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QUALITATIVE PAPER

A qualitative evaluation of the effect of a longitudinal dementia education programme on healthcare student knowledge and attitudes

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Abstract

Background and objectives: There is a need to ensure that the future healthcare workforce has the necessary knowledge and skills to deliver high quality compassionate care to the increasing number of people with dementia. Our programme has been set up to address this challenge. In the programme, undergraduate healthcare students (nursing, medical and paramedic) visit a family (person with dementia and their carer) in pairs over a 2-year period. This qualitative study sought to understand the student experience of the programme.

Methods: Participants were undergraduate healthcare students who were undertaking our programme at two universities. We sampled for variation in the student participants in order to generate a framework for understanding the student experience of the programme. Students were invited to take part in the qualitative study, and written consent was obtained. Interviews and focus group transcripts were analysed using thematic analysis.

Results: Thirty-nine (nursing, medical and paramedic) student participants took part in individual in-depth qualitative interviews and 38 took part in five focus groups. Four key themes were identified from the analysis; relational learning, insight and understanding, challenging attitudes and enhanced dementia practice.

Discussion: Student experience of our programme was shown to be positive. The relationship between the students and family was most impactful in supporting student learning, and the subsequent improvement in knowledge, attitudes and practice. Our model of undergraduate dementia education has applicability for other long-term conditions.

Keywords: healthcare education, dementia, Alzheimer's disease, long-term conditions, relational learning, older people

Key points

- This paper demonstrates the impact of delivering a large-scale longitudinal dementia education programme, on healthcare student knowledge, attitudes and practice.
- The active ingredient of the programme, relational learning between student learners and families (person with dementia and their carer) over time is identified.
- The effectiveness of this model of dementia education in embedding meaningful and person-centred learning is highlighted.
- The potential transferability of this educational approach to other long-term conditions is demonstrated.

Introduction

Dementia is one of the major global social, health and economic challenges of the 21st century. It is estimated that there are 50 million people with dementia globally, costing US \$1 trillion [1]. These numbers and costs are set to increase threefold by 2050. This means that the workforce needs to be able to adapt their working practices to meet the needs of those who are living with dementia, who are also likely to be older, more frail and living with other co-morbidities. It requires the development of essential dementia-related skills, attitudes and empathy to meet needs and deliver a healthcare service which is truly person-centred, regardless of specialism. We know however, that this is not always the case, with people with dementia having worse health outcomes than those without the condition [2]. Poor healthcare experiences are commonplace, with a recent qualitative synthesis on the experiences of people with dementia in hospital highlighting that disempowerment, environmental challenges and reliance upon restraint as being common experiences for this group of patients [3]. We therefore need to improve how we prepare future generations of healthcare professionals to develop and deliver care that supports people affected by dementia to live well from diagnosis through to the end of life. The need to increase and improve dementia education has been identified [4,5], specifically at undergraduate level.

One of the problems is that typical undergraduate healthcare education tends to focus on block clinical placements with an emphasis on crisis, or acute illness, and these do not provide students with a true understanding of what it is like to live with a long-term condition such as dementia. Current ways of learning rarely enable students to understand and challenge stigma, to experience and create a person-centred approach to their care and interactions, or build the compassion and understanding needed to help those affected by dementia. Seeing people with dementia only as patients and in acute settings can also build attitudes to, and beliefs about, dementia that are negative and that are not appropriately optimistic about the possibility of living well with dementia.

We therefore need complementary methods of teaching that allow students to understand the experiences of people with dementia and that to engage learners at an emotional level to help address negative perceptions about working with people with dementia [6]. One approach that aims 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). 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 [7]. LICs in clinical populations other than dementia are increasingly well established. More recently, educational programmes with a longitudinal component where student learners connect with a person with dementia, and in some cases, a family

carer have been developed. The US 'Buddy program' [8,9] pioneered this and has reported positive student outcomes. However these have been an elective rather than a mandatory component of curricula, reaching only a small proportion of the student body and it has been delivered principally to medical students, rather than other healthcare professionals in training.

Working on these principles, our programme was established as a mandatory component of the curricula for medical students at our Medical School and nursing (adult and mental health) and paramedic students at a collaborating University [10]. In the programme, uniprofessional pairs of students visit a family affected by dementia every 3–4 months over a 2-year period. The programme is designed to enable students to see how a diagnosis of dementia can affect people, the challenges and changes that they face over time, and the response of the healthcare system to them. The students participate in supporting workshops, tutorials and lectures. The programme was extended in 2017 to a wider range of healthcare training programmes across the South of England. To date, the programme has involved over 3500 students and 1500 families.

As part of the programme's mixed methods evaluation [10], we carried out a qualitative evaluation of the effect of the programme upon student attitudes, understanding, knowledge and behaviours towards dementia.

Methods

Sample and setting

We recruited undergraduate healthcare students who were undertaking the programme at either our Medical School or the collaborating University. This included second and third year medical students, and first and second year nursing and paramedic students. We sampled for variation in the characteristics of the student participants, in order to generate a framework for understanding the student experience of the programme across all student groups. NHS Health Research Authority Ethics approval was obtained (Ref 15/LO/0046).

Procedure

Student participants were invited to take part in the study following their programme preparatory workshop. Study information was provided and written consent was obtained by student participants for approach for an individual interview or focus group. A broad sample of students was identified from the first two cohorts of students undertaking the programme at each site. Students were approached first by email. Interviews and uniprofessional focus groups were carried out at 12 and 24 months (after starting the programme) by researchers at both sites. Individual interviews took place at a time that was suitable to the student participants during working hours and took between 30 and 45 minutes. Two focus groups took place at 12 months and three took place at 24 months, and all were arranged at lunch-times with lunch

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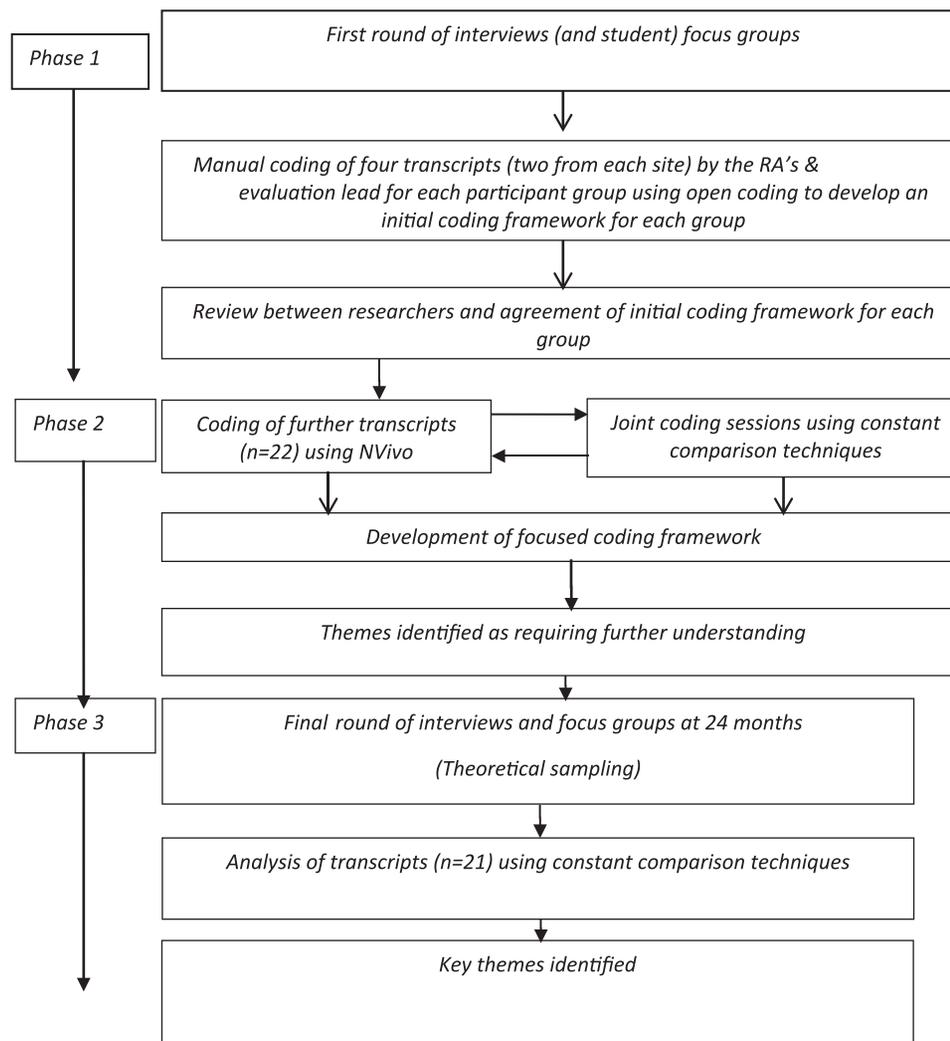


Figure 1. Process of analysis for analysis.

provided. Each focus group was facilitated by two researchers and took between 60 and 90 minutes.

Topic guides were developed from an initial review of the literature, and key topic areas included: experience of the overall programme, experience of the visits, depth of dementia knowledge and the implications for their own practice and future career preferences. Additionally, the topic guide for interviews and focus groups at 24 months was amended to explore change over time in student learning and the relationship with the family, as well as possible student disengagement. All interviews and focus groups were audio-recorded, transcribed verbatim and checked for accuracy.

Analysis

Transcripts were analysed in three stages as shown in Figure 1.

The analysis started with descriptive coding of transcripts at 12 months by the two researchers, who manually coded four transcripts by giving descriptive codes to meaningful

segments of text. The researchers met to review their respective preliminary codes and identify areas of differences and to develop an initial framework. The remaining 12 month transcripts ($n = 22$) were coded to develop a focussed framework. The topic guide was amended at this stage, to gain further understanding of developing themes and to explore any student dissatisfaction with the programme. During the second phase of the analysis (24 month data), further interview and focus group transcripts ($n = 21$) were coded by researchers.

The computer software package, NVivo 10 (QSR International, 2012) was used to enable the systematic collation and review of the data grouped within each code. This involved comparing coding and data between existing and new transcripts in order to check on the use of codes for consistency as well as exploring possible relationships between codes. To support this process, researchers held weekly analysis sessions to jointly review data collated within each code and to identify relationships between codes, as well as areas of uncertainty. The researchers noted possible relationships between codes, came to agreement relating to areas of uncertainty, as

Table 1. Participant characteristics ($n = 77$)

Student demographics	Median	Range
Age	23	19–54
	Frequency	Percentage (%)
Course		
Medical	39	50.6%
Adult nursing	15	19.5%
Mental health nursing	10	13%
Paramedic	13	16.9%
Gender		
Male	23	29.9%
Female	54	70.1%
Ethnicity		
White British/European	64	83.1%
Mixed/Multiple	2	2.6%
Asian/Asian British	5	6.5%
Black/African/Caribbean/Black British	3	3.9%
Other	2	2.6%
Not known	1	1.3%
Marital status		
Never married	60	77.9%
Currently married	8	10.4%
Cohabiting	5	6.5%
Separated/divorced	3	3.9%
Not known	1	1.3%
Experience of dementia		
Yes	47	61%
No	30	39%
Details of experience		
Family member/friend	25	54.3%
Paid/unpaid work	10	21.7%
Both	11	23.9%
Not known	1	-

well as comparison with existing theory. In the third phase of the analysis, a final framework was produced from which four overarching themes were identified.

Rigour in the research process was supported in two ways. First, the lead researcher met frequently with the researchers for academic supervision to review coding, the development of themes and reflexivity. Second, all researchers kept fieldwork diaries.

Results

Seventy-seven student participants took part in 39 individual in-depth qualitative interviews and five focus groups. Forty-four student participants took part at 12 months and a further 33 took part at 24 months. The numbers recruited were determined by thematic saturation, the point at which no new themes arose. Table 1 presents the participant characteristics. Four key themes were identified from the analysis: (i) relational learning, (ii) insight and understanding, (iii) challenging attitudes and stigma and (iv) enhanced dementia practice. These are discussed in detail below.

Relational learning

Students identified the benefit of ‘real life’ learning by the programme providing more exposure to dementia, making

the condition more visible, and allowing time that they would not normally get to spend with people with dementia. Students perceived this to be of value, with the view that it was more realistic compared to lectures as it allowed an opportunity to work with ‘real’ people in their homes. Students stated that seeing the illness in this way brought the condition to life, and gave dementia a real face and emotions. Students also reported these factors meant that learning from the visits was quicker to transfer into practice, and was easier to remember than formal lectures or presentations.

‘I think certainly with the Programme what it’s done is it’s given dementia actual emotions, like a human face and human emotions.’ (Nursing Student).

Students also made clear that their learning was in the context of a relationship. Students discussed their families warmly, frequently describing the relationship as being open, trusting and honest. Students reported feeling welcomed, and as though they were visiting a friend or relative. Over time, students described the relationship deepening, and being able to explore deeper issues, with the families appearing more comfortable to disclose personal information, feelings or worries.

‘I’m like wow, she’s about to really open up to me and what, it’s like the third time I’ve ever met her but obviously it’s quite a compliment because clearly we’ve built up that trust with her just by sitting there and chatting away.’ (Paramedic Student).

Finally, students also reported that families demonstrated a desire to help and educate the students, often wishing to know more about their training, and by doing so, there was a reciprocal element to the relationship with students and families learning together.

Insight and understanding

Students described having an improved understanding of what it is like to have dementia or to support someone with the condition. They also described increased awareness of the feelings of the person with dementia, for example, loss of identity, independence, confidence, anxiety and isolation.

‘... he’s still realising that he’s not doing stuff properly and that he can’t remember as well because he was quite intellectual and he likes talking to us about how intellectual he was and his education and then saying that he feels like he’s becoming, he’s losing his self really because that’s what defined him and that also causes lack of confidence...’ (Adult Nursing Student).

Students also described developing insight into the impact on carers, for example, feeling under pressure to be constantly available, or to be the ‘perfect’ carer, or guilt if frustrated or annoyed.

‘her daughter was quite honest about it being a tough job and the strain on her life. That sounds really bad, but yes, an added pressure to her life and it was a challenge, for sure.’ (Medical Student).

Students valued the unique opportunity that programme provided in allowing them to hear how families experienced services and professionals. Students gained first-hand

understanding about how families perceived service delivery, for example, becoming aware that many families did not feel services were tailored to meet their needs, were difficult to navigate or that for some, dementia services were not specifically useful in helping families to live with the condition.

'I think sometimes it was quite distressing with some of the examples they were giving from even how they'd been treated in hospital, or how they might have been neglected.' (Adult Nursing Student).

Additionally, students reported having a more in-depth understanding of how dementia impacts on multiple aspects of everyday life for both the person with dementia and their wider family. Students reported that their limited understanding about symptoms had been expanded, leading to an increased understanding of how the condition changes over time, as well as an improved understanding of less common symptoms and types of dementia.

Finally, students valued the opportunity to hear first-hand about how families cope with dementia on a day to day basis, and strategies for managing the condition.

'... she's very proactive about her diagnosis. At every avenue she's trying to do something actively to prevent the development of the disease, the degeneration...' (Paramedic Student).

Challenging attitudes and stigma

Students identified that their original perceptions of people with dementia had changed through the visits. Students felt able to see beyond negative stereotypes about dementia, and instead recognise that the person could remain intelligent, humorous and continue to make decisions and accomplish challenges and tasks.

'... he is still quite switched on, and he makes jokes and stuff, which is, I wasn't expecting that at all. Because you know, in, like, films and stuff, dementia is, like, so stereotyped, like, it's not really like that at all...' (Paramedic Student).

Participants also reported that the programme had helped them to recognise that people can live well with dementia; that people can be well supported by family or services and cope well with the condition, and that not everyone with dementia is isolated and struggling and many people with dementia can still find joy in everyday life.

'They have shown me how much the person can still do and enjoy and how they can still develop skills and interests.' (Medical Student).

Enhanced dementia practice

Students consistently reported an improvement in their communication skills. They specifically mentioned that they started: speaking more slowly, not changing subjects too quickly, explaining what they were saying more clearly, checking out understanding, using prompts and giving only one instruction at a time. Students reported being more aware of things to consider when communicating with families, for example, the importance of speaking separately to family members.

'Because someone's got dementia, it doesn't mean, you know, that they can't communicate, it just means you really have to find different ways of going about that' (Medical Student).

Students also reported applying broader dementia skills and awareness into practice, this included involving families in care, exploring carer wellbeing, adapting hospital procedures, and being aware of possible signs and symptoms of undiagnosed memory problems. They identified that medication alone was insufficient in treating dementia, and that psychosocial interventions, support networks and carer support held great value.

'I previously placed too much emphasis on the medical treatment of dementia. The psychosocial aspects of care may actually have the biggest impact on quality of life and outcomes for the patient.' (Medical Student).

Students reported a better understanding of person-centred care principles, being able to see the person beyond the condition, and having an appreciation for their personal history, likes and dislikes. They also became interested in the use of tools, such as the hospital passports, which provide information about the person with dementia and their care preferences.

Finally, some students reported increased interest in dementia, and an increase in the desire to work with people with dementia in the future, as well as decreased apprehension about this group of patients.

'It's definitely made me more interested in working with people that have dementia rather than not. I think I was a little bit scared by elderly medicine and people that have dementia and cognitive deficits before this and now it's definitely changed, for sure' (Medical Student).

Discussion

The findings identify four areas where the programme appears to have had an impact on undergraduate healthcare students; these were via relational learning, insight and understanding, challenging attitudes and stigma, and enhanced dementia practice. The key effective component of the programme appears to be the relationship between the student learners and the family, which allows the students to 'hear' the reality of life with dementia. Being able to hear and absorb these real life experiences, increased insight and understanding into the condition, and in turn, challenged pre-existing (negative) attitudes and stigma. The relationship between relational learning and its subsequent impact upon student learning, attitudes and practice is shown in [Figure 2](#).

These findings are consistent with the theory of relationship learning, where learning takes place and knowledge is constructed due to the relationship/s with one has with the 'other' [11]. As a pedagogic model, its origins lie in the relationship between student learning and educator, however, its potential use within healthcare education has been recognised to include a 'wider community' approach to include those patients and their families [12] as well as interprofessional education [13]. In our programme, people with dementia and their carers are the educators.

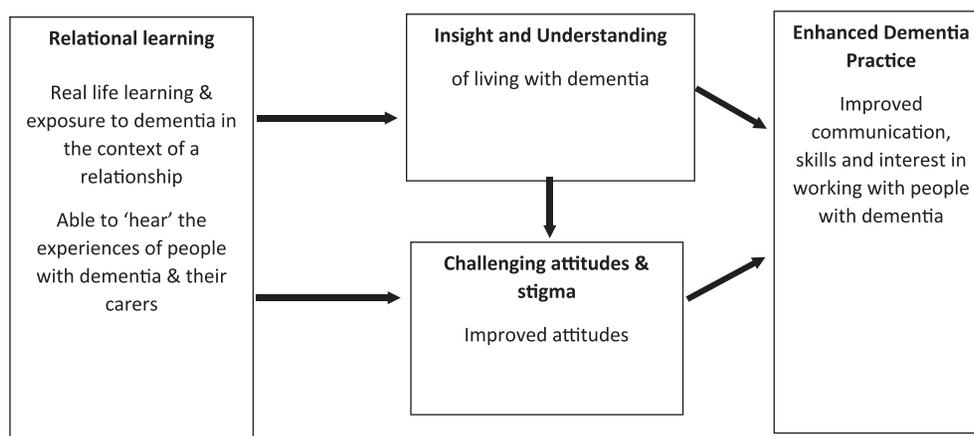


Figure 2. . Impact of relational learning on knowledge, attitudes and practice.

In the programme, on-going contact between the students and families over time allowed for relationships to deepen, leading to enhanced trust and increased willingness of family members to open up and share experiences honestly with students. This continuity is a component of the LICs model of medical education where relationships between medical student learners and their patients or a clinic setting may be established over time. Time for Dementia differs from LICs in that student learners are not involved in the care of person with dementia, however continuity between patients and students is highly valued [14]. In Time for Dementia, the knowledge and insights of those with dementia and their carers are explicitly given value and weight by those running the programme, so routine hierarchies can be ignored [13].

The significance of the relationship was identified in the Buddy Program [15], however in that programme, students were individually matched (based on common interests) with the person with dementia. Due to the scale of our programme, students and families were matched only based on geography, and students showed themselves able to build and maintain meaningful learning relationships with people with whom they may no areas of obvious commonality.

It is of interest that students reported that their initially limited understanding about symptoms had been expanded, so the programme also delivered more traditional learning outcomes from an innovative teaching method. It is positive that students reported an increase in the desire to work with people with dementia in the future, as well as decreased apprehension about this group of patients. This seems to align with the requirement of the UK new Outcomes for Graduates on long-term conditions, learning in the patient's home, and integration with mental health and social care [16].

If relational learning is the active ingredient within the programme, then this might suggest that the model may have applicability to other long-term conditions where there is unfamiliarity and negative attitudes in the student body. The programme shows that such schemes can be delivered at scale as a mandatory component of a curriculum. This may be useful for areas where student interest may not

be high and associated 'softer' skills may be challenging to teach. Additionally, the programme has significant potential to be expanded as an intraprofessional learning opportunity, which we have been recently piloted with supporting evaluation.

There are three main limitations to this study. First, this study has sought to identify the general experience of the programme for undergraduate healthcare students, and has not focussed on the more nuanced differences that may occur between professional groups. We will be exploring possible differences as part of a planned programme of secondary analysis. Second, while we sought to understand dissatisfaction, it was not possible to identify students who were unsatisfied with the programme. It may be that the process of selection of subjects may have led to bias, with only students with more positive experiences having taken part. Finally, interviews were carried out at 12 and 24 months, respectively and were reliant upon student recall. Interviews earlier on in the programme, or at the time of the visits might well have produced different appraisals.

There are however two key strengths to this study. First, we studied a good sample size and a broad range of students, which strengthens both the representativeness and generalizability of the findings. Second, a high level of rigour was adopted in the analysis of the findings, which enhances the reliability of the findings.

In summary, we have demonstrated that it is possible to deliver a longitudinal dementia education programme at scale, and for it to be a positive student experience. Taking part in the programme enhanced dementia knowledge, attitudes and practice in the students involved through relationship learning with their families. Students showed themselves able to develop positive reciprocal learning relationships, which improves their outcomes in a way that cannot be replicated in the classroom. These data support the potential value of the programme as a complement to more traditional educational approaches for healthcare students.

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