Status</i>	
Married	
Divorced	71.43
Separated	14.29
Widowed	0
Never Married	0
Other	7.14
Currently have a job	3.57
Yes	
No	46.43
If not working, reason to leave job	57.57
To care for elder	
Reached retirement age	30.77
Own health problems	0
Other family commitments	23.08
Laid off or fired	38.46
Other	0
Elder living with caregiver	7.69
Yes	
No	39.29
If not living with caregiver, would consider it	60.71
Yes	
No	94.44
If living with caregiver, Who moved?	5.56
Caregiver with elder	0
Elder with caregiver	72.73
Always lived together	27.27
Help with elder's care	
Relative	84
Other	16
<i>Institutionalization</i>	
Would consider institutionalization of elder	
Yes	10.71
No	89.29
Elder shares opinion with caregiver	
Yes	69.23
No	30.77
Discussed topic with other	
Yes	10.71
No	85.71
Discussed topic with elder	
Yes	14.81
No	85.19
Perception of institutionalization in culture	
Acceptable	35.71
Unacceptable	64.29
<i>Institutionalization and homecare are similar in Puerto Rico and In the United States</i>	
Yes	30.43
No	69.57
Cultural background influences perception of institutionalization	
Yes	48
No	52

Procedure

An initial structured interview was conducted to gather demographic data about caregivers and those for whom they provide care (see Appendix A). The items in the questionnaire elicited information about the caregivers' age, sex, ethnicity, place of birth, years living in current country (U.S. or P.R.), religion, education, employment, annual income, marital status, presence of others in the house, and relationship to the elder. Respondents were also asked the sex and age of the elder, the length of time as a primary caregiver, and the amount of hours they provide daily help to the elder. Following the interview, participants were asked to answer several indicators which served to provide further information about their feelings and experiences as caregivers. In addition, they were asked to answer questions about their perceptions of their relative's level of functioning.

Interviews were conducted in Spanish, either at the caregivers' house (46.43%) or on the phone (53.57%). Participants in the PR group were interviewed significantly more often over the phone than those in the US group ($p=.007$). However, this difference did not yield significant results in terms of the dependent variable

($t = -.92$; $p = .37$). Thus, the level of depression reported by participants interviewed over the phone (mean=12.6) was not significantly different from those interviewed in person (mean=15.77).

Instruments

Depression. The Spanish version of the Center for Epidemiological Studies (CES-D) Depression Index (Radloff, 1977) was used to assess the current level of caregivers' overall depression (see Appendix B & Appendix I). Item responses were weighed by frequency of symptom occurrence in the last week using a Likert scale ranging from (0) "rarely" to (3) "most of the time."

The CES-D is a 20-item self-report checklist originally designed to measure the current level of depressive symptomatology, with emphasis on depressed mood (Radloff, 1977). While some researchers argue that this scale is not sensitive to the diagnosis of major depression according to DSM-III R criteria, and are skeptical of its use as a diagnostic device in clinical settings (Roberts, Vernon, & Rhoades, 1989), other researchers indicate the measure is reliable and shows fairly good convergent discriminant validity (Radloff, 1977). Using Cronbach's coefficient alpha and the Spearman-Brown split-halves methods, it was reported

that internal consistency reliability of the CES-D is high for sex, age, ethnic, and educational subgroups. The coefficients alpha ranged from .83 to .87 in the subgroups examined.

Additional research studies have documented the current validity and reliability of the CES-D for both the Spanish and the English versions. Reliability, validity, and factor structure of the CES-D were found to be similar across a wide variety of demographic characteristics in the general population samples tested. In all subgroups, coefficient alpha was .80 or above and .90 for community samples and patient populations respectively (Zich, Attkisson, & Greenfield, 1990).

The factor structure of the CES-D has been examined with multi-ethnic populations in order to report any differences on how the patterning of depressive symptoms differ across cultural groups; however, these findings have been controversial. While some researchers argue for the similarity of factor structures between Latino and non-Latino populations (Roberts, Vernon, & Rhoades, 1989), others argue for differences between the two groups (Guarnaccia, Angel, & Lowe-Worobey, 1989).

Roberts and colleagues (1989) conducted a study to assess the effects of ethnic status and language on the reliability, validity, and dimensionality of the CES-D. Subjects, identified as Anglos and Mexicans, were interviewed using the CES-D at two different times. Anglos were identified as one group and Latinos were classified into four groups based on the language used during the first and second interview respectively (Spanish/Spanish, English/English, Spanish/English, and English/Spanish). Analyses for the internal consistency and test-retest reliability were conducted for each of the five groups. Results showed internal consistency coefficients around .90 for all groups at the first and second time of interviews. The test-retest coefficients were fairly high as well but showed more variability across groups. The highest test-retest coefficient corresponded to the Anglos (.75) and the lowest to the Spanish-dominant group (.61); both coefficients indicate good reliability. In general, Roberts and colleagues (1989) found no systematic variation across the five ethnic/language groups in terms of reliability, validity, and dimensionality of the scale.

Guarnaccia and colleagues (1989) also examined the factor structure of the CES-D with a sample constituted by

the three major Latino groups: Puerto Ricans, Cuban-Americans, and Mexican-Americans. Their findings suggest that there are different factor structures for the Latino groups as compared to previous analyses done with non-Latino populations; however, factor structures amongst the three Latino groups were similar. Each of the three groups yielded a three factor solution instead of four factors because Latinos tend to combine affective and somatic factors. This combination of two factors accounted for the greatest variance (Guarnaccia et al., 1989).

Guarnaccia and colleagues (1989) suggest that their findings raise issues of validity in the measurement of depressive symptomatology across cultures. If there are differences in the pattern and meaning of symptoms for Latinos and non-Latinos, then we must be careful in using the same criteria in the diagnosis of depression for both cultures.

The utility of the CES-D as a screening instrument of depression for Latino populations has been further documented. Research by Mahard (1988) indicates that it has high internal consistency and reliability when used with Puerto Rican patient and nonpatient samples (alphas of .87). These findings are consistent with Roberts' (1980) who

reported fairly high reliability of the scale when used with Spanish-speaking respondents (alpha of .87).

Comparative studies of the Spanish version of the CES-D with the Spanish versions of three forms (E,F,&G) of Lubin's Depression Adjective Check Lists (DACL) and of the CES-D with the Beck Depression Scale (BDI) indicate alpha coefficients of .86 and .80 respectively. The Pearson correlations between the CES-D and the DACL were .49 (E), .47 (F), and .64 (G). The Pearson correlation between the CES-D and the BDI was .59. All Pearson correlations were found to be significant at $p < .001$ (Masten, Caldwell-Colbert, Alcala, & Mijares, 1986). CES-D's adequate internal consistency reliability, test-retest reliability, and concurrent validity serve to document this instrument as useful for research with Latino populations.

Burden. Caregiver burden was assessed with two indicators (see Appendix C). The first measure used was a 9-item index developed by Pruchno and Resch (1989) that measures how often caregivers experience each of the given items (i.e. trapped feelings, very tired, isolated and alone) as a result of caring for their relative. Item responses were measured with a rating scale ranging from (1) "never" to

(5) "nearly always." Research by Pruchno and Resch indicates a coefficient alpha of .89.

The second indicator was a single item: "Overall, how burdened do you feel in caring for your relative?" The item response was measured using a rating scale ranging from (1) "not at all burdened" to (5) "very greatly burdened."

Research data indicates that the single item correlates at a level of .65 with a multiple-item index of burden on a sample of 632 caregivers (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989).

Elders' health. Elders' health was assessed using three indicators (see Appendix D). The first measure was used to assess elders' physical health. Based on a given list of conditions, caregivers were asked if their relative had any of these conditions in the past year; respondents had to answer "yes" or "no."

The second instrument was a list of tasks (see Appendix E) encompassing 7 Activities of Daily Living (ADL) and 8 Instrumental Activities of Daily Living (IADL) designed by Pruchno et al. (1989). Caregivers were asked to provide information about the degree of assistance their relative needed with each of the tasks. Answers were scored using a rating scale which assessed the degree to which the elder

could perform each skill, (3)"without help," (2)"with some help," or was (1)"unable" to do the task. Reliability of these scales measuring help provided by the caregiver and/or by others was analyzed giving alpha coefficients of .83 and .91 respectively (Pruchno et al., 1989).

The third instrument asked caregivers to assess the extent in which a list of behaviors may have characterized their older relative during the past month (see Appendix F). Each behavior was rated using a scale ranging from (1) "never" to (5) "almost everyday." This measure is a modification of a similar scale previously used by Pruchno et al. (1989) for which they found an alpha coefficient of .80.

Formal help use. The frequency with which elders used health services was measured using three open ended questions. Caregivers were asked how many days in the last 12 months had their elder spent in a hospital, nursing home or rehabilitation center, or received home visits from a nurse, physical therapist, or other therapist at home. The total number of days were summed.

Cultural belief. Information about caregivers' feelings regarding their cultural beliefs and expectations of future living arrangements for their elder relative as well as the possibility of institutionalization were asked with standard

questions (see Appendix G). Further information about respondents' history of caregiving and use of formal help was obtained from an open ended questionnaire (see Appendix H).

CHAPTER III

RESULTS

This study examined factors that may affect caregivers' subjective experience and well-being. It was designed to address two questions: (1) Do Puerto Rican caregivers living in the United States (US group) and those living in Puerto Rico (PR group) experience different levels of depression? (2) Are factors such as a) Puerto Rican elders' tendency to underutilize health services, b) likelihood to become functionally impaired at a relatively young age, c) caregivers' feelings of burden, and d) culture's negative perception of elders' institutionalization, related to the level of caregivers' depression?

Hypothesis 1

The Spanish version of the Center for Epidemiologic Studies (CES-D) for Depression (Randolff, 1977) was used to measure the current level of caregivers' overall depressive symptomatology. Each item was measured by a Likert scale ranging from 0 to 3, with higher scores indicating higher levels of depression. Scores across 20 items were summed yielding a range of 0 to 32 with a mean of 14.18. The most commonly used cutoff score for depression is 16 or higher.

Thus, according to these standards, only 39.29% of the sample appeared to be depressed.

An ANOVA was calculated to assess between group differences in depression level; however, as shown in Table 2, the results were not significant ($F= 0.040$, $p=.84$). The US group had a mean of 13.714 and the PR group a mean of 14.429. In addition, 42.86% of participants in the PR group were depressed compared to 35.71% in the US group (chi-square NS). Following these results, hypothesis 1 was rejected (See Table 2).

Table 2

Analysis of Variance: US Group vs PR Group

Source	Sum-of-Square	DF	Mean-Square	F-ratio	p
Group	3.57	1	3.57	0.040	0.84
Error	2298.29	26	88.40		

In an attempt to detect further possible differences between both groups of caregivers (PR vs US), multiple t-tests were calculated (See Table 3).

Table 3

t Tests: Between Group Comparison of Variables

Variable	US Group		PR Group		t	p	Total	
	Mean	SD	Mean	SD			Mean	SD
<u>Elder</u>								
Age	69	7.36	79	8.47	-3.03	0.01*	74	9.05
Years living in U.S./P.R.	13.8	13.5	73.8	20.1	-9.27	0.00	44	34.83
Years in marital status	20.8	15.3	18.1	15.1	0.47	0.65	19	14.96
Days/used formal help	32	50.54	41	45.13	-0.49	0.63	36	47.24
<u>Elders' Health</u>	-0.94	1.97	0.94	2.05	-2.46	0.2	0	2.19
IADL	13.86	4.38	19.29	3.67	-3.55	0.002*	16.6	4.83
ADL	7.79	1.31	12.07	5.17	-3.01	0.009*	9.9	4.29
Elders' behavior	-0.20	1.06	0.20	0.93	-1.06	0.30	0	1.00
Physical health	-0.17	0.98	0.17	1.02	-0.89	0.38	0	1.00
<u>Caregiver</u>								
Age	43	10.73	48.36	8.78	-1.35	0.19	46	9.95
Years living in U.S./P.R.	21.3	12.88	45.57	13.49	-4.88	0.00	33	17.91
Education	10	4.04	13.93	3.20	-2.62	0.015*	12	4.02
Hours at job	33	9.64	39	12.19	-0.99	0.35	35	10.88
<u>Caregiver Role</u>								
Members living at home	3	1.57	3	1.65	0.58	0.56	3	1.59
Years elder at home with caregiver	11	15.98	13	18.8	-0.15	0.88	12	16.12
Hours working at home with elder	29	24.15	41	26.2	-1.26	0.22	35	25.48
Hours received help from others	12	13.28	25	23.4	-1.61	0.13	18	19.11
Years as caregiver	9	8.29	10	11.4	-0.28	0.78	10	9.80
<u>Caregivers' burden</u>								
Burden item	2.07	0.92	2.21	1.3	-0.35	0.73	2.14	1.08
Burden scale	16.71	5.94	21.14	7.1	-0.79	0.09	18.93	6.82
<u>Depression</u>	13.71	8.35	14.43	10.5	-0.20	0.84	14.07	9.23

* $p < .05$

As shown in Table 3, out of all the variables only elders' health and age, and caregivers' education were significantly different between groups ($p=.006$, $p=0.02$, $p=0.015$, respectively). Thus, care recipients living in Puerto Rico seem to be older and have poorer health than those living in the United States. Caregivers in Puerto Rico seem to have obtained, on average, a higher level of education than those living in the United States.

Hypothesis 2

The second hypothesis was tested by means of multiple regression analysis. Four independent variables were included in the equation: elders' health, use of formal help, caregivers' burden, and cultural influence. Since there were no significant between group difference in terms of the dependent variable (depression), groups were collapsed for the purposes of the regression analysis.

Elders' Health

Due to the small sample which limits the amount of variables that can be introduced in a regression equation, coupled with an interest to obtain a global measure of the elders' health, three different instruments were combined to create a "health" variable. The first dichotomous scale measured elders' physical health. Participants had to

report whether their elder had any of the medical conditions provided in a list; respondents answered (1) "yes" or (2) "no." The number of elders' medical conditions reported by their caregivers was calculated. Results ranged from 3 to 17 with a mean of 10.14.

The second measure examined elders' physical behavior and tapped into cognitive functioning. Each item was measured with a rating scale ranging from 1 to 5, with higher scores indicating lower functioning. Item scores were added giving a range of 15 to 55 with a mean of 27.82.

The third scale was a measure of the elders' ability to perform activities of daily living and instrumental activities of daily living. The scale was measured on a rating scale ranging from 1 to 3, with lower numbers indicating lower functioning. The scores in this scale were reversed and then added giving a range of 16 to 45 with a mean of 26.5.

Each of these scales was standardized and then combined to provide a global measure of elders' health. Elders' health was conceived as a combination of both physical and mental health.

Use of Formal Help

The frequency with which elders used health services was measured with open ended questions. The total number of days that each elder had received some kind of formal help (i.e. hospital, rehabilitation center, visiting nurses or therapists) during the last 12 months was calculated. The amount of days of formal help use ranged from 0 to 187, with a mean of 36.25.

Caregivers' Burden

Caregivers' burden was measured with two different scales that were combined. The first instrument was a 9-item burden measurement that used a rating scale ranging from 1 to 5, with higher numbers indicating more burden. The total number of scores for each subject was added. Scores ranged from 9 to 28 with a mean of 18.93. The second indicator was a burden item measured on a rating scale ranging from 1 to 5, with higher scores indicating stronger feelings of burden. Research data indicates that the single item correlates at a level of .65 with the multiple-item burden scale (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). These two scales were combined and scores were added together to create a new total for a global assessment of

caregiving burden. Scores for the final burden measurement ranged from 10 to 36 with a mean of 21.07.

Cultural Influence

To examine whether caregivers' cultural background influenced their general views about utilization of long-term care facilities, they were asked whether institutionalization of elders was (1) "acceptable" or (2) "unacceptable" in their culture. Results revealed that 35.71% of the caregivers thought it was perceived as acceptable compared to 64.29% who thought of it as unacceptable.

Regression Analysis

Results from the multiple regression analysis explained 38.7% of the variance ($F\text{-Ratio} = 5.26, p < .01$) when predicting caregivers' depression. There were three significant predictor variables: the variable for caregivers' burden yielded a regression weight of .65 and standard error of .25 ($p = .015$); use of formal help variable yielded a regression weight of .072 and a standard error of .03 ($p = .049$); and the cultural influence variable yielded a regression weight of 8.13 and a standard error of 3.06 ($p = .014$) (See Table 4).

Table 4

Multiple Regression Analysis Model: Predictors of Depression

Variable	Coefficient	SE	t	p
Constant	15.59	7.80	-1.99	0.058
Health	-00.82	0.87	-0.95	0.353
Cultural influence	8.13	3.06	2.65	0.014
Caregivers' burden	0.65	0.25	2.62	0.015
Use of formal help	0.07	0.03	2.08	0.049

Congruent with the proposed hypothesis, caregiver's burden and depression were positively correlated ($r = .53$), suggesting that the more burden caregivers feel the more depressed they become (See Table 5). Caregivers who perceived institutionalization of elders as unacceptable in their culture were also more likely to get depressed.

Contrary to what was expected, there appears to be a positive relationship between depression and the number of days that elders received formal help ($r = .36$). It had been proposed that because Puerto Rican elders tend to underutilize health services, they were more likely to put demands on their relatives, and caregivers in turn were more likely to feel burdened and become depressed. Thus, the relationship was expected to be negative: the less formal help elders received, the more depressed their caregivers would be. A plausible explanation for the positive

relationship between these two variables is that elders who seek formal help are more impaired and difficult to care for, thus more burdensome for their caregivers(See Table 5).

Table 5

Correlation Coefficients

	Depression	Health	Cultural influence	Caregivers' burden	Use of formal help
Depression	*	.33	.32	.53	.36
Health	.33	*	.14	.63	.39
Cultural influence	.32	.14	*	.02	-.26
Caregivers burden	.53	.63	.02	*	.36
Use of formal help	.36	.39	-.26	.36	*

It was proposed that elders' health would be negatively correlated with caregivers depression, indicating that as the elders' health deteriorated, caregivers would feel more depressed. Although results were not significant ($p=.35$), the obtained negative regression weight (-0.82) suggests that there is an apparent negative trend that describes the relationship of these two factors.

Analysis of Model Equation

Analyses were performed to test whether the proposed multivariate equation met the regression assumptions. There was no evidence of specification error. The plot of partial residuals revealed a linear relationship between the dependent and independent variables as well as homoscedasticity. In testing for possible multicollinearity, the lowest tolerance value obtained was 0.53, indicating no significant correlation between the independent variables. In an effort to detect possible outliers, studentized residuals revealed one score with high leverage. These results are not surprising given a small data set.

In order to assess the degree of influence exerted by the outlier score, further regression analyses were conducted excluding the outlier. Results revealed that the equation accounted for 33% of the variance ($p < .01$). The variables, caregiver burden and cultural influence were also significant in this model yielding regression weights of 0.71 ($p=0.01$) and 7.25 ($p=0.04$), respectively. However, the variable indicating the frequency of formal help use, found to be significant in the original model, was not significant in the second model ($b = -0.004$; $p=0.96$). The health

variable was not significant in either model. Since no substantial reasons were found to delete the outlier or extreme score from the data, the original model was preserved.

CHAPTER IV

DISCUSSION

The present study examined factors that may lead to increased levels of depression among Puerto Rican caregivers of older adults. First, the experiences of Puerto Rican caregivers who live in the United States and caregivers who live in Puerto Rico were compared. Then, four predicting variables (health, use of formal help, cultural influence, and caregivers' burden) were considered as possible risk factors for depression among these two groups.

It was hypothesized that Puerto Rican caregivers living in the United States would be more depressed than those living in Puerto Rico; however, results showed that these two groups were not significantly different in terms of their level of depression ($F=0.04$; $p=0.84$). This hypothesis was based on two assumptions: First, it was proposed that Puerto Rican elders living in the United States would be less likely to use health services, and consequently rely on their caregivers more often when compared to their counterparts living in their home country. Second, it was proposed that elders in Puerto Rico would be more likely to have a larger caregiving network than those living in the

United States. To the extent that elders underutilize health services and place increasing demands upon their relatives, caregivers are more likely to feel burdened, and as a result more depressed. Hence, based on these two assumptions, caregivers living in the United States were predicted to be more depressed than those living in Puerto Rico.

The assumption that elders in Puerto Rico use health services more frequently than Puerto Rican elders in the United States stems from the fact that the former group is not faced with the same barriers to obtaining adequate health care as the latter. Research studies have shown that Puerto Rican elders have a low tendency to use formal help. Instead, Latino elders are more likely to live with their relatives and rely on family-based support systems when compared to non-Latino whites (Bean et al., 1987; Bengston et al., 1990; Green et al., 1990; Sirroco, 1989; Wallace et al., 1994; Worobey et al., 1990a). However, these studies have exclusively focused on Puerto Rican elders living in the United States and have failed to compare this group to elders living in Puerto Rico. Thus, it is possible that Puerto Rican elders living in their country of origin are more likely to use health services than their counterparts in the United States.

Studies that have considered possible explanations for the lower tendency of minority elders to use formal help have identified factors such as cultural aversion, societal discrimination (Mui, 1993; Wallace, 1990b), language barriers (Wallace et al., 1994), and unfamiliar institutional norms of a predominantly non-Latino white population. It has been suggested that these factors serve as obstacles for Puerto Rican elders to obtaining adequate health care in the United States. However, elders living in Puerto Rico are less likely to encounter these factors, and consequently more likely to use health services. In fact, the present study provides supporting evidence for this assumption. Although there were no significant between group differences in the frequency of health services use, elders living in Puerto Rico used formal help more often (mean=41 days) than those living in the United States (mean=32 days).

The first hypothesis was also based on the assumption that elders in Puerto Rico are more likely to have an extended caregiving network than Puerto Rican elders living in the United States. Results from this study also provided supporting evidence for this assumption. Puerto Rican caregivers living in their country of origin were more likely to receive help from other relatives (mean= 25 hours

a week) than those living in the United States (mean= 12 hours a week). However, this difference was not significant.

Although elders who live in the United States were less likely to use formal help and to have an extensive caregiving network than those living in Puerto Rico, their caregivers did not appear to be more depressed than their counterparts in Puerto Rico. Instead, the US group (mean=13.71) was less depressed than the PR group (mean=14.43). In addition, more caregivers living in Puerto Rico were depressed (42.86%) when compared to caregivers in the United States (35.71%). According to the most frequently used cut off point for the CES-D (16), neither group was significantly depressed. Following these results, the first hypothesis was rejected.

It is possible that a larger sample would have introduced more variance into the data, and thus more between group differences. For example, care recipients in Puerto Rico were significantly older and more impaired than their counterparts in the United States. Furthermore, their caregivers were also more burdened compared to their corresponding group. Even though these factors should have increased the likelihood of depression among caregivers in

Puerto Rico, there were no significant differences between the two groups. Perhaps, if elders in the United States were as old and impaired as their counterparts in PR, and their caregivers as burdened, they would have been significantly more depressed. A larger sample would have increased the amount of variance in the data yielding a more representative range of subjects.

The second hypothesis stated that depression among Puerto Rican caregivers would be related to four factors: (1) elders' low tendency to use formal help, (2) elders' poor health, (3) caregivers' burden, and (4) culture's negative perception of elders' institutionalization. Results showed that some of the factors that seem to place Puerto Rican caregivers at risk of depression are similar to those identified in previous research studies on non-minority populations. For example, it has previously been proposed that elders' increased impairment (Rosenthal et al., 1993) and caregiving burden (Pruchno et al., 1990) appear to be common factors affecting caregivers' depressive symptomatology.

The present study showed that caregivers' feelings of burden significantly increased their risk of depression. There was a positive correlation between Puerto Rican

caregivers' burden and depression ($r=.53$). In addition, this variable had a regression weight of .65 in the regression equation ($p=.015$). Although causation cannot be inferred from this analysis, it is possible that this variable has a negative effect on caregivers' depressive symptomatology.

Although the level of elders' impairment did not appear to affect significantly the caregivers' well-being in the present study, it certainly showed a negative trend as evidenced by its regression weight ($b=-0.82$). These results suggest that as elders' health decreases, caregivers depressive symptomatology increases. Even though these results were not significant, a larger sample would have possibly increased the likelihood of significance.

The variable that looked at elders' tendency to use formal help was also significant in predicting depression. This variable yielded a regression weight of 0.07 ($p=0.05$). However, contrary to what was expected, the correlation between caregivers' depression and elders' use of formal help appeared to be positive ($r=.36$). It was predicted that as elders' tendency to use health services decreased, they would be more likely to place demands on their relatives, and consequently their caregivers would be more

depressed. Results showed an opposite trend: as the number of days that elders used formal help increased, so did their caregivers' level of depression. This trend may be possibly related to the fact that elders who used formal help more frequently were more impaired, and thus more dependent on their caregivers as well. A correlation analysis showed that this trend appeared to be true for the present sample ($r=.39$).

The predicting variable that seemed to be most relevant for the present study, yielding the highest significant regression weight ($b=8.13$), was cultural influence. This variable looked at Puerto Rican caregivers' view of institutionalization. It was hypothesized that a culture's negative perception of elders' institutionalization would increase the likelihood of depression among caregivers. Results showed a positive correlation between negative perception of institutionalization and caregivers depression ($r=.32$). These results suggest that as the use of long-term care institutions is perceived as unacceptable in the culture, the likelihood of caregivers' depression increases. It appears that, as a result of tradition, Puerto Rican caregivers may feel more responsible to care for their

elders at home and weary about even considering institutionalization as an option.

Puerto Rican culture's negative perception of elders' institutionalization appears to be a differential factor among Puerto Rican and nonminority caregivers. Puerto Rican caregivers seem to be greatly influenced by their culture's negative perception of elders' institutionalization, and thus feel more responsible to care for their elders at home.

A review of the open ended questions related to elders' institutionalization showed that both Puerto Rican caregivers living in their home country as well as those living in the United States see this practice as unacceptable (See Appendix G). For example, caregivers were asked to explain their answer to a question that asked whether institutionalization of elders was viewed as "acceptable" or "unacceptable" in their culture. Responses included: "It is not acceptable. People who put their parents in an institution after they had cared for them for so long don't have hearts;" "As long as we can care for them we should. We owe them our lives;" "My mother lives with me; she needs me and I need her. She is going to die right here with me;" "For Puerto Ricans, that's a duty that the family has. We have to stay together until the end.

[Institutionalization] would mean splitting the family." Thus, it seems that even Puerto Ricans who have been living away from their home country still maintain their cultural values and beliefs.

Limitations of the study

It is important to acknowledge the limitations of this study most which are related to the small sample data. A larger sample would have not limited the amount of variables that were included in the regression equation. For example, if a larger number of variables could have been included, it would not have been necessary to combine the scales that measured elders' behaviors, physical and functional impairments to form a global health variable. The combination of these scales creates more room for measurement error and consequently, decreases estimates' efficiency. It is possible that an increased number of variables would have resulted in additional factors affecting caregivers' well-being, and perhaps more significant results.

Another limitation of the present study is that a higher number of caregivers living in Puerto Rico were interviewed over the phone compared to those living in the United States; however, there were no significant between

group differences in terms of the dependent variable, depression. Furthermore, due to the fact that the majority of Puerto Ricans living in the United States have a low socioeconomic status with a high percentage living below the poverty line, the sample from Puerto Rico had to be matched to the one from the United States in terms of SES. Thus, this study is limited to Puerto Rican caregivers from a low socioeconomic status.

CHAPTER V

CONCLUSION

Results from this study suggest that there are factors such as elders' increased impairment and caregiving burden that tend to affect caregivers' well being regardless of their background. However, there are additional factors that place minority caregivers at further risk of depression. For example, results from the present study showed that Puerto Rican culture's negative perception of institutionalization has a strong impact on caregivers. As a result, they seem to feel burdened and depressed, perhaps because they cannot even consider long-term institutions as an option.

In addition, results also showed that Puerto Rican elders who live in their home country are more likely to use health services than those who live in the United States. This finding suggests that although traditionally Puerto Ricans prefer to care for their elders at home, when they are not faced with structural barriers they are more likely to use health services.

In general, these findings suggest that it is important to understand how a culture interprets health and family. This information seems particularly important for providers

so that they are able to provide assistance, particularly to elders, in a manner that is more acceptable and comfortable for them. In addition, as it has been previously suggested "providers must not allow racial and ethnic differences to limit access to health care services that meet medically accepted standards of care aimed at maximizing health outcomes" (Damron-Rodriguez, Wallace, & Kington, 1994, p.59). The present study should serve to indicate the importance of considering cultural background in the area of health services, and minority groups in caregiving research.

APPENDIX A
DEMOGRAPHICS

1. The elderly person we will be discussing with you today is your:

Mother _____ 1
Father _____ 2
Mother-in-law _____ 3
Father-in-law _____ 4
Spouse _____ 5
Other _____ 6

2. How old is your (ELDER)? Years _____

2a. Where was your (ELDER) born? _____

2b. How long has your (ELDER) been living in the United States/Puerto Rico? Years _____ Mos _____

3. Is your (ELDER):

Widowed _____ 1
Separated _____ 2
Divorced _____ 3
Never married _____ 4
Other _____ 5

4. How long has your (ELDER) been (widowed/separated/divorced)? Years _____ Mos _____

-Next, I'd like to ask you some questions about yourself.

(NOTE SEX OF RESPONDENT)

Female _____ Male _____

5. What is your year of birth? Year _____

6. Some people consider themselves to be members of a particular ethnic group. Do you consider yourself to be part of such a group?

Yes _____ No _____

(IF YES:)

6a. What group? _____

6b. Where were you born? _____

6c. How long have you been living in the United States/
Puerto Rico?

Years _____ Mos _____

7. What is your religion?

None	_____	1
Protestant	_____	2
Catholic	_____	3
Jewish	_____	4
Other (SPECIFY)	_____	5

8. What is the highest grade of school you have completed?

Grade _____

9. Are you:

Married	_____	1
Divorced	_____	2
Separated	_____	3
Widowed	_____	4
Never married	_____	5
Other	_____	6

10. What kind of work have you done most of your life?

(OCCUPATIONAL TITLES OR DUTIES)
(IF HOUSEWIFE, SKIP TO 11b)

10a. For what kind of business, company or agency was that?

(INDUSTRY TYPE OF BUSINESS)

11. Do you currently work for pay?

Yes	_____	1
No	_____ (SKIP TO 11b)	2

(IF WORKING NOW, ASK:)

11a. How many hours a week do you currently work?

Hrs/Wk _____

(IF NOT WORKING NOW, ASK:)

11b. When did you last work?

Month _____ Year _____

(IF NEVER WORKED FOR PAY, SKIP TO #12)

11c. What are the reasons why you stopped working?
(CIRCLE ALL THAT APPLY)

To care for (ELDER) _____ 1
Reached retirement age _____ 2
Own health problems _____ 3
Other family commitments _____ 4
Laid off, fired _____ 5
Other (SPECIFY) _____ 6

12. Who lives with you, including children that live away?

NAME RELATION AGE SEX SCHOOL-AWAY

Check here if caregiver lives alone

13. Do you live with your (ELDER)? Yes _____ No _____

(IF YOUR ANSWER IS NO, SKIP TO #20)

14. How long have you and your (ELDER) been living together?

Years _____ Mos _____

15. Who moved?

You moved in with your (ELDER) _____ 1
Your (ELDER) moved in with you _____ 2
You have always lived together _____ 3

16. At the time that you began to live together, did you think that it would be:

Temporary _____ 1
Permanent _____ 2
Uncertain _____ 3

17. How did it come about that you were living together?
That is, what were the reasons for this arrangement?

18. Who was involved in the decision to live together?

RELATIONSHIP

19. Do you see living together as:

Temporary_____1
Permanent_____2
Uncertain_____3

20. If it were necessary or convenient, Would you consider
the possibility of living with your (ELDER)? That is,
that you would move in with your (ELDER) or your (ELDER)
would move in with you?

Yes_____ No_____

Explain_____

APPENDIX B

CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE

Now think of the way you have been feeling during the past week. I am going to read some statements about feelings you may have had in the past week. I'd like you to tell me how often you felt that way.

- 1 Rarely/none of the time (less than 1 day)
- 2 Some, or a little of the time (1-2 days)
- 3 Occasionally/moderate amount of time (3-4 days)
- 4 Most or all of the time (5-7 days)

	Rarely	Some-	Occa-	Most of
	times	sionally	the time	
During the past week:				
a) I was bothered by things that usually don't bother me.	1	2	3	4
b) I did not feel like eating; my appetite was poor.	1	2	3	4
c) I felt that I could not shake off the blues even with help from my family or friends.	1	2	3	4
d) I felt that I was just as good as other people.	1	2	3	4
e) I had trouble keeping my mind on what I was doing.	1	2	3	4
f) I felt depressed.	1	2	3	4
g) I felt that everything I did was an effort.	1	2	3	4
h) I felt hopeful about the future.	1	2	3	4
i) I thought my life had been a failure.	1	2	3	4
j) I felt fearful.	1	2	3	4
k) My sleep was restless.	1	2	3	4
l) I was happy.	1	2	3	4
m) I talked less than usual.	1	2	3	4
n) I felt lonely.	1	2	3	4
o) People were unfriendly.	1	2	3	4
p) I enjoyed life.	1	2	3	4
q) I had crying spells.	1	2	3	4
r) I felt sad.	1	2	3	4
s) I felt that people disliked me.	1	2	3	4
t) I could not get "going."	1	2	3	4

APPENDIX C

BURDEN SCALE

Now I am going to talk about some feelings you may be having in caring for your (ELDER). For each statement, please tell me if you agree a lot, agree a little, neither agree or disagree, disagree a little, or disagree a lot.

- 5 Agree a lot (A/lot)
- 4 Agree a little (A/little)
- 3 Neither agree or disagree (neither)
- 2 Disagree a little (D/little)
- 1 Disagree a lot (D/lot)

A/ A/ Nei- D/ D/
lot little ther little lot

- | | | | | | |
|--|---|---|---|---|---|
| a) I can fit in most of the things I need to do in spite of the time taken by caring for my (ELDER). | 5 | 4 | 3 | 2 | 1 |
| b) Taking care of my (ELDER) gives me a trapped feeling. | 5 | 4 | 3 | 2 | 1 |

Now I will talk about some feelings you may have in caring for your (ELDER). For each question, please tell me how often you feel this way: "never, rarely, sometimes, quite frequently, or nearly always."

- 5 Nearly always
- 4 Quite frequently
- 3 Sometimes
- 2 Rarely
- 1 Never

How often do you feel:	Nearly	Quite	Some-	Rare-	Never
	always	freq	times	ly	

- | | | | | | |
|--|---|---|---|---|---|
| c) ...that your health has suffered because of the care you must give your (ELDER)? | 5 | 4 | 3 | 2 | 1 |
| d) ...that because of the time that you spend with your (ELDER) you don't have enough time for yourself? | 5 | 4 | 3 | 2 | 1 |
| e) ...that your social life has suffered because you are | | | | | |

	caring for your (ELDER)?	5	4	3	2	1
f)	...very tired as a result of caring for your (ELDER)?	5	4	3	2	1
g)	...that you will be unable to care for your (ELDER) much longer?	5	4	3	2	1
h)	...isolated and alone as a result of caring for your (ELDER)?	5	4	3	2	1
i)	...that you have lost control of your life because of caring for your (ELDER)?	5	4	3	2	1

When caring for another person, some people experience a sense of burden. Overall, how burdened do you feel in caring for your (ELDER)? Would you say you are:

not at all burdened _____
a little burdened _____ 4
moderately burdened _____ 3
greatly burdened _____ 2
very greatly burdened _____ 1

APPENDIX D

PHYSICAL HEALTH OF ELDER

Now I would like to ask you some questions about your (ELDER)'s health in the past year. Tell me whether (s/he) had any of the following conditions. You can just answer yes or no.

1. In the past year your (ELDER) had:	Yes	No
a) Arthritis	1	2
b) Chronic bronchitis	1	2
c) Emphysema	1	2
d) Any heart trouble	1	2
e) Hardening of the arteries	1	2
f) Stomach ulcer	1	2
g) Cataracts	1	2
h) Glaucoma	1	2
i) Cancer	1	2
j) Nervousness of been tense	1	2
k) Trouble getting to sleep or staying asleep	1	2
l) Headaches	1	2
m) Parkinson's disease	1	2
n) Diabetes	1	2
o) Hypertension of high blood pressure	1	2
p) Stroke or effects of stroke	1	2
q) Pneumonia	1	2
r) Circulation trouble in arms or legs	1	2
s) Asthma	1	2
t) Broken hip	1	2
u) Other broken bones	1	2
v) Bladder problems	1	2
w) Liver problems	1	2
x) Gall Bladder	1	2
y) Kidney trouble	1	2
z) Anemia	1	2
aa) Back problems	1	2
bb) Alzheimer's disease, dementia, or senility	1	2
cc) Serious vision problems	1	2
dd) Serious hearing problems	1	2
ee) Other (SPECIFY) _____	1	2

Continued, next page

2. How many days in the last 12 months has your (ELDER) spent in the hospital?

Days _____

3. How many days in the last 12 months has your (ELDER) spent in a nursing home or rehabilitation/convalescent center?

Days _____

4. In the past year, about how many days did your (ELDER) receive home visits from a nurse, physical therapist, or other therapist?

Days _____

APPENDIX E

INSTRUMENTAL ACTIVITIES OF DAILY LIVING

Now I am going to ask you about how your (ELDER) manages (her/his) daily life.

(For all responses, ask: Has anyone helped (her/him) with the (TASK) during the last month? That is, not only family members, but also friends and neighbors, paid workers, visiting nurses, etc.)

NAME

1. In general,

a) Can your (ELDER) do (her/his) housework:

3 without help (can do heavy housework)?	2 with some help (can do light housework but can't do heavy work)?	1 or is (she/he) completely unable to do any housework?
--	--	---

b) Can your (ELDER) do (her/his) own laundry:

3 without help (can take care of all laundry or all except for sheets and towels?)	2 with some help (can do small items only)?	1 or is (she/he) completely unable to do laundry?
--	---	---

c) Can your (ELDER) prepare (her/his) own meals:

3 without help (can plan and cook full meals)?	2 with some help (can prepare some things but can't cook full meals herself/himself?)	1 or is (she/he) completely unable to prepare any meals?
--	---	--

d) Can your (ELDER) go shopping for (his/her) groceries:

3 without help (can take care of all shopping needs herself/himself)?	2 with some help (needs someone to go with her/him on all shopping trips)?	1 or is (she/he) completely unable to any shopping?
---	--	---

e) Can your (ELDER) go to places out of walking distance:
 3 without help (can travel alone on buses, in taxis or drive own car)? 2 with some help (needs someone to help or accompany)? 1 or is (she/he) completely unable to travel unless special arrangements are made for a vehicle like an ambulance?

f) Can your (ELDER) use the telephone:
 3 without help (including looking up numbers and dialing)? 2 with some help (can answer phone, dial operator in an emergency, but has a special phone or needs help in getting a number or dialing)? 1 or is (she/he) completely unable to use the telephone?

g) Can your (ELDER) manage his/her own money:
 3 without help (write checks, pay bills, etc.)? 2 with some help (can manage day-to-day buying but has help with her/his checkbook and paying bills)? 1 or is (she/he) completely unable to handle day-to-day buying?

h) Can your (ELDER) take (her/his) medications:
 3 without help (in the right doses at the right time)? 2 with some help (can take medicine if someone prepares it for her/him and/or reminds her/him to take it)? 1 or is (she/he) completely unable to take her/his own medicine?

Activities of Daily Living

(If 1 or 2 ask: Has anyone helped (him/her) with the (TASK) during the last month? That is, not only family members, but also friends and neighbors, paid workers, visiting nurses, etc.).

2. In general,

NAME

i) Does your (ELDER) get around (her/his) house/apartment/room:

3 without any help (except for a cane)?	2 with some help (from a person or using a walker, crutches, or chair)?	1 or doesn't she/he get around her/his home at all unless someone moves her/him?
--	--	--

j) Does your (ELDER) eat:

3 without any help?	2 with some help (cutting food, identifying for the blind, etc.)?	1 or does someone feed her/him?
---------------------	--	---------------------------------

k) Does your (ELDER) dress and undress (herself/himself):

3 without any help (pick out clothes, dress and undress self)?	2 with some help (dressing or undressing)?	1 or does someone dress and undress her/him?
---	---	--

l) does your (ELDER) take care of (her/his) appearance, things like combing (her/his) hair (FOR MEN: shaving):

3 without help?	2 with some help?	1 or does someone do all this type of thing for her/him?
-----------------	-------------------	--

m) Does your (ELDER) get in and out of bed:

3 without help?	2 with some help (from a person or device)?	1 or doesn't she/he get in and out of bed unless someone lifts her/him?
-----------------	--	---

APPENDIX F

ELDER'S BEHAVIOR

Now I will ask you some questions about your (ELDER'S) behavior. These behaviors may or may not apply to your (ELDER).

- 5 Almost every day (6 or more times per week)
- 4 2-5 times per week
- 3 3-4 times per week
- 2 1-2 month per week
- 1 Has never occurred in the past month

	Almost everyday	2-5x/wk	3-4x/mo 1x/wk	1-2x/mo	Never in past mo
How often during the past month:					
a) did (she/he) have trouble breathing?	5	4	3	2	1
b) did (she/he) yell, swear, curse, or threaten?	5	4	3	2	1
c) did (she/he) keep you up during the night?	5	4	3	2	1
d) did (she/he) choke or have trouble swallowing?	5	4	3	2	1
e) did (she/he) hear or see things that were not there?	5	4	3	2	1
f) did (she/he) ask the same thing over and over again?	5	4	3	2	1
g) was (her/his) behavior embarrassing?	5	4	3	2	1
h) was (she/he) unable to express thoughts or wishes?	5	4	3	2	1
i) did (she/he) fall?	5	4	3	2	1

j) did (she/he) not recognize others?	5	4	3	2	1
k) was (she/he) unaware of the day of the week or year?	5	4	3	2	1
l) did (she/he) forget recent events?	5	4	3	2	1
m) did (she/he) not remember your name?	5	4	3	2	1
n) was (she/he) resistant or uncooperative?	5	4	3	2	1
o) did (she/he) lose (her/his) temper?	5	4	3	2	1

APPENDIX G

INSTITUTIONALIZATION

Now I would like to ask you some questions about placement in institutions for long term care.

1. In the last year have you ever thought about placing your (ELDER) in a nursing home, or other institution? Have you thought about it:

very seriously _____ 1
 somewhat seriously, or _____ 2
 haven not thought about it _____ 3

2. In the last year, have you discussed it with anyone?

Yes _____ 1 No _____ 2

3. How is institutionalization of elders perceived in your culture?

Acceptable _____ 1
 Unacceptable _____ 2

Explain _____

4. Have you ever discussed with your (ELDER) the possibility of placing her/him in a long-term care institution?

Yes _____ 1 No _____ 2

5. Do you and your (ELDER) share similar opinions about long-term care institutions for elders?

Yes _____ 1 No _____ 2

Explain _____

6. Do you feel that your culture and the american culture have the same conceptions about:

	Yes	No
a) taking care of older relatives at home	1	2

Explain _____

b) institutionalizing older adults	1	2
------------------------------------	---	---

Explain _____

7. Do you believe that your culutre has influenced the way you perceive the institutionalization of elders?

1 2

Explain _____

APPENDIX H

HISTORY OF CAREGIVING

Now, I am going to talk to you about when your caregiving began.

1. Can you tell me how it happened that you were the one in the family who became the main caregiver?

2. Thinking about things like these (Show list of ADL/IADL), what was it that made you recognize that you had become a caregiver rather than someone who simply helps your (ELDER) once in a while?

3. What were your (ELDER'S) (other) needs that made you begin to think of yourself as a caregiver?

4. What were (other) tasks that you had to do that made you begin to think of yourself as a caregiver?

5. When was it that you became a caregiver for your (ELDER)?

____/____/____
MONTH DAY YEAR

APPENDIX I

SPANISH VERSION OF QUESTIONNAIRE

1. El envejeciente que estaremos discutiendo con usted hoy es su:

Madre _____ 1
Padre _____ 2
Suegra _____ 3
Suegro _____ 4
Cónyuge _____ 5
Otro _____ 6

2. ¿Qué edad tiene su (envejeciente)?

Años _____

2a. ¿Dónde nació su (envejeciente)? _____

2b. ¿Cuanto tiempo hace que su (envejeciente) vive en
Puerto Rico/los Estados Unidos? _____

3. Es su (envejeciente):

Viudo/a _____ 1
Separado/a _____ 2
Divorciado/a _____ 3
Soltero/a _____ 4
Otro _____ 5

4. ¿Cuánto tiempo hace que su (envejeciente) esta (viudo/a /separado/a / divorciado/a)?

Años _____ Meses _____

-Ahora, deseo hacerle unas preguntas sobre usted.
(Anotar el sexo del que contesta)

F _____ M _____

5. ¿En qué año nació usted? Año _____

6. Algunas personas se consideran parte de algún grupo étnico. ¿Se considera usted miembro de algún grupo étnico en particular? Sí _____ No _____

(Si contesta en la afirmativa)

- 6a. ¿Qué grupo? _____
6b. ¿Dónde nació usted? _____
6c. ¿Cuántos tiempo lleva usted viviendo en Puerto Rico\ los
Estados Unidos? _____
7. ¿Cual es su religión, si alguna? o ¿A que religion
pertenece?

Ninguna _____ 1
Protestante _____ 2
Católica _____ 3
Judía _____ 4
Otra _____ 5
(Especifique)

8. ¿Cuál fue el ultimo grado escolar que completo?
Grado _____

- 8a. Aproximadamente, ¿ Cual es su ingreso?

_____ \$15,000 or less	_____ \$56,000-75,000
_____ \$16,000-35,000	_____ \$76,000-95,000
_____ \$36,000-55,000	_____ \$100,000 or more

9. Es usted:

casado/a _____ 1
divorciado/a _____ 2
separado/a _____ 3
viudo/a _____ 4
soltero/a _____ 5
Otro _____ 6

10. ¿En qué tipo de trabajo se ha desempeñado usted la mayor
parte de su vida? o ¿Que clase de trabajo usted ha
realizado la mayor parte de su vida?

(TITULO OCUPACIONAL O DEBERES)

(Si es usted ama de casa o esta desempleada/o, siga con
la pregunta 11b)

- 10a. ¿Para qué tipo/clase de negocio, compañía o agencia?

(TIPO DE INDUSTRIA O NEGOCIO)

11. ¿ Esta usted actualmente trabajando con sueldo?

Sí _____ 1
No (siga con 11b) _____ 2

(SI ESTA TRABAJANDO ACTUALMENTE, PREGUNTE:)

11a. ¿Cúantas horas a la semana esta usted actualmente trabajando?

Horas/semanas _____

(SI NO ESTA TRABAJANDO ACTUALMENTE, PREGUNTE:)

11b. ¿Cuándo fue la última vez que usted trabajó?

_____/_____
Mes Año

(SI NUNCA HA TRABAJADO CON SUELDO, SIGA A LA #12)

11c. ¿Por que razones dejo usted de trabajar?

(CIRCULE TODAS LAS QUE APLICAN)

Para cuidar a (envejeciente)	_____	1
Llegue a la edad del retiro	_____	2
Problemas de salud propia	_____	3
Otros compromisos familiares	_____	4
Fui cesanteado, despedido	_____	5
Otra razón (especifique)	_____	6

12. ¿Quien vive con usted? Incluya hijos que esten estudiando/viviendo fuera de la casa.

NOMBRE	RELACION	EDAD	SEXO	ESCUELA/FUERA
--------	----------	------	------	---------------

_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Marque aqui si usted vive solo/a _____

13. Vive usted con su (envejeciente)?

Si _____ No _____

(SI SU RESPUESTA ES "NO," SIGA CON LA PREGUNTA # 20.)

14. ¿cuanto tiempo usted y su envejeciente han vivido juntos?

Anos _____ Meses _____

15. ¿Quien se mudo?

Usted se mudo con su (envejeciente) _____ 1

Su (envejeciente) se mudo con usted _____ 2

Siempre han vivido juntos _____ 3

16. Cuando empezaron a vivir juntos, usted penso que seria:

temporero _____ 1

permanente _____ 2

Incierto/desconocido _____ 3

17. ¿Como fue que empezaron a vivir juntos? Es decir,

¿Cuales fueron las razones para este arreglo?

18. ¿Quien o quienes estuvieron envueltos en la desicion de vivir juntos?

PARENTESCO O RELACION

19. Actualmente, ve usted el vivir juntos como algo:

Temporero _____ 1

Permanente _____ 2

Incierto/desconocido _____ 3

20. Si fuera necesario o conveniente, ¿consideraria usted la posibilidad de vivir con su (envejeciente)? Es decir, que se mudaria usted con su envejeciente o que su envejeciente se mudaria con usted? Si _____ No _____ Explique

CENTRO DE ESTUDIOS EPIDEMIOLOGICOS DE DEPRESION (CEED)

Ahora piense en la forma en que usted se ha estado sintiendo durante la semana pasada. Ahora le voy a leer unas expresiones sobre sentimientos que usted puede haber experimentado durante la semana pasada. Quiero que me conteste con que frecuencia se sintio de esta forma.

1. Rara vez, o casi nunca _____ menos de 1 dia
2. Alguna vez, o muy pocas veces _____ 1-2 dias
3. Ocasionalmente _____ 3-4 dias
4. Casi siempre, o la mayor parte del tiempo _____ 5-7 dias

Durante la semana pasada: Rara vez/ Algunas Ocasional- casi
nunca veces mente siempre

a. Me moleste por cosas que usualmente no me molestan	1	2	3	4
b. No tenia deseos de comer	1	2	3	4
c. Senti que no podia salir de mi tristeza aun con la ayuda de familiares y amigos	1	2	3	4
d. Senti que yo era tan bueno/a como los demas	1	2	3	4
e. Me dio trabajo concentrarme en lo que estaba haciendo	1	2	3	4
f. Me senti deprimido/a	1	2	3	4
g. Senti que todo loque hacia requeria esfuerzo	1	2	3	4
h. Me senti esperanzado/a sobre el futuro	1	2	3	4
i. Pense que mi vida habia sido un fracaso	1	2	3	4
j. Me senti temeroso/a	1	2	3	4
k. Mi sueno estaba inquieto	1	2	3	4
l. Estaba feliz	1	2	3	4
m. Hablaba menos de lo usual	1	2	3	4
n. Me sentia solo/a	1	2	3	4
o. Las personas eran poco amigables	1	2	3	4
p. Disfrutaba de la vida	1	2	3	4
q. Tenia ataques de llanto	1	2	3	4
R. Me sentia triste	1	2	3	4
s. Sentia que le desagradaba a las personas	1	2	3	4
t. No podia seguir adelante	1	2	3	4

ESCALA DE PESADUMBRE

Ahora voy a hablar de algunos sentimientos que usted puede haber experimentado al cuidar a su (envejeciente). Por cada exprecion, por favor indique si usted está:

- 5 muy de acuerdo (Muy A)
- 4 un poco de acuerdo (Poco A)
- 3 ni de acuerdo ni en desacuerdo (Ni A-Ni DA)
- 2 un poco en desacuerdo (Poco DA)
- 1 muy en desacuerdo (Muy DA)

	Muy A	Poco A	Ni/A Ni/DA	Poco DA	Muy DA
a) Puedo llevar a cabo la mayor parte de las cosas que tengo que hacer a pesar del tiempo que paso cuidando a mi (envejeciente).	5	4	3	2	1
b) Me siento atrapado/a al cuidar a mi envejeciente	5	4	3	2	1

Ahora voy a hablar sobre algunos sentimientos que usted puede experimentar al cuidar a su (envejeciente). Para cada pregunta, por favor indique con qué frecuencia usted se siente de esta manera/forma: nunca, escasamente, algunas veces, frecuentemente, casi siempre:

- 5 Casi siempre
- 4 Frecuentemente
- 3 Algunas veces
- 2 Escasamente
- 1 Nunca

	casi siempre	frecuen- temente	Algunas veces	Escasa- mente	Nunca
Con que frecuencia siente usted:	5	4	3	2	1
c)...que su salud ha sufrido a causa del cuidado que tiene que darle a su (envejeciente)?	5	4	3	2	1
d)...que a causa del tiempo que usted pasa con su (envejeciente) no tiene suficiente tiempo para usted?	5	4	3	2	1

	siempre	casi frecuen- temente	algunas veces	escasa- mente	nunca
e)...que su vida social ha sufrido porque usted está cuidando de su (envejeciente)?	5	4	3	2	1
f)...muy cansado/a como resultado de cuidar a su (envejeciente)?	5	4	3	2	1
g)...que usted no podra cuidar a su (envejeciente) por mucho más tiempo?	5	4	3	2	1
h)...aislado/a y sólo/a como resultado de cuidar a su (envejeciente)?	5	4	3	2	1
i)...que usted ha perdido control de su vida por estar cuidando a su (envejeciente)?	5	4	3	2	1

Algunas personas experimentan una sensación de carga/pesadumbre cuando cuidan a otras personas. En términos generales, ¿cuán apesumbrado/a o sobre cargado/a se siente usted al cuidar a su (envejeciente)? Usted diría que está:

No sobre cargado/a _____ 5
 Un poco sobre cargado/a _____ 4
 Moderadamente sobre cargado/a _____ 3
 Grandemente sobre cargado/a _____ 2
 Muy grandemente sobre cargado/a _____ 1

IMPEDIMIENTOS DE SALUD FISICA DEL ENVEJECIENTE

Ahora me gustaría hacerle unas preguntas sobre la salud de su (envejeciente) en el año pasado. Dígame si él o ella ha tenido alguna de las siguientes condiciones. Puede contestar simplemente sí o no.

1. El año pasado su (enejeciente) tuvo:	Sí	No
a. Artritis	1	2
b. Bronquitis Crónica	1	2
c. Enfisema	1	2
d. Algún problema de corazón	1	2
e. Endurecimiento de las arterias	1	2
f. Ulceras estomacales	1	2
g. Cataratas	1	2
h. Glaucoma	1	2
i. Cáncer	1	2
j. Nerviosismo o tension nerviosa	1	2
k. Problemas para dormirse o mantenerse dormido/a	1	2
l. Dolores de cabeza	1	2
m. Enfermedad de Parkinson	1	2
n. Diabetes	1	2
o. Hipertensión o presión alta	1	2
p. Derrame cerebral o efectos de derrame cerebral	1	2
q. Pulmonía	1	2
r. Problemas circulatorios en brazos o piernas	1	2
s. Asma	1	2
t. Fractura de cadera	1	2
u. Fractura de otros huesos	1	2
v. Problemas de vejiga	1	2
w. Problemas de hígado	1	2
x. Problemas de vesicula	1	2
y. Problemas de los riñones	1	2
z. Anemia	1	2
aa. Problemas de espalda	1	2
bb. Enfermedad de Alzheimer, demencia o senilidad	1	2
cc. Problemas serios de visión	1	2
dd. Problemas serios de audición	1	2
ee. Otros (especifique)	1	2

2. ¿Cuántos días en los últimos 12 meses ha pasado su (envejeciente) en el hospital?

Número de días _____

3. ¿Cuántos días en los últimos 12 meses ha pasado su (envejeciente) en un asilo o centro de rehabilitación/convalecencia?

Número de días _____

4. ¿En el año pasado, aproximadamente, cuántos días su (envejeciente) recibió visitas en su hogar de enfermeras, terapeuta físico, o algún otro terapeuta?

Número de días _____

ACTIVIDADES INSTRUMENTALES DEL DIARIO VIVIR

Ahora voy a preguntarle sobre cómo su (envejeciente) se desenvuelve en su diario vivir.

(Para todas las respuestas, pregunte: ¿Alguien le ha ayudado a el/ella en el (trabajo/labor) durante el pasado mes? Es decir, no sólo miembros de la familia, si no que también amigos y vecinos, empleados a sueldo, enfermeras visitantes, etc.)

1. En general,

NOMBRE

a. Puede su (envejeciente) hacer trabajo en la casa:

3 Sin ayuda	2 Con ayuda puede	1 él/ella
(puede hacer	hacer trabajo	no puede
trabajo casero liviano pero no		hacer el
pesado)?	trabajo pesado?	trabajo
		casero?

b. Puede su (envejeciente) lavar su propia ropa:

3 Sin ayuda	2 Con ayuda puede	1 él/ella
(puede lavar	lavar piezas	no puede
toda la ropa	pequeñas	lavar su ropa?
con excepcion	solamente?	
de las sábanas		
y toallas)?		

c. Puede su (envejeciente) preparar su propia comida:

3 Sin ayuda	2 con ayuda puede	1 él/ella
(puede plani-	preparar algunas	no puede
ficar y coci-	cosas pero no	preparar
nar comidas	puede cocinar	ninguna
completas)?	comidas comple-	comida?
	tas para sí	
	mismo?	

d. Puede su (envejeciente) ir de compras:

3 sin ayuda	2 con ayuda nece-	1 o él/ella
(puede com-	sita ir con al-	no puede
prar todo	guien para todas	hacer ningún
lo que	sus salidas de	tipo de compra?
necesita por	compra?	
sí mismo)?		

e. Puede su (envejeciente) ir a lugares distantes, a los cuales no puede ir caminando:

3 sin ayuda	2 con ayuda (necesita a alguien que le ayude o le acompañe)?	1 o él/ella no puede viajar a menos de que se le hagan arreglos especiales para un vehículo o ambulancia?
-------------	--	---

f. Puede su (envejeciente) usar el teléfono:

3 Sin ayuda	2 con ayuda (puede contestar el teléfono, marcar para el operador/a en caso de emergencia, pero tiene un teléfono especial o necesita ayuda para buscar números telefónicos o para marcar?)	1 o él/ella no puede usar el teléfono?
-------------	---	--

g. Puede su (envejeciente) manejar su propio dinero?

3 Sin ayuda	2 con ayuda	1 o él/ella
(escribir cheques, pagar cuentas, etc.)?	manejar sus comprobantes diarios pero necesita ayuda con su libreta de cheques y para pagar cuentas?	no puede manejar su dinero diariamente?

h. Puede su (envejeciente) tomar sus medicinas:

3 sin ayuda	2 con ayuda	1 o él/ella
(las dosis correctas a las horas indicadas?)	tomar las medicinas si alguien se las prepara y/o recuerda tomárselas?	no puede tomar sus medicinas?

ACTIVIDADES DEL DIARIO VIVIR

(Si contesta 1 ó 2, pregunte: ¿Le ha ayudado alguien con el (TRABAJO) durante el mes pasado? Por ejemplo, no sólo miembros de la familia, pero también amigos y vecinos, empleados, enfermería visitante, etc...)

2. En general,

NOMBRE

i. Puede su (envejeciente) moverse/caminar por su casa/apartamento/cuarto:

3 sin ayuda	2 con ayuda de	1 no se mueve
(excepto	una persona o	él/ella en su
por un	usando un anda-	hogar a menos
bastón)?	dor, muletas,	de que alguien
	o silla?	la/lo mueva?

j. Puede su (envejeciente) comer:

3 sin ayuda?	2 con ayuda (para	1 o alguien le
	cortar la comida,	da de comer?
	identificarla	
	para los ciegos,	
	etc.)?	

k. Puede su (envejeciente) vestirse y desvestirse:

3 Sin ayuda	2 con ayuda para	1 o alguien
(escoge su	vestirse o	lo/la viste
ropa, se	desvestirse?	y desviste?
viste y se		
desviste		
sólo/a?		

l. Puede su (envejeciente) ocuparse de su apariencia, como peinarse o si es hombre, afeitarse:

3 Sin ayuda?	2 Con ayuda	1 o alguien le hace
(de persona		todo este tipo de
o artefacto)?		cosas?

m. Puede su (envejeciente) acostarse y levantarse de la cama:

3 Sin ayuda?	2 Con ayuda (de	1 o no se acuesta
	una persona o	o levanta de la
	de algún	cama a menos que
	artefacto)?	alguien lo/la
		levante?

n. Puede su (envejeciente) banarse, ducharse, o lavarse:

3 Sin ayuda? 2 Con ayuda (de 1 o solamente
una persona o cuando alguien
de algun lo/la baña
artefacto)? (lo/la levanta
o lo/la baña)?

o. Puede su (envejeciente) ir al baño o usar un inodoro portátil:

3 Sin ayuda? 2 Con ayuda? 1 o no usa el baño
ni el inodoro
portátil a menos
de que alguien
lo/la mueva?

Ahora, me gustaría que me diga cuánto tiempo usted ha ayudado a su (envejeciente) a hacer las cosas de las cuales hemos hablado. Es decir, ¿Le ha ayudado con la lista de cosas que hemos repasado? (Refiera a la lista de AIDV y la lista de ADV).

3. En promedio, ¿Al rededor de cuántas horas a la semana pasó usted actualmente ayudando con las tareas que acabamos de mencionar? Incluya fines de semana en su total.

CODIGO

HORAS/SEMANA

(Anote todos los comentarios)

Por cada nombre que usted mencionó en las preguntas anteriores sobre el manejo de la vida diaria de su (envejeciente) deseo que me diga al rededor de cuántas horas él/ella ayudó durante el mes pasado.

4. ¿Alrededor de cuántas horas a la semana (_____)
ayudó durante el mes pasado? Nombre

AYUDANTE

RELACION AL R

HORAS/SEMANA
(MES PASADO)

FRECUENCIA DE COMPORTAMIENTO

Ahora, le voy a hacer unas preguntas sobre el comportamiento de su (envejeciente). Estos comportamientos puede que apliquen o que no apliquen a su (envejeciente).

- 5 Casi todos los días (6 o más veces por semana)
- 4 2-5 veces por semana
- 3 3-4 veces al mes
- 2 1-2 veces al mes
- 1 Nunca ocurrió en el mes pasado.

	Casi todos los días 5	2-5x/sem 4	3-4x/mes 1x/sem 3	1-2x/mes 2	nunca 1
Con qué frecuencia durante el mes pasado:					
a. El-ella tuvo problemas de respiración?	5	4	3	2	1
b. El-ella gritó, dijo malas palabras, maldijo, o amenazó?	5	4	3	2	1
c. El/ella lo/la mantuvo despierto/a durante la noche?	5	4	3	2	1
d. El/ella se ahogó o tuvo problemas tragando?	5	4	3	2	1
e. El/ella escucho o vio cosas imaginarias?	5	4	3	2	1
f. El/ella preguntó lo mismo una y otra vez?	5	4	3	2	1
g. Su comportamiento fue vergonzoso?	5	4	3	2	1
h. El/ella no pudo expresar sus pensamientos y deseos?	5	4	3	2	1
i. El/ella sufrió una caída?	5	4	3	2	1
j. El/ella no reconoció a otras personas?	5	4	3	2	1

k. El/ella no era consciente del día, de la semana o del año?	5	4	3	2	1
l. El/ella se olvidó de sucesos recientes?	5	4	3	2	1
m. El/ella no se acordó de su (usted) nombre?	5	4	3	2	1
n. El/ella mostro resistencia o no cooperaba?	5	4	3	2	1
o. El/ella perdió la paciencia o demonstro mal genio?	5	4	3	2	1

INSTITUCIONES

Ahora, me gustaria hacerle unas preguntas sobre instituciones permanentes.

1. En el ultimo ano, ha usted considerado internar a su (envejeciente) en un asilo de ancianos o en alguna otra institucion permanente? Lo ha usted considerado:

Muy en serio _____ 1
En serio _____ 2
No lo ha considerado _____ 3

2. En el ultimo ano, ha usted discutido este tema con alguien?

Si _____ No _____

3. En su cultura, como se considera el internado de envejecientes en asilos otras instituciones permanentes?

Aceptable _____ 1
No es aceptable _____ 2

Explique _____

4. Ha discutido usted alguna vez con su (envejeciente) la posibilidad de internarlo/a en una institucion permanente?

Si _____ No _____

5. Su (envejeciente), comparte con usted las mismas opiniones sobre asilo de ancianos e instituciones permanentes para envejecientes?

Si _____ No _____

Explique _____

6. Cree usted que la cultura puertorriquena y la cultura americana tienen la misma concepcion sobre:

	Si	No
a) cuidar a los enfermos en la casa.	1	2

Explique _____

b) internar a los familiares de mayor edad en instituciones permanentes.	1	2
--	---	---

Explique _____

7. Cree usted que su bagaje cultural tiene alguna influencia sobre su opinion acerca del internado de envejecientes?

1 2

Explique _____

HISTORIA

Ahora, le voy a hacer unas preguntas sobre el comienzo de sus responsabilidades como proveedor/a de cuidado.

1. Me podria explicar usted como sucedio el que, de toda su familia, se convirtiera usted en el/la proveedor/a de cuidado o encargado/a principal de su (envejeciente)?

2. Considerando cosas como estas (ensenar lista de Actividades Instrumentales y Actividades del Diario Vivir), que le hizo a usted reconocer que se habia convertido en el/la proveedor/a de cuidado o encargado/a principal de su (envejeciente) en vez de simplemente alguien que le ayudaba de vez en cuando?

3. Cuales fueron otras necesidades de su (envejeciente) que le hicieron realizar que usted era el/la proveedor/a de cuidado o encargado/a principal de su (envejeciente)?

4. Mencione otro tipo de trabajos y deberes que usted comenzo a hacer por su (envejeciente) que a la vez le hicieron realizar que usted era el/la proveedor/a de cuidado o encargado/a principal de su (envejeciente).

5. Cuando fue que usted se convirtio en el/la proveedor/a de cuidado o encargado/a principal de su (envejeciente)?

_____/_____/_____
MES DIA AÑO

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