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Computational Modeling of Caregiver Stress

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Abstract

Caregivers providing support to family members with Alzheimer's disease often encounter high levels of stress within the fragmented long-term care system. To address this emerging issue affecting millions of families, we applied agent-based computational modeling methods to better understand the impacts of policy alternatives. Potential options include increased respite care, tax incentives, work place policies, and adult day services as alternatives to reduce caregiver stress. Experiments with our model demonstrate that policy options providing programs, services, and support for caregivers can reduce their stress by providing a minimum of 16 hours per week of respite care.

Keywords: Agent-based modeling, caregiving, complex adaptive systems, respite, older adults, social policy

Computational Modeling of Caregiver Stress

Caregiver stress is an ongoing and multidimensional issue that will continue to affect millions of families. A likely contributor to caregiver stress is the fragmented long-term care system that has developed over many years to address specific problems without an overarching directed effort to create a seamless wraparound approach. Policymakers cannot agree on the best policy solutions, particularly to fund long-term care services. Although there are no easy answers, agent-based modeling provides a computational method to forecast individual and group interactions occurring within dynamic systems, and therefore is an ideal method for testing various policy solutions for a complex issue. The increased computational power available to even the casual user over the past decade facilitates using this bottom-up approach for creating simulated environments in which experiments may be conducted. Agent-based modeling provides an approach for investigating complex phenomena by computationally simulating the interactions of autonomous agents in order to assess their effect on whole systems. Agent-based models (ABMs) create a “social reality” generated from several variables or inputs. ABMs are created to model an environment in which interactions, characteristics, and behaviors of individual agents are identified; this leads computational simulations to forecast the emergent behavior for the entire group.

Review of Literature

Social work researchers have begun to embrace agent-based modeling. In recent decades, complexity theory, as implemented in complex adaptive systems, has become an accepted natural science paradigm. Its assumptions, however, have posed significant challenges to its implementation in the social work literature. Until the past few years, the application relied on its metaphorical use (Bolland & Atherton, 1999; Halimi, 2003; Hudson, 2000; Hudson, 2004;

Trevillon, 2000; Warren, Franklin & Streeter, 1998; Woehle, 2007). Although identified as a promising approach more than three decades ago (Wooldridge, 1981), social science researchers and evaluators have begun to apply this approach to the third pillar of science (after data and theory). Models are created to simulate an environment or reality, and then experiments are run within these environments in order to forecast specific phenomena (Epstein, 1999; Wolf-Branigin, 2012). Unlike the more widely used systems dynamics modeling (Sterman, 2000) which focus on macro-level system behavior, agent-based modeling starts at the opposite end and models interacting individuals as agents to understand the emergent group behavior. Modeling allows us to visualize the larger patterns resulting from the individual-agent-level interactions and allows for information concerning individual decisions and preferences to be entered into model building (Wolf-Branigin, 2013).

Agent-based Modeling in Social Work

Use of agent-based modeling in social service-related research though limited has begun to be published (Israel & Wolf-Branigin, 2011). Examples vary and address topics including public health and epidemiology (Auchincloss & Diez Roux, 2008; Gorman, Mezic, Mezic, & Gruenewald, 2006), racial segregation (Chen, Irwin, Jayaprakash, & Warren, 2005; Schelling, 1978), and behavioral and ecological interactions (Epstein & Axtell, 1996). More recently, agent-based modeling has begun to appear in the social work literature as demonstrated by its use to investigate social and cultural capital (Woehle, Jones, Baker, & Piper, 2009), home care services (Isern et al., 2009), and caregiving and older adults (Ihara, Horio, & Tompkins, 2012).

Agent-based modeling has a potential role in detailed policy analysis in the era of big data (Couldry & Powell, 2014; Pentland, 2014) because of the increased availability of

individual level data. Problems still exist, however, in matching current modeling schemes and social realities (Miller, 2014). In an effort to increase a realism perspective to the development and use of this modeling approach in the social policy arena, this methodological article seeks to explain how to design and document the process of agent-based model building using our model of caregiver stress as an example.

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 by 2050 (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 also 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 many caregivers try to keep their family members 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).

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 unable to provide supervision 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 care aide. 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 verbally. 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.).

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 can alleviate

caregiver burden and maintain individuals with dementia at the most appropriate level of care (Etters, Goodall, & Harrison, 2008).

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 individuals 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 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 can 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 factors coming 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. For the current study, a model was developed to explore public policy options to support family caregivers providing long-term, family-based, in-home caregiving.

Policy Options

For 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 public laws such as (1) the Family Medical Leave Act (P.L. 103-3), provisions under Title III, (2) Part E of the Older Americans Act related to the National Family Caregiver Support Program (P.L. 109-365), and (3) 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 (P.L. 111-148) 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 (National Alliance for Caregiving, 2009). To test this policy option, Ihara, Horio and Tompkins (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 are the foundation for 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.

Unlike mathematical models of a society, which represent all or large portions of a society as single unit, agent-based models represent the individuals and emerge their collective behavior. This leads to the research question of how to forecast caregiver stress for those providing support to individuals with dementia. We took an agent-based modeling approach and explain the details on how the model was built, run, and analyzed.

Methods

Agent-Based Modeling

Agent-based modeling is a computer-based simulation methodology that can support testing of policy options. The idea is to formalize processes in a computer program, which can then be run with different policies implemented and the simulation can report the effects. Such a

simulation includes models, i.e., computational representations, of the conditions and processes people live in (their environment), the people themselves (called agents), and how they interact. This is not simply having the computer calculate the overall effects through mathematical formulae for the behavior of the overall system for different initial conditions. The key idea in agent-based modeling is that the modeling is at the level of individual agents who sense the environment and respond reasonably. Agent-based models (ABMs) can represent the diversity in a human society and then produce individual and appropriately varied behavior in their responses to changes in the environment.

While modeling cannot provide an exact fit to reality, Epstein (2008) discussed 16 reasons, or benefits, for modeling. For the purposes of this paper, the salient reasons for addressing this topic by modeling include:

- (1) the tendency of humans to create implicit models in our minds with ABMs being explicit and calibrated to actual data;
- (2) modeling assumptions are laid out in detail so that changes can be observed when the assumptions are altered;
- (3) sensitivity analysis can be conducted;
- (4) models can lead to new questions; and
- (5) modeling enforces a “scientific habit of mind.”

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 simple 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 “ODD”, for overview, design concepts, and details (Grimm et al., 2010) and extended it to

ODD+D (Müller et al., 2013), which added a “D” for agent decision-making. This paper is not a full description of the model, but focuses on the agents and their behavior and uses an ego-centric approach that models the dyads of older adults and their caregivers. The model and its associated ODD+D are available on the website Open ABM (<https://www.openabm.org/model/4776/>).

Our notional model has 100 agents representing older adults and approximately 60 agents as their associated caregivers because approximately 40 of the older adults provide their own care. This magnitude of these values was chosen to be an appropriate scale for representational validity and to avoid the appearance to precision that is not inherent in the model’s details. The caregivers may be family members (spouse, adult daughter, or other kin), professional caregivers, or institutions. We could have had many more types of caregivers, but it would be inappropriate given the other modeling assumptions. Each step of the model represents events and changes that occur over a year. A year was chosen to be consistent with the level of precision for the overall model. Other models could use a time step of a season, month, week, or day, but they would need more reliable models of events on their selected scale. 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. The older adult might also pass away during the modeled year. New older adults are added in each step to keep the population of older adults at a steady count of 100 agents. The mix of care providers is driven by the health of the associated older adult.

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

given characteristics that replicate the population statistics mean and standard deviation as appropriate for the simulated age of the agent (Fowler and Fisher, 2009). They are also initialized with different levels of physical and mental challenges consistent with the data (Federal Interagency Forum on Aging Related Statistics, 2012). Many are initially their own care providers. Over time, their need for care due to their general health and level of dementia increases.

With each step of the model, representing a year, the older adult's 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). Figure 1 shows the likelihood of surviving into the next age band. Obviously, our health does not decline linearly, and how our general and mental health decline is a subject of much research. The plot is based on the data for 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.

The decline in general health and mortality is represented in our model using the shape of the curve in Figure 1 rather than a linear assumption. To model the decline in mental health for our agents, i.e., the probability of transition from one stage to the next, 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. 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.

Agents Representing Caregivers

Caregivers are also represented as agents in the system because the focus of this model is the stress on caregivers. Caregiver agents have characteristics describing their capabilities and

motivation. Their motivation is keyed to 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 the needs of their frail older adult) by assistance using 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 may be reduced by 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 (i.e., above the caregiver's capacity), 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.

A Summary of Modeling Presumptions

Every tool used to evaluate policy options presumes its appropriateness to the task. A hammer is appropriate for driving nails and, although it can drive screws, there is a better tool for that purpose. We begin with the presumption of appropriateness of our tool and then explicitly describe the key modeling bases:

1. Our model's level of analysis, 100 older adults and their caregivers with a time step of a year, is appropriate to explore the impact of adult daycare on caregiver stress.
2. The health of older adults can be reasonably represented by the number of activities of daily life (ADLs) they cannot perform and four levels of dementia.
3. The decline in the physical health of older adults is similar to data on the survivability of Americans by age.

4. The stress felt by a caregiver is directly related to the number of ADLs their older adult cannot perform plus their level of dementia and is proportional to the average number of hours per week the caregiver is caring for the older adult.
5. A simulation exploring different caregiving conditions using an agent-based model can provide insights into the policy options for addressing caregiver stress.

There are, of course, additional presumptions or approximations used in the model and they are discussed in the ODD+D.

Model Operation

The model begins with an initialization of the starting population of older adults and caregivers. Then, for each step, every agent becomes a year older and several other changes could occur. The physical and mental health of each older adult may degrade. The stress of each caregiving agent is reevaluated and arrangements for the associated older adult could change. Each agent may also die. New older adults and caregivers are added to the simulation to bring the number of older adults to 100. Each caregiver agent may become older adults in need of care themselves. Finally, data is collected on all agents. These actions repeat with each new step throughout the duration of the experiment.

Experiment and Results

The experiment demonstrates that in our model, providing services and support for the caregiver can reduce the stress of caregivers, potentially helping them to continue to care for their family members 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. Taking care of the older adult for M hours a day every day causes the stress. 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 modeled our expectation that 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. Again, our model's step represents a whole year to smooth out the week-to-week variations in caregiver stress.

Experimentation with the model allowed us to examine whether the number of hours of relief per week 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. Each run was for 100 simulated years without any adult day-care (establishing the baseline) followed by 100 years with the specified weekly hours of adult daycare. The baseline caregiver stress was established when zero hours of relief were provided. An increase of eight hours per week did not reduce the caregiver stress a statistically significant amount in 30 runs of the model. Increasing relief to 16 hours per week, however, showed statistically significant differences in the average level of caregiver stress compared to the baseline caregiver stress in 30 runs of the model, with continued statistically significant reductions for higher levels of relief. What is important about the statistical tests is that there is a real reduction in the caregiver stress for some level of relief. The specific number of hours where this first occurs is a result of the modeling assumptions and should not be taken as justification for a specific number of hours of relief per week sufficient for caregivers to continue providing care in the long term.

Discussion and Implications

Adult day centers provide a cost-effective 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, \$26,280 per year. Compared to the cost of a non-medical home health aide (\$168 for an 8-hour day, \$61,320 per year), \$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, lower cortisol levels (indicating stress), and less 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).

To address this problem, we recommend using agent-based modeling. The process of building a computational model requires quantifying the issues involved and combining theory, engineering approximations, and expert or at least the modeler's opinions on how the world works and these should always be considered. The key presumptions of our model are presented above.

As demonstrated, agent-based modeling provides social service researchers and evaluators with a powerful tool for exploring and testing the impact of policy changes and

assumptions as social service researchers use this modeling more frequently. There are strengths and limitations of this methodology that need to be borne in mind.

The reliability of these results requires much more than just analysis of the statistical significance of the results. The multiple runs conducted to support the significance testing only address the sensitivity of the results to the random numbers involved. In addition, we have conducted sensitivity analysis of three model design presumptions. We tested the presumption that a population of 100 older adults appropriate by trying populations of 50 and 200. We varied the number of hours per day a caregiver was subject to stress. The default was 18 and we tested down to 6 and up to 24 hours per day. Finally, we tested the presumption relative weighting of ADLs and levels of dementia in contributing to the stress of the caregiver. The default presumption was that they both contributed equally to the level of stress of caregivers. We tested evaluations where ADLs were twice as important as the levels of dementia and vice versa. The results were not surprising except one. For a population of only 50 older adults, that was so few agents that one of the levels of adult day care relief (40 hours per week) was statistically different at the 5% level with 30 runs. We believe this was just a random event but in the process of doing the sensitivity analysis we did identify areas of the model that need research to improve the credibility of our model. And, of course, many more tests of the reliability of the model are possible and appropriate when simulation is used for regulatory and legislative purposes (Hammond, 2015). However, for the purpose of presenting agent-based modeling as an approach to exploring policy options, we assert we have demonstrated the usefulness of this methodology.

Agent-based modeling allows us to explore and test policy options that are inconvenient, illegal, and immoral to perform with live human subjects. However, by representing humans in code, there are assumptions, approximations, and abstractions that have to be made and justified

concerning the agents, their environment, and their interactions for the results to be creditable. The wise saying is that “All models are wrong; some are useful” (Epstein, 2008), because a simulation is not the actual phenomenon being studied.

Given the complicated nature of dementia caregiving, our future work will expand this model to incorporate other aspects of the care-giving decision-making process. We hope to include other family members in our model, and will begin to ascertain the different combinations of relief (in the form of services and support) that may contribute to a decrease in the family caregiver’s stress level.

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 public policymakers and service providers continue to tackle the social complex issue of dementia caregiving, specialized adult day services may be a feasible alternative that is currently out of reach for many families and would be a significant and appropriate public service.

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

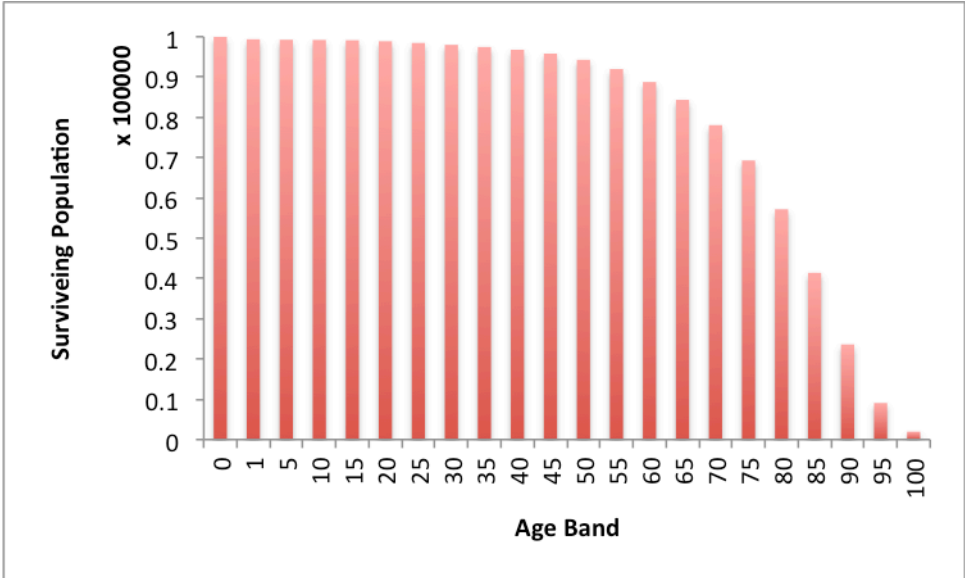


Table 1. Model Runs and Statistical Significance

Relief (hours/week)	Average Caregiver Stress level
0	1.508 (baseline)
8	1.478
16	1.452**
40	1.404**
70	1.268**
84	1.164**
98	0.988**

** indicates statistical significance in change from baseline ($p < 0.01$)