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# The Impact of Dementia on the Self: Do We Consider Ourselves the Same as Others?

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Abstract The decline in autobiographical memory function in people with Alzheimer's dementia (AD) has been argued to cause a loss of self-identity. Prior research suggests that people perceive changes in moral traits and loss of memories with a "social-moral core" as most impactful to the maintenance of identity. However, such research has so far asked people to rate from a third-person perspective, considering the extent to which

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MARCS Institute for Brain, Behaviour and Development, Western Sydney University, Locked Bag 1797, Penrith, NSW 2751, Australia e-mail: celia.harris@westernsydney.edu.au hypothetical others maintain their identity in the face of various impairments. In the current study, we examined the impact of perspective, comparing first- and thirdperson perspectives, as well as memory type. This online study asked 201 participants to consider hypothetical scenarios in which either themselves or another person (their parent, partner, or a stranger) experienced different types of memory failures associated with a diagnosis of AD. For each scenario, participants rated the degree to which the depicted individual remained the same person, and how impactful the impairment was. Social semantic memory failures - involving failures to recognise a loved one - were rated as most detrimental to self-continuity, and procedural memory failures the least. Averaged across all memory types, people considered their own and their partner's self-continuity to be more resilient to memory failures than that of a parent or stranger. However, this pattern was reversed for some memory types: forgetting semantic or episodic information about close relationships was rated as more detrimental from a firstperson than third-person perspective. Our findings suggest that perspective and type of memory impairment interact to impact judgements about the extent to which people maintain their identity when they experience dementia, and highlight the importance of social relationships to maintaining a sense of self.

**Keywords** Memory · Alzheimer's disease · Dementia · Self · Identity · Self-continuity

#### Background

What happens to our sense of self if we develop dementia? This question is highly relevant given the way populations worldwide are ageing, and the corresponding growing rates of dementia [1]. There are numerous definitions of the 'self' both within and between disciplines. Nevertheless, there is widespread agreement that the self is multifaceted, comprising various aspects and requiring multiple definitions [2, 3], and that our sense of self is informed by our autobiographical memories [4]. That is, we know who we are because we remember the things that have happened in our lives. One specific aspect of self - the one we focus on in the current study, is self-continuity: "knowing and experiencing that we are, in a fundamental way, the same person over time" (p. 55) [5]. Several authors have highlighted the importance of autobiographical memory to maintaining one's sense of self [5-7], with both episodic and semantic memory functions supporting self-continuity across the lifespan ('phenomenological continuity' and 'semantic continuity') [8]. The impaired ability to retrieve autobiographical memories has thus been associated with a diminished or 'lost' sense of self and a disruption to selfcontinuity [9].

Alzheimer's Dementia (AD) is the most common type of dementia with the hallmark symptom of impaired memory, including autobiographical memory [10]. Given that most people have some familiarity with AD, we use this type of dementia as the hypothetical example in the current study about the impact of dementia-related memory impairment on the self. The complex relationship between autobiographical memory and the self in the context of AD has been addressed by several authors [11-13]. Some theorists consider that a decline in the ability to recall autobiographical memories corresponds with a diminished sense of self [11], or a failure to update self-knowledge resulting in a static, outdated self-concept [14] or a 'petrified' self [12]. Others present a more multifaceted viewpoint in which the integrity of narrative construction from semantic memory underpins the sophistication and certainty in beliefs about self-persistence over time. Given this, intact semantic knowledge may be sufficient to support an individual's sense of self in the face of other memory impairment [13].

In a recent review addressing this topic, Strikwerda-Brown and colleagues [15] proposed different profiles of loss and sparing of discrete facets of self across three types of dementia: Alzheimer's (AD), Semantic (SD) and Behavioural-variant Frontotemporal dementia (Bv-FTD). They highlight that both episodic (event-based) and semantic memory (conceptual knowledge) support self-continuity, in recalling the past and projecting oneself into the future. Disruption of episodic autobiographical memory function (as assessed by the level of contextual detail and event specificity of recalled memories across recent and remote lifetime periods) is observed across all dementia types, and has received the most research attention in regard to its impact on the self. Strikwerda-Brown et al. [15] highlight the important contribution of semantic autobiographical memory to the narrative continuity of self, including both personal semantics (personality traits and autobiographical facts) and general event memories (repeated or extended episodes). For example, in the face of impaired episodic retrieval (inability to recall specific events), particularly for recent time periods, people with AD often default to their relatively preserved semantic memory (knowledge of general events or personal facts) with a focus on the remote past. In contrast, people with SD show spared recent episodic and semantic memory, but impaired remote memory, which has been interpreted as reflecting the 'semanticisation' of older episodic memories. People with SD may draw upon their memory for recent episodes to support a degree of narrative continuity that relates to the current self. Klein's amnesic case studies contribute to a growing body of evidence showing that specific facets of the self can be selectively spared in the face of profound cognitive impairment [14, 16]. Following Klein and Gangi's [17] notion of the multiplicity of self, Strikwerda-Brown et al. [15] argue, therefore, that the self is not 'lost' in dementia. Rather, different types of dementia are associated with the preservation, transformation, or loss of various memory functions which have different outcomes for the self.

One aspect of the self that our study targeted is the social self. Our social identities are constructed in concert with others, and so an important source for our sense of self beyond our individual memories is our social relationships. The character of these social relationships depends in turn on our social position, such as the roles we occupy, our self-presentations in social company, our careers, sense of status (or its lack), and the groups we belong to (and what they mean to us). Ryan et al. [18] describe these as "fluid selves (or personae), which collectively comprise an individual's social identity" (p. 146). Strong versions of social identity theory, such as social constructionism, reify these selves into essential parts of personal ontology. As Ryan et al. put it, certain of our personae are such that acceptance of them by others is prior to their (possible) existence. Quoting Ray, they remark that identity is "a social manifestation that is created and re-created through language acts, social patterns and human relationships" (p. 21) [18]. Research examining the social co-construction of self in dementia [19, 20] charts how one's relationships shape the lived experience of dementia and direct its impact on identity. Given this, understanding how others might perceive symptoms associated with dementia (e.g., memory impairment) to impact upon the self is crucial, precisely because our relationships and social identities comprise such a fundamental part of our sense of self.

Although both autobiographical memory and social relationships have been tightly linked to a sense of self, the importance of 'non-memory' aspects of self, such as morality, has also been raised. The idea of morality being at the core of identity is longstanding. As Erikson put it: "As a subjective sense of an invigorating sameness and continuity, what I would call a sense of identity seems to me best described by William James in a letter to his wife [quoting James]: A man's character is discernible in the mental or moral attitude in which, when it came upon him, he felt himself most deeply and intensely active and alive. At such moments there is a voice inside which speaks: 'This is the real me!'" (p. 19) [21]. More recently, Strohminger and Nichols' 'essential-moralself hypothesis' [22] proposes that moral traits are more central to self-identity than other psychological functions (including memory) or personality factors. They conducted multiple studies [22, 23] to isolate various mental, social, and physical traits and independently assess their perceived impact on identity. In a series of online survey studies [22] participants read a story about a character in various hypothetical scenarios, ranging from the supernatural (e.g., reincarnation) to the more mundane (e.g., memory loss associated with ageing), and rated the extent to which they remained 'the same person'. In a further study focusing specifically on dementia [23], they recruited carers (mainly partner or parent) of people diagnosed with different types of dementia or another neurological condition, and asked them to rate the extent to which the person in their care was 'still the same'.

Across all studies, [22, 23] found that traits implicating morality (e.g., honesty, altruism, humility) were perceived as most pertinent to the self, with only modest importance placed on other aspects of personality, desire, mood, or memory. When examining memory impairments, Strohminger and Nichols [22] found that episodic memories with 'social and personal reverberation' (e.g., cherished memories of time spent with a parent) were considered more important to the self than semantic or procedural memory types (e.g., knowledge of mathematics). They concluded that memory is not considered crucial to self-identity in and of itself, but rather for its connectedness to one's social-moral core. In this view, episodic memory supports identity not as a "unique, haphazard collection of memories a person acquires across a lifetime, but a particular strain of remembrance of times past ... people are keying into a self that is, at its core, about social relationships, both past and possible" (p. 169) [22]. This view links the previous memorybased and relationship-based accounts of self, suggesting an interaction between memory, social relationships, and one's social-moral core.

In these studies, Strohminger and Nichols investigated the self from a third-person perspective by utilising hypothetical scenarios regarding strangers [22] and ratings by carers of people with dementia [23]. Given that their findings challenged the "vaunted status" often granted to memory in philosophical discussions of the self, they speculated that the first-person experience of the self, and one's perceptions about another person's identity, may not operate in uniform ways: "If you lose all your episodic memories tomorrow, you may feel unmoored in a way that is more salient to you than to others. If your friend loses all his episodic memories, his identity may have changed less in relation to the factors you consider important to your friendship and love for him" (p. 169) [22]. These theoretical considerations motivated the current study, designed to expand beyond the thirdperson perspective and to compare whether memory impairments are rated differently when experienced by oneself versus another person.

#### The Current Study

In this study we aimed to extend the work of Strohminger and Nichols [22, 23] to investigate how people perceive the impact of dementia-related memory failures on the self, comparing scenarios involving firstperson perspectives to those involving a third-person perspective. We hypothesised that people may consider themselves differently to others, and may perceive memory loss as more detrimental to themselves than others, as predicted by Strohminger and Nichols [22]. We also examined whether the type of memory impairment depicted influenced ratings. Prior theory and research from cognitive psychology has emphasised the importance of episodic memory for identity [4], whereas more recent theory has suggested that semantic memory may support sense of self in the face of episodic memory loss [13, 15]. We therefore hypothesised that impairments in episodic and semantic memory would be more detrimental to identity than impairments in procedural memory. Additionally, the social identity model of dementia [19, 20], as well as the essential-moral-self view [22, 23], suggest that social relationships are crucial to identity. Therefore, we hypothesised that memory failures involving social content relating to close relationships would be more detrimental to identity than non-social memory failures. Finally, we compared different kinds of third-person perspectives, from close others to strangers, and predicted that close others would be rated more similarly to the self.

Across these comparisons, we examined the role of key individual differences, including gender, age, experience with dementia, identity strength, and memory complaints. We hypothesised that people with more experience of ageing and dementia would be more likely to view identity as being preserved despite memory failures, consistent with Strohminger and Nichols' [23] carers. Therefore we hypothesised that older people, people with experience of dementia, people with a stronger identity, and people with more everyday memory complaints would give higher ratings of identity preservation across scenarios.

#### Method

#### Participants

Participants were 201 individuals recruited via Amazon's Mechanical Turk (MTurk) survey platform. The description of the online survey read, "We will ask you to imagine a variety of situations and briefly reflect on your response to them, and to complete two questionnaires about memory in your daily life. The entire survey should take approximately 30 minutes to complete." We specified eligibility criteria that participants were living in the United States, and were MTurk "Masters", meaning they were certified reliable participants.

At the beginning of the survey we asked participants to report their age, gender, native language, and whether they knew anyone who had been diagnosed with dementia. If they answered 'yes' to the final question, we asked them to identify their relationship to the person and the type of dementia. Participants ranged in age from 22 to 72 years (M=39.23, SD = 10.79). The majority (124) self-identified as men (61.7%) and the remainder (77) as women (38.3%). Almost all participants (99%) reported English as their first language. 118 of 201 (58.7%) participants reported knowing someone who had been diagnosed with dementia. Of these participants, the majority (81.4%) knew a family member, namely a parent (15; 12.7%) grandparent (61; 51.7%), or other family member (20; 17%), while 22 (18.6%) reported knowing a friend with dementia. Of the 118 participants who reported knowing someone who had been diagnosed with dementia, the majority (81; 68.6%) identified Alzheimer's dementia, while others identified Parkinson's related dementia (8), alcohol-related dementia (4), frontotemporal dementia (2) and Lewy body dementia (1), with the remainder (22) stating that they did not know the type of dementia.

We paid participants US\$5 for completing the survey, and they took an average of 21.13 minutes to complete it, representing an approximate pay rate of USD \$14.20/hr, consistent with reimbursement rates for participants tested in our campus-based laboratories and with recommendations for ethical online data collection practices [24].

#### Measures

Scenarios We developed a survey to measure the extent to which participants judged a person's sense of self to be impacted by different kinds of memory failure (see Appendix A). We presented participants with 24 hypothetical scenarios in which they, their parent, their partner, or a stranger were experiencing memory difficulties associated with a diagnosis of dementia (e.g., "You go to visit your father. You mention that your sister visited him yesterday, but he can't recall her visiting and insists he hasn't seen her for years"). Among these 24 scenarios we varied Memory Type (Episodic vs. Semantic vs. Procedural), Social Type (Social vs. Non-Social), and Perspective (Own vs. Parent vs. Partner vs. Stranger). We intentionally varied the specific content in each scenario to avoid demand characteristics whereby participants could directly compare their responses on each scenario to the others. However, within each memory type yielded by the Memory Type×Social Type interaction, the content of the specific memory failure was closely matched across relationship types (see Appendix A).

Participants were provided with the following instructions: "In each of the following scenarios you will read about a person (yourself, your parent, your partner, or a stranger) who has been diagnosed with Alzheimer's dementia. The main symptom of this type of dementia is memory difficulties. Please read each scenario carefully and answer the questions that follow." After each scenario, participants were presented with five questions which followed the statement "In your opinion, if this happened": (1) Would you still be the same person? (2) Would you still know who you are? (3) Would you still feel like yourself? (4) Would you be very upset if this occurred? (5) Would this impact on your daily life? For each scenario, the pronouns in these five questions were adjusted to match the given scenario (you/they/he/she). Participants responded on a 5-point Likert scale (1 = not at all, 5 = to the fullestextent).

**Sense of Self Scale (SOSS)** The SOSS [25] is a self-reported measure of the strength of one's sense of self, consisting of 12-items across 4 sub-scales: difficulty in keeping one's own identity separate from that of others (6 items); a lack of knowledge

about one's own interests, opinions, and personality (1 item); sudden shifts in feelings, values, and preferences (2 items); and the feeling of a tenuous existence (3 items). Questions 4, 7, and 12 are reverse-scored. Participants were provided with the following instructions: "In the following section you will read a number of statements concerning your personal attitudes and characteristics. Please read each statement and rate the extent to which it describes you." Participants responded on a 4-point Likert scale (1 = very uncharacteristic of me, 4 = very characteristic of me). Results were calculated with a possible maximum score of 48, with lower scores indicating a stronger sense of self. We used the overall scores in the analyses reported below.

Everyday Memory Questionnaire (EMQ) The EMQ [26] is a self-reported measure of memory failures in everyday life consisting of 35-items across 5 sub-scales: Speech (13 items); Reading and Writing (4 items); Faces and Places (6 items); Actions (6 items); and Learning New Things (6 items). Participants were provided with the following instructions: "Below are listed some examples of things that happen to people in everyday life. Some of them may happen frequently and some may happen very rarely. We would like to know how often on average you think each one has happened to you over the past month." Participants rated how frequently each memory failure occurred during the past month on a 5-point Likert scale (for sub-scales 1-4, 0=never, 4 = several times a day; for sub-scale 5, 0 = never,  $4 = on \ every \ occasion$ ). Results are calculated with a possible maximum score of 140, with higher scores indicating greater frequency of everyday memory failures. We used the overall scores in the analyses reported below.

#### Procedure

Participants were recruited via Amazon's Mechanical Turk survey platform (www.mturk.com), where they received a link to complete the study in the online Qualtrics survey platform. After answering some demographic questions, participants completed the ratings of the 24 scenarios in Appendix A. For each participant, the scenarios were presented in a unique random order. Participants then completed the SOSS followed by the EMQ, in their own time and on their own personal computer or device. No additional questionnaires or items were included. Responses were screened for quality by checking that participants had correctly responded to at least four out of five attention check questions (e.g., How many 'p's are in the word 'apple'?).

#### Results

#### Data Reduction

We asked participants to rate each scenario on 5 different items (see Appendix A). To assess whether we could collapse across these dependent variables, we conducted a Principal Components Analysis of participants' ratings of the 5 items across all scenarios in all conditions (i.e., 4,824 responses). We used a varimax rotation to reduce cross-loadings, and fixed an eigen-value criterion of 0.5. This analysis, as well as inspection of the scree plot, supported a two-factor solution. Items A, B, and C loaded on Factor 1 (factor loadings > 0.76). Items D and E loaded separately on Factor 2 (factor loadings > 0.81). Together this twofactor solution accounted for 84.85% of the variance. Therefore, we averaged across items A, B, and C to give each scenario an "Identity Preservation" (Factor 1) score out of 5, where higher scores indicated greater perceived preservation of the self. We averaged across items D and E to give each scenario a "Daily Importance" (Factor 2) score out of 5, where higher scores indicated greater perceived impact of memory failures on daily life. We used these composite scores as dependent variables in our analyses below.

#### Identity Preservation: Own vs. Other Perspective

Our primary research question was whether Identity Preservation ratings would vary depending on whether scenarios had a first- or third-person perspective. For these initial analyses, we collapsed across the three types of 'Other' perspectives (Parent, Partner, Stranger). To examine this, we conducted a 3 (Memory Type: Episodic, Semantic, Procedural) $\times 2$ (Social Type: Social, Non-Social) $\times 2$  (Perspective: Own, Other) repeated measures analysis of variance (ANOVA), and obtained marginal means and confidence intervals for post-hoc comparisons for main and interaction effects.

This analysis yielded a significant main effect of Memory Type, F(2,199) = 341.05, p < 0.001,  $\eta_{p}^{2} = 0.63$ , a significant main effect of Social Type,  $\dot{F}(1,200) = 276.52, \ p < 0.001, \ \eta_p^2 = 0.58, \ and \ a \ sig$ nificant main effect of Perspective, F(1,200) = 17.13, p < 0.001,  $\eta_p^2 = 0.08$ . The post-hoc comparisons indicated that people gave lowest Identity Preservation scores (indicating greater impact on sense of self) for semantic memory failures, M=3.21, 95% CI [3.11, 3.32], followed by episodic memory, M = 3.39, 95% CI [3.28, 3.50], then by procedural memory, M = 4.15, 95% CI [4.07, 4.24]. People gave lower Identity Preservation scores for social impairments, M=3.32, 95% CI [3.23, 3.42], than non-social impairments, M=3.85, 95% CI [3.75, 3.94]. Most importantly for our research questions, people gave lower Identity Preservation scores for others, M=3.54, 95% CI [3.45, 3.63], compared to themselves, M = 3.63, 95%CI [3.54, 3.72], averaged across memory types.

All the two-way interactions were significant, all Fs > 24.60, all ps < 0.001. The 3-way interaction was not significant, F(2,199)=2.34, p=0.098,  $\eta_p^2=0.012$ . Table 1 presents the planned comparison between Own and Other perspectives across scenario types. Although the main effect indicated that on average, people gave themselves higher Identity Preservation scores than they gave to others, this was not the case for all scenario types. Specifically, there were two scenarios for where people considered their own identity as more negatively impacted than that of others (see Table 1). For social impairments associated with both episodic and semantic memory failures (forgetting a recent social event or not

Table 1	Identity	Preservation	Ratings	across	Scenarios
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	Own	Other	t	D
Social	3.04 (1.08)	3.26 (0.86)	4.32*	0.31
Non-social	3.75 (0.96)	3.51 (0.84)	4.67*	0.33
Social	2.41 (1.06)	2.54 (0.92)	2.83*	0.20
Non-social	4.02 (0.89)	3.89 (0.76)	2.99*	0.21
Social	4.38 (0.74)	4.31 (0.62)	1.71	0.12
Non-social	4.18 (0.84)	3.73 (0.75)	9.54*	0.67
	Social Non-social Social Non-social Social Non-social	Own   Social 3.04 (1.08)   Non-social 3.75 (0.96)   Social 2.41 (1.06)   Non-social 4.02 (0.89)   Social 4.38 (0.74)   Non-social 4.18 (0.84)	Own Other   Social 3.04 (1.08) 3.26 (0.86)   Non-social 3.75 (0.96) 3.51 (0.84)   Social 2.41 (1.06) 2.54 (0.92)   Non-social 4.02 (0.89) 3.89 (0.76)   Social 4.38 (0.74) 4.31 (0.62)   Non-social 4.18 (0.84) 3.73 (0.75)	Own Other t   Social 3.04 (1.08) 3.26 (0.86) 4.32*   Non-social 3.75 (0.96) 3.51 (0.84) 4.67*   Social 2.41 (1.06) 2.54 (0.92) 2.83*   Non-social 4.02 (0.89) 3.89 (0.76) 2.99*   Social 4.38 (0.74) 4.31 (0.62) 1.71   Non-social 4.18 (0.84) 3.73 (0.75) 9.54*

\* indicates p values <0.008 for the pairwise comparison between Own and Other perspectives;  $\alpha = 0.05/6$  with a Bonferroni adjustment for multiple comparisons recognising a loved one), scenarios received higher Identity Preservation scores when they involved an Other perspective, and lower when they involved an Own perspective. This pattern was reversed for nonsocial scenarios (getting lost or forgetting a holiday destination), which received higher Identity Preservation scores from an Own perspective than an Other perspective (see Table 1). That is, both episodic and semantic memory impairments were considered particularly detrimental to one's own sense of self when they involved close social relationships. For procedural memory, there was no difference between Own and Other perspectives for social scenarios, but nonsocial scenarios (using a mobile phone) showed the largest discrepancy, with Own perspective scenarios receiving higher Identity Preservation ratings than Other perspective (see Table 1). Overall, there were differences in the impact of different kinds of memory impairments, and the impact also depended on whether the scenario involved an Own perspective or an Other perspective.

#### Daily Importance: Own vs. Other

We compared 'Daily Importance' ratings (that is, the extent to which participants perceived memory impairment to be upsetting and impactful on daily life) across memory types and social vs. non-social scenarios, depending on whether scenarios were based on an Own perspective or an Other perspective. For these initial analyses, we again collapsed across the three types of 'Other' perspectives (Parent, Partner, Stranger). We conducted a 3 (Memory Type: Episodic, Semantic, Procedural)×2 (Social Type: Social, Non-Social)×2 (Perspective: Own, Other) repeated measures analysis of variance (ANOVA), and obtained marginal means and confidence intervals for post-hoc comparisons for main and interaction effects.

For Daily Importance ratings, there was a significant main effect of Memory Type, F(2,199)=359.61, p<0.001,  $\eta_p^2=0.64$ , a significant main effect of Social Type, F(1,200)=46.08, p<0.001,  $\eta_p^2=0.19$ , and a main effect of Perspective, F(1,200)=19.55, p<0.001,  $\eta_p^2=0.09$ . Overall, people gave highest Daily Importance ratings to episodic memory failures, M=3.98, 95% CI [3.89, 4.07], followed by semantic memory, M=3.69, 95% CI [3.61, 3.77], then procedural memory, M=3.00, 95% CI [2.91, 3.10]. People also gave higher Daily Importance scores for social, M = 3.67, 95% CI [3.60, 3.74] compared to non-social memory impairments, M = 3.46, 95% CI [3.35, 3.54] (see Table 2). People gave higher Daily Importance ratings for Other perspectives, M = 3.562, 95% CI [3.52, 3.69], compared to Own perspectives, M = 3.50, 95% CI [3.42, 3.59]. In other words, episodic and social memory types were considered most important for daily life, but averaged across the different memory tasks, participants considered themselves less impacted by memory impairments than other people.

All the 2-way interactions were significant, all Fs > 69.81, all ps < 0.001. However, these effects were moderated by a significant 3-way interaction, F(1,200) = 4.04, p = 0.018,  $\eta_p^2 = 0.02$ . Table 2 presents the planned comparison between Own and Other perspectives across scenario types. Results mirrored those for Identity Preservation. Although the main effect indicated that on average, people gave themselves lower Daily Importance scores than they gave to others, this was not the case for all scenario types. Specifically, there were two scenarios where people considered impairments to have more importance to themselves than to others (see Table 2). For social impairments associated with both episodic and semantic memory failures (forgetting a recent social event or not recognising a loved one), social scenarios received higher Daily Importance scores when they involved an Own perspective and lower when they involved an Other perspective. This pattern was

Table 2 Daily Importance Ratings across Scenarios

		Own	Other	t	D
Episodic	Social	4.12 (0.84)	3.77 (0.67)	7.75*	0.55
	Non- social	3.92 (1.03)	4.11 (0.72)	3.36*	0.24
Semantic	Social	4.51 (0.65)	4.34 (0.61)	4.34*	0.31
	Non- social	2.90 (1.05)	3.00 (0.79)	2.20	0.15
Proce- dural	Social	2.53 (0.99)	2.74 (0.75)	4.26*	0.30
	Non- social	3.05 (0.99)	3.70 (0.73)	11.86*	0.84

\* indicates p values < 0.008 for pairwise comparison between Own and Other perspectives;  $\alpha = 0.05/6$  with a Bonferroni adjustment for multiple comparisons reversed for non-social scenarios (getting lost or forgetting a holiday destination), as well as for both types of procedural scenarios, which received lower Daily Importance scores from an Own perspective than an Other perspective (see Table 2). That is, both episodic and semantic memory impairments were considered to be of particularly high daily importance to oneself, when they involved close social relationships.

#### Impact of Specific Types of 'Other' Relationships

Two separate repeated measures ANOVAs were conducted to compare the differences between 'Own' perspective scenarios (that is, first-person), and the three specific 'Other' perspective scenarios, namely Parent, Partner and Stranger, for both Identity Preservation and Daily Importance scores, collapsed across different event types. For these analyses, we were only interested in the effects of Perspective. We conducted 4 (Perspective: Own, Parent, Partner, Stranger) separate within-subjects ANOVAs, and obtained marginal means and confidence intervals for post-hoc comparisons for main effects. For Identity Preservation, the main effect of Perspective was significant, F(3,198) = 35.14, p < 0.001,  $\eta_p^2 = 0.15$ . Follow up pairwise comparisons (with a Bonferroni adjustment) indicated that all Perspectives were significantly different from each other. People gave the highest Identity Preservation ratings (indicating lower impact on self) to their partner, M=3.66, 95% CI [3.56, 3.75], followed by themselves, M=3.63, 95% CI [3.53, 3.72], their parent, M = 3.52, 95% CI [3.43, 3.62], and a stranger, M=3.44, 95% CI [3.34, 3.53]. Therefore, the relationship type appeared to influence overall Identity Preservation ratings, with partners perceived to have higher Identity Preservation in the face of memory impairments compared with other relationship types, and strangers rated the lowest. The results for Daily Importance mirrored the results for Identity Preservation. For Daily Importance, the main effect of Perspective was significant, F(3,198) = 24.35, p < 0.001,  $\eta_p^2 = 0.11$ . Follow up pairwise comparisons (with a Bonferroni adjustment) indicated that Daily Importance ratings were highest (indicating greater impact on daily life) for strangers, M = 3.71, 95% CI [3.62, 3.79], followed by parents, M=3.61, 95% CI [3.53, 3.69]. Ratings for partners and one's own perspective were lowest, and not significantly different from each other, M = 3.52, 95% CI [3.44, 3.60] and M=3.50, 95% CI [3.42, 3.58], respectively. In other words, the self and close others were perceived to experience lower impact of memory impairments on daily life.

Individual Differences in Identity Preservation & Daily Importance Ratings

In terms of demographic variables, we examined whether participant age, gender, or knowing someone with dementia impacted their Identity Preservation and Daily Importance ratings for each of the four Perspectives, averaged across memory types. A mixed 2 (Gender: Male, Female)  $\times$  2 (Know a person with dementia: Yes, No)×4 (Perspective: Own, Parent, Partner, Stranger) ANOVA indicated no main or interaction effects, all Fs < 1.57, all ps > 0.19. For Daily Importance ratings, there was a significant main effect of gender, F(1,197) = 6.72, p = 0.010,  $\eta_{\rm p}^{2} = 0.03$ , but no main effect of knowing someone with dementia, F(1,197) = 0.60, p = 0.440,  $\eta_p^2 < 0.01$ . Overall, women gave higher Daily Importance ratings, M=3.69, 95% CI [3.58, 3.79], than men, M = 3.48, 95% CI [3.37, 3.59], across the four Perspective types. Interestingly, there was an interaction between knowing a person with dementia and Perspective type, F(3,591) = 3.33, p = 0.019,  $\eta_p^2 = 0.02$ . Follow up comparisons suggested that there was a difference between people who knew someone with dementia and those who did not, specifically on the Partner scenarios, t(199) = 1.92, p = 0.056, d = 275, but not for the other Perspectives, all ts < 1.24, all ps > 0.21, although the effect was only marginally significant. Overall, gender and personal experience with dementia did not have a reliable impact on ratings of Identity Preservation and Daily Importance, although there was some evidence that women consider memory failures as more important than men.

Correlational analyses indicated a significant association with participant age and ratings of the scenarios. There were significantly positive relationships between participant age and Identity Preservation ratings for Partner, r=0.146, p=0.038, Parent, r=0.181, p=0.010, and Stranger scenarios, r=0.203, p=0.004. For Own scenarios, the relationship was in the same direction, but not significant, r=0.135, p=0.055. These results imply that older participants perceived greater Identity Preservation across memory types and scenarios, suggesting that

with age, people perceive identity as being more resilient to memory impairments. For Daily Importance, there were weak and inconsistent effects of age across Perspectives: Own, r=0.173, p=0.014, Partner, r=0.139, p=0.049, Parent r=0.072, p=0.308, and Stranger, r=0.119, p=0.093. Overall, across measures, Identity Preservation Scores and Daily Importance scores both tended to increase with age, with weak to moderate positive correlations.

Finally, we conducted correlational analyses to examine relationships between sense of self (overall SOSS scores), memory problems in daily life (overall EMO scores), and Identity Preservation and Daily Importance ratings. Participants with a weaker sense of self on the SOSS (indicated by higher scores) gave lower Identity Preservation ratings (indicating greater perceived impact to sense of self) for both the Own perspective scenarios, r = -0.145, p = 0.040, and the Stranger perspective scenarios, r = -0.163, p = 0.021, with Partner and Parent perspective scenarios showing non-significant relationships in the same negative direction, r = -0.112, p = 0.114, and r = -0.097, p=0.169, respectively. Overall, these suggest that people with a weaker sense of self perceived memory impairments to have a more detrimental impact on identity. For Daily Importance ratings, there was a positive relationship between scores on the SOSS and importance for Own perspective scenarios, r=0.166, p = 0.018. For all other Perspectives there was no significant relationship, all rs < 0.10, all ps > 0.159. That is, people with a weaker sense of self perceived memory impairments to have a greater impact on daily life, but only for themselves. Overall, this implies that when people have a stronger sense of self, they perceive that identity is more resilient to memory impairments. For the EMQ, there were no significant relationships with Identity Preservation or Daily Importance ratings for any of the Perspectives, all rs < 0.08, all ps > 0.263. Thus there was no evidence that people's self-reported memory difficulties in their own daily life impacted on their ratings.

#### Discussion

This study contributes to the literature on the relationship between memory and identity, and how the self is maintained in the context of memory impairment caused by AD. We aimed to extend work by Strohminger and Nichols [22, 23], which assessed the perceived impact of memory impairment on the self from a third-person perspective. In the current study, we compared perspectives, particularly focused on whether people rated the impact of memory impairment differently when thinking about themselves, compared to various others (a parent, partner, or stranger). We also examined different types of memory impairment (involving episodic, semantic or procedural memory, and social or non-social content) to explore the impact of these variables on beliefs, feelings, and attitudes in relation to self-identity, and its impact on daily life. We will discuss the main results relating to perspective, relationship type, and memory type in turn.

#### Perspective & Relationship Type

Previous studies examining the perceived impact of memory impairments on identity [22, 23] only used scenarios involving other people, precluding any examination of the impact of perspective on such judgements. We found that when averaged across memory types, people perceived memory impairments to have a more detrimental impact on the selfcontinuity of other people, compared to themselves. However, our findings revealed variable impacts of perspective across different memory types, which we explore in more detail in the following section. These results provide the first demonstration that the perspective from which one thinks about a memory impairment (whether it is happening to oneself or to someone else) might change our perceptions about the extent to which that impairment impacts sense of self.

We also found that the specific type of 'other' relationship differentially impacted on judgements about self-continuity. Specifically, people gave the highest Identity Preservation ratings to scenarios involving a partner, followed by a parent and stranger. In fact, across both Identity Preservation and Daily Importance measures, partner's perspective scenarios were rated similarly to own perspective scenarios. This suggests that the closeness of a relationship might impact how people view the integrity of self, which would have implications for dementia care: for example, it may play a role in decision-making about placement into aged care. These findings link to previous work on cognitive interdependence in older couples [27], showing that people view themselves and their intimate partner in similar ways, including in the nature of their self-identity and the impact of cognitive decline. Future research could examine how other relationship factors can impact the degree to which an intimate partner is considered similar to oneself and maintains their identity in the face of cognitive decline.

# Interaction Between Perspective, Memory Type, & Social Relevance

Overall, people considered procedural memory impairment to have the least impact on self-continuity, while semantic memory impairment (recognising a familiar person or recalling a holiday destination) was considered to have the greatest impact on self-continuity. The notion that semantic memory-in particular, self-knowledge about one's traits, relationships, and life events-is of critical importance to identity is supported by research from Klein and colleagues [17], who demonstrated through numerous patient case studies that semantic memory may support self-continuity even in the face of extensive episodic memory loss [15, 28]. In a study of people with AD, Tippet et al. [13] linked the ability to construct a quality life story to more sophisticated explanations as to how and why one continues to be "the same person", suggesting that semantic selfknowledge "scaffolds the ability to understand and explain one's persistence across time" (p. 14). Klein et al. [17] and Tippet et al. [13] examined continuing sense of self from patient self-reports. Our participants from the general population also rated semantic memory impairment as most detrimental to self-continuity suggesting that people might hold intuitions about the important contribution of semantic memory to the self even without personal experience of its loss. Meanwhile, episodic memory impairment was perceived to have the greatest impact on daily life, consistent with other studies documenting the importance of episodic memory to our everyday functioning [29]. Although procedural memory impairments also compromise everyday functioning, we speculate that episodic memory failures are viewed as more of a threat to self because such impairments represent a more global loss to executing a range of tasks, whereas a loss in (say) the ability to perform at dance is task-specific, leaving other abilities intact.

The social nature of the memory impairment also had a significant impact on its perceived detriment to the self. People gave lower Identity Preservation scores, reflecting a greater disruption to selfcontinuity, to those with social memory impairments (e.g., failing to recognise a familiar person) compared with non-social memory impairments (e.g., forgetting a holiday destination) for both episodic and semantic scenarios regardless of perspective. This suggests that impairment of social memories is more disruptive to sense of self than non-social memories. This is perhaps unsurprising given the centrality of social knowledge and close relationships in constructing and supporting our sense of who we are [30]. We observed the opposite pattern in procedural memory scenarios. However, we note that our procedural memory scenarios involved using a mobile phone (non-social) and attending a dance class (social). The distinction between social and non-social in these scenarios may not have been as clear cut as in our episodic and semantic scenarios, which may have contributed to this result (see Appendix A). Future research could follow up these findings by testing a range of different scenarios that vary along social and memory type dimensions.

Importantly, we found that factors of memory type, social relevance, and perspective resulted in shifting perceptions of self-continuity in complex and interacting ways. While on average, people perceived memory impairments to have a more detrimental impact on the self-continuity of others compared to themselves, there were two scenarios where we observed the opposite pattern-failure to recognise a loved one (social semantic) and forgetting a recent social event (social episodic). For both scenarios, participants rated these (social) memory failures as more detrimental to their own self-continuity than that of others, and of higher daily importance to themselves than in the case of others. Therefore, while "memories are important to the extent that they have resonance with personal relationships" (p. 168) [22], our results suggest that this may hold especially true when one is considering one's own memories and personal relationships. Perhaps this is because imagining scenarios about losing memory of one's own loved ones is more emotionally distressing than considering the same hypothetical from a more distanced, third-person perspective. This raises the possibility that perspective mediates the importance we place on social aspects of identity, which would be a valuable avenue for further research.

Overall, the critical importance of close relationships in maintaining the self was evident in our findings. Participants considered failure to recognise a family member to have the most detrimental impact on the self, followed by forgetting a recent visit or outing with a family member. These findings reinforce the notion that social relationships underpin our sense of self [20], and reveal that disruptions to these relationships (e.g., through lack of recognition or forgetting time spent together) are perceived to have a devastating impact on one's identity. These findings nuance the emphasis on episodic memory in previous theory and research, suggesting that social memory – regardless of whether episodic or semantic – is critical for maintaining a continuous sense of self.

#### Strength of Self

We explored the relationship between participants' own sense of self (as measured by the SOSS), and their responses to the scenarios. We found people with a weaker sense of self judged memory failures to be more detrimental to self-continuity than those with a stronger sense of self, with small but consistent negative relationships across scenarios. The same pattern was evident for Daily Importance ratings, but only for Own perspective scenarios. This suggests that people with a stronger sense of self perceive that identity is more resilient to everyday memory failures and persists despite them. This finding is consistent with the essential moral-self hypothesis [22] and extends it, suggesting that non-memory aspects of identity may be more important to identity maintenance especially for people who have a stronger sense of self. Future work could explore these relationships in clinical populations of people with memory impairment and disorders of self (e.g., schizophrenia), as well as examining whether similar effects of identity strength are found for both memory and non-memory aspects of self (e.g., moral traits).

#### Impact of Other Demographic Factors

Participant age was the demographic factor with the clearest association with self-ratings. We found that older participants tended to give higher Identity Preservation ratings across memory impairments and scenarios. This may be considered a form of self-protection, as older participants are entering a time in their life when the possibility of developing dementia or age-related cognitive decline is more likely. In facing this reality and fear, they may not wish to acknowledge the potential significant impact of memory impairments on the sense of self. This aligns with findings by Haslam and colleagues of 'age related self-categorisation' and its effects on cognitive performance [31] and extends it to perceptions of the self. Future studies could employ a longitudinal repeated measures methodology to monitor perceptions of the self in relation to memory function over time as people age.

Another possibility is that older adults may be more likely to discover that memory failures are not necessarily catastrophic, and that much is maintained even when memory failures begin to occur. In other words, 'all is not lost' in the face of dementia [15, 32]. Their experiences may make them more forgiving of memory failures and more likely to perceive identity preservation despite them. However, we did not find clear effects of experience with memory failures influencing people's ratings either in terms of their knowing a person with dementia, nor in their responses on the EMQ, so this interpretation of the source for age effects requires further research.

#### Limitations and Future Research

Our methodology has advantages and limitations. We were able to assess lay perceptions of self from a relatively large and diverse sample of the general public, using controlled scenarios that systematically varied the factors we were interested in. One limitation of this approach is that we focused on AD, to the exclusion of other pathologies. Another methodological limitation is that the distinct types of memory impairment presented in our scenarios in fact rarely occur as discrete impairments in AD or in real world activities. Rather, in real world scenarios typically multiple memory functions are engaged (or impaired) simultaneously. Therefore, although it is of theoretical interest to distinguish between memory types, such distinctions may not readily apply to real-world experience. A similar issue is evident in our categorisation of social and non-social memory impairments, with some scenarios (e.g., mobile phone use) being somewhat ambiguous and non-social impairments still having potential social implications. We matched the memory content across scenarios (e.g., all procedural-social scenarios involved forgetting dance steps) which allowed controlled comparison of the different perspectives, but may limit generalisability to all kinds of memory content. The diversity of our sample allowed us to examine individual differences. Although half of our sample had some personal experience of dementia, we did not find evidence that this experience made a difference to ratings. Age, by contrast, had a reliable impact, suggesting that experience or knowledge over sufficient time matters, and that people may become more tolerant of memory failures as they get older. Overall, future research could build on our initial findings by focusing on a broader range of memory and non-memory impairments, use multiple examples for each category, and a fuller range of cases examining different kinds of dementia and different social contexts. Future research should also focus on the experiences of people living with dementia themselves, as well their direct carers, to examine beliefs about ways in which self is maintained by people who have immediate and close experience of cognitive impairments. In our own recent work, we have noted the complex ways in which familial carers navigate change and stability in the identity of their loved ones living with dementia [33].

# Conclusion

In conclusion, this study provides the first evidence that perspective and relationship type impact on judgements of maintaining self-continuity, or "being the same person", in the face of dementia-related memory impairments. The findings contribute to the growing evidence that different types of memory contribute to our sense of self in various ways, and highlight the importance of socially salient semantic memories. Perspective and scenario interacted, such that forgetting close others was considered more detrimental to oneself, while other kinds of memory impairment were considered more detrimental to other people. These findings help nuance our understanding of the various cognitive and non-cognitive processes that contribute to a multi-faceted sense of self, and may have implications for dementia care, given the importance of having social scaffolds that support self-orientation and well-being.

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#### Declarations

**Ethics Approval** This research was approved by the Macquarie University Human Research Ethics Committee (Approval #5201831634903).

**Disclosure of Interests** The authors have no conflicts of interest to report.

## **Appendix A: Scenarios**

- 1. Your daughter comes to visit you, and the next day you call her on the phone and ask why she has not visited for so long. [Episodic Social Own]
- 2. You go to visit your father. You mention that your sister visited him yesterday, but he can't recall her visiting and insists he hasn't seen her for years. [Episodic Social Parent]
- 3. You go to see a play with your partner. The next day, you ask your partner a question about it, but they have forgotten the outing altogether. [Episodic Social Partner]
- 4. You pass your neighbour's house and stop to talk to him in the garden. He tells you he has not had any visitors for a long time, even though you know his daughter visits every week. [Episodic Social Stranger]
- 5. You go to the local grocery shops and get lost on your way home. [Episodic Non-Social Own]
- Your father calls you and tells you that he cannot find his way home from the local shops. [Episodic Non-Social Parent]
- Your partner calls you on their way home from grocery shopping as they are lost and cannot find their way home. [Episodic Non-Social Partner]
- 8. In the corner shop, you overhear someone telling the shop assistant that they are lost and don't know how to find their way home. [Episodic Non-Social Stranger]

- 9. When your son drops in to visit you, you don't recognise him and think he must be selling something. [Semantic Social Own]
- 10. When you go to visit your mother, she does not recognise you and mistakes you for a childhood friend. [Semantic Social Parent]
- 11. Your partner wakes up distressed in the middle of the night and asks who you are. [Semantic Social Partner]
- As you walk down the street, you see your neighbour refusing to let their son into their house, saying they don't know who he is. [Semantic Social Stranger]
- You are looking through old photo albums and find some from a previous overseas holiday, but you cannot recall which country you visited. [Semantic Non-Social Own]
- 14. You discuss an overseas family holiday with your father and he cannot recall the country that you visited. [Semantic Non-Social Parent]
- 15. You are looking at photos of an overseas trip you took with your partner and they cannot recall the country that you visited. [Semantic Non-Social Partner]
- 16. You see someone printing photos at the kiosk in front of you, complaining to their daughter that they can't remember the trip on which the photos were taken. [Semantic Non-Social Stranger]
- 17. You go to your regular dance class but find that you forget the dance steps you were taught the week before. [Procedural Social Own]
- 18. Your mother tells you that she is having trouble keeping up with her dance class as she cannot recall the steps. [Procedural Social Parent]
- 19. You attend a weekly dance class with your partner and they cannot recall the dance steps they were taught the week before. [Procedural Social Partner]
- 20. You overhear someone in a café telling their friend that they will have to stop going to their dance class as they cannot recall the steps. [Procedural Social Stranger]
- 21. You try to add an appointment into your phone calendar. You have done this many times before but cannot recall how to do it. [Procedural Non-Social Own]
- 22. Your mother complains that she cannot figure out how to use her mobile phone, even though she has been using it successfully for several years. [Procedural Non-Social Parent]

- 23. Your partner cannot figure out how to send a text message to you, even though they have done this many times before. [Procedural Non-Social Partner]
- 24. Waiting for the doctor, you hear someone asking the receptionist for help using their mobile phone to call a taxi. They say they have forgotten how to use it, even though they have done it many times before. [Procedural Non-Social Stranger]

N.B. although scenarios are presented in blocks in this appendix, they were presented to each participant in a unique random order.

Identity Preservation (a, b, c) & Daily Importance (d, e) Questions:

- a) Would you/they/he/she still be the same person?
- b) Would you/they/he/she still know who you/they/ he/she are/is?
- c) Would you/they/he/she still feel like your/their/ him/her self?
- d) Would you/they/he/she be upset if this occurred?
- e) Would this impact on your/their/his/her daily life?

0 =not at all, 5 =to the fullest extent.

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