

# How do we enhance undergraduate healthcare education in dementia? A review of the role of innovative approaches and development of the Time for Dementia Programme

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**Objectives:** Traditional healthcare education, delivered through a series of time-limited clinical placements, often fails to deliver an understanding of the experiences of those with long-term conditions, a growing issue for healthcare systems. Responses include longitudinal integrated clerkships and senior mentor programmes allowing students' longer placements, continuity of contact and opportunities to learn about chronic illness and patient experience. We review their development and delivery in dementia and present the Time for Dementia (TFD) Programme, a novel 2-year interdisciplinary educational programme.

**Design:** The study design involves a scoping review of enhanced placements in dementia for healthcare professionals in training including longitudinal integrated clerkships and senior mentor programmes and a case study of the development of TFD and its evaluation.

**Results:** Eight enhanced programmes in dementia were identified and seven in the USA. None were compulsory and all lasted 12 months. All reported positive impact from case study designs but data quality was weak. Building on these, TFD was developed in partnership between the Alzheimer's Society, universities and NHS and made a core part of the curriculum for medical, nursing and paramedic students. Students visit a person with dementia and their family in pairs for 2 h every 3 months for 2 years. They follow a semi-structured interaction guide focusing on experiences of illness and services and complete reflective appraisals.

**Conclusions:** We need interprofessional undergraduate healthcare education that enables future healthcare professionals to be able to understand and manage the people with the long-term conditions who current systems often fail. TFD is designed to help address this need. © 2016 The Authors. International Journal of Geriatric Psychiatry Published by John Wiley & Sons Ltd.

**Key words:** healthcare education; dementia; Alzheimer's disease; longitudinal integrated clerkship; senior mentorship programme; interdisciplinary learning; long-term conditions; multi-morbidity

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## Introduction

Traditionally, healthcare education, whether that of doctors, nurses or other health professionals, has been delivered through a series of discreet and short-term clinical placements. During these, students are based for some weeks in acute, primary care or community settings and see patients opportunistically under the clinical supervision or mentorship of a qualified professional. There have been increasing concerns about this mode of educational delivery (Hirsh *et al.*, 2007; Norris *et al.*, 2009). In particular, it may be better suited to developing knowledge about acute illness, rather than delivering understanding of the experiences of those with long-term conditions who are a growing issue for healthcare systems (Department of Health, 2012a; Greenaway, 2013; Pruitt and Epping-Jordan, 2005); building attitudes that over-emphasise the importance of acute care and the technical medicine of general hospitals and undervalue community-based and long-term care (Banerjee, 2014; Gillespie, 2013).

Dementia is a powerful exemplar of such long-term conditions, embodying the challenges that the ageing population and chronic conditions present to healthcare delivery (Banerjee, 2014). It is one of the most common and serious disorders we face with over 850 000 affected in the UK alone (Prince *et al.*, 2014), costing £23bn annually (Luengo-Fernandez *et al.*, 2010). It causes irreversible decline in global intellectual, social and physical functioning; behavioural and psychological disturbances are common (Department of Health, 2009). The negative impacts on those with dementia and their families are profound (Alzheimer's Society's, 2012). A global issue (46 million affected, costing \$600bn p.a.), numbers will double and costs at least triple in the next 20 years (Alzheimer's Disease International's, 2010; Alzheimer's Disease International, 2009; Prince *et al.*, 2013). The need for international and national action to improve care for people with dementia has been acknowledged by the WHO (World Health Organization, Alzheimer's Disease International's, 2012), national strategy and the G8/G7 (Department of Health, 2012b; Department of Health, 2009; Department of Health, Prime Minister's Office's, 2013). These strategies and national clinical guidelines (National Collaborating Centre for Mental Health, 2007) all identify the need to improve the attitudes, knowledge and skills of professionals caring for people with dementia. This has been identified as the 'most significant gap' in current healthcare education and training (Department of Health, Skills for Care, 2010). Recently, Health Education England

(2014) introduced minimum core dementia curricula criteria for all undergraduate health and social care training programmes.

Critical reports (Cavendish, 2013; Francis, 2013) make clear the need for healthcare education to adapt and change to meet the challenges presented by the increasingly old and frail clinical populations with multi-morbidity that present to health services of all kinds. Effective care for individuals with long-term conditions requires a different set of proficiencies to those with acute conditions. Future healthcare professionals therefore need to be equipped with the knowledge, skills, attitudes and professional values necessary (Cavendish, 2013; Francis, 2013; Greenaway, 2013; Willis Commission, 2012; World Health Organization, 2005) to deliver better care. The realisation that healthcare education may not be producing the attitudes, compassion, understanding and empathy needed in the workforce has led to the development of novel complementary approaches to undergraduate education and training (Norris *et al.*, 2009).

There is a developing literature on the value of time-limited placements in non-traditional settings such as care homes. Alushi *et al.* (2015) reviewed such programs for pre-registration healthcare students and found them to be focussed on improvement in dementia knowledge, attitudes and comfort when working with people with dementia, but generally to be of short duration with their evaluations often short-term, using unvalidated quantitative tools and not including impacts on people with dementia.

Two approaches that aim to allow students to participate in longer-term placements to provide continuity of care and opportunities to learn about chronic illness are longitudinal integrated clerkships (LICs) and senior mentor programmes (SMPs). In LICs, the curriculum is designed so students (i) participate in the comprehensive care of patients over time, (ii) participate in continuing learning relationships with these patients' clinicians and (iii) meet the majority of the year's core clinical competencies, across multiple disciplines simultaneously through these experiences (Norris *et al.*, 2009). In SMPs, students are introduced to healthy, community-dwelling older adults as teachers and exemplars to facilitate student learning of attitudes, knowledge and skills related to ageing and geriatrics as well as more general objectives in medical school curricula (Eleazer *et al.*, 2009). Although the emphasis of these programme types differs, both approaches provide students with the opportunity to engage with a specific population for an extended period of time. LICs in clinical populations other than dementia are increasingly well established

and can enhance knowledge, attitudes and empathy (Norris *et al.*, 2009; Ogur *et al.*, 2007; Poncelet *et al.*, 2013; Walters *et al.*, 2012), with continuity of patients, peers and supervisors valued by students (Poncelet *et al.*, 2011).

Here, we review the literature on such developments in dementia before presenting the rationale, aims and development of the Time for Dementia (TFD) Programme, a novel 2-year interdisciplinary scheme for medical, nursing and paramedic students in South East England.

## Method

We adopted a scoping review format (Armstrong *et al.*, 2011) to explore LICs and SMPs in dementia and the data published on them. A scoping review is similar in many ways to a systematic review, although a scoping review tends not to involve quality assessments and is reported in a narrative format (Armstrong *et al.*, 2011; Grant and Booth, 2009; Rumrill *et al.*, 2010). This was used because it was clear from the start that using formal systematic review methodology would yield a null set given the nature of data available.

In the scoping search, we used broad search terms (e.g. ('longitudinal integrated clerkship' OR 'mentor' OR 'education program') AND (dementia OR 'Alzheimer's disease') AND students) within electronic databases; PubMed, SCOPUS and PsycINFO. To ensure, we captured these education programmes outside research studies and we also searched the grey literature and used snowballing techniques. We included all professional groups in training with specific searches for medical, nursing and paramedic students.

Studies were excluded if the education programmes did not focus on university students or healthcare professionals in training and persons with dementia. The education programme had to be part of the students' curriculum, regardless if it was compulsory or not. We did not include schemes where normal short-term placements occurred in novel settings (e.g. care homes).

## Results

On 3 June 2016, 46 articles were identified across electronic databases. Following removal of duplicates, 35 articles remained. After screening abstracts and titles, only two articles met inclusion criteria, both reporting variations of 'The Buddy Program' (Jefferson *et al.*,

2012; Morhardt, 2013). Six additional programmes were identified through snowballing and searching the grey literature (Table 1). Seven programmes were for medical students, and one was not specific about the professional group of students; we found no initiatives that were interdisciplinary in nature. Seven were from the USA, one from Italy and none were compulsory; they therefore included only a small self-selected proportion of all students. None lasted more than a single academic year.

### The Buddy Program

Created in 1997, 'The Buddy Program', pairs individuals with dementia with first year medical students at Northwestern University (Morhardt, 2013). The programme enables individuals with dementia, 'mentors', to share their experiences and further student understanding of what it is to be a person with cognitive impairment (Morhardt, 2006). It has five aims:

- (1) Socialisation for the mentor.
- (2) The opportunity for the mentor to share their experiences of dementia.
- (3) To educate medical students about early stages of dementia.
- (4) To introduce students to clinical and research work in dementia.
- (5) To inform students of issues in the daily care and support of people with dementia.

The format allows first year students to meet people with mild dementia for 'mutually satisfying activities' (Morhardt *et al.*, 2013). Students attend orientation sessions, spend 4 h a month for 8 months with the mentor, attend monthly hour-long meetings with programme staff and complete knowledge questionnaires before and after the programme (Morhardt and O'Hara, 2012).

Several sites have replicated The Buddy Program and use its manual (Morhardt, 2013; Morhardt and O'Hara, 2012). There is variation in the information available about these programmes, with some programme guides freely available online (e.g. The Alzheimer's Learning Experience for Students at Dartford College), while others provide no information (e.g. Partners in Alzheimer's Instruction Research Study at the University of Kansas). A conference report provides the most comprehensive overview about the programmes in a number of sites (Morhardt *et al.*, 2013). Programmes differ in the education material supplied to students, the student population included and evaluation. One element that is consistent

Table 1 Innovative dementia educational programmes identified in scoping search, including the details on program content and reported findings

Name	Source of information	Compulsory	Student population	Visit schedule	Visit activities	Quantitative findings
The Buddy Program (Northwestern University)	(Morhardt <i>et al.</i> , 2013; Morhardt and O'Hara, 2012)	No	First year medical students	4 h/month	Not prescriptive, optional attendance to medical visits.	Dementia knowledge improved ( $p < 0.001$ ) (Morhardt <i>et al.</i> , 2013)
The PAIRS Program (Boston University)	(Jefferson <i>et al.</i> , 2012; Morhardt <i>et al.</i> , 2013)	No	First year medical students	Minimum 4 h/month	Not prescriptive	Improved dementia knowledge ( $p < 0.001$ ) (Jefferson <i>et al.</i> , 2012; Morhardt <i>et al.</i> , 2013)
The TALES Program (Dartmouth College)	(Morhardt <i>et al.</i> , 2013)	No	Junior and senior pre-med; first and second year medical students	2 visits/month (~1 h each visit)	Not prescriptive	Improvement in some attitude scale items, significance not reported (Morhardt <i>et al.</i> , 2013).
The DUO Program (Washington University, St. Louis)	(Morhardt <i>et al.</i> , 2013)	No	First and second year medical students	2 h/month	Not prescriptive	Increase in student self-report knowledge, significance not reported (Morhardt <i>et al.</i> , 2013).
The New Friends Program (University of Wisconsin)	(Wisconsin Alzheimer's Institute's, <i>n.d.</i> )	No	Health profession students	2–4 h/month for at least one semester.	Not prescriptive	No data
The Generations Together Program (Albany Medical College)	(Albany Medical College, 2015; Morhardt, 2013)	No	No data	No data	No data	No data
The PAIRS Program (University of Kansas)	(Morhardt, 2013)	No data	No data	No data	No data	No data
Mentorship Program at the University of Bari	(Morhardt, 2013)	No data	No data	No data	No data	No data

TALES, The Alzheimer's Learning Experience for Students; PAIRS, Partners in Alzheimer's Instruction Research Study; DUO, Dementia Understanding Opportunity.

across all sites is its non-compulsory nature, with it offered as an elective choice to a small number of interested students each year.

### Effectiveness

In the initial Buddy Program, it was reported that average quantitative scores of knowledge and attitude improved over the mentorship, but statistics were not reported (Morhardt, 2006). The prime measure was analysis of students' monthly reflective journals as they 'best reflected' the impact of the programme. From these reports, it was reported that student knowledge of dementia improved alongside their capacity for empathy and compassion. More recently, it was reported that students ( $n=68$ ) scored statistically significantly higher on the Buddy Program Knowledge Test, a study-specific measure of dementia knowledge, following completion of the programme (Morhardt *et al.*, 2013).

In the Partners in Alzheimer's Instruction Research Study Program, Jefferson and colleagues analysed the reflective essays of students and found participation improved student attitudes towards dementia (Jefferson *et al.*, 2012). Witnessing the everyday impact of the condition on patient lives allowed students to gain more humanistic insights into dementia. One student stated 'Medical students don't always get such personal accounts, yet such experiences enrich our understanding [so] that we remember for future patients to treat the person as well as the disease, a concept that ... sometimes is lost' (Jefferson *et al.*, 2012). Further, students' opinions of geriatric medicine and dementia care were positively influenced by participation. Analysis of dementia knowledge questionnaires suggested that students' dementia knowledge increased over the course of the programme (Morhardt *et al.*, 2013).

In The Alzheimer's Learning Experience for Students Program, students were presented with the statement 'It is rewarding to work with people with Alzheimer's disease', before and after participation.



Students responded on a seven-point Likert scale from 'strongly disagree' to 'strongly agree'. After the programme, there was an increase in those responding either 'agree' or 'strongly agree' compared with before (significance not reported) (Morhardt *et al.*, 2013). Students participating in the Dementia Understanding Opportunity (DUO) Program ( $n=7$ ) said that they would participate in the programme again (86%), and would recommend the programme to a friend (100%).

## Discussion

A number of innovative educational programmes in dementia have developed, mostly in North America; reports suggest they are well received and of value (Table 1). However, even in those universities where they have been established successfully, they are an elective part of the curriculum, so only a small and self-selected sample of students participate. None of the programmes appear to provide more than 12 months' contact. Equally, all are time-intensive and all but one appears to be limited to medical students. These characteristics may limit the potential of such approaches to develop the necessary improvements in knowledge, attitudes and behaviour to those with long-term conditions in general and dementia in particular, across our future healthcare workforce as a whole rather than just in a small selected group of interested professionals.

Drawing on these data, we therefore developed TFD, a programme to give all students a longitudinal experience of a family affected by dementia in a sustainable complement to their existing education. Its purpose is to enhance undergraduate learning about dementia specifically and older people's health, long-term conditions and the role of families in care more generally.

### Development of Time for Dementia

The scope and content of TFD was developed over 9 months in 2014 funded by Health Education England—Kent, Surrey and Sussex (HEE-KSS). Health Education England is the 'arms-length' body that supports and funds the development of the existing and future NHS workforce through education, training and lifelong learning development. At a set of public meetings, dementia had been identified as a priority for educational development in KSS with enhancing the attitudes and understanding of dementia of undergraduates of particular importance. The programme board, chaired by S. B., met with the Alzheimer's society, the six universities in KSS, current students, groups

of people with dementia and family carers and NHS staff to develop the aims and content of the programme iteratively. It was agreed that TFD should be interdisciplinary, long-term (2 years), a core part of curricula and that a good quality evaluation should be completed.

### Time for Dementia aims

Operationalising these principles, we set the following aims:

- (1) To provide all students with a longitudinal experience of how individuals and their families are affected by a long-term condition using dementia as an exemplar.
- (2) To improve students attitudes, compassion, empathy and knowledge of dementia.
- (3) To ensure that TFD did not worsen the quality of life of the people with dementia and carers participating.

### The Time for Dementia Programme

The programme lasts 2 years and starts in their first year of study for nursing and paramedic students and in their second year for medical students. The programme starts with an initiation meeting where the programme is introduced after which the students visit a person with dementia and their family in pairs for 2 h every 3 months for 2 years. Paired visits were chosen for pedagogic (joint learning and reflection), safety and efficiency (effective use of recruited families) reasons. TFD was made a core element of the curriculum for medical students at Brighton and Sussex Medical School and for adult nursing, mental health nursing and paramedic students at the University of Surrey in the 2014/2015 academic year. Two cohorts of students from each university have been enrolled into the programme, the first in the 2014/2015 and the second in the 2015/2016 academic year.

A critical element of the programme is the recruitment of the large number of people with dementia and carers needed for the students to visit. All those recruited have a clinical diagnosis of dementia (including Alzheimer's disease, mixed dementia, vascular dementia, Lewy Body dementia or frontotemporal dementia) and a family carer available to support visits. They are recruited from those accessing Alzheimer's Society support services and those in contact with NHS mental health trusts in Surrey and Sussex.

Recruitment of families is led by a TFD Network Manager employed by the Alzheimer's Society who approaches and assesses potential participants to determine eligibility and interest in programme and who manages the network following recruitment.

Dedicated administrative support at the universities works with the network manager to link pairs of students with people with dementia. Visits are organised every 3–4 months, at the family home, at a time convenient for the patient and the carer. Each visit lasts around 2 hours and includes time with both the person with dementia and their carer. During the visits, students follow a visit guideline that includes:

- (1) *Conversation*—Effective and inclusive conversation is an integral element of person-centred care (Kitwood, 1997). Students are encouraged to talk with the person with dementia and their carer on a wide range of topics. Students discuss the person with dementia's life and the impact of dementia including their experiences of health and social services. They also discuss the challenges posed in helping them from the perspective of the carer. Students do not provide health advice.
- (2) *Life story work*—Time is spent reviewing and discussing an individual's life (Thompson, 2011). It involves reminiscence and storytelling creating an understanding of important experiences, people and places. It draws upon an individual's long-term memory that is relatively well preserved in dementia. As such, it emphasises what an individual can do rather than what they cannot and can therefore be an enjoyable and empowering activity.
- (3) *Assistance in completion of 'This is Me'*—'This is Me' is a simple and practical tool created by the Royal College of Nursing and the Alzheimer's Society for individuals with dementia to inform health and social care professionals about their needs, interests, preferences, likes and dislikes (Alzheimer's Society's, 2010; Thompson, 2011). It provides a structure to help students understand person-centred care and how services might reduce distress for the individual with dementia and their carer and avoid communication problems.

Students are required to complete a practice portfolio about their visits for assessment. The portfolio includes a narrative of the person's life and the impact of dementia on it. In the reflection, students write about the challenges posed in looking after a person in this position from the perspective of the relatives/family. Within each school, students come together in classroom sessions to share experiences and

draw on the diversity of cases across the student group. A yearly conference brings together all students across disciplines to enable interdisciplinary learning in a set of shared facilitated workshops including a mixture of medical, nursing and paramedic students along with people with dementia and carers from the programme.

#### Time for Dementia evaluation

The TFD evaluation was developed alongside the programme. A mixed methods approach was adopted built around a cohort study of all participants followed up for the duration of the programme with complementary qualitative and quantitative data collection at baseline and 12 and 24 months. The evaluation was approved by a Health Research Authority Research Ethics Committee. As a contemporaneous control group, medical, paramedic and nursing students in schools where TFD is not available have been recruited and will be followed up for 2 years as for the intervention group using the same measures.

*Aims.* The aim of this study are as follows: (i) to evaluate the feasibility of delivering the TFD programme; (ii) to evaluate TFD in terms of process and its impact on student attitudes, understanding and knowledge towards dementia; and (iii) to evaluate the satisfaction and views of the people with dementia and their carers enrolled in TFD and to assess its impact on patient quality of life and carer burden.

*Sample.* All students, people with dementia and family carers enrolled onto the TFD Programme who give their informed written consent to participate.

*Feasibility evaluation.* The following criteria to establish feasibility were set:

- (1) Establishment—the programme to be developed and established within the curricula at Brighton and Sussex Medical School and the University of Surrey within a single academic year.
- (2) Patient recruitment—recruitment of the cohorts of people with dementia and family carers to enable the programme to be delivered.
- (3) Initiation—the programme to be delivered to the 2014/2015 cohort of first year nursing and paramedic students and second year medical school.
- (4) Consent to evaluation—consent from at least 75% of students, people with dementia and family carers to participate in the evaluation.
- (5) Data completeness—baseline data collection successful defined as at least 75% complete data.

**Quantitative student assessments.** The following are to be completed by the students in a TFD session at baseline, 12 and 24 months: (i) Alzheimer's Disease Knowledge Scale (Carpenter *et al.*, 2009), 30-item questionnaire to assess students' knowledge of AD; (ii) Dementia Knowledge Questionnaire (Shanahan *et al.*, 2013), 20-item questionnaire to assess dementia knowledge; (iii) Approaches to Dementia Questionnaire (Lintern *et al.*, 2000), 19-item questionnaire to assess attitudes towards dementia; (iv) Dementia Attitude Scale (O'Connor and McFadden, 2010), 20-item questionnaire to assess attitudes towards dementia; (v) Medical Condition Regard Scale (Christison *et al.*, 2002), a measure of biases, attitudes and emotions to specific medical conditions; (vi) Jefferson Scale of Empathy: Health Professional/Medical Student Version (Hojat *et al.*, 2001), 11-item questionnaire of empathy in healthcare students; and (vii) Student Satisfaction Survey, a questionnaire (not completed at baseline) to assess students' opinions about TFD, based upon that used in the Buddy Program (Morhardt, 2006).

**Quantitative patient and carer assessments.** Completed by TFD research workers visiting the person with dementia and their carer in their own home at baseline, 12 and 24 months: (i) standardised minimal state examination (Molloy and Standish, 1997), a global measure of cognitive function; (ii) DEMQOL (Smith *et al.*, 2007)—28-item interviewer-administered dementia-specific health-related quality of life measure answered by the individual with dementia; (iii) DEMQOL-Proxy (Smith *et al.*, 2007)—31-item interviewer-administered dementia-specific health-related quality of life measure answered by the caregiver on the individual with dementia; (iv) Zarit Carer Burden Inventory (Zarit *et al.*, 1980), 22-item self-report carer burden questionnaire; (v) Patient Satisfaction Survey—a questionnaire to assess patients' opinions about TFD echoing the student satisfaction survey; not completed at baseline; and (vi) Carer Satisfaction Survey—a questionnaire to assess carers' opinions about TFD echoing the student satisfaction survey; not completed at baseline.

**Qualitative assessments.** One year after their start in the programme, a subset of people with dementia, carers and students will complete a qualitative assessment on an annual basis. These will include (i) focus groups to evaluate the impact of TFD on students; we will conduct focus group discussions with medical students, nursing students and paramedic students and each group will have 8–10 participants; and (ii) in-depth individual interviews used to access the experiences of

those who have taken part in TFD. The number of interviews will be determined by the point at which no new themes emerge via thematic analysis for each of the four groups: (i) medical students, (ii) nursing and paramedic students, (iii) people with dementia and (iv) carers.

## Conclusions

It is essential that future healthcare professionals are equipped to care for those with long-term conditions such as dementia. We need to enhance undergraduate healthcare education to enable the health professionals of the future to be able to understand and manage the people with these conditions who current systems often fail. TFD is a programme designed to start to address this need. The programme's innovative inclusion of multi-professional groups, involvement of the patient group (here people with dementia and their carers) and co-production with an advocacy organisation (the Alzheimer's Society) enables it to address the broad impacts of a disorder like dementia. In its multi-method evaluation, we will assess whether it is feasible and acceptable to deliver this 2-year programme in dementia to medical, nursing and paramedic students. An assessment of the value of the programme will be provided by the longitudinal quantitative and qualitative data on changes in knowledge and attitudes to dementia and the wider impacts of the programme that are being collected.

## Conflict of interest

None declared.

### Key points

- Traditional healthcare education, delivered through a series of time-limited clinical placements, often fails to deliver an understanding of the experiences of those with long-term conditions such as dementia.
- We review the published data on educational responses such as longitudinal integrated clerkships and senior mentor programmes in dementia that allow students' longer placements, continuity of contact and opportunities to learn about patient experience.
- We present the development and the content of the Time for Dementia Programme where undergraduate medical, nursing and paramedic students visit a person with dementia and their family in pairs for 2 h every 3 months for 2 years.



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