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## **Dementia education in Higher Education Institutions, now and in the future: the role of the professional regulatory bodies in the UK**

Chris Knifton, Rhoda Macrae, Anna Jack-Waugh, Margaret Brown, Claire Surr, Rachel Thompson and Lesley Baillie

### **Abstract**

Dementia is a global challenge and educating and upskilling the workforce is a policy imperative. A World Health Organisation priority area is the development of dementia knowledge and skills amongst health and social care professionals. The European Parliament has called for European countries to develop action plans and create common guidelines to provide education and training to professionals caring for people with dementia and their family caregivers. The inconsistencies and gaps in dementia education have been repeatedly highlighted internationally as well as in the United Kingdom (UK); this is despite the four home nations having voluntary frameworks and guidelines for dementia education.

This perspectives article on dementia education is written by representatives of the Higher Education Dementia Network (HEDN), a well-established group of academics involved in dementia education and research in over 65 Higher Education Institutions across the UK. HEDN works collaboratively with Dementia UK to promote consistent, high quality dementia education and share best practice. At HEDN we believe that reference to the knowledge and skills frameworks of the four nations within Professional Regulatory Body (PRB) requirements would ensure a more rigorous and consistent approach to dementia education across the UK. Reference to the Frameworks would support their adoption as a required and monitored sector minimum standard across professional boundaries. HEDN therefore recommends that application of the knowledge and skills within these frameworks becomes a requirement for (re)validation/approval of relevant health, social and housing professional programmes. In this article we explain the rationale behind the recommendations made by HEDN and the implications for PRBs and Higher Education Institutions.

## Background

There are 850,000 people with dementia in the UK with current population numbers indicating that there will be over one million people with dementia in the UK by 2025 (Green, 2017). There are increasing numbers of people with dementia living longer and living in both the community and long-term care facilities, with periods in hospital for a range of acute and chronic health problems. Therefore, all staff working in health, social care and housing need appropriate education to prepare them to respond to the experiences of people affected by dementia and the complexity and diversity of their needs. The report 'A Call to Action' states workforce training is essential to build capacity and to relieve the strain placed on family carers (Rubenstein et al., 2015). Practitioners need to understand how to support people who are affected by dementia, to live well throughout the condition, from diagnosis to end of life.

Gaps in dementia specific knowledge and skills amongst general hospital staff have been consistently noted (Cowdell, 2010; Elvish et al., 2014), with staff working in acute care particularly reporting a lack of dementia training as a significant need (Galvin et al., 2010; Surr and Gates, 2017). The quality of care for people living in the community (Alzheimer Scotland, 2008), and in care home settings (Alzheimer Society, 2007, 2013; Care Quality Commission, 2014), have also been identified as areas of concern. This has led to a consistent call for all health and social care staff to become better informed about dementia (Alzheimer's Society, 2007, 2013; Boaden, 2016; Royal College of Psychiatrists, 2011) with an ever-increasing emphasis on better dementia education for those who work in this area (Banerjee et al., 2016) Therefore appropriate levels of support for people with dementia and their families is relevant to the entire health, social care and housing system (Alushi et al., 2015). We feel this creates a real and present need for these workforces to be adequately prepared through education.

However, the first professional preparation of most of these staff is lacking (Pulsford et al., 2007, Collier et al., 2015) with a particular lack of dementia education amongst those professions who work outside of mental health services. This extends beyond the UK and is an international issue (Hvalič-Touzery et al., 2017). A worrying finding from a recent literature review points to nursing curricula being a contributing factor in nursing students selecting acute or critical care over working with older people

(Garbrah et al., 2017). The low status afforded to working with older people is not new but to find that education curricula continue to reinforce negative perceptions about working with older people is, we feel, of great concern. These findings resonate with evidence about dementia education, not only in nursing but across interprofessional education. For example, successive multiprofessional practitioners undertaking a Dementia Champions education programme in Scotland reported a widely held view that dementia is considered the responsibility of mental health services (Brown et al., 2017). A combination of socialisation, lack of education and a perception that people with dementia were not part of their patient group has created a 'perfect storm' (Brown et al., 2017). Therefore, we believe that pre and post qualifying education curricula need to include opportunities for students to interact with, and be taught by, positive enthusiastic and knowledgeable role models. Regardless of specialisation options there should be an age friendly curriculum with career pathways supported (Garbrah et al., 2017).

### **Dementia education guidance**

The Higher Education Dementia Network (HEDN) is a group of academics representing the Higher Education sector with an integral focus on supporting dementia education. Its membership, which we are part of, comprises a range of academics from over 65 individual institutions from across the UK. Notably in 2013 HEDN published the first national guidance on dementia education, a 'Curriculum for Dementia Education' (HEDN, 2013) detailing both content and learning outcomes across a range of academic levels and aimed at both health and social care staff (Knifton et al., 2014). Developed through consultation with people with dementia and their carers/family members and across HEDN members, the document mapped existing provision as well as identifying additional core content and learning outcomes. This work proved to be an underpinning source for Health Education England's (HEE) subsequent development of the Dementia Core Skills Education and Training Framework (Department of Health, Skills for Health and Health Education England, 2015), updated to the Dementia Training Standards Framework in 2018, which is now adopted as the sector standard in England for dementia education for the health and social care workforce. The other UK nations have similar dementia education and training frameworks or standards, these being the 'Good Work: Dementia learning and

development framework' in Wales (Care Council for Wales et al., 2016), 'Promoting Excellence Framework' in Scotland (Scottish Government, 2011) and 'Dementia Learning and Development Framework' in Northern Ireland (Health and Social Care Board, 2016).

Despite these strides forward, coverage of dementia within pre-qualifying or preparatory educational programmes for the health and social care workforce remains patchy (Hvalič-Touzery et al., 2018). We feel it is also unclear with what quality or depth learning outcomes are being covered where programmes do provide dementia content. Therefore, further progress needs to be made in promoting the inclusion of dementia within pre-qualifying and preparatory curricula and also in monitoring the quality of this provision. In November 2017 HEDN published its first position paper, aimed at PRBs (Surr et al., 2017). It set out a rationale for why dementia should be included explicitly within pre and post-qualifying curricula. Additionally, the assertion was made that PRBs have a role to play in ensuring educational providers comply with best practice guidelines through referring to and requiring curricula to meet national dementia knowledge and skills frameworks. HEDN, within the position paper, called on PRBs to make application of the relevant frameworks a requirement for (re)validation of health and social care pre-qualifying or preparatory curricula.

## **Discussion**

Importantly, PRBs have a responsibility for ensuring the content of educational provision for professional and pre-qualifying courses adequately prepares the current and future dementia workforce. However, despite the consistent and frequent concerns raised regarding the lack of adequate preparation for the health, social care and housing workforce to support those living with dementia, PRBs do not yet explicitly include dementia in a comprehensive way in their requirements for pre-qualifying education providers. For nursing specifically, the introduction to the Nursing and Midwifery Council's (NMC) '(2018a) Future nurse: Standards of proficiency for registered nurses' includes a statement that registered nurses provide care for people living with dementia. We found the only other reference to dementia is in the list of communication and management skills, with a requirement for registered nurses to 'share information and check understanding about the causes,

implications and treatment of a range of common health conditions'(p.28) , with dementia one of the examples given. There is no specific reference to any of the nationally published knowledge and skills frameworks used across the four nations, leaving it open to HEIs to decide on whether to provide a comprehensive programme of dementia education. In England, the newly created role of the Nursing Associate will soon be regulated by the NMC, following legislative changes. **References to dementia in the proficiencies for this new role (NMC, 2018b) mirror those in the NMC's (2018a) standards for registered nurses.**

We strongly believe that as HEIs base their curricula on the standards published by the relevant PRBs, the lack of specific reference to nationally published dementia education frameworks is likely to result not only in variations in dementia education across HEIs but also significant gaps in relevant knowledge and skills. HEIs wishing to embed quality dementia education within their pre-qualifying and professional courses will therefore need to go above and beyond PRB regulations to include clear reference to these nationally agreed outcome frameworks. Given existing HEI concerns about fullness of curricula and the ability to deliver content within current programmes, we are concerned that ensuring coverage of dementia education and training framework content may not be considered as a priority by many.

Service user involvement in engaging people with dementia and their carers in the design and delivery of curricula should also remain at the heart of any programme, due to the reciprocal benefits for people with dementia and the students (Russell, 2016; Turner et al., 2017). The NMC (2018c) standards framework for nursing and midwifery education requires that programmes are co-created, designed, developed, delivered, evaluated and co-produced with service users, and other stakeholders. In addition, we feel there must be partnership working with service users in student recruitment and selection and service user involvement in assessment. However, the extent of the participation of people with dementia in this range of activities remains unclear.

These two strategies of adopting existing national dementia outcomes frameworks, and service user/carer involvement, work together to support standardisation,

consistency, currency and quality across HEIs and pre-qualifying/professional programmes and we argue that these ought to become essential criteria for the validation and successive re-validation/approval of any professional programme. However, in addition, supporting dementia education within the curriculum also requires staff with the appropriate level of knowledge, skills, experience and enthusiasm for the subject (Collier et al., 2015). We feel there is a risk that the compulsory need to implement dementia education on courses could lead to staff undertaking this role who are ill-prepared, under-skilled and demotivated. The retention of dementia educators also raises some important guiding principles for HEIs in supporting the continuing professional development for existing staff as well as planning for the educators of the future, considering workforce issues such as recruitment, retention, retirement, severance and redundancy. HEIs are under increasing pressure to save money and it is important to consider how issues such as voluntary severance, redundancy or a freeze on staff recruitment may affect dementia education. Added to this, given that most of dementia educators are likely to be experienced mental health nurses who may have accrued Mental Health Officer status (a historical provision introduced to compensate clinicians caring for patients with mental health disorders), retirement from age 55 might leave some HEIs with a potential teaching gap for experienced dementia specialists. However, this also creates opportunities for experienced dementia clinicians to contribute to dementia education within HEIs.

The status of dementia education within programmes for staff who undertake these teaching roles ought to be given specific consideration, not only to recruit and retain good dementia lecturers but also as a clear outward facing sign of the value placed by the HEI on dementia education. Such posts include Professorial posts in dementia studies, which drive forward dementia research, increasing available evidence to inform best practice, and raising the profile of dementia care and education within the academic community. Other roles include specific dementia leads or lecturing posts within professional and pre-qualifying programmes. As an example, at De Montfort University in Leicester, the Faculty of Health and Life Sciences have an appointed 'Faculty lead for Dementia' and 'School Leads for Dementia' whose role includes overseeing dementia education within pre-qualification curricula such as nursing, pharmacy, social work, policing, and speech and language therapy and the inclusion

of service user perspectives and adoption of national dementia outcome frameworks. At the University of the West of Scotland, the Alzheimer Scotland Centre for Policy and Practice have lecturers in dementia who support the inclusion of dementia knowledge and skills content in undergraduate, postgraduate and continuing professional development programmes for health and social care professionals.

## **Conclusion**

Here in this article we outline and discuss the implications of the position paper for PRBs in health and social care, which was launched by the Higher Education Dementia Network in 2017. It is a recognised global issue that health and social care staff working outside specialist dementia care services lack the requisite knowledge, skills and attitudes to deliver high quality dementia care. Therefore, we believe all practitioners, whatever their professional role or the service setting, need dementia education to understand how to deliver best evidence-informed dementia practice. Dementia education, developed in partnership with people with dementia and their families, needs to begin during professional preparation as well as being provided as part of ongoing professional development. To support best practice in dementia education, we have argued that PRBs should make specific reference to the UK wide national knowledge and skills frameworks in their (re)validation requirements. In doing so, the quality and content of dementia education would be subject to their quality monitoring procedures, therefore, potentially reducing variation of curricular content and quality. In doing so the knowledge and skills gaps across the health and social care workforce may be reduced in their essential initial professional education and socialisation.

However, recruiting and retaining educators in HEIs to support quality dementia education and research still, we feel, remains a challenge despite the creativity some HEIs have employed. The historic and current knowledge and skills gap is at present concerning for academics, since many come from professional backgrounds where a lack of dementia education was a feature. The role of the PRBs we feel is about ensuring dementia education is of high quality care now. Their role is also essential for the education of future generations of both educators and health and social care



professionals to ensure people with dementia and their families can access and receive contemporary and evidence based care.

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