Health professional perspectives on barriers to broad acceptance of rehabilitation for people with dementia

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ABSTRACT

Background and objectives
Multidisciplinary rehabilitation is not incorporated into the usual care pathway for dementia despite increasing demand from key advocates. Clinician views regarding the relevance of rehabilitation in dementia care are not well known. This qualitative study explored the perspectives of health professionals regarding barriers to provision of multidisciplinary rehabilitation programs for people with dementia.

Research design and methods
Sixteen health professionals from a variety of settings and professional backgrounds were purposively sampled using maximum variation sampling. Semi-structured interviews were conducted to explore attitudes towards the care of people with dementia and beliefs about the feasibility and value of multidisciplinary rehabilitation in this population. Thematic analysis was used to identify themes.

Results
Participating clinicians acknowledged problems with existing dementia care pathways in Australia, but rarely conceptualised rehabilitation as relevant to this pathway. Analyses yielded two main and related themes: (1) Difficulty defining worthwhile outcomes of a rehabilitation program for people with dementia, and; (2) Perceived barriers to participation in this population. Clinicians felt that achievable outcomes for people with dementia were not sufficiently worthwhile for investment.

Discussion and implications
Broader acceptance of multidisciplinary rehabilitation as relevant to dementia care will require a reframing of practice that both educates emerging health professionals regarding the outcomes that may be achievable for people with dementia and persuades staff to appreciate that the investment is worthwhile.

KEYWORDS
Service provision; aged care; geriatrics; re-ablement; care pathways
INTRODUCTION

Clinical guidelines for dementia care recommend that people with dementia should have access to care pathways that support them to maintain their independence and community participation for as long as possible (Guideline Adaptation Committee, 2016; National Collaborating Centre for Mental Health, 2007). However, people with dementia and their families report that they receive insufficient professional support after their diagnosis (Cations, Withall, et al., 2017; Low, Swaffer, McGrath, & Brodaty, 2017; Prorok, Horgan, & Seitz, 2013).

Multidisciplinary rehabilitation programs appear to be well placed within the pathway because they can identify goals that are meaningful to the person, regularly adapt in delivery as needs change, and provide a structured approach to guide the person and their family (Cations, Laver, Crotty, & Cameron, 2017). This is consistent World Health Organisation (WHO) definition of rehabilitation as "a set of measures that assist individuals who experience or are likely to experience disability to achieve and maintain optimum functioning in interaction with their environments" (World Health Organization, 2011, p. 96). The WHO’s ‘Rehabilitation 2030’ campaign launched in 2017 further reiterated this point by emphasising that rehabilitation should be a holistic approach to chronic disease management that optimises independence and prolongs community engagement. The campaign urges the field to move away from the historical framing of rehabilitation as a means to support recovery after physical injury (World Health Organization, 2017b).

The efficacy of some non-pharmacological treatments to delay functional and cognitive decline in people with dementia is increasingly recognised, particularly prescribed exercise programs and dyadic interventions (Cooper et al., 2012; Laver, Dyer, Whitehead, Clemson, & Crotty, 2016; Livingston et al., 2017). Intensive cognitive rehabilitation improves self-rated competence in performing meaningful personal goals, memory capacity, and quality of life amongst people with dementia (Clare et al., 2010). However, rehabilitation programs are not routinely available to treat the symptoms of dementia. This is in contrast to post-diagnosis care following other degenerative neurological conditions (like multiple sclerosis) or acquired brain injuries (like stroke), for which rehabilitation is more accepted in the clinical pathway (Khan, Turner-Stokes, Ng, Kilpatrick, & Amatya, 2007). Additionally, people with dementia are sometimes excluded from rehabilitation programs for acute conditions including fracture (Isbel & Jamieson, 2016; Mitchell, Harvey, Brodaty, Draper, & Close, 2016) despite evidence that
they benefit similarly to people without dementia (Cameron, Schaalmsa, Wilson, Baker, & Buckley, 2012; McGilton et al., 2013; Resnick et al., 2016; Seitz et al., 2016).

Although models of rehabilitation are relatively absent from dementia care research and practice, similar concepts are described in an international shift toward wellness care. This approach, described as ‘re-ablement’ or ‘restorative care’, promotes goal setting, shared decision making, and maintenance of abilities to facilitate higher quality of life and delayed institutionalisation (Poulos et al., 2017). The adoption of these models is in part based on evidence that non-pharmacological interventions such as exercise and dyadic interventions (e.g. delivered jointly to both the person with dementia and their carer) can delay the progression of functional decline more so than pharmacological treatments (Laver et al., 2016).

Although rehabilitative in nature, these treatments are not referred to as such in research, clinical guidelines, or clinical practice.

The absence of rehabilitation pathways for people with dementia is not well understood. Possible barriers have been suggested but not formally investigated (Cations, Laver, et al., 2017). Understanding the perceived barriers to delivery of rehabilitation among health professionals working with people with dementia can help health professionals to see its potential benefits and facilitate faster translation of research into practice (Phillipson, Goodenough, Reis, & Fleming, 2016). Accordingly, the aim of this study was to explore the views and attitudes of health professionals from a variety of professional backgrounds and service contexts regarding the barriers to provision of multidisciplinary rehabilitation programs for people with dementia.

DESIGN AND METHODS

Participants

Health professionals were purposively sampled for this grounded theory study via direct approach through researcher networks and snowball sampling. All lived and worked in Adelaide, Australia aside from one who lived and worked in Sydney, Australia. The research team have held clinical positions and are knowledgeable about service delivery and staffing in the Australian health system. This knowledge was used to employ maximum variation sampling to invite participants from a variety of professional backgrounds, service settings, and training cohorts. Maximum variation sampling facilitates gathering shared patterns and themes that cut across heterogeneous conditions (Palinkas et al., 2015). Health professionals were invited to participate if they (a) were employed in a health care setting that regularly
provided service to older people and/or people with dementia; (b) their service was relevant to rehabilitation care (e.g. rehabilitation or geriatric medicine, allied health, nursing), and; (c) they provided informed consent to participate and to be audio recorded. Recruitment and analysis were conducted simultaneously and continued until data saturation was achieved (Hamberg, Johansson, Lindgren, & Westman, 1994).

Data collection

Once-off, private and semi-structured interviews were conducted from June to November 2017 by MCa either in person at clinician workplaces or over the phone. The interviewer has worked in clinical and research with people with dementia in clinical and research roles, and has been trained in qualitative interview techniques in higher education and practical settings. The interviewer had not worked with any of the participants prior to the study, though many of them were known to or had worked with other members of the research team. The confidentiality of their responses was emphasised to participants at all stages of data collection. The interview schedule was designed to capture participant attitudes toward people with dementia and beliefs about the barriers to delivery of multidisciplinary rehabilitation in this population. Questions were purposively open to avoid imposing the interviewer’s assumptions and theoretical position (which have been published, Cations, Laver, et al., 2017) on the participants. Discussion topics included attitudes towards the current service pathways available for people with dementia, relevance of rehabilitation in this pathway, general understanding of rehabilitation, potential outcomes, perceived benefits and risks, and perceived barriers to delivery. Participants were also prompted to consider whether they believed their views align with others in their profession. Interviews lasted between 60 and 90 minutes and were audio-recorded and transcribed verbatim. Transcripts were returned to participants for comment and correction. Demographic and service-related data including health professional age, gender, professional background and setting, years practicing, number of consultations with people with dementia per week, and number of other full-time equivalent staff with an equivalent role within the service were collected.

Data analysis

Data from the interviews were transcribed and entered into NVivo version 11 (QSR International Pty Ltd., 2015). Three authors (NM, MCa and KL) each read the transcripts to gather an overall understanding of the content and develop a thematic analysis plan. This also facilitated audit of the research methods to ensure the findings were consistent and confirmable.
One author (NM), who had never worked clinically nor conducted research in the dementia or rehabilitation fields, conducted an iterative process of reading and re-reading each transcript to achieve familiarity and used line-by-line open coding to develop a coding and category system. For example, the statement “if there was some evidence that it was useful, I think it should be available” was coded under the category “evidence required”. This system was validated by applying it to two transcripts by another author (MCa). Coding of the data resulted in the generation of a number of categories which were linked where appropriate using the guidance provided by Ezzy (2013). For example, the category “cognitive deficits” was linked to the category “comorbidities” as both were identified as barriers to participation in rehabilitation. The categories and the links between categories were discussed amongst NM, MCa and KL until final agreement regarding the categories and relationships was reached (Saldaña, 2015). There were no marked differences in the themes emerging from phone interviews compared to in-person interviews. Participants did not provide feedback on the findings. The interviewer and data analysts maintained written reflections about how they may have influenced the results and this was included in analysis. The quotations included in this paper have been selected as the most representative examples of the themes identified in the data.

Ethics
The Southern Adelaide Clinical Human Research Ethics Committee granted ethical approval for this study on 2 February 2017 (HREC/16/SAC/454). We report according to the Consolidated Criteria for Reporting Qualitative Research Checklist (see Supplementary Material; Tong, Sainsbury, & Craig, 2007)

RESULTS
We approached 24 health care professionals to participate in interviews but eight declined (participation rate 67%). Reasons for non-participation included insufficient time and extended leave during the study period. Participants were 11 women and five men (age range 28 to 60 years) with between one and 38 years of professional experience. Professional backgrounds included geriatric medicine (n=3), rehabilitation medicine (n=2), primary care (n=2), nursing (n=2), physiotherapy (n=2), occupational therapy (n=1), exercise physiology (n=1), dietetics (n=1), clinical neuropsychology (n=1), and social work (n=1).

Most participants worked in the public system (n=12) including inpatient settings (n=6), a combination of inpatient and outpatient settings (n=5), and community settings (n=1). The remainder worked for private or not-for-profit organisations (both n=2), and all consulted with
both clients living in the community and in long term care. Health professionals reported conducting an average of one to 40 consultations with people with dementia each week, though two participants in non-clinical roles (a clinical nurse consultant and an occupational therapist) were not presently conducting clinical consultations. Both of these participants had extensive clinical experience with people with dementia. The level of cognitive disability among clients was mixed for most participants ($n=12$), while the remainder worked only with people with mild to moderate disabilities ($n=4$).

Findings of the interviews

Overall, participating clinicians were hesitant about whether or not rehabilitation services should be widely implemented for people with dementia. Most clinicians had not previously thought about the relationship between rehabilitation and the symptoms of dementia.

“I’m struggling with the word rehabilitation… So having been stimulated to think about it now, I can see a role for using people’s abilities in different ways.” (HP15)

They could acknowledge broader problems with currently available dementia care pathways in Australia, but generally did not conceptualise rehabilitation as fitting well within this pathway.

There was a common perception that the wider public would not support such services.

Analysis revealed two dominant but interrelated themes from the qualitative data: (1) outcomes, referring to the difficulty with defining worthwhile outcomes of a rehabilitation program for people with dementia, and; (2) participation, referring to a variety of perceived barriers to rehabilitation participation in this population.

Theme 1: Difficulty defining meaningful outcomes

The most prominent theme to emerge from the data was the difficulty with defining meaningful and worthwhile outcomes of a rehabilitation program for people with dementia. This theme was informed by four major sub-themes: (a) “You’ve got to have a clear goal”; (b) “Does rehabilitation belong in a palliative diagnosis?”; (c) “Struggling with the word ‘rehabilitation’”, and; (d) “Making sure they have realistic expectations”.

“You’ve got to have a clear goal”

Allied health professionals who deliver rehabilitation programs were typically ‘results driven’ and derived professional fulfilment from helping their clients achieve measurable goals. These
were usually associated with cognitive or physical function outcomes. Several participants expressed concerns that if a person with dementia is unable to reach such measurable goals this would undermine their worth as a health professional and the worth of the program more broadly.

“If we make goals that people with dementia can’t reach then it is not possible to demonstrate the worth of the program. It’s not like when someone’s had a stroke and you get them from being bed-bound to walking again.” (HP01)

Participants were unclear overall about what goals could be established to make provision of rehabilitation programs worthwhile, particularly in cases of severe impairment. They inferred at times that people with dementia could not learn new things.

“I imagine it’s a ‘time will tell’ type of thing, but my initial instinct in terms of dementia being a life-ending condition, that towards the severe end of the dementia spectrum that it might be more difficult to rehabilitate in terms of actually applying new learning strategies or even new equipment and so forth, and then actually have that be effective.” (HPO5)

This was accompanied by uncertainty about the evidence base for rehabilitative therapies in this population:

“I think if – the same as any other services, if there was some evidence that it was useful, I think it should be available” (HP14)

There was a view, particularly amongst medical practitioners, that it was necessary to have information from research studies about both the efficacy and cost-effectiveness of rehabilitation programs for this population.

Some clinicians considered personalised goal-attainment a feasible and worthwhile outcome while others considered this more achievable for younger clients or those with mild symptoms of dementia. References were made to community attitudes toward older people and people with dementia, exemplified by a comment from one clinician that people with dementia in their service were not viewed with the same level of therapeutic optimism as other clients:

“I know from just a couple of comments that a couple of the physios in particular make about the [older] patients, that… goal setting is more a mindset for younger people, I’m not sure that it really works for older people.” (HP01)
“I think it has got this stereotype that people with dementia don’t remember anything. There is no point. They are deteriorating anyway. [The stereotype is that] there is no point.” (HP08)

Clinicians inferred or directly referenced a sense of nihilism about people with dementia. They talked about a generally negative community and health professional perception that people with dementia would not benefit sufficiently from rehabilitation programs to justify funding by the taxpaying public. One participant noted their perception that elderly people were not valued in the general community as citizens who have accumulated “social capital” and that their care was rather considered an unnecessary burden on the health system.

“Does rehabilitation belong in a palliative diagnosis?”

A second sub-theme was a perceived theoretical incompatibility between rehabilitative therapies and the palliative, compensatory approach often used when treating people with dementia. To many participants, intensive rehabilitation programs were potentially detrimental to optimal quality of life especially in the later stages of the condition and could do more harm than good:

“I don't think we should be providing stuff that's of no benefit. I mean I don't want to sound horrible... but even if the carer or family are of a view to say that the individual must have it. Well, if you've got somebody with severe dementia and you're sending them to go to physiotherapy, but they're not going to remember it and it's not going to help anyway, well is there any point whatsoever at that point?” (HP14)

None of the clinicians reported awareness of lobbying from consumer groups related to rights for rehabilitation amongst people with dementia. Clinicians were unsure whether people with dementia wanted rehabilitative services at all and recounted instances where this scepticism extended to family members of the person with dementia:

“I went to see a patient recently in triage and the family was actually really resistive to him participating in rehabilitation because they thought it would be too much information for him. He wouldn’t be able to cope with it so they preferred a really slow-stream rehab option which they were really fighting for.” (HP17)

Although it was a minority view, some participants considered palliative and rehabilitative care as complimentary rather than opposing:
“To me palliative care means you have come to terms with the fact that your condition is not going to be cured and you have taken a certain slant on how you are going to be treated. It is not that you are refusing all treatment and ‘I am going to die tomorrow’. It is about ‘I want a good quality of life but rushing off to a hospital every time I feel unwell is not what I want’. Do they not deserve to be informed about maintaining their nutrition as best as possible and maintaining their fidgeting, maintaining their physical activity? Maintaining for as long as they can and within their capacity?” (HP08)

This quote, however, exemplifies the larger definitional issues evident in the interviews.

“Struggling with the word rehabilitation”
There was confusion among participating health professionals about how to define rehabilitation, and what could be labelled a rehabilitation activity or outcome in the context of a degenerative neurological condition.

“Most people haven’t really been using that term in their practice… most people have been using sort of restorative care, reablement and wellness and those sorts of terms.” (HP3)

Participants appeared to lack a reference point to guide their understanding of rehabilitation for this population, and one rehabilitation registrar noted that rehabilitation specifically for dementia had not been a covered in their education. Clinicians remained largely focussed on physical outcomes (from exercise in a gym) or cognitive outcomes (from cognitive training) in lieu of the quality of life or wellbeing outcomes advocated by some proponents (e.g. Clare, 2017; Swaffer, 2016).

In contrast, a minority of participants referred to common aspects of dementia care that may not meet the generally recognised definition of rehabilitation as rehabilitative therapies. One geriatric medical specialist noted that pain causes significant distress, impairment, and behaviour change in people with dementia and so treatment should be considered a rehabilitative therapy. A clinical nurse consultant believed that advanced care planning should occur during rehabilitation programs as it facilitates shared-decision making even after capacity is lost.

“Making sure they have realistic expectations”
Finally, there was concern that referring to programs with rehabilitation terminology would give people with dementia and family members false hope for reversal of their impairments.
One rehabilitation physician who conducts triage services reported that in general the people who are assessed for rehabilitation perceive that “[rehabilitation] is going to be awesome, we’re going to get back to everything” (HP16), but felt cautious about this because it might give people the impression that they would make significant improvements.

On this basis, many participants were in favour of alternative language like ‘re-ablement’:

“I like the word ‘enabling’. Rehabilitation is about restoring to baseline - but imagine saying to someone [that] the only chance for success is for them to reach that goal. You want to enable someone to be able to do what they want to do as they are - you know, their life wishes, what they want to happen to them, and to me that’s better. Enabling someone to spend more time having coffee with their best friend before they die from Alzheimer's. That’s better, right?” (HP10)

Theme 2: Barriers to participation

The second theme, barriers to participation, referred to the perceived importance of the capacity to complete a traditional rehabilitation program. Overall, there was belief among health professionals that people with dementia are not able to fully participate in rehabilitation programs.

“I think if there’s significant degree of dementia that pretty much - well, I think that’s an exclusion criterion for rehabilitation.” (HPO1)

This perception was related to a range of perceived barriers to participation: (a) “They may not be able to take it on-board”; (b) “They’re not going to remember it”; (c) “Geared towards the patient and caregiver”, and; (d) “Variability”.

“They may not be able to take it on-board”

Many health professionals considered insight into one’s own cognitive disabilities to be an essential inclusion criterion for rehabilitation programs and were concerned that most people with dementia would not meet this criterion.

“Seeing the benefits for themselves [is a problem] because if they’re going to go ‘there’s nothing wrong with me’ then they’re not going to want to participate. From a service provider point of view, I’m not entirely sure how we move ahead with that.” (HP12)
Where insight is retained, there were also issues associated with the stigma attached to a dementia diagnosis. Some professionals pointed out that people with dementia might refuse or resent participating in a program aimed at treating dementia. A number of the participants raised themes around paternalism, discussing how the behaviour of people with dementia could be risky and that improving safety was important “so that they can function better, or be safer” (HP14). When discussing people with dementia, it was apparent that most of the participants were envisaging an older person who had dementia in addition to other comorbidities. Their thoughts tended to reflect their perceptions of how a rehabilitation approach would fit with people who had dementia but were also older and frail.

“They’re not going to remember it”

Several references were made to the cognitive features of dementia that would influence participation in rehabilitation. These included memory disabilities that may limit ongoing adherence between treatment sessions:

“A lot of nurses that I’ve come across have said, “The patient is not going to remember how to do any of this so why are we doing it?”” (HP17)

However, many could see the benefits even where adherence outside of treatment sessions was low:

“You're preventing them from becoming bed-bound, because they're often left to their own devices. They don't initiate. They’ll just sit.” (HP01)

Clinicians were concerned about the intensity and length of treatment sessions in a traditional rehabilitation program being too demanding for people with dementia. Many suggested that the model of rehabilitation care would need to be altered for this population to be delivered outside of inpatient settings recognising that people with dementia tend to function best in their own environments. They also felt adjustments should include specialist staffing, less intensive therapies, and regular revisiting of goals. Behaviour change was also noted as a key barrier to participation in rehabilitation for acute conditions among people with cognitive impairment, and an area for consideration for potential programs:

“I think [the nurses] get very stressed out about patients that might have any behavioural, memory [problems that] cause them any extra time, any extra hassle when they're doing their ADLs and meds and things. I often feel like when I have to tell them that we’re getting in someone with dementia in the background I really have to
downplay the dementia bit and focus on why they're here because the nurses will kick up…” (HP16)

“Geared towards the patient and caregiver”

Many regarded the ongoing support of an informal carer essential to a person with dementia’s participation in a rehabilitation program, more so than rehabilitation for other conditions. Some clinicians went as far as to say that a person with dementia could not successfully complete a rehabilitation program (for their dementia or any comorbid condition) if no informal carer was available to support:

“I feel the success of such a program would be very dependent on the active inclusion of family, carers, or substitute decision makers, which is not always a focus of the usual rehabilitation population.” (HP05)

Clinicians who were in favour of rehabilitation programs for this population noted the potential flow-on benefits for informal carers. Many recounted instances of informal carers looking for ‘something to be done’ after the diagnosis and considered that a rehabilitation program may provide some structure to the care pathway:

“It’s then almost certainly beneficial for the other family members to see their relatives doing – being involved and happy and so on, and I think that would reduce their grief. It may also reduce carer [stress] if the person with the disease is busily involved in something, whether it be at home or somewhere else for some part of the week or day or whatever.” (HP15)

“Variability”

Finally, some participants noted the unpredictable nature and course of dementia. Concerns were raised about the variable trajectory after dementia onset, and some clinicians believed this was a unique barrier to rehabilitation provision in this population:

“It’s that lack of a clear sense of what will happen. I think again the variability and the fact that you can have a sudden drop and then perhaps a bit of a rise, rather than a steady decline which many other conditions [have].” (HP06)

Clinicians compared the nature of dementia with other conditions such as stroke where the trajectory can be more predictable.
DISCUSSION

The aim of this qualitative study was to explore the views of health professionals about barriers to widespread delivery of multidisciplinary rehabilitation programs for people with dementia. We framed our exploration to capture attitudes towards rehabilitative treatments specifically for dementia as well as rehabilitation for acute conditions in people with comorbid dementia.

The main themes identified in the data are discussed below.

Main findings

A key finding from this study was that health professionals delivering rehabilitation programs derive professional fulfillment from helping their patients achieve positive and quantifiable outcomes. They do not, however, consider the outcomes achievable by people with dementia to be enough to provide this fulfillment. Clinicians were aware that rehabilitation services are rationed and felt that dementia is low priority for intervention. Research exploring health professional understanding of dementia management has identified a broad underestimation of the potential benefits of intervention (Robinson et al., 2014; Turner et al., 2004). Nonetheless, even outcomes proposed by advocates of rehabilitation in dementia care (e.g. goal attainment, quality of life, delayed institutionalisation; Cations, Laver, et al., 2017; Clare, 2017; Swaffer, 2015) may be unfulfilling for a practitioner accustomed to seeing patients achieve significantly higher occupational or mobility goals. Indeed, rehabilitation professionals are drawn to the profession because of the potential to achieve profound improvements in functioning and quality of life (Devinuwara, Burden, & O’Connor, 2013), and may be less confident providing therapy to people with a neurodegenerative conditions.

There was a general belief among participants that palliative and rehabilitative approaches to care are non-compatible, and that dementia care is most appropriately managed with a palliative, compensatory approach. These beliefs were related to an almost exclusive tendency to refer to people with dementia with severe disabilities and rarely consider community-dwelling people with mild dementia (who account for a majority of cases, Brown, Hansnata, & La, 2017). While this may reflect that most were working in acute, sub-acute, or residential settings, it also belies a stigma among health professionals that equates any dementia with global infirmity (Swaffer, 2014). This stigma can lead clinicians to apply late-stage management techniques to all cases of dementia, reducing the perceived utility of rehabilitative therapies.
Participants were sceptical overall about the capacity of people with dementia to participate in rehabilitation programs. Anosognosia, memory impairments, and behaviour change were noted as key barriers to participation and ongoing adherence between therapy sessions. These symptoms are known to contribute to reluctance to accept people with comorbid dementia into rehabilitation for acute injuries (Hopper, 2003) and do necessitate greater resource use to achieve equivalent outcomes (Young, Xiong, & Pruzek, 2011). Nonetheless, if provided with appropriate support people with dementia can benefit from rehabilitation similarly to people without dementia despite their cognitive disabilities (Cameron et al., 2012). Whether sufficient supports could be provided to facilitate success of a program specifically targeting dementia is not known. In addition, identifying a level of impairment at which intervention becomes harmful (e.g. stressful, overwhelming) rather than helpful was raised by several participants and is a well-documented clinical challenge (Rockwood, 2014).

Finally, participants could not envisage delivery of multidisciplinary rehabilitation programs for dementia within the current rationed service framework. Most participants felt that intensive inpatient environments with a focus on physical recovery are unlikely to be suitable or successful for this population. Some suggested that community rehabilitation services may be well-placed but could not conceptualise exactly what these models would look like. Clinicians were steadfast that an informal carer would be required to achieve meaningful outcomes. While informal support is known to improve rehabilitation outcomes in stroke (Harris, Eng, Miller, & Dawson, 2010; Tsoua-Hadjis, Vemmos, Zakopoulos, & Stamatelopoulos, 2000) and fracture (Hershkovitz, Kalandariov, Hermush, Weiss, & Brill, 2007), blanket exclusion of those without an informal carer undermines the individual agency that people with dementia have fought to have recognised (Boyle, 2014). Finally, the length of a rehabilitation program for this population was a key point of concern given that a person with dementia may live and require support for several decades following diagnosis. One participant noted that rehabilitation programs for fracture and other conditions are becoming shorter (Teasell et al., 2009) despite evidence that ongoing community interventions are associated with better outcomes (Chu et al., 2016).

Implications

Researchers and advocates have begun to conceptualise how rehabilitation programs might be delivered to people with dementia (Cations, Laver, et al., 2017; Clare, 2017; Poulos et al., 2017), and people with dementia themselves have argued that access to such programs is a human right (Dementia Alliance International, 2016; Swaffer, 2016). The World Health
Organization has recognised a need for the field to better understand that rehabilitation can be relevant to all health conditions and at all stages of disability (World Health Organization, 2017b), and that dementia is the leading cause of disability and dependence among older people (World Health Organization, 2017a). An increasing evidence base supports the use of non-pharmacological treatments including cognitive rehabilitation to treat the symptoms of dementia (Clare et al., 2010; Cooper et al., 2012; Laver et al., 2016; Livingston et al., 2017).

The results of this study, however, suggest that health professionals are far from accepting rehabilitation as relevant to dementia care. Most participants had never thought about rehabilitation being relevant to dementia care, signifying the work to be done for health professionals to embrace the evidence. To bridge this gap, a reframing of practice is required to encourage health professionals to value the individualised outcomes that are achievable for people with dementia (Oltra-Cucarella et al., 2018). This may be most successfully done by restructuring rehabilitation training programs to move away from the current focus on higher participation outcomes. Specific training in goal-setting and attainment, cognitive rehabilitation, exercise prescriptions, and other rehabilitative therapies for dementia will help students build confidence to address many of the barriers mentioned here. Incorporating these topics into other training programs may help students to understand the value of interdisciplinary care incorporating both rehabilitative medicine and palliative care approaches.

Strategies aimed at improving health professional skills in adapting to behaviour changes and cognitive disabilities will help to change the perception that these are insurmountable barriers to delivery of rehabilitation.

This shift will likely also require a broader change in community attitudes toward dementia. Education is needed to move away from the tendency to consider people with dementia only through the narrow lens of late-stage disease. Clare (2017) and Swaffer (2016) argue that conceptualising dementia as a social disability would frame the symptoms and their secondary effects as barriers to activity engagement and community participation. From this perspective, access to therapies that support inclusion and promote functioning would be easier to accept.

Further research is needed to demonstrate the efficacy and cost-effectiveness of rehabilitation programs for dementia. Policy makers will look for evidence that the redeployment of resources can result in tangible benefits such as reduced hospitalisations or delayed institutionalisation. Research that clearly articulates potential goals and outcomes for this
group will help to address health professionals’ confusion about what rehabilitation would look like for this group.

**Limitations**

The results of this study should be interpreted in the context of some important methodological limitations. Although we employed maximum variation sampling to canvas a variety of professional views, the sample is not representative of all health professionals who work with people with dementia or provide rehabilitation care. Each clinical field was represented by only a small number of clinicians, so the views expressed also may not reflect those of others in that field. All clinicians lived and worked in a metropolitan region and most provided services in the public sector. Some may also have agreed to participate because they held especially strong views on the topic, and views may have differed according to rehabilitation training experience. As such, the results here may not be transferable and reflect a particular experience rather than an established view. Canvassing of a wider demographic of views may identify additional themes. Additionally, the participants in this study were vulnerable to a response bias tending toward social desirability. This was demonstrated by their tendency to attribute negative views about older people or people with dementia to their colleagues or the wider community rather than themselves. The interviewer explicitly encouraged participants to be open with their thoughts prior to the interview, but some participants may not have shared the entirety of their perspectives because of the sensitivity of the topics discussed. The interviewer has published her views about the potential value of rehabilitation for people with dementia (Cations, Laver, et al., 2017). Despite efforts to reduce interviewer bias, clinicians may have been aware of these views and this may have influenced the interview outcomes. Finally, the credibility of the findings would have been enhanced with triangulation of data or other methods.

**Conclusion**

Multidisciplinary rehabilitation is incorporated into the usual care pathway for many chronic neurological conditions, but not dementia. Widespread adoption of multidisciplinary rehabilitation will require a reframing of education and practice that encourages health professionals to value the outcomes that may be achievable for people with dementia and to appreciate that the investment needed to overcome barriers to participation is worthwhile.

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CONFLICTS OF INTEREST

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Table 1. Overview of themes.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
<th>Illustrative quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty defining meaningful outcomes</td>
<td>“You’ve got to have a clear goal”.</td>
<td>“It’s not like when someone’s had a stroke and you get them from being bed-bound to walking again.” (<em>HP01</em>)</td>
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<td></td>
<td>“Does rehabilitation belong in a palliative diagnosis?”</td>
<td>“I mean this is essentially palliative care. It's a progressive incurable disease for which we have no treatment that’s going to arrest or reverse the process. So whilst it might be over a long period of time, it still really is palliative care. We should be focussing very much on those quality of life and dignity issues.” (<em>HP11</em>)</td>
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<td></td>
<td>“Struggling with the word ‘rehabilitation’”</td>
<td>“[When I think of rehabilitation] people are going to improve to a pre-morbid state or regain 50% - 25% of function or whatever it might be, whereas dementia, the word that comes to mind is more management rather than rehabilitation.” (<em>HP15</em>)</td>
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<td></td>
<td>“Making sure they have realistic expectations”</td>
<td>“I think it would have to be very clear; it’s a real balance between not destroying any hope and also not giving them false hope that this is actually going to cure the issue.” (<em>HP06</em>)</td>
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<td>Barriers to participation</td>
<td>“They may not be able to take it on board”</td>
<td>“I think one big thing is the person. If they know it’s a program for dementia; well, a lot of people don’t believe they have dementia.” (<em>HP12</em>)</td>
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<td></td>
<td>“They’re not going to remember it”</td>
<td>“Look, I hate to say this, but I think it is how we value our older people really. It is all the negatives. There is no value in an older person.” (<em>HP08</em>)</td>
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<td>“I guess it just depends on the type of dementia. You get some people with that real short-term memory loss where they're not remembering one thing from one minute to the next, but they can still in that time and place do what you want them to do. They can come to the gym and do a whole program. They won’t remember five minutes later that they’ve done it, but I guess they're still getting the physical benefit.” (<em>HP01</em>)</td>
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<td>“I find that with patients with cognitive decline and dementia, they find it really difficult to get motivated to do things and they don’t understand. They don’t see the reasons that they need to be doing exercises… they don’t understand the goal of [rehabilitation].” (<em>HP17</em>)</td>
</tr>
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<td></td>
<td>“Geared towards the patient and caregiver”</td>
<td>“For me personally, unless you have got family on board, your rehab is going to fall apart.” (<em>HP08</em>)</td>
</tr>
</tbody>
</table>
“Variability”

“It’s that lack of a clear sense of what will happen. I think again the variability and the fact that you can have a sudden drop and then perhaps a bit of a rise, rather than a steady decline which many other conditions [have].” (HP06)