Digital delivery of non-pharmacological intervention programmes for people living with dementia during the COVID-19 pandemic

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SUMMARY
The COVID-19 pandemic significantly impeded face-to-face health and social care delivery for people living with dementia and their carers. Interruption of meaningful activity engagement along with increased social isolation is known to be associated with loss of skills, increased loneliness, physical deterioration and decline in cognition and mood in people with dementia. To ensure continuity of care for people living with dementia, for whom multimodal, non-pharmacological intervention programmes were being provided, there was an urgent need to adopt a remote delivery model. Guidance on digitally delivered assessment and care specific to non-pharmacological interventions for dementia is lacking. This paper provides guidance on the delivery of one-to-one and group therapeutic programmes for people living with dementia during the COVID-19 pandemic.

BACKGROUND
Alzheimer’s disease is the most common cause of dementia, a term that is used to describe the group of symptoms which affects a person’s capability to engage in everyday activities due to difficulties with memory, language, problem-solving, other thinking abilities, physical functioning and neuropsychiatric symptoms. Despite the availability of a limited number of medications to treat cognitive and neuropsychiatric symptoms, people with dementia usually experience cognitive, functional and social decline and have escalating needs for medical and psychosocial care and support. There are around 50 million people living with dementia globally, with almost 10 million new cases of dementia diagnosed each year. Of the global population over the age of 60 years, about 5%-8% have been diagnosed with dementia. It is predicted that by 2030, there will be 82 million people living with dementia. That prevalence means that these 82 million people will need day-to-day support from a carer as the dementia progresses. Support of carers to people living with dementia is already an significant need. Non-pharmacological interventions, including individual therapies and structured therapeutic activities, have shown benefit in cognitive, neuropsychiatric, functional and social symptom domains as well as quality of life for people living with dementia and their carers.

The onset of the COVID-19 pandemic has resulted in the interruption of non-urgent health and social care and support as well as participation in regular meaningful activities for many people living with dementia and their carers. The COVID-19 pandemic has also increased social isolation because of the need for many people with dementia to self-isolate. It is well established that social isolation has detrimental effects for people living with dementia including loss of previous skills, loss of social contact, loneliness and cognitive decline. Unsurprisingly, self-isolation during the COVID-19 pandemic has increased isolation-related problems for both people with dementia and their carers, who have in the main had to minimise outside interactions and attendances at usual group or participatory recreational activities or rehabilitation services.

Participation in meaningful, personalised and recreational activities has been shown to increase positive emotions, improve activities of daily living, enhance quality of life, decrease challenging behavioural symptoms, and promote self-esteem and confidence and overall sense of well-being in a person with dementia. Meaningful activities have also been shown to engender positive attitudes towards carers, increase participatory engagement, create meaningful moments and support interpersonal connection for people living with dementia and their carers, particularly as dementia progresses. Stimulating creative and cognitive therapeutic activities have been shown to benefit cognition, physical functioning and social interaction for people living with dementia and are widely recommended by health and social care organisations.

Our multimodal, non-pharmacological intervention programmes for people living with dementia have previously been delivered by trained therapists in-person to individuals and groups in communities in the UK and China. Once the COVID-19 pandemic regulations required that populations social distance and self-isolate, there was also significant interruption of vital social care support services for many people living with dementia and their carers. Our therapists rapidly sought remote means to connect with people living with dementia and their carers by setting up one-to-one video or telephone consultation sessions to replace our in-person one-to-one sessions and adapted our programmes to a technology-enabled care approach. To replace community group therapeutic
activity sessions, the team scripted and filmed a series of therapeutic activities and explanatory videos delivered by a therapist and other experts which were made freely available on an award-winning YouTube channel17 (https://www.youtube.com/channel/UCDgSgADiyhNKFmmSVBLhJA).

There are four key roles in the consideration of the challenges of providing continued therapeutic care for dementia: the person living with dementia, the caregiver, the healthcare provider/therapist and future research. In this case report, we describe the transition from in-person dementia therapy and group-based therapeutic activity delivery to digital delivery. This case demonstrates the challenges and potential for successful digital delivery of non-pharmacological intervention programmes for people living with dementia and their carers. We also illustrate the potential to provide continued digitally-based dementia support post-COVID, for example, for people who live in remote regions with few face-to-face dementia support resources available locally.

CASE PRESENTATION

A man in his late 60s was referred to our dementia therapists by the local memory clinic following a confirmed diagnosis of Alzheimer’s disease. Initial assessment by our therapist identified neuropsychiatric symptoms of dementia, namely apathy and low mood, periodical agitation, and both visual and auditory hallucinations which were distressing for him and his wife. His wife was his primary carer and did all she could to help her husband. He enjoyed regular walks, swimming, boccia (bowling) and social events. He liked watching many types of sport on television and was described as having a good sense of humour. He and his wife received regular social visits from their nearby extended family.

Investigations

The patient had initial investigations to confirm the diagnosis of Alzheimer’s disease done by the local memory clinic. Our team does not conduct diagnostic services but does conduct a person-centred evaluation and monitors outcomes as part of providing the therapeutic programmes for people with confirmed diagnoses of dementia. Outcomes and results are displayed in tables 1 and 2.

Treatment

Memantine, risperidone and mirtazapine had been prescribed by the local memory clinic for his cognitive and neuropsychiatric symptoms. In September 2019, in-home, one-to-one non-pharmacological intervention dementia therapy programme was initiated. He also started attending a day centre and community group therapeutic activity sessions.

Following the initial COVID-19 lockdown and government restrictions, the couple did not leave their apartment or receive visitors for 3 months. The only contact with family and the therapist was through phone or subsequently Skype which was set up by a family member.

Personalised activities within a multimodal programme of interventions were provided by the therapist online with the aim of attaining meaningful engagement in activities and were designed to focus on global stimulation and sense of success. Therapeutic activities included the following:

► Cognitive stimulation activities including the use of numeracy activities, picture recognition, puzzles, music quizzes, problem-solving, language skills and discussions on sport, especially football being a favourite topic.30
► Reminiscence therapy using pictures, photos and music.38
► Music therapy including listening to pieces of music, playing an instrument and singing.7 8 39 40
► Physical exercises including chair-based activities and ball games.5 6 19
► Reality orientation.6
► Validation therapy.8

The couple also started to watch the weekly YouTube videos presented by the same therapist and examples of which are available at the following link: (https://www.youtube.com/playlist?list=PLYGjP3lwLX9nRtBXbAuenAVqJVBGGcHl).

Outcomes and follow-up

The timeline and outcomes relating to this case are represented in table 1. After the end of March 2020, no further formal scored assessments (table 2) were done due to lack of tools validated for online use at the time. Throughout the COVID-19 lockdown, increased apathy and loss of usual sense of humour were notable. However, there were noted periods of more energetic participation and positive emotions observed during the therapeutic activity sessions. The man’s wife also reported that positive emotions and increased levels of conversation persisted for a number of hours after each session. Despite these short-term observations, over the ensuing time of the COVID-19 pandemic, the man became more easily distracted during the online sessions and could become increasingly fatigued towards the end of a session. Despite the stress and isolation of lockdown, as a carer his wife has done incredibly well to continue to engage her husband in meaningful activities in between sessions and always emphasised her absolute willingness to help. Resumption of regular walks after lifting of lockdown restrictions was associated with significant physical fatigue not experienced previously, indicative of physical deconditioning.

GLOBAL HEALTH PROBLEM LIST

► The COVID-19 pandemic has resulted in the urgent need for adoption of digital tools for remote consultation to enable continuity of care, especially those who need supported care at home.
► Disruption of psychosocial care and meaningful activity participation for a person living with dementia can be associated with faster symptom progression.
► Available guidance on the application of digitally delivered care specific to therapeutic interventions for people with dementia is lacking.
► Adoption of technology-enabled care for people living with dementia may be hindered by the ability to use technology, new methods of therapeutic delivery, lack of interpersonal connection through a screen and confusion between live and pre-recorded sessions.
► Remote methods of interaction between therapists and people living with dementia require a different approach to increasing engagement and maintaining interaction along with assistance from a carer.
► Safety-netting concerns exist around remote assessment which may not as clearly detect causes for deterioration in symptoms and environmental changes.
► Lack of validation for the use of dementia assessment tools and scales for remote assessment needs to be addressed through further research.

GLOBAL HEALTH PROBLEM ANALYSIS

There are four key roles in the consideration of the challenges of providing continued therapeutic care for dementia: the person...
Table 1  Timeline with significant events, interventions and outcomes

<table>
<thead>
<tr>
<th>Month/ year</th>
<th>Significant history, presentation and observation details</th>
<th>Interventions</th>
<th>Significant outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sept–Nov 2019</td>
<td>Diagnosed with Alzheimer’s disease and associated depression. Symptoms of impaired cognition in addition to hallucinations. Medical history of hypertension. No pre-existing psychiatric history or family history of dementia. Ex-smoker and teetotal.</td>
<td>Memantine, risperidone and mirtazapine had been prescribed by the local memory clinic.</td>
<td>None for our programmes</td>
</tr>
<tr>
<td>Jan 2020</td>
<td>One-month interruption of programme due to annual seasonal holidays and a temporary change in care arrangements.</td>
<td>One-to-one and group sessions re-initiated. Therapy focused on his interests in arithmetic and multilingual abilities as a speaker of 5 languages.</td>
<td>Deterioration in early January MMSE score noted in orientation to time and place, mental arithmetic, naming ability and short-term memory. GDS and FAST scores indicated deterioration in global functioning and cognition. NPI scores improved due to fewer hallucinations and associated agitation.</td>
</tr>
<tr>
<td>Feb 2020</td>
<td>Initial person-centred, goal-oriented assessment performed in-person in the man’s home. Staging scores indicated moderate to moderately severe stage of dementia. Significant difference in patient and proxy quality of life scores noted.</td>
<td>Continued in-person programme.</td>
<td>MMSE improved on orientation time and place and mental arithmetic. GDS/FAST remained unchanged but Barthel’s improved.</td>
</tr>
<tr>
<td>End Mar 2020</td>
<td>There was a significant qualitative improvement in his conversational ability compared with the early January sessions. In addition, numeracy and language skills, including reading and writing, were observed to improve in the cognitive stimulation activities.</td>
<td>Cessation of in-person programme and initiation of digitally delivered therapeutic activity programme online.</td>
<td>No further formal assessment due to lack of tools validated for online use.</td>
</tr>
<tr>
<td>Apr–May 2020</td>
<td>After the period of isolation, qualitative observation noted worsening of cognition observed in deterioration of language skills and speech production; there were two episodes of wandering and getting lost which had not occurred before. Worsening nocturnal restlessness resulted in poor sleeping patterns. Non-elective hospital admission for pneumonia.</td>
<td>Two times weekly 30-minute interactive online therapy sessions continued except during hospital admission.</td>
<td>Qualitative verbal feedback and visual observation in video sessions noted signs of improved mood post-session with more laughter, smiling and interaction with the therapist and carer.</td>
</tr>
<tr>
<td>Jun–July 2020</td>
<td>Increased distractibility; reduced attention and concentration; disinterest in usual activities such as watching sport on television; decline in comprehension; deterioration in language abilities with reversion to languages spoken in earlier life and fatigue observed especially after physical activity. Increased distress due to hallucinations noted to be more frequent during the period of reduced physical and social activity. Occasional episodes of incontinence started to occur.</td>
<td>Online session frequency was increased from 2 to 3 times a week in response to noted attention and language deterioration and cognitive stimulating activities were increased in intensity. Returned to some socialisation with family following cessation of lockdown.</td>
<td>An associated improvement in attention and concentration to session activities noted after increasing online session frequency. The accumulative effect of repeated sessions, for example, with mental arithmetic challenges, was evident by improvement in responsiveness and quicker task completion. Improved engagement during session activities was noted by increased alertness, reduced apathy and observed positive emotions (smiling and laughter) with his wife noting “that was the first time he smiled all day.”</td>
</tr>
<tr>
<td>August 2020</td>
<td>Returned to day centre second half of August.</td>
<td>Attendance at the day centre resumed 3 times a week.</td>
<td>It was noted that within 2 weeks of returning to the day centre, the man’s comprehension of spoken word and interactions during the online session seemed to have improved.</td>
</tr>
</tbody>
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Global health

Table 1  Continued

<table>
<thead>
<tr>
<th>Month/ year</th>
<th>Significant history, presentation and observation details</th>
<th>Interventions</th>
<th>Significant outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>September–November 2020</td>
<td>Independent attempts at physical exercise within the flat were noted by his wife. Some objective symptoms of dementia progression continued including reduced attention, occasional episodes of incontinence, increased apathy outside of sessions.</td>
<td>Continued 2 online therapeutic activity sessions a week and attended the day centre for 3 days a week.</td>
<td>Ongoing stimulating activities were noted to be associated with reduced apathy and increased signs of positive emotions within the sessions. Plans to return to in-person sessions were still pending at the end of November 2020 due to continued COVID-19 restrictions.</td>
</tr>
</tbody>
</table>

Table 2  Results of relevant dementia cognition, global stage, quality of life and activities of daily living scores over 6 months

<table>
<thead>
<tr>
<th>Assessment month end</th>
<th>MMSE</th>
<th>CDR</th>
<th>GDS</th>
<th>FAST</th>
<th>QoL-AD (patient)</th>
<th>QoL-AD (proxy)</th>
<th>Barthel</th>
<th>NPI severity</th>
<th>NPI distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sept 2019</td>
<td>18</td>
<td>2</td>
<td>5</td>
<td>6.2</td>
<td>47</td>
<td>19</td>
<td>85</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Oct 2019</td>
<td>17</td>
<td>2</td>
<td>5</td>
<td>6.2</td>
<td>42</td>
<td>33</td>
<td>85</td>
<td>18</td>
<td>25</td>
</tr>
<tr>
<td>Nov 2019</td>
<td>18</td>
<td>2</td>
<td>5</td>
<td>6.2</td>
<td>42</td>
<td>35</td>
<td>85</td>
<td>17</td>
<td>31</td>
</tr>
<tr>
<td>Jan 2020</td>
<td>13</td>
<td>2</td>
<td>6</td>
<td>6.6</td>
<td>45</td>
<td>32</td>
<td>75</td>
<td>11</td>
<td>15</td>
</tr>
<tr>
<td>Feb 2020</td>
<td>16</td>
<td>2</td>
<td>6</td>
<td>6.6</td>
<td>45</td>
<td>30</td>
<td>80</td>
<td>17</td>
<td>16</td>
</tr>
<tr>
<td>Mar–Nov 2020</td>
<td>No further in-person assessments</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

MMSE scored out of 30.71,72

CDR scale ratings: 0=normal; 0.5=very mild; 1=mild; 2=moderate; 3=severe.19

GDS staging levels: 1=no cognitive decline; 2=very mild cognitive decline; 3=mild cognitive decline; 4=moderate cognitive decline; 5=moderately severe cognitive decline; 6=severe cognitive decline; 7=very severe cognitive decline. FAST levels: 1=normal adult; 2=normal older adult; 3=early AD; 4=mild AD; 5=moderate AD; 6=moderately severe AD; 7=severe AD.14,73

Barthel Index of Activities of Daily Living scale (Barthel’s): out of 100.76

NPI maximum score 36 for severity and 60 for caregiver distress.44

QoL-AD scale with a maximum score of 52.78

AD, Alzheimer’s disease; CDR, Clinical Dementia Rating; FAST, Functional Assessment Staging; GDS, Global Deterioration Scale; MMSE, Mini-Mental State Examination; NPI, Neuropsychiatric Inventory.
family who obtained a tablet computer and set up Skype. There was also initial anxiety around the use of the novel technology for the couple as well as a new method of interaction with their therapist. The provision of adequate technology and having sufficient support to advise people on how to use the technology is an important consideration in the development of a digital mode of service delivery. It is also worth noting that the use of the screen for communication can be a barrier for some people with dementia who may have reduced concentration and attention related to their cognitive impairment. Increasing engagement and interaction therefore requires even more energy and animation from the therapist on screen to maintain engagement for the duration of the one-to-one interactive online session. When viewing the pre-recorded YouTube videos of the same therapist playing guitar, it was also noted by the man’s wife that the man would think she was live on the screen and would try to talk and interact with her. This was an important consideration we had not previously recognised in that people with dementia may find it confusing switching between an interactive live session and pre-recorded sessions on screen when presented by the same therapist.

In-person programmes supervised by a therapist allow carers to have some time for themselves while the therapist facilitates sessions directly; however, for digital delivery, in-person supervision by the carer for the duration of the session was needed. The carer’s support was also very much needed in terms of resolving any intervening technology issues and helping to demonstrate and supervise physical and manual activities. Digital delivery also limited some of the types of therapies that could be delivered which required more complex or intense physical exercise supervision or physical equipment, for example, using skittles, indoor tennis, hoopla equipment or practical tactile objects. Remote consultation may also limit the ability to gain a complete impression of how a carer may be coping as it is difficult and upsetting to be able to speak about concerns when confined to the home environment and the person with dementia is in close proximity. The more limited interactions with a carer could result in lack of recognition that a carer may be struggling more than is evident from the more positive appearance on the video sessions which in this case the carer did look forward to and seemed happy during sessions.

There are also safety-netting concerns for a therapeutic provider regarding delivering a programme remotely as having visual sight and contact only via video or phone may reduce the therapist’s ability to identify any issues in the person’s environment that may be contributing to distress or restlessness, as well as recognise progressing or waxing and waning symptoms of dementia as opposed to other causes of deterioration such as delirium during a time of infectious disease pandemic. These concerns could be shared by the dementia care dyads who are used to having the therapist present in person. Safety-netting concerns are compounded by a cocooning person’s fear of attending medical services in person due to the potential risk of infection in the healthcare setting. The therapist was able to overcome these concerns by maintaining clear and available lines of communication with the man and his wife including telephone and email support in addition to the video support. It was also important that the man’s wife was available to supervise the online sessions in person, help navigate technological access and provide encouragement during activities to ensure safety and calm participation.

Monitoring and evaluation of progress of people with dementia are integral to any therapeutic programme delivery. The biggest challenge relating to symptom and clinical progress monitoring was that following lockdown and transition to online delivery of the sessions, no further scored assessments were conducted due to lack of validation for online use of the dementia assessment scoring tools. All further monitoring during online sessions from the end of March onwards was done through qualitative observation of the therapist and the man’s wife as carer. It was only through on-screen interactions during sessions that the therapist was able to observe changes in mood, functioning and cognition of the man as well as his wife by observing their affect for signs of positive emotion, interaction and engagement in specific activities. The use of cognitive, depression and carer scales has been evaluated and compared with smaller pilot and feasibility studies, with some studies showing slight differences between results obtained via telemedicine versus face-to-face which could change clinical decisions, yet most concluded optimistically that telemedicine is a suitable medium for dementia assessment including use of tools such as the MMSE, Alzheimer’s Disease Assessment Scale–Cognitive Subscale and Montreal Cognitive Assessment (MOCA). Delivery of remote clinical dementia diagnosis and care has similarly shown promising results with caveats to consider the emotional implications of the use of telemedicine on people with dementia. Having considered remote delivery of the assessment tools, challenges involve the practical aspects of delivering, for example, some points in the MMSE via video call. Tasks involved in the MMSE which could prove more challenging include asking someone to copy the intersecting pentagons from a more distant screen than an adjacent piece of paper and read ‘close your eyes’ from a screen when the person may have attention difficulties. Clinical assessment inevitably enables more personalised, person-centred assessment but currently only general impression of deterioration or improvement could be ascertained through video observation and verbal report. By not getting an overall impression of the person with dementia, one can get caught in the cycle of assess–reassess without critical improvement. Having a validated tool can help to break that cycle as specialist tools enable one to have a structured and directed method of assessment beyond questions from general conversations. As we had not yet used any other validated online tools such as the MOCA, this would not have been as useful without initial baseline measures. In planning further delivery of remote sessions, our team has since been in touch with the copyright holders of the various dementia assessment tools to establish validity or plans to further validate for online use and delivery.

Despite the challenges discussed, we observed several qualitative benefits associated with the online video-based one-to-one sessions. Through on-screen interactions, the therapist observed an improvement in mood observed through increased positive emotions of the man and his wife with the wife reporting continued topics of conversation lasting a few hours after the sessions. It was noted that over the months of the initial COVID-19 lockdown, there were objective symptoms of overall dementia progression which included reduced attention, deterioration of language abilities, increased need for assistance, increased apathy outside of sessions and occasional episodes of incontinence. There was also increased difficulty for the therapist in monitoring these without validated online dementia assessment tools. However, the ability to maintain some meaningful engagement within the online sessions and through day centre attendance seems to have been associated with positive emotions, improved engagement and tasks related to cognition within sessions and enhancement of the couple’s interpersonal relationship through mutual interesting discussions and sense of anticipation for future sessions. The therapist also noticed that...
she had to access a higher level of creativity in designing activities for remote sessions with the available resources and equipment in the man’s home. The man’s maintained confidence was notable in that he started to take on the role of the educator, something he had previously enjoyed, in some of the online sessions by teaching the therapist some of his home language which seemed to have a positive impact on his self-esteem while tapping into his own sense of identity and capability.

Despite remote consultations limiting in-person supervision and interaction by a therapist, there have been benefits observed qualitatively in mood, cognition and engagement from the continued online therapeutic activity sessions. In anticipation of the potential continued need for vulnerable populations to self-isolate, the therapists have been able to adapt our programmes based on the available therapeutic professions’ guidance and available evidence on remote delivery of therapeutic dementia care for both one-to-one and group sessions online. Our team has also continued to produce pre-recorded videos to enable on-demand access to therapeutic activity videos if not able to attend sessions online (eg, see one of the YouTube videos in the link (https://youtu.be/bF8EyXYJKU)).70 These efforts have not only ensured continuity of care but the potential to reach more dementia caregiving dyads situated in remote regions. Remote digital delivery of a dementia therapy programme is novel in concept and application. Further research is required and being planned to demonstrate the feasibility, acceptability and efficacy of digitally delivered therapy programmes for people living with dementia and their carers.

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