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2024

## Effective Communication with People with Dementia: An Exploratory Study of Pre-registration Occupational Therapy Students

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### Recommended Citation

Kirve, S., & Perkins, L. (2024). Effective Communication with People with Dementia: An Exploratory Study of Pre-registration Occupational Therapy Students. *Journal of Occupational Therapy Education*, 8 (3). Retrieved from <https://encompass.eku.edu/jote/vol8/iss3/4>

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# Effective Communication with People with Dementia: An Exploratory Study of Pre-registration Occupational Therapy Students

## Abstract

Dementia is a major global concern, with 50 million people already affected worldwide in 2018, and this number is expected to triple by 2050. Healthcare practitioners, specifically occupational therapists, are responsible for providing care and ensuring the well-being of people with dementia. However, occupational therapy students may not always have the necessary knowledge and skills to effectively communicate and support dementia patients, which could negatively impact the quality of care they provide. To explore this issue, a study was conducted with final-year pre-registration occupational therapy students at a public university in England. The study used a qualitative methodology, with semi-structured interviews of students. The objective was to understand the perspective of their learning experiences about communicating with dementia patients. The analysis revealed three main themes: dementia content and teaching methods, gaps in learning about communication with people with dementia, and limited placement opportunities. The study also encouraged occupational therapy students' suggestions for improving the curriculum for future students. The findings also contributed to existing literature in the field and suggested areas for further research.

## Keywords

Dementia, higher education in dementia, communication, occupational therapy, higher education

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## Acknowledgements

We would like to thank Occupational Therapy students, staff and Faculty of Health and Life Sciences at the Oxford Brookes University for support with this study.

# JOTE

Journal of Occupational  
Therapy Education

Volume 8, Issue 3

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## Effective Communication with People with Dementia: An Exploratory Study of Pre-registration Occupational Therapy Students

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### ABSTRACT

Dementia is a major global concern, with 50 million people already affected worldwide in 2018, and this number is expected to triple by 2050. Healthcare practitioners, specifically occupational therapists, are responsible for providing care and ensuring the well-being of people with dementia. However, occupational therapy students may not always have the necessary knowledge and skills to effectively communicate and support dementia patients, which could negatively impact the quality of care they provide. To explore this issue, a study was conducted with final-year pre-registration occupational therapy students at a public university in England. The study used a qualitative methodology, with semi-structured interviews of students. The objective was to understand the perspective of their learning experiences about communicating with dementia patients. The analysis revealed three main themes: dementia content and teaching methods, gaps in learning about communication with people with dementia, and limited placement opportunities. The study also encouraged occupational therapy students' suggestions for improving the curriculum for future students. The findings also contributed to existing literature in the field and suggested areas for further research.

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## **Introduction**

Dementia is a degenerative illness that causes irreversible damage within areas of intellectual, social, physical, behavioral, and psychological functioning (Donegan et al., 2017). It affects memory, thinking, learning, judgment, and language (World Health Organization [WHO], 1992). Until 2018, the global number of people living with dementia had been estimated at 50 million (Alzheimer's Disease International, 2018). Astoundingly, there is a new case globally every 3 seconds, with numbers expected to triple by 2050 (Alzheimer's Disease International, 2018). It is a major challenge for families, healthcare/social care systems, and society to care for patients with dementia (Etters et al., 2008). Global costs of the disease are about a trillion United States (US) dollars per year and is forecast to double by 2030 (Cao et al., 2020); more specifically, the total cost of dementia in the United Kingdom (UK) in 2019 amounted to £34.7 billion, with this predicted to rise to £94.1 billion by 2040 (Wittenberg et al., 2019). Subsequently, WHO (2022) announced dementia as an international health priority.

Despite dementia representing a significant proportion of healthcare users in the UK (Smith et al., 2019), higher education provisions provide poor coverage of dementia, and it is sometimes non-existent within nursing and other health-related disciplines including occupational therapy (OT; Pulsford et al., 2007). Kwok et al. (2011) examined university learning content for pre-registration OT students and found all students' knowledge about dementia was generally poor. Gavin et al. (2022) added that while education is provided, knowledge is not optimal and OT students feel they require more in-depth dementia education.

The National Dementia Strategy (Department of Health, 2009) highlighted the inadequate knowledge and skills of healthcare professionals. The Department of Health and Skills for Care (2010) concluded the lack of dementia education in early healthcare training is a significant gap that needs to be addressed. The Higher Education Dementia Network (HEDN; 2013) attempted to address this by publishing national guidance on dementia education for healthcare courses at a university pre-registration level. However, the implementation of such frameworks within the curriculum is not mandatory. Considering this, the HEDN produced a position paper aimed at professional regulatory bodies to emphasize the importance of explicitly including dementia education in pre-registration healthcare courses (Knifton et al., 2019; Surr et al., 2017a).

Dementia can cause language difficulties such as trouble finding words, difficulty understanding, and incoherent speech (Kempner & Goral, 2008). Healthcare professionals are concerned about their ability to communicate effectively with dementia patients, as there is a lack of evidence-based training on the topic (O'Brien et al., 2018; Stanyon et al., 2016). The National Institute for Health and Care Excellence (2018) in the UK emphasized the importance of staff training in communicating with dementia patients. Healthcare professionals must understand the needs of dementia patients early in their careers to improve future care (Goldman & Trommer, 2019). Communication is a core aspect of dementia education and should be taught in pre-registration healthcare courses (HEDN, 2013).

This study aims to investigate the content of dementia education for healthcare pre-registration OT students, with a focus on their knowledge of communication. It is well-known that communication care plays a significant role in influencing dementia outcomes (Eggenberger et al., 2013). By exploring this topic, we hope to highlight the importance of learning about communication in dementia care and provide suggestions for improving the content of pre-registration courses for OT students.

The study focused on final-year pre-registration OT students at a public university in the UK and how they were educated on communicating with those with dementia. To achieve this, we constructed the following research question: "How does the current OT curriculum at a public university in the UK educate OT students to communicate with those with dementia?"

In the UK, the term "pre-registration" or "Pre-reg" refers to an education and training program that leads to a professional qualification. Pre-reg students can be either BSc (undergraduate) and/or MSc (postgraduate) pre-registration students, and this terminology is commonly used in Higher Education Institutions across the UK. This pre-reg qualification is necessary for inclusion in the professional register maintained by the Health and Care Professions Council (HCPC, 2018), which is the regulating body for the OT profession in the UK.

This study addressed the following objectives:

1. Examine final year pre-reg BSc & MSc OT experiences about dementia learning in the OT program.
2. Identify strengths and gaps in education on communicating with dementia patients.
3. Offer suggestions on ways to improve OT curriculum with dementia learning.

### **Methods**

The study was qualitative, focusing on understanding educational experiences from the perspective of those studying OT, by asking "how" questions instead of "how many" (Lee, 2014). The researchers used a semi-structured interview method (Moser & Korstjens, 2018; Renjith et al., 2021) because of the flexibility in gathering information (DeJonckheere & Vaughn, 2019). The interview questions were mostly open-ended to provide useful insights into the topic, but some closed questions were also included to allow for easy analysis (Kelley et al., 2003).

### **Recruitment**

Purposive sampling was used. This study specifically focused on final-year pre-reg BSc and MSc OT students, as they had completed most of the required teaching in the curriculum at this stage and may have had a better understanding of all topics covered in the program. Researchers recruited final-year pre-registration BSc and MSc OT students from one public university in England. First-year MSc and first-year and second-year BSc OT students were excluded. Students from other healthcare courses and OT students from other universities were also excluded from this study.

To conduct the study, the researchers obtained approval from the university's ethics committee after seeking permission from the gatekeeper to advertise the study. An advertisement was then posted on OT Hub (an online communication platform for all OT students and teaching staff) at the university to recruit participants, and interested students were then invited to contact the researchers. Those who expressed interest were provided with a privacy notice, participant information sheet, and consent form, and allowed to discuss further details in a meeting. Participants who agreed to take part and signed the consent form then underwent a 1:1 interview, either in person or online via a password-protected Zoom link, between December 2022 and February 2023.

### **Data Collection and Analysis**

The research involved conducting a semi-structured interview with 10 questions (see Appendix A), which took 45-60 minutes to complete. The questions were focused on students' experiences of learning about dementia, particularly communication, and recommendations for dementia content in the curriculum. Before collecting data, a pilot sample was taken from two participants to ensure instructions were clear and questions were interpreted consistently (Kelley et al., 2003). Audio recordings were transcribed, and findings were reported.

To analyze the data, Braun and Clarke's (2006) thematic analysis method was used, which involves six steps. NVivo, a commonly used qualitative software tool (Castleberry, 2014), was used to assist with coding. Step 1 involved researchers familiarizing themselves with the data by transcribing the audio recordings and comparing notes to ensure accuracy and consistency. The supervisor of the dissertation project also checked the transcriptions. Step 2 involved highlighting sections of individual transcripts and common content between them to generate initial codes. In Step 3, initial coding was grouped into identified themes. Step 4 involved reviewing the identified themes to ensure enough data to support them, while others were broken down into separate themes. Step 5 involved assigning titles to the themes, which were then developed further and reviewed to ensure coherence with the research question. Step 6 involved producing a report based on the research study findings.

Data saturation was achieved during the coding process when no further themes or codes were identified. The sample size was based on a systematic review of qualitative studies, which found that between 9-17 interviews enabled saturation of data to be achieved (Hennink & Kaiser, 2022), while Braun and Clarke (2013) recommended at least 12. For this study, 12 final-year students agreed to participate.

The interviews were recorded and analyzed by two researchers. The researchers/interviewers were final-year MSc (pre-reg) OT students and not part of the faculty who taught the dementia content to the students. They cross-checked the data with the principal investigator/supervisor to ensure that the information was not edited to suit their own perceptions and to avoid any potential biases. The researchers provided sufficient detail about the study process to ensure that it could be repeated.

### **Ethical Considerations**

The University Research Ethics Committee approved the study ahead of data collection and analysis. Informed consent was given by participants, and to ensure confidentiality, all identifying words were removed from interview transcripts. Anonymity was ensured by coding the recordings and removing any identifiable information from the transcripts. Participants were identified using codes, avoiding names or any other personal identification methods.

Recordings of Zoom interviews were stored on a secure Google Drive that only the researchers and supervisor could access. Transcripts were completed electronically on a Word document, transferred onto the secure Google drive, and deleted. Recordings were deleted from Zoom after they were transferred to Google Drive. Recordings and transcripts will be destroyed from Google Drive post-completion of the study. Since findings were likely to be published, permission was obtained via consent forms to use quotes in publications/conferences.

Precautions were considered before the study, assessing potential risks to participants, e.g., becoming emotional during interviews due to experiences with dementia; in which case appropriate support would be offered through signposting to the university's well-being support.

### **Results**

Twelve students across final year MSc and BSc pre-registration OT students participated in this study. Thematic analysis identified three themes: dementia content and teaching methods, gaps in learning about communication with people with dementia, and limited placement opportunities.

#### **Dementia Content and Teaching Methods**

Many interviewees reported having lectures that included content about dementia: *"We covered the core principles of supporting people who have dementia and what we can do to help"* (Participant 3).

(Participant 10) added more detail for content learned: *"I remember learning about brains, and about aphasia... class helped me realize that dementia is not a normal part of aging."*

(Participant 11) said: *"...we were taught about adaptive equipment that could be issued... I remember we were taught about the impact of dementia like caregiver burden."*

Most of the learning appeared to emerge from independent reading, students reported lecture content was brief or that they chose a case study to develop their understanding; highlighting they would have a limited understanding of dementia from lectures alone:

*“I think the way Enabling Occupation 1 module was structured... was very self-taught. We were given a brief introduction and then sent on our way to solve case studies, so I think any knowledge would have come from readings” (Participant 11).*

Some participants expressed that they struggle to recall content regarding dementia:

*“...I keep repeating the same thing, maybe because I just don’t remember. There wasn’t anything that stuck with me from dementia-specific lectures” (Participant 2).*

*“I don’t recall dementia lesson, or I just forgot about it” (Participant 4).*

Participants not remembering content may suggest gaps in relevant teaching methods as one participant noted the following:

*“The fact that I’m not able to recall it now doesn’t necessarily mean that we haven’t been taught it, but it’s not been taught in a way that I’m remembering” (Participant 5).*

A few participants stated that due to limited dementia education in the OT program, they had not felt confident in supporting people with dementia:

*“I don’t think it’s enough, during my second placement I met loads of dementia patients, and I remember that I didn’t feel as if I was equipped with everything happening” (Participant 12).*

A few participants expressed a lack of interest in the dementia topic and being this topic was optional, they did not think it was necessary to attend the dementia teaching session.

*“...it was important to tell us about dementia, but I feel like I didn’t care...it wasn’t anything I was interested in” (Participant 10).*

*“There is a full-day workshop but it’s optional. A lot of people could miss out on the learning opportunity in favor of other things that they might find more interesting” (Participant 6).*

### **Gaps in Learning About Communication with People with Dementia**

All participants mentioned that communication with people with dementia was inadequately covered in their curriculum. One participant mentioned that they struggled to respond to questions during their placement in a healthcare setting.

*“If someone thinks that they’re 20 years younger than they are, and they think they’re talking to their parents instead of you, there are ways that you should react to that, and we weren’t taught anything” (Participant 11).*

Some participants recalled examples of how to communicate were discussed and learning was applied during placement.



*“I met a patient who had dementia who needed a home assessment, and I was able to communicate with her through eye contact, speaking very clearly and repeating what she had said to me...”* (Participant 3).

However, few participants reported that although communication skills were discussed, they felt that the education around communication with people with dementia specifically was limited.

*“I remember doing pre-reading and watching videos about communicating and it was kind of a script. I do feel they should have gone into how to communicate more”* (Participant 7).

Participant 2 added: *“...this is something I feel they didn’t do very well; we did cover some effective communication skills and how to communicate with patients, but not specific to people with dementia”* (Participant 2).

*“...we’ve been taught that you use simplistic language, don’t question what they’re saying, go with their beliefs”* (Participant 5).

Some students had previous experience of working in dementia settings and subsequently felt more confident working with dementia. One participant stated prior experience aided their communication skills training in the OT course:

*“I understand from my own experience of it. I don’t think it was covered in the curriculum at all”* (Participant 5).

Lastly, over half of the participants reported that content from other lectures provided transferable skills that could be utilized, though this may be difficult initially.

*“...we have more skills than we realize that we’ve developed over the course... but I think it’s hard, and to kind of join it all together in a way, like this is relevant to when I’m supporting people with dementia”* (Participant 2).

### **Limited Placement Opportunities**

Participants mentioned that they had learned most about dementia while on placement in a dementia setting. They explained this experience helped them put the condition into context, which was more valuable than in-class learning or independent reading. However, most participants agreed there were a limited number of placement opportunities to work with people with dementia. Some participants expressed lack of placement opportunities to work with dementia patients made it difficult to transfer learning and develop a plan to support it.

*“It was nice to have that encounter with people on placement because it’s easy to read about it in books... but when you meet people, it’s like, this is a real thing, and it’s not easy”* (Participant 10).

*“...it’s a good introduction. I don’t feel that I know a massive amount about dementia and all its different forms, but I have a good overview” (Participant 3).*

*“...In the Core Skills module, it was brought up briefly, but I don’t think it’s been covered that much. It’s been vague” (Participant 8).*

A desire for more information on physiological processes and treatment options was also expressed.

*“...there is a biological foundation to Alzheimer’s, we didn’t get an insight into within our anatomy and physiology module and that might have been helpful and just giving us a better understanding of how these diseases present themselves...” (Participant 6).*

### **Discussion**

This study explored how final-year pre-registration OT students learned about dementia, with a specific focus on communication. The research identified three themes, including dementia content and teaching methods, gaps in learning about communication with people suffering from dementia, and limited placement opportunities. The study found that dementia education lacked depth, with limited communication skills taught in the program. Many students relied on their prior experience and knowledge of working with people affected by dementia. Although transferable skills were taught, most of the learning happened through independent reading and during placement, instead of classroom lectures. The research findings will be discussed in relation to other studies on dementia education for healthcare students, and recommendations will be made for the OT curriculum. The study’s limitations will also be considered.

### **Dementia Learning Experience**

Occupational therapy students reported they received education on dementia in their program, but the content was not comprehensive enough. This aligns with previous research by Scott et al. (2019) which found that healthcare students lacked the necessary knowledge on this subject. Similarly, when examining OT students’ learning experience of dementia, Gavin et al. (2022) found that the depth of education was limited, suggesting that healthcare courses across the board are not providing adequate education to equip healthcare students to work effectively with this population. These findings align with the suggestions of the HEDN network (2013), which highlighted the need for comprehensive education, including communication content related to dementia. However, based on the results of this study, it appears that such education is still poorly taught. These results should be considered when designing healthcare courses on the topic of dementia and re-evaluating whether components of the topic should be made compulsory, as they are currently only recommended (Knifton et al., 2019).

It was brought to attention that students often rely on independent reading and prior knowledge of dementia to self-teach. This can be concerning because not all students may have experience in caring for this population, and some may be influenced by social attitudes towards dementia, perceiving it as a natural part of aging or stigmatizing

patients as "insane/demented." (Heggestad et al., 2015; Parker et al., 2021). These negative attitudes can lead to poor delivery of dementia care and discourage students from working with this population (Daley et al., 2023).

Furthermore, the learning content can be disjointed and may not focus enough on dementia compared to other conditions in older adults, such as stroke. This lack of specific learning can be disappointing for students, and it is reasonable to expect healthcare professionals working with dementia to receive detailed and specific education. However, research suggests that it may not be possible for healthcare professionals to learn about every condition in depth. Still, rather the ability to transfer knowledge and skills to different areas is crucial (Succi & Canovi, 2019). Students who had a placement opportunity to work with people with dementia tended to learn the most while on placement, allowing them to put the condition into context. Interventions that include clinical hands-on experience with dementia patients have consistently improved students' knowledge and attitudes toward people living with dementia (Basri et al., 2017).

Interestingly, some students had difficulty recalling the content taught on dementia, despite the education provided. One student suggested that the method of teaching could impact students' ability to remember rather than a lack of education on the topic. It may not be sufficient to rely solely on didactic teaching and placements to prepare students for the complex challenges of dementia (Daley et al., 2023). Another possible explanation for this difficulty in recalling information could be a considerable lapse in time since the topic was taught.

### **Dementia Communication Learning**

Participants recalled some learning on how to communicate with dementia patients, though felt the content was vague; with the majority unable to report communication skills taught, indicating learning was limited, as supported by literature (Wood et al., 2016). Contrastingly, Smyth et al. (2023) found that students are educated on how to communicate with dementia patients, though this study focused on enhancing communication learning through a special training program, which indicates more education is required to boost confidence when communicating with dementia patients. The uncertainty of students' acquired knowledge may be due to the inconsistent nature of the content taught, which is supported by research exploring communication skills taught in healthcare courses (Hegarty et al., 2008).

Some participants reported that although a general overview of dementia was provided, due to a lack of education on the topic of communication, some students have reported feeling unprepared during their placements with older adults. This indicates a gap that needs to be addressed in the curricula. This notion is supported by Quick et al. (2022), who focused on physiotherapy students, but OT students also reported the same issue. Students further reported requiring more in-depth education on communication, specifically dementia versus general communication skills, and reported lacking the confidence to interact with dementia patients. The implications for this in clinical practice are vast. If students do not feel confident in supporting and communicating with

dementia patients, this inevitably leads to inadequate care (Jootun & McGhee, 2011; Shrestha & Tranvåg, 2022). There is an argument that healthcare staff are not linguists and that communication skills for dementia are complex, requiring specific training (Weirather, 2010). However, time constraints of healthcare courses hinder comprehensive training, despite the identified need (Williams & Song, 2016).

### **Limitations**

It is important to note that the findings of this study, which examined the experiences of final-year OT students in one program, may not be easily transferable to other OT courses across the UK or the United States due to its limited geographic scope. To improve recruitment, universities from different regions could have been approached to examine their experiences and compare them with each other. However, readers can still compare and apply the findings relevant to their profession, given the context and inclusion criteria that have been discussed.

It is worth mentioning that despite being open to both BSc and MSc pre-registration OT students, only one BSc pre-registration student took part in the study. This might be due to various reasons such as placement and exam schedules and/or difficulty in reaching out to the researchers. To encourage more participation in the future, it could be helpful to get in touch with the student representative of the BSc pre-registration program and provide them with the details of the study.

Lastly, the peer relationship between participants and researchers may have led to response bias, such as providing more positive responses to please the researchers. To mitigate this, mostly open-ended questions were asked, which were not misleading in nature, and the purpose of gaining participants' perspectives was reiterated.

### **Implications for Occupational Therapy Education**

During the discussion on dementia, the participants proposed several recommendations. They suggested that more time and structured lectures should be allocated to this topic. They also recommended inviting carers to share their experiences and providing further education on communication skills, interventions, and assessments. Participants also suggested watching videos, attending online clinics, and hearing from experienced clinicians. Finally, there was a recommendation to have a placement/work experience day. Other suggestions included applying OT models to these patients, conducting cross-disciplinary sessions, and engaging in simulations/role play. The most reported recommendations were dementia focused modules, learning effective communication, and placement opportunities.

### **Dementia Focused Modules**

One recommendation from participants was to incorporate more dementia content within the classroom, utilizing anatomy and physiology lessons to cover dementia in more depth. Research certainly supports the notion that improving the duration of learning improves knowledge and skills to utilize when caring for this population (Surr et al., 2017b). The quotes that follow demonstrate participants' recommendations to increase dementia content in occupational therapy academic preparation:

*“...more structured lessons on dementia, much more taught material” (Participant 11).*

*“A lot of OT can be advocacy but you can't advocate for something you don't understand... we should think about how that could be incorporated outside of the classroom, but maybe not make it a placement, just learning opportunities” (Participant 2)*

*“...more case studies to read... readings they provide have a lot of case studies to learn about” (Participant 4).*

*“Inviting carers of patients with dementia...maybe even the patients with dementia themselves, to give us a seminar and share their experiences” (Participant 1).*

### **Learning Effective Communication**

To improve learning about how to communicate effectively with people with dementia, participants suggested adding simulations, placement/work experience, communication toolkits, role plays, case studies, videos, and in-depth learning to apply communication skills to this clientele.

*“Give a toolkit for working with people with dementia...on the topic of communication, we were given that video. I don't think I learned much from it... there's research to show how you should communicate with someone” (Participant 11).*

*“...simulations help students feel how patients with dementia experience, and that helps us put ourselves in their shoes and then we can think of ways to change our communication skills” (Participant 1).*

Research has found this to be effective for OT students as it increases knowledge, confidence, and satisfaction with communication skills for dementia (Lairamore et al., 2019). However, a barrier to engagement with dementia learning was identified; students expressed disinterest in the subject and opted not to attend additional learning opportunities, such as workshops, as they did not perceive their importance.

As a recommendation based on the previous paragraph, it is suggested that workshops covering communication content should be made mandatory. Research supports the notion that training can enhance knowledge, leading to improved dementia care (Scerri & Scerri, 2013). Choi and Park (2017) disagreed that additional learning in classrooms is enough to change attitudes and knowledge and may need other learning approaches in dementia education. Furthermore, research indicates that students may exhibit reluctance to engage with this population due to inadequate skills in interacting with patients with communication impairments (Wong et al., 2014).

### **Placement Opportunities**

In-class learning cannot change knowledge entirely (Choi & Park, 2017), with researchers suggesting that clinical placements are where the learning happens (Lorio et al., 2017). Research has shown that incorporating classroom learning into

placements, as well as providing toolkits and practical examinations based on communication skills, improves outcomes for students' learning (Tullo et al., 2018). Some participants highlighted that placements provided valuable learning opportunities and suggested communication toolkits and practical examinations based on these skills would be beneficial, therefore it is recommended that these are incorporated into the OT curriculum for future cohorts.

### Conclusion

The study found that the curriculum for OT students did not have enough specific content on communication with people with dementia. Instead, it focused more on general communication skills, which did not prepare them sufficiently to support dementia patients. This highlighted a lack of education on language deficits and the need for better education on communication for dementia patients. The study recommends improvements to course content to ensure that students are properly educated on communicating with patients with dementia. Additionally, the study identified gaps in other areas such as teaching content and methods, and lack of placement opportunities which also affected students' interest in the dementia topic, which should be addressed when delivering healthcare courses. Future research may also examine cultural differences in communication for dementia patients to improve the quality of care delivered.

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## Appendix A

Semi-structured interview questions designed by authors in alignment with the research question and objectives. This cannot be reproduced or used without the author's permission.

1. What is your experience about dementia learning during the OT programme in the last two years? What did you anticipate prior to starting the course?
2. What was effective about learning about dementia in the OT curriculum? What did not work and why?
3. What would you recommend to change in the OT curriculum to improve teaching future students about dementia?
4. What topics have you learnt about dementia in your OT training so far?
5. What is your learning experience about a topic on communicating effectively with people with dementia?
6. Do you feel that you have been provided with enough information/training about communication difficulties and subsequently how to communicate with someone with dementia? If so, what was effective?
7. What recommendations would you give to improve the education content on dementia, in particular to the topic of communication?
8. Do you think you had enough knowledge to treat a person in dementia as an OT student on placement in health care settings?
9. What would you suggest a pre placement training should include regarding dementia education?
10. Would you like to receive the summary of the results of this study? If yes, the research team will contact you about the same.