# Secondary study: family caregiver Burden, satisfaction with care, and hospice care for residents at the end of life in the nursing home

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ABSTRACT

**Introduction**: Family caregivers are crucial in the end-of-life (EOL) care of nursing home (NH) residents. As the population ages and requires NH care at the EOL, families experience increased burden and less satisfaction with nursing home care. Little is known about how the time involved and hospice care affect family caregivers’ burden and satisfaction with EOL care.

**Purpose**: The study aims are to describe and explore the relationships among the time spent in caregiving, satisfaction with nursing home care, hospice care, and the caregivers’ perceived burden (strain and distress) during the resident’s EOL.

**Methodology**: From a larger study examining EOL in nursing homes, data were collected for a descriptive secondary analysis from families of deceased residents (*N=*1,282). Descriptive statistics depicted the *Caregiver Strain/Distress Indexes*, the *Satisfaction with Care Scale*, and *Time Involved in Caregiving and Hospice Care.* Pearson(*r*) correlations and *t*-tests were conducted to explore the relationship among the variables.

**Findings**: Caregivers were involved an average of 9.11 hours per week (*range* = 0 to 120). Time involved in caregiving was positively related to strain (*r* = .17, *p* < .01) and distress (*r* = .18, *p* < .01), and negatively related to satisfaction with nursing home care (*r* = -.07, *p* < .01). The 418 caregivers (33.8%) involved with hospice in the past 14 days reported more time involved in caregiving (*t* = -2.19, *p <* .05), higher distress (*t* = -2.628, *p* < .01) and strain (*t* = -2.71, *p* < .01), and slightly higher satisfaction with nursing home care (*t* = -1.43, *p* = .15).

**Implications**: As time spent in caregiving increases, it is important to identify interventions (e.g., communication, support, or palliative and hospice measures) that assist family members in reducing burden they perceive during the EOL experience for residents.

INTRODUCTION

Since family members endure the emotional burden of caring for and eventually living with the decisions made by and for deceased loved ones, nursing home residents, along with their family caregivers, have been key targets for palliative care interventions. The number of residents along with their family caregivers in the nursing home is expected to grow to 40% by 2020 (Kelly et al., 2010). Thus, identifying causes and solutions for caregiver burden will be beneficial to maintain caregivers’ psychological and physical health during and even after a resident’s death. Caregiver burden that includes both distress and strain—often referred to as caregiver distress—has been recognized as an issue in the nursing home. However, there is insufficient literature on the causes of the caregiver burden revolving around the time involved and the quality of time spent with the resident, as well as the variation of these variables in hospice versus non-hospice care settings.

Several qualitative studies have been conducted to advance research about end-of-life care by studying the family caregivers’ experiences (Forbes, Bern-Klug, & Gessert, 2000; Teno et al., 2004; Wetle, Shield, Teno, Miller, & Welch., 2005). Quantitative studies, including in-person and telephone interviews, have been reported (Burns, Graney, Martindale-Adams, Nichols, & Zuber, 2011; Murphy, Hanrahan & Luchins, 1997; Tilden, Tolle, Drach, & Perrin, 2004). While less time involved in caregiving has been associated with decreased caregiver burden (Burns et al., 2011), little is known about the amount and quality of time involved with the resident during the end-of life process and how this affects caregiver burden and, ultimately, resident outcomes.

Advanced directives help reduce strain during the decision-making process of withdrawing life-sustaining treatment (Tilden et al., 2001). Tilden et al. (2004) reported higher levels of caregiver strain regardless of advance directives and hospice enrollments. Even though less than 1% of the deceased residents were uninsured, families from this study reported high out-of-pocket expenses related to medications, and this was another factor that contributed to higher perceived levels of strain. In contrast, other studies revealed that interventions such as education and grief counseling greatly decreased caregiver burden and strain (Burns et al., 2011; Murphy, et al. 1997). However, they also reported that grief and bereavement resources are limited in nursing homes.

Referral to hospice has been shown to improve care at the end of life, such as fewer hospitalizations and more effective pain management according to clinical guidelines (Zheng, Mukamel, Caprio, & Temkin-Greener, 2012). However, when residents in the nursing home want to enter hospice, they experienced problems. Either the referral never happened or it happened late and very close to the time of the resident’s death. The spectrum of different family caregiver perceptions about experienced burden (i.e., strain and distress) has not been studied. No comparisons have been reported from family caregivers of residents who received hospice care versus those who did not receive hospice care

In summary, the reports of these studies emphasized the following: (a) a high prevalence of caregiver burden; (b) causes for unfavorable family caregiver experiences at the end of life; (c) risk factors for burden and strain; and (d) the lack of services to address the issues. Even with the emphasis in these areas, research has not been done on three key elements pertaining to the end-of-life process in the nursing home: the amount of time that a family caregiver spends with the resident, the impact on their satisfaction with the resident’s care, and the difference between these variables in hospice versus non-hospice care.

This study under discussion focused on the dynamics of caregiver burden and family caregiver perceptions in terms of end-of-life care. Understanding these essential components of quality end-of-life care is important in order to improve care for nursing home residents and reduce burden for their family caregivers.

*Purpose*

The purpose of this secondary analysis study was to describe and explore the relationships among the time that families spent on caregiving, satisfaction with nursing home care, the caregivers’ perceived burden (strain and distress), and the use of hospice care in the past 14 days. Six research questions guided the study: (a) How involved was the caregiver in the resident’s life in a typical week?; (b) How much caregiver burden (strain and distress) was reported by the caregiver?; (c) How much satisfaction with nursing home care was reported by the caregiver?; (d) How many residents were receiving hospice care in the past 14 days?; (e) What are the relationships among burden (strain and distress), satisfaction with nursing home care reported by the caregiver, and time involved in caregiving at the end of life?; and (f) Is there a difference in family member burden (strain and distress), satisfaction with nursing home care, and time involved in caregiving at the end of life for residents receiving hospice care in the past 14 days versus those who did not?

*Review of Literature*

Stress and burden are defined as the “individual’s physical and/or emotional response to challenges in the caregiver role” (Thornton & Travis, 2003, p. S127). Caregiver distress has been described in multiple ways, including “feelings of burnout, depression, isolation, sadness, fear, anxiety, grief, and loneliness” (Cuellar & Butts, 1999, p. 24). More caregivers report depression, psychological distress, low self-efficacy, poor life satisfaction, and higher usage of psychotropic drugs than the general population.

The Family Memorial Symptom Assessment Scale - Global Distress Index (FMSAS-GDI) is a 69-item telephone questionnaire for gathering data on: (a) advance directives; (b) use of life-sustaining treatments; (c) decedent symptom experience and perceived symptom distress; (d) financial burden; and (e) caregiver distress measured with four responses (sleep disturbance, physical drain, emotional drain, confinement) (Tilden et al., 2004). According to Tilden and colleagues (2004), caregiver strain was associated with higher perceived decedent symptom distress and greater hospice enrollment, especially when palliative needs were not met, as well as more caregiver involvement and greater financial burden. The strongest factors correlated with perceived resident distress by the family caregiver were preventable symptoms such as constipation, pain, or dyspnea. Over half of the caregivers reported high scores on the FMSAS-GDI, which included feeling emotionally drained, physically drained, and confined with sleep disturbances. Interestingly, older caregivers and caregivers of Asian descent reported less caregiver strain, potentially due to a cultural discouragement of expressing distress about family matters. Age appeared to be protective against caregiver strain as well. While race and age may predict perceived caregiver strain, the quality of nursing home care has not been shown to influence caregiver strain. Tilden et al. (2004) showed higher than expected caregiver strain and financial burden in a state (Oregon) that was ranked high in providing quality end-of-life care for elders. Consequently, caregiver strain, distress, and burden need to be addressed in younger caregivers as well as across the nation, even in high quality facilities.

Many factors can lead to caregiver burden. Wetle and colleagues (2005) reported that family burden increased when caregivers perceived that professional care was lacking and focused on tasks, rather than patient-centered care. Agreeing with Tilden et al. (2004), Teno (2004) noted that this is especially the case when it comes to a resident’s unmet needs for: (a) treating symptoms of dyspnea and pain, (b) treating the resident with respect, (c) providing coordinated care, and (d) providing communication about decision making in care facilities. Through the use of telephone interviews, Teno et al. (2004) evaluated family perspectives on satisfaction with care and unmet needs of the residents. Bereaved family members of home hospice patients reported higher satisfaction with care than those receiving nursing home services (70.7% versus 46.5%, respectively). They also reported fewer unmet needs when compared with home nursing care, specifically for pain (18.3% versus 42.6%, respectively), dyspnea (25.6% versus 38%, respectively), and emotional support (34.6% versus 70%, respectively). Even with these differences, the authors recommended improvements to hospice care in terms of symptom management, care coordination, and physician communication regarding decision-making.

According to the Centers for Disease Control and Prevention (2017), most Americans prefer to die at home. Even though they have a preference for dying at home, only one third of American adults have advance directives, and only 50% of adults 60 years and older have an advance directive. On the other hand, 88% of hospice patients had advance directives (Jones, 2011). Still, fewer than 50% of severely or terminally ill patients had advance directives, and 65% to 76% of physicians reported that they were unaware that their patients with advance directives had those documents (Kass-Bartelmes & Hughes, 2003).

Advance directives and adequate professional care are equally important in providing high quality end-of-life care. In 2001, a study was conducted that focused on caregiver burden and decision making at the end of life. The researchers indicated that caregiver burden from withdrawing life-sustaining treatment for terminally-ill loved ones without advance directives was the highest following the resident’s death, and it even remained high for a year and a half after the death (Tilden et al., 2001). Another study found that family members were unprepared to make end-of-life decisions due to a lack of informational and emotional support (Forbes et al., 2000). However, another study by Tilden et al. (2004) concluded that despite high rates of advance directives and hospice enrollment, perceived symptom distress was still high for residents, and caregiver strain was common.

In a separate study at a dementia care facility, caregivers perceived that routine “pre-death work” by the hospice team positively influenced their mourning and well-being after the resident’s death (Murphy et al., 1997). The authors emphasized that grief services are not common in nursing homes for family caregivers or for staff. Grief service interventions that were utilized at the nursing home have been helpful to caregivers during the resident’s end-of-life process.

According to the Health Care Financing Administration (HCFA), recommendations for Medicare hospice bereavement (Murphy et al., 1997), otherwise known as grief services, should include services from the nursing home staff. Examples of the services include the following: (a) sending sympathy cards to family members, (b) providing materials on the grieving process before and after death, (c) sending invitations to family caregivers for local bereavement support groups, (d) providing referral to outside counseling, if appropriate, (e) visiting the family at the funeral or visitation at least 50% of the time, and (f) visiting, making phone calls, or sending letters that include bereavement newsletters within the first thirteen months of death.

The Resources for Alzheimer’s Caregiver Health (REACH II) reported a study that implemented personalized caregiver education and resulted in improved distress and burden, as well as decreased hours of caregiver time involved that led to positive resident outcomes, such as fewer dementia-related behaviors (Burns et al., 2011). This demonstrates that increasing caregiver self-awareness in terms of problem-solving strategies, behaviors, and communication related to caregiving can be beneficial.

Another study examined the caregiver decision-making process in the later stages of dementia, focusing on the emotional effect, values, and goals surrounding treatments. It was concluded that the caregivers were not prepared to make important end-of-life decisions about treatment, and they lacked the informational and emotional support of a consistent provider to help them make decisions (Forbes et al., 2000). The authors also indicated that there is missing structural and educational support from the health care team; this professional care is crucial during the end-of-life process for residents and their family caregivers.

In summary, studies that examined caregiver distress and burden concluded that less time involved with caring for the residents reduced caregiver distress and burden. In one study (Burns et al, 2011), this improvement even led to better resident outcomes. Caregiver burden increased with resident distress due to unmet needs (e.g. dyspnea and pain), unmet emotional needs of family members, lack of advance directives, professional care, and informational resources, lower and even higher standards of palliative and hospice care, and lack of grief observation after the resident’s death.

METHODS

*Design*

A descriptive, secondary analysis was conducted using de-identified data funded by the National Institute of Nursing Research (NINR) study, “Impact of Quality End-of-Life Care in Nursing Homes” (Thompson, Gajewski, Bott, & Tilden, 2012). The primary study analyzed the quality of care, life, and death in nursing homes. Using a sub-sample of data, we examined the relationship between the following variables: family caregiver burden (distress and strain), family caregiver time involved with residents at the end of life, satisfaction with nursing home care, and hospice care within the past 14 days.

*Sample and Setting*

A sample of 100 Midwestern nursing homes with more than 60 beds were randomly selected from 180 facilities that met the criteria for enrollment in the primary study. Eighty-five facilities agreed to participate. The sample included family caregivers (*N*=1,282) of residents at the end of life who participated in the primary study. Family and resident characteristics are presented in Table 1 (see Appendix A).

Most of the family caregivers were female (70.9%), white (98.9%), Protestant (74.2%), and at or under the age of 64 years (56.5%). Over half (61.8%) of the caregivers reported being the main caregiver and very involved. Over half (64.8%) of the caregivers were children of the residents; almost half (44.1%) of the caregivers were a daughter or stepdaughter, and about one-fifth (20.7%) of the caregivers were a son or stepson. A little over than half (54.8%) of the caregivers were employed outside of the home, and 39% of the caregivers reported that they worked full time (between 40 and 80 hours per week).

Most of the residents were also female (67.7%), white (98.6%), and Protestant (74.5); however, they were at or above the age of 85 years (64.2%). Most of the residents died in the nursing home (87.2%), with a little over one-tenth (12.4%) of the residents dying in the hospital.

*Procedures*

The initial sampling strategy randomly selected 100 eligible nursing homes in Midwestern states. Once administrators of the nursing home were informed about the study, nursing administrators provided consent for nursing home participation. Investigators of the primary study contacted family members following the death of the resident and asked them to complete the study questionnaires. Data were de-identified for use by the researcher for this study, and determination of non-human subjects research was made by a Midwestern academic medical center institutional review board (IRB).

*Measures*

*Caregiver burden.*Caregiver burden (distress and strain) was measured using the Caregiver Strain Index (CSI). The CSI was originally developed to measure *caregiver strain* (Robinson, 1983) and measures both subjective (e.g., emotionally draining, feeling overwhelmed) and objective (e.g., financial strain, sleep disturbance, demands on time) elements of caregiver strain. This is a 13-item dichotomous scale (yes = 1, no = 0) with established reliability (Cronbach’s alpha = .86) and construct validity (Robinson, 1983). *Caregiver distress* was added based on Tilden and colleagues’ (2004) work with the symptom distress scale. It is a 13-item scale with 5-point response options (not at all = 0 to a great deal = 4) that measures the level of distress for each element in the caregiver strain scale. For both scales items are summed (caregiver strain *range* = 0-13, *midpoint* = 7.5; caregiver distress *range* = 0-52, *midpoint* = 26). A higher score indicated higher strain and distress (see Table 2 in Appendix B).

*Time involved in caregiving.**Time involved in caregiving* was measured by one item that asked the resident’s family caregiver, “How many hours per week were you involved in caregiving for the resident?” The scale ranged from 0 to 168 (*midpoint* = 84) (see Table 2 in Appendix B).

*Satisfaction with nursing home care.*The variable *satisfaction with nursing home care* was measured using a 6-item scale with established reliability (Cronbach’s alpha = .94). Each item had a 10-point response option (worst care possible = 0 to best care possible =10). The items measured the family caregiver satisfaction with the care the resident received from the staff. This included physical comfort (e.g., pain, shortness of breath) and emotional support (e.g. emotional distress) (Teno et al., 2004). Other items included: involvement of shared decision making, respect, attending to family caregiver needs for information, emotional support, and coordinated care (Teno et al., 2004). Items are summed (*range* = 0-60, *midpoint* = 30) where a higher score represented higher satisfaction (see Table 2 in Appendix B).

*Hospice care.*Hospice care was measured by one dichotomous item that asked, “Was the resident receiving hospice in the past 14 days?” This information was extracted from the Minimum Data Set (MDS) 2.0 data provided by the nursing home. Response options with a yes (1) or no (0) format (see Table 2 in Appendix B).For this study, hospice care referred to residents who had documented hospice care in the past 14 days by the nursing home staff.

*Demographics.*Demographic information about the family members included: (a) relationship to the resident, (b) age, (c) gender, (d) ethnic background, (e) religious preference, (f) relationship to resident, and (g) hours worked. Information about the resident included: (a) age, (b) gender, (c) ethnic background, and (d) religious preference.

*Data analysis*

Using SPSS 23.0, descriptive statistics including mean, median, standard deviation, and ranges were calculated. The first four research questions — (a) time involved in caregiving, (b) amount of caregiver burden (strain and distress), (c) amount of satisfaction with nursing home care, and (d) how many nursing home residents received hospice care in the past 14 days — were evaluated using descriptive statistics. For the fifth research question examining the relationship between time involved in caregiving with caregiver burden (strain and distress) and satisfaction with nursing home care, a Pearson (*r*) correlation was reported. *T-tests* were conducted for the sixth research question examining the differences between residents receiving hospice care in the past 14 days and residents not receiving hospice care.

RESULTS

*Time Involved in Caregiving, Caregiver Burden, Satisfaction with Nursing Home Care, and Hospice Care*

For the first research question, caregivers reported an average of 9.1 hours (*range* = 0-120) that they spent with the resident in a typical week (see Table 3 in Appendix C). For the second research question, the mean (5.5) for caregiver’s strain was below the midpoint of 6.5, and the mean (11.6) for caregiver distress was well below the midpoint of 25. For the third research question, caregivers reported high satisfaction with nursing home care (*M* = 52, *range* = 0-60). For the fourth research question, 33.8% of the caregivers reported that residents were using hospice services at the end of life within the past 14 days. Table 4 (see Appendix D) depicts the correlations among satisfaction with nursing home care, caregiver strain, and caregiver distress with time involved in caregiving (Research Question 5). There was a small negative correlation (*r* = -.07) between satisfaction with nursing home care and the time involved in caregiving with the residents. Positive correlations were found between caregiver strain and caregiver distress and time involved in caregiving (*r* = .17 and *r* = 18, respectively).

*Differences between Hospice Care and Non-Hospice Care*

To answer the sixth research questions, a *t-test* was conducted to determine if there were significant differences between hospice care in the past 14 days and non-hospice care for the following variables: satisfaction with nursing home care, caregiver strain, caregiver distress, and time involved in caregiving (see Table 5 in Appendix E). Family caregivers reported a significant (t(1,233) = 2.6, *p* < .001) mean difference (12.53 versus 11.07) for hospice care and non-hospice care, respectively. They also reported significant (t(894) = -2.71, *p* < .01) mean differences (5.83 versus 5.31) on the caregiver strain scales for hospice and non-hospice care, respectively. There were no significant differences (*p* = .152) reported by caregivers for satisfaction with nursing home care for hospice and non-hospice care. Significant differences (*t*(1,231) = -2.19, *p* < .05) were reported for time involved in caregiving for residents receiving hospice care in the past 14 days and those residents who did not receive hospice care (*M* = 10.03 and *M* = 8.83, respectively).

DISCUSSION

According to the results of the secondary analysis, family caregivers of residents at the end of life in the Midwestern nursing homes reported spending an average of a little over an hour per day caring for their resident. They also were highly satisfied (*M* = 52) with nursing home care at the end of life, and they reported lower levels of caregiver strain (*M* = 5.5) and distress (*M* = 11.6). As time spent caring for the resident increased (*M* = 9.1 hours per week), caregiver burden (strain and distress) slightly increased and satisfaction with nursing home care had almost a negligible decrease. Therefore, spending more time caring for a loved one in the nursing home at the end of life did not seem to have a strong relationship with their satisfaction with nursing home care. This may indicate that increased family involvement and needs at the end of life are part of the process, and the amount of time they spend involved in caregiving does not indicate how satisfied they are with the professional care provided to the residents.

Although the caregivers in this sample reported some degree of strain and distress, we found that they did not report higher levels of strain and distress as we had anticipated. While caregiver strain and distress had small positive correlations with time involved in caregiving, there may be other contributing factors that affected perceived burden and how caregivers view the time they spent with residents at the end of life. The small correlations, particularly with strain and distress with time involved, also could indicate that the Midwestern nursing homes are addressing the majority of the family caregivers’ needs for the residents.

Approximately 33.8% of the residents used hospice services in the past 14 days in this study. On average, family caregivers of residents in hospice reported higher caregiver distress and strain, slightly higher satisfaction with nursing home care, and more the time involved in caregiving. It was anticipated that they would report higher satisfaction with nursing home care; however, reporting lower levels of strain and distress was unexpected.

According to a study by Zheng et al. (2012), nursing homes face challenges such as staffing shortages, high turnover, and inadequate staff training in end-of-life and palliative care, along with limited financial resources. Zheng et al. (2012) also reported lower hospice use in the nursing home (18%) with an average length of stay of 3 months (93 days); the observation of low hospice enrollment was supported by these study findings. Residents with unstable prognoses (e.g. dementia, COPD, and/or heart failure) and potentially longer stays also may affect provider willingness to enroll residents earlier in hospice.

Five years ago, less than 20% of nursing homes provided special training for staff in palliative/end-of-life care (Zheng et al., 2012). Therefore, it is important to advocate for modifying and updating end-of-life care guidelines continually to stay current with the aging and diverse population. Tilden et al. (2004) reported over 60% of Oregon nursing home residents were enrolled in hospice at the time of their death (over twice the enrollments in this study). Therefore, Oregon nursing homes may be able to provide resources to create end-of-life care recommendations and guidelines for other nursing homes and hospice programs.

In a study by Wetle et al. (2005), families found that hospice services enhanced end-of-life care. However, they also reported that there were late referrals to hospice services and misunderstandings about the scope of hospice services that would be available to the resident. Zheng et al. (2012) also reported nursing homes in the U.S. tended to enroll residents in hospice closer to death. Compared to other countries, such as Belgium where end-of-life care is commonly accepted, discussed and decided upon, Americans fear death. Therefore, end-of-life conversations frequently were not initiated earlier within families, especially families where caregivers were younger. Misconceptions and lack of discussions and education could delay hospice enrollment and/or increase family caregiver burden. Increased burden also may be due to limited financial resources for nursing home care, or even due to the stress of witnessing a loved one experience the dying process.

It is estimated that 44.6% of deaths in the U.S. are under the care of a hospice program (National Hospice and Palliative Care Organization [NHPCO], 2012). According to the NHPCO (2012), the median length of hospice service in 2012 was 17.4 days. Approximately 35.5% of patients died within seven days of referral to hospice, and half (50.3%) of patients spend two weeks or less in hospice care. Therefore, many patients or residents are not in hospice long enough to take advantage of the benefits it offers. However, as financial coverage is expanding for hospice care for our aging population, it is imperative that referrals are made in a timely manner.

FUTURE RESEARCH

Future researchers could analyze and compare the time family caregivers spend in the nursing home and the impact of other factors on the variables studied, such as the use of advance directives, palliative care, the number of hospitalizations, the use of feeding tubes, and the length of time a resident received hospice care before death. In this study, only 33.8% of nursing home residents used hospice services in the past 14 days. End-of-life care interventions, such as staff education for hospice referral, communication, and caregiver support similar to the personalized caregiver education studied by the Resources for Alzheimer’s Caregiver Health, or REACH II (Burns et al., 2011) could be implemented and tested in nursing homes. Education and program improvements potentially could lead to earlier hospice enrollments and decreased caregiver burden. A similar study could be replicated in diverse populations across the U.S.

Family caregivers will increase along with the aging population. Since 40% of deaths will occur in the nursing home by 2020, future research could study risk factors for increased family caregiver burden during the end of a resident’s life in the nursing home; this could guide the development of therapeutic interventions for both elderly residents and their families. Interventions that improve family caregiver outcomes also could serve as a primary intervention for depression and psychological problems related to caregiver burden. Breaking misconceptions and educating the population about end-of-life and palliative care options, as well as more timely hospice referrals, could potentially reduce the burden experienced by family caregivers.

STUDY LIMITATIONS

Secondary data are limited to the data collected from the primary study, and may not include all relevant variables or relevant information needed for the study. For example, the only variable available from the primary data set on hospice care was the use of hospice in the last 14 days. The date of the reported data from the MDS 2.0 was not included in the data set. Therefore, it is not known if the hospice care was reported specifically during the last 14 days of the resident’s life; it also could mean that hospice use was under-reported for this study.

Other variables that could affect caregiver burden that were not included in the data include terminal diagnoses of nursing home residents, use of advance directives, the length and severity of the illness, and how long the residents utilized the benefits of hospice care. Outside variables that cause burden could contaminate the results, such as conflicting issues in the caregiver’s personal life: taking care of a family or working a full-time job. Another study limitation includes lack of sample diversity residents recruited from Midwestern nursing homes that are primarily Caucasian and rural; this makes generalizability difficult outside of this region.

SUMMARY

Associations among the study variables (caregiver burden, satisfaction with nursing home care, hospice care within the past 14 days, and the length of time family members were involved in caring for residents) can guide the development of interventions to improve end-of-life care. With the growth of the elderly population, time spent in caregiving will continue to increase. It is important to identify ways such as communication, support, or palliative and hospice measures that assist family members in reducing the strain and distress they perceive during the end-of-life experience for residents.

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APPENDIX A

Table 1. *Sample Demographics (*N*=1,282)*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Family Member** | | **Resident** | |
| **Variable** | ***n*** | ***%*** | ***n*** | ***%*** |
| **Age (years)** | | | | |
| ≤ 64  65-74  75-84  ≥ 85 | 724  346  159  53 | 56.5  27.0  12.4  4.1 | 16  79  350  798 | 1.3  6.4  28.2  64.2 |
| **Gender** | | | | |
| Male  Female | 373  909 | 29.1  70.9 | 407  852 | 32.3  67.7 |
| **Race** | | | | |
| Latino/Hispanic  Other/American/Alaskan Indian  African American  White | 5  2  7  1,268 | 0.4  0.2  0.5  98.9 | 6  3  8  1,219 | 0.5  0.2  0.6  98.6 |
| **Religious Preference** | | | | |
| None  Catholic  Jewish  Protestant  Other | 51  257  11  951  11 | 4.0  20.1  0.9  74.2  0.9 | 67  240  9  954  11 | 5.2  18.7  0.7  74.5  0.9 |

APPENDIX B

Table 2. *Scales for Strain, Distress, Satisfaction with Nursing Home Care, Time Involved in Caregiving, and Hospice Care*

| Scale | Source | Items | Responses | Reliability |
| --- | --- | --- | --- | --- |
| The Caregiver Strain Index (CSI) | Robinson, 1983 | 13 | *No=0*  *Yes = 1* | *KR-*21=0.80 |
| Caregiver Distress | Tilden et al., 2004 | 13 | *0=Not at all*  *1=A little bit*  *2=Somewhat*  *3=Quite a bit*  *4=A great deal* | *α*=0.86 |
| Satisfaction with Nursing Home Care | Teno et al., 2004 | 6 | *Range:*  *0 (worst care possible) to*  *10 (best care possible)* | *α*=0.94 |
| Time involved in Caregiving in a typical week | NA | 1 | *Range: 0 to 168 hours* | NA |
| Hospice care  in the past 14 days | MDS 2.0 | 1 | *No=0*  *Yes = 1* | NA |

APPENDIX C

Table 3. *Measured Frequencies from Family Caregivers*

| Variable | *Mean* | *SD* | *Range* | *MidPoint* |
| --- | --- | --- | --- | --- |
| Time Involved in Caregiving | 9.1 | 10.8 | 0-120 | 60 |
| Satisfaction with Nursing Home Care | 52.0 | 10.2 | 0-60 | 30 |
| Caregiver Strain | 5.5 | 3.3 | 0-13 | 6.5 |
| Caregiver Distress | 11.6 | 9.3 | 0-50 | 25 |
| Hospice care  In past 14 days | *n* | *%* |  |  |
| Yes | 418 | 33.8 |  |  |
| No | 817 | 66.2 |  |  |

APPENDIX D

Table 4. *Correlations among Satisfaction with Nursing Home Care, Strain, and Distress with Time Involved in Caregiving*

|  |  |  |
| --- | --- | --- |
| Variable | Time Involved in Caregiving | |
| *r* | *p* |
| Satisfaction with Nursing Home Care | -.07 | <.01 |
| Caregiver Strain | .17 | <.001 |
| Caregiver Distress | .18 | <.001 |

APPENDIX E

Table 5.  *Differences on Study Variables between Hospice Care Versus Non-Hospice Care*

|  | Hospice Care | | Non-Hospice Care | | t-statistics (*df*) |
| --- | --- | --- | --- | --- | --- |
| Variable | *M* | *SD* | *M* | *SD* | *p* |
| Distress | 12.53 | 9.34 | 11.07 | 9.11 | -2.628(1,233)  .009 |
| Strain | 5.83 | 3.12 | 5.31 | 3.36 | -2.71(894)  .007 |
| Satisfaction with Nursing Home Care | 52.61 | 9.36 | 51.77 | 10.52 | -1.43(928)  .152 |
| Time Involved in Caregiving | 10.03 | 11.18 | 8.63 | 10.32 | -2.19(1,231)  0.029 |