Barry Aveyard examines the sometimes complex issue of how the educational needs of professional carers of people with dementia might be best facilitated.

An examination of the work of educational establishments and various independent bodies associated with the provision of dementia care suggests that there is an increasing number of courses being provided for those working in the field of dementia care. However, a review of the available literature suggests that there is a limited amount published on the best ways to approach planning and implementation in dementia care. One of the problems may be the diversity of professionals involved in the provision of care for people with dementia. It is no longer the case that the field is predominantly in the domain of qualified mental health nurses.

The concept of person-centred care, developed by the late Tom Kitwood, has become a driving force in the philosophy of care for people with dementia, and could provide a valuable framework on which to base educational programmes. Person-centred care puts the needs of the person with dementia at the very heart of care provision. If those needs are also at the heart of education for people working in the field, then, arguably, the contents of an educational programme will reflect the needs of the person with dementia.

What is dementia?
It is increasingly difficult to find an acceptable working definition for dementia. New research is extending the boundaries of our understanding of the range of diseases that might be encompassed by the term dementia. However, it is clear that most definitions of dementia include the concept that dementia is encompassed by multiple cognitive deficits (Matteson et al 1996). Dementia is a terrible, disabling condition, which is negatively stereotyped and poorly presented by many elements of the media (Aveyard 1997). The number of people in the UK with dementia is around 750,200 (Alzheimer’s Society 2000), which is more than the population of Sheffield.

When considering the issues for ensuring quality education for professional carers, it is important to recognise the full range of care settings and backgrounds of those working with people with dementia – from designated NHS dementia care, acute adult NHS, independent sector residential and nursing care and, of course, in the community within the person’s own home. Evidence suggests that many of those who are professional carers of people with dementia have limited formal education in the field. This is an important point when considering the debate surrounding definitions of nursing care and the government’s position on assessment and provision of nursing care in relation to funding issues (RCN 2000).

Developments in dementia care education
Despite problems with the way the media deals with dementia, the interest in dementia care within professional care has experienced an increasingly high profile in recent years. The work of Tom Kitwood is widely known, but the work of others should not go unrecognised. The Alzheimer’s Society has done much to improve awareness of dementia across all fields of care. The Stirling Dementia Care Unit has produced a range of high quality and stimulating educational materials, and the RCN Gerontological Nursing Programme is very involved in various aspects of research. There are professional qualifications in various aspects of dementia care, from diplomas to masters degrees, within educational establishments across the UK.

It would be good to think that some of the prejudice associated historically with dementia care is finally dissipating, and that nurses...
will no longer be subjected to comments from senior managers, as I was on being offered a charge nurse job some years ago: ‘if you stay working with older people more than 18 months you will commit career suicide’. Yet, anecdotal evidence suggests that recruitment of experienced, qualified and motivated staff across both the public and independent sectors remains difficult.

Some of the old stereotypes referred to by Kitwood as the ‘old culture’ of dementia care, still exist in people’s perceptions of the field. It may well be seen as hard, physical work, mentally stressful and, perhaps more importantly, unrewarding and undervalued. These issues, while important for the professional carer, inevitably have an impact upon the person with dementia.

It is also important not to lose sight of the fact that many of those caring for people with dementia are not doing so in designated dementia care settings. Tolson et al (1999) describe the particular problems experienced by nurses working in hospitals with acutely ill older people who also have dementia. They highlight the importance of recognising the special needs associated with dementia. Kydd (2000) suggests that there is an increasing need for community nurses to have greater levels of understanding about the needs of people with dementia and their carers.

The complexities of dementia care education

Education for dementia care is complex and should be specific to the carer’s own field of practice. I have run modules at various academic levels with groups from a range of backgrounds. The most problematic have been those with mixed backgrounds; where members have come from adult and mental health nursing settings, some hospital and some community-based. While there is an element of shared learning and shared experiences, there is a sense that the content of the module does not fully meet the expectations of individual members because it is not clearly related to their own needs.

I have found the process of education to have been much more productive when members of the group have all had a common focus – for example, a group where all the members work for the same independent sector company, albeit from different care homes. Because the focus of the education was clearly placed in the context of working in a care home, group members could share their experiences and difficulties.

This experience suggests that there may be an alternative to the traditional approach to the provision of clinical education for nurses. That is, nurses enrol on a course, in many cases a recognised ENB course related to a particular field of practice, and then attend an educational establishment for the theoretical component of the module. If that module was focused more specifically on an area of practice, and maybe delivered geographically closer to the practice areas, then there could be a much clearer focus for the educational experience. It could also foster stronger relationships between providers of care and providers of education.

Principles of dementia care education

Nicholls (1998), on behalf of the Centre for the Study of Dementia Care, highlights research findings which stressed that collaboration and empowerment in the caring environment can be instrumental in improving patient care. This appears to link with Loveday and Kitwood’s (1998) claim that the key to good dementia care services is staff who are properly prepared for their task. If education is to be effective then it needs to focus on the practice of dementia care, and aim to empower carers to provide the best standards of care possible. Loveday and Kitwood (1998) propose that the way to structure education is to ensure that it encompasses the principles of person-centred care. The notion of person-centred care is well documented within the work of Kitwood. This concept centres around seeing the individual as unique, respecting their past, and focusing on what the person with dementia is able to do rather than the skills that have been lost.

The concept of person-centred care is a firm foundation on which to base any educational programme in dementia care, because it will always keep the focus on the person with dementia. If we are to look at what is often described as ‘problem behaviour’, the question to ask is, for whom is this behaviour a problem, the care staff or the person with dementia? However, does a person-centred approach solely provide a framework for attitudinal approaches to dementia care education? If this is the case, does it lead to a lack of focus of the skill element of dementia care? This is an important issue in terms of ensuring that dementia care is viewed as a skilled area of nursing.

I would argue that, in many respects, this is a less important issue than it might initially seem. If skills are not underpinned, a person-centred approach to care will be meaningless because the carer will...
never be able to connect with the person on a human level. The nurse who has a truly person-centred approach to care will be in a much stronger position to develop the so-called skills of dementia care. Despite a lack of work to clearly identify what skills are required in dementia care, an extensive literature search suggests that there is some research-based work which has tried to establish what skills are actually needed to care for a person with dementia.

For many nurses, the most difficult areas of care are those of patient rights, risk taking and promoting autonomy. These are complex issues which involve balancing professional responsibility to promote safety, against the issues involved in the potential to restrain the individual or abuse their rights. It would be foolish and naïve to suggest that there are any easy answers, a fact acknowledged by the RCN in its Guidelines on Restraint: Rights Risks and Responsibilities (RCN 1999).

However, a person-centred approach to dementia education may help, as it allows for an exploration of the issues from the perspective of the person with dementia. It also allows for a consideration of their rights. Kitwood often wrote about the need to ask ‘for whom is behaviour a problem?’ It is a question of the utmost importance. If education encourages the consideration of problems associated with autonomy from the person with dementia’s point of view, then a whole different perspective can be placed on the discussion. If the focus moves away from ‘how can we stop this person wandering and putting themselves in danger?’ to ‘how can we facilitate this person’s needs in a meaningful and constructive way?’ then the discussion becomes so much more meaningful, and has the potential to lead to the empowerment of professional carers and people with dementia.

Models of dementia care – organic versus social

While there has been much criticism of the organic model of dementia care (Cheston and Bender 1999), it is sometimes a mistake to create a distinction between the two paradigms and, indeed, a greater understanding of the organic model can contribute to a better ability to provide person-centred care. My own experience has provided me with evidence of issues that seem to be of importance and appear to have influenced the practice of those taking part in educational programmes. It has become apparent to me that the physiology of dementia is important in helping people understand the reasons behind some of the behaviours exhibited by people with dementia. If people are better aware of the changes that take place within the brain associated with varying types of dementia then they are better able to make sense of some of the possible behaviours of the person with dementia.

Knowing that physical damage within the frontal lobe of the brain will impact on the ability to initiate certain actions, will help to explain why a person may sit and look at a plate of food in front of them and yet apparently not want to start eating it. Yet, if prompted to start eating, they will then finish their meal. This kind of seemingly basic, yet vitally important, information has helped many students to consider aspects of their own and others’ practice, and to reflect on how such information can be used to help improve the wellbeing of people with dementia. I believe it also illustrates that the organic and social models of dementia can work together to promote better understanding, and need not be opposed to each other.

Conclusion

It has not been the intention of this article to criticise the good work being done in the field of dementia care education. This work is well developed and is contributing to the continuing development of interest, illustrated by the increasing amount of literature published in the field. It does, however, point out that there is a gap in research and published literature on the subject of education in dementia care. The concept of person-centred care is so well established within the many areas of dementia care, that its use as a basis for the provision of dementia care education seems sensible.

One of the most overused phrases in nursing currently is ‘making a difference’. However, in the context of dementia care it is a very valid concept. If dementia care education embraces patient-centred care, there is a real potential for encouraging those within the field to really look at the needs of the person they are caring for and to work with them to move towards delivery of truly empowering care.

For those of us working in the provision of dementia care education, it gives the potential to move away from the idea that: ‘this course will enable the student to deliver a better standard of care for the person with dementia’. Instead, it provides the opportunity to provide an increasingly developmental type of learning that has the potential to challenge existing ideas and beliefs, and encourages a reflection on the needs of the person with dementia at a deeper emotional level.

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References


