

Embedding effective dementia education into undergraduate medical curricula – a realist review

Running title: Embedding dementia education

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Abstract

Background

Despite the growing global population of people with dementia, education about dementia is not systematically integrated across undergraduate healthcare curricula. This study set out to explore the reasons behind this inconsistency.

Methods

An earlier realist review identified barriers and facilitators to integrating effective dementia education in medical schools through the development of an initial programme theory (IPT). This study examined further supporting literature and undertook interviews with a wide range of stakeholders, including people with dementia and carers, to refine the IPT, synthesising the contexts and mechanisms that influence dementia education.

Results

Twenty-nine educational interventions about dementia were included in the data synthesis and supported the domains of the IPT. Twenty-three stakeholders, including clinical educators, people with dementia and their carers, and medical students, were interviewed to interrogate the IPT. Stakeholders agreed that the IPT appropriately represented the challenges of embedding effective dementia education. All stakeholders highlighted the failure to mandate education about dementia in medical curricula as a sign of a lack of institutional commitment. In contrast to the literature, stakeholders did not think that

negative student attitudes were a significant barrier, rather a lack of confidence due to limited contact with people with dementia.

Conclusions

Embedding effective dementia education in medical curricula is possible if contextual barriers are identified and facilitatory mechanisms are developed. Our programme theory offers a roadmap for educators to embed undergraduate dementia education in their own medical school.

Key words: dementia, medical education, curriculum, realist synthesis, older people.

Key points

- There is a strategic need to increase the amount of dementia education embedded in undergraduate medical curricula.
- Realist synthesis combines systematic literature review with involvement of stakeholders, including people with dementia.
- Realist synthesis can identify the barriers and facilitators to integration of effective dementia education.
- Using realist synthesis, we refine a programme theory to guide integration of dementia education.

Introduction

As the longevity of global populations continues to increase, age-related conditions such as dementia become more prevalent. Worldwide, an estimated 55 million people live with dementia and 60 percent of them reside in developing countries [1]. Recognition of the challenges presented by dementia prompted the World Health Organisation (WHO) to adopt a Global Action Plan (GAP) on dementia in 2017 to consider how the needs of people with dementia (PWD) can be better acknowledged and managed [2].

In developed countries with older populations such as the UK and US, most healthcare professionals (HCPs) will work with PWD daily. Demographic projections suggest this will become increasingly important in less developed countries in the coming decades. It is critical that HCPs receive comprehensive education about how to care for PWD and their supporters with compassion, and training on evidence-based clinical interventions.

However, dementia education is not embedded systematically in curriculums in the UK [3] or elsewhere in the world [4], meaning that the workforce does not always possess the necessary knowledge and skills to provide high quality care [5]. Arguably, this reflects a degree of systemic ageism in medical education, whereby complexity of care and hospital environments can exacerbate negative attitudes of students [6].

There is an expanding evidence base as to what constitutes effective education and training about dementia for HCPs. Key features of good educational interventions for HCPs include collaboration with community organisations, and involvement of PWD and carers in experiential learning [7]. One example of an effective educational intervention for undergraduate healthcare professions including medicine, nursing and paramedicine is the

UK-based “Time for Dementia” (TfD) programme [8]. Similar programmes exist in the United States (US) [9]. Despite this evidence, effective education about dementia is not yet systematically integrated into medical schools meaning that not all graduates are afforded the opportunity to obtain adequate experience [4].

There are barriers to the dissemination and integration of high-quality teaching and learning about dementia. The medical curriculum is often historically compartmentalised according to body-systems, with reluctance from institutions to disassemble these long-standing structures to make space for syndromes such as dementia that do not fit neatly into a specific “ology”. Dementia traditionally “belongs” to old age psychiatry as a speciality, who tend to have minimal visibility in the medical curriculum, whereas in reality people with dementia present across medical specialities. Existing healthcare services structures can be slow to incorporate good practice in relation to dementia care meaning that students are unlikely to be exposed high quality care for people with dementia. The prioritisation of placements in secondary care may confine student experience to people with dementia in crisis rather than to the majority who live well in a community setting.

In response to the gap between the evidence about effective dementia education and widespread integration into the undergraduate medical curriculum, we initiated a realist review to outline the circumstances in which good practice was established and the barriers to integration in other environments. A realist approach allows for complex processes and interventions to be applied to our real-world in a more actionable manner due to its grounding in context-specificity [10].

Our research questions were: firstly, why might effective interventions not be systematically integrated into medical school curricula? Second, for whom and in which circumstances is successful dementia education effectively implemented? The early stages of our review, culminating in an initial programme theory (IPT) has been published previously [11]. This report outlines the validation and refinement of our IPT (Figure 1) with recommendations for effective integration of dementia education into the medical curriculum.

Methods

Rationale for realist approach

Rather than identifying the features of an effective intervention in isolation, a realist approach acknowledges that contextual factors are important in the success or otherwise of an intervention [12]. Improved ability of medical graduates to care competently for PWD, in this case, is unlikely to be a direct result of a single intervention – rather, multiple mechanisms impacted by contextual factors likely influence outcomes. Transposition of a successful intervention from one educational environment will not necessarily lead to the same outcomes elsewhere. Realist reviews look beyond the nature of an intervention to consider context and mechanisms including cultural, historical and geographical [13]. The realist approach has demonstrated utility in exploring complex processes such as anti-microbial prescribing behaviours [14], and supporting international medical graduates [15]. We selected the realist approach as the most appropriate strategy to meet our objectives. Our report is structured according to Realist and Meta-narrative Evidence Syntheses Evolving Standards (RAMESES) [16].

Search processes

Previously, our review included an exploratory search of relevant databases identifying twenty educational interventions for analysis and synthesis in 2022 to produce an initial programme theory (IPT) (Figure 1). We subsequently repeated the search using the same terms, databases and inclusion criteria in October 2024 to capture more recently published eligible studies. We searched PubMed, Embase, CINAHL and PsycINFO using the Mesh terms *Schools, Medical; Students, Medical; Education, Medical AND Neurocognitive disorders* or the closest possible set of terms.

Inclusion criteria

- Undergraduate or graduate entry medical school programme
- Teaching and learning focussing on dementia (rather than cognitive impairment more broadly)
- Evaluating participant outcomes > satisfaction, knowledge, skills, attitudes or behaviours
- Interventions described clearly enough to classify teaching method
- Any research design (quantitative and qualitative)
- English language

Selection, appraisal and data extraction

Our method of selection, appraisal, and analysis of papers identified by our exploratory search is available elsewhere [11]. Following our updated search, we adapted our pre-existing spreadsheet to categorise data extracted according to our IPT structure. Our research team entered information relating to each of the four contextual barriers (culture, concern for patient welfare, student attitudes and logistics) into relevant columns of a

spreadsheet. Team members also entered any data that did not correlate with our IPT structure and concerns about the methodological approach of each study.

In keeping with the realist model, ideas generated from the exploratory review prompted the consideration of different domains that might help inform our IPT. In this case, through discussion with expert educators we became aware of parallels between the integration of education about dementia and the implementation of education about learning difficulties (LDs).

Analysis and synthesis

In the context of realist review, analysis and synthesis is akin to refining theory. The validity of our IPT was strengthened by systematic attention to evidence, however, scientific articles cannot capture the personal experiences of people involved in education about dementia, namely educators, students, people with dementia (PWD) and their carers. Further, it is atypical for published studies to include detail of context in which an intervention takes place – this limits the potential to determine which contextual factors are likely to have influenced outcomes. To gain further insight into contextual factors and to test the validity of our IPT we contacted stakeholders to seek their views.

We contacted convenience samples of educators within higher education and medical students. Through the Alzheimer's Society, a key partner of the team delivering the TfD programme [8], we invited PWD and their carers to contribute. Participants, who had all taken part in TfD, were provided with an information sheet and we confirmed consent for remote interview. Interviews followed a semi-structured topic guide (supplemental material S1) with flexibility for participants to recount their experience beyond TfD and the domains

of the IPT. Interviews were recorded and transcribed. Team members analysed transcripts to identify data that supported the IPT, data that suggested refinement in terminology around contexts, mechanisms and outcomes, alternative interpretation of concepts, and any divergent data. The IPT was used as a coding framework with transcript data categorised according to the four barriers (Figure 1). Data was coded as concordant with each barrier or as a potential facilitator to each barrier. Any data divergent or additional to the four barriers was specifically highlighted for further discussion. Once data was categorised, team members (all of whom have experience of delivering healthcare education), discussed to what extent data supported the existing IPT or where amendment or additions should be made. Each iterative version of the evolving Programme Theory (PT) was reviewed by all team members and finalised by consensus.

Ethical approval was granted by the University of Sunderland

Results

From a starting list of 693 studies via database searches we identified 26 eligible studies for inclusion in our data synthesis (Figure 2). We found three further studies via manual searching of references from the eligible studies to make a total of 29 (Table 1).

Document characteristics

Of the 29 studies evaluating dementia education, seventeen involved only medical students [9, 17, 20, 22, 28-29, 30, 32-35, 36, 38, 44-47] and nine involved other healthcare professions students including pharmacy and nursing [18, 21, 24-27, 31, 37, 39]. One study involved staff contributing to an educational intervention [19], one involved PWD and carers [23], and one was descriptive [43]. Cohort sizes ranged from eleven [38] to 386 [17] and the

29 studies reported a range of outcomes including student knowledge and attitudes, and qualitative data from focus groups, interviews and reflections.

Stakeholder interviews

We conducted eighteen interviews with 23 stakeholders (Table 2) – nine clinical educators including eight doctors and one dentist, ten PWD and carers (five interviews of two pairs), three medical students and one educational programme organiser. Eighteen stakeholders were based in the UK, two in Malaysia and one in South Africa, one in Taiwan and one in Brazil.

Main findings – literature review

All 29 studies included in the literature review referred to one or more of the contextual barriers represented in our IPT although rarely matched to all four. This was to be expected - by virtue of publishing a study about an (often effective) educational intervention, the authors demonstrated that they had overcome such barriers and therefore did not always describe the context in which their intervention took place. In relation to institutional culture, the majority of the interventions were voluntary for students. This means that it was rare for any intervention to be given sufficient value to be integrated as a mandatory part of curriculum. The exception was the TfD programme which emphasised committed senior leadership as critical for its successful implementation [17-19]. Contextual logistical challenges included finding space within a crowded curriculum, particularly for longitudinal programmes [9,17,19,20], coordinating timetables for interprofessional learning [21], and expenditure on simulation technology [22]. The most important mechanisms to overcome logistical barriers were iterative implementation alongside committed senior leadership.

For interventions that involved people with dementia or carers, risks to patient welfare were considered by educational teams who used various mechanisms to mitigate risk including collaboration with dementia advocacy groups [23-27], involvement of PWD and carers in the design of the programme [23], and ongoing dialogue with carers and healthcare staff [23,28,29]. As an alternative to direct contact with PWD, simulation was an option for integration of dementia education with fewer risks to participant welfare [22,24,25,30].

Evidence as to the presence of negative attitudes amongst students, educators and wider faculty was variable. Negative attitudes were frequently cited as a potential contextual issue [9,17,18,20,26,28-29,31-39], but not formally evaluated at an institutional level. Where authors used a validated tool to evaluate attitude change amongst students [17,24,25,29,33-35,37-39], the meaning of any numerical change is unclear, particularly in contexts where students are volunteering to participate and therefore may hold more positive attitudes to begin with.

Main findings – stakeholder interviews

All stakeholders endorsed the overarching structure and components of the IPT, although there was variation in experience of each of the contextual barriers according to role. For example, people with dementia and their carers were less likely to reflect on the logistical barriers to implementing an educational programme, but were able to add depth to evidence around mechanisms to overcome concerns about participant welfare. In relation to cultural context, people with dementia, carers, educators and students were united in

their view that dementia is under-represented in the medical curriculum and that this reflects a failure of institutions to meet the needs of the population:

More awareness of prevalence is important to raise the value of dementia. (Educator)

Educators believed that the cultural environment of medical school prompted students to prioritise the acquisition of technical skills in the acute care environment in preference to complex patient centred communication skills:

there's that sort of push like they want someone that's fast and operatively very skilled.

(Educator)

communication or empathy or understanding someone's lived experience or undertaking a capacity assessment around consent, those kind of maybe what would be considered previously softer skills (Educator)

To overcome these challenges all groups emphasised the importance of dementia education being mandatory, including in student assessment. As per the literature review, the impact of a committed senior leadership to challenge existing orthodoxy is a vital component:

I think you've got to have somebody driving it or some team driving it. Otherwise it's just not going to happen (Carer)

Educators and students were more concerned about risk to patient welfare than PWD or carers, who frequently emphasised the benefits to them of participation in teaching. One PWD expressed frustration with their perception of overly prescriptive safeguarding procedures of medical institutions as “using a sledgehammer to crack a nut.” Collaboration

with dementia advocacy groups was perceived to be a helpful way to appropriately recruit and communicate with participants by all stakeholders.

One element of the IPT that did not have optimal validity in the minds of stakeholders was the contextual concern about students holding negative attitudes towards PWD. Rather, educators, PWD and carers thought that a lack of confidence due to absence of previous contact with PWD was closer to reality. Participating students suggested that they would like more contact with PWD during their training to gain experience and confidence.

Educators ran the risk of perpetuating lack of contact between students and PWD due to concerns that contact with PWD would be too complicated:

maybe the student or the supervising clinician might suspect that someone has a cognitive impairment like dementia, then very quickly ... that patient will be moved off the student clinic because it will be seen as too complicated for the student to be dealing with (Educator)

All groups of stakeholders agreed on the importance of encouraging students to reflect on their level of confidence throughout longitudinal contact with PWD, and to work through difficult conversations or moments of discomfort with the support of staff. Further, educators should be encouraged to include “complex” patients with cognitive impairment to help to break the cycle of hesitation (of educators and students) to engage with PWD.

Educators identified similar logistical challenges identified from our literature review, namely lack of space and flexibility within medical curricula. Mechanisms to overcome these challenges included “sharing” with other medical and surgical specialties (given the frequency with which PWD present across services) and linking and expanding on transferable skills acquired through contact with other under-represented groups such as

people with learning difficulties. Given the importance of multidisciplinary care for PWD and carers, dementia was proposed as an ideal “case study” for students to learn about the contribution of allied HCPs, who might support those educators who felt less confident in including PWD in teaching.

Finalised programme theory

Based on analysis of data from the literature review and stakeholder interviews we made collaborative revisions to our IPT through discussion (Figure 3). The overarching structure remained the same, but changes were made to terminology, for example “participant welfare” in preference to “patient welfare” to reflect the input of carers. Facilitators that appeared to be less of a priority for stakeholders, for example following national guidelines on dementia care, were replaced by those of greater importance such as formal assessment of students to drive learning and ensure preparation for practice. A list of amendments of the IPT is available as Supplemental material S2.

Discussion

Summary of findings

There is scope for effective dementia education to be systematically embedded into the undergraduate curriculum. There was consensus opinion from our stakeholders that dementia education must form a mandatory part of the medical curriculum, with committed senior leadership to ensure ongoing institutional support. The engagement of geriatricians, psychiatrists and general practitioners in curriculum planning is likely to facilitate this, although representatives from the majority of medical specialties have a potential role in advocating for the needs of people with dementia.

Whilst negative student attitudes towards dementia is frequently highlighted in the literature, stakeholders did not recognise this as a significant issue in reality. Rather, lack of experience managing the complexities of interacting with people with cognitive impairment prevails – this is likely to require specific targeted teaching and exposure.

The involvement of PWD and carers in the design and delivery of education is feasible, and desirable in terms of minimising risks to participants and building students' confidence. Stakeholders felt that concerns about the welfare of PWD participating in education were disproportionate and led to overly prescriptive safeguarding restrictions. There was agreement that public participation led to benefits to all parties. The growing evidence base as to the positive impact of working collaboratively with advocacy groups such as the Alzheimer's Society can be presented to curriculum leaders to demonstrate both the need for better dementia education and the benefits of adopting such interventions.

Our findings align with the literature about learning disabilities (LD) education. Here, a range of interventions exist but a lack of integration into medical curricula reduces consistent opportunities to equip professionals with the knowledge and skills to care for people with LDs. There is also a parallel with apparent negative attitudes stemming from lack of exposure, experience and confidence with this patient cohort [40]. Complex patients and complex communication, such as PWD and people with LD, can be daunting for medical students to engage with in the clinical environment and require the support of supervisors and teachers, rather than being shielded from exposure to complexity [41].

International differences

With the exception of Griffiths et al in Malaysia [37], all of the studies included in our data analysis took place in developed countries such as the US, the UK and Australia. With the intention of modifying our IPT to be relevant internationally we included stakeholders from middle-income countries including Malaysia, South Africa and Brazil. However, our interviews highlighted major differences in the epidemiology of dementia, available services for PWD and carers, and educational cultures across countries. This meant that our PT is unlikely to be fully applicable to these settings. Stakeholders from middle income countries agreed that there was a need to improve education about dementia and adapt UG curriculums. They were also interested in the involvement of PWD in education which did not generally go beyond clinical observations in these contexts. They recognised that HCP training needs would grow with the ageing of populations and the resultant increases in age-related conditions and costs [42]. However, the significant existing differences as to the needs of PWD, carers and healthcare students in low and middle-income countries will require more in-depth exploration and evaluation of those specific contexts.

Strengths and limitations

Strengths of our study include an in-depth iterative review of literature on undergraduate dementia education coupled with stakeholder interviews from people involved in the design and delivery of education. This allowed a process of review and refinement of an IPT to better represent the realities of the contexts in which education takes place, and the mechanisms influencing integration of dementia education. Stakeholders were from a variety of healthcare and educational settings and roles - this allowed for the breadth of

possible barriers and context to be fully explored at interview and lending credibility to the IPT.

The key limitation is over-reliance on published studies from the UK and US, and stakeholder input specific to the UK. However, international representation allowed some insight into the particular challenges of embedding dementia education in developing countries. Accordingly, our final PT is likely to be less helpful in some international contexts where dementia epidemiology, resources and educational culture are significantly different. Further exploration of dementia education in international contexts could help to appropriately adapt our PT to other global settings. A further limitation is the lack of empirical testing of our PT via the generation of new data. Future research could include testing the utility of the PT during the implementation of a new undergraduate educational intervention about dementia. In developing countries, further exploration of existing and novel provision of dementia education could be used to adapt the PT to better reflect the specific needs of different global contexts.

Conclusion

Embedding effective dementia education in medical curricula is achievable if contextual barriers are identified and facilitatory mechanisms are developed. Our programme theory offers a map for educators to embed undergraduate dementia education in their own medical school. Major differences in epidemiology of dementia, available services for patients and carers, and educational cultures across countries will require further exploration for this to occur internationally.

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Declaration of Conflict of interest

None

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None

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Table 1. Papers included in exploratory literature review. (Papers identified through manual searches in **bold**).

Author	Title	Participants
Annear et al [32]	Encountering aged care: a mixed methods investigation of medical students' clinical placement experiences	61 Y5 MS
Banerjee et al [43]	How do we enhance undergraduate healthcare education in dementia?	n/a (descriptive)
Banerjee et al [17]	A comparative study of the effect of the Time for Dementia programme on medical students	386 Y2/3 MS
Bard et al [22]	Increased medical student understanding of dementia through virtual embodiment	150 pre-MS
Berning et al [26]	Effect of a dementia friends information session on health professional students' attitudes and knowledge related to dementia	128 healthcare students
Blazek et al [44]	Medical Students in a Dementia Care Facility: and Enhanced Geriatric Psychiatry Experience	99 Y3 MS
Cashin et al [23]	Involving people with dementia and their carers in dementia education for undergraduate healthcare professionals: a qualitative study of motivation to participate and experience	18 pairs of PWD and carers
Daley et al [18]	A qualitative evaluation of the effect of a longitudinal dementia education programme on healthcare student knowledge and attitudes	77 healthcare students
DeCaro et al [39]	Educating students while recruiting underrepresented populations for Alzheimer's disease research: the Student Ambassador Program	37 healthcare students
de Abreu et al [31]	A Simulation Exercise to Raise Learners' Awareness of the Physical and Cognitive Changes in Older Adults	49 healthcare students
Feeney et al [19]	Barriers and facilitators to implementing a longitudinal dementia education programme into undergraduate healthcare curricula: a qualitative study	12 staff
Garric et al [38]	Medical students' perceptions of dementia after participation in poetry workshop with people with dementia	11MS
George et al [28]	Impact of participation in TimeSlips, a creative group-based storytelling program, on medical student attitudes toward persons with dementia: a qualitative study.	15 Y4 MS

George et al [33]	Evaluating an arts-based intervention to improve medical student attitudes toward persons with dementia using the dementia attitudes scale.	22 Y4 MS
George et al [34]	An arts-based intervention at a nursing home to improve medical students' attitudes toward persons with dementia	22 Y4 MS
George et al [35]	How a creative storytelling intervention can improve medical student attitude towards persons with dementia: a mixed methods study	22 Y4 MS
George et al [29]	An arts program to improve medical student attitudes toward persons with dementia	52 Y1 and 2 MS
Gilmartin-Thomas et al [24]	Impact of a Virtual Dementia Experience on Medical and Pharmacy Students' Knowledge and Attitudes Toward People with Dementia: A Controlled Study	278 Y3MS and Y4 pharmacy students
Gilmartin-Thomas et al [25]	Qualitative evaluation of how a virtual dementia experience impacts medical and pharmacy students' self-reported knowledge and attitudes towards people with dementia	53 Y3 MS and Y4 pharmacy students
Goldman et al [20]	A qualitative study of the impact of a dementia experiential learning project on pre-medical students: a friend for Rachel	95 pre-MS
Griffiths et al [37]	Perceptions and attitudes towards dementia among university students in Malaysia	97 MS and pharmacy students
Jefferson et al [9]	Medical student education program in Alzheimer's disease: the PAIRS Program.	45 Y1 MS
Matsumura et al [30]	Simulating Clinical Psychiatry for Medical Students: A Comprehensive Clinic Simulator with Virtual Patients and an Electronic Medical Record System	79 Y5 MS
McCaffrey et al [21]	Interprofessional education in community-based Alzheimer's disease diagnosis and treatment	110 MS and NP trainees
Moehl et al [45]	How to Teach Medical Students About Pain and Dementia: E-Learning, Experiential Learning, or Both?	161 Y3MS
Morhardt [36]	The effects of an experiential learning and mentorship program pairing medical students and persons with cognitive impairment: A qualitative content analysis.	71 Y1 MS

Van Zuilen et al [46]	Achieving medical student mastery in screening for cognitive impairment: Results from a blended learning curriculum	60 MS
Yang et al [47]	3D (dementia, delirium, depression) didactic for medical students.	23 Y3/4 MS
Zuccherro et al [27]	An interdisciplinary symposium on dementia care improves student attitudes toward health care teams	150 healthcare students

MS – medical student; NP – nurse practitioner; PWD – patient with dementia; Y – year

Table 2 – Stakeholder interviews

Role	Country
Time for Dementia educator team member	UK
Specialty doctor geriatric medicine	UK
OAP trainee	UK
Consultant psychiatrist	UK
Professor in Geriatric Medicine	South Africa
Patient and carer participant (2)	UK
Patient and carer participant (2)	UK
Patient and carer participant (2)	UK
Patient and carer participant (2)	UK
Patient and carer participant (2)	UK
Professor of Geriatric Medicine	Taiwan
Professor of Geriatric Medicine	Malaysia
Professor of Geriatric Medicine	Malaysia
Medical student	UK
Medical student	UK
Medical student	UK
Special Care dentist	UK
Professor of Neurology	Brazil

Figure 1. Initial Programme Theory

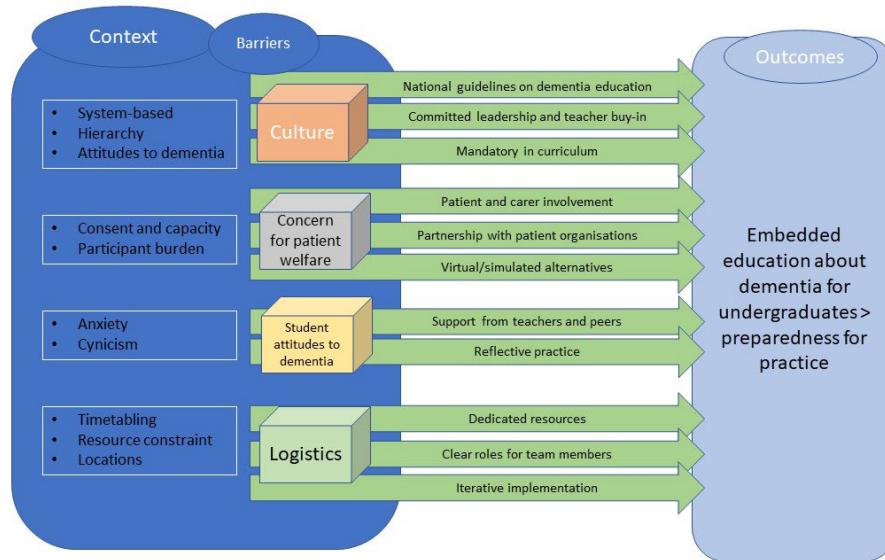


Figure 2. PRISMA diagram

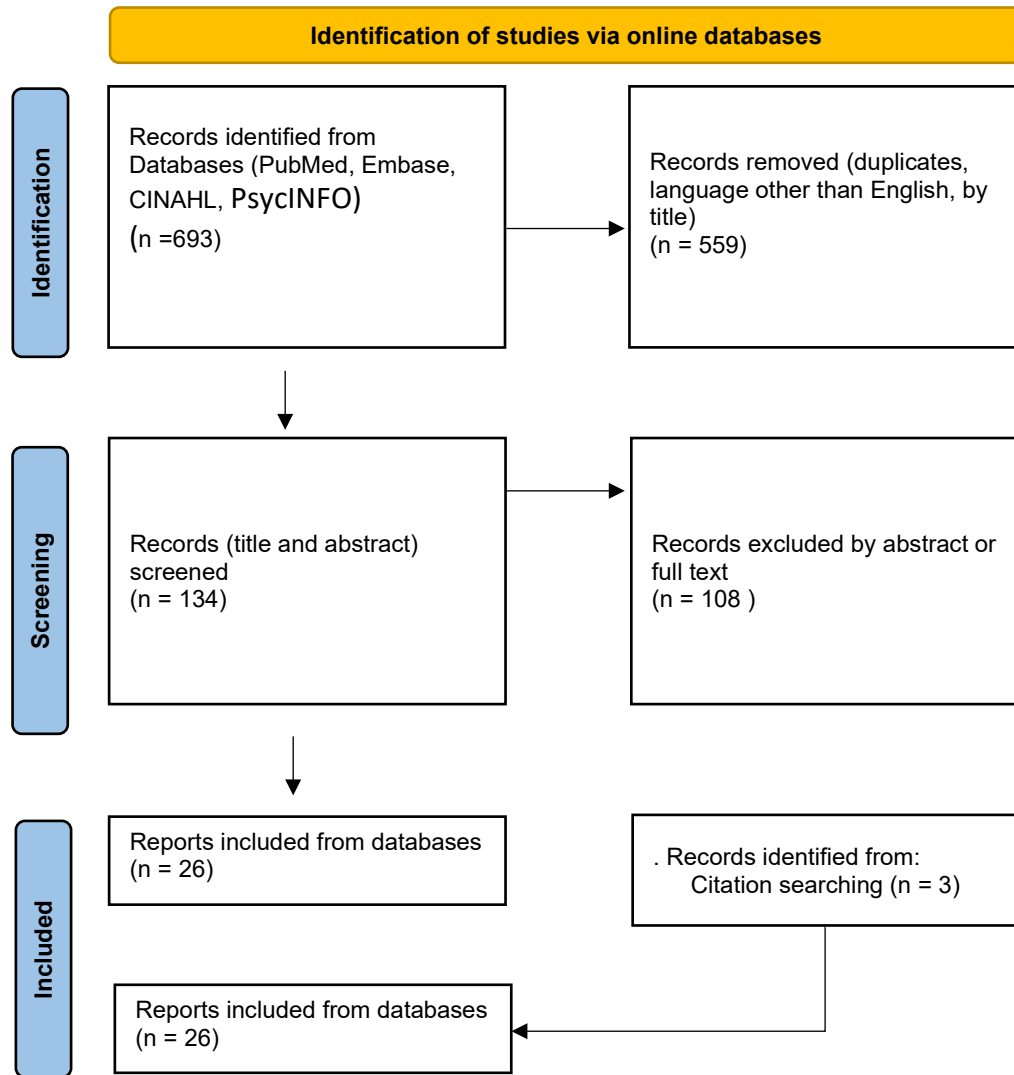


Figure 3. Final Programme Theory

