

Carington ver 5.0: Overview, Design Concepts, Decision-making, and Details

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1. Overview

This is the documentation of an agent-based model of long-term care called “Carington”. The documentation design is based on (Grimm et al., 2010) who introduced the “ODD” for overview, design, and details, and (Müller et al., 2013) who introduced the “ODD+D” terminology by adding agent decision-making to the mix. The additional topics to be addressed under decision-making are included in the design section. We are using this document not just to document the model after it is built, but to specify the model’s design as it is being built.

1.1 Purpose

This model is designed to provide insights into the factors affecting informal health care for older adults. The Carington model is the centerpiece of this work. It encompasses older adults, caregivers, and factors affecting informal health care. The Carington model includes no submodels.

1.2 Entities, State Variables, and Scales

The Carington model represents a collection of older adults and associated caregivers. Conditions change on a time step of one year.

1.3 Process Overview

Each year, older adults and caregivers get a year older and, in the case of the older adults, their health generally declines and there is an increase in the number of activities of daily living (ADLs) that they cannot perform on their own. Caregivers may be family members, professionals, or institutions and the capacity of family members to provide care generally declines with time. Only family members serving as caregivers are modeled as agents. The other caregivers are only represented by counts. When the care recipient’s needs exceed the capacity of their current associated caregiver, changes in the care giving must be made. The focus of this model is coping with the stresses by the caregivers and the decision-making involved in changing the caregiving conditions.

2. Design Concepts

The design concepts of each agent type will be discussed. The agent types are older adults and caregivers who may be a family member, a professional, or an institution. Figure 1 shows the major components and their relationships.

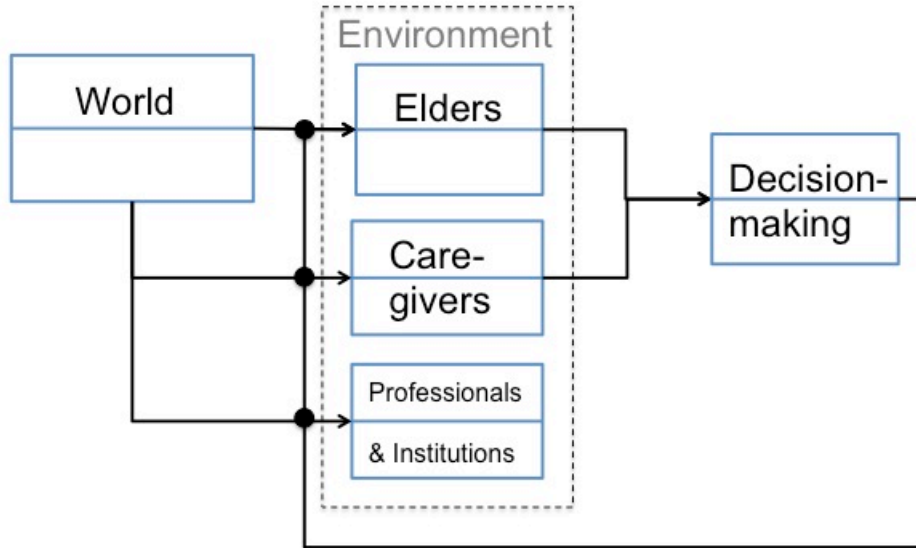


Figure 1. Diagram of the major components of Carington

2.1 Older Adult Agents

Agents in the system representing older adults that need care maintain a level of general health, level of dementia, and a count of ADLs they cannot perform. The agents are initialized randomly but so as to replicate the population statistics mean and standard deviation as appropriate for the simulated age of the agent. Then, with each step of the model, their conditions may change to match the changes in the population statistics (Federal Interagency Forum on Aging-Related Statistics 2012). Agents representing older adults needing care are paired with a caregiver. The status of an older adult needing care provides input to the decision-making the care provider agent makes concerning the source of the needed care.

2.1.1 Theoretical and Empirical Background

Our goal here is not to model each person at a deep physiological level but to model his or her general and mental health at a level of specificity appropriate to studying informal health care. The level of detail of the modeled informal health care is not the daily activities of the caregiver, but the caregiver burden on an annual level and we will associate the number of ADLs and level of dementia with the burden. So, what is needed

is a general theory of aging and how it relates to increases in the burden for the caregiver. There is work toward a general theory of aging (Robine & Michel 2004) and although it is useful, the primary focus is on the compression of morbidity with improved healthcare.

General Health and ADLs

Without a general causal model of general health we will approximate general health through periodic data on the population of people in different conditions of health. The general trends are the individuals' general health declines with age, based on using actuary data as an indicator of general health. Figure 2 shows the general trends in surviving Americans (data from National Vital Statistics Reports, Vol. 63, No. 7, Nov. 7, 2014). 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.

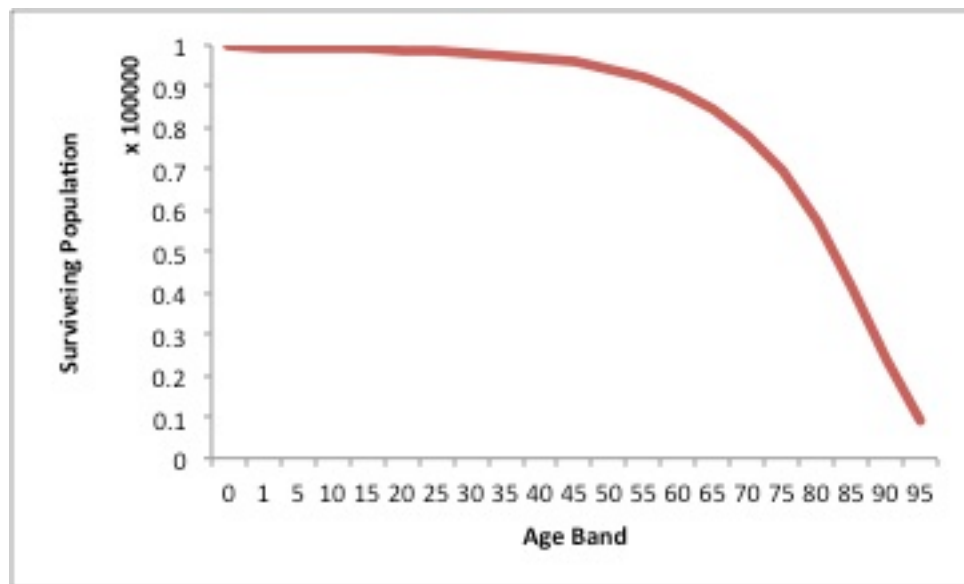


Figure 2 Survival of Americans by Age for 100,000 Live Births

Using this data, we can estimate the likelihood of a person who lived to age 65 dying before reaching age 70. Then, using a linear change over that 5-year period, we can estimate the likelihood of that person dying in each single year between ages 65 and 69.

That calculation yields the following table.

Table 1. Probability of Dying Each Year During in 5 Year Bands

Age Band	60-64	65-69	70-74	75-79	80-84	85-89	90-94	95-99	100+
Probability	0.0498	0.0744	0.1123	0.1748	0.2759	0.4296	0.6153	0.7834	1.0000

Again, presuming survival is an indicator of general health, we further presume that the number of ADLs trends the same way. Specifically, these probabilities of death are directly comparable to the probabilities of additional disabilities in daily living each year. This gives our model a stochastic progression from an overall healthy condition to dying, not a causal theory but a stochastic description of the aging process based on data.

Progression of Dementias

Alzheimer's disease and other dementias are not directly life threatening but 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 estimates using 2010 Census data indicate that 13.9% of individuals 71 years and older have dementia (Alzheimer's Association, 2014).

As Alzheimer's disease and other dementias progress, both behaviors and 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, 2014).

To model the progression of dementia we will key on the data provided by the CDC on mental health. They say (<http://www.cdc.gov/mentalhealth/basics/mental-illness/dementia.htm>) that "Starting at age 65, the risk of developing the disease doubles every five years. By age 85 years and older, between 25 and 50 percent of people will exhibit signs of Alzheimer's disease." That statement is the basis of the following table for the likelihood of showing dementia. We used the higher figure, 50 percent, for ages 85 and above and worked backwards to estimate the probability of showing signs of dementia shown in Table 3.

Table 3. Probability of Exhibiting Signs of Alzheimer's Disease

Age Band	60-64	65-69	70-74	75-79	80-84	85+
Band Probability	0.0156	0.0312	0.0625	0.125	0.25	0.50

Linearly annualizing this data over the 5-year windows produces Table 4.

Table 4. Annualized Probability of Exhibiting Signs of Alzheimer's Disease

Age Band	60-64	65-69	70-74	75-79	80-84	85+
Annual Probability	0.0031	0.0062	0.0125	0.025	0.05	0.1

We will use these probabilities to represent for the progression of dementia from onset and 5 levels. For example, a mentally healthy adult age 72 would have a 0.0125 chance of exhibiting the first stage of dementia before age 73 and an adult with level 2 dementia the same age would have the same probability of advancing to level 3 before age 73. This provides our model with a stochastic process for increasing dementia.

2.1.2 Individual Agent Decision-Making

Older adults contribute to the decision-making concerning changes in their care providers, but basically the trajectory of their health, both general and mental, are stochastic and their health status determines the burden on their caregiver.

2.1.3 Learning and Adaption

Older adult agents do not learn or adapt.

2.1.4 Individual Agent Sensing

Older adult agents only respond to the passage of time.

2.1.5 Individual Agent Prediction

Older adult agents do on prediction.

2.1.6 Interaction

Older adult agents only interact with their caregivers as input to their stress and decision-making.

2.1.7 Collectives

Statistics on older adults are maintained, but older adult agents do not act as a collective.

2.1.8 Heterogeneity

Older adult agents characteristics are heterogeneous representing the population statistics and aging differences, i.e., rates of change in health conditions.

2.1.9 Stochasticity

Changes in the health status of older adult agents, their general health, their mental health, and their death, are driven by random variables to replicate the population statistics based on the age of the older adult.

2.1.10 Observation

Description statistics of the population of older adults are maintained for comparison with the population statistics to ensure the general trends in the health status of the older adult agents is consistent with available data.

2.2 Caregiver Agents

Caregivers are the primary agents in the system. Caregiver agents have characteristics describing their capabilities and motivation. Their capabilities are in terms of discretionary time available, financial resources, support from friends, family, and the community, their own health status, their subjective wellbeing, and employment. Their motivation is described by their relationship to the older adult, experience as a caregiver, level of difficulty associated with care giving, and their own needs.

2.2.1 Theoretical and Empirical Background

Caregiver workload increases with the general decline and increased number of ADLs for which assistance is needed. Given our model can only estimate the number of ADLs but not which activities the older adult needs help with, we will use the count to be an indicator of the average workload for caregivers.

Caregiving needs of older adults during the middle stages of Alzheimer brain damage may have changes in their 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, 2014). 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 stay home with 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.

Informal family caregivers provide the majority of care to frail older adults; this assistance is invaluable and fulfills an important role not only for frail, older family members, but for society as a whole. There are many complexities that come into play while family members are realizing the need for additional care needed for a frail older family member. Ihara, Horio, and Tompkins (2012) grouped some of the variables family members may need to consider conceptually into whether or not a family member was motivated and capable of providing care. These researchers 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.

Our model will handle the burden for general health and mental health as separate variables associated with the health of the older adult and simply combine both the ADLs and dementia level as an overall indicator of burden and stress for the caregiver.

2.2.2 Individual Agent Decision-Making

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. If the level of stress becomes too high, a decision is made to evaluate possible changes the arrangement for the assistance the associated older adult needs. This evaluation and decision about changes in implemented using inputs from the care recipient, simulated other family members, and the economic status of the group as well as the conditions of the long-term care industry. Changes in caregiving arrangements can include various coping means for the caregiver including changing who provides the needed care.

2.2.3 Learning and Adaption

Caregivers stress level is based on an individualized Systems Dynamics model (Homer and Hirsch 2006). Each caregiver has a current level of caregiving, which is increased by additional stresses and decreased by assistance. If the level of caregiving exceeds an individualized threshold, that situation is cause for reconsidering the caregiving arrangement.

We model burden as the combination of the count of ADLs and dementia level. An increase in burden is an additional stress on the caregiver. During the year the burden changed, we represent the stress as the sum of the old stress and twice the change in burden. We represent the adaption of the caregivers to the change as taking on average half a year such that with no other changes, the stress the next year is again just the sum of the ADLs and dementia level as shown in Table 5.

Table 5.

Year	Burden	Change	Peak
1	2	0	2
2	2	1	4
3	3	0	3
4	3	0	3

If the peak stress level exceeds the capacity of the caregiver, then other caregiving arrangements need to be considered.

2.2.4 Individual Agent Sensing

Caregivers have full access to the health status of their associated older adult.

2.2.5 Individual Agent Prediction

Caregiver agents do not project future needs of their associated older adult.

2.2.6 Interaction

Caregivers obtain information from their associated older adult, but do not interact directly with the other caregivers or any other older adult. Their decision-making can change the utilization statistics of professionals and institutions.

2.2.7 Collectives

Statistics on caregivers are maintained, but caregiver agents do not act as a collective.

2.2.8 Heterogeneity

Caregivers are heterogeneous in their capacities, family resources, and financial resources.

2.2.9 Stochasticity

Initialization of caregiver characteristics will be randomized to represent the population statistics based on the age of the caregiver.

2.2.10 Observation

Description statistics of the population of older adults are maintained for comparison with the population statistics to ensure the general trends in the health status of the older adult agents is consistent with available data.

3. Details

3.1 Implementation Details

Carington is implemented in NetLogo (Wilensky 1999). The development of Carington was supported by the Department of Computational Social Science, part of the Krasnow Institute for Advanced Study and the Department of Sociology at the George Mason University.

The code for modeling the aging process, or general & mental health trajectories uses the conceptual model shown in Figure 3.

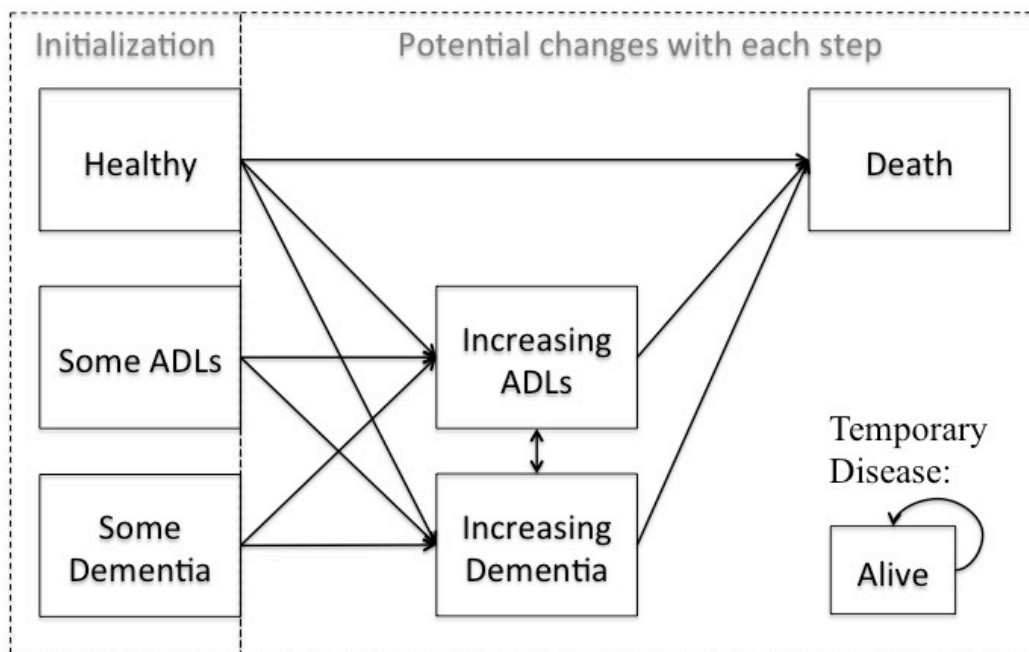


Figure 3. Conceptual Model of Initialization and Aging Trajectories

3.2 Initialization

The initialization process establishes the older adults, the caregivers, and the care providers (family caregiver, professionals, or institutions) and initializes the heterogeneity of the older adults health status and care providers based on available population statistics.

3.3. Input Data

3.3.3 Initial Older Adult Agent Health Status:

Older adult agent health status is initialized based on the Federal Interagency Forum on Aging Related Statistics 2012 report "Older Americans 2012: Key Indicators of Well-being and judgment with the intent of replicating population data. The 2012 report has many tables of detailed information. We used the data for non-Hispanic white population reported good-excellent general health for:

82% of the population aged 65-74,
76% of the population aged 75-84, and
69% of the population aged 85+.

These were spread over a five-level general health status as follows:

82% good-excellent => 20% excellent + 30% very good + 18% good, and
18% fair-poor => 10% fair + 8% poor.

The initialized age is selected from a normal distribution with a mean of 71 years and a standard distribution of 7 years, with 59% women, and 67% married. (Note that the sex and marital status is not currently used in the model's trajectory of agent health.)

3.3.4 Caregiver data:

When a caregiver is initialized, the caregiver's age is initialized. We had difficulty finding a source for the age of the kin providing caregiving. Fowler and Fisher (2009) reported ages of children of older adults in their survey, but they did not restrict respondents to being caregivers but they did restrict the respondents to being over 40 years old. Given that their survey identified the age of the older adults needing some care as having a mean of 75.78 years old with a standard deviation of 6.75 years, we decided to use a figure 30 years younger with the same standard deviation. Therefore, caregivers in our model are initialized using a normal distribution with a mean of 45 years old and standard deviation of 6.75 years. Their stress capacity is set at 3 as a representative value.

4. Experiments

The intent of the experiments is to explore the impact of policy options on the aging-in-place support provided by informal caregivers.

Policy options exist to support aging-in-place. These options may include increased respite care availability, tax incentives, work place policies (Chen, 2014), and adult day services to name a few. These options are 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, Horio & Tompkins, 2012). Other advocacy efforts for legislation that would increase community services and flexible workplace accommodations for caregivers, or provide additional tax credits have been unsuccessful (Colello, 2009). 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. 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.

Aging-in-place can address two dimensions, environmental-focused and person-focused (Greenfield, 2012). Environment-focused initiatives concentrated on the physical and social aspects of older adults' environments; the relative distance of the older adults' interrelationships; and types of social structures, systems, and their interconnections. Conversely, person-focused dimensions concentrated on older adults as leaders of person and environment changes, and initiating person-environment changes in a life transitions.

Long-term care inquiry under the Affordable Care Act (Naylor, Kurtzman, Grabowski, Harrington, McClellan, & Reinhard, 2012) currently includes Hospital Readmissions Reduction Program, the National Pilot Program on Payment Bundling, and the Community-Based Care Transitions Program. These policy options potentially underlie an older adults' and their families' decision-making process as to whether independent living, home-based supportive living, assisted living, or nursing home placement provides the best option.

4.1. Experimental Setup

The purpose of the first experiment is to demonstrate the reduction in the stress of caregivers provided by older adult care. To model the effects of, 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 to account to time the older adult is asleep and the time the caregiver is asleep. We used 18 hours per day. The adult day care would then also be 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 daycare 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.

4.2. Data Collection

For our paper (Ihara et al., 2015) and in the code is the setup to use the “Behavior Space” feature of NetLogo to run experiments. The variables adjusted each run are: hrsPerWeek set to 8, 40, 70, 84, and 98; and the initial number of older adults in the system, reset for each run to 100 initially. We collected data on the count of caregivers that are kin (spouse or family) and the average stress of all caregivers. We ran 30 repetitions of each condition with a time limit of 200 steps.

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