

FAMILY CAREGIVER STRAIN AND RESIDENT DISTRESS IN THE
DEMENTIA POPULATION OF NURSING HOME FACILITIES

Brynn Harris, BSN Honors Student

Marjorie J. Bott, PhD, RN

University of Kansas School of Nursing

3901 Rainbow Blvd. MSN 4043

Kansas City, Kansas 66160

Abstract

End-of-life care in the U.S. is increasingly provided in nursing homes (NHs), and over half of all NH residents have some degree of cognitive impairment. Given the prevalence of this cognitive decline, there is a surprising gap in research related to the management of distress in this patient population and their family caregivers. Symptoms of distress vary based on multiple factors (e.g., pain, cognitive status, type of caregiver) and can be masked in the cognitively impaired due to communication difficulties. The purpose of this study was to examine whether resident and family caregiver distress and strain are different among three NH resident groups based on diagnoses: (a) Alzheimer's, (b) other dementia disorders, and (c) non-cognitive diagnoses. This exploratory study was a secondary analysis of data collected from a longitudinal study examining end-of-life care in NHs. The sample was comprised of 1,282 pairs of NH residents and their family caregivers from two Midwestern states. Caregiver and resident distress and strain were measured with the *Caregiver Strain Index* and the *Family Memorial Symptom Assessment Scale Global Index*, respectively. ANOVA procedures were used to test for differences among the groups, and follow-up tests were conducted using *Duncan/Dunnett's T3* tests. Findings indicated significant decreases in distress ($F_{(2,1267)} = 34.16, p < .001$) and strain ($F_{(2,1267)} = 10.08, p < .001$) among cognitively-impaired residents from those who were cognitively intact. No significant differences were found in caregiver distress or strain based on the cognitive status of their loved one. It is uncertain whether the reported differences are attributable to communication difficulties of the cognitively-impaired residents or whether they are experiencing less distress and strain. Research in other geographic locations using larger samples are needed to provide further insight.

Introduction

Nursing homes are of ever increasing occurrence in American culture as the population ages. Currently, 20% of all deaths occur in nursing homes, and this number is expected to increase to 40% by the year 2020 (Forbes, 2001). With death such an integral part of nursing home culture, there are surprising gaps in research regarding quality end-of-life care in the nursing home setting. Most research to this point has focused on patients with cancer diagnoses or on those in the hospital setting. Thus the research always is not applicable because patients with long-term, non-cancer diagnoses usually present differently, having periods of instability intermixed with periods of stability, with death frequently occurring abruptly. Demographic characteristics and comorbidities of the

nursing home population lead to increased vulnerability of nursing home patients, both to physical and emotional stress and trauma.

Over half of all nursing home residents have some degree of cognitive impairment (DeVellis, Hanson, Henderson, Reynolds, & Steinhauser, 2008). Distress or pain in a patient with Alzheimer's or other dementia diagnoses must be evaluated with different measures than for those with no cognitive impairment. For example, pain assessment must rely on other expressions like fidgeting, grimacing, or 'crying out' if the patient's cognitive disorder prevents reliable verbal reports. Up to this point, research related to patients with cognitive impairment has centered on pain management rather than overall patient distress and strain. Looking more closely at the strain and distress experienced by nursing home residents that are cognitively impaired and comparing them to those that are not impaired will allow us to identify if there is inadequate pain management among this group. Strain and distress may be harder to measure due to the communication challenges and memory lapses that occur with cognitive impairment, and so may be undertreated. However, in recent years there has been as an increase in medical studies involving this population, as well as improvement in the development of pain assessment tools specifically geared to geriatrics and the cognitively impaired. Effort is being made to qualify dementia patients for end-of-life care instead of waiting for them to meet Medicare's current required prognosis of six months or less to live. This will assist in improving comfort measures for this patient group, who may remain in the advanced stages of their disease for many years before passing (Diwan, Hougham, & Sachs, 2004).

Research examining caregiver role strain for cognitively-impaired individuals has mainly focused on those who care for their loved one at home, and not on families of residents residing in the nursing home setting. Family caregivers of the cognitively impaired face unique challenges related to the change in personality and outbursts frequently experienced by this patient group, and this type of stressor exists whether the patient is cared for at home or in alternative settings. Many family caregivers of this patient group report feeling as though they are "on duty" 24-hours a day, and a high degree of guilt is not uncommon (Diwan et al., 2004, p.798). Comparing caregiver strain and distress for families of cognitively-impaired patients to families of the non-cognitively impaired will help to identify if there is a lack of the appropriate caregiver support among this group.

Purpose

The purpose of this secondary analysis is to examine whether resident distress and the corresponding family caregiver strain differ among patients with varied cognitive status. The following research questions will be explored: (a) is there a difference in the number of resident strain symptoms and amount of associated distress reported among three diagnostic groups of residents (Alzheimer's, other dementia, and no dementia), and (b) is there a difference in the number of caregiver strain symptoms and the amount of distress reported among the Alzheimer's, other dementia, and no dementia residents?

Background

Many studies have examined pain management in older adults with cognitive impairment, along with caregiver role strain for family members acting as the primary providers for these people. Literature has demonstrated clear differences in pain reporting and management based on the cognitive status of the individual, focusing primarily on the patients' inability to express pain in a way their caregiver can understand (Ferrell et al., 1995). Additionally, caregiver role strain has been shown to be unique in many ways for those family members who must face their loved one's cognitive impairment instead of or in addition to their physical challenges.

Pain Management. Improperly managed pain in older adults is considered to be a pandemic across nursing homes in this country, with chronic pain estimates ranging from 40% to 80% of all residents (Forbes, 2001). Pain is difficult to identify and manage in older adults with all forms of diagnosis, but it is of little surprise that it is even more challenging consistently to identify pain from among approximately half of these residents who are suffering from some degree of cognitive impairment (DeVellis et al., 2008). Several factors are attributed to the difficulty in identifying pain in older adults: (a) the use of pain assessment instruments that have not been validated for the elderly population, (b) difficulty in establishing consistency of care in nursing homes, (c) higher incidence of side effects related to pharmacology for this age group, and (d) a fear of using analgesics due to heavy scrutiny of these facilities by state and federal authorities (DeVellis et al., 2008; Ferrell, 1995).

Pain usually is reported verbally by the residents; however scales designed for patients who are unable to communicate verbally typically look for pain associated non-verbal symptoms or cues such as fidgeting, grimacing, and verbal outbursts (DeVellis et al., 2008). These symptoms or cues obviously can be difficult to interpret and measure consistently at times. However, the increased interest in the topic and a required focus on

pain management mandated by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has led to the development of more varied pain assessment measures. Encouragingly, several studies have shown that 83% of cognitively-impaired residents with pain could complete at least one of the self-assessed, non-verbal pain scales (e.g., horizontal visual analogue scale with anchors of “no pain” and “worst possible pain”; Rand Coop Chart with facial expressions indicating degree of pain; or the pain thermometer visually indicated increasing pain) (Ferrell et al., 1995). For those patients unable to complete any kind of self-reported pain assessment, the Minimum Data Set (MDS) 3.0 includes a non-verbal provider assessed pain intensity scale guide that measures groaning, sighing, restlessness, withdrawal, crying and immobility (Quality Partners of Rhode Island, 2006). The next step will be to convince those in charge of policy making for nursing home facilities that such scales are needed in addition to the traditional self-reported 0-10 pain scale in order accurately to assess pain in the cognitively-impaired.

There is a social myth that pain is a normal part of aging, but the importance of measuring pain accurately cannot be under-estimated. A 2010 study focusing on pain and memory in adults showed that persistent pain can lead to an exacerbation of cognitive dysfunction even in those who are cognitively intact, let alone those individuals who are cognitively impaired (Brown, 2010). Further motivation to identify pain in these residents as early as possible is the fact that the declined functioning of residents suffering from cognitive impairment make them more likely to acquire additional painful conditions such as pressure ulcers and contractures (Brown, 2010).

Unfortunately, studies examining pain management have consistently found pain to be under-detected in all nursing home residents, especially those with cognitive impairment. A 2004 study examining analgesic provision in a nursing home in the United Kingdom found that prescriptions of opioid and non-opioid analgesic decreased as cognitive impairment increased (Barr, Briggs, & Closs 2004). Similarly, a measure of daily pain in nursing home residents taken as part of a 2004 study in the United States found that 3.7% of those surveyed with normal cognitive status reported daily pain that was excruciating at least once in the last week. In contrast, caregivers reported that those with cognitive impairment had this level of pain only one-fourth as often (Kabumoto, Mor, Roy, Teno, & Wetle, 2004). A 2010 analysis of the Resident Assessment Instrument (RAI) data used to collect information about residents for Minimum Data Set (MDS) reporting focused on pain in communication-impaired dementia residents. The study reported that residents with

impaired communication were less likely to have their pain rated as moderate to extreme, and less likely to receive the wide range of medications available per week when compared to those residents with no impairment (Brown, 2010). They also found in examining the RAI pain ratings that some residents who were experiencing pain never received any analgesic treatment (Brown, 2010).

A 2008 study (DeVellis et al., 2008) examined disparities in pain management based on level of cognition. Despite the fact that there was no variation between the groups in diagnoses likely to cause pain, they found that 80% of cognitively intact residents received some pain medication throughout the study, versus only 56% of residents with severe cognitive impairment. Similarly, a 2005 study (Jarland & Nygaard, 2005) looking at pain revealed that nurses were likely to over-estimate pain in cognitively intact patients as only 47% of this patient group self-reported pain versus the 67% described as being in pain by their nurses. In contrast, analgesics given as needed (PRN) were bestowed to 33% of cognitively-intact patients, 27% of cognitively-impaired patients, and 12% of demented patients, showing that those with dementia diagnoses were less likely to receive PRN medications.

Caregiver Strain. Caregiver role strain results from a wide variety of factors related to both the patient and the caregiver. Personal orientation, or an individual caregiver's self-perception, has a large impact on the stress one experiences; but for nearly all, caring for a loved one with a dementia diagnoses leads to a high degree of strain (Goodman, Steiner, & Zarit, 1997). The symptoms specific to dementia of behavioral changes, decreased communication skills, decreased ability to perform one's own activities of daily living, and declining motor function lead to a high degree of strain for their caregiver, who often feels they no longer are able to recognize the person they love within the disease-defined characteristics of the patient they now care for (Annerstedt, Elmstahl, & Grafstrom, Samuelsson, & Samuelsson, 2001). The *Caregiver Strain Index* defines three dimensions of strain for the caregiver: role, personal, and emotional (Diwan et al., 2004). Role strain can include having to make adjustments to normal routine, losing personal time, and taking time off work. Personal strain can include financial hardships, sleep disturbances, and physical challenges of care (Diwan et al.). Emotional strain, which includes changes in the personality of their loved one and upsetting behaviors such as incontinence or memory loss, is most prominent among caregivers of cognitively-impaired family members. Researchers have found that problem behaviors related to the patient,

specifically patient functional limitations, predict both personal and role strain (Diwan et al.).

Along these lines, a 2010 study (Ito, Miyamoto, & Tachimori, 2010) examining caregiver burden used a multiple linear regression model to predict the burden on caregivers. Results supported that there was a positive relationship between behavioral and psychological symptoms of dementia (BPSD) such as aggression, screaming, and low activities of daily living (ADL) levels with reported caregiver burden. They recommended that the effectiveness of training designed to decrease BPSD in dementia patients should be examined as a possible method to decrease this elevated caregiver strain.

Burden of responsibility experienced by family caregivers of dementia sufferers was examined effectively in a qualitative study in Sweden in 2001. The study showed that 100% of caregivers felt a “heavy burden” early on in the process, particularly before a diagnosis was made (Annerstedt et al., 2001). The quality of the relationship between the caregiver and dementia patient had an effect on the caregiver’s stress as the disorder progressed. Those that described themselves as having been on poor terms with their loved one before the dementia experienced more ambivalence towards the decline, less sympathy, less guilt, and emotional distance (Annerstedt et al.). Those that had a close relationship suffered more strain as they watched their relationship change. One caregiver described the difficulty of his wife’s dementia as “not being able to reach her any longer...to talk to each other...to get contact” (Annerstedt et al., p.29).

More research is needed on caregiver role strain specific to family members whose loved one is in a nursing home or assisted living facility rather than at home. Examination of the differences in caregiver strain across cognitively impaired and cognitively intact residents needs to be explored, as well as additional research comparing other indicators of resident distress besides pain management in these same groups.

Methods

Design

This study was a secondary analysis of data from the NINR-funded “Impact of Quality End-of-Life Care in Nursing Homes” Study, a longitudinal study examining end-of-life care in nursing homes. The primary study used a multi-level structural equation model to examine both the personal resident/family factors and the facility-level factors such as staff communication and palliative care practices that contribute to quality of end-of-life

care for residents. The purpose of this secondary analysis was to examine whether resident distress and family caregiver strain differ among patients of varied cognitive status.

Sample and Setting

The sample included 1,282 resident/family caregiver pairs from 88 nursing homes in two Midwestern states. A target of 100 participating nursing homes was randomly selected from an initial sampling strategy that generated 180 facilities that met the criteria of the parent study. The criteria for inclusion were: free standing nursing facilities, not hospital based, and at least 60 beds per facility.

Family caregivers were recruited for residents that had died in the nursing home in the past month. Resident/caregiver pairs per institution ranged from 8 to 25, with a mean of 15. The nursing home residents were divided into three groups based on three diagnoses: Alzheimer's disease ($n=246$; 19.5%), other dementia disorders ($n=439$; 34.9%), and all other non-cognitive diagnoses ($n=575$; 45.6%).

Measures

Caregiver Strain and Distress. *Caregiver strain* and *distress* were measured using the *Caregiver Strain Index* (Robinson, 1983; Thorton & Travis, 2003). The index was comprised of two scales looking first at strain and then at associated distress, designed to determine the degree of challenge experienced by family caregivers while their loved one was in a nursing care facility. Reliability (*Cronbach's alpha* .86) and construct validity have been demonstrated (Robinson, 1983).

Caregiver Strain was measured using 13 questions addressing the issues of sleep disruption, physical challenges, emotional challenges, less time for self, adjustment of work schedules, financial strain, adjustment of family routines, changing of personal plans, inconveniences, other demands on time, upsetting behaviors, changes seen in the resident, and overwhelming feelings. Item responses were 'yes' or 'no' with a value of one given for each yes response. Questions were formatted as follows: In caring for the resident, was your sleep disturbed? Scores across the thirteen items were summed to create a scale. Scores ranged from 0 (no strain) to 13 (highest strain).

Caregiver Distress was similarly structured with 13 questions addressing the same items as those identified for caregiver strain, but through follow-up questions asking for the amount that the caregiver was distressed or bothered by each area of strain. For example: In caring for the resident, how much did your sleep disruption distress or bother you? Response options were: 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit), or 4 (a

great deal). Scores were summed across the 13 items and ranged from 0 (no distress) to 52 (most distress).

Resident Strain and Distress. *Resident strain* and *distress* were measured using the Family Memorial Symptom Assessment Scale Global Distress Index [MSAS_GDI] (Kornblith et al., 1994; Hickman, Tilden, & Tolle, 2001). The two scales were designed to evaluate the stress experienced by the residents of the participating nursing homes, considering their three diagnoses groups. The MSAS-GDI has demonstrated reliability and validity (Portnoy et al., 1994; Viet & Ware, 1983). Strain was measured through an 11-item scale with one point given for each positive response to questions addressing experience of sadness, worry, irritability, nervousness, lack of appetite, lack of energy, feeling drowsy, constipation, dry mouth, difficulty breathing, and pain. Questions were formatted as follows: Did the resident seem to feel sad in the last week of his or her life? If a response of yes was given, one point was added to the resident strain scale. Scores then ranged from 0 (no strain) to 11 (most strain). Similarly, resident distress was measured through the examination of the same issues, but with questions addressing how often the stress was experienced, and how much the experience seemed to distress the resident. For example: How often did the resident seem sad? Responses included 0 (never), 1 (rarely), 2 (occasionally), 3 (frequently), or 4 (almost constantly). Also how often did feeling sad seem to distress the resident? Responses included 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit), and 4 (very much). Final scores then ranged from 0 (no distress) to 60 (most distress).

Procedures

After an initial sampling strategy using public lists of nursing facilities generated 180 eligible nursing homes in two Midwestern states, 100 nursing facilities were randomly selected to be included in this study. Based on average death rates and a desire to encourage enrollment, inclusion criteria was a minimum of 60 beds for the homes. Once selected, the facilities received a letter describing the study, and a telephone call to answer any questions and to seek consent. Facilities that decided to participate selected a staff member to serve as site coordinator for monthly reports. Contact information for resident and family caregivers was obtained from the site coordinator, and family caregivers were contacted by phone to give consent and complete the surveys.

Data Analysis

The following research questions were explored: (a) Is there a difference in the number of resident strain and distress symptoms reported among the Alzheimer's, other dementia, and other non-cognitive diagnoses groups, and (b) Is there a difference in the number of caregiver strain and distress symptoms reported in the Alzheimer's, other dementia, and other non-cognitive diagnoses groups? Analysis of Variance (ANOVA) procedure was performed by selecting for each dependent variable (resident strain and distress, and caregiver strain and distress). A one-way layout ANOVA looks at one treatment factor at two or more levels, and quantifies the differences in mean among the levels. ANOVA assumptions are that the treatment effects are additive and errors are random, independently distributed, follow a normal distribution, and have a mean of zero with constant variance. Correlation analysis also is done on random samples with normal distribution to determine whether two variables are associated. The correlation coefficient is a number between -1 and 1 which indicates the degree to which a change in one variable leads to a change in the other. The correlation coefficient is statistically significant only if there is a less than 5% probability you would have reached the same result with a true correlation coefficient of zero. This is indicated by a p value of $<.05$.

ANOVA procedures were used to test for differences among the three nursing home resident diagnostic groups: Alzheimer's disease, other dementia disorders, and all other non-cognitive diagnoses. Follow-up tests were conducted using Duncan and *Dunnett's T3* tests based on whether the assumption for homogeneity of variance was met or not met, respectively.

Results

Our sample was comprised of 1,282 resident/family caregiver pairs. Mean age of family caregivers and involvement in the residents' lives are outlined in Table 1, as well as other demographic information of both the resident and family caregiver. Our sample residents and caregivers were predominantly female, non-Hispanic white, and Protestant. The largest resident age group was 85 years and older; and nursing homes were the primary location of death.

Means and standard deviations for caregiver strain, caregiver distress, resident strain, and resident distress can be found in Table 2. Caregiver strain and distress were analyzed to determine if statistical differences existed between our three resident diagnostic groups. Testing the assumption of equal variances, or that the three groups would have equal slopes if plotted independently, there were non-significant ($p = .19$ and

.34) findings for caregiver strain and distress, respectively, confirming that we met the assumption for equal variances. The ANOVA revealed non-significant ($p = .46$ and $.75$) differences for the means of both caregiver stress and strain, respectively, among the three resident diagnostic groups.

Resident strain and distress were examined to determine if differences for these measures existed between our resident diagnostic groups. The homogeneity of variance test resulted in significance ($p = .03$ and $.00$) for resident strain and distress, respectively, indicating the assumption of equal variances had been violated. The overall *F test* for the ANOVA among the three resident diagnoses groups revealed significant differences for both resident strain and distress (See Table 2). Follow-up tests using the *Dunnett's T3* showed that for resident strain the Alzheimer's group ($M = 4.85$) was significantly ($p < .01$) lower than the other dementia group ($M = 5.10$) and all other non-cognitive diagnoses group ($M = 5.52$). For resident distress, the *Dunnett's T3* test revealed significant ($p < .01$) differences between all groups: Alzheimer's ($M = 4.21$), other dementia ($M = 5.54$), and all other non-cognitive diagnoses groups ($M = 6.68$).

Discussion

Resident strain and distress are important measurements for improving quality end-of-life care. This especially is true but more difficult to quantify in those with cognitive impairment, due to communication difficulties and personality changes that make it difficult to identify varying degrees of agitation. The use of self-assessed, non-verbal scales, as well as caregiver-assessed scales, can help more accurately to measure strain and distress for this group. Pain management has been studied extensively in the cognitively impaired population, but other variables such as sadness, lack of appetite, and fatigue need to be examined as well.

Caregivers face unique strain and distress when caring for a loved one with Alzheimer's or other dementia disorder. The change in personality of their loved one, when combined with the physical challenges of caregiving, can be overwhelming. There has been a fair amount of research on this topic when the caregiver and the patient live together, but more research is needed to examine how the cognitive decline of the patient affects caregiver strain and distress when the patient lives in a nursing home.

Our study found no significant difference in caregiver strain or distress based on diagnoses of Alzheimer's, other dementia disorder, or non-cognitively impaired residents. This was a surprising finding as we anticipated increased strain and distress for

the caregivers due to the particular characteristics that impact residents who have cognitive disorders such as personality change, volatility, communication impairment, and low ability to perform ADL's independently. In examining the caregiver strain and distress means, the caregivers for the Alzheimer's residents reported lower strain and distress even though the findings were non-significant. The lack of significant variance could be due to the successful use of non-verbal assessment measures providing comfort to residents, personal attributes of the caregivers, or simply a true lack of variability in the strain and distress between caregivers for those with cognitive impairment and caregivers of those without. Also these findings were reported for residents who had recently passed away, and it could be that strain and stress for the family caregivers during the resident's end-of-life experiences were about the same regardless of type of cognitive impairment level of the resident.

However, the findings revealed significant difference in resident strain and distress based on diagnoses groups. For resident strain, the significant variances existed between the Alzheimer's group and the other non-cognitive diagnoses groups, as well as between the dementia and the other non-cognitive diagnoses groups. For distress, significant variance existed between all three diagnoses groups. Strain and distress was much higher for residents in their last days of life for those who were cognitively intact than for those who were not. This may be that they were more able to express this to their loved ones or it may have been due to the fact that the family caregivers had clearer communication from these residents.

Results of this study can be used to anticipate lower visible strain and distress among residents who are cognitively-impaired. Nursing care should be adapted to consider the possibilities of why this is occurring. It is possible these patients are truly experiencing less strain and can manage better with less medication geared towards reducing anxiety and pain towards the end of life. Other possible explanations for this decline in strain and distress also should be considered. If these cognitively-impaired residents are simply less able to express their strain verbally, effort must be made on the part of healthcare providers to attempt to measure strain in other ways, such as through non-verbal, caregiver-provided assessment scales.

Summary

In summary, symptoms of strain and distress can vary based on multiple factors, and may be difficult to assess in those with cognitive impairment. Findings of this study revealed that: (a) caregiver strain and distress did not significantly vary between caregivers

whose loved one is cognitively-intact and those whose loved one is cognitively-impaired, and (b) resident strain varied significantly between the Alzheimer's group and the other non-cognitive diagnoses groups, as well as between the dementia and the other non-cognitive diagnoses groups. Resident distress showed significant variance between all three diagnoses groups. The limitations of this study include the racial and gender homogeneity of our sample. Additionally because this research was conducted in the Midwest, it cannot be generalized to other areas of the U.S. Findings should be confirmed through further research in more diverse sample and in other geographic locations.

References

- Annerstedt, L., Elmstahl, S., Grafstrom, M., Samuelsson, A.M., & Samuelsson, S.V. (2001). Burden of responsibility experienced by family caregivers of elderly dementia sufferers. *Scandinavian Journal of Caring Science, 15*, 25-33.
- Brown, C. (2010). Pain in communication impaired residents with dementia: Analysis of resident assessment instrument (RAI) data. *Dementia, 9*(3), 375-389.
- Closs, S.J., Barr, B., & Briggs, M. (2004, December). Cognitive status and analgesic provision in nursing home residents. *British Journal of General Practice, 54*, 919-921.
- DeVellis, R., Hanson, L., Henderson, M., Reynolds, K., & Steinhauer, K. (2008, April). Disparities in pain management between cognitively intact and cognitively impaired nursing home residents. *Journal of Pain and Symptom Management, 35*(4), 388-396.
- Diwan, S., Hougham, G., & Sachs, G. (2004). Strain experienced by caregivers of dementia patients receiving palliative care: Findings from the palliative excellence in Alzheimer care efforts (PEACE) program. *Journal of Palliative Medicine, 7*, 797-807.
- Ferrell, B. (1995). Pain evaluation and management in the nursing home. *Annals of Internal Medicine, 123*, 681-697.
- Ferrell, B.A., Ferrell, B.R., & Rivera, L. (1995, November). Pain in cognitively impaired nursing home patients. *Journal of Pain and Symptom Management, 10*(8), 591-598.
- Forbes, S. (2001, November). This is heaven's waiting room. *Journal of Gerontological Nursing, 27*(11), 37-45.
- Goodman, C., Steiner, V., & Zarit, S. (1996, September). Personal orientation as a predictor of caregiver strain. *Aging & Mental Health, 1*(2), 149-157.
- Hickman S.E., Tilden V.P., & Tolle S.W. (2001). Family reports of dying patients' distress: the adaptation of a research tool to assess global symptom distress in the last week of life. *Journal of Pain & Symptom Management, Jul*, 565-574.
- Ito, H., Miyamoto, Y., & Tachimori, H. (2010). Formal caregiver burden in dementia: Impact of behavioral and psychological symptoms of dementia and activities of daily living. *Geriatric Nursing, 31*(4), 246-253.
- Jarland, M. & Nygaard, H. (2005, February). Are nursing home patients with dementia at increased risk for inadequate pain treatment? *International Journal of Geriatric Psychiatry, 20*, 730-737.

Harris, B. Dementia Population of Nursing Homes: Caregiver Strain and Resident Distress. 2011

Kabumoto, G., Mor, V., Roy, J., Teno, J., & Wetle, T. (2004). Daily pain that was excruciating at some time in the previous week: Prevalence, characteristics, and outcomes in nursing home residents. *Journal of American Geriatrics Society, 52*, 762-767.

Portenoy R.K., Thaler H.T., Kornblith A.B., et al. (1994). The Memorial Symptom Assessment Scale: An instrument for the evaluation of symptom prevalence, characteristics and distress. *European Journal of Cancer, 30A(9)*, 1326-36.

Quality Partners of Rhode Island (2006). Minimum Data Set 3.0.

Robinson B.C. (1983). Validation of a caregiver strain index. *Journal of Gerontology, 38(3)*, 344-8.

Rubio D.R., Berg-Weger M., & Tebb S.S. (1999). Assessing the validity and reliability of well-being and stress in family caregivers. *Social Work Research, 23(1)*, 54-64.

Thornton M. & Travis S.S. (2003). Analysis of the reliability of the modified caregiver strain index. *Journal of Gerontology B Psychological Science Social Sciences, 58(2)*, S127-32.

Veit C.T. & Ware J.E. (1983). The structure of psychological distress and well-being in general populations. *Journal of Consulting and Clinical Psychology, 51(5)*, 730-42.

Table 1 Demographic Characteristics of the Sample by Diagnostic Group

Characteristic	Diagnostic Groups			Total (N=1,282)
	Alzheimers (n=246)	Other Dementia (n=383)	Non- Cognitive (n=653)	
Family Caregiver	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)
Age	65.95 (10.25)	63.26 (11.20)	62.88 (10.75)	63.58 (10.85)
Involvement	3.55 (0.62)	3.54 (0.63)	3.56 (0.61)	3.55 (0.62)
	%	%	%	%
Gender (Female)	71.1	73.1	69.5	70.9
Race (Non- Hispanic White)	98.4	99.0	99.1	98.9
Employed	47.6	56.4	56.7	54.8
Religion (Protestant)	76.3	73.6	73.8	74.2
Resident	%	%	%	%
Age				
<65	0.8	0.5	1.9	1.3
65-74	3.3	4.0	9.0	6.4
75-84	30.5	28.0	27.4	28.2
>85	65.3	67.5	61.8	64.2
Gender (Female)	69.3	69.7	65.8	67.7
Race (Non-Hispanic White)	98.7	98.1	98.9	98.6
Religion (Protestant)	75.2	75.7	73.5	74.5
Place of Death (NH)	91.1	88.8	84.8	87.2

^aScale of 1-4; Higher score=more involvement

Table 2 Resident and Caregiver Stress and Strain by Diagnostic Groups

	Diagnostic Groups			ANOVA
	Alzheimer's	Other Dementia	Non-cognitive	<i>F Value</i>
	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	(<i>p</i>)
Caregiver Strain	5.26 (3.17)	5.58 (3.38)	5.52 (3.29)	.78 (.46)
Caregiver Distress	12.20 (8.70)	12.77 (9.24)	12.44 (8.97)	.29 (.75)
Resident Strain	4.85 ^a (2.01)	5.10 ^b (2.16)	5.52 ^{ab} (2.21)	10.08 (<.001)
Resident Distress	4.21 ^c (4.77)	5.54 ^c (6.05)	7.74 ^c (6.68)	34.16 (<.001)

^aAlzheimer was significantly different from other Non-cognitive diagnoses

^bOther dementia was significantly different from other Non-cognitive diagnoses

^cAll diagnostic groups were significantly different from each other