

Short title: memory of diagnosis

The “sickness” memory:

Can patients with Alzheimer’s disease remember the diagnosis announcement?

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Background: Diagnosis of Alzheimer's disease (AD) can cause substantial psychological distress in patients. We thus assessed how patients with AD remember the announcement of diagnosis.

Methods: We recruited 47 participants with mild AD (26 women; M age = 68.89 years, SD = 7.37; M years of formal education = 9.74, SD = 3.00). We invited the participants to remember the moment when their clinicians announced their diagnosis, within 6 months of the event, as well as a control memory, over the same period. We analyzed memory retrieval regarding specificity, as well as the subjective experience of retrieval (i.e., regarding mental time travel, visual imagery, emotion and importance).

Results: No significant differences were observed between memory of diagnosis and control memory regarding specificity, mental time travel and visual imagery. However, memory of diagnosis triggered a more intense emotional experience and feeling of importance than control memory.

Discussion: Retrieval of the diagnosis announcement can activate a strong emotional and personally important experience in patients with AD. When remembering the diagnosis announcement, patients with AD may re-experience some features of that turning point in which they shift from "person" to "patient".

Keywords: autobiographical memory; Alzheimer's disease: diagnosis; diagnosis announcement;

The diagnosis of Alzheimer's disease (AD) can be considered as a turning point in the patients' life and in their sense of identity, which may shift from "person" to "patient". The consequences of the diagnosis are not limited to the announcing moment, but also extend to the long term. After diagnosis, patients must deal with the "patient" identity and face decisions about available treatment options and consequences to everyday life (e.g., quit driving, asking for assistance with challenging tasks.). Because receiving an AD diagnosis can be regarded as a turning point and a highly distressing event in the patients' life, we assessed in this preliminary study how patients integrate the diagnosis in their autobiographical narratives. More specifically, we assessed AD patients' memory of the diagnosis announcement in terms of its specificity and elements of subjective experience (i.e., regarding mental time travel, visual imagery, emotion and importance). We hypothesized that, since diagnosis announcement can be associated with strong subjective and emotional experience (e.g., shock, sadness, fear, anger or even deny) and represent a turning-point in their life, patients with AD can successfully retrieve specific details of that memory and that retrieval would be emotionally-laden.

Methods

Participants

We recruited 47 participants-with-mild-AD (26-women; $M_{age}=68.89$ years, $SD=7.37$; $M_{years\ of\ formal\ education}=9.74$, $SD=3.00$). Diagnosis was made following criteria developed by the Alzheimer's-Association-criteria-for-probable-Alzheimer's disease¹. Exclusion criteria for all participants were significant neurological/psychiatric-illness and alcohol or drug-use. The sample size was determined using G*Power. As our experimental design involved non-parametric data compared within subjects (see, section "statistical analysis"), sample size calculation was

conducted for Wilcoxon-tests. This calculation was based on 95% power, an estimated probability of making Type I error of .05, and a medium effect size of .50.

Procedures

We assessed memory for two autobiographical events: the memory for the diagnosis announcement vs a control memory. Regarding the memory of their diagnosis, we provided participants with the following instruction: “I would like to invite you to remember that moment when your doctor announced your Alzheimer’s-disease-diagnosis. Your memory should be, as far as possible, specific. You may also reconnect to the feeling and emotions that you experienced during that event”. Regarding the control memory, we provided participants with the following instruction: “I would like to invite you to remember a personal event that occurred on the last six months. Your memory should be, as far as possible, specific. You may also reconnect to the feeling and emotions that you experienced during that event”. The patients had two-minutes to retrieve each event. Note that in the control memory condition, patients were invited to retrieve an event that occurred in the last six months because the diagnosis announcement for all recruited participants also occurred in the last six months.

To assess the subjective experience of remembering, patients were invited after the memory of diagnosis and control memory to rate four items on a five-point scale (one point= not at all, five points= extremely). The four items assessed were: time-travel (“I feel that I am traveling back to the time it happened”); visual-imagery (“I can see the event in my mind”); emotion (“I can feel now the emotions I felt then”); and importance (“that event is significant for my life”).

Analysis of autobiographical specificity.

For each of the two-memories, we attributed zero-points, if there was no memory or only general information about a theme; one-point for a repeated or an extended event; two-points for an event situated in time and/or space; three-points for a specific event lasting less than 24h and situated in time and space; and four-points for a specific event situated in time and space enriched with subjective details.

Results

We compared specificity of retrieval and the four items reflecting subjective experience (as shown in Table1) between the two-conditions (i.e., memory of diagnosis vs. control memory). Analysis demonstrated no significant differences regarding specificity ($Z=1.34$, $p=1.81$, **Cohen's $d=.39$**), mental-time-travel ($Z=.58$, $p=.56$, Cohen's $d=.17$), or visual-imagery ($Z=.54$, $p=.59$, **Cohen's $d=.16$**) between memory of diagnosis and control-memory. However, patients rated memory of diagnosis as triggering higher levels of emotional-experience ($Z=4.10$, $p<.001$, **Cohen's $d=1.49$**), and as having greater importance ($Z=4.32$, $p<.001$, **Cohen's $d=1.62$**) than control memory.

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Discussion

Because the diagnosis announcement can be a turning-point in the patients' life, we assessed how patients with AD remember this event, by comparing the specificity and subjective experience of retrieval for the memory of AD diagnosis and for a control memory. We observed that the two memories were not different in terms of specificity, mental-time-travel and visual-

imagery. However, the memory of diagnosis triggered a more intense emotional-experience and higher importance was attributed to it than to the control-memory

The higher level of emotional-experience during retrieval of the memory of AD-diagnosis may correspond to the emotional-state experienced during the actual event of diagnosis announcement. When the clinician communicates the diagnosis, patients may experience strong emotional experiences including fear or shock that may encompass both psychological and physiological embodied states. The emotional experience during the announcement of diagnosis may also trigger denial, emotional dissociation, or conversely over-reactivity or even anger, especially in patients with anosognosia. Besides reporting higher levels of emotional-experience, patients with AD in our study also attributed a higher importance to the memory-of-diagnosis compared to the control memory, as can be expected for a turning point in the patient's life, during which they shift from "person" to "patient". The diagnosis may impact the patients' identity by evoking negative self-images, such as images of sickness and loss of autonomy. The diagnosis can also result in a discontinuity in the patients' life-story, potentially representing an exit point from the trajectory of a healthy life and an entry point into the trajectory of sickness trajectory towards the end of life. Therefore, retrieval of the AD diagnosis announcement by patients can rightfully activate strong emotional responses and be marked by high levels of personal experience.

Interestingly, no significant differences were observed regarding specificity of retrieval, against our hypothesis that higher specificity would be seen for the memory of AD diagnosis compared to the control-memory. The over-generality of autobiographical retrieval in AD^{2, 3} may hamper the ability of patients to retrieve any specific memories, even salient ones. Additionally, our analysis has demonstrated no significant differences between the two memories for mental-time-travel and visual-imagery. This finding is very important because, if the memory of diagnosis

had triggered high levels of mental-time-travel and visual-imagery, then this memory could have been processed as a traumatic event.

We propose that the memory of AD diagnosis can be regarded as a special case of autobiographical memory. Although patients with AD may fail to retrieve specific information regarding the diagnosis announcement, probably because of their prevailing retrograde-amnesia and general-cognitive-decline, they may be able to process the emotional and importance load of this memory. Thus, the memory of diagnosis can be situated in a level besides other self-defining memories, i.e., memories that lead to the creation of narrative scripts that serve as the ingredients for “chapters” across the lifespan⁴. In our view, similarly to other self-defining-memories, the memory of AD diagnosis activates identity processes by which patients with AD mark a turning point in which their identity shifts from “person” to “patient”. This assumption should however be tested in future research on self-defining-memories.

To summarize, this preliminary study demonstrates how, despite their amnesia, patients AD may successfully process the emotional and personal load of the memory of announcement of the AD diagnosis. The AD diagnosis announcement is arguably a turning point in the patients’ life-story and shapes their sense-of-identity.

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Conflict of Interest

The authors declare no conflict of interest.

Description of authors' role

MEH carried out the assessment, supervised by GC, CBB, & KG. PhA, PA, & DK contributed to data analysis and interpretation. All authors contributed to the study design and writing of the final manuscript.

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Table 1.

Specificity and subjective experience of memory of diagnosis and control memory in patients.

	Diagnosis memory	Control memory
Specificity	2.81 (.85) ^{n/s}	2.57 (.92)
Mental time travel	2.53 (.14) ^{n/s}	2.36 (1.11)
Visual imagery	2.13 (.95) ^{n/s}	2.28 (1.17)
Emotion	3.38 (1.26) ^{***}	2.15 (.95)
Importance	3.43 (1.02) ^{***}	2.23 (.96)

Note. Specificity score ranged from zero (lack of retrieval) to four (high specific retrieval) points, the subjective experience (i.e., mental time travel, visual imagery, emotion, importance) was rated from one (not at all) to five (extremely) points; ^{n/s} non-significant; ^{***} $p < .001$