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

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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: 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

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of patients' caregivers' perspectives. It also provides insights to improve nurses' training and for organizations to make the care and environment more dementia-friendly.

KEYWORDS

acute care, caregivers, challenging behaviour, dementia, experiences, hospitals, nursing care

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 judgement. The impact for patients and caregivers can be physical, psychological, social and economic (World Health Organization, 2019). The number of people with dementia is expected to double in the next 20 years (Alzheimer Europe, 2020). Most people with dementia live at home, where informal caregivers take care of them, sometimes in combination with professional caregivers (Alzheimer Europe, 2018). In the Netherlands, the number of people with dementia is approximately 260,000 (Alzheimer Europe, 2020). There are 350,000 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 h a week (Alzheimer Nederland, 2019). People with dementia have, on average, three or more somatic diseases for which they are at risk of hospital admission (Dewing & Dijk, 2016).

During the hospitalization of patients with dementia, a close caregiver's presence is essential because it makes patients feel safer and less vulnerable (Hynninen et al., 2015). 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 (Toye et al., 2019). Person-centred care, including taking into account the needs of caregivers, is seen as the best care for people with dementia (Nilsson et al., 2013; Røsvik & Rokstad, 2020). However, nurses miss many opportunities to provide person-centred care to patients with dementia, thereby undermining their needs (Fogg et al., 2018; Nilsson et al., 2019).

1.1 | 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 (Beardon et al., 2018; Røsvik & Rokstad, 2020). 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 (Bronson & Toye, 2015; Burgstaller et al., 2018). 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 (Burgstaller et al., 2018). 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 (Bronson & Toye, 2015). When caregivers feel that they are not adequately informed, they can feel ignored and neglected (Jamieson et al., 2016), 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 (Burgstaller et al., 2018). 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 (Prato et al., 2018). 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 (Sampson et al., 2014). When patients show challenging behaviour, caregivers often experience that nurses have insufficient skills to deal professionally with this behaviour (Petry et al., 2019). Finally, caregivers are not always involved in hospital discharge planning as they should be (Dewing & Dijk, 2016; Mockford, 2015).

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) (OECD, 2020). 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 (Bressan et al., 2017).

2 | THE STUDY

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 and 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.

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 (Polit & Beck, 2017). The design of the quantitative part was a descriptive cross-sectional design. The design of the qualitative part was a qualitative descriptive study (Kim et al., 2017; Polit & Beck, 2017). 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 (Noyes et al., 2019). The good reporting of a mixed-methods framework (GRAMMS) was used to report the study (Cameron et al., 2013).

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 remains unknown.

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 (Hynninen et al., 2016; Keuning-Plantinga et al., 2020). 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 (Hynninen et al., 2016; Keuning-Plantinga et al., 2020). 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 five 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

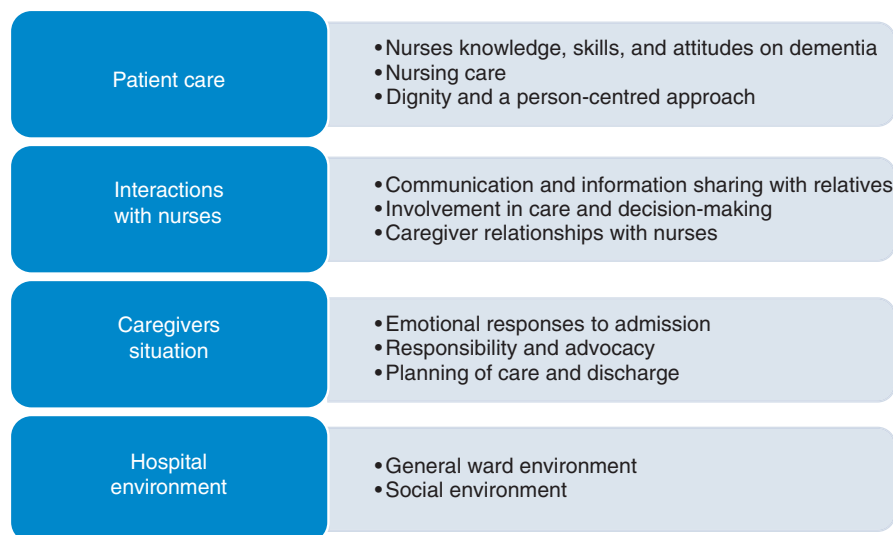


FIGURE 1 Adjusted theoretical framework of Beardon et al. (2018)

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 in. 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.

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.

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 (Nowell et al., 2017) 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 et al., (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'.

2.7 | Validity and reliability/Rigor

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 (Nowell et al., 2017).

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 S1.

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 the 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.

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' ($n = 32$).

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 to 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,

TABLE 1 Background caregivers and their person with dementia

			% (n)
Caregiver	Gender Carer (n = 129)	Female	72 (93)
		Male	28 (36)
	Level of education Caregiver (n = 120)	Primary school	0.8 (1)
		Secondary education	41.1 (26)
		Vocational education	18.3 (22)
		Higher education/University	59.2 (71)
	Employment status Caregiver (n = 122)	Retired	32 (39)
		Part-time	26.2 (32)
		Full-time (32 h or more)	18 (22)
		Jobseeker/ Incapacitated/Student	13.9 (17)
		Housewife/househusband	9.8 (12)
	Relation with person with dementia (n = 117)	Partner	38.9 (40)
		Parent	39.7 (48)
		Son or daughter	7.9 (10)
I do not care for my relative with dementia anymore ^a		7.0 (8)	
Other family or friend		8.6 (11)	
Living with person with dementia (n = 68)	Yes	38.2 (26)	
	No	61.8 (42)	
Person with dementia	Gender person with dementia (n = 111)	Female	53.2 (59)
		Male	46.8 (52)
	Living condition person with dementia (n = 118)	Living with a partner and/or children	44.5 (51)
		Nursing home	28.6 (34)
		Living alone	17.5 (21)
		Other	9.5 (12)
	Type of dementia (n = 104)	Alzheimer's dementia	52.9 (55)
		Vascular dementia	19.2 (20)
		Frontotemporal dementia	5.8 (6)
		Lewy body dementia	4.8 (5)
	Other	11.6 (11)	
	No diagnose	5.8 (6)	

^aBecause patient with dementia has died or moved to a nursing home.

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.'

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

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)

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*'.

3.4 | 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 towards 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'*.

3.5 | 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 towards 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."*

3.6 | 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 | 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.

4.1 | 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 (Burgstaller et al., 2018; Featherstone et al., 2019; Hynninen et al., 2015; Røsvik & Rokstad, 2020). 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 (Hynninen et al., 2016; Keuning-Plantinga et al., 2020). 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 (Royal College of Psychiatrists, 2019). '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 (Royal College of Psychiatrists, 2019).

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 (Burgstaller et al., 2018; Featherstone et al., 2019; Royal College of Psychiatrists, 2017, 2019; Petry et al., 2019; Reilly & Houghton, 2019).

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 (Feast et al., 2020). 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 (Toye et al., 2019).

4.2 | 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 (Beardon et al., 2018). 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 (Royal College of Psychiatrists, 2019). 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 (Pel-Littel, 2020). 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 remains unknown. However, nurses state that this does not happen often enough (Keuning-Plantinga et al., 2020).

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 (Beardon et al., 2018; Toye et al., 2019). 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 (Petry et al., 2019; Toye et al., 2019; Weitzel et al., 2011). As also described in other studies, caregivers feel that they have to take the initiative to receive information (Burgstaller et al., 2018; Clissett et al., 2013; Hynninen et al., 2015). 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 (Carers Trust, 2016). 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 (Royal College of Psychiatrists, 2019).

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.

4.3 | Caregivers' situation

Rooming-in and unrestricted visiting times are part of the Dutch guidelines for the care of patients with dementia (Nederlandse Vereniging voor Klinische Geriatrie, 2015). 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 (Burgstaller et al., 2018). 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 (Hall et al., 2019).

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 (Beardon et al., 2018).

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 (Beardon et al., 2018). 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 (Burgstaller et al., 2018; Mockford, 2015).

4.4 | 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 (Hung et al., 2017).

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 (Prato et al., 2018). 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 (Department of Health, 2015).

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 the advantages and disadvantages of a separate ward for care for patients with dementia.

4.5 | 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 et al., (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 towards other patients (13%). The most plausible explanation is that this is because family caregivers were not always present. Because the data were 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 are 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 were collected before COVID-19 became actual in the hospitals. We expect the findings to remain relevant.

5 | 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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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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DATA AVAILABILITY STATEMENT

Data available on request from the authors

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