Nursing and Midwifery Council review of pre-registration education: report on the experiences and views of people with dementia and carers

March/April 2010

To inform Alzheimer’s Society’s response to the Nursing and Midwifery Council’s review of pre-registration nursing education, we ran three focus groups. These were attended by people with dementia and carers and were facilitated by Alzheimer’s Society.

1. Introduction

1.1 Dementia and its prevalence

1.1.1 What is dementia?
Dementia is a serious degenerative and progressive condition. The term dementia is used to describe a number of different diseases that affect the brain, with Alzheimer’s disease being the most common (62%). The symptoms of dementia can change over time:
- Symptoms in the early stages can include some memory loss, mood changes, and people being less willing to be involved in hobbies.
- Symptoms in the later stages can include severe memory loss (confusion about time and place), severe communication problems (for example, loss of speech) and physical symptoms (for example, loss of mobility).

The different types of dementia affect individual people differently and not everyone experiences all symptoms in the same way. As one carer has described it: ‘Once you’ve met one person with dementia, you’ve met one person with dementia’.

1.1.2 How many people have dementia?
- An Alzheimer’s Society report\(^1\) states that there are currently 750,000 people in the UK with dementia and this is forecast to increase to over a million by 2025. Over 16,000 people with dementia under 65 have dementia in the UK.
- One in three people over 65 will end their lives with a form of dementia.\(^{ii}\)
- Only one third of people with dementia receive a formal diagnosis.\(^{iii}\)
1.2. The health and social care challenge of dementia

1.2.1 People with dementia are significant users of health and social care services

- Two thirds of people with dementia live in the community and one third of people with dementia live in care homes (Alzheimer’s Society, 2007).
- Two thirds of care home residents have a form of dementia (Alzheimer’s Society, 2007), however, only 28% of care home places are registered to provide specialist dementia care (under the current registration system).
- People with dementia over 65 years of age occupy up to one quarter of general hospital beds at any one time and are admitted to hospital for a range of reasons. Counting the cost (2009) found that 97% of nurses surveyed said that they worked with people with dementia.
- Nearly 1/3 of people over 85 dying with cancer, circulatory or respiratory disease also have dementia.
- People with dementia and their carers are therefore significant users of mainstream health and social care services. Supporting people with dementia is a core role of the health and social care workforce, including the work of all nurses.

1.2.2 Unacceptable variation in the quality of dementia care provided by an unskilled workforce who are desperate for training

Despite working with people with dementia being a core role of the health and social care workforce, a series of reports have shown that services are struggling to deliver good quality dementia care, with the lack of an informed and effective workforce as a key issue.

For example, Counting the cost (2009) explored the quality of dementia care provided in general hospitals and surveyed people with dementia, carers and nursing staff. It was found that people with dementia, carers and nurses were being let down by a lack of training in dementia care. All felt that training is desperately needed.

- Only 12% of the nurses who responded to the survey said that they had had enough pre-registration training in dementia.
- 76% of nurse mangers said that their nursing staff not having pre-registration training was a key challenge in providing good dementia care on the ward.
- Nurses find working with people with dementia a huge challenge - 89% of nursing staff identified working with people with dementia as very or quite challenging.
- 77% of carers were dissatisfied with the overall quality of dementia care provided. The report found that people with dementia are staying in hospital far longer than other people who go in for the same procedure and that when individuals do leave hospital they have deteriorated in terms of their physical health (for example, malnourished, dehydrated, constipated) and their dementia (more confused and distressed; less independent).

1.2.3 The policy response: prioritising dementia

In response to growing evidence on the dementia challenge, dementia has become a health and social care priority with dementia plans published in England, Wales and Scotland, and one in development in Northern Ireland.
Key recommendations on developing an informed and effective workforce for people with dementia are included. However, evidence still suggests that the workforce is not adequately equipped to work with people with dementia. Work is ongoing to address what needs to be done, for example:

- In January 2010 the National Audit Office assessed progress of the National Dementia Strategy in England and found that there is still no progress in training. One of the key recommendations was that: ‘The Department should include in the Workforce Development Action Plan a timetable for incorporating dementia awareness and care into pre-registration medical and nursing training’.
- The Department of Health asked Skills for Care and Skills for Health to complete scoping work on what accredited training is available and how equipped the workforce is to work with people with dementia. This is due shortly and will highlight the need for pre-registration training for all professionally qualified staff to be reviewed and developed to ensure the inclusion of learning outcomes relating to dementia care.

2. The focus groups

Three focus groups for people with dementia and carers were held (one at an Alzheimer’s Society office and two at NMC premises). These involved around 23 people with dementia and carers in total.

The focus groups were very informal and a chance for people with dementia and carers to share their experiences and raise issues that are important to them. However, discussions centred on:

Qu 1. What are your experiences of being cared for by nurses?
Qu 2. How do you think that nurses can best be helped to understand what dementia is?
Qu 3. What would you like nurses to understand about people with dementia?

**Qu 1. Experiences of being cared for by a nurse**

Experiences and viewpoints covered a range of issues and situations. The key points that arose were:

- **People with dementia are having care provided by nurses who are not trained in dementia. Training is desperately needed.**
  
  ‘Your profession [nurses] should be treating us, but at the moment it’s the other way round. We are called upon to train them so that they can treat us’.
  
  ‘Train the nurses please’
  
  ‘People who are [informal] carers in [their own] homes get more training in Alzheimer’s than nurses.’

  ‘We still need to achieve the coverage that cancer and heart disease get… until then we are banging our heads against a brick wall…they don’t treat it as urgent, it’s a person’s memory and that’s all they can see’.
‘Anybody who is a nurse or doing a nurse’s job should be qualified enough to recognise dementia’.

- **Attitude and compassion:** people with dementia and carers would like to be treated by nurses who show them compassion, affection and a caring attitude. This one thing would make a huge difference.

  ‘I think it’s all about attitude.’

  ‘They stand down the bottom all laughing at you. Laughing at you. And I didn’t take that. …People laugh at people with Alzheimer’s but you don’t expect nursing staff to.’

You have to be cool, calm and collected. Which you can’t always be at the time of problems, but I think that’s where training or an approach of being cool, calm is needed, because whatever your attitude is it reflects on the patient.’

  ‘Nursing starts from the ground floor; care and consideration is far better than seeing the top person in the hospital, because nursing is nursing, you know’.

  ‘They need affection as much as anyone. It’s not hard and it does make a big difference.’

  ‘Affection does magic and it’s not hard to give them it, is it?’

  ‘If people don’t care, it won’t get no better’.

  ‘You have to get people with the right kind of characters and attitudes… because otherwise they can be hell for the people with dementia’.

- **Dignity and respect:** despite the growing dignity and respect agenda, this is not being reflected in the care of people with dementia. It must become a priority.

  ‘Give dignity priority, because with that comes a lot of other things.’

  ‘In this particular home, they change their pads at certain times of day ie morning, lunchtime, afternoon 4pm and eve. But not everyone needs to be changed at the same time. I got shouted at by one of carers “she was changed at lunchtime”. May well have been, but she’s dirty now. These people are not in care homes for a week, but have often been in there 12 or 15 years. So surely they not be changed not by the clock but by need. But you can’t keep going to the nurses as they don’t listen’.

  ‘Going to the toilet used to upset me I think…she used to be changed by a man. Why couldn’t she have a lady to take her in? That used to upset me more than her. I couldn’t see why that had to happen.’
• Person-centred care. People with dementia are not receiving person-centred care. Getting to know the individual and understanding their needs would make a huge difference in the type of care provided.

‘I look at them [people with dementia] and think I wonder what she did in the past. If we knew it might make some of us feel a little bit ashamed.’

‘Because he was restless they just put him out. He slept all afternoon. So obviously they didn’t know how to treat him. They gave him medication to keep him quiet. It was a young nurse. They could leave him.’

‘They [the nurses] have a routine and they won’t do anything different.’

‘I ended up in the corridor shouting “will somebody take some notice of me”’. 

‘They need to know it changes, that we have good days and bad days, sometimes I’m good old [name], and another day I wake up and I’m quiet…. some days I get tearful’.

• Communication: many people with dementia and carers feel that nurses cannot communicate with them. This requires specific skills, as well as an understanding of dementia and a willingness to engage. Communication is essential for person-centred care.

‘I had to stay because they couldn’t communicate the nurses with my wife, because she couldn’t talk and she couldn’t say she had a pain… I had to stay at the hospital and sleep in a chair for five days because I had to be the sort of arbitrary person between nurses and my wife and I found that quite extraordinary.’

‘Communication is a big issue which is ignored’.

• Excluding the carers: carers feel that they are excluded from being with the person with dementia and supporting them. Nurses should see carers as a resource that they can use to improve the quality of care provided.

‘Listen to the carer’.

‘Because he’s got this condition he does get worked up.. he doesn’t like me far from him, he likes to know I’m around… He phoned me and I went up and was sitting with him. Well, that was it, when the sister saw me she said what are you doing here? So I said he’s called for me and I ought to be there. She said there is nothing wrong with him and I had to go out. I had to wait downstairs. It’s not policy. But did it hurt me sitting there? It would have eased him.’

‘You [the carer] are the one living with the person… you know what they were like before this [the dementia]’
Qu 2. How do you think that nurses can best be helped to understand what dementia is?

People with dementia and their carers strongly assert that nurses must understand the experience of dementia if they are to truly provide compassionate and respectful care that acknowledges the person behind the dementia and their needs and wishes.

This can come from visiting someone with dementia in different care settings, or from a person with dementia or a carer speaking to student nurses about their experiences.

‘A lot of people think “just pull yourself together “ and things like that… they’ve got to experience it.’

‘If nurses go to someone’s house where there is a personal carer and see the experiences the carer is going through to fulfil their duties… would be learning curve…see problems that arise, behaviour etc…grass roots experience is better than all the books…. People with dementia their attitude can change from hour to hour.’

‘Spend some time in a care home, to just be in there for a morning and note some of the things…. the deal should be 24 hours!’

‘Personal contact is needed... it may jolt them, because we are hard work to care for… we keep saying the same thing over and over again, we keep asking “what am I doing today? We need to make them aware. ”

‘First hand experience is the only way to learn…. And not a flying visit, because what happened at 9 o’clock yesterday morning will not happen at 9 o’clock today’.

Qu 3. What should nurses understand about dementia?

In summary, people with dementia and carers have told us that the most important knowledge and skills that they would like nurses in any care setting to have are:

- Being able to recognise the signs of dementia
- The experience of dementia – what having dementia is like for the individual.
- Addressing attitude and dignity and respect issues - knowing how to connect with a person with dementia, showing compassion, providing emotional care and being respectful.
- The principles of person-centred care in the context of dementia - seeing behind the label of dementia and getting to know the individual.
- How to communicate with a person with dementia and the importance of social interaction and a good chat.
- To use the carer as an expert and a resource for help and support.
People with dementia and carers in the focus groups run for this consultation didn’t expect nurses to have an in-depth knowledge of dementia. Whilst nursing is a highly skilled role, we appreciate that not all nursing staff require specialist expertise. However, recognising the condition, developing sensitive communication skills, handling situations with dignity and respect and seeing the individual rather than the disease can make a huge difference. These are the minimum skills that the public should expect from a registered nurse.

Louise Lakey  
Policy manager  
Alzheimer’s Society

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¹ Alzheimer’s Society (2007) Dementia UK, a report to the Alzheimer’s Society by King’s College London and the London School of Economics. Alzheimer’s Society: London


