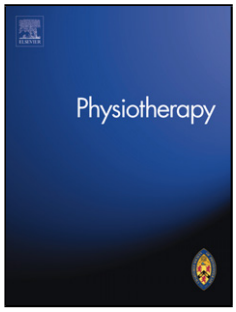
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A qualitative study of the dementia-care experiences and educational needs of physiotherapists in the Republic of Ireland

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Abstract

Objectives: Gait disturbance and impaired balance lead to a greater risk of falls and hip fractures for people with dementia. Physiotherapists play an important role in multidisciplinary dementia care. This study aimed to explore physiotherapists' experiences of dementia care and sought to identify their dementia-specific educational needs.

Design: Qualitative design, using focus group interviews.

Setting: Primary care and secondary care physiotherapy services in the Republic of Ireland.

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Participants: Six focus groups with thirty-two physiotherapists, working in community care and hospital settings.

Results: Physiotherapists described a significant dementia-related workload. Challenges to care included absence of a formal diagnosis, clinical uncertainty, scarcity of resources, physical working environment and the assessment of rehabilitation potential. Dementia care was enhanced by the involvement of family members and by collaboration with other allied healthcare professionals. Participants expressed a wish to receive further dementia training and clear evidence-based physiotherapy guidelines. Identified areas of educational need included enhanced communication techniques, use and interpretation of cognitive screening tools, sub-typing of dementia, and ethical issues in dementia care.

Conclusions: Our findings indicate that physiotherapists remain challenged by complex aspects of dementia care. Tailored dementia training for physiotherapists should be developed, focusing on their educational needs. Delivery of training should incorporate interactive case-based activities and interprofessional education with other allied healthcare professionals.

Keywords: Dementia; Physiotherapy; Education; Qualitative research; Focus groups

Introduction

Dementia is one of the greatest health and social care challenges of our time [1]. As the population ages, increasing numbers of people are living with dementia. There were around 47 million people living with dementia worldwide in 2015, a number that is projected to rise to 131.5 million by 2050 [2]. Recently, the global cost of dementia was calculated to be US$818 billion, representing 1.09% of global gross domestic product [2]. Dementia impacts heavily on the lives of individuals and families, in terms of years spent living with a disability and premature mortality.

Physiotherapy can play a key role in many aspects of dementia care, including the maintenance of mobility, falls risk reduction, post-fracture rehabilitation, pain assessment, discharge planning and end-of-life care. Gait impediments and

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reduced balance, in combination with impairments in cognition lead to a greater risk of falls and fractures for people with dementia [3]. People with dementia have a higher risk of hip fractures and poorer outcomes after fracture, compared with people who are cognitively intact [4]. An Irish study found that 24% of all patients with hip fracture had co-existent dementia [5].

Despite evidence that higher physiotherapy frequency is associated with shorter length of hospital stay and greater functional recovery [6], patients with dementia receive less physiotherapy care than other older patients [6,,7].
A retrospective cohort study found that 40.1% of people with dementia did not receive any physiotherapy following hip fracture contrasting sharply with people without dementia who received more intensive rehabilitation [8].
The World Health Organization has identified developing the knowledge and skills of all healthcare professionals who are involved in dementia care, as a priority [9]. Definitive information about undergraduate dementia content in programmes across health and social care has been difficult to ascertain [10].
The design of educational programmes for physiotherapists needs to take their clinical experiences, learning styles and educational needs into consideration [11]. However, there is a paucity of literature on the dementia care educational needs of physiotherapists. A scoping review of the physiotherapy management of people with dementia who fracture their hips highlighted the lack of research in this field that explored the views of either physiotherapists or of people with dementia [12]. A subsequent qualitative study of physiotherapists working with people with dementia found that physiotherapists felt significant pressures and challenges regarding many aspects of management, but that study did not seek

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to examine specific educational needs [13]. To address this gap in the literature this study aimed to explore physiotherapists' experiences of dementia care and to identify their dementia care educational needs.

Methods

Study design and recruitment

A phenomenological approach was employed to explore physiotherapists' lived experiences and roles around dementia care. Phenomenology is a methodology that has been employed in qualitative healthcare research to explore participants' lived experience in order to reveal the meanings of experience [14].

A purposive sampling strategy was employed to ensure the recruitment of physiotherapists from a variety of grades, working in a range of clinical areas, in primary and secondary care settings. The researchers identified a number of appropriate sites, based on setting and relevant clinical case-mix. Researchers contacted the physiotherapy manager, gatekeepers at these sites, to outline the details of the study. Managers then contacted potentially eligible participants on behalf of the researchers. Participant eligibility criteria included; fully qualified physiotherapist, working in the public health service. Eligible participants contacted the researchers by e-mail. Interested participants were sent a participant information leaflet prior to receipt of written informed consent. Participants in each focus group were known to each other and some participants were known to one of the researchers (TS, a physiotherapist).

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Ethical approval

Ethical approval for the study was granted by the Social Research Ethics Committee of University College Cork, Log 2017-100.

Procedure - Focus groups

Focus groups were conducted, with between 4 and 8 participants in each. These numbers afforded participants the opportunity to contribute individually, while also permitting group discussion and debate. All focus groups were held during participants' working days.

The focus groups were facilitated by three researchers. The principle researcher TF (a GP with an interest in dementia care) moderated each discussion. TS (a physiotherapist with an expertise in clinical education), and CS (an experienced qualitative researcher) sat on the periphery of the group, observing participants' behaviour and noting significant comments,

Reflecting the study's overarching aims, a topic guide was developed by the research team, drawing on themes identified from relevant literature (Appendix A). In addition a brief survey was designed, for completion by physiotherapists at the start of the focus group, in order to capture relevant demographic details (Appendix B). This survey included questions regarding estimated work-load with older patients and specifically patients with dementia, in order to assess the clinical relevance of the subject matter for participants. Focus groups were held between December 2017 and July 2018, at approximately monthly intervals, with different participants in each group. Interviews were audio-recorded and

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transcribed verbatim. The focus group transcripts were analysed iteratively in order to identify new themes and insights as they emerged. The COREQ standardised reporting guidelines were followed in both the conduct and reporting of this research [15].

Data analysis

A constant comparison method was used to analyse data, refining initial codes and comparing between codes, thereby producing major themes and sub-themes. Two researchers (TF and CS) read and analysed all of the transcripts independently and agreed on themes and sub-themes. In line with the phenomenological approach, themes were derived but were also interpreted and understood as the structures of experience that contribute to participants' whole experience. Where disagreement arose, issues were discussed and agreed with another researcher (AJ), a GP with an academic interest in dementia care and qualitative research) who read the transcript. Scrutiny of the data showed that data saturation had been reached at the end of analysis, such that no new themes were emerging from the data. N-Vivo version 11 was used to store and organize data.

Results

Six focus groups were held, after which data saturation had been achieved. Three focus groups took place in primary care centres and three took place in hospital settings. Each focus group lasted for approximately 50 minutes (range 42-60 minutes). In total 32 participants took part.

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Survey Results

Of the 19 community-based participants, 9 were senior physiotherapists and 10 were staff (junior) grades, while of the 13 hospital-based participants 4 were senior physiotherapists and 9 were staff grades. Overall, participants estimated that patients over-65years/age constituted 62% of their case-load (range 25-100%) and that patients with dementia constituted 17% of their case-load (range 5-50%). Demographic characteristics of the participants are shown in Table 1.

(Table 1 here)

Focus Group Results

Physiotherapists' experiences of dementia care

Three major themes were identified regarding physiotherapists' experiences of dementia care.

I. Perceived role
II. Clinical challenges
III. Need for a team-based approach

Within each major theme, between three and five minor themes were identified in each (Figure 1). Findings are reported here, supported by direct quotations from the focus group transcripts. Quotations are referenced with a number from 1 to 6; corresponding to each focus group and numbered 1 to 8; corresponding to the individual participants within that focus group.

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Figure 1 here

Theme 1. Perceived Role

1.1 Falls & Fractures

Physiotherapists who worked in the acute hospital setting explained that their predominant role in dementia care was in the management of falls and associated fractures (Table 2, theme 1.1). Frustration was described by physiotherapists that referral to them was frequently delayed until the latter stages of dementia, missing the opportunity for earlier interventions. (Table 2, theme 1.1). They explained the significant complications arising in patients with dementia that can make fracture rehabilitation even more challenging. (Table 2, theme 1.1).

1.2 Functional assessment & Discharge planning

Physiotherapists described their role focusing on the assessment of patients' functional abilities. Allied to this they had a social care remit, judging a patient's safety to be discharged home and matching patients' abilities with their environment. To achieve this, they often worked closely with Occupational Therapists (OTs) (Table 2, Theme 1.2)

1.3 End-of-life care

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Physiotherapists who worked in long-stay unit described their role in advanced dementia treating patients with respiratory infections caused by swallowing difficulties and aspiration. (Table 2, theme 1.3). They recognized patients' increasing care needs and the limitations of the public healthcare system, when patients and their families needed more intensive care in the home.

1.4 Supporting families

Physiotherapists spoke about their remit to engage with family members, to educate them about exercise programmes, falls risk reduction strategies and mobility aids. (Table 2, theme 1.4). Others described their role in social terms, referring to other professionals in order for patients and families to access other non-clinical services. (Table 2, theme 1.4)

Theme 2. Clinical Challenges

2.1 Absence of a formal diagnosis

Physiotherapists described treating patients who evidently had significant memory loss and communication difficulties but who had not received a formal diagnosis of dementia. This contributed to clinical uncertainty and also raised an ethical dilemma about whether they could openly discuss this with family members. (Table 2, theme 2.1)

2.2 Behavioural and psychological symptoms of dementia

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Patients' inability to actively engage with physiotherapy, because of behavioural and psychological symptoms of dementia (BPSD), was emphasized as a significant barrier to care. While this was recognized as a core symptom of the dementia itself, participants described the challenge of knowing what to do when patients did not want to engage. (Table 2, theme 2.2)

2.3 Memory

Poor short-term memory, led to what physiotherapists described as impaired 'carry-over'. Exercise instructions frequently needed to be repeated at each treatment session. Consequently an increased amount of clinical time was required. (Table 2, theme 2.3)

2.4 Environment

Dementia-friendly aspects of the working environment, that enhanced care for patients with dementia was described. One physiotherapist who worked in a long-stay residential unit used the unit's grounds to exercise the patient, away from the bustle of the ward. (Table 2, theme 2.4). However, a physiotherapist who worked in the acute hospital setting explained that the clinical environment of both outpatient clinics and hospital wards had a detrimental effect on patients' care. (Table 2, theme 2.4)

2.5 Assessing rehabilitation potential

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Physiotherapists struggled with knowing whether physiotherapy care was clinically indicated for patients with dementia, defining this in terms of 'rehabilitation potential'. They reported trying to balance the potential benefit and risk for patients (Table 2, theme 2.5). Consequently, when resources were limited, people with dementia were at risk of being excluded from physiotherapy care. (Table 2, theme 2.5)

Theme 3. Team-based approach

3.1 Family involvement

Family involvement in therapy sessions was viewed as essential, though time-pressures and work commitments of family members were also acknowledged. Family presence enhanced patient-clinician communication and also served to reduce the effects of patients' anxiety and agitation. In some instances physiotherapists described recruiting family members as proxy physiotherapy assistants. (Table 2, theme 3.1)

3.2 The multidisciplinary team

Physiotherapists worked closely with other clinicians, both in the community and in the hospital setting. They appeared to value their role as members of a multidisciplinary clinical team, though sometimes there were logistic challenges around organizing team and family meetings. They described needing to be flexible in order to work as members of a multidisciplinary team. (Table 2, theme 3.2)

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3.3 Occupational therapy

In particular, physiotherapists described working closely with OTs, frequently undertaking joint assessments of functional abilities, mobility assessments and domiciliary reviews. In some instances there was a more formal arrangement, where physiotherapists had developed services in collaboration with their local team OT. (Table 2, theme 3.3)

Physiotherapists' educational needs

Our survey revealed that physiotherapists estimated that 17% of their caseload involved treating people with dementia. Despite this the participating physiotherapists reported that they had received minimal structured dementia education during their undergraduate and postgraduate training. Rather, they relied on informal learning from experienced peers while on clinical placements or once qualified, in the workplace.

"I'd say it was about one lecture in college and then it was what you picked up on your clinical placements" FG4P1

and

"you learn on the job" FG1P1

In the context of this experience the following dementia-specific educational needs of physiotherapists were identified:

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I. Overview of dementia
II. Sub-types if dementia
III. Cognitive screening tools
IV. Communication techniques
V. Ethical issues

Overall, physiotherapists were keen to receive further education around dementia care. Interactive, case-based face-to-face workshops was the preferred mode of delivery of educational sessions, rather than e-learning or formal lectures.

> *"Yeah kind like a work shop type of or like it might be hard to get an actual patient but like you know like a case study or a scenario"* FG3P4

Interprofessional education was highlighted so that relevant multidisciplinary team members could learn about each other's role in dementia care.

> *"I think we do have a need to be in a multidisciplinary training session... we still need to know what they do"* FG6P4

Physiotherapists wanted to learn more informally from experienced peers and felt that getting the opportunity to work with an expert physiotherapist would be a effective way to learn on the job.

> *"link up with one of the other physios who might be more expert in the area and learn from them as well…and see how they approach different patients"* FG5P2

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An overview of dementia itself was requested for a better understanding of the presenting features, diagnostic criteria and risk factors (Table 3, Content 1). Others wanted to know more about the various subtypes of dementia, as this was frequently mentioned on referral letters to them (Table 3, Content 2).

The need for training on the use and interpretation of cognitive screening tools was emphasized (Table 3, Content 3). Though they did not routinely perform cognitive screening assessments themselves, physiotherapists frequently received reports from other clinicians who used a variety of assessment tools.

Physiotherapists described using one-stage simplified communication techniques in order to effectively engage with people with dementia. However, others described the challenges around communication and highlighted the need for more training in this area (Table 3, Content 4).

Ethical dilemmas and the sensitivities around particular aspects of dementia care were frequently described. During their clinical time spent with patients physiotherapists became aware of issues like non-disclosure of diagnosis and patients' capacity to make informed decisions. Physiotherapists described struggling with these dilemmas and wanted guidance on how to manage these issues (Table 3, Content 5).

Discussion

Main findings

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Our findings indicate that physiotherapists receive limited structured dementia education despite frequently caring for patients with dementia. Team-based approaches involving other healthcare professionals and family members facilitates enhances care while the physical environment, poor carry-over, lack of a formal diagnosis and BPSD are all barriers to optimal physiotherapy care.

Comparison with previous research

The lack of dementia education of healthcare professionals is a recurring theme in the literature [10, 16, 17]. Despite calls for education and training of clinicians who work with patients with dementia [2], reviews have identified that dementia education is limited for medical, nursing and allied healthcare professionals [10]. Our findings indicate that physiotherapists value more informal educational opportunities, learning through active participation with experienced peers in the work-place, a finding supported by literature on the preferred learning styles of physiotherapists [11]. However in order for training and education to be most effective, it is important that active participation with practice-based learning is underpinned by theoretical or knowledge-based content [18].

Many of the challenges and facilitators of optimal physiotherapy care encountered in caring for patients with dementia reflect the findings from other studies that focus on other chronic illnesses. For example, limited resources and time constraints have been identified as barriers to physiotherapists caring for palliative care patients [19]. Rationing of care and the concept of 'no rehabilitation potential' has previously been identified as a factor that limits the

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ability of healthcare professionals to work in a patient-centred way, denying patients access to rehabilitation [2]). The absence of a formal diagnosis of dementia has been cited as a major barrier to dementia care. In one study just 35.6% of patients with dementia admitted to hospital had received a previous diagnosis [21], while formal diagnosis and coding of the diagnosis is similarly suboptimal in primary care [22]. The advantages of family involvement in physiotherapy dementia care has previously been identified, both for obtaining a detailed collateral history and for exercise supervision at home [13]. Family members play an important role alongside physiotherapists treating other chronic conditions too, such as recovery from stroke [23]. This highlights the need to support family members, who may be under considerable stress in their caring role.

This is the first study, of which we are aware, that has set out to identify physiotherapists' dementia care educational needs. The need to know more about cognitive screening tools is unsurprising. Physiotherapists are working in teams alongside other healthcare professionals who use a large range of cognitive screening tools and other standardized tests too. However, while quality measures and clinical tools can bring focus and clarity to caring for patients with dementia [24], inevitably clinicians will need to be up-skilled in their use and interpretation. The importance of physiotherapists using effective communication strategies has been described previously, breaking down instructions, using short sentences and speaking slowly [13]. However, our findings go further, suggesting that physiotherapists also need to know about more advanced communication skills when dealing with anxiety, agitation and

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sensitive ethical dilemmas. In line with physiotherapists' preferences, evidence suggest that communication skills training should be interactive and skills based, involving practice and discussion [25, 26].

Study strengths and limitations

The use of focus group methodology was appropriate for this under-researched area and was ideal for providing a breadth of experiences, views and collective understanding of a topic through discussion and debate [27]. Our overall sample was heterogenous in terms of physiotherapists' age, experience and place of work, permitting the capture of a broad range of experiences and educational needs.

This study had a number of limitations. More junior physiotherapists may have had limited clinical experience caring for patients with dementia and so may have been less aware of the shortcomings in the delivery of physiotherapy care. While group homogeneity has been recommended in focus groups in order to capitalise on people's shared experiences [27], it can also be advantageous to bring together a heterogenous group to maximize the exploration of different perspective [28]. One of the interviewers, a physiotherapist, was personally known to participants, which may have influenced responses. However, to ensure methodological rigour and to address the potential influence of the researcher on the research process, at least two researchers were involved in each step of data collection and analysis. Although the lead-researcher was not a physiotherapist, as a general practitioner with a research interest in dementia care, he has an understanding of the clinical complexities of managing a person

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with dementia. This facilitated discussion of clinical cases as part of the focus group. Furthermore, a practicing physiotherapist (TS) and a non-clinician (CS) were also involved in data collection and analysis helping to reduce bias in the analysis process. Finally, in our brief survey we chose to not ask participants about their previous dementia education, choosing instead to explore this issue in the focus group interviews. Further quantitative research could help to ascertain the dementia educational experiences of physiotherapists at both undergraduate and postgraduate level.

Conclusion

As the number of people with dementia continues to rise there is a need to ensure that physiotherapists are appropriately prepared. Recognising the important role of physiotherapists in dementia care, services need to be adequately resourced and patients with dementia should have timely access to physiotherapy for rehabilitation following fractures and also access to physiotherapy for gait assessment and falls risk reduction classes.

Our findings have the potential to contribute to the design of dementia educational programmes for physiotherapists. The content of dementia training needs to meet the specific educational needs of physiotherapists who work across a variety of settings, in acute hospitals, long-stay residential units and in primary care. The delivery of training should involve active participation relevant to their clinical practice and should reflect the multidisciplinary nature of dementia care by incorporating opportunities for interprofessional education.

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Further research is required on the developing role of physiotherapists and should include the opinions of people with dementia, their families and other healthcare professionals too. This triangulation of perspectives will help to ensure that curriculum design and service delivery is meaningful to patients and the wider healthcare system and promotes effective interdisciplinary collaboration too.

Conflict of interest: There are no conflicts of interest.

Ethical approval: Social Research Ethics Committee, University College Cork, Log 2017-100

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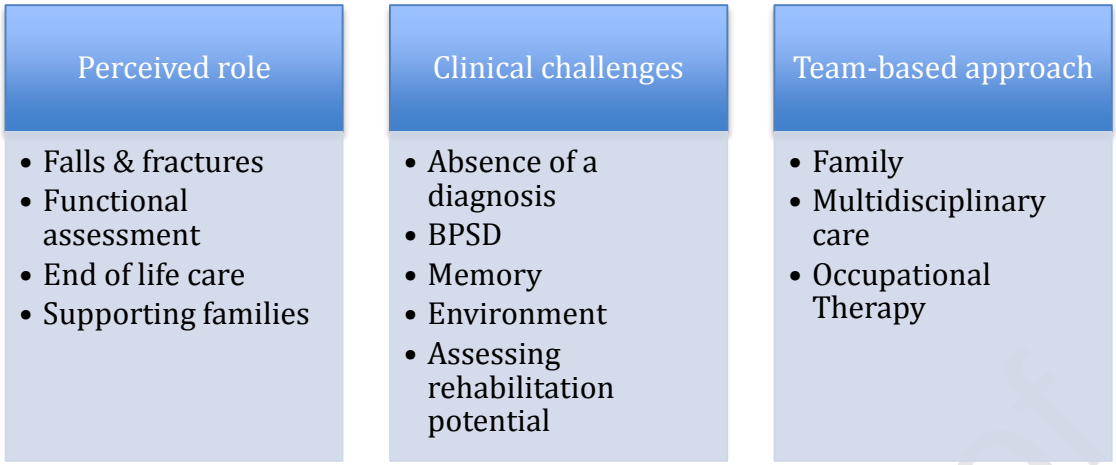
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Figure 1
Overview of major and minor themes



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Table 1 Characteristics of participants

Focus Group	**Sex**	**Experience (Years)**	**Work grade**	**Work setting**	**Average case-load of patients >65 yrs/age**	**Average case-load of patients with dementia**
1 (n=7)	7 female	17 (9-21)	5 senior 2 staff grade	Community	53%	13%
2 (n=8)	8 female	17 (8-30)	3 senior 5 staff grade	Community	51%	12%
3 (n=4)	4 female	14 (7-28)	1 senior 3 staff grade	Community	50%	6%
4 (n=5)	4 female 1 male	12 (3-22)	2 senior 3 staff grade	Hospital	60%	19%
5 (n=4)	3 female 1 male	8 (3-18)	1 senior 3 staff grade	Hospital	61%	20%
6 (n=4)	4 female	9 (1-17)	1 senior 3 staff grade	Hospital: Long-stay unit	100%	36%

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Table 2
Major and minor themes with supporting quotes from the interviews.

Major Theme	Minor Theme	Supporting Quote
1. Perceived role	1. Falls & fractures	*"I suppose the big thing I would see be falls risk; people that are presenting in to ED that are having falls."* FG4P3 *"I'd like to see a mild case…and maybe we should be seeing a lot more. It's the end stage ones that everyone knows about, and we still have trouble with it, but it's catching them earlier"* FG6P2 *"it is all traumatic falls and hip fractures and surgeries so we see a lot of delirium on a back ground of dementia so their cognitive status might be worse than normal"* FG4P1
	2. Functional assessment	*"can they transfer, can they mobilise, are they safe to be in their environment at home… can they dress on their own can they make a cup of tea or can they go out in the garden?"* FG3P1
	3. End of life care	*"patients with end-stage dementia will get chest infections also so there is that side of it as well that we would be involved in too"* FG5P3 "*So where there is dementia – massive care – now – they'd be ending up stepping in with private care; now there's 24 hour care going into the house"* FG6P4
	4. Supporting families	*"a lot of it is educating the carers.. I think about the carers and commands for the patient, like introducing a walking aid earlier on, so that they can learn it"* FG6P1 *"and families are struggling and you can provide different options for the family lets say we might be able to increase the home help, things like that in planning for discharge"* FG4P3
2. Clinical challenges	1. Absence of a diagnosis	*"sometimes we would say, 'look it hasn't been formally confirmed can somebody talk to the family and if you can clarify a diagnosis so that then we all know what we are talking about'"* FG3P2
	2. BPSD	*"day one you know they might be really agitated and they might be a little bit aggressive but another day they can be very hypo-actively delirious and you know just totally drowsy and unable to participate with physio"* FG4P2
	3. Memory	*"poor recall, poor carry over, every week it was like nearly starting all over again"* FG2P5
	4. Environment	*"I find if its possible to take themselves on the bridge or something where they can see the river you know something that again a bit more normal for them you get a bit more engagement from them you know"* FG5P3 *"they could be in a six bedded ward and one day they will go to the bed and the next day they will wake up and there is different faces across the way from them"* FG4P3
	5. Assessing rehabilitation potential	*"It's the dilemma of it if they're falls risk, and you want to give them a rollator or something, are you then enabling them to maybe go out and get disorientated and go wandering?* "FG6P3 *"I can see eight people in a group who are okay cognitively or I can see two people in that same time who are cognitively impaired"* FG2P2
3. Team-based approach	1. Family	*"I remember we had this man and whenever we went in to him to try and work he would not do anything with us but as soon as his wife was there he was grand and he would work away with us no problem"* FG4P2

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	2. Multidisciplinary care	*"OT, Public Health Nursing would have huge amount of input, and you might be on to the GPs and face to face with them, or on the phone, and you would have a domiciliary team input"* FG2P2
	3. Occupational Therapy	*"I work with an OT and we developed programmes together, and we try to bring other people in, and we do an educational programme around falls prevention and we do it week in week out"* FG1P4

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Table 3
Educational needs of physiotherapists

Content	Supporting quotation
1. Overview of dementia	*"I would like to understand dementia first, and before you go into the practical issues"* FG1P4
2. Dementia subtypes	*"I'd like to know more about what dementia is, what the sub-types are"* FG2P3
3. Cognitive screening tools	*"Should we use the MMSE or QMCA …and education maybe on how to use them, and how to interpret them"* FG2P3
4. Communication strategies	*"The communication with them is something I would definitely struggle with…..* *I'd like to know about other interventions like validation therapy, reminiscense, managing challenging behavior"* FG1P5
5. Ethical issues	*"or even around the consent like we are big here on getting the patients consenting to their treatment and so if someone says no I am going for a walk today or no I am not doing this and you know you go and explain as much as you can"* FG5P2

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