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Time for Dementia: Quantitative evaluation of a dementia education programme for healthcare students

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Abstract

Objectives: The future healthcare workforce needs the skills, attitudes, and empathy to better meet the needs of those with dementia. Time for Dementia (TFD) is an educational programme in which healthcare students from a range of professional groups visit a person with dementia and their family carer over a two-year period. The aim of this study was to evaluate its impact on student attitudes, knowledge and empathy towards dementia.

Methods: Measures of dementia knowledge, attitudes and empathy were administered to healthcare students at five universities in the south of England before and after (24 months) they completed the TFD programme. Data were also collected at equivalent time points for a control group of students who had not taken part in the programme. Outcomes were modelled using multilevel linear regression models.

Results: 2,700 intervention group students, and 562 control group students consented to participate. Students undertaking the TFD programme had higher levels of knowledge and positive attitudes at follow-up compared to equivalent students who did not undertake the programme. Our findings indicate a positive relationship between the number of visits undertaken and increasing dementia knowledge and attitudes. No substantial differences in the development of empathy was observed between groups.

Conclusion: Our findings suggest that TFD may be effective across professional training programmes and universities. Further research into the mechanisms of action is needed.

KEYWORDS

Dementia, healthcare students, longitudinal education models

Abbreviation: TFD, Time for Dementia.

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Key points

- The data suggests the Time for Dementia programme is effective in improving the knowledge and attitudes of healthcare students across different professional groups and universities.
- Dementia education that meaningfully involves people with dementia and their carers can be delivered at scale for healthcare professionals.
- The number of visits (contact with people with dementia and their family carers) completed by students is positively related to student outcomes.

1 | INTRODUCTION

The delivery of healthcare to people with dementia is widely recognised as being sub-optimal and a lack of understanding about dementia in the workforce is seen as a contributing factor.¹ The increasing numbers of people with dementia, driven by population ageing, demand a future healthcare workforce with the necessary knowledge, positive attitudes, and skills to deliver effective assessment and support to those living with the condition. To date, dementia education for undergraduate healthcare students has generally failed to meet this aspiration.² With its reliance on didactic teaching and emphasis on acute episodes of care, there is a need for undergraduate teaching to adapt to produce a future multi-professional workforce able to rise to the complex challenges of ageing and dementia for both generalists and specialists.

Educational innovation to meet this challenge has taken place through the involvement of people living with dementia and their carers. Allowing healthcare students at the beginning of training to engage with people with dementia and their carers provides an opportunity to build more positive attitudes towards dementia before more negative and pessimistic attitudes can take hold and become fixed. Newer models of dementia education which directly involve people with dementia include longitudinal approaches and activity-based interventions such as intergenerational art projects.³ The longitudinal model developed by Mordhardt and colleagues,⁴ the *Buddy Program*, is an elective curricular component, where medical students are paired with a person with dementia and undertake community visits and activities together. The original programme has grown across North America, and the model has been used across a number of different contexts, such as the 'Friend for Rachel' model for pre-medical students (undergraduate and post-baccalaureate students preparing for medical school).⁵

The advantages of such longitudinal models are that healthcare students can hear first-hand what it is like to live with dementia and gain an understanding of living with long-term chronic illness, and through continuity of contact build relationships that may foster positive attitudes and person-centred care.^{6,7}

One programme that builds on this concept, is the TFD programme which was developed in the UK, with support from Health Education England, at Brighton and Sussex Medical School in 2014.⁸ Unlike the *Buddy Program*, which is designed to accommodate only a relatively small number of interested students in any institution, TFD

is delivered as a mandatory component of the curriculum. This means that the whole year participates, not just those with an interest in dementia. It was also explicitly developed to be delivered to all healthcare student groups, not just medical students. The learning objectives of TFD are to increase positive attitudes, knowledge, and empathy in students by developing a broader understanding of the impact and experience of dementia.

An initial evaluation of the TFD programme showed that: (a) it was possible to deliver the programme at scale as a mandatory component of the curriculum; and (b) there were improvements in dementia knowledge and attitude change in medical students who undertook the programme compared to students who did not.⁹ Qualitative interviews and focus groups with medical, nursing and paramedic students also identified improvements in the depth of dementia understanding, challenging of negative attitudes, and increased confidence in delivering person-centred care in practice.^{10,11} Due to these positive preliminary findings, TFD was expanded across the south of England to include a wider range of healthcare students. The aim of the study reported here was to evaluate this wider and more representative expansion of TFD in terms of its impact on student attitudes, knowledge and empathy towards dementia.

2 | METHODS

2.1 | Design

A longitudinal survey was administered to healthcare students before (Baseline) and at the end of the programme (24 months), and at equivalent time points in training for a control group of students who had not taken part in the programme. Measures of knowledge, attitudes, and empathy were completed at both timepoints; demographics and previous experience of dementia were ascertained at baseline.

2.2 | Time for Dementia intervention

Students undertaking the TFD programme visit a family (person with dementia and their carer) over a 2-year period. Students attend a 1 hour introductory session; which introduces the aims of the programmes and involves a person with dementia and a student who has

already undertaken the programme describing their experience. Students then undertake a 2-h preparatory session which makes clear the expectations of the programme, structure and guidelines for visits, and communication with people with dementia. After this, pairs or trios of students visit a person with dementia and their family for 2 h every 3–4 months for a total of 5–6 visits. During the visits, students follow a suggested visit structure linked to core learning objectives. For example, the first visit is focussed on understanding the family's background, events leading up to diagnosis of dementia and the experience of diagnosis, whereas the second visit is focussed on life since the diagnosis, and experiences of services. Further details of the intervention can be found in previous publications.^{8,9} In this study, the programme was delivered to nursing, medical, paramedic and allied health professional (AHP; including occupational therapy, physiotherapy, speech and language therapy, radiology) students. Depending on curriculum fit, the programme starts in either the first or second year of training.

2.3 | Study setting and participants

The intervention group consisted of healthcare students participating in TFD between 2014 and 2020 at five universities in the south of England: Brighton and Sussex Medical School, University of Surrey, University of Brighton, University of Greenwich, and Canterbury Christ Church University. Participation in TFD was mandatory for students where TFD was included in the curriculum, but participation in the evaluation was not. The control group included cohorts of equivalent healthcare students who did not take part in TFD at these five universities as well as Norwich Medical School. In total 24 intervention and 8 control student cohorts were invited to take part in the study. All students were invited to take part in the evaluation within scheduled lectures. They were given an information sheet in advance, and written consent was obtained. The study was approved by the NHS Health Research Authority London Queen Square Research Ethics Committee (15/LO/0046).

In March of 2020 the COVID-19 pandemic led to the cessation of face-to-face visits to TFD families. The student cohorts affected by this disruption had a reduced number of visits and their last contact with their allocated families was conducted over the telephone. For the analysis, this disruption was recorded as those who completed the programme and their 24-month follow-ups before the 1st of March 2020 (no disruption) or post this date (possible disruption).

2.4 | Outcomes measures

All students completed the same battery of instruments at baseline and 24 months later. For all outcomes, higher scores indicate a higher, or more positive, level of the attribute.

- Approaches to Dementia Questionnaire (ADQ),¹² 19 items assessing attitudes towards dementia, each scored 1–5 (total: 19–95) with two subscales 'hopefulness' and 'person-centeredness',

- Alzheimer's Disease Knowledge Scale (ADKS),¹³ 30 true/false items (total: 0–30) assessing students' knowledge of Alzheimer's disease;
- Dementia Knowledge Questionnaire (DK-20),¹⁴ 20 true/false items (total: 0–20) assessing dementia knowledge;
- Dementia Attitude Scale (DAS),¹⁵ 20 items assessing attitudes toward dementia scored on a 7-point Likert-type scale (total: 20–140) with two subscales 'dementia knowledge' and 'social comfort';
- Medical Condition Regard Scale (MCRS),¹⁶ 11 items scored on a 6-point Likert-type scale (total: 11–66) assessing the extent students find patients with a given condition to be enjoyable, treatable and worthy of medical resources; and
- Jefferson Scale of Empathy (JSE): Medical Student Version and Health Professional Version.¹⁷ 20 items scored on a 7-point Likert-type scale (total: 20–140) measuring student empathy.

2.5 | Statistical analysis

Demographic and outcome data were summarised by group (intervention or control) using means and standard deviations for normally distributed variables, medians and means for skewed continuous variables and frequencies and percentages in categories for categorical variables.

For the primary analysis, outcomes were modelled using two-level multilevel linear regression models. Students attended visits in pairs or trios and therefore group membership was included as a random effect. Independent variables included in the models were: the outcome at baseline (continuous), student age (continuous), student gender (female/male), student previous experience of dementia (yes/no) and ethnicity (White British or European/other ethnic groups), COVID-19 disruption (yes/no), and intervention group (intervention/control).

The secondary analysis included replicating these models, and adjusting for the same variables, except the intervention group (intervention/control) which was replaced with the number of TFD visits completed by students to explore the relationship between the number of visits and outcomes. This was possible due to variation in the number of visits completed, influenced in part by the disruption caused by COVID-19. For both analyses assumptions for linear regression were examined, and robust standard errors were calculated as residuals deviated from normality. Analyses were performed in Stata 17.0.¹⁸

3 | RESULTS

3.1 | Student recruitment and demographics

In the intervention group, 3619 students were eligible¹ to take part and 2700 (74%) consented to participate in the evaluation. In the control group, 863 students were eligible and 562 (65%) consented. At baseline, 2570 (95%) of the consenting intervention group and 498 (89%) of the consenting control group contributed to the data.

TABLE 1 Descriptive summaries of demographics and other characteristics of student participants.

	Control (n = 562)		Intervention (n = 2,700)		Total (n = 3,262)	
	Median 23.0 No.	IQR 20.0 to 29.0 %	Median 21.0 No.	IQR 19.0 to 27.0 %	Median 21.0 No.	IQR 19.0 to 28.0 %
Age (years)						
Type of student						
Medical	112	19.9	631	23.4	743	22.8
Nurse	324	57.7	1,274	47.2	1,598	49.0
Paramedic	84	14.9	317	11.7	401	12.3
AHP	42	7.5	478	17.7	520	15.9
University						
Brighton and Sussex Medical School	0	0.0	631	23.4	631	19.3
University of Surrey	41	7.3	1,014	37.6	1,055	32.3
University of Brighton	220	39.1	445	16.5	665	20.4
Norwich Medical School	112	19.9	0	0.0	112	3.4
University of Greenwich	68	12.1	149	5.5	217	6.7
Canterbury Christ Church University	121	21.5	461	17.1	582	17.8
Student gender						
Male	109	19.8	572	21.4	681	21.1
Female	442	80.2	2,095	78.5	2,537	78.8
Other	0	0.0	2	0.1	2	0.1
Student ethnicity						
White British/European	383	70.7	1,899	72.6	2,282	72.3
Mixed/Multiple ethnic groups	14	2.6	87	3.3	101	3.2
Asian/Asian British	58	10.7	277	10.6	335	10.6
Black/African/Caribbean/Black British	77	14.2	282	10.8	359	11.4
Other	10	1.8	70	2.7	80	2.5
Experience of knowing someone with dementia						
Yes	324	60.0	1,433	54.9	1,757	55.7
No	216	40.0	1,179	45.1	1,395	44.3
Details of students' experience with dementia						
Family member/Friend	104	32.2	521	36.6	625	35.8
Paid/Unpaid work	150	46.4	622	43.7	772	44.2
Both	69	21.4	279	19.6	348	19.9
COVID-19 disruption						
No	483	85.9	1,401	51.9	1,884	57.8
Yes	79	14.1	1,299	48.1	1,378	42.2
No. of completed TFD visits						
0	562	100.0	3	0.3	565	32.6
1	0	0.0	78	6.7	78	4.5
2	0	0.0	104	8.9	104	6.0
3	0	0.0	176	15.0	176	10.2
4	0	0.0	222	19.0	222	12.8

TABLE 1 (Continued)

Age (years)	Control (n = 562)		Intervention (n = 2,700)		Total (n = 3,262)	
	Median	IQR	Median	IQR	Median	IQR
	23.0 No.	20.0 to 29.0 %	21.0 No.	19.0 to 27.0 %	21.0 No.	19.0 to 28.0 %
5	0	0.0	309	26.4	309	17.8
6	0	0.0	279	23.8	279	16.1

Abbreviations: AHP, Allied health professionals (Occupational therapy; Physiotherapy, Speech and language therapy and Radiography); IQR, interquartile range; TFD, Time for Dementia.

TABLE 2 Descriptive summaries of scores on outcome measures at baseline.

	Baseline								
	Control			Intervention			Total		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
ADQ total (19–95)	78.1	7.6	489	79.0	6.6	2,549	78.8	6.8	3,038
ADQ—Hopeful (8–40)	28.2	4.3	489	28.9	4.0	2,549	28.8	4.1	3,038
ADQ—Person-centredness (11–55)	49.9	4.9	489	50.1	4.3	2,549	50.0	4.4	3,038
ADKS total (0–30)	22.6	3.1	496	22.9	3.1	2,582	22.8	3.1	3,078
DK-20 total (0–20)	14.5	3.0	498	15.1	2.9	2,544	15.0	2.9	3,042
MCRS total (11–66)	53.9	7.3	489	54.2	6.8	2,570	54.2	6.8	3,059
DAS total (20–140)	112.0	14.6	483	112.3	13.4	2,549	112.2	13.6	3,032
DAS—Comfort (10–70)	50.5	9.8	483	50.4	9.5	2,549	50.4	9.6	3,032
DAS—Knowledge (10–70)	61.5	7.5	483	61.8	6.4	2,549	61.8	6.6	3,032
JSE total (20–140)	113.9	12.2	466	114.9	11.7	2,503	114.8	11.8	2,969

Abbreviations: ADKS, Alzheimer's Disease Knowledge Scale; ADQ, Approaches to Dementia Questionnaire; DAS, Dementia Attitude Scale; DK-20, Dementia Knowledge Questionnaire; JSE, Jefferson Scale of Empathy; MCRS, Medical Condition Regard Scale; SD, standard deviation.

TABLE 3 Descriptive summaries of scores on outcome measures at 2 year follow up.

	24 Month follow up								
	Control			Intervention			Total		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
ADQ total (19–95)	79.7	6.6	232	80.6	6.8	1,199	80.4	6.8	1,431
ADQ—Hopeful (8–40)	29.4	3.9	232	29.9	4.0	1,199	29.8	4.0	1,431
ADQ—Person-centredness (11–55)	50.3	4.1	232	50.7	4.2	1,199	50.7	4.2	1,431
ADKS total (0–30)	24.3	2.8	236	24.7	2.8	1,215	24.6	2.8	1,451
DK-20 total (0–20)	15.5	2.8	232	16.3	2.4	1,199	16.2	2.5	1,431
MCRS total (11–66)	53.6	6.9	233	54.0	6.7	1,199	53.9	6.8	1,432
DAS total (20–140)	113.8	13.1	231	116.6	12.4	1,196	116.2	12.5	1,427
DAS—Comfort (10–70)	51.6	9.1	231	53.8	8.5	1,196	53.5	8.6	1,427
DAS—Knowledge (10–70)	62.2	6.5	231	62.8	6.0	1,196	62.7	6.1	1,427
JSE total (20–140)	115.0	12.9	228	116.8	12.9	1,182	116.5	12.9	1,410

Abbreviations: ADKS, Alzheimer's Disease Knowledge Scale; ADQ, Approaches to Dementia Questionnaire; DAS, Dementia Attitude Scale; DK-20, Dementia Knowledge Questionnaire; JSE, Jefferson Scale of Empathy; MCRS, Medical Condition Regard Scale; SD, standard deviation.

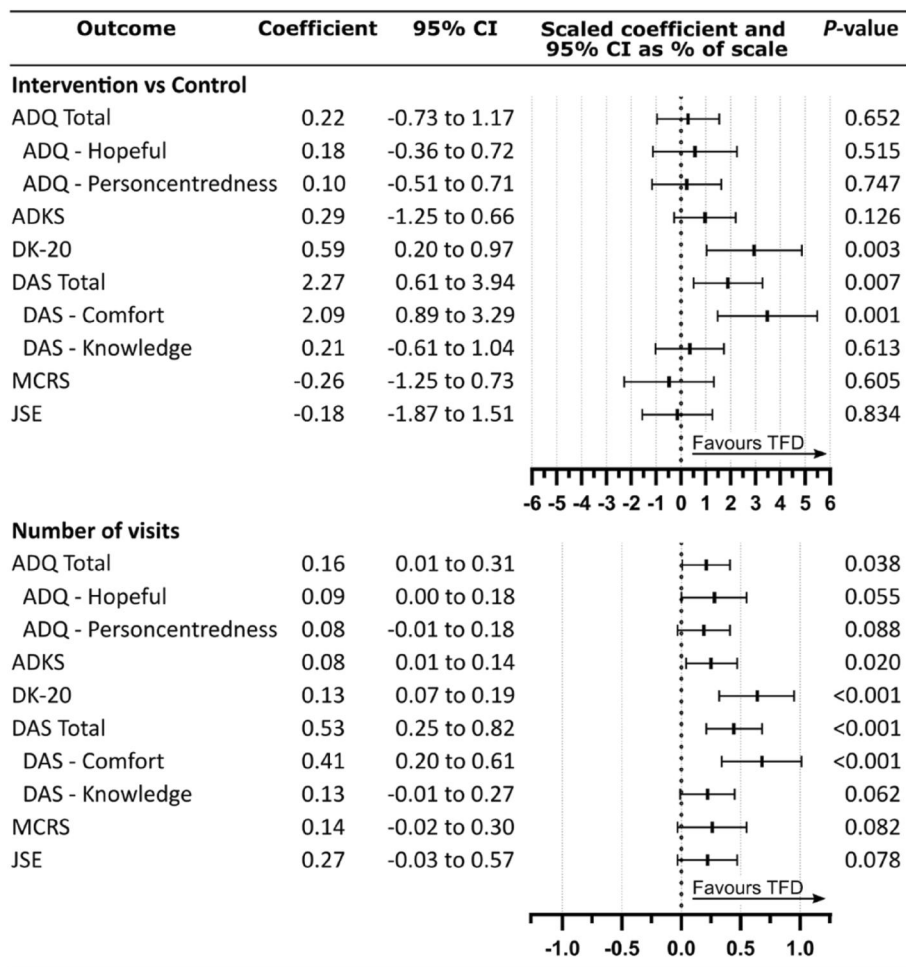


FIGURE 1 Adjusted multilevel models comparing 2-year outcomes in Time for Dementia (TFD) recipients with controls and association of 2-year outcomes with the number of TFD visits, with adjusted regression coefficients as a percentage of each scale. ADKS, Alzheimer's Disease Knowledge Scale; ADQ, Approaches to Dementia Questionnaire; DAS, Dementia Attitude Scale; DK-20, Dementia Knowledge Questionnaire; JSE, Jefferson Scale of Empathy; MCRS, Medical Condition Regard Scale; CI, confidence interval. Each multilevel model is adjusted for the student outcome at baseline, age, gender, previous experience of dementia, ethnicity, COVID-19 disruption, and a random effect is included for student group identity.

At 24 months 1215 (45%) in the intervention group and 236 (42%) control group completed a follow up assessment. Details of demographics, COVID-19 disruption, and the number of completed visits are presented in Table 1.

3.2 | Intervention group

The scores on the study outcomes for baseline and follow up are presented in Tables 2 and 3. Figure 1 presents the results of the adjusted multilevel models comparing 2-year outcomes in TFD recipients to controls for the primary analysis. To illustrate the magnitude of the differences Figure 1 also displays the adjusted regression coefficients for the TFD group versus the control group as a percentage of each scale. Overall there was strong evidence supporting improvements for those receiving TFD in attitudes to dementia in the DAS total (coefficient: 2.27, 95% confidence interval [95% CI]: 0.61–3.94, $p = 0.007$) and its comfort scale (2.09, 95% CI:

0.89–3.29, $p < 0.001$). There was also strong evidence for more positive scores of dementia knowledge on the DK-20 (0.59, 95% CI: 0.20–0.97, $p = 0.003$) but not for the ADKS (0.29, 95% CI: –1.25 to 0.66, $p = 0.126$) or DAS Knowledge subscale (0.21, 95% CI: –0.61 to 1.04, $p = 0.613$). There was no evidence for differences on the other attitude measures; for the ADQ (0.22, 95% CI: –0.73 to 1.17, $p = 0.652$) or its subscales, MCRS (–0.26, 95% CI: –1.25 to 0.73, $p = 0.605$) and JSE (–0.18, 95% CI: –1.87 to 1.51, $p = 0.834$).

3.3 | Number of visits

Figure 1 presents the results of the adjusted multilevel models exploring 2-year outcomes with the number of TFD visits completed and illustrates these differences with the adjusted regression coefficients for the number of visits as a percentage of each scale. There was evidence that the number of visits completed by students was associated with increased positive attitudes as measured by the ADQ

(0.16, 95% CI: 0.01–0.31, $p = 0.038$) and weaker evidence for its hopefulness (0.09, 95% CI: 0.00–0.18, $p = 0.055$) and its person-centredness subscale (0.08, –0.01 to 0.18, $p = 0.088$). There was strong evidence of differences in the DAS (0.53, 95% CI: 0.25–0.82, $p < 0.001$) including its comfort subscale (0.41, 95% CI: 0.20–0.61, $p < 0.001$) and less strong evidence for its knowledge subscale (0.13–0.01 to 0.27, $p = 0.062$). Increases in knowledge were observed as measured by the DK-20 (0.13, 95% CI: 0.07–0.19, $p < 0.001$) and the ADKS (0.08, 95% CI: 0.01–0.14, $p = 0.020$). There was weak evidence for a positive association with visit numbers for the MCRS (0.14, 95% CI: –0.02 to 0.30, $p = 0.082$) and JSE (0.27, 95% CI: –0.03 to 0.57, $p = 0.078$).

4 | DISCUSSION

Our findings indicate that, across professional backgrounds, students undertaking the TFD programme developed higher levels of knowledge and more positive attitudes to people with dementia compared with equivalent students not enrolled in the programme. Our results also suggest that these positive impacts increase with the number of visits undertaken. We believe these to be the first quantitative data indicating the potential value of a dementia training initiative across the range of healthcare professionals in training and applied at a whole cohort level. Taken with the positive multi-professional qualitative analyses of TFD we have completed¹⁰ these data provide encouraging evidence for the positive impact of TFD on healthcare professionals in training.

These findings build on our earlier quantitative evidence of the effectiveness of TFD for medical students alone.⁹ They indicate that TFD has a complementary positive impact on student learning about dementia in addition to traditional didactic class-room based teaching and placements which do not provide the profound level of deep learning that more experiential learning can offer.¹⁹ In TFD, the experiential component is longitudinal first-hand exposure to the challenges that people living with dementia and their carers experience on a daily basis. The students are in effect taught by the people with dementia and their families, and it enables them to see the world and healthcare through their eyes.²¹ This identification with the person with dementia and their carer and relational learning which takes place appears to be powerful in terms of knowledge and attitude change.

These findings are also consistent with positive outcomes identified by other experiential longitudinal models, such as the Buddy program.²⁰ In such programmes, participation in the programme is elective, and students are matched with a person with dementia based on similar interests. Therefore, there are notable differences between TFD and these programmes, specifically the mandatory nature of the programme, the pairing of 2-3 students with a family rather than 1 student and pairing based on geography rather common interests. This might explain the modest nature of TFD positive outcomes, with a focus on broadly upskilling the entire medical student cohort as opposed to more in-depth outcomes for a smaller number of interested students.

It is interesting to note that there appears to be a 'dose response' relationship, in that student outcomes are higher for students who complete more visits. The importance of longitudinal contact is supported by our qualitative findings¹⁰ which identified the importance of relational learning within TFD. Learning takes place within an authentic meaningful relationship between the person with dementia, their carer and students, which deepens over time. Further research is needed to understand the optimal number of visits, and how the longitudinal nature of the visits underpins the effects observed.

As in our earlier study of medical students,⁹ TFD did not appear to change quantitative measures of empathy, unlike our two qualitative studies^{10,21} which identified positive change in terms of empathy towards people with dementia. In terms of potential explanations, first JSE is a generic empathy measure, and its potential limitation in measuring empathy towards people with dementia has been identified in a wider systematic review of empathy interventions for people with dementia.²² It may be that the measure itself is not sufficiently responsive to change in dementia. Second, there may be issues related to social desirability in students, due to a perception that it may be professionally unacceptable to admit to lower levels of empathy.²³ Third, it is interesting to note that there was a positive change in both intervention and control groups, which challenges the existing body of work that suggests a decline in empathy during healthcare training²⁴; and it may be that other factors such as placement experiences including role models and ward culture might have positive impacts on empathy. Finally, it may be that alternative methods of assessing empathy, for example, patient or carer feedback, might have yielded a more accurate reflection of empathy in practice,²⁵ which could have been a more meaningful outcome.

There are two main limitations of this study. First, the study was affected by the COVID-19 pandemic through unplanned alterations to the TFD evaluation and programme delivery. Data collection sessions could not take place in person as planned. Despite active attempts to obtain follow up measures from students, overall this means that the loss to follow up was greater than expected. In terms of the TFD programme and altered delivery, we do not know how the final telephone interactions that took place after March 2020, compared to face-to-face visits. Life for both families and students would have been heavily impacted by the pandemic, and this is likely to have been the focus of the telephone contact, and not wider dementia learning. The impact of the pandemic therefore adds complexity to the interpretation of the research. Second, due to the study design, a number of potential confounders and biases cannot be accounted for in the analyses such as differences in the content of university curriculums, in control groups, and potential responder bias across intervention groups and at follow up. However, this study does have strengths. First, it is a real-life pragmatic study, which has managed to recruit a high number of participants. Second, the use of comparison groups and controlling for potential confounders (including COVID-19 disruption) within the statistical modelling strengthens the conclusions that can be drawn. Third, the inclusion of a broad range

of professional groups in training across different universities widens the generalisability of the findings.

5 | CONCLUSION

There is a pressing global requirement that the future workforce is better equipped to support people living with dementia. Evidence based dementia education programmes, such as TFD illustrate that this aspiration can be met and how it can be met. The size and scope of this evaluation demonstrates that TFD can be delivered across a range of training programmes and universities, and suggests that in doing so, TFD can improve the dementia knowledge and attitudes of future healthcare professionals. The future of care for complex conditions such as dementia is teamwork, and strategies like TFD that enable symmetrical understanding of patient needs and experiences are likely to be of particular value in facilitating effective teamwork. The demonstration that people with dementia and their family carers can be deployed at scale as a teaching resource for healthcare students is also an encouragement to the meaningful involvement of patient groups in healthcare education. Further research is required to more fully understand the mechanisms of action of TFD, as well as differential impacts between student types, the optimal number of sessions, and whether change in knowledge and attitude translates into practice.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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ENDNOTE

¹ The number approached for research could not be calculated as registers for attendance at recruitment sessions or the numbers approached via email were not available. Therefore, the number presented for eligible students is based on intake numbers of student cohorts.

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