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## **Change in the psychological self in people living with dementia: a scoping review**

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## **Change in the psychological self in people living with dementia: a scoping review**

### **Abstract**

Alternations in one's sense of self are often considered a significant psychological symptom of dementia. However, the self is not a unified construct; it consists of a set of closely connected, yet substantive, manifestations which might not be equally impacted by dementia. Recognising the multidimensional nature of the self, the current scoping review aimed to explore the nature and scope of the evidence demonstrating change in the psychological self in people living with dementia. A hundred and five (105) quantitative and qualitative studies were reviewed, and findings were organised into three main types of self-manifestations: high-order manifestations, functional aspects of the self, and foundational manifestations. Overall, the results show that although there are alterations in some of these different manifestations of the self, these do not imply a global loss of selfhood. Despite notable cognitive changes during dementia, it seems that preserved aspects of self are enough to compensate for potential weakening of some self-processes such as autobiographical recall. Better understanding alterations in selfhood is key to addressing psychological symptoms of people living with dementia, such as feelings of disconnection and reduced agency, as well as to inform new pathways for dementia care interventions.

**Keywords:** Dementia, Self, Selfhood, Review

## Introduction

Over 46 million people live with dementia globally, a number expected to triple by 2050 (Mukadam et al., 2019). Although there are different forms of dementia with distinct symptomatology, the pronounced impact on cognition, notably the progressive disintegration of memory, is a common characteristic (Hutmacher, 2021). Changes in individuals' behaviour and psychological experiences are also recognised as being at the core of dementia (D'cruz, 2021). It has been reported that one of the most distressing psychological symptoms of dementia, for patients and caregivers, is alterations in one's sense of self (D'cruz, 2021). Having access to a life narrative is considered central to the human experience of selfhood (Jetten et al., 2010). Given that self and memory are closely linked, it has been suggested that fragmented episodic memories and gaps in autobiographical self-knowledge can result in the 'weakening' of selfhood in people with dementia (Jetten et al., 2010; Addis & Tippett, 2004). However, the self is a complex construct with many different manifestations, among which self-related memory is only one (Hutmacher, 2021). Following a cognitive psychological framework, the human experience of 'selfhood' can be conceptualised here as the knowledge of having a unique identity and intentional physical presence in the world, accompanied by a strong sense of continuity overtime (Ross et al., 2011).

When exploring dementia's impact on self, terms such as 'total loss', 'impairment' and 'erosion' of selfhood have been historically used in the literature to describe the pronounced changes in the self-experience of people living with dementia, implying the existence of a unitary construct of self (Kontos, 2014; George, 2010). Such descriptions can promote perceptions of complete disintegration of selfhood, exacerbating the stigma as well as fear associated with a dementia diagnosis (Hillman & Latimer, 2017). Consequently, modern opinions caution against viewing the self as a 'monolithic entity', since this conceptualisation could be considered oversimplified, failing to capture the real implications of dementia on the sense of self (Strikwerda-Brown et al., 2019, p.2). Thus, recognising the multidimensional nature of the self, the current scoping review aims to explore the nature and scope of the evidence demonstrating change in multiple aspects of the psychological self in people living with dementia.

Although self-related functions have been extensively explored in the dementia literature, the inherent difficulty of a precise definition of the self has contributed to potential

misinterpretations about changes to the sense of self in people with dementia (Tolhurst et al., 2012). Although we experience a unified sense of self, the self might be considered as a set of closely connected, yet substantive, aspects, from which unity emerges (Klein & Gangi, 2010). Accordingly, it has been suggested that the diverse manifestations of the self have a hierarchical relationship, with self-processes developing earlier providing the foundation for the emergence of higher-order processes (Bomilcar et al., 2021; Summa, 2014). Self-related functions linked with sophisticated cognitive processes could be characterised as higher-order manifestations of the psychological self; these include autobiographical memory, sense of having a life-narrative and self-knowledge (Huntley et al., 2021; Mograbi et al., 2021). There are also aspects of the self that people are not necessarily conscious they experience; this is particularly notable in the processes that are based on the awareness of one's body as their own, having a causal influence both in the physical and social world, such as agency and embodiment, which could constitute the foundational manifestations of the self (Huntley et al., 2021; Mograbi et al., 2021).

Although it is theoretically reasonable to distinguish between high-order and foundational manifestations, this might not be an unequivocal distinction; different levels dynamically interact with each other to form a network of cross-connections (Summa, 2014). This is what Summa (2014, p. 484) refers to as the 'grey zones' in between the two types of manifestations. The self has a central functional role in human cognition (Cunningham & Turk, 2017), underpinning several cognitive processing biases that occur automatically, without necessarily conscious awareness, and involve the cognitive organisation of self-related information. For example, humans preferentially attend to self-related information, which is elaborated and organised within existing semantic and autobiographical self-knowledge, sustaining the self-system (Rathbone et al., 2019). Such processes might be considered to operate in the 'grey zone', uniting high-order manifestations of self-knowledge with foundational aspects of selfhood, such as the agentic experience of an event. Thinking of the different manifestations as existing along a continuum, functional aspects of self might connect the high-order and foundational manifestations together allowing for bidirectional interactions.

The existence of different aspects of the psychological self demonstrates that dementia's impact on selfhood is unlikely to be absolute. The most recent systematic review of the

psychological self in dementia, conducted by Caddell and Clare (2010), concluded that self and identity are mostly preserved throughout the course of dementia, at least to some degree, with qualitative aspects of the subjective experience of self remaining undisrupted. However, although it is true that some aspects of the self remain intact in dementia, manifestations of self involving complex high-order processes are susceptible to negative impact (Weiler et al., 2016). Since Caddell and Clare's (2010) review, evidence for this conclusion has continue to grow. For instance, the consequences of declining episodic memory on selfhood in people living with dementia are well-documented; as self-memories fade and self-knowledge of one's life narrative disintegrates, access to self-related autobiographical information is compromised leading to alterations on perceived sense of self (El Haj et al., 2015a). Additional findings show that self-knowledge, and subsequently self-continuity, can become outdated, often reflecting young adulthood (Bomilcar et al., 2021; Klein & Gangi, 2010). Taken together, it has been suggested that only self aspects related to memory might be weakened in dementia while foundational aspects of self might be preserved, including self-related experiences of living at the present (Hutmacher, 2021; see Strikwerda-Brown et al., 2019 for a narrative review).

Overall, alteration in one's sense of self is undoubtedly a significant psychological symptom of dementia, resulting in the experience of fragmented selfhood. Emergent evidence seems to reach agreement concerning the complexity and multidimensional nature of the psychological self, demonstrating that its different aspects might not be equally impacted by dementia. However, existing empirical research on the impact of dementia on selfhood consists of distinct studies employing diverse methods as well as often focusing on individual manifestations of the psychological self. These diverse findings are often not integrated within a single theoretical framework that considers the multidimensional nature of the self. Consequently, the literature investigating the potential implications of dementia on self has not reached consensus on the extent of changes in the psychological self. Thus, although researchers have answered Caddell and Clare's (2010) call, providing more research to better understand how the psychological self is impacted by dementia, this research has not been systematically reviewed and synthesised within a psychological framework.

To address this theoretical gap, the scoping review method (Arksey & O'Malley, 2005) was used to explore dementia's potential impact on different aspects of selfhood, which have

been studied using distinct conceptual approaches and methods across the literature. The aim of this review is to gain greater understanding of the patterns of dementia-related changes in the psychological self. Exploring the literature on selfhood and dementia over the past 12 years, the current scoping review expands on Caddell and Clare's (2010) findings by adopting a rigorous systematised methodology, in accordance with the latest Joanna Briggs Institute guidelines, and offering a nuanced deconstruction of the self using a cognitive psychological framework. We expand Caddell and Clare's (2010) broad search terms to include individual manifestations of selfhood and a focus on the psychological impact of the condition. In our search and inclusion criteria, rather than focusing on the self as a unitary construct, we apply a cognitive psychological framework, conceiving of the self as a complex system with high-order, functional and foundational aspects. This allows us to offer the first systematic exploration of the impact of dementia on the psychological self, recognising the complexity of the self-system.

## **Method**

The conduct and reporting of this scoping review followed the guidelines recommended by the JBI Joanna Briggs Institute (JBI) and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist was used (Tricco et al., 2018). The review protocol has been pre-registered on the Open Science Framework (<https://osf.io/b4t6n>). Deviations from the originally published review protocol are declared and discussed in detail in the following sections.

## **Review question**

*Recognising the multidimensional nature of the psychological self, what is the nature and scope of the evidence demonstrating change in the psychological self in people living with dementia?*

## **Eligibility criteria**

The inclusion and exclusion criteria were formulated a priori of the screening of relevant articles (Table 2). The systematic review of Caddell and Clare (2010) acted as a reference point for the current scoping review. Given that their database search was conducted on the 16th of March 2009, we decided to focus on studies published over the last 12 years (2009-2021)

to identify the newest developments in the field. Recognising the multidimensional nature of the self, the cognitive aspects of the psychological self closely match the aspects of self conceptualised in recent theoretical papers (e.g., Klein & Gangi, 2010; Bomilcar et al., 2021), which share common elements. As we were interested in exploring only cognitive aspects of the psychological self, socially and culturally constructed aspects of selfhood (e.g., marital identity and romantic relationships, sexual identity, spirituality etc.) were not considered. Anosognosia (i.e., lack of awareness about disease and cognitive difficulties) was also not considered because it has been conceptualised as a process requiring ‘a third person perspective’ (Weiler et al., 2016) while this review was interested in reflections of self as an object of awareness.

Table 2. Inclusion and exclusion criteria of the current scoping review.

	Inclusion Criteria (IN)	Exclusion Criteria (EX)
1	<b>Studies reporting data from adults diagnosed with dementia (e.g., Alzheimer’s disease, vascular dementia, frontotemporal dementia, dementia with Lewy bodies, mixed dementia, young-onset dementia)</b>	Studies not reporting data from adults diagnosed with dementia (including diagnosis of alcohol-related dementia, HIV-associated neurocognitive disorder, Creutzfeldt-Jakob disease, Wernicke–Korsakoff syndrome, mild cognitive impairment)
2	<b>Studies published between 17th March 2009 - 25th November 2021</b>	Studies published before 17th March 2009 and after 25th November 2021
3	<b>Empirical studies of all designs (qualitative, quantitative and mixed methods)</b>	Non empirical articles (e.g., book or book chapter)
4	<b>Primary data</b>	Non primary data (e.g., review article or opinion piece)
5	<b>English language title and abstract</b>	Not English language title and abstract

6	<b>Studies directly gathering data on people living with dementia's experiences or capacities</b>	Studies not directly gathering data on people living with dementia's experiences or capacities (e.g., the perspectives of caregivers or staff members)
7	<b>Studies gathering data on any aspect the psychological self [e.g., self-(concept, awareness, recognition, continuity, narrative, consciousness), personhood, selfhood, identity, agency, autobiographical memory, embodiment, life narrative]</b>	Studies not gathering data on any aspect of the psychological self (e.g., papers mentioning the importance of agency or identity, but not gathering data on these capacities)
8	<b>Studies focused on the impact of dementia on the psychological self</b>	Studies not focused on the impact of dementia on the psychological self (e.g., studies focused on the impact of interventions on the self in dementia)

### **Search strategy**

Comprehensive literature searches were conducted by the research team. In the first stage, an initial limited search was conducted in the databases PubMed and CINAHL to ensure that the keywords in the search string were able to identify relevant papers and necessary adjustments were made before the official searches (see Table 3 for search strings). Subsequently, six electronic bibliographic databases were searched to identify relevant papers in the published literature: Scopus, PubMed, ASSIA, CINAHL, Web of Science and PsycINFO. These databases were used as they capture literature on psychological experiences of people with dementia. Table 3 contains detailed descriptions of the search strings implemented in each database. The initial search period was limited to articles published after March 16th, 2009 until November 25th, 2021. Grey literature was also searched, specifically the Open Grey Repository (which has been transferred to DANS EASY data archive) and Google (first 10 pages). Grey literature that met inclusion criteria was accepted for screening. Reference sections of the selected for inclusion full-text papers were examined for additional relevant studies. After the completion of the pre-registered search strategy as well as of a preliminary title/abstract screening, it was noticed that mostly relevant qualitative articles were identified and well-known quantitative articles on the topic had not been detected. For this reason, the following additional qualifiers of 'change' to the original search string were added aiming to make the search terms more inclusive and facilitate the identification of



quantitative literature: greater, less, more, better, worse, higher, lower, fewer, compromise, enhance, impair, improve. These were derived from the abstracts of some quantitative papers not identified in the official database search and were considered as suitable to detect relevant quantitative papers. Follow-up database searches were conducted with the inclusion of the new keywords. Although the initial database search was conducted on 25<sup>th</sup> November, 2021, an update search was also conducted (using the same keywords and databases) to identify new studies published up to October 14<sup>th</sup>, 2022, ensuring all the latest studies were included in the review, which resulted in four additional articles eligible for inclusion (El Haj et al., 2022a; El Haj et al., 2022b; Chapman et al., 2022; Berntsen et al., 2022). Please see Figure 1 for the PRISMA flow diagram with overall information of article identification and screening.

Table 3. Examples of search strings expressed using Boolean operators that were implemented to different databases.

<b>PUBMED</b>	(("self"[Title/Abstract] OR "identity" [Title/Abstract] OR "personhood" [Title/Abstract] OR "selfhood" [Title/Abstract] OR "agency" [Title/Abstract] OR "autobiographical" [Title/Abstract] OR "embodiment" [Title/Abstract] OR "continuity" [Title/Abstract] OR "narrative"[Title/Abstract]) AND ("dementia" [Title/Abstract] OR "alzheimer's"[Title/Abstract])) AND ("change" [Title/Abstract] OR "difference" [Title/Abstract] OR "impact" [Title/Abstract] OR "transition"[Title/Abstract])
<b>PsycINFO</b>	TI ( (self OR identity OR personhood OR selfhood OR agency OR autobiographical OR embodiment OR continuity OR narrative) ) AND AB ( (self OR identity OR personhood OR selfhood OR agency OR autobiographical OR embodiment OR continuity OR narrative) ) AND TI ( (dementia OR alzheimer's) ) AND AB ( (dementia OR alzheimer's) ) AND TI ( (change OR difference OR impact OR transition) ) AND AB ( (change OR difference OR impact OR transition OR greater OR less OR more OR better OR worse OR higher OR lower OR fewer OR compromise OR enhance OR impair OR improve) )

### **Study selection**

All the results of the bibliographic database searches (official and follow-up) were combined to a unique folder in the referencing software 'EndNote 20'. The PRISMA flow diagram (Figure 1) gives an overview of the literature search and the screening process. Duplicated articles were initially removed. During level 1 screening, the titles and abstracts of identified studies were screened by the first author, by applying the inclusion and exclusion criteria, to examine their relevance to the current scoping review. To ensure reliability among the research team, a shared 10% of the identified articles of level 1 screening was independently reviewed by all

the reviewers. This results in 762 articles in the selected pool. During level 2 screening, the full-text copies of the 264 included studies of level 1 screening were screened independently by two authors, by applying the inclusion and exclusion criteria. Another round of reliability checks was performed; a shared 10% of randomly selected full-text articles were independently reviewed by all the authors. This resulted in 26 articles in the selected pool. Potential disagreement or uncertainty at any of the stages of study selection would be solved through discussions with the wider research team until consensus would be achieved. In the case that a study's full-text was not accessible through University of Dundee's journal subscription, the corresponding author would be contacted to provide an authorised copy. When a study's full-text was not available in the English language, the corresponding author would be contacted to provide a translated copy, if available. All communications were conducted via email and if corresponding authors could not be contacted after two attempts two-weeks apart, the studies were excluded from the screening. All exclusion decisions were recorded and stored electronically. Both included and excluded papers identified in the screening were stored on 'EndNote 20'. At the end of level 2 screening, 105 articles were included in the review dataset.

### **Data extraction**

Following level 2 screening, the included full-text articles were thoroughly reviewed in the familiarisation process. Data extraction was performed by the first author and checked for accuracy by a second reviewer. Data extracted from full-texts included: study aims, sample information, methodology, procedures, measures, results, aspect(s) of self explored and evidence for change in the psychological self.

### **Data synthesis**

A hundred and five (105) studies met the inclusion criteria for the review. Given that different aspects of the self were explored using varied methods and methodologies, the results are organised and presented in three main types of self-manifestations: 1. High-order manifestations (i.e., autobiographical memory, self-knowledge, future self-thinking, perceived change), 2. Functional aspects of the self (i.e., self-reference effect, enactment effect, pronoun use), and 3. Foundational manifestations (i.e., self-continuity, embodiment, agency). These categories emerged after comprehensively reviewing the included studies,

focusing on the different manifestations of self explored as well as on the relevant evidence for potential change in dementia. Details about the time trend of the studies as well as the different self-aspects explored, can be found on Figure 2. This shows the dominance of autobiographical memory studies over the period of the review, with less sustained activity exploring other aspects of selfhood.

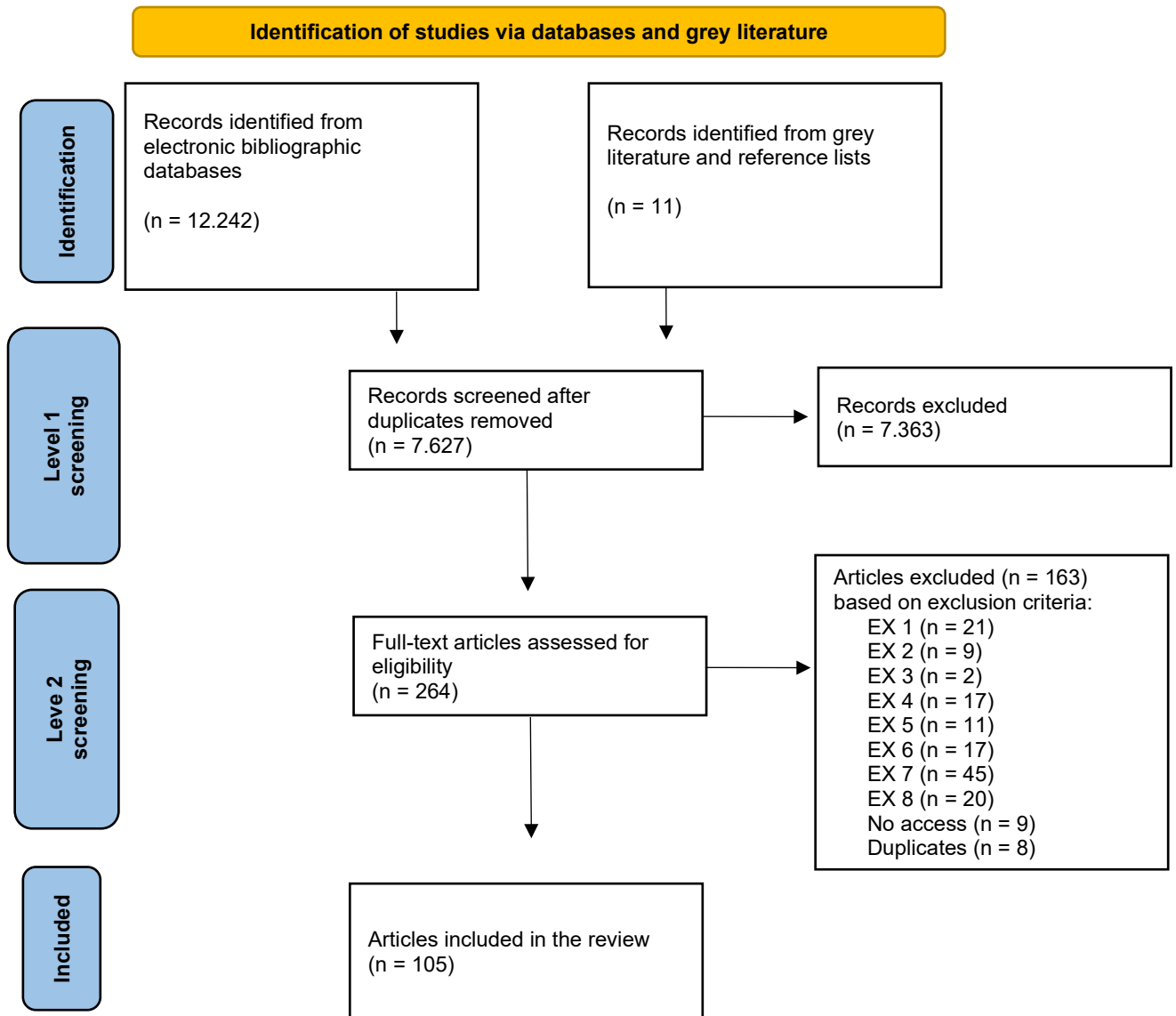


Figure 1. PRISMA flow diagram illustrating the process of our article identification and screening.

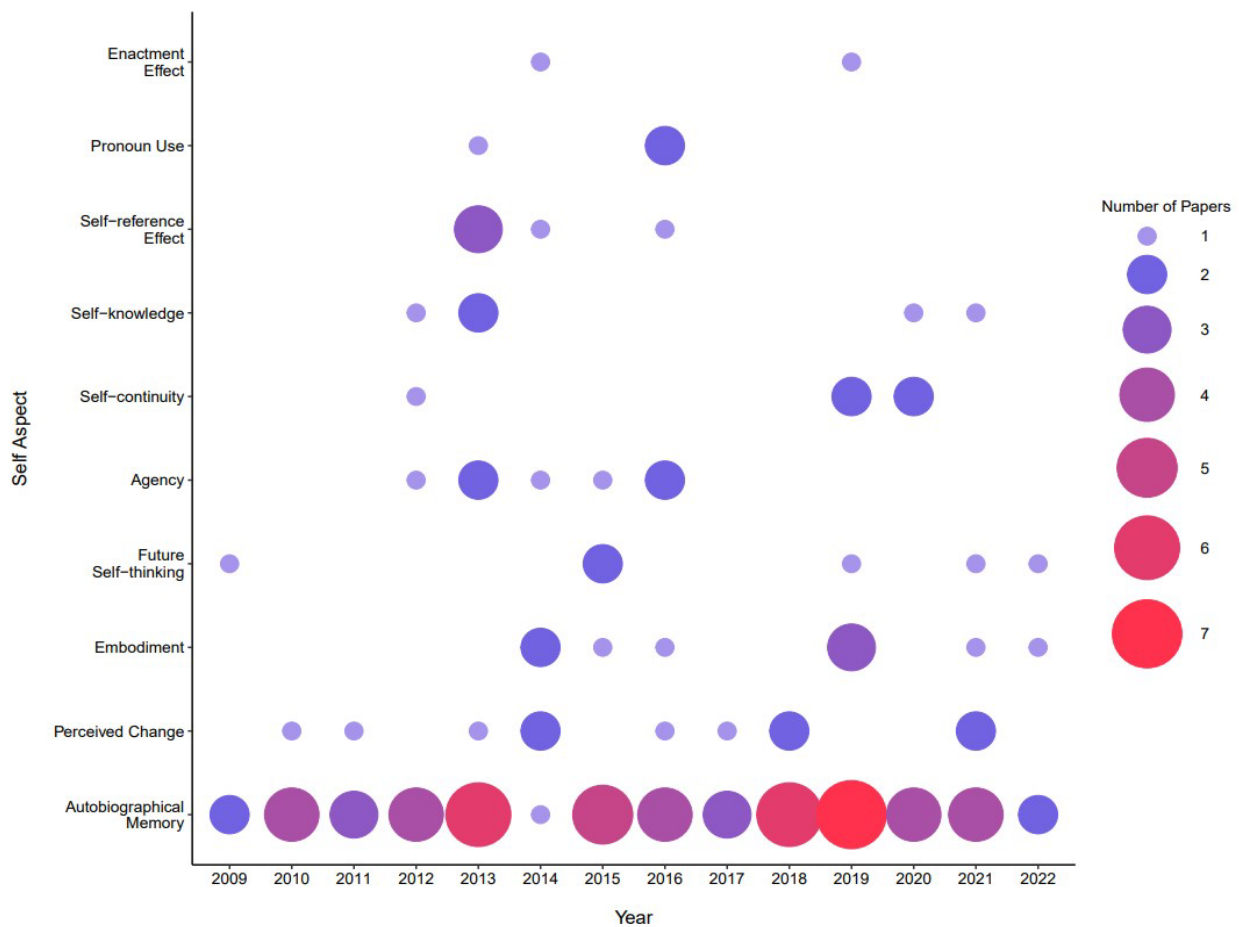


Figure 2. Bubble plot illustrating the time trend and different self-aspects explored across the reviewed articles. The size of each ‘bubble’ is representative of the number of papers published in each year.

## Results

### High-order manifestations

#### **Autobiographical memory**

Autobiographical memory constitutes a unique type of episodic recall in which the self is encoded as the ‘experiencer’ of an event (El Haj et al., 2015a). Given its inseparable connection with the self, autobiographical memory plays a key role not only in constructing but also maintaining one’s life narrative and, subsequently, promoting a coherent sense of self across time (Barnabe et al., 2012). Accordingly, it has been widely explored in people with dementia as it has been argued that disruptions in autobiographical memory could result in a

compromised sense of self. The review dataset indicated that different quantitative methods have been used to assess autobiographical recall in people with dementia, specifically: a.) verbal recall for a given number of autobiographical memories (El Haj et al., 2017; Ben Malek et al., 2019; El Haj & Antoine, 2018; El Haj et al., 2020a; Irish et al., 2011a; Irish et al., 2018; Benjamin et al., 2015; Liechti et al., 2019; El Haj & Antoine, 2017b; El Haj et al., 2019b; El Haj & Allain, 2020; El Haj et al., 2016; El Haj et al., 2015d), b.) structured verbal recall using standardised interviews, such as the Autobiographical Memory Interview (Kopelman et al., 1989) or the Autobiographical Interview (Levine et al., 2002), and their adaptations (Barnabe et al., 2012; Irish et al., 2014; Irish et al., 2011b; De Simone et al., 2016; Kirk & Berntsen, 2018a; Leyhe et al., 2009; Meulenbroek et al., 2010; Muller et al., 2016; Caddell & Clare, 2012; Jetten et al., 2010; Rathbone et al., 2019; Rauchs et al., 2013; Berntsen et al., 2022), c.) verbal cues (Greenberg et al., 2011, El Haj et al., 2020b; Irish et al., 2011a), d.) word cues (Donix et al., 2010; Viard et al., 2013; Philippi et al., 2012; Philippi et al., 2015; El Haj et al., 2022a; Kirk & Berntsen, 2018b; Addis et al., 2009; Martinelli et al., 2013), e.) pictorial cues (Maguire et al., 2010; Baird et al., 2018; Baird et al., 2020; El Haj et al., 2020b).

Indeed, deteriorated autobiographical memory performance in people with dementia has been demonstrated by the majority of studies, with findings showing a diminished capacity to recall and produce specific past personal episodes (Barnabe et al., 2012; El Haj et al., 2017; El Haj & Antoine, 2020; El Haj et al., 2020a; Irish et al., 2018 ; Irish et al., 2011b; Benjamin et al., 2015; De Simone et al., 2016; Donix et al., 2010; Baird et al., 2020; Kirk & Berntsen, 2018a; Kirk & Berntsen, 2018b; Leyhe et al., 2009; Liechti et al., 2019; El Haj et al., 2022a; Meulenbroek et al., 2010; Viard et al., 2013; Rauchs et al., 2013; Philippi et al., 2012; Philippi et al., 2015; Baird et al., 2018; Berntsen et al., 2022; Muller et al., 2016; Caddell & Clare, 2012; El Haj et al., 2015d; El Haj & Allain, 2020; El Haj & Antoine, 2017b; Addis et al., 2009; El Haj et al., 2019b; El Haj et al., 2020b; El Haj et al., 2016; Jetten et al., 2010; Martinelli et al., 2013 ; Rathbone et al., 2019; Maguire et al., 2010). In one case study, autobiographical memory performance progressed from intact to significantly deteriorated within 3 years (Maguire et al., 2010), while in another longitudinal study autobiographical memory performance was mostly the same in a 1-year follow-up, with specific disruptions in performance of personal semantic memory (Irish et al., 2018). Some studies have also explored self-defining memories (i.e., memories of key events that defined one's life) as a component of autobiographical

recall. Findings showed that people with dementia tend to report less episodic self-defining memories than healthy older adults (El Haj & Allain, 2020; Martinelli et al., 2013) and these memories are less frequently integrated to the self (Ben Malek et al., 2019).

Although the above studies provide evidence for disruptions in autobiographical memory, it would be difficult to make definite conclusions of a global loss of autobiographical memory in dementia. For instance, when exploring the existence of a temporal gradient in the deterioration of autobiographical recall in dementia, research has shown that remote memories, usually from young adulthood, seem to be better preserved than more recent memories (Barnabe et al., 2012; De Simone et al., 2016; Kirk & Berntsen, 2018a; Kumfor et al., 2016; Leyhe et al., 2009; Philippi et al., 2012; Muller et al., 2016; Berntsen et al., 2022). Rauchs and colleagues (2013) also demonstrated better performance for remote events as well as very recent ones (i.e., the previous day). An aspect of episodic recall known as personal semantic memory (i.e., knowledge of facts of one's own past) has also been studied in dementia indicating that this seems to remain intact (Barnabe et al., 2012; Martinelli et al., 2013; Addis et al., 2009; Benjamin et al., 2015; Meulenbroek et al., 2010; Irish et al., 2018). However, this evidence is inconclusive as some studies found diminished performance (Caddell & Clare, 2012; Kirk & Berntsen, 2018a; De Simone et al., 2016; Leyhe et al., 2009).

Methodological considerations can also provide evidence against the idea of total deterioration of autobiographical recall. Different types of sensory cues have been shown to successfully elicit autobiographical memories over non-sensory cues. In these studies, participants are often presented with a cue (e.g., songs or instrumental music, pictures, familiar odours etc.) and they are asked to report all the memories that come to their mind when exposed to this cue. Music evoked autobiographical memories in people with dementia have similar scores as control participants without dementia (Basaglia-Pappas et al., 2013; Cuddy et al., 2017; Baird et al., 2018; El Haj et al., 2015c; El Haj et al., 2013; El Haj et al., 2012a; El Haj et al., 2012b; El Haj et al., 2018). More autobiographical memories were also evoked in music condition than in silence (El Haj et al., 2012a; El Haj et al., 2012b; El Haj et al., 2018), with some evidence showing higher scores for self-selected musical cues compared to researcher selected music (El Haj et al., 2015c; El Haj et al., 2012b). Musical cues have also been shown to provide linguistic advantages in people with dementia since music-evoked memories tend to have higher grammatical complexity and propositional density (El Haj et

al., 2013). Odour cues seem to benefit autobiographical recall over no sensory stimulation (El Haj et al., 2018; El Haj et al., 2021; Glachet et al., 2019; Glachet & El Haj, 2020b; Glachet & El Haj, 2019 ) or verbal recall (Glachet & El Haj, 2021). Evidence for pictorial cues is inconclusive as it is uncertain whether they facilitate autobiographical recall (Glachet & El Haj, 2021; El Haj et al., 2020b; Baird et al., 2018; Lopis et al., 2021). It is important to note that a recent study did not find any differences between pictorial and verbal cues, with odour evoked memories having the worst performance (Greenberg et al., 2021).

Ecologically valid sensory cues have also given promising results. More specifically, based on the evidence showing that memories from one's distant past are better preserved in dementia than memories from the more recent past, Kirk and Berntsen (2018b) cued autobiographical memories using concrete objects, historically dated to participants' young adulthood. Object cues (a childhood toy e.g., skipping rope), compared to verbal cues (name of the toy), produced more memories with higher levels of episodic content. In two studies, self-representations were used to elicit autobiographical responses; however, no benefit of self-cues was found over non-self related cues (Rathbone et al., 2019; El Haj & Antoine, 2017a). Films from people's youth have also been used, having a benefit for autobiographical memory eliciting even more memories in people with dementia than control participants (Rasmussen et al., 2021). Further extending these findings, Miles et al., (2013) examined autobiographical memory retrieval in an everyday setting as well as in a museum setting which recreated the historic and cultural context of participants' youth. Cues of all modalities (e.g., verbal, concrete etc.) were presented in both settings, with notably more autobiographical memories been recalled in the museum setting (Miles et al., 2013). Finally, sensory evoked autobiographical memories seem to be particularly benefited from cues derived from one's young adulthood (e.g., Baird et al., 2018; Baird et al., 2020; Rasmussen et al., 2021). These studies provide evidence that autobiographical memory performance might benefit from ecologically valid methods.

### **Self-knowledge**

In addition to autobiographical memory, semantic self-knowledge has an important evidential role in maintaining a coherent sense of self across time. This review indicated that self-knowledge has been studied using a.) standardised questionnaires about self-traits, such as the Tennessee Self-concept scale or twenty statements test and their adaptations (Caddell &

Clare, 2012; Ben Malek et al., 2019; Caddell & Clare, 2013; Clare et al., 2013; Duval et al., 2012; El Haj & Antoine, 2017a; El Haj et al., 2019b; Glachet & El Haj, 2020a; Arroyo-Anllo et al., 2016; Rathbone et al., 2019) and b.) self-ratings from a set of traits (Caddell & Clare, 2012; Duval et al., 2012). Findings revealed that participants are relatively accurate in their assessment of their own traits (Caddell & Clare, 2012) and the quantity of self traits or representations almost the same as healthy adults (Caddell & Clare, 2013; Duval et al., 2012; Clare et al., 2013; Arroyo-Anllo et al., 2016). Nevertheless, other studies have showed fewer self-statements compared to controls (El Haj & Antoine, 2017a; El Haj et al., 2019b; Glachet & El Haj, 2020; Ben Malek et al., 2019; Rathbone et al., 2019), even when sensory cues were used to elicit self-related statements (Glachet & El Haj, 2020a).

### **Future self-thinking**

Temporally extended self-representations are not only involved in projecting oneself into the past but also into the future. Thus, a key aspect of the temporally extended self is future self-thinking. In addition to past autobiographical memories, few studies identified in this review have also asked participants to imagine future autobiographical events (El Haj et al., 2015b; El Haj et al., 2015c; Addis et al., 2009; El Haj et al., 2019c; Strikwerda-Brown et al., 2021; El Haj et al., 2022b). People with dementia tend to produce fewer past and future autobiographical events (Addis et al., 2009; El Haj et al., 2022b), with notable similarities having been identified between past and future autobiographical events as participants seem to imagine the future based on often fragmented autobiographical information (El Haj et al., 2015b; El Haj et al., 2015c). Difficulties in visual imagery has also been explored in relation to future self-thinking (El Haj et al., 2019c), since remembering the past and imagining the future require to visually imagine experienced events.

### **Perceived change**

Qualitative approaches explore the experiences of people with dementia directly through their subjective perspectives, aiming to gain in-depth knowledge of the lived reality of this disease (Caradec & Chamahian, 2017). Having a more exploratory perspective, these studies do not focus on a specific aspect of the self, but rather they explore the self as a unitary construct, facilitating the expression of high-order subjective experiences and interpretations of selfhood (Scott, 2021). In order to explore interview responses, this review indicates that



most studies used some form of interpretive phenomenological analysis (Borley et al., 2016; Caddell & Clare, 2011; Hennelly & O'Shea, 2021; Larsson et al. 2018; Caradec & Chamahian, 2017; Scott, 2021), with some using grounded theory (Johannessen et al., 2018), or interactionist perspective analysis (MacRae, 2010). Some studies have employed a longitudinal design (Johannessen et al., 2018; Steeman et al., 2013), while others explored perceived change by seeing the self within a narrative framework (Karlsson et al., 2014; Angus & Bowen-Osborne, 2014).

Findings demonstrate that participants did not report changes to their current self or feelings of discontinuity to their past self, expressing that they feel they are the same person as before the onset of dementia (Borley et al., 2016; Caddell & Clare, 2011; Caradec & Chamahian, 2017; Hennelly & O'Shea, 2021; MacRae, 2010; Borley & Hardy, 2017). The few longitudinal qualitative studies identified (Johannessen et al., 2018; Steeman et al., 2013) did not report substantial alterations to participants' self; minor changes were described, mostly everyday difficulties and cognitive challenges, but people with dementia do not feel that they have changed in a major way. Exploring the self as a narrative, studies show that people with dementia perceive themselves the same across past and present, providing emotional and reflective life stories to demonstrated resilience and self-reliance against the challenges of living with dementia (Karlsson et al., 2014; Angus & Bowen-Osborne, 2014). Nevertheless, there is also some evidence for perceived change; some participants explicitly state that they do not feel the same person to what they used to be in the past (Caddell & Clare, 2011; Borley & Hardy, 2017), even feeling changed in a fundamental level (Scott, 2021). Other studies also report instances of subjective self losses, which were usually specifically related to past capacities (Caradec & Chamahian, 2017), meaningful activities (Larsson et al., 2018) and previous self-representations (MacRae, 2010). Although changes in the sense of self were described, most participants tend to feel that no major changes had occurred to themselves 'as a whole', they were not radically changed (Caddell & Clare, 2011; Borley et al., 2016; Caradec & Chamahian, 2017; Borley & Hardy, 2017; Larsson et al., 2018).

### **Functional aspects of the self**

Dementia research on the sense of self has not only explored its high-order manifestations, but also the functional role of the self in human cognition. These refer mostly to self-

processing that occurs automatically, without necessarily conscious awareness and is related to organisational and elaborative properties of the self.

### **Self-reference effect**

Research has shown that self-related information is encoded and retrieved more easily, resulting in self-referent memory biases. This mnemonic advantage of information encoded with reference to the self can be operationalized by the self-reference effect (SRE), which has demonstrated the unique properties of the self in memory (Leblond et al., 2016). By exploring self-referential processing in dementia, an insight can be gained on whether the sense of self has a preserved functional role in memory. The SRE studies in dementia, identified in this review, have employed the traditional trait paradigm that involves presenting participants with trait words, which they have to process in relation to self and another person (Genon et al., 2014; Kalenzaga & Clarys, 2013; Leblond et al., 2016) or semantically (e.g., 'Provide a short description of this trait') (Kalenzaga et al., 2013; Leblond et al., 2016; Lalanne et al., 2013). Afterwards, participants are presented with a surprise memory test in which they need to recall whether a trait word was presented in the encoding phase. Although some participants with dementia experience difficulties completing the SRE task (Leblond et al., 2016), findings show a tendency for a self-related mnemonic benefit in the self-encoding condition compared to the semantic processing condition (Leblond et al., 2016; Kalenzaga et al., 2013) as well as a bias in remembering positive words from the self-condition (Lalanne et al., 2013). Employing an other-related condition can provide evidence on whether mnemonic advantages are self-specific rather than a depth of processing effect arising from social processing. Critically, when comparing performance for self-related and other-related stimuli, studies have not found an SRE, with participants having the same performance in both conditions (Genon et al., 2014) or higher recognition scores for other-related information (Kalenzaga & Clarys, 2013). In a modified SRE paradigm, Bond and colleagues (2016) presented participants with words presented either with the participants' voice or another person's voice; no self-related advantage was found. However, for people with dementia, memory for words presented with another person's voice showed less impairment compared to the self-condition (Bond et al., 2016). Taken together, these studies confirm that functional aspects of self relating to memory may be negatively impacted in dementia.

### **Enactment effect**

Expanding on the SRE methodology, few studies, identified in this review, have also explored the role on self-initiated actions on memory performance. The enactment effect refers to the mnemonic advantage for stimuli that participants have acted upon rather than read or listened (De Lucia et al., 2019). The enactment effect task involves presenting participants with verbal stimuli (e.g., action/instruction phrases); in some sessions, participants perform the actions (e.g., 'Open the window') themselves while in others the actions are performed by the experimenter or there is only recall of the stimuli with no enactment (Charlesworth et al., 2014). A mnemonic advantage was found for subject-performed condition over the traditional verbal task (Charlesworth et al., 2014), but participants with dementia also demonstrated an equal benefit for experimenter-performed condition (De Lucia et al., 2019). Although in both studies participants with dementia had worse memory performance than healthy controls, their memory benefited from enactment but without a self-specific advantage. Similar to the SRE studies, this implies that although social processing still ensures depth of processing relative to other conditions, the strength of self as a cognitive or physical anchor for memories may be negatively impacted in dementia.

### **Pronoun use**

The use of first-person pronouns can be seen as an important linguistic aspect of cognitive self-functioning, which has been conceptualised as an unambiguous reflection of people with dementia's awareness of their self as a distinct and unique entity, reflecting preserved sense of self (Skaalvik et al., 2016). The review found that few qualitative studies have also explored pronoun use in dementia by assessing whether participants would use first-person pronouns during interviews (Betra et al., 2016; Hedman et al., 2013; Skaalvik et al., 2016). Findings showed that people with dementia use first-person pronouns frequently in their answers when describing themselves as well as when communicating self-related information (e.g., 'my children'), without experiencing any challenges or confusion (Hedman et al., 2013) and showing no differences compared to control participants (Betra et al., 2016). Successful use of first-person pronouns was interpreted as unequivocal linguistic expressions of the sense of self, expressing one's experiences of being a singular person (Skaalvik et al., 2016).

### **Foundational manifestations**

#### **Self-continuity**

Self-continuity, or diachronic unity, refers to the subjective experience of being the same person across the lifespan, despite indisputable developmental changes. It has been suggested that feelings of self-continuity are supported by autobiographical memory since recalling the self over time facilitates people to mentally travel back to past events and to relive them in the present, allowing for a coherent and stable sense of self (Tippett et al., 2018). The review indicated that studies exploring self-continuity in people with dementia, usually employ a.) questions explicitly enquiring whether participants feel they are the same individuals across time (Clare et al., 2020; El Haj & Allain, 2020; Tippett et al., 2018), b.) self-statements across past, present and future (Duval et al., 2012) and c.) a self-rated questionnaire (El Haj et al., 2019a). The majority of participants reported preserved or slightly altered self-continuity, despite alterations in autobiographical recall and future self-knowledge (El Haj & Allain, 2020; El Haj et al., 2019a; Tippett et al., 2018; Clare et al., 2020; Duval et al., 2012). Nevertheless, it is important to note that Clare and colleagues (2020), found that 21% of participants (in a sample of ~1500) reported discontinuity.

### **Embodiment**

Foundational manifestations of selfhood are not only those that the participants explicitly talk about, but also those subjective experiences that one experiences through his/her own body. The concept of embodiment in dementia research suggests that the sense of self in people diagnosed with dementia is preserved at the level of the pre-reflective body, manifested in habits and purposeful actions (Kontos, 2014). It has been suggested that in dementia, where cognitive processes deteriorate and verbal abilities weaken, the self is manifested through embodiment (Kontos, 2014). This review indicates that the expressions of the self at an embodied level have been qualitatively explored through both interviews (Tatzer, 2019; Hellstorm et al., 2015) and observations (Boddington et al., 2021; Robbins, 2019; Tatzer 2019; Chapman et al., 2022), which are interpreted by the researchers rather than the participants.

It is suggested that embodiment is manifested through personal objects and their perceived meaning for the sense of self. Handbags and their contents (Buse & Twigg, 2014; Tatzer, 2019) as well as clothes (Buse & Twigg, 2016; Boddington et al., 2021) are seen as extensions of the self, having personal meaning and supporting the 'enactment of self' (Buse & Twigg, 2014, p.14). Personally significant objects constitute ways of self-presentation, reflecting preserved selfhood at an implicit level. Even the maintained participation in household chores

(Hellstorm et al., 2015), is seen as an embodied manifestation of the self as people with dementia express who they are through enacted narratives and actions, even when verbal communication is compromised. In the instances when the choice of clothing was not possible, feelings of distress and loss of selfhood were observed, as in the cases of mandatory institutional clothing (Boddington et al., 2021). The corporeal complexity of the self is also reflected in socially embodied ways of expressing the self in people with dementia, through expressive facial expressions and gestures (e.g., expressing disapproval and social status) and inside jokes (e.g., which might not be obvious to caring staff) (Robbins, 2019; Chapman et al., 2022). Distinctive personality traits (e.g., creativity, adventurousness, resourcefulness) (Frazer et al., 2012) as well as spontaneous emotionally-motivated comments (Baird, 2019) demonstrate that embodied elements of the self are preserved in dementia.

### **Agency**

Sense of agency can be cognitively defined as the experience of having a causal impact on the world accompanied by a feeling of having control over one's actions. This review shows that different studies have employed varied methods to assess sense of agency in people with dementia.

Some quantitative studies explored affective reactions to self-regulated music (i.e., participants were able to monitor music with their movements) versus random-regulated music (i.e., music was played automatically) as implicit manifestations of agency (Lancioni et al., 2013a; Lancioni et al., 2013b; Lancioni et al., 2015). Results showed that participants tended to have increased positive affective states and behaviours (e.g., smiling, singing etc.) in the self-initiated condition where they were able to enjoy their causal influence on music, demonstrating preserved sense of agency. Another manifestation of cognitive agency that has been assessed via tracking participants' ability to differentiate self-generated touch (remotely controlling the strokes of a paintbrush on the hand) from non-self-generated touch (when the brush strokes were remotely controlled by the experimenter) (Downey et al., 2012; Bond et al., 2016). Downey and colleagues (2012) found that although all participants with dementia had flawless attribution of self-generated actions, there were potential difficulties with self-other differentiation as average performance of the non-self conditions was reduced compared to healthy participants. This implies that participants with dementia were more prone to erroneously perceive another's touch as their own. However, this set up lacks

ecological validity, and Bond and colleagues (2016) did not find any differences in performance of people with dementia with control participants.

In contrast to quantitative research, qualitative studies have explored sense of agency almost in an all-encompassing way demonstrated by a range of behaviours and subjective experiences. For instance, through interviews, agency has been conceptualised from a decision-making perspective (Boyle, 2014) as well as self-mastery and past achievements (Hedman et al., 2016). Boyle (2014) explored agency as a form of intact decision-making demonstrated when people act in a deliberate way in order to have an impact on their personal circumstances, either explicitly (e.g., expressing opinions) or implicitly (e.g., emotional reactions and expressing preferences non-verbally). Hedman and colleagues (2016) explored manifestations of agency in the past and present, which was reflected in intact self-mastery (e.g., mastering the consequences of dementia and deliberately preserving one's autonomy) and achievements (e.g., pride in past accomplishments and taking responsibility for one's health), as well as in the future, which was reflected in perceptions of potential loss of agency by becoming more dependent.

## **Discussion**

Recognising the multidimensional nature of the self, the current scoping review aimed to explore the nature and scope of the evidence demonstrating change in the psychological self in people living with dementia. The self was not perceived as a unitary construct, but rather as consisting of closely connected, yet distinctive, manifestations (Klein & Gangi, 2010). Expanding the findings of Caddell and Clare (2010), which did not provide a theoretically comprehensive account of the different types of the cognitive self, different manifestations of the sense of self were explored in this review, which have not been previously considered (notably with regards to the functional aspects of the self), allowing for a better understanding of self-related alterations in dementia. Thus, the findings were presented into three main types of self-functions: high-order manifestations, functional aspects of the self, and foundational manifestations.

Overall, the findings demonstrated that not all aspects of the self are equally impacted by dementia, providing support for recent conceptual frameworks of the self as a multifaceted construct (e.g., Bomilcar et al., 2021; Huntley et al., 2021). For different aspects of the self,

there seems to be some evidence that high-order complex manifestations are more likely to be altered (e.g., autobiographical memory, self-knowledge) while foundational manifestations are more likely to remain intact (i.e., agency, embodiment, self-continuity). It is important to note that these foundational manifestations should not necessarily be considered as less sophisticated; they have inner depth and potentially interact with each other as well as with the functional aspects of the self, becoming integrated to produce emergent high-order cognitive properties, possibly explaining the relative perseverance of self in dementia (Hutmacher, 2021; Bomilcar et al., 2021). These emergent properties might be enough to counteract the progressive self-alterations, sustaining subjective feelings of a stable and unified sense of self despite the notable changes (Mograbi et al., 2021). This idea is reflected in the empirical evidence showing that, even though people with dementia acknowledge diminished cognitive functioning, they still feel they are essentially the same person as they have always been, having intact experiences of selfhood. Consequently, it would be erroneous to believe that having deteriorated memory undoubtedly results in total fragmentation of every aspect of the self. Additionally, as results showed, even fragmented episodic information might be sufficient to provide access to one's life story and subsequently maintain strong feelings of a coherent sense of self across time (Tippett et al., 2018). Only when this connection to one's past is lost, fundamental changes to the core of self may become more prevalent (Tippett et al., 2018).

Although people with dementia encounter progressive cognitive difficulties, empirical evidence does not demonstrate that the sense of self becomes totally lost, at least for participants with dementia who still had functioning capacity to complete the tasks. It might be possible that self-alterations are more absolute in later stages of the disease, nonetheless, the hierarchical nature of the self renders less likely the prospect of total loss. Accordingly, an absolute change was not found in this review for any aspect of the self, with most findings showing an inconclusive pattern of self-alterations (i.e., with regards to autobiographical memory, self-knowledge, SRE, enactment effect and perceived change). Given the heterogeneity of results, it is challenging to make any definite conclusions about the exact pattern of self-alterations since changes in the sense of self in dementia are not a binary phenomenon, and focus should be placed on the strength of changes rather than the mere existence of changes. For instance, although a large number of studies has provided evidence

that autobiographical memory performance is particularly diminished in dementia, sensory cueing methods show that episodic memory is not totally diminished but, rather, retrieval difficulties might be more prominent (Kirk & Berntsen, 2018b). Furthermore, preserved self-continuity shows that not all aspects of temporally extended self-representations are lost as well as that diachronic unity is not only supported by autobiographical memory, but, evidently, also from additional manifestations of the self which enable the creation of a coherent life narrative. For example, it has been argued that embodiment may be a key aspect of the self, potentially providing insights to the perceived continuity of one's self, despite memory deficits (Bomilcar et al., 2021).

Focusing on the high-order manifestations, the exact pattern of self-changes has not yet been established, potentially attributed to the fact that research exploring cognitive self-processes has predominantly focused on autobiographical memory and self-knowledge, reflecting a potential bias towards mnemonic components of selfhood (please also see Figure 2 that visualises this bias). These aspects of self might have been traditionally considered as the core aspects of the self because they are discursively used in explicit ways when presenting oneself (Hutmacher, 2021). However, they only constitute two among several aspects of self that may contribute towards maintaining a coherent sense of self, which are often manifested reflexively (Hutmacher, 2022). While the close relationship between self and memory is indisputable, the suggested centrality of memory as the ultimate manifestation of selfhood has been challenged by the presented findings of this review. As research on self-continuity has shown, people with dementia often feel the same individuals across time, providing strong support for the role of less studied manifestations of the self, especially foundational aspects of self, to maintain subjective feelings of preserved selfhood. Future research of the sense of self in dementia should adopt a more encompassing approach, trying to explore the interaction between different manifestations of self in a more holistic way.

This variability of results could also be attributed to the predominant use of verbal tasks when assessing self-processes in people with dementia. These, often quantitative, methods require sophisticated self-reflection abilities which are known to be compromised in dementia (Strikwerda-Brown et al., 2019). Additionally, it is difficult to make define conclusions about what performance on these tasks mean; alternative accounts of responses could easily exist, maybe reflecting intellectual disengagement with the complexity of the questions rather than



a loss of self-processing abilities (Tippett et al., 2018). Nevertheless, it is important to mention that these tasks do not take into account pre-existing individual differences. Better insights into the pattern of self-alterations could be achieved with the use of sensitive methods that do not place additional cognitive demands to participants with dementia. Employing more naturalistic and ecologically valid tasks, aiming to capture self-processing abilities as used in everyday life, which might be implicitly manifested, could result in a more accurate picture of self-alterations in dementia (Mentzou & Ross, 2022). Only few identified studies used ecologically valid and sensitive methods (e.g., Rasmussen et al., 2021; Miles et al., 2013), which not only facilitated recall but also enhanced motivation, since participants with dementia reported even more memories compared to control participants. Immersing participants into multisensory experiences as well as historically authentic and personally meaningful settings have revealed a different picture of self-alterations, showing promising results of preserved episodic recall in dementia.

Qualitative research exploring the lived experiences, feelings of perceived change and embodied manifestations in dementia have many advantages. They allow people with dementia to express their own feelings and interpretations of progressive self-alterations after a dementia diagnosis, providing insights into how changes in the psychological self are perceived. This reflects the idea that, despite the undisputable alterations of cognitive self-processes, these might not always be perceived as having a significant impact in the sense of self of people with dementia. Research on embodiment, which was mostly based on observations and everyday encounters, provides new methodological opportunities to explore foundational manifestations of self using sensitive research designs. Findings also showed that although the majority of studies reported preserved subjective experiences of selfhood, there have been instances of reported changes. Given the inherent subjectivity of the self-experience, these studies demonstrate that potential changes are perceived differently, having a greater impact for some people than others (Caradec & Chamahian, 2017). Notably, perceived changes might not be stable; as dementia progresses, challenges to the sense of self might become more pronounced (MacRae, 2010). An important limitation of the qualitative approaches reviewed here is that they often perceive the self as a singular entity, as it was also identified in Caddell & Clare (2011). Terms such as identity, sense of self and personhood are often used interchangeably, without the provision of a specific definition,

even though such terms can be defined differently with subsequent different methodological implications.

Research on the functional aspects of the self further demonstrates that self-processes can be successfully studied implicitly using intelligently designed cognitive tasks, that might not place strong linguistic demands on participants. These studies have provided further support for the complexity of the different presentations of the sense of self. There is no binary distinction between high-order and foundational manifestations, rather different self-functions exist along a continuum with functional aspects allowing for cross-connections, demonstrating that self-related changes in dementia are more complex than originally thought, potentially without a dualistic distinction of alterations. Although these, mostly implicit, manifestations of self can provide a promising new direction for the study of self-related changes in dementia, the existing evidence is scarce and characterised by methodological limitations. For instance, agency seems to be preserved in dementia; both quantitative and qualitative studies have shown intact agency using different approaches. However, agency is conceptualised differently in the different studies reviewed here, which is particularly true for qualitative studies that seem to explore agency in an all-encompassing way without a clear conceptual explanation. This is also the case with the pronoun use research identified in this review; perceiving instances of successful use of first person indexical as solely a manifestation of intact sense of self is flawed since pronoun use might also be considered as a socially acquired ability that does not necessarily constitute an aspect of the self per se, but rather a linguistic by-product of higher-order cognitive self-processes.

Overall, the results of the current scoping review showed that although there are some alterations in different manifestations of the self, these do not imply unified change. Given that some elements of autobiographical memory and self-knowledge seem to still be preserved in dementia, together with the findings of intact embodiment and agency, the self-system still functions in dementia, albeit a progressive 'break down' might be occurring. Despite these notable cognitive changes during dementia, it seems that those aspects of self that are still preserved could be enough to compensate for potential weakening of some self-processes. In accordance with Bomilcar and colleagues (2021), the current review reveals that foundational manifestations of the self are complex and more sophisticated than it might have been initially assumed as they interact with each other to potentially sustain a subjective

experience of stable and coherent sense of self across time, despite notable alterations in high-order manifestations. Given the multidimensional nature of the self, only preliminary conclusions can be made as not all manifestations of selfhood have been adequately explored in the dementia literature. Better understanding of alterations in selfhood, ensuring that people's experiences are not undermined by perceptions of total loss, is key to address psychological symptoms of people living with dementia as well as to inform new pathways for dementia care interventions. Person-centered psychological care can only be achieved by recognising the centrality of selfhood in people's wellbeing and quality of life (Hennelly et al., 2021).

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