REVIEW ARTICLE

Preferences for attributes of long-term care in dementia: a scoping review of multi-criteria decision analyses

Christian Speckemeier[1] 🄳

Abstract

Aim Long-term care considerations for persons with dementia are complex. Multi-criteria decision analysis (MCDA) methods are increasingly used to support healthcare decisions. The objective of this scoping review was to identify and analyze published MCDAs in which preferences for living and care concepts for persons with dementia are determined.

Subject and methods A literature search was conducted in PubMed, EMBASE, Web of Science, and Google Scholar in October 2021. Searches were limited to peer-reviewed articles published up to October 14, 2021. The included publications aimed at eliciting care preferences for persons with dementia from patients, relatives, healthcare practitioners or the broader public by means of MCDA.

Results Ten studies were included of whom seven were published in 2017 or afterwards. In nine studies, a discrete choice experiment (DCE) was conducted. The majority of studies surveyed the general population or caregivers of persons with dementia. Five studies assessed preferences for attributes of home care and two for long-term care facilities. Willingness to pay was addressed in eight studies. Choice task structure and experimental design varied widely. Despite different objectives, strong preferences for continuous care by the same person, organizational aspects, and caregiver expertise were found across studies.

Conclusion This review shows that MCDA methods have successfully been applied to analyze preferences for living and care arrangements for persons with dementia. The majority of publications report on DCEs, and a variety of different study objectives and methodological approaches have been observed. Further research is needed to inform the design of innovative concepts which are a valuable alternative to existing care options.

Keywords Dementia · Long-term care · Living environment · Multi-criteria decision analysis · Discrete choice experiment · Conjoint analysis

Background

The global number of persons with dementia is estimated to increase from around 57 million in 2019 to more than 150 million persons in 2050 (GBD 2019 Dementia Forecasting Collaborators 2022). Dementia does not only affect cognitive functions, but also medical health, psychological well-being, physical functions, and social integration, thus representing a heavy burden on families, health care systems, and lawmakers (Eichler et al. 2016). Current treatment options are insufficient, and as dementia progresses, intensive support and care are required (Flöer 2020).

International evidence indicates a high prevalence of people with medium/moderate dementia receiving care at home (Matthews et al. 2016). The cost of home care is known to be significantly lower than the cost of institutional care even after accounting for the cost of informal care providers, with the most notable cost differences seen in formal costs (Bu and Rutherford 2019; Hollander and Chappell 2007). When home care is no longer possible due to the natural progression of the disease, institutional care is necessary. In recent years, new care environments have been developed for the provision of long-term care for persons with dementia (Verbeek et al. 2009; Stiefler et al. 2020). Examples for new concepts featuring changes in physical environment and care philosophy are the Domus philosophy in the

✉ Christian Speckemeier
christian.speckemeier@medman.uni-due.de

1   Institute for Healthcare Management and Research, University of Duisburg–Essen, Thea-Leymann-Str. 9, 45127 Essen, Germany

United Kingdom (Dean et al. 1993), the Small-Scale Living concept in the Netherlands (te Boekhorst et al. 2009), and the Japanese Group Home concept (Yokota et al. 2006). It can be assumed that the demand for innovative living and care concepts will increase in the future, among other things due to the fact that a decrease of informal care potentials in OECD countries is forecast. This is inter alia due to a higher labor market participation of women, and the fact that fewer adult children will be available to care for their older parents (Bu and Rutherford 2019; Siciliani 2013).

Differing characteristics of care recipients and a variable influence of context and financial factors make long-term care decisions challenging (van Leersum et al. 2019). Before decisions can be made, often a consensus about the primary outcome (e.g. autonomy, safety, improved function) must be reached within the family (Kane et al. 2007). An involvement of individual needs, expectations, and preferences in care decisions has found to be associated with better engagement, health, and quality of life (Wilberforce et al. 2016). In such decisions, complexity is inevitable, as a number of alternatives exist and they are influenced by multiple factors. Usage of explicit and structured approaches can improve the quality of decision making.

A number of techniques, known under the umbrella term multi-criteria decision analysis (MCDA), can be useful (Thokala et al. 2016). MCDA is used to break down complex decisions into manageable components. According to a definition from Belton and Stewart, MCDA includes "formal approaches which seek to take explicit account of multiple criteria in helping individuals or groups explore decisions that matter" (Belton and Stewart 2002). MCDA is used increasingly in the field of health care, and consists of a multitude of methodological approaches.

In healthcare, value measurement techniques using stated preference approaches are by far the most prevalent (Marsh et al. 2016). While value measurement techniques per se share some similar steps, multiple methods exist to elicit weights and scores, including direct rating, swing weighting, discrete choice experiments (DCEs), and analytic hierarchy process (AHP) (Marsh et al. 2014). For example, conjoint analyses (CAs) and employ ranking, rating, or choice designs to quantify preferences for different aspects of an intervention. These aspects are called attributes, which have different properties, which are called levels (Bridges et al. 2011).

Decision-makers have shown interest in the application of MCDA (Marsh et al. 2014). The Institute for Quality and Efficiency has investigated CA and AHP to identify, weight, and prioritize attributes for different indications (Drummond et al. 2011). In addition, the International Society for Pharmacoeconomics and Health Outcomes has already published a number of taskforce reports on the topic of MCDA (Bridges et al. 2011; Thokala et al. 2016; Marsh et al. 2016).

No literature review of MCDAs relevant to living and care concepts for persons with dementia has been conducted yet. The purpose of this review is to close this gap. The aim of this scoping review is to analyze MCDAs which were designed to elicit preferences from persons with dementia, their relatives, healthcare professionals, or the broader public regarding their purpose, characteristics, methods, and results.

The method of scoping review was found feasible, as the focus was to identify, report, and discuss different approaches and their characteristics (Peters et al. 2020). In delineation to a systematic review, scoping reviews allow addressing questions beyond those directed at the effectiveness of an intervention (Peters et al. 2015). Although preferences which are expressed by persons living with dementia might differ from preferences obtained in MCDA directed at persons without a diagnosis of dementia (e.g. relatives, healthcare professionals, or the broader public) (Neumann et al. 2000), both perspectives will be included in this review.

Methods

Conduct of this scoping review was guided by the JBI guide for scoping reviews (Peters et al. 2020) and reporting was guided by the PRISMA extension to scoping reviews (Tricco et al. 2018). No review protocol was published in advance.

Search strategy

The search was performed using the MIP scheme (Strech et al. 2008). The MIP scheme contains the aspects Methodology (MCDA), Issues (living and care preferences of persons with dementia), and Participants (patients, relatives, healthcare practitioners, broader public).

The search strategy comprised a range of keywords including 'preference' and terms for different MCDA methods. The keywords were combined and customized for each database. To keep the search as sensitive as possible, 'issues' were covered only by the indication (dementia/Alzheimer) and not by keywords describing living and care arrangements, as it was expected that this would have restricted search results. The search strategy was pilot tested. It was decided to not account for the aspect *Participant* in the final search to avoid limiting the breadth of the search. The literature search was performed in the electronic indexed databases PubMed, EMBASE, and Web of Science. The electronic search strings are shown in Online Resource 1. In addition, a manual search in Google Scholar was carried out, considering the search tips provided by Google Scholar. The literature search was executed in June and July 2021, and rerun in October 2021 to incorporate the most recent evidence. This update

was performed following the methodology published by Bramer and Bain (2017). The searches were limited to peer-reviewed articles published up to October 14, 2021. No restrictions on publication date were imposed. Reference lists of included publications were hand-searched for additional articles.

Studies were included if they met all the following inclusion criteria: (1) presented the results of multi-criteria decision analyses, (2) targeted the topic of dementia, and (3) aimed at eliciting care preferences from patients, relatives, healthcare practitioners, or the broader public. Full-text studies in German or English were included.

Studies lacking an element of choice were not included. As this review sought to obtain literature on preferences for innovative housing concepts in their entirety, studies focusing solely on specific aspects of care (e.g., digital life story work) were not included. Similarly, studies presenting fixed care options (e.g., choice between home, residential home, nursing home) in which no flexible configuration of the concepts was possible were excluded. Due to the focus on long-term care options for persons for whom home care is no longer possible, studies focusing on end-of-life/palliative treatment were not included. Also, due to differences in symptoms and the unique needs of persons with young-onset dementia, studies focusing on young-onset dementia were not included (Couzner et al. 2022).

Results were downloaded into the End-Note reference management program (version X9). Duplicates were removed and all unique references were screened in terms of their potential relevance based on title and abstract by two reviewers. Documents considered to be potentially relevant were reviewed in full-text by two reviewers, and retained if the study met inclusion criteria.

Data extraction and assessment

Included studies were extracted in pre-specified tables comprised of criteria describing purpose, characteristics, methods, and results of the MCDAs. Aspects covered were the year of publication, country of origin, types of MCDA, indication, participants, research aims, preliminary work, survey administration, sample size, response rate, additional items, task structure, number of tasks, experimental design, number of attributes and levels, estimation procedures, subgroup analyses, funding source, and results. Definition of these criteria was influenced by published reviews on MCDA (e.g., Marsh et al. 2017b; Michaels-Igbokwe et al. 2017; Wahlster et al. 2015). The focus of this work was to present an overview of MCDAs, and thus the methodological quality of the included documents was not assessed.

Results

Included publications

The selection process for studies and the numbers at each stage are shown in Fig. 1. The search in EMBASE PubMed and Web of Science yielded 10,311 hits. After removal of duplicate records, 7040 articles remained. In addition, 16 articles were identified in the Google Scholar search. Based on title and abstract screening, 7035 articles were excluded. Full-text analysis led to exclusion of another 11 articles. Finally, ten articles met the inclusion criteria. Hand-searching of reference lists yielded no additional articles to be included. See Online Resource 2 for a table of excluded studies.

Characteristics of the included articles

Year of publication and country of origin

The oldest included study was published in 2010 (Nieboer et al. 2010) and seven of the ten studies were published in 2017 or afterwards (Chester et al. 2017; Chester et al. 2018; Fahey et al. 2017; Jasper et al. 2018; Kampanellou et al. 2019; Teahan et al. 2021; Walsh et al. 2020). Four studies were conducted in the United Kingdom (Chester et al. 2017; Chester et al. 2018; Jasper et al. 2018; Kampanellou et al. 2019), three in Ireland (Fahey et al. 2017; Teahan et al. 2021; Walsh et al. 2020), two in the Netherlands (Groenewoud et al. 2015; Nieboer et al. 2010), and one in Japan (Sawamura et al. 2015). It should be noted that the publications from the United Kingdom, Ireland, and the Netherlands were conducted by the same institutions and/or partially by the same individuals.

Types of MCDA

In nine of the ten included studies, a DCE experiment was conducted (Chester et al. 2017; Chester et al. 2018; Groenewoud et al. 2015; Jasper et al. 2018; Kampanellou et al. 2019; Nieboer et al. 2010; Sawamura et al. 2015; Teahan et al. 2021; Walsh et al. 2020), and in one study, the method of CA was applied (Fahey et al. 2017).

An overview of the main characteristics of the included studies is shown in Table 1.

Indication

In seven of the ten studies, the surveys exclusively focused on persons with dementia, with three studies not specifying the severity of the disease (Chester et al. 2017;

Fig. 1 Study selection flow chart
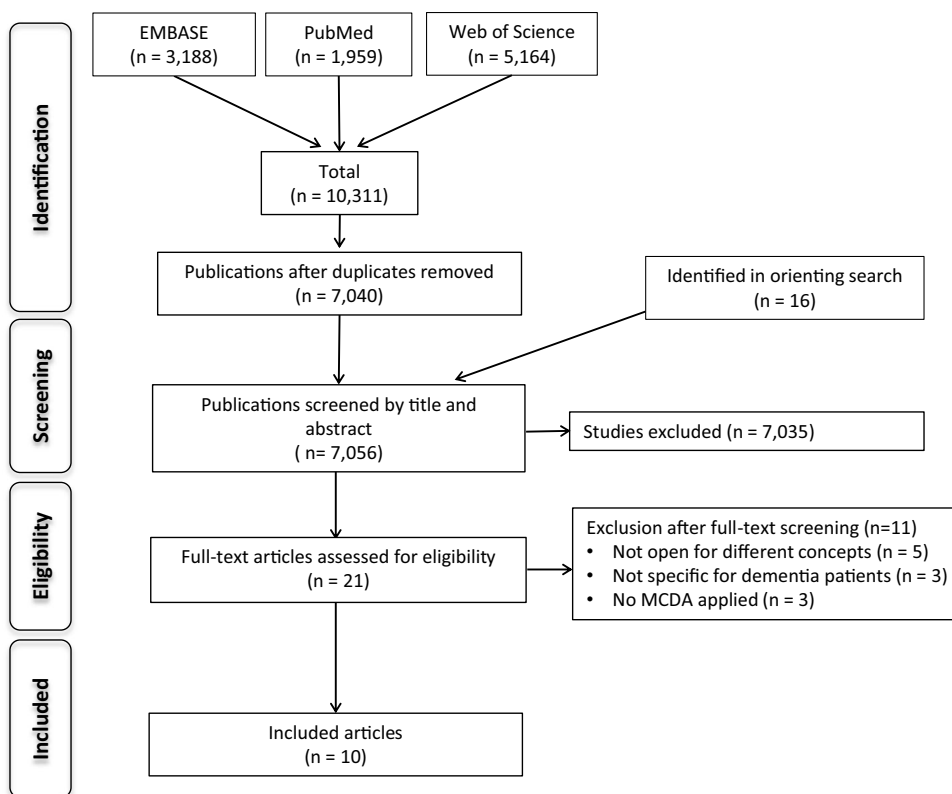
Groenewoud et al. 2015; Teahan et al. 2021), two studies including early-stage dementia (Walsh et al. 2020; Chester et al. 2018), and the remaining two studies focusing on persons with later stage dementia (Fahey et al. 2017; Kampanellou et al. 2019). Three studies did not focus on persons with dementia alone. Two of these studies deal with elderly people and persons with dementia (Jasper et al. 2018; Nieboer et al. 2010), and one study offered participants one of two vignettes of an 80-year-old person with either dementia or a fracture (Sawamura et al. 2015).

Participants

Of the ten included publications, four studies include responses from the general population. In two of these studies, persons aged 50–65 years (Nieboer et al. 2010; Sawamura et al. 2015)were surveyed, and in the other two studies, persons > 18 years (Teahan et al. 2021; Walsh et al. 2020). In three studies, the survey was directed to caregivers/representatives of persons with dementia (Chester et al. 2017; Kampanellou et al. 2019; Groenewoud 2015), and in one study, persons with dementia and caregivers were surveyed (Chester et al. 2018). In the remaining studies, surveys were directed at hospital inpatients (Fahey et al. 2017) and practitioners (Jasper et al. 2018).

Research aims and outcome measures

Five of the ten included studies aimed to assess preferences for attributes of home care (Chester et al. 2017; Chester et al. 2018; Kampanellou et al. 2019; Teahan et al. 2021; Walsh et al. 2020), and two studies assessed factors that influence the choice for long-term care facilities (Nieboer et al. 2010; Sawamura et al. 2015). In one study, preferences for different attributes of health care providers were assessed (Groenewoud et al. 2015). Another study aimed to elicit practitioners' preferences for attributes of care coordination (Jasper et al. 2018). Finally, one study assessed how older people trade off between different factors that might arise if they developed significant dementia (Fahey et al. 2017). In seven of the ten studies, a cost attribute was included to address willingness to pay in addition to attribute importance (Chester et al. 2017; Chester et al. 2018; Jasper et al. 2018; Kampanellou et al. 2019; Sawamura et al. 2015; Teahan et al. 2021; Walsh et al. 2020).

Preliminary work

In eight of the ten included studies, preliminary work included a review of the literature (Chester et al. 2017; Chester et al. 2018; Fahey et al. 2017; Jasper et al. 2018; Kampanellou et al. 2019; Nieboer et al. 2010; Teahan et al. 2021; Walsh et al. 2020). In addition, seven publications

Table 1 Characteristics of included studies

Author/year of publication	Country of origin	Research aim	Participants	Indications	Type of MCDA	Estimation procedure
Chester et al. (2017)	United Kingdom	To assess preferences for attributes of home care	Caregivers of persons with dementia	Dementia	DCE	Conditional logit model, random effects logit model
Chester et al. (2018)	United Kingdom	To assess preferences for attributes of home care	Persons with dementia and caregivers	Early-stage dementia	DCE	Conditional logit model, panel probit model
Fahey et al. (2017)	Ireland	To assess how older people trade off between different factors that might arise if they developed significant dementia	Hospital inpatients	Significant dementia	CA	Linear regression analysis
Groenewoud et al. (2015)	Netherlands	To assess preferences for different attributes of health care providers	Representatives of persons with dementia	Dementia	DCE	Conditional logit model
Jasper et al. (2018)	United Kingdom	To assess practitioners' preferences for attributes of care coordination	Practitioners	Older people, dementia as subgroup	DCE	Conditional logit model, random effects logit model
Kampanellou et al. (2019)	United Kingdom	To assess preferences for attributes of home care	Caregivers of persons with dementia	Later-stage dementia	DCE	Conditional logit model, panel probit model
Nieboer et al. (2010)	Netherlands	To assess factors that influence the choice for long-term care facilities	General population aged 50–65 years	Physically frail elderly and patients with dementia	DCE	Conditional logit model
Sawamura et al. (2015)	Japan	To assess factors that influence the choice for long-term care facilities	General population aged 50–65 years	Dementia and fracture as options	DCE	Conditional logit model, mixed logit model, random effects probit model
Teahan et al. (2021)	Ireland	To assess preferences for attributes of home care	General population aged > 18 years	Moderate dementia	DCE	Conditional logit model, mixed logit model
Walsh et al. (2020)	Ireland	To assess preferences for attributes of home care	General population aged > 18 years	Moderate dementia	DCE	Conditional logit model, mixed logit model

CA Conjoint analysis, *DCE* Discrete choice experiment

report that semi-structured interviews, consultations, or focus groups with lay representatives or carers were undertaken (Chester et al. 2017; Chester et al. 2018; Groenewoud et al. 2015; Jasper et al. 2018; Kampanellou et al. 2019; Teahan et al. 2021; Walsh et al. 2020). The analysis was piloted in seven studies (Groenewoud et al. 2015; Jasper et al. 2018; Kampanellou et al. 2019; Nieboer et al. 2010; Sawamura et al. 2015; Teahan et al. 2021; Walsh et al. 2020), while one study is described as a pilot study itself (Chester et al. 2017), providing information for a larger study to be undertaken afterwards (Chester et al. 2018).

Survey administration, sample size, and response rate

In six of the ten studies, surveys were self-administered. In three of these studies, online surveys were used (Nieboer et al. 2010; Walsh et al. 2020; Teahan et al. 2021), two studies used mail-in paper surveys (Groenewoud et al. 2015; Sawamura et al. 2015), and one study administered the survey both as paper and online version (Kampanellou et al. 2019). In three of the ten studies, surveys were interviewer administered in face-to-face meetings (Chester et al. 2017; Fahey et al. 2017; Jasper et al. 2018). Finally, in one study both a web-based survey and face-to-face

interviews were used (Chester et al. 2018). In a minority of publications, details about sample size calculation are provided. In three studies, the minimum sample size was estimated based on a methodology proposed by Hensher et al. (2005) (Chester et al. 2018; Jasper et al. 2018; Kampanellou et al. 2019). In one publication, the authors refer to previous reports indicating that in general, 50 to 100 respondents are sufficient to see robust results (Fahey et al. 2017).

The sample sizes of the included studies ranged from 28 respondents to 1082 respondents. Six of the ten studies included 100 to 500 participants.

In three of the six studies which used a self-administered survey, response rate is reported. A Japanese study mailed paper surveys to 2400 persons which were identified through Basic Resident Registers. Response rate was 15.5% (Sawamura et al. 2015). A study conducted in the Netherlands invited 3870 persons between 50 and 65 years of age from a stratified random sample of the Dutch Survey Sampling International Internet panel and reached a response rate of 28% (Nieboer et al. 2010). Finally, a study contacted carers who had expressed their willingness to participate in advance and reached a response rate of 77% (Groenewoud et al. 2015).

Additional items

All included studies asked for basic sociodemographic characteristics, in most cases including gender, age, education, and income. In three studies, health-related characteristics were assessed (Fahey et al. 2017; Groenewoud et al. 2015; Sawamura et al. 2015). Two studies applied the three-level EQ-5D (EuroQol 1990) and converted the results to utility values in order to express health status (Chester et al. 2018; Kampanellou et al. 2019).

Task structure and number of tasks

In all the nine publications reporting on , a multinomial choice structure was employed. Seven of these studies asked participants to choose from two alternatives without a possibility to opt out (Chester et al. 2017; Chester et al. 2018; Groenewoud et al. 2015; Jasper et al. 2018; Kampanellou et al. 2019; Nieboer et al. 2010; Sawamura et al. 2015). In one of these studies, the absence of an opt-out option was justified by the fact that people in urgent need of long-term care are forced to select one of the available options (Nieboer et al. 2010). The remaining two asked participants to choose from three alternatives, while one of these represented the current status quo of care provision, thereby ensuring that respondents are not forced to choose between unappealing alternatives (Teahan et al. 2021; Walsh et al. 2020). In the included nine DCEs, the number of choice tasks presented to each participant ranged from eight to 18. In five studies, respondents had to answer between eight and 12 tasks (Groenewoud et al. 2015; Nieboer et al. 2010;

Sawamura et al. 2015; Teahan et al. 2021; Walsh et al. 2020), and in four studies, each respondent had to answer 18 tasks (Chester et al. 2017; Chester et al. 2018; Jasper et al. 2018; Kampanellou et al. 2019). In the publication reporting on a CA, respondents were asked to rank nine cards in order of their preference (Fahey et al. 2017).

Experimental design

Eight of the ten included publications provide details on design generation. In six studies, software was used to generate the fractional factorial design, including a software from Burgess (2020) in two studies (Chester et al. 2017; Jasper et al. 2018), the Orthoplan package of SPSS (IBM Corporation, Armonk, NY) in two studies (Fahey et al. 2017; Sawamura et al. 2015), and Ngene (ChoiceMetrics, Australia) in two studies (Teahan et al. 2021; Walsh et al. 2020). Additionally, published design catalogues (Sloane 2010) were used in two studies (Jasper et al. 2018; Nieboer et al. 2010).

Attributes and levels

In our studies, the number of attributes ranged from four to 11. In seven studies, between four and seven attributes were used (Chester et al. 2017; Chester et al. 2018; Fahey et al. 2017; Jasper et al. 2018; Kampanellou et al. 2019; Teahan et al. 2021; Walsh et al. 2020) and in three studies, between eight and 11 attributes were used (Groenewoud et al. 2015; Nieboer et al. 2010; Sawamura et al. 2015). The number of levels ranged from two to five. In five studies, the attributes had a heterogeneous number of levels (Fahey et al. 2017; Groenewoud et al. 2015; Nieboer et al. 2010; Teahan et al. 2021; Walsh et al. 2020).

Estimation procedures

In all nine included studies reporting on a DCE, a conditional logit model was applied. In addition, three of the identified discrete choice studies also used mixed logit models, which estimate all coefficients as random parameters (Sawamura et al. 2015; Teahan et al. 2021; Walsh et al. 2020). In two studies, logit models with random effects (also referred to as mixed-effects logit) were estimated in addition (Chester et al. 2017; Jasper et al. 2018). Panel probit models were used in a further two studies (Chester et al. 2018; Kampanellou et al. 2019) and one study used a random effects probit model (Sawamura et al. 2015). In the CA, linear regression analysis was performed (Fahey et al. 2017).

Subgroup analyses

In eight studies, subgroup analyses were performed (Chester et al. 2018; Groenewoud et al. 2015; Jasper et al. 2018;

Kampanellou et al. 2019; Nieboer et al. 2010; Sawamura et al. 2015; Teahan et al. 2021; Walsh et al. 2020). Two studies performed subgroup analyses according to the method of survey administration (Chester et al. 2018; Kampanellou et al. 2019). The remaining studies defined a variety of different subgroups, including people with dementia vs carers, severity of disease, family caring experience, length of practitioner's employment, orientation towards choices in healthcare, and living alone vs living with a partner.

Results of the included studies

In the following, the attributes that attained highest preferences or willingness to pay are reported.

Five studies aimed to assess preferences for home care (Chester et al. 2017; Chester et al. 2018; Kampanellou et al. 2019; Teahan et al. 2021; Walsh et al. 2020). Results of these studies show strong preferences for higher levels of psychosocial interventions, including care by the same person, support with personal feelings and concerns, training on how to manage behavior and difficulties, and staff qualified in dementia care. In addition, three of these studies found high preferences for respite care opportunities (Chester et al. 2017; Kampanellou et al. 2019; Teahan et al. 2021). This is followed by high preferences for better levels of flexibility of service provision, e.g., the availability of home care workers on weekends (Chester et al. 2017; Walsh et al. 2020). In the studies assessing factors that influence the choice for long-term care facilities, high preferences were seen for aspects of continuity, e.g., care by the same person (Nieboer et al. 2010) and no necessity of relocation because of medical deterioration (Sawamura et al. 2015), followed by preferences for organizational aspects, including immediate occupancy (Sawamura et al. 2015) and transportation services (Nieboer et al. 2010). In the study assessing preferences for the choice of health care providers, better levels of caregiver expertise, reduced travel distance, and care delivery according to agreements were the most important factors for representatives of patients with Alzheimer's disease (Groenewoud et al. 2015). In the study assessing practitioners' preferences for attributes of care coordination, high preferences for service provision by the same person and for a wider range of care coordination activities were seen (Jasper et al. 2018). In the study assessing how older people trade off between different factors that might arise if they developed significant dementia, most important concerns expressed by participants were minimizing the burden on their family and trying to remain at home (Fahey et al. 2017).

Eight studies include information on the willingness to pay. In one study, it was not possible to calculate willingness to pay due to insignificance of the cost variable (Chester et al. 2017). In the second study by Chester et al. (2018), participants were willing to pay the highest amount, £ 31 (US\$ 47 in 2015, when survey was conducted) per week, for a trained counsellor who

supports with personal feelings and concerns. In the study by Jasper et al., participants were willing to pay approximately £ 10 (US\$ 15 in 2015) per hour for both service provision by the same person and a wider range of care coordination activities (Jasper et al. 2018). Kampanellou et al. (2019) found that respondents were willing to pay £ 235 (US\$ 318 in 2016) weekly for 'respite care regularly available'. In the study from Nieboer et al. (2010), participants were willing to pay € 177 (US\$ 219 in 2005) per week for an apartment building in the proximity of care compared to living independently at home in case of being demented and without a partner. Participants in the study from Sawamura et al. (2015) were willing to pay ¥ 105.000 (US\$ 997 in 2014) for not relocating because of medical deterioration. Walsh et al. (2020) found that the public are willing to pay € 117.28 (US\$ 157 in 2018) for a home-care system that offers high flexibility relative to low flexibility, and € 116.65 (US\$ 156) for 20 hours of care relative to 10 hours. Teahan et al. (2021) found that citizens would be willing to pay additional yearly taxes in the amounts of € 338 (US\$ 465 in 2021) and € 448 (US\$ 616) for family caregivers to receive 1 and 2 days of day-care per week respectively.

Funding source

While one study received no funding (Fahey et al. 2017), the remaining eight studies were funded by public grants or institutes involved in health research.

Journals

Six of the ten included studies were published in journals covering aspects of aging, partially in conjunction with mental health, social work, or long-term care (Chester et al. 2017; Chester et al. 2018; Fahey et al. 2017; Jasper et al. 2018; Kampanellou et al. 2019; Sawamura et al. 2015). The remaining studies were published in journals dealing with social science and medicine (Nieboer et al. 2010; Teahan et al. 2021; Walsh et al. 2020) and health services research (Groenewoud et al. 2015).

Discussion

The present review aims to shed light on MCDA directed at living and care concepts for persons with dementia. Results of the literature search without time constraints show that preference elicitation in this area is an evolving field, and limited to a rather small number of countries and selected research institutions. In addition, many of the countries in which the studies were carried out are among those in which notable initiatives and efforts in the field of dementia care, for instance directed at living and care concepts for persons with dementia, were advanced early on.

Recent applications of MCDA to elicit preferences in the context of dementia incorporate AHP (Rädke et al. 2022), ranking tasks (Cohen-Mansfield et al. 2019), or best–worst scaling (Janus et al. 2017). However, the methodological approaches to elicit preferences for attributes of long-term care in dementia which were identified in this review are restricted to DCEs in nine of the ten which included MCDA (Chester et al. 2017; Chester et al. 2018; Groenewoud et al. 2015; Jasper et al. 2018; Kampanellou et al. 2019; Nieboer et al. 2010; Sawamura et al. 2015; Teahan et al. 2021; Walsh et al. 2020), and the method of CA in one study (Fahey et al. 2017). In published studies, the terms CA and DCE are often used synonymously (e.g. Sawamura et al. 2015). However, in strict terms, the approaches differ. CA is a theory about the behavior of sets of numbers in response to factorial manipulations of attributes which may allow researchers to derive the preferences for combinations of attribute levels (Amaya-Amaya et al. 2008). CAs usually draw on the general linear model (Großmann et al. 2002). In contrast, DCEs are based on a long-standing theory of choice behavior (Louviere et al. 2010). The decision-making process in a DCE can be seen as involving a comparison of indirect utility functions. When making choices, the participant chooses the option that leads to a higher level of utility (Ryan et al. 2006). The basic axiom is:

$$U_{in} = V_{in} + \varepsilon_{in},$$

where U_{in} is the utility that individual n associates with choice alternative i, V_{in} is the observable component of utility that individual n associates with alternative i and ε_{in} is the random component associated with individual n and option i. The probability P of choosing an alternative i over alternative j for respondent n is given by:

$$P_{in} = \Pr \left(V_{in} + \varepsilon_{in} \right) > \left(V_{jn} + \varepsilon_{jn} \right).$$

When the error terms are independently and identically distributed with a type 1 extreme-value (Gumbel) distribution, the participants' choice probabilities can be expressed using McFadden's conditional (multinomial) logit model (McFadden 1974). Advantages of these models include that they can consider more than two response options, and they also allow respondents to opt-out. In all nine included studies reporting on a DCE, a conditional logit model was applied. This is in line with an observation made by Clark et al., who found an increased use of conditional logit analyses in health-related DCEs in recent years (Clark et al. 2014).

One of the challenges in DCEs and CAs is the complexity related to the number of tasks. In so-called full factorial designs, combinations of all attribute levels are used. In practice, these designs are often not feasible, as the number of evaluations required from each respondent becomes prohibitively large (Großmann et al. 2005). For example, an experimental design consisting of six attributes with three levels each would result in $n = 3^6 = 729$ possible combinations. Consequently, instead of a full factorial design, all of the included studies used so-called fractional factorial designs, incorporating only a fraction of possible choice profiles. In general, a manageable number of around six or seven attributes is recommended in order to minimize the burden on respondents (Helter and Boehler 2016) In three of the included publications, this recommended number of attributes is exceeded (Groenewoud et al. 2015; Nieboer et al. 2010; Sawamura et al. 2015). Groenewoud et al. (2015) argue that, despite this high number of attributes, careful selection of attributes contributed to the good response rate in their study.

In most of the included studies, preliminary work comprised literature searches and qualitative techniques, including semi-structured interviews, consultations, or focus groups. Thus, the preliminary work described in the included DCEs in large parts corresponds to the four stages of DCE development proposed by Helter and Boehler (2016), namely (i) collection of raw data, (ii) reduction of data, (iii) removing inappropriate attributes, and (iv) adaptation of wording.

The studies included in this review show large differences in terms of survey administration, task structure, and attribute and level characteristics, which is presumably a consequence, among other things, of the different objectives. Research aims of the included studies include preferences for attributes of home care, long-term care facilities ,and health-care providers. Due to these different emphases, a focus of this review lies on methodological aspects related to the conduct of MCDA rather than comparing the results. In addition, different attribute sets and different definitions of statistical significance in the included studies made an overall comparison of preferences only possible to a limited extent. However, an overarching theme which attained high preference values was delivery of care by the same person (Chester et al. 2017; Chester et al. 2018; Jasper et al. 2018; Kampanellou et al. 2019; Nieboer et al. 2010; Walsh et al. 2020). In addition, studies report preferences for high levels of staff qualification regarding dementia (Chester et al. 2017; Chester et al. 2018; Groenewoud et al. 2015), good interpersonal treatment (Groenewoud et al. 2015), and support with personal feelings and concerns (Chester et al. 2018). This accentuation of the relationship between caregivers and care recipients and staff-related attributes in the MCDA's responses is also part of a new understanding of care for persons with dementia which has developed in recent years. A paradigm shift occurred from care that merely focused on safety, uniformity, and medical issues to person-centered care, which places the person with dementia in the center of the care setting (Brooker 2003). The move away from an institutional model of care toward person-centered care impacts aged-care services around the world (Brownie and Nancarrow 2013). The foundation of

this change is a focus on the importance of the relationship between care recipient and caregiver (White-Chu et al. 2009). Frequently mentioned features of person-centered care incorporate social stimulation and satisfying relationships, assignment of residents to specific care workers, inclusion of residents and staff in decision-making, staff empowerment and an individualized philosophy of care, and an improvement of the environment (Stranz and Sörensdotter 2016). Other attributes which attained high levels, such as opportunities for social and recreational activities (Chester et al. 2018), high flexibility of care provision and personalized care (Walsh et al. 2020), feeling safe and comfortable (Groenewoud et al. 2015) and having an own room (Sawamura et al. 2015) also integrate well into this concept. As noted, the heterogeneity of the studies precludes from drawing further common conclusions. Nevertheless, these similarities between the literature and the results of the included studies may give an indication of a certain degree of validity of the results of the included studies. In published DCEs conducted on health topics, validity testing widely focuses on an assessment of the internal validity. This is frequently done by checking if signs of estimated parameters are as expected and if choices are rational, which may then lead to the exclusion of individuals with irrational choices (Lancsar and Louviere 2008). However, although rationality of participants' choice behavior is frequently assessed with the help of dominance tests, there is currently no consensus on how to consider the results in analysis and interpretation of DCE data (Schmidt-Ott et al. 2017). Of the nine DCEs included in this review, three performed a dominance test (Ryan et al. 2006; Teahan et al. 2021; Walsh et al. 2020) and in one of these studies, inconsistent participants were dropped from the analysis (Ryan et al. 2006). In the other two studies, no significant differences were found when estimating the conditional logit model with and without irrational respondents, and thus all participants were retained (Teahan et al. 2021; Walsh et al. 2020). In another study, a ranking exercise was included to check respondents' understanding of the attributes which were also contained in the DCE (Jasper et al. 2018). Finally, Groenewoud et al. (2015) justified the omission of a consistency test with the fact that not all attributes in their DCE had a logical preference ordering.

In contrast, external validity examines the extent to which the preferences obtained in a DCE reflect actual choices made in reality. While some methodological elaborations on external validity have been published (Lancsar and Swait 2014; Ryan and Gerard 2003), only few empirical works address this issue. It should be noted that Quaife et al. (2018) conducted a meta-analysis of six DCE studies in which predictions were compared to choices in reality, resulting in pooled sensitivity and specificity estimates of 88% [95% confidence interval (CI) 81, 92%)] and 34% (95% CI 23, 46%) respectively. The authors conclude that DCEs can produce moderately, but not exceptionally, accurate predictions of health-related decisions.

The validity of results is likely also influenced by the group of persons being surveyed. In the ten included studies, surveys were directed at different groups, including the general population, caregivers of persons with dementia, hospital inpatients, and practitioners. Persons with dementia were included as participants in only two studies (Chester et al. 2018; Groenewoud et al. 2015). This observation correlates with findings from Engelsma et al. (2020), who found that only a minority of DCEs dealing with care decisions included cognitively impaired persons. In the study by Nieboer et al. (2010), the decision to opt for proxy elicitation is justified by stating that (i) care decisions are often taken by family members, and (ii) patients may have problems with imaging future scenarios due to the current care they receive. Studies indicate that preferences of persons living with dementia could differ from proxies' preferences (Neumann et al. 2000; Smebye et al. 2012). A study by Feinberg & Whitlatch suggests that care preferences of persons with dementia and their caregivers are broadly congruent. However, persons with dementia discussed daily care preferences with their caring relatives more often than their preferences about long-term care in a nursing home and consequently, the perceptions of the two groups might not necessarily be congruent (Feinberg and Whitlatch 2002). Similar challenges have been discussed in the measurement of quality of life in persons with dementia (Kelly et al. 2021).

This review has some limitations. First, due to the fact that many different MCDA methods exist in a fragmented field (Marsh et al. 2017a), it cannot be ruled out that some MCDA methods have not been covered by the search. However, a sensitive search strategy was developed to provide good coverage of the relevant literature. In addition, the combination of EMBASE, PubMed, Web of Science, and Google Scholar has been found to be feasible to achieve adequate and efficient coverage in literature reviews (Bramer et al. 2017). Some publications have been dismissed due to the non-inclusion of studies which focus on specific aspects of care (e.g., digital life story work) and studies presenting fixed care options (e.g., choice between home, residential home, nursing home). Further, the fact that many publications were conducted by the same institutions and/or partially by the same individuals restricts the generalizability of findings. As outcome measures between studies are different, no overarching conclusions can be derived. Finally, limitations arise due to the language restriction to English and German. Thus, it cannot be ruled out that a different specification of these criteria would have led to the inclusion of other studies.

Conclusions

The studies included in this review show that MCDAs are feasible to elicit preferences relevant to living and care concepts of persons with dementia. Survey respondents included the

general population, caregivers of persons with dementia, hospital inpatients, and practitioners. Persons with dementia were surveyed In only two studies. The expressed preferences may help to support policy decisions and ultimately achieve efficient resource allocation in the respective contexts. However, further research is needed with regards to innovative living and care arrangements for persons with dementia. For example, recent public research data from Germany indicate that a great desire exists to live in assisted residential groups for the elderly, especially for persons with dementia. However, this accommodation option is not widely used and therefore, further studies are needed to determine how to address the needs of interested persons (Haumann 2020). These studies should take into account the heterogeneity and diversity of persons with dementia, e.g., with regard to disease severity and cultural background. Considering the predicted challenges that dementia care will face in the future, the preferences expressed in these studies may help to inform the design of innovative concepts which are a valuable alternative to existing care options.

Declarations

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Consent to participate Not applicable.

Consent for publication Not applicable.

Competing interests None.

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