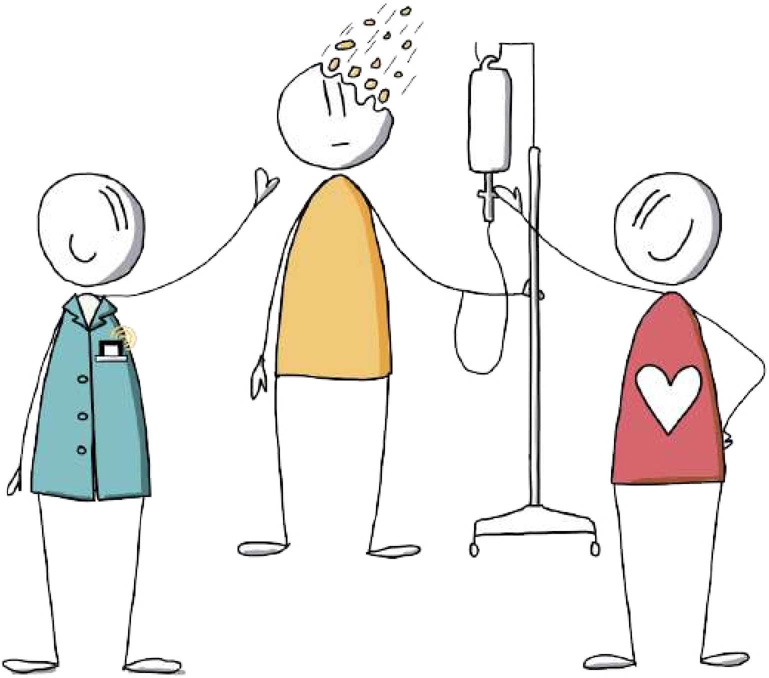
Dementia Care in Dutch Hospitals:

Perspectives on Person-Centred Nursing Care and Shared Decision-Making

Annette Plantinga



Stellingen

behorende bij het proefschrift

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door

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1. Het toevoegen van criteria over persoonsgerichte zorg aan de criteria voor kwaliteitsbeoordeling in ziekenhuizen, zoals bijvoorbeeld de HKZ (Harmonisatie Kwaliteitsbeoordeling in de Zorgsector), draagt bij aan een beter inzicht in de kwaliteit van zorg van daar opgenomen patiënten met dementie - hoofdstuk 2
2. Door in de opleiding van verpleegkundigen meer aandacht te besteden aan verpleegkundige zorg voor patiënten met dementie in de ziekenhuizen verbetert de kwaliteit van zorg voor deze kwetsbare groep in die setting - hoofdstuk 3
3. Verbeteren van de communicatie tussen verpleegkundigen en naasten van patiënten met dementie tijdens een ziekenhuisopname, leidt tot minder stress en ontevredenheid bij beide groepen - hoofdstuk 4
4. Verpleegkundige zorg voor patiënten met dementie verbetert wanneer verpleegkundigen actief betrokken zijn bij multidisciplinaire besluitvorming - hoofdstuk 6
5. De kwaliteit van zorg voor patiënten met dementie in het ziekenhuis verbetert als de organisatie psychosociale zorg even belangrijk acht als lichamelijke zorg - dit proefschrift
6. Als een ziekenhuis persoonsgerichte zorg toepast in alle lagen van de organisatie verbetert de kwaliteit van zorg en tevredenheid van patiënten (ongeacht of zij al dan niet leven met dementie) - dit proefschrift
7. Omdat een ziekenhuisopname voor mensen met dementie vaak tot negatieve consequenties leidt voor hun functioneren, moet preventie van ziekenhuisopname bij deze patiëntencategorie in de eerste lijn worden versterkt - dit proefschrift
8. Het grootste goed dat we hebben in de zorg is de menselijkheid die we bieden. Dat mag nooit verloren gaan - Els Borst
9. Nursing is both a science and an art. It is a science in that it is based on scientific knowledge and research; it is an art in that it requires the application of this knowledge compassionately and effectively – Virginia Henderson

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A.S. TALMA STICHTING

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Dementia care in Dutch hospital settings: perspectives on person-centred nursing care and shared decision-making

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Zien

Het leven heeft mij dag aan dag
heel duidelijk laten blijken,
de mooiste dingen die je ziet,
die zie je, zonder te kijken.

Ze blijven bij je bovendien,
je hebt ze met je hart gezien.

Toon Hermans

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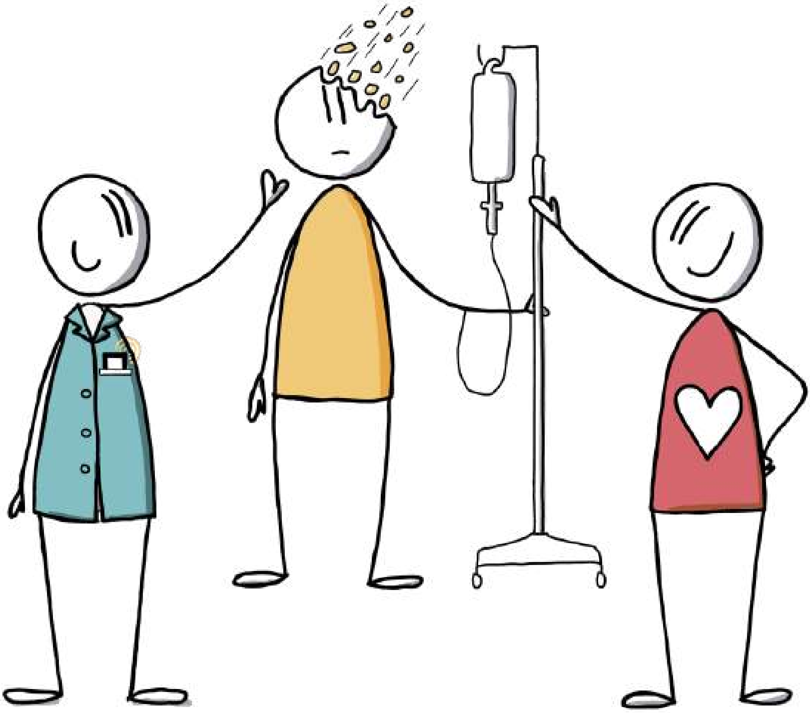

CHAPTER 1

General Introduction

Chapter 1. General Introduction

Once, a man who had recently become a widower approached me and told me a deeply touching story about caring for his wife with dementia. He explained how challenging it was, especially as she refused to be cared for by others. As a result, he was looking forward to his wife going into hospital for a minor operation as he believed she would receive the specific care she needed. However, he was left frustrated by a catalogue of mishaps and neglect encountered on the hospital ward: his wife could not eat because she did not know how to lift the lid of her meal tray her medication needed to be ground up but was not, and her drinks were untouched. Instead of relief, he felt additional pressure.

This experience made me, as a researcher and as nurse (not practising), curious about the standard of nursing care of hospital patients with dementia and the impact this has on their relatives.

1.1 Background

Dementia is a neurodegenerative disorder caused by several diseases that, over time, destroy nerve cells and damage the brain beyond what would be expected from the normal effects of biological ageing (1). Dementia has a significant impact on cognition and behaviour, which, by definition, interferes with a person's daily functioning (2). Alzheimer's disease is the most prevalent form of dementia, accounting for 60-70% of the cases. The impact of dementia can differ from person to person, depending on the underlying causes, other health issues, and the individual's cognitive function before becoming ill. Common behavioural symptoms of dementia include extreme mood swings and personality changes, feelings of anxiety and depression, bouts of anger, self-absorption, and withdrawal from social situations. In addition, dementia leads to progressive functional decline (3). There is currently no known cure for dementia, so symptoms typically worsen over time, and as the disease progresses, the need for assistance with personal daily care increases (1).

Research has highlighted issues with identifying hospital patients as those with dementia because of the difficulty of obtaining an official diagnosis. One of the key problems is that more than 85% of patients with dementia have three or more comorbidities (4). In comparison, the United Nations reports that between 27% and 46% of people over 65 in EU countries have at least two chronic diseases (5). Moreover, people with dementia are frequently admitted to hospital for exacerbations of one of these chronic conditions or other conditions such as fractures or respiratory, urinary, or gastrointestinal infections (6,7). The precise percentage of hospitalised patients with dementia is unknown because of the lack of explicit registration of dementia as a comorbidity and because formal diagnoses are not always received.

Currently there are approximately 728 million people over the age of 65 worldwide, with the United Nations predicting this figure will double to 1.5 billion by 2050 (8). With neurodegenerative diseases commonly linked to old age, cases of dementia are also expected to increase worldwide, from 55 million in 2023 to 152.8 million cases by 2050, almost triple (1,9). By 2040, dementia is predicted to cause the highest mortality and disease burden (9).

In the Netherlands, approximately 290,000 people live with dementia (10,11). Contrary to what international literature shows, in 2019, the hospital admission rate for people with known dementia in the Netherlands was 22%, comparable to the admission rate for older people (65+) in the same year (12). However, there is a difference in the type of admission. For people with dementia, admissions of more than one day are more frequent (77%) than for older people without dementia (53%) (12).

In contrast to most European countries, the Netherlands is characterised by a robust primary care system and gatekeeper policies, and a cautious policy regarding the admission of patients diagnosed with dementia, resulting in lower and shorter hospital admission rates (13). The focus during hospital treatment of patients with dementia is on the physical disease that caused their admission, with less emphasis on their need for dementia-related support and care (14,15). However, hospitalisation of people with dementia can lead to unintended negative consequences such as discomfort and a decline in cognitive and functional abilities (16,17).

1.2 People with dementia and their relatives in hospitals

People with dementia often experience hospitalisation as disruptive to their daily routines (18,19). Moreover, they desire more control over their treatment than mostly is the case, and furthermore, they may feel neglected by nurses (14). Qualitative interviews with hospitalised patients with dementia reveal that patients with dementia want to be treated with the same respect, kindness, and privacy as other patients (20). Another study reported that patients with dementia frequently experience differential treatment compared to those without dementia. This included the use of patronising language and unprofessional behaviour by nurses, which can cause increased anxiety in patients with dementia (19).

Notably, patients with dementia have highlighted that the support of a relative is essential and that they may feel anxious when they are not present. Relatives typically have a deeper understanding of the patient's behaviour and daily routines (20), and therefore nursing care for patients with dementia should also incorporate their relatives. Furthermore, relatives also play the significant role of advocates for the patient with dementia during hospitalisation. A meta-synthesis of qualitative studies shows that hospital admission of a person with dementia can increase this burden on relatives (21–23). During this time, the respite that relatives might typically expect is frequently compromised due to their involvement in caregiving. This was not anticipated by relatives, who had expected the patient to receive person-centred and engaged care throughout their hospital stay (21). In the UK, 77% of relatives of people with dementia report dissatisfaction with the quality of care provided in hospitals, mainly due to inadequate recognition and understanding of dementia, lack of social interaction, limited involvement in decision-making, and insufficient attention to aspects of dignity and respect (14).

1.3 Nursing care

It should be recognised that hospital nurses face significant challenges in caring for patients with dementia due to typical dementia patient behaviours such as agitation, resistance to care, aggression, wandering, and persistent calling (24,25). Dealing with these behaviours requires specialist skills in responding to and managing the deterioration of cognitive functioning, such as memory, attention, language, and judgment (1,26,27), which these nurses are not trained in.

The limited number of international research studies conducted to date suggests that there is significant room for improvement in nursing care for patients with dementia in hospitals (28-30). Nurses have reported a lack of the necessary knowledge and skills required for providing complex psychosocial care. They also indicate that their training does not adequately prepare them to assist in the daily care of patients with dementia or to handle challenging behaviours effectively (25,31).

1.4 Person-centred care

Person-centred care is the international standard for people with dementia (28,29), encompassing the structure, process, and outcomes of care to holistically address their needs. It has several definitions (30), ranging from a general focus on care (31), an explicit focus on nursing care (32), or focusing on dementia (33). This thesis adopts Brooker's definition of person-centred care for people with dementia (33,34), which builds upon Kitwood's theory of dementia care. Brooker's definition underscores the importance of emphasising psychosocial needs and 'seeing the person' (30). Notably, this definition is applicable across different settings, including hospitals (35). Brooker defined person-centred care as comprising four elements that form the acronym VIPS (33–36):

- *Valuing people with dementia and those who care for them (**V**alue)*
- *Treating people as individuals (**I**ndividuals)*
- *Looking at the world from the perspective of the person with dementia (**P**erspective)*
- *Recognising that all human life, including that of people with dementia, is grounded in relationships (**S**ocial environment).*

Person-centred care emphasises Shared Decision-Making (SDM) as an essential element (31,32). Although there are many definitions of shared decision-making, the core elements of SDM include goal-team, goal-option, and goal-decision talks (37,38).

Observational research revealed that nurses applied the physical aspects of patient care over psychosocial and relational aspects (39). This prioritisation may be due to hospital organisations' growing emphasis on task performance and outcome measures, which can come at the expense of the quality of care provided (19,39,40). The application of person-centred care for patients with dementia in Dutch hospitals is unknown.

1.5 The scientific gap

In summary, person-centred care is the preferred international standard for managing people with dementia during hospitalisation. However, research on nursing care for these patients in hospital settings is currently sparse, primarily consisting of qualitative studies or those focused on specific types of wards. Consequently, it is unclear how Dutch nurses consider dementia in their care practices for hospitalised patients with dementia.

1.6 Aim of the thesis

The aim of this thesis is to address a notable gap in existing research by exploring nursing care for people with dementia in Dutch hospitals. Specifically, it focuses on examining the role of nurses in delivering person-centred care and shared decision-making from the perspectives of both nurses and the relatives of patients with dementia. This study seeks to enhance understanding of how dementia care is implemented in practice within these settings.

1.7 Methodology and outline of the thesis

The overall design of the thesis takes a sequential exploratory mixed-methods approach to explore nursing care in hospitals for people with dementia. It should be noted that the term ‘dementia’ is used in this thesis to encompass all patients experiencing cognitive impairment, regardless of the underlying diagnosis, including those with temporary cognitive impairments. This chapter has covered the background and reasoning for undertaking research in this field. **Chapter 2** describes a cross-national validation and psychometric evaluation of ‘The Person-centred care of Older People with dementia in Acute Care’ (POPAC) scale. This scale was developed in Australia for the acute hospital setting and measures the person-centredness of care for older people with dementia. **Chapter 3** is a cross-national survey study examining nursing care from the perspective of nurses with the objectives of describing the following aspects of nursing care: 1. Nurses’ attitudes and perceptions in caring for patients with dementia, 2. How nurses deal with challenging behaviour, and 3. Background variables associated with caring for people with dementia. **Chapter 4** is a descriptive mixed-method study about how relatives of patients with dementia experience care in hospitals. Based on the findings that shared decision-making is an area for improvement and is an essential part of person-centred care, **Chapter 5** describes an integrative review to explore nurses’ involvement in shared decision-making, the topics of SDM, and nurses’ roles. **Chapter 6**, an explorative qualitative study, focuses on how nurses apply SDM with patients with dementia and how they consider the dementia of the patient in this process. Finally, in the general discussion of **Chapter 7**, the results of the separate studies are summarised, the findings are interpreted using the VIPS framework, and the methodological considerations and recommendations are discussed.

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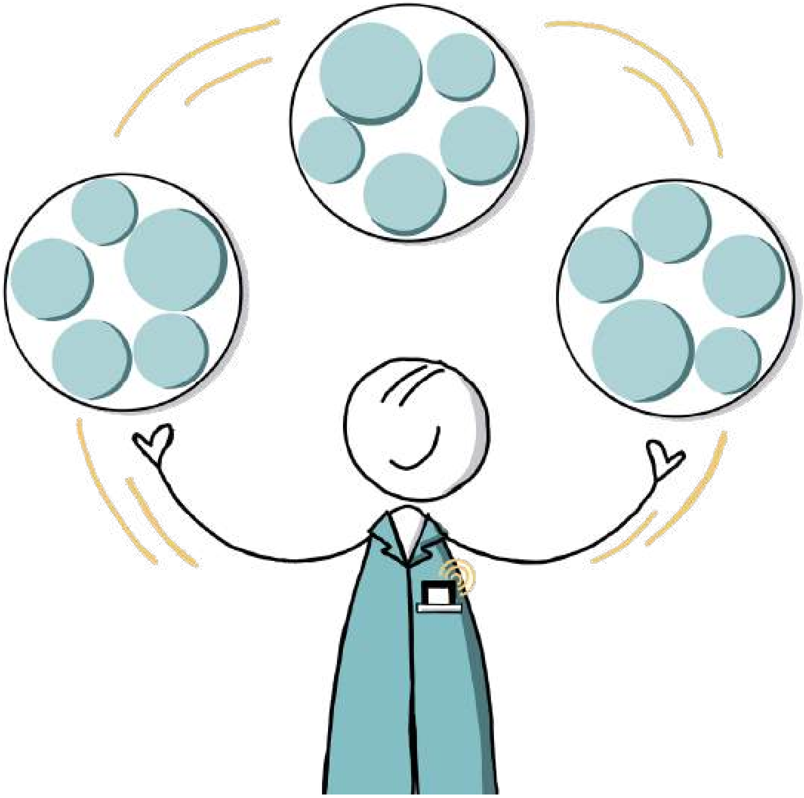

CHAPTER 2

Validation and psychometric evaluation of the Dutch Person-centred care of Older People with cognitive impairment in Acute Care (POPAC)

Chapter 2. Validation and psychometric evaluation of the Dutch Person-centred care of Older People with cognitive impairment in Acute Care (POPAC)

Keuning-Plantinga, A., Finnema, E. J., Krijnen, W., Edvardsson, D., & Roodbol, P. F. (2021). BMC Health Services Research, 21(59), 1–10.

Abstract

Background: Person-centred care is the preferred model for caring for people with dementia. Knowledge of the level of person-centred care is essential for improving the quality of care for patients with dementia. The Person-centred Care of Older People with Cognitive Impairment in Acute Care Scale (POPAC) is a tool to determine the level of person-centred care. This study aimed to translate and validate the Dutch POPAC and evaluate its psychometric properties to enable international comparison of data and outcomes.

Methods: After double-blinded forward and backward translations, a total of 159 nurses recruited from six hospitals (114) and via social media (45) completed the POPAC. By performing confirmatory factor analysis, the construct validity was tested. Cronbach's alpha scale was utilized to establish the internal consistency.

Results: The confirmatory factor analysis showed that the Confirmatory Fit Index (0.89) was slightly smaller than the cut-off value of 0.9. The Root Mean Square Error of Approximation (0.075, p=0.012, CI 0.057-0.092) and the Standardized Root Mean Square Residual (0.063) were acceptable with values less than 0.08. Findings confirm a three-dimensional structure. The loadings of the items (0.69-0.77) indicate that these are strong associated with each of the factors. This study confirms that deleting Item 5 improves the Cronbach's alpha of the instrument as well as of the subscale. Instead of deleting this item, we suggest considering rephrasing it into a positive item.

Conclusions: Our findings suggest that the Dutch POPAC is sufficiently valid and reliable and can be utilized for assessing person-centred care in acute care hospitals. The study enables nurses to interpret and compare person-centred care levels in wards and hospital levels between regions and countries. The results form an important basis for improving the quality of care and nurse-sensitive outcomes, such as preventing complications and hospital stay length.

2.1 Background

Worldwide, approximately 50 million people are living with dementia. Due to the ageing population, this number will increase (1). People with dementia are regularly hospitalized due to comorbidities; they occupy approximately 25% of the hospital beds (2,3). This population is at risk for falls during a hospital stay, inadequate hydration and nutrition, delirium, infection, and functional decline (4–6). These factors impact the duration of stay, the person's functioning, and the care required following discharge (7). Nursing care for people with dementia should be based on evidence, best-practice care, and processes combined with person-centred care to prevent complications (6,8–11). It is known that person-centred care can improve their quality of life. In spite of that, specific knowledge about person-centred care, also referred to as patient-centred or client- centred care, is limited in hospitals (11). However, worldwide, it is the paragon in the care of people with dementia (10,12). The basis of person-centred care in caring for people with dementia is laid by Tom Kitwood (13,14). In a broader context, the framework of McCormack and McCance is often used (15–17). In the care for people with dementia, Brooker's definition and framework are often used (3,18).

To improve the quality of care for people with dementia in an acute care setting, knowledge of the level of person-centredness of the care is important. The literature reports a limited number of instruments that measure person-centred care for dementia patients in an acute hospital setting (8,19). Available instruments are aimed at long-term care (20) or more generically on person-centred care in the acute hospital setting and lack a specific focus on the quality of care for people with dementia (21–24).

The person-centred care of older people with cognitive impairment in acute care (POPAC) scale (19) was developed for the acute hospital setting and measures the person- centredness of care for older people with dementia. The scale consists of three subscales, which can be connected to the elements of person-centred care of the definition used. The subscale 'using cognitive assessments and care interventions' is suitable for valuing people; 'using evidence and cognitive expertise' is suitable for understanding situations from the perspective of the person with dementia; and 'individualizing care' is related to individualizing approaches and the social environment. In addition to measuring and improving the quality of care, translating tools into different language versions enables international comparisons of data and comparative analysis of levels, correlations, and person-centred care outcomes. In addition, there are no Dutch-language instruments available that measure person-centred care in the hospital setting.

The POPAC scale was designed in 2013 by Edvardsson in Australia to establish quantitative measurements to assess experienced levels of person-centred care for people with dementia in acute hospital settings (19,25). Based on the literature, eight dimensions of best practice were used to construct the instrument. Further development with a panel of international experts led to an instrument that consisted of statements on recognizing cognitive impairment, consulting specialist expertise, using evidence-based care protocols or guidelines, making environmental adjustments, providing social enrichments, prioritizing staff continuity and close interactions, avoiding restraints, and individualizing care (19). The degree to which participants agree with item statements is expressed on a 6-point Likert scale with the categories 'never' (1), 'very rarely' (2), 'rarely' (3), 'frequently' (4), 'very frequently' (5), and 'always' (6) (10,19,25). A significant Bartlett's spherical test and a Kaiser-Meyer-Olkin (SME) sample adequacy measurement of >0.7 were used to assess the construct validity. Construct validity was then assessed using principal component analysis with oblimin rotation due to the factors' expected correlation (19).

The original instrument was pilot tested with a sample of 212 nurses from different types of wards, such as neurology, orthopaedics, and cardiology, in an acute care hospital in Melbourne, Australia. After the preliminary test, six items were removed because they did not meet the cutoff for acceptable homogeneity (>0.3). A retest was conducted with 25 nurses from an orthopaedic ward, and the outcomes indicated satisfactory temporal stability (19). The assumption that all items reliably measure a single underlying construct was supported by the item-total correlations ranging from 0.40 to 0.67, where values 0.4 and above indicate very good discrimination (26). The subscales can be combined into a total score, where higher scores indicate higher person-centredness levels to evaluate the overall level of person-centred care. An interpretation of the score is not yet available. The totals of the items per subscale suggest possible areas for improvement of care. The instrument allows the comparison of person-centred care at both national and international levels (19).

Nilsson psychometrically evaluated the instrument in Sweden (2013), and Grealish (2017) evaluated the scale in Australia (10,25). Both Nilsson and Grealish used Cronbach's alpha and corrected total correlation for internal consistency and CFA for construct validity. In addition, in Nilsson's study, temporal stability was measured through the correlation between test and retest scores (10). Both studies reported that the POPAC scale is valid and reliable and can be used to provide insight into nursing care's person-centredness in a hospital setting. However, the high correlations between the subscales and the authors' conclusion that the instrument's dimensionality requires further research are important tenets for this study (10,25). For using the POPAC scale in the Netherlands to study person-centred care in a hospital setting, the instrument needed to be translated into Dutch. Measuring psychometric properties is important for assessing validity and reliability (27). Nurses and nursing managers can use the outcomes of the POPAC scale to improve the quality of care in their ward, and outcomes and data can be used for national and international comparison. Therefore, this study aimed to conduct a cross-national validation and psychometric evaluation of the Dutch version of the POPAC scale.

2.2 Methods

This study aimed to translate and validate the POPAC scale into Dutch and test the Dutch version of the questionnaires for psychometric properties among Dutch nurses working in acute hospital settings (28). Data were collected with the online questionnaire program QualtricsXM (version 2018, Provo, UT USA).

2.2.1 The instrument

The POPAC scale consists of 15 items, as shown in Table 1. The items describe care procedures and processes in patients with dementia in hospitals (19). With the self- report of nurses in hospitals, the POPAC scale measures the extent to which nursing interventions are based on best practices in association with person-centred care. The items are divided into three subscales: cognitive assessments and care interventions (items 1–5), evidence and cognitive expertise (items 6–8), and individualizing care (items 9–15) (19). The scores can be evaluated per subscale, or the score of the total scale can be used. The subscale or total scale scores can be calculated by dividing the sum of the scores by the number of items, whereby higher scores imply higher levels of person-centredness (10,19,25).

2.2.2 Translation of the person-centred care of older people with cognitive impairment on the acute care scale

The instrument's principal author was involved in the translation, validation, and writing of the evaluation. Therefore, the instrument was translated according to the guidelines described by Sousa (29). Two independent translators from a certified translation agency translated the questionnaire into Dutch. Two researchers (AK and EF) independently assessed these two translations to determine the optimal translation of the question formulations and the answer options.

Table 1. Original items POPAC (Edvarsson, 2013)

Item	
1	We assess the cognitive status of our older patients on admission
2	We make environmental adjustments to avoid over-stimulation in older people with cognitive impairment (e.g. single rooms, noise reductions etc.)
3	We diagnose symptoms of cognitive impairment (e.g. dementias, delirium etc.)
4	We spend more time with older patients with cognitive impairments as compared to cognitively intact patients
5	We leave older people with cognitive impairments alone in the ward
6	We use evidence-based tools to assess cognitive status of older patients (e.g. the MMSE, SPMSQ, CAM)
7	We consult specialist expertise (e.g. psychologist, gerontologist) if we find that a patient has cognitive impairment
8	We use evidence-based care guidelines in the care of older cognitively impaired patients
9	We use biographical information about older patients (e.g. habits, interests and wishes etc.) to plan their care
10	We involve family members in the care of older patients with cognitive impairment
11	We provide staff continuity for older patients with cognitive impairments (e.g. the same nurses providing care to these patients as often as possible)
12	We systematically evaluate whether or not older patients with cognitive impairment receive care that meets their needs
13	We involve older patients with cognitive impairment in decisions about their care (e.g. examinations, treatments etc.)
14	We ensure that older patients with cognitive impairment have tests/examinations/consultations in the unit rather than having to go to another department
15	We discuss ways to meet the complex care needs of people with cognitive impairment

During the translation process, there was some discussion about using the term 'cognitive functioning' or 'cognitive status', whereby all translators agreed upon the choice for 'cognitive functioning' because this term is commonly used in nursing care in the Netherlands. There were no disagreements on a lingual or cultural basis. There was unanimous consensus for the final selection of all items.

This Dutch version was also translated back into English by two other independent translators from the same certified translation agency. These translations were again independently assessed by the same researchers to decide on the best translation. This time, there was consensus on all of the items. The author reviewed this final

English version, and the conclusion was that the outcomes closely resembled the original version. There were no specific reasons to expect systematic errors during the translation due to linguistic or cultural differences (30). The final version is attached as Additional file 1.

2.2.3 Sample size

According to the scientific literature, the sample size depends on the number of factors and the factor load, where a minimum sample size of 100 is recommended, and a sample size of 150 is suggested for three-phase models (30, 31). The COSMIN (Consensus- based Standards for the selection of health status measurement instruments) checklist advocates seven times the number of items (33). Based on this knowledge, the optimal sample size was at least 150 (34, 35). It may be noted that in the post hoc analysis, the sample size was sufficient for almost all estimated parameters to be (highly) significant.

2.2.4 Setting, recruitment, and participants

Six hospitals in the northern part of the Netherlands participated in this study and were supplemented by Dutch nurses who were recruited via LinkedIn and Facebook. The data were collected in one university hospital, two non-university teaching hospitals, and three rural hospitals. The capacity of the hospitals varied from 241 to 1300 beds, with additional outpatients.

Nurses with at least three months of experience in the clinical setting, working in the direct care of people with dementia, and willing to participate were included in the study. All hospital departments were included, except for paediatrics and obstetrics. The data collection took place from July 2018 to March 2019.

The recruitment of participants in the hospitals was performed by contact persons working in the hospital based on a convenience sample (27). The authors also used LinkedIn and Facebook to recruit hospital nurses. A general request was made for nurses to participate via LinkedIn, in which nursing managers are active and then the call was repeated once. For Facebook, which is often used by Dutch nurses, a different approach was used for which the authors requested two groups on Facebook. One was in a private group for questionnaires of a professional nursing magazine, and the other was in an open group for nurses in general. On Facebook, a daily update of the response was provided. This Facebook group has many members; however, it is not known how many members are active.

2.2.5 Data analysis

For the data analysis, we used IBM SPSS statistics (for Macintosh, version 25, Armonk, NY: IBM Corp.). Only complete scales were used in the data analysis. To perform confirmatory factor analysis (CFA), JASP (Version 0.11.1) with Lavaan was used (34). Before starting the analysis, Item 5 was reverse coded due to the negative wording of this item. The decision to use only completed scales was made based on the response rate of 159 complete cases instead of 164 with the inclusion of incomplete scales. Because the sample was sufficiently large and the differences in outcomes were minimal, it was decided that only completed questionnaires would be included. This makes the data as accurate as possible.

The Shapiro-Wilk test was used to assess the normality of the distribution. Descriptive analyses were used to describe the sample. Item performance was assessed by calculating item means and standard deviations, the inter-item correlation matrix, and the corrected item-total correlation.

The CFA was performed by robust maximum likelihood estimation, after which four types of fit indices were used to evaluate the fit of the model to the data: the chi-square model fit, the comparative fit index (CFI), the root mean square error of approximation (RMSEA), and the standardized root mean-square residual (SRMR). The Hoelter index was utilized to check the smallest sample size at which the chi-square interpretation would not be significant. As a criterion for significance, a p-value <0.05 was used. The model fit was considered acceptable if the following criteria were met: p-value for the $\chi 2$ model fit compared to the baseline model smaller than 0.05, CFI and GFI values between 0.90 and 0.95 or above RMSEA and RMR values of 0.08 or below (35).

Cronbach's alpha on the total scale and its subscales were assessed to determine the internal consistency.

2.2.6 Ethics approval and consent to participate

The study was performed following the Helsinki declaration, and all of the participants provided written informed consent before filling out the questionnaire. Nurses had an option to choose whether the results would also be available for further research. The Medical Ethical Committee of the University Medical Center Groningen considered approval unnecessary (decision M17.221048) because the questionnaire was intended for staff. The questionnaire was completely anonymous; no one could be identified based on the results. The managers received an email with a general explanation and a link to the questionnaire to forward it to the nurses of their team. Managers were not informed about the number of participating nurses from their ward or about their responses. Based on the contact persons' information and the response per ward, there was no reason to believe that nurses felt obliged to participate in this survey. The voluntary nature of participation was emphasized in the explanations.

2.3 Results

2.3.1 Characteristics of the sample

In total, 159 hospital nurses completed the POPAC scale; 114 nurses were recruited directly from hospitals, and 45 nurses were recruited through social media. The hospitals' general response rate was 33%, based on the managers of the participating wards' information. More specifically, responses came from nurses working in medical (21.4%), surgical (20.1%), and geriatric (13.2%) wards as well as in wards with different combinations of specialized care (45.3%), as shown in Table 2. The education of the nurses varied from a care assistant level to a master level. The nurses had an average experience of 18 years of working with the elderly population, ranging from a few weeks to 45 years (SD 12.6). A total of 43.3% of the nurses had participated in a course in the past year about care for people with dementia. They graded their skills on caring for people with dementia with an average of 7.3 on a scale from 1 to 10 with a range from 4 to 9 (SD 0.095).

2.3.2 Item performance

The mean score per item varied between 3.59 and 5.28, as shown in Table 3. The total score was 66.88 (SD 10.04), with a mean of 4.46 (SD 0.53). The Shapiro-Wilk test indicated that the data were skewed. The skewness per item varied between -0.04 and -1.83. Internal consistency was based on a cutoff point of Cronbach's alpha 0.7, an item-total correlation of 0.3, and inter-item correlations between 0.2-0.4 (26). The correlation between the different items revealed some negative correlations with Item 5. It shows a corrected item-total correlation of 0.11. The other values varied from 0.34 (Item 14) to 0.63 (Items 8 and 9). The Cronbach's alpha increased by 0.1 when Item 5 was deleted. The visual expectation of the data gave indications for a three-block structure.

Table 2. Characteristics of nurses (n=159)

		Directly from hospital		Via social media		Total	
		Frequency	Percent	Frequency	Percent	Frequency	Percent
Level of nurses	Student level	0	0	1	2.2	1	0.6
	Care assistant	1	0.9	1	2.2	2	1.3
	Secondary vocational level	60	53.5	24	53.3	64	52.8
	Bachelor level	52	46.6	8	17.8	60	37.7
	Master level	1	0.9	11	24.4	12	7.6
Ward type	Medical	17	14.9	17	37.8	34	21.4
	Surgical	23	20.2	9	20	32	20.1
	Geriatric	17	14.9	4	8.9	21	13.2
	Other	57	50	15	33.3	72	45.3
		Mean	SD	Mean	SD	Mean	SD
Years' experience in working with elderly		19.7	12,7	13,7	11.15	18	12.6
Grade skills		7.1	1,5	7.2	1.1	7.2	1.8
Followed a course on dementia last year	Yes	50	43.8	19	42.2	69	43.4
	No	64	56.1	26	57.8	90	56.6

2.3.3 Construct validity

Construct validity was evaluated with the CFA loadings for the items and the interfactor correlations based on ML estimation. Lavaan’s iterative maximum likelihood estimation converged after 22 iterations. An overview of the different fit indices is shown in Table 4 and indicates an acceptable model fit. The Hoelter’s critical N was 106.8, which means that the sample size was adequate.

Table 3. Median (SD), Mean (SD), Item-rest correlation, Item-total correlation, Cronbach's alpha if item deleted, Cronbach's alpha overall, and Cronbach's alpha per subscale (n=159)

	Median	SD[a]	IQR[b]	Mean	SD[a]	Item-rest correlation	Item-rest correlation	Cronbach's alpha if item deleted	Cronbach's alpha overall	Cronbach's alpha per subscale
Item1	6	1.05	1	5.28	1.06	0.48	0.54	0.84	0.85	**1. Using cognitive assessments and care interventions** with item 5: 0.60 without item 5: 0.72 **2. Using evidence and cognitive expertise** 0.78 **3. Individualizing care** 0.80
Item2	5	1.05	1	4.75	1.05	0.56	0.67	0.84		
Item3	5	1.06	2	4.90	1.06	0.46	0.49	0.84		
Item4	4	1.20	2	3.87	1.20	0.43	0.48	0.84		
Item5	5	1.31	2	4.64	1.31	0.11	-0.32	0.86		
Item6	6	1.32	1	5.09	1.32	0.55	0.59	0.84		
Item7	5	1.05	1	5.06	1.05	0.48	0.51	0.84		
Item8	5	1.13	1	4.45	1.13	0.63	0.67	0.83		
Item9	5	1.07	2	4.27	1.07	0.63	0.64	0.83		
Item10	5	0.88	1	4.77	0.88	0.48	0.51	0.84		
Item11	4	1.29	2	3.62	1.29	0.52	0.51	0.84		
Item12	4	1.37	2	3.59	1.37	0.59	0.58	0.83		
Item13	4	1.12	2	4.16	1.12	0.34	0.34	0.85		
Item14	4	1.46	3	4.26	1.46	0.35	0.37	0.85		
Item15	4	1.18	2	4.15	1.18	0.73	0.73	0.83		

[a] *Standard Deviation*

[b] *Interquartile Range*

Table 4. Fit indices

Metric	Value
Comparative Fit Index (CFI)	0.89
Root mean square error of approximation (RMSEA)	0.08
RMSEA 90% CI lower bound	0.06
RMSEA 90% CI upper bound	0.09
RMSEA p-value	0.01
Standardized root mean square residual (SRMR)	0.06
Hoelter's critical N (α = .05)	106.88
Goodness of fit index (GFI)	0.99
Expected cross validation index (ECVI)	1.64

A chi-square test was performed to check the model fit. This test showed that the factor model differed significantly from the baseline model, χ2 (87, N=159) =164,84, p<.001. The obtained CFI of 0.89 was slightly smaller than the cutoff value of 0.9. Both the RMSEA (0.075, p=0.012, CI 0.057-0.092) and the SRMR of 0.063 were acceptable, with values less than 0.08.

The CFA showed that all loadings were fairly large, positive, and significantly different from zero, as presented in Table 5 with Item 5 as the only exception. The factor correlations were between 0.69 and 0.77, indicating that the factors were strongly associated. Figure 1 provides the final model with significant correlations between the subscales, residual variances, and factor covariances.

Table 5. Factor loadings

							95% Confidence Interval	
Factor	Indicator	Symbol	Estimate	Std. Error	z-value	p	Lower	Upper
Factor 1	Item1	λ11	0.675	0.117	5.754	< .001	0.445	0.905
	Item2	λ12	0.711	0.095	7.465	< .001	0.524	0.898
	Item3	λ13	0.649	0.094	6.944	< .001	0.466	0.833
	Item4	λ14	0.641	0.106	6.058	< .001	0.434	0.849
	Item5	λ15	0.057	0.106	0.538	0.590	-0.150	0.264
Factor 2	Item6	λ21	1.000	0.127	7.878	< .001	0.751	1.249
	Item7	λ22	0.671	0.098	6.814	< .001	0.478	0.864
	Item8	λ23	0.899	0.098	9.176	< .001	0.707	1.091
Factor 3	Item9	λ31	0.756	0.078	9.706	< .001	0.603	0.909
	Item10	λ32	0.496	0.069	7.171	< .001	0.360	0.631
	Item11	λ33	0.753	0.099	7.589	< .001	0.559	0.948
	Item12	λ34	0.930	0.092	10.120	< .001	0.750	1.110
	Item13	λ35	0.501	0.085	5.891	< .001	0.334	0.668
	Item14	λ36	0.606	0.127	4.790	< .001	0.358	0.854
	Item15	λ37	0.948	0.078	12.198	< .001	0.796	1.100

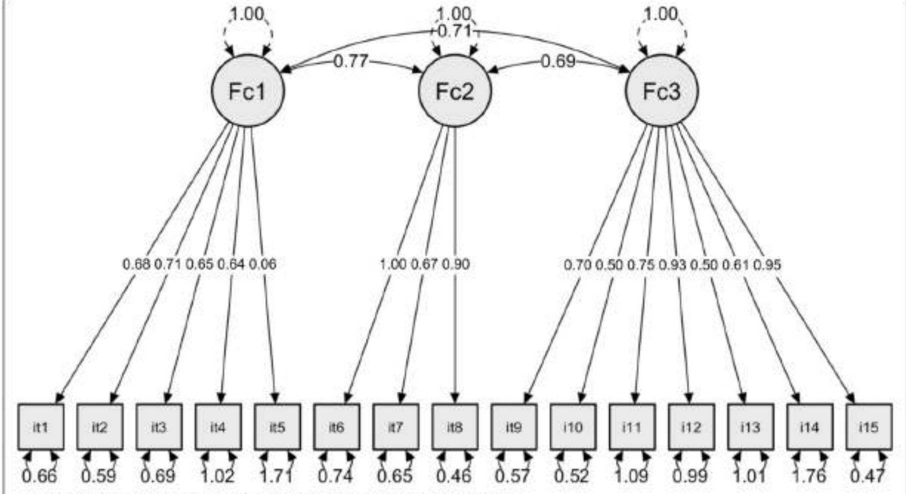

Fig. 1 Model with factor loadings, residual variances, and factor covariances (*n*=159)

2.3.4 Internal consistency

For measuring internal consistency, Item 5 was reversed. The total instrument's internal consistency measured by Cronbach's alpha was 0.85 (CI 0.82-0.88). The internal consistency of using cognitive assessments and care interventions was 0.60 (CI 0.45-0.66) with item five and 0.72 (CI 0.63-0.78) without it; using evidence and cognitive expertise had an internal consistency of 0.78 (CI 0.70-0.83) and individualizing care 0.8 (CI 0.74-0.84).

2.4 Discussion

This study aimed to translate and validate the Dutch version of the POPAC scale and evaluate the psychometric properties to make international comparisons possible. The outcomes confirm that this Dutch version of the POPAC scale is a valid and reliable instrument for measuring person-centred care and the quality of care of people with dementia in acute care (10,19,25).

The results obtained from the factor analysis with three factors were comparable with those from earlier research (10,19,25). All of the earlier studies derived a three-factor solution whereby Nilsson found that Cronbach's alpha values of Subscales 2 (using evidence and cognitive expertise) and 3 (using evidence and cognitive expertise) did not reach the necessary cut-off point of 0.7 (10). Grealish used an exploratory factor analysis because the items did not meet the predetermined cut-off points for using confirmatory factor analysis (25). They created a revised version of the instrument in which Item 5, concerning leaving people with cognitive impairments alone in the ward, was deleted, and several items were grouped into another subscale. The model fit confirmed the three-factor solution. That is, the Chi-square rejected the model. However, this test has been found to be unreliable for small sample sizes (36). The CFI indicated a nearly acceptable model fit, as with Nilsson and Grealish, who reported CFIs of 0.88 and 0.90, respectively (10,25). The RMSEA and the SRMR suggested an acceptable model fit (36). However, the findings confirmed the three-dimensional structure suggested by previous research. The loadings of the items indicate that these are strong associations with each of the factors. In addition, the factor correlations also indicated that there were strong associations, which indicated that the factors were strongly associated with one general factor of the POPAC scale. Future research is necessary to elucidate the scientific benefits of distinguishing three factors in explaining person-centred care over that of a single generic POPAC factor. The Dutch version of the POPAC scale has similar results as the Edvardsson and Nilsson study (10,19). Grealish assigned three variables to other subscales (25). In the current study, evidence was found that the POPAC has psychometric properties very similar to those previously reported in the literature. For this reason, the POPAC can be applied in the Netherlands as three separate subscales as well as a total scale measuring the level of person-centred care.

Furthermore, Cronbach's alpha of 0.86 corresponds with earlier research in which the internal consistency varies from 0.83 to 0.87. (10,19,25). Additionally, this research confirms that, statistically, Item 5 (about leaving patients with cognitive impairments alone), which is on the 'Using cognitive assessments and care interventions' subscale, could be deleted to improve the instrument's internal consistency. This is because this subscale has an internal consistency of 0.6, which is lower than the cutoff of 0.7 (26,27). Instead of deleting this item, the authors suggest rephrasing it into a positively worded item. It is the only negatively formulated item, which may influence the outcomes. The background of the instrument's construction can provide direction in changing the focus of this question. Nurses are always present in the hospital ward, so they do not experience leaving patients by themselves. However, this does not mean that people with dementia are always visible to nurses and monitored when needed, which might influence care. Our suggestion is to reformulate this question from:

> *"We leave older people with cognitive impairments alone in the ward."*

to:

> *"We make sure older people with cognitive impairments are not left alone in the ward."*

The mean scores in our study were higher than the scores in earlier studies. A higher score reflects a higher level of the construct of person-centred care (19). This score can partly be explained by the obtained high score found for Item 1 regarding assessing cognitive status. In the Netherlands, assessing cognition is a criterion on which hospital care quality is judged, which might have influenced this positive outcome.

Scores on the POPAC scale among a sample of nurses can be utilized to measure the level of person-centred care for people with dementia in hospitals. Nursing professionals and nursing managers can use the outcomes as indicators to determine which areas of care can be improved in their ward (37). Additionally, the POPAC scale can be used in the education of nurses and nursing students to create awareness of person-centred care. The POPAC scale is applicable in research on person-centred care, for example, to investigate if a relationship exists between the outcomes of the POPAC scale and complications such as falls, poor hydration and nutrition, delirium, infection, and functional decline. It can also be used to determine whether there is a relation between the level of person-centredness of the care and the length of the hospital stay. In brief, the POPAC scale can be applied to investigate various important research questions regarding interventions for people with cognitive impairment in acute wards. The authors will use this instrument to determine nurses' perceptions of person-centred care for people with dementia.

2.5 Limitations

The POPAC scale is a relatively novel instrument, and its validity and reliability need to be further developed. There is no gold standard available to compare the results with. This study aimed to measure the validity by using factor analysis, as in previous studies. This was done using one group. To improve construct validity, the authors suggest using other methods to strengthen the theoretical basis, such as item response theory, the use of multiple groups, and a test-retest construction.

Our study had a lower response rate (33%) in the hospital setting than those of previous studies, e.g., 59% (19), 51% (10), and 54.3% (25), possibly due to the different methods of recruiting responders. There were two primary aspects. On the one hand, nursing managers did not always want to cooperate because there were only a small number of people with dementia in their ward, or they perceived no added value in the study. This could result in a nonresponse bias and affect the external validity of the study. The nonresponse may have caused some bias in the direction of the null. However, since our results were mainly in line with those previously found in the literature, we consider this bias to be relatively weak.

By using a convenience sample, participating nurses with a high affinity for the topic may be overrepresented. This leads to a limitation of the external validity and, consequently, the generalization. Since the recruitment was rather general, yielding a rather broad sample of participants, we expect the results to be generalizable for the setting of general hospitals. In future research, it may be useful to validate actual care provision and behaviour in practical working situations. However, the combination of nurses from hospitals and via social media provided a significant scope of the Netherlands.

The questionnaire was conducted in combination with another lengthy questionnaire. The numerous questions negatively influenced the motivations to complete the questionnaire, which could have caused missing information. This may affect internal validity negatively. We used different orders of the questionnaire to prevent this bias.

2.6 Conclusions

The findings of this study confirm the validity and reliability of the Dutch version of the POPAC scale. However, the results provide grounds for further research on the instrument's dimensionality with a rephrased Item 5. The results can help nursing managers improve person-centred care in hospitals for people with dementia. The authors advise using total sum scores for interpretation of the scale for national and international comparison. Further research can provide insight into the relationship of person-centred care with the quality of care and nurse-sensitive outcomes, such as preventing complications hospital stay length.

2.7 Implications for nursing practice

The results are of significance for nurses in facilitating the improvement of care for people with dementia. The instrument can be used to hold reflective discussions in clinical settings about the extent to which nurses can perform person-centred care and how they can improve this care. This study's findings also enable the broader use of the POPAC scale: a total sum score can be calculated and consequently used to determine and interpret the level of person-centred care. Person-centred care and evidence-based nursing are important ingredients for high-quality nursing care for people with cognitive impairments. Therefore, the instrument is easy for nurses to use as an instrument for practice improvement. Furthermore, nurses can employ the results of the POPAC scale for benchmarking the level of person-centred care at a hospital as well as on a national or international level.

Declarations

Ethics approval and consent to participate

The study was performed following the Helsinki declaration, and all of the participants provided written informed consent before filling out the questionnaire. Nurses had an option to choose whether the results would also be available for further research. The Medical Ethical Committee of the University Medical Centre Groningen considered approval unnecessary (decision M17.221048) because the questionnaire was intended for staff. The questionnaire was completely anonymous; no one could be identified based on the results.

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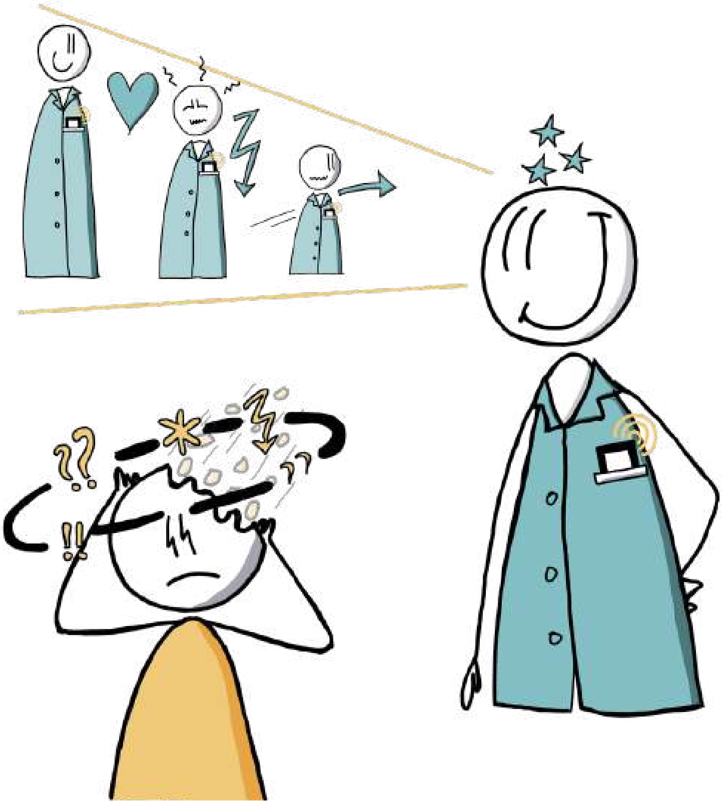

CHAPTER 3

Nurses' perceptions of caring for people with dementia in Dutch acute hospitals

Chapter 3. Nurses' perceptions of caring for people with dementia in Dutch acute hospitals

Keuning-Plantinga, A., Roodbol, P. F., Krijnen, W. P., & Finnema, E. J. (2022). Journal of Clinical Nursing, 31(13–14), 1800–1816.

Abstract

Aims and objectives: Overall, this study aimed to describe nursing care for patients with dementia in acute hospitals, with the objectives of describing the provided nursing care (1), nurses' attitudes and perceptions in caring for patients with dementia (2) and exploring how nurses deal with challenging behaviour (3). Additionally, we determined background variables associated with caring for people with dementia.

Background: Due to comorbidities, people with dementia are frequently admitted to acute care hospitals. Here, they are at high risk of complications. Nurses strive for good care but regularly experience insufficient knowledge and skills regarding caring for people with dementia.

Design: A cross-sectional survey study design.

Methods: Data were collected in seven Dutch acute hospitals and through social media. In total, 229 hospital nurses completed the questionnaire. We used the Geriatric In-Hospital Nursing Care Questionnaire and two subscales of Hynninen on managing challenging behaviour. This report followed the STROBE checklist.

Results: Nurses express that they often apply general preventive interventions not explicitly related to dementia care. In general, nurses have mixed feelings about the nursing care provided in their department. For challenging behaviour, a variety of approaches, including restrictive measures and medication, are applied. The nurses' attitudes and perceptions are influenced by the type of hospital where the nurses work, the level of education, the number of hours nurses work, and if the nurses completed a course on dementia in the last year.

Conclusions: Despite a positive attitude, nurses do not have the specific knowledge and skills needed to provide proper care. Nurses who recently completed a course on dementia had more positive attitudes and perceptions towards caring for patients with dementia.

Relevance to clinical practice: The results of this research can be used to improve the quality of nursing care for patients with dementia in acute hospitals.

3.1 Introduction

Worldwide, approximately 50 million, mostly older people, have dementia. Annually, this number increases by 10 million (1). In the Netherlands, over 280,000 people are currently living with dementia (2). People with dementia are regularly hospitalised, not for their dementia but because of, for example, fractures, chronic diseases or infections, such as respiratory, urinary, or gastrointestinal infections (3). On average, people with dementia have three or more physical illnesses (4). The national average percentage of people with dementia admitted to the hospital in 2017 is 25.3%, compared to 17% in a comparable group without dementia (5). The exact percentage of patients with dementia in hospitals is unknown. An estimate is that people with dementia occupy approximately one-quarter of hospital beds (6,7). People with dementia have an increased risk of complications during their hospital stay by infections, a decline in functional and nutritional status, and incontinence, and the result is an unwanted longer hospital stay (8,9). In addition to the variety of comorbidities of people with dementia, nurses often must manage patients' challenging behaviour, such as aggression, agitation, resistance to care, or wandering (10,11).

3.1.2 Background

The focus in acute hospitals is primarily on physical care and meeting medical targets, whereby nurses experience time pressures and staff shortages (12). The individual care needs of people with dementia are not always recognised and understood by nurses (10).

Earlier studies show that nurses tend to avoid caring for patients with dementia, especially when they exhibit challenging behaviour (13,14). Also, nurses experience difficulties in dealing with and caring for the family of these patients (15). Especially for patients with dementia, care must be adapted to their specific needs (7). The nurses' attitude toward dementia affects their provision of care and the amount and type of physical restraints and restrictive medical measures they apply (10). Nursing care is related to patient safety and quality of care, and an assumption is that there is also a strong relationship between the provided care, nurses' attitudes, and perceptions on dementia and nursing outcomes (Persoon, Bakker, van der Wal-Huisman, & Olde Rikkert, 2015).

Nurses experience deficits in their knowledge, skills, and attitudes regarding the specific care needs of patients with dementia, and managing challenging behaviour is an issue (18). Most studies on care for patients with dementia in an acute hospital setting have used a qualitative perspective as shown in recent reviews (11,19), or focus on a specific part of the nursing care, like orthopaedic care (20). In addition, it is unknown if acute hospital type, the experience of nurses, their level of education, courses, and the number of hours that nurses work on the ward influence the quality of care for patients with dementia, the nurses' attitudes toward caring for patients with dementia, and their perceptions of this care. This knowledge gap also accounts for the Dutch acute hospitals setting.

Therefore, in this paper we aim to describe the results of a quantitative study about nursing care for patients with dementia in acute hospital settings, nurses' attitudes toward caring for patients with dementia, and their perceptions of this care; additionally, we gain insights into how nurses manage challenging behaviour of hospitalised patients with dementia. Finally, a number of variables influencing caring for patients with dementia are taken into account.

3.2 Methods

3.2.1 Design

A cross-sectional survey study design was applied. During June 2018 and July 2019, data collection took place in seven acute care hospitals in the northern region of the Netherlands: one university hospital, three non-university teaching hospitals, and three general hospitals. The hospitals' size varied from 263 beds to 542 beds, and the university hospital had 1300 beds. An online questionnaire, including all relevant information, was distributed through contact persons who sent this questionnaire to department managers. The survey was also nationally distributed through Facebook because of its widespread use among nurses. We did a call on a national private nursing group for questionnaires of a professional nursing magazine and on an open group for nurses in general. After three weeks, a reminder was sent. On Facebook, a request was performed and repeated once after one week. Because the hospitals participated at different times, nurses had the opportunity to participate throughout the entire investigation period. The hospital sampling was based on convenience, and social media sampling was based on self-selection.

We included all nurses directly caring for patients with dementia in a hospital, with at least three months of experience as a nurse, and a willingness to participate. All types of wards were included, except for paediatrics and obstetrics. QualtricsXM (version 2018, Prove, UT USA) was used as an online survey tool for distribution. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement has been applied for the current article (21).

3.2.2 Data sources

To assess the provided nursing care, nurses’ attitudes toward and perceptions of nursing care for patients with dementia in acute hospitals, we combined two validated questionnaires. The questionnaire was based on the Dutch Geriatric In-Hospital Nursing Care Questionnaire (GerINCQ)(16). This instrument measures the performed nursing care of older patients, nurses’ attitudes toward this care, and the perception of caring for older patients in an acute hospital setting from the perspective of nurses. The internal consistency was α=0.86. The GerINCQ had five subscales with 67 items and two additional open questions. The five subscales were *performed intervention*, α =0.72 (13 items), *aging-sensitive care*, α =0.88 (13 items), *professional responsibility*, α =0.89 (12 items), *attitudes toward caring for older patients*, α =0.64 (14 items), and *perceptions of caring for older patients*, α =0.67 (18 items)(16). The content validity of the instrument is high (16). The original questionnaire addressed nursing care for older patients in acute hospitals. Because we focused on older patients with dementia, the original term “older patients” was altered to “patients with dementia” in consultation with the authors. Following the recommendation of the authors, the original five-point Likert scale was changed into a four-point Likert scale (16). Based on the literature, one question was added on “disruptive behaviour to other patients” to the subscale perception (22,23).

To gain more insight into how nurses manage challenging behaviour, we simultaneously took two validated subscales of the questionnaire of Hynninen (2016). These were developed to describe care practices of older patients with dementia: *managing challenging behaviour* (11 items) and *use of alternative approaches instead of physical restraints* (9 items) (14). These subscales provided a satisfactory impression of the possible reactions of nurses in managing challenging behaviour. The reliability of these subscales was respectively 0.63 and 0.77 (14). In order to compare the results of both questionnaires, it was decided to adjust these scales to a 4-point Likert scale as well.

For the translation of the subscales of Hynninen, we performed the forward-backwards translation of the English version by two independent translators from a certified translation agency. The translations were independently assessed by two researchers (AK and EF) to determine the optimal translation of the question formulations and the answer options (24). There were no differences of opinion on a linguistic or cultural basis. The final selection of all items was made unanimously.

Finally, we added relevant background variables such as the level of education, experiences, skills, working hours per week, and completed courses on dementia in the last year. A small pilot (n=10) was done. Based on the pilot, the duration of filling in the questionnaire was estimated, and the introduction was clarified.

To prevent bias, we emphasised that there were no right or wrong answers. In addition, we used different orders per questionnaire to increase the chance of fully completed surveys and to prevent the last part from being filled in the least accurate.

3.3 Measurement

3.3.1 Analyses

To measure nursing care, we used the subscales performed interventions and dementia-sensitive care (16). These subscales measure on a team level to what extent nurses use physical and geriatric care-related interventions in the care for older patients with dementia and how satisfied nurses are with dementia-sensitive, psychosocial-related, geriatric care delivery in their department.

Attitude and perception were measured by the use of the subscales professional responsibility, attitudes toward caring for older patients, and perceptions of caring for older patients. Regarding their attitude, nurses were asked about how responsible nurses feel for diverse aspects of nursing care, such as the development of complications and miscommunication. They were also questioned on their daily experience of dementia care-related items, for example, involvement and admission. Finally, to evaluate the perception of nurses, different items were used on the experience of dementia-related care for patients with dementia and the experience of disruptive behaviour. In the open questions nurses were able to indicate what they find demanding in the care of patients with dementia and what training their department needs (16).

Additionally, the subscales reactions to challenging behaviour and the use of alternative approaches instead of physical restraints were applied (14). Nurses were asked how often they use different types of responses when a patient displays challenging behaviour and which alternative approaches they use instead of physical restraints.

Data were analysed using the IBM SPSS statistics (version25). Only the data of complete questionnaires were included in the study. We started with descriptive analyses of the background characteristics of the nurses. Item performance was applied by item means, Cronbach's alpha if item deleted, and percentage per answer (Appendix A). There were no indications that would lead to adjustments to the scale. We continued with performing Cronbach's alpha of the total scale and the subscales to evaluate the internal consistency and calculating means with confidence intervals. In order to compare the outcomes of the subscales, we rescaled the outcomes of each subscale total by dividing the number of variables, which led to new outcomes on a scale from one to five. Spearman's rho was used to analyse if there were significant ($p<0.01$) correlations between the subscales and background variables, and the items and background variables. Finally, the two open questions were briefly analysed by thematic analysis by Atlas.ti computer software (version 7.5) (Atlas.ti Scientific Software Development GmbH, Germany) to get more insight into the data. Inductively, the answers were coded, clustered in themes, and iteratively refined by two researchers.

3.3.2 Ethical considerations

The study was performed following the Helsinki declaration, and all the participants provided digitally informed consent before filling out the questionnaire. The regional Medical Ethical Committee considered approval unnecessary (decision M17.221048) because the questionnaire was intended for staff. Permission to access staff was given in participating hospitals. The response was utterly anonymous. No one could be identified based on the results.

3.4. Results

3.4.1 Participants and descriptive data

We received 429 questionnaires from hospital nurses and 113 from nurses through social media (total n=542). Of this, 229 nurses (=42%) completed the questionnaire. The average time to complete the questionnaires was 15 minutes. The response rate based over five hospitals is 29%, for the two other hospitals, it was not clear how many nurses received the survey. The length of the questionnaire and the lack of affinity with the target group were the main reasons for not completing it. The distribution of nurses between the university hospital, non-university teaching hospitals, and general hospitals was evenly spread. Some ward managers sent it to all the nurses, and some decided to send it to a few nurses in their ward. The participating number of wards per hospital varied from one to four.

An overview of the characteristics of the nurses is presented in Table 1. A small percentage of nurses work in other hospital types, e.g. private hospitals. In practice, most nurses work on combined wards such as medical-geriatric, medical-surgical, or intensive care. For this reason, this ward variable was an unsuitable background variable in the analyses. Almost half of the nurses were educated at a secondary vocational level, and a similar portion had a bachelor's degree. However, in the Netherlands, nurses are educated on two different levels, vocational level and on bachelor level. In practice, they perform the same tasks. Although we report the highest completed education, the respondents were able to fill in all completed education in the questionnaire. This shows that some nurses worked with older people as a care assistant before they became a nurse. The experience of nurses was evenly spread between the groups. In all, 61.1% of the nurses worked more than 24 hours per week, of which only 9% of the nurses worked more than 33 hours per week. The group of nurses who participated via social media is comparable to the group from the northern hospitals. The nurses graded their skills in caring for patients with dementia at on average 7.2 on a scale from 1 to 10, with a range of 3 to 10. In all, 62.5% of the participating nurses completed a course on caring for patients with dementia the past year.

Table 1. Characteristics of the nurses (n=229)

Characteristics of the nurses		n	Percent
Hospitals*	University	50	21.8
	Non-university teaching hospital (Top-Clinical)	60	26.2
	General	99	43.2
	Other	23	8.7
Ward type	Medical	38	16.8
	Surgical	66	29.2
	Geriatric	20	8.8
	Other	102	45.1
Level of education (n=218)*	Nursing student	4	1.8
	Secondary vocational level 4	109	48.9
	Bachelor level	105	47.1
	Master level	5	2.2
Experience nurse (n=223)*	≤5 years	115	51.6
	6-10 years	36	16.1
	11-20 years	14	6.3
	21-30 years	33	14.8
	31 years or more	25	11.2
Experience current hospital (n=223)	≤5 years	167	73.9
	6-10 years	26	11.5
	11-20 years	13	5.8
	21-30 years	13	5.8
	≥31 years	7	3.1

Characteristics of the nurses		n	Percent
Experience current ward (n=226)	≤5 years	183	81.0
	6-10 years	16	7.1
	11-20 years	19	8.4
	21-30 years	7	3.1
	≥31 years	1	0.4
Experience working with elderly (n=226)	≤5 years	57	25.2
	6-10 years	43	19.0
	11-20 years	48	21.2
	21-30 years	46	20.4
	≥31 years	32	14.2
Hours per week[a]	Flexible	2	0.9
	≤16	9	4.0
	17-24	79	35
	25-32	116	51.3
	≥33	20	8.8
Grade Skills (n=221)	Mean (range) 7.2 (3-10)		
Course on dementia in the last year (n=226) [a]	Yes	144	63.7
	No	82	36.3

[n]= *number of participants, if different*

[a] *variables used for correlation with subscales*

3.4.2 Reliability

The internal reliability of the GerINCQ (0.83) was good, as measured by Cronbach's alpha (25). The reliability of the subscales varied between .62 and .86, as shown in Table 2. The Cronbach's alphas of the GerINCQ and the subscales we found are comparable. Although the Cronbach's alphas of the subscales attitude and perception are lower than the desired 0.7. The Cronbach's alphas of the subscales of Hynninen were lower than in the original study. The reliability of the scale about reactions on challenging behaviour was already low, but the scale about the use of alternative approaches was 0.17 lower and changed from good to poor (26).

Table 2. Overview psychometric properties of the GerINCQ and Hyninnen per subscale

			95% Confidence interval			95% Confidence interval	
Subscale	Questionnaire	Item mean	Lower	Upper	Cronbach's alpha	Lower	Upper
Performed interventions	GerINCQ	3.46	2.81	2.89	0.69	0.62	0.74
Dementia-sensitive care delivery	GerINCQ	3.29	2.82	2.90	0.84	0.81	0.87
Professional Responsibility	GerINCQ	3.11	3.06	3.17	0.89	0.86	0.91
Attitude toward caring for patients with dementia	GerINCQ	3.12	3.08	3.15	0.71	0.66	0.77
Perceptions of caring for patients with dementia	GerINCQ	2.64	2.61	2.67	0.62	0.55	0.69
Reaction when a patient with dementia displays challenging behavior	Hyninnen	2.71	2.68	2.74	0.51	0.41	0.60
Use of alternative approaches instead of physical restraints	Hyninnen	3.10	3.07	3.14	0.60	0.51	0.67

3.4.3 Nursing care, attitudes, perceptions, and managing challenging behaviour

As shown in Table 2, the item means vary from 2.64 to 3.46, and the weighted mean between 2.71-3.11. De data is summarised in a box-and-whisker plot, as presented in Figure 1. Concerning the overall median, five of the seven measured subscales have a median above the mean. De subscale responsibility has the most extensive spread and the subscale reactions the smallest. The results of the single item analysis are shown in Appendix B.

3.4.4 Nursing care

As shown in Table 2, the mean score of the subscale Performed interventions is 3.46. A comparison of this score is difficult because the original study used a five-point Likert scale (16). There, the average score varied between 3.2 and 3.4. Most

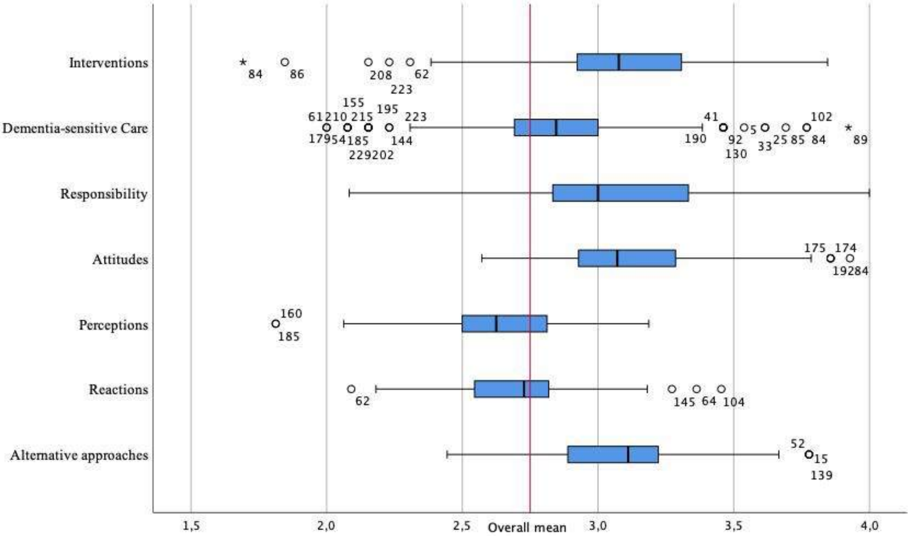

Figure 1. Box-and-whiskers plots

nurses (n=192) perceive that in the last 12 months, less than half of the percentage of the patients they care for were patients with dementia. In addition, two-third of the nurses (n=148) assert that the proportion of their shift that they devote to care for patients with dementia is less than half.

To gain insight into the meaning of the result of the subscale, outcomes at a single item level are relevant. The most performed interventions are the following: interventions to prevent pressure ulcers (n=219), prevent a delirium(n=217), and prevent a fall (n=220). The lowest score of enteral nutrition as an intervention to prevent malnutrition, with a mean of 1.94. stands out here. This means that nurses mention rarely or never perform enteral nutrition as an intervention to prevent malnutrition (n=200). Another rarely used intervention is the use of physical movement restrictive measures (n=160).

Because the focus of our study is dementia care, we are specifically interested in dementia-related interventions. More than half of the nurses (n=142) imply that they never or rarely organise activities for patients with dementia, as an intervention to prevent delirium. Additionally, nearly half of the nurses (n= 113) indicate that they often use urinary catheters. Concerning the use of restrictive measurements, nearly two-thirds of the nurses state that they often or always use restrictive medical measures (n=161) and sleep medication (n=135). Almost one-third (n=69) of the nurses point out that they almost or often use physical movement restrictions, despite the risks of these interventions.

In general, the participating nurses are satisfied with the dementia-sensitiveness of care provided in their department. The average score on this subscale is 3.29 (Table 2). The original study reported a score varying between 3.1 and 3.6 on a five-point Likert scale (16). Nurses state that they are most satisfied with how often patients with dementia are treated with respect (n=222). The points with which nurses are less satisfied concern the adjustment of the care activities to the pace to patients with dementia in their department (n=119) and more than half of the nurses (n=116) are discontented with how the presence of patients with dementia is considered in the planning of the shifts, for example, when determining the number of nurses needed for a shift or when dividing the care among the nursing staff.

3.4.5 Attitude and perception

As presented in Table 2, the mean score of Professional Responsibility is 3.11. The interpretation on single item level shows that the score differs from 2.61 to 3.33. Nurses feel most responsible for the development of pressure ulcers (n= 218) and arranging the discharge (n=218) of patients with dementia. Nurses feel least responsible for behavioural problems (n=100), urinary tract infections (n= 64) and development of delirium (n=68) in patients with dementia.

The mean score of the subscale attitudes (Table 2) is 3.12. The means of the single item scores varies between 2.63 and 3.52. Nurses often or always create optimum communication conditions (n=228) and keep a close eye on confused patients with dementia (n=228). The lowest scores show that around a quarter of the participating nurses indicate they rarely or never allow more time for starting discharge planning at admission (n=94), allow more time for preparing the discharge (n=89) and allowing extra time for the admission (n=85).

The mean score of the item perception is 2.64. The items with the highest mean concern the perception of negative behaviour like the experience that patients are restless at night (n=212) and demand much attention (n=195). Also, nurses indicate feeling sufficient or very proficient (n=201) in providing care for patients with dementia. The lowest scores are related to the experience of the proportion of patients with dementia in the past 12 months less than half of the patients (n=192), and the experience of the proportion of patients with dementia during the shift more than half of the patients (n=158). The mean of the item about how nurses experience training is also low. More than half of the nurses (n=115) feel that they have had insufficient training to provide adequate nursing care to patients with dementia.

3.4.6 What makes the care for patients with dementia demanding (qualitative)

As described, more than half of the nurses frequently experience caring for patients with dementia as demanding. Nurses were asked to explain what they find demanding in the care for patients with dementia. Nurses express a broad range of situations concerning the organisation of care, professional aspects, and aspects of the disease.

Insufficient time is mentioned as an essential factor in what makes the care for patients with dementia demanding. This insufficient time is related to the perceived high workload but also to the perceived complexity of care because of dementia, the combination of care for other patients, the presence and absence of informal carers, and the availability of volunteers.

> *"It takes time and patience from a nurse to provide the care they deserve to a confused patient or patient with dementia. This means that time is often too short for the other duties of the nurse."*

Nurses indicate that they are dissatisfied with the lack of opportunities for proper care, to pay attention to patients, for adequate monitoring of patients. Additionally, a small number of nurses say that they do not have an affinity with the target group, are not interested in patients with dementia, or even stronger, believe that patients with dementia should not be admitted to their ward.

> *"Our department is not suitable for patients with dementia."*

Finally, the responding nurses indicate that the unpredictable behaviour of patients with dementia is stressful, as are restless behaviour, aggression, wandering, and disorientation. The nurses are concerned about possible complications such as falls, malnutrition because the patient does not want to eat, and delirium and safety, for example, when wandering.

> *"Care must be taken that they do not fall (…) and do not wander around and bother other patients, start shouting about the ward because they do not know how the bell works and, as a result, make other patients restless."*

3.4.7 Needs regarding training (qualitative)

Nurses were asked to describe their needs regarding training. These needs are partly disease-focused, and partly nursing care focused. Nurses express that they want knowledge of dementia, delirium and depression, gerontology, geriatrics, medication in general, and specifically about problem behaviour.

> *"Repetition of which medication to give the best, and practical tips that patients also take this."*

In addition, nurses mention that they want to learn how to manage dementia, particularly with problem behaviour such as wandering and aggression. They state they require more knowledge of restrictive measures and interventions aimed at safety.

> *"Managing different types of dementia, freedom restrictive measures (which exist and how to use them). There are several restrictive measures, but these are not always used in a timely and effective matter."*

3.4.8 Managing challenging behaviour

The mean score on this subscale is 2.71 (Table2). The means per factor scores (sub-sub scales) are presented in Table 3. The means vary from 1.41 on the subscale react by ignoring to 3.30 on react with care. Nurses use various ways to respond to challenging behaviour. The mean of the factor *react with care* is the highest, at 3.30. Nurses react, for example, by being present, asking what is wrong, and organise activities. Nurse state that they rarely *react by ignoring* this factor has the lowest mean score of 1.41. The factor possible *reactions with power* has a mean of 2.63. This factor describes how often nurses state that they use physical force to calm the situation or take the patient to his or her room and give orders to the patient. As nurses react *casually*, with a mean of 2.98, to challenging behaviour, they use humour or tolerate the challenging behaviour because the patient has the right to be angry.

The mean score on the scale of the use of alternative approaches is 3.10 (Table 2). Nurses use different approaches as an alternative approach to physical restraints. As shown in Table 3, the factor with the highest score is the use of professional knowledge, with a mean of 3.25 Nurses indicate that they regularly negotiate with colleagues or family about the best way to respond. Regarding the *use of medication*, the mean score is 2.65. This factor describes how often nurses point out that they provide painkillers or sedative medication as a reaction to challenging behaviour. Finally, the mean of the factor *use problem-solving* is 3.19. This factor describes techniques such as distracting the patient's attention and attempt to organise an expert consultation, for example, a clinically geriatric.

Table 3. Means per subscale of responses managing challenging behaviour (n=229)

	Reaction when a patient with dementia displays challenging behaviour				Use of alternative approaches instead of physical restraints		
	F1 React with care	F2 React by ignoring	F3 Reaction with power	F4 react casually	F1 use of professional knowledge	F2 use of medication	F3 use of problem-solving
Mean	3.30	1.41	2.63	2.98	3.25	2.65	3.19
Std. Error of Mean	0.02	0.03	0.03	0.03	0.02	0.03	0.03
Median	3.25	1.50	2.67	3.00	3.20	2.50	3.00
Std. Deviation	0.35	0.44	0.40	0.40	0.33	0.45	0.38
Minimum	2.50	1.00	1.67	2.00	2.20	1.00	2.50
Maximum	4.00	3.00	3.67	4.00	4.00	4.00	4.00

3.4.9 Associations between background variables and items

The correlations between the background variables and the subscales and between the background variables and the items were computed. Statistically significant relationships are reported (Table 4). We expected that experience would correlate with the items. However, we found no statistically significant relations. We only found correlations with items about attitudes and perceptions.

At scale level, we found a positive correlation between the subscale *attitudes towards caring for people with dementia* if nurses followed a course of dementia last year. Taking a course on dementia could lead to a better attitude in the care of patients with dementia. We found a negative correlation between the subscale *perceptions of caring for patients with dementia* and the hospital type. In order to understand these outcomes, the outcomes at item level are relevant.

We found negative correlations between some items and the type of hospital, the level of education, and the number of hours nurses work in the ward. The participating nurses working in university hospitals spend a lower proportion of their shift on patients with dementia, and they feel less competent. These nurses consider the training for dementia-related care in their department to be inadequate. Nurses with a bachelor or master level feel less responsible for the behavioural problems of patients with dementia; they feel less competent and less recognised by colleagues for their care for patients with dementia. The fewer hours nurses worked on the ward, the less responsible they felt for behavioural problems.

Table 4. Significant (P<0.01) correlations between subscales and background variables, and items and background variables (n=229)

Subscale/Item		Hospital	Education	Hours	Course
Subscale Attitudes	Rho				-.230
	P value				.001
Items					
Behavioral problems in a patient with dementia?	Rho		-.205	-.204	.184
	P value		.002	.002	.005
Development of delirium in patients with dementia?	Rho				.171
	P value				.010
I create optimum communication conditions for patients with dementia by making use, for example, of the patient's glasses or hearing aid	Rho				.171
	P value				.010
I allow more time for preparing the discharge of patients with dementia than I do for the discharge of an older patient without dementia	Rho				.187
	P value				.005
Subscale perception	Rho	-.185			
	P value	.005			
Items					
In the past 12 months, which proportion of the patients you cared for were patients with dementia?	Rho	-.229			.178
	P value	.000			.007
Roughly what proportion of your shift do you devote to the care of patients with dementia in your department?	Rho	-.208			
	P value	.002			
How proficient do you think you are in providing care for patients with dementia?	Rho	-.201	-.187		.223
	P value	.002	.005		.001
To what extent do you feel recognized by your colleagues for your care of patients with dementia?	Rho	-.222			.174
	P value	.001			.009
How do you experience the training of nurses in the provision of care to patients with dementia in your department?	Rho	-.233			.176
	P value	.000			.008

Hospital Type: 1= university - 2=non-university teaching hospital - 3=general hospital

Education: level of education 1= nursing student, 2= secondary vocational level 4, 3= bachelor level, 4= master level

Hours: hours per week

Course on dementia: 1=no - 2 =yes

Positive correlations were found between the items, and if nurses followed a course on dementia last year. Nurses that completed a course on dementia in the last year devoted a more substantial part of their shift to caring for patients with dementia, they felt more responsible for behavioural problems and for the development of delirium. Additionally, they created optimum communication conditions for patients with dementia by making use, for example, of the patient's glasses or hearing aid. Eventually, nurses that followed a course felt more recognised by their colleagues for the care they provided to patients with dementia.

3.5 Discussion

This study focused on the nursing care for patients with dementia in Dutch acute hospital settings and the nurses' attitudes toward and perceptions of this care, to gain additional insights into how nurses manage challenging behaviour, and finally, which variables influence the nursing care of patients with dementia.

Although it is not precisely known how many patients with dementia are on average in a ward, the perceptions seem to be in line with estimates of 25-40 per cent (6,7). The findings of nursing care show that participating nurses often perform general preventive interventions. However, they perform fewer interventions related to dementia care, such as organising activities, to prevent delirium. Previous research has shown that when preventive interventions are carried out from person-centred care, this can prevent complications (7). The literature has demonstrated that day structure, and activities are essential for patients with dementia and play a role in preventing delirium (27,28). Additionally, the use of urinary catheters, of which half of the nurses in our study state to use often or always, is a possible cause of agitation and increases the risk of infections and delirium as a result (29). In addition, the literature has demonstrated that the use of urinary catheters influences the length of hospital stay of elderly patients because their recovery is delayed by their limited ability to mobilise (30). A possible explanation for this is that nurses have a basic knowledge of care, but no specific knowledge of interventions related to the care for patients with dementia. The low score concerning the use of tube feeding seems appropriate, regarding international guidelines, where the use of tube feeding in a temporary crisis is described as a possibility (31).

The participating nurses indicate that they often use medical and physical restrictive measures. The use of medical restraints leads to a higher risk of complications. Therefore, patients' mobility, the situation before admission, and the perspective from the view of the person with dementia must be considered (22). The choice of medical restraints is often used by nurses as a last resort for managing challenging behaviour, because of insufficient time, to increase safety or insufficient knowledge of alternatives to restraint, but this choice is also influenced by a negative attitude and nurses' insufficient knowledge (32,33). However, our findings show that participating nurses say that they mostly 'react with care' as a reaction to challenging behaviour and that they use 'professional knowledge' as an alternative approach. These desirable reactions seem to contradict the frequent use of freedom-restricting measures. Follow-up research is needed to gain more insight into the situations that lead to the use of these restrictive measures. In addition, more research is necessary to investigate the possible preventive role of activities during admission in relation to challenging behaviour.

The nurses report various aspects related to the dementia-sensitiveness of care in their department that could be improved. The care activities could be more adapted to the needs and pace of patients with dementia. Internationally, personal care is described as the gold standard for the care of people with dementia (34). The basic principles of person-centred care are based on approaching the person as an individual from the perspective of the person with dementia (35). Person-centred care is not only about the level of care providers but is also essential at other organisational levels. This means that people with dementia are also taken into account in the planning of shifts, whereby the complexity of care at the psychosocial level is higher. However, in acute hospitals, the complexity of care is determined mainly by physical aspects related to the cause of admission and are therefore not considered in the planning of shifts (10,28). Ward managers also relate planning problems to the insufficient number of nursing staff on duty (36). For the provision of care, the high complexity of care for patients with dementia must be taken into account in the planning of care.

Related to the results of attitudes and perception, our findings show that the participating nurses often feel responsible for the consequences of treatment but seem unaware of how to prevent behavioural problems and delirium. This finding corresponds to other studies where the cause of behavioural issues is placed on the patient and not on the environment (37,38). Another possibility is that nurses do not recognise delirium in patients with dementia. Studies have demonstrated that 30% of patients with dementia are screened for delirium (9,36). Delirium is a severe complication for patients with dementia and associated with increased morbidity and mortality (39). The most effective treatment of delirium is prevention (40). In order to be able to recognise changes in behaviour, nurses must be aware of how the patient behaved prior to admission in coordination with the close relatives, who know the patient well and therefore see changes in behaviour faster. Based on the score of the scale, we conclude that the nurses in our study have a positive attitude toward caring for patients with dementia, and this is demonstrated, for example, by keeping a close eye on confused patients with dementia. Not all nurses allow extra time for admission and discharge. This extra time is essential because when additional time is spent on admission to learn more about the patient with dementia, this can positively influence the quality of care. Ineffective communication can lead to misunderstanding and negative feelings or anxiety and helps nurses understand the behaviour of patients with dementia (27,41,42). It is unclear whether these results describe how the participating nurses intend to provide their care or how they actually provide this care. For example, nurses indicate that they often involve the person with dementia in decisions concerning their care and treatment. However, they also indicate that reasoning with a patient with dementia is not possible. Additionally, the results of the open questions provide another impression of the attitude of nurses. To gain more clarity on this topic, it is essential to compare these results with the experiences of patients with dementia and their informal carers or observations in hospitals. Although the nurses say they feel proficient, they find it challenging to combine the care for patients with dementia with their responsibilities for other patients. The nurses indicated that caring for patients with dementia is demanding because of the insufficient for this more complex care, a high workload, and a shortage of nursing staff. This finding corroborates results in the literature (43–45). Reinforcement of organisational support is a condition for improving the quality of care (11).

Our research shows that that the fewer hours nurses work per week, the less responsible they feel for behavioural problems. Almost all the participants in this study work part-time. Although the Netherlands has the highest number of part-time employees in Europe, it is not known how the number of part-time nurses relates to other countries (46). The number of part-timers might negatively influence the continuity of care, which is important, particularly for patients with dementia because it helps them feel safe (47). Compared with nurses working in a university hospital, nurses working in a general hospital had more experience, more often completed a course on dementia in the last year, and a lower level of education. Additionally, these nurses may have had more positive experiences in caring for patients with dementia. Some of these nurses worked as a care assistant before they became a nurse. Therefore, these nurses have a higher affinity with dementia care and are more motivated to complete a course on dementia. Higher educated nurses experience more difficulties in caring for patients with dementia and have taken a course less often. The literature has demonstrated that the gerontological and geriatric content of nursing courses in the Netherlands is insufficient (Bleijenberg, 2012) and that training can be effective (50–52). Based on the increasing number of patients with dementia and shortages of nursing staff, new approaches to caring for patients with dementia are vital (11). Nurses are aware of their insufficient knowledge and skills in caring for patients with dementia and want to learn more about the disease and how to manage problem behaviour. Our study shows that nurses who have taken a course feel more responsible for the development of delirium and behavioural problems, create optimum communication conditions and allow more time to prepare for discharge, even though the content of the courses is unknown. Nurses with an affinity for patients with dementia may also choose more quickly to complete a course on this subject.

We could not confirm the correlations between background the variables and subscales about managing challenging behaviour (14). However, our study showed that medical restraints as an alternative approach to physical restrictions are regularly used. Nurses believe that potentially challenging behaviour is under control, but restraints often cause complications and negative experiences for patients with dementia and their informal carers (19,22,53,54). The focus of this article is on outcomes on scale level. Both instruments are relatively new. With regard to the GerINCQ, concerning measuring the care for patients with dementia, the researchers believe that several concepts can be measured per subscale. Further research could focus on research into these factors within the subscales. Both scales seem to contain items that might be better encoded reversed so that the results per subscale can be better interpreted. A follow-up study may provide more clarity about this.

3.6 Limitations

This study has several limitations. First, selection bias may have influenced the results of this study. More than 60% of the participating nurses completed a course on dementia in the last year. In addition, we expected that the nurses recruited through social media would have an affinity for the topic; this probably affected the generalizability of our findings. Plausibly, in reality, the outcomes are less favourable.

By using self-report, we measure the care from the perspective of nurses. We do not know how patients with dementia experience nursing care in the Netherlands. Despite the anonymity of the questionnaire, some of the answers seemed socially desirable. For example, nurses score high on the attitude scale and low on the perception scale. The picture that emerges from the open questions is also more negative than that based on the quantitative part. We posit that nurses strive to provide satisfactory care, but in reality, they cannot always realise this objective.

More generally, questionnaires tend to have low response rates and, therefore, risk bias (55). In order to increase the chance of response, we have paid much attention to the invitations. The contact persons have also tried to motivate departments to participate in the survey.

We altered the original instrument by changing the term elderly to patients with dementia and transforming the five-point Likert to a four-point Likert scale. The reliability of the total scale is comparable to the original version, and this also applies to the reliability of the subscales. However, in the two used subscales of Hyninnen, on managing challenging behaviour, we found a difference in Cronbach's alpha, especially in the scale about reactions to challenging behaviour; the change to a four-point Likert scale or selection bias could explain this part. However, we have not been able to find a suitable explanation for the low score of the scale reactions on challenging behaviour. This requires more research in similar groups. In general, more psychometric evaluation, for example, factor analysis to reduce the number of items and improve the interpretation by coding some items reversed, could improve the usability of the total scale. The GerINCQ does not measure positive behaviour related to patients with dementia. Adding items on positive behaviour provides an improved picture of the perception of nurses toward patients with dementia.

Finally, the generalizability could have been influenced by cultural differences, differences in the general health system, and differences in ward levels such as the culture of care, staffing levels, types of leadership, and type of ward.

3.7 Conclusion

The nurses participating in our study are insufficiently aware of specific dementia-related care aspects, such as the prevention of delirium and challenging behaviour and regular use of urinary catheters. Medical and physical restrictive measures are frequently applied as an intervention in the care for patients with dementia. This seems inconsistent with how nurses indicate that they react to challenging behaviour.

Nurses express a positive attitude toward caring for patients with dementia and strive to provide adequate care. Although nurses have a strong sense of responsibility in preventing delirium, it is not clear whether they have sufficient knowledge about delirium in patients with dementia to succeed in this. In addition, nurses do not always experience the care for patients with dementia as satisfying but regularly as demanding. This phenomenon is due mostly to dementia-related aspects and particularly challenging behaviour such as restless behaviour, aggression, wandering, and disorientation.

The participating nurses feel proficient and use different approaches in managing challenging behaviour. However, they still use medical and physical restraints as necessary, despite the professional standards focusing on alternative psychosocial interventions. The nurses indicate that the training of nurses could be improved, even though this study shows a positive relation between completed a course on dementia in the last year and attitudes and perceptions. Among the research population, the given care is influenced by the hospital type, level of education, and the number of hours that nurses work in the ward. Research on dementia care on the level of ward managers and directors could provide additional insights into the awareness of the importance of dementia-friendly nursing care. Finally, more research is necessary on sufficient forms of education and training, during formal education and on the job, because nurses indicate that they want to provide proper care but are insufficiently equipped to do so.

3.8 Relevance to clinical practice

In order to improve care for patients with dementia in the hospital, nurses must become aware of their ability to influence the behaviour of patients with dementia through the use of dementia-related preventive interventions. Awareness can be stimulated by deploying dementia nurses in each department, who act as role models and for teaching on the job. This requires a positive learning climate and a policy aimed at quality improvement and person-centred care. In addition, patients' stories can be used. In future training and education, more emphasis should be put on nurses' awareness of their skills and abilities.

What does the paper contribute to the global clinical community?

- *This quantitative study confirms results from earlier qualitative studies, namely, nurses strive to provide proper care but have insufficient knowledge about caring for patients with dementia. The attitudes toward and perceptions of caring for patients with dementia in acute hospitals can be improved.*
- *A quantitative approach to a relevant topic makes international comparisons possible.*
- *The attitudes and perceptions of nurses are influenced by the type of hospital where nurses work, the level of education, the number of hours nurses, work in the ward, and if they completed a course on dementia in the last year.*

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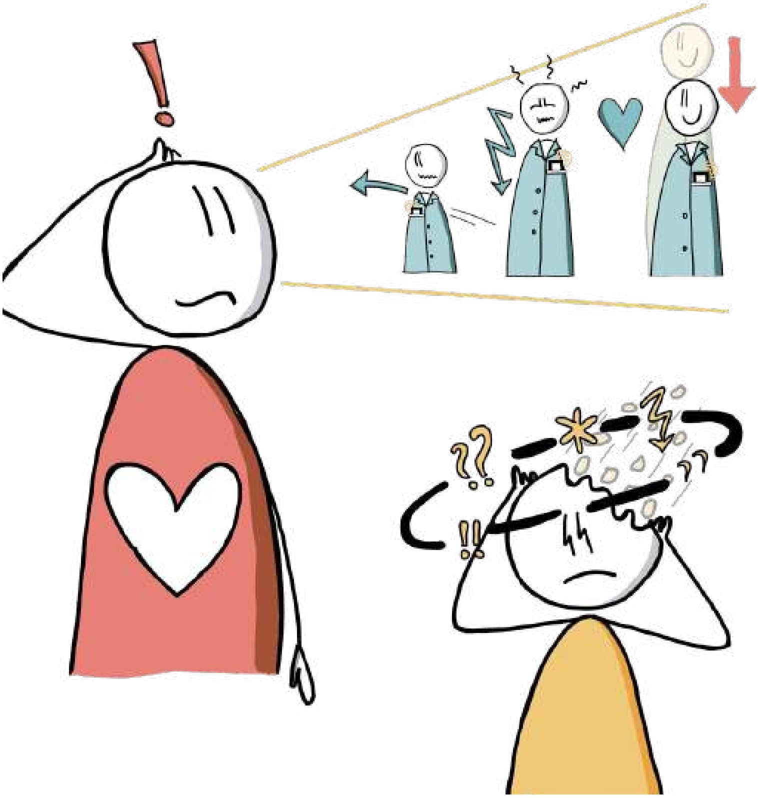

CHAPTER 4

Experiences of informal caregivers of people with dementia with nursing care in acute hospitals: A descriptive mixed methods study

Chapter 4. Experiences of informal caregivers of people with dementia with nursing care in acute hospitals: A descriptive mixed methods study

Keuning-Plantinga, A., Roodbol, P., Munster, B. C. van, & Evelyn J. Finnema. (2021). Journal of Advanced Nursing (Wiley-Blackwell), 00, 1–13.

Abstract

Aims: To explore the experiences of informal caregivers of people with dementia with the hospitalization of their relative concerning patient care, interactions with nurses, caregivers' situation, and the acute hospital environment.

Design: Descriptive mixed methods design.

Methods: The data were collected using an online questionnaire among a panel of caregivers (n= 129), together with a focus group and individual interviews from February to November 2019. The data were triangulated and analysed using a conceptual framework.

Results: Almost half of the respondents were satisfied with the extent to which nurses considered the patient's dementia. Activities to prevent challenging behaviours and provide person-centred care were rarely seen by the caregivers. Caregivers experienced strain, intensified by a perceived lack of adequate communication, and did not feel like partners in care; they also expressed concern about environmental safety. A key suggestion of caregivers was to create a special department for people with dementia, with specialized nurses.

Conclusion: Positive experiences of caregivers are reported in relation to how nurses take dementia into account, involvement in care, and shared decision-making. Adverse experiences are described in relation to disease-oriented care, ineffective communication, and an unfamiliar environment. Caregivers expressed increased involvement when included in decisions and care when care was performed as described by the triangle of care model. Caregivers reported better care when a person-centred approach was observed. Outcomes can be used in training to help nurses reflect and look for improvements.

Impact: This study confirms that caregivers perceive that when they are more involved in care, this can contribute to improving the care of patients with dementia. The study is relevant for nurses to reflect on their own experiences and become aware of patients' caregivers' perspectives. It also provides insights to improve nurses' training and for organizations to make the care and environment more dementia friendly.

4.1 Introduction

Approximately 50 million people worldwide have some form of dementia. Dementia is an umbrella term for diseases that can affect memory, thinking, orientation, language, and judgment. The impact for patients and caregivers can be physical, psychological, social, and economic (1). The number of people with dementia is expected to double in the next 20 years (2). Most people with dementia live at home, where informal caregivers take care of them, sometimes in combination with professional caregivers (3). In the Netherlands, the number of people with dementia is approximately 260,000 (2). There are 350,00 people who care for someone with dementia who lives at home. Half of these people combine this care with a job and care for the children. Nearly a third of these caregivers take care of their loved ones for more than 40 hours a week (4). People with dementia have, on average, three or more somatic diseases for which they are at risk of hospital admission (5).

During the hospitalization of patients with dementia, a close caregiver's presence is essential because it makes patients feel safer and less vulnerable (6). For nursing care, patients' and caregivers' information about the patient's needs, preferences, and habits with dementia is important for the provision of person-centred and safe care (7). Person-centred care, including taking into account the needs of caregivers, is seen as the best care for people with dementia (8,9). However, nurses miss many opportunities to provide person-centred care to patients with dementia, thereby undermining their needs (10,11).

4.1.2 Background

When a person with dementia is admitted to an acute hospital, good communication, involvement, and cooperation between nurses and caregivers is essential to support caregivers and ensure that their individual needs are taken into account when providing care (9,12). Caregivers of people with dementia are often dissatisfied with the quality of care in hospitals. This concerns nurses' recognition and understanding of dementia, the social interaction of the nursing staff with the patient, the patient and caregivers' involvement in decision-making and aspects of dignity and respect, and patient and caregivers' involvement in the discharge process (Dewing & Dijk, 2016).

Caregivers experience the admission of patients with dementia as a serious disruption. They worry about their medical condition and the consequences of their relatives' hospitalization (13,14). A relative can be a family member or a close friend with dementia who is receiving care from an informal caregiver. In addition, caregivers often feel that they are the only ones that represent the patient's interests

(14). When caregivers are poorly informed about care policy and concerns, it is more challenging to advocate the patient's needs. Cooperation between nurses and caregivers during the hospitalization of patients with dementia is important because it enables appropriate nursing care to improve the quality of life of these patients (13). When caregivers feel that they are not adequately informed, they can feel ignored and neglected (15), and they frequently experience that they are insufficiently involved in decision-making. Often times, they doubt whether nurses are interested in receiving information because they always seem in a hurry (14). Nurses indicate that they want to take the patient's dementia into account; however, in practice, they expect patients and their families to adapt to the routines of the ward and the hospital (16). The combination of an unfamiliar, disorienting, and often noisy environment combined with physical illness and unfamiliar caregivers increases the probability of challenging behaviour, like anxious, agitated or confused behaviour, during admission (17). When patients show challenging behaviour, caregivers often experience that nurses have insufficient skills to deal professionally with this behaviour (18). Finally, caregivers are not always involved in hospital discharge planning as they should be (5,19).

Based on Dawn Brooker's person-centred care model, the VIPS framework (Values, Individuals, Perspective, Social) and the results of a systematic review, Beardon et al. (2018) have defined a theoretical framework with four overarching themes from the perspective of caregivers on hospital care for patients with dementia: "patient care," "interaction with nurses," "caregivers' situation" and "hospital environment." The model reflects the main elements of common perspectives of people with dementia in a hospital setting.

Until now, there has been no knowledge about the experiences of informal caregivers in the Netherlands. In the Netherlands, the standard quality of care is high, the average length of hospital stay is short (5.1 days) (20). To improve care and nursing education, it is essential to determine whether the results from other countries are also applicable in the Netherlands. In addition, earlier studies describing caregivers' experiences are mostly about care in general and have a qualitative nature; the extent of the problem is not known. This article explicitly describes nursing care from the perspective of caregivers. We used a quantitative and qualitative perspective to gain more insight into the prevalence and scope of the problem. The combination of these two methods provides a scientific basis for practice and the richness of qualitative research and helps nurses in practice (21).

4.2 The study

4.2.1 Aim

This study investigated the experiences of caregivers of people with dementia with the acute hospitalization of their relative. More specifically, the aim of the quantitative part is to describe how often informal caregivers perceive that the dementia of their relative is taken into account during the hospital admission of their relative ant to which extent they are involved in nursing care and in decision making. The aim of the qualitative part is to gain insight into the underlying experiences that contribute to these quantitative outcomes.

4.2.2 Design

A descriptive sequential explanatory mixed-methods design was used. We have collected qualitative data after analysing the quantitative data to get more in-depth insight into the meaning of the quantitative data and a dynamic view of experiences (22). The design of the quantitative part was a descriptive cross-sectional design. The design of the qualitative part was a qualitative descriptive study (22,23). The quantitative part evaluates how often informal caregivers perceive that the dementia of their relative is taken into account during the hospital admission of their relative in general and consists of an online questionnaire. After this, the qualitative part aims to gain a more in-depth understanding of how caregivers experience different elements of dementia-related nursing care for their relative with dementia. For this part, we organized a focus group with six caregivers and five individual interviews. We used a semi-structured interview method based on the questionnaire topics.

Integration of the qualitative and quantitative results occurs in the results section by fitting the topics to the four main themes. The exploratory findings are presented starting with quantitative results and followed by qualitative outcomes to give depth and meaning to the outcomes (24). The good reporting of a mixed-methods framework (GRAMMS) was used to report the study (25).

4.2.3 Sample/Participants

Participants were Dutch-speaking caregivers who had a relative with dementia who had been admitted to an acute hospital in the Netherlands in the past year. No additional criteria were used. A convenient sample has been applied. The caregivers who participated in the questionnaire and focus group were recruited via the Alzheimer Nederland Caregiver Panel. In addition, through contact with regional case managers for dementia and an online call on the regional Alzheimer's association website, five caregivers signed up for an interview. One interviewee participated in the survey; for the others, this is unknown.

4.2.4 Data collection

Quantitative data collection took place via an online questionnaire. In collaboration with Alzheimer Nederland, an online questionnaire was sent to a Dutch national panel of caregivers (n=1016). An online reminder was sent after three weeks. The questionnaire focused on the experiences of hospital care of patients with dementia, from the perspective of their caregivers. The sub-questions focused on the nature of admissions of people with dementia, how do family caregivers perceive that their relative's dementia and possibly challenging behaviour are taken into account, and how do family caregivers perceive that they are involved in care and decision-making. Because a validated instrument was lacking, the questionnaire was developed in an iterative process with dementia experts in collaboration with Alzheimer Nederland to increase face validity. The content is based on the literature and a questionnaire for nurses based on a study of Hynninen (26,27). The questionnaire consisted of 24 questions, of which two were open-ended, and in addition, there was an opportunity to comment on the questionnaire. Most of the answers allowed the choice of yes-no-not applicable or, yes-no-I don't know. Other options included choice in type of department, a 5-point Likert, and giving a grade. The questionnaire included questions about various aspects of patient admission, how nurses take into account the patient's dementia, and the involvement of caregivers in care, decision-making, and discharge. Because patients with dementia in the hospital sometimes show challenging behaviour, the questionnaire was supplemented with two subscales on this topic (26,27). The first subscale focused on how nurses responded to challenging behaviour according to caregivers and applied a four-factor model: *reacted with care*, *reacted by ignoring*, *reacted with power* or *reacted casually*. The second subscale focused on what approaches nurses used according to informal caregivers to prevent freedom-restricting measures. This consists of three factors, use of professional knowledge, use of medication, and use of problem-solving. In the questionnaire, the participants could indicate whether or not they could be approached to participate in a focus group.

Subsequently, qualitative data collection took place by organizing a focus group with six participants together with the Alzheimer's Nederland followed by 5 face-to-face interviews. The advantage of this approach was that the themes from the focus group could be explored in more depth. After three interviews, it appeared that no new themes emerged and two additional interviews were conducted for verification, which also did not provide more depth to the themes.

The qualitative part focused on gaining insight into positive and negative experiences of loved ones with dementia in the hospital, where in addition to the themes from the questionnaire, there was also room for other points, such as the hospital environment and rooming inn. That's why the focus group started with a wall of jubilation and complaints. In this method, participants were given time to describe both positive and negative experiences on a post it and stick it on a sheet for positive experiences or a sheet with negative experiences. Next, similar experiences were grouped together, and themes were jointly determined. These themes formed the guiding principle of the focus group. In addition, the results from the questionnaire were further explored. For the interviews', semi-structured interviews were used, starting with an open-ended question to the respondents to describe their experiences with nursing care for their relative in the hospital. The topic list was based on the topics from the questionnaire, supplemented by topics from the focus group, like information and communication, and environment and orientation. By using different interview techniques, such as probing and giving small compliments, more depth was obtained in the interviews. Themes from the focus group and previous interviews were further explored, such as experiences with ''rooming-in'', shared decision making, dignity, and involvement in care. Both the focus group discussions and the interviews were recorded and transcribed verbatim.

4.2.5 Ethical considerations

The study was performed in line with the Helsinki declaration, and all participants provided informed consent before completing the questionnaire. The need for approval was waived by the Medical Ethical Committee of the University Medical Centre Groningen (decision M17.221048). The questionnaires were immediately anonymized upon reception of the same. The recordings of the focus group interviews were anonymized during transcription, and the original sound recordings were destroyed once transcription was completed. All participants provided verbal and written consent to the recording of the interviews and the anonymized use of the interviews for research purposes.

4.2.6 Data analysis

Quantitative data were analysed using IBM SPSS Statistics (version 27). First, we performed descriptive analyses of the caregivers' background characteristics, followed by descriptive statistics of the questionnaire's items. Before starting the focus group, we analysed the results received up to that point date. The focus group and interview transcriptions were integrated and analysed with using the steps of thematic analysis (28) using ATLAS.ti computer software (version 8.4.4; ATLAS.ti Scientific Software Development GmbH, Germany). We also included answers to the open-ended questions of the questionnaire in this qualitative analysis. Two independent researchers coded the data were coded in an inductive and iterative process, based on the framework of Beardon (2018). This framework is in line with our research aim, and we used this model as the theoretical basis of our analysis. We made some minor adaptations to the framework related to our focus on nursing care instead of the original focus on medical and nursing care (Figure 1). The "attitudes" are explicitly mentioned with skills and attitudes; the word "medical" has been removed from patient care. In addition, the term "navigation systems and processes" has been replaced by "planning of care and discharge." This corresponds to the meaning described in this article and is more focused on nursing care. Finally, we replaced the word "staff" with "nurses."

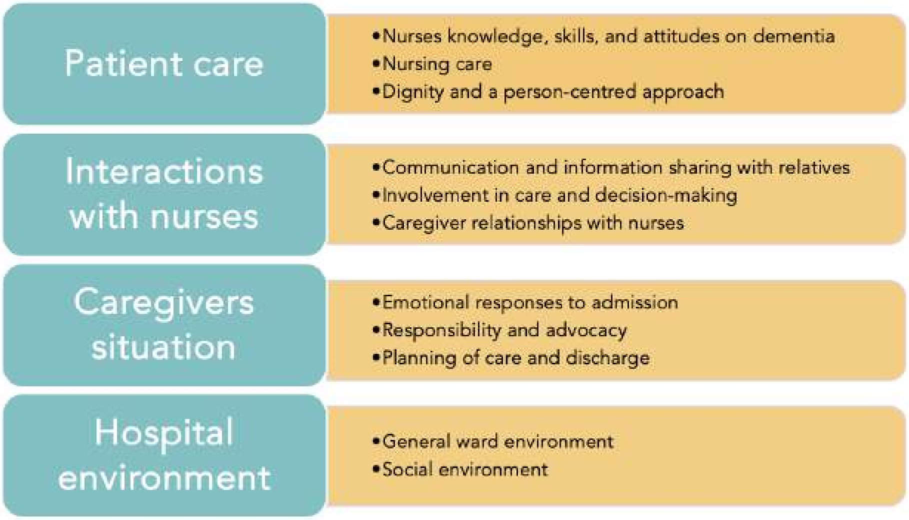

Figure 1. Adjusted theoretical framework of Beardon (2018)

4.2.7 Validity and reliability/Rigormn

The notes taken by one of the researchers during the focus group were later used to write a report. In addition, we transcribed the recordings and performed a member check to improve the internal validity. This was accomplished by summarizing the interviews after they were completed and by submitting the results to a sample of respondents for review. Adequate time was reserved for both the focus group and the interviews so that all participants could be adequately listened to, to obtain in-depth and detailed information. In the focus group and interviews, the results of the questionnaire were explored in greater depth. We kept a log for reflection and discussed the recordings and transcripts with the research team. We followed the steps of thematic analysis, in summary, coding, searching for themes, reviewing and defining themes, and enhancing trustworthiness (28).

4.3 Results/findings

The quantitative and qualitative results are integrated and discussed using the four main themes of patient care, interactions with nurses, caregivers' situation, and hospital environment. An overview of the general quantitative results is provided in Appendix C.

4.3.1 Participants

A total of 396 (39%) caregivers completed the questionnaire. According to the Alzheimer's Nederland, the response rate for the questionnaire mirrors the average response rate of the panel Of these, 129 caregivers (33%) had a relative who had been admitted to the hospital in the past year; this group filled in the corresponding part of the questionnaire. There were no missing values. As shown in Table 1, most of the participants were women, highly educated, and had a job. Mostly, they cared for a partner or parent.

Regarding the focus group, five women and one man participated, where one person cared for the partner and the others for a parent or parent-in-law. In addition, we interviewed four women and one man, where two were caring for a partner, two for a parent, and one for a parent-in-law. This was a convenience sample because most of the approached caregivers indicated that they could not participate because their caregiving duties did not allow it.

The caregivers' relative mostly remained in the surgical (n = 29) and medical units (n = 21). Only 15% stayed in the geriatric ward (n = 19). Most patients were admitted to hospital via the emergency room (n=106); a small number (n= 18) of the admission was planned or arrived at the outpatient clinic (n=5). The average length of stay was eight days. Fractures due to falls and heart problems were the most frequently cited reasons for admission. Some of the patients had multiple diagnoses that required admission, such as various infections or complications.

Table 1. Background caregivers and their relative with dementia (n=129)

			Number (%)
Caregiver	Gender Carer	Female	72
		Male	28
	Level of education Caregiver	Primary school	0.8
		Secondary education	31.7
		Vocational education	18.3
		Higher education/University	49.2
	Employment status Caregiver	Retired	32
		Part-time	26.2
		Full-time (32 hours or more)	18
		Jobseeker/ Incapacitated/Student	13.9
		Housewife/househusband	9.8
	Relation with person with dementia	Partner	38.9
		Parent	38.1
		Son or daughter	7.9
		I do not care for my relative with dementia anymore*	7.1
		Other family or friend	5,3
Person with dementia	Gender person with dementia	Male	44.8
	Living condition person with dementia	Living with a partner and/or children	44.5
		Nursing home	28.6
		Living alone	17.5
		Other	9.5
	Living with person with dementia	Yes	38.2
		No	61.8
	Type of dementia	Alzheimer's dementia	53.4
		Vascular dementia	16.9
		Frontotemporal dementia	4.3
		Lewy body dementia	4.2
		Other	11.9
		No diagnose	5.9

*Because patient with dementia has died or moved to a nursing home

4.3.2 Patient Care

In general, almost half of the respondents (n=59) were very satisfied with the extent to which nurses took the dementia of the patient into account. Two-thirds of the participants (n=86) stated that their relatives were treated with understanding. Around half of the respondents indicated insufficient supervision during mealtimes (n=67), and more than a half (n=70) implied inadequate supervision to prevent people with dementia from wandering.

More than half of the caregivers (n=78) indicated that their relative showed behavioural problems during admission, particularly nocturnal unrest (n=57), and suspicious (n=52) and anxious (n=48) behaviours. Nurses were perceived as reacting differently to patients' challenging behaviours (Table 2), with the most frequently mentioned response being "reacted with care." This included situations where the caregiver had seen nurses asking the patient "what is wrong" (n=46) or "the nurse was there for my relative, talked, listened, and touched him" (n=32).

Table 2. Reactions and approaches to challenging behaviour (n=78)

Subscales and items	% (n)		
	Yes	No	I do not know
Reactions			
Reacted with care			
Asked my relative what's going on.	59 (46)	22 (17)	19 (15)
Checked my relative's file on his/her background and possible instructions.	27 (21)	26 (20)	47 (37)
Organized activities for my relative, such as turning on the television in his/her room.	17 (13)	60 (47)	23 (18)
Was there for my relative; Talked and listened and touched him/her.	41 (32)	32 (25)	27 (21)
Reacted by ignoring			
Did nothing.	18 (14)	44 (34)	38 (30)
Pretended that she/he didn't hear, see or notice anything.	21 (16)	32 (25)	21 (27)
Reacted with power			
Brought my relative to his/her own room	12 (39)	58 (16)	31(23)
Used physical strength to bring calmness to the situation.	47 (9)	27 (45)	26 (24)
Gave my relative instructions, for example, to stay in bed or stay in the room.	47 (37)	27 (21)	26 (20)

Reacted causally			
Used humour.	36 (28)	28 (22)	36 (28)
Tolerated his/her behaviour because a patient has the right to get angry.	33 (26)	22 (17)	45 (35)
Approaches			
Use of professional knowledge			
Restricted my relative's freedom (e.g., removed sharp objects, raised the bed rail).	45 (35)	42 (33)	13 (10)
Could deal with my relative's behaviour.	47 (37)	31 (24)	22 (17)
Consulted with colleagues about the right approach.	32 (25)	17 (13)	51 (40)
Consulted with me about the right approach.	46 (36)	49 (38)	5 (4)
Use of medication			
Gave calming medication to my relative.	32 (38)	10 (22)	58 (18)
Gave my relative painkillers.	49 (47)	28 (17)	23 (14)
Use of problem-solving			
Try to distract my relative.	60 (25)	22 (23)	18 (30)
Arranged a consultation with an expert.	32 (21)	29 (38)	38 (19)

We also asked caregivers what type of responses nurses showed to their relatives' challenging behaviour. Caregivers observed "use of problem-solving" as the most commonly used approach by nurses, which consisted of distracting the patients (n=60). However, activities to prevent challenging behaviour and provide person-centred care, such as bringing personal belongings (n=33), making the environment incentive-free (n=24), providing a day structure (n=34), and organizing activities (n=16), were rarely seen by the caregivers. Looking back, participants graded nurses with a 6.4 (SD1.2, range 1-9) on a scale from 1-10.

In addition, qualitative research showed that caregivers mentioned frustration when they experienced that nurses had insufficient knowledge of dementia. In these situations, they observed a lack of understanding of patients' needs. Participants experienced that nursing care was, in particular, disease-orientated, and that somatic care predominated. Caregivers also perceived that some basic nursing care was not provided in their absence. Examples included no assistance with dressing, no assistance with brushing teeth, no assistance with toileting, no support in opening pre-packaged food, or no help with taking medication. It also happened that in the caregivers' presence, somatic-related interventions, such as providing medication, were carried out without talking with patients or caregivers. Caregivers stated that challenging behaviour arose because the nurses did not understand the patient's behaviour and, therefore, could not respond in time. In addition, caregivers reported problems related to the organization of care; they did not know who was responsible for the patients' care or had difficulty getting in touch with the nurses. Some caregivers indicated that they felt that they were taking over the nurses' tasks, such as providing basic care, like washing, dressing, and giving medication.

Concerning dignity, participants reported several incidents related to the patient's behaviour, which were perceived as undignified or led to unnecessary complications. For example, one patient was found in his pants, tied to a chair, and covered with food; another patient had pulled off the curtains, thrown crockery, and his feet were full of shrapnel, and the nurse reacted by asking the caregiver if there was a need for a brush and dustpan. Caregivers indicated that patients were sometimes yelled at by nurses when they showed challenging behaviours. The respondents felt that these incidents, alongside hospital admission, had a significant impact on patients, who often felt overwhelmed and confused in a strange environment with strange people.

During admission, no attention was paid to the patient's life story in the caregivers' view, an essential aspect of person-centred care, enabling a better interpretation of the patient's behaviour. In the focus group, a respondent stated that the patient was taken to the geriatric department because daycare was available. The other participants indicated that this was a great option that could be applied more often. One caregiver described:

> *"The biggest problem, I think, is that the nurses want the patients to keep quiet, so they keep them heavily medicated so that they do not cause any trouble, and then close the door because then they do not see it."*

4.3.3 Interactions with Nurses

More than two-thirds (n=89) of the participants stated that they were always or often involved in care decisions. Half of the respondents (n=67) were satisfied with their involvement in these decisions. According to half of the respondents (n=68), their relative often or always felt taken seriously by nurses.

From the interviews, it became apparent that the decisions in which participants were involved were mainly about whether to hospitalize, operate, and whether patients would go to a rehabilitation facility, nursing home, or their own home. In general, respondents stated that they believed that it is essential to include all three parties—patients, caregivers, and professional caregivers—in the decision-making process. Participants did not mention shared decision-making in the nursing field, for example, regarding the time or date of discharge. When respondents felt that the patient was not welcome in the ward, they also felt that the nurses avoided contact with them. In addition, respondents occasionally felt that nurses did not seriously consider the symptoms of the patients.

All participating caregivers indicated that communication could be improved. They reported that nurses did not take dementia into account when communicating with their relative. Caregivers also felt that nurses preferred to focus on physical care rather than answering their questions. When caregivers were frequently present, communication was enhanced. When their relative was restless at night, caregivers experienced diverse reactions from nurses; some would call them, while others would not inform them and they accidentally found out. When a patient showed challenging behaviour, and caregivers explained this behaviour, they felt that nurses did not always understand this and did not do anything to address it.

Some caregivers indicated that they appreciated that there was always a nurse available to listen to them and to pay sufficient attention to the patient and themselves. On the other hand, caregivers frequently mentioned that nurses were very busy. On the one hand, this was respected, but on the other hand, this led to frustration. Caregivers felt that nurses were not available for communication and therefore, felt that they were not being listened to or ignored. One caregiver reported *"I made the decisions along with the doctors and nurses. They first asked me how I wanted things to go and took my views seriously"*, another one revealed: *"We were present at discussions but our views were not taken seriously. They had the experience, and we just had to follow their judgments."*

4.4.4 Caregivers' situation

Half of the respondents indicated that they could stay day and night (n=95) at the hospital. More than half of the respondents (n=77) recommended their hospitals for people with dementia. The reasons for recommending the hospital included the provision of good physical care, the possibility of unrestricted access, and the fact that dementia was taken into account. Remarkably, there were also reactions that expressed serious concerns about the care provided, such as *"I do not know what would have happened if I had not been around."* The reasons for not recommending a hospital included the view that the patient's dementia had not been taken into account, experiencing insufficient knowledge of dementia, and a negative attitude of healthcare providers. More than three-quarters of the participants (n=100) pointed out that they were involved in their relatives' discharge. About half of the caregivers (n=63) were satisfied with the extent to which they were involved in the process of discharge.

The qualitative findings showed that respondents indicated that they provided most of the nursing care. Although rooming-in was frequently arranged, it was sometimes seen as a way to unburden the nurses and not for the patient's wellbeing. Caregivers often felt pressured to be present and take over part of the care, whereby their personal situation and overburdening were not sufficiently taken into account. The caregivers missed a lack of explanation and guidance on dealing with their relatives' restless and sometimes difficult behaviour. In addition, they felt that they had to solve problems for the nurses.

Respondents mentioned experiencing strain, which was increased by the hospitalization of their loved one. This was intensified by a perceived lack of adequate information and the feeling of not being treated as partners in care by the nursing staff. Many respondents said that they were generally outspoken, but that they were less able to advocate for their relatives' needs due to stress. Sometimes, stress also impacted caregivers' attitudes toward their relative, with whom they were less patient or even became angry. Caring for a restless relative during hospitalization took much energy, and participants expressed that they were intensely tired after the period of admission. In general, caregivers expressed finding it challenging to leave care to the nurses, as they were afraid that the patient would be unwanted.

Respondents mentioned that the case manager or home care services were not involved in care or discharge planning during hospitalization. Caregivers knew the discharge date at least one day in advance, although there were exceptions where the caregivers were called to pick up the patient immediately. The discharge date was generally planned in cooperation with the caregivers. Regarding the transfer, respondents mentioned a medical discharge letter and not a nursing handover or the case manager's involvement. They stated that the information in the handover did not correspond to the actual situation. For example, one respondent said: *"I think that translating what the patient means is an important task of the family caregiver."*

4.4.5 Hospital environment

Because the analysis model was added after conducting the questionnaire, quantitative data were not available for this topic.

In general, caregivers indicated that a hospital ward environment is not appropriate for people with dementia. Patients staying in a non-geriatric ward were often referred to by caregivers as being in the wrong ward, although this was seen as appropriate for physical illnesses. Opinions were divided based on the appropriateness of a single room. Some participants were happy with a single room for their relative with dementia, while others consider that they had a lack of stimuli or were too isolated. As a disadvantage of a shared room, caregivers reported that it was impossible to visit outside visiting hours or stay overnight, and that there were too many triggers for the patient. When patients stayed in a shared room and showed restless, aggressive, or disruptive behaviour toward other patients, nurses transferred the patient to a single room. When patients were alone, caregivers were worried about their feelings of loneliness. In addition, they found it unpleasant if their loved one bothered other patients and felt responsible for explaining their relatives' behaviour. They were also dissatisfied when their loved ones did not stay in a geriatric ward or moved from a ward or room.

Caregivers also had concerns about the safety of the environment, especially the risk of falling and wandering. It was remarkable that caregivers only once mentioned fall detection and did not mention the use of other technologies. One caregiver stated: *"My husband started wandering about the corridor. After six days, I had the choice to stay with my husband day and night or to take him home, and I chose the latter."*

4.4.6 Suggestions

In both the comments of the questionnaire and the interviews, caregivers gave suggestions on how to improve the care for patients with dementia in hospitals. A key suggestion of caregivers was to create a special department for people with dementia, with specialized nurses and care provided by the same nurses. Caregivers found it difficult to notice that when a nurse was on a different shift or after some days off, they cared for other patients and no longer for their loved ones. In addition, respondents suggested developing a protocol for the admission of people with dementia, whereby it is instantly visible in the record that the patient has dementia. Some caregivers advocated the use of volunteers and activities on the weekend. Finally, respondents considered it important that admissions were carefully evaluated with all those involved to learn from the experiences.

4.5 Discussion

This study aimed to describe the experiences of caregivers related to nursing care for people with dementia in acute hospitals in the Netherlands; how often informal caregivers perceive that the dementia of their relative is taken into account during the hospital admission of their relative and to which extent they are involved in nursing care and in decision making added with the underlying experiences that contribute to these outcomes. By combining both quantitative and qualitative outcomes, insight was gained not only into the prevalence to which caregivers are involved in care and decision-making but also what the underlying experiences were that led to these reactions. Caregivers felt positive when nurses took the dementia of patients into account, cooperated with the nurses in the patient's care, nurses showed awareness of the caregiver's situation, and the hospital environment was safe and adjusted for patients with dementia. Caregivers mentioned negative experiences when nurses focused solely on somatic care, such as symptoms of the disease. When they experienced that, communication could be improved, especially around the patients' changed and sometimes challenging behaviour, and when they experienced a clinical, unfamiliar hospital environment that was not appropriate for people with dementia.

4.5.1 Patient care

Our research shows that caregivers perceive that the attitude and knowledge of Dutch nurses caring for people with dementia can be improved. This is in line with previous research in countries with comparable dementia care (6,9,14,29). Caregivers' satisfaction with patient care seems to be related to the perceived competences of nurses. For caregivers, it is important that nurses consider patients' dementia. Caregivers' experience is partly consistent with how nurses perceive that they are dealing with challenging behaviours (26,27). Caregivers, like nurses, perceive "reacted with care" as the most frequent response to challenging behaviour. However, they experience a difference in their approach. Nurses often prefer "use of professional knowledge," while caregivers mainly observe approaches aimed at "problem-solving."

Regarding nursing interventions and reactions to challenging behaviour, this study confirmed that interventions based on person-centred care, such as providing activities and bringing personal belongings, are also not often seen by caregivers. This corresponds to how nurses perceive themselves to be performing these interventions. For improving the care options, "This is me" or other documents containing detailed information about the patient could be used (30). "This is me" is a leaflet that can be used to describe a person, such as important people around them, preferences and habits, and important experiences, and enables person-centred care.

In addition, in the Netherlands, there are no criteria for dementia-friendly care in hospitals. As in other European countries, regular audits can provide more insight into the different aspects of this care (30).

People with dementia are hospitalized because of other diseases, in addition to dementia. This requires nurses to know about dementia care, in addition to their specialties. Our results show that caregivers experience that the focus of nursing care is somatic. This seems consistent with the culture and structure of hospitals organized based on diseases.

Caregivers indicated that they prefer separate wards for their relative, where nurses are specialized in dealing with people with this condition and also have knowledge related to the illness. This seems complicated to execute because, in Dutch hospitals, people with dementia are not always admitted to the geriatric ward but to the ward appropriate to the condition that led to their admission. Our results are comparable with those of previous studies (14,18,29–32).

To improve patient care, several studies show that training is an effective method to raise nurses' awareness of the patient's dementia and to teach person-centred care (33). When nurses are trained in dementia care, they can be made aware of the caregivers' perspective, for example, by including caregivers in this training and sharing stories. In addition, it is essential that all caregivers provide person-centred care and support it (7).

4.5.2 Interactions with nurses

Respondents were not always satisfied with the extent to which they were involved in the decisions regarding their relative. This might be because caregivers often experience that they are not heard or seen as partners in care (12). The literature describes policies about best practices around the involvement of caregivers in decision making, where information is given, and agreements are made about this involvement (30). For patients with dementia, the best treatment for a disease may not always be the best treatment for the patient. Therefore, goal-directed treatment and care might be more appropriate than disease-directed treatment (34). The extent to which shared decision-making and goal-oriented care are used in caring for people with dementia is unknown.

Respondents were very understanding of nurses' perceived time constraints, and almost by default mentioned that nurses are busy and do not have enough time. This could be because the general perception of nurses is that they work hard and are always busy. Another possible explanation is that caregivers also feel dementia care as extra care rather than regular care. Another aspect of the relationship with nurses is that caregivers deal with many different nurses, making it impossible to build a relationship. Warm relationships increase satisfaction with care, and caregivers feel reassured when staff recognize the importance of their relationship with the patient and involve them adequately in the care. The extent to which patients with dementia are considered in daily planning and their care is distributed among nurses is unknown. However, nurses state that this does not happen often enough (27).

Effective communication with both the caregivers and the patient is an important aspect of the quality of nursing care, which can be challenged by competing clinical priorities (7,12). For caregivers, having contact with nurses and receiving information is important, especially as patients with dementia are often unable to explain it themselves. This is also reflected in previous studies (7,18,35). As also described in other studies, caregivers feel that they have to take the initiative to receive information (6,14,36). Some caregivers care for relative in a nursing home. In this context, there is a different and prolonged contact with nurses. As a result, it is possible that the expectations of caregivers are not appropriate for an acute hospital setting with a shorter hospital stay and a higher number of nurses. The triangle of care model describes the importance of collaboration between the patient, caregiver, and nurse (37). Based on six key standards, this model describes how meaningful involvement and inclusion of caregivers can contribute to better care for people with dementia. From the patient's perspective, caregivers' involvement is important (30).

Nonetheless, caregivers indicate that they would like their personal situations to be taken into account. It appears that nurses expect caregivers to know how to manage patients' difficult behaviour. However, caregivers experience this as very difficult and plead for instruction and support. The extent to which nurses are aware of this and whether this is part of their training are unknown aspects.

4.5.3 Caregivers' situation

Rooming-in and unrestricted visiting times are part of the Dutch guidelines for the care of patients with dementia (38). This can create pressure on the caregiver when personal circumstances are not considered, when the caregiver feels like they have no choice, and when there is little discussion about alternative options. This corresponds with the previously described feelings of obligation to care because of inadequate care by professional caregivers (14). To relieve caregivers, the use of volunteers can also be considered. The involvement of volunteers in hospitals, specifically for patients with cognitive impairment or dementia, leads to increased care satisfaction (39).

Caregivers' feelings regarding the admission of their relative are mainly related to patient behaviour and nurses' competencies. Respondents feel vulnerable and, hence, unable to advocate for the patient's needs. This has also been shown by previous research, which indicates that good communication is important, as it involves caregivers in the care and building up a relationship with them. These elements lead to better experiences and better quality of care for the patient (12).

Our research provides insights into caregivers' experiences of admission, stay, and discharge. Concerning the process of care, our results are consistent with those of previous studies (12). Our research shows that the process of discharge is important for the overall experience of admission, as it reflects the admission as a total, the extent to which caregivers are involved in care and decisions, and how caregivers and nurses communicate (14,19).

4.5.4 Hospital environment

Caregivers state that they experience the hospital environment as not tailored to patients with dementia and their caregivers and is not always safe enough. Key aspects of a supportive hospital environment include a safe place that enables independence, where social interaction is supported, and where patients and caregivers are treated with respect. A safe hospital environment feels emotionally safe, affords opportunities for activities, and prevents anxiety and stress (40).

Although most guidelines recommend a single room for patients with dementia, there are also circumstances in which caregivers prefer their relative to be in a shared room. Therefore, it is important to discuss preferences with both while taking into account the caregiver's personal situation (16). In addition, a dementia-friendly environment has a calm appearance, with a minimum of unnecessary clutter, noise from televisions, alarms, etc., inviting people to see, touch, feel, or smell things, such as artwork, soothing music, and providing patients with clues about where they are and what they can do (41).

Caregivers have a variety of ideas about how to improve patient care in hospitals, for example, the creation of a separate ward for people with dementia. To the best of our knowledge, no research has focused on this topic, which supports advantages and disadvantages of a separate ward for care for patients with dementia.

4.6 Limitations

This study has several limitations. First, because many adverse experiences regarding care for patients with dementia have been described in the literature, there is a risk of confirmation bias in the qualitative part of the research. Therefore, both in the focus group and the interviews, we explicitly asked caregivers to focus on their positive experiences. Consequently, we used the jubilant-complaint wall in the focus group to give both parts equal attention, and we also used these results in the interviews. In addition, when the experiences were negative, we asked the caregivers if they could also give out small compliments to the nurses. Consequently, we expect that this did not affect the results.

Second, regarding the interviews, we noticed that these were sometimes emotional for participants due to unprocessed emotions. We cannot exclude the possibility that this influenced the results negatively.

Third, the questionnaire can be further developed by including topics related to communication and hospital environment. These topics come from the theoretical model of Beardon (2018), which was not published at the time the questionnaire was developed. In addition, the psychometric properties can be tested. This questionnaire lacked sufficient focus on communication and hospital environment. As a result, not all data can be fully compared both quantitatively and qualitatively. This might have influenced inference transferability.

In the results of the questionnaire, we saw a percentage between 3% and 19% of “ I don’t know” in the answers. A number of responses were notable; caregivers do not know whether nurses made the environment incentive-free (19%), and caregivers did not know whether their relative exhibited confused behaviour (14%), shouting behaviour (13%) or disruptive behaviour toward other patients (13%). The most plausible explanation is that this is because family caregivers were not always present. Because the data was also collected qualitatively, whereby questions could be extended, we do not expect this to have influenced the results.

Combining both types of data has provided greater insight into the generalizability of informal caregivers’ experiences enabling more quantitative research to be conducted in the future. In our study, Beardon’s framework was not used in the design of the study, the quantitative data of the environment component is limited, and therefore no thorough integration of the data took place on this part of the Beardon framework. This limits the generalizability of the outcomes of these results.

Finally, the data was collected before COVID-19 became actual in the hospitals. We expect the findings to remain relevant.

4.7 Conclusion

A slight majority of caregivers were satisfied with the care of their relative in acute hospitals. These caregivers are more satisfied with care when nurses take dementia into account and value the patients, and when they are involved in decision-making. Hospitals focus on somatic care rather than person-centred care. Although involving caregivers is very important in the care of patients with dementia, there are indications that nurses do not adequately consider the caregivers’ personal situation. The hospital environment can be adjusted more for people with dementia. Outcomes can be used in training to help nurses reflect and look for improvements. In systematically evaluating care by nursing staff, the caregiver’s perspective can be added structurally as a caregiver report. Finally, caregivers can be involved in improvement projects for the care of patients with dementia in the hospital.

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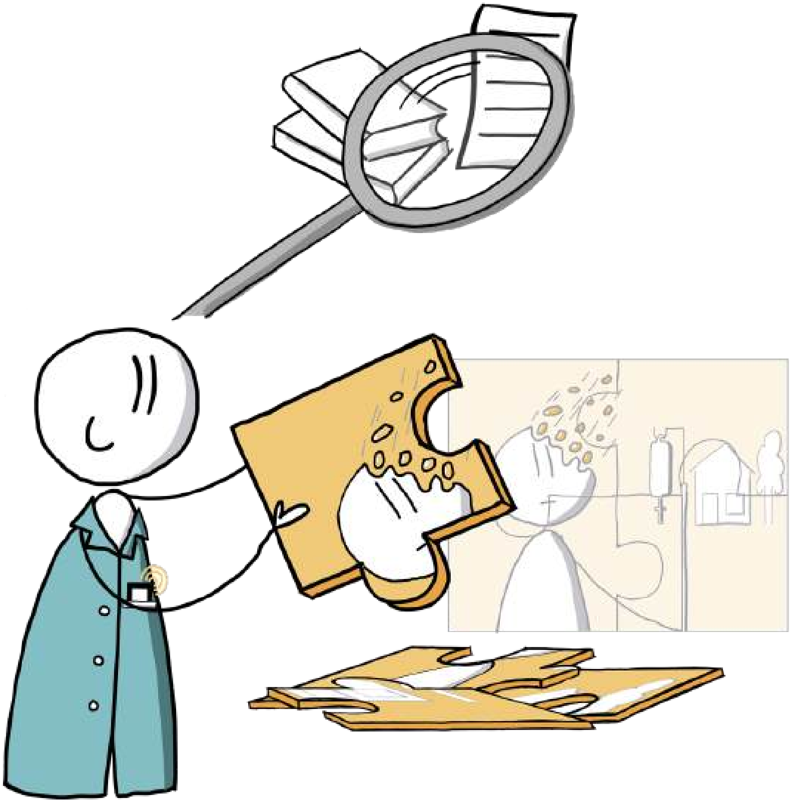

CHAPTER 5

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

Chapter 5. Involvement, topics, and roles of nurses in shared decision-making with patients with dementia in acute hospitals: An integrative review

Keuning-Plantinga, A., Stoffels, J., Roodbol, P. F., Finnema, E. J., & Van Munster, B. C. (2023). Nursing Open, 00, 1–14.

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 hand 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.

No Patient or Public Contribution

5.1 Introduction

Worldwide, more than 55 million people live with dementia; by 2050, this number is expected to increase to 139 million (1). People with dementia are frequently acutely admitted to a hospital (2) and primarily because of comorbidities (3). Because of multi-morbidity 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 (3–5). Person-centred care is the gold standard of caring (6). To explicitly allow for taking into account the patient's values, preferences, and goals, decisions should be optimally made with the patient (7–9). Shared decision-making within person-centred care implies that the patient and the healthcare providers share responsibility for empowerment, autonomy, and involvement in care and treatment (10). For hospitalized patients with dementia, good cooperation between patients, informal carers, and healthcare providers is essential (11–13), 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 (14).

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 legally consent and establishing the family caregiver's responsibilities as a surrogate decision-maker (15). 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 (16). In addition, healthcare providers often consider the relatives representing and speaking for the patient (17–19). 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 (20). Nurses influence treatment decisions to varying degrees and wish to be more involved (21,22).

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 (23). Groen's conceptual model was developed for patients with dementia in dementia care networks according to the principles of person-centred care (24). 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 (24).

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 (25). 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.

5.2 Methods

5.2.1 Design

An integrative review was performed using the framework of Whittemore and Knarfl (26). The integrative review method is an approach that allows different methodologies to be integrated and provide 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 (26,27). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 checklist was used to guide and report the integrative review (28).

5.2.2 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.

5.2.3 Information sources

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

5.2.4 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.

Table 1. Search strings

Pubmed	("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]) AND ("Decision Making"[Mesh] OR "Clinical Decision-Making"[Mesh] OR "Decision Making, Shared"[Mesh] OR decision making[tiab]) AND ("Hospitals"[Mesh] OR hospital*[tiab] OR geriatric department*[tiab]) AND (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*)) **AND** ((MH “Advance Care Planning”) OR (MH “Decision Making+”)) **AND** ((MH “Hospitals+”) OR TI (hospital* OR “geriatric department*”) OR AB (hospital* OR “geriatric department*”)) **AND** (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*)) **AND** (DE “Decision Making” OR DE “Choice Behavior” OR DE “Group Decision Making” OR DE “Management Decision Making” OR “decision making”)) **AND** (DE “Hospitals” OR DE “Psychiatric Hospitals” OR DE “Sanatoriums” OR TI (hospital* OR “geriatric department*”) OR AB (hospital* OR “geriatric department*”)) **AND** 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*) **AND** (“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”) **AND** (hospital* OR “geriatric department*”) **AND** nurs*

5.2.5 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 (29,30). Of these 35 articles, nine articles met the inclusion criteria. We excluded studies based on methodological criteria, inappropriate population, or setting. A Prisma flow diagram of the search results is shown in Figure 1 (28). Two researchers (AK and JS) independently reviewed the articles in Rayyan (31). In the case of different judgments, 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) 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 judgments, the decision was deliberated and made by consensus.

5.2.6 Data collection process

A standardised, 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.

5.2.7 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 (32). 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 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.

5.2.8 Synthesis methods

In data synthesis, we used 'data reduction,' 'data comparison,' 'conclusion drawing,' and 'verification' to increase rigor ((26). The data synthesis started by selecting all relevant text fragments concerning the research question and organizing this into a

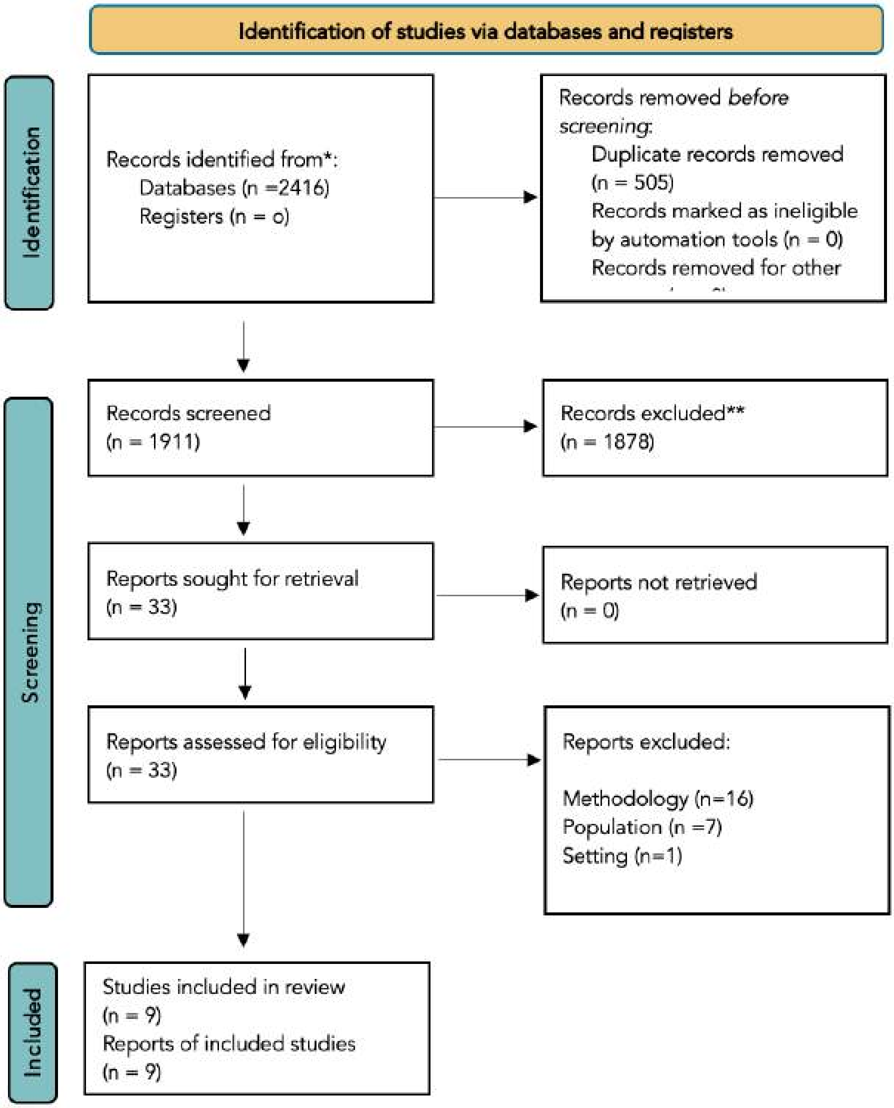

Figure 1. Prisma flow diagram (Page, 2021)

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. This data was summarized, analysed in several phases until consensus was reached, and discussed with the research team, where the data was increasingly solidified. Finally, the data were categorized in more detail by the stages of shared decision-making of Groen's model (24).

5.3 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 (33) 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 (34) 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 were 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.

5.3.1 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 (17,18,34,35). 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 (36,38,39). 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 (33,40).

5.3.2 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* (24) (Table4). Nurses fulfilled different roles in the steps of the shared decision-making process of Groen's model (24).

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 (33). Nurses discussed plans and recorded stakeholders' opinions (40).

Nurses were messengers and communicators by intermediating between the patients and the physician, the family, and the nursing team (17,33–35,38). 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 (33,37,38,40). For this purpose, nurses used non-verbal communication cues, for example, regarding pain (38,39). 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 (40). Finally, in 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 (18,36,40).

Developing tailor-made options
Developing tailor-made options is described as weighting treatment options and the value associated with treatment options (38). Involved roles in this phase were to advocate for the family and try to influence decisions, if possible, in favor of the patient's wishes (36).

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 (18,34). In addition, concerning artificial nutrition or hydration, it was indicated that the physician was responsible for making a decision (17,35).

Regarding the roles in this phase, two studies explicitly described nurses as part of the team that made a collaborative decision (18,39). Additionally, nurses 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 (17,35). Nurses evaluated the decision made and compared this to their perception of proper care (17,18,34,35).

5.4 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.

5.4.1 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 (21,22,41). 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 (42). 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.

5.4.2 Topics

The identified topics were not specific to patients with dementia. However, the topics correspond to research on treatment decisions involving patients with dementia (16). 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 (15).

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 (30,43).

5.4.3 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' (21). 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 (44).

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 (45). 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 (21). 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-centred care (46). However, our review shows insufficient how 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 (16). 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 (21). Finally, nurses discuss the goals of care and treatment. As Elwyn describes in his article, it is unusual that in the older models, the goals component is not included (8). 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.

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.

Deliberating and trying options to reach a decision

Deliberating was described from two perspectives. Hanson (2019) described the final decision-making in this phase. In contrast, Dyrstad (2015) and Rhynas (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' (21). 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 (24). 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 (8,23,47). This is intriguing because it may suggest that nurses have already excluded possible options from their discussion with the patient (48).

5.4.4 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 (24). 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 (23,47). 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 (24). In addition, people with dementia want to be involved in decision-making about their care (46). 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 (49,50).

Finally, some criticisms indicate that shared decision-making requires relational autonomy (51,52). 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 (24). 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.

5.4.5 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 (26). 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 (53). A subsequent study could expand the search strategy to include hand-searching, unpublished reports, and conference abstracts to reduce the impact of publication bias.

5.4.6 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-centred 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 hospitalised 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-centred 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.

5.5 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.

5.5.1 Relevance to 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-centred 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-centred 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.

What does this paper contribute to the wider global clinical community?

- *Nurses are involved at three levels of shared decision-making with patients with dementia in the hospital, as members of the treatment team, intermediates, or supporters of the patient.*
- *Nurses’ involvement and roles in shared decision-making vary by topic. Mainly described are their roles in preparing decision-making.*
- *Nurses have an essential role in advocating for the patient, messaging, and communicating between the professionals and the patient and informal caregivers.*

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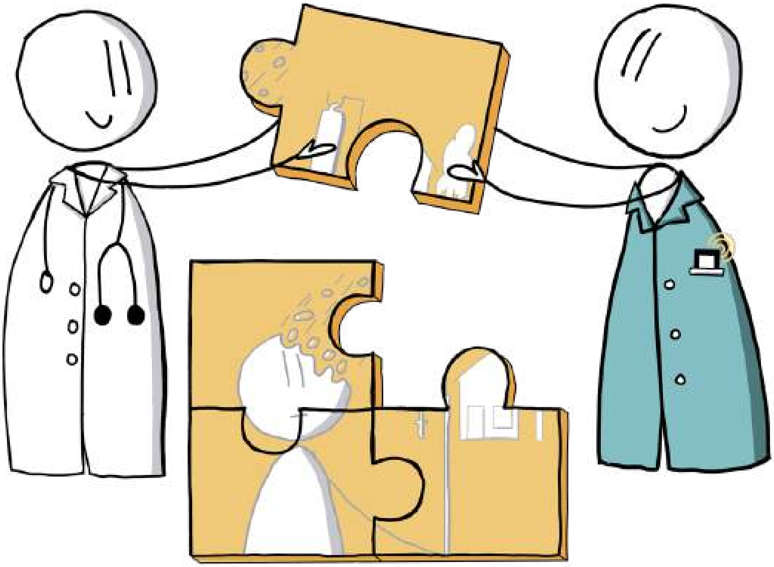

CHAPTER 6

Nurses' Perspectives on Shared Decision-making in the Daily Care of Hospitalized Patients with Dementia: An Exploratory Qualitative Study

Chapter 6. Nurses' Perspectives on Shared Decision-making in the Daily Care of Hospitalized Patients with Dementia: An Exploratory Qualitative Study

Plantinga, A., Roodbol, P., Munster, B. C. van, & Evelyn J. Finnema. (2024). Journal of Advanced Nursing (Wiley-Blackwell) 00:1-11.

Abstract

AIM: Gain insight into the process of shared decision-making (SDM) in daily hospital care for patients with dementia from nurses' perspectives.

Design: Explorative qualitative design.

Keywords: Care, Dementia, Hospitals, Nurses, Shared decision-making

Methods: In-depth digital interviews were conducted with 14 registered nurses between June and November 2022. A phenomenological approach was applied using Colaizzi's seven-step method.

Results: Five themes were identified in the data: 1) SDM in daily care: How shared decision-making is applied; 2) Nurses' perceptions and competence: How nurses perceive and manage SDM; 3) Nurses' roles and advocacy: The evolving roles of nurses and their advocacy efforts, 4) Recognition of dementia and its impact: How nurses recognise and manage dementia; and 5) Interventions to support SDM: Strategies and interventions to facilitate SDM.

Conclusion: This study highlights the complexity of SDM in patients with dementia. It demonstrates the importance of the involvement of relatives, omission of patient goals in discussions, and perceived deficiencies of nurses. The early identification of dementia, evaluation of nuanced capacity, and targeted communication are essential. Further research and enhanced training are required to improve care in this context.

Impact: Potential areas for further research on SDM in nurses involving patients with dementia include investigating the effects of integrating goal discussions into SDM training for nurses, overcoming barriers to SDM competence, and challenging the idea that SDM is solely the responsibility of physicians. These findings highlight the need for policies that encourage interdisciplinary collaboration, address misconceptions, and recommend training programmes that focus on applying SDM to the daily care of patients with dementia, thereby improving the overall quality of patient care.

Reporting Method: The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used for reporting.

Patient or Public Contribution: No patient or public contribution

6.1 Introduction

Shared decision-making (SDM) is widely recognised as the optimal approach for patients, including those with dementia, to receive care and treatment consistent with their individual preferences, choices, and goals(1–3). Dementia is a syndrome commonly associated with chronic or progressive conditions resulting from various brain disorders that affect memory, cognition, behaviour, and the ability to perform daily tasks (4). The number of hospitalised patients with dementia is estimated at 25–40% (5–7). Because of multimorbidity and the frequent need for urgent care, dilemmas regarding treatment and care often arise(8–10). Patients with dementia are more likely to experience decision-making uncertainty because they do not fully understand their intentions regarding care and treatment (10). Nurses can make valuable contributions in supporting patients with dementia during the decision-making process(11). However, little is known about the role of nurses in the SDM of patients with dementia in hospital settings (11–13).

SDM is an integral part of person-centred care and is considered the standard treatment for all patients, including those with dementia (14–16). According to Elwyn and Vermunt (2020), the core elements of SDM include goal-team, goal-option, and goal-decision talks. Goal-team talk focuses on supporting patients by suggesting choices and understanding their goals to guide decision-making. Goal-option talk compares alternatives using the principles of risk communication. Finally, goal-decision talk involves making decisions consistent with patients' informed preferences using the experience and expertise of healthcare providers (17,18). The goals and priorities identified in the first step of the shared decision-making process serve as consistent threads that run through each subsequent step. These goals can encompass diverse areas, including symptom management, such as reducing pain, functional improvement (e.g. the ability to climb stairs), and preserving independence in daily life (e.g. returning home) (18). SDM is expected to cultivate stronger relationships between providers and patients, improve decision quality, and contribute to improved perceived health outcomes (19).

6.1.2 Background

Patients with dementia can significantly benefit from SDM, which allows their values, preferences, and goals to be explicitly included in decision-making (20–22). Healthcare providers do not consistently recognise dementia (23).

The Bachelor of Nursing 2020 (Netherlands) educational profile describes interventions and competencies indicating that nurses should be able to handle different phases of the shared decision-making process and use appropriate conversation techniques (24,25). How nurses perform SDM during this process, particularly with patients with dementia and their relatives, is currently unknown. Nurses can have different roles in the SDM of patients with dementia. They serve as preparers, facilitators, and supporters of patients, also ensuring the quality of a decision(12,26). In addition to playing a role in SDM for treatment decisions, nurses are also responsible for making decisions regarding nursing interventions, including daily care. Nurses can autonomously conduct SDM with patients (11,12,27). As dementia progresses, the involvement of relatives with SDM becomes increasingly important (28). Previous research has shown that the application of SDM to patients with dementia and their relatives remains unclear (26,28,29). Known from long-term care, involvement in the decision-making process of daily care is as significant for patients with dementia as the decision itself. Nurses consistently underestimate the desire of patients with dementia to participate in decision-making (30). Little research has been conducted on nurses' experiences in SDM with patients with dementia in hospitals (26). How nurses apply SDM to patients with dementia in daily care and how they consider patients' dementia in this context remains unclear.

6.2 The study

6.2.1 Aim(s) and Objective

This study primarily aims to explore SDM in the context of daily care hospitals, explicit focusing on patients with dementia from nurses' viewpoints. It aims to achieve the following objectives:

1. *Describe nurses' practices and perceptions regarding shared decision-making in the daily nursing care of hospitalised patients with dementia.*
2. *Describe how nurses consider patients' dementia when making decisions together.*

6.3 Methods

6.3.1 Design

This qualitative study used a descriptive, interpretive, and phenomenological approach to gain insight into nurses' experiences of SDM for people with dementia (31–33). Descriptive phenomenology comprises four steps: bracketing, intuition, analysis, and description. Bracketing recognises and restrains existing beliefs about the phenomena and views under study (33). Intuition was applied by remaining receptive as researchers to the nurses' interpretations of the phenomenon. The analysis involved retrieving salient statements and organising and understanding the underlying meanings of the phenomenon, as outlined in Table 2 (33,34). A comprehensive description was created by synthesising all thematic clusters and the corresponding formulated meanings elucidated by the researcher (34).

Semi-structured interviews were conducted using open-ended questions based on an interview guide (Table 1). The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used to report the study (35).

Table 1. Interview Guide

Introduction	Aim, duration of the interview, context, identifying topics and eliciting general data
Main part	Process of shared decision-making • In your opinion, what is shared decision making (SDM)? • How do you apply SDM in providing care to patients with cognitive impairments? • What goes well in SDM with patients with cognitive impairment in your department, and what could be improved? • What do you perceive as your role in applying SDM in patients with cognitive impairment? Impact of cognitive impairment • How do you recognize and assess cognitive impairments in patients? • How do these cognitive impairments affect the process of shared decision-making? • How do you consider the patient's cognitive impairments when conducting SDM? • What is the role of relatives in the SDM process for patients with cognitive impairments?
Conclusion of interview	Wrap up and unaddressed issues

6.3.2 Sampling and Recruitment

The participants were invited using maximum variation sampling. We asked nurses from different types of hospitals (university, non-university teaching, and general), settings (surgical and non-surgical wards), and years of work experience. The nurses were actively approached through existing contacts within their networks and invited to participate in the study. When the nurses expressed interest in participating, they received an email with a letter about the study and an informed consent form. Upon confirmation of participation, specific arrangements were made for the online video interviews. Participation was voluntary, and informed consent was obtained. The participants could withdraw or stop at any time. The researcher did not know the participants personally.

6.3.3 Sample Size

The sample size was based on data saturation. After data saturation, two additional interviews were conducted for verification purposes.

6.3.4 Population and Sample

Registered nurses were eligible if they cared for patients with dementia at the hospital. Nurses in the intensive care unit and emergency room were excluded from this study because the focus in the ED and ER is on acute care and medical decision-making. The study involved registered nurses in hospitals in the Netherlands who provided care to patients with dementia and had experience in shared decision-making. Our sample comprised nurses who voluntarily participated in online interviews and met the predefined inclusion criteria.

6.3.5 Data Collection

Data were collected between June and November 2022. In-depth, semi-structured digital interviews were conducted by an AP (MSc, RN), an experienced researcher with a nursing background. The interviews explored how and when nurses applied SDM in their daily care practice and the influence of patients' dementia on SDM (see Table 1). Prior to the primary interviews, two pilot interviews were conducted to assess whether the interview topics were appropriate for answering the research questions. These pilot interviews provided rich insights into the topic; thus, they were included in this study. Data saturation with sufficient heterogeneity was achieved after 12 interviews were conducted. After data saturation was achieved, two additional interviews were conducted. Fourteen nurses were interviewed.

The interviews were recorded digitally and lasted approximately 30–60 minutes each. The interviews began with the respondents' perceptions of SDM, followed by a detailed exploration of whether and how nurses apply SDM in the daily care of patients with dementia and their relatives. During the interviews, the researcher emphasised active listening, summarising answers, and asking additional questions. The researcher strived to maintain a neutral and curious stance by consciously refraining from imposing any

Table 2. A summary of the analysis steps using Colaizzi method (1978) *

Step	Summary
1. Read all interviews to acquire a feeling for them.	• Interviews were transcribed verbatim. • Examining nurses' experiences of shared decision-making in the daily care of patients with dementia and their informal caregivers through repeated readings to develop comprehension and gain insight.
2. Review each interview and extract significant statements	• Selecting significant statements. • Coding in Atlas TI V23.3.0.
3. Spell out the meaning of each significant statement (i.e., formulate meanings).	• Formulating meanings. • Compared the original quotes with the formulated meanings to achieve consistency. • 511 Quotes classified into 511 meanings.
4. Organize the formulated meanings into clusters of themes. *a. Refer to these clusters back to the original protocols to validate themes.* *b. Note discrepancies among of between the various clusters, avoiding the temptation of ignoring data of themes that do not fit.*	• The meanings were inductively coded. • 57 Codes were obtained and classified into 5 themes.
5. Integrate results into an exhaustive description of the phenomenon under study.	A comprehensive and cohesive description of the nurses' experiences based on the five formulated themes.
6. Formulate an exhaustive description of the phenomenon under study in as unequivocal a statement of identification as possible.	The exhaustive description is summarized to provide insight into the essential structure of the process of shared decision-making in daily care in acute hospitals with patients with dementia from the perspective of nurses.
7. Asking participants about the findings, thus far as a validating step	A summary of the results was sent to the participating nurses, of which seven replied.

*Description of steps based on (33)

knowledge or opinions. Notably, the researcher had no pre-existing relationship with the interviewees. As nurses signed up independently to participate in the interviews, no organisational pressure could potentially influence their responses.

6.3.6 Data Abstraction and Data Analysis

The analysis was performed using Colaizzi's seven-step method (1978) by three experienced nursing researchers (AP, PR, and GD) who were part of the research team (33). We chose Colaizzi's method because it validates the results with participants

(33). The application of Colaizzi's seven-step method in this study is summarised in Table 2. Interviews were transcribed verbatim and analysed inductively within ten working days of completion. Bracketing and reflective logs were maintained throughout the analysis to ensure rigorousness.

6.3.7 Ethical Considerations

This study followed the ethical principles outlined in the Declaration of Helsinki. Ethical approval for the study was obtained from the University Medical Center, Groningen (UMCG, Netherlands) (study number 2022239). Participants' involvement in the study was voluntary, and they provided both verbal and written informed consent before participating in the interviews. Only eligible participants who met specific inclusion criteria—registered nurses with experience in shared decision-making and care of patients with dementia—were invited to participate. Confidentiality and anonymity of participants' data were strictly maintained throughout the study to protect their privacy.

6.3.8 Rigour

This study used a phenomenological approach and operationalised accuracy using criteria such as credibility, transferability, reliability, and confirmability. Credibility was ensured by transparently describing the steps of the study, sharing a comprehensive summary of the results with the participating nurses for peer review, and incorporating their feedback into the final analysis. Transferability was enhanced by sampling with maximum variation and selecting participants with diverse characteristics to capture a wide range of nursing perspectives. Reliability was emphasised through a detailed description and robust data, in-depth analysis, and repeated review of interview transcripts by experienced researchers. The coding process was carried out by three researchers with collaborative dialogue and consensus building to resolve discrepancies. Confirmability was maintained by keeping a logbook, acknowledging implicit assumptions, and minimising bias through self-awareness and regular discussions with the research team. The methodological rigour of the study was maintained through this consistent approach, ensuring the credibility, transferability, reliability, and confirmability of the study findings.

6.4 Findings

The participants (n=14) had an average age of 36 years and 12 years of nursing experience. An overview of the characteristics of the participating nurses is presented in Table 3. Eight nurses had a bachelor's degree, and seven had vocational training at

Table 3. Characteristics of the participating nurses

	Age	Hospital type	Ward	Highest education	Years' experience as a nurse
1	36	Regional	Internal	Vocational	10
2	21	Regional	Internal	Vocational	2
3	33	University hospital	Surgical	Bachelor	5
4	29	Regional	Internal	Vocational	5
5	23	Non-university teaching hospital	Flexible	Bachelor	4
6	42	Regional	Internal	Vocational	20
7	40	Regional	Internal	Bachelor	20
8	51	Non-university teaching hospital	Surgical	Vocational	33
9	34	Regional	Internal	Bachelor	11
10	23	University hospital	Internal	Bachelor	2
11	55	Non-university teaching hospital	Internal	Vocational	13
12	43	University hospital	Internal	Vocational	8
13	51	University hospital	Internal	Bachelor	31
14	26	University hospital	Surgical	Bachelor	4

their highest level of education. The nurses worked in university hospitals (n = 5), non-university teaching hospitals (top clinical) (n = 3), and regional hospitals (n = 6) throughout the country. Nurses worked in both surgical and non-surgical clinical departments.

The interview results are classified into five themes: SDM in daily care, nurses' perceptions and competencies, nurses' roles and advocacy, recognition of dementia and its impact, and interventions to support SDM.

6.4.1 SDM in Daily Care

Participants described SDM as decision-making with patients with dementia, their relatives, and healthcare providers. They emphasised the importance of considering the patients' preferences, values, and autonomy. SDM aims to meet patients' needs and goals, and involves gathering information, discussing options, respecting patient input, and providing guidance and support. For SDM in patients with dementia, an enhanced role for relatives in achieving the best possible outcomes and patient satisfaction is essential.

> *'Family meetings are often scheduled in the hospital. Options are discussed in a triangular relationship or with four, if the physician is also there. Choices are discussed. The conversation always involves the patient, regardless of the severity of their dementia'. (Nurse 4).*

Nurses distinguished between two types of decision-making in daily care: monodisciplinary and multidisciplinary.

Monodisciplinary decisions

In everyday somatic care, nurses observed that patients with dementia can make their own decisions, such as whether to shower or what to eat. This was described as an iterative process that focused on determining the most appropriate care through active consultation with a patient with dementia. These decisions are primarily **monodisciplinary**. The nurses did not consciously apply the SDM steps. Additionally, they sometimes included more paternalistic techniques, such as enticing, persuading, and encouraging, from the perspective of providing good care. For example, nurses may convince patients to take their prescribed medications, gently encourage them to get out of bed, or effectively persuade them to maintain their mobility. As the outcome of SDM could vary from moment to moment, nurses also visited the patient multiple times to ask the same question, recognising that the patient might have different wishes at different times of the day.

> *'In general, it is natural for the patient to decide on ADLs, but it is different with this group of patients. In this case, we decide together; patients can't decide alone because they depend on us'. (Nurse 2)*

Multidisciplinary decisions

The second type involves complex multidisciplinary patient care and treatment deliberations. The extent to which nurses were involved in these decisions varied between hospitals and wards. We used Elwyn's (2020) three-stage model as an illustrative framework to highlight the practical implementation of SDM in a **multidisciplinary** manner as perceived by nurses. Interestingly, none of the interviewed nurses reported using a specific decision model in their clinical practice.

Nurses reported minimal use of goal talk, the first step in SDM, particularly in goal-team discussions. Their primary focus remains on managing specific diseases or conditions to which patients with dementia are admitted. Nevertheless, the participants confirmed that they had discussions with the patient and relatives about the expected admission outcomes, such as regaining the ability to perform activities and returning the patient to their former home environment. Dementia patients were actively involved in SDM processes whenever possible.

> *'We don't ask about goals; we often do it the other way round. Once we have a picture of the patient, what is going on, and how we will treat it, we always have a family discussion. The doctor mainly does this. Then, we discuss what we think is going on and what we are working towards. Then you have patients who can say: oh, I want this, or I don't want that. But it's not like: what do you want? Sometimes it is, but generally, I think it comes more from us: this is the goal we have set'. (Nurse 9)*

In the second step, options (team consultation and different alternatives) were discussed and evaluated. Nurses particularly emphasised their involvement in exploring and discussing various medical treatment options to provide comprehensive explanations and informed recommendations to patients with dementia and their relatives while working closely with physicians. Additionally, post-discharge care emerged as an essential topic of discussion.

The final step in SDM goal-team decision talk, is often applied in family meetings and is sometimes preceded by multidisciplinary team meetings. Relatives often make decisions about treatments, such as starting tube feeding, surgery, or drug treatment by infusion.

6.4.2 Nurses' Perceptions and Competency

Participants perceived SDM for patients with dementia as necessary because of its holistic approach, focusing on the patient rather than the disease and enhances patient dignity by involving them in decision-making. They believe that SDM contributes to better care, greater patient satisfaction, improved adherence, and fewer readmissions. However, nurses identified the disadvantage—in the early stages of a patient's admission, significant interaction with relatives is crucial to ensure their well-being and clarify treatment plans. This creates the expectation that nurses will provide daily updates, which they experience as an additional workload. Nurses tended to communicate only when there was new information about the patient's status and treatment.

SDM in daily care decisions (monodisciplinary) for patients with dementia, such as nursing interventions, is usually considered a routine and is applied unconsciously. In contrast, treatment decisions (multidisciplinary) often require a multidisciplinary approach, and SDM is used more consciously. Nurses see these treatment decisions as the responsibility of physicians.

> *'Making decisions together is something I do, sometimes consciously and sometimes unconsciously. It is often unconscious and part of my work routine in day-to-day care. But when discussing post-discharge care or the treatment pathway, I do it consciously'. (Nurse 8)*

Eight nurses felt insufficiently competent to use SDM with dementia patients and their relatives. This applies to both types of decisions. Monodisciplinary decisions are related to challenging behaviours due to dementia; multidisciplinary decisions are associated with the SDM process. This feeling seems independent of the type of education but is mainly related to practical experience. It concerns knowledge about SDM in general, such as the ability to explain what SDM is and, more specifically, how SDM can be applied in nursing care, communication skills with patients with dementia, and dealing with the hierarchy when working with physicians.

Nurses found it challenging to identify what goes well in the SDM of patients with dementia. This is indicated by the observation during the interviews that they seemed to struggle with SDM despite frequent and varied questioning. They focused their responses on what goes well in caring for patients with dementia rather than on SDM. Some nurses were proud of their expertise in SDM for patients with dementia. Other positive experiences included increased multidisciplinary involvement in SDM for patients with dementia and the way in which physicians took nurses' expertise seriously.

In addition to positive experiences, the nurses identified aspects that could be improved. The first was decision-making regarding continuing treatment. Nurses feel that treatment is often continued for too long, and discussions about non-treatment or palliative care are either not initiated or initiated too late. Although several nurses discuss this with the physician, most nurses perceive it primarily as the physician's responsibility. Second, the awareness of patients' perspectives can be improved. Nurses do not always have enough time to reflect on the decisions made by relatives and patients, often because of time constraints. This is particularly evident in decisions regarding post-discharge care. They noted that these decisions do not always feel like shared decisions for relatives and patients because wishes, rules, and possibilities cannot always be reconciled, and time pressure plays a role. Third, the context and patient's wishes should be considered. They specifically mentioned the importance of mapping the spiritual context and wishes in advance care planning, which can start during hospital admission. The nurses were not explicit in describing their roles in this process.

6.4.3 Nurses' Roles and Advocacy

Facilitator SDM-monodisciplinary

Nurses are essential for facilitating the SDM process by supporting patients and their relatives. They gather information on patients' and relatives' preferences for care and treatment as well as the care received before admission. Furthermore, nurses react to patients' desires and requirements at a specific moment of care, which may include returning to providing care at another time. They prioritised patient autonomy at all moments of care to facilitate SDM.

Facilitator SDM-multidisciplinary

Nurses play a role in facilitating the SDM process by organising family discussions and ensuring that relevant information is available to other care professionals, such as the patient's capacity to make decisions, patients' and relatives' preferences for care and treatment, and the care received before admission. They are also available to patients and relatives to explain and answer questions about SDM. Nurses supplement patient information and act as intermediaries between patients with dementia, relatives, and physicians, thereby representing and advocating for patient interests. When deemed necessary, nurses take responsibility for determining whether relatives' wishes are the best for patients with dementia.

Role as advocates in monodisciplinary decisions

The role of advocates is primarily utilised when relatives have wishes that are not appropriate or feasible from the perspective of proper person-centred care. These wishes involve matters such as bathing and wearing clean clothes.

Role as advocates in multidisciplinary decisions

Nurses assert their role as patient advocates when consulting with different disciplines, including in multidisciplinary meetings. Patient advocacy is a recurring theme among nurses for patients with dementia and occurs in different scenarios. These situations include situations where a patient's relative wished to pursue treatment against the patient's wishes or where the perceived benefits of treatment do not outweigh the potential challenges and dilemmas of procedures such as catheterisation, probing, showering, and wearing clean clothes. Nurses are often confronted with differences between the needs of patients with dementia and their priorities. For example, an accurate diagnosis is not always necessary for effective care, and the need for a daily bath may not be consistent with a patient's well-being, even if relatives feel that it is essential.

> *'You must take your role as a nurse so that you can say: I had this conversation with the patient this morning, and this was indicated. Let's include this in the overall decision. That is happening more and more'. (Nurse 14)*

6.4.4 Recognising Dementia and its Impact

Nurses have attempted to gain insight into cognitive function to estimate patients' decision-making abilities. Nurses perform this evaluation when patients lack insight into their illness, exhibit altered and inconsistent behaviour, or when their intuition indicates cognitive problems. Where possible, relatives were consulted, and findings were verified. One nurse used the Delirium Observation Scale to evaluate changes in the cognitive function of patients with dementia. In addition, the nurses indicated that geriatricians should be consulted to assess their decision-making capacities. Nurses reported that most patients with dementia make decisions regarding daily care.

Nurses reported that communication with dementia patients notably affected SDM. Patients are not always consistent in what they say, which makes SDM even more difficult. Communication options vary from patient to patient and from situation to situation. This requires nurses to have more skills to adapt their communication methods and pay more attention to whether the information is understood. In cases of mild dementia, patients' understanding can be overestimated, as illustrated by patients agreeing to a feeding tube but refusing it during insertion. Nurses emphasised that patients with dementia may not always understand important information. This can delay or hinder SDM. Therefore, participants preferred triadic consultations with patients and their relatives, particularly for patients with dementia. The extent of the involvement of the patient's relatives depends on the type of decision and the severity of dementia.

The SDM process is often complex because of a distorted understanding and lack of insight into the illness. In some situations, the recovery process is compromised by the patients' behavioural refusal to make decisions, such as refusing to take medication, not complying with bed rest, or experiencing falls due to a lack of understanding of the disease. Decisions on invasive tests and treatments are approached cautiously, and procedures such as scans or colonoscopies are not always performed. The SDM process is often challenging and time-consuming.

> *'Patients are sometimes very inconsistent in their decision-making, which makes it even more difficult. One moment, the patient will say, "I don't want to do this anymore; let me be." And then the next moment: "My grandchildren are here. I still enjoy them so much." Also, sometimes, I see a difference between nonverbal and verbal. Patients can't always communicate well what they really want and need'. (Nurse 12)*

6.4.5 Interventions to support SDM

Monodisciplinary interventions

Nurses use several interventions to address dementia during SDM. First, regarding monodisciplinary decision-making, nurses reported reducing the number of options and sometimes providing more guidance. This approach is primarily used for decisions regarding activities of daily living, eating, and drinking; however, it can also be used for treatment and care. The second intervention involved the adaptation of communication techniques. Nurses achieve this by maintaining a calm tone, avoiding medical jargon, providing information in manageable chunks, reinforcing key points, ensuring comprehension through checking, and being attuned to the patient's emotional state, considering factors such as agitation or anxiety.

Multidisciplinary interventions

Regarding multidisciplinary decisions, nurses increase the involvement of relatives of patients with dementia in SDM. Nurses are involved in assessing the patients' ability to participate in decision-making and in each step of the decision-making process. Additionally, a relative is often used to represent patients with progressive dementia. The patient's wishes cannot always be fully respected; for example, in post-discharge care, when a patient wants to go home but cannot.

> *'There are cases where the patient wants to go home after admission, but the family rejects. These are aspects that we take into consideration, and then there is a meeting with the family about our and their options. You want to hear both stories. Then, together, you have to figure out what is a good option'. (Nurse 10)*

In addition, the timing of SDM discussions was considered critical. Choosing an appropriate time means ensuring that the patient's emotions are not high and the environment is as disincentive-free as possible. Although monodisciplinary discussions naturally occur during care, SDM meetings are often planned for multidisciplinary treatment decisions. Nurses reported that the patient was always present during SDM meetings. However, some nurses indicated that they assessed whether the patient could be present at a meeting for consultation with patients and relatives. If the patient is present but distressed, a solution might be to excuse the patient from immediate discussion. The patient can then be informed and involved in the decision-making process according to their cognitive capacity.

6.5 Discussion

Five main themes emerged from the findings: (1) the use of SDM in daily care, where there seems to be a distinction in SDM between monodisciplinary nursing and multidisciplinary decisions; (2) nurses ' perceptions and competence; and (3) nurses' roles and advocacy. Two themes were identified regarding how nurses considered patients' cognitive function: (4) recognising dementia and (5) impact and Interventions to Support SDM. The findings highlight the importance of involving relatives in decision-making, adapting communication for patients with dementia, and discussing the interventions that nurses use to facilitate SDM in patients with dementia.

How nurses describe the concept of SDM is inconsistent with Elwyn's definitions (17,18,21). Elwyn and Vermunt stated that SDM consists of three core elements: goal team talk, which focuses on supporting patients by offering choices and understanding their goals to guide their decisions. Goal-option discussions compare alternatives using the principles of risk communication. Goal-decision talk involves making decisions consistent with the patients' informed preferences by utilising the experience and expertise of healthcare providers (18,36). However, the nurses' definition of SDM lacks the addition made by Elwyn in 2020, which involves incorporating patients' goals in all stages of the decision-making process. The lack of patient goals was also reflected in how nurses applied SDM to patients with dementia. Discussing goals is part of person-centred care, but interviewed nurses rarely used it. However, we did not find any explanation for this. In addition, when examining hospitalised older adults without known dementia, research indicates that set goals are frequently left unaccomplished during admission (37) and whether nurses are trained to discuss goals during the SDM process is unknown. Additionally, it appears that nurses view monodisciplinary SDM as an iterative process that often occurs during moments of care. This is consistent with the findings of a review that described SDM as a comprehensive, ongoing process between nurses and patients that does not end with a decision (27).

Approximately half the nurses felt insufficiently competent to apply SDM to patients with dementia in daily care. This could be partly explained by the fact that they considered SDM to be a task for physicians. This is not specific to the care of patients with dementia. Nurses involvement in SDM can be improved in other care settings (11). The lack of understanding of SDM is also apparent in other research ((38,39) not feeling competent in monodisciplinary SDM may stem from the fact that nurses often encounter challenges in caring for patients with dementia and face organisational dilemmas when providing person-centred care (40).

The interventions identified by nurses to address dementia are related to communication and fit for a person-centred care approach (14). Nurses reported recognising dementia based on patient behaviour, consultation with relatives, and intuition. However, research has shown that this is insufficient because the assessment of decision-making capacity is related to the complexity of the SDM issue. There is no consensus on which cognitive abilities are required and how these functions can be reliably assessed (41). However, dementia is known to be under-recognised in hospital admissions (23) Although there is no doubt about the good intentions of nurses, this study confirms that in general practice, nurses' behaviours, such as enticing and persuading, can limit patients' participation in care activities rather than promoting what is patient-centred (42).

6.5.1 Strengths and limitations of the work

One strength of this study is the diverse range of participants recruited from different types of hospitals nationwide. The participating nurses came from various departments and had different levels of training and experience. In addition, member checks revealed that the respondents recognised the results.

The study's limitations relate to participant recruitment. Nurses were able to apply themselves, so they may have had a greater affinity for the topic, making the results more favourable than in reality. The concept of SDM in nursing is a recent development, which may have led to a positive bias in the results.

6.5.2 Recommendation for further research, policy, and practice

The study results suggest potential areas for future research. Follow-up research could focus on the impact of discussing goals as part of SDM training for nurses in the context of patients with dementia and assess whether this improves patient goal attainment during hospitalisation. In addition, research should focus on the barriers that prevent nurses from feeling competent in using SDM and the perception that SDM is primarily a physician's role in the context of patients with dementia.

Policies are necessary to promote SDM through interdisciplinary collaboration and effective person-centred communication within nursing teams and across healthcare disciplines. Specific policies can encourage collaboration among nurses, physicians, and paramedics in the SDM process and correct the misconception that SDM is solely the physician's responsibility.

This study of nurses' experiences with SDM in patients with dementia has profound implications for nursing practice. This underscores the complexity of the process, the importance of communication, and the maintenance of patient autonomy. We recommend training programs for nurses that focus on applying SDM in daily care, specifically focusing on patients with dementia and integrating patient goals into the SDM process. It should focus on identifying dementia and appropriate interventions to assess capacity. Nurses' distinct roles in the multidisciplinary SDM process should be emphasised to enhance clarity. Implementing these recommendations can improve SDM practices within the nursing domain, particularly in hospital care for patients with dementia, leading to better quality patient care.

6.6 Conclusion

This study explores nurses' application of the SDM in hospital care for patients with dementia. This highlights the complexity of SDM in these patients and the need for a comprehensive strategy to address specific challenges of SDM in combination with dementia. The involvement of patients' relatives is vital to facilitate effective communication and maintain patient autonomy. Nurses often fail to discuss patient goals, indicating the need for further research, particularly in hospital settings.

Timely recognition of dementia is required for appropriate support in applying SDM, which requires a nuanced approach to capacity assessment. Interventions should prioritise adapted communication and person-centred care, with the participation of relatives enhancing the understanding of patients' needs.

In conclusion, this study highlights the complexity of SDM in patients with dementia and calls for improved training, recognition of dementia, and tailored interventions to ensure patient-centred care. Further research and development are vital for the progress of healthcare practices in this field.

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CHAPTER 7

General discussion

Chapter 7. General discussion

This thesis has explored the nursing care provided to individuals with dementia in Dutch hospitals, with a specific emphasis on the roles of nurses in person-centred care and shared decision-making. It has aimed to gather insights from both nurses and relatives of patients with dementia to gain a comprehensive understanding of the dynamics involved. This general discussion summarises the main findings, followed by a discussion using Dawn Brooker's VIPS framework for interpretation. The thesis concludes with methodological considerations, recommendations, and a general conclusion.

7.1 Summary of main findings

7.1.1 Validation and psychometric evaluation of the Dutch Person-centred care of Older People with cognitive impairment in Acute Care (POPAC)

This study has aimed to validate and assess the psychometric properties of the Dutch version of the POPAC scale. The scale evaluates person-centred care for older people with dementia in acute hospital settings. The results confirm the original scale, with strong associations between items and their respective factors (factor loadings ranging from 0.69 to 0.77). The study indicates that the Dutch version of the POPAC scale is a valid and reliable tool for evaluating person-centred care for patients with dementia in hospital settings.

7.1.2 Nurses' perceptions of caring for people with dementia in Dutch acute hospitals

The cross-sectional survey carried out for this study explored nursing practices for patients with dementia in hospitals. Based on these findings, this study has described the level of care provided to these patients, nurses' attitudes and perceptions of dementia care, and strategies for managing challenging behaviour. The findings also highlight how participating nurses were only qualified to apply general preventive measures, like interventions to prevent pressure ulcers, rather than those explicitly tailored to dementia. Different approaches, including restrictive measures and medication, were used to manage challenging behaviour. In examining the associations with background variables at the scale level, the analysis revealed a positive correlation between nurses' attitudes toward caring for people with dementia and their attendance at a dementia-related course in the past year. This suggests that participation in such courses may foster more positive attitudes among nurses towards caring for patients with dementia. Conversely, a negative correlation was observed between nurses' attitudes towards dementia care and the type of hospital, indicating that hospital type may influence these attitudes.

7.1.3 Experiences of informal caregivers of people with dementia with nursing care in acute hospitals

The experiences of informal carers of individuals with dementia during hospitalisation was the central topic in the study described in Chapter 4. The main themes were patient care, interactions with nurses, the carers' situation, and the hospital environment. Almost half of the respondents appeared satisfied with how nurses considered the dementia of the patient. Relatives rarely observed activities aimed at preventing challenging behaviour and providing person-centred care. They reported feeling strained, exacerbated by perceived inadequate communication with nursing staff and not feeling considered a partner in the care of their loved ones. Relatives raised concerns about environmental safety, such as the lack of monitoring of wandering. More involvement of informal carers was associated with shared decision-making (SDM) and adherence to the triangle of care model, resulting in better care experiences.

7.1.4 Involvement, topics, and roles of nurses in SDM with patients with dementia in acute hospitals

In an integrative review, including nine studies, we explored nurses' involvement, topics, and roles in SDM with older patients with dementia in the hospital. Three levels of nurse involvement were identified: nurses as care team members, facilitators, and patient advocates. During the SDM process, nurses played a significant role as advocates, messengers, communicators, and intermediaries between professionals, patients, and relatives. Although their roles were most prominent during the preparatory phase, developing tailor-made options was less emphasised. The deliberation and decision-making steps were mainly described from an outsider's perspective, with nurses attempting to influence decisions.

7.1.5 Nurses' perspective on SDM in the daily care of hospitalised patients with dementia

This explorative qualitative study has aimed to gain an insight into the SDM process in daily hospital care from the perspectives of nurses treating patients with dementia. Five themes were identified from the data:

- *SDM in daily care: how SDM is applied*
- *Nurses' perceptions and competence: how nurses perceive and manage SDM*
- *Nurses' roles and advocacy: the evolving roles of nurses and their advocacy efforts*
- *Recognition of dementia and its impact: how nurses recognise and manage dementia*
- *Interventions to support SDM: strategies and interventions to facilitate SDM The study highlights the complexity of SDM in patients with dementia and demonstrates the importance of the involvement of relatives, the omission of patient goals in discussions, and the perceived inadequacies in the training provided to nurses.*

7.2 Discussion of the main findings

This study deployed Brooker's VIPS framework (2007) to interpret findings and with a view to developing a deeper understanding of nursing care from a person-centred perspective. Brooker developed the VIPS framework in line with the definition, elaborating the four elements into key indicators: valuing individuals with dementia and their carers (**V**alue), treating individuals as unique persons (**I**ndividuals), adopting the perspective of the person with dementia (**P**erspective) and providing a positive social environment (**S**ocial Environment) (1–4). Figure 1 shows the indicators of the VIPS framework per element. The indicator 'part of the community' has been changed to 'involvement of relatives' as this is more appropriate in the context of hospitals.

7.2.1 Valuing people with dementia and those who care for them (**V**alue)

> *Valuing people with dementia and their families entails advocating for their civil rights and entitlements, irrespective of age or cognitive impairment, and eliminating discriminatory practices. Vital valuing elements comprise* ***vision****,* ***human resource management****,* ***management ethos****,* ***training and staff development****,* ***service environments****, and* ***quality assurance*** *(2).*

To implement person-centred care, a clear and comprehensive **vision** is necessary. Notably, hospital visions were not explicitly measured in this thesis. However, Chapter 3 has discussed various situations related to the organisation of care with the **human resource management** indicator. Caring for people with dementia presents a significant challenge due to time constraints resulting from the perceived high workload and complexity of dementia care, as well as the combination with the care of other patients. The absence of informal caregivers and the lack of availability of volunteers also contribute to this challenge (Chapter 3).

Regarding the **management ethos** indicator, the nurses who participated in this study expressed dissatisfaction over the limited opportunities available to provide quality care and effective monitoring when tending to patients with dementia. The outcomes of the POPAC can be used as a tool to facilitate reflective discussions in clinical settings at the departmental level to address this level of dissatisfaction (Chapter 2). Nurses also indicated dissatisfaction with how patients with dementia are considered when planning shifts, for example, when determining the number of nurses needed or the distribution of care among staff (Chapter 3). These experiences align with relatives' perceptions that care primarily focuses on illness and somatic care (Chapter 4).

Concerning the **training and staff development** indicator, the results show that nurses require training to deal with dementia, delirium, depression, medication, and challenging behaviours, such as wandering and aggression. Further, nurses highlighted that they desired training in restrictive safety measures and interventions. Notably, despite SDM being recognised as an essential aspect of person-centred care, around half of the nursing staff involved in this study reported feeling incompetent when applying SDM to care plans involving patients with dementia and their families. They said they experienced difficulties in explaining SDM to people with dementia, communicating effectively with them and navigating the hierarchical structure when working with physicians (Chapter 6). Relatives also highlighted extra training for nurses as an important step forward, and patients with dementia were shown to become frustrated if they perceive a nurse's lack of knowledge and skills related to their needs (Chapter 4). Regarding the **service environment indicator**, nurses are able to draw on the specialist skills of psychologists and geriatricians in complex situations, as described in Chapter 2. It is essential to ensure that the roles and responsibilities of nurses and other care providers are clearly defined (Chapter 4). In addition, the physical and social environments must support the well-being of patients with dementia. From the relatives' perspective, they have expressed the view that a hospital environment is unsuitable for patients with dementia due to the presence of stimuli, limited opportunities for rooming in or being present outside visiting hours, and concerns about patient safety – as outlined in Chapter 4.

Brooker defines **quality assurance** as the implementation of mechanisms for continuous quality improvement based on knowledge of and action on the needs and concerns of patients with dementia and their informal caregivers to enhance the quality of care for patients with dementia (2). Regarding **quality assurance**, Chapter 3 notes that nurses often lack knowledge in specific areas of dementia care, including the prevention of delirium, management of challenging behaviour, and the regular use of urinary catheters; the latter area posing particular risks for people with dementia. Additionally, relatives have reported issues with the inadequate transfer of care to other settings. As detailed in Chapter 4, problems with care transitions include missing nurse handovers, uninformed case managers or community nurses, or discrepancies between the information relayed during handovers and the actual situation. Chapter 2 highlights that organising regular discussions within nursing teams or at the ward level about dementia care could enhance the quality of care provided.

7.2.2 Treating people as individuals (Individuals)

*Recognising the uniqueness of individuals' lives requires an understanding that each person has a distinct history, personality, physical and psychosocial capabilities, and requirements, alongside social and economic resources that shape their response to dementia. Customising care and support based on these factors is vital. Key indicators include **care and support planning**, **regular reviews**, **personal possessions**, **individual preferences**, **life history**, and **activity and occupation** (2).*

Care and support planning is critical to nursing care and should promote individual identity (2). Chapter 2 highlighted how care planning should begin at the point of admission with an assessment of the cognitive status of older people. However, as revealed in Chapter 3, nurses rarely take extra time to admit a patient with dementia or allocate additional time to initiate discharge planning at admission. This extra time is relevant because anamnesis and hetero anamnesis with their relatives are vital opportunities to gather as much information as possible about the patient. Care must follow evidence-based guidelines and be provided by the same nurses as much as possible while ensuring patients with dementia can receive tests, examinations, and consultations on the ward (Chapter 2). Regarding care and support planning, nearly half of relatives reported being satisfied with how nurses take the patient's cognitive function into account when providing care, as documented in Chapter 4. However, relatives expressed concerns that certain basic care tasks, such as assistance with dressing, brushing teeth, using the toilet, or administering medication, are sometimes neglected in their absence. Additionally, the planning of discharge times often involves relatives but fails to include the case manager or home health organisation, which could impact the continuity of care post-discharge.

The care needs of patients with dementia can fluctuate frequently, necessitating a high degree of flexibility in the care provided by nurses. Chapter 2 emphasises the importance of conducting **regular reviews** to ensure that the care delivered aligns with the needs and preferences of patients with dementia. Although the Delirium Observation Scale (DOS) is a valuable tool for monitoring potential delirium-related changes in cognitive function, it is rarely used. Moreover, systematic evaluations to determine if patients with dementia are receiving adequate care are also uncommon, as discussed in Chapter 6.

Chapter 4 notes that relatives have observed that nurses seldom request personal possessions be brought in to help mitigate challenging behaviours or prevent delirium. Personal items can make unfamiliar surroundings feel more comfortable for people with dementia and play a role in reducing the likelihood of delirium. To ensure that care is tailored to **individual preferences**, Chapter 2 highlights how involving people with dementia in SDM is a crucial aspect of a care plan as this process considers the patient's context and preferences. This study has also confirmed that nurses play an essential role in gathering information about the patients' and relatives' preferences for care and treatment, pre-admission care, and considering spiritual context and wishes.

While the perspectives of individuals with dementia are valued, plans involving patients and their relatives are not consistently perceived as shared decisions. This perception arises because reconciling wishes, rules, and options is not always possible, and time constraints further complicate decision making. This issue is particularly prominent in decisions related to post-discharge care. Nurses also recognise the importance of improving their awareness of the patient's viewpoint, as discussed in Chapters 5 and 6.

Chapter 4 also revealed that relatives felt no attention was paid to a relative's **life history** and biographical information (habits, interests, preferences, etc.), which can help to explain behaviour and plan care and activities as well as facilitate nursing staff in interpreting the reactions and behaviour of the patient. However, this experience contradicts the findings in Chapter 2, where the POPAC results show that nurses 'very frequently' used biographical information about older patients to plan their care (item 9 of the scale). Based on these hobbies and interests, relatives have suggested establishing **activities and occupations** for patients with dementia, as outlined in Chapters 3 and 4. Relatives reported that activities to provide daily structure or to prevent delirium are, currently, rarely carried out but that, from experience, a positive solution could be for patients to visit a geriatric ward during the day to participate in daytime activities, which are often organised there. Relatives also suggested organising weekend activities and using volunteers for the daytime structure and activities.

7.2.3 Looking at the world from the perspective of the person with dementia (Perspective)

Viewing the world from the personal perspective of people with dementia implies acknowledging the unique psychological validity of each person's experience. Key indicators include ***communication****,* ***empathy and acceptable risk****,* ***physical environment****,* ***physical health****,* ***challenging behaviour as communication****, and* ***advocacy*** *(2).*

Effective **communication** with patients with dementia demands specialised skills, and this study has shown that two-thirds of relatives believe that patients with dementia are treated with understanding upon hospital admission. Additionally, relatives have noticed that nurses often manage challenging behaviours by distracting the patients, aligning with the nurses' own accounts of their approaches. However, relatives have reported observing nurses engaging in somatic interventions such as administering medication without talking to the patient, leading all participating relatives to agree that communication could be improved. Additionally, relatives frequently felt that nurses were not available to speak to and that their concerns were either ignored or not adequately addressed. However, nurses who have completed a dementia care course within the past year demonstrated more effective communication skills with people with dementia, as discussed in Chapters 3 and 4.

Regarding SDM, this study has shown that nurses **communicate** with relatives about treatment and care. During the initial stages of admission, there is often extensive contact with relatives to guarantee the well-being of patients with dementia and to clarify treatment plans. However, when considering communication with the patients with dementia themselves, nurses indicated that there are challenges when applying SDM to a situation, especially considering communication alternatives differ from patient to patient and depend on the given situation.

This study underscores how nurses are required to refine their communication techniques to ensure that information is thoroughly understood. Nurses currently tend to simplify decision-making by limiting options and providing guidance. They also adjust their communication style by using a calm tone, avoiding medical jargon, presenting information in small, manageable segments, emphasising key points, and confirming understanding by checking back with the patient. Additionally, they tailor their approach to the patient's emotional state, taking into account factors such as agitation or anxiety, as well as the overall condition of the patient, as detailed in Chapters 5 and 6.

Another area of concern expressed by relatives in this study is day-to-day environmental safety, particularly the risk of falls and wandering. The use of care technology in this area is rarely observed, as shown in Chapter 4, and Chapter 3 reveals relatives' concerns are well-founded because nurses reported feeling the least responsible for a dementia patient's behavioural problems and the development of delirium. The item 'we make sure that elderly people with cognitive impairments are not left alone on the ward' from the POPAC can be used to measure **empathy and acceptable risk** in relation to environmental safety. Further, the effect of the **physical environment** on the person with dementia is crucial as it can cause overstimulation or understimulation.

This study has highlighted how adapting the environment to meet the unique needs of each person with dementia is critical, and that this often poses problems. According to some relatives, hospital environments are often unsuitable for people with dementia due to overstimulation and thus prefer a single room to reduce stress, while others believe the patient would benefit from more stimulation or social interaction. The study results also show that dissatisfaction arises if the person with dementia is not placed in a geriatric unit or if there are frequent transfers between units or rooms, as discussed in Chapter 4.

In addition to paying attention to the physical environment, nurses need to focus on the **physical health** of the dementia patient. When caring for these types of patients, nurses have expressed concerns about potential complications such as falls, malnutrition, delirium, and safety. However, enteral nutrition, which can prevent malnutrition, is often overlooked, as highlighted in Chapter 3, and, according to relatives, nurses prioritise physical care over answering relatives' questions, as reported in Chapter 4. Additionally, this study reveals that SDM primarily focuses on managing the specific disease or condition for which patients with dementia were admitted, often neglecting discussions about broader care goals (discussed in Chapters 5 and 6). Nurses reported that in care planning, medical treatments are frequently continued for extended periods without considering options to discontinue treatment or initiate palliative care (Chapter 6).

Study results show that most relatives acknowledged that their family members with dementia exhibited challenging behaviours during hospitalisation. The most common behaviours cited were night-time restlessness and suspicious and anxious behaviour (Chapter 4), which aligns with the observations reported by nurses, as highlighted in Chapter 3. However, when relatives relay their observations of **challenging behaviours** to the nursing staff, they often report that the staff either do not fully understand or fail to take action. According to the results of this study, nurses have perceived the unpredictable behaviour, agitation, aggression, wandering, and disorientation of people with dementia as stressful, mainly due to factors such as insufficient time, a heavy workload, and complexities of caring for a dementia patient. This stress is compounded by patients' unpredictable behaviour, safety concerns, and dissatisfaction with opportunities for proper care and supervision. Additionally, some nurses may lack an affinity with the patient group or have negative attitudes towards patients with dementia, which can contribute to their stress and dissatisfaction with the care provided. Nurses have reported falling back on their professional expertise to manage challenging behaviours and have stated they regularly negotiate with colleagues or relatives about the best response tactics. Therefore, to improve the care of people with dementia in the hospital, it is crucial for nurses to recognise their ability to influence the behaviour of people with dementia using dementia-related psychosocial interventions, as highlighted in Chapter 3.

Advocacy is also crucial in nursing care, particularly in decision-making contexts where relatives and nurses recognise its importance. However, relatives feel they are not included enough in care decisions and are not seen as partners in care. It is important to note that, although relatives generally feel confident, the stress of the situation can make it difficult for them to advocate effectively for their family members, as reported in Chapter 4. Chapters 5 and 6 highlighted that nurses have had to serve as intermediaries between patients with dementia, relatives, and physicians, representing and advocating for the patient's interests.

7.2.4 Recognising that all human life, including that of people with dementia, is grounded in relationships (Social environment)

*The social environment refers to the significance of establishing a social setting that acknowledges the essential nature of human existence in relationships. Individuals with dementia require an enriched environment that not only addresses their cognitive challenges but also provides opportunities for personal development. Key indicators are **inclusion**, **respect**, **warmth**, **validation**, **enabling**, **being part of the community** and **relationships** (2).*

This study's exploration of **inclusion** within the context of SDM has demonstrated that people with dementia are actively involved whenever possible. Chapter 6 highlights that the extent of involvement also depends on the nature of the decision and the severity of the dementia. Results show that nurses generally hold positive attitudes toward caring for people with dementia and aim to provide compassionate and appropriate care with **warmth**; when faced with challenging behaviours, most nurses respond with empathy and understanding. However, Chapter 3 revealed that some nurses lack a natural affinity for working with patients with dementia. Relatives have often expressed a preference for nurses who are consistently available, attentive to both the patient and their family, and who actively listen to their concerns, as shown in Chapter 4. Due to frequent interactions, nurses have ample opportunities to foster positive relationships with people with dementia (Chapter 5). However, while nurses have reported a high rate of **respect**ful treatment towards people with dementia in their wards (Chapter 2), relatives have claimed they occasionally witnessed incidents as disrespectful, undignified, or contributing to unnecessary complications (Chapter 4). This discrepancy highlights the ongoing need for awareness and training to ensure all nurses can provide the level of care and respect that patients with dementia and their families expect.

Nurses report that patients with dementia often experience a loss of function, which can lead to feelings of sadness or anger. In the realm of patient care, Chapter 6 has shown that participating nurses underscored the importance of considering the patient's emotions when making difficult decisions on their behalf. According to feedback from relatives, nurses demonstrated that they take their family members with dementia seriously (**validation**). Results also show that nurses frequently assisted with communication and closely monitored patients with dementia who may become confused. Recognising the challenges posed by dementia, nurses who have undergone recent training have indicated they spend more time caring for people with dementia and feel more responsible for behavioural problems and the onset of delirium (Chapter 3). Nurses **enable** patient and relative participation in decision-making using more extensive and intensive contact with patients. In promoting inclusivity in decision-making, nurses have stated a preference for an appropriate moment in consultation with relatives to ensure that patients' emotions do not overwhelm them (Chapters 5, 6).

Incorporating the indicator of **being part of the community** within the hospital setting presents challenges. In this synthesis, community involvement is interpreted to include the participation of relatives during a patient's hospital admission. Relatives are often allowed to stay with the patient around the clock to provide support (Chapters 2, 4). However, they frequently report that during such rooming-in periods, they end up providing most of the care themselves. Relatives have indicated that they view this practice as primarily serving to lessen the workload on nurses, rather than genuinely enhancing the patient's well-being. They reported that they often felt compelled to address issues on behalf of the nursing staff and experienced pressure to be constantly present, taking on significant caregiving responsibilities without adequate consideration of their own circumstances or potential for burnout. Furthermore, relatives have expressed a need for better explanations and guidance on managing their relative's agitated and sometimes challenging behaviour, as covered in Chapter 4. This underscores the need for a more balanced approach to involving relatives, one that genuinely enhances patient care while acknowledging and supporting the relatives' roles.

7.3. Methodological considerations

Mixed methods approach: A significant strength of this thesis lies in its utilisation of a mixed methods approach. By deploying both quantitative and qualitative methods, it was possible to comprehensively explore the care of patients with dementia, resulting in a nuanced understanding of nursing care for hospitalised patients with dementia (5,6). The research focused on a realistic contextual understanding and multiple perspectives, which is crucial when studying complex issues such as the care of people with dementia (5,7).

Triangulation methods: The use of triangulation methods, including data triangulation, involved examining nursing care for people with dementia from different perspectives: 1. Research triangulation, which consisted of reviewing the data with a team of experts, 2. Theory triangulation, which consisted of using the VIPS framework to synthesise all of the findings, and 3. Methodological triangulation, which included using multiple methods of data collection (8). This enhances the validity and reliability of the findings by confirming evidence from different sources.

Deviation from the original plan: The deviation from the original research plan, mainly the exclusion of managers from the research process, limited the exploration of certain aspects, such as organisational vision and the broader social environment.

Conducting research with people with dementia: It has been recognised that people with dementia wish to be involved in research related to their disease (9). However, this study only partially incorporated the perspective of patients with dementia. Although a person with dementia was initially involved as a consultative partner, this proved too complex in practice due to the rapid decline of this person’s cognitive and physical health. Additionally, there are several factors to consider when conducting research with dementia sufferers. Firstly, obtaining informed consent can be challenging as patients with dementia may not fully comprehend the implications of their consent (10). And, secondly, cognitive impairment and communication problems in people with dementia may affect the reliability of collected data, leading to biases in results and limitations in interpreting study findings. For this thesis, an attempt was made to interview patients with dementia upon admission to the hospital. Unfortunately, due to the outbreak of COVID-19, this study had to be stopped.

7.4 Recommendations

7.4.1 Recommendations for Care

Integrating person-centred nursing care into the vision of the organisation

Integrating person-centred care into hospitals’ organisational vision is crucial. This integration includes creating a supportive work culture that promotes psychosocial care in addition to physical care and recognises the challenges of nursing patients with dementia. Despite barriers such as heavy workloads and staff shortages, this study has highlighted opportunities to improve care. For instance, supporting tools such as knowledge networks or peer support groups can be established to help nurses cope with the complexities of caring for a dementia patient. Prioritising person-centred nursing care facilitates the creation of personalised care plans that promote autonomy and well-being, among other benefits. Additionally, improving person-centred care for patients with dementia in a hospital, patient experience stories can be used for education and relatives can become actively involved in improvement projects.

7.4.2 Recommendations for education

Integrated curriculum

This study has shown the importance of integrating training on dealing with patients with dementia as well as person-centred care into the nursing curriculum to ensure that all nursing staff gain this essential knowledge in different settings. Simulation-based training exercises would be suitable to introduce nursing students to typical scenarios in dementia care, such as managing challenging behaviours, facilitating communication with patients with cognitive impairments and addressing safety issues. Furthermore, simulation training allows students to practice skills in a safe and controlled environment before working with real-life patients. During nursing training, internships in dementia care settings can offer students valuable hands-on experience. These internships should be supervised by experienced nurses specialised in dementia care, enabling students to apply their theoretical knowledge in practical settings.

Specialised training programmes for hospital nurses

This study also recommends developing and implementing specialised training programmes on dementia care, delirium management, and person-centred approaches. These programmes could cover topics such as understanding the unique needs of people with dementia, effective communication strategies, behavioural interventions, and techniques to promote autonomy and dignity in care. Continuing education opportunities should also be provided for nurses to improve their knowledge and skills in dementia care. These could include workshops, seminars, online courses, and regular updates on best practices in dementia care. Finally, nurses should be encouraged to become certified in gerontology or dementia care to enhance their expertise further.

Practical training and simulation

Practical training and simulation exercises, such as virtual reality or serious gaming, could be a valuable learning tool for nursing students and nurses as they can practice their skills in a controlled environment. Simulation scenarios must mimic real-life situations commonly encountered in dementia care so that students and nurses can develop confidence and competence in dealing with challenging behaviours and communication barriers and applying SDM.

7.4.4 Recommendations for Future Research

To improve the care of patients with dementia in hospitals, the primary recommendation for further research is to explore how these patients' needs can be met in a dementia-friendly environment. For this to occur, it is necessary to understand the nature of care that people with dementia currently receive in hospitals. Stakeholders from hospitals, the community and nursing homes such as nurses, physicians, geriatricians, and nurse specialists, can work with people with dementia and their relatives to develop new initiatives in this area, such as temporary admission to a nursing home, home care, or nurse-led clinics. In addition, advanced care planning is essential, therefore more research into respite options is needed to prevent admissions because of overstretched relatives. Research can identify how to improve these options.

Additionally, this thesis recommends further research into exploring how nursing care in hospitals can successfully deal with challenging behaviour in patients with dementia and better understand the situations that result in the use of restrictive measures.

Moreover, although existing evidence suggests that nurses' involvement can improve the SDM process, further research is needed to explore the contributing factors and to understand the benefits for both patients and their relatives when nurses actively participate. Further research could investigate the effect of including goal discussions in SDM training for nurses working with patients with dementia and whether this leads to improved patient goal attainment during hospitalisation. Finally, further research is recommended to explore the barriers that prevent nurses from feeling confident in using SDM and the perception that SDM is primarily the responsibility of physicians when working with patients with dementia.

7.5 General conclusion

This thesis has aimed to explore the quality of nursing care for people with dementia in Dutch hospitals, focusing on the role of nurses in person-centred care, including SDM, from the perspectives of nurses and patients with dementia' relatives. The results highlight the multifaceted nature of nursing care for patients with dementia in a hospital setting. By adopting a person-centred care approach, enhancing communication skills, promoting environmental modifications, prioritising staff support and training programmes, and implementing quality assurance measures, nursing practice can be optimised to meet the complex needs of this vulnerable patient population, ultimately improving the quality of care.

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Appendices

Appendix A. The Dutch version of the POPAC

POPAC-NE

1 We beoordelen de cognitieve status van onze oudere patiënten bij opname.
2 We passen de omgeving aan om prikkels te vermijden bij ouderen met cognitieve stoornissen (bijvoorbeeld eenpersoonskamers, lawaaibeperking).
3 We diagnosticeren symptomen van cognitieve stoornissen (bijvoorbeeld dementie, delier, etc.).
4 We brengen meer tijd door met oudere patiënten met cognitieve stoornissen in vergelijking met patiënten zonder cognitieve problemen.
5 We gebruiken evidence-based hulpmiddelen om de cognitieve status van oudere patiënten te beoordelen (bijvoorbeeld de MMSE, SPMSQ, CAM, DOS).
6 We raadplegen specialistische expertise (bijvoorbeeld psycholoog, gerontoloog) als we vaststellen dat een patiënt cognitieve beperkingen heeft.
7 We gebruiken evidence-based zorgrichtlijnen bij de zorg voor oudere cognitief beperkte patiënten.
8 We gebruiken persoonlijke informatie over oudere patiënten (bijvoorbeeld gewoonten, interesses en wensen etc.) om hun zorg te plannen.
9 We betrekken familieleden bij de zorg voor oudere patiënten met cognitieve stoornissen.
10 We bieden personeelscontinuïteit voor oudere patiënten met cognitieve stoornissen (bijvoorbeeld dezelfde verpleegkundigen die zo vaak mogelijk zorg verlenen aan deze patiënten).
11 We evalueren systematisch of oudere patiënten met cognitieve stoornissen al dan niet zorg ontvangen die aan hun behoeften voldoet.
12 We betrekken oudere patiënten met cognitieve stoornissen bij beslissingen over hun zorg (bijvoorbeeld onderzoeken, behandelingen enz.).
13 We zorgen ervoor dat oudere patiënten met cognitieve stoornissen testen/onderzoeken/consulten op de afdeling hebben in plaats van naar een andere afdeling te moeten gaan.
14 We bespreken met elkaar manieren om tegemoet te komen aan de complexe zorgbehoeften van mensen met cognitieve stoornissen.
15 We beoordelen de cognitieve status van onze oudere patiënten bij opname.

Appendix B. GerINCQ and Hyninnen Overview Mean, Cronbach's alpha if item deleted, Percentages per category

Table I. GerINCQ Overview Mean, Cronbach's alpha if item deleted, Percentages per category

Subscales and items			Percent			
Performed interventions (*Please state to what extent the following interventions are used with the patients with dementia you care for*)	Mean	Cronbach's alpha if item deleted	Never	Rarely	Often	Always
Nursing interventions to prevent pressure ulcers	3.46	0.65	1	3	45	51
Nursing interventions to prevent a delirium	3.40	0.65	0	5	50	45
Nursing interventions to prevent a fall	3.40	0.67	0	4	52	44
Nursing interventions to prevent malnutrition	3.39	0.65	0	6	48	45
Offering activities	2.30	0.69	17	45	28	10
Use of incontinence material	3.08	0.68	0	7	78	15
Active mobilization policy	3.17	0.66	1	10	59	30
Enteral nutrition	1.94	0.68	19	68	11	1
Urinary catheters	2.50	0.67	2	48	47	3
Pain medication	2.92	0.68	1	20	66	14
Sleep medication	2.56	0.68	4	37	57	2
Medical restrictive measures	2.70	0.67	5	24	66	5
Physical movement-restrictive measures	2.21	0.67	11	59	28	2

Dementia-sensitive care delivery (*At the department where you work how satisfied are you about the extent to which*)	Mean	Cronbach's alpha if item deleted	Highly unsatisfied	Unsatisfied	Satisfied	Very satisfied
Patients with dementia treated with respect	3.29	0.83	0	3	64	33
Pace adjusted to people with dementia	2.49	0.82	4	48	42	6
Independence of people with dementia is encouraged	2.85	0.83	0	21	71	8
Patients with dementia can make decisions about their care and treatment	2.69	0.83	0	32	65	3
Informal carers of patients with dementia receive information	3.05	0.83	0	13	69	18
Communication takes place with informal carers about decisions concerning the care and treatment of patients with dementia	3.17	0.83	0	8	67	23
There is monitoring of and attention to the burden on informal carers of patients with dementia	2.90	0.83	2	18	66	13
Nurses adapt the care to the needs of patients with dementia	2.90	0.82	0	17	74	9
Nurses are aware that there can be a difference in the effect of medical/nursing interventions on patients with dementia compared with younger patients	2.90	0.83	0	19	70	10
Nurses request information about the patient's situation prior to admission	2.70	0.83	5	29	56	10
Patients with dementia are considered in the planning of each shift	2.48	0.83	7	44	43	7
Continuity of care between hospital departments is adequate	2.49	0.82	1	21	73	5
Continuity of care after discharge is adequate	2.85	0.83	0	17	73	10

Professional Responsibility (*How responsible do you feel for*)	Mean	Cronbach's alpha if item deleted	Never responsible	Rarely responsible	Frequently responsible	Frequently responsible
Fall incidents among people with dementia	3.26	0.87	0	8	58	34
Development of pressure ulcers among patients with dementia	3.33	0.87	0	5	58	38
Deterioration in the nutritional status of patients with dementia	3.08	0.87	0	14	64	22
Urinary tract infections among patients with dementia as a consequence of urinary catheters	2.86	0.87	3	24	55	17
Retention of mobility among patients with dementia?	3.21	0.88	0	7	67	27
Behavioural problems in a patient with dementia?	2.61	0.88	5	39	47	9
Patients with dementia who are anxious and/or dejected?	3.00	0.87	1	16	65	18
The development of delirium in patients with dementia?	2.90	0.88	3	26	48	23
Wounds as a consequence of using sedative medication in patients with dementia?	3.18	0.87	0	11	59	30
Wounds as a consequence of using restrictive measures in patients with dementia?	3.38	0.88	0	6	51	43
Miscommunication with patients with dementia and informal carers?	3.20	0.88	1	6	66	27
Arranging the discharge of patients with dementia?	3.32	0.89	0	4	58	37

Attitude toward caring for patients with dementia (*How would you describe your everyday experience for each of the following items?*)	Mean	Cronbach's alpha if item deleted	Never	Rarely	Often	Always
I observe patients with dementia more carefully than younger patients	3.14	0.69	1	11	59	29
I keep a close eye on confused patients with dementia	3.48	0.69	0	0	51	48
I talk in simple language to patients with dementia	3.31	0.70	0	3	62	35
I talk more loudly and clearly when I speak with patients with dementia	2.97	0.73	3	21	52	24
I create optimum communication conditions for patients with dementia by making use of, for example, the patient's glasses or hearing aid	3.52	0.69	0	0	47	53
I allow extra time for the admission of patients with dementia	2.70	0.69	3	34	52	11
I use the case history details of patients with dementia to plan the care	3.14	0.69	1	10	62	27
I involve patients with dementia in decisions concerning their health	2.98	0.70	0	13	76	11
For the patients with dementia, I start the discharge planning when they are admitted	2.63	0.71	9	32	46	13
I allow more time for preparing the discharge of patients with dementia than I do for the discharge of an older patient without dementia	2.69	0.70	6	33	47	14
I take the patient's health history from the informal carer's point of view	3.21	0.71	1	11	54	34
I involve informal carers of patients with dementia in the care of that patient	3.37	0.70	0	3	56	41
I am aware that patients with dementia can be less assertive	3.17	0.69	0	7	68	25
I encourage patients with dementia to retain their independence during a hospital admission	3.31	0.70	0	8	53	39

Perceptions of caring for patients with dementia	Mean	Cronbach's alpha if item deleted	Almost none	Less than half	More than half	Nearly all
In the past 12 months, which proportion of the patients you cared for were patients with dementia?	2.00	0.59	18	66	14	2
Roughly what proportion of your shift do you devote to the care of patients with dementia in your department?	2.17	0.59	18	51	27	4
			Never satisfying	Rarely satisfying	Frequently satisfying	Always satisfying
How satisfying is your work with patients with dementia?	2.68	0.65	4	30	59	7
			Never demanding	Rarely demanding	Frequently demanding	Always demanding
How demanding do you find the work with patients with dementia?	2.57	0.63	4	38	56	2
			Never difficult	Rarely difficult	Frequently difficult	Always difficult
How difficult do you find it to care for restless patients with dementia?	2.78	0.64	2	29	58	10
			Not proficient	Insufficient proficient	Sufficient proficient	Very proficient
How proficient do you think you are in providing care for patients with dementia?	2.98	0.63	0	12	78	10
			Never	Rarely	Often	Always
To what extent do you feel recognized by your colleagues for your care of patients with dementia?	2.85	0.59	2	20	70	8
To what extent do you feel supported by your superiors in the provision of care for patients with dementia?	2.57	0.61	7	37	49	7
			Poor		Good	Excellent
How do you experience the training of nurses in the provision of care to patients with dementia in your department?	2.48	0.61	4	46	47	3

Some patients can exhibit behaviour that others experience as disruptive, and that applies to older patients as well. During your provision of care, how often do you experience that older patient:			Never	Rarely	Often	Always
Note: Of course, older patients can be lovely, funny, touching, modest, et cetera, but these aspects will not be enquired about here.						
Cannot be reasoned with	2.38	0.59	3	56	41	0
Are not cooperative	2.62	0.60	0	39	60	1
Demand a lot of attention	2.92	0.61	1	14	78	7
Are confused	2.93	0.60	0	9	88	3
Are restless at night	2.99	0.62	1	7	86	7
Are slow	2.92	0.61	1	13	79	7
Display disruptive behaviour toward other patients	2.45	0.60	2	52	45	0

Table II. Hyninnen Overview Mean, Cronbach's alpha if item deleted, Percentages per category

Subscales and items	Percent					
Reaction when a patient with dementia displays challenging behaviour	**Mean**	**Cronbach's alpha if item deleted**	**Never**	**Rarely**	**Often**	**Always**
F1 React with care						
I ask her/him what is wrong	3.41	0.48	0	3	53	44
I check the patient record for patient's background and possible instructions	3.42	0.46	1	4	48	47
I organize activities for the patient, for example, switching on the TV in the patient room	3.08	0.46	1	8	72	18
I am present for the patient; I touch, speak, and listen	3.29	0.46	0	3	66	31
F2 React by ignoring						
I do nothing	1.33	0.55	67	32	0	0
I pretend not to hear, see, or notice anything	1.49	0.54	56	40	4	0
F3 react with power						
I take her/him to her/his room	3.17	0.47	2	6	64	28
I use physical force to calm the situation	1.52	0.54	56	36	7	0
I give orders to the patient	3.18	0.45	1	7	63	29
F4 react casually						
I manage humour	3.23	0.47	0	4	69	27
I tolerate the behaviour because the patient has the right to become angry	2.73	0.50	1	29	65	5

Use of alternative approaches instead of physical restraints	Mean	Cronbach's alpha if item deleted	Never	Rarely	Often	Always
F1 use of professional knowledge						
I try to make the physical care environment safer	3.44	0.53	0	2	52	45
I am present for the patient; I touch, speak, and listen	3.28	0.54	0	2	69	29
I can manage the patient's challenging behaviour	2.98	0.58	0	10	82	8
I negotiate with my colleagues about the correct approach	3.21	0.53	0	4	69	26
I negotiate with the patient's family about the correct approach	3.34	0.53	0	3	60	37
F2 use of medication						
I give sedative medication to the patient	2.64	0.62	0	37	61	2
I give painkillers to the patient	2.66	0.60	3	32	61	4
F3 use of problem-solving						
I try to draw the patient's attention elsewhere	3.13	0.57	0	4	79	17
I try to organize expert consultation for the patient	3.24	0.58	0	9	56	34

Appendix C-Quantitative Outcomes

Table A1. Type admission (n=129)

Was the admission of this relative planned?

	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	18	13.95	13.95	13.95
No, my relative first came to the emergency room	106	82.17	82.17	96.12
No, my relative first came to the outpatient clinic	5	3.88	3.88	100.00
Missing	0	0.00		
Total	129	100.00		

Table A2. Department (n=129)

In which department was your relative admitted?

	Frequency	Percent	Valid Percent	Cumulative Percent
Medical	21	16.28	16.28	16.28
Surgical	29	22.48	22.48	38.76
Lung	6	4.65	4.65	43.41
Geriatric	19	14.73	14.73	58.14
Cardiology	11	8.53	8.53	66.67
Intensive care	3	2.33	2.33	68.99
Other	37	28.68	28.68	97.67
Neurology	3	2.33	2.33	100.00
Missing	0	0.00		
Total	129	100.00		

Table A3. Awareness of dementia (n=129)

Do you believe nurses were aware that your relative has dementia?

	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	79	61.24	61.24	61.24
No	50	38.76	38.76	100.00
Missing	0	0.00		
Total	129	100.00		

Table A4. Ways in which dementia was taken into account (n=129)

	Percentage; N=129			
	Yes	No	I don't know	Not applicable
My relative was treated understanding.	66.67	25.58	6.20	1.66
There were separate rooms for people with dementia and their families.	18.60	59.69	12.40	9.30
A specialist in the field of care for people with dementia was involved, e.g. a clinical geriatrician or geriatric consultation team.	41.09	43.41	9.30	6.20
I was able to come to the pre- and post-operation rooms after surgery.	17.05	21.71	3.10	58.14
I could be there as much as I wanted (day and night).	50.39	32.56	8.53	8.53
Bringing my relative's personal belongings, such as photos, was encouraged.	20.16	49.61	6.20	24.03
Activities were organised.	9.30	56.59	10.08	24.03
The environment was made incentive-free.	13.18	55.04	19.38	12.40
Day Structure was provided. e.g., by a visible daily schedule.	19.38	51.94	9.30	19.38
There was a special bed, e.g., an extra-low bed or a tent bed.	20.16	60.47	6.20	13.18
There was sufficient supervision for my relative when eating and drinking.	41.09	37.98	14.73	6.20
There was sufficient supervision to prevent my relative from wandering.	25.58	41.09	10.85	22.48

Table A5. Satisfaction about the extent nurses took dementia into account (n=129)

How satisfied are you with the extent to which nurses took the dementia of your relative into account?

	Frequency	Percent	Valid Percent	Cumulative Percent
Very satisfied	21	16.28	16.28	16.28
Satisfied	38	29.46	29.46	45.74
Neutral	23	17.83	17.83	63.57
Dissatisfied	30	23.26	23.26	86.82
Very dissatisfied	17	13.18	13.18	100.00
Missing	0	0.00		
Total	129	100.00		

Table A6. Taking patients' feelings seriously (n=129)

To what extent did the nurses take your relative's feelings and emotions seriously?

	Frequency	Percent	Valid Percent	Cumulative Percent
Always	16	12.40	12.40	12.40
Usually	52	40.31	40.31	52.71
Sometimes	34	26.36	26.36	79.07
Rarely	19	14.73	14.73	93.80
Never	8	6.20	6.20	100.00
Missing	0	0.00		
Total	129	100.00		

Table A7. Involvement in decision-making (n=129)

To what extent were you involved in decisions about caring for your relative?

	Frequency	Percent	Valid Percent	Cumulative Percent
Always	43	33.33	33.33	33.33
Usually	46	35.66	35.66	68.99
Sometimes	20	15.50	15.50	84.50
Rarely	11	8.53	8.53	93.02
Never	9	6.98	6.98	100.00
Missing	0	0.00		
Total	129	100.00		

Table A8. Satisfaction regarding involvement in decision-making (n=129)

How satisfied are you with the extent to which you have been involved in decisions about your relative's care?

	Frequency	Percent	Valid Percent	Cumulative Percent
Very satisfied	17	13.18	13.18	13.18
Satisfied	50	38.76	38.76	51.94
Neutral	27	20.93	20.93	72.87
Dissatisfied	23	17.83	17.83	90.70
Very dissatisfied	12	9.30	9.30	100.00
Missing	0	0.00		
Total	129	100.00		

Table A9. Experiences behavioural problems (n=129)

People with dementia who have been admitted are more likely to have behavioural problems. Did your relative show any behavioural problems during admission?

	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	78	60.47	60.47	60.47
No	51	39.53	39.53	100.00
Missing	0	0.00		
Total	129	100.00		

Table A10. Experienced behavioural problems (n=78)

Possible behavioural problems are described below. Would you like to indicate for each behaviour whether your relative showed this behaviour during the admission?

	Percentage; N=78		
	Yes	No	I don't know
Anxious behaviour	68	23	9
Agitated behaviour, such as restlessness, irritable or aggressive behaviour	62	36	3
Shouting behaviour	44	44	13
Nocturnal unrest	73	19	8
Sexually disinhibited unaccepted behaviour	8	86	6
Frequently asking questions	58	35	8
Doesn't want to cooperate	41	49	10
Apathetic behaviour	44	50	6
Disruptive behaviour towards other patients	28	59	13
Confused behaviour	45	41	14
Slow behaviour	67	28	5
Other	31	56	13

Table A11. Involvement discharge (n=129)

Were you involved in planning your relative's discharge from the hospital?

	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	100	77.52	77.52	77.52
No	29	22.48	22.48	100.00
Missing	0	0.00		
Total	129	100.00		

Table A12. Satisfaction involvement discharge (n=129)

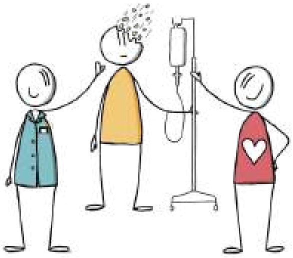
How satisfied are you with the extent to which you were involved in planning the discharge of your relative?

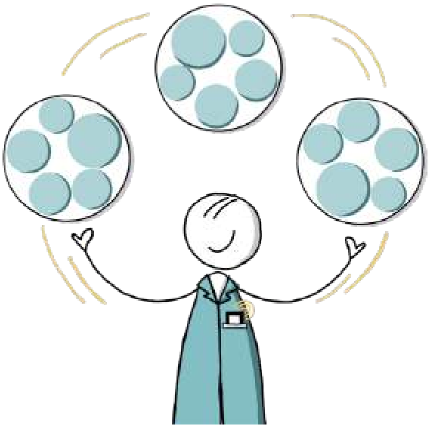
	Frequency	Percent	Valid Percent	Cumulative Percent
Very satisfied	18	13.95	13.95	13.95
Satisfied	45	34.88	34.88	48.84
Neutral	28	21.71	21.71	70.54
Dissatisfied	29	22.48	22.48	93.02
Very dissatisfied	9	6.98	6.98	100.00
Missing	0	0.00		
Total	129	100.00		

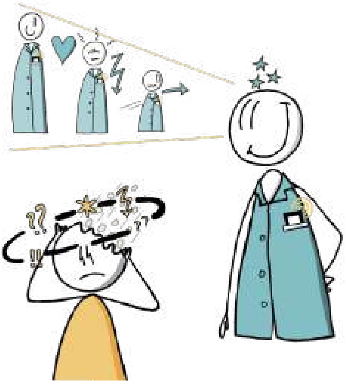
Table A13. Involvement case manager (n=129)

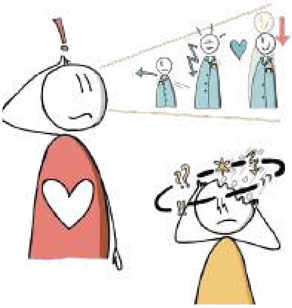
Has the hospital informed the case manager for dementia about the consequences of the illness and/or the treatment of your relative?

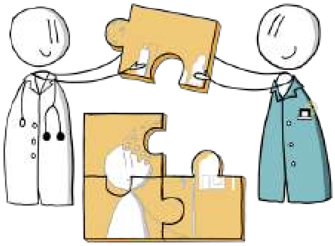
V28	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	33	25.58	25.58	25.58
No	51	39.53	39.53	65.12
Not applicable, we do not have a case manager dementia	45	34.88	34.88	100.00
Missing	0	0.00		
Total	129	100.00		

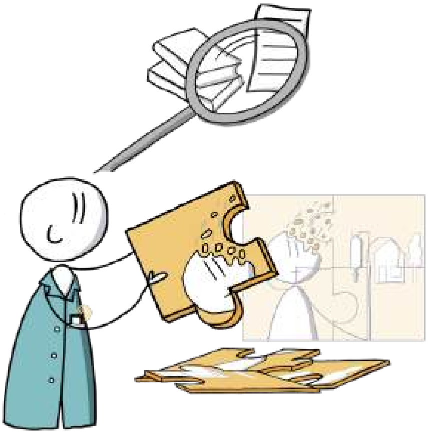












SUMMARIES

Summary

Chapter 1 General Introduction

The global ageing population is expected to double to 1.5 billion by 2050, with 728 million people currently aged 65 and over. This demographic shift is leading to an increase in people with dementia, a neurocognitive disorder that affects cognition and behaviour. In the Netherlands, approximately 290,000 people are estimated to have dementia. People with dementia frequently experience multiple physical illnesses, on average three or more. In 2019, hospital admissions for people with dementia in the Netherlands were 22%, with admissions primarily attributed to conditions other than dementia, such as bone fractures or chronic illnesses. Nursing care tends to focus on physical illness rather than providing support and care for patients with dementia. This approach can have unintended negative consequences, such as discomfort and a decline in cognitive and functional skills. Research indicates that hospital nurses may prioritise tasks over patient needs, contributing to a lack of person-centred care.

Providing person-centred care is the preferred international standard for people with dementia. Currently, there is limited research on nursing care for patients with dementia in the hospital context, with existing studies mainly being qualitative or focused on a specific type of ward. It remains uncertain how Dutch nurses take dementia into account in the care of patients with dementia in hospital settings.

The aim of the thesis is to explore nursing care for people with dementia in Dutch hospitals, focusing on the role of nurses in person-centred care and shared decision- making from the perspectives of nurses and relatives of patients with dementia.

The overall design of this research involves a sequential exploratory mixed-methods approach to explore nursing care in hospitals for people with dementia.

Chapter 2 Validation and psychometric evaluation of the Dutch Person-centred care of Older People with cognitive impairment in Acute Care (POPAC)

This chapter reports the results of a cross-national validation and psychometric evaluation of the Dutch version of the POPAC scale. This scale was developed for the acute hospital setting and measures the person-centredness of care for older people with dementia. The scale consists of 15 items in three subscales with a 6-point Likert scale. The subscale 'using cognitive assessments and care interventions' is related to valuing people; 'using evidence and cognitive expertise' concerns the understanding of situations from the perspective of the person with dementia; and 'individualising care' is related to individualising approaches and the social environment. After double-blind forward and backward translation, 159 nurses recruited from six hospitals and via social media completed the POPAC scale. The results confirmed the three-dimensional structure. The factor loadings (0.69-0.77) indicated that the items were strongly associated with their respective factors. Our findings suggest that the Dutch POPAC scale is sufficiently valid and reliable and can be used to assess person-centred care in acute care hospitals. The Dutch version of the POPAC enables hospital nurses to interpret and compare the level of person-centred care at the ward and hospital level nationally and internationally. The results provide an essential basis for nurses and policymakers aiming to improve the quality of care and nurse-sensitive outcomes, such as preventing complications and length of hospital stay for patients with dementia.

Chapter 3 Nurses' perceptions of caring for people with dementia in Dutch acute hospitals

This cross-sectional survey study aimed to describe nursing care for patients with dementia in acute hospitals, with the objectives of describing the nursing care provided (1), nurses' attitudes and perceptions in caring for patients with dementia (2) and exploring how nurses deal with challenging behaviour (3). Additionally, background variables associated with caring for people with dementia were identified. To assess nurses' care, attitudes, and perceptions of caring for people with dementia in acute hospitals, we combined two validated questionnaires. The basis of the questionnaire was the Dutch Geriatric In-Hospital Nursing Care Questionnaire. This instrument measured the performed nursing care for patients with dementia, nurses' attitudes toward this care, and the perception of caring for patients with dementia in a hospital setting from the perspective of nurses. To gain more insight into how nurses react to challenging behaviour, we used two validated subscales of Hynninen's questionnaire. These subscales measured care practices of patients with dementia: *managing challenging behaviour and use of alternative approaches instead of physical restraints*. 229 Nurses in seven Dutch hospitals completed the questionnaire, consisting of 87 4-point Likert scale items and two open-ended questions. The results show that the participating nurses express that they often use general preventive measures that are not explicitly related to dementia care. In general, the participating nurses have mixed feelings about the care provided in their unit. A variety of approaches are used to manage challenging behaviour, including restrictive measures and medication. Nurses' attitudes and perceptions are influenced by the type of hospital (university, non-university teaching, or general hospital) they work in, their level of education, the number of hours they work and whether they have completed a course on dementia in the last year. Despite positive attitudes, nurses reported a lack of specific knowledge and skills to provide appropriate care. Nurses who had recently completed a course on dementia had more positive attitudes and perceptions towards caring for people with dementia. The results of this research can be used to improve the quality of care in hospitals for people with dementia.

Chapter 4 Experiences of informal caregivers of people with dementia with nursing care in acute hospitals

This descriptive mixed-method study aimed to explore the experiences of informal carers of people with dementia during their relative's hospitalisation regarding patient care, interactions with nurses, the carers' situation, and the acute hospital environment. Quantitative data were collected via an online questionnaire in collaboration with the national panel of caregivers of Alzheimer Nederland (n=129). Subsequently, qualitative data were collected by organising a focus group with six participants and five face-to-face interviews with Alzheimer Nederland. The data were triangulated and analysed using a conceptual framework. Almost half of the respondents were satisfied with the extent to which the nurses took the patient's dementia into account. Activities to prevent challenging behaviour and provide person-centred care were rarely seen by informal carers. Informal carers experienced strain, exacerbated by a perceived lack of adequate communication with the nursing staff. They did not feel they were considered as the nurses' partners in care; they also expressed concerns about environmental safety. An essential suggestion from carers was to create a dedicated unit for people with dementia staffed by specialist nurses. Positive experiences of informal carers are reported about how nurses take dementia into account, involvement in care, and shared decision-making (SDM). Negative experiences are described concerning disease-oriented care, ineffective communication, and an unfamiliar environment. Informal carers expressed greater involvement when they were involved in decisions and care when care was delivered according to the triangle of care model. Participants reported better care when a person- centred approach was observed. The results can be used in training to help nurses reflect and seek improvement. This study confirms other international studies that informal carers perceive that being more involved in care can help to improve care for people with dementia. The study is relevant for nurses to become more aware of the informal carer's perspective; it also provides input to improve nurse training and to make care and environments more dementia friendly.

Chapter 5 Involvement, topics, and roles of nurses in SDM with patients with dementia in acute hospitals

An integrative review was conducted to gain further insight into the literature on Shared Decision Making (SDM) with patients who have dementia. The review describes the roles of nurses, their involvement, and the topics related to SDM with older patients who have dementia in acute hospitals. Nine studies were included. The results showed that nurses were involved as treatment team members, intermediates, or patient supporters. The data were categorised by Groen's model's SDM stages (Groen -Van de Ven, 2017a). The findings establish that nurses participated as patient advocates, members of the treatment team, or intermediaries. The nurse's role was most apparent during the preparatory stage of SDM. Developing customised options was only partially identified. The deliberation and option evaluation process for decision-making was depicted from an external vantage point, with nurses seeking to influence the decision.

In summary, nurses play a fundamental role in SDM by providing additional patient information. Three levels of nurse involvement in SDM were identified: nurses as care team members, facilitators, and patient advocates. Specific roles related to patients with dementia are primarily described during the preparation phase. Additionally, nurses have a crucial role in the decision-making process, providing supplementary information about the patient. Nurses act as advocates, messengers, communicators, and intermediaries between professionals, patients, and informal caregivers. Nurses' roles were most explicit in the preparatory phase of SDM. 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. Because nurses have an essential role in care, their voice in SDM seems crucial and should be made more explicit in developing person-centred care in hospital care.

Chapter 6 Nurses’ perspective on shared decision-making in the daily care of hospitalised patients with dementia

This explorative qualitative study aimed to gain insight into the SDM process in daily care in hospitals with patients with dementia from nurses’ perspectives. In-depth digital interviews were conducted with 14 registered nurses. Five themes were identified from the data: 1. SDM in daily care: how SDM is applied, 2. Nurses’ perceptions and competence: how nurses perceive and manage SDM, 3. Nurses’ roles and advocacy: the evolving roles of nurses and their advocacy efforts, 4. Recognition of dementia and its impact: how nurses recognise and manage dementia, and 5. Interventions to support SDM: strategies and interventions to facilitate SDM. The study highlights the SDM complexity in patients with dementia. It demonstrates the importance of the involvement of relatives, the omission of patient goals in discussions, and the perceived deficiencies of nurses. Early identification of dementia, nuanced capacity evaluation, and targeted communication are essential. Further research and enhanced training are required to improve care in this context. Findings highlight the requirement for policies that encourage interdisciplinary collaboration, address misconceptions, and recommend training programs that focus on applying SDM in the daily care of patients with dementia, thereby improving the overall quality of patient care.

Chapter 7 General discussion

The thesis concludes with a general discussion of the findings of the chapters. The main findings in relation to each of the research aims are summarised. Dawn Brooker’s VIPS framework was used to interpret the findings. This thesis contributes to our knowledge of the care of people with dementia in hospitals. It also shows what is needed to prevent complications, functional decline, and prolonged hospitalisation in this population. The dissertation presents the current state of care for people with dementia in Dutch hospitals, focusing on the role of nurses in this care. The use of the VIPS framework to analyse data on Dutch hospital care is innovative, as there is little literature on the nursing care of people with dementia in Dutch hospitals. Finally, recommendations are made for practice, education, and future research.

Samenvatting

In **Hoofdstuk 1** wordt de achtergrond van dit proefschrift geschetst. Dementie is een voor patiënten en hun naasten ingrijpende hersenziekte, die veelal voorkomt bij ouderen. Er bestaan ruim 50 soorten, waarvan de ziekte van Alzheimer de meest voorkomende is. Het bekendste symptoom is vergeetachtigheid. Daarnaast kunnen onder andere problemen met dagelijks handelen, vergissingen in tijd en plaats, sociaal-emotioneel functioneren, sociale terugtrekking en taal ontstaan. In Nederland zijn ongeveer 290.000 mensen met dementie. De ziekte is nog niet te genezen en symptomen verergeren in de loop van de tijd waardoor mensen met dementie steeds meer hulp nodig hebben. Door de toenemende vergrijzing is de verwachting dat het aantal mensen met dementie wereldwijd stijgt.

Mensen met dementie hebben gemiddeld drie of meer andere chronische aandoeningen en worden regelmatig opgenomen in een ziekenhuis voor problemen met deze chronische aandoeningen of bijkomende aandoeningen zoals breuken of infecties. Ziekenhuisopname heeft vaak onbedoelde gevolgen, zoals het ontstaan van complicaties en langere opnameduur. Voor mensen met dementie en hun naasten is een opname in een ziekenhuis ingrijpend. Voor patiënten omdat zij uit hun normale omgeving met vaste routines zijn en voor naasten omdat dit leidt tot extra belasting. Verpleegkundigen ervaren het zorgen voor patiënten met dementie als uitdagend, met name als sprake is van probleemgedrag, zoals: agitatie, weerstand tegen zorg, agressie, dwalen en aanhoudend roepen.

Persoonsgerichte zorg is de internationale standaard voor patiënten met dementie. Samen Beslissen is een belangrijk onderdeel van persoonsgerichte zorg.

Op dit moment is beperkt onderzoek gedaan naar verpleegkundige zorg voor patiënten met dementie in een ziekenhuissetting. Bestaande studies zijn voornamelijk kwalitatief of zijn gericht op een specifieke afdeling. Het is onbekend hoe Nederlandse verpleegkundigen rekening houden met de gevolgen van dementie in de zorg voor patiënten met dementie in een ziekenhuissetting in Nederland.

Het doel van dit proefschrift is om de verpleegkundige zorg voor mensen met dementie in Nederlandse ziekenhuizen te onderzoeken, waarbij de nadruk ligt op de rol van verpleegkundigen in persoonsgerichte zorg en Samen Beslissen vanuit het perspectief van verpleegkundigen en naasten van patiënten met dementie.

Hiervoor zijn vijf studies uitgevoerd met verschillende methodologieën. **Hoofdstuk 2** beschrijft de resultaten van een validatie en psychometrische evaluatie van de Nederlandse versie van de POPAC-schaal. Deze schaal meet de persoonsgerichtheid van zorg voor oudere patiënten met dementie in de ziekenhuissetting. De vragenlijst is ingevuld door 159 verpleegkundigen geworven uit zes ziekenhuizen en via sociale media. Onze bevindingen laten zien dat de Nederlandse POPAC-schaal voldoende valide en betrouwbaar (Cronbach's alpha 0.85) is en kan worden gebruikt om persoonsgerichte zorg in ziekenhuizen te beoordelen. De Nederlandse versie van de POPAC stelt ziekenhuisverpleegkundigen in staat het niveau van persoonsgerichte zorg op afdelings- en ziekenhuisniveau, nationaal en internationaal te interpreteren en te vergelijken. De gevalideerde POPAC biedt input voor verpleegkundigen en beleidsmakers die streven naar verbetering van de kwaliteit van zorg en 'nursing-sensitive' uitkomsten, zoals het voorkomen van complicaties en verkorting van de duur van ziekenhuisopname voor patiënten met dementie.

Hoofdstuk 3 geeft een onderzoek weer naar de percepties van verpleegkundigen over de zorg voor patiënten met dementie in Nederlandse ziekenhuizen. Subdoelen waren inzicht krijgen in de uitgevoerde verpleegkundige zorg (1), beschrijven van attitudes en percepties van verpleegkundigen bij de zorg voor patiënten met dementie (2) en verkennen hoe verpleegkundigen omgaan met probleemgedrag (3). Bovendien zijn achtergrondvariabelen geïdentificeerd die verband houden met de zorg voor patiënten met dementie.

Verpleegkundigen (n=229) passen vaak algemene preventieve maatregelen in de zorg aan patiënten toe die niet expliciet gerelateerd zijn aan dementiezorg, zoals het voorkomen van decubitus. Zij gebruiken diverse benaderingen om met probleemgedrag van patiënten met dementie om te gaan, waaronder het toepassen van vrijheidsbeperkende maatregelen en gebruik van medicatie. De attitudes en percepties van verpleegkundigen worden geassocieerd met het type ziekenhuis (universitair, top-klinisch of algemeen ziekenhuis) waarin ze werken, hun opleidingsniveau, het aantal uren dat ze werken en of ze het afgelopen jaar een cursus over dementie hebben gevolgd. Ondanks positieve attitudes geven verpleegkundigen aan dat zij een gebrek aan specifieke kennis en vaardigheden hebben om passende zorg te bieden.

Hoofdstuk 4 presenteert een 'mixed-method' studie gericht op ervaringen van mantelzorgers van patiënten met dementie met betrekking tot patiëntenzorg, interacties met verpleegkundigen, de situatie van de zorgverleners en de ziekenhuisomgeving tijdens de ziekenhuisopname van hun naaste.

Bijna de helft van de 129 mantelzorgers is tevreden over de mate waarin verpleegkundigen rekening houden met de dementie van de patiënt. Activiteiten om probleemgedrag te voorkomen en persoonsgerichte zorg te bieden, worden zelden gezien door mantelzorgers. Mantelzorgers ervaren stress, wat wordt verergerd doordat ze de communicatie met verpleegkundigen als inadequaat ervaren en ze het gevoel hebben dat ze niet als partners in de zorg worden beschouwd door verpleegkundigen. Daarnaast uiten ze zorgen over de veiligheid van de omgeving voor hun naaste met dementie. Mantelzorgers hebben positieve ervaringen wanneer verpleegkundigen rekening houden met de dementie van hun naaste, en wanneer zij worden betrokken bij de uitvoering van en beslissingen over de zorg. Negatieve ervaringen worden beschreven wanneer zij ervaren dat de zorg alleen gericht is op de ziekte waarvoor patiënt opgenomen is. Mantelzorgers geven aan meer betrokkenheid te voelen wanneer zorg wordt verleend in de driehoek patiënt-mantelzorger-verpleegkundigen en als de zorg als persoonsgericht wordt ervaren.

Dit onderzoek bevestigt uitkomsten van andere internationale studies waaruit blijkt dat mantelzorgers van mening zijn dat wanneer zij meer betrokken worden bij de zorg, dit kan bijdragen aan een betere zorg voor patiënten met dementie.

Hoofdstuk 5 belicht een integrative review over betrokkenheid, onderwerpen en rollen van verpleegkundigen in Samen Beslissen met patiënten met dementie in ziekenhuizen. Deze review is uitgevoerd om een overzicht te maken van kennis over Samen Beslissen met patiënten met dementie in ziekenhuizen. Negen studies zijn geïncludeerd. Het model van Samen Beslissen van Groen-van der Ven is gebruikt voor de analyse. In dit model is het besluitvormingsproces iteratief en gebaseerd op de balans tussen autonomie en veiligheid en de wensen en voorkeuren van de patiënt en de naasten. Samen Beslissen begint met een voorbereidingsfase, waarin samen een probleem wordt geïdentificeerd, gevolgd door het ontwikkelen van opties op maat en het overleggen en uitproberen van opties om tot een beslissing te komen.

Er zijn drie manieren geïdentificeerd waarop verpleegkundigen betrokken zijn bij Samen Beslissen: lid van het behandelteam (1), facilitators (2) en pleitbezorgers van de patiënt (3). Daarnaast hebben verpleegkundigen een cruciale rol in het besluitvormingsproces door aanvullende informatie te verstrekken over de patiënt. Verpleegkundigen hebben een rol als pleitbezorgers, boodschappers, communicatoren en bemiddelaars tussen professionals, patiënten en naasten. De rollen van verpleegkundigen zijn het meest expliciet in de voorbereidingsfase van Samen Beslissen. De stap van '*ontwikkelen van opties op maat*' is beperkt herkend in de literatuur. '*Overleggen en opties proberen*' is met name beschreven vanuit een extern perspectief waarbij verpleegkundigen proberen als buitenstaander de door artsen genomen beslissing te beïnvloeden. De conclusie is dat verpleegkundigen voornamelijk een rol spelen bij het nemen van beslissingen door patiënten informatie aan te vullen.

Hoofdstuk 6 beschrijft een verkennende kwalitatieve studie naar het perspectief van verpleegkundigen op Samen Beslissen in de dagelijkse zorg voor in het ziekenhuis opgenomen patiënten met dementie. Het doel van deze studie was inzicht krijgen in het proces van Samen Beslissen in de dagelijkse zorg in ziekenhuizen met patiënten met dementie vanuit het perspectief van verpleegkundigen. Er zijn digitale interviews gehouden met 14 verpleegkundigen.

Uit de resultaten zijn vijf thema's zijn geïdentificeerd:

1. *Samen Beslissen in dagelijkse zorg: hoe Samen Beslissen wordt toegepast,*
2. *Percepties en competenties van verpleegkundigen: hoe verpleegkundigen Samen Beslissen waarnemen en begeleiden,*
3. *Rollen van verpleegkundigen en pleitbezorging: de evoluerende rollen van verpleegkundigen en hun pleitbezorgingsinspanningen,*
4. *Herkenning van dementie en de impact ervan: hoe verpleegkundigen dementie herkennen en begeleiden,*
5. *Interventies ter ondersteuning van Samen Beslissen: strategieën en interventies om Samen Beslissen te faciliteren.*

De uitkomsten bevestigen de complexiteit van Samen Beslissen met patiënten met dementie. Uit de resultaten blijkt het belang van de betrokkenheid van naasten. Daarnaast worden patiëntdoelen vaak niet geïnventariseerd en voelen niet alle verpleegkundigen zich competent om Samen Beslissen toe te passen. Verpleegkundigen geven aan dat vroegtijdige herkenning van dementie, genuanceerde beoordeling van de cognitieve functies en doelgerichte communicatie voorwaarden zijn om Samen Beslissen met patiënten met dementie in de dagelijkse zorg in ziekenhuizen toe te passen.

Hoofdstuk 7 betreft de discussie van dit proefschrift waar de verpleegkundige zorg voor patiënten met dementie in Nederlandse ziekenhuizen centraal staat. De nadruk ligt op de rol van verpleegkundigen in persoonsgerichte zorg en Samen Beslissen vanuit het perspectief van verpleegkundigen en naasten van patiënten met dementie. Het VIPS- raamwerk van Brooker is gebruikt om de resultaten te interpreteren. Het blijkt dat verpleegkundigen vaak respectvol en warm omgaan met patiënten met dementie. Echter, persoonsgerichte zorg wordt onvoldoende toegepast en de communicatie van verpleegkundigen kan worden verbeterd.

Om de verpleegkundige zorg voor patiënten met dementie in ziekenhuizen te verbeteren wordt aanbevolen om persoonsgerichte zorg onderdeel te maken van de visie van de ziekenhuizen. Daarnaast kan de opleiding voor verpleegkundigen worden verbeterd door onderwijs over dementie en persoonsgerichte zorg in het curriculum te integreren. Verder is meer onderzoek nodig naar wat verpleegkundigen nodig hebben voor Samen Beslissen.

Vervolgonderzoek kan zich daarnaast richten op herkennen van risicogedrag en de toepassing van passende interventies met betrekking tot vrijheidsbeperkende maatregelen. Tenslotte kan het interessant zijn te verkennen of sommige behandelingen, zoals infusiebehandelingen en postoperatieve zorg, niet in het ziekenhuis plaats hoeven te vinden, maar in een voor patiënten met dementie passender omgeving, bijvoorbeeld thuis of in een andere zorgvorm, waardoor eventuele negatieve consequenties van opname in een ziekenhuis kunnen worden voorkomen.

Dankwoord

Zeven jaar geleden begon deze prachtige reis en wat vond ik het spannend. De eerste jaren heb ik enorm getwijfeld of ik het wel zou kunnen, terwijl ik ondertussen genoot van alles wat er te leren viel. Ik ben dan ook erg dankbaar dat ik deze reis heb mogen maken. Graag wil ik iedereen bedanken die een bijdrage heeft geleverd aan dit proefschrift, meegeleefd heeft of heeft gezorgd voor de nodige afleiding, zowel op mijn werk als privé. Een aantal mensen wil ik graag in het bijzonder bedanken.

Evelyn, jij was vanaf het allereerste moment betrokken bij deze promotie. Het proces startte met een ander onderwerp waarna we heel wat brainstormsessies hebben gehad bij jou thuis, in de tuin en telefonisch om tot een passend onderwerp gerelateerd aan dementie te komen. Je hebt veel kennis over persoonsgerichte zorg en dementie, en bent bovenal een inspirator, enthousiast, positief en gedreven. Je hebt me gestimuleerd het beste uit mezelf te halen en ik bleek meer te kunnen dan ik dacht. Ook hielp je me om de focus vast te houden en me niet te veel af te laten leiden door alle interessante andere onderwerpen die ik tegenkwam. Ik kan altijd bij je terecht met vragen, onzekerheden of gewoon voor een goed gesprek. Daarnaast heb ik ontzettend genoten van onze gezamenlijke reizen naar onder andere Ljubljana, Kopenhagen, Berlijn en Rotterdam. Je bent begonnen als copromotor en wat fijn dat je dit nu als promotor af mag ronden. Dat maakt de cirkel voor mij rond. Ik kijk er naar uit om samen met jou aan projecten te blijven werken en het Netwerk Verpleegkundig Onderzoek Noord Nederland (NVONN) nog mooier te maken.

Petrie, zodra ik groen licht had vanuit NHL Stenden werd jij als promotor betrokken bij het schrijven van het onderzoeksvoorstel. Je gaf meteen een deadline aan waar binnen het proefschrift af zou moeten zijn, omdat je bijna met pensioen ging. Helaas heb ik die deadline niet gehaald. Ik ben blij dat je toch tot aan het einde betrokken bent gebleven. Je altijd positieve houding heeft mijn zelfvertrouwen gesterkt. Je was altijd ondersteunend, dienend in het proces en bereid om mee te denken. We hebben samen heel wat interviews gecodeerd, waarbij onze verschillen in kennis en inzichten zorgden voor meer diepgang. Zelfs in je vakantie was je beschikbaar en nam je vanuit je camper of appartement deel aan onze online overleggen, waarbij er soms bijzondere situaties ontstonden. Ik vond het erg bijzonder om bij je bruiloft aanwezig te mogen zijn.

Barbara, toen we elkaar tijdens deze reis tegenkwamen was er meteen een klik. Jouw expertise is van toegevoegde waarde voor mijn proefschrift en ik ben erg blij dat jij deel wilde uitmaken van het promotieteam. Je gaf me de gelegenheid om de impact van mijn onderzoek te vergroten door mij de kans te bieden om als verpleegkundig onderzoeker bij het Alzheimer Centrum het UMCG dementievriendelijker te maken. Je bent altijd vriendelijk en behulpzaam en ik heb veel van je geleerd. Je bent enthousiast, positief en gedreven. Je vragen en opmerkingen hielpen me om me verder te ontwikkelen als onderzoeker en als mens. De bijeenkomsten met promovendi bij jou thuis waren bijzonder en waardevol.

Ik gun iedereen die promotieonderzoek doet een begeleidingsteam zoals dat van mij. Jullie vullen elkaar aan, blijven positief en ondersteunend, dat is zo ontzettend fijn geweest. Jullie hebben een belangrijke rol gehad in mijn ontwikkeling tijdens het schrijven van dit proefschrift. Hier wil ik jullie heel hartelijk voor bedanken.

Dank aan de beoordelingscommissiecommissie, prof. dr. **Sytze Zuidema**, prof. dr. **Lisette Schoonhoven** en prof. dr. **Marieke Schuurmans** voor de bereidheid en de tijd die jullie hebben geïnvesteerd in het lezen en beoordelen van mijn proefschrift.

For my first article on the POPAC, I contacted Professor **David Edvardsson**. Thanks for reading along with the article, David. You were always friendly, positive, and supportive, which I really appreciated. I'd love to work with you again in the future.

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Over de auteur

Op 17 maart 1971 ben ik geboren in Garijp. Via Bergum, ben ik in Drachten opgegroeid in een warm gezin, waarin ik de oudste van vier kinderen ben. Mijn HAVO-diploma heb ik behaald aan het Andreas College in Drachten. Daarna heb ik de opleiding Verpleegkunde aan de Noordelijke Hogeschool Leeuwarden gevolgd.

Na mijn diplomering, in 1993, ben ik in eerste instantie blijven werken bij Maartenswouden, waar ik na mijn eerste stage een oproepcontract had gekregen. Na twee jaar kreeg ik de kans om in de Tjongerschans aan het werk te gaan op de afdeling Neurologie. Inmiddels had ik mijn wiskunde op VWO-niveau behaald en werd ik door de Tjongerschans gefaciliteerd om in deeltijd de studie Verplegingswetenschap aan de universiteit van Maastricht (in Groningen) te volgen. Mijn afstudeeronderzoek ging over de ontwikkeling van een richtlijn voor de begeleiding van familie van CVA-patiënten in de acute fase in het ziekenhuis. In de Tjongerschans heb op verschillende afdelingen gewerkt en daarna een kort uitstapje naar de thuiszorg gemaakt. In 2005 ben ik gestart met de opleiding tot dialyseverpleegkundige in het Medisch Centrum Leeuwarden. Hier studeerde ik af met een onderzoek naar de mogelijke bijdrage van de nurse practitioner aan de kwaliteit van zorg voor de (pre-)dialysepatiënten van het dialysecentrum in Leeuwarden. Na diplomering werkte ik op de high care unit en gaf ik af en toe, met veel plezier, een les op de dialyseopleiding. Vervolgens heb ik als verpleegkundig consulent palliatieve zorg geleerd hoe het is om te pionieren en samen te werken met andere organisaties, netwerken en beleidsmakers. In 2012 maakte ik de langgewenste overstap naar NHL Stenden Hogeschool als docent-onderzoeker bij de opleiding Verpleegkunde. In 2013 startte ik bij het Talmalectoraat Wonen, Welzijn en Zorg op Hoge Leeftijd.

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