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Nurse Experience and Challenges of Dementia Care in Acute Settings: A Qualitative Study

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Abstract:

Background: Acute hospital admission rates for people living with dementia are far higher than those without it. Dementia care in acute settings has its own challenges.

Aim: The study aims to explore the experience and challenges for nurses caring for people living with dementia in an acute setting.

Method: This qualitative research used semi-structure interviews. Eight registered nurses working in an acute NHS Trust discussed their experiences.

Findings: Three main themes were developed from the thematic analysis: attributes of dementia care; planning care effectively; and education and training needs for staff. Participants highlighted the importance of person-centred care and the difficulties of providing this due to staff shortages which resulted frustration, exhaustion, upset and stress.

Conclusion: Additional time is needed for nurses to improve skills and training.

Family and carer involvement is important to provide good care for people living with dementia.

Key Words: dementia, acute care, nursing, semi-structured interviews, qualitative

Introduction

Dementia is a general term used to describe an impaired ability to think, remember and make decisions which affect daily activities. It is progressive with three stages including mild, moderate, and severe. Patients with dementia can often experience

significant changes in mood, which can impact on their language and behaviour. Vision may be affected and can be a result of severe nutritional deficiencies (Alzheimers Society, 2014). Dementia is an urgent health and social care challenge costing the UK £25 billion in 2021 (Royal Collage of Nursing RCN 2023). In the UK dementia currently affects 944,000 individuals, with this number predicted to rise to over 1 million by 2030 and over 1.6 million by 2050 (Public Health England 2021 and RCN 2023). Dementia's prevalence is increasing, resulting in more admissions to acute hospital settings. Acute hospital admission rates for people living with dementia requiring treatment for comorbidities have increased to 1.5 times compared to those patients without dementia (Fukuda et al 2015). It has been reported that the readmission rate is 7-35% and 23% of people living with dementia who experience long term hospitalisation are in acute care settings for over 180 days which impacts upon their health and recovery (Fukuda et al 2015). Alzheimer Europe (2023) published its 10 year national dementia strategy plan in Scotland's *Everyone's Story*, which examined how dementia impacts everyone regardless of gender, age, ethnicity, or disability and in all healthcare settings. This creates a requirement to listen and respond to the needs of people from diverse backgrounds and communities. The vision of the nurse's role in caring for people living with dementia is primarily an interpersonal and social nursing model that incorporates person-centred care. Such care considers the unique experiences of the patient along with creating and maintaining a relationship with that patient and their family (WHO 2022).

The complexities of delivering dementia care in an acute setting can impact upon nurses. It is vital for nurses to provide individualised patient care. Nurses who care for people living with dementia in acute settings have reported several challenges. These range from staff and patient safety to stress and frustration caused by insufficient

resources, opportunities, and skills (Fukuda et al 2015, Hartung et al 2021, Kang and Hur 2021, Cevik et al 2022). Additionally, a lack of knowledge about the complex needs of people living with dementia often causes mental exhaustion and stress for nurses (Kang and Hur 2021, Cevik et al 2022). Baumbusch et al (2015) highlight factors that affect nurses' abilities to care for older patients with complex needs and found that hospitals lack the education and environmental support to enable care at the level nurses would wish to provide. Stress has been highlighted as a factor by nurses caring for older people which impacts upon job satisfaction leading to problems around the recruitment and retention of registered nurses (El-Hneiti et al 2018). Existing literature about people living with dementia and the healthcare professionals who care for them emphasises the need for further research on nurse education, training, and knowledge regarding the care of patients with dementia (Kang and Hur 2021, Hartung et al 2021).

Method

Design and setting

This qualitative study aims to explore the experiences and challenges of registered nurses caring for people living with dementia in an acute setting. A qualitative approach was appropriate due to the nature of the enquiry, which focuses on registered nurses challenges of caring for people living with dementia in an acute setting. The study setting took place in an older people's acute ward at a local National Health Service Trust in outer London with 136 beds. The patient group included older people with acute conditions and co-morbidities with complex needs as well as patients with dementia. Both researchers have nursing backgrounds and contributed equally to the research design and analysis of the findings.

Participants

Participants were permanent registered ward nurses. Newly qualified, students, agency, bank nurses and other health care professionals were excluded from this study. Although agency and bank nurses are registered, they are not permanent ward staff. Permission to undertake the study was obtained from a matron in the Trust. Posters were created and placed within the Trust to advertise the study with these outlining the aim of the study, inclusion and exclusion criteria and researcher contact details. An email invitation including a participant information sheet and consent form were sent to all registered nurses (Bands 5-8a) in the older people's wards totalling 120 invitees. A total of 8 nurses volunteered to be interviewed.

Data Collection

Data were collected by semi-structured interviews as these allow for open-ended responses from participants eliciting more in-depth information. The questions were developed using the literature and informal conversations with lead nurses in the area of older people's care. The semi-structured interviews helped participants to have exploratory conversations about the topic. A participant information sheet explaining the aim of conducting the study and how the findings would be disseminated was provided to all the participants 1 week before the interviews. The participants signed a consent form before the interview. The interviews took approximately 45 minutes and were digitally recorded by author DE at a mutually agreed time in a private office in the hospital between April and May 2023. Interview questions covered care delivery experiences in the Trust, such as 'What are the challenges when caring for patients with dementia?' and 'What support do you receive from the Trust?'

Data Analysis

The authors selected the well established scientifically descriptive approach to thematic analysis (Braun and Clarke 2022). Thematic analysis is a useful method for examining participant experiences and perceptions by asking open-ended questions to identify themes and thoughts on the topic. It was important to ensure the objectivity, reliability and accuracy of the coding along with minimising any potential researcher bias. The literature on nurse experience and challenges in dementia care clearly identifies a number of issues and concerns. In these studies the nurse meaning and use of language and allied concepts is well defined by the context care is delivered in and there are few (if any) latent or implicit meanings or concepts (Braun and Clarke 2023). The data were analysed using the Braun and Clarke (2006 and 2022) six stage thematic approach (Table 1). Such themes were identified and grouped together in preparation for deeper analysis.

Table 1: Data analysis using six stages of thematic framework (Braun and Clarke, 2006 and 2022)

| | |
|---|---|
| Stage 1. Data familiarisation | Data were reviewed and transcripts were read and re-read. The audio recordings were checked for errors and adjusted accordingly. |
| Stage 2. Initial code generating | Initial codes were generated by both authors separately and then discussed to agree on the division of codes into recurring themes. |

| | |
|---|--|
| | |
| Stage 3. Generating Initial themes | The initial themes were generated using labelled codes. Broader umbrella themes were identified. |
| Stage 4. Reviewing the themes | The themes were reviewed to create the possible main themes and sub-themes. |
| Stage 5. Defining and naming the themes | The themes were defined and named. |
| Stage 6. Producing and writing up the report | The report was produced including writing up the findings of the research study to create the final paper. |

To address issues of rigour and trustworthiness the coding framework in Table 1 both authors separately carried out coding and then discussed this to reach agreement on the codes. Author discussion was used to reach a consensus on themes and subthemes prior to the last stage of data analysis.

Ethical considerations

Ethical approval was obtained from the University Ethics Committee (reference NWSC2023MAY01) as well as from the NHS. Prior to participating in the research all the participants were given a comprehensive participant information sheet, which clearly stated the rationale for the study and included occupational health information for staff wellbeing. Sufficient time was given to make an informed decision about

participation. There were no financial incentives for participants in this research. Participation was voluntary and participants had the right to withdraw from the study without giving any reason. A consent form was signed by each participant before the interview and they were told they could withdraw their data at any time without giving any reason. Given the risk of potential upset to participants it was made clear that there was an option to stop the interview and be debriefed. Confidentiality was maintained by allocating numbers to each of the participants.

Findings

Three main themes and five sub-themes emerged from the data. The main themes were: (1) attributes of dementia care (2) planning care effectively (3) staff training and education needs (Table 2). Participant demographics were reported in Table 3.

Table 2 : Themes and Sub-themes

| Theme 1: Attributes of Dementia Care | Theme 2: Planning care effectively | Theme 3: Education and training needs for staff |
|--|---------------------------------------|--|
| Dementia caregiving | Operational factors | |
| Perceived difficulties in care provision | Staff shortage | |
| Participant feeling | | |

Table 3: Participant Demographics

| Participant Identification number | Age | Gender | Grade | Education Level | Experience in older people's wards |
|-----------------------------------|-----|--------|-------|-----------------|------------------------------------|
| 1 | 29 | Female | 6 | Degree | 7 years |
| 2 | 50 | Female | 5 | Degree | 9 years |
| 3 | 30 | Female | 6 | Degree | 12 years |
| 4 | 20 | Female | 5 | Degree | 18 months |
| 5 | 30 | Female | 5 | Degree | 4 years |
| 6 | 40 | Female | 7 | Degree | 22 years |
| 7 | 50 | Male | 8a | Masters | 22 years |
| 8 | 55 | Female | 7 | Degree | 28 years |

Attribute of Dementia Care

Dementia caregiving

The participants highlighted their interpretations of nursing roles in dementia care. Some participants focused on the challenges of caring for people living with dementia whilst others talked about the care needs.

“We care for patients with dementia who are elderly and need to monitor their behaviour. Checking for any underlying condition that may affect the challenges whilst care is being given.” Participant 2: Band 5.

Participants stated that knowing the patients helps to provide care.

“Support from my colleagues as sometimes they know the patient well and can help.”

Participant 1: Band 6.

“We need to know their diet, swallow assessment from the dietician to know what they can eat and encourage them to eat”. Participant 4: Band 5.

Patient safety and being a patient advocate were mentioned by participants.

“To ensure the patient is safe being in a new environment, being the patients advocate because they might be confused, observe them and put in measures to prevent falls on the ward”. Participant 5: Band 5

“To ensure patient is safe, being the patient advocate.” Participant 3: Band 6.

The participants had good insights from being registered nurses caring for people living with dementia and were able to recognise the patient care needs and behaviour challenges which can occur whilst giving care in an acute setting.

Perceived difficulties in care provision

All participants described behaviour that challenges (such as aggression) which is disruptive when caring for people living with dementia. However, they also mentioned being an advocate for their patients.

“It varies when it comes to people living with dementia, presenting with chronic confusion not being told how severe their confusion is. Showing aggression or both having physical and mental challenges.” Participant 6: Band 7.

A participant recalls being initially scared to be caring for people living with dementia.

“Being scary as a previous cardiac nurse not knowing how to handle them, how to intervene due to the challenges.” Participant 7: Band 8a.

“Caring for them is challenging having 2-3 people living with dementia on a shift is difficult to manage.” Participant 4: Band 5.

A participant mentioned the difficulty of caring for people living with dementia and that it could impact upon other patients in their care.

“Um ... Feeling I am running out of time other patients get compromised care that makes me feel stressed with the ward being very busy.” Participant 5: Band 5.

A participant expressed the challenges of being short staffed when caring for people living with dementia.

“Very challenging, disturbing other patients, not taking medications and being aggressive at times especially when we don’t have enough staff.” Participant 2: Band 5.

Some participants emphasised individual differences and providing person-centred care as a challenge.

“Everyone has different symptoms, repeating themselves, thoughts are not in the present. It is important to debrief as it is physically and mentally exhausting. Caring for the same patient every day and the challenges.” Participant 8: Band 7.

Participant feelings

Almost all participants expressed negative feelings such as frustration, exhaustion, and upset, which were mostly due to being unable to give patients the care they needed.

“Frustration not being able to give care, feeling exhaustion physically and mental.”

Participant 6: Band 7.

“Upset not being able to help them.” Participant 1: Band 6.

“Exhausted needing more time with them to make them ok, its overwhelming.”

Participant 5: Band 5.

“Not happy as it does not allow you to care as you want to treat and make them medically fit.” Participant 3: Band 6.

Two participants identified the benefits of a positive approach to delivering care.

“Positive by doing the right thing to deliver the right approach for better engagement with them.” Participant 7: Band 8a.

“Exhausting, if you manage to resolve the challenges this is very satisfying in my job helping someone physically and mentally.” Participant 8: Band 7.

Planning Care Effectively

Operational Factors

Participants highlighted some operational factors which raised challenges such as the number of patients, risk assessments and transferring patients to other wards out of

hours. A participant expressed the importance of having a person who knows what the dementia patient needs, when they are sun downing.

“Risk assessments need to be completed early for support that is needed to provide patient care if they are a sun-downing they need a person with them knowing their needs.” Participant 8: Band 7.

A participant expressed patient moves out of hours that create challenges.

“Moving patients to the wards via the bed team, late in the afternoon / evenings causes challenges, better to move when the sun is up.” Participant 7: Band 8a.

“Feeling I am running out of time other patients get compromised care that makes me feel stressed with the ward being very busy.” Participant 5: Band 5.

A participant expressed the difficulty of having lots of people living with dementia to care for.

“It can be difficult, having lots of people living with dementia all at once on the ward to care for their needs and having support from my colleagues as sometimes they know the patient well and can help.” Participant 1: Band 6.

Another participant stated knowing the patient routine and working to this would be beneficial.

“It would be great if we knew the patient’s routine and to be able to work around their routine every shift and finding out their likes and dislikes to help us to provide care.” Participant 4: Band 5.

One participant encouraged the relatives of people living with dementia to become involved in their care.

“Sometimes we encourage their relatives to help us to provide care.” Participant 2: Band 5.

Another participant stated the need for extra support when there is a shortage of staff as this can impact on people living with dementia and delay discharge.

“We need extra support when we are short- staffed as it has impacted upon not being able to discharge properly leading to a failed discharge if we don’t get it right leading to readmitting our dementia patient.” Participant 3: Band 6.

Staff shortage

Participants stressed that being short staffed was a challenge for providing effective care and ensuring patient safety. They highlighted that additional staff would enable one-to-one care with people living with dementia, which would benefit patients and staff.

“Having enough staff to help monitor the dementia patient and having the dementia care team, there is not enough of them.” Participant 3: Band 6.

“More staff to help to supervise as it is patient safety to reduce falls, making sure that we have enough staff on the ground so we can have the one-to-one care.” Participant 4: Band 5.

A participant highlighted that staff allocation in an acute setting needs to be evaluated and having people living with dementia together in a bay of 4 beds with 1 registered nurse was a challenge.

“Splitting the people living with dementia around on the ward, not having them altogether in a bay of four beds and to have different nurses allocated to them, as if I have three people living with dementia in a bay together to care for it is too much for me.” Participant 2: Band 5.

The importance of documentation when caring for people living with dementia was emphasised by one of the participants.

“We cannot prevent people living with dementia coming through the door, we do have an aging population it is important to identify and do your assessment, observation, and engagement documentation to be able to provide care.” Participant 8: Band 7.

Another participant that recognised family were important as they knew the dementia patient better than the nurses and having their support helps patient management.

“We need more family, carers to help with one-to-one care to help us learn how to manage better.” Participant 1: Band 5.

Education and Training Needs for Staff

All participants had received their mandatory training, annual dementia training and Mental Capacity Assessment and Deprivation of Liberty Safeguards training. However, they highlighted the need for training and education about dementia care in an acute setting. One of the participants stated that they felt they needed extra training

about the skills required to care for people living with dementia rather than just being provided with knowledge about this.

“Dementia care, acute care, deteriorating patient study day and falls training are needed.” Participant 3: Band 6.

A participant expressed a training need around understanding behavioural differences in dementia types.

“Frailty course, training in terms of dementia care equipped me to have an understanding and acknowledge of dementia. Understanding the different challenges that are faced with what type of dementia and care requirements are needed.” Participant 7: Band 8a.

A participant stated their training was insufficient to provide the level of care they wished to provide.

“We need to get some additional training or some study days to explain how to care having a yearly update on dementia does not feel like we have enough training.” Participant 1: Band 6.

In summary, the participants highlighted the need for training to reduce the challenges through understanding behavioural differences resulting from different types of dementia.

Discussion

Participants in the study had good insight into their role in dementia care through recognising patient needs and behavioural challenges. This aligns with a study which

defines the role of the dementia nurse as understanding dementia through education and training while providing person-centred care (Abbott et al 2022). Person-centred care is identified as the best approach to caring for people living with dementia as it can create positive impacts on both the patient and healthcare professional (Fazio et al 2018). Enabling nursing staff to provide person-centred care while building relationships is crucial when caring for people living with dementia (Alzheimers Society, 2022). Nurses in the study highlighted the importance of person-centred care and the difficulties of providing this due to staff shortages, which resulted in negative feelings such as frustration, exhaustion, upset and stress. These findings are similar to the study by Cevik et al (2022) which indicated staff shortages creates barriers to care. Several studies identified nurses could not meet patient needs due to inadequate staffing, which compromised patient safety (Fukuda et al 2015, Houghton et al 2016). In our study staff shortages were linked to nurses not having enough time to provide the person-centred care that people living with dementia needed. Staffing in acute medical settings should be increased to enable good care for patients with and without dementia as people living with dementia have additional care demands (Yous et al 2019). It is important for people living with dementia to have familiar nurses and continuity of care. The challenges around the staff shortages are well known, as nurses are less keen to work in older adult settings where most people are living with dementia. As a result, recruiting and retaining staff is essential for dementia care (Care Quality Commission 2022, Vasquez et al 2023). Dementia symptoms are elevated in acute care environments causing people living with dementia to display behaviour that challenges (such as aggression and disorderly conduct) resulting in nurses requiring more time and skills to cope with care demands. All study participants described behaviour that challenges and the problem of addressing it. A qualitative study by

Yous et al (2019) examined nurse perceptions of caring for older adults with dementia with 10 registered nurses and 5 allied health professionals in an acute medical setting. The findings showed that nurses find responsive behaviour, such as wandering, yelling, hitting and restlessness challenging and dealing with it needs additional time and skills. There are no prescribed standards for dementia education and training in the UK but there is a dementia training standards framework (Skills for Health 2015). This framework describes the knowledge and skills that are required to care for people living with dementia. Our study participants identified that they had insufficient knowledge, skills and training to provide care for people living with dementia and needed additional time as well as family and carer involvement to provide good care for people living with dementia. This finding is linked to a qualitative study by Baumbusch et al (2015) which explored 41 registered nurses' experience through 6 focus groups examining the factors that influence nurse readiness to provide care for older people in hospital. These findings show that nurses required a new set of skills for hospital care for older people with complex health needs. They also required additional time and the involvement of families in providing holistic person-centred care. Nurses in acute care facilities often find it challenging to care for patients with dementia as these environments are busy and unfamiliar to patients (Ross et al 2014). Education needs for dementia nurses is a consistent theme in several studies (Yous et al 2019, Dookhy and Daly 2021, Hartung et al 2021). Training should target person-centred holistic care in order to be effective in helping nurses in hospitals care for people living with dementia (Surr et al 2016). Developing dementia specific education training to enhance nurse knowledge and skills, focusing on responsive behaviours and stress management is both necessary and beneficial (Dahlke et al 2018, El-Hneiti et al 2018, Dookhy and Daly 2021). A study by Smith et al (2019) revealed that training

packages were required in dementia awareness, interaction and behaviour in dementia care, communication, and person-centred care. These are skills nurses need to develop in assessing patients with cognitive impairments. Fry et al.'s (2016) study explored nurses working in emergency departments and showed that nurses find it challenging to assess and manage pain in people living with dementia using a pain assessment tool. These findings are similar to those in this study.

Developing dementia friendly health and social care environments helps support people living with dementia by reducing their confusion, anxiety, and feelings of isolation (DOH 2015). People living with dementia should receive personalised items and pictures whilst in acute hospital settings and families should be welcomed because admission to a hospital can be frightening for people with dementia (Rosvik and Rokstad 2020). A cross-sectional mixed method study by Ernest et al (2020) investigated care provision with cognitively impaired patients by recruiting 339 health professionals. The study found that they were enthusiastic about providing person-centred care for these patients, but felt constricted by being in an environment, which was not appealing to these patients. That finding is linked to this study, as participants identified the acute setting environment as not being organised for dementia care, as it was noisy and busy saw people living with dementia being transferred to other wards late in the evenings. The institutional timetables of routines in hospitals of mealtimes, visiting times, medication rounds, and personal care times shaped nursing staff and dementia patient experiences and triggered dementia patient resistance to bedside care (Featherstone et al 2019). Participants were clear that family and carers providing information about patients and supporting their care improved outcomes. There is evidence that training families and carers to recognise acute illness or carry out

assessments may prevent hospital admission of people living with dementia (Steis et al 2019).

Study Strengths and Limitations

The study strengths were reports of the challenges of registered nurses caring for people living with dementia. Capturing these issues is important for improving care. Interview trustworthiness was ensured by having the two authors separately carrying out the coding and then discussed this to reach agreement on the codes. The limitation of the study was that it was conducted in one Trust.

Implications for Practice

The staff wellbeing provision in NHS Trusts need to consider offering additional support to nurses, which should include free or discounted holistic therapy sessions, with some of these covering mindfulness meditation. Nurses caring for people living with dementia should have a dementia champion and a dementia link nurse or manager they can receive support from (Gibson et al 2021). Support from specialist nurses and managers would also enhance the knowledge and skills of registered nurses caring for people living with dementia. Dementia training for registered nurses must cover knowledge which is specific to different types of dementia because symptoms vary according to dementia type (Takeuchi et al 2020). The training should also focus on person-centred dementia care, which is effective in helping nursing staff care for patients (Surr et al 2016). Nurses who have completed a course on dementia are more likely to understand and how to defuse challenges than those without this training (Keuning-Plantinga et al 2020). Training all registered nurses about dementia care would be desirable considering the aging UK population. Involving families and

carers was highlighted by participants in helping people living with dementia to receive holistic person-centred care. This would improve understanding of patient needs and ensure care is tailored to their needs and preferences (Alzheimer's Society 2014).

Conclusion

Registered nurses emphasised the challenges of caring for people living with dementia in acute settings and how these pressures resulted in feelings of being stressed, frustrated and overwhelmed. Adequate staffing and an appropriate nurse to patient ratio is crucial for addressing this issue. Nurses indicated a need for education and training to enhance their knowledge and skills for caring for people living with dementia. Dementia person-centred holistic care is crucial with one-to-one care involving families and carers.

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