Patient Education and Counseling 137 (2025) 108815

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.journals.elsevier.com/patient-education-and-counseling

Determinants of shared decision-making between people with dementia and informal caregivers: A systematic review

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ARTICLE INFO

Keywords:
Shared decision-making
People with dementia
Informal caregivers
Determinants
Interpersonal factors
Care arrangement decision-making

ABSTRACT

Objectives: Shared decision-making (SDM) between people with dementia and their caregivers is essential for home care arrangements. However, systematic understanding of influencing factors remains limited. This study aimed to identify modifiable determinants of shared decision-making and explore underlying theoretical mechanisms.

Methods: A comprehensive search across seven databases yielded fourteen studies, extracted using Covidence, including study design, decision topics, determinants, primary outcome, and theoretical frameworks. Quality assessment was based on the Critical Appraisal Skills Programme Qualitative Checklists and Cohort Study Checklists.

Results: Results showed that twelve studies used qualitative or mixed methods, with determinants primarily focusing on individual factors (e.g., PwD symptoms, caregiver burden), while interpersonal, community, and societal levels were overlooked. Care arrangement decisions were underexplored, and research lacked robust theoretical foundations.

Conclusions: Current research focuses predominantly on individual-level factors while paying less attention to modifiable determinants from broader levels. The insufficient attention to care arrangement decisions and theoretical frameworks calls for a more comprehensive approach.

Practice implications: Using Social Ecological Model, SDM interventions should simultaneously address individual needs, prioritize modifiable interpersonal factors, and incorporate broader environmental determinants to create comprehensive support systems on dementia caregiving.

1. Introduction

An estimated 152.8 million people will be living with dementia by 2050 worldwide [1]. Currently, 80 % of people with dementia receive family caregiving [2]. Regarding home care, people with dementia (PwD) and caregivers need to decide on many issues, such as everyday care, medical treatment, long-term care arrangements, financial affairs, and end-of-life care planning [3–5]. Therefore, decision-making often happens between PwD and caregivers outside of the clinical environment [6–8]. As people with dementia gradually lose the capacity to make autonomous decisions regarding their health care and treatment, their friends and family caregivers, who are familiar with their wishes and preferences, often play a crucial role in decision-making on their behalf. However, proxy decision-making is challenging, distressing, and lacking caregiver support [9]. Shared decision-making is needed to empower PwD and support caregivers when making decisions.

The principle of shared decision-making was first presented in 1982 [10]; further explained as making decisions for a patient at a health crossroads [11]; and finally defined as an approach by which clinicians and patients shared the best available evidence, and patients are supported in considering options and achieving informed preferences [12, 13]. Our study extends the shared decision-making for people with dementia to PwD and caregivers, as many critical decisions about daily care and living arrangements often occur outside the clinical settings and rely heavily on the interactions between PwD and informal caregivers. During this shared decision-making process, all actors exchange information, become aware of the options and their benefits and risks, employ their decision criteria actively and equally, clarify their

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https://doi.org/10.1016/j.pec.2025.108815
Received 7 October 2024; Received in revised form 9 April 2025; Accepted 30 April 2025

expectations for one another, and reach a shared decision [14]. As one of the important components of person-centered care, shared decision-making emphasizes PwDs' involvement in making decisions regarding their care and treatment [15]. Shared decision-making can improve PwDs' health-related quality of life [16], reduce decision conflict [17], improve caregivers' quality of life, and reduce depression among caregivers [18,19].

Given the paramount significance of shared decision-making in the context of PwD and informal caregivers, it is imperative to understand this process comprehensively. Several reviews have examined different aspects of shared decision-making in the context of dementia. Specifically, some reviews investigated expectations and the degree of shared decision-making [20–22], commonly addressed topics [7], tools and resources used to facilitate decisions [7,21], and effectiveness of interventions designed to enhance shared decision-making in the provision of health care for people with dementia [23]. However, reviews on determinants of shared decision-making in the context of dementia have been limited in providing a comprehensive understanding of the subject. Although some reviews have highlighted how certain caregiver characteristics, such as educational attainment, living area, nationality [20], and caregiving burden [4], and PwD factors like cognitive function and quality of life are associated with shared decision-making by people with dementia and caregivers [4], these factors are largely unmodifiable and pertain to personal characteristics. As a result, they provide limited guidance for intervention designers seeking to enhance and promote shared decision-making between PwD and caregivers.

More importantly, current reviews reveal several gaps in factors, theory, and assessment aspects. They only provided a general description of the topic with limited exploration of modifiable affecting factors at different levels. Furthermore, comprehensive reviews on the theoretical foundations influencing shared decision-making are also scarce, resulting in a superficial understanding of these determinants without a theoretical basis. Theoretical frameworks are essential for guiding research and developing targeted interventions, yet they remain underdeveloped in this field. Additionally, there is an absence of quality assessment in the existing reviews, highlighting the need for more rigorous methodologies to ensure the scientific validity of findings. As a result, influences on shared decision-making and future directions for research in this area remain unclear. Given these limitations of prior reviews and guidance by the P (Population) I (Intervention) C (Comparison) O (Outcome) clinical evidence-based framework [24], this study aimed to summarize the determinants, particularly modifiable factors, of shared decision-making between people with dementia and informal caregivers and elucidate the theoretical underpinnings that shape their influence.

2. Methods

This systematic review was conducted based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines and registered on PROSPERO: CRD42024524702.

2.1. Inclusion and exclusion criteria

Studies were included based on the following criteria: (a) people with dementia aged 60 years old or older; (b) people with dementia living in the community; (c) informal caregivers aged 18 years old or older; (d) focus on the shared decision-making between people with dementia and informal caregiver; (e) peer-reviewed; and (f) available in written English. Conversely, studies were excluded if they met any of the following criteria: (a) shared decision-making did not occur between the people with dementia and caregiver but rather, for example, between nurses or health professionals and people with dementia; (b) study did not involve people with dementia; (c) people with advanced dementia; (d) proxy decision-making occurred instead of shared decision-making; (e) determinants of shared decision-making were not mentioned; (f) not published in a journal; or (g) full-text article was not available.

2.2. Search strategy

A comprehensive and systematic search was conducted across multiple prominent electronic databases, including Scopus, Web of Science, PubMed, Embase, MEDLINE, PsycInfo, and CINAHL. The search was conducted by H.L., who meticulously examined titles, abstracts, and keywords of journal articles published before November 16, 2023, and checked by V.L. and T.M. The search was limited to articles published in English. The search strategies and queries employed are outlined in Table 1. To ensure the robustness and thoroughness of the search strategy, a social science librarian with the affiliated university contributed to the enrichment of the strategy. During the data extraction process, H.L. and T.M. independently screened the retrieved articles for eligibility based on predefined inclusion and exclusion criteria. Any discrepancies or disagreements between the researchers regarding selection were resolved through discussion and consensus. In cases where consensus could not be reached, a third reviewer (V. L.) was consulted to make the final decision. This approach ensured the reliability and consistency of the study selection process.

2.3. Study selection

This review process was facilitated using the web-based literature review tool Covidence (https://www.covidence.org). Following the identification of relevant articles and removal of duplicates, two reviewers (H.L. and T.M.) collaboratively screened the titles, abstracts, and full-text articles. A third researcher (V.L.) was consulted to make decisions if any uncertainty occurred during the process.

2.4. Data extraction

For each article, the reviewer extracted and synthesized the following components, which were stored and organized in Microsoft Excel: (a) author, publication year, and study country; (b) research type and study design; (c) participants; (d) disease stage; (e) decision topics; (f) determinants and level; (g) primary outcome; and (h) theoretical framework or perspective.

2.5. Quality assessment

Quality assessment was based on the Critical Appraisal Skills Programme Qualitative Checklists for included qualitative studies and Cohort Study Checklists for quantitative studies [25,26]. No records

Table 1
General search strategies and queries in the database.

General queries	Boolean operators
decision OR decision-making OR "shared decision-making" OR "decide together" OR "joint decision-making" OR "interactive decision-making" OR "collaborative decision-making" OR "consensus decision-making" OR "inclusive decision-making" OR "patient-engage* decision-making"	AND
caregiver* OR carer* OR "family caregiver* " OR "family carer* " OR "informal caregiver* " OR "informal carer* " OR "spouse caregiver* " OR "spouse carer* " OR "family member* " OR "non-professional care* " OR "unpaid care* " OR "adult children" OR "adult grandchildren"	AND
dementia OR "Alzheimer's Disease" OR "Lewy body dementia" OR "Frontotemporal dementia" OR "Vascular dementia" OR "cognitive impairment" OR "cognitive decline" OR "memory problem" OR "memory disturbance" OR "cognitive disturbance"	AND
factor* OR influenc* OR contribut* OR element OR variable OR affect*	AND NOT
"review" OR "systematic review" OR "meta analysis" OR meta-analysis OR "narrative review"	

were excluded based on this quality assessment to present the evidence in context.

3. Results

3.1. Search results

Fig. 1 provides an overview of the review process. The initial search across seven electronic databases resulted in 2189 articles. After removing 1038 duplicates, the titles and abstracts of the remaining articles were screened. Following this, the full-text articles were reviewed; ultimately, 14 articles met the inclusion criteria for this systematic review.

Detailed information on the included studies is provided in Appendix A. The sample sizes of these studies varied, ranging from eight to 2364 individuals. The publication years of the included studies spanned 2004–2023. Eight studies employed qualitative methodologies [3, 27–33], three studies adopted mixed-methods approaches [34–36], and the remaining three studies used quantitative methods [37–39].

3.2. Characteristics of included studies

The extracted data are shown in Table 2. Regarding the type of participants, three studies focused on spousal caregivers and PwD [3,29, 30], without separately exploring factors influencing shared decision-making for adult child caregivers and PwD. In terms of the PwD ’s disease course, six articles examined people with mild to moderate dementia [27,30,31,34,35,39]. One article focused on people with mild dementia [37], another included only people with moderate dementia [32], one study involved people with early stage to advanced dementia [3], one study involved people with mild cognitive impairment and dementia [33], and four studies did not provide details on the disease course [28,29,36,38].

Shared decision-making topics between PwD and caregivers primarily involved health care and daily life. Several studies examined these themes simultaneously, indicating their interconnectedness and relevance to the decision-making process. Nine articles delved into health care decisions [28–30,32–37]. Additionally, five studies explored everyday decision-making [30–32,38,39]. Notably, two articles addressed financial decisions [3,30] and one article focused on housing transition decisions [27].

3.3. Quality assessment results

Five of the eleven qualitative studies (eight qualitative studies and the qualitative parts of three mixed-methods studies) demonstrated high quality. Only these five studies met the criterion of examining the researcher’s role in formulating research questions and responsiveness to events during the study. They mentioned researcher bias when collecting [29,30] and interpreting the interview transcripts [33]; achieving data saturation [27]; and if a participant felt confused or disoriented during the interview, how the researcher would respond [31].

Fewer quantitative studies were found, and only two of six demonstrated high quality. In mixed-methods studies, the quantitative research component merely supplemented the qualitative study without incorporating regression analysis or follow-up studies [36]. Many studies had small sample sizes, which restricted generalizability. For instance, one study had a sample of 48 dyads [34] and another included 31 dyads [35]. Although one study included 215 dyads, it was a cross-sectional study, preventing the establishment of causal relationships regarding the focal issue [38]. Three of these six studies had follow-up periods, with one study achieving a 100 % follow-up rate with 77 dyads for the

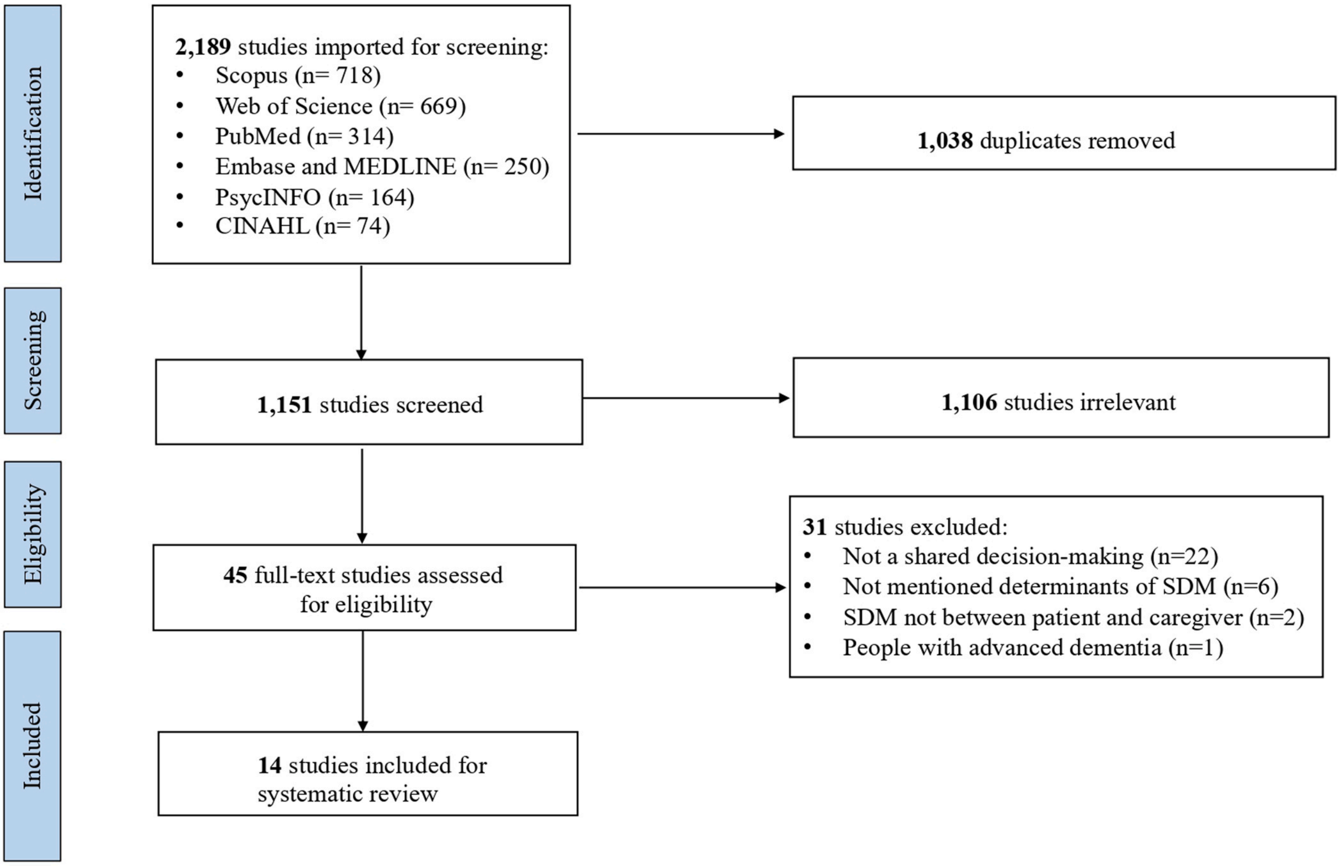

Fig. 1. Flow diagram of search.

Table 2
Data extraction.

Study, country	Research type (study design)	Participants	Disease stage	Decision topics	Determinants	Primary outcome	Theoretical framework or perspective
Sinclair et al., 2019, Australia	Qualitative (semistructured interviews)	25 patients; 32 family members	Mild or moderate dementia	Health care, lifestyle, financial, everyday decision-making	Individual: time for making decisions, financial constraints Community: specific cultural beliefs, community expectations	Patient involvement	Relational autonomy perspective: individual autonomy can evolve and find expression through enduring, intimate relationships that involve mutual recognition
McWilliams et al., 2018, UK	Qualitative (semistructured interviews)	10 patients, 9 caregivers; 12 health care professionals	No details	Cancer treatment decision-making	Individual: functional level (communication ability) of patients	Patient involvement	No theory
Menne & Whitlatch, 2007, USA	Quantitative (survey)	215 patient–family caregiver dyads	No details	Everyday decision-making	Individual: patients' age, gender, educational attainment,; caregiver type; diagnosis time; activities of daily living; depressive symptoms; level of autonomy and self-identity	Patient involvement	No theory
Hirschman et al., 2005, USA	Mixed methods (semistructured interviews and survey)	48 patient–caregiver dyads	Mild to moderate Alzheimer's disease	Alzheimer's disease treatment decision-making	Individual: patient dementia severity, patient insight into prognosis and diagnosis, patient capacity to make a decision, gender, caregivers' view on patients' capacity to make a decision	Patient involvement	No theory
Horton-Deutsch et al., 2007, USA	Mixed methods (survey and semistructured interviews)	31 patient–caregiver dyads	Mild to moderate dementia	Health care decision-making	Individual: patients' symptoms, resources, function, trust in health care, normality, safety, activity, maintenance of identity Interpersonal: reliance on family	Patient involvement	Maslow's hierarchy of needs: physiological (activity, function), safety (resources, reliance on family, trust in health care), love and belonging (reliance on family, function), self-esteem (function, normality, identity)
Sinclair et al., 2018, Australia	Qualitative (semistructured interviews)	13 patients, 15 spousal caregivers	Mild to moderate	Healthcare, lifestyle, financial, everyday decision-making	Individual: patient (stage of dementia, self-efficacy, preference to have control or delegate) and spouse (stress and burden, beliefs and attitudes about dementia, caregiving and communication skills), type of decision, importance to patients, complexity, risk, time available Interpersonal: relationship quality, trust and familiarity, relational history of decision-making, relational values system), influence of family members Societal: interactions with professional, institutional processes, access to services, social networks, information	Patient and caregiver involvement	No theory
Smebye et al., 2012, Norway	Qualitative stud (multicase; semistructured interview)	10 patients, 10 family caregivers, 10 health care professionals	Moderate dementia	Health and daily care decision-making	Individual: mental capacity, available choices, opportunity to participate, personal values, relationships	Patient involvement	Thompson's model of patient involvement in decision-making: noninvolvement, information seeking or

(continued on next page)

Table 2 (*continued*)

Study, country	Research type (study design)	Participants	Disease stage	Decision topics	Determinants	Primary outcome	Theoretical framework or perspective
							receptive, information dialogue incorporating exchange of information, shared decision making, autonomous decision making
Hirschman et al., 2004, USA	Quantitative (survey)	77 patient–caregiver dyads	Mild dementia	Medical decision-making	Individual: patients' age, caregiver burden, patients' dementia severity	Patient involvement	No theory
Barry et al., 2021, Northern Ireland	Mixed methods (survey and semistructured interviews)	18 patients, 15 caregivers	No details	Medicine management	Individual: importance of caregivers, patients' beliefs about medicine Interpersonal: relationship between patients and health care professionals	Patient involvement	Theoretical domains framework: 14 theoretical domains they may act as barriers or facilitators to an individual's behavior—knowledge; skills; memory, attention, and decision process; behavioral regulation; social or professional role and identity; beliefs about capabilities; optimism; beliefs about consequences; intentions; goals; reinforcement; emotion; environmental context and resources; social influences
Sabatini et al., 2023, UK	Quantitative (survey)	1182 patient–caregiver dyads	Mild to moderate	Everyday decision-making	Individual: patients (cognitive capacity, functional difficulties, neuropsychiatric symptoms), caregiver stress Interpersonal: relationship quality	Patient involvement	No theory
Garvelink et al., 2019, Netherlands	Qualitative (multicase)	4 patients, 4 caregivers	Mild to moderate	Housing transition decision-making	Individual: Personal characteristics, work history, living arrangement Interpersonal: family relations	Patient involvement	Interprofessional shared decision-making model: explanation of decision to be made; information exchange; eliciting values and preferences; discussing feasibility of options; preferred choice versus decision made; planning and implementing decisions; outcomes
Boyle, 2013, UK	Qualitative (participant observation and interviews)	21 patient–spousal caregiver dyads	Early stage to advanced dementia	Financial management decision-making	Individual: gender control (male wants more control in financial decision-making), gender dynamics adopted earlier in marriage	Patient involvement	No theory
Taylor et al., 2023, USA	Qualitative (semistructured interviews)	24 patients, 37 caregivers	Mild cognitive impairment and dementia	Health care decision-making	Individual: cognitive function (disease brings unknowns and uncertainty), participant values (maintain current life status) Societal: environmental realities (prefer living at home), social structures (resource constraints on availability of informal caregivers, ability to pay for formal caregivers, access to affordable care facilities)	Patient and caregiver involvement	No theory
Meyer et al., 2016, Australia	Qualitative (semistructured interviews)	25 patient–spousal caregiver dyads	No details	Health care decision-making (fall prevention strategies)	Individual: knowledge of certain decision, resources, value	Patient and caregiver involvement	No theory

first two follow-ups [37] and another achieving a 80.20 % rate at 12-month follow-up and a 59.81 % rate at 24-month follow-up with 1182 dyads [39]; the follow-up rate for 20 dyads was not reported in the other study [35]. Therefore, only one quantitative study demonstrated high quality, encompassing 1182 PwDs and caregivers followed for 2 years. However, one of the findings contradicted the qualitative studies, suggesting that PwD-perceived relationship quality was not associated with caregiver-perceived PwD involvement in everyday decision-making [39]. This highlights the importance of collecting both PwD and caregiver perspectives on shared decision-making. The details of the quality assessment can be seen in Table 3 and Table 4.

3.4. Determinants of shared decision-making

In this study, we defined “determinants” as factors that influence or shape shared decision-making behavior, based on their association with shared decision-making outcomes in the literature. These factors were identified through a systematic synthesis of both quantitative and qualitative evidence, which explored their roles in facilitating or hindering shared decision-making. Guided by the Social-Ecological Model (SEM) [40], determinants of PwD’s and caregivers’ shared decision-making behavior were summarized into individual, interpersonal, community, and societal levels, which can be seen in Table 5. These studies explored determinants primarily at the individual level of PwD and caregivers. Specifically, regarding PwD, key factors included demographic factors (age, gender, and educational attainment) [3,34]; disease-related factors (cognitive function, dementia severity, and diagnosis time) [37,39]; functional ability (activities of daily living and communication ability) [28]; neuropsychiatric symptoms (depression and stress) [38,39]; ability to make decisions (autonomy and self-identity) [34,35,38]; and financial status [31]. As for caregivers, caregiver type (spousal or nonspousal), mental health status (caregiving burden and stress), beliefs and attitudes about dementia, and skills in caregiving and communication all contributed to the involvement of both PwD and caregiver in the shared decision-making process [30,37–39].

Decision-related factors, such as time for making decisions, opportunities to participate in decision-making, available choices, and the importance of decisions, also led to different degrees of involvement in shared decision-making [31,32]. At the interpersonal level, studies mainly used qualitative or mixed methods to explore the relationship between PwD and caregiver, including relationship quality and history of decision-making [27,30,35,36].

Only one study examined cultural beliefs and community expectations, representing a community-level factor [31]. Additionally, determinants at the societal level included social networks (interactions with professional social networks), environmental realities (living arrangements), and social structures (resources and accessibility of caregiving) [33].

3.5. Measurements of determinants at the interpersonal level

Many factors at the individual level, such as diagnosis time, disease severity, and functional ability, are unmodifiable, and studies focusing on the community and societal levels have been limited due to the intricate context and inability to effect short-term modifications. Consequently, considering the decision-making process that occurs between individuals and the need to guide future research toward factors that can be improved in a feasible way, this study comprehensively reviewed how the included studies measured interpersonal factors.

Quantitatively, only one study measured interpersonal factors, employing a modified version of the Positive Affect Index to assess relationship quality as perceived by PwDs and caregivers—focusing on communication quality, closeness, similarity of views on life, engagement in joint activities, and overall relationship quality[39].

Additionally, most qualitative studies collected interpersonal determinants of shared decision-making by combining observation and open-ended interviews. Specifically, these interview guidelines started with certain decisions, PwD and caregiver experiences, discussion, participants’ involvement, and facilitators and barriers in making certain decisions. Thus, affecting factors, such as family relationships, trustiness, relational history, and reliance on family, emerged naturally during interviews [27,30,32,35].

3.6. Theoretical frameworks of included studies

Theoretically guided research on shared decision-making among people with dementia and family caregivers is lacking. Only six of the included studies described a theoretical framework. Among them, four studies explained the mechanism of influence from an individual or interpersonal perspective. One used Maslow’s hierarchy of needs theory [35] to elucidate family treatment choices in a human needs-based model, one used the stress process model to explore predictors of decision-making involvement among PwDs [38], one used the theoretical domains framework to identify facilitators and barriers related to medicine management decision-making [36], and one employed the

Table 3
Quality assessment of qualitative studies.

	1	2	3	4	5	6	7	8	9	10	Total
Sinclair et al., 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
McWilliams et al., 2018	Yes	Yes	Yes	Yes	Yes	Unknown	Yes	Yes	Yes	Yes	9
Menne & Whitlatch, 2007	/	/	/	/	/	/	/	/	/	/	/
Hirschman et al., 2005	Yes	Yes	Unknown	Yes	Yes	Unknown	Yes	Yes	Yes	Yes	8
Horton-Deutsch et al., 2007	Yes	Yes	Yes	Yes	Yes	Unknown	Yes	Yes	Yes	Yes	9
Sinclair et al., 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Smebye et al., 2012	Yes	Yes	Yes	Yes	Yes	Unknown	Yes	Yes	Yes	Yes	9
Hirschman et al., 2004	/	/	/	/	/	/	/	/	/	/	/
Barry et al., 2021	Yes	Yes	Yes	Yes	Yes	Unknown	Yes	Yes	Yes	Yes	9
Sabatini et al., 2023	/	/	/	/	/	/	/	/	/	/	/
Garvelink et al., 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Boyle, 2013	Yes	Yes	Yes	Yes	Yes	Unknown	Yes	Yes	Yes	Yes	9
Taylor et al., 2023	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Meyer et al., 2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9

The assessment criteria were as follows: 1. Was there a clear statement of the aims of the research? 2. Is a qualitative methodology appropriate? 3. Was the research design appropriate to address the aims of the research? 4. Was the recruitment strategy appropriate to the aims of the research? 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between researcher and participants been adequately considered? 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. How valuable is the research? (Critical Sills Appraisal Programme 2018b). “Yes” signifies that this study follows this criteria, “Unknown” means this information is not provided in the study, and “No” indicates this study does not follow this criteria.

Table 4
Quality assessment of quantitative studies.

	1	2	3	4	5	6	7	8	9	10	11	12	Total
Sinclair et al., 2019	/	/	/	/	/	/	/	/	/	/	/	/	/
McWilliams et al., 2018	/	/	/	/	/	/	/	/	/	/	/	/	/
Menne & Whitlatch, 2007	Yes	Yes	Yes	Yes	Yes	Yes	Unknown	Unknown	Yes	Yes	Yes	Yes	10
Hirschman et al., 2005	Yes	Yes	Yes	Yes	Yes	Yes	Unknown	Unknown	Yes	Yes	Yes	Unknown	9
Horton-Deutsch et al., 2007	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unknown	11
Sinclair et al., 2018	/	/	/	/	/	/	/	/	/	/	/	/	/
Smebye et al., 2012	/	/	/	/	/	/	/	/	/	/	/	/	/
Hirschman et al., 2004	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unknown	11
Barry et al., 2021	Yes	Yes	Yes	Yes	Yes	Yes	Unknown	Unknown	Yes	Yes	Yes	Unknown	9
Sabatini et al., 2023	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	12
Garvelink et al., 2019	/	/	/	/	/	/	/	/	/	/	/	/	/
Boyle, 2013	/	/	/	/	/	/	/	/	/	/	/	/	/
Taylor et al., 2023	/	/	/	/	/	/	/	/	/	/	/	/	/
Meyer et al., 2016	/	/	/	/	/	/	/	/	/	/	/	/	/

The assessment criteria were as follows: 1. Did the study address a clearly focused issue? 2. Was the cohort recruited in an acceptable way? 3. Was the exposure accurately measured to minimize bias? 4. Was the outcome accurately measured to minimize bias? 5. (a) Have the authors identified all-important confounding factors? 5. (b) Have they taken account of the confounding factors in the design and/or analysis? 6. (a) Was the follow-up of subjects complete enough? 6. (b) Was the follow-up of subjects long enough? 7. What are the results of this study? 8. How precise are the results? 9. Do you believe the results? 10. Can the results be applied to the local population? 12. What are the implications of this study for practice? (Critical Sills Appraisal Programme 2018a). "Yes" signifies that this study follows this criteria, "Unknown" means this information is not provided in the study, and "No" indicates this study does not follow this criteria.

Table 5
Determinants of shared decision-making.

Level	Variable
Individual factors	
Patient	Demographics (age, gender, education)
	Cognitive function, dementia severity, diagnosis time
	Functional ability (communication ability; activities of daily living)
	Neuropsychiatric symptoms (depression, stress)
	Ability to make decision (autonomy and self-identity)
	Financial status
Caregiver	Caregiving burden
	Caregiving stress
	Type (spouse or other)
	Beliefs and attitudes about dementia
	Caregiving and communication skills
Decision characteristics	Time for making decisions
	Opportunity to participate in decision-making
	Available choices
	Importance of the decision
Interpersonal factors	
Relationship	Relationship quality
	Relational history of decision-making
	Trust in their caregiver
Community factors	
	Specific cultural beliefs and community expectations
Societal factors	
Social networks	Interactions with professional
	Social networks
Environmental realities	Preference on living arrangement
Social structures	Resources constrains on availability of informal caregivers
	The ability to pay for formal caregivers
	Access to affordable care facilities

relational autonomy perspective to explore the development and expression of individual autonomy in relationships [31].

The remaining two studies focused on theories related to the decision-making process. One study adopted Thompson's model, which delineates five levels of PwD involvement in decision-making, ranging from noninvolvement to autonomous decision-making [32]. The other study used the interprofessional shared decision-making model (IP-SDM), which encompasses the shared decision-making process from the initiation of the decision to the post-decision-making phase [27].

While many existing theories focus on the individual level, frameworks like relational autonomy and interprofessional shared decision-making models demonstrate the potential for more ecologically comprehensive approaches from interpersonal and environmental levels. Future theoretical development should bridge these levels to better explain shared decision-making processes between PwD and caregiver. Moreover, although some theories offer generalizations about decision-making levels and processes, none of them sufficiently captures the specific and in-depth influences that shape shared decision-making behaviors or the PwD's involvement, especially at the interpersonal level.

4. Discussion and conclusion

4.1. Discussion

To the best of our knowledge, this study represents the first systematic review comprehensively synthesizing the determinants and theoretical framework of shared decision-making in the context of people with dementia and their informal caregivers. We broaden the shared decision-making context to include PwD and caregiver dynamics and encourage the integration of diverse actors in the decision-making process. Notably, this review highlighted the pivotal role of interpersonal factors in shaping shared decision-making between people with dementia and their informal caregivers, especially how the quality of the PwD-caregiver relationship contributes to their involvement in the decision-making process.

During this systematic review, we found that PwD perceptions of shared decision-making are still neglected in the study design, with researchers mainly relying on the caregivers' reports. Despite the belief in person-centered care—that people with early-stage dementia still have the capacity to make rational decisions on their own or with the support of a family caregiver [4,41]—PwD's viewpoint continues to be ignored when it comes to decision-making [42–44]. To be specific, five out of the fourteen studies primarily relied on caregivers to provide information about shared decision-making, rather than directly capturing the perspectives of PwD or ensuring adequate PwD engagement in the research process [3,28,32,37,39]. Although the remaining nine studies collected dyadic perspectives, they acknowledged limitations such as small sample sizes and challenges in generalizing their findings [27,29–31,33–36,38]. This creates a gap in the current evidence by excluding the perceptions of PwDs and overlooking their inclusion in shared decision-making studies. Therefore, this study underscores the significance of including PwDs not only in the decision-making process but also as active participants in research. By incorporating the perspectives of PwDs, a more comprehensive understanding of their involvement in decision-making can be attained, leading to more robust and person-centered research outcomes.

As for determinants of shared decision-making, prior studies mostly focused on individual factors. Some modifiable individual factors, including PwD's depression and autonomy, caregivers' mental health, beliefs, and communication skills, remain vital SDM determinants despite the field's predominant individual-level focus. These should be retained as intervention components while developing more comprehensive approaches. Notably, few studies have examined the interpersonal, community, and societal dimensions of shared decision-making. Given the complex context and challenges associated with modifying community and societal factors in a limited timeframe, it is crucial to consider the inherent nature of shared decision-making as an interpersonal process [45]. Thus, exploring determinants on an interpersonal level between people with dementia and caregivers that are modifiable and feasible represents a more suitable approach for guiding future interventions to enhance their shared decision-making.

Care arrangement decision-making, which determines living arrangements and assistance for health and functional activities [46], is often underemphasized in research on shared decision-making for people with dementia and their caregivers. While day-to-day care decisions, such as health care [30,31,35], everyday life [38,39], treatment [28,34], medication [36,37], and finances [3,30], also carry long-term implications, care arrangement decisions uniquely shape the overall care system, influencing all subsequent caregiving dynamics and resource allocation about where and how the people with dementia will live and receive care. These decisions have far-reaching and enduring impacts on both PwD and caregivers, as they shape the overall care environment and influence all subsequent decisions. For example, deciding whether to move a PwD to a nursing home or keep them at home with family support is a complex, often irreversible decision that requires input from multiple stakeholders and carries significant emotional, financial, and logistical implications. Only after making this care arrangement decision can PwDs and caregivers proceed to more detailed decisions regarding everyday care, medication, financial affairs, and other related matters. This underscores the unique importance of care arrangement decision-making and the need for increased attention in dementia research.

Regarding research methods, eight of the 14 included studies adopted a qualitative approach, three employed a mixed-methods design, and three used a quantitative methodology. This predominance of qualitative studies may result in a prevalence of experiential accounts and subjective interpretations from a specific population, thereby restricting the generalizability of findings due to sample size limitations [7]. Therefore, it is necessary to verify the determinants of shared decision-making with larger samples of PwDs and caregivers using a quantitative methodology.

In addition, this study identified a lack of robust theoretical foundations in the existing research. Only six studies were grounded in theoretical frameworks. One category of these frameworks pertained to individual behavior; the other category focused on decision-making research. Current applications of relational autonomy theory and interprofessional shared decision-making models (IP-SDM) provide partial insights but remain insufficient for comprehensively understanding shared decision-making in the dementia caregiving context. To advance this field, we identified several promising concepts and theoretical frameworks from other illness settings that could be adapted. For example, the "decision partner" [47] and "shared mind" [48] concepts both emphasized the collaborated decision-making between individuals and networks. Additionally, the Three talk model, through team talk, option talk, and decision talk, establishes an active listening and deliberated decision-making process [49]. From a triadic perspective, the triadic DM (TRIO Framework) encompasses a clinician-patient-family caregiver triangle in the cancer treatment decision-making, highlighting a dynamic decision-making process under the influence of the caregiver [50]. These concepts and theories collectively suggest that a robust theoretical foundation for dementia care arrangement decisions must integrate multiple actors and levels of ecological environment. Future research should focus on developing such an integrated framework that specifically addresses the unique challenges of progressive cognitive impairment while maintaining person-centered care.

This study has several limitations. To begin, the generalizability of our results may be limited because we only included studies in English. Because different databases have different starting points of data collection, we only collected those included in the searched databases; thus, research only available in hardcopy form were not included in this review. After accumulating additional quantitative evidence, it is necessary to conduct a meta-analysis to examine the effectiveness of determinants at different levels in the future.

5. Conclusion

In conclusion, despite growing attention toward shared decision-making in the context of people with dementia and their informal caregivers, prior research has several notable limitations. These limitations include a lack of PwD perspectives, insufficient exploration of interpersonal factors influencing shared decision-making behavior, neglect of care arrangement decision topics preceding day-to-day care decisions, challenges in generalizing findings due to limited quantitative evidence, and a dearth of theoretical foundations regarding the influencing mechanisms.

5.1. Practical implications

Given the limitations identified in this review, future studies should adopt a dyadic perspective, considering the viewpoints of both people with dementia and their caregivers in understanding the shared decision-making process. By doing so, we can gain a more comprehensive understanding of the determinants and dynamics involved. Additionally, it is crucial to further investigate modifiable factors at the interpersonal level, recognizing that shared decision-making is an interactive process. To gain a comprehensive understanding of the decision-making process and provide long-term solutions for PwD care arrangements, future studies should prioritize investigating care arrangement decisions before day-to-day decision-making. This approach could offer valuable insights into factors that shape subsequent choices and enable the development of effective interventions to support optimal care arrangements for people with dementia. These findings can contribute to the theoretical foundations of shared decision-making in dementia care and provide practical guidance for interventions by improving communication and shared decision-making between people with dementia and their caregivers, ultimately enhancing well-being and maximizing PwD independence.

Funding

This study was supported by the Univeristy Grants Committee Grants Council General Research Fund (No. 17611924) and The University of Hong Kong Seed Fund (No. 2302101712).

CRediT authorship contribution statement

Lou Vivian W. Q.: Writing – review & editing, Supervision, Project administration, Funding acquisition, Conceptualization. **Liu Huanran:** Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Mo Tianhong:** Data curation, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgment

Nil.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.pec.2025.108815.

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