

Long-Term Dementia Care: Modeling the Decision Process

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ABSTRACT: *Prior to a crisis situation, family members often state that they will not have a loved one placed in a long-term care facility (nursing home care); however, when the situation arises, what enables some family members to hold true to this statement and others unable to follow through? This paper explores the complex decision-making process that family members may go through while caring for a loved one with dementia. Decisions may fluctuate as the challenges resulting from behavioral changes characteristic of different stages of dementia (specifically Alzheimer's disease) occur. This paper combines system dynamic modeling and agent-based modeling to represent a notional model of older adults with dementia and their associated caregivers. A caregiving stress and coping paradigm and current policy provisions are used to inform the decision-making process family members may experience while making the decision to become caregivers and maintain community-based caregiving responsibilities. Experimentation of different levels of relief showed that certain levels alleviate caregiver stress. Implications of these findings are discussed.*

1. Caregiving for Individuals with Dementia

Alzheimer's disease and other dementias are debilitating, progressive, and costly, affecting individuals, their families, and the long-term care system. Approximately 5.2 million people were diagnosed with Alzheimer's disease in 2014 and projections are that these rates may nearly triple to 13.8 million (Alzheimer's Association, 2014). Informal family caregivers provide the majority of care to frail older adults; this assistance is invaluable and fulfills an important role not only for persons with dementia, but for society as a whole (Robison, Shugrue, Fortinsky, & Gruman, 2014).

Dementia caregiving can be a frustrating and difficult experience depending on the symptoms of the individual with dementia and the environmental supports that are in place to assist the family caregiver. Although families try to keep their loved ones out of institutions as long as possible, the absence of relief for the dementia family caregiver may have deleterious outcomes for both the family caregiver and the

individual with dementia. The family caregiver may experience high levels of stress, depression, and illness (Schulz, Boerner, Shear, Zhang, & Gitlin, 2006), leading to poorer quality of life for both the individual with dementia and family caregiver and possible early nursing home placement (Benjamin, Matthias, Kietzman, & Furman, 2008; Gaugler, Kane, Kane, & Newcomer, 2005; Yaffe et al., 2002).

1.1 Stages of Dementia

As Alzheimer's disease and other dementias progress, behaviors and subsequent caregiving responsibilities change. In the early stage of the disease, an individual may experience mild cognitive difficulties, but is typically able to continue to perform activities of daily living (ADLs) and communicate. Caregiving at this stage is often more supportive, helping the individual cope with memory loss. During the middle stages, damage to the brain may affect a person's behavior, ability to communicate, and ability to perform basic tasks. Common behaviors as the disease progresses may include wandering, repetitive behavior, physical and verbal outbursts, and sleep changes (Alzheimer's

Association, n.d.). Caregiving at this stage involves more hands-on assistance with ADLs, such as dressing, bathing, eating, and grooming. Wandering behavior often creates a safety issue for those living in the community, and preventing wandering becomes a prime caregiving challenge. For those living alone, the individual may need to move in with relatives or to a residential care facility. Caregivers who are not able to supervise their loved ones all day must find a way to keep the individual safe, and may turn to options such as adult day health care or a personal companion. The middle stage of the disease typically lasts the longest and may have several crisis points as the level of independence decreases. During the later stages of the disease, an individual may have difficulty eating or swallowing, may need assistance with walking, may need extensive personal care, and may lose the ability to communicate with words. At this point, the needs of the individual may exceed the caregiver's ability to provide the necessary care at home (Alzheimer's Association, n.d.).

Studies have shown that behavioral issues rather than cognitive abilities are more highly correlated with caregiver burden and depression, especially behaviors such as aggression, agitation, and wandering at night (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Gaugler et al., 2005; Gonyea, O'Connor, Carruth, & Boyle, 2005; Rinaldi et al., 2005). Appropriate interventions are necessary to alleviate caregiver burden and maintain individuals with dementia at the most appropriate level of care (Etters, Goodall, & Harrison, 2008).

1.2 Theoretical Framework: Stress and Coping

This study uses Lazarus and Folkman's (1984) stress and coping paradigm to model the decision-making process for family caregiving of loved ones with dementia across the different stages. The caregiver stress and coping paradigm depicts the adaptational outcomes related to the stressors of caregiving based on the appraisal, coping responses, and social support of the individual caregiver. Stressors experienced by family caregivers of people with Alzheimer's disease and other dementias include the specific stage of the disease (depicting the severity of cognitive impairment), behavioral problems such as wandering and aggressive behavior, and the inability to perform activities of daily living (Haley, Levine, Brown, & Bartolucci, 1987).

The caregiver's appraisal of the level of stress he/she is experiencing, the ability to manage the stress appropriately, and the level of social support that is available may determine a caregiver's decision to move a family member from community-based care to a long-term, institutional caregiving environment such as nursing home placement. In particular, crisis situations may create a sudden increase in stress that is beyond the caregiver's ability to cope. Interventions that assist the caregiver and prevent inappropriate or unwanted nursing home placement may contribute to sustainable solutions that enhance the quality of life for the individual with dementia and the family caregiver.

There are many complexities that come into play as family members consider the need for increased care for frail family members. Ihara, Horio, and Tompkins (2012) conceptually grouped variables into two domains – motivation and capability – in their study of grandchildren opting to provide care for their grandparents. They defined capability as a family member's discretionary time and proximity to the frail older family member and motivation as the desire and sense of obligation to provide care after considering the costs and benefits.

1.3 Policy Options

In our model, possible interventions include increasing options that will support family caregivers. Policy options such as increased respite care availability, tax incentives, work place policies, and adult day health services may support aging-in-place (Chen, 2014). Some of these options are currently available through laws such as the Family Medical Leave Act (P.L. 103-3), provisions under Title III, Part E of the Older Americans Act related to the National Family Caregiver Support Program (P.L. 109-365), and the Lifespan Respite Care Act (P.L. 109-442) (Ihara et al., 2012).

Unfortunately, home- and community-based services are often out of reach for near-poor older adults who may not qualify for publicly funded services. Provisions for long-term care under the 2010 Patient Protection and Affordable Care Act have provided several expansions of home- and community-based services (HCBS) under state Medicaid programs, including the Balancing Incentives Program, the Community First Choice state plan option, and the home health state plan option (O'Shaughnessy, 2013). These and other programs such as the Community Innovations for Aging in Place Program help promote aging in place (Greenfield, 2012), but the growing need

for services may not match the availability or ability of state and local communities to meet all of the demand.

In 2009, the National Alliance for Caregiving reported that more than half of caregivers who responded to a survey asking them to rate six potential policies or programs indicated that a \$3,000 tax credit would be either their first or second choice. To test this policy option, Ihara et al. (2012) used an agent-based model to explore the likelihood that grandchildren would become a primary caregiver for a frail grandparent. They found that a targeted-policy scenario where high-income families do not get a tax credit, middle-income families receive a \$3,000 tax credit, and low-income families receive a higher tax credit had better results for motivating grandchildren to become caregivers than the universal policy of a flat tax credit for all caregivers.

These various policy options potentially underlie the decision-making process of an older adult and his/her family regarding the best living situation including independent living, home-based supportive living, assisted living, or nursing home placement. Further, these options may not necessarily alleviate the burden for all families, pointing to the need to better understand what mix of services and support can enhance the decision for caregivers and care recipients.

2. Simulated Model

To focus on the decision-making involved with this topic, we use a mixed approach. Overall, this is an agent-based model (Gilbert, 2008) with the individual agents built on system dynamics models of their health and stressors. The model is implemented in NetLogo (Wilensky, 1999) and this description of our model is based on the approach described as an ODD (Grimm et al., 2010) and ODD+D (Müller et al., 2013). This paper is not a full description of the model, but focuses on the agents and their behavior.

Our notional model, named Carington, has 100 agents representing older adults and approximately 60 agents for their associated caregivers because approximately 40 of the older adults provide their own care. The caregivers may be family members (spouse, adult daughter, or other kin), professional caregivers, or institutions. Each step of the model represents a year. With each step, the general and mental health of the older adults may decline. If conditions change, the provider of the care may change from self to family, from family to a professional, or from a professional to an institution. Changes in conditions are based on the health of the older adult or the perceived stress of the

caregiver. The older adult or the caregiver may also pass away. New older adults are added in each step to keep the population of older adults at 100 agents. The mix of care providers is driven by the health of the associated older adult.

2.1 Agents Representing Older Adults

Agents in the system representing older adults have variables for their age, general health, mental health, and who provides their care. The agents are initialized randomly, but are assigned behavioral characteristics that replicate the population statistics mean and standard deviation as appropriate for the simulated age of the agent. They are also initialized with different levels of physical and mental challenges consistent with the data. Many are initially their own care providers. Over time, their need for care due to their general health and level of dementia rises.

With each step of the model, their general and mental health conditions are changed probabilistically to match the changes in the population statistics reported by the Federal Interagency Forum on Aging Related Statistics (2012). As shown in Figure 1, general and mental health decline is not linear; the plot is based on 100,000 live births and is for the total population. Data is also available broken down by sex and race. We use the data for the total population in this model.

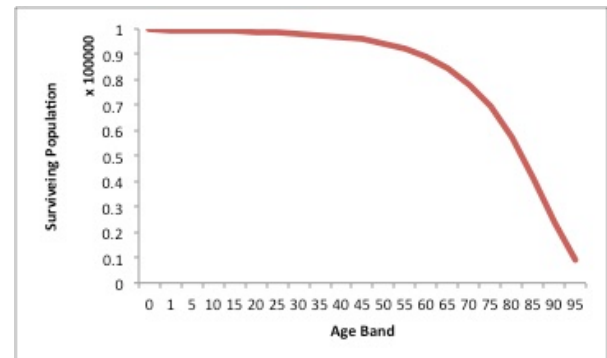


Figure 1. Surviving Americans by Age for 100,000 Live Births

We model the decline in general health and mortality using the data (shape) of the curve in Figure 1. To model the decline in mental health for our agents, we use data provided by the Centers for Disease Control and Prevention (CDC) on exhibiting signs of Alzheimer's disease as the model for the general level of dementia in Carington.

Older agents needing care are paired with a caregiver agent. The status of an older adult needing care provides input to the decision-making concerning the source of the needed care.

2.2 Agents Representing Caregivers

Caregivers are also represented as agents in the system. Caregiver agents have characteristics describing their capabilities and motivation. Their motivation is described by their relationship to the older adult, level of difficulty associated with caregiving, and their own needs.

Caregivers are modeled as having a current level of caregiving capacity and a current caregiving load, which is increased by additional stressors (such as an increase in their frail older adult’s needs) by assistance as a systems dynamics model. At each step, an evaluation of the caregiver’s previous stress level increases due to changes in the status of the associated care receiver, other stressors, and support systems. We modeled a change in needed care as an additional stressor for one step (a modeled year). If the level of stress becomes too high, a decision is made to change the arrangement for the assistance the associated older adult needs. Changes in caregiving arrangements can include various coping mechanisms for the caregiver, including changing who provides the needed care.

3. Experiment and Results

The purpose of the experiment is to demonstrate that providing services and support can reduce the stress of caregivers, potentially helping them to continue to care for their loved ones at home for a longer period of time. To model the effects of this, we presumed that the relief would reduce the stress proportional to the amount of the time relief relative to the total time. The stress is caused by taking care of the older adult for M hours a day every day. We use less than 24 hours per day (18 hours per day) to account for time the older adult is asleep and the time the caregiver is asleep. The adult day care hours would then also be included in hours of relief for the caregiver. Although the caregiver may still be responsible for the older adult, we are looking for effective hours of relief for the care provider. Using N for the effective adult day care hours per week, we believe the stress would be reduced by the fraction $(7 * 18 - N) / (7 * 18)$. We ran our model with and without relief for the care providers. Relief was provided at different levels – 8, 16, 40, 70, 84, and 98 hours per week.

Experimentation with the model allowed us to examine whether the number of hours of relief per week averaged over one model step of a year, had an effect on caregiver stress. Table 1 presents the results of this experiment and shows the difference between the stress levels with and without the relief. As expected, there was no change in caregiver stress when zero hours of relief were provided. An increase of eight hours per week was also not statistically significant. However, increasing relief to 16 hours per week showed statistically significant differences in the average level of caregiver stress, with continued statistically significant results for higher levels of relief. While the average stress of the family caregivers declines significantly, the average number of caregivers is not consistently significant or insignificant. With our maintenance of 100 older adults needing care throughout the runs, their caregivers seem to also have been maintained.

Table 1. Model Runs and Statistical Significance

Relief (hours/week)	Average No. Family Caregivers (SD)	Average Caregiver Stress level (SD)
0	34.2(5.15)	1.508(0.272)
8	33.5(4.80)**	1.478(0.267)
16	33.8(4.84)	1.452(0.262)**
40	33.7(5.00)	1.404(0.235)**
70	33.6(5.06)	1.268(0.183)**
84	33.9(4.91)	1.164(0.201)**
98	33.7(4.92)*	0.988(0.178)**

* indicates statistical significance (p<0.05)

** indicates statistical significance (p<0.01)

4. Discussion and Implications

Given the results of our experimentation, there are various ways that existing services could be applied to 16 hours of relief per week, including home health aides, adult day centers, and assisted living. The most feasible of these for a family caregiver would be adult day centers, which are a cost-effective way to provide specialized health and social support services for the individual with dementia and a form of respite for the caregiver. Typically, costs for adult day centers average \$72 per day. Compared to the cost of a non-medical home health aide (\$168 for an 8-hour day), \$43,756 per year cost of assisted living or \$83,230 to \$92,977 per year for nursing home care (Alzheimer’s Association, 2014), adult day centers are a feasible

alternative for enhancing the quality of life for both care recipients and caregivers.

Beyond the cost savings for the long-term care system and the family, studies have shown that use of adult day centers have beneficial effects for individuals with dementia and their caregivers on the days the individual attended the adult day center. These benefits include fewer behavior problems, better sleep, and decreased caregiver stress, cortisol levels, and depression (Gaugler et al., 2003; Klein et al., 2014; Zarit et al., 2011; Zarit, Kim, Femia, Almeida, & Klein, 2014; Zarit, Stephens, Townsend, Greene, & Femia, 2003).

Further, a study of specialized dementia adult day services shows moderately successful results (Logsdon, Pike, Korte, & Goehring, 2014) and provides some evidence for further testing of the effectiveness of such programs to address the needs of a growing population of individuals and families affected by Alzheimer's disease and other dementias. As policymakers and service providers continue to tackle the complex issue of dementia caregiving, specialized adult day services may be a feasible alternative that is currently out of reach for many families.

Given the nature and complexity of dementia caregiving, our future work will build on this model to incorporate other aspects of the decision-making process. We plan to include support networks in our Carington model and interactions among caregivers and among older adults. We also plan to experiment with different combinations of policy options and relief (in the form of services and support) that may contribute to a decrease in the family caregiver's stress level.

5. References

- Alzheimer's Association. (2014). 2014 Alzheimer's disease facts and figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 10(2), e47–e92. doi:10.1016/j.jalz.2014.02.001
- Alzheimer's Association. (n.d.). Seven stages of Alzheimer's & symptoms. Retrieved January 26, 2015, from http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp
- Benjamin, A. E., Matthias, R. E., Kietzman, K., & Furman, W. (2008). Retention of paid related caregivers: Who stays and who leaves home care careers? *Gerontologist*, 48, 104–113. doi:10.1093/geront/48.Supplement_1.104
- Chen, M.-L. (2014). The growing costs and burden of family caregiving of older adults: A review of paid sick leave and family leave policies. *The Gerontologist*, gnu093. doi:10.1093/geront/gnu093
- Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20(8), 423–428. doi:10.1111/j.1745-7599.2008.00342.x
- Federal Interagency Forum on Aging-Related Statistics. (2012). *Older Americans 2012: Key indicators of well-being*. Washington, DC: U.S. Government Printing Office. Retrieved from <http://www.agingstats.gov>
- Gallicchio, L., Siddiqi, N., Langenberg, P., & Baumgarten, M. (2002). Gender differences in burden and depression among informal caregivers of demented elders in the community. *International Journal of Geriatric Psychiatry*, 17(2), 154–163.
- Gaugler, J. E., Jarrott, S. E., Zarit, S. H., Stephens, M.-A. P., Townsend, A., & Greene, R. (2003). Adult day service use and reductions in caregiving hours: Effects on stress and psychological well-being for dementia caregivers. *International Journal of Geriatric Psychiatry*, 18(1), 55–62. doi:10.1002/gps.772
- Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005). Unmet care needs and key outcomes in dementia. *Journal of the American Geriatrics Society*, 53(12), 2098–2105. doi:10.1111/j.1532-5415.2005.00495.x
- Gilbert, N. (2008). *Agent-based models*. Thousand Oaks, CA: Sage Publications.
- Gonyea, J. G., O'Connor, M., Carruth, A., & Boyle, P. A. (2005). Subjective appraisal of Alzheimer's disease caregiving: The role of self-efficacy and depressive symptoms in the experience of burden. *American Journal of Alzheimer's Disease and Other Dementias*, 20(5), 273–280. doi:10.1177/153331750502000505
- Greenfield, E. A. (2012). Using ecological frameworks to advance a field of research, practice, and policy on aging-in-place initiatives. *The Gerontologist*, 52(1), 1–12. doi:10.1093/geront/gnr108
- Grimm, V., Berger, U., DeAngelis, D. L., Polhill, J. G., Giske, J., & Railsback, S. F. (2010). The ODD protocol: A review and first update. *Ecological Modelling*, 221(23), 2760–2768.

- Haley, W. E., Levine, E. G., Brown, S. L., & Bartolucci, A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging, 2*(4), 323–330.
- Ihara, E. S., Horio, B. M., & Tompkins, C. J. (2012). Grandchildren caring for grandparents: Modeling the complexity of family caregiving. *Journal of Social Service Research, 38*(5), 619–636. doi:10.1080/01488376.2012.711684
- Klein, L. C., Kim, K., Almeida, D. M., Femia, E. E., Rovine, M. J., & Zarit, S. H. (2014). Anticipating an easier day: Effects of adult day services on daily cortisol and stress. *The Gerontologist, 54*(4), 600–606. doi:10.1093/geront/gnu060
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Publishing Company.
- Logsdon, R. G., Pike, K. C., Korte, L., & Goehring, C. (2014). Memory care and wellness services: Efficacy of specialized dementia care in adult day services. *The Gerontologist, 54*(4), 607–613. doi:10.1093/geront/gnu012
- Müller, B., Bohn, F., Dreßler, G., Groeneveld, J., Klassert, C., Martin, R., ... Schwarz, N. (2013). Describing human decisions in agent-based models – ODD + D, an extension of the ODD protocol. *Environmental Modelling & Software, 48*, 37–48. doi:10.1016/j.envsoft.2013.06.003
- O’Shaughnessy, C. V. (2013). *Medicaid home- and community-based services programs enacted by the ACA: Expanding opportunities one step at a time* (Background Paper No. 86). National Health Policy Forum. Retrieved from http://www.nhpf.org/library/background-papers/BP86_ACAMedicaidHCBS_11-19-13.pdf
- Rinaldi, P., Spazzafumo, L., Mastroforti, R., Mattioli, P., Marvardi, M., Polidori, M. C., ... Study Group on Brain Aging of the Italian Society of Gerontology and Geriatrics. (2005). Predictors of high level of burden and distress in caregivers of demented patients: Results of an Italian multicenter study. *International Journal of Geriatric Psychiatry, 20*(2), 168–174. doi:10.1002/gps.1267
- Robison, J., Shugrue, N., Fortinsky, R. H., & Gruman, C. (2014). Long-term supports and services planning for the future: implications from a statewide survey of Baby Boomers and older adults. *The Gerontologist, 54*(2), 297–313. doi:10.1093/geront/gnt094
- Schulz, R., Boerner, K., Shear, K., Zhang, S., & Gitlin, L. N. (2006). Predictors of complicated grief among dementia caregivers: a prospective study of bereavement. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry, 14*(8), 650–658. doi:10.1097/01.JGP.0000203178.44894.db
- Wilensky, U. (1999). *NetLogo*. Center for Connected Learning and Computer-Based Modeling, Northwestern University: Evanston, IL. Retrieved from <http://ccl.northwestern.edu/netlogo/>
- Yaffe, K., Fox, P., Newcomer, R., Sands, L., Lindquist, K., Dane, K., & Covinsky, K. E. (2002). Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA, 287*(16), 2090–2097.
- Zarit, S. H., Kim, K., Femia, E. E., Almeida, D. M., & Klein, L. C. (2014). The effects of adult day services on family caregivers’ daily stress, affect, and health: outcomes from the Daily Stress and Health (DaSH) Study. *The Gerontologist, 54*(4), 570–579. doi:10.1093/geront/gnt045
- Zarit, S. H., Kim, K., Femia, E. E., Almeida, D. M., Savla, J., & Molenaar, P. C. M. (2011). Effects of adult day care on daily stress of caregivers: A within-person approach. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 66B*(5), 538–546. doi:10.1093/geronb/gbr030
- Zarit, S. H., Stephens, M. A. P., Townsend, A., Greene, R., & Femia, E. E. (2003). Give day care a chance to be effective: A commentary. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 58*(3), P195–P196. doi:10.1093/geronb/58.3.P195

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