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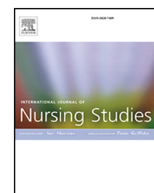
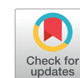


Supporting autonomy for people with dementia living in nursing homes: A rapid realist review



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A R T I C L E I N F O

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A B S T R A C T

Background: For people with dementia living in nursing homes, autonomy is important. However, they experience difficulty with being heard as an autonomous person, as well as with expressing their preferences and choices. The question is how to support their autonomy.
Objective: Despite extensive efforts to support autonomy in daily care for people with dementia living in nursing homes, we do not know exactly what works for whom, in which context, how and why. The objective of this realist review is to explore what is known in literature on autonomy support interventions for people with dementia in nursing homes.
Design: A rapid realist review of literature.
Review methods: To understand how autonomy is supported, a realist approach was applied that entailed identifying the research question, searching for information, performing a quality appraisal, extracting data, synthesizing the evidence and validating the findings with a panel of experts. Causal assumptions were derived from articles found in four bibliographic databases (PubMed, PsychInfo, Cochrane and CINAHL) leading to context (C)–mechanism (M)–outcome (O) configurations.
Results: Data extraction from the included articles ultimately resulted in sixteen CMO configurations on four themes: a. *preferences and choice*: interventions for supporting autonomy in nursing homes and their results, b. *personal characteristics of residents and family*: people with dementia and their family being individuals who have their own character, habits and behaviors, c. *competent nursing staff* each having their own level of knowledge, competence and need for support, and d. *interaction and relationships* in care situations: the persons involved are interrelated, continuously interacting in different triangles composed of residents, family members and nursing staff.
Conclusion: The findings showed that results from interventions on autonomy in daily-care situations are likely to be just as related not only with the characteristics and competences of the people involved, but also to how they interact. Autonomy support interventions appear to be successful when the right context factors are considered.

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What is already known

- The number of people with dementia around the world is sharply rising;
- Despite their need to feel autonomous, people with dementia have difficulty being heard as an autonomous person;
- Autonomy interventions have been found to be facilitating under specific circumstances because certain elements of interventions have been identified as factors that influence residents' autonomy.

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What this paper adds

- In this study, four themes were defined that describe the interventions to support autonomy in daily care for people with dementia in nursing homes: "preference and choice, personal characteristics of residents and family, competent nursing staff and interaction and relationships".
- Personal characteristics of the people involved significantly impact the results of the autonomy interventions.
- This realist review demonstrates that a realist approach is helpful for understanding nursing practice for supporting autonomy for people with dementia in nursing homes.

1. Background

Worldwide, 55 million people – or roughly 5% of the global population of older people – are affected by dementia; a figure that is predicted to rise to 75 million in 2030 and to 132 million by 2050. Recent reviews estimate that globally, nearly 9.9 million people develop dementia each year. Dementia is a degenerative disorder that, over time, causes significant cognitive decline that necessitates the need for assistance with life's daily activities. As the condition progresses, assistance is also required for decision-making which is usually done in consultation with surrogate decision-makers. This is especially true when people are no longer living at home, as they experience a progressive loss of choice and control (Huijsman et al., 2020).

Nursing-home care used to primarily focus on physical care and safety. Over the last decades however, this focus has shifted toward a more person-centered approach to care (Kitwood, 2019) together with a positive outlook on health (Huber, 2013). In the framework for person-centered care by McCormack et al. autonomy is associated with quality of life and a feeling of well-being. They state that people feel comfortable being who they are, when closely connected to others and respecting each other regardless of deficiencies. It has also been suggested that the need to feel autonomous increases when people experience difficulties in their independence (Fetherstonhaugh et al., 2016). In line with these developments, autonomy and its practical application have become important aspects in the care for older people.

Because of this focus on autonomy, the question has been raised as to how to adequately support the autonomy of people with dementia who are living in nursing homes. Van Loon et al. established that, for older people with *physical impairments* who are dependent on long-term care, facilitators and barriers to interventions for supporting autonomy are typically relational in nature and so are dynamic. The characteristics of caregivers as well as those of the institutional policies also impact the effect of autonomy interventions (Van Loon et al., 2019). Following this line, Boumans explores the influence of caregiving approaches when applying interventions to maintain the autonomy of people *with dementia* in long-term care. Staff members' behavior, attitudes and interactions with residents and informal caregivers appear to contribute toward the autonomy of people with dementia. Both studies, however, recommend conducting additional research to learn more about how interventions work and what makes them work (Van Loon et al., 2019; Boumans et al., 2019). According to the studies, to support the autonomy of people with dementia living in nursing homes, it is also important to improve the personal skills of the people involved. In various ways these skills were found to be a factor that influenced the outcome on residents' autonomy. It is not, however, precisely known how the various types of interventions relate and how personal interaction and competences are influential, for whom and why.

It is important to understand how these interventions – that may have various specific objectives such as attitude, competence, frequency of contact or flexibility in working processes – work in different contexts and to define how they may cohere to optimally support the autonomy of nursing-home residents. It has been established that interventions that work within a specific resident–family–nurse (triangle) relationship, do not necessarily work in another relationship (Martin and Younger, 2000). Personal characteristics and other contextual factors will impact the results of a specific action. In light of this, there is no such thing as a 'one-size-fits-all' intervention (Martin and Younger, 2000). We can state that certain interventions work under certain conditions and are influenced by the way people react to them.

The objective of this realist review is to explore what is known about autonomy interventions for people with dementia in nursing-homes in daily care: what works for whom, in which context, how and why.

2. Methods

2.1. Rapid realist review

We undertook a rapid realist review (Pawson et al., 2005). Theory was developed using research literature and by consulting experts. The rapid realist review has been developed as a research method that – in a briefer timespan than a realist review – enables blending knowledge development with daily practice, resulting in outcomes that can be applied to real-life situations.

According to Pawson et al. (2005), realist studies begin with, and are based on, initial hypotheses about how and why an intervention may or may not work, in which contexts and leading to particular outcomes. A hypothesis takes the shape of a CMO configuration. The underlying principles of realist approaches are the links between interventions, contexts (C), mechanisms (M) and outcomes (O). Realist reviews, therefore, have an explanatory focus and aim to uncover the mechanisms of complex interventions, with particular reference to contexts (see Box 1 for working definitions of key elements).

Our rapid realist review is consistent with Realist And Meta-narrative Evidence Synthesis (Rameses). This involves evolving standards and identifying the research question, searching for information, performing a quality appraisal, extracting data extraction, synthesizing evidence and validating findings with a panel of experts (Eidin et al., 2018).

2.2. The search strategy

We began our rapid realist review methodologically by entering mesh terms into four electronic databases (PubMed, PsychInfo,

Box 1
Definition of realist terms (Van Hees et al., 2021).

Intervention: an action taken to support autonomy of people with dementia living in nursing homes.
Context: context refers to 'something that enables or disables the current mechanism of interest to fire'. It often refers to the 'setting' of programs and research. As conditions change over time, the context may also reflect aspects of those changes while the program is being implemented.
Mechanisms: mechanisms are underlying entities, processes or structures that influence the outcome. This can refer to processes within the participant during an intervention or exposure, as well as his or her cognitive and emotional responses, but are typically related to the intervention or exposure being offered. But mechanisms can also refer to the context, such as the company in which the participant is working.
Outcome: an outcome is what can be measured in terms of impact across the target population, using measurable or measured indicators. Outcomes can be considered as quantitative or qualitative, intended or unintended.
CMO configuration: this concept describes the causal links between context, mechanisms and outcome that are considered as causative explanations pertaining to the evidence on the topic of interest.

PubMed

("Dementia"[Mesh] OR Dementia[tiab] OR Alzheimer*[tiab]) AND ("Long-Term Care"[Mesh] OR "Nursing Homes"[Mesh] OR "Residential Facilities"[Mesh] OR "Inpatients"[Mesh] OR Long term care[tiab] OR Nursing home*[tiab] OR Residential care[tiab] OR Residential facilit*[tiab] OR geriatric residents [tiab] OR care unit [tiab] OR care home [tiab] OR institutionalized [tiab] OR institu tional care [tiab] OR inpatients [tiab] OR inpatient care [tiab] OR institutionalization [tiab]) AND ("Personal Autonomy"[Mesh] OR "Relational Autonomy"[Mesh] OR "Self-Management"[Mesh] OR "Self Efficacy"[Mesh] OR "Self Care"[Mesh] OR "Patient Participation"[Mesh] OR "Empowerment"[Mesh] OR "Self-Control"[Mesh] OR "Decision Making, Shared"[Mesh] OR "Stakeholder Participation"[Mesh] OR Autonomy[tiab] OR self-management[tiab] OR self care[tiab] OR self medication[tiab] OR self-efficacy[tiab] OR self-help[tiab] OR self control[tiab] OR shared decision making[tiab] OR participation[tiab] OR patient involvement[tiab] OR patient engagement[tiab] OR empowerment[tiab] OR choice and control[tiab]) AND english[la]

Filters: **from 2011 – 2022**

Fig. 1. Search string

Cochrane and CINAHL). We employed forward and backward strategies to find all relevant literature. During our first search, we combined the mesh terms 'dementia', 'autonomy' and 'long-term care', including synonyms for each term. Fig. 1 shows the search string for the PubMed database. Similar search strings – adapted to the demands of the database – were used for PsychInfo, Cochrane and CINAHL. Additional search strategies included citation tracking, to identify relevant papers by citing earlier work and to check the citations within the papers identified. These searches were performed up to February 2022. Given that studies exploring the impact of autonomy support interventions for people with dementia in nursing homes are relatively new and our aim was to build on the more recent publications and their references, we restricted the articles to a 10-year period (Jan 2012–Feb 2022). Finally, we only searched for English-language studies.

2.3. Selection and appraisal

At the stage of identifying and selecting papers, the articles were screened to determine their relevance for answering our research question. In order to perform this process consistently, the research team (HvdW, ML, DG, KL) defined specific inclusion and exclusion criteria (Table 1). During a title–abstract screening, two reviewers (HvdW, ML) identified articles that had the right focus and could therefore contribute to our theory development. As part of this screening the research team searched for articles that could provide valuable insights and detail on processes, context and empirical findings. This was followed by a full-text screening of the remaining articles. The relevance of the included studies was once more carefully assessed against the inclusion and exclusion criteria (HvdW, ML). Articles were further selected based on their relevance to contributing toward the review question based on the richness of their data. Articles were included if the publication highlighted the focus of our study: interventions for supporting autonomy in daily-care situations. The term intervention was interpreted in the widest sense of the word. We included articles that focused on a specific approach to caregiving, on descriptions of experiences with a caregiving approach or on a conditional action when we considered it relevant to our study. Studies were assessed for the quality of the evidence that they provided. Articles on specific themes, such as sexuality, freedom of mobility and end-of-life decisions, were excluded. Although these themes are closely connected to the concept of autonomy, the main focus was specifically the themes indicated, not autonomy. The reviewers discussed any disagreements until they were able to reach a consensus. In case a consensus could not be reached, a third researcher was consulted to arrive at a decision (DG or KL). For rigor, studies were selected based on the quality of the evidence that they provided (HvdW, ML). Decisions on whether to include primary studies in the review were thus based on relevance and rigor (Hunter et al., 2022) (Box 2).

Table 1
Criteria of inclusion and exclusion.

Theme	Inclusion	Exclusion
Design	Empirical studies.	Reviews Protocols Opinion pieces
Appraisal	Adequate relevance and rigor	Inadequate relevance and rigor
Time setting	Date of publication: Jan 2011–Feb 2022	Date of publication: Before 2011
Language	English language	All other languages
Setting	Long term care settings	Living at home Staying at a hospital People living at hospices
Participants	People aged 65 and older With a dementia diagnosis	People under 65 without a dementia diagnosis People with young onset dementia People with physical impairments People with intellectual disabilities
Focus of study	Autonomy interventions in daily-care situations	Articles specifically focusing on e-health Articles specifically focusing on independent functioning Articles specifically focusing on end-of-life decisions, freedom of mobility or sexual expression

2.4. Data analyses

Two reviewers independently performed data analysis (HvdW and ML) on the first three articles. After that, one reviewer made the selections (HvdW) and the other reviewer checked the results (ML). The overall results were discussed in the research team (HvdW, ML, DG and KL). Coding was performed on the intervention elements, context, mechanism and outcome elements of all the paragraphs of the included articles. These codes were subsequently transformed into several CMO configurations related to our review question. Classifying the findings on overall context factors and overall outcome factors, led to the emergence of similar and complementary CMO configurations. On a more abstract level we classified chains of coherence that were appropriate to link these CMO configurations. Next we defined themes by categorizing

Box 2
Questions to help determine relevance and rigor in a realist review (Wong, 2018).

Relevance: Does this piece of literature help to refine, refute, or substantiate program theories?
Rigor: Is this piece of literature good enough to be included? Were the methods used to generate the data credible, plausible, and trustworthy?

all the CMO configurations addressing the same topic, into a single theme. This provided us with a shortlist of CMO configurations, which lead to the core of our findings.

Finally, to obtain full relevant data, we included an expert panel. Setting up such a panel reflects current thinking on practice and is central to the success of a rapid realist review in that it ensures a relevant practical focus (Eidin et al., 2018).

Our expert panel consisted of representatives of relevant stakeholders: close relations of clients from two nursing homes (a son and a daughter), as well as experts that were selected due to their expertise in dementia, long-term care practice and/or public health. After collecting and analyzing the data, the expert panel was consulted for their comments and additions to the findings. The configurations were presented to our expert panel by e-mail, accompanied by three questions:

- Do you understand the scope and relevance of the configurations presented?
- Based on your expertise, do you recognize its contents?
- Are any topics or themes missing you would have expected to find in these configurations?

On account of COVID-19, our expert panel members were interviewed on these questions in four online groups. Our panel consisted of experts on different aspects of our study: they either had scientific, professional or personal experience expertise. As we intended to give each form of expertise its full weight, we decided not to converse with all the members at the same time, but to divide them into small groups of people who share the same expertise. After conducting these interviews, relevant data were added to complement the ultimate overview of CMO configurations.

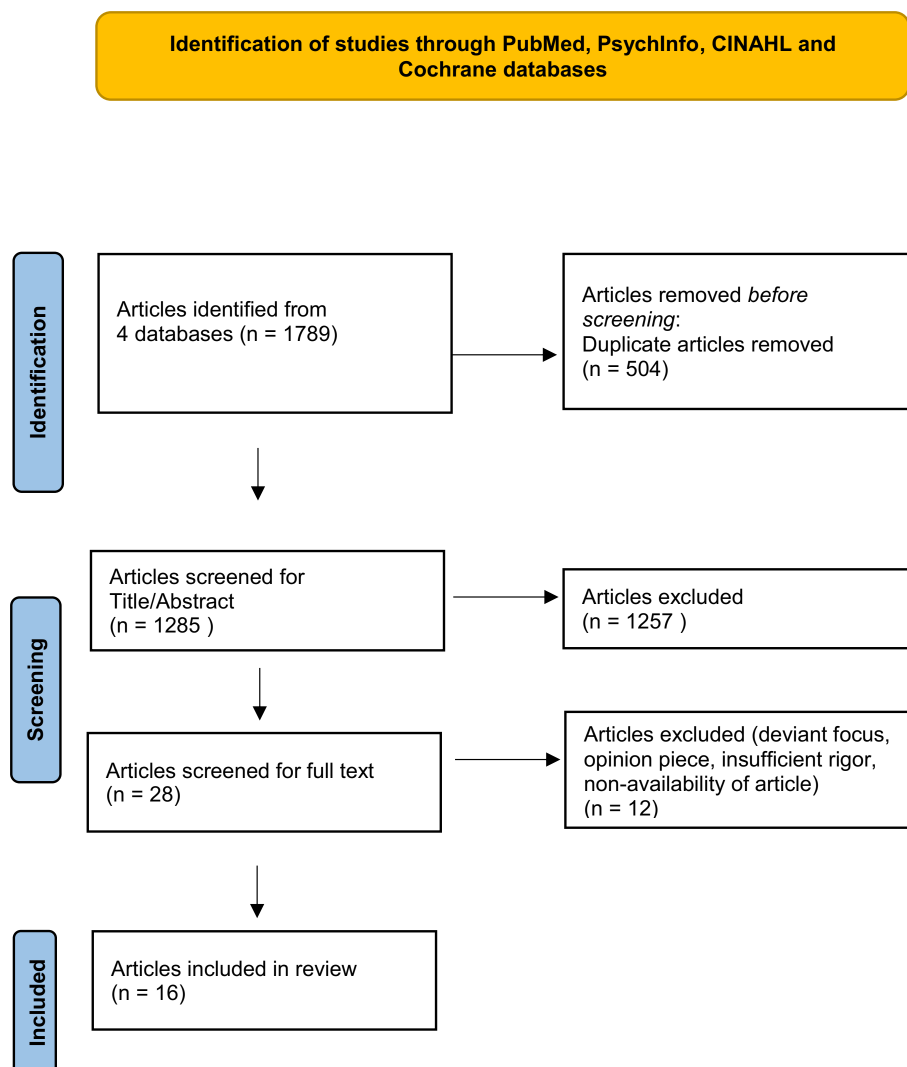
3. Results

3.1. Literature search

Our literature search resulted in 1285 publications. Eventually, sixteen published articles were included after following the agreed stages and applying the inclusion and exclusion criteria (see the Flowchart). The articles all had a primary focus on autonomy for people with dementia in nursing homes and consisted of seven studies on advance care planning, four studies that described relevant daily-care approaches and five studies that shared a perspective on participation and interaction (Table 2).

3.2. Data synthesis

While categorizing the CMO configurations, we identified the following four themes: preferences and choice, personal characteristics



Flowchart. Flowchart for the selection process.

Table 2
The included articles.

Author/title/country/year	Study design	Setting/participants		Data collection/instruments	Study results
Ampe S. et al., 2015, Belgium Advance care planning for nursing home residents with dementia: policy vs. practice.	Observational, cross-sectional study on policy and practice of Advance care planning	Nursing homes (20); clinical staff and management (153); people who have dementia or lack mental capacity.	Direct care staff, including nurses	Advance care planning audit: on policy, according to shared decision making three-step model Advance care planning criteria: on practice, assessed on four levels OPTION: on residents and family members' involvement in decision-making.	Nursing homes generally met most of the predefined criteria for advance care planning policy Agreements on shared decision making and family involvement are in practice only met at a basic level Only practical information at the time of admission No room for emotions in advance care planning in crisis situations Residents involved personally in half of the audited conversations
Ampe S. et al., 2016, Belgium Advance care planning for nursing home residents with dementia: Influence of "we DeCide" on policy and practice.	Quasi experimental pre-test and post-test study with intervention and control group.	18 dementia care units in 18 Belgian nursing homes;	Nursing home staff	Post-test data were collected on policy and actual practice Advance care planning by audit = structured questionnaire Advance care planning criteria and OPTION, interviews on degree of involvement at the time of admission and time of crisis.	Advance care planning was more compliant after WeDECide (a national survey) in the intervention group. Advance care planning was not discussed better or more often after the intervention. Residents and family were not involved to a higher degree Barrier: staff's limited responsibilities Facilitators: Support from management and staff, involvement of organization.
Boumans J. et al., 2021, the Netherlands Exploring how residential care facilities can enhance the autonomy of people with dementia and improve informal care.	A realist evaluation multiple case study	Two residential care facilities in the south of the Netherlands 8 relatives	8 direct care staff, mainly nurses	Document analysis Semi-structured interviews Resident observations	The behaviors, attitudes and interactions between staff members, residents and informal care givers promoted the autonomy of people with dementia in residential care facilities and improved informal care. The physical environment of the residential care facilities and their use of technologies were less relevant although they could support formal caregivers to provide person-centered care in daily practice.
Cameron N. et al., 2021, Australia Challenges faced by residential aged care staff in decision-making for residents with dementia.	A qualitative exploratory design study	80 research participants, mainly in direct care roles in Residential Aged Care Facilities in Australia	Direct-care staff mainly nurses	Grounded theory approach through interviewing subjects about a few preconceived notions	Care staff often receive little guidance regarding which residents' decisions should be supported or how to make decisions on their behalf. This lack of guidance can result in a denial of residents' rights and inconsistent treatment by staff, placing residents' well-being at risk.
Cameron N. et al., 2020, Australia How do care staff in residential aged care facilities conceptualize their non-verbal interventions with residents with dementia and what relevance has this for how residents' preferences and capacity for decision-making are understood?	Qualitative study using semi-structured interviews	14 Australian Residential Aged Care Facilities; dementia care; 80 direct-care staff at all levels	Direct-care staff mainly nurses	Individual interviews or group interviews (choice)	Staff are highly reliant on residents' body language to establish their needs and preferences as well as their capacity to participate in decision making. Few staff appear to be aware that their behavior can emotionally impact the residents and their ability to decide. Many staff fail to consider residents' non-verbal communication and behavior with due consideration of residents' individual histories.
Cameron N. et al., 2021, Australia How residential care staff conceptualize the identities of residents with dementia and its relevance for decision-making.	A qualitative exploratory design study	80 participants, mainly in direct-care roles in Residential Aged Care Facilities in Australia	Direct-care staff mainly nurses	Grounded theory approach to decision-making processes through semi-structured individual and group interviews	Staff possesses disparate ideas about what comprises residents' identities and, accordingly, which sources of knowledge are the most relevant for learning about residents. This article argues for the application of a multidimensional and temporally inclusive understanding of identity by those who provide care to people with dementia.
Fetherstonhaugh D. et al., 2016, Australia "The red dress or the blue?" How do staff perceive that they support decision making for people with dementia living in Residential Aged Care Facilities	Qualitative study	80 direct-care staff in Residential Aged Care Facilities in Australia	Direct-care staff including nurses	Semi-structured interviews and focus groups at the choice of participants Recorded conversations	The following strategies were indicated to help people with dementia make decisions: keeping it simple in various ways; knowing the person through family and experience; negotiating a compromise offering an alternative both parties find satisfactory.
Goossens B. et al., 2020, Belgium Shared decision making in Advance care planning for	A cross-sectional study on a national survey: WeDECide	65 nursing home wards 46 Belgian nursing homes, 311	Nursing staff and	Residents or family members rated the level of shared	Score rates on Shared Decision Making were consistently lower for professionals than for residents: almost all the

(continued on next page)

Table 2 (*continued*)

Author/title/country/year	Study design	Setting/participants		Data collection/instruments	Study results
persons with dementia in nursing homes: a cross-sectional study.	Optimized	health professionals and 42 residents with dementia	management	decision making using a questionnaire External raters assessed audio recordings of actual conversations. Professionals completed an additional self-report questionnaire (OPTION)	professionals mentioned Advance Care Planning as a subject, only 25% of residents/family referred to Advance Care Planning as a topic. Perceived competence of professionals was positively associated with frequency of use. Overall the residents appreciated being involved in the decision-making. Professionals hardly explore residents' preferences on approach. Person-centered communication is challenging for professionals.
Goossens B. et al, 2020, Belgium Improving shared decision making in Advance care planning: implementation of a cluster randomized staff intervention in dementia care	Pre-test and post-test cluster randomized trial	65 nursing homes Dementia care; 311 staff members	Direct-care staff mainly nurses	Conversations about advance care planning were recorded, questionnaires completed and feedback provided by all participants	Wards demonstrated a higher level of shared decision making after a training intervention The time spent on the conversations did not increase. The participants felt more competent and perceived shared decision making as more important; the staff benefits from shared decision making training.
Helgesen A.K. et al., 2014, Norway Patient participation in special care units for persons with dementia: A losing principle?	An explorative design based on grounded theory methodology	Special care units in 3 nursing homes for people with dementia	11 nursing staff	Qualitative study using semi-structured interviews	Patient participation had to be adjusted to the individual resident. The following four different levels of participation were established: letting residents decide, adjusting choice, making decisions on behalf of residents, forcing residents. Nurses' competences had a considerable impact on level of participation. Relationships between professionals and residents affected residents' opportunity to participate. Amount of personnel was found to be crucial.
Hoek L.J.M. et al., 2019, the Netherlands Factors influencing autonomy of nursing home residents with dementia: the perception of care givers.	Qualitative research	3 psychiatric nursing homes, for people with dementia	58 family caregivers; no nurses	Qualitative study using semi-structured interviews The participation level was tested on six themes contributing to autonomy	Participants' reflections were hard to obtain, because most residents could not express their wishes and needs; The activities adjusted to residents' personal preferences were rarely centrally organized; Stimulating the social environment for residents helps to support their autonomy.
Hoek L.J.M. et al., 2020, the Netherlands Autonomy support of nursing home residents with dementia in staff-resident interventions: Observations of care.	Exploratory, cross-sectional, observational study	6 nursing homes; 120 residents; 9 psychogeriatric wards for people with dementia	Nursing care staff; providing morning	Qualitative and quantitative approaches combined. Staff-resident interventions and morning care observations	1770 care interventions were observed. These were categorized into four levels of autonomy support: initiative, autonomy approach, residents response, reaction to residents response and undefined

		5 large scale wards and 4 small scale wards	care		Autonomy support was found in 60% of the interventions, leaving a large portion in which the autonomy was impeded (when staff take over tasks and are insensitive to residents wishes). More support was found among residents with a high cognitive level of dementia, less when the cognitive level of dementia was low.
MacLeod M.Z., 2020, United States A phenomenological exploration of autonomy and related psychological needs among the residents of a memory care unit.	Quality descriptive study	Assisted living facility, memory care unit; 7 adults 65 years old and older, early to middle-stage dementia	All interviews were conducted with patients	Phenomenological interviews as well as residents' and staff observations	A central finding of this study was the importance of allowing as much autonomy as possible within the scope of a resident's capabilities. Development of core themes: - Autonomy: real and imagined; - Implicit belief of competence - A preference for routine and comfort The interconnectedness of these constructs leads to the idea that autonomy is the vehicle through which other needs are actualized. The need to belong was evident. The ability to negotiate relationships was utilized in order not to feel left out and to feel connected to others. Routine, comfort, stability, familiarity and predictability were important determinants
Mariani E. et al., 2017, Italy, the Netherlands Shared decision making in dementia care planning: Barriers and facilitators in two European countries.	Explorative study on influencing factors during the implementation of Shared Decision Making intervention	Two nursing homes in Italy and in the Netherlands similar in terms of the care planning; 19 healthcare professionals	Direct-care staff, including nurses	Focus-group interviews	Seven themes were found in 15 categories: - Professional outcomes and tools - Environmental factors - Professionals' relational skills - Care recipients' attitude and cognition - Own culture; - Facilitators: communication skills and nursing home policy; - Barriers: regulations, lack of funding and involvement of family caregivers; The difference between the two countries lies in the residents' cognitive status, which influences the degree of involvement in decision-making.
Saevereid T. et al., 2019, Norway Improved patient participation through Advance care planning in nursing homes – A cluster randomized clinical trial.	Part of study “End of life, implementation study” A pair-matched cluster randomized clinical trial in end-of-life situations	8 wards in 8 nursing homes, including all patients over 70 years old; both physical and cognitive impairment;	Just clients, conclusions beneficial for nurses	Mixed methods study Documentation in patient electronic health records Chart reviews Clinical questionnaire Care plans Selected notes by nurses and physicians	Intervention group showed greater participation by residents, more documentation on hopes, preferences and worries in concordance with provided treatment Next of kin participation increased after training. Advance care planning can be improved through a whole-ward approach.

Table 3
Context mechanism outcome configurations.

Intervention	Context	Mechanism	Outcome on autonomy	Reference articles
Preference and choice				
Improve autonomy and choice by employing advance care planning	For people with dementia in nursing homes, family members, nursing home staff	Residents *are grateful* to be involved Residents *are happy* to attend and speak up for themselves	In general, autonomy prospects are improved by residents having a strong sense of self, as this makes them feel (as if) they are making their own decisions.	Ampe et al., 2015 Goossens et al., 2020a, 2020b Saevereid et al., 2019 Saevereid et al., 2020 MacLeod, 2020
Improve autonomy by using advance care planning throughout the stay, discussing not only medical issues but also care issues	For people with dementia in nursing homes, family members and nursing home staff	Residents *are unaware* about topics involving autonomy, but they do have faith in their own decision making capacity	Residents and family members do not initiate autonomy topics, which results in diminished autonomy. Care planning conversations must be held for everyday decision-makings, which will improve the prospects for autonomy. Care topics should be included in care planning conversations, thereby improving autonomy.	Ampe et al., 2015 Goossens et al., 2020a, 2020b
Limit choices, try to visualize choices for the residents and offer them compromises	For people with dementia in nursing homes, family members and care staff	Residents will then feel confident and less overwhelmed; offering all choices feels time consuming for staff so they can be self-serving and offer choices that are in their own best interest	This way residents can understand the options available to enhance their autonomy. Staff who feel pressured for time, may not facilitate autonomous decision-making as much.	Fetherstonhaugh et al., 2016 Hoek et al., 2019 MacLeod Kampf, n.d. Boumans et al., 2021
Competent nursing staff				
Know the residents, their background and their lifestyles	For nursing home staff caring for people with dementia	Staff feel *confident, sometimes even over-confident*, knowing resident and preferences, but care staff *may be unaware* of how non-verbal communication can vary among residents due to personal differences and backgrounds	Knowing residents is supporting autonomy, but over-confidence may lead to less direct and diminished autonomy. Even when talking incoherently, insight into residents' preferences is revealed if you know how to see it	Ampe et al., 2015 Fetherstonhaugh et al., 2016 Cameron et al., 2020 Cameron et al., 2021a Hoek et al., 2019
Be thoroughly educated about dementia care and have adequate conditions in place to support autonomy	For nursing home staff caring for people with dementia	Residents and nursing staff both are *at risk of* being institutionalized Nursing staff *might not be or feel fully equipped* to know about the complexity of dementia care	In spite of a care planning policy, staff may be inadequately equipped, which leads to diminished autonomy for residents	Ampe et al., 2015 Ampe et al., 2017 Goossens et al., 2020a, 2020b Hoek et al., 2020
Improve the ability of nursing staff to communicate, interpret and investigate the residents' preferences	For nursing home staff caring for people with dementia	Staff sometimes *feel reluctant* to address emotions and may be avoiding burden; Staff *may also feel* rushed;	Advance care planning and shared decision making will then lack positive results; nursing staff has difficulty estimating residents' ability to make decisions (autonomy). The insufficient investigation of a particular behavior results in residents being misunderstood, diminishing their autonomy.	Ampe et al., 2015 Cameron et al., 2020 Helgesen et al., 2014 Mariani et al., 2016 Boumans et al., 2021
Be aware of the impact of your personal attitude and biases due to the residents' differences in culture and background	For nursing home staff caring for people with dementia	Staff seem to be *unaware* of the impact of their own body language and tone of voice as well as how their behavior can emotionally impact the residents	Positive body language, a positive attitude and communication are all crucial to improving the residents' decision making capacity	Cameron et al., 2020
Create a facilitating organization with adequate policy, time and staff competence Develop team goals and encourage team collaboration	For nursing home staff caring for people with dementia	Nurses *are sometimes reluctant* to encourage care planning conversations, because staff *feels this may additionally burden* their workload, especially with limited personnel available Team members *feel* more secure when they have productive team collaboration;	Being competent is good, but feeling competent is more effective for improving the residents' prospects for autonomy. Management providing necessary support and adequate time to make the training sustainable does improve the residents' autonomy.	Goossens et al., 2020a, 2020b Ampe et al., 2017 Saevereid et al., 2019 Saevereid et al., 2020 Mariani et al., 2016

			The abilities of nurses to collaborate in teams, improves the residents' involvement and autonomy. There is a lack of guidance on how to support residents' decision-making.	Boumans et al., 2021 Cameron et al., 2021a, 2021b
Personal characteristics of residents and family				
Residents being understood with regard to their wishes and preferences	For people with dementia in nursing homes; nursing staff; family members	Staff *sometimes makes assumptions* about the residents' ability to make decisions and they *rely on* residents' body language and their own interpretation thereof Relatives *do not always understand* the complexity of dementia	When staff makes general assumptions about the residents' body language, residents are at risk of being misunderstood which will diminish their autonomy. Relatives usually trust staff to know what residents want, therefore they do not interfere when they should, which can sometimes diminish the likelihood of autonomy for residents.	Fetherstonhaugh et al., 2016 Cameron et al., 2020 Saevereid et al., 2019 Hoek et al., 2020
Residents feeling like they belong and feeling relaxed and at home Residents feeling like they are involved and taken seriously	For people with dementia in nursing homes; nursing staff; family members	Residents *need to feel acknowledged*, since they are happy to be involved, Residents *usually feel vulnerable, dependent and anguished*, especially in end-of-life discussions	When struggling with their dementia, residents need comfort and stability in order to improve their autonomy; all participants need to feel like they belong and feel connected to others.	MacLeod Kampf, n.d. Mariani et al., 2016 Boumans et al., 2021
Improving family participation and educating the relatives about the impact of dementia	For people with dementia in nursing homes, nursing staff, family members	Family members need encouragement *to feel capable of* participating but they also *feel grateful* to be involved. Next of kin, however, can sometimes experience *feelings of uncertainty*	The family's support of the residents is important for their comfort and for providing information. This is so, that given the opportunity, family members can be properly involved in decision making, thereby improving residents' autonomy.	Ampe et al., 2015 Saevereid et al., 2019 Saevereid et al., 2020 Hoek et al., 2019
Interaction and relationships				
Build a trusting relationship between resident, relative and nursing professional, making residents feel at home Build trusting and positive relationships between each nursing staff team member and as a team	For people with dementia in nursing homes, family members and nursing staff	Family *need to feel welcome* and they *greatly appreciate* having a trusting relationship with nurses Residents *need to feel like they belong and need to feel* relaxed and at home	As residents' preferences will always be influenced by their network of relationships they are in, family members need to feel welcome to genuinely become involved and improve residents' autonomy. Family members experience greater satisfaction about autonomy in case of a good relative-nurse relationship. Little to no personal contact prevents autonomy improving. When struggling with their dementia, all participants need to feel connected to others in order for their autonomy to improve.	Saevereid et al., 2019 Saevereid et al., 2020 Helgesen et al., 2014 Hoek et al., 2019 MacLeod Kampf, n.d. Mariani et al., 2016 Boumans et al., 2021
Handle complex interventions in the resident-family-nurse triangle Be aware of the impact of personal styles of interaction	People with dementia in nursing homes family members and nursing staff	Family and nurses should be aware of how interaction styles affect the residents' emotional state	Family members and nurses can be more sensitive to all interactions, especially with regard to their own role, which lead to more trusting relationships and therefore improves residents' autonomy.	Cameron et al., 2020 Boumans et al., 2021
Expert panel CMO configurations				
Offer alternative choices through person-centered communication accompanied by flexible working conditions and schedules	For people with dementia in nursing homes and family members	Residents *feel they have to adapt* to organization rules and procedures Sometimes residents *feel like they are equal* and accept diminished autonomy due to organizational conditions.	Creating choice options in a flexible organization system, will improve residents' autonomy Alternatives may lead to an autonomous decision, though it may be a second-best option.	
Implement independent client support	For people with dementia in nursing homes and family members	Residents and relatives sometimes *feel unequally equipped* in care planning conversations and residents are sometimes *incapable of* knowing about the options for choosing and making decisions	To improve autonomy, residents and relatives need to participate in a triangle relationship, in which all are equally equipped Providing residents with actual options to choose from and explanations about those options, will lead to residents having greater autonomy.	
Nurses, residents and relatives regularly matching care expectations and care possibilities	For people with dementia in nursing homes; family members	Sometimes, professionals *are stuck* in rigid procedures and protocol Clients sometimes *believe they are entitled* to have things exactly their way	Creative solutions and realistic expectations promote a satisfactory interaction and a trusting relationship, thereby improving the prospects of greater autonomy for residents.	

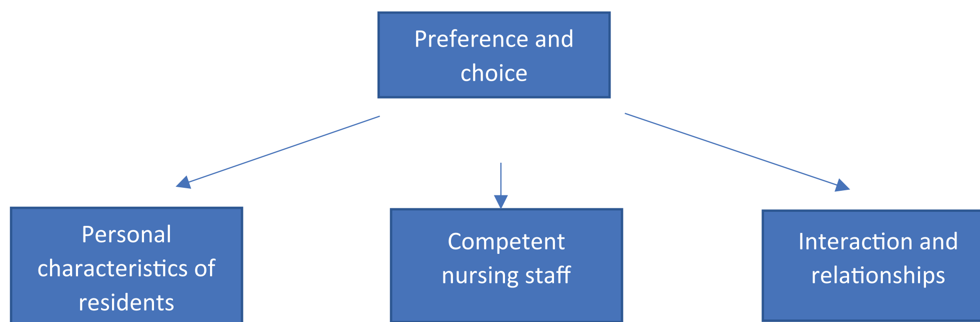


Diagram 1. Autonomy categories and their coherence.

of residents and family, competent nursing staff (the articles included used different terminologies such as nursing-home staff, direct-care staff and nursing-care staff) and interaction and relationships. After the coding process, the data extracted from all the included articles resulted in a total of 66 configurations. Each of these 66 CMO configurations was then placed into its matching theme, thus revealing overlapping, additional and contradictory configurations, which ultimately resulted in thirteen CMO configurations. The expert panel that we consulted unanimously validated the results. Furthermore they provided additional information about the residents and the residents' family members feeling unequally equipped to communicate with the nursing staff about care. The experts also pointed out the high employee turnover which makes it difficult for staff to get to know the resident adequately. Finally the expert panel stated that the nursing staff perceives that there is insufficient time available to regularly match up mutual expectations. The expert panel input was converted into three additional CMOs, resulting in a total of sixteen CMO configurations (Table 3).

3.3. Context mechanism outcome findings

The studies that we analyzed described the introduction and performance of interventions to support the residents' autonomy. After structuring all causal configurations, we were able to identify the following overall context factors: 'people with dementia', 'living in a nursing home environment', and 'interacting with families and nursing staff (in a triangle relationship)'. The interventions described can be divided between two categories: content interventions that related to the core of autonomy and interventions on context factors, referring to their surroundings (Diagram 1). The interventions we identified were related to arrangements concerning daily care, daytime activities and advance-care-planning and they were usually introduced by the nursing staff and care organizations, to help improve the residents' autonomy. The mechanisms that we identified included feelings of (in)competence, trust, (in)security, reluctance and (un)awareness. These mechanisms concerned every person involved in the triangle. All configurations showed an outcome for autonomy.

3.3.1. Preference and choice

The primary concept of autonomy was explored in several studies. The theme 'preference and choice' entails the development of content interventions meant to support the autonomy of people with dementia living in nursing homes. Advance care planning was found to be useful as an autonomy intervention, but it needs to be applied more frequently in daily-care situations (Ampe et al., 2017). Also, 'knowing the resident' was indicated as an important factor for supporting autonomy (Fetherstonhaugh et al., 2016). Additionally, studies highlighted three interventions: supporting decision-making by simplifying (limiting) choices and visualizing them, offering alternative choices in a flexible process and raising the awareness of autonomy topics to be discussed in daily life situations (Goossens et al., 2020a, 2020b; Saevereid et al., 2019, 2020; MacLeod Kampf, n.d.).

3.3.2. Personal characteristics of residents and family

People with dementia living in nursing homes all have a personality. They have developed as individuals over the years and their dementia has influenced them as a person. The personal characteristics of residents and family members are extremely important when implementing autonomy interventions. As a context factor, it impacts the success or failure of – in itself – constructive interventions. It is therefore essential to continuously investigate personal preferences (Fetherstonhaugh et al., 2016; Cameron et al., 2020, 2021a, 2021b). The articles that we included regularly referred to these personal characteristics by concluding that residents need to feel like they belong and are known and they need to feel relaxed and at home (MacLeod Kampf, n.d.; Mariani et al., 2016). They also need to be heard, to be actively involved and to be taken seriously, especially when they feel vulnerable and dependent (Mariani et al., 2016).

3.3.3. Competent nursing staff

The competences of nursing staff are a second theme that can be influential as a context factor. It is a theme that has an important influence on the successful implementation of an intervention (Ampe et al., 2017; Boumans et al., 2021; Cameron et al., 2020). Residents' family members are reliant on the competency of nursing staff to understand, interpret and communicate adequately with the residents and with them (Goossens et al., 2020a, 2020b). Studies have indicated which competences and abilities are necessary to support the residents' autonomy (Cameron et al., 2020; Boumans et al., 2021). The primary findings for this theme were the following: the abilities to communicate and address emotions, to see, understand and interpret residents' preferences and the professionals being aware of the impact of their own personalities, attitudes and biases (Cameron et al., 2020; Mariani et al., 2016; Boumans et al., 2021). Knowing the resident in every way that is relevant, including their cultural background and life's history, was also an enabling factor (Hoek et al., 2019). Finally, the need to establish team goals and have constructive team collaborations was found to be influential for a successful implementation of an intervention (Boumans et al., 2021).

3.3.4. Interaction and relationships

The studies that we included indicated that interaction and positive relationships were highly important and can be considered as a third context factor. Autonomy only appears to be valuable for people with dementia when they are interacting in a relationship with other people, whether their next of kin or the nursing staff that provide them with their care (Helgesen et al., 2014; Mariani et al., 2016). The included studies regularly mentioned this triangle relationship and the importance of fostering positive connections between family members and nursing staff. Residents thrive when family members and professionals

have a trusting relationship (Hoek et al., 2019). Nursing staff, in particular, should be aware of the complexity of this interaction and of their matching styles of interaction. The relationships between residents and care professionals exert a substantial influence on achieving autonomy for people with dementia (Cameron et al., 2020, 2021a, 2021b), as does the family members feeling and being made welcome (Boumans et al., 2021).

4. Discussion

In our rapid realist review sixteen theoretical propositions (context mechanism outcome configurations) were outlined for increasing the understanding of how to support autonomy for people with dementia in nursing homes. Context mechanism outcome configurations showed that several interventions were implemented in nursing homes to support the autonomy of people with dementia. The interventions seemed to cohesively support autonomy. Content interventions alone (preference and choice) did not always and entirely make a difference. Three additional themes ('personal characteristics of residents and family, nursing staff competences and interaction/relationships in the triangle') emerged as context factors that were determinative for the results. Therefore these factors also need to be addressed when taking measures to support autonomy of people with dementia in nursing homes.

Similar to other studies, we also observed a deeper connection between autonomy and dementia. People value self-determination, choice and control, as primary aspects of their self-worth, especially when it is no longer possible for them to execute their wishes independently (Daly et al., 2018). Our results seem complementary to the outcome of the systematic literature review Boumans et al. performed in 2019. They stated that improving the relationship between residents and formal or informal caregivers is valuable and will contribute to the autonomy of people with dementia living in nursing homes (Boumans et al., 2019). What our study adds is, that these elements must be considered interdependent and equally important.

Content interventions to maintain autonomy are regularly encountered in the complex process of daily care. For example the action of simplifying the choices offered or finding alternatives to support autonomy can be a facilitator, but this also means that autonomy must be limited in order for it to be successfully realized (Fetherstonhaugh et al., 2016). For example, nursing staff might decide on the choices being offered, which could be interpreted as limiting autonomy. In this respect, the ability to express preferences and choices may also be viewed as a person's competence, considering our finding that nursing staff or family members might be offering different choices that are more in line with their own values or even for their own benefit (for example, to save time). Abma and Bendien (2019) state that the ability to handle autonomy will differ depending on the people and their personal situations. In keeping with our results, Koster and Nies (2021) demonstrated that the people involved (in a client–family member–professional carer triangle) all individually influence the outcome of an intervention, as they all have different personalities, abilities and competences. The actors, having their own interests, also appear to be dependent on the relationships and interaction that they experience in their own situational triangle (Sherwin and Winsby, 2000). Future research should address these issues. Our study shows that a facilitating organization is needed to ensure that interventions can be fully implemented and properly secured in care processes. We would further recommend that future studies utilize this outcome to explore how context situations, such as organizational rules and restrictions due to procedures, influence the outcome on autonomy interventions.

The findings of our review shed light on why autonomy interventions work differently in different situations (Fazio et al., 2018; Boumans et al., 2019). The interventions performed to support autonomy for people with dementia in nursing homes were usually found to be positive, and they were found to be clear, logical and encouraging to residents with dementia (Ampe et al., 2015; Goossens et al., 2020a, 2020b; Cameron et al., 2020).

Our findings on the autonomy interventions sometimes struck the members of our expert panel as self-evident, which is remarkable given that lasting positive results on autonomy interventions are difficult to achieve in practice (Boumans et al., 2021).

This review explored the probability that context factors and personal mechanism factors are particularly important to consider when taking measures to support the autonomy of people with dementia in nursing homes. In fact, more context factors were found in 'personal characteristics and competent nursing staff', than were found when developing a content intervention. It seems that, generally speaking, interventions can work, but more research incorporating our findings, is required to explore how the results can be improved when applied within a complex context.

4.1. Limitations and strengths

Our study was limited by the fact that we only included English-language publications, which may have excluded studies from other countries where different cultures play a role in how autonomy is perceived. We also limited our research by excluding important decisions about situations involving intimacy, life and death situations as well as issues on freedom of mobility, because they do not have a particular focus on autonomy. Certain insights on autonomy, however, could have been obtained through these topics. Moreover, our study incorporated a wide variety of articles, which made it harder to compare their results. Ten of the studies that we included are related to the Dutch or European situation. The outcome therefore may not be fully representative for other parts of the world. Our focus on daily-care situations in nursing home conditions – where many people with dementia live in – can be considered a strength because daily-life decisions primarily reflect the residents' way of living. The review process is also regarded to be a strength based upon the expert panel's contribution of practice findings, as we specified in three additional CMO configurations.

5. Conclusion

Based on our results, sixteen context mechanism outcome configurations have illustrated that content interventions on 'preference and choice' should be reinforced with three other themes in order to support the autonomy of each individual. People with dementia living in nursing homes depend on others to help them fulfill their desire for autonomy. Autonomy, therefore, was found to be an interactive process that requires the support of others to be effective.

Autonomy interventions for people who have dementia can only be individually successful when applied in accordance with the right set of conditions, bearing in mind the characteristics and competences of the nursing staff, residents and family members and maintained in productive interactions in an effective triangle relationship.

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CRediT authorship contribution statement

All persons who meet authorship criteria are listed as authors, and all authors certify that they have participated sufficiently in the work to take public responsibility for the content, including participation in the concept, design, analysis, writing, or revision of the manuscript. Furthermore, each author certifies that this material or similar material has not been and will not be submitted to or published in any other publication before its appearance in the International Journal of Nursing Studies: Improving care for older people.

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Data availability

Open source article, full data are available, analysis on request at the corresponding author.

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.

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