The factors that influence care home residents' and families' engagement with decision-making about their care and support: a literature review

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INTRODUCTION

As care homes play an important role in the lives of older people, it is pivotal to understand how residents' and their families engage in decision-making about their care and support, and how care home staff support their residents to exercise voice, choice, and control over their lives. On 1st October 2018, there were 16,007 beds in all registered nursing and residential care homes across Northern Ireland. This represents a 4% increase in the total number of beds in the sector over a ten-year period [*1*]. Older people are entering care homes with more complex conditions and higher levels of physical and cognitive impairment than previous years. During the recent pandemic, almost one in six residents in care homes had confirmed COVID 19 [*2*]. The combination of these multiple and complex needs, along with the experience of moving to the care home, present older people, and their relatives with significant challenges [*3*]. Research by Ryan and McKenna, [*4*], and O'Neill et al. [*5*] reveals that communication and a caring partnership between residents, families and care home staff are crucial and need to be developed to maximise the quality of life of older people in care homes and their families. Shared decision-making is considered the pinnacle of relationship-centred care [*6,7*] and is one of the eight best practice themes that supports the international 'My Home Life' (MHL) movement which aims to improve quality of life for care home residents, relatives, and staff [*8*]. Shared decision-making is a process where care home staff, the resident and their family make decisions together, using the best available evidence [*9*]. It integrates the values, goals and concerns of the resident and their family with the best available evidence about benefits, risks, and uncertainties, not only of treatments and care, but in all aspects of home life.

Very little is known about shared decision-making in care homes despite increasing emphasis on resident choice and autonomy outlined in standards and aged care reforms internationally [*10,11*]. Although the World Health Organization [*12*] advocates for a human rights approach for health and ageing, including the right of a person to actively participate in decision-making about their health care, the key steps required to successfully achieve shared decision-making in the care home setting remain somewhat unknown. The Mental Capacity Act (Northern Ireland) 2016 [*13*] provides a new statutory framework to protect and empower people to participate in decisions about their life and care unless there is evidence to the contrary. Evidence suggests, however, that shared decision-making is not often used in long-term care settings with persons with dementia and care home staff often make day-to-day care decisions on behalf of the person [*14*].

Whilst the research literature strongly indicates that shared decision-making benefits residents, families, and staff [*9,10,11,12*] to date, there remains a paucity of literature specific to the implementation steps required to successfully achieve shared decision-making in the

care home environment. Building and expanding on previous work, this review provides an up-to-date synthesis of shared decision-making in the care home sector and discusses potential enabling and inhibiting factors that influence residents' and families' engagement with decision-making about their care and support. The report also incorporates the engagement approaches that work best in the care home context and includes recommendations that advocate embedding shared decision-making in a bottom-up approach based on relationship-centred care.

METHODS

In undertaking the literature review, we adopted a triple-pronged approach:

1. A formal systematic review of the literature.

2. Inclusion of grey literature incorporating examples of shared decision-making initiatives in Northern Ireland (NI) care homes.

3. Integration of engagement approaches that have the potential to work best in the care home sector.

1. A formal systematic review of the literature

Research design

Using the methodological framework proposed by Arksey and O'Malley [*15*] and refined by the Joanna Briggs Institute methodology [*14*] we performed a scoping review of the literature and adopted the following steps:

Identifying the research question

Our research question was: What is known from the existing literature about the factors that influence (enable and inhibit) care home residents' and families' engagement with decision-making about their care and support?

Search strategy

To identify the relevant articles, literature published from 2011 to 2021 was selected for review from three electronic databases (CINAHL, Medline Ovid and ProQuest Health and Medical), between July-August 2021. These databases were chosen due to the scope of disciplines represented, in conjunction with the wide representation of international journals deemed of relevance for this topic. The search strategy involved defining key words which were refined

and grouped within three categories: 1) 'Care home resident' OR 'nursing home resident' OR long-term care resident'; 2) Families of care home residents' OR 'families of nursing home residents' OR 'families of long-term care residents'; 3) 'Decision-making OR 'shared decision-making'. To capture the relevant literature in care home settings these, search terms were combined with 'AND' for: 'Nursing home' OR 'care home" OR 'long term care'.

Inclusion and exclusion criteria

Table 1 below presents the inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
• Written in the English language. • Studies published in international peer reviewed journals. • Studies inclusive of qualitative, quantitative, and mixed methodologies and case studies. • Systematic literature reviews. • Only studies conducted in care homes or nursing homes or long-term care facilities. • Studies that focus on the perspective of care home residents, families of care home residents and staff in relation to shared decision-making.	• Written in language other than English. • Studies conducted in acute care or transitional care settings. • Studies conducted in the community setting. • Studies prior to 2011 were excluded to give account of existing models and processes. • Studies related to governance and occupational health, as the aim was to explore practice and processes relevant to shared decision-making in care homes

Table 1. Inclusion and exclusion criteria

RESULTS

Review process

A systematic search of the databases retrieved 913 results. Duplicates were removed. The initial screening process was undertaken by one researcher (BL) who identified a total 559 articles which were reviewed by title and abstract and 516 found not to be relevant. A total of 43 articles were reviewed fully to assess if they met the inclusion criteria for the review. Further discussion between two researchers enabled consensus to be reached (AR; SP), and finally

22 met our inclusion criteria. Following a manual screening of the reference list of these articles, one additional article was included (n=23), (**Figure 1**).

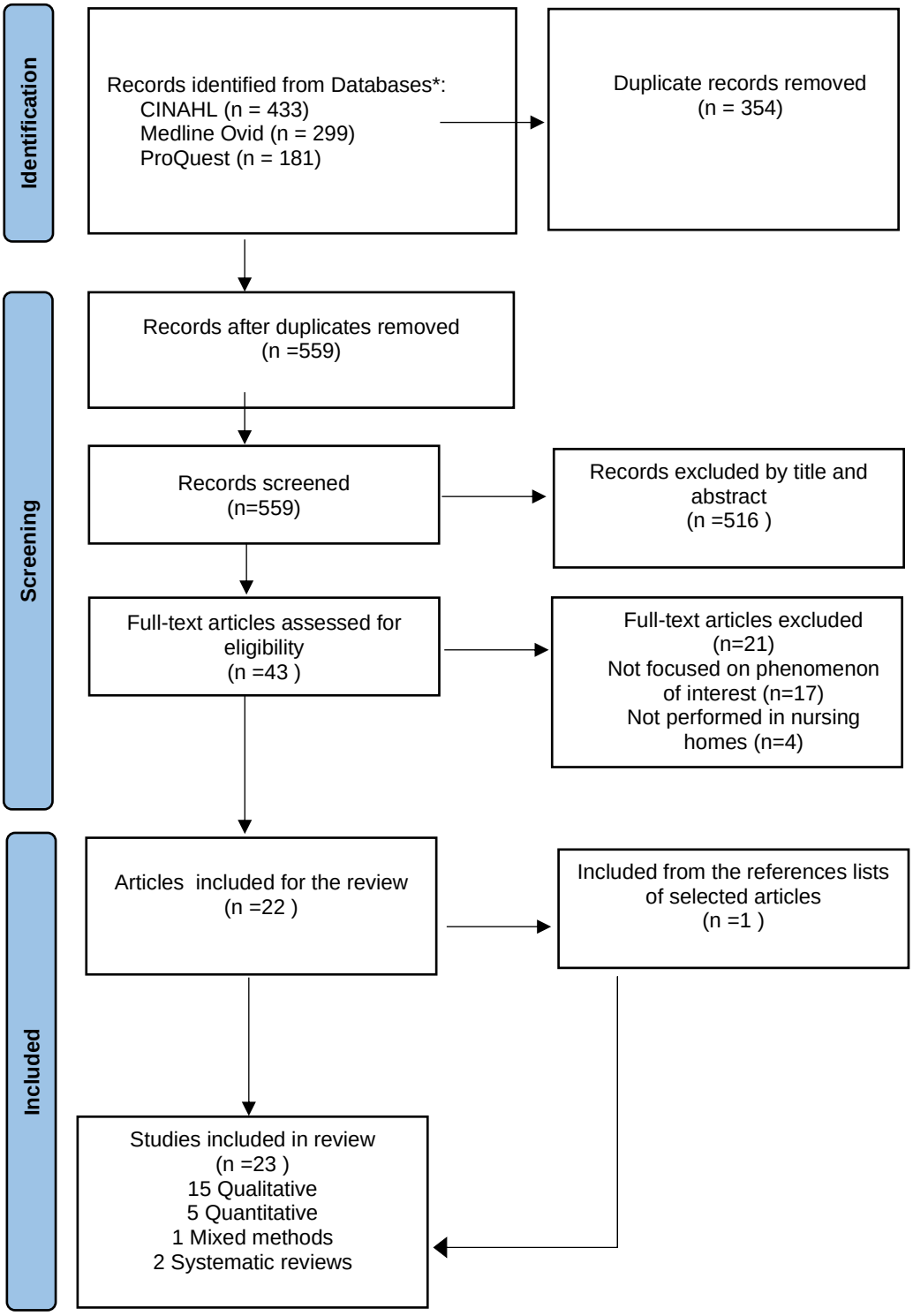

Figure 1. PRISMA flow-chart depicting the main stages of the review process

Charting the data

A total of 23 papers were deemed eligible for inclusion as they met inclusion criteria previously outline in **Table 1**. The research team developed a data charting form to collect the following data: author(s), the country of origin**,** the year of publication, the context/setting, the methodology, the sample (residents/families/staff), and the key findings, which are summarised as potential enabling and inhibiting factors that influence shared decision-making, (please refer to **Appendix 1**).

Characteristics of included studies

Most of the studies were conducted in Australia (n=6), followed by Norway (n=4), then Europe (n=4), USA (n=3), Canada (n=2), Northern Ireland (n=2), England (n=1) and Switzerland (n=1). Most of the studies included in the review used qualitative research designs (n=15), with a combination of in-depth interviews (n=10) and focus groups (n=5). The total population for this review, based on the primary studies, was n=2,763 and comprised: residents (n=764), families of residents (n=1,348), and staff (n=651).

A comprehensive review of each study was undertaken to determine enablers and inhibitors to shared decision-making in care homes, and environmental issues, from the perspectives of staff, residents, and families. The thematic analysis identified six key factors that enable shared decision-making, four key factors that inhibit shared decision-making and four key environmental issues. These were subsequently categorised into three main themes that illustrate the complexities of shared decision-making in care homes (please see **Table 2**).

The three themes are:

- A positive culture of collaborative and reciprocal relationships
- A willingness to engage and a willingness to become engaged
- Communicating with intent to share and support rather than inform and direct

Table 2: Overview of Themes

Note: SDM = Shared decision-making

Themes	Enabling factors	Inhibiting factors	Environmental issues
A positive culture of collaborative and reciprocal relationships	Trust and communication Existing culture of relationship-centred care Role of the Registered Nurse: knowing the personhood of the resident & being able to adapt & respond with careful regard to each resident as an individual.	Time pressure, low staffing levels, inadequate skill mix and knowledge levels of staff	Management support and participation are necessary conditions for SDM
Willingness to engage and a willingness to become engaged	Suggested strategies to facilitate SDM: for example, developing the skills of staff in relation to SDM, and assigning a key worker for each resident to support SDM	Lack of competence & confidence by staff in how to apply SDM in their conversations Residents and families' unpreparedness for SDM	Staff assume that people with dementia are no longer able to talk about their preferences. Residents & families acquiesce, deferring decision-making to the staff
Communicating with intent to share and support rather than inform and direct	Balancing an appropriate level of independence with an appropriate level of risk Seeing decision-making as a supportive process rather than a once off event	Paternalistic practices of staff	Top-down approach versus a bottom-up approach

A positive culture of collaborative and reciprocal relationships

Trust and communication

Supporting and nurturing collaborative relationships between residents, families, and staff is an essential component of shared decision-making in care homes. Central to collaborative relationships is the notion of trust and communication [*17,18,19,20*]. In the study by Bauer et al. [*18*], family members identified that being listened to, responded to, and valued was central to their trusting relationships with staff and this relationship-centred approach played a significant role in their ability to participate in shared decision-making [*18,19,20*]. Constructive relationships between the staff and family were seen to develop when there was a reciprocal sharing of information about the resident's care. Families expressed that when they shared their knowledge about their relative, this was respected and utilised by the staff. Equally, staff described that they trusted the families' observations when they reported noticing subtle changes in their relative's condition.

Helgesen et al. [*21*] reported contradictory results in their study exploring relatives' participation in everyday care in special care units for persons living with dementia. Most relatives felt their point of view was listened to by staff and staff supported them in their role as relatives. However, they reported that they seldom participated in decisions concerning the resident's everyday care, feeling that these could be left with the staff who had the knowledge and whom they trusted. In contrast, relatives in the study by Bollig et al. [*22*] reported that Advance Care Planning (ACP) and shared decision-making is lacking in nursing homes and many family members are unaware of their relative's wishes in relation to their life in a care home. For this reason, most relatives felt that it was too difficult to decide for the resident and therefore tried to avoid making important health-related and end-of-life care decisions, deferring these decisions to the expertise of the staff. Whilst the absence of ACP may not seem to be problematic for the resident, it can and often does lead to psychological stress for the relatives.

Seven articles focused on advance care planning (ACP) or end-of-life perspectives of residents, families, and staff [*22,23,24,25,26,27,28*]. One study found that whilst there was an ACP policy in place, and staff did involve residents with dementia and their families in the initial admission conversation, ACP conversations were not ongoing over time and did not accommodate or allow for a change in the person's original decision [*23*]. Two studies found a lack of provision of information to residents and their families and reported that staff rarely discussed the risks and benefits of treatment options [*23,29*]. In a narrative review of the literature, Beck et al. [*28*] found evidence that dementia remains unrecognised by many staff working in long-term care settings as a condition requiring palliation. Staff perceived communication difficulties with both the person with dementia and their families and viewed

this difficulty as an inhibiting factor to the initiation of shared decision-making in the long-term care setting.

Existing culture of relationship-centred care

Nine of the studies analysed concepts related to a relationship-centred or person-centred approach to care [*17,18,19,20,22,29,30,31,33*]. In two of the studies, an existing relationship-centred culture was highlighted by staff as being a key enabler to shared decision-making and family involvement [*30,31*]. Findings from other studies included in the review illustrated that where a relationship-centred approach to care was not fully embraced, or embraced only in rhetoric, staff adopted various tactics that resulted in a lack of shared decision-making [17,31]. Time pressure, inadequate skill mix, inadequate knowledge levels of staff, and routine linked to task orientated care were key inhibiting factors to promoting meaningful staff-resident and family relationships and shared decision-making [*17,18,20,28*]. The study by Bauer et al. [*18*] provided a detailed picture of staff–family relationships within an Australian residential aged-care context. Families reported that collaborative relationships and the development of trust between staff and families were sometimes hampered because staff from other cultures did not have English as their first language. Many families suggested that management support and participation were necessary conditions for shared decision-making in the care homes and they also expressed the need for knowledgeable and dependable staff who consistently provided quality care [*20*,*21,31*].

Role of the Registered Nurse

The literature review identified three papers highlighting the importance of the expertise of the Registered Nurse (RN) in nursing homes [*20,28,33*]. This was identified as being a key enabling factor necessary for shared decision-making [*33*]. The necessary expertise in the nursing function comprises diagnostic, therapeutic, and ethical judgment, and acting in the best interests of the person who is receiving care. Evidence shows that the registered nurse is the central axis of the multiple relationships that she/he must maintain with other staff, the residents, and their relatives. The aim of this web of relationships is to share decision-making. The study emphasised that management support and participation are necessary conditions for the registered nurse's leadership mission in the care home sector to be fulfilled. Research by Phelan and McCormack [*34*] which explored the expertise of registered nurses in residential care for older people in the Republic of Ireland, supports these findings. This empirical research revealed several important attributes that represent nursing expertise in residential care of older people, among them are knowing the personhood of the resident and being able to adapt and respond with careful regard to each resident as an individual. A key finding from the research indicates how nurses, in their day-to-day practice, demonstrate their expertise

by assessing up-to-date evidence and evaluating the quality of that evidence to ensure it is appropriate for the individual resident and their condition. The related conversations the nurse has with the resident based on their assessment, interpretation and application of evidence is a crucial factor in enhancing the ability of the residents (and that of their family) to make decisions on their own behalf. In a culture of relationship-centredness, shared decision-making utilises evidence to provide the resident with various options to support their decisions, as opposed to coercing residents into practices/treatments that conflict with their preferences and values. Whilst both studies have demonstrated the uniqueness of nursing expertise in relation to shared decision-making in the care home setting [*33, 34*], they both recommend the necessity of further research that will help elucidate the capabilities of nurses in this setting.

Willingness to engage and a willingness to become engaged

Acquiescence: deferring decision-making to the staff

The degree to which family members were willing or ready to engage in decision-making was variable within and across studies, particularly in relation to ACP and end-of-life care [*21,22,25,35,37*]. In five of the studies, resident and family willingness to become engaged was shown to be a significant enabling factor in the process of shared decision-making. Whilst most relatives and a number of residents expressed a desire to engage in end-of-life conversations, many residents did not find it essential to have these conversations or were more reluctant to talk about these issues. The literature points to multi-factorial reasons for the low incidence of such conversations. Arendts et al. [*17*] found that residents as a group are least likely to be active participants in the decision-making process and are more likely to acquiesce as a means of preserving dignity. Abrahamson et al. [*29*] explored family members' experience in relation to hospital transfer decisions for the resident and identified that family roles are variable depending on their willingness to engage in decision-making. Most family members' perceptions were that staff did not address changes in the resident's condition promptly enough to avoid hospitalisation. These families believed that staff should have identified and communicated a need for hospitalisation earlier. However, families also reported that staff familiarity with their resident was a benefit of remaining in the care home and avoiding hospitalisation.

Helgesen et al. [*21*] reported that most family members (n=233) of persons with dementia surveyed, did not participate nor express a desire to engage in decision-making. This was even though half of the families in the study saw their participation as being crucial for person-centred care. With respect to end-of-life care conversations, Gjerberg et al [*25*] reported that some residents and families expressed unpreparedness for shared decision-making and

wanted to leave the decisions more or less completely to the nursing home staff. Findings from a Spanish study [*27*] revealed that most family members (n=84) of persons living with dementia expressed an enormous emotional burden and a strong sense of guilt in their role as decision-maker for their relative. Families indicated that having a key member of staff to provide informational and emotional support would have helped with decision-making and eased the burden. Willingness of families to become engaged in shared decision-making was assessed in one study [*23*] by staff asking the families about their preferred approach to receiving information to assist in their decision-making: for example, by discussing various issues with a staff member in one-to-one consultations, receiving printed material and/or receiving information through the use videotapes or other media. Despite this, the study revealed that staff generally talked about preferences with the families instead of the residents and assumed that people with dementia were no longer able to articulate their preferences. Mariani et al. [*40*] emphasise that whilst there is a deterioration in the person's abilities to answer fact-based questions after the early stages of dementia, their abilities to answer preference questions remain more stable over time. Studies in the literature reviewed indicate that it is possible to assess the personal preferences of people with dementia and enhance their decision-making involvement [*30,39*]. The lack of skills by staff to recognise and facilitate the resident's desire and ability to decide is a significant and consistent inhibiting factor throughout the literature reviewed [*17,26,28,32,387,41*].

Two studies highlighted staff's feelings of 'uneasiness' and a sense of 'discomfort' towards discussing ACP or end-of-life issues which resulted in a general hesitancy by staff to engage in shared decision-making [*18,31*]. Suggested possible reasons for this discomfort was a reluctance by staff to discuss death and a fear of upsetting the people in their care. Gjerberg et al. [*25*] found that most residents and families wanted conversations about end-of-life care. However, if such conversations were not initiated by the staff, then the residents' and families' needs remained unmet.

The willingness of staff to engage residents in shared decision-making is largely determined by resident-staff communication during day-to-day care. It is evident from the literature reviewed that in the absence of communication support, many residents will continue to have trouble expressing preferences about their care and participating in shared decision-making [*25,38,39*]. Findings from a Norwegian study [*25*] recommend that nursing home staff should take responsibility for initiating conversations about preferences for end-of-life care, assisting and supporting residents to talk about these issues, while at the same time being sensitive to the diversity in opinions and the timing of such conversations. Most residents stated there was no opportunity to discuss their values and preferences for treatment and care related to

end-of-life with the nursing home staff. Some explicitly said that they wanted or missed this kind of conversation.

Suggested strategies to facilitate shared decision-making

Whilst education and training in shared decision-making was not a focus of the literature reviewed, many of the articles suggested strategies to improve communication and cooperation between staff and families and to facilitate shared decision-making [*23,29,35*]. Hanson et al. [*35*] and Brazil et al. [*24*] differed somewhat by providing education to families and not staff. The study by Mariani and colleagues [*40*] adopted the philosophy that shared decision-making was an opportunity for people with dementia to express their opinion and wishes during the care planning process. Following communication skills training for staff, shared decision-making conversations took place between a triad composed of the resident, the family member, and a care home professional as the facilitator. The role of the family caregiver was to support and facilitate the resident's expression of opinion during the conversations. The findings indicated that communication skills training is an essential prerequisite for implementing shared decision-making in dementia care. Staff scheduled moments during their daily practice to ask the residents direct questions about their wishes, and offered residents, together with their family caregivers, an opportunity to express their views and preferences. This approach prompted staff and family caregivers to become aware of, and acknowledge, residents' autonomy and personhood. The contribution of the nursing home managers in the implementation of shared decision-making was seen as essential, not only to the accomplishment of the primary objectives of the intervention but also to the improvement of other secondary aspects. Several articles in the review echo the importance of the care home manager's contribution and role in shared decision-making [*19,33*].

Similarly, following a competence-building programme for staff, Norheim et al. [*31*] reported that the programme had raised consciousness among staff and influenced a change in staff attitudes. The emphasis in the culture of care had moved from a focus on tasks and routines to a more person-centred focus. Along with highlighting the importance of providing staff with training and developing their skills in shared decision-making, several studies also recognised the importance of assigning a key worker for each resident to support the resident in decision-making and facilitate open, proactive communication with the resident, their family and the staff [*19,24,31,37*].

Communicating with intent to share and support rather than inform and direct

Balancing an appropriate level of independence with an appropriate level of risk

Several studies demonstrated contrasting approaches to utilising evidence with the intention of facilitating shared decision-making. Sims-Gould et al. [*32*] describe a top-down approach where staff held the knowledge of best practice and used it to inform and direct residents in the use of hip protectors as a tool for injury prevention. This belief was so deeply engrained in staff care practices that in some instances, staff would insist on the use of hip protectors even when residents had explicitly declined their use. The residents' choice and autonomy were strongly denied. In relation to residents' perspectives concerning transfers to emergency departments, Arendts et al. [*17*] found that shared decision-making and meaningful engagement rarely occurred. In some instances, staff adopted a paternalistic attitude, denying residents' and relatives' choice. Paternalistic attitudes are frequently driven by the staff's belief that they know what is best for residents. However, there is also evidence that care home staff experience moral distress when they feel they must transfer a resident to acute care (at the behest of relatives), even though they know the residents would prefer to stay in the care home environment [*41*]. Communicating with intent to share and support is contingent on finding the right balance between introducing evidence-based practice and ensuring the approach to utilising evidence does not take precedence over residents' preferences and values.

Communicating with intent to share and support is perceived as a bottom-up approach where residents and families are provided with evidence of treatment risks and benefits. In the study by Hanson et al. [*35*], a bottom-up approach was used, in which a decision aid about treatment (feeding) options in advanced dementia was effective in improving the quality of decision-making by families of nursing home residents with dementia. Family members were more likely to discuss treatments with staff, indicating that the decision aid supported rather than replaced communication.

Seeing decision-making as a supportive process rather than a once off event

In exploring the challenges faced by staff in decision-making for residents living with dementia, Cameron [*37*] reported that most staff suggested that residents can only make decisions on matters where the consequences carry very little risk or that they cannot generally make decisions at all. Without support around decision-making for residents with dementia, staff felt they had the added burden of having to decide from one instance (scenario) to the next about which of the resident's preferences they should support or facilitate.

There is evidence in the literature of models that use a guided, staged approach to achieve shared decision-making. Decision-making is viewed as a supportive process rather than a once off event [*23,30,26,35*]. In its simplest terms, the process involves, providing people with choices, then narrowing those choices down to options and then making a decision. Two studies used 'The three-talk model' [*9*] as a guided approach to achieve shared decision-making during ACP conversations with persons with dementia. It consists of introducing options (choice talk), discussing these options (option talk), and then making a decision after exploring preferences (decision talk). It provides a practical, easy way to skill up clinicians in shared decision-making and has utility beyond ACP.

Fetherstonhaugh et al. [*30*] reported that there was an existing culture of person-centred care in the care homes recruited to their study, and staff had an awareness of strategies to support resident decision-making. These strategies had the aim of simplifying the process of decision-making for the person with dementia. For example, when staff members helped the person to get dressed, rather than opening the wardrobe to show the residents all the clothing on display, causing them to become overwhelmed, they reduced the number of options for the resident to choose from. This encouraged the resident to make a decision and avoided them becoming confused or upset.

Communicating with intent to share and support was clearly demonstrated in Godwin's study [*39*]. The study illustrated the communication opportunities that staff afforded residents living with dementia in an extended care environment. In consulting the residents about the care home décor, staff helped to develop an unpatronising, person-centred approach to shared decision-making which minimised the need for speech for residents with communication difficulties. Visual aids helped in seeking the residents' opinions and choice. The approach supported communication, deemphasised the spoken word and promoted inclusion. The researcher noted that the residents appeared to be 'surprised and pleased' to be asked their opinion and to be included in decision-making (p.114). Godwin argues that this kind of consultation could enhance the self-esteem of persons with dementia and contribute to their quality of life. The findings reveal that the use of visual aids, observation, activity, and non-verbal communication achieved higher than expected levels of participation from the residents.

2. Inclusion of grey literature incorporating examples of shared decision-making initiatives in NI care homes.

Grey literature is defined by Wood [*44*] as any information, materials and research produced by organisations outside of the traditional commercial or academic publishing and distribution channels. The grey literature we included in this review comprise examples of best practices

used to promote shared decision-making in care homes across Northern Ireland which often do not get the recognition they deserve. To find evidence of this good work, we engaged with over sixty care home managers who completed the My Home Life (MHL) Leadership Support and Quality Improvement Programme delivered by Ulster University. Our main aim was to explore examples of what care home managers and their teams are doing to help residents and families be more actively involved in decision-making. The ethos that the care home managers adopt from having undertaken the MHL Leadership Support programme is one of involving residents and families, as far as possible, in any changes they plan to make in the care home. In this section of the report, we present examples of shared decision-making initiatives in the Northern Ireland care homes.

A 'Decision Tree'

One group of managers developed a 'Decision Tree' which they used to facilitate the involvement of residents in decisions about life in their care home. A small artificial tree was kept in the lobby and the residents used luggage tags to write their suggestions (for example, where to go to for their next outing) before placing them on the tree. The approach worked well and provided alternative communication opportunities, particularly for residents who may have felt uncomfortable speaking out in a group. Further information about the decision tree can be found at: https://www.myhomelifeni.co.uk/ (currently under development).

A quality improvement initiative to improve the oral health of residents

A recent group of managers who participated in the MHL Leadership Support programme, engaged care home residents, their families, and staff in a quality improvement initiative to improve the oral health of the residents in their care homes. This involved using pictures/images to elicit views on oral health care from residents with cognitive impairment. Using carefully chosen pictures and both verbal and non-verbal communication helped these residents to give their opinion on how their oral health could be improved.

Care home managers who participate in the MHL Leadership Support programme, are encouraged to use different approaches to promote discussion and engagement. One approach is using 'Emotion' cards with 'emotion' words. Residents, their family members, and staff can choose cards that describe their experience of aspects of day-to-day life in the care home. Examples of the cards are illustrated on the left (Figure 1). The cards support meaningful conversations and shared decision-making between residents, families, and staff.

Likewise, a second useful approach that is frequently used at staff and resident meetings is the use of 'Evoke' cards that depict various images, as illustrated below (Figure 2). Care home managers who have undertaken the MHL Leadership programme use both approaches regularly and have reported that they find them very effective for engagement with residents, families, and staff.

Figure 1: Examples of 'Emotion' cards

Figure 2: Examples of images on Evoke cards

Recruitment and induction of new care home staff

Two care home managers have adopted the approach of involving residents in the recruitment process for new staff. Residents compile their own questions, sit on the interview panel and share in the decision-making to appoint the successful candidate. Residents are also involved in the induction process of newly appointed staff.

Relative hub meetings

Another manager introduced relative hub meetings where families can discuss any concerns, review the care plans, and contribute to the delivery of person-centred care. This was an initiative that the care home manager had implemented in a previous care home and found that it significantly improved two-way communication and dialogue between staff and families. The virtual meetings are held monthly and one day a month is allocated to each unit in the care home. Pre-arranged dates are scheduled for the families so they can link in whenever it suits them. The Residential Unit Manager / Deputy Manager / Team Leader is available throughout the day to meet with families. Relatives choose what they wish to discuss, so the tendency is not to set a formal agenda. However, if there is something that the staff wish to share with the family, they email the chair who communicates this at the meeting.

Relatives Gateway: a new person-centred software system

A care home manager and her team have implemented a new record system which has an application called 'Relatives Gateway'. This system is a secure communications tool, developed in response to the outbreak of COVID-19, that has helped to keep the dialogue between staff and residents open with their relatives. It provides relatives with access to the resident's care plan as a live document and helps in the sharing of mutual information about the resident. Families can review the care plans and contact the staff with any suggestions or changes they feel would be required to enable the staff to provide appropriate person-centred care. Relatives Gateway is designed to promote inclusive and transparent care, giving family members peace of mind through easy online access to records, charts, and analysis about the resident. Photos and messages showing the resident enjoying meals, activities and trips can be shared through the secure system.

3. Integration of engagement approaches that have the potential to work best in the care home sector

In exploring the grey literature, we also undertook engagement with our MHL colleagues in the UK, Germany and Australia, our partners Age NI and the Independent Health Care Providers (IHCP), Nursing Homes Ireland (NHI), colleagues in AIGNA (*All Ireland*

Gerontological Nurses Association) and researchers of a new Advance Care Planning Intervention (BABEL) in the United States. Through this engagement, a number of approaches that have the potential to facilitate shared decision making in the care home sector have been identified. These are summarised below.

*BABEL (**B**etter T**a**rgeting, **B**etter outcomes for frail **El**derly) Advance Care Planning Intervention for Nursing Homes (Garland et al.,2020)**

The BABEL ACP intervention is a structured discussion between a resident, their substitute decision-maker (SDM), and nursing home staff. Requiring approximately 60 minutes, it:

1) confirms the identity and role of the SDM.
2) prepares the SDM for medical emergencies.
3) explains the resident's clinical situation and prognosis.
4) ascertains the resident's preferred "philosophy of care" to guide decision-making; and
5) identifies preferred treatment options for the medical emergencies most likely to be faced by that resident

*South Australia Innovation Hub (Simon Charlton, Executive Officer)**

Simon Charlton, Executive Officer of the South Australia Innovation Hub has been engaged in a programme of work on Quality of Life & Consumer Centred Care spanning a 7–8-year period. The work focuses on residents in Residential Aged Care Facilities in Australia and the basic premise is that achieving quality of life is not viable without active support for choice and control. A wellbeing profile is developed for each resident, highlighting the things that are important to them and including things like ambitions and aspirations, preferences about how care is provided, often including aspects the person wants complete control over and any other preference that are important to them. A training package has been developed for all staff, based on the Quality of Life & Consumer Centred Care approach.

Unpublished MSc dissertation on "What are the experiences of care home residents' in the use of patient held records?" by Dr Jill Will, Lecturer, School of Nursing, Midwifery and Paramedic Practice, Robert Gordon University Aberdeen

The main aim of this MSc was to improve resident held records and documentation and the process around completing them. The resident's individual records were moved to their room and the resident decided where they would be held (cupboard/drawer etc…). Staff had to seek permission to write something in the records. There was greater input from the resident to their care documentation. Significantly, the new approach included details that were important to residents and relatives in addition to reflecting the priority issues from a nursing

perspective. This study highlights the need for the inclusion of care home residents in all aspects of their care including that of documentation. The findings suggest that resident held records support residents' understanding of the roles of professionals involved in their care as well as encouraging an open holistic dialogue of the care home residents' experiences.

The Nurses Role in Promoting a Human Rights Based Approach to Autonomous Decision Making in Older Person Residential Care (Florence Hogan, Quality and Patient Safety Manager, Leopardstown Park Hospital, Foxrock)

Staff in Leopardstown Park Hospital, a residential care facility for older people in Dublin, have been engaged in an innovation aimed at promoting a human rights-based approach to autonomous decision-making for their residents. In 2018 all nurses in the facility undertook an education programme focusing on the legal and ethical issues regarding self-determination, consent and the duty to advocate for residents. A 'Healthcare Decision Making Care Plan' was implemented to outline actions required to evidence the primacy of the residents' rights to consultation on all healthcare decision making. This was further augmented in 2019 by discussion and circulation of the Health Information and Quality Authority (HIQA) 'Guidance on a Human Rights-based Approach in Health and Social Care Services'. In August 2018 following the education initiative, 32% of residents engaged in decision making and by March 2020, this number had increased to 98% of residents engaging in decision making about their care. The main outcome from the initiative was a sustained culture in the organisation of a human rights-based approach to autonomy for the residents.

*Nursing Homes Ireland** (*Deirdre Shanagher, Strategic Clinical Nurse Expert with Regulatory Compliance)*

Deirdre Shanagher, Strategic Clinical Nurse Expert with Regulatory Compliance, Nursing Homes Ireland (NHI), has been engaged in a programme of work focusing on advance care planning and facilitating conversations. An advance care planning algorithm has been developed by Deirdre and her colleagues in an attempt to illustrate engaging in the advance care planning process with a person with dementia and is available at:
https://hospicefoundation.ie/wp-content/uploads/2021/03/FACTSHEET-Advance-Healthcare-Planning-and-Advance-Healthcare-Directives-with-a-person-with-dementia.pdf

DISCUSSION

The review aimed to explore the enabling, inhibiting, and environmental factors that influence care home residents' and families' engagement with decision-making about their care and support. The themes outlined in this review illuminate the complexities involved in engaging

residents and their families in shared decision-making. In this section of the report, we discuss the findings in relation to the following four significant influencing factors that form the cornerstone of successful implementation of shared decision-making in care homes: a c*ulture of relationship-centred care; reciprocity; the role of the Registered Nurse; and strategies to facilitate shared decision-making.*

A culture of relationship-centred care

One of the key findings that has emerged from the review is that shared decision-making in care homes is highly dependent on the nurturing of collaborative and reciprocal relationships between residents, families, and staff. Shared decision-making is the key component of 'Relationship-Centred Care' [*6*], which recognises the importance of seeing the care home as a community where the quality of life of staff, family, friends, and residents are all crucial to improvements in practice. As the review has evidenced, an existing relationship-centred culture of care is a key enabler to shared decision-making and family involvement. Evidence from the review indicates that factors such as time pressure, inadequate skill mix, inadequate knowledge levels of staff, and routines linked to task-orientated care, inhibit the promotion of a relationship-centred approach and shared decision-making.

The difficulty for staff in balancing an appropriate level of independence for the resident with an appropriate level of risk was evident in the review as a potential inhibitor to relationship-centred care. In these situations, the imbalance can manifest as a paternalistic approach to care, driven by the staff's belief that they know what is best for residents. Two contrasting approaches were evidenced in the review. In a top-down approach to utilising evidence [*32*], staff held the knowledge of best practice and residents' choice, and autonomy were denied. A bottom-up approach [*35*], provided families with evidence of treatment risks and benefits, increased family members knowledge, and facilitated shared decision-making with staff. Evidence from research by Thompson et al. [*41*] revealed that the tension between strong commitment by staff to keeping the resident safe and violating their right to choose and autonomy is not always based on a paternalistic approach. Care home staff experience moral distress when they feel they have to transfer a resident to acute care (at the behest of relatives), even though they know the residents would prefer to stay in the care home environment.

Whilst trust and communication were seen as central to collaborative and reciprocal relationships, there was conflicting evidence regarding the level of support and information provided to residents and their families by staff. This was particularly evident in relation to the risks and benefits of treatment options with regards to ACP and end-of-life care decisions.

Findings suggest that family members are not always involved, or consulted, in decisions, and many do not always know their relative's preferences. Most families felt that it was problematic to decide for the residents and tried to avoid making important health-related and end-of-life care decisions, deferring these decisions to the knowledge of the staff. Similarly, the three studies that explored residents transfer to acute hospital decisions found that residents as a group are least likely to be active participants in the decision-making process and acquiesce, accepting that the staff are the 'experts.

Reciprocity

Reciprocity, by the contribution of the resident in the decision-making process is an important element that can improve the health and well-being of the resident [*42*]. Studies have identified that consultation with residents with dementia about their preferences heightens their self-esteem, purpose, and feeling of self-worth [*39,45*]. Smebye et al. [*43*] indicate that shared decision-making seems to be the most typical pattern that occurs in decision-making situations where the person with dementia, a family member and a professional caregiver are involved. However, despite this potential, the review provides evidence that the use of shared decision-making with people with dementia and their families is limited, especially in care homes. The review revealed that staff found it challenging to involve residents and their families in the decision-making process [*28*]. This may be due to the cognitive deficits that impair the residents' ability to express their wishes and the lack of skills by staff to recognise and facilitate residents' desire and ability to decide. Further evidence from the review indicates that it is possible to assess the personal preferences of people with dementia and enhance their decision-making involvement. Evidence from the study by Mariani et al. [*40*] shows that communication skills training is an essential prerequisite for implementing shared decision-making conversations between the person with dementia, the family member, and a care home professional as the facilitator.

The role of the Registered Nurse

The care home professional as the facilitator of shared decision-making is evidenced in the review as being the Registered Nurse (RN). The related conversations the nurse has with the resident based on their assessment, interpretation and application of evidence is a crucial factor in enhancing the ability of the residents (and that of their family) to make decisions on their own behalf. The review provides evidence of several important attributes that represent nursing expertise in residential care of older people, among them are knowing the personhood of the resident and being able to adapt and respond with careful regard to each resident as an individual [*34*]. Bedin et al. [*33*] highlight that management support and participation are necessary conditions for the RN's leadership mission to be fulfilled in care homes, particularly

in relation to facilitating shared decision-making. This review corroborates these observations. The contribution of the nursing home managers in the implementation of shared decision-making was seen as essential, not only to the accomplishment of the primary objectives of the intervention but also to its sustainability [*19,33*].

Strategies to facilitate shared decision-making

To date, little research has been undertaken to determine staff skills, or previous training, in relation to strategies that facilitate shared decision-making in the care home setting. Moreover, the review confirms that there remains a paucity of literature specific to the implementation of shared decision-making in care homes. The absence of studies, however, may not reflect current practice as can be evidenced from the inclusion of examples of shared decision-making initiatives in Northern Ireland care homes as presented in this review (p.15).

The review highlights a number of guided approaches that view decision-making as a supportive process rather than a once off event. The process involves, providing people with choices, then narrowing those choices down to options and then making a decision. 'The three-talk model' by Elwyn et al. [*9*], a guided approach to achieve shared decision-making, is one example. It provides a practical, easy way to skill up clinicians in shared decision-making and has applicability in various settings, including dementia care. Other guided approaches evidenced in the review included skills training such as role-play exercises and learning from on-site role models. This approach was found to be particularly helpful for staff who lacked experience in conducting ACP conversations [*26*]. Another finding was the involvement of families of residents in specific education sessions to address those aspects that may prevent their involvement in decision-making [*40*]. Strategies based on a person-centred and relationship-centred approach identified communication skills training [*19*], and a competence-building programme for staff [*31*]. Parallel to these skills' development programmes, the importance of assigning a key worker for each resident was seen as essential to facilitate shared decision-making in the care home environment.

KEY RECOMMENDATIONS

1. There is a need to undertake an evaluation study to explore the shared decision-making experiences of care home residents, their families, and staff about their care and support. This will provide a baseline for future shared decision-making intervention studies.

2. Guided approaches and strategies evidenced in the review could be further co-developed with care home staff, residents, and their families, and tested and implemented to facilitate shared decision-making.

3. There is a need to provide staff with education and training to enable the implementation of shared decision-making in care homes.

4. There remains a lack of literature specific to the implementation steps required to successfully achieve shared decision-making in the care home environment. Therefore, further research needs to be undertaken to explore how shared decision-making can be better facilitated in care homes.

5. Despite evidence of shared decision-making in care homes across NI, there is currently no clear mechanism in place to disseminate this good practice other than via word of mouth. Care home staff should be encouraged to publish their work and to present at conferences and seminars.

CONCLUSION

This review points to the complex factors that influence care home residents' and families' engagement with decision-making. One of the most important findings emerging from the review is that the implementation of shared decision-making in care homes is highly dependent on the support and nurturing of collaborative and reciprocal relationships between residents, families, and staff. Part of this process includes ascertaining the willingness of residents and families to become engaged in shared decision-making. The review highlights the importance of finding the right balance between introducing evidence-based practice and ensuring the approach to utilising evidence does not take precedence over residents' preferences and values. In presenting examples of best practices used to promote shared decision-making, the review illuminates a range of tools and resources that are having a positive impact on residents' and families' decision-making participation in the care homes in Northern Ireland.

**The researchers have given permission for Professor Assumpta Ryan and her team to use the training packs outlined in the summary.*

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Appendix A: Summary of included studies related to Care Home Residents' and Families' Shared Decision-Making (SDM) about their care and support

Author/Year/Title	Country of Origin	Setting	Methodology & Method	Study Participants & Sample	Findings: • **Enabling & inhibiting factors that influence SDM** • **Environmental issues related to residents, families & staff**
Abrahamson et al. (2016) *"The experiences of family members in the nursing home to hospital transfer decision"* **[29]**	USA	Nursing Home	Qualitative study Semi-structured interviews	20 Family members	**Inhibiting factors:** Family members of residents felt they were left to make decisions in the absence of clear, accurate information from staff. **Enabling factors**: Study recommends development & training for staff to enhance their skills to communicate with families as partners in decisions about transfers. **Environmental issues:** Family roles are variable depending on their willingness to engage in decision-making.
Ampe et al. (2015) *"Advance care planning for nursing home residents with dementia: policy vs. practice"* **[23]**	Belgium	Nursing Home/ Dementia care units	Quantitative study The OPTION instrument -used to measure SDM	Staff from 20 dementia care units	**Inhibiting factors:** An ACP policy was in place. Whilst staff did engage in ACP conversations with residents with dementia and their families on admission, ACP conversations were not ongoing over time. **Enabling factors:** Study recommends development of strategies to translate ACP policy into practice. **Environmental issues:** staff assumed that people with dementia are no longer able to talk about their preferences.
Arendts et al. (2015) *"They never talked to me about...': Perspectives on aged care resident transfer to emergency departments"* **[17]**	Australia	Residential Aged Care Facility (RACF)	Qualitative descriptive study	6 RAC facilities 14 Family members 17 Staff	**Inhibiting factors:** The results identified that low staffing levels, inadequate skill mix and knowledge levels of staff limited staff's capacity to promote SDM.

					Enabling factors:. Family meetings are seen as one way to include families and improve the uptake of SDM. **Environmental issues: R**esidents as a group are not active participants in the decision-making process and acquiesce as a means of preserving dignity.
Bauer et al. (2014) *"Staff–Family relationships in residential aged care facilities: the views of residents' family members and care staff"* **[18]**	Australia	Residential Aged Care Facility (RACF)	Qualitative study Family members small group interviews (2-4 participants) or individual interviews. Staff focus groups	5 RAC facilities 14 Family members 27 Staff	**Enabling factors:** Effective communication and the sharing of mutual information about the resident between staff and families were identified as key factors that promoted SDM and quality care delivery. **Inhibiting factors**: Understaffing, staff with English as a second language, non-regular or agency staff, and low education levels, affect staff-family relationships and SDM. **Environmental issues:** There are unidentified factors that seem to prevent this knowledge from being successfully translated into practice.
Beck et al. (2017) *"Health care professionals' perspective of advance care planning for people with dementia in long-term care settings: A narrative review of the literature"* **[28]**	Northern Ireland	Long-term care(LTC) settings	A narrative literature methodology	205 articles screened from four databases published in English, within time limitation (2002-2014)	**Inhibiting factors:** Lack of knowledge/ recognition by health care professionals (HCPs) that dementia was a condition that would benefit from a palliative approach to care and subsequent initiation of ACP. **Enabling factors:** The importance of education and training for HCPs. Registered nurse seen as having the expertise to see and understand the ultimate consequences of ACP. **Environmental issues:** HCPs perspectives towards ACP were influenced by moral and ethical concerns which in turn had a direct influence on whether or not ACP was initiated.
Bedin et al. (2013) *"Caring for elders: the role of registered nurses in nursing homes"* **[33]**	Switzerland	Nursing Home	Qualitative study inspired by activity analysis	9 Nursing Homes 16 Registered Nurses	**Enabling factors:** The importance of the expertise of a Registered Nurse (RN) in nursing homes is a key enabling factor necessary to facilitate SDM. Among the attributes of the RN are, knowing the personhood

					of the resident and being able to adapt and respond with careful regard to each resident as an individual. **Environmental issues:** Management support and participation are necessary conditions for the RN's leadership mission to be fulfilled in nursing homes.
Bennett et al. (2020) *"Resident perceptions of opportunity for communication and contribution to care planning in residential aged care"* **[38]**	Australia	Residential Aged Care Facility (RACF)	Qualitative inductive study Individual interviews.	6 not-for-profit RAC facilities 102 Residents	**Enabling factors:** SDM and care planning in Residential Aged Care Facilities (RACFs) is determined by the communication opportunities afforded to the residents and the quality and nature of resident-staff communication during daily care. **Inhibiting factors:** Without communication support many residents experience difficulty expressing preferences about their care and participating in SDM. **Environmental issues:** Lack of explicit reference to communication needs and support in aged care policy and funding assessments, hinder communication support services in RACFs.
Bollig et al. (2016) *"They know!—Do they? A qualitative study of residents and relatives views"* **[22]**	Bergen, Norway	Nursing Home	Qualitative study based on interpretive description Semi-structured in-depth interviews with residents and focus group interviews with relatives	9 Nursing Homes 25 Residents 18 Relatives	**Enabling factors:** A systematic approach to ACP with repeated conversations and a staff key worker to support residents and relatives through the process. **Inhibiting factors:** The absence of ACP in many nursing homes seems not to be problematic for the residents but may lead to psychological stress for the relatives. **Environmental issues:** Many relatives avoided making important health-related and end-of-life care decisions, deferring these decisions to the knowledge of the staff.
Brazil et al. (2018) *"Effectiveness of Advance Care Planning with Family Carers in Dementia Nursing*	Northern Ireland	Nursing Home	Quantitative study Paired cluster randomized controlled trial	24 nursing homes with a dementia nursing	**Enabling factors:** Study identifies 5 key elements to a successful ACP intervention: 1) a trained facilitator; 2) family education; 3) family meetings; 4) documentation of ACP decisions; and

Homes: A Paired Cluster Randomized Controlled Trial" **[24]**				category (as per RQIA)	5) orientation of GPs and nursing home staff to the intervention. **Inhibiting factors:** Without the support of education, family carers find it difficult to weigh burdens/ benefits of treatment options and make decisions for advanced stages of dementia.
Cameron, (2020) *"Challenges faced by residential aged care staff in decision-making for residents with dementia"* **[37]**	Australia	Residential Aged Care Facility (RACF)	Qualitative exploratory design Individual or group interviews	14 RAC facilities 80 staff	**Inhibiting factors**: Most staff felt that the extent of residents' participation in SDM should reflect the stage to which their dementia had progressed. Others suggested that residents cannot generally make decisions at all. **Enabling factors:** Support for staff needs to include robust policies and procedures outlining the organisation's approach to SDM along with a decision-making tool that will empower staff in SDM with residents. **Environmental issues:** Staff decided from one instance (scenario) to the next about which of residents' preferences they should support or facilitate.
Cranley et al. (2020) *"Strategies to facilitate shared decision-making in long-term care"* **[19]**	Canada	Long-Term Care Home (LTCH)	Qualitative descriptive design Individual semi-structured interviews	40-bed non-for-profit LTCH 3 Residents 3 Family members 3 Staff	**Inhibiting factors:** Residents and families require more emotional support when making difficult decisions on behalf of the resident. **Enabling factors:** Study identifies key strategies essential to facilitate SDM in long-term care that include training staff to communicate effectively with residents and families and assigning a key worker for each resident to support the resident in decision-making.
Fetherstonhaugh et al. (2016) *"The Red Dress or the Blue?" How Do Staff Perceive That They Support Decision*	Australia	Residential Aged Care Facility (RACF) Persons with dementia	Qualitative study Individual & group interviews	80 direct care staff	**Enabling factors:** There was an existing culture of relationship-centred care. Staff utilised a range of strategies to support decision-making for the person living with dementia.

Making for People With Dementia Living in Residential Aged Care Facilities?" **[30]**					**Environmental issues:** By limiting the choices offered, staff felt they could preserve the decisional autonomy of the person with dementia whilst also helping to reduce confusion.
Gjerberg et al. (2015) *"End-of-life care communications and shared decision-making in Norwegian nursing homes - experiences and perspectives of patients and relatives"* **[25]**	Norway	Nursing Home	Qualitative study Semi-structured interviews and focus groups	6 Nursing Homes 35 Residents 33 Relatives	**Inhibiting factors**: Residents and families expressed unpreparedness for SDM. Most patients stated that they had not had an opportunity to discuss their preferences for treatment and care related to end-of-life with the nursing home staff. **Enabling factors:** Findings show that nursing home staff should take responsibility for initiating conversations about preferences for end-of-life care. SDM should be individualised and iterative. **Environmental issues:** Residents and families acquiesce, deferring decision-making to the staff.
Godwin (2014) *"Colour consultation with dementia home residents and staff"* **[39]**	UK	Specialist Dementia Nursing Home	Qualitative study Mixed methods consultation:	1 Specialist Dementia Nursing Home 34 Residents 42 Staff	**Enabling factors:** Visual aids supported communication with people living with dementia, de-emphasising the spoken word and promoting SDM. Study found the approach achieved higher than expected participation and improved self-esteem. **Environmental issues:** Staff helped develop an unpatronising, person-centred approach to SDM.
Goossens et al. (2020) *"Shared decision-making in advance care planning for persons with dementia in nursing homes: a cross-sectional study"* **[26]**	Belgium	Nursing Home	Quantitative study Cross-sectional design ACP conversations were compared to the three-talk model and rated on the achieved level of SDM	46 Nursing Homes 311 Staff members 42 Residents	**Enabling factors:** The three-talk model by Elwyn et al (2012) is a guided approach to achieve SDM, and views decision-making as a supportive process rather than a once off event and has utility beyond ACP. **Inhibiting factors**: Staff do not perceive themselves sufficiently competent to practice this guided approach frequently, and lack role models in how to apply SDM in their conversations.
Hanson et al. (2011) *"Improving decision-making for feeding*	USA	Nursing Home	Quantitative study Randomized controlled trial -	24 Nursing Homes	**Enabling factors:** Utilising decision aids reduced decisional conflict for families and increased knowledge of treatment options. Family members

options in advanced dementia: A randomised, controlled trial" **[35]**			Questionnaire (Decisional conflict scale administered at 1 and 3 months)	Residents with advanced dementia & eating problems and their families	were more likely to discuss treatments with a healthcare provider, indicating that the decision aid supported rather than replaced clinical communication. The intervention residents were provided with dysphagia diets and experienced less weight loss.
Helgesen et al. (2015) *"Relatives' participation in everyday care in special care units for persons with dementia"* **[21]**	Norway	Nursing Home- Special Care Unit (SCU)	Quantitative study Study-specific questionnaire (derived from 2 previous studies by same researcher)	23 Nursing Home SCU's 233 Relatives	**Enabling factors: F**requent visits by family members are valuable for quality of care, as there is a mutual sharing of information between families and staff and this increases residents' possibility of participating in SDM. **Environmental issues: F**amilies felt decisions about everyday care could be left with staff whom they trusted.
Mann et al. (2013) *"Do-not-hospitalize orders for individuals with advanced dementia: Healthcare proxies' perspectives"* **[36]**	USA	Nursing Home	Qualitative study Semi-structured interviews	2 Nursing Homes 16 Family members (Health Care Proxies/HCPs)	**Enabling factors**: Families who have had a personal experience in healthcare, an understanding of the prognosis of advanced dementia, and a desire to limit resident distress. **Inhibiting factors**: Families who have a perceived lack of physician involvement in decision-making and a limited understanding of 'Do-not-hospitalise' orders and the resident's prognosis.
Mariani et al. (2017) "Shared decision-making in dementia care planning: barriers and facilitators in two European countries" (An Italian and a Dutch LTC setting) **[40]**	Italy & The Netherlands	Nursing Home	Qualitative study Focus group interviews with healthcare professionals who, after 6 months of being trained, applied the SDM framework	2 Nursing Homes: 11 Healthcare professionals (Italy) 9 Healthcare professionals (Netherlands)	**Enabling factors**: Following communication skills training for staff, SDM conversations took place between a triad composed of the resident, the family member and a care home professional as the facilitator. A role-play and feedback system was used for specific education sessions targeted at family caregivers. **Inhibiting factors:** Financial aspects and regulations, were the major inhibitors.
Monson et al. (2021) *"What are the shared decision-making experiences of adult children in regard to their*	Australia	Residential Aged Care Facility (RACF)	Scoping literature review Mixed methods appraisal tool (version 2011)	597 articles screened from four databases published in English, during	**Inhibiting factors:** Limited staffing levels and inadequate skill sets of staff have an inhibiting influence on families' participation in SDM and affects the communication of important information about the resident's health care. Findings indicate a need for

parent/s' health care in residential aged care facilities?" A scoping literature review **[20]**				period 1985-2019	higher educated staff in RCAF's (seen as being the Registered Nurse) in order to promote and engage in SDM with residents and families. **Enabling factors:** In practice, formal SDM and having an equal say are not common.
Norheim et al. (2012) *"Factors that influence patient involvement in nursing homes: staff experiences"* **[31]**	Norway	Nursing Home	Qualitative study Focus group interviews	1 Nursing Home/different wards 16 Multidisciplinary team members (nurses, nursing assistants, physiotherapists and 1 occupational therapist)	**Enabling factors:** The competence-building programme raised consciousness among staff and contributed to a change in staff attitudes about person-centred care (PCC) for resident involvement in SDM. **Inhibiting factors:** Time pressure was a key limiting factor to PCC and SDM. **Environmental issues:** Lack of sufficient time was considered a key factor that risked generating low-quality care.
Sarabia-Cobo (2016) *"Decisions at the end of life made by relatives of institutionalized patients with dementia"* **[27]**	Spain	Long-Term Care Home (LTCH)	Qualitative study based on naturalistic principles Focus groups Reflective notes by researchers	5 LTC Nursing Homes 84 Family members of residents with dementia	Five major issues identified as **inhibiting factors** that influence family members' engagement with decision-making: 1) *the emotional effect:* families of residents with dementia felt an overwhelming emotional burden and guilt when making decisions on the resident's behalf. 2) *the "living death" of the person with dementia:* life for the person with dementia is drastically altered by the disease, leading to functional and cognitive impairments, as well as changes in personality. 3) *the two faces of death*: family members were torn between the two faces of death - the tragedy versus the blessing. 4) *values and objectives regarding treatments at the end of life:* most family members said that their loved ones no longer had a good quality of life. 5) *lack of knowledge about progression of dementia, especially in the later stages:* the lack of a specific/key professional figure to help family members understand the processes of the disease made the decisions even more difficult.

Sims-Gould et al., (2014) *"Autonomy, Choice, Patient-Centered Care, and Hip Protectors: The Experience of Residents and Staff in Long-Term Care"* **[32]**	Canada	Long-Term Care (LTC)	Qualitative study Focus groups (Part of a larger mixed methods study)	2 LTC facilities 27 Residents 39 Staff	**Inhibiting factors:** Evidence based research and the use of hip protectors as a tool for injury prevention took precedence over resident choice. Findings illustrate the tension between a strong commitment by caregivers to safekeeping and violating a resident's right to choice and autonomy. **Enabling factors:** Staff require training on safeguarding individual choice and autonomy as well as injury prevention and best practices**.** **Environmental issues:** Policies need to support staff to work in an environment that allows them to respect individual choice even when residents make a choice contrary to what best practice policies might suggest.