

PHYSICAL AND EMOTIONAL SYMPTOM BURDEN
AND ADVANCED CHRONIC ILLNESS:
DYADIC CONCORDANCE

by

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ABSTRACT

Over 40 million Americans act as an informal caregiver to someone over the age of 65. While there are many benefits to informal caregiving, research has highlighted associated challenges, such as accurately understanding the care recipient's medical and emotional symptoms. The current study aims to understand symptom reporting of informal caregivers by examining dyadic concordance of physical and emotional symptom reports. In addition to examining baseline correlations with demographic and psychosocial variables, the study examines a reminiscence and creative activity project as a possible intervention to increase concordance. Participants included 45 African American or Caucasian dyads, comprised of one chronically-ill older adult and one caregiver. Pearson correlations and six mixed ANOVAs were performed. Concordance was examined for symptom presence/absence as well as associated symptom distress. Physical and emotional symptom concordance were examined separately. Results indicated only two demographic variables (caregiver income adequacy and care recipient education) significantly related to concordance. Caregiver stress was related to lower concordance as was care recipient negative affect. Higher symptom reports by the care recipient were associated with decreased concordance for physical but not emotional symptoms and distress. Results of the ANOVAs indicated no improvement in concordance for intervention dyads compared to control dyads (N=28). Results are discussed in light of previous research on concordance as well as a model of caregiving stress. Limitations and future directions are discussed.

LIST OF ABBREVIATIONS AND SYMBOLS

- M* Mean: the sum of a set of measurements divided by the number of measurements in the set
- N* Total number in a sample
- F* Fisher's *F* ratio: A ration of two variances
- p* Probability associated with the occurrence under the null hypothesis of a value as extreme as or more extreme than the observed value
- r* Pearson product-moment correlation
- SD* Standard deviation
- t* Computed value of *t* test
- < Less than

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The unofficial motto around the Allen Lab is “pay it forward.” In research, as life, I think this is one of the greatest sentiments to cling to. It reminds us that we should seek to acknowledge those who came first, built us up, and supported our work and, in turn, we should move to provide that care and support for those who come next.

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INTRODUCTION

People in the United States are living longer and with more chronic illnesses than ever before (Federal Interagency Forum on Aging-Related Statistics, 2012). Furthermore, in 2010, 62% of non-institutionalized adults over 65 reported a disability that limited their daily activities (National Center for Health Statistics, 2011). Due, in part, to the rising costs of health care, many older persons needing assistance are cared for by family members, spouses, or friends. A national survey suggests that some 43.5 million Americans are caring for an aging person informally, for example in a home setting (National Alliance for Caregiving and AARP, 2009). While informal caregiving allows older adults to spend more time living at home and reduces the sometimes difficult transition to an institution, family caregiving also provides challenges to both aging adults and their caregivers. One such challenge is that of accurate symptom reporting on the part of caregivers, and is addressed by the current study.

Common symptoms experienced as a result of chronic illness and aging range from visible and noticeable (i.e., weight loss and vomiting) to quite subtle (i.e., anxiety, pain, fatigue, and feeling sad) and vary depending on the type and extent of illness (Levenson, McCarthy, Lynn, Davis, & Phillips, 2000; Nordgren & Soronsen, 2003; Solano, Gomes, & Higginson, 2006; Walsh, Donnelly, & Rybicki, 2000). Directly related to the diverse nature of symptoms experienced in chronic illness is the caregiver challenge of accurately assessing and reporting (i.e., to doctors) the symptoms of their care recipient. Adding another complication to proxy accuracy, some older adults may choose to conceal their symptoms from their caregivers in order to protect them from distress or burden (Dar, Beach, Barden, and Cleeland, 1992; McPherson, Wilson, & Murray, 2007). For these reasons, researchers have questioned the accuracy of proxy reports and sought to understand systematic differences between symptom descriptions given by

care recipients and caregivers (Allen, Haley, Small, & McMillian, 2002; Higginson & Gao, 2008; McPherson & Addington-Hall, 2003; McPherson, Wilson, Lobchuk, & Brajtman, 2008).

Overall, the literature indicates that proxy reports of the symptom experience of their care recipients are moderate at best (Kutner, Bryant, Beaty, & Fairclough, 2006). Meta-analyses have shown that for both physical and emotional/psychological symptom clusters there is a trend for proxies to report more negative symptom experiences (Lobchuk & Degner, 2002; McPherson & Addington-Hall, 2003). In comparing the types of symptoms most often associated with discrepant reports, McPherson and Addington-Hall (2003) noted that concrete, observable symptoms such as those affecting activities of daily living were more accurately reported than symptoms related to the subjective experience of the care recipient (i.e., pain and mood symptoms). In addition to problematic reporting of the presence or absence of symptoms, studies have shown problems in proxy reports of intensity of symptoms. For example, family caregivers have been shown to be unable to reliably report on the intensity of symptoms experienced by their loved ones with advanced cancer (McMillian & Moody, 2003).

Other studies highlight specific factors associated with increased or decreased concordance accuracy. For example, Allen et al. (2002) found that cognitive impairment of care recipients with advanced cancer was related to discrepancy in pain symptom reports of caregivers and care recipients. Another study by Jones and colleagues (2011) found the opposite and suggested the finding was a result of higher accuracy in “clear-cut” cases of obvious care recipient suffering. Across several studies, caregiver burden and outlook seem to affect accuracy in symptom reports such that caregivers with higher burden or strain also tend to be the most discrepant reporters (Higginson & Gao, 2008; McPherson et al., 2008). In a 2006 study specifically focusing on spousal caregivers, Martire et al. (2006) found that, although errors still

tended to occur, spouses who reported less stress associated with caregiving were also more accurate at reporting pain symptoms of their partner/care recipient. In sum, the literature seems to converge on the findings that caregivers tend to overestimate the symptoms of their loved one and that caregivers who are especially burdened suffer from the most discrepant reporting.

Although the findings that caregivers tend to overestimate their loved one's symptoms may seem less harmful than the alternative, it is, in fact, problematic. Foremost among the resultant concerns is the potential for unnecessary or premature institutionalization, which can be traumatic for both older adults and family members and may be precipitated by miscommunications about symptom distress (Ryan & Scullion, 2000). Further, caregiver burden may be increased as a result of overestimating symptoms, leading to harmful behaviors even before institutionalization. Sun et al. (2013), for example, found a positive association between caregivers' potentially harmful behaviors and their desire to institutionalize their care recipient with dementia. Overestimating the symptom distress levels of their loved ones likely causes additional stress for caregivers (Monin & Schulz, 2009). This stress may contribute to high levels of caregiver burden and, in turn, result in yet more inaccurate symptom assessments. Finally, if caregivers are also acting in a role as a health care advocate, formally (i.e., as a Durable Power of Attorney for Health Care) or informally, accurate understanding of symptoms becomes important to insure proper medical decisions regarding medication and other treatments or palliative measures (Ditto et al., 2001; Schmid, Allen, Haley, & DeCoster, 2010).

Few studies have attempted to target the well-documented problem in proxy report accuracy via interventions. Though there is a lack of precedence to understand how interventions may affect outcomes, studies have shown that proxy accuracy may increase over even short periods of time (Jones et al., 2011). Additionally, Allen et al. (2008) reported that participants

who completed a reminiscence intervention project unanimously reported that the project had improved their family communication at least somewhat, with 84% of participants reporting that communication was improved “a great deal”. This is a probable mechanism by which the LIFE Project, the intervention examined in the present study, could increase the accuracy of proxy reports; that is, by increasing the quantity and/or quality of dyadic communications, caregivers might gain better insight as to the true nature of the symptoms experienced by their loved one.

In 2003, Lobchuk and Vorauer published results on one of the scarce studies examining interventions aimed to increase the accuracy of informal caregiver symptom reports. Their study utilized a perspective-taking exercise in which caregivers were asked to report symptoms experienced by their loved one following one of four prompts (*neutral*: no prompt; *self-report*: report on how you think and feel about your loved one’s symptoms; *imagine-self*: identify your thoughts and feelings as you imagine yourself having your loved one’s diagnosis; *imagine-care recipient* : take the perspective of the care recipient). Overall, Lobchuk and Vorauer found that caregivers’ reports under no prompt were most similar to reports when prompted to imagine the care recipient’s perspective (2003). According to the authors, these results indicate that caregivers may be utilizing a similar, perspective-taking process to understand care recipient symptoms. These results indicate another mechanism—increased perspective taking through the process of creating a Legacy Project— by which LIFE may work to increase concordance rates.

The specific aims of the present study include the following: (1) To evaluate the rates of concordance for three different symptom clusters (physical, emotional, and both) in a sample of chronically-ill older adults and their caregivers; (2) To understand caregiver and care recipient factors that are related to concordance; (3) To evaluate the efficacy of the LIFE intervention in improving concordance of symptom reports. We hypothesized the following: (1) Concordance

scores at baseline will not be significantly different for control versus intervention dyads; (2) Following the intervention, concordance scores regarding symptom presence will be significantly higher for the intervention group compared to the control group; if differences are found: (3) Improvements in concordance will be greater for physical symptoms than for emotional symptoms; (4) Caregivers who score higher on a depression measure will be less likely to show improvement in concordance scores; and (5) Caregivers who score lower on a measure of positive aspects of caregiving will be more likely to benefit from the intervention, thus showing more improvement in concordance scores. In addition to these analyses, correlations among variables at baseline will be explored in an effort to understand how they relate to concordance rates.

METHODS

Participants

Data for this study were taken from a dataset of a randomized control trial examining the effectiveness of a reminiscence-and-creative-activity therapeutic intervention as implemented by older adult volunteers (The LIFE Project; R21NR011112, R. S. Allen, Principal Investigator). Notably, the intervention was not designed to increase concordance rates for symptom report.

Participants consisted of 45 community-dwelling older adults with advanced, chronic illnesses and functional decline indicative of increased risk of mortality within two years as measured by the Vulnerable Elders Survey-13 (VES-13; Saliba et al., 2001). Participants were recruited from within a sixty mile radius of Tuscaloosa and Birmingham.

Participants with advanced, chronic illness were eligible if they: (1) were age 55 or older; (2) were living in the community; (3) had an advanced, chronic illness or combination of chronic illnesses; (4) received a score of three or greater on the VES-13; (5) had no more than mild cognitive impairment as measured by a score of 18 or greater on the Modified Telephone Interview of Cognitive Status (TICS-m; Brandt, Spencer, & Folstein, 1998); (6) received an average of four hours per week of instrumental or basic daily care from a family caregiver; and (7) read and spoke English.

Caregivers for a person with advanced, chronic illness were eligible if they (1) were over the age of 19 years (the age of majority in Alabama) and were a family member or fictive kin of an eligible care recipient; (2) were currently providing an average of four hours per week of instrumental or basic daily care for the care recipient; (3) were cognitively intact as measured by a score of 28 or greater on the TICS-m; (4) lived close enough to the care recipient to participate

in interviews at the care recipient's home; (5) read and spoke English; and (6) had phone contact availability.

Dyads were excluded if the care recipient or caregiver: (1) was currently involved in another clinical trial of psychosocial interventions; (2) had schizophrenia or bipolar disorder, (3) had an education-adjusted TICS-m (Brandt et al., 1998; de Jager et al., 2003) score lower than their respective minimum as listed above; or (4) had a nursing home admission planned within three months. Dyads were also excluded if the care recipient was receiving hospice care.

Measures

Symptoms. The Memorial Symptom Assessment Scale-Short Form (MSAS-SF; Chang, Hwang, Feuerman, Kasismis, & Thaler, 2000) is a 32-item measure of physical and emotional symptoms and associated bother (see Appendix 1). Both caregivers and care recipients responded with regard to the care recipient's symptoms. Symptoms are assessed on a present/absent format and were divided into the two subscales that were used in the current study. The first subscale consisted of 28 physical symptoms (e.g., pain, cough, vomiting, swelling of arms or legs). The second subscale consisted of four emotional or psychological symptoms (i.e., nervous, worried, sad, irritated). For physical symptoms that are present, participants are asked about the extent that the symptom bothers them on a five-point scale ranging from 0 = *Not at all* to 4 = *Very Much*. For the four emotional symptoms, they are asked how frequently the symptom bothers them on a four-point scale from 0 = *Never* to 3 = *Almost always*, if they note the presence of the symptom. For symptoms that are absent, a score of 0 was assumed on the bother/frequency scale. Cronbach's alpha coefficients for the MSAS-SF subscales range from .76 to .87. In the current sample, Cronbach's alpha coefficients for care recipients all fell in the acceptable range: .76 for the physical subscale and .80 for both the full

scale and emotional subscale. For caregivers, Cronbach's alpha coefficients were acceptable for the full scale (.81) and physical subscale (.75) but fell in the poor range for the emotional subscale (.55).

Concordance scores. Percent agreement (concordance) scores were calculated for each unique participant dyad for each of the 32 symptoms assessed by the MSAS-SF both at a symptom presence level and a symptom intensity/distress or frequency level. These 32 symptom-presence concordance scores were averaged across the symptom clusters giving each dyad three concordance scores (i.e., full scale, physical and emotional subscales), expressed as decimals such that .00 would mean no agreement whatsoever and 1.00 would mean total agreement on each symptom. For distress/frequency scores, a dyad was considered concordant if their responses fell within \pm one point of each other. These were then treated in the same way as the symptom-presence scores and the resulting scale is the same (i.e., .00=no agreement).

Demographics. For both caregivers and care recipients, information was collected on age, race, gender, and education in years. Health was measured for caregivers by a simple self-report question with four response options (*Poor, Fair, Good, Excellent*). For care recipients, health was measured via the Vulnerable Elders Survey (VES; Saliba et al., 2003). The VES is a 13-item measure using a function-based scoring system that considers age, self-rated health, limitation in physical function, and functional disabilities in the identification of older community-dwelling adults "at risk" of death or functional decline within 1-2 years (Saliba et al., 2003; see Appendix 2).

Cognition. Participants (caregivers and care recipients) were screened prior to baseline interviews using the Modified Telephone Interview of Cognitive Status (TICS-m; Brandt, Spencer, & Folstein, 1998). The TICS-m is a 21-item measure administered over the phone and

is designed to detect cognitive decline (Breitner et al., 1990; see Appendix 3). Scores of < 21 have been compared to scores of < 25 (de Jager, Budge, & Clarke, 2003) on the Mini Mental State Exam (Folstein, Folstein, & McHugh, 1975). In a study of post-stroke individuals, a cut-off score of 20 or lower provided sensitivity of 92% and specificity of 80% for detecting cognitive decline (Barber & Stott, 2004).

Future Time. The Future Time Perspective Scale was used to measure individual's motivation and approach to life (Cartensen & Lang, 1996). The scale consists of ten items such as "Many opportunities await me in the future," "My future is filled with possibilities" and "I have the sense that time is running out" (see Appendix 4) These items are assessed on a 7-point Likert scale indicating degree of agreement and keyed such that higher scores indicate a greater sense of future time. The internal consistency of the scale is good (Cronbach's alpha=.92). In the current sample, the alpha for caregivers is .80 and for care recipients is .88.

Depression. The Center for Epidemiological Studies-Depression scale (CES-D; Radloff, 1977) is a 20-item scale that asks about the frequency of depressive symptoms within the past week, with a score of 16 or greater indicating clinically significant levels of depression (see Appendix 5). The CES-D has good internal consistency: Cronbach's alpha = .73 to .81. Most commonly, a score of 16 or higher indicates high depressive symptoms (Radloff, 1977). In the current sample, the mean baseline CES-D score for caregivers is 9.69, with 22.1% of caregivers scoring 16 or above on the CES-D at baseline. For care recipients, the mean score is 12.93, with 28.9% of care recipients scoring 16 or above on the CES-D at baseline. In the current sample, the alpha for caregivers is .84 and for care recipients is .83.

Affect. In order to understand the frequency and range of affect for participants, the Positive and Negative Affect Schedule (PANAS) was used (Tellegen, Watson, & Clark, 1988; see

Appendix 6). The PANAS is a 20-item scale that asks participants about their feelings with responses ranging from 1 to 5 for 10 positive and 10 negative adjectives (total scores for positive affect and negative affect range from 10 to 50). The PANAS has good internal consistency for positive affect (Cronbach's alpha = 0.84) and for negative affect (Cronbach's alpha = 0.87) scales and the two are largely uncorrelated, yielding meaningful measures of both positive and negative affect independently (Crawford & Henry, 2004; Tellegen, Watson, & Clark, 1988). For caregivers, the alpha for positive affect is .90 and for negative affect is .86. For care recipients, the current alpha values are .78 for both positive and negative affect.

Meaning in Life. The 8-item Meaning in Life Scale created by Krause (2007) assessed four domains: (1) values, (2) purpose, (3) goals, and (4) reflections on the past (see Appendix 7). Respondents rated the extent to which they agreed or disagreed (1 = *disagree strongly*, 4 = *agree strongly*) with statements such as "I have a sense of direction and purpose in life" and "I feel good when I think about what I have accomplished in life." Total scores (vs. domain specific scores) were used in analysis. In the current sample, the alpha for caregivers is .84 and for care recipients is .76.

Caregiving Stress. The caregivers in the sample completed the Caregiver Stressors Scale-Revised (Zarit, Stephens, Townsend, & Greene, 1998). This 25-item measure of caregiving competency, strain, role overload, role captivity, and emotional control, is reported to have good internal consistency (.60 to .82). The scale includes items such as "I worry about my relative" and "I have time for myself," which caregivers rate over the past month on a four-point scale from "Never" to "All the time," with higher scores indicating greater caregiving stress (see Appendix 8). The alpha in the current sample is .77.

Positive Aspects of Caregiving (PAC; Tarlow et al., 2004). The PAC is a nine-item instrument that assesses caregivers' subjectively perceived gains from, desirable aspects of, or positive affective returns from providing care for their loved one (see Appendix 9). Respondents rated the extent to which they agreed or disagreed with statements such as "The care recipient made me feel more useful." The scale has been reported to have good internal consistency, Chronbach's alpha = .88 (Tarlow et al., 2004). The alpha in the current sample is .81.

Procedure

The Legacy Intervention Family Enactment, or LIFE Project, was delivered via retired senior volunteers (RSVs) recruited by the PI and research staff from the Retired Senior Volunteer Program at FOCUS on Senior Citizens in Tuscaloosa and from the RSV program at Positive Maturity in Birmingham, which are both part of the national Senior Corp program serving Tuscaloosa, Hale, Jefferson, and Shelby counties. RSVs were included if they: (1) had at least a high school education; (2) read and spoke English; (3) had a car and drove independently; and (4) had phone contact availability.

Participant dyads were randomized into a *minimal contact control* and *intervention* group. Dyads assigned to the *intervention group* were paired with an RSV who helped the dyad chose a Legacy project. The *LIFE Volunteer Interventionist Manual* and *LIFE Participant Notebook* (Allen, Hilgeman, & Shin, 2009) assisted intervention dyads in creating a legacy project and included: (1) an introduction to the LIFE project; (2) deciding on a personal Legacy using the steps of problem solving; (3) constructing a personal Legacy; (4) evaluation of the Legacy activity; and (5) an appendix with specific life review questions for those dyads that found generation of stories more difficult. Manuals were available in 14-point font to enhance readability.

In the first intervention session, RSVs, guided by the *LIFE Volunteer Interventionist Manual* and *LIFE Participant Notebook* (Allen, Hilgeman, & Shin, 2009), talked to the dyad about problem solving techniques and helped the care recipient and their family caregivers to decide on a LIFE activity. During the second visit, the RSV assisted with work on the LIFE activity and further engaged dyads in conversations with one another about the project. During the third visit, the RSV encouraged the care recipient and caregiver to share their LIFE activity and discuss their feelings about the process, including an evaluation of the LIFE project and what the family learned.

Dyads randomized to the *minimal contact control group* were provided emotional support administered individually via telephone. Care recipients and caregivers in the control group participated in separate calls with a member of the research team. Control callers asked general questions of care recipients and their caregivers and then engaged in supportive conversations using empathic listening and reflection.

Baseline and post-intervention assessments for all participants were completed in separate, concurrent interviews with the care recipient and caregiver. Post-intervention assessments occurred approximately one week after the completion of the intervention or control contacts. Quantitative survey measures were administered with response cards. Response cards contained all possible response options for a given item for each assessment instrument to facilitate accuracy and item understanding by the participants.

Data Analyses

All analyses were completed using IBM SPSS Version 20.0 (IBM Corp., 2011). Concordance scores for the presence/absence of symptoms for each dyad (at baseline and post-intervention) were generated via contingency tables. Contingency tables (Figure 1) were

constructed such that a dyad was considered ‘concordant’ if both the caregiver and care recipient reported that a symptom was present or both reported that the symptom was absent.

Symptom: X	Care recipient Report: YES	Care recipient Report: NO
Caregiver Report: YES	<u>CONCORDANT = 1</u>	NOT CONCORDANT = 0
Caregiver Report: NO	NOT CONCORDANT = 0	<u>CONCORDANT = 1</u>

Figure 1. Example contingency table

Dyads were considered ‘not concordant’ if there was disagreement on the presence of the symptom (i.e., a care recipient reported that the symptom was present but their caregiver reported that it was not). Dyads were assigned a score of 1 for each symptom for which there was a concordant rating and 0 points for each symptom for which there was a non-concordant rating. Contingency tables were constructed for each dyad on each of the 32 symptom measurements contained within the MSAS-SF. Scores were averaged, providing each dyad a score between .00 and 1.00 at baseline and post-intervention for each of the 32 symptoms. Then, these scores were averaged across the full scale symptoms (i.e., all 32), the physical symptoms (28 total), and the emotional symptoms (four total).

A similar method was used to create concordance scores for symptom distress reports or symptom frequency reports, with dyads being within \pm one point of each other being considered concordant and those greater than \pm one point being considered not concordant.

Mixed (between-within subjects) Analysis of Variance (ANOVA) was used to compare overall concordance scores (for symptom presence/absence and distress/frequency) of the control group and intervention group at baseline and post-intervention. Physical and emotional concordance scores were analyzed separately following the overall comparison in order to determine if there was any difference between these types of reports. Pearson *r* correlations were

calculated for baseline concordance values and predetermined caregiver and care recipient demographics and psychosocial variables.

RESULTS

Characteristics of care recipients and caregivers at baseline and Time 1 (post-intervention) data are presented in Tables 1 and 2, respectively. Caregivers reported being related to care recipients in a variety of ways including adult child (44.4%), spouse (17.8%), other family (i.e., sibling, grandchild, or niece/nephew; 11.1%), friend (4.4%) or paid (2.2%). An additional 20% of caregivers (N=9) did not list a relationship.

Thirty-two of our participants lived in their own homes (71%) while the remaining 29% lived in assisted living facilities (18% of total), HUD housing or residential care (11% of total). Care recipients reported a variety of chronic illnesses at baseline, but the most commonly reported illnesses were central nervous system disorders, pain/arthritis, diabetes, cancer and heart disease. Comparison of dyads with baseline data only (N=45) vs. those who completed the

Table 1

Care Recipient and Caregiver Demographic Variables at Baseline (N=45)

	Care recipient	Caregiver
Age	78.22 (11.59)	59.85 (11.76)
Gender	82% Women	71% Women
Race/ethnicity	40% AA	44% AA
Education	12.45 (4.05)	13.53 (2.74)
Income Ad.	--	2.84 (1.01)
Self-rated Health	--	2.04 (.67)
VES	7.29 (1.95)	--
TICs	25.49 (4.85)	32.51 (4.57)

Table 2

Care Recipient and Caregiver Demographics at Time 1 (N=28)

	Care recipient	Caregiver
Age	77.5 (12.13)	60.71 (11.02)
Gender	82% Women	68% Women
Race/ethnicity	43% AA	43% AA
Education	12.48 (4.25)	13.71 (3.24)
Income Ad.	--	2.89 (.93)
VES / Health	7.0 (2.31)	1.96 (.69)
TICs	26.04 (4.80)	32.43 (4.20)

intervention (N=28) revealed no differences for care recipient and caregiver age, race/ethnicity, gender, cognitive status, health (VES-13), or concordance scores.

Baseline Analyses

Before comparing concordance rates on a symptom-by-symptom basis, symptom and distress/frequency rates were compared via sum totals. Overall, care recipients and caregivers reported similar symptom and distress/frequency totals at baseline, with no pair except physical symptom distress being significantly different (see Table 3).

The mean concordance for reports of the presence or absence of all 32 symptoms was .73 (SD=.08). Physical symptoms alone yielded concordance rates of .75 (SD=.08), fairing similarly to the total 32. Emotional symptom concordance was substantially lower, with a mean of .57 (SD=.26). Similar patterns emerged when considering the concordance of symptom distress/frequency reports (± 1 point). Total symptoms distress reports yielded a mean value of

.81 (SD=.08), physical symptoms had a mean of .84 (SD=.09), and emotional symptoms had a mean of .64 (SD=.27).

Table 3

Caregiver and Care Recipient Reports of Symptom Presence/Absence and Distress/Frequency

		Symptom Presence/Absence <i>M</i> (<i>SD</i>)	Symptom Bother/Frequency <i>M</i> (<i>SD</i>)
Total	Caregiver	10.66(5.22)	19.11(11.68)
	Care Recipient	11.27(5.31)	21.69(12.80)
Physical	Caregiver	8.50(4.28)	14.71(9.41)*
	Care Recipient	9.43(4.45)	18.13(10.81)*
Emotional	Caregiver	2.16(1.30)	4.40(3.17)
	Care Recipient	1.80(1.58)	3.56(3.28)

* $p < .05$

Further analyses revealed that some symptoms emerged as more often concordant than others. Symptoms including vomiting (.98), problems with sex (.93), sores (.93), problems eating (.87), not feeling like self (.87), constipation (.84), pain (.82), and difficulty swallowing (.82) were, on average, concordant over 80% of the time. Symptoms such as problems with skin (.60), dry mouth (.60), difficulty concentrating (.56), and trouble with sleep (.53) were, on average, concordant less than 60% of the time. Notably, all of these symptoms are categorized as “physical” in the MSAS-SF.

Concordance and Other Variables at Baseline

Care recipient report of total physical and emotional symptom sums (i.e., how many symptoms they endorsed) and physical distress and emotional symptom frequency sums (i.e.,

how much total distress/frequency did they endorse) were examined in relation to concordance scores (see Table 4).

Table 4

Care Recipient Symptom Reports and Correlations with Concordance (Baseline)

Concordance Type	Physical Symptom Sum ⁺	Emotional Symptom Sum ⁺	Physical Bother Sum ⁺	Emotional Symptom Frequency Sum ⁺
Total Symptom	-.42**	-.23	-.36*	-.29
Physical Symptom	-.48**	-.31*	-.43**	-.37*
Emotional Symptom	.05	.12	.09	.11
Total Bother	-.61**	-.22	-.75**	-.34*
Physical Bother	-.61**	-.23	-.78**	-.33*
Emotional Frequency	-.15	-.05	-.13	-.11

+ higher numbers indicate higher care recipient reported symptom number or distress
 *p<.05, **p<.01

An overall pattern emerged suggesting that greater care recipient reports of symptoms and distress were significantly related to lower total and physical symptom presence/absence and bother concordance. Specifically, total symptom concordance was negatively related to physical symptom sum and physical symptom bother, such that care recipients who reported greater numbers of physical symptoms and greater distress from physical symptoms were more likely to belong to a dyad with lower concordance ($p<.05$). Physical symptom concordance was significantly related to physical symptom sum, physical distress sum, emotional symptom sum, and emotional symptom frequency sum, such that care recipients who reported higher physical and emotional symptom numbers and higher physical and emotional symptom distress/frequency were more likely to have lower concordance scores. For distress and frequency concordance, the

pattern continued: care recipients reporting higher physical symptom sums, physical distress sum, and emotional symptom frequency sum were significantly more like to belong to a lower concordance dyad ($p < .05$). Notably, emotional symptom concordance and frequency concordance were not significantly related to any care recipient report predictor.

Caregiver and care recipient demographics and psychosocial variables were also examined in relation to concordance. Concerning demographics (see Tables 5 and 6), only caregiver income adequacy was significantly related to physical intensity concordance (with greater income adequacy relating to higher concordance; $r = .31$, $p < .05$), while care recipient education was significantly related to emotional symptom concordance (with higher education relating to lower concordance; $r = -.32$, $p < .05$). With regard to psychosocial variables (see Tables 7 and 8), caregiver scores on the Caregiver Stressor Scale were negatively related to both total intensity concordance ($r = -.34$, $p < .05$) and emotional intensity concordance, such that caregivers indicating more caregiving-related stress were less likely to be concordant ($r = -.31$, $p < .05$).

Table 5

Caregiver Demographic Variables and Correlations with Concordance (Baseline)

	Age	Race	Health	Education	Income Adequacy	TICS
Total Concordance	-.19	.05	.18	-.02	-.02	.05
Physical Symptom Concordance	-.13	-.06	.17	.04	.07	.09
Emotional Symptom Concordance	-.17	.24	.05	-.14	-.20	-.07
Total Intensity Concordance	.01	.13	.02	.10	.20	-.10
Physical Intensity Concordance	-.04	.09	.10	.16	.31*	-.09
Emotional Intensity Concordance	.10	.10	-.16	-.10	-.21	-.05

* $p < .05$

Table 6

Care Recipient Demographic Variables and Correlations with Concordance (Baseline)

	Age	Race	Health	Education	TICS
Total Concordance	.12	.00	.12	-.04	-.12
Physical Symptom Concordance	.09	-.08	.04	.10	-.10
Emotional Symptom Concordance	.09	.18	.21	-.32*	-.06
Total Intensity Concordance	.09	.15	-.14	-.01	.10
Physical Intensity Concordance	.02	.16	-.17	.00	.12
Emotional Intensity Concordance	.20	.03	.03	-.03	-.01

*p<.05

Care recipient variables proved more predictive of concordance scores with more meaningful patterns of associations. Specifically, care recipient negative affect was negatively associated with total symptom concordance ($r=-.42$, $p<.01$), physical symptom concordance ($r=-.51$, $p<.01$), total intensity concordance ($r=-.43$, $p<.01$), and physical intensity concordance ($r=-.39$, $p<.01$), such that greater reported negative affect was related to lower concordance in each case mentioned. Care recipient total Meaning in Life scores were negatively associated with emotional symptom concordance ($r=-.31$, $p<.05$) such that care recipients reporting higher meaning in life were more likely to belong to a dyad low on this type of concordance. Finally, care recipient depression scores were positively associated with emotional symptom concordance ($r=.30$, $p<.05$), such that care recipients scoring higher on the depression measure were more likely to be a higher concordance dyad.

Table 7

Caregiver Psychosocial Variables and Correlations with Concordance (Baseline)

	FTP	MIL	PAC	Positive Affect	Negative Affect	Depression	CSS
Total Concordance	.10	-.11	-.02	-.04	.09	-.07	.00
Physical Symptom Concordance	.05	-.06	-.07	.03	.00	-.14	.02
Emotional Symptom Concordance	.13	-.13	.10	-.17	.22	.13	-.05
Total Intensity Concordance	-.12	.02	-.05	-.13	-.14	-.18	-.34*
Physical Intensity Concordance	-.12	.02	-.18	-.03	-.15	-.21	-.24
Emotional Intensity Concordance	-.04	.01	.25	-.25	-.01	.00	-.31*

*p<.05

Table 8

Care Recipient Psychosocial Variables and Correlations with Concordance (Baseline)

	FTP	MIL	Positive Affect	Negative Affect	Depression
Total Concordance	-.07	-.19	-.16	-.42**	-.01
Physical Symptom Concordance	.01	-.07	-.19	-.51**	-.14
Emotional Symptom Concordance	-.19	-.31*	.04	.13	.30*
Total Intensity Concordance	.11	.08	.10	-.43**	-.20
Physical Intensity Concordance	.16	.13	.04	-.39**	-.26
Emotional Intensity Concordance	-.09	-.10	.15	-.20	.08

*p<.05, **p<.01

Intervention Analyses

Six mixed (between-within subjects) ANOVAs were conducted to assess the impact of the LIFE intervention on concordance scores (total symptoms, physical symptoms and emotional symptoms; total distress, physical distress and emotional symptom frequency) at baseline and post-intervention follow-up (Tables 9 and 10). No significant interactions between time (baseline vs. post-intervention) and group (control vs. intervention) were found for the concordance of the total symptoms, Wilks Lambda=.99, $F(1, 26)=.39$, $p=.54$, physical symptoms, Wilks Lambda=.98, $F(1, 26)=.44$, or emotional symptoms, Wilks Lambda=.99, $F(1, 26)=.04$, $p=.85$. Likewise, there was no significant main effect for time for total symptoms, Wilks Lambda=1.00, $F(1, 26)=.01$, $p=.93$, physical symptoms, Wilks Lambda=1.00, $F(1, 26)=.00$, $p=.97$, or emotional symptoms, Wilks Lambda=.99, $F(1, 26)=.04$, $p=.85$. There were also no significant main effects for group for total symptom concordance, $F(1, 26)=.90$, $p=.35$, physical symptom concordance, $F(1, 26)=.55$, $p=.46$, or emotional symptom concordance, $F(1, 26)=.40$, $p=.53$.

Table 9

Dyadic Concordance Scores for Symptom Presence/Absence

		Baseline			Post Intervention		
		N	<i>M</i>	SD	N	<i>M</i>	SD
Total	Control	18	.72	.08	18	.70	.10
	Intervention	10	.73	.07	10	.74	.09
Physical	Control	18	.74	.09	18	.72	.09
	Intervention	10	.74	.06	10	.76	.11
Emotional	Control	18	.57	.25	18	.57	.28
	Intervention	10	.63	.21	10	.60	.13

No significant interactions between time (baseline vs. post-intervention) and group (control vs. intervention) were found for the concordance of the total distress concordance, Wilks Lambda=.99, $F(1, 26)=.19$, $p=.67$, physical distress concordance, Wilks Lambda=.99, $F(1, 26)=.19$, $p=.66$ or emotional symptom frequency concordance, Wilks Lambda=1.0, $F(1, 26)=.02$, $p=.89$. Likewise, there was no significant main effect for time for total distress concordance, Wilks Lambda=.94 $F(1, 26)=1.69$, $p=.21$, physical distress concordance, Wilks Lambda=.94, $F(1, 26)=1.56$, $p=.22$, or emotional symptom frequency concordance, Wilks Lambda=.99, $F(1, 26)=.34$, $p=.57$. There were also no significant main effects for group for total distress concordance, $F(1, 26)=.40$, $p=.53$, physical distress concordance, $F(1, 26)=.29$, $p=.60$, or emotional symptom frequency concordance, $F(1, 26)=.26$, $p=.61$.

Table 10.

Dyadic Concordance for Symptom Distress/Frequency

		Baseline			Post Intervention		
		N	M	SD	N	M	SD
Total	Control	18	.82	.08	18	.79	.12
	Intervention	10	.79	.09	10	.78	.09
Physical	Control	18	.84	.08	18	.81	.10
	Intervention	10	.82	.08	10	.80	.11
Emotional	Control	18	.57	.25	18	.57	.28
	Intervention	10	.63	.21	10	.60	.13

DISCUSSION

The present study extends the current literature not only by providing a fuller picture of correlations of concordance of both physical and emotional symptoms but by testing a possible intervention to improve dyadic concordance across time. Overall, the present sample of chronically-ill older adults and their caregivers reported similar average symptom loads across both physical and emotional symptom clusters. Both parties in the dyad also reported similar average burden/frequency resultant from symptoms, except for physical burden for which the care recipients reported significantly more burden. This runs contrary to a majority of the concordance literature, which suggests that caregivers tend to over report both symptom number and distress levels compared to self-reports from care recipients (Lobchuck & Degner, 2002; McMillian & Moody, 2003; McPherson & Addington-Hall, 2003). Notably, the samples in many of the existing studies and those used in meta-analysis papers are often terminally-ill cancer patients, often receiving something akin to home hospice or palliative care. This type of sample differs from the one in the present study, which, although comprised of individuals with chronic illness, was not restricted by type or number. Results of this examination help inform discussions about end-of-life care preferences, planning, and execution, especially when family caregivers are involved.

Results of baseline correlations with the six categories of concordance indicated relatively little predictive value of demographic information, yielding significant correlations only for caregiver-reported income adequacy (such that greater income adequacy was related to better physical distress concordance) and care recipient education in years (such that lower care recipient education years attained was related to better emotional symptom concordance). It is possible that caregivers with greater perceived income adequacy feel less burdened and retain

more cognitive resources available to accurately perceive symptoms of their care recipient, as has been suggested in prior research (McPherson et al., 2008). Care recipient education may be functioning as a proxy estimator for guilt or burden, such that care recipients who have received more years of education feel more shame regarding needing a family caregiver and thus conceal emotional symptoms from their caregiver, leading to lower concordance (Dar, Beach, Barden, & Cleeland, 1992). However, since significant correlations were restricted in each case to only one type of concordance, it is unfounded to draw strong conclusions from these results.

Psychosocial variables at baseline provided more useful patterns of results. For caregivers, only scores on the Caregiver Stressor Scale were significantly related to concordance, such that higher stress scores were related to lower total symptom distress and emotional symptom frequency concordance. This is congruent with research indicating that caregiver burden negatively impacts concordance of symptom reporting (see McPherson & Addington-Hall, 2003), but notably only functioned for distress concordance and not symptom presence/absence concordance. Care recipient psychosocial variables provided more interpretable patterns, namely the impact of negative emotionality on concordance. Dyads with care recipients scoring higher on negative affect were more likely to have significantly lower concordance for all concordance categories except those for emotional symptoms. Interestingly, positive affect did not have the opposite effect, with no significant relationships owing to positive affect scores.

Isolated significant results relating to care recipient meaning in life reports and depression scores should be interpreted cautiously, as they do not exist in a larger structure of significant correlations. Higher care recipient meaning in life scores were significantly related to lower emotional symptom concordance. This result may be related to research that has found that

older adults with religious beliefs may be better able to cope with stressful situations such as chronic illness symptoms (Hackney & Sanders, 2003; Pargament, 1997). For example, perhaps older adults with greater meaning in life (i.e., through a higher power) cope more privately (i.e., through prayer) with emotional symptoms and thus caregivers are less likely to become aware of them, thus resulting in lower concordance. Care recipients with higher depression scores were more likely to belong to dyads with greater concordance related to emotionally symptom presence/absence. This result may be interpreted similarly to the study by Jones and colleagues (2011), which suggested that higher accuracy of proxy symptom reports may result from “clear-cut” cases of obvious care recipient suffering, as may be the case in more severe depression.

A model proposed by Monin and Schulz (2009) may help frame the relationships among variables discussed above. Taking into account the stress experienced by those in the caregiver role, Monin and Schulz (2009) expand on the standard stress-health model in order to incorporate the nuances of an older adult caregiving relationship. The Monin and Schulz (2009) Caregiver Stress-Health Model (Figure 2) not only recognizes the strain that results from the support-related demands of caregiving, but also highlights the connection between a care recipient’s suffering (as displayed through various outward signs and symptoms) and a caregiver’s emotional symptom frequency.

As demonstrated in Figure 2 (from left to right), the model offers a pathway explaining how both physical disability and suffering behaviors displayed by an older adult contribute to caregiver stressors, thus affecting caregiver outcomes such as psychological distress and physical morbidity.

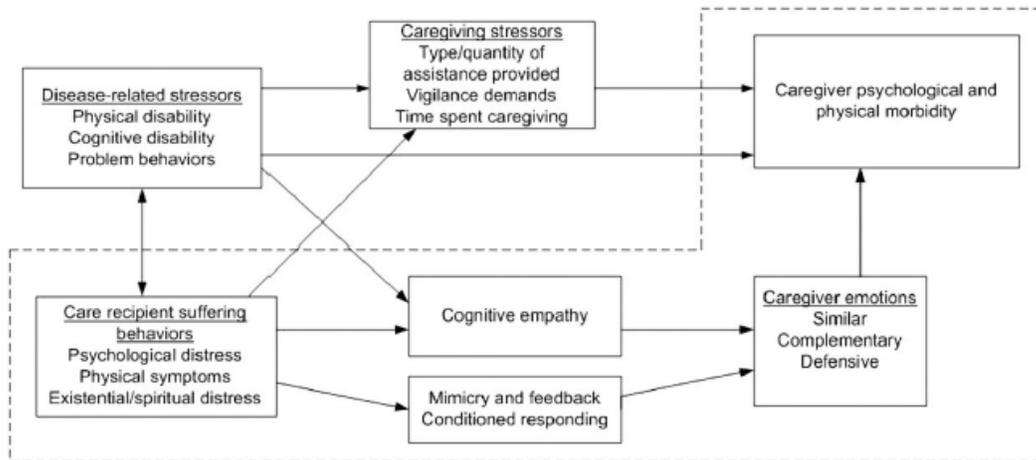


Figure 2. Monin & Schulz (2009) Caregiver Stress-Health Model. The dotted line indicates the aspects of the model directly related to suffering.

This model also offers two possible response patterns caregivers may take in response to a care recipients' suffering behavior: cognitive empathy and conditioned emotional response (Monin & Schulz, 2009). Cognitive empathy refers to the shared or complementary (i.e., love or concern in response to distress) emotional experience of the caregiver to the care recipient in response to his or her suffering (Monin & Schulz, 2009). Conditioned emotional responses occur when the caregiver has paired certain emotions with past experiences of care recipient suffering (i.e., becoming angry when their loved one is in pain due to a history of difficulty dealing with their loved one's pain) and can cause a caregiver to display defensive emotions (Monin & Schulz, 2009).

Viewed through the lens of this model, our results may speak even more clearly to the issue of caregiver burden. Caregivers who scored higher on the measure of caregiving stressors were more likely to belong to dyads with lower concordance on two of the six concordance outcomes. In terms of the Monin and Schulz model, these caregivers may be responding to the suffering of their loved one via pre-conditioned, largely automatic processes ("conditioned

responding”) instead of effortful understanding of their current symptom picture. In other words, faced with the burden of a suffering care recipient, a caregiver may choose to do their best to alleviate symptoms and perform daily tasks without attempting to elicit from the caregiver an updated or accurate assessment of their symptoms. Thus, they respond via conditioned mechanisms (i.e., moaning means a dose of analgesics) and not internalize the current symptoms to later report accurately. Another possibility this model suggests is a defensive reaction of higher stressed caregivers to the suffering of their loved ones, perhaps resulting in discomfort with acknowledging the degree to which their care recipient is suffering.

Baseline correlations of concordance with care recipient reported symptoms and distress similarly highlight the diminished concordance rates for those dyads in which the care recipient reported high symptom presence and burden. Like the previous situation, this may also relate to the increased burden on the caregiver, difficulty discerning more complicated array of symptoms, or a defensive reaction to suffering.

Finally, results indicated that the LIFE Project did not significantly impact concordance scores. There were no significant differences in pre and post-intervention concordance scores for the 28 dyads that completed post-intervention follow-up. This was true of both concordance of symptom presence/absence reports (i.e., agreement on what symptoms care recipient is experiencing) and concordance of distress/frequency reports (i.e., agreement on how much/often the present symptoms bother the care recipient). Because of a small sample size, the failure to detect a significant difference in pre/post concordance may be due to limited power. Moreover, the intervention was not designed to specifically improve concordance in symptom reporting.

Though the present examination failed to produce significant improvement in concordance, it still represents one of the few studies that have tested interventions that may

result in increased dyadic concordance. As noted, the reminiscence and creative activity components of the intervention tested were not designed specifically to increase symptomatic concordance for the population tested, but were hypothesized to increase concordance through various means including increasing communication between caregivers and their care recipients, or increasing the purpose or meaning caregivers experience as a result of their caregiving situation. Non-significant improvements in concordance suggest that interventions likely need to target improved communication specific to physical and emotional symptoms and distress levels in order to impact the deficit in concordance.

Like all studies, the research presented here has several limitations. Foremost, the small sample size (N=28) of those dyads that completed the intervention and provided viable data at a post-intervention assessment point likely hindered the statistical power of the analyses. For this reason, the analyses at baseline utilizing the entire sample (n=45) were more powerful, representative, and ultimately useful. Additionally, the poor Cronbach's alpha value for the caregiver-reported emotional symptom subscale of the MSAS-SF likely impacted the results and limits the interpretation and generalizability of findings. Generalizability of the current study may be limited in some ways, owing to the demographics of the participants as largely female, from a limited geographical area in the Southern United States, and being only Caucasian or African American in self-reported racial identity. Lastly, because of study criteria, some variables may be restricted in range and thus limit our ability to find significant results. For example, cognitive status was restricted to certain lower-limit values via the requirement that participants achieve a predetermined score on the cognitive examination.

In other ways, the study provides a widely representative sample of chronically-ill older adults suffering from a variety of illnesses that differs from much of the research on symptom

concordance which often utilizes cancer patients only. The results discussed above indicate a complex array of variables, related to both caregivers and care recipients, which are significantly associated with physical and emotional symptom concordance. Moreover, the failure of the LIFE Project to improve upon concordance scores of dyads in the intervention group begs loudly for future research investigating interventions aimed specifically at this important task. Especially as the number of older adults, and informal caregiving dyads, in the United States continues to rise, it will become increasingly important for these interventions to provide an even fuller understanding of caregiving.

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Appendix 1

Memorial Symptom Assessment Scale- Short Form (MSAS-SF)

Below is a list of symptoms. Say NO if you/your loved one hasn't experienced it in the past WEEK and YES if you/he/she has experience it in the past WEEK. If you choose YES, please indicate how much the symptom DISTRESSED or BOTHERED you/him/her.

Difficulty concentrating

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Pain

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Lack of energy

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Cough

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Changes in skin

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Dry mouth

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Nausea

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Feeling drowsy

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Numbness/tingling in hands and feet

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all
A little bit
Somewhat
Quite a bit
Very much

Difficulty sleeping

YES
NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all
A little bit
Somewhat
Quite a bit
Very much

Feeling bloated

YES
NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all
A little bit
Somewhat
Quite a bit
Very much

Problems with urination

YES
NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all
A little bit
Somewhat
Quite a bit
Very much

Vomiting

YES
NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all
A little bit
Somewhat
Quite a bit
Very much

Shortness of breath

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Diarrhea

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Sweats

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Mouth sores

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Problems with sexual interest or activity

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat
Quite a bit
Very much

Itching

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all
A little bit
Somewhat
Quite a bit
Very much

Lack of appetite

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all
A little bit
Somewhat
Quite a bit
Very much

Dizziness

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all
A little bit
Somewhat
Quite a bit
Very much

Difficulty swallowing

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all
A little bit
Somewhat
Quite a bit
Very much

Changes in the way food tastes

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Weight loss

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Hair loss

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Constipation

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Swelling of arms or legs

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

- Not at all
- A little bit
- Somewhat
- Quite a bit

Very much

“I don’t look like myself”

YES

NO

If yes, how much did it DISTRESS or BOTHER you?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Below are some other commonly listed symptoms. Please indicate if your loved one had the symptom during the PAST WEEK, and if so, how OFTEN it occurred.

Feeling sad

YES

NO

If yes, how OFTEN did it occur?

Rarely

Occasionally

Frequently

Almost constantly

Worrying

YES

NO

If yes, how OFTEN did it occur?

Rarely

Occasionally

Frequently

Almost constantly

Feeling irritable

YES

NO

If yes, how OFTEN did it occur?

Rarely

Occasionally

Frequently

Almost constantly

Feeling nervous

YES

NO

If yes, how OFTEN did it occur?

Rarely
Occasionally
Frequently
Almost constantly

Appendix 2

Vulnerable Elders Survey (VES)

1. Age ____ (1 points for age 75-84, 3 points for age 85 or above)

2. In general, compared to other people your age, would you say that your health is:

- poor (1 point)
- fair (1 point)
- good
- very good, or
- excellent

3. How much difficulty, on average, do you have with the following physical activities:

SCORE: 1 point for each * response in question 3a through 3f. Maximum of 2 points.

a. stooping, crouching, or kneeling?

- no difficulty
- a little difficulty
- some difficulty
- a lot of difficulty *
- unable to do *

b. lifting, or carrying objects as heavy as 10 pounds?

- no difficulty
- a little difficulty
- some difficulty
- a lot of difficulty *
- unable to do *

c. reaching or extending arms above shoulder level?

- no difficulty
- a little difficulty
- some difficulty
- a lot of difficulty *
- unable to do *

d. writing, or handling and grasping small objects?

- no difficulty
- a little difficulty
- some difficulty
- a lot of difficulty *
- unable to do *

e. walking a quarter of a mile?

- no difficulty
- a little difficulty

- some difficulty
- a lot of difficulty *
- unable to do *

f. heavy housework such as scrubbing floors or washing windows?

- no difficulty
- a little difficulty
- some difficulty
- a lot of difficulty *
- unable to do *

4. Because of your health or a physical condition, do you have any difficulty:

SCORE: 4 points for one or more * responses in questions 4a through 4e.

a. shopping for personal items (like toilet items or medicines)?

- yes → do you get help with shopping? yes * no
- no
- don't do → is that because of your health? yes * no

b. managing money (like keeping track of expenses or paying bills)?

- yes → do you get help with shopping? yes * no
- no
- don't do → is that because of your health? yes * no

c. walking across the room? USE OF CANE OR WALKER IS OK.

- yes → do you get help with shopping? yes * no
- no
- don't do → is that because of your health? yes * no

d. doing light housework (like washing dishes, straightening up, or light cleaning)?

- yes → do you get help with shopping? yes * no
- no
- don't do → is that because of your health? yes * no

e. bathing or showering?

- yes → do you get help with shopping? yes * no
- no
- don't do → is that because of your health? yes * no

Appendix 3

Telephone Interview for Cognitive Status – Modified (TICS-M)

I would like to ask you some questions to check your memory and concentration. Some of the questions may be easy and some will be harder. Take your time if you need to. We can skip over questions if you don't understand them.

1. Please tell me your full name. (Prompt: **Your name as it appears on your birth certificate.**)

You may ask the client to provide his first or last name if he does not provide both automatically.

	Circle:	<u>Correct</u>	<u>Incorrect</u>	<u>DK</u>	<u>Refused</u>
First: _____		1	0	7	8
Middle: _____		1	0	7	8
Last: _____		1	0	7	8
	Circle:	<u>Correct</u>	<u>Incorrect</u>	<u>DK</u>	<u>Refused</u>
2. What is your age? Age _____		1	0	7	8
3. Without looking at a calendar or watch, what is today's date?					
Month: _____		1	0	7	8
Day: _____		1	0	7	8
Year: _____		1	0	7	8
4. What day of the week is it?					
_____		1	0	7	8
5. What season is it?					
_____		1	0	7	8

6. **Without looking at your phone, can you tell me your phone number?** 1 0 7
8

Maximum of two attempts on Item # 7:

7. **Now I would like you to count backwards** 2 0 7 8
from 20 to 1.

Indicate Errors:

20 19 18 17 16 15 14 13 12 11 10 9 8 7 6 5 4 3 2 1

Administer a 2nd time if 1st attempt was incorrect:

OK. Let's try this one more time. 1 0 7 8

Indicate Errors:

20 19 18 17 16 15 14 13 12 11 10 9 8 7 6 5 4 3 2 1

8. **Now I'm going to read you a list of 10 words. Please listen carefully. When I am done, tell me as many words as you can, in any order. [Please do not write anything down.] I will read the list only once. If you don't understand a word, that's all right. Just try to repeat what you heard. If you're ready, I'll begin.**

(You can repeat the instructions but not the word list. Read the words at the rate of one word every two seconds.)

The words are:

Cabin.....Pipe.....Elephant.....Chest.....Silk.....

Theatre.....Watch.....Whip.....Pillow.....Giant

Now please repeat the words that you remember.

(Record all words up to 20 words even if not on the list. Only the words from the list are scored as correct. Repeated words are recorded but not scored.)

1 _____ 6 _____ 11 _____ 16 _____

2 _____ 7 _____ 12 _____ 17 _____

3 _____ 8 _____ 13 _____ 18 _____

e.g. “Prickly Pear” as correct.)

13. **What animal does wool come from?** 1 0 7 8

(Accept only “sheep” or “lamb” as correct.)

14. **Please say this exactly as I say it:** 1 0 7 8

“No ifs, ands, or buts.”

15. **Say this: “Methodist Episcopal.”** 1 0 7 8

(Listen carefully. Each word must be said clearly and distinctly. For example, “Methodis Epistopal” would be scored as incorrect.)

16. **Who is the President of the United States right now?**

First: _____ 1 0 7 8

Last: _____ 1 0 7 8

17. **Who is the current Vice-President?**

First: _____ 1 0 7 8

Last: _____ 1 0 7 8

For Item # 18: Do not repeat the instructions. You may say, “**Just try to do what you think I said.**”)

18. **With your finger, please tap 5 times on the** 1 0 7 8

part of the phone that you speak into.

[or **With your finger, please tap 5 times on the top of the table.**]

19. **Now I’m going to say a word and I want** 1 0 7 8

you to say its opposite. For example, I might say “hot” and you would say “cold.”

What is the opposite of “east”?

(Accept only “west” as correct.)

20. **What is the opposite of “generous”?** 1 0 7 8

Score any of the following as correct:

NIGGARDLY SELFISH MISERLY NOT GENEROUS SPARSE SCROOGE GREEDY
 MEAN UNGENEROUS CHINTZY TIGHTWAD STINGY MEAGER
 PENURIOUS FRUGAL
 HOARDING TIGHT SKIMPY PARSIMONIOUS SCOTCH
 RESTRICTIVE SKINFLINT CHEAP

Record any other word: _____

21. A few minutes ago, I read you a list of ten words and asked you to repeat them back to me. Please tell me all of those words you can still remember.

- 1 _____ 6 _____ 11 _____ 16 _____
 2 _____ 7 _____ 12 _____ 17 _____
 3 _____ 8 _____ 13 _____ 18 _____
 4 _____ 9 _____ 14 _____ 19 _____
 5 _____ 10 _____ 15 _____ 20 _____

TOTAL OF CORRECT RESPONSES (Max. of 10 pts.): _____

Was the client speaking nonsense words? Circle: Yes No

TICS-M TOTAL SCORE: _____

(Total Possible = 50)

Appendix 4

Future Time Perspective

Please indicate your agreement with each of the items using the scale on the card in front of you.

1. Many opportunities await me in the future.

- 1 = Disagree completely
- 2 = Disagree strongly
- 3 = Disagree
- 4 = Neutral
- 5 = Agree
- 6 = Agree strongly
- 7 = Agree completely

2. I expect that I will set many new goals in the future.

- 1 = Disagree completely
- 2 = Disagree strongly
- 3 = Disagree
- 4 = Neutral
- 5 = Agree
- 6 = Agree strongly
- 7 = Agree completely

3. My future I filled with possibilities.

- 1 = Disagree completely
- 2 = Disagree strongly
- 3 = Disagree
- 4 = Neutral
- 5 = Agree
- 6 = Agree strongly
- 7 = Agree completely

4. My future seems infinite to me.

- 1 = Disagree completely
- 2 = Disagree strongly
- 3 = Disagree
- 4 = Neutral
- 5 = Agree
- 6 = Agree strongly
- 7 = Agree completely

5. Most of my life is ahead of me.

- 1 = Disagree completely
- 2 = Disagree strongly
- 3 = Disagree
- 4 = Neutral

- 5 = Agree
- 6 = Agree strongly
- 7 = Agree completely

6. I could do anything I want in the future.

- 1 = Disagree completely
- 2 = Disagree strongly
- 3 = Disagree
- 4 = Neutral
- 5 = Agree
- 6 = Agree strongly
- 7 = Agree completely

7. There is plenty of time left in my life to make new plans.

- 1 = Disagree completely
- 2 = Disagree strongly
- 3 = Disagree
- 4 = Neutral
- 5 = Agree
- 6 = Agree strongly
- 7 = Agree completely

8. I have the sense that time is running out.

- 1 = Disagree completely
- 2 = Disagree strongly
- 3 = Disagree
- 4 = Neutral
- 5 = Agree
- 6 = Agree strongly
- 7 = Agree completely

9. There are only limited possibilities in my future.

- 1 = Disagree completely
- 2 = Disagree strongly
- 3 = Disagree
- 4 = Neutral
- 5 = Agree
- 6 = Agree strongly
- 7 = Agree completely

10. As I get older, I begin to experience time as limited.

- 1 = Disagree completely
- 2 = Disagree strongly
- 3 = Disagree
- 4 = Neutral
- 5 = Agree

6 = Agree strongly
7 = Agree completely

Appendix 5

Center for Epidemiological Studies Depression Scale (CES-D)

This section deals with statements people might make about how they feel. For each of the statements, please indicate how often you have felt that way during the past week.

Options:

Rarely or none of the time (<1day)

Some or a little of the time (1-2 days)

Occasionally or a moderate amount of the time (3-4 days)

Most or almost all of the time (5-7 days)

1. I was bothered by things that usually don't bother me.
2. I did not feel like eating; appetite was poor.
3. I felt that I could not shake off the blues, even with help from my family and friends.
4. I felt that I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
14. I felt lonely.
15. People were unfriendly.
16. I enjoyed life.
17. I had crying spells.
18. I felt sad.
19. I felt that people disliked me.
20. I could not get going.

Appendix 6

Positive and Negative Affect Schedule (PANAS)

This scale consists of 20 words that describe different feelings and emotions. Read each item and then mark the appropriate answer. Indicate to what extent you've felt this way during the last week.

1. Interested

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

2. Distressed

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

3. Excited

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

4. Upset

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

5. Strong

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

6. Guilty

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

7. Scared

- Very slightly or not at all

- A little
- Moderately
- Quite a bit
- Extremely

8. Hostile

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

9. Enthusiastic

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

10. Proud

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

11. Irritable

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

12. Alert

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

13. Ashamed

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

14. Inspired

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

15. Nervous

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

16. Determined

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

17. Attentive

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

18. Jittery

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

19. Active

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

20. Afraid

- Very slightly or not at all
- A little
- Moderately
- Quite a bit
- Extremely

Appendix 7

Meaning in Life Scale

1. I have a system of values and beliefs that guide my daily activities

- Disagree strongly
- Disagree somewhat
- Agree somewhat
- Agree strongly

2. I have a philosophy of life that helps me understand who I am

- Disagree strongly
- Disagree somewhat
- Agree somewhat
- Agree strongly

3. I feel like I am living life fully

- Disagree strongly
- Disagree somewhat
- Agree somewhat
- Agree strongly

4. I feel like I have found a really significant meaning in my life

- Disagree strongly
- Disagree somewhat
- Agree somewhat
- Agree strongly

5. In my life, I have goals and aims

- Disagree strongly
- Disagree somewhat
- Agree somewhat
- Agree strongly

6. I have a sense of direction and purpose in life

- Disagree strongly
- Disagree somewhat
- Agree somewhat
- Agree strongly

7. I feel good when I think about what I have accomplished in life

- Disagree strongly
- Disagree somewhat
- Agree somewhat
- Agree strongly

8. I am at peace with my past

- Disagree strongly
- Disagree somewhat
- Agree somewhat
- Agree strongly

Appendix 8

Caregiver Stressor Scale

During the past month, how much of the time have these statements been true for you?

Within the past month:

1. I can get a lot done during the day

- Never
- Some of the time
- Most of the time
- All of the time

2. I worry about my relative

- Never
- Some of the time
- Most of the time
- All of the time

3. I am able to relax

- Never
- Some of the time
- Most of the time
- All of the time

4. I can count on having a block of time to use as I like

- Never
- Some of the time
- Most of the time
- All of the time

5. I am exhausted when I go to bed at night

- Never
- Some of the time
- Most of the time
- All of the time

6. I feel responsible for my relative

- Never
- Some of the time
- Most of the time
- All of the time

7. I have more things to do than I can handle

- Never
- Some of the time
- Most of the time
- All of the time

8. I am in control of my emotions

- Never
- Some of the time

Most of the time
All of the time

9. I have difficulty concentrating on my activities because of thoughts of my relative

Never
Some of the time
Most of the time
All of the time

10. I have time for myself

Never
Some of the time
Most of the time
All of the time

11. I think about plans for arrangements for care of my relative

Never
Some of the time
Most of the time
All of the time

12. I am patient with my relative

Never
Some of the time
Most of the time
All of the time

13. The physical strain on me is more than I can take

Never
Some of the time
Most of the time
All of the time

14. I feel confident that I am meeting the needs of my relative

Never
Some of the time
Most of the time
All of the time

15. I feel more and more tense as the day goes on

Never
Some of the time
Most of the time
All of the time

16. I wish I were free to live a life of my own

Never
Some of the time
Most of the time
All of the time

17. I feel competent in my ability to care for my relative

Never
Some of the time
Most of the time

- All of the time
- 18. I wish I could just run away**
- Never
Some of the time
Most of the time
All of the time
- 19. I wish I could take more breaks during the day**
- Never
Some of the time
Most of the time
All of the time
- 20. I feel that I am doing a good job as a caregiver**
- Never
Some of the time
Most of the time
All of the time
- 21. I feel trapped by my relative's illness**
- Never
Some of the time
Most of the time
All of the time
- 22. I don't know what to expect from one hour to the next**
- Never
Some of the time
Most of the time
All of the time
- 23. My patience is stretched to the limit**
- Never
Some of the time
Most of the time
All of the time
- 24. Physically, I am strong enough to do everything that I need to do.**
- Never
Some of the time
Most of the time
All of the time
- 25. I feel if things continue like this, I will not be able to care for my relative at home.**
- Never
Some of the time
Most of the time
All of the time

Appendix 9

Positive Aspects of Caregiving

Some caregivers say that in spite of all the difficulties involved in giving care to a family member with memory or health problems, good things have come out of their caregiving experience too. I'm going to go over a few of the good things reported by some of the caregivers. I would like you to tell me how much you agree or disagree with these statements.

Providing help to my loved one has...

1. Made me feel more useful

- 1 = disagree a lot
- 2 = disagree a little
- 3 = neither agree nor disagree
- 4 = agree a little
- 5 = agree a lot
- 3 = refused
- 4 = unknown

2. Made me feel good about myself

- 1 = disagree a lot
- 2 = disagree a little
- 3 = neither agree nor disagree
- 4 = agree a little
- 5 = agree a lot
- 3 = refused
- 4 = unknown

3. Made me feel needed

- 1 = disagree a lot
- 2 = disagree a little
- 3 = neither agree nor disagree
- 4 = agree a little
- 5 = agree a lot
- 3 = refused
- 4 = unknown

4. Made me feel appreciated

- 1 = disagree a lot
- 2 = disagree a little
- 3 = neither agree nor disagree
- 4 = agree a little
- 5 = agree a lot
- 3 = refused
- 4 = unknown

5. Made me feel important

- 1 = disagree a lot
- 2 = disagree a little
- 3 = neither agree nor disagree
- 4 = agree a little
- 5 = agree a lot
- 3 = refused
- 4 = unknown

6. Made me feel strong and confident

- 1 = disagree a lot
- 2 = disagree a little
- 3 = neither agree nor disagree
- 4 = agree a little
- 5 = agree a lot
- 3 = refused
- 4 = unknown

7. Enabled me to appreciate life more

- 1 = disagree a lot
- 2 = disagree a little
- 3 = neither agree nor disagree
- 4 = agree a little
- 5 = agree a lot
- 3 = refused
- 4 = unknown

8. Enabled me to develop a more positive attitude towards life

- 1 = disagree a lot
- 2 = disagree a little
- 3 = neither agree nor disagree
- 4 = agree a little
- 5 = agree a lot
- 3 = refused
- 4 = unknown

9. Strengthened my relationships with others

- 1 = disagree a lot
- 2 = disagree a little
- 3 = neither agree nor disagree
- 4 = agree a little
- 5 = agree a lot
- 3 = refused
- 4 = unknown