Educating nursing staff involved in the provision of dementia care

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Evidence from several studies suggests that general nurses and acute health care staff do not always have an adequate understanding of the needs of people with dementia. This has major implications for the quality of care that is delivered and the well-being of people with dementia and a concurrent medical or surgical condition. This article describes how the creation of the role of nurse educator in dementia care helped to address this problem in one NHS trust.

Dementia is a clinical syndrome evidenced through a set of symptoms that classically include a decline in memory and thinking – present for six months or more – of a degree sufficient to impair functioning in daily living (World Health Organization, 1993). From the onset the individual experiences difficulty with communication or in the completion of everyday activities such as managing finances, shopping or food preparation. As the disease progresses, basic functions such as mobility, continence, sleeping and personal care may also be affected. Individuals may experience mental health problems, such as visual hallucinations or depression, and may develop physical problems such as tremor, stiffness and slowness of movement.

It is conservatively estimated that 700,000 people in the UK have dementia. The incidence of dementia increases with age and is thought to double every five to six years after the age of 65. The service provision to people with dementia in England and Wales costs over £1bn annually in health and social care (Patel and Knapp, 1998). Demographic studies predict that the aged population will steadily increase over the course of this century and the number of people with dementia in the UK will increase to almost one million by 2020 (Alzheimer’s Disease International, 1999).

Dementia and hospital admission

People with dementia aged 75 years and older are highly vulnerable to acute physical illness, accidents and falls, all of which may lead to general hospital admission. The circumstances precipitating admission are often traumatic for people with dementia, resulting in severe stress and feelings of insecurity. The person’s inability to articulate such feelings verbally can lead to changes in his or her behaviour that are generally regarded as ‘problematic’ by nursing staff.

Challenging behaviour is commonly associated with frustration, disorientation, distress or anxiety and is particularly apparent when the person with dementia is placed in an unfamiliar environment (Alzheimer’s Scotland, 2003). The person needs to communicate this distress to others and often conveys the message through a change in behaviour. The immediate management of this behaviour often results in the overuse of neuroleptic medication, which can have detrimental effects on the person’s physical and mental well-being.

These unwanted effects, which can include drowsiness, increased confusion and a risk of falls, in addition to the challenging behaviour, may result in that person remaining in hospital for prolonged periods of time, probably moving between different wards as the problem is pushed from one department to another (Packer, 2000). Delayed discharge invariably occurs and the pressure to discharge may lead to inappropriate placement in the community resulting in readmission, which in turn leads to further disorientation.

As a result of this pattern, care staff begin to distance themselves from the person with dementia who requires their care. In such a culture simply sitting and talking to patients is actively discouraged in favour of completing

![FIG 1. PRINCIPAL INTERVENTIONS MADE BY NURSE EDUCATORS](https://www.nursingtimes.net)
Mrs Blue, a lady with vascular dementia, was admitted following a stroke. This resulted in visual and coordination problems, inability to weight bear and loss of speech. When staff approached her she was hostile. She spat and lashed out at them and was resistant to any intervention. She frequently made loud, incoherent noises and refused to allow staff to help her to eat, only eating with her hands, which often resulted in spillages on the floor and on herself. Staff were reluctant to clean her up as this would often result in them being physically abused. The nursing team reported feelings of despair, inadequacy, helplessness, anger and frustration towards Mrs Blue. Most had started to avoid her, and interaction took place only when absolutely necessary. There was a serious risk of care breaking down altogether.

The nurse educator challenged the team to consider how Mrs Blue’s visual impairment, misidentification of objects, coordination deficits and aphasia, plus her long-standing memory loss, were impacting on her ability to function, to independently take medication, eat, and make her needs known verbally. The nurse educator also observed that Mrs Blue was restless and agitated when she sat out of bed in her chair and considered the correlation that this may have with Mrs Blue’s shouting behaviour. When asked about this Mrs Blue indicated her agreement to the suggestion that she may be in discomfort or pain. However, the staff felt this could not be the case as they left regular analgesia in front of her, which she did not take.

Prior to her stroke Mrs Blue was a very independent woman, albeit with memory problems, and nursing actions such as attempting to feed her and take over her care could act as reminders of her lack of competence. It was clear that Mrs Blue felt happier feeding herself, even if this resulted in eating the food with her fingers. Alternative options to address the potential of maintaining her independence, such as finger foods, toast, pizza, sandwiches, and so on, were explored with the nursing team.

Attitudes of staff were also discussed with them to highlight how their inadvertent negative attitudes towards Mrs Blue could reinforce her behaviour. A care plan was developed, which encouraged nurses to interact with Mrs Blue, rather than avoid her. They were encouraged do this outside of delivering care tasks as it would help to develop a rapport with her and gain her trust and confidence. This was initially difficult due to Mrs Blue’s hostility, but with support and perseverance they were able to develop a more positive and calm approach towards her. She moved from the side room into a more stimulating part of the ward and the increase in frequency and quality of interaction had the desired effect resulting in a calmer, more relaxed Mrs Blue, who was subsequently able to establish positive relationships with a number of staff members.

non-patient related tasks (Bayer and Powell, 1999). The smooth running of the ward takes precedence over the needs of those being cared for. This corresponds with early findings from an unpublished study in Leeds of general nurses caring for people with dementia in an acute setting. In this study one nurse said that, due to her lack of understanding in dementia care, she found it easier to put away the laundry than to communicate with the patient.

Communication is fundamental to human existence and being deprived of it can lead to social isolation, depression, despair and disintegration of personality (Bayer and Powell, 1999). Meaningful communication is a prerequisite of person-centred dementia care and its absence can lead not only to poor quality of life, but also to a state of malignant social psychology as defined by Kitwood (1997). Such a state is one in which staff inadvertently create an environment that damages or diminishes the essence of personhood and nurtures the development of unmet needs. As a consequence, patients’ psychological needs are overlooked, communication becomes a low priority and care becomes a physical exercise dominated by task-orientated approaches.

**Recognising an unmet need**

In 1999 a survey of 300 nurses was undertaken at South Manchester University Hospitals NHS Trust to examine the unmet needs of both people with dementia and those caring for them in an acute setting. The survey revealed difficulties in the provision of effective care for people with dementia.

Results showed that 77 per cent of nurses experienced considerable stress in trying to respond to challenging behaviour, while 91 per cent wanted support from the specialist mental health services for older people. This is consistent with the Not Because They are Old document (Health Advisory Service, 2000), which highlights difficulties in accessing psychiatric help on acute wards when staff have specific concerns regarding the management of confused older people.

**A new nurse role**

In August 2001, South Manchester University Hospitals NHS Trust, in collaboration with Manchester Mental Health Partnership, introduced the role of nurse educator in dementia care. The aim was to improve quality of care by reducing stress among staff who, due to lack of knowledge of dementia, were finding it increasingly difficult to care for these patients.

The post was also intended to be the first step in the provision of integrated services for people with dementia in a general hospital setting. It was therefore developed within a framework influenced by national reports and guidelines such as the National Service Framework for Older People (Department of Health, 2001). Two years’ funding was provided by the Greater Manchester East Education and Training Consortium. Further funding for a final year was provided by the Greater Manchester Workforce Development Confederation.

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The G-grade nursing post operates from Monday to Friday within office hours, although a degree of flexibility is essential. The nurse educator is employed by the acute trust with clinical supervision from the specialist mental health services. The aims of the post are to support health care staff in a non-mental health setting through situation-based education so that they:
- Respond appropriately to the person with dementia and any challenging behaviour;
- Improve the quality of care given to the person with dementia on acute wards through the use of person-centred approaches;
- Promote positive changes in personal and organisational culture evidenced through changing attitudes towards the person with dementia or other mental health problems;
- Acquire new skills in the care of the person who has dementia.

The initial functions of the role include: taking referrals from staff in acute areas who are experiencing difficulties in the delivery of care to the person with dementia; leading the nursing assessment of mental health problems; working with care staff to develop a nursing care plan that is person-centred, goal-orientated and evidence-based; and acting as a role model in the delivery of the prescribed nursing interventions.

The educational remit is aimed at increasing the skills, knowledge and confidence of the acute staff and is offered to encourage health care workers to consider their attitudes towards mental health, challenging behaviour and dementia.

**Training provision**

A basic aim for this project has been to support nurses presented with real challenges within the workplace. A training package has been devised and delivered, which complements previous learning while also acknowledging the potential limitations of previous education with respect to dementia care. The package not only takes place in the form of a traditional didactic approach but also promotes working on the wards delivering situation-based education and role modelling.

Rather than telling the team how to do something the nurse educator works with teams who are delivering care to patients with challenging behaviour. This presents a perfect opportunity to put theory into practice and to develop the skills required to implement person-centred nursing care.

Taking a lead on certain aspects of care planning is also important in order for the team to become familiar with prescribing care that empowers the patient and focuses on strengths, abilities and needs rather than problems and difficulties. The benefits of situation-based education are illustrated in a case study (Box 1; p35).

**Evaluation strategy**

An evaluation framework was drawn up to measure the effectiveness of implementing the role and consists of:
- Patient data, demographic characteristics;
- Data collection of the number of referrals received, number of visits entailed, interventions required, nursing actions, types of interventions, outcomes of interventions and types of challenging behaviour exhibited;
- A series of focus groups, which involve nurses and service users.

**Results of evaluation**

**Demographics**

Of the 375 referrals received, 63 per cent were female (n=235) and 37 per cent were male (n=140). The age ranged from 44 to 100 with the mean age at referral being 83 years. People over the age of 80 accounted for 57 per cent (n=212) of referrals. Some 60 per cent of people referred (n=225) had a pre-existing diagnosis of a dementing illness, 33 per cent (n=125) acquired a diagnosis of dementia when seen by the nurse educator and the remaining 7 per cent (n=25) did not have dementia.
Challenging behaviour underpinned a significant number of referrals (59 per cent) and was second only to concerns regarding the patient’s cognitive state, which fuelled 64 per cent of referrals. As the post became more established a more diverse variety of referral triggers were identified (Fig 2). The range of challenging behaviour underpinning referral encompassed a whole spectrum of behaviours and included agitation, aggression, resistance to nursing intervention, ‘wandering’, refusing to take food or fluids and withdrawn behaviour probably reflecting a depressive illness.

Outcomes

The principal target for the nurse educator has been to improve the quality of care delivered to people with dementia by supporting and educating those nurses who have the responsibility for delivering care. The impact of this pilot was evaluated through a series of focus groups involving members of staff and service users.

A total of 172 staff members were consulted regarding the impact of formal education. Of those attending these formal sessions 88 per cent (n=152) reported a greater understanding of dementia and the needs of those affected by it. Furthermore, 95 per cent (n=164) reported increased confidence in their ability to deliver person-centred nursing care to people with dementia.

The 100 nurses who had been involved in situation-based education sessions were consulted regarding its impact on their knowledge and skills in respect of dementia care. Some 75 per cent reported a significant increase in their knowledge base regarding the presentation of challenging behaviour in dementia, while 65 per cent reported a greater degree of confidence in delivering care to people with challenging behaviour.

Nurses were asked to write, if they wished, a case study highlighting the impact of the nurse educator role. Such an impact is explored in a case study (Box 2; left).

As part of the evaluation, 52 relatives of patients with dementia, who had contact with the nurse educator, were approached at random and consulted about the impact of the service. Prior to involvement from the nurse educator most (84 per cent) were concerned that their relatives’ mental health needs were not being met while in hospital, and a high number (67 per cent) were so concerned that they had considered making an official complaint about the overall standard of care.

Following the involvement of the nurse educator, 80 per cent (n=42) of relatives stated that the quality of care had improved significantly and that they had benefited from the service (Fig 3). However, 10 relatives (19 per cent) perceived no evident improvement and seven (13 per cent) subsequently made either a formal or informal complaint about the standard of care.

Conclusion

Living with dementia is never easy and when those affected need admission to hospital due to physical illness or trauma the inherent difficulties will always be evident. Nurses have the power to make admission to the general hospital a positive experience, or a thoroughly miserable one. The high prevalence of clinical depression among older inpatients suggests that too often it is the latter experience that predominates.

This need not be the case and this pilot, introducing a nurse with specialist skills in dementia care, has shown how ward teams can be supported to deliver the high quality of care they would wish to, especially to individuals who previously would be seen as challenging. This raises the question of whether such posts should be more widespread throughout acute hospitals. Current evidence leans towards supporting such initiatives.

REFERENCES


