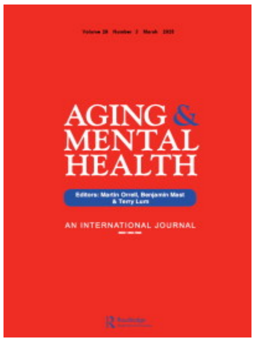

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Exploring health and social care preferences for people with dementia and mild cognitive impairment: a systematic review of discrete choice experiments

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ABSTRACT

Objectives: Dementia is associated with behaviour change, and impaired ability to remember and think. This review focuses on key findings and methodological processes from discrete choice experiments (DCEs) to inform health and social care interventions for people living with dementia or mild cognitive impairment.

Method: Six databases were searched to July 2023 using terms for DCEs, dementia and mild cognitive impairment. Titles, abstracts, and full texts were individually screened by two reviewers. PRISMA reporting guidelines were followed throughout. Study quality was assessed using the Lancsar and Louviere checklist. Results were summarised in a narrative synthesis. The study was PROSPERO registered (CRD42022368182).

Results: Nine studies were included. DCE attributes included service provision, setting characteristics, provider characteristics, availability, cost, and clinical outcomes. Studies predominantly included the general population or patient representatives with only two studies incorporating preferences of people living with dementia.

Conclusion: Respondents preferred individualised home support, and to avoid relocation. Studies suggested benefit to day centres, and greater flexibility in dementia care provision. Authors noted relative preference could differ according to personal characteristics reinforcing the need for tailored provision. Future DCEs should include respondents with early-stage dementia and other cognitive impairments, taking care to ensure appropriate design for such populations.

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KEYWORDS
Dementia; mild cognitive impairment; discrete choice experiment; systematic review; health and social care

Background

Dementia describes a collection of symptoms, which impair cognitive ability and thinking skills enough to impact daily life and the ability to function independently (Alzheimer's Association). There are approximately 50 million people living with dementia (PLWD) worldwide and this is predicted to rise to 152 million by 2050 (Patterson, 2018). Mild cognitive impairment (MCI) describes presence of a mild cognitive or memory deficit while maintaining independence in performing most daily living activities (Petersen et al. 2014; Song et al. 2023). Worldwide prevalence of MCI was estimated to be around 20% in a recent meta-analysis (Song et al. 2023).

PLWD or MCI live with a long-term condition which often requires support from family, friends, and health and social care services to optimise quality of life. Health and social care services can include a range of medical, and non-medical approaches. Current evidence for effective treatments remains limited, despite newer medications (Lecanemab and Donanemab), and non-pharmacological interventions such as cognitive stimulation therapy, reminiscence therapy, support groups for caregivers and for PLWD, respite care, socialisation/activity supports, adult day services, and congregate long-term care settings. Thus, there is a need to develop 'service-user informed interventions'(Profyri et al. 2022) including the voices of people living with dementia or MCI and their caregivers in describing preferences, perspectives, and priorities for different interventional approaches.

To inform person-centred intervention design we must first seek to understand service-user preferences. This can be achieved using discrete choice experiment (DCE) methodology which captures preferences using a number of hypothetical choice scenarios, each containing characteristics (attributes) with varying attribute-levels (Lancsar & Louviere, 2008). Previous reviews in dementia have largely focused on dementia care preferences (Engelsma et al. 2020; Lepper et al. 2020; Speckemeier, 2023). Engelsma and colleagues concluded through a scoping review that there is a need to further explore the use of DCE methodology in care-related decision making for more severe cognitive impairment and PLWD given evidence of the methodology's ability to yield meaningful responses amongst older adults with cognitive impairment (Engelsma et al. 2020). Lepper et al. considered care preferences for PLWD using DCE and ranking exercises (Lepper et al. 2020). They found preferences differed according to living situation, and the type of respondent (PLWD vs caregiver). Lepper et al. also noted that very few studies applied quantitative methods for preference

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elicitation of PLWD suggesting more research is needed in this area. Finally, Speckemeier and colleagues investigated preferences for long-term care in dementia again using scoping review methodology (Speckemeier, 2023). They found that most studies were conducted with caregivers or the general population (not PLWD) and noted wide variety in choice task structure and experimental design.

Overall, the authors observed strong preferences for continuity of care (e.g. same person and no relocation), organisational aspects (e.g. immediate occupancy and transport services), and caregiver expertise. These existing studies however have a number of limitations including: utilising only scoping review processes (Engelsma et al. 2020), and the inclusion of multiple preference elicitation methods such as discrete choice experiments, conjoint analysis, and ranking tasks thus reducing the review focus (Lepper et al. 2020; Speckemeier, 2023). They also include only limited description of the methodological challenges and resulting solutions for DCEs with PLWD (Lepper et al. 2020), and present no consideration of study quality or risk of bias (Engelsma et al. 2020; Speckemeier, 2023).

This review first aims to identify studies that attempt to understand the preferences and demand for access to health and social care for PLWD or MCI using DCE methodology. Second, this review seeks to answer questions related to the methodological processes of previous DCEs in this population focusing on the identification of attributes and levels, recruitment, mode of administration as well as quality assessment of included studies, and explore their methodological and practical implications for designing future DCEs.

Methods

This systematic review was registered prospectively on PROSPERO (CRD42022368182) and followed the PRISMA reporting guidelines (Moher et al. 2009).

Identification of studies

Information specialists used pre-tested published terms for discrete choice studies (de Bekker-Grob et al. 2012) to search electronic databases from 2000 to 26th July 2023. Given the rise in DCE popularity from 2000 onwards, only studies published thereafter were included, consistent with other DCE reviews (de Bekker-Grob et al. 2012).

Searches were conducted in Medline, Embase, PsycINFO, HMIC, Web of Science, EconLit and NHS EED. DCE terms were combined with those for dementia, including dementia, Alzheimer*, *cognitive dysfunction, 'mild cognitive impairment', 'Lewy Body Disease', Parkinson*, frontotemporal. Dementia search terms were developed by the review team with input from an information specialist where appropriate (Aryankhesal et al. 2024). Forward and backward citation chasing was conducted for included studies.

Study selection

Included studies were to explore the experiences or exposure to interventions or services providing care and support for dementia or mild cognitive impairment by using a DCE framework to understand preferences for health and social care. Thus, the study population was PLWD/MCI, the intervention considered any health and social care servicers or support, the comparator was standard care, and the outcome assessed preferences for these services.

Inclusion criteria

1. Reports the design and results of a DCE.
2. Focussed on the preferences of individuals with any dementia and/or MCI, carers of people with dementia or MCI, or health and social care professionals or general population respondents provided they were responding to attributes capturing preferences regarding care for people with dementia or MCI.
3. Published in English but no geographic restrictions.
4. Full texts available.

Exclusion criteria

1. Conjoint analyses were excluded unless incorrectly labelled as such.
2. Studies considering preferences of PLWD in hospital or hospice care, or participants with life-expectancy of three month or less, as they have more limited agency and availability of care options

Two reviewers (NM and AML) independently screened titles and abstracts with any disagreement resolved by discussion. Following this shortlisting procedure, studies were retrieved at full text and screened by the same two reviewers.

Data extraction, quality appraisal and synthesis

Relevant information was extracted into a standardised data form. This included: author; year; study aim; study population; mode of administration; sample size; attributes and levels; DCE methodology (e.g. pilot test, forced choice and financial incentive etc.) analysis method; and study outcomes. Study quality was evaluated using the DCE checklist proposed by Lancsar and Louviere (Lancsar & Louviere, 2008). Findings on study quality can be used to inform current DCE practice and methodological challenges in terms of relevance, reliability, validity, and applicability. DCE methodology and preferences were compared across studies with findings summarised in a formal narrative synthesis of included studies.

Results

Database searches identified 268 records, yielding 213 unique studies after deduplication. Of these, 184 were excluded based on title and abstract screening and 21 at full text leaving eight studies eligible for inclusion. Citation chasing revealed one additional paper for inclusion. Thus, in total nine studies were included in a narrative synthesis. Further details are presented in the PRISMA diagram (Figure 1).

Study and respondent characteristics

Study aims and respondent characteristics are reported in Table 1. Included studies were published between 2008 and 2023. Sample size for analysis ranged between 84 and 1082 respondents. Participants mainly came from Europe ($n = 7$; 3 UK, 2 Netherlands, 1 Ireland, 1 Spain), alongside one each from USA and Japan. Samples consisted of the general population ($n = 4$), PLWD and their caregivers ($n = 2$), representatives of people with

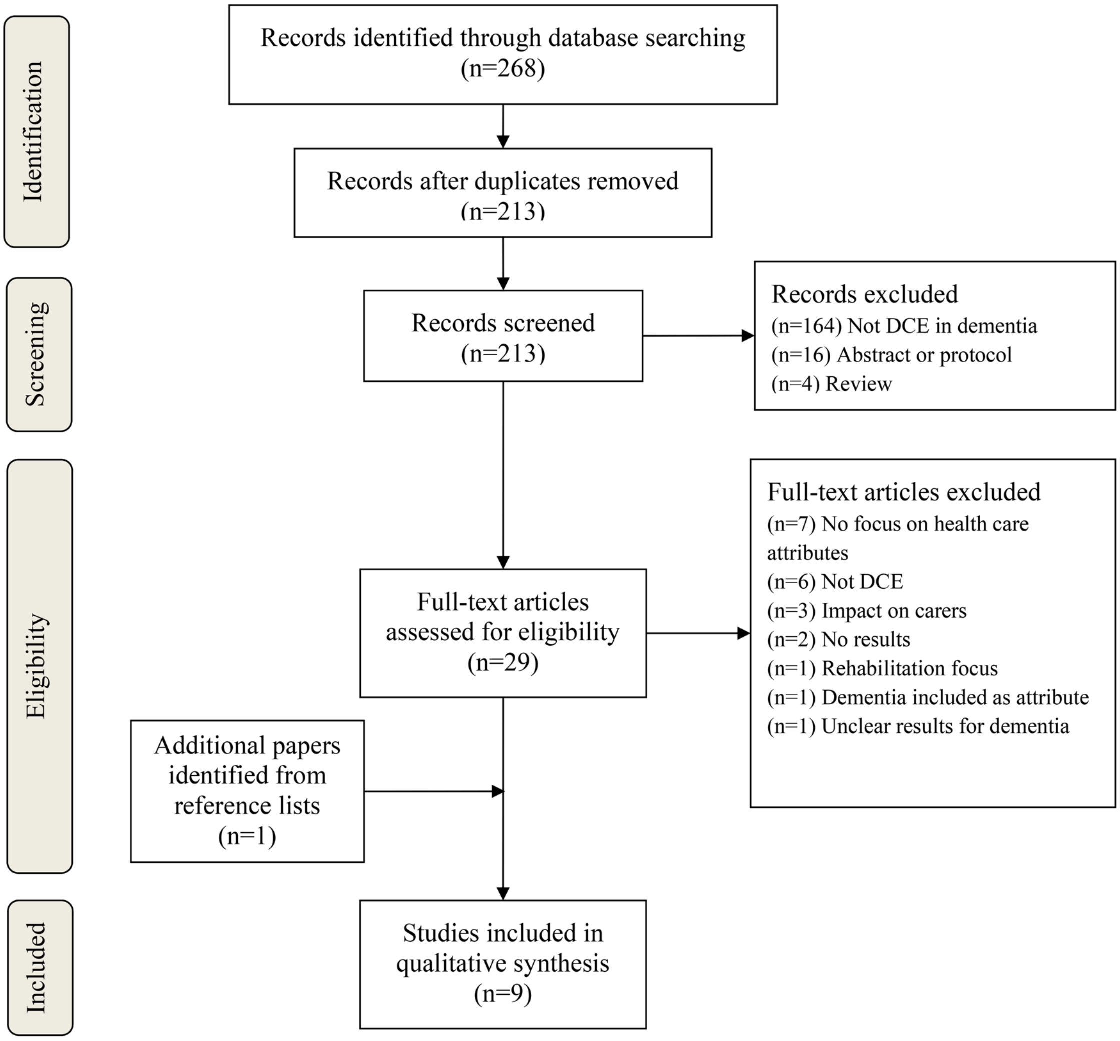

Figure 1. PRISMA diagram. Moher, D., Liberati, A., Tetzlaff, J., Altman, D., The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement*. PLoS Medicine, Vol. 6(7). Available from http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000097.

Alzheimer's disease ($n = 1$), carers of PLWD ($n = 1$), caregivers and neurologists ($n = 1$). No studies focussed on a population with MCI. Where reported, dementia severity spanned from early, through moderate, to late stages, as detailed in Table 1. Caregivers were described as family/friend/professional (O'Philbin et al. 2020), informal (Kampanellou et al. 2019), family/friend (Dranitsaris et al. 2023), or unspecified (Chester et al. 2018). While data were collected across the adult population, participants were generally of middle to older age and female respondents were in the majority ranging between 50% and 83%. Ethnicity was only reported in three studies (Chester et al. 2018; Dranitsaris et al. 2023; Kampanellou et al. 2019) so was not included in the Tables.

Where reported, participants were recruited *via* online database ($n = 3$), carer or memory organisations ($n = 2$), health services ($n = 1$), resident register ($n = 1$) or a convenience sample ($n = 1$). Surveys were administered online ($n = 4$), paper/mail-in ($n = 2$), face-to-face interviews ($n = 1$), face-to-face and online ($n = 1$), online and paper ($n = 1$). Response rate was reported in five studies varying from 15% to 100%, completion rate was recorded in six studies from which most ($n = 4$) were over 99%, one was 83%, and one was 28%(Nieboer et al. 2010). Only one study used an incentive to enhance response rate, being a £5 voucher given to participants (O'Philbin et al. 2020). Total number of respondents included in the final analysis ranged from 84 to 1082. Time taken to complete the survey online was around 15 min as reported in three studies while face-to-face interviews took between 30 and 60 min to complete.

DCE characteristics

DCE characteristics are presented in Table 2 with additional information on study quality presented in Appendix 1. Definitions of terms related to DCEs are provided in Appendix 2. Attributes contained between two and four levels and were presented by providing between two and four alternative scenarios across up to 18 choice sets. Scenarios were communicated using written scenarios ($n = 5$), images ($n = 1$), or a combination of pictures and words ($n = 1$). One study (Chester et al. 2018) reported that carers/family were consulted on capacity if it arose as an issue. Blocking was used in three studies to reduce the number of choice sets. A status quo opt-out alternative was included in two studies, justified by one study as being more reflective of the real world (Walsh et al. 2020). Meanwhile, a forced choice design was employed in the other seven studies limiting the number of alternatives presented. Justification for a forced choice design was only provided by one study (Nieboer et al. 2010) who claimed a forced choice better reflects real life decisions where people in need of urgent long-term care are forced to choose out of the options available.

Studies were piloted in five studies, no piloting was conducted in two studies, and two studies did not report whether

Table 1. Study and respondent characteristics.

Author (year)	Sample population	Country	Age mean (SD) [range]	Gender (%female)	Dementia severity/detail	Recruited from	Mode of administration	Response rate (%)	Completion rate (%)	Number of respondents in final analysis	Length of time to complete	Health status measure
Negrín et al. (2008)	General population	Spain	Overall= 43.65(17.61); model A = 43.82(18.03); model B = 44.53(17.79); model C = 42.62(16.97)	Overall= 49.82%; model A = 49.74%; model B = 48.62%; model C = 51.10%	NR	NR	Face-to-face interviews	NR	598/600 (99.67%)	598	30–40-min interviews	NR
Nieboer et al (2010)	General population	The Netherlands	Total = 56.53(4.1); patient profile 1 = 56.51(4.2); profile 2 = 56.69(4.2); profile 3 = 56.20(4.1); profile 4 = 56.74(4.1)	Total = 51.4%; patient profile 1 = 51.1%; profile 2 = 50.0%; profile 3 = 50.4%; profile 4 = 54.1%	NR	Internet panel	Online survey	48	28%	1082	NR	NR
Groenewoud (2015)	Representatives of patients with Alzheimer's disease	The Netherlands	57 (10.1)	81%	NR, results split between low and high	Nursing homes, elderly residential homes, and ambulatory mental health care services. Magazine advert.	Paper questionnaire	77	15/421 had missing values, 2/421 always preferred the same option. All (100%) responses were obtained	421	NR	DSM-IV-TR-Dysthymic Disorder
Sawamura et al. (2015)	General population	Japan	Total= 58.3 (4.4); dementia = 58.2 (4.4)	Total= 57.7%; dementia= 57.1%	NR	Randomly extracted from Basic Resident Register	Mail-in survey	15.4	NR	Total= 371; dementia= 196	NR	NR
Chester (2018)	People with early-stage dementia and their carers	UK	Overall= 65 [20–94]; PwD= 77 [57–94]; Carers= 60 [20–89]	Overall= 66%; PwD= 61%; Carers= 68%	Early stage	Memory clinics and carer's organisation	Overall: 104 (71%) face-to-face interview; 43 (29%) online survey. PwD: 44 (100%) face-to-face. Carers: 60 (58%) face-to-face; 43 (42%) online	NR	100%	147 (44 PwD, 103 carers)	Interviews = 35–60 mins. Online = 15 min average [range 6-58]	EQ-5D-3L
O'Philbin et al. (2020)	Patients with dementia and caregivers (family, friend or professional)	UK	PwD= 61.65 (12.33); Caregivers= 54.12 (16.34)	PwD = 52.9%; caregivers= 83.6%	Patients with dementia and caregivers	Convenience sample	Online survey (email link)	100	99%	84	NR	NR

(*Continued*)

they con-

Table 1. Continued.

Author (year)	Sample population	Country	Age mean (SD) [range]	Gender (%female)	Dementia severity/detail	Recruited from	Mode of administration	Response rate (%)	Completion rate (%)	Number of respondents in final analysis	Length of time to complete	Health status measure
Kampanellou (2019)	Informal carers of people with later-stage dementia	UK	Overall= 61 [20–85]; Online= 60 [20–85]; Paper= 63 [45–82]	Overall = 83%; online= 81%; paper= 87%	Later-stage	Carers' organisations	Online and paper version	NR	NR	100	Average 15 mins [range 5–29]. However, $n = 16$ took over 1 h 7 of which took over a day	EQ-5D-3L
Walsh (2020)	General population	Ireland	15% age 18-34; 41% age 35-49; 32% age 50-64; 12% age 65+	61%	Moderate	A company's online panel	Online survey	NR	NR	551	NR	NR
Dranitsaris (2023)	Caregivers (family or friend) and neurologists	USA	15% age 18-34; 19% age 35-44; 15% age 45-54; 31% age 55-64; 20% age 65+	65%	89% moderate or severe	Database of neurologist and Alzheimer's disease caregivers	Online survey	73%	83%	298 (137 caregivers, 161 neurologists)	NR	NR

ducted a pilot. Of those including a pilot, coverage of attributes and levels was explored in two studies and understanding and complexity was checked in three studies. No study reported that length and timing was checked in the pilot. Data were analysed using logit models ($n = 8$), or hierarchical Bayesian models with random effects ($n = 1$). Logit models included mixed, conditions, multinomial, and random effects. Socio-demographics and other covariates were not explicitly included in any of the models; however, most studies ($n = 7$) did conduct some form of sub-group analysis to consider different characteristics.

Validity was discussed informally in three studies, based on comparison to prior or hypothetical expectations in two studies, and formally considered by including two choice sets to examine internal validity in one study (Dranitsaris et al. 2023). The remaining three studies did not discuss validity. Two studies deleted respondent answers, one due to inadequate attention or failing an a priori set of comprehension-based criteria (Dranitsaris et al. 2023), while the other ran a regression only on completed questionnaires where the respondent did not always choose the same option (Groenewoud et al. 2015).

Attributes and levels

DCEs describe choices between two or more alternatives. These alternatives are made up of various 'attributes' which have different 'levels' describing the different options. Participants then choose their preferred alternative by making a trade-off revealing their preferences for each attribute and level (Lancsar & Louviere, 2008). Further definition of terminology related to DCEs is provided in Appendix 2.

For the included studies, attributes and levels were identified through: systematic review of the literature; consultation, focus groups or interviews with stakeholders (PLWD, carers, expert opinion); reviewing policy documents; and/or social production function theory. Studies included between four and eleven attributes with up to four levels, as detailed in Table 2. Themes are summarised in Table 3. Included attributes could be categorised as related to cost (7/9), setting characteristics (7/9), service, availability (5/9), service provided (4/9), provider characteristics (4/9) and clinical effects/study outcomes (2/9). These attributes are further described below first for social care and second for pharmacological healthcare services.

Social care attributes

Most of the studies (8/9) summarised attributes related to social care intervention. These included care services (i.e. hours of home care, day care, long-term care, residential care and/or respite)(Groenewoud et al. 2015; Kampanellou et al. 2019; Negrín et al. 2008; Nieboer et al. 2010; Sawamura et al. 2015; Walsh et al. 2020), information and advice (Chester et al. 2018), non-pharmacological therapies and activities (Chester et al. 2018; Nieboer et al. 2010), and psychosocial support (O'Philbin et al. 2020). While reported here due to the relevance of psychosocial support to social care services, it should be noted that the memory aids assessed by O'Philbin et al. could also encompass some aspects related to wider healthcare services.

Cost

Cost attributes included trade-offs between co-payment and no co-payment for the service, and between cost levels which

Table 2. DCE characteristics.

Author (year)	Pilot test	Financial incentive	Use of forced choice	Number of surveys generated (blocks)	Number of choice sets per respondent	Number of alternatives presented in each choice set	Number of attributes	Method of data analysis
Negrín et al. (2008)	No	NR	No. Includes status-quo option	NR (20 optimal scenarios into balanced incomplete block designs)	5	4 (3 choices + status quo)	4	Mixed logit (maximum likelihood and Bayesian methods)
Nieboer et al. (2010)	Yes	NR	Yes	32 blocks	8	2	10	Conditional logit model
Groenewoud (2015)	Yes	NR	Yes. Chose between options A and B	3 (27 scenarios blocked into 3 sets of 9 scenarios)	9	2	11	Conditional logit
Sawamura et al. (2015)	Yes	NR	Yes. Not specifically mentioned but can infer	Not blocked	8 or 9	2	8	Conditional logit
Chester (2018)	NR	NR	Yes. Choose between options A and B	1 (not blocked)	18	2	7	Multinomial logit model (conditional logit model)
O'Philbin et al. (2020)	No	Yes	Yes	Not blocked	16	2	5	Random effects logit model
Kampanellou (2019)	NR	NR	Yes. Not specifically mentioned but can infer	NR	18	2	7	Multinomial logit model (conditional logit model)
Walsh (2020)	Yes	NR	No. Includes status-quo option	Not blocked	12 + 1 rationality	3	5	Conditional logit, mixed logit, G-MNL models
Dranitsaris (2023)	Yes	NR	Yes	1 (not blocked)	12	2	7	Hierarchical Bayesian models with random effects

ranged up to a maximum of around £2200 per month to the service user through direct payments or taxation. This upper limit of £2200 was recorded in a 2015 study considering the general population of Japan reporting 400,000 yen per month. Overall, low-cost care packages were preferred by PLWD and the public (Chester et al. 2018; Kampanellou et al. 2019; Negrín et al. 2008; O'Philbin et al. 2020). The public were generally opposed to compulsory co-payment (Walsh et al. 2020) though one study found marginally more PLWD would pay for a service (53%) than only use it free of charge (47%) (O'Philbin et al. 2020).

Service provision

Service provision detailed the type of service or support provided in an intervention. This included organisation of social activities (Nieboer et al. 2010), availability of individual choice (Sawamura et al. 2015), advice and information on coping with dementia (Chester et al. 2018; Kampanellou et al. 2019), recreational and relaxation activities (Chester et al. 2018), support with personal feelings and health advice (Chester et al. 2018; Kampanellou et al. 2019), home care and respite frequency (Kampanellou et al. 2019), home adaptations (Kampanellou et al. 2019), and training to manage behaviour (Kampanellou et al. 2019). Thus, attributes are seen to focus on characteristics related to social and behaviour activation (i.e. connecting people to activities and community services) and home adaptation services.

Preferences were seen to change slightly, dependent on the intervention. For example when implementing provision *via* an app, computer capability dictated the preference for session focus and level of technical help needed (O'Philbin et al. 2020). The importance of person-centred care was clear throughout the included studies (Groenewoud et al. 2015; Sawamura et al. 2015; Walsh et al. 2020) and it was considered that consumer information should be tailored to patient groups (Groenewoud et al. 2015). Individualised care was particularly valued by those with experience as a family caregiver as those respondents negatively valued unavailability of individual choice on schedule and food (Sawamura et al. 2015). Additionally, carers valued frequent and individualised home support or care, and regular respite (Kampanellou et al. 2019). Conversely, for PLWD, one study found social and recreational activities were instead deemed most important, followed by support with personal feelings (Chester et al. 2018). Meanwhile the general population recognised the value of increasing the number of formal care hours (Walsh et al. 2020).

Availability

Attributes related to availability included ability to attend desired service, transport and travel, living situation, wait time, and app accessibility. The general population placed high importance on assurance that those wishing to attend a service would be able to do so, with a day centre being preferred over home care if more would be able to attend (Negrín et al. 2008). They also preferred reduced waiting time in comparing immediate occupancy to waiting for over one year (Sawamura et al. 2015). Additionally, avoiding relocation was highly valued compared to private rooms with individualised care (Sawamura et al. 2015). Results indicated a preference for closer facility proximity which strengthened with respondent experience of being a family caregiver but was not reliant on family caregiver experience (Sawamura et al. 2015).

Setting

Setting characteristics described the format and surroundings of the service provided. This included aspects such as hours of care, inclusion of interpersonal interaction, group vs individual

Table 3. Attributes and levels.

Negrín et al. (2008)	Nieboer et al. (2010)	Groenewoud (2015)	Sawamura et al. (2015)	Chester et al. (2018)	O'Philbin et al. (2020)	Kampanellou et al. (2019)	Walsh et al. (2020)	Dranitsaris et al. (2023)
Cost • €12 • €24 • €48 • €72	**Weekly co-payment** • No co-payment • 50 euro • 100 euro • 150 euro	**Hours of personal care per week** • 4 • 10 • 16	**Monthly fee** • 100,000 yen • 250,000 yen • 400,000 yen	**Cost** • £15 per week • £30 per week • £44 per week	**Cost** • Free • £25 • £50	**Cost** • £75 per week • £115 per week • £150 per week	**Co-payment** • No co-payment • Means-tested co-payment • Compulsory co-payment	**Treatment administration** • Intravenous every 2 weeks • Intravenous every 4 weeks • Subcutaneous every 2 weeks
Home care • 3 hours per day • 6 hours per day • 9 hours per day	**Organised social activities** • Not available • 1 half day per week • 2 half days per week • 3 half days per week	**Residents experiencing good interpersonal treatment** • 25% • 50% • 75%	**Availability of individual choice of daily schedule and meals** • Not available • Partially available • Entirely available	**Advice on the use of memory aids is** • Not available • Available at a clinic • Provided by a trained worker at home	**Setting** • Community group • One to one at home	**General home care is** • Available irregularly • Available regularly but for short periods • Provided regularly for as long as needed	**Additional tax per year** • €50 • €100 • €150 • €200 • €250	**Treatment duration (entire course)** • 1 year • 3 years • 5 years
Day centre care • 50% of patients who wished to attend could do so • 70% of patients who wished to attend could do so • 100% of patients who wished to attend could do so.	**Number of hours of care per week** • 4h • 8h • 12h • 16h	**Deliver care as agreed** • Seldom • Sometimes • Always	**Room** • Shared (2-4) room • Personal room	**Information on coping with dementia is** • Available in writing only on request • Available over the phone or internet when needed • Provided by an experienced worker at home	**Follow up** • Manual only • Manual and follow up	**Information on coping with dementia is** • Available in writing only on request • Available over the phone or internet when needed • Provided by an experienced worker at home	**Number of care hours** • 10h per week • 15h per week • 20h per week	**Treatment titration (at initiation)** • Does not require dosage titration • Requires dosage titration (typically for 3-8 months)
Medium- and long-stay centre care • 20% of patients who wished to attend could do so • 50% of patients who wished to attend could do so • 100% of patients who wished to attend could do so.	**Individual preferences** • Standardised care • The content of care is determined individually	**Alzheimer's expertise of the institution** • Not specialised • Specialised unit/ward • Institution is specialised	**Main daily interaction** • Mostly alone • Mostly with staff and other residents • Mostly with family and friends	**Opportunities for social and recreational activities are** • Not provided • Available through outside organisations • Provided by a dedicated worker at home	**Session focus** • Book only • Book & learn how to use app	**Respite care is** • Not available • Available only for emergencies/ special events • Available regularly to fit your needs	**Flexibility** • Low • High	**Clinical effects (average years of delay in progression to moderate stage of Alzheimer's, compared to standard of care)** • 1.5 years • 2.5 years • 3.5 years

(*Continued*)

Table 3. Continued.

Negrín et al. (2008)	Nieboer et al. (2010)	Groenewoud (2015)	Sawamura et al. (2015)	Chester et al. (2018)	O'Philbin et al. (2020)	Kampanellou et al. (2019)	Walsh et al. (2020)	Dranitsaris et al. (2023)
	Coordinated care services delivery • Have to arrange little • Have to arrange a lot	**Provider recommended by** • No one in particular • Family or friends • GP or medical specialist	**Regular care staff** • Not available • Available	**Relaxation therapy is** • Not available • Available at clinic by appointment • Provided when needed at home	**App accessibility and usability** • Advanced • Intermediate • Elementary	**Aids and adaptations in the home are** • Not available • Available if requested • Available regularly to fit your needs	**Communication** • Standardised • Personalised	**Clinical effects (variation among patients)** • Narrow • Wide
	Who provides care • Regular care provider • Varying care providers	**Representatives satisfied with communication with staff** • 50% • 70% • 90%	**Relocation because of medical deterioration** • Necessary • Unnecessary	**Support with personal feelings and concerns is** • Not provided • Available through a helpline • Provided by a trained counsellor at home		**Training on how to manage behaviour and difficulties is** • Not provided • Provided in a support group • Provided by a dedicated worker at home		**Biomarker response (amyloid clearance)** • 30% • 70%
	Transportation service • Available • Not available	**No. of personnel per 15 residents** • 1 • 2 • 3	**Waiting time** • Over 1 year • Within 1 year	**Health promotion advice is** • Not provided • Available at a clinic by appointment • Provided regularly at home		**Emotional support to you is** • Not provided • Available through a 'helpline' • Provided regularly at home		**Adverse events (symptomatic ARIA-E)** • 1% • 5% • 25%
	Living situation • Living independently at home • Apartment building in the proximity of care • Sheltered accommodation • Elderly or nursing home	**Travel distance** • 60km • 20km • 5km	**Distance from present residence** • Forty minutes by car • Twenty minutes by car • Within walking distance					
	Punctuality • Max. 15 min wait time • Max. 1h wait time • Max. 2h wait time • Max. 3h wait time	**Waiting time** • 12 months • 8 months • 4 months						
	Waiting list in months • Directly available • 4 months • 8 months • 12 months	**Percentage of residents feeling safe and comfortable** • 50 • 70 • 90						
		Risk of pressure ulcers • 20% • 10% • 2%						

Key: ORANGE = Cost; PURPLE = Service provision (what is being provided); BLUE = Setting characteristics (e.g. hours per day group/individual, shared room, manual etc.); GREEN = Service provider characteristics (e.g. who provided, communication); YELLOW = Availability (e.g. wait time, travel, able to attend); RED = Clinical/study outcomes.

provision, accommodation, flexibility, coordination of and preferences for standard vs individualised care, and provision of follow-up sessions.

In early stages of dementia, home support (including care, emotional support, and training delivered at home) was preferred by both PLWD and carers (Chester et al. 2018; Kampanellou et al. 2019). PLWD preferred recreational activities to be provided by a 'dedicated worker at home' or 'through outside organisations'(Chester et al. 2018). PLWD also placed importance on individual intervention setting. However, while not in the majority, group-based services were preferred by one-third of PLWD so should not be disregarded in all cases (O'Philbin et al. 2020).

Meanwhile caregivers placed importance on individual (rather than group) setting and additional follow up (O'Philbin et al. 2020). Also, conversely to PLWD preferences, carers preferred support and information to be provided at home and given by trained/experienced individuals (Chester et al. 2018).

Preferences varied according to disease severity. Respondents representing people with high severity of Alzheimer's disease placed higher value on increased hours of care and lower value on reduced travel distance (Groenewoud et al. 2015). The public wanted greater flexibility in dementia care provision due to heterogeneity of preferences (Walsh et al. 2020). They also preferred a private room, but negatively valued services where the PLWD resident spent most of their time alone (Sawamura et al. 2015).

Provider characteristics

Provider characteristics detailed the expertise and availability of staff including regularity of care staff, institution specialism, provider recommendation, communication, and staff-resident ratio. PLWD both with and without a partner valued regular care providers and transport services. Those without a partner additionally valued coordinated care services, shorter waiting time, protected housing, and more participation in organised social activities (Nieboer et al. 2010). Meanwhile this preference for regular care staff was not deemed important in other studies (Sawamura et al. 2015). Current caregivers valued emotional support and training by skilled professionals (Kampanellou et al. 2019), better caregiver expertise (Groenewoud et al. 2015), reduced travel distance (Groenewoud et al. 2015), and care delivery in accordance with agreements (Groenewoud et al. 2015). Day centres were highly valued by the general population if facilitating greater service availability (Negrín et al. 2008). Members of the general population with experience as a family caregiver particularly valued individualised care and communication (Sawamura et al. 2015).

Outcome

Outcome attributes were included in only one study for social care. These outcomes focussed on feeling safe, risk (Groenewoud et al. 2015).

Pharmacological healthcare attributes

Only one study evaluated preferences for a pharmacological healthcare intervention (Dranitsaris et al. 2023). Attributes covered only setting and outcome related aspects of the intervention.

Setting

For pharmacological healthcare, attributes related to setting concerned treatment administration, more specifically frequency, mode, and duration of the treatment course (Dranitsaris et al. 2023). These aspects were however less important than clinical effects and adverse events (Dranitsaris et al. 2023).

Outcome

Outcome attributes included clinical effects such as disease progression, and adverse events. Where treatment outcomes were considered, variation in clinical effects (i.e. distribution of clinical effects across patients) was one of the least important therapeutic attributes, alongside treatment duration (Dranitsaris et al. 2023). Overall caregivers and neurologists preferred longer-lasting clinical effects and fewer adverse events (Dranitsaris et al. 2023).

Strengths and limitations of included studies

Common study strengths, as detailed by the cited authors, included choosing attributes on extensive preliminary research including evidence synthesis and consultation (Chester et al. 2018; Groenewoud et al. 2015; Kampanellou et al. 2019) and achieving a good (or target) sample size (Chester et al. 2018; Kampanellou et al. 2019). Nieboer claimed that restricting their sample to older people would facilitate greater awareness of the challenges associated to care (Nieboer et al. 2010), while Dranitsaris commended their inclusion of two important groups in dementia healthcare (carers and neurologists)(Dranitsaris et al. 2023). Varying questionnaire format was also considered beneficial with both face-to-face and online options allowing for in person engagement for PLWD alongside geographically dispersed carers through online access (Chester et al. 2018).

As is common in DCEs, a number of authors cited the potential for differences between observed and true preferences (Negrín et al. 2008), and trouble with hypothetical questions (Dranitsaris et al. 2023; Sawamura et al. 2015; Walsh et al. 2020), which could likely become more difficult as cognitive impairments increase. Other methodological limitations included the use of forced choice design which may overestimate active choice behaviour given the limited and forced selection of choice sets (Groenewoud et al. 2015), and restriction to only main effects thus disregarding potential interactions between attributes (Groenewoud et al. 2015). Regarding attribute selection, one study commented that their results only showed societal value of resources and did not evaluate clinical benefits (Negrín et al. 2008), and noted that the evaluated programmes were not interchangeable, and the most appropriate programme was likely dependent on a person's characteristics and state of illness as well (Negrín et al. 2008).

A number of studies stated potential for their sample not to be representative of the general population of interest (Dranitsaris et al. 2023; Groenewoud et al. 2015; O'Philbin et al. 2020; Sawamura et al. 2015; Walsh et al. 2020). Some more specifically commented on limitations due to a small sample size for PLWD (O'Philbin et al. 2020), or preferences being elicited from the general population or carers but not PLWD (Dranitsaris et al. 2023; Kampanellou et al. 2019; Nieboer et al. 2010). Additionally, limited reporting restricts the opportunity for inference on differing preferences with respect to ethnicity or disease severity.

Chester commented on the potential cognitive burden of the DCE process (Chester et al. 2018) while Groenewoud specifically linked potential burden to concern over including too many attributes (Groenewoud et al. 2015). Conversely other authors raised the limitation of including a restricted selection of attributes to reduce cognitive burden, but at the expense of results being dependent on the attributes chosen (Chester et al. 2018; Dranitsaris et al. 2023; Kampanellou et al. 2019; O'Philbin et al. 2020; Sawamura et al. 2015; Walsh et al. 2020).

Additionally, two studies expressed that their online survey administration could introduce selection bias towards younger or more internet minded respondents (Dranitsaris et al. 2023; O'Philbin et al. 2020).

Suggestions for future research

Suggestions for future research, as reported in included studies, consist of the need to compare pharmaceutical to non-pharmacological interventions (Negrín et al. 2008), include broader populations such as early onset dementia (Dranitsaris et al. 2023; Negrín et al. 2008; O'Philbin et al. 2020), consider the impact of phase of illness on preferences (Negrín et al. 2008), explore less cognitively challenging preference elicitation methods for use with later stage dementia (Chester et al. 2018; O'Philbin et al. 2020), examine backgrounds and expectations to better frame preferences (Sawamura et al. 2015), larger sample sizes (O'Philbin et al. 2020), and comparison of findings between PLWD and their caregivers to validate caregiver responses (O'Philbin et al. 2020).

Discussion

The first aim of this review was to explore preferences for health and social care services for PLWD or MCI. Overall, studies suggest health and social care packages should be designed for specific individuals using an optimal mix of services with individualised care prioritised (Nieboer et al. 2010; Sawamura et al. 2015). Care home system design should incorporate greater flexibility to cater for a wider range of preferences (Walsh et al. 2020). Most PLWD prefer individual intervention sessions and so this, rather than group sessions, should be prioritised. However this is not the case for all PLWD as around one-third preferred group settings, again supporting a level of individualisation in care packages (O'Philbin et al. 2020). For example, nursing homes were an example of a group setting considered particularly appropriate for PLWD without a partner (Nieboer et al. 2010). This is consistent with insights from a recent review by Lepper who also found preferences to differ according to living situation (Lepper et al. 2020).

This review suggests that services should be offered on a regular basis and by a skilled professional (Kampanellou et al. 2019), in line with the conclusions by Speckemeier who observed strong preferences for continuity of care and caregiver expertise (Speckemeier, 2023). The included studies considered that welfare gains could be achieved by increasing home care hours, but even greater welfare gains achieved by incorporating home care system changes reflecting a move towards person-centred care (Walsh et al. 2020). Preference for at home delivery suggests possible inclination towards more personal contact and face-to-face interactions (Chester et al. 2018). Additionally, where explored it is suggested that benefit could arise from including additional sessions (O'Philbin et al. 2020). Findings of a preference for home support is evidenced in both early (Chester et al. 2018) and late-stage dementia (Kampanellou et al. 2019). Additionally, Groenwould and colleagues found higher value for increased hours of care with higher severity of Alzheimer's disease (Groenewoud et al. 2015).

The relative value of different attributes differed according to personal characteristics, including resources available to the person with dementia such as having a partner (Nieboer et al. 2010). This further supports the notion that care packages should provide an optimal mix of service characteristics for specific PLWD (Nieboer et al. 2010).

The second aim of this review was to explore the methodological and practical implications of designing DCEs for PLWD or MCI. A number of strengths and limitations associated with the DCE process in PLWD were noted in this review. Authors of included papers stated the strength of using robust methods, and for this population including both evidence synthesis and stakeholder consultation for attribute and level selection. They deem it key to target a relevant and experienced population, and to consider the use of online and face-to-face formats to meet the needs of PLWD, carers, and health professionals. Limitations were also noted in selection of a study sample not reflective of the desired population, potential confounding from digital literacy if administered online, or the impact of participant characteristics, experience, or personal illness. Thus, future DCEs for PLWD or MCI should be mindful of tailoring questionnaire format and recruitment methods to the population to gather representative and meaningful responses.

Additionally, several common limitations arose including concern over the hypothetical nature of a DCE not reflecting true real-world preferences, and cognitive burden from the DCE process and/or number of attributes. While some participants thought the DCE a good and useful idea (Chester et al. 2018; Kampanellou et al. 2019), others struggled with the hypothetical nature, number of choices, and could be preoccupied with cost (Chester et al. 2018; Kampanellou et al. 2019). This occurred not only between PLWD but also for different respondent groups, such as carers.

Of note, most studies utilised a forced choice design. While this may be beneficial for the participant in making the choice simpler, and for researchers in providing data on preferences, it is less reflective of the real world and forces a decision where in reality a PLWD may not be able to make one. Thus, one could suggest including an opt-out or indifference option in pilot testing, moving to a forced choice in the main DCE if appropriate.

Our findings demonstrate that future DCEs for PLWD should ensure a thorough and robust process for the selection of attributes, levels and participants. Consideration should be given to inclusion of PLWD, carers, and health professionals to ensure a broad understanding of preferences, and format should be tailored to best suit the needs of the chosen population. DCE design should take care not to overburden participants, particularly PLWD, where for example fewer attributes or scenarios may be required. As such, appropriate patient and public involvement should be conducted to ensure the attributes, levels, format, and DCE design are appropriate.

Strengths and limitations of current review

This review strengthens the search strategies employed in existing reviews. First it ensures a thorough overview of existing primary studies through a rigorous systematic search and screening process, followed by forward and backward citation chasing. Second, inclusion criteria are limited to discrete choice experiments only providing more focussed consideration of the methodology. Finally, study quality is evaluated using the Lancsar and Louviere checklist (Lancsar & Louviere, 2008) to facilitate deeper understanding of study characteristics. It is important to consider however that some studies may be missed by the search strategy, as is always a possibility in conducting a systematic review. Additionally, this study is limited by its exclusion of PLWD in hospital, secondary, tertiary or hospice care, or participants with life-expectancy of three month or less. However, the needs and preferences of this group of people are likely to be significantly different, and therefore likely better studied separately.

Future DCEs related to dementia

Included studies highlight a number of opportunities for future research in DCEs related to dementia care. Shorter questionnaires are used to reduce cognitive load (O'Philbin et al. 2020) and future research should seek to determine the most efficient number of alternatives to present in a choice scenario for PLWD (Negrín et al. 2008). Work by Wammes et al. suggests a median of six choice tasks with up to three attributes for PLWD, and claims benefit from illustrations for improved understanding of attributes, though also acknowledges that their findings are only a starting point with a small sample size (Wammes et al. 2023).

This review suggests benefit to future comparisons across treatment methods (e.g. pharmacological vs. non-pharmacological), or different stages of dementia diagnosis (Negrín et al. 2008). It also suggests exploration of preferences amongst a broader population of stakeholders, for example care home residents, staff, and relatives (Dranitsaris et al. 2023; O'Philbin et al. 2020). Furthermore, as the impact of participant characteristics is noted as a study limitation, there is a need to examine and incorporate the background and expectations of participants (Sawamura et al. 2015).

It is suggested that more work is required to validate DCE methodology in PLWD by comparing responses from PLWD and their caregivers (O'Philbin et al. 2020). Wammes et al. considered dyadic preferences alongside individual preferences for PLWD and for caregivers in their recent paper (Wammes et al. 2023). They note around two-thirds had full agreement across all three DCEs and suggest benefit to individual, followed by dyadic, DCEs given the trade-off between carers facilitating PLWD to respond to a greater number of choice tasks and attributes and the need to capture the voice of PLWD independently.

Additionally, cited authors state the need to explore other preference elicitation methods as the cognitive complexity of a DCE may pose difficulty in administration, particularly for late stage (Chester et al. 2018). DCE design should take care not to overburden participants. Appropriate patient and public involvement should be conducted with service users, caregivers, and where appropriate healthcare specialists to ensure the attributes, levels, format, and DCE design are appropriate. Finally of note, cited authors suggest potential benefit to incorporating DCE results into a cost-benefit analysis (Negrín et al. 2008).

Conclusion

Overall, preference for individualised health and social care is a priority in dementia care. Continuity of care and service flexibility are also greatly valued. It should also be recognised that needs will differ according to personal characteristics and available support from family and friends. While acceptable in this population, DCE methodology needs further exploration in confirming the most appropriate methods (format and content) and expanding to include additional populations including greater insight on preferences of PLWD themselves.

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Ethical approval

No ethical approval was required for this study as it analysed previously published literature and did not include any new data collection.

Disclosure statement

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Data availability statement

We will store anonymised research data and outputs in the University of Exeter's Open Research Exeter repository (https://ore.exeter.ac.uk/repository/) in order to facilitate open access to, and the impact of, our research.

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