THE RELATION BETWEEN ALZHEIMER’S DISEASE CAREGIVING STATUS,
HEALTH-RELATED POSSIBLE SELVES, AND HEALTH BEHAVIORS

by

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LIST OF ABBREVIATIONS AND SYMBOLS

\( B \) Beta: Type II error rate; also, standardized regression coefficient

\( F \) Fisher’s \( F \) ratio: A ratio of two variances

\( M \) Mean: the sum of a set of measurements divided by the number of measurements in the set

\( \eta^2 \) Eta squared: proportion of variation accounted for

\( p \) Probability associated with the occurrence under the null hypothesis of a value as extreme as or more extreme than the observed value

\( r \) Pearson product moment correlation coefficient

\( R \) Sample correlation coefficient

\( > \) Greater than

\( < \) Less than

\( = \) Equal to
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ABSTRACT

Possible selves are personalized representations of the self in the future that may motivate individuals to strive toward desired states and avoid feared outcomes. Possible selves have been explored among many populations but have not been investigated among Alzheimer's disease caregivers. In this study, the health-related possible selves of two groups were compared: individuals caring for someone with Alzheimer's disease, and individuals who are not caring for anyone with Alzheimer's disease. It was hypothesized that an individual’s status as an Alzheimer’s caregiver would increase the likelihood of having possible selves related to the development of Alzheimer's disease. It was also hypothesized that caregivers would engage in health behaviors at a lower rate than non-caregivers. Thirty-one non-caregivers and 18 Alzheimer’s disease caregivers participated in this study. Caregivers were significantly younger and tended to be White, while non-caregivers were significantly older and tended to be African American. After controlling for age and race, results did not support the hypotheses regarding group differences. However, White participants were more likely to report possible selves related to Alzheimer’s disease than were African American participants. Limitations of the current study, as well as implications for future studies, are discussed.
THE RELATION BETWEEN ALZHEIMER’S DISEASE CAREGIVING STATUS, HEALTH-RELATED POSSIBLE SELVES, AND HEALTH BEHAVIORS

Introduction

Alzheimer’s disease (AD) is a degenerative brain disorder that currently afflicts about 5 million Americans (Alzheimer’s Association, n.d.; LaCapra, 2007). It is expected that within 50 years, nearly 13 million people in this country will suffer from AD (LaCapra, 2007). AD is the most common form of dementia, and as the disease advances and intensifies, individuals experience disorientation, forgetfulness, difficulty with thinking or speaking clearly, and significant shifts in their actions and demeanor (Alzheimer’s Association, n.d.). Because of these changes, which significantly limit independent functioning, most people with AD require an increasing amount of daily caregiving assistance throughout the duration of their illness, often from a family member (Fisher Center for Alzheimer’s Research Foundation, n.d.).

At the present time, approximately 33.8 million Americans, or 16% of the U.S. population, care for an older relative (Castro, King, Housemann, Bacak, McMullen, & Brownson, 2007). About 5 million of these individuals provide unpaid, in-home caregiving assistance to an individual with dementia (Castro, Wilcox, O’Sullivan, Baumann, & King, 2002). This care is often quite extensive, and it is not unusual for a caregiver’s responsibilities to demand 70 hours per week of their time (Castro et al., 2002). While the duties performed by AD caregivers can help to maintain the health of
individuals with this disease, the wide-ranging demands posed by caregiving often take a
toll on caregivers’ health.

A wide variety of physical ailments have been attributed to the burden of
caregiving (Belle et al., 2006; Castro et al., 2007; Castro et al., 2002; Hooker, Frazier, &
Monahan, 1994; Schulz, Visintainer, & Williamson, 1990). Caregivers have higher death
rates than non-caregivers (McDonald, Fink, & Wykle, 1999), and the act of caregiving
itself has been identified as an independent risk factor for mortality among older adult
caregivers (Castro et al., 2007; Castro et al., 2002; King, Baumann, O’Sullivan, Wilcox,
& Castro, 2002). Caregiving has also been linked with impaired immune system
functioning (Castro et al., 2007; Castro et al., 2002), an increased incidence of coronary
artery disease (Castro et al., 2007), and heightened cardiovascular reactivity among
caregivers (Castro et al., 2007; Castro et al., 2002). Such health declines often cause
caregivers to take a higher number of prescription drugs and make more health care visits
than are common among non-caregivers (McDonald et al., 1999). At the same time,
there is evidence that caregivers may have more difficulty accessing medical care than
non-caregivers (Scharlach, Midanik, Runkle, & Soghikian, 1997).

The pressures associated with providing care not only have physical
repercussions, but they have also been found to cause poor mental health among
caregivers (Belle et al., 2006; Castro et al., 2007; Castro et al., 2002; Hooker, Monahan,
Bowman, Frazier, & Shifren, 1998; Hooker et al., 1994; Schulz, Visintainer, &
Williamson, 1990). While many caregivers report positive experiences associated with
their responsibilities (Hooker et al., 1998; Roff, Burgio, Gitlin, Nichols, Chaplin, & Hardin, 2004), the stresses caused by the caregiving role have been linked to a wide range of problems (Schulz et al., 2003), including conflicts with spouses and children, sleep disturbances, heightened psychological distress, depression, and overall poor mental health (Castro et al., 2007; Castro et al., 2002; Hooker et al., 1998; Hooker et al., 1994; Scharlach et al., 1997; Schulz, Visintainer, & Williamson, 1990).

Health Behaviors

Fortunately, adopting certain health behaviors may help caregivers to avoid or delay the physical and mental declines related to their caregiving responsibilities. In an early study of health behaviors among caregivers (Harris & Guten, 1979, as cited in McDonald et al., 1999), five categories of behaviors that may be adopted by caregivers were identified: Personal health practices, safety practices, preventive health care, avoidance of environmental hazards, and avoidance of harmful substances. Some examples of health behaviors that fall into these categories are nutrition, exercise, cognitive strategies, rest, recreation and socializing, spiritual activity, following professional health advice, avoiding harmful practices (such as drinking alcohol or using drugs), volunteering, using moderation or common sense, and seeking help (McDonald et al., 1999).

Despite their increased risk for poorer physical and mental health, research has generally found that caregivers engage in fewer health behaviors (Castro et al., 2007; O’Brien, 1993, as cited in Scharlach et al., 1997) and more unhealthy behaviors
(Scharlach et al., 1997) than non-caregivers. However, some studies (Baumgarten, Battista, Infante-Rivard, Hanley, Becker, & Gauthier, 1992, as cited in Scharlach et al., 1997; Dura, Stukenberg, & Kiecolt-Glaster, 1991, as cited in Scharlach et al., 1997; Walsh, Yoash-Gantz, Rinki, Koin, & Gallagher-Thompson, 1991, as cited in Scharlach et al., 1997) have produced conflicting results. Studies that have lower levels of health behaviors among caregivers have often attributed this trend to a lack of time created by the demands of the caregiving role (Castro et al., 2002), which may constrain caregivers from exercising, eating properly, or seeking medical care (Scharlach et al., 1997). In one investigation (Killeen, 1989, as cited in McDonald et al., 1999), a subsample of caregivers was surveyed about their health behaviors and half of the respondents did not feel they had enough time to be concerned about their own health. These participants were also unable to name any behaviors in which they had engaged to improve or sustain their health (Killeen, 1989, as cited in McDonald et al., 1999). There is evidence to suggest that the tendency for caregivers to sacrifice their own health behaviors decreases with time, however, as a longer history of caregiving was related to increased engagement in health behaviors (Killeen, 1989, as cited in McDonald et al., 1999).

While the tendency for AD caregivers to engage in health behaviors at lower rates than non-caregivers has traditionally been blamed on a lack of time, there may be additional explanations. For example, caregivers may not see a connection between the health behaviors they could adopt in the present and the possibility that they will develop AD in the future. Additionally, the threat posed by the potential of acquiring AD may be
so great for caregivers, and their knowledge about and understanding of AD may be so limited, that they feel overwhelmed and resort to ignoring thoughts about AD. As a result, it is important to consider caregivers’ knowledge and beliefs about AD in order to better understand their adoption of health behaviors.

*Information and Beliefs about Alzheimer’s Disease*

The amount of information about AD that is available to the general public has greatly increased since the mid-1970s (Cutler & Hodgson, 1996; Hodgson & Cutler, 2003). National surveys conducted during the 1980s (Cutler, 1987, as cited in Hodgson & Cutler, 2003) and 1990s (Alzheimer’s Association, 1993, as cited in Hodgson & Cutler, 2003) indicate that this information has had an impact as adult respondents were very aware of the disease. Unfortunately, increases in the amount of AD information and an overall heightened awareness of the disease have not been entirely positive. Media accounts of AD, which represent one of the primary means of acquiring information about AD among members of the general public, have typically been negative and filled with stereotypes (Jolley & Benbow, 2000, as cited in Corner & Bond, 2004). Additionally, visits to friends or family members with AD may have the undesirable effect of causing people to fear developing dementia themselves while discouraging them from making future visits to loved ones with AD (Corner & Bond, 2004). It has also been suggested that increased familiarity with AD may lead to a heightened concern about having symptoms of the disease in a phenomenon Mechanic (1980) referred to as “medical students’ disease” (Hodgson & Cutler, 2003).
Not only are individuals often confused by the general facts pertaining to AD, but they also seem unsure about what may cause, or how one may avoid, AD. Community-dwelling individuals sometimes cite stress and inactivity as two of the factors that most commonly lead to AD (Corner & Bond, 2004). There are a number of risk factors for acquiring AD and other dementias, including demographic characteristics (such as lower levels of education), medical issues (e.g., cardiovascular disease, depression, head injury), and increasing age (Corner & Bond, 2004). Frequent engagement in leisure time activities during young and middle adulthood has been related to a lower risk for developing AD (Crowe, Andel, Pedersen, Johansson, & Gatz, 2003), and genetics has been found to play a role in some types of AD (Corner & Bond, 2004; Cutler & Hodgson, 1996; Hodgson & Cutler, 2003). In fact, knowledge about AD among first-degree relatives of individuals with AD is higher than that of the general population (Roberts & Connell, 2000, as cited in Sullivan, Muscat, & Mulgrew, 2007). In a study by Sullivan and her colleagues (2007), for instance, AD caregivers demonstrated significantly greater levels of knowledge about AD than did AD patients and non-caregivers.

As heredity is a factor contributing to the development of numerous genetic disorders (Wexler, 1979, as cited in Hodgson & Cutler, 2003), including some forms of AD, being related to an individual with AD plays a role in determining one’s fears about acquiring the disease. This was substantiated in a study by Green (2003, as cited in Hodgson & Cutler, 2003), who found that heredity was especially salient among the families of people with AD and contributed to their fears about one day having the
disease themselves. Being genetically related to someone with AD is not a necessary precursor to fears about developing AD, but people who have a relative with AD have been found to be more likely than others to fear that they will develop the disease (Corner & Bond, 2004; Cutler & Hodgson, 1996; Hodgson & Cutler, 1997).

Because memory deficits are the most recognizable symptom of AD (Cutler & Hodgson, 1996), difficulties with one’s memory may engender fears that one will someday have AD (Cutler & Hodgson, 1996; Hodgson & Cutler, 2003). Several of the older adult participants in the Corner and Bond (2004) investigation mentioned both concerns about their memory and fears of acquiring AD. Memory problems among middle-aged adults are also commonly interpreted as a sign of dementia, even when more accurate explanations exist (Hodgson & Cutler, 2003). As a result, middle-aged individuals are becoming more likely to express concerns about developing AD (Centofanti, 1998, as cited in Hodgson & Cutler, 2003).

Individuals who view their memory problems as a harbinger of AD may search for proof that their memory declines are in fact AD. This behavior is known as “symptom seeking” and is yet another expression of fear about developing AD (Hodgson & Cutler, 2003). Like anticipatory dementia, symptom seeking is typically seen among first-degree relatives of someone with a genetic disorder, but AD-related symptom seeking also exists among non-related individuals (Hodgson & Cutler, 2003). Symptom seeking can be so intense that individuals may seek medical care for a disorder before symptoms are even noticeable (Wexler, 1979, as cited in Hodgson & Cutler, 2003).
Symptom seeking individuals begin by imagining themselves with AD. According to Hodgson and Cutler (2003), people who have a parent with AD and believe that their memory deficits are similar to those experienced by their parent are more likely to engage in symptom seeking. This finding would suggest that people who have parents with AD may look into their futures and see themselves facing the same fate, and anecdotal evidence from the children of individuals with AD would seem to support this suggestion (Bristow, 1996, as cited in Hodgson & Cutler, 2003).

The contribution of individuals’ fears about having AD in the future was also evidenced among participants in the Corner and Bond (2004) study. For example, one participant discussed the manner in which memory declines lead to anxieties about the future: “As soon as you get forgetful you think, ‘Is it going to happen to me?’ It’s frightening, really” (Corner & Bond, 2004, p. 147). Another participant commented, “They suddenly get frightened about going to see [a friend with dementia]…I think they can put themselves…see themselves perhaps landing up in the same position” (Corner & Bond, 2004, p. 151).

Studying the concept of possible selves (Markus & Nurius, 1986) among AD caregivers may help to more fully explain both individuals’ fears about developing AD and their participation in health behaviors. Gaining a better understanding of the influence of possible selves on health behavior may in turn help us to improve and protect the health of both caregivers and the individuals for whom they provide care.
Possible Selves

“Possible selves,” as described by Markus and Nurius (1986), “represent individuals’ ideas of what they might become, what they would like to become, and what they are afraid of becoming (p.954).” That is, possible selves are the experiences that individuals think they may go through, and the types of people they believe they may become, when they imagine their lives in the future. Some possible selves are positive or hoped-for selves, while others are negative or feared selves (Markus & Ruvolo, 1989).

Possible selves in the health domain typically assume a dominant theme among older adults (Cross & Markus, 1991; Frazier, Cotrell, & Hooker, 2003; Hooker, 1999; Hooker, 1992; Hoppmann, Gerstorf, Smith, & Klumb, 2007; Smith & Freund, 2002), and one explanation for the prominence of health issues, especially among older adults’ feared selves, is that older individuals tend to have more chronic illnesses than members of other age groups (Hooker & Kaus, 1992). As AD and dementia are most commonly thought of as diseases of old age, it might be expected that older adults would have more feared possible selves related to memory loss and AD than younger individuals.

Research would seem to suggest, however, that fears about memory loss and AD may not directly lead to the acquisition of feared possible selves. In an investigation by Cotrell and Hooker (2005), cognitively intact older adults were relatively unlikely to generate future selves related to cognitive impairment. This was an unexpected finding as it is not unusual for older adults to express fears pertaining to memory loss (Cotrell & Hooker, 2005; Roberts, 1992). Cotrell and Hooker (2005) posited two potential
explanations for their surprising results. First, older adults without cognitive impairment may have fewer feared selves related to cognitive impairment because, even though they fear memory loss, they are not able to visualize it as a likely scenario. Second, older adults who are free of cognitive impairment may have relatively fewer feared selves related to cognitive impairment because they fear the possibility of memory loss and dementia so greatly that they cannot even imagine what it would be like to experience a cognitive impairment unless it becomes a distinct and impending possibility.

Individuals of all ages acquire possible selves by comparing themselves to other people (Markus & Nurius, 1986). As someone witnesses the manner in which AD debilitates a friend or family member, for example, it seems reasonable to think that the individual’s possible selves will grow to be based upon the condition of their loved one. This phenomenon was illustrated in a recent Newsweek article (Kantrowitz & Springen, 2007) in which the authors noted that, “As they watch their parents’ inevitable decline, boomers can’t help but see a disturbing glimpse of their own potential future” (p.55). Since caregiving duties demand frequent and intensive contact with a chronically ill or dying individual, providing the caregiver with a first-hand view of the effects of AD, it is expected that individuals caring for someone with AD may be even more likely to develop feared selves related to cognitive decline. The tendency to acquire possible selves related to AD might be further heightened among relatives caring for an individual with AD as certain types of the disease are passed on genetically (Crowe et al., 2003). As a result, people who are caring for a relative with AD may be even more likely to have
possible selves pertaining to cognitive impairment, especially when compared to both similar individuals who are not caring for someone with AD and individuals who are caring for someone with AD to whom they are not related.

Possible Selves, Health Behaviors, and Motivation

The manner in which possible selves exert an influence upon behavior has not yet been determined, and there is some disagreement about the motivational power of possible selves. According to Cross and Markus (1991), both hoped-for and feared possible selves are capable of motivating individuals to engage in health behaviors. Possible selves that are more frequently activated, it has been suggested, are more likely to lead to a change in actions than possible selves that are rarely considered or thought about (Hoyle & Sherrill, 2006; Norman & Aron, 2003). The frequent activation of feared possible selves, however, may actually lead to a decrease in motivation as feared possible selves offer the possibility of an undesirable future without designating a way to avoid it (Hooker, 1992; Hoppmann et al., 2007).

It is unclear, then, whether the AD-related possible selves of AD caregivers would be more likely to influence behavior change than the AD-related possible selves of non-caregivers. AD caregivers, who might spend as many as 70 hours per week witnessing the ravaging effect that AD has exacted upon their care recipient, would almost certainly have AD-related possible selves that are activated on a much more frequent basis than non-caregivers, who might rarely have direct contact with others who are chronically ill or actively dying from AD. It might therefore be expected that AD caregivers would be
more strongly motivated than non-caregivers to engage in health behaviors that might help them avoid or postpone poor health related to AD, but only if they believe that health behaviors will be effective in helping them to avoid such illnesses, and only if the fear and anxiety generated by their AD-related possible selves do not lead to unproductive or avoidant behaviors. On the other hand, AD caregivers (and in particular, AD caregivers who are genetically related to their care recipient) may develop feared possible selves in which they too will eventually acquire the disease. If these caregivers feel that AD is inevitable, and if they believe that engaging in health behaviors will neither help them avoid nor postpone the disease, they may be less motivated to engage in health behaviors than non-caregivers.

Need for Study

While the concept of possible selves has been investigated among a variety of different groups, including adolescents, college students, adults of all ages, people with Parkinson’s disease, and individuals with AD, it has not commonly been studied among AD caregivers. Learning more about how AD caregivers view their future health may provide a basis for interventions targeting this population. As Cross and Markus (1991) asserted that possible selves can motivate individuals to adopt health behaviors, information about the possible selves possessed by AD caregivers could help to determine which health behaviors are salient to these individuals as they cope with the physical and psychological stressors stemming from their caregiving duties.
The current study has two primary aims. The first is to investigate differences in the health-related possible selves generated by older adults who care for an individual with AD and the health-related possible selves generated by older adults who do not care for an individual with AD. It is hypothesized that older adult AD caregivers will have more health-related possible selves, and in particular, more AD-related possible selves, than older adult non-caregivers. The second aim of this study is to explore the relation of health-related possible selves to preventive health behaviors among older adults who care for an individual with AD and older adults who do not care for an individual with AD. It is hypothesized that despite the greater number of health-related possible selves among older adults who care for an individual with AD, members of this group will engage in health behaviors at a lower rate than older adults who do not care for an individual with AD.

In addition to these two aims, the relations between demographic characteristics (i.e., mean age and years of education), health status, mood, knowledge of AD, and symptom seeking behaviors will be explored among two groups: (1) older adults who care for an individual with AD, and (2) older adults who do not care for an individual with AD.

Method

Participants

A total of 55 individuals were recruited to participate in this study. Many of these individuals were recruited from a database of potential research participants compiled by
the Center for Mental Health and Aging at The University of Alabama. All of the individuals in this database are older adults residing in Central and West Central Alabama who have participated in previous research studies or have expressed an interest in future studies. The remaining individuals were recruited from a senior center in West Central Alabama or from one of three caregiver support groups located in Central or West Central Alabama.

Of the 55 individuals recruited, two declined to participate, citing a lack of time. Additionally, two individuals who were recruited to participate were screened out of the study due to a TICS-m score of less than 20, and two participants were excluded as they were caring for the same care recipients as other participants in this study and their data were redundant. As a result, 49 participants were enrolled in this study. For descriptive characteristics of the study sample, see Table 1.

AD caregiver group

Of the 49 participants in this study, 18 adults ages 43 to 83 years who were caring for an individual with AD at the time of the study made up the Alzheimer’s disease caregivers group. Table 2 shows the descriptive characteristics of the participants in the AD caregiver group.

Non-caregiver group

The remaining 31 individuals, all of whom reported that they were not currently caring for an individual with Alzheimer’s disease or dementia, made up the non-caregiver
group. These individuals ranged in age from 59 to 87 years, and Table 2 shows the descriptive characteristics of the participants in the NCG group.

Measures

The measures below are listed in the order in which they were presented to study participants. The sociodemographics questions and the Telephone Interview for Cognitive Status-Modified were administered to participants during telephone screening interviews, while the remaining instruments comprised the content of in-person interviews.

Sociodemographics

General demographic information was collected from each participant, including date of birth, gender, race, years of education, highest level of education, income adequacy, family incidence of AD, and both past and current caregiving status (see Appendix 1).

Telephone Interview for Cognitive Status-Modified

The Telephone Interview for Cognitive Status-Modified (TICS-m; Breitner, et al., 1990) was used to ensure that all participants met eligibility criteria for this study. The TICS-m (see Appendix 2) is a revision of the Telephone Interview for Cognitive Status (TICS), which was developed by Brandt and colleagues (1988) and was based upon the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). The TICS-m measures orientation, memory, delayed recall, language, verbal comprehension, praxis, abstraction, calculation, repetition, and general knowledge and has been
demonstrated by Gallo and Breitner (1995) to be valid for assessing cognitive function among individuals with AD. A TICS-m score of 20 or greater was required of all participants in this study to ensure that their responses to other questions in the study were reliable. Scores below this threshold have been described as indicative of cognitive deficits (de Jager, Budge, & Clarke, 2003).

*Positive and Negative Affect Schedule*

The Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988) was used to assess the emotional states of participants in this study. The PANAS measures 10 positive (i.e., interested, excited, strong, enthusiastic, proud, alert, inspired, determined, attentive, and active) and 10 negative (i.e., distressed, upset, guilty, scared, hostile, irritable, ashamed, nervous, jittery, and afraid) emotions as participants rate instrument items on a Likert-type scale (see Appendix 6). Based upon their responses to items on the PANAS, each participant received two summed scores: a PANAS Positive, or the sum for the 10 positively-valenced PANAS items, and a PANAS Negative, or the sum for the 10 negatively-valenced PANAS items. Scores obtained from the PANAS have been shown to be stable for a period of at least two months, and the instrument has demonstrated high internal consistency (Spiegel, n.d.) and good discriminant validity $r = -.09$.

*Short Form-12 Health Survey*

The Short Form-12 Health Survey (SF-12) was used to collect information about the functional health and wellbeing of each participant (see Appendix 3). The SF-12 is a
subset of the Short Form 36 Health Questionnaire (SF-36; Brazier et al., 1992), which was cited in an article by Garratt and colleagues (2002) as the most commonly-tested “quality of life” health outcome measure. The SF-36 provides an assessment of physical and emotional health on eight dimensions (i.e., physical function, role physical, bodily pain, general health, vitality, social function, role emotional, and mental health) (Brazier, et al., 1992), and the SF-12 replicates no less than 90% of the variance in the physical and mental component summary scales from the SF-36 using fewer questions (SF-36.org, n.d.). For the purposes of this study, only the answer to first question from the SF-12 (i.e., “In general, would you say your health is Excellent, Very Good, Good, Fair, or Poor?”) was used to represent participants’ self-rated health.

Health Survey

Questions drawn from the National Health Interview Survey (NHIS; National Center for Health Statistics, 2007) comprised the health survey used to obtain information about the health behaviors of participants in this study. The NHIS, which has been administered by the National Center for Health Statistics (NCHS) on an ongoing basis since 1957, is designed to gather data about the health behaviors of noninstitutionalized citizens of the United States in order to track illness and disability patterns, develop public health interventions and policies, and monitor advancements toward national health goals (see Appendix 5).
Health-Related Possible Selves

Health-related possible selves were assessed using a protocol originally developed by Cross and Markus (1991), refined for use with older adults by Hooker (1999) and Cotrell and Hooker (2005), and further modified by the author to specifically elicit possible selves in the health domain. Participants were presented with an introduction that was read aloud by the interviewer (see Appendix 4) and were requested to freely list both hoped-for and feared selves related to their future health.

To facilitate the identification of health-related possible selves, participants were provided with prompts (e.g., “What do I hope my health will be like in the future?” “How might my health change for the worse in the future?”). After participants indicated that they had described all of the health-related possible selves they could think of, the interviewer asked follow-up questions regarding the likelihood that each possible self would occur and the degree of control participants felt they had over their possible selves. These questions were asked to allow participants an opportunity to elaborate on their possible selves and to ensure that they had completely discussed all of their hoped-for and feared health-related possible selves.

Both the hoped-for and feared possible selves listed by participants were documented by the interviewer, who recorded the participants’ verbal responses using a digital recorder or, for those participants who preferred not to be recorded, wrote the participants’ responses on a piece of paper. When all of the participant interviews had been completed, an undergraduate research assistant helped the author transcribe content
from the Health Related Possible Selves portion of the interviews. The resulting
transcripts were distributed to the author and two independent coders, who met to discuss
how the possible selves would be coded. Using a possible selves coding scheme
described in previous publications (e.g., Frazier & Hooker, 2006; Hooker, 1999), the
author and three coders selected five interviews to code together in order to become
familiar with the coding process. The author and two coders then coded the remaining 44
interviews separately. Inter-rater reliability (IRR) was calculated using the following
formula:

\[
\text{IRR} = \frac{\text{The number of possible selves assigned by a rater}}{\text{The number of possible selves assigned by all raters}}
\]

The inter-rater reliability for possible selves coded within the domain of health was 58%,
and inter-rater reliability for possible selves related to Alzheimer’s disease was 43%.

*Center for Epidemiological Studies-Depression Scale*

The Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977) was used to screen participants in this study for symptoms of depression.

Developed by the Center for Epidemiologic Studies, the CES-D consists of 20 items that
assess various depressive symptoms by asking participants to rate how often they have
experienced certain feelings during the past week (see Appendix 7). Scores on the CES-
D range from a high of 60, which would be indicative of higher levels of depressive
symptoms, to a low of 0, which would reflect a relative lack of depressive symptoms
(Radloff, 1977). Cronbach’s alpha reliability for older adult populations is reported between .86 and .89 (Schein, & Koenig, 1997).

**Symptom Seeking Measure**

Three questions drawn from a study by Hodgson and Cutler (2003) were utilized to detect symptom seeking behavior among participants in this study (see Appendix 8). The responses to these closed-ended items, which were scored “no” = 0, “yes” = 1, rendered scores ranging from 0 to 3 for each participant, with higher scores reflecting a greater tendency to engage in symptom seeking behaviors. In an earlier study by Hodgson and colleagues (1999), the three questions included in this measure were found to be the most significant factors related to symptom seeking behaviors.

**Questions about Alzheimer’s Disease Knowledge**

Fourteen questions featured in a study by Werner (2002) were used to assess the AD knowledge possessed by participants in this study (see Appendix 9). These closed-ended items, which were scored “False” = 0, “True” = 1, rendered scores ranging from 0 to 14 for each participant, with higher scores reflecting a greater amount of knowledge about AD, including issues related to developing and treating the disease.

**Procedures**

Potential participants were contacted via telephone by the author or an undergraduate research assistant and were asked for sociodemographics and administered the TICS-m. Participants who met inclusion criteria (i.e., earned a TICS-m score of 20 or greater) during the phone screening were invited to participate in this study. Upon
agreeing to participate, appointments were scheduled with these participants to be held at
a location of their choosing. Most participants agreed to meet with an interviewer for an
appointment in their homes, while others preferred for their appointments to be
conducted in a public place such as a library or church.

At the time of their interviews, which were conducted by the author or a graduate-
level research assistant, participants completed informed consent and a one-time 45-60
minute interview. All participants who completed the 45-60 minute interview received
monetary compensation for their time ($20) at the conclusion of the interview.

Four participants who were interested in additional information regarding
depression, memory problems, or memory training (as well as two individuals who were
screened out of the study due to a TICS-m score of less than 20) were offered feedback
by way of an individualized report (based on their performance on the TICS-m and CES-
D) that was explained by the author during an additional face-to-face meeting following
the 45-60 minute interview. These participants were also provided with referrals to
medical and mental health providers in the community, along with additional information
about memory, during this second face-to-face meeting.

Statistical Analyses

Quantitative data from each of the 49 participant interviews was entered into an
SPSS dataset by the author and a graduate-level research assistant. Before data were
analyzed, all variables were examined using SPSS for accuracy of data entry, missing
values, and fit between their distributions and the assumptions of multivariate analyses.
Six individuals had missing values (four individuals were missing one item, and two were missing two values from various scales), and mean imputation was used to derive sums for instruments with missing data.

A bivariate correlation matrix was conducted to identify significant associations with group status (AD caregivers vs. non-caregivers). As group differences in age and race were found, partial correlations were utilized to control for these effects. A regression analysis was performed to explore the relations between possible selves, health behaviors, group membership, age, and race.

Results

Health-related Possible Selves

The participants in this study generated a total of 78 hoped-for health-related possible selves. AD caregivers produced 28 of the hoped-for health-related possible selves, and the remaining 50 hoped-for health-related possible selves were listed by non-caregivers. The participants in this study also reported a total of 115 feared health-related possible selves, with 44 of the feared health-related possible selves being produced by AD caregivers and 71 of the feared health-related possible selves being generated by non-caregivers. Of the 115 total feared health-related possible selves, 15 involved Alzheimer’s disease. Nine of these feared health-related possible selves involving Alzheimer’s disease were listed by AD caregivers, and six were provided by non-caregivers.
Bivariate and Partial Correlations

Bivariate correlations revealed that statistically significant relations existed between participants who were not caring for an individual with Alzheimer’s disease and participant age (.412, \(p < .001\)), self-report of being African American (.385, \(p < .001\)), number of possible selves related to Alzheimer’s disease (-.294, \(p < .05\)), amount of light exercise (-.282, \(p < .05\)), and having more recently attended a dental appointment (.284, \(p < .05\)). When controlling for group differences in age and race using partial correlations, no significant associations were found between caregiving status and possible selves or health behaviors.

Regression analyses

Regression analyses were performed to explore the relations between group membership, age, race, and hoped-for health-related, feared health-related, and AD-related possible selves. The analyses including hoped-for health-related and feared health-related possible selves revealed no significant findings. The model for AD-related possible selves, which also included years of caregiving experience, was significant, \(F(3,45) = 4.49, p = .008\), partial \(\eta^2 = .23\). White participants were more likely to report AD-related possible selves (\(M = .59\)) than were African American participants, (\(M = .17\)).

Post-hoc exploratory analyses were conducted to examine potential explanations for the difference in AD-related possible selves due to race. Significant bivariate associations with race included number of years of education (\(r = .31, p = .03\), total
score for positive PANAS items ($r = .41, p = .003$), most recent visit with a medical
doctor ($r = -.34, p = .02$), amount of fruit consumed during the past week ($r = .32,
p = .02$), and Alzheimer’s disease knowledge ($r = -.35, p = .01$). Of these, number of
years of education ($r = -.34, p = .02$) and Alzheimer’s disease knowledge ($r = .38, p =
.007$) were also significantly associated with AD-related possible selves. A regression
analysis was conducted predicting AD-related possible selves by race, number of years of
education, and Alzheimer’s disease knowledge. The model was significant, $F(3, 45) =
6.88, p = .001, R^2 = .56$, adjusted $R^2 = .27$. Race ($\beta = -.30, p = .04$) and Alzheimer’s
disease knowledge ($\beta = .26, p = .056$) were significant predictors of AD-related possible
selves. White participants and those with greater knowledge of Alzheimer’s disease were
more likely to report AD-related possible selves.

A regression analysis was performed to explore the relations between group
membership, age, race, and health behaviors. There were no significant findings.

Discussion

While the hypothesis that AD caregivers would have more health-related possible
selves than non-caregivers was not supported, a significant difference in the number of
Alzheimer’s disease-related possible selves was found to exist based on race. White
participants were more likely to generate possible selves pertaining to Alzheimer’s
disease than were African American participants, and this difference may be due to a
number of factors. Of the factors related to participant race (i.e., education, positive
affect, time since most recent visit with a medical doctor, fruit consumption, and
Alzheimer’s disease knowledge), differences between White and African American participants with respect to Alzheimer’s disease knowledge is the most likely explanation for the racial difference in the number of Alzheimer’s disease-related possible selves. In this sample, African American participants had completed more years of education on average than White participants, but White participants earned higher average scores on a test of knowledge about Alzheimer’s disease. It would appear then that knowing more about Alzheimer’s disease, or simply being more aware of the disorder, might increase the likelihood that individuals form images of themselves having the disease in the future.

Having possible selves related to the development of Alzheimer’s disease may appear to be a negative outcome, but it is important to remember that possible selves can serve a motivational purpose. Individuals who imagine themselves having Alzheimer’s disease in the future may seem more inclined to engage in health behaviors intended to help them avoid or delay the disease. This tendency was not demonstrated in the current study, however, as no significant differences in health behavior rates were detected. A potential explanation for this finding may be drawn from Protection Motivation Theory (PMT; Fry & Prentice-Dunn, 2006; McMath & Prentice-Dunn, 2005; Prentice-Dunn, Floyd, & Flourney, 2001; Prentice-Dunn & Rogers, 1986). According to PMT, the likelihood that one will change their behavior in response to a health threat is increased when they: (a) feel they are vulnerable to the threat, (b) view the threat as serious, (c) feel confident they can change their behavior, and (d) believe that their behavior change will help them avoid the threat. In the case of Alzheimer’s disease, individuals may have
a high threat appraisal for Alzheimer’s disease, but due to the uncertainty surrounding the causes of and remedies for Alzheimer’s disease, coping appraisal is likely to be low. Therefore, beliefs about developing the disease in the future may not lead to preventive health behaviors, especially if individuals perceive that preventive health behaviors are unlikely to help them prevent or ameliorate Alzheimer’s disease.

Limitations

A limitation of this study is the difference in both age and racial makeup between the AD caregiver and non-caregiver groups. As a group, the AD caregivers were significantly younger and more likely to be White than were the non-caregivers in this study, and this likely resulted from both the difficulty recruiting AD caregivers relative to non-caregivers and the outlets through which both AD caregivers and non-caregivers were recruited for this study.

Before recruiting commenced, it was anticipated that the AD caregivers included in the current study would in large part be drawn from among the participants in a pre-existing AD caregiver study being conducted in Central Alabama. This plan never came to fruition, however, as the agency sponsoring the AD caregiver study did not agree to refer their participants to the current study. In order to find an adequate sample of AD caregivers for the current study, the author contacted numerous caregiver support groups in Central and West Central Alabama, eventually finding three support groups that would permit the author to recruit from among their members. The resulting sample of AD caregivers in the current study largely represents the demographic characteristics (i.e.,
age, race) of the caregiver support groups from which they were drawn, and is consistent with the demographic makeup of all Alabama residents.

Another important limitation of this study is the low inter-rater reliability obtained for both the health-related possible selves and the health-related possible selves related to Alzheimer’s disease. While the author and two independent coders followed the possible selves coding scheme employed in previous studies (e.g., Frazier & Hooker, 2006; Hooker, 1999), the current study represented the first attempt at coding possible selves undertaken by the author or either of the two independent coders.

The author and the two independent coders experienced several difficulties in coding health-related possible selves. First, it was found that while using the aforementioned possible selves coding scheme, many of the possible selves reported by participants could be categorized into more than one category. For instance, possible selves related to exercise might be classified as a physical-, lifestyle-, health-, or independence/dependence-related possible selves. Second, the distinction between possible selves and current states of being was quite fuzzy. For example, a participant might proclaim that they “try to exercise,” but it was not always clear whether this indicated that exercise is something the participant attempts (and maybe even fails) to do only at the present time, or if the participant truly envisions themselves exercising at some point in the future. More practice conducting possible selves interviews, more familiarity with coding possible selves, and more experience with the possible selves
coding scheme used in this study would likely result in an improvement in the inter-rater reliabilities reported for this study.

**Implications for Future Studies**

In spite of this study’s limitations, a number of legitimate ideas remain for investigation in future studies. First, it would appear that the concept of health-related possible selves, including those pertaining to Alzheimer’s disease, had salience for the participants in this study. Participants generally had no difficulty generating thoughts, ideas, and images about their health in the future, and comments about Alzheimer’s disease were not uncommon. The prevalence of Alzheimer’s disease-related possible selves was illustrated by quotes from participants. One participant reported, “I have a fear of becoming Alzheimer’s because so many people now have it.” Another participant explained, “I have a mother who is in the end stages of Alzheimer’s disease and not knowing whether that disease is hereditary or not has caused for a little bit of anxiety.” Such quotes demonstrate the potential impact that knowing others who have Alzheimer’s disease or fearing the contribution of heredity have on developing Alzheimer’s disease-related possible selves. Initial analyses suggested that, as predicted, AD caregivers might generate a significantly greater number of possible selves related to Alzheimer’s disease, even as this relation was ultimately accounted for by race. Continuing the current study with AD caregiver and non-caregiver groups that are balanced in regard to age and race holds promise and may help to clarify whether it is age, race, or caregiving status that plays the greater role in the generation of health-related and AD-related possible selves.
Second, it was noted that participants in this study commonly reflected on the role of religion and spirituality in the maintenance of their health. When prompted to discuss any feared possible selves in the domain of health, one participant responded, “I don’t fear any of that. I pray all the time, and when I pray, I turn it loose.” Another participant gave a similar response: “I’m a Christian, and I know God will take care of His own, and I trust Him.” While religious faith or spirituality can certainly serve as a positive coping mechanism in the health domain, particularly when one’s health complications are outside their control, the possibility exists that some participants in this study may be ceding their ability to ward off preventable illness by deferring control over their health to their religious or spiritual beliefs. Individuals with such a passive reliance on religion or spirituality may be denying themselves the benefits that come from the active practice of preventive health behaviors while putting themselves at risk for chronic illness. Studying the relation between religion/spirituality and health behaviors may distinguish whether religious/spiritual coping serves as a protective or a risk factor for AD caregivers and non-caregivers and may also inform efforts to encourage the adoption of preventive health behaviors.
References


on September 19, 2007.


Appendix 1

Sociodemographics
1. What is your date of birth?
2. How old are you now?
3. What is your sex or gender?
   - Male
   - Female
   - If “other”, please specify
4. How would you describe your primary racial or ethnic group?
   - White, Caucasian
   - Black, African American
   - Native American, Eskimo, Aleut
   - Asian or Pacific Islander
   - Hispanic, Latino
   - No primary group
   - Other
   - If “other”, please specify
5. How many years of education have you completed?
6. What is the highest level of education you have achieved?
   - Less than high school diploma
   - High school diploma/GED
   - Some college
   - Associates or Bachelors degree
   - Graduate school
7. Are you currently employed?
   - No
   - Yes (20 hours or less per week)
   - Yes (more than 20 hours per week)
8. How hard is it for you to pay for the basics like food, housing, and heating?
   - Very difficult
   - Difficult
   - Not very difficult
   - Not at all difficult
9. Has a doctor diagnosed anyone in your family with Alzheimer’s disease or dementia?
   - No
   - Yes
10. If “yes” to Question 9, how is this person related to you?
11. Have you ever provided caregiving services for a family member, friend, or another individual?
   - No
   - Yes
12. If “yes” to Question 11, did this individual have Alzheimer’s disease or dementia?
13. If “yes” to Question 12, how long ago did you provide caregiving services?
14. If “yes” to Question 12, for how long did you provide caregiving services?
15. Do you currently provide caregiving services for a family member, friend, or another individual?
   • No
   • Yes
Appendix 2

Telephone Interview for Cognitive Status – Modified (TICS-M)

I would like to ask you some questions to check your memory and concentration. Some of the questions may be easy and some will be harder. Take your time if you need to. We can skip over questions if you don’t understand them.

1. Please tell me your full name.  (Prompt: Your name as it appears on your birth certificate.)
   You may ask the client to provide his first or last name if he does not provide both automatically.

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2. What is your age? Age _____

3. Without looking at a calendar or watch, what is today’s date?

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4. What day of the week is it?

   ____________________________

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5. What season is it?

   ____________________________

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6. Without looking at your phone, can you tell me your phone number?

Maximum of two attempts on Item # 7:

7. Now I would like you to count backwards from 20 to 1.

   Indicate Errors:
   
   20  19  18  17  16  15  14  13  12  11  10  9  8  7  6  5  4  3  2  1

   Administer a 2nd time if 1st attempt was incorrect:

   OK. Let’s try this one more time.

   Indicate Errors:
   
   20  19  18  17  16  15  14  13  12  11  10  9  8  7  6  5  4  3  2  1
8. Now I’m going to read you a list of 10 words. Please listen carefully. When I am done, tell me as many words as you can, in any order. [Please do not write anything down.] I will read the list only once. If you don’t understand a word, that’s all right. Just try to repeat what you heard. If you’re ready, I’ll begin.

(You can repeat the instructions but not the word list. Read the words at the rate of one word every two seconds.)

The words are:

Cabin………Pipe…………Elephant……..Chest……..Silk………
Theatre…….Watch……….Whip…………Pillow……..Giant

Now please repeat the words that you remember.

(Record all words up to 20 words even if not on the list. Only the words from the list are scored as correct. Repeated words are recorded but not scored.)

1_______________ 6_______________ 11______________ 16______________
2_______________ 7_______________ 12______________ 17______________
3_______________ 8_______________ 13______________ 18______________
4_______________ 9_______________ 14______________ 19______________
5_______________ 10______________ 15______________ 20______________

TOTAL OF CORRECT RESPONSES (Max. of 10 pts.): ______

Was the client speaking nonsense words? Circle:  Yes  No

9. Please subtract 7 from 100 and then subtract 7 from that number until I tell you to stop.

Record exact responses. Do not inform client of errors. Stop client after five responses. If client refuses to complete the task ask them: “What is 100-??” Record the response. Then say: “Subtract seven from that number.” Record each response. If the client refuses to continue after first response, score remaining items as incorrect.

1_______ 1  0
2_______ 1  0
3_______ 1  0
4_______ 1  0
5_______ 1  0
10. What do people usually use to cut paper?
   (Accept only “scissors” or “shears” as correct.)
   Correct: 1  Incorrect: 0  DK: 7  Refused: 8

11. How many things are in a dozen?
   (Accept only “12” as correct.)
   Correct: 1  Incorrect: 0  DK: 7  Refused: 8

12. What do you call the kind of prickly plant
    that lives in the desert?
   (Accept only “Cactus” or a kind of cactus,
    e.g. “Prickly Pear” as correct.)
   Correct: 1  Incorrect: 0  DK: 7  Refused: 8

13. What animal does wool come from?
   (Accept only “sheep” or “lamb” as correct.)
   Correct: 1  Incorrect: 0  DK: 7  Refused: 8

14. Please say this exactly as I say it:
    “No ifs, ands, or buts.”
   Correct: 1  Incorrect: 0  DK: 7  Refused: 8

15. Say this: “Methodist Episcopal.”
   (Listen carefully. Each word must be said clearly
    and distinctly. For example, “Methodis Epistopal” would be
    scored as incorrect.)
   Correct: 1  Incorrect: 0  DK: 7  Refused: 8

16. Who is the President of the United States
    right now?
    First: ____________  Correct: 1  Incorrect: 0  DK: 7  Refused: 8
    Last: ____________   Correct: 1  Incorrect: 0  DK: 7  Refused: 8

17. Who is the current Vice-President?
    First: ____________  Correct: 1  Incorrect: 0  DK: 7  Refused: 8
    Last: ____________   Correct: 1  Incorrect: 0  DK: 7  Refused: 8

For Item # 18: Do not repeat the instructions. You may say, “Just try to do what you
think I said.”

18. With your finger, please tap 5 times on the
    part of the phone that you speak into.
    [or With your finger, please tap 5 times on
     the top of the table.]
   Correct: 1  Incorrect: 0  DK: 7  Refused: 8

19. Now I’m going to say a word and I want
    you to say its opposite. For example, I
    might say “hot” and you would say “cold.”
    What is the opposite of “east”?
    (Accept only “west” as correct.)
   Correct: 1  Incorrect: 0  DK: 7  Refused: 8
20. **What is the opposite of “generous”?**

Score any of the following as correct:

Niggardly  Selfish  Misery  Not generous  Sparse  
Scrooge  Greedy  Mean  Ungenerous  Chintzy  
Tightwad  Stingy  Meager  Penurious  Frugal  
Hoarding  Tight  Skimpy  Parsimonious  Scotch  
Restrictive  Skint  Cheap

Record any other word: __________________

21. A few minutes ago, I read you a list of ten words and asked you to repeat them back to me. Please tell me all of those words you can still remember.

1_____________ 6_____________ 11_____________ 16_____________ 
2_____________ 7_____________ 12_____________ 17_____________ 
3_____________ 8_____________ 13_____________ 18_____________ 
4_____________ 9_____________ 14_____________ 19_____________ 
5_____________ 10_____________ 15_____________ 20_____________

**TOTAL OF CORRECT RESPONSES (Max. of 10 pts.): ______**

Was the client speaking nonsense words? Circle:  Yes  No

**TICS-M TOTAL SCORE:** ______

*(Total Possible = 50; Cut-off < 20)*
The Short Form-12 Health Survey

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Thank you for completing this survey!

1. In general, would you say your health is:
   - Excellent
   - Very Good
   - Good
   - Fair
   - Poor

2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
   Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf
   - Yes, Limited a Lot
   - Yes, Limited a Little
   - Not Limited at All
   Climbing several flights of stairs
   - Yes, Limited a Lot
   - Yes, Limited a Little
   - Not Limited at All

3. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?
   Accomplished less than you would like
   - All of the time
   - Most of the time
   - Some of the time
   - A little of the time
   - None of the time
   Were limited in the kind of work or other activities
   - All of the time
   - Most of the time
   - Some of the time
   - A little of the time
   - None of the time
4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

Accomplished less than you would like
- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

Did work or other activities less carefully than usual
- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
- Not at all
- A little bit
- Moderately
- Quite a bit
- Extremely

6. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much time during the past 4 weeks:

Have you felt calm and peaceful?
- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

Have you felt downhearted and depressed?
- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time
Did you have a lot of energy?
- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?
   Have you felt downhearted and depressed?
   - All of the time
   - Most of the time
   - Some of the time
   - A little of the time
   - None of the time
Appendix 4

Health-related possible selves

Hoped-for health-related possible selves introduction

Probably everyone thinks about the future to some extent. When doing so, we usually think about the kinds of experiences that are in store for us and the kinds of people we might possibly become. Sometimes we think about what we probably will be like, other times about the ways we are afraid we might turn out to be, and other times about what we hope or wish we could be like.

One way of talking about this is to talk about possible selves – selves we might possibly be. Some of these possible selves seem quite likely, for example, ‘being a grandparent’ or ‘vacationing in Florida’. Others may be only vague thoughts or dreams about the future, like ‘traveling in space’ or ‘winning the lottery’. In addition, we may have possible selves that are feared or dreaded, such as ‘having cancer’ or ‘being a bag lady’. Some of us may have a large number of possible selves in mind while others may have only a few.

In the space below, please list all the hoped-for possible selves related to your health that you currently imagine for yourself.

Feared health-related possible selves introduction

In addition to having hoped-for possible selves related to our health, we may have images of ourselves in the future that we fear or dread. Some of these feared possible selves may seem quite likely, like ‘being in poor health’, while others may seem quite unlikely, like ‘being a bag lady’. Some of us may have a large number of feared possible selves in mind, while others may have only a few.

In the space below, please list the feared possible selves related to your health that you currently imagine for yourself.

Prompts

What do I hope my health will be like in the future?
How might my health change for the worse in the future?

Follow-up possible selves questions

How capable do you feel of accomplishing (preventing) this possible self?
How likely do you think this possible self is to come true?
Think about the role this possible self has played in your life this month. We often do things (or don’t do things) to make a possible self more likely to come true (for example, going on a diet to become the ‘thin’ possible self). Please list anything you have done (or not done) in the last month to make this possible self come true.
Appendix 5

*Health Survey (adapted from the National Health Interview Survey)*

1. **On average, how many hours of sleep do you get in a 24-hour period?**
   
   1-24 hours 1-24

2. **In the PAST YEAR, how often did you drink any type of alcoholic beverage?**
   * Read if necessary: "How many days per week, per month, or per year did you drink?"
   
   Never 0
   1-365 day(s) 1-365

3. **On how many of the PAST 30 DAYS did you smoke a cigarette?**
   
   None 0
   1-30 days 01-30

4. **How often do you do LIGHT OR MODERATE LEISURE-TIME physical activities for AT LEAST 10 MINUTES that cause ONLY LIGHT sweating or a SLIGHT to MODERATE increase in breathing or heart rate?** * If necessary, prompt with: How many times per day, per week, per month, or per year do you do these activities?
   
   Never 0
   1-995 time(s) 1-995

5. **How often do you do VIGOROUS leisure-time physical activities for AT LEAST 10 MINUTES that cause HEAVY sweating or LARGE increases in breathing or heart rate?** * Read if necessary: How many times per day, per week, per month, or per year do you do these activities?
   
   Never 0
   1-995 time(s) 1-995

6. **How often do you do LEISURE-TIME physical activities specifically designed to STRENGTHEN your muscles such as lifting weights or doing calisthenics?** (Include all such activities even if you have mentioned them before.) * Read if necessary: How many times per day, per week, per month, or per year do you do these activities?
   
   Never 0
   1-995 time(s) 1-995
7. About how long has it been since you last saw or talked to a doctor or other health care professional about your own health? Include doctors seen while a patient in a hospital.

- Never 0
- 6 months or less 1
- More than 6 mos, but not more than 1 yr ago 2
- More than 1 yr, but not more than 2 yrs ago 3
- More than 2 yrs, but not more than 5 yrs ago 4
- More than 5 years ago 5

8. DURING THE PAST 12 MONTHS, HOW MANY TIMES have you seen a doctor or other health care professional about your own health at a DOCTOR'S OFFICE, A CLINIC, OR SOME OTHER PLACE? DO NOT INCLUDE TIMES YOU WERE HOSPITALIZED OVERNIGHT, VISITS TO HOSPITAL EMERGENCY ROOMS, HOME VISITS, DENTAL VISITS, OR TELEPHONE CALLS.

- None 0
- One 1
- Two-Three 2
- Four-Five 3
- Six-Seven 4
- Eight-Nine 5
- Ten-Twelve 6
- Thirteen-Fifteen 7
- Sixteen or more 8

9. DURING THE PAST 12 MONTHS, have you had a flu shot? A flu shot is usually given in the fall and protects against influenza for the flu season.* Read if necessary: A flu shot is injected in the arm. Do not include an influenza vaccine sprayed in the nose.

- Yes 1
- No 2

10. About how long has it been since you last saw a dentist? Include all types of dentists, such as orthodontists, oral surgeons, and all other dental specialists, as well as dental hygienists.

- Never 0
- 6 months or less 1
- More than 6 mos, but not more than 1 yr ago 2
- More than 1 yr, but not more than 2 yrs ago 3
- More than 2 yrs, but not more than 5 yrs ago 4
- More than 5 years ago 5
11. OVER THE PAST WEEK, on how many days did you eat five or more servings of vegetables?

Zero 0
One 1
Two 2
Three 3
Four 4
Five 5
Six 6
Seven 7

12. OVER THE PAST WEEK, on how many days did you eat five or more servings of fruit?

Zero 0
One 1
Two 2
Three 3
Four 4
Five 5
Six 6
Seven 7
Appendix 6

Positive and Negative Affect Schedule (PANAS)

This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you’ve felt this way during the last week.

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Slightly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>or</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at All</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

|                    |     |     |     |     |     |
|______ | Interested |     |     |     |     |
|______ | Distressed |     |     |     |     |
|______ | Excited |     |     |     |     |
|______ | Upset |     |     |     |     |
|______ | Strong |     |     |     |     |
|______ | Guilty |     |     |     |     |
|______ | Scared |     |     |     |     |
|______ | Hostile |     |     |     |     |
|______ | Enthusiastic |     |     |     |     |
|______ | Proud |     |     |     |     |

|______ | Irritable |     |
|______ | Alert |     |
|______ | Ashamed |     |
|______ | Inspired |     |
|______ | Nervous |     |
|______ | Determined |     |
|______ | Attentive |     |
|______ | Jittery |     |
|______ | Active |     |
|______ | Afraid |     |
This section deals with statements people might make about how they feel. Let me give you a card with possible responses. [Give respondent card.] For each of the statements, please indicate how often you have felt that way during the past week.

1. I was bothered by things that usually don’t bother me.
   a. Rarely or none of the time (<1 day)
   b. Some or a little of the time (1-2 days)
   c. Occasionally or a moderate amount of the time (3-4 days)
   d. Most or almost all of the time (5-7 days)

2. I did not feel like eating; appetite was poor.
   a. Rarely or none of the time (<1 day)
   b. Some or a little of the time (1-2 days)
   c. Occasionally or a moderate amount of the time (3-4 days)
   d. Most or almost all of the time (5-7 days)

3. I felt that I could not shake off the blues, even with help from my family and friends.
   a. Rarely or none of the time (<1 day)
   b. Some or a little of the time (1-2 days)
   c. Occasionally or a moderate amount of the time (3-4 days)
   d. Most or almost all of the time (5-7 days)

4. I felt that I was just as good as other people.
   a. Rarely or none of the time (<1 day)
   b. Some or a little of the time (1-2 days)
   c. Occasionally or a moderate amount of the time (3-4 days)
   d. Most or almost all of the time (5-7 days)

5. I had trouble keeping my mind on what I was doing.
   a. Rarely or none of the time (<1 day)
   b. Some or a little of the time (1-2 days)
   c. Occasionally or a moderate amount of the time (3-4 days)
   d. Most or almost all of the time (5-7 days)

6. I felt depressed.
   a. Rarely or none of the time (<1 day)
   b. Some or a little of the time (1-2 days)
   c. Occasionally or a moderate amount of the time (3-4 days)
   d. Most or almost all of the time (5-7 days)

7. I felt that everything I did was an effort.
   a. Rarely or none of the time (<1 day)
   b. Some or a little of the time (1-2 days)
   c. Occasionally or a moderate amount of the time (3-4 days)
   d. Most or almost all of the time (5-7 days)

8. I felt hopeful about the future.
   a. Rarely or none of the time (<1 day)
b. Some or a little of the time (1-2 days)
c. Occasionally or a moderate amount of the time (3-4 days)
d. Most or almost all of the time (5-7 days)

9. **I thought my life had been a failure.**
a. Rarely or none of the time (<1 day)
b. Some or a little of the time (1-2 days)
c. Occasionally or a moderate amount of the time (3-4 days)
d. Most or almost all of the time (5-7 days)

10. **I felt fearful.**
a. Rarely or none of the time (<1 day)
b. Some or a little of the time (1-2 days)
c. Occasionally or a moderate amount of the time (3-4 days)
d. Most or almost all of the time (5-7 days)

11. **My sleep was restless.**
a. Rarely or none of the time (<1 day)
b. Some or a little of the time (1-2 days)
c. Occasionally or a moderate amount of the time (3-4 days)
d. Most or almost all of the time (5-7 days)

12. **I was happy.**
a. Rarely or none of the time (<1 day)
b. Some or a little of the time (1-2 days)
c. Occasionally or a moderate amount of the time (3-4 days)
d. Most or almost all of the time (5-7 days)

13. **I talked less than usual.**
a. Rarely or none of the time (<1 day)
b. Some or a little of the time (1-2 days)
c. Occasionally or a moderate amount of the time (3-4 days)
d. Most or almost all of the time (5-7 days)

14. **I felt lonely.**
a. Rarely or none of the time (<1 day)
b. Some or a little of the time (1-2 days)
c. Occasionally or a moderate amount of the time (3-4 days)
d. Most or almost all of the time (5-7 days)

15. **People were unfriendly.**
a. Rarely or none of the time (<1 day)
b. Some or a little of the time (1-2 days)
c. Occasionally or a moderate amount of the time (3-4 days)
d. Most or almost all of the time (5-7 days)

16. **I enjoyed life.**
a. Rarely or none of the time (<1 day)
b. Some or a little of the time (1-2 days)
c. Occasionally or a moderate amount of the time (3-4 days)
d. Most or almost all of the time (5-7 days)

17. **I had crying spells.**
a. Rarely or none of the time (<1 day)
b. Some or a little of the time (1-2 days)
c. Occasionally or a moderate amount of the time (3-4 days)
d. Most or almost all of the time (5-7 days)

18. I felt sad.
   a. Rarely or none of the time (<1 day)
   b. Some or a little of the time (1-2 days)
   c. Occasionally or a moderate amount of the time (3-4 days)
   d. Most or almost all of the time (5-7 days)

19. I felt that people disliked me.
   a. Rarely or none of the time (<1 day)
   b. Some or a little of the time (1-2 days)
   c. Occasionally or a moderate amount of the time (3-4 days)
   d. Most or almost all of the time (5-7 days)

20. I could not get going.
   a. Rarely or none of the time (<1 day)
   b. Some or a little of the time (1-2 days)
   c. Occasionally or a moderate amount of the time (3-4 days)
   d. Most or almost all of the time (5-7 days)

**Scoring:**
This each item on this 20-item scale is scored from 0-3, ranging from “Rarely or none of the time” = 0 to “Most or almost all of the time” = 3.

Rencode: Items 4, 8, 12, and 16 should be reverse-scored so that “Rarely or none of the time” = 3 and “Most or almost all of the time” = 0.

The items should be summed for a total between 0 – 60, with higher numbers indicating higher levels of depression.
Appendix 8

Symptom Seeking Measure

1) Do you ever look for symptoms of Alzheimer’s disease in your own behavior?
   • No
   • Yes

2) Do you ever attribute symptoms which you have to Alzheimer’s disease?
   • No
   • Yes

3) Do you ever ask other people whether they notice your symptoms?
   • No
   • Yes
Appendix 9

Questions about AD Knowledge

1. Although most people with AD are older adults, people in their 30s and 40s can be diagnosed with AD. True
2. There is no cure for AD. True
3. Most family physicians are trained to diagnose AD. False
4. AD can be diagnosed by a blood test. False
5. Men are more likely to develop AD than women. False
6. Hardening of the arteries is a common cause of AD. False
7. Most people with AD live in nursing homes. False
8. The primary symptom of AD is memory loss. True
9. Aluminum is a significant cause of AD. False
10. Health law covers the cost of nursing homes for people with AD. False
11. Significant loss of memory and mental ability, commonly known as senility, is a normal part of aging. False
12. Drugs are available to treat the symptoms of AD. True
13. AD is fatal. True
14. Most cases of AD are hereditary. False
Table 1

Descriptive Characteristics of the Study Sample

<table>
<thead>
<tr>
<th>Demographic variable</th>
<th>Mean (Standard deviation) / Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years)</td>
<td>69.18 (9.78)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>41 (83.67%)</td>
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<tr>
<td>Male</td>
<td>8 (16.33%)</td>
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<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>31 (63.27%)</td>
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<tr>
<td>White</td>
<td>18 (36.73%)</td>
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<tr>
<td>Years of education</td>
<td>15.84 (3.23)</td>
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<tr>
<td>Perceived income adequacy</td>
<td>2.85 (.95)</td>
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<tr>
<td>Self-rated Health</td>
<td>2.57 (.96)</td>
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<tr>
<td>Cognitive Status</td>
<td>33.73 (6.67)</td>
</tr>
</tbody>
</table>

Note. Standard deviations and percentages are in parentheses. Perceived income adequacy was measured on a four-point Likert-type scale, with 1 = Very difficult, 2 = Difficult, 3 = Not very difficult, and 4 = Not at all difficult. Self-rated Health was measured on a five-point Likert-type scale, with 1 = Excellent, 2 = Very Good, 3 = Good, 4 = Fair, and 5 = Poor. Cognitive status was measured using the Telephone Interview for Cognitive Status-Modified TICS-M. Scores on the TICS-M range from 0 to 50.
Table 2
Descriptive Characteristics of Alzheimer’s Disease Caregivers and Non-caregivers

<table>
<thead>
<tr>
<th>Demographic variable</th>
<th>Condition</th>
<th>AD Caregivers (n = 18)</th>
<th>Non-Caregivers (n = 31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years)</td>
<td></td>
<td>63.94 (10.45) *</td>
<td>72.23 (8.07) *</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td></td>
<td>7 (38.9%) *</td>
<td>24 (77.4%) *</td>
</tr>
<tr>
<td>White</td>
<td></td>
<td>11 (61.1%)</td>
<td>7 (22.6%)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td>13 (72.2%)</td>
<td>28 (90.3%)</td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td>5 (27.8%)</td>
<td>3 (9.7%)</td>
</tr>
<tr>
<td>Years of education</td>
<td></td>
<td>15.17 (2.88)</td>
<td>16.23 (3.40)</td>
</tr>
<tr>
<td>Perceived income adequacy</td>
<td></td>
<td>2.61 (.98)</td>
<td>3.00 (0.91)</td>
</tr>
<tr>
<td>Self-rated Health</td>
<td></td>
<td>2.44 (.78)</td>
<td>2.65 (1.05)</td>
</tr>
<tr>
<td>Cognitive Status</td>
<td></td>
<td>34.11 (7.11)</td>
<td>33.52 (6.52)</td>
</tr>
</tbody>
</table>

* Significant at the .05 level; standard deviations and percentages in parentheses.

Note. Perceived income adequacy was measured on a four-point Likert-type scale, with 1 = Very difficult, 2 = Difficult, 3 = Not very difficult, and 4 = Not at all difficult.

Self-rated Health was measured on a five-point Likert-type scale, with 1 = Excellent, 2 = Very Good, 3 = Good, 4 = Fair, and 5 = Poor. Cognitive status was measured using the Telephone Interview for Cognitive Status-Modified TICS-M. Scores on the TICS-M range from 0 to 50.