

Qualitative assessment of self-identity in people with advanced dementia

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Abstract

This study aimed to understand the preserved elements of self-identity in persons with moderate to severe dementia attributable to Alzheimer's disease. A semi-structured interview was developed to explore the narrative self among residents with dementia in a residential care facility, and residents without dementia in an independent living setting. The interviews were transcribed verbatim from audio recordings and analyzed for common themes, while being sensitive to possible differences between the groups. The participants with dementia showed evidence of self-reference even though losses in explicit memory were evident. The most noticeable difference between the two groups was time frame reference. Nonetheless, all participants showed understanding of their role in relationships and exhibited concrete preferences. Our findings suggest that memory loss and other cognitive deficits associated with moderate to severe dementia do not necessarily lead to a loss of "self."

Keywords

Alzheimer's disease, care, dementia, personhood, self

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Introduction

Dementia due to Alzheimer's Disease (AD) historically has been understood in terms of a medical model that identifies the causes of the disease as brain-based and promotes the idea that medication is the best method for managing symptoms. According to this model, persons with AD experience a loss of *explicit memory*, the ability to consciously recollect and declare information about previous experiences, as a result of cell loss in medial temporal lobe structures that subserve this form of memory. The widespread acceptance of this model has contributed to the perception that people diagnosed with AD are "missing something"; they are less than whole persons because they cannot connect the past with their current state. Additionally, the model rules out the possibility that the selves of persons with AD may be implicitly expressed in behavior despite the loss of conscious recall (see for example, Sabat, 2006). Medical professionals who endorse the model thus often treat persons with AD as if they lack "selves" (see for example, Cohen & Eisendorfer, 1986; Franssen & Souren, 1994). Further, they either implicitly or explicitly encourage primary caregivers of persons with AD, including friends and relatives, to do the same.

Despite the pervasiveness of the medical model of AD, over the past 25 years it has been criticized by a subset of medical professionals and philosophers who have sought to better understand the purported loss of "self" that accompanies AD. Some authors who concede that persons with AD experience a loss of self deny that a loss of explicit memory is the cause. Rather, they attribute the loss to how persons with AD are treated by others—most notably, their primary caregivers. In the early 1990s, two groups of authors, Kitwood and Bredin (1992) and Sabat and Harré (1992) arrived at this conclusion independently (Sabat & Harré, 1992, p. 444).

According to Kitwood and Bredin (1992), a tension exists between medical models of dementia that emphasize losses and deficits on the one hand, and the recognition on the part of primary caregivers that the intrinsic humanity of people with diseases that lead to dementia symptoms remains intact. Specifically, they claim that:

On the one hand, people involved in caregiving often have a strong intuitive sense that even an individual who is disastrously impaired is still recognizably a person: on the other hand the progress of a dementing illness, especially if it involves a long stay in residential or nursing care, seems to be taking personhood away. (p. 274)

Recognition of this tension prompted the development of a movement towards "person centered" care of people with dementia, perhaps best embodied in Kitwood's *Dementia Care Mapping* approach for people with dementia in residential care facilities (Kitwood, 1993). Use of Kitwood's approach, however, has not been widespread.

In contrast to Kitwood and Bredin, Sabat and Harré (1992) argue that persons with AD retain those aspects of the self that are associated with their personal identities, but may lose those aspects that require validation by others. In their view, persons with AD have a self of personal identity ("Self 1") insofar as they exhibit "a reflexive grasp of the conditions for maintaining a specific self" and retain the ability to make either "self-indexed physiognomic avowals" (p. 451) or "communicate the indexical 'I', or 'my' or 'mine' via gesture" (p. 452). Yet, they maintain that there is a second sense of self ("Self 2"), the "socially constructed self," that is lost in AD. This notion of self is constituted by the multiple distinct social identities that emerge during a person's lifetime as s/he interacts with others and comes to occupy multiple distinct social roles (e.g. mother, grocery store clerk, school teacher,

traffic guard). For an individual to have a given social role requires an acknowledgment by other relevant people that the individual has that role. For example, a woman is only a mother insofar as her children and her spouse (for example) acknowledge this role and behave accordingly. The selves that constitute “Self 2” for Sabat and Harre are thus “joint productions” that “depend for their existence upon the cooperation of others in the social context” (pp. 452–453). Sabat and Harré (1992) and Sabat (2001, 2002b) explain that the reason persons with AD are often regarded as having lost their “selves” is that those who care for them fail or “refuse to cooperate in the constructive process” (p. 453), that is required for the “different social personae” (Sabat, 2002b, p. 27) that constitute the constructed self to emerge. They thus attribute “the primary cause of the loss of self” in persons with AD to “the way in which others view and treat the Alzheimer’s sufferer” (Sabat & Harre, 1992, p. 453).

Sabat and Harré (1992) and Sabat (2010) encourage primary caregivers to cooperate in the construction of the selves of persons with AD in a manner that reflects how that person views him/herself. Indeed, this is the approach they themselves take across numerous publications insofar as when they interview persons with AD they acknowledge not only the self of personal identity but also the social roles these persons previously occupied before they developed AD. Implementing Sabat and Harré’s strategy in practice thus requires that primary caregivers engage persons with AD in an effort to determine who they are and how they view themselves. Sabat and Harré’s prescription, therefore, is that primary caregivers should focus on what “selves” remain in persons with AD and play an active role in preserving these constructed selves rather than exclusively focusing on what has been lost. This strategy is exemplified and has been argued for by Sabat in a number of publications over the past 10 years (see for example, Sabat, 2001, 2002a, b; Sabat & Collins, 1999; Sabat & Gladstone, 2011; Sabat, Napolitano, & Fath, 2004). This strategy is also consistent with Kitwood’s person-centered approach to treating persons with AD.

However, current suggestions for improving the care of persons with AD still suffer from at least two limitations. First, the construct of self intrinsic to personhood has been defined in many ways across the philosophical and scientific literature (Herskovits, 1995), with no obvious way to adjudicate between competing definitions. While Sabat and Harré distinguish between the self of personal identity and socially constructed selves, Sabat (2001, 2002b) adds another distinct notion of self to this framework namely, a self that “is comprised of a person’s physical and mental attributes and beliefs about those attributes” (2002b, p. 27). He dubs this notion “Self 2,” renaming the socially constructed self of Sabat and Harré (1992, 1994) “Self 3.” As Sabat (2002b) demonstrates, in the context of interviews, persons with AD often express their beliefs about who they once were (e.g. a wordsmith) and those attributes they have lost (the ability to skillfully use words). For him, this constitutes a unique type of self.

In contrast to Sabat and Harré, other authors, like the cognitive scientist Ulric Neisser (1988), have suggested that research in cognitive science indicates *five* distinct kinds of self including, the ecological self (self in physical world), the interpersonal self (self in social world), the extended self (self of past and future), the private self (self behind the scene of social interactions), and the conceptual self (self that represents the self to the self). While Neisser’s framework has some overlap with that of Sabat and Harré, it points to other possible aspects of self that may be either lost or preserved in AD.

While each of the available definitions of the self, taken independently or in combination, may serve as valuable heuristics in research contexts for investigating the self in persons with

and without AD, the diversity of definitions and absence of a clear consensus is a potential obstacle to developing viable strategies in clinical contexts for improving the lives of persons with AD. We therefore developed a questionnaire for this study, which we intended to be a step in the general direction of creating an accessible and readily implementable tool for health care professionals. Our starting point was to take seriously findings about the self in persons with AD in the extant literature, but to remain agnostic about how many different kinds of self there might be. Instead, we began with the widespread assumption that all persons' lives are accompanied by a narrative. To determine the contents of this narrative, our approach was to ask persons with AD "Who are you?" using a set of questions that we took to be characteristic of the kinds of questions that a person is asked and asks when they meet someone for the first time and the two are trying to get to know each other.

A second limitation of current approaches to understanding the self in persons with AD, as Sabat claims, is that "there are no standard tests which measure aspects of selfhood in some quantitative way," and so "we must turn to other means by which this aspect of a person's being may be illuminated" (Sabat, 2002b, p. 26). We agree with Sabat that operationalizing the self is difficult, but that developing effective tools for detecting it in individuals is not impossible. In fact, despite a clear understanding of what the self is and whether it is many things or just one, there are at least points of consensus about how to access it. In this study, our starting point was to hypothesize that a semi-structured interview may assist in revealing preserved narrative qualities of "self" in those living with advanced AD.

We were motivated by two additional considerations in designing the questionnaire that we used to conduct our interviews. First, Sabat and Harré (1992, 1994) have emphasized the importance of using casual conversational methods for accessing the "self" of persons with AD. Saunders and colleagues (Saunders, de Medeiros, Doyle, & Mosby, 2011) also examined the role of discourse in forming identity roles in friendships among persons with dementia. They found "many of the elements of conversation that one would expect in the conversation of non-impaired adults" and that "their discourse serve[d] socially to construct the residents' identities" (Saunders et al., 2011, p. 356). We thus regarded it as important to employ a similar conversational method to engage with persons with AD.

Second, we found it essential to structure our conversational approach in a way that the same set of open-ended questions could be asked of persons with and without AD whom we interviewed. To this end, we were influenced by McRae's semi-structured interview approach (2010). McRae used a battery of questions in the context of a semi-structured interview to determine "how individuals with AD interpret and deal with perceived changes in self and changes in others' perception of them" in a way that "accentuat[ed] the interactional dimension of their experience" (p. 295). In interviews with nine persons with AD, she sought to determine their

reaction to the diagnosis; the impact of AD on their daily lives, relationships, and interactions; their outlook on the future; their perception of others' view and treatment of them; their current view of 'self' and extent to which they believed they had changed as a result of their illnesses. (p. 295).

When study participants with AD were asked the question, "Thinking about yourself, I would like you to give as many different answers as you can to the question, 'Who am I?'," none of the participants associated the illness with his or her current perception of self (MacRae, 2010, p. 296). MacRae (2010) also pointed out that "in this study, participants

were fortunate to have significant others who enabled their efforts to live active, meaningful lives and manage identity” (p. 301).

In summary, prompted by a persistent discordance between the medical literature that attributes a loss of “self” to people with AD, and evidence that preserved elements of self-identity can be explored in people with dementia through discourse (MacRae, 2010; Sabat & Harré, 1992; 1994; Saunders et al., 2011). This study was designed to assess whether the narratives of self are similar in people with AD and others without cognitive impairment sufficient to warrant a medical diagnosis of AD. We sought to better understand two core questions. First, can preserved qualities of “self” be discerned using a semi-structured interview? Second, are these preserved qualities of “self” identifiable in people with AD.

Method

Research design

To determine those aspects of “self” preserved in persons with AD, an informal, conversational-style semi-structured interview was developed. The interview was composed of simple, casual questions to help draw out the conversational narrative self. The questions aimed to allow the interviewer to engage in conversations with the participants to establish a better understanding of the “sufferer” as a person (i.e. MacRae, 2010; Sabat & Harré, 1992).

Fourteen participants—seven people with dementia (identified as due to AD by standard clinical criteria) and seven people without dementia—were interviewed individually in a private room. All responses were recorded using an audio recorder. All participants were between the ages of 60 and 90. Among the participants with AD, there were five women and two men; those without dementia included six women and one man. Other factors, such as socioeconomic status and educational level, were not considered, as those were not determined to be indicative of the “self” that remains intact in the interview-based approach reported by MacRae (2010).

Participant characteristics

Participants with AD were recruited upon referral from nursing staff at a residential dementia care facility in Birmingham, Alabama. Eligibility requirements included language function and cooperation sufficient to participate in a 30 minute conversation and a medical diagnosis of dementia. Participants without dementia were recruited from residents at an independent living residential facility in the same city via staff referrals and word of mouth. With one exception, all participants resided in single-occupant living quarters in a large building with communal spaces and took at least one meal daily in a common dining room. One participant with dementia resided with his cognitively healthy spouse in a single apartment. Both facilities provided structured and scheduled activities for residents’ voluntary participation.

Medical diagnosis and dementia staging

For people with dementia, a neurologist with extensive experience in clinical research approaches to dementia assessment and staging obtained informed consent for research participation, followed by a medical history of dementia-related symptoms and

progression from the participants legally authorized representative. Oral assent for interview and recording was obtained from the person with dementia. Information provided by the facility and legally authorized representative along with direct interaction with the participant was sufficient to assign a diagnosis of AD by DSM-IV-TR criteria (American Psychiatric Association, 2000). The neurologist used methods from the Clinical Dementia Rating scale (CDR; Hughes, Berg, Danzinger, Coben, & Martin, 1982) to determine dementia severity as “moderate” or “severe” to qualify people with dementia for the study. All participants with dementia were observed to have the following impairments.

- Memory for recent news and personal events (e.g. family visits) was nearly absent. Following the structured interview format of the CDR instrument, the adult child providing consent was asked about recent activities in which the affected person participated. The interviewer then asked the affected person open-ended questions about recent events. All participants with dementia were unable to spontaneously recall core elements (e.g. who, what, when, where) of the activities described by family members. This represents a lack of explicit recall, which is intrinsic to the clinical criteria (and thus the medical diagnosis) of dementia associated with AD.
- Orientation to time and place were impaired (e.g. the participant was unable to state month, the name of the facility, the duration of residence in response to questions. As called for by the CDR methodology, cuing and multiple choices were not offered).
- Recognition or ability to recall the names of familiar people was impaired (e.g. caregiving staff).
- The family member or facility staff affirmed that assistance was required for completion of at least some basic activities of daily living (e.g. grooming, bathing).

While the authors recognize that explicit recollection of the date or recent events may not be immediately relevant to the daily life residents of a dementia-care facility, they are the standards for assignment of dementia severity in clinical research and cognitive deficits meeting criteria, for moderate or severe dementia (CDR 2 or 3) were intrinsic to the research questions being explored.

Ethical considerations

The local Institutional Review Board approved the study. Because the intended participants with AD were identified as decisionally impaired, informed consent was obtained from their legally authorized representative. In all cases, this was an adult child. Additionally, the participants with AD provided oral assent to being interviewed and audio recorded for the purposes of transcription. Older adults, identified as not decisionally impaired by the staff of the residential facility where they lived, volunteered for the study and provided informed consent. The study was supported by internal funding from the Department of Neurology at the University of Alabama at Birmingham.

Data collection

A semi-structured interview was constructed around a series of open-ended questions. See Table 1. Both the primary interviewer and the neurologist who obtained the participants' assent for participation engaged in the interviews of people with dementia.

Table 1. Semi-structured interview.

-
1. Tell me about a typical day for you.
 - a. What kind of things do you like to do?
 - b. What kind of things do you do?
 - c. Have you had anything to eat yet today? If so, can you describe what you ate.
 - d. Do you have favorite foods? If so, what are they?
 - e. Describe meal time to me.
 2. Tell me about your childhood.
 - a. Where did you grow up?
 - b. Share with me some memories of your childhood.
 3. Have you ever been married? If so, are you still married?
 - a. Tell me about your spouse.
 - b. What was/is he/she like?
 - c. What do you remember the most about your marriage?
 - d. What is your favorite memory of an anniversary?
 4. Tell me about your education. (If male, were you in the military?) If yes, tell me about your experiences in the military and the kind of things they taught you. If no, continue the questions below.
 - a. How many years did you go to school?
 - b. Share with me some memories of your schooling.
 - c. What did you study in school?
 - d. What did you enjoy studying the most in school?
 - e. How did you use your education to make a living.
 5. Did you work? If so, what kind of work did you do?
 - a. What kind of things about your job did you like?
 - b. What kind of things about your job did you dislike?
 - c. Did you have more than 1 job?
 - d. Can you tell me about any other jobs you may have had?
 6. Do you have children?
 - a. Tell me about your children.
 - b. Do your children live close by?
 - c. How often do you see your children?
 - d. Do you like one of your kids more than the other?
 - e. Why are they your favorite?
 - f. Do your children have children of their own?
 7. Tell me about sleep.
 - a. When do you sleep?
 - b. How well do you sleep?
 - c. When do you prefer to sleep?
 - d. How is this different from here?
 8. Tell me about places where you have visited.
 - a. Tell me about places where you have lived.
 - b. Tell me what you liked about the places you have been.
 - c. Tell me what you liked about where you have lived.
 - d. What's your favorite place of all? Can you describe it?
 - e. Why is it your favorite place?
 9. What are you most proud of in your whole life?
 - a. What has brought you the most happiness?
 - b. How do you want to be remembered?
-

(continued)

Table 1. Continued.

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10. What is your favorite color and why?
 11. What is your favorite day of the week and why?
 12. What is your favorite season and why?
 13. What is your favorite thing to watch on television and why?
 14. How do you feel about how your life is today?
 - a. What do you wish your life were like?
 15. What's been on your mind lately?
 - a. Is anything bothering you?
 16. What is it like to live here?
 - a. Do you like it?
 - i. What do you like about it?
 - ii. What do you dislike about it?
 - b. How is it different from living at home?
 17. What kind of things do you remember most?
 - a. What kind of things do you wish you could remember that you don't?
 18. Is there anything else you would like to tell me today?
-

The questions were used to prompt dialogue related to self-identity in an informal, conversational style similar to the method used in the common social task of developing an understanding of an acquaintance. As it was difficult to determine the direction the conversation would take during the interview process, the interviewer navigated the conversation as a means to explore more qualities of "self," based on the responses provided by participants. The prepared items only provided a structure for the interview. The questions generally were asked in the intended order; however, if the participant answered one of the follow-up questions while responding to the main question, the follow-up question was skipped.

We employed a purposive sampling approach. Throughout the interview process, we monitored the data for the emergence of new thematic categories and conceptual classifications that would enrich our understanding of the preserved self in persons with dementia. We determined that saturation had been achieved after seven interviews of persons with dementia. This was the point when the data collection no longer provided new insights or relevant information for informing the development of the thematic framework (Saumure & Given, 2008).

Transcription

The primary interviewer transcribed the interview data by listening to the audio-taped recording and typing the interview content verbatim into a word processor to create a series of documents for qualitative analysis. This is considered to be the standard method for transforming verbal data into textual data (Kvale & Brinkmann, 2009). Throughout the transcription process, the interviewer had assistance from the neurologist who had observed the interview sessions and was able to assist the interviewer with segments of the audiotape that were difficult to decipher.

Data analysis

Analysis of data was carried out by the primary interviewer and the neurologist who had direct participation in all of the interviews with participants with dementia. The neurologist

also participated in two of the interviews of people without dementia. An inductive application of the sensitizing concept “self-identity” was used to examine how self-identity was manifest within the sample of individuals with dementia. Emergent themes were identified through a series of interactive conversations among the authors. Conflict resolution was iterative between the two interviewers. A third party (another IRB-approved investigator with experience in narrative analysis) was available for conflict resolution, but no case required escalation. The analytic process followed these steps:

- Debriefing conversations between interviewers at the conclusion of each interview with a person with dementia.
- Transcription from the audio records, noting common ideas in each, and assessing how those ideas are linked to narrative expressions of personhood.
- Identification and characterization of common themes across participants.
- Dialog among investigators determined additional similarities and differences in the expression of the themes between participants with dementia and those without.

Results

There was considerable overlap in responses to autobiographical questions between people with AD in a special care unit and individuals without dementia living independently in senior apartments. As expected, participants with AD demonstrated failures in explicit memory resulting in disorientation to time and place and difficulty in spontaneously recounting specific recent activities.

Differences between groups

Although we expected similarities in narrative themes related to self-identity (see below), we also identified potentially important differences between the people with AD and those without dementia.

Narrative breadth and depth. We noted differences between participants in the two groups in the extent to which they typically elaborated on their responses (breadth) and in the degree of detail they provided in their descriptive accounts (depth). Although not true for all questions, or all participants, persons with AD tended to respond to the interviewer’s questions in an abbreviated, less detailed way. We did not observe this tendency among those without dementia. The following examples illustrate this observation:

Interviewer: Tell me about a typical day for you.

Person with AD (RWT):

1. So far it’s been going good. Good food, good drink, couldn’t ask
2. for more.

Person with AD (VL):

1. A typical day at different times is different, but most of the time it’s good.

Person with AD (HGJ):

1. Well...kinda normal, I work with momma at home if she needs me
2. and...and I don’t know what else I do. But I do, I’m at home all
3. the time with momma.

Person without dementia (EBL):

1. I get up about 7 or 7:30 and have breakfast, usually fix it for my
- 2 wife if it's just extremely simple, like cereal. And [chuckles] I
- 3 have no duties that I have to do. I read a lot. Uh [pauses] I-I have
- 4 to take care of my wife who is somewhat disabled. And uh that
- 5 takes some time during the day. I usually go on errands let's say to
- 6 the grocery store or something. We have a daughter who is
- 7 disabled who lives on the other side of town and frequently I have
- 8 to go do something with her or for her. And we go down for supper
- 9 and I'm tryin to learn some stuff to help my son with getting into
- 10 the stock business. And that's about it. I read a lot. I'm in the
- 11 moment half way through 9/10s of the way through *Rise and Fall*
- 12 *of the Third Reich*, which is horrible. And uh [clears throat] a novel
- 13 or two and that's about, I don't have anything else to do. I play
- 14 bridge 3x a week for 2 hours at a time. And that's about it.

Person without dementia (LH):

1. A typical day. I usually wake up about 7 o'clock and if I'm not too
- 2 lazy, I'll get up and make my coffee then. I'll cook my breakfast
- 3 and start my regiment of pills. See my pill box here? [shows pill
- 4 box] Well anyways, uh I start them and then uh I bake I get ready
- 5 and go down for arm chair exercise in the basement. And if it's a
- 6 Wednesday, I'll go uh [pauses] let's see Wednesday is the day we
- 7 have uh [pauses] yesterday we had [pauses] communion.
- 8 Communion. That's it communion. It's uh on the communion, I
- 9 mean on the schedule it's listed as uh uh I guess as as as uh what
- 10 do we have on Sunday? We have Chapel on Sunday so I guess it's
- 11 also called the chapel on Sunday.

Person without dementia (MEB):

1. I get up around 8:30-9. I do things around the house. If there is a
- 2 class here of some sort I take it. I fix my own breakfast and lunch
- 3 and then in the afternoon there is usually a program at 3.
- 4 Sometimes I go and sometimes I don't. I usually eat supper around
- 5 5:30 and then go to bed around 10.

The verbalizations of people with AD were generally briefer, covering a single topic or answering with a broad generalization. There was limited description of different activities at different times. In contrast, participants without dementia provided specific time-centered descriptions with extensive detail. This may reflect the differences in explicit memory that characterize AD, but—given our focus on self narrative—it suggests that individuals with AD are less able to provide the narrative of their activities than those without dementia. This has significant implications for Sabat's "Self 2" since the losses of explicit memory represented by the truncated narrative limit the opportunities for the listener to formulate a sense of the speaker's true identity.

Temporal rigidity and flexibility. We identified differences in the temporal properties of responses in the two groups. Participants with AD often gave responses limited to one period of their life. They were more likely to be anchored in a specific time of the life cycle and unable to move beyond that point in their responses. We defined this phenomenon as *rigidity*. *Flexibility* was defined as the ability to adjust responses to the specific context of the question, expressing its relevance across the life course. As the following examples

illustrate, flexibility was more frequently observed in the responses of non-dementia participants.

Interviewer: Tell me about your spouse.

Person with AD (HGJ):

1. Oh, he's a good man. Worked at uh...keeping up with the farm and
- 2 The... what is it in the office, in the yard, in the business, but
- 3 anyhow he worked and drove school buses. He hadn't been
- 4 working in the last few years cause he's 72 and he farmed for a
- 5 few years and he drove school buses. What else did he do? I don't
- 6 know...it's been a long time... He... well...I don't know if that
- 7 helps you or not...and I washed clothes and helped momma cook
- 8 and clean the house and stuff like that. I was the oldest child and I
- 9 had sisters and brothers that I helped with.

Person without AD (MEB):

1. Well he was an interesting fella. He came from a little town in
- 2 Georgia. And him and his brother were the only ones from his
- 3 family that ever went to college. But he had to go to war, and he
- 4 was in the Philippines most of the year. And he came back and his
- 5 mother had a boarding house in Atlanta and him and his brother
- 6 went to Georgia Tech. And he was bright, but he had a
- 7 unfortunately he didn't have a good voice, his voice was too high.
- 8 He was a handicap somewhat. But anyhow, he boarded down the
- 9 street from me in Forest Park and I saw me going to work on a bus,
- 10 decided to get to meet me, and he did. And he became a member of
- 11 the family before we married because my sister couldn't do math
- 12 and he was an engineer. And I was going out with somebody else
- 13 and he was a very, he had a quick temper which was bad but he
- 14 was a very good provider shall we say. We bought a house after
- 15 about 4 years. And he died when the children were 9 and 11.

Interviewer: Tell me about your children.

Person with AD (HGJ):

1. Oh they're fine. My children...my children. Well I think of my
- 2 mother's children more than mine but they help with yard work
- 3 and the field and things like that. The boys...and the girls help in
- 4 the kitchen and I had never thought of trying to tell all of that.

Person without dementia (MEB):

1. Well they're very interesting children. That was one of them. They
- 2 were both smart but uh one of them Vand, they both got to go to
- 3 the private girls school that I had been at which was good because
- 4 they were smart. And uh well one of them went to Vanderbilt first.
- 5 The older one. She was not happy there. Her roommate brought
- 6 her boyfriend in to spend the night with them in a small room and
- 7 she was not accustomed to that. So she got herself to Rice
- 8 University that's in Texas. And she married a boy she met there.
- 9 And the other one wasn't supposedly smart but she probably
- 10 turned out better than the one that was. She went first to Mount
- 11 Holyoke. But she stayed one semester. Then she went to Georgia
- 12 Tech. And she graduated from Georgia Tech and done very well.
- 13 She married a boy she met there.

Interviewer: What kinds of things do you like to do?

Person with AD (VL):

1. Well for one thing I like to cook for my husband, my mother and
- 2 daddy, and the children. They seem to enjoy and I enjoy it. I enjoy
- 3 cooking.

Interviewer (A few minutes later during the same interview): Have you ever been married?

Person with dementia (VL):

1. No.

Interviewer: Is there anything else you would like to tell me today?

Person with AD (VL):

1. Well...there were 6 children and my mother, 3 girls and 3 boys
- 2 and my sister was the oldest and I was next and we did a lot of
- 3 things together that we enjoyed and my momma and daddy didn't
- 4 mind because she was the first one who was able to drive a car and
- 5 I was next and we were able to go.

These examples illustrate temporal rigidity. When participant HGJ was asked about her spouse, she described issues relating to her youth and her father. Similarly, when asked about her children, she reflected on her siblings. Participant VL showed a similar pattern, describing her role as a cook for her husband, but immediately followed that with statements about her role in her family of origin. A few minutes later, she denied ever having been married. Thus, even when directed to a specific life epoch (e.g. marriage, parenting), these participants seemed unable to sustain the time reference on life events from those epochs, returning to their youth in each case. In contrast, MEB, a participant without dementia, described a coherent timeline for her children from early schooling into marriage and adulthood. The ability to maintain the progression of time in the narrative was much more characteristic of the participants without dementia.

Group similarities evident in thematic coding

Several themes emerged from participants in both groups and were identified as ways in which the participants categorized the "self."

Attachment. This theme highlights the sense of value or importance the participants felt towards the most prominent experiences in their life. Some participants were attached to their families, while others identified with their work.

Interviewer: What kinds of things do you like to do?

Person with AD (VL):

1. Well, for one thing, I like to cook for my husband, my mother and
- 2 daddy, and the children. They seem to enjoy and I enjoy it. I enjoy
- 3 cooking.

Person without dementia (MMA):

- 1 What I liked to do is be with my little family. I have two
- 2 grandchildren and then I have my husband and I celebrated our
- 3 50th wedding anniversary, and my daughter is in the big picture
- 4 here. And that's my granddaughter and way down there is my
- 5 grandson.

Interviewer: What are you the most proud of in your whole life?

Person with AD (LG):

1 Oh well, I guess probably I got lucky and got the best florist in
2 town when I took a job with him and he was a gay guy who had a
3 gay parent who I fell, well I started to say who I fell in love with
4 but that doesn't have anything to do with me the story I just told
5 and he has been my friend for over 30 years, probably closer to 40
6 and we still communicate by telephone and keep each other up to
7 date about what's going on with each other and I never disturbed
8 his way of life because I figured he has the right to be and do what
9 he wants to if it's legal.

Person without dementia (EBL):

1 Gosh I don't know. At the moment I don't feel like I've done
2 anything worth mentioning. I was a good student, but that doesn't
3 count. I don't know. I was director of the division of cardiology for
4 a while. I guess I'm proudest of that.

Interviewer: What has brought you the most happiness?

Person with AD (LG):

1 My children.

Person without dementia (EBL):

1 My family.

In these examples, the participants from both groups identify personal experiences within family, with friends, or at work, representing themselves as associated with other people in social structures.

Role identity

This theme highlights the role relationships played in self-identity. The following are examples of representative dialogues in which subjects exhibited "role identity."

Interviewer: Tell me about your childhood.

Person with AD (VL):

1 Well I think I had a nice childhood. My sister was older than I and
2 we were close in age and we seemed to have a good time best I
3 can remember.

Person without dementia (EBL):

1 Well we lived in Florida. My father worked for the Texas
2 Company. And his job was such that they transferred him
3 every few years from one town to another, always in Florida.
4 So I went from one school to the other.

Interviewer: Tell me about your spouse.

Person with AD (WO):

1 I was married and I had her son. And my dear darling wife, one
2 cold winter night got sick and I took her to the hospital and got her
3 there and she stayed there about a month and a day and a half and
4 died. Which was my greatest loss, which I have ever had and ever
5 will have. I had that son and can't say he's still with me, but he's
6 still my son. And but we do good. He lives on one side of the
7 country and I live on the other so that makes it better.

Person without dementia (MBG):

- 1 Well after I graduated I went to work for a lawyer, and I was a
- 2 secretary and then uh this young man and I decided to get married.
- 3 So we got married and I quit working but then I was very lonely
- 4 and I went back to him and asked if I could have my job back so I
- 5 worked there.

Interviewer: Tell me about your job.

Person with AD (WO):

- 1 I was a railroad man. I ran a railroad for long years. I started off, I
- 2 don't know. About 20 years old, about 18 years old when I got a
- 3 job working on, working on railroads. They put me there and I
- 4 stayed there and I liked it.

Person without dementia (ASV):

- 1 I was just an at home mother, but in the military they insist on
- 2 spouses being volunteers so I did a lot of volunteer work.

Participants from both groups identified specific roles, such as child, spouse, parent, homemaker, and employee.

Loss of autonomy. This theme highlights the sentiments of both participant groups as they tried to face the limitations that occur due to aging and the changes associated with living in a residential care facility instead of a private home. The following dialogues are representative examples in which subjects express a loss of autonomy.

Interviewer: What do you wish your life were like?

Person with AD (RWT):

- 1 I wish there was a little more activity, a little more fun.

Person without dementia (ASV):

- 1 Just like it was.

Follow-up question: When? Before you came here?

Person without dementia (ASV):

- 2 "Mhmm."

Interviewer: What do you dislike about living here?

Person with AD (RWT):

- 1 Keeping your clothes straight and orderly. That's always a hassle.

Person without dementia (MMA):

- 1 I have to do my own laundry and I have to do my own dishes. I
- 2 don't have a dishwasher and uh they don't clean like how I want to
- 3 be clean. I believe in cleanliness and keep everything in order and
- 4 in...-in shape. I'm a little crowded but, but I wanted something I
- 5 would be able to pay for.

Members of both groups describe limitations on activities and chafing at requirements for orderliness in a communal living situation.

Preferences. This theme highlights the tendency of participants from both groups to identify preferred experiences and activities.

Interviewer: Tell me about your favorite foods.

Person with AD (ELW):

- 1 I like steaks and seasoned foods, stuff like that.
 Person without dementia (MMA):
 1 I like Reuben Sandwiches and chicken salad.
 Interviewer: What do you enjoy watching on television?
 Person with AD (RWT):
 1 Preferably football game.
 Person without dementia (MMA):
 1 Game shows.
 Interviewer: What's your favorite color?
 Person with AD (ELW):
 1 I guess green.
 Follow-up question: Why?
 Person with AD (ELW):
 2 I don't know. I guess I've had a lot of green cars.
 Person without dementia (MMA):
 1 Blue and pink.
 Follow-up question: Why?
 Person without dementia (MMA):
 2 They just look better on me.

The preferences expressed by both groups in these examples are straightforward and expressed simply, without much elaboration or explanation.

Referentiality. Both participant groups expressed a sense of association through reference to current or past possessions and attributes with language structures, frequently involving the use of “my.”

- Person with AD (ELW): He just had to sell all the old cars I had.
 Person without dementia (MMA): ...my skin looks terrible.
 Person with AD (WO): My education?
 Person without dementia (LH): My own breakfast.
 Person with AD (VL): My job.
 Person without dementia (MEB): My first assignment.

As with preferences, statements of referentiality are direct, and made with similar structure and emphasis among both people with AD and those without dementia.

Discussion

Previous research studies have shown that when asked about who they are, people with AD do not associate their illness with their perception of “self” (MacRae, 2010). The starting point for the current study was to ask persons with AD questions about their “selves” in the way that one might do if they are meeting a person for the first time. In trying to get to know them, we treated them as persons rather than persons with AD. In other words, we approached persons with and without AD in exactly the same way, asking them the same kinds of questions in an attempt to determine, on the assumption that having a self involves the development of a narrative, what aspects of that narrative were present.

The findings from this study indicate that specific elements of “self” are consistent across persons with and without dementia. The theme we labeled “attachment” revealed that subjects in both the experimental and control groups attributed much of the value in their

life to their interpersonal relationships. For example, persons in both groups enjoyed being with their family members and indicated that having children or strong relationships with their family members brought them great happiness. Members of each group also expressed pride about friendships they had maintained throughout their lifetimes (VL) or leadership positions they had held (EBL). In response to questions we associated with a different theme (e.g. role identity), members of both groups expressed the impact other people had on their lives or life choices (e.g. WO, MBG) and the losses they had experienced (WO). The questions we associated with “role identity” also revealed that members of both groups understood their roles in the context of their interactions with other people, and how others perceived them also shaped how they understood their “selves.” Members of both groups indicated they had experienced a “loss of autonomy” or lack of independence that they attributed to living at a residential care facility. Through “preferences” it was clear that members of both groups had very concrete ideas of what they liked and disliked. Finally, “referentiality” was notable among members of both groups through their use of words indicating possession such as “my” or “I had.”

Differences between the groups of people with AD dementia and those without dementia also were observed. When asked about a typical day, some participants with dementia matched the participants without dementia in the breadth—the overall variety—of responses; however, the participants without dementia provided more elaborative response in comparison to the dementia group. This can be seen in short, single sentence responses of participants with dementia in contrast to the longer, more detailed narratives from those without dementia. This could stem from the differential salience individuals with dementia place on certain aspects of their lives. The work of Phinney, Chaudhury, & O’Conner (2007) is illustrative of this phenomenon. In their paper, “Doing as much as I can: The meaning of activity for people with dementia,” Phinney and colleagues assert that meaningful activity (as opposed to mundane day to day activity) fosters a connection/belonging and supports a retained sense of autonomy and personal identity. It is not surprising that the breadth and depth of participants’ accounts is greater when they are asked questions about roles and relationships compared to when they are asked to describe a typical day.

More noticeably, persons with dementia were more likely to be rigid with respect to the temporal characteristics of their responses. For instance, in one interview after the discussion about childhood (HGJ), nearly all of the participant’s responses seemed to reflect back to her childhood experiences. This is illustrated by her response (above) in which she admits she thinks more about her “mother’s children” more than her own. Such rigidity makes sense in light of the fact that AD is accompanied by anterograde amnesia, or the inability to recall the recent as opposed to remote past. In other words, it is possible that the individual has lost the ability to consciously recall memories of her spouse and her children (although such an ability may still be implicit in how she behaves towards these individuals), yet she remains able to recall memories of her own childhood. Similar phenomena were not observed to the same extent in the people without dementia, as they were able to demonstrate flexibility, or adjust their responses to the timeline of the question.

To make more precise, the potential implications of our results for understanding what aspects of the self remain in persons with AD, some conceptual tools are relevant. Given its direct relevance to the aims of the current research study, we want to situate our results within Sabat’s (2002b) social constructionist conceptual framework. First, insofar as the persons with AD we interviewed responded to questions about themselves using the first-person pronouns “I,” “my,” or “mine” and used these pronouns to communicate

information about themselves, such as their likes and dislikes, interpersonal relationships (e.g. “my spouse,” “my children,” “my friend,” “my sister”) and referentiality or association (e.g. “my childhood”), they exhibit Sabat’s “Self 1.” Using these pronouns, they were able to reveal autobiographical details of their lives. In other words, our results indicate that the self-narrative of persons with AD is accompanied by a discrete subject much like that self-narrative of persons without dementia.

Persons with AD also possess Sabat’s “Self 2” as demonstrated by their ability to describe self-attributes and express pride, and in some cases regret about those attributes. Such expression occurred across the various themes we identified. For example, VL told us that she enjoyed cooking for her family, LG was proud of her friendship with a former employer whose “way of life” she acknowledged being liberal about, WO was still saddened by the loss of his spouse, RWT wanted to have more fun in the residential care facility and did not enjoy having to be tidy, and ELW liked steaks. It is interesting to note that none of the persons with AD whom we interviewed seemed to associate themselves with their illness. One possible interpretation is that because we did not treat them as persons with AD, the fact that they were did not arise in nor shape the discussion.

It was also clear across the various themes that persons with AD also exhibit Sabat’s “Self 3” insofar as they identified certain roles that they had played during their lifetimes—roles that required recognition by others that they had played those roles. For example, HGJ described herself as a “helpful daughter” to her mother and father, VL indicated she was a good cook according to her family who seemed to like her cooking, LG was a friend to her former boss, and WO “was a railroad man.” Our questions, especially those associated with the theme “role identity,” were intended to directly probe for these social roles and the results are suggestive that such questions may be a useful starting point for caregivers to make salient those aspects of the self in persons with AD that they may be able to play an active role in helping to maintain.

Our study is not without certain limitations. First, we were working with a small sample size and pathological confirmation of AD as the principal cause of dementia was lacking. After the first two interviews of people with dementia, based on participant responses and interaction, the interview method was changed. Originally, a structured interview that contained only the main questions was administered. However, the authors found that it limited the range of the participants’ responses and introduced unnecessary repetitiveness to the interview process. The authors modified the interview method to allow for more flexibility in follow-up questions and to help facilitate richer responses to the main questions.

Another challenge of this study was interviewing the people with dementia and precisely transcribing their verbalizations. It was difficult for some participants to hear or understand the primary interviewer’s questions, resulting in the more experienced interviewer (the neurologist) asking most of the questions to this group. Because of the speech patterns of people with AD, transcribing the verbatim verbalizations of those participants was challenging.

Conclusion

The “loss of self” frequently attributed to people with dementia is not supported by the verbalizations of those who participated in this study. Healthcare providers and caregivers may confuse the consequences of memory impairments and loss of awareness of deficits with the loss of self-identity. As such, opportunities exist to improve care of those living with AD

by recognizing intact elements of self-identity in people with advanced dementia. These opportunities include training caregivers and healthcare providers how to interact with people with advanced dementia in a way that accounts for retained aspects of narrative self-identity.

Future studies might include longitudinal approaches to assess changes in narrative self-identity within individuals as dementia becomes more severe. This could inform caregivers and healthcare providers about both stable and changing aspects of self-identity that need to be addressed in people with dementia over time.

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