

## Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

### Introduction

Hip fracture is a common injury, especially in older people, resulting in the estimated occupation of over 4000 inpatient beds in the UK at any time. Over 70,000 people sustain a hip fracture in the UK each year, costing £2.3 billion in health and social care (Royal College of Physicians, 2015). People who fracture their hip often have multiple co-morbidities (de Luise, Brimacombe, Pedersen, & Sorensen, 2008) of which it is estimated that dementia is the most prevalent, with studies reporting that 19 - 40% of older adults with a hip fracture have dementia (Seitz, Adunuri, Gill, & Rochon, 2011). The UK is mirroring the global picture and experiencing an ageing population (Office for National Statistics, 2017) resulting in a significant increase in the number of people diagnosed with dementia, with global incidences of dementia doubling every twenty years to reach over 130 million people living with dementia by 2050 (Prince, 2015). It is also estimated that people with dementia have a significantly greater risk of fracturing their hip (Melton, Beard, Kokmen, Atkinson, & O'Fallon, 1994).

People with dementia who fracture their hip have more complex care needs with greater risks of complications, physical disabilities and social care requirements compared to people without dementia (Beaupre, Carson, Noveck, & Magaziner, 2015). Indeed, the outcomes for people with dementia following hip fracture are poor, with a two-fold increase in mortality at twelve months post-operatively in comparison to those without dementia (Ruggiero et al., 2017) and have a higher risk of morbidity (Berggren, Stenvall, Englund, Olofsson, & Gustafson, 2016; Heruti, Lusky, Barell, Ohry, & Adunsky, 1999). This population experience longer hospital stays and a significantly greater proportion will require long term care home placement, with only 30% of people with dementia returning home within 30 days of fracture (Royal College of Physicians, 2015).

The rehabilitation of people with hip fracture is often challenging due to issues such as pain, co-morbidities (Morrison et al., 2003; Roche, Wenn, Sahota, & Moran, 2005) and loss of confidence

Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

resulting from the injury, however, the addition of dementia or cognitive problems is likely to increase the challenge to provide effective and appropriate physiotherapy. The “rehabilitation potential” of people with dementia is often debated, but authors suggest that the use of the term is little understood and currently under researched, with no formal definition or method of assessment. One review (New 2009) found no standard, accepted or validated definition by what was meant by ‘*rehabilitation potential*’, finding great variability of accepted interpretation. It has been used as a prognostic indicator of the likelihood of a person being able to remain in their own home for a one year period (Zhu, Chen et al. 2007) as well as an indicator of likely functional recovery of activities of daily living (Rentz 1991). Several other authors support our findings that it is often used to determine whether further rehabilitation should take place (Cunningham, Horgan et al. 2000, Poulos and Eagar 2007). However, despite suggesting its use to determine the future rehabilitation pathway, the reliability of the clinical judgement of different members of the multidisciplinary team in determining the rehabilitation potential of people has been questioned (Poulos and Eagar 2007), with the suggestion that, in the case of older people, the reliability of the clinical judgement was in general quite poor.

A previous scoping review (A.J. Hall, Lang, Endacott, Hall, & Goodwin, 2017) highlighted that existing evidence lacked detail regarding the physiotherapy intervention for people with dementia following hip fracture, often describing it just as “physiotherapy”, assuming that this is a treatment in itself rather than an umbrella term for multiple potential treatment techniques. This is further supported by a recent systematic review which defined this ambiguity as the “black box of physiotherapy” (Chu et al., 2016).

## Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

This study forms part of a larger feasibility study exploring delivering a dementia-specific physiotherapy treatment to people with dementia following hip fracture. Recruitment to the study was not possible as, contrary to the expectations of the researchers and physiotherapists, people with dementia were not routinely being referred for physiotherapy following discharge from the acute setting after surgical fixation. The purpose of this study was to explore the reasons why people were not being referred for ongoing physiotherapy as well as exploring the pressures and difficulties that community based physiotherapists face treating this population.

## Methods

A qualitative approach was used as it enabled in depth exploration of participants' experiences and perspectives. To gain an understanding of the reasons people with dementia were not being referred for community based physiotherapy, we undertook focus groups and semi-structured interviews with physiotherapists and therapy assistants working in community settings in the South West of England between February 2018 and May 2018.

### Recruitment and Participants

Physiotherapists and therapy assistants were recruited who had taken part in a prior feasibility study. The feasibility study was undertaken in the South West of the UK and involved various community rehabilitation teams agreeing to take part. The feasibility study failed to recruit sufficient participants, but the therapists involved agreed to take part in the focus groups and interviews to explore reasons for the failure to recruit participants to the initial study and thus examine the potential reasons why people with dementia were not being referred for ongoing physiotherapy following hip fracture as well as seeking to better understand the difficulties they face treating this

Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

population. The therapists were approached via email to determine whether they were agreeable to taking part in this aspect of the study following completion of the feasibility study.

#### Data Collection and analysis

Focus groups and semi-structured interviews were undertaken following a topic guide (supplementary file). As the study sought to recruit patients from NHS sites and involved the treatment of patients, full NHS ethical approval was obtained (reference 17/SC/0243). Participants were given full explanation of the purpose of the study, confidentiality and anonymity were assured and written informed consent was obtained prior to each discussion. All participants gave individual written consent to take part in the study. The sessions were audio recorded, transcribed verbatim following completion and the data was anonymised so that individual participants could not be identified. Each transcript was coded independently by two researchers and then discussed in a process of analyst triangulation.

Framework analysis was used to make sense of the data, adopting a deductive approach, whereby data was compared to the theory generated (Pope, Ziebland et al. 2000), in this case from two previously undertaken qualitative studies (Abigail. J. Hall, Burrows, Lang, Endacott, & Goodwin, 2018; A. J. Hall, Watkins, Lang, Endacott, & Goodwin, 2017). Although the framework approach may generate theories, analysis utilises a deductive approach developed to meet pre-set aims, objectives and test initial themes (Pope, Ziebland et al. 2000). Data from the qualitative studies guided the development of initial theories surrounding factors that would affect the acceptability and feasibility of the intervention, with framework analysis aiding the exploration of these theories. The use of framework analysis in this study was guided by Gale and colleagues (2013) who outlined the process in a detailed worked example in nursing literature.

## Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

### Findings

Three focus groups were undertaken with physiotherapists and assistants working in community rehabilitation teams in the South West of the UK. There was a range of levels of experience and job role from therapy assistant up to clinical specialists (table 1). A total of eleven people took part in these discussions, eight of whom were physiotherapists and the remaining being assistants. All were working in community, inpatient or outpatient settings within the NHS and had significant experience of treating people with dementia. Three main themes emerged from the data exploring reasons for failure to refer patients for ongoing physiotherapy, challenges in treating this population in the community and the effects of a lack of knowledge and education.

*Table 1 - Demographics of participants*

		Number of participants
Job role	Physiotherapist	8
	Therapy support worker/physiotherapy assistant	3
Place of work	In-patient	2
	Community	7
	Out-patient	2
Gender	Male	2
	Female	9
Years of experience	<5	2
	5-10	4
	10-20	3
	20+	2

#### ***Failure to be referred for physiotherapy***

Unanimously all clinicians reported astonishment at the lack of people with dementia and hip fracture who were being referred to community rehabilitation settings.

Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

*“I think we were all fairly shocked about [that] really... we didn't really realise” (PA1)*

The beliefs of the healthcare professionals appeared to affect the likelihood of a person with dementia being referred for physiotherapy after hip fracture. There was the suggestion that the lack of referral for such people may have been due, in part, to historical beliefs that people with dementia could not be rehabilitated.

*“There's an attitude that we can't help them because they have dementia. I don't agree with that - I'm just saying.” (PA3)*

It was reported that the aim of physiotherapy for such people was about ensuring their safety on return home, rather than actively trying to provide rehabilitation for them. Thus, people were often referred for occupational therapy (OT) rather than physiotherapy.

*“a hospital discharge and fractured NOF [neck of femur], living on their own with dementia we would have got out to her.....she would've been prioritised quickly to OT. Although that would have been primarily to check safety” (PA1)*

Concerns were also raised that providing physiotherapy for a person with dementia could actually increase the risk to that patient. Thus, physiotherapy was often aimed at preventing risk and not progressing people. This “fear” of increasing risk by providing physiotherapy could suggest why some people were not being referred for physiotherapy.

*“Instead of a standing programme, you might give them a sitting programme. Which means that you are not doing what, actually, what they need. They're.... they're being rehabbed at a lower level than they should be.” (PA6)*

It was reported that there were no standard pathways of care for people with dementia and this led to inconsistent referrals of people to physiotherapy. The typical pathway that somebody with dementia would follow has altered in recent years and thus people are frequently not getting onward referral.

Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

*"The rehab pathway has shifted forwards. So it used to be that they would have spent a week or 2 weeks in hospital, an acute hospital, then they might have come, if they needed to at that point, they might have come here [community hospital] for another up to 5-6 weeks and then they would've gone to the community. But now if they are in there 4-5 days they are lucky. They are allowed to be here for 3 weeks at the most." (PA5)*

Lack of progress during the acute stage of rehabilitation was suggested to lead people to be deemed to have "no rehabilitation potential". This label would then prevent them from being referred for ongoing physiotherapy in the community.

*"... maybe when someone with dementia gets hip fracture... it's just about can we get them home and get them safe and not really the rehab element is totally lost.... and forgotten... there's that horrible phrase – 'they've got no rehab potential'" (PA1)*

For people with dementia, who may take longer to progress with rehabilitation, this excluded them from being given a fair opportunity to improve physically. The lack of opportunity to undertake physiotherapy led to them being given the permanent label of having "no rehabilitation potential" and thus restricting the future services and interventions that were available to them. Where people were deemed to have no rehabilitation potential in the acute setting, they were reported to not be referred for ongoing therapy and therefore were discharged directly home or to nursing or residential home placements.

*"The phrase is used too frequently, too often, too quickly. .... but "no rehab potential" is a phrase that we hear quite a lot and yet you find that there is potential, it depends on what that individual wants or what their circumstances are, but I think it's a very poor phrase and I think it should never be used to be truthful" (PA7)*

***Challenges of treating people with dementia in the community***

## Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

Clinicians reported that if people with dementia were treated in the community, treatment would rely heavily on the use of support workers due to resource pressures they experienced. It was felt that in view of the current lack of supporting evidence, investing a lot of time and resources into people with dementia and hip fracture was difficult to justify. The use of assistants was advocated as a way to make providing physiotherapy to this population more cost effective, however this was viewed with caution. While some support workers had experience treating people with dementia, it was recognised that ideally a qualified physiotherapist may have been better placed to treat the patient. However, resources meant that a physiotherapist may only ever do the initial assessment, then the patient was transferred to the assistant to continue their treatment. This was considered standard practice within the community, but notable comparisons were drawn to the lack of use of assistants in outpatient physiotherapy settings where “re-assessment was required continuously”. One participant reflected that this was no different to the constant re-assessment required in community settings, but potentially was just a historical approach that assistants had always been used, or a perceived greater importance of treating people in out-patient settings.

The major difficulty described by therapists treating people with dementia related to ensuring adherence to physiotherapy. This was frequently cited to be due to the person’s memory difficulties rather than their unwillingness to take part in actual rehabilitation. The use of functional exercises with visual cues was reported to be of benefit, however the person still needed verbal prompting to look at the exercise sheets, further emphasising the importance of having a carer or relative to assist with the exercise programme.

*“She was doing them because I was talking her through it every single step of the way. We had them up in the kitchen on the cupboards, but she still couldn’t work out that what we were doing was on the cupboards. I said to her “look at the image, what can you see that person doing?” but it wasn’t really helping, but was she wasn’t able to translate that herself, so she could look at it, but she struggled to relay it.” (PA2)*



Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

### ***Lack of knowledge about dementia***

Physiotherapists described a lack of knowledge and education surrounding dementia and how to alter their practice to accommodate the cognitive problems that a patient may have. This lack of knowledge further exacerbated the belief that people with dementia may not be able to be rehabilitated.

*“We know that we should be working with these patients, just because they have dementia doesn't mean we shouldn't work with them, but actually, practically how do you do it? You know, there is such a range in dementia. It's kind of like, somebody at this end of the spectrum is going to be completely different to somebody at that end of the spectrum. And so, it is almost like a specialism, you know, to be able to kind of cover that whole spectrum really.” (PA7)*

There was a universal lack of education regarding dementia reported by the participants. Several had sought extra education around treating people with dementia but had been unable to find any appropriate training. The only training received was the standard electronic learning resources that their organisation provided to all staff members. This was not specific to physiotherapy and was described as being insufficient.

## Discussion

This study sought to explore reasons why people with dementia may not be referred for community based physiotherapy following discharge from hospital after a hip fracture as well as exploring the pressures and difficulties that community based physiotherapists face treating this population. Data from the National Hip Fracture Database demonstrated that around 40% of people with dementia would return to their own home or to a community hospital (Royal College of Physicians, 2015), however data we collected suggested that very few people with dementia are actually being

## Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

referred for physiotherapy in the community. Our data proposes that there were a variety of reasons why people with dementia may not be referred for community based physiotherapy, largely relating to the beliefs around the rehabilitation of people with dementia, underpinned by pressures felt by clinicians to provide rehabilitation with a lack of knowledge and resources to support their interventions.

“Rehabilitation potential” was a term that was central to the likelihood of a person receiving ongoing physiotherapy input. The use of the term is little understood and currently under researched, with no formal definition or method of assessment. However, the adoption of this term appears critical in determining the pathway of the patient. One review (New, 2009) found no standard, accepted or validated definition by what was meant by ‘rehabilitation potential’, finding great variability of accepted interpretation. It has been used as a prognostic indicator of the likelihood of a person being able to remain in their own home for a one year period (Zhu, Chen, Hirdes, & Stolee, 2007) as well as an indicator of likely functional recovery of activities of daily living (Rentz, 1991). Several other authors support our findings that it is often used to determine whether further rehabilitation should take place (Cunningham, Horgan, & O’neill, 2000; Poulos & Eagar, 2007). However, despite suggesting its use to determine the future rehabilitation pathway, the reliability of the clinical judgement of different members of the multidisciplinary team in determining the rehabilitation potential of people has been questioned (Poulos & Eagar, 2007), with the suggestion that, in the case of older people, the reliability of the clinical judgement was in general quite poor. This highlights the necessity for a more reliable means of determining ‘rehabilitation potential’ to be developed (Cunningham et al., 2000). Our participants suggested that where there was deemed to be no rehabilitation potential, the patient was excluded from receiving further physiotherapy. This supports data from our qualitative work (Abigail. J. Hall et al., 2018; A. J. Hall et al., 2017) whereby such potential was often prejudged, with an assumption that people with dementia could not be rehabilitated, therefore not even attempting to engage them in physiotherapy.

## Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

The judgement of “rehabilitation potential” could be considered akin to therapeutic nihilism, whereby people with dementia were assumed to be unable to improve, therefore they were not offered further input. Therapeutic nihilism was first noted by Dunkelman and Dressel (1994) who proposed that it was a form of ageism, whereby it is assumed that older people will get dementia as they age. Alongside this there is an expectation that the person will physically decline, therefore providing physiotherapy could be considered ineffective and unnecessary. While there has been little research specifically looking at physiotherapist’s attitudes towards people with dementia, negative attitudes or behaviours have been found in doctors and other health care providers (Ellingson, 2003; Gatz & Pearson, 1988).

Some historical practices were noted when physiotherapists which could limit the receipt of physiotherapy in the community. There was reliance on the biomedical approach, where physical impairments are seen as paramount. The approach typically underpins physiotherapy practice, in which the body is seen as a “machine” (Nicholls & Gibson, 2010). Reliance on this biomedical paradigm, aiming to treat body structure and disability, limits physiotherapists ability to manage aspects of person-centred practice, such as valuing patient preferences, fostering hope, managing expectation and building a positive therapeutic relationship (Mudge, Stretton, & Kayes, 2014).

## Limitations of the study

It must first be noted that this study was undertaken in the South West of England and we have no conclusive evidence to suggest whether it is generalizable to the rest of the UK. However, the results are comparable to previous qualitative work (A. J. Hall et al., 2017), which was undertaken with physiotherapists working in various locations throughout the UK, which suggests some generalisability. However, as with qualitative research, the aim is not to create generalizable

Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

findings, but to represent the experiences of a small sample, thus highlighting potential issues across the continuum.

## Conclusion

The aims of this study were to explore the reasons why people with dementia may not be referred for ongoing physiotherapy in the community following hip fracture. The apparent lack of people with dementia being referred to community rehabilitation teams following hip fracture directly opposes data generated from the National Hip Fracture Database which suggests that a significant proportion of people with dementia do receive ongoing physiotherapy. Data from the National Hip Fracture Database was collected in 2015, so it is possible that this data is no longer accurate. This is an important and valuable finding in itself as it highlights a greater concern, that people with dementia are not currently being given an opportunity to receive physiotherapy following hip fracture.

Beaupre, L. A., Carson, J. L., Noveck, H., & Magaziner, J. (2015). Recovery of walking ability and return to community living within 60 days of hip fracture does not differ between male and female survivors. *Journal of the American Geriatrics Society, 63*(8), 1640-1644.

Berggren, M., Stenvall, M., Englund, U., Olofsson, B., & Gustafson, Y. (2016). Co-morbidities, complications and causes of death among people with femoral neck fracture—a three-year follow-up study. *BMC Geriatrics, 16*(1), 120.



Community physiotherapy for people with dementia following hip fracture: fact or fiction? A qualitative study

- Ruggiero, C., Bonamassa, L., Pelini, L., Prioletta, I., Cianferotti, L., Metozzi, A., . . . Santoro, G. (2017). Early post-surgical cognitive dysfunction is a risk factor for mortality among hip fracture hospitalized older persons. *Osteoporosis International, 28*(2), 667-675.
- Seitz, D. P., Adunuri, N., Gill, S. S., & Rochon, P. A. (2011). Prevalence of dementia and cognitive impairment among older adults with hip fractures. *J Am Med Dir Assoc, 12*(8), 556-564. doi:10.1016/j.jamda.2010.12.001
- Zhu, M., Chen, W., Hirdes, J. P., & Stolee, P. (2007). The K-nearest neighbor algorithm predicted rehabilitation potential better than current Clinical Assessment Protocol. *Journal of Clinical Epidemiology, 60*(10), 1015-1021.