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*Published in:*
Nursing Open

*DOI:*
10.1002/nop2.1618

Received: 30 May 2022 | Revised: 14 October 2022 | Accepted: 13 January 2023

DOI: 10.1002/nop2.1618

NursingOpen Open Access WILEY

INTEGRATIVE REVIEW

# Involvement, topics, and roles of nurses in shared decision-making with patients with dementia in acute hospitals: An integrative review

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## Abstract

**Aim:** To describe nurses' roles, involvement, and topics in shared decision-making with older patients with dementia in acute hospitals.

**Design:** An integrative review.

**Methods:** A systematic search was performed until April 2022 in PubMed, PsychInfo, CINAHL, and Cochrane, followed by a manual search on the reference lists of relevant systematic reviews. Studies were independently screened, appraised using the Joanna Briggs Institute (JBI) methodology, and extracted by two reviewers.

**Results:** Nine studies were included. Nurses were involved as treatment team members, intermediates, or patient supporters. Nurses' roles were most explicit in the preparatory phase of shared decision-making. The step of 'developing tailor-made options' was limitedly identified. 'Deliberating and trying options to reach a decision' were described from an outsider's perspective in which nurses attempted to influence the decision. In conclusion, nurses primarily have a role in decision-making by supplementing patient information. Patient and Public Contribution No Patient or Public Contribution.

KEYWORDS
acute care, decision-making, dementia, hospital care, nurse roles

## 1 | INTRODUCTION

Worldwide, more than 55 million people live with dementia; by 2050, this number is expected to increase to 139 million (World Health Organization, 2021). People with dementia are frequently acutely admitted to a hospital (Briggs et al., 2017) and primarily because of comorbidities (Bunn et al., 2014). Because of multimorbidity and the often acute admission, treatment dilemmas often arise, such as whether or not to operate, how to deal with challenging behaviour, and whether or not to provide invasive treatment (Bunn et al., 2014; Fetherston et al., 2018; Griffiths et al., 2020). Person-centered care is the gold standard of caring (The American Geriatrics Society Expert Panel on Person-Centered Care, 2016). To explicitly allow for taking into account the patient's values, preferences, and goals, decisions should be optimally made with the patient (Elwyn et al., 2012, 2016; Geddis-Regan et al., 2021).

No Patient or Public Contribution.

Shared decision-making within person-centered care implies that the patient and the healthcare providers share responsibility for empowerment, autonomy, and involvement in care and treatment (Håkansson Eklund et al., 2019). For hospitalized patients with dementia, good cooperation between patients, informal carers, and healthcare providers is essential (Burgstaller et al., 2018; Carers Trust, 2016; Digby et al., 2016), especially since the patient cannot always make decisions due to dementia and external factors, such as unfamiliar health care professionals and being in a novel environment (O'Brien et al., 2020).

The decision-making process regarding medical decisions for persons with dementia and their relatives is complex because ethical and legal dilemmas may also be involved, such as determining the capacity to legal consent and establishing the family caregiver's responsibilities as a surrogate decision-maker (Miller et al., 2016). It is known that the decision-making process with patients with dementia is complex and that knowing the patient, the progression of dementia, the patient's values, and the quality of life are critical to effective decision-making (Pecanac et al., 2018). In addition, healthcare providers often consider the relatives representing and speaking for the patient (Bryon et al., 2010; Donnelly et al., 2021; Peixoto et al., 2018). However, research shows that relatives do not only consider the patient's preferences, health, and well-being when making decisions but also include their own perspective and that of family members (Faiman & Tariman, 2019). Nurses influence treatment decisions to varying degrees and wish to be more involved (Arends et al., 2022; Bos-van den Hoek et al., 2021).

Forty models of shared decision-making have been described in the literature. However, there is no consensus in the field on how shared decision-making should proceed (Bomhof-Roordink et al., 2019). Groen's conceptual model was developed for patients with dementia in dementia care networks according to the principles of person-centered care (Groen -Van de Ven, 2017). To our knowledge, this is the only model focusing explicitly on shared decision-making with patients with dementia. Within this model, the decision-making process is iterative and based on balancing autonomy and safety and balancing the wishes and preferences of the patient and the informal caregivers. A decision need starts with *preparatory work*, in which a problem is identified together, followed by *developing tailor-made options* and *deliberating and trying options to reach a decision*. In the preparatory phase, it is essential to define and prioritize the problems and the decision themes that this will involve. This is important because patients with dementia often have complex and multifaceted problems with multiple actors. In patients with dementia, treatment options are not always clear in advance. This requires an exploration of the situation from multiple perspectives to find appropriate alternatives. In the second phase, several options are developed. In the last phase, deliberation in decision-making with people with dementia involves exchanging information and, if possible, trying out options. It is difficult for most patients to predict how they will feel when a particular option is implemented, so trying out options can be crucial in arriving at decisions that genuinely fit the preferences of the person with dementia and relatives. Initial preferences based solely on information may change after people with dementia have experienced the options (Groen -Van de Ven, 2017).

Although shared decision-making involves multiple professionals, this study focuses on nurses in this process. The involvement and roles of nurses in shared decision-making are particularly relevant because nurses frequently have more and more prolonged interactions with patients in which aspects of shared decision-making could be addressed (Truglio-Londrigan & Slyer, 2018). Despite the worldwide interest in shared decision-making, little is known about nurses' roles, topics, and tasks in shared decision-making with elderly with dementia admitted to acute hospitals. Therefore, we aim to provide an overview of what is known about the involvement, topics, and roles of nurses in shared decision-making with patients with dementia in acute hospitals. With the role, we refer to a number of related tasks. The word topics refers to the topics on which treatment decisions are made.

## 2 | METHODS

### 2.1 | Design

An integrative review was performed using the framework of Whittemore and Knafl (2005). The integrative review method is an approach that allows different methodologies to be integrated and provides a summary of empirical and theoretical literature on a topic. Given the lack of direct focus in the literature on this topic, this method was deemed most appropriate (Whittemore et al., 2014; Whittemore & Knafl, 2005). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 checklist was used to guide and report the integrative review (Page et al., 2021).

### 2.2 | Eligibility criteria

We included peer-reviewed full-text studies published in English or Dutch for this study. In addition, Randomized Clinical Trials (RCT), non-randomized intervention studies, observational studies (cohort, case–control, and cross-sectional studies), and qualitative studies about shared decision-making related to nursing care for admitted elderly with dementia were included. Systematic reviews and meta-analyses were used to check the reference lists for additional studies. We included studies that described shared decision-making with hospitalized patients ≥65 years of age with dementia, which also described the involvement and roles of nurses. We excluded studies focusing on hospitalization in nursing homes, tertiary hospitals, or rehabilitation hospitals. Additionally, we excluded systematic reviews, opinion pieces, commentaries, methodological papers, protocols, and articles that were not peer-reviewed.

## 2.3 | Information sources

We systematically searched PubMed, CINAHL, PsycInfo, and Cochrane, including all articles till April 2022.

## 2.4 | Search strategy

We used predefined search strings adapted to the individual databases, developed with support from an experienced clinical librarian. The base of the search was formed on the terms "elderly," "decision-making," "hospitals," and "nurses" (see Table 1 for the search strings). The terms "dementia" and "cognitive impairment" were not included as search terms but used instead as selection criteria to keep the search as broad as possible.

## 2.5 | Selection process

Based on the title and abstract, we initially selected 33 studies. We added two articles based on the reference list of the two systematic reviews we found (King et al., 2018; Moon et al., 2018). Of these 35 articles, nine articles met the inclusion criteria. We excluded studies based on methodological criteria, inappropriate population,

**TABLE 1** Search strings.

| | |
|---|---|
| Pumed | ("aged"[mesh] OR "aging"[mesh] OR "age factors"[mesh] OR elderly[tiab] OR older patient*[tiab] OR old patient*[tiab] OR older person*[tiab] OR old person*[tiab] OR older subject*[tiab] OR older adult*[tiab] OR old adult*[tiab] OR older people [tiab] OR senior*[tiab] OR very old[tiab] OR geriatr*[tiab] OR very-old[tiab] OR very-elderly[tiab] OR oldest[tiab] OR nonagenarian*[tiab] OR octogenarian*[tiab] OR centenarian[tiab] OR 80-and-older[tiab] OR over-80[tiab] OR over-85[tiab] OR over-90[tiab] OR frail*[tiab])<br>AND<br>("decision making"[mesh] OR "clinical decision-making"[mesh] OR "decision making, shared"[mesh] OR decision making[tiab])<br>AND<br>("hospitals"[mesh] OR hospital*[tiab] OR geriatric department*[tiab])<br>AND<br>(hospital* OR "geriatric department*") AND nurs* |
| CINAHL | ((MH "Aged+") OR (MH "Aging+") OR (MM "Age Factors") OR TI (elderly OR "older patient*" OR "old patient*" OR "older person*" OR "old person*" OR "older subject*" OR "older adult*" OR "old adult*" OR "older people" OR senior* OR "very old" OR geriatr* OR "very-old" OR "very-elderly" OR oldest OR nonagenarian* OR octogenarian* OR centenarian OR "80-and-older" OR "over-80" OR "over-85" OR "over-90" OR frail*) OR AB (elderly OR "older patient*" OR "old patient*" OR "older person*" OR "old person*" OR "older subject*" OR "older adult*" OR "old adult*" OR "older people" OR senior* OR "very old" OR geriatr* OR "very-old" OR "very-elderly" OR oldest OR nonagenarian* OR octogenarian* OR centenarian OR "80-and-older" OR "over-80" OR "over-85" OR "over-90" OR frail*))<br>AND<br>((MH "Advance Care Planning") OR (MH "Decision Making+"))<br>AND<br>((MH "Hospitals+") OR TI (hospital* OR "geriatric department*") OR AB (hospital* OR "geriatric department*"))<br>AND<br>(MH "Nurses+") OR (MH "Nursing Role") OR TI nurs* OR AB nurs* |
| Psychinfo | (DE "Aging" OR DE "Aging in Place" OR DE "Cognitive Aging" OR DE "Healthy Aging" OR DE "Physiological Aging" OR TI (elderly OR "older patient*" OR "old patient*" OR "older person*" OR "old person*" OR "older subject*" OR "older adult*" OR "old adult*" OR "older people" OR senior* OR "very old" OR geriatr* OR "very-old" OR "very-elderly" OR oldest OR nonagenarian* OR octogenarian* OR centenarian OR "80-and-older" OR "over-80" OR "over-85" OR "over-90" OR frail*) OR AB (elderly OR "older patient*" OR "old patient*" OR "older person*" OR "old person*" OR "older subject*" OR "older adult*" OR "old adult*" OR "older people" OR senior* OR "very old" OR geriatr* OR "very-old" OR "very-elderly" OR oldest OR nonagenarian* OR octogenarian* OR centenarian OR "80-and-older" OR "over-80" OR "over-85" OR "over-90" OR frail*))<br>AND<br>(DE "Decision Making" OR DE "Choice Behaviour" OR DE "Group Decision Making" OR DE "Management Decision Making" OR "decision making"))<br>AND<br>(DE "Hospitals" OR DE "Psychiatric Hospitals" OR DE "Sanatoriums" OR TI (hospital* OR "geriatric department*") OR AB (hospital* OR "geriatric department*"))<br>AND<br>DE "Nurses" OR DE "Psychiatric Nurses" OR DE "Public Health Service Nurses" OR TI nurs* OR AB nurs* |
| Cochrane | (elderly OR "older patient*" OR "old patient*" OR "older person*" OR "old person*" OR "older subject*" OR "older adult*" OR "old adult*" OR "older people" OR senior* OR "very old" OR geriatr* OR "very-old" OR "very-elderly" OR oldest OR nonagenarian* OR octogenarian* OR centenarian OR "80 and older" OR "over-80" OR "over-85" OR "over-90" OR frail*)<br>AND<br>("advanced life care planning" OR "advanced care planning" OR "advance care planning" OR "advance health care planning" OR "end-of-life-plan*" OR "life-planning" OR "lead guid" OR "eol planning" OR "end-of-life care plan*" OR "decision making")<br>AND (hospital* OR "geriatric department*")<br>AND nurs* |

or setting. A Prisma flow diagram of the search results is shown in Figure 1 (Page et al., 2021). Two researchers AK and JS between (…) independently reviewed the articles in Rayyan (Ouzzani et al., 2016). In the case of different judgements, the decision was deliberated and made by consensus. Titles and abstracts of studies retrieved using the search strategy and those from additional sources were screened independently by two review authors AK and JS between (…) to identify studies that potentially met the inclusion criteria. The full text of these potentially eligible studies was retrieved and independently assessed for eligibility by these two review team members. In the case of different judgements, the decision was deliberated and made by consensus.

## 2.6 | Data collection process

A standardized, pre-piloted form was used to extract data from the included studies to assess study quality and evidence synthesis. The same two researchers performed data extraction. Extracted information included authors; location; type of study; aim; sample; data collection, intervention; data-analysis/ and outcome measures, shared decision-making topics in care, the roles and tasks of nurses, and finally, the process of shared decision-making.

## 2.7 | Study risk of bias assessment

All articles were assessed for quality by the review team. For this purpose, the critical appraisal tools of the Joanna Briggs Institute (JBI) were used (Joanna Briggs Institute, 2020). These tools critically evaluate published articles' reliability, relevance, and outcomes. For this study, forms have been used for qualitative studies (8) and an RCT (1). The reviewers independently completed the risk of bias checklists and discussed the differences until a consensus was reached. The criteria were assessed with *Yes-No, NA* (not applicable), or *unclear*. Studies in which no items were rated with *No* or *unclear* were judged to be of good quality. Studies with a maximum of one 'no' were considered sufficient. Studies with two 'no' were rated as mediocre and three or more 'no' as insufficient.

## 2.8 | Synthesis methods

In data synthesis, we used 'data reduction', 'data comparison', 'conclusion drawing', and 'verification' to increase rigour (Whittemore & Knafl, 2005). The data synthesis started by selecting all relevant text fragments concerning the research question and organizing this into

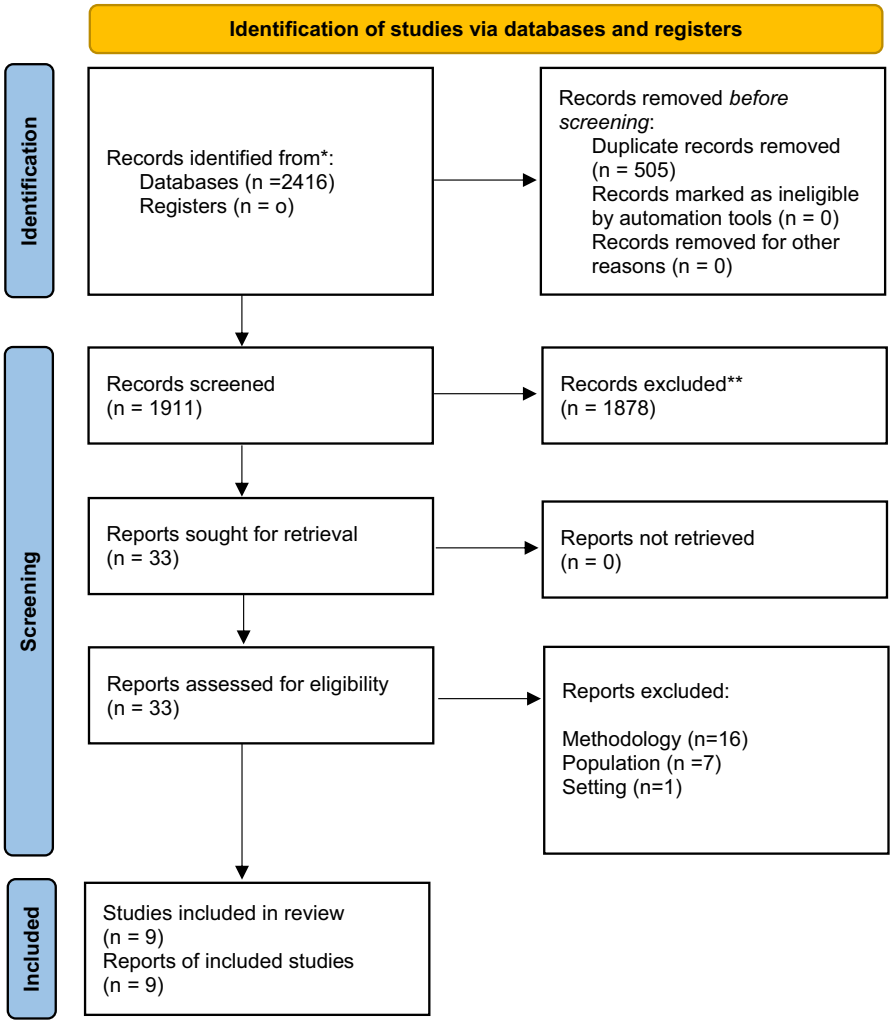


FIGURE 1 Prisma flow diagram (Page et.al., 2021).

a table. This table included the following categories: involvement of nurses, topics of treatment decisions, the role of nurses, and the process of shared decision-making. These data were summarized, analysed in several phases until consensus was reached, and discussed with the research team, where the data were increasingly solidified. Finally, the data were categorized in more detail by the stages of shared decision-making of Groen's model (Groen -Van de Ven, 2017).

## 3 | RESULTS

Totally nine studies were included. The studies have been conducted in the U.K. ($n = 4$), USA ($n = 3$), Ireland, and Norway. Most studies were qualitative ($n = 8$), and one study was a randomized controlled trial (RCT). The goals of the studies were diverse, such as describing experience and gaining insight into the decision-making process, sometimes in specific disease-related situations. The study of Hanson et al. (2019) was added because the start of the experiment takes place in the hospital phase, and here a start is made with the shared decision-making process. The article by Wong et al. (2020) is broad and describes, among other things, a case of a hospitalized patient with dementia and describes the decision-making of the discharge process from the perspective of person-centered care.

In addition to nurses, patients, informal caregivers, physicians, and social carers participated in the studies. Data collection took place using interviews, observations, file reviews, and specialized care, among others. The characteristics of the studies are specified in Table 2.

The quality of five studies was assessed as good (Table 3) (Bryon et al., 2012, 2010; Dyrstad et al., 2015; Wong et al., 2020). The quality of the remaining studies was judged to be sufficient. One study was rated as mediocre (Hanson et al., 2019).

None of the articles explicitly focused on the involvement and roles of nurses in shared decision-making with people with dementia in acute hospitals. However, each article has described information about this to a more or less extent. In addition, the articles included shared decision-making with patients with dementia, but this was not the direct focus of any of the studies.

### 3.1 | Involvement of nurses and related topics

The level of involvement of nurses in shared decision-making was diverse (Table 4). First, four studies described that nurses participated as members of the treatment team in making shared decisions, contributing professional expertise and knowledge of the patient's situation (Bryon et al., 2012, 2010; Donnelly et al., 2021; Wong et al., 2020). In this regard, nurses were involved in all stages of the shared decision-making process. These studies described shared decision-making on artificial nutrition or hydration, care planning, and hospital discharge.

Second, three studies specified that nurses were involved as intermediates between the patients and the physician, the family, and the nursing team (Baker et al., 2019; Dyrstad et al., 2015; Lichtner et al., 2016). This also includes supporting the patient. The intermediate involvement applied to shared decision-making in treatment decisions regarding hip fractures, hospital discharge, and pain treatment.

Finally, the nurses were involved solely to support the patient in decision-making. This supporting involvement applied to shared decision-making focusing on palliative care and hospital discharge (Hanson et al., 2019; Rhynas et al., 2018).

### 3.2 | The roles of nurses in the process of shared decision making

Five of the nine studies described parts of the shared decision-making process, which we categorized into the steps from Groen's model: preparation, *developing tailor-made options*, and *deliberating and trying options to reach a decision* (Groen -Van de Ven, 2017; Table 4). Nurses fulfilled different roles in the steps of the shared decision-making process of Groen's model (Groen -Van de Ven, 2017).

#### 3.2.1 | Preparation

*The preparation* phase is described as forming a picture, whereby each team member creates a perspective of the patient and situation from their expertise. In the preparation phase, the activities of the professional include gathering information and identifying resources, such as family and home care (Wong et al., 2020).

An essential role for nurses in this phase was to prepare the decision by assessing the patient's situation and taking the initiative to start the decision-making process. Hanson et al. (2019) described the process of assessing the patient in detail, which involved assessing the patient's stage of dementia, prognosis and trajectory, assessment of the physical state, and the social, cultural, and spiritual context. Furthermore, nurses discussed the goals of care decision-making and important treatment decisions such as feeding options, antibiotic use, and rehospitalization with informal carers (Hanson et al., 2019). Nurses discussed plans and recorded stakeholders' opinions (Rhynas et al., 2018).

Nurses were messengers and communicators by intermediating between the patients and the physician, the family, and the nursing team (Bryon et al., 2010, 2012; Hanson et al., 2019; Lichtner et al., 2016; Wong et al., 2020). Nurses provided information, adapted communication to the patient, discussed options, discussed goals of care and follow-up, and were also sensitive to if and how information was received and facilitated the patient to be actively involved (Hanson et al., 2019; Jensen et al., 2020; Lichtner et al., 2016; Rhynas et al., 2018). For this purpose, nurses used non-verbal communication cues, for example, regarding pain (Baker et al., 2019; Lichtner et al., 2016). Nurses enable patients and informal caregivers to contribute to decision-making by taking advantage of their more extended and more intense contact with patients. They have both access and the opportunity to positively build relationships with patients and informal caregivers. They can take every opportunity to discuss and, crucially, record individual preferences and conversations about discharge planning (Rhynas et al., 2018). Finally, in

**TABLE 2** Characteristics of included studies.

| Authors, (year)/country | Type of study/data collection/ intervention | Aim | Sample | Data analysis/outcome measures |
|---|---|---|---|---|
| Baker et al. (2019) USA | Qualitative design Interviews by phone and in person | Determine what factors are considered when deciding on a surgical intervention in patients with hip fractures and dementia | Physicians ($n = 15$) Nurses ($n = 95$) | Summaries for each theme |
| Bryon et al. (2010) UK | Qualitative design One-on-one semi-structured interviews | Explore and describe the involvement of nurses in the care regarding decisions about artificial nutrition or hydration in hospitalized patients with dementia | Nurses ($n = 21$) | Grounded theory approach |
| Bryon et al. (2012) UK | Qualitative design One-on-one semi-structured interviews | Explore and describe how nurses experience their involvement in artificial nutrition or hydration decision-making for hospitalized patients with dementia. | Nurses ($n = 21$) | Grounded theory approach |
| Donnelly et al. (2021) Ireland | Qualitative design Semi-structured interviews | Explore and describe experiences of supported decision-making to identify barriers and incentives to assisted decision-making in people with dementia | Health and social care professionals' ($n = 26$) | Thematic analysis |
| Dyrstad et al. (2015) Norway | Qualitative design Participant observations | Explore older patients' participation during admissions to and discharges from, a hospital. | Patient ($n = 41$) | Systematic text condensation approach |
| Hanson et al. (2019) USA | Pilot randomized controlled trial Protocolized specialty palliative care consultation, and telephone support 2 weeks after discharge | Develop a best-practice model of palliative care for dementia and conduct a pilot project for palliative care for patients with dementia following hospitalization for acute illness | Intervention dyads ($n = 26$) Control dyads ($n = 31$) Patients: aged 65 years or older | 1. Hospital or emergency department visits in the 60 days after discharge, defined as hospital readmissions or emergency room visits reported in family interviews. 2. Patient- and family-related outcomes |
| Lichtner et al. (2016) UK | Qualitative design Non-participant observation, Semi-structured interviews, Existing policies and procedures, Medical and nursing notes | Examining how healthcare professionals recognized, assessed, and managed pain in patients with dementia in acute settings with the goal of developing a decision support tool to improve the management of pain | Patients ($n = 31$): Hours of observation ($n = 170$) | Thematic analysis |
| Rhynas et al. (2018) UK | Qualitative design Written narratives | Gain an in-depth understanding of the decision-making processes, described in case files, that play a role in the discharge of older people admitted to the hospital from home and discharged to a nursing home | Case records ($n = 5$) | Three stage narrative data-analysis |
| Wong et al. (2020) USA | Qualitative design Hypothetical case | Explore frameworks and models of care that can be utilized to improve transition-of-care out comes and alleviate some of the ethical dilemmas surrounding decision-making capacity, safe discharge planning, and supporting older adults in the community | Hypothetical clinical case about older patient with cognitive impairment | Ethical analysis |

**TABLE 3** Critical appraisal of selected studies.

| Qualitative studies | Baker et al. (2019) | Bryon et al. (2010) | Bryon et al. (2012) | Donnelly et al. (2021) | Dyrstad et al. (2015) | Lichtner et al. (2016) | Rhynas et al. (2018) | Wong et al. (2020) |
|---|---|---|---|---|---|---|---|---|
| Congruity between the stated philosophical perspective and the research methodology | NA | NA | NA | NA | NA | NA | NA | NA |
| Congruity between the research methodology and the research question or objectives | YES | YES | YES | YES | YES | YES | YES | YES |
| Congruity between the research methodology and the methods used to collect data | YES | YES | YES | YES | YES | YES | YES | YES |
| Congruity between the research methodology and the representation and analysis of data? | YES | YES | YES | YES | YES | YES | YES | YES |
| Congruity between the research methodology and the interpretation of results | YES | YES | YES | YES | YES | YES | YES | YES |
| A statement locating the researcher culturally or theoretically | YES | YES | YES | YES | YES | YES | YES | YES |
| Influence of the researcher on the research, and vice- versa, addressed | NO | YES | YES | NO | YES | NO | NO | NA |
| Participants, and their voices are adequately represented | YES | YES | YES | YES | YES | YES | YES | NA |
| The research is ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body | UN-CLEAR | YES | YES | YES | YES | YES | YES | NA |
| Conclusions drawn in the research report flow from the analysis, or interpretation, of the data | YES | YES | YES | YES | YES | YES | YES | YES |
| Conclusion |  |  |  |  |  |  |  |  |
| **Randomized controlled trial** | Hanson et al. (2019) | | | | | | | |
| Was true randomization used for assignment of participants to treatment groups? | YES | | | | | | | |
| Was allocation to treatment groups concealed? | YES | | | | | | | |
| Were treatment groups similar at the baseline? | YES | | | | | | | |

(Continues)

TABLE 3 (Continued)

| Qualitative studies | Baker et al. (2019) | Bryon et al. (2010) | Bryon et al. (2012) | Donnelly et al. (2021) | Dyrstad et al. (2015) | Lichtner et al. (2016) | Rhynas et al. (2018) | Wong et al. (2020) |
|---|---|---|---|---|---|---|---|---|
| Were participants blind to treatment assignment? | NO | | | | | | | |
| Were those delivering treatment blind to treatment assignment? | NO | | | | | | | |
| Were outcomes assessors blind to treatment assignment? | YES | | | | | | | |
| Were treatment groups treated identically other than the intervention of interest? | YES | | | | | | | |
| Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed? | YES | | | | | | | |
| Were participants analysed in the groups to which they were randomized? | YES | | | | | | | |
| Were outcomes measured in the same way for treatment groups? | YES | | | | | | | |
| Were outcomes measured in a reliable way? | YES | | | | | | | |
| Was appropriate statistical analysis used? | YES | | | | | | | |
| Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial? | YES | | | | | | | |
| Conclusion |  | | | | | | | |

*Note*:  , Good Quality;  , Sufficient quality;  , Mediocre quality.

collaboration with other disciplines, nurses had the task of assessing the extent to which informal carers took the patient's wishes seriously or whether other stakes were involved (Donnelly et al., 2021; Dyrstad et al., 2015; Rhynas et al., 2018).

### 3.2.2 | Developing tailor-made options

*Developing tailor-made options* is described as weighting treatment options and the value associated with treatment options (Lichtner et al., 2016). Involved roles in this phase were to advocate for the family and try to influence decisions, if possible, in favour of the patient's wishes (Dyrstad et al., 2015).

### 3.2.3 | Deliberating and trying options to reach a decision

Trying options as an intermediate step was not mentioned in the articles found. Decision-making took place in family meetings or with an interprofessional team, where the patient and family were given time and space to think about what decision they wanted to make (Donnelly et al., 2021; Wong et al., 2020). In addition, concerning artificial nutrition or hydration, it was indicated that the physician was responsible for making a decision (Bryon et al., 2010, 2012).

Regarding the roles in this phase, two studies explicitly described nurses as part of the team that made a collaborative decision (Baker et al., 2019; Donnelly et al., 2021). Additionally, nurses

**TABLE 4** Involvement, topics, and roles of nurses per phase.

| | **Involvement:** ***Member of the decision-making team*** | **Involvement:** ***Intermediator*** | **Involvement:** ***Supporter of patients*** | **Process of SDM** |
|---|---|---|---|---|
| Identified topics | • Artificial nutrition or hydration<br>• Care planning<br>• Hospital discharge | • Treatment decision hip fractures<br>• Hospital discharge<br>• Pain treatment | • Palliative care<br>• Hospital discharge | |
| Role-Preparation[a] | Preparator:<br>• Assessing the patient's situation and initiating the decision-making process<br>• Messengers and communicators:<br>• Intermediate between the patients and the physician, the family, and the nursing team<br>• Build a relationship with the patient<br>• Personalizing information provision<br>• Evaluation to which extent the informal carer takes the patient's opinion seriously | Preparator:<br>• Bring valuable insight, that complements clinicians' perspectives, such as that nurses assess the rehabilitation potential of the patient with dementia considering quality of life<br>Messengers and communicators:<br>• Providing information to patient and family<br>• Adapt communication to patient<br>• Identify non-verbal communication cues regarding pain<br>• Advocating for family. | Preparator:<br>• Identify stage, prognosis, and trajectory of dementia<br>• Assessment and treatment of pain and other physical symptoms<br>• Assessment and management of neuropsychiatric symptoms<br>• Spiritual needs assessment<br>• Cultural concerns framing care<br>• Discuss discharge plans, influence decision-making, and record the opinions of stakeholders<br>• Goals of care decision-making<br>• Key clinical decisions such as feeding options, antibiotic use, and rehospitalization<br>• Messengers and communicators:<br>• Social support for informal caregiver stress<br>• Build relationships with patients and informal carers positively so that every opportunity to discuss and, crucially, record individual preferences and conversations about discharge planning is taken<br>• Discuss discharge plans, influence decision-making, and record the opinions of stakeholders | • Information, trying to build a picture by gathering information (*accurate diagnosis, capacity evaluation, functional evaluation, family observation)*<br>• Elicit goals and preferences (*where to live, who and what are important, lifelong habits and practices)*<br>• Identify resources *(family, community, home health, adult day health, support groups)*<br>• Educate patient and family on resources and options<br>• Each member of the team forms a picture of the patient and situation from their own expertise<br>• Hypothesis generation and evaluation<br>• Judgement |
| Role-Development of tailor-made options[a] | | • Advocating for family<br>• Influencing decisions, if possible, in favour of the wishes of the patient | | • Weighting of treatment options and value associated with treatment option |
| Role-Deliberating and trying options to reach a decision[a] | • Spectator and team player during decision-making in team; representing the family; physician making the final decision<br>• After decision, evaluation of decision and comparison to own perception of proper care (position taking)<br>• Part of the interprofessional team. and the extent to which other considerations are involved<br>• Providing post discharge evaluation | • After decisions, the nurse calls the family | | • Decisions are made during a family meeting<br>• Physician is responsible of making the final decision<br>• Interprofessional team allows family and patient time and space to make decisions |

[a]Steps in tasks based on the conceptual model of Groen (Groen -Van de Ven, 2017).

guided the family throughout the process and represented the family in meetings. Nurses acted as spectators and team players during decision-making in the team. After deciding, they evaluated it and determined whether they agreed and adjusted their handling accordingly (Bryon et al., 2010, 2012). Nurses evaluated the decision made and compared this to their perception of proper care (Bryon et al., 2010, 2012; Donnelly et al., 2021; Wong et al., 2020).

## 4 | DISCUSSION

This integrative review aimed to describe nurses' roles, topics, and involvement in shared decision-making with elderly with dementia in acute hospitals. Despite the extensive literature review, there appears to be relatively little literature available on the roles of nurses and, in general, in shared decision-making with patients with dementia in the hospital. We found only nine studies, of which just one was quantitative. In addition, none of the articles described a definition of shared decision-making. Finally, the expertise of the decision-makers regarding cognitive impairment has not been described, nor is the role of the hospital setting clear. Further research on the roles and tasks of nurses in shared decision-making related to the influence of the patient's dementia can provide more insight.

### 4.1 | Involvement

The results show that nurses are involved to varying degrees in the shared decision-making process. Previous research shows that hospital nurses are frequently less involved in shared decision-making than they prefer (Arends et al., 2022; Bos-van den Hoek et al., 2021; Tariman et al., 2018). In addition, research shows that it is essential for nurses to know their patients' goals and that most of them are not achieved at discharge from the hospital (van Munster et al., 2022). Nurses often have intensive contact with patients and their relatives. They are easily approachable, usually build a confidential relationship with the patient, and focus on all aspects of the patient's life. This makes nurses particularly qualified to identify with the patient's essential goals and values. This is an important step in the process of shared decision-making. The degree of involvement might depend on the type of decisions. For example, a medical or multidisciplinary decision, such as hip surgery, will involve the nurse differently than a decision related to nursing care. More research is needed to determine how nurses' involvement is related to the type of decisions and what is a preferred situation in this regard.

### 4.2 | Topics

The identified topics were not specific to patients with dementia. However, the topics correspond to research on treatment decisions involving patients with dementia (Pecanac et al., 2018). Topics focused on everyday care decisions, such as grooming, socializing, eating, and drinking, were missing. In long-term care, it is known that these are topics on which patients can often still make their own decisions for a long time (Miller et al., 2016).

We expected to find more research explicitly related to dementia-related dilemmas, such as whether to provide invasive treatment. It is not clear whether shared decision-making is not applied here or whether nurses are not involved. We also expected to find studies on specific nursing topics, such as dealing with challenging behaviour or how and when to involve family caregivers in care and decision-making. In the studies found that it is not clear whether and how advance care planning was involved and whether it may have been initiated during the admission (Moon et al., 2018; Sellars et al., 2019).

### 4.3 | Roles

In general, the nurses' roles correspond partly to previously described roles of the nurse in shared decision-making in general care: 'facilitating shared decision-making', 'complementing shared decision-making', and 'checking the quality of a decision' (Bos-van den Hoek et al., 2021). The nurse's neutrality and role as a coach were not explicitly mentioned in this study as part of shared decision-making. However, the role of the supporter is very similar and fits to the role of the coach: to help patients and their relatives to be involved in decision-making and make informed and effective decisions (Stacey et al., 2008).

#### 4.3.1 | Preparation

In the preparatory phase, the tasks of nurses were described most extensively. Nurses supported the patient, built a relationship with the patient and the treatment team, identified a possible decisional conflict in the patient, remained neutral in the process, and provided decision coaching (Lewis et al., 2016). An added value seems to be that nurses complement the perspective of other healthcare providers through their relationship with the patient. This is consistent with the role of nurses described earlier (Bos-van den Hoek et al., 2021). The role of adapting the information, preparing decisions by repeating information, and adhering to the patient's situation and understanding are specific for shared decision-making with patients with dementia and fit well with person-centered care (Daly et al., 2018). However, our review shows how insufficient nurses incorporate informal carers in these roles seems. This is relevant because patients with dementia cannot always decide for themselves. Some nursing tasks seem more specific to patients with dementia, such as adapting communication if required, assessing the patient's situation, and enabling patients and informal carers to contribute to the decision-making process. In addition, it is known that relatives indeed experience insufficient involvement in the decision-making process (Pecanac et al., 2018). Because nurses are present 24 hours

a day, they have more opportunities for contact with the patient and informal carers. This makes it easier for them to build a relationship with patients and informal carers more quickly and therefore have more information about the patient. This allows for a more complete picture of the patient's specific situation, with particular wishes and preferences. Nurses share information with physicians that they consider relevant to the decision (Bos-van den Hoek et al., 2021). Finally, nurses discuss the goals of care and treatment. As Elwyn et al. (2012) describes in his article, it is unusual that in the older models, the goal component is not included. His latest model uses the phases of goal-team talk, goal-option talk, and goal-decision talk. These new insights are not yet apparent in the studies used in our review.

#### 4.3.2 | Developing tailor-made options

The step of developing tailor-made options was identified to a moderate extent in the included studies. This may be due to the topic areas on which decisions were made. It seems more logical that this is done but not explicitly described.

#### 4.3.3 | Deliberating and trying options to reach a decision

Deliberating was described from two perspectives. Hanson et al. (2019) described the final decision-making in this phase. In contrast, Dyrstad et al. (2015) and Rhynas et al. (2018) described that nurses tried to influence decision-making more from the outside, without direct involvement. This was also found in another review, where the nurse's contribution to shared decision-making in general care was described as 'checking the decision' (Bos-van den Hoek et al., 2021). It is not apparent how the decisions are made in the final phase, except for Bryon, because they indicated that the physician is responsible for the final decision (2010, 2012). It is unclear to what extent the patient and/or informal carer are involved in the decision-making, especially when the nurse does not represent them.

Trying options was not explicitly described. We expected to see examples such as that in the context of preventing delirium, the patient could try daytime activities, such as in a geriatric ward, or at discharge, the patient could try a day in a new residential facility or daycare center (Groen -Van de Ven, 2017). A logical explanation for the absence of this step is that the step does not appear in the models limited to choice talk, option talk, and decision talk (Bomhof-Roordink et al., 2019; Elwyn et al., 2012; Stiggelbout et al., 2015). This is intriguing because it may suggest that nurses have already excluded possible options from their discussion with the patient (Van Humbeeck et al., 2020).

### 4.4 | Shared decision making

In this study, we chose to use Groen's model for analysis. This model was developed for dementia networks, not acute hospitals (Groen -Van de Ven, 2017). The type of decisions and timing are often quite different in acute hospitals. For shared decision-making with frail elderly patients in acute hospitals, Stiggelbout's model is often used (Bomhof-Roordink et al., 2019; Stiggelbout et al., 2015). This model is also applicable for shared decision-making with patients with dementia as long as the relatives and the patient's goals and preferences are involved. Because it is not known how to take into account the patient's dementia when using this model, it is less applicable. Currently, no appropriate model is available for this purpose (Groen -Van de Ven, 2017). In addition, people with dementia want to be involved in decision-making about their care (Daly et al., 2018). Then, it is notable that asking about the patient's preferences has only been described in the preparation phase. This could explain the experiences of family caregivers and patients that their preferences are not considered (Bridges et al., 2020; Keuning-Plantinga et al., 2021).

Finally, some criticisms indicate that shared decision-making requires relational autonomy (Gómez-Vírseda et al., 2019; Lewis, 2019). This is often not possible in patients with dementia, so the healthcare provider can make decisions with the patient's representatives. Groen's model fits the advice from this article because it starts with balancing autonomy and safety and balancing the wishes and preferences of the patient and the informal caregivers (Groen -Van de Ven, 2017). However, the health care provider is required to allow the patient to accept or refuse a particular treatment based on the patient's sovereignty. This can lead to dilemmas in practice, which are not described in the articles found.

### 4.5 | Limitations

This integrative review provides directions for future nursing research on nurses' roles and tasks concerning shared decision-making with patients with dementia in acute hospitals. This study is strengthened by assessing the study quality of the included studies, which is not a standard step in integrative reviews (Whittemore & Knafl, 2005). Additionally, we rated the quality of eight of the reviewed studies as adequate to good and one as mediocre. We reduced bias by involving two independent reviewers in the selection process.

A major limitation of our review is that the topic has been studied to a minimal extent; therefore, we must consider the results cautiously. The outcomes identified are heterogeneous because the aims of the studies varied. The results gave no insight into the extent to which the patients' dementia, or the effect of cognition on the patient's ability to participate in decision-making, affects the shared decision-making process. More research is needed to understand the role of nurses in shared decision-making with patients with dementia in acute settings, focusing on care-related dilemmas and the impact of the patient's dementia.

Finally, there is a possibility of publication bias. We found only one RCT, which may indicate this (Polit & Beck, 2017). A subsequent

study could expand the search strategy to include hand-searching, unpublished reports, and conference abstracts to reduce the impact of publication bias.

### 4.6 | Relevance for clinical practice

Nurses' roles and tasks in shared decision-making in patients with dementia focus on facilitating and complementing decision-making. In addition, they can have a role in representing the patient and in supporting the informal caregiver when asked for it. Because nurses are involved in the care, their voice in the decision-making process seems essential and should be made more explicit in the development of person-centered care in acute care.

To get a more comprehensive understanding of shared decision-making with patients with dementia, it is valuable to understand the dilemmas faced in the care and treatment of hospitalized patients with dementia. Shared decision-making should focus on care and treatment decisions, e.g., challenging behaviours and decisions in daily care. A focus on the role of the patient and the informal caregivers is necessary from the perspective of person-centered care. Only if patients, nurses, and other professionals cooperate optimally and, more explicitly, decision-making on complex topics with patients with dementia will evolve into decisions taken together.

Concerning the roles and tasks of nurses, we need to establish in further studies how shared decision-making with patients with dementia in acute hospitals occurs and how the patients' cognitive impairment influences the ability of shared decision-making. Although there is some evidence that nurses' influence can add value to the shared decision-making process, more research is needed to gain insight into the contributing factors and the benefit for the patient and their informal caregivers when the nurse is involved.

## 5 | CONCLUSION

This integrative review provides an overview of nurses' roles, topics, and tasks in shared decision-making in the care of patients with dementia in acute hospitals. This study demonstrated three levels of involvement of nurses in shared decision-making, namely, that of a member of the treatment team, intermediates, and supporter of the patient. Specific roles focusing on the patient's dementia are primarily described in the preparation phase. In addition, nurses play an essential role in decision-making by completing information about the patient. Nurses advocate, are messengers and communicators, and intermediates between the professionals and the patient and informal caregivers. Further research should focus on the roles and tasks of nurses in shared decision-making related to specific dementia-related dilemmas in care to understand better nurses' role in shared decision-making and how patients' dementia affects the ability of decision-making.

### FUNDING INFORMATION

No external funding.

### CONFLICT OF INTEREST

None.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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**How to cite this article:** Keuning-Plantinga, A., Stoffels, J., Roodbol, P. F., Finnema, E. J., & Van Munster, B. C. (2023). Involvement, topics, and roles of nurses in shared decision-making with patients with dementia in acute hospitals: An integrative review. *Nursing Open*, *10*, 3519–3532. https://doi.org/10.1002/nop2.1618