The impact of discrimination against older people with dementia and its impact on student nurses professional socialisation

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Summary This paper aims to review the literature to identify persistent areas of concern in the care of the older person with dementia, and factors that may impact on the students experience both now and in the future. It is argued that despite recent policy initiatives, professional socialisation is impacted upon by resource limitations, negative attitudes and poor practice development in the care for people with dementia. A recognition of the interaction between societal, practice and curriculum issues is fundamental to overcoming negative professional socialisation and is a key aspect towards providing social justice for this group. The feasibility of making progress in this area is explored.

Introduction

It is estimated that world wide 24 million people currently have dementia and the prevalence may double every 20 years to 42 million by 2020, and 81 million by 2040 (Ferri et al., 2005). Although projected increases in the developed world may be less steep than in the developing nations, the UK needs to plan ahead to ensure its services keep pace with need. However, problems permeate all levels of society, from front line practice to policy. In 2001 the Department of Health in the UK published the much anticipated 'National Service Frameworks for Older People' but a recent review of progress by the Commission for Healthcare Audit and Inspection stated that although some physical care standards had improved, the care of the older person with mental health problems had not made substantial progress (Commission of Healthcare...
Audit and Inspection 2006). This paper reviews recent literature in the care of people with dementia to highlight areas of concern and explores the implications for practice, and the corresponding socialisation of student nurses.

The search strategy

In order to gain an understanding of current issues relating to student nurses socialisation in practice, a comprehensive search of diverse topics relating to dementia care was undertaken using the following databases: CINHAL 1982 to date, BNI 1994 to date, MEDLINE 1996 to date, EMBASE 1996 to date, KINGSFUND 1979 to date and psychINFO 1806 to date. The key words used were ALZHEIMER, DEMENTIA, DISCRIMINATION, ATTITUDE, PREJUDICE, AGEISM, MENTAL HEALTH SERVICES, HEALTH CARE, SOCIAL CARE, ELDERLY CARE, GERIATRIC CARE AND OLDER PEOPLE. An electronic search was also undertaken of key web-sites, including the DOH, Department for Work and Pensions, NICE, the NMC and pressure groups such as the ALZHEIMER DISEASE SOCIETY and AGE CONCERN. A supplementary search of the above CINHAL and the BNI databases was also undertaken using the key words EDUCATION, ATTITUDE, and CURRICULUM.

Stigmatisation and discrimination in society

The literature supports the contention that ageism and stigmatisation of people with dementia is embedded in society and that this is reflected in the care systems in the UK. This is transferred through a variety of mechanisms such as the media and family role modelling, and has become so pervasive that ageism is often unrecognised. Competing pressures interact to ensure the older person is projected as a problem for society with financial and commercial pressure combining to promote a reduction in the amount of time spent in retirement (Department for Work and Pensions, 2006). Clearly if this economic target is to be met then ageist attitudes will need to be challenged (Age Positive, 2006). Wanless (2002, 2004) estimated that the changing age structure is likely to have a limited impact on health spending over the next 20 years, and may even decline with improvement in public health, a view contrary to media driven public perception. However, the ageing of the population is likely to be a more important cost pressure for personal social services under the current funding system for the care of older people in need of long term care in the UK.

Interestingly, in 2005 the UK charity Age Concern reported that, of a nationally representative sample of 1843 adults aged 16 and over, more respondents reported suffering age discrimination than any other form of discrimination. Other research indicates that the older person is seen in a negative light across Europe. Stratton and Tadd (2005; p. 39 and 41) reported on 89 focus groups involving young and middle-aged adults in the UK, Ireland, Spain, France, Slovakia and Sweden and found that in all centres participants considered that older people were ‘seen as a burden depriving the young of social benefits’. Overall societal values were seen as ‘overtly ageist’ and health care systems were seen as lacking the resources necessary to provide good quality care. These views have been subsequently reinforced by high profile reports regarding unacceptable care standards provided to the older person in hospital (Age Concern, 2006).

Concurrently the observation that mentally ill people experience discrimination is also generally accepted in the literature (Johnstone, 2001). Historically people with mental illness were seen to lack rationality, which has often been viewed as a prerequisite for personhood (Gillon, 2003 citing Kant). This has been underpinned by the pejorative use of the term dementia and the tendency towards subjectivity in applying diagnostic criteria (Sachdev, 2000). Arguably, the individual with dementia may be perceived as manifesting all the most feared aspects of the ageing process. Furthermore the perception that dementia is incurable may also serve to ensure that dementia care is seen as problematic, particularly in cases where there is severe cognitive impairment or where there are coexisting behavioural difficulties such as agitation, restlessness and even aggressiveness. It is therefore reasoned that older people with dementia often experience the double jeopardy of mental illness and ageism throughout society and that students entering the profession may need considerable encouragement in recognising discriminatory practice and internalising positive attitudes towards this group.

Recent policy initiatives

A number of changes in policy frameworks and legislation reflect the need to protect the rights of vulnerable and marginalised people in care services and local government provision, many of which may be taught within the curriculum. These include
the Human Rights Act 1998 and the Capacity Act 2005. The National Service Framework for Older People set out 8 service standards, including rooting out ageism and discrimination, promoting health, providing patient centred care and promoting independence (Department of Health, 2001). However, within practice investment in mental health services for older people still tends to lag behind that for younger adults (Philp and Appleby, 2004; DH/CISP, 2005). The Department of Health published its National Service Framework for Mental Health in 1999 which was supported by considerable investments and practice development; but much of these developments focused on people of working age and excluded those over the age of 65 (an arguably discriminatory action). The corresponding low level of investment in Older People Mental Health Services impacts on the recruitment and retention of staff, particularly in the in-patient services which may tend to have high usage of agency staff — inevitably affecting continuity of care and the student experience.

It seems clear that the anti-discrimination and social exclusion agenda on the grounds of mental illness and age is slowly attaining a higher profile in statutory services (DH, 2004a; Social Exclusion Unit, 2005). However upper age barriers to many available specialist mental health services continue to exist in explicit and tacit forms thus maintaining inequalities in the field of mental health (Commission for Health Care Audit and Inspection 2006). Indeed a recent ‘Call for Evidence’ by the Joint Committee on Human Rights lists 12 examples of breaches of the Human Rights Act potentially experienced by older people in care settings (Joint Committee on Human Rights, 2006). Some recent initiatives have provided additional impetus for change. For example, the NHS Knowledge and Skills Framework (Department of Health, 2004b) requires anti-discriminatory practice to be incorporated in core role descriptors and the NMC draft code of conduct reflects the current emphasis on dignity in care (Nursing and Midwifery Council, 2007a). Furthermore although recent National Institute for Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE) Guidelines on dementia care have proved controversial regarding prescription of anti-dementia drugs, they do however contain many useful priorities for implementation (NICE and CSIE, 2006).

Practice concerns

Shortfalls in the caring of people with dementia have been found across the span of care delivery. The Mental Health Act Commission has raised concerns about the Human Rights aspect of de facto detention (Mental Health Act Commission, 2003). This was supported by Macdonald et al. (2004) who found in a cross sectional study amongst 445 residents in randomly selected non EMI (Elderly Mentally Ill) nursing homes that a significant number of residents (6.1%) were prevented from leaving, while less than half of that number did not appear to have the capacity to consent to residence. Worryingly, 4.7% of residents had received medication covertly. The Mental Health Act Commission have also noted a tendency for the overuse of phenothiazines (MHAC 2003), which implies that phenothiazines are being utilized when other interventions may be more appropriate. In an albeit small sample Mowat (2004) noted that withdrawing neuroleptic drugs from people suffering from dementia produced no noticeable difference to their quality of life, psychiatric symptoms or behaviour — a view supported by current recommendations (NICE and CSIE, 2006).

As much of the direct care is undertaken by poorly paid care assistants with minimal training in the care of people with dementia, the view that dementia care is a speciality may be challenged by a sense that ‘anyone can care for people with dementia’, ensuring that dementia care may be ascribed low professional status. Indeed, Macdonald et al. (2003) found that of 455 residents in randomly selected non-EMI nursing homes, 74% had probable clinical dementia with 38% of all residents having severe cognitive impairment. They concluded that with such rates it would be difficult to label dementia care as a specialist area of nursing home care.

In older people mental health services there have been a number of promising developments in clinical practice e.g. liaison services in acute hospitals, and memory clinics. But many of these developments are initiated and sustained largely by innovative and enthusiastic individual practitioners in a variety of service models and standards, and few are implemented systematically in mainstream services with adequate support funding or are properly evaluated. Furthermore few of the promising cognitive stimulation, cognitive rehabilitation and psycho-social approaches in dementia care (Pusey and Richards, 2001; Woods, 2002) are given the support for development and implementation in mainstream practice in either community or in-patient services. The exposure of students to these initiatives is therefore limited while negative experiences may predominate.
The combined impact of socialisation and education

When referring to direct care practice several authors have viewed respect for persons as the basis for all caring relationships (Gaut 1986; Kitson, 1987), yet concern has been expressed about nurses’ negative attitudes towards working with older people (Lothian and Philp, 2001). It has also been suggested that health care workers are particularly vulnerable to ageist attitudes due to their exposure to ill or infirm people (Adelman et al., 1991; Scott et al., 1991). Indeed, McKinlay and Cowan (2003) identified the negative role professional socialisation has in reinforcing ageist attitudes and that disappointingly this was often reinforced by teaching staff, who have tended to focus on a medicalised view of old age.

Clients with dementia often have complex needs and may be challenging to work with, and this has not been aided by the concept of Alzheimer as a progressive and irreversible neurological disorder. This view has led to the suggestion of Alzheimer’s is ‘worse than death’ (Woods, 1989). Herskovits (1995) suggested that if Alzheimer is seen a ‘living death’ by society then politicians and health workers need not concern themselves with providing high quality care.

Conversely, Kitwood (1997) developed a model which was critical of the medical or ‘standard paradigm’ approach to dementia care, emphasising relationships and the social being, which underpin the concept of ‘personhood’ — the very element traditionally denied by the Kantian approach as described by Gillon. This approach emphasises rationality as a prerequisite for personhood, leading to discriminatory action towards the mentally ill, who may be seen as less than fully human. However Kitwood was not without his critics; Greenwood et al. (2001) pointed out that he was not able to transfer this concept into care practice again reducing the likelihood that students will be able to experience alternative approaches to care.

Curriculum issues

The contention that better education would improve attitudes both towards the older person is supported by a number of authors (Hope, 1994; Skog et al., 1999; Peach and Pathy, 1982; Lothian and Philp, 2001). Yet despite regular calls for an improvement in education in this field it is clear much needs to be done.

In a study to examine whether nurse education actually promotes ageism, Haight et al. (1994) concluded that good education had a positive effect on attitudes. They also identified that:

(a) older nurses tended to have better attitudes towards older people,
(b) grandparents create positive role models for ageing
(c) exposure to well older people as clients has a lasting effect on nursing students’ attitudes towards older people.

If the need to promote anti-ageist attitudes is seen as a prerequisite for the adoption of positive attitudes towards dementia care, then nursing curricula should place emphasis on exposure to healthy ageing, particularly on the Common Foundation Programme when professional attitudes are being formed. Indeed this would mirror the views expressed in other areas of provision which challenge a medically driven illness model of old age with consequent ageism and disempowerment of the older person (Audit Commission and Better Government for Older People, 2004). There had been criticism that Project 2000 students did not have sufficient clinical skills on completion of their training; it was therefore hardly surprising that the reaction would be to increase the branch length and corresponding historic emphasis on specialist related skills (UKCC, 1999; UKCC, 2001; Moore, 2005; NMC, 2005). Indeed concern continues to be expressed in this area (DoH, 2005). A limitation of exposure to holistic care is an inevitability of this process, particularly as students are mentored by staff who have themselves been subject to a specialist pre-registration, socialisation and may have had limited exposure to healthy ageing and alternative approaches. Unsurprisingly, the need for positive role modelling in a variety of professional settings is supported by literature (Donaldson and Carter, 2005; Murray and Main, 2005) while difficulties in supernumerary status continues to ensure students tend to focus on ‘fitting in’ with the prevailing clinical climate (Elcock et al., 2007). Furthermore there is substantial evidence of a lack of rigour in workforce planning and implementation of effective skill mix to provide quality care (SNMAC, 2002). Therefore, although there are moves towards providing a shift from traditional models of nurse education (SNMAC, 2005; DH, 2006; Nursing and Midwifery Council, 2007b) the potential for internalising discriminatory attitudes must remain, regardless of the impact of changes to the formal curriculum.
Discussion

Poor education is not sufficient justification for a system which places the individual with dementia in a worse position than other citizens would be with different health problems. Yet throughout the literature there is a persistent suggestion of inequitable care standards, task orientated care, over-usage of medication and, by default, paucity of development or systematic implementation of skills and psycho-social interventions in the area of dementia care. Indeed it would seem that not addressing many of the concerns discussed in this paper must merit the label of continued discriminatory practice. If change is to occur it is clear that such practices must be challenged as a matter of urgency and the impact of negative role modelling actively considered.

Nurse education does not occur in a vacuum and with an ageing population dementia care has an inevitable political component. From current evidence it is in the political arena that change is most likely to be generated. The raft of initiatives promoting anti-discriminatory practice should challenge negative role modelling, however policy imperatives do not in themselves reduce de facto discrimination at practice level, as it must also be coupled with educational initiatives promoting good role modelling. Whether this will translate into positive change at practice level will depend on several antagonistic factors. Firstly, although the literature reflects a need for good education to challenge discriminatory practice, a disease-dominated view of the ageing process still tends to promote negative stereotypes. Secondly as the population ages it is likely that this will generate interest in the care of older people, and with that dementia care.

The political drivers of Government policy have provided an impetus for change in the past; and European-wide legislation demanding a reduction in discrimination will also add to the political drivers as the public has shown an increased tendency to challenge those in authority and the status quo. The current middle-aged 'baby boom' generation of the 1950s and 1960s is likely to be more vocal than previous generations and more at ease with the consumerist view of health care trumpeted by the Thatcher Government in the 1980s. Managers are likely to be put under increasing pressure to demonstrate adherence to best practice while improved communication via media such as the internet will hopefully lead to greater public awareness.

Counteracting this will be the issue of costs and difficulty with recruitment to an unpopular area of care. As identified even when there is sufficient literature to justify changes in practice this has remained patchy at best. Indeed, despite several consultations the evidence from grass roots indicates that UK nursing curricula remain limited in terms of the positive exposure available to student nurses caring for these individuals. Although curriculum may be adjusted to account for changes in health care provision, these will be unlikely to produce a significant shift in practice standards if it is not coupled with significant attitudinal shift within the profession.

It is likely that if better care standards evolve it will be as a result a complex interaction of greater public awareness of the needs of those with dementia, media generated interest and political necessity. Despite the demographic trend, financial stringency may mean that there is a risk that any future funding increase is likely to maintain the status quo rather than bring about an improvement in services. The current political agenda is a move in the right direction but more initiatives will be needed to ensure greater parity and an improvement in general standards in this problematic area of care.

Conclusion

Despite UK Government imperatives designed to reduce discriminatory practice, there remain a number of ambiguities that will continue to impact on students’ positive attitude formation towards this client group. Inequity of funding for older people mental health services will continue to undermine efforts to develop practice and services for people with dementia, and with that the climate of professional socialisation. The fact that care standards could be improved in this area is supported by improvement noted in the physical care of the older person since the implementation of the National Service Framework (Commission for Healthcare Audit and Inspection, 2006). It is essential that greater emphasis on self-awareness and anti-discriminatory practice is integrated into nursing curricula or it is unlikely that real change will occur at the level of direct care in the near future. Educationalists need to scrutinise attitudinal exposure carefully to actively promote positive role modelling, both in the formal curriculum and in clinical practice. This area must be addressed as a matter of urgency if progress is to be made. Furthermore educationalists, students and mentors
need a clear understanding and recognition of the pervasive nature of discriminatory practice and the impact of both negative and positive role modelling. It is therefore incumbent on both teaching and practice staff to challenge discriminatory practice and the transmission of negative attitudes wherever it occurs. The current standards of care provision of dementia care may be at odds with European Human Rights legislation and ultimately there may be further legal challenges from organisations, service users and their families or members of the public that produce a long overdue shift with regard to the socialisation of student nurses towards anti-discriminatory practice.

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