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Short title: who will I be?

“Who will I be?”:

the future of the self as described by Alzheimer’s disease patients

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Conflict of Interest

The authors declare no conflict of interest.

We assessed how Alzheimer's disease (AD) patients would imagine their self in the future. AD patients and healthy controls were asked to generate statements beginning with "*I-will-be*" to describe how they saw themselves or how they wished to be in the future. These statements were analyzed in terms of four self-dimensions, i.e., physical self, social self, psychological self and self-cessation. The latter was investigated to assess how AD patients processed the idea of their own mortality. Findings demonstrated fewer total "*I-will-be*" statements in AD participants than in controls, suggesting that the construction of future self-concepts becomes weaker in the disease. Our results also demonstrated fewer statements related to the physical-self, the social-self and the psychological-self, and more statements related to self-cessation in AD participants than in controls. These findings suggest that AD patients are highly preoccupied by the idea of death when thinking about the future of their self.

Keywords: Alzheimer's disease; I will be; self; self-cessation

While research has demonstrated a diminished sense of self in patients with Alzheimer's disease (AD), this research has not assessed the ability of patients to generate concepts related to the future self. Our study addresses this issue by investigating how patients with AD would imagine their self in the future. However, and prior to turn to discuss our aim, it would be of interest to provide readers with insight into the multi-dimensional nature of the self. Although understanding the concept of the self is a major challenge for researchers, there is still little consensus about its definition. A crucial difficulty is that many conceptually similar terms have been used interchangeably, especially the terms "identity" and "self". Identity has been defined as the "extended self"¹ or the "narrative self"². Another challenge in the study of the self is its multi-dimensionality. A distinction has been suggested between the physical self, the social self and the psychological self³, inspired by the conception of William James⁴. This theory considers the physical self as the knowledge about one's own appearance (e.g., I am bald, I am overweight, I am tall), the social self as the knowledge about one's own social category (e.g., I am a clinician, I am a researcher), and the psychological self as the knowledge about one's own personality traits (e.g., I am kind, I am helpful).

The multi-dimensional nature of the self can be further understood by highlighting another distinction between the "minimal self" and the "reflexive self"⁵⁻⁸. While the "minimal self" refers to the biological urges that make organisms react to their goals with respect to the world's exteroceptive stimuli, the "reflexive self" refers to the consciousness of oneself as a subject of experience. The "minimal self" can therefore be considered as the most basic level of the self that does not require language or executive function^{5,6}, while the "reflexive self" can be related to the ability to project oneself in time as self-consciousness requires remembering who we are now, who we were before and, crucially, who we will be in the future^{1,9-11}. Clare, Marková, Roth and Morris

⁵ suggested another model dividing the self into four different dimensions: sensory registration, performance monitoring, evaluative judgment, and meta-representation. While sensory registration can be related to basic internal representations (i.e., “minimal self”), performance monitoring refers to monitoring ongoing task performance and identifying errors, evaluative judgment corresponds to the awareness of our abilities, and meta-representation refers to the fact of considering the perspective of others or other situations ⁵. Another conceptualization of the self was proposed by Klein, Cosmides and Costabile ¹², who defined five isolable components of the self: specific personal memories, facts about one’s personal history, representations of one’s own personality traits, experience of personal agency, and ability to introspect our own internal experiences (e.g., thoughts). Although there is no consensus about the definition and measure of the self, basic dimensions can be defined as the physical self, the social self and the psychological self ³.

The multidimensional nature of the self has been investigated by research in AD ¹³⁻¹⁸ (for a review, see ^{19,20}). This is illustrated in a study by Addis and Tippett ²¹, who evaluated AD patients and controls using the Twenty Statements Test ²² in which participants were required to provide 20 statements in response to the question “*Who am I?*”. Answers were later categorized as statements related to attributes (e.g., preferences, activities, traits), social identities (occupation, family information, roles), evaluative descriptions (e.g., abilities, beliefs) or physical descriptions. They obtained fewer responses on the Twenty Statements Test from AD participants than from controls, suggesting that access to self-concepts becomes weaker in the disease. **Although the study by Addis and Tippett (2004) has assessed self-concepts in AD, this study was not concerned by the ability of patients to describe their self in the future, which was the aim, and originality of our paper. This aim was, somehow, inspired by research on future thinking in AD.**

In a pioneering study on future projection in AD, Addis et al.²³ asked AD participants to remember past events and to simulate future events. They found a lack of specificity of both past and future thinking in the disease (for similar findings, see^{24, 25}). The subjective experience of future projection in AD was investigated by another study that analyzed both past and future projection in AD participants and controls with respect to specificity, ability to remember contextual information (e.g., when, where, and who), and personal significance²⁶. Participants were also asked to evaluate the subjective experience of past and future thinking by providing “relive/re-experience” responses if they recollected fair subjective experiences (e.g., emotion, thoughts, physical sensations) or a “recognize” response if retrieval did not trigger such an effect. Results showed that past and future projection in AD participants triggered similar autobiographical specificity and contextual performance, similar personal significance, and similar subjective experience. Interestingly, fewer “remember” responses were provided by AD participants than by controls during both past and future projection, suggesting a compromised subjective experience in both past and future projection in AD participants. **While research has demonstrated diminished future thinking in patients with AD (for a review, see²⁷), this research has not been concerned by the concept of self. Our paper thus focuses on the ability to generate concepts related to the future self in AD.**

Our study was inspired by another study assessed this issue in healthy populations. Based on the Twenty Statements Test, Rathbone, Conway and Moulin²⁸ designed the “I Will Be Task”, a task where undergraduate students (mean age = 19.43 years, SD = 1.26) had to generate three “*I will be*” statements (e.g., a role, a personality trait) describing the selves they might become in the future. According to the authors²⁸, the “I Will Be Task” can be used to examine phenomenological features of concepts related to the future self in both healthy and pathological populations. Using

the “I Will Be Task”, our study assessed how AD patients generated “*I will be*” statements to describe their future self. Another objective was to analyze their descriptions to understand which future self-dimension is compromised in the disease. In line with the conceptualization of Charlesworth et al. ³, we considered the three basic self-dimensions, i.e., physical self, social self, and psychological self, as they are inspired from the conception of William James ⁴. We also investigated a fourth dimension that we coined “self-cessation”. It was evaluated in light of a study assessing reminiscence, i.e., the process of thinking or telling about past experiences ²⁹. That study found that AD patients reminisce about their past to prepare themselves for the idea of their own mortality. Being preoccupied with death was attributed to the pressure of time as AD diagnosis entails the idea of a relatively short time remaining before death ²⁹. This preoccupation was also attributed to the physiological decline and the gradual loss of cognition and physiological functions that AD patients may be constantly confronted with ²⁹. The preoccupation with death may therefore trigger a concept of “self-cessation” when AD patients think about the future of their self.

To summarize, research has demonstrated a diminished ability to process concepts of the self in patients with AD. However, this research has not assessed the ability of patients to process concepts related to the future self. Our study addresses this issue by assessing AD patients’ ability to produce future concepts of the self, thanks to the “I Will Be Task” ²⁸. Another originality of our paper was that we further analyzed the “*I will be*” statements with regard to three basic self-dimensions, i.e., the physical self, the social self, and the psychological self ³, adding in a fourth dimension that seemed to be particularly relevant when AD patients think about their future self, i.e., self-cessation. Regardless of the self-dimension (i.e., physical, social, psychological, self-cessation), we hypothesized that, compared to controls, patients with AD would demonstrate poorer ability to generate statements describing the future self. We also hypothesized that,

compared to controls, patients with AD would produce fewer statements related with the physical self, the social self and the psychological self. We finally hypothesized that, compared to controls, patients with AD would produce more self-cessation statements.

Method

Participants

The study included 31 participants with a clinical diagnosis of probable AD at the mild stage (21 women and 10 men; M age = 71.26 years, SD = 5.15; M years of formal education = 8.48, SD = 2.39) and 34 older control adults (22 women and 12 men; M age = 68.94 years, SD = 7.59; M years of formal education = 9.44, SD = 2.58). AD participants were recruited from local retirement homes. The patients were diagnosed with probable AD dementia by an experienced neurologist or geriatrician based on the National Institute on Aging-Alzheimer's Association clinical criteria (McKhann et al., 2011). The fact that all patients had the amnesic form of AD was confirmed by their performance in the neuropsychological battery. Control participants, who were often the spouses or companions of the AD patients, were independent and living at their homes. They were matched with AD patients according to age [$t(63) = 1.42, p > .10$], gender [$X^2(1, N = 65) = .07, p > .10$] and educational level [$t(63) = 1.54, p > .10$].

Exclusion criteria for both AD patients and control participants were: significant psychiatric or neurological illness, history of clinical depression, alcohol or drug use. All participants presented no major visual or auditory acuity difficulties that would have prevented completion of the study tasks. They freely consented to participate and were able to withdraw whenever they wished. Note that the original approached sample included 42 AD participants. We

excluded seven patients due to history of psychiatric disorders, one because history of stroke, two because they did not complete the cognitive battery, and one patient wished to withdraw. Also note that we tested the ability to sign the consent by inviting the patients to explain the purpose of the study back to the investigator. Finally, note that the mild stage of AD was defined at the level of 20 points and more on the Mini Mental State Exam (MMSE), as described below.

Cognitive characteristics

The cognitive characteristics of all participants were evaluated with a battery tapping general cognitive functioning, episodic memory, working memory, verbal fluency, shifting, and depression. General cognitive functioning was assessed with the MMSE³⁰. Verbal episodic memory was evaluated with the task of Grober and Buschke³¹ in its French adaptation³². Participants had to retain 16 words, each of which describes an item that belongs to a different semantic category. After immediate cued recall, the participants proceeded to a distraction phase, during which they had to count backwards from 374 in serial 20 s. This phase was followed by two minutes of free recall and the score from this phase (out of a maximum of 16) provided a measure of hippocampal-dependent verbal memory, which is closely linked to episodic memory. For working memory assessment, participants had to repeat a string of single digits in the same order (i.e., forward span) or in the reverse order (i.e., backward span). Verbal fluency was assessed with a task on which participants had two minutes to generate as many words as they could beginning with the letter P. Proper nouns and variations on words (e.g., “psychology” and “psychologist”) were not allowed. The score was the number of correctly generated words. Shifting was assessed with the Plus–Minus task, and the score referred to the difference between the time for List 3 (shifting between addition and subtraction) and the average times for Lists 1 (addition) and 2 (subtraction). For assessment of depression, the Hospital Anxiety and Depression

Scale ³³ was administered. This self-report scale consists of seven items on a four-point scale ranging from 0 (not present) to 3 (considerable). As recommended by Herrmann ³⁴, the cut-off for definite depression was set at > 10/21 points. Neuropsychological and clinical scores for study participants are summarized in Table 1.

INSERT TABLE 1 HERE

Procedures

I Will Be Task

Participants were asked to verbally produce short sentences to describe themselves in the future. They were instructed that the sentences should begin with “*in the future I will be*” and were explained that these sentences should describe “*how they may see themselves in the future or how they wish to be in the future*”. Participants were also instructed “*don’t worry about logic or importance, just provide the first words that come to your mind*”. When participants asked for more details, they were instructed that they may describe “*their future appearance, personality trait, or anything else they felt would describe their identity or existence in the future*”. During the task, a cue card was provided with the phrase “*in the future I will be...*”. There was no time constraint to provide the statements. When a participant stopped after producing a statement, the experimenter waited a few seconds before asking “*is there any other statement you would like to provide?*”. The task was interrupted when the participants had no more statements to produce.

Data coding

Data were coded according to four categories: physical self, social self, psychological self and self-cessation. In line with the procedures of Rathbone, Conway and Moulin ²⁸, statements were considered as describing the physical self if they reflected attributes that related to appearance

(e.g., beautiful, healthy, sick, AD-free), the social self if they reflected a social attribute or role (e.g., grandmother, worker, volunteering) and the psychological self if they reflected a personality trait (e.g., honest, confident) or an emotional state (e.g., happy, sad, calm). Statements were considered as describing self-cessation if they referred to mortality (e.g., dead, buried, deceased, gone, extinct, resting in peace). While some statements were easy to assign to a particular category (e.g., beautiful, grandmother), some were more difficult to classify, e.g., “*I will be resting*” was assigned to the physical category as long as it was not completed by a word related to mortality (e.g., resting in peace). In line with guidance by Rhee, Uleman, Lee and Roman³⁵, statements describing two self-dimensions were analyzed considering the main unit of meaning. For instance, the statement “*I will be a good grandmother*” was assigned to the social category, as “a grandmother” is the main unit of meaning before “good”. When responses contained several closely related meanings (e.g., “*I will be kind and caring*”), only the first meaning was coded. Repeated statements were considered only once and those not beginning with “*I will be*” were excluded (e.g., some participants answered “*I will have*”). Vague descriptions were not taken into account (e.g., “*I will be someone*”) Data were coded by two independent judges and a post-coding comparison revealed 91% agreement between judges. Cases generating disagreement were discussed until consensus was reached.

The score referred to the total number of statements and the number of those attributed to each self category (see Figure 1).

Results

We first compared differences in the total number of statements and in those related to each dimension of self between AD participants and controls. We then compared the number of statements across the four self dimensions for each population. Owing to abnormal distribution of

the data, non-parametrical tests were conducted. Effect size was calculated by using Cohen's d criterion³⁶ (0.20 = small, 0.50 = medium, 0.80 = large).

A Mann-Whitney's U test showed that fewer total "*Who will I be?*" statements were generated by AD patients than by control participants ($Z = -4.32, p < .001, d = 1.25$), with means of 6.42 ($SD = 2.84$) and 10.26 ($SD = 3.28$), respectively. As illustrated in Figure 1, fewer statements related to the physical self ($Z = -3.14, p < .01, d = .89$), the social self ($Z = -3.63, p < .001, d = 1.02$) and the psychological self ($Z = -3.68, p < .001, d = 1.04$) were observed in AD participants than in controls. However, more statements related to self-cessation were observed in the former group than in the latter ($Z = -2.16, p < .05, d = .56$).

Although Friedman's ANOVA showed no significant differences between the production of statements related to the four self dimensions in AD participants [$X^2(3, N = 31) = .58, p > .10$], such differences were observed in controls [$X^2(3, N = 34) = 30.03, p < .001$]. A post-hoc Wilcoxon signed rank test showed that controls produced fewer statements related to self-cessation than to the physical self ($Z = -4.10, p < .001, d = 1.92$), social-self ($Z = -4.19, p < .001, d = 2.05$), or to the psychological self ($Z = -4.35, p < .001, d = 2.27$). All other comparisons were not significant. Unlike AD participants, controls produced few statements related to self-cessation.

INSERT FIGURE 1 HERE

Discussion

Thanks to the "I will be task"²⁸, our paper assessed whether AD patients would produce "*I will be*" statements to describe their future physical self, social self, psychological self, and self-cessation. Our findings demonstrated fewer total "I will be" statements in AD participants than in controls, suggesting that the construction of future self-concepts becomes weaker in the disease.

Our findings also demonstrated fewer statements related to the physical self, the social self and the psychological self but more statements related to self-cessation in AD participants than in controls. Although the former produced a similar number of statements in each of the four self dimensions, the latter produced fewer statements related to self-cessation than to the other three dimensions.

The impairment of the production of “*I will be*” statements in AD participants, as observed in our study, leads us to suggest that the ability to construct images and concepts related to the future self becomes weaker in the disease. The compromised ability to produce concepts related to the future self in AD, as observed in our study, adds to findings demonstrating that access to concepts related to the present self becomes weaker in the disease ²¹. Although the degradation of access to the past and present self has been extensively assessed in the literature, little is known about how patients with AD processes images related to future self. Our findings demonstrate a compromised ability to construct images and concepts related to the future self in AD and, interestingly, a preoccupation in the patients regarding self-cessation. This preoccupation may mirror how the patients with AD can prepare themselves for the idea of their own mortality. The preoccupation with death in AD can be attributed to the pressure of time. Indeed, AD diagnosis conjures up the idea of a relatively short amount of time left before death, as well as the notion of physiological decline and gradual loss of cognition. This preoccupation can be regarded in light of the Terror Management Theory that deals with fear of death ³⁷⁻³⁹. According to this theory, all humans are instinctively driven towards survival and continued existence, while simultaneously being aware of their inevitable mortality.

At a practical level, we suggest that, although caregivers should focus on the patients’ survival and continued existence, the patients’ preoccupation about death should also be considered. We believe that it is important to realize that such preoccupation may be normal as

some patients, especially those in the advanced stages of AD, may feel a sense of relief toward death. Within such approach, an interconnected link can be established between patients and medical staff about death preparation, which is inevitable at a given stage. This interconnected link should also involve families to prepare them for upcoming bereavement. Also, by accompanying patients with AD in processing self-cessation, clinicians can engage with patients in candid discussions about what the patients may expect throughout the decline continuum and the options available for care and support. Besides proposing a comprehensive picture for death preoccupation in patients with AD, another clinical contribution of our study is that it highlights how the “I will be task” may be used by clinicians to obtain information about how AD patients think about their future self. We believe that this task may provide clinicians with qualitative data on the accessibility of statements and concepts related to the future self in AD patients.

In normal aging, although one might expect that healthy older adults have a greater fear of death than younger people because they are closer to death, research suggests that fear of death declines with increasing age⁴⁰⁻⁴². This decline may be attributed to social, religious and moral meaning that older adults may build towards the idea of their own mortality (e.g., achieving symbolic immortality through the transmission of one's achievements to future generations, religious faith that may lead to the promise of immortality or the continuation of life in another form after bodily death)⁴³. The decline of the preoccupation with death in normal aging can also be understood in light of the Socioemotional Selectivity Theory^{44, 45}, according to which the perception of having limited time left in older adults generates the “positivity effect”, i.e., the disproportionate preference for positive information and the selective inhibition of negative affect in normal aging. The Socioemotional Selectivity Theory and the Terror Management Theory may

explain the poor production of statements related to self-cessation in our control participants, while AD patients show a major preoccupation with death when thinking about their future self.

A limitation of our study is the absence of autobiographical memory assessment, as this type of memory has been found to support the feeling of continuity in time⁴⁶. Autobiographical decline as observed in AD⁴⁶⁻⁵¹ may therefore result in a compromised sense of the future self. **Another limitation may be lack of assessment of pre disease beliefs (e.g., whether patients have a particular idea about death prior to diagnosis).**

In conclusion, the human sense of self encompasses multiple dimensions, ranging from the “minimal self” to the consciousness of oneself as an immediate subject of experience (i.e., the “reflexive self”). The literature suggests that AD patients present impairments in many aspects of the self, especially those including higher-level self-awareness. Our paper extends these findings by demonstrating a compromised ability to construct images and concepts related to the future self in AD.

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Table 1

Cognitive characteristics of Alzheimer's disease (AD) patients and control participants

	Task	AD <i>n</i> = 31	Older adults <i>n</i> = 34	Effect size
General cognitive functioning	Mini-Mental State Examination (MMSE)	21.45 (1.42)***	27.94 (1.49)	3.90
Verbal memory	Grober and Buschke	5.77 (2.35)***	10.85 (3.06)	1.87
Working memory	Forward span	5.03 (1.08)***	6.56 (1.64)	1.11
	Backward span	3.65 (1.19)**	4.56 (1.59)	.71
Verbal fluency	Letter "P"	16.42 (5.68)***	23.15 (5.22)	1.24
Shifting	Plus-Minus	11.59 (6.03)***	6.06 (3.16)	1.17
Depression	HADS	8.48 (1.56)***	6.79 (2.30)	.92

Note. Standard deviations are given between brackets; maximum score on MMSE was 30 points; maximum score on the Grober and Buschke (1987) task was 16 points; performances on forward and backward spans referred to number of correctly repeated digits; fluency score was number of correctly generated words; scores on Plus-Minus tasks referred to reaction time; cut-off on HADS (Hospital Anxiety and Depression Scale) was > 10/2 points; differences between groups were significant at: ** $p < .01$, *** $p < .001$; after checking for normality of distributions, comparison for MMSE and forward span was established with Mann-Whitney's U test (abnormal distribution) and comparisons for remaining tasks were established with Student's t-test (normal distribution). Effect size was calculated by using Cohen's d criterion³⁶ (0.20 = small, 0.50 = medium, 0.80 = large).

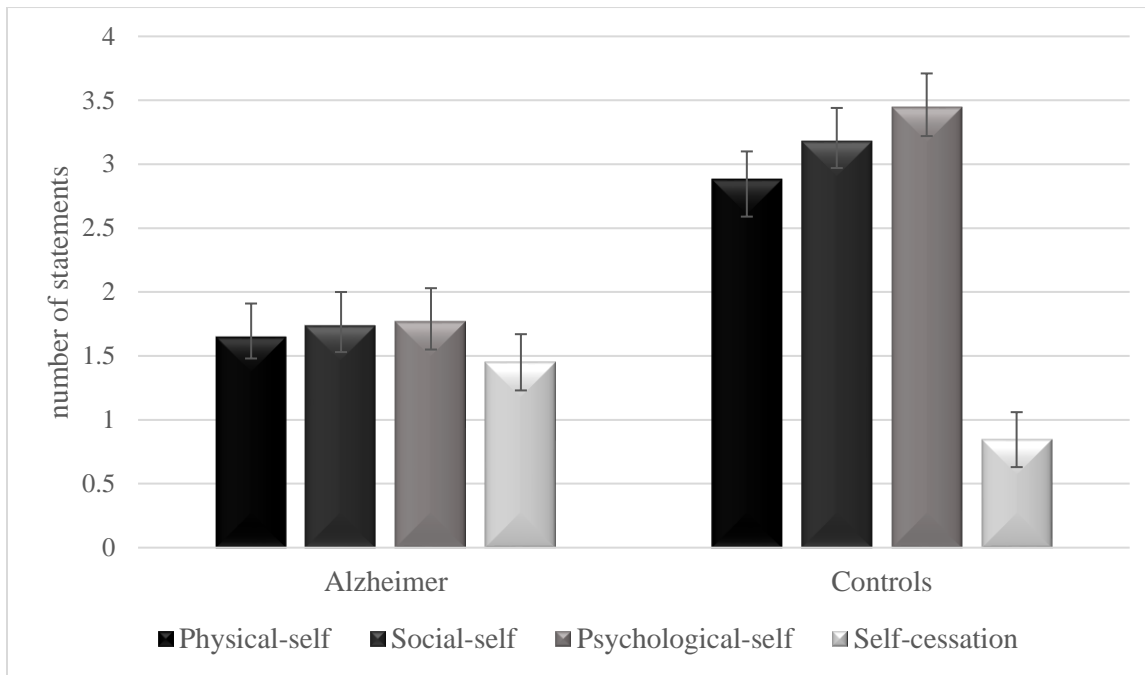


Figure 1.

Number of “*I will be*” statements related to each self dimension in Alzheimer’s disease participants and controls; error bars are within a 95% confidence interval.