# A Qualitative Study on the Experiences of Therapists Delivering the Promoting Activity, Independence and Stability in Early Dementia (PrAISED) Intervention During the COVID-19 Pandemic

Alison Cowley<sup>a,b,\*</sup>, Vicky Booth<sup>a,b</sup>, Claudio Di Lorito<sup>b</sup>, Pooja Chandria<sup>c</sup>, Olivia Chadwick<sup>d</sup>, Catherine Stanislas<sup>e</sup>, Marianne Dunlop<sup>f</sup>, Louise Howe<sup>b,f</sup>, Rowan H. Harwood<sup>f</sup> and Pip A. Logan<sup>b,g,h</sup> <sup>a</sup>Nottingham University Hospitals NHS Trust, Nottingham, United Kingdom <sup>b</sup>Unit of Injury, Inflammation and Recovery Sciences, School of Medicine, University of Nottingham, Nottingham, United Kingdom <sup>c</sup>School of Medicine, University of Nairobi, Nairobi, Kenya <sup>d</sup>Faculty of Biology, Medicine and Health, The University of Manchester, Manchester, United Kingdom <sup>e</sup>Isokinetic Medical Group, Harley Street, London, United Kingdom <sup>f</sup>School of Health Sciences, University of Nottingham, Nottingham, United Kingdom <sup>g</sup>NIHR Applied Research Collaboration East Midlands (ARC-EM), Nottingham, United Kingdom

Accepted 11 October 2022 Pre-press 15 November 2022

# Abstract.

**Background:** The Promoting Activity, Independence and Stability in Early Dementia (PrAISED) intervention is a programme of physical activity and exercise designed to maintain participation in activities of daily living, mobility, and quality of life for people living with dementia. During the COVID-19 pandemic first national lockdown in England, the PrAISED physiotherapists, occupational therapists, and rehabilitation support workers adapted to delivering the intervention remotely via telephone or video conferencing.

**Objective:** The aim of this study was to explore therapists' experience of delivering the PrAISED intervention during the COVID-19 pandemic and derive implications for clinical practice.

**Methods:** Qualitative semi-structured interviews were conducted with 16 therapists using purposive sampling. Thematic analysis was used to analyze the transcripts.

<sup>\*</sup>Correspondence to: Alison Cowley, Research & Innovation, Nottingham University Hospitals NHS Trust, QMC Campus, Derby Road, Nottingham NG2 7UH, UK. Tel.: +0115 9691169 Ext. 77148; E-mail: alison.cowley@nuh.nhs.uk.

ISSN 1387-2877 © 2023 – The authors. Published by IOS Press. This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial License (CC BY-NC 4.0).

**Results:** Therapists reported a change in the relationship between themselves, the person with dementia and the caregiver, with an increased reliance on the caregiver and a loss of autonomy for the person living with dementia. There was concern that this would increase the burden on the caregiver. The therapists reported using creativity to adapt to different modes of delivery. They felt their sessions were mostly focused on providing social and emotional support, and that assessing, progressing, and tailoring the intervention was difficult.

**Conclusion:** It is possible to deliver some elements of a physical intervention using remote delivery, but a dual modal approach including remote and face-to-face delivery would optimize treatment efficacy. Educational support would be required to enable people living with dementia and their caregivers to overcome barriers relating to digital literacy.

Keywords: COVID-19, dementia, exercise, physical activity, rehabilitation, telerehabilitation

# INTRODUCTION

People living with dementia experience a wide range of symptoms including a progressive loss of motor skills [1-3], which may have a negative impact on their daily functioning, independence, and wellbeing. Keeping physically active can slow down the process of deterioration and help people living with dementia to maintain their independence, mobility, executive functioning, activities of daily living, and quality of life [4-15]. A number of interventions have been developed to promote physical activity in people living with dementia [16, 17]. Among these is the Promoting Activity, Independence and Stability in Early Dementia (PrAISED), delivering a programme of exercises and physical activities (including dual tasks, i.e., physical exercises with a cognitive element and Activities of Daily Living - ADLs) in the homes of participants living with dementia [18]. The intervention lasts 52 weeks and includes up to 50 therapy visits from a multidisciplinary team comprising physiotherapists, occupational therapists, and rehabilitation support workers. Together with participants and their caregivers, the PrAISED therapists set goals to be achieved from the participant at the end of their involvement in PrAISED, which are based on the person's preferences, needs, and aspirations. An individualized programme is then designed, which is tailored around the participant's capabilities and goals. The participant is supported to continue with the programme in between therapy visits, which are scheduled with a maximum frequency of two/week, and aim to monitor progress toward the end goal, assess risk, motivate the participant, and provide information on dementia and opportunities to get active in the community. Visits are tapered towards the end of the programme to support independence.

In the early months of 2020, COVID-19 was declared a pandemic by the World Health Orga-

nization [19], and In March 2020, measures were mandated in England to slow the spread of COVID-19. These included the introduction of social distancing, a national lockdown, and advice that the clinically vulnerable should be shielded from avoidable interactions [20]. As a result of these measures, it became impossible for PrAISED therapists to deliver face-to-face visits in the participants' homes. To ensure continuation of support, therapy visits were converted to remote delivery either through the telephone or via video conferencing, depending on participants' preferences and local availability of technology. Telehealth is an umbrella term describing the use of electronic means and telecommunications 'to support long-distance clinical healthcare... education, public health and health administration' [21].

The COVID-19 pandemic has caused a huge shift in therapists' way of working and has necessitated the exponential growth in telehealth [22]. While the literature identified the integral role of telehealth in today's healthcare which has been proved essential due to the pandemic, it also raised concerns about its efficacy in particular groups, such as those with cognitive impairment or dementia [23]. Generational barriers including computer literacy are exacerbated by cognitive impairment-specific difficulties such as memory problems [23] and may make people living with dementia hesitant or simply unable to access support through technology [24]. This may not only negatively impact the person and their wellbeing, but also increase caregiver burden [25].

Despite advances in the practice of telerehabilitation, to date, there is limited literature discussing therapists' experiences of their delivery of telehealth either generally, or specifically to people living with dementia. The conversion of PrAISED to remote delivery during the COVID-19 pandemic presented a unique opportunity to bridge this gap in research. This was explored as part of the PrAISED process evaluation [26]. The aim of this study was therefore to explore therapists' experience of delivering PrAISED during the COVID-19 pandemic and derive wider implications for clinical practice.

# MATERIALS AND METHODS

Qualitative semi-structured interviews were undertaken to gather rich data on therapists' experience of remotely delivering PrAISED. This qualitative interview study is reported in accordance with the consolidated criteria for reporting qualitative research (COREQ) [27] (Supplementary Material 1). The study was conducted in accordance to the Declaration of Helsinki [28].

## Study setting and population

Therapists who had experience of delivering the PrAISED intervention face-to-face (pre-pandemic lockdown) and virtually (during the national lockdown) were eligible to take part in the study. There were five study sites delivering the PrAISED intervention. Virtual delivery included either video platforms (i.e., Q Health) and/or phone. Q Health is a video patient consultation solution approved for use by the National Health Service (NHS) Digital and NHS England. It was introduced into the PrAISED study in March 2020 in response to the COVID-19 pandemic. Users needed an internet connection and computer, tablet, or smart phone and were required to download the Q Health application. Q Health enabled therapists and study participants to set up and access digital appointments to continue with the PrAISED intervention. The therapy team developed a simple set of instructions and supported PrAISED participants via the phone to download and set up the Q Health application.

Purposive sampling was used to obtain a range of experiences and views of therapists delivering the PrAISED intervention virtually. This approach involves selecting participants with specific characteristics which enables the research question and objectives to be addressed [29, 30]. Ethical approval for the study was sought and obtained from the Bradford Leeds Research Ethics Committee (Reference 18YH/0059).

# Data collection

Therapists delivering PrAISED remotely were identified through the study database. CDL

approached them by email and invited them to take part in a qualitative semi-structured interview. Therapists were sent a study information sheet and a consent form. Those wishing to take part were asked to contact a member of the study team. A mutually convenient time was arranged for the interview which took place by telephone. Consent was taken orally on the day of the interview.

Interviews were conducted by CDL, a postdoctoral researcher with expertise in qualitative methodology and a background in psychology between 22 June and 24 July 2020. CDL had no prior relationship with the participants. An interview guide was developed (Supplementary Material 2) informed by the PrAISED study team and in collaboration with two Patient and Public Involvement (PPI) contributors with experience of caring for someone with dementia, who were also involved in the development of the study. The use of speakerphone enabled CDL to record verbal consent and the interview session through an encrypted password-protected digital audio-recorder. Recordings were downloaded onto a password protected data storage area at the University of Nottingham (UoN) and were fully anonymized. Therapists were assigned a study number to protect anonymity. Transcription was completed by a professional transcriber and checked by the study team for accuracy. Data collection continued until data saturation was reached (i.e., no new themes emerged from the data) [31]. Participants were able to drop out of the interviews at any time. There were no instances of this occurring.

## Data analysis

Data were analyzed using thematic analysis which allows the identification, analysis, and reporting of data [32]. Reflective diaries were kept by the study team and integrated into data analysis. Data familiarization involved repeated reading of the transcripts independently by two members of the research team (stage one); they then identified codes (stage two) and developed these into an initial thematic framework (stage three). The emerging framework was discussed and refined with the study team (stages four and five) and was then applied to the remaining transcripts by a combination of AC, CDL, VB, and LH (stage six). This framework was approved by the study team and reviewed by PPI collaborators (MD, MG). Themes were discussed in relation to the research question and clinical evidence base (stage seven) to enhance methodological rigor [33].

Study therapist participant characteristics	
Site	Number of participants
1	4
2	3
3	5
4	3
5	1
Profession	Number of participants
Occupational therapist	7
Physiotherapist	4
Therapy Support worker	5

Table 1 Study therapist participant characteristics

# RESULTS

Sixteen therapists were recruited across five study sites and interviews were completed. Participant demographics are displayed in Table 1 above. Interviews were all completed and ranged from 40 to 60 minutes. All participants had no experience of telehealth prior to the COVID-19 pandemic.

Two themes emerged from the data: *Changes* to roles and adaptations and creativity in delivery. Occupational therapists, physiotherapists, and rehabilitation support workers will be referred to as therapists, and people living with dementia taking part in the PrAISED study referred to as participants.

# Changes to role

This theme described how therapists experienced the changes of roles within their therapeutic relationship with the person living with dementia and their caregiver when delivering the PrAISED intervention remotely. Therapists spoke of the increased reliance on the caregiver (where present) to be their eyes, ears, and hands during remote intervention delivery. Two sub themes emerged which explored their perceived increased reliance on caregivers and the subsequent changed relationship with the person with dementia and how this affected the participants' autonomy and motivation. These two sub themes will now be explored.

#### 1a. Increased reliance on caregiver

Therapists spoke of increasingly relying on caregivers during remote PrAISED sessions. They compared their usual face-to-face practice with remote delivery and the frustration of not being able to receive 'real time' feedback and therapeutic cues during treatment sessions. "I think in terms of rapport and feedback from people when you are seeing them face-toface... you want to get feedback to see how they are managing and see how they are physically doing it. Just talking them through is quite different to actually how they are doing it." [Therapist 2, Occupational Therapist]

To address this, therapists reported becoming increasingly reliant on caregivers to provide feedback on participants' performance.

"I feel a lot more reliant on the caregiver now, in terms of where the participant is and how they are progressing just explaining what it is that you want them to do, just making sure that they understand what you have said as well." [Therapist 2, Occupational Therapist]

Therapists reflected on the nature of their clinical practice and their reliance on using feedback during therapeutic interactions to establish if the PrAISED exercises/activities needed progressing or adapting. This was said to be particularly challenging with individuals who had greater levels of cognitive impairment and communication difficulties. Therapists reported feeling ill-prepared and frustrated by their inability to draw on their usual battery of clinical skills. It was in this context that caregivers and family members became increasingly crucial.

"I think because we can't be there face-to-face so we can't demonstrate things and we can't work through activities and progress goals in the same way. We are quite reliant on verbal feedback and things that require instruction and step by step guidance we are obviously not there to do it faceto-face." [Therapist 30, Physiotherapist]

In essence, caregivers were said to become the surrogate therapist during remote intervention delivery. They became conducive to understanding risk and progressing participants, in line with PrAISED delivery and principles.

"You don't always pick up on the phone but if you are there and you have your ears and eyes seeing things you can really see what is happening." [Therapist 5, Occupational Therapist]

"We have to rely so much more on whoever is in the house. Because we can't go and see people to check on progress and get an accurate representation over the phone of what is happening." [Therapist 30, Physiotherapist] For participants who did not have a caregiver or family member present during PRAISED intervention delivery, therapists spoke of the challenges they faced in not only understanding performance and progression of activities, but also accessing digital and remote platforms such as video conferencing software.

"They are not very technical, it is quite difficult because most of them I see live alone and they are sort of 80 odd, they don't have smart phones or laptops and things like that." [Therapist 4, Rehabilitation Support Worker]

In some instances, therapists felt less confident in progressing activities in the remote setting, as they were unable to observe performance or be present to provide physical assistance, compared to their usual face-to-face practice.

"There is also a slight scariness about a therapist in this situation as well because we are often asking people to do things that are slightly balance challenging, when we are there as a safety net." [Therapist 20, Physiotherapist]

Despite therapists concerns over their perceived reliance on caregivers, this was not always viewed negatively. During the pandemic lockdown, therapists spoke of the social isolation that both participants and their caregivers reported during their PrAISED sessions. They reported building a greater rapport with caregiver in order to deliver PrAISED, but this also enabled them to provide greater level of emotional and social support.

"When we do have the telephone calls, you know we don't just talk about exercises we talk about general things as well. Because of the whole situation, everybody has been really isolated, if they live on their own their family aren't visiting either, so they are feeling quite low anyway. Even if just to speak to them about life really, they enjoy that as well." [Therapist 4, Rehabilitation Support Worker]

Although this may have in some instances changed the focus of goals/PrAISED programme, providing wellbeing support was viewed as critical in retaining participants in the study and working towards personalized goals.

# 1b. Change in therapeutic relationships

With a perceived increased reliance on caregivers and family members, therapists described how this may have changed their relationship with participants and their engagement with the PrAISED intervention. Understanding and encouraging individuals' motivation is a key component of the PrAISED intervention. Therapists reported the challenges faced by individuals with cognitive impairment accessing remote delivery platforms (phone or video conferencing software) and how relying on caregivers or others to support this may have affected individuals' motivation and autonomy.

One therapist described a situation during a telephone and face-to-face consultation, where they were discussing with a participant if they had been completing their exercises/activities.

"I spoke to one of my participants the other day and he said yes I am doing my exercise programme but when you actually meet them face-to-face you get the wife interaction, shaking her head behind him." [Therapist 30, Physiotherapist]

This discrepancy between the participant and their caregiver could tactfully be managed by the therapist in a face-to-face session, so as to avoid any disruption to the therapeutic relationship established. However, over virtual platforms, this was more difficult and could be seen to negatively impact the autonomy of the individual. Therapists were cognizant of how this "checking up" could be perceived by participants and potentially undermine independence and motivation to take part in the intervention/study.

"I would reassure people that I wasn't checking up on them, which I would anyway if I was doing the face-to-face visits. I think it is just difficult because you haven't got that non-verbal, neither of us have got that non-verbal communication, to judge how someone is feeling about it." [Therapist 8, Rehabilitation Support Worker]

The enhanced communication possible within a face-to-face session was recognized as valuable for both therapists and participants, and without it, the ability to tailor the intervention content or approach to support the individual's motivation was more challenging.

"People with memory problems, dementia do need to see the person that they are talking to, they can pick up on our body language as we do on theirs. Yes, part of the feeling they trust and understand you, is by I think they go by our body language." [Therapist 27, Occupational Therapist] "Some clients it's a bit more tricky where you're asking them what they're doing and are you doing your programme and they're saying oh well  $\Gamma$  m doing this and  $\Gamma$  m doing this and they're skirting around the exercise and you think if I was there I could probably go in and help with their motivation of what isn't working." [Therapist 16, Physiotherapist]

In some instances, this led to therapists focusing their energy on supporting caregivers/family members to deliver /support PrAISED rather than on participants. Therapists reflected on the dilemma of whether to elicit more support and involvement from caregivers/family members or not but recognized that this also could undermine the independence and autonomy of participants.

"I do try and speak to the caregiver if I can. But I don't want to undermine the participant either because you don't want them to think that you are undermining them." [Therapist 13, Rehabilitation Support Worker]

## Adaptation and creativity

This theme described how therapists adapted the delivery of the PrAISED intervention from faceto-face to virtual approaches during the lockdown period. Therapists reported that they had limited experience of remote/virtual working and as a result, that they felt unprepared. Some of this related to specific IT skills:

"I am not very good at technology....I don't think any of us are IT wizards and especially when you have to work from home and everything is new and the internet connection isn't always very good because of where we live. I think it doesn't look very professional if you come across not knowing what you are doing." [Therapist 5, Occupational Therapist]

This was further exacerbated by participant and caregiver participants' perceived lack of digital literacy which was also viewed as a barrier to intervention delivery.

"Our problem with Q health [digital delivery platform] is that every time you go into it, they [the patient/carer] have to put their name, their date of birth, their surname into the computer and that's where one of our participants was finding it *really difficult because she struggles with typing.*" [Therapist 11, Rehabilitation Support Worker]

Despite these initial technical challenges for both therapists and recipients of the intervention, therapists spoke of the benefits of this new way of working both in terms of time, access and increased social support during national lockdowns.

"We have a lot of clients that live very far away that don't get access to community services just because they're too far away. They're very remote so that [virtual] can be very beneficial." [Therapist 16, Physiotherapist]

However, despite these challenges, therapists spoke of finding a previously untapped source of therapeutic creativity to their practice. One therapist explained how they had adapted an exercise programme to support an individual with communication and cognitive difficulties over the remote platform.

"[I developed] a little video of me doing the exercises, or I can find a video online that shows the exercises I want them to do and email over." [Therapist 16, Physiotherapist]

These new approaches allowed the therapists to find creative ways to engage and motivate participants and caregivers, but some felt that this was highly dependent on where participants were in terms of the study. One therapist stated that they did not feel confident that such approaches would be as successful, if they did not already have a therapeutic relationship with a participant. They suggested that for future implementation, virtual delivery should not be considered for new study participants.

"I don't feel very confident that I would be able to deliver this to new clients, so if I've never met them before I wouldn't want to start a programme remotely with somebody I've never seen face-toface." [Therapist 16, Physiotherapist]

This inability to 'see' participants and deliver a face-to-face treatment also saw therapists consider different components of rehabilitation. In addition, many of the goals set by participants as part of the intervention were no longer possible due to the national lockdown. Being creative with the goal and content of the intervention meant that additional components of the intervention, such as dual-tasking or more cognitively focused activities, were included.

"I' ve started sequencing games as well and I do it is quite a lot... it just keeps the 'visit' a bit more fun and stops it from going stale. Because like we said we can't go out for walks and stuff like we normally would." [Therapist 11, Rehabilitation Support Worker]

"If you set a goal for like a social outlet goal or a physical health goal as in going out walking or going to a class or a physical group, ... because lots of them have closed down the goals that you perhaps initially set, they have become a lot more constrained because of the environment." [Therapist 5, Occupational Therapist]

Despite these creative solutions in adapting to the restrictions of the national lockdown, therapists yearned for face-to-face interactions with the participants and their caregivers. They reported that they were superior in terms of creating and building a therapeutic relationship and gave them greater confidence in progressing activities associated with PrAISED.

"I think there is no replacement for face-to-face contact in my opinion and actually being able to see people seeing the non-verbal cues, as to whether they are getting upset or what the environment is like, there such a lot that you miss out on when it is just phone contact. And it is ok generally, having a general conversation to people but it is hard to give them goals of things to do...a lot of people have missed out, particularly people who have been anxious and depressed as well as having dementia so the rapport that people were gaining with the support worker or us going in, that's all been lost and all been put on to the carer really as well." [Therapist 5, Occupational Therapist]

# DISCUSSION

## Summary of findings

The aim of this study was to explore therapists' experience of delivering PrAISED during the COVID-19 pandemic and derive implications for clinical practice. Through interviews with 16 therapists who delivered the PrAISED intervention in different locations across the UK, two main themes emerged exploring the changing role of the therapist and how they utilized adaption and creativity. The role changes reported included an increased reliance on the caregiver and altered therapeutic relationship between therapist and the person living with dementia.

# Comparison to other studies

A change in the therapist's role was strongly described by those delivering the intervention during the pandemic. They relied more heavily on the caregiver to be able to support the person living with dementia to participate in the exercise and activity intervention and felt that the remote platform and the external contextual influence of a pandemic altered the nature of their therapeutic relationship. This finding highlights the fragility and carefully constructed nature of living with and supporting people living with dementia, which has been well discussed by other authors [34-36]. The importance of the caregiver in helping the person living with dementia live well is also well documented [37], and this study confirms and contributes to that knowledge by adding a unique perspective of this relationship from within a pandemic.

However, our findings suggest that this increased reliance on the caregiver during the telehealth intervention resulted in reducing the autonomy of the person living with dementia. Complications inevitably arose regarding the autonomy of the participant during the period of remote delivery, and therapists voiced the barriers to keeping the participant at the center of the intervention [38]. Similar drawbacks have been documented in cardiac rehabilitation, although here, interventions were more general, and telerehabilitation was used for group classes rather than tailored, complex interventions [39].

The value of the therapeutic relationship, or alliance, developed within rehabilitation between professional and individual has been explored in multiple rehabilitation settings, such as mental illness [40], chronic pain [41], stroke [42], as well as in dementia [43]. The findings from this study expand this to illustrate how a different delivery platform can impede the therapeutic relationship, mainly through difficulties with communication and a change of content that reflects the external influences of a global health crisis.

It was identified that the remote platform influenced communication with the person living with dementia, which in turn impacted the self-efficacy and autonomy of the individual. In a similar study exploring the views of a nursing team delivering telecare for Chronic Obstructive Pulmonary Disease patients, the main barriers of reduced confidence and their diminished self-efficacy in providing healthcare in a remote context, show very similar correlations to barriers found in this study [44]. However, this study uncovered more diverse challenges to telehealth, as therapists working on PrAISED highlighted difficulties in tailoring the intervention to the participant when it was delivered remotely. This arose as a result of the inability to establish a complete narrative from the participant, the inability to visually assess the participant and their home environment, and the difficulties in gauging their values via phone or video. Each of the aforementioned features have been identified by the National Institute for Health and Care Excellence [45] as being key to providing patientcentered care. Similarities to a study by Green et al.'s [46] investigating perceptions of telehealth are observable, in that both showed that perceived depersonalization of care was a result of the barriers to virtual health interventions.

There has been an increase in publications detailing remotely delivered interventions that were necessitated by the pandemic [47]. However, many of these telehealth innovations are not reporting as complex an intervention as PrAISED, which is not only multi-factorial but multi-professional. Therefore, this study significantly advances our understanding of remote delivery of rehabilitation and the clinical implications thereof.

The adaption and creativity utilized by the therapists to continue to deliver the intervention and support adherence and motivation in the participants living with dementia emerged as a theme from the interviews. Therapists spoke of the need to be creative to adapt their approaches and treatments to take into account virtual delivery in order to meet the PrAISED components. Although many reported feeling ill-prepared and frustrated about working virtually, they ultimately drew upon different skills and creative thinking which embraced the progressive and person-center principles of PrAISED, and through clinical creativity the adaptations appeared to work and were acceptable to all. This feeling of being under-prepared has been reported in other telehealth studies. Bulik [48] reported that providers felt less control over the non-verbal aspects of the telehealth sessions. It is worth considering a deeper interpretation, where professionalism and identity as the lead within an intervention session could be underpinning the therapists' unease in this altered delivery context. In a study with clinical research nurses, Tinkler et al. [49] found that professional identity was influenced by changes to role, workload, and work relationships, which all had an impact on participants' practice. The therapists delivering the PrAISED intervention

experienced a significant change, which is unsurprisingly influenced more than just reported on the surface.

# Strengths and limitations of the study

This study provides a valuable insight into therapists' experiences of adapting a community-based complex rehabilitation intervention for people living with dementia and cognitive impairment, during the COVID-19 pandemic. It provides a unique perspective into a natural, unintended phenomenon because of the lockdown and social restrictions put in place in March 2020. This is unlikely to be replicable and therefore important to document and report findings. Only the perspectives of the therapists were included, and the views of the person living with dementia or the caregiver were not provided. Considering one of the subthemes is so intertwined with the caregiver, it would have been valuable to explore their perspectives and give a balanced account. Research should include people living with dementia [50] to give them their voice [51], particularly during the COVID-19 pandemic [52]. Nevertheless, this paper focused on the therapist's experience, and therefore there is value in focusing on this population, particularly for clinical recommendations and future telehealth interventions that are potentially delivered by therapists.

Another weakness is that the interviews were completed for the process evaluation of the main study and the interview schedule was not specifically developed for the analysis conducted in this paper [53]. Therefore, there is the potential that the issues were not explored with the depth and detail deserved. It does make use of the data that have already been collected, resulting in less burden and greater efficiencies for the therapists, and provides a focused study that otherwise might have been lost in the main process evaluation findings.

On reflection, the results are somewhat negative to the introduction of telehealth and because the therapists have the physical, face-to-face intervention to compare it too then their perspective will always reflect this. This is reinforced by the findings of Cranen et al. [54] who found that purely homebased telerehabilitation with minimal contact with healthcare professionals was preferred least when compared to a mixed approach, or purely face-toface. Including therapists who have only delivered a remote version of the PrAISED intervention would give a more accurate account of the value or experience of that version of delivery. However, that is not the aim of this paper and the changing situation was of itself interesting.

Lastly, because the therapists were being interviewed about the intervention by a member of the study team, their responses may have been influenced by prior expectations. Similarly, the analysis was conducted by therapists who also may have imparted their underlying opinions on the interpretations. To counter this, an experienced qualitative researcher with a different background was utilized, as well as double-data entry on all transcripts, in line with recommendations for high quality qualitative research methods [32, 55].

# Implications for practice

Therapists in this study identified strategies to overcome the barriers of remote delivery and suggested that a hybrid approach could be employed. While remote delivery has its benefits, they proposed the use of both remote and face-to-face delivery in order to improve treatment efficacies. Alongside this overall implication for future telehealth for people living with dementia, a number of clinical implications to enhance and improve service provision can be made, including:

- Providing educational support for the participants living with dementia and their caregivers may help overcome some of the barriers related to IT literacy and accessibility. Educational packages may include teaching them how to use the devices which can be done through an information sheet and explained verbally too.
- Ensuring that all the different services included in intervention delivery have access to video calls will enhance the consultations, as they were reported to be superior to telephone calls.
- Provision of digital training for the service providers may help reduce the disparities between therapists in using technology for healthcare. This would avoid therapists' learning as they go' and lead to greater confidence in the use of telerehabilitation.
- To reduce the impact of the lack of nonverbal communication, enhancing other skills such as active listening (especially during telephone consultations), increased use of nodding, gestures, active body language, and facial expressions (during video consultations) may be useful.

- Alternative formats for intervention support, e.g., DVD, CD, or online videos, should be considered and the study materials expanded to standardize these for the different sites.
- Ensure that the end-users (participants) have a safe and clear environment by asking them, prior to prescribing the exercises. Although this may not necessarily prevent them from falling, given that the exercises are balance-challenging, it may reduce the risk of accidents. Ensure that caregivers are present and close to the participants when prescribing exercises.

# Future research

While this study has illustrated a number of challenges to delivering a complex rehabilitation intervention over a remote platform, it has also highlighted practical implications that could support it. The empirical testing of this is therefore the next logical step for future research. While telerehabilitation has shown to be successful in areas such as stroke and pulmonary rehabilitation, there has been limited implementation in dementia care [56].

There is a significant difference between adapting out of necessity, such as due to a pandemic, versus designing with purpose. Practical guidance published by the Chartered Society of Physiotherapy during the pandemic highlighted the need to identify specific therapist training needs to share learning and maximize effectiveness of consultations [57]. Future studies into telehealth could utilize co-design or co-production principles to do this to the greatest extent, with both therapists that have, and do not have telehealth experience, as well as people living with dementia and their caregivers. It would also be important to include representatives from service and organizational perspective as the challenge of having technologically skilled staff is relevant to service providers. Therefore, as well as an empirical study, there is also the potential to use expanded mixed methods to fully explore telehealth for people living with dementia.

Alongside this, using measures that document the experience and self-efficacy of the person living with dementia to use technology would be an interesting addition to the more rehabilitation-focused outcomes. Measures such as the CATEQ [58] for caregivers' experience would be useful and developed specifically for dementia.

The altered therapeutic relationship and increased emotional and social support provided by the therapists also indicates a need to explore interventions specifically focused on that skill development, both for the person living with dementia, their caregiver, and therapists. Considering the increase in literature in telehealth, a rigorous literature review to pool findings would be the first step to identify further gaps in the literature. Ultimately, the aim of future research should be to develop evidence-based guidance on using telehealth in people living with dementia that could be used internationally.

## Conclusion

It is possible to deliver some elements of a physical intervention for people living with dementia using remote delivery and this brought out the creativity of the therapists involved. Using telehealth did result in a change in therapeutic relationship between the therapist, participant and caregiver, and therapists felt limited in their abilities to support the participants' progression. In order to overcome barriers in assessing, progressing, and managing risks via telehealth, a multi modal approach of both remote and face-to-face delivery could be further explored. Video conferencing was seen as more effective than telephone calls however educational support would be required to enable people living with dementia and their caregivers to overcome barriers relating to IT literacy.

# ACKNOWLEDGMENTS

This study presents independent research funded by the United Kingdom National Institute for Health Research (NIHR) under its programme Grants for Applied Research funding scheme (RP-PG-061-20007). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of health and Social Care. We would like to thank Maureen Godfrey for her contributions to data analysis and interpretation.

Authors' disclosures available online (https:// www.j-alz.com/manuscript-disclosures/22-0424r1).

## SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: https://dx.doi.org/ 10.3233/JAD-220424.

## REFERENCES

- Martyr A, Clare L (2012) Executive function and activities of daily living in Alzheimer's disease: A correlational metaanalysis. *Dement Geriatr Cogn Disord* 33, 189-203.
- [2] Giebel CM, Sutcliffe C, Stolt M, Karlsson S, Renom-Guiteras A, Soto M, Verbeek H, Zabalegui A, Challis D (2014) Deterioration of basic activities of daily living and their impact on quality of life across different cognitive stages of dementia: A European study. *Int Psychogeriatr* 26, 1283-1293.
- [3] Giebel CM, Sutcliffe C, Challis D (2015) Activities of daily living and quality of life across different stages of dementia: A UK study. *Aging Ment Health* 19, 63-71.
- [4] Potter R, Ellard D, Rees K, Thorogood M (2011) A systematic review of the effects of physical activity on physical functioning, quality of life and depression in older people with dementia. *Int J Geriatr Psychiatry* 26, 1000-1011.
- [5] Forbes D, Forbes SC, Blake CM, Thiessen EJ, Forbes S (2015) Exercise programs for people with dementia. *Cochrane Database Syst Rev* 2015, CD006489.
- [6] Blankevoort CG, van Heuvelen MJG, Boersma F, Luning H, de Jong J, Scherder EJA (2010) Review of effects of physical activity on strength, balance, mobility and ADL performance in elderly subjects with dementia. *Dement Geriatr Cogn Disord* 30, 392-402.
- [7] Heyn P, Abreu BC, Ottenbacher KJ (2004) The effects of exercise training on elderly persons with cognitive impairment and dementia: A meta-analysis. *Arch Phys Med* 85, 1694-1704.
- [8] Hauer K, Schwenk M, Zieschang T, Essig M, Becker C, Oster P (2012) Physical training improves motor performance in people with dementia: A randomized controlled trial. J Am Geriatr Soc 60, 8-15.
- [9] Lamb SE, Sheehan B, Atherton N, Nichols V, Collins H, Mistry D, Dosanjih S, Slowther AM, Khan I, Petrou S, Lall R (2018) Dementia And Physical Activity (DAPA) trial of moderate to high intensity exercise training for people with dementia: Randomised controlled trial. *BMJ* 361, k1675.
- [10] Lowery D, Cerga-Pashoja A, Iliffe S, Thuné-Boyle I, Griffin M, Lee J, Bailey A, Bhattacharya R, Warner J (2014) The effect of exercise on behavioural and psychological symptoms of dementia: The EVIDEM-E randomised controlled clinical trial. *Int J Geriatr Psychiatry* 29, 819-827.
- [11] Schwenk M, Zieschang T, Englert S, Grewal G, Najafi B, Hauer K (2014) Improvements in gait characteristics after intensive resistance and functional training in people with dementia: A randomised controlled trial. *BMC Geriatr* 14, 73.
- [12] Suzuki T, Shimada H, Makizako H, Doi T, Yoshida D, Tsutsumimoto K, Anan Y, Uemura K, Lee S, Park H (2012) Effects of multicomponent exercise on cognitive function in older adults with amnestic mild cognitive impairment: A randomized controlled trial. *BMC Neurol* 12, 128.
- [13] Telenius EW, Engedal K, Bergland A (2015) Effect of a high-intensity exercise program on physical function and mental health in nursing home residents with dementia: An assessor blinded randomized controlled trial. *PloS One* 10, e0126102.
- [14] Hoffmann K, Sobol NA, Frederiksen KS, Beyer N, Vestergaard K, Brændgaard H, Gottrup H, Lolk A, Wermuth L, Jacobsen S, Laugesen L, Gergelyffy R, Høgh P, Bjerregaard E, Vogel A, Johannsen P, Cotman C, Hassalbalch SG, Waldemar G (2015) Moderate to high-intensity physical

exercise in patients with Alzheimer's disease. *Alzheimers Dement* **11**, P324-P5.

- [15] Schwenk M, Zieschang T, Oster P, Hauer K (2010) Dual-task performances can be improved in patients with dementia: A randomized controlled trial. *Neurology* 74, 1961-1968.
- [16] Pitkälä KH, Pöysti MM, Laakkonen M-L, Tilvis RS, Savikko N, Kautiainen H, Strandberg TE (2013) Effects of the Finnish Alzheimer Disease Exercise Trial (FINALEX): A randomized controlled trial. *JAMA Intern Med* 173, 894-901.
- [17] Prick AE, Lange J, Scherder EJA, Twisk JWR, Pot AM (2016) The effects of a multicomponent dyadic intervention on the mood, behavior, and physical health of people with dementia: A randomized controlled trial. *Clin Interv Aging* 11, 383-395.
- [18] Bajwa RK, Goldberg SE, Van der Wardt V, Burgon C, Di Lorito C, Godfrey M, Dunlop M, Logan P, Masud T, Gladman J, Smith H, Hood-Moore V, Booth V, Das Nair R, Pollock K, Vedhara K, Edwards RT, Jones C, Hoare Z, Brand A, Harwood RH (2019) A randomised controlled trial of an exercise intervention promoting activity, independence and stability in older adults with mild cognitive impairment and early dementia (PrAISED) - A Protocol. *Trials* 20, 815.
- [19] Shereen MA, Khan S, Kazmi A, Bashir N, Siddique R (2020) COVID-19 infection: Origin, transmission, and characteristics of human coronaviruses. J Adv Res 24, 91-98.
- [20] Smith GD, Spiegelhalter D (2020) Shielding from covid-19 should be stratified by risk. *BMJ* 369, m2063-m.
- [21] Seelman KD, Hartman LM (2009) Telerehabilitation: Policy issues and research tools. *Int J Telerehabil* 1, 47-58.
- [22] Valentino LA, Skinner MW, Pipe SW (2020) The role of telemedicine in the delivery of health care in the COVID-19 pandemic. *Haemophilia* 26, e230-e231.
- [23] Wang M, Liu S (2018) The old people using intelligent mobile equipment influence extent. In *Human Aspects of IT* for the Aged Population Applications in Health, Assistance, and Entertainment, Zhou J, Salvendy G, eds. Springer.
- [24] Hayes D (2020) Telerehabilitation for older adults. *Geriatr Rehabil* 36, 205-211.
- [25] Cohen G, Russo MJ, Campos JA, Allegri RF (2020) Living with dementia: Increased level of caregiver stress in times of COVID-19. *Int Psychogeriatr* 32, 1377-1381.
- [26] Di Lorito C, Pollock K, Harwood R, Nair Rd, Logan P, Goldberg S, Booth V, Godfrey M, Dunlop M, Van Der Wardt V (2019) Protocol for the process evaluation of the promoting activity, independence and stability in early dementia and mild cognitive impairment (PrAISED 2) randomised controlled trial. *Maturitas* 122, 8-21.
- [27] Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 19, 349-357.
- [28] World Health Organization (2001) World Medical Association Declaration of Helsinki. Ethical principles for medical research involving human subjects. *Bull World Health Organ* 79, 373-374.
- [29] Bowling A (2014) Research Methods in Health: Investigating health and health services, McGraw Hill, Maidenhead.
- [30] Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K (2015) Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health* 42, 533-544.

- [31] Guest G, Bunce A, Johnson L (2006) How many interviews are enough?: An experiment with data saturation and variability. *Field Methods* 18, 59-82.
- [32] Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qual Res Psychol* 3, 77-101.
- [33] Hansen E (2006) Successful Qualitative Health Research. A Practical Introduction. Open University Press, England.
- [34] Etters L, Goodall D, Harrison BE (2008) Caregiver burden among dementia patient caregivers: A review of the literature. J Am Acad Nurse Pract. 20, 423-428.
- [35] Edwards HB, Ijaz S, Whiting PF, Leach V, Richards A, Cullum SJ, Cheston RI, Savovic J (2018) Quality of family relationships and outcomes of dementia: A systematic review. *BMJ Open* 8, e015538.
- [36] Hale L, Mayland E, Jenkins M, Buttery Y, Norris P, Butler M, Holland M, Ngocha-Chaderopa E, McKenzie-Green B, Czuba K, Sezier A, Kayes N (2020) Constructing normalcy in dementia care: Carers' perceptions of their roles and the supports they need. *Gerontologist* **60**, 905-915.
- [37] Quinn C, Nelis SM, Martyr A, Morris RG, Victor C, Clare L (2020) Caregiver influences on 'living well' for people with dementia: Findings from the IDEAL study. *Aging Ment Health* 24, 1505-1513.
- [38] Harris J (2003) Consent and end of life decisions. J Med Ethics 29, 10-15.
- [39] Spindler H, Leerskov K, Joensson K, Nielsen G, Andreasen JJ, Dinesen B (2019) Conventional rehabilitation therapy versus telerehabilitation in cardiac patients: A comparison of motivation, psychological distress, and quality of life. *Int J Environ Res Public Health* 16, 512.
- [40] McCabe R, Priebe S (2004) The therapeutic relationship in the treatment of severe mental illness: A review of methods and findings. *Int J Soc Psychiatry* 50, 115-128.
- [41] Vowles KE, Thompson M (2012) The patient-provider relationship in chronic pain. *Curr Pain Headache Rep* 16, 133-138.
- [42] Bishop M, Kayes N, McPherson K (2021) Understanding the therapeutic alliance in stroke rehabilitation. *Disabil Rehabil* 43, 1074-1083.
- [43] Jootun D, McGhee G (2011) Effective communication with people who have dementia. *Nurs Stand* 25, 40-47.
- [44] Mair FS, Hiscock J, Beaton SC (2008) Understanding factors that inhibit or promote the utilization of telecare in chronic lung disease. *Chronic Illn* 4, 110-117.
- [45] National Institute for Health and Care Excellence (2012) Patient Experience in Adult NHS Services: Improving the Experience of Care for People Using Adult NHS Services: Patient Experience in Generic Terms. NICE.
- [46] Green T, Hartley N, Gillespie N (2016) Service provider's experiences of service separation: The case of telehealth. J Serv Res 19, 477-494.
- [47] Brody AA, Sadarangani T, Jones TM, Convery K, Groom L, Bristol AA, Daniel D (2020) Family- and personcentered interdisciplinary telehealth: Policy and practice implications following onset of the COVID-19 pandemic. J Gerontol Nurs 46, 9-13.
- [48] Bulik RJ (2008) Human factors in primary care telemedicine encounters. J Telemed Telecare 14, 169-172.
- [49] Tinkler L, Smith V, Yiannakou Y, Robinson L (2018) Professional identity and the Clinical Research Nurse: A qualitative study exploring issues having an impact on participant recruitment in research. J Adv Nurs 74, 318-328.
- [50] Wilkinson H (2002) The perspectives of people with dementia: Research methods and motivations. Jessica Kingsley Publishing, London.

- [51] Moore TF, Hollett J (2003) Giving voice to persons living with dementia: The researcher's opportunities and challenges. *Nurs Sci Q* 16, 163-167.
- [52] Rochford-Brennan H, Keogh F (2020) Giving voice to those directly affected by the COVID-19 pandemic - the experience and reflections of a person with dementia. *HRB Open Res* 3, 29.
- [53] Jacob S, Furgerson S (2012) Writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research. *Qual Rep* 17, 1-10.
- [54] Cranen K, Groothuis-Oudshoorn CG, Vollenbroek-Hutten MM, Ijzerman MJ (2017) Toward patient-centered telerehabilitation design: Understanding chronic pain patients' preferences for web-based exercise telerehabilitation using a discrete choice experiment. *Int J Med Res* 19, e26.
- [55] Tracy S (2010) Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qual Ing* 16, 837-851.

- [56] Di Lorito C, Masud T, Gladman J, Godfrey M, Dunlop M, Bosco A, Harwood RH (2021) Deconditioning in people living with dementia during the COVID-19 pandemic: Qualitative study from the Promoting Activity, Independence and Stability in Early Dementia (PrAISED) process evaluation. *BMC Ger* 21, 529.
- [57] Chartered Society of Phyisotherapy (2020) COVID-19: Guide for rapid implementation of remote consultations. Practical advice for physiotherapists and support workers on how to implement remote consultations rapidly and efficiently. Online: https://www.csp.org.uk/publications/covid-19-guide-rapid-implementation-remote-consultations;
- [58] Sriram V, Jenkinson C, Peters M (2020) Using rapid cycle tests of change to develop the Carers Assistive Technology Experience Questionnaire: A cognitive interview study in the UK. *BMJ Open* 11, e042361.