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Psychosocial and behavioral outcomes for persons with cognitive impairment and caregivers following Amyloid-β PET scan disclosure: a systematic review

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Abstract

Background: Positron emission tomography (PET) scans for amyloid-β can aid in the early and accurate detection of Alzheimer's disease. The results of amyloid PET scans could help people with cognitive impairment and caregivers better understand their diagnosis; however, there are concerns that they could also cause psychological harm.

Methods: A systematic review of psychosocial and behavioral quantitative outcomes following the disclosure of an amyloid PET scan for persons living with cognitive impairment (subjective cognitive decline, mild cognitive impairment (MCI), Alzheimer's Disease and other dementias) and caregivers.

Findings: 10 papers were identified from 7 studies. There was little evidence of an association between disclosure and depression. However, persons with MCI and their caregivers with elevated levels of amyloid had an increased risk of distress or anxiety compared with those without elevated amyloid. Participants correctly recalled the scan results; however, it is unclear whether this led

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Conflicts of interest: None to declare

to an increased understanding of their diagnosis. We did not identify any studies measuring behavioral outcomes.

Conclusions: We found mixed evidence on the relationship between amyloid scans and psychosocial and behavioral outcomes in people with cognitive impairment and caregivers. These findings highlight the need for more methodologically rigorous research on this topic.

Keywords

amyloid PET scan; disclosure; biomarkers; mild cognitive impairment

Introduction

There has been rapid progress in the development of biomarkers for detecting the neuropathology associated with Alzheimer's disease, potentially enhancing the accuracy of diagnoses, and transforming how Alzheimer's disease and related dementias are diagnosed and treated[1]. Amyloid-β is a pathophysiological change which can be detected using positron emission tomography (PET) scans[2]. The results from amyloid scans are disclosed to recipients as a binary outcome, where a positive scan result indicates elevated levels of amyloid, consistent with the pathology of Alzheimer's disease, and a negative scan does not indicate elevated amyloid[3]. This can have differing implications depending on the scan recipient's level of cognitive impairment. For persons with Alzheimer's disease and related dementias (ADRD), amyloid scans can be used to make a differential diagnosis[4]. For persons with Mild Cognitive Impairment (MCI), elevated amyloid may indicate an increased risk of developing dementia[1]. However, this relationship is not definitive. Elevated levels of amyloid may occur in persons with other neurodegenerative diseases or in cognitively healthy individuals[5,6]. In the US, amyloid scans have been limited to use for research purposes due to their limited predictive value at the individual level[7]. Evidence from the Imaging Dementia - Evidence for Amyloid Scanning (IDEAS) study shows amyloid scans are associated with changes in the clinical management of ADRD[4], although the impact of disclosure on scan recipients and their caregivers is less understood.

Ethical debates regarding the disclosure of amyloid scan results in clinical practice center on the potential benefits and harms to the scan recipient and caregivers. Arguments in support of disclosure propose the scan recipient and caregiver would benefit from a more accurate diagnosis, allowing them to better understand their condition, receive appropriate treatments and engage in advance care planning[8,9]. Counter arguments cite concerns that scan recipients may experience psychological harm, workplace or social stigmatization[9–11]. Two previous systematic reviews have summarized the evidence of the impact of amyloid disclosure on cognitively healthy persons[8,10] and found there was very little change in psychological outcomes following the disclosure of the scan result. However, previous research has yet to summarize caregiver outcomes following the disclosure of an amyloid scan. As amyloid scans can be used to assess suitability for amyloid targeting therapies (anti-amyloid monoclonal antibodies), it is becoming increasingly more likely that they will be incorporated into routine clinical care for people with dementia. Therefore, the objective of this systematic review is to update the findings from the two previous reviews on this topic and summarize quantitative psychosocial and behavioral outcomes following

the disclosure of an amyloid PET scan for persons living with cognitive impairment and their caregivers.

Methods

This review was developed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines[12,13] (eTable 1 in supplementary materials) and was registered in advance on PROSPERO (ID: CRD42022371876).

Eligibility criteria

Studies had to meet the following criteria: 1) studies included participants with subjective cognitive decline, MCI or ADRD, and/or their caregivers. Studies of cognitively healthy participants were included if subjective cognitive decline was explicitly stated as an inclusion criterion; 2) all study designs (with or without comparison groups) were included, however, outcomes were limited to those reported after the participant received the results from their own amyloid PET scan; 3) reported quantitative psychosocial and/or behavioral outcomes for patients or caregivers. Psychosocial outcomes were broadly defined as measures capturing mood, emotions, reaction to the scan, quality of life, and caregiver burden. Behavioral outcomes were broadly defined as changes in behavior, knowledge, or decision making following amyloid disclosure. 4) studies published in English, and 5) studies published in peer reviewed journals. Papers which reported outcomes from larger studies were included if outcomes were not duplicated.

Studies were excluded if they: 1) reported associations between amyloid positivity/deposition without the disclosure of the scan result, 2) only reported qualitative data 3) disclosed hypothetical or fictitious results to participants, 4) tested other dementia-related biomarkers, or reported outcomes from plasma or cerebrospinal fluid biomarkers, 5) only include cognitively healthy participants without subjective cognitive decline, or 6) were reviews, discussion articles, case studies, pre-prints or conference abstracts.

Information sources, search strategy and selection process

We searched Embase, MEDLINE and PsychInfo, independently on OVID, on 3rd October 2022 with no limits on the search. The search terms included variations on the key words: amyloid, PET scan and dementia. MesH terms were also included for dementia, Alzheimer's disease and PET scan. See eMethods 2 for the full search strategy.

The search results were exported to Covidence, where duplicates were removed. References were screened by title and abstract and then by full text. All articles were double screened by EC and MA and conflicts were resolved by MP.

Data Items and extraction

Relevant data items were extracted by EC using Covidence and a second author (WZ) checked the extracted items for accuracy. Extracted information included: study name, author names, year, country, study aims, design, participant diagnosis, details of amyloid disclosure, number of participants, participants average age, number and proportion of

women, number and proportion of white participants, number and proportion of participants with elevated amyloid, outcomes and measures reported, analysis used, and results.

Study critical appraisal

Studies were critically assessed using the Joanna Briggs Institute (JBI) critical appraisal tool that corresponded to their study design[14,15]. EC conducted the critical appraisal, which was double checked for accuracy by WZ.

Synthesis

Due to the heterogeneity of designs, participants, and outcomes used by the included studies a meta-analysis would not be meaningful; therefore, results were summarized by a narrative synthesis[16]. Results for persons with cognitive impairment and caregivers were presented separately. We tabulated the key findings from each study by outcome.

Results

Study selection

We identified 16,534 references (Figure 1). After duplicates were removed, we screened 10,495 references for inclusion. We screened the full text of 59 papers and included 10 in this systematic review. Reasons for exclusion included wrong publication type (N=25), outcomes were not collected post-disclosure (N=9), participants were cognitively normal (N=7), scan results were hypothetical or fictitious (N=3), only qualitative data were reported (N=3), and papers did not include psychosocial or behavioral outcomes (N=2).

Study and participant characteristics

We identified ten papers from seven studies. Table 1 presents an overview of the study characteristics. Three studies presented data from the CARE-IDEAS study, a cross-sectional survey of people with MCI, ADRD and their caregivers[17–19], and two studies presented data from the RAISR randomized controlled trial (RCT), comparing amyloid PET scan disclosure with psychoeducation[20,21]. Four papers presented findings from pre/post designs, two with participants with subjective cognitive impairment[22,23] and one with participants with early onset ADRD[24], and one with participants with MCI and mild ADRD[25]. One study presents findings from a cross-sectional study of caregivers[26]. Sample sizes ranged from 11 to 3,690 (1,845 caregiving dyads). The quality of the included studies varied greatly (see eTables 1, 2 and 3). Although most studies aimed to understand the participant's emotional responses to amyloid PET scan disclosure, 6/9 reported associations between the scan result and outcomes. Another key weakness was the lack of a comparison group among the included studies. Only the RAISR study compared outcomes between scan recipients and non-scan recipients[20]. All studies included in this review reported psychosocial outcomes. We did not identify any behavioral outcomes.

Table 2 summarizes the characteristics of included participants. The average age of persons with cognitive impairment was 69.6 and 46.8% were female. The proportion of scan recipients with elevated amyloid ranged from 23.8% - 78.1% (mean = 43.7%). Caregivers had an average age of 65 and 64% were female. Only the CARE-IDEAS and

RAISR studies presented information on the participants race/ethnicity. Most persons with cognitive impairment and caregivers were white, 94.1% and 93.0% respectively. Persons with cognitive impairment and caregivers in the included studies were highly educated in terms of degrees earned and number of years in education.

Results of individual studies

The association between amyloid scan disclosure and outcomes for persons with cognitive impairment—Eight studies assessed the association between amyloid PET scan disclosure and psychosocial and behavioral outcomes for persons with cognitive impairment (Table 3).

Five studies assessed the association between amyloid PET scan disclosure and depressive symptoms in persons with MCI (N = 2), MCI & ADRD (N = 1), and subjective cognitive decline (N = 2)[20–23,25]. These studies assessed depressive symptoms at a wide range of time points following the scan. The shortest timepoint was 14 days and the longest timepoint was 52 weeks. None of these studies detected any significant changes in depressive symptoms at any timepoint after the scan. Similarly, four studies assessed levels of anxiety at multiple timepoints ranging from 14 days to 52 weeks after the scan. None of these studies found significant changes in levels of anxiety after the scan at any timepoint[20–22,25]. However, one study found greater variation in anxious and depressive symptoms among persons with MCI and elevated amyloid compared to those without elevated amyloid in the 2 weeks following disclosure[21].

The association between disclosure and test-related distress varied depending on the participant's level of cognitive impairment and the scan result. Two studies of participants with subjective cognitive decline found there was no differences in test-related distress between those with elevated and non-elevated amyloid[22,23]. One study measured test-related distress 6 weeks after post-disclosure[22] and the other measured distress 9 or 18 months post-disclosure[23]. However, a RCT comparing amyloid PET scan disclosure to psychoeducation in persons with MCI found those with elevated amyloid experienced greater levels of distress on two separate measures compared to those without elevated amyloid[20]. This study measured test-related distress 4, 24, and 52 weeks post-scan. Participants with elevated amyloid's distress scores did decline over time, however they remained consistently higher than those without elevated amyloid.

One study assessed the impact disclosing scans as part of the diagnostic process on quality of life measures in persons with young onset AD[24]. They found a change in diagnosis was associated with improvement in Alzheimer's related quality of life and increased clinician confidence following the scan was associated with improvement in a generic measure of quality of life. Although, the size of this effect may not constitute a clinically meaningful difference. Lingler et al[20] also assessed the impact of amyloid scan disclosure on person's with MCI's self-efficacy for coping and found no significant difference in scores between those randomized to receive the scan and those randomized to receive psychoeducation.

Two studies assessed patient's understanding of the scan result or diagnosis following disclosure. James et al[18] found 83% of persons with MCI or ADRD correctly recalled their

scan result 4.5 months after disclosure. Lingler et al[20] found scan recipient's knowledge of MCI/Alzheimer's disease or perceived ambiguity of MCI did not change between baseline and 4, 24 or 52 weeks after disclosure. Furthermore, knowledge scores did not differ between those randomized to receive an amyloid scan and those who received psychoeducation. However, a subgroup analysis found that participants who received a result for non-elevated amyloid reported greater perceived ambiguity about MCI. The authors suggest that participants correctly understood that their symptoms remained unexplained.

Jutkowitz et al[19] assessed the impact of amyloid PET scan disclosure on participant's willingness to accept risky treatments to restore their memory. They found on average, participants were willing to accept a 27.94% risk of death to restore their memory to normal and participants with elevated amyloid were willing to accept more 5.6% risk than those without elevated amyloid.

The association between amyloid scan disclosure and caregiver outcomes— Five studies included in this review reported caregiver outcomes following the disclosure of an amyloid scan (Table 4).Three studies assessed the effect of disclosure on depressive and anxious symptoms among caregivers[17,20,26]. There were no significant differences in depressive symptoms[17,20,24]. Likewise, Bensaidane et al[26] did not find an association between the scan result and caregiver anxiety, however the authors did not use a validated scale. Belanger and Lingler[17,20] both assessed caregiver anxiety using some form of the Spielberger State Anxiety Inventory. Lingler et al found anxiety increased in the 4 and 24 weeks after disclosure but returned to baseline levels at week 52 for all caregivers[3]. They did not detect differences in levels of anxiety by scan result[20]. However, they noted that the increase in anxiety was below the cut off for clinical significance. On the other hand, Belanger et al stratified their analysis by the scan recipient's level of impairment and found that elevated amyloid was associated with increased anxiety for caregivers to persons with MCI but not ADRD approximately 4.5 months following disclosure[17].

Bensaidane et al[26] assessed the impact of amyloid PET scan disclosure on caregiver quality of life and found no significant difference between elevated and non-elevated groups. Lingler et al[20] found caregivers to scan recipients experienced decreased self-efficacy for coping compared to those who received psychoeducation. For caregivers to persons with elevated amyloid this decline occurred at 4 weeks post disclosure, whereas the decline occurred at 24 weeks for caregivers to persons without elevated amyloid.

Three studies assess caregivers' understanding of the diagnosis or scan result[18,20,26]. James et al[18] found that 85% of caregivers correctly recalled the scan result 4.5 months after disclosure. Lingler et al[20] found caregiver knowledge of MCI/Alzheimer's disease improved for all caregivers between baseline and 52 week follow-up. However, there was no significant difference in knowledge scores between caregivers to persons who received an amyloid scan and those who received psychoeducation. Similarly, there was no difference in knowledge scores between caregivers to persons with elevated amyloid compared to non-elevated amyloid. Bensaidane et al[26] found no significant difference in understanding of the scan result between caregivers to persons with elevated and non-elevated amyloid on an

author-developed measure. Similarly, they found no significant difference in expectations for the future between caregivers to persons with elevated and non-elevated amyloid[26].

Jutkowitz et al[19] assessed caregiver perceptions of the scan recipient's willingness to accept risky treatment to return their memory to normal. On average, caregivers believed scan recipients would accept at 29.68% risk of death. Approximately one quarter of caregivers were in exact agreement with the amount of risk the scan recipient was willing to accept. However, 35% underestimated and 41% over-estimated the amount of risk they were willing to accept.

Discussion

The aim of this review was to summarize the association between the disclosure of amyloid PET scan results and psychosocial and behavioral outcomes for persons with cognitive impairment and caregivers. We identified ten papers from seven studies. All but one of the included studies used observational designs and two thirds were conducted in the US. We found some evidence that the psychological impact of receiving an amyloid scan on psychological responses varied by the scan recipients' level of impairment. Participants were able to correctly recall the scan result, however, it is not clear whether this is associated with increased knowledge of their diagnosis. We did not identify any studies reporting behavioral outcomes. The small number of papers included and the heterogeneity of study design, participant characteristics and outcomes limit the strength of the conclusions we can draw.

Amyloid scan disclosure had little association with measures of anxiety, depression and self-efficacy for coping for persons with cognitive impairment, which is consistent with findings from two systematic reviews of amyloid disclosure on cognitively healthy participants[8,10]. However, test-related distress may vary depending on the participant's level of impairment and scan result. One study found persons with MCI and elevated amyloid reported greater levels of test-related distress on two separate measures (the Impact of Events Scale (IES) and Impact of Genetic Testing – Alzheimer's Disease (IGT-AD)[20]. Similar effects were not found in those with subjective cognitive decline as measured by the IES[22,23] however, neither of these studies stratified their analysis by the scan result and the timing of the assessments differed greatly. Therefore, it is not possible to be sure if the observed differences at due to the participant's level of cognitive impairment or are a result of differing methodologies. A more recent study of persons with subjective cognitive decline, found a positive amyloid scan was associated with increased test-related distress[27]. Similarly, two studies in this review found caregivers to persons with elevated amyloid and MCI may experience increased anxiety post-disclosure[17,20]. The observed increases in distress among persons with MCI and elevated amyloid and their caregivers may be due to the implication of the scan result. A scan showing elevated amyloid among people with MCI indicates a strong risk of developing Alzheimer's disease in the future. Persons with MCI and elevated amyloid and their caregivers may require additional post-diagnostic support following the disclosure of an amyloid PET scan.

Most participants with MCI, ADRD and their caregivers correctly recalled the scan result[18]. Participants included in this review were highly educated, however, James et al[18] found

neither scan recipient nor caregiver levels of education affected the likelihood of correctly recalling the scan result. It is unclear what impact accurate recall has on participants' understanding of their diagnosis. Lingler et al[20] found generally scan recipients' knowledge of their condition did not change after disclosure and did not differ significantly from the control group who received psychoeducation for MCI, although a subgroup analysis found persons with MCI and elevated amyloid may correctly understand their symptoms remain unexplained. Furthermore, caregiver's knowledge of the condition did improve but a similar improvement was also observed in participants randomized to receive psychoeducation[20]. Findings from the analysis of qualitative data indicate scan recipients and caregivers can be confused by the language used when disclosing the scan result[18]. The included studies reported using a variety of protocols for disclosing the amyloid PET scan results. In most cases, the results were disclosed by a member of the study team, which may not reflect clinical practice. Future research should explore how the delivery of amyloid scan results influences the patient and caregiver's understanding of the diagnosis.

Ethical debates regarding the use of amyloid PET scan during the dementia diagnosis process focus on the potential benefits and the risk of harm. The findings of this review indicate there may be a small risk of psychological harm among persons with MCI and elevated amyloid and their caregivers. However, this relationship is not conclusive. Similarly, there is no clear benefit of amyloid PET scan disclosure in terms of enhancing persons with cognitive impairments and caregivers understanding of the diagnosis. Despite concerns held by clinicians and researchers, people with cognitive impairment may wish to know their amyloid status. Future research should explore how to lessen the impact of potential "bad news" when disclosing amyloid PET scan results, especially in the case of elevated amyloid among persons with MCI or subjective cognitive decline where there are no disease modifying treatments available. Researchers have proposed this could be done through pre-disclosure counselling and by providing follow-up support post-disclosure[28].

Strengths and limitations

This review draws together the evidence on the impact of amyloid disclosure on persons with cognitive impairment and caregivers and indicates a nuanced and mixed experience of amyloid disclosure by the scan recipients' level of impairment and scan result. Patient and caregivers experiences of amyloid PET scan disclosure is a growing area of research - four new studies have been published on this topic since running our search[27,29–31]. We used broad search terms and did not include search terms for outcomes to capture as many studies in this area as possible. We identified a small number of studies, which varied greatly in terms of participants characteristics, sample size, study design, and outcomes, limiting the strength of the evidence on this topic. Only three studies included participants with ADRD, two of which also included participants with MCI. It is possible that psychosocial and behavioral responses may differ between those with MCI and ADRD due to the differing implications of the scan result. A scan result indicating elevated amyloid can be used to make a differential diagnosis for persons with ADRD but can only be used to determine the risk of developing Alzheimer's disease in the future for persons with MCI. This is an important area for further investigation. Although we aimed to explore the association between receiving an amyloid scan on psychosocial and behavioral outcomes,

most studies compared associations between the scan result and outcomes, making it difficult to determine if the observed effects are from getting the scan or from the recipient's amyloid status. Additionally, we did not identify any behavioral outcomes. Therefore, we cannot determine whether an amyloid scan leads to changes in behaviors for persons with cognitive impairment or their care partners. Future research should examine if receiving an amyloid scan is associated with changes to lifestyle, employment, health service utilization or advanced care planning. Furthermore, only one study included in this review used a comparison group meaning changes in outcomes cannot be attributed to the scan alone. Finally, only two out of seven studies reported the race/ethnicity of their participants, who were predominantly white, limiting the generalizability of the findings from this review. Future research should be methodologically rigorous, with a comparison group and ethno-culturally diverse samples.

Conclusions

It is becoming increasingly important to understand the impact of amyloid PET scan disclosure on persons with cognitive impairment and caregivers. In this review, we identified a small number of studies assessing the psychosocial and behavioral impact of amyloid disclosure. The scan recipient's level of distress and caregiver's levels of anxiety post-disclosure may vary depending on the scan recipient's level of cognitive impairment and the scan result. Scan recipients and caregivers could correctly recall the scan result, but it is not clear this is associated with a better understanding of their diagnosis. More rigorous research with diverse samples of cognitively impaired participants and their caregivers is needed before firm conclusions can be drawn regarding the potential harms and benefits of disclosing amyloid PET scan results.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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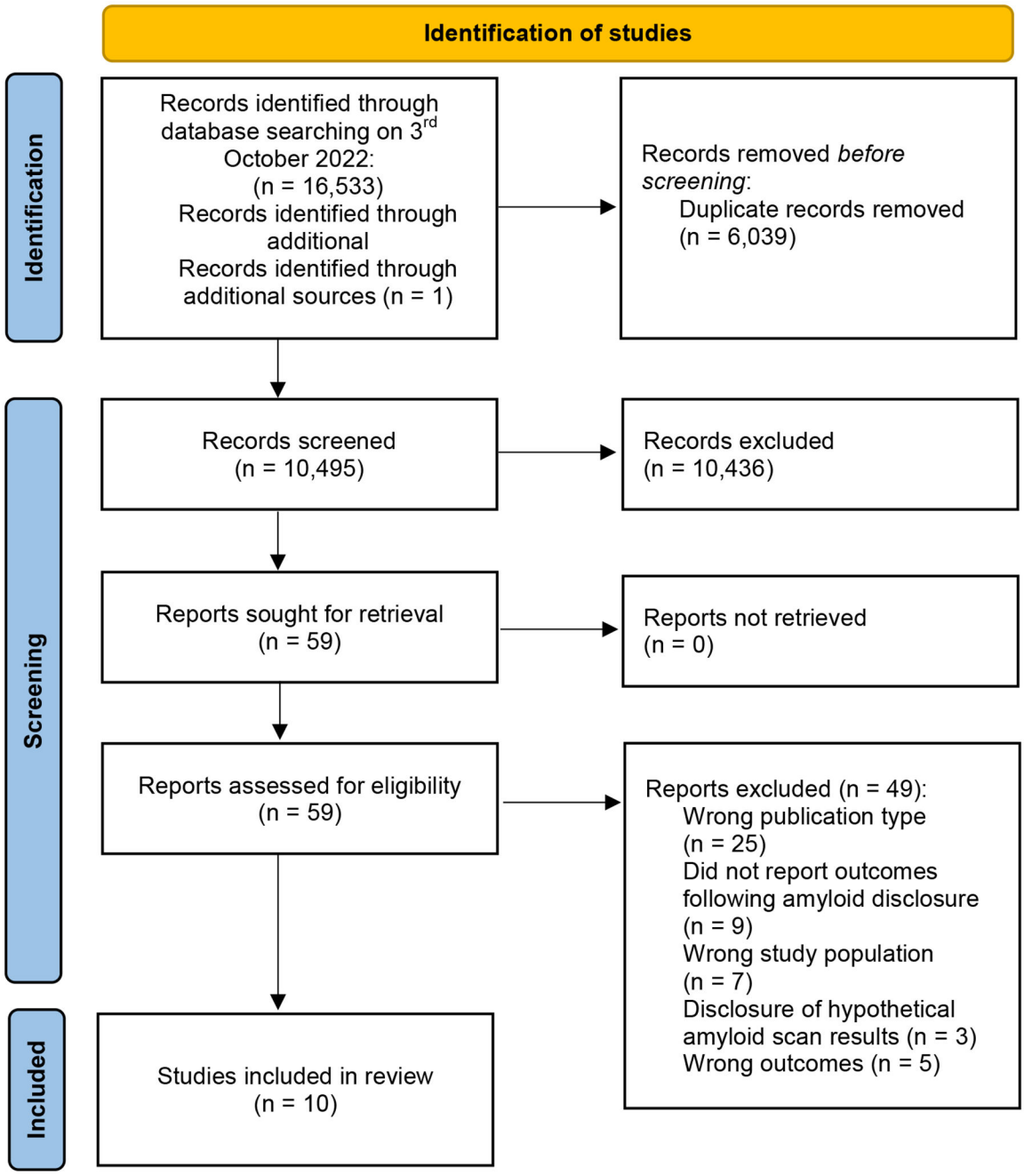

Figure 1.
PRISMA Diagram

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Table 1.

Characteristics of included studies by study design

Author (Year)	Study name	Country	Sample size (n)	Details of amyloid PET scan disclosure	Study aim	Level of comparison(s)	Outcomes
Randomized controlled trials							
Lingler (2020)	RAISR	USA	MCI (N = 82); Caregivers (N = 82)	Disclosure followed standardized script: including verbal and visual presentations of scan results; short-term risk estimates for conversion to AD; brain health information; and follow-up monitoring instructions.	To determine the effect of receiving amyloid PET results on understanding of, and perceived efficacy to cope with MCI, compared with psychoeducation	Amyloid PET scan vs psychoeducation. Sub-group analysis comparing elevated vs non-elevated amyloid amongst scan recipients	Understanding of scan result/ diagnosis; self-efficacy for coping; depression; anxiety; test related distress
Mattos (2019)	RAISR	USA	MCI (N = 24)		To examine the impact of disclosing amyloid PET results to individuals with MCI		Adverse events following amyloid PET scan disclosure
Pre/Post studies							
Lim (2016)		USA	Subjective Cognitive Decline (N = 11)	Scan results were mailed to participant's board-certified neurologists	To explore impact of amyloid PET scan disclosure on psychological outcomes	Elevated vs non-elevated amyloid (all participants received a scan)	Depression; anxiety; stress; test related distress
Wake (2018)		Japan	Subjective Cognitive Decline (N = 42)	Two study psychiatrists disclosed the PET results to each participant	To examine the short-term psychological impact of delivering amyloid PET results to asymptomatic Japanese elderly with SCD	Elevated vs non-elevated amyloid (all participants received a scan)	Depression; anxiety; stress; test related distress
van der Doelen (2022)		The Netherlands	Young onset ADRD (N = 154)	Participants underwent the full diagnostic process including amyloid PET scans	To explore the association between diagnostic outcome and clinician's level of certainty with quality of life (QoL) after amyloid PET results were disclosed in young onset dementia patients in a memory clinic cohort	Pre scan vs post scan (all participants received a scan)	Quality of life
Taswell (2017)		Australia	MCI or ADRD (N = 133)	Scan results were initially disclosed by the referring physician followed by a more in-depth disclosure by a member of the study team.	To assess the psychological impact of disclosing amyloid PET scan results on people with MCI or mild ADRD	Pre scan vs post scan, elevated vs non-elevated amyloid, and MCI vs ADRD (all participants received a scan)	Depression; Anxiety
Cross sectional studies							
Bensaidane (2016)		Canada	Caregivers (N = 23)	Scan result was disclosed by a member of the study team to the patient and caregiver. Patients and caregivers were shown the scan.	To explore the clinical utility of amyloid PET scans in the differential diagnosis of dementia and its impact on caregivers	Elevated vs non-elevated amyloid (all participants received a scan)	Anxiety; depression; understanding of the disease; expectation of the future; quality of life
Jutkowitz (2020)	CARE-IDEAS	USA	MCI or ADRD (N = 1551); Caregivers (N = 1551)	Scans were performed and interpreted at each participating PET facility. Results were then provided to the ordering provider. Study	To evaluate determinants of willingness to accept a treatment to return memory to normal among persons with cognitive impairment	Elevated vs non-elevated amyloid (all participants received a scan)	Willingness to accept risky treatment

Author (Year)	Study name	Country	Sample size (n)	Details of amyloid PET scan disclosure	Study aim	Level of comparison(s)	Outcomes
					who received an amyloid PET scan and their care partner		
James (2020)	CARE-IDEAS	USA	MCI (N = 1349); ADRD (N = 496); Caregivers (N = 1845)	protocol specified that providers disclose the PET scan results, preferably in person, to patients and care partners as a part of clinical care with no specified timeframe	To understand how accurately patients with MCI or dementia and their care partners report results of amyloid PET scans and the concordance between their reports, and identify factors that influence correct reporting of scan results and concordance within the patient-care partner dyad	Elevated vs non-elevated amyloid (all participants received a scan)	Understanding of scan result/ diagnosis
Belanger (2022)	CARE-IDEAS	USA	Caregivers (N = 1872)		To explore caregiver emotional responses to amyloid PET Scans	Elevated vs non-elevated amyloid (all participants received a scan)	Anxiety; depression

Note: MCI = Mild cognitive Impairment; ADRD = Alzheimer's disease and related dementias; PET = Positron Emission Tomography; RAISR = The return of amyloid imaging scan results study; CARE-IDEAS = The caregivers' reactions and experience supplemental study of the imaging dementia evidence for amyloid scanning study.

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Table 2.

Characteristics of included participants

	Persons with cognitive impairment					Caregivers			
Study	**Age (mean)**	**% women**	**% white participants**	**% Amyloid Positive**	**Level of education**	**Age (mean)**	**% women**	**% white participants**	**Level of education**
RAISR (Lingler 2020 & Mattos 2019)	72.6	40.0	92.0	33.3	82.9% bachelor's degree or above	66.8	76.0	90.0	80.5% bachelor's degree or above
CARE-IDEAS (Belanger 2022, James 2020, Jutkowitz 2020)	74.5	38.8	96.1	67.6	58.9% bachelor's degree or above	70.0	68.3	96.1	57.7% bachelor's degree or above
Lim (2016)	63.0	62.0	NR	16.0	17 years of education on average	-	-	-	-
Wake (2018)	74.8	52.3	NR	23.8	Average age on leaving education 15 years old	-	-	-	-
Van Der Doelen (2022)	62.0	42.0	NR	NR	59 % high levels of education	-	-	-	-
Taswell (2017)	70.9	45.9	NR	78.1	NR	-	-	-	-
Bensaidane (2016) *	59.3	46.4	NR	50.0	13.3 years of education on average	NR	NR	NR	NR
Average	**69.6**	**46.8**	**94.1**	**43.76**	**N/A**	**68.4**	**72.2**	**93.0**	**69.1% bachelor's degree or above**

Note: RAISR = The return of amyloid imaging scan results study; CARE-IDEAS = The caregivers' reactions and experience supplemental study of the imaging dementia evidence for amyloid scanning study; NR = Not reported.

*Authors present characteristics of scan recipients but present outcomes from caregivers. This data is not included in the averages.

Table 3.

Key findings of the impact of amyloid disclosure on patient outcomes

Outcome	Measure	Author (year)	Level of Cognitive Impairment	Study design	Timing of outcome	Analysis	Key Findings
Depression	Patient health questionnaire (PHQ-4)	Mattos (2019)	MCI	RCT	Each day, for 14 days after amyloid PET scan disclosure	Random coefficient modelling	No significant difference in depressive symptoms by scan result. Those with positive scans showed greater daily variability in depressive symptoms over the follow-up period compared to those with negative scans
	Center for Epidemiological Studies Depression Scale (CESD)	Lingler (2020)	MCI	RCT	Before and 4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	No significant difference in depressive symptoms between those who received and amyloid scan and those who received psychoeducation
		Taswell (2017)	MCI & ADRD	Pre/Post	Before the scan and approximately 57 days after the scan	Paired-samples t-test	No significant difference before and after scan. No significant difference between amyloid positive and amyloid negative groups. No significant differences between participants with MCI and participants with ADRD.
	Depression subscale of depression anxiety and stress scale (DASS)	Lim (2016)	SCD	Pre/Post	Before disclosure and 9 or 18 months post scan	Not reported	Amyloid positive participants showed little change in DASS scores
	Beck Depression Inventory (BDI-II)	Wake (2018)	SCD	Pre/Post	Before disclosure and 6 week follow-up	ANOVA	Depression scores did not change over time, nor were there any differences in depressive symptoms between amyloid positive and amyloid negative groups
	Geriatric Depression Scale (GDS)	Taswell (2017)	MCI & ADRD	Pre/Post	Before the scan and approximately 57 days after the scan	Paired-samples t-test	No significant difference before and after scan. No significant difference between amyloid positive and amyloid negative groups. No significant differences between participants with MCI and participants with ADRD.
	Hospital Anxiety and Depression Scales (HADS-D)	Taswell (2017)	MCI & ADRD	Pre/Post	Before the scan and approximately 57 days after the scan	Paired-samples t-test	No significant difference before and after scan. No significant difference between amyloid positive and amyloid negative groups. No significant differences between participants with MCI and participants with ADRD.
Anxiety	Spielberger State Anxiety Inventory (STAI)	Lingler (2020)	MCI	RCT	Before and 4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	All participant's symptoms of anxiety remained stable over the entire follow-up period
		Wake (2018)	SCD	Pre/Post	Before disclosure and 6 week follow-up	ANOVA	Anxiety scores did not change over time, nor were there any differences in anxiety scores between amyloid positive and amyloid negative groups
		Taswell (2017)	MCI & ADRD	Pre/Post	Before the scan and approximately 57 days after the scan	Paired-samples t-test	No significant difference before and after scan. No significant difference between amyloid positive and amyloid negative groups. No significant

Outcome	Measure	Author (year)	Level of Cognitive Impairment	Study design	Timing of outcome	Analysis	Key Findings
							differences between participants with MCI and participants with ADRD.
	Anxiety subscale of patient health questionnaire (PHQ-4)	Mattos (2019)	MCI	RCT	Each day, for 14 days after amyloid PET scan disclosure	Random coefficient modelling	No significant difference in anxious symptoms by scan result. Those with positive scans showed greater daily variability in anxious symptoms over the follow-up period compared to those with negative scans
	Hospital Anxiety and Depression Scales (HADS-A)	Taswell (2017)	MCI & ADRD	Pre/Post	Before the scan and approximately 57 days after the scan	Paired-samples t-test	No significant difference before and after scan. No significant difference between amyloid positive and amyloid negative groups. No significant differences between participants with MCI and participants with ADRD.
Test related distress	Impact of Event Scale (IES)	Lingler (2020)	MCI	RCT	4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	Amyloid positive participants scored higher on the IES compared to amyloid negative. Although IES scores declined for amyloid positive patients over the study period, scores remained greater than for amyloid negative participants
		Lim (2016)	SCD	Pre/Post	9 or 18 months post scan	Not reported	Learning the PET scan results had low impact on participants IES scores
		Wake (2018)	SCD	Pre/Post	At 6 week follow-up	ANOVA	IES scores were below the cut off for determining high levels of distress. There were no significant differences between IES scores between amyloid positive and amyloid negative participants
	Distress and Positive Impact subscales of the Impact of Genetic Testing-Alzheimer's Disease (IGT-AD)	Lingler (2020)	MCI	RCT	4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	Amyloid Positive participants scored higher on the IGT-AD than amyloid positive patients 4 weeks after disclosure and remained stable over time. However, scores for amyloid negative gradually increased at each follow-up time point.
Quality of Life	Quality of Life-Alzheimer's Disease (QOL-AD)	van der Doelen (2022)	ADRD	Pre/Post	Before disclosure and at 3 month follow-up	Multivariate regression models	Change in diagnosis was associated with quality of life, when adjusting for other variables
	EuroQoL EQ-5D	van der Doelen (2022)	ADRD	Pre/Post	Before disclosure and at 3 month follow-up	Multivariate regression models	Change in clinician confidence in diagnosis was associated with a small change in quality of life, when adjusting for other variables
Self efficacy for coping	Self efficacy for coping scale (CSE)	Lingler (2020)	MCI	RCT	Before and 4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	There were no significant differences in self efficacy between participants who received an amyloid scan and those who received psychoeducation. There was no significant difference in scores over time
Understanding of scan result or diagnosis	Accurate reporting of scan result	James (2020)	MCI & ADRD	Cross-sectional	Approximately 4.5 months following disclosure	Chi-squared test	83% of participants correctly reported the result of the amyloid PET scan. Participants with dementia were more likely to correctly recall the scan result than participants with MCI.

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Outcome	Measure	Author (year)	Level of Cognitive Impairment	Study design	Timing of outcome	Analysis	Key Findings
	MCI/AD Knowledge Assessment	Lingler (2020)	MCI	RCT	Before and 4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	No significant difference in knowledge scores between time points or between those who received an amyloid PET scan and those who received psychoeducation.
	Illness coherences subscale of the revised illness perception questionnaire (IPQ-R)	Lingler (2020)	MCI	RCT	Before and 4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	No significant difference in understanding of MCI between amyloid PET scan and psychoeducational group. However, sub-group analyses showed increased perceived ambiguity amongst amyloid positive participants compared with amyloid negative.
Willingness to accept risky treatment	The following question: Suppose there is a new technology that can return your memory to normal but has a risk of death. What is the highest risk of death, if any, that you would be willing to accept for this treatment? The number you give can be anywhere between 0% and 100%	Jutkowitz (2020)	MCI & ADRD	Cross-sectional	Approximately 4.5 months following disclosure	Marginal effects estimated through logistic and linear regression models	Patients on average were willing to accept a treatment that carried a 27.94% risk of death. Receiving a positive scan result was associated with an increased risk taking willingness to accept risky treatments. Scan recipients with a positive result were willing to accept 5.62 percentage points of a risk of death than those with a negative scan result.

Note: SCD = subjective cognitive decline; MCI = Mild cognitive Impairment; ADRD = Alzheimer's disease and related dementias; RCT = randomized controlled trial; PET = Positron Emission Tomography.

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Table 4.

Key findings of the impact of amyloid disclosure on caregiver outcomes

Outcome	Measure	Study	Study design	Timing of outcome	Analysis	Key Findings
Depression	Patient Health Questionnaire (PHQ-2)	Belanger (2022)	Cross-sectional	Approximately 4.5 months following disclosure	Multivariate logistic regression	No significant difference in odds of depressive symptoms by scan result
	Center for Epidemiological Studies Depression Scale (CESD)	Lingler (2020)	RCT	4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	No significant difference in depressive symptoms between caregivers to scan recipients and those who received psychoeducation. There was no significant difference in scores over time
	4 questions developed by authors Scored on a likert scale	Bensaidane (2016)	Cross-sectional	At least 30 days after amyloid disclosure	Independent samples t-test	There was no significant difference between amyloid positive and amyloid negative groups
Anxiety	Spielberger State Anxiety Inventory (STAI)	Lingler (2020)	RCT	4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	Caregivers' anxiety levels increased from baseline at both 4 and 24 weeks of follow-up, returning to baseline at week 52. However, anxiety levels remained below the cut-off for clinical significance
		Belanger (2022)	Cross-sectional	Approximately 4.5 months following disclosure	Multivariate logistic regression	Elevated amyloid PET scan results were associated with higher levels of anxiety among caregivers of persons with MCI, even after controlling for covariates
	4 questions developed by authors Scored on a likert scale	Bensaidane (2016)	Cross-sectional	At least 30 days after amyloid disclosure	Independent samples t-test	There was no significant difference between amyloid positive and amyloid negative groups
Test related distress	Impact of Event Scale (IES)	Lingler (2020)	RCT	4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	No significant differences between caregivers to scan recipients and those who received psychoeducation. No significant differences in IES scores over time
	Distress and Positive Impact subscales of the Impact of Genetic Testing - Alzheimer's Disease (IGT-AD)	Lingler (2020)	RCT	4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	Caregivers of persons with elevated amyloid reacted more negatively to test results on the distress and positive subscales
Quality of life	3 questions developed by authors Scored on a likert scale	Bensaidane (2016)	Cross-sectional	At least 30 days after amyloid disclosure	Independent samples t-test	There was no significant difference between amyloid positive and amyloid negative groups
Self efficacy for coping	Self efficacy for coping scale (CSE)	Lingler (2020)	RCT	4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	Decreased self-efficacy for coping was most pronounced among caregivers of persons with elevated amyloid at 4 weeks post disclosure and those of amyloid negative patients at 24 weeks post disclosure
Understanding of scan result or diagnosis	Accurate reporting of scan result	James (2020)	Cross-sectional	Approximately 4.5 months following disclosure	Chi-squared test	85% of care partners correctly reported the results of the amyloid PET scan; In 75% of dyads, both patient and care partner correctly reported results, while in 7% of dyads, both incorrectly reported results; The remaining 18% of dyads were discordant in their reporting of scan results. Caregivers to people with dementia were more likely to correctly recall the results than caregivers to people with MCI.

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Outcome	Measure	Study	Study design	Timing of outcome	Analysis	Key Findings
	MCI/AD Knowledge Assessment	Lingler (2020)	RCT	4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	Objective knowledge of MCI/AD increased from baseline among caregivers to scan recipients and those who received psychoeducation. There was no significant difference between intervention groups
	Illness coherences subscale of the revised illness perception questionnaire (IPQ-R)	Lingler (2020)	RCT	4, 24, and 52 weeks post-disclosure	Intention to treat using linear mixed modelling	There was no significant difference in perceived ambiguity of MCI between caregivers of scan recipients and those who received psychoeducation. There were no significant differences between caregivers to persons with positive and negatives scans
	6 questions developed by authors Scored on a likert scale	Bensaidane (2016)	Cross-sectional	At least 30 days after amyloid disclosure	Independent samples t-test	There was no significant difference between amyloid positive and amyloid negative groups
Expectations for future	4 questions developed by authors Scored on a likert scale	Bensaidane (2016)	Cross-sectional	At least 30 days after amyloid disclosure	Independent samples t-test	There was no significant difference between amyloid positive and amyloid negative groups
Willingness to accept risky treatment	The following question: Suppose there is a new technology that can return your memory to normal but has a risk of death. What is the highest risk of death, if any, that you would be willing to accept for this treatment? The number you give can be anywhere between 0% and 100%	Jutkowitz (2020)	Cross-sectional	Approximately 4.5 months following disclosure	Marginal effects estimated through logistic and linear regression models	On average, care partners believed the patient would accept a treatment that carried a 29.68% risk of death; 24% of dyads agreed precisely on the amount risk that would be accepted, 35% of care partners underestimated and 41% of care partners overestimated the amount of risk the patient would accept by an average of 1.65 percentage points.

Note: RCT = randomized controlled trial; PET = Positron Emission Tomography.

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