**Examining the relationship between autobiographical memory impairment and carer burden in dementia syndromes**

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**Abstract**

**Background** Autobiographical memory (ABM) refers to the capacity to remember one’s own past, and is known to be central for supporting one’s identity and sense of self. This capacity is commonly affected in Alzheimer’s disease (AD), as well as semantic dementia (SD) and behavioural-variant frontotemporal dementia (bvFTD). Importantly, ABM plays a critical social function, facilitating relationship intimacy and empathy, and thus loss of ABM may also negatively affect families and carers.

**Objective** To explore the relationship between ABM disruption and carer burden in AD, SD and bvFTD, and establish whether characteristic ABM profiles differentially relate to carer burden across dementia syndromes.

**Methods** We recruited 12 AD, 10 SD and 13 bvFTD patients and their primary carer. All participants completed the Autobiographical Interview to assess memory for recent and remote events. Carers completed: the Zarit Burden Interview; Depression, Anxiety and Stress Scale (DASS-21); and the Intimate Bond Measure (IBM).

**Results** In AD, loss of recent ABM was associated with worse psychological wellbeing of carers on the DASS-21. In contrast in SD, remote ABM dysfunction was associated with SD patients showing greater controlling behaviour within their intimate relationships. In bvFTD, surprisingly, despite pervasive ABM impairment, no relationship between extent of ABM loss and carer burden was observed.

**Conclusion** These preliminary results reveal that ABM impairment impacts on patients’ families and carers and suggest that these influences vary according to the pattern of ABM dysfunction. Disease-specific interventions focusing on preserved aspects of ABM may improve quality of life for both patients and carers.

**Abstract word count:** 250

**Keywords:** frontotemporal dementia, Alzheimer’s disease, semantic dementia, wellbeing, quality of life, relationships

**Introduction**

Autobiographical memory (ABM) refers to the capacity to remember personally relevant past events and facts about oneself [1, 2]. This complex, multifaceted ability generates a sense of recollection or reliving upon retrieval [3], with these memories often emotionally-laden and rich in sensory detail [4]. Moreover, because of its unique connection to one’s past, ABM is essential to support an individual’s sense of identity and their feeling of continuity across time [2, 5]. ABM also plays an important role in social functioning [6, 7]; the sharing of previously experienced events facilitates intimacy within a relationship and is involved in eliciting empathy from others [6]. Such widespread implications suggest that the impact of ABM impairment may go beyond the individual level, potentially leading to loss of intimacy within relationships, and poorer psychological wellbeing and increased feelings of burden in individuals caring for people with ABM disruption.

Disruption of ABM is a common feature of dementia, however, patterns of ABM deficits differ between dementia syndromes. Patients with Alzheimer’s disease (AD) display deficits in recent episodic memory which are a key feature of the disease [8]. In these patients, ABM for recent events is profoundly impaired, with ABM for remote events comparatively less affected ([9-14] but see [15, 16]). Previous studies in AD have demonstrated that ABM loss, especially for events in early adulthood, impinges on the integrity of one’s identity and sense of self [17]. This is similar to case reports of extensive loss of retrospective autobiographical memory, with these individuals reporting emotional detachment from their autobiographical memories and the sense of being a “new person” (e.g., Case D.V. reported by [18]). Although this ABM disturbance has widespread implications for the individual living with AD, surprisingly, the impact of this pervasive loss of identity and memory for one’s past on carers of AD patients has not yet been investigated.

ABM deficits are also commonly observed in non-Alzheimer’s younger-onset dementia syndromes including semantic dementia (SD) and behavioural-variant frontotemporal dementia (bvFTD) (reviewed by [19]). SD is typified by language impairments, due to profound loss of semantic or general world knowledge [20]. Interestingly, SD patients typically demonstrate relatively preserved recent ABM in the context of impaired remote ABM retrieval; the reverse profile to that typically reported in AD ([9, 11, 12, 15] (but see [21, 22]). Recent efforts have been made to understand the potential relationship between ABM and representations of the self in SD [e.g., 23], although the potential impact of this degradation of remote ABM beyond the individual patient has been unexplored.

In contrast to SD and AD, patients with bvFTD present with impaired social conduct, personality changes and apathy [24], together with executive dysfunction and variable episodic memory difficulties [25-27]. Of relevance here, bvFTD patients exhibit a flat ABM profile, with impaired ABM retrieval reported irrespective of time period [9, 11, 15, 27-29]. These individuals therefore face difficulty accessing autobiographical events from both formative remote time periods as well as more recent life events. To date, much of the literature examining carer burden in bvFTD has focused on patient characteristics, including behavioural disturbances, disease severity and cognitive changes [30-32]. Importantly, given the global loss of ABM in this cohort, it is likely that ABM dysfunction also impacts on carers of individuals with bvFTD; however, this has not yet been explored.

Thus, despite increasing research exploring the patterns and mechanisms of ABM disruption across these dementia syndromes, the day-to-day impact of ABM impairment, particularly on carers, remains unknown. The present study represents the first attempt to examine the relationship between ABM, carer burden and psychological wellbeing and the quality of the carer-patient relationship, across dementia syndromes. We hypothesised that ABM disruption would impact negatively on the carer and the quality of the carer-patient relationship. Our secondary aim was to establish whether characteristic recent and remote ABM impairments across these syndromes, would differentially relate to carer burden and psychological wellbeing.

**Materials and Methods**

**Participants**

***Patients***

Twelve AD, 10 SD and 13 bvFTD participants were recruited from FRONTIER, the younger-onset dementia clinic in Sydney, Australia. All patients underwent neuropsychological assessment and were assessed by an experienced behavioural neurologist. Diagnosis was reached by consensus across the multidisciplinary team based on current diagnostic criteria [8, 20, 24]. AD patients showed characteristic episodic memory impairments, with additional deficits in confrontation naming and/or visuospatial dysfunction [8]. SD patients showed pervasive semantic deficits manifesting as impaired naming and comprehension ability [20]. The bvFTD patients presented with characteristic impairments in personality and behaviour, with a degree of executive dysfunction and social cognition decline [24]. At the time of assessment all patients were living in the community. Sixteen healthy age- and education-matched controls were recruited from the NeuRA volunteer healthy control database. Participants with current or prior history of psychiatric illness, significant head injury, cerebrovascular disease, alcohol or drug abuse or neurological disorders were excluded, as were those with limited proficiency in English. All controls scored above 88/100 on the Addenbrooke’s Cognitive Examination - Revised (ACE-R) [33].

***Carers***

A carer willing to take part in this study was available for all patients. The person completing the carer questionnaires was the individual who attended the neurology appointment with the patient. Among carers, 27 (77.1%) were the patient’s spouse or partner, 4 (11.4%) were the patient’s child, 3 (8.6%) were the patient’s sibling and 1 (2.9%) was the patient’s friend and primary carer. The carer-patient relationship did not differ amongst patient groups ($χ2=4.145$, *p* = .657; AD: 10 spouse, 1 child, 1 friend; SD: 8 spouse, 1 child, 1 sibling; bvFTD: 9 spouse, 2 child, 2 sibling). The majority of carers were female (30; 86.7%), however, carers’ sex did not differ according to patient diagnosis ($χ$2 = 4.239, *p* = .120).

The South Eastern Sydney Local Health District and the University of New South Wales ethics committees approved the study. Participants or their person responsible provided informed consent in accordance with the Declaration of Helsinki. Participants volunteered their time and were reimbursed for travel costs.

**Materials**

***Background Neuropsychological Assessment***

General cognition was assessed using the ACE-R [33]. Attention and working memory were assessed using Digit Span [34] and the Trail Making Test [35]. Verbal episodic memory was assessed using the delayed recall subscale of the Rey Auditory Verbal Learning Test (RAVLT) [36] and the Rey Complex Figure (RCF) was employed to assess non-verbal episodic memory and visuospatial construction [37]. Naming, comprehension, repetition and non-verbal semantic matching were assessed with the Sydney Language Battery (SYDBAT) [38].

***Autobiographical Memory Assessment***

The procedure for this study has been described in detail previously (see [15]). Briefly, the Autobiographical Interview (AI) was employed to assess ABM [39]. This structured interview is designed to assess retrieval of both autobiographical episodic and semantic information within the same test. Participants are asked to describe one personally experienced event in detail, across 4 time periods (Teenage Years, Early Adulthood, Middle Adulthood and Recent Time (within the past 12 months)) with no prompting provided. Note, the original version of the AI assesses 5 time epochs, however, here the AI was reduced to 4 time periods (removing the Childhood epoch) to reduce patient demands (see [15]). The Free Recall section is followed by General Probes (i.e., generic cues to focus on a specific event if this had not been achieved during Free Recall). Following Free Recall and General Probing for all time periods, the Specific Probing section is administered. Here, specific questions covering five categories (Event, Time, Place, Perceptual, Emotion) are asked for each of the events previously elicited. Each event recalled must be a one-off occurrence, time-restricted (not more than a few hours), and specific to a particular location.

Each interview was recorded and transcribed for scoring. Scoring of the AI is based on the number of details generated by the participant and parses details into those internal to the event, from those external to the event. Here, we focused on internal event details, as these reflect episodic re-experiencing [15, 39]. Next, we created scores to compare recent and remote ABM performance. Total Remote Recall included the total number of details following general and specific probing averaged across the 3 remote time periods: Teenage Years, Early Adulthood and Middle Adulthood. Total Recent Recall referred to the total number of details following general and specific probing in the Recent time period. Additional scoring information has been reported previously [e.g., 15].

***Assessment of Behavioural Symptoms and Functional Impairment***

Presence of behavioural change was measured using the informant-rated Cambridge Behavioural Inventory-Revised (CBI-R) [40]. The CBI Total score was used to minimise the number of correlational analyses. This score was calculated as the average frequency of behaviours across the following domains: memory and orientation, everyday skills, self-care, abnormal behaviour, mood, beliefs, eating habits, sleep, stereotypic behaviours, and motivation. To describe the types of behavioural changes observed across dementia syndromes, we also provide percentage scores for each of the subdomains in Table 1.

The Frontotemporal dementia Rating Scale (FRS) was used to assess level of functional impairment and as a proxy for disease severity [41].

***Carer Burden and Wellbeing***

The Zarit Burden Interview (ZBI) was used to assess carer burden [42]. This 12-item questionnaire measures the impact of the disease on carer’s personal, health and financial wellbeing. We used a cut-off of ≥ 12 as indicative of high burden based on recommendations by Higginson et al [43]. This cut-off has high sensitivity (92%) and specificity (94%) in clinical populations including dementia. The 21-item Depression, Anxiety and Stress Scale (DASS) was used to evaluate carer emotional state/ psychological wellbeing [44]. We then calculated a Total score combining the Depression, Anxiety and Stress subscales for subsequent analyses. Finally, the quality of the carer-patient relationship was assessed using the Intimate Bond Measure (IBM) [45]. This 12-item questionnaire measures the carer’s perception of the patient’s level of “care” (e.g., “Is very considerate of me”; “Is physically gentle and considerate”) and “control” (e.g., “Tends to order me about”; “Wants to know exactly what I’m doing and where I am”) within a relationship, with higher scores indicating higher perceived care (a positive perception) and higher perceived control (a negative perception).

**Statistical Analyses**

Data were analysed using IBM SPSS (Version 22). Between groups, continuous variables were investigated using univariate analyses of variance (ANOVA). Categorical variables (e.g., sex) were analysed using chi-square tests. Autobiographical memory performance was investigated with repeated-measures analysis of covariance, with time (Remote vs. Recent) as the within subjects variable and Diagnosis (AD, SD, bvFTD, controls) as the between subjects variable, and age included as a covariate. Sidak post-hoc tests were used to investigate between group differences. The rationale for using Sidak modification of the traditional Bonferroni post hoc test is that the statistical power of the analyses is not affected [46]. Because of our *a priori* hypotheses about the direction of the relationship (i.e., worse memory would be associated with higher carer burden; greater functional impairment and greater behavioural changes would be associated with higher carer burden), one-tailed Pearson correlations were conducted to examine relationships between variables of interest. This approach has the additional advantage of maximising power in small sample sizes, as was the case here. Statistical significance was set at *p* < 0.05.

**Results**

**Demographics and cognition**

As shown in Table 1, all groups were matched for age, education and sex (all *p* values > .05). Consistent with previous studies, the bvFTD group had significantly greater functional impairment than SD (*p* = .046), with no difference between bvFTD and AD (*p* > .05). On the ACE-R measure of general cognition, all patient groups performed worse than controls, (all *p* values< .001), with the SD patients also performing worse than bvFTD and AD (*p* = .001 and *p* = .002 respectively), likely reflecting the significant language demands of this task.

The general neuropsychological assessment revealed profiles characteristic of each patient group, which are detailed in Table 1. In brief, compared to controls AD patients showed impaired verbal and non-verbal episodic memory (RCF % Retention: *p* < .001, RAVLT Recall: *p* < .001), while all components of language, except Naming, were relatively preserved (Naming: *p* = .001, Semantic: *p* = .380, Comprehension: *p* = .409, Repetition: *p* = .521). In contrast, compared to controls SD patients showed significant language deficits across all subtests except repetition (Naming: *p* < .001, Semantic: *p* = .013, Comprehension: *p* = .003, Repetition: *p* = .372), while attention, working memory and visuospatial ability was relatively preserved (Digit Span Forwards: *p* = .523; Digit Span Backwards: *p* = .996; RCF copy: *p* = .193). Finally, compared to controls bvFTD patients were impaired on measures of attention and working memory (Trails B: *p* = .008, Digit Span Forwards: *p* = .016, Digit Span Backwards: *p* =.007). The bvFTD group also showed reduced performance across all memory measures (RCF Percentage retention, *p* < .001; RAVLT, *p* < .001), however, they performed similarly to controls on the visuospatial task (RCF Copy, *p* = 1.0).

***Table 1.*** Demographic characteristics, neuropsychological performance and behavioural profiles in patient groups and healthy controls

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **AD** | **SD** | **bvFTD** | **Controls** | ***F*** | ***p*** | ***Post hoc*** |
| Sex (M/F) | 9/3 | 8/2 | 11/2 | 10/6 |  | .557 |  |
| Age (y) | 67.4±9.5 | 61.0±9.2 | 60.2±8.7 | 66.2±5.3 | 2.495 | .071 |  |
| Education (y) | 12.5±3.2 | 12.5±2.9 | 11.8±2.9 | 13.4±3.4 | 0.654 | .585 |  |
| Duration (m)# | 41.4±32.9 | 63.0±22.5 | 51.7±31.7 | - | 1.385 | .265 |  |
| FRS logit score^ | 0.8±1.6 | 1.5±1.2 | -.07±1.4 | - | 3.357 | .047 | bvFTD < SD |
| ACE-R (/100) | 76.0±11.0 | 62.9±11.0 | 77.5±8.2 | 93.8±3.1 | 29.106 | <.001 | Patients < controls; SD < bvFTD, AD |
| Trails A (s) | 68.6±36.2 | 33.6±5.2 | 51.1±18.6 | 35.7±10.8 | 7.338 | <.001 | AD > SD, controls |
| Trails B (s)1 | 128.5±39.5 | 89.7±34.9 | 155.6±69.3 | 96.3±28.9 | 5.416 | .003 | bvFTD > SD, controls |
| Digit span-F (max span)2 | 5.9±1.4 | 6.3±1.3 | 5.8±1.2 | 7.3±1.2 | 4.257 | .010 | bvFTD, AD < controls |
| Digit span-B (max span) | 4.4±1.1 | 4.9±0.7 | 3.8±1.0 | 5.1±1.2 | 4.421 | .008 | bvFTD < controls |
| RCF-copy | 28.1±7.4 | 34.1±1.4 | 30.8±3.5 | 30.3±3.1 | 3.413 | .025 | AD < SD |
| RCF-delay | 3.0±4.2 | 13.8±9.2 | 6.2±5.3 | 16.1±5.9 | 13.025 | <.001 | bvFTD < controls; AD < SD, controls |
| RCF % retention | 9.8±12.3 | 40.2±26.6 | 20.9±17.5 | 52.7±17.0 | 14.716 | <.001 | AD, bvFTD < SD, controls |
| RAVLT 30-min3,4 | 3.25±3.1 | - | 2.36±3.1 | 9.3±2.7 | 21.965 | <.001 | Patients < controls |
| Naming | 20.9±5.0 | 4.9±2.2 | 21.7±3.9 | 26.2±2.1 | 80.750 | <.001 | Patients < controls; SD < bvFTD, AD |
| Semantic | 24.7±3.3 | 18.8±5.5 | 23.5±2.7 | 27.0±2.0 | 12.385 | <.001 | SD < bvFTD, AD, controls |
| Comprehension | 26.6±2.0 | 21.0±5.4 | 25.8±2.7 | 28.6±1.6 | 13.258 | <.001 | SD < bvFTD, AD, controls |
| Repetition | 29.0±1.2 | 28.8±1.8 | 28.9±2.6 | 30.0±0.0 | 1.640 | 0.193 | - |
| *CBI frequency of behaviours %* 5 |  |  |  |  |  |  |  |
| Memory | 57.8±24.2 | 47.5±18.9 | 52.7±26.7 | 7.5±8.3 | 17.869 | <.001 | Patients > controls |
| Everyday | 29.1±34.0 | 15.0±16.0 | 33.6±19.0 | 1.3±2.3 | 6.705 | .001 | bvFTD, AD > controls |
| Self care | 9.4±20.2 | 1.4±4.2 | 13.0±18.4 | 0.0±0.0 | 2.565 | .067 | - |
| Abnormal behaviours | 12.8±19.0 | 25.0±24.8 | 33.5±23.4 | 1.9±3.5 | 7.226 | <.001 |  |
| Mood | 17.7±18.6 | 15.3±11.7 | 29.2±20.5 | 4.6±6.9 | 5.851 | .002 | bvFTD, SD > controls |
| Beliefs | 2.1±5.2 | 1.9±3.7 | 6.9±17.0 | 0.0±0.0 | 1.379 | .262 | - |
| Eating | 17.2±22.2 | 16.0±18.0 | 36.5±24.8 | 0.8±3.2 | 8.326 | <.001 | bvFTD > controls |
| Sleep | 29.2±33.0 | 16.7±18.8 | 26.0±24.7 | 6.7±9.3 | 2.691 | .058 | - |
| Stereotypical | 25.0±27.0 | 49.3±38.1 | 55.2±24.4 | 2.9±5.7 | 12.261 | <.001 | bvFTD, SD > controls; bvFTD > AD |
| Motivation | 23.3±19.6 | 41.3±24.8 | 58.3±36.7 | 2.0±4.1 | 19.946 | <.001 | bvFTD, SD > controls; bvFTD > AD |
| Total | 22.4±17.9 | 22.9±13.3 | 34.5±14.6 | 2.8±2.4 | 14.163 | <.001 | Patients > controls |

*Note:* Values are means ± standard deviation. Abbreviations: ACE-R = Addenbrooke’s Cognitive Examination-Revised; RCF = Rey Complex Figure; RAVLT = Rey Auditory Verbal Learning Test. ^ Logit scores on the FRS are subdivided into 6 equal categories to facilitate clinical interpretation: very mild (>4.12), mild (4.11 to 1.92), moderate (1.91 to -0.40), severe (-0.39 to -2.58), very severe (-2.57 to -4.99), and profound (below -4.99). Higher scores on the FRS denote higher functioning . Data missing for: **#** 1 AD; 1 4 AD (test discontinued); 2 1 bvFTD; 3 2 bvFTD and 4 AD. 4 SD were not tested on the RAVLT due to their language deficits. 5 1 bvFTD; 1 SD

**Autobiographical Interview Performance**

Autobiographical Interview total memory performance across Recent and Remote time periods is depicted in Figure 1. The overall effect of diagnosis on ABM retrieval was significant (*F*(3,46) = 5.137, *p* = .004). Irrespective of time period, both bvFTD and AD patients performed worse than controls (*p* = .005 and *p* = .034 respectively). SD patients, in contrast, did not differ significantly from controls for overall ABM retrieval (*p* = .233). No significant differences were present between patient groups (all *p* values >.05). The overall effect of time was also significant (*F*(1,46) = 4.785, *p* = .034), reflecting a higher number of details recalled in the Recent than Remote time period, irrespective of group. The interaction between time and diagnosis approached significance (F(3,46) = 2.262, *p* = .094). Given our *a priori* hypothesis of differential performance for each group in Recent and Remote time periods, however, planned analyses according to diagnostic group for each time period were conducted.

These analyses revealed that AD patients performed similarly to controls in the Remote time period (*p* = .156), but importantly performed significantly worse than controls in the Recent time period (*p* = .030). Within AD, no significant difference across time periods was present (*p* = .240). SD showed differential ABM impairment across time periods, with a trend for impaired Remote ABM compared to controls (*p* = .053) in the context of relatively intact Recent ABM retrieval (*p* = .892). In addition, Recent ABM performance was significantly higher than Remote performance in this group (*p* = .021). The bvFTD group performed significantly worse than controls across both Remote and Recent time periods (*p* = .005 and *p* = .031 respectively). No difference between Remote and Recent retrieval was present (*p* = .413), confirming the flat ABM retrieval profile typically reported in bvFTD.

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***Figure 1.*** Autobiographical Interview (AI) performance in Alzheimer’s disease (AD), semantic dementia (SD) and behavioural-variant frontotemporal dementia (bvFTD) and healthy controls.

*Note.* Scores are total number of internal details recalled following probing, adjusted for age, across Remote and Recent time periods. Error bars show standard error of the mean. \* *p* < .05 compared to controls. T *p* = .053 compared to controls.

**Carer burden and wellbeing**

As shown in Table 2 all carer groups showed an equivalent and high level of burden on the ZBI, with no significant difference across patient groups (*p* = .330). Using a cut-off of ≥ 12 [43], the number of carers with high burden were: bvFTD: 11/13; SD: 7/10; AD: 9/12. A chi-squared analysis revealed no difference in the number of carers reporting high levels of burden according to diagnostic group ($χ2=.732; $*p* = .693). In addition, all carers reported equivalent levels of depression, anxiety and stress on the DASS, with no significant differences seen across patient groups (Depression: *p* = .993, Anxiety: *p* = .722, Stress: *p* = .222; Total: *p* = .682). Perceived quality of the relationship as measured by the IBM significantly differed across patient groups. Notably, the level of perceived Care within the relationship was significantly greater in AD than in bvFTD (*p* = .002) reflecting reduced care in bvFTD, when compared with AD relationships. SD did not differ from AD (*p* = .464) or bvFTD (*p* = .080). In contrast, the degree of Control within the patient-carer relationship was greater in SD than in AD (*p* = .023), but not in bvFTD (*p* = .671), with individuals with SD perceived as being more controlling within the relationship. No difference in level of control was seen between AD and bvFTD (*p* = .208).

***Table 2.*** Differences in carer burden and carer wellbeing according to dementia type

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **AD** | **SD** | **bvFTD** | **F** | ***p*** | **Post hoc** |
| ZBI (/48) | 17.5±10.1 | 17.0±10.7 | 22.5±8.7 | 1.148 | .330 | - |
| DASS Depression (/42) | 6.0±9.3 | 6.4±8.1 | 6.2±5.9 | .007 | .993 | - |
| DASS Anxiety (/42) | 3.3±6.6 | 5.0±5.2 | 5.1±5.8 | .329 | .722 | - |
| DASS Stress (/42) | 12.2±8.0 | 10.8±9.1 | 16.2±6.0 | 1.576 | .222 | - |
| DASS Total (/128) | 21.5±20.4 | 22.2±20.5 | 27.4±13.5 | .387 | .682 | - |
| IBM Care^ (/36) | 27.9±4.9 | 23.1±7.9 | 14.6±11.2 | 7.381 | .002 | AD > bvFTD |
| IBM Control^ (/36) | 6.9±5.5 | 15.7±7.7 | 12.5±8.3 | 4.242 | .024 | SD > AD |

*Note:* Values are means ± standard deviation. ^ Scores missing for 2 bvFTD patients. Maximum scores provided in parentheses. ZBI: scores ≥ 12 indicative of high burden

**Correlational analyses**

One-tailed Pearson correlations between AI performance and carer burden and wellbeing, according to diagnosis, are reported in Table 3. In AD, reduced Recent ABM retrieval was associated with poorer psychological wellbeing in carers (DASS Total: *r* = -.509, *p* = .045). In contrast in SD, reduced Remote ABM retrieval was associated with increased perceived control within the carer-patient relationship (*r* = -.592, *p* = .036). In bvFTD no significant correlations between ABM performance and burden, quality of carer-patient relationships, or carers’ psychological wellbeing were observed.

To explore the extent that ABM disturbance contributed to carer burden, in comparison with other typical burden influences, we also examined the relationship between behaviour, functional ability and burden in our patient groups. In AD, behavioural change reported on the CBI was associated with increased carer burden (*r* = .512, *p* = .045) and poorer psychological wellbeing (DASS Total *r* = .736, *p* = .003). In SD, increased behavioural change correlated with increased carer burden (*r* = .740, *p* = .011), less care within the relationship (*r* = -.611, *p* = .040) and poorer psychological wellbeing (DASS Total: *r* = .676, *p* = .023). Greater functional impairment was also associated with increased burden (*r* = -.578, *p* = .040). In bvFTD, the only significant correlation was between the FRS and the perceived level of care within the relationship, with greater disease severity and functional impairment being associated with reduced levels of care (*r* = -.626, *p* = .020).

***Table 3.*** Correlations between ABM, Behaviour and Functioning and Carer Burden and Wellbeing according to diagnosis

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **AI Remote**  |  | **AI Recent**  |  | **CBI Total** |  | **FRS** |
|   | **AD** | **SD** | **bvFTD** |  | **AD** | **SD** | **bvFTD** |  | **AD** | **SD** | **bvFTD** |  | **AD** | **SD** | **bvFTD** |
| **ZBI** | .052 | -.239 | -.035 |  | -.121 | .127 | .090 |  | .**512\*** | **.740\*** | -.141 |  | -.346 | **-.578\*** | -.448 |
| **DASS Total** | -.133 | -.385 | .454 |  | **-.509\*** | .044 | .486 |  | **.736\*\*** | **.676\*** | .060 |  | -.192 | -.498 | .069 |
| **IBM Care** | .226 | .242 | .268 |  | -.214 | -.029 | .284 |  | .164 | **-.611\*** | -.386 |  | .335 | .401 | **.626\*** |
| **IBM Control** | .269 | **-.592\*** | .501 |   | .655 | -.267 | .367 |   | -.076 | .504 | .335 |   | -.269 | -.391 | -.035 |

*Note.* \* *p* < .05; \*\* *p* < .01. All correlations reported are 1-tailed Pearson correlations.

**Discussion**

This study aimed to investigate how loss of ABM impacts on burden, psychological wellbeing and quality of the carer-patient relationship in younger-onset dementia. Overall, our findings indicated that ABM loss is related to aspects of carer burden and wellbeing in AD and SD, but not in bvFTD, with differential effects observed depending on the time period of ABM disruption. These associations, however, were not as robust as we had initially predicted, with behavioural changes and functional ability also influencing carer burden and psychological wellbeing. In the following sections we discuss our findings in the context of the functional role of ABM for social interactions and relationships.

Our AD cohort demonstrated the typical profile of impaired recent ABM retrieval in the context of relatively intact remote memory retrieval, in line with previous findings [e.g., 15, 47, 48]. Importantly, consistent with our hypotheses, this deficit in retrieving recent autobiographical events was associated with poorer psychological wellbeing in carers of AD patients. One of the most common and burdensome behavioural changes in AD is repetitive questioning [49, 50]. In addition, AD has been associated with a tendency for patients to rely upon over-general memories and difficulty distinguishing between accurate and false memories [51]. Degradation of recent ABM likely contributes to the increased repetitive questioning and over-general memories, which become increasingly stressful for carers to manage. Such an account warrants further examination. Importantly, the current findings highlight the impact of ABM disturbance beyond the individual. Changes in ABM, however, only appear to partially account for the degree of burden in carers of individuals with AD. Our findings revealed that behavioural changes in AD were also associated with increased burden and poorer psychological wellbeing in carers, converging with previous reports [52, 53]. Of note, while behavioural changes are less prominent in AD compared with bvFTD [54], with disease progression AD patients can become increasingly difficult to manage, due to increased episodes of agitation and wandering [55-57]. Our results suggest that carers of AD patients experience significant psychological distress and mood changes, as a result of both ABM degradation and behavioural change.

In contrast to AD, SD patients displayed relatively preserved recent ABM in the context of impaired remote ABM capacity, in line with previous reports [e.g., 9, 11, 12, 15]. Notably, our correlational analyses revealed that this impairment in remote ABM retrieval negatively influences relationship quality, with worse remote ABM capacity associated with greater controlling behaviour within SD carer-patient relationships. The progressive degradation of the semantic system and associated loss of remote autobiographical memories appears to result in an increased need by SD patients to control their environment. In the face of an increasingly confusing and unfamiliar world, it is plausible that SD patients become rigid and assume authority within their relationships in an attempt to regain a diminishing sense of control. Of relevance here, SD is also associated with increased rigidity in patients’ behaviour, such as eating the same meals at specific times or only wearing particular clothes [58-60]. While speculative, this position is consistent with our current and previous findings of increased burden, poorer psychological wellbeing and less care within the relationship being associated with emerging behavioural changes in these patients [32].

In the bvFTD group, ABM was impaired irrespective of time period, consistent with previous findings [9, 11, 15, 28]. Interestingly, however, this global loss of autobiographical memories was not associated with increased carer burden or worse psychological wellbeing of carers. ABM is incredibly complex and draws upon multiple cognitive processes including fluency, strategic monitoring, introspection, and emotion processing. Of relevance here, any number of factors may disrupt ABM in bvFTD (for discussion see [15]) and as a result many of these factors may also relate to carer burden. Moreover, the strong link between ABM and social cognitive processes has been well-established [61]. The current study is not able to determine what aspect of ABM loss affects the carer; it may be the provision of details or disruption to the act of reminiscing together over shared experiences and the social bond that this instils. Some evidence, however, suggests that the loss of emotional content of memories is common in bvFTD [62, 63], and this detachment from the emotional quality of ABMs is likely to negatively impact the carer and the nature of the patient-carer relationship. Future studies which qualitatively rate the phenomenological aspects of ABM retrieval, to determine whether patients are engaging in imagery, emotional re-experiencing and mental time travel [e.g., 64] will be helpful to explore these important issues further. It is also possible that the burden questionnaire used here was too coarse to detect the impact of ABM impairment on burden. Indeed, we did not see an association between burden *per se* and ABM performance in the AD or SD groups either. The Zarit Burden Inventory employed here is a gross indicator of burden which measures the impact of disease on personal strain, finances and health of the carer [42]. For future studies, sensitive measures specifically designed to assess the influence of ABM on carer burden, for example focusing on grieving of the relationship and loss of feelings of connectedness, may be needed to detect and understand these specific relationships.

Although we did not see an association between carer burden and behavioural change in the bvFTD group, previous studies have identified changes in social cognition and functional impairment as predictors of burden in this cohort [30, 65]. Other cognitive variables that contribute to burden and their relationship with ABM, together with research to explore the complex interaction between carer burden, ABM and behaviour will be interesting for future studies to examine. Specifically, the extent that aspects of executive function, such as generativity and retrieval strategies, contribute to ABM dysfunction in these syndromes has only recently begun to be explored [15]. Moreover, there is a need to devise novel ecologically valid measures that tap into the distressing aspects of ABM loss.

The stronger association between behavioural change and carers’ psychological wellbeing, in SD than in bvFTD, was somewhat unexpected. It is possible that bvFTD carers are better informed about behavioural changes from the time of diagnosis, when behavioural features are strongly emphasized [66]. In contrast in SD the focus is usually on language changes and thus unexpected behavioural and personality changes may lead to greater psychological distress for SD carers [67]. Additionally, it is likely that the underlying factors in the burden of care in bvFTD are highly complex and even more intricate than in other dementia subtypes, given its devastating characteristic symptoms.

A number of methodological caveats warrant further discussion. Firstly, the sample size was relatively small, in part reflecting the demanding nature of assessment of ABM. It was therefore not possible to fully correct for multiple comparisons in the correlational analyses, without increasing the risk of Type II error. It is notable, nonetheless, that our findings map well onto previously published reports in the literature. A second methodological issue is the quantification of a multifactorial and complex concept such as carer burden, as discussed in some detail above. Here, we employed a range of self-report measures to attempt to delineate potential influences of ABM on carer wellbeing, including relationship quality, mood and burden. Self-report measures, however, are susceptible to differences in reporting style and personality. For example, individuals with an optimistic outlook may downplay or re-evaluate patients’ symptoms in a positive light, leading to less reported burden. Even within the same individual, over time, levels of burden may be reported differently as carers develop new techniques to better equip themselves throughout the disease course [68]. In addition, cultural differences may influence the degree of carer burden reported; in some cultures it may be considered inappropriate to report that caring for an older family member or friend is a burden. Moreover, the potential impact of carer profile (e.g., spouse vs. child) has been relatively underexplored. These potential issues apply to all carer burden studies and highlight the need for objective measures to complement existing self-report scales.

In line with this hypothesis, it is likely that carers’ experience of ABM disturbances change with disease progression. For example, in the pre-diagnosis and early diagnosis stages, the emergence of ABM deficits are likely to be very distressing, particularly in AD where the loss of recent events is commonly the precipitating factor leading to diagnosis. After this early adjustment period, however, carers may become increasingly adept at discussing memories from spared remote epochs, thus minimising the feelings of loss and distress. Our cohort primarily comprised of individuals who have had some time to adjust to the diagnosis, with diagnosis confirmed in all cases. Examining this relationship in individuals transitioning from mild cognitive impairment to dementia will help to further understand these dynamic interactions between patient symptoms and carer burden across the disease course. A second issue is that ABM was assessed using the Autobiographical Interview, which only assesses one memory across pre-defined epochs. It is therefore possible that patients provide their “favourite” memory, which may represent a semanticized or gist-based account. Whether similar profiles of recall would emerge if a second or third ABM event was probed remains unclear. While this approach was chosen to minimise burden and testing requirements on our patients, it would be interesting to examine how the testing of more than one memory per time period influences the profile of results.

ABM capacity is undoubtedly of importance to the individual’s sense of self [2, 6, 7] and therefore likely has a dynamic influence on the people around those with ABM deficits. This study represents the first attempt to characterise these relationships in three younger-onset dementia syndromes in which ABM disruption is a pervasive feature. Our findings suggest that disease-specific tailored therapies are likely necessary to improve the quality of life of both patients and carers. For example in AD, reminiscence of shared memories that occurred during the remote time period (i.e., childhood and early adulthood), which are better preserved, may help enhance the emotional connection between patients and carers. Moreover, engaging individuals in conversations in which they are able to meaningfully contribute, may boost the individual’s sense of competence. In contrast in SD, interventions focusing on recent events and memories may be more beneficial and less distressing for these patients, and may help maintain important intimate relationships in this cohort. Further examination of the broader implications of ABM dysfunction in dementia will assist in informing future interventions targeting both patients and carers affected by these devastating syndromes.

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